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Representative Aman, there you are of the 14th, you have the floor.

REP. AMAN (15th):

Thank you. Thank you very much, Mr. Speaker. I rise for a point of personal privilege for the purpose of making an introduction.

DEPUTY SPEAKER ALTOBELLO:

Please proceed, sir.

REP. AMAN (15th):

Thank you, Mr. Speaker. Today I'm very pleased to have here at the chamber the Super 60's Club from the town of South Windsor. These gentlemen are here to learn about how we do business and I'm very glad to have them here and I'd ask the chamber to give them a big round of applause.

DEPUTY SPEAKER ALTOBELLO:

Thank you, sir. Thank you, Representative Aman and nice to have you all here today.

Further announcements or points of personal privilege?

If not, would the Clerk please call Calendar 263, two six three, please.

THE CLERK:

On Page 14, Calendar 263, substitute for House

Bill Number 5499, AN ACT CONCERNING REGULATIONS RELATING TO HOSPICE CARE. Favorable report on the Committee of Public Health.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter of the 38th, you have the floor, madam.

REP. RITTER (38th):

Thank you, Mr. Speaker. I move for acceptance of the joint committee's favorable report and passage of the Bill.

DEPUTY SPEAKER ALTOBELLO:

Question before the chamber is passage of the Bill. Please proceed, ma'am.

REP. RITTER (38th):

Thank you, Mr. Speaker. Mr. Speaker, as the title implies, this Bill concerns a change in the regulations relating to Hospice care in the State of Connecticut. Mr. Speaker, the Clerk is in possession of an amendment, LCO 3261. I would ask the Clerk to please call the amendment and I be granted leave of the chamber to summarize.

DEPUTY SPEAKER ALTOBELLO:

Would the Clerk please call LCO 3261, which shall be designated as House Amendment Schedule "A". 3261,,

please.

THE CLERK:

LCO Number 3261, House "A" offered by Representative Ritter and Senator Gerratana, et al.

DEPUTY SPEAKER ALTOBELLO:

Good Representative begs leave of the chamber to summarize. Seeing no objection, please proceed, madam.

REP. RITTER (38th):

Thank you very much, Mr. Speaker. Mr. Speaker, this amendment makes some substantial changes to the original Bill starting with some technical corrections in the beginning and to simplify the discussion, I would move its adoption at this time and then discuss the Bill as amended.

DEPUTY SPEAKER ALTOBELLO:

Question before the House is adoption of House "A". Please proceed, madam.

REP. RITTER (38th):

I move adoption of the amendment.

DEPUTY SPEAKER ALTOBELLO:

Question before the House is adoption of House "A".

Further on House "A"? Further on House "A"?

Further on House "A"?

Representative Candelora of the 86th on House "A".

REP. CANDELORA (86th):

Thank you, Mr. Speaker. If I may, Mr. Speaker, a question to the Chairwoman of the Public Health Committee?

DEPUTY SPEAKER ALTOBELLO:

Please proceed, sir.

REP. CANDELORA (86th):

Thank you, Mr. Speaker. In line 7 and 8 of the amendment, it provides for -- or references an organization license as a Hospice facility under two scenarios. Number one, that provides inpatient services or two, provides home health care services. Under our current law in section B, if a facility is providing inpatient services they're also required to have home Hospice services. Does this particular amendment "A" seek to continue that practice so that if there's an inpatient Hospice facility, they are still required to provide home care services? Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker, the answer is yes.

DEPUTY SPEAKER ALTOBELLO:

Representative Candelora.

REP. CANDELORA (86th):

Thank you, Mr. Speaker. I appreciate the answer.

DEPUTY SPEAKER ALTOBELLO:

Further on House "A"?

Representative Perillo, you have the floor, sir.

REP. PERILLO (113th):

Sir, I appreciate that and I'll speak on the Bill once amended.

DEPUTY SPEAKER ALTOBELLO:

Thank you, sir.

Further on House "A"? Further on House "A"?

If not, I'll try your minds. All those in favor please signify by saying Aye.

REPRESENTATIVES:

Aye.

DEPUTY SPEAKER ALTOBELLO:

All opposed?

The Ayes have it. The Amendment is adopted.

Further on the Bill as amended? Further on the Bill as amended?

Representative Ritter.

REP. RITTER (38th):

Thank you very much, Mr. Speaker. Mr. Speaker as we've already alluded, current law authorizes the Department of Public Health to license a facility to operate a specialized residence for the terminally ill that provides Hospice homecare and supportive services and as indicated in the discussion in the amendment, any facility so licensed to provide inpatient services, must under current law also offer home based services. Mr. Speaker, this Bill does not change that requirement. The Bill does allow entities to create new facilities under regulations that are based -- I'm sorry, that are somewhat less stringent than the Department's current short-term hospital regulations and the reasoning is that those regulations are based on a model of a skilled nursing home and the new regulations are contemplated to be more appropriate today's health care environment and the needs of people that would be interested in a Hospice or residential Hospice services and I urge my colleagues to support the Bill.

DEPUTY SPEAKER ALTOBELLO:

Thank you, madam.

Further on the Bill as amended?

Representative Perillo of the 113th, you have the floor, sir.

REP. PERILLO (113th):

Mr. Speaker, thank you very much. If I may through you, a few questions to the proponent of the Bill.

DEPUTY SPEAKER ALTOBELLO:

Please proceed, sir.

REP. PERILLO (113th):

Thank you, Mr. Speaker. One of the discussions that we heard during the public hearing on this Bill was that there is potential for a detrimental impact to patient care. A number of reasons were suggested as to why that might be the case. I'm wondering if the proponent could just address some of the concerns that were heard during the public hearing.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

I will do my best, Mr. Speaker. That was an open ended question, very good. Thank you very much, Representative Perillo. In the extensive testimony, Mr. Speaker, we learned several things about the

Hospice business in Connecticut and I really should preface my comments by pointing out that Connecticut has been a national leader in provision of these services. The first Hospice in Connecticut which came to us in the 70's in Branford, has been a national model and has provided an exemplary leadership really for the country and the Hospice movement and it's something that we are and remain very proud of here in Connecticut. Since then, the need for hospital services in the state has changed and grown and many more people are interested in the provision of those services, particularly in areas of the state that perhaps lie outside of the immediate Branford area and the model has also changed a little bit. That model originally, as I indicated, what contemplated something far closer to a skilled nursing home facility requirement of the type that you saw in the 1970's and our regulations have not moved really at all since then. The model currently attracting a lot of interest is a model for smaller facilities, a more home-like or residential basis that would provide, among other things, for private rooms and for the opportunities for patients to have greater ability to not only have their own privacy but have space and

time to in the privacy of their families, perhaps, spend some of their last days as they receive care in this facility. So, things have changed quite a bit and that has brought the Department of Public Health wisely, in my opinion, to the point where they are suggesting new regulations. There has been a lot of discussion as to the type of care that would be offered and if indeed it continues to meet the specifications for quality that we've been so proud of here in Connecticut. And, certainly discussions and testimony from the Department of Public Health indicate, if anything, an increased level of scrutiny to those points as we look forward to perhaps seeing a different kind of Hospice residence emerge. In terms of the specifics of the proposals, there has been a lot of discussion throughout healthcare I know, over the years about how we form those regulatory requirements. If they are perhaps more based on hours or minutes or if they are more patient centered and this effort really reflects a shift to the more patient or acuity centered model. So, that would be the philosophy which guides this attempt, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Perillo.

REP. PERILLO (113th):

Thank you, Mr. Speaker. And, the Representative alluded to the likelihood that there will be small facilities opening that are more personal in nature in terms of their ability to attend to the emotional and psychological needs of patients. One of the concerns though that we did hear during the public hearing that these smaller facilities might not be able to deliver some of the services that the larger facility here in Connecticut can deliver. Specifically the issue of pharmacy and access to pharmaceuticals was addressed. Going forward it would appear that there would no longer be -- or that there would not be a need for 24/7 access to pharmaceuticals but, we've heard discussion on both sides of that issue. And, I'm wondering, through you, if the Chair can identify any potential ways that after this is approved, these facilities would still have secured access to pharmaceuticals?

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker, yes, the Representative is correct. We had a great deal of discussion on --

particularly to pharmaceuticals and I first would call the attention of the chamber to the fact that under current regulations, these pharmaceutical services are required to be provided under the direction of either an employee or a person duly licensed pharmacist under the terms of a written agreement or a contract and they're required to be available as one might suspect, to patients on a 24 hour basis. In 2012, things have changed a little bit in the world of pharmacy and actually it's not so much the presence of the on-site pharmaceutical room that makes the difference so much as the availability of services. Today, these facilities would have a multiple of options including, first, a contract with a 24 hour pharmacy, like Omnicare which is currently used at most of the nursing homes around our state. We heard in discussion considerable concern that the on-site pharmacy is not required in the regulations and I'd like to point out it's not required today for any of these facilities and it will not be required potentially in the future as it is not required or existent in any of the nearly 300 nursing homes we have in this state with the exception of two. Indeed, we have had in the past two years, no complaints about

the system of availability of pharmaceuticals. In addition, we have available the use of 24 hour pharmacy's which are pretty ubiquitous in Connecticut and use of an on=site lockbox which can contain supplies of the most commonly used medications for the Hospice facility. That would include pain medications, anti-nausea, anti-inflammatory and the like. Also, Hospice admissions are preplanned, Mr. Speaker, virtually all the time or very close and the patients physician has the capability through standing orders and through prearranged medication packs in that preplanning position to provide, if not orders for the medication, arrangements for the facility to store in its lockbox medications that were contemplated to be required and a variety of combinations of any of these above. I would like to point out the regulations. The hospital providers would still have to provide that access on a 24 hour, seven basis. Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Perillo.

REP. PERILLO (113th):

Thank you, Mr. Speaker. And, just one final question before I have some remarks. The Chair of the

Public Health Committee stated earlier that there were regulations in process that would address the issue of Hospice. And, just to clarify, I would like to know, through you, sir, if this piece of legislation would in any way, shape or form, interrupt or impact negatively the passage of those regulations through the system? Through you, sir.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Mr. Speaker, the answer to the question, I believe, is no.

DEPUTY SPEAKER ALTOBELLO:

Representative Perillo.

REP. PERILLO (113th):

Thank you, Mr. Speaker. One of the things that we have seen obviously, as the population ages, is that the need for Hospice care does continue to rise. Connecticut has been and continues to be a leader in the field of Hospice and in our ability to really appropriately treat patients who are in need of that level of care. I believe this Bill will expand access to that level of care that is needed by so many in our communities, and I would urge adoption of the Bill

that's before us today. Thank you, sir.

DEPUTY SPEAKER ALTOBELLO:

And, I thank you, Representative Perillo.

Representative Scribner of the 107th, you have the floor, sir.

REP. SCRIBNER (107th):

Thank you, Mr. Speaker. I rise in strong support of the Bill before us. I have had the privilege of serving on the Public Health Committee and I want to thank the leaders and members of that Committee for bringing this Bill before us. I've also had the privilege to serve as a member of the Board of Directors of a regional Hospice in Western Connecticut for about six years and learned a lot about what Hospice care really is and all that it is and also the tremendous need that there is for people at that stage in their lives along with their families. I can't speak highly enough for the process that has brought the Bill before us today and I understand thoroughly there were a lot of concerns, some very legitimate concerns brought forward. This is something that should not be taken lightly, should not be expanded lightly, and I can assure you, it has not been. I have sat in meetings where we went through with the

capable staff at the Department of Public Health, line by line with the regulations that were first adopted in 1977 by the Department in large part to have a regulatory oversight of the Connecticut Hospice facility that had been previously built and served those in need in Branford which continues to thrive today. It's kind of amazing when you look at some of the language that's in the original language that even makes reference to some things like telephone booths being provided to the families and that's a clear indicator of how long it's been since those regulations were first put into place. I have experienced from working closely through -- with this legislation along with members of regulation review, with the Department of Public Heath and certainly the capable leadership of the Public Health Committee, there has been tremendous focus on ensuring that every single aspect of this Bill would emphasize and strengthen the regulatory environment for the provision of Hospice care in in-patient facilities. It's also important for everyone to realize that we all think of Hospice care as pertaining to cancer patients in the last period of their life. They serve many others. It's not only people that are diagnosed

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with cancer. It is many other people which includes children when they're diagnosed with terminal illness and the receive the palliative care that is based on a national model when they need it the most and when their families need it the most. From being involved in our regional Hospice, I've had the experience of becoming aware, for instance, of a 14 year old cancer victim in the final weeks of their life, having to be admitted to a nursing home next to a patient who had had a hip replacement because there was no other adequate facility to put that individual in and they couldn't leave this dying 14 year old at home side by side with their sibling under those circumstances. And, I think that from looking at all of the information that's been brought forward, keep in mind that we had a very extensive regulations review, public hearing that was sponsored by the Department of Public Health. I attended it; there was several hundred people there. Great interest in what this legislation and what these regulatory changes do. And, I think, I can say from first-hand experience that people listened intently and considered the thoughts and concerned that people voiced. The same type of thing happened when we had the public hearing

in Public Health hearing that went on for, as I recall, about seven hours, maybe more. There were nearly 100 people that spoke on this Bill by itself and we learned a lot through that process and I observed that we all listened intently and carefully considered the thoughts and experiences that people shared with us. I think the Department came forward with these regulatory changes over a year ago and during that 13 month period, there's been extensive and very thorough discussion and evaluation to ensure that when these regulatory changes are brought before us for the first time in about 35 years, that they be not only adequate but be as best as they can be to have clear and appropriate oversight of the care that's provided in these circumstances for the people most in need and certainly there are organizations within the State of Connecticut that are prepared to respond to these changes and expand and enhance the level of opportunity for this important and specialized area of care to the people most in need. And, I'm very convinced that that's exactly what this language will do and provide. And, I urge the support of the entire membership. This Bill comes before us with 54 co-sponsors on it which demonstrates a broad

and sound level of support for the people that we all serve. Thank you.

DEPUTY SPEAKER ALTOBELLO:

Thank you, sir.

Representative Godfrey of the 110th, you have the floor.

REP. GODFREY (110th):

Thank you, Mr. Speaker. I do also rise in support of this very important Bill and I do it because of the human and the humane, the moral and the morale aspects of the situation that families, loved ones, find themselves in, in the final weeks and days of a loved one's life, to require someone facing a very stressful situation, a very sad situation, the beginnings of grief and telling them that, "I'm sorry, we're going have to transport you miles and miles away from all that is familiar, from all that is home, from all our friends, from many members of the family," is just to me, not the right way to act. To allow the proliferation of small, very personally oriented facilities across the State of Connecticut, I think is important. These are facilities that should be nearby, that should be easily accessible by family, by friends, by the clergy, by other people in support of

the family that is going through this very difficult situation, and this Bill does accomplish that. I want to personally thank my good friend, Representative Scribner for his fine work in the continuing attempts to create and build and open a facility in Western Connecticut, my part of the state. It is a group of people he has made us very familiar with over the last several years. They are such good hearted individuals, such caring people, totally passionate about the mission of their organization and they do want to break ground relatively soon to get the facility under way and this Bill will speed that effort by making the permitting process much simpler and much easier, making sure that they qualify under the law so that they can construct, open and run this facility. And, then, let me thank Representative Ritter and the members of the Public Health Committee for listening to us. We've been talking back and forth for the better part of a year now and all of those discussions and debates and public hearings and committee meetings that have resulted in a very fine Bill, one that I think is fair, is fitting to everybody both in the industry, but most importantly to families and friends who want to have that access,

who want to be part of the support team for the individuals who will be admitted to these facilities. So, thank you to them and I do urge all of my colleagues to join us in voting for this Bill. Thank you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Thank you, Representative Godfrey.

Representative Miller of the 122nd, you have the floor.

REP. MILLER (122nd):

Thank you, Mr. Speaker. First of all, I'd like to associate myself with the remarks of both Representative Scribner and Godfrey, but I did get some calls from a couple of people regarding the Branford facility. From what I understand, the Branford Hospice is a national model recognized as a super operation and there was some -- I don't know what their concerns really were, how this is going to affect them, if I could ask the lady about what impact having additional Hospice's around the state, how would it impact the Branford operation. Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker. Mr. Speaker the contemplated changes will have no regulator impact on the Hospice in Branford. Indeed, they will be grandfathered, to use a term we use here often, in for as long as they chose to be so, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Miller.

REP. MILLER (122nd):

And, currently, I read somewhere it said in the Bill, I think there's only one Hospice in Connecticut at this time, is that true?

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, there are two.

DEPUTY SPEAKER ALTOBELLO:

Representative Miller.

REP. MILLER (122nd):

Thank you. And, are there any state funding that goes into this as far as providing funds for people that do go there? Do we in any way help them?

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, I believe the answer is no.

DEPUTY SPEAKER ALTOBELLO:

Representative Miller.

REP. MILLER (122nd):

Well, thank you for those answers and I will be supporting the Bill. I think obviously we have a lot of problems in our state health-wise and the more facilities we have, the easier it will be for these people to live out their lives in a proper manner and with responsible individuals caring for them at the time that they need it the most. So, thank you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Thank you, Representative Miller.

Representative Fox of the 148th, you have the floor, sir.

REP. FOX (148th):

Good afternoon, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Afternoon, sir.

REP. FOX (148th):

Mr. Speaker, I stand today in strong support of

House Bill 5499 and I would like to take a moment and thank the Chairs and ranking members and all the members of the Public Health Committee for their work in piecing together this piece of legislation and getting it to the floor of the chamber today. Currently as was stated earlier, around the State of Connecticut there are only two facilities that are licensed by the Department of Public Health as Hospice facilities. Two facilities in the entire State of Connecticut to serve this great, great need. Connecticut Hospice located in Branford and Atlantic in-patient Hospice unit at St. Mary's Hospital in Waterbury. House Bill 5499 I believe will change that. It will provide for the opportunity for a facility whose primary purpose is Hospice care to be located in each of our communities. I stand today, Mr. Speaker, as a resident of the City of Stamford that just a few months ago saw the doors to its own community based Hospice facility close. In the 1990's this chamber passed legislation supporting a pilot program to create the Rosenthal Hospice in Stamford, Connecticut. This program was championed by former State Representative from Stamford, Christel Truglia. The Rosenthal Hospice opened its doors in the year

2000 and over the course of the next 11 years, provided care, compassion and support to over 1,100 individuals who died within its walls. Just as importantly the staff of that great facility provided similar care, comfort and compassion to the families and friends of those individuals who passed away. On December 8, 2011, Peggy Antrall, a Stamford resident, died at the Rosenthal Hospice. Immediately thereafter, the facility shut down. Unfortunately, as proven by the Rosenthal Hospice, community based facilities whose primary purpose is Hospice care, are unable to survive in Connecticut pursuant to the regulations as currently drawn. I am hopeful and both -- I am both hopeful and optimistic that the legislation put forth today will change that and that all of our communities, all of our constituents will have the opportunity and access to facilities whose primary purpose is Hospice care located within the very communities that they call home. Mr. Speaker, I urge my colleagues support of this legislation and thank the chamber for its time.

DEPUTY SPEAKER ALTOBELLO:

Thank you, Representative Fox.

Representative Candelora of the 86th, you have

the floor, sir.

REP. CANDELORA (86th):

Thank you, Mr. Speaker. Mr. Speaker, if I might, a couple of questions to Representative Ritter.

DEPUTY SPEAKER ALTOBELLO:

Please proceed, sir.

REP. CANDELORA (86th):

Thank you, Mr. Speaker. In listening to some of the discussions here, the underlying Bill that was before the Committee, had dealt with mandating that the Department of Public Health adopt Hospice guidelines under the federal Medicaid standards. Under this current Bill, as I read it as amended, there's no longer any such mandate. Am I correct, through you, Mr. Speaker?

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker. Mr. Speaker, the current Bill does not change in any way the ability of the Department of Public Health to promulgate regulations or new regulations or regulation changes. Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Candelora.

REP. CANDELORA (86th):

Thank you, Mr. Speaker. And, we've heard some discussions today about the 24 hour pharmaceutical requirements under Hospice, the patient rooms, the size of the facilities -- those issues are currently not contained or mandated under this Bill but rather those discussions relate to the regulatory process, through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, that is correct.

DEPUTY SPEAKER ALTOBELLO:

Representative Candelora.

REP. CANDELORA (86th):

Thank you, Mr. Speaker. And, I appreciate the good Representative's answers to my questions. I think when this Bill had started out I certainly was one of the people that had opposed it because I was concerned of the public policy of mandating the Department of Public Health to pass particular type of regulations that are based on a federal prescription and I'm very appreciative that the ranking members and

the Chairs of Public Health have I think appropriately addressed this issue with this Bill and is putting this Bill forward in the process and allowing our regulatory process to continue onward. As an individual that is located in the service area of Branford Hospice, I certainly have had the good fortune of being able to take loved ones, not just to the in-patient facility in times of need, but also to receive their home health care services. And, they certainly do a phenomenal job and take great pride, I think as many of our Hospice facilities throughout the State of Connecticut do. And, as we are seeking to change this process, in order to create templates that marries our Branford Hospice which is the national model I think in this country, I think we all need to just be mindful that we certainly can lift barriers but we need to make sure that the quality of care continues to exist through the State of Connecticut. And, I think that this Bill does not tread on that and certainly as we move forward on the regulations, I think that we need to listen to the individuals, not just the ones that are in need of this care, but the ones that are currently providing it because they are the experts. Currently in the State of Connecticut we

do have 200 nursing home facilities that are provided in the state that provide Hospice care along with 200 hospitals. So, the services are still being provided in Connecticut. And, I think this debate really lies around in-patient services. And, just generally speaking, what I put out there is, individuals that are receiving these services will never come before us at a public hearing to speak on this issue because they're in the last stages of their life and so, it's very difficult for us to garnish the information in order to make sure that they're getting the quality care and will continue to receive it before we legislate. And, while I appreciate the Department of Public Health's efforts in this, I am just very mindful of keeping those individuals in mind because even the Department when they visit these facilities, I think they're only visiting them twice a year. So, the ones that are delivering it on a daily basis, are the ones that should be listed to in the process and I hope that as this continues, that Branford Hospice will be at the table and will continue to provide their input on providing -- on making sure that these regulations will be the best for all patients. Currently in Connecticut -- there's sort of been, I

think with this Bill, a very clear struggle that was established that seemed to be geographic. We have the parts of the state that don't receive Branford Hospice care that are advocating for this Bill and for the regulations and then there are those of us within the service area of Branford that have the good fortune of receiving the services and are advocating to keep things the way they are. And, I think we all understand that change may be necessary at times, but I think that the reason why people in our service areas are advocating the way we do, is not to protect what Hospice is providing, not necessarily to protect their fiefdom, which is sometimes what I hear, but it is about maintaining quality services in Hospice care. The Branford Hospice does not have a monopoly on Hospice care in the State of Connecticut. They provide about 18 percent of the in-patient services throughout the state. Eighty-two percent of their services are with the home care which many agencies provide through the State of Connecticut. Additionally, their in-patient service is only about 20 percent of the Connecticut market. And, so, there certainly are many other agencies within the State of Connecticut that are providing Hospice care currently.

And, I think what our goal is, is to try to make sure that we could have appropriate in-patient facilities established. I think this Bill is making a good step of sort of brining it in line statutorily I think with the way the Department of Public Health is regulating Hospice care. I think we always need to make sure that those individuals that have in-patient services are also required to provide home health care services, which from the answers earlier, that is going to currently be the case because so much of our Hospice care really does revolve around home patient services and by making sure we continue to have that nexus, that connection, we're going to make sure that it's the experts in Connecticut that are providing the services as opposed to some other medical industry that might be here already and would open up a wing and add in Hospice services. We really want these facilities to have skin in the game and make sure that they truly are the ones that are providing the home care service as well as the in-patient service. And, so I'm pleased to see that those provisions remain intact under this Bill. So, as this Bill moves forward I think that we still have much work to do through the regulatory process and making sure that

our patients are receiving the quality care because these are our most vulnerable. They aren't going to be in a position to be able to advocate for themselves, and so we really need to be the ones to do that. Thank you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Thank you, Representative Candelora.

Representative Mikutel of the 45th, you have the floor, sir.

REP. MIKUTEL (45th):

Thank you, Mr. Speaker. I rise in strong support of this piece of -- this Bill which is in my opinion, long overdue. As was said earlier, the existing model of Hospice care is really no longer serves the people of Connecticut. The regulations were adopted many decades ago and I would disagree with those who say that these changes in the regulations will lower the standards for Hospice care, I disagree with that strongly and certainly the regulations were developed by the Connecticut Department of Public Health along with all the other Hospice advocates, 29 Hospice programs in Connecticut. But, we only have two Hospice residential facilities in the State of Connecticut; one in Branford and one in Middletown.

And, quite frankly, that does not serve the needs Eastern Connecticut. People need more options. We should have these facilities closer to home so people don't have to travel long distances, so I would just urge and I know my fellow legislators will be supporting this much needed legislation. Thank you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Thank you, Representative.

Representative Srinivasan, you have the floor, sir.

REP. SRINIVASAN (31st):

Good afternoon, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Good afternoon.

REP. SRINIVASAN (31st):

Thank you, Mr. Speaker. I too, join my colleagues and rise in strong support of this Bill. Accessibility is what this Bill is all about and by having this opportunity to our most vulnerable of our population we have opened the doors where their last days are in peace, in comfort, near their homes along with their family. That is what this piece of legislation is able to do for us. Through you, Mr.

Speaker, if I can have some questions to the proponent of the Bill?

DEPUTY SPEAKER ALTOBELLO:

Please proceed, sir.

REP. SRINIVASAN (31st):

Thank you, Mr. Speaker. When and application is made to the Department of Public Health to open a Hospice facility, are there other agencies also involved in the process of decision making process or will it be the decision of the Department of Public Health to guarantee and give them their license for opening up a Hospice? Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker, that sounds just a little bit better. Mr. Speaker, in this State of Connecticut, the licensing process itself is determined by the Department of Public Health.

DEPUTY SPEAKER ALTOBELLO:

Representative Srinivasan.

REP. SRINIVASAN (31st):

Thank you, Mr. Speaker. Thank you for that answer. I appreciate that. Concerns have been

raised, and I'm not sure there's any legitimate reason for their concern, but we've heard that quite extensively in the public hearings that in these institutions that may arise, somehow -- and, of course I don't understand that, I do not agree with that, but, somehow quality of care of these patients may be compromised. And, of course, that's one thing none of us ever want for our patients at all, any compromise in their care. Through you, Mr. Speaker, will the Department of Public Health be monitoring these facilities on a very frequent basis and are we aware of what the frequency will be in these new places that will be giving Hospice care and Hospice treatment? Through you, Mr. Speaker.

REP. RITTER (38th):

Through you, Mr. Speaker, the short answer to the question is, yes. There is no change in the regulatory requirements in terms of oversight of visitation both on-sight and review of records, the recordkeeping requirements and the monitoring requirements that come from the Department of Public Health under any of the proposals that I've had the opportunity to review. Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Scrinivasan.

REP. SRINIVASAN (31st):

Thank you, Mr. Speaker. And, a final question to you, Mr. Speaker is if I understand this right, earlier in the Bill it was said that to open a Hospice in facility, they should also have home Hospice care. Through you, Mr. Speaker, is it possible for somebody to apply for only home Hospice care alone and not be involved with the in-patient Hospice care through this piece of legislation? Through you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Representative Ritter.

REP. RITTER (38th):

Through you, Mr. Speaker, the answer is, yes.

DEPUTY SPEAKER ALTOBELLO:

Representative Srinivasan.

REP. SRINIVASAN (31st):

Thank you very much, Mr. Speaker and I want to thank the Chairwoman of the Public Health Department for all her hard work on this Bill and for answering my questions. I appreciate that very much. Thank you.

DEPUTY SPEAKER ALTOBELLO:

Thank you, sir.

Representative Reed of the 102nd, you have the floor, madam.

REP. REED (102nd):

Thank you, Mr. Speaker. I can't believe I'm saying this, but I rise to support this Bill. When this long process began, being from Branford, we were very concerned. And, it wasn't a fiefdom issue, it was a concern that the high quality that had been established by the Connecticut Hospice in Branford which is the first Hospice in the nation, we're being rolled back. And, I have to congratulate the Committee, the Public Health Committee and also the Department of Public Health which is promulgating new regulations for, I think, listening to us. I think one of the concerns that I had is drawing from my own experience. Hospice is a resource that you encounter when you are tired, exhausted, broken-hearted, about to lose someone whom you love beyond description and you don't even know what Hospice is supposed to be in precise detail. And, so, there are concerns about people declaring themselves a Hospice facility without really adhering to the Hospice protocols among which are no invasive procedures for a dying person that are going to cause unnecessary pain or discomfort, and, a

real outreach to not only the patient but also to the loved ones. So, that was concerning and I feel that that's being addressed. And, one thing I think going forward we talked a lot about doing these things and making Hospice available to everyone which it should be accessible, easy to get to, in a neighborhood near you so that your loved ones can come back and forth and that the Hospice personnel can go back and forth if you're in the facility and then you can go home for a few days, go home with the kind of care you need. We talk a lot about that and it's really important to have oversight and I think this is something that the Public Health Committee and also the Department of Public Health are really hearing us about as well. We really need to make sure that Hospice care is being given in the appropriate way and that it will continue being given that way going forward. I would even suggest, and we don't need legislation for this, but creating a very easy to read Hospice Bill of Rights for consumers that perhaps the Department of Public Health could put on their website, just two or three bullet points of things that you should look for as you're taking your loved one into a facility. Again, no invasive care that it's going to create discomfort

or pain for your loved one, that kind of thing; easy to get to, again, at a time when you are so distraught you can barely, barely put one foot in front of the other. So, again, thank you to the Public Health Committee, thank you to the Department of Public Health and thank you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Thank you, Representative Reed.

Representative Molgano of the 144th, you have the floor, sir. Good afternoon.

REP. MOLGANO (144th):

Good afternoon, Mr. Speaker. Thank you very much. Mr. Speaker, I too rise in strong support of this Bill. I heard comments this afternoon on the importance of the location. I want to share with my colleagues a very sad story in Stamford. We had a family whose loved one was in need of Hospice care and because we didn't have a facility in Stamford, was travelling to Branford and unfortunately the person passed away en route. His lost moments were in the back of an ambulance instead of in a home-like environment like a Hospice care. I do understand that we do have nursing homes, but the nursing home in my opinion is an institution-like environment whereas a

Hospice care is like a home away from home. As I stated in my testimony before Public Health, I believe every person deserves to live his or her last days at home. And, circumstances may prevent this. Having a nearby residence that provides an atmosphere that emulates home or allow persons time of passing to be a private one and a personal one and a family to spend these last moments with their loved ones in peace and dignity and that's what these regulations I hope will provide for everyone in the State of Connecticut. Thank you, Mr. Speaker.

DEPUTY SPEAKER ALTOBELLO:

Thank you, Representative Molgano.

Representative P.B. Miller of the 145th, you have the floor, madam.

REP. MILLER (145th):

Thank you, Mr. Speaker. I rise in support of this Bill. In July of 2010, my brother -- I lost my brother. While we were making the funeral arrangements, we were told that our mother could possibly have cancer. We later found out that my mother had pancreatic cancer. So, we didn't even have a chance to mourn our brother's death when we had to deal with the illness of my mother or our mother. At

the end of life we were told that we had to take our mother to Branford and I told the doctor that that was not an option because there was no way that we could logistically get back and forth to Branford and be there for my mother. At this point we're dealing with six siblings. So, we tried to take care of our mother at home to the best of our abilities but I quickly learned that the worse the patient get's, the more professional help that they need. So, Thanksgiving of that year in 2010, we rush our mother to the hospital and I stayed with my mother all night in a cold, dark, sterile room; stayed with my mother to make sure that she received the pain medicine so she would not feel the pain from the cancer; stayed with my mother to see her body racked with pain and to see a beautiful woman, a woman who was so beautiful go beyond, look beyond recognition. The next morning someone from the health based Hospice care facility as representative Dan Fox told you about a few minutes ago, came in and looked at my mother and realized that she was at the end of life. This social worker pulled whatever strings she needed to pull to get my mother admitted to the facility that morning. The next night, the next day or morning, early morning, my mother died.

And, it was with great comfort that my mother died in a warm facility where there was privacy, and to see that woman whose face was so racked with pain that I could not recognize her -- excuse me, to see the peaceful look on her face and to see her in an environment where my family could feel and find comfort and to see her in an environment where we could all stand at her bedside. And, if we had to go to Branford, I don't see all of us being at my mother's bedside. And, I imagine my mother dying alone or with one of her seven -- six remaining children. And, so, when I heard that that facility was going to close, it broke my heart when I heard those families testify, to hear the heart wrenching stories about how one person whose father was taken to Branford and as soon as he got there, he died and they were in Stamford. And, it is not fair to the family to be separated from their loved ones and it's not fair to the person that's dying to be separated from their loved ones and not have them with them. So, I am in strong support of this Bill because it's very, very important. And, I know -- I'll be honest with you, since this experience, I have a new respect for Hospice because they not only help the patient, but

they help the family because when you're going through this, you can't think, you can't make decisions. But, Hospice has individuals there that can help you through the process. So, I'm asking and I'm pleading with my colleagues to please vote for this Bill.

Thank you.

DEPUTY SPEAKER ALTOBELLO:

Thank you, Representative Miller.

Representative Nardello of the 89th, you have the floor, madam.

REP. NARDELLO (89th):

Thank you, Mr. Speaker. Mr. Speaker, I rise in support of this Bill, but I did want to speak about the fact that when we were discussing this Bill in the Public Health Committee there were some issues that were raised regarding the regulations and oversight. And, I do think as we're going forward we want to make sure that we bring the philosophy of Hospice care which is a very singular philosophy, to other parts of the State and as was just so eloquently said, to families so they can be close to their loved ones in this very difficult time. But, I also want to remind this chamber that as we go through the regulatory process, that it is incumbent upon us to make sure

that the proper oversight of all these facilities does occur. I've had the opposite experience where I have been through a facility that did not provide the proper Hospice philosophy and that can be incredibly difficult. So, I'm just asking that we provide funding for oversight and I'm going to say that word as we go forward because this is an area we as a legislature often fall down on the job. We like things to be checked on, we like to make sure that people hold the highest standards, but then we don't have the monetary funds to allow that to happen. So, as we go forward, as we look at the regulations, it's incumbent upon all of us to make sure that we have the highest standard of care and the ability to evaluate that standard of care. With that said, I ask people to support the Bill.

DEPUTY SPEAKER ALTOBELLO:

Thank you, Representative Nardello.

Further on this Bill as amended? Further on the Bill?

If not, staff and guests please retire to the well of the House. Members take your seats. The machine will be open.

THE CLERK:

The House of Representatives is voting by roll call. All members to the chamber, please. The House of Representatives is voting by roll call.

DEPUTY SPEAKER ALTOBELLO:

Have all the members voted? Please check the board to make sure your vote is properly cast. If all the members have voted the machine will be locked.

Would the Clerk please take a tally and would the Clerk please announce the tally?

THE CLERK:

House Bill 5499 as amended by House "A".

Total number voting	149
Necessary for adoption	75
Those voting Yea	149
Those voting Nay	0
Those absent and not voting	2

DEPUTY SPEAKER ALTOBELLO:

The Bill as amended passes.

Would the Clerk please call Calendar 108, one zero eight, please.

THE CLERK:

On Page 34, Calendar Number 108, substitute for House Bill Number 5107, AN ACT CONCERNING CAPTIVE INSURANCE COMPANIES. Favorable report on the

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ROBERT GREENSTEIN: I believe it would because those terms do not occur in the licensing process of the existing bodies. For example, the American College of Medical Genetics, the American Board of Medical Genetics or the American Board of Genetic Counselors don't recognize that particular language, so it would make it a conflict of trying to fit people into too many different roles.

REP. LEGEYT: Thank you. And do you foresee or is it assumed that a genetic counselor, who is an assistant or is a supervising counselor, would have to have two levels of licensure because of the --

ROBERT GREENSTEIN: It would be unclear how many different bodies they have -- they owe allegiance to, whereas, if they go through the Department of Public Health, through that licensing process, it makes it a level playing field.

REP. LEGEYT: Thank you.

SENATOR GERRATANA: Thank you.

Any other questions?

If not, thank you so much for coming --

ROBERT GREENSTEIN: Thank you very much.

SENATOR GERRATANA: -- today and giving your testimony.

Next is Representative Lonnie Reed.

HB 5499

REP. REED: Good morning. Good morning, Senator Gerratana and Representative Ritter and all the distinguished members of the Public Health Committee. I have to say after sitting through

the testimony I've heard this morning, it gives me even a new appreciation for the kinds of issues that you address. I mean, they really impact people's lives in the most important ways.

I am, for the record, State Representative Lonnie Reed. I represent the 102nd District in Branford.

I am here to oppose HB 5499, AN ACT CONCERNING REGULATIONS RELATING TO HOSPICE CARE.

I want to say -- begin by saying that I am a fervent believer that every family should have access to a high quality hospice facility when the time comes to say goodbye to their loved one. And I believe that we should encourage the creation of all kinds of hospices to serve our Connecticut communities: small facilities, hospital rooms and units in hospitals -- the kinds of things we already have in Connecticut -- programs that deploy trained caretakers to go into people's homes when they choose to die at home, and also hospitals, such as our own Connecticut Hospice in Branford, which as everyone knows is an award-winning facility and the first in the United States.

Again, more high quality hospice care in Connecticut is a goal I share, but the key words here are "high quality." I am very concerned that HB 5499 will move us in the opposite direction by commanding the Department of Public Health to adopt regulations that, among other things, reduce to merely adequate the critical ratios of medical professionals to patients in keeping with Medicare's minimum health and safety requirements.

I also fear that HB 5499 will invite into our State for-profit -- a for-profit hospice

industry that includes some parent companies that are now under investigation by the US Department of Justice. The -- Justice is looking at them for potentially unlawfully pocketing Medicare dollars without delivering high quality hospice services and also for systematically recruiting nonterminal patients from nursing homes who are warehoused then in long-term hospice care facilities that are understaffed for-profit facilities. And these patients who do belong in hospice facilities are deprived of the medications they need, the care they need, the activities they need, the things they need to go with their lives.

I am not suggesting that proponents of HB 5499 intend for bad things to happen. Indeed, I'm looking at the list of sponsors and, of course, the people on this committee are among the finest in the legislature, and I mean that sincerely. So I know this is not intentional.

On the contrary, I know they are eager to make excellent hospice care more accessible to more people in facilities and settings that are an easy commute for the families of dying loved ones. My concern is that HB 5499 will have consequences that are totally unintended.

Forty years ago, our State made history by opening the very first hospice in the United States. We helped pioneer a whole new way of experiencing the end of life. Terrified patients and grieving frightened families have become transformed and able to find peace, love, comfort and even moments of laughter and joy because of hospice care as they say their final goodbyes.

That is the kind of high quality hospice care we need to protect and to encourage in the State of Connecticut. We've already set a very

high bar. Please reject HB 5499. And I thank you so much to the committee for allowing me to testify.

SENATOR GERRATANA: Thank you, Representative.

Representative Ritter.

REP. RITTER: Thank you, Senator Gerratana.

And thank you, Representative Reed, because you did a wonderful job of helping us all keep our eyes on the goal, which is to provide safe, quality, adequate, accessible, and I would add "affordable" hospice, not just to some of the residents in our State but all of them. And I think we agree on that. And as far as we are able to move forward with this, I would like to also state, it's certainly a concern of mine that the part about accessible, affordable and available to residents across our State is indeed a motivation for this proposal. And I thank you very much for, as I said, helping us remember all of our goals.

Thank you, Senator.

SENATOR GERRATANA: Thank you, Representative Ritter.

Representative Nardello.

REP. NARDELLO: Thank you, Representative Reed, for being here today.

And I share some of your concerns so I would like to -- and I understand what the issue is. The issue is the bottom line is Branford is far away for a number of people, and it's very hard and they don't want to be away from their families so we want to have hospice in other areas of the State. But having just been

through this, by the way in a very painful way, I really was unhappy with the hospice care that was provided and was designated a hospice but truly was not hospice. I'm going to state that for the committee. It was rated hospice but I can tell you from a healthcare professionals' point of view that there were numerous things that I then discussed with my physician who agreed with me that things should have been done that weren't and things were done that should not have been done.

So my question to you is, What mechanisms are in place to ensure and to monitor the quality if we extend these hospice facilities, if we make them more accessible -- which is one thing, again, I support -- how do we ensure the quality and that they actually follow the hospice model, as opposed to just to putting in health professionals who are not actually hospice trained, are technically in a hospice facility? So I -- I -- you can see that I've having -- just had this been recent, it's very fresh in my mind and actually quite painful.

SENATOR GERRATANA: Thank you, Representative.

REP. REED: Was that -- was that a question?

REP. NARDELLO: For you, yes, I think it was. I'm asking you if there is a way that you know of to ensure that the standards of quality -- what do we have in place for monitoring and quality as we extend hospices throughout the State? If not, it might be appropriate to ask me this of another, you know, of another speaker but from your perspective, I know that the standards in Branford are different than the rest of the State. But what is the monitoring process for these other -- what other healthcare institutions that are doing hospice?

SENATOR GERRATANA: Representative Nardello and Representative Reed, I just want this to be clear that the question before us and to you is: The bill that we have before us -- if I understand correctly, how does that ensure that the standard of care would be appropriate in a hospice setting? And I think the bill cites a federal law or regulation so that might be helpful information, too, but please proceed.

REP. REED: I think our very concern is that the bill, as I understand and I read it several times, goes to minimal standards. And I think Connecticut is known to have at least pursued -- and certainly at Connecticut Hospice -- higher standards. I think the ratio is three professionals per patient. We offer a lot of other services that I know not every hospice can offer. I mean we offer activities and music and art and that kind of thing. And I know that for some families that's probably unaffordable, although we have a nonprofit hospice and money goes to help everyone who comes to our hospice.

But our hospice stands ready to train anybody. And I think that's helpful. To really train -- we have 40 years of experience and that is at every level from the person who's on duty, every professional technician, all the way up to the oncologists and all of the people who are interacting with the patient. And we love being asked to help so that's something we want to do.

And -- and I think, you know, that helps ensure a standard where we all kind of can get a sense of what's working and what isn't. I think, certainly, Representative Nardello, your experience should be somewhere put into some form of testimony that we can look at because I think we really need to look at people's

personal stories to sort of figure out how hospices are doing.

But the one final point I wanted to make is that I think we need to be collaborative on this. I think somewhere along the line the nature of being collaborative on making this all happen for all of Connecticut has gone off the rails a bit and some entities are being pitted against other entities. I think we want to ensure that there are several possible hospices that are all high quality that they can all coexist and they will all help each other achieve the same goal.

SENATOR GERRATANA: Thank you so much.

Are there other questions?

-- excuse me -- Representative Scribner.

REP. SCRIBNER: Thank you, Madam Chair.

Good morning, Representative Reed.

I -- I first want to applaud you for your advocacy of the Connecticut Hospice located in Branford. I share great applause to the -- what they have provided to patients and their families in need for, I guess, approaching four decades.

As you indicated the Connecticut Hospice was a trailblazer of sorts and, certainly, was the first in the country. And I think the example that it set has provided a high standard for others to follow. As I -- as I have observed the interest and efforts through the Department of Public Health, who does have regulatory authorization over a facility, such as the Connecticut Hospice facility, they have set that high bar and high standard. Is there

something that is either within the language of this bill that is before us or the proposed regulations coming out of the Department of Public Health that particularly concerns you as it somehow reduces the high standard that has been set by the Department and followed by the existing Connecticut Hospice facility?

REP. REED: I have to go back and reread the bill as currently written. But the thing that caught my eye initially was the word "adequate," talking about "adequate" staffing. That opens up a whole hornet's nest of possibilities, and I -- that really, really, I have to say, gave me pause.

REP. SCRIBNER: I also want to state for the record that I happen to serve on the board of directors of the Regional Hospice and Home Care of Western Connecticut, which is headquartered in Danbury, Connecticut. And I have a fairly strong knowledge of their interest among other areas of the state to be able to follow the fine example that Connecticut Hospice has established throughout the years and be able to provide, at least, an equal-type facility that would be available to the benefit of patients in need and their families in a much more close and convenient circumstance.

I do not see or believe that there is a potential threat to the quality that would be required by any additional facility. I think, if anything, there provides a much greater opportunity for residents of Connecticut who require such service to have that service provided. And -- and I have followed very carefully the recommendations for the regulatory changes that this bill seeks to address, including attending a regulatory

hearing along with probably about 200 other people a few months back.

I -- I am very reassured by the folks at the Department of Public Health that maintaining the highest standard possible is optimum and -- and nothing less would be acceptable or allowed for and so I -- I guess I just have the interest based on the comments that you've made before the committee today that somehow you seem to be under the impression, which is different than mine, that standards are being lowered and, therefore, additional facilities shouldn't be allowed.

REP. REED: That is my concern. I have to say I know the fine work that's happening in Danbury and that does not. I'm in no way suggesting that Danbury is in that position. But I think -- what our concern is, is that reduced standards will invite in some for-profit individuals or companies that are in the for-profit game, and -- and we just want to make sure that -- that Connecticut keeps those standards high. And as Representative Nardello suggested that, perhaps, oversight is a little bit more stringent so that we really know what's going on.

As we all know, we can write bills all we want, but the reality is what happens in the real world. And what happens in the real world is something that needs oversight, care and attention. And -- and so I, you know, I think it behooves us all, because we all are going in the same place; we all want the same thing -- to just be very wary of the forces that are out there that are in a for-profit game that has very little to do with tender love and care when you say your final goodbye.

REP. SCRIBNER: I -- I thank you for your testimony and thank you for your responses to my concerns and questions. I anticipate that there will be a lot more dialogue on this bill before the end of the day.

Thank you.

SENATOR GERRATANA: Thank you, Representative Scribner.

Are there any questions or comments from the committee?

I also anticipate that we will be discussing this further before the day is over, Representative Reed, and I also hope that you'll have the opportunity to come and discuss it with myself, my co-chair, anybody else on the committee as we move forward.

REP. REED: Thank you so much.
And I have to just reassert how much I respect all of you, and I'm eager to work with you.
Thank you.

SENATOR GERRATANA: We've more than exceeded the first hour of our public hearing, and so, as is our custom, we are going to go to the public speaker registration and we will be alternating between the two lists until we're finished with the public officials list. So looking at that list, our next speaker would be Linda Wallace and she would be followed by Anthony DaRos. And Linda will be speaking on Senate Bill 369.

Is -- is she here in the room?

LINDA WALLACE: Good morning -- or close to afternoon now, Senator Gerratana, Representative Ritter, Senator Welch,

Jonathan Steinberg. Oh, he spoke already. I'm sorry. Okay. Great. Then it's Anthony -- I believe it's -- DaRos, D-a-R-o-s, first selectman of Branford? Ah, yes.

Welcome, Mr. DaRos.

FIRST SELECTMAN ANTHONY DAROS: Good morning, Senators and Representatives, and I want to thank you for allowing me to be here today and testify.

My name is Anthony DaRos, and I'm the first selectman of Town of Branford, and I'm also the vice chairman of the board of directors of Connecticut Hospice, as such, I am here to testify against Bill Number 5499.

My reasons are rather straightforward. First, Connecticut has been at the forefront of providing excellent hospice care to patients and their families. They should remain the leader in that movement not a follower.

Second, the Department of Public Health proposed regulations more than a year ago that were intended to change to level of care provided to hospice patients and their families. I opposed these regulations when they were introduced, and I oppose changing the current regulations as incorporated in this legislation. I know, as a board member of the Connecticut Hospice and as a family member of a hospice patient, that it is -- that it is unreasonable to enact the legislation that is supposed to help the sick and needy by reducing the number of nurses, doctors and other caregivers that hospice must provide.

Well, I know that there will be others who can testify to the medical issues involved, I am sure that this is one situation where less is

not more. Since our regulations were enacted in 1993, patients have had an access to in-patient hospice services in the state in hospitals and in nursing homes. The legislation will not give better access to the proper care -- and I say "proper care." There is no point to enacting legislation that is meant to give patients greater access to inadequate services.

Third, reducing the level of care that would be provided in the hospice in-patient setting creates an environment that is ripe for abuse. Hospice -- hospice providers would receive benefit payments from the government and insurers will, if the regulations permit it, have the incentive to provide only the minimum mandated services, thereby cutting costs and increasing profits. This is not conjecture on my part.

The press had reported that the federal Department of Justice and the Office of the Inspector General, among others, are currently involved in investigating for-profit hospice providers in other parts of the country. While some of those providers are being investigated also operate here, you should keep those questionable practices and investigations out of Connecticut by maintaining the high standards that have been the hallmark of hospice regulations in this state.

I believe that this legislation should not be passed because it is not good for the people of Connecticut who need hospice services. At the very least, this legislation should be put on hold at least until there is a study and better understanding of the results of the investigations and practices by hospices in other parts -- other parts of the country that are subject to the lesser standards that are

being proposed. Now is not the time to rush into this legislation that will adversely affect the patients and families in their most trying times.

That is part of my written testimony to this, Madam Chair, but I would like to say that I've also had to -- had to use hospice services in the past. And the care goes beyond just the -- the passing of a loved one. It goes beyond that. And I could agree with the Senator who knows the high quality of hospices, and I know the one out west does do a good job.

I'm in favor of having this level of services throughout the State of Connecticut, and I think we can accomplish that. And we should look at the caregiving as opposed to the profits. And I think if we maintain that high standard that the hospice care in Connecticut will continue to be the leader throughout the nation.

I thank you very much, Madam Chair.

SENATOR GERRATANA: Thank you very much for coming today and giving us your testimony. We do appreciate that.

Are there any other comments or questions?

If not, sir, thank you again for coming.

FIRST SELECTMAN ANTHONY DAROS: Thank you very much.

SENATOR GERRATANA: You're welcome.

We go back to the public portion, and I -- I think it's either Mary or Manny Kenney on Senate Bill 369? 369? I think it's a Mary.

Welcome.

REP. CANDELORA: -- Ranking Member, Perillo and Senator Welch. I'm here to testify in opposition to House Bill 549, AN ACT CONCERNING REGULATIONS RELATING TO HOSPICE CARE. HB 5499

I did submit testimony. I'm not going to read it, but just in -- in summary, on a public policy level, I don't think that we should be dictating that the Department of Public Health adopt minimum standards for hospice care. Forty years ago Connecticut was a pioneer in adopting hospice care, and we have quite comprehensive regulations that have served us well. Connecticut Hospice being the beacon of -- of the services that that they're provided. And I just would caution us all as the direction that we're going in with these regulations. While they may be well-intended to attempt to allow hospice facilities to open up in the state of Connecticut, these federal standards are minimum guidelines that other states have adopted and are grappling with on the level of fraud coming in, the for-profit industry coming in, and the individuals that are hurt by this are our most vulnerable, the individuals that are at the end of life care. And I think what is, particularly, touching for me is that these individuals are never in a position or rarely be in a position to be able to come here and advocate for themselves. And so I don't think we have an appreciation or feel necessarily unless we've gone through hospice care from -- with a family member. And so the advocacy really lies with the people that are providing the services, and -- and I think we really need to pay attention to that.

I'm concerned of the unintended consequences of this type of bill if passed, because what we are essentially doing is by lowering these standards, we are painting a very broad brush, and we will be eliminating the existing way

hospice care is provided in the state of Connecticut. Connecticut Hospice is certainly a unique situation in being a specialty care hospital. These regulations, if adopted, would effectively eliminate their status as a specialty hospital, and they would have to operate under these minimum guidelines. Now, one could say, well, they'll just continue to operate at these higher standards that they currently have, but as we all know, they wouldn't be able to compete under that playing field. And if we lower the thresholds, hospice care is going to come down to that lower threshold. And ultimately, I believe what is going to happen is that these large companies that are existing in other states are going to come in and reap the benefit of the profits at the expense of our loved ones.

So I strongly urge you to reject this bill. Thank you.

SENATOR GERRATANA: Thank you, sir.

Are there any other comments or questions?

If not, thank you for your testimony today.

REP. CANDELORA: Thank you.

SENATOR GERRATANA: Next is Jane Schachter.

SB 369

JANE SCHACHTER: Good afternoon. My name is Jane Schachter. I'm the school counselor for Solomon Schechter Day School.

I sat here last year with a litany of issues, events, concerns that besieged my little friend Alyssa. She wept while separating from mom, clung tenaciously to the teachers during the school day and would not walk anywhere near the

is not bothered by having GSD, but having a nurse hanging around the classroom would not be helpful. All the dynamics would change and Alyssa would have more of a chance of having a stigma of being a sick kid. As being Alyssa's babysitter, I got to learn how having a disease does not change who you are or what you can do. Alyssa is a normal six year-old girl who just needs a little extra attention to keep her healthy.

Thank you.

SENATOR GERRATANA: Thank you, ladies. Thank you very much. Before you go --

Are there any questions or --

If not, thank you both for coming today and giving your testimony.

JANE SCHACHTER: Thank you.

SENATOR GERRATANA: Okay.

Finally, on our elected officials and agencies, Representative Dan Fox.

Welcome.

REP. FOX: Welcome. Good afternoon, Madam Chair and distinguished members of the Public Health Committee.

My name is Dan Fox. I am a state representative from Stamford, representing Connecticut's 148th District. I thank you for allowing me the opportunity to speak today in support of House Bill 5499.

I appear today as a state representative in support of the very important piece of

legislation, yet, I speak as the resident of a city -- the City of Stamford with a personal and intimate awareness of the invaluable service once provided to our community that is no more.

On July 16, 2011, a dear family member passed away at the Rosenthal Hospice in Stamford, Connecticut. My Aunt Berdie left behind three children, a husband, two granddaughters and a tremendous amount of other family members and friends. She loved books, talking, teaching, and everything and anything having to do with Cape Cod.

The caring environment provided by the Rosenthal Hospice for both my Aunt Berdie and just as importantly, her family, was absolutely remarkable, and I believe unlike the care that was available anywhere else in our surrounding area.

The Rosenthal Hospice opened in the year 2000 with the intent for the facility to ultimately be licensed as a hospice. However, until the regulations governing hospices in Connecticut were revised, Rosenthal fell under the nursing home licensure and regulations. The revisions did not happen. It proved remarkably difficult for a 12-bed hospice facility to fulfill the standards governing nursing homes. Sadly, in December of 2011, the Rosenthal Hospice closed its doors, following the death of Peggy Andrall, its final resident, on December 8, 2011.

A 12-bed hospice facility, such as the Rosenthal Hospice, cannot operate in the state of Connecticut under current regulations. It has been tried in my hometown and sadly, failed.

Our family members, our friends, our neighbors and our constituents should have access to facilities whose primary purpose is hospice care, care within or in close proximity to the communities that these people call home.

Six weeks ago my wife and I welcomed our third child, a beautiful little girl named Maura Kelley Fox. Over the past few sleepless weeks, I've reflected upon the manner by which we prepare for a loved one's arrival so as to ensure that this time period is one filled with care and compassion.

Connecticut has done remarkable things in the field of hospice care. There's no doubt about it. We must continue to do what is necessary to ensure that the care and compassion we provide for our loved ones at the beginning of their lives is similarly available and provided for them at the end of their lives.

I believe that the underlying legislation is a significant step in that direction. I asked for the Committee's support of this legislation and thank you for your time and consideration.

SENATOR GERRATANA: Thank you, Representative.

Actually, I do have a question of you, if you would be so kind. There was a Rosenthal Hospice that was established in Stamford and, you know, according to your testimony, a 12-bed facility, and I know that we do have, of course, regulations regarding one hospice -- hospital, if you will, in our state. The Rosenthal Center could not meet any of those regulations or requirements; and therefore, it was determined that it would be appropriately licensed or regulated under nursing home regulations; is that correct?

REP. FOX: Correct. Yes, Madam Chair. It was -- it was initiated through legislation passed by the General Assembly as a pilot program back in the year 2000. The goal was to ultimately have the regulations governing hospice be revised so that a facility -- a 12-bed facility could operate in the state of Connecticut.

Unfortunately, the revisions never occurred. Rosenthal had to operate pursuant to the nursing -- the guidelines governing nursing homes. It then had to -- in an attempt to -- to continue to survive, transitions -- and made significant renovations so that it would be able to operate under the regulations governing skilled nursing facilities, and unfortunately, it did not work out. They were unable to maintain the facility -- or they weren't able to provide the services while maintaining the standards for the other types of facilities.

SENATOR GERRATANA: Okay. Thank you, again, just for that clarification.

Are there any other questions?

Representative Srinivasan.

REP. SRINIVASAN: Thank you, Madam Chair.

Thank you, Representative, and congratulations to the new addition to your family.

REP. FOX: Oh, thank you.

REP. SRINIVASAN: Enjoy.

REP. FOX: Yes.

REP. SRINIVASAN: The years fly by very quickly.

REP. FOX: They do -- they do. Unfortunately, the nights don't go as fast.

REP. SRINIVASAN: Yes, exactly right.

The facilities in terms of the 12-bed facility that you were talking about when they did not meet the criteria, is that what I -- am I understanding that -- is that, or they had different guidelines that they had to be as a nursing home, as opposed to a hospice? Are you -- I was not clear about why the facility had to be closed down.

REP. FOX: It was closed down -- as I said it was -- it was created pursuant to a pilot program by the State of Connecticut. And it was -- it had came into existence as a -- at the time it came into existence, it was governed by the nurse -- the regulations that govern nursing homes. At -- the idea was that eventually the regulations governing hospices would be revised so that a facility such as the Rosenthal Hospice, a smaller facility, maximum of 12 beds, could operate and function pursuant to the hospice regulations in the State of Connecticut. Those regulations were never revised. The hospice had to maintain different standards and operate pursuant to the regulations governing nursing homes and, then, in 2008, regulations governing skilled nursing facilities -- as I said, it was an effort by the -- the organization to continue operation in the hopes of -- they realized the regulations governing hospice care were likely not going to change. They thought they may have a better chance at surviving if they qualified as a skilled nursing facility as opposed to a nursing home. They made that transition. And just due to the standards that were required of the facility to operate, as a skilled nursing facility and, first, as a -- as a nursing home with only 12 beds and then

providing an entirely different service, essentially, then that which is provided pursuant to nursing home regulations or skilled nursing facilities, they were unable to -- to keep the operation going.

REP. SRINIVASAN: Thank you, Representative. To the best of my knowledge, we do have hospice hospitals right now in the state. What regulations govern them? Are they -- are they going as nursing home facilities? Are those the regulations that regulate them, or are they being regulated by another set of rules?

REP. FOX: To be honest, I may defer to others who are much more knowledgeable at that. I mean, for instance, the Rosenthal Hospice, it's -- it was -- had been located in the City of Stamford. It was on a piece of property, which also on the property is Stamford Hospital. The Rosenthal Hospice was a freestanding facility behind Stamford Hospital, and then directly adjacent to Rosenthal and Stamford Hospital is a separate facility called the Tandet Center. Stamford Hospital provides hospice services. Tandet Center, which is a skilled nursing facility and a long-term rehabilitation facility, also provides hospice services.

I -- I think the hope -- the idea being that Rosenthal Hospice, they're different services provided by a hospice, or there's a different focus in a hospice, then there is in a hospital or in a long-term rehabilitation facility.

So to answer your question, I'm not -- I can get -- I can attempt to get you that information and may defer to others here today who are much more knowledgeable as to those regulations. I think the idea of being that the primary purpose of a hospice facility is hospice care. The primary purpose, in my

opinion, of a hospital is acute care. The primary purpose of a nursing home is long-term care. So I think there's different primary purposes for each type of organization, all of which are valuable to our community, all of which we think should be made available to our -- our communities.

REP. SRINIVASAN: Thank you, Representative. We did hear a previous testimony where there was concern about the quality of care in the -- in this place and, you know, there was a suggestion that somehow quality would suffer, for competition others would come in just to rake money. Do you have any concerns or any thoughts on quality of care in these institutions? If we were to, quote/unquote, change the standards considered by some as lowering the standards? I'm not sure that's true, but if one looks at it in that particular way.

REP. FOX: I think I -- two points in response to your question, Representative. I think the first point is the -- the legislation as drafted makes reference to federal regulations within which are standards, whether it be for nursing staff, for fire safety, for the types of rooms with facilities that would be established within hospice facilities and things of that nature. So I think there are standards set. I'm reluctant to use the word "minimum." And I'm concerned by the use of the word "minimum." I know from my perspective -- and if it were my family member as it was just a few months ago, I would be much more comfortable knowing that at that point in their life they had access to that care rather than having no access. So I'm -- I think the idea of saying it's "minimum" -- I understand why the word is used and why the term is used and, perhaps, that is a base level of care.

Being as familiar as am and was with the Rosenthal Hospice, I can tell you that individuals trained in that field take their work very seriously. And the idea of there being a minimum that they are just trying to reach and then stay at, my experience has been that's not the case. So I think whether there be minimum standards or whatever you want to call them, there are standards in place. I think access is the key. Currently in Stamford, my hometown, there is no access, whether it be minimum care or maximum care or however you want to define it, that is not available in a facility whose primary purpose is hospice care, and so that -- that is my concern.

REP. SRINIVASAN: Thank you, Representative.

Thank you, Madam Chair.

SENATOR GERRATANA: Thank you.

No other questions or comments?

Thank you so much. Congratulations on your --

REP. FOX: Oh, thank you. And Madam Chair, if I may, just -- one more brief second. I have testimony and remarks here today from former state representative, Christel Truglia, who's quite sick, was unable to join us today, but asked that I present to the clerk for the Committee's review --

SENATOR GERRATANA: Absolutely, absolutely. I --

REP. FOX: -- comments that she had concerning this issue which I know is of very utmost concern to her --

SENATOR GERRATANA: -- served with Christel --

REP. FOX: Yes --

SENATOR GERRATANA: -- and I hope, certainly, that she gets better.

REP. FOX: Yes, thank you.

SENATOR GERRATANA: Thank you

REP. FOX: Thank you for your time.

SENATOR GERRATANA: The clerk will get it or you can drop it off there. Thank you so much, Representative.

Next is David Jacobs. I think David might have been with the Ross Family so he might have already given testimony.

Donna Kosiorowski.

SB369

DONNA KOSIOROWSKI: Good morning, Senator Gerratana and members of the Public Health Committee.

My name is Donna Kosiorowski. I'm here on behalf of the Association of School Nurses of Connecticut. I'm also a member of the American Federation of Teachers.

I've submitted written testimony to you already and it -- to some of you, it might appear detailed and graphic, but I wanted you to understand the -- the actual administration of rectal diastat. In my experience, I have not seen injectable valium at school. We are beginning to see some sublingual, under the tongue, valium, but, primarily, the mode of administration for all the students that we have in my district is rectal administration.

that's why we don't have too many questions for you.

Thank you very much.

LESLIE SIMOES: Thank you very much. Thank you.

REP. RITTER: That testimony brings us to our next bill, which is House Bill Number 5499, AN ACT CONCERNING REGULATIONS RELATING TO HOSPICE CARE.

And our first speaker is Carol Garfield, to be followed by Mag Morelli.

CAROL GARFIELD: Good afternoon.

REP. RITTER: Good afternoon.

CAROL GARFIELD: Thank you for the opportunity, members of the Public Health Committee. My name is Carol Garfield. I live in Wolcott.

I'm testifying today in support of the HB 5499, AN ACT CONCERING REGULATIONS RELATED TO HOSPICE CARE.

I wanted to testify today to express my gratitude for the great care that my dad received during his short stay at the Vitas Hospice Center in Waterbury. I'm sorry.

REP. RITTER: Take your time. We're here for a little while.

CAROL GARFIELD: He passed away in late January. Please note that although very difficult to speak of, I am so very thankful and overwhelmed by the amount of support both physically and spiritually, everything that each of the Vitas staff so lovingly, genuinely, has generously gave during such a difficult time.

In all of my years, I have never known this field to be so filled with the epitome of kindness gathered all in one place. On behalf of myself and my children, this type of care needs to be offered everywhere in the state. In the words of my 25-year-old daughter, Tiffany, who collaborated with my 23-year-old daughter, Britney, to write the obituary.

She said, Finally, you are with people who truly care about the patient, the family and each other. You are finally right where you belong.

I don't think truer words could ever have been said. This inpatient unit allowed my son, who arrived from the West Coast, to focus on his last visit with his hero. My daughters went to sleep by his side with me in a quiet and nurturing environment. From the moment of arrival to the last moment when my son was allowed to escort his grandfather respectfully down the elevator with the American flag draped over him because he's lived up to everything that they so proudly stand for.

Words, although don't ever fully express the appreciation, they gave my dad back his dignity, and I thank them.

To having experienced the love and support of Vitas and watching it as it is extended to my dad, I want to say that unless each and every person who has a life-limiting illness gets cared for by great hospice service, only then will we have reached our full potential as a state.

So please support the HB 5499 so that every available patient can experience the love, the support and the beautiful care -- excuse me --

that my dad was able to receive. And thank you for the opportunity to speak to you today.

REP. RITTER: Thank you very much, Carol. I know this wasn't easy for you, and we very much appreciate the chance to hear from you on this issue.

Are there any questions from the committee?

Thank you that was so very lovely.

Our next speaker will be Mag Morrelli, and she will be followed by Maureen Collins.

MAG MORELLI: Thank you, Representative Ritter, members of the Public Health Committee.

My name is Mag Morelli, and I am the president of LeadingAge Connecticut, a membership organization representing over 130 mission-driven and not-for-profit provider organizations serving older adults across the continuum of long-term care, including nursing homes and home health care agencies.

LeadingAge Connecticut was formally named the Connecticut Association of Not-for-profit Providers for the Aging or CANPA.

On behalf of LeadingAge Connecticut, I'd like to submit the following testimony in support of House Bill 5499, AN ACT CONCERNING REGULATIONS RELATED TO HOSPICE CARE.

LeadingAge Connecticut maintains a vision in which every community offers an integrated and coordinated continuum of high quality and affordable long-term health care, housing and community-based services. We have, therefore, supported the Department of Public Health's effort to update the current regulations

governing inpatient hospice facilities. I has been our hope that these revisions would encourage the development of new inpatient hospice facilities, residences or units established throughout partnerships, integrations or new initiatives so that -- so as to provide health care consumers throughout the state with increased access to quality end-of-life care options. We support the bill before you today that we believe will encourage the passage of these updated regulations.

The state is currently embarking on a rightsizing strategic plan for our long-term care system. In line with that initiative, LeadingAge Connecticut has been encouraging our nonprofit long-term care providers to develop business plans to restructure and or diversify existing facilities and services to strengthen the full continuum through the development of enhanced models of care. The common goal is to reshape the long-term care system to meet current consumer demands, market needs and the goals of the State's long-term care plan. The opportunity to provide high quality, facility based end-of-life care to meet the needs of the community should be available as an option for existing long-term care providers to consider in such planning. That is why it's important that the State move now to adopt new hospice facility regulations while the State is investing in a long-term care rightsizing initiative and while quality long-term care providers are strategically planning for the future of aging services.

Thank you for this opportunity to present this testimony.

REP. RITTER: Thank you for your testimony.

Are there any questions from the committee?

Representative Srinivasan.

REP. SRINIVASAN: Thank you, Madam Chair.

Thank you very much for your testimony. In the previous testimony that we've heard earlier on today, the concern that was raised was that in the new regulations the standards of the hospice care would be reduced -- reduce significantly, or we are not aware of what the new standards are. And I know the Department of Public Health is going to oversee this, I'm well aware that. But do you have the comparison of the standards where they were before to where we are going to be right now or -- I do agree that we -- we do need these homes for -- for our patients and everything else, but the standard of care and that it may be profit driven or profit motivated are some of the concerns that people have expressed, and I just wanted to see the what your thoughts were on that.

Thank you.

MAG MORELLI: Right. I don't think this -- I'd -- I don't believe at all this is going to affect the standard of care. We've currently have several hospice providers in our membership who are home health agencies and provide hospice services through nursing homes and in people's homes, and that standard of care will remain the same, if not to be improved. This -- we're looking at this from the facility base, and we seen opportunity right now where we have a lot of high-quality nonprofit long-term care providers who envision being able to provide smaller units or residences of inpatient hospice that could really provide a great environment, an enhanced environment from what their current nursing home residents or people

in the community, consumers in the community, might be able to come into the facility to receive. And so we see it as enhancing what's already out there in community and really an opportunity to provide a really invaluable high-quality inpatient hospice services throughout the state.

REP. SRINIVASAN: Madam Chair, one -- thank you very much for that.

So -- so you feel very comfortable and confident in saying that a person or a family that chooses the hospice care under the new regulations, if and when passed, that their level and the standard of care in no way -- because they're not aware, they're not --

MAG MORELLI: Right.

REP. SRINIVASAN: -- they are an unknown public so they have no clue of what is the difference between A and B, and they have gone to B let us say, because it is closer to them, more convenient, so on and so forth, as far as quality of care is concerned in this location because of the -- of the new regulations, you feel comfortable that quality of care will not be compromised?

MAG MORELLI: Yes, I feel very comfortable. And I also believe that if people are able to establish inpatient hospice facilities throughout the -- throughout the state, while you could come into a nursing facility and received hospice services, I think the ability to communicate the option of having that hospice service there would be enhanced. I think that the actual surroundings would be enhanced, because you'd be providing just hospice care within that unit or that smaller area of the nursing home. So I think it opens

a great opportunity. Of course, we always have to be astute and aware and make sure that high-quality care is being provided throughout the health care system. And I would never -- we would never stand for a lower qualities of care -- a lower quality of care. But we just believe that this would really provide an opportunity for really high quality, nonprofit long-term care providers to provide this option for people in their communities.

REP. SRINIVASAN: Thank you very much.

Thank you, Madam Chair.

REP. RITTER: Thank you.

Are there any other questions from the committee on the --

Thank you very much, Mag, for your testimony.

Next we'll be hearing from Maureen Collins, to be followed by JF Andrews.

MAUREEN COLLINS: Good afternoon. My name is Maureen Collins. I am the director of clinical services for Hospice Southeastern Connecticut and I am a registered nurse. I am here today to testify in support of House Bill 5499, AN ACT CONCERNING REGULATIONS RELATING TO HOSPICE CARE.

I strongly support the concept set forth in this bill, and I'm asking you to favorably support it. The intent of the legislation is to increase access to the highest quality of hospice care. However, there is a technical defect in this bill, and I am recommending the following be amended -- and I know you have my testimony so I don't have to read it word for word -- but what it does add is that there has

to be the importance of including the quality of care of -- on all the levels, routine home care, general inpatient care, continuous and respite care.

Supporting House Bill 5499 with these revisions will require that Department of Public Health to adopt Inpatient Hospice Regulations.

The current hospice regulations were established 35 years ago. The proposed regulations written with 28 of the 29 hospices in -- in the Department of Public Health comply with the latest Medicare conditions of participation.

The regulations would allow the full continuum of hospice care. This includes care in the home, hospital, skilled nursing homes and a hospice residence. Currently, there are only two hospice residences in Connecticut located in Middletown and Branford.

My sister and two of my closest friends died on a hospice program. Because they had the support of family and friends, they were able to stay at homes surrounded by their loved ones. Had they not had the support or if they had had symptoms, which could not be managed in the home, possibly they could've gone to Connecticut Hospice in Branford, where I know they would've received excellent care. However, I would not have been with them all the time because it's at least 50 miles for me to travel one way. I may not have been with them when they were actively dying. I may not have been with them to hold their hand as they died. This is a burden that should not be imposed on terminally ill patients in Connecticut.

I strongly urge you to support House Bill 5499 with the above recommendations to ensure quality state-of-art care and access to hospice care throughout the state, allowing hospice patients and their families to receive care in their community.

Thank you, at this time, for considering my testimony, but I'd also like to thank Dr. Mullen for working with us to resolve this issue. Quality and access to hospice care cannot be separated.

Thank you.

REP. RITTER: Thank you for your testimony.

Are there any questions from the committee?

And thank you, Maureen, for what you do because you're the hospice in my section of Connecticut, and there are many, many people in my community that thank you all every day.

MAUREEN COLLINS: You're welcome.

REP. RITTER: Our next speaker will be JF Andrews, to be followed by Rebecca Paul.

J.F. ANDREWS: Madam Chair, and members of the committee -- distinguished members of the committee. Thank you for having me, and I'm a medical director of The Connecticut Hospice in Branford, and I am going to speak against the adoption of HB 5499, because I really do believe that it dilutes patient care standards.

The old regulations under Section 19-13-D4b, prescribed a nurse for six patients -- a nurse's aide for six patients, physicians, social workers and pharmacists and other team members, including spiritual guides, ancillary

therapists and volunteers to be present at the facility and to be there on a daily basis.

The new regs do not specify numbers of caregivers per patients. They say, "available, acceptable," words that are very, very elastic in terms of legal meaning. And I think that's a pitfall. The old regs under 19-13-D4b have provided us with 35 years or 40 years of experience. We've taken care of 4,000 patients a year and attended to their families, up to a quarter of a million people, so we have a good experiential base for what we say.

Our position is that bill is another variant on an attempt to vitiate or negate the standards under 19-13-D4b that the Health Department wanted to do away with last year and this is another method for that. We're going to continue to do what we do. We have proven staff ratios according to the old regs, and we're going to continue our full care team on a daily basis. "Available" is really not enough. And we will also continue to support research and teaching in palliative care through the John D. Thompson Foundation, another not-for-profit activity of ours.

Recently, we were certified by the Joint Commission in a survey that gave us no recommendations for change. I've been doing this for 40 years, and I have never had a survey that was that positive. We, therefore, feel very endorsed by the Joint Commission, and we can't change our methods now.

Also, this is a very poor time to weaken standards. Numerous for-profit agencies, many backed by venture capital firms, are entering our field of vocation, many of them under Justice Department investigation in several states for palpable and outrageous Medicare and

Medicaid fraud. It's reasonable to surmise that people who practice sharply in these fashions would like to bring their activities from several other states to our state. I think it's not something we want to encourage.

I don't think you can call a service "hospice" unless you have the veteran interdisciplinary team to do the work. And I'm afraid that the residences will wind up referring patients to emergency rooms for acute crisis of pain management and other activities and that standards, if maintained statewide, I think we would welcome colleagues in other areas, Danbury, north, west and south, but the standards have to be maintained. And that's where I'm coming from and thanks for listening.

REP. RITTER: Thank you for your testimony.

Are there any questions from committee members?

And I want to thank you also for your work at Branford.

Our next speaker will be Rebecca Paul, to be followed by John Drakos.

HB5499

REBECCA PAUL: Good afternoon. I've prepared this testimony on behalf of Connecticut Hospice and my position there, which right now is a volunteer.

Good afternoon. My name is Rebecca Paul, and I'd like to share my position with you on the topic of this hearing.

There is a time in life when we have experienced many deaths, those of our parents, relatives, close friends and business colleagues. And we have come to witness various models for end-of-life care provided to

our loved ones as recommended by those who supposedly know best. I'm afraid I have experienced courses of care for the dying that were truly unacceptable.

Most tragic was that of my mother's end-of-life. She was diagnosed one April with stomach cancer, and the recommendation was made to remove her stomach. After surgery in a prominent hospital, the surgeon advised the cancer was in her stomach, liver and pancreas. She was terminal. She returned home to recuperate. She was not told she had cancer by her general practitioner, gastroenterologist or her surgeon. She was referred to another specialist who told her she had a tumor. The word "cancer" was never stated.

After a few weeks of radiation she became dehydrated and weak. One morning she was picked up off her bedroom floor by EMTs and return to this prominent hospital. After being rehydrated, she was delivered to a skilled care facility where she lay curled up in a bed by herself in dirty diapers being cared for by the CNAs. Once a day a nurse came by. She could not see a doctor unless he happened to be in the facility. She could not eat by yourself. She could not receive comfort. She wasn't offered that comfort. She did not have anyone to ask her who she was, what her hobbies were or if she'd like to pray. She was told -- she was not told she was dying and neither were we, because, obviously, they didn't know.

I had her removed immediately and sent back to the hospital because she could not breathe because her abdomen was so distended it looked as if she was nine months pregnant. Again, this was in the skilled nursing facility. She was admitted, brought into a private room on the oncology floor and left alone in a dark

room. She told me she was scared. I did not know what to say because I was, too.

After a week though, she was alert, communicative, she was given morphine and moved, but this time to The Connecticut Hospice, who we had not been told about by any social worker or any other person on the staff, of even the important hospital or the skilled nursing facility.

If you'll pardon me, I'm just going to continue with one more statement.

Something changed for our family then. We were welcomed at The Connecticut Hospice by staff, a social worker, nurse and doctor who explained to us what was happening and asked questions about our family. We were taught the signs and symptoms of dying. We were told my mother could hear us even though she was at the effect of morphine, and we were directed to speak to her, to touch to her, she knew we were there. The spiritual contact called our priest. When he arrived, our family stood in a circle around my mother and said those prayers that she loved to hear, that we loved to pray. We became a unit of care. It was no longer just my mother and her illness.

Less than 48 hours later she died. Our family was invited to come to The Connecticut Hospice to join my mother at her bedside. She was clean, her hair was brushed, she was covered by a handmade afghan that a volunteer had made, and we were asked whatever you need, you could just stay here with your mom until it was time to take her away. I have never ever heard of that occurring in one of the other types of facilities she had been in.

One year later, I entered their volunteer program at The Connecticut Hospice, and I was educated for nine weeks. I also received interdisciplinary (inaudible) --

REP. RITTER: If you could quickly conclude.

REBECCA PAUL: Yes.

REP. RITTER: Thank you.

REBECCA PAUL: Over the last 10 years as a volunteer at Connecticut Hospice being highly trained for numerous hours, I am confident that I personally have impacted lives of numerous patients and families who were under The Connecticut Hospice's gold standard of care. Today, I am a member of the interdisciplinary team as a spiritual care provider.

After 40 years of setting the standard in the United States as the quality provider of hospice care, should there be any question whatsoever of why The Connecticut Hospice's mission, methods, and business model should be affected by the insatiability of for-profit institutions?

Thank you very much.

REP. RITTER: Thank you very much for your -- sharing your story.

REBECCA PAUL: Uh-huh.

REP. RITTER: Are there any questions from the committee?

Thank you.

REBECCA PAUL: Thank you very much (inaudible).

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REP. RITTER: Next we will be hearing from John Drakos, to be followed Diane Grenier.

JOHN DRAKOS: Madam Chair and distinguished committee members, my name is John Drakos. I have volunteered at The Connecticut Hospice for 10 years. I am just one of some 500 volunteers who are required to take nine weeks of training. The volunteer department is opposed to this bill because it would lower the standards. HB5499

There is a fundamental human good that The Connecticut Hospice provides to their patients and patient families. We live in a time when we hear from multiple and diverse sources about what is best for us. Now we hear of the possibility that the hospice model will be diluted down, and we fear patients and families will receive substandard care when only profit becomes the goal.

The Connecticut Hospice mission is not very complex. It is simply to provide the best palliative and supportive care to patients and families during their time of immeasurable pain, stress and sadness. Every department at The Connecticut Hospice contributes to bringing peace and comfort to those most in need.

I can attest that I have never been around a more caring and professional group of individuals. I witnessed the clinical staff, the doctors, nurses, CNAs, pharmacy, all providing a high level of medical care with kindness and respect and an awareness of patient dignity. That's why many families refer to this group of people as "Angels." It's true.

The social work staff provides support to patients and especially to families when most

are at a very desperate time in their lives, not knowing what to do or expect. The staff counsels and guides patient families to better cope with what is happening to their loved one. It is hard to quantify, but, you know, without this group of caring individuals, The Connecticut Hospice would not be able to offer the exceptional care it provides.

Spiritual care is very -- is very important to patients and families at The Connecticut Hospice. It is provided under the guidance of Hospice Chaplain, the Reverend Charles Woody. Reverend Woody with his beautiful voice can often be heard throughout the hallways singing a hymn or a show tune. He lifts up those of all faiths whose hearts are filled with sadness.

The arts department, you might ask what -- what does an art department provide to patients and families. The Connecticut Hospice is blessed to have talented individuals who actually go bedside with patients to provide them with art supplies to draw or paint. There are other departments -- I'll sum up in just a second --

REP. RITTER: Thank you.

JOHN DRAKOS: -- there are other departments at The Connecticut Hospice from security to maintenance to kitchens to administrative, all that contribute to the fundamental goal of The Connecticut Hospice, bringing the highest level of care to patients and their families.

What I am saying is that every component is critical to the functioning of The Connecticut Hospice. The Connecticut Hospice, the first hospice in America, is a gift to the citizens of Connecticut. Please see that all hospices to come maintain the same status.

Thank you very much.

REP. RITTER: Thank you very much for your testimony and for your volunteerism.

Is there any questions from the committee?

Thank you.

Our next speaker will be Diane Grenier, to be followed by Soozi Flannigan. And in the interest of the dwindling afternoon, I would hope that people are able to stay to their three minutes. Thank you very much.

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DIANE GRENIER: Madam Chair, hello, I'm Diane Grenier, RN, diploma graduate nurse since 1986. I practice hospice care and palliative nursing at The Connecticut Hospice Inpatient, and I also worked with their home care. I have also had experience, short-term experience, with two other hospice programs in the state of Connecticut, and it was short-term for a reason.

I strongly oppose the proposed regulations because as written it would negatively impact patients. The regulation 19-13-D4b under which The Connecticut Hospice is currently operating works to protect hospice patients and provide quality care. The proposed new regulation allow for decreased staffing, especially nursing, pharmacy, medicine, social work support. When reading the new proposal, there has been a mix combination to develop these hospice homes, which I know would be smaller units, but decreasing the level of education and expertise of the staff within those homes.

Currently, inpatient hospice services provide intense nursing care to our most ill clients

who cannot stay at home. In my 17 years experience in the home care inpatient experience, I have come to understand that patients and families would prefer to stay home whenever possible. There are times when symptoms, safety and caregiver needs lead to the decision to bring a person to an inpatient care setting. This -- the continuous care option under the Medicare hospice benefit which would allow a patient to stay home in their own setting with a nurse in the home is often not visited by hospice services -- not ours in particular -- but some services because of the expense that the hospice incurs leading to more need for inpatient services.

The decision for placement in an inpatient program is often due to the complexity of managing symptoms at the end of life. The process of dying is not easy. The management of symptoms is complex. A person can experience a multitude of symptoms, such as respiratory distress, intractable pain, terminal restlessness, fear and skin and tumor problems. It is necessary to provide a good death for the patient and for the family to experience. The Connecticut Hospice inpatient services currently has a nurse and patient ratio that protects the safety of the patient with the administration of medications, and the new regulations delete that ratio, which I find a great disparity. Nursing ratios were developed for safety and they need to continue in this process because of the severity of the patients who do come to an inpatient setting.

REP. RITTER: Thank you very much for your testimony.

I would also mention, I know there are many people here still to testify on this, and in the instance that you cannot get through your

written testimony, it is in front of all of us here on the committee already and will continue to be available so, hopefully, that won't cause you any other anxiety that we'll miss any paragraphs.

Thank you very much.

Are there questions from the committee?

Thank you.

Next we will hear from Soozi Flannigan, to be followed by Meg Wayton, I believe, and apologize for the names I'm probably butchering.

SOOZI FLANNIGAN: Good afternoon, distinguished committee members. My name is Soozi Flannigan, and I am a hospice nurse and a nurse practitioner with The Connecticut Hospice for 19 years, and I am in opposition of Bill 5499.

We are here today with our different viewpoints on how hospice inpatient needs to be provided. For us, it is about maintaining the standards of care and patient rights.

For the opposition is about access and being close to home.

Currently, every hospice must provide inpatient level care in order to have their hospice license. There is local access in nursing homes and hospitals across the state. In the last four years, both my Aunt Rita and Uncle Jim died on hospice beds in Danbury Hospital, where their immediate symptom needs were met, the care was excellent and the family could stay around the clock.

I have serious and justified concerns about the proposed changes in our hospice regulations and how they will impact patient care.

The changes are frightening, even if they, quote, unquote, comply with the federal guidelines. Here's a snapshot of one nurses experience practicing in an inpatient hospice under the Medicare guidelines this bill supports. Here's the nurse.

I am working in an inpatient hospice facility with 20 beds. The staffing is one RN, one LPN and two nurse's assistants. As hospice has begun taking more acutely ill patients, the staffing has become inadequate. I work the three to eleven shift. I am running from room to room putting out fires and not doing any quality hospice care at all. It feels more like a MASH unit or a hospice ICU than a true hospice setting. When I complain, I am told that staffing, quote, unquote, meets national standards.

Is this the hospice care model Connecticut wants to provide?

The staffing model being proposed totally underestimates the serious nature of the dying patient. No on-site physician, on-site pharmacist for complex symptom management and no mandated nurse to patient ratios. In the event of uncontrolled symptoms, the emergency departments will be flooded with dying patients in their last hours. I find this to be a disgrace and a disservice to the dying patient and family.

I hope, also, those in high positions of responsibility are aware of the hospice fraud and abuse being investigated all over our country -- almost done -- by the Department of

Justice. Everyone gets the same dollar but not everyone offers the services the dying patient and family have the right to receive. With no mandated staffing, our state is at risk for these abuses.

I could go on and on. I just would like to say decisions to change hospice clinical practice models must be made by those who are fully informed. We can uphold hospices to the higher standards of care hospice patients and families deserve and Connecticut is known for through you, our government.

I urge you to stop this bill, this wolf in sheep's clothing.

Thank you.

REP. RITTER: Thank you very much for your testimony.

Next we will hear from Meg Wayton, to be followed by Mike Sweeny.

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MEG WAYTON: Hi, I'm Meg Wayton. I'm a volunteer for The Connecticut Hospice, and I have been for the past year. I went through the training program, and then I worked at The Connecticut Hospice for several months and saw what a wonderful job they do and what a wonderful facility it is and how dedicated everybody there is, then I moved to home care. I'm now working with patients and their families in their homes. I currently work with two families. I feel the service that I offer them is invaluable. Both of my patients have ALS, and this is a horribly overwhelming illness for the patients and their loved ones. They need care all of the time and there is no break for the caregiver.

When I come in I provide Reiki services for the patient to help relieve their pain and their anxiety. While I am with the patient, it also gives the caregiver some time to get out, do errands or just to relax themselves. I am also provide emotional support and a lending ear to the families who need it so desperately, and Reiki treatments for any other family members who need relaxation and stress relief. My diversified duties can include a full range of things from companionship for the patient, reading, talking, just being there, to playing with the kids, whatever seems to be needed at a particular time. I am there to help out. The families depend on us, and we've become to them and they trust us to help. I feel like my presence in these homes every week is very valuable service to these patient and to their loved ones who need it very much. It truly helps them.

I am also a Loving Whisperer, which is a service provided by The Connecticut Hospice, where I sit with patients at the time of their death and transition. When a family member can't be with them or their alone or they're afraid to be with someone as they're passing, we are called in, the Loving Whisperers, and we sit with the patient until they pass. We offer them comfort and support so that they're not alone and their families are not alone. Connecticut Hospice provides very well for the patients at the end of life, with total respect, anticipating their needs and their family's needs, and I am very proud to be a member of this organization.

Thank you.

REP. RITTER: Thank you very much for your testimony.

Are there any questions?

Thank you.

Our next speaker will be Mike Sweeney, to be followed by Edward Blair.

MIKE SWEENEY: Good afternoon. My name is Mike Sweeney. I'm a registered nurse at Connecticut Hospice. I've been there for approximately 15 years. I'm here to present a letter from Dr. Martin Katz, who's an oncologist at Yale-New Haven Hospital and also in private practice in New Haven. Dr. Katz was unable to come today for the hearing, and he has written a letter which I'm sure you have a copy of. I won't read the whole letter, but I'd like to read -- highlight certain portions of his letter. Dr. Katz -- he also has referred hundreds of patients to our inpatient and also home care facility. So we're very familiar with him, and we have a great deal of respect for him.

Dr. Katz states that he's adamantly opposed to passage of Raised Bill 5499. He is currently a full-time member of the section of Oncology, Department of Medicine at Yale University School of Medicine and The Smilow Cancer Center in New Haven. Prior to his current appointment he was in private practice for approximately 34 years, specializing in cancer and blood diseases. Dr. Katz indicates that changing the current structure of the inpatient and hospice facility in Branford, Connecticut, and the associated home hospice services would be tragic and unnecessary in his opinion. Hospice inpatient services and hospice outpatient services are unique in character and cannot be mimicked or re-created by visiting nurse agencies or skill nursing facilities.

He goes on to indicate that in his 34 and a half years of practicing medical oncology and hematology in New Haven, his patients with cancer and allied disorders have always received outstanding and excellent care from Connecticut Hospice. None of the other general nursing agencies or skilled nursing facilities can provide adequate hospice care in his personal opinion in taking care of hundreds of his patients.

The letter has been submitted for your review and, basically -- and I'd also state that I also oppose the passage Connecticut Bill 5499, as a registered nurse and, also, a caregiver in our hospice facility.

REP. RITTER: Perfect timing. You get an A plus for that.

MIKE SWEENEY: I'm quick.

REP. RITTER: Obviously, you must be a nurse. Thank you for your testimony.

Are there questions?

Representative Nardello.

MIKE SWEENEY: Yes.

REP. NARDELLO: Thank you, Representative Chairman Ritter.

I do have a question. As someone who works at the hospice facility, can you tell me if you are aware of what kind of oversight and monitoring takes place at your facility in terms of any type of inspection or quality control versus what might happen in a hospice facility, that is, of course, not Branford that, you know, as we've extended this, are you

familiar with those types of regulations? And if you're not I understand, but I was hoping that as one of the practitioners you might be.

MIKE SWEENEY: Well, the Connecticut Health Department has very strong control over our organization, and I would hope that if there is -- this bill does pass, which I hope it doesn't, that they would also maintain the integrity and the strict control like they do with our organization. So far as what is in place, I don't have that information.

REP. NARDELLO: Well, I would ask if -- since you may not be able to answer that, but maybe someone -- I'm sorry -- I was upstairs listening but couldn't run down fast enough so I apologize for that -- to tell me what the oversight and monitoring is, and is there any difference between the two types of facilities and also if you could tell me very clearly what the difference is in the personnel requirements between the two -- what -- not two, but the Branford Hospice versus the other hospices. So if you could do that for me, and, particularly, like I said in the area of quality control, I would be very interested in having that information. Thank you.

REP. RITTER: Are there any further questions from the committee?

Thank you for your testimony.

MIKE SWEENEY: Thank you.

REP. RITTER: Next we'll be hearing from Edward Blair, to be followed by Catherine Henningsen.

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EDWARD BLAIR: Madam Chairman, committee members, my name is Ed Blair, and on behalf of Judge Donald Pogue, Connecticut Hospice board member, who

was not able to be here today, I'm going to read his testimony to you, seeking rejection of House Bill 5499.

The full testimony is in your package. The statement is as follows: For almost 40 years the staff, administration and board of the Connecticut Hospice have worked diligently to provide the support that patients and their families need when a family member is dying. Working in interdisciplinary teams of nurses, doctors, social workers and clergy with the families' needs and welfare, as the focus, we have studied hard to learn how to provide the care that is needed. The services that the hospice provides and the staffing levels that we maintain are those that are required by the families we serve. We published a proposed DPH regulations because they do not secure the level of care that, in our experience, families need at this time in their lives.

Perhaps, the most important lesson we have learned over the last 40 years is that, clearly, most patients prefer to die at home, surrounded by their loved ones. We have found that with a highly skilled team trained in palliative care this preference can be honored. And the vast majority of patients can be cared for in dying at home as they prefer. This facility located at Branford is at the center of the network of learning of the provision of services that has been a hallmark, The Connecticut Hospice, it is a living symbol of what we do. Article 1, Section 10 of the United States Constitution provides a relevant part that no state shall pass any law impairing the obligation of contract. And impairing the obligation of our contracts is exactly what these regulations do. They frustrate immediately the legitimate expectations of all the parties to the contracts into which The

Connecticut Hospice has entered in reliance on this existing license.

Moreover, they do so for no governmental purpose that we can discern. Even if the Department wants to pursue this misguided role of lowering standards for hospice care, there is no justification that we can see for failing to permit The Connecticut Hospice from continuing to provide care under the existing license and at the standards provided by Section 19-13-D4b.

I'll close by saying, I ask you to reject these proposed regulations. They undermine the level of care needed by Connecticut families as they face the death of a loved one, and they unconstitutionally deprive The Connecticut Hospice of the specialty hospice license we have worked so hard to maintain.

Thank you very much for your consideration and support. There is the full testimony in the file and in that is some sections from the Constitution with the Connecticut and Supreme Court decisions that are relevant.

REP. RITTER: Thank you.

EDWARD BLAIR: I haven't had time to do it.

REP. RITTER: Thank you, and you know that our attorneys will also be reviewing that.

EDWARD BLAIR: I'm sure they will.

REP. RITTER: Thank you.

EDWARD BLAIR: Thank you very much, Madam Chair.

REP. RITTER: Are there questions?

Representative Widlitz.

REP. WIDLITZ: Thank you, Madam Chair.

No questions but I apologize for not having been here earlier. I was conducting another public hearing but just would like to go on the record as thanking everybody at The Connecticut Branford Hospice for setting the standard very high and offering wonderful, wonderful care to people in their time of need, and sorry to have missed the earlier testimony but just wanted to lend my support. Thank you.

EDWARD BLAIR: Thank you for your kind words.

Thank you, Madam Chair.

REP. RITTER: Are there further questions from the committee?

Thank you.

Next we'll be hearing from Catherine Henningsen, and then I have Maureen Collins on the list, but I believe she already spoke, so the person after that would be Katherine Blossom.

CATHERINE HENNINGSEN: Madam Chairwoman, distinguished members of the committee, thank you for allowing me to testify before you this afternoon.

My name is Catherine Henningsen, and I am a career book author, an award-winning journalist, and for the past year and a half I've been working on a book on the for-profit hospice industry entitled "Predators at Death's Door." And I'm here today to strongly urge you not to support Bill 5499.

Proponents of 5499 will tell you that this bill is about access. They want to provide better access to hospice care in Connecticut. The fact is anyone in the state who wishes to open a hospice under the existing regulations already can.

5499 is not about access, ladies and gentlemen, it is about getting you to reduce the benefits and services that patients were entitled to in order to increase profits. Several of the for-profit hospices here today are targets of major fraud investigations by the Department of Justice, the Office of the Inspector General at the Department of Health and Human Services and the Securities and Exchange Commission for the following crimes: One, enrolling patients who are not terminally ill, and then continuously re-certifying them in order to gain Medicare and Medicaid assistance; two, colluding with HMOs and nursing homes to enroll patients who are considered not profitable; three, egregious violations of the federal Stark Laws through the payment of kickbacks to ensure referrals to their own facilities and no one else's -- this by the way is killing not for-profit hospices in the state of Connecticut. Stark Law violations are felonies punishable by five years in federal prison -- four, signing up nursing home doctors as their own medical directors in their hospices and using that one doctor to sign the patient in twice for the two physician certification required to admit a patient to hospice.

These fraudulent schemes have artificially inflated the average number of days spent in hospice care. Subtract the fraudulently enrolled patients from the equation and you lose the access argument. The Journal of the American Medical Association agrees, as does the National Hospice and Palliative Care

Association. Connecticut enjoys better access to hospice care than all states in the union, save one.

Finally in closing, 5499 proposes to set up hospice residences for hospice home care services. The Hospice Care Alliance has shown that for-profit hospices deliberately under staff their home care continuous care function in order to manipulate dying patients out of their homes. If you pass 5499 soon, no one in Connecticut will be able to die in their own homes. They will be shunted off to these small hospice homes where four to six patients reside.

Finally, 5499 asks that the hospices themselves be allowed to determine the standards for licensure and operation in conjunction with the commissioner of Public Health. May I remind you, ladies and gentlemen, they are the regulated class and not the regulators. Patient --

REP. RITTER: Thank you --

CATHERINE HENNINGSEN: -- benefits do not exist --

REP. RITTER: Thank you if you could quickly --

CATHERINE HENNINGSEN: You may read the full text o of my comments in the written.

REP. RITTER: Actually, I was going to ask if you have submitted -- I'm looking at my list here.

CATHERINE HENNINGSEN: I understand they're going to be made available to you sometime this afternoon.

REP. RITTER: Thank you very much. I appreciate that.

Are there any questions from the committee?

Yes, Senator Welch.

SENATOR WELCH: Thank you, Madam Chair.

I have a few questions. So when -- when you did your research, what states were you looking at?

CATHERINE HENNINGSEN: I -- every state in the union. I'm covering for-profits throughout the United States.

SENATOR WELCH: Okay. And so you're -- you're -- are you saying the -- the grievances are that you've discussed are taking place in every state of the union or some --

CATHERINE HENNINGSEN: They are indeed. They are indeed.

SENATOR WELCH: Okay. And do all these --

CATHERINE HENNINGSEN: And again, you have major hospice chains operating, both, in the state and nationally, and they are among the largest providers of hospice care.

SENATOR WELCH: And do you -- do all -- all these states have regulations similar to the ones that the Department of Public Health is proposing?

CATHERINE HENNINGSEN: No, they don't. Regulation of hospices varies state to state.

SENATOR WELCH: Okay. And so what you've seen out there from your investigation, are the things that could be dealt with appropriate

regulations, or you think they're going to take place no matter how outstanding the regulation?

CATHERINE HENNINGSEN: I believe if you have sufficient regulation on the books, yes, Senator. However, what I have seen already is that even more rampant violations are taking place in states in our union that have even less regulation than is being proposed in 5499.

SENATOR WELCH: Okay.

CATHERINE HENNINGSEN: I'm vitally concerned as a citizen and someone who's had five family members in hospice and as a proponent of hospice care, we are going to see even more rampant violations here once 5499 is passed, which is why I urge you not to pass it.

SENATOR WELCH: And when does your report coming out?

CATHERINE HENNINGSEN: My book is probably about a year and a half off, but I have published several articles recently. One in Hearst papers throughout the state of Connecticut, a copy of which is attached in the package that you will receive some time this afternoon. I have multiple other articles in progress and the book is the larger form of that.

SENATOR WELCH: Appreciate that. Now is this a subject matter that you pretty much focus on or you mentioned you got award-winning articles and whatnot.

CATHERINE HENNINGSEN: I am a business book specialist.

SENATOR WELCH: Okay. Great, thank you.

Thank you, Madam Chair.

REP. RITTER: Thank you, Senator Welch.

Representative Srinivasan.

REP. SRINIVASAN: Thank you, Madam Chair.

Thank you for your testimony. You focused quite extensively on fraud.

CATHERINE HENNINGSEN: Yes.

REP. SRINIVASAN: And unfortunately, that fraud exists not only in hospice care, it exists across the entire span of medical delivery. And so is this any different than what we hear of an ongoing basis at the state level, at a federal level, of fraudulent claims. The people are going to do it there. They're going to do the appropriate things, but is that the -- is that the reason why you feel so concerned about this particular bill?

CATHERINE HENNINGSEN: If the question is, is it any different? I have no medical basis upon which to answer that.

REP. SRINIVASAN: Right.

CATHERINE HENNINGSEN: I do believe that any level of reduction of services to patients is unacceptable. I believe we have current regulations which allow anyone in the state to open any type of hospice they desire. So why would we be looking at taking the risk, given this fraud -- fraudulent industry that's cropping up around the good providers? Why not, for instance, go -- launch a bill here in Connecticut that improves on the Stark Laws that insists that every single provider in this state be made known to every patient going into hospice care. That's not happening. The only

providers being known to patients are the ones who are on the for-profit lists. Why? Because massive kickbacks are being paid in the state to ensure that the not-for-profits don't even appear on lists that are given to patients. We could improve on that in 10 minutes and become a leader in this country ending Stark Law violation.

REP. SRINIVASAN: Thank you very much for your very passionate answer for the not being fraudulent. I appreciate that very much. Could you also share your thoughts about the level of care, which is obviously quite different but you didn't talk about.

CATHERINE HENNINGSEN: Yes.

REP. SRINIVASAN: And I want to get to your opinion since you've traveled across the country as to what you feel. How -- are we going to drop that -- that level, which is the major concern for us.

CATHERINE HENNINGSEN: All right. This is -- this is very vital. This is the heart of the entire question. One, as I suggested and there are further explanations in my written testimony. You have a situation where they want to set up the model as small houses all over the state, which will house four to six patients each. All right. Right away, right there, you will no longer be required to have a doctor physically on the premises with patients. You will no longer be required to have a pharmacist present right there with patients. You will no longer be required to run a pharmacy in that facility. All of those things will be outside of the facilities. That's one.

Two, I think the potential for financial fraud is built into the system. I honestly believe

what you're being asked to do is to enact the for-profits business model, which is -- and there is a very good example already in Arizona among for-profits -- with the for-profit in Arizona did is exactly this. They set up all the small houses. They provided both homecare and hospice services in those small houses. And as soon as they got established in the small houses, they split their stock. One side was the hospice and the homecare agencies; the other was the newly acquired real estate portfolio to house those new four to six member hospices. Both stocks are doing enormously well. So what I would suggest to you, as cynical as it sounds, that what you're being asked to enact with 5499 is their business plan to make more money.

REP. RITTER: Any further questions from the committee?

Thank you very much for your testimony, and I look forward to being able to read it once we get a hold of it here. Thank you.

Next we will be hearing from Katherine Blossom, to be followed by Anne Nugent.

KATHERINE BLOSSOM: Good afternoon, Madam Chair and distinguished committee members. My name is Katherine Blossom. As the director of The Connecticut Hospice Arts Program for the last 15 years, I'm speaking to urge you not to place the hospice regulations formally under 19-13-D4b with the proposed House Bill number 5499.

Under this bill, art services would no longer be required in an inpatient hospice setting. So that you may understand just what would be lost for many patients and families if this bill is implemented, I will describe the scope of our work. Our arts program is multifaceted,

incorporating staff, board certified clinical therapist, supervised volunteers and master's degree interns, all experts in the variety of media. We function as a integral member of the interdisciplinary team, consulting daily with other clinical professionals in all disciplines and are on-site 365 days a year. We serve 6000 patients a year -- make 6000 arts visits -- I'm sorry.

Art services have been mandated in any freestanding inpatient hospice setting in Connecticut since 1979. This has been so because of the wide range of physical spiritual and emotional benefits that arts intervention have been proven to provide. Experience providers of true hospice care understand that quality of life, dignity and patient and family control are more than just catchphrases promised on a shiny new brochure. These fundamental tenets of hospice care are all addressed by the arts by facilitating creativity and choice, providing autonomy and control by providing a conduit for emotion and a language in which to express that emotion, through a painting, for instance, a poem, or a song; by facilitating unfinished business, for example, a memory album made by a 40-year-old patient to leave for her estranged daughter. By fostering rapport and trust, stimulation, relief of boredom, fear or anger, diversion, emotional support, and assistance in coping; by offering opportunity for life review, an almost universal need at the end of life.

I'll sum up quickly.

This holistic approach views every patient as no longer merely a person with a list of symptoms, passively receiving care, but as a whole person, who can produce create and express themselves actively. Some patients

have asked to learn something they've never had a chance to pursue before, like playing the guitar or watercolor painting. As the late Dr. Jean Cohen wrote, there is no denying problems that accompany aging, but what has been universally denied is the potential, the ultimate expression of potential is creativity.

The art services assists with relief of physical symptoms, often needing fewer pharmacological invention -- interventions, which is not only cost-effective, but also more importantly, allows patients to remain free of their associated side effects and more able to have quality time with their families.

More and more healthcare organizations across the country --

REP. RITTER: If you could quickly sum up?

KATHERINE BLOSSOM: I am.

REP. RITTER: Thank you.

KATHERINE BLOSSOM: I'm on my last piece.

More and more healthcare organizations across the country are introducing arts and music therapies as their advantages become more widely understood. In contrast the proposed new regulations in this bill make expressive arts therapies only optional. If palliative care optimizes quality-of-life addressing physical, intellectual, emotional, social, and spiritual needs and the facilitation of autonomy and choice, I ask why the proposed bill strips the integral services that make this possible. Leaving instead a bare bones diluted version.

I urge you to reject this proposal as it would leave patients and families without the very standards of hospice care it purports to provide.

REP. RITTER: Thank you. Thank you for your testimony.

Are there questions?

Thank you very much.

Our next speaker will be Anne Nugent, and she will be followed by Alden Murphy.

ANNE NUGENT: Hello and good afternoon, Madam Chair and distinguished committee members. I'm going to try to consolidate my remarks just a little bit, but you have the full testimony. My name is Anne Nugent. I have a bachelor's degree in nursing, an MA in gerontology and an MBA in healthcare administration. I am currently the director of inpatient nursing at Connecticut Hospice. I have been a nurse for 35 years.

As the director of inpatient nursing, I just would like to, hopefully, clarify some of the concerns that we have regarding the passage of Bill Number 5499. Connecticut Hospice was the first freestanding hospice in the US. And as such it adhered to regulations that were specific and whose aim was the comfort and safety of patients served. 19-13-D4b was the landmark legislation which set the bar very high for the care and provision of these patients. This is how it should be as the dying patient is one of the most vulnerable people we will ever serve.

Patients under this regulation would be entitled to rigorous staffing requirements: One RN to six patients, in the provision of

virtually every service that might be needed by a patient who is facing the most difficult time in their life.

Having had the opportunity to observe many patients and families at this difficult time, I realize that regulations were necessary to maintain the dignity of the people involved. To do less would only diminish the inherent dignity that each and every patient and family deserves. I'm concerned with the passage of any legislation that has the potential to diminish the quality and quantity of services provided to a very vulnerable patient population. We at Connecticut Hospice continually strive to provide excellence in clinical practice and continually challenge ourselves to enhance the skills of our healthcare professionals to ensure the state-of-the-art treatment is available to all of them.

The patients we serve require immediate crisis intervention with no margin for error, and with the proposed legislation this cannot be accomplished.

In conclusion am asking you to reconsider the proposed legislation and -- and avoid the creation of two levels of hospice care. We'll continue to provide the best possible care that we can. They'll never be a shortage of dying patients, but we -- it will be the end of an era if we're forced to provide -- if we are forced to change our level of care for the competition that's satisfied to provide sufficiency versus excellence. Thank you for the opportunity.

REP. RITTER: Thank you very much for your testimony.

Are there any questions?

Thank you very much.

ANNE NUGENT: You're welcome.

REP. RITTER: Our next speaker will be Alden Murphy, to be followed by James Prota.

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ALDEN MURPHY: Good afternoon, Madam Chair and distinguished committee members. My name is Alden Rockwell Murphy, I'm a board-certified music therapist at The Connecticut Hospice, and I'm here to read the testimony by Peter Yarrow, of Peter, Paul, and Mary, who is also a board member of The Connecticut Hospice.

In May of 2011, I wrote a letter to the editor of the Hartford Courant expressing my deep concern for the possibility that, as a matter of policy and funding, the level of care The Connecticut Hospice might be downgraded, as well as the level of care at other hospice care organizations. Since then, on two occasions when I visited The Connecticut Hospice to sing for the patients, the family's of the patients and caregivers, I've become even more passionate about the issue, which is what happens when you deal with policy in flesh and blood terms, rather than in the hypothetical of columns of numbers.

I wrote to the newspaper last June: The issue being debated regarding lowering the standards for the quality of hospice care in Connecticut, has me deeply saddened and worries me that, as a sign of our times, the care we owe people at perhaps the most sacred, sensitive, and potentially beautiful part of their life, their last chapter before passing, will now become diminished as it becomes part of the frequently painful cutbacks we see all around us.

Here are imperatives I see as basic to the humanity of our nation. Without our being able to point to our refusal to be compromised in these two areas, I believe that we will rightfully have to hang our collective heads in shame. The first is the care for the elderly and the young in the last chapters of their lives. The second is our children's health and education.

As you consider the economics of the situation, please ask yourself what it is you would want to stand for if you were to be asked the following two questions by, let us say, a grandchild. One, how important did you feel the care of your parents was in the last period of time before they died? How important is it to you that I make your passing a beautiful, painless, caring, heartfelt last few weeks, days, or hours?

I extend my gratitude to you for allowing me the privilege to share my words with great respect. Peter Yarrow.

REP. RITTER: Thank you very much for that lovely testimony and please send our thanks.

Are there questions from committee?

Thank you. It's always a pleasure to see a friend come in. Thank you.

Next we will be hearing from James Prota, followed by Ralph Papp.

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JAMES PROTA: Madam Chair and distinguished committee members, thank you for the opportunity to speak today on the behalf of The Connecticut Hospice. I'm James Prota, director of pharmacy. I'm here in opposition to the

raised Bill 5499, specifically, opposed to the making of on-site pharmacy services optional for hospices that provide direct inpatient care.

I have previously testified before the DPH, under the conditions of participation it states that the staffing must reflect the volume of patients, their acuity, and the level of intensity of services needed to ensure that the plan of care outcomes are achieved. In order to fulfill these conditions, the sites providing acute care and receiving reimbursement for high acuity services must have a requirement for pharmacy presence on-site.

I speak from two perspectives: Firstly, as an employee of Connecticut hospice for the past five years; and secondly, as a family member who has lost a loved one who needed hospice care. I direct a small department consisting of both technicians and pharmacists. I'm amazed by the notion of removing these on-site pharmacy services from the hospice model. Present regulations enforced by the DPH and standards set by the Joint Commission are patient-safety focused. The Joint Commission has an entire chapter devoted to medication management standards. These regs and standards are quite complicated and quite detailed all in the name of patient safety. It seems contrary to the mission of the Department of Public Health and the Joint Commission to want to remove or make optional the on-site presence of pharmacy services or facilities providing acute end-of-life care.

Removing the requirement for on-site pharmacy services from the hospice regs and enacting this bill would be a setback for clinical pharmacy practice; a setback for the people of

Connecticut, who have had the best end-of-life care available; and most importantly will jeopardize the safest and most effective end-of-life care.

Please include specific requirements for on-site pharmacy services where acute end-of-life care is being provided and reimbursement warrants acute clinical services. With regards to the staffing condition of participation, pharmacists will ensure that the plan of care outcomes are achieved and negative outcomes avoided resulting in a dignified end-of-life experience. Thank you very much.

REP. RITTER: Thank you for your testimony.

Are there any questions?

Representative Widlitz.

REP. WIDLITZ: Thank you very much for your testimony. Without -- could you separate out requiring a physician to be on 24 hours and having an on-site pharmacy. If you had an on-site pharmacy, wouldn't that require -- in order to utilize that to full extent, having a full-time physician there, as well?

JAMES PROTA: Well, you know, we work as an interdisciplinary team and what works best is the ongoing collaboration from minute to minute. We meet formally every morning. It's a formal meaning but we meet informally all day long. So having a physician there or -- and having the nursing staff, as this core team, it strengthens the process. So, I don't know if I'm specifically answering your question, but the ideal is what we have in terms of an interdisciplinary team.

REP. WIDLITZ: And as a follow-up, if I may, Madam Chair, in a situation where there is not an on-site pharmacy and there is not a doctor on-site, what do the staff do? If a patient is in excruciating pain and they don't have the ability to do anything about it, what recourse do they have?

JAMES PROTA: That's my concern, exactly, the acuity, the turnaround time, how quickly you can make an adjustment. The plan of care changes moment to moment. You do need to have the ability to turn things around quickly and to assess patients ongoing. I mean, we have a patient -- a young man who was on a continuous infusion of Dilaudid, had side effects, didn't tolerate it well, needed to be -- we had to reduce his dosage, we included methadone. We converted him to morphine -- not something you would be able to do from afar. Certainly, there needs to be ongoing assessment and collaboration in a complicated case like that.

REP. WIDLITZ: Thank you very much, and I know Branford Hospice does an outstanding job in managing the difficulty for patients.

JAMES PROTA: Thank you.

REP. RITTER: Thank you, and I was looking for your testimony. And I wanted to be sure that you did submit it so that we'll be able to see it here.

JAMES PROTA: Absolutely. I have copies for you.

REP. RITTER: Thank you very much and make sure those copies find their way to the desk that would be very helpful. Thank you.

Next we'll be hearing from Ralph Papp, to be followed by Sherra Stewart-Rego, perhaps. I'm sure I didn't do good job with that.

RALPH PAPP: Good afternoon, Madam Chair and distinguished committee members. My name is Ralph Papp. I am a master's trained social worker and a licensed clinical social worker. I am here to testify against Raised Bill Number 5499. I've been a hospice social worker at Connecticut Hospice for eight years, and I am currently the director of social work. It is my professional belief that most of the patients and families we care for at Connecticut Hospice's Acute Care Hospital are in a state of crisis during this delicate end-of-life time. And studies of human behavior tell us that during crisis, people don't improve, they decompensate in the face of that crisis; thus, the social worker and the entire clinical team is a required to provide extensive assessment, counseling, support, education and connection to services in the community. This level of acute support in responsiveness to a crisis does not seem possible under the proposed legislation, which does seem to standardize a diluted level of interdisciplinary team availability.

One of the primary tenets of hospice philosophy is to treat the patient and the family as the units of care utilizing a holistic approach. Our patients and families frequently tell us that they are accustomed to being treated as cases in other settings and are appreciative of the humanistic comprehensive approach that acute care team at the inpatient setting provides to them.

I would, again, argue that this level of care cannot be provided in a diluted form that seems to be presented in the proposed legislation.

The hospice plan of care is vast and all-encompassing. It takes into account patients from every age, every diagnosis, every walk of life. We care for pediatric patients, and certainly that crisis model, in my opinion, is even more acute in those situations and the level of team responsiveness to care for those pediatric patients is even higher.

Everything that happens out there in the world funnels through the door of a acute-care hospice unit, so we have to have expertise not only physical palliative management of symptoms, but in mental health, suicidality, substance abuse, elder abuse, child abuse, broken family relations, financial stressors, and other matters. Our patients don't get a do-over. There is no second chance. That happens only once for them and as for most of our patients and families, the time frame that this occurs is quite brief. We do not have the luxury of time. We have to have an acute care team available to our patients and families at the moment that they need it. Hospice patients do not get a do-over. Thus, I strongly urge you to reject Raised Bill 5499, as I believe it will do a grave disservice to future hospice patients and families in this state. Thank you.

REP. RITTER: Thank you for your testimony.

Are there questions from committee?

No. Thank you very much.

So, maybe I'll try again on the name.

SHERRA STEWART-REGO: No. You said it exactly right.

REP. RITTER: That's a miracle. That's all I can say.

SHERRA STEWART-REGO: Good afternoon.

REP. RITTER: And you will be followed by Lynn Waters.

Thank you and if you would for the record, please repeat your name.

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SHERRA STEWART-REGO: Good afternoon, I am Sherra Stewart-Rego. Perfect. And I am a clinical supervisor for one of the The Connecticut Hospices busiest homecare offices. I testified last April, before the Department of Public Health in opposition to the repeal of Conn. Gen. Stat., Section 19-13-D4b, and I'm here today to voice my ongoing concern regarding the proposed modifications to the hospice inpatient facility regs.

I think, as you've heard, it goes without saying that the dying process is very different for every patient and every family, and there can often be periods of crisis in the course of this process. The care needs of patients for home routine hospice intervention have been effective, are very, very different than the care needs of patients who find themselves in acute pain crisis, in an acute delirium or in the throes of terminal restlessness, respiratory distress. In these instances, the services of an on-site hospice interdisciplinary team are essential. Hospice registered nurses, a hospice physician present to assess and treat, a palliative care pharmacist present to collaborate and dispense necessary medication stat, and on-site pastoral care social workers, art therapists, and volunteers, all, the whole team, we need them all. This is the high quality of inpatient

care that originated with The Connecticut Hospice nearly 40 years ago. And it's the standard of care that our Connecticut residents deserve.

The proposed legislation seeks to -- the word I've seen is "modernize" the existing regulations, but this modernization is allowing for a lesser standard of inpatient care, and it severely undermines the quality of care for the hospice patients in crisis whose needs really have not changed over the last 40 years.

So I would recommend that proposal to modify these existing regulations be carefully, carefully considered in collaboration with the experts who have provided the high quality of care current -- that's currently enjoyed by the patients of Connecticut. And so I respectfully urge you to not enact Bill 5499. Thank you.

REP. RITTER: Excellent. As I said, another A plus -- thank you very much for your testimony.

Are there any questions for you from the committee?

Seeing none.

SHERRA STEWART-REGO: May I say one quick thing in answer to your question --

REP. RITTER: Oh, I might have to take away the A plus. No, it's -- it's okay. Go ahead if it's quick.

REP. WIDLITZ: Madam Chair, if it helps I'll ask the question.

REP. RITTER: Thank you, Representative Widlitz.

SHERRA STEWART-REGO: I just wanted to say you had a question about patients who in a setting -- in an inpatient setting where they may find themselves needing medication and there is no doctor or pharmacist available, and what happens in those situations. So we find that happens in some of the settings, like an inpatient -- inpatient in a nursing home, for example. So what happens is, the nurse calls the doctor. They collaborate with the hospice team to find out what is going to be needed. They call the physician that's in the facility. The facility physician has to fax an order to whoever pharmacy is that this facility uses; that facility then has to prepare the medication once they actually receive the fax and then transport the medication to the nursing home so that it could be administered to the patient. This whole process, when it's -- you know, urgent and stat, can take about four hours, if you're lucky. If you get the doctor right away; if the doctor has access to a fax machine that can fax the prescription to the pharmacy and then the pharmacy has to, you know, step into action and mix it up, so. I don't know if that helps to answer your question.

REP. RITTER: Thank you very much for your testimony.

And thank you, Representative Widlitz for asking a carefully timed question.

Next we'll be hearing from Lynn Waters, to be followed by Mark Shiffrin.

LYNN WATERS: Good afternoon, Madam Chairman and committee members. My name is Lynn Waters, and I'm here against 5499.

I am a night, eleven to seven, CNA at hospice. Okay? I'm not going to read, totally what's on here. But I chose hospice, I've been there over 12 years, okay, because of the type of service that we do. One of the problems that you are asked to review and look at is care. All right? Right now, eleven to seven, all right, I have nurses to support me. If a patient is dying, bleeding out, in terminal restlessness, I have someone to go to. In your proposed plan, there may be one nurse in the building. I assess and I see a patient who is in distress. What do I do? Who do I go to? And how much time does that patient actually have? Now, unfortunately, about, maybe six or nine months ago, I lost my mother. All right? She had adamantly refused hospice all her life. No. I got a phone call while I was home, and it was from the homecare nurse who had gone out because my mother just, quote, didn't feel well. All right. She wanted to go inpatient hospice. She signed herself in. And when she got there was a doctor, another CNA, the pharmacy, the social worker, there -- right there at her disposal.

Within a matter of minutes, the doctor came to me and he said, Lynn, her symptoms do not follow her diagnosis.

He called her other doctors, outside doctors, they collaborated. They found that her heart had jumped out of rhythm. Now, in the plan, she may not have been seen for 24 to 48 hours. What would she have done? She had a good team of people there. And weakening or lessening the regs that you have now, all right, you only get to do this once. If you -- right now, you are protecting the patients and the people of the state. If you weaken, do they have the right to come back after us and say that you

protected us, now we get to sue you? Because you weakened something that protected us.

And I just wanted to be mindful that we are all going to go this route. We only have one chance. How do you want to go? And how will it be available to you? Thank you.

REP. RITTER: Thank you for the humbling reminder, as well as for your testimony.

Were there questions from the committee?

Thank you. Thank you so much.

Next we'll be hearing from Mark Shiffrin, to be followed by, hopefully, the Reverend Charles Woolsey? Woolsey? No, that's not right. I heard him over there.

MARK SHIFFRIN: Madam Chairman, may I --

REP. RITTER: Thank you. They're giving me a very hard time here.

MARK SHIFFRIN: If I could begin, my name is Mark Shiffrin. I'm an attorney in New Haven. I'm also the former consumer protection commissioner of Connecticut; the former deputy general counsel of the US Department of Education, responsible for regulations and legislation of the education department, and I have some familiarity with -- with the issues concerning 5499. I am not speaking from prepared testimony. I was hoping that I'd be able to share some views with you and, perhaps, provide some technical assistance from my areas of expertise in what is before you.

I have some familiarity with Connecticut Hospice in Branford, Connecticut, and it's a wonderful place, but this isn't about

Connecticut Hospice. This is about hospice care in Connecticut. And this bill presents a serious inadvertent regulatory challenge, which is that it would take the regulations that are -- that are provided for hospice care and conform them to the Medicare reimbursement level of care. And that's a lesser level of care than is currently provided through the regulatory scheme and, in doing that we have often heard that this hospice care is provided differently in Branford than in the rest of the state. That's just not true. When my sister had hospice home care that was provided by Connecticut Hospice, it was provided by Connecticut Hospice in Trumbull. When people have hospice care in Stamford, there are hospice beds meeting these levels of care, the same, the Connecticut standard in Stamford -- at Stamford Hospital. Throughout the state, hospice care is accessible. Inpatient hospice care and home hospice care. This is vitally important. And if I may, if you might indulge me a moment.

REP. RITTER: Well, I can indulge you by asking you if you would give us a few more details to that point.

MARK SHIFFRIN: Thank you. Thank you, Madam Chairman.

What hospice care is available at the current high level of care. What this -- what this proposed legislation would do is it would change the minimum level of care. And there are many businesses in the hospice business. This really -- we hear about this being Connecticut Hospice; this isn't about Connecticut Hospice. This is more about the businesses that would like to provide hospice care in collaboration with nonprofits and can

profit more if they are being paid the same level, but they can provide less care.

This is -- this is a serious problem because looking at this, as someone who has a background as a consumer regulator, I look at this as a bit of bait and switch. Because when people go for hospice care, they go for hospice care. As laypeople, we don't know what hospice care means. We're -- I just went through this situation in my family a couple of weeks ago. We've all been through, or will go through, the situation. We all feel close to it and it's raw for all of us. But when we go for hospice care, we are really vulnerable as consumers.

The people who are patients and those of us who are caring for our loved ones are at our most vulnerable. The minimum standards that Connecticut has had are strong standards. What we are hearing from Connecticut Hospice is how those standards can lead to excellent care. I have seen and heard of examples of excellent care elsewhere. Attorney General Blumenthal and I provided charitable approximation funds to the Rosenthal Hospice, and I left office in 1999. Representative Fox's father, I know was quite -- was quite involved with that. And that -- and that hospice did not -- that hospice was a unique model and did not make it. I can't tell you why you didn't make it, but they're a hospice beds at the same time at Stamford Hospital that -- and any patient also had that option of care available. So I would ask for this legislation really to be put aside. And what I would suggest is that the Public Health Commissioner certainly has discretion in this area. The program reviews and -- the Program Review Committee has discretion in reviewing any proposal regulation. I don't see a circumstance where the discretion of the Commissioner needs to be

impinged with a regulatory -- with a legislative effort. And I do see a situation where, if the threshold of care is lowered, the -- by conforming it to the Medicare standard, then the question becomes what needs to be done in order to get the reimbursement? Not what needs to be done to best serve our consumers. That's -- that's really the bottom line here.

REP. RITTER: Thank you and -- thank you.

I would submit to you that if you having information to those points or any of the points that you wanted to submit to the committee, I would very much appreciate the chance to review it again. I would also -- I'm sure you're aware that the process that you alluded to through the Department of Public Health and regulations involving the Attorney General's Office, as well, is in process right now concerning these regulations. I didn't know if you are aware that.

MARK SHIFFRIN: I testified before the Public Health Commissioner and, indeed, Madam Chairwoman, this is the first time I've appeared before the legislature since leaving as commissioner, but I thought this was very important and that I could bring a different perspective because this really isn't about Connecticut Hospice. This is about hospice in Connecticut, and this has broad implications for -- for consumers around the state.

REP. RITTER: Thank you and welcome back.

MARK SHIFFRIN: Thank you.

REP. RITTER: I'm sure -- I hope will be seeing you again sooner.

Are there any questions from the committee?

Representative Widlitz.

REP. WIDLITZ: Thank you, Madam Chair.

Not really a question, just welcome back, Mark. It was good to have that information. You're very wise and bringing all of this before us. So basically what you're saying it is that this particular legislation is driven by money. It's driven by a reimbursement formula that would lower the quality of care in order to access that money.

MARK SHIFFRIN: Absolutely.

REP. WIDLITZ: That's not good public policy in my humble opinion. Thank you.

MARK SHIFFRIN: Thank you, Representative.

REP. WIDLITZ: Thank you.

REP. RITTER: Any other questions or comments?

Thank you.

MARK SHIFFRIN: Thank you, Madam Chairwoman.

REP. RITTER: Next we'll be hearing from a Reverend Charles Woody, followed by another name, I cannot read. I might as well admit that up front. And it could be the Reverend -- uhm, I'm going to get it trouble -- pardon?

A VOICE: (Inaudible.)

REP. RITTER: Don't even try it. I've been advised.

REV. CHARLES WOODY: How are you?

REP. RITTER: Reverend Woody.

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REV. CHARLES WOODY: Thank you, Madam Chairman and members of the committee. Madam Chairman, permission to stand rather than to sit?

REP. RITTER: Absolutely.

REV. CHARLES WOODY: I certainly appreciate all of you who sit here all day and listen. I certainly appreciate that. You have my testimony. My thoughts are more and, kind of, in an ethical vein.

On the second floor, here, in this building, there is a Connecticut Hall of Fame. And on that Hall of Fame there, we have such people as Katharine Hepburn, Paul Newman, Jackie Robinson, Marian Anderson. And Connecticut Hospice who has been in business for, you know, how many years, is not on that Hall of Fame. But, yet, seemingly is put in a position to look as if it belongs in the Hall of Shame. And yet our issue is is that we insist on providing the best of care, not only from a medical point of view, but also from an emotional, psychological and spiritual point of view. And that if you're going to have institutions that are going to call in clergy, we can meet the folks who come in the hospice right at the door. We've done it a number of times. People have -- have had need of our service, and we were right there. But if you call somebody in and or somebody who's in charge of spiritual care has to call somebody -- and, you know, our technology today. You call somebody you get an answering service, and what you got, so you playing a waiting game.

My whole idea here is that we need to provide care for our patients and families in real time. And so we don't want to be undermined, we want to be able to know that the care the

people receive is good care; that if we're going to belong to the Hall of Shame, were going to belong to the Hall of Shame because we want to give the best of care. We want to share with them our talents, our abilities, and our graces.

And that old hymn, "The Old Rugged Cross," it says, "to the old rugged cross, I will ever be true; it's shame and reproach gladly bear.

I just want to change that a little bit to say, to Connecticut Hospice, I will always be true; it's shame and reproach gladly bear; If I have to bear it under the guise that we should undermine the care that we give people here in Connecticut. To know that one day we, too, are going to be maybe in a hospice bed.

Hello, somebody. Is this thing working? One day, we are going to have, too, come up and receive some care. And if you don't want the best, I do. Amen.

A VOICE: Amen.

REV. CHARLES WOODY: Praise the Lord.

REP. RITTER: Thank you very much, Reverend Woody.

Representative Widlitz has a question for you. You're going to have to come back.

REP. WIDLITZ: Not a question just praise. I would like to say representing the Town of Bradford, I've seen Reverend Woody in action many times, and he is a treasure. And I was hoping you were going to belt out a song for us because that's always very powerful. A little unconventional --

REV. CHARLES WOODY: (Singing.) "To the old rugged cross. I will ever be true. It's shame and reproach gladly bear. Then he'll call me someday to my home far away where his glory forever I'll share."

REP. RITTER: Right. Good luck. We have not been sung to in this caucus -- in this room in quite a while, Reverend Woody. Thank you very much.

And if you could please give us your name for the record. I cannot read your writing.

REV. WARREN GODBOLT: I will. I, too, would like to stand and give my name. My name is Reverend Warren Godbolt. I'm a volunteer chaplain at Connecticut Hospice. And I don't know if I could follow all that singing, but it's one thing I can say is that you cannot legislate love. And all the testimony that was here tonight or here today, it was all about legislation. But at Connecticut hospice, love is the key. Because when a person is their bed at the moment of death, the only thing that the family wants to hear is a caring heart, compassion, because that person is on a journey. And in that journey, you will call in the staff, and we will work together as one. HB 5499

We work together as one and you will call in the chaplain, and the chaplain will take another journey. And in that journey, he will -- he will go into the soul. This is why we're known as the "Soul Brothers," because we work with the soul. We work with the soul, and in that soul, you have to be patient, you have to be loving, you have to be kind and you have to be gentle, because you're working with -- not only the patient, you're working with the family. And it's very, very important when you bring those two together, because of the fact, the journey may be long and it may be short,

but, yet, it's still the quality of the journey is very important.

Because it reminds me when I was changing the light bulb by my garage, I called my nephew out because I was on a ladder. The ladder was shaking, but he put his hand on the ladder, and when he put his hand on the ladder, the ladder became sturdier. The reason why the ladder was so sturdy and I felt comfort to change the light bulb was because all the supports that I needed was in place. So I'm tell you tonight -- today, that Connecticut Hospice is like a ladder, but they put their hands on the support of the ladder, so the quality of care can be stable.

REP. RITTER: Thank you.

There may be some questions from the committee, you might want to come back.

Representative Stallworth.

REP. STALLWORTH: Thank you, Madam Chair and Reverend Godbolt, both, my colleague in Bridgeport in another capacity. I believe this is the first day that I've heard two sermons in a committee meeting, but I want to say thank you for the work you do and thank you for being here.

REV. WARREN GODBOLT: One more statement. Trust. It's all about trust. We tell our children to model behavior. We also tell our agencies to have the best practices. We have the best practice in place, and we can definitely take this model throughout Connecticut.

REP. RITTER: Thank you very much for your testimony.

Let's see. I've lost my place. Next on my list is Sylvia Van Heerden, to be followed by -- I might think about the next one for a few minutes.

SYLVIA VAN HEERDEN: Dear Madam Chair and distinguished committee members, I'm testifying against Bill 5499.

A VOICE: (Inaudible.)

SYLVIA VAN HEERDEN: Thank you. That better? I'm Sylvia Van Heerden, a hospice nurse and a nurse leader at The Connecticut Hospice. I've been a registered nurse for the past 23 years and in Connecticut for the past 10. I've worked in a few acute care settings and home care in Connecticut, New Jersey, and South Africa. I'm very concerned about the new proposed law. The precursor to the Raised Bill 5499 was originally enacted by the legislature to provide a residence for homeless AIDS patients by The Connecticut Hospice.

My BSN in graduate studies in South Africa included the US standards of practice and also included the history of hospice in the United States with the establishment of the first hospice in Connecticut. Other countries learn about nursing practice and US standards because the US is considered the leader in healthcare and an example to the world. Connecticut is considered the pioneer for hospice care and setting hospice standards and the US. I understand it is challenging to accomplish and sustain the high levels of care that we are currently providing under our existing regulations. But the goal is to strive for excellence and improvement in patient care, not to reduce or do away with it. This would be devastating to the population in Connecticut, who is used to high, safe, quality care.

As an RN, I worked under conditions where I had to oversee the care of 25 critically ill patients, very symptomatic, with hardly any physician and pharmacy backup. Struggling with prioritizing patient's needs, not even mentioning the other needs, like spiritual, psychological, social support to patients and families. Hospice patients are the sickest and the most fragile of patients from our pediatric patients, throughout the span of life. These pressure cooker working conditions lead to errors, burnout, staff turnover, and, ultimately, poor and unsafe patient care. Not the care I would want for my family or myself.

It is not the mission or the philosophy of hospice to institutionalize patients, but to keep them (inaudible). But for the small population of hospice patients that are symptomatic, we want to ensure high standards.

SENATOR GERRATANA: Thank you very much for your testimony.

Could you give us a summary statement now? Thank you.

SYLVIA VAN HEERDEN: We need to see our -- we need to see, as nurses, our patients throughout the shift, multiple times. This proposed law doesn't protect the patients or the people providing the care in Connecticut. And, unfortunately, it is up to the facility administrators to have the final say in the standards of care. Those are often the people that create the poor thresholds in the hospitals. So I would really say, if there is no rules, there are no rules to be broken. Thank you.

SENATOR GERRATANA: Thank you so much.

Are there any questions or comments?

If not, thank you so much for coming today.

Next is -- is hard to discern the handwriting -- it looks like Ronnie -- oh, I'm sorry. We skipped a person apparently. Marcel Blanchet and then that will be followed by, I think it's either Rennie or Ronnie Knight or -- I'm so sorry. I can't make out --

A VOICE: (Inaudible.)

SENATOR GERRATANA: Knight? Pretty good. Is Marcel Blanchet here? Here we go.

MARCEL BLANCHET: My name is Marcel Blanchet, and -- and I am the chief information officer at The Connecticut Hospice -- and now almost 23 years.

The biggest part of this bill, 5499, that I oppose is that the substandard care that can and will happen to the citizens of the State of Connecticut.

The issue is that, currently, The Connecticut Hospice is licensed under the current regulations and their -- this model of care can be used in all hospices in the state of Connecticut. And at this point, the quality of care is at the highest level: nursing, staffing, physicians within the facility, social work, and the pharmacy within the facility. Other hospices that are proposed should continue to be staffed with at the highest level. When you're looking at unemployment rates that are currently starting to go down -- thank God for that.

Nursing care, you need very fine nursing, licensed nurses to provide the care,

physicians. And when you dumb down the current legislation proposal in 5499, you will diminish the number of employed physicians that are at this level of care that can be now staffed into those places, so I oppose 5499 for that reason. Thank you.

SENATOR GERRATANA: Thank you, Mr. Blanchet.

Any questions?

Oh, Representative Srinivasan.

REP. SRINIVASAN: Thank you, Madam Chair.

MARCEL BLANCHET: Sorry.

REP. SRINIVASAN: Thank you very much for your testimony.

In concept, we all have primary care hospitals, secondary hospitals, and tertiary care hospitals. Obviously, they all provide different levels of care. And what a primary hospital can do, obviously, a tertiary hospital does much, much more of that and is beyond what can be achieved at a primary and a secondary level. Do you see at any place in having in the hospice care delivery system, also, a single tier -- we have a single tier now, as long as we don't compromise the quality of care and leave it to the individual family to decide whether they want to go to Hospice A or Hospice B. Do you have a major problem with that particular concept, because that is what I'm envisioning. We hear testimony where the people could not go because they were 50 miles away one way, and they were not there in those final moments, and all of that. And maybe for them, they are ready to say, you know, this particular place is in my backyard, and I will be able to spend more quality time with my

loved one, as opposed to somebody 50 miles or 60 miles away.

MARCEL BLANCHET: I understand that issue. And I heard you question that earlier. Currently, there's no reason why a hospital in, say, Torrington, Connecticut, or in North -- northeastern part of Connecticut or the southwestern part of Connecticut can have hospice care at the level of the current standard. There's no reason. And it is happening. And what we're looking at here is, basically, a physician on staff, the right number of nurses to care for the patient. Okay. So, for example, say you live in Northwestern Connecticut and it's your mother that is dying of a very horrible type of cancer that needs intensive-type care. Well, she's in lots of pain, your mother is in lots of pain. If there's a physician on staff and the right number of nurses around the clock that are looking after your mother and there's a pharmacy available, on staff, that allows you to get that pain administered to your mother and she's more comfortable, and you live in that area, then I think that's a great thing to happen.

And The Connecticut Hospice, part of what they do, as an educational arm that will also help provide technical assistance to help the hospice programs in that part of the state to receive the current licensing that they can get today.

Well, the thing is, part of what you're saying in this 5499 is modernization. It's not modernization. You know what modernization is, on that level, is, okay, well, you know a for-profit hospice wants to make some money. That's what they call a for-profit, so they -- instead of having six nurses, they have three

nurses or two nurses or like our example, that one nursing home, one nurse, but seeing 20 patients. So your mom is one of those patients of -- and that nurse is running around, in eight hours, dealing with six, seven, eight other patients like that, and having to fax to a physician in the community to say, well, I need morphine for my patient because she's in a lot of pain. And you don't get it for four hours and your mother suffers for four hours. Okay. So now, you are working here in Hartford and your mom's 20 miles away. You get the phone call, by the time you get there, she's still in pain. Okay?

So, yes, I think it's important but at a level of care so that when you get that phone call and you get there, because you're working -- you're hard working -- get to your mom. Then you can say my mom got the best care, and she's not in pain and she's welcomes you, and says, My son I'm glad that you're here.

REP. SRINIVASAN: Thank you. Thank you.

Can I ask one more question, Madam Chair?

SENATOR GERRATANA: Absolutely.

REP. SRINIVASAN: Thank you. Just for my clarification. In terms of the credentials of the physician, the nurse, is the nurse and RN or an LPN, or you have any other requirements like that?

MARCEL BLANCHET: Well, currently the requirements are six -- I'm sorry. I'll give that to Ronnie Knight, he's next --

REP. SRINIVASAN: Okay. So he'll give us those details about the --

MARCEL BLANCHET: Yeah. He'll be able to give it to.

REP. SRINIVASAN: Thank you, I appreciate that.

MARCEL BLANCHET: Thank you. Thank you.

SENATOR GERRATANA: Thank you.

Are there any other questions?

No, then we'll go on to Ronnie Knight.

RONNIE KNIGHT: Thank you.

SENATOR GERRATANA: You're welcome.

RONNIE KNIGHT: If I could figure brief moment before you start the clock to address some of the questions that went around that haven't been answered. Can I do that?

SENATOR GERRATANA: I'll tell you what. Why don't you give your testimony and then you may answer questions. I know Representative Srinivasan has questions for you.

RONNIE KNIGHT: Thank you.

SENATOR GERRATANA: You're welcome.

HB 5499

RONNIE KNIGHT: My name is Ronnie J. Knight, I serve as senior vice president of The Connecticut Hospice. I come before you today representing an institution that will forever be noted as the founder of hospice care, not only in the state, but in this country. I join many of my colleagues and other interested parties in opposing the proposed bill, which has generated these hearings.

We began offering hospice home care services back in 1974. Years later with the support of the, then, current Governor Ella Grasso and legislators locally and throughout the state, in July of 1980, the first hospice patient was admitted to the hospice inpatient facility. The fundamental principles of death were dignity, both, the patient family as a unit of care, and bereavement services following the death of the patient were shared by the 14 participants of the HIPPA demonstration project on hospice, a study in which we were a participant. This study establish the basis for Medicare hospice benefit, which was enacted shortly following this demonstration project in fiscal 1983 and forever made hospice care services available to all elderly citizens if they so chose to elect.

It is true that the original Medicare hospice conditions of participation have only minimally been changed in the 25 years since inception, but this lack of modification speaks to the wisdom of the early founders in the state of Connecticut who sought to ensure that hospice services would not only be provided at home but also in institutions capable of providing the care to the sickest of the patients, sickest of the sick in a matter that was safe. Consequently, all hospices must, by federal statute, provide inpatient services now. The difference is that federally, the care must be provided in a hospital or a SNF level facility unless the individual state grants a pass and approves something less, as in a hospice residence with minimal staffing services on-site.

With the passage of these regulations, what will surely follow is the proliferation of residences throughout the state. Would this be an improvement? No, because the sickest of the

sick cannot be cared for in such residences and will end up in the emergency room or, at worst, the dying prematurely. And, yes, the issue -- it is the issue of staffing that causes us great concern. Staffing, as needed, and left to the discretion of individual hospice providers, will surely lead to abuse.

Let us not be naïve to think that our state, with its history of high standards, are impervious to predatory -- predatory practices.

I have a lot of other written testimony, but if I can just summarize. Hospice care was once a charitable cause. Now, it is a growth industry. Revenues have gone from 300 million in 1992 to 14 billion currently. The number of hospices in this country have tripled, with 1800 for-profit providers now providing -- accounting for 50 -- 60 percent of all claims. Hospice patient -- the base of hospice patients have gone from 2000 -- have gone -- have doubled to 1.4 million in less than nine years.

One of the main reasons for this growth is the very issue were discussing today. We keep hearing proponents talk about advocating support of hospice residences as if it's like Branford. Let's be clear. They won't be like Branford. Our ratio is 1 to 6. The hospice Association of America, the national ratio was 1 to 8.6. These regulations present the barest minimum. It could be 1 to 10, 1 to 15, 1 to 20. With the only guideline as the discretionary directive to provide services "as needed." "As needed" to the stockholder translates to more staff than necessary to ensure that profit is a likely outcome.

SENATOR GERRATANA: Thank you for summary.

RONNIE KNIGHT: Okay. The one summary -- this is very important. I also know there are many people here today that are -- are of earnest intent and deserve my utmost respect as hospice and home care providers. We will continue to join them in support of their advocacy in most issues. We cannot, however, agree to this issue. We oppose the lessening of standards which would invite predatory abuse that has run rampant in some states. We believe it not to be in the public's best interests.

Senator Nardelli?

SENATOR GERRATANA: I'm sorry. Can I help you with something.

RONNIE KNIGHT: No. It was --

SENATOR GERRATANA: Oh, Representative Nardello. She's not here.

RONNIE KNIGHT: I'm sorry. I apologize. Okay.

SENATOR GERRATANA: Did you want to answer some questions right now? Is that what you would like to do?

RONNIE KNIGHT: One of them was from Representative Nardelli. That's who I am referring to.

SENATOR GERRATANA: Nardello.

RONNIE KNIGHT: Nardello.

SENATOR GERRATANA: Nardello.

RONNIE KNIGHT: Apologize to her for me.

SENATOR GERRATANA: That's quite all right.

RONNIE KNIGHT: She had a question as to what regulatory oversight is in place now versus that which would be available under these regulations. And I can answer that question by this, right now, in mandating that inpatient services be provided in a hospital, in a SNF, by definition being a hospital and being a SNF, there's a state inspection that happens because they license these facilities, I believe, it's every couple years. For hospitals with joint -- joint commission accreditation hospitals, accreditation which happens every three years. Both of these facilities generally are Medicare certified. Medicare certification -- recertification requires for hospitals and home health agencies are every two to three years.

The problem with hospice -- and as would be under these residences, is that the residence wouldn't fall under these categories and hospice regulations or hospice certification only requires, there's no time limit and it happens every six to seven years. So what happens and what has happened in the past, as Ms. Henningsen was making some reference, there's been a lot of abuse, and part of the abuse has been caused by the fact that the hospices haven't been regularly -- regulated routinely as other types of facilities. It happens every six to seven years, but by the time you find somebody has had the abuse. They packed up and gone on down the road because they're looking at five-year-old data.

And forgive me I didn't mean to cut off my colleague, but there was another question. What was the difference, you know, why can't anybody go to the hospice they want to because everybody should want freedom of choice. And this is very true. The problem is that, as we probably all know, hospices are something that are very unfamiliar to you till you need it.

And without some type of regulatory oversight and some type of quality control and quality care standards, there's a likelihood, as has happened in other parts of the country, not so much in Connecticut because this is a regulated state and we have a tradition of high quality care, so forth and so on, you don't know you're -- you're involved with the program that is of lesser standards because you don't have anything to compare it to, so that is fortunate of why there is some type of regulatory oversight.

You go to one on the street and there might be one nurse to whatever number of patients, or you might not get the aide; you might not get, you know, the pharmacy; you might not get all the robustness that is available and required under -- under statute because you don't know any better. So that's why this oversight and regulations are very important. If that helps --

SENATOR GERRATANA: Thank you very much for that.

Representative Srinivasan, did you want to comment, or did you have a question, a follow-up or were your questions answered?

REP. SRINIVASAN: They were inserted to a point --

SENATOR GERRATANA: Oh, good.

REP. SRINIVASAN: -- but if -- if you could just give us the -- what I was interested in was your nursing ratio so that we can look at it, as opposed to leaving it open ended as is what this bill says.

RONNIE KNIGHT: Our ratio, as is the standard, our ratio is one nurse to six patients.

REP. SRINIVASAN: One to six?

RONNIE KNIGHT: Yes.

REP. SRINIVASAN: And your -- and your pharmacist is 24/7?

RONNIE KNIGHT: Pharmacist is available 24/7 on-site for most of the day. Connecticut Hospice -- we've been fortunate in this state. Connecticut Hospice is a very unique program, and which is why people come from all over the country to learn about what we do. And we're not -- we're available to offer that assistance to other folks throughout the state. We do know that there are hospice beds 21 of the 30-some-odd hospitals within the state. Obviously, all hospices have to have some inpatient hospice and that's being done in hospitals and skilled nursing facilities.

REP. SRINIVASAN: And my final question on the physician, that is the physician is in-house 24/7, also?

RONNIE KNIGHT: Yes, the physician is in-house -- again, Connecticut Hospice, there are generally four or so physicians available, and when you come to Connecticut Hospice, you have -- you are a patient. You are directly a patient and that patient is given a primary physician and that something that we are fortunate to have available to us. But by statute, there has to be physician involvement in the team. So you've heard somebody probably talk about --

REP. SRINIVASAN: No. That's not my question. I understand that.

RONNIE KNIGHT: I'm sorry.

REP. SRINIVASAN: I understand that. I understand is a physician involved in the team that there is no question at all. My question -- my specific question was, is a physician in these facilities physically present, available, 24/7, or the other times is on-call, available over the phone.

RONNIE KNIGHT: You are talking about for us in particularly?

REP. SRINIVASAN: Yes, yes.

RONNIE KNIGHT: Okay. For us, in particularly, there is a physician available on-site every day, generally 10 hours of the day, and other times -- parts of the -- there is a physician on-call availability 24/7.

REP. SRINIVASAN: Yeah. Thank you very much.

Thank you, Madam Chair.

SENATOR GERRATANA: Certainly.

Senator Welch, followed by Representative Betts.

SENATOR WELCH: Thank you, Madam Chair.

I have a number -- number of questions and, you know, to the extent that you can't answer them, if you could point me in the right direction that would be great. So as -- I'm sorry -- your position, again, is vice president of --

RONNIE KNIGHT: I am senior vice president of Connecticut Hospice.

SENATOR WELCH: Senior vice president of the hospice. So I imagine you take a look at demand and population changes and what the

expectation is going to be for your services, one, two, three, four, ten years down the road. Can you elaborate on that. Are you saying an increase in the need for hospice, and then, if so, to what extent? Are you prepared to meet that demand based on your current facilities and projections?

RONNIE KNIGHT: One of the challenges for all of us that are providing hospice services is that enough people don't receive the services. So part of the ongoing practice is the Enlightenment, education, constant teaching of what hospice care services are and why they should be made available to patients who are clinically appropriate for that care. That education -- because we can't render the care without the patient being directed our way. So, consequently, we spent a lot of time interacting with physician populations, and that in and itself is a challenge because there are still parts of the physician community that that associate hospice care with a failure in their practice. And it's our constant advocacy that a hospice is indeed a patient right, should be made available to the patient and is always better sooner rather than later.

Now that has always been the challenge of hospice from its early days up until now. The difference -- and it's an unfortunate difference, but the difference is that now probably in the last ten years, hospice services have been made available to patients for quite a different reason. And the profit motive has generated an incredible explosion of hospice services across the continuum. Hospice is the fastest -- is the fastest growing clinical service within Medicare. And it's grown like that because it has been perceived as an opportunity that has been taken advantage of to the extent that is unbelievable to -- to

us, and I'm quite sure many of the people that are just as interested in providing good care.

So you have a twofold -- you have two different forces, you have the challenge of educating the physician community -- medical community, public, in general, as to these services can do you some good. And there's no disadvantage to you receiving the services so there's that challenge; and at the same time you have economic forces that are, you know, sign up here, sign up here, sign up here, you know, and we'll give you extra this, that and the other. And there is a -- there is a profit motive that increases --

SENATOR WELCH: Well, if -- if -- setting the profit motive aside, setting the lack of education side, let's just talk pure demographics. So how --

RONNIE KNIGHT: Oh.

SENATOR WELCH: What part of your patients are, you know, 70 and older, as far as a percentage?

RONNIE KNIGHT: Well, hospice, by definition, dying patients tend to be -- not being facetious, but, obviously, dying patients tend to be older so there's always been 65, 70 percent of the population. The difference is that over the last 10 years. Hospice usually used to be primarily associated with a cancer diagnosis. That's another one of things that has changed is that hospices is being provided more so to noncancer patients and those patients tend to be younger and tend to be more complex. But, overall, baby boomers -- I guess, we all are -- and the -- with the grain of America. People are getting older and there'll be more and more of a need for hospice services, consistent with the aging of the population.

SENATOR WELCH: And so consistent with -- an understanding that the population and the need for your services are going to grow, short of bringing in other institutions willing to service those populations, I'm assuming you have a plan that addresses that growth at this point in time or maybe you don't.

RONNIE KNIGHT: Well, our plan, from the institution's standpoint, is to -- when you talk about Connecticut Hospice, everyone thinks of our hospice in Branford and the facilities, so to speak, but quite frankly, most of our patients remain at home. So we're out there in, you know, probably 80 percent of the state. So that's how we're addressing it in these communities, in Norwalk community, in Waterbury community, Hartford community, so forth and so on. So there's that issue. But as far as, you know, can we do it all? No, we can't, which is why have to we do is we are and advocacy role and we teach and we train. And we have, you know, people come in, you want to know how we do it; well, come in. We're glad to show you how to do it and -- and whether that's a physician fellowship or nursing fellowship or the pharmacy students, on and on and on and on, and then they go out and you'll work, you know, train the trainer, so to speak. You know, we train people, they come through, learn what we do and then they go out into their community and they -- they, you know, replicate it to the extent that they can.

SENATOR WELCH: Got it. And so what percent of your patients are in Branford, and then what percent are outside of your Branford facility? It doesn't have to be precise. I'm just trying to get a feeling, an understanding of the situation.

RONNIE KNIGHT: Probably a quarter of our patients are in the Branford/New Haven area. I would say.

SENATOR WELCH: And then how much of the reimbursement that you get for the service you provide is Medicare, Medicaid, and how much is of a private source?

RONNIE KNIGHT: Federal programs, Medicare, would probably be half, 60 percent, because we're dealing with aging population. I don't want put all our business out there, but commercial payers are very important.

SENATOR WELCH: Yes.

RONNIE KNIGHT: I mean the under 65 population, that's one of the challenges. A person 55 dying of cancer, you know, 20 years ago -- 30 years ago, there wasn't any place for them to go and that was the genesis of how we came about. Because we came about as a facility that was an institution, a hospital institution that was able to contract with the Blue Cross or Aetna or -- or somebody else who could provide the services. Now, we still do that and so you have the aging population, the Medicare program, you got the impoverished population for the core Medicaid programs, so that federal and that's probably about 60 percent of what we do. And then, you know, everybody else. I will also say that a significant number of our patients have had no funds and, you know, thank goodness for the philanthropic community, such that if you are clinically appropriate and dying, we will take care regardless of ability of pay.

SENATOR WELCH: And that's my next question. So what percentage of your patients are actually unreimbursed?

RONNIE KNIGHT: Are unreimbursed?

SENATOR WELCH: There's no commercial payer, or there's no reimbursement from Medicare/Medicaid?

RONNIE KNIGHT: Can I say it's significant without getting more specific than that?

SENATOR WELCH: That's fine. No, that's fine.

RONNIE KNIGHT: Yeah, I don't want to get more specific than that.

SENATOR WELCH: And then I guess the last kind of thought that, hopefully, you can help me with is have you taken a look at the Affordable Care Act? And if so, what's the perceived impact on --

RONNIE KNIGHT: The Affordable Care Act in the ACO legislation and all that, is that the part that you're referring to or --

SENATOR WELCH: The federal legislation, if that even has any impact on your institution.

RONNIE KNIGHT: I'm not sure what aspect of the Affordable Care Act you're referring to. There is a part of the Affordable Care Act, I believe, which is the Accounting Care Organization legislation which all provider types are supposed to get together and have a shared risk with the government and, you know, away we go. And if you meet certain parameters, there's savings. If you go beyond that, you lose money. But that's an issue made primarily by the hospitals and the physician community of which will be a part of that, but none of it has really taken hold.

SENATOR WELCH: Okay. And that's fair. Thank you.

SENATOR GERRATANA: Thank you, Senator.

Representative Betts I think had a question.

REP. BETTS: Thank you very much, Madam Chairman.

Thank you for your testimony. I just have a couple of questions. One of which I wanted to follow-up from a previous conversation I had. For the doctors that are on-call or available, but are not physically there, what type of doctors are we talking about? Are we just talking about generalists, specialists, primary care doctors? How does that work?

RONNIE KNIGHT: Generally, you're talking specialists. I mean, we have a whole credentialing procedure. But, generally, you're talking -- they could be either. They could be specialists, they could be general practitioners. I don't want to step outside my element. I have to refer to Doctor Andrews.

REP. BETTS: Well, that's fine. I just wanted to get a sense as to what type of coverage was provided. What type of doctors were going to be covering?

RONNIE KNIGHT: Well, in addition to our medical staff, which are there every day. This is what they do. In addition to them, we do have relationships with the area hospitals that provide the nighttime, moonlighting cover, so to speak, weekend coverage. And that's part of their tutelage, so to speak, to have that opportunity to, you know. Let me go moonlight so to speak, at Connecticut Hospice and get that exposure. So, generally, they're eager young doctors -- or maybe I'm older. They look younger and younger, but different specialties

and then we have a particular need. For instance, we take care of a lot of babies. So we have a pediatric physicians come in, and so forth and so on. We had a recent case of extreme diabetics, so we find that -- I can't think of the specialty name -- endo -- somebody help me.

A VOICE: Endocrinologist.

RONNIE KNIGHT: Endocrinologist. So you know we have an access to another -- other physicians other than the ones on staff or given the need.

REP. BETTS: Okay. You know, I was thinking you -- you and many other speakers have probably talked about the high standards at The Connecticut Hospice offers, you know, the intense coverage you have at Connecticut hospice vis-à-vis the other ones that are out there. Have you -- do you have any idea as to -- are the costs the same between what Connecticut Hospice offers versus the other ones, which I would assume it would not be because you have a higher standard and have more coverage, or how much of a disparity is there between -- between the two different models?

RONNIE KNIGHT: There is quite a disparity but -- but, as I said Connecticut Hospice, with all this history, first hospice in the country and with the philanthropic support, it does have a -- it does have a higher level, high quality program, I mean, not to despair to any of the other providers.

REP. BETTS: No, I understand that. You're not doing that.

RONNIE KNIGHT: It's important. Our concern is if -- it's a tough business in and of itself and

it's challenging business in and of itself and we find ourselves in an advocacy role because regardless of the quality standard that we might have, and we're just really concerned about keeping all those that might want to emulate what we do, but when we look around and see what has happened within hospice care, nationally, not so much, you know, a little somewhat locally but mostly nationally, there's has been quite a bit of abuse. So we're vigilant because we really don't want that abuse to come home here.

So the answer to your question, unfortunately, it does come down to an economic issue. It costs more money to have a higher intensity of staffing. If you -- if you remove all oversight and make it discretionary -- if you remove all oversight and make it discretionary, someone will say, well, for -- if I get paid this much money and I only have to provide -- if I'm getting such and such money and I don't have to spend all that money providing the care, I won't. And that's what has happened, you know, throughout the country.

So, you know, from a patient advocacy standpoint, we know from having done it so long how challenging it is. And it's, you know, it's -- it's very easy. If you don't have the staffing, you kind of cherry pick the patients you take care of.

REP. RITTER: Thank you.

Are there any other questions from the committee? And if you wait one minute, I think Senator Gerratana some questions.

SENATOR GERRATANA: There are some administrative problems here.

Thank you, Mr. Knight, I do have a number of questions. What sets your facility's hospice care part from how hospice care is delivered to other parts of the state?

RONNIE KNIGHT: Forgive me. I'm trying to be humble here. I think a good way to answer the question is just to reflect on a lot of the testimony you've heard here, from our pharmacist, from our social worker, from our nurses, from our arts program, from our pastoral people. The Connecticut Hospice has a wealth of disciplines that routinely interact, you know, to comport with the best care they could provide to a patient. There's that and The Connecticut Hospice -- well, The Connecticut Hospice is a hospital. Connecticut Hospice has a higher intensity of care than you're going to find anyplace else in the country. So I want to set ourselves up as -- as, you know, what can be easily replicated. Connecticut Hospice just receive the -- was the first institution in the country accredited by the Joint Commission for an advanced palliative care program. Connecticut Hospice is very unique. But -- but it's always been that way. The Connecticut Hospice and the principles that they aspire to predate the Medicare hospice benefits so when the Medicare hospice benefit came about, it was at a level here, but we had already been above that standard. So, okay, the Medicare hospice benefit established a standard for all hospices to have to maintain. And that is the one that said, well, all of you have to inpatient; if you're going to do inpatient, you have to do it in a hospital or a skilled nursing facility. That changed over the last, some odd years which gave states some discretion. But with that discretion came, Oh, you're going to let me do it in something less than a hospital and skilled nursing? Oh, yeah I want some of that.

And now you have a lot of the investors, which is why the fact that hospice providers -- 60 percent of hospice providers are for-profit. That's incredulous. The hospital community I would -- I would think that that's probably like 20 percent, at most, would be for-profit. Well, there's a reason for that, it's because it's become a big business, if that answers your question somewhat.

SENATOR GERRATANA: Well, a little bit. You stated that about a quarter of your patients or care is in the Branford/New Haven area; is that correct?

RONNIE KNIGHT: Well, I say that because you have the inpatient institution -- the inpatient facility is in Branford and that facility, by the nature of the being there, you have a lot of New Haven population, but we also -- I would say half of our patients come from outside, you know, the New Haven area, in and of itself.

SENATOR GERRATANA: Oh, I see, you were referring to patients, not -- not where --

RONNIE KNIGHT: So that's --

SENATOR GERRATANA: They all get their care in a facility. I'm sorry. I misunderstood completely.

RONNIE KNIGHT: Right. So what -- I was trying to do my quick math because I was folding in the inpatient with the home care program.

SENATOR GERRATANA: No, no, no.

RONNIE KNIGHT: I'm sorry.

SENATOR GERRATANA: I actually -- just to clarify -- I'm sorry -- when you made that statement I thought, perhaps, you were also giving care outside of the hospital setting, but you are not. It's all within the hospital setting.

RONNIE KNIGHT: No, I'm sorry. What I'm trying to say is we have the inpatient program, and we also have the home care program. The home care program covers most of the state.

SENATOR GERRATANA: Oh, so you do have a home care program.

RONNIE KNIGHT: Yes. That's why I'm trying to be more clear. We have -- we have -- I'm sorry. I didn't mean to cut you off.

SENATOR GERRATANA: Oh, no. Is that similar -- the home care program is that similar to, for instance, my dad received hospice care in the home. Is that what you're talking about?

RONNIE KNIGHT: Yes, yes, yes.

SENATOR GERRATANA: Okay. And these are people who are employed by the Branford facility, who --

RONNIE KNIGHT: Oh, I'm sorry.

SENATOR GERRATANA: No.

RONNIE KNIGHT: Let me be clear. Yes. Most of hospice is provided at home. Most of our patients are at home. They are at home. We have the Branford office, which covers New Haven. We have a Shelton office that covers, you know, Fairfield County. We have the Norwalk office, which covers lower Fairfield County, you know, on and on. So we have a -- we cover a wide cross-section of the state. In

addition to that, we have the inpatient facility.

Now those other -- well, let me stop. Yes, we have patients all over the place.

SENATOR GERRATANA: It's okay. And those that cannot receive care at the hospital. Do they receive at home as an alternative setting?

RONNIE KNIGHT: Yes. The primary goal is to take care of a patient in their home; that is, that's generic to hospice. It's predominantly a home care based program. The Connecticut Hospice is different in that it has the inpatient facility in addition to --

SENATOR GERRATANA: Right, right. Yes. That's my understanding, also, that most patients would prefer to receive their palliative care in a home setting --

RONNIE KNIGHT: Yes.

SENATOR GERRATANA: -- rather than institutional.

RONNIE KNIGHT: And the challenges for all of us, is that that's becoming obviously more and more, you know, more and more difficult.

SENATOR GERRATANA: Thank you. And has your facility turned anybody way -- not having been able to accommodate those people who seek to enter your facility, your hospital?

RONNIE KNIGHT: We have 52 beds. We get maxed out, but other than that, I mean --

SENATOR GERRATANA: You don't know or don't -- are not aware of --

RONNIE KNIGHT: No. I know -- I'm trying to hear -- we don't turn anyone away if -- we don't -- we would only not pick someone up if we didn't have any bed availability. I guess that's what I'm trying to say.

SENATOR GERRATANA: Thank you very much.

Are there any other questions? Okay.

RONNIE KNIGHT: Just so you know, just for clarification, in addition to Branford, because we have offices all throughout the state, we do have inpatient care at other locations throughout the state, too, not at just in the Branford location.

SENATOR GERRATANA: Now, I -- yes, I understand.

RONNIE KNIGHT: Okay.

SENATOR GERRATANA: I thank you for that.

Representative Srinivasan?

REP. SRINIVASAN: Thank you, Madam Chair.

When you -- when most of the patients receiving hospice care, by and large, are at homes, and as you said about 25 percent in that ballpark, give or take, are in the hospital setting. So when we talk about these regulations, which are going to be, according to you all, downgraded quite intensively, we're talking about only in the hospital setting. Right? Because none of this would apply in a home setting where, obviously, you don't have a physician there or a nurse there all the time or an in-house pharmacy so all those things that you brought up apply -- are applicable only to the hospital setting. Are you also concerned about the home healthcare setting, which is the bulk of the

hospice care, which is about 75 to 80 percent? That is my understanding.

RONNIE KNIGHT: Right. None of this refers -- none of this we're talking about today really applies to home hospice home care. None of this applies, you know, and that's -- if you have to -- if hospice has to be provided and it can't be provided at home, then it has to be provided in a residential facility, inpatient facility, that has some basic minimals someplace. That's -- I guess what we're saying. And that is, indeed, the difficulty, because obviously you get paid for more money when a person is an inpatient, so you have to make sure that, if they're an inpatient, they are an inpatient for reason and they might be difficult to manage, which is why the pharmacy and the physician, oversight needs to be ideally, readily available.

SENATOR GERRATANA: Representative Scribner.

REP. SCRIBNER: Thank you, Madam Chair.

Good afternoon. You may have offered this information previously, and I apologize if I missed it. I think I heard you say that your current in-facility that capacity at the Branford hospice facility is 52?

RONNIE KNIGHT: Yes.

REP. SCRIBNER: How often do you reach that capacity?

RONNIE KNIGHT: It could happen I want to say every week but it's frequently, frequently.

REP. SCRIBNER: So would it -- would be safe to ascertain that --

RONNIE KNIGHT: Well, let me answer the question --

REP. SCRIBNER: At times there is a waiting list for people to be admitted to the facility?

RONNIE KNIGHT: At times, there is a waiting list, yes.

REP. SCRIBNER: You did make some reference in your comment to other inpatient facilities that are operated by Connecticut Hospice in other areas of state. Did I understand it correctly?

RONNIE KNIGHT: Yes, yes.

REP. SCRIBNER: And where would those be located?

RONNIE KNIGHT: As is -- well, hospitals and skilled nursing facilities. I mean, that's what the regs allow you to do. That is what we do. Yes. We have -- I mean, we do recognize that everybody can't get to Branford, and everybody does want to come to Branford. And so we do have relationships with other hospitals and others. There's this whole skilled nursing facility population that have -- that need hospice services also that have been living in, you know, in a nursing facility for some years and you don't want to have to take them out of what, you know, they're familiar with, so we go into skilled nursing facilities to provide services they're also.

REP. SCRIBNER: Just so that I'm clear. The other facilities, outside of the Branford facility, that you've referenced, maybe an arrangement or an agreement worked out with a hospital where you would have some oversight of the palliative care --

RONNIE KNIGHT: Yes.

REP. SCRIBNER: -- was being exercised within another healthcare facility?

RONNIE KNIGHT: Yes. By the regulations require that the hospice maintain professional management responsibility for the patient, even if they're in another facility. So there's a lot of collaboration between, you know, our nursing, their nursing, our physician, you know, the attendings that are available there. But, yes, we, kind of -- they just work off this collaborative program -- process by which, you know, patients get taken care of.

The one thing you -- since you're contracting with and have relationships with hospitals and skilled nursing facilities that are also Medicare certified, state licensed, ACHC credits, there are certain things that you can -- there are certain things that you know are in place in terms of -- of the safety issues and medication administration and -- and staffing, you know, which is one of the reasons why it's important that that be required.

REP. SCRIBNER: So I'm gathering then that, each of these other facilities that you referenced, which appeared to be care that's provided within an otherwise healthcare facility, which may be a hospital, but not necessarily a hospital, all would fall under the Department of Public Health regulation and oversight --

RONNIE KNIGHT: Oh, yes, they do.

REP. SCRIBNER: And can you just give me a number of how many of those satellite agreement locations there might be in the state?

RONNIE KNIGHT: Number of facilities that we might have a relationship contracts with?

REP. SCRIBNER: Well, to -- yes.

RONNIE KNIGHT: Is it fair for me to say that we have a number of hospital and skilled nursing facility contracts supporting all of our area offices, both, throughout the whole state, but whether it's 25 or 80, I don't really want to say that.

REP. SCRIBNER: Well, to be clear, it's very fair for you to say anything you like to say, sir, but I'm trying to identify how many other locations, which might be referred to as satellite facilities, but I don't know if that's clear identification of them because it appears to me from what you've responded that they are actually --

RONNIE KNIGHT: Yes. See I don't you think that we are running satellite facilities. No, we have --

REP. SCRIBNER: I don't.

RONNIE KNIGHT: Okay. Good. So we have contractual relationships with a number of hospitals that, you know, support our -- I mean it's fair to say that the goal is to have a relationships with every one of the hospitals in the state of Connecticut that have patients for whom we can render care. So that is definitely a goal and we're pretty -- we're pretty well thought of in the hospital community so they -- we provide a very good service for them, so if that's -- you know, that helps.

REP. SCRIBNER: Are you aware of there being any pre-existing similar arrangements with other hospice agencies within the state of Connecticut, having a similar arrangement with a hospital?

RONNIE KNIGHT: I guess, what I'm saying is by -- to be licensed in the state of Connecticut and to be a Medicare certified agency, you have to have arrangements with hospitals or skilled nursing facilities, you know, by definition. I mean so all of them do.

REP. SCRIBNER: I think what I was getting at is that, I'm trying to identify if there are previously established collaborations with a hospice agency and a hospital facility, are you aware of there being any that have discontinued such an offering?

RONNIE KNIGHT: Discontinuing that sort of arrangement?

REP. SCRIBNER: Yes. Where a palliative care hospice circumstance was in agreement to be provided within a hospital facility and that opportunity no longer exists.

RONNIE KNIGHT: Yes. I mean, because, obviously, the hospital has to be satisfied with that arrangement and there have been instances where they're no longer satisfied with that arrangement so they choose to have that arrangement with someone else.

REP. SCRIBNER: And then, in such a situation, are you aware of what alternative has been offered other than, perhaps, The Connecticut Hospice, for patients that might have taken advantage of that opportunity to receive palliative hospice care in a hospital within their region, and they no longer have that opportunity.

RONNIE KNIGHT: I don't know of any hospital that doesn't have a hospice program available to them. If that's the question, no. Whether they've discontinued a relationship with a specific hospice, that may be true, but there's

no hospital that does not have hospice available to their patients. None.

REP. SCRIBNER: Thank you.

SENATOR GERRATANA: Thank you.

Are there any other questions or comments?

If not, thank you, Mr. Knight.

RONNIE KNIGHT: Thank you.

SENATOR GERRATANA: That was a long, long course.

RONNIE KNIGHT: That's what I'm here for. Thank you for your time.

SENATOR GERRATANA: But we appreciate your information. Thank you.

Next is Carol Maier.

Hi, welcome.

CAROL MAIER: Thank you. Good afternoon. Senator Gerratana and committee members, thank you very much for this opportunity. My name is Carol Maier. I'm the director of Hospice Southeastern Connecticut, a nonprofit community-based program serving all of New London County. I have been there for 24 years and a nurse for 48 years, a hospice nurse for 32 years. And in our hospice program over 9000 patients have been served in our time with this committee.

I'm submitting testimony in support of HB 5499 with revisions as I have submitted in my testimony, which I will not read. I also strongly support the passing and implementation of the revisions to the hospice facility

regulations. And I want to clarify that the revisions speak to the regs that were first written for Connecticut Hospice, as Ronnie so mentioned in the 1980s, which had multiple waivers. So the new regulations are, again, ones that bring, as people have said, contemporary regulations. They are developed by the Department of Public Health, who has expertise and in collaboration with the 28 of the 29 hospice programs in the state, who are licensed and certified. All of us are hospice experts who demand quality care from our programs and will not stand for anything less. These hospice facility regulations and revisions must be passed soon because access to all hospice residents care to all residents of the state is severely compromised due to the distance that's been mentioned.

I think it's very important that we understand, as people have said, the patients at the end of life and trust their end-of-life time to us. Our excellent quality that is provided is not meant to be adequate, which is a word that's been mentioned quite often here. When a patient goes into a hospice residence because the contracted arrangement with the nursing home or the contracted arrangement with the hospital, or the home care does not work, we have to look at this very seriously. The only focus that we have is to provide access to the complete continuum of end-of-life care for every person in the state.

The regulations, as have been stated, are mirroring the federal guidelines. And I think the two points I want to make is that the regulations stand for high quality. The scrutiny the people are looking for, the numbers, we are scrutinized as a -- in Connecticut, you have to be a licensed home care agency to become a hospice program, and

then these regulations would come underneath. The scrutiny is the same for Connecticut Hospice as for us. We are scrutinized regularly by the state, by the federal government. We are also CHAP accredited. There are regulators that look at us for reimbursement. The scrutiny does not give direct numbers, but when they come to us they look for those numbers. The regulations do not state direct numbers, but the scrutiny that we are all, all, all beholding to, so we make sure we have those numbers so I support that.

SENATOR GERRATANA: Thank you. And I thank you for your testimony.

And are there any questions?

Representative Scribner.

REP. SCRIBNER: Thank you, Madam Chair.

Good afternoon. Thank you for your patience in waiting to provide us with your message, and I would especially like to thank you for your long commitment and care in the hospice program. Can you just explain to me -- I understand that you're a kind of standalone --

CAROL MAIER: Yes.

REP. SCRIBNER: -- regional hospice agency. And you have a facility?

CAROL MAIER: We do not have a facility. We have a plot of land where we intend to build a 12-bed hospice residence. The intention is predicated on the new regulations. We could follow the regulations as they currently exist, but I don't believe that they are speaking to what is necessary today for patients and families at the end of life. And I certainly don't believe

that the intended regulations that are proposed are anything less than outstanding. I would never stand for that lesser-than-quality care, never.

REP. SCRIBNER: Thank you. You identified that you, as a hospice care provider, regardless of where the actual care is being provided --

CAROL MAIER: Right.

REP. SCRIBNER: -- are subject to the same standards and regulations that Connecticut Hospice is or any other would be. Correct?

CAROL MAIER: Yeah.

REP. SCRIBNER: Does your hospice agency presently have an arrangement with one or more hospital facilities, or similar facilities to provide inpatient care?

CAROL MAIER: Yes, yes. We have two hospitals that we have contracts with for beds. We have area nursing homes, 17 of them, where we have contracts. The care is very difficult, though, because we are not directly involved in the care. By contractual arrangement means just that. We can -- we can direct the care, but we are not at the bedside. A hospice resident, with the expertise of the clinician at that bedside, it is what is absolutely needed. When the care is third hand, the patient suffers. And that is not -- you can do your very best, but that is not the best way to have it happen. You hope for the best.

REP. SCRIBNER: It sounds as if you experienced some level of challenge in attempting to provide the standard of care that is established by hospice when you are trying to provide that care and another facility where, obviously, you're

subject to the separate standards of that facility and what's required of their staffing professionals. Is that an accurate assessment?

CAROL MAIER: That is. And that's where I take issue to the statement that hospice beds are available to anyone within their community in a very short distance. A bed is not a hospice residence. A hospice bed that we contract with is wonderful, but it's -- the care is at the mercy of the staff, who is on that shift, what they see as their assessment skills. They can call us and we'll be there in a heartbeat, but we have to rely on them.

If there's a clinician that walks away from the bed, that is uncomfortable with death, does not know the parameters, has no good assessment skills, that patient suffers. And that is what we are trying very hard to educate the clinicians in the different residences or different -- different facilities that we work with, but it's an uphill battle. And the patient is always at risk, and I would be remiss if I did not say that. And that -- that means that there are not beds all over as everyone says. There is a hospice residence in Branford, there's Middlesex Hospice and that is it. And the rest, we are all subject to the whatever happens in that facility when we are not there, and we are not providing direct care. We oversee it, and we are responsible for it, which makes it even worse. That we're responsible for that and we are judged on that.

REP. SCRIBNER: Do you also face challenges in regard to availability with the arranged facilities that you --

CAROL MAIER: Yes.

REP. SCRIBNER: -- have one there is a need and it either cannot be met or certainly not be met optimally?

CAROL MAIER: Absolutely. In a nursing home in our county -- and I hope am not speaking out of turn -- for a patient going to this facility, either needs to be a large sum of money, well over $10,000 put in upfront so that patient may even enter that nursing home, because there is no pay source. The patient is just needing to go there because they cannot stay in their own home. If they don't want to travel to Branford, they can elect to stay in their community and go to a nursing home, which demands payment. If they want to go in to the hospital, they have to have a skillable need that an insurance will pay for. And insurance system pay for you to go in to die, unless you have something they can do. If you do something, then -- then, perhaps, you are really changing the palliative nature of the care. It is a very difficult thing. And our hospitals right now want their mortality rates down, and they want their readmissions cut, so they don't want patients to stay in there to die or to come back in to die.

REP. SCRIBNER: Thank you.

SENATOR GERRATANA: Thank you, Representative.

Are there other questions?

I do have just a follow-up. It sounds to me as, though, perhaps, there's two levels of care, or two tiers of care because of the situation right now in the state, at least that would appear that that is somewhat your argument. And are you saying that by not being able to have a facility, but rather having those people who need palliative care -- I'm

trying to understand how this works, do you have a contract with facility to assign beds --

CAROL MAIER: Correct.

SENATOR GERRATANA: -- for palliative care?

CAROL MAIER: Correct.

SENATOR GERRATANA: And that people who administer care in --

CAROL MAIER: -- are the facility employees. Correct.

SENATOR GERRATANA: The facility employees, in those beds that they administer care but they are not hospice specialists or --

CAROL MAIER: Correct.

SENATOR GERRATANA: I see. So they have to call you to come in or those who are trained in hospice care.

CAROL MAIER: Correct. So when people say there are hospice beds all around the state, that's true, but they're contracted. Every one of the 30 hospices in the state have contracted beds, but those beds are not directly under our care. Technically, under Medicare COP, we are responsible, but we are not delivering the care, so it is very difficult. Hence, we need a residence in areas of the state where people don't have to drive far, where we can provide competent, excellent, not substandard care. We would never do that. The regulations that we must follow and the scrutiny that we are all under does not allow us, we don't have to set numbers. The scrutiny says, How many staff do you have? What do you do? What's your outcome? We can't get away with stuff. Yes,

there's fraud and abuse. There's always fraud and abuse, but that doesn't mean there's no scrutiny, and that doesn't mean there is not a standard that we uphold.

SENATOR GERRATANA: Well, I -- I didn't know that. I didn't completely understand that distinction, and I guess because one facility that is licensed. However, you did mention Middlesex -- Middlesex --

CAROL MAHIER: Yes.

SENATOR GERRATANA: -- has a facility.

CAROL MAHIER: A colleague is here today. She will testify.

SENATOR GERRATANA: Oh, she will testify. Okay. I'll wait for her to testify. So there's actually, if you will, two licensed facilities, is that correct, in the state?

CAROL MAHIER: I'm not certain of the exact the licensure, but they do have a general inpatient unit of care on the top floor of their hospital. Yes.

SENATOR GERRATANA: Okay. All right. Well, thank you for that.

Any other questions?

Representative Srinivasan.

REP. SRINIVASAN: Thank you, Madam Chair.

Thank you for your testimony. When the you talk about the regulations, which you need to comply with and, obviously, that's what sets you apart compared to anybody else, which we are very thankful for, for your very high

standards. But could you also enlighten us that if you have waivers and how many waivers have you got from the Department of Public Health --

CAROL MAHIER: We have none. We have none. I was referencing the original set of regulations written in the early eighties for Connecticut Hospice because they were the very first in the United States. There were a variety of waivers that they had and that is why we believe the relations need to be revised so that we can create a set of environmental regulations that work today, you know. And we still would be receiving scrutiny as a licensed provider. We are looked at every two years; as a hospice, every three years by Medicare. We are also CHAP, which is every three years. So all of that overlays and regulations that DPH are setting out, you know, are the beginning point of all of this that is above us that's not going to go away. This isn't going to evaporate because the regulations are here.

REP. SRINIVASAN: From the Department of DPH you do not have any waivers from the original --

CAROL MAHIER: None at all.

REP. SRINIVASAN: Okay. Thank you. Thank you very much.

SENATOR GERRATANA: Absolutely. Is that it? Okay.

Thank you so much first giving your testimony today. .

CAROL MAHIER: And thank you to the committee and to Department for doing all of this.

SENATOR GERRATANA: Thank you.

Next is Emily Cherin, perhaps.

EMILY CHERLIN: Good afternoon, Madam Chair, members of committee, my name is Dr. Emily Cherlin and I'm speaking on behalf of Dr. Elizabeth Bradley, professor of Yale School of Public Health and a resident of New Haven. And I'm speaking in opposition of Raised Bill 5499.

Since 1974, Connecticut residents can be proud of the availability of the highest standard of hospice care currently being delivered in the state. The use of hospice care -- the use of hospice has been an indicator of high quality end-of-life care. And many studies that have been carried out by the Yale School of Public Health of family caregivers, of patients who receive care at The Connecticut Hospice have demonstrated the benefits to patients and families. The benefits of seriously ill patients receiving hospice care include: improved pain management and symptom control; high perceived quality of care for emotional needs, such as depression and anxiety. Hospice has also been shown to benefit the family of hospice patients in terms of improved family functioning, better bereavement adjustment, greater (inaudible) for satisfaction, and reduced caregiver anxiety. Currently, there is no shortage of geographic access to hospice and palliative care beds at the current institutions, which include short-term hospital, general, special, chronic and convalescent rest homes. Twenty of the 31 hospitals in Connecticut have inpatient beds. Connecticut currently ranks among the top states in the country for ample access to need of hospice services, with more than 90 percent of the population living in the community within 30 minutes of driving time to a hospice.

We know that Connecticut leads the country in the quality of care for people with serious illness and their families due in large part to the current regulations. The quality of care for patients and families of Connecticut will be -- if Raised Bill 5499 is passed will be -- will suffer. Although the proposed regulations are consistent with Medicare certification record -- requirements, these federal requirements present a very low bar for performance. Critical issues, which are upheld by the existing regulations, are not addressed or are far more lenient than the proposed regulations. And these include, which you've heard, the registered nurse to patient ratios, the on-site pharmacist, physicians, and availability of special --

SENATOR GERRATANA: Thank you for your testimony. Could you please give us a summary statement?

EMILY CHERLIN: Definitely.

SENATOR GERRATANA: Thank you.

EMILY CHERLIN: Raised Bill 5499 is ambiguous and leaves room for interpretation as far as the provision of hospice services. If new hospices are allowed to operate under Raised Bill 5499, it remains to be seen how this will affect the high quality of care that has been delivered in our state for the past 40 years. Thank you.

SENATOR GERRATANA: Thank you, again. Before you go, there may be questions?

No, thank you so much.

EMILY CHERLIN: Thank you.

SENATOR GERRATANA: Next is Maureen Canavan.

A VOICE: (Inaudible.)

SENATOR GERRATANA: Oh, it was. I'm sorry. Okay.

Carolyn Wolfe?

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CAROLYN WOLFE: Madam Chair and to the committee, I am Carolyn Wolfe, MSW, volunteer director of social worker for Regional Hospice and Home Care of Western Connecticut. We are a nonprofit agency with nearly 30 years of experience of quality patient-driven interdisciplinary care. I've been privileged to work with the Regional Hospice and Home Care for nearly five years, and I can attest from experience how much Western Connecticut could benefit from revised hospice facility regulations. -- excuse me.

Recently, I worked with a woman named Mary. Mary was in her late eighties, had N stage lung disease but was alert, oriented and incredibly self-directed in her plan of care. She had lived alone since she was widowed 20 years earlier and fiercely independent, something she prided herself on. Mary was terrified of what would happen to her when she was no longer able to live independently. She had strained relations with her adult children and vowed she would never burden them with moving in with them or have them in with her. Additionally, she had past negative experiences with live-in help, and she was incredibly anxious about the idea of someone living in her home. Mary and I talked for months about developing her plan of care. She talked openly about wishing there was a facility nearby where her grandchildren could visit, where she can maintain her privacy and her own room, where she was not reliant on her family to provider care. She did not want an institutional setting, like a nursing home. She needed a homelike environment, quality

staff whom she trusted, an expert symptom management like she was already receiving at home.

In the end, Mary agreed to have a private caregiver live in her home. Unfortunately, the anxiety of this arrangement exacerbated her illness and heightened the existing strain she and her adult children already have. Mary ended up going to the hospital in a crisis -- and it's important to note that in our state, our part of the state, there is no option for inpatient -- general inpatient level of care in a hospital setting. We do have those contractual relationships with area SNFs.

Anyway, in the end, Mary died alone in the hospital in a setting that she never wanted and had there been something closer to home, she wouldn't have had that.

SENATOR GERRATANA: Miss --

CAROLYN WOLFE: To sum up-

SENATOR GERRATANA: Thank you, thank you.

CAROLYN WOLFE: I just want to say that --

SENATOR GERRATANA: I actually have some questions, but go ahead.

CAROLYN WOLFE: Absolutely. As a hospice social worker, I often put myself in the situation of if this was my mother, my father, God forbid, it was me. What would I want from my family. Would I want my husband to risk losing his job and our insurance coverage so that he could stay home to take care of me? Would I want my children to have to leave all of their afterschool activities to drive 90 minutes to visit me in an inpatient facility. What I want

-- I'm sorry. What I want my kids to visit me in a nursing home where the rest of the residents, where the residents there are more than twice my age. No, of course, I wouldn't. I would want something that is close to home, in my community, with the staff and the home care expertise that was already given in the community in an inpatient facility.

SENATOR GERRATANA: Thank you so much for your testimony. And there are -- I have to ask, you're not able to contract for hospice beds in your area or region?

CAROLYN WOLFE: Oh, we have many contracts in the area with area skilled nursing facilities. Currently, the hospital in our area of the state does not have any contracts with any outside hospice organizations to provide inpatient palliative care hospice beds.

SENATOR GERRATANA: Okay. That answered that question, and I noticed that you suggested some substitute language --

CAROLYN WOLFE: Yes.

SENATOR GERRATANA: -- in your testimony-

CAROLYN WOLFE: Yes.

SENATOR GERRATANA: -- and actually, I did have questions. The last statement -- or in your testimony for substitute language is the hospice facility, including a hospice residence, must be able to provide the following level of hospice care, routine, general inpatient, continuous or respite.

CAROLYN WOLFE: That's correct.

SENATOR GERRATANA: And could you explain to me with that sentence means --

CAROLYN WOLFE: Sure.

SENATOR GERRATANA: -- how you interpret it? Thank you.

CAROLYN WOLFE: Sure. Under the Medicare conditions of participation, there are four levels of care that the hospices can provide --

SENATOR GERRATANA: Okay.

CAROLYN WOLFE: And that is the routine hospice level of care, which would be a very much that community-based hospice care that is sometimes done in an inpatient setting but often done in the home. There is also what is known as the general inpatient level of care where if the patient meets a specific medical criteria for symptom management and palliation of symptoms, it's a higher level of care that is only able to be done in a certain type of setting that is able to manage those general inpatient level of care.

Continuous care is when the patient's symptoms are so severe that they need ongoing constant management with interventions as frequently as every 10 to 15 minutes, needing skilled medical interventions. And then respite care for when they are patients and caregivers in the community, where there are some sort of breakdown or the family needs some respite, that there is an option for the patient to go into an inpatient setting, temporarily, for just a few days while the family is able to come up with other plans of care.

SENATOR GERRATANA: Thank you so much. That was very helpful for me.

Are there other questions?

If not, thank you for coming today and thank you again for your testimony.

CAROLYN WOLFE: Thank you.

SENATOR GERRATANA: Next is Dr. Steve Wolfson. Welcome, Dr. Wolfson, and it's good to see you again. I appreciated your testimony last year in the Judiciary Committee. I remember talking with you about palliative of care and regarding marijuana, so that was very interesting.

STEVE WOLFSON: Thank you so much.

SENATOR GERRATANA: Thanks for coming.

STEVE WOLFSON: Senator Gerratana, hearty members of the committee, it's good to see you all. I'd like to speak specifically to one of the levels of care that the previous witness spoke to, and that's the inpatient care of the intensely ill patient, which is the whole source of my concern about the reduced standards of staffing and facility that are implied by this Raised Bill 5499.

I've had a lot of experience referring patients to hospice, but I thought that what might be most helpful to you is my personal experience with my late wife who died in hospice. And I've written this down because it's a little hard for me to talk about it off-the-cuff, but I think that her experience illustrates just how intensive care is at an inpatient facility. Particularly one that is freestanding and independent of a hospital.

My late wife, Susan Wolfson, was an inpatient at the Yale New Haven Hospital seven years ago

after a long fight with ovarian cancer. She was confined to bed with a broken right arm sustained in a fall, intestinal obstruction and large tumor masses filling her abdomen and pressing on her nerves to her right leg. She was in constant pain, she could not eat, and when her surgeon suggested that she might benefit from more surgery. Her reply was, how about hospice? She was transferred the next day and we lived through a miraculous change. She was seen immediately by a team of physicians, nurses, social workers and pharmacists. Her intravenous pain medication were adjusted and within half an hour, she was free of pain. Sent to hospice for help of dying, she came to life.

Two hours later, holding hands, we attended a concert on the common room on the floor. We were able to bring her bed out of doors into the sun so she could watch gulls circling over the sound. After a week, we were introduced to new capability, she was placed in the hoist, lifted up and lowered into a huge Jacuzzi-like bath for her first bath in months. I sat outside listening to the three aides attending her as they sang songs together.

Each morning physicians, nurses, and team members made rounds to check on each of the patients. The physicians order the minor but crucial changes in medications to ensure that she was free of pain or nausea and not sedated. And these changes were instantly put into place by the in-staff pharmacist.

SENATOR GERRATANA: Dr. Wolfson --

STEVE WOLFSON: I'll sum up.

SENATOR GERRATANA: Yes. Thank you so much.

STEVE WOLFSON: The day came when the pain returned with a vengeance and she needed enough medication so that she slept, and this was done instantly. I was sleeping with her in a cot in her room, and so I witnessed that 2 a.m., as rounds were made those patients who were awake, were given a sponge bath, and she was given a sponge bath.

In short, I hope that you'll understand that patients who need inpatient hospice care, like my wife, need what can only be described as intensive care. With this care, many can have peaceful, hopeful, even mirthful days as they are dying. Without the ability to deliver this care, they will only have more suffering.

SENATOR GERRATANA: Thank you so much for your eloquent testimony. We do appreciate it.

Are there any questions?

Representative Widlitz.

REP. WIDLITZ: Thank you, Madam Chair.

Hi, Dr. Wolfson. It's nice to see you.

STEVE WOLFSON: We tried to meet yesterday.

REP. WIDLITZ: Yes, we did.

STEVE WOLFSON: It's good were doing it today.

REP. WIDLITZ: I had the benefit of shadowing Dr. Wolfson for day a few years ago. And I'll tell you, he's one busy doctor. We ran back and forth between hospitals, and it was a wonderful experience for me. And I just want to say, I know it's difficult, but I appreciate you sharing your story. It's not just about the patient, it's about the whole family and

it's different and important so I thank you for being here.

SENATOR GERRATANA: Thank you.

Representative Srinivasan.

REP. SRINIVASAN: Thank you, Madam Chair.

Thank you, Dr. Wolfson for testimony. In your experience, do the patients who are taking care of at home before the inevitable happens, do they come to the hospital before it happens or what would be your educated guess in terms of percentage-wise, people coming into acute-care setting like the hospice hospital?

STEVE WOLFSON: Most of the patients who want -- or at least most of my patients, who wind up making the decision about going to hospice, do so once they are in the hospital. And the decision is made where to go from there. Many of them feel very strongly that they would like to be at home to die and here hospice -- Connecticut Hospice and the other regional hospices offer superb service to support patients and families at home.

Patients, such as my wife, it is clear would have been miserable at home. They need 24-hour care, they need frequent adjustments of medications. They need support with all the activities of daily living. And they need to support that only a full-time staff can give. There is also -- and my wife expressed this. She expressed to me the fear that if she died at home I could no longer live comfortably in our home. And that's a very real phenomenon. Of those of my friends who have lost spouses, the majority have sold their homes very shortly thereafter. And hospice is a center that has somehow a way to institutionalize love. It is

a remarkable experience. I don't think that anyone is proposing that it is essential that everyone match Connecticut Hospice in terms of the -- their offerings, but what I feel and what many feel -- and you've had testimony on this behalf -- is that if one is to offer inpatient services to seriously ill patients, the reduced standards that are suggested by the Raised Bill 5499 will simply not be adequate.

SENATOR GERRATANA: Thank you.

Are there any -- no.

Thank you, Dr. Wolfson. Take care.

Next is Ellen Raspitha. Welcome.

ELLEN RASPITHA: Thank you. Good afternoon Madam Chair and committee members. I am Ellen Raspitha, a 15-year volunteer with Regional Hospice and Home Care of Western Connecticut. For 11 of those years, I served patients and their families as part of the hospital visiting team. Patients alone or with spouses and family no longer able to care for them face admission to a nursing home. A decision I can tell you that leaves these patients and their loved ones extremely distraught during an already trying and upsetting time. HB5499

Why do I know the situation so well? In May 2009, my husband Gus in his final decline from ALS Lou Gehrig's, experience shortness of breath. As there is no treatment for ALS, Gus had refused any breathing assistance or a feeding tube so now is the time to keep them as comfortable as possible. I could not manage Gus's symptoms alone at home with morphine drop, particularly since at the same time I was dealing with vertigo. On Friday, May 8th, Gus was admitted to Danbury Hospital on his hospice

benefits, by Saturday morning, a mere 18 hours later, we were discussing where Gus would go when his symptoms stabilized, which they did over that weekend. Gus knew that by Monday, May 11th, he would be placed somewhere, where, we did not know. Instead on Monday, May 11th, Gus passed away.

With the residential hospice in Danbury, both Gus and I would've had relief and peace for our last three days together. I also come to you today from Brewster, New York, Putnam County, which borders Fairfield County -- two more sentences, three.

SENATOR GERRATANA: You can finish. You're just about done.

ELLEN RASPITHA: Numerous Putnam and Westchester residents already drive the short distance to Danbury for medical care and would benefit tremendously from the local residential hospice under Regional Hospice's excellent standard of care, compassion, and hope. As both a caregiver in the volunteer, or as I say, from both sides of the bed, respectfully, I ask you to please stop these shenanigans by honoring the hospice movement with the clearly needed change in regulations. Thank you.

SENATOR GERRATANA: And thank you for your testimony. I'm so sorry for your loss, too.

ELLEN RASPITHA: Thank you.

SENATOR GERRATANA: But we appreciate it.

Are there any questions?

No. Thank you for coming all that way today and sticking it out. We appreciate it.

ELLEN RASPITHA: It has to be changed.

SENATOR GERRATANA: Next is Robert Tendler.

ROBERT TENDLER: Well, it's been an interesting five hours listening to this testimony --

SENATOR GERRATANA: Thank you. Thank you for coming.

ROBERT TENDLER: -- so I'm not going to stick to the script. I'm just going to try and rip through this as quickly as possible.

SENATOR GERRATANA: Okay.

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ROBERT TENDLER: My name is Robert Tendler. I am a senior consultant pharmacist. I'm a board member of the Connecticut branch of the American Society of Consultant Pharmacists. I'm a past president of the Connecticut Pharmacists Association, and for the last 25 years, I've served as the consultant pharmacist for Regional Hospice and Home Care, being a part of their weekly team meetings, as well as their medical advisory board, for which I do not ask for any compensation. I've done that for 25 years. I'm a notary public and one of the things I do as a notary public is going to our clients' homes when they do not have a DNR or do not have advanced decisions for their life, so I visit a lot of our clients in their homes.

I met with somebody in -- I'm a senior who lives in Heritage Village. It's the largest senior community in Connecticut. And there are almost 4,000 people there. So I met with this one gentleman and his wife was pretty ill and there was a decision about placing her in some kind of residence. I recommended going to the facility in Branford, and he said to me, it was

just not possible for a 90-year-old gentleman to have a wife being anywhere from 1 and a half hours to 2 and a half hours away depending on whether there was traffic or construction, and traffic issues. And it's just not possible with many clients who are in similar circumstances need facilities closer to their home.

Finally, as a 25-year veteran for the Regional Hospice and Home Care, I can tell you that in the kind of facility that's being proposed by some -- some of our hospices were they'll be 12 beds, there is absolutely no need for an inpatient pharmacist. If you have a quality consultant pharmacist to be there, to be involved -- you don't have to have an on-premises pharmacy.

The other thing is, there is no such thing as minimal care or lowering the standards, when you're involved with hospice. It's all the way or it's nothing. And I have heard representatives here. I've heard people get up and talk, and I think that some of those people have become brainwashed. It's all about them. It's all about their facility. That's not what it's all about. It's all about the patient. It's all about the --

SENATOR GERRATANA: Bob --

ROBERT TENDLER: It's all about the client and their family.

SENATOR GERRATANA: Thank you so much for your testimony. Did you want to summarize?

ROBERT TENDLER: I'll just summarize by saying 5499 is something that this State needs. To be sucked in by the stories of one facility with 52 beds comparing itself to be able to provide

the best of quality care in your own neighborhood, close to your home, where your parents, where your spouse is, where your children can come visit you is something that we really need. And I hope that you will not let anything stand in your way in passing 5499. Thank you.

SENATOR GERRATANA: Thank you so much. Before you leave, we do have -- one of our committee members has a question.

Representative Scribner.

REP. SCRIBNER: Thank you, Madam Chair.

Bob, I'd just like to thank you for enduring the time here today, but more than that, thank you so much for your professional contribution so generously over the years, to hospice provision, which has meant so much to so many. It's greatly appreciated and recognized.

ROBERT TENDLER: Thank you. Thank you. I appreciate that.

Thank you, Madam Chair.

SENATOR GERRATANA: Thank you. Good to see you again.

All right. Next is Cynthia Roy Squittier --

A VOICE: Squitieri.

SENATOR GERRATANA: Squitieri, I'm sorry. I can't make out the handwriting.

CYNTHIA ROY SQUITIERI: Madam Chair and members of the committee, thank you so much for allowing us to talk about this issue today. I am Cynthia Roy Squitieri. I'm the president and

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CEO of Regional Hospice and Home Care in Western Connecticut. We are way over on Exit 5 off of 84, so we are right on the Westchester border. We are an organization that has been doing nonprofit hospice for 29 years -- wonderful, wonderful care to thousands of patients in the Western Connecticut community.

We have the largest community bereavement center in the state of Connecticut. We provide care to thousands of children, teenagers, and adults that come through our center every year. We are recipients of the MetLife Caregiver Award, and we are a finalist in the Premiere Care Award in 2009, of which there were 10,000 applicants. There's no doubt that we provide fantastic quality care. We would never, ever have a hospice residence that didn't provide that. I'm also the chair of the hospice and palliative care committee and I'm on the -- I'm a board of the Connecticut hospice -- Connecticut Association of Home Care and Hospice. I have been a hospice administrator for 14 years. I'm a clinical family social worker, with experience in bereavement and grief.

I'm testifying in support of 5499, and as you see in my written testimony, I have also outlined some specific revisions that need to be made to this particular bill. As I said, we are nonprofit hospice and we fully intend to build a 35,000 square-foot building in the Danbury area, starting in September. We are planning to have 12 resident beds. There is a reason why we only want 12 beds -- 12 residence beds. We want private rooms for patients and their families, so they can have peace and quiet and die with dignity. We are also planning on moving our 3000 square-foot community bereavement center into that location. We must, must have a hospice

residence in Western Connecticut. There are no hospitals in our area that provide inpatient hospice care. So despite what you've heard today, that is not an option for residents of Western Connecticut.

So, in closing, I'm going to say to you that there is concern across the country about for-profit hospice. We all worry about this in healthcare, in general. We certainly are concerned about it in the nonprofit world, as well, but certainly the regulations in the state are very stringent. We have a tremendous, tremendous woman who is the Commissioner of Public Health. She doing a wonderful job making sure that our standards are high. There is no concern that we are going to diminish that care. And we really need to move forward with this. Twenty-eight of the 29 hospices in this state are in support of this change.

SENATOR GERRATANA: Thank you. Thank you for your testimony.

Are there any questions?

Representative Scribner.

REP. SCRIBNER: Thank you, Madam Chair.

Good afternoon, Cynthia, and welcome to your seat before the Public Health Committee. I want to thank you personally for your level of professionalism and commitment to the highest standard and quality, which I've observed firsthand, that the Regional Hospice of Western Connecticut has provided. And I couldn't be more excited or impressed with the plan to create a facility that allows for the provision of that highest level of quality -- be provided people in the most need, as well as their

families, which, under present circumstances, has been incredibly challenging for people in all of Western Connecticut at that time in someone's life when they're faced with something that may be very imminent and also very uncertain to the people involved most closely. I think it's easy to understand why you would want to provide the highest level of quality care in the most comfortable and private environment as possible.

I would like to have you identify, as you mentioned, about not having a hospital facility readily available or in existence at this point in time. Could you just elaborate on that a little bit to identify what may have been and what is, in as broad an area as possible? Thank you.

CYNTHIA ROY SQUITIERI: A number of hospitals I think in our area, as well as nationally, are looking at the cut to the reimbursement. And it has been said by multiple people, they are choosing to not have hospice beds so that they can make those beds available to their acute care patients. So the options available to hospice patients are a nursing home, so in December when a 14-year-old of ours died on our hospice program, the options were he could go to an assisted living facility or he could go to a nursing home. That is totally unacceptable to me, or he could die at home with his eight-year-old and six-year-old in his home, his siblings. So those are the options, or he could come off of hospice and he could die in a acute-care bed in a hospital, which is not acceptable either. So, for us, to build a residence means to be able to allow somebody like that boy, the opportunity to be in a homelike environment with his family around him.

REP. SCRIBNER: Thank you for that clarification. When a couple of public officials testified earlier today, there seemed to be a concern suggested in that testimony about the maintaining high standards and that, perhaps, the legislations that for us or the regulations that are associated with this language that are also in progress, simultaneously, would somehow reduce the standard of care or the quality requirements that are established by the Department of Public Health. Could you share with us your thoughts about that?

CYNTHIA ROY SQUITIERI: Sure, sure. There are over 250 nursing homes in our state. Two of them have a pharmacist that's on-site, 24/7. All of them use the modern technology of having medi-box and med-rooms, where they can access pharmacy meds for patients within 20 minutes. They don't need a live pharmacist in the building to actually do the medication. You do have to have a physician available and that, of course, is something that's in our -- in our regulations. We would never have a hospice residence without a physician overseeing the plan of care. That's the standard of care.

The second piece is that most hospices already have an art therapy program built into their concept. Our bereavement program is based on an art therapy component. Does it need to be in the regulations in black and white in order to have that? I don't believe so. I think -- that's part of the hospice philosophy that you bring in holistic care into the care of patients. I don't think it needs to be in black and white. We are ready have for-profit hospices in our state. We have them across the country. It's an issue in all of healthcare. As long as your Department of Public Health maintains stringent regulations that -- and oversee the care and come in and provide the

on-site supervision, which they do every 24 months, I think we will be fine.

Oh, I want to add one more comment, and that's around nurse staff ratios. With the new quality measures that are coming out and both on the CMS levels and the issuance MedPAC, there are no requirements that say you have to have a certain number of staff per patient to make sure you have good quality. That doesn't ensure good quality. You could have a nursing home with four patients being seen to one nurse. If it isn't a good nurse, forgot it. The quality isn't going to be good. So, yeah, is a good idea to have it? Sure. Does it mean you're going to have good quality? No. It's up to the Department of Public Health to make sure that the organizations that are licensed are quality organizations.

REP. SCRIBNER: Thank you. The facility in Western Connecticut that is proposed has been identified as having 12 beds planned. What area of Western Connecticut do you envision that covering as far as the outreach and provision? Would it be virtually all of Western Connecticut, from Greenwich, Stamford area, all the way up to the Massachusetts line?

CYNTHIA ROY SQUITIERI: I believe that it depends on where people are coming from that are comfortable in driving. Certainly, our families by Exit 1 are not going to travel 90 minutes to Branford. So I do believe that we'll go down to Greenwich and as far up as Waterbury. I think that's a very reasonable guess that families will do that. It is only 12 beds. We picked that specifically because that is the national norm for hospice. If you look at the National Hospice Palliative Care Organization statistics, most the hospices in the country are only building 12 beds. People

aren't building 50-bed facilities anymore with for patients to a room. They're building single patient rooms. That's the way the hospitals are going, as well.

REP. SCRIBNER: It's been identified during the testimony today that Southeastern Connecticut also has a plan underway to build, perhaps, a similar facility with what I understand to be an equal number of beds, 12. So I guess that is the magic number.

Are you aware of there being any other hospice organizations within the state of Connecticut, presently, that might have such a plan other than those two?

CYNTHIA ROY SQUITIERI: No, I'm not. No, and I serve on the board of directors for the Connecticut Association for Home Care and Hospice, and I'm not aware of any other hospice that plans to build.

REP. SCRIBNER: So, then, it sounds like, at the present time, potentially, should the regulations or this legislation go through, we could envision an additional 24 beds entirely, at least in the short term here in the state of Connecticut?

CYNTHIA ROY SQUITIERI: Yes. Of the 29 hospices in the state, only four of us are standalone. The rest of the hospices in the state are very teeny, tiny, little hospices that are part of Visiting Nurse Services. We are all standalone hospices. We only specialize in end-of-life and palliative care. We don't do VNA rehab services, at all. We only take care of very ill people. So it's my understanding from the other hospices that are VNAs, they don't have any intention to build a residence. And, in

fact, they're looking forward to us building ours because they want to collaborate with us.

REP. SCRIBNER: Part of the earlier testimony, also, in particularly, when we have folks here representing The Connecticut Hospice facility and identified that they have 52 beds and I did question as far as the frequency that they reached capacity and would actually not be able to admit a patient in need of such a facility. What has been your experience since the discontinuation of arrangements with hospitals in Western Connecticut, as far as some kind of eligibility for patients in other areas well beyond the Branford area to get into their facility or another facility?

CYNTHIA ROY SQUITIERI: This is a very serious concern to us because when we had the hurricane in October, all the nursing homes were packed with patients who had no place to go. And certainly, for us, there were not a lot of options available. We had to hire and have extra home health aides to go in and be with patients in their homes to make sure they were safe. So, certainly, it's of great concern that if that were to happen again and we don't have residences, like this, to have patients go to, what are we going to do with them? You're going to find, you know, lots and lots and lots of elderly people in emergency rooms.

REP. SCRIBNER: In regards to professional staffing, there were some dialogue and questions that were raised earlier as to the number of physicians that would be on staff, and we did get some information from officials from The Connecticut Hospice facility. Could you identify for us what the plan is for this 12-bed facility, as far as staffing, and what's your view is as far as what might be comparable

to ratio staffing at the current Connecticut Hospice?

CYNTHIA ROY SQUITIERI: Certainly, we all -- every hospice in the state are certified by Medicare. So we all have to follow very specific Medicare conditions of participation for hospice -- hospice and also the state guidelines, which in the state it's far more stringent for hospice than other states in the country. And in that, there is a very specific regulations about having a full-time medical director. We have a full-time medical director available to us 24/7, and does he go out and do visits to patients? Absolutely. Does he consult on patient care? Absolutely. Is he available at two o'clock in morning if the patient has an issue? Absolutely. We all have that requirement. No difference.

So, as we go into this facility, we have to have a physician there. We wouldn't think to not have a position there. You have to have your medical team together in collaboration to be able to take a holistic look at the patient. So that is not concern to my hospice, and I know it's on a concern for the hospice in Southeast as well. We fully intend to have full -- physician involvement. We can't do this without our docs.

REP. SCRIBNER: Thank you and, again, thank you for your time and your patience in providing us you so generously with some thoughtful information for us to consider.

CYNTHIA ROY SQUITIERI: Thank you, again, thank you members of the committee.

SENATOR GERRATANA: Thank you.

Representative Srinivasan.

Oh, don't go away, Cynthia.

CYNTHIA ROY SQUITIERI: Sorry.

SENATOR GERRATANA: And I have a question for you, too. Okay.

REP. SRINIVASAN: Thank you very much Madam Chair.

Thank you very much for your testimony. In the same line of the concerns that we have, you -- you alluded to the physician. When you say a physician is available, are you meaning at site or available on call 24/7.

CYNTHIA ROY SQUITIERI: No. We are going to have a physician in our building during the day. And after-hours, we will have a physician available by phone, just like Connecticut Hospice does.

REP. SRINIVASAN: Wonderful. I just wanted to clarify that -- that when you meant that. And you are nursing ratios, are they going to be any different than what the --

CYNTHIA ROY SQUITIERI: Our nursing ratios are 4 to 1, for our residence; four patients to one nurse.

REP. SRINIVASAN: As opposed to what we heard was 6 to 1. So yours is even actually better than that, for four patients, you're going to have one nurse.

CYNTHIA ROY SQUITIERI: That is our plan.

REP. SRINIVASAN: Okay. And the final question is, in terms of the in-house pharmacy, are you planning to have that or --

CYNTHIA ROY SQUITIERI: We are not going to have an in-house pharmacy, we have a very sizable in-house med room. And will be using Omnicare and some of the licensed pharmacy organizations to actually work with us to have our med room. But we will be a certified IV provider, so we can do IVs right on -- on premises.

REP. SRINIVASAN: So let's say you're physician on call, you're a physician on site, for a patient's acute situation that occurred and have prescribed Medicine A and Medicine B. Since you do not have an in-house pharmacy what do you anticipate the turnaround time for that medicine to be delivered for the patient to receive the medicine?

CYNTHIA ROY SQUITIERI: Well, we do the exact same thing a nursing home does. You have a med box, you have an E-box, you have all your emergency medications available in case a patient develops those kinds of symptoms. You never -- in our hospice world, we never -- and I know you're a physician -- we never go into the environment where you aren't prepared for the worst case scenario.

REP. SRINIVASAN: Okay.

CYNTHIA ROY SQUITIERI: We are always prepared for the worst case scenario. Even in our home setting, we have something called a comfort care box, which has about six different medications for symptoms that may develop over the course of the illness that, perhaps, the patient is not having right now. So that in two in the morning if the patient develops restlessness or nausea and vomiting, we going to that medication box, and we make sure the patient gets the meds they need. Patients don't wait hours for meds that they need in a

nursing home when we're taking care of them, and they wouldn't in our facility.

REP. SRINIVASAN: Thank you very much for clarifying that. That means a lot to us. I appreciate that. Thank you.

Thank you, Madam Chair.

SENATOR GERRATANA: I'm sorry. Thank you, also.

Were there other questions?

Actually, I was trying to pull up the other testimony that we heard. There was some substitute language that was submitted. Are you familiar with that language?

CYNTHIA ROY SQUITIERI: Yes, I am.

SENATOR GERRATANA: You are. Okay. And are you on board with that?

CYNTHIA ROY SQUITIERI: I am. It's in my written testimony, as well.

SENATOR GERRATANA: Oh, I didn't see it there. I'm sorry. Okay. Thank you very much.

Representative Widlitz.

REP. WIDLITZ: Thank you very much for your testimony. I missed some of the testimony earlier in the day, and I wondered if you could just identify for me, if this bill should not pass, what effect does that have on your plans and why?

CYNTHIA ROY SQUITIERI: Well, certainly we hope that the regulations that have been put forth by the Department of Public Health will pass. And we, certainly -- we intend of that will happen. If

they don't, we could go into the 1977 regulations and apply under those regulations, that Connecticut Hospice and others are underneath. But I want to note that those are not contemporized regulations, and they have had substantial waivers to them so they are not contemporized and don't represent the 2012 needs of patients.

SENATOR GERRATANA: Thank you.

Representative Scribner has a question. I'm sorry. We're not going to what you leave.

CYNTHIA ROY SQUITIERI: That's okay.

SENATOR GERRATANA: Thank you.

REP. SCRIBNER: Thank you, Madam Chair, and thank you for raising the question about substitute language.

Before you go, Cynthia, because I don't -- to my knowledge, that's not been discussed earlier today. I am aware that there is substitute language that is presently being considered, and I know that you are familiar with it. Could you just explain to us, from your perspective, exactly what difference that might be? I think it's important for the members to know that as we're focused on the subject matter.

CYNTHIA ROY SQUITIERI: Sure. There is a very specific technical wording that needs to be and this bill and in our regulations. It's already in our regulations that Dr. Mullen has put forth to the Attorney General's Office, and that is, that all four levels of care in hospice -- as my colleague Carolyn Wolfe said earlier -- need to be provided in a hospice residence of this size and scope. So you need

to be able to have the routine level of care, the respite level of care, the continuous level of care, and your general inpatient level of care, to ensure that patients are getting all that they need in a hospice residence facility. And those four levels were missing from this bill, certainly by accident, so I encourage that to be added.

REP. SCRIBNER: Would it, then, also be your interpretation that the regulations that have worked their way through the process and initiated by the Department of Public Health, would, in fact, mirror the substitute language of this proposal?

CYNTHIA ROY SQUITIERI: Exactly.

REP. SCRIBNER: So if the Attorney General's Office gives clearance to the regulations -- which I gather is at least near the last stop on the trail -- the substitute language of this legislation wouldn't necessarily be necessary?

CYNTHIA ROY SQUITIERI: Correct.

REP. SCRIBNER: Thank you so much.

CYNTHIA ROY SQUITIERI: Thank you.

SENATOR GERRATANA: Thank you very much.

Are there other comments, questions?

No. You can go now.

CYNTHIA ROY SQUITIERI: Thank you.

SENATOR GERRATANA: Thank you so much for your testimony.

Next is Deb Healey.

DEB HEALEY: Thank you, Chairman Gerratana --

SENATOR GERRATANA: Welcome.

DEB HEALEY: -- and members of the Public Health Committee, thank you for allowing my testimony today. Can you hear me? Okay. My name is Deborah Healey, and I'm the executive director of Middlesex Hospital Home Care and Hospice. I'm an employee of Middlesex Hospital. Middlesex Hospital is a top 100 hospital magnet certified, and I'm here today to testify in support of the hospice facility regulations, as have been stated before and their revisions. HB5499

My testimony has been submitted as written by Melanie Cama, who is the program director of our hospice program and on behalf of the entire hospice team; including Dr. William Zeidler, who is our full-time medical director.

Over the past years, about 20 years, our facility has taken care of over 12,000 hospice and palliative care patients and their families. Middlesex Hospital does have a short-term inpatient unit that has 12 beds that provide private rooms to our patients versus four-bed rooms, and as I said, previously, we have full-time certified hospice medical director, backed up by APRN -- two APRNs and the staff of hospice certified professionals. And our patient ratio for inpatient is 4 to 1.

The unit currently does provide a homelike environment, but due to the current DPH regulations, we only provide short-term hospice care. We are licensed as an acute care facility, not a long-term freestanding facility as Branford hospice is. Our unit does have 24-hour physician presence and a pharmacist on-site, inpatient because we are an acute care

hospital. And because of best practice and DPH oversight, we can only keep patients in house, in our hospice beds while they have acting symptoms or while they're actively dying. So when their symptoms stabilize, we must send them out to another facility.

So as the time is short, in closing, I'd like to say that all hospices give love at the end of life. They provide for family members, care for family members and patients at home, in the hospital, and at Branford hospice. All of the hospices work with the soul. There is room enough for all of us. What we're asking for is more access so that we can take this journey with our patients, and if we all think about the patients, we can give the right care to the patient in the right setting.

Recently, my mother-in-law has entered hospice care, I honor the care that she's being given by a competing hospice because I trust that they have the same philosophy that I would have were I caring for her in my hospice. I chose to keep her in her local environment, and I trust the care that she's receiving.

SENATOR GERRATANA: Thank you and I know how difficult time it is. I've been through that, also, but I do appreciate that you took the time come here and give us your testimony today.

DEB HEALEY: Thank you.

SENATOR GERRATANA: Are there any questions or comments?

No. Thank you so much. Take care.

Next is Diane Bowden. Hello, welcome.

DIANE BOWDEN: Good afternoon.

SENATOR GERRATANA: Good afternoon.

DIANE BOWDEN: Madam Chair and committee members, thank you. My name is Diane Bowden. I'm a registered nurse at Connecticut Hospice in Branford. I have been a nurse for more than 28 years in pediatric oncology, organ transplant, and adult and pediatric hospice care. I am speaking here today to oppose the Department of Public Health's proposed changes as stated in Bill 5499.

I'm going to read you part of this, but it's written, and then I'm going to just summarize. There's been questions today whether it does or doesn't reduce the staffing. Bill 5499 would add the statement and I quote, such regulations shall include provisions that are substantially the same as the provisions of 42 CFR 418.110, end of quote. That's the federal regulation. It states in that federal regulation, and I quote, the federal regulation, staffing -- the hospice is responsible for ensuring that staffing for all services reflect its volume of patients, their acuity, and the level of intensity of services needed to ensure that plan of care outcomes are achieved and negative outcomes are avoided, end of quote. It does not state a nurse to patient ratio standard.

The current Connecticut standard is one nurse to six patients for an eight-hour shift. That's not Connecticut Hospice's standard. That's a Connecticut state standard. We frequently have far less than that, that's the minimum. We have 3 to 1, considering nursing and staffing frequently -- depending on -- much more than that -- this is the minimum.

The federal regulations go on to state, quote, if at least one patient in the hospice facility is receiving general inpatient care, then each shift must include a registered nurse who provides direct patient care, end of quote. It is stating in the federal regulations you need one, just one. It is a reduction in care.

And may I just add one more statement --

SENATOR GERRATANA: Oh, absolutely. We appreciate your testimony. If you can give a summary.

DIANE BOWDEN: I'm a foot soldier. I'm on the floor doing what you're regulating. I have -- we all do care in hospice. Anyone involved in hospice loves what they do and does it to the utmost. I see the job as a legislator as putting minimum standards so we can continue to go above and beyond it as most will continue to do. But the job here is to decide what's the minimum. And these new regs take that out. I don't know what I would do, and those four levels of they talk about -- in the acuity of the situation, without my in-house pharmacy, and my in-house doctor. We are forever talking to them all day long because patients -- not in the regular everyday calm, when things are stable or for the respite -- but those in the acute situations of those four levels need that intervention acutely. And the rest of my written testimony, of which was submitted, gives examples of the respiratory stress and severe pain and the vomiting -- tumor bleed outs that require that.

I'm asking you to empower all these people. If we need more facilities, that's a different issue. That's fine. They need the standard set. We're doing the work. Listen to us doing the work. But you need this to do that work for those patients. And that you set, as

legislators, standards that require them to also keep this Connecticut standard that has been testified to. That's all.

SENATOR GERRATANA: Thank you. Thank you very much. Got the message.

Are there any questions?

No. Well, thank you for coming today. Thanks for sticking around.

DIANE BOWDEN: Thank you very much.

SENATOR GERRATANA: Okay.

Next is Carmen Lopez.

Hello, Carmen, welcome.

CARMEN LOPEZ: Good afternoon.

SENATOR GERRATANA: Good afternoon.

CARMEN LOPEZ: Okay. Thank you very much. I'm a resident of the Bridgeport, Connecticut. For 20 years, I practiced law in the city. I then served the State of Connecticut as a superior court judge before stepping down -- before stepping down to pursue other interests that I had. I'm here to speak in opposition to 5499, AN ACT CONCERNING REGULATIONS RELATED TO HOSPICE CARE.

I first came into contact with hospice about three years ago, when I had a relative that was dying. And I had the opportunity to go up to the Branford facility and see what that was about. As you've already heard today, lots of folks don't know about hospice until you yourself need to come into contact with that. What I can say is that the support and the

respect that my family received from the providers of the service was of the highest quality. Now, I came up here today -- and as you know, I've been here all day waiting for my name to be called because I'm really sad to learn that the Public Health Committee is proposing a bill that would require the State Department of Public Health to develop a set of regulations that would dramatically change the delivery of inpatient hospice care in Connecticut.

As you read the statute -- and I know the speaker before me just read it to you, you know -- and, of course, you know it, you're proposing it. The statute contains language that requires the State Department of Public Health to promulgate regulations that would mirror the minimum federal standards for hospice care, thereby it would be reducing the medical services and the spiritual support that hospice patients and their families need.

Now, I know you've heard a lot today, and I have a lot here about what this bill would do and how these -- the services are going to be reduced so I want to take your time going through all that, but I would like to just say this to you. As Hubert Humphrey stated in his last speech, "The moral test of government is how that government treats those who are in dawn of life, the children; those who are in the twilight of life, the elderly; and those who are in the shadows of life, the sick, the needy, the handicapped, and the dying.

So I ask you to not let Connecticut begin the journey down that slippery slope of lowering their high quality hospice standards to the lowest common denominator. And if we do, I would ask you to be truthful and recognize that

in the conflict between morality and profit, the State of Connecticut chose profit.

Thank you for your attention. Thanks for everything. Okay.

SENATOR GERRATANA: Thank you so much. Oh, don't leave.

CARMEN LOPEZ: Oh, don't leave.

SENATOR GERRATANA: We have Representative Stallworth has a question.

REP. STALLWORTH: Hi, Carmen, good seeing you today.

CARMEN LOPEZ: Oh, yes, my representative from Bridgeport.

REP. STALLWORTH: It's good to have someone from Bridgeport.

CARMEN LOPEZ: Thank you. It's good to see you, too.

REP. STALLWORTH: Could you compare and contrast, just briefly, what it would mean to pass this bill versus not passing this bill?

CARMEN LOPEZ: Well, as I -- the statute, this bill requires that the State Department of Health shall pass regulations that mirror the federal ones. Right? If you don't pass it, we have regulations that are in place right now. So those regulations would stay in place and would not be changed unless there were other efforts made by the folks in charge of that to change them.

So I feel strongly about keeping the regulations as they are. I do have, I was provided a copy of the regulations, the

proposed regulations and the current regulations, and I also saw, like the speaker before me, the changes that are in there in terms of having folks that are available as opposed to having these professionals that would be on the floor.

And I have to tell you, Representative, if you've never experienced that, I mean it is something we're all going to have to go through that. And to see -- and many folks have said it here today, the love and the compassion that is shown by everyone on the staff from the moment you walk in.

I just think it's something that if Connecticut is a pioneer everybody has said that, Connecticut is the pioneer, it started here, and we've set the standard. Why in the world would we want to not have it continue down that path if we have that chance? You know how things are happening in so many areas of our life, right, Representative, education, all kinds of things. Things aren't going the way they should. That's just kind of a Bridgeport thing, but anyway, so I would just hope that as you deliberate and you consider this that you would seriously consider not supporting this bill.

Thank you. All set. Right. Thank you so much.

SENATOR GERRATANA: Absolutely, thank you for coming.

Next is Geraldine Marrocco.

GERALDINE MARROCCO: I started my testimony with good morning. I have to change it.

SENATOR GERRATANA: It could be good evening, now.

GERALDINE MARROCCO: Good afternoon, Madam Chairman and members of this esteemed committee. My name is Dr. Geraldine Marrocco. I am a advanced practice registered nurse. I'm a member of the faculty at Yale University School of Nursing. And as you know, we are the very proud organization that had Florence Wall here as a former dean of Yale School of Nursing, and the person who is responsible for bringing the hospice movement to the United States.

I have a private practice in primary care in Fairfield, Connecticut. I live in Trumbull. I have been employed as an educator in nursing for over 36 years. I have taught across all spectrums in nursing education, including: Nursing assistance, diploma nursing, associate degree nursing, bachelor's degree in nursing, master's degree in nursing, and doctoral degree. I have also participated in the development, in evaluation of curriculum across all levels of nursing.

I'm very disturbed by the proposed change in the regulation. I urge you to reject HB 5499.

The current level that is here is specific and effective and it assures the quality of care to support and treat the dying patient. Supplanting this specific regulation will alter the landscape and provide a slippery slope that will only lead to disorganization and grant an open interpretation for implementation.

The standard will be lowered at the very time in our health care reform when standards should be high. There is too much room for error and harm by lowering the standard. A regulation suggesting an impatient hospital facility model will create this lower standard. We already have an inpatient level of hospice care where

patients and families can seek expert care during the terminal stages of life by qualified professional staff, included but not limited to license registered nurses, licensed and registered advanced practiced nurses, clinical nurse specialists, physicians, pharmacists, social workers, all who have earned credentials in the very specialized care of the dying patient.

Instead of holding to an established standard of care, you're looking at the potential for nurses aides who are unqualified and not licensed to administer medication or therapeutics to the dying patient. Let's face it, these aides are not legally allowed to administer medications. They are not trained in the assessment of patients, who are so complex and whose needs change from minute to minute during the dying process. These patients are striving to die at home. They are hospitalized because they can no longer manage at home --

SENATOR GERRATANA: Thank you, Dr. Marrocco. Thank you for your testimony.

Could you give us a summary of it for us, a summary statement.

GERALDINE MARROCCO: I just have one more sentence --

SENATOR GERRATANA: Thank you.

GERALDINE MARROCCO: These patients are unstable and that's why they are hospitalized. Certified nurse's aides who are working have no authority under the statutes, the regulations, or declaratory regulations. They are not licensed. This proposal is a red flag to substandard care and I urge you to reject 5499.

SENATOR GERRATANA: Thank you so much.

Are there any questions or comments?

No?

Thank you for coming. Thanks for sticking through -- sticking it out here.

Next is Zach Taylor.

ZACHARY TAYLOR: Good afternoon, Madam Chairman --

SENATOR GERRATANA: Good afternoon.

ZACHARY TAYLOR: -- and members of the committee. HB 5499
My name. Is Zachary Taylor. I live in Newtown, Connecticut, and I am a volunteer for Regional Hospice of Western Connecticut.

We, hospice volunteers, try to bring a little reassurance and some humor to the patients who are facing the imminent end of their lives. We are bedside hand holders, book readers and providers of some comfort. Occasionally, we are able to build relationships with both the patients and their families. Those of us who focus on the patients in nursing facilities team up and augment the staff of the facilities as they cannot devote the time that is required by our patients and their grieving families.

Our organization in Danbury has been in business for 30 years and is highly regarded. Many of the surrounding towns and corporations help in our support. We are a large and well-trained group of volunteers and employees, and we hold ourselves to the highest of standards. Despite all our dedications, however, we are not able to have our own nearby dedicated facility entirely focused on end-of-life care.

In 2006, my dying mother-in-law had to share a room with three other women in the only in-patient facility in the state, Connecticut Hospice in Branford. Family visitations were awkward because they were so public and the distance made the different -- made the trip very difficult, and we were basically restricted to weekends.

HB 5499 will change all this. In the future visitations will be far more comfortable and visits, even after work, would be possible.

This bill will permit the construction of modern, local, in-patient hospice care facilities. As you've heard, we have plans in place and they're well underway. They would have private rooms for intimate family visits and adjoining accommodations for family members to spend the evenings.

Thank you for your consideration of this bill.

SENATOR GERRATANA: And thank you very much for your testimony, we appreciate it very much.

ZACHARY TAYLOR: Thank you.

SENATOR GERRATANA: Mr. Taylor, thank you for sticking around.

Are there any questions?

No?

Thank you.

Next is Marshall Collins.

MARSHALL COLLINS: Good afternoon.

SENATOR GERRATANA: Good afternoon.

MARSHALL COLLINS: My name is Marshall Collins. I'm not appearing as a paid lobbyist or an employee of anybody involved on the -- involved in the Bill 5499.

As a -- in disclosure, some 15 years ago, I did represent the, then, Hospice Council of Connecticut, who came in trying to modernize the regulations that are before you today that was blocked.

The other reason that I'm testifying, as I sat here and listened to all this today, the question before you today is whether or not the regulations provide for the highest quality of care.

Access, you can't separate access from that highest quality. You heard about people having to drive long distances. Clearly -- well, let me tell you there's a qualifier, the -- my mother was a hospice patient in Glastonbury Home Care, received wonderful care from a nonprofit hospice. I'm, obviously, familiar with Hospice of Southeastern Connecticut and my sister-in-law and my closest friend for forty years came into our house to live for several months to die as a hospice patient home care. They didn't have any place else to go. It was either a hospital or a nursing home. It was too far to go to Branford.

The quality of care that's given by Branford in their home care operation is the same as these home care hospices. It's the inpatient facility that you're looking at here. If these regulations are old, they were adopted in '74, you've heard. They haven't been updated in some 25 years. Even Branford, Connecticut, Hospice won't tell you that this -- these

regulations represent the most modern standards. Ask them how many waivers they've received in those 25 years. They've got to have -- I don't know the exact number, that's their -- 10, 15, 20?

If they have to have 20 waivers, why should everyone else coming in here be held to a higher standard? I think it's appalling when I hear people talk about dumbing down the level of care that these non -- dedicated people provide. It's not necessary.

This is about access to people that need help. Branford is the only one. It's not state of the art, four patients in a room is not state of the art. They wouldn't build the same facility today. Ask them. They know that these need to be modernized. They just don't -- give people the chance to get the care they need.

SENATOR GERRATANA: Thank you so much.

MARSHALL COLLINS: By the way, Florence Wall came in here 15 years ago and testified before the Department of Public Health in favor of amending these regulations to modernize them.

SENATOR GERRATANA: I guess there's -- there's two issues that I guess we'll have to consider. One is access to a facility to get, you know, comprehensive care, if you will, as some people in the state are able to do at the Branford facility.

MARSHALL COLLINS: You raise a good question, Senator. But we've heard testimony today for the proposed residents that they're proposing both Southeastern and Western Connecticut, that they wouldn't have, you know, a pharmacist on

site 24/7 or physician on -- in the building 24/7. You heard Branford say, they don't have that either. And, you know, and it's -- so, you know, that's not -- again, we're talking quality of care. And they're talking about doing it, you know, the same way, on-call pharmacies, the services. And, you know, to think that these people, these nonprofit agencies are here for that evil word, "profit," which has been tossed out a lot as people that are opposing this change, is really wrong. And, you know, 28 of 29 hospices, are they all in it for profit? I just had to testify.

SENATOR GERRATANA: I know but I think the other thing that the committee has to consider, of course, is that standard of care that everyone gets, you know, appropriate care and that will be something that, of course, we'll discuss, but I thank you for your testimony --

MARSHALL COLLINS: That's why -- that's why you have regulators in the department. They're involved in this --

SENATOR GERRATANA: Right, right.

MARSHALL COLLINS: -- and they have done as -- they're doing a good job regulating Branford, why wouldn't they do equally as good of job --

SENATOR GERRATANA: Right.

MARSHALL COLLINS: -- regulating anyone else?

SENATOR GERRATANA: Thank you.

Representative Srinivasan has a question.

REP. SRINIVASAN: Thank you, Madam Chair.

Thank you very much for your testimony.

You brought up the question of waivers and in your assessment you said they have or you think they have because when I asked that question earlier on I was told very clearly they have none whatsoever. So that, obviously, is, you know, something that we have to look into between what they have in the original language and what waivers they have, which may not be legitimate for other people.

MARSHALL COLLINS: Representative Srinivasan, I think I was in the room when -- I heard you ask that question and you asked it of the person from the Hospice of Southeastern, Connecticut, which is not Connecticut Hospice. You asked it of the wrong -- right question, a very good question.

I think if you asked it of the Department of Public Health, I mean they're the ones that would know how many waivers Branford has received over the years. How many variances they've gotten, in essence, you know. And so, I mean, because the Hospice of Southeastern Connecticut, the woman when you asked their executive director, how many waivers they had, it's a different program. If they built -- if they built a residence, would they have to then have to ask for all the same waivers that Branford did? And if they did, would that be a reduction in care?

So does every time that Branford comes in and asks for a reduction -- asks for a waiver, is that a reduction in quality of care? If these regs are so good and so modern, absolutely not. And I don't question the intent, you know, the mission driven -- the mission that Branford is -- the people in Branford try and, you know, fulfill. It's the same as the rest, but if you

can't get that, if you're in Sprague or Versailles or Windham and you can't --

My father was a heart patient. He couldn't drive if we had to put my mother in Branford. Okay? He couldn't drive there to take care of her, you know, to visit her every night. So that's what we're trying to do is to make sure that everybody has the same access in a home setting, not in a hospital, not in a nursing home.

REP. SRINIVASAN: Thank you very much for the clarification and that obviously is what we, as a committee, will have to get -- go back and check and see what these waivers are but thank you for bringing that up. We appreciate that. Thank you.

MARSHALL COLLINS: You're welcome.

REP. SRINIVASAN: Thank you, Madam Chair.

SENATOR GERRATANA: Thank you very much.

That concludes the testimony on House Bill 5499. We'll now move onto Senate Bill 373 and the first person to testify is Marjorie Rosenthal.

Welcome.

MARJORIE ROSENTHAL: Thank you. Good evening --

SENATOR GERRATANA: Thank you.

MARJORIE ROSENTHAL: Madam Chair and other members of the Public Health Committee, as a pediatrician, my mission is to work with families to keep children healthy and safe. As 60 percent of children under six years old, both, in Connecticut and across the nation,

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TRANSPORTATION COMMITTEE

March 16, 2012

Senator Gerratana, Representative Ritter, and distinguished members of the Public Health Committee,

I am State Senator Michael McLachlan, and I am here today to testify in support of House Bill 5499, *An Act Concerning Regulations Relating to Hospice Care*. These revisions are based on the collaboration and input from the Connecticut Association of Home Care and Hospice (CAHCH) and 27 of the 28 hospice providers across Connecticut, as well as the Connecticut Department of Public Health.

The most important piece of this legislation is how it allows for all licensed hospice providers in Connecticut to offer terminally-ill patients access to hospice services for both in-home and hospital-based facilities within their own community. Currently regulations provide for hospital-based hospice only. With this legislation there will be opportunity for hospice agencies through out Connecticut to build their own hospice residences. The Regional Hospice in Western Connecticut, in the district which I represent, has seen an 8.5 percent increase in the average daily census of their hospice program, showing that there is a growing need for this type of care. This bill allow for small hospice facilities to be built around Connecticut, especially is areas where the large hospital-based hospice is scarce. Opening up the access allows for convenience for patients and their families. In addition, the type of care one receives in a smaller facility is more intimate, which leads to a higher patient and family satisfaction rate. Additionally, smaller facilities help decrease costs.

Furthermore, this bill increase the amount of hospice facilities overall in Connecticut. Due the limited number of facilities currently hospice stays are shorter, and are in many ways inconvenient for both patients and their families. As the life of our resident's comes to an end, we should provide them and their families with an environment that is comfortable and affordable. This legislation provides just that.

I urge the committee to pass this legislation.

Thank you.

State of Connecticut

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Testimony

In Support of Raised House Bill 5499

AN ACT CONCERNING REGULATIONS RELATING TO HOSPICE CARE

Public Health Committee

March 16, 2012

Honorable Chairs, Senator Gerratana and Representative Ritter, Honorable Vice-Chairs, Senator Slossberg and Representative Lyddy, Ranking Members Senator Welch and Representative Perillo, and Members of the Public Health Committee,

Thank you for the opportunity to submit testimony on Raised Bill No. 5499, AN ACT CONCERNING REGULATIONS RELATING TO HOSPICE CARE.

I fully support Raised Bill 5499 to put into statute the correct and necessary regulations authorizing hospice home care services for terminally ill persons to operate as a residence versus a nursing home type facility. Families of loved ones in the last days of their lives are not always able to provide aid and services during these trying times, and hospice affords them a peaceful and comforting place where they can spend quality and meaningful time as family. A grave injustice is done when comparing a hospice residence to a nursing home. As much as a nursing home can give proper care and attention to its residents, its purpose is to care for a wide range of needs from rehabilitation for patients who are admitted on a temporary basis to assisting with activities of daily living patients who are there permanently. Respectfully, serving in this capacity, a nursing home

legitimately presents an institutional-like environment, not the home away from home atmosphere a hospice residence offers.

Every person deserves to live his or her last days at home and circumstances may prevent this. Having a near-by residence that provides an atmosphere that emulates home will allow a person's time of passing to be a private and personal one and the family to spend these last moments with their loved one in peace and dignity. Raised Bill 5499 makes it possible, and I urge you to pass this bill in committee.

Thank you for your time and attention.

Sincerely,

Michael L. Molgano

Michael L. Molgano
State Representative, District 144
Stamford

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Testimony of
Senator Eileen M. Daily
On HB 5499
"An Act Concerning Regulations Relating to Hospice Care"

Co-chairs Gerratana and Ritter. Members of the Public Health Committee. I am submitting testimony in **opposition to HB 5499, "An Act Concerning Regulations Relating to Hospice Care."**

Our state has pioneered hospice care in this country. Almost forty-years of experience with end-of-life hospice care has provided our medical community with a clear understanding of the staffing needs, pharmaceutical requirements and physician services necessary to allow our terminally ill patients to spend their last hours, days and weeks without pain and in the comfort of family and spiritual care.

Over two years ago, under the administration of Governor Rell, our state Department of Public Health began a process to review and rewrite Connecticut's regulations for the delivery of inpatient hospice care. Tragically, rather than learn from and rely on best practices and clinical experience with thousands of hospice patients, the Department of Public Health attempted to lower Connecticut's hospice standards by proposing to mirror the "minimum health and safety requirements" established by Medicare. Fortunately, these proposed regulations have not been adopted by the Malloy administration.

What HB 5499 seeks to do is to force the Department of Public Health to promulgate these "hospice-lite" regulations. Such an effort will only open the door in our state to organizations that want to pocket federal Medicare dollars without delivering full hospice services to our friends, families and loved ones at the end of life. The citizens of our state now enjoy the highest quality inpatient hospice care in both single and double bed settings, delivered in 20 of the state's 31 hospitals and by Connecticut Hospice in

Branford. In addition, over 200 of our nursing homes in Connecticut have separate hospice beds for patients not requiring rigorous care. Experts tell us the citizens of Connecticut are extremely fortunate to have complete access to all levels of hospice care in every region of our state.

Anyone who has had a personal experience with hospice care quickly realizes Connecticut has developed the national and international model for quality hospice care. Let's not continue down the path of devaluing this care. Let's not go back to a time when our sick and dying failed to receive immediate attention to their medical and emotional needs and the full support of a dedicated team of hospice physicians, nurses, social service directors, clergy and volunteers.

I urge you to reject HB 5499. We should not stray from our important and historic mission to provide quality end-of-life care for our most vulnerable citizens.

State of Connecticut

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Testimony before the Public Health Committee
Friday, March 16, 2012

Re: HB 5499- An Act Concerning Regulations Relation to Hospice Care

I would like to thank the Honorable Co-Chairs Senator Terry Gerratana and Representative Elizabeth Ritter, the Honorable Vice-Chairs Senator Gayle Slossberg and Representative Christopher Lyddy, and the Ranking Members Senator Jason Welch and Representative Jason Perillo, and the entire membership of the Public Health Committee for their time this afternoon in addressing this important issue.

Although I cannot be present, I would like to lend my full support to HB 5499 An Act Concerning Regulations Relation to Hospice Care, and more specifically to the Hospice Facility Regulations 19a-122b-1 to 19a-122b-14. The current regulations (19-13-D46) allow access for hospital based hospices only. These regulations do not support small home-like hospice facilities which are prevalent throughout the United States. These regulations need to be updated to keep Connecticut comparable with other states in the country. I would, however like to suggest a revision be made to Section (a) after "pursuant to 42 USC 1395x" in line 6 and have it read **shall be authorized to operate a hospice facility, including a hospice residence, for the purpose of providing hospice services for terminally ill patients who are in need of hospice home care or hospice inpatient services. The hospice facility including a hospice residence, must be able to provide the following levels of hospice care: routine, general inpatient, and continuous respite.**

With these new regulations, terminally ill patients will have access to all levels of hospice services both in hospitals as well as within their own communities. It will also allow for small hospice residences to be built within towns across the state where accessibility to care is difficult to obtain. In Danbury, where access to care is particularly a problem, CT Association for Home Care and Hospice is willing and ready to break ground on a community facility. It will offer close to home care which benefits not only the economy in Danbury but also improve the quality patient and family satisfaction.

In summary, I urge the members of the Public Health facility to support HB 5499 and the proposed revisions to the current regulations. These new regulations will only work to enhance the care and respect that Connecticut's system provides for so many.

Thank you for your time and should you have any questions, please do not hesitate to contact my office.

Respectfully submitted,

Janice R. Giegler
State Representative

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CITY OF STAMFORD
OFFICE OF THE MAYOR

Sen. Terry Gerratana
Rep. Betsy Ritter
Public Health Committee
Legislative Office Building
Room 3000
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March 15, 2012

Dear Sen. Gerratana and Rep. Ritter,

As Mayor of the City of Stamford. I am writing to you today to express my support for Bill 5499, AN ACT CONCERNING REGULATIONS RELATING TO HOSPICE CARE. This act seeks to institute specific hospice facility regulations in Connecticut.

I speak from a platform of recent disappointment here in Stamford when the Richard Rosenthal Residence, a wonderful 12 bed hospice facility that was providing much needed hospice care was forced to close after serving our community for 11 years. It closed not because of a lack of support or need, but to a significant extent due to the complex regulations that are currently in place that are not appropriate for such a facility. The January 2012 edition of *The Flutter*, a national newsletter published by The Hospice House Network, attributes the closing of the Rosenthal to the "...state law requiring it to be licensed as a SNF, rather than as a hospice, which imposes requirements for additional staffing and other costs that wouldn't be needed in a licensed hospice."

Since Connecticut led the way in 1979 by creating the first American hospice, current regulations have reached a level of complexity and reach that was never envisioned by those who initiated hospice care more than 30 years ago. The current regulations are antiquated and reflect a medical and long term care model which multiple surveys have indicted is not want people want at the end of life. In fact, Connecticut ranks last nationally in the average length of stay for

Medicare hospice days. How can the state that pioneered the hospice movement have fallen so far behind?

Connecticut now has only one operating hospice facility, located in Branford. That so many communities in our state are without a nearby hospice facility or residence is disgraceful. The proposed regulations put forth by the Department of Public Health match current Medicare Conditions of Participation. Every Connecticut resident deserves access to end-of-life care options close to home.

We currently have a very real opportunity to create a new hospice in Stamford through the generosity of a group of Fairfield County residents. We are asking for relief from the need to recreate a medical model that is not only cost prohibitive at that scale, but is not what any person seeking hospice care would expect.

I ask you to look favorably in support of the aforementioned bill.

Respectively submitted,

Michael A. Pavia
Mayor of Stamford

Dear Senator/Representative,

HB5499

I urge you to support the Hospice Facility Regulations 19a-122b-1 to 19a-122b-14 created by the Department of Public Health (DPH).

These regulations are sorely needed and will provide opportunities for licensed hospice providers throughout the state to offer terminally-ill patients access to all levels of hospice services both in home and in facilities within their own communities. They will allow for small hospice residences (usually 12 or fewer beds) to be built in areas around the state where accessibility to all levels of hospice care is currently a problem (Greater Danbury, Southeastern CT and Fairfield County to name a few). These hospice residences will be close to home and convenient to friends and family with less worry about travelling distances/hours to visit. They will also offer enhanced hospice care provided by hospice designated and trained staff in a home-like setting (not a nursing home or a hospital). Overall, they will ensure greater patient and family satisfaction at end-of-life.

Thank you for your time and consideration of this important hospice issue.

Sincerely,

Richard F. Herrington

President

Nicholas/Tobin Insurance

111 Danbury Rd, New Milford, CT. 06776

Dear Sen. Gerratana, Rep. Ritter, Rep. Perillo, and Sen. Welch,

HB5499

I strongly urge you to support the Hospice Facility Regulations 19a-122b-1 to 19a-122b-14 created by the Department of Public Health (DPH), with the proposed revision of words: **Shall be authorized to operate a hospice facility, including a hospice residence, for the purpose of providing hospice services for terminally ill patients who are in need of hospice home care or hospice inpatient services. The hospice facility including a hospice residence , must be able to provide the following levels of hospice care: routine, general inpatient , continuous or respite.**

These regulations are sorely needed and will provide opportunities for licensed hospice providers throughout the state to offer terminally-ill patients access to all levels of hospice services both in home and in facilities within their own communities. They will allow for small hospice residences (usually 12 or fewer beds) to be built in areas around the state where accessibility to all levels of hospice care is currently a problem (Greater Danbury, Southeastern CT and Fairfield County to name a few). These hospice residences will be close to home and convenient to friends and family with less worry about travelling distances/hours to visit. They will also offer enhanced hospice care provided by hospice designated and trained staff in a home-like setting (not a nursing home or a hospital). Overall, they will ensure greater patient and family satisfaction at end-of-life.

As someone who lost my precious wife to cancer, our final days together with family, would have been better served if the Greater Danbury area had this type of Hospice facility.

Thank you for your time and consideration of this important hospice issue.

Sincerely,

Steve Greenberg

Steve Greenberg

11 Wellington Court

Danbury CT 06811

State of Connecticut
HOUSE OF REPRESENTATIVES
STATE CAPITOL
HARTFORD, CONNECTICUT 06106-1591

REPRESENTATIVE LONNIE REED
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MEMBER
ENERGY AND TECHNOLOGY COMMITTEE
GENERAL LAW COMMITTEE
PLANNING AND DEVELOPMENT COMMITTEE

Good morning Senator Gerratana, Representative Ritter and all distinguished members of the Public Health Committee. For the record, I am State Representative Lonnie Reed, of the 102nd District, Branford.

I am here to oppose HB-5499, An Act Concerning Regulations Relating to Hospice Care.

I want to begin by saying that I am a fervent believer that every family should have access to a high quality Hospice facility when the time comes to say goodbye to their loved ones And I believe that we should encourage the creation of all kinds of Hospices to serve our Connecticut communities– small, six bed facilities; hospital rooms and units dedicated to hospice care; programs that deploy trained hospice caregivers to assist and support those people who wish to die in their own homes; and, where possible, Hospice Hospitals, with a full complement of programs and activities, such as our own Connecticut Hospice in Branford—the nation's very first Hospice.

Again more high quality hospice care in Connecticut is a goal I share. But the key words here are "high quality". I am very concerned that HB5499 will move us in the opposite direction by commanding the Department of Public Health to adopt regulations that, among other things, reduce to merely "adequate" the critical ratios of medical professionals to patients in keeping with the Medicare's minimal health and safety requirements.

I also fear that HB5499 will invite into our state a for-profit hospice industry that includes parent companies now under investigation by the U.S. Justice Department for unlawfully pocketing Medicare dollars without delivering high quality hospice services. And also for systematically recruiting non-hospice patients from nursing homes who are then warehoused long term in understaffed for-profit hospice facilities and deprived of the medications, activities and care they truly need

I am not suggesting that proponents of HB5499 intend for bad things to happen. On the contrary - They are eager to make excellent Hospice Care more accessible to more people in facilities and settings that are an easy commute for the families of dying loved-ones. My concern is that HB5499 will have consequences that were totally not intended

Forty years ago, our state made history by opening the very first Hospice in the United States. We developed best practices and helped pioneer a whole new way of experiencing the end of life. Terrified patients and grieving, frightened families are now transformed and able to find peace, love, comfort and even moments of joy as they say their final Good-Byes.

That is the kind of high quality hospice care we need to protect and to encourage in Connecticut.

Please reject HB5499. Thank you to the Committee for allowing me to testify.

State of Connecticut

HOUSE OF REPRESENTATIVES
STATE CAPITOL
HARTFORD, CONNECTICUT 06106-1591

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DEPUTY REPUBLICAN LEADER

MEMBER
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PLANNING AND DEVELOPMENT COMMITTEE
LEGISLATIVE MANAGEMENT COMMITTEE

HB 5499 - An Act Concerning Regulations Relating to Hospice Care
Public Health Committee Public Hearing
March 16, 2012

Senator Gerrantana, Senator Slossberg, Senator Welch, Representative Ritter, Representative Lyddy, Representative Perillo and Members of the Public Health Committee:

I am here to express my opposition to ***HB 5499, An Act Concerning Regulations Relating to Hospice Care***. This bill mandates the Commissioner of Public Heath to adopt the minimum federal guidelines for hospice care.

This bill proposes reductions in state regulations for hospice care. he Connecticut Department of Public Health is considering radical reductions in state regulations for hospice care. National for-profit hospice care companies have been lobbying for these changes since Governor Rell's administration. That is because reduced regulations equal reduced operating costs and greater profits. Many of the companies pushing to get Connecticut's hospice regulations reduced are themselves the current targets of state and federal investigations for fraud against Medicare—fraud that in many cases involves reductions in the quality of patient care; fraud and reduced care that Connecticut's terminally-ill patients have thankfully avoided due to our current regulations.

Connecticut's in-patient hospice care regulations require rigorous standards, including on-site medical professionals and pharmaceutical and religious services. The new proposed regulations would repeal some of these requirements and reduce patient/medical staff ratios.

Connecticut's existing regulations have assured our loved ones will receive the best care at their most vulnerable point in their lives. Should the new regulations go through, Connecticut hospice care runs the risk of sliding into the mire that threatens other states. At a time, when Connecticut struggles to identify and correct fraud in some of our social service programs, why would we want to replace our nationally acclaimed hospice standards with Medicare minimum standards that will invite fraud and allow the for-profit industry to take advantage of our most vulnerable and terminally-ill patients.

Respectfully Submitted,

Vincent J. Candelora

Vincent J. Candelora
Deputy House Republican Leader

VJC/pb

LeadingAge Connecticut
Formerly CANPFA

Testimony to the Public Health Committee

Presented by Mag Morelli, President, LeadingAge Connecticut

March 16, 2012

Regarding House Bill 5499, An Act Concerning Regulations Relating to Hospice Care

Good afternoon Representative Ritter, Senator Gerratana, and Members of the Public Health Committee. My name is Mag Morelli and I am the President of LeadingAge Connecticut, a membership organization representing over 130 mission-driven and not-for-profit provider organizations serving older adults across the continuum of long term care including nursing homes and home health care agencies. (LeadingAge Connecticut was formerly named the *Connecticut Association of Not-for-profit Providers for the Aging or CANPFA.*)

Our members are sponsored by religious, fraternal, community, and municipal organizations that are committed to providing quality care and services to their residents and clients. Our member organizations, many of which have served their communities for generations, are dedicated to expanding the world of possibilities for aging.

On behalf of LeadingAge Connecticut, I would like to submit the following testimony in support of *House Bill 5499, An Act Concerning Regulations Relating to Hospice Care.*

LeadingAge Connecticut maintains a vision in which every community offers an integrated and coordinated continuum of high quality and affordable long term health care, housing and community based services. We have therefore supported the Department of Public Health's effort to update the current regulations governing inpatient hospice facilities to reflect both the recently revised Medicare Conditions of Participation and the current standards of quality and patient-centered care. It has been our hope that these revisions would encourage the development of new inpatient hospice facilities, residents or units established through partnerships, integrations or new initiatives so as to provide health care consumers throughout the state with increased access to quality end of life care options. We support the bill before you today that we believe will encourage the passage of these updated regulations.

The state is currently embarking on a right sizing strategic plan for our long term care system. In line with that initiative, LeadingAge Connecticut has been encouraging long term care providers to develop business plans to restructure and/or diversify existing facilities and services to strengthen the full continuum through the development of enhanced models of care. The common goal is to reshape the long term care system to meet current consumer demands, market needs and the goals of the state's long term care plan. The opportunity to provide high quality, facility-based end of life care to meet the needs of the community should be available as an option for existing long term care providers to consider in such planning. That is why it is imperative that the state move now to adopt new hospice facility regulations while the state is investing in a long term care right sizing initiative and quality long term care providers are strategically planning for the future of aging services.

Thank you for this opportunity to present this testimony.

Mag Morelli, President, LeadingAge Connecticut

1340 Worthington Ridge, Berlin, CT 06037 (860)828-2903 mmorelli@leadingagect.org

Testimony of

Hospice Southeastern Connecticut

Before the Legislature's Public Health Committee

10:00 AM, Friday March 16, 2012

Room 1D, Legislative Office Building Hartford, Connecticut

My name is Maureen Collins. I am the Director of Clinical Services for Hospice Southeastern Connecticut and a registered nurse. **I am here today to testify in support of House Bill 5499 (Raised) An Act Concerning Regulations Relating to Hospice Care.** I strongly support the concept set forth in the bill and I am asking you to favorably support it. The intent of this legislation is to increase access to the highest quality hospice care. However, there is a technical defect in this bill and I am recommending the following be amended: Suggested Revisions for H.B.5499 section (a) after "pursuant to 42 USC 1395x" (line 6):**Shall be authorized to operate a hospice facility, including a hospice residence, for the purpose of providing hospice services for terminally ill patients who are in need of hospice home care or hospice inpatient services. The hospice facility including a hospice residence, must be able to provide the following levels of hospice care: routine, general inpatient , continuous or respite.**

Resuming in the H.B. 5499 with the sentence (line 11)"The residence shall provide a homelike environment..."

Supporting **HB 5499** with these revisions will require the Department of Public Health to adopt the Inpatient Hospice Regulations **19a-122b-1 to 19a-122b-14.**

The current hospice regulations were established 35 years ago. The proposed regulations written with 28 of the 29 hospices in Connecticut and the Department of Public Health comply with the 2008 Medicare Conditions of Participation.

These regulations would allow the full continuum of hospice care. This includes care in the home, hospital, skilled nursing facility and a hospice residence. Currently there are only two hospice residences in Connecticut, located in Middletown and Branford.

Terminally ill patients and their families in Southeastern Connecticut deserve to have access to a hospice residence, with a home like environment, when care in the home is not possible.

My sister and two of my closest friends died on our hospice program. Because they had the support of family and friends they were able to remain at home to die surrounded by their loved ones. If that support had not been available or had they had symptoms not easily controlled in the home I would have had to travel more than 50 miles one way to be with them at the end of their life. This is a burden that should not be imposed on terminally ill patients and their families

I strongly urge you to support HB 5499 with the above recommendations, to ensure quality state of the art care and **ACCESS** to hospice care throughout the state, allowing hospice patients and their families to receive care in their own community.

Thank you for taking the time to consider my testimony. Please feel free to contact me if you have any questions at 860.848.5699 or mcollins@hospicesect org.

I am Dr. Joe Andrews, Medical Director at the Connecticut Hospice.

I urge that the Committee reject Raised Bill 5499 because it permits unacceptable dilution of patient care standards, which have been brought forward since 1980 under the 19-130D4b Section of the Health Code.

In April 2011 we at Connecticut Hospice organized strong resistance to the Department of Public Health plan to repeal 19-13-D4b and replace it with amorphous and imprecise specifications consistent only with national CMS Standards, which are far poorer and weaker in patient protection than the Connecticut Standards.

It would seem that the votes have been lacking to repeal the 1980 standard and in consequence this Bill has been raised to obtain the same goal by a more indirect approach.

First, the Connecticut Hospice will continue to offer care with our proven staff ratios and members of our entire care team present on a daily basis. "Available" is not enough. We also support research and teaching through the John D. Thompson foundation, and will continue to do so.

Because of our standards, we were honored recently to obtain the Joint Commission's Gold Seal Certification as a specialized palliative care hospital-hospice. The Joint Commission clearly endorsed our methods and we don't intend to compromise them.

Second, this is a poor time to weaken our state's standards for patient protection. Numerous for-profit agencies, many backed by venture capital firms, are entering our field of endeavor. Many have been under USDJ investigations and actions in Texas, Arkansas and Illinois for palpable, outrageous medicare fraud. It is reasonable to surmise that sharp practices, perfected in some states may be introduced here. Those who steal can be plausibly presumed to lie, as well.

Finally, we don't believe "access" by a creation of "residences" can offer safe, efficient and humane care for critically ill and dying patients. Many of these patients will be referred to emergency departments with soaring expenses and disjointed care plans and poor outcomes.

You cannot call a service "hospice" without a large veteran interdisciplinary team to make the service a hospice. There is no magic in an empty title.

Proponents of the Bill may say that a horse chestnut and a chestnut horse are the same. We disagree.

Thank you Ladies and Gentlemen.

Testimony on behalf of The Connecticut Hospice, Inc.
State of Connecticut Department of Public Health Hearing
March 16, 2012

HB5499

Good morning,

My name is Rebecca Paul and I would like to share my position with you today on the topic of this hearing.

There is a time in life when we have experienced many deaths – those of our parents, relatives, close friends and business colleagues. And, we have come to witness various models for end-of-life care provided to our loved ones as recommended by those who supposedly knew best.

I'm afraid I have experienced courses of care for the dying that were truly unacceptable.

Most tragic was my mother's end-of-life. She was diagnosed one April with stomach cancer, and the recommendation was made to remove her stomach. After surgery the surgeon advised that cancer was in her stomach, liver and pancreas. She was terminal. She returned home to recuperate. She was not told she had cancer by her general practitioner, gastroenterologist, or her surgeon. She was referred to "another specialist" (oncologist) who told her she "had a tumor". The word cancer was never spoken.

After a few weeks of radiation the patient became dehydrated and weak. One morning she was picked up off her bedroom floor by EMT's and returned to the hospital. After being rehydrated she was delivered to a care facility where she lay curled up in bed by herself in dirty diapers being cared for by CNA's. Once a day a nurse came by. She could not see a doctor unless he happened to be in the facility. She could not eat by herself, she did not receive comfort, she did not have anyone ask her who she was, what her hobbies were, or if she'd like to pray. She was not told she was dying. And, neither were we.

I had her removed and sent back to the hospital because she could not breathe and her abdomen was distended as if she was nine months pregnant. She was admitted, brought into a private room on the oncology floor and left alone in a dark room. She told me she was scared. I did not know what to say because I was too.

After a week, though she was alert and communicative, she was given morphine and moved but, this time to The Connecticut Hospice.

Something changed for our family then. We were welcomed by staff – a social worker, nurse and doctor who explained what was happening, and asked questions about our family. We were taught the signs and symptoms of dying. We were told my mother could hear us even though she was at the affect of morphine, and we were directed to speak to her and touch her – she knows you are here. The spiritual contact called our priest. When he arrived our family

stood together around her bedside holding hands and praying the prayers that she so loved – comforting all of us. We were invited to share her end-of-life journey by staying with her through the night. Volunteers offered us anything we needed.

Less than 48 hours later she died. The family was invited to visit her before she was moved to a funeral home. We did. She was clean, her hair was brushed, she was holding a favorite doll, and covered with a beautiful hand-made afghan. She was finally at peace and she was beautiful. And, our family was at peace.

Exactly one year later I was able to enter the volunteer training program at The Connecticut Hospice. It was my personal mission to volunteer in a role to educate others that there is a "better" way to die – a "Gold Standard" of care that addresses the needs of the patient and their family – one that is proven and in pure form.

That was ten years ago. I was trained in a 9-week training program to learn about the Interdisciplinary Team who deliver multi-dimensional care to patients and families – on-site doctors, nurses, social workers, chaplains, art therapists, and volunteers. I've taken numerous other sessions of specialized training, as well as an extensive training course on providing spiritual care – all provided through Connecticut Hospice. I've attended many sessions by The John D. Thompson Institute to receive further hospice education.

Over the last ten years I am confident that I have impacted the lives of numerous patients and families who were under The Connecticut Hospice's Gold Standard of Care. Today I continue to be a member of the Interdisciplinary Team as a Spiritual Care Volunteer

After 38 years of setting the standard in the United States as THE quality provider of hospice care, should there be ANY question whatsoever of why The Connecticut Hospice's mission, methods, and business model should be affected by the insatiability of for-profit institutions?

I'm afraid that once changed, too many people will suffer the effects of an "end-of-life" business commodity so similar to that our family witnessed before being enlightened.

Thank you.

The Connecticut Hospice
Testimony State Legislative Committee
March 16, 2012

HB5499

My name is John Drakos. I have volunteered at The Connecticut Hospice for 10 years. I am just one of some 500 volunteers who are required to take 9 weeks of training. The volunteer department is opposed to this bill, because it would lower the standards.

There is a fundamental human good that The Connecticut Hospice provides to their patients and patient families. We live in a time when we hear from multiple and diverse sources about what is best for us. Now we hear of the possibility that the Hospice model will be diluted down. And we fear patients and families will receive sub standard care when only profit becomes the goal.

The Connecticut Hospice mission is not very complex. It is simply to provide the best palliative and supportive care to patients and families during their time of immeasurable pain, stress and sadness. Every department at The Connecticut Hospice contributes to bringing peace and comfort to those most in need.

I can attest that I have never been around a more caring and professional group of individuals. I witness the clinical staff - the doctors, nurses, cna's, pharmacy - all providing a high level of medical care with kindness and respect and an awareness of patient dignity. That's why many families refer to this group of people as angels. It's true.

The Social Work staff provide support to patients and especially to families when most are at a very desperate time in their lives, not knowing what to do or expect. The staff counsels and guides patient families to better cope with what is happening to their loved one. It is hard to quantify, but you know without this group of caring individuals, The Connecticut Hospice would not be able to offer the exceptional care it provides.

Spiritual care is very important to patients and families at the Connecticut Hospice and is provided under the guidance of Hospice Chaplain the Rev. Charles Woody. Reverend Woody with his beautiful voice can often be heard throughout the hallways singing a hymn or a show tune . He lifts up those of all faiths whose hearts are filled with sadness.

The Arts department. You might ask what does an arts department provide to patients and families. The Connecticut Hospice is blessed to have talented individuals who actually go bedside with patients and provide them with art supplies to draw or paint. This too is a form of providing comfort and compassion. The arts department is rich in providing an ongoing group of musicians who perform on a regular basis and are most welcome especially during the holidays.

There are other departments at The Connecticut Hospice from security to maintenance to kitchen to administrative, all who contribute to the fundamental goal of The Connecticut Hospice - bringing the highest level of care to patients and their families.

What I am saying is that every component is critical to the functioning of The Connecticut Hospice. The Connecticut Hospice - the first hospice in America - is a gift to the citizens of Connecticut. Please see that all hospices to come maintain the same status, including for the pediatric population. I actually work across from the pediatric suite. Our pediatrician Doctor Joe MacNamara commented "*The quality of care that my patients receive from the whole Connecticut Hospice Interdisciplinary team including nurses, aides, social work, the chaplain, the nutrionist, clinical pharmacist, the arts and dedicated volunteers is exceptional. Kudos to the great care that our pediatric patients, their siblings and families receive. The counsel and caring provided to the parents and caregivers of these children have been unparalleled. My pedi patients have needed multiple high-tech/high-touch intervention 24/7. The Connecticut Hospice Hospital provides*

vigilant staffing, the skill and the experience to manage these complex kids with serious life-limiting diseases, in addition to providing the level of understanding and compassion the family requires. The pediatric population is very unique and the standard of care provided at The Connecticut Hospice is definitely needed for these poor kids as they go through this difficult part of life's journey."

Respectfully,

John P. Drakos

Eileen

From: MICHAEL GRENIER [mpgrenier@snet.net]
Sent: Thursday, March 15, 2012 1 21 PM
To: emino@hospice com
Subject: testimony

TESTIMONY BILL #5499 3/16/2012

Dear Madame Chair and Distinguished Committee Members:

Hello, I am Diane Grenier RN Diploma graduate nurse 1986, Ad 2010 and currently seeking a BSN degree. My area of practice is Hospice and palliative care nursing for the past 17years, currently working with The Ct. Hospice Inc. I come before this legislation to provide testimony against the health care bill.

I strongly oppose the proposed regulations because as written, it will negatively impact patients. The regulations (19-13 D4b) under which The ct. hospice is currently operating works to protect hospice patients and provide quality care.

The proposed new regulations allow for decreased staffing, especially nursing, pharmacy, medicine and social work support. When reading the new proposal it looks as though there was a combination of home-care and the in-patient unit combined to make a quasi nursing model in the name of an inpatient facility.

Currently in-patient hospice services provide intense nursing care to our most ill clients that cannot stay at home. In my 17 years experience in the home-care and inpatient experience, I have come to understand that patients and families would prefer to stay home whenever possible. There are times that symptoms, safety, and care giver needs lead to the decision to bring a person to an in-patient care setting. A discussion regarding the option of providing Continuous care in the home, a benefit under the Medicare Hospice Benefit, should take place with the family. This option is often underutilized or not even offered by some hospice programs due to the cost incurred to the hospice program providing services.

The decision for placement in an inpatient program is often due to the complexity of managing symptoms at the end of life. The process of dying is not easy, and the management of symptoms is complex. A person can experience a multitude of symptoms such as respiratory distress, intractable pain, terminal restlessness, fear, and skin and tumor problems. When these symptoms occur the person needs more intense medical services. The current legislation for Hospice Houses does not take this into consideration.

It is a necessity to provide a good death for the patient and for the family to experience. The Ct. Hospice inpatient services currently has a nurse to patient ratio of 1 to 4 nurses on day shifts, 1 to 6 on evenings and 1 to 7 on night shifts with an addition of CNA services. Without such intense nursing service, patients would not receive the care that they need during such a fragile difficult time.

Yes, the ideal would be a home like setting, the reality though, is that patients who need inpatient services needs to have a pleasant atmosphere with trained licensed staff 24/7 at a ratio that guarantees quality. There are no second chances in hospice care. The current provisions allow for an open ended "sufficient staffing" to be determined by the agency running the Hospice House. I have worked for three different hospice services and choose to work for Ct. Hospice due to their commitment to provide nursing excellence, meet the Medicare Hospice Benefit guidelines to the fullest where as other agencies did not.

The removal of onsite pharmacy services which provides an integral part of quick symptom management is a means to cut cost at the detriment of the patient. That practically assures that patients will suffer while they wait for the delivery of medication.

I am also concerned with the statement that nursing assistants could administer medications to the patient in the Hospice Home that the patient would normally take at home. Nursing Assistants are limited in handling of medications in the home and it is completely inappropriate for a hospice setting. (There is also contradictory information that suggests only a licensed person can administer medications in the current bill). Nursing assistants are credentialed by the department of public health, their training does not include nursing assessment, making judgment on which medication may manage symptoms, and taking actions as well as understanding when those symptoms are not well managed. Many end of life medications are given by the IV route for rapid onset and management of symptoms. These medications require a skilled nurse to assess the patient and adjust medications when needed according to the orders of a physician. The new guidelines that are proposed are against nursing standards of care and endanger the safety of the patient.

In closing, the dying patient and their family are often unaware of the depth of services that they are entitled to under the Medicare Hospice Benefit. When they are in crisis there often isn't time nor the ability for them to understand the impact that their choices will have on their loved one. The current Bill for Hospice Homes allows for agencies to decrease their cost of delivery of services without improving quality of care. It is up to the Department of Public Health to protect them from agencies whose financial goal is put before quality care of the patient despite the cost.

Thank You Diane Grenier RN AD

TESTIMONY BILL #5499

Dear Madam Chair and Distinguished Committee Members:

My name is Soozi Flannigan and I am a hospice nurse and nurse practitioner with the Connecticut hospice for 19 years and I am in opposition of BILL 5499

We are here today with our different view points on how hospice inpatient care needs to be provided. For us it is about maintaining the Standards of Care and Patient Rights

For the opposition it is about access and being close to home.

Currently, Every hospice must provide in-patient level care in order to have their hospice license. THERE IS LOCAL ACCESS IN NURSING HOMES AND HOSPITALS ACROSS THE STATE. In the last 4 years, both my Aunt Rita and Uncle Jim died on hospice beds in Danbury Hospital where their immediate symptom needs where met, the care was excellent and family could stay around the clock.

I have serious and justified concerns about the proposed changes in our hospice regulations and how they will impact patient care.

The changes are frightening-even if they "comply" with the minimalist Federal guidelines. Frightening how you say? Here is a snapshot of one nurses' experience practicing at an inpatient hospice under the minimal MEDICARE guidelines this bill supports:

"I am working in an inpatient Hospice facility with 20 beds. The staffing is 1 RN 1 LPN and 2 CNA's . As hospice has begun taking much more acutely ill patients, the staffing has become inadequate. I work the 3-11 shift. I am running from room to room putting out fires and not doing any quality hospice care at all. It feels more like a MASH unit or Hospice ICU than a true hospice setting. It is becoming more and more unsafe. When I complain, I am told that the staffing "meets national standards".

Is this the hospice care model Connecticut wants to provide?

The staffing model being proposed totally underestimates the serious nature of the dying patient. No onsight physicians, onsite pharmacists for complex symptom management and no mandated nurse to patient ratios. In the event of acute symptoms, the Emergency Departments will be flooded with dying patients in their last hours. I find this to be a disgrace and a dis-service to the dying patient and family.

I also hope those in high positions of responsibility are aware of the hospice fraud and abuse being investigated all over our country by the department of justice. Hospice has become a HUGE BUSINESS for the for-profits. Ask yourselves why? Everyone gets the same dollar, but not everyone offers the services the dying patient and family have a right to receive. With no mandated staffing our state is at risk for these abuses. This BILL is supporting this same model under the guise of becoming contemporary.

We can't stop big business, nor would we want to, however, WE CAN UPHOLD HOSPICES TO THE HIGHER STANDARDS OF CARE HOSPICE PATIENTS AND FAMILIES DESERVE and CT is known for through you, our government.

Our State has a lot at stake. Power struggles aside, decisions to change hospice clinical practice models must be made by those who are fully informed and aware of the ramifications. It is the responsibility of our government to protect the people, especially the dying patient.

I urge you to stop this bill, this wolf in sheep's clothing.

Thank you.

HB5499

March 15, 2012

I have volunteered for The Connecticut Hospice for a year. I went through the training program and in the beginning volunteered a few hours a week in the Branford Hospice I provide Reiki services and diversified services for Hospice I felt I wanted to help people in home care so I am now working with patients and their families in their homes. I am currently working with two families I feel the service I offer them is invaluable Both of my patients have ALS, this is a horribly overwhelming illness, for the patients and their loved ones They need care all the time, there is no break for the caregiver. When I come in I provide Reiki services for the patient to help relieve their pain and anxiety While I'm with the patient it gives the caregiver some time to get out, do errands, or just to relax themselves I also provide emotional support and a lending ear to the families who need it so desperately, and Reiki treatments for any other family members who need relaxation and stress relief My diversified duties can include a full range of things from companionship for the patient, reading, talking, just being there, to playing with the kids Whatever seems to be needed at a particular time, I am there to help out. The families depend on us, we become close to them and they trust us to help. I feel like my presence in these homes every week is a very valuable service that these patients and their loved ones need very much It truly helps them.

I am also a Loving Whisperer, which is a service provided by The Connecticut Hospice, where I sit with patients at the time of death and transition When a family member can't be with them or is afraid to be alone at the time of death, a Loving Whisperer sits with the patient until they pass, offering comfort and support. The Connecticut Hospice provides very well for patients at the end of life, with total respect, anticipating their needs and their families needs, and I am very proud to be a member of this organization.

Meg Wayton

Catharine A. Henningsen
Fairfield, CT 06825
CELL: 203-435-6211

Testimony Opposing HBO5499

Honorable Chairpersons, Honorable Members of the Committee:

Thank you for the opportunity to testify before you this morning.
I am an award-winning journalist and business book author currently writing a book about the for-profit hospice care sector entitled PREDATORS AT DEATH'S DOOR. In that capacity, I have been engaged in researching the hospice care industry in the U.S. and that research brings me here today to urge you not to pass Raised Bill 5499. Proponents of 5499 will tell you that they need the proposed reductions to the regulations governing hospice care in order to provide better access to hospice in this state. But in fact, I believe that 5499 has been raised for one reason and for one reason only: to enable the for-profit hospices currently operating in our state to reduce benefits and services to one of our most vulnerable populations--the terminally ill—in order to take as much of every hospice benefit dollar as possible away from the patients—whose benefit its is—and put it into the pockets of their shareholders.

Proponents of 5499 claim that Connecticut ranks 51st in the nation in access to hospice care because the average length of stay in hospice care in Connecticut is 49 days, compared to a "national average" of 71 days. But here's the problem with their "access" argument. The Department of Justice has launched major fraud investigations into at least four of the for-profit hospices currently lobbying you to reduce the regulations, accusing them of massive schemes to defraud Medicare by enrolling patients who are not terminally ill into hospice and then re-certifying them for the Medicare hospice benefit every 60 days. In a whistle blower suit recently lodged against the biggest for-profit provider of hospice both nationally and in Connecticut, Vitas Innovative Hospice, it is alleged that over 22% of their patients in one office had been continuously receiving hospice care for over 500 days! Because some of the for-profits have been gaming the Medicare system in this way for years, they have artificially inflated the "national average" they are basing their entire access argument upon. Take the non-terminal patients they are enrolling out of the equation and suddenly the for-profits lose their access argument. *The Journal of the American Medical Association* agrees citing that, "Patients admitted to for-profit hospices typically stayed there longer, were likelier to remain in hospice for more than a year, and were more likely to have dementia and other non-cancer diagnoses." So does the National Hospice and Palliative Care Association which cites that the length of stay figure has been drawn higher by the 12% of patients who remain in hospice longer than six months. In other words, those who are not terminal and have been fraudulently admitted to hospice. Current statistics show that 35.3% of hospice patients-the largest cohort nationally-- spend 7 days or less in hospice and over half die within 19.7 days of admission.

The fact of the matter is that citizens of Connecticut enjoy better access to hospice care than any state in the union save one. It is also a fact that anyone can open a hospice residence in this state under the existing regulations which better protect patients. So, if as they claim, the proponents of 5499 are so vitally concerned about our citizens access to hospice care, why haven't they opened the facilities they propose already? The answer is that this bill is not about access. It is about getting you to reduce the services and benefits they are legally required to provide to patients and their families so that they can

increase their profit margins.

A far more frightening impediment to hospice access in this state is the rampant violation of Federal Stark laws which mandate that all discharge planners provide patients with a list of the names of at least three providers. Unfortunately, Justice Department records show that for-profit hospices have engaged in massive kickback schemes to ensure that patients are referred only to their own facilities. Billed out as "incentive bonuses" and "consulting fees," for-profits typically pay doctors between 4-5k a month to refer only to their facilities. The Office of the Inspector General at the Department of Health and Human Service will tell you, however, that wherever the Medicare or Medicaid programs are concerned, kickbacks in cash or in kind are a felony punishable by fine and up to 5 years in Federal prison. Unfair trade practices such as this are burying Connecticut's not-for-profit hospices, because kickbacks ensure that not-for-profits are almost never on discharge planners lists. And yet no one in this state is lifting a finger to stop the Stark Law violations.

5499 proposes to set up hospice residences for "hospice home care services." They further propose to do this in houses of 4 to 6 patients each. Terminally ill patients want to be able to die in their own homes and under our existing regulations they can. But staffing continuous home care is expensive. The Hospice Care Alliance cites another fraudulent practice that many for profit hospices are already engaged in: Deliberately under-staffing their home care divisions in order to manipulate dying patients into facilities they control where care is less expensive. Because their proposal is to open hospice residences in small houses all over the state, they are then still entitled to collect the higher reimbursement rate for caring for a patient in their own home. Are the patients being cared for at home where they want to be? No. Are they ever told, "We don't provide home care hospice?" No, because that would be illegal. What they say is, "Oh we're so sorry but there's a nursing shortage or an aide shortage and we simply can't find anyone to come to you in your home. You'll have to die in one of our hospice residences." And dying patients and their families, overcome by the stresses of imminent death cannot muster the resources to fight the hospice's deception. Again, ladies and gentlemen, 5499 is not about access, it is not about patient care. It is about profits.

Finally, 5499 asks that the hospices themselves develop the standards for the licensure and operation of the homes they propose in conjunction with the Commissioner of Public Health. This proposal is perhaps the most ludicrous of all since it obliterates the checks and balances of our government. The people put their trust in the government to protect them from certain harm. Even if we were not talking about a scandal-ridden industry being prosecuted by the Department of Justice, the SEC and the Office of the Inspector General at The Department of Health and Human Services, at no time should the regulated industry be given the position of determining the standards and regulations of their industry. They are the regulated class. They are not the regulators! It is an embarrassment to our state that anyone would even suggest such an obvious breach in how our government is designed to function.

In conclusion, 5499 is a barely concealed attempt to get you to increase the profit margins for greedy for-profits who will then cannibalize patient care by taking away benefits and services our Federal government is paying for them to have. Our government is not handing out hospice benefits so for-profits have a better day on Wall Street. The issue here is patient care for a vulnerable population who cannot be expected to fight off fraud in their final hours. Ask yourselves why the hospices arguing for 5499 have not already opened their facilities? The answer is simple. Because they would be forced to pay for the quality care for patients that our government requires them to provide. 5499 is a prescription for disaster for patients and their families and you have a moral obligation to see that hospice patients in Connecticut receive the quality care they are entitled to using the benefits they paid for. Please say No to 5499 and send the profit-vultures packing. Thank you for your kind attention.

CATHARINE A. HENNINGSEN

Should shareholder concerns govern our end-of-life care?

Business owners will tell you that the ideal business environment is one with low taxes and minimum regulation But when we're talking about the regulations that govern hospice care in the state of Connecticut, adequate regulation is protecting our citizens from certain harm.

Connecticut residents are incredibly fortunate when it comes to access to hospice care More than 90 percent of our citizens live within minutes of a hospice facility But not all hospice care is created equal In recent years, the proliferation of for-profit hospices owned by publicly traded companies has turned the hospice marketplace into a $14 billion growth industry with over 18,000 for-profit hospice providers Having shareholders thrust into the patient-care equation creates conflicts of interest when it comes to how those profits are made. According to the Hospice Patients Alliance, with that growth there is also rampant Medicare fraud and abuse revolving around reduced medical services for hospice patients, including

1. Manipulating staff ratios to make it impossible to provide continuous care at home.

2 Deceptive marketing practices that fail to disclose who is eligible for the Medicare hospice benefit

3. Hospice admissions staffs not providing full, informed consent about the benefits to which patients are entitled.

4 Reducing visits from nurse case managers, counselors, chaplains, bereavement staff and social workers and using Licensed Practical Nurses and aides to perform medical services which only Registered Nurses are legally entitled to perform

5 Refusing medical care in a crisis and even reducing pain medication because of the expense

Ironically, Connecticut is proposing regulatory changes that mirror almost exactly the reduction of services in for-profit dominated states In effect, for-profit hospices are asking the state of Connecticut to legalize their existing means of committing fraud against Medicare

Just last week, the Department of Justice announced that it is joining a whistleblower suit against national hospice chain AseraCare, alleging that they admitted and retained individuals who were not eligible to receive Medicare hospice benefits They are charged with diverting Medicare funding from patient care to boost corporate profits Fraudulently enrolling non-terminal patients has become the for-profit hospice sector's game of choice in states less well-regulated than Connecticut In one version of this scam, unsavory hospices have gone to Medicare patients asking if they want, say, an extra bath a week Or perhaps a weekly visit from a chaplain? When the unwitting Medicare recipient says yes, they are signed into hospice care even though they are not suffering from any terminal disease Since hospice care pays for palliative and not curative care, those non-terminal patients are then taken off of the medications they need to manage serious medical conditions Death is often the result and numerous wrongful death suits have been filed recently in light of such criminal abuses

Among the biggest for-profit hospice players nationally, and in Connecticut, is Vitas Innovative Hospice A subsidiary of parent company Chemed, which also owns Roto-Rooter, Vitas's activities are currently under both federal and state microscopes Chemed's stock tanked more than 11 percent in one day this past November on news that one of Vitas' employees had lodged a whistleblower suit against them. More than a dozen law firms, including Izard Nobel in West Hartford, are currently suing Vitas on behalf of Chemed's shareholders alleging that Vitas committed Securities and Exchange violations

That, combined with a major fraud investigation into Vitas by the Department of Justice, which alleges that they have defrauded the Medicare and Medicaid systems out of nearly $200 million, should make Connecticut look very hard at who is knocking on the door of our Department of Public Health attempting to have the regulations governing hospices radically reduced

Similarly, Amedisys, the new owner of Beacon Hospice, is a defendant in several class action suits that allege corporate malfeasance The suits allege that Amedisys intentionally increased the number of in-home therapy visits to patients for the purpose of triggering higher reimbursement rates under Medicare Since the company's reported sales and earnings growth were inflated by this scheme, the company is being charged with a material violation of its code of Ethical Business Conduct. Justice Department records also show that Gentiva, the nations' fastest growing for-profit hospice, agreed to pay $12.5 million to settle Medicare fraud claims

Connecticut residents currently enjoy some of the nation's highest standards for hospice care, but if our state allows the proposed reduction in regulations to go through, it will open the door to the heinous abuses already being perpetrated elsewhere in the country The move to repeal the existing regulations did not happen on Gov. Malloy's watch. Lobbyists have been angling for these changes for years The fact that an inordinate number of state and federal investigations into massive fraud on the part of at least four of the for-profit hospices operating in our state have come to light, however, ought to bring any discussion of reducing our state regulations to a screeching halt In what version of reality would anyone allow those same companies to call the shots on how we regulate the very industry they are abusing?

Connecticut's careful regulation of the hospice industry has thus far kept our citizens out of harm's way We have a moral imperative to continue to protect the dying from the predators who have figured out how to game the system in answer to Wall Street's greed Hospice has always stood for compassionate, clinical care to improve our quality of life at the end It was never intended to be just another business to line shareholders' pockets Connecticut must continue to exercise prudence and wait until the major federal and state investigations into hospice fraud are concluded before evaluating whether any change in how our state regulates hospice care is warranted To do anything else would not only be irresponsible, for many of our citizens it could also prove lethal

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Catharine A Henningsen, a Fairfield resident, is a business author and journalist

Bonhomme, Penny

From: Gene Mazur [GMazur@hospicesect org]
Sent: Thursday, March 15, 2012 12 58 PM
To: PHC Testimony
Cc: hoyt@cahch.org, Maureen Collins; Carol Mahier; Gene
Subject: Testimony for Fri. March 16 and Bill number HB 5499

Testimony of

Hospice Southeastern Connecticut

Before the Legislature's Public Health Committee

10:00 AM, Friday March 16, 2012

Room 1D, Legislative Office Building Hartford, Connecticut

My name is Gene Mazur . I am a Connecticut resident and a proud supporter of Hospice Southeastern Connecticut.

I am submitting testimony in support of House Bill 5499 (Raised) An Act Concerning Regulations Relating to Hospice Care .

Please support HB 5499 which requires the Department of Public Health to adopt the Inpatient Hospice Regulations 19a-122b-1 to 19a-122b-14.

These regulations are about the dying patients and families in every corner of Connecticut having access to the full range of hospice care services. These contemporized regulations preserve the hospital standard set in Connecticut 30 years ago and establish a regulatory environment that allows for other models of inpatient hospice care that suit their respective communities.

Patients and families in every corner of Connecticut deserve access to an inpatient hospice model that suits their communities.

Currently, the full continuum of hospice care is not readily accessible to all our state residents. This care includes care in the home, care in the hospital, care in a skilled nursing facility and care in a hospice residence or facility. Of the 5150 hospice providers in the US, one in five also operates an inpatient facility. CT has only 1 inpatient facility licensed under regulations from 35 years ago.

A Hospice Residence would provide a place for quality end of life care when home care, hospital care or skilled nursing home care are not appropriate or possible. The 12 private rooms would have access to the outside garden, accommodations for family to visit and stay overnight with their loved one. The Residence would provide a relaxed atmosphere

where you can find a cup of tea in the kitchen, sit in the great room to read, find a quiet place for reflection in the library, take time to find solace in the non-denominational chapel, gather with family in the dining room.

We need your support to help us provide this care to CT residents. Please support Department of Public Health in moving the regulations forward to the Regulations Review committee.

Thank you for taking the time to consider my testimony. Please feel free to contact me if you have any questions at 860-748-8947 or GMazur2@cox.net.

Testimony for Public Health Committee
AN ACT CONCERNING REGULATIONS RELATING TO HOSPICE CARE *H.B No. 5499
Hospice Facility Regulations 19a-122b-1 to 19a-122b-14

March 16, 2012

Members of the Public Health Committee, my name is Melanie Cama and I am the Director of Hospice and Palliative Care for Middlesex Hospital Homecare in Middletown, CT My agency represents over 600 hospice and palliative care patients and their families each year. I am strong support of the proposed regulations which are based on the current Medicare Hospice Conditions of Participation. These changes will provide opportunities for all licensed hospice providers in the state to provide terminally-ill patients greater access to hospice services and care

Middlesex Hospital has a short term inpatient facility that currently that has been caring for both hospice and palliative patients for 20 years Passage of these hospice facility regulations would open access to more patients and families to receive hospice services in the appropriate setting and closer to home with skilled clinicians who can provide safe, dignified and compassionate care at the end of life. These new regulations would also ease the strain on families who are faced with care location decisions when homecare is not feasible for their loved one I believe all patients facing this most stressful time in their lives should have access to facilities that are in their communities close their families but still afford them true hospice care This is well established across our state in the homecare setting and Skilled Nursing facilities But for some patients, an inpatient environment with 24 hour hospice care is necessary and should be an opportunity for CT state residents. Passage of these regulations would allow patients the right level of care in the right setting at the right time without needing to change caregivers and agencies.

I strongly urge you to support the passage of the hospice facility regulations and become a champion for end of life care for patients and families through out our state.

Thank you for considering my testimony Please feel free to contact me if you have questions

Melanie Cama, BSN, RN, CHPN

Director Hospice and Palliative Care
Middlesex Hospital Homecare
28 Crescent Street
Middletown, Ct 06457

TESTIMONY

BEFORE THE PUBLIC HEALTH COMMITTEE

H.B. 5499 AN ACT CONCERNING REGULATIONS RELATING TO HOSPICE CARE

March 16, 2012

Senator Gerratana, Representative Ritter and members of the Public Health Committee, my name is Kimberly Skehan and I am Director of Home Care & Hospice Services for Healthcare Management Solutions, Inc. which provides consultation and billing services to many Connecticut home care and hospice agencies. I am also the Policy Committee Chair and a Board Member of the Connecticut Association for Home Care & Hospice. I am a Registered Nurse with twenty five years of oncology, home care and hospice experience.

I am writing to testify in **support** of H.B. 5499 AN ACT CONCERNING REGULATIONS PERTAINING TO HOSPICE CARE with some proposed revisions as noted below. For more than two years, the Connecticut Association for Home Care & Hospice (CAHCH), along with 28 of 29 licensed hospice providers in the State of Connecticut, have been working in conjunction with the State of Connecticut Department of Public Health (DPH) to develop proposed revisions to Section 19a-122b-1 to 19a-122b-14 Hospice Facility regulations which are based on the current Medicare Hospice Conditions of Participation and provide opportunities for all licensed hospice providers in the state to provide terminally ill patients greater access to hospice service and care. It is time for these regulations to be passed and implemented. There are several hospices in our state awaiting these regulations to begin the process of developing their own facility based programs to meet the needs of the clients and families their communities. If the passage of H.B. 5499 will facilitate the implementation of the DPH hospice facility

regulations as currently drafted, then this bill must be supported with two recommendations as noted below:

The language in H.B. 5499 section "a" references only hospice residences, and the regulations developed with DPH during the past two years address all facility based hospice care. The current draft of the DPH regulations are more comprehensive and addresses the intent of the current statute which supports the vitally important need for hospice services to be provided in *all* settings, and for hospices to be licensed *and* certified to provide this care. These requirements insure that our clients can receive qualified hospice staff in all settings, and provide for additional quality oversight to insure safe client care. Therefore I recommend that the language in this bill be amended to reference hospice facilities, not just residences.

In addition I support the technical wording recommendations that will be submitted by Hospice of Southeastern Connecticut and the Connecticut Association for Home Care & Hospice which seek to further clarify that hospices must be able to provide all levels of hospice care (routine, general inpatient, continuous home care or respite). This way our citizens can be assured to receive the full spectrum of qualified hospice services in their communities by their local hospice provider as their needs warrant. The draft DPH hospice facility regulations, which I have previously referenced, correctly identify the parameters around which hospice residences and facilities should be developed and operated. It is recommended that CAHCH and the hospice provider representatives be able to review the most recent draft of the proposed DPH regulations to insure that there have been no substantive changes to what had previously been developed.

It is also important to note that the implementation of these DPH regulations as proposed will allow other hospice providers to partner with either their local SNFs or hospitals to operate a hospice facility or residence Not only will this increase access and improve quality of care, but it will also allow for an opportunity to utilize SNF or hospital beds that may be unused as we continue to strive for rebalancing and moving appropriate patients from institutional settings to community-based care.

Finally, on a personal note, my mother was a patient under The CT Hospice home care program in 2005 where she received excellent care. But when my Mom reached her final days, we chose to have her receive care at the Middlesex Hospice & Palliative Care Unit, for many reasons, but primarily because this way she would be close to her family, including her mother who was 100 years old at the time. I know that if my Mom had been in Branford, she would have received outstanding care, but no way would she have been able to experience the very special time that she was able to have with so many of our family members in addition to receiving the high quality, compassionate care she was able to experience at Middlesex.

It is for this reason that I applaud the Public Health Committee and the Department of Public Health for taking the initiative to update these regulations which will insure quality of care as well as increased access to care for hospice patients and family members throughout the state.

Thank you for consideration of this testimony. Please feel free to contact me with any questions you may have.

Kimberly Skehan, RN, MSN
Director of Home Care & Hospice Services
Healthcare Management Solutions, Inc
860-729-4680/kimskehan@sbcglobal.net

CAROLYN WHITE COUTANT
154-12 Pepper Ridge Road, Stamford, Connecticut 06905
203 595 9332
cicicoutant@gmail com

March 14, 2012

HB 5499

Dear Ms. Gerratan, Ms. Ritter, and Members of the Committee:

I urge you to support the revisions to the **Hospice Facility Regulations 19a-122b-1 to 19a-122b-14.**

The provisions for Hospice Facility Regulation that the Connecticut Association for Homecare and Hospice has suggested to the Department of Public Health are not only appropriate, but needed.

The disagreement over proposed changes in Connecticut's Hospice regulations has sparked an intense debate, and one that is long overdue. Connecticut is considered the birthplace of the American Hospice movement; however the state has fallen far behind others in embracing the concept of residential hospices. Connecticut Hospice established a solid foundation for end-of-life-care and is a wonderful institution; however, it is just that – *an institution.* There is a reason why 28 of the 29 hospice providers in the state support the proposed regulation. The regulations that Connecticut Hospice falls under are specific to their own hospice and were established over 30 years ago. Connecticut is not the first state to experience the uniqueness of hospice residence regulations. Virginia has recently enacted licensure regulations for dedicated hospice residences – homes where the patients and their families can find dignity, support, and comprehensive physical, emotional and spiritual care. Massachusetts has 9 hospice residences and specific licensure.

Connecticut Hospice believes that in-patient facilities must have an in-house pharmacy, a physician on site, and a higher ratio of doctors and nurses to patients – a medical and long term care model that survey after survey has told us is **not** what Americans want at the end of life. Furthermore, Hospice is a program of care and depends on a team approach with the patient and family at the center of the care.

The assumption that these new laws would somehow inhibit hospice workers from providing exceptional levels of care is refuted every day in hospices across the country where residential hospices are operational.

The time has come to fulfill the mission of the original hospice pioneers and return to the model of care that supports patient and family preferences to remain home while seriously ill, surrounded by family and friends. It is time to return the dying to our communities and not place them in institutional settings like nursing homes, hospitals, and even Connecticut Hospice's facility in Branford.

The vision of our Hospice founders was to offer the community a safe, dignified and comfortable death at home or home-like setting, support for the family, and effective grieving. The last thing they wanted was more fragmented medically-driven care that never addressed the patient's and family's goals of care and preferences for a peaceful and dignified death.

Respectfully,

Carolyn Coutant
Stamford, Connecticut

TESTIMONY TO THE DEPARTMENT OF PUBLIC HEALTH

REGARDING PROPOSED

***H.B. No. 5499 (RAISED) AN ACT CONCERNING REGULATIONS RELATING TO HOSPICE CARE**

March 16, 2012

Dr. Mullen and members of the Department of Public Health., my name is Dianne Welch and I am Director of Hospice at Visiting Nurse & Health Services of Connecticut in Vernon. As a long standing and well respected home health and hospice provider, we would like to express our support of the proposed revisions to the Hospice Facility Regulations H.B. No. 5499. We believe these revisions will bring Hospice care in Connecticut in line with National practices and provide access to quality inpatient care.

Currently, the majority of Hospice patients in Connecticut have access to the inpatient level of care that is **contracted** through either a nursing facility or acute care hospital and the local Hospice agency. Although the Hospice is responsible for the plan of care for these patients, the actual 24 hour care is provided by the hospital or SNF staff that has had some education but may not be of the Hospice philosophy. Very often these staff members are also caring for non-Hospice patients and find it hard to do both effectively. In the contracted setting the Hospice agency may not have control over the environment to create the atmosphere that they desire to have their patients and families experience. With extremely short inpatient stays at end of life, the family may not even realize the extent of Hospice involvement with their loved one. We believe each Hospice agency should have the option to create and operate an inpatient facility where our patients could have access to an increased level of the true Hospice experience. By creating our own environment and providing our own full complement of dedicated Hospice staff, our patients and families will experience an increased quality of Hospice inpatient care. We believe that patients and families in Connecticut have a right to receive this standard of Hospice care in the communities in which they reside. Presently this option is only

available to a limited number of patients and families, as relocating or driving long distances is not a desirable option to most.

The proposed revisions will also help modernize hospice care and services in the state of Connecticut. They will comply with both the Connecticut home health agency regulations and with the Medicare Conditions of Participation (CoPs). Therefore, compliance with all of these state and federal regulations will ensure appropriate, safe care for hospice patients in this setting. Concerns about the proposed revisions have been addressed by the members of CAHCH with recommendations put forth.

In summary, we at Visiting Nurse and Health Services of Connecticut see this as an opportunity to give all Hospice patients and families in Connecticut equal access to the full Hospice inpatient experience by giving Hospice agencies the option to operate facilities under these revisions. We therefore strongly urge you to support and approve them and thank you for your time and consideration of this important Hospice issue.

Please feel free to contact me if you have questions.

Respectfully submitted,

Dianne Welch, RN,MSN
Director of Hospice
VNHSC 860 872-9163

Testimony of

Hospice Southeastern Connecticut

Before the Legislature's Public Health Committee

10:00 AM, Friday, March 16, 2012

Room 1D, Legislative Office Building, Hartford, Connecticut

My name is Paula J. Ranelli. I am a Clinical Nursing Supervisor for Hospice Southeastern Connecticut. **I am submitting testimony in support of House Bill 5499, An Act Concerning Regulations Relating to Hospice Care.**

The proposed regulations written with 28 of the 29 hospices in Connecticut and the Department of Public Health, which comply with the 2008 Medicare Conditions of Participation, allow the full continuum of hospice care. This includes care in the home, hospital, skilled nursing facility and a hospice residence. Currently, there are only two hospice residences in Connecticut: one in Middletown, located in Middlesex Hospital, and Connecticut Hospice in Branford.

There is, therefore, a great need for a hospice residence in Southeastern Connecticut. Terminally ill patients and their families deserve to have access to a hospice residence close to their home, with a home-like environment, when care in the home is not possible.

This past Fall, my mother died on our hospice program. We were fortunate to have the support of family and friends so she was able to remain at home to die surrounded by her loved ones. If that support had not been available, or if her symptoms were not easily controlled in the home, my 88 year old father, as well as my 8 brothers and sisters and family, would have had to travel more than 50 miles one way to be with her at the end of her life. This would have been an enormous hardship on all of us.

I strongly urge you to support **HB 5499** to ensure quality state of the art care and **ACCESS** to hospice care throughout the state, allowing hospice patients and their families to receive care in their own community.

Thank you for taking the time to consider my testimony. Please feel free to contact me if you have any questions at 860.848.5699 or pranelli@hospicesect.org.

Paula J. Ranelli, RN, MSN

TESTIMONY BEFORE THE LEGISLATURE'S PUBLIC HEALTH COMMITTEE

10:00 AM, FRIDAY MARCH 16, 2012

ROOM 1D, LEGISLATIVE OFFICE BUILDING

HARTFORD, CONNECTICUT

My name is David Hooper and I am the manager of Quality Assurance at Hospice Southeastern Connecticut. Our hospice agency cares for hospice patients who reside in New London County.

I am submitting testimony in support of House Bill 5499 An Act Concerning Regulation Relating to Hospice Care.

There is little quality of life for patients who are separated from family and friends in their final days because their only choice for a home-like hospice residence may be so far away from them. Hospice Southeastern Connecticut has been providing hospice home care for the residents of New London County for twenty five years. We are actively working toward the goal of constructing a residence that will conveniently serve the residents of the state that live east of the Connecticut River. It is imperative that residents throughout the state have convenient access to a facility where terminally ill patients can live out their final days in a home-like atmosphere under the care of hospice health care professionals. It would be unimaginable for one facility in the state to argue that they should be the only facility where you can go to give birth. It is equally unimaginable that one hospice should argue that theirs is the only facility where you can go to die.

I strongly urge you to **support HB5499** and become a champion for quality of end-of-life care for patients and their families throughout the state.

Thank you for taking the time to consider my testimony. Please feel free to contact me it you have questions.

David Hooper
Manager of Quality Assurance
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Syracuse University

HB 5499

"Empathy is not simply a matter of trying to imagine what others are going through, but having the will to muster enough courage to do something about it. In a way, empathy is predicated upon hope," Cornel West, Professor in the Center for African American Studies, at Princeton University draws attention to one of the most underutilized emotions in society today. Anyone can "feel sorry" or "sympathize" for others, but to have the courage to do something about it and to make a difference, no matter how small, is true empathy.

Hospice. It's amazing the broad range of emotions that, that seven letter word can evoke in people: fear, comfort, avoidance, passion, compassion, and unfortunately sometimes nothing. When I hear the word Hospice, it is hard to even put into words my emotions.

My first contact with volunteering, now six long years ago, was at the Richard Rosenthal Hospice Residence, a place that had given the best of care to my grandmother, years earlier. At the age of twelve, I had my first visit with a patient. Her name was Emma, a ninety year-old, four foot tall, retired librarian, with more spunk than anyone I have ever met. The bond Emma and I shared was unique. Emma would sit there, with such patience, and try to teach me Bridge, a game to this day that I have not mastered. Other times we would stand in the kitchen for hours, slaving over her homemade cranberry jam. Still other times, we would just sit as I held her fragile hands in mine,

quietly talking. Unfortunately, I soon learned the hard lesson about volunteering at a Hospice residence. Emma passed away a few months into our friendship.

As heartbreaking as this was for me, the bond Emma and I shared taught me one of the most important lessons in my life. To change a person's life, no matter how big or small a difference, or when in their life you do so, is one of the greatest gifts, not only for that person, but for the volunteer as well. The sadness I felt with Emma did not discourage me, rather it fueled me to go on to volunteer with countless patients for years to come. I went into the Hospice Residence with the goal of changing the lives of these patients, however I came out changed as well. With every patient there was a different story, a different lesson to teach me, a different secret to share.

That is why I am an advocate of hospice. Not only do I wish to educate the world about hospice, but I hope to motivate others to volunteer as well, not only because volunteering has offered a sense of comfort and care to those who otherwise might have been alone, but it has also given me a sense of purpose, fulfillment, and understanding that I know I could not have gotten from any other experience. I hope that others can experience the empathy and resolve of making a change in the world. Alone that change is small. Together we can alter the world.

Innovative Hospice Care®
VITAS®

Public Health Committee
Public Hearing Revised Inpatient Hospice Facility Regulations
March 16, 2012

Testimony of Theresa Bachhuber, RN
Administrator
VITAS Innovative Hospice Care®
Inpatient Unit at Saint Mary's Hospital

Senator Gerratana, Representative Ritter and members of the Public Health Committee, my name is Theresa Bachhuber, RN. I am the Administrator for the VITAS (pronounced VEE-tahs) inpatient hospice unit at Saint Mary's Hospital. VITAS Innovative Hospice Care ("VITAS"), the nation's leading provider of hospice services, provides hospice care throughout the state to more than 350 patients and families each day.

I have been a registered nurse for 26 years and hold a graduate degree in Public Health from the University of Connecticut and a baccalaureate degree in nursing. I have been working in hospice and homecare, in Connecticut, for 24 years.

I am submitting this testimony **in support** of HB 5499, An Act Concerning Regulations Relating to Hospice Care which requires the Department of Public Health to revise the Hospice Facility Regulations 19a-122b-1 to 19a-122b-14 so that patients and families throughout the State of Connecticut can have access to full delivery of quality hospice care services.

Your vote in support of HB 5499 will benefit patients and families in every corner of Connecticut and establish a regulatory environment that protects patients while providing important flexibility that will foster models of inpatient hospice care that best suit the needs of communities throughout our state.

VITAS supports HB 5499 because the legislation will allow hospice programs throughout Connecticut to assess and respond to local need for inpatient care. Absent your adoption, hospices will remain very limited in how they can meet that need. Under current rules, the only way a hospice program can effectively develop an inpatient hospice program is either to build a hospital like facility or to pursue a daunting regulatory process which is expensive and uncertain.

In our quest to meet inpatient needs in Waterbury, VITAS conformed to the existing regulatory structure licensed for 19-13-D4b (Short-term hospitals, special, hospice). That approach, in fact, was time consuming, expensive and enormously cumbersome. Fortunately, we were successful, but our experience of navigating the regulatory maze is not one that other hospice providers should have to undertake.

Our state should embrace forward thinking regulations that promote hospice access rather than impede such access by erecting unnecessary regulatory barriers.

VITAS' new inpatient hospice unit has been a tremendous success to patients and families in Greater Waterbury. Since the nearest inpatient hospice facility is more than 50 miles away, this 12 bed unit is meeting the growing healthcare needs of its community. The hospice unit allows patients and families to receive the full delivery of hospice care, including high acuity inpatient care, in the most responsive, appropriate and cost-effective manner in the location of their choice

The first of its kind in Greater Waterbury, this 12 bed Inpatient Hospice Unit provides a tranquil, home-like atmosphere for patients and their families. The unit features spacious private rooms, a family living room and kitchen, family laundry, shower facilities and capability for families to spend the night with their loved one.

VITAS' inpatient unit at Saint Mary's Hospital is being held to strict compliance with rules and regulations that protect high quality patient care. As a certified hospice program, we operate under Medicare's Conditions of Participation (CoP) for Hospice, 42 C.F.R. § 418 et. seq. ("CoPs"). Under the CoPs, hospices can provide inpatient hospice care directly, as well as under arrangements with a Medicare certified hospital or skilled nursing facility. According to the Centers for Medicare and Medicaid ("CMS"), "[w]hen the hospice provides inpatient care directly, it may do so either in space that it owns or leases or in space shared with a Medicare certified hospital, SNF, or Medicaid certified nursing facility (NF)." CMS State Operations Manual, § 2084.1.

VITAS has been providing hospice services in Connecticut since 2004 and operates two Medicare certified hospice programs in the State of Connecticut. VITAS Innovative Hospice Care has been a pioneer and leader in the hospice movement since 1978. VITAS operates 53 hospice programs in 18 states. VITAS employs nearly 10,000 professionals who care for terminally ill patients daily, primarily in the patients' homes, but also in the company's 34 inpatient hospice units as well as in hospitals, nursing homes and assisted living communities/residential care facilities for the elderly. VITAS provided 4,640,285 days of care in 2010 and our current average daily census is over 13,000.

Hospice provides the quality care patients and families deserve, in the location they desire. While most patients and families receive hospice care at home, the option of an inpatient hospice unit is an important one that is necessary when symptoms such as pain, respiratory distress, anxiety and others are too challenging to be managed at home.

In summary, VITAS urges you to support these regulations as they will enhance all hospices' ability to provide the full delivery of quality hospice care services throughout the State of Connecticut.

Thank you for the opportunity to submit these comments.

56 Franklin Street, Xavier 4, Waterbury, CT 06706
(203) 709-7700

No Name

TESTIMONY BILL #5499 3/16/2012

Dear Madame Chair and Distinguished Committee Members:

Today I ask you to think for a moment about how our patients die. If death arrived like Sandburg's fog "...on little cat feet...on silent haunches and then moves on.' then patients could die quietly in their beds at home. But many struggle in the throes of death, grappling--physically, emotionally, spiritually, and psychologically, and it is for those individuals and their caregivers that we have the level of hospice care we call 'inpatient.'

In the last days of life, the intensity of symptoms such as escalating pain or delirium can cause unbearable caregiver distress, despair, confusion, and anger. A poor understanding of the dying process, the uses of opioids and sedatives as well as the need to make funeral arrangements and to begin to think about life without the loved one can create a state of disequilibrium that often compromises family coping. A transition to inpatient hospice at this moment of crisis and uncertainty necessitates an interdisciplinary team surround the family with expertise and support, to be present as 'first responders' to attend to the acute needs of both patient and family, to comfort, to educate, to allay anxiety and diffuse conflict anger.

In December of 2010, an 80-year-old with end-stage dementia male received care at CT Hospice Inpatient. He was experiencing increasing agitation called terminal restlessness, a state of pre-death delirium common in moribund patients and considered a palliative care emergency

- At daily rounds the IDT of physicians, APRN, pharmacists, nurses and social workers examined possible etiologies of restlessness, including work up for UTI, medication review and evaluation of lab work and review of environmental factors
- 31 references to agitation were noted on chart review, including 'wandering, shaking of bed rails, climbing OOB and stripping.'
- Multiple notes by nursing, social work, pharmacy and medicine recorded ongoing support and education to the wife regarding safe feeding as evidence of dysphagia and aspiration were present
- The patient died on day 22 with respiratory congestion having received multiple doses of scopolamine and Dilaudid to relieve respiratory distress
- Such refractory restlessness required ongoing efforts at medication management made by the APRN in consultation with pharmacy. Total medications given were 360; as needed medications for agitation were 40 (in addition to trials of scheduled Haldol, benzodiazepines, atypical antipsychotics and finally Thorazine for severe agitation)

We at CT. Hospice are deeply distressed that the proposed changes to inpatient regulations threaten quality of care to the most seriously ill patients in our state by implementing minimum standards that pertain directly to nursing and medical staffing, provision of pharmacy services, and the elimination of an assembled, ever-ready, complete and onsite interdisciplinary team which performs initial assessments immediately upon admission with medication review and oversight and development of an initial interdisciplinary plan of care. Proposed regulations beg the question of how facilities with 'sufficient' staffing will adjust to changing levels of acuity? Will agency nurses be scheduled or home care nurses be called in to work? Who would have the expertise to respond to the crisis of a an elderly patient with dementia or of a 51 year old with cholangiocarcinoma? This young man with intractable pain and restlessness required daily and more frequent changes in his medications which included high-dose intravenous methadone and morphine and both Phenobarbital and pentobarbital. Would off-site 'consultative' pharmacy services be adequate to oversee the plan of care to assure optimally dosed and safely and effectively administered medications? Would those medications be readily available for this patient's comfort as his symptoms escalated exponentially day by day and hour by hour? Without the direct involvement of a truly skilled interdisciplinary team, this patient would have suffered inexorably and most certainly have been transferred to a hospital setting.

While it is difficult to quantify the time an RN may spend at the bedside in providing hands-on care with bathing and hygiene and performing physical assessment or in medicating for the constellation of symptoms that crescendo over the course of a day, consider that under the present staffing ratios, a Ct Hospice RN may have an assignment with *one, two or even three such seriously ill patients* as described above, all requiring intensive intervention due to

- Terminal Restlessness
- Seizure management for patients with brain metastasis, brain tumors, renal failure and end-stage dementia and stroke
- The disfigurement and dysfunction, pain and hemorrhage associated with head and neck, gynecologic and gastrointestinal tumors
- The respiratory distress of end-stage cardiac and respiratory illness
- The total dependence of those with ALS and other neurological disease as well as those with brain tumors
- The heart-wrenching challenges of pediatric and adolescent cases
-

The issue at hand is not access to care: we all want hospice patients in our state to have access to quality inpatient care that is close to home and maintains relationships with established providers. **The key word is *quality:*** so we emphasize that we are here today again asking for a guarantee that quality is assured by stipulated staffing ratios and onsite pharmacy and medical services.

Because we know how challenging the care of our inpatient population is, CT. Hospice educates every newly hired RN, and every nursing assistant in two Fellowships funded by the Norma Pfriem Foundation. Since the inception of the Nursing Fellowship in 2005 approximately 40 RNs have been credentialed by national exam in hospice and palliative nursing under the Hospice and Palliative Nursing Association.

The current regulations offer the most effective, timely, safe and holistic experience for the hospice family and ***assure our shared mission to provide comfort and dignity, and support the ethical tenet to do no harm.*** For 35 years Connecticut has served as a model of excellence to the nation: why now lower the bar by changing the existing regulations for inpatient hospice care?

JANICE E. CASEY
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Testimony to be submitted to the Public Health Committee regarding HB 5499, An Act Concerning Regulations Related to Hospice Care

March 16, 2012

Senator Gerratana, Representative Ritter, and members of the Public Health Committee, I regret that I cannot attend today's hearing, but I sincerely appreciate the Public Health Committee's effort to address the need for licensure and regulations for Hospice Facilities/Residences.

I would be in support of HB 5499 if the language were amended to include the ability to provide inpatient hospice care at the Hospice Facility. The following change is suggested:

> (a) Notwithstanding the provisions of chapters 368v and 368z, an organization licensed as a hospice [pursuant to the Public Health Code] by the Department of Public Health or certified as a hospice pursuant to 42 USC 1395x, shall be authorized to operate a ~~residence for terminally ill persons, for the purpose of providing hospice home care arrangements including, but not limited to, hospice home care services and supplemental services.~~ **hospice facility, including a hospice residence, for the purpose of providing hospice services for terminally ill patients who are in need of hospice home care or hospice inpatient services. The hospice facility, including a hospice residence , must be able to provide the following levels of hospice care: routine, general inpatient , continuous or respite.** ~~Such arrangements shall be provided to those patients who would otherwise receive such care from family members.~~ The residence shall provide a homelike atmosphere for such patients **and their family members**. ~~for a time period deemed appropriate for home health care services under like circumstances.~~ Any hospice that operates a **hospice facility or** residence pursuant to the provisions of this section shall cooperate with the Commissioner of Public Health to develop standards for the licensure and operation of such **facilities and residences** ~~homes~~.

No doubt you are aware that over the last two years, 28 of the 29 hospices in CT worked cooperatively with the CT Association for Home Care & Hospice (CAHCH) and the CT Dept. of Health (DPH) to develop regulations for "hospice facilities". Those regulations include Hospice Residences as a type of hospice facility. Approval of those regulations would be a great step forward for the State of CT and its residents.

I served as President & CEO of the Stamford Hospice for 21 years. It was under my leadership that the Rosenthal Hospice Residence came into existence. Former Representative Christel Truglia provided critical assistance to the Residence by introducing legislation that allowed the Residence to serve as a pilot for the State of CT and by securing bonding money which was used to retrofit an existing building for use as the Hospice Residence. Christel is very knowledgeable about the Stamford Residence not only from a legislative perspective but a personal one as well. Her mother was admitted to the Residence for end-of-life care only a few months after it opened in 2000

The pilot legislation included a sunset clause. The sunset date was extended several times but in 2007-2008, when there still were not any regulations for Hospice Residences, those in charge of the Residence at that time decided to apply for licensure as a SNF. While it allowed the Hospice to provide and bill for inpatient hospice care, it imposed many new regulations which did not enhance the hospice care that was being provided and it added significant operating costs. The Rosenthal Hospice Residence was closed in the fall of 2011 to the great dismay of the greater Stamford community.

I apologize if my testimony and suggestions for revised wording in this bill comes on too strong. It is due to frustration that after more than 30 years, the State of CT still lacks legislation and regulations that would not only ensure, but "promote", access to all the components of hospice care for all the residents of the State. The closure of the Rosenthal Hospice Residence, which truly served the patients and families as it was intended to, has been permanently closed. Families are suffering as a result ... and that is shameful.

I thank you for your efforts to finally resolve this problem in 2012.

Sincerely,

Janice Casey, RN, MS

former President & CEO, Visiting Nurse & Hospice Care of SW CT
former VP, Hospice & Home Care Services, Stamford Health Systems
former director, National Organization for Hospice & Palliative Care, CAHCH, etc.

Testimony of

Hospice Southeastern Connecticut

Before the Legislature's Public Health Committee

10:00 AM, Friday, March 16, 2012

Room 1D, Legislative Office Building Hartford, Connecticut

My name is Lauren Watson. I am the Volunteer Program Administrator for Hospice Southeastern Connecticut. **I am submitting testimony in support of House Bill 5499 An Act Concerning Regulations Relating to Hospice Care.**

Please support HB 5499 which requires the Department of Public Health to adopt the Inpatient Hospice Regulations 19a-122b-1 to 19a-122b-14.

Currently, the full continuum of hospice care is not readily accessible to all our state residents. This care includes care in the home, care in the hospital, care in a skilled nursing facility and care in a hospice residence or facility.

We need your support to help us provide this care to CT residents. Please support Department of Public Health in moving the regulations forward to the Regulations Review committee.

Thank you for taking the time to consider my testimony. Please feel free to contact me if you have any questions at 860.848.5699 or lwatson@hospicesect org

Testimony of
Hospice Southeastern Connecticut
Before the Legislature's Public Health Committee
10:00am, Friday March 16, 2012
Room 1D, Legislative Office Building Hartford, CT

My name is Lisa DeCarlo. I am a clinical nursing supervisor at Hospice Southeastern Connecticut. I am submitting testimony in support of House Bill 5499 An Act Concerning Regulations Relating to Hospice Care.

These regulations would allow the full continuum of hospice care. This includes care in the home, hospital, skilled nursing facility, and a hospice residence. Currently there are only two hospice residences in Connecticut.

Terminally ill patients and their families in Southeastern Connecticut deserve to have access to a hospice residence with a homelike environment when care in the home is not possible.

I have worked as a hospice nurse for Hospice Southeastern Connecticut for nearly five years. Throughout these years I have seen many family members struggle with the decision to determine an end of life plan for their loved one. Often, due to the patient's physical symptoms as well as the family's emotional distress, they are unable to provide care in the patient's or their own home. In these cases, the patients and families often suffer, as usually their only option is to have the patient placed in a nursing facility.

While local nursing facilities provide excellent care to their residents, most do not have hospice trained nurses to provide care to terminally ill patients.
A hospice residence would solve this problem as many families would like their loved one to be cared for by an inpatient hospice, but are not able to travel the distance to one of the two hospices in our state, both of which are over an hour away.

I urge you to support HB5499 **to ensure quality, state of the art care, and** access to hospice care for all residents of our state. Thank you for considering my testimony. Please feel free to contact me if you have any questions at 860-848-5699 or ldecarlo@hospicesect.org.

Testimony of

Hospice Southeastern Connecticut

Before the Legislature's Public Health Committee

10:00 AM, Friday March 16, 2012

Room 1D, Legislative Office Building Hartford, Connecticut

My name is Aruna Iyer. I work in the Human resources at the Hospice Southeastern Connecticut. I am submitting testimony in support of House Bill 5499 (Raised) An Act Concerning Regulations Relating to Hospice Care .

Present you case here

- Patients and families in every corner of Connecticut deserve access to an inpatient hospice model that suits their communities.

Patients and families should not be put in a position that they have to drive a long way to care for their loved one especially during this difficult time of their lives.

Thank you for taking the time to consider my testimony. Please feel free to contact me if you have any questions at 860.848.5699 or (email address)

Proposed Hospice Facility Regulations
H.B. No. 5499

Throughout nursing school I always wanted to be a midwife. Now as a hospice nurse I tell my patients that I am a midwife helping them transition into their next life. It is a different type of birthing process that should be accessible on all levels to all of Connecticut's terminally-ill residence within their own community. This issue of accessible hospice care in the state of Connecticut is reminiscent of the transition the child birthing process went through during the 1970's. It was once thought acceptable, and more over necessary to deliver a baby into this world in a very aseptic, medical manner with the mother of the baby sedated and made unaware of the delivery of her own child. Through much community education and the concerted efforts of dedicated individuals the birthing process transitioned to a natural, calm and cognizant practice in a home like atmosphere that enabled the family to remain together during a most sacred time. What a beautiful concept for hospice care in the state of Connecticut whose time has come.

As a health care professional I assist those I serve in making ethical end of life decisions. Choosing to pass this regulation is the ethically right decision to make. Do no harm; do good; the common good; distributive justice; human dignity are all ethical principles that apply to this issue. As a society we are called to uphold these in all aspects of our decisions. Allowing equal access to all levels of hospice care is beneficial to the residence of our state. Not passing this regulation would continue to harm the terminally-ill patients of Connecticut by propagating an undue financial and emotional burden on them and their families who have to travel great distances for this equal access to hospice care. The common good is not met and distributive justice not served in this manner since distributive justice requires that everyone receives

equitable access to health care necessary for living a fully human life. Society has a duty to the individual in need. The state of Connecticut has a duty to its residences to pass hospice regulations that would be ethically beneficial for the common good.

Human dignity is an intrinsic principle that hospice care is base upon. Care of the whole individual through their natural dying process and their family is the reason for choosing hospice level of care at the end of life. Every terminally-ill patient is acknowledged as physical, psychological, social and spiritual with worth and value. Human persons must be treated with respect that recognizes their human dignity. Connecticut needs to respect the individuals of the state and their end of life need for equal access to all levels of hospice care. Passing this regulation as based on the Medicare Conditions of Participation would maintain this standard of human dignity by not limiting inpatient hospice facilities. These dated limitations have left the residence of the state with shorter hospice lengths of stay and fewer Medicare admissions to hospice than the national average resulting in costlier end of life care that does not provide support for the dignity of the human person due to the inadequate access to the full hospice benefit.

I strongly urge you to pass this hospice facility regulation in support of equal access to all levels of hospice care for all residence of the state of Connecticut. It is the right thing to do right now!

Laura Borrelli, R.N., B.S.N.
Hospice Director
Franciscan Home Care and Hospice Care
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Meriden, CT
203-238-1441
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001543

Regional Hospice and Home Care of Western Connecticut

Petition to CT. State Senators/Representatives

Petition Summary and Background	**We urge you to support** the Hospice Facility Regulations 19a-122b-1 to 19a-122b-14 created by the Department of Public Health (DPH). These regulations are sorely needed and will provide opportunities for licensed hospice providers throughout the state to offer terminally-ill patients access to all levels of hospice services both in home and in facilities within their own communities. They will allow for small hospice residences (usually 12 or fewer beds) to be built in areas around the state where accessibility to all levels of hospice care is currently a problem (Greater Danbury, Southeastern CT and Fairfield County to name a few). These hospice residences will be close to home and convenient to friends and family with less worry about travelling distances/hours to visit.
Petition Statement	We, the undersigned, are concerned citizens who urge our leaders to act now to support the passage of Hospice Facility Regulations 19a-122b-1 to 19a-122b-14 created by the Department of Public Health (DPH).

Printed Name	Signature	Address	Comment	Date
William R. Davidson		19 COVE RD BROOKFIELD CT 06804	I STRONGLY SUPPORT THIS LEGISLATION.	3-15-12
Marjorie Davidson		19 Cove Rd Brookfield CT 06804		3/15/12
MARK x. Paladino		6 Belden Hill Rd Brookfield CT		3.15.12
Vivian Maletzky		5 Shamrock Dr. Brookfield		3.15.12
Billie P Gardner		82 South Obtuse Rd.		3/15/12
Richard Blessey		6 DUNSINANE RD		3/15/12
ART KERLEY		13 Obtuse Rocks Rd Brookfield CT 06804		3/15/12
Lisi Marcus		209 Lonetown Rd,	Redding CT 06896	3/15/12
Neil Marcus		209 Lonetown Rd,	Redding CT 06896	3/15/12

Full Petition Available Online And Upon Request

March 15, 2012

To LEGISLATORS
General Assembly
State of Connecticut

RE: Raised Bill #5499
LCO #: 2036

I am adamantly opposed to passage of Raised Bill #5499. I am currently a full-time member of the Section of Oncology, Department of Medicine, Yale University School of Medicine and the Smilow Cancer Center in New Haven, Connecticut. Prior to my current appointment, I was in private practice for approximately 34 years specializing in cancer and blood diseases.

Changing the current structure of the inpatient hospice facility in Branford, Connecticut (Connecticut Hospice) and the associated home hospice services would be tragic and unnecessary in my opinion. Hospice inpatient services and hospice outpatient services are unique in character and cannot be mimicked or recreated by visiting nursing agencies or skilled nursing facilities.

Patients with cancer and serious blood diseases need to receive professional services from physicians and allied support personnel (nurses, social workers) who have specialized training in hospice-related issues and cancer.

In my 34-1/2 years of practicing medical oncology and hematology in the New Haven, Connecticut area, my patients with cancer and allied disorders have always received outstanding and excellent care from Connecticut Hospice. None of the other general nursing agencies or skilled nursing facilities can provide adequate hospice care in my personal experience taking care of many hundreds of patients.

Patients receiving home care services from Connectict Hospice Inc. are at great risk for displacement and dislocation from their homes if the current Connecticut Hospice structure is disrupted or eliminated by Raised Bill #5499. It is most likely, in my opinion as a Board-certified medical oncologist, that this would apply to very similar hospice facilities in other parts of the State of Connecticut.

Sincerely yours,

Martin E Katz MD

Martin E. Katz MD
Assistant Clinical Professor of Medicine

MARTIN E. KATZ, M.D., F.A.C.P.
2080 WHITNEY AVENUE
HAMDEN, CT 06518

March 15, 2012

Dear Members of the Public Health Committee,

My name is Alison Iannotti and I would like to express my opposition to Bill 5499.

Late last year my ninety three year old grandmother was admitted to Connecticut Hospice where she spent the last few weeks of her life. During the last week of her life our family had at least one family member at her bedside around the clock. Regardless of the day of the week or the hour of the night the nursing and support staff were always right there assuring that my grandmother received the best of physical care and that we received emotional support during a very trying time in our lives.

We can never overstate the superb care and attention both my grandmother and my family received from Hospice. We will forever be grateful that Hospice exists and operates as it does–it allowed my grandmother to die pain free and with dignity and it allowed us a chance to be with her at the end of her life.

Sincerely,

Alison M. Iannotti

HB5499

Christel Truglia
7 Gipsy Moth Landing
Stamford, CT 06902
(203) 357-7786

February 14, 2012

Regarding Proposed Hospice Regulations

Hospice: it is a solemn word associated with the final weeks or days of life. Here in Stamford, through the sincerely dedicated care provided at the Richard L. Rosenthal Hospice Residence, it was a word that had come to mean hope, and a kind of nurturing that allows sorrowful endings to become profound, new beginnings. Hospice is about the quality of final experiences during those precious final days.

Connecticut proudly created the first American hospice in 1979, based upon, what was then, pioneering State regulations. However, the State has neglected to modernize these regulations to meet the naturally evolving needs of Connecticut's population. We have fallen from being innovators of conscientious care to a State that fails to provide accessible end-of-life care to all.

While Connecticut's current largest growing population is 85 years of age and older, our regulations allow for only one hospice residence in the entire State, denying the majority of patients and, their families, access to hospice care. The entire ideology that defines hospice requires that it be easily accessed within the very community that supported the life of the person who now faces death. If only one hospice was allowed to exist statewide, then Connecticut's entire mission to create a more humane, family based, community centered end-of-life support is completely eradicated.

Some have argued that end-of-life care can be met by hospitals or nursing homes. However, even with their adjunct hospice departments, hospitals remain focused on acute care and are not inherently equipped to provide the full range of patient and family support that is the singular mission of a hospice facility. Similarly, nursing homes also lack this singularity of focus. Their concentration is on long-term care or rehabilitation.

Nonetheless, however one wishes to view the ability of hospitals or nursing homes to act as fully functioning hospice facilities, patients facing death should have the right to choose the care of a *local* hospice if they so desire. This is a fact that drove Connecticut to initiate hospice care to begin with.

I have heard it said, "People don't get cancer, families do." This is so true because the lives of every single person in a patient's family will change forever as they share the anguish brought on by cancer or other serious illnesses. In Stamford, The Rosenthal Hospice had aided over 1,100 patients along with their families, enabling them to walk this uniquely arduous path in a home-like setting, in an atmosphere of comfort and privacy, with exceptional emotional and spiritual support. I have experienced firsthand this very special place, where families grew to include the staff whose compassion extended beyond typical healthcare, as if we, and our suffering, belong to them as well.

Here, most appropriately hospice meant family, one bigger than we could have imagined or hoped for. And most importantly, it was accessible. There was no added stress or strain of driving across the state, and the location meant that everyone within each patient's community could be present to the needs at hand and the anticipated passing as it unfolded.

At the Rosenthal Residence, hospice meant when someone is too ill to face the inevitable in their own beds, there was a home away from home easily accessible to them and their loved ones. It meant medical professionals who go beyond the textbook definition of their jobs to treat all patients and their families with added dignity and comfort.

Over 20 years ago a group of people had the dream of a local hospice facility and saw it realized in the best way possible through the Rosenthal Residence, only to have the harsh and sudden news of its closing forced upon us, with little to no time to find a solution to the previously undisclosed financial strain that took this essential gift from our community.

The Rosenthal Hospice is gone, not because it suffered financial losses due to a lack of need, a lack of community support, or because of a trend towards shorter patient stays. It's gone because of outdated, 30 year old State regulations that are not viable for a service of this kind in this day and age.

The residents of our State desperately need and deserve a broad network of community based hospice facilities. This is not simply a renewed dream of a small group, but rather an essential personal right that must be made available, conveniently to all, and can only be realized by the passing of new State regulations that allow such a facility to remain competitive and financially solvent. It is such a shame that the standing regulations were not reviewed and updated in time to save the Rosenthal Hospice. However, if the State acts quickly and wisely to pass more current and broader regulations, new community based hospice facilities can begin forming here in Stamford and across all of Connecticut.

When I was on the committee to create it, I thought I knew why the Rosenthal Hospice Residence was important to our community. I honestly didn't discover the depth of its importance until I was there, experiencing firsthand what felt like bottomless despair soothed by an environment and staff that blanketed my mother, and all who cared for her, with such mindful and tender attention.

Each day that passes without new regulations is a day where patients, with precious little time left here on this earth, are denied the comforts I witnessed and experienced first hand at the Rosenthal Residence; comforts that are not only their right, but are their very last wish.

I implore our State Legislature to pass these more viable and broader hospice regulations immediately.

Thank you -
With Respect
Christel

A prayer for hospice, and families

Published 06:56 p.m., Friday, November 4, 2011

To the editor:

I have had the privilege of working for Hospice here in Stamford for a number of years. I have been witness to numerous families of every creed, religion and color. I have felt the deep sense of gratefulness, even awe that families hold for the residence, the care and the staff. There simply is no other place like it that I know of in this entire region.

One family member said to me, "Being there has changed my life. I have felt the presence of God in that place."

Last month I sat with a local family who's loved one was dying. They had planned to transfer him to Rosenthal when his level of care increased to beyond what they could handle at home. Then they got the devastating news that Rosenthal was closing its doors.

Faced with a very difficult decision, they at last resigned to having their loved one transferred to a hospice facility north of New Haven, not ideal in any way but they felt there was no other choice. I talked with them and commiserated, remarking on how unfair the timing was for them in particular; and thinking to myself, "How many families will be left in this position in the future?"

Just before the ambulance came to transfer the patient, I stood beside him in his bed and said a prayer for peace and protection and that the journey ahead would be smooth. I said my goodbyes to the family and wished them the best of luck, feeling a knot in my stomach at the thought of leaving them at this juncture.

Two hours later I received the call: the patient died minutes after arrival, apparently the transfer was just too much. I could only imagine how this family felt, knowing that their loved one had spent the last hour of his life in an ambulance, and likely feeling a loss of control on all fronts.

My prayers go out to them now.

My prayers also focus on the future, on all the families that will have to face this decision on the road ahead. I pray that our churches, leaders, officials and public will see how vital a hospice residence is. I pray that this will be a call to action and that we will summon the nerve, the energy and resources to do what we did to build this country: come together with our neighbors for a common purpose and achieve our goals through our own blood, sweat and tears.

Our forefathers and mothers knew this intrinsically. No one sat around waiting for some government or state entity to intervene and make the improvements that were needed.

The Rev. Katherine Silvan

001550

AROLYN COUTANT

State falling behind on hospice care

The announcement that Visiting Nurse and Hospice Care of Southwestern Connecticut is closing the Richard L. Rosenthal Hospice Residence is due in part to the lack of specific hospice facility regulations in the state.

The recent disagreement over proposed changes in Connecticut's Hospice regulations has sparked an intense debate, and one that is long overdue. Connecticut is considered the birthplace of the American Hospice Movement; however the state has fallen far behind others in embracing the concept of residential hospices. Connecticut Hospice established a solid foundation for end-of-life-care and is a wonderful institution; however, it is just that — an institution. The regulations that Connecticut Hospice falls under are specific to their own hospice and were established more than 30 years ago.

The amendments for Hospice Facility Regulation that the Connecticut Association for Homecare and Hospice has suggested to the Department of Public Health are not only appropriate, but needed. Stamford was a trailblazer more than 10 years ago when the community came together to open the Richard L. Rosenthal Hospice Residence, but had to undergo the expensive and time-consuming exercise of becoming a skilled-nursing facility due to the state's lack of specific regulations. Connecticut is not the first state to experience the uniqueness of hospice residence regulations. Virginia has recently enacted licensure regulations for dedicated hospice residences — homes where the patients and their families can find dignity, support, and comprehensive physical, emotional and spiritual care.

Connecticut Hospice believes in-patient facilities must have an in-house pharmacy, a physician on site, and a higher ratio of doctors and nurses to patients — a medical and long-term care model that survey after survey has told us is not what Americans want at the end of life. Furthermore, hospice is a program of care and depends on a team approach with the patient and family at the center of the care.

Connecticut Hospice's assertion that these new laws would somehow inhibit hospice workers from providing exceptional levels is refuted every day in hospices across the country where residential hospices are operational.

The time has come to fulfill the mission of the original hospice pioneers and return to the model of care that supports patient and family preferences to remain home while seriously ill, surrounded by family and friends. It is time to return the dying to our communities and not place them in institutional settings like nursing homes, hospitals, and even Connecticut Hospice's facility in Branford.

The time has come to fulfill the mission of the original hospice pioneers and return to the model of care that supports patient and family preferences.

It is a shame that Connecticut Hospice, the organization that helped promote the Hospice philosophy in the United States, does not support the proposed legislation. The vision of our hospice founders was to offer the community a safe, dignified and comfortable death at home or home-like setting, support for the family, and effective grieving. The last thing they wanted was more fragmented medically driven care that never addressed the patient's and family's goals of care and preferences for a peaceful death at home.

Carolyn Coutant is a Stamford resident.

March, 15, 2012

Dear Legislators,

I am unable to attend the hearing tomorrow, so I am submitting written terstimony in support of the following revision to the Hospice regulations :

Suggested Revisions for H.B.5499section (a) after "pursuant to 42 USC 1395x" (line 6) :

Shall be authorized to operate a hospice facility, including a hospice residence, for the purpose of providing hospice services for terminally ill patients who are in need of hospice home care or hospice inpatient services. The hospice facility including a hospice residence , must be able to provide the following levels of hospice care: routine, general inpatient , continuous or respite.

Resuming in the H.B. 5499 with the sentence (line 11)"The residence shall provide a homelike environment..."

As a practicing physician and Hospice Medical director in Northeast CT, I am painfully aware of how difficult it is for our hospice patients to go to a hospice residence when necessary. Currently Branford, CT is the closest hospice residence in our state. When a family is confronted with providing end of life care for a loved one, choices about where the care may be provided is often crucial. The revised hospice regulations will provide this choice. To allow for hospice residences to be built in more communities the new regulations must be approved.

At the end of life most people want to stay in their own homes, surrounded by loved ones, but sometimes this just isn't possible. If a hospice patient can't remain at home, they may have to go to a nursing home or into the hospital. Another choice is to go into a hospice residence. A hospice residence provides a home-like environment with specialized hospice care. This is a great option for patients who do not want to go into a nursing home and do not need the type of care provided in a hospital. The problem is that there are only three hospice residences in the entire state of Connecticut. If the patient is not lucky enough to live near one of the three hospice residences, their family will have to travel from as far as 2 hours away to visit. The revised hospice regulations will allow for more residences to be built throughout the state, allowing loved ones to stay locally.

Connecticut Hospice in Branford has been fighting the revised regulations. The current proposed revisions will allow Branford to continue providing care as they always have. In addition it allows other licensed hospices the opportunity to provide all levels of hospice care in their communities. There has been concern brought forward that the new regulations do not mandate a physician or pharmacist to be present in the facilities 24/7. Each Medicare certified and state licensed hospice has access to those disciplines 24/7 and the hospice medical director is available to assess a patient if necessary. Hospice is a team approach and there is ongoing input by team members, and medical issues are anticipated in advance so that crisis is avoided. The purpose of a local facility is to provide excellent and compassionate end of life care in the home or a home-like environment with the easy availability for

family, friends and even pets to visit. That care can happen with the entire input of all team members demonstrating excellent outcomes under the new hospice facility regulations. In addition, this model allows the family to be intimately involved until the last moment.. it allows for excellent memories that last with family forever. The social and emotional care is core to hospice and is best provided as close to home as possible.

The revised regulations allow for additional residences to be built and also focus on the increased need for hospices to evaluate quality, outcomes and compliance. The revised regulations are supported by every hospice in Connecticut except CT Hospice in Branford. Approving the revised regulations is vitally important to allow the development of additional hospice residences by licensed hospice programs throughout Connecticut.

The updated hospice facility regulations will improve access to a hospice residence in more communities. Having a nearby hospice residence will assure hospice patients and their families easy access to state of the art, compassionate patient care in a home-like environment.

As our population grows, more individuals will choose hospice care during their most vulnerable time. Access to a hospice residence in one's own community must be a choice. This choice was not available recently to a young adult who lived on his own yet when struck by a devastating terminal illness could not go back to his home. He could not go to live with his parent who had to maintain a job. He did not want to go into a "nursing home" because he was so young. He did not need to stay in the hospital because all of the technology necessary to control his symptoms could be administered at home. He had no choice in our community

Sincerely,

Joseph Alessandro, DO, CMD

Dear Madame Chair and Distinguished Committee Members: HB5499

In May of 2011, I wrote a letter to the editor of the Hartford Courant expressing my deep concern for the possibility that, as a matter of policy and funding, the level of care at The Connecticut Hospice might be downgraded as well as the level of care at other hospice care organizations.

Since then, on two occasions when I visited the Connecticut Hospice to sing for the patients, the families of the patients and the care-givers, I have become even more passionate about the issue, which is what happens when you deal with policy in flesh-and-blood terms, rather than in the hypothetical, on papers with columns of numbers.

Allow me to excerpt a few portions of my letter to the editor and make some additional remarks in this letter that I would be grateful and honored for you to consider as you deliberate changes in policy or practice at Connecticut Hospice.

I wrote, last June: *"The issue being debated regarding lowering the standards for the quality of hospice care in Connecticut has me deeply saddened and worries me that, as a sign of our times, the care we owe people at perhaps the most sacred, sensitive, potentially beautiful part of their life – their last chapter before passing – will now become diminished as it becomes part of the frequently painful cutbacks that we see all around us."*

Further, I wrote, *"I worry that our society, having to attend to the bottom line of pragmatics and money, will be depriving itself of an essential dimension of respect for life that could injure us deeply, and bruise our, already deeply bruised American heart."*

I feel that at this point in our lives, as Americans, we need to hold on to some things that demonstrate that we truly do care about each other. Some things are sacred and, even though as a nation, we will surely have to make sacrifices on many levels, for our dignity and our pride, we need to prioritize a few basic things, one of them being the last chapter of the lives of those who will soon leave us.

Here are imperative areas as I see as basic to the humanity of our nation. Without our being able to point to our refusal to be compromised in these two areas, I believe that we will, rightfully, have to hang our collective heads in shame.

- The first is care for the elderly and the young in their last chapters of their lives.
- The second is our children's health and education.

As a society, even though times are tough, financially and in other ways, I submit that for us to hold our heads up high we have to show ourselves and the next generation that we believed in <u>something</u> – that just as our war dead are not easily left behind, we have the courage, the decency and the caring heart as a nation to hold the line on some essentials, no matter how tough things get.

Please, as you consider the economics of the situation, please ask yourself what it is you would want to stand for if you were to be asked the following two questions by, let us say, a grandchild:

"How important did you feel the care of your parents was in that last period of time before they died? How important is it to you that I make your passing a beautiful, painless, caring, heartfelt last few weeks, days or hours?"

In spite of the challenges of these times, let's make sure that we have answered these questions with words that make us proud of what we stand for at this moment in our history.

I send you my gratitude for allowing me the privilege of sharing these few words.

With great respect,

Peter Yarrow
Peter, Paul and Mary
Board Member of The Connecticut Hospice

3/15/12

HB 5499

Dear Sen. Gerratana, Rep. Ritter, Rep Perillo, and Sen. Welch,

I urge you to support the Hospice Facility Regulations 19a-122b-1 to 19a-122b-14 created by the Department of Public Health (DPH), with the proposed revision of words: **Shall be authorized to operate a hospice facility, including a hospice residence, for the purpose of providing hospice services for terminally ill patients who are in need of hospice home care or hospice inpatient services. The hospice facility including a hospice residence , must be able to provide the following levels of hospice care: routine, general inpatient , continuous or respite.**

These regulations are sorely needed and will provide opportunities for licensed hospice providers throughout the state to offer terminally-ill patients access to all levels of hospice services both in home and in facilities within their own communities. They will allow for small hospice residences (usually 12 or fewer beds) to be built in areas around the state where accessibility to all levels of hospice care is currently a problem (Greater Danbury, Southeastern CT and Fairfield County to name a few). These hospice residences will be close to home and convenient to friends and family with less worry about travelling distances/hours to visit. They will also offer enhanced hospice care provided by hospice designated and trained staff in a home-like setting (not a nursing home or a hospital). Overall, they will ensure greater patient and family satisfaction at end-of-life.
Thank you for your time and consideration of this important hospice issue.

Sincerely,

Chris Mastropietro

Christine Mastropietro RN CHPN
Case Manager/Perinatal Hospice Coordinator
Regional Hospice and Home Care of Western Connecticut

Testimony of

Hospice Southeastern Connecticut

Before the Legislature's Public Health Committee

10:00 AM, Friday March 16, 2012

Room 1D, Legislative Office Building Hartford, Connecticut

My name is Jennifer H. Christopher, RN, BSN. I am in support of Services for Hospice Southeastern Connecticut. **I am submitting testimony in support of House Bill 5499 (Raised) An Act Concerning Regulations Relating to Hospice Care** .

As a Registered Nurse, I ask that support be considered for proposed **HB 5499**, section 19a-122b-1 to 19a-122b-14, in support of live-in Hospice Residence Facilities. There are several reasons for support, including but not limited to patient dignity and respect for the dying and their families at a time when privacy and respect are most important.

The Connecticut Hospice in Branford, CT is the only real live-in hospice facility in this state. Privacy of patients and families and their loved ones would be considered a luxury. Patients do not have privacy as there are up to four patients per room. One could try to spend quality time with a loved one. Sadly, there are no other options in the state of Connecticut for dying with dignity and privacy in a live-in facility.

The zeitgeist calls for a change to focus on patient-centered care. The majority of the hospice agencies in the State of Connecticut are asking for legislation to offer privacy while receiving care in a live-in facility. Having more than one live-in facility for end-of-life care gives families a choice for care during one of the most difficult times for families.

Thank you for your consideration of my thoughts and I hope that the elected representatives of the State of Connecticut will see the benefit of support of HB5499.

Thank you for taking the time to consider my testimony. Please feel free to contact me if you have any questions at 860.848.5699 or jchristopher@hospicesect.org

A prayer for hospice, and families

Published 06:56 p.m., Friday, November 4, 2011

To the editor:

I have had the privilege of working for Hospice here in Stamford for a number of years. I have been witness to numerous families of every creed, religion and color. I have felt the deep sense of gratefulness, even awe that families hold for the residence, the care and the staff. There simply is no other place like it that I know of in this entire region.

One family member said to me, "Being there has changed my life. I have felt the presence of God in that place."

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My prayers go out to them now.

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The Rev. Katherine Silvan

001559

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Connecticut Hospice's assertion that these new laws would somehow inhibit hospice workers from providing exceptional levels is refuted every day in hospices across the country where residential hospices are operational.

The time has come to fulfill the mission of the original hospice pioneers and return to the model of care that supports patient and family preferences to remain home while seriously ill, surrounded by family and friends. It is time to return the dying to our communities and not place them in institutional settings like nursing homes, hospitals, and even Connecticut Hospice's facility in Branford.

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Carolyn Coutant is a Stamford resident.

TESTIMONY of
HOSPICE SOUTHEASTERN CONNECTICUT

Before the Legislature's Public Health Committee
10 am, Friday March 16, 2012
Room 1D, Legislative Office Building Hartford, Connecticut

My name is Joanne Davis. I am a Patient Care Volunteer for Hospice Southeastern Connecticut in Norwich. I am submitting testimony in support of **House Bill 5499 (Raised): An Act Concerning Regulations Relating to Hospice Care**.

At last year's public hearing, I listened with keen attention to the testimony of hospice professionals and representatives about these proposed regulation changes. One message that saddened me was that patient care would be intentionally decreased and negatively impacted if they were enacted. Today, I come before your committee to share a patient's personal story that, had a hospice residence been available, his care would have been more compassionate because he would have been encircled by caregivers who "gentle the journey."

My testimony is about a **PERSON**: He was 61 years old and spent the last 4 months of his life in a nursing home when he was no longer able to be cared for in his own home. His lower legs were purple and hard and his skin was dry and cracked. He fell a couple of times, broke his nose, and had bruises and skin tears on his back from scraping the door hinge as he slid down against the closet door to the floor. As the days shortened, I wheeled him to the end of the corridor to get a glimpse of the trees and the setting sun. There wasn't much of the day left and it may have been the first . . . and last . . . time he saw nature while he was in the nursing home. All he wanted was to be at home with his wife; he even considered leaving the nursing home just to be with her at their home. He was so very disappointed to hear that he would never be able to leave. He deserved a better ending of his life's journey than this.

My testimony is about a **FAMILY**: They had only been married 8 years. Her caregiver stress increased significantly after he was admitted to a nursing home. She was concerned about the staff's lack of skin care, burdened by the need to do his laundry, and troubled about his decreasing ability to eat independently. She physically cared for him when she could be there and worried about him when she couldn't. The visible strain on her face and the deterioration of her own health told the story of how difficult this experience was. She deserved to be with him in a place where her hand . . . and nature . . . were just a touch . . . and a glance . . . away. He wanted this and she wanted this.

My testimony is about **2 ENVIRONMENTS**. The one that <u>was</u> and the one it <u>should have been</u>: He was in a nursing home where the sights and sounds were not pleasant and were best dealt with behind a

closed door, heightening his sense of isolation. His life, as turbulent as it had been, should be honored by the same dignified death that each of us wants, but even this became elusive in an environment in which he was often physically and emotionally separated from the most important person in his life – his wife.

This is the family for whom every aspect of a hospice residence is designed. He deserved a place that felt like home and where his dignity was respected. She deserved a place where she had peace of mind, comfort, and rest They deserved a place where they were cared for and supported as individuals and as a couple. When I think of this couple, the hospice residence "comes to life" as the optimal environment to promote a meaningful and peaceful death and to reduce the emotional agony of the family members facing the loss of their loved one.

We all deserve options and choices that "gentle the journey" at the end of life. Everyone in this room knows families like this couple who deserve no less. Isn't your family 1 of them?

I strongly urge you to support the proposed changes and become a champion for quality of end-of-life care to clients and their families throughout our state. Having access to all levels of hospice services across the continuum of care (home, nursing home, hospital, hospice residence) is a critical and strategic component of the provision of care that hospice patients, and their families, deserve. The adoption and subsequent implementation of these proposed regulations assure that access to this level of care is available to all patients throughout our state - care that is based on patient and family need, is consistent with clinical practice standards, strives for continuous quality improvement, and is without regard to geographical location.

Thank you for taking the time to consider my testimony. Please feel free to contact me if you have any questions at (860) 848-5699 or Joanne_Davis@comcast.net.

Dear Sen. Gerratana, Rep. Ritter, Rep Perillo, and Sen Welch,

HB5499

I urge you to support the Hospice Facility Regulations 19a-122b-1 to 19a-122b-14 created by the Department of Public Health (DPH), with the proposed revision of words· **Shall be authorized to operate a hospice facility, including a hospice residence, for the purpose of providing hospice services for terminally ill patients who are in need of hospice home care or hospice inpatient services. The hospice facility including a hospice residence , must be able to provide the following levels of hospice care: routine, general inpatient , continuous or respite.**

These regulations are sorely needed and will provide opportunities for licensed hospice providers throughout the state to offer terminally-ill patients access to all levels of hospice services both in home and in facilities within their own communities. They will allow for small hospice residences (usually 12 or fewer beds) to be built in areas around the state where accessibility to all levels of hospice care is currently a problem (Greater Danbury, Southeastern CT and Fairfield County to name a few). These hospice residences will be close to home and convenient to friends and family with less worry about travelling distances/hours to visit. They will also offer enhanced hospice care provided by hospice designated and trained staff in a home-like setting (not a nursing home or a hospital) Overall, they will ensure greater patient and family satisfaction at end-of-life

Thank you for your time and consideration of this important hospice issue

Charles Ryan (Deborah Ryan)

Sincerely,

35 Stone Hill Rd

New Milford CT

06776

Cheryl Clark
538 Berkshire Road
Southbury, CT 06488

HB5499

3/15/2012

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Sincerely,

Cheryl Clark

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HB5499

March 15, 2012

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Thank you for your time and consideration of this important hospice issue.

Sincerely,

Paula Boa Sousa

Bonhomme, Penny

From: Denise Hawk [DHawk@hospicesect org]
Sent: Thursday, March 15, 2012 2 28 PM
To: PHC Testimony
Cc: 'hoyt@cahch org'
Subject: Testimony for Fri March 16 and Bill number HB 5499.

Testimony of
Hospice Southeastern Connecticut
Before the Legislature's Public Health Committee
10:00 AM, Friday March 16, 2012
Room 1D, Legislative Office Building Hartford, Connecticut

My name is Denise E. Hawk . I am Annual Giving and Special Events Manager for Hospice Southeastern Connecticut. **I am submitting testimony in support of House Bill 5499 (Raised) An Act Concerning Regulations Relating to Hospice Care .** I will not be able to testify in person and so will submit this written testimony

Please support HB 5499 which requires the Department of Public Health to adopt the Inpatient Hospice Regulations 19a-122b-1 to 19a-122b-14. These regulations are about the dying patients and families in every corner of Connecticut having access to the full range of hospice care services. **These contemporized regulations preserve the hospital standard set in Connecticut 30 years ago and establish a regulatory environment that allows for other models of inpatient hospice care that suit their respective communities. Please ensure that these regulations allow patients to have access to routine home care and general impatient care at a hospice residence close to their family's home.**

Patients and families in every corner of Connecticut deserve access to an inpatient hospice model that suits their communities. Currently, the full continuum of hospice care is not readily accessible to all our state residents. This care includes care in the home, care in the hospital, care in a skilled nursing facility and care in a hospice residence or facility. Currently Connecticut ranks last or 51st (including Washington DC) in average length of stay for Medicare hospice days (National average is 71, CT is 49). The State of CT ranks last in the country in average length of stay for hospice patients resulting in more costly end of life care in acute care settings. **Of the 5150 hospice providers in the US, one in five also operates an inpatient facility. CT has only 1 inpatient facility licensed under regulations from 35 years ago.**

Allowing Hospice Residences to be created under updated regulations, would allow every resident in Connecticut to have a place for quality end of life care when home care, hospital care or skilled nursing home care are not appropriate or possible. Yet, they can be close enough to home so their loved ones can visit frequently. Such a resident under updated regulations could have *private* rooms with access to an outside garden, accommodations for family to visit and stay overnight with their loved one. The Residence would provide a relaxed atmosphere where you can find a cup of tea in the kitchen, sit in the great room to read, find a quiet place for reflection in the library, take time to find solace in the non-denominational chapel and gather with family in the dining room. This is what the every resident of Connecticut could look forward to having in their own community.

These regulations are supported by 28 of the 29 hospice providers in the state. We need your support to help us provide this care to CT residents. Please support Department of Public Health in moving the regulations forward to the Regulations Review committee.

Thank you for taking the time to consider my testimony. Please feel free to contact me if you have any questions at 860.848.5699 or dhawk@hospicesect.org,

Denise E. Hawk
Annual Giving and Special Events Manager
Hospice Southeastern Connecticut
227 Dunham Street
Norwich, CT 06360
860-848-5699
860-886-0467 (Fax)
dhawk@hospicesect.org

Bonhomme, Penny

From: Edele [unionmemorialchurch@gmail com]

Sent: Thursday, March 15, 2012 7.54 PM

To: PHC Testimony

Subject: Proposed Hospice Regulations

The Rev Dr. Blaine Edele, Ph D
Union Memorial Church
58 Church Street
Stamford, CT 06906

March 15, 2012

Dear Senator Terry B. Gerratana and Representative Elizabeth B Ritter,

I have served as the Pastor of the Union Memorial Church in Stamford for the past twenty years I have ministered to numerous parishioners who have died under the care of the former Rosenthall Hospice in Stamford, various nursing homes in the area and regional hospitals I have concluded that the quality of care offered in a residential hospice ministered more compassionately, competently and consistently to both patients and families who sought end-of-life care. Therefore, I have a keen interest in the pending bill H B No 5499 (Raised) An Act Concerning Regulations Relating to Hospice Care

I appreciate that the legislature must address a tension between those advocating new regulations, which reportedly will increase access to hospice care, and those supporting the existing regulations, which reportedly will preserve the high standard of hospice residential care in our State. I understand that those in favor of the existing regulations cite that Connecticut is a national leader in providing hospice care. I also understand that those in favor of the current regulations cited that 80% (or sometimes cited as 90%) of Connecticut residents live within a 30 minute drive (sometimes cited as a 60 minute drive) to hospice agencies

I applaud the residential hospice services in Connecticut for achieving such highly acclaimed standards In light of the recent closure of the Rosenthall Hospice in Stamford, I question the degree of accessibility to hospice care in our State May I cite a heart-breaking story to illustrate my position.

At the Public Heanng on the closure of the Rosenthal Residence in Stamford, a middle aged couple spoke mournfully about their late father's death For several months they couple had provided care for their aged parent in their own home They promised to care for him until his dying hour When they heard that the Rosenthal Hospice might close, they decided to send their informed father to the Branford Hospice, which, can be as much as a 90 minute drive on Interstate 95 from Stamford when heavily congested. They tearfully watched attendants transfer their father into an ambulance and promised to meet him at the Hospice Residence in Branford as soon as possible. To their dismay, they later learned that he died in the ambulance, apart from his beloved family I imagine that the elderly man could have died at any time in any place, but how sad that ,due to commuting distance from Stamford, he died away from his devoted family

This story is a dire example, but it serves to illustrate in a severe degree the importance of providing accessibility to residential hospice care across our State

A pressing issue for me is not exclusively if and to what extent these proposed regulations may reduce the quality of hospice care in our State The issue for me is will these proposed regulations encourage the development of residential hospice facilities across the State for the many patients who currently face the end-of-life in nursing homes and hospitals. For families to drive to the Hospice in Branford from Sharon, Greenwich, Pomfret, or Norwich on a daily, or even regular basis, during prolonged periods of caring for their dying loves would be a terrible burden on those families. When a caregiver wants to be the daily companion for their dying loved ones, a two-hour or more round trip is prohibitive. I believe that encouraging quality hospice for more throughout our State, rather than offering nationally acclaimed care only for those fortunate to live close to the center of the State is a most just position.

I urge you to endorse these proposed regulations

Sincerely,

The Rev Dr. Blaine Edele, Ph D.

Robert V. Rodia, *Chairman, Board of Directors*
William F. Sullivan, Jr., *President and CEO*

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TESTIMONY

BEFORE THE PUBLIC HEALTH COMMITTEE

H B. 5499 AN ACT CONCERNING REGULATIONS RELATING TO HOSPICE CARE

March 15, 2012

Senator Gerratana, representative Ritter and members of the Public Heath Committee, my name is Tina Bernacki and I am Director of Visiting Nurse Services of Ct Inc Hospice At Home Program. I am also a member of the Connecticut Association for Home Care and Hospice. I am a Registered Nurse with thirty years of hospice home care experience.

I am writing to testify in support of H.B. 5499 AN ACT CONCERNING REGULATIONS RELATING TO HOSPICE CARE with proposed revisions favored by CAHCH, our state organization, and Board of Directors.

VNS of Connecticut Hospice at Home program provides hospice services to residents in Fairfield, New Haven and Litchfield Counties. Hospice families will be better served with more options for care should they require services in a facility/residence. If home is not possible then closer to home is best. The support and presence of family and loved ones are readily available and what patients and their families need at the end of life is the familiarity of community, be it physical, emotional or spiritual.

Please support the updated regulations that will ensure increased access to care for all state resident when facing end of life decisions.

Thank you for your patience in considering this testimony.

Tina M. Bernacki

Tina M Bernacki RN MS CHPN

Hospice Director

Visiting Nurse Services of CT

tbernack@vnsct.org 860-482-6419

Testimony of

Hospice Southeastern Connecticut

Before the Legislature's Public Health Committee

10:00 AM, Friday March 16, 2012

Room 1D, Legislative Office Building Hartford, Connecticut

My name is Tina Eldridge . I am a Registered Nurse with Services for Hospice Southeastern Connecticut. I am submitting written testimony in support of House Bill 5499 (Raised) An Act Concerning Regulations Relating to Hospice Care .

Inpatient Hospice Regulations Talking Points

- These regulations are about the dying patients and families in every corner of Connecticut having access to the full range of hospice care services.
- These contemporized regulations preserve the hospital standard set in Connecticut 30 years ago and establish a regulatory environment that allows for other models of inpatient hospice care that suit their respective communities.
- Patients and families in every corner of Connecticut deserve access to an inpatient hospice model that suits their communities.
- Currently, the full continuum of hospice care is not readily accessible to all our state residents. This care includes care in the home, care in the hospital, care in a skilled nursing facility and care in a hospice residence or facility.
- The State of CT ranks last in the country in average length of stay for hospice patients resulting in more costly end of life care in acute care settings.
- Of the 5150 hospice providers in the US, one in five also operates an inpatient facility. CT has only 1 inpatient facility licensed under regulations from 35 years ago.
- A Hospice Residence would provide a place for quality end of life care when home care, hospital care or skilled nursing home care are not appropriate or possible. The 12 private rooms would have access to the outside garden, accommodations for family to visit and stay overnight with their loved one. The Residence would provide a relaxed atmosphere where you can find a cup of tea in the kitchen, sit in the great room to read, find a quiet place for reflection in the library, take time to find solace in the non-denominational chapel, gather with family in the dining room.

Thank you for taking the time to consider my testimony. Please feel free to contact me if you have any questions at 860.848.5699 or TEldridge@hospicesect org

Kind Regards,

Tina Eldridge

Testimony of
Hospice Southeastern Connecticut
Before the Legislature's Public Health Committee
10:00 AM, Friday March 16, 2012
Room 1D, Legislative Office Building Hartford, Connecticut

My name is Sharon Schaffer and I am a Clinical Social Worker for Hospice Southeastern Connecticut. I am submitting, as written only, testimony in support of House Bill 5499 (Raised) An Act Concerning Regulations Relating to Hospice Care.

As a Clinical Social Worker for Hospice Southeastern Connecticut, I work directly with patients who have life limiting illnesses, and who desire to remain within the comfort of their own homes and communities until they die. Sometimes, care no longer becomes possible within the home and it is necessary to find a safe place for patients to go, all the while obtaining the best quality inpatient hospice care available. Patients and families in every corner of Connecticut deserve access to an inpatient hospice model that suits their communities and speaks to their hearts. Currently, the full continuum of hospice care is not readily accessible to all of our state residents. This care includes care in the home, care in the hospital, care in a skilled nursing facility and care in a hospice residence or facility. Of the 5150 hospice providers in the US, one in five also operates an inpatient facility. CT has only 1 inpatient facility licensed under regulations from 35 years ago, and that facility is a very far distance from the communities Hospice Southeastern Connecticut serves.

The decision to send loved ones so far away is often a sad and difficult one, but without having a choice, many families are forced into sending their loved ones away. As their social worker, I am charged with providing the emotional support necessary to assist patients and families in dealing with the feelings associated with having to make such a decision. Often, especially in the case of our most elderly, the family is unable to visit their loved one regularly which, in turn, creates strong feelings of guilt that must

be dealt with. Knowing that death occurs just once for each of us, I work toward making the experience the best it can be for patients and families alike. The ability to have a Hospice Residence within our community would provide a place for quality end of life care when home care, hospital care or skilled nursing home care are not appropriate or possible. It would give our patients and families the well deserved opportunities to spend each and all moments possible, together, until death parts them.

Please support HB 5499 which requires the Department of Public Health to adopt the Inpatient Hospice Regulations 19a-122b-1 to 19a-122b-14, knowing these regulations are supported by 28 of the 29 hospice providers in the state and knowing that supporting HB5499 is in the best interest of those hospice patients and their families who need your support.

Thank you for taking the time to consider my testimony. Please feel free to contact me if you have any questions.

Sharon Schaffer, LCSW, ACHP-SW
Hospice Southeastern Connecticut
227 Dunham Street
Norwich, CT 06360

t. 860.848.5699 - f. 860.848.6898
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www.hospicesect.org

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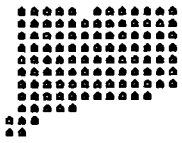

Connecticut Association for
HOME CARE
& HOSPICE

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TESTIMONY

BEFORE THE PUBLIC HEALTH COMMITTEE

H.B. 5499 AN ACT CONCERNING REGULATIONS RELATING TO HOSPICE CARE

March 16, 2012

Senator Gerratana, Representative Ritter and members of the Public Health Committee, my name is Tracy Wodatch. I am a registered nurse with nearly 30 years' hospice and home care experience and the Vice President of Clinical and Regulatory Services for the Connecticut Association for Home Care and Hospice (CAHCH), a non-profit trade organization that provides leadership, advocacy and educational membership support to all the licensed and certified hospice providers in Connecticut.

On behalf of CAHCH and 27 of its 28 hospice provider members, I am writing in **support** of H.B. 5499 An Act Concerning Regulations Relating to Hospice Care but request specific language changes to section (a) which will be outlined further in my testimony. For more than two years, CAHCH and the licensed hospice providers in Connecticut have been working collaboratively with the Department of Public Health (DPH) to develop proposed revisions to Section 19a-122b-1 to 19a-122b-14 Hospice Facility regulations which are based on the current (2008) Medicare Hospice Conditions of Participation.

These regulations will open up access to all levels of hospice care but specifically allow for hospice facilities or residences. The current regulations (19-13-D4b) are for hospital based hospices only. They do not support the small home-like hospice facility or residence, a model that is prevalent throughout the United States. Of the 5150 hospice providers nationally, 21.7% have hospice facilities or residences (just over one in five)-*source: The 2010 Medicare Facts and Figures report.* In Connecticut, there are only two (6.7%) facilities but they are licensed under CT regulations 19-13-D4b (Short-term hospitals, special, hospice) which were written 35 years ago for CT Hospice to be provided in the hospital setting.

The proposed regulations will not modify the current licensing of CT Hospice in Branford, yet will allow other hospice providers throughout the state to offer terminally-ill patients access to all levels of hospice services both in home and in facilities within their own communities. They will allow for small hospice residences (usually 12 or fewer beds) to be built in areas around the state where accessibility to all levels of hospice care is currently a problem (Greater Danbury, Southeastern CT and Fairfield County to name a few). These hospice residences will be close to home and convenient to friends and family with less worry about travelling distances/hours to visit. They will also offer enhanced hospice care provided by hospice designated and trained

staff in a home-like setting (not a nursing home or a hospital). Overall, they will ensure greater patient and family satisfaction at end-of-life.

Should H.B. 5499 be passed, it will surely expedite the implementation of the DPH proposed hospice facility regulations. However, as written, H.B 5499 needs the following revisions to meet the intended goals of the proposed regulations which is to offer all levels of hospice care in all settings. In section (a) "a hospice pursuant to 42 USC 1395x…", delete the remaining portion of this sentence and the next sentence (lines 2 and 3 of section a) and the following language should be inserted, "**shall be authorized to operate a hospice facility, including a hospice residence, for the purpose of providing hospice services for terminally ill patients who are in need of hospice home care or hospice inpatient services. The hospice facility, including a hospice residence, must be able to provide the following levels of hospice care: routine, general inpatient, continuous or respite."** Continue thereafter with the next sentence, "The residence shall provide a homelike…".

Bringing hospice care in Connecticut into the 21st century is sorely needed. Please pass H.B. 5499 with the recommended language changes as it will ensure access to the full complement of hospice services for our terminally ill residents throughout Connecticut. If you have any questions, please feel free to contact me at wodatch@cahch.org or 203-294-7348.

Thank you,
Tracy Wodatch, RN, BSN
VP of Clinical and Regulatory Services

Regarding Hospice Legislation
Elizabeth Edele
Stamford, CT
March 14, 2012

HB5499

Dear Senator Terry B. Gerrantana and Representative Elizabeth B. Ritter,

I understand that you will be considering the best options regarding Hospice Legislation in Connecticut. I wanted to convey two points that may be helpful to consider in your decision making.

I am a teacher in Greenwich, CT. Two weeks ago one of our younger teachers was in the office with some of the staff. She was relaying sadly that her father, who was in his fifties, was in Greenwich Hospital facing the final days of his life. A staff member asked if he could be referred to the Stamford Hospice. Another staff member replied, "No it is closed."

The teacher who's father was dying said that each week the family was having to file paperwork in order for her father to stay in Greenwich - near family. The hospital staff, as she put it, was trying to move her father to Branford for the final days of his life - on a good day with traffic - two hours away from his family.

This event is playing and replaying here at this end of Connecticut. Would you please strongly consider a way of providing access to Residence Hospice care back to Fairfield County. We are languishing here for a place where our loved ones can end their lives with dignity and caring staff familiar with the particular medical needs of dying patients and their families.

Thank you for your time.

Most sincerely,

Elizabeth Edele
203-359-9416

Nancy Wildman
16 Heather Lane
Terryville, CT 06786
(860) 583-2545

HB 5499

March 15, 2012

Dear Sen. Gerratana, Rep. Ritter, Rep. Perillo, and Sen. Welch,

I urge you to support the Hospice Facility Regulations 19a-122b-1 to 19a-122b-14 created by the Department of Public Health (DPH), with the proposed revision of words: **Shall be authorized to operate a hospice facility, including a hospice residence, for the purpose of providing hospice services for terminally ill patients who are in need of hospice home care or hospice inpatient services. The hospice facility including a hospice residence , must be able to provide the following levels of hospice care: routine, general inpatient , continuous or respite.**

These regulations are sorely needed and will provide opportunities for licensed hospice providers throughout the state to offer terminally-ill patients access to all levels of hospice services both in home and in facilities within their own communities. They will allow for small hospice residences (usually 12 or fewer beds) to be built in areas around the state where accessibility to all levels of hospice care is currently a problem (Greater Danbury, Southeastern CT and Fairfield County to name a few) These hospice residences will be close to home and convenient to friends and family with less worry about traveling distances/hours to visit They will also offer enhanced hospice care provided by hospice designated and trained staff in a home-like setting (not a nursing home or a hospital) Overall, they will ensure greater patient and family satisfaction at end-of-life.
Thank you for your time and consideration of this important hospice issue

Sincerely,

Nancy Wildman

15 Belvedere Court

Ridgefield, CT 06877

March 15, 2012

HB5499

Dear Sen. Gerratana, Rep. Ritter, Rep. Perillo, and Sen Welch,

I urge you to support the Hospice Facility Regulations 19a-122b-1 to 19a-122b-14 created by the Department of Public Health (DPH), with the proposed revision of words. **Shall be authorized to operate a hospice facility, including a hospice residence, for the purpose of providing hospice services for terminally ill patients who are in need of hospice home care or hospice inpatient services. The hospice facility including a hospice residence , must be able to provide the following levels of hospice care: routine, general inpatient , continuous or respite.**

These regulations are sorely needed and will provide opportunities for licensed hospice providers throughout the state to offer terminally-ill patients access to all levels of hospice services both in home and in facilities within their own communities. They will allow for small hospice residences (usually 12 or fewer beds) to be built in areas around the state where accessibility to all levels of hospice care is currently a problem (Greater Danbury, Southeastern CT and Fairfield County to name a few). These hospice residences will be close to home and convenient to friends and family with less worry about travelling distances/hours to visit. They will also offer enhanced hospice care provided by hospice designated and trained staff in a home-like setting (not a nursing home or a hospital). Overall, they will ensure greater patient and family satisfaction at end-of-life.

Thank you for your time and consideration of this important hospice issue.

Sincerely,

Sherri Renne

Sherri Renne, MSW

Social Worker, Regional Hospice and Home Care of Western CT

Karl F. Rickel, CLU, CFP®
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e-mail. krickel@finsvcs com

Dear Senator/Representative,

HB 5499

March 15th, 2012

I urge you to support the Hospice Facility Regulations 19a-122b-1 to 19a-122b-14 created by the Department of Public Health (DPH).

These regulations are sorely needed and will provide opportunities for licensed hospice providers throughout the state to offer terminally-ill patients access to all levels of hospice services both in home and in facilities within their own communities. They will allow for small hospice residences (usually 12 or fewer beds) to be built in areas around the state where accessibility to all levels of hospice care is currently a problem (Greater Danbury, Southeastern CT and Fairfield County to name a few) These hospice residences will be close to home and convenient to friends and family with less worry about travelling distances/hours to visit. They will also offer enhanced hospice care provided by hospice designated and trained staff in a home-like setting (not a nursing home or a hospital). Overall, they will ensure greater patient and family satisfaction at end-of-life.

Thank you for your time and consideration of this important hospice issue.

Sincerely,

Karl

Insurance Representative of Massachusetts Mutual Life Insurance Company (MassMutual) and affiliates • Springfield MA 01111-0001
Registered Representative of and securities products and investment advisory services offered through MML Investors Services, Inc , a MassMutual subsidiary • Supervisory Office 530 Fifth Avenue 12th & 14th Floors New York NY 10036 (212) 536-6000 Cowan Financial Group, Howard B Cowan, CLU, ChFC, General Agent

March 14, 2012.

15 Bobbys Court
Ridgefield, CT 06877.

Carolyn Wolfe
Western CT Regional Hospice
and Home Care
405 Main Street
Danbury, CT 06810.

HB5499

Dear Carolyn,

I am very supportive of legislation that will revise Hospice Facility regulations and enable Regional Hospice and Home Care of Western CT to build a new facility in Danbury and provide residential hospice care for local patients. I have been a Family Support Volunteer at Regional Hospice since 1990, and have seen first hand the wonderful care, skill, and compassion the Regional Hospice staff provides every day for our patients, and I have also seen many cases where there is great need for in-residence care during some end of life situations. Unfortunately, there is no reasonable way to provide that support today, because there are no facilities locally that can do it, and transferring local patients to Branford, the only facility available, is not practical because of the distance. Families want to be there for their loved ones, and a ninety minute journey each way is very much a barrier.

Not only would a new, state-of-the-art facility here in Danbury offer first class care, but the patients and families can continue to have the support of the Hospice staff that they have become safe and comfortable with. It will also improve the care we can provide because there will be someone with the patients twenty four/seven, and our staff, especially the nurses, will no longer have to travel to patients homes when emergencies occur, and care givers will not have to take care of their loved ones twenty four hours a day. I know from my experience how difficult this can be, and how much the care-givers and patients have to deal with during this difficult and emotional time.

I will do anything in my power to help revise the current legislation and make it possible for Western CT Regional Hospice and Home Care can proceed with plans for a new facility. I look forward to that day. Let me know if I can help in any way.

Sincerely,

William M. Morlock

William M. Morlock

An Independent Member of BDO SEIDMAN ALLIANCE
Actis-Grande, Ronan & Company, LLC
CERTIFIED PUBLIC ACCOUNTANTS

March 14, 2012

HB5499

Dear Representative Scribner:

I urge you to support the Hospice Facility Regulations 19a-122b-1 to 19a-122b-14 created by the Department of Public Health (DPH).

These regulations are sorely needed and will provide opportunities for licensed hospice providers throughout the state to offer terminally-ill patients access to all levels of hospice services both in home and in facilities within their own communities. They will allow for small hospice residences (usually 12 or fewer beds) to be built in areas around the state where accessibility to all levels of hospice care is currently a problem (Greater Danbury, Southeastern CT and Fairfield County to name a few). These hospice residences will be close to home and convenient to friends and family with less worry about travelling distances/hours to visit. They will also offer enhanced hospice care provided by hospice designated and trained staff in a home-like setting (not a nursing home or a hospital). Overall, they will ensure greater patient and family satisfaction at end-of-life.

Thank you for your time and consideration of this important hospice issue.

Sincerely,

Edward F. Ronan Jr.

EFR/aer

30 Main Street, Suite 500, Danbury, CT 06810-3047
Phone: (203) 797-0056 ▪ Fax (203) 778-9623 ▪ Stamford: (203) 324-4710 ▪ www.AGRCO.com

March 15, 2012

Dear Sen. Gerratana, Rep. Ritter, Rep Perillo, and Sen. Welch,

HB5499

I urge you to support the Hospice Facility Regulations 19a-122b-1 to 19a-122b-14 created by the Department of Public Health (DPH), with the proposed revision of words: **Shall be authorized to operate a hospice facility, including a hospice residence, for the purpose of providing hospice services for terminally ill patients who are in need of hospice home care or hospice inpatient services. The hospice facility including a hospice residence , must be able to provide the following levels of hospice care: routine, general inpatient , continuous or respite.**

These regulations are sorely needed and will provide opportunities for licensed hospice providers throughout the state to offer terminally-ill patients access to all levels of hospice services both in home and in facilities within their own communities. They will allow for small hospice residences (usually 12 or fewer beds) to be built in areas around the state where accessibility to all levels of hospice care is currently a problem (Greater Danbury, Southeastern CT and Fairfield County to name a few). These hospice residences will be close to home and convenient to friends and family with less worry about travelling distances/hours to visit. They will also offer enhanced hospice care provided by hospice designated and trained staff in a home-like setting (not a nursing home or a hospital) Overall, they will ensure greater patient and family satisfaction at end-of-life.

Thank you for your time and consideration of this important hospice issue

Sincerely,

Marybeth Hamilton

Danbury, CT

TESTIMONY
FOR THE DEPARTMENT OF PUBLIC HEALTH
REGARDING:

Revised Hospice Facility Regulations

HB5499

Friday, March 16, 2012

Dear Senators/Representatives.

I am **Robin Viklund, RN, BSN, CHPN**. Seven years ago I joined Regional Hospice and Home Care of Western Connecticut as a Nurse Case Manager I quickly realized that this nursing specialty was a calling for me—not just a profession.

I first experienced hospice in 1988 when my daughter was born at an age when survival was unlikely Some hospitals would have tried many interventions to keep the baby alive but in the end the baby would have known only the pain of being poked, prodded and not the true love of human touch. My husband and I chose to hold our daughter and have her only know love and peace until her short life ended. The importance of my daughter's life led me down the path I now walk

I was a maternal child nurse for many years but 8 or 9 years ago I worked in a skilled nursing facility. This is when I first saw the unmet need of patients who have a life limiting illness and the specialty of Hospice Care This was the beginning of my dream to have a local Hospice House with inpatient care in Western Connecticut. The goal for most patients and families is to stay at home On the occasions that this is not possible the patients and families of our region have very few options

I would like to speak to the question about pharmacy needs. With my extensive background as a hospice nurse case manager and educator, as well as experience with inpatient nursing care, **I do not see a need for an on-site pharmacist at a hospice residence.** Skilled nursing facilities do not have the requirement for a pharmacist on site—but they do have medications available to them 24 hours a day, 7 days a week A hospice residence with inpatient care would be no different As long as medications are available patients will be kept physically comfortable without a pharmacist on site—quality of care will still be exceptional.

For a patient to be able to have an inpatient Hospice facility within their community would allow them to receive local care and benefit from a skilled team that embraces the entire Hospice philosophy Hospice is really no different than any specialty care If you are having a baby you are cared for by an obstetrician and clinicians in the labor and delivery unit—it wouldn't make sense to be on a hospice floor When you need inpatient hospice care at the end of your life, you don't want to go to a rehab unit or a nursing home—you want to be cared for at a hospice residence by the experts in hospice care

When talking with patients about what happens if the family cannot care for their loved one at home and mentioning that the only free standing hospice facility is in another part of the state you can see disappointment in their eyes and hear it in their voices as they say it is too far for them They would not be able to travel to be with the patient and they promised never to place them in a skilled nursing facility or return to the hospital

To be able to go to an inpatient hospice residence with a home like environment, within the patient and family's own community—not 1 to 2 hours away—makes the holistic mission of hospice better accomplished To be able to keep patients close to their loved ones and in their community makes the goal of assisting with the things most important to them easier When patients have to leave their community, more often than not the ability for their family, clergy, and friends to visit and be with them is limited.

It is so important to have the proposed Regulations passed as there is such a need that is not being met My dream for many years has been to bring hope to families in Western Connecticut—so they can have the best possible care in the best facility to offer what they need without traveling a great distance.

I urge you to support the Hospice Facility Regulations 19a-122b-1 to 19a-122b-14 created by the Department of Public Health (DPH), with the proposed revision of words: **Shall be authorized to operate a hospice facility, including a hospice residence, for the purpose of providing hospice services for terminally ill patients who are in need of hospice home care or hospice inpatient services. The hospice facility including a hospice residence , must be able to provide the following levels of hospice care: routine, general inpatient , continuous or respite.**

These regulations are solely needed and will provide opportunities for licensed hospice providers throughout the state to offer terminally-ill patients access to all levels of hospice services both in home and in facilities within their own communities They will allow for small hospice residences (usually 12 or fewer beds) to be built in areas around the state where accessibility to all levels of hospice care is currently a problem (Greater Danbury, Southeastern CT and Fairfield County to name a few). These hospice residences will be close to home and convenient to friends and family with less worry about travelling distances/hours to visit. They will also offer enhanced hospice care provided by hospice designated and trained staff in a home-like setting (not a nursing home or a hospital) Overall, they will ensure greater patient and family satisfaction at end-of-life.

Thank you for your time and consideration of this important hospice issue

Yours truly,

Robin Viklund, RN, BSN, CHPN

TESTIMONY BEFORE THE DEPARTMENT OF PUBLIC HEALTH
REGARDING H.B. No. 5499,
PROPOSED HOSPICE FACILITY REGULATIONS
March 13, 2012

To Department of Public Health., my name is ***Carol Emmerthal, RN, MSN.*** I am the Director of Hospice and Palliative Care of Northeastern Connecticut, a program of Day Kimball HomeCare. This letter is being sent as **written testimony** in support of H.B. No. 5499. The regulations are based on the Medicare Hospice Conditions of Participation and provide opportunities for **all** licensed hospice providers in the state to be authorized to operate a hospice facility, including a hospice residence, for the purpose of providing hospice services for terminally ill patients who are in need of hospice home care or hospice inpatient services. The hospice facility including a hospice residence must be able to provide the following levels of hospice care: routine, general inpatient, continuous or respite.

My testimony advocates for equal access to the full realm of hospice services for all residents across Connecticut.

During my 20 plus years with hospice, I have developed a deep appreciation for the care provided by hospice providers throughout Connecticut, be they not-for-profit or for profit agencies. We all focus on the special end of life care needed for our patients and their families. We are all united in our missions and philosophies to provide quality care to the terminally ill patients we serve. We advocate for the needs and safety of our patients and families including where they wish to live the last days of their lives

This leads to discussion regarding the area that I have seen significant **inequities;** that of access to hospice facilities. Presently, Connecticut Hospice is able to provide a full spectrum of inpatient and outpatient care in the Branford area. The new regulations expand the ability for all hospice programs in Connecticut to provide this care in their communities without altering the structure that is established at Connecticut Hospice. Personally, my father in law died at the Branford facility. I will be forever grateful for the care that he received and the support that being able to place him in that facility gave our family. They predominantly lived in close proximity to Branford so access was close and easily negotiated.

That being said, the same access is not available in eastern and northeastern Connecticut. In my experience, access to this type of care is nearly impossible for our residents. Branford is 2 hours away

and driving that distance on unfamiliar roadways is not reasonable or safe. Families and friends who would like to visit are torn The four hour round trip severely impacts their ability to work and to provide the care needed to maintain their families They are forced to make difficult choices that include limited visits to their loved ones who are dying a distance away. For our terminally ill patients, having to be transferred out of our community further isolates them from the ones that are most important to them. This is a time when making these last memories with family and friends are essential to the patient's comfort and to the family and friends ability to cope through the illness and into bereavement. Family and friends of those dying should not have to make these difficult choices. They are already stressed.... Significantly stressed with their anticipated loss of a loved one.... But to lose the ability to spend time and to make forever memories should not be part of the equation. Transfer to Connecticut Hospice in Branford is not a compassionate option for our patients and families.

Our program has had to transfer patients from northeast Connecticut to hospice facilities in Massachusetts and Rhode Island. These facilities having inpatient levels of care with the specialized hospice focus were closer to our patient's homes. The closest facilities still require families to have to negotiate urban roadways and highways. Although closer, they are out of state and remain a distance from our community. This transfer also poses issues with some insurance carriers who may not have agreements with out of state organizations. Out of state transfer is not an option for our patients who have Connecticut Medicaid.

From a personal standpoint, were my mom to require hospice inpatient level of care, I could not consider sending her to Branford for this care. This transfer would mean that she would lose access to many of her senior citizen friends. Family members.... her sister, grandkids, her nieces and nephews would only be able to visit sporadically. At a time when she should be surrounded by love, she would find herself isolated and alone. Her true access to this level of care would not be possible in eastern Connecticut and our family would not have the choice as we did with my father in law. Is that fair when your life is truly limited and families are already stressed by their anticipated loss?

Another option is to provide this level of care in area nursing homes. We presently have contracts with area nursing homes to provide care. This is the option that is often chosen by our patients, not because that is truly where they choose to go but because those nursing homes are in our community and they, at the very least, will be able to have family and friends close. Although an option, it is not optimal for some at end of life. I will give an example of one person who was cared for by our program. This was a

younger woman. She was unable to stay at home due to lack of a caregiver 24 hours a day. Her husband had to work to maintain the family. In order to see her family on a daily basis, they made this decision. It was difficult for her, her family and even for our staff. The nursing home did an excellent job with her care. That was not the issue. The issue was that she was in a facility more designed for our elderly geriatric populations with chronic illnesses. There were limited facilities for overnight stays for the family or private homelike spaces for family to gather. Many nursing homes will not allow IV or subcutaneous means of administering symptom medications. A hospice facility, located in the local community would have provided the total package of hospice care.... the physical, emotional, social and spiritual care that is critical at end of life. She deserved this... her family deserved this. Our community deserves this option.

I personally don't believe that there will be hospice facilities popping up in all communities, however I do feel that this is a time for hospice organizations regionally to work together to establish hospice facilities with multi care levels that are much closer to where patients live, to their home communities and to their families. It is not about competition but about good quality care. These regulations would support greater access to excellent quality hospice care in Connecticut.

Speaking as a hospice professional and resident of eastern Connecticut and representing the issues of our communities, I strongly support H.B. No. 5499. I strongly urge you to support the proposed changes and become a champion for quality of end-of-life care to clients and their families throughout the state. The proposed regulations are not only about convenience, it is about opportunity and patient choice at the end of their life. The regulations are about the delivery of comprehensive hospice services that includes hospice facilities throughout our state.

Thank you for taking the time to consider my written testimony. Please feel free to contact me it you have questions.

Carol Emmerthal, MSN, RN
Director of Hospice and Palliative Care of Northeastern Connecticut
320 Pomfret Street
Putnam, CT 06260
860-928-0422
cemmerthal@daykimball org

Testimony of

Hospice Southeastern Connecticut

Before the Legislature's Public Health Committee

10:00 AM, Friday March 16, 2012

Room 1D, Legislative Office Building Hartford, Connecticut

My name is Naomi Nomizu, MD. I am the Medical Director for Hospice Southeastern Connecticut. I am submitting testimony in support of House Bill 5499 (Raised) An Act Concerning Regulations Relating to Hospice Care.

I am currently employed by WW Backus Hospital in Norwich, Ct as a hospitalist. Prior to my employment at Backus I was in private practice in New London and also a medical director in a skilled nursing facility and an attending physician in several others. It has come to my attention that one of the issues reported concerning the proposed regulations, Hospice Facility Regulations 19a-122b-1 to 19a-122b-14, is that there is not an "in house pharmacy." In southeastern CT the skilled nursing facilities do not have an "in house pharmacy" and that has not posed a problem. The patients have their own medications delivered directly to the facility and there is an emergency supply of medication on site.

Our proposed hospice facility would follow the same protocols. In addition there would be a contract with a local pharmacy available 24hr/day as well as an arrangement with our local hospitals to provide any emergency medications not available in the facility.

This is not an issue that should be of any concern.

I strongly urge you to support HB 5499. These regulations are desperately needed to allow terminally ill patients access to all levels of hospice care in their communities.

Thank you for taking the time to read my testimony. Please feel free to contact me if you have any questions at nanomizu@wwbh.org.

Testimony of

Hospice Southeastern Connecticut

Before the Legislature's Public Health Committee

10:00 AM, Friday March 16, 2012

Room 1D, Legislative Office Building Hartford, Connecticut

My name is Vinessa Job. I am the Intake Nurse for Hospice Southeastern Connecticut. I am submitting testimony in support of House Bill 5499 (Raised) An Act Concerning Regulations Relating to Hospice Care .

Please support HB 5499 which requires the Department of Public Health to adopt the Inpatient Hospice Regulations 19a-122b-1 to 19a-122b-14.

These regulations are about the dying patients and families in every corner of Connecticut having access to the full range of hospice care services.

Patients and families in every corner of Connecticut deserve access to an inpatient hospice model that suits their communities.

Currently, the full continuum of hospice care is not readily accessible to all our state residents. This care includes care in the home, care in the hospital, care in a skilled nursing facility and care in a hospice residence or facility. Currently Connecticut ranks last or 51st (including Washington DC) in average length of stay for Medicare hospice days (National average is 71, CT is 49).

The State of CT ranks last in the country in average length of stay for hospice patients resulting in more costly end of life care in acute care settings.
Of the 5150 hospice providers in the US, one in five also operates an inpatient facility. CT has only 1 inpatient facility licensed under regulations from 35 years ago.

A Hospice Residence would provide a place for quality end of life care when home care, hospital care or skilled nursing home care are not appropriate or possible. The 12 private rooms would have access to the outside garden, accommodations for family to visit and stay overnight with their loved one. The Residence would provide a relaxed atmosphere where you can find a cup of tea in the kitchen, sit in the great room to read, find a quiet place for reflection in the library, take time to find solace in the non-denominational chapel, gather with family in the dining room.

These regulations are supported by 28 of the 29 hospice providers in the state. We need your support to help us provide this care to CT residents. Please support Department of Public Health in moving the regulations forward to the Regulations Review committee.

Thank you for taking the time to consider my testimony. Please feel free to contact me if you have any questions at 860.848.5699 or vjob@hospicesect.org

Testimony of

Hospice Southeastern Connecticut

Before the Legislature's Public Health Committee

10:00 AM, Friday March 16, 2012

Room 1D, Legislative Office Building Hartford, Connecticut

My name is Dawn McDermott, I am a registered nurse with Hospice Southeastern CT. I am submitting testimony in support of House Bill 5499 (Raised) An Act Concerning Regulations Relating to Hospice Care.

Currently in Connecticut there are only 2 inpatient facilities licensed under the current regulations developed 35 years ago.

When care to my terminally ill hospice patients cannot be delivered in the home due to symptoms difficult to control there is not a choice to remain in the community and receive care in a homelike environment provided by qualified hospice staff. If they go into the hospital, they are in an acute care setting, usually not in a private room and amidst the hustle and bustle that goes along with the hospital setting. If we can find a bed in a nursing home we cannot guarantee a private room or the hospice expertise of the staff. If they go to CT Hospice their families have to travel 30-50 miles one way to be with their loved one and they are not able to remain in the room with them. It is heart breaking to see my patient separated from his wife during the last days of his life because she is unable to drive the distance to be with her husband.

Our proposed hospice residence would have private rooms with available space and furniture to allow families to remain with the patient 24/hr per day. There would be a chapel, a library, counseling rooms, a dining room for families, access to the outside, overlooking a garden, from each room. But most important my patient could remain in his community convenient to family and friends during the last days of his life.

I strongly urge you to support HB 5499 to allow access to all levels of hospice services both in the home and in a hospice facility to my patients within their community.

Thank you for taking the time to consider my testimony. Please feel free to contact me with any questions dmcdermott@hospicesect.org.

Testimony of

Hospice Southeastern Connecticut

Before the Legislature's Public Health Committee

10:00 AM, Friday March 16, 2012

Room 1D, Legislative Office Building Hartford, Connecticut

My name is Kathy Franco RN . I am the hospital liaison for Backus Hospital for Hospice Southeastern Connecticut. I am submitting testimony in support of House Bill 5499 (Raised) An Act Concerning Regulations Relating to Hospice Care .

As a Hospice hospital liaison ,it saddens me when I have to send someone over 50miles away to a inpatient Hospice unit. This is so very stressful for the patient and the love ones at the most difficult time of their lives. Please pass the regulations so we can care for our patients in Southeastern Connecticut. Patient s and families in every corner of Connecticut deserve to have access to an inpatient hospice service in their own area. Please support HB 5499 which requires the Department of Public Health to adopt the Inpatient Hospice Regulations 19a-122b-1 to 19a-122b-14.

Thank you for taking the time to consider my testimony Please feel free to contact me if you have any questions at 860.848.5699 or kfranco@hospicesect.org.

Testimony of

Hospice Southeastern Connecticut

Before the Legislature's Public Health Committee

10:00 AM, Friday March 16, 2012

Room 1D, Legislative Office Building Hartford, Connecticut

My name is Donna Simpson. I am the Community Liaison for Hospice Southeastern Connecticut. I am submitting testimony in support of House Bill 5499 (Raised) An Act Concerning Regulations Relating to Hospice Care.

The current regulations guiding this work are 35 years old. Healthcare has changed and the time is right for the regulations to do the same.

The proposed regulations are supported by 28 of the 29 Hospice providers in Connecticut. I think that speaks volumes on the need for small hospice facilities serving the various corners of the state when other options for care are not available or appropriate.

The full continuum of service includes providing quality end of life care for people where they live or in an appropriate option. This would include hospice care being provided in the home, hospital, skilled nursing facility, or in a hospice facility.

Passing these regulations will allow this full continuum of hospice care to be available more conveniently throughout the state.

Thank you for your consideration.

Donna Simpson

New London, CT

Thank you for taking the time to consider my testimony. Please feel free to contact me if you have any questions at 860.848.5699 or (email address)

Testimony of

Hospice Southeastern Connecticut

Before the Legislature's Public Health Committee

10:00 AM, Friday March 16, 2012

Room 1D, Legislative Office Building Hartford, Connecticut

My name is Bernice LaRochelle. I am in Billing Services for Hospice Southeastern Connecticut. I am submitting testimony in support of House Bill 5499 (Raised) An Act Concerning Regulations Relating to Hospice Care.

- Of the 5150 hospice providers in the US, one in five also operates an inpatient facility. CT has only 1 inpatient facility licensed under regulations from 35 years ago.

- A Hospice Residence would provide a place for quality end of life care when home care, hospital care or skilled nursing home care are not appropriate or possible. The 12 private rooms would have access to the outside garden, accommodations for family to visit and stay overnight with their loved one. The Residence would provide a relaxed atmosphere where you can find a cup of tea in the kitchen, sit in the great room to read, find a quiet place for reflection in the library, take time to find solace in the non-denominational chapel, gather with family in the dining room.

- Please support HB 5499 which requires the Department of Public Health to adopt the Inpatient Hospice Regulations 19a-122b-1 to 19a-122b-14.

Thank you for taking the time to consider my testimony. Please feel free to contact me if you have any questions at 860-848-5699 or blarochelle@hospicesect org.

Testimony of

Hospice Southeastern Connecticut

Before the Legislature's Public Health Committee

10:00 AM, Friday March 16, 2012

Room 1D, Legislative Office Building Hartford, Connecticut

My name is Ellen Giggi. I am a secretary and receptionist for Hospice Southeastern Connecticut, in Norwich. **I am submitting testimony in support of House Bill 5499 (Raised) An Act Concerning Regulations Relating to Hospice Care**.

I'm asking if you would please support HB 5499 which requires the Department of Public Health to adopt the **Inpatient Hospice Regulations 19a-122b-1 to 19a-122b-14**. These regulations are about the dying patients and families in every corner of Connecticut having access to the full range of hospice care services. These contemporized regulations preserve the hospital standard set in Connecticut 30 years ago and establish a regulatory environment that allows for other models of inpatient hospice care that suit their respective communities. Patients and families in every corner of Connecticut deserve access to an inpatient hospice model that suits their communities. **These regulations are supported by 28 of the 29 hospice providers in the state.**

Connecticut has only 1 inpatient facility licensed under regulations from **35 years ago**. People in our community are unhappy that the only residence available in Connecticut is in Branford. It's just too far away for visitation, so they must settle for other care options. At the present moment, Connecticut ranks last, or 51st (including Washington DC) in average length of stay for Medicare hospice days (National average is 71, CT is 49). Of the 5150 hospice providers in the United States today, one in five also operates an inpatient facility.

We need your support to help us provide this care option to more Connecticut residents. Please support the Department of Public Health in moving the regulations forward to the Regulations Review committee.

Thank you for taking the time to consider my testimony. Please feel free to contact me if you have any questions at 860-848-5699 or egiggi@hospicesect.org

Testimony of

Hospice Southeastern Connecticut

Before the Legislature's Public Health Committee

10:00 AM, Friday March 16, 2012

Room 1D, Legislative Office Building Hartford, Connecticut

My name is Antonio Okosky. I am a Bereavement Counselor for Hospice Southeastern Connecticut. I **am submitting testimony in support of House Bill 5499 (Raised) An Act Concerning Regulations Relating to Hospice Care**.

I believe that by supporting this bill we are supporting the state's ability to provide a form of care that currently being underutilized and neglected At this time the full continuum of hospice care is not readily accessible to all our state residents. This care includes care in the home, care in the hospital, care in a skilled nursing facility, and care in a hospice residence or facility. By affirming this bill we would be able to accomplish something that would begin to bring us up to the standards of other states. Of the 5150 hospice providers in the US, one in five also operates an inpatient facility.

CT has only 1 inpatient facility licensed under regulations from 35 years ago. Patients and families in every corner of Connecticut deserve access to an inpatient hospice model that suits their communities. A Hospice Residence would provide a place for quality end of life care when home care, hospital care or skilled nursing home care are not appropriate or possible. The 12 private rooms would have access to the outside garden, accommodations for family to visit and stay overnight with their loved one. With The Residence would provide a relaxed atmosphere where you can find a cup of tea in the kitchen, sit in the great room to read, find a quiet place for reflection in the library, take time to find solace in the non-denominational chapel, gather with family in the dining room. In addition to these incredible amenities the residence would offer a forum for providing bereavement support in a way that has not been possible.

We need your support to help us provide this care to CT residents. Please support Department of Public Health in moving the regulations forward to the Regulations Review committee. Thank you for taking the time to consider my testimony. Please feel free to contact me if you have any questions at 860.848.5699 or aokosky@hospicesect.org

Thank you for taking the time to consider my testimony. Please feel free to contact me if you have any questions at 860.848.5699 or (email address)

Testimony of

Hospice Southeastern Connecticut

Before the Legislature's Public Health Committee

10:00 AM, Friday March 16, 2012

Room 1D, Legislative Office Building Hartford, Connecticut

My name is Christine Johnson . I am Volunteer Coordinator for Hospice Southeastern Connecticut. I am submitting testimony in support of House Bill 5499 (Raised) An Act Concerning Regulations Relating to Hospice Care .

A Hospice Residence would provide a place for quality end of life care when home care, hospital care or skilled nursing home care are not appropriate or possible. The 12 private rooms would have access to the outside garden, accommodations for family to visit and stay overnight with their loved one. The Residence would provide a relaxed atmosphere where you can find a cup of tea in the kitchen, sit in the great room to read, find a quiet place for reflection in the library, take time to find solace in the non-denominational chapel, gather with family in the dining room.

We need your support to help us provide this care to CT residents. Please support Department of Public Health in moving the regulations forward to the Regulations Review committee.

Thank you for taking the time to consider my testimony. Please feel free to contact me if you have any questions at 860.848.5699 or (cjohnson@hospicesect.org)

TESTIMONY BILL #5499 3/16/2012

Dear Madame Chair and Distinguished Committee Members:

As the Director of The Connecticut Hospice Arts Program for the last 15 years I am speaking to urge you not to replace the hospice regulations formerly under 19-13-D4b with the proposed bill, #5499.

Under the proposed bill arts services would not be required in an in-patient hospice setting. So that you may understand just what would be lost for many patients and families if this bill is implemented, I will describe the scope of our work. Our arts program is multi-faceted, offering music, music therapy, visual arts, art therapy, crafts, literary arts such as poetry and creative writing, life review, dance and movement therapy, and concerts and exhibits from community artists and performers. We are staffed by a full-time director, 7 paid staff, including board certified clinical therapists, and 40 volunteers. We offer services to patients and families 365 days a year, and we make approximately 6000 arts visits per year. We function as an integral member of the Interdisciplinary Team, consulting daily with other clinical professionals in all disciplines. Our mission is to provide a variety of arts experiences for hospice patients and their families, according to their individual wishes and interests. We strive to enable patients to live life fully and to add to the quality of life as long as life is lived. We facilitate expression and thereby afford dignity to the dying and their families, and we complement medical and other interventions by providing interventions which ease physical symptoms and nurture the spirit, using a variety of media.

Arts services have been mandated in any free-standing in-patient hospice setting in Connecticut since 1979. This has been so because of the wide range of physical, spiritual and emotional benefits that arts interventions have been proven to

provide. Experienced providers of *true* hospice care understand that quality of life, dignity, and patient/family control are more than just catch-phrases promised on a shiny new brochure.

These fundamental tenets of hospice care are all addressed in surprising and profound ways by the arts:

- By facilitating creativity and choice, the arts have the power to provide autonomy and control for patients and families at a time when very few aspects of their lives present are under their control. This often allows a dying person to transcend seeming chaos or despair.

- The arts can provide a conduit for emotion, and a language in which to express that emotion. When patients and families find it too painful to talk about the inevitable, the arts can become a catalyst for those discussions by providing a metaphorical framework, such as a painting, poem or song, and thereby ease understanding or acceptance of the complexity of the dying process. Unfinished business can be facilitated – for example, a memory album made by a 40 year old patient to leave for her estranged daughter.

- Every patient and family member is an individual with a unique life story, and the arts offer ideal opportunity for life review, an almost universal need at end of life. This holistic approach views every patient as no longer merely a person with a list of symptoms, on the receiving end of care, passive and not productive, but as a *whole* person, who can produce and create, express themselves actively. Through arts involvement a hospice patient can affirm him or her self and take pride in accomplishment. Some patients have asked to learn something they've never had the chance or the

time to pursue before, like playing the guitar or painting with watercolor. As the late Dr. Gene Cohen wrote: "There is no denying the problems that accompany aging. But what has been universally denied is the potential. The ultimate expression of potential is creativity."

- The arts can regenerate the body, mind and spirit. Enjoying the arts, either actively or passively, can bring tranquility and peace, a connection to the beautiful in life and a connection to nature.

- Involvement in the arts fosters rapport and trust; stimulation, relief of boredom, fear or anger; diversion, recreation and play; emotional support, and assistance in coping.

- Significantly, there are many ways in which arts services can assist with relief of physical symptoms. When patients are focused and relaxing, for instance with music therapy, they often need fewer medications for pain, anxiety, agitation, shortness of breath, nausea and so on. Using fewer pharmacological interventions is not only cost-effective, but also, more importantly, allows patients to remain free of the associated side effects and more energetic and interactive, able to have quality time with their families.

More and more health care organizations across the country are introducing art and music therapies as their advantages become more widely known. In contrast, the new regulations make arts therapies an afterthought, barely mentioned as a remote ***option*** under complementary therapies. They would focus on a "deficit" approach that stresses losses and decline instead of focusing on an "asset" approach that recognizes the strengths, achievements and potential of later life.

The Department of Public Health's definition of palliative care is "patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and the facilitation of patient autonomy, access to information, and choice".

And yet the proposed bill strips the integral services that make this possible, that make true hospice care what it is, leaving instead a bare-bones, diluted version. The proposed regulations mention "quality care that meets current professional standards" but leave nebulous definitions of just what that means. I propose it should mean the professional standards that have brought hospice care in Connecticut to the high level it enjoys, care which has evolved with fully enlightened experience of what patients and families truly need, not a return to the dark ages. I urge you to reject this proposal, as it would leave patients and families without the very standards of hospice care it purports to provide.

Katherine Blossom
Arts Director
The Connecticut Hospice

TESTIMONY BILL #5499 3/16/2012

Dear Madame Chair and Distinguished Committee Members:

My name is Anne Nugent. I have a BS in Nursing, MA in Gerontology and an MBA in Health Care Administration. I have been a registered nurse for 35 years-30 of which were in a large teaching hospital. I am currently the Director of Inpatient Nursing at Connecticut Hospice.

As the Director of Inpatient Nursing, I am here to hopefully elucidate the mission of our organization and clarify some of the concerns we have regarding the passage of this proposed legislation.

Since our inception, Ct. Hospice has had the sole purpose of providing care and comfort to those patients who, sadly, find themselves at the end of life's journey. Many times their priorities change at this critical juncture in their lives and their hopes and dreams change. Some wish to continue to battle a disease that is ravaging them and some want to be made as comfortable as possible so that they may enjoy whatever amount of time is left for them with their families and friends. At hospice, we attempt to meet the patient and family wherever they are and work with them as a unit to provide a collaborative plan of care that meets these needs. This has always been our goal-patient driven, compassionate care.

Ct. Hospice was the first freestanding hospice in the U.S., and as such, it adhered to regulations that were specific and whose aim was the comfort and safety of patients served. 19:13d4b was landmark legislation which set the bar very high for care and provision. This is how it should be as the dying patient is one of the most vulnerable patients we may ever serve. Patients, under this regulation would be entitled to rigorous staffing requirements. 1 RN to 6 patients and the provision of virtually every service that might be needed by a patient who was facing the most difficult time in their life. Having had the opportunity to observe many patients and families at this difficult time, I realize that these regulations were necessary to maintain the dignity of the people involved. To do less would only diminish the inherent dignity that each and every patient and family deserves.

I am very concerned with the passage of any legislation that has the potential to diminish the quality and quantity of services provided to a very vulnerable patient population. We at Connecticut Hospice, continually strive to provide excellence in clinical practice and continually challenge ourselves to enhance the skills of our health care professionals to ensure that state of the art treatment of hospice and palliative care patients will always be the norm and not the exception.

The patients we serve require immediate crisis intervention with no margin for error: the proposed regulations, in my opinion, will not accomplish this. We have never felt that the word "sufficient" has any place in our organization. The new regulations use this word very liberally-sufficient staffing, sufficient access to services within a sufficient amount of time, etc. The goal of these changes appears to be very noble, enhanced areas of coverage and increased accessibility of hospice care. My

question is at what cost? Connecticut Hospice already serves most of the state with our homecare and inpatient services while maintaining the highest level of care.

In conclusion, I am asking you to re-consider adopting the proposed legislation and avoid the creation of two levels of hospice care. We will continue to provide the best possible care to the most deserving people who are facing the biggest challenge of their lives and are unable to speak for themselves. Sadly, there will never be a shortage of dying patients but there will be an end of an era if Connecticut Hospice is forced to change its level of care by competition satisfied to provide "sufficiency" versus excellence.

Thank you for the opportunity to voice my concerns on this matter.

3/16/2012 Testimony James A. Prota RPh.

Thank you for the opportunity to speak today on behalf of The Connecticut Hospice. I am James Prota, Director of Pharmacy. I am here today in opposition to the raised Bill No 5499. I am specifically opposed to the making of on-site pharmacy services optional for Hospices that provide direct inpatient care. I have previously testified before the DPH. Under the Condition's of participation, It states that the staffing must reflect the volume of patients , their acuity and the level of intensity of services needed to ensure that the plan of care outcomes are achieved. In order to fulfill these conditions the sites providing acute care and receiving reimbursement for high acuity services must have the pharmacist's presence on-site. I speak from two perspectives, firstly as an employee of Connecticut Hospice for the past five years and secondly as a family member who has lost a loved one and has needed hospice care.

I direct a small department consisting of both technicians and pharmacists. I am amazed by the notion of removing these on-site pharmacy services from the hospice model. Present regulations enforced by the DPH and standards set by the Joint Commission are patient safety focused. To quote the the Joint commission medication management Chapter: "Medication management is an important component in the Palliative, symptomatic and curative treatment of many diseases and conditions. However, medications are also capable of causing great harm if the incorrect dose or medication is inadvertently administered to a patient. To eliminate any potential harm that could be caused by medications, hospitals need to develop an effective and safe medication management system". The chapter goes on in detail to describe planning, selection and procurement, storage, ordering, Preparing and dispensing, administration, monitoring and evaluation. Additionally, today drug shortages are causing disruptions in therapy for many patients. These regulations and standards are quite complicated and quite detailed, all in the name of patient safety. It seems contrary to the mission of the Department of Health and the Joint Commission to want to remove or make optional the onsite presence of the Pharmacy for facilities providing acute end of life care.

At Connecticut Hospice the pharmacist responsibility goes deeper than this. We are an equal and a core member of the interdisciplinary team. We round daily with nursing and medicine as a scheduled meeting, but additionally meet informally often and as necessary throughout the day. The pharmacists are visible to staff members, patients and families. We reconcile medication orders upon patient admission and we also reconcile and educate patients upon discharge. We are following the trail of medications from start to finish. Medication reconciliation is an area where health systems struggle to

comply, the accurate transfer of medication orders from one institution to another, a difficult task, a much more difficult and unsafe task without pharmacy services available on site.

The input of the interdisciplinary team cannot be overstated, a team combined strength developing the most effective treatment plan to achieve the goal of terminal comfort. A common misconception of Hospice care is that patients receive morphine and the dosage is adjusted until the patient slides off to sleep. You desire for the process to be that smooth. It can be a much more complicated process that requires the expertise and assessment of a team experienced in Pain management and in all aspects of palliative care and end of life symptom management, where patient change can take place very quickly. You only have one opportunity to get the plan of care right. The need must be to have the on-site presence of pharmacy services, to tend to the changing patient condition and medication needs, to rapidly respond and provide continuous pain management, or to facilitate conversions between different opioids, to recommend dosages or monitor for drug interactions.

I have experienced Hospice personally, my father needed Hospice care approximately 2 years ago. I witnessed his care both in a nursing home and in an acute care hospital. Neither setting could provide the comfort care that Connecticut Hospice did. These other sites did not have the palliative care mindset to offer comfort care, the use of medications to relieve his anxiety, the use of opioids to ease his labored breathing, they did not have the interdisciplinary team including pharmacy to manage the medications throughout the course of care to ensure that all aspects of my father's comfort were met. There was no other Hospice model that I would have wanted for him.

Removing on-site pharmacy services from the hospice regulations and enacting this Bill will be a setback for the profession of pharmacy and clinical pharmacy practice, a setback for the people of Connecticut who have had the best end of life care available, and most importantly a setback for a patient's safety at the end of life. Please include specific requirements for on-site pharmacy services where acute end of life care is being provided and reimbursement warrants acute clinical services. With regard to the staffing condition of participation, Pharmacists will ensure that plan of care outcomes are achieved and negative outcomes avoided. Thank you.

TESTIMONY BILL #5499 3/16/2012

Dear Madame Chair and Distinguished Committee Members:

I am here to testify against Raised Bill No. 5499.

I have been a hospice social worker at The Connecticut Hospice for 8 years, and am the current Director of Social Work.

It is my professional assertion that most of the patients and families receiving care at Connecticut Hospice's acute care hospice hospital are in a state of crisis during this delicate end-of-life process. And studies of human behavior tell us that, during crisis, coping does NOT improve – indeed, patients and families DECOMPENSATE in the face of crisis. Thus, the social worker (and indeed the entire acute care hospice team) needs to engage in: comprehensive assessment; supportive counseling; crisis intervention; education; and connection to community resources in order to ameliorate this crisis. Every one of our patients and families is assessed on admission in order to circumvent, to the extent possible, a crisis, and to provide the family with stronger coping mechanisms. This level of acute support and responsiveness to a crisis does not seem possible under the proposed legislation, which seems to standardize diluted levels of interdisciplinary team availability.

One of the primary tenets of Hospice philosophy is to treat the patient and the family as a single unit of care, utilizing a holistic approach to health and well-being. Our patients and families frequently tell stories of feeling as if they are not treated as human beings, but simply as "cases" in many other health care settings, and that they value the humanistic, comprehensive approach that is offered at our acute care hospice hospital. Thus, the social work role (and indeed the entire acute care hospice team) is to assess the needs of the patient and family using a humanistic systems approach. The counseling and education provided by the entire team improves their overall coping. I would argue that this level of care cannot be provided in the diluted form that seems to be defined in the proposed legislation.

The hospice plan of care is vast and all-encompassing. Figuratively, everything that happens "out there in the world" eventually funnels through the front door of an acute hospice setting. Thus, the acute care hospice team is required to have expertise not only in palliative approaches to physical symptoms, but also in mental health, suicidality and other high risk behaviors, substance abuse, elder abuse, child abuse, broken family relations and communication, financial stressors and lack of resources, legal matters, anticipatory grief, and helping patients and families complete "unfinished business." And during this historic time in our country when resources are decreasing, financial stressors are increasing, and the inherent psychosocial stressors are increasing, the need for the level of care that an acute care hospice hospital provides has never been higher.

Our patients and families don't get a "do over!" There is no "second chance." Death

happens only once for them. And for most of our patients and families, the timeframe in which all of this occurs is quite brief. We simply DO NOT have the luxury of time. The interventions that are needed from the acute care hospice team to support patients and families through the acute end-of-life phases require immediate action. Without adequate levels of an acute care hospice team present to take immediate action, it is simply not possible to meet the needs of patients and families in a timely enough manner. And let me say again...hospice patients and families do not get a "do over!"

Thus, I strongly urge you to reject Raised Bill No. 5499, as I believe that this bill represents a diluted definition of in-patient hospice care in Connecticut, and will do a grave disservice to future hospice patients and families in this state.

Respectfully,
Ralph Papp, LCSW
Director of Social Work
The Connecticut Hospice

Testimony – Lynne Waters, CNA

HB5499

I Am Part of a Team that Wouldn't Exist Anymore

Thank you for allowing me the opportunity to verbally show you how the Branford Hospice is unique and specialized in caring for the terminal, dying and actively dying 54 patients. I chose Branford hospice for its concise program for end of life care. I am just a baby to some, employed there almost 11 years, while some have been frontline for 30. As a CNA, I am front line although at our hospice, the nurse and I are a team. The nurse and I do care rounds together and even take turns sitting with the patients for all kinds of reasons, doing anything to make their journey less stressful. We order briefs (diapers) in different sizes, because no one size fits all, as no one facility is right for everyone. I am at Branford Hospice because the way we care for patients is the right way and the compassionate way.

If a terminal patient has anxiety from their disease, a dying patient has gone into respiratory distress or an actively dying patient is draining or bleeding out—with your new proposed regulations, who do I go to if there's only one (1) nurse in the building with 54 patients? Presently, when a patient needs a change in medication, our on site resources allow us to respond quickly, getting the patient calmer, in less pain and safe.

As a Branford Hospice CNA, I am specialized, I have been trained by our nurses to assess the changes our patients may go through. Dying is so scary, painful and for the family ... sad. Our approach is to treat the whole family with constant on-going teaching so it is understood what is happening and why. At the end, they most likely will cry but knowing their loved one passed pain free as possible and with dignity is a comforting feeling. Just as we have life choices, shouldn't one have a choice in where and how they want to end life's journey. We all will be taking the same journey at some point, but with no choice. Will our journey end with the best possible care or left to be found deceased for lack of on-site support services (nurses, doctors, pharmacy, social workers, etc.)

Now committee members, let me provide you with a very recent visual. My mother, an elected official and tireless political activist, Bernice Bowman, passed away in February. Now she had always said in no uncertain terms "no" to Hospice. I was at home when she called saying she just didn't feel well. The hospice home care nurse went out to her home and I received another call. My mother wanted to be admitted to hospice inpatient. I was with her as she signed herself in. She was greeted by a CNA, a nurse and the doctor. After the initial assessment, the doctor came over to me, concerned that her symptoms didn't match her diagnosis of stomach cancer. He contacted her outside doctors, came back and rechecked my mother; her heart had jumped out of rhythm. She had a choice to make, options – go to the hospital, be placed on machinery in the hopes of correcting her heart (now in all reality, the doctor told me that because of all the health problems and weakness, he didn't think that option would in all likelihood, extend her life.) or stay at hospice for comfort care. Her choice, her

decision, she opted to stay at Branford Hospice. While she was able, she told family, friends, hospice staff and everyone that "she was in the right place."

In this era of "Wal-Mart's", Branford Hospice may be the "mom & pop"; it certainly is the FIRST hospice ... setting the standards for the care of terminal, dying and actively dying patients. I am a CNA, trained to help patients and families go through the hard process of dying and I am committed to that end. There is no way to do that humanely under the new regulations. Do you or your family have a choice about how you or their journey will end?

Reverend Charles Woody

Testimony Bill #5499

3/16/12

Dear Madame Chair and Distinguished Committee Members:

I am Rev. Charles H. Woody and hold a Master of Divinity degree, have completed five units of CPE, have been an Ordained Elder in the African Methodist Episcopal Zion Church since 1975, a pastor for 38 years and a chaplain for 14 years.

I am here to testify against Bill #5499. Like other professional practitioners such as a pharmacist who is licensed, you need to have spiritual people who have formal pastoral education. These spiritual practitioners need more than an interest in faith, they need formal education. The proposed regulations do not require formal pastoral education. Sure, they must be trained as to the policies and practices of the facility, but they must be sensitive. They should not be just your "fly by night" person; they must be persons who are committed to the spiritual well being of the patient. Think of a diverse group of people. . . all backgrounds; all walks of life; all with different mindsets of what it is that spiritual care should be; while with all the best intention they may carry their private spiritual agenda into the patient family interaction. At Connecticut Hospice we have a broad base of people that walk through the door. That's why it is so difficult to get spiritual care volunteers. There are people that come in here that want to preach, want to proselytize people and have all kinds of ideas of what spiritual care should be. That's what you're going to get out there under these new regulations; all kinds of spiritual input that may not be sensitive. This is because the educational requirements are absent. Trained people have education and experience which render them able to be sensitive. This enables them to help patient and families to get from several different ideas to a single concept so that their focus is the same. We don't want to take away their diversity of beliefs because that's a plus for us that everyone is a little different; but what is significant is the fact that we want to foster the time spent with the patient and family who is going through a difficult time in their life in a supportive and appropriate manner and not risk injecting an untrained person's spiritual belief into that situation.

Clinical Pastoral Education provides the foundation to work with the patient and family you have in front of you. And the confidence to know who you are as a caretaker will not be threatened by being involved with people of other beliefs that are different from yours. Clinical experience helps you because you are exposed to people of all different faiths. Then to learn by reflection what did or did not take place thus growing in the End of Life Ministry.

The difference between what they have proposed and what we do is dramatic. Within 20 minutes after we are contacted some response will take place; that means in real time when you have a dying patient, you don't know when their last breath is going to be

so it's not that you have time to "beat around the bush," you have to do something that's going to be in this patient/family's best interest so if the family is looking for religious rites of a priest then you're on the phone trying to connect with someone with whom you already have contracted with to be available to help this family at this time. Don't forget, when someone is admitted inpatient, the patient and family have immediate support when they walk through the door. It is not some time later. We take care of their religious needs when they come in the door; there's an affirmative solicitation of what needs they might have. Faith beliefs are especially important to many patients and families. These needs will probably not be timely addressed as outlined in the new regulations.

For example, we have a process/policy of getting a priest in for religious rites. Who knows what the new regulations/hospice would have because they're not obligated to have an ordained pastor among their professionals, or someone who has had Clinical Pastoral Education. One thing lost under the new regulations will be the professional rapport; so when one clergy contact another clergy, there is a certain level of respect. When a lay person calls, it could be because the clergy who you are speaking with is going to say, "Have you assessed the situation, how serious is it, is it something that you feel can wait?" We have doctors, nurses, and pharmacists available to help understand the urgency of care. With the medical person's assistance, you kind of know who won't be here today and who will be here tomorrow. You have something to judge and to go by, but if you have no clinical experience, how do you know and if you have an agenda, your agenda is going to come first if you have not set up any kind of situations or scenarios that say that say if I get a call. The new regulations just simply say that you have to be a counselor and that can be called on to offer support. And in the old regulation, you have to be ordained and have to have five years of clinical experience. Patients and families at the end of life deserve better spiritual intervention than the new regulations requires.

Public Health Committee Testimony
HB 5499

Who's holding your ladder when it comes to your journey at Connecticut Hospice? We support families, friends and loved ones as they venture through the journey.
A death journey involves more than the individual, but the whole family. It is a journey of trust between numerous individuals and it is vital that the journey be led in a loving and helpful manner.

Rev. Warren Godbolt

TESTIMONY BEFORE PUBLIC HEALTH COMMITTEE H.B. 5499
AN ACT CONCERNING REGULATIONS RELATING TO HOSPICE CARE

MARCH 16, 2012

Members of the Public Health Committee my name is Carol Mahier and I am the Director of Hospice Southeastern CT for the past 24 years, former board member of CT Association for Home Care & Hospice (CAHCH), former chair of the CAHCH Hospice & Palliative Care Committee.

I am submitting testimony in support of H.B.5499 with revisions as proposed below.

I also strongly support the passing and implementation of revisions to hospice facility regulations (Section 19a-122b-1 to 19a122b-14) as developed by DPH in collaboration with 28 of the 29 licensed and certified hospice programs in Connecticut.

These hospice facility revisions must be passed as soon as possible since access to hospice residence care for terminally ill patients is compromised due to distance necessary to travel to the one hospice residence in CT. Patients who entrust the end of life time to a hospice program deserve the choice to have care across all settings available to them in their own community. If hospice care can no longer be provide in their own home, care in a hospital under a contacted agreement with the hospice program is not necessary and care in a skilled nursing facility (again under a contract with the hospice program) is not acceptable, then the choice of care in a hospice residence must be available. A hospice residence is a place where the dying person is in a private room, family may visit and stay overnight with their loved one, highly skilled professional hospice care givers provide direct care, solace can be found in the chapel, private time in the library or a cup of tea in the dining area. A hospice residence must be close to where loved ones live; traveling to Branford from anywhere in the state to access that residence care takes valuable time away from being with a loved one. Families in Connecticut deserve access in their own community to this type of care

I suggest Revisions for H.B.5499section (a) after "pursuant to 42 USC 1395x" (line 6) :
Shall be authorized to operate a hospice facility, including a hospice residence, for the purpose of providing hospice services for terminally ill patients who are in need of hospice home care or hospice inpatient services. The hospice facility including a hospice residence , must be able to provide the following levels of hospice care: routine, general inpatient , continuous or respite.

Resuming in the H.B. 5499 with the sentence (line 11)"The residence shall provide a homelike environment..."

There can be only one focus here and that is to provide access to the continuum of quality end of life hospice care for every person in our state. The proposed regulations have been written mirroring the federal Medicare standards and provide for quality end of life care. The proposed regulations are supported by all but one of the Medicare certified hospice programs in CT; all of whom are licensed, certified with many, many years of providing quality care to thousands of our neighbors. All of whom have NO desire WHATSOEVER to in any way diminish or alter the quality care we have been and are committed to providing. We seek access and advocate for the neighbors in our communities to have access to care in a hospice residence.
The concerns brought forth by opponents to the revised regulations are not valid. None of us would tolerate such poor quality guidelines because the care is about what is the BEST for the patient.

Concerns regarding no pharmacy on site in the proposed hospices regulations are not valid. With current medication delivery and access even in people's homes to "comfort packs "that include the medications necessary to treat untoward symptoms and guidelines for administration, medications are not an issue. Of the over 200 skilled nursing homes in CT there are only 2 who have their own pharmacy. Patient's medications are delivered and stored in the residence along with emergency medications to treat multiple situations.
The concern of not having a medical director on site 24/7 is not a quality issue. Skilled hospice nurses who are providing direct patient care have expertise in accurately assessing and treating a myriad of symptoms and are in constant communication with the physician. These clinicians are highly trained and used to anticipating the issues faced by those at the end of life. Palliative care and excellent symptom management are cornerstones of their practice.

Thank you to this Committee for advocating for access and to the Department of Public Health for doing the same. The citizens of our state are counting on us.

Should you have any questions please contact me,

Carol L. Mahier RN MSN CHPCA
Executive Director, Hospice Southeastern CT

P. 860.848.5688 · F. 860.848.6898 · HOSPICESECT ORG

TESTIMONY

BEFORE THE DEPARTMENT OF PUBLIC HEALTH

REGARDING:

Revised Hospice Facility Regulations

HB5499

Friday March 16, 2012

Dr. Mullen and Members of the Department of Public Health. I am **Carolyn Wolfe, MSW, Volunteer Director and social worker** for Regional Hospice and Home Care of Western Connecticut. I have been privileged to work with Regional Hospice and Home Care for nearly 5 years, and can attest from experience how much Western Connecticut could benefit from revised hospice facility regulations.

Recently, I worked with a woman named Mary. Mary was in her late 80s, had end stage lung disease, but was alert, oriented and incredibly self-directed in her plan of care. She had lived alone since she was widowed 20 years earlier, and was fiercely independent – something she prided herself on. Mary was terrified of what would happen to her when she was no longer able to live independently. She had strained relations with her adult children, and vowed she would never burden them with moving in with them or to have them in with her. Additionally, past negative experiences with live in help had her incredibly anxious about the idea of someone living in her home.

Mary and I talked for months about her developing plan of care. She talked openly about wishing there was a facility, nearby where her grandchildren could visit, where she could maintain her privacy in her own room, and where she was not reliant on her family to provide her care. She did not want an institutional setting like a nursing home; she needed home-like atmosphere, quality staff whom she trusted, and expert symptom management like she was already receiving at home.

In the end, Mary agreed to a private live in caregiver in her home. Unfortunately, the anxiety of this arrangement exacerbated her illness, and heightened the existing strain she and her adult children already had. Mary ended up going to the hospital in a crisis, and died, alone, contrary to all of her hopes and plans. Had there been an inpatient hospice facility in the greater Danbury area, Mary could have continued to direct her own plan of care with the Regional Hospice team whom she had grown to trust, and continued in a home-like environment where her family could visit her without taking on the direct caregiving role.

As a hospice worker, I often try to think about how I would manage should it be my mother, my father, my husband, or god forbid, myself in need of hospice services. In working with our younger patients, I hear the time and time again the struggles of these young families in trying to find the right balance of providing the direct hands-on care they want to for their loved ones, countered with the reality of also juggling employment (often necessary to keep their insurance benefits) and the needs of their children or other family members.

Would I want my sons, ages 5 and 7, to always associate our living room as the space that Mommy died? Would I want my husband to risk losing his job in having to stay home to care for me? Would I want my children to have to decide between the social networks that are critical to their development, and ultimately, to their bereavement, versus their ability to visit their mom regularly? Would I want them to visit me in a nursing home, where the other residents were twice my age and the facility staff unaccustomed to working with young families in this same manner? Clearly these would not be my choices – and sadly, these are not the choices that the young families we work with are comfortable making. The time has come that we allow families in Western Connecticut the chance to provide real options for how they will live the end of their lives – and hopefully in a place that is not that different from where they lived the rest of their lives.

Regional Hospice and Home Care of Western Connecticut has provided quality end of life care for nearly 30 years. It has built a reputation of professionalism, skill, empathy and humanity. Medicare Conditions of Participation guide our quality assurance standards (which we not only meet, we exceed), as do the staff themselves who are committed to providing the very best for each and every patient and family member. I strongly urge you to support the proposed revisions to the hospice facility regulations, including the following suggested wording: **Shall be authorized to operate a hospice facility, including a hospice residence, for the purpose of providing hospice services for terminally ill patients who are in need of hospice home care or hospice inpatient services. The hospice facility including a hospice residence , must be able to provide the following levels of hospice care: routine, general inpatient , continuous or respite.**

HB5499

3/16/12
Heanng re Section 19-13-D4b of the Regulations of the Connecticut State Agencies

Based on my years as a physician referring patients for inpatient Hospice care, and my personal experience with my wife's stay at the Connecticut Hospice, I feel that the proposed change is unwise, in that it opens the door for reducing the standards for staff and facilties for inpatient Hospice care. I believe that my personal experience may be most useful for your consideration of this issue

My late wife, Susan W Wolfson, was an inpatient at the Yale-New Haven Hospital 7 years ago, after a long and gallant fight with ovarian cancer She had willingly and cheerfully undergone 3 major abdominal operations for this cancer, had lived through too many runs of chemotherapy to count But now she was confined to bed, with a broken right arm sustained in a fall, intestinal obstruction, and large tumor masses filling her abdomen and pressing on the nerves to her right leg. She could not eat Her stomach contents were being continuously suctioned, and she was in constant pain.

Her surgeon suggested that she might benefit from more surgery, and her reply was "How about Hospice". She was transferred the next day, and we lived through a miraculous change She was seen immediately by a team of physicians, nurses , social workers, and pharmacists. Her intravenous pain medications were adjusted, and within one half an hour, she was free of pain Sent to Hospice for help with dying, she came to life

Two hours later, holding hands, we attended a concert, in the common room on the floor Over the next days, we were able to wheel her bed out of doors, and she sat in the sun, watching gulls fly over the sound A physical therapist came by to help her transfer to a commode and even take a few halting steps. A volunteer visited and Sue participated in arts and crafts, using her left hand

She was thirsty and hungry She was on continuous suction and so could not eat. But rules at this Hospice are made for the patients! She was told that she could drink-it would be sucked out anyway, and she could have taste, and the feeling of drinking. She started with apple juice and then begged for chicken soup Our friends participated in a "cook out, " competing for the most flavorful chicken broth I am forbidden to reveal the winner of this contest

After a week, we were introduced to a new capability She was placed in a hoist, lifted up, and then lowered into a huge jaccuzi-like bath, for her first bath in months! I sat outside, listening to the 3 aides attending her as they sang songs with her

My children and I took turns sleeping in a cot by her side And so we witnessed the nurses and aides making rounds at 2 am Anyone who was awake was offered, and received, a sponge bath And then slept.

Each morning, the physicians, nurses and social service team members made rounds to check on each of the patients The physicians ordered the minor but crucial changes in medications to ensure that patients were free of pain or nausea, but not oversedated. And these changes were instantly put into place by the onsite pharmacists. Those with constant cough, with respiratory distress, with pain, or itching, diarrhea or constipation, received care None needed,to wait hours for changes in their regimen to take place

As a family, we were supported, listened to, loved by the staff We met other families there, shared our gratitude for the care our loved ones were receiving We were allowed to have parties for our families and friends in the common room. And free of pain, alert and awake, Sue was able to say goodbye to all of us

The day came when the pain returned, with a vengeance. And she needed enough medication so that she slept Three days later, I helped the staff give her a bath at 2 am. And they saw signs that the end was near I called my children. We sat with her And her last breath came as the sun rose, over the Sound

I hope that you all understand that patients who need inpatient Hospice care, like my wife, need what can only be described as intensive care With this care, many can have peaceful, hopeful, even mirthful days, as they are dying.

The staff levels contained in the current Regulations are totally appropriate, and should be met by anyh facility that undertakes the care of terminally ill patients -to repeat, this is intensive care. Thank you for listening
Steven Wolfson, MD

Bonhomme, Penny

From: Ellen Raspitha [Ellenraspitha@hotmail.com]
Sent: Thursday, March 15, 2012 2:40 PM
To: PHC Testimony; hoyt@cahch org
Cc: cjones@regionalhospicect org; ellenraspitha@hotmail com
Subject: Hartford Testimony, 16 Mar 12

Written Testimony for Friday, March 16, 2012
HB 5499
To Be Presented in Person at the Hearing
Ellen Raspitha
914 954 1006

Good Morning,

I am Ellen Raspitha, a 15-year volunteer with Regional Hospice and Home Care of Western CT.

For eleven of those years I served patients and their families as part of a Hospital Visitors Team. Patients, alone or with spouses and families no longer able to care for them, face admission to a nursing home; a decision, I can tell you, that leaves these patients and their loved ones extremely distraught during an already trying and upsetting time.

Why do I know this situation all too well?

In May 2009 my husband, Gus, in his final decline from ALS/Lou Gehrig's disease, experienced shortness of breath. As there is no treatment for ALS, Gus had refused any breathing assistance or a feeding tube. So now was the time to keep him as comfortable as possible. I could not manage Gus's symptoms alone at home with morphine drops, particularly since, at the same time, I was dealing with vertigo.

On Friday, May 8, Gus was admitted to Danbury Hospital on his hospice benefit. By Saturday morning, a mere eighteen hours later, we were discussing where Gus would go when his symptoms stabilized, which they did over that weekend.

Gus knew that by Monday, May 11, he would be going "somewhere else." Where we did not know.

Instead, on Monday, May 11, Gus passed away. With a residential hospice in Danbury, both Gus and I would have had relief and peace for our last three days together.

I also come to you today from Brewster, NY, Putnam County, which borders Fairfield County. Numerous Putnam and Westchester residents already drive the short distance to Danbury for medical care and would benefit tremendously from a local residential hospice under Regional Hospice's excellent standard of care, compassion, and hope.

As both a caregiver and volunteer, or as I say, "from both sides of the bed," please stop these shenanigans by honoring the Hospice movement with the clearly needed change in regulations.

Jewel Mullen, MD, MPH, MPA
Commission Members
State of Connecticut, Department of Public Health

RE: H.B. No.5499 (RAISED) An Act Concerning Regulations Relating to Hospice Care

I would like to present this testimony in both in person oral testimony and written form.

Good Morning Ladies and Gentlemen,

Thank you for this opportunity to appear before you concerning "Hospice Inpatient Facilities" and the request of "Regional Hospice" to be allowed to build its own hospice residence in order to offer in-patient care.

My name is Robert Tendler. I am a Registered Pharmacist and Fellow of the American Society of Consultant Pharmacists.

I would like to suggest the following revisions for H.B 5499 (a) after "pursuant to 42 USC 1395X" (line 6)

"Shall be authorized to operate a hospice FACILITY, including a hospice residence, for the purpose of providing services for terminally ill patients who are in need of hospice home care or hospice inpatient services. The hospice facility including a hospice residence, must be able to provide the following levels of hospice care: routine, general inpatient, continuous or respite.

During the last 25 years I have volunteered as the Consultant Pharmacist for Regional Hospice. I have been present at almost 1,200 interdisciplinary Team Meetings as well as over 75 meetings of the Regional Hospice Professional Advisory Committee. In addition to providing Regional Hospice with my "Pharmacist" input, I have served as their personal Notary Public by visiting patients and their families both in hospital and home settings to assist in making official end-of-life arrangements at their bedsides as well as monitoring their pharmaceutical needs.

For 25 years, I have been privileged to sit at meeting tables with Registered Nurses, Licensed Practical Nurses, Physicians, Social Workers, Aides, Care Givers, and Volunteers as this extraordinary group of people displayed the highest levels of compassion and superb quality of care.

There have been hundreds of occasions where I fielded late night and early morning calls with questions about pharmaceutical concerns of professional staff who on a daily basis deal with the pain, anxiety, and fear by their patients, patients' relatives and friends. We are here today because one of Connecticut's best managed hospice organizations now wishes to expand the scope of their quality, professional end-of-life services by offering the option of in-patient care outside of the hospital setting.

Based on my 25 years of experience serving as a Consultant Pharmacist to a hospice provider, I would like to make a comment concerning the need for an on-site Pharmacy and Pharmacist at an in-patient facility. For the last five years, I have been employed as a Consultant Pharmacist by the Omnicare Company. Omnicare is the nation's largest provider of prescription medications to patients in "Long Term Care settings"; they are also the owners of Hospice Pharmacia, this country's largest provider of prescription medication to Hospice providers I do not see the need for an on-site Pharmacy or Pharmacist at an in-patient Hospice Residence. I believe it would force the cost of maintaining in-patient services to sky rocket without a realistic benefit to the patient.

By allowing Regional Hospice to move forward with their plan to provide a quality in-patient, non hospital facility, you would be doing the right thing for potentially hundreds if not thousands of people approaching end-of-life who would then be able to have their families and friends with them for comfort and to say goodbye. It's just not happening in the majority facilities currently available.

Twenty-five years ago, almost 90% of hospice patients had cancer diagnoses. Today, in addition to people with cancer, those with Alzheimer's, other dementias, terminal coronary artery or, chronic obstructive pulmonary disease and more exotic malignancies wish to spend their final days pain-free and close to home. You can help grant them that wish.

Thank you,

Robert Tendler, RPh, FASCP
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TESTIMONY
BEFORE THE PUBLIC HEALTH COMMITTEE
H.B. 5499 AN ACT CONCERNING REGULATIONS RELATING TO HOSPICE CARE
March 16, 2012

Senator Terry Gerratana, Chairman Representative Betsy Ritter, Representative Jason Perillo and Senator Jason Welch and members of the Public Health Committee, my name is Cynthia Roy Squitieri and I am the President and CEO of Regional Hospice and Home Care of Western CT which is located in Danbury, CT and provides hospice and palliative care to patients in Western CT. We have the largest community bereavement center in Connecticut, which has received the Met Life Caregiver award, and we were a finalist in the Premiers Cares award in 2009 We have served thousands of palliative care and hospice patients and their families for the last 29 years. We serve young children, teenagers and adults who are all in their remaining days, weeks and months of life

I am also the Chair of the Hospice and Palliative Care Committee and a Board Member of the Connecticut Association for Home Care & Hospice I have been a hospice administrator for the last 12 years and have a background in clinical social work, bereavement, international policy and administration. I hold a Master's Degree in Science from Columbia University and a Bachelor's degree in Science from Boston University

I am writing to testify in **support** of H B. 5499 AN ACT CONCERNING REGULATIONS PERTAINING TO HOSPICE CARE with some proposed revisions as noted below. For more than two years, the Connecticut Association for Home Care & Hospice (CAHCH), along with 28 of 29 licensed hospice providers in the State of Connecticut, have been working in conjunction with the State of Connecticut Department of Public Health (DPH) to develop proposed revisions to Section 19a-122b-1 to 19a-122b-14 Hospice Facility regulations which are based on the current Medicare Hospice Conditions of Participation and provide opportunities for all licensed hospice providers in the state to provide terminally ill patients greater access to hospice service and care. It is time for these regulations to be passed and implemented.

Regional Hospice and Home Care of Western Connecticut has already completed a feasibility study and has plans drawn to build a 35,000 square foot, twelve private bed hospice residence in southern Danbury which also encompasses our 3,000 square foot bereavement center for the community. We simply cannot go any longer sending dying patients to nursing homes for hospice beds and with no local hospitals in our area providing hospice care. We MUST build a hospice residence. Traveling over an hour and a half to Branford is unacceptable Families want to remain in their own community and have

access to a residence with private rooms to live out their remaining days. It is simply not appropriate to have a 14 year old who cannot die at home because there are other young siblings in the home, die next to a patient in a nursing home who had a hip replacement. This is the suggestion of those who oppose our set of hospice regulations. This inhumane alternative to a hospice residence is unacceptable.

If the passage of H.B. 5499 will facilitate the implementation of the DPH hospice facility regulations as currently drafted, then this bill must be supported with two recommendations as noted below:

The language in H.B. 5499 section "a" references only hospice residences, and the regulations developed with DPH during the past two years address all facility based hospice care. The current draft of the DPH regulations is more comprehensive and addresses the intent of the current statute which supports the vitally important need for hospice services to be provided in *all* settings and for hospices to be licensed *and* certified to provide this care. These requirements insure that our clients can receive qualified hospice staff in all settings, and provide for additional quality oversight to insure safe client care. Therefore I recommend that the language in this bill be amended to reference hospice facilities, not just residences

In addition I support the technical wording recommendations that will be submitted by Hospice of Southeastern Connecticut and the Connecticut Association for Home Care & Hospice which seek to further clarify that hospices must be able to provide all levels of hospice care (routine, general inpatient, continuous home care or respite). This way our citizens can be assured to receive the full spectrum of qualified hospice services in their communities by their local hospice provider as their needs warrant. The draft DPH hospice facility regulations, which I have previously referenced, correctly identify the parameters around which hospice residences and facilities should be developed and operated We have not seen the final draft of the proposed regulations that were going to the Attorney General's office last week. We would like to review them to ensure that there have been no substantive changes to what had previously been developed

I applaud and acknowledge the tremendous work of the Public Health Committee and the Department of Public Health for taking the initiative to update these regulations which will ensure quality of care as well as increased access to care for hospice patients and family members throughout the state. I also would be remiss if I didn't acknowledge the support of Representative's Bob Godfrey, David Scribner, Christopher Lyddy, Janice Giegeler, Dan Carter, Joe Taborsak, Dan Fox, and Senator Michael McLachlan

Thank you for consideration of this testimony

Please feel free to contact me with any questions.

Best Regards,

Cynthia Roy Squitieri, MS,LCSW, CHCM,CHA
President and CEO
Regional Hospice and Home Care of Western CT

TESTIMONY BILL #5499 3/16/2012

Dear Madame Chair and Distinguished Committee Members:

My name is Diane Bowden, and I am a registered nurse at the Connecticut Hospice in Branford. I have been a nurse for more than 28 years in pediatric oncology, bone marrow transplant and adult and pediatric hospice care. I am speaking here today to oppose the Department of Public Health's proposed changes as stated in Bill No. 5499.

Bill 5499 would add the statement, "Such regulations shall include provisions that are substantially the same as the provisions of 42 CFR 418.110." It states in 42 CFR 418.110, "Staffing. The hospice is responsible for ensuring that staffing for all services reflects its volume of patients, their acuity, and the level of intensity of services needed to ensure that plan of care outcomes are achieved and negative outcomes are avoided." But it doesn't state a nurse to patient ratio standard to achieve this. The current Connecticut standard is one registered nurse to six patients per eight hour shift.

42 CFR 418.110 goes on to state, "If at least one patient in the hospice facility is receiving general inpatient care, then each shift must include a registered nurse who provides direct patient care." One registered nurse is the only stated standard. This is far below the current standard of care that Connecticut residents now receive.

How does this all affect the patient? Let me translate more graphically. Inpatient hospice requires acute medical care for acute symptom control. Sudden and severe pain is a common symptom in end of life care. Patients can have tumor pain in the liver, the back, or in bone. There can be pathological fractures of a bone, meaning a tumor that has grown in the bone and broken it in pieces. That is severe pain. Patients need quick nurse intervention, with direct medical and pharmaceutical access. Reducing staffing reduces response time.

Another common symptom in end of life care is respiratory distress. This also is sudden and severe. Respirations are labored and ineffective. They can't breathe. Or the lungs are filling with fluids, and they are effectively drowning. These situations need an immediate response of care and medication, which means adequate staff and in-house pharmacy and medicine.

And lastly, let me explain end of life tumor growth. We see here the ravages of tumors on the human body. Tumors that can rupture or bleed at any time, that erodes into deep tissue, which causes severe pain and purulent drainage. These need extensive dressing changes, often three times a day. This requires knowledgeable and adequate medical, nursing and pharmaceutical staffing.

Stated minimum levels of care need to be in any regulation concerning patient care. These are absent in proposed Bill 5499. I urge you to reject this Bill in total.

Let us continue to provide the optimal care that we know. Let us continue to care for your loved ones, and those across the state of Connecticut.

Testimony - Diane Bowden, RN, BSN

March 16, 2012

To: The Public Health Committee

Subject: Testimony for March 16, 2012 on Bill No. HB 5499

An Act Concerning Regulations Relating To Hospice Care

Gentlemen:

I am a retired business-executive who has volunteered for five years in health care for the elderly, and for past three years, for *Regional Hospice and Home Care of Western Connecticut,* as a 'Hospice Patient and Family Support Volunteer'.

Hospice Volunteers try to bring a little reassurance and some humor to those patients who are facing their imminent end of life. We are "bedside hand-holders", "book readers" and providers of some comfort, often building relationships with both the patients and their families. Those of us who focus on the Hospice patients in nursing facilities, team up and augment the staff of the facility, as they cannot devote the time that is required by our patients and their grieving families.

Our organization in Danbury has been in business for 30 years and is highly regarded. Many of the surrounding towns and corporations help in our support. We are a large and well trained group of volunteers and employees, and we hold ourselves to the highest of standards. Despite all our dedication, we are not able to have our own, dedicated facility entirely focused on end-of-life care.

The Bill **HB 5499** is designed to enable the establishment of regional facilities designed to today's standards. In 2006, my dying mother-in-law had to share a room with three other women in the only In-Patient Facility in CT; Connecticut Hospice. She had a great view, but the family visitations were awkward beyond description and it took us well over an hour to get there. **HB 5499** would change all this; visitations would be private and comfortable and brief visits after work would be possible.

This Bill would enable local facilities to be established with private rooms, and adjoining accommodations for out-of town family members to spend the night. Changing the existing regulation seems long over-due.

I thank you in advance for your support,

W Zachary Taylor

29 Cannon Drive, Newtown, CT 06470

The Bill before you today, provides for specialized and dedicated Hospice care that cannot be provided in the patient's home or even in the best of nursing facilities This Bill will insure that all hospice patients are provided care in keeping with today's standards and will allow all Hospice organizations in Connecticut, to provide up-dated in-patient facilities

These modernized facilities allow only one patient per room and can even provide adjoining over-night accommodations for family members.

This is an important improvement to the existing legislation that allowed four dying patients in one room, such as our family experienced in 2006

State of Connecticut
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CHAIRMAN
FINANCE, REVENUE AND BONDING COMMITTEE
MEMBER
BANKS COMMITTEE
PUBLIC HEALTH COMMITTEE

March 16, 2012

In Opposition to HB 5499 - An Act Concerning Regulations Relating to Hospice Care

Senator Gerratana, Representative Ritter, and my fellow Members of the Public Health Committee, I write today to express my opposition to **HB 5499, An Act Concerning Regulations Relating to Hospice Care**.

Almost forty years of experience have helped establish rigorous standards for Connecticut's hospice care regulations. Thanks to this, Connecticut citizens have high-quality inpatient hospice care in two-thirds of the state's hospitals as well as Connecticut Hospice in Branford. Connecticut Hospice is, in fact, the birthplace of hospice care in America. They set the model for care, and continue to set a high standard for full-service hospice.

To reduce our standards to the minimum federal guidelines would be a giant step backwards in patient care. These patients are our parents, our brothers and sisters, our children and our friends. They deserve more than the minimum.

I urge you to reject HB 5499. Any dilution our standards would be an injustice to our current and future hospice patients.

Sincerely,

Patricia Widlitz

Patricia Widlitz
State Representative, 98th District

My name is Anthony "Unk" DaRos and I am First Selectman of the town of Branford. I am also the Vice Chairman of the Board of Directors of Connecticut Hospice. As such, I am here to testify against Bill No. 5499.

My reasons are rather straight forward.

First, Connecticut has been at the forefront of providing excellent hospice care to patients and their families; and it should remain the leader in that movement, not a follower.

Second, the Department of Public Health proposed regulations more than one year ago that were intended to change the level of care provided to hospice patients and their families. I opposed those regulations when they were introduced, and I oppose changing the current regulations as incorporated in this legislation. I know as a Board member of Connecticut Hospice and as a family member of a hospice patient that it is unreasonable to enact legislation that is supposed to help the sick and needy by *reducing* the number of nurses, doctors and other caregivers that hospices must provide. While I know that there will be others who can testify as to the medical issues involved, I am sure that this is one situation where LESS is not MORE. Since our regulations were enacted in 1993 patients have had access to inpatient hospice services in the state in hospitals and nursing homes. The legislation will not give better access to the *proper care*. There is no point to enacting legislation that is meant to give patients greater access to inadequate services.

Third, reducing the level of care that will be provided in the hospice in-patient setting creates an environment that is ripe for abuse. Hospice providers who receive benefit payments from the government and insurers will, if the regulations permit it, have the incentive to provide

only the minimum mandated services, thereby cutting costs and increasing profits. This is not conjecture on my part. The press has reported that the federal Department of Justice and the Office of the Inspector General, among others, are currently involved in investigating for-profit hospice providers in other parts of the country. While some of those providers being investigated also operate here, you should keep those questionable practices and investigations out of Connecticut by maintaining the high standards that have been the hallmark of hospice regulations in this state.

I believe that this legislation should not be passed because it is not good for the people of Connecticut who need hospice services. At the very least, this legislation should be put on hold at least until there is study and better understanding of the results of the investigations into the practices by hospices in other parts of the country that are subject to the lesser standards that are being proposed. Now is not the time to rush into new legislation that will adversely affect patients and families in their most trying times.

State of Connecticut
HOUSE OF REPRESENTATIVES
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TESTIMONY
IN SUPPORT OF HOUSE BILL NO. 5499
AN ACT CONCERNING REGULATIONS RELATING TO HOSPICE CARE

Public Health Committee
March 16, 2012

Honorable Co-Chairs Senator Gerratana and Representative Ritter, Honorable Vice-Chairs Senator Slossberg and Representative Lyddy, Ranking Members Senator Welch and Representative Perillo, and other distinguished members of the Public Health Committee:

Thank you for allowing me the opportunity to submit testimony in support of House Bill 5499, An Act Concerning Regulations Relating to Hospice Care. As I understand it, there will be proposed today by several speakers a revision to section (a) beginning at line 6 of this legislation which I support.[1]

I appear today as a state representative in support of a very important piece of legislation; yet, I speak as a resident of the City of Stamford with a personal and intimate awareness of an invaluable service once provided to our community that is no more.

On July 16, 2011, a dear family member passed away at the Rosenthal Hospice in Stamford, Connecticut. My Aunt Berdie left behind three children, a husband, two granddaughters and a tremendous amount of other family members and friends. She loved books, talking, teaching, and everything and anything having to do with Cape Cod.

[1] Revisions for H.B.5499 section (a) Notwithstanding the provisions of chapters 368v and 368z, an organization licensed as a hospice [pursuant to the Public Health Code] by the Department of Public Health or certified as a hospice pursuant to 42 USC 1395x, shall be authorized to operate a ~~residence for terminally ill persons, for the purpose of providing hospice home care arrangements including, but not limited to, hospice home care services and supplemental services~~ hospice facility, including a hospice residence, for the purpose of providing hospice services for terminally ill patients who are in need of hospice home care or hospice inpatient services. The hospice facility, including a hospice residence , must be able to provide the following levels of hospice care: routine, general inpatient , continuous or respite. ~~Such arrangements shall be provided to those patients who would otherwise receive such care from family members.~~ The residence shall provide a homelike atmosphere for such patients and their family members. ~~for a time period deemed appropriate for home health care services under like circumstances.~~ Any hospice that operates a hospice facility or residence pursuant to the provisions of this section shall cooperate with the Commissioner of Public Health to develop standards for the licensure and operation of such facilities and residences homes.

The care and environment provided by the Rosenthal Hospice for both my Aunt Berdie and just as importantly, her family, was absolutely remarkable and I believe unlike the care that was available anywhere else in our surrounding area.

The Rosenthal Hospice opened in the year 2000 with the intent being for the facility to ultimately be licensed as a hospice; however, until the regulations governing hospices in Connecticut were revised Rosenthal fell under the nursing home licensure and regulations. The revisions did not happen. It proved remarkably difficult for a twelve-bed hospice facility to fulfill the standards governing nursing homes. Sadly, in December 2011, Rosenthal Hospice closed its doors following the death of Peggy Andrall, its final resident, on December 8, 2011.

A 12-bed hospice facility like Rosenthal cannot operate in the State of Connecticut under current regulations. It has been tried in my hometown and it failed.

Our family members, our friends, our neighbors and our constituents should have access to facilities whose primary purpose is hospice care within or in close proximity to the communities that they call home.

Six weeks ago my wife and I welcomed our third child, a beautiful little girl named Maura Kelley Fox. Over these past few sleepless weeks I have reflected upon the manner by which we prepare for a loved one's arrival so as to ensure that this time period is one filled with care and compassion.

Connecticut has done remarkable things in the field of hospice care. We must continue to do what is necessary to ensure that the care and compassion we provide for our loved ones at the beginning of their lives is similarly available and provided for them at the end of their lives.

I believe that the underlying legislation is a significant step in that direction. I ask for the Committee's support of this legislation and thank you for your time and consideration.

Sincerely,

Daniel J. Fox
State Representative, 148th District
Stamford, CT

S - 649

CONNECTICUT
GENERAL ASSEMBLY
SENATE

PROCEEDINGS
2012

VOL. 55
PART 14
4223 – 4505

Those Voting Yea 21
Those Voting Nay 15
Those Absent and Not Voting 0

THE CHAIR:

The bill in concurrence with the House passes.

Mr. Clerk.

THE CLERK:

On page 10, Calendar Number 408, Substitute for House Bill Number 5499, AN ACT CONCERNING REGULATIONS RELATING TO HOSPICE CARE, as amended by House Amendment Schedule "A", favorable report of the Committee on Public Health.

(The President in the Chair.)

THE CHAIR:

Senator Gerratana. Good evening there, ma'am.

SENATOR GERRATANA:

Good evening to you, Madam President.

Madam President, I move acceptance of the joint committee's favorable report and passage of the bill in concurrence with the House.

THE CHAIR:

The motion is on acceptance and passage in concurrence with the House.

Will you remark, ma'am?

SENATOR GERRATANA:

Yes. Thank you, Madam President.

For the Senate circle here, I want to describe to you what the bill that we have before us as amended does. Currently, there is more than one level of care for people

seeking hospice out of home care in Connecticut.

There are two hospitals in the state, and only two that are licensed as short-term care hospitals that offer hospice care. One is hospice in Connecticut Hospice, in Branford. The other is VITAS in Waterbury. They are unaffected by this bill.

THE CHAIR:

Excuse me, ma'am, for one moment, Senator.

Ladies and gentlemen, it is very difficult to hear the senator bringing out the bill. I would ask that you could take your conversations outside of the Chamber so that we can -- so that all the senators can hear.

Please proceed, ma'am. Sorry to interrupt.

SENATOR GERRATANA:

Not at all. Thank you, Madam President.

And I'll just repeat that there are two licensed short-term care hospitals in our state. One is in Branford, one in Waterbury. And they are unaffected by the legislation before us.

Other hospice care entities do exist in the State of Connecticut. They exist and are usually administered by home healthcare agencies. These agencies contract with facilities, such as nursing home or other hospitals, for beds that will be designated as hospice care beds and used as needed.

The ideal hospice offers, not just physical needs and medical care, but an approach that is comprehensive, a full spectrum of approach -- of support, I'm sorry -- respite care for families, spiritual and physical comfort, mental health support and, of course, helping the individual and the family understand what is going on and helping them throughout the end of life. The emphasis is on quality of life and living each day as fully as possible.

The bill before you clarifies, in essence, what has been going on in our state. More importantly, it establishes the ability for home healthcare agencies everywhere in our

communities to establish residences or facilities that will be dedicated to hospice care.

I hope that the Chamber will support me in the passage of this bill, and have our loved ones be able to stay close to home and close to the families that they love.

Thank you, Madam President.

THE CHAIR:

Thank you.

Senator Leone. He asked first. Senator Leone first.

SENATOR LEONE:

Thank you, Madam President.

I rise to support this very important piece of legislation. And I want to first thank Senator Gerratana and Representative Ritter for allowing this discussion to take place, to working with all the parties involved.

And the reason for that is because it's an issue that's been affecting us statewide in terms of making sure that those who need hospice care are able to obtain it close to home, in a dignified manner, close to their family -- excuse me -- and still have a quality of life.

In my community, in Stamford, we had a wonderful hospice facility, the June Rosenthal Hospice Facility. And due to some economic circumstances and others, it was forced to close down. And since it closed down, it's been very difficult for the opening of a newer facility so that we can continue to provide that level of care that people so desperately need and want close to their home.

And so I believe that this legislation, if it passes, which I sincerely hope it does, will allow us to open a new facility. And we've had interest in doing just that. But this legislation will make sure -- will bring our regulations up to code and will foster the competitive spirit that will make everyone and everyone who provides hospice care that much better.

It doesn't take away anyone's ability to provide the care

that they're currently doing, but it does allow the ability to provide care close to home. And that's an important thing because not being able to be close to your loved one is a travesty. If you have to move someone far away, it could be the difference between them getting the care and them not getting the care and not having that quality of life that I believe everyone deserves.

And so I think the two chairs, along with the ranking committee and all the members of the Public Health Committee, worked hand in hand to really resolve all the issues, to take all the issues that came up and take into consideration to foster an agreement. And it was evident by the fact that when it passed in the House, it passed unanimously. And that says a lot.

There's not too much legislation that has far-reaching consequences that gets that kind of a vote, and that's due to the leadership that was provided in shepherding this bill.

So I want to say thank you to Senator Gerratana and Representative Ritter and everyone who contributed to fostering this legislation so that we can provide the best care throughout the state. So that everybody has the ability to have care in their community. And I think that's something that we all would want for each other and for our loved ones.

Thank you, Madam President.

THE CHAIR:

Thank you.

Senator Meyer.

SENATOR MEYER:

Through you, Madam President, to Senator Gerratana, just for a brief question.

THE CHAIR:

Please proceed, sir.

SENATOR MEYER:

I represent a senate district that includes Branford Hospice, which was the first hospice in Connecticut and it's renowned residential facility that has helped so many of Connecticut's families through difficult times.

And Senator Gerratana represented a few moments ago, that this bill does not affect Branford Hospice. And I wondered if she would elaborate on that.

Thank you, Madam President.

THE CHAIR:

Senator Gerratana.

SENATOR GERRATANA:

Thank you, Madam President.

Yes, Senator Meyer. As I said in my introduction, the hospice care in Branford is actually a short-term care hospital. It is licensed and regulated differently.

I've tried to make the point that this piece of legislation actually clarifies, if you read the underlying bill, what has been existence -- in existence in our state, and that is the ability to give hospice care.

I think that there's a lot of confusion about -- about what hospice is and how it is defined. But just so you know, Senator, that these are two different areas of our statutes, and it does not at all affect the hospice hospital, if you will, in Branford. Thank you.

Through you, Madam President.

THE CHAIR:

Will you remark?

Senator Welch.

SENATOR WELCH:

Thank you, Madam President.

I just quickly rise as the ranking member to voice my support for this bill and encourage my colleagues to do the same.

Thank you, Madam President.

THE CHAIR:

Thank you very much.

Will you remark? Will you remark?

Senator McLachlan.

SENATOR McLACHLAN:

Thank you, Madam President.

I rise in strong support of this bill. I'd like to thank Senator Gerratana, Representative Ritter, obviously, Representative David Scribner who has helped shepherd this bill through.

I might add I know there were an awful lot of points that had to be negotiated over the last couple of years, actually, on this topic. But what this translates into is a privately funded -- all by private donations, multimillion-dollar 12-bed hospice facility that can begin construction next month in Danbury.

This means a lot to the western Connecticut communities. I thank this Chamber for your support.

Thank you, Madam President.

THE CHAIR:

Senator Fasano.

SENATOR FASANO:

Thank you, Madam President.

Madam President, to you -- to Senator McLaughlin, if I may?

THE CHAIR:

The question to Senator McLaughlin, I'm sorry.

SENATOR FASANO:

If I may?

In the statement that you made that, as a result of the bill, construction can begin, what in the bill would permit that construction to begin? Or in the alternative, what current law prohibits the construction from beginning?

Through you, Madam President.

THE CHAIR:

Senator McLachlan.

SENATOR McLACHLAN:

Thank you, Madam President. And thank you, Senator, for your question.

I believe, for further clarification, this bill doesn't address construction at all of a project in Danbury. What this bill does, though, is solidify the business plan proposed for the new facility in Danbury that will serve western Connecticut. So it's not construction directly.

Through you, Madam President.

THE CHAIR:

Senator Fasano.

SENATOR FASANO:

I thank you, Madam President. I thank Senator McLachlan for his answers.

You know, the conversation really is not about care for the elderly or for those, I should say, in the latter stages of life. In Branford, as Senator Meyer indicated, that facility is a great facility and there's another facility of equal caliber.

The issue is what are the services we're going to allow these facilities? What standards are we going to put in

these facilities? And if there's any hint that we are going to take those standards and lessen them, people should be outraged. People should be outraged.

There's nothing in Connecticut that prohibits facilities from operating. Nowhere, no law. What some are seeking, by virtue of regulation, as I understand it, is to lower the standards. There's not a prohibition. Everybody can do it, you've just got to do it to the existing standards.

And when we get to the last stages of our life -- I know my grandparents passed there -- when you get to the last stages of your life, you can only hope and wish that the highest possible care for the people in the latter part of their life is maintained. And if we're searching for a way to figure out how we can lessen those standards, we should be very, very cautious.

I don't have a dog in the fight. I don't have that facility in my -- in my 34th district. The closest is Branford, but I don't have a facility in my district. But what I do know from going through experiences, many of us, unfortunately, may have experienced, is you want a facility that has the highest standards. You want a facility that's held accountable to the higher standards. And any notion of lessening those standards by reducing a doctor that's there, by reducing staff hours, by not requiring a doctor to be on premises all the time, or not having the best nurses on staff all the time, to me, personally, no interest in the outcome, have an issue.

And I know the regulations are being bantered about. I'm not on regs review. But I'm keeping an eye on it, not because I'm protecting a business or an entity, but because I feel, as I said, people going through this, you cannot settle for less than the best quality of care. To me, that's all this issue is about.

This bill, as I understand it -- maybe I missed it -- but this bill, as I understand it, takes authorizing a facility to licensing a facility. And in the regulations it doesn't really matter because when they authorize they essentially license any regulations. And if it's something more than that, then I missed it, but I don't think so. It's going to come down to the regulations. And we should all -- because I know we all care. I know we all care. We should all be very careful not to lower

the standards.

Thank you, Madam President.

THE CHAIR:

Thank you, Senator Fasano.

Will you remark? Will you remark?

If not, will the Clerk please call for a roll call vote. The machine will be open.

THE CLERK:

An immediate roll call vote has been ordered in the Senate. Immediate roll call vote is ordered in the Senate. All senators please report to the Chamber.

THE CHAIR:

If all members have voted -- if all members have voted, the machine will be closed.

Mr. Clerk, will you please call the tally.

THE CLERK:

House Bill 5499 as amended by House Schedule "A."

Total Number Voting	36
Necessary for Adoption	19
Those Voting Yea	33
Those Voting Nay	3
Those Absent and Not Voting	0

THE CHAIR:

The bill passes.

Mr. Clerk.

Oh, I'm sorry. For a point of personal privilege, I apologize. Senator LeBeau.

SENATOR LeBEAU: