

PA 11-023

HB6481

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**CONNECTICUT
GENERAL ASSEMBLY
HOUSE**

**PROCEEDINGS
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Development.

DEPUTY SPEAKER KIRKLEY-BEY:

Representative Tallarita, you have the floor,
ma'am.

REP. TALLARITA (58th):

Thank you, Madam Speaker.

I ask that this item be passed temporarily.

DEPUTY SPEAKER KIRKLEY-BEY:

Is there any objection? Is there any objection?
Hearing none, the bill is passed temporarily.

Will the Clerk please call on Calendar Number 89.

THE CLERK:

On page 36, Calendar 89, Substitute for House
Bill Number 6481, AN ACT CONCERNING THE ESTABLISHMENT
OF A LUPUS EDUCATION AND AWARENESS PLAN, favorable
report of the Committee on Government Administration
and Elections.

DEPUTY SPEAKER KIRKLEY-BEY:

Representative Ritter, you have the floor, ma'am.

REP. E. RITTER (38th):

Thank you, Madam Speaker.

Madam Speaker, I move for acceptance of the joint
committee's favorable report and passage of the bill.

DEPUTY SPEAKER KIRKLEY-BEY:

The motion before us is on acceptance of joint committee's favorable report and passage of the bill.

Will you remark further?

REP. TALLARITA (58th):

Thank you, Madam Speaker.

Madam Speaker, this bill establishes it -- within the department of public health, an advisory panel on lupus. The panel must develop and implement a comprehensive lupus education and awareness plan after evaluating and analyzing existing educational materials and resources.

Madam Speaker, the Clerk is in possession of an amendment, LCO 5885. I ask that the Clerk please call the amendment and that I be granted leave of the Chamber to summarize.

DEPUTY SPEAKER KIRKLEY-BEY:

Will the Clerk please call LCO 5285.

THE CLERK:

LCO 5285, House "A," offered by Representatives Ritter, Aresimowicz, Olson and Senator Gerratana.

DEPUTY SPEAKER KIRKLEY-BEY:

Representative, would you like to summarize?

Is there any objection? Hearing none, please proceed, ma'am.

REP. TALLARITA (58th):

Thank you, Madam Speaker.

Madam Speaker, this amendment changes from the original bill the appointment process. Rather than specifically naming legislators to this panel it specifies appointment by our legislative leaders.

Madam Speaker, I move adoption.

DEPUTY SPEAKER KIRKLEY-BEY:

Will you remark? Will you remark further on the amendment that is before us?

Representative Perillo, you have the floor, sir.

REP. PERILLO (113th):

Madam Chair, thank you very much.

If I may, a question through you to the proponent?

DEPUTY SPEAKER KIRKLEY-BEY:

Representative Ritter, prepare yourself for questioning.

Representative Perillo, please proceed, sir.

REP. PERILLO (113th):

Madam Speaker, thank you very much.

One of the original intents of this was to involve a number of different organizations outside the State of Connecticut, outside the government, but that had much information and value to add to this effort on

lupus. I'd just like to clarify whether or not those organizations are still included given the amendment.

Through you, madam.

DEPUTY SPEAKER KIRKLEY-BEY:

Representative Ritter.

REP. E. RITTER (38th):

Madam Speaker, the answer is. Yes. They are included.

DEPUTY SPEAKER KIRKLEY-BEY:

Representative Perillo.

REP. PERILLO (113th):

Thank you, Madam Speaker.

And that's good news. I think that's very, very important. We heard wonderful testimony about this bill from these organizations and they can certainly have a lot of value and insight to add to the process. And I would support the amendment in light of that.

DEPUTY SPEAKER KIRKLEY-BEY:

Thank you.

Representative O'Neill, you have the floor, sir.

REP. O'NEILL (69th):

Thank you, Madam Speaker.

Also a question relating to the amendment.

The -- having the speaker and the various other

legislative officials make appointments, is that effectively replacing the legislators that are going to be on this panel? Or is that in addition to the people that are already listed in the underlying bill?

Through you, Madam Speaker.

DEPUTY SPEAKER KIRKLEY-BEY:

Representative Ritter.

REP. E. RITTER (38th):

Thank you, Madam Speaker.

It replaces the legislators named in the original bill.

DEPUTY SPEAKER KIRKLEY-BEY:

Representative O'Neill.

REP. O'NEILL (69th):

Thank you, Madam Speaker.

Is this part of -- I've seen in other pieces of legislation, efforts made to -- or being told that we have to not have legislators serving on certain kinds of boards and commissions and advisory panels and that sort of thing, that there's apparently a constitutional or some sort of amendment.

Is this being done in part because of that, because it's prohibited to put legislators on this type of an organization?

Through you, Madam Speaker.

DEPUTY SPEAKER KIRKLEY-BEY:

Representative Ritter.

REP. E. RITTER (38th):

Thank you, Madam Speaker.

This amendment would support the effort.

DEPUTY SPEAKER KIRKLEY-BEY:

Representative O'Neill.

REP. O'NEILL (69th):

. Thank you, Madam Speaker.

DEPUTY SPEAKER KIRKLEY-BEY:

Will you remark? Will you remark further on the amendment that is before us, House Amendment "A?" If not, let me try your minds. All those in favor of House Amendment "A," please indicate by saying, aye.

REPRESENTATIVES:

Aye.

DEPUTY SPEAKER KIRKLEY-BEY:

Against, nay.

The ayes have it. The amendment is adopted.

Will you remark further on the bill as amendment -- as amended?

Representative Ritter.

REP. E. RITTER (38th):

Thank you, Madam Speaker.

Madam Speaker, this bill -- we're really received, as Representative Perillo also indicated, very strong and moving testimony from people across this state regarding the need to increase and strengthen our awareness and knowledge about lupus. And I'm very, very pleased to see the Chamber first adopt the amendment and then proceed to go forward with the bill.

As you may or may not know, the month of May is lupus awareness month, something that increases, I think, the impetus perhaps to proceed with this effort here today. And I urge adoption of the bill as amended.

DEPUTY SPEAKER KIRKLEY-BEY:

Thank you, Madam Speaker.

REP. E. RITTER (38th):

No, I'm not the Speaker.

DEPUTY SPEAKER KIRKLEY-BEY:

Representative Hetherington, you have the floor, sir.

REP. HETHERINGTON (125th):

Thank you, Madam Speaker.

I rise in strong support of this bill. Lupus, although is a disease that I was unaware of until a

number of years ago, it is a particularly insidious disease because it goes unrecognized and undiagnosed for so long. It is a disease, an autoimmune disease that affects predominantly women and disproportionately minority women and it can in the end be fatal.

The thrust of this bill is to increase awareness and awareness is a very critical part of the battle against lupus because it is unrecognized generally. Many, many members of the medical profession do not recognize lupus because it has been so poorly understood and the symptoms are not generally ones that fall into the usual diagnostic tracking.

So I strongly support this. It affects a great many people in our state. It affects people who are not aware that they are affected. And bringing greater awareness will be a major step forward in battling this pernicious disease.

As a matter of full disclosure, I -- my wife Hope is a member of the board of the Lupus Research Institute. It is a non-compensated position and in fact there's no fiscal note to this, but I mention that as a matter of full disclosure.

Hope has been very committed to this cause since

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her sister suffered through it for many years and alternately succumbed to lupus several years ago. So I appreciate so much the work of our legislative leaders including Chairman Ritter to advance this bill. And I recognize and appreciate the work of the lupus organization that has a chapter here in Connecticut in advancing the publicity and bringing this bill to the forefront. So I would strongly urge its adoption.

Thank you, Madam Chair -- Madam Speaker.

DEPUTY SPEAKER KIRKLEY-BEY:

Thank you.

Representative Sawyer, you have the floor, ma'am.

REP. SAWYER (55th):

Thank you, Madam Speaker.

You know, the television show House has had a long run. And in the first couple of years when they would be reviewing one of the cases invariably across the panel of docs that were sitting around the table they would run through, well, what could it be? And invariably lupus would be one of them. And the response was, it's not lupus.

And I can tell you that that comment became sort of an icon of the show, it's not lupus. But that's because at that time the awareness of lupus, it was felt

it was very important to heighten it across the United States. And Hollywood picked up on it and it showed up repeatedly in that particular program.

I think it's essential that as a State we look at what is available to us, where we can take that information. And because of that, I would like to just ask one question to the proponent of the bill.

DEPUTY SPEAKER KIRKLEY-BEY:

Representative Ritter, prepare yourself.

Representative Sawyer, please proceed.

REP. SAWYER (55th):

Thank you, Madam Speaker.

Madam Chairman, with this particular bill and looking at the makeup of the panel, if there were philanthropists that wished to help assist financially, is there a way for them to be able to assist in this particular endeavor? Is the State able to take, say, a gift to the State? Or will you be working with enough agencies -- I'm sorry, enough advocacy groups that they could channel that kind of assistance through that?

Through you, Madam Speaker.

DEPUTY SPEAKER KIRKLEY-BEY:

Representative Ritter.

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REP. E. RITTER (38th):

Thank you, Madam Speaker.

As I previously emphasized also to Representative Perillo, the two advocacy groups who are primarily responsible for bringing us this bill have positions on this advisory panel and would be the appropriate channels to direct that.

DEPUTY SPEAKER KIRKLEY-BEY:

Representative Sawyer.

REP. SAWYER (55th):

I thank the chairwoman for her answer.

I think for legislative intent that there really is no heavy government cost to this, that we will be looking through those advocacy groups for their assistance. But it also is a channel way for those people who wish to become involved and be able to offer assistance financially to spread the word about this terrible disease.

Thank you, Madam Chairman.

DEPUTY SPEAKER GODFREY:

Thank you.

Representative Srinivasan, you have the floor.

REP. SRINIVASAN (31st):

Thank you very much, Madam Speaker.

I too rise in strong support of this bill. Lupus awareness is extremely critical because once a diagnosis is made of lupus in a physician's office or in a hospital, there are a million questions the patient and the family has.

And the first question in their mind is, is it a death sentence? And education of the medical entity that they have is very crucial, very important because lupus is a lifelong disease. Unfortunately once one has it you have to learn how to live with it. The family has to learn how to cope with lupus.

And with all of that and knowing very well it is definitely not necessarily a death sentence by any stretch of the imagination, the information to families, the information to patients is very crucial. And this awareness will be very critical in helping our patients cope with this medical entity.

And as we all know, you know, when you all go to a physician's office you are there for very short period of time and in that short period of time. And in that short period of time the diagnosis is given to you and one does not even have time to recover from what you have been told.

So going back to this education group, learning

from them what is this entity all about, that it is not malignancy, it is not cancer. The first question I'm always asked, is this cancer? The moment you make the diagnosis, to make that separation is very important for families, for patients. And I am in strong support of this education awareness.

Thank you, Mr. Speaker.

DEPUTY SPEAKER KIRKLEY-BEY:

Thank you, sir.

Representative Hwang, you have the floor, sir.

REP. HWANG (134th):

Thank you, Madam Speaker.

I rise in strong support of this timely bill as May is Lupus awareness month and May 10th is actually lupus awareness day. It would be great to approve this bill to commemorate the efforts to eradicate this insidious disease.

Lupus is a disease that causes, not only physical damage to the body, but it also has a profound emotional impact of the patients and their family. We need to educate and find a cure for this disease.

This bill has tremendous bipartisan support and is a testimonial to the great efforts of Chairwoman Ritter and Representative Hetherington for all their

great work. I urge strong support of this bill, ma'am.

DEPUTY SPEAKER KIRKLEY-BEY:

Thank you, sir.

Representative Miller, you have the floor, sir.

REP. P. J. MILLER (36th):

Thank you, Madam Chair.

I also rise in strong support of this bill. As many of you know, there are 17,000 people who live in Connecticut who have lupus. There has been no new medications for this insidious disease in over 40 years and there's no cure. And we don't even really understand the cause.

It's clearly a deadly affliction that we need to understand more about and this bill will -- could be a very good start at raising the consciousness which is so -- such a necessity for us to hopefully find a cure and bring relief to our fellow citizens.

Thank you, Madam Chair.

DEPUTY SPEAKER KIRKLEY-BEY:

Thank you, sir.

Will you -- anyone else like to speak on the bill as amended? If not, staff and guests please come to the well. The machines will be open and please cast your votes.

THE CLERK:

The House of Representatives is voting by roll call. Members to the Chamber. The House is taking a roll call vote. Members to the Chamber, please.

DEPUTY SPEAKER KIRKLEY-BEY:

Have all members voted? Have all members voted? Please check the board to see that your vote has been properly cast. The machine will be locked and the Clerk will prepare the tally. Will the Clerk please announce the tally.

THE CLERK:

House Bill 6481 as amended by House "A."

Total Number voting	141
Necessary for adoption	71
Those voting Yea	141
Those voting Nay	0
Those absent and not voting	10

DEPUTY SPEAKER KIRKLEY-BEY:

The bill as amended passes.

Are there any announcements or points of personal privilege? Are there any announcements or points of personal privilege?

Representative Rovero, you have the floor, sir.

Representative Rovero, did you have an

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SENATOR FASANO: Madam Chair, thank you and your Committee.

REP. RITTER: Thank you. Before we go on to our next bill I just want to return to the officials list and first see if Commissioner O'Meara is here yet. I'm not sure he is. The other person would be Frank Sykes. Is Frank Sykes present? Yes. Would you like to give your testimony? Mr. Sykes, just one moment before you start because one of our new Committee members has just arrived and I would like to give him the opportunity to be welcomed by the Committee. Representative Charlie Stallworth is here. And Representative welcome. You're here boots on the ground. So here we go. I might give you the opportunity to greet the Committee if you wish and introduce yourself quickly. Thank you.

REP. STALLWORTH: Good morning. It's a pleasure to be here and have the opportunity to serve with this Committee. And I look forward to meeting each of you personally and working with you. Thank you.

REP. RITTER: Thank you, Representative. And we share the pleasure in having you joining us. Okay. So, Mr. Sykes.

FRANK SYKES: Good morning, Senator Gerratana -- I hope I've pronounced your name correctly -- Representative Ritter and members of the Public Health Committee. My name is Frank Sykes. I'm the Legislative Analyst with the African American Commission. For those who don't know the Commission it's a nonpartisan State agency and we

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advocate for the African American community and certainly for the people too.

We accomplish our mission primarily through research, policy analysis, outreach and information sharing. Today I'm here to testify in support of House Bill 6481, AN ACT CONCERNING THE ESTABLISHMENT OF LUPUS EDUCATION AND AWARENESS PLAN. And House Bill 5608, AN ACT CONCERNING THE IMPLEMENTATION OF CULTURALLY AND LINGUISTICALLY APPROPRIATE STANDARDS. In reference to 6481, we recognize that there is a need to educate the public and increase awareness about lupus. It is reported that lupus affects more than 17,000 Connecticut residents and an estimated one point five million citizens in the nation.

While it affects people of all races and ethnicities, research tells us that African American women in particular are two to three times more likely of developing this condition. The symptoms of lupus tend to mimic the symptoms associated with a number of common illnesses like the flu, cold, et cetera. Therefore diagnosing lupus can be overlooked and sometimes misdiagnosed.

In view of this, 5608 seeks to educate the medical community and public about the diagnosis, management and treatment of lupus. We are confident that the work of the panel which, you know, will be created will precipitate further insight and the standard of lupus condition. So this leads me to 5608, AN ACT CONCERNING THE IMPLEMENTATION OF CULTURALLY AND LINGUISTICALLY

APPROPRIATE STANDARDS. Cultural competence for medical providers is critical for a number of reasons.

First of all the demographics of Connecticut's population is changing. Immigration patterns have led to significant increases in diverse populations that experience cultural and language barriers. African Americans even with healthcare coverage in some cases receive improper or incomplete medical attention partly due to a cultural misunderstanding. In view of these differences this population segment will need a continuum of services responsive to their unique cultural needs.

Secondly, understanding the cultural norms of and history of different racial and ethnic groups will only lead to better outcomes in healthcare delivery for the healthcare providers and patients alike. I remember a few years back the Connecticut Health Foundation conducted a survey of the Connecticut physicians across 17 specialties and the survey identified a variety of gaps in physician education programs as it relates to cultural competency.

It revealed that fewer than two in five physicians received some kind of cultural competency training in medical school or residency. Seventy percent were not even aware of educational programs in the area that they could take advantage of if they chose to do so. And 80 percent of physicians work in the small practices were least likely to have received any training in cultural literacy.

Even from a cost perspective strengthening the cultural competence of medical providers really helps in improving health outcomes and overall helps in reducing the healthcare costs. So it's even -- from a cost perspective it's even a good policy. So in view of these findings we urge you all to support, you know, both bills. And I thank you for the opportunity to testify.

REP. RITTER: Thank you for your testimony. Are there questions from the Committee? Thank you very much. In the earlier testimony I had offered the opportunity for some input on the composition of the council after the discussions we had had. And I just wanted to put that back to you as well that if you have a chance to look closely at that in the next day or so and if you have any quarrels or questions with the way the bill is set up -- is drafted, we'd like to hear them as quickly as possible so that were -- that was an area we had some questions when drafting the bill.

FRANK SYKES: Okay. I'm just not quite -- what were the issues?

REP. RITTER: Questions as to the number of people and the -- they weren't -- to be on the proposed council as well as the areas of expertise. In some cases -- usually when we see these things we have more specifics. This gave a range in the total number I think between 15 and 20 which is just unusual for us. As well as boundaries for areas of expertise or experience they might come from but we just would be interested in your

comments if you have any more to give us. Thank you.

FRANK SYKES: Okay. I mean I'll take a look at it and most certainly will get back to you on that.

REP. RITTER: Great. Thank you very much. And thank you for your testimony. And again we're back into our initial hour testimony and we have Commissioner Peter O'Meara. Yes. The Commissioner has joined us. Thank you.

COMMISSIONER PETER H. O'MEARA: Good morning. Senator Stillman, Representative Ritter and distinguished members of the Public Health Committee. I am Peter O'Meara, Commissioner of the Department of Developmental Services. I'm here today to testify in support of House Bill 6392, AN ACT CONCERNING BIRTH TO THREE SERVICES AND REHAB SERVICES FOR CHRONIC GAMBLERS. I would specifically like to address the portion of the bill which implements Governor Malloy's recommended budget related to the Connecticut Birth to Three Program and respectfully request that the Committee consider substitute language for sections one, two, four and five which we have attached to our testimony to insure that the intent of the legislation is fulfilled and the proposed savings can be achieved.

With me is Linda Goodman, the Director of our Birth to Three System. And the intent of this bill is to implement provisions of the Governor's recommended budget which reflects a savings of one point six million dollars in fiscal year 2012 and three point two million dollars in fiscal

first speaker will be Lisa Sartorius followed by Anita Kuan.

LISA SARTORIOUS: Good afternoon, Chairman Ritter and other members of the Public Health Committee. I want to thank you for the opportunity to speak with you today about the importance of bill 6481, AN ACT ESTABLISHING A LUPUS EDUCATION AND AWARENESS PROGRAM. My name is Lisa Sartorius and I'm the CEO of the Lupus Foundation of America.

Every half hour another person is diagnosed with lupus and oftentimes when a woman is first diagnosed she's pregnant and has to choose between having a baby or living. Uncontrolled or undiagnosed lupus during pregnancy may result in the death of the mother as well as the baby. H.B. 6481 provides a means for these young women and their physicians to learn the symptoms of the disease so she does not have to wait until she is pregnant to learn that she has lupus.

For those of you that do not know lupus is an acute and chronic autoimmune disease in which the immune system is unbalanced causing inflammation and tissue damage to virtually every organ in the body. Nothing is left untouched. Long term health effects include heart attacks, strokes, seizure, kidney failure, miscarriages oftentimes early in a person's life.

But yet, only one in five Americans is aware of lupus symptoms and its health effects. Particular at risk are women 18 and 34 years of age. That is the largest population that is

affected by lupus but yet they have the least awareness about the disease. Ninety percent of all the women who develop lupus are women.

Lupus is two to three times more common in women on color and as many as one in 250 African Americans will develop lupus. Currently there are 17,000 people in Connecticut with lupus and one point five million nationwide. This is more than cystic fibrosis, muscular dystrophy and multiple sclerosis combined yet no one has heard about lupus.

The fact that African American women are impacted by lupus at an earliest age and have the highest overall death rates among all people with lupus. They are three times more likely to die from lupus than their Caucasian counterparts. H.B. 6481 will provide women with a tool so that they can get diagnosed early and therefore prevent serious health complications or even risk death.

The average annual cost of medical treatment for a person with lupus can be up to \$30,000 a year. Nationally it costs the United States thirty one point four billion in direct and indirect costs and 47 million in the State of Connecticut. There is an urgent need for this bill because it will create awareness about the symptoms of lupus so that it can be detected earlier, make available a directory of lupus related healthcare services so people with lupus know where to go.

It will also identify educational materials for healthcare providers and identify key scientific medical information and help educate health and

community service professionals about the importance of lupus diagnosis and treatment. Through these objectives individuals with lupus will be able to be diagnosed earlier and not suffer the extensive health consequences of the disease.

We ask the Public Health Committee and the Connecticut Legislature to join with other states and the lupus community here in Connecticut and across the United States to raise awareness and educate about lupus -- almost done -- so that one day we will have better treatments that will eventually lead to the cure. Without awareness and education many people go undiagnosed and many suffer in silence.

Please help us to give the more than 17,000 people in Connecticut living with lupus hope. Hope for change. Hope for awareness. Hope for understanding. Please make it possible for them to no longer hear we do not know enough about lupus. Thank you very much. Anybody have any questions?

REP. RITTER: Thank you very much for your testimony. Are there questions from the Committee? I want to thank you very much for your efforts to -- your relentless efforts to bring this to our attention. And I -- I see you've assembled a list of people to speak and this will be very useful for all of us to understand so many of the issues around lupus and it's diagnosis.

LISA SARTORIOUS: Thank you very much.

REP. RITTER: And our next speaker will be Anita Kuan and she will be followed by Hope Hetherington.

ANITA KUAN: Good afternoon, Representative Ritter and members of the Public Health Committee. Thank you for this opportunity to testify in support of bill 6481. My name is Anita Kuan. I'm a resident of Connecticut. I live in Lyme. I have lupus. Growing up every year I would get what we thought was a bad flu but then one year this flu wouldn't go away.

I had a fever of 104. I had low blood counts, swollen joints, mouth sores, and the list kind of goes on. I couldn't keep food or liquids down. After months of testing and visiting doctors I was -- I wasn't getting any better. And I had lost 40 pounds. Yet still no one could explain to me what was happening.

Yet I actually had classic symptoms of lupus. It was really a textbook case. But no doctor had thought to test me for lupus. If this bill existed back then my doctors may have thought of lupus but it wasn't and they didn't. I was actually lucky because my mother kept trying to find answers and eventually she brought me to a rheumatologist.

This rheumatologist took one look at me with my butterfly rash, fever, joint pain, and mouth sores and he knew right away it was lupus. If this bill was already in place my doctors would have thought that I might have lupus. They might have caught the disease earlier.

We could have tried less aggressive treatments in which case I might not have some of the long term effects and organ damage that I do have now. Things, issues with my eyes, my lungs, my liver among other things. Anyway that was back in my adolescent years. What's frightening to me is that that was 26 years ago and yet today patients can still go through the same thing that I have been through.

And it -- it can take months and even years before they get diagnosed. And then on another personal note having lupus has influenced my life. I wanted to understand what was happening inside me so I went to graduate school and got my degree in immunology and then took a research position at a university.

There I found funding for research was very competitive and grants for lupus research was limited. It seemed to me that public awareness can also effect lupus research both in funding for basic research and in clinical trials. If people -- people have heard of cancer. They've heard of heart disease and they donate to the cancer foundation. And these are all worthy causes but lupus it's not so much -- not so much heard of.

On the bright side it is inspiring that lupus research is really progressing now and I hope that lupus awareness and research continues to advance and that funding and support for this serious condition improves. Thank you for introducing this legislation. I believe it can

really have a positive impact on people living with lupus. Thank you for listening.

REP. RITTER: Thank you very much for your time and also for your dedication to acquiring more knowledge to help people who come behind you. That's very impressive. Is there anyone from the Committee with a question? No. Thank you very much.

ANITA KUAN: Thank you.

REP. RITTER: We will next be hearing from Hope Hetherington and she will be followed by Matthew Dolan. And in the interest of disclosure.

HOPE HETHERINGTON: In the interest of disclosure my husband sits on the Committee. But I would like to start off by saying good afternoon to Chairman Ritter and the whole Committee. And respectfully I urge your favorable support -- your support and favorable action on this bill concerning the establishment of the lupus education and awareness plan.

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Currently I serve on the Board of Directors of the Lupus Research Institute, an organization founded by lupus patients and their families dedicated to funding research to find better treatment and a cure for this dread disease. Over the last ten years LRI and their partner the SLE Foundation have awarded almost two million dollars in grants to lupus investigators right here in the State of Connecticut.

We are proud to join the Connecticut chapter of the Lupus Foundation of America in an effort to promote education and awareness concerning lupus and we ask that in the final version of this bill simply that include the participation of both organizations. New educational initiatives for healthcare providers are desperately needed to eliminate the numerous barriers to early medical diagnosis of lupus. Connecticut could be a vanguard State in this effort by passing the bill and positioning the State to be in concert with the new federal lupus provider education effort entitled the lupus initiative.

As the new federal program funded and initiated by the Office of Minority Health develops, the State would be able to quickly take advantage of the information and the materials for providers that are being developed currently.

I find it shocking that the average lupus patient waits three to five years in what we call the agony years before she is diagnosed and receiving treatment of any kind. Ninety percent of lupus patients are women of child bearing years. And disproportionately effects women of color. A health disparity that remains unexplained.

My younger sister was diagnosed at age 25 and lost the long and courageous battle with lupus just after her 50 birthday, seven years ago. I know too well the challenges of life with a chronic disease that is often not recognized or misdiagnosed by physicians and for which patients still await the first drug developed specifically

for their treatment. Not one drug for lupus has been approved in over 50 years.

We must educate healthcare providers so they may diagnose and treat patients. We must educate the citizens of Connecticut so that they recognize lupus symptoms and seek medical care. And we must support the scientific investigators working to unravel the mysteries of this little understood disease. Your favorable support and action on this bill and the ensuing education and awareness just might save the life of a young woman you know. Thank you.

REP. RITTER: Thank you very much for your testimony. And we very much appreciate your time. I think you waited a while. Probably if you came up here together you waited a long time. And we very much appreciate it.

HOPE HETHERINGTON: Not as long as you all do.

REP. RITTER: Well --

HOPE HETHERINGTON: We appreciate all that you do on behalf of everyone in the State.

REP. RITTER: I might add not as long as many of the people that you talk about in your testimony have to wait to be diagnosed.

HOPE HETHERINGTON: That is true.

REP. RITTER: Thank you.

HOPE HETHERINGTON: Thank you.

REP. RITTER: Are there any further questions or comments? Representative Ackert.

REP. ACKERT: Thank you, Chairman. Thank you, Hope. And I just -- that was the number that was just staggering to me is the three to five years.

HOPE HETHERINGTON: Yes.

REP. ACKERT: Is it three to five years and visiting a doctor --

HOPE HETHERINGTON: Yes.

REP. ACKERT: -- or somebody and it takes that long so.

HOPE HETHERINGTON: Commonly -- lupus is a very difficult to diagnose disease. Sometimes the symptoms are obvious and sometimes they're not so obvious. And what commonly happens is that a patient has different organ systems that are involved. So she might go to a dermatologist. She might go to a nephrologist. She might go to a pulmonary specialist. And no one puts together the full picture.

And -- and because the medical community is lacking in the training and education about lupus -- medical schools -- one of the lupus initiative efforts is to develop curriculum for medical schools and others, nurses, et cetera. But they're working -- Dr. Garth Graham who's in the Office of Minority Health has as his goal to have

his legacy be healthcare education nationwide.
Pretty exciting initiative.

REP. ACKERT: That's great. Thank you. Now you did mention being part of the input and maybe possibly the board so I'm not sure if the groups are recognized as part of the -- as the group that's going to be, you know, heading this up.

HOPE HETHERINGTON: They are. In the bill as it's currently written I think it says that the Lupus Foundation of America would have a role on the committee or right to name someone who would be on the committee and I would ask that the Lupus Research Institute have a similar opportunity.

REP. ACKERT: Great. Thank you for your testimony.

HOPE HETHERINGTON: Thank you.

REP. ACKERT: Thank you, Madam Chair.

REP. RITTER: Thank you. Actually your comment raised an interesting question in my mind. And that is you talked about the -- the sort of -- the search from specialist to specialist and we heard that earlier also. Is there a particular place where it's most commonly diagnosed?

HOPE HETHERINGTON: I -- I don't know that I would say where it's most commonly diagnosed but I will tell you that the specialty that -- under which lupus is treated is rheumatology.

REP. RITTER: Correct.

HOPE HETHERINGTON: But they -- but the thing is it's not just the rheumatologist who's usually the point man since it's such a multifaceted. And you need specialists in a variety of areas.

REP. RITTER: And that was kind of -- my understanding as well and I was just sort of interested in the sort of common or most frequently traveled path or route and --

HOPE HETHERINGTON: You know it just --

REP. RITTER: I think you answered the question. Great. Anything else from the Committee? Thank you very much.

HOPE HETHERINGTON: You're welcome. Thank you.

REP. RITTER: Next we will be hearing from Matthew Dolan to be followed by Pauline Birgnano. Possibly. Thank you.

MATTHEW DOLAN: Good afternoon, Chairperson Ritter and members of the Public Health Committee. My name is Matthew Dolan. I live in West Hartford. And I'm here to provide a personal anecdote in support of House Bill 6481. About two and a half years ago my wife Vanessa was diagnosed with lupus. Before being diagnosed Vanessa saw many different doctors to treat many different symptoms. All -- all symptoms were quite different and seemingly unrelated but all where there's a lupus.

Vanessa spent several years self treating seemingly isolated symptoms before seeing doctors

to treat those isolated symptoms and then probably another year or two before those -- before we realized that the symptoms were not isolated. They were all the result of lupus. And before we understood that lupus was the cause of the symptoms the treatment process involved many different specialists to address individual symptoms with no cooperation among doctors and no comprehensive approach to treatment.

All of the doctors treated the symptoms but not the cause and the symptoms got worse. The cycle continued until a close family friend suggested that lupus might be the cause of the symptoms. And since then treatment has been focused on the cause of the problem, lupus, and the results have been significantly better. Vanessa started meaningful treatment in part thanks to a good friend with a keen eye and an awareness of lupus.

House Bill 6481 is the first step toward building an awareness of lupus that would help others shortcut that frustrating and dangerous cycle of treating symptoms but not the disease. Learning to see lupus as a forest and not as a collection of different trees will help people see the right doctors, get meaningful treatment and improve the quality of life sooner rather than later.

Awareness of what lupus is and how to treat it is important for those living with lupus, their families, their doctors, their communities and ultimately our healthcare system. House Bill 6481 will increase lupus awareness, advance those goals. Please take favorable action on this bill

and persuade your colleagues to do the same.
Thank you very much.

REP. PERILLO: Mr. Dolan, thank you very much. Are there any questions representatives here (inaudible)? Sir, thank you very much for your time. We appreciate it.

MATTHEW DOLAN: Thank you.

REP. PERILLO: Next to testify is Pauline. And I'm just going to say Pauline because I don't want to butcher your last name. Thank you.

PAULINE BIRGNANO: Thank you members of the Committee. My name is Pauline Birgnano. I live in West Hartford. I have lupus like many thousands of patients here in Connecticut. I was -- my first encounter with lupus or awareness of symptoms that I had lupus began in the 1970s. However, due to the lack of education awareness I was not diagnosed until 1994. At that time I presented at UConn with a severe rash across my face, down my neck and one arm. I had joint pain and debilitating fatigue.

HB 6481

At that time my major concern was that I would be confined to a wheelchair and not lead -- the life that I had been leading previous. Soon after I started being treated for lupus I realized that there was very little education and awareness about lupus. People that I referred to did not seem to know. So I joined the Lupus Foundation of America to educate myself.

At which time I ended up joining the organization and becoming a volunteer. Eventually my volunteerism took me into health fairs and trying to help other people be educated and giving them information. The biggest health fair I think gave me the biggest impact where people coming from with lupus was the NBC wellness in Hartford here.

At which time I went out and I looked for people. I looked for specific people to talk to, mainly Native Americans, people of color because at that time I knew that lupus was going to hit them a lot sooner and more probably than other people. And asked them about lupus and what they knew. And very few of them did.

What shocked me was that in talking to the people that they all knew somebody with lupus. Many of them. The majority knew somebody with lupus, either a relative or a coworker or a friend. And so they knew about lupus. They knew it existed. They had a friend. They had a mother. They had an aunt. And then they'd walk away and turn around and say well what -- what is lupus.

And I was just horrified to think that they had a mother, a sister, a brother, a friend, a close one with lupus and this family was living with no one that knew anything about the disease. African American women -- young African American women that were being diagnosed with lupus and did not know what their resources were.

That leads me into this bill and how important it is to the people of Connecticut. They need the

education. They need to know where to go. They need to know the symptoms and when to go to seek help. I appreciate your -- your listening to my testimony. I am glad that I am here. I am walking and I'm talking and able to share this testimony with you. And I thank you so much.

REP. PERILLO: Well we certainly thank you for your time. It's not easy to get up and talk about something so personal but that oftentimes crystallizes the issue for us who don't necessarily have the -- the firsthand experience. So thank you very much. Are there any questions from the Committee? Representative Ackert.

REP. ACKERT: Thank you, Chairman. Thank you, Pauline for coming out and speaking on this. And more importantly I think sometimes we get impacted by a disease but then like you did turn around and be proactive in helping others. The statistic that Lisa gave was about 17,000 people. Do you know there's a number, a guesstimation as to how many people are going undiagnosed at this time? Have you guys talked about that at all?

PAULINE BIRGNANO: Actually no I do not. And the reason for that is Connecticut does not have a registry so we -- which we definitely do need. It would help in so many ways and especially the physicians treating lupus patients. Where geographically, you know, we need to educate people the most. People that we aren't reaching and talking to and offering this education. That's -- that's where this bill becomes so much more important is trying to reach the people that need it the most.

REP. ACKERT: Thank you. Well you've educated one legislator already. The four testimonies already. So thank you for coming today.

PAULINE BIRGNANO: Well thank you for having me.

REP. PERILLO: Thank you, Representative Ackert. Representative Hetherington.

REP. HETHERINGTON: Thank you. Thank you so much for being with us here today and sharing that information. What -- what was the specialty of the physician that finally made the positive diagnosis?

PAULINE BIRGNANO: I saw -- I went -- I saw three dermatologists and the last dermatologist said you need to go to UConn. The last -- I saw three dermatologists -- different dermatologists. And one of them referred me to UConn at which time that dermatologist called in rheumatology.

REP. HETHERINGTON: Thank you very much.

PAULINE BIRGNANO: You're welcome.

REP. RITTER: Thank you for your testimony. Are there any further questions? Thank you very much.

PAULINE BIRGNANO: Thank you.

REP. RITTER: Our next speaker will be Marilyn Sousa followed by Anna Mirabello.

MARILYN SOUSA: Chairman Ritter and members of the Public Health Association, I thank you so much for allowing us to come and speak today. I'm Marilyn Sousa. I live in West Hartford but I founded the Connecticut chapter and also the National Lupus Foundation. And I have to tell you the reason that happened was because I was diagnosed with lupus.

HB6481

I could not even pronounce this word because the doctor said you have systemic lupus erythematosus. I didn't know how to spell it. I couldn't pronounce it. And I couldn't find out any information about it. I said we've got to do something about this.

So I said do you know anybody else that might have it that we could get together and try to get more information, get education and awareness out to these people. We went ahead and had a meeting and decided that that would be what we would do. We established the Connecticut Lupus Chapter.

And from then on we had several people coming in and saying what is lupus. I think I have it. We needed so much education and awareness about it. So I went back to my doctor and I said do you have any information about lupus that I can give these people? He said well the main thing is don't get pregnant, stay out of the sun and don't read anything about it.

The reason he said that was because if you look at the manual it said it's a fatal disease within five years. And who wants to spread that kind of awareness and education? So we decided we were

going to try to find out all we could about this illness and it wasn't easy and it still isn't easy. Now I have to tell you this happened in 1973.

It's been 38 years and we're still trying to spread awareness and education about lupus. The treatment hasn't really changed that much. The side effects of medication have -- have taken its toll on me. I've been in and out of ICU. I have -- I think every doctor at the UConn health center is my buddy. Dermatologists, rheumatologists, hematologists, cardiologists, and they've all been wonderful. But nonetheless we need to spread more awareness and education to others so that they can deal with this. I did follow the doctors directions. I didn't get pregnant.

You know whatever we can do now to try to spread more awareness and education about lupus would be so wonderful. I thank you so much. Incidentally this walker's handy because I keep information in that walker and somebody will come up to me and say do you know anything about lupus.

Oh, I just happen to have -- oh, would you like to see the latest national magazine. So I always have something with me at least inside the walker. And then the other thing that we've done is we've organized support groups and we've had a lot of education with them and awareness and it's been wonderful for them. Thank you so much.

REP. RITTER: No thank you so much. And I'm so glad also that you did not follow your doctor's orders

not to read or learn anything about the disease because I think you've done a wonderful job of ignoring at least two thirds of the advice that you received. Are there questions from the Committee? Representative Perillo.

REP. PERILLO: I just have one. And you may have mentioned it. Where do you live?

MARILYN SOUSA: I live in West Hartford.

REP. PERILLO: Okay. I represent Shelton. So that's good news to me because if you ran against me I would not stand a chance.

MARILYN SOUSA: I would start a support group in Shelton right away. We don't have one there. We need one.

REP. PERILLO: Actually if you don't mind I'd like to catch you after -- after you testify and we can talk about that.

MARILYN SOUSA: Absolutely.

REP. PERILLO: Thank you.

REP. RITTER: Representative Hetherington.

REP. HETHERINGTON: Thank you, Madam Chair. Really just an observation and probably better said by Representative Perillo that the advocates on this -- on this issue are certainly very fortunate to have you. Thank you.

MARILYN SOUSA: Thank you so much.

REP. RITTER: Anything else. We wish you at least minimally another happy 38.

MARILYN SOUSA: Oh, thank you.

REP. RITTER: And keep right on going.

MARILYN SOUSA: Because I've got a lot of work to do yet.

REP. RITTER: A lot of support groups, right?

MARILYN SOUSA: Definitely.

REP. RITTER: Get them going. Thank you very much.

MARILYN SOUSA: Thank you.

REP. RITTER: Our next speaker will be Anna Mirabello.

ANNA MIRABELLO: Hi. Good afternoon, Representative Ritter and members of the Public Health Committee. My name is Anna Mirabello. I am 13 years old. I am a current resident of West Hartford. And I've been -- I was diagnosed with lupus about three years ago. When I was diagnosed in 2008 they told me that the daily doses of prednisone that I was taking and the frequent blood work that I was getting would be part of who I was and that I should get used to it because from now on this was going to be part of who I was and I accepted that.

HB 6481

The flares that I have the symptoms of them include excruciating joint pain, the common

butterfly rash across the cheeks, fatigue, really high fevers sometimes, just the common flu symptoms but a lot of times intensified by a lot. I handled a lot of the flares pretty well. I get sick and my body wouldn't know how to handle it sometimes.

But besides that it was pretty -- pretty manageable until this past summer. I was flown out to California alone to visit some family and since my knowledge is not great about my personal triggers and neither were the people who I was staying with. They didn't know anything about it. We didn't know how sick I was until I had to be hospitalized for 14 hours at UCLA with a severe, severe rash, temperature and I'd lost 15 percent of my body weight. So it was pretty extreme. And to fix it I was put on 1,000 CCs intravenously of prednisone which compared to my daily five milligrams was a lot for my body which did what it was supposed to do.

It kicked out the infection and the lupus and it got me back to normal but the side effects of the 1,000 were really intense including extreme hair loss including my hair coming out in chunks and a lot of swelling in my jaw line and in my stomach. So I dreaded going back to school because when I got there people didn't recognize me. They said Anna what happened to your face.

So I'm in full support of this bill because I have been there and I know what it's like to have all the symptoms. But I also know that it doesn't have to be that way because since I've been treated I was able to be on two sports teams

in one season including being the only girl who's played in the boy's basketball league. Scored a lead role in my play. Got to sing alone at a talent show.

So it's totally possible to lead a normal life but not without the education, not without the support from your community and your family and the medical support. And most importantly not without the knowledge because each person that we educate is one step closer, one person closer to our goal which is finding a cure for lupus. I'll finish up.

And I'm just overall I'm in support of this bill because I don't think kid -- I've been through it all and now I'm finding out what causes my triggers and what has -- gets my body into a flare but I don't think any kid should have to go through a lot of the pain that I went through. And a lot of the pain that they went through that they talked about before so.

REP. RITTER: Thank you so much for sharing your story with us. It truly makes a difference to us when we are able to hear from people personally and I know it's not always easy for you but thank you so much.

ANNA MIRABELLO: My pleasure.

REP. RITTER: Are there questions from the Committee? Representative Ackert.

REP. ACKERT: Thank you, Madam Chairman. Anna, thank you for coming. You can tell you've been on

stage or something because you came up here and took charge right away. But were you one of the fortunate ones that was diagnosed quite quickly from -- from your --

ANNA MIRABELLO: I started -- it actually started -- I was in fifth grade in 2008 and I was a gymnast and it got to the point where my joint -- it started out with joint pain. And it got to the point where I had to sit out. In school I would have to stop writing. So that summer -- it went on for awhile. It got to the point I could not turn doorknobs or open a bottle of water.

And so we went to my pediatrician and they thought it was things like Lyme disease and juvenile arthritis. And I went to a rheumatologist over at the Children's Hospital and within that summer they were able to diagnose me. So I was very fortunate to get the support but unfortunately people who are living in silence with this disease who do not have the knowledge, how are they supposed to know what they have? So they're suffering but I was fortunate enough to have the support medically very quickly.

REP. ACKERT: Great. Thank you for coming and -- and testifying before us. Thank you, Madam Chair.

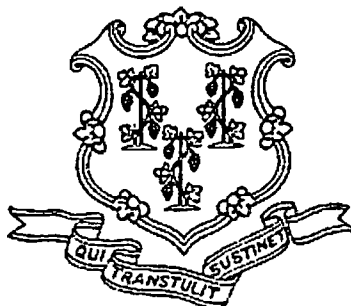
REP. RITTER: Thank you. Again we absolutely wish you the best. Thank you so much.

ANNA MIRABELLO: My pleasure.

**JOINT
STANDING
COMMITTEE
HEARINGS**

**PUBLIC
HEALTH
PART 4
1054 – 1417**

2011



**AFRICAN-AMERICAN AFFAIRS COMMISSION
STATE CAPITOL
HARTFORD, CONNECTICUT 06106-1591
(860) 240-8555
FAX (860) 240-8444**

Testimony before the Public Health Committee

Wednesday, March 2nd, 2011

10:00 am in Room 1D of the LOB

Good morning/afternoon Senator Gerratana, Representative Ritter and members of the Public Health Committee. My name is Frank Sykes the Legislative Analyst with the African-American Affairs Commission (AAAC) a non-partisan state agency. This Commission is an advocate for the African-American community and for the people. We accomplish our mission primarily through research, policy analysis, outreach and information sharing.

We are here today to testify in support of House Bill (HB) 6481 – An act concerning the establishment of a Lupus Education and Awareness Plan and (HB) 5608 – An act concerning the implementation of culturally and linguistically appropriate standards. In reference to HB 6481 we recognize that there is a need to educate the public and increase awareness about lupus. It is reported that Lupus affects more than 17,000 Connecticut residents and an estimated 1.5 million citizens in the nation. While it affects people of all races and ethnicities, research tells us that African-American women in particular are 2 to 3 times more

likely of developing this condition.¹ The symptoms of lupus tend to mimic the symptoms associated with other common illnesses such as the flu; the common cold etc. therefore diagnosing lupus can be overlooked or misdiagnosed. In view of this HB 5608 seeks to educate the medical community and public about the diagnosis, management and treatment of lupus. We are confident that the work of the panel will precipitate further insight and understanding of the lupus condition.

This leads me to HB 5608 – *An act concerning the implementation of culturally and linguistically appropriate standards*. Cultural competence for medical providers is critical for a number of reasons. First of all the demographics of Connecticut's population is changing. Immigration patterns, have led to significant increases in diverse populations that experience, cultural and language barriers. African-Americans even with health care coverage in some cases receive improper or incomplete medical attention partly due to a cultural misunderstanding. In view of these differences this population segment will need a continuum of services responsive to their unique cultural needs. Secondly understanding the cultural norms and history of different racial and ethnic groups will only lead to better outcomes in health care delivery for the medical providers and patients alike.

A few years back, the Connecticut Health Foundation conducted a survey of Connecticut physicians across 17 specialties. This survey identified a variety of gaps in physician education programs, as it relates to cultural competency. It revealed that fewer than 2 in 5 physicians received some kind of cultural competency training in medical school or residency, 70 percent were not even aware of educational programs in the area that they could take advantage of if they chose to and 80 percent of physicians working in small practices were least likely to have received any training in cultural literacy.² Finally strictly from a cost

¹ Connecticut Lupus Foundation

² Connecticut Health Foundation, *Providing Medical Care To Diverse Populations*

perspective strengthening the cultural competence of medical providers will mean improved health outcomes and overall help in reducing health care costs.

In view of these findings we urge you all to support both bills and thank you for the opportunity to testify.

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Testimony of
The Permanent Commission on the Status of Women
Before the
Public Health Committee
March 2, 2011

Re: H.B. 5608, AAC the Implementation of Culturally and Linguistically Appropriate Standards in Health Care Settings
H.B. 6481, AAC The Establishment of a Lupus Education and Awareness Plan

Senators Stillman and Welch, Representatives Ritter and Perrillo, and members of the committee, thank you for this opportunity to provide testimony on behalf of the Permanent Commission on the Status of Women (PCSW). PCSW is particularly concerned about gender, racial, and ethnic diversity in health care because there is a clear racial and ethnic disparity as African-American and Hispanic women are at a greater risk for certain diseases than White women. The extent of the problem with Asian populations is unknown due to lack of sufficient data. Both of the above referenced bills would directly impact gender health disparities.

H.B. 5608, AAC the Implementation of Culturally and Linguistically Appropriate Standards in Health Care Settings

As a member of the Commission on Health Equity, the PCSW supports passage of H.B. 5608, which would establish a collaborative committee to monitor the implementation of standards 4 to 7 of the Culturally and Linguistically Appropriate Standards issues by the United States Department of Health and Human Services' Office of Minority Health. Adopting such standards would:

- Make language access services readily available to diverse populations including patients with limited English proficiency.
- Ensure accountability for existing federal mandates among healthcare providers and facilities in Connecticut that receive federal funds

PCSW Testimony
Before the Public Health Committee
March 2, 2011
Page 2 of 2

- Provide an opportunity for committed health care entities to self-monitor their progress on an ongoing basis to implement and or improve compliance of federal mandated CLAS Standards.

H.B. 6481, AAC The Establishment of a Lupus Education and Awareness Plan

PCSW also recommends passage of H.B. 6481, which would establish an Interagency and Partnership Advisory Panel to raise awareness about lupus. This bill could impact the 17,000 people in CT who have lupus.¹ The vast majority of people with lupus are women – 90% of all individuals diagnosed with lupus are women and people of color.² African-American women are impacted by lupus at an earlier age, experience greater disease severity, have the highest overall death rates among all people with lupus and are three times more likely to die from lupus than their White counterparts.³

Public awareness is needed because most people do not realize they have a potentially disabling disease because symptoms, such as fatigue, skin rashes, joint pain and hair loss mimic other conditions, and are dismissed as a minor health condition. PCSW looks forward to working on this initiative

We look forward to working with you to address these important issues. Thank you for your consideration.

¹ Lupus Foundation of America, Connecticut Chapter. *Talking Points*, January 2011.

² Ibid.

³ Ibid.

Written Testimony of
Michael F. Ganino
Treasurer of the Lupus Foundation of America, Connecticut Chapter
March 2, 2011
Public Health Committee

**Testimony in support of HB6481, An Act Concerning the Establishment of a Lupus
Education and Awareness Plan**

Senator Stillman, Representative Ritter and members of the Public Health Committee. I am submitting the following written testimony in support of House Bill #6481 "AN ACT CONCERNING THE ESTABLISHMENT OF A LUPUS EDUCATION AND AWARENESS PLAN."

In 2007, I joined the Lupus Foundation of America Connecticut Chapter's Board of Directors. As the volunteer Treasurer, every day I see how hard our organization works to provide resources such as support groups and educational materials to those with lupus, but as the son of someone who has lupus, I've seen firsthand, the personal toll this disease can take on a loved one.

After years of seemingly endless doctor visits, none of which produced any significant diagnosis or improvements, my mom, Patricia Ganino, was diagnosed with lupus in 1991. As she was soon to discover, there were no support groups, no lists of doctors to visit and seemingly no one else to understand what she was going through. It would take years for her to realize that there were thousands of others in just Connecticut that were living with the same condition that she was.

Even back then we knew the best way to educate people about lupus was to talk about it, so in 1992, my senior year at SCSU, I choose "Living with Lupus" as my Communications class project. As I spoke, I realized the majority of my peers had never heard of lupus, despite the fact that more people were afflicted with lupus than multiple sclerosis, muscular dystrophy and cystic fibrosis...combined. . Lupus appeared to be a disease that no one talked about and even more people had never even heard of.

Since then, I've been introduced to hundreds of people living with lupus and those with loved ones or friends in similar circumstances. I've met those who have endured the effects of lupus for far longer than my mom has, and in some cases even more heartbreaking, young children with lupus. At every opportunity, I try to discuss lupus and how our organization can help those who suffer from it, even if it's only an opportunity for them to talk with another sufferer about shared experiences or how they cope with lupus.

It is for my mom and these individuals, especially the children, that I ask for your support of House Bill #6481. This bill, among other things will help develop and implement a comprehensive plan to improve education and awareness surrounding lupus for health care practitioners, public health personnel, patients and persons who may have lupus. I can only wonder how things would have been different for my mom had this bill been in place when she was diagnosed.

I'm sorry I could not offer my testimony in support of House Bill #6481 in person. Thank you again for introducing this important legislation. I'm confident that with your support, lupus will one day be a distant memory and with the high quality of home grown research facilities we have in our state, that this effort will begin in Connecticut and will have taken root in the passing of this bill.

Respectfully yours,
Michael F. Ganino

HB 481

Good Morning Senator Stillman and Representative Ritter and members of the Public Health committee. My name is Matthew Dolan, I live in West Hartford, and I am 28 years old. My wife Vanessa and I were married about 3 years ago, and about 2.5 years ago Vanessa was diagnosed with lupus. Before that Vanessa saw many doctors for many different symptoms, all of which were quite different and seemingly unrelated, but all were related to lupus. Before we understood that lupus was causing symptoms, the treatment process involved visits to different doctors with different specialties without the benefit of cooperation. All doctors treated the symptoms within their expertise, but no doctor actually addressed the disease. This cycle of treating symptoms but not their cause continued until a family friend suggested that lupus may be the cause. Since that time treatment has been focused on the cause of the problem, lupus, and the results have been significantly better. Vanessa started meaningful treatment, in part, because of a good friend with a keen eye.

This bill would be the first step toward building an awareness that would help others shortcut the frustrating cycle of treating various symptoms but not the cause. Learning to see lupus as a forest and not simply a collection of trees would help people see the right doctors, get meaningful treatment, and improve their quality of life sooner rather than later. Awareness of what lupus is and how to best address it on a systematic level is important for those with lupus, their families, and, ultimately, our communities. This bill will advance that goal. Please vote to pass this bill and encourage your colleagues to do the same.

Thank you very much.

Written Testimony of Corrienne Gagliardi

3/1/11

Public Health Committee

Testimony in support of HB6481, An Act Concerning the Establishment of a Lupus Education and Awareness Plan

Senator Stillman, Representative Ritter and members of the Public Health Committee. I am submitting the following written testimony in support of House Bill #6481.

Hello. My name is Corrienne Gagliardi, and I am 22 years old. I live in Newington, CT with my mother, step father, and siblings. My mother was diagnosed with Lupus almost 4 years ago, but that was no easy road to get to. She went away on vacation, and when she returned her ankles were extremely swollen. She called her primary doctor that she had had all her life. The doctor didn't feel the importance to see her immediately. He actually felt no importance to see her at all because of how "common" her symptoms were. A month went by without her being able to make an appointment, where she probably made the best decision of her life and get a second opinion. That doctor took one look at her ankles, ordered a lupus blood test, and figured out immediately what was going on. This sounds like its great news right? Well, that doctor also informed my mother that she was only two weeks away from dying. Her kidneys were below 40% functioning. This meant my mother had to go on endless medications, see doctor after doctor, just to try and save her life. If the first physician was aware of the symptoms that lupus exposed and how serious they were, she would have never been holding onto a mere thread of her life. The prednisone that my mother was taking made her gain 100 pounds, and completely took away her personality. It was so difficult to watch the strongest figure in my life slowly deteriorate in front of my eyes. Things just got worse when she had to go through all of the chemotherapy. Watching her get sick every day, loose her hair, how tired and worn down she was all the time, just to think that all of this could have been avoided had she just been diagnosed earlier.

If this bill was passed my mother would never have been that close to death. There is just no reason as to why lupus is something so many people have never heard of. I have an overwhelmingly large chance of getting lupus myself, and I would take comfort in knowing that there are people out there who are informed, who do know what is going on, and realize what a powerful disease lupus is. Affecting millions of people each and every year, it honestly still surprises me how little the world knows about it. How many millions more does lupus have to affect before the world hears about it?

Pass this new legislation and change the lives of millions. You have so much power right in your hands to make a difference for the state of Connecticut. What are you waiting for.

TESTIMONY

In Support of Raised Bill 6481 AAC The Establishment Of A Lupus Education And Awareness Plan

Public Health Committee
Wednesday, March 3, 2011

Dear Senator Gerratana, Representative Ritter, Senator Welch, Representative Perillo and members of the Public Health Committee:

I respectfully urge your support and favorable action on Raised House Bill No. 6481, AAC The Establishment Of A Lupus Education and Awareness Plan.

Currently I serve on the board of directors of the Lupus Research Institute, an organization founded by lupus patients and their families and dedicated to funding research to find better treatments and a cure for this dread disease. We are proud to join the Connecticut Chapter of the Lupus Foundation of America in an effort to promote education and awareness concerning lupus, and we would ask that in its final version this bill simply include the participation of both organizations.

In today's economic climate, we must collaborate between lupus organizations, between the state organizations and with federal initiatives in order to most effectively accomplish the goals set forth in HB6481.

The federal government's program, "Eliminating Health Disparities in Lupus Initiative" (EHDLI), funded through the Office of Minority Health is a national effort to train and educate healthcare professionals to diagnose this often unrecognized disease. Lupus is a significant national health issue that deserves a comprehensive and coordinated response by state and federal government with involvement of the health care provider, patient, and public health communities.

The goal is national but for them to succeed, we must do our part locally beginning with the passage of HB 6481. EHDLI serves as a growing and valuable resource for Connecticut to draw on in this public health initiative.

Page 2

Connecticut has world-class healthcare professionals, thousands of lupus patients and some of the finest medical schools and researchers anywhere. I find it shocking that the average lupus patient waits 3 to 5 years in what we call the "agony years" before she is diagnosed and receiving any treatment or disease management. 90% of lupus patients are women between the ages of 15 and 45, and it disproportionately affects women of color. A health disparity that remains unexplained.

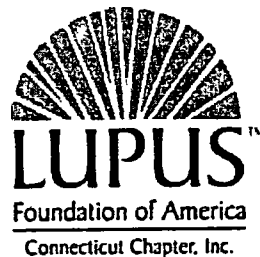
My younger sister was diagnosed at age 25 and lost a long and courageous battle with lupus just after her 50th birthday seven years ago. I know too well the challenges of a life with a chronic disease that is often not recognized or is misdiagnosed by physicians, and for which patients still await the first drug developed specifically for their treatment. Not one drug for lupus has been approved in over 50 years.

We must educate our healthcare providers so that they diagnose and therefore treat lupus patients. We must educate the citizens of Connecticut so that they recognize lupus symptoms and seek medical care. And we must support the scientific investigators as they work to unravel the mysteries of this little understood disease.

Your passage of HB 6481 and the ensuing education and awareness just might save the life of a young woman you know.

Thank you again for your time and consideration on this very important issue.

Hope Hetherington



Written Testimony of
Lisa Sartorius
The Lupus Foundation of America, Connecticut Chapter
3/2/2011
Public Health Committee

**Testimony in support of HB6481, An Act Concerning the Establishment of a
Lupus Education and Awareness Plan**

Senator Stillman, Representative Ritter and honorable members of the Public Health Committee The Lupus Foundation of America, Connecticut Chapter would first like to thank you for raising this important bill to help patients affected by this disease and improve the care they receive in Connecticut.

The Lupus Foundation of America, Connecticut Chapter (CTLFA) would like to express strong support of HB6481 and encourage its passage. The CTLFA is the foremost nonprofit health organization dedicated to finding the causes of and cure for lupus, and providing support, services, and hope to all people affected by lupus in the state. The Lupus Foundation of America and national network of chapters, branches, and support groups conduct programs of research, education, and advocacy to help all those impacted by lupus.

Lupus is a chronic autoimmune disease in which the immune system is out of balance, causing inflammation and tissue damage to virtually any organ in the body. People with lupus suffer from a total loss of control; many lose their jobs, their homes and their ability to care for their families. Thousands die each year from lupus in the U.S. Lupus can be unpredictable and potentially fatal, yet no satisfactory treatment or cure exists. Every half hour another person is diagnosed with lupus. An estimated 1.5 million Americans and over 17,000 people living in Connecticut have lupus. Despite these significant figures, for the majority of people living with lupus, they had to wait over 4 years and see three physicians before they were able to receive a proper diagnosis.

Ninety percent of the people who develop lupus are women. Young women ages 18 to 34 are least aware of lupus, yet they are the group that is most often affected. Uncontrolled or undiagnosed lupus during pregnancy may result in the death of the mother. This contributes to one-third of lupus-related deaths occur among individuals younger than age 45.

Lupus is also two to three times more common in women of color. 90 percent of all individuals diagnosed with lupus are women and People of Color, African-Americans, Hispanics/Latinos, Asians and Native Americans are two to three times more likely to develop lupus. As many as 1 in 250 African American women will develop lupus. African American women are impacted by lupus at an earlier age, experience greater disease severity, have the highest overall death rates among all people with lupus and are three times more likely to die from lupus than their Caucasian counterparts. Health effects of lupus include heart attacks, strokes, seizures, miscarriages, and organ failure.

There is an urgent need for an arsenal of new treatments as current therapies have side-effect profiles that often prove worse than the disease itself. The Lupus Foundation of America is committed to finding new treatments and a cure. We were excited to be able to work with Congress to secure funding for the U.S. Health and Human Services' Office on Women's Health (OWH) for the Ad Council Campaign, "Could I Have Lupus?" This national campaign funded at \$2.3 million has leveraged in another \$60 million in earned media. I do not tell you this fact because we have hope of getting a large appropriation, but to demonstrate the need and desire that is out there to know more about this devastating disease.

Currently, only one in five Americans is aware of lupus symptoms and it's health effects. Most people with lupus don't realize they have a potentially disabling and life-threatening disease because symptoms, such as fatigue, skin rashes, joint pain and hair loss mimic other conditions, appear differently in different people, and can increase or decrease in severity from day to day. There is no single test to diagnose lupus so it can take years to diagnose lupus. It is because of these factors that more than half of the people with lupus visited multiple doctors and suffered with the disease for years before being diagnosed.

The Lupus Education and Awareness Program (LEAP)

This legislation would create an Interagency and Partnership Advisory Panel who will be responsible for evaluating the current systems in place to educate patients and providers about lupus and developing a comprehensive plan to improve lupus awareness and education in the state. The goal of the plan would be to identify and address the lack of information and coordination around lupus identification and treatment in three key areas.

1. Public Education and Awareness-

What is most troubling about the lack of public awareness of lupus is that early recognition, diagnosis, and proper medical care often can reduce or prevent serious health complications, such as heart disease, strokes, seizures, and kidney failure caused by lupus.

2. Healthcare Practitioner Education-

Lupus is difficult to diagnose because some early symptoms may be dismissed as nothing serious. Because the disease develops most often in young people, and disease activity

can come and go over time, it is not uncommon for individuals with lupus to suffer several years before doctors make an accurate diagnosis.

If left untreated, the health consequences of lupus can be devastating and potentially fatal. One in four people with lupus is permanently disabled and thousands of people die each year from lupus complications.

3. Coordination of Public Health Efforts Concerning Lupus-

Current public health efforts surrounding lupus awareness and education have been disjointed, sporadic and not effective enough.

While most Americans are aware of the signs and health risks of breast cancer or heart disease, relatively few are aware of lupus which is another potentially fatal disease that disproportionately strikes young African American women between the ages of 15 and 45. Low awareness contributes to late diagnosis and treatment of this potentially fatal disease

There are many sources for educational materials, i.e. the Lupus Foundation of America, the Alliance for Lupus Research, the National Institutes of Health, the Centers for Disease Control and Prevention, the Social Security Administration, and the S.L.E. Lupus Foundation, concerning lupus identification and treatment that could be used part of an overall educational strategy.

As with any chronic disease early diagnosis and preventative treatments are vital in controlling what can be outrageous costs to the healthcare system. The average annual cost of medical treatment for a person with lupus is \$10,000 to \$30,000. This leads to annual costs totaling \$31.4 billion in direct and indirect costs in the U.S. and \$47,100,000 in total costs for Connecticut.

We urge the Public Health Committee and the Connecticut Legislature to join with Illinois (who has enacted this measure), Massachusetts, Rhode Island, and Washington (who are also in the early stages of consideration) and the lupus community here in Connecticut and across the United States to raise awareness and educate about lupus so that we may one day have better treatments that will eventually lead to a cure. By authorizing HB6481 you will be giving the 17,000 people in this state living with lupus a voice in becoming a partner in their fight.

Thank you again for your consideration of HB6481, we look forward to your support in fighting lupus.

Sincerely,

Lisa Sartorius
CEO/President
Lupus Foundation of America, CT Chapter

Written Testimony of

Pauline A. Brignano

Lupus Foundation of America, Connecticut Chapter, Inc.

March 1, 2011

Public Health Committee

Testimony in support of HB6481, An Act concerning the
Establishment of a

Lupus Education and Awareness Plan

Senator Stillman, Representative Ritter and members of the
Public Health Committee. I am submitting the following
written testimony in support of House Bill #6481.

My name is Pauline Brignano. I am one of many people in
Connecticut who suffer from lupus.

I am a volunteer for the Lupus Foundation of America (LFA),
CT Chapter

My history with lupus goes back to 1970's; however, after
seeing and being treated by four other physicians, it was
not until 1994 that I was referred to the University Of
Connecticut Health Center Dept. of Rheumatology. I was
presented with a severe rash, joint pain and debilitating
fatigue. I could barely walk and my fear was that I would
spend the rest of my life in a wheelchair. Fortunately, I
have the ability to walk and be here to give testimony.

It was at that time that I realized how little, if
anything, people knew about lupus so I became involved with

the Lupus Foundation to educate myself. As time went on as volunteer I participated in health fairs in various communities and was shocked to hear from people that had lupus, or had a relative, a friend or co-worker they knew who suffered or died with lupus and then asked the question, "What is lupus?" Imagine a mother, a sister or a brother with lupus and no one in the family knows anything about the disease or that they themselves unknowingly may have an increased risk of developing lupus. A majority of persons I spoke with were young people of color and had very little knowledge of lupus. This is disturbing, a fatal disease such as lupus strikes young African American woman between the ages of 15 and 45. What resources does a young family have when a mother is disabled with lupus? At present the chapter has two paid staff members and a handful of volunteers, reaching out to those in need of lupus information and education and we cover the entire State of Connecticut.

Bill 6481 The Lupus Education and Awareness Program (LEAP) will expand upon improving lupus awareness and education throughout our state, therefore, creating better recognition of lupus, earlier diagnosis and treatment which can reduce or prevent serious health complications. Families, Schools, physicians, employers and health care workers need to have a better understanding and awareness of lupus. Through the Department of Public Health and Partnership Advisory Panel, we will achieve our goal of greater education and awareness of lupus in the state of Connecticut.

Thank you again for introducing this important legislation. I believe it will have a positive impact on the lives of people living in Connecticut.

Written Testimony of Sheryl Candia
February 28, 2011
Public Health Committee
Testimony in support of HB6481, An Act Concerning the Establishment of a Lupus
Education and Awareness Plan

Senator Stillman, Representative Ritter and members of the Public Health Committee. I am submitting the following written testimony in support of House Bill #6481

I am a sixty-one year old, white, married, female, mother of seven grown children. My education is limited to High School, and some college; and when I was able to work I was a Special Deputy Sheriff for New Haven County. I live in a middle class neighborhood, in West Haven; from which I have resided for the past thirty four years.

I was finally diagnosed with Lupus, after suffering with many illnesses and ailments and excruciating pain for about four years. I couldn't seem to find a physician who knew a reason or a cause of all of my problems. Even now I will come across a physician who understands nothing about the disease of Lupus! I will say that I do have a group of many specialists for all of my individual health issues, that are very knowledgeable and helpful. However there are a list of people in the community that will show no compassion or understanding, for such a disease! These include Nurses and Physicians, and Pharmacists, as well as Dentists and regular neighbors. It is very frustrating to have the need to explain over and over what Lupus is and what it causes and does. If there was more awareness about Lupus, and more Physicians educated on the illness, many patients may not have to go through the frustration, and the months and years of wondering what is wrong with them. It is very frightening to feel so sick and be in so much pain, and have no one that can tell you what is wrong! No relief in sight!!!! It is also an awful feeling to have a Physician not believe you, or criticize you for the symptoms you are describing. I had one Physician tell me that he would have to put me through all the same tests, and scans etc. that I had already suffered through for the past four years. This was all because my diagnosing Physician had moved away. In my search for another Doctor, I encountered many very ignorant and uninformed Doctors, about the disease of Lupus. The mental and emotional abuse I was put through, should have been avoidable. Maybe if this Education and Awareness Plan was in place at that time; I wouldn't have had to suffer in that manner. I would like to hope that this Bill will save many people the agony that I experienced.

Thank you again for introducing this important legislation. I believe it will have a positive impact on the lives of patients living with lupus in Connecticut.

Sincerely,

Sheryl Candia

Written Testimony of Heidi Maynard

03-01-2011

Public Health Committee

**Testimony in support of HB6481, An Act Concerning the Establishment of a
Lupus Education and Awareness Plan**

Senator Stillman, Representative Ritter and members of the Public Health Committee. I am submitting the following written testimony in support of House Bill #6481.

I am 26 years old, and I was diagnosed with Lupus in 2004, my freshman year in college. I have lived in Connecticut my whole life, and I have seen more doctors than a typical family would see in their lifetime. My diagnosis, like many others was very complicated. I have had numerous health problems since I was a child and no one ever put the pieces together. I was officially diagnosed by a team of specialists at Yale New Haven Hospital. A spinal tap was done because I had lost all sensation in the lower half of my body. I had been tested for MS multiple times which is extremely scary to even think about. My family and I went through a very long and stressful time while they tried to diagnose me. No one in my family has ever had an auto immune illness, and my primary care doctor never even considered it. I had to withdraw from college as the stress was making my disease worse and the doctors didn't want anymore stress on my body. This was all very difficult to take in at 20 years old. My whole life was about to change and no one had any idea.

After I was officially diagnosed I started seeing a group of rheumatologists and other specialists to get me stabilized which took about 5 years. I have been taking handfuls of medication forever. I have finally gone into remission, and I am now 3 months pregnant which has brought up even more concerns for my health. I have been seeing many specialists but there are a lot of unanswered questions because the doctors just don't know the answers.

By passing this bill to put awareness and education out there would make a huge difference. I wish more doctors knew about Lupus, as it may not have taken so long for them to get me on the correct medications and stabilized. I could have completed college and been a normal 20 year old. I spent 5 years in a chronic state of pain and fatigue because the doctors just didn't know what was going on. This disease is just starting to finally get the much needed attention it deserves.

Thank you again for introducing this important legislation. I believe it will have a positive impact on the lives of patients living with lupus in Connecticut.

Heidi Maynard

Wethersfield, CT

March 1, 2011

Senator Stillman, Representative Ritter, and members of the Public Health Committee:

I am a physician and the head of pediatric rheumatology at Connecticut Children's Medical Center, as well as Professor of Pediatrics at the University of Connecticut School of Medicine. I am writing to you today in support of House Bill 6481. I evaluate and treat children and adolescents with systemic lupus, and have been doing so for the past 35 years. I wholeheartedly endorse the need for a Lupus Education and Awareness Plan in the state of Connecticut.

My partner and I currently evaluate 10 new lupus patients each year, and we are following approximately 50 kids with lupus currently. Here are several key points about pediatric lupus:

- There are perhaps 300 children in Connecticut with SLE at this time.
- It is more severe than the adult version of the disease. Kids get more severe kidney complications, and the survival rate is approximately 85% after 5 years.
- 40-50% of adolescents with lupus have brain disease, resulting in poor cognition
- Teens with SLE miss, on average, 20 days of school each year
- Depression and suicide can complicate pediatric lupus
- Certain medications can cause severe cosmetic disturbances

Early detection of SLE can be a life or death difference in children. We know that prompt recognition and treatment can improve survival and quality of life. I encourage the committee to pass this important legislation.

Sincerely,

Lawrence Zemel, MD
Chief, Division of Pediatric Rheumatology, CCMC
Professor of Pediatrics, University of Connecticut School of Medicine

Written Testimony of
Anita P. Kuan, PhD
3/2/2011
Public Health Committee

**Testimony in support of HB6481, An Act Concerning the Establishment of a
Lupus Education and Awareness Plan**

Senator Stillman, Representative Ritter and members of the Public Health Committee. I am submitting the following written testimony in support of House Bill #6481.

My name is Anita Kuan. I have lupus.

Growing up, I had "a bad case of the flu" every year. One year, I had one of the worst "flu" cases ever – complete with vomiting, 104°F fever, swollen joints, mouth sores, bleeding gums, fatigue ... the works. I was unable to eat and could not keep liquids down. I was dehydrated and had lost 40 pounds out of my then 125 pound frame (~1/3 of my body weight). After months of tests and trips to the doctors, still no one could explain what was happening to me. I was rapidly going downhill. I no longer noticed, or cared, what happened around me, or to me. Meanwhile, my mother kept asking questions, talking to friends, colleagues and doctors, and reading, always reading and trying to educate herself about childhood diseases, joint pain, etc. Her inquiries eventually brought her to a rheumatologist, Mitchell Forman, D.O. Dr. Forman took one look at me with my butterfly rash, fever, joint pain, and mouth sores and said simply, "lupus." Blood tests confirmed the diagnosis.

I had classic symptoms of lupus. A textbook case. Why had no one thought of lupus? If House Bill #6481 existed then, my doctors may have thought of lupus. But, it wasn't and they didn't. Yet, I was lucky. My mother was a scientist – she was an expert at asking questions and extremely persistent. She educated herself. She thought to get a rheumatologist's opinion. But, not everyone has a scientist as a parent.

If this bill was already in place, my doctors would have known about lupus. They might have diagnosed me. The disease could have been caught earlier, before it progressed so far. We could have tried less aggressive treatments. Perhaps high dose steroids would not have been necessary. I would not have the beginnings of cataracts in my eyes now (a side effect of steroids). I would not have missed so much of high school, of life. The time I did spend in the classroom, and outside the walls of my bedroom, may have been easier if people knew something of lupus. I was tired all the time. My face was a balloon and I had drastically gained weight (the result of high steroid doses). I was self-conscious and people can be cruel without realizing how much pain they are causing.

Fast forward 26 years. New decade. In fact, a new century. But, the story is still the same. How can this be? Today, patients can still go years without a diagnosis, all the while suffering needlessly. Not to mention the days of missed work, lost jobs, lost relationships, missed opportunities, all the while medical bills piling up. Why? Lupus is not a new disease. The systemic form of lupus (SLE) was described in the year 1872. The treatment of systemic lupus was revolutionized in the early 1950's by the

discovery of the efficacy of cortisone (steroids). But, here we are in 2011 and cases of lupus can still take months and even years before being properly diagnosed.

My grandmother always told me, study hard. Learn things. What you learn is yours. It's in your head and no one can take that away from you. Her wisdom would seem to apply here, too. Education and awareness – it's the starting point, and cornerstone, for so much in life. If my doctors were more informed about lupus, they would have realized I had lupus.

Having lupus has shaped my life. It also fueled an interest in autoimmunity. How does the immune system work? *How, where, and when* does *what* go wrong that makes the immune system attack self? I pursued my studies in immunology, received my doctorate degree and took a position at the University of Pennsylvania. I saw how public awareness can affect lupus research, both in funding for basic research and in clinical trials, e.g., obtaining a good sample size for basic research studies or sufficient patient participation for clinical trials. The squeaky wheel does get the grease. People have heard of cancer. They've heard of AIDS. They've heard of heart disease. They donate to the Cancer Foundation or the American Heart Association (all worthy causes). But, lupus? Not so much. I found funding for research was competitive and grants for lupus research limited. And unfortunately, my health was declining. I did obtain research support from The Arthritis Foundation, but this career path seemed to be stressing my already precarious health. When my grant ended, I left the academic world and tried my hand at medical writing. I was hoping for flexibility in work, while staying involved in ongoing biomedical research. It seemed to be working. My most recent lupus flare has made it difficult. It has been a long, unpredictable flare. I have improved, but am still on many medications in the attempt to control my symptoms (debilitating fatigue, nausea, joint pain, headaches and migraines, low blood counts).

If this bill was already in place, perhaps more people would understand the debilitating effects of lupus and its flares and remissions. I am well-educated (PhD). I believe I have marketable skills (several years experience in academics and in the medical communications industry). Yet, I find it difficult to find work that can accommodate the unpredictability of lupus. If more people had heard of lupus, it might be easier to explain my fatigue. Lupus would generally be seen as a legitimate disorder, and not all in your head. I am now freelancing and working whenever I am able.

I often think about others with lupus, whether they have been diagnosed yet or not, and I think of the wasted talent and resources. Because of the lack of awareness, the lack of better treatments, and the late diagnoses, many people often do not reach their full potential. Instead they suffer, while their talents and skills go wasted or are not fully utilized. It is a deep loss.

On the bright side, it is inspiring to see that lupus research is progressing. I hope that lupus awareness and research continues to advance and that funding and support for this serious condition improves.

Thank you again for introducing this important legislation. I believe it will have a positive impact on the lives of patients living with lupus in Connecticut.

I have had Lupus since I was 42 years of age. Was almost bed ridden for the first 10 years
an have been hospitalized on an off since. I am now 74 1/2 yrs old but still have many
complications Any bill that's passed will help people with this crippling an often deadly disease

Senator Stillman, Representative Ritter and members of the Public Health Committee. I am submitting the following written testimony in support of House Bill #6481.

I am the mother of a strong vibrant young man who was struck with lupus nephritis at the age of 11. It was fairly rare for a young boy to be struck with such an aggressive form of lupus. We were lucky that our pediatrician Dr. James Ralabate and the excellent doctors at Yale Children's Hospital were so quick and aggressive with his treatment or we may have lost him. Jake went through chemo for 6 months and was in and out of Yale multiple times. All that time, he was back and forth to school, and not only did the kids in school not know what lupus was - but neither did the teachers. He is 15 today and living with lupus every day. Jake, my son, is a sophomore at Stratford High School and a talented baseball player. Although he can tell you almost anything about lupus, it is very rare that anyone knows what it is. Even the adults around him. Although there are a few limitations in his life, he works with them and around them to live a happy and full life.

The motto "Someone you know has Lupus" is really true!

Please help educate the people of Connecticut about Lupus and how pervasive it really is.

Thank you again for introducing this important legislation. I believe it will have a positive impact on the lives of patients living with lupus in Connecticut.

*Thank you
Catherine Miko
59 Elmhurst Avenue
Stratford, CT 06614
203-377-7430*



Eric D. Fischer
Senior Director, Consumer Communication Solutions
UnitedHealthcare National Accounts
CT039-19B
185 Asylum Street, Hartford, CT 06103
Tel 860-702-7642; Fax 860-702-9830

Date: February 28, 2011

Re: Written testimony of Eric D. Fischer in Support of HB6481

To: Senator Stillman, Representative Ritter and members of the Public Health Committee

I am submitting the following testimony in support of HB6481, An Act Concerning the Establishment of a Lupus Education and Awareness Plan.

Thank you for reading my testimony. In addition to working at UnitedHealthcare National Accounts, I am also Vice Chair of the Lupus Foundation of America, Connecticut Chapter. I want to thank you for introducing this bill, in that it is so critical to so many people in three key areas:

- Building lupus awareness, both as a debilitating disease and in an effort to help the provider community properly diagnoses and treat the disease. In addition, because the disease disproportionately strikes minorities and women, increased awareness will help a significant portion of Connecticut's population.
- Investing in research to find a true cure. While the FDA is currently evaluating Benlysta, there hasn't been a new drug for this disease since Eisenhower was president.
- Providing support for those afflicted with this disease in part through monthly seminars and group meetings.

Again, thank you for your consideration, and thank you for introducing this bill.

Sincerely,

Eric D. Fischer
Senior Director, UnitedHealthcare National Accounts

Written Testimony of
James and Lorraine Rogers
Public Hearing 3/02/2011
Public Health Committee

Testimony in support of HB6481, An Act Concerning the Establishment of a Lupus Education and Awareness Plan

Senator Stillman, Representative Ritter and members of the Public Health Committee.

We are submitting the following written testimony in support of House Bill # 6481.

Because our daughter, Sharon, has lupus (Systemic Lupus Erythematosus), we know firsthand the need for increased education and awareness of lupus, both in the medical community and among the general public.

Lupus is a chronic, autoimmune disease that is debilitating and potentially fatal. Sadly, the complex, often seemingly unrelated symptoms, along with poor awareness of the disease among some doctors and the general public, make it difficult to diagnose. Sufferers often wait significant periods of time before seeking diagnosis or treatment. Yet, the faster they're diagnosed, the better chance they have at surviving and prospering. Our daughter is among the fortunate ones who was diagnosed relatively quickly. Yet we have heard of and met others who have been ill for literally years without being properly diagnosed and treated.

At the beginning of her illness, Sharon had debilitating headaches that lasted for 4-8 days without relenting, mental confusion while driving and taking public transportation, and intense fatigue that left her sleeping or resting up to 16 hours in a day. Her hands were often so numb that she had difficulty using her computer, which is how she earns a living. She had infections in her nose and ears, and severe joint pain that made it difficult, for example, to pour juice from a half-gallon container.

Yet, since she had recently moved back to the US after several years of working abroad and was unaware of lupus and its symptoms, she initially believed that she simply had a case of bad skin, a persistent cold, and stress-related pain and fatigue. She waited 6 weeks to seek a doctor, until even using the toilet became difficult.

After seeing several doctors for specific symptoms, she found a general practitioner who saw that the problems might be related and systemic. He referred her to a neurologist and a rheumatologist, as well as ordering a

range of blood tests. She was extremely fortunate that several of her specialists shared information and continued seeking a systemic explanation for her symptoms. Sharon was also fortunate that her doctors were persistent. Although initial blood work failed to show the markers of lupus, the dermatologist, whom she saw to treat a seemingly unrelated problem, the itchy, red bald spot on her head, suspected lupus was the cause and re-tested her. This time the blood work found definitive lupus indicators.

In all, 4 months passed from the time she first felt ill, to the time she began taking medication to quiet her out-of-control immune system and more than a year before the lupus flare died down and she entered a period of remission. Fortunately, treatment began before she had incurred permanent damage to her brain or kidneys or other organs. And with continued, life-long treatment, we all hope her lupus flares will be infrequent and not severe.

In addition to general lupus education and awareness, the medical community needs constantly updated knowledge of the drugs useful in treating lupus. Most of the drugs currently in use were originally developed to treat other diseases and have, over the years, been found to be also useful in dealing with lupus. It is vital that physicians be aware of the full range of drugs used, since many drugs have intolerable and deleterious side effects and some lose their effectiveness over time, so that trying alternative treatments is a common necessity.

Thank you again for introducing this important legislation. We believe it will have a positive impact on the lives of patients living with lupus in Connecticut.

James and Lorraine Rogers
1 Converse Rd.
Bolton, CT 06043
860-643-2558
Rogers1515@aol.com

To whom it may concern,

HB6481

My name is Gloria Teran, I writing regarding the Lupus awareness. Please pass the bill in CT, people need to be informed about lupus. .I wish my family and I were informed about Lupus disease earlier, so we could have helped my aunt deal with her disease. Also, I wished the doctors knew with my aunt had at the time and maybe my aunt would still be here with the rest of us. I am only 24 years old, I am not that old, but I feel so because we still are unaware of this disease. We do not have sufficient funds to find a cure either. Please do pass the bill, so we can safe lives in the future and no more families have to miss or dwell on their love ones.

Sincerely,
Gloria Teran

RE: Connecticut Lupus Bill

Written Testimony of Sean Mulligan, Uncle of a Lupus Patient

2/27/2011

Public Health Committee
Room 3000, Legislative Office Building
Hartford, CT 06106
Phone: 860-240-0560

Testimony in support of HB6481, An Act Concerning the Establishment of a Lupus Education and Awareness Plan

Senator Stillman, Representative Ritter and members of the Public Health Committee.

I am submitting the following written testimony in support of House Bill #6481.

- I am the Uncle of a Lupus Patient and I believe more Lupus Education must be done.
- I support the proposed CT Lupus Bill as being an important Educational Tool
- With more education families may be able to better identify and treat this condition.
- Lupus is a scary and potentially fatal disease that takes a toll on many people.

*Thank you again for introducing this important legislation.
I believe it will have a positive impact on the lives of patients living with lupus in Connecticut.*

Sincerely,
Sean Mulligan

Sean P. Mulligan
35 Oak Street #1
Stamford, CT 06905
(203) 981-1021
seanpmulligan@gmail.com

Written Testimony of
Lori Carpenter
3/2/11
Public Health Committee

**Testimony in support of HB6481, An Act Concerning the Establishment of a
Lupus Education and Awareness Plan**

Senator Stillman, Representative Ritter and members of the Public Health Committee. I am submitting the following written testimony in support of House Bill #6481.

My name is Lori Carpenter, my husband and I "were" the parents of a Lupus patient.

The summer of 1999 we brought our son for a routine physical for school. The pediatrician found irregularities in his blood tests which led to a CAT scan. Nothing was found in the scans so the pediatrician decided he was going to do periodic blood work as a follow up.

By the fall of 1999 more issues arose and he was hospitalized.

Looking back he wasn't a sick child but did develop colds and sinus infections quite often, could that have been a sign of things to come?

It took three weeks in the hospital for our eleven year old son to be diagnosed with Lupus (SLE) which involved several blood tests, scans and finally a kidney biopsy.

We thought great now we have a cause of the problem and the doctors will give us the answer. Unfortunately that wasn't the case. We were told not much is know about Lupus, it usually causes joint pain and is most common in African American women in their 20's. We looked online for any help we could find and it just wasn't out there. We went from kidney specialists to arthritis specialists even to pain management doctors with no direct answers or actually help.

At the time of his diagnosis (October 1999) we along with everyone we knew had no idea what Lupus was or how he ended up with it. At the time of his death at the age of 16 (September 24, 2004) still no one could give us the answer.

It was a long hard journey for Kyle. Everyone who loved him watched helplessly as he went from doctor to doctor all trying to figure out how and what to treat him with. There were many drugs and many side effects along with a surgery to place a catheter for peritoneal dialysis.

Kyle was dealing with many issues emotionally and physically. No eleven year old should have to go through this alone. The information available for him and for us, as parents was very limited.

With education, research and awareness of Lupus, we believe this could help the medical community; along with the general public have a better understanding on how to help other Lupus patients.

Thank you again for introducing this important legislation. I believe it will have a positive impact on the lives of patients living with lupus in Connecticut.

Email Public Hearing Testimony to:

PHC.Testimony@cga.ct.gov

Mailing Address:

Public Health Committee
Room 3000, Legislative Office Building
Hartford, CT 06106
Phone: 860-240-0560

Written Testimony of
Mary Luciano
Newington, CT 06111
Parent of affected Child with Lupus Nephritis
3/2/11
Public Health Committee

**Testimony in support of HB6481, An Act Concerning the Establishment of a
Lupus Education and Awareness Plan**

Senator Stillman, Representative Ritter and members of the Public Health Committee. I am submitting the following written testimony in support of House Bill #6481.

My name is Mary Luciano. I am a parent and care giver of an amazing 17 girl afflicted by the horrible disease with no cure. I represent a family that is now reliving the same process that took place 40 years ago when my mother-in-law died from this same disease due to lack of knowlege and access to physicians that knew how treat this disease.

This bill is so important to pass. Every day I am explaining and sharing with people the devastation this disease has had on my daughter and family. In the three years since we have been LIVING with this disease. I have spoken to hundreds of people who are unaware of what this disease is, what it does and what isn't available for resources. I have educated the teachers who are responsible for my daughters education. I have spoken at lengths with physicians that are not hands on with this type of disease. There is still lots of education that needs to be done and provided to the employers for the parents/spouses who take care of our children/spouses and have to take FMLA, schools where children try to be every day no matter how they are feeling. There is an urgent need to have every bit of information available to the public, support groups, physician offices to get current materials for their patients and families.

Thank you again for introducing this important legislation. I believe it will have a positive impact on the lives of patients living with lupus in Connecticut.

Written Testimony of:

Amanda Danielle Faught
March 2, 2011
Public Health Hearing

Senator Stillman, Representative Ritter and members of the Public Health Committee,

I am submitting the following testimony in support of House Bill #6481.

As a young woman living with lupus, I can speak first hand about the complications, and the physical and emotional implications that come with the disease. I was a young, active college student when I first got sick 7 years ago. What started as headaches and fatigue, turned into a life-changing experience. From hair and memory loss, to crippling pain and weight loss, the disease is merciless. Over the last 7 years, I have aged about 70. The pain, stiffness and fatigue I face on a daily basis is at best, limiting. At its worst, it is debilitating. While I have learned to be strong, prioritize my life and deal with the symptoms the best way I know, one of the most difficult aspects of dealing with the disease is the lack of awareness about it.

Without understanding, there is no compassion. Without compassion, there is no sense of community. Without a community, people suffering from lupus are left alone in the fight against this crippling disease.

This bill is a means to giving us the voice we need. We deserve to be heard, and we deserve the chance to be understood and to continue working toward a better quality of life.

Thank you for introducing this important legislation. I believe it will have a positive impact on the lives of patients living with lupus in Connecticut.

Amanda Faught

Written Testimony of

Marilyn Sousa

3/1/2011

Public Health Committee

REVISED

**Testimony in support of HB6481, an Act Concerning the Establishment of a
Lupus Education and Awareness Plan**

Good morning Senator Stillman, Representative Ritter and members of the Public Health Committee. Thank you for giving me the opportunity to testify in support of House Bill #6481. My name is Marilyn Sousa and I am a Lupus patient.

I was diagnosed in 1973 with a disease that I could not pronounce nor could I understand. , nor could I find anyone else who could pronounce it or understand it. My Doctor told me not to read anything about it, not to get pregnant and to stay out of the sun. But of course I did read about it and the only information I could find was that it was a fatal disease within five years. So he prescribed prednisone, and I learned that it caused many side effects, including bone loss, eye problems to name a few. I realized there was a great need for education and awareness about this disease so I founded the CT Lupus Chapter and organized support groups for Lupus awareness and education for the public. There is still much more to be done.

Marilyn Sousa
West Hartford, CT

Written Summary of Anna Mirabello

3/1/11

Public Health Committee

**Testimony in support of HB6481, an Act Concerning the
Establishment of a Lupus Education and Awareness Plan**

Senator Stillman, Representative Ritter, and the members of the
Public Health Committee, I am submitting the following written testimony
in support of House Bill #6481.

My name is Anna Mirabello, and I am a current resident of
West Hartford Connecticut. I am 13 years old, am in 8th grade and am in full
support of the bill. I was diagnosed with Lupus 3 years ago and it has not
been an easy battle. Though it was tough at times, I also learned that it is
very manageable with proper care. Raising awareness about Lupus is so
important because each person informed about this auto immune deficiency,
is one person or one step closer to a cure for the disease. About 500,000
people are affected by Lupus in the U.S., 90% of them being women and
young ladies. I have been fortunate enough to have gotten a diagnoses and
treatment to help manage it. However, there are many people out there, I'm
sure, that haven't been tested, who are weak, under-weight, and wondering
why everything hurts all the time. What I am hoping this bill will do, is raise

awareness and help people get diagnosed and get them started on treatment. I'm also hoping that it will lower the amount of invasive procedures that are done when being tested during a flare. This bill will benefit all the patients dealing with lupus and will help all their friends, family, and supporters know more about it, to hopefully help foresee the signs of a flare and stop them quicker. I have learned that this deficiency is very manageable when you know the telltale signs of a flare and how to treat them, but with out the treatment available, or lack of knowledge about it, many are living in pain and suffering. Over all, passing this bill will help so many people and families dealing with the disease and the whole community if they get educated on the topic.

Thank you again for introducing this important legislation. I believe it will have a very positive impact on the lives of patients living with Lupus in Connecticut.

Written Testimony of
Tonya Lynne Plefka
3/2/2011
Public Health Committee

**Testimony in support of HB6481, An Act Concerning the Establishment
Of a Lupus Education and Awareness Plan**

Senator Stillman, Representative Ritter and members of the Public Health Committee. I am submitting the following written testimony in support of House Bill #6481.

I am here today in support of Bill #6481, and in hopes of increasing Lupus awareness and education in the state of CT. I am a survivor of Lupus. As you may or may not be aware, Lupus is an extremely debilitating disease as debilitating as Lyme Disease if not worse. It is an autoimmune disease that causes the body to attack itself and attack the body's most vital organs including the heart, kidneys, lungs and liver. I would like to share my personal story with you. I was diagnosed in 2004 at the age of 30 during a routine doctor's appt. with my PCP in Manhattan, and had a positive ANA test. At that time I was immediately referred to a Lupus Specialist/Rheumatoid Arthritis Specialist Doctor Robert Fafalak of Manhattan. I am one of the lucky ones who was diagnosed immediately, treated aggressively, cured within a year, and fortunately it has not recurred. So often though, that is not the case. I am one of the 2% in the country where it has not recurred. My Physician Dr. Fafalak treated my Lupus very aggressively for a period of 1 year with the drug methotrexate, which is used most often to treat cancer. During that time because I was ill from both the medication and the illness itself, I was unable to work and was bedridden for an entire year. As a result of the Lupus I had many devastating life altering symptoms including losing 75% of my hair, gained 60 lbs which was caused by the side effects of the medication, the disease itself, and of course inactivity. Many of my other symptoms included: mini strokes, numbness in my hands and arms, overall weakness and complete exhaustion, dizziness, asthma, high blood pressure and Sjogren's Syndrome. To this day I still suffer from Sjogren's Syndrome and have severe sinusitis as a result, and every 2 months to due to dry eye I am required to have tear duct punctal insertion at my Optometrist office which costs 500.00 per visit. I am also constantly battling fatigue and have to devote 8 solid hours a night to sleep in order to avoid exhaustion and function properly throughout the day. Though I am healthy and working full time, I am still affected by the residual effects of Lupus.

Because so many women and men throughout the country, 1.5 million in the United States, are diagnosed with this debilitating disease I am here today asking you to support this bill in order to increase LUPUS advocacy, awareness, support, and research funding in the state of CT. I believe that with increased funding in my lifetime we will be able to find a cure. And with increased awareness and education, patients will be diagnosed in a quicker time frame, treated properly with the correct and safest medications available, and will be able to be treated by Doctors who are knowledgeable about Lupus and who

specialize in the treatment of Lupus. In addition, increased awareness and education will then lead to health insurance coverage for all those who suffer from Lupus.

At this time if I may, I would like to touch on health insurance briefly, because it is such an issue for myself and others in CT who suffer from Lupus currently, or who have been diagnosed previously. In 2010 I was denied health insurance in the state of CT by United Health Care through the broker Golden Rule, and was blatantly told by Golden Rule that the reason I was being denied coverage was because I "was diagnosed with the Lupus in the past." After hearing this, I immediately explained to Golden Rule that I have not had Lupus for 6 years and it has never recurred. I also indicated that my Physicians in NY had submitted and faxed signed letters stating that I have not had lupus for 6 years. I proceeded to question Golden Rule asking "how much time has to pass before United through Golden Rule will cover someone who has had Lupus without a recurrence of the illness?" I was immediately told by Golden Rule that they "do not insure anyone who has been diagnosed with Lupus even if 20 years, 25 years or 5 years has gone by without a recurrence, anyone who has had Lupus in the past is outright denied." I currently have individual health insurance however, because I have had Lupus I can only qualify for high risk health insurance in the state of CT, through Health Reinsurance Association of CT. When applying for individual health insurance, I am immediately put into a "high risk" category because of my past Lupus. My health insurance is 900.00 per month which is exorbitant to say the least, and it is twice the amount per month of what I would have paid through Golden Rule but because I am put into a high risk category in the state of CT, the least expensive individual health insurance I can obtain is 900.00 per month. In addition if my Lupus ever recurs, my health insurance company may drop me immediately and they do not cover Lupus medication as stated in my contract. This is a scary fact and the scary reality that many Lupus patients or past sufferers of Lupus in the state of CT face on a daily basis. And those who suffer from Lupus may not even be able to obtain insurance or keep health insurance in order to receive the medical care for their Lupus they deserve and require. What is also worth mentioning is that Lyme Disease which is also equally debilitating and devastating is covered by United Health Care through Golden Rule, is not considered high risk by United Health Care in general, and all medication including home IV therapy for Lyme Disease which is extremely costly is fully covered by United Health. Why is it that Lyme Disease is respected by these insurance companies and taken seriously, yet Lupus is not? Why is Lupus not given the same respect?

I am asking today that the lawmakers and legislation of CT realize how devastating and debilitating Lupus is, and as a result facilitate this bill. I truly believe that this legislation is a positive beginning, and bring hopes of Lupus finally receiving the respect and recognition it deserves, and the education and funding it demands. With this legislation also brings great hope to the Lupus sufferers of CT that one day soon, a cure will be attained.

Thank you again for introducing this important legislation. I believe it will have a positive impact on the lives of patients living with Lupus in CT.

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**CONNECTICUT
GENERAL ASSEMBLY
SENATE**

**PROCEEDINGS
2011**

**VOL. 54
PART 6
1735- 2085**

djp/gbr
SENATE

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May 12, 2011

(Chamber at ease.)

SENATOR LOONEY:

Madame President.

THE CHAIR:

The Senate will come back to order.

Senator Looney.

SENATOR LOONEY:

Thank you, Madame President. Madame President another item to mark, I want to mark it go and have it be called as the next item. That is Calendar page 24, Calendar 472, substitute for House Bill 6481, AN ACT CONCERNING THE ESTABLISHMENT OF A LUPUS EDUCATION AND AWARENESS PLAN.

THE CHAIR:

Mr. Clerk.

THE CLERK:

Madame President, calling from the top of page 24, Calendar 472, substitute for House Bill 6481, AN ACT CONCERNING THE ESTABLISHMENT OF A LUPUS EDUCATION AND AWARENESS PLAN, as amended by House Amendment Schedule "A", LCO 5885, Favorable Report of the Public Health and the Government Administration and Elections

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Committees.

THE CHAIR:

Senator Gerratana.

SENATOR GERRATANA:

Thank you, Madame President. Good afternoon.

THE CHAIR:

Good afternoon.

SENATOR GERRATANA:

Madame President, I move acceptance of the joint committee's Favorable Report and passage of the bill in concurrence with the House.

THE CHAIR:

Acting on approval of the bill, will you remark?

SENATOR GERRATANA:

Thank you, Madame President. The bill before us is a bill which establishes within the Department of Public Health an interagency and partnership advisory panel on Lupus. Lupus as many people know is a chronic inflammatory disease that occurs and affects the body's immune system and attacks its own -- has the body attack its own tissues and organs. This is a bill that comes at a very timely fashion and way, Madame President, this month of May, 2011 is Lupus awareness month. Thank you, Madame President.

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THE CHAIR:

Will you remark? Senator Welch.

SENATOR WELCH:

Thank you, Madame President. I too rise in support of this bill. Lupus is a disease that has impacted my family in very challenging ways so anything we can do to bring awareness of this situation to create a task force to better understand this disease that has ravished and hurt so many is a good thing and I too rise in support of this bill. Thank you, Madame President.

THE CHAIR:

Thank you, Senator Welch.

Will you remark? Senator McKinney.

SENATOR MCKINNEY:

Thank you, Madame President. I also rise in support of the bill before us and echo the comments of Senator Welch. Not too long ago I stood in the circle and asked for a moment of silence for a former House colleague, I believe of yours, Madame President, former Representative Carl Dickman who passed away recently.

I don't think many of his colleagues know that Carl also had Lupus as well and so I think Carl is

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smiling up there somewhere, his Red Sox are doing well and now the Legislature's making some positive movement on Lupus. So, thank you Senator Gerratana for brining this forward.

THE CHAIR:

Thank you, Senator McKinney.

Will you remark? Will you remark? Senator Gerratana.

SENATOR GERRATANA:

Madame President, if there is no objection, I request this be moved to the Consent Calendar.

THE CHAIR:

Seeing no objection, so ordered.

Senator Looney.

SENATOR LOONEY:

Madame President, if we might stand at ease for just a moment.

THE CHAIR:

Senate will stand at ease.

(Chamber at ease.)

THE CHAIR:

The Senate will come back to order. Senator

the Clerk might call the items on the second Consent Calendar so that we might move for a vote on that second Consent Calendar.

THE CHAIR:

Mr. Clerk, please call the bills.

THE CLERK:

Madame President.

THE CHAIR:

Mr. Clerk.

THE CLERK:

Starting on page 4, Calendar 102, page 5,
Calendar 125, page 6, Calendar 191, page 7, Calendar
104, page 9, Calendar 187, page 11, Calendar 287, page
12, Calendar 240, page 12, Calendar 328, page 12,
Calendar 334, page 14, Calendar 366, page 17, Calendar
318, page 18, Calendar 338, page 24, Calendar 472,
page 34, Calendar 176, page 37, Calendar 90, page 43,
Calendar 197, page 46, Calendar 251. These are the
items that the Clerk has on the second Consent
Calendar.

HB6176

SB153

SB1078

SB1069

HB6445

HB6484

SB38

HB6481

SB958

THE CHAIR:

Mr. Clerk will you now call for a roll call vote and the machine will be open on Consent Calendar two.

THE CLERK:

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An immediate roll call vote on Consent Calendar two has been ordered in the Senate. Will all Senators please return to the Chamber? An immediate roll call vote on Consent Calendar two has been ordered in the Senate. Will all Senators please return to the Chamber?

THE CHAIR:

Mr. Clerk will you please call the roll call vote again, please?

THE CLERK:

An immediate roll call vote on the second Consent Calendar has been ordered in the Senate. Will all Senators please return to the Chamber? An immediate roll call vote on the second Consent Calendar has been ordered in the Senate. Will all Senators please return to the Chamber?

THE CHAIR:

Have all members voted? Have all members voted? The machine will be locked and the Clerk will call the tally.

Do you want to call it again and this time we'll all -- we're going to recall that vote.

THE CLERK:

An immediate roll vote call has been ordered in

the Senate. Will all Senators please return to the Chamber?

THE CHAIR:

The machine will be open.

Have all members voted? All the members voted the machine will be locked and will the Clerk please call the tally.

THE CLERK:

Madame President,

Total Number voting 34

Necessary for adoption 18

Those voting Yea 34

Those voting Nay 0

Those absent and not voting 2

THE CHAIR:

The Consent Calendar number two has been adopted.

Senator Looney.

SENATOR LOONEY:

Thank you, Madame President. Madame President that will conclude our business for today but at this point would yield the floor for any members for purposes of announcements of committee meetings or other points of personal privilege.

THE CHAIR: