Act Number:	09-020	
Bill Number:	6263	
Senate Pages:	1709-1713, 1819-1821	**8**
House Pages:	1139-1150	**12**
Committee:	Public Health: 74-78, 192-206, 529-542	**34**
	Page Total:	**54**

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Aye.

THE CHAIR:

Opposed, nays.

The ayes have it. Senate Amendment A is adopted. Senator LaBeau.

SENATOR LeBEAU:

If there's no objection, could we move this bill to the consent calendar?

THE CHAIR:

Motion is on the floor for consent on Senate Bill 881 as amended by Senate A. Seeing no objection, so ordered, sir. Mr. Clerk.

THE CLERK:

Calendar number 244, File Number 20, House Bill 6263, AN ACT REQUIRING THE ADMINISTRATION OF A SCREENING TEST FOR CYSTIC FIBROSIS TO NEWBORN INFANTS, favorable report of the Committee on Public Health.

THE CHAIR:

Senator Harris.

SENATOR HARRIS:

Good afternoon. I'm over my jet lag, Mr. President.

THE CHAIR:

Good afternoon. We'll be into evening pretty soon.

SENATOR HARRIS:

I move acceptance of the joint committee's favorable report and passage of the bill.

THE CHAIR:

Acting on approval and acceptance of the bill, will you remark further, sir?

SENATOR HARRIS:

Thank you. I will, Mr. President.

This bill requires all health care institutions that care for newborn infants to test them for cystic fibrosis, a condition that's very dangerous, life threatening, of course, and affects one in every 3,5000 births. The only exception to the testing would be as we have in other areas of the law, if the parents object on religious grounds. I urge on passage of the bill, Mr. President.

THE CHAIR:

Thank you, sir. Will you remark further on the bill? Senator McLaughlin.

SENATOR McLACHLAN:

Thank you, Mr. President. Through you, for

the purpose of question and comment on the bill.

THE CHAIR:

Senator Harris.

Please proceed, sir.

SENATOR McLACHLAN:

Thank you, through you, Mr. President. Senator Harris, I wonder if you could share with us the reason why only half of the babies born in Connecticut are tested, currently.

THE CHAIR:

Senator Harris.

SENATOR HARRIS:

Through you, Mr. President, well, there is no requirement for testing. There are also people that object to testing and so there are numerous reasons why, there, not everyone is covered, but this Bill would get to the heart of that and make it a requirement of all health care institutions that care for new born infants to test for cystic fibrosis.

THE CHAIR:

Senator McLaughlin.

SENATOR McLACHLAN:

Thank you, and through you, Mr. President,

will this have any significant impact on the cost of insurance for Connecticut residents? Through you, Mr. President.

THE CHAIR:

Senator Harris.

SENATOR HARRIS:

Mr. President, no. It is -- I am understanding that it will not.

THE CHAIR:

Senator McLaughlin.

SENATOR McLACHLAN:

Thank you, Mr. President. I'd like to support this bill vigorously, and thank Senator Harris for his hard work on this and the Public Health Committee. I also would like to remind this circle that my predecessor, former Senator Cappiello, worked on this for a period of time, but especially, I want to acknowledge, if I may, residents from the city of Danbury, Jahad and Kathy Sibah, who have worked on this issue for many years since their eldest son, Ryan Sibah, was diagnosed with cystic fibrosis and has since past away from that disease. This is a great day for the Sibah family. I urge this circle to support

this bill and urge passage. Thank you, Mr. President.

THE CHAIR:

Thank you, Senator McLaughlin.

Will you remark further on the bill? Senator Harris.

SENATOR HARRIS:

Thank you, Mr. President. For the second time, I just want to thank Senator McLachlan for his questions and support of the Bill. Senator Debicella also played an important role. And this is very important as the Senator said, because early diction means early and prompt treatment, which can extend the lives and the quality of life of the children suffering from cystic fibrosis and also have a beneficial effect on our health care cost. By detecting early we can help lower our health care costs, which is what we're striving to do.

And Mr. President, there is no objection, I'd ask that this be placed on the consent calendar.

THE CHAIR:

There's a motion on the floor to place the item on consent. Without objection, so ordered.

Senator Looney.

SENATOR LOONEY:

Yes. Mr. President, that item might be marked passed, retaining its place on the calendar.

THE CHAIR:

Without objection, so ordered, sir. Senator Looney.

SENATOR LOONEY:

Yes. Mr. President, if the remaining items that we had marked earlier, Calendar page 28, Calendar 367; Calendar page 29, Calendar 415; might also be marked passed, retaining their place on the calendar. And if the Clerk might proceed to vote on the consent calendar.

THE CHAIR:

Mr. Clerk, please call consent calendar.

THE CLERK:

Roll call has been ordered in the Senate on the consent calendar. Will all senators please return to the chamber. Roll call has been ordered in the Senate on the consent calendar. Will all senators please return to the chamber.

Mr. President, before voting on the consent calendar, those items placed on the consent

calendar began on calendar page 3, Calendar Number 165, substitute for Senate Bill 781; Calendar page 4, Calendar 208, substitute for Senate Bill 881; Calendar 244, House Bill 6263; Calendar page 7, Calendar 394, substitute for House Bill 5834; Calendar page 17, Calendar Number 102, substitute for Senate Bill 710; Calendar page 19, Calendar 145, Senate Bill 974; Calendar page 20, Calendar 155, substitute for Senate Bill 451; Calendar page 22, Calendar 198, Senate Bill 989; Calendar page 23, Calendar 222, substitute for Senate Bill 957; Calendar page 28, Calendar Number 354, substitute for Senate Bill 499. Mr. President, I believe that completes those items previously placed on the consent calendar.

THE CHAIR:

Okay. The Clerk, please call the consent calendar for a roll call. The machine will be open.

THE CLERK:

Immediate roll call has been ordered in the Senate on the consent calendar. Will all senators please return to the chamber. Immediate roll call

has been ordered in the Senate on the consent calendar. Will all senators please return to the chamber.

THE CHAIR:

Have all senators voted? If all senators have voted, please check your vote. The machine will be locked. The Clerk will call the tally.

THE CLERK:

Motion is on adoption of Consent Calendar Number 1.

Total Number Voting	35
Those voting Yea	35
Those voting Nay	0
Those absent and not voting	1

THE CHAIR:

The consent calendar passes.

Senator Looney.

SENATOR LOONEY:

Yes. Thank you, Mr. President. Mr. President, I believe the Clerk is in possession of Senate Agendas 1 and 2.

THE CHAIR:

Mr. Clerk.

THE CLERK:

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Those voting Nay 0

Those absent and not voting 9

SPEAKER DONOVAN:

The bill is passed. Will the Clerk please call Calendar Number 78.

THE CLERK:

On page 4, Calendar 78, House Bill Number 6263, AN ACT REQUIRING THE ADMINISTRATION OF A SCREENING TEST FOR CYSTIC FIBROSIS TO NEWBORN INFANTS, favorable report of the Committee on Public Health.

SPEAKER DONOVAN:

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker. Mr. Speaker, I move for acceptance of the Joint Committee's favorable report and passage of the bill.

SPEAKER DONOVAN:

The question before the Chamber is acceptance of the Joint Committee's favorable report and passage of the bill. Will you remark?

REP. RITTER (38th):

Mr. Speaker, thank you, Mr. Speaker. Mr. Speaker, this bill requires all health care institutions caring for unborn infants to test them

for cystic fibrosis, unless, as allowed by law, their parents object on the basis of religious grounds. It requires this testing to be done as soon as medically possible. Under the bill, the cystic fibrosis test will remain separate from but additional to the current newborn screening tests that we routinely do in our hospitals today. I urge acceptance of the Joint Committee's report and passage of the bill.

SPEAKER DONOVAN:

Thank you, representative. Will you remark further? Remark further? Representative Giegler.

REP. GIEGLER (138th):

Thank you, Mr. Speaker. This bill, during our public hearing, there was compelling testimony from families whose children have cystic fibrosis, stating that this life-threatening genetic disease with early detection has a documented benefit. I would like -- through you, Mr. Speaker, I have a question to the cochair of the Public Health Committee.

SPEAKER DONOVAN:

Please proceed.

REP. GIEGLER (138th):

Thank you, Mr. Speaker. Does Subsection B of this bill add cystic fibrosis testing to the newborn

screening program operated by the Department of Public Health and therefore, entail a cost to the State for expanding the screening program? Or is it the intent of this bill to require hospitals to arrange and pay for this testing outside of the state program? Thank you, Mr. Speaker.

SPEAKER DONOVAN:

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker. I would first like to thank Representative Giegler for her summation of the compelling testimony that we heard in regards to this bill. It really was very powerful. In answer to her question, I would direct your attention to lines 33 through 35 of the bill. The wording is as carefully stated there to clearly state that the intent of the bill is to require that the hospitals arrange -- and arrange to have paid for, the cystic fibrosis screening outside of the Department of Health Newborn Screening Program. Therefore, there's no additional cost to DPH for arranging for this screening. Thank you, Mr. Speaker.

SPEAKER DONOVAN:

Representative Giegler.

REP. GIEGLER (138th):

Thank you, Mr. Speaker, and I thank the cochair for her answer. And I urge my colleagues' support of this very important bill. Thank you.

SPEAKER DONOVAN:

Thank you, Representative. Representative Carson.

REP. CARSON (108th):

Thank you, Mr. Speaker. I too rise in support of this bill. One of the things that I wanted to bring forward was, and not a surprise to us now, that our former Senator David Cappiello is in this Chamber today. And senator -- former Senator Cappiello fought long and hard for this bill to become a reality.

I am very, very pleased that, finally, he's here in some way shape or form to see the fruit of all his hard labor. I would also like to say that for anyone who is in doubt about this bill, we are the only state in the union who does not test for cystic fibrosis. Some hospitals do on a voluntary basis but, we're the only ones who don't have this as part of our newborn screening, or at least now, in this form. So I stand in strong support of this legislation. I think it's great public policy, and I encourage my colleagues to

vote for this. Thank you.

SPEAKER DONOVAN:

Thank you, Representative. Representative Rowe.

REP. ROWE (123rd):

Thank you. Thank you. Good afternoon, Mr. Speaker.

SPEAKER DONOVAN:

Good afternoon, Representative.

REP. ROWE (123rd):

Thanks. A couple brief questions to the proponent. Was there any -- I know there was some compelling testimony indicated in favor -- was there any opposition at the public hearing to this from any corners?

SPEAKER DONOVAN:

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker, and you're correct. There was compelling testimony in favor of the bill. There were some questions and concerns about the bill, and no substantive opposition to this bill that I am aware of.

SPEAKER DONOVAN:

Representative Rowe.

REP. ROWE (123rd):

I didn't -- you said there was no substantive opposition. I just missed the word.

SPEAKER DONOVAN:

Representative Ritter. Excuse me, Representative. I don't know if the microphone is not working --

REP. RITTER (38th):

How is that?

SPEAKER DONOVAN:

That's much better.

REP. RITTER (38th):

That is correct.

REP. ROWE (123rd):

I read your lips that time, so I got that. And also, how is a newborn -- is that a blood test that a newborn goes through?

SPEAKER DONOVAN:

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker. Yes, you are correct, Representative Rowe.

REP. ROWE (123rd):

Do you have any figures on how may different

tests we administer to newborn babies? I think the answer is a lot, but I'm not sure how many we do. Through you.

SPEAKER DONOVAN:

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker. The answer is a lot. You are correct. We did have some discussion around this because -- and in the process, learned quite a bit about that testing. Shortly after birth, it is a testing done by a stick in heel, and it's a blood test. This would, in most cases, resolve in a second test, as I indicated in my earlier testimony, to be done at the same time.

SPEAKER DONOVAN:

Representative Rowe.

REP. ROWE (123rd):

Thank you. It's -- I think I'll be supportive. It's a shame that we have to poke and prod, and do so much to our newborn babies when they're fresh out of the womb. They're crying enough and we're going to make them cry some more, I guess. But if it saves some long-term major problems, then I guess, it's worth it. Maybe a final question, you talked a little

bit before with Representative -- I don't remember who it was. And you talk about the costs. If the hospital is not footing this bill, do we expect that most insurance companies foot it, and if not, I suppose it will be the parents -- and asking the compound question, do you know what this test would cost? Through you, Mr. Speaker.

SPEAKER DONOVAN:

Representative Ritter.

REP. RITTER (38th):

Thank you, Mr. Speaker. I'll answer those questions, although not perhaps in the same order you answered them. The cost of the testing, we heard in testimony at the University of Connecticut Health Center, is currently $15. And you are correct about the coverage of the test. And I think -- was that all your questions, or did you have a question about numbers?

SPEAKER DONOVAN:

Representative Rowe.

REP. ROWE (123rd):

No. I think that wraps it up. I thank the gentle lady for her responses. I thank Representatives Hamzy and Barry for standing in

between us, so we couldn't see one another. And I appreciate the responses. Thank you.

SPEAKER DONOVAN:

Thank you.

Representative Taborsak.

REP. TABORSAK (109th):

Thank you, Mr. Speaker. I rise in support of House Bill 6263. There isn't much I can add to the testimony in support, other than I'd like to thank the chairs, the ranking members of the Public Health Committee and your leadership for bringing this bill up early in the session and giving it the importance it deserves, so that we can finally vote this bill out of the House and do a very good thing for all Connecticut parents and children by giving them the benefit of early detection of cystic fibrosis. So thank you.

SPEAKER DONOVAN:

Thank you, Representative. Representative Scribner.

REP. SCRIBNER (107th):

Thank you, Mr. Speaker. I rise in support of the bill before us. I also, would like to thank the leaders of the Public Health Committee, which I am a

member of for bringing this forward. It has been before us before. I have constituents who have had children who did not get early detection and wound up being diagnosed later on with cystic fibrosis. One in 3500 babies are born with it, and the earlier that we detect it, the better their chances are at being properly treated so that they don't have to go through a guessing game later on and a lot of potential consequences. I also would like to mention that I thank former Senator David Cappiello for his long-time and strong advocacy on this issue. He was really a champion for it all along and deserves our thanks.

SPEAKER DONOVAN:

Thank you, Representative. Representative Mioli.

REP. MIOLI (136th):

Thank you, Mr. Speaker. I too rise in support of this bill. It was brought to my attention by a friend. She's your constituent. And a son -- cystic fibrosis. And a few months ago, I invited them to the capital, and they participated in a tech session. It was quite exciting. And I'm glad to finally -- this has come to the well, and I urge all my colleagues to support it unanimously. Thank you, Mr. Speaker.

SPEAKER DONOVAN:

Thank you, Representative. Will you remark further? Will you remark further on the bill before us? Will you remark further? If not, staff and guests please come to the well of the House. Members take their seats. The machine will be open.

THE CLERK:

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

SPEAKER DONOVAN:

Have all the members voted? Have all the members voted? Members, please check the board to make sure your vote has been properly cast. If all the members have voted, the machine will be locked and the Clerk will please take a tally. Will the Clerk please announce the tally?

THE CLERK:

House Bill 6263.

Total Number Voting 141

Necessary for Passage 71

Those voting Yea 140

Those voting Nay 0

Those absent and not voting 10

SPEAKER DONOVAN:

The bill is passed. Are there any announcements or introductions?

REP. MERRILL (54th):

Mr. Speaker.

SPEAKER DONOVAN:

Representative Merrill.

REP. MERRILL (54th):

Thank you, Mr. Speaker. For purposes of an announcement.

SPEAKER DONOVAN:

Please proceed.

REP. MERRILL (54th):

Thank you, Mr. Speaker. I also wanted, first of all, to welcome our new member, Representative Rebimbas. So congratulations to her, and it's nice to have her here in the Chamber. And in addition, we have another new potential member, I guess. He's not quite sworn in yet.

SPEAKER DONOVAN:

Thank you, Representative.

REP. MERRILL (54th):

Yes, and I -- beyond welcoming our new Representative, and it's nice to have you here. I would also like to mention that we have a new

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the more we know about what we're putting in our bodies and in the bodies of the people we care for, that it makes a big difference. So as we go along, I'm short, I'm sweet on this, please let me help you and support you any way I can.

Thank you.

REP. RITTER: Thank you, Representative Boukus.

I don't think anyone on the committee or in the room would like to have your mood changed, especially today.

REP. BOUKUS: Absolutely, I knew that would be the power point.

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

Thank you very much. It's a pleasure.

REP. BOUKUS: See how easy. Very good. Thank you. I may come back. Thank you.

REP. RITTER: I want to make a quick exception to our order here. We have two people who want to speak to House Bill 6263, An Act Requiring the Administration of a Screening Test for Cystic Fibrosis to Newborn Infants, and they are Mary Corcoran and Annalisa Sega. I hope I pronounced your name correctly. They are students. Thank you so much.

MARY CORCORAN: Madam Chair, Health Committee, my name is Mary Corcoran and I'm 14 years old. This is my little brother Will, and he is 11 years old and is now in sixth grade. When my brother was first born in 1997, he never gained any weight. My entire family was very concerned about his health and malnourishment.

My mother was trying to feed him as much as possible and took him to the pediatrician daily to weigh him. After three long months of malnutrition he was finally diagnosed with Cystic Fibrosis in Yale New Haven Hospital. Because Will wasn't able to get the nourishment he needed, Birth to Three had to come to our home for three years. It is a program for infants who need developmental health and is paid for by the state.

All of the time spent with Birth to Three was just to help him regain his strength and meet milestones. Having newborn screening for Cystic Fibrosis would be very beneficial because then other families with CF children won't have to go through the same thing that we did. The only two states in the country that don't have -- that don't screen for CF are Texas and Connecticut. And according to the Journal of Pediatrics, newborn screening is actually a cost-saving alternative. Starting treatments earlier will help the children with CF to maintain or improve lung function, increase life expectancy and reduce hospitalizations.

This is very important to me, and I thank you for taking the time to listen.

REP. RITTER: Thank you very much for your testimony. It was very clear and very concise.

Are there any questions from the committee?

I want to thank you for taking the time to come, I know that -- and for your family. This has been very helpful for us, and I think we'll be having a lot of future discussions. We appreciate it.

MARY CORCORAN: Okay, thank you.

ANNALISA SEGA: Good morning, everyone, my name is Annalisa Sega, and I'm 12 years old; attend Apollo Middle School in Southington, and I'm in the seventh grade. I came to speak to you about being born premature, in hopes that you will agree with me that the March of Dimes is a wonderful organization, and without them, I may not have turned out as healthy as I am.

I was born at 31 weeks, weighing only 3 pounds half ounce and 16 and a half inches long. I don't remember what my birth or infancy was like, but I have plenty of pictures and family members to remind you. My dad's wedding ring fit over my hand and up my arm. We have pictures. And my very first handprint was on a gift tag, so I was really small. It took me a long time to realize that, and when I look at the pictures and videos and I see full-term babies now, I can't believe the difference. I can't believe that babies are born that small and even smaller, live to grow up to be healthy. This is all thanks to the tireless research that the March of Dimes has done.

My mom had something called toxemia preeclampsia. In normal words, she had really high blood pressure and she was sick, and her doctor knew this and gave her some shots so that when I was born my lungs would be okay. I needed a special medicine called surfactant was given to me to keep my lungs from sticking together. Both of these medications are due to the research the March of Dimes has done.

I spent six and a half weeks in the newborn special care unit of Yale New Haven Hospital. My first Easter was there. My mom has told me some stories of people trying to be helpful by saying well, at least, she came home before

her due date so you've had her longer, or well, think how lucky you are, you can sleep through the night the first few weeks. If you hadn't had a premature baby or a sick child, you just can't understand how off-base remarks like that are.

And please remember this story in case any of your family or friends do have a premature child. My mom cried every time she had to leave me at the hospital. She gladly would have taken sleepless nights. Yes, I have survived, and I am somewhat healthy but it has taken a lot to get me where I am today.

So I am here because I want to tell people about the March of Dimes and the great work they do, and I want to thank them for helping the part they played in me and my family's life. I've had moderate reflux most of my life, much worse as an infant, and I have also had asthma for 12 years, but it is better than when I was younger. I had physical therapy as an infant and toddler, but I'm proud to say now that I'm a competitive dancer, cheerleader and high honor's student.

I am here to convince you to please add Cystic Fibrosis to newborn screening exams. When this opportunity came to speak today, my mom told me about when I was screened for Cystic Fibrosis. It was after I wasn't growing. I was eating poorly, and I had severe reflux and respiratory problems. I was over one year old. Fortunately, me and my family, the test was negative, but what if it wasn't. What if it was positive and I was one and a half years old and I could have been treated from day one. I believe that my overall chances would have to be better.

So please understand that early detection and

treatment is best for survival for newborns with Cystic Fibrosis. My mom was my biggest advocate as an infant, whether it was speech and hearing concerns, respiratory issues, allergies or anything else, she was there fighting for me. Don't we want that for all newborns? Not all newborns have someone like my mom, but they do have you. You can speak on their behalf by ensuring their health in Connecticut and mandating that all newborns be screened adding Cystic Fibrosis to that screening.

Thank you for listening to my story, and agreeing that we need to end prematurity and continue our fight for all newborns making their health our number one priority, so other families do not have to go through what me and my family did.

Thank you.

REP. RITTER: Thank you very much, Annalisa.

Are there any questions from the committee?

Thank you again --

A VOICE: Thank you.

REP. RITTER: -- for coming and sharing your story, and I can speak as a mother, I'm sure she is so very proud to hear your words. Thank you.

Our next speaker will be Tim Phelan and we're back on our public schedule speaking to House Bill 6328.

TIMOTHY G. PHELAN: Thank you Representative Ritter, Senator Harris, Senator Debicella, Representative Giegler and members of the Public Health Committee, this is my first

that's what confused me, on the fly, trying to multitask here.

Okay, thank you for your testimony, much appreciate it.

BRUCE DOUGLAS: Great. Thank you.

REP. RITTER: Are there any other questions?

Thank you very much.

We're going to go to our next bill which is House Bill 6263, An Act Requiring the Administration of a Screening Test for Cystic Fibrosis to Newborn Infants.

And our first speaker is Susan Castonguay followed by Craig Lappin.

She's not here yet?

Is Craig Lappin here, please? To be followed by Mel Collins.

CRAIG LAPPIN: Good afternoon, Senator Ritter -- sorry -- Representative Ritter, Senator Harris, members of the Public Health Committee, thank you for giving me the opportunity to testify in support of House Bill 6263, An Act for Administration of a Screening Test for Cystic Fibrosis to Newborn Infants.

My name is Craig Lappin. I'm the center director for the Central Connecticut Cystic Fibrosis Center and an associate professor of pediatrics at university of Connecticut. Our cystic fibrosis center is actually the amalgam of Connecticut Children's Medical Center, Hartford Hospital and University of Connecticut, and we serve pretty much the

middle to northern part of Connecticut. Yale is the other certified accredited center and serves the southern part.

I would like to apologize, Dr. Collins is not going to be here. She just left because it was -- she had to get back to take care of patients. Last Thursday, you'll see from my testimony, that we actually identified cystic fibrosis by the first newborn screen of 2009. We have been doing voluntary screening in Connecticut since 1983, and at UConn since 1993. This patient was identified by the screen on Thursday and they had their diagnosis confirmed on Friday.

I saw the family on Tuesday and talked to them at length, and then saw the baby on Wednesday. That's what newborn screening does. It means that you can identify and get people in and help take care of their issues.

You'll be hearing, I'm sure, personal testimony from some families. I'd like to go ahead and talk medically. In my testimony you'll see a list of multiple diseases with long names and multiple numbers in them. These are all newborn screens that we do here at Connecticut. And the point here is that for many of those screens that we do, they occur much less frequently in the population than cystic fibrosis does.

The last -- over the two-year period of time we identified seven cases of cystic fibrosis at UConn alone. Yale does also newborn screening, but UConn does about three times as many. But seven doesn't sound like a lot of -- like a very big number in terms of, you know, why try and do this, but the point here is that it was seven identified, but we screened close to about 40,000 people. That's

40,000 infants that we were able to go ahead and eliminate practically with a 97, 98 percent probability that they were going to have cystic fibrosis.

Why is that important? It's because cystic fibrosis causes multiple problems, both respiratory and nutritional, and extensive studies show that, first of all, if you identify -- when you identify people early, they're all doing better. Once you identify them early and you look at them over time, they continue to go ahead and do significantly better.

I'll finish up here by saying essentially that over roughly the last 16 years we've screened -- oh, there have been about 200,000 children who have not been screened for cystic fibrosis because it hasn't been mandatory. We screen approximately 20 out of -- 20 birthing hospitals in Connecticut, out of a total of 30. The largest that still doesn't screen is in Danbury, and the majority of the hospitals that don't screen are down in Fairfield -- Fairfield County rather. But the problem is is that unless it's mandated even hospitals that sometimes voluntarily screen, there's no guarantee that everybody will go ahead and have that opportunity.

So I would ask you, for the sake of the infants and children and adults both with CF and to eliminate this diagnosis so that folks don't have to worry about it, that you pass this program.

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

Are there any questions from the committee?

Yes, Representative LeGeyt.

REP. LEGEYT: Thank you, Madam Chairman.

Dr. Lappin, just help me understand why it's so important to have this screening done as a newborn activity as opposed to allowing pediatricians to make those considerations instead? Is it time urgent, or is it -- I know some people who have cystic fibrosis, and I'm not aware that it's -- there's such an immediacy on the early end of life.

CRAIG LAPPIN: That's -- that's a great question and in actual fact it is time urgent. The studies go ahead and show and that was -- it's, again, in part of the testimony, that when you look at children who are identified by newborn screening versus children who are not, at the time that they're identified, again, across general -- across the population that's being looked at for cystic fibrosis, the people who are screened are three times as likely to be in good nutrition. The ones who are not screened, who are diagnosed by clinical symptoms, are three times as likely to be in poor nutrition; that the people who are identified by clinical symptoms are twice as likely to have serious CF infections compared to those who were diagnosed by newborn screen and, therefore, were able to go ahead and be watched over more closely and those types of infections might be avoided. And that the people who are identified by clinical symptoms were three times as likely to be hospitalized at the time of the diagnosis than the ones who were being diagnosed by newborn screening. So there is actually just -- and there's actually 5 percent who can have really, really bad life threatening malnutrition.

So there's actually, at the time of diagnosis, there's a benefit from being diagnosed early than rather to wait for even an astute physician to go ahead and pick up on the disease state.

Additionally, when you look at -- you then go ahead and look at that group, not at the time of diagnosis, but five years and ten years and 15 years later, the group that's been diagnosed by newborn screening is doing significantly, both clinically and statistically, significantly better at those periods of time than the group that was diagnosed even if they -- sorry, as the group that was diagnosed by clinical symptoms.

So there is definitely an urgency and evidence to show that the earlier you can diagnose these patients, the better they do. That's aside from the issue that perhaps some of the families that will be talking will be relating to the problem of what happens when you've got a child who is presenting with symptoms which could be chest infections, chronic respiratory infections, not growing, and if they're not figured out, if the doctors or whoever is seeing them are not figuring out why they are having the problem, that this family and this child are being sent from doctor to doctor that they're dealing with a chronically ill child and they're not getting any answers and that goes ahead and can be very very tough on a family.

REP. LEGEYT: So I'm thinking that some of the balance to be struck here is the urgency and the need for that testing to occur and as opposed to allowing the symptoms to present themselves later on. And you said that out of 40,000 tests that were done they found seven active cases?

CRAIG LAPPIN: Uh-huh. Well, again, the -- we always -- we screen for, as I say, roughly about 23,000 to 26,000 children a year at the UConn Center. That's where -- that's the information I'm privy to. In that group over the last two years we have identified seven patients. I would point out that in the same period of time, for the other -- for some of the other newborn screening diseases that we have been -- that screen for here in Connecticut, there were no maple syrup urine diseases of cases identified in two years. There were three cases of medium chain, it called, it abbreviated to MCATs identified. There were six cases of a disease of I'll identify as PKU.

So, again we're not -- we're talking about significantly more or equivalent to many, many, many of the diseases that we are already looking at here in Connecticut. And again, the point is is not -- it isn't -- is, in part, getting care for those seven patients, but it's also, in part, eliminating the potential in multiple other families as well.

I'd also like comment briefly that Connecticut was one of the first states to do newborn screening on a voluntary basis, when the technology became available. Since that time, the rest of the country has caught up with us. And again, just like, I think, in the case of the asthma and Epinephrine situation, which I also strongly support by the way, is that we will be the second last state -- no, sorry. We are the second last state. The only state that is not going to be screening as of the end of 2009 will be Texas, and us if we don't pass it.

REP. LEGEYT: Thank you. And one last question.

What is the expense and the time investment to do this test on a newborn?

CRAIG LAPPIN: That's a good questions as well. The newborn screen done in the -- across the state or in the current frequency that we're doing it at UConn is roughly about $15 per screen. Essentially, as I -- as it's being done currently, and as I understand it being proposed, what happens is is the hospitals themselves bundle that charge into the cost of the delivery. So, as far as I'm aware, there isn't a direct cost or charge either to the patients or potentially to the state. I'm not sure about that.

REP. LEGEYT: Does it take three months, one week, two days, 48 hours?

CRAIG LAPPIN: That's an excellent question as well. The -- the goal of the newborn screening program is to identify somebody early, and any newborn program, again, at least for cystic fibrosis that takes more than two weeks, is probably not worth its salt.

The -- you know, again, the case that I gave you as an example of was diagnosed in I think by the tenth day. We knew that the baby had cystic fibrosis and I was seeing them on his second weeks' birthday.

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

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

Thank you Dr. Lappin for your testimony.

It's my understanding that Dr. Collins is not present.

A VOICE: No.

REP. RITTER: The next speaker will be Erin Jones to be followed by Paul Drury.

ERIN JONES: Good afternoon. My name is Erin Jones, and I'm here to represent the March of Dimes.
Many of you may know, the March of Dimes is one of the leading national organizations on maternal and child health.

This morning we had a young lady Annalisa who testified on behalf of the March of Dimes, who also was screened for CF. We're here really just to let you know that we're here supporting the Cystic Fibrosis Foundation. You have my testimony that gives you more of the medical backgrounds of why the March of Dimes is so interested in this cause.

We are really interested in making sure that every baby is born healthy. And we know that that doesn't always happen. So on the other end we want to make sure that when they are born, if there's any way that we can help that baby, we do it right away.

So to your question about should we wait? Should it be done immediately? Can it be done at the hospital? Can it wait until symptoms come up? I would -- I would, from the March of Dimes perspective, strongly encourage the preventive, which is to have it done right away.

So that's really what we're here to support. I'm not going to belabor the issue. We've got lots of testimony, and there's other families who have personal experiences, I think, that weigh a little bit more.

But just to reemphasize what Dr. Lappin said, Connecticut is in the dead last heat with Texas. So we would like to see this happen. That puts us ahead -- behind, I should say, the state of Mississippi. So I hope I'm not offending anyone from Mississippi, but in the world of March of Dimes, when I go to my national meetings, people look at me as one of the wealthiest states and say, What's going on in Connecticut that we're not screening for CF mandatory. So, please help me when I go to my national meetings, as well as the families and kids that live and are born here in Connecticut.

Thank you.

REP. RITTER: Thank you for your testimony.

Are there any questions from the committee?

Thank you very much.

Our next speaker will be Paul Drury to be followed by Patty Powers.

PAUL DRURY: Thank you very much for having me here today. My name is Paul Drury. I'm a 42-year-old adult with cystic fibrosis. I'm here to ask you to consider making newborn screening mandatory here in Connecticut.

As a CF patient, I've been hospitalized well over 20 times in my life. The majority being seven to ten day, what we call clean outs in hospital. These usually consists of IV, antibiotics, respiratory -- respiratory therapy, and some times tube feedings to keep -- keep our weight on as nutrition is always an issue with CF.

These antibiotics are necessary to help move the thick sticky mucus away from our lungs and deter life-threatening lung infections. And it's important to say that CF, and I know you had asked them how important it is to testing early, but CF remains the number one genetic killer of children in the U.S. And the life expectancy now is 37. When I was born it was five. But in addition to the stuff previously mentioned, I've had, you know, ten pneumonias. I've had four lung collapses. Two operations where they literally glued my lungs to the side of my chest cavity so my lungs wouldn't collapse again. I was on oxygen 24 hours a day for over a year. Finally, as a result of these damaged lungs, I was put on a waiting list for double lung transplant for over a year. I was transplant at the age of 29 at Loyola University out in Chicago, the only center that would take a chance on me because I was so sick. I ended up 30 days on a respirator there. And they had never transplanted anybody from a respirator before. So, I was, you know, very lucky to even -- even get the chance.

And, you know, we know cost is always -- always an issue when we're talking about, you know, medical costs and everything. My transplant bill alone for my lung transplant, I was on Medicaid at the time because I was unable to work, was well over a half a million dollars. And that didn't even include the after care for the last 13 years since.

So that's -- that's, you know, one month for one patient with CF. So the, you know, the cost will definitely, $15 seems -- doesn't seem too much to deter that.

In 13 years since my lung transplant, I've had lung rejection. Four more pneumonias, and

four years ago, as a result of the necessary medications I was on, I went and had a kidney transplant. And again, you know, we -- you know, I do this not to say, you know, to complain or anything, but it's just we need to get this done because the sooner we do it, the healthier the kids -- the kids are.

So that's -- thank you.

REP. RITTER: Thank you very much.

Are there any questions from the committee?

It's good to see you looking so well.

PAUL DRURY: Oh, thank you.

REP. RITTER: And thank you very much for being here.

PAUL DRURY: Thank you.

REP. RITTER: Our next speaker will be Patty Powers.

PATTY POWERS: Senator Harris, Representative Ritter, members of the Public Health Committee, thank you for giving me the opportunity to speak to you today about House Bill 6263.

My name is Patty Powers. I have three children. My middle daughter, Cameron, is five-and-a-half years old. She has cystic fibrosis. I'm submitting this testimony to provide evidence that newborn CF screening to be mandatory in the state of Connecticut. Cameron's medical issues started at around two-and-a-half months of age. She began coughing which worsened as time passed. We took her to the pediatrician immediately and were sent home believing it was just a little

cold.

The cough persisted and we returned to the pediatrician again. This time she was given a nebulizer and albuterol for her cold, so-called cold. Her cough was a bit better for the time on albuterol, and a short time after, but again, her cough started to worsen. She was now coughing very violently and throwing up two to three times a day. We were having trouble getting her to eat, keeping any calories she was getting down, and becoming more and more stressed as time went by. We again, returned to the pediatrician, and were told it could be acid reflux. We tried liquid antacids and no improvement occurred. We were sent to the pediatric respiratory specialist at Danbury Hospital. He said it was perhaps the whooping cough, since that had been popping at the time, and stated that it was considered to be the 100-day cough in which there was no treatment for, so nothing was done.

He stated in his notes that because her jowls, her chubby cheeks, Cameron would not a candidate for cystic fibrosis. Six weeks -- six weeks later, and several more pediatrician visits, we desperately went to a different pediatrician that happened to be available on a Sunday. Cameron was failing to thrive and coughing and throwing up regularly. This doctor heard something in her lungs and sent her for a chest x-ray. We were informed that something was showing up and that we needed to go back to the same pediatric respiratory specialist the next morning.

Cameron was admitted, and a CF sweat test showed that, in fact, she did have cystic fibrosis. Cameron was then five-and-a-half months old and had a partially blocked lung

and pneumonia. We were sent to Connecticut Children's Medical Center the next day and remained there for two weeks. She needed a bronchoscopy, intensive IV medication, and intense airway clearance and also further testing. We left the hospital and remained on home IVs for another two weeks.

Cameron has permanent lung damage today because of this. She has pseudomonas -- which is a dangerous bacteria -- in her lungs today and takes some medications that most five-and-a-half year olds don't need yet.

Can I place some of the blame on the physicians that saw her, initially? Perhaps. But the fact remains the same, if she were tested at birth, Cameron may not have suffered needlessly for three months and have permanent lung damage today.

Thank you for your time and consideration.

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

Are there questions from the committee?

No. Thank you. We appreciate your time and sharing your story.

PATTY POWERS: Thank you.

REP. RITTER: I'll try to get -- I'll try to get this right. It is my understanding that Mel Collins is not here. Is that correct?

But that Susan Castonguay is here. And she'll be next. And she will be followed by Stan Soby.

SUSAN CASTONGUAY: Good afternoon. Representative

Ritter and Committee members. My name is Susan Castonguay, and I, too, have a daughter with cystic fibrosis who is 11 years old.

Some of you may remember from the last time I testified that I'm an Assistant Attorney General with the State of Connecticut in the Department of Child Protection. And every day including today, I've been out in the courts and in the DCF offices fighting for kids, but never has my fight been more vigilant and more ardent than it is to get this bill finally passed. And here's why.

The story you heard from Patty could not be more night and day different than the story I'm going to tell you. Nine -- 11 years ago when my daughter -- 11 years ago, on January 27th, 1998, my daughter was diagnosed at three weeks of age with CF. Why? Because Bristol Hospital, the hospital that I had decided to deliver my baby at had also decided voluntarily that they were going to test. Then, as now, the Connecticut Legislature has said it's up to the hospital, if they want to test, great; and, if they don't, fine. Well, thank God they did. Because my daughter is now 11 years old, and has never spent a single night in the hospital for cystic fibrosis.

At three weeks of age, she went to CCMC, and I met for four hours along with my husband and my family, on January 28th with Dr. Lappin who testified, for four hours, I was deluged with information about CF, and guess what, I knew what to do. I knew how to go home and save my daughter's life. But, Patty didn't know. And she didn't know because she didn't have the one tool in her arsenal that she needed, information. Information that her child had CF.

This committee can change all of that, for the lives of every child born in Connecticut who tests positive for CF. Every study done conclusively demonstrates that there is a direct correlation between the time -- the age of diagnosis, and the patient's longevity. Direct correlation between date of diagnosis and longevity. Patty's daughter has permanent lung damage. Dr. Lappin told me 11 years ago in that meeting, Mr. and Mrs. Castonguay, do everything you can to preserve Caroline's lungs, because when the cure comes, and it's coming, it is coming, whatever damage is done will be irreversible.

Caroline was at CCMC on Wednesday of this week for her two-month check up. She's seen every two months like all CF patients are at CCMC. I'm here to tell you what her lung function tests were, 114 percent. What's normal? 100 percent. And I don't know if any of us would -- would measure out at 100 percent given our age and what life has done to all of us. She's at 114 percent.

Now that's out of the general population. So what does that tell you? No lung damage. No hospitalizations. Every time I come here to testify what I don't understand is why there is not a bevy of insurance lobbyists in this audience. My God, we should be fighting to get this done, to lower health costs.

We know how to treat Caroline's disease. We know how to save her life. We have the information. Believe me, I've got the drive. All I needed was the tool. The information. The knowledge. Give that to every CF family. Give them that tool.

And I thank you so much for your time today.

JOINT
STANDING
COMMITTEE
HEARINGS

PUBLIC
HEALTH
PART 2
313 - 623

2009

Connecticut Children's Medical Center

Central Connecticut Cystic Fibrosis Center

HARTFORD HOSPITAL

Testimony of Craig Lapin, MD, Director, Central Connecticut Cystic Fibrosis Center and Associate Professor of Pediatrics, University of Connecticut Health Center to the Public Health Committee regarding *House Bill 6263, An Act Requiring The Administration Of A Screening Test For Cystic Fibrosis To Newborn Infants.*

February 6, 2009

Senator Harris, Representative Ritter, Members of the Public Health Committee. Thank you for the opportunity to testify in support of *House Bill #6263, An Act Requiring The Administration of a Screening Test for Cystic Fibrosis to Newborn Infants*. My name is Dr. Craig Lapin and I am Director of the Central Connecticut Cystic Fibrosis Center and Associate Professor of Pediatrics at the University of Connecticut Health Center.

Last Thursday we had our first infant identified with CF by NBS for 2009; they had the diagnosis confirmed on Friday; the family had a 2 hour meeting with the CF center on three days ago, and the baby was seen Wednesday. That is the power and benefit of the CF NBS program. If this infant had not been born at a hospital that does screening, we do not know when and how sick he would have been when finally diagnosed.

You will be hearing the personal impact that a delayed diagnosis has for families with cystic fibrosis. I would like to present the medical case to add cystic fibrosis to mandated newborn screening (NBS). CF is the most common lethally inherited disease in caucasians, although it also affects other ethnicities as well. CF occurs in 1 in 3000 newborns. It occurs 3 times more frequently than Phenylketonuria and 50 times more than Maple Syrup Urine Disease. In past two years screening for the whole of Connecticut there have been six cases of phenylketonuria, 5 medium-chain acyl-dehyrogenase deficiency, one long-chain acyl-dehyrogenase deficiency, no maple syrup urine disease; these are all amongst the screened diseases here in Connecticut. For the past two years, screening at UCONN/CCMC alone has identified seven cases of CF. This is not meant as an argument not to screen for other diseases, just that from a public health standpoint, cystic fibrosis occurs as often as or more frequently than most of the diseases for which we currently screen.

CF causes multiple problems but primary are respiratory and nutritional. There is extensive medical research that shows early diagnosis makes a significant difference in the health outcomes (and therefore lives) of patients with CF. In the short term – for infants diagnosed at less than 1 year of age because of CF symptoms (i.e. not by NBS) 33% were grossly malnourished compared with 11% diagnosed by NBS. Significant CF infections were found twice as frequently (29% not NBS vs 15% NBS), and patients were hospitalized three times as much (64% not NBS vs 22% NBS). Of even greater concern,

5% of patient diagnosed with CF over a 3 year period had life-threatening malnutrition, compared with none by NBS.

In the long term over years, the national CF registry database shows that as people with CF grow older, for every age group, those diagnosed symptomatically are always at least twice as likely to be malnourished compared with those diagnosed by NBS. Those diagnosed with CF by NBS are statistically less likely to be stunted, or to have the special CF infections that lead to more rapid pulmonary function decline and therefore decreased quality of life. By the second decade of life, people diagnosed by NBS are less likely to require hospitalization (thus significantly decreasing cost of care).

Solid research and multiple studies, document that delayed diagnosis of CF and malnutrition in this disease leads to failure to thrive, increased infections, a more rapid decline in lung function, subsequent decreased quality of life, and decreased life span. In other words, people die earlier. Waiting until patients have symptoms of CF is associated with higher complications rates and morbidity compared to diagnosis by NBS. Dr. Collins recently published data from Connecticut showing that patients diagnosed by NBS maintain significantly better pulmonary function and nutrition.

The Center for Disease Control (CDC) has determined that screening for CF is justified. Screening for CF involves a two-stage process performed on the single heelstick done at birth. Currently, the University of Connecticut Health Center (UCHC) and Yale New Haven Hospital (Yale) perform the tests using blood samples provided by the 20 of the 30 birthing hospitals in Connecticut. We estimate there are approximately 13,000 Connecticut babies unscreened each year, or over 200,000 children since 1993 when the voluntary CF NBS program began. After a positive screen the family's primary care provider is notified by phone, fax, and registered letter recommending the infant be sent to one of the two Cystic Fibrosis treatment centers in Connecticut (UCHC/Connecticut Children's or Yale) for a definitive sweat test following a positive Stage 2 test.

Our CF center has been part of the voluntary newborn screening program that has been extremely efficient and supportive of families for sixteen years, screening approximately 26,000 infants a year. Yale screens approximately 8,000 patients a year. Please, for the sakes of the infants, children, and adults with CF, mandate newborn screening for cystic fibrosis that extends the current program to all. Thank you.

Craig D. Lapin, M.D.
Director, Central Connecticut Cystic Fibrosis Center
Associate Professor of Pediatrics
Connecticut Children's Medical Center
University of Connecticut Health Center

Connecticut Children's Medical Center

Central Connecticut Cystic Fibrosis Center

HARTFORD HOSPITAL

The Case for Newborn Screening for Cystic Fibrosis

The Disease

- Cystic Fibrosis (CF) is a chronically debilitating genetic disease that affects the respiratory, gastrointestinal and reproductive systems.
- CF occurs in approximately one of every 3,500 live births and about 1,000 new cases of CF are diagnosed each year.

Diagnosis

- The major symptoms of CF are not unique to the disease.
- According to the CDC, half of all individuals in the United States with CF were diagnosed after six months of age.
- Universal newborn screening would prevent delayed diagnoses.

Newborn Screening

- Voluntary newborn screening for CF began in Connecticut in 1993 – one of the first states in the country to do so. If not mandated, by the end of 2009 Connecticut will be the only state in the country that does NOT screen all its newborns.
- 20 of Connecticut's 30 birthing hospitals participate in the voluntary program.
  - ◊ As a result, about 2/3 of Connecticut newborns are tested.
  - ◊ Of the 10 hospitals that do not participate, Danbury and other Fairfield area hospitals account for most of the births.
- The cost of the blood test for CF (called the immunoreactive trypsinogen test or IRT) is $15-$20 per child.
- An HRSA-commissioned report released on March 8, 2005, calls for the standardization of newborn screening tests throughout the country; CF is on the report's list of 29 recommended tests. The report is available at http://genes-r-us.uthscsa.edu.

The Impact of Early Detection

- Early diagnosis leads to immediate intervention with specialized therapies that include pancreatic enzymes to aid digestion and a high-calorie, high-fat diet.
- Immediate interventions result in:
  - ◊ Improved height, weight and cognitive function
  - ◊ Decreased risk of life-threatening malnutrition
  - ◊ The maintenance of respiratory function
  - ◊ Increased life expectancy, and
  - ◊ Reduced hospitalizations

February 6, 2009

To: Members of the Connecticut Public Health Committee

From: Susan Castonguay

Re: Legislation requiring cystic fibrosis genetic testing

Dear Committee Members,

Eleven years ago on January 8, 1998, my first child, Caroline was born. A mere three weeks later, she was diagnosed with cystic fibrosis. This diagnosis was made because Bristol Hospital, where I delivered Caroline, had voluntarily decided that it would test all children born at that hospital for cystic fibrosis. At that time, eleven years ago, only two states in the United States had legislation requiring all children born in those states to be tested at birth for cystic fibrosis. Those two states were Wisconsin and Colorado. That was then. Today, there are only two states in the United States that do NOT mandate that when a child is born in that state it will be tested for cystic fibrosis. With huge disappointment and tremendous dismay, I am here to inform all of you that those two states are **Connecticut** and Texas. How, in good conscience, can we justify this denial of needed, essential medical care to Connecticut babies and their families? Every study done in the scientific community demonstrates a clear and significant correlation between the age of diagnosis and longevity for CF patients. With the median age of survival at 37 years, we don't have a single day to waste. We need this legislation immediately.

This week in her speech to the state, Governor Rell stated that she wanted Connecticut to be poised for prosperity when this economic crisis has turned itself around. I, speaking on behalf of all CF parents, say to each of you: I want my child poised in the best possible health when the cure for CF is found. The CCMC pulmonary team advises all of its CF parents that any damage to the lungs prior to the discovery of the cure for CF will be permanent, therefore, parents and CF patients must do everything possible in our power to keep the CF patient's lungs healthy. The number one tool to aid parents in that task is fundamentally information, namely, the knowledge that our children have this disease. Without legislative action, newborn children in Connecticut will, like those in Texas will continue to be some of the most disadvantaged citizens in our country. The question is simple: how much longer will you allow this to continue?

Thank you for your time and attention in this vital matter.

Susan Castonguay

43 Sheffield Lane, Avon, CT. 06001 Phone: 860-506-2240

Hello, my name is Mary Corcoran and I am fourteen years old; I have a little brother with Cystic Fibrosis named Will, he is 11 years old and is now in sixth grade. When my brother was first born in 1997 he never gained any weight, my entire family was very concerned about his health and mal-nourishment. My mother was trying to feed him as much as possible, and took him to the pediatrician daily to weigh him. After three long months of mal-nutrition, he was finally diagnosed with Cystic Fibrosis in Yale New Haven Hospital. Because Will wasn't able to get the nourishment he needed Birth to Three had to come to our home for three years; it is a program for infants who need developmental help and is paid for by the state. All of the time spent with Birth to Three was just to help him regain his strength and meet milestones. Having newborn screening for Cystic Fibrosis will be very beneficial because then other families with CF children wont have to go through the same thing that we did. The only two states in the country that don't screen for CF are Texas and Connecticut, and according to The Journal of Pediatrics newborn screening is actually a cost-saving alternative. Starting treatments earlier will help the children with CF to maintain or improve lung function, increase life expectancy and reduce hospitalizations. This is important to me, thank you for taking the time to listen.

Good morning and welcome. My name is Annalisa Sega, I am 12 yrs old, and attend DePaolo Middle School in Southington where I am in the 7th grade.

I came to speak to you about being born premature in hopes that you will agree with me that the March of Dimes is a wonderful organization and without them I may not have turned out as healthy as I am.

Born at 31 weeks, weighing only 3lbs 1/2oz and 16 ½ inches long, I WAS tiny. My mom has nicknamed me chicken because she says that's what I looked like when I was born! Now of course I don't remember what my birth or infancy was like, but I have plenty of pictures, videos and family members to remind me. Would you believe that my dad's wedding band fit over my hand and up my arm! We have pictures! And my very first hand print fit on a gift tag - that's how small I was.

It took me a long time to realize just how small I was, when I look at the pictures and videos and I see full term babies now, I cannot believe the difference! I can't believe that babies are born that small and even smaller yet live and can grow up to be healthy. Thanks to the March of Dimes we are growing up and staying healthy. Their tireless research helped both me and my mom. My mom had something called toxemia/pre-eclampsia in

normal words it was really high blood pressure and she was becoming ill. Her doctor knew this and gave her some shots so when I was born early my lungs would be okay. It helped some but not enough and I still needed a tube down my throat and special medicine-called Surfactant was given to me to keep my lungs from sticking together so I could breathe. Both of these medications are due to the research the March of Dimes has continuously done.

I spent 6 ½ weeks in the Newborn Special Care Unit of Yale New Haven Hospital, my first Easter was there!

My mom has told me some stories of people trying to be helpful by saying, "well at least she came home before her due date so you've had her longer, or well think how lucky you are - you can sleep through the night the first few weeks." If you haven't had a premature baby you just can't understand how off base remarks like that are. And please remember this story in case any of your family or friends do have a premature baby. My mom cried everytime she had to leave me at the hospital. She gladly would've taken sleepless nights. Yes, I survived and am overall healthy but it has taken a lot to get me where I am today. So I am here because I want to tell people about the March of Dimes and the great work they do, I want to thank them for helping me to

survive and have the best chances at being healthy. I am in my third year working with the March of Dimes to give back for the part they played in me and my family's lives.

I have had moderate reflux most of my life, much worse as an infant. I have asthma which I've had for almost 12 years but it is better than when I was younger. I had physical therapy as an infant and toddler but I am proud to say now, that I am a competitive dancer, cheerleader, high honors student and recently crowned Greater Waterbury's Outstanding Pre-Teen 2009, as part of the Miss Connecticut Organization.

I am here to convince you to **please** add Cystic Fibrosis to newborn screening exams, when this opportunity came to speak today my mom told me about when I was screened for Cystic Fibrosis. It was after I wasn't growing, I was eating poorly, had severe reflux and respiratory problems I was over 1 years old! Fortunately for me and my family the test was negative, but what if it wasn't? What if it was positive and I could have been treated from day one, I believe that my overall chances would have to be better. So please understand that early detection and treatment is best for survival for newborns with Cystic Fibrosis. My mom was my biggest advocate as an infant, whether it was speech and hearing concerns, respiratory issues, allergies or any other

concerns, she was there fighting for me. Don't we want that for all newborns, not all newborns have someone like my mom, but they do have **YOU**. You can help speak on their behalf by insuring their health in Connecticut and mandating that **ALL** newborns be screened and adding Cystic Fibrosis to that screening.
Thank you for listening to my story and agreeing that we need to end prematurity and continue our fight for all newborns making their health our number one priority so other families do not have to go through what me and my family did.

THANK YOU!

Public Health Committee Hearing
February 6, 2009
Raised House Bill No. 6263
An Act Requiring New Infant Health Screening for Cystic Fibrosis

By: Erin E. Jones, March of Dimes

Good Afternoon Members of Congress. My name is Erin Jones and I am here today representing the March of Dimes Connecticut Chapter in support of S.B No. 6263, **An Act Requiring New Infant Health Screening for Cystic Fibrosis.**

.The March of Dimes supports comprehensive NBS for every baby born in the U.S. and its territories for conditions that meet the following criteria: there is a documented benefit to the affected infant from early detection and there is a reliable screening test that enables early detection from newborn blood spots or other means. March of Dimes recommends screening all newborns for 29 treatable conditions recommended in a 2004 report by the American College of Medical Genetics (ACMG) to the Federal Health Services Resources Administration (HRSA). The March of Dimes supports parents' rights to be promptly and thoroughly informed about their babies' screening results, and supports expansion of health care provider education programs. NBS programs should include high quality screening tests with the state-of-the-art technology, trained personnel, and resources for timely follow-up and program evaluation.

In Connecticut, mandatory testing for Cystic Fibrosis (CF) is still not required by law. CF is a life threatening genetic disease that causes mucus to build up and clog some organs in the body, particularly in the lungs and pancreas. When the mucus clogs the

lungs, it can make breathing very difficult. The thick mucus also causes bacteria to get stuck in the airways, which causes inflammation and infections that leads to lung damage. Early diagnosis and treatment for CF through newborn screening is critically important because of the benefits, a better chance for improved growth, improved lung functioning, reduce hospital stays and a longer life.

Newborn Screening is done by testing a few drops of blood, usually from a newborn's heel, before hospital discharge. A positive result does not always mean the infant has the disorder. If the screening result is positive, the infant is re-tested through a series of tests, to confirm a positive screen, and then given treatment as soon as possible.

Connecticut has made great strides in advocacy and awareness in the last few years. But today, Connecticut still only requires screening for 28 or 29 core conditions.
The March of Dimes Connecticut Chapter asks for your support in passing SB. No. 569 and mandating that every newborn be screened for Cystic Fibrosis and give these children with the disease the best chance for a healthy future.

Testimony of Patty Powers to the Public Health Committee regarding *House Bill 6263, An Act Requiring The Administration Of A Screening Test For Cystic Fibrosis To Newborn Infants*

February 6, 2009

Senator Harris, Representative Ritter, members of the Public Health Committee Thank you for giving me the opportunity to speak to you today about *House Bill 6263, An Act Requiring The Administration Of A Screening Test For Cystic Fibrosis To Newborn Infants* My name is Patty Powers. My daughter Cameron is 5 1/2 years old and was diagnosed with Cystic Fibrosis at the age of 5 1/2 months I am submitting this testimony to provide evidence of that newborn CF screening should be mandatory in the state of Connecticut and every other state for that matter

Cameron's medical issues started at around 2 ½ months of age She began coughing which worsened as time passed We took her to the pediatrician immediately and were sent home believing it was just a little cold The cough persisted and we returned to the pediatrician again This time she was given a nebulizer and Albuterol for her "cold." Her cough was a bit better for the time on Albuterol and a short time after but again her cough started to worsen. She was now coughing very violently and throwing up 2-3 times a day We were having trouble getting her to eat, keeping any calories she was getting down, and becoming more and more stressed as time went by. We again returned to the pediatrician and were told it could be reflux. We tried a liquid antacid and no improvement occurred We were then sent to a pediatric respiratory specialist at Danbury Hospital He said it was perhaps the "whooping cough" since that had been popping up at the time and stated that it was considered the 100 day cough in which there is no treatment for. He stated in his notes that "because of her joules (chubby cheeks), Cameron is not a candidate for Cystic Fibrosis. Six weeks later and several more pediatrician visits, we desperately went to a different pediatrician that was available on a Sunday. Cameron was failing to thrive and coughing and throwing up regularly This doctor heard something in her lungs and sent her for a chest x-ray We were informed that something was showing up and that we needed to go back to the pediatric respiratory specialist the next morning Cameron was admitted and a CF sweat test showed that in fact she did have Cystic Fibrosis

Cameron was then 5 ½ months old, had a partially blocked lung, and pneumonia. We were sent to Connecticut Children's Medical Center the next day and remained there for 2 weeks. She needed a bronchoscopy, intensive IV medication, intense airway clearance, and further testing. We left the hospital and remained on home IV's for another 2 weeks Cameron has permanent lung damage today because of this She has pseudomonas (a dangerous bacteria) and takes some medications that most 5 ½ year olds with CF don't need yet Can I place some blame on the physicians that she saw initially? Perhaps But the fact remains the same..... ***IF SHE WERE TESTED AT BIRTH; CAMERON MAY NOT HAVE SUFFERED NEEDLESSLY FOR 3 MONTHS AND HAVE PERMANENT LUNG DAMAGE AS A RESULT.***

Thank you for your time and consideration Please feel free to contact me with any questions or comments that you may have.

Sincerely,

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Connecticut Children's Medical Center

Central Connecticut Cystic Fibrosis Center

HARTFORD HOSPITAL

Testimony of Melanie Sue Collins, MD, Assistant Director, Central Connecticut Cystic Fibrosis Center and Assistant Professor of Pediatrics, University of Connecticut Health Center to the Public Health Committee regarding *House Bill 6263, An Act Requiring The Administration Of A Screening Test For Cystic Fibrosis To Newborn Infants.*

February 6th, 2009

Senator Harris, Representative Ritter, Members of the Public Health Committee. Thank you for the opportunity to testify in support of House Bill #6263, An Act Requiring the Administration of a Screening Test for Cystic Fibrosis to Newborn Infants. My name is Dr. Melanie Collins and I am Assistant Director of the Central Connecticut Cystic Fibrosis Center and Assistant Professor of Pediatrics at the University of Connecticut Health Center.

As you may know, cystic fibrosis is the most common life-limiting inherited disease of Caucasians. It affects approximately 1 in 2,800 children in the state of Connecticut. Most patients are severely affected experiencing symptoms in almost every organ in the body. Without early, aggressive treatment, most patients with CF will die of respiratory failure. In fact, prior to introduction of newborn screening for CF in the late 1970s-early 1980s, patients with CF were malnourished, experienced frequent severe respiratory infections and died in their early teenage years. I'm proud to inform you that our state was one of the first to begin voluntary newborn screening for CF in the 1980s. However, I am embarrassed and ashamed to report that we are now one of only a handful of states who has not mandated screening for CF. While children in the state of CT benefit from the improved therapies for CF that have occurred in the last 3 decades, simply by being born in a state that does not mandate screening for CF they are placed at a significant disadvantage.

I realize that financially this is a challenging year for the state of CT. However, I believe mandating newborn screening for cystic fibrosis is worth the cost-in fact, I can guarantee it. In the July 2008 issue of Pediatric Pulmonology, I published our investigation of the efficacy of our newborn screening program at the University of Connecticut Health Center. This spanned more than 20 years of screening infants at the hospitals in CT which voluntarily screen for CF. Interestingly, there was no difference ethnically or socioeconomically between those hospitals which do and do not screen for CF. Our newborn screening program is effective, identifying CF in approximately 97% of children with the disease. As the majority of children identified by this program have chosen to continue their care at our CF center, we compared the newborn screened children with CF (about 50% of our patient population) to our symptomatically diagnosed patients with CF (also about 50% of our patient population). Most of the children screened for CF were identified and began receiving CF care by about 2 weeks of age where the children

who were diagnosed by symptoms were not diagnosed until 2 YEARS of age. We found results similar to that other states in that newborn screened children with CF grow and develop NORMALLY as would any healthy child. Unfortunately those symptomatically diagnosed children with CF are significantly behind their peers and in fact, despite receiving years of the exact same nutritional treatments, will likely NEVER catch up and have normal growth.

Most importantly, this study of our patients with CF in the state of CT and our 20+ years of voluntary screening for CF, have shown that newborn screened patients with CF not only have better pulmonary function than those symptomatically diagnosed patients, BUT as teenagers, our newborn screened patients still have NORMAL pulmonary function. This same group of patients who medical experience would have shown us would die in their teen years from their CF lung disease are thriving and still have NORMAL pulmonary function, thanks to early identification of their CF through newborn screening. Unfortunately, those symptomatically diagnosed patients with CF do not have normal pulmonary function. Furthermore, while pulmonary function continued to IMPROVE by 4% over time in the newborn screened patients with CF, those symptomatically diagnosed patients experienced a 14% decline.

As you can clearly see, our voluntary newborn screening program for CF has made a significant difference in the progression and severity of disease for those children who were fortunate enough to participate in the program. How were they so lucky? It seems silly but they were simply born in the right hospital, at the right time. Fortunately, we do not need to rely on luck or good fortune to identify ALL patients with CF in our state in the newborn period. By mandating newborn screening for cystic fibrosis, you will provide all children in the CT, the opportunity to be identified with cystic fibrosis early and immediately begin receiving early aggressive care at a CF foundation certified care center.

I implore you to mandate newborn screening for cystic fibrosis in the state of CT. Please, join us in making a difference.

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