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education programs. And out of 11 years, which is pretty remarkable, out of 11 years, Our Lady of Mercy School has competed in the mock trials; they have been our state champions seven times. So please join me in congratulating them.

Thank you.

SPEAKER DONOVAN:

Congratulations. Thanks for coming here; nice to see you.

Will the Clerk please call Calendar 411.

THE CLERK:

On page 29 -- oh, State of Connecticut House of Representatives' Calendar for April 26, 2012 -- on page 29, Calendar 411, Senate Bill Number 56, AN ACT CONCERNING PULSE OXIMETRY SCREENING FOR NEWBORN INFANTS, favorable report by the Committee on Public Health.

SPEAKER DONOVAN:

Representative Christopher Lyddy, you have the floor, sir.

REP. LYDDY (106th):

Thank you, Mr. Speaker.

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

SPEAKER DONOVAN:

The question is on acceptance of the Joint Committee's favorable report and passage of the bill.

Will you remark?

REP. LYDDY (106th):

Yes, Mr. Speaker. Thank you.

Mr. Speaker, this bill makes a simple change in our current statute which requires all health care institutions caring for newborn infants to perform pulse-oximetry tests on them, unless, of course, as allowed by their -- by law, that their parents object on religious grounds.

Mr. Speaker, this bill passed unanimously in the Public Health Committee and also has the support of the Hospital Association, the pediatricians, and the Department of Public Health. I think it's important to also note that the cost is very minimal and does not have any impact on the State or municipalities. The cost is approximately $10 to do the screening.

Mr. Speaker, the Clerk is in possession of an amendment, LCO Number 3213. I ask that the Clerk please call the amendment and I be granted leave of the Chamber to summarize.

SPEAKER DONOVAN:

Clerk, please call LCO 3213, which is previously designated Senate "A."

THE CLERK:

LCO 3213, Senate "A," offered by Senator Gerratana, Rep. Ritter, Senator Welch, Rep. Perillo, and Senator McLachlan.

SPEAKER DONOVAN:

The Representative seeks leave of the Chamber to summarize. Any objection? Hearing none, Representative Lyddy, you may proceed.

REP. LYDDY (106th):

Thank you, Mr. Speaker.

Mr. Speaker, this basically puts in -- in statute the timeframe for this to be implemented and specifies that in line 12 -- excuse me -- that a screening test for critical, congenital heart disease is listed very specifically.

Mr. Speaker, I move adoption of this amendment.

SPEAKER DONOVAN:

The question is on adoption. Remark further on the amendment?

Representative Perillo.

REP. PERILLO (113th):

Mr. Speaker, thank you very much.

If I may, sir, through you, a few questions to the proponent of the bill.

SPEAKER DONOVAN:

Please proceed, sir.

REP. PERILLO (113th):

Thank you, Mr. Speaker.

I -- the gentleman addressed, very, very briefly cost and stated that --

SPEAKER DONOVAN:

Excuse me, Representative. We're on the amendment right now. Do you want to speak on the amendment or on the bill, itself?

REP. PERILLO (113th):

The -- the amendment.

SPEAKER DONOVAN:

Okay.

REP. PERILLO (113th):

This is relative to the amendment too.

SPEAKER DONOVAN:

All right; then please proceed.

REP. PERILLO (113th):

Thank you.

If I could just get a better understanding, in

terms of the cost. The gentleman said that there would be no cost impact on the State and no cost impact to municipalities; however, this is an additional procedure that we are now requiring and from hospitals for newborns. I'm wondering if there would be any cost to insurance companies and whether that may perhaps have some sort of impact on premiums.

Through you, sir.

SPEAKER DONOVAN:

Representative Lyddy.

REP. LYDDY (106th):

Thank you, Mr. Speaker, and I thank Representative Perillo for the question.

There is no testimony or discussion around that issue, and the -- the bill certainly does not speak to -- to that issue. Again, the cost is minimal, and it is estimated by Senator McLachlan, who testified on behalf of this bill, that the cost would be approximately $10 per screening.

Through you, Mr. Speaker.

SPEAKER DONOVAN:

Representative Perillo.

REP. PERILLO (113th):

Thank you, Mr. Speaker.

And, again, through you, one of the things that we heard during the public hearing was that this is a very simple test. And this is something that's terribly involved; it seems as though this is something that should be win -- within the proper best practices in terms of delivering care for newborns.

I'm wondering if that best practice were to change down the road, if there was some sort of, you know, a new technology, a change in technologies, change in studies that indicated that perhaps this wasn't necessary or perhaps that it wasn't beneficial in any way, shape or form, how would we then handle that? This is something that we are writing into law now. If there were a change in clinical guidelines, how would we address that issue?

Through you, sir.

SPEAKER DONOVAN:

Representative Lyddy.

REP. LYDDY (106th):

Thank you, Mr. Speaker.

Another great question, an important one, as technology continues to involve. This particular amendment specifically addresses that concern, and we're not naming the test any longer, we're naming the

-- the disease which -- with which we are trying to find, which is the screening test for critical, congenital heart disease.

Through you, Mr. Speaker.

SPEAKER DONOVAN:

Representative Perillo.

REP. PERILLO (113th):

Thank you, Mr. Speaker.

And, again, through you. Again, the original version of this bill was specifically for pulse oximetry, and I understand the reason for the amendment and the reason for the change that we're not identifying that specific technology. But I am wondering, though, as we have expanded the scope of perhaps some technology that could be delivered, some testing that could be delivered, are there any other types of screening besides pulse oximetry that would apply in this case.

Through you, sir.

SPEAKER DONOVAN:

Representative Lyddy.

REP. LYDDY (106th):

Thank you, Mr. Speaker.

And through you, I'm not aware of any, which is,

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again, why we are specifically naming the disease and not the technology that we're using. But, again, there very well could be other technologies that I'm not aware of.

Through you, Mr. Speaker.

SPEAKER DONOVAN:

Representative Perillo.

REP. PERILLO (113th):

Thank you, Mr. Speaker.

I do believe that this amendment has been handled very, very well. There was very much concern early on in the game and early on in the discussions that perhaps we had pigeon-holed ourself into a corner that we couldn't get out of. And if, as I said, there were changes in technology, changes in the delivery of care, that perhaps being very, very specific in the bill as originally proposed would be inappropriate.

The amendment before us does expand the scope and gives providers, hospitals, physicians some latitude in the manner in which they deliver care and the manner in which they accommodate this testing.

I believe the amendment is appropriate. I support the amendment. And I should say that the amendment was handled in a way that was very

bipartisan, that it was very inclusive. It involved the relevant parties. It involved the hospitals. It involved individuals on both sides of the aisle, on both sides of the issue, and this is something that was reached quite well and quite appropriately.

And I, again, I thank the Chair and the Vice Chair of the Public Health Committee, and I would urge adoption of the amendment before us.

Thank you, sir.

SPEAKER DONOVAN:

Thank you, Representative.

Would you care to remark further on the amendment? Would you care to remark further on the amendment?

If not, let me try your minds. All those in favor of the amendment, please signify by saying aye.

REPRESENTATIVES:

Aye.

SPEAKER DONOVAN:

Opposed, nay.

The ayes have it. The amendment is adopted.

Remark further on the bill as amended? Remark further on the bill as amended?

Representative Carter.

REP. CARTER (2nd):

Thank you, very much, Mr. Speaker.

I rise in strong support of this bill. Ladies and gentlemen of the Chamber, each year birth defects affect about 40,000 babies. Now the problem is you may not have the opportunity right away to even know there was a birth defect. If it's a congenital birth defect, it may be a situation where that infant is taken home, and sometime later the parent finds that infant has passed away.

It can also manifest itself long into their life, 10, 15 years old, and all of a sudden, out of the blue, you hear about a young child dying on the football field or dying at home, out of the blue. This bill is a very prudent way for us to take a little extra step when those babies are born, to make sure they get a pulse oximetry test.

Now, for those in the Chamber who don't know what that is, basically it's just a measure about the amount of oxygen that's in the blood. By doing that, not only can you tell if there's a congenital heart defect, but you can also tell if there's a lung defect. The bottom line is for just a little extra time, we have the opportunity to protect a lot of

children.

Now hospitals, specifically Danbury Hospital has already begun this practice. It's not an expensive practice, by any means; it has wide acceptance, and -- and I should say growing acceptance in the medical community.

Ladies and gentlemen of the Chamber, this is a no-brainer. I hope that everyone will agree to support this a hundred percent.

Mr. Speaker, thank you.

SPEAKER DONOVAN:

Thank you, Representative.

Representative Srinivasan.

REP. SRINIVASAN (31st):

Thank you, Mr. Speaker. Good morning, Mr. Speaker.

SPEAKER DONOVAN:

Good morning, sir.

REP. SRINIVASAN (31st):

I, too, rise in strong support of this bill. We heard in the public hearings the importance of early detection, and through this test, as was just alluded to by -- by Representative Carter earlier on, it's relatively a simple test, a test which will enable us

to diagnose these cases very early; and, therefore, I would definitely urge all my colleagues, both sides of the aisle, to support this bill as well.

Through you, Mr. Speaker, if I can have a question to the proponent?

SPEAKER DONOVAN:

Please proceed, sir.

REP. SRINIVASAN (31st):

Thank you, Mr. Speaker.

When this pulse oximetry is done and the numbers do not look favorable, obviously that's where we want to pick up and detect. Are we sure that when we mandate this or require this to be done, it, at all hospitals they have the immediate backup that the appropriate cardiac consultations, cardiac evaluations will also be available or are we leaving it to the hospitals to take care as the need arises?

Through you, Mr. Speaker.

SPEAKER DONOVAN:

Representative Lyddy.

REP. LYDDY (106th):

Thank you, Mr. Speaker.

Mr. Speaker, I can't speak to each and every individual case that may result in this screening;

however, I can speak to the fact that the Connecticut Hospital Association, the Department of Public Health, and the pediatricians have all been in support of this bill. And I trust that the hospitals would act accordingly in the best interest of that particular newborn, should a screening result in an unfavorable report.

Through you, Mr. Speaker.

SPEAKER DONOVAN:

Representative Srinivasan.

REP. SRINIVASAN (31st):

Thank you, Mr. Speaker.

And I want to thank the proponent of the bill for the answer, because that is extremely important that we have the appropriate setup in the event we have a result which is not favorable. Not detecting is bad, obviously, but detecting and not being capable of doing something right at that moment is even far more worse in this, in that particular situation.

So when we have the appropriate backup that (a) the screening test will be done at the hospitals, and when the screening test is done and the numbers unfortunately in that particular situation are not favorable, action will be taken right away when we

have that comfort zone that definitely is the intent of this bill. And I would urge adoption.

Thank you, Mr. Speaker.

SPEAKER DONOVAN:

Thank you, Representative.

Representative Betts.

REP. BETTS (78th):

Good morning, Mr. Speaker. Thank you, very much.

SPEAKER DONOVAN:

Good morning, sir.

REP. BETTS (78th):

A question, through you, if I may, to the proponent.

SPEAKER DONOVAN:

Please proceed.

REP. BETTS (78th):

I'm not familiar with this test but obviously it's a very important one to detect heart disease. How reliable are these tests and how long has this been going on for?

Through you, Mr. Speaker.

SPEAKER DONOVAN:

Representative Lyddy.

REP. LYDDY (106th):

Thank you, Mr. Speaker.

Mr. Speaker, these tests are quite reliable, and they are administered a number of times to ensure the validity of the results. The test is quite simple and is a little device that is put on your finger. The Representative probably has had this test done in the past, if he has been in any kind of medical setting.

Mr. Speaker, it basically screens to ensure appropriate -- hold on one second -- if there's an unfavorable report, Mr. Speaker or finding, it will then result in further consultation with a pediatrician.

Through you, Mr. Speaker.

SPEAKER DONOVAN:

Representative Betts.

REP. BETTS (78th):

Thank you, and that's very reassuring.

I know I've witnessed at UConn Hospital, when my kids were born, so many really sick new babies that could have avoided some really serious problems if this test had been administered. And I strongly support this and would really urge the rest of the Chamber to pass this legislation as well.

And I thank the Public Health Committee for what

I think is a strong bipartisan effort to do something very good for these young, little kids.

Thank you, very much, Mr. Speaker.

SPEAKER DONOVAN:

Thank you, Representative.

Representative Smith.

REP. SMITH (108th):

Thank you, Mr. Speaker, and good morning, again.

This is a -- a very noninvasive test. This is a screening that has a minimal cost to the hospitals but at a terrific result. What is does do is that it -- it screens these infants for this potential heart disease. And when they catch it at the early stages, it can prevent not only astronomical cost for a future surgery, well all types of really -- could -- it could result in death if you, in fact, you don't catch it early on. So this minimal-invasive test is something that many hospitals are doing already. In fact, Danbury Hospital just volunteered to recently sign on to this. It is a great asset to our state. It is something that I strongly support.

One of our constituents in Sherman unfortunately had a -- a -- a young child who had a heart disease, and had they had this test done at that time, the

child who suffers a great deal now would not have had to suffer what he is going through.

So I urge the Chamber to support this. It's a very worthwhile bill, and it's something we should be proud of as a state to engage in.

So thank you, Mr. Speaker.

SPEAKER DONOVAN:

Thank you, Representative.

Representative Hetherington.

REP. HETHERINGTON (125th):

Thank you, Mr. Speaker.

If I may, a question or two to the proponent.

SPEAKER DONOVAN:

Please proceed, sir.

REP. HETHERINGTON (125th):

Through you, Mr. Speaker.

Are all of these three conditions which are identified in the, in the bill, are these ones that can be treated immediately; that is, by diagnosing any of these abnormalities at the outset, can treatment be commenced immediately to remedy them?

Through you, Mr. Speaker.

SPEAKER DONOVAN:

Representative Lyddy.

REP. LYDDY (106th):

Thank you, Mr. Speaker.

Mr. Speaker, this test simply screens for abnormalities, and therefore each individual case would have to be dealt with in that way, individually. And so I'm sure some of these situations may need immediate attention, but early intervention and monitoring of a congenital heart defect in the future may be dealt with not in the immediate future of that test.

Through you, Mr. Speaker.

SPEAKER DONOVAN:

Representative Hetherington.

REP. HETHERINGTON (125th):

Thank you, Mr. Speaker.

I notice that the screening for a congenital heart disease is effective January 1, 2013. The others are effective October 1, 2012. Is there a reason for the difference in the effective dates?

Through you, Mr. Speaker.

SPEAKER DONOVAN:

Representative Lyddy.

REP. LYDDY (106th):

Thank you, Mr. Speaker.

Mr. Speaker, through you.

In discussions with the hospitals and the pediatricians, they wanted to ensure that proper policies were put in place and updated to accommodate for this change.

Through you, Mr. Speaker.

SPEAKER DONOVAN:

Representative Hetherington.

REP. HETHERINGTON (125th):

Thank you.

Through you, Mr. Speaker.

Is there special equipment required for this that a hospital ordinarily would not have?

Through you, Mr. Speaker.

SPEAKER DONOVAN:

Representative Lyddy.

REP. LYDDY (106th):

Thank you, Mr. Speaker.

Through you, the testimony indicated that many of these facilities are already doing this or have the capacity to do this.

Through you, Mr. Speaker.

SPEAKER DONOVAN:

Representative Hetherington.

REP. HETHERINGTON (125th):

Thank you.

I thank the proponent, very much, for his answers. And I -- I'm in strong support of this, urge my colleagues to vote for it. Many of these conditions, particularly a congenital heart disease can be, in effect, a -- a time bomb. And I know of instances where a condition such as that occurred to threaten the wife, actually take the wife of somebody in my own, extended family, later in life. So I'm -- I'm very happy to support this, and I -- I urge my colleagues to do the same.

Thank you, Mr. Speaker.

SPEAKER DONOVAN:

Thank you, Representative.

Representative Perillo.

REP. PERILLO (113th):

Mr. Speaker, thank you, very much.

Just -- just to wrap up on this very quickly, I do have one, follow-up question.

Because this is an effective date that is, you know, coming up in 2013, and obviously we have newborns who will, goodness, be born before then, is there any plan or indication or expectation that there

would be some sort of look-back period, that newborns who are not screened, you know, between passage of this bill and the date required for implementation, would there be a requirement that the hospitals, the physicians perform this type of test to ensure there were no congenital defects?

Through you, sir.

SPEAKER DONOVAN:

Representative Lyddy.

REP. LYDDY (106th):

Thank you, Mr. Speaker, and through you.

The bill certainly is silent on that, however, there's nothing preventing or prohibiting a physician or a pediatrician from doing that on there own recognizance in looking back to their newborn babies for whatever time period they determine necessary.

Through you, Mr. Speaker.

SPEAKER DONOVAN:

Representative Perillo.

REP. PERILLO (113th):

Mr. Speaker, thank you, very much.

I thank the gentleman for his time in answering the questions.

As has been said before and I would concur, this

really is an excellent bill. It's going to make a very, very big difference in the lives of families and, of course, in the future, in the health and prosperity of our children. So I would, indeed, urge passage of the bill.

Thank you, sir.

SPEAKER DONOVAN:

Thank you, Representative.

Would you care to remark further on the bill as amended? Would you care to remark further on the bill as amended?

If not, staff and guests please come to the well of the House. The 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 taking a roll call vote; members to the Chamber, please.

SPEAKER DONOVAN:

Have all the members voted? Have all the members voted? Please check the roll call board to make sure your vote has been properly cast.

If all the members have voted, the machine will be locked. The Clerk will please take a tally.

Clerk, please announce the tally.

THE CLERK:

Senate Bill 56 as amended by Senate "A, " in concurrence with the Senate.

Total number voting	140
Necessary for passage	71
Yea	140
Nay	0
Absent, not voting	11

SPEAKER DONOVAN:

The bill passes, in concurrence with the Senate.

Any announcements or introductions?

Representative Gerry Fox.

REP. FOX (146th):

Thank you, Mr. Speaker.

For purposes of an introduction.

SPEAKER DONOVAN:

Please proceed, sir.

REP. FOX (146th):

Thank you, Mr. Speaker.

Today in the Chamber we have with us -- accompanied by Undersecretary of the Office of Policy and Management, Mike Lawlor, as well as Appellate Court Judge Mike Sheldon -- we have five lawyers from

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commissioner to overturn or in -- intercede on any of the decision that the board makes. I think that, again, as Ellen said, the independence is going to be maintained, and we changed the language to very specifically address that.

REP. RITTER: Thank you. And I -- I really appreciate those efforts to work on the language, and I think you rightly suspected that that might be a concern for many particularly when you speak to the, at least inability as you understand it, of the agency to actually overturn any decisions made on the part of the board.

And my concern, as I said, was that while I understand that that indeed may be the situation, I'm still not comfortable that this language is strong enough in addressing that. So I guess I might suggest that if there is a way to more clearly state that in this language as you just did, that might be something I'd be very interested in seeing.

COMMISSIONER PATRICIA REHMER: I think we'd be more than willing to work on that with you.

REP. RITTER: That would be helpful. Thank you.

SENATOR GERRATANA: Thank you, Representative. And thank you Commissioner Rehmer. I think we have asked you many questions, and we thank you for your testimony and coming here today.

COMMISSIONER PATRICIA REHMER: Thank you.

SENATOR GERRATANA: You're welcome.

Next to testify is Senator Michael McLachlan. Welcome, Senator. Good morning.

SENATOR MCLACHLAN: I also would like to thank Senator

SB 56

Welch and Representative Perillo and distinguished members of the Public Health Committee for raising Senate Bill 56 this morning which talks about pulse oximetry screening. And it's sort of a complicated name for a very simple test that we believe will save lives of children in the future.

With me here today is sort of the star of this whole issue, who the co-chairs I understand have had an opportunity to meet, Mrs. Marie Hatcher from Sherman, who is my constituent and contacted me last year asking for assistance in bringing this -- an issue forward here in the state of Connecticut where it has already seemed to have gained some terrific support. And with Marie Hatcher is Matthew. And Matthew is quite a -- quite a likable little guy who is a patient of a heart defect.

And it's Matthew that's really the genesis of this bill here in Connecticut. You'll hear from Marie soon. Matthew is voicing his opinion as I speak, and we're very grateful that Marie and her friends have traveled from far and wide here to the State Capitol to advocate for a very simple test we believe will cost about ten dollars per child and that it will be an early identification of a heart defect, when identified early means that it can be successfully treated in most cases and not develop into a much more serious ailment as the child grows. So I hope that we can engage your support in this idea and welcome any questions. Thank you.

SENATOR GERRATANA: Senator, thank you so much. You know you had me when you told me this was going to save lives. So I appreciate that very much and chairing this hearing, I'd like to bring Mrs. Hatcher up with her son now, if you don't mind, so we can hear from her and meet Matthew. Welcome, Mrs. Hatcher.

MARIE HATCHER: Good morning.

SENATOR GERRATANA: Good morning.

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MARIE HATCHER: Good morning, Senator Gerratana, Representative Ritter, nice to see you again, and distinguished members of the Public Health Committee. I'm here today both as a mother and a registered nurse of over 20 years. Today is a huge day for all future newborns and the potential to save their lives in the state of Connecticut. I sit here today because of two very important little people. This is, Matthew, my youngest, he was born with a serious congenital heart defect. (Inaudible) who also had a congenital heart defect, which she passed away on December 22, 2010.

I decided to use an acronym of the word heart to get my message across today appropriately. H is for hope. Hope that one day we will find a cure for congenital heart defects. Hope for Matthew's Hearts of Hope, an organization founded by me in honor of Matthew, to raise awareness of congenital heart defects (inaudible) Faith's sister who's actually here today in such -- to share in such a special day in honor of her sister, Faith. E is for education. I commend you all for being here to learn and educate yourself more on such an important piece of legislation.

A is for angel. More children pass away every year from CHD than all the childhood cancers combined, yet there is very little awareness. It is the number one birth defect, it affects one in 100 babies annually, yet nobody talks about it when you're pregnant. R is for Raised Senate Bill 66 also to be known as Matthew and Faith's Law. It will save lives. It's that simple. No parent should have to learn from a coroner that

her baby passed away of an undetected heart defect.

T is for touched. I am touched every day by the fact that Matthew is still here as a result of an ultrasound technician who took a close look at his heart at 20-week ultrasound. I believe everything in life happens for a reason, and Matthew and Faith were put in my life to help save others. I will end with two of my favorite quotes. The first is from Eleanor Roosevelt, a woman is like a tea bag, you never know how strong she is until you put her in hot water. My tea bag day was April 15, 2008, the day we learned about our -- that our baby was very sick. We have had many bumps in the road, but we are all stronger from them.

I am inspired every day by Matthew, Matthew's courage and strength. He is an amazing little man, and I am blessed to be his mother. Lastly, my message to my son and hero, Matthew, every day is from Winnie the Pooh, if ever there comes a time when we can't be together, keep me in your heart, I'll stay there forever. I leave you with this final thought, my son Matthew was diagnosed in utero. Because pulse ox screening is not mandated, there's a good chance that he might not be here today.

Ask Christine McCormick, Cora's mom, Gage's dad, who will testify a little bit later, Sean Pietras. And Debbie Prince, Sam's mom, if they think this is worth mandating. Their lives are very different because of no pulse ox screening on their newborns. The parents of Dillon Gordon and Brandon (inaudible) are certainly happy that pulse ox screening was mandated in the state of New Jersey. Please support House Senate Bill 56, you will save lives. It's that simple. Thank you.

SENATOR GERRATANA: Thank you so much, Marie. Thank you for bringing this to the attention of our General Assembly. And thank you also for educating us. I know I learned quite a bit when we did meet. And, you know, very often we wonder why very young people who are engaged in athletics, you know, contests and competitions and sports, unfortunately, you know, may become ill or even collapse and die on -- on the field, and that is extremely upsetting.

And this is just a simple and effective way to prevent that from happening. So we're happy you are here and Matthew is here. And also, Senator McLachlan, thank you so much for your bringing this bill to our attention also.

Are there any questions, comments? If not, thank you both for coming today. Thank all three of you. Bye-bye, Matthew. I want to hold that baby.

A VOICE: (Inaudible.)

Go bye-bye now. Next on our list, a hard act to follow, Commissioner Bremby, but we welcome you here. Commissioner Bremby from the Department of Social Services. Good morning.

COMMISSIONER RODERICK BREMBY: Good morning. Matthew, would you like to come up. Well, we're out of money. Good morning, Senator Gerratana, Representative Ritter, and distinguished members of the Public Health Committee. My name is Rod Bremby. I'm the Commissioner of the Department of Social Services. I'm here before you this morning to speak very briefly in relationship to three bills before you.

HB 5243
HB 5038

The first is Senate Bill 55, it's AN ACT EXPANDING THE MEMBERSHIP OF THE PHARMACEUTICAL AND THERAPEUTICS COMMITTEE. This committee

MINDI DAVIDSON: Good morning.

SENATOR GERRATANA: Good morning. Good afternoon, actually.

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MINDI DAVIDSON: -- and I came here today to tell you why I support the addition of CCHD to Connecticut's newborn screening panel. I would've deferred to Matthew, but I think he's outside playing at the moment. I was a healthy 30 year-old female when I became pregnant with triplets. Eight weeks into the pregnancy, we lost a baby. There was no known cause at the time, but from there I did have a problem-free pregnancy until I was approximately 28 weeks into gestation. At that point, my water broke. I was admitted into the hospital and put on bed rest, and from then on we tried to enhance and grow their lungs.

At approximately 30 weeks, the twins couldn't stay in any longer and were born via emergency C-section. It was at that moment that my life changed forever. While each twin had their own health issues, my son, Evan, was born with a ventricle septic defect, a form of CCHD. This particular defect required immediate decisions within 24 hours of birth. But if I may, let me back up a moment. From the minute the twins were born, they left the operating room. I never even caught a glimpse of what they looked like. When I got back to my hospital room, it was 15 hours before I could even see them for the first time.

From there, it was only through the glass of the NICU. I could not go in. And while I was starting to feel awful, I decided to go back to my room where it was eventually determined that I had an infection and needed immediate care. As my nurses were dealing with my fever and symptoms, my husband was going back and forth from the NICU room and my room, and the on-call

peds doctor came in looking very grave. At this point the twins are 18 hours-old. I immediately began to cry, fearing the worst was possibly going to happen.

He explained that Evan had a heart defect and that his heart essentially was not working properly and he was fighting just to breath. He has a hole in his heart, the doctor told me, and we need to decide to operate and see if he survives without the surgery if we choose to do that. But please if you would for a moment, close your eyes and just imagine you're sick, feeling awful from surgery and sickness, you haven't even held your newborn twins, let alone coming close to even seeing what they look like. What's their eye color? What skin tone do they have?

But yet you have to decide should you crack your son's chest wide open and operate on his heart? Right there, right then, what do you want to do? And by the way, we're talking about an infant that's three and-a-half pounds. Can he even survive the surgery? What happens if we choose not to do it? What happens if we choose to?

The fear and the cold ice that fills you from your head through to your fingertips to your toes takes over. You can't call your family to help make the decision, you can't sit there and Google out the symptoms, you're alone and your son's life is quite literally in your hands. And yet you still haven't held him.

So I am here today to make sure no mom or dad goes home from a hospital without knowing. This simple test, this non-evasive little sensor will stop so many painful decisions, so many tears, and just by determining the O_2 saturation in a baby's blood. This is a simple, painless test, but it can do so much. Please help other

families to not have to go through what we did. Let them decide without the emergency. Let them hold their child, look into their eyes, and be informed with just a simple test. I urge Connecticut's Legislature to pass Raised S.B. 56 so that every baby can receive critical congenital heart disease screening upon birth. Thank you.

SENATOR GERRATANA: Thank you so much, Mindi, for your powerful testimony. Does anyone on the committee have any questions? If not, thank you for coming today.

Next is Luz Osuba and Representative Minnie Gonzalez. Are they here? Yes, we got written testimony.

If not, then we'll go to Representative James Albis.

REP. ALBIS: Senator Gerratana, Representative Ritter, Representative Perillo, and other distinguished members of the Public Health Committee. Thank you so much for the opportunity to -- to come here and testify before you today in support of House Bill 5333, AN ACT CONCERNING ORGAN AND TISSUE DONATION AWARENESS.

I think many of us know personally know someone whose life has been impacted by organ or tissue donation. My good friend, former Mayor of East Haven, April Capone, famously donated a kidney to someone she met through Facebook when he posted a desperate message asking for help. The father of another friend of mine whom I have known for nearly 25 years was a recent recipient of a new heart just as it seemed his days were numbered. But these success stories are not always the case. All too often a person in need is left waiting until it's too late.

REP. ALBIS: Thank you.

SENATOR GERRATANA: Thank you. Thank you for coming today --

REP. ALBIS: Thank you very much.

SENATOR GERRATANA: -- and bringing the bill to our committee. Thank you.

Next is Jonathan Shapiro followed by Vicki Veltri. Jonathan Shapiro? He's not here. Okay.

Then we'll go on to Erica Venezia followed by Vicki Veltri. Here comes Erica. Welcome.

SB 56

ERICA VENEZIA: I'm a friend of Marie Hatcher and Faith's mom (inaudible). Faith was born with a severe congenital heart defect, and we're here today in favor of the pulse ox bill. We were lucky enough that Faith's heart was diagnosed in utero, though completely unexpected since we ended up at a high-risk specialist because of an uncooperative baby, not because of her heart. Had her heart not been discovered in utero, we would've gotten a much shorter time with her. Faith lived to be 2 years, 2 months, and 22 days old.

The pulse ox bill is something that's very important to us. We -- I was three months pregnant when we lost Faith. And it was the first thing we said, it was like the number one thing that I wanted done when my daughter, Hope, was born. We just -- it was very important to us that they do that testing first. And I think it was kind of confusing for the staff, you know, at the hospital as to why it was so important because it wasn't something that was done on a regular basis. And we -- it just -- it's so important to me that all my children get tested and all children. I think it's important for

everyone to have the opportunity that we had and to hopefully avoid the tragedy that we did.

SENATOR GERRATANA: Thank you so much for your testimony today. Are there any questions?

Representative Srinivasan.

REP. SRINIVASAN: Thank you, Madame Chair. Thank you for your testimony. I'm sorry for the tragedy that you've gone through. In trying to understand this, I -- I definitely agree that a pulse oximeter is a very important part of evaluation not only of the newborn, anybody with any respiratory condition. Myself being a physician, we do that routinely in our office for asthmatics and things like that. So I definitely understand the value of pulse oximetry.

My question is, will you -- are you suggesting, and the people -- people before you, that every newborn gets screened with a pulse oximeter, is that what your intent is or only the -- only the patients who have, you know, problems that have been identified, which I'm sure the pulse ox would've already been done in those situations?

ERICA VENEZIA: No, what we're asking for is for all newborns to be screened. Right now anybody that's admitted to the hospital, it's the first thing they do.

REP. SRINIVASAN: Right.

ERICA VENEZIA: First thing they do when they go in the hospital is put that on, but not for newborns. Babies that, you know, when they take -- we're asking that when they take the baby and do the, you know, the prick and the weighing and everything, that this is just part of the routine process that they do. Everybody else gets it done when they go into the hospital except for

newborn babies.

REP. SRINIVASAN: And -- and are you aware, and obviously I can look at this myself too when I get back to work, are you aware of where the pulse ox would be low or abnormal and you not -- and the pediatrician or the immunologist not -- not detect that right away at the time of birth or on the follow up? Is that -- is there such situations that you're aware of?

ERICA VENEZIA: -- such situations where it would drop --

REP. SRINIVASAN: Yes.

ERICA VENEZIA: -- after -- after birth?

REP. SRINIVASAN: Yes.

ERICA VENEZIA: To be honest, I'm not sure. I don't -- I believe that this would take out, you know, cover the vast majority of the CHDs that are out there. For example, like what my -- my daughter had. She -- when they first put her onto the pulse ox monitor she was (inaudible) around like 80 -- and for, you know, when she should be around 100. So that would -- that's an automatic indicator that there's something wrong. Can it drop? Potentially, but it's something that would definitely take -- cover a majority of CHDs that are out there, you know, from less serious to the more serious ones.

REP. SRINIVASAN: And are you suggesting that the newborn, that they get just one screen, right? They just check out once to see what the pulse ox is, is that what you're suggesting that we pass?

ERICA VENEZIA: Yes. Yes.

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

SENATOR GERRATANA: Thank you. I don't think there's any other questions, so thanks for coming today.

Next is Dr. Sandi Carbonari from the American Academy of Pediatrics. There she is. Welcome.

SANDRA CARBONARI: Good morning and thank you for having me. As you said, I'm Sandi Carbonari, and I'm a primary care pediatrician in Waterbury and currently the President of the Connecticut Chapter of the American Academy of Pediatrics. And I'm testifying on S.B. No. 56, AN ACT CONCERNING PULSE OXIMETRY SCREENING FOR NEWBORN INFANTS. As an addendum, we're also going to be submitting written testimony on several other bills.

So incorporation of pulse oximetry to the assessment of the newborn infant can enhance detection of critical congenital heart disease. And recently the Secretary of Health and Human Services recommended that screening for CCHD be added to the uniform screening panel such as the BKU, cystic fibrosis, et cetera. I'm way used to that, that doesn't bother me a bit.

SENATOR GERRATANA: We knew that was coming.

SANDRA CARBONARI: The AAP has been a strong advocate of early detection of -- of CCHD and fully supports the decision of the Secretary of HHS. The AAP National has published strategies for the implementation of pulse oximetry screening which address critical issues such as necessary equipment, personnel, and training, and also provided specific recommendations for assessment of oxygen saturation by using pulse oximetry as well as appropriate management of a positive screen.

The AAP is committed to the safe and effective implementation of pulse oximetry screening and is

working with other advocacy groups and governmental agencies to promote -- to promote the widespread surveillance for CCHD. Going forward, the Connecticut Chapter will partner with Connecticut's DPH to implement the new screening strategy and will work to ensure that there's an adequate system for referral for endocardiographic and pediatric cardiac evaluation after a positive screening result.

It's imperative that AAP members engage their respective policymakers in adopting and funding the recommendations made the Secretary of HHS. So we recognize that as Connecticut chooses to include the critical congenital heart disease screening in our newborn screening panel, they may go about achieving it in several different ways, Legislation, regulation, or adoption as a standard practice.

In any of these ways, we are recommending that the following be emphasized, how all newborns will be screened. The -- the recommendation is that it should be between 24 and 48 hours of age and the screening is done with a pulse oximetry reading of the right hand and either right or the left foot simultaneously. Then how are those results going to be reported to the person that is involved in their care?

How those who are not screened at birth, specifically home births, how -- how is that going to be done especially in a timely manner? And also how infants who have a positive screen will be evaluated? The proper evaluation of a positive CCHD screen is that the congenital disease has to be excluded by diagnostic electrocardiogram which is not available in -- in -- for children in many of the hospitals in which births take place. Also how payers will recognize and cover the cost of the work-up and consultation needed when an abnormal screen is

identified.

There's also financing and payment issues so existing state newborn screening programs are not jeopardized during these challenging economic times, and, finally, how the State Health Department will ensure the effectiveness of the agency's role in implementing the program. Unfortunately, there are some unintended consequences of a bill like this, which is something that we certainly are in favor of. There are a large number of false positives so that, especially until people are really well trained, it's not simple to do a pulse ox on anyone especially when you have to do two and they have to be done simultaneously.

What -- what unfortunately can happen with a false positive, you know, there is an algorithm which I have with me, which, you know, repeat it in an hour, you repeat it again in another hour, if it's still positive, then you're faced with -- if you're -- if you're at Yale, if you're at CC -- Connecticut Children's, there -- there isn't much of an issue because their services are available.

However, if you're in another hospital, and there are many of them in the state, then we need to discuss with the parents, gee, your child's oxygen screening is abnormal and he or she needs to have an echocardiogram soon, very soon. That involves transport of the child away from the parents to a -- a tertiary care center where that test can be done. And so now we have distraught parents, we have babies that are separated, so we need to really make sure we have a system that is going to work for benefit -- to the benefit of everyone.

SENATOR GERRATANA: Thank you, Dr. Carbonari, I'm sorry. I actually had a question. Are you

through or do you want to summarize? I'm sorry.

SANDRA CARBONARI: No, I mean, there is one other important point --

SENATOR GERRATANA: Yes, please state it.

SANDRA CARBONARI: That pulse oximetry is a very specific measurement and I would recommend thinking about possibly changing that language a little bit because in another year or two there may be something that's not pulse oximetry that is an even better technology. So perhaps thinking about changing -- changing that.

SENATOR GERRATANA: Thank you.

SANDRA CARBONARI: And just as an -- an addendum is that my oldest child was born with serious congenital heart disease. And she is now 29 so there was no such thing as pulse oximetry in those days. In fact, pediatric echocardiograms were very rudimentary at that time also. And so I certainly understand parents who have -- have been through it, because I've been there on the other side of the crib with a very, very ill baby who needed open heart surgery when she was particularly vulnerable. So as I said, we're very strong advocates.

SENATOR GERRATANA: Thank you. And I thank you for also bringing forth some of the practice standards. My question goes to what the test actually is, you know, since this is being televised and we have quite a few people here. Perhaps you could, it is in your professional scope, explain to us what the test actually is, because we're talking about the procedure and I think perhaps people would like to know what that is.

SANDRA CARBONARI: And here we are. What it does it

is -- it's basically a light type of a sensor. And so there's a little light sensor and then you just, well, with a child with a finger this big, you could use (inaudible) it can be on the hand and it has to be on the foot.

SENATOR GERRATANA: So that is the instrument, if you will, and there's a little Velcro?

SANDRA CARBONARI: It's a little -- there's a sensor and there's Velcro.

SENATOR GERRATANA: Okay. So the Velcro goes around the infant, in this case, child's finger?

SANDRA CARBONARI: Child -- yeah, it can be a finger, a thumb, a toe, and then it gives the reading of -- it gives a pulse and the oxygen saturation level.

SENATOR GERRATANA: Okay. Okay. So it's not invasive --

SANDRA CARBONARI: No, no.

SENATOR GERRATANA: -- there's no needles involved --

SANDRA CARBONARI: No.

SENATOR GERRATANA: -- that sort of thing?

SANDRA CARBONARI: No, there -- there's nothing invasive about it. There's no pain involved with it. It is -- it is something especially in a newborn that really requires a level of skill that would be --

SENATOR GERRATANA: Yeah.

SANDRA CARBONARI: -- probably at a -- at least an R.N. level of -- of skill needed to be really, I mean, people can be trained to do it, but you

have to do lots of them. Thank you.

SENATOR GERRATANA: Thank you for that.

SANDRA CARBONARI: It's similar to like if you ever go into an emergency room, they put a little clippy-thing on your finger or if you've had surgery or whatever, that's the same -- it's the same principle --

SENATOR GERRATANA: Same principle. Okay. Thank you. Any questions?

Doctor -- excuse me, Representative Srinivasan.

REP. SRINIVASAN: Thank you, Madame Chair. Thank you very much for your testimony. Earlier in this testimony, I don't know if you were here in the hall at that time, there was a mention of a cost factor of ten dollars per test. I'm not sure if you're familiar with that or you have any idea what this test will cost, any idea?

SANDRA CARBONARI: Well, the -- the cost would be the equipment, you know, capital costs, and then the time that it would take for it to be done and -- and for the actual sensor. I don't -- I honestly don't know what the cost is. We -- there are portable pulse oximeters that we use in our offices and -- but many of the payers do not reimburse for that.

REP. SRINIVASAN: I -- I definitely agree in that it's an extremely important test, extremely important. And I felt that it would not even cost us ten dollars, that's what I was thinking because the R.N. is already there, it's not that, you know, you -- you know, you're recruiting a new R.N. to do this particular procedure. So the -- the nursing staff is there. It's a one-time equipment that you've got to pay. And for the price, you know, that you're going to pay, the

benefits are actually astronomically so I really think it's probably costing us even less than the ten dollars that was talked about.

SANDRA CARBONARI: I'm not sure, but I'm sure that someone from -- from the hospital group would be able to let you know what -- what they would figure the cost would be.

REP. SRINIVASAN: Thank you. Thank you, Madame Chair.

SENATOR GERRATANA: Yes, thank you.

Representative Carter.

REP. CARTER: Thank you, Madame Chair. Thank you for your testimony. You mention about the false positives, and I just wanted to kind of clarify there. Would a false positive be a situation where there was a low O_2 saturation and then the child was followed up and there's no problem? Is that what a false positive would be?

SANDRA CARBONARI: Actually a false positive, you -- you would repeat it in an hour. Then if it was normal, then you're okay. And if it's still abnormal, repeat for a third time. And at that point, if it's still abnormal, then it would be considered a -- it would be considered positive.

REP. CARTER: Okay. And then with respect to positives, is there any data that would suggest --

SANDRA CARBONARI: That's the algorithm.

REP. CARTER: Okay. Very nice. I happen to know that one of my local hospitals is way out in front on this, Danbury Hospital. And Danbury and New Milford are both doing this as part of their regular screening now. I'm told it -- it isn't an extravagant cost. It is not reimbursable

necessarily, but it's not an extravagant cost. And there's something about the problems are reusable or something like that with the equipment?

SANDRA CARBONARI: Yes, there are problems that -- that are reusable.

REP. CARTER: Okay. Okay. And the only other question I had, you were -- you were talking about electrocardiograms for infants that there could be some outlying hospitals that would have a problem getting that?

SANDRA CARBONARI: I'm sorry. I may have misspoke, echocardiogram.

REP. CARTER: I apologize. It's my fault, I want to get it right. Echocardiograms for infants that, what is the limiting factor on that? Is it having somebody who's able to read it, having the equipment, what makes it difficult at an outlying hospital to have that done?

SANDRA CARBONARI: The ultra-stenographer actually doing it and -- and then having it read.

REP. CARTER: Okay.

SANDRA CARBONARI: So those -- those are the two -- the two factors. It's not -- they're not -- it's not insurmountable, but -- but you need to have some, even at my hospital, we do have very well-trained ultra-stenographer, but they work nine to five and not weekends.

REP. CARTER: I understand. Well, I'd like to thank you for your testimony. It was very thoughtful and very --

SANDRA CARBONARI: Thank you for having me.

REP. CARTER: Thank you, Madame Chair.

SENATOR GERRATANA: You're welcome. Thank you. I think that's it. Thank you so very much --

SANDRA CARBONARI: Thank you.

SENATOR GERRATANA: -- for your testimony, and we look forward to it in writing also, that would be helpful. Thank you.

Next is Jeannette DeJesus. Welcome. And I believe you have two others of your staff or experts on your bill.

JEANNETTE DEJESUS: Yes, thank you.

SENATOR GERRATANA: Thank you.

HB 5038

JEANNETTE DEJESUS: I had hoped that we could deliver this testimony because of its somewhat technical nature with you having full stomachs, right after breakfast, so I'm glad to see some of you having lunch.

I'm Jeannette DeJesus, and I work as the Governor's Advisor on Health Reform. And I'd like to, because of the nature of my testimony on an all-payer claims database, it -- it being somewhat technical, I'd like to introduce our General Counsel in the Office of Health Reform Innovation and our Senior Policy -- Health Policy Analyst, Laurie Graham and Bobbi Schmidt. And they are here because they are somewhat expert in the area of all-claims database -- databases, and will be available to answer your questions.

So let me apologize in advance. I generally don't stick closely to testimony, but because of the technical nature of this, I will. And we do have additional copies if the committee would like them.

think we will be very willing to help you provide that to every committee meeting. And it might be that some of common themes that you heard here would be most appropriately addressed specifically in that. So I would ask for that.

JEANNETTE DEJESUS: Thank you. We would be very happy to -- to provide that. And I would like to offer this committee obviously access to my colleagues. Please feel free to call them. They will come to you, they will work around your schedule, and you should feel free to have conversations with them or with me with regard to your concerns and your interest in this. And we will make that a priority in our office. Thank you.

REP. RITTER: Thank you. And I suspect we may take you up on that.

Next we will be hearing from Olwen Gurry and to be followed by Debbie Prescott.

OLWEN GURRY: Good afternoon. My name is Olwen Gurry. I am a practicing registered nurse at Danbury Hospital. And I am the mother of two wonderful children and patient advocate. Can you hear me now?

REP. RITTER: If you could speak up just a bit, it would be helpful.

OLWEN GURRY: Okay. My name is Olwen. And I'm a registered nurse at Danbury Hospital. I'm the mother of two wonderful children, two healthy children, and I'm also a patient advocate. I was fortunate to become involved with Marie Hatcher and her wonderful son, Matthew, who's living testimony of the positive outcome to early intervention. I came today to urge you to support Senate Bill Number 56.

As mentioned earlier, congenital heart defects is

the most common of all birth defects, 1 in 100 births. All newborns in the state of Connecticut, I believe, should be automatically screened for congenital heart defects with pulse oximetry. Pulse oximetry should automatically be the fifth vital sign in newborn screening. I could sit here and quote study after study that endorses pulse oximetry. But there was one study that I wish to refer to from the *Archives of Pediatric and Adolescent Medicine* regarding "Missed Diagnosis of Critical Congenital Heart Disease." I'm going to refer to it as CCHD.

There was a 15 year California study which was based on 898 infants who died of CCHD in infancy. One hundred and fifty-two were determined to have missed congenital heart defects diagnosis, and 299 had late diagnosis.

According to national statistics of the approximately 4,000 babies born nationally with CCHD each year, one can assume that 2,000 babies would die due to undiagnosed or late diagnosis of critical congenital heart defect. The median age of death, deaths in California, was less than two weeks and more than 50 percent with missed CCHD died at home or in their hospital emergency room.

In the State of Indiana, a beautiful baby girl named Cora, she died in her mother's arms while breastfeeding five days after her birth. No mother should have to experience this tragedy especially when there was a simple screening test available to detect congenital heart defects.

The American Academy of Pediatrics and The Centers for Disease Control and Prevention both endorse pulse oximetry screening for CCHD. Danbury Hospital, where I work as a registered nurse, are implementing this test without a mandate because without screening, some newborns with CCHD might be missed because the signs might

not be evident before an infant is discharged from the hospital after birth as was the case with Cora. Thank you for supporting this bill.

SENATOR GERRATANA: And thank you very much too for coming today and testifying. I just found your testimony. I was going through trying to find it. And, of course, we do appreciate your testimony in favor of the bill. Any questions? If not, thank you very much.

OLWEN GURRY: Thank you.

SENATOR GERRATANA: Next is Debbie Prescott. Are you Frank? Oh good. Debbie Prescott and Frank Sykes, is that correct? Good. Thank you both for coming here today.

FRANK SYKES: We wanted to, you know, make it, you know, there's a lot of people who want to speak, so --

SENATOR GERRATANA: We do appreciate that. Thank you.

HB 5333

FRANK SYKES: My -- my name is Frank Sykes. I'm the Legislative Analyst with the African-American Commission. And I'm here today with Debbie Prescott, she is a heart transplant recipient, and so she's going to be speaking once I'm done. I'm just going to speak briefly about some statistics over here. Finding a suitable organ donor is a complicated problem for anyone no matter your race, income, or class. However, the lack of available donors is extremely challenging for many in the African-American community.

Nationally minorities make up about 20 percent of the population, but slightly more than 50 percent of waiting list for organ transplants. Here in Connecticut, as of February 24th of this year, 34 percent of those on the waiting list for donors are African-American, a disproportionate number

SENATOR GERRATANA: Yes.

FRANK SYKES: I appreciate it.

SENATOR GERRATANA: Yes, very much so.

DEBBIE PRESCOTT: Thank you.

SENATOR GERRATANA: Thank you.

Next is Sean Pietras. Hi, Sean.

SEAN PIETRAS: How you doing? Thank you for having me here.

SENATOR GERRATANA: Thank you.

SB56

SEAN PIETRAS: I'm here today on behalf of my son, Gage, who passed here unexpectedly from an undetected heart defect. When I first found out I was having a son, I was very, very blessed that we'd be passing on my last name. Everything was right on target with all the ultrasounds, they were normal with no concerns. My son seemed to be normal, young boy growing up, but it came to a halt on January 24, 2004, when my son suddenly passed away at the age of 20 months.

At this time my world came crashing down. I felt like there was no reason to live. Thank God I have a precious daughter to keep me thriving to survive. She's now 12 years-old. When we found out my son passed from an undetected heart defect, I was really confused on what and why this happened. He was diagnosed with acute myocardial infarction, AMI. In his case, his coronary artery was non-existent.

To this day I believe this could have been prevented from the pulse oximetry test if it was available at the time when he was born.

Congenital heart defect is the number one birth defect affecting 40,000 babies annually. Of those, 33 percent are considered critical or may lead to death if undetected. One in 100 babies dies each year with undetected heart defects, like Gage. A simple solution to this problem would be to have a simple pulse oximetry test. This cheap, easy, painless method to find -- finding something of most serious heart defects.

So to me this is cost effect, a non-evasive means of testing for CHD. I hope at the end of that -- of -- of this, that you will support this bill requiring pulse oximetry testing for every newborn. It will save lives. Please let Connecticut join New Jersey and Indiana as the current states with this important law and the many other states moving quickly to mandate this simple test to benefit newborns throughout the United States.

SENATOR GERRATANA: Thank you so much. I'm so sorry for your loss, Sean, but I appreciate very much you coming here and giving your testimony today. And I certainly hope, you know, as we go forth from this day that we can save some lives. Would you just do me a favor; I may have mispronounced your name, could you state it into the record.

SEAN PIETRAS: Sean Pietras.

SENATOR GERRATANA: Pietras.

SEAN PIETRAS: Yes.

SENATOR GERRATANA: Okay. Thank you so much.

SEAN PIETRAS: Thank you.

SENATOR GERRATANA: Are there any questions or, no. Thank you for coming.

SEAN PIETRAS: Thank you very much for having me.

SENATOR GERRATANA: You're welcome.

Next is Dr. Richard Berning.

RICHARD BERNING: Good afternoon, Senator Gerratana and distinguished members -- members of the Public Health Committee. My name is Dr. Richard Berning, I'm a practicing pediatric cardiologist in the western Connecticut area. I come -- to put -- to put my glasses on -- I can confidently state that passage of Bill 56 will save lives.

As you've heard, this bill mandates routine screening of all babies before discharge to home from the nursery after birth. And what that screening looks for is low oxygen levels using that pulse oximeter that was demonstrated before, so you can see how simple it is.

This is a tool that every hospital has and many doctor's offices have and it's used on a regular basis. Currently oxygen levels are only checked when you have a suspicion that the patient is ill. So newborn infants who appear healthy and don't give any symptoms like turning blue or having a murmur or breathing hard aren't necessarily checked for their oxygen level before they're sent home. As you heard also, congenital heart disease occurs in approximately one percent of all newborn babies.

Now many of these babies are identified prenatally or otherwise soon after birth when they present with symptoms. Just to give you -- not to get too technical, but before birth the baby receives oxygen from the placenta and the blood is diverted away from the lungs through a blood vessel called a ductus arteriosus. Now this ductus is a muscular tube that's programmed to close once the baby starts breathing air and

some hormone changes. But this ductus can stay open or patent for many hours or days depending on different factors.

So when babies have serious congenital heart disease, this PDA, this patent ductus arteriosus, can actually keep them alive because it provides a detour past the defective portion of their heart. So when -- when this ductus is open, a baby can fool a doctor or a nurse because the baby will look healthy, won't have symptoms, and they can be sent home and at some point later, it can be hours, it can be days, it can be weeks, the baby will suddenly die when that ductus closes and that's a tragedy.

So passage of this bill will standardize the evaluation of newborn infants before discharged to home and likely catch many of the infants who are presumed to be healthy, but, in fact, have serious congenital heart disease. As you know, the test is simple, it's inexpensive, and the equipment is already available at every hospital in Connecticut. Passage of this bill will help detect previously missed, seriously ill infants and ultimately I think will save health care dollars, unnecessary deaths, and save their families heartache and grief.

SENATOR GERRATANA: Thank you very much, Dr. Berning. I really appreciate your testimony on the bill, very helpful.

Representative Perillo followed by Representative Srinivasan.

REP. PERILLO: Madame Chair, thank you very much. I actually just have one question, it's a question that we discussed in -- in bill screening and I was just discussing with Representative Srinivasan, I -- I just don't understand why this isn't done already. It's pretty much free.

RICHARD BERNING: Yeah, it's just a matter of adding the protocol. It's one more thing for nurses to do. I mean, you know, as it is nurses take care of a lot of babies in one day. So this test, the way the protocol was written, is every baby will get checked once, and if their oxygen saturation is below 95 percent, an hour later they're going to be checked again.

And if they fail that, then they'll be checked yet a third time. But at that point -- and this is, you know, assuming there's no other symptoms, if they need that third test, a phone call would be made to somebody like me, we'll come, we'll do the ultrasound, we'll look at the EKG, we'll listen with our stethoscopes.

But I -- to answer your question, that's a travesty. I totally agree. It's so simple to -- to do a test like this. Again it's cheap, it's non-invasive, there's no needle or pain, it's like they mentioned before, should be the fifth vital sign.

REP. PERILLO: I -- I was just wondering if it was some other reason why it was impractical or difficult to -- I mean, I know the procedure --

RICHARD BERNING: Because it wasn't done, it's the way things used to be, you know, it just needs to change.

REP. PERILLO: All right. Thank you.

SENATOR GERRATANA: Representative.

REP. SRINIVASAN: Thank you, Madame Chair. Thank you, Doctor, for your testimony. Could you just enlighten us on false positives and false negatives? The false positive reading is, I'm sorry, the false positive reading is something in

as much as it is negative but the child is fine. We can all (inaudible) it's just a question of extra evaluations, maybe an echo, something (inaudible) and at the end of the day everything is great.

I'm concerned about the false negative as much as the -- the pulse ox is reasonable, looks good, and -- and so you are lulled into this false sense of security that everything is fine. But -- but unfortunately the baby does have a congenital heart disease. A, is that possible, B, what would be the incidence, and what can we do to prevent that -- to prevent even that?

RICHARD BERNING: Well, yes, no test is perfect. As far as the false positives, the study that this protocol is based on was done at the Washington -- National Children's Hospital in Washington, D.C. The false positive rate was 1 out of 3,000. So and in many of the babies when something was found, it may not be heart disease, but they're found to have lung disease or some other reason their oxygen level was low. So it's not going to -- but -- but this test is only going to detect that heart disease that causes the oxygen level to be low.

So if the blood is flowing in the normal circulation but they have other issues, like their heart muscle is infected, the myocarditis, this test may not necessarily diagnose that. So it's not a perfect test, but I think it's going to really cut down on the number of -- of missed diagnoses and -- and, you know, if nothing else, every baby that can be looked at a little more closely now. So I think it's -- it's such a no-brainer to me to do this.

SENATOR GERRATANA: Certainly. Thank you.

Representative Carter.

Excuse me, Dr. Berning --

RICHARD BERNING: Oh, I'm sorry.

SENATOR GERRATANA: -- one more question.

REP. CARTER: You thought you were going to get away that easy. He's the hard one.

SENATOR GERRATANA: That's okay.

REP. CARTER: They get you in the hot seat for a reason. Thank you, Madame Chair.

Doctor, you mentioned something very interesting to me. Oftentimes children who are picked up with a low O_2 saturation may have other problems as well?

RICHARD BERNING: Correct.

REP. CARTER: Problems with lungs, problems with blood?

RICHARD BERNING: Babies who have low oxygen even if they're infected, asepsis, and maybe these things aren't functioning like it should, so it's a very subtle sign. As you know, babies can't always tell you when there's a problem, so you look for these subtle signs, and it's easy to miss a low oxygen level. I mean, a baby has to be quite blue for your eye to pick it up. You have to be under certain lights. You've got to take them by the window so the sunlight can hit them.

You can have an oxygen saturation -- normal is like 96 to 100 percent. You can have an oxygen saturation of 92 percent, have serious congenital heart disease and look pink as ever, and -- and you wouldn't even know it.

REP. CARTER: And -- and you're attached to Danbury Hospital currently?

RICHARD BERNING: That's my main hospital (inaudible).

REP. CARTER: Your main hospital? And they're doing this at Danbury?

RICHARD BERNING: Yes.

REP. CARTER: What has been the response from the staff?

RICHARD BERNING: They're very enthusiastic. As -- as -- as was mentioned. It's just, you know, one more thing to do, but I think everybody just feels better that, you know, it's just one more check. I haven't -- we haven't had any pushback.

REP. CARTER: Okay. Excellent. Thank you for your time. Thank you, Madam Chair.

SENATOR GERRATANA: Absolutely. I think you can go now. Thank you.

RICHARD BERNING: Thanks.

SENATOR GERRATANA: Thank you so much.

Next to testify is Erin E. Jones.

ERIN JONES: Good afternoon.

SENATOR GERRATANA: Hi, Erin. Good afternoon.

ERIN JONES: Oops, that's my (inaudible).

SENATOR GERRATANA: That's okay.

SB56

ERIN JONES: All right (inaudible). I did submit my testimony, so you have it in front of you, and I also gave some supporting document to this.

My name is Erin Jones. I'm with the March of Dimes. I'm here today to support Senate Bill Number 56. You've heard a lot about that this morning, so I'm not going to go into too much detail. We had Dr. Berning here who talked to you more about the physiological parts of this, but really what the March of Dimes wants to just point out is that this is another newborn screening that we can do that's relatively inexpensive where we can save lives. And I think we've heard that -- a lot of that today.

You know, the March of Dimes is a leader in advocacy for newborn screening for all infants in the United States. Our mission is to improve the health of women of childbearing age, infants and children by preventing birth defects, premature birth, and infant mortality. This is one of the ways that we can do that. So we support this. We ask for your support in the bill.

I did want to point out one thing and I think we talked about this earlier today is the -- the actual name of the bill. We -- March of Dimes is suggesting that we not name the bill based on pulse oximetry because of the technology, and I think someone else had testified to that earlier today, really talking more about testing for the congenital heart disease versus the technology use behind it.

That's really, you know, I have other -- well, you've heard a lot today on this bill, so I won't belabor it. Does everyone have the sheets?

SENATOR GERRATANA: Thank you, Erin, and I have your testimony as well as the attachment, you know, and I believe the whole committee does, too. So thank you very much. We can use you as a resource if we need to.

Does anyone have any questions? No?

ERIN JONES: Okay.

SENATOR GERRATANA: If not, thank you.

ERIN JONES: Thank you.

SENATOR GERRATANA: Take care.

Next is Len Wallace.

LEN WALLACE: Good afternoon, Senator and members of the Health Committee. I am here to speak to you on behalf of the American Heart Association about S.B. 56 which we've all heard very much about today. I am going to speak on the sort of opposite spectrum of what Mark's mother is speaking on.

I am a survivor of CHD. I have been living with my congenital heart defect for the past 29 years. When I was born, pulse oximetry was not around. It took doctors saying that I was fine to my mother several times before one doctor listened to my heart and noticed that I had a murmur, and that doctor pretty much saved my life because otherwise I probably would have gone home and just been one of those other statistics.

Pulse oximetry screenings are a very good thing. They're here to, you know, help identify these problems in kids before they become a problem. My particular CHD is something that over the years is not even an issue anymore. It's something that can be fixed in utero. I'm currently the oldest living survivor of my particular condition from what I've been told. My condition is called a -- what it is -- an endocardial cushion defect of the hypoplastic left ventricle. You should note that. But yes --

SENATOR GERRATANA: Okay.

LEN WALLACE: Basically what it is is I have a very -- I was born with a very weak ventricle in my heart, and what happened was that they went into my heart when I was an infant, put kind of a pulmonary banding around it to kind of keep it strong, and then once I turned eight years old and my body was strong enough to deal with the big surgery, my mother took me to the Mayo Clinic and I had

an open heart surgery that basically, in lay terms, ended up knocking out the wall between my two ventricles, and now I have a fully functioning heart. I don't have any problems. I don't really even have to take medication any more. So it's just one of those things.

So this -- this is why I'm here, is to speak on behalf of kids growing up with CHD and, you know, to be kind of a messenger for them, tell them that, you know, even if they have issues like I do, or issues like they do, it's not always going to be the end of the world.

SENATOR GERRATANA: Well, we're glad you're here, and we are very glad that you have spoken out.

LEN WALLACE: (Inaudible).

SENATOR GERRATANA: And we appreciate very much your taking the time today to come and speak to us.

LEN WALLACE: Absolutely.

SENATOR GERRATANA: All right. Any questions, or, if not, thank you very, very much.

LEN WALLACE: Thank you.

SENATOR GERRATANA: Take care, Len.

LEN WALLACE: You, too.

SENATOR GERRATANA: Next is John Bailey from the American Heart Association.

SB56

JOHN BAILEY: Good afternoon, Senator and members of the Public Health Committee. I have submitted testimony, so I'll be brief. As you've just heard, Len actually exemplifies what technology can do, and what -- what a -- a young child with congenital heart disease can look forward to.

And I would like to say about Mr. Wallace is that he is actually a transplant from Kentucky where he was an ardent advocate for the American Heart on this particular issue, and we're very grateful that he took the time today to testify on this.

Just to recap, the American Heart Association is very dedicated to seeing this piece of legislation passed, and as mentioned before this -- this type of screening is -- is in place in other states: New Jersey, Maryland and India -- or Indiana. And it just happens in New Jersey, when this piece of legislation came into effect at 12:00 on a certain day, a young -- a young newborn, Dillon, who was born the day before this bill came into effect, had to undergo the screening because of the bill and it -- he was discovered with congenital heart disease.

So and as was mentioned before by the doctor, he had an oxygen rate of something like 80 percent, but at the same time he looked -- he had pink cheeks. He looked as healthy as can be. So if it wasn't for that piece of legislation passing and the hospital having to administer that test, he would probably not have survived longer than a couple of days. So that is just an example of how important this legislation is. And thank you, Chairs, for raising it, and I'm happy to take any questions.

SENATOR GERRATANA: Thank you. Any questions? No. Thank you for your testimony.

JOHN BAILEY: Thank you.

SENATOR GERRATANA: And next is Dr. Gilead Lancaster, Connecticut Chapter of the American College of Cardiology. Welcome, Dr. Lancaster.

GILEAD LANCASTER: Thank you. Thank you, Senator Gerratana, SB56 Representative Ritter, and members of the health -- the Public Health Committee. My name is Dr. Gil Lancaster, Gilead Lancaster. I'm a Board Certified Cardiologist, the director of Non-Invasive Cardiology at Bridgeport Hospital, an Associate Clinical Professor of Medicine at

Yale, and the president of the Connecticut Chapter of the American College of Cardiology, an organization that represents most of the doctors and nurses that treat heart patients in Connecticut.

Our national organization, the American College of Cardiology, was an innovator of evidence-based medicine with the development of medical guidelines and appropriate use criteria for tests, tools that are now the backbone of quality health care around the world.

I'm here before you to testify in support of S.B. 56. In 2008 the United States Health and Human Services Secretary's Advisory Committee on Inheritable Disorders in Newborns and Children was authorized by Congress to provide guidance to the Secretary about which conditions should be included in newborn screening and how systems should be developed to assure appropriate screening and follow-up care.

In 2010 the committee recommended that critical congenital cyanotic heart disease be added to the recommended uniform screening panel based on findings from a comprehensive review of the available evidence.

The goal is to identify those newborns with structural heart defects usually associated with low oxygen saturation in the blood, with a simple and relatively inexpensive screening test called the pulse oximeter.

As you have all ready heard, pulse oximetry is a non-invasive test that estimates the percentage of hemoglobin in blood that is saturated with oxygen, and many hospitals all ready use pulse oximetry as a standard of care in their new -- newborn nurseries and, as in Danbury Hospital now, even for screening for newborns who have congenital heart disease.

We -- we believe that many of the newborn lives could be saved by earlier detection and treatment of congenital cyanotic heart disease if hospitals were required to perform this simple, non-invasive newborn screening

method, and so we, the American College of Cardiology, urge that this bill be adopted. (Inaudible).

SENATOR GERRATANA: Thank you very much. That's okay. Any questions? Nope. Oh, I'm sorry. Representative Carter.

REP. CARTER: Thank you, Madam Chair. I just want to make a quick comment actually, and given special thanks to Dr. Lancaster and Dr. Berning for being here. We know that you've just gotten three minutes here today, but -- but having you take your day off from a busy practice means a lot to us, so I want to publicly thank you both.

A VOICE: Thank you. Thanks very much.

SENATOR GERRATANA: Thank you. Next we will be hearing testimony on House Bill 5333, and we start with Bruce Adams, Connecticut Donate Life. Here he comes.

BRUCE ADAMS: Senator Gerratana, Representative Ritter and esteemed members of the Public Health Committee. I appreciate this opportunity to speak in support of House Bill Number 5333.

My name is Bruce Abbott Adams. This legislation will increase opportunities to educate the residents of Connecticut of -- in the importance of organ and tissue donation. I, myself, am a double organ transplant recipient. I received my gift on July 18, 2010. It was a liver and kidney from my donor family. That donor family had actually received that liver from another donor family. Yes, my liver has been transplanted twice.

My family also knows the pain that comes from watching a loved one pass away while on the waiting list. My mother-in-law, Gail Kopcik, passed away on January 6, 2006 while waiting for a liver to come available.

I am a volunteer with Donate Life Connecticut. I support Donate Life Connecticut by being an ambassador to the Hamden Branch of the Department of Motor Vehicles. I also share my story by speaking at colleges, hospitals,

JOINT
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HEARINGS

PUBLIC
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PART 2
353 – 705

2012

American Academy of Pediatrics
HEZEKIAH BEARDSLEY CONNECTICUT CHAPTER

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104 HUNGERFORD STREET • HARTFORD, CT 06106 • TEL. (860) 525-9738 • FAX (860) 727-9863

I am Dr Sandra Carbonari. I am a pediatrician in Waterbury, and am currently the President of the CT Chapter of the American Academy of Pediatrics. Today, I am testifying on **S.B. No. 56 (RAISED) An Act Concerning Pulse Oximetry Screening For Newborn Infants**

I also will be submitting testimony of a few other bills on today's agenda.

Incorporation of pulse oximetry to the assessment of the newborn infant can enhance detection of critical congenital heart disease (CCHD). Recently, the Secretary of Health and Human Services (HHS) recommended that screening for CCHD be added to the uniform screening panel. The American Academy of Pediatrics (AAP) has been a strong advocate of early detection of CCHD and fully supports the decision of the Secretary of HHS.

The AAP has published strategies for the implementation of pulse oximetry screening, which addressed critical issues such as necessary equipment, personnel, and training, and also provided specific recommendations for assessment of saturation by using pulse oximetry as well as appropriate management of a positive screening result. The AAP is committed to the safe and effective implementation of pulse oximetry screening and is working with other advocacy groups and governmental agencies to promote pulse oximetry and to support widespread surveillance for CCHD.

Going forward, CT-AAP chapters will partner with CT's DPH to implement the new screening strategy for CCHD and will work to ensure that there is an adequate system for referral for echocardiographic/pediatric cardiac evaluation after a positive screening result. It is imperative that AAP members engage their respective policy makers in adopting and funding the recommendations made by the Secretary of HHS.

We recognize that as Connecticut choose to include critical congenital heart disease (CCHD) screening in our newborn screening panel, they may go about achieving it in a number of different ways — legislation, regulation, or adoption as standard of practice.

In any of these ways, we are recommending that the following be emphasized:

- how all newborns will be screened
- how their results will be reported to those involved in their care
- how those who are not screened at birth are identified and screened in a timely fashion
- how payers will recognize and cover the costs of the work-up and consultation needed when an abnormal screen is identified
- how financing and payment issues are addressed so existing state newborn screening programs are not jeopardized during these challenging economic times
- how state health departments will ensure the effectiveness of the agency's role in implementing the program

While CT SB 56 specifically mentions pulse oximetry screening, we should recognize that the technology could change in the future and having pulse ox as the single defined screening measure would mean going back into the statute to change it at a future date. Working with interested partners, we may want to amend the bill to require "a newborn screening test for critical congenital heart disease" and have regulationss that name pulse oximetry at this time, but would change if a newer, more accurate, cost effective screening comes along in the future.

State of Connecticut

SENATE

STATE CAPITOL
HARTFORD, CONNECTICUT 06106-1591

SENATOR MICHAEL A. McLACHLAN
TWENTY-FOURTH SENATE DISTRICT

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March 7, 2012

ASSISTANT MINORITY LEADER

RANKING MEMBER
GOVERNMENT ADMINISTRATION & ELECTIONS COMMITTEE

MEMBER
JUDICIARY COMMITTEE
LEGISLATIVE MANAGEMENT COMMITTEE
TRANSPORTATION COMMITTEE

Dear Senator Gerratana, Representative Ritter, and distinguished members of the Public Health Committee,

I am State Senator Michael McLachlan, and I am here today to speak in support of ***Senate Bill 56, An Act Concerning Pulse Oximetry Screening for Newborn Infants.***

In June 2011 I was contacted by a constituent named Marie Hatcher. Mrs. Hatcher was on a very simple mission – to ensure that every newborn in the state of Connecticut receives a life-saving test called pulse oximetry screening.

Mrs. Hatcher's youngest son, Matthew, who is now three, suffers a serious congential heart defect called hypoplastic right heart syndrome. He has undergone multiple heart surgeries since his birth, the latest having occured this past August. As a nurse, Mrs. Hatcher knew to ask for the elective pulse oximetry screening in-utero, a procedure that literally saved Matthew's life. Not all families are as fortunate.

As stated previously, currently, the screening is elective, and primarily occurs when it is requested by a parent or recommended by a physician. Due to its elective nature many newborns go home with undetected heart defects and later pass away from them. Such events are disastrous for families and communities.

Senate Bill 56 aims to require pulse oximetry screenings be administered to newborns born in Connecticut. A pulse oximetry screening is a simple, non-invasive, procedure used to measure the amount of oxygen in one's blood. It is the most effective way to screen for congenital heart defects.

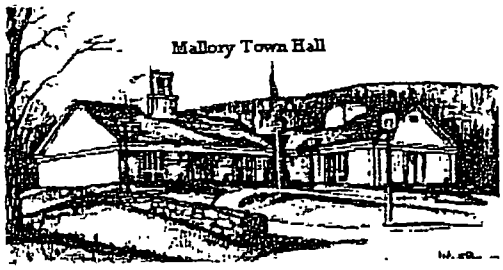
The equipment necessary to administer this screening is already in all Connecticut's hospitals. Additionally, the staff who would administer this test is already trained in the proper way to do such. This is due to the fact that the procedure is currently elective.

The cost per screening is approximately $10. This is far less expensive than what it would cost to provide a lifetime of medical care to a child diagnosed with a heart defect later in life, or the emotional cost to a family if their child was to be lost.

Similar legislation has already been passed into law, or is pending passage in many other states. Connecticut's neighbors New York, New Jersey, Pennsylvania, and most recently New Hampshire all have laws on the books that mandate pulse oximetry screening on newborns. These are just a hand full of states already mandating this life-saving procedure.

Overall, this legislation is about ensuring Connecticut's children are healthy, and stay that way I urge the committee to support this legislation.

Thank you for your time.



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March 5, 2012

Public Health Committee
Legislative Office Building
Hartford, Connecticut 06106-1591

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

My name is Andrea O'Connor. I regret that I am unable to attend the hearing regarding Senate Bill 56, An Act Concerning Pulse Oximetry Screening for Newborn Infants and ask that you accept this letter as written testimony in support of the passage of this important Act.

I currently serve on the Board of Selectmen for the Town of Sherman and previously served for eight years as the Town's First Selectman. It was in this capacity that I first met Marie Hatcher and learned of her campaign to ensure that all babies born in Connecticut have the benefit of pulse oximetry screening to detect the presence of a congenital heart defect. I also hold a license as a Registered Nurse and have earned a doctoral degree in nursing education as well as a law degree from the University of Connecticut. I served for 14 years as head of the Nursing Programs at Western Connecticut State University in Danbury.

As a Registered Nurse and nurse educator, I am very aware of the devastating effect of congenital heart disease on the infants it strikes as well as on their families. Failure to detect such defects before a newborn child is released from the hospital can result in developmental delays that have the potential to impact the entire life of the child and his or her family. At worse, undetected congenital heart defects can lead to sudden infant death.

The profound impacts of congenital heart disease can be averted through the mandatory pulse oximetry screening of each newborn. This simple, inexpensive, and non-invasive test is currently mandated in neighboring states as well as others across the nation. The test serves as a screening device that permits early detection of a potential congenital heart defect exists, leading to more definitive tests to identify the nature of the defect and permitting early treatment of the disease.

Connecticut's newborn infants and their families deserve the very best care available to ensure these children's healthy and productive adulthood.

Sincerely,

Andrea O'Connor

Andrea O'Connor, Ed.D., J.D., R.N.
Selectman

WESTERN CONNECTICUT HEALTH NETWORK
DANBURY HOSPITAL

24 Hospital Ave
Danbury, CT 06810
203 739 7000
DanburyHospital org

March 1, 2012

Public Health Committee
Legislative Office Building, Room 3000
Hartford, Ct. O6106

Re: Support for Bill #RHB 56

Dear Public Health Committee,

I am the Director of Patient Care Services for the Women's and Children's Service Lines at Danbury Hospital, in Danbury Connecticut. I have been a practicing Registered Nurse for over 30 years, and have dedicated my entire career to the care of expectant and new mothers, babies and children, in pediatric units, pediatric and neonatal intensive care units, pediatric home care, and family birthing centers.

As a pediatric nurse, I have cared for many children who have undergone cardiac surgery. Often, they go into surgery extremely compromised from the symptoms caused by their disease, which makes them a poor surgical risk, setting them up for long term complications, and potentially death. Early diagnosis of congenital heart disease with a simple screening test allows for intervention and treatment at a time when an infant is seemingly well, increasing their chances for a successful surgical intervention.

A few months ago, I became aware of a simple screening test for all newborns, which if done in the hospital before the infant goes home to their family, can save the lives of infants and children. This screening test, done by measuring the oxygen level in an infant's blood by applying a probe to a hand and a foot, takes only a few minutes, and costs less than a cup of coffee. This simple procedure can detect a heart defect that if missed, can lead to an infant dying at home, or coming back to the hospital, critically ill and fighting for his or her life.

Today I am asking that you support Bill # RHB 56, which would mandate newborn pulse oximetry screening for congenital heart disease in every hospital in Connecticut. I confess that we at Danbury plan on implementing this test without a mandate, because the nurses and doctors on our staff see this as a simple just do it, because it is simply the right thing to do. Mandating this screening test will assure that every hospital in Connecticut is doing the right thing for the most vulnerable members of our communities. Saving a child's life and the devastation to families that accompany the death of a child, is well worth implementing this one simple measure.

Sincerely,

Maryalice Cullen, RN
Director of Patient Care Services
Women's and Children's Service Lines

Senator Terry Geratana

Co-Chair, Public Health Committee

Legislative Office Building, Room 3003

Hartford, CT 06106-1591

March 4, 2012

RE: Support for Bill #RHB 56

Dear Senator Geratana and members of The CT Public Health Committee:

We became parents July 16, 2011 to a beautiful baby boy whose name is Ayden Arthur Armando. Ayden was born with a Congenital Heart Defect (CHD). His diagnosis was Atrioventricular Canal Defect and he had clef valve that needed repairing. We were so blessed and very lucky. We say lucky and blessed because we found out about his heart condition while 18 wks pregnant. Only about half of babies born with a CHD are diagnosed while in utero. Doctors were able to prepare and plan for Ayden's arrival and health care plan, as were we. Ayden had his open heart surgery December 5, 2011 at Connecticut Children's Medical Center. Today he is doing amazingly well and continues to progress.

Of course we didn't know anything about CHDs. In fact we had never even heard of them. We were shocked to learn that CHDs is the #1 birth defect that affects 40,000 babies each year! We just do not understand why there seems to be no awareness or education about CHDs until it affects your life. Our hearts go out to those parents who take their babies home not knowing that their baby has a heart issue. We can't imagine the possibility being home with our baby and see him/her turn blue due to lack of oxygen, or seeing that baby grow into a child playing sports and suddenly he/she collapses. This can easily be prevented. Doctors can have a test done at the hospital before going home called; Pulse Oximetry Test, which costs approximately $1 to do. A missed diagnosis of newborns with CHD can result in numerous consequences for the baby; surgical compromise, neurological impairment, developmental delays, organ failure, and long-term feeding issues. So many parents are jobless or don't have health insurance and rely on the State of CT for medical assistance. A missed diagnosis resulting in the preceding adverse effects on a baby can weigh heavily on the State of CT's Healthcare costs.

Since having Ayden, we tell all of our friends and family members expecting a baby to ask the hospital to do a Pulse Ox test on their newborn before leaving the hospital. The majority of parents just don't have any knowledge about CHDs or to know to ask for this test. The

importance of early detection of CHDs in newborns is simply this... **SAVING A LIFE**. No parent should have to lose their child from a CHD that was never caught. The advances in modern medicine are amazing and doctors can work miracles on babies with a CHD.

As a leader if our great State of Connecticut and your experience in public health we ask you to support this important Bill. Bill # RHB 56, calls for requiring Pulse Oximetry testing for every newborn born in the State of Connecticut. As residents of Connecticut, we would be so proud being one of the leaders in the country to have such a law!

In addition, we also ask that you consider amending the wording in the Bill to cover 'Any & All Screening for Critical Congenital Heart Defects'. As technology advances, we can continue to screen effectively without having to re- introduce legislation to cover such advancements.

Thank you for your time and consideration.

Sincerely,

Yvonne Nunes
Mike Armando
(Ayden's Mom and Dad)

SB56

February 2012

To Whom it May Concern:

In January of 2003 I gave birth to what I thought was a healthy child. I had no reason to think otherwise, I already had a healthy 4 year old at home and a normal pregnancy.

I took my baby home from the hospital after 48 hours of his birth, still thinking he was going to live a healthy, uncomplicated life. At 5 weeks old, during a routine well baby visit, a heart murmur was detected. I was immediately sent to a local pediatric cardiologist and from there our lives were changed forever.

Word, such as, congestive heart failure, saturation levels, Hypoplastic Left Heart Syndrome were being thrown at us left and right.

After many tests, it was discovered that our baby was born with many complex congenital heart defects. He was operated on many times, the first being at 6 weeks old. The doctor's weren't quite sure if they could begin to repair some of his defects because he was not diagnosed at birth.

My son is now 9 years old, has had 2 open heart surgeries, many cardiac catherizations , and ultimately, a heart transplant. I have become very educated on the workings of the heart, cardiac medications, procedures and tests. The first and simplest test I learned about was pulse ox testing. It is a simple, non-invasive, easy, inexpensive test that shows how much oxygen is running through the body. If you can put a Band-Aid on, you can administer a pulse ox test. If this simple Band-Aid with a little red light on it was put on my son when he was born, the doctors would have been aware that his saturation levels were in the 70's, as opposed to the normal 100 reading. I would not have been sent home with a baby in congestive heart failure, and although he would have still faced surgical repair, the risks would have been far less.

Most people who enter a hospital for the first time, whether it be via the emergency room or for a procedure, almost always have their saturation levels checked. Why should this be different for a baby entering a hospital for the first time upon their birth?

Bonhomme, Penny

From: Fournier, Kelley
Sent: Friday, March 02, 2012 8:20 AM
To: PHC Testimony
Subject: Testimony for March 7th Public Hearing – SB 56

Attachments: MarieHatcher.PHTestimony.Mar7.docx; DebbiePrince.PHTestimony.Mar7.docx; MelissaServiss.PHTestimony.Mar7.doc

To Whom It May Concern,

Attached please find three documents, all of which are testimony from Sen. McLachlan's constituents regarding SB 56, AAC Pulse Oximetry Screening for Newborn Infants, which will be heard at the March 7th Public Hearing. Please let me know if you have any questions. I can be reached at extension 0068.

Best,

Kelley A. Fournier

Legislative Aide to Senator Michael A. McLachlan
24th District
(860) 240-0068
Kelley.Fournier@cga.ct.gov

MarieHatcher DebbiePrince MelissaServis
Testimony.Mar Testimony.Mar Testimony.M

March 7, 2012

Testimony

Public Health Committee

Support for Raised Bill Number 56

An Act Concerning Pulse Oximetry Screening for Newborn Infants

Submitted by Kelly Morrissey, a resident of Southington, CT

As a mother with a daughter diagnosed with Tricuspid Atresia, a critical congenital heart disease (CCHD) and a volunteer advocate for the American Heart Association, I am writing in support of S.B. 56 'An Act Concerning Pulse Oximetry Screening for Newborn Infants.'

I would like to thank Senator Gerratana and Representative Ritter for raising this incredibly important legislation. I urge the committee to vote S.B 56 out of committee and work to ensure this lifesaving bill reaches the governor's desk for his signature. I believe my daughter's brave story will help make clear why early detection of CCHD is so critical.

Alice was born June 7, 2011 at Hartford Hospital weighing 6 lbs. 3oz, 19 ½ in. long. Due to Alice's known heart defect she was taken to the Neonatal Intensive Care Unit (NICU) where her heart would be evaluated. Her team of cardiologists evaluated her for three days during which time she was connected to a constant pulse oximeter. It was determined that the Atrial Septal Defect was sufficient for Alice and would be sufficient until it was time for the Glen Shunt Procedure. Alice's oxygen levels were in the high 80's, excellent for someone with her type of heart defect

My husband Paul and I brought Alice home from the hospital on June 9, 2011. We were excited about going home, introducing Alice to our dog Rufus, her great grandmother Julia, her grandparents and her aunts and uncles. We were nervous, not because of her heart defect because looking back we had no idea what extreme trauma and life altering moments we would soon have. No, we were first time parents so we worried about "doing things right".

For 10 days we worried about "doing things right". Then we had one of those days you never forget, a day we call black Monday.

Paul and I took Alice to her scheduled follow up appointment. She was tested with a pulse oximeter, and it was found that her oxygen levels had dropped to dangerous levels, her readings varied from 70's to the low 60's. These readings were far below safe. With oxygen levels this low she could suffer from brain damage. Alice was immediately taken to the intensive care unit, where things began to move very fast. Alice was Med Flighted that day to Boston Children's Medical Center, where she underwent emergency open heart surgery. Because of swelling and excess liquid, it was not immediately clear if the surgery was successful.

Within days of the first surgery, Doctors determined the shunt Alice received was too big and they would need to perform a second open heart surgery to clip the shunt making it smaller to match her tiny body. When it was time to leave the hospital our doctors told us some sobering facts. If we had not had that routine cardiologist appointment, if they had not insisted on an accurate pulse oximeter reading, if they

had not intubated, if they had not Med Flighted Alice, if the amazing team of doctors had not done everything they did in the exact order in which they did it, we would have lost our Alice.

Congenital heart defects are the number one killer of infants with birth defects. Congenital heart defects are structural abnormalities of the heart that are present at birth. These defects range in severity from simple holes or murmurs to severe malformations, such as the complete absence of one or more chambers or valves. Some critical congenital heart defects can cause severe and life-threatening symptoms that require intervention within the first days of life. Pulse oximetry testing before discharge may be one important strategy that can be an effective, noninvasive, inexpensive tool to assist in diagnosing critical congenital heart disease.

Paul and I understand firsthand how important it is to identify CCHD as soon as possible.

This committee can help our young ones live longer and fuller lives by passing S.B. 56 to pinpoint critical or possibly life-threatening heart conditions that might otherwise be missed. This simple, non-invasive test could significantly improve the outcomes for hundreds of Connecticut's babies born with heart defects.

I encourage you to help give our children a healthy start in life by assuring newborns are screened for congenital heart defects using pulse oximetery. So many young lives depend on it.

Thank you.

Bonhomme, Penny

From: Fournier, Kelley
Sent: Friday, March 02, 2012 8:20 AM
To: PHC Testimony
Subject: Testimony for March 7th Public Hearing – SB 56

Attachments: MarieHatcher.PHTestimony.Mar7.docx; DebbiePrince.PHTestimony.Mar7 docx; MelissaServiss.PHTestimony Mar7.doc

To Whom It May Concern,

Attached please find three documents, all of which are testimony from Sen. McLachlan's constituents regarding SB 56, AAC Pulse Oximetry Screening for Newborn Infants, which will be heard at the March 7th Public Hearing. Please let me know if you have any questions. I can be reached at extension 0068.

Best,

Kelley A. Fournier

Legislative Aide to Senator Michael A. McLachlan
24th District
(860) 240-0068
Kelley.Fournier@cga.ct.gov

MarieHatcher DebbiePrince MelissaServis
estimony.Mar estimony.Mar Testimony.Mi

My name is Melissa Serviss, and I am the mother of a five month old with a Congenital Heart Defect called Coarctation of the Aorta.

Arabella was diagnosed early and was given medicine after birth to help her body keep her "fetal blood flow going" until she could have the life saving open heart surgery she so desperately needed. Arabella was not sent home like a healthy newborn. But she could have been. Others in her situation went home only to be airlifted back to the hospital hours or days later due to this condition. I know because I have heard their stories. And then there are some that never made it back to the hospital. I have heard their stories too, and I would like to represent and honor them today through this letter.

Every day critically ill newborns are released from the hospital because they have a Congenital Heart Defect that has gone undetected. Looking healthy and normal these babies are not diagnosed until they present with symptoms such as turning blue or becoming cyanotic or weak. For many the help comes too late and parents are left to bury a child that could have been saved. .

A simple pulse oximetry screening can let doctors know that there is an issue with the heart before they are discharged. It takes a few minutes, requires a band aid like device on the foot or hand, and costs less than a dollar. Once diagnosed, these infants can then get the life saving medicine or surgery that they need. Many defects are very treatable and the prognosis is rather good if caught early.

Some say a society can be measured in the way it helps those who cannot help themselves. By passing this bill you are promising the newborns of Connecticut a chance at life, and helping those who cannot speak for themselves.

Please join other states which have adopted and are on their way to adopting similar legislation. I believe and trust in you to make a difference. Please vote YES to RSB 56.

The Bocompani Family, Five Partridge Trail, Sherman, CT

March 1, 2012

Senator Terry Geratana and Representative Betsy Ritter
Co-Chairs, Public Health Committee
Legislative Office Building, Room 3003 & 3004
Hartford, CT 06106-1591

RE: Support for Bill #RHB 56

Dear Senator Geratana and Representative Ritter:

As friends and supporters of Marie Hatcher's herculean efforts to raise awareness and funding for Congenital Heart Defects, we are proud to support Bill #RHB 56. This important piece of legislation, hopefully to be renamed to 'Matthew & Faith's Law', would make Pulse Oximetry testing a requirement for all newborns, prior to leaving the hospital.

Congenital Heart Defects (CHD) is the #1 Birth Defect affecting 40,000 babies annually. Half of the babies with CHD are diagnosed in utero, but the other half can go undiagnosed for days, weeks, months and sometimes years, with dire consequences. In fact, at this very moment, babies are being discharged from hospitals with a hidden disease that could take their lives. The Hatcher's son Matthew is a CHD Warrior. Matthew, diagnosed in utero, has undergone three open-heart surgeries and three cardiac caths in his short life of three and a half years. He currently takes eight doses of medicine a day and is doing very well in big part to the excellent team of doctors and nurses and his early diagnosis. Heartbreakingly, thousands of other CHD babies are not as fortunate and sadly, CHD Angel, Faith lost her fight at only the age of two.

At best, the missed diagnosis of newborns with CHD will result in surgical compromise, neurological impairment, developmental delay, organ failure, and long-term feeding issues...all at huge costs to the healthcare system. Additionally, physicians, hospitals, and advocates clearly understand the importance of early detection of newborn diseases and disorders in saving lives and reducing healthcare cost burdens associated with late diagnosis.

There is solution available for this problem; a simple Pulse Oximetry Test, which costs approximately $1, is a cost-effective, non-invasive means of testing for CHD. Pulse Oximetry, considered the fifth vital sign, is a test routinely done on any adult with the slightest ailment or injury, including mothers during labor and delivery. Remarkably, their babies, who just ventured into this world and are breathing oxygen for the first time ever, are not tested. This testing needs to become a standard of care for all newborns, prior to discharge.

Therefore, we urge you to leverage your leadership and expertise in public health to support this important Bill. **Bill # RHB 56 will save lives, it is that simple!!** Please let Connecticut join New Jersey and Indiana, as the current states with this important law and the many other states moving quickly to mandate this simple test to benefit newborns throughout the United States.

Sincerely,

Robert & Amy Bocompani

cc: Senator Gayle Slossberg, Vice-Chair, Public Health Committee
Representative Christopher Lyddy, Vice-Chair, Public Health Committee
Senator Jason Welch, Ranking Member, Public Heath Committee
Representative Jason Perillo, Ranking Member, Public Heath Committee

Raising hope, one and a half hearts at a time

Testimony of the Connecticut Children's Medical Center
to the Public Health Committee Regarding
Senate Bill 56, An Act Concerning Pulse Oximetry Screening For Newborn Infants

March 7, 2012

Senator Gerratana, Representative Ritter, members of the Public Health Committee, thank you for the opportunity to share my thoughts about *Senate Bill 56, An Act Concerning Pulse Oximetry Screening For Newborn Infants*. My name is Victor Herson, MD, and I am Director of Neonatology at the Connecticut Children's Medical Center and I am submitting this testimony in support to the proposed legislation.

According to the Centers for Disease Control and Prevention, congenital heart defects account for 24% of infant deaths due to birth defects. In the United States, about 4,800 (or 11.6 per 10,000) babies born every year have one of seven critical congenital heart defects. Babies with one of these defects are at significant risk of disability or death if not diagnosed soon after birth. Some of these defects could be detected using pulse oximetry screening, which is a test to determine the amount of oxygen in the blood and pulse rate. The American Academy of Pediatrics (AAP) has recently recommended pulse oximetry screening for congenital heart disease and planning for implementing this recommendation is already underway at many hospitals in Connecticut.

At Connecticut Children's, mandated pulse oximetry testing will affect our cardiologists who will be asked to provide consultation services to families with infants who "fail" the screen. Connecticut Children's physicians from our Divisions of Neonatology and Cardiology are involved in a group formed through the Connecticut Chapter of the AAP that is developing a regional process to address referrals in an effective and efficient manner.

I urge you to support SB 56 because it will have a positive impact on children and families. Thank you for your consideration of our position. If you have any questions about this testimony, please contact Jane Baird, Connecticut Children's Director of Government Relations, at 860-545-5861.

Testimony of

Dr. Gilead Lancaster

Public Health Committee

March 7th, 2012

Senator Gerratana, Representative Ritter and members of the public Health Committee, my name is Dr. Gilead Lancaster. I am the director of Non-Invasive Cardiology at Bridgeport Hospital, an Associate Clinical Professor of Medicine at Yale and the President of the Connecticut Chapter of the American College of Cardiology- an organization that represents most of the doctors and nurses that treat heart patients in Connecticut. Our national organization, the American College of Cardiology, was an innovator of evidence based medicine with the development of medical guidelines and appropriate use criteria for tests- tools that are now the backbone of quality healthcare around the world.

I am before you today to testify in support of **SB 56: AN ACT CONCERNING PULSE OXIMETRY SCREENING FOR NEWBORN INFANTS.** In 2008, the United States Health and Human Services Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) was authorized by Congress to provide guidance to the Secretary about which conditions should be included in newborn screening and how systems should be developed to assure appropriate screening and follow-up care.

In 2010 the committee recommended that critical congenital cyanotic heart disease be added to the recommended uniform screening panel based on findings from a comprehensive review of the available evidence. The goal is to identify those newborns with structural heart defects usually associated with hypoxia (low oxygen saturation in the blood) in the newborn period with this simple and relatively inexpensive screening device called pulse oximetry.

Pulse oximetry is a noninvasive test that estimates the percentage of hemoglobin in blood that is saturated with oxygen. The device itself is relatively inexpensive and reusable, and many hospitals use pulse oximetry as a standard of care in their newborn nurseries.

We believe that many newborn lives could be saved by earlier detection and treatment of congenital cyanotic heart disease if hospitals were required to perform this simple, noninvasive newborn screening method; and so we, the American College of Cardiology urge that this bill be adopted.

I am happy to answer any questions. Thank you.

March of Dimes Foundation
Connecticut Chapter

Greater Connecticut Division
500 Winding Brook Dr., Ste 8
Glastonbury, CT 06033
Telephone (860) 815-9365
Fax (860) 815-9366

March 7, 2012

Testimony
Public Health Committee
Support for Raised Bill Number 56
An Act Concerning Pulse Oximetry Screening for Newborn Infants

Submitted By: Jonathan M. Shapiro, Vice-Chair, March of Dimes Connecticut Chapter State Board

My name is Jonathan Shapiro, and I submit this statement in support of Bill Number 56, An Act Concerning Pulse Oximetry Screening for Newborn Infants. I currently serve as the Vice-Chair for the March of Dimes Connecticut State Board, and have been a long-time supporter of the March of Dimes—the leader in advocacy for newborn screening of all infants in the United States. I began my involvement with the March of Dimes when I was in high school as a way to honor my older sister, Jennifer. Jennifer was born with a congenital heart defect, the type of condition that this bill would mandate screening for. After a twelve years and a courageous battle, Jennifer ultimately lost her battle passing away when she was twelve (12).

While Jennifer's her condition was detectable upon her birth due to its extreme severity and the lack of oxygen circulating through her tiny body, many children are born with similar congenital heart defects that are not as readily detectable. Undetected critical congenital heart diseases (CCHD) can cause severe, life threatening symptoms and may require medical treatment within the first months, or even days of an infant's life. If left undetected, CHD can result in disability or even death to unsuspecting parents.

This bill addresses the danger, and would allow for screening of newborns for CCHD via pulse oximetry. Pulse oximetry is a non-invasive and painless test administered at the newborn's bedside that determines the percent of oxygen saturation in a baby's blood through a sensor that is usually attached to the baby's finger or foot. If low levels of oxygen saturation in the blood are detected, then further testing can be performed to diagnose any abnormalities in the heart structure or blood flow through the heart.

Given the ease of this test and the dangers it helps uncover, I fully support the addition of CCHD to Connecticut's newborn screening panel and ask that our legislature pass this bill

Please feel free to contact me for more information, questions or concerns,
Jonathan M. Shapiro, Esq.
Shapiro Law Offices, LLC
860-347-3325 or jshapiro@shapirolawofficesct.com

Raising hope, one and a half hearts at a time

Matthew's Hearts of Hope, Inc.
1 Farm Road, Sherman, Connecticut 06784
www.matthewsheartsofhope.org matthewsheartsofhope@hotmail.com

March 1st, 2012

Public Health Committee

Legislative Office Building, Room 3000

Hartford, CT 06106

RE: Support for Bill #RHB 56

Dear Public Health Committee:

I write this letter to you as both a mother and a Registered Nurse of over 20 years. My youngest of three sons, Matthew, was born with a very serious Congenital Heart Defect called 'Hypoplastic Right Heart Syndrome'. We were extremely fortunate that Matthew's condition was diagnosed in utero, enabling him to be born at Columbia Presbyterian Hospital in New York. He has undergone three open-heart surgeries and three cardiac caths in his short life of three and a half years. He currently takes eight doses of medicine a day and is doing very well in big part to the excellent team of doctors and nurses and his early diagnosis.

Congenital Heart Defects (CHD) is the #1 Birth Defect affecting 40,000 babies annually. Half of the babies with CHD are diagnosed in utero, but the other half can go undiagnosed for days, weeks, months and sometimes years, with dire consequences. In fact, at this very moment, babies are being discharged from hospitals with a hidden disease that could take their lives.

At best, the missed diagnosis of newborns with CHD will result in surgical compromise, neurological impairment, developmental delay, organ failure, and long-term feeding issues...all at huge costs to the healthcare system. However, there is solution available for this problem; a simple Pulse Oximetry Test, which costs approximately $1, is a cost-effective, non-invasive means of testing for CHD.

We all know Pulse Oximetry is considered the 5th vital sign. It's routinely done on any adult with the slightest ailment or injury, including mothers during labor and delivery. Remarkably, their babies, who just ventured into this world and are breathing oxygen for the first time ever, are not tested before discharge. Physicians, hospitals, and advocates clearly understand the importance of early detection of newborn diseases and disorders in saving lives and reducing healthcare cost burdens associated with late diagnosis. This is also a huge issue for our rural and underserved populations, who will continue to fall through the cracks, if this simple evaluation does not become a standard of care for all newborns.

I urge you all to leverage your leadership and expertise in public health to support this important Bill. Bill # RHB 56, requiring Pulse Oximetry testing for everyone newborn, will save lives, it is that simple!! Please let Connecticut join New Jersey and Indiana, as the current states with this important law and the many other states moving quickly to mandate this simple test to benefit newborns throughout the United States.

In addition, I also ask that you consider amending the wording in the Bill to cover 'Any & All Screening for Critical Congenital Heart Defects'. As technology advances, we can continue to screen effectively without having to re- introduce legislation to cover such advancements.

Yours in appreciation,

Marie Hatcher RN

5 Briarwood Drive
Sherman,
CT 06784

March 7, 2012

Public Health Committee
Legislative Office Building, Room 3000
Hartford, CT 06106

Re: Support for Bill # SB 56

Dear Public Health Committee,

I am here today to urge you to support SB#56. Congenital Heart Defects is the most common of all birth defects - 1 in 100 births! All newborns in the state of Connecticut should be automatically screened for CHD with pulse oximetry. Pulse oximetry should automatically be the 5th Vital sign in newborn screening.

As a mother of two wonderful healthy children, a practicing Registered Nurse and patient advocate, I was fortunate to become involved with Marie Hatcher and her wonderful son, Matthew, who is living testimony of a positive outcome to early intervention.

I could stand here and quote study after study that endorses pulse oximetry for CCHD, the study I wish to refer to is from the Archives of Pediatric and Adolescent Medicine regarding "Missed Diagnosis of Critical Congenital Heart Disease." There was a 15 year California study which was based on 898 infants who died of CCHD in infancy. 152 were determined to have missed CCHD diagnosis; 299 late diagnosis. According to National Statistics, of the approximate 4,000 babies born nationally with CCHD each year, "one can assume 2,000 babies would die due to undiagnosed or late diagnosis of CCHD." The median age of death for the deaths in CA was less than 2 weeks and more than 50% with missed CCHD died at home or in the hospital emergency room.

In the state of Indiana, a beautiful baby girl, named Cora, died in her mother's arms while breastfeeding 5 days after her birth. No mother should have to experience this tragedy especially when there is a simple screening test available to detect CHD.

The American Academy of Pediatrics and The Centers for Disease Control and Prevention both endorse Pulse Oximetry Screening for Critical Congenital Heart Defects. Danbury Hospital, where I work as a R.N., are implementing this test without a mandate because without screening, some newborns with CCHDs might be missed because the signs of CCHD might not be evident before an infant is discharged from the hospital after birth as was the case with Cora. Please mandate screening.

Sincerely,

Olwen M. Gurry, RN

Sean Pietrus

Support for Bill #RHB 56

Dear Public Health Committee:

I am here today for my son Gage who passed unexpectedly from an undetected heart defect. When I first found out I was having a son I was very blessed that he would passing on my last name. Everything was right on target with the ultrasounds they were normal with no concerns. My son seemed to be a normal young boy growing up but that came to a halt on January 24, 2004 when my son suddenly passed away at home. At this time my world came crashing down it felt there was no reason to live but thank God I have a precious daughter to keep me thriving to survive. When we found out that my son passed from an undetected heart defect I was really confused on what and why this happened. He was diagnosed with Acute Myocardial Infarction (AMI) in his case his coronary artery was nonexistent. To this day I believe this could have been prevented if the Pulse Oximetry Test was available at the time of his birth.

Congenital Heart Defects (CHD) is the #1 birth defect affecting 40,000 babies annually. A simple solution to this problem would be to have a simple Pulse Oximetry Test which costs approximately $1. So to me this is cost effective and non invasive means of testing for CHD. I hope at the end of this that you will support this Bill. Bill #RHB 56, requiring Pulse Oximetry Testing for every newborn it will save lives. Please let Connecticut join New Jersey and Indiana as the current states with this important law and the many other states moving quickly to mandate this simple test to benefit newborns throughout the United States.

American Heart Association. | American Stroke Association.
Learn and Live.

Education Committee
March &, 2012
John Bailey, Government Relations Director
American Heart Association

Support for S.B. 56: An Act Concerning Pulse Oximetry Screening for Newborn Infants

Good morning Senator Gerratana, Representative Ritter, and member of the Public Health committee.

My name is John Bailey, State Director of Government Relations for the American Heart Association, and I am here today to testify in support of S.B. 56: An Act Concerning Pulse Oximetry Screening for Newborn Infants.

Nearly one in three infants who die from birth defects has a heart defect. We could potentially save these tiny lives if more emphasis is placed on assuring newborns are appropriately screened for heart defects before being discharged from the hospital.

Congenital heart defects (CHDs) are structural abnormalities of the heart that are present at birth; CHDs range in severity from simple problems such as holes between chambers of the heart, to severe malformations, such as the complete absence of one or more chambers or valves; some critical CHDs can cause severe and life-threatening symptoms which require intervention within the first days of life.

The pulse oximetry test, or pulse ox, consists of sensors placed on a baby's hand and foot to check blood oxygen levels. If their levels are too low, additional tests are conducted to detect critical or possibly life-threatening heart defects that might otherwise be missed. With congenital heart defects considered to be the leading cause of birth-defect related deaths in the U.S., new research suggests wider use of pulse ox screening could help identify more than 90 percent of heart defects.

U.S. Secretary of Health and Human Services Kathleen Sebelius has suggested that critical congenital heart defects screening be added to the "Recommended Uniform Screening Panel" for newborns before they are released from a hospital or birthing facility. To achieve this goal, the American Heart Association and volunteers are working in states across the country to enact pulse ox screening policies that will allow babies with heart defects to live longer and fuller lives. Thanks to the work of board coalitions, New Jersey, Maryland and Indiana have all recently passed laws requiring newborns to have pulse ox screenings prior to being discharged from the hospital. In New Jersey, just hours after their law took effect; a newborn's life was saved.

Let's make Connecticut the next state to enact this lifesaving legislation.

Thank you for your time.

March of Dimes Foundation
Connecticut Chapter

Greater Connecticut Division
500 Winding Brook Dr, Ste 8
Glastonbury, CT 06033
Telephone (860) 815-9365
Fax (860) 815-9366

March 7, 2012

Testimony
Public Health Committee
Support for Raised Bill Number 56
An Act Concerning Pulse Oximetry Screening for Newborn Infants

Submitted By: Erin E. Jones, Director of Public Affairs

The March of Dimes is the leader in advocacy for newborn screening of all infants in the United States. Our mission is to improve the health of women of childbearing age, infants, and children by preventing birth defects, premature birth, and infant mortality. As part of that mission, we support screening for conditions and disorders for which there is a documented medical benefit to the affected infant from early detection and treatment; there is a reliable screening test for the disorder; and early detection can be made from newborn blood spots or other specific means. **As such, the March of Dimes supports the addition of Critical Congenital Heart Disease (CCHD) to Connecticut's newborn screening panel and supports SB 56, which would allow for screening of newborns for CCHD via pulse oximetry.**

Why Screen for Critical Congenital Heart Disease (CCHD):
Congenital heart disease (CHD) is a problem with the heart's structure and/or function which is present at birth. Critical congenital heart disease (CCHD) means that the heart defect causes severe, life threatening symptoms and requires intervention (e.g., medical treatment or surgery) within the first few hours, days or months of life.

- Babies with CCHD are at significant risk for death or disability if their condition is not diagnosed soon after birth
- In the United States, about 4,800 babies are born each year with CCHD according to the CDC
- In the United States, an estimated 280 infants are discharged from nurseries with undetected CCHD

How to Screen for Critical Congenital Heart Disease (CCHD):
CCHD can be identified using a non-invasive and painless method called pulse oximetry in the newborn period before the baby is discharged from the hospital or birthing center. Pulse oximetry is a bedside test that determines the percent oxygen saturation in a baby's blood through a sensor that is usually attached to the baby's finger or foot. If low levels of oxygen saturation in the blood are detected, then further testing can be performed to diagnose any abnormalities in the heart structure or blood flow through the heart.

Several states, New Jersey, Indiana, and Maryland, have adopted legislation to include CCHD screening in their Newborn Screening Programs. March of Dimes urges Connecticut to do the same. All types of CCHD have medical and surgical interventions that can improve outcomes. Early detection via newborn screening will allow affected infants to receive such life-saving interventions promptly.

Please feel free to contact me for more information, questions or concerns,
Erin E. Jones, State Director of Public Affairs, 860.815.9352 or ejones2@marchofdimes.com

Newborn Screening
Fact Sheet
Prepared by the March of Dimes Connecticut Chapter

BACKGROUND

Newborn screening (NBS) is a public health program which provides early identification and follow-up for treatment of infants affected by certain genetic, metabolic, hormonal and/or functional conditions.

The Newborn Screening Program in CT screens all newborns for a wide spectrum of congenital and inherited diseases. Each year the CT Department of Public Health screens more than 40,000 newborns and save the lives of or greatly improves the outcomes for approximately 25 to 40 children "confirmed positive" with a disorder each year. These early medical interventions prevent severe disabilities and death.[1] As required under Connecticut State Law (19a-55), the state currently screens for 50 disorders including 30 of the 31 conditions recommended by the U.S. Secretary of Health and Human Services.

WHY SCREEN FOR CRITICAL CONGENITAL HEART DISEASE (CCHD)

Congenital heart disease (CHD) is a problem with the heart's structure and/or function which is present at birth. Critical congenital heart disease (CCHD) means that the heart defect causes severe, life threatening symptoms and requires intervention (e.g., medical treatment or surgery) within the first few hours, days or months of life. Some infants born with CCHD can appear healthy at first and can be sent home with their families before their heart defect is detected. It has been estimated that at least 280 infants with an unrecognized CCHD are discharged each year from newborn nurseries in the United States.[2] CCHD can be identified using a non-invasive and painless method called pulse oximetry in the newborn period before the baby is discharged from the hospital or birthing center. Pulse oximetry measures the percent oxygen saturation of hemoglobin in the arterial blood through a sensor that is attached to the baby's finger or foot. If low levels are detected and confirmed on repeat testing, then further testing can be performed to diagnose any abnormalities in heart structure or blood flow through the heart.

MARCH OF DIMES POLICY

The March of Dimes is the leader in advocacy for comprehensive newborn screening for all infants in the United States. Our mission is to improve the health of women of childbearing age, infants, and children by preventing birth defects, premature birth and infant mortality. As part of that mission, we support screening for conditions and disorders for which there is a documented medical benefit to the affected infant from early detection and treatment; there is a reliable screening test for the disorder; and early detection can be made from newborn blood spots or other specific means. **As such, the March of Dimes supports the addition of CCHD to CT's newborn screening panel.**

For more information contact:
Erin E. Jones, State Director of Program Services
Connecticut Chapter, March of Dimes
500 Winding Brook Drive., Glastonbury, CT 06033
860-815-9352
ejones2@marchofdimes.com

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[1] Connecticut Department of Public Health, Newborn Screening Program

[2] Knapp, AA, Metterville, DR, Kemper, AR, Prosser, L, Perrin, JM. Evidence review: Critical congenital cyanotic heart disease, Final Draft, September 3, 2010. Prepared for the Maternal and Child Health Bureau, Health Resources and Services Administration.

Public Health Committee

March 7, 2012

Support for Raised Bill Number 56

An Act Concerning Pulse Oximetry Screening for Newborn Infants

Good morning Senator Gerratana, Representative Ritter, and member of the Public Health committee.

My name is Len Wallace and I am here to testify in support of S.B. 56 **An Act Concerning Pulse Oximetry Screening for Newborn Infants.**

Congenital heart defects are the number one killer of infants with birth defects. Congenital heart defects are structural abnormalities of the heart that are present at birth. These defects range in severity from simple holes or murmurs to severe malformations, such as the complete absence of one or more chambers or valves. Some critical congenital heart defects can cause severe and life-threatening symptoms that require intervention within the first days of life. Pulse oximetry testing before discharge may be one important strategy that can be an effective, noninvasive, inexpensive tool to assist in diagnosing critical congenital heart disease.

I was born in 1982 with a rare congenital heart defect known as an endocardial cushion defect with a hypoplastic left ventricle. In laymen's terms, I was born with a weakened left ventricle which would take a pulmonary banding in my infancy to the time I was eight years old, when I underwent an experimental procedure known as a modified fontan. The day I was born, doctors could not regulate my temperature and they did not know how about your heart problem until the second day when they noticed a very loud heart murmur. As medical science has advanced in the last twenty-nine years, this particular condition could even be cured in utero. I've been told that I may be the oldest living survivor of my particular condition. With the introduction of pulse oximetry screenings, conditions like mine have become something that can be detected early and corrected much more easily than they were in my personal case. Now, I live a full life, unencumbered by the restraints of most people living with CHD and well past the "expiration date" that doctors had given me when I was born. My borrowed time is now old enough to drink, and I show no signs of slowing down.

This committee can help our young ones live longer and fuller lives by passing S.B. 56 to pinpoint critical or possibly life-threatening heart conditions that might otherwise be missed. This simple, non-invasive test could significantly improve the outcomes for hundreds of Connecticut's babies born with heart defects.

I encourage you to help give Connecticut's newborns a healthy start in life by assuring they are screened for congenital heart defects using pulse oximetery. So many young lives depend on it.

Thank you.

March 7, 2012

Testimony
Public Health Committee
Support for Raised Bill Number 56
An Act Concerning Pulse Oximetry Screening for Newborn Infants

Submitted By: Mindi Davidson

Good Morning,

My name is Mindi Davidson and I came here today to tell you why I support the addition of CCHD to CT's newborn screening panel.

I was a healthy 30 year old female when I became pregnant with triplets. 8 weeks into the pregnancy, we lost one baby. There was no known cause. From there, I had a problem free pregnancy until I was approx 28 weeks, and my water broke. I was admitted into the hospital and put on bed rest from then on while they tried to enhance and grow their lungs. At approx. 30 weeks, the twins could not stay in any longer and were born via emergency c-section. It was at that moment, my life changed forever.

Each twin had their own health issues, but my son, Evan, was born with a Ventricle Septic Defect, a form of CCHD. This particular defect required immediate decisions within 24 hours of birth. Let me back up for a moment. From the minute the twins were born, they left the operating room. I never even caught a glimpse of what they looked like. When I got back to my hospital room, it was about 15 hours before I could see them **for the first time**. From there, it was only though the glass of the NICU, I could not even go in. I was starting to feel awful, so I went back to my room where it was eventually determined that I had an infection that needed immediate care. As my nurses were dealing with my fever and symptoms and my husband was going back and forth from the NICU and my room, the on call Peds doctor came in looking very grave. They are at 18 hours old at this point. I immediately began to cry, fearing the worst.

He explained that Evan had a heart defect and that his heart was essentially not working properly and he was fighting to just breathe. He has a hole in his heart, the doctor told me, and we need to decide to operate or see if he survives without the surgery. Please, for a moment, just close your eyes and imagine. You are sick, feeling awful from surgery and sickness, you have not held your newborn twins, let alone even come close to seeing what they look like....what their eye color is, and you have to decide if you want to crack open your son's chest and operate. Right there, right then....what do you want to do? And by the way? We are talking about an infant that is only 3 ½ pounds. Can he even survive the surgery? What happens if we chose not to do it? What happens if we do?

That fear, that cold ice that fills you from your head, through your finger tips, to your toes, takes over. You can't call your family to help make the decision, you can't google out the symptoms and the

process, you are alone, scared, and your son's life is quite literally in your hands. And yet, you still have not held him.

So, I am here today to make sure no mom or dad goes home from the hospital without knowing. This simple test, this non invasive little sensor will stop so many painful decisions, so many tears, by just determining the O2 saturation in the babies' blood. This simple, painless test. It can do so much...please help other families to not have to go through what we did. Let them decide without the emergency. Let them hold their child, look into their eyes, be informed, with just this simple test.

I urge Connecticut's legislature to pass Raised S.B. 56. So every baby can receive Critical Congenital Heart Disease screening upon birth.

RICHARD BERNING, MD, FAAP, FACC
PEDIATRIC HEART SPECIALISTS, LLC

107 CHURCH HILL. ROAD, SUITE I-A
SANDY HOOK, CT 06482-1108

MAIN. 203-426-0225
FAX: 203-426-0249

March 6, 2012

Sen. Terry Geratana

Co-Chair, Public-Health Committee

Legislative Office Building, Room 3003

Hartford, CT 06106

RE: Support for Raised Bill #56

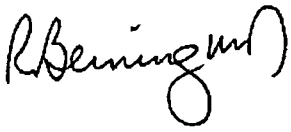
Dear Sen. Terry Geratana:

As a practicing Connecticut pediatric cardiologist for over 15 years in Connecticut, I can confidently state that passage of Bill #56 will save lives. This Bill mandates routine screening of all babies before discharge to home from the nursery after birth for cyanosis (bluish skin caused by decreased oxygen levels in the blood) using a pulse oximeter, a tool that every hospital and even most doctors' offices already use on a regular basis. Currently oxygen levels are typically only checked on ill patients. Newborn infants who appear healthy (and not blue enough to raise anyone's concern) can be sent home from the hospital never having had there oxygen level checked with the pulse oximeter equipment.

Congenital heart disease occurs in approximately 1% of all newborn babies. Many of these babies will be identified prenatally or otherwise after birth when they present with murmurs and breathing difficulty. Before birth the baby receives oxygen from the placenta and the blood is diverted away from the lungs via a blood vessel called the ductus arteriosus. The ductus arteriosus is programmed to squeeze closed once the baby is born and begins breathing. The ductus can stay patent, or open, for hours or days and even longer depending on many factors. When babies have serious congenital heart disease, this patent ductus arteriosus (PDA) can actually keep them alive by providing a detour past the defective portion of their heart. A baby with serious congenital heart disease and a patent ductus arteriosus can look well enough to fool a doctor or nurse into misdiagnosing them as a healthy baby. At some later point, usually when they are home, the ductus arteriosus can close causing the baby to become very sick and even die suddenly.

Passage of Bill #56 will standardize the evaluation of newborn infants before discharge to home and likely catch many of the infants who were presumed to be healthy but in fact had serious congenital heart disease. The test is simple and inexpensive, and the equipment needed is already available at every Connecticut hospital. Detecting these previously missed seriously ill infants early will ultimately save healthcare dollars, unnecessary deaths, and save their families heart ache and grief. I urge you to vote for passage Bill #56!

Sincerely,



Richard A.Berning, MD FAAP, FACC

Pediatric Cardiologist

March of Dimes Foundation
Connecticut Chapter

Greater Connecticut Division
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Glastonbury, CT 06033
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Fax (860) 815-9366

March 7, 2012

Testimony
Public Health Committee
Support for Raised Bill Number 56
An Act Concerning Pulse Oximetry Screening for Newborn Infants

Submitted By: Erin E. Jones, Director of Public Affairs

The March of Dimes is the leader in advocacy for newborn screening of all infants in the United States. Our mission is to improve the health of women of childbearing age, infants, and children by preventing birth defects, premature birth, and infant mortality. As part of that mission, we support screening for conditions and disorders for which there is a documented medical benefit to the affected infant from early detection and treatment; there is a reliable screening test for the disorder; and early detection can be made from newborn blood spots or other specific means. **As such, the March of Dimes supports the addition of Critical Congenital Heart Disease (CCHD) to Connecticut's newborn screening panel and supports SB 56, which would allow for screening of newborns for CCHD via pulse oximetry.**

Why Screen for Critical Congenital Heart Disease (CCHD):
Congenital heart disease (CHD) is a problem with the heart's structure and/or function which is present at birth. Critical congenital heart disease (CCHD) means that the heart defect causes severe, life threatening symptoms and requires intervention (e.g., medical treatment or surgery) within the first few hours, days or months of life.

- Babies with CCHD are at significant risk for death or disability if their condition is not diagnosed soon after birth
- In the United States, about 4,800 babies are born each year with CCHD according to the CDC
- In the United States, an estimated 280 infants are discharged from nurseries with undetected CCHD

How to Screen for Critical Congenital Heart Disease (CCHD):
CCHD can be identified using a non-invasive and painless method called pulse oximetry in the newborn period before the baby is discharged from the hospital or birthing center. Pulse oximetry is a bedside test that determines the percent oxygen saturation in a baby's blood through a sensor that is usually attached to the baby's finger or foot. If low levels of oxygen saturation in the blood are detected, then further testing can be performed to diagnose any abnormalities in the heart structure or blood flow through the heart.

Several states, New Jersey, Indiana, and Maryland, have adopted legislation to include CCHD screening in their Newborn Screening Programs. March of Dimes urges Connecticut to do the same. All types of CCHD have medical and surgical interventions that can improve outcomes. Early detection via newborn screening will allow affected infants to receive such life-saving interventions promptly.

Please feel free to contact me for more information, questions or concerns,
Erin E. Jones, State Director of Public Affairs, 860.815.9352 or ejones2@marchofdimes.com

Pulse Oximetry Screening for Critical Congenital Heart Defects

- Babies with a critical congenital heart defect (CCHD) are at significant risk for death or disability if their condition is not diagnosed soon after birth.
- Pulse oximetry newborn screening can identify some infants with a CCHD before they show signs of the condition.
- Once identified, babies with a CCHD can be seen by cardiologists and can receive special care and treatment that can prevent death or disability early in life.
- Certain hospitals routinely screen all newborns using pulse oximetry screening. However, pulse oximetry screening is not currently included in most state newborn screening panels.

Understanding Critical Congenital Heart Defects

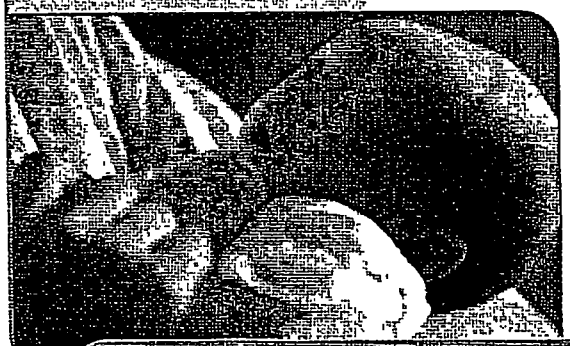
- **Congenital heart defects (CHDs) account for 24% of infant deaths due to birth defects.**
- **In the United States, about 4,800 (or 11.6 per 10,000) babies born every year have one of seven *critical congenital heart defects* (CCHDs, which also are known collectively in some instances as *critical congenital heart disease*).**
- **These seven CCHDs are:**
  - **Hypoplastic left heart syndrome**
  - **Pulmonary atresia (with intact septum)**
  - **Tetralogy of Fallot**
  - **Total anomalous pulmonary venous return**
  - **Transposition of the great arteries**
  - **Tricuspid atresia**
  - **Truncus arteriosus**

Babies with one of these CCHDs are at significant risk for death or disability if their CCHD is not diagnosed and treated soon after birth. These seven CCHDs among some babies potentially can be detected using *pulse oximetry screening*, which is a test to determine the amount of oxygen in the blood and pulse rate. Other heart defects can be just as severe as these seven CCHDs and also require treatment soon after birth. However, pulse oximetry screening may not detect these heart defects as consistently as the seven disorders listed as CCHDs.

The Importance of Screening for Critical Congenital Heart Defects

Some babies born with a heart defect can appear healthy at first and can be sent home with their families before their heart defect is detected. It has been estimated that at least 280 infants with an unrecognized CCHD are discharged each year from newborn nurseries in the United States. These babies are at risk for having serious complications within the first few days or weeks of life and often require emergency care.

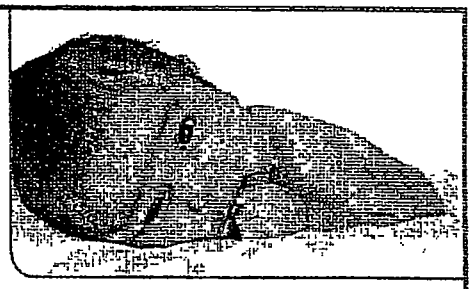
Pulse oximetry newborn screening can identify some infants with a CCHD before they show signs of a CCHD. Once identified, babies with a CCHD can be seen by cardiologists and can receive specialized care and treatment that could prevent death or disability early in life. Treatment can include medications and surgery.



National Center on Birth Defects and Developmental Disabilities
Division of Birth Defects and Developmental Disabilities

CS227141

When and How Babies Are Screened



Pulse oximetry is a simple bedside test to determine the amount of oxygen in a baby's blood and the baby's pulse rate. Low levels of oxygen in the blood can be a sign of a CCHD. The test is done using a machine called a *pulse oximeter*, with sensors placed on the baby's skin. The test is painless and takes only a few minutes. Screening is done when a baby is 24 to 48 hours of age, or as late as possible if the baby is to be discharged from the hospital before he or she is 24 hours of age.

Pulse oximetry screening does not replace a complete history and physical examination, which sometimes can detect a CCHD before the development of low levels of oxygen in the blood. Pulse oximetry screening, therefore, should be used along with the physical examination.

Pulse Oximetry Screening Results

If the results are "negative" (in-range result), it means that the baby's test results did not show signs of a CCHD. This type of screening test does not detect all CCHDs, so it is possible to still have a CCHD or other congenital heart defect with a negative screening result. If the results are "positive" (out-of-range result), it means that the baby's test results showed low levels of oxygen in the blood, which can be a sign of a CCHD. This does not *always* mean that the baby has a CCHD. It just means that more testing is needed.

The baby's doctor might recommend that the infant get screened again or have more specific tests, like an *echocardiogram* (an ultrasound picture of the heart), to diagnose a CCHD. Babies who are found to have a CCHD also might be evaluated by a clinical geneticist. This could help identify genetic syndromes associated with CCHDs and inform families about future risks.

Centers for Disease Control and Prevention Activities

The Centers for Disease Control and Prevention (CDC) is part of the U.S. Department of Health and Human Services (HHS) Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC). SACHDNC was authorized by Congress to provide guidance to the HHS Secretary about which conditions should be included in newborn and childhood screening programs, as well as how systems should be developed to ensure that all newborns and children are screened and, when necessary, receive appropriate follow-up care. In September 2010, SACHDNC recommended that the HHS Secretary add pulse oximetry screening for CCHDs (i.e., the heart defects listed previously) to the Recommended Uniform Screening Panel. Some states currently are developing their own policies on pulse oximetry screening for CCHDs. As this screening is implemented, CDC will play an important role in the surveillance and tracking of babies with a CCHD found through pulse oximetry screening.

For more information on pulse oximetry screening for CCHDs, please visit
http://www.cdc.gov/ncbddd/pediatricgenetics/CCHDscreening.html

National Center on Birth Defects and Developmental Disabilities
For more information please contact the Centers for Disease Control and Prevention
1600 Clifton Road NE, Atlanta, GA 30333
Telephone: 1-800-CDC-INFO (232-4636) TTY: 1-888-232-6348
Email: cdcinfo@cdc.gov Web: www.cdc.gov

Newborn Screening
Fact Sheet
Prepared by the March of Dimes Connecticut Chapter

BACKGROUND

Newborn screening (NBS) is a public health program which provides early identification and follow-up for treatment of infants affected by certain genetic, metabolic, hormonal and/or functional conditions.

The Newborn Screening Program in CT screens all newborns for a wide spectrum of congenital and inherited diseases. Each year the CT Department of Public Health screens more than 40,000 newborns and save the lives of or greatly improves the outcomes for approximately 25 to 40 children "confirmed positive" with a disorder each year. These early medical interventions prevent severe disabilities and death.[1] As required under Connecticut State Law (19a-55), the state currently screens for 50 disorders including 30 of the 31 conditions recommended by the U.S. Secretary of Health and Human Services.

WHY SCREEN FOR CRITICAL CONGENITAL HEART DISEASE (CCHD)

Congenital heart disease (CHD) is a problem with the heart's structure and/or function which is present at birth. Critical congenital heart disease (CCHD) means that the heart defect causes severe, life threatening symptoms and requires intervention (e.g., medical treatment or surgery) within the first few hours, days or months of life. Some infants born with CCHD can appear healthy at first and can be sent home with their families before their heart defect is detected. It has been estimated that at least 280 infants with an unrecognized CCHD are discharged each year from newborn nurseries in the United States.[2] CCHD can be identified using a non-invasive and painless method called pulse oximetry in the newborn period before the baby is discharged from the hospital or birthing center. Pulse oximetry measures the percent oxygen saturation of hemoglobin in the arterial blood through a sensor that is attached to the baby's finger or foot. If low levels are detected and confirmed on repeat testing, then further testing can be performed to diagnose any abnormalities in heart structure or blood flow through the heart.

MARCH OF DIMES POLICY

The March of Dimes is the leader in advocacy for comprehensive newborn screening for all infants in the United States. Our mission is to improve the health of women of childbearing age, infants, and children by preventing birth defects, premature birth and infant mortality. As part of that mission, we support screening for conditions and disorders for which there is a documented medical benefit to the affected infant from early detection and treatment; there is a reliable screening test for the disorder; and early detection can be made from newborn blood spots or other specific means. **As such, the March of Dimes supports the addition of CCHD to CT's newborn screening panel.**

For more information contact:
Erin E. Jones, State Director of Program Services
Connecticut Chapter, March of Dimes
500 Winding Brook Drive., Glastonbury, CT 06033
860-815-9352
ejones2@marchofdimes.com

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[1] Connecticut Department of Public Health, Newborn Screening Program

[2] Knapp, AA, Metterville, DR, Kemper, AR, Prosser, L, Perrin, JM. Evidence review: Critical congenital cyanotic heart disease, Final Draft, September 3, 2010. Prepared for the Maternal and Child Health Bureau, Health Resources and Services Administration.

S - 639

CONNECTICUT
GENERAL ASSEMBLY
SENATE

PROCEEDINGS
2012

VOL. 55
PART 4
942 – 1311

THE CLERK:

Immediate roll call vote has been ordered in the Senate. Senators please return to the chamber. Immediate roll call has been ordered in the Senate.

THE CHAIR:

Have all members voted? Have all members voted?

If so, the machine will be closed, and, Mr. Clerk, will you call the tally please.

THE CLERK:

On Senate Bill Number 38.

Total Number Voting		35
Necessary for Passage	18	
Those voting Yea	25	
Those voting Nay	10	
Those absent and not voting	1	

THE CHAIR:

The bill passes.

Senator Looney.

SENATOR LOONEY:

Thank you, Madam President.

Madam President, if the Clerk would as the next two -- next two items. First, Calendar Page 3, Calendar 89, Senate Bill 56; and then Calendar Page 4, Calendar 91, Senate Bill 276.

THE CHAIR:

Mr. Clerk.

THE CLERK:

On page 3, Calendar 89, Senate Bill Number 56, AN ACT CONCERNING PULSE OXIMETRY SCREENING FOR NEWBORN INFANTS, favorable report of the Committee on Public Health.

THE CHAIR:

Good evening, Senator Gerratana.

SENATOR GERRATANA:

Good evening, Madam President. And it's beautiful outside, I know --

THE CHAIR:

Oh, really?

SENATOR GERRATANA:

But we're in here working.

Madam President, I move acceptance of the joint committees' favorable report and passage of the bill.

THE CHAIR:

On acceptance and passage, will you remark, please?

SENATOR GERRATANA:

Thank you, Madam President.

Before I proceed in the explanation, I would like to at this time produce an amendment and that is LCO Number 3213.

THE CHAIR:

Mr. Clerk, will you please call Amendment LCO 31 --

SENATOR GERRATANA:

3213.

THE CHAIR:

3213.

THE CLERK:

LCO Number 3213, Senate "A" offered by Senators Gerratana, Ritter, Welch, Perillo and -- Representative Perillo, and Senator McLachlan.

THE CHAIR:

Please proceed.

SENATOR GERRATANA:

Thank you, Madam President.

Madam President, this amendment clarifies --

THE CHAIR:

On acceptance --

SENATOR GERRATANA:

I'm sorry. I move adoption.

Thank you.

THE CHAIR:

The question is on adoption, will you remark?

SENATOR GERRATANA:

Thank you.

Madam President, this amendment clarifies the underlying bill. Pulse oximetry is a test using a pulse oximeter that actually tests for oxygen saturation in -- in us, in human beings, and this underlying bill had asked for a test on pulse oximetry. However, more correctly in consistency with our statute, it would, this amendment, would change it to a screening test for critical congenital heart disease, which indeed, in this case, is the intent of the legislation.

The test is rather simple. We've probably all had it if you've been in a hospital or clinical situation. It's a simple device which goes on your finger to measure the O2 that you are taking in and utilizing.

In the case of an infant, and for this bill, it would be on the foot of the infant.

Madam President, the testimony that came before our committee and the people who asked for this legislation was very compelling. This would prevent a -- and detect any sort of defects or disease in infants long before they are sometimes manifested and that is usually down the road at some point. We've all heard of athletes playing in some sports competition and collapsing during that competition with the results of sometimes of being a fatality. This very simple test, right upfront, will save lives.

And, Madam President, I, of course, hope that the Chamber will join me in eventually voting for this legislation.

Thank you.

THE CHAIR:

Thank you.

And the question is on Amendment "A." Would you remark?

Senator Welch.

SENATOR WELCH:

Thank you, Madam President.

I rise in support of the amendment as it technically changes the bill to state what it's originally intent is medically. And, as Senator Gerratana said, this is a good bill. This bill will save lives. It's -- it's something that, you know, we should be doing. We should have been doing here in the state long before the discussion started today. So I would encourage my colleagues to stand in support of this amendment and, of course, the underlying bill when that comes up.

Thank you, Madam President.

THE CHAIR:

Thank you, Senator.

Will you remark? Will you remark?

Senator Suzio

SENATOR SUZIO:

Thank you, Madam President.

If I may, a question for the proponent of the legislation of the bill?

THE CHAIR:

This is on the amendment, sir.

SENATOR SUZZIO:

I'm sorry.

THE CHAIR:

On the amendment? We're on Senate "A."

SENATOR SUZIO:

I'm just trying to think would it pertain to the amendment or would it pertain to the underlying bill. I guess it's the underlying bill so I'll have to wait for that.

THE CHAIR:

Thank you, sir.

Will you remark? Will you remark?

If not, all in favor please signify by saying aye.

SENATORS:

Aye.

THE CHAIR:

Opposed?

The amendment passes.

Senator Suzio.

SENATOR SUZIO:

Thank you, Madam President.

If I may now ask the proponent of the bill?

THE CHAIR:

Please proceed, sir.

SENATOR SUZIO:

I would like to ask, apparently, this is not part of the standard of care at this point in time. It's something that we have to mandate be done. It's not something that would be considered protocol in medical practice?

THE CHAIR:

Senator Gerratana.

SENATOR GERRATANA:

Thank you, Madam President.

Yes. As I understand it, this is not standard practice. However, I do understand from the testimony that was given -- first of all, that Danbury Hospital is going to institute this voluntarily. That most hospitals settings where births happen do have this device, and they can use it but they're not, of course, obliged under law to do so.

THE CHAIR:

Senator Suzio.

SENATOR SUZIO:

Thank you.

And through you, Madam President.

In terms of -- it sounds to me like the cost is probably very, very minimal. It's certainly no cost to the legislature, but it's a cost that has to be absorbed by somebody. In this case, I presume, it's going to be absorbed by the hospital? It's not picked up by insurance costs? Through you, Madam President.

THE CHAIR:

Senator Gerratana.

SENATOR GERRATANA:

Thank you, Madam President.

I do understand that it is absorbable, and that I think if memory serves that the test itself costs somewhere around $10 and that the device itself is, from my understanding, is standard in hospitals and hospital settings, this pulse oximeter.

THE CHAIR:

Senator Suzio.

SENATOR SUZIO:

Thank you, Madam President.

Those are the only questions I have, and again, I do applaud and support the bill, and I hope it will pass the Chamber unanimously.

Thank you very much.

THE CHAIR:

Thank you.

Senator McLachlan.

SENATOR MCLACHLAN:

Thank you, Madam President.

I stand in strong support of this bill, and I want to thank Senator Gerratana and the Public Health Committee for entertaining this idea.

A constituent of mine contacted me last summer, Marie Hatcher, and introduced me to her beautiful son, Matthew and this is the story of Matthew Hatcher's malady, if you will, that a test of this nature can identify very serious problems in newborn children.

I'm grateful to Marie Hatcher and her group of supporters who have created Matthew's Hearts of Hope, a nonprofit organization here in Connecticut that has sought, now successfully, to bring to the attention of the public and this State Legislature the importance of this test, and also have done so to -- to bring a requirement for medical services to the attention of the public but something that's not real expensive to do.

It's an amazing story about saving lives. The State of Connecticut, should we successfully pass this bill here in the Senate and in the House, I hope successfully before the session can -- expires will give the State of Connecticut the strong support of newborn children by way of this important health exam.

As I mentioned, Connecticut will also join many other states across the country who have already passed this idea and are entertaining this idea as we speak. So I think it's the right thing to do.

Once again, thank you, Senator Gerratana, in your leadership on this. It's much appreciated.

Thank you, Madam President.

THE CHAIR:

Thank you.

Will you remark? Will you remark?

Seeing not --

Senator Gerratana.

SENATOR GERRATANA:

Madam President, if there's no objection, I would request this bill be placed on our Consent Calendar?

THE CHAIR:

Seeing no objections, so ordered.

Mr. Clerk.

THE CLERK:

On page 4, Calendar 91, Substitute for Senate Bill Number 276, AN ACT CONCERNING LICENSING REQUIREMENTS FOR ACUPUNCTURISTS, favorable report of the committee on Public Health.

THE CHAIR:

Senator Gerratana.

SENATOR GERRATANA:

Thank you, Madam President.

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

THE CHAIR:

On acceptance and passage, will you remark, please?

SENATOR GERRATANA:

Thank you, Madam President.

Certainly, from time to time, we do get requests from a variety of professions who work in the public health area, and this is one of them to update some of their licensure requirements. And this request comes from the acupuncturists. Because of that, I do have an amendment, Madam President, just to make some corrections to the underlying bill.

Madam President, if we might call now to have the Clerk read the items on the Consent Calendar and then to move to a vote on the Consent Calendar.

THE CHAIR:

Mr. Clerk, will you please read the items on the Consent Calendar.

THE CLERK:

On page 1, Calendar 300, House Joint Resolution Number 78; page 1, Calendar 301, House Joint Resolution Number 79.

Page 2 Calendar 302, House Joint Resolution Number 80; page 2, Senate Bill -- Calendar Number 64, Senate Bill 37.

Page 3, Calendar 89, Senate Bill 56.

Page 4, Calendar 110, Senate Bill 184; page 4, Calendar 91, Senate Bill Number 276.

Page 5, Calendar 127, Senate Bill 320.

Page 8, Calendar 203, Senate Bill 408.

Page 9, Calendar 226, Senate Bill 411; also, on page 9, Calendar 224, Senate Bill Number 339.

Page 10, Calendar 232, Senate Bill Number 186.

On page 11, Calendar 238, House Bill 5250.

On page 12, Calendar 258, Senate Bill 340; also on page 12, Calendar 259, Senate Bill 157; page 12, Calendar 265, Senate Bill 176.

Page 13, Calendar 271, Senate Bill 350; page 13, Calendar 273, Senate Bill 293; page 13, Calendar 274, Senate Bill 294.

Page 14, Calendar 285, Senate Bill 404.

Page 15, Calendar 296, Senate Bill Number 307.

And page 24, Calendar 132, Senate Bill 337.

THE CHAIR:

The Senate will stand at ease for a second.

(Chamber at ease.)

THE CHAIR:

Okay. Those are the items listed. The machine will be open.

Mr. Clerk, will you please call for a roll call vote on the Consent Calendar. Thank you.

THE CLERK:

Immediate roll call has been ordered in the Senate. Senators please return to the chamber. Immediate roll call has been ordered in the Senate.

THE CHAIR:

Have all members voted? If all members voted, the machine will be locked.

And Mr. Clerk, will you please call the tally.

THE CLERK:

On today's Consent Calendar.

Total Number Voting	35
Necessary for passage	19
Those voting Yea	35
Those voting Nay	0
Those absent and not voting	1

THE CHAIR:

Consent Calendar has passed.

Senator Looney.

SENATOR LOONEY.