

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office

Health and Human Services Committee
January 24, 2013

[LB23 LB156 LB225]

The Committee on Health and Human Services met at 1:30 p.m. on Thursday, January 24, 2013, in Room 1510 of the State Capitol, Lincoln, Nebraska, for the purpose of conducting a public hearing on LB225, LB23, and LB156. Senators present: Kathy Campbell, Chairperson; Bob Krist, Vice Chairperson; Tanya Cook; Sue Crawford; Mike Gloor; Sara Howard; and Dan Watermeier. Senators absent: None.

SENATOR CAMPBELL: (Recorder malfunction) ...everyone, and welcome to the hearings for the Health and Human Services Committee. I'm Kathy Campbell and I serve District 25, which is Lincoln and east Lancaster County. Before we have the senators and everyone do their introduction, I want to go through a few things with all of you today to make it easier for you should you be testifying. Remind everyone in the audience that if you have a cell phone to please turn it off or make sure it's on silent so you do not disturb anyone else. If you will be testifying today, you need to complete one of the bright orange sheets that are on either side of the hearing room and please print and spell legibly. When you come forward to testify, you can just give your orange sheet and any handouts that you might have to the clerk, Diane Johnson, who's sitting at the end. When you sit down to testify, we will ask that you state your name for the record and spell it. The orange sheets give Diane an idea of how your name is spelled and for the record. The reason we have you say it and spell it is for the transcribers who listen and have to put the permanent record together. We do use the light system in the Health Committee. When you start you have five minutes, and that will be green and it will be green for a long time, and then it will go to yellow, which means you have one minute, and then it goes to red. And you'll look up, and I'll be trying to get your attention to have you kind of wrap up your testimony. If you need any assistance with copies of your testimony, do let one of the pages know and they certainly can help you. With that, we will start with introductions, and I'll start to my far right, Senator.

SENATOR HOWARD: I'm Senator Sara Howard. I represent District 9 which is in midtown Omaha.

SENATOR COOK: I'm Senator Tanya Cook from Legislative District 13, northeast Douglas County and city of Omaha.

SENATOR KRIST: Bob Krist, northwest Omaha, north central Douglas County, and the city of Bennington, and I forgot to turn my phone off.

SENATOR CAMPBELL: It's okay. Right under the wire.

MICHELLE CHAFFEE: I'm Michelle Chaffee. I serve as the legal counsel to the committee.

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office

Health and Human Services Committee
January 24, 2013

SENATOR GLOOR: Mike Gloor, District 35, that's Grand Island.

SENATOR CRAWFORD: Sue Crawford, Bellevue, Offutt, and eastern Sarpy County.

DIANE JOHNSON: And I'm Diane Johnson, the committee clerk.

SENATOR CAMPBELL: And our pages today are Kaitlyn and Deven. And so if you need help, the pages will be glad to help you. With that, we will start into the afternoon hearings, and our first hearing today is LB225. Senator Smith, if you'd come forward. Senator Smith's bill would adopt the Newborn Critical Congenital Heart Disease Screening Act. Welcome, Senator Smith. And you can start whenever you're ready. [LB225]

SENATOR SMITH: (Exhibits 1, 2, and 3) Thank you. And good afternoon, Senator Campbell and members of the Health and Human Services Committee. For the record, my name is Jim Smith, J-i-m S-m-i-t-h, and I represent the 14th Legislative District in Sarpy County. I'm here this afternoon to introduce LB225. LB225 would require all newborns in the state to be screened for critical congenital heart disease, or CCHD, in a manner that is similar to our existing required screenings for metabolic and inherited disorders and hearing. I'm pleased that others have expressed support for this bill and that some are here today to testify. There are also experts that will follow me who can give a more knowledgeable explanation as to how this screening would work and why screening newborns for CCHD is important. Many of you on the committee heard testimony on this issue last fall as part of an interim study I introduced. The study brought together a group of people that included medical professionals, hospitals, representatives of the insurance industry, and advocacy groups such as the Heart Association and the March of Dimes. LB225 is the result of that study. I hope the testimony today serves as a helpful refresher for those of you familiar with this issue, and that it's educational for the committee members new to the subject of CCHD screening. CCHD is among one of the leading causes of morbidity and death in newborns; but can be detected with a simple, noninvasive, inexpensive procedure called pulse oximetry. About 3 percent of babies born in Nebraska each year will be born with a heart defect. Screening doesn't prevent CCHD. And I repeat, screening does not prevent CCHD. But early detection is key to the infant...so that the infant can get the support care that is necessary. Babies that go home with undetected CCHD can suffer damage to other organs, including brain damage or death. I have three handouts. For some of you these may be duplicates, so I apologize. One is a letter from the United States Secretary of Health, Kathleen Sebelius, recommending CCHD screening; one is an endorsement from the American Academy of Pediatrics for adding CCHD screening to the uniform screening panel and using pulse oximetry; and the third is a map. The map shows that, to date, at least six states have adopted or are in the process of adopting this requirement. This number is expected to grow significantly in the next year. I also want to note that last year the Nebraska Newborn Screening Advisory

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office

Health and Human Services Committee
January 24, 2013

Committee released its recommendation for screening all newborns for CCHD. This bill is drafted very broadly and does not particularly mention pulse oximetry specifically nor get into detail as to when or how the screening is to be conducted. I certainly understand that the medical community usually has concerns with the Legislature dictating standard of care, and I wanted to be sensitive to that. So this bill is flexible enough for experts to develop those standards through rules and regulations and to be able to more easily change screening methods as technology advances. At this time, it is very likely that pulse oximetry will be used to conduct this test. I have been assured that due to the nature of the test, use of the pulse oximeter in newborn screening will not compete with the use of that same device in critical care situations at the same location. You may hear or receive information regarding false positives and the costs associated with follow-up tests for newborns who have a false-positive reading. According to the American Heart Association, studies indicate that if done properly, pulse oximetry has less than 1 percent chance of yielding a false positive and that in many cases, that false positive does not identify CCHD; but does identify other conditions that require medical attention. When weighing the potential cost of follow-up tests or sending a child home with an undetected heart defect, I would rather err on the side of protecting the newborn. Generally I'm not one who supports government mandates such as this; but after studying this issue and visiting with professionals and families impacted by CCHD, I became convinced that requiring screening is the right thing for us as a state to do. Early detection saves money in the long run, and it saves families unnecessary prolonged worry; and most importantly, it saves lives. Thank you for your time and I hope after hearing the testimony this afternoon that this committee will advance LB226 (sic) to General File and I will certainly try to answer any questions, but ask that you save the technical questions for those that follow me. Thank you very much. [LB225]

SENATOR CAMPBELL: Thank you, Senator Smith. Questions? Senator Gloor. [LB225]

SENATOR GLOOR: (Exhibit 4) Yes, thank you, Senator Campbell. And I promise you this won't be a clinical question, Senator Smith. But have you had a chance to see the letter from Dr. Schaefer yet that was sent over to Senator Campbell? [LB225]

SENATOR SMITH: Regarding the fiscal note? [LB225]

SENATOR GLOOR: No. It related to the bill specifically and a couple of observations that were made about the bill. [LB225]

SENATOR SMITH: Oh, yes, from DHHS. [LB225]

SENATOR GLOOR: Yeah, yeah. [LB225]

SENATOR SMITH: Yes. [LB225]

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office

Health and Human Services Committee
January 24, 2013

SENATOR GLOOR: One of my questions that I had that she's identified right off the bat is, are we really going to, is there really a need to set up a monitoring system, because that's where some of your cost is going to be included and most of your cost is included? And, you know, I have kind of an aversion, given my past life, for collecting information that people don't do things with; and even though it's...it seems to me the issue is that this is worth doing because it can make a difference in lives, cost, etcetera. But if we gather that information, are we doing anything additionally with it? You may not be the person to answer that, but I ask it so other testifiers might be able to address it also. [LB225]

SENATOR SMITH: Well, first of all, we did interact with DHHS late last year, and we engaged them on concerns that they may have with this legislation. And what we have received recently from them on this we believe that we can work through with any type of amendment on this bill. I did have a conversation as late as yesterday on the concerns with the fiscal note and additional expenditures, and we're very open to understanding how we can work with them to make certain that the costs are contained. We're trying to replicate as much as possible the procedures that are used for current screening, so for hearing and blood diseases and such. So as much as those costs are incurred for those types of screening activities, I would assume that they would be necessary for this. [LB225]

SENATOR GLOOR: Well, and that's my point exactly which is with some familiarity on that. I'm a skeptic that that information actually finds its way into the hands of people that can make a difference. And maybe there are epidemiologists who gather it for reasons unbeknownst to us, but gathering information to gather information to look at it's one thing. I just wonder if the key part of your bill is doing the screening, it's not data collection. And if the expense is data collection, then maybe we need to revisit that issue on behalf of this bill and your ability to move it forward, so. [LB225]

SENATOR SMITH: I would absolutely agree with you. Thanks for bringing up that point. [LB225]

SENATOR CAMPBELL: Any other questions from the senators? Thank you, Senator Smith. [LB225]

SENATOR SMITH: Thank you. [LB225]

SENATOR CAMPBELL: And will you be staying? [LB225]

SENATOR SMITH: Yes, I will. [LB225]

SENATOR CAMPBELL: (Exhibits 5 and 6) Okay. Thank you so much. I want to make a

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office

Health and Human Services Committee
January 24, 2013

brief announcement for anyone in the room before we start is that at the request of the sponsor of LB23, it will be moved into the last position. Okay. So we will proceed from LB225 to LB156, and then we will come back to LB23. And so I just didn't want anyone in the hearing room who is waiting for that one to know you'll have to wait a little bit longer. Okay. All right. With that, we will start on the testimony for LB225 and take the proponents. So those who are in support and wish to testify. While we are setting up for the first testifier, is there someone in the hearing room from the Nebraska Hospital Association? Will you be testifying? Okay. So that we need to note for the record that we received a letter from the Nebraska Hospital Association to all the senators in support of the bill. And is someone here from the Nebraska Medical Association? Will you be testifying? Okay. We will note for the record that we have a letter in support from the Nebraska Medical Association. I was just trying to double check. Okay. Thank you very much for your patience while we took care of some of that. State your name for the record and spell it. [LB225]

ROBERT SPICER: (Exhibit 7) My name is Robert L. Spicer, R-o-b-e-r-t S-p-i-c-e-r. [LB225]

SENATOR CAMPBELL: And you can go right ahead and start. [LB225]

ROBERT SPICER: I have some prepared comments here. I'm not sure that I'll be able to add much more than Senator Smith enlightened you on this. He did a very good job of explaining it. Thank you, Senator Campbell and members of the Health and Human Services Committee for this opportunity to speak with you this afternoon on LB225. I am the chief of cardiology at Children's Hospital and Medical Center in Omaha. I am also the president of the board of the American Heart Association Omaha chapter for 2013 and '14. Before coming to Omaha in 2012, I served as the director of the cardiology fellowship and cardiac transplant programs at Cincinnati Children's Hospital Medical Center. My purpose in speaking to you this afternoon is to provide you with information on critical congenital heart defects and pulse oximetry screening in newborns, the purpose of this test, and what it can and cannot do. Congenital heart disease or CHD is the most common birth defect in newborns. Infants with congenital heart disease have an abnormal structure to their heart which creates abnormal blood flow patterns. Approximately 8 of every 1,000 infants born in the United States each year have a form of congenital heart disease, some of which cause no or very few problems in the health and development of the child. But critical congenital heart disease, which occurs in approximately 1.2 per 1,000 births, can bring a significant risk of complications and even death if not diagnosed soon after birth. Failing to detect critical congenital heart disease in the newborn nursery may result in cardiogenic shock or death. Pulse oximetry can detect cases of critical heart disease which might otherwise go undetected. Pulse oximetry is a simple, noninvasive, and painless test used to measure the percentage of hemoglobin in the arterial blood that is saturated with oxygen. It was developed in the 1970s and is widely used, accepted as the standard of care, and

endorsed by numerous medical associations. It is safe to say that every hospital in Nebraska has a pulse oximeter. For our purposes, we are focusing on screening newborns for critical congenital heart disease. Obtaining reliable pulse oximetry readings on a newborn is not difficult, but does require some training and strict adherence to protocol. For example, excessive ambient light, an improperly-sized probe, a wiggly child, or a child who is cold can all result in false or inaccurate readings. Congenital heart disease cannot be completely ruled out by a normal pulse oximetry reading nor can the screen detect all forms of congenital heart disease. In addition, false positives and false negatives may occur. But the rates of false positives are diminished when recommended protocols are followed. The timing of the test is very important. It needs to be done between 24 hours after birth and just prior to discharge. Pulse oximetry testing does nothing in terms of treating structural heart defects. The purpose of pulse oximetry screening is to catch those babies with certain types of serious heart defects and possibly prevent poor outcomes. The test does not replace but rather supplements a high-quality physical examination. As noted previously, a pulse oximeter is standard hospital equipment. If you have ever had a surgical procedure done, then you have probably had pulse oximetry. For adults it is the small clothespin-like item that was clipped to your finger. On newborns, a small sticky strip like a Band-Aid is placed on the fleshy part of both the foot and the hand and is connected to a special monitor that shows the pulse oximetry reading. The probe may or may not be disposable. The models, such as what you're viewing now, run from \$500 to \$3,000, and this is a one-time cost. One unit can be used for hundreds of patients. The costs of the probe are minimal. The test takes just a few minutes to perform while the baby is still, quiet, and warm. The probe does not puncture the skin and the measurement can usually be read in 30 to 60 seconds. If an abnormal pulse oximetry reading is identified, the test should be repeated one hour later. If the child fails a second and then third screening, full clinical assessment including an echocardiogram should be performed. This poses potential problems for rural communities because pediatric echocardiography is a specialized test available only in relatively few cities. In planning for any large-scale pulse oximetry screening, the availability of neonatal echocardiography is critical. There is little doubt among pediatric experts that the advantages of this test far outweigh the disadvantages. Pulse oximetry is a reliable, cost-effective way of screening for certain life-threatening forms of congenital heart disease, and it has the ability to detect babies with critical congenital heart disease who might otherwise be missed and could be harmed by the missed diagnosis. Thank you for the opportunity to speak with you. [LB225]

SENATOR CAMPBELL: Thank you, Dr. Spicer. Questions from the senators? Senator Gloor. [LB225]

SENATOR GLOOR: Thank you, Senator Campbell. Same question that I directed toward Senator Smith. [LB225]

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office

Health and Human Services Committee
January 24, 2013

ROBERT SPICER: Oh, boy. [LB225]

SENATOR GLOOR: I mean, is there a reason that we need to go through data collection on this? [LB225]

ROBERT SPICER: I think it's vital for us to be able to report to the various agencies that are going to be looking at the patients to see whether or not the screening was done appropriately, what kinds of false positives and false negative results we've had to see if we can or need to modify the test or our approach to these patients. I do think that it's important to collect the data. Since we're going to be doing the tests, it has to be collected in a way that will allow us to review it. [LB225]

SENATOR GLOOR: But there are dozens or hundreds of tests that are done on children and adults that we don't report, at least not individually, let's put it that way, out of labs and clinics all across the state and the country. Why, again, would this be important above and beyond, you know, some general reporting at the end of the year perhaps? [LB225]

ROBERT SPICER: I think it would be useful if in fact for example a patient is discovered to have a congenital heart defect who escapes screening, who at age two or three months is looked back and said, well, gee, why did this get discovered now. What was the information that we had available in the newborn nursery that we were...had a false negative report on? [LB225]

SENATOR GLOOR: Okay. So it's...in that instance it's a quality assurance, falls sort of into a quality assurance. [LB225]

ROBERT SPICER: I think that's probably a good way to describe it, yes. [LB225]

SENATOR GLOOR: Okay. Thank you, Dr. Spicer. [LB225]

SENATOR CAMPBELL: Dr. Spicer, in Dr. Schaefer's note to the committee, one of the points, and I certainly know that Senator Smith will work with the department on those, but she brought a question to my mind that I thought would be important to ask you. One of the questions she raises is in terms of...the bill obviously deals with children born in hospitals, but what about children who are born in birthing centers? Would birthing centers have the instrument on hand to provide that test or would they have to take the infant to a hospital? [LB225]

ROBERT SPICER: I think it would probably vary from center to center. As my testimony stated, I think it's very safe to say that birthing centers likely have pulse oximetry for moms who are in labor. The same piece of equipment could be used. The probe would have to be different. The probes for neonates are different than the clothespin kind of

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office

Health and Human Services Committee
January 24, 2013

thing that you and I would have, and it may require that they have that done. The additional problem that I would see with birthing centers is that the children are often released from the centers before the critical 24-hour time frame. And I think if we did tests on them before they left the birthing center, we would likely get more false positives than would be warranted. So we would I would think have to come up with some alternative strategy to make sure that those patients are screened. [LB225]

SENATOR CAMPBELL: Okay. And I'm sure that Dr. Schaefer will be glad to discuss that, but she raised it in the letter and I thought, well, maybe I should ask you. [LB225]

ROBERT SPICER: Well, I think it is a very important question to ask. [LB225]

SENATOR CAMPBELL: Okay. Any other follow-up questions from the senators? Thank you, Dr. Spicer... [LB225]

ROBERT SPICER: Thank you. [LB225]

SENATOR CAMPBELL: ...and for the information. You brought a lot of information that we can look at. [LB225]

ROBERT SPICER: Yes. [LB225]

SENATOR CAMPBELL: So appreciate that. Our next testifier in support. Good afternoon. [LB225]

COLE KLEIN: (Exhibit 8) Good afternoon. [LB225]

SENATOR CAMPBELL: Would you tell me your name and spell it please? [LB225]

COLE KLEIN: My name is Cole Klein, C-o-l-e -K-l-e-i-n. [LB225]

SENATOR CAMPBELL: Excellent. And you have a handout apparently for all of us. Okay. We'll wait just a minute and we'll make sure that we have that. I have to tell you that in, this is now my fifth year, I think you are the youngest testifier we have had before the committee. It isn't easy being a testifier, so you take your time and just feel real comfortable. Okay? All right. I think everybody has it, so you go right ahead and start. [LB225]

COLE KLEIN: My name is Cole Klein. I am ten years old. I like to go fishing, ride my four-wheeler, and play football at recess with my friends. I've parred more than a couple of golf holes and progressed enough to join the swim team. And if you would ask, I'd tell you that my favorite subject is P.E. And my little brother can be a little annoying; but he can also be a lot of fun, too. In many ways I am like a lot of boys my age. Unlike my

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office

Health and Human Services Committee
January 24, 2013

friends, however, I was born with a critical congenital heart defect. Just by looking at me now, you may not be able to tell that I have had three open-heart surgeries and a couple of heart cath. You also may not be able to look at me and know that I have a stint in my pulmonary artery trying to buy me some time before I need another open-heart surgery. Like many children born with a heart defect, it is difficult to know about our hearts by simply looking at us. It doesn't matter if we are ten years old or ten hours old. Usually it is only once we are really sick before someone knows. And too many times it is too late before anyone knows. I am here today to respectfully ask the committee to support LB225. It is my hope that all babies born in Nebraska will be screened for congenital heart defects. Screening babies for heart defects will give many children like me a fighting chance, a chance we need, a chance I think we should have. Thank you. [LB225]

SENATOR CAMPBELL: Excellent job. [LB225]

COLE KLEIN: Thank you. [LB225]

SENATOR CAMPBELL: I wish that we had all testifiers who would just time that just so. That was very well done, Cole, and very well to the point. Questions from the senators for Cole? Cole, when do you think or do you know when you'll have to have that next heart surgery? As you get older, is that every periodically the years they do it? [LB225]

COLE KLEIN: Yes, yes. [LB225]

SENATOR CAMPBELL: Excellent. So do you see a doctor one, two times a year that they check that? [LB225]

TIFFANY MYTTY-KLEIN: Four times a year (inaudible). [LB225]

SENATOR CAMPBELL: We have a little help from the audience (laughter). Four times a year. That's great. And so how are you doing on the swim team? [LB225]

COLE KLEIN: Mostly good. (Laughter) [LB225]

SENATOR CAMPBELL: Mostly good. You're doing just swell, Cole, thank you very much for coming today and providing your testimony. Okay. I pity the next testifier, really I do. (Laughter) That's a hard act to follow. We have someone else in the room who wishes to testify. I think this testifier can meet the challenge. (Laughter) [LB225]

TIFFANY MYTTY-KLEIN: (Exhibit 9) I don't know. Genetically we should have some advantage, but (inaudible). [LB225]

SENATOR CAMPBELL: So we need you to state your name and spell it for the record.

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office

Health and Human Services Committee
January 24, 2013

[LB225]

TIFFANY MYTTY-KLEIN: All right. My name is Tiffany Mytty-Klein, T-i-f-f-a-n-y M-y-t-t-y-K-l-e-i-n. [LB225]

SENATOR CAMPBELL: And you go right ahead. [LB225]

TIFFANY MYTTY-KLEIN: Okay. Good afternoon, Senators. I want to thank each of you for the opportunity to speak to you today and also to let you know I appreciate the patience of many of you for listening to me for maybe the second and sometimes even the third time. But I also want to thank Senator Smith for supporting and believing in the importance of this bill and its impact. On August 5, 2002, Grant Michael Goughnour was born. Fourteen days later my son, Cole Michael Klein, was born. Both boys arrived at the end of a first-time, noneventful, full-term pregnancy. And though Grant's birthweight of nine pounds, five ounces surpassed Cole's by more than one-and-a-half pounds, both were gorgeous little boys who were born with ten perfect little fingers, ten perfect little toes, and heads full of silky dark hair. And, sadly, when both were discharged from the hospital in the days following their birth, they left with an undiagnosed critical congenital heart defect called truncus arteriosus. On August 22, 2002, Grant suddenly stopped breathing. He passed away in his mother's arms as they rushed to the hospital. After his death, his heart defect was diagnosed by a coroner. And Grant was 17 days old. On October 17, 2002, Cole was admitted to the hospital in distress and his heart defect was diagnosed by a cardiologist. He was 53 days old. Three times since that day, I have left trembling lines of ink on standard consent forms indicating my understanding of what would occur and what could go wrong. Three times I have had the same nurse gently say to me, we will take good care of him, mom, as she removed him from my arms. Three times the crushing weight of the emptiness that remained in his absence has dropped me to my knees and stolen the air from my lungs. And three times I have given blind trust to a man I knew would stop my son's heart, and desperately prayed it would beat again. And I am grateful to be so blessed. I am grateful because in August of 2007 while Grant's parents prepared a fund-raiser to celebrate his life and honor his memory, I prepared for my son's fifth birthday and his first day of kindergarten. I am grateful because each night when he goes to bed, I get to hug him and tell him that I love him. I am grateful because I have the opportunity to worry about echo results, future surgeries, and if we are doing enough to prepare him for his future. I am grateful because my son has a future. Every 15 minutes a baby is born in the United States with a congenital heart defect, 100 babies each day. It is the leading cause of death in our country for infants and also one of the most unrecognized. And whether it's days or weeks, undiagnosed babies can suffer from significant medical complications, developmental delays, learning disabilities, and physical disabilities related to brain injury. And in the worst-case scenarios, babies go undiagnosed and die. Of the 40,000 babies born each year in this country with a CHD, 4,000 will die within their first year of life. One out of every six of these daughters and these sons will not live to see their first

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office

Health and Human Services Committee
January 24, 2013

birthday simply because they were not diagnosed before their death. Over 660 babies will not even have a chance. Newborn screening for critical congenital heart defects would not have prevented either Cole or Grant's heart defects. It may have minimized the weeks we spent in the hospital trying to get our son healthy enough to survive his first surgery. And it may have minimized the bouts of pneumonia his damaged lungs seemed to contract so easily during the first half of his life. And maybe it could have minimized the years of speech therapy and physical therapy needed to help him to catch up to his peers. But most importantly, screening newborns for heart defects may have given Grant a chance to sit here today, beside my son, and tell you about his favorite subjects in school or what he wanted to be when he grew up. Screening babies for heart defects can be achieved through simple, noninvasive and economically feasible methods utilizing equipment already available in hospitals throughout Nebraska. In the past three years, screening newborns for congenital heart defects has been mandated by legislation in nine states and has been initiated or is currently pending by more than a dozen more...dozen others, including recently added Missouri, Iowa, and Oklahoma. Routinely screening all newborns for critical congenital heart defects can give many of our children a fighting chance at life and, as my son already said, a chance they should have and a chance they deserve. Thank you. [LB225]

SENATOR CAMPBELL: Questions from the senators? I know that you have been a tenacious advocate, and it's great to see you again for when we first started talking. [LB225]

TIFFANY MYTTY-KLEIN: Thank you very much. [LB225]

SENATOR CAMPBELL: Thank you for your testimony today. Our next proponent. Good afternoon. [LB225]

DAVID MINDERMAN: (Exhibit 10) Good afternoon, Senator, council here. My name is David Minderman. I'm a medical doctor, a neonatologist at the Women's Hospital in Omaha. My name is D-a-v-i-d M-i-n-d-e-r-m-a-n. And I've come to talk to you informally about the...in support of this screening program. I represent myself, my medical practice, Neonatal Care PC, and I've brought a letter from the Nebraska Chapter of the American Academy of Pediatrics in support of this measure. As Dr. Spicer and Senator Smith have already presented, congenital heart disease is a very common problem. About 9 per 1,000 infants are diagnosed with congenital heart disease of some ilk. And about a quarter of those infants have this critical congenital heart disease that we're so worried about. As a neonatologist, I see hundreds of babies every year. My primary job is to recognize babies who are sick and support them during their initial hospital stay. I don't get a chance to see them when they come back very often anymore. But I've seen a number of babies who have congenital heart disease who have come in in extremis that we've had to resuscitate, and it's really something that to a large extent this bill will help to prevent. As a clinician, there really isn't a good way to predict which babies are

going to get in trouble in that first critical 48 hours that they're in the hospital. Now if you're skilled at physical examination, you might do a better job of picking up these kids. But not all of them for a number of important reasons are going to demonstrate the blue tone of cyanosis or the heart murmur that we're all taught to expect when we're looking at those babies in the delivery room. And frankly, I consider my exam skills to be quite good; and I would not pick up all of these babies. I wouldn't want to claim to be able to do that. And many of the folks who are looking at these babies to determine whether or not they can go home safely don't have the repetitions that I have in that field. So my group, Methodist Women's Hospital, have the department of pediatrics at the Women's Hospital which includes a number of folks who practice elsewhere in town, including the Children's Hospital and other places, have voted as a group to implement this strategy at the Methodist Women's Hospital as described by the American Heart Association and the American Academy of Pediatrics. It's been active for about nine months in our facilities, and we're very happy with it. We're not seeing very many false positive screens. We found that we do have a lot of technology available to us, but we have not found any significant problems with administering the test. We're not seeing a lot of false positives. I don't know that we've even had to perform more than an echo or two to determine whether these babies need, you know, ongoing follow up. And we deliver about 3,800 babies a year in our setting. If you look at the statistics from the Academy and the American Heart Association, about 35 in 10,000 will fail three consecutive screens at 24 hours of life. And for a birthrate, Nebraska delivers somewhere 25,000 to 30,000 babies a year. So you're looking at on the order of 100 kids who would need an echocardiogram. So the numbers are relatively small that would need that kind of support given that a large number of those babies are born in Lincoln or Omaha where the centers actually have the capability to do the test. I don't think that the extra costs...I haven't done the accounting on it, but I don't think the extra costs from the test standpoint make any sense to forego doing this test, so. Really that's the stuff I really wanted to tell you about, and I don't know if any of you have questions for me from... [LB225]

SENATOR CAMPBELL: Questions from the senators? Senator Gloor. [LB225]

SENATOR GLOOR: Thank you, Senator Campbell. Thank you, Doctor, for taking time out of your busy schedule to share your views with us, but I've got to ask the same question about reporting relationships. You know, to repeat my concern is that this bill for all its merits is saddled with some expense; some of it, quite a bit of it, related to reporting, data collection and collating and sharing. Do you see the reporting component of it as necessary at all from your clinical standpoint? [LB225]

DAVID MINDERMAN: To the extent that it validates the test and it validates that the test is being done properly and appropriately and that it ensures that babies who are born in a, you know, more...a less technologically substantial environment get the support that they need, I do. I don't quite understand exactly what the reporting requirements are as

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office

Health and Human Services Committee
January 24, 2013

far as what they involve and the paperwork involved, the data collection. I would imagine there has to be an efficient way to do that. You know, in 2013, that we could do that in a cost-effective manner. [LB225]

SENATOR GLOOR: It's a mystery for a lot of us, trust me. We're not sure how the numbers are derived at, but. But I appreciate your insight on that. Thank you. [LB225]

SENATOR CAMPBELL: Doctor, do you expect that at some point this will be in a standard of care and just done by everyone? I think that was a question that we took a look at in the interim when people testified, whether this would just fold into that without, you know, understanding that some states are going to pass legislation. But at some point would it not become just a standard of care? [LB225]

DAVID MINDERMAN: Boy, that's a dangerous question to answer. But I do think that the important bodies, the important scientific bodies that speak about pediatrics and that speak about cardiology have made that gesture anyhow, so. [LB225]

SENATOR CAMPBELL: Okay. The next question, and you may not have come into contact with it, but goes back to the birthing center question that I asked about. Have you had any experience with a baby born in a birthing center and would they be prepared to administer the test and know what they should be looking for? [LB225]

DAVID MINDERMAN: You know, at least the test that we are using, and I know the bill doesn't specify a particular type of screening test, but the test that we use involves putting the proper probe on a finger or wrist and an ankle and reading a number back. The criteria as to passing and failing the test are a specific set of numbers and difference between the two numbers. And I don't know why that anyone capable of delivering a baby wouldn't be able to administer such a test in an appropriate fashion. And I wouldn't think you'd need extra licensing or anything like that to do so. [LB225]

SENATOR CAMPBELL: That's very helpful. The last question is, and I do understand that certainly a large majority of those births would take place in the more populace areas, but if the test was done across the state and they had three, you know, where the baby does not pass this test, then would they rush that baby at that point to a hospital that could do all of the tests that would be necessary, and how long would they have to get that baby to care? [LB225]

DAVID MINDERMAN: I think they would need to be expedient about getting the baby to a center that could do the test, you know, within, you know, four to eight hours. [LB225]

SENATOR CAMPBELL: Okay. [LB225]

DAVID MINDERMAN: The reality of this medical problem is most of these babies are

dependent on a specific blood vessel called the ductus arteriosus that each and everyone of us had when we were developing in utero. And the normal physiology is for that blood vessel to close any time in the first 48 hours to, you know, three to five weeks of life. I'm sure Dr. Spicer could be more specific about how that closes. But, anyway, most babies with critical congenital heart disease do okay until that blood vessel closes, and then either they have trouble delivering blood to their body for their vital organs to use to extract oxygen or they have trouble delivering blood to the lungs so that the blood can be reoxygenated. So as long as that blood vessel is kept open the babies generally do okay. When that gets to a critical diameter, then those babies immediately become ICU type of ill patients and need immediate services. And that's what we're trying to pick up. If that's not picked up, babies develop lack of oxygen to whichever tissues aren't...either to the whole body if the lungs aren't getting blood flow or to a specific set of organs, and that's when organ injury, brain damage, all of those sorts of things occur. You know, in the vast majority of these echocardiograms that we do are going to be relatively normal or show noncritical problems, at least we think. But the ones who we find, the ones that we're looking for in this screening program would need critical care or at least the ability to be initiated on a medicine called prostiglandin to help keep that blood vessel open. [LB225]

SENATOR CAMPBELL: So it would be a very critical time period. [LB225]

DAVID MINDERMAN: It would be a critical time period. [LB225]

SENATOR CAMPBELL: Okay. Any other questions from the senators? Yes, Senator Howard. [LB225]

SENATOR HOWARD: Thank you, Madam Chair. Just as a clarification, are you already regularly performing this test upon discharge for babies? [LB225]

DAVID MINDERMAN: We are. [LB225]

SENATOR HOWARD: So it's already in your regular standard of care at your facility? [LB225]

DAVID MINDERMAN: It is. It is. [LB225]

SENATOR HOWARD: Thank you. [LB225]

SENATOR CAMPBELL: Okay. Any other questions? Thank you, Doctor, that's very helpful. So thanks for coming today. Our next proponent. Good afternoon. [LB225]

JILL DUIS: Good afternoon. [LB225]

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office

Health and Human Services Committee
January 24, 2013

SENATOR CAMPBELL: You can go ahead and state your name for the record. [LB225]

JILL DUIS: (Exhibit 11) My name is Jill Duis, J-i-l-l D-u-i-s. [LB225]

SENATOR CAMPBELL: And go right ahead. [LB225]

JILL DUIS: Good afternoon, Madam Chairperson and members of the committee. My name is Jill Duis, and I am a volunteer for the American Heart Association; and I am a heart survivor. I'm a much older, but female version of Cole. Today I want to offer testimony on behalf of the American Heart Association in support of LB225. I also want to be able to thank Senator Jim Smith for introducing this very important bill. In addition to being a volunteer for the American Heart Association, I'm also a registered nurse and have worked in the field of nursing for more than 30 years. I've been fortunate to work in a number of settings, including the emergency department, intensive and coronary care, as well as being able to teach nursing. As a medical professional, I must stress that early detection of critical congenital heart defects, CCHD, is absolutely essential to reducing morbidity and death from CCHD. Congenital heart defects are malformations of the heart not identified...of major blood vessels that occur before birth. In many cases, however, hospital staff may not identify these defects and outwardly healthy-looking infants may be admitted to nurseries and discharged from hospitals before signs of the disease are detected. This bill would ensure that all Nebraska newborns will receive CCHD screening. Although prenatal ultrasounds and postnatal physical exams successfully detect many heart defects, they are not sufficient to diagnose all cases of CCHD. New research suggests that when infants are screened using pulse oximetry in conjunction with routine practices, CCHD can be detected in over 90 percent of the newborns who have CCHD. Pulse oximetry screening is low-cost, noninvasive, and painless. It's a bedside test that can be completed by a technician in as little as 45 seconds. Pulse oximetry, in addition to that, is not an expensive procedure. In fact, a recent cost-effectiveness analysis estimated that universal newborn pulse oximetry screening would cost just under \$4 per infant. Research suggests that the cost savings associated with early detection in a single case of CCHD could exceed the cost associated with screening 2,000 infants. Once detected, many heart defects can be surgically repaired. And it is estimated that 85 percent of neonates who undergo surgery for CCHD will reach adulthood. I should also add that newborn screening is a well-established state-based public health program that involves testing all infants for metabolic, hormonal, genetic, and developmental disabilities. Each year, more than 98 percent of newborns are screened across the United States for these disorders. Recently, U.S. Secretary of Health and Human Services endorsed the addition of CCHD screening to the recommended uniform screening panel for newborns. The Secretary's Committee on Inheritable Disorders in Newborns and Children recommends that hospitals use pulse oximetry to screen infants for CCHD. This is a very important bill and I respectfully urge the passage of this legislation. And I thank you for the opportunity to testify today. [LB225]

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office

Health and Human Services Committee
January 24, 2013

SENATOR CAMPBELL: Thank you, Ms. Duis. Questions from the senators on the testimony? Seeing none, thank you so much for coming today. [LB225]

JILL DUIS: Thank you. [LB225]

SENATOR CAMPBELL: Our next proponent. Welcome. [LB225]

MARY LARSEN: (Exhibit 12) Thank you. My name is Mary Larsen, M-a-r-y L-a-r-s-e-n. Good afternoon, Senator Campbell and members of Health and Human Services Committee. I am Mary Larsen, March of Dimes director of program services and advocacy. 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 a 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 for a newborn, blood spots or other...by newborn blood spots or other specific means. As such, the March of Dimes supports screening of newborns for the critical congenital heart disease. Congenital heart disease is a problem with the heart's structure and/or function which is present at birth. Critical congenital heart disease means that the heart defect causes severe, life-threatening symptoms and requires intervention, medical treatment or surgery, within the first few hours, days, or months of life. 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. Currently, CCHD can be identified using a noninvasive and painless method called pulse oximetry in the newborn period before the baby is discharged from the hospital or birthing center. LB225 would allow the Department of Health and Human Services, working with experts, to develop approved methods to screen for critical congenital heart disease. March of Dimes urges Nebraska to support legislation to screen newborns for CCHD. 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 lifesaving interventions promptly. Thank you. [LB225]

SENATOR CAMPBELL: Any questions this afternoon from the senators? Thank you very much for your testimony today. [LB225]

MARY LARSEN: Sure. [LB225]

DON WESELY: (Exhibit 13) Madam Chairman, members of the Health and Human Services Committee, for the record, I'm Don Wesely, D-o-n W-e-s-e-l-y, lobbyist, registered lobbyist on behalf of the Nebraska Nurses Association. You're getting a

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office

Health and Human Services Committee
January 24, 2013

handout, a one-pager, prepared by Julie Sundermeier in support of the bill. I won't read it to you. I'll just tell you that we are glad that Senator Smith introduced the bill, we support the bill. And also for the record would like to indicate to Cole you did a great job. We will have a position open for you when you graduate from college (laughter) and keep us in mind because we think you'd do a great job. Thank you very much. That's my... [LB225]

SENATOR CAMPBELL: Absolutely. Are there any questions for Mr. Wesely? For our new senators, we need to note Mr. Wesely--I keep wanting to say Mayor Wesely, he was the mayor of the city of Lincoln--was a longtime chair of the Health and Human Services Committee. So it's always good to see you. [LB225]

DON WESELY: Thank you very much. Take care. [LB225]

SENATOR CAMPBELL: Thank you. Our next proponent. All right. Those in the hearing room who wish to testify in opposition to the bill. Those who wish to provide neutral testimony. Senator Smith, I think we're back to you. [LB225]

SENATOR SMITH: And thank you, again, Madam Chair and senators. I appreciate the committee's time and interest and engagement on this very important issue. I also want to say thank you to those that came to testify in support of this bill today and particularly the Mytty-Kleins. I know they've gone through quite a bit in their life, and I know this is very personal to them; and I thank them for their time to be here today. I wanted to just conclude my comments and come back around to Senator Gloor's numerous questions on the same topic of cost, the fiscal note, and the purpose of collecting the data and exactly what are we going to do with this data. I understand that simply collecting data is not good enough. We need to have a purpose if we're incurring that type of cost as to why we're collecting that data and exactly what we're going to do with it. I wanted to kind of relate to you a conversation we had with Dr. Schaefer yesterday. We did ask her very pointedly about those costs, and she expressed her position that the screening would work very similar to the already existing newborn hearing screening and that there's currently one-and-a-half FTEs or full-time equivalents of personnel that are set aside for that program. So that's where she came up with her numbers. And in that discussion with her, she expressed also that it was primarily for compliance. I think we also heard from one of the physicians here today that there may also be a quality assurance purpose for that data, for the review of that data. So hopefully that gives you a little bit more information about the fiscal note and why we would have to incur the cost of that FTE. Once again, I want to thank you for your time, and I wanted to assure you that I want to work with those that have expressed some small concerns with this legislation, and also want to assure you that I want to work with this committee to make certain we're able to resolve any concerns you may have so we can have success in moving this legislation forward. So once again, thank you very much. [LB225]

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office

Health and Human Services Committee
January 24, 2013

SENATOR CAMPBELL: Thank you, Senator Smith. Any follow-up questions from the senators? You've always worked really hard to answer the questions that the committee has, so when you finish your discussions with the department let us know. [LB225]

SENATOR SMITH: All right. Thank you. [LB225]

SENATOR CAMPBELL: (See also Exhibit 14) Thank you, Senator Smith. With that, we will close the hearing on LB225. And as I indicated, the schedule is now rearranged. And so Senator Watermeier, would you want to proceed to get set up and we'll let our guests...thank you, Cole. Well, we lost a great part of our audience today. Okay. I think we'll proceed to open the hearing on LB156, Senator Watermeier's bill to eliminate a report made to the Department of Health and Human Services by counties utilizing a community service program. Glad to have one of the members of the committee. So go right ahead, Senator Watermeier. [LB225 LB156]

SENATOR WATERMEIER: Thank you, Chairman Campbell and members of the Health and Human Services Committee. I am Senator Dan Watermeier, spelled Dan, D-a-n, Watermeier, W-a-t-e-r-m-e-i-e-r, representing District 1 in the southeast corner of the state. I'm here today to introduce LB156. LB156 repeals the section of a statute that requires any county utilizing a community service program for employable recipients to file an annual written report with the Department of Health and Human Services. This written report included the number of persons placed through the program, the number of hours of experience provided, the duration and location of each placement, and any specific skills learned in the placement. Only two counties have provided these reports to the department--Scotts Bluff and Douglas Counties. Furthermore, very few parties have asked to review this report. Previously, the department was required to compile the reports from each county and summarize the findings in written report to the Legislature. This requirement of DHHS was eliminated in 2005 through the passage of LB301. Since the report is not being utilized, the department asked if I would introduce this legislation to repeal the statute requiring the report to be submitted. The elimination of the reporting requirement would reduce staff time for the county officials that have submitted the report. I urge you to advance LB156 from the committee. If you have any questions, I would try to answer them; but more qualified people are following me, specifically Matt Clough, the Chief Operating Officer with the Department of Health and Human Services that will testify following me. [LB156]

SENATOR CAMPBELL: Thank you, Senator Watermeier. Senator Gloor. [LB156]

SENATOR GLOOR: Thank you, Chairman Campbell. Now that's what I'm talking about. We're getting rid of data that we don't need. (Laughter) [LB156]

SENATOR CAMPBELL: Exactly. [LB156]

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office

Health and Human Services Committee
January 24, 2013

SENATOR WATERMEIER: I'm here to tell you that I'm a data person, too, so I like it. [LB156]

SENATOR GLOOR: Thank you. That's all. [LB156]

SENATOR CAMPBELL: This is like short and sweet here. Just for the record...well, I'll ask the department. [LB156]

SENATOR WATERMEIER: Thank you. Do you mind, Madam Chairman, (laughter) if I sit at my spot or would you rather I stay? [LB156]

SENATOR CAMPBELL: No, at your spot is just fine. Thank you, Senator Watermeier. With the opening, we will proceed with testimony in favor of LB156. Good afternoon. [LB156]

MATT CLOUGH: Good afternoon. How are you today? [LB156]

SENATOR CAMPBELL: Very good. [LB156]

MATT CLOUGH: Good. [LB156]

SENATOR CAMPBELL: It's really nice to meet you. [LB156]

MATT CLOUGH: (Laugh) Well, it's a pleasure to be here. [LB156]

SENATOR CAMPBELL: I mean, I hear about you and we see your name; but we've not had you testify before us, so. For the record, we need to you state your name and spell it and then we'll start with your testimony. [LB156]

MATT CLOUGH: (Exhibit 15) Very good. My name is Matt Clough. I'm the Chief Operating Officer for the Department of Health and Human Services. The name is spelled M-a-t-t C-l-o-u-g-h. Good afternoon, Senator Campbell and members of the Health and Human Services Committee. As stated, my name is Matt Clough. I'm the Chief Operating Officer for DHHS, and I'm here to testify in support of LB156 which eliminates a report made to the Department of Health and Human Services by counties that use a community service program for employable recipients of county general assistance. Nebraska Revised Statute Chapter 68 requires counties to establish general assistance programs and eligibility standards for poor persons who are not eligible for other government assistance and who do not have others responsible for their support. LB227 was passed in 1991 giving counties the option of starting a community service program. The bill required counties with community services programs to file an annual report with DHHS. The department was also required to file an annual report to the Legislature summarizing the county reports. In 2005, LB301 ended the requirement that

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office

Health and Human Services Committee
January 24, 2013

the department submit a report to the Legislature. The county report requirement remained. LB156 removes the county reporting requirement. Scotts Bluff and Douglas counties are the only counties in Nebraska that continue to file reports. Since the reports are no longer used by DHHS, our recommendation is to end the county requirement. Thank you for the opportunity to be here today. I'd be happy to answer any questions. [LB156]

SENATOR CAMPBELL: Questions? Senator Cook. [LB156]

SENATOR COOK: Thank you, Madam Chair. Welcome. [LB156]

MATT CLOUGH: Thank you. [LB156]

SENATOR COOK: So from my understanding this next to last paragraph says that all the other 91 counties just quit sending it in anyway, so technically they're out of compliance with what the statute reads right now. [LB156]

MATT CLOUGH: That would be correct. Yeah. [LB156]

SENATOR COOK: Okay. Thank you. [LB156]

SENATOR CAMPBELL: Senator Gloor. [LB156]

SENATOR GLOOR: Thank you, Senator Campbell. Haven't we tried to do this before a couple of years ago? [LB156]

MATT CLOUGH: You know, I'm not familiar. I know that... [LB156]

SENATOR GLOOR: I think I might have carried a bill. And we...I mean, I'd have to go back and look at my records, but I don't think this is the first time it's come up. It just is such low-hanging fruit, let's put it that way, that it's hard to elbow it's way onto the agenda, so. [LB156]

MATT CLOUGH: Yeah. However, as Senator Watermeier stated, it does save the counties time and energy and effort. [LB156]

SENATOR GLOOR: Oh yeah, yeah. [LB156]

MATT CLOUGH: It's, you know, I think it makes sense. [LB156]

SENATOR GLOOR: Hard to argue with I believe. [LB156]

SENATOR CAMPBELL: Does the department even have knowledge of any other

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office

Health and Human Services Committee
January 24, 2013

counties who do a community service project anymore? [LB156]

MATT CLOUGH: You know, I can't answer that right off hand, although I would think that there would be other counties that do. [LB156]

SENATOR CAMPBELL: But they probably don't call it that or they may use an agency within the community. In other words, they may reference to another, you know, a nonprofit and do that. I just, I was trying to even recall from Lancaster whether we ever did such a project. [LB156]

MATT CLOUGH: Okay. [LB156]

SENATOR CAMPBELL: Memory fades. [LB156]

MATT CLOUGH: And I do have a report, the most recent report that was submitted by Douglas County that gives you some ideas to the information that's disclosed. You know, if you would like copies of that I'd be happy to give it to you. [LB156]

SENATOR CAMPBELL: Perhaps the Douglas County senators might like to take a look at it just to know what's been turned in. I think that would be helpful if you could make a copy for everybody or we could have the page take it... [LB156]

MATT CLOUGH: (Exhibit 16) We'd be happy to. [LB156]

SENATOR CAMPBELL: ...and make a copy. We probably should look at it. [LB156]

MATT CLOUGH: Okay. [LB156]

SENATOR CAMPBELL: Any other questions from the senators? Yes, Senator Howard. [LB156]

SENATOR HOWARD: Thank you, Madam Chair. Just from my background, how is this community service program paid for? Is it paid for by the county? [LB156]

MATT CLOUGH: Yes. [LB156]

SENATOR HOWARD: Okay. So it doesn't come from General Funds? [LB156]

MATT CLOUGH: No. [LB156]

SENATOR HOWARD: Great. Thank you. [LB156]

SENATOR CAMPBELL: It probably comes from their general fund. (Laughter) I think it's

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office

Health and Human Services Committee
January 24, 2013

great. I'm with Senator Gloor. Boy, if we don't use the report, don't need it, let's find more of these. And welcome for the testimony. It's good to meet you. After reading your name many times, we're glad you came. [LB156]

MATT CLOUGH: Thank you. [LB156]

SENATOR CAMPBELL: Our next proponent in support of the bill. Anyone? Anyone? All right. Those who might be opposed to LB156. Anyone wanting to provide testimony in a neutral position? Okay. Senator Watermeier. [LB156]

SENATOR WATERMEIER: I'll just waive. [LB156]

SENATOR CAMPBELL: Okay. Senator Watermeier waives closing. Thank you very much. A very efficient start from Senator Watermeier. Okay. If you are leaving, I'd just ask you to leave real quietly. We will next take up the hearing for LB23. Senator Hadley is here. I see him coming forward. The bill by Senator Hadley would change allocations of the ICF/MR Reimbursement Protection Fund. And, Senator Hadley, we certainly have had this issue before us in the past, so hopefully we'll be ready to go. So you go right ahead, spell your name for the record, and start whenever you like. [LB156]

SENATOR HADLEY: My name is Galen Hadley. I represent the 37th District, that's Galen, G-a-l-e-n, Hadley, H-a-d-l-e-y. And as the Chair stated, Yogi Berra, his famous statement it's deja vu all over again. I thought I would bring the other two folders that I have on this concept to show you that we have had this battle before; and you have seen it before this committee when I brought it three, four years ago. You had the same thing when you had the nursing home tax. So we're now back to ICF/MR, which is what I would like to talk about today. The ICF/MR Reimbursement Protection Act was originally placed in statute by the Legislature at the request of the ICF/MRs, that's Intermediate Care Facilities for the Mentally Retarded, themselves in 2004. It is a so-called provider tax on Nebraska's intermediate care facilities for persons with developmental disabilities that allow us to earn additional federal financial participation in the Medicaid reimbursement to these facilities. Over subsequent sessions the Legislature each time at the initiative of the providers has fine-tuned the statute to make it more effective and equitable. The purpose of LB23 is this year to do some additional fine-tuning. One of the bill's two major purposes is to identify state General Funds paid to ICF/MRs as revenue for the purpose of this statute. This simple change would allow Nebraska to draw down additional federal dollars each year to replace state General Funds in the reimbursement of ICF/MRs. Scott Hoffman of Mosaic will be following me and Scott can explain in whatever detail the committee wishes to pursue exactly how this and the ICF/MR provider tax works. Just as a quick note, basically the idea is we send a dollar to Washington, we get the dollar back plus we get about 65 cents back. That's basically what it is in a nutshell. And the reason we're having to define what revenue is, is that HHS had a different interpretation of revenue that precluded state

Health and Human Services Committee
January 24, 2013

General Funds in the definition, so we needed to bring this to put it in statute what I believe revenue should be defined as--to maximize the amount of reimbursement we can get from the federal government. In addition to the change in definition of the term revenue, LB23 will reorder the priority of expenditures of the resources of the provider tax by moving the appropriation of monies to providers of community-based services for persons with developmental disabilities from its present position of coming before reimbursement of ICF/MRs to coming right behind ICF/MRs. This change takes nothing away from the importance of community-based developmental disability programs which Mosaic also provides all across Nebraska. The original appropriation of community-based monies in this bill was to support taking clients off the waiting list for community services and at the time was essentially the first significant appropriation for this purpose. In the years since that time, the waiting list has come to be appropriated funds as part of the general budget process. Because of this and because of the ICF/MR Protection Act does have as its purpose the generation of additional federal financial participation in the reimbursement of ICF/MRs--and they do all pay the provider tax upon which the statute is based--we believe this reordering is both timely and appropriate. Finally, in an effort to make room for additional federal revenues that we can get that will be generated by participation in a provider tax of the six small ICF/MRs that Mosaic has brought on-line over the past year at the request of the state of Nebraska and which will pay or will pay this tax, the limit on payment to ICF/MRs is increased to the amount of \$1 million. Now I'm not an expert on fiscal notes, but this is the same concept that we ran into with the last one. You see, the fiscal note has a potential of \$400,000 because the concept is is that that money could go to the General Fund, and that's what was happening for years and years and years and years and years. And so that's why you see the fiscal note of a potential \$400,000. My point is, is the General Fund comes in after the ICF/MRs have been reimbursed their amount that they're providing for this provider tax. So I think that's an important concept that really it's a neutral concept at that point in time. The state is not losing any money that they're getting now in this process. And, finally, I think this is important. Those of us that have been around and those of you that are new, you certainly understand the problems that they had at BSDC. And we made sure in the last bill we put in that this provider tax concept did not come into play until BSDC was fully accredited again, because at that point in time they would get their Medicaid reimbursement back and we did not want to take money out of the state General Fund or worry about that when the state was not getting the money from Beatrice. So this bill just not too long ago kicked in because the state basically got BSDC fully recertified and is now getting the Medicaid reimbursement. I think it's a good bill. We want to encourage Mosaic, and if there are any other ICF/MRs, to do this because the state does not want to continue...does not want to get more involved than they are in this business at this point in time. I would be happy to answer any questions about this particular bill. [LB23]

SENATOR CAMPBELL: Questions from the senators? Senator Hadley, this is much like what we've put into place a couple of years ago with LB600 in which the nursing care

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office

Health and Human Services Committee
January 24, 2013

facilities provided a tax on themselves... [LB23]

SENATOR HADLEY: That's right. [LB23]

SENATOR CAMPBELL: ...in order to draw down more dollars. It's the same principle, isn't it? [LB23]

SENATOR HADLEY: Yes. Same principle. Chairwoman, it's exactly the same principle. [LB23]

SENATOR CAMPBELL: Yeah. And at this point, one of the things for the record that we note that when we've had this before is that the providers are coming forward taxing themselves in order to draw this money down. [LB23]

SENATOR HADLEY: That's exactly right. And if we do not ask for it and do this, we're leaving money on the table that can help individuals who need help. That's the bottom line. [LB23]

SENATOR CAMPBELL: I was just going to follow up, Senator Gloor. I just want to say that I, too, was somewhat confused by the fiscal note. I wasn't quite sure. [LB23]

SENATOR HADLEY: I think I might but maybe Scott might have more information, but that's my take on it that the way our fiscal notes, that since it could possibly go to the General Fund, it potentially could be a loss that I don't quite understand that reasoning, but... [LB23]

SENATOR CAMPBELL: We probably need to follow up on that. Senator Gloor. [LB23]

SENATOR GLOOR: Thank you, Senator Campbell. I think the hospitals did this and then the long-term care facilities did it. Now we're talking about the ICF/MRs. But why has this bill not progressed? I mean, prime my memory. Why when we have looked at this in the past didn't it advance? [LB23]

SENATOR HADLEY: We passed the bill, Senator Gloor, and we found out that the department had, according to their regulations, that the state General Funds would not count toward revenue. [LB23]

SENATOR GLOOR: Oh, I see. Now I understand. Yeah. [LB23]

SENATOR HADLEY: They had...their interpretation was state General Funds to a private entity would not account...would not be accounted for as revenue. And I believe they are revenue. And if the federal government wants to tell us they're not, that's the federal government's choice. But I don't believe we should be making that decision that

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office

Health and Human Services Committee
January 24, 2013

keeps...so that's the reason behind the bill and that was the primary reason, and then we increased to the million dollars because of the six new units that we're bringing on-line. [LB23]

SENATOR CAMPBELL: Senator Crawford. [LB23]

SENATOR CRAWFORD: So just to clarify how this bill then corrects that problem that you were just talking about. [LB23]

SENATOR HADLEY: Senator Crawford, what I have done is I have defined revenue... [LB23]

SENATOR CRAWFORD: Okay. All right. [LB23]

SENATOR HADLEY: ...to say it includes General Funds so there will not be a question by the department as to what the definition of revenue is. [LB23]

SENATOR CAMPBELL: Further questions? [LB23]

SENATOR COOK: I had a question. [LB23]

SENATOR CAMPBELL: Senator Cook. [LB23]

SENATOR COOK: Thank you, Madam Chair, and thank you, Senator Hadley. For my own education, beyond Mosaic, who were the other providers that might be impacted who are under this definition that might...? [LB23]

SENATOR HADLEY: I believe Mosaic is the only one. [LB23]

SENATOR COOK: Okay. Mosaic is the only one that the state of Nebraska... [LB23]

SENATOR HADLEY: I believe Mosaic is the only nongovernmental provider. [LB23]

SENATOR COOK: Okay. [LB23]

SENATOR HADLEY: I can be corrected by the next person, but that's my understanding. [LB23]

SENATOR COOK: All right. All right. Thank you. [LB23]

SENATOR CAMPBELL: And for the new senators to the committee, we've also followed this whole issue after BSDC with a special committee that had been appointed, and Senator Lathrop chairs that special committee. And we have had some joint hearings

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office

Health and Human Services Committee
January 24, 2013

with that special committee, the senators will recall, on this whole topic and we've had a lot of testimony from Mosaic, if you remember, in terms of how they are helping to provide housing for residents that come out of BSDC. Okay. So this is a continuation... [LB23]

SENATOR HADLEY: That's right. [LB23]

SENATOR CAMPBELL: ...of a lot of efforts. And Senator Hadley has always carried the bills having to do with this whole revenue mechanism. Am I saying that right, Senator Hadley? [LB23]

SENATOR HADLEY: That's correct. [LB23]

SENATOR CAMPBELL: Okay. [LB23]

SENATOR HADLEY: You may give me too much credit though. [LB23]

SENATOR CAMPBELL: I think not. [LB23]

SENATOR HADLEY: Thank you. [LB23]

SENATOR CAMPBELL: Will you be staying? [LB23]

SENATOR HADLEY: Yes, I will. [LB23]

SENATOR CAMPBELL: Okay. With that, we will take the first proponent for LB23. Good afternoon. [LB23]

SCOTT HOFFMAN: (Exhibit 17) Good afternoon. My name is Scott Hoffman, S-c-o-t-t H-o-f-f-m-a-n. Good afternoon, Senator Campbell and members of the Health and Human Services Committee. I'm the senior vice president of finance for Mosaic, and I want to briefly explain the ICF/MR provider tax. As Senator Hadley mentioned, the ICF/MR Reimbursement Protection Act was introduced at the request of Mosaic in the 2004 session for the purpose of instituting a provider tax on ICF/MRs. Presently, there are ten ICF/MRs in Nebraska including the Beatrice State Development Center. Mosaic operates two ICF/MRs, campus settings in Beatrice, Axtell, and seven small ICFs in Grand Island, York, Norfolk, Papillion, and Omaha. These nine facilities support approximately 260 individuals. As the only private provider of these services, we are testifying in favor of LB23. The provider tax is a means of maximizing the federal Medicaid reimbursement. At first glance it may seem to be like a fast shuffle, but is in fact entirely legitimate and used by many states as a means of capturing additional federal financial participation for their Medicaid programs. It works like this: The state levies a tax on all ICF/MRs, private and BSDC, currently at 6 percent of our net patient

Health and Human Services Committee
January 24, 2013

revenue. The facilities pay this tax into the fund. And that tax is a reimbursable expenditure in the Medicaid program which generates approximately 60 percent in federal Medicaid matching funds. And currently, those funds are allocated in the following order: First thing that goes out of the fund is \$55,000 to the department for the administration of the fund. And then the cost of the tax that the provider's paid into the fund gets reimbursed. So that if we pay a dollar in, we get the dollar back. And then \$312,000 goes to reduce the community-based waiting list. And \$600,000, or the lesser of the amount available in the fund, is used for the nonstate-operated ICF/MRs. And then the remaining balance is transferred to the state General Fund. It should be noted, since 2004 over \$7.9 million have been transferred to the state General Fund. Until recently back two or three years ago, we amended the bill and the \$600,000 started coming back to the nonstate operated. LB23 has three purposes, like Senator Hadley mentioned. The first one is to clarify the definition of revenue in statute so it clearly includes the state appropriations. And this was...mainly came into play when Beatrice State Development Center was not certified, and it was in regards to how the state was defining the revenue that Senator Hadley talked about. The second purpose for this bill is to reprioritize the allocation of funds by moving the nonstate-operated distribution ahead of the community-based waiting list. Mosaic supports addressing the community-based waiting list; however, we feel the distribution to ICF/MR services should occur first since the tax and the additional federal match is being generated by the ICF/MR services. It should be noted that there is not change to the amount being allocated; it still remains at the \$312,000. And the third purpose is to increase the maximum distribution amount from \$600,000 to \$1 million for the nonstate-operated ICF/MRs. The original distribution amount was set prior to Mosaic partnering with the state in 2010 to assist with the right sizing of Beatrice State Development Center by opening the six additional ICF/MRs. The additional six homes increased the tax paid into the ICF/MR Reimbursement Protection Fund as well as increased the federal match available for distribution. The distribution cap, so the \$600,000 or the \$1 million, is based on the federal match being generated by the nonstate-operated ICF/MRs. So in summary, Mosaic is advocating that the ICF/MR protection fund being generated by the nonstate-operated ICF/MRs be used to support those services instead of being allowed to go into the General Fund. For example, back in FY10, Mosaic was paying \$1.1 million into the fund and it was generating about \$690,000 back then. And with bringing on the six additional ICFs, we're paying \$1.7 million into the fund, and it's generating over...close to \$1 million. And so that's how we've established that base. So I'd be happy to answer any questions. [LB23]

SENATOR CAMPBELL: Mr. Hoffman, just before we start into questions, for the record, explain what ICF/MR stands for just so that everybody is clear and the record is clear and what they do. [LB23]

SCOTT HOFFMAN: It's an intermediate care facility for the mentally retarded, so it's to provide services for individuals with developmental disabilities. [LB23]

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office

Health and Human Services Committee
January 24, 2013

SENATOR CAMPBELL: Okay. Just so that everybody is clear. Questions? Senator Gloor. [LB23]

SENATOR GLOOR: Thank you, Senator Campbell. Mr. Hoffman, and you may not know this, but as we've talked about already, this same approach was used by hospitals, and then the long-term care industry specifically; now ICF/MRs. But it's my understanding and recollection that HHS or some branch of the feds put a stop to that as it relates to hospitals using that to recapture some additional money. For any reason...is there any reason that you know of that this may move on down the line and is it being looked at right now as far as ICF/MRs? [LB23]

SCOTT HOFFMAN: I think the federal government is, you know, with all the discussion on the deficit reduction or there's talk about looking at the IC...or provider taxes across the board. [LB23]

SENATOR GLOOR: Yeah. [LB23]

SCOTT HOFFMAN: But nothing has been set in stone. There's a lot of talk in regards to what percentage would be allowed. At one point, the percentage dropped down to 5.5 and then it went back up to the 6 percent and that's the maximum amount right now. So until the federal government changes the rules of the games, we might as well play by the rules and get the federal additional federal match. [LB23]

SENATOR GLOOR: But there are limitations. [LB23]

SCOTT HOFFMAN: Yeah. [LB23]

SENATOR GLOOR: I mean, it is specifically, to speak to your point and Senator Hadley's point about this is common practice, there's even regulations that govern how much of this can be. [LB23]

SCOTT HOFFMAN: Yeah. Yeah, it's currently capped at 6 percent. [LB23]

SENATOR GLOOR: Thank you. [LB23]

SENATOR CAMPBELL: In the legislation that we did on LB600 for the nursing care facilities, I think we had a phrase that should the federal government suspend this program that the...it would not be an expectation that the state would fill that in with state General Funds. Do you remember that, Senator Gloor? [LB23]

SENATOR GLOOR: Yeah, yeah. [LB23]

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office

Health and Human Services Committee
January 24, 2013

SENATOR CAMPBELL: And...go ahead, Mr. Hoffman. [LB23]

SCOTT HOFFMAN: There's currently in the bill that this has to be approved by the CMS, so there's some language in there. [LB23]

SENATOR CAMPBELL: Okay. It all seems very complicated, but it certainly has proved to be an effective program. While you are here, Mr. Hoffman, and I can ask you a question, how are you doing in terms of the census in the new Mosaic homes? [LB23]

SCOTT HOFFMAN: We're actually pretty full at capacity on the ICFs. We've got two openings throughout the six homes. So actually we've made great strides on the ICFs. [LB23]

SENATOR CAMPBELL: Senator Lathrop talked with me about doing another joint committee to do an update on how things are going because the last committee, you will remember the members that were on the committee at that point, we...Mosaic was having difficulty on the census and I think that all go worked out. [LB23]

SCOTT HOFFMAN: Right. Yes. [LB23]

SENATOR CAMPBELL: So I'm really glad to hear that. That's excellent. [LB23]

SCOTT HOFFMAN: So are we. [LB23]

SENATOR CAMPBELL: So have all of the residents who are coming into these ICF/MRs, have they come from BSDC? [LB23]

SCOTT HOFFMAN: Not all of them. Some of them transitioned out of some of our existing services... [LB23]

SENATOR CAMPBELL: Oh, okay. [LB23]

SCOTT HOFFMAN: ...that ended up needing more medical care, and then some of them transitioned out of other nursing homes across Nebraska. [LB23]

SENATOR CAMPBELL: Does Mosaic run the small home on the BSDC campus? [LB23]

SCOTT HOFFMAN: No, we do not. [LB23]

SENATOR CAMPBELL: Okay. So BSDC runs all of the facilities, including the small home that we toured I think a couple of years ago. [LB23]

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office

Health and Human Services Committee
January 24, 2013

SCOTT HOFFMAN: To my understanding, yeah. [LB23]

SENATOR CAMPBELL: Okay. Follow-up questions for any of the senators? Thank you, Mr. Hoffman, for coming today... [LB23]

SCOTT HOFFMAN: Thank you. [LB23]

SENATOR CAMPBELL: ...and answering those extreme sort of off-the-topic questions. Other proponents for the bill, for LB23. Okay. Those who wish to testify in opposition. Those who wish to testify in a neutral position. Senator Hadley, we're back to you. [LB23]

SENATOR HADLEY: I would like to close. I will keep it brief because I know your committee is very busy and hardworking. A couple of things. One is that this is not a windfall for Mosaic because by law they cannot be reimbursed more than their costs. We're reimbursing their costs. We're not talking about profit to Mosaic. We're not talking about them suddenly somehow getting a windfall. This is limited to a reimbursement of their costs. So basically what we're doing here is changing the definition of revenue. We're going to reorder the priority of how the funds are distributed. And you do see in there that \$55,000 goes to the department for administration. Thirdly, we're going to up the limit to the nongovernmental ICF/MRs to \$1 million for taking into account the seven new units that the state has asked them to undertake to try and take some of the pressures off of BSDC. I would hope that you will support this bill. I think it's an important bill. I will certainly push for its going to the floor and being adopted on the floor. [LB23]

SENATOR CAMPBELL: Senator Hadley, one last question. On the fiscal note, will there be any changes to it before we go to the floor? [LB23]

SENATOR HADLEY: I think so because I believe one of the comments on it is that DAS has not...they did not have sufficient time for the analysis and an analysis of the bill will continue. [LB23]

SENATOR CAMPBELL: Okay. [LB23]

SENATOR HADLEY: So I would assume we'll have another forthcoming fiscal note on it. [LB23]

SENATOR CAMPBELL: Okay. We'll keep a watch for it from Liz. [LB23]

SENATOR HADLEY: Okay. Thank you. [LB23]

SENATOR CAMPBELL: Thank you, Senator Hadley. And with that, we will close on

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office

Health and Human Services Committee
January 24, 2013

LB23, and that concludes our hearings for the day. I'm sure we will see a number of you again. [LB23]