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Health and Human Services Committee
February 10, 2010

[LB858 LB1022 LB1036 LB1067 CONFIRMATION]

The Committee on Health and Human Services met at 1:30 on Wednesday, February 10, 2010, in Room 1510 of the State Capitol, Lincoln, Nebraska, for the purpose of conducting a public hearing on LB858, LB1036, LB1022, LB1067, and gubernatorial appointments. Senators present: Tim Gay, Chairperson; Dave Pankonin, Vice Chairperson; Kathy Campbell; Mike Gloor; Gwen Howard; and Norman Wallman. Senators absent: Arnie Stuthman. []

SENATOR GAY: Thank you for joining us today, Health and Human Services Committee. I'm just going to do some housekeeping duties while we're waiting for some senators to arrive. If you could, we've got, let's see, four bills today to hear and a couple of appointments so we've got a very busy day. What we do here in this committee, just to be fair to everyone at the beginning of the day and at the end of the day, the days can get long, we have a timing system here. So we try to watch the five-minute time rule and what happens is at about four minutes a yellow light will come on, at about five minutes a red light will come on. We don't, you know, we try to work with people, but if you could start wrapping it up by then, appreciate it. The introducer of a bill can get as long as they need to describe the bill and then any questions that a committee member will ask you, we'll ask you to stay there and if there's any questions for you, that doesn't count towards that five minutes, so sometimes...but when you add that all together, it can start taking some time. So that's what we do here. We do have testifier sheets. If you're going to be testifying as a proponent, opponent, or even neutral if you could fill out a sheet. There on the front desk there are some, but they're at the sides of the committee hearing room too. If you can fill those out prior to coming up, it's helpful because you're filling that out on your time, I guess, if you want to fill it out up here at the table. So if you're going to be testifying and you know it on a bill, fill that out and we certainly appreciate it. Other than that, if you have a cell phone if you could silence that we appreciate it out of respect for everyone here. And when you come up to testify, if you could state your name and spell it out it's very helpful because the clerk needs to transcribe these. This is all being tape recorded and also it's on video on the Web and also broadcast throughout the Capitol. So...but a lot of times when they're transcribing these things, and it could be in the summer or by the time they get around to some of these things, it's very helpful if we state who's speaking and spell it out because memories lapse as we move on. If there is a question, I will ask the senator to ask the question and then you respond. But if there are no questions, you know, we can track you down that way, too, if questions come up later. So we'll get started. I'm Senator Tim Gay from District 14 from Papillion-La Vista.

MICHELLE CHAFFEE: I'm Michelle Chaffee, legal counsel to the committee. []

SENATOR GLOOR: I'm Senator Mike Gloor, District 35, Grand Island. []

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SENATOR PANKONIN: I'm Dave Pankonin, District 2. I live in Louisville. []

SENATOR WALLMAN: Senator Norm Wallman, District 30, south of Lincoln. []

ERIN MACK: Erin Mack, the committee clerk. []

SENATOR GAY: And joining us, Senator Gwen Howard. Also on the committee, Senator Kathy Campbell and Senator Arnie Stuthman. Senator Stuthman had a commitment that he will not be joining us today. Senator Campbell and others may have to go during the committee hearing. They may be testifying on a bill in another committee because we're still at the stage where we're introducing bills in other committees. So if people are getting up and down, no disrespect but they're out doing other bills at that time. The pages are here to help. They do a good job. If you need something handed out, hold it up and they will hand it out. If you are going to hand out something, usually about ten copies is what we need--one for every senator and a couple to keep in our office. So with that, we will get started. Right now I see we have two appointments: Nancy Oltman, if, Nancy, you want to step forward. []

NANCY OLTMAN: Yes, I'm right here. [CONFIRMATION]

SENATOR GAY: Thank you. And, Nancy, applied for the Commission for the Blind and Visually Impaired, huh? [CONFIRMATION]

NANCY OLTMAN: Yes. My name is Nancy Oltman, O-l-t-m-a-n, and the Governor reappointed me to another term on the Nebraska Commission for the Blind and Visually Impaired. And I really appreciate the opportunity to do this. Making lives better for blind people is one of my real passions, and I enjoy being on the board to make sure that our commission, which is a very fine commission, one of the notable ones in Nebraska, continues to be so or, if possible, be even better. So I want to thank you for this opportunity, and I think that's all I have to say. [CONFIRMATION]

SENATOR GAY: All right. Well, thank you very much for that and thank you for serving. Let's see if there's any questions for you from any committee members. Senator Gloor has a question. [CONFIRMATION]

SENATOR GLOOR: Ms. Oltman, this is Senator Gloor from Grand Island. I know that you worked at Mary Lanning for a while, which is a plus. It's a great institution. But more importantly, you went to Hastings College, which is my alma mater, so you're kind of a shoe in. (Laughter) [CONFIRMATION]

NANCY OLTMAN: (Laugh) So I have a real in with the... [CONFIRMATION]

SENATOR GLOOR: You have a real in. [CONFIRMATION]

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NANCY OLTMAN: Wonderful. [CONFIRMATION]

SENATOR GLOOR: Thank you for your service and thank you for your willingness to serve again. [CONFIRMATION]

NANCY OLTMAN: Okay, thank you very much. [CONFIRMATION]

SENATOR GAY: Thank you very much. Is there any other questions? I don't see any. Thank you very much. And, Nancy, while you're...and Darrell is coming up next, Darrell Walla, but just so you know, we look at these appointments and then we'll have an executive committee and vote on them and then we advance them out to the floor. Usually there's no problem and they'll contact you, and we try to get on that fairly quick. But just so you know the process. [CONFIRMATION]

NANCY OLTMAN: Okay. [CONFIRMATION]

SENATOR GAY: Thank you very much for your service too. [CONFIRMATION]

NANCY OLTMAN: Thank you. [CONFIRMATION]

SENATOR GAY: Welcome, Darrell. How are you? [CONFIRMATION]

DARRELL WALLA: Thank you. Thank you. My name is Darrell, D-a-r-r-e-l-l, Walla, W-a-l-l-a. I thought I'd spell the Darrell because there's different ways to spell it so. I'm starting my second term with the Nebraska Board of Commissioners for the Commission for the Blind. I was reappointed in December. Working for the commission...as a board member for the commission, it's been a real honor. As Nancy stated, our services for the blind is probably, you know, is really second to none across the country. Our state is a model for the services for the blind. The different programs that we have in Nebraska educationally for the blind and just in general in education and rehab are really good programs. I teach in the public schools. I'm at Omaha Public Schools Burke High School. This is my 30th year of teaching different--at Aurora, Raymond Central, Wahoo Neumann Catholic High School for a while, and now at Omaha Burke. And the commission has helped me in the process and I'm honored to serve and help the board and the commission in any way I can. Thank you. [CONFIRMATION]

SENATOR GAY: Thank you, Darrell. Senator Pankonin has a question. [CONFIRMATION]

SENATOR PANKONIN: Thank you, Senator Gay. Darrell, I note on, as you've noted in your testimony that you've had a long career as a public school teacher and so I think

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this committee wants to thank you for two things: one of them for your service on this board but also for that long career of working with youth in Nebraska. And so it's been a life of public service it looks like to me that is appreciated by this group.

[CONFIRMATION]

DARRELL WALLA: Thank you so much. [CONFIRMATION]

SENATOR GAY: Darrell, I've got a question for you. Is there anything, and we do appreciate the service, is there anything that ever committee members can help out with on issues that come up that you...it would do any service to call any of us? Because I haven't received a ton of calls from committee members. It sounds like the committee is run pretty smoothly. Every now and then there's an exception, but is there anything we can do as senators to help you out or just pay attention to what's going on?

[CONFIRMATION]

DARRELL WALLA: I think just paying attention to, you know, what's going on. The senior blind, it's always an issue that we want to make sure we can maintain adequate funding for because we have so many, you know, different senior blind individuals. We've been also...youngsters, with the making sure that they can have adequate books in Braille and are taught the Braille skills they need. That's always a concern for all of us in the blind community, and that benefits the whole world when students can get the education that they need. I think those are, you know, those two issues, the Braille and the continued aid for the senior blind programs. [CONFIRMATION]

SENATOR GAY: Thank you. Well, if there's anything ever comes up, a lot of times...I think I could speak for most members of the committee, but as senators, you know, we get very busy and a lot of different issues, but feel free, you or Nancy, anytime, though, to make sure you let us know. Because if you don't, you know, things happen. So feel free to contact any one of us if you have some issues. [CONFIRMATION]

DARRELL WALLA: Thank you. [CONFIRMATION]

SENATOR GAY: All right. Thank you. Is there any more questions? All right. Seeing none, all right, thank you, Darrell. [CONFIRMATION]

DARRELL WALLA: Thank you much. [CONFIRMATION]

SENATOR GAY: All right. We've got Senator Sullivan is here to introduce LB858, change provisions relating to service animals and mobility-impaired or otherwise disabled persons. Welcome, Senator Sullivan. [LB858]

SENATOR SULLIVAN: (Exhibits 1, 2) Thank you, Chairman Gay. Good afternoon, colleagues, members of the Health and Human Services Committee. I'm Senator Kate

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Sullivan, K-a-t-e S-u-l-l-i-v-a-n, representing the 41st Legislative District. LB858 adds provisions concerning service animals to the statutes so that our laws work in today's world, substantially comply with the Americans with Disabilities Act, and make it easier for people with disabilities to use their service animals to assist them in their daily lives. LB858 does the following: (1) expands the policy statement on the rights of the disabled in Section 60-126 to include mobility-impaired or otherwise disabled persons; (2) amends Section 20-126(1) to expand the definition of physically disabled person to include mobility impairment; (3) amend Section 20-127(1)(2)(3) to add mobility-impaired or otherwise disabled; (4) adds new language allowing a mobility-impaired or otherwise disabled person to be accompanied by a service animal in general public places as listed in subsections (1) and (2); (5) adds new language allowing a trainer to be accompanied by a service animal in training in general public places as listed in subsections (1) and (2); (6) adds new language to allow a trainer that's part of a three-unit service animal team to conduct continuing training of the service animal in general public places as listed in subsections (1) and (2); (7) adds a new subsection (5) which defines that three-unit service animal team as a team consisting of a service animal or a service animal in training, a disabled person, and a person who is an adult and has been trained to handle the service animal; (8) amends Section 20-129(1)(2) to clarify that anyone who interferes with the rights of a disabled person to enjoy general public places is guilty of a Class III misdemeanor, and anyone who interferes with the rights of a trainer of a service animal is also guilty of a Class III misdemeanor; and (9) amends Section 20-131.02(1)(2) and Section 20-131.04 to clarify that in addition to partially or totally blind persons, hearing impaired persons, and physically disabled persons that mobility-impaired or otherwise disabled persons are entitled to have a service animal and full and equal access to all housing accommodations without being required to pay extra compensation for the service animal; (10) amend Section 28-1009.01(1)(2)(3) to include a mobility-impaired person or an otherwise disabled person--these subsections prohibit violence, injury, harassment, or threat to any service animal; (11) adds a new subsection (4)(d) to provide a definition of mobility-impaired person. Violence on or interference with a service animal remains a Class III misdemeanor. The information is directly from an ADA business brief on service animals. Service animals are animals that are individually trained to perform tasks for people with disabilities. These tasks include but are not limited to guiding people who are blind, alerting people who are deaf, pulling wheelchairs, alerting or protecting a person who is having a seizure, or performing other special tasks. Service animals are working animals. They are not pets. Under the ADA, businesses and organizations that serve the public must allow people with disabilities to bring their service animals into all areas of the facility where customers or citizens are normally allowed to go. The ADA applies to all businesses open to the public, including restaurants; hotels; taxis; shuttles; grocery, department stores and convenience stores; hospitals; medical offices; theaters; health clubs; parks; zoos; on and on. In addition, service animals must be allowed in any areas of local, state, or federal buildings where citizens are allowed, as you can see today. Businesses may ask if an animal is a service animal or ask what tasks the animal

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has been trained to perform but cannot require special identification for the animal or ask about the person's disability. People with disabilities who use service animals cannot be charged extra fees, isolated from other patrons, or treated less favorably than other patrons. However, if a business such as a hotel normally charges guests for a damage that they cause, a customer with a disability may be charged for damage caused by his or her service animal. A person cannot be asked to remove his or her service animal from the premises unless the animal is out of control and the animal's owner does not take effective action to control it, for example, if the dog barks in a movie theater or if the animal poses a direct threat to the health and safety of others. In these cases, the business should give the person with the disability the option to obtain goods and services without having the service animal on the premises. Businesses that sell and prepare food must allow service animals in public areas even if state or local health codes prohibit animals on the premises. A business is not required to provide care or food for a service animal or provide a special location for it to relieve itself. Allergies and fear of animals are generally not valid reasons for denying access or refusing service to people with service animals. Violators of the ADA can be required actually to pay money, damages, and penalties. I introduce LB858 at the request of a constituent. Unfortunately, Jill, my constituent, could not be here in person today due to a preplanned trip out of the state. But I believe that each of you received an individual e-mail from Jill explaining why she asked me to introduce the bill. And I have--the page could pass this out--Jill's four-year-old daughter Hailey has autism combined with other behavioral and developmental disabilities. Their family is working through the challenges of having a child diagnosed with autism. When they learned that a specially trained autism service dog could help them manage Hailey's condition and help Hailey manage herself, the family thought it was a great idea. They searched the idea and found an organization called 4 Paws for Ability in Ohio. And I also have some copies that explains what this organization is. 4 Paws was the first agency to begin placing skilled autism service dogs with families and continues to be the largest organization in the United States working with autism service dogs and other service dogs. The family filled out an application for a dog and sent it along with the prescription for the dog from Hailey's doctor. 4 Paws worked with Jill and her family to raise the \$13,000 it cost to obtain the dog. Following completion of their fund raising, Jill, her husband, and Hailey went to Ohio a little over a year ago to meet their service dog, Anise, and train on-site with 4 Paws. Jill, Hailey, and Anise had to train together to become that three-unit service animal team. Anise is also trained to search for and rescue Hailey if she wanders off, which is a great relief for Hailey's parents. Although it took some time, Hailey and Anise have bonded and their working relationship is a genuine delight and a huge help to Jill. Now she can go off to the grocery store without Hailey having a tantrum or running off. But the problem arises when Jill needs to work with Anise, the service dog, to reinforce her training without Hailey along with her. Whenever Hailey is with them, Anise is working. However, Anise's training must be reinforced. Several businesses in Jill's area will allow Anise in their doors when she's accompanied by Hailey and Jill, but they won't allow Jill to bring Anise in alone for training. And this is

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precisely why I introduced LB858. Although the ADA says that businesses must allow trainers and their dogs in their businesses, the owners don't think it applies to just Jill and Anise without Hailey. Since I introduced the bill, I've heard similar stories from other trainers and disabled persons with service animals. And I think you'll hear from some of them today. LB858 puts the definition of a three-unit service animal team in Nebraska statutes and gives that three-unit team the same legal standing as any other service animal or service animal in training. In addition, we broaden the statutes to include the terms "mobility-impaired or otherwise disabled" because there are disabilities that are not visible to the average observer. My goal is to ensure that my constituent and every disabled person in Nebraska is free to utilize service animals for assistance and to go wherever they need to go with those service animals without being stopped, harassed, mistreated, or interfered with by people who are ignorant of the civil rights of the disabled. I'm aware that at least one business organization has an objection that includes dogs not being under control. Now I believe the ADA provides them with a method to deal with that situation. In addition, on page 3 of the bill, lines 10-17 contain new language requiring "a harness, backpack or vest identifying the animal as a service animal" or a service animal in training. However, this requirement is not in line with the ADA and should be actually stricken from the bill. I believe in LB858 and plan to make it my priority bill this session. I thank you for your time and your interest. I'll try to answer any questions right now or in my closing. [LB858]

SENATOR GAY: Thank you, Senator Sullivan. You did a fine job explaining that. Any questions from committee members? I don't see any right now. Thank you. [LB858]

SENATOR SULLIVAN: Okay. Thank you very much. [LB858]

SENATOR GAY: How many people will be testifying in favor of this? Okay. How many opposed? I see no one opposed. How many neutral? Okay. If you want to step up, proponents, we'll hear from...don't be shy. [LB858]

STEPHANIE AUSCHWITZ: Shy is not exactly a definition used to describe me very often, maybe a little nervous. Stephanie Auschwitz, A-u-s-c-h-w-i-t-z, and I'm representing myself and hopefully helping represent Tonja, Tryston, and Michelle as well. There were three things that I wanted to discuss when I talk to you guys about this bill. Number one is the training of a service dog without the person who it will be servicing there. I believe that this is a very important step for the dog. They need to understand exactly what their job is and they also need to be reminded what their job is, as do the rest of us from time to time. So it is important to be able to work these dogs in public places. Very rarely do we run into issues with that, but usually when I was working with Tryston and Tank and Michelle, Tryston was there in some shape or form. However, there are times where I would take him on an escalator or an elevator and I have people look at me interestingly and try and determine what was wrong with me. And there isn't anything wrong with me. I'm honestly just trying to help Tryston and Tank

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and Michelle live the life that Tryston deserves, to have that independence, which is very, very important to him. Another thing that I wanted to cover is what can go wrong in a situation like that where I am training with the dog and we are approached and oftentimes very caustically approached by people--what are you doing here? Why is this dog here? There was an incident that involved Tank and I was not there. He was working with Michelle and the incident grew to a level where Tank was visibly shaken by it, tail tucked, shaking, head down. The most important thing for a service dog is that confidence, and that is something that we could have very easily lost in five to seven minutes of a caustic conversation with someone in a supermarket. So it's important that we protect Tank as he's being trained as well as while he's doing his work. Because if he loses his confidence and has a fear of going inside a public place or causing a disturbance, then he's not the dog that we need him to be. He won't be able to be there for Tryston when Tryston needs him. The last thing that I want to cover, and I think that mostly Tryston and Tonja are going to be able to speak to this better than I will, and it's what this mobility bill means to these people. It offers them independence and freedom to go about daily living, things that you and I take for granted. It allows them the comfort and safety of knowing that they have someone there to help them if they falter, if they lose their footing, to help them stand up or brace themselves if they need that. And what this gives them really, you guys, literally is someone to lean on when times are tough or when they need that support. And that's what this mobility dog is going to offer people like Tonja and Tryston. Thank you. [LB858]

SENATOR GAY: Thank you. Any questions? I don't see any. Thank you, Stephanie.
[LB858]

STEPHANIE AUSCHWITZ: Thank you. [LB858]

SENATOR GAY: Other proponents. Come on up. [LB858]

TONJA PETERSON-WENDT: My name is Tonja Peterson-Wendt, T-o-n-j-a P-e-t-e-r-s-o-n-W-e-n-d-t. First I'd like to start by thanking all of the senators and everyone else here for the time to share my thoughts and most importantly Senator Sullivan for introducing the proposed adjustments to the law. My name is Tonja Peterson-Wendt and this is my service dog Luka. He was gifted to me unexpectedly and has become a very stabilizing factor in my life. For over 20 years I've lived within the boundaries of the disabling, unspoken mental trauma of posttraumatic stress disorder. I have learned to manage my life avoiding things that would set off my attacks. In 2004 the car I was driving was involved in an accident. At that instant, my physical limitations changed forever. It's hard for people to comprehend that I have a need for a service dog or for a handicapped parking permit. I'm not the picture of a typical person that people visualize when they think of someone that's disabled. I have poor balance. I have problems getting up and down. I have problems negotiating stairs. I occasionally feel like my legs are going to fall right out from underneath of me. I get very severe

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migraines and I'm easily exhausted as well as many other things. I live most of my life in bed or in therapy, and before having Luka the only times I could leave the house would be when my husband Jason would take me out. My service dog Luka helps me get off the floor, gives me stability on the stairs, tells me when I need to take my migraine medication, braces me when I pick something up off of the floor or get something from a low shelf. He carries my groceries in his pack when we walk home from the store. He helps me up and down curbs. He pulls me along and steadies me while walking, and he helps me out of short chairs. While I've never been a shy person, I have been a very private person. I now write a blog. My blog is pinkdoberman.blogspot.com. I share my blog with people who want to understand what has happened to me as well as why I utilize a service dog. I no longer enjoy shopping. I like to shop, but I don't like to go shopping anymore. It has nothing to do with my disabilities and has everything to do with how I'm treated. I don't mind polite questions. I don't even mind doing public education. For me, having the service dog is the only way I'm able to go out safely on my own while at the same time he's a huge inconvenience. It's to some degree like living your life with a six-year-old at your side. I'm constantly bombarded by people, some well-meaning and others not so much, and these are some of the things I find myself saying: Oh, don't touch him. Ma'am, ma'am, please watch your baby. Don't let him climb on my service dog. Yes, lady, your daughter is correct--he is a service dog and you're not supposed to pet him. He's working. Hey, hey, please don't feed my dog. For me the worst part of having a disability is when you're confronted by ignorant and mean people. At a store in Omaha I had an encounter I will never forget. This was one of my first times out since the accident without my husband and I was so excited. A lady working at the store came up and interrupted my shopping and told me Luka and I had to leave. She rudely insisted that we leave the store and shared that if I left him outside I would be welcome to shop again in the store. I told her he was a service dog, that he's protected under the Americans with Disabilities Act. She didn't even bother to look at his vest. She then started to well, well, and was still very rude for quite some time. Finally she said we could stay and shop, but the damage to me was done. I had heard of others with service dogs having problems, and I felt so helpless and alone when it happened to me. Every time I walk into a new store or even one that I frequent, I'm filled with fear. I hate going places now. I carry the law with me in my purse. One day later I stopped to eat at a favorite restaurant. I came to the restaurant and was completely ignored. They noticed I had a dog and wouldn't look at me, wouldn't talk to me, and wouldn't acknowledge my presence. While I was volunteering one afternoon, a couple with a little dog kept walking by Luka and I. Their dog was barking viciously at Luka. The couple thought it was funny. They and their dog had tormented us the year before as well. People are just so thoughtless. On the other hand, many places have been just great. It still doesn't stop the anxiety that I feel. I would like to be able to call their local police department for support if I felt we were being threatened. I know I can file a complaint with the American Disabilities Act, but that does nothing for immediate needs and well-being. While I do not utilize Luka for my posttraumatic stress disorder, the next service dog that I get will have that training as well. My panic attacks have become

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more apparent again with the situations I have encountered while I'm out and about with Luka. What I once had under a good degree of control is now controlling many aspects of my life again. Basic independence is something that most people take for granted. People utilizing service dogs in order to lead a more productive and independent life should not be able to be taken advantage of, treated rudely, or dismissed. As a member of the Nebraska community, I work hard to be as productive as possible and independent. I did not create the hand I was dealt, but I'm doing the best I can to live the most productive life possible. I appreciate the proposal to make Nebraska safer and easier to negotiate and less of a burden for myself and others like me. Thank you.
[LB858]

SENATOR GAY: Thank you. Are there any questions from any members? I don't see any. Thank you for coming, though, and bringing... [LB858]

TONJA PETERSON-WENDT: Luka. [LB858]

SENATOR GAY: I don't see any questions. Thank you. [LB858]

TONJA PETERSON-WENDT: Thanks. [LB858]

MICHELLE DEGARMO SHAPLAND: Michelle DeGarmo Shapland, D-e-G-a-r-m-o S-h-a-p-l-a-n-d. My name is Michelle DeGarmo Shapland. I am the mother of Tryston DeGarmo who is 12 years old. Tryston has suffered from various illnesses that have led him to have a stroke at the age of four and a massive brain bleed at the age of five. Tryston suffers as a side effect from degenerative cerebellar ataxia. Tryston's future is unsure and his conditions...and he suffers from with the ataxia and the TBI issues along with the risk of having another brain bleed at any moment are uncertain. We are not here today to ask for your sympathy, but to speak to you on Tank's, Tryston's mobility dog, behalf. Tank has been raised and trained with Tryston for the last two years. Tank serves many things to Tryston to include being his best friend, companion, and mobility aid dog. Tank has not only learned how to serve these needs, but has taught himself how to be sensitive to the whole family's needs. Tank is the first to tell us when Tryston or his brother is sick and will not leave their sides. Tank being with Tryston has given him the strength to do many things that doctors have said that he would never be able to do. One of the many things Tryston has learned late in life was how to ride a bike. This is because Tank gives him the comfort to know that if he falls Tank will come and get help for him. I would like to share with you a devastating experience that we have faced here in our hometown of Lincoln, Nebraska. At a local grocery store that we have worked with Tank in before, Tank and myself were in the grocery store without Tryston reestablishing some training. While walking him in the grocery store and in the hardware department, we were approached by a store employee. He started yelling at us about not being able to have a service animal in the store. Tank was dressed in his harness and special leash as you see today. When we proceeded to tell her that he was a

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service animal and that he was still doing some continuing training, she went off on us using curse words and loud voice and telling us that he is not a service animal and that she wanted to contact the manager as this was, yet again still cursing at us. I followed her to the counter and asked her to call the manager. When the manager was not in, she continued to curse at us and tell us that if they lost their food license it was our fault. Through all this yelling at us, this was very demoralizing to myself and to Tank. Tank was severely demoralized and traumatized as she is yelling at us with him. He knew this was about him, his head hung, his tail between his legs, shaking. Tank has been trained to not only serve...be a service animal and mobility aid, but has benefited by being raised in the family that serves him...he serves. Since this situation, we no longer have the proud dog who holds his head high with confidence of what his job and mission is for my son. Tank has been traumatized by this situation and we are having to set aside two years of training to rework his confidence and what his job and mission is for my son. Tank consistently now looks over his shoulder for when the next person is going to come and demoralize his family because of him. He has lost his security and confidence, and we don't know if we can reestablish this. This has been devastating to our family. Not only has Tank been traumatized, but it has affected us as a whole. We now worry about upcoming situations of having a service animal. Thankfully Tryston, my son, was not with us that night that we ran into this situation, as I know how this would impact my 12-year-old son who has gone through so much and just wants to be a normal child and live a daily life. Tryston today does not need to have Tank by his side. The doctors don't know what my son's future is. We know that the progress of the degenerative cerebellar ataxia, but that he is progressively getting worse and that in the future Tank will be an everyday need for my son to have a fulfilled life. Thank you.

[LB858]

SENATOR GAY: Thank you. Any questions? I don't see any. Thank you. Any other proponents who would like to speak? [LB858]

MICHELLE DEGARMO SHAPLAND: My son would like to speak. [LB858]

SENATOR GAY: Okay. [LB858]

TRYSTON DEGARMO: My name is Tryston DeGarmo, D-e-G-a-r-m-o. I am 12 years old. I have had many surgeries and procedures in my life. Tank is my best friend and has been raised with and by me. I have helped train him along with my mom and Stephanie for what I need. I can rely on Tank to understand me and all my quirks. Tank gives me unconditional love and comfort and it's comforting for me to have my best friend. I love Tank and he loves me. I know as he does that I need him and his abilities to assist me with my mobility needs. I would like all of you to see the bond a service animal has with its owner and that he is not a pet but an aide to me. Thank you. [LB858]

SENATOR GAY: Thank you, Tryston. How long have you been working with Tank?

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[LB858]

TRYSTON DEGARMO: About two years. [LB858]

SENATOR GAY: Oh. Let's see if there's any questions. I don't see any. You did a good job there. Thank you. Any other proponents? Any opponents who would like to speak on this issue? [LB858]

RICHARD SKERBITZ: (Exhibit 3) I have copies of my testimony and some other material. My name is Richard Skerbitz, R-i-c-h-a-r-d S-k-e-r-b-i-t-z, systems change coordinator for the League of Human Dignity. I'm testifying this afternoon in opposition to LB858 as written. As an organization providing services for people with cross-disabilities over the last 39 years, the League of Human Dignity values the protection of rights of persons with disabilities and the trainer...including those using service animals to maximize their independence and the trainers training them. As I was researching the intent of this bill, I learned it was twofold: to protect the rights of people with disabilities using service animals and to eliminate abuse of those who call their pets a service animal. We are concerned this bill, due to vague definitions, stricter requirements than the federal regulations would mark people with disabilities for greater scrutiny of their disability and need for service animals rather than protecting their rights. In addition, due to the fact that the Americans with Disabilities Act would provide greater protection for a person using a service animal than this bill would, we foresee this bill opening merchants up to lawsuits that could have been prevented had they received training on the ADA guidelines for service animals or had the state law provided equal or greater protection. In order to qualify for a service animal under the ADA, a person must have a disability according to one of its three-prong definition. Senator Sullivan talked about the definition of a service animal so I'm going to skip through that part of my testimony. If the animal...if a person has a disability and the animal is covered under the definitions, they are protected under the ADA. The ADA does allow for merchants, as we heard earlier, if in doubt to ask if the animal is required because of a disability and what skills the animal is trained to perform. LB858 defines a service animal as "an animal in a harness, backpack, or vest identifying the animal as a service animal." Service animals under federal law are not required to be trained by service animal training organizations or wear harnesses, backpacks, or vests. Not all organizations provide these harnesses, backpacks, or vests. So where would these identifiers come from? And what would stop the individuals who are claiming their pet as a service animal from making their own vests, harnesses, and backpacks? We believe the definitions in this bill not only contradict the ADA but it will provide less protection for individuals with disabilities using service animals. We are concerned it would give the merchants a false sense of security. If, for instance, an individual and their service animal, without identification required by this bill, came into a store and was immediately asked to leave due to the lack of identification under state law, that merchant still could be sued under federal law. And finally, what about the individuals from out of state or

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those that have come in to be students here who are covered under the ADA? They, too, will have a right to sue under federal law. This, however, does not make up for the scrutiny and loss of dignity the individual was put through during the enforcement of a state law inconsistent with the federal law. Just a couple of weeks ago, a resolution was signed which partially states that the Legislature reaffirms its support of and commitment to the Americans with Disabilities Act. We believe the requirement for a service animal to wear harnesses, backpacks, or vests is not only inconsistent with federal law but it's discriminatory. We are asking for LB858 to be amended so the rights for people with disabilities using service animals are equal to or greater than those provided by the Americans with Disabilities Act. Thank you for your time and consideration. [LB858]

SENATOR GAY: Thank you, Richard. Are there any questions from committee members? I've got a question for you real quick. Did you, when you reviewed the bill, did you have ideas on amendments other than just making sure it's in compliance? If it was in compliance with the federal regulations, that would...that's the amendment you think we need to... [LB858]

RICHARD SKERBITZ: Right. We're concerned about the...I don't have a copy of the bill in front of me, but we're concerned about the definitions of the service animal that was input from the original statute. I think it's on page 3, line 8 or page 2, line 8. That's what we're concerned about. [LB858]

SENATOR GAY: But the general concept you agree with. [LB858]

RICHARD SKERBITZ: Right. We believe that the rights of people with disabilities and the trainers should be protected. [LB858]

SENATOR GAY: Okay. Thank you. Any questions from committee members? I don't see any. Thank you for bringing that to our attention. [LB858]

RICHARD SKERBITZ: Thank you. [LB858]

SENATOR GAY: Are there any other opponents? Is there anyone who would like to speak neutral on this issue? Senator Sullivan, do you want to close? [LB858]

SENATOR SULLIVAN: Thank you very much. I'll be brief. But I hope that this hearing has helped us all understand a little bit more about the importance, important role service dogs play in helping people with disabilities lead independent lives. I believe that LB858 more carefully defines the role of service dogs, the relationship to the person that they're helping, and most importantly also to the trainer. I'm sorry that the League of Human Dignity has chosen to oppose this, but I hope that through some amendments, as I indicated in my testimony, that I prefer that that definition of identification of a

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service dog be stricken from the bill. So...and at the end of the day, you know, I guess we've seen how important these animals play in the independence for individuals. It would be nice if we didn't have to have some of these bills, but the reality is, as you can see today, it's important that we do. So thank you for your consideration. [LB858]

SENATOR GAY: Thank you, Senator Sullivan. Are there any questions? I don't see any. Thank you very much. [LB858]

SENATOR SULLIVAN: All right. Thanks a lot. [LB858]

SENATOR GAY: All right. We'll close the public testimony on LB858 and Senator Council is here to introduce LB1036. Senator Council, we have a list here of some speakers that wanted to speak on your bill. It's my understanding that you'll do a brief introduction and turn it over to Mr. Ruth... [LB1036]

SENATOR COUNCIL: Yes. [LB1036]

SENATOR GAY: ...to describe the intricacies of the...yeah. And then what I have on here is Milton and Janet Bemis, Connie Ring, Kyle Herber, and Thomas Quinn; and those people in that order is what we'd like to do. One of those...you know, we have four different bills today. We do have a time limit. So you get as long as Mr. Ruth will take to describe it. But then...and I know one might take a little bit longer, but we're kind of watching that because we've got four or five bills to get through today and a couple of confirmations so turn it over to you. Thank you, Senator Council. [LB1036]

SENATOR COUNCIL: Thank you, Chairman Gay. I certainly appreciate the time of the committee. I am Brenda Council, C-o-u-n-c-i-l. I'm the senator representing the 11th Legislative District out of Omaha, Nebraska, and I appear before you this afternoon to introduce LB1036. LB1036 revises Nebraska's Uniform Anatomical Gift Act by adopting with some revisions the 2006 version of the Uniform Anatomical Gift Act. By way of background, in 1971 Nebraska adopted its Uniform Anatomical Gift Act that was based on the act that was promulgated in 1968. The Nebraska Uniform Anatomical Gift Act has not been substantially revised since that time, I believe, with the exception of a 1987 revision of the National Uniform Act and that was enacted in every state. LB1036 is necessitated by the fact that the law on anatomical gifts is no longer uniform or harmonious because of changing federal law, new technologies, and current practice with regard to organ tissue and eye donation. LB1036 harmonizes the Nebraska Uniform Anatomical Gift Act with federal law, current technology and practice, and advanced medical directives, and will facilitate and encourage donations. As the Chairman indicated, there are a number of individuals here to testify, including Nebraska's representatives on the Uniform Law Commission, one of the members of the Uniform Law Commission who can go into much greater detail with regard to the specifics of the bill. I will advise the committee that there will be an amendment

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introduced that's designed to address some of the concerns that have been expressed during the course of the development of LB1036. I've worked closely with the Uniform Law Commission and the Nebraska members. I've engaged in discussions with some representing organization that has some concerns. I had hoped to introduce the full amendment to the committee this afternoon, but I neglected to include in the amendment one of the issues that I had. If you look at the bill, the current law in Nebraska speaks to...the uniform law speaks to the age at which someone can make a designation as a donor and it's tied to, if it's a minor, when they obtain a license to drive. Well, as you know, in Nebraska you can obtain that as early as 13. It would be my intent to amend that to age 16, which is more consistent with tying it to driver's license and for driver's benefits. The additional revisions will be discussed by Mr. Ruth, but I do want to point out one of the amendments that will be made and offered to the committee goes to the fiscal note. You will see a very substantial fiscal note, and that fiscal note is the result of the fact that the green copy of the bill did not include the State Anatomical Board as one of the organizations that can receive donations of whole body or parts of bodies. The amendment would add Nebraska State Anatomical Board to that list of organizations and thereby eliminate any possibility of the need to purchase cadavers from outside of the state. And that's what that fiscal note refers to--the estimated cost of purchasing cadavers. And with that, I will conclude my introduction and turn it over to Mr. Ruth, who is one of Nebraska's members of the Uniform Law Commission. [LB1036]

SENATOR GAY: So, Senator Council, on that amendment, and we'll talk about the bill, but...and you describe the amendment, when do you think the committee would have that in our possession? [LB1036]

SENATOR COUNCIL: Well, you know, in fact, Senator Gay, I can give you the amendment with the understanding that there would be the further amendment of the section that deals with the age. But we have that amendment, and I can leave that with the committee. [LB1036]

SENATOR GAY: Well, what I'd rather see maybe just for our benefit is if we can get...if it's coming and you told us, that's fine. I'd rather have it all together... [LB1036]

SENATOR COUNCIL: Right. [LB1036]

SENATOR GAY: ...so we don't have one or two and then we can look at that. And then we could get a revised fiscal note as well if that's the case that it would help this fiscal note because that is a problem. [LB1036]

SENATOR COUNCIL: (Exhibit 1) Right. And I would also like to offer for the official record a letter of support from the Nebraska Medical Association. [LB1036]

SENATOR GAY: Okay. We'll get that out. And then are you going to stay around if

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there's any questions for closing? [LB1036]

SENATOR COUNCIL: Yes, yes. [LB1036]

SENATOR GAY: Is there any right now that are? Okay. Thank you. [LB1036]

SENATOR COUNCIL: Thank you. [LB1036]

LARRY RUTH: (Exhibits 2, 3) Senator Gay and members of the committee, my name is Larry Ruth, L-a-r-r-y R-u-t-h, and I appear today on behalf of the Uniform Law Commission, the commissioners in this state, on behalf of them, in supporting LB1036. Just a little bit of background, some of you may be familiar with the Uniform Law Commission and some others may not. The Uniform Law Commission is an organization over 100 years old. Every state in the Union belongs to it. You can have members who are selected either by the Legislature or the Governor to go to this commission with headquarters in Chicago. And we draft uniform laws for the states to consider. Members of the commission now are Eighth Circuit Court of Appeals Judge Arlen Beam, Harvey Perlman, Amy Longo, who is with us today, Steve Willborn, who is the former dean of the law school, and your own Joanne Pepperl. I am the other commissioner. What we do is draft legislative bills in areas where we think uniformity is of value. And some of you sit on the Banking, Commerce and Insurance Committee and you just had a long, long bill dealing with limited liability companies. It's that kind of stuff we get involved with, whether it's business or, in this particular case, organization support for donation of parts and bodies. And I bring you a very important law today for your consideration. The Uniform Law Commission, as Senator Council said, drafted the first uniform law on anatomical gifts back in 1968, adopted by this state in 1970 or '71, without substantial change since then. But the law, of course, has changed a lot amongst the states, and especially at the federal level. Maybe we'll have some testimony on that. But there is a need for us to update it and that's why we have this bill today. I might now give out to you an amendment which does incorporate the proposal for Senator Council on changing the minimum age from 13 to 16. It also incorporates changes which would put the Anatomical Board into the proper place for the receipt of bodies and does away with the \$400,000 fiscal note that we have. We do have organized testimony. You've read that, but let me also pass out, now that I have the pages going, Kitty, the substitute here, huh. Thank you very much. I have a kit that I'd like to give to you. I call it a kit. It's a little portfolio of material on the Anatomical Gift Act, and I'd just like to review it very briefly with you because it just shows very starkly, I think, why we need this act. In the kit is a copy of the Uniform Act, not necessarily the one we have in front of you but the one promulgated by the Uniform Law Commissioners. And there are comments after each section which help to identify the issues in those sections, and I'll just point that out. It's on the left-hand side of your kit. And I would ask that I'm making special reference to it because this draft with its comments provides a wealth of material on how you interpret certain sections because

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it says why we adopted certain sections. Sometimes the comment is far longer than the words of the section itself, but it is part of the overall goal of having uniform law amongst the states so that, in this particular case, there can be a movement of transplantable organs across state lines. And we can promote in this case also the...promote and facilitate organ donation. Now on the right-hand side of that kit I just want to point out, after a couple of pieces that explain the Uniform Anatomical Gift Act, a stark map. And I know we don't like to see maps necessarily, but this shows the states that have adopted this version of the Anatomical Gift Act and they're all in blue. The ones that are in white are ones that have not yet addressed the issue, although I think Kentucky is about to. The ones in pink are the ones that were introduced in 2010, so you can see that this map is very up to date. And we believe that it is important for our community that works with donations and transplantations to not be a part of the country that has the old act that applies. We are in fact able to have common definitions and common procedures with the rest of the country, and that's really a very important part. I would also then say that the latter part of the kit--I'm losing my voice so I apologize--the latter part of the kit has a couple of letters that I want to bring to your attention. One is from the Association of Organ Procurement Organizations, that's the national association, in support of the Uniform Act. Another one is the American Association of Tissue Banks, which supports the Uniform Act; American Academy of Ophthalmology; and the Cornea Society; and then the Eye Bank Association of America. So we have quite an impressive list of folks who support it. Then I might also say, and Connie Ring will perhaps say this, that the drafting process encourages groups to come in, stakeholders to come in and be a part of the process so that when we get done hopefully we can have a uniform act that will be adopted in the states. Now I would like to introduce: Connie Ring will probably be the next one; our next people we have are Milton and Janet Bemis. They're from David City, Nebraska. They'll follow me and tell you about how important donation and transplantation is. And then after that Mr. Ring will be testifying. He's from Virginia and has come back through the weather to be with us. And finally then two witnesses who will introduce themselves for Nebraska Organ Retrieval System and from the Anatomical Board. So, Mr. and Mrs. Bemis. First of all, do you have any questions? Senator Wallman. [LB1036]

SENATOR WALLMAN: Thank you, Chairman Gay. This just relates to organs, right, not the whole body? [LB1036]

LARRY RUTH: It can be the whole body, yes. [LB1036]

SENATOR WALLMAN: Can be the whole body. [LB1036]

LARRY RUTH: Yeah, um-hum. [LB1036]

SENATOR WALLMAN: Well, if I donate my body to UNMC or Creighton you mean right now they don't have to follow through on what I...? [LB1036]

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LARRY RUTH: No. There is a current law on how you donate organs and that, I'm assuming, would take care of your question. It's just that this draft is more current. It uses more appropriate language, but it also works in the federal aspect of this which came about after we adopted ours in 1971. [LB1036]

SENATOR WALLMAN: Okay. Thank you. [LB1036]

LARRY RUTH: You're welcome. [LB1036]

SENATOR GAY: Senator Gloor. Senator Gloor has a question. [LB1036]

LARRY RUTH: Senator Gloor. [LB1036]

SENATOR GLOOR: Thank you, Mr. Ruth. Does anything about this change our current opt-in approach towards donation to an opt-out provision? [LB1036]

LARRY RUTH: Well, it's really interesting that you would ask that and you're asking me to get in the middle of a major issue right now. Not in this bill. I sent an e-mail to my son who lives in Atlanta, Georgia, a couple days ago and said I'm going to be working on the Uniform Anatomical Gift Act and he said, well, you ought to consider opt-out version rather than the opt-in like they have in Great Britain, at least that's what he said. For you who don't know what I'm talking about necessarily, it means that right now in order to donate your organ you have to make an affirmative donation or someone makes the donation in your behalf. In some countries the direction is in the other direction that you will have your body parts and your, at least as I understand it, the organs donated unless you're opting out of that. I really am not going to get in the middle of that. I think there's some tremendously important moral and philosophical issues involved with that. I know that we, as an organization, have not...are not considering that. We want to make the opt-in as valuable as it can be. And I will say this: that part of this bill is a purpose, and I want to be clear about it, the purpose is to encourage donation. And that we say it should be the state policy for the state is to encourage donation as opposed to any opt-out approach. And that in large part drives the way we look at proposed amendments, the way we draft the bill to begin with. It's to encourage donation. So that's our comment. [LB1036]

SENATOR GLOOR: Well, and anything personal perspective, anything that encourages more donation I see as a good thing and move in the right direction. [LB1036]

LARRY RUTH: With appropriate safeguards obviously, yeah. [LB1036]

SENATOR GLOOR: Absolutely. [LB1036]

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SENATOR GAY: So we'll save that for another day, huh? [LB1036]

LARRY RUTH: That's exactly right, when maybe some of you won't be in the Legislature. [LB1036]

SENATOR GAY: All right. Thank you. [LB1036]

LARRY RUTH: Thank you very much. [LB1036]

SENATOR GAY: Milton and Janet Bemis. [LB1036]

MILTON BEMIS: Good afternoon. I'm Milton, this is my wife Janet, Bemis, B-e-m-i-s. [LB1036]

JANET BEMIS: Senator Gay and committee members, we appreciate the opportunity to share our story to you today. [LB1036]

MILTON BEMIS: Twenty-six years ago this coming August we lost our son in a drowning. After two days at Children's Hospital, we knew that Matthew as we knew him was no longer with us. My wife was holding Matthew, rocking him, and she looked at me and she said, I wonder if we could, and she stopped. And I said, donate? And she said, yeah. A little girl from Tucson, Lilly (phonetic), was at UCLA Medical Center at that time. She ended up being the recipient of our son's liver. This is a picture of our son Matthew when he was two and a half years old. Lilly received Matthew's liver in a transplant. She had a condition where her liver was full of noncancerous tumors. She was days away from dying and we have pictures we'll show you, we'll pass around, shows Lilly three weeks before transplant and three weeks after transplant. She could eat a tablespoon of food, it filled her up. She was starving. She was on respirator, her lungs could no longer work or breathe for her. Through a series of unique situation, we saw a video of Lilly the night we left Children's Hospital, saw her family put out a nationwide plea for a donor, and we saw Lilly in her condition and saw this young couple going through what they were going through, and we knew at that time we'd made the right decision. Very, very unique, unheard of that we would actually sit there and know who received our son's liver in a transplant. Although these pictures show Lilly with her extended stomach, terrible condition, we have even more miraculous pictures of Lilly that we'd like to share with you and that is Lilly 24 years after receiving our son's liver at her wedding, which we attended her wedding in Syracuse, New York. I cannot tell you what a joyful occasion it was for us. We actually stood in the receiving line and were introduced as Lilly's donor parents, and we received a lot of hugs from her friends and family. She got married 24 years to the day after what she calls her second birthday, which was the day we lost Matthew, and it was a very, very special day. The other picture we want to share with you is one that when we got back from Lilly's wedding we found out that the donate life committee had chosen Matthew to be one of the people to honor on the Rose

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Parade float. And my wife and I were able to recreate a floragraph of Matthew that was to be on the Rose Parade float, and we have a picture of that that we'd like to pass around. It shows Lilly. She got to ride on that float under Matthew's floragraph, and I'm going to tell you this young lady is just the most excited, full of life and love young girl that we know. And she's married and her and Brian (phonetic) are dear friends of ours. And through working with Nebraska Organ Recovery and other organizations around the country, we're able to meet up with each other every now and then and get to see each other and share each other's lives, which we are very, very grateful for. [LB1036]

JANET BEMIS: Obviously, you can't have a successful transplant without a donation, and donation should be facilitated and encouraged by the laws of the state. It was a tragedy to lose our son, but it would have been a much worse tragedy to lose two children. And because of medical advances, you can save even more. Thank you for the opportunity to share our story with you. It has been an amazing ride for us. Twenty-six years ago almost we never dreamt that we would ever be in a place like this, and we really appreciate your time. Thank you. [LB1036]

SENATOR GAY: We appreciate you coming. Thank you. Are there any questions from any members? I don't see any. Thank you very much for sharing that. [LB1036]

MILTON BEMIS: Thank you. [LB1036]

CARLYLE RING: (Exhibit 4) My name is Carlyle Ring, R-i-n-g. You heard me referenced as Connie Ring and that's my nickname and comes from my middle name. I am handing out a statement, but I will immediately indicate that I'm not going to read this statement to you. (Laughter) I would like to highlight a couple things in this statement and then address some issues that we have been discussing with various groups that have an interest in this subject. You just heard one of thousands of stories of people whose lives were extended and improved as a result of a medical miracle that has to begin with a donation. Unfortunately, there are not enough donors and that's the critical concern. There are 100,000-plus people on the waiting list. And in the year 2003, there were 23,000 donations to meet that need of 100,000-plus. Every hour somewhere in the United States a patient is dying because there is no available organ that they desperately need. And the undertaking of the national conference was to update and improve the original Anatomical Gift Act for the purpose of encouraging and facilitating the donations. A little word about how we proceed as a national conference. All of us who were appointed by the governor or the legislature are volunteers in the real sense of the word. We try to improve the law. We don't do it perfectly because no human product is perfect. But we do a very careful and deliberate work in trying to come up with laws that are important for uniformity among the various states. And this is a topic that is important for uniformity because the donor may well be in one state, and you just heard that, and the recipient is in another state. There isn't time for lawyers to argue about dotting the i's and crossing the t's. The law has got to be relatively uniform so that

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both the recipient state and the donating state have essentially the same laws. And there are certain aspects of the Uniform Act that you have before you that are simply procedures within Nebraska. And it's those changes ought to be harmonized to be consistent with Nebraska practice. But there are other provisions of this proposed Uniform Act that we would like to see as uniform as possible for the reason I just articulated. We try to assemble all the various groups that might have an interest. And in my prepared statement, you saw a list of organizations that participated. We sat around the table together, about 35 people; 8 or 10 of them were members of the committee. The others were interested groups. They from Friday morning until Sunday noon participated actively in the deliberations. We went word by word, section by section each time we met as a drafting committee. Not all the people that we invited to come or sent out a letter soliciting their interest responded. And one of the groups that did not respond by sending a representative was the National Catholic Bishops Conference. However, we kept in touch with them through a member of our drafting committee who is a very active Catholic living in Arkansas, and we did get some feedback. When we completed the undertaking, we had a number of Catholic communities that took an active interest in what we were doing. And I undertook, as chairman of the drafting committee, along with the reporter, to have extensive meetings and conference calls with the National Center for Bioethics in Philadelphia. Marie Hilliard and her direct report, who is the director of the center, participated in those meetings. Dr. Delmonico (phonetic) who was one of the doctors that they relied upon, and Dr. Robert Sade (phonetic) participated in those calls. He was a representative of the American Medical Association and faithfully attended all the meetings of the drafting committee. We were concerned about what were the key ethical issues that might be of concern to the Catholic community. And we had four, in particular, that were identified in that dialogue. One of them is in Section 2 of the act, the definition of decedent. And we agreed with them, and you'll find it in the bill in Section...page 3, lines 19 and 20, that we have added in that page on line 19, "The term decedent does not include a blastocyst, embryo, or fetus that is the subject of an induced abortion." And that was included in the bill which was prepared and drafted. We had also an extended discussion with the center on Section 14, which is at page 20, beginning at lines 24. And this deals with what are the obligations of the hospital and the doctors in terms of end of life care? And the language which is set forth at lines 20 on page 20 and 21 are words that we worked out very carefully together. It begins at line 24 at the bottom of page 20 and continues until line 6. We went through a number of iterations of this with the bioethical center. And every time we came up with a solution, someone would say, doesn't work in medical science. And we finally agreed collectively that this was language that came to the right answer and the right solution. And that is included in the bill as presented to you. We also had a discussion with them about the tension which is in Section 20 and that is at page 24 and 25 to 26. The problem can arise that there is a tension or can be a tension between the living will as we used to call it, now the declaration, where the patient gives direction as to how they want to deal with a terminal illness and the fact that they have also indicated they want to make an anatomical gift. And there is a

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period, a short period where there is a need to provide ventilation, oxygen to the organs so that they maintain their vitality and suitability for transplant and which do you give priority to? Our first effort at that was not as artful as we thought it was. And we, after extended discussion again with them, came up with the language that you find in the act here. It basically provides that if there is a tension between the two that first you will go to the donor, if the donor is capable. That's going to be a rare... [LB1036]

SENATOR GAY: Mr. Ring, Mr. Ring, I know there will be people from the Catholic Conference behind you to give their point of that, too, so I know you've been communicating with them, but I'm going to need you to kind of get going just a little bit. [LB1036]

CARLYLE RING: I will go faster. [LB1036]

SENATOR GAY: Thank you. [LB1036]

CARLYLE RING: But part of my reason with skipping over the statement was to deal with the issues that I think are going to be before you in a statement that they're making. [LB1036]

SENATOR GAY: Well, and they will...yeah, and we'll look at both sides of it, of course. Go ahead. Continue on. [LB1036]

CARLYLE RING: Let me summarize and then if there are questions later that you would like to raise with me, I'm available and delighted to answer them. Altogether there were a large number of questions that were raised by Jim Cunningham. And let me say at the outset I wish that the attentiveness and the care with which he has given to this is something that you would wish to have in every legislature in every bill. Altogether there are about 25 wording issues that have been raised. Of the 25, 13 I believe have been in whole or in part addressed by either the amendments that you have in front of you or the issues I was just addressing. The other issues are issues that we feel impinge upon the uniformity and the policy of encouraging donations. And if it is your wish, Senator Gay, I will defer commenting on those until they have been raised by the Catholic Conference. But we would like an opportunity to provide our response. [LB1036]

SENATOR GAY: Yeah, and there will be time on a complex bill like this that it will get a lot of attention so let's see if there's any questions for you from our committee members. Senator Gloor. [LB1036]

SENATOR GLOOR: Thank you, Chairman Gay. Let me just by way of brief...and I don't want to belabor this, but on Section 9 and on page 14 it lists the classes of priority decision makers when it comes to making these important decisions. And I'm looking at (9) and (10). I believe I understand the intent of "An adult who exhibited special care

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and concern for the decedent," you know, people who cohabit, same-sex households. On the other hand, I have a mail carrier who has pushed me out of snowdrifts, I think has occasionally dug into his own pocket to pay postage due; he has certainly exhibited special care and concern for me, but I ask that somewhat jokingly. There hopefully is a clear definition somewhere of who that might be, and maybe that already exists within the law. [LB1036]

CARLYLE RING: That is a addition to the list that wasn't there in the original act back in 1968. It covers more than you mentioned. For example, we had in our family a proxy grandmother, and I was the special caretaker in many, many ways, providing housing for her and care. And it's more to cover that. For the person who is living together, it's much more likely in my experience in Virginia that I would prepare a healthcare directive that appoints them the agent. [LB1036]

SENATOR GLOOR: Sure. [LB1036]

CARLYLE RING: And that moves them up in the list to near the top and...well, is the top in our recommended Uniform Act. I'm not sure that answers completely your question... [LB1036]

SENATOR GLOOR: No, but I... [LB1036]

CARLYLE RING: ...except to say that the official comments do extend out what we mean by special care. And you should always keep in mind that the order of priority there's no family, no spouse, no parent, no grandparent, no siblings, you have to go down a long ways before you get to that individual. Secondly, in the amendments that you have before you, we have accepted a proposed addition to that particular category that was suggested by the Catholic Conference. [LB1036]

SENATOR GLOOR: Okay. Thank you. [LB1036]

SENATOR GAY: Senator Wallman. [LB1036]

SENATOR WALLMAN: Thank you, Chairman Gay. Yeah, thanks for being here. This is tremendous comprehensive legislation. And I want to know a few things if you're able to give it to me. Say I abuse my body all my life and I'm 45 years old and need a new liver or something. Am I on a...how do you scale the donor thing there if you're a doctor or hospital? [LB1036]

CARLYLE RING: Well, that's where we tie into the federal law because the federal law has preempted the allocation. They have a standard where they determine who is the best candidate for that particular body part, the organ. That is not true. The federal law doesn't fully preempt tissue and whole body donation. [LB1036]

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SENATOR WALLMAN: Okay. Thank you. [LB1036]

SENATOR GAY: Anything else? Thank you. Since you traveled all the way through a snowstorm from Virginia to get here, I was a little...gave you some leeway, but thank you very much for the... [LB1036]

CARLYLE RING: I appreciate that. [LB1036]

SENATOR GAY: ...and we had talked about that prior. [LB1036]

CARLYLE RING: I was actually escaping the snow (laugh). [LB1036]

SENATOR GAY: Yeah. But we had talked about that prior. I would make a comment, though, with the sponsor of the bill asked, as a respect, and I do need to get back, though, to a light system in order to get through the rest of the day. So we are going to enforce the lighting system fairly strictly throughout the rest of the day. I think Nebraska organ retrieval system is here to testify, but we will do that. [LB1036]

KYLE HERBER: (Exhibit 5) Thank you, Senator Gay, fellow committee members. My name is Kyle, K-y-l-e, Herber, H-e-r-b-e-r. I am the operations director for Nebraska Organ Recovery System, the federally designated organ procurement organization for Nebraska. Organ and tissue donation saves, extends, and enriches lives. Currently, as Connie alluded to, there are more than 105,000 individuals in the United States waiting for a lifesaving organ transplant, 500 of whom are Nebraska residents. Currently, Nebraska operates under the original 1968 version of the Uniform Anatomical Gift Act. Nebraska's version was drafted and enacted long before our current advances in organ and tissue transplantation that make the gift of life a reality to so many Nebraskans and so many Americans. Similar bills such as the one that created the Nebraska Organ and Tissue Donor Registry have helped progress donation and transplantation. For example, prior to the registry Nebraska averaged about 30 organ donors per year. Since the inception of the donor registry, Nebraska averages about 43 organ donors per year, which directly accounts for an additional 45 to 50 organs available for transplant each year. Nebraska is one of the minority of states that has not passed the revised UAGA. NORS has reviewed LB1036 and has met and discussed with its drafters. LB1036 with the proposed amendments has no fiscal impact on the state of Nebraska. LB1036 improves the recognition and evaluation of potential organ and tissue donors by first responders and healthcare professionals. This will increase the number of organ and tissue referrals and result in more lives saved, extended, and enriched. Improves the use of the statewide donor registry and expands consent methods, enabling more Nebraskans to become organ and tissue donors and more saved lives. Expands and clarifies the consent process; includes guardians and caretakers, who play an active and influential role in the medical decision process; and also recognition of other state

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donor registries as consent for out-of-state donors. Nebraska Organ Recovery Systems supports LB1036 which will foster and improve the donation process and, most importantly, save, extend, and enrich Nebraskans' lives. Thank you. [LB1036]

SENATOR PANKONIN: Mr. Herber, thank you. Senator Gay is going to be out for the rest of the day. So as Vice Chair, I will run the hearing from there. And we appreciate you being with us. We'll see if there are any questions. Seeing none, thank you. [LB1036]

KYLE HERBER: Thank you. [LB1036]

SENATOR PANKONIN: I've got one quick one. Where are you at then? You're in Omaha? [LB1036]

KYLE HERBER: We are based in Omaha, correct. [LB1036]

SENATOR PANKONIN: Okay. [LB1036]

KYLE HERBER: And we cover the entire state of Nebraska and also Pottawattamie County in Iowa. [LB1036]

SENATOR PANKONIN: All right. Thank you for being here. [LB1036]

KYLE HERBER: You're welcome. [LB1036]

SENATOR PANKONIN: Next proponent testimony. [LB1036]

THOMAS QUINN: (Exhibit 6) Good afternoon, everyone. Thank you for allowing us to testify today. I am, in fact, a proponent of LB1036. My name is Thomas H. Quinn, Q-u-i-n-n, and I'm a professor of anatomy and surgery at Creighton University School of Medicine. I also direct the clinical anatomy graduate program there. I'm here today especially, though, as president of the...and treasurer of the Anatomical Board of the state of Nebraska. I was surprised to find that first we had not had a chance to have input into LB1036, and subsequently we've had some good discussions once we knew that it had been read once. And now we have been able to underline the statutory purpose of the board and so forth and to get language in the bill, I think, in the amendment, AM1839, that I think you now have copies of, that do provide for the Anatomical Board actually to receive whole body donations. We've been doing that as a board since 1916 in the state of Nebraska and we are particularly interested in providing orderly receipt and maintenance, distribution, and use of the bodies for medical education and dental education and research. We also ensure that proper and considerate care is given to human bodies used for medical research and education, and we ensure that equitable procedure is used for allocation of the bodies to colleges,

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universities, and the medical schools in the state. One of the things that I like to underline with our students, and rather than read the whole handout that I would have, had the amendments not been proposed, I would like to just tell you that one of the things that we try to push when our students start medical or dental school or other health science training is that really the donors that they have are actually their first patients. And because of that, they learn honor and respect and they learn teamwork as medical caregivers, and that is their first brush with that in some cases. When we get a body for the Anatomical Board, that body is usually designated by the donor to go to either the University of Nebraska or Creighton or no special preference. And if those are the preferences, we do honor those. And one thing that I especially want to underline is that when we do get a donation in the state of Nebraska with the Anatomical Board, that body does stay in the state of Nebraska. It's cremated here and the cremains are returned either to the family, if that's their wish, or they're interred by the schools that have them. In the case of Creighton, we have a place at Catholic Cemetery in Omaha to bury the cremains. So it's I think with a lot of relief that I see that there is an amendment that does again put the Anatomical Board back in the standing that it originally had back in the early days of medical education in the state. And because of that, I think we can throw our support behind it 100 percent. One caveat, I guess, that I need to say before I step aside here is that there is a rather big business, let's say, in body brokering. And by that I mean intermediate companies that will get people to sign up with their company and make a donation, which is true, they give it free to the company. And then from there on the body can be divided and actually sold either internationally or nationally. So that's a major caveat that I think the committee should keep in mind as we go. And thank you for your time. I'll have the page hand these out. [LB1036]

SENATOR CAMPBELL: Dr. Quinn. [LB1036]

THOMAS QUINN: Yes, ma'am. [LB1036]

SENATOR PANKONIN: Yeah. We were just making sure you were going to stay for questions, Dr. Quinn. Go ahead and have a seat. Senator Campbell wants to ask a question. [LB1036]

SENATOR CAMPBELL: Thank you, Senator Pankonin. Dr. Quinn, I'm just curious how many people are on the Anatomical Board. [LB1036]

THOMAS QUINN: I haven't counted them. [LB1036]

SENATOR CAMPBELL: Just a round number, just... [LB1036]

THOMAS QUINN: There are about I think seven. They're representatives from each of the medical schools, the dental schools, and there's a lay representative, and the director of the anatomical facility is also in attendance. [LB1036]

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SENATOR CAMPBELL: I was once asked by an elderly relative of mine, what's the oldest that someone could or should donate? [LB1036]

THOMAS QUINN: Even in the last few years, especially as time goes on, medicine is so much better, the care, that we do have quite a few people that are over 100. And some of them are in, unfortunately, better shape than I am (laugh) so I'm envious. There are not very many younger people, most younger people opt to do organ donation if they're healthy individuals. Most of our individuals are close to 80 I would say and have had a lot of medical procedures done. [LB1036]

SENATOR CAMPBELL: So is there a directive that you can give if you say, well, I'm going to donate some of my organs but the remainder...would you take a body that had... [LB1036]

THOMAS QUINN: No, we can't do that because we have to embalm the body completely. And, of course, the students would like to see all the organs in place, too, so they get a proper idea about that. [LB1036]

SENATOR CAMPBELL: Thank you, Doctor. Thank you for clarifying that. [LB1036]

THOMAS QUINN: Okay. Thank you. [LB1036]

SENATOR PANKONIN: Senator Wallman, you have a question. [LB1036]

SENATOR WALLMAN: Thank you, Chairman Pankonin. Thank you for being here, Doctor. Are you...is there a shortage of bodies now? [LB1036]

THOMAS QUINN: From year to year there may be. At the moment we're, after an initial scare, I think this year I think there are going to be enough for all of the schools. Surgical interest is increasing, too, though, so there's always a need for more bodies. [LB1036]

SENATOR WALLMAN: Thank you. [LB1036]

SENATOR PANKONIN: Dr. Quinn, I don't think I see any other questions so thanks for coming forward. Thanks for coming down today and for your important work. [LB1036]

THOMAS QUINN: Thank you very much. [LB1036]

SENATOR PANKONIN: Any other proponents for LB1036? Anyone that's opposed to this bill that would like to come forward and testify? [LB1036]

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DON WESELY: Senator Pankonin, members of the Health and Human Services Committee, I'm Don Wesely representing Nebraska Association of Trial Attorneys. And our objection is on simply one section of the bill. It's on page 23. It is Section 18. It provides an immunity clause. And as you know, the trial attorneys generally oppose immunity clauses. This one in particular is somewhat problematic to us. In the summary of the bill, Senator Council talks about remedies for intentional acts in violation of the act are provided while retaining immunity for good faith action under the act. But if you read this section, it talks about a person that acts in accordance with the Revised Uniform Anatomical Gift Act or with the applicable anatomical gift act of another state or attempts in good faith to do so is not liable for the act in a civil action, criminal prosecution, or administrative proceedings. It's the series of "ors" that seems to not follow the intent of what was discussed here. So we would prefer that the whole section in immunity be stricken, but perhaps at least an amendment to this that indicates someone has to act in good faith in compliance with the law would at least be more in keeping with what was stated as the intent of the law. So we do object to that section. That's a suggested language change and would appreciate your help in clarifying that. [LB1036]

SENATOR PANKONIN: Thank you, Mr. Wesely, for coming. I see a lot of people jotting notes in the audience so I think your point is well made. We'll see if there's any questions. Seeing none, thank you. [LB1036]

DON WESELY: Thank you. [LB1036]

SENATOR PANKONIN: Any other testifiers in opposition to this bill? Seeing none, we'll now accept testimony in the neutral position. Welcome, Mr. Cunningham. [LB1036]

JIM CUNNINGHAM: (Exhibits 7, 8) Thank you, Senator. Good afternoon, Senators. My name is Jim Cunningham, that's spelled C-u-n-n-i-n-g-h-a-m. I'm appearing in my capacity as executive director for the Nebraska Catholic Bishops Conference, and I'm testifying in a neutral capacity. What is being handed out to you is something that I have shared previously with committee counsel so it's something that the committee has. It's a list of questions and issues and concerns that we have identified about this bill. In the Catholic moral tradition, the free and voluntary gift of organs and tissue after death is legitimate and justified by the principle of charity. It is an act of self-giving of the human person that can be noble and meritorious, the continuation or enhancement of the life of another. One essential and important caveat of this teaching is that the process of procuring organs or parts must never kill or otherwise bring harm to the donor or, as this bill would designate, the prospective donor. Given the stated purposes of this bill and their apparent consistency with the overview I've just described of our religious tradition, the purpose of my testimony today in the neutral capacity is to explain to you why the Nebraska Catholic Conference cannot see fit to support this bill. Generally stated, it's because of a number of concerns and issues regarding the means and mechanisms

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that are used in seeking to accomplish the purposes of more easily facilitating organ and tissue donations and procurement. This is a complex bill, and I appreciate the comments that Mr. Ring made about my reading of this bill. I have indeed read it. I've read it a number of times, and I've read it to try to get a better understanding of how this might have implications and effects on processes and practices. The bill is 42 sections in length, and it involves a complex mix of definitions and operative sections, default provisions, and outright repealers of current statutes. I've also read the ULC model act and the comments a couple of times. And I've had the very good fortune of discussing this matter not only with Senator Council and Larry Ruth and Amy Longo but also with Mr. Ring and Nicole Julal from the National Conference of Commissioners on Uniform State Laws. I've learned a great deal. I feel like I should have a higher level of confidence in my understanding of this bill than I do. And a lot of that is probably due to my own inadequacies. But my point is, is that one should not take for granted that everything about this legislation, all of its aspects, is necessarily sound or appropriate public policy. I think it needs to be approached with some caution and conscientiousness. It is a sensitive subject matter. And another motivation for our review of this and discussion that we've had in the conference is to address issues that might otherwise cause people to not be comfortable or not be confident or to be reluctant to make organ donations. And let me just mention a couple of the primary issues that we have. A couple of them have already been alluded to. The first one would be Section 14(c) and that's on page 20 and 21 of the bill. This has to do, as Mr. Ring told you, has to do with situations in which there is a prospective donor who is either dead or near death, that is near death being still alive, and it has to do with the administration of measures to maintain the suitability of a part. I want to acknowledge that this language that you see on lines 24 on page 20 through line 6 on page 21 was added in response not so much to questions that we raised but questions that were raised in the state of Maryland. We still have some lack of comfort with this language, and we have requested and our request has been rejected, but our suggestion would be that it be further strengthened by stating it in the negative so that at the top of page 21 it would say "may not be administered if it is determined that the administration of those measures would not provide the donor with appropriate end-of-life care." And I have an amendment that I'm going to submit to you that would do that. Next, I want to just quickly, because I know I'm running out of time, I want to mention what Senator Gloor brought up regarding Section 9(9)(10). Those have to do with the descending order of priority for those who can authorize gifts on behalf of another. And I would just say for our purposes these are quite low standards. There's no assurances of any familiarity with the personal values or wishes of the person, especially with regard to subsection (10). We requested initially that these two provisions be stricken. They come very close to the opt-out provision. They come very close to presumed consent, especially subsection (10) because that has to do with someone who might be homeless, a transient, someone who has no one else to be able to speak for them. And to say that whoever has authority over disposing of that body should have the authority to make an anatomical gift on the part of that person to our way of review certainly suggests a

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presumed consent without any personal knowledge or relationship. And presumed consent amounts not to a gift or a donation; it amounts to a taking. And in our view, that is a policy that should be upheld very strongly so that this is actually an act of giving and not an act of taking. Could I finish just with one other point that has not yet been brought up? I want to acknowledge also that this act, Section 7, does provide for refusals. However, the way to effectuate a refusal is by no means consistent with the way to effectuate a donation. We've asked the question, if a person, for whatever reason they have, sees fit to not make...to refuse an organ donation, which really is to bar anyone else from making one in their behalf, if that's the case, and it's an issue of personal autonomy, why not also allow that refusal to be part of the organ registry? Why not also allow a person to indicate a refusal on their driver's license to honor their wishes? I understand that there are issues about who sponsors and conducts the organ registry. Apparently it's possible to operate privately a refusal registry. I'm not aware that that's the case in Nebraska. I doubt that it is, but if there was one or if there would be one, it would seem to be reasonable that the procurement organization would have to consult the refusal registry and try to determine the person's wishes as well as the gift registry, the donation registry. So those are just some things that are spelled out in what I have given you. And I appreciate also the fact that Senator Council has addressed the issue of minors. From our perspective, setting the age at 16 rather than 13 is certainly an improvement because otherwise it allows the minor to be a first-person organ donor without consent of the parents, perhaps even without involvement of the parents. And although it does allow parents to revoke that gift if that individual dies while a minor, that really puts the parents in a difficult situation given the urgency and the circumstances that they're in. With that, I'll quit and take any questions you might have. Thank you.

[LB1036]

SENATOR PANKONIN: Thank you, Mr. Cunningham. See if we have any questions.
Senator Campbell. [LB1036]

SENATOR CAMPBELL: Thank you, Senator Pankonin. Mr. Cunningham, you have provided 22 items, I believe, to us to take a look at. Are those 22 items in addition to your discussion with...you know, he said you had agreement on... [LB1036]

JIM CUNNINGHAM: Yes. [LB1036]

SENATOR CAMPBELL: ...on half and are these in addition to... [LB1036]

JIM CUNNINGHAM: Right. I'd be happy to clarify. These would encompass those that we...in fact, Mr. Ring might be delighted to know that our initial list of 30 has been cut back to 22 (laugh). So...and, but no, they would encompass...there may be one or two that we did not have in our original, but this is based on what we submitted to the National Commission initially. Some of these have been addressed in the amendments, not those that we regard as the most significant, which would be the one with respect to

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the administration of measures to maintain the suitability of the organ, Section 14(c). But there are some others that they have responded positively to our input think.
[LB1036]

SENATOR PANKONIN: Seeing no other questions, thank you, Mr. Cunningham.
[LB1036]

JIM CUNNINGHAM: Thank you. [LB1036]

SENATOR PANKONIN: Are there any other testifiers in a neutral position on this bill on LB1036? Okay, Senator Council is going to come forward to close on LB1036. [LB1036]

SENATOR COUNCIL: Thank you, Senator Pankonin. I will be brief, and I want to begin by thanking the committee for its patience and indulgence. This is indeed a complicated issue. I want to thank all the stakeholders who have engaged in discussion and negotiations in trying to arrive at the best possible piece of legislation that we could advance at this particular time. Mr. Cunningham, Mr. Ring, this is like my third time meeting with Mr. Ring, coming in from D.C. I think we began working on this in November, if my recollection is correct, and from the outset with the objective of trying to address as many of the concerns as could possibly be addressed while maintaining the primary objectives of the Uniform Anatomical Gift Act: that is to facilitate and encourage donation and to provide uniformity across the states. And with regard to some of the issues that may not have been addressed in the amendment that Mr. Cunningham has alluded to, rightly or wrongly, the determination was made that it so much affected the uniformity, particularly with regard to those particular aspects of the gift act, that when we're looking at what does one state to the next state to the next state, that those were areas where sacrificing the uniformity outweighed any concern about the intricacies of the operation of that particular provision. So that's to give you an explanation as to how we arrived at the issues that are addressed in the amendment and those which are not. And I appreciate Mr. Cunningham, he's met with me, he has communicated with me via mail, via e-mail, via snail mail in trying to arrive at this legislation. So I want to commend and thank all of them. And I do want to note and I explained to my brethren in the legal profession the issue about the immunity section. LB1036 adopts the new version of the Anatomical Gift Act so it repeals the existing Nebraska Uniform Anatomical Gift Act. If you look at the current Nebraska Uniform Anatomical Gift Act, the exact same immunity language is found. So since 1971 that's been the language and that's the immunity that's provided. And if you look at it, it speaks to good faith, maybe not to the extent that my brethren would like for it to do. But in the absence of, you know, some compelling reason for eliminating that, that's why that provision has not been addressed in the amendment. And with that, I will close and thank you again for your time and indulgence. [LB1036]

SENATOR PANKONIN: Thank you, Senator Council. See if there's any questions.

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Seeing none, thank you for bringing this bill. [LB1036]

SENATOR COUNCIL: Thank you. [LB1036]

SENATOR PANKONIN: That will close the hearing on LB1036. We will now move to LB1022 and I see Senator Rogert is here to introduce. [LB1036]

SENATOR ROGERT: I thought people talked a lot in Judiciary. My goodness. [LB1022]

SENATOR PANKONIN: Welcome, Senator Rogert. [LB1022]

SENATOR HOWARD: You cleared the room here. [LB1022]

SENATOR ROGERT: I'm either filling a room or clearing a room, Gwen. They either don't care or they're really mad at me. Senator Pankonin, members of the Health and Human Services Committee, my name is Kent Rogert. I represent the Legislative District 16, and I'm here today to present LB1022 to you. The University of Nebraska Medical Center brought me this proposal to permit a more ecologically friendly option for the disposal of human remains. The Medical Center is in the process of assessing the best way for them to dispose of human remains that have been donated to the Medical Center for science. The current incinerator that is used to cremate remains is not operational anymore. By law, human bodies must be cremated or buried as a method of final disposition. Cremation, though, through the incineration process, requires a great deal of energy, produces much carbon dioxide. Both have adverse impacts to the carbon footprint. Alkaline hydrolysis is a method that breaks down the soft tissues of the body in a very similar manner and when it decomposes in a grave. With that, it's pretty simple. I'll try to answer any questions you may have. There are a couple of folks behind me that can answer any more detailed questions that you have. [LB1022]

SENATOR PANKONIN: Thank you, Senator Rogert. Are there any questions? Seeing none, right now, I know you're going to be around because you got to introduce another bill so. [LB1022]

SENATOR ROGERT: Staying around. [LB1022]

SENATOR PANKONIN: So we'll talk to you later. Okay. Any proponents for LB1022 come forward, please. [LB1022]

CAROL LOMNETH: (Exhibit 1) Carol Lomneth, L-o-m-n-e-t-h, and I am a proponent of LB1022. I am in favor of LB1022. I'm an associate professor at the University of Nebraska Medical Center, been teaching there for about 15 years. I am also a member of the Nebraska Anatomical Board. There are about seven of us. As Tom mentioned, we're from both medical colleges and the dental colleges in the state of Nebraska. As

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he also mentioned, we're charged with the preparation, the storage, and the care of the donors. It just so happens the Anatomical Board facility is at UNMC so we have the morgue director at UNMC who I supervise and I have oversight over the daily operations of the Anatomical Board at UNMC. The anatomy department at UNMC owns the crematory and it's used to cremate those bodies that are used at UNMC for medical education and research. Each donor at UNMC educates at a minimum of four different healthcare professionals. Once the donor studies are completed, the donors are then cremated and, at the family's request, the ashes are either returned to the family or interred in a local cemetery. At the end of the academic year, students from the medical, physician assistant, and physical therapy program hold a memorial service for the families of the donors. It is at this time the students give their thanks and express their gratitude to the families for providing this precious gift that allows them to deepen their understanding of the human body. UNMC's crematorium was installed in 1974. It has pretty much outlived its expected usefulness. And because the crematory is now in constant need of repair, we're investigating other options to replace the existing unit. One option is to adopt a technology that is being considered by other body donation programs across the country. It has been used at the University of Florida since 2005 and the Mayo Clinic since the mid-1990s. This alternative technology breaks down the soft tissue of the human body by alkaline digest so the body is placed into an alkaline solution, added heat and pressure which helps accelerate this breakdown process. The process is actually very similar to what happens when a body is buried in a grave. Whether the body is cremated, whether it's put in a grave, or whether it goes through alkaline digest, the beginning and the end product is pretty much the same. Adopting this alternative means or alternative technology is desirable for a number of reasons. From an environmental standpoint, it is a clean technology emitting no fumes, odors, or toxins into the environment. From a financial standpoint, it's pretty much a wash. The cost of operation is about the same as cremation, but the mechanical device to achieve the job is simpler which ends up costing less in repairs. Third, from a public safety standpoint, the public is protected because there are no known pathogens or infectious agents that can survive this process, and that includes the misfolded protein that causes Creutzfeldt-Jakob disease in humans or chronic wasting disease in animals. Finally, from a legal and emotional standpoint the public is protected because all the rules that apply to the safe and ethical handling of human remains for cremation would apply to this process. In conclusion, the use of human donors to educate our healthcare providers is in the fundamental discipline of anatomy is critical. UNMC's crematory, which has been in use for almost 40 years, is in need of replacement. I'm asking you to support this bill which would allow us to adopt the technology which will not only meet the current air and water safety standards but is likely to meet the standards that will be set in the future as well. It is important that we adopt this bill in a timely fashion so that we can continue to operate our program in an economical and environmentally responsible fashion. Thank you for your time. [LB1022]

SENATOR PANKONIN: Thank you for your testimony and coming today. We'll see if

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there are some questions. I think we have them. Senator Gloor. [LB1022]

SENATOR GLOOR: Thank you, Chairman Pankonin. I'm trying to do a look back into my days of organic and inorganic chemistry. I'm trying to decide why, if it's a strong alkaline solution and if it's under pressure and heat, why there would be no fumes, why there would be...certainly there's decomposition. And if there's decomposition, then there has to be a breakdown; and that breakdown I would think will give off fumes, carbon, etcetera. So help me understand why this is... [LB1022]

CAROL LOMNETH: Different. [LB1022]

SENATOR GLOOR: Yeah, different. [LB1022]

CAROL LOMNETH: You're right. I imagine there are fumes, and I may let Nick, our facilities management person, speak to that. I think the difference is particulate. There is no particulate released into the air. So in the incineration process there is smoke. That smoke means small particles. Those small particles are released into the air. [LB1022]

SENATOR GLOOR: Okay. That makes sense. Thank you. [LB1022]

SENATOR PANKONIN: Senator Howard. [LB1022]

SENATOR HOWARD: Thank you, Senator Pankonin. I'm wondering if your crematorium is not up to the job there are plenty of others in Omaha. Why don't you have an arrangement with one of the other ones? [LB1022]

CAROL LOMNETH: We could and we actually do for the time being because our crematory is shut down. But it is more cost effective for us to have this on campus. We would be charged from \$200 to \$250 per donor. We would have to tack those costs back onto purchase, well, purchasing the donor from the Anatomical Board for UNMC. That would translate into higher costs for the students. [LB1022]

SENATOR HOWARD: I thought these individuals were donated. [LB1022]

CAROL LOMNETH: They are donated. But if we have to...the funeral homes aren't going to donate their services for cremation. We have to pay them for that cremation. [LB1022]

SENATOR HOWARD: Seems like a small price to pay for a human being. [LB1022]

CAROL LOMNETH: Certainly. [LB1022]

SENATOR PANKONIN: Any other questions? Thank you for your testimony. [LB1022]

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CAROL LOMNETH: You're welcome. [LB1022]

SENATOR PANKONIN: We'll now take any other proponent testimony for LB1022.
[LB1022]

NICK COMBS: (Exhibit 2) Good afternoon. My name is Nick Combs, C-o-m-b-s. I'm the director of maintenance, utilities, and renovations for the University of Nebraska Medical Center. I'm here representing the University of Nebraska to testify in favor of LB1022. I can speak only to a purely technical perspective when it comes to the apparatus itself. I'm not involved in the Anatomical Board operation, only with the facilities operation. I can address your question on the odor issue when I'm finished. Again, from a purely technical perspective, the alkaline hydrolysis process is less complex, it's cleaner, and it's equally cost effective to operate as compared to incineration. The process takes place in a sealed vessel with no pollutant effluent to the atmosphere. And that is the key--the vessel is sealed. The by-products of the alkaline hydrolysis process are discharged into the sewer system for the safe and sanitary treatment with no smoke, odor, or pollutant discharge. The process consumes less energy overall and produces less carbon dioxide significantly than incineration. The reduced carbon footprint of this equipment could have an even greater impact economically if the carbon tax is implemented in the future. The approval of this technology would likely produce a more competitive pricing atmosphere for anyone that would need to purchase a new or replacement crematory device in the future. Thank you for your consideration of my testimony. Are there any questions? [LB1022]

SENATOR PANKONIN: Are there questions for Mr. Combs? Yes, Senator Howard.
[LB1022]

SENATOR HOWARD: I'm sorry. Did you say these people are put in the sewer?
[LB1022]

NICK COMBS: The effluent from the device, which is nothing more than the remains of the alkaline product, goes down the sewer. The human remains, same as in the crematory, the incineration process, are still in the vessel when the process is finished. As opposed to the remains going up a smokestack into the atmosphere, that effluent goes down the sewer. [LB1022]

SENATOR HOWARD: Thanks. [LB1022]

SENATOR PANKONIN: Senator Wallman. [LB1022]

SENATOR WALLMAN: Thank you, Senator Pankonin. Now is that any problem with the sewer system? [LB1022]

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NICK COMBS: No, it is not. The pH of the discharge material from the device is around 11.5 to 12 in the pH range. We would have to negotiate with the city of Omaha for approval of the discharge of that pH. But with the additional water discharge from the campus diluting that, the pH by the time it hits the treatment plant would be unnoticeable considering the small quantity. [LB1022]

SENATOR WALLMAN: Thank you. [LB1022]

SENATOR PANKONIN: Senator Gloor. [LB1022]

SENATOR GLOOR: Thank you, Mr. Chairman. Mr. Combs, is the solution able to be used multiple times or is it a single use? [LB1022]

NICK COMBS: It is a single use, sir. [LB1022]

SENATOR GLOOR: Okay, thank you. [LB1022]

NICK COMBS: And the reason there is no odor discharge is that the vessel is continuously sealed. All of the material goes down through the sewer first and then a flush takes place, a cleaning wash takes place of the remains. Therefore, when the vessel is opened, there are no odors discharged to the atmosphere. [LB1022]

SENATOR PANKONIN: Mr. Combs, I've got a question. It seems to me in a little bit of a sense I'm kind of following up with Senator Howard, but, you know, I think people...we heard earlier today that donations of these whole bodies is important for the medical education and that sometimes there's been a sense of can we get enough and timing and this sort of thing. But I wonder has there been any kind of survey done of people that may donate or families because this is something new that is I think there's some queasiness on the part of some folks that maybe, you know, is this the way we want to go? The point being, could this be a situation where if not handled properly people would say I don't want my remains or my family members, loved ones handled this way and it would preclude them from donating? Do you think there's... [LB1022]

NICK COMBS: I suppose there would be a... [LB1022]

SENATOR PANKONIN: ...a survey? I mean since this hasn't been done that many places in the country, right? [LB1022]

NICK COMBS: I suppose it would be a possibility. Again, I can only speak to the technical aspects of the process itself and the equipment. Truly it would have to be a question answered by either the Anatomical Board or Carol. [LB1022]

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SENATOR PANKONIN: Right. Thank you. Any other questions? Seeing none...
[LB1022]

NICK COMBS: Thank you. [LB1022]

SENATOR PANKONIN: All right. Any other proponents for LB1022? Seeing none, anybody in the opposition for LB1022? Does anyone want to testify in a neutral position? [LB1022]

BILL LAUBER: Good afternoon, Senators. Members of the committee, my name is Bill Lauber, L-a-u-b-e-r, past president of the Nebraska Funeral Directors Association, and I sit on the state Board of Funeral Directors and Embalmers. And on a side note, I was the chairman who helped draft legislation with crematory operators and funeral directors and the language to develop the Cremation of Human Remains Act that the Legislature passed in 2003. And what that act says, that act has licensed and inspected crematories in the state of Nebraska and it has also outlined procedures and guidelines for crematory authorities, funeral establishments, and families who choose cremation as a form of disposition. When we speak of dispositions in the state of Nebraska, approximately 70 percent or so of the dispositions are earth burial or aboveground mausoleum dispositions. The other 25 percent or so is cremation as a form of disposition, and the minor chosen dispositions are anatomical donations or ship outs to another state. So that kind of gives you a breakdown of our current disposition choices in the state of Nebraska. And it kind of mimics the Midwest as well and other states surrounding us. Some states on the East and West Coast, their dispositions are obviously different with the choices that the citizens of those states make. And that brings us to the hearing and the new form of disposition called resummation or alkaline hydrolysis. I don't really know how the outcome or the impact of resummation will have in the future. I don't have a crystal ball up here to see and predict. But I do know from my learning of this process that it has had a great impact, a wonderful impact in the medical dispositions of hospital waste and amputations and of that kind of nature. It's also been very successful in the anatomical donations from state anatomical boards, which you heard earlier. And in fact, I think veterinarians have been using some forms of resummation in the disposal of pets to some success. And then finally, we are starting to learn that there may be, if the society has accepted this form of disposition, there may be some commercial resummations. In fact, there are some resummation chambers being built by funeral homes, not very many. There's just a handful with one hand being built today, but we don't know what success resummation will have at this point. The funeral directors and crematory operators that I have visited with in the last couple of weeks about the subject of resummation are overwhelmingly supportive of it when it's limited to the medical cadaver research arena. We just also know that the visits we have with the community regarding this mode of disposition, this new mode of disposition you mentioned earlier of the uneasiness that they have. They're not really willing to accept it yet. So commercially resummation is far down the road that we see.

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As far as the resummation with people who donate their whole body to science, as funeral directors we are, of course, in that line where they come to our funeral homes and they wish their desire that before his or her own death that they donate their body to the State Anatomical Board. The State Anatomical Board provides us bequeath forms that we have the family fill out. And a portion of that bequeath form indicates their decision as to what to do with the remains of their body once it's completed. And years ago when I first got in the business, we used to have earth burial as one choice. Then the other choice was cremation. And, of course, now most of them, if not all of them, are cremated now. So their choice is cremation and they just need to decide whether they want the ashes returned back to their next of kin or to be commingled with others and have a memorial service. If we proceed with resummation, I think we should make sure that those bequeath forms explain the new option of resummation and also give a brief explanation of the process so that the donor who wants to donate their body to science understands that they have a choice and they should have a choice whether they should be cremated or should they be resummed and, if they're resummed or cremated, what to do with their cremated remains or the resummation remains.

[LB1022]

SENATOR PANKONIN: Thank you. Thanks for your testimony. Just so I don't forget, we want to make sure you fill out one of those testifier forms, but we'll see if there's any questions. Senator Wallman. [LB1022]

SENATOR WALLMAN: Thank you, Chairman Pankonin. Yes, is there a huge difference in cost then for the funeral homes between the two methods? [LB1022]

BILL LAUBER: Right now it would be hard to say, although I would venture to predict that early on the cost of resummation might be higher than the cost of cremation. But over time if resummation is commercially accepted, they will probably ultimately be the same cost as a cremation. [LB1022]

SENATOR WALLMAN: Thank you. [LB1022]

SENATOR PANKONIN: Okay. Seeing no other questions, thank you for coming today. Thanks for your testimony and make sure we get a testifier sheet. Okay. Others in the neutral. It looks like we have another testifier in the neutral position. [LB1022]

JON REICHMUTH: My name is Jon Reichmuth, R-e-i-c-h-m-u-t-h. I'm current president of the Nebraska Funeral Directors Association, and on behalf of the board of directors for the Nebraska association we did want to address the issue briefly. We have the neutral position here. We feel that in the future it may become a viable option. Our only thoughts on this are that it be properly regulated, consistently creating oversight on an ongoing basis, and that full disclosure of the process and the end result is given to each family or individual that would choose this. And that's very simply the position of our

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board. [LB1022]

SENATOR PANKONIN: Mr. Reichmuth, thanks for coming and I want to make sure you get a testifier form filled out before you leave today, too, for the purposes of our committee clerk. Are there any questions? Senator Gloor. [LB1022]

SENATOR GLOOR: Thank you, Chairman Pankonin. So is cremation highly regulated? [LB1022]

JON REICHMUTH: I wouldn't say highly but it's much better regulated and that probably is the reason for our concern about regulation. Twenty years ago cremation was not well regulated. We had retorts that were not well kept or operated. And that's why we've learned through the cremation process evolving into a viable choice for people, and from the association's standpoint, we would like to miss out on that problem. We want to right up-front have everything taken care of so that we don't have to revisit resummation like we had to revisit cremation regulations. [LB1022]

SENATOR GLOOR: Okay. Thank you. [LB1022]

SENATOR PANKONIN: Any other questions? Seeing none, thank you for coming today. [LB1022]

JON REICHMUTH: Thank you. [LB1022]

SENATOR PANKONIN: Any other testifiers in a neutral position? Seeing none, Senator Rogert, would you like to close? Senator Rogert waives closing. We will end the hearing on LB1022 and we'll now move to LB1067. Senator Rogert. [LB1067]

SENATOR ROGERT: Okay. Senator Pankonin, members of the Health and Human Services Committee, for the record again my name is Kent Rogert. I represent the 16th Legislative District, here today to introduce LB1067. LB1067 is a bill that would mandate a procedure called pulse oximetry on newborns in hospitals in Nebraska in order to screen for congenital heart diseases in the first 24 hours of birth. A physical examination is often performed on newborns by a pediatrician to detect signs such as heart murmurs, overt cyanosis, and tachypnea, I believe, that may occur 48 hours before hospital discharge. A hospital is inclined to discharge at the 48-hour time period in order to keep in mind with noninterference with the bond between a mother and her newborn baby. However, if CHD, as I'll refer to for congenital heart disease, is not diagnosed or the signs relevant to CHD are not detected, the morbidity or mortality rate is high. Few children survive if CHD is not treated soon enough since the clinical status worsens with time. Early detection serves as a preventive method and preventive public health screening programs that may be necessary in order to prevent death within the first days or weeks of a newborn's life. Often as time continues, the newborn dies before

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surgical intervention. Physical examination within the first 24 hours will not always catch the nuances in a heart murmur relative to the second beat. And even though a prenatal ultrasound performed at 18 to 20 weeks of gestation may be used to detect congenital heart abnormalities or lesions that indicate CHD, many European studies report that fewer than 50 percent of the CHD cases are detected with just this ultrasound. Furthermore, medical professionals from a wide array of experience perform ultrasounds which may give rise to concern about the quality of the procedure. It has also been noted by the American College of Obstetricians and Gynecologists that this procedure encompasses a very limited four-chamber view of the heart. Southwestern Medical School in Texas conducted a study in 1998 and concluded that with this ultrasound procedure only one quarter of the heart defects are identified. Other tests aside from the physical examination such as electrocardiograms and chest radiographs may be used when there is suspicion of CHD. Electrocardiograms are very effective in CHD, but they are also very expensive. Pulse oximetry was established in the '70s and its use is prevalent in some hospitals in Florida and Texas in the United States. It's widely accepted in European studies, more specifically in the UK, Sweden, and Norway, as a very noninvasive method to determine oxygen saturation. When pulse oximetry is used, a small sensor is taped to the baby's foot that beams a red light through the foot and measures how much oxygen is in the blood. The procedure takes a minute, it's very inexpensive, quick, and little risk of any harm. According to a New York Times article, "Screening Babies for Broken Hearts" by Tara Parker Robe on April 9, 2009, a Norwegian study confirmed that within a few hours of birth, pulse oximetry detected three quarters of critical heart defects that had been previously missed with other tests. For every 2,000 newborns screened with the toe light, roughly one with a critical heart defect might have been prevented from going home. If we can detect CHD in newborns early with the success rate cited in crucial studies that I have available upon request, we may have to anticipate follow-up testing and diagnosis. However, the false positive rate is minimal, and we can save lives rather than encroach upon uncertainty and emotional distress for parents based upon inconclusive detection. Thank you for consideration of LB1067. I'll ask for any questions if I can help. I don't know a lot about the technicalities, but folks behind me certainly do and are very excited to talk to you about it. [LB1067]

SENATOR PANKONIN: Thank you, Senator Rogert. Are there any questions? Senator Wallman. [LB1067]

SENATOR WALLMAN: Thank you, Chairman. Yes, Senator Rogert, thanks for being here. [LB1067]

SENATOR ROGERT: You bet. [LB1067]

SENATOR WALLMAN: Do you think the fiscal note, is that realistic here if it's that simple of a test? [LB1067]

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SENATOR ROGERT: Well, it's been...it takes just a minute literally. I suppose if you look at how much time, what an hour costs in the birthing suite in a hospital, whatever that is divided by a minute, I suppose it's probably 35 bucks a minute. But if you look it does explain the fact that Medicaid is responsible for half the births in the state. When I saw it, too, I was astonished. I'm like, come on, how is it going to cost that much? But \$35 times that many babies adds up pretty fast. However, it does not reflect the fact that those that are undetected will cost hundreds of thousands of dollars to fix the problem if they're not (inaudible). So a small investment in this type of procedure could save millions of dollars for the state throughout the life of a young child. [LB1067]

SENATOR PANKONIN: Senator Gloor has a question. [LB1067]

SENATOR GLOOR: Thank you, Chairman Pankonin. Senator Rogert, do you have people behind you who are going to talk about the science behind this? [LB1067]

SENATOR ROGERT: Yeah, I do. [LB1067]

SENATOR GLOOR: Okay. And I'm assuming that there isn't anything in this that precludes institutions from charging for doing this procedure. [LB1067]

SENATOR ROGERT: I assume that they will charge. [LB1067]

SENATOR GLOOR: Or (inaudible). Okay. [LB1067]

SENATOR ROGERT: Yeah. I mean if the fiscal note reflects a charge, then I will assume that the charge will come on to every...but like I said, even the Fiscal Office, which likes to charge for everything, only says it's a \$35 charge. And I thought, well, for \$35 I'd pay for that. [LB1067]

SENATOR GLOOR: Okay. Thank you. [LB1067]

SENATOR ROGERT: And if you don't get the questions on the science answered, I've got a whole stack of stuff right here that I can certainly get you at any time. [LB1067]

SENATOR GLOOR: Thank you. [LB1067]

SENATOR PANKONIN: Seeing no other questions at this point, we'll let Senator Rogert go and are you going to stick around? [LB1067]

SENATOR ROGERT: I've got to go back but I may be back so I'll be in and out. [LB1067]

SENATOR PANKONIN: Okay, we'll see. All right, we will take proponent testimony for

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LB1067. Come forward whenever you want. [LB1067]

TIFFANY MYTTY-KLEIN: (Exhibit 1) Good afternoon. My name is Tiffany, T-i-f-f-a-n-y, my last name is Mytty-Klein, M-y-t-t-y-K-l-e-i-n. I thank the committee for their time this afternoon to pay attention to the matter that we have brought forth and especially to Senator Rogert for his assistance in helping Nebraska to be the first state to proactively screen our children for CHDs. My son Cole (phonetic) was born in 2002 at the end of a very normal, noneventful pregnancy. During his first examination in the hospital, his pediatrician noted a heart murmur but assured us it was very normal. During his two-week, four-week, and six-week baby checkups, the murmur was noted again and followed by the reassurance that it was very normal for some babies. At eight weeks of age, we took our son to the hospital in severe distress and he was diagnosed with congenital heart defect or CHD and then congestive heart failure. We arrived at Children's Hospital on a life flight where we spent the next six weeks. Because of Cole's late diagnosis, four of those weeks were spent trying to get him strong enough to survive surgery. Many of these weeks may have been avoided if he was diagnosed at birth. Cole was three months old when he underwent his first open-heart surgery. Prior to Cole's diagnosis, the existence of congenital heart defects was not only unfamiliar for us, it was unheard of. The pregnancy books we pored over did not talk about it, neither did the books that contained the vital information for caring for our son in the first year of his life. We were not handed information regarding signs or symptoms to watch for in the event his murmur was not simply very normal. We did not have any comprehension of all that could be wrong, after all, we were handed a gorgeous baby with ten fingers and ten toes that they let us take home from the hospital. Our rationale was that they would have not let us take a baby home that had a life-threatening birth defect. It would or should have been caught. The reality of congenital heart defects is overwhelming. Over 40 known congenital heart defects will affect 40,000 newborns each year in the United States. Unfortunately, an estimated 4,000 of those babies will not live to see their first birthdays. Ninety-one thousand lives are estimated to be lost each year to CHD. It is the leading cause of infant deaths in our country. Twice as many children will die from congenital heart defects this year as all childhood cancers combined. It has been found, however, that the earlier a congenital heart defect is detected and treated the more likely the child will survive and have less long-term health problems. These problems can include strokes, seizures, and neurological and developmental disabilities. CHD screening at birth needs to be a necessity. Echocardiograms and MRIs are some of the methods that can assess detection. However, these tests are costly and require additional equipment that may not be readily available. Pulse oximetry provides an inexpensive, noninvasive method that utilizes equipment currently found in hospitals and pediatrician offices throughout the state of Nebraska. When my second son was born in the fall of 2010 (sic), he was given an audiology test which is an automatic part of the Nebraska newborn screening. The charge was \$168. Three out of every thousand babies are born with congenital hearing loss. His newborn screening test also included the Nebraska routine screening panel. These test for disorders such as cystic

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fibrosis, which is 1 in every 35,000 babies affected; congenital primary hypothyroidism, which is 1 in every 3,000-4,000 live births; and congenital adrenal hyperplasia, which is 1 in 16,000 affected. The laboratory charge in 2007 for these screenings was \$254. Our children are not currently screened for congenital heart defects, yet it affects 1 out of every 110 births; 1 out of every 110. The cost of an infant sensor probe needed for pulse oximetry is \$10. Some congenital heart defects are discovered during routine sonograms. Unfortunately, the technicians do not receive specialized training to recognize heart defects so many are not discovered until birth. Many more are not discovered until hours, days, or even months after birth when the child is in congestive heart failure or their heart has stopped. A study released yesterday surveyed the parents and 60 percent of them did not know that they had a child with CHD until after they gave birth. As a result, too many babies are fighting a fight that's harder than it needs to be. Routinely screening newborns for congenital heart defects can give many of our children a fighting chance, a chance they should have and a chance they deserve. When I explained the purpose of this bill to my son Cole, his response was simple--why wouldn't they do it? I didn't have an answer for him and I hope to not need one. [LB1067]

SENATOR PANKONIN: Thank you for your testimony. We'll see if there's some questions. I've got one. First of all, how old is Cole now? [LB1067]

TIFFANY MYTTY-KLEIN: Cole is 7.5 years old as of the 19th. [LB1067]

SENATOR PANKONIN: And hopefully he's doing fairly well. [LB1067]

TIFFANY MYTTY-KLEIN: He has had a second open-heart surgery and we are particularly looking at one this summer for a third. [LB1067]

SENATOR PANKONIN: Wow. [LB1067]

TIFFANY MYTTY-KLEIN: So he is...other than that, he is fantastic. We're very fortunate. [LB1067]

SENATOR PANKONIN: That's good. We'll see if there's other questions. Seeing none, thank you for coming today. [LB1067]

TIFFANY MYTTY-KLEIN: Thank you very much. [LB1067]

SENATOR PANKONIN: Next testifier as a proponent. Welcome. [LB1067]

MARCI SMITH: (Exhibit 2) Hello. My name is Marci Smith, M-a-r-c-i S-m-i-t-h. Thank you so much for the opportunity to voice my support for LB1067. I applaud Senator Rogert for developing the bill, and I hope the Nebraska Legislature will carefully and

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compassionately consider the positive impact this bill could have on the lives of Nebraska newborns. My daughter Leila was born with a severe, and oftentimes fatal, congenital heart defect called hypoplastic left heart syndrome. Simply put, she was born with half of a heart. The left side of her heart was severely underdeveloped, and without treatment, HLHS is uniformly fatal. My pregnancy with Leila was quite normal. Both a 20-week and a third trimester ultrasound failed to divulge the heart defect. Leila was born full term at 4:00 a.m. on May 24, 2003, at St. Francis in Grand Island. She was normal size and showed no signs of distress. She passed all of her initial assessments and, as far as we knew, she was perfectly healthy. What we didn't know was that there was a major heart defect lurking in her little chest, and it was uniquely undetectable by listening with a stethoscope. After eight hours after birth, Leila started to show trouble. She was refusing to eat so a lactation consultant was called in to assist. This specialized nurse noticed a blue tinge to Leila's lips. After listening with her stethoscope and hearing nothing out of the ordinary, as many other nurses and doctors had done before her, she decided to try another test, the pulse oximeter. This test revealed that Leila's blood oxygen level was only 80 percent and normal is 100 percent. The next 12 hours Leila was observed by two doctors and several nurses in the nursery and treated for possible aspiration pneumonia, but her condition was worse. It was clear she was in trouble and 24 hours after birth she was finally diagnosed by echocardiogram that she had HLHS. At one day old, Leila was life flighted to Omaha Children's Hospital from St. Francis in Grand Island. We were presented with three options for her treatment: she could have a heart transplant; she could have a series of three open-heart surgeries; or we could let her pass away. She was a full-size, full-term baby and we were told at the time that that was in her favor--that she was full term, good size, and that her heart defect had been detected early. So we chose the surgical route. We thank God that our wonderful nurse in Grand Island put that pulse oximeter on Leila. Her early intervention may have been the pivotal moment that actually saved Leila's life. At five days old, Leila underwent her first open-heart surgery--a massive and difficult replumbing of her circulatory system. At three and a half months old, Leila underwent a second open-heart surgery called the bidirectional Glenn. At four months old, we finally were able to bring her back home to Grand Island for the first time. And at three years old, she reentered Children's Hospital with a third open-heart surgery. Leila has had many challenges in her life due to her heart defect and in addition to her heart defect. She continues to have mediocre health status. She has asthma. She has developmental delays, physical delays, speech delays. But she is in kindergarten now and doing very well. At this point, we don't anticipate any more open-heart surgeries, but it's very likely she will need a heart transplant at some point in her life. Because of my experience with Leila, I was inspired to get involved with a small e-mail support group and ended up developing it into a statewide CHD support, awareness, and research organization. I served as the president and executive director for 2004-2008, and my position allowed me to meet hundreds of families in Nebraska that are affected by CHD. I have met a few of those families whose children were undiagnosed with heart defects and one family in particular whose child died because of an undiagnosed heart defect. I'm here today to

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give a voice to their suffering. Through my experience with these Nebraska families and my own experiences as a CHD parent, I've learned some unsettling facts and things I'd like to pass along. First, many heart defects left undiagnosed and untreated can and do result in death. Heart defects left undiagnosed can cause serious damage to the brain, kidneys, liver, lungs, and stomach. If diagnosed late, CHD babies may not be healthy enough to undergo surgical treatments and may require extended hospital stays to stabilize their condition for further treatment. Traditional newborn assessments include listening to heart sounds with a stethoscope. But as in our experience with Leila, even the most severe heart defects can go undetected with a stethoscope. CHD is the number one occurring birth defect and the number one cause of birth defect related deaths, yet there's no standard procedure for diagnosing CHD in newborns, unlike other substantially less frequently occurring and less fatal diseases. Statistically we know that there are children and adults in Nebraska dying each year from undetected heart defects. Whether it's 1 or 10 or 100, using pulse oximetry could be an effective tool to prevent those deaths. I urge you to consider the passage of this bill. By requiring the use of pulse oximetry on newborns, you'll be saving the lives of Nebraska babies. In studies of hospitals testing pulse oximetry screening in newborns, heart defect detection was higher and death rates were lower. Every hospital already has the equipment. Healthcare providers know how to use it. The screening is noninvasive, unlike blood draws on newborns, it's quick, and it gives an immediate response. Please consider requiring pulse oximetry for newborns in Nebraska. It's time that we as a state put the focus on a childhood disease that is occurring in overwhelming numbers but never talked about. I thank you for your time. My husband and I thank God every day for the wonderful doctors and nurses at St. Francis Hospital and also at Omaha Children's Hospital for their clinical excellence and the care that they gave Leila throughout her hospital stays. Please help give every family the same opportunity that we have had to enjoy the blessing of watching our CHD child grow and thrive. [LB1067]

SENATOR PANKONIN: Thank you, Ms. Smith, for your testimony. And one thing I'm sure this committee would agree with me that your daughter and the previous testifier's son have two things going for them--great moms that care. So we appreciate you coming... [LB1067]

MARCI SMITH: Thank you. [LB1067]

SENATOR PANKONIN: ...and sharing that with us. And also want you to know that we've got a gentleman here from Grand Island has something to do with that... [LB1067]

MARCI SMITH: Yep, I know. [LB1067]

SENATOR PANKONIN: ...that outfit out there that you went to so we appreciate that. Any other questions? Senator Gloor. [LB1067]

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SENATOR GLOOR: Thank you, Senator Pankonin. I'm glad it went well at St. Francis. I'd like to meet Leila some day. [LB1067]

MARCI SMITH: Certainly. [LB1067]

SENATOR GLOOR: I'm sure we could probably arrange that since I get back there on occasion. But a question for you. Were you led to believe by the staff, whether it was the nurses, doctors, that it was the pulse oximeter that made a difference in their having concerns or raising the red flag? Or was it one of a number of tests that they were doing? [LB1067]

MARCI SMITH: Leila had been examined several times beginning right at birth and throughout her first day of life. Consistently they had used a stethoscope to listen to her heart, and that came up with no unusual results. She had trouble eating, starting about eight hours after birth. And so when the lactation consultant was brought in, she was trying to help that process along and noticed that Leila was blue in her lips. Essentially she was suffocating because she wasn't getting enough oxygen. And so once she listened, didn't hear anything odd with her heart sounds, she then went on to the next thing that she had available to her that was quick and easy and noninvasive to be able to test if there was something more going on with Leila and that was the pulse oximetry. [LB1067]

SENATOR GLOOR: Was she hooked up to a monitor of any kind? Do you know (inaudible)? [LB1067]

MARCI SMITH: After that point when they noticed that she was at 80 percent with her blood oxygen level, from that point on she spent the rest of her time in the nursery at St. Francis hooked up to monitors... [LB1067]

SENATOR GLOOR: Okay. [LB1067]

MARCI SMITH: ...administering antibiotics and monitoring and things like that. [LB1067]

SENATOR GLOOR: Okay. Thank you. [LB1067]

MARCI SMITH: Um-hum. [LB1067]

SENATOR PANKONIN: Thank you. Any other questions? Seeing none, thank you for your testimony and for coming today. [LB1067]

MARCI SMITH: Thank you. [LB1067]

SENATOR PANKONIN: Any other proponent testimony on this bill? [LB1067]

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MINDY DALRYMPLE: Hi there. [LB1067]

SENATOR PANKONIN: Welcome. [LB1067]

MINDY DALRYMPLE: My name is Mindy Dalrymple, D-a-l-r-y-m-p-l-e. I'm kind of a crier so. My daughter Claire was born in October of '08 at Bergan Mercy Hospital in Omaha, Nebraska. I experienced what I was led to believe was a normal pregnancy and healthy birth of a full-term baby. My baby had two pediatricians visit and assess her while in the hospital nursery. Neither doctor heard a heart murmur and her blood pressure initially showed no cause for concern. We brought her home at three days old and we didn't see any adverse signs until four days old when she wouldn't eat and had muscle tension in her legs and her cheek. At five days old she was rushed to Children's ER in an ambulance in Omaha. Upon initial examination, we were told that my daughter had kidney failure, liver failure, acidotic blood, and they gave her a 50 percent chance to survive that night. It took them hours to days to diagnose that she had two heart defects. After a couple of days when her body began to stabilize, an MRI revealed that because of the trauma from the shock which her body underwent from the undiagnosed heart conditions she had developed a grade 4 head hemorrhage. This delayed her surgery yet another six weeks while she stabilized from the head insult. We were in Children's Hospital PICU, pediatric intensive care, for two months until we were released. We met many other families like ours who were shocked to find out that their babies had gone undiagnosed. While we were there, we endured daily labs along with other invasive testing and even agreed to some genetic testing which revealed that the only cause for all of this was her two heart defects. The neurologists were uncertain what lifelong brain functions she would lose and led us to believe that she would need more help to overcome this. Therefore, I believe that there is a need to do better newborn screenings for congenital heart disease in all babies. This way we can catch these heart defects at birth before they escalate to the level of trauma that they did in my daughter. I wish I would have had the chance to monitor my daughter at birth. I'm unsure if it would have caught or led to further testing, but I sure would have loved to have tried. I was naive to believe that my husband and I were so healthy and that this couldn't happen to us. By monitoring a pulse ox, it helps parents like myself who have no clue how random and how common it is for babies to be born with birth and heart defects. I feel a strong need to mandate these screenings because birth defects are very common, and I would have never asked had I not been given an option on my own. Even if monitoring these babies on a pulse oximeter could catch one in every thousand heart defects, I think it would be well worth it. I would have given anything for that one in a million chance to have caught my daughter's. I'm looking for the state of Nebraska to help better protect future babies because the need for better screening is there.
[LB1067]

SENATOR PANKONIN: Mindy, thank you for coming. You did a great job. You did fine.

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So...you got to wait here for just a minute. We may have a question. Thank you for taking the seat again. We'll see if there are any questions. I'm sorry there isn't, but thanks for coming. You did fine. [LB1067]

MINDY DALRYMPLE: Thank you. [LB1067]

SENATOR PANKONIN: Any other proponent testimony? [LB1067]

CARRIE MILLER: My name is Carrie Miller, C-a-r-r-i-e M-i-l-l-e-r. I just have a short story. My daughter Claire is two and she was born with a congenital heart defect as well. She was born at Bergan Mercy, and I have a close friend that works there in the nursery. And she noticed that Claire was looking blue and dusky in color and did the pulse oximeter test on her and caught her birth defects. But she did pass her Apgar test to begin with, and we were told she was healthy. I don't know if I hadn't known Jody (phonetic), the nurse, personally if she would have caught her heart defect. I could be one of these three women here. I'm not, though, and I'm grateful for that. I just...I hope that you'll take a look at all the statistics and the numbers and listen to their stories and do the right thing. Thank you. [LB1067]

SENATOR PANKONIN: Thank you, Ms. Miller. We'll see if there's any questions. Seeing none, you're free to go. [LB1067]

DON WESLEY: (Exhibit 3) Mr. Chairman, members of the Health and Human Services Committee, I'm Don Wesely, here representing the Nebraska Nurses Association. I'm passing out a letter from Missy Fleck, who is a neonatal nurse who's got 20 years of experience. It's a very technical paper that goes through a number of items that I won't go over with you, but it's for your background. And also there's a reference sheet with some materials if you want to look up further some of the research that she did on this. The bottom line is that congenital heart disease occurs in about 1 percent of live births as was mentioned earlier. So it is a serious problem. Of all the congenital malformations causing infant death in the United States and other developed countries, critical congenital heart disease is responsible for more deaths than any other type of malformation. So this is a serious problem. That's the point there. Physical examinations fail to detect critical congenital heart disease in 69 percent of the cases. That's mostly how you find how a baby is doing, the physical exam. So this through different studies, 69 percent fail to detect it. So the physical examination route misses a lot. What this says later on in the report is that published studies have all reported that pulse oximetry is able to identify some newborn infants with critical congenital heart disease who are otherwise asymptomatic. I think you'll be hearing later from the Medical Association that it's not going to catch everybody, but with some individuals, some babies you won't catch a physical examination, but this testing at a very low price will catch some, will save some lives, and you won't hear some of the stories you just heard earlier. So the nurses do stand in support of the bill. [LB1067]

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SENATOR PANKONIN: Thank you, Don, for testifying. Senator Wallman. [LB1067]

SENATOR WALLMAN: Thank you, Chairman. Yeah, Don, thanks for being here. Do other states have something like this in place? Do you know? [LB1067]

DON WESLEY: I don't think so. [LB1067]

SENATOR WALLMAN: So we'd be a pioneer? That would be good, huh? [LB1067]

DON WESLEY: Well, we have on occasion actually in Nebraska. We're usually not. There are actually some examples in the past where we were the first state to do some things to try and help people that had needs. And I was around in this committee when we've done a number of the testing that we do now, PKU testing and other types of testing, on newborns to try and catch some things. And so we have taken the step before, and I would like to have you consider taking it in this case. [LB1067]

SENATOR WALLMAN: And do you think there would be any in opposition to this by new mothers or not? [LB1067]

DON WESLEY: By the new mothers? No, it's very noninvasive. It's just a little, yeah, it's hardly anything at all. [LB1067]

SENATOR WALLMAN: On your finger, isn't it, or something? [LB1067]

DON WESLEY: Yeah, yeah, and you're talking about very low cost so. [LB1067]

SENATOR WALLMAN: Thank you. [LB1067]

SENATOR PANKONIN: Thank you. Any other questions for Mr. Wesely? Seeing none, thank you. [LB1067]

DON WESELY: Thank you. [LB1067]

SENATOR PANKONIN: Other proponent testimony? Seeing no other proponent testimony, is there any testimony in opposition? Mr. Buntain. [LB1067]

DAVID BUNTAIN: Senator Pankonin, members of the committee, my name is David Buntain. It's B-u-n-t-a-i-n. I'm an attorney and a registered lobbyist for the Nebraska Medical Association. This is obviously an odd position to be in and I would say that we agree generally with just about everything that the proponents have said on this bill. We agree that there are issues with congenital heart defects. Obviously our profession is doing...wants to do everything it can to prevent that. We also agree that oximetry

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screening, pulse oximetry screening is a tool that can be used and is part of several things that professionals do to try to ascertain whether there are congenital heart defects. Our concern is that this is a matter of standard of care that the Legislature should not be put in the position of legislating standard of care. There's no indication in the situations you've heard about that had the Legislature required pulse oximetry that the problem would have been caught. The predictive value of this test is not as high as, for example, the blood testing that's done during newborn screening. And rather than have the Legislature, based on specific situations related to you, require across-the-board testing of all infants, we think that it is better left to the professions. This is an evolving area as was indicated, this particular test wasn't even available until the 1970s. I think the reason you don't see other states legislating in this area is that it is a matter of standard of care within the hospitals and the healthcare community rather than a matter of legislation. So again, I realize that it may not be the solution that the proponents want to hear, but, you know, we'd be happy to work with the advocacy group as far as raising awareness of this issue and improving the practices to the extent we can have input into that. Our ob-gyns and our pediatricians are concerned about this issue, but they don't think the Legislature should be telling them what tests they should do or how they should be practicing in this area. [LB1067]

SENATOR PANKONIN: Thank you, Mr. Buntain. Any questions? Senator Gloor.
[LB1067]

SENATOR GLOOR: Thank you, Chairman Pankonin. Mr. Buntain, on one of the handouts, the handout from the Nebraska Nurses Association, there are a couple of references here to oxygen saturation as screening test for critical congenital heart disease. One is from the Pediatric Cardiology journal; the other is from Pediatrics.
[LB1067]

DAVID BUNTAIN: Right. [LB1067]

SENATOR GLOOR: I mean I'm just wondering...I'm assuming these are an argument for as opposed to against or they wouldn't have been included as references. But has any of that...how does the Nebraska Medical Association take a look at some of those studies, as an example, to decide if, like some of the other newborn screenings that AMA has been supportive of, that maybe it's time yet for another one? [LB1067]

DAVID BUNTAIN: Well, I'm not familiar with what you've been handed or with the studies. The input we have are from physicians who practice in this area who indicate that, yes, pulse oximetry is a valuable tool in diagnosing congenital heart defects. A lot depends on when it is done. And I think at least one case you had a situation there are certain indications where...which would suggest using pulse oximetry. There are many times where you can have, you know, a standard or acceptable test and it hasn't detected that there's a congenital heart defect. So I think part of our problem is singling

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this out and saying, well, this is the solution rather than, you know, that it's one of a number of tools which a good practitioner, good hospital should have available. [LB1067]

SENATOR GLOOR: And that's probably why I will look up these references just to see if the articles, in fact, say this is the test as opposed to this is one of the multiple tests that should be done looking for... [LB1067]

DAVID BUNTAIN: Right. [LB1067]

SENATOR GLOOR: I don't know what it says specifically. [LB1067]

DAVID BUNTAIN: And I'd be happy to put some of our physician experts in touch with you on those issues. [LB1067]

SENATOR GLOOR: Okay. Thank you. [LB1067]

SENATOR PANKONIN: Senator Campbell. [LB1067]

SENATOR CAMPBELL: Thank you, Senator Pankonin. And I don't see anyone here from the Department of Health and Human Services, but we did receive a letter from Dr. Schaefer (Exhibit 4). And I would hope in any conversations that you might have or Senator Rogert might have on this would be with Dr. Schaefer. One of the things that she calls into question in the letter is the relatively high false positive and false negatives, differences in oxygen in where you do the test, and also depending upon the pigment of the skin, how reliable the tests might be. So I really think there are some questions here, and I would just hope that Dr. Schaefer would be brought into the conversation. [LB1067]

DAVID BUNTAIN: Yes. And again, I've not seen her letter, but we would be happy to work with the department on that. [LB1067]

SENATOR CAMPBELL: Right. And we kept looking, I think Senator Gloor and I were going, is there going to be a medical expert, you know, a nurse, in terms of...or a doctor that works with the test just because of Dr. Schaefer's questions. [LB1067]

DAVID BUNTAIN: Right. I guess I would just add this is the first time that this issue has been brought to the Legislature. And again, it's apparently new nationally. And with so many issues, there's an educational process involved, and we would be happy to work with the advocacy...with the advocates of this to see what can be done. [LB1067]

SENATOR PANKONIN: Thank you, Mr. Buntain. I see no other questions. Others that would like to testify in opposition to this bill. Anyone to testify in the neutral position on

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LB1067? Yes, sir, come forward. [LB1067]

DAVID SUNDBERG: I'm David Sundberg, S-u-n-d-b-e-r-g, and I represent the Nebraska Association of Insurance and Financial Advisers. And our position with any requirements or mandates is the word we all hear bantered around from Washington to here and that's the cost of the health insurance. And when we talk about adding requirements and adding mandates, then we're increasing the cost of healthcare. And our position would be neutral and we would just ask you to consider the consequences of adding on mandated requirements or benefits. [LB1067]

SENATOR PANKONIN: Mr. Sundberg, thank you. And did you bring a testifier sheet? Do you have a testifier sheet? [LB1067]

DAVID SUNDBERG: Yes, I put it in earlier. [LB1067]

SENATOR PANKONIN: Okay, good. I'm sorry, I missed that. Thanks for coming. We'll see if there's any questions. Seeing none, thank you. Thanks for being with us. Any other neutral testimony? [LB1067]

SENATOR HOWARD: Did you make mention of Joann's letter? [LB1067]

SENATOR PANKONIN: (Exhibit 4) That's true. Thank you, Senator Howard. And it was mentioned, but for the record we did receive a letter from Dr. Joann Schaefer, Chief Medical Officer of the state of Nebraska, that could either be considered in opposition or neutral, but it had a number of questions as Senator Campbell has alluded to that we will need to further investigate. Thank you, Senator Howard. Okay, Senator Rogert, if you'd like to come to close. [LB1067]

SENATOR ROGERT: Briefly. Thanks for everybody coming down and testifying. I know it's tough to do. Senator Campbell, if you'd look in the information handed to you by the nurses, Mr. Wesely's information. [LB1067]

SENATOR CAMPBELL: Okay. [LB1067]

SENATOR ROGERT: On the second page it does mention in there that studies suggest false positive rates of less than a tenth of a percent when the test is done after the first 24 hours of birth. I think we often get lots of different stuff after the stress of birth and it's hard on the heart and hard on the skin and everything for the baby. So a lot of those things go down if you wait until that second day to test it. So it's not something that needs to be done...it needs to be done in the first 48 hours. It should be able to...probably be best within that second day. And I understand the Medical Association's position and the insurance guy's position. I know that mandated care and legislating a standard of care is never something that sits well with everybody, and I normally would

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agree with that. I've heard today while I was wandering the halls between here and the other bills I had up that I visited with a couple of other folks and they said there are doctors that are doing this. I think that's great. I think there's a lot of them that aren't and hospitals that aren't. And this today is, if nothing else, to put the...put a face to the issue and get it out in front for discussion. And how much money is too much money? That's always a question that's asked of you guys a lot in this committee. How much shall we spend for a little bit of investment to just hopefully save a lot of money down the road? And that's what we have to decide and draw the line and that's what I request to think about in this issue. [LB1067]

SENATOR PANKONIN: Senator Rogert, thanks for coming. And as you know, Senator Wallman has a question, too, but I'm going to ask one first. As you know and just for the fact of the folks being here, oftentimes when an issue is raised, it maybe doesn't happen the first time around. But I think you've raised an important issue that there will be further discussion as even indicated by Mr. Buntain. So I think we all appreciate you bringing this issue so we can start to talk about it. [LB1067]

SENATOR ROGERT: Great. No problem. [LB1067]

SENATOR PANKONIN: Senator Wallman. [LB1067]

SENATOR WALLMAN: Thank you, Mr. Chairman. Yeah, thanks for bringing this forward. I think that maybe the hospitals now will put literature out, you know, that it's available and so it would be nice. [LB1067]

SENATOR ROGERT: Yeah. I think there's a lot of ways that we can continue to talk about it. [LB1067]

SENATOR PANKONIN: Thank you. Any other questions? Seeing none, that concludes the hearing on this bill and also all of our hearings for today. Thanks, everyone, for your attendance. [LB1067]