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Transcriber's Office

Health and Human Services Committee
January 25, 2008

[LB806 LB809 CONFIRMATION]

The Committee on Health and Human Services met at 1:30 p.m. on Wednesday, January 25, 2008, in Room 1510 of the State Capitol, Lincoln, Nebraska, for the purpose of conducting a public hearing on gubernatorial appointments, LB806, and LB809. Senators present: Tim Gay, Vice Chairperson; Philip Erdman; Tom Hansen; Gwen Howard; Dave Pankonin; and Arnie Stuthman. Senators absent: Joel Johnson, Chairperson. []

SENATOR GAY: It's 1:30. I'd like to call the Health and Human Services Committee meeting to order, as soon as Senator Howard settles down. (Laugh) I'm going to call the meeting to order. (Laughter) It's a Friday afternoon. I'd like to introduce the committee first: Senator Gwen Howard, Senator Tom Hansen, Senator Arnie Stuthman, our clerk Erin Mack, I'm Tim Gay, our legal counsel Jeff Santema, and Senator Dave Pankonin here today. Senator Erdman will be joining us later and Senator Johnson is away today so he won't be with us today. Just a few rules I wanted to go over quickly is if you have any cell phones, please turn those off for obvious reasons. What we'd like to do here today is in order to give everybody a fair hearing, if you're at the first of the agenda or the last agenda is the opening and closing will allow some leniency as long as you want, but if you're a testifier we'd like to keep that to five minutes. Erin will help time that and I'll just give you the "let's wrap it up" signal. But I do think in between and if...so we're not repetitive again and again hearing the same things, we'd ask for your help with that. Any questions that we ask you would of course not be allowed into any of your time. So feel free to go ahead and answer those completely as well. But during testimony, if we could limit that and not be repetitive, it would certainly help. So we are going to start the day today. And also just one thing, if you could sign in when you come in, we'd appreciate it. And state your name and spell your name out for the clerk; it helps, so appreciate that. We'll get started today. We have a confirmation hearing--John Hilgert for the Nebraska Department of Health and Human Services veterans' department. John, welcome. [CONFIRMATION]

JOHN HILGERT: (Exhibit 1) Thank you, Senator Gay. Good afternoon, members of the Health and Human Services Committee. My name is John Hilgert, J-o-h-n H-i-l-g-e-r-t. I began as director of the Division of Veterans' Homes for the Department of Health and Human Services on July 1. I'm honored that Governor Heineman appointed me to this position and would appreciate your confirmation of his appointment. Let me start quickly by sharing a little information about myself, my education, military service, and background. I graduated with a bachelor's degree in business administration from the University of Nebraska of Lincoln and earned my law degree from Creighton University School of Law in Omaha. My schooling continued but in a different way when I joined the United States Army in 1989 to 1992. I was a captain in the Army, part of the Judge Advocate General's Corps. The Judge Advocate General's Corps is composed of Army officers who are also lawyers and provide legal services to the Army at all levels of

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command. 1990 and 1991, I served in Operation Desert Shield, Desert Storm in the First Infantry Division. My education and military experience led me to pursue some exciting opportunities in public service. I was appointed to the Nebraska Legislature in 1995 to represent Omaha in District 7. I served two terms as a state senator and resigned my position in 2001 to accept an appointment as director of the Nebraska Department of Veterans' Affairs. It's a responsibility I continue to hold to this day and I consider that an advantage, giving me a better perspective to serve as the director of the Division of Veterans' Homes. I also worked for ten years for Catholic Charities in Omaha as a senior director, specifically as vice president for institutional advancement. On a personal note, I live in Omaha, lived in Omaha my entire life except of course when I was serving in the Army. I met my wife Cara in Omaha and we've been married since 1995. We have two children: Jack and Caroline, and enjoy being involved in the things that make them happy, like soccer, piano, ballet. My son Jack is also a cub scout and I'm currently serving as assistant cub master of his pack. When the Health and Human Services System restructured in July, we were given a unique opportunity to highlight our veterans' homes and create a more unified system across the state. The four homes--located in Bellevue, Norfolk, Grand Island, and Scottsbluff--focus on wellness and allowing people to live their lives to the fullest extent possible. We've been able to look at best practices from the four homes and we do what works best systemwide. The new structure has made a huge impact on the veterans' homes and I'm excited to be part of that process. I also look forward to continuing to work with CEO Christine Peterson in providing leadership for the Division of Veterans' Homes. In the first six months as the director, the division has moved ahead in several areas. We've successfully opened the new Eastern Nebraska Veterans' Home in Bellevue. We celebrated 120-year anniversary, Grand Island Veterans' Home. For the first time in two years, all of our homes are probation-free. We're putting new emphasis on survey readiness, which is a series of self-inspections to make sure that administrators and staff are checking their facilities, listing deficiencies and correcting any problems that they find. We will continue to strengthen this process, so we are always improving our facilities and always ready for inspections. We've also increased the census in the Veterans' Home Division as we continue to strive to operate at full capacity. We've hired new administrators and reduced staff turnover and the mandatory overtime that some of the homes were experiencing. For quality and consistent care, we believe it's best for the members when they are served by staff they know and who know them. It makes everyone more accountable and creates a positive difference in the quality of life for our members. I'm excited to be part of history and serve as the first director of the Division of Veterans' Homes and look forward to continuing to build a division that's responsive and better positioned to serve Nebraska's veterans. I would be more than happy to answer any questions that you might have at this time. [CONFIRMATION]

SENATOR GAY: Thank you, John. Are there any questions? Senator Hansen.
[CONFIRMATION]

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SENATOR HANSEN: Thank you, Senator Gay. John, nice to see you again.
[CONFIRMATION]

JOHN HILGERT: Good to see you, sir. [CONFIRMATION]

SENATOR HANSEN: When we were on a tour this summer, we learned about the 75-25 rule in veterans' homes where no more than 25 percent can be nonveterans, including spouses I believe it was. Has anything...do you think anything could be done with that? Because we have empty beds in Scottsbluff. [CONFIRMATION]

JOHN HILGERT: Senator, you're certainly on point and correct when they said there was a rule, but it's a rule that's in the federal system and we certainly can't change that rule. We could ask for that, we could look for an exemption, a waiver of some type. But the issue that you raised at that time at the legislative hearing kind of guided us into looking at how we do things. For example, there's been a bill before the Legislature for decades about peacetime veterans being allowed into the home. They would be counted as those nonveterans. We found out that in fact those would be counted as veterans. We have...we're looking at how would we...for example, if a wartime veteran is in one of our homes, they're able to access services with the United States Department of Veterans' Affairs. How would...if we expanded the peacetime, should we be requiring a Medicaid, Medicare supplement; Medicare Part D? These are the things that we are looking at. So your suggestion and your observation was certainly on point in Scottsbluff and has led us to look on how we do these services. Furthermore, in Scottsbluff in particular, we do have a waiting list for nursing care. We don't have a waiting list for assisted living, which was the beds that your study team had identified. One of the things we're looking for is if we do have people waiting for nursing beds but yet we don't have any, how could we convert perhaps some of those assisted-living beds to nursing beds, and how do we make those assisted-living beds more competitive with the private sector for the veterans in our Panhandle? So we've started looking at quite a number of things. To answer you directly though, we have not submitted a waiver to waive that. I think that the secretary himself would have to do that. But it has raised a lot of issues and our research is expanding because of your inquiry. [CONFIRMATION]

SENATOR HANSEN: Thank you for looking into it. [CONFIRMATION]

JOHN HILGERT: Absolutely, Senator. [CONFIRMATION]

SENATOR GAY: Are there any other questions for John? John, I have one just comment, I guess. When we toured the Bellevue facility, Bellevue Veterans' Home, I asked you about regulations that were maybe unnecessary or a duplication. And I said, well, who gives you the most, and I think you made a comment maybe just off the cuff, but...well, the state gives me many. But is there ways that we can help you to get rid of some of those? [CONFIRMATION]

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JOHN HILGERT: And I probably spoke and misled you, and I apologize for that, Senator. What I meant to say is that we're the most...that we're fairly highly regulated because we have the state coming in and doing inspections, be they a regular scheduled inspection or as a result of a complaint or a concern. We also have our federal partners, since they're a primary funder of our per diem for our veterans and the construction of facility, inspect us as well. So we do have a lot of inspections coming in. I don't think that that's necessarily a big problem right now. In fact, we're positioning ourselves that it really doesn't matter. We're becoming survey-ready and we're addressing...we should be able to be inspected by whatever authority and it shouldn't be onerous because we should be providing high-quality care and we're going to that direction. You know, as I referenced, not a single home is on probation and in fact our East Nebraska Veterans' Home was licensed after, I think, July 19, if I'm not mistaken, as a deficiency-free facility. Obviously the East Nebraska Veterans' Home is the follow-on facility from the Thomas Fitzgerald Home. So I can't say enough about the staff that helped us get to that deficiency-free status. So I don't see it as a huge problem, Senator, but I appreciate your willingness to help us out and would certainly avail ourselves of our assistance should we need it. [CONFIRMATION]

SENATOR GAY: Okay. Senator Pankonin. [CONFIRMATION]

SENATOR PANKONIN: Thank you, Senator Gay. John, what group surveys veterans' homes? Is it a federal group or is it... [CONFIRMATION]

JOHN HILGERT: We have the state and the federal. The federal has a VA team that comes in and it's made up of long-term care experts and the United States Department of Veterans' Affairs out of our VISN--veterans integrated service network. Many states, Nebraska and western Iowa is a subset of the VISN. But suffice it to say the regional authority for the veterans' health administration, part of the USVA comes in and does our surveys. [CONFIRMATION]

SENATOR PANKONIN: But does the state, do they do it concurrently like one and then the next time you get the state, or how does that work, the survey schedule? [CONFIRMATION]

JOHN HILGERT: They operate independent of each other. [CONFIRMATION]

SENATOR PANKONIN: So they could be there a week apart? [CONFIRMATION]

JOHN HILGERT: They could be a week apart or they could be six months apart or...especially if it's driven by a complaint or a concern. [CONFIRMATION]

SENATOR PANKONIN: You know, as you know, we've had other facilities that are

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related to Health and Human Services that have had problems in this area. And is there any sharing of information and where you had this relative success? How can we, when we have these other problems, how can we share that information or what's the key here that we can do differently, or... [CONFIRMATION]

JOHN HILGERT: Well, I'm really proud to be asked that question. We had 120 years of inertia and we've been a division for 6 months, after you passed LB296. So we've come a long way. We have all of our administrators, three of them are retired military, one served the military. So we kind of...and maybe some of you have heard this term "combat readiness." It's something that a unit always should strive towards. They should be ready at all times. The same type of theory we try to inculcate in our veterans' homes, that we should be ready for a survey whether it's March or January or December. We are planning on sharing some of our best practices with the other division directors; for example, how we track maintenance projects, how do we identify them as identified deficiency maintenance projects versus self-identified deficiencies in our maintenance projects. And our survey readiness person, Pat Moeller is our systems clinician and she not only...we plan on presenting to our other division directors. But, Senator, you might be interested to know that the United States Department of Veterans' Affairs asked us to maybe put something together so they could show it to other homes within our multistate area. [CONFIRMATION]

SENATOR PANKONIN: Well, that's the point, that obviously if you've had this relative success, then we need to try to share that within the other divisions to try to bring up the whole system. [CONFIRMATION]

JOHN HILGERT: Well, I always go back to the staff as the number one reason we're successful. And, Senator, I don't want to share them with any other division. (Laughter) [CONFIRMATION]

SENATOR GAY: Are there any other questions? John, one minute. The Eastern Nebraska Veterans' Home, I wanted to give yourself one commercial here because you moved from Thomas Fitzgerald to...can you explain that process in one minute, because I think it's amazing how well it went. [CONFIRMATION]

JOHN HILGERT: Well, I certainly couldn't do it one minute. [CONFIRMATION]

SENATOR GAY: Or two, we'll give you... [CONFIRMATION]

JOHN HILGERT: But you know, we had Bob Muthard was our facility operating officer, and his nickname was "Bob the Builder," if you will. He kind of took that on as a personal passion. And we were able to move our equipment ahead of time in a phased approach. And it finally came down to one day where in the morning everyone was at the Thomas Fitzgerald Veterans' Home and in the evening everyone was at the Eastern

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Nebraska Veterans' Home. We asked and we received volunteers from the United States Air Force, Strategic Air Command assets at Offutt Air Force Base, and we had moving buddies where two active duty service people would basically be the moving buddy of each one of our members. They would get to know them, they helped them pack, they helped them shepherd their personal belongings, and they accompanied them, having preestablished a relationship, on that day of the move. When the members arrived at the facility and the buses and vans, we had over, I believe, 100 Air Force personnel waiting for them and greeted each one of them like a hero's return. And we wanted to welcome them home. And truly this is their home. And it was a very emotional day and a wonderful event and one of our volunteer veterans' service organizations sponsored the dinner that night. And it happened and it happened within just about, I think about a four-hour time frame was when the first veteran arrived and the last one arrived. And it was done seamlessly and you should have seen the look on their faces when the bus opened up and you'd have all these, you know, 100 folks in uniform cheering. It was a wonderful event and one I took my family to. I wanted them to see what this is all about and why we're in the service that we're in. [CONFIRMATION]

SENATOR GAY: Thank you very much. That's a great example of what Senator Pankonin was...the staff and just incorporate. That's a great story. [CONFIRMATION]

JOHN HILGERT: Thank you, Senator. [CONFIRMATION]

SENATOR GAY: Thank you very much. I don't see any further questions. Thank you. [CONFIRMATION]

JOHN HILGERT: Thank you. [CONFIRMATION]

SENATOR GAY: Next up, Todd Landry, Nebraska Department of Health and Human Services for the Division of Children and Family Services. Welcome. [CONFIRMATION]

TODD LANDRY: (Exhibit 2) Good afternoon, Senator Gay, members of the committee. My name is Todd Landry, L-a-n-d-r-y. I began as director of the Division of Children and Family Services for the Department of Health and Human Services on July 23, 2007. I'm honored to have received Governor Heineman's appointment and confidence in me for this position and would appreciate your confirmation. Just to share a little bit of background, previous to coming to this role I served as president and CEO of Child Saving Institute, a child welfare agency in Omaha. Prior to that I was president and CEO of Spaulding for Children in Houston, Texas. And before that and before coming in to the children and family-centered programs in this sector, I spent 13 years with Conoco energy company working in various divisions ranging from investment appraisal, international business development, marketing, and others. I've also been involved in several advocacy and professional groups that you can see there in my written testimony. From an educational background, I graduated from Lamar University

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in Beaumont, Texas, with a bachelor's of science degree and received a master's in business administration degree from Southern Methodist University. On a personal note, my wife Kari and I have one daughter, Madison, who is 13 years old. The new department and division structure has provided me with the opportunity to really focus on my areas of responsibility, which include administering the state's child welfare, juvenile justice, protection and safety, and economic and family support programs, overseeing the department's five geographic service areas. My division's focus is to provide the least disruptive services when needed for only as long as needed to give children the opportunity to succeed as adults, to help the elderly and disabled live with dignity and respect, and to help families care for themselves, resulting in healthier families and safer, more prosperous communities. I'd like to share with you just a few of the division's successes over the past several months, and more are listed in my written testimony but I'll just hit a couple of them. One is we were eligible and received high-performance TANF bonuses in several areas. For example, we're one of six states in food stamp accuracy and one of the top four states in the country in the negative error rate for food stamps. We're currently ranked eighth nationally in the collection of current child support. We've decreased the number of state wards, an important goal of ours and the Governor's. We're now under 7,000 state wards for the first time since July of 2004. State wards reached an all-time high in our state of over 7,800 in April of '06. We are also top in the nation, number one in the nation in the federal outcome of establishing permanency for children in foster care for long periods of time. We've also increased finalized adoptions of state wards by over 50 percent from 2003 to 2006 and in an effort to become much more transparent to the public, we introduced COMPASS, a Web-based interactive database that clearly shows to everyone how we're performing on key federal measures. But we are also facing some major challenges. For one, our child support enforcement program did not recently meet the federal reliability standard for paternity establishment in a fiscal year 2006 audit. We've implemented a corrective action plan to ensure that we pass the audit next year. We continue to have a very high rate of children in out-of-home care, higher than virtually any state in the country according to a 2004 CWLA--Child Welfare League of America--report, and we have to do more to move children to permanency more quickly, to keep children in their home whenever safely possible, provide placement stability while they're in our system, and achieve timely reunification when appropriate. Another major challenge is meeting the needs of youth 16 to 18 years of age served through our Office of Juvenile Services, and we have much work to do there. Regarding our goals for the division, you can see them listed there, but maybe most importantly in our child welfare area is: improving on our child and family services review outcome, that federal review is scheduled for July of this year; creating a balanced array of services that really supports in-home placements; flipping, if you will, our current status of 70 percent of state wards being served in out-of-home care so that by 2011, 70 percent are receiving appropriate, safe in-home services; and reducing the number of state wards to 6,000 by a year from now. We also need to keep the focus on our food stamp accuracy, strengthening our child support enforcement program, and increase our TANF work participation rate. There

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are others listed there, but to sum it up: I realize that this division has a ways to go, but I believe we can make a very positive difference to our children and families. By collaborating with our partners, I believe we can ensure our kids' safety, permanency, and well-being. And while there's more in my written testimony, I'll open it up now to any questions that you may have. [CONFIRMATION]

SENATOR GAY: Thank you, Todd. Any questions? Senator Howard.
[CONFIRMATION]

SENATOR HOWARD: Thank you, Senator Gay. I really want to thank you for the work that you've done with children. You and I have had a number of conversations and I'm glad you've come on board with Health and Human Services. One of the recent developments that I've been really pleased about was I've learned that Child Saving Institute has gone smoke-free in their foster homes, which I think is wonderful and I really encourage you to continue to work in that direction with our state foster homes. I know that your concern is that children are safe in foster care as well as when they're able to be returned home. So I appreciate your work in that area and hope we can continue on the smoke-free track. [CONFIRMATION]

TODD LANDRY: Well, certainly we want to make sure that all of our kids are safe, particularly kids that are in our care and, as you said, in our foster homes or in some other type of congregate care, and that is certainly one aspect that we'll continue to look at among many in order to make sure that our kids are receiving the best in services that they can receive and making sure that they're safe at all times. [CONFIRMATION]

SENATOR HOWARD: Thank you. [CONFIRMATION]

SENATOR GAY: Senator Hansen. [CONFIRMATION]

SENATOR HANSEN: Thank you. Todd, it's good to have you here today. What is the number per capita that Nebraska should be for state wards? [CONFIRMATION]

TODD LANDRY: Well, if you look at...the absolute number is a little bit hard to say. But what I can tell you is, if we were the national average, if we were just the median state in the country based on that 2004 Child Welfare League study, we would have about 4,000 kids in our custody. And certainly that's a number that we are aiming towards. We didn't get to over 7,000 kids overnight, we're certainly not going to reduce that number overnight, but we're heading in the right direction and I believe we're doing it in the right way. One of the big questions that I personally had when the Governor came out with his initiatives in the summer of 2006 was to say, okay, but are we going to do it right or are we just going to simply push these kids back into their homes just to have them, quote, unquote, bounce back into our system. What I have found is that we are doing it the right way because at the same time that our total number of state wards has

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dropped from 7,800 to below 7,000, our reentry rate, our rate of kids coming back into care after being placed in a permanent situation or back home, has actually gone down. So right now, to maybe use a bad colloquialism, we're having our cake and eating it too, in that we're reducing our total number of state wards but we're also keeping them safe when we return them back home or to a permanent outcome. That's the kind of work that we need to continue to do. Our staff is absolutely committed to achieving that and they're focusing on the pieces that matter to help make it happen. [CONFIRMATION]

SENATOR HANSEN: Thank you. One follow-up question, I guess. Since it's been introduced, we have a bill in the Legislature this year to privatize foster care. Like to get your input on that. And then do you think that would be worthy of an interim hearing? [CONFIRMATION]

TODD LANDRY: Well, I appreciate the question. I'm sure that we'll have an opportunity to have a much more complete and full dialogue about the bill that was introduced. And so I'll save a lot of the specifics for that in recognition of your time restraints today. But in general, I think it's something that we always want to look at. We always want to see how can we be the most efficient and most effective in achieving the outcomes that we're trying to achieve, of safety, permanency, and well-being for our kids in the child welfare system. In general terms--very, very general terms--I do have a fundamental belief that we are usually best served when you do not have the same entity that's being the funder, the provider, and the evaluator. And I think for any of our services, what we need to do is ask the question, how can we make sure that we're getting the outcomes that we want and potentially consider not having either us or someone else fulfill all three of those roles? But it is much more complicated than that, obviously. It involves a significant question that we have to address of how to make sure we're providing services across our entire state in both rural and urban areas. And we have to make sure that if we go in that direction, we have the pieces in place to make sure that we're going to be able to hold everyone accountable--ourselves as well as the providers that we may contract with. [CONFIRMATION]

SENATOR HANSEN: Thank you. [CONFIRMATION]

SENATOR GAY: Senator Pankonin. [CONFIRMATION]

SENATOR PANKONIN: Thank you, Senator Gay. Todd, obviously you've been on the job about six months now and I know you've got a full plate. But one of the issues that came up last year consistently was the issue of staff retention, caseworkers specifically and training and some of those issues related to that. I noticed it was on your list of challenges, although I know there's a lot of challenges. But how do you feel we're doing in this area recently and what are your plans for continuous improvement there? [CONFIRMATION]

TODD LANDRY: Well, certainly one of the key components to achieving the outcomes that we want to achieve is consistency in our caseworkers and our case supervisors. That's certainly a very vital component, one that we are focusing on. We are always looking at what our turnover rates are by category of staff. And I will share with you that I think our turnover rates are too high and we need to do more in order to retain our staff and retain our quality staff. There are several things that I think we're doing to make steps in the right direction on that. But first, before I get into that let me say that our overall turnover rate right now as a division in all of our area and all of our levels is about 20 percent, 20 to 25 percent. Now that compares nationally to something like around 40 percent. So we're significantly below the national average. But you know what? When you're talking about individual cases, whether it's one time or ten times, it matters tremendously on those individual cases and we know as a rule it extends the process every time you have a changeover. And so we need to do a better job about that. One thing that we have done, we have taken a hard look at our training program. Our training program right now is a six-month program that involves classroom as well as in-field work, and we're doing a pilot right now for two cohorts of training groups, one in Omaha and one in Lincoln. To shorten that up, we're doing a condensed training program of six weeks, intensive in classroom, and then immediately getting them out in the field, pairing them up with an experienced mentor, experienced caseworker or supervisor that then works with them for an extended period of time. And we're testing that out to see a couple of things. One; does that help retain our staff, because we lose too many in a six-month training process. But also, are we getting the kind of outcomes that we need as far as experience and skills once these folks get into the field? So we're looking at those as, you know, that's one example of how we're trying to address the issue of staff retention while at the same time making sure that our staff are completely prepared for what they're going to face in the field. But it is a significant issue and one that we'll continue to work on. [CONFIRMATION]

SENATOR PANKONIN: Thank you. [CONFIRMATION]

SENATOR GAY: Thank you. Anything else? Senator Howard. [CONFIRMATION]

SENATOR HOWARD: I have to thank Senator Pankonin for bringing up that issue. That's really important. I'm glad you remembered to ask about that. The turnover and the training are really critical in this. But the comment I wanted to make was, I always have concerns about privatization. I've seen firsthand when I did case management the contracts that we had regarding adoption with the department. And I think we need to be very cautious before we move in the direction of privatization and to always remember that service delivery is the primary, our primary mission, to reach the goal of permanency for the children that are in our care, whether it's through a return home or through a permanency in adoption. I think that one of the key things to remember is, number one, it hasn't proven to be financially less costly to privatize clearly. And the second, and just as important, is to remember always that the responsibility remains

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with the Department of Health and Human Services, even if it's subcontracted to another agency. So the primary care and concern of the child remains with the department. [CONFIRMATION]

TODD LANDRY: Senator, you're obviously exactly right on that, and on point. That is why I think if we move in any direction, we need to do so cautiously and to make sure we've got all the pieces in place in order to support it. I will say that, you know, that when the Legislature passed LB296, when the Governor decided to sign LB296, we heard very loud and clear--from the Legislature, from the Governor, from the advocates, from our families and youth most importantly--that the current system was not working to support them and we were not getting the outcomes that we needed. We had to change in order to improve those outcomes. As a result, I'm coming into this with a fresh set of...trying to have a fresh set of eyes. This is my first time to work in a government role and I want to look at everything. I want to put it all out on the table and say what are the best ways that we can go about achieving the results that everyone wants us to achieve. It means that we're going to have to change. What we have to do is make sure we change in a smart way and a way that's going to get those outcomes that we so dearly want. [CONFIRMATION]

SENATOR HOWARD: Thank you. [CONFIRMATION]

SENATOR GAY: Thank you. Are there any other questions? I don't see any. Thank you for your service. I know it's a very difficult position. And this is on behalf of the whole committee, I'm sure I can speak for everyone, we truly appreciate it. I see Chris Peterson is back there and the new staff that is in place, and like you say, it's your first time on board. I think there's exciting things happening and anything we can do to help you... [CONFIRMATION]

TODD LANDRY: Thank you very much, Senator. I appreciate that. [CONFIRMATION]

SENATOR GAY: You bet. Thank you. Okay, with that we'll close the appointment hearing and we will move to LB806. Senator Wallman is here. It's to change provisions relating to dog guides, hearing aid dogs, and service dogs. Welcome, Senator Wallman. [CONFIRMATION]

SENATOR WALLMAN: Thank you, Chairman Gay, members of the committee. Pleased to be here. LB806 is intended to clean up some of the language in the Nebraska Revised Statutes to comply with the Americans with Disabilities Act. Currently in our statutes we have language that uses dog guides, hearing aid dogs, service dogs. This would make it all consistent by referring to them as service animals. The ADA defines a service animal as any guide dog, signal dog, or other animal individually trained to provide assistance to an individual with a disability. If they meet this definition, animals are considered service animals under the ADA regardless of whether they have been

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licensed or certified by a state or local government. Additionally, under Nebraska Revised Statutes 54-603, service animals are exempt from licensing fees if they have graduated from a recognized training school. This bill proposes to exempt all service animals regardless if they have graduated from a recognized training school. Service animals play a vital role in a person with a disability's life. They're animals that are individually trained to perform tasks such as guiding people who are blind, alerting people who are deaf, pulling wheelchairs, alerting and protecting a person who is having a seizure, or performing other special tasks. Service animals are working animals, not pets. And I'd appreciate your concerns on this issue. You know, we're in the people business. We just heard this here. And people with disabilities, I think we should give them any kind of break we can. And I'll waive closing for now and thank you, Chairman Gay. [LB806]

SENATOR GAY: Okay. Thank you, Senator Wallman. [LB806]

SENATOR WALLMAN: And there's people behind me who will have more information on this. I have a hearing on water issues in Natural Resources. [LB806]

SENATOR GAY: Oh, so you're going to waive your closing? [LB806]

SENATOR WALLMAN: So I'll waive the closing. [LB806]

SENATOR GAY: Okay. Thank you for joining us. Thank you. Those proponents for LB806? Can I see a show of hands, who would like to speak? Okay, just one. Any opponents here that want to...okay. Okay, come on up. We'll hear from proponents. If you can state your name and spell it out. [LB806]

ROXANN HAMILTON: My name is Roxann Hamilton, R-o-x-a-n-n H-a-m-i-l-t-o-n. Good afternoon, members of the Health and Human Services Committee. As I said, my name is Roxann Hamilton. I'm from Beatrice, Nebraska. I am a person with a disability as defined in the Americans with Disabilities Act. I use a service dog named Bob to mitigate my disability. Bob is not here with me today, as he's completing his training. I'm asking you to support the rewording of Nebraska Revised Statutes to comply with the wording of the ADA by rewording the NRS to refer to guide dogs, hearing aid dogs, and service dogs to read as service animals. I am also asking that NRS 54-603 be reworded to include all service animals to be exempt from licensing fees; an example, the dog license fees and taxes. Presently NRS 54-603 states that to qualify for that exemption, a service animal must be graduated from a recognized training school. The ADA and the Department of Justice do not require or define that a service animal be a graduate of a recognized training school. They require that the service animal be individually trained to provide assistance to an individual with a disability. There are no federal laws requiring service animals to be trained in a training school, registered, or certified. I reviewed state dog licensing laws for all 50 states and I found that 11 states currently

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exempt service animals in their statute from licensing fees and taxes. These states are Kentucky, Georgia, New York, Florida, California, Maryland, New Jersey, Michigan, New Mexico, Pennsylvania, Washington, and West Virginia. And according to the University of Arizona studies, only .9 percent of persons with disabilities are partnered with a service animal and that equals approximately 15,000 service animals across the United States. The misrepresenting of a dog as a service animal in order to obtain benefits of a civil rights law can be prosecuted as felony fraud. This would include public access rights and representing one's pet dog as a service animal to obtain a license fee exemption. I support the changes proposed in LB806 and I'm asking you to do the same. LB806 is really important to me because the waiver of and exemption of license fees would mean that I could afford a month's worth of lifesaving medications for me. I invite you to ask any questions that you might have of me at this time and I thank you very much for your time, attention, and support of LB806. [LB806]

SENATOR GAY: Thank you, Roxann. Are there any questions from the committee? I don't see...Senator Stuthman. [LB806]

SENATOR STUTHMAN: Thank you, Senator Gay. Roxann, what type of a service dog do you have? [LB806]

ROXANN HAMILTON: I have a medical alert service dog. The dog is trained to assist me when certain biochemical changes happen within my body to alert me in order to get medication or go to a place of safety or call for help before a crisis would occur. And also my service dog is trained to find my vehicle, locate my vehicle when I am not able to concentrate or I'm too distracted because of illness and disability to locate my vehicle. [LB806]

SENATOR STUTHMAN: And you find this really is beneficial to you? [LB806]

ROXANN HAMILTON: Absolutely. It greatly improves my quality of life. [LB806]

SENATOR STUTHMAN: Okay. Well, thank you. [LB806]

SENATOR GAY: Are there any other questions? I don't see any. Thank you for joining us today. [LB806]

ROXANN HAMILTON: Thank you very much. [LB806]

SENATOR GAY: You bet. Thank you. Okay, any other proponents, just in case I missed somebody? Any opponents? Anybody who'd like to speak in neutral capacity on this issue? I don't see any. Okay, with that we'll close the public hearing on LB806. And Senator Synowiecki, do we see here...what's that, Matt? Yeah, why don't you real quick. We'll take a short break and wait for Senator Synowiecki. [LB806]

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BREAK []

SENATOR GAY: Senator Synowiecki, thanks for joining us. LB809. Thanks for joining us. Go ahead. [LB809]

SENATOR SYNOWIECKI: (Exhibit 1) Thank you, Mr. Chairman, members of the Health and Human Services Committee. I'm John Synowiecki. I represent District 7 in the Legislature. Today I bring for your consideration LB809. LB809 is a bill to create a religious exemption for mandatory infant screening. Under LB809, an infant would be exempt if a parent or guardian of the infant objects to the screening test based on grounds the test conflicts with sincerely held religious beliefs of the parent or guardian. The written objection would be reported to the Department of Health and Human Services and the bill does protect state of Nebraska healthcare providers by removing liability from them. Members, I brought this bill before. I think this is actually my third time. Speaker Bromm had brought this bill before. The reason why I've been involved with this is I have constituents who have these very closely held religious beliefs. I disagree with them. I profoundly disagree. I think they should have their kids tested. But should my belief or the state supersede or overrule their religious belief? That's the question. I profoundly disagree with my constituents. I think they should have their kids tested. But does my belief, does a state policy overrule and supersede their deeply held religious belief? That's the question before you. This situation with this bill took a profound turn of events in October of '07 when county sheriffs and the state child protective services came in and removed, physically removed, Joel Anaya from the safety, care, and comfort of the parents. The child was removed from the parents by a government action, against the will of the parents, and the child was subjected to this testing contrary to, again, the deeply held religious beliefs of the parents. What's striking to me is that this government action would not have occurred in 45 other states, in 45 other states. And 31 states, in particular, have a specific exemption for deeply held religious beliefs for this metabolic testing. So we use state resources via the county sheriff's department, state resources via the child protective services, removed a healthy child, removed a healthy child from the arms of their parents, and subjected that child to testing that the parents deeply did not want their child subjected to. And what's further striking to me is not only are we in a minority of states that do not allow a religious exemption for deeply held religious beliefs for infant screening, our policy within the state is profoundly inconsistent. I have here from the Department of Health and Human Services Web site. For immunizations, which some can argue are contagious in terms of the health and safety of the state of Nebraska, citizens of the state of Nebraska, could even have more profound negative implications. I have here, right here the refusal of immunization of a student for religious reasons, and I'll read it to you. This is provided by our Department of Health and Human Services. "Immunization conflicts with the religious tenets and practice of a recognized religious denomination of which the student is an adherent or member or immunization conflicts with the student's

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personal and sincerely held religious beliefs." Additional information of the Nebraska Department of Health and Human Services Web site gives further direction on how a parent can utilize the religious exemption that's currently in place for immunizations. I think on two levels: number one, the inconsistency within our existing policy relative to immunizations and infant testing is inconsistent, we've got to go one way or the other with this; and secondly, the fact that we are in the profound minority of states that do not allow a level of exemption and now becoming aware that the state is beginning to act upon this and take police action against parents who have these beliefs. I just thank you for your consideration and hopefully we can get this bill out this session and deal with this matter. Thank you. [LB809]

SENATOR GAY: Thank you, Senator Synowiecki. Do you want to hand those out to us? We can make copies. [LB809]

SENATOR SYNOWIECKI: Sure. I do have enough copies here. [LB809]

SENATOR GAY: Leave it there, we'll get them made and we'll hand them out to the...are there any questions? [LB809]

SENATOR SYNOWIECKI: Should be enough copies here. [LB809]

SENATOR GAY: Are there any questions for Senator Synowiecki? Oh, sorry, Phil. Senator Erdman. [LB809]

SENATOR ERDMAN: Thank you. [LB809]

SENATOR GAY: Didn't know you joined us. [LB809]

SENATOR ERDMAN: Most people don't have that problem, Mr. Chairman. [LB809]

SENATOR GAY: (Laugh) I'm sure we won't from now on. [LB809]

SENATOR ERDMAN: Senator Synowiecki, the penalty now, I'm looking for that in the existing law, for an individual that fails to comply with the law is similar to what the Anaya family or the family that was in the news, is the result of the child being taken into custody of the state for the best interest of the child. Is that kind of the remedy? Is that why we... [LB809]

SENATOR SYNOWIECKI: Yes, Senator, I don't think there are criminal penalties or any such penalties assigned. I believe the action was actually taken by the Douglas County Attorney's Office pursuant to notice given by the Department of Health and Human Services. And that's when enacted the law enforcement element of it. I think it's a civil action, I think it was done civilly. And as you indicated, an action in the best interest of

the child. [LB809]

SENATOR ERDMAN: Talk to me about the 45 other states. Is their provision similar--or 31, I guess maybe it was specific, but the other states that have options for the parents. Is their process...do they have a similar process to what's in this? Is that what this is modelled after? Or in the event that a person in those states doesn't comply with the screening, what method is taken to inform them of the opportunity? I'm just trying to understand the...because it is clear that we have a difference in our vaccination laws and there are different provisions that individuals that choose not to have their children vaccinated have to be aware of, the risks of...if there's a disease or something that happens at school, they may be asked to go home. I mean, there's safeguards in place. I'm just wondering, other states, we're not screening all the kids, we've gotten letters here that say we have to screen all the kids for these reasons, but I'm wondering if it was such a big deal in those other 45 states why there's still 45 of them that allow an exemption. I'm just trying to connect the dots. [LB809]

SENATOR SYNOWIECKI: Yeah, Senator, that's a great question. Hopefully some people behind me have some awareness of the processes in other states. I don't explicitly have what the process is. I would hesitate...I would guess that they're very similar to the process involved with our immunization affidavit and so forth and the process involved in that. I would suspect it's very similar to what we do with immunizations. [LB809]

SENATOR ERDMAN: And I think generally--just one last comment, Mr. Chairman--I think generally, whether they like it or not, people have accepted the immunization laws as they are, even though there's largely the expectation that everybody will be immunized. But we do have that exemption and I'm interested. We have a letter, obviously, from the department. They're in the middle of a pending legal matter with this topic. But I think there is an interesting correlation there that you've drawn out about required activity in one area that doesn't require in another that don't necessarily match up, and it's for the same rationale that you're proposing in your bill. So I'll be interested to hear the comments. [LB809]

SENATOR SYNOWIECKI: I appreciate that, and I appreciate your comments. And I'll just reiterate, I profoundly disagree with my constituents. I think they should have their kids tested. I think they should have them immunized and I think they should have them tested. But does my opinion and the state's opinion overweigh or supersede their religious belief? I don't think we should. I think we should have a religious exemption. These cases would be very few, obviously. We're not talking about a lot of children involved. But nevertheless, they should have afforded them the rights that are afforded parents in the other states, I believe. And particularly, particularly considering the immunization religious exemption that we currently have. [LB809]

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SENATOR GAY: Senator Erdman has another question. [LB809]

SENATOR ERDMAN: I'm assuming there will be somebody...we've gotten a letter from some in the medical community that support this, and I'm assuming that there may be different ways of providing similar results from screening that may be less invasive or less objectionable to the families involved because of some of the practices and what their beliefs require of them at certain times in the child's life, which I recall from the previous times we've heard this bill. Are the processes...and maybe you could just say you don't know, obviously, if you don't. But are the processes similar for all other states? Is it the same metabolic screening? Is there different types of screening that may be able to be utilized that we may be able to allow for so that it's maybe not how we do...it's maybe not whether we do it, but how we do it that may be as much of an issue? [LB809]

SENATOR SYNOWIECKI: You know, I don't know, but I would suspect that the medical practice is probably universal in terms of the testing methodologies. But I don't know. [LB809]

SENATOR ERDMAN: And not to clutter your bill with another issue, but Nebraska is one of two states that don't allow midwives to attend home births. Now my wife and I had a daughter and she will never have a child outside of a hospital or some approved facility unless we can't get there in time. But Senator Stuthman, who's not here, was born at home and, aside for a few quirks, I think he turned out all right. (Laughter) [LB809]

SENATOR SYNOWIECKI: I'm not going there. [LB809]

SENATOR ERDMAN: But it is interesting, John, to look at it. And we want people to be responsible consumers of healthcare. We want people to take ownership in their medical responsibilities, both for their well-being financially, and at times for the state financially to make sure they're being responsible. But to the same point, we know that people are more informed, that they have greater opportunities, and I...you don't set the speed limit on the interstate at 35. That's because people won't follow that. And I think we have to be sensitive to the realities that are out there. And if we're not...and I, you know, with your bill, I'm open to it. I don't know whether I'll ultimately support it but I'm inclined to, I mean, just from a logic standpoint. But I think there is a strong compelling case to look at the rationale for bringing this, especially since there's already an existing exemption for religious purposes under immunization. And I'm not a rocket scientist but I can pretty much remember why the people came to America. It wasn't just free land. So I appreciate you bringing the bill and bringing the discussion back to the Legislature. I think it's important. [LB809]

SENATOR GAY: Thank you, Senator Erdman. Senator Howard. [LB809]

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SENATOR HOWARD: Thank you. Thank you, Senator Gay. Just a point of clarification, if I remember correctly, this action was through juvenile court... [LB809]

SENATOR SYNOWIECKI: Yes. [LB809]

SENATOR HOWARD: ...the juvenile court in Douglas County and the child was removed on a temporary basis in order to have the testing done and the results come back for the court to see those. And then he was returned to the family. So just if there was any question about the reason the sheriff, that he was placed in care. [LB809]

SENATOR SYNOWIECKI: Taken from the parents. [LB809]

SENATOR HOWARD: Placed in the temporary custody, right. [LB809]

SENATOR SYNOWIECKI: Placed in care, and placed in temporary custody while the testing went forward. And they're behind me here so they'll fill you in more precisely. But I believe the baby was held out of home placement until the test results came back, I believe. [LB809]

SENATOR HOWARD: Right, right. Thank you. [LB809]

SENATOR GAY: Okay. Any other questions? I don't see any. Thank you, Senator. Senator Synowiecki, earlier when you weren't here...can I see a show of hands how many proponents want to speak on this issue. So we can see there's quite a few. How many opponents? So about everybody in this room wants to talk on this issue and we want to hear you all. But what we did, Senator, is you get as long as you want. Any questions that we ask won't be against the time, but we're giving about everybody five minutes. I just jot down about when they start speaking and if everyone could work with me on that, it just prevents things from being repetitive. And if it's a handout, feel free to hand it out and summarize, too. But do what you want, but we need to kind of do that in order to speed things up. [LB809]

SENATOR SYNOWIECKI: Sure, sure. [LB809]

SENATOR GAY: I just wanted to let you know, as sponsor of the bill. Thank you. [LB809]

SENATOR SYNOWIECKI: And the reason I was late, again, I was in Revenue... [LB809]

SENATOR GAY: Oh, you don't need to... [LB809]

SENATOR SYNOWIECKI: I was next in the queue in Revenue... [LB809]

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SENATOR GAY: Well, you're busy, you better waive close. [LB809]

SENATOR SYNOWIECKI: So unfortunately, I might have to exit out and waive closing if I'm not here. [LB809]

SENATOR GAY: No, do whatever you got to do. Thank you for joining us. [LB809]

SENATOR SYNOWIECKI: All right. Thank you, Senator. [LB809]

SENATOR GAY: Okay. Okay, with that we'll start with proponents. So if you want to kind of work your way up here and make sure you sign a testifier sheet and put it in the box and state your name and spell it out please, if you could, for the record. [LB809]

MARY ANAYA: (Exhibit 2) My name is Mary Anaya, A-n-a-y-a. I live in Omaha, Nebraska. I believe that LB809 is necessary to preserve the rights of conscience that our forefathers fought so hard to obtain. I consider the blood of my babies as something precious in my sight and in the sight of God and not to be tampered with lightly. Although many in the medical community would have you to believe that not participating in blood screening is highly dangerous, I disagree. The diseases that are screened are rare, genetic diseases, not more common communicable diseases. Dr. Norman Frost, professor of pediatrics and director of the program in medical ethics at the University of Wisconsin, said in a quote to The New York Times, the majority of newborn screenings have failed. Thousands of normal kids have been killed or gotten brain damage by screening tests and treatments that have turned out to be ineffective and very dangerous. Treating infants who have no symptoms of disease simply because of a positive test result is at best a questionable practice, but to have this practice forced upon families by the state is simply unconscionable. Seven of my ten children were born in the state of Nebraska and none of them had been screened until my most recent child, Joel, was legally kidnapped by the state. Our two oldest children were not born in Nebraska. My oldest, now 20, went to college at 14, graduated from Bellevue University with two degrees at the age of 17. My second oldest is now a sophomore honor student at the same university. Obviously, neither one is suffering from any undiagnosed metabolic disease. Our first encounter with Nebraska's newborn screening program was over 14 years ago. A couple of weeks after a peaceful home birth we received a certified letter telling us to take our baby to a laboratory for blood screening. We researched the Bible for scriptures that related to the issue, prepared a statement of our objections, and had it notarized. Nothing happened then. The state ignored us for the next five home births. After each of the births, we received two or three certified letters informing us of the law. Then after the birth of our eighth child, our sixth in the state of Nebraska, we received a subpoena to appear in district court when she was 2.5 months old. We found a lawyer and fought. The case was only heard by the local district court judge who was unfamiliar with the law and the Nebraska Supreme

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Court. The Nebraska Supreme Court moved the case from the appeals court, and though we appealed, the U.S. Supreme Court did not hear the case. We thought the judicial system would certainly overturn the current legislation on this issue since its unconstitutionality seemed obvious. However, the only court to hear our case--the Nebraska Supreme Court--ruled in essence that you, the state Legislature, can make legislation without proving a compelling reason. However, compelling reason was once the national standard and is still the standard in many states. Unfortunately, since the Religious Freedoms Restoration Act was overturned, Nebraska has been reduced to rational basis. I hope and pray that each of you fears God enough to take that responsibility of making laws very seriously. I'm a law-abiding citizen who's never received so much as a traffic ticket. I do not take civil disobedience lightly. That is why when I was in labor with my ninth child two years ago, I crossed the border into Iowa. After our long ordeal here in Nebraska, I decided that as much as I hated to leave my home in the middle of labor, we should make every effort to both obey the law and our conscience. In Iowa, it was such a simple matter. In the birth registration packet, a screening waiver is automatically included. We simply filled it out and sent it back. Other families who have used the waiver in other states will not want to move to Nebraska if this state does not offer that same option. Due to various reasons, Joel ended up being born in Nebraska. And believe me, if I had any idea what would happen, I would have made a greater effort to make it to Iowa. After Joel was born on September 2, we found an attorney familiar with constitutional issues. On September 19, we received a certified letter about the screening law and giving us just until September 21 to test. Then we received a follow-up phone call from newborn screening asking if we would test. We replied no. Krystal Baumert, the follow-up coordinator, asked if I knew what would happen next. I replied yes, because I believed that we would be subpoenaed into district court, as stated in the statute. In the meantime, we discussed new legal arguments with our lawyer based upon the Nebraska State Constitution. Weeks went by without hearing anything. We hoped that the newborn screening program had decided to continue ignoring us...return to ignoring us. Then on the morning of October 11, just after I'd gotten Joel up from his nap, my doorbell rang. When I answered the door, an armed sheriff's deputy came barging into my house, yelling he had a court order for Joel Anaya. I was screaming that I had not given him permission to enter my home. He said he had a court order. I said I wanted to call my lawyer. He said there's no time. There were two other deputies with guns guarding my doorways. He heard my children downstairs and ran downstairs to where they all were. He snatched Joel out of my son's arm and headed for the door. As I expected, Joel was fussing. He had not eaten in three hours. I begged to be allowed to nurse him. The deputy told me there's no time, he will be cared for by professionals. He ran out the door with my baby, leaving me begging to nurse my baby and yelling for my son to call the lawyer. It was a cold day and the CPS people were not there yet to hand the baby over to, so the cold weather forced him back inside. I was crying and pleading to nurse. My husband came home from the store just then. The sheriff's deputies blocked him from entering the house. The way our rights were trampled by the sheriff's deputies and the Department of Health still

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astounds me. I relive the scene over and over again. The unethical, cruel behavior of the juvenile court judge further endangered my nursing infant and prolonged our horror story for nearly six days. However, that's not really the matter at hand. Metabolic diseases are rare and the incidence is greatly decreased in ethnically diverse populations. Our particular ethnic combination, a Hispanic from Central American and a Caucasian of mostly German and English descent, would have a much lower than average incidence of any of these mostly genetic disease. Dr. Frost summed it up well in an interview with Fred Knapp on Nebraska Public Radio, saying it's more risky to put your child on a football team than it is to skip newborn screening. The opposition will no doubt parade anecdotal evidence from the rare cases where a disease was found. My heart goes out to those families. However, for decades other states have maintained their exemption statutes; 46 states--and here I've heard it's 45 now--allow for some type of religious exemption to newborn screening. The other three states have never prosecuted anyone for refusal. Nebraska stands alone in forcing parents to perform blood screening against their will. Furthermore, as Senator Synowiecki already pointed out, the state is being very inconsistent. Nebraska does allow for religious exemption to vaccinations which are for disease which are both more common and communicable. The diseases screening for in these tests are extremely rare and completely noncommunicable. Benjamin Rush, one of the signers of the Declaration of Independence, believed that Americans should enshrine the right to medical freedom in the constitution, much as the right to freedom of religion is expressly guaranteed. Rush is reported to have argued that unless we put medical freedom into the constitution, the time will come when medicine will organize an undercover dictatorship to restrict the art of healing to one class of men and deny equal privilege to others, will be to constitute the bastille of medical science. All such laws are un-American and despotic and have no place in a republic. The constitution of this republic should make special privilege for medical freedom as well as religious freedom. Since the people in opposition to this bill are either paid by a medical association that profits from this screening or a relative of one of the very rare cases and most of those who actually support this amendment have to work today, I also brought along petitions with signatures of Nebraska residents who support this exemption bill. I only started the petition eight days ago because of the short notice that I had for the hearing. That's when I received the number for the bill. I'm confident that over time I could have received many more signatures. Not a single person that I asked to sign has turned me down. I believe that it's because Nebraskans believe that individuals, not the state, should determine the medical care that is appropriate for each person's family in accordance with his or her beliefs. Please allow me to be a voice for voiceless infants and for the many parents who have been afraid to object to this screening because of the fear that their children will be removed from their families. The state has already used the ultimate weapon against my family--the forcible removal of our baby. Please end this misuse of power and taxpayer funds and send LB809 to the floor for a vote. Do not allow anyone else to suffer at the hands of the newborn screening department in the manner that my family has suffered. If anyone has any questions...everybody behind me is much shorter, I'm pretty sure. [LB809]

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SENATOR GAY: No, that's fine. Thank you. Are there any questions? Senator Erdman. [LB809]

SENATOR ERDMAN: Mary, thanks for coming. I recognize that when you don't agree with the laws, it's very difficult to operate. And so I can't imagine what that's like and what it would be like for my family to have gone through. Explain to me the objection. Is it...your objection is to the screening altogether. Is it the way that the screening is done? Is it when the screening is done? [LB809]

MARY ANAYA: It's the manner, taking blood. If it was a urine test, which actually the PKU originally started out as a urine test. I wouldn't have an objection to a urine test. But now they say they have done away with urine testing, it's all blood testing. We went through this before, you were asking that question earlier. And now they said that they're only set up to do it by blood, that they're no longer just set up to do the urine testing any longer. [LB809]

SENATOR ERDMAN: So it's not that you're opposed to the screening, it's the way that the screening is being done because it's a blood test, it's drawing blood from your child. And again, it doesn't matter when; it's the fact that that's being done at all. [LB809]

MARY ANAYA: Right. The timing doesn't have anything to do with it. [LB809]

SENATOR ERDMAN: And would that be the...just to follow up on that. So in your situation, you have the same opinion and belief then about someone drawing blood from you? Is that... [LB809]

MARY ANAYA: Yes. [LB809]

SENATOR ERDMAN: Okay. I just wanted to make sure that it was...we had booked in the parameters. But I appreciate you being here and thank you for your testimony. [LB809]

MARY ANAYA: Thank you. [LB809]

SENATOR GAY: Mary, thank you for that testimony. I did grant you some leeway obviously, but it's very...you know, your testimony was very compelling. But you're right, if I allow that to go on and on, we're looking at 6:30, I figure it out, about this time. (Laughter) But thank you so much for that and appreciate it. Any other questions? Thank you very much. Any other proponents? Can you state your name, please? [LB809]

RAY SPIERING: (Exhibit 3) My name is Ray Spiering, S-p-i-e-r-i-n-g. [LB809]

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SENATOR GAY: Ray, can I ask you one thing? You were handing out a testimony. If you want to read it, that's fine. If you want to summarize it, that's fine too. But I'm going to be a little stricter on you than I was with Mary. [LB809]

RAY SPIERING: This is only one page. It should be less than five minutes. [LB809]

SENATOR GAY: Okay, go ahead. [LB809]

RAY SPIERING: I got all ready to read it. (Laughter) Good afternoon. My name is Ray Spiering. My family and I live in Saunders County, and three of my four children were born in the state of Nebraska. I believe that this is my third visit to the Health and Human Services Committee in support of bills to allow a waiver to the Nebraska statute, a statute involving mandatory infant screening, also called a PKU or metabolic disorder screening. The reason I support LB809 is because the restrictiveness of the current Nebraska statute has caused my family a great deal of hardship in years past. It is my hope that this amendment will make the law more lenient for other couples and upon future families. During the birth of three of my children in Nebraska, that statute as currently written interfered with my understanding of what health is and how I as a parent wanted to promote health in my children. I follow the teaching of Dianetics and silent birth, which purport to maintain an infant's mental health. Following those teaching collided with the current state statute and my family spent a great deal of effort, money, and worry while trying to get all health-related issues accomplished in a reasonable way. By our third born-in-Nebraska child in December 2004, we had no remaining option to but to challenge the Nebraska law in order to get a delay in the infant screening process. This effort was expensive for everyone involved, including the state of Nebraska. Underlying our reasoning, we felt that we were using a broader view of what good medicine is; that good medicine includes physical health, mental health, spiritual health, and so on. Speaking in general terms, mental health and physical health would be given equal consideration. The importance of mental health to society as a whole is not a controversial position and is reinforced whenever an occasional killing rampage makes the news. In my opinion, the current Nebraska state law focuses solely on physical health to the exclusion of the mental health. In my opinion, this is not good parenting. At the risk of oversimplification, I've included a copy of a figure from an early childhood development textbook that illustrates a broader view of health. It was a pleasant surprise to me to find an illustration that exactly reflected my conceptualization of health. Hopefully it's simplicity will not insult anyone's intelligence. I find predicting the future to be difficult, so I can only sincerely suggest or assume that the other couples like us will continue to fight or avoid the law. We assume that we are no longer directly a part of this since we assume that our child-producing days are over. However, the current statute puts couples into a difficult situation since they are risking legal action against themselves and/or their family when they stand behind their beliefs. In my personal discussions with parents of an opposing point of view, there are many parents

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who do want the current barrage of infant screening tests. I am okay with that because the LB809 amendment does not take anything away from those parents. Anyway, I'm trying to persuade you to support LB809 and would ask that you consider the parents who are directly affected by the consequences of the current law. My wife was not able to be here today but she has forwarded her comments as well, which are stapled to the back of mine. And if this particular bill is not successful, then God willing, I will see you all again in some future January. Thank you for the opportunity to speak. [LB809]

SENATOR GAY: Thank you, Ray. Are there any questions from the committee? I don't see any. And then we will put into the record Louise's testimony too, okay. So we'll include that. Thank you. [LB809]

RAY SPIERING: Thank you. Very quickly; our first child, Allison, was born in 1995 in Minnesota. Mr. Erdman had asked that question. We simply signed a form, a waiver, and there was nothing more said about it. [LB809]

SENATOR GAY: Thank you. Oh, Senator Erdman has a question. [LB809]

RAY SPIERING: That was an earlier question. [LB809]

SENATOR ERDMAN: No, no, you're fine. Just stay here, I have another one. So in Minnesota, you exercised that right. [LB809]

RAY SPIERING: In 1995. [LB809]

SENATOR ERDMAN: In 1995. In Nebraska, we have the exemption for immunization. Have you also exercised that right? [LB809]

RAY SPIERING: No, I haven't. [LB809]

SENATOR ERDMAN: Okay. So your children get immunized but you would object to the metabolic screening. So is it the timing, the process? It's a similar line that I was asking Mary earlier. Is it the testing that's being done when it's being done? Is it how it's being done? [LB809]

RAY SPIERING: What we objected to was that the testing caused pain during the first seven days after child birth in relation of silent birth. So you had asked earlier about the urine test. We would have no problems with a urine test. [LB809]

SENATOR ERDMAN: Would you have a problem if you were allowed to have the testing done when the child was two weeks old, a month old? [LB809]

RAY SPIERING: And actually, for the three that were born in Nebraska, they were all

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tested after that period. [LB809]

SENATOR ERDMAN: Okay. [LB809]

RAY SPIERING: And the one in 2004 was tested like exactly eight days later, like to the minute. [LB809]

SENATOR ERDMAN: Okay. Do you know off the top of your head what the requirement is? Because I can't find it in the statute. It's probably in rules and regs or somewhere that when a child... [LB809]

RAY SPIERING: Going from memory, it was something in the 48 hour to 72 hour...might have been sooner, 24 to 72 hours, somewhere in that period. So 72 hours would have been the latest allowed by law. [LB809]

SENATOR ERDMAN: I would imagine there's some medical reason for that, but I'm just thinking out loud. If we're arguing over how to do it, that's probably a different discussion than whether we should do it. And again, the effectiveness of that testing may not be as effective later. But at the same point, the overall effectiveness can't be effected that much...and I'm not a doctor, I'm not...you know, I'm a dirt farmer from western Nebraska. So I'm just trying to think logically about what the possibilities are or what the parameters are between this discussion. It appears that at one end there are people that are opposed to how it's being done. Sounds like your position is when it's being done. And that may have some folks oppose the bill because of those reasons. But I'm just trying to get a good sense of where we're at with the discussion. [LB809]

RAY SPIERING: Okay. [LB809]

SENATOR ERDMAN: But you did good. [LB809]

RAY SPIERING: Okay, thanks. [LB809]

SENATOR ERDMAN: Thanks. [LB809]

SENATOR GAY: Very good. Thanks, Ray. Is there any other questions by the committee? I don't see any. Any other proponents who would like to speak? [LB809]

RICHARD DUNCAN: Good afternoon, Senators. My name is Richard F. Duncan, D-u-n-c-a-n, and I'm the Welpton Professor of Constitutional Law at the University of Nebraska College of Law. But I wish to make clear that I'm here testifying simply on my own behalf as a citizen of Nebraska who strongly supports religious liberty as a fundamental right; indeed as the first freedom protected by the Bill of Rights. Now if this were a court, I think I would be arguing that a religious exemption from the blood

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screening law is required by both the First Amendment and the religious freedom clause of the Nebraska State Constitution. But this is not a court, and so I am here today to ask you to exercise in the best tradition of federalism, your legislative judgment and compassion, by enacting a religious freedom exemption into the law governing infant blood screening. I believe that religious freedom is much more than a constitutional liberty. It is a value that all men and women of good conscience support because we recognize the terrible dilemma a person finds herself in when her government commands her to do something that her God forbids. I know some people believe that religious exemptions are a kind of anarchy, a demand by certain people to be, as Justice Scalia once put it, a law unto themselves. But that is the exact opposite of the true nature of religious liberty. Religious liberty is not about anarchy or about being above the law. It is about the dilemma one faces when he has two sovereigns who issue inconsistent commands. One sovereign, the state, says you must submit your child to blood screening. And the other sovereign, your god, says you may not do so. So what does a law-abiding citizen do in a case like this? Does he obey Caesar or does he obey God? James Madison, the primary force behind the free exercise clause, recognized that God's claim on our obedience is both earlier in time and higher authority than Caesar's claim on our obedience. You must obey God, not Caesar, when there is a direct conflict like this. And this is what it means every day in the public schools when we invite our children to pledge allegiance to one nation under God. God is above; Caesar is below. So I ask you senators today to consider the wisdom and compassion of James Madison and adopt a religious freedom exemption from the newborn screening law. This is not an unusual request. We've heard testimony today that many of our sister states have enacted similar religious freedom exemptions from blood screening laws. It is the tolerant thing to do, it is the compassionate thing to do, and it is the right thing to do. I hope I never have to read another news account of a nursing baby being forcibly taken from his home, from his loving parents, solely because they have chosen to obey their religious conscience. This bill is a very good one and I humbly ask you to advance it and to enact it into law. Thank you for your time and consideration. [LB809]

SENATOR GAY: Thank you, Mr. Duncan. Are there any questions from the committee? I don't see any. Thank you very much. [LB809]

RICHARD DUNCAN: Thank you. [LB809]

AMY MILLER: (Exhibit 4) Good afternoon. My name is Amy Miller, that's A-m-y M-i-l-l-e-r. I'm legal director for ACLU Nebraska. You have my written comments. I'm really just here to provide a few fill-ins. ACLU represented both of the families that you've seen before you already today. We were primary counsel representing Ray and Louise Spiering asking for a delay in the testing of their baby due to their religious beliefs and we filed an amicus curiae brief, or friend of the court brief, on behalf of the Anayas in front of the Nebraska Supreme Court asking for an outright waiver. Senator

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Erdman has asked some good questions about the sort of range of where people's religious beliefs are asking. Is it the method of testing, is it the timing of the testing. The difficulty, of course, is that there are so many different religious beliefs and such a multitude of different faiths that might end up being implicated by this statute that just tinkering with the timing, just tinkering with the method is never probably going to be adequate to affect all the peoples whose religious beliefs might be affected. Therefore, that's why we continue each year to come back supporting an outright exemption for people of a sincerely held religious belief. Again, at this point it looks as if this is in the hands of the Legislature unless subsequent litigation is successful because two high courts now have said this is in your domain, not the judiciary's domain. The last thing that I would like to add is the back page of my testimony is from the Department of Health and Human Services statistics. In the first column you see the diseases that are being tested for by the PKU test that's at issue here. In the next two columns you see what the risk is, and it's slightly different in Nebraska and on the national level so we've given you both figures. And the way to read that, for example, is in the very first column, congenital primary hypothyroidism--that's 1 out of 2,963 babies has that disease occur. The final column of course is the most interesting because this then reflects the ways in which children die from other causes in Nebraska. And let's face it; the people that you're going to hear in opposition to this bill are going to be telling you these are very serious diseases with serious repercussions for the children. That's true. But bathing your child in the bath tub, taking your kid to summer camp, or owning a dog also put your child at high risk of dying in some way, often statistically much higher than the PKU testing. There are so many reasons to say that life is one of those uncertain things. Nebraska state law says that we only intervene in a parent's religious beliefs if there's an immediate and substantial risk. That's quoted on the second page of my testimony. If there was an immediate and substantial risk, you wouldn't see me standing here. For example, if we knew that a child had the disease and the parents were objecting to treatment, the ACLU would not take the position that the parent's religious rights trump the child's rights to medical care, if there's a known risk. But this is screening only, screening for incredibly rare diseases. One of the questions about why Nebraska does not have the exemption, I would suggest from previous years of testimony there's some indication that some of the doctors who were pioneers in formulating the formula for doing the testing started out in Nebraska. Therefore, they kind of had a captive audience here. We stand out alone across the nation as allowing the sort of tragic stories. You've heard about the Anayas. We ask you to pass this bill. It's not likely to be used by very many parents, but for those who need it, it is of high, high importance. Do you have any questions? [LB809]

SENATOR GAY: Any questions from the committee? Senator Erdman. [LB809]

SENATOR ERDMAN: Amy, thank you for your testimony and your background. Obviously you've been here before. And we could have a hearing and people could come forward and say I oppose this bill, and we would have no idea why. And so from

my perspective in trying to determine a possible solution, it's good to kind of find out why people are opposed. But I appreciate your comments. As I read the bill, in looking for the direction in the law, Section 1 requires all parents to be screened or have all their children screened or...I'm mutilating the statute, but essentially there's that obligation. Section 7, the new Section 7 which is the old 6, says that in the event that the screening is done, a physician may draw a second test. It doesn't say what happens if they don't, and I'm thinking out loud that the reason that they do that is so that the parents don't have to come back in for an additional test. But can you instruct me on what the pertinent process is then for the state to follow? Because in the bill there's no process outlined. Is there a guiding judicial process? Is it, as Senator Synowiecki pointed out, simply an issue where the state takes custody and goes to a hearing? I'm interested in that because generally if we have someone break the law, we saw in the law what the penalty is, what the remedy is for the state to be able to ensure compliance with the law. [LB809]

AMY MILLER: I think that in this case, I think the Anayas were extremely lucky that they didn't face criminal charges in juvenile court, that notwithstanding the fact that there isn't an explicit penalty in this law, the state of Nebraska has taken the position that the test is necessary and required by law. Parents' knowing refusal to comply with the law that is considered to be medically necessary, they very easily could have been charged with abuse and neglect. Douglas County in this case obviously chose only to exercise its power and flex its muscle by seizing the baby and then returning it. But this could have been an even more tragic circumstance where the parents could be chasing the child either being permanently removed from their home or them facing jail time. So the normal child abuse statutes would be the penalty here that would kick in. It does also strike me that you asked the factual question of why the law currently doesn't say the time period. That is in DHHS regulations and it's just 48 hours. In the depositions that we took in the litigation with the Spierings' case, there was no medical reason for having it happen within that time frame. Rather, the offer of evidence from the state was it's more convenient because most people have hospital births and they can get the baby tested before the family leaves, rather than allow the baby to leave and hope that the parents will bring it back. [LB809]

SENATOR ERDMAN: Thank you, Amy. [LB809]

SENATOR GAY: Amy, I've got a question. If the test is required and they do find...and it turns positive, a positive test, on the 99 percent of other people that are doing this, the parents then are required to seek treatment for whatever they find out. Is that the current statute? [LB809]

AMY MILLER: That's not only the current statute, that would be prevailing law across the country. Once there's a known medical risk, a parent does not have the alternative, even if they have a sincerely held religious belief... [LB809]

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SENATOR GAY: Okay, so that's... [LB809]

AMY MILLER: ...a parent doesn't have the right to waive once there's a known medical problem. And that's even in some states. I mean, this is an area of strong debate. In some states there's even an open question about elective surgery. If you have a child born with a cleft palate and parents believes that there should not be unnecessary medical surgery, in some states the courts will override that and say if it's necessary for the child, we're going to override the parent's religious beliefs. So parental rights are often very severely "bookended" by states' laws. Here it's the difference of there's not a known problem. There's a very attenuated risk of any harm to the child, not a known one. [LB809]

SENATOR GAY: Okay, thank you. Are there any other questions? I don't see any. Thank you very much. [LB809]

AMY MILLER: Thank you. [LB809]

JEFF DOWNING: (Exhibit 5) My name is Jeff Downing, D-o-w-n-i-n-g, and I'm an attorney here in Lincoln. And let me admit my biases right up front: I am the attorney for the Anayas and I was the lawyer whose name they were scrambling to find as Mary Anaya was on her driveway and the social workers and the deputy sheriffs were driving away with her five and a half week old nursing baby. I rode the roller coaster with the Anayas for those five traumatic, difficult, and terrifying days when their son was removed from their custody. I have prepared, perhaps more for the benefit of the legal counsel who is seated here today, essentially a research paper showing that this current screening program, which does not provide for religious exemption, actually flies in the face of the religious liberty guarantees of the Nebraska State Constitution. I will leave that with you and let you digest that, but that is one of the positions that we are taking in the appeal of the Anaya case as we now continue on in litigation over this seizure back in the fall of 2007. A couple of things that I just want to make in addition to my written submission: I think it's important for the committee to recognize that this is not a left or a right issue. A constitutional law scholar from the University of Nebraska, Rick Duncan, who was one of my professors, I don't think I did very well in his class but he was tough, and then Amy Miller from the ACLU have both testified in support of this bill. And it really comes down to it being a bill or a change that has to do with recognizing a constitutional freedom that already exists. It's just whether or not we're going to write it into our statutes the way, by last count, 45, 46 or 47 other states have already done. As Mary and I had testified, with child number nine she went across the river to Iowa and I had an opportunity to take a look at Iowa's statute and the Iowa statute simply says newborn screening, this law doesn't apply if the parent objects. It doesn't even qualify it as being a religious objection; it just says for any reason, if the parent objects, then we're not going to mandate the screen. That's why Nebraska really

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is behind the times in this regard. I believe that Mr. Spiering testified that Minnesota, even as early as 1995, allowed them to opt out, but I know that it went into Minnesota statutes, in I think 2007, a specific religious exemption from the newborn screening mandate. So I think this is a matter bringing Nebraska law into line, first of all, with the Nebraska State Constitution, which guarantees not only the right of religious liberty but rights of conscience, and that is a very important feature. It is our liberty as United States and Nebraska citizens. Another thing I want to hand out is I just wondered whether or not this had ever come up in the Legislature until these recent cases with the Spierings and with the Anayas. And so I'm going to ask that the page distribute some debate from way back in 1987 when there was an early modification to the newborn screening program, and some revered names in the history of the Legislature, Senator Wesely and Senator Moore, had an exchange when they were looking at adding additional metabolic diseases to the screening regimen. And Senator Moore actually raised, and I've highlighted it for you in yellow on...in the record, he raised the record of, now wait a minute, I see this bill says all infants born in the state of Nebraska shall be tested. And he says, what about people like Christian Scientists? They have a problem with these blood screening tests. Senator Wesely responds to him: well, we're not changing anything else in the statute; I think we've already addressed that. He says, evidently we've resolved it and I haven't heard any problems since we passed it, so we're just adding this test to what we've had before. Senator Moore then says, well, the only reason I raised the question is because it says all infants, and glancing through it I see no provision for a waiver, so that is something I may need to work out between now and Select File. I think as early as 1987 this was an issue and it just somehow got missed or dropped. Somewhere between this discussion and the bill being passed on the floor of the Legislature, it just sort of dropped out. And so perhaps it was something that was intended early on. Certainly we had some people thinking about it early on. It just simply fell through the cracks. If anything, the proposal that is in front of you, I would say, doesn't go far enough. The way I read it, it still gives some discretion to the Department of Health and Human Services as to whether or not they should grant exemptions. It says they may grant an exemption. It seems to me that it should be mandatory; that if the parent objects based upon a sincerely held religious belief or upon their right of conscience, that indeed the waiver should be granted. Just to answer one of Senator Erdman's questions, there are no criminal penalties attached to the newborn screening program. One of the very mystifying things about the way Douglas County chose to handle the Anaya case was there's nothing in the statute that says you take the child away from the parents or that you charge them with neglect or with abuse. In fact, it was stipulated at the hearing that we had that these are great parents; they've got beautiful children, all healthy, all doing well. We just have this blood screening issue and, because of that, there was a tremendous overreach by the government and a disruption to this family's life. [LB809]

SENATOR GAY: Thank you, Jeff. Thank you. Are there any questions? Senator Erdman. [LB809]

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SENATOR ERDMAN: Jefferson, good to see you. [LB809]

JEFF DOWNING: Thank you. [LB809]

SENATOR ERDMAN: Let me ask you, if you can, about where we're at now in the process. Is it being...is it district court, federal court, where? What is the... [LB809]

JEFF DOWNING: Yeah, we have a couple of things going. We have an appeal from the juvenile court's decision to the Nebraska...either Court of Appeals or Supreme Court, whoever ends up deciding it. The second thing that I felt that I had to do in order to properly represent the Anayas was to bring a claim in federal court as well for a denial of their due process rights in the way that this was handled. And so as you've seen from the Spiering case, from the first round with the Anayas back in 2003, and from what happened in 2007, without having a religious exemption this thing is nothing but a litigation factory. It's spawning needless litigation. And I don't want to talk myself out of work, but I would encourage you...in fact, you could go back to your constituents with a feather in your cap saying, we figured out a way to finally shut those lawyers down in Lincoln who file all these lawsuits with regard to at least one aspect of Nebraska law, and that would be to carve in this exemption. [LB809]

SENATOR ERDMAN: Glad you qualified that because I'm sure you'd be creative to keep your practice going. The comment that you made about it not being as instructive as it should be, as I read the language in lines 12 and 13, and you may not have the bill in front of you, says: A parent or legal guardian of an infant born in the state of Nebraska shall be granted an exemption from the requirements of subdivision (a) on behalf of the infant upon the filing of a written objection with the department based on religious beliefs. And then it says below that the persons responsible for causing the tests to be performed shall inform the parents of that right that they have. Am I...and that's the only new language that I see. It's on... [LB809]

JEFF DOWNING: Yep. That is right and that is... [LB809]

SENATOR ERDMAN: ...page...page 2, line 13. [LB809]

JEFF DOWNING: I saw an earlier, I believe, iteration of the bill, so that actually helps. I think that clears it up. [LB809]

SENATOR ERDMAN: See, look, we've already solved that. We've already solved that problem for you. [LB809]

JEFF DOWNING: I believe that's right. [LB809]

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SENATOR ERDMAN: How about that? [LB809]

JEFF DOWNING: Now pass this thing out of committee and let us have a vote on the floor. [LB809]

SENATOR ERDMAN: Thanks for being here, Jeff. [LB809]

JEFF DOWNING: Thank you all very much. [LB809]

SENATOR GAY: Thank you very much. Any other questions? I don't see any. Thank you very much. Other proponents? [LB809]

AL RISKOWSKI: Good afternoon. Al Riskowski with Nebraska Family Council. [LB809]

SENATOR GAY: Spell that. [LB809]

AL RISKOWSKI: I get that all the time. [LB809]

SENATOR GAY: I bet. [LB809]

AL RISKOWSKI: R-i-s-k-o-w-s-k-i. We're...I'm testifying in behalf of this bill. I was not aware of what this screening was like. We had a family call us asking that you even mention to state senators that they would like to have a matter of conscience exemption here and opt out, because they didn't realize how traumatic this test would be until actually their child had to undergo it; that apparently there are these five little circles that you've got to put the blood in these circles, and perhaps this has been described to you before but hadn't been to me, and perhaps you're not aware of what the test is like either. But they do a prick on the heel of the child but they said in their case, of which obviously is not the only case that way, it took over a half hour of working on the heel of this baby to get enough blood out to fill these five circles, and the baby just cried on and on and on, and they said had we known how traumatic this would have been for us and our newborn baby, we would have never done it. And a number of states do allow for a matter of conscience as an opt out in regard to these tests because they can be very, very traumatic. In 2006, the newborn screening program stated that there 26,819 babies tested, 2 percent were positive for one of the dozens diseases, and only .2 of 1 percent, 43, of those results were confirmed out of all of those tests. And so I don't believe there is an immanent danger in regard to these tests of screening. We would...you know, we certainly at Nebraska Family Council understand that this is a real cost-effective public health program. It is a great way to screen out newborns. However, it is a traumatic test. It is a difficult test and I believe it does warrant a fresh look by our Legislature as...in regard to at least an opt out option for parents who do see it as a very invasive and, in many cases or in some cases at least, a religious conflict that they have of interest here. So thank you for hearing me this afternoon. [LB809]

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SENATOR GAY: Thank you, Al. Are there any questions from the committee? Don't see any. Thank you very much. [LB809]

AL RISKOWSKI: I thank you. [LB809]

SENATOR GAY: Other proponents? How many more proponents do we have? Just one more? Oh, come on up, Dave. I think you're the last one. Go ahead, Dave. Oh, one more? Any other proponents? Come on, work your way up. Go ahead and state your name and spell it. [LB809]

DAVE BYDALEK: Senator Gay, members of the committee, my name is Dave Bydalek. I'm the executive director and attorney for Family First, which is a nonprofit research and education organization, with a particular interest in protecting religious liberty, and really it's on that aspect that I'd like to make my testimony today. And if I make any misstatements, I'm going to blame it on Professor Duncan, since he's left, since he was my constitutional law teacher. But the importance of the respect to be afforded sincerely held religious beliefs has been enshrined in the United States Constitution and in the Nebraska Constitution, and some would argue even to a greater extent in the Nebraska Constitution. And the rationale is that, unless there is a compelling state interest, a person's deeply held religious beliefs trumps the state's interest. To deny the opportunity for a religious exemption, we believe, does a disservice to the spirit of respected deeply held religious beliefs. And I think what's even more troubling in this particular case with the Anayas is the use of state power in this particular case, the manner in which the state decided to use its power. If in fact they had a compelling state interest, the constitutional law out there says that, in terms of religious matters, if they have that compelling state interest they have to use the least restrictive means. And I think that anybody who hears Mrs. Anaya's story clearly would say the state did not use the least restrictive means in doing the testing. So I believe the committee here has an excellent opportunity to do something and to see that something like this never happens to a family in the state of Nebraska again when they are exercising their sincerely held religious beliefs. And for that reason, I'd ask that you advance LB809 to the entire Legislature for General File debate. Thank you. [LB809]

SENATOR GAY: Thank you, Dave. Are there any questions from the committee? Senator Erdman. [LB809]

SENATOR ERDMAN: First, a comment: I want a copy of the bill back when you're done because it's mine. Second question is, is that if it's so obvious to the constitutional scholars in here, why is the case proceeding with the state being upheld? I'm just trying to think. [LB809]

DAVE BYDALEK: Well,... [LB809]

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SENATOR ERDMAN: I'm not a lawyer. I didn't go to Doctor or Professor, whoever's constitutional law class. [LB809]

DAVE BYDALEK: Well, I think...all right. I think what we have here is a case of first impression and we have a situation where I think when it moves through the system, on the briefs I think that there...once again, who knows what the court is going to do, but I believe as somebody who has worked in the area of constitutional law for the last 12-13 years, I used to be a state Assistant Attorney General as well, wrote many opinions on state constitution, federal questions, I do believe that there is a very, very solid basis for this appeal and I like the state's...or I like the Anaya's chances on appeal and I think the appellate courts, in my opinion, will uphold their arguments. [LB809]

SENATOR ERDMAN: Help me with a procedural question then. So if I'm a member of the Legislature and would request an Attorney General's Opinion as to whether the statute being amended by LB809 is in conflict with the state constitution, would that be something that the Attorney General may offer an Opinion on? [LB809]

DAVE BYDALEK: Yes, I believe it would. [LB809]

SENATOR ERDMAN: Okay. Thank you. [LB809]

SENATOR GAY: Dave, I have one question. If...this was the juvenile court first? [LB809]

DAVE BYDALEK: I believe so. [LB809]

SENATOR GAY: And then they're appealing it. [LB809]

DAVE BYDALEK: Yeah. [LB809]

SENATOR GAY: Would the juvenile court look at it differently than a county or district court or...they would have the same legal background and training, wouldn't they? [LB809]

DAVE BYDALEK: They...I think they'd look at the legal questions presented, yeah. And I guess what I'm saying here is I don't think in this particular instance the...and Mr. Downing feels the same way, that they didn't give a valid consideration of the religious action or the religious claim being made in the case. But once again, we'll see from the appellate courts... [LB809]

SENATOR GAY: Of course that's...yeah. [LB809]

DAVE BYDALEK: ...what's going to happen. [LB809]

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SENATOR GAY: Yeah, of course that's your opinion, but I guess the question I was getting at, would a juvenile court judge, even though they're lawyers and... [LB809]

DAVE BYDALEK: Uh-huh. [LB809]

SENATOR GAY: ...had...would they...they wouldn't have the same experiences maybe as you go up higher in the court system as the district court or a Supreme Court justice, obviously. [LB809]

DAVE BYDALEK: Right. It's a more...it's a more directed area of law,... [LB809]

SENATOR GAY: Narrow defined. [LB809]

DAVE BYDALEK: ...more narrowly focused. [LB809]

SENATOR GAY: More narrowly defined. So do you think that had a say in... [LB809]

DAVE BYDALEK: It may have. [LB809]

SENATOR GAY: ...in your opinion? [LB809]

DAVE BYDALEK: It may have. [LB809]

SENATOR GAY: All right. Thank you. Senator Howard. [LB809]

SENATOR HOWARD: This was heard in juvenile court in Douglas County and I don't want to speak for Judge Crnkovich, she handled it, but I know that she's very careful, and all the juvenile court judges are, to look at the rule of law rather than let their own opinions or what they may perceive as religious convictions to enter in. They really look at the issue of is this violating child welfare law. [LB809]

DAVE BYDALEK: Right. And Judge Crnkovich used to be a Douglas County Attorney and when I did criminal stuff for the Attorney General's Office she always did an excellent job. What I will say is, just looking at this from a broad perspective of constitutional law, I mean the rule is pretty...the rule is pretty standard: Does the state have a compelling state interest? And if they do, they have to exercise that compelling state interest in the least restrictive means. In this particular case, doesn't sound to me, from all the evidence that we've gathered and the research we've done on the case, that there's a compelling state interest. As such, I believe that the exemption really...you really need to take a good look at putting the exemption into law. [LB809]

SENATOR GAY: All right. Thank you. Any other questions? I don't see any. Thank you.

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[LB809]

DAVE BYDALEK: Right. [LB809]

SENATOR GAY: Last call, proponents? One more proponent. Go ahead and state your name and spell it for us, please. [LB809]

JOHN ANAYA: (Exhibit 6) My name is John Anaya, J-o-h-n... [LB809]

SENATOR GAY: Scoot up a little closer to the microphone. There you go. [LB809]

JOHN ANAYA: My name is John Anaya, J-o-h-n A-n-a-y-a. My name is, as I said, John Anaya and I live in Omaha. I'm asking you to support LB809. Although I am only in the 8th grade and not yet old enough to vote, I'm here today because of the freedom stolen from my family by the actions of the Nebraska department of newborn screening. Since this committee refused to act during the previous session on a similar bill, LB250, my family experienced a terrible event on October 11, 2007. On that Thursday morning, when the doorbell rang that Thursday morning I was pleased that my mother allowed me to hold my baby brother Joel since she usually gave him to my sister Rachel if she had to leave the schoolroom for some reason. I did not have any time to react when sheriff deputies came charging down the stairs and took my baby brother Joel from my arms. I was too shocked to think. After they ran up the stairs and I heard my mom and my siblings crying, I began to realize what had happened. The next six days were a nightmare till my baby brother was returned. I have read dozens of biographies of great Americans. One thing I have noticed again and again is that those who fight against injustice, in whatever form it is found, were usually in the minority. Whether it was fighting to abolish slavery or for a woman's right to vote, often people now seen as heros were persecuted by the authorities of that time. I'm glad my parents are willing to stand up for their convictions, even if it means civil disobedience to the state of Nebraska. I'd rather stand for religious liberties than fall for anything. I believe history shows that we are in good company. I hope that this committee will take the responsibility seriously and move forward on LB809 before more families experience the miscarriage of justice ours did. [LB809]

SENATOR GAY: Thank you very much, John. Are there any questions from the committee? I don't see any. Thank you very much. Okay, I didn't see any other proponents. We'll go into any... [LB809]

SENATOR ERDMAN: Hold on. Hold on. [LB809]

SENATOR GAY: Oh, we have some more? Come on up if you want to talk in favor of this. Go ahead and state your name, if you could. [LB809]

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JEREMIAH ANAYA: (Exhibit 7) Good afternoon. My name is Jeremiah Anaya, J-e-r-e-m-i-a-h A-n-a-y-a, and I'm a resident of Omaha. I'm also a student at Bellevue University. Once I turn 18 in June, I will be registering to vote. Furthermore, I am a proponent of LB809 for many reasons, the main reason being that I believe personal freedom should take precedence over medical screenings, such as this for highly rare diseases. As stated in an Associated Press article: Last year, out of 26,819 babies tested, 537 tested positive for one of the dozens of diseases; only 43 of the results were confirmed, according to the state's newborn screening program. This is the worst case scenario--.16 percent. One must realize that this is simply the general public's risk of having the disease, not the risk of dying. The false positive rate is 96 percent. In other words, 494 babies may have undergone unnecessary treatments. There are numerous accounts of parents who are told that their child had the disease, only to discover later that the testing that revealed the disease was inaccurate--a false positive. Some of the cases that have been reported are actually very mild. Just because the initial screening is not performed does not mean that the disease cannot be discovered and treated later. Of course, early treatment is more effective if one actually has one of these diseases. It's important to note, however, that none of my nine siblings have had any of these metabolic diseases. Since my siblings and I have parents that come from different ethnic backgrounds, it's improbable that both of them would be carriers of the same recessive gene responsible for these types of metabolic diseases. Thus, the chances of any of us having these diseases are even less than those of the general public. Last year, an attorney from the ACLU, Amy Miller, who has already testified before you today, brought a list of various things to the last legislative hearing in which this matter was addressed. All of the many different causes of death that were listed were statistically far more dangerous than metabolic diseases. Nevertheless, they are completely legal. For example, drowning is a more common way for children to die, much more common way for children to die than metabolic diseases, yet citizens are still allowed to install in-ground pools. Furthermore, playing competitive football is statistically more dangerous, yet that particular activity would never be illegal in the state of Nebraska. Another example of a more serious threat to public health is HIV. Although HIV is communicable and much more common than diseases that are included in these metabolic screenings, no one is advocating that adults of a particular age be forced to undergo HIV screening. Why is this? Adults wish to have a say in their medical treatment. They would also resist such a state mandatory screening. Yet, from a public health standpoint, there would be greater justification for that screening to be mandated than there is for this screening to be mandated. As any reasonable person can see, the state of Nebraska cannot protect children from every possibility of harm. This issue regarding metabolic screening exemptions has been brought before this committee numerous times without actually being moved out of committee and brought before the Legislature. Please realize, however, that this issue will not simply disappear. I think Mr. Spiering communicated that to you as well when he testified earlier. So please do not let this bill to languish...leave this bill to languish another year. Allow LB809 to go to the floor for a vote this year. [LB809]

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SENATOR GAY: Thank you very much. Any questions from the committee? Senator Erdman. [LB809]

SENATOR ERDMAN: Jeremiah, I think there were some people in Nebraska that were hoping we would outlaw football the way that some of us were playing football, but I think that's right. Let me ask you a little bit about you, though. You're 18 and you attend Bellevue University? [LB809]

JEREMIAH ANAYA: I'm 17. [LB809]

SENATOR ERDMAN: 17. And your mother, her testimony earlier spoke that you're a sophomore at Bellevue University? [LB809]

JEREMIAH ANAYA: Yes. [LB809]

SENATOR ERDMAN: So then I'm assuming that you were either in some accelerated program or homeschooling? [LB809]

JEREMIAH ANAYA: Yes, I was homeschooled. [LB809]

SENATOR ERDMAN: Okay. Well, I have an interest in that as well, but we won't bring that up here. But I appreciate you coming forward and I think you did a good job. [LB809]

SENATOR GAY: Thank you very much. Any other questions? I don't see any. Thank you, Jeremiah. Other proponents who'd like to speak on this issue? Okay, I see none. We'll turn it over, let's get into any opponents who would like to testify. Please come forward. And how many opponents are we going to have talk? About four. And I do have some letters. I'm going to read all the letters I received at the end. We did receive letters in support, against, and neutral, so I'll read those into the record when we're done. So, okay. [LB809]

KHALID AWAD: (Exhibit 8) Hello. My name is Khalid Awad, K-h-a-l-i-d A-w-a-d. I have...you have copies of my testimony. At the risk of sounding less than eloquent, I will briefly summarize it and then entertain questions from the committee. Thank you for letting me speak today with you, Senator Gay and others. I am a board certified pediatrician and neonatologist. I'm a partner in a medical practice at Children's Hospital. I am also currently the vice chairman of the Nebraska Newborn Screening Advisory Committee. I'm also a member of the Nebraska Medical Association. And I am here to voice my opposition to the creation of a religious exemption to the Nebraska newborn screening program, as contemplated by LB809. Obviously, several comments have been made about the legality/constitutionality of this current law as it exists, and I am

not an attorney but I would like to reiterate the point that the courts have upheld the position on many occasions, including the specific case of mandatory newborn metabolic screening, that it is legal and it is constitutional. That has been tried in Nebraska as well. I'd also make the short point to say that there is no way that anyone, including a parent, can reasonably predict if a child...if their child will be a victim of one of these diseases, and that is just a certain fact. All we as physicians need to help these children are a few drops of blood, collected with minimal intrusion by a small prick of the heel. To speak a little more extemporaneously, people talk about the immanent threat to the a child before the state would assert its right to intercede in a family or in a parental circumstance. I think that misunderstands the risk of some of these inherited, albeit rare, genetic diseases. There were 40 diseased children who were positive for some of these diseases last year in Nebraska, approximately 40 the year before. Had they not been tested and diagnosed, they would have suffered, irrevocably, irrevocably from the disease. That's not a potential; that's a real damage to the child. The ability to diagnose the child initially, in the early few days of life, is the key to preventing that injury. If we had the luxury of waiting six months, six years and then interceding I'd understand that, but we don't. If misdiagnosed, if not appreciated early on, they will suffer the disease and that represents the immanent threat to the child. Okay? The question has been brought up, inconsistencies in the regulations regarding vaccinations. There is, without question, a very clear distinction between injecting a medication, albeit a vaccine that is potentially life saving, from drawing a few drops of blood to diagnose a patient with a disease. We're not talking about injecting. I understand the religious objection to injecting medications. I don't ascribe to it. I, personally, have my daughter vaccinated with everything that we can find to prevent her from becoming ill, but that is different than doing blood testing to diagnose a disease. The attorney from the ACTUAL mentioned the fact that if a child was known to have a disease they would argue strongly in favor of the state's responsibility to intercede and mandate treatment for that child. If we could wait till six months of age and safely diagnose a child with hypothyroidism, they would then assert that child needs to be treated. We don't have that luxury. We can only diagnose it safely at the beginning of life, in the first few days. And then, once we get that information, that they're reluctant to pursue early on, then they would turn around and endorse our position that the child needs to be treated. We cannot play an ostrich and bury our head in the sand. Forty children last year were diagnosed with these diseases, forty children the year before. It will happen year, after year, after year. They will be born with these diseases, they will become victims of these diseases unless we intercede early and effectively. Newborn screening is the key to being able to accomplish that. Questions? [LB809]

SENATOR GAY: Senator Erdman. [LB809]

SENATOR ERDMAN: Let me...I appreciate your expertise. Let me walk through the practice in other states. As a member of the Screening Advisory Committee, you probably have experience or contacts with people outside of Nebraska regarding similar

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issues. [LB809]

KHALID AWAD: Uh-huh. [LB809]

SENATOR ERDMAN: Do we see a great deal of interest in these exemptions? I'm just trying to understand, what is the population, what is the mass of the 26,000 children that are born annually,... [LB809]

KHALID AWAD: Uh-huh. [LB809]

SENATOR ERDMAN: ...of which 40, whether it's your facility or statewide, I don't know what? [LB809]

KHALID AWAD: It's statewide. [LB809]

SENATOR ERDMAN: Okay. Are we talking a couple hundred kids, are we talking two or three kids? Do you know generally what the other statistics show that the people who actually opt out of the testing in other states as a percentage? [LB809]

KHALID AWAD: I don't know a percent. I would agree that it's a small percentage of all potential screen babies, the parents assert the right to opt out. [LB809]

SENATOR ERDMAN: Help me then with the medical side of this process,... [LB809]

KHALID AWAD: Uh-huh. [LB809]

SENATOR ERDMAN: ...because I...we can write the political side, the policy side to reflect whatever we want. [LB809]

KHALID AWAD: Sure. [LB809]

SENATOR ERDMAN: Talk to me about the time line. Right now it's up to the department to determine that it's within the first 48 hours,... [LB809]

KHALID AWAD: Uh-huh. [LB809]

SENATOR ERDMAN: ...either out of convenience or out of medical necessity that that happened at that time. [LB809]

KHALID AWAD: Uh-huh. [LB809]

SENATOR ERDMAN: If I'm looking at this objectively and I say there's a group of people that are opposed to the testing altogether, there's another group of people that

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are opposed to how the testing is being done, and then there's another group of people that are opposed to when the testing is being done. [LB809]

KHALID AWAD: Right. [LB809]

SENATOR ERDMAN: Is it possible to consider a scenario where an exemption could be offered where you still get a majority of those individuals, because of how it's being done, as being objected to it as opposed to what; and talking about why the timing of 48 hours is chosen; and why alternative testing is not available or pursued? Is it...and I'll just stop there and you... [LB809]

KHALID AWAD: Yeah, that's quite a lot to cover. [LB809]

SENATOR ERDMAN: I know. I talk like it's drinking out of a fire hydrant, I recognize. So let's start with this: talking about the time line, just talking about the time line. [LB809]

KHALID AWAD: Well,...the time, the initial time for doing the screening is...the regulations are between 24 and 48 hours. We do early screening for emergent circumstances. But the main reason is you need some time for the baby's metabolic pathways to start predominating. In utero, the overwhelming majority of these diseases are asymptomatic because the mom's body, through the placenta, filters and processes the metabolite, so the child is really not at risk. It's only after birth that it becomes a risk. And you need to wait 24 to 48 hours for those processes to really represent the baby's metabolism. You also need to initiate feedings in the baby, because many of these disorders are only present once their ability to properly metabolize their diets create abnormalities. [LB809]

SENATOR ERDMAN: Could one make an assumption then, and you can correct me if this isn't right, if the thought, and I have a two-year-old daughter and when Mr. Riskowski was talking about them trying to get the blood out of her heel because she had...oh, they put her in the tanning bed. She had jaundice. [LB809]

KHALID AWAD: The bilirubin lights. Yeah, she had jaundice. Sure. [LB809]

SENATOR ERDMAN: She had...I mean that same scenario took 30 minutes after the second time to make sure they got that out. So, I mean, I understand the process. If we're waiting for the child's system to begin functioning... [LB809]

KHALID AWAD: Uh-huh. [LB809]

SENATOR ERDMAN: ...within 48 hours, depending upon whether that child has begun nursing, and some circumstances they eat right away, others are...I mean, it's a little slower, is a week too late? Is there a...I mean, obviously, the sooner you... [LB809]

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KHALID AWAD: Yeah. [LB809]

SENATOR ERDMAN: ...catch it the better, but help me understand. Is there a medical reason why we're at 48 hours, or is it a convenience issue? [LB809]

KHALID AWAD: No. [LB809]

SENATOR ERDMAN: And would a week be sufficient to catch...and assuming the body would be functioning more normally even at a later date but not maybe too late. [LB809]

KHALID AWAD: There would be two parts to that. For some of the diseases, a week would be too late. Galactosemia, the child would be, you know, critically ill at that point if we did not diagnose it sooner, okay? So some of the diseases we need to diagnose sooner than a week of age. You know, do you want to talk about 48 hours versus 72 hours? You start to get into a couple here, couple there. When you line up all the diseases that we can screen now effectively, you know, 48 hours is really a good time to do it. Now there are a lot of logistic benefits to that as well. Since the overwhelming majority of children are born in hospitals, they're 48-hour hospitalizations. We have an opportunity to capture the specimen quickly and effectively, and then the families move on to home. They're in the hospital already. The families that have home deliveries, you know, they have the opportunity to have the child at home and then they have 48 hours to then present themselves to a lab, to their doctor's office, to wherever to have the tests done. So there is a real efficiency in terms of a public health policy, how you're going to administer a program like this, as opposed to trying to stretch it out over seven days or having some people do it on one day or another day. The other question that was touched on, and I think you brought it up again, is other methodologies. Urine screening was early on the way to test for the PKU, but that's 1 out of 30-odd diseases we test for, and it's not the best way to test for that disease process. The modern technology we have with modern biochemistry, modern analytical chemistry, all the computers we have now allows us to do that with a blood spot much more accurately, much more effectively. [LB809]

SENATOR ERDMAN: Last...go ahead. [LB809]

KHALID AWAD: Oh, I was going to say, and to another point it reminds me of, you know, there are false positives. It is a screening test and every screen that's positive does bear repetition. We repeat it with more of a diagnostic test than a screening test. Once we confirm the presence of the disease, children are not harmed by being treated. That is just a misnomer. Dr. Frost is wrong. That does not happen. We confirm the diagnoses, we make services of the diagnoses, and we implement effective medical therapy. Is every medical therapy perfect? No. Who's kidding who? Surgeons have left instruments in patients. But just because a surgeon forgets a sponge in a patient

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doesn't mean that coronary artery bypass surgery is ineffective or risky or dangerous. Okay? Occasionally there's an anecdote of something being done wrong, but the reality is that treatment is not dangerous to these children, because they have diseases that they benefit from the therapies. [LB809]

SENATOR ERDMAN: Let me add...and I actually have two questions after that, and I'll stop asking questions because I'm sure that everyone else is interested in me not asking them. Under the law, the department outlines that within 48 hours under the rules and regs every child must be screened. And so the law says all children must be screened. The department says it has to be within 48 hours per their rules and regs. [LB809]

KHALID AWAD: Uh-huh. [LB809]

SENATOR ERDMAN: The statute then further goes on and says that, in the effort of getting the first sample, the physician may offer or may request an additional sample. And I'm, again, logically looking at that and saying, if I'm going through the process of having my child's blood drawn within the first 48 hours and they're going to take five dots on a paper to be tested, why not do ten dots and just be done with it? What happens if they say no? What happens if you do the initial screening and there's the five that they do, the five different samples? The law doesn't require the second set. [LB809]

KHALID AWAD: Uh-huh. [LB809]

SENATOR ERDMAN: So then you have a false positive or you have a positive, depending upon what the second set of tests would come back. So then you have the child that has already gone home. Have you ever had a circumstance where they have not done the second set? I'm assuming it's customary to do the two, just as an outset, but the statute specifically says that you have to ask or offer a second set of testing... [LB809]

KHALID AWAD: Right. [LB809]

SENATOR ERDMAN: ...in the discourse of the required one. What happens if they deny the second one? Don't we... [LB809]

KHALID AWAD: If the parent refuses? [LB809]

SENATOR ERDMAN: If the parent refuses, there's nothing in the law that requires them. It's "may." The previous language about the initial one is "shall." [LB809]

KHALID AWAD: Right. [LB809]

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SENATOR ERDMAN: Can you give us... [LB809]

KHALID AWAD: Right. If we had a positive screening test, the people who work in the newborn screening program would contact the primary care physician, as identified, as well as the family, notify them both that the test...the screening test came back positive and it needs to be repeated. If the family were to refuse or not respond, the physician would be obliged to, you know, pursue that with the assistance of the newborn screening program, and at that point that we have a presumptive positive test then it would be like the attorney from the ACU mentioned: We believe a child as a disease, they're not being adequately managed medically, they would...I would expect that I would...and what I would do is I would go to the department of social services and pursue that avenue. The child needs to have a repeat test done because they have a positive screening test and we have to confirm whether the child has that disorder and initiate treatment. [LB809]

SENATOR ERDMAN: But to go back to your earlier comment then, potentially that test could come a week later. [LB809]

KHALID AWAD: Absolutely. [LB809]

SENATOR ERDMAN: And it still runs the risk... [LB809]

KHALID AWAD: It does take about a week to get the...five days to get the results back. [LB809]

SENATOR ERDMAN: It still runs the risk that you're beyond the window that you would like to see for the rest of the screen. I'm...and here's what I'm looking at. I mean I'm looking at the balancing act that... [LB809]

KHALID AWAD: Uh-huh. [LB809]

SENATOR ERDMAN: ...that appears to need to be done. There are going to be people who we know are not going to comply with the law. [LB809]

KHALID AWAD: Uh-huh. [LB809]

SENATOR ERDMAN: There are going to be people that will comply with the law if it's reasonable. [LB809]

KHALID AWAD: Uh-huh. [LB809]

SENATOR ERDMAN: And there are going to be people that, regardless of whatever other people think, they want them to comply with the law no matter what because they

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believe that it's ultimately in the best interest. [LB809]

KHALID AWAD: Right. [LB809]

SENATOR ERDMAN: If we create ourselves a mousetrap that catches everything, including mice, we're going to be cleaning the mousetrap quite a bit. But if we can figure out an opportunity to target but still provide that benefit, I think that's always a balancing act we have to make. And I think your testimony has been very instructive for me to kind of understand the dynamics here and what's available, what's not available, why things are being done. I also would think that based on the way that this is written or the law that is currently written, with the exception of the people who don't want to participate at all, I would think that the department, by rule and reg, could provide for a variance for people that would rather do it after the seven days because it prescribes the time in rules and regs, not in statute. And so for the individual, I think it was Ray, that came up here, the department could say you have the option of this. They would not be opting out of the test. They would simply be authorized, under the rules and regs, to do it at a time that's more appropriate to them, under the risk... [LB809]

KHALID AWAD: Uh-huh. [LB809]

SENATOR ERDMAN: ...that it may not be as effective. There are going to be folks that don't want to do it... [LB809]

KHALID AWAD: Right. [LB809]

SENATOR ERDMAN: ...and I think, at least to me, I look at this statute and I say, that's probably the impetus for any change in law. But to the individuals that say we just want to do it a little bit later in the child's life, I've got to think that there's an opportunity for the department to review that consideration and determine is it in the best interest of the screening program to have those people comply at some point than to be a part of a group that doesn't want to comply at all. [LB809]

KHALID AWAD: I understand what you're... [LB809]

SENATOR ERDMAN: And it's not a question. It's just an observation and... [LB809]

KHALID AWAD: ...what you're trying to fix, yeah, but I think if you...when one looks at what all the state requirements are for screening, regardless of whether they allow exemptions or not, it's always between 24 and 48 hours. Because I think when you bring all the forces to bear, all the issues to balance, the most effective, efficient way to practice a public health policy is a 48-hour screening. And it would be nice to be able to be solemn and create the other exception for seven-day screening that would capture a whole other host of people that are interested in participating but have that time issue.

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At the end of the day, it creates a never-ending permutation of or seven days or ten days or one week or two weeks, and then it becomes an unmanageable bureaucracy, unmanageable system, and then the whole thing will collapse. [LB809]

SENATOR ERDMAN: Just one last follow up. We drive...and the public health idea is a valid one for the benefit of the society and for maintaining order and the overall health of the civilization, country, region, whatever. We cannot prohibit children from having children at home. [LB809]

KHALID AWAD: No, we can't. [LB809]

SENATOR ERDMAN: But we can prohibit professionals from assisting them in having those children at home, and we do under our state law. [LB809]

KHALID AWAD: We do. [LB809]

SENATOR ERDMAN: Which is to the chagrin of the Nebraska Hospital Association because they'd love to have every kid born in their hospital. I recognize that because of that fact, and there's a legal right, there's a constitutional right and there's an opportunity to that, that has. Plus there's a practical limitation that if you require everyone be born in a hospital, the person that has the kid in a cab is now a criminal. So there's some practicality in that. But medicine isn't necessarily designed to be convenient for the practitioners. You have a great responsibility to take care of a ton of people, and I am convinced that you do a fantastic job. But at the same point, our society requires some amount of freedom that doesn't always mean it's convenient. And it's not convenient to be in a lot of occupations all of the time, but at the same point, when we get to the point, and I would think you would concur, that the more active and involved individuals are in their medical care, the more ownership that they take in it and generally the more informed that they are, whether we agree with the decisions that they made. I had a doctor who recommended me a procedure of \$2,000 that was highly invasive, that was trying to keep guys like Jeff Downing and others from suing them because they didn't recommend the right test, and I did some research and I said, well, what if it was this? And they said, very well could be; you make that decision, but the standard of care is this. We need to get...and I know it's difficult, especially with malpractice and things. Again, the idea is balancing the interests of the patient with the convenience of the system we've created to deliver healthcare, with the overall benefit of the state. And I...and I won't continue to ask questions and you can comment at the end and I'll stop. But this has been very instructive to me today, to hear both sides of this and to hear the comments. And for the benefit of everyone, I will stop asking questions and listen. (Laugh) [LB809]

SENATOR GAY: Doctor, I'm not so sure that was a question so... [LB809]

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SENATOR ERDMAN: I will allow you to comment. [LB809]

SENATOR GAY: So let's do this... [LB809]

SENATOR ERDMAN: I will allow him to comment, if you will, Mr. Chairman. [LB809]

SENATOR FULTON: Very, very quickly, I guess, if you want to comment quickly, but go ahead and... [LB809]

KHALID AWAD: I would make the comment that it is essential to remember that the patient here is the newborn infant, and they need to have their best interests for their life represented and spoken for. I don't question sincerity of people's beliefs. I don't question the sincerity and the intention to rear their children well and succeed, as the Anaya family has with their education and their productivity and what great Nebraska citizens they are, how much they contribute to this society. But at the end of the day, people make ill-informed decisions and there are irreversible repercussions to the child. It isn't a matter of convenience for the medical community; it is a matter of what works best for the state of Nebraska to collect these specimens and test all these children effectively and efficiently. It's not my convenience; it's what's best for the child. [LB809]

SENATOR ERDMAN: Fair enough. Thank you, sir. [LB809]

SENATOR GAY: Thank you. Thank you. Any other questions? I don't see any. Thank you very much. [LB809]

KHALID AWAD: All right. Thank you. [LB809]

SENATOR GAY: Thank you. Other opponents? [LB809]

PATRICIA CRAWFORD: (Exhibit 9) I'm Patricia K. Crawford, P-a-t-r-i-c-i-a C-r-a-w-f-o-r-d. I live in Omaha and I have strong opposition to the bill. Oh, here, I have some copies, too, and those...they're two pages each, Matt. Thank you. My husband and I have five grown children. Our middle child Matt has PKU. For couples with the recessive gene, the chance of having another affective child...or an affected child is one in four with each pregnancy. He was born in New Orleans and had no testing, though it was available for PKU at that time. Three months later we moved to Lincoln and later on I took him to the pediatrician in Lincoln and...because we were concerned about his obvious decline, and...but the doctor was not very interested. Matt was a healthy child at birth and very normal and perky and did all the baby...cute little baby things, as we expected him to do, for three, four, five months. But subsequently, he declined so gradually and so insidiously that it took awhile before we realized that he wasn't performing as he should. At age 13 months, we took him to the medical center at Iowa City, where he was promptly diagnosed with PKU, put on a special diet of altered

protein, and almost immediately started to improve. Unfortunately, it was much too late to save him from profound mental retardation. He lived with our family until he was 14, when we placed him at the Beatrice State Development Center where he could get the care he needed and where he has received excellent care and training and seems to be contented living in a cottage with 15 other men. But Matt, because of his PKU, has an inborn metabolic error. He is unable to digest one element of protein, phenylalanine, which builds up on the blood and damages the brain, and damage it, it did. He cannot speak. He's never uttered a word. He needs help in every aspect of living; needs someone to direct his life at all times. He can't tie his shoes, can't button his shirt. He's unaware of ordinary hazards, such as danger from cars, hot water or getting lost. If he had been started on the appropriate diet immediately after birth, none of the above would have happened. Every time Matt was fed, it was an insult to his brain. There are no medical miracles to repair the damage from genetic diseases. Once brain damage has occurred there's no going back. A parent can impose his will on a child until 18, with luck. Then the child more or less makes his own life. In the case of a person devastated by genetic disease, whose parents make a grievous lack of judgment by opting out of newborn screening, the parents dominate until his death. The child seems to have no rights. You know, his parents are responsible for him till he's 18, but then he has a whole life to go on after age 18, and if he has...if he's...and if they've opted out for...and even though he's an American citizen, he seems to have no rights to a whole span of life. In 2007, as the doctor said, 40 infants were...in Nebraska were saved from brain damage, disabilities and/or death by the Nebraska newborn screening program. In the past ten years, approximately 250 children have been saved, 250 who do not suffer from profound disabilities and who do not require lifelong public services. So I urge you to kill the bill. [LB809]

SENATOR GAY: Thank you. [LB809]

PATRICIA CRAWFORD: Thank you very much. [LB809]

SENATOR GAY: Thank you. Senator Howard. [LB809]

SENATOR HOWARD: Thank you, Senator Gay. Patricia, I remember you coming down here last year and I remember really feeling how hard it must have been for you, not to bring up difficult times, but I really thank you for having the courage to come down here and express yourself and to really put a personal side to the damage this can do. [LB809]

PATRICIA CRAWFORD: Well, it's...it's... [LB809]

SENATOR HOWARD: That's really...it's noble of you to be able to step forward and... [LB809]

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PATRICIA CRAWFORD: Well, thank you very much, but I just feel an obligation so I guess... [LB809]

SENATOR HOWARD: Well, thank you. [LB809]

PATRICIA CRAWFORD: Thank you very much. [LB809]

SENATOR GAY: Thank you. Any other questions? I don't see any. Thank you very much. Other opponents? Any other opponents? Go ahead. [LB809]

JANICE SODERQUIST: (Exhibit 10) Senator Gay and members of the Health and Human Services Committee, I am Janice Soderquist, S-o-d-e-r-q-u-i-s-t. I live in Axtell and I'm a constituent of Senator Johnson, Dr. Joel Johnson. He's not here today. I urge you to vote against LB809 and to maintain Nebraska's requirement of metabolic screening for all babies. A parent's religious belief should not give him or her the right to deprive a child of medical care. I grew up in a Christian Science household. I was 18 when my sister was born in 1966. Although Christian Science opposes medical care, it allows women to have babies in hospitals. I could tell when my mother and sister came home from the hospital that something was wrong. My grandmother and parents looked very worried. A doctor was calling our house. Nobody would tell me what was wrong. I was frightened. Finally, my grandmother told me that my sister had tested positive for phenylketonuria, PKU. Because of their religious beliefs, my parents refused to put my sister on the diet needed to prevent the damage from this terrible disease. Back in those days the state did not follow up with our family. My parents got to do what they wanted to do. Fortunately, praise the Lord, the test must have been a false positive because my sister developed normally without the diet. She was more fortunate than your son, but it could have been easily the other way. To my mother and grandmother, this was a great victory for Christian Science, but it looks to me now like Russian roulette and a very foolish risk to take with a child's life. I also testify as a member of Children's Healthcare Is a Legal Duty, or CHILD, Incorporated, which is a national membership organization headquartered in Sioux City, Iowa. We urge legislators to oppose LB809. All babies deserve the benefit of detecting metabolic disorders in time to prevent the lifelong catastrophic damage they will inflict if left untreated. Nebraska has required metabolic screening without a religious exemption since 1983, 25 years. According to state records, Nebraska has not missed a baby with a metabolic disorder since 1973. That's an excellent record and we hope you will want to keep it that way. In 2003, parents of an Omaha baby refused to have their baby screened because of their religious beliefs against withdrawing blood. The Douglas County prosecutor filed charges against the parents, who argued that the state had no right to interfere with a parent's religious practice until the child was actually sick. Child advocates point out, however, that the metabolic screening is necessary in order to know if the child has a metabolic disorder. These disorders typically--it's already been said--do not show clinically observable symptoms in time for effective treatment. A mother's metabolism corrects that of the

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fetus so the baby is born apparently normal. After birth, however, the metabolic poisons accumulate, brain growth retards, and brain damage may ensue. Yes, it might be years before this damage is seen or, in your case, a few months. Some babies will seem fine when unstressed, but even minor to moderate stress, such as a cold, can cause metabolic crises that leads to serious illness or sudden death. The metabolic screening is a very small intrusion into family privacy. Only a few drops of blood are needed to test for all the diseases listed in Nebraska's law--a very small thing compared with a lifelong sentence of profound mental retardation or a whole series of others, other issues, but PKU is the one I'm most familiar with. Often the treatment consists only of dietary manipulation. These simple measures prevent the terrible damage inflicted by these diseases, including mental retardation, growth retardation, failure to thrive, liver disease, sudden death. The state has a compelling interest in preventing mental retardation and reducing the high financial burden of institutional care. That's the big one that the kids have to go down to Beatrice and thousands, millions of dollars to take care of this...these individuals. The Nebraska Court unanimously upheld the state's right to require metabolic screening without a religious exemption. The U.S. Supreme Court declined to review the ruling, so we've got the U.S. Supreme Court on our side. Nebraska was also sued in federal court by members of the Church of Scientology, whose religion opposes doing the test in the baby's first week of life. But there are good reasons that Nebraska requires the test to be done when the baby is between 24 and 48...this is repetition. Georgia... [LB809]

SENATOR GAY: So you...yeah,... [LB809]

JANICE SODERQUIST: Go quicker? [LB809]

SENATOR GAY: Start wrapping it up. Thank you. [LB809]

JANICE SODERQUIST: The federal district court in Nebraska ruled against the parents, holding that the state need have only a rational basis for requiring the metabolic screening. It also ruled that the screening was not an unreasonable search or seizure because the law gives parents the right to present their objections. The parents waived their right to appeal the ruling. Our state and federal courts have ruled that Nebraska has good reasons and the right to require metabolic screening of all babies, without exception for parents' religious beliefs. In all courts in this country, U.S. citizens have a right to raise their First Amendment rights to religious freedom. In cases of children's health, the courts then do a balancing act, weighing the state's interest in the child's health and safety against the parent's right to free practice of religion. Usually the court rules that a child's health and safety takes precedence over the parent's rules. Our beautiful state motto is equality before the law. Please do not discriminate against a group of children by depriving them of protections we extend to others. Please vote against LB809. [LB809]

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SENATOR GAY: Thank you very much. Senator Erdman has a question for you. [LB809]

SENATOR ERDMAN: Janice, thanks for your testimony. Your...one of the paragraphs on the front of your handout said Nebraska has required metabolic screening without a religious exemption since '83, and according to state records Nebraska has not missed a baby with a metabolic disorder since 1973. How do we, first of all, how do we know that? What records are we referring to? [LB809]

JANICE SODERQUIST: I do not know. I just would say that evidently there has been no evidence jumped and said, well, we've...there's a child with metabolic problems. It has not been...has not shown on the records that they were missed. [LB809]

SENATOR ERDMAN: Okay. And I'm just asking because it's a pretty profound statement to me. I'm just making sure, because it says according to state records. Is it through the research done through your organization, or is it from the screening board or...? [LB809]

JANICE SODERQUIST: Could you answer that? [LB809]

SENATOR GAY: No. [LB809]

JANICE SODERQUIST: You don't know either. [LB809]

SENATOR ERDMAN: I'll follow...Janice... [LB809]

SENATOR FULTON: Ma'am. Ma'am, no. [LB809]

SENATOR ERDMAN: Janice, I'll follow up with the department later, but the question that I was going to ask, if you had a definitive answer, was if we didn't miss a screening since '73 but it didn't become law till '83, did the law catch the screens or were we already catching them? And I'll follow up to find that. But the other question that I have is you mention that in the previous case, I think it was the '03 case, that the federal district court ruled against the parents, and that they had their right to appeal during the hearing. Regardless of whether you agree with what the Anayas did, it sounds like they didn't get that right before their child was tested this time. Do you see a problem with that, or is that part of that balancing that you're talk about? Because I'm trying to understand. The '03 case is what I'm assuming you're referring to, or maybe the previous case in Omaha. The case before us today that we've...not before us, but the case we heard about today in '07, in October of '07, was that they showed up with a court order and they took the child away and had it tested. And I think in theory you're right. I'm just...the example today appears that it didn't follow that, and I would imagine that if they'd a had that right, they probably wouldn't have gone to court to seek a

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different injunction. And the courts can decline to hear rulings for many reasons and it doesn't necessarily mean that they ultimately agree with a ruling. It just means that they didn't hear the case. But I have just...those are just some observations that I had but, I mean, I think you've done your homework. I appreciate you being here and I know that this is not a light issue for anyone. [LB809]

JANICE SODERQUIST: Could you state your question in one sentence? [LB809]

SENATOR ERDMAN: It wasn't a question. The second was an observation. The question that I had for you was regarding the facts that you stated about the state not missing any. [LB809]

JANICE SODERQUIST: Oh, yeah. Well, you'll have to look that one up. [LB809]

SENATOR ERDMAN: The second one was just an observation about the rights that an individual has under the courts to exercise their First Amendment objections. And I just made the observation. I didn't expect you to respond, but you could if you want to. [LB809]

JANICE SODERQUIST: Okay. [LB809]

SENATOR ERDMAN: Do you think that their First Amendment rights were trampled on, in the case that we heard today in 2007, where they were not allowed to have it heard before a judge before the child was tested? And you may not have heard the testimony, so if you don't want to answer, don't. I mean, I don't want to put you on the spot. [LB809]

JANICE SODERQUIST: Well, I just...I just...I just think any time that anything like this comes up, the lifelong health of a baby trumps a blood test. [LB809]

SENATOR ERDMAN: And I think you've made that point very well. Thank you. [LB809]

SENATOR GAY: Thank you very much. All right. Other opponents? I don't think...any other questions? I don't think we have any. Thank you. Thank you very much. [LB809]

JEANNE EGGER: Good afternoon, senators and council. My name is Jeanne Egger, J-e-a-n-n-e and my last name is Egger, E-g-g-e-r, and I would like you to not pass LB...this bill for the religious exemption. I am a parent of six children. Two of them have galactosemia, and by a week of age my first son diagnosed with it was...had to have a complete blood transfusion because of his bilirubin count being so high. It's not something that 48 or 72 hours or later would have...it was not mandated by the state at the time, so it was just a matter...he was born in 1980. At that time, there was no opportunity to catch it because PKU, there was a very small number of stuff that was being checked on. But my religion at the time, God first, is take care of my baby and so,

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you know, if the test results now that show that they have it, that would be fine. It's not something I think that as a parent I want to see other people go through, missing...you know, the potential missing, since we can find it. So I would like to see this bill not brought to the floor. Do you have any questions? [LB809]

SENATOR GAY: Any questions from the committee? Senator Pankonin has one. [LB809]

SENATOR PANKONIN: Thanks for coming. How...just tell me of the health of your children now or... [LB809]

JEANNE EGGER: They're both serving in the United States Navy. Two of my children have it, and they're both serving. [LB809]

SENATOR PANKONIN: So the testing was able... [LB809]

JEANNE EGGER: No, there was no testing at the time. [LB809]

SENATOR PANKONIN: At the time. [LB809]

JEANNE EGGER: No, back in 1980, galactosemia was not one of the mandated tests for the state. [LB809]

SENATOR PANKONIN: And it is now. [LB809]

JEANNE EGGER: It is now. Back then we just happened to have a very extremely, I don't know, directed set of circumstances where we had a pediatrician who was very aware of what the possibilities, and he said it could be a couple things when the bilirubin count was so high for my son. He said, well, it could be this and this and this, and I'll treat it; the best case, the best practices would be to treat it for the galactosemia, which is what my son had. And it didn't...you know, he's...the two of them that have, they're both fine, high school graduate, college graduate, both serving in the Navy. So as a productive citizen, it was worth, you know. And the potential for catching it with other children, you know, by day seven he had a blood transfusion, by day eight he could have been dead in other states that don't mandate it. The religious exemption is a possibility in those states and people do sign it and, as a consequence, their babies might not thrive. [LB809]

SENATOR GAY: Jeanne, I've got a question for you. So your pediatrician caught this and said, let's do the test, since it wasn't mandated. Had they said, you know, this is probably a good test, would you have said, yeah, go ahead and do it? I mean even if it weren't mandated but highly recommended, as a parent, what would you have done at that point? [LB809]

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JEANNE EGGER: At that point I would have said test. And, you know, my subsequent children have been tested. [LB809]

SENATOR GAY: Absolutely. Yeah. [LB809]

JEANNE EGGER: I mean it wasn't mandated, but I'm glad. I mean,... [LB809]

SENATOR GAY: Thank goodness. Yeah. [LB809]

JEANNE EGGER: ...they had the other part of the test. [LB809]

SENATOR GAY: You're very fortunate, very fortunate. [LB809]

JEANNE EGGER: Yes. [LB809]

SENATOR GAY: So... [LB809]

JEANNE EGGER: And it's not...I mean, recessive genetic traits are, yes, with the genetic...you know, how things work out, but we had no clue that we were going to have this in our child until he was a couple of days old, that he started getting jaundiced, so... [LB809]

SENATOR GAY: Yeah. Absolutely. [LB809]

JEANNE EGGER: I would have the test. [LB809]

SENATOR GAY: You would have had the test. Okay. Thank you. Any other questions? I don't see any at this time. Thank you. Any other opposition? I don't see any. Anyone who would like to speak in a neutral capacity on this issue? It's kind of hard to be neutral on this, but...okay. Senator Synowiecki is here and would like close. Thank you all for coming too. Appreciate it. [LB809]

SENATOR SYNOWIECKI: (Exhibits 11, 12, and 13) Thank you again, Senator Gay, members. I know it's been a long hearing and the only purpose for me getting up to close was, as the hearing progressed, my recommendation of Mary Anaya was to...we had a few more testifiers on the proponent side and, in consideration of the committee's time, I recommended that we submit this testimony in writing. This is a very important issue to them, so I very much encourage the committee to review this testimony. It's offered on behalf of Joshua, Josue, and Rachel Anaya, and I want to submit this for the permanent record to the committee and please note also that the only reason why this is being submitted in writing is in consideration of the committee's time. [LB809]

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SENATOR GAY: Thank you. And, Senator, just...we appreciate that and the one thing actually we...these are serious issues. We read the testimony. So a lot of times it's better, you know, when you give from your heart, as you did on your open, but we do read these and they're very helpful. So I appreciate you doing that. I appreciate it from the family too. Thank you very much for that and your time. With that, thank you, Senator. And just with that, we do have some letters too. (Exhibits 14, 15, 16, 17, 18, and 19) Nebraska Hospital Association submitted a letter in opposition. The Department of Health and Human Services had no position at this time. We talked about Louise's support for the bill is here. James Harper has a letter, opposed, that is here as well. And Katherine Rossiter is opposed. And also Linda Walker Gardels from Nebraska Planning Council on Development Disabilities has an opposition letter here too. So we do have those all for the record and will be read, I'm sure, by the members before we make any actions or recommendations on this. So with that, we'll close the public hearing. And then, Senator Synowiecki, by the way, just read these into the record, too, so our clerk will get these into the record. So with that, we will close the public hearing on LB809. Thank you all. [LB809]

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Disposition of Bills:

LB806 - Advanced to General File.

LB809 - Advanced to General File.

Chairperson

Committee Clerk