HANSEN: All right. Good afternoon and welcome to the Health and Human Services Committee. My name is Senator Ben Hansen. I represent the 16th Legislative District in Washington, Burt, Cuming, and parts of Stanton Counties and serve as Chair of the Health and Human Services Committee. I would like to invite the members of the committee to introduce themselves, starting on my right with Senator Ballard.

BALLARD: Beau Ballard, north-- District 21 in northwest Lincoln and northern Lancaster County.

WALZ: Lynne Walz, Legislative District 15, which is Dodge County and Valley.

HARDIN: Are you safe sitting by me? Brian Hardin, District 48. We are the real west, Banner, Kimball, Scotts Bluff Counties.

M. CAVANAUGH: Machaela Cavanaugh, District 6, west central Omaha, Douglas County. The real east, I guess.

HANSEN: Also assisting the committee is our legal counsel, Benson Wallace, our committee clerk, Christina Campbell. And our committee pages for today are Molly and Maggie. A few notes about our policy and procedures. Please turn off or silence your cell phones. We will be hearing five bills and we'll be taking them in the order listed on the agenda outside the room. On each of the tables near the doors to the hearing room you will find green testifier sheets. If you are planning, if you're planning to testify today, please fill one out and hand it to Christina when you come up to testify. This will help us keep an accurate record of the hearing. If you are not testifying at the microphone, but want to go on record as having a position on a bill being heard today, there are white sign-in sheets at each entrance where you may leave your name and other pertinent information. Also, I would note if you are not testifying but have an online position comment to submit, the Legislature's policies is that all comments for the record must be received by the committee by 8 a.m. the day of the hearing. Any handouts submitted by testifiers will also be included as part of the record as exhibits. We would ask if you do have any handouts that you please bring ten copies and give them to the page. We will be using a light system for testifying. Each testifier will have 3 to 5 minutes to testify depending on the number of testifiers per bill. When you begin, the light will be green. When the light turns yellow, that means you have one minute left. And when the light turns red, it is time to end your testimony and we will ask you to wrap up your final thoughts. When you come up to testify, please begin by stating your name clearly into the microphone, and then please spell both your first and last names. The hearing on each bill will begin with the introducer's opening statement. After the opening statement, we will hear from the supporters of the bill, then from those in opposition, followed by those speaking in the neutral capacities. The introducer of the bill will then be given the opportunity to make closing statements if they wish to do so. On a side note, the reading of testimony that is not your own is not allowed unless previously approved. We have a strict no prop policy in this committee. With that, we'll begin today's hearing with LB1035, and welcome Senator Hughes to open. Welcome.

HUGHES: Thank you. All right. I feel tiny in these chairs.

HANSEN: We do that for a reason.

HUGHES: I know, right? Let's make it even more intimidating. Good afternoon, Chairman Hansen and members of the committee. I am Jana Hughes, J-a-n-a H-u-g-h-e-s, and I represent District 24, which is Seward, York, and Polk Counties, along with Butler County west of Road G. I am before you today to discuss LB1035, and it is one of my favorites. Early last February almost about, just a little less than a year ago, I received an email from a constituent who urged me into looking at the possibility of creating a prescription drug donation program here in Nebraska. The constituent sent me this email after she struggled to find a home for her father's prescriptions after he passed away. Starting with this email, we began to look into what other states were doing with unused prescriptions. That led us to Iowa, our neighbors to the east, and SafeNetRx. We reached out and were invited over to visit their facility in Grimes, Iowa, which is a suburb of Des Moines. Senator Riepe joined us on the visit, and Senator Walz's staff Zoomed in. We returned from this visit impressed by the amount of medication and SafeNetRX's advanced inventory system, their safety inspections, their staff and their facility. We also learned that the Iowa legislature had asked SafeNetRx to join forces with other states to better utilize Iowa's growing inventory of donated prescription medications. I will be brief in my remarks here, as I've talked to each of you individually and many of you are co-sponsors. In fact, we currently have 41 co-sponsor-- co-sponsors on LB1035. There are a number of people here to testi-- testify on the specifics of LB1035. We will have the CEO of SafeNetRx, Jon Rosmann. We will also have Haley Pertzborn and Amy Holman from the Nebraska Pharmacists Association to speak about two different aspects of LB1035. And we will have Jalene Carpenter testifying on behalf of the Nebraska Healthcare Association and the Nebraska Nursing Homes and

Assisted Living Communities. I'm happy to answer any questions you may have at this point, but I anticipate that most of your questions will be answered by those behind me. If you still have any outstanding questions after their testimony, I'd be more than willing to answer those at close.

HANSEN: All right. Thank you for that opening. Are there any questions from the committee? Seeing none, we'll see you at the close, then.

HUGHES: Sounds good. Thank you.

HANSEN: Thank you. All right. How many people are planning to testify on LB1035, OK? Please raise your hand. Easy. Good. Great. OK. So let's have the first supporter of LB1035 please come up and testify. Welcome.

MAGGIE BALLARD: Thank you. All right. Good afternoon, Chairperson Hansen and members of the Health and Human Services Committee. My name is Maggie Ballard, M-a-g-g-i-e B-a-l-l-a-r-d, and I'm here on behalf of Heartland Family Service in support of LB1035. I wanted to give you all a present. And since there are so many cosponsors on this bill, and the fact that you do have John Rosmann himself from SafeNetRx here to testify, I'm planning to keep this short. So, I would like to express our gratitude to Senator Hughes for introducing this bill. We care a lot about prescription drug issues. And as you may know, hopefully do know, Heartland Family Services serves both Iowa and Nebraska. So in 2007, Iowa implemented legislation that created the Prescription Drug Donation Repository, which is partnered, of course, with SafeNetRx. And since 2007, more than $74.2 million worth of medication and supplies have been redistributed to over 123,000 patients throughout Iowa. Obviously, it's better to be in the hands of those that need the medications and have that prescription, but cannot afford it, rather than adding to the $5 billion worth of medications that are wasted each year. I will offer some feedback that I got from a friend of mine who is the pharmacy director at Jennie Edmundson Hospital in Council Bluffs. And I did mention this to Senator Hughes, so she's aware of this already. But that pharmacist, pharmacist I spoke to commented that on page two of the bill, line 30, that she did think that the language was a bit too restrictive. So instead of saying a prescription drug or supply is in its original unopened, sealed and tamper evident packaging, she thought that it would be OK if it said or tamper evident packaging. So that's all I wanted to offer today. But I'd be happy to answer any questions.

HANSEN: All right. Thank you. Are there any questions from the committee? Pretty confident this is going to pass with 41, you know, people's support.

MAGGIE BALLARD: I'm fairly confident. I don't want to-- I don't like to assume, we know what that means, but hoping.

HANSEN: Yeah. All right. Thank you for your testimony. All right, we'll take the next testifier in support, please.

JON ROSMANN: Good afternoon. Thank you for the opportunity, Chairman, Senators. My name is Jon Rosmann, J-o-n R-o-s-m-a-n-n, and I am CEO of SafeNetRx. We are the nonprofit 501(c)(3) that operates the drug donation repository in the state of Iowa. So what we do is we collect unused medicine that accumulates all across the country in all 50 states. These are unused drugs that accumulate in nursing homes, prison systems, hospitals, clinics. It's all unexpired medicine, non-controlled substances that are packaged in sealed, tamper evident packaging. And what happens is these prescriptions are dispensed in nursing homes for example. And just simply the drugs do not get used. They've already been paid for by Medicare or Medicaid or private insurance. And once the, the patient can no longer use these medicines, they get classified as hazardous pharmaceutical waste. And they become very expensive to incinerate. So these drugs accumulate for a variety of reasons. They accumulate because the patient no longer needs the prescription, they may have been transferred to a different location, or they may have passed away. And we are talking about massive amounts of drugs, thousands of tons every year, every year. At nursing homes alone, it's 740 tons of medicine in sealed, tamper evident packaging. And these are perfectly good drugs that could go on to have another chance at healing. So we collect this medicine from all across the country. These drugs come to our facility just outside of Des Moines. And then the medicines are inspected to make sure they are safe for redistribution. So these drugs are inspected by pharmacists to ensure that the product has not deteriorated, that the packaging has not been compromised, and that it's safe for consumption by the patient. We then put it in an online inventory system, and we fill orders for clinics and pharmacies that are taking care of indigent patients. So an indigent patient for this program means individuals that are low income, up to 200% of the federal poverty level, uninsured or underinsured. So we don't provide-- try and provide medicine in place of Medicare or Medicaid. What we do is we take care of all the individuals that fall between the cracks. So these are uninsured individuals, people who no longer qualify for Medicare or Medicaid. But in most instances, we're talking about working Americans that just simply cannot afford their needed prescriptions due to high, high copayments, and inadequate insurance from their employer in the marketplace. So we have operated this program since 2007, and we have now redirected 114 million and donated medicine and provided care to 141,000 individuals in Iowa. And we look forward to the opportunity to collaborate in the state of Nebraska. Our legislature in Iowa has been a long-time supporter of SafeNetRx since 2007, but that support is also provided to us knowing that we want to expand the program and develop partnerships with other states and the opportunity to collaborate, and that Nebraska is just a natural fit. We have collect-- collected unused medicine in Nebraska for well over a decade, and it's time that we start returning some of those drugs to the state of Nebraska. I would be happy to answer any questions that any of you may have.

HANSEN: Thank you for testifying. Are there any questions from the committee? Yes, Senator Hardin.

HARDIN: Hi. Thanks for being here. Are there any of these drugs that are Tier 4?

JON ROSMANN: Tier 4.

HARDIN: Bio-injectables, those kinds of things, or do they tend to be capsules?

JON ROSMANN: So for the most part we're talking about oral tablets and capsules. I believe you're referring to REMS drugs?

HARDIN: I'm referring to some modern cancer oriented drugs and those kinds of things. The latest and greatest, anything you see on TV for we all look at it and go, I have no idea what that's advertising, that's a Tier 4 drug.

JON ROSMANN: So we handle-- the drugs are largely coming from nursing homes, prison systems, veterans homes. So in those environments, many of the medications are for chronic conditions. Drugs coming from the corrections system would be mental health medications. We do receive some injectables, but they have to be injectables that do not require any refrigeration. We do not accept any controlled substances. And we do not accept any medications that we would classify as REMS 3 or 4. These are drugs that require special handling requirements, and have to be administered by physicians or--

HARDIN: And so all of the drugs that you are collecting are institutional in nature. Is that correct, they're not from individuals?

JON ROSMANN: So 80%, 75 to 80% of the drugs are coming from long term care institutional settings. That other 20 to 25% would come from a variety of settings that include primary care, community pharmacies, specialty providers like cancer centers, as well as individuals.

HARDIN: Thank you.

JON ROSMANN: You're welcome.

HANSEN: Yes, Senator Walz.

WALZ: Thank you. Thanks for being here. And thanks for what you're doing. I'm just curious, and maybe this is part of the bill and I'm not seeing it, but-- So currently, Iowa is able to collect from other states. Are they currently able to dispense to people from other states?

JON ROSMANN: So there are no federal regulations on drug donation. Drug donation is regulated in each state by the State Board of Pharmacy, and each state has their own version of administrative rules for their program. So, for example, across the US, there are now 43 states that have adopted enabling legislation, and each state has their own set of administrative rules. There are 16 states in the US where the administrative rules have been developed that very closely mirror Iowa. So we're focusing on those states to partner with first.

WALZ: OK. All right. Thank you.

HANSEN: Any other questions? I'm seeing none. Thank you very much.

JON ROSMANN: Thank you.

HANSEN: Take our next testifier in support. Welcome.

AMY HOLMAN: Chairman Hansen, members of the Health and Human Services Committee, my name is Amy Holman. A-m-y H-o-l-m-a-n, and I submit this testimony as the project manager for the Nebraska Pharmacists Association. I want to first thank Senator Hughes for introducing LB1035. The NPA manages a grant funded with legislative appropriations for the statewide MEDS disposal program. This program allows all Nebraskans to dispose of unwanted or unneeded or expired medications at almost 300 pharmacies across the state, keeping these medications out of our groundwater and soil, preventing accidental poisonings, and making sure they are not misused by someone else. Since 2016, this program has disposed of over 234,000 pounds of unwanted or unneeded medications, including over-the-counter products, vitamins, and supplements. 30,000 pounds, give or take, are disposed of every year in our state. Approximately 8,000 of those pounds come from long term care facilities. With LB1035, a large quantity of those medications could go to fellow Nebraskans that cannot afford their medications, and so do not take them. This program would help us to continue to keep Nebraskans safe, along with helping fellow Nebraskans to get their much needed medications. The NPA would respectfully request that the committee advance LB1035 for further consideration by the full Legislature. Thank you for your time, and I'll answer any questions.

HANSEN: Short and sweet.

AMY HOLMAN: Yep.

HANSEN: All right. OK. Any questions from the committee? Seeing none, thank you. We'll take our next testifier in support. Welcome.

HALEY PERTZBORN: Thank you. Chairman Hansen, and the members of the Health and Human Services Committee, my name is Haley Pertzborn, H-a-l-e-y P-e-r-t-z-b-o-r-n. I'm a licensed pharmacist and the Executive Fellow at the Nebraska Pharmacists Association. I appreciate Senator Hughes introducing LB1035. According to census.gov. Nebraska has a population of roughly 2 million. Roughly 7% of our population is without insurance. According to the National Institute on Minority Health and Health Disparities, in Douglas County alone, there are 18,374 individuals that are uninsured and are at or below 200% of the federal poverty line. This program will help those individuals connect with a reliable program to obtain their medications. Not only will this program help to insure-- help the uninsured, it will also serve those in between coverage and with gaps in their health care. The NPA, SafeNetRx, and Nebraska pharmacies intend to make the program as seamless and easy as possible for drug donation, and for clinics and pharmacies to dispense the donated medication to our Nebraska patients. The NPA has made great progress with the drug disposal program, and this drug donation program would help to expand and support this vital service. Together, we can repurpose medication, ensure unused medications are disposed of properly, and eligible medications can be used to help our Nebraska patients. Thank you so much for your time and I will answer any questions.

HANSEN: Thank you. Any questions from the committee? I don't see any.

HALEY PRETZBORN: All right.

HANSEN: Thank you.

HALEY PRETZBORN: Thank you guys.

HANSEN: Anybody else wishing to testify in support? Welcome.

JALENE CARPENTER: Thank you. Good afternoon, Chairman Hansen and members of the Health and Human Services Committee. My name is Jalene Carpenter, J-a-l-e-n-e C-a-r-p-e-n-t-e-r, and I represent Nebraska Health Care Association. We are here in support of behalf of our 401 nonprofit and proprietary skilled nursing facility and assisted living members, and we are very much in support of LB1035. This bill would require the department to develop a program and process for donating unused medications that can safely be redistributed to those in need. Our association became aware of the program in Iowa a few years ago, and we are pleased to be part of bringing that similar project to Nebraska. To comply with the FDA policy and state laws, many nursing homes and assisted living facilities destroy unused prescription drugs. These prescription drugs are unused only because a resident may have passed away, had their prescription changed, or left the facility. While stored at the facility, these drugs are maintained at appropriate temperatures and conditions that allow for safe reuse. We've had lot of testify-- testimony in support so far, so I'll skip to the bottom of-- We think this is a fantastic bill, and we're very much in support and would love to answer any questions you may have.

HANSEN: I wish all the hearings were like this. Everyone should get 41 co-sponsors from now on. That's awesome. Any questions from the committee? Seeing none. Thank you.

JALENE CARPENTER: Sorry, I think I had the last one, so.

HANSEN: We'll see.

JALENE CARPENTER: I know. After this one maybe somebody will oppose it, I don't know.

MACKENZIE FARR: I get the feeling I'm also very short, so this, yes. Chairperson Hansen and members of the Health and Human Services Committee. My name is Mackenzie Farr, M-a-c-k-e-n-z-i-e F-a-r-r, and I'm a pharmacist with Consonus Pharmacy in Gretna. It's a long term care pharmacy, with locations in Nebraska, two locations in Nebraska, one in Iowa or, sorry, two in Iowa, and one in Minnesota. On behalf of the NPA, I am here in support of LB1035, and I want to thank Senator

Hughes for introducing this legislation. So we care for pharmacy, or for residents in long term care facilities, including both skilled nursing facilities and assisted living facilities. This is an area, an area of health care where, unfortunately, we see a large amount of unused medications that are wasted each year. For instance, last year alone, our facilities collected through the SafeNetRX program in Iowa over 308,000 individual prescriptions. Residents in these, in these settings are often found admitting with a higher level of care requirement, meaning they often admit on more medications, having a list of multiple medical providers they visit, and with more disease states. As a pharmacy, our goal has been to work to ensure residents are on appropriate medications and for appropriate lengths of therapy. The two locations in Iowa are partnered with SafeNetRx, and last year alone, we collected over 208,000 prescriptions that were able to be re-utilized through this program, which is approximately 65% of medications that would otherwise have to be destroyed. This is a win, win. The patient is able to give back, individuals can utilize these medications, and it reduces the amount of overall waste. The medications are likely to be disposed of incorrectly, such as in our water system or in the trash. As our population continues to age, it is crucial we find solutions for unused medications to decrease the lasting effects of improper medication disposal. And I appreciate your time and the opportunity to testify. Any questions?

HANSEN: Thank you. Are there any questions? All right. Seeing none, thank you.

MACKENZIE FARR: Thank you.

HANSEN: Anybody else testifying in support? Sounds close. OK, anybody testifying in a neutral capacity? Actually, skip that. Anybody testifying in opposition? Is there anybody testifying in a neutral capacity? All right, seeing none, we'll welcome back up, Senator Hughes to close. And before she closes, just for the record, we did have some letters in support, we had eight letters in support, one in opposition, and one in a neutral capacity. So.

HUGHES: OK.

HANSEN: Well, welcome back.

HUGHES: So thank you, Mr. Chairman and members of the committee for giving your time today to listen. And for the record, we did talk to all our testifiers to try to make sure they weren't doing the same thing, saying the same thing over and over. So appreciate all you guys behind me. I want to quickly comment that I would like to work with the committee to clarify that we aren't going to be creating an entirely new prescription drug prona-- promot-- drug donation program here in Nebraska. The intent is to work with Iowa and use their expertise, infrastructure and systems and not reinvent the wheel here or pay for that wheel. I'm happy to look into language to clarify this intent so that the cost reflected in this fiscal note is around $400,000, if not less, depending on the needs of SafeNetRx to work with us here. I appreciate the legislative Fiscal Office's work in sharing a range of expected costs based on how the program is implemented. So if you look at that fiscal note, I'm assuming it's in your binders or with you, you'll see a range up to over $1 million, as if we would do our own donation program, which would be silly. In addition to those who testified in support, I'd like to mention that the Nebraska Hospital Association, the Nebraska Medical Association, the Nebraska Oncology Society, the Association for Clinical Oncology, the Nebraska Psychology Association, Nebraska Appleseed, and LeadingAge Nebraska have all endorsed LB1035. Colleagues, if we can even utilize a fraction of the 30,000 pounds of unused medication, and also with the large amount that is destroyed just already in our skilled nursing facilities and that goes into the drug disposal program each year to benefit Nebraskans who are unable to afford the medications they need, this program would be a resounding success. Continuing our current drug disposal program is critical for keeping open and expired medications out of our soil and water, and it's also critical for removing unused controlled substances like opioids from homes. However, LB1035 is a logical and practical next step in building upon our current drug takeback program. Reducing emergency room visits, reducing recidivism, promoting healthier families and a healthier workforce, and providing donated prescriptions to those who cannot currently afford them are all benefits to advancing LB1035 to the floor for further consideration. I thank you for your time, and I urge you to advance LB1035 from the committee, and I welcome any questions you guys have.

HANSEN: Are there any questions? Senator Cavanaugh?

M. CAVANAUGH: Thank you. Thanks for bringing this bill. I did have a question about the one opposition letter. It looked like it had a concern about civil liability.

HUGHES: Right. It was from the trial attorneys.

M. CAVANAUGH: And I, I just saw it, so I don't, I don't know if that's something--

HUGHES: They just-- they said by what they represent, they have to, because a program like this, if you put-- if you would allow that kind of lawsuits to happen, then it wouldn't happen. It's kind of the--

M. CAVANAUGH: OK. And then the other question.

HUGHES: Yes.

M. CAVANAUGH: This fiscal note is--

HUGHES: It ranges from $50,000 to $1 million.

M. CAVANAUGH: It's a journey.

HUGHES: It is a journey.

M. CAVANAUGH: So.

HUGHES: And that's where I don't know if we need to-- if we can make the intent in the bill.

M. CAVANAUGH: OK.

HUGHES: Narrow that sucker down.

M. CAVANAUGH: We might have to have a more in-depth conversation about it outside of committee. According to-- sometimes when they've testified, Senator Riepe can attest that sometimes they just find the money in the seat cushions. So maybe--

HUGHES: Just shake them out.

M. CAVANAUGH: We need to shake it out, but--

HUGHES: OK.

M. CAVANAUGH: Yes. This fiscal note is confusing, so I'll probably be following up with questions. But thank you for bringing this bill.

HUGHES: OK. Thank you.

HANSEN: Any other questions?

HUGHES: Nothing?

HANSEN: Nope.

HUGHES: Guy's are letting me off easy.

HANSEN: Yeah, I think so.

HUGHES: I know, I'll take it. Thank you very much.

HANSEN: All right. All right. Thank you for coming. All right, that'll close our hearing for LB1035. And we will open it up for LB1060. And I will take the podium.

HARDIN: Welcome.

HANSEN: Thank you. All right. Good afternoon, Vice Chair Senator Hardin and members of the HHS Committee. My name is Ben Hansen, that's B-e-n H-a-n-s-e-n, and I represent Legislative District 16. Today I'm presenting LB1060 to address requirements for newborn screening. I'd like to preface this conversation with consideration toward who has ultimate responsibility of a child. It's not the state. It's not DHHS. It's not a physician. It's a parent. LB1060 adds one change to current statute that reflects the parent's right to be involved in medical procedures, such as newborn screening. All infants born in the state of Nebraska are required, and will continue to be required, to receive screening within the timeframe given by the Department of Health and Human Services. That does not change. There are 33 conditions that are screened for, and 27 more with the screen that provide more in-depth testing. Early detection of these conditions and diseases are crucial to the treatment and health of a child. Hospital records and reports-- hospitals record and report the results of the screening to DHHS. Included in the report is information about the infant and mother's location and contact information, the care and treatment of the infant. DHHS has the authority over the use, retention, and disposal of the blood specimens and information connected with the screening. There is extensive care taken in making sure they are consistent with federal laws and keeping information confidential. They have gathered information about the benefits of newborn screening, and provided them to hospitals across the state to be distributed to parents upon request. It is specifically written that parents shall be responsible for the dietary and therapeutic management of the infants if the screening comes back positive. All this is current with Nebraska state statute. LB1060 simply adds that if a parent objects to screening, the infant is made exempt from the requirements to be screened. I wrote LB1060 in a way that makes sure infants getting the newborn screening is still the norm. For individuals who are unaware of the risks of possible conditions or benefits to early screening, their children will still be screened. For individuals who are aware of the risk of benefits, their children will also be screened. For parents who have some reason, an objection to the newborn screening, one we agree with or don't, they will be able to-- they will be given the right to decline the screening. Here's a reason for adding this portion to the newborn screening legislation. One, my constituents have asked for it. This is a bill constituent led request, as parents are looking to have a say in procedures that take place after birth. Second, as it is now, Nebraska is one of three states, Michigan and West Virginia are the other two, that says you are breaking the law for simply existing. If your baby is born, you are guilty of violating state statute and reported to the Attorney General for investigation unless you get a procedure done. 47 other states allow for exemptions to newborn screening in some form or fashion. 47 other states agree that a parent is capable of making the right decision for their child when it comes to newborn screening. And finally, informed consent is protocol for all medical practice. Medical professionals suggest countless procedures that require consent. I see no reason to deny the option for consent. This is not a debate about if the screening is safe or effective, which I'm sure you'll hear about. In the latest re-- in the latest released report, 61 newborns received a positive test for one of the 33 main conditions screened for. The parents were then able to begin proper care to enhance the health and life of the child, care that they consented to. I appreciate your time today, and am open to any questions you may have, and I will stick around for closing if there are additional questions, which I'm sure there might be.

HARDIN: Thank you.

HANSEN: Yep.

HARDIN: Any questions from the committee? Senator Cavanaugh?

M. CAVANAUGH: Thank you. Thank you, Senator Hansen. Something you said in your opening sparked this question about the Attorney General. Have we had prosecution over people refusing newborn screenings in Nebraska?

HANSEN: Yes. There was-- and I can share this more in depth with you later, I just want to make sure I get right where-- I can, I can mention More in my closing.

M. CAVANAUGH: That's fine, I just thought--

HANSEN: Believe in 2008, there was a case where they actually removed a child from their parents.

M. CAVANAUGH: A newborn?

HANSEN: Yes.

M. CAVANAUGH: OK.

HANSEN: Because the parents decided, I think, for religious reasons, that they did not want to get the screening done.

M. CAVANAUGH: OK. I'll follow up with you later.

HANSEN: Yep.

M. CAVANAUGH: Thank you.

HARDIN: Any other questions? We'll see you at the end.

HANSEN: All right. I'm sure this will be really quick, so.

HARDIN: Wonderful. Do we have any proponents here for LB1060? If so, come on down.

ALLIE FRENCH: Good afternoon. I wasn't planning on going first, but nobody set up quickly, so I guess I will. My name is Allie French, A-l-l-i-e F-r-e-n-c-h. I am representing the grassroots group Nebraskans Against Government Overreach, and we are in full support of LB1060. Parents, mothers should be free to choose any and all medical procedures done on or to their child or children. In all other areas of the newborn process, there is choice. You may opt out of, or submit religious exemption from all other medical interventions and testing. LB1060 is not eliminating nor changing access to, or the process of, the newborn screening. Parents with a higher risk pregnancy or history of disease or disorders are not less likely to utilize the newborn screening, especially if they have a knowledgeable health care provider. Most people do not look into this process, or would consider altering their course from the standard care provided. However, LB1060 would provide parents who believe in pain free births, and or limited medical intervention the freedom and ability to make that choice without threat from the government taking their newborn or withholding of their child's birth certificate. Support moms, please, and parents, support babies and please support LB1060. I did also want to mention that as it's currently written, written and it's requiring testing, it allows research, but nowhere does it require a course of action upon positive results. So this is simply testing. We're not requiring the parents do anything for their kid. It's just allowing them to prick your child's heel, and for some people, they want that pain free birth. They don't want that child to have that experience right then and there out of the womb. And it's important to provide that option.

I will also mention that some or much of the opposition to LB1060 have no personal stake in LB1060, but are focused on opposing any and all of the efforts of our grassroots group. And they're doing so regardless of the effect that it may have on Nebraskans that have absolutely no connection to our efforts. So thank you.

HARDIN: Thank you. Any questions?

WALZ: I have a question.

HARDIN: Senator Walz.

WALZ: Thanks for coming. So it's been a little while since I've had a baby, and I don't plan on having one anytime soon.

RIEPE: Some planning.

WALZ: You mentioned that the, the screening is a prick of the-- is that all it is, is a prick of the heel?

ALLIE FRENCH: Yeah.

WALZ: OK, I, I just--

ALLIE FRENCH: They're just filling two blood panels, which they send off. They can actually request for an additional blood sample to be taken and stored, for, what was it, future identification. There we go. That word was not coming to me.

WALZ: OK.

ALLIE FRENCH: And it's also important to understand that they even have a disclaimer on DHHS's website that this test does come up with false positives. It is not a perfect test. And I think that's important to consider when parents are making this choice, that they're simply choosing not to subject their child to a medical intervention that isn't actually always right anyhow.

WALZ: Sure, well, nothing is always on--

ALLIE FRENCH: Nothing is always right, anyhow.

WALZ: I just wanted to make sure that it was simply a prick of the heel.

ALLIE FRENCH: Yeah.

WALZ: OK. All right. Thank you.

ALLIE FRENCH: Absolutely.

WALZ: Thanks.

HARDIN: Any other questions? Seeing none, thank you.

ALLIE FRENCH: Thank you very much.

HARDIN: The next proponent for LB1060. Hi there.

SHANNON SPLONSKOWSKI: Hi. Hi, my name is Shannon Splonskowski, S-h-a-n-n-o-n S-p-l-o-n-s-k-o-w-s-k-i. I'm a proponent of the LB1060 to give parents the right to refuse newborn genetic screening. Nebraska is currently only one of three states that does not allow parents to refuse, as Senator Hansen said. I understand that the concern of allowing parental rights in this area is that parents would refuse, and children would go under the radar having certain illnesses or genetic issues that could have been addressed easily had they been treated soon after detection. I honestly don't believe that most parents would refuse. But let me give you a few examples of times when refusal should be at the parent's discretion. I have seven children at home, with one more baby on the way. For my first three children when they completed newborn screening, the nurse would remove my child from the room and bring them to the nursery to complete any testing or evaluation. I didn't like to give up my newborn to someone I did not know to do screening, but that was common practice 12 to 16 years ago. With my fourth child, I requested they keep her in their room for all tests. When they completed the newborn screening on my daughter in the room, I was shocked and upset. They use a small razor blade-like tool. It's on a subq needle. It's a about a quarter-inch long sharp instrument that they cut the baby's foot to get enough blood to fill four circles on a piece of paper that will be sent for testing. After receiving the vitamin K shot that is common for a majority of newborns to receive, they don't always bleed very easily by the 24 hour mark. The nurse completing my daughter's testing had to slice her foot four times before she had enough blood to adequately complete the test. My 24 hour old baby was screaming for close to ten minutes in her bassinet, while the nurse continued to poke her foot and squeeze her calf and foot, trying to coax more blood out. Had I the freedom to refuse, I would have stopped this process much sooner. It was heartbreaking watching my sweet baby screaming without being able to comfort her. Another instance where I would have preferred to refuse is in the case of my fifth and sixth children's births, I delivered both of these children with a midwife in a birth center, and was allowed to leave the center at six and 12 hours, respectively, as long as the baby and I both appeared healthy. It was nice to be able to go to my own home to recover, rather than have to stay in an uncomfortable hospital bed. Unfortunately, the midwives told me my children had to go through the newborn screening twice if I wanted to be able to leave before the 24 hour mark. Here's what they explained to me. Either due to hospital policy or law, all babies are required to complete the newborn genetic screening before leaving the hospital, no matter how old they are. Then, because the testing is not accurate when completed before 24 hours, the hospital disregards the results of the first test, and at the one day in-home visit with a midwife, they will complete the test again so they can have an accurate result. When I asked her about refusing at least the first testing, the midwife said I could technically refuse, but their practice would be penalized and their license potentially put in jeopardy if too many of their patients refused to comply. I felt that my hands were tied. If I wanted to have the freedom to be able to use the midwives for future pregnancies and deliveries, I would have to comply with a rule that made no sense and put my baby through the trauma of multiple heel pricks for no reason. Another reason that this multiple testing frustrated me is that for all seven of my children, I have received no information back from the testing. I'm assuming that means that all tests came back negative, but it makes it feel even more needlessly redundant to have my children be forced to take the test twice. I encourage you to support this bill to put the power and right to choose back in the parents' hands, and I believe most people will still comply with complete testing for their-- completing the testing for their newborns. But as I've explained, there are times when the right to refuse makes sense, saves a newborn from unnecessary pain, and the parents from unnecessary heartache. The second paper that I provided for you is a little snapshot of Heritage Defense's website's grade for Nebraska on this issue. They gave Nebraska an F, the only other state that received an F for this issue is West Virginia. And the reason for this-- so Heritage Defense is a legal defense that's available to Christian homeschool families. And they look at issues that are common that CPS is sometimes involved in. And this is one of the issues. So, Nebraska received a grade of F because not only is it required, but they will use CPS and civil enforcement to, to enforce this screening being taken. So.

HARDIN: Thank you. Any questions? I have one or two.

SHANNON SPLONSKOWSKI: Sure.

HARDIN: Help me understand. Are there, to your knowledge, challenges that go on with a newborn that have to be collected at that point? If they were to wait a little longer, would there be different results than would be collected immediately after the birth takes place? As far as you know.

SHANNON SPLONSKOWSKI: So you're asking if the testing results would be different if they took them later, as opposed to right away?

HARDIN: Right.

SHANNON SPLONSKOWSKI: The only information I was given as far as that goes is that after the 24 hour mark, it's supposed to be more accurate. When I leave the hospital before 24 hours, they are legally required to make me take the test for my child before I leave. But they said those test results aren't accurate, so they just dispose of them really. I don't think that if you had the test later than 24 hours that it would affect the results. I think the reason that they enforce that is because once the child leaves the hospital, it's a lot harder to get the parents to come in for a heel prick test. At that point, it's more difficult to reinforce.

HARDIN: Did you have your children in more than one facility or were they different facilities? Same facility?

SHANNON SPLONSKOWSKI: Yes, I've had different facilities.

HARDIN: OK. And kind of the notion is no news is good news.

SHANNON SPLONSKOWSKI: Yes. Yes.

HARDIN: OK. Thank you.

SHANNON SPLONSKOWSKI: Yeah.

HARDIN: Anyone else who is a proponent of LB1060. Welcome.

BEN STACHURA: Hello. My name is Ben Stachura, B-e-n S-t-a-c-h-u-r-a. Thank you for letting me come here and testify. Let me pull up my notes. So, as a father, I, I strongly promote this bill. I take the responsibility and well-being of my family and take it very seriously, and do my best to do the research, research the information that is available to me to be able to discern and make informed decisions. I'm grateful for the country we live in, to have the freedom to make decisions and be responsible for my decisions. I do believe this bill promotes parents to be informed on medical decisions for their family, and encourage them to discuss with their health care provider what is best and choose if the screening is best for their family. I believe my child is my responsibility and take full responsibility for them, and do not think it is right for someone else who has no responsibility for them to be forcing them without consent in these decisions. The child does not belong to the state, their blood does not belong to the state, and the information in the blood samples does not belong to the state. This much is clear. Therefore, do not-- do the right thing. Don't force parents to be subject to their child to be intrusive and to a non-consensual medical invasion. The decision is clear and is easy. Support LB1016. I strongly support this.

HARDIN: Thank you. Any questions? They're letting you off easy.

BEN STACHURA: Cool.

HARDIN: Thank you.

BEN STACHURA: Yep.

HARDIN: Anyone else in support of LB1060? Welcome.

JACY RUWE: My name is Jacy Ruwe, J-a-c-y R-u-w-e. And I'm speaking in support of LB1060. As a mother of five, soon to be six Nebraska born children, I am very familiar with the Nebraska newborn screening process. I understand that this screening brings a sense of comfort to some families, and believe that it absolutely should be an option for those families. That said, I do not believe in the mandated testing of healthy individuals. Nebraska is a fairly free state, and I appreciate that greatly. I believe medical decisions made within this great state should be no exception. My child's health is my responsibility, not the state's. I believe the screening should be akin to genetic testing in the womb, available to those who want it, but certainly not mandated. That's the way medical testing and data collection should be. Speaking of data collection, I find it intrusive that our children are forced to have this heel prick done, and we as parents have absolutely no say in what happens to the data collected. In fact, in four out of five of my children, I did not receive results of my children's heel prick. If our children are to be used as lab rats, we parents should get a say in whether or not they participate. It is my belief that our medical information is just that, ours. Forcing parents to share this information rather than simply giving them the option to do so, sets a dangerous precedent when it comes to the broader, broader medical privacy. Lastly, and most importantly to me, I find the practice of withholding federal and state documents and threatening to remove a newborn from their loving and stable home as methods of forcing parents' compliance to be both classist and clear forms of coercion. These screenings run between $600 and $1,000 in our family's experience, and that's the cash pay price. We would have paid more if we went through insurance. If we don't find a way to come up with the funds for this testing, or if you don't qualify for financial assistance, your child is denied a birth certificate, a social security card, and they're at risk from being ripped away from their parents at days old, as evidenced by baby Joel Anayas' case. As long as the state is allowed to hold these important documents over parents' heads and use emotional manipulation in this matter, we will take issue with this testing being mandated. It is absolutely shameful that Nebraska has a history of separating a baby from their family due to the refusal of a heel prick. Nothing else. It is my hope and prayer that going forward, we will join the other 47 states that recognize a parent's right to choose. Thank you so much.

HARDIN: Thank you. Any questions? Senator Walz.

WALZ: Thank you. I think, you said, and I'm just trying to clarify this. It was at $600-- Wait, how much was it for the--

JACY RUWE: So we price, we price checked with our last child and it was between $600 was the cheapest we could get it and $1,000 was-- it was all of them were between $600 and $1,000. The lowest cost we could find was $600.

WALZ: OK. I thought you said something--

JACY RUWE: And again, that was cash pay, so we would be charged more had we gone through insurance. Over $1,000 usually.

WALZ: Thanks for the clarification.

JACY RUWE: Sure.

WALZ: Thanks.

HARDIN: OK. Any other questions? Seeing none, thank you.

JACY RUWE: Thank you.

HARDIN: Any other proponents for LB1060? There's a traffic jam, they're coming down. Welcome.

LESLEY STANGL: Good afternoon. My name is Lesley Stangl, L-e-s-l-e-y S-t-a-n-g-l, and I'm speaking in support of LB1060. First off, I'm thankful whenever parents can voluntarily test their children for potential health situations that the parents may be concerned about. It can be a good resource for parents who want that option. However, I disagree that any testing should be mandated by the state. I believe that it is my responsibility as a parent to make the best informed decisions for my child's medical care. It is my responsibility as a parent to be involved in my child's medical decisions, to research, ask questions, and discuss with our health care provider what is best for my child's health. I can do, and have done, all these things for other medical decisions, and the newborn screening should be no different. Parents should have the right to decline any medical test or procedure that they decide is not in their child's best interest. It is not the state's right or responsibility to make that decision for any child or parent. 47 other states agree that parents are more than capable to make their own decisions on whether to test their newborns or not. It's time that Nebraska joined them in supporting parental rights and trusting parents with their God given right in choosing what is best for their children. Please approve. LB1060. Thank you.

HARDIN: Thank you. Any questions? Seeing none, thank you.

LESLEY STANGL: Thanks.

HARDIN: Any other proponents for LB1060? Hi there.

ASHLEY MASON: Hi. Sorry for the traffic jam in the back there. My name is Ashley Mason, A-s-h-l-e-y M-a-s-o-n. Excuse me. Ladies and gentlemen, I want to start by saying I'm here in favor of LB1060. Thank you for gathering here today to discuss a crucial aspect of our constitutional rights, the right to refuse medical procedures, particularly on infants. Our constitution is a document that not only safeguards our liberties, but also serves as a compass guiding us through the ethical and moral, moral considerations of our society. Our fundamental aspect, or one fundamental aspect of our constitutional framework, is the autonomy of individuals, a principle that extends to parents and guardians when making decisions for their children. Today, we focus on the delicate matter of medical procedures on infants, a realm where the constitutional right to refuse becomes paramount. The right to refuse medical procedure on infants is not just a legal provision, but a reflection of our commitment to the principle of informed consent. It recognizes that parents are the primary decision makers for their children's well-being, ensuring that crucial medical choices align with their values, beliefs, and ethical considerations. It is essential to acknowledge that medical science advances rapidly, bringing forth new possibilities and interventions. However, as we navigate this landscape, we must tread carefully, respecting the autonomy of parents to make decisions that align with their deeply held convictions. In the context of infants, these decisions often revolve around vaccinations, surgeries, and other medical interventions. While our societal well-being is important, our focus today is on the rights of parents to make decisions for their children, guided by their individual values. In conclusion, the constitutional right to refuse medical procedure on infants is a testament to our commitment to individual autonomy and parental rights. As we navigate the complexities of modern medicine, let us foster a society that respects the importance of informed decision making while upholding the rights of parents to make choices for their children. Thank you.

HARDIN: Thank you. Any questions? Seeing none. We appreciate it.

ASHLEY MASON: Thank you.

HARDIN: Thanks. Anyone else in support of LB1060? Welcome.

ANGEE HOCK: Thank you. Good afternoon. My name is Angee Hock, A-n-g-e-e H-o-c-k. I'm one of the administrators of Nebraskans Against Government Overreach. I am the founder and lead member of Nebraska Birth Keeper PMA. I have assisted many families through the hospital and home birth process. I am the mother of six, and two of those being at home. We're not here today to discuss whether or not the Nebraska newborn screening is good or bad, or whether it enhances lives through early detection or not. What we're here for is to uphold parental, medical, and religious rights and freedoms, which should include the refusal of any and all testing and screenings. The language of LB1060 should be added to the Nebraska statute to protect the parents' decisions that they believe is in the best interest of their children, which is their parental authority. I can personally and professionally attest to the abuse afflicted on home-birth families due to the current statutes. I have worked with families under duress of threats from either CPS investigation, to threats of removal of the child from the home, to withholding the birth certificates. This is an abuse of authority, which is why we need LB1060 in the statute. Many of you, men and women, have had new babies. Think of how you would feel days after giving birth of losing your baby, unless you surrendered your baby to a test that violated your beliefs, or that you believed was not in the best interest of your child. Think of the pressure you might feel trying to navigate having this test done while-- and paying for it while receiving threatening mandates. This causes harm to the recovering mother, thus the newborn and the family. In hospital birth settings, I've witnessed many families who didn't even know the test was done until after the fact. This left the families feeling betrayed and violated by medical staff, who did not inform the parents of the screening, which includes the removal of blood before it was complete. Again, parents have the right to informed choice, whether that would be by consent or refusal. It is our duty as Nebraskans to uphold this choice, as 47 other states do. Lastly, it could be suggested that this current Nebraska statute and the precedents set by it are unconstitutional according to the U.S. Constitution, Amendment 14, section 1, which reads, all persons born or naturalized in the United States and subject to the jurisdiction thereof, are citizens of the United States and of the state wherein they reside. No state shall make or enforce any law which abridges the privileges or immunities of a citizen of the United States; nor shall any state deprive a person of life, liberty, or property without due process of law; nor deny any persons within its jurisdiction of legal protection of the law. Privileges, property, equal protection, all could reasonably include birth certificates, which vital records has withheld from Nebraska families until the newborn screening is complete. Therefore, could Nebraska eventually be legally challenged in violating a family's constitutional rights if LB1060 is not added. Therefore, I ask you to advance LB1060. Thanks.

HARDIN: Thank you. Any questions? Seeing none, thank you.

ANGEE HOCK: Thank you.

HARDIN: Any more proponents for LB1060? Going once, going twice. Here's one. Welcome.

ARIANNA BEASLEY: Hello. My name is Arianna Beasley, A-r-i-a-n-n-a B-e-a-s-l-e-y. I came here to testify today because LB1060 is something I feel very strongly about. I would like to start by saying how grateful I am for people in the health care field and the medical workers. They provide wonderful care for my family when it is needed. However, it has come to my attention that 40 of-- 47 other states in this country have the freedom to choose what they do with their children's bodies in health care shortly after being born that we as Nebraskans do not have. I would like the freedom to choose what is best for my child, discuss with my health care provider and figure out what is best for my family. I recently had my first child in August, a beautiful baby girl. Shortly after being born, I had to-- I had to be calling my doctor's office to schedule an appointment for her, for her to receive her newborn screening. I also had to fill out paperwork, wait for calls back, and finally was able to go to the hospital. I go into the hospital and everyone is so kind and gracious. The nurse that was performing the newborn screen on my baby filled out all the paperwork and information that was needed, one of them being what time she was born. She was training another nurse on how to perform the newborn screen. They pricked my baby's heel, and the drops of blood were put on the piece of paper. Once the test was finished, the training nurse looked at the paper and said, oh no, she's not 24 hours old yet. We have to do the test again. She was 23 hours and 40 minutes old. I asked if that was close enough of a margin to where they would not have to prick my baby again. She said, no, it is not. We had to wait in the room for 20 extra minutes. They came back and they pricked my baby's other heel and they performed the test again, not to mention the $623 this cost my husband and I. What about the families who cannot afford this kind of test? What about the families who do not have the health insurance to cover it? I believe as parents we know what is best for our children. I believe as parents we can choose whether or not our baby is needing the newborn screen. I believe as parents we can decide what is best for our child. As parents, we notice things. We notice when our baby is not acting normal. We notice when they are needing medical care. I believe that parents know their children best, and I have the best judgment when it comes to what they need. I believe that Nebraska should pass this bill and allow parents to choose for themselves, like the 47 other states in this country who trust their parents to make the right decisions for their children medically. Thank you.

HARDIN: Thank you. Any questions? Just curious. Were the medical personnel ready with the actuarial studies of how many children had developed unfortunate chronic illnesses in those 20 minutes between when your little girl was stabbed in one foot and the other foot?

ARIANNA BEASLEY: No, they did not. I asked if they could give me some information. They said, sorry, we don't have any answers. We just have to do it again.

HARDIN: Wow.

ARIANNA BEASLEY: So.

HARDIN: Thank you.

ARIANNA BEASLEY: Yep.

HARDIN: Appreciate it. Anyone else in support of LB1060? Anyone else? Anyone in opposition to LB1060? Welcome.

ANN ANDERSON BERRY: Hello. Good afternoon, Senator Hardin, members of the Health and Human Services Committee. I am Doctor Ann Anderson Berry, A-n-n A-n-d-e-r-s-o-n B-e-r-r-y. I'm a faculty member of UNMC, and the Medical Director of the Nebraska Perinatal Quality Improvement Collaborative, or NPQIC. However, I am not speaking as a representative of the university, and today I am here speaking as an individual and on behalf of the Nebraska Medical Association as well as NPQIC. I am here testifying with regards to LB1060. As a Medical Director of NPQIC and a neonatologist, I care for hundreds of families each year with high risk medical situations for both mother and baby. Through NPQIC, we support healthcare professionals from across the state who provide care that leads to best outcomes for Nebraska mothers and infants, working to ensure that every family has the healthiest heart possible. One of the premier efforts in ensuring the health of infants in Nebraska is our state newborn screening program. It has been designed by state DHHS and Nebraska health care professionals based on evidence and supported by decades by our Legislature to protect newborns by early identification and intervention of illnesses that would otherwise be devastating or even deadly. In Nebraska, newborn screening works. There is no need to change a highly functioning and safe system that is protecting newborns every day. In my practice, I see the system identify serious diagnoses that I can then treat with preventative interventions. The diseases we screen for in Nebraska are all initially silent. They have profound health and development impacts, and can all be medically managed to improve outcomes. Early recognition and treatment matters. Time to treatment in Nebraska in 2021 is significantly lower than national and regional time to treatment. See figure A in my written testimony. Without newborn screening, a newborn's time to treatment would be extended significantly as the family would wait until symptoms appear to seek care, and then the infant's physician would need to work through complicated diagnostic processes for a definitive diagnosis. Newborn screening numbers for 2021 show the potential negative impact of this bill. There were almost 25,000 births in 2021, and 61 infants with a confirmed disease were identified by a screen. Additionally, 453 infants were found to have a hemoglobinopathy, such as sickle cell disease or thalassemia. Notice in figure B in 2021, 2% of infants had an abnormal newborn screen that needed to foll-- needed follow up by a physician for monitoring or disease diagnosis and immediate treatment. So if just 100 families opt out of newborn screening, the state is likely to have two infants who will not get prompt and timely diagnosis and treatment for a serious medical condition that could have been identified and managed early in life, leading to life altering lifelong complications. Newborn screening in Nebraska is private, and blood spots are not used for research. While screening tests are for disorders that are genetic in origin, the program does not collect or store genetic information about newborns. In fact, Nebraska blood spots are destroyed after 3 to 4 months to protect the newborn's privacy. In Nebraska, newborn screening works. There is no need to change a highly functioning and safe system that is protecting newborns every day. Usually when I'm here talking to you, I'm here telling you about bad outcomes for moms and babies. I don't have any stories like that today because our program works. So let's keep it the way it is. I'd like to thank the committee for their time today, and urge you to maintain the integrity of the state newborn screening system by voting no on LB1060. Thank you, and I'll take any questions.

HARDIN: Thank you. Any questions? I, I have one. What are 46 states getting wrong? If 46 states give an option, and we're one of four, that doesn't, what are 46 states not doing as well as we are?

ANN ANDERSON BERRY: Senator Hardin, I think that's a good question for a legal expert. I'm a medical expert, and I can tell you that our mandatory screening likely improves our time to diagnosis and treatment as represented in figure A. But I can't tell you what 46 other states legally have made a decision about this for. I can tell you what I think is right for Nebraska babies to keep them well, to protect those babies and to protect the state from the costly care of misdiagnoses, which can be lifelong. And, you know, many of these diagnoses, if missed early in life, can lead to lifelong significant educational needs as well. So if, if LB1060 were to pass, we would incur significantly increased costs in the state for medical and educational needs for infants that had a misdiagnosis.

HARDIN: Is it your sense that, not on the legal side, I'm curious about the medical side. Are there medical problems in these other 46 states that we simply don't have because we approach it different medically?

ANN ANDERSON BERRY: I can point to our time to diagnosis and treatment as saying that we are above the curve. So we're getting something right. I did not go state by state to see what they're getting wrong. I can just tell you that we're getting this right, and I see no need to change that.

HARDIN: OK? I think we had, what, about 25,000 kids or so born in 2021?

ANN ANDERSON BERRY: Yes.

HARDIN: So we were busy during the Covid season.

ANN ANDERSON BERRY: It appears so, sir.

HARDIN: If I understand correctly though, we actually also had more than twice that many samples taken in 2021. How come we had more than twice as many samples when there were only 25,000 children born?

ANN ANDERSON BERRY: Yeah, that's a great question. So we have those additional samples taken for every baby that's cared for in our neonatal intensive care unit. Those infants often need blood transfusions or receive life-saving therapies like infusions, a protein solution for their nutrition. And many of the medical treatments that we provide, our infants that are cared for in neonatal intensive care units alter the results of the newborn screen. And so, because the screen tests for so many different things, as standard practice, those infants will have an initial screen at delivery, before those treatments start. So those treatments often start within 20 to 30 minutes of life. So we get one right at delivery, and we get one at 24 hours. But because of critical illness, many of our neonatal intensive care unit infants will receive three or four screens. And so that's the discrepancy between the number of births and the number of screens per year.

HARDIN: One person, up to four screenings?

ANN ANDERSON BERRY: Yeah.

HARDIN: I see. Very well. Any other questions? Thank you.

ANN ANDERSON BERRY: Thank you.

HARDIN: Any other opponents to LB1060?

SHANNON HAINES: Hello Senator.

HARDIN: Hi there.

SHANNON HAINES: Hi. Senator Hardin and other members of the Health and Human Services Committee. My name is Doctor Shannon Haines, S-h-a-n-n-o-n H-a-i-n-e-s. I am a pediatrician who cares for children in Nebraska, and I live in Papillion. Though I am-- though my thoughts might not necessarily express those of my employer, I am here representing the Nebraska Chapter of the American Academy of Pediatrics and my own personal opinion in opposition to LB1060. I think we've heard quite a bit on the, the benefits of newborn screening and catching inherited diseases early to prevent long term consequences, as most of these diseases present with symptoms far after long term damage is already done. Providing the screen to all children is important. And so that is the purpose of our testimony today. Though I have cared for many children helped by the newborn screen, I am most personally touched by the story of a friend's child. I grew up going to church with Rory [PHONETIC], who was a wonderful man and became a Lutheran pastor. When he and his wife were expecting their first child, they had no idea this child would be at risk of a deadly condition. The newborn screen found that their baby boy had spinal muscular atrophy, which is a le-- what used to be a lethal condition, but is now treatable with medication. Their child is now five and about to enter kindergarten, and spunky, and he would likely be dead by now if it weren't for the newborn screen and the treatment provided by it. 1 in 35 Caucasian people carry the gene for this disease alone, let alone the other diseases on the newborn screen, making it fairly common. So ultimately, the newborn screening could lead to-- but declining newborn screening can lead to the avoidable death of a child. The newborn screen is a shining example of Nebraska's dedication to caring for its children. Currently, because all children are screened, Nebraska leads the nation in how quickly diseases are found and treated before lasting damage is done as Doctor Anderson Berry just attested to. Regarding concerns about the constitutional parental autonomy, it's important to note that the Nebraska Supreme Court already addressed this issue in 2008 and found that mandatory newborn screening is constitutional according to the Nebraska law and protects children, which is in the state's purview. According to the Parent's Guide to Newborn Screening published by the Nebraska DHHS, the blood specimen is only used for research if parental consent has been obtained. Otherwise it's destroyed after 90 to 100 days. And I know that's a concern. We all want rights to what we allow our children to participate in research about, which is understandable. Simply put, the universal newborn screening saves lives, and this bill would risk harm to children and families in Nebraska. I'm happy to both speak a little bit more. I have read about the 2008 case. Although I'm not a legal expert by any means, I just have recently read that case law. And then to answer a couple of questions that were raised earlier about the timing of the newborn screening. Thank you. And I'll answer any questions you might have.

HARDIN: Any questions for Doctor Haines? So can you comment on those--

SHANNON HAINES: Sure.

HARDIN: --additional pieces for us?

SHANNON SPLONSKOWSKI: Sure. So specifically, the timing of the newborn screen is important because in-- after 24 hours is important because of certain thyroid levels that change directly after birth. And so the timing being after 24 hours, that is why that is. And then as far as the 2008 case, there-- again the-- there is a nice statement by the Nebraska Supreme Court, an opinion piece after the 2008 case that ruled that it was constitutional, that perhaps the timing of when the child was taken away, wasn't ideal, but that the child still could have benefited from a newborn screening if it was dine. But I am happy to send that brief to the committee if you would like.

HARDIN: OK. May I ask a question or two? One. What is your familiarity with these other 46 states that do it differently than we do? Do you have a sense about how many families in those states that have the freedom to not do this, execute, execute on that? How many don't engage it, any sense, percentage wise, of how many families don't choose to have the screening done?

SHANNON SPLONSKOWSKI: I can't speak to that, I apologize.

HARDIN: OK.I was just curious. My second question was contingent on that first one, so I'll pick on someone else as regards it.

SHANNON HAINES: But I'm happy to look it up though, and get back to you if you'd like.

HARDIN: That'd be great. Just would like to get a sense of how often this goes on and how often it's turns out to be a challenge, particularly in light of what the other physician just shared with us about. Sometimes there's multiple screenings done because life throws surprises at us, and so we need to go back in for a health related issue with our our young ones at another time, and certainly earlier is better. I certainly understand that. I also understand personal liberty. So that's, that's what we do here is wrestle with those things. So. But thank you. We appreciate you being here.

SHANNON SPLONSKOWSKI: Thank you.

HARDIN: Who else is in opposition to LB1060? Come on down. Welcome.

EMILY KURTENBACH: Hello. Good afternoon. My name is Emily Kurtenbach, E-m-i-l-y K-u-r-t-e-n-b-a-c-h. I'm 29 years old, originally from Lincoln, currently living in Aurora, Nebraska. I'm married, a mom to an almost two year old and another one on the way. To look at me, I look like a perfectly normal, healthy 29 year old woman. What you don't know by just looking at me, is that my parents received my life altering diagnosis at just three days old, diagnosed through the newborn screen. My parents often tell me about the call they received after my three day old pediatrician appointment, after just being told how healthy and normal I looked. My newborn screen had come back positive for a recessive genetic disorder called phenylketonuria, or PKU for short. Basically, my body was born with a deficient pH enzyme that's responsible for breaking down a protein, a protein, excuse me, an amino acid in protein called phenylalanine, breaking that down into tyrosine. If phenylalanine builds up in the blood, it becomes extremely toxic to the brain and can cause irreversible brain damage. Because of this diagnosis, I was immediately placed on a low protein, strictly monitored diet for life. You couldn't tell by simply looking at me. According to the Department of Health and Human Services webpage, it states even after a baby is born, there are usually no signs or symptoms, so parents cannot tell whether or not their babies have a condition. This is why newborn screening is so important. Let me repeat that. By just looking at me, you could not tell that I have a life threatening diagnosis. My parents also had absolutely no idea they were carriers for the disorder, even after the birth of my older brother who received the same screen and doesn't have PKU. The incidence for the general population to be specifically a carrier for PKU is one in 50, and most people don't know they're carriers until their child is diagnosed in the newborn screen. And growing up, I was told how extremely important my immediate diagnosis and intervention was. I was often shown those video-- shown videos of those whose diagnosis was missed. And I can truly say it's heartbreaking. Had my diagnosis not been caught, I'd likely be extremely mentally handicapped, and likely institutionalized or worse. I get emotional just thinking about how truly different my life would be without this newborn screen, and all the lives that could be impacted. While I was-- I-- while I respect religious beliefs and those shared today, I too am thankful for my Heavenly Father who gave Doctor Robert Guthrie, the founder of the newborn screen, the knowledge and tools to develop this screen, and the knowledge that God has given doctors and researchers about these disorders and diseases. I get it. As of recently, anything mandated by the state or government can be scary and seem untrustworthy. Again, referring back to the Nebraska DHHS web page, under Nebraska law, the laboratory only keeps blood specimens used in newborn screens for 90 days, after which they have 30 days to discard it, usually by burning, to protect the health information of the baby. A vote for this bill would be a vote against the voiceless. I didn't get a choice in whether or not to save my life as a baby. We talk again and again about being a mostly pro-life state, and this too is part of that, being a voice for the voiceless. There's just not enough information shared with parents-to-be about the importance of this newborn screen, to allow those to opt out of it. Thankfully, because of this mandate and for the trust my parents put in the outcome, I am able to live a perfectly normal life. Babies don't get a say. There was absolutely no doubt in my mind that my child would receive the simple heel prick that saved the-- could have potentially saved his life. I, too, recall receiving the call my parents got when I was three days, three days old, but about my son, but with a more positive outcome that he truly was perfectly fine and normal. What a relief. Something so simple as a heel prick, five drops of blood. That could mean so much to so many people. For those who are concerned about the impact the heel prick has on a baby, I can 100% assure you I don't remember it. And if, if I did, it's a sacrifice I'm willing to, to make for the outcome it provided for me. So I ask you to truly take a moment to listen to those testimonies of those who live day in and day out with these genetic disorders, and those who treat those genetic disorders today. My ask is that you also please vote no and please do not advance this bill. Thank you.

HARDIN: Thank you. Any questions? Seeing none, thank you.

EMILY KURTENBACH: Thank you.

HARDIN: Anyone else in opposition to LB1060. Welcome.

ROBIN LINAFELTER: Wow, how do you follow that? I guess with their father. My name is Robin Linafelter, R-o-b-i-n L-i-n-a-f-e-l-t-e-r, and I live in here in Lincoln, Nebraska, and I am Emily's father. And she was, was diagnosed with phenylketonuria at age three. You heard her story. So I'm not going to go into her story much. I'll just tell you about kind of a little bit of history and what it's like to be a parent. From a historical perspective, mandatory testing was put in place in Nebraska in 1967. I want to thank Doctor Mark Crawford, who was an ophthalmologist here in the state of Nebraska, and his wife, for supporting that legislation. They supported it as a result of their son going undiagnosed before the testing. Their son, unfortunately, I believe, spent the majority of his time institutionalized, Beatrice Development Center, and he-- Just a second, I knew that somebody would try to call me right during my testimony. Sorry, not used to technology, right? Undiagnosed, undiagnosed at significant emotional cost to the Crawfords, but that also significant cost to the state of Nebraska to treat for him for life. So that's why they fought so hard to get mandatory testing back in 1967. That's when it started. So. My wife and I, my story is about mandatory newborn screening saved our daughter's life 29 years ago. You heard it, you heard that a few minutes ago. We'd been at the doctor for her three day checkup, and the doctor told us she looked great. She was perfect, and we could take her at-- home to enjoy her. As we walked in the door for-- from being at the doctor's office, the phone rang to tell us that her newborn screening came back positive. And it was positive for PKU. While she looked perfectly normal, healthy, but we knew right away, left undiagnosed that she would potentially live a life with irreversible brain damage. She would, she would be severely mentally handicapped for the rest of her life and mostly institutionalized. Because it was caught in newborn screening, they were able to put her on a strict, low protein diet. And she's a perfectly healthy, normal young woman that you saw today. She's brilliant, married with an almost two year old and another one on the way. Had we opted out for the screening, the outcome would have been totally devastating. How can we give our children a chance at a normal, healthy life? How can we not give them a chance at a normal, perfect life? Currently, Nebraska, screens for over 60 disorders. While I believe it's an individual's-- I believe in an individual's right to choose. I do believe at times government must step in and protect those that are unable to protect themselves, and that being the newborns. What parent using the argument of it's a right to, to choose for their, for their child is willing to take that risk that potentially, by not doing the test, that their child could potentially live a life institutionalized. It's not a risk that I would be willing to take. And I would encourage them to have a-- reconsider that thought. A vote in favor of this bill is reckless and irresponsible for our newborn babies that don't have a voice in this matter. Are parents really willing to take that risk? I would have hated to have to live a life-- the fact that I had-- could have done something to prevent such a tragedy in my child, and I didn't do it. My ask is a vote to oppose this legislation. Thank you for me-- allowing me to testify.

HARDIN: Thank you. Any questions? Seeing none--

ROBIN LINAFELTER: Thank you.

HARDIN: --thank you. Anyone else in opposition to LB1060? Here's someone we all recognize. Welcome.

TIMOTHY TESMER: Thank you. Good afternoon, Vice Chair Hardin and members of the Health and Human Services Committee. My name is Doctor Timothy Tesmer, T-i-m-o-t-h-y T-e-s-m-e-r, and I'm the Chief Medical Officer for the Division of Public Health within the Department of Health and Human Services, DHHS. I am here to testify in opposition to LB1060, which provides for an exemption to the mandated newborn screening if a parent or guardian objects. Newborn screening, also referred to as blood spot screening, involves pricking the infant's heel to gather a small blood sample on specialized filter paper, which is then analyzed for the presence of certain genetic, metabolic, or endocrine disorders. This screening process is mandatory in Nebraska. The mandate for newborn screening is driven by various factors, including the imperative for early intervention. Timely detection of genetic, metabolic, and endocrine disorders enable swift medical intervention, often preventing or minimizing the development of severe symptoms and complications or death. This approach significantly improves the long term, healthy-- health outcomes and quality of life for individuals affected by these conditions. The current mandate is crucial because the disorders screened for via dried blood spot caused severe health problems, including death. These disorders are treatable, and would often remain undetected until symptoms manifest. Allowing parents to refuse to screen their infant for these disorders increases the risk of the child experiencing severe consequences. Nebraska has always carefully weighed mandatory screening with the protection of the rights of the child and their parents. All blood spots collected from infants are incinerated 90 days after birth, unless the family request the sample for their own use or to be provided for research purposes. Late detection often leads to more advanced stages of the condition, requiring intensive medical intervention, hospitalization, surgery, and or ongoing treatment. If the child survives, there's a significant impact on their quality of life, and medical costs can add up quickly, especially if the condition leads to complications that affect multiple organ systems. Several points to consider if newborn screening conditions are detected late. One, a condition diagnosed late can affect a person's ability to participate in school, work and other aspects of daily life, an unnecessary outcome when screening occurs on time and treatment is readily available. Two, late onset cases may require more specialized care from a team of health professionals, including pediatricians, geneticists, endocrinologists, and other specialists. Achieving and coordinating this level of care can be complex. Often, one or more parents are unable to work due to the amount of time needed to care for and transport these children to medical and therapy appointments, in addition to higher care needs inside the home for affected children. Families also may require an extensive social and community support network to cope with the challenges associated with the disorder. Access to these support services may require additional resources from families, the state of Nebraska, and our taxpayers. Three, individuals with late onset disabilities may require long term rehabilitation services to address developmental delays, cognitive impairments, physical disabilities, and other consequences of their condition. This can include treatments such as physical therapy, occupational therapy, and behavioral interventions that may be needed over time. Four, late onset disorders often impair cognitive function and learning abilities, requiring educational support services such as special education programs, individualized learning plans, and educational interventions. These services may be needed throughout the individual's academic journey. And five, according to the Journal of the American Medical Association Pediatrics, raising a child with an intellectual disability to the age of 17 can cost as much as 1.4 to $2.4 million, which is significantly higher than the U.S. Department of Agriculture's estimate of $233,610 to raise a non-disabled child to the age of 17. Newborn babies carry all the risk of serious, long term negative health consequences or death, and do not have the ability to advocate for themselves. Therefore, mandatory newborn screening ensures that every child in the state of Nebraska has the same opportunity to grow into healthy, productive adults. We respectfully request that the committee not advance the bill to general file. Thank you for the opportunity to testify today. I'd be happy to answer any questions pertaining to newborn screening.

HARDIN: Thank you, Doctor Tesmer. Any questions? I'll repeat my question I asked someone else earlier. Do you have a sense with those other 46 states that do not allow this, or that do allow this as an option? How many people opt to not have their newborn go through this? Do you have any sense of that?

TIMOTHY TESMER: Senator, I do not. I do not. If that information is available--

HARDIN: Sure.

TIMOTHY TESMER: --we would be happy to research and provide that if you so desired. May I make one--

HARDIN: Sure.

TIMOTHY TESMER: --corollary comment to a question you asked--

HARDIN: Yes.

TIMOTHY TESMER: --Doctor Anderson Berry.

HARDIN: Yes.

TIMOTHY TESMER: I think you were referring to the 2021 report.

HARDIN: Right.

TIMOTHY TESMER: And the numbers I'm going to state are rough numbers. But in the vicinity.

HARDIN: Yes.

TIMOTHY TESMER: Roughly 25,000 births--

HARDIN: Right.

TIMOTHY TESMER: --in the state of Nebraska in 2021.

HARDIN: Yes.

TIMOTHY TESMER: The report indicated 51,000--

HARDIN: 57,000.

TIMOTHY TESMER: 57,000. That report is incorrect.

HARDIN: Oh, OK.

TIMOTHY TESMER: We, we, we recently-- and I-- it's on us it's on me, whatever you want to say. We recently found out that that number is incorrect due to a computational error in the case reporting. The actual number, close to the number of screening tests that were done in 2021 for the 25,000 births was around 28,850. And that and that difference there--

HARDIN: That would seem to make more sense.

TIMOTHY TESMER: --is consistent with what other years have shown.

HARDIN: OK. Thank you. That's very helpful.

TIMOTHY TESMER: And those additional, if I may add, those additional tests are screened come-- because of-- if a screen comes back positive, it's suggestive of a disorder, but it's not confirmatory, and it needs to be corroborated. Another reason for tests that-- screens that may need to be done again is because of inadequate sampling, or the test procedure itself, for whatever reason, was improperly done. Doesn't happen very often at all. But it can happen. And then the third instance for the additional screening would be, especially in those premature infants, which do require additional screens over time, which could include two, three, whatever screens over the first 28 days of their life. And then there's other categories. If you're less than 2,000g when you were born, you have to wait, and you may need to get additional screens done after you get a little bit-- after you weigh a little bit more.

HARDIN: I see. Very good. Thank you. That's helpful. Any other questions?

M. CAVANAUGH: Thank you.

HARDIN: Senator Cavanaugh.

M. CAVANAUGH: Thank you. That actually spurred a question for me because, at the bilirubin screening, is that part of the newborn screening? I guess I should have asked Doctor Anderson very probably.

TIMOTHY TESMER: I, I--

M. CAVANAUGH: OK.

TIMOTHY TESMER: How much time? I don't want to take a ton of the--

M. CAVANAUGH: Well, I--

TIMOTHY TESMER: --committee's time, but I can check on that.

M. CAVANAUGH: I'm just asking because I'm now recalling being in the hospital, and my son had to have his tested multiple times while we were there, and it just didn't occur to me if that was part of the newborn screening, or it is part of the newborn screening, which is great. So I guess, I guess I benefited from that. So, OK, that was it. Just wondering. Thank you.

TIMOTHY TESMER: Thank you.

HARDIN: Thank you. Any other questions? Senator Riepe doesn't have a voice today, otherwise we would be here till 9 p.m..

RIEPE: I'll give you a pad of paper. And you can write something out, I guess.

M. CAVANAUGH: There's no financial questions for him to ask, so.

HARDIN: Thank you so much, Doctor Tesmer.

TIMOTHY TESMER: Thank you.

HARDIN: Anyone else in opposition to LB1060? Welcome.

JULIE SHIVELY: Thank you. Hello. My name is Julie Shively, J-u-l-i-e S-h-i-v-e-l-y. I am here, in opposition of LB1060. I am trying to understand the rationale behind Senator Hansen's introduction of this dangerous bill, which would potentially allow any parent to refuse newborn screening for any reason. I am the parent, the mom, the lucky mom of a beautiful, intelligent daughter, and a successful health care provider whose life was saved by Nebraska newborn screening. Currently, every Nebraska baby has a blood test done to screen for potentially life threatening inherited disorders. Once identified, interventions and treatments are started for the best possible outcomes. Our daughter's genetic disorder is PKU, phenylketonuria. PKU is an inherited disorder that increases levels of a substance called phenylalanine. If not treated, phenylalanine builds up to harmful levels of the body, causing intellectual disability and other serious problems. Neither my husband nor I knew that we carried the gene for PKU, as there were no signs or symptoms, or that we'd passed it to our daughter. Try living with that. Few people know what anomaly genes they have that may be passed on to their children.

HARDIN: Thank you.

JULIE SHIVELY: I'm not done.

HARDIN: Oh I'm sorry, keep going.

JULIE SHIVELY: That's OK. Give me a minute.

HARDIN: Certainly.

JULIE SHIVELY: Nebraska newborn screening program effectively lowers medical costs through early detection, intervention, and treatment, and decreases the toll of human suffering from a late diagnosis when cognitive damage is irreversible. This bill sentences unscreened babies who are born with an inherited disorder to a life of seizures, physical disabilities, developmental disabilities, and chronic illness. This bill sentences their parents to a lifetime of anguish, thinking what might have been had screening been completed. The worst thing is all this potential suffering is preventable through the effective current newborn screening process. Senators, imagine your child or grandchild having one of the inherited disorders and not being screened. Are you prepared to bear the guilt of a treatable catastrophe? How will you look at constituents in the eyes if their baby is neurologically devastated because of this bill? In conclusion, LB1060 will harm our most vulnerable citizens, our babies. Thank you for hearing my testimony. And do you have any questions that I can answer?

HARDIN: Thank you.

JULIE SHIVELY: You're welcome. Thank you for having me.

HARDIN: Any questions?

JULIE SHIVELY: OK.

HARDIN: Seeing none.

JULIE SHIVELY: All right.

HARDIN: Thank you.

JULIE SHIVELY: Thank you.

HARDIN: Anyone else in opposition to LB1060? They're rushing the gates. Welcome.

JENN HARNEY: Thank you. Do I look like the last speaker?

HARDIN: Almost.

JENN HARNEY: Almost. Thank you. Chairman Hansen and members of the DHS-- HS Committee, my name is Jenn Harney, J-e-n-n H-a-r-n-e-y. I'm a physician hospitalist living in Omaha, but coming to you today as a patient also born with PKU, which we've heard about a few times so far. So I'm not going to reintroduce what it is, you know, by now. Should I have been born prior to newborn screening, my life would look much like that of a 70 year old patient I hospitalized who's forever burned in my memory. I imagine this patient was born 70 years ago to two excited and doting parents, overjoyed at the birth of their healthy child and headed home to start their lives as a family of three. But as their baby grew older, he or she began to show signs of delay. They were unable to crawl or walk until months later than normal. Their arms and legs were stiff and unable to move and cause pain and spasms. The now toddler couldn't talk and had few words and clearly had cognitive delays as well as a small head, severe skin problems, and behavior problems. The child needed a permanent tube surgically put into their stomach so the family could give them nutrition and water and medicine. The once normal child was permanently impaired and unable to ever have an independent life. They developed frequent seizures, and as a young adult, they eventually moved to a facility for people with severe cognitive impairment and high health needs to live out the rest of their days. Then they were hospitalized with me for a severe infection and a poor quality of life, and I took care of them. After I visited my patient that day, I quietly sat at my desk and cried. I mourned this patient's livelihood. I cried in thanks that I was born at a time that I was in a country with access to modern medicine, and to loving and capable parents. Through newborn testing, attentive parents, and an incredible metabolic team, I continue to live a successful life. My parents, and later I, modified my diet to be low in phenylalanine, and I got extra calories from an amino acid formula that my friends tell me tastes like cat food. I have a strong career and a beautiful family, and PKU is, of course, what got me into medicine. Currently, a newborn screen is collected on every infant in our state, and parents are unable to refuse the tests given its overwhelming benefits, this isn't an eye ointment, a lotus birth, delayed bathing, or even a hepatitis vaccine. This is life and death, permanent brain damage or a normal life. And it is irreversible once the damage has been done. I ask each of you, like others, have, to just consider if your own child or grandchild or another relative had this disease and it wasn't caught because you opted out of the test, how that child would look, how your life would look, what your conscience would say to you, if that's something you can live with. LB1060 will harm children. It will cause physical and emotional pain to the child and endless emotional trauma to their parents. It will cost a child's life. It will cost hundreds of thousands of health care dollars when medical intervention is inevitably needed. It will occupy school, health care and vocational resources that could have otherwise been used for someone else in need. This bill stomps on and degrades the life of each person here today who has a disease picked up on newborn screening. In closing, I'm thankful to live in a state that's always been so proactive and supportive of those of us with inborn errors of metabolism. And I'm thankful I have the physical and cognitive health and privilege to come advocate here today. I appreciate your time and attention, and I hope you allow us to continue routine screening as mandated.

HARDIN: Thank you. Any questions? Seeing none, thank you. Anyone else in opposition to LB1060? Welcome.

EDISON MCDONALD: Hello. My name is Edison McDonald, E-d-i-s-o-n Mc-D-o-n-a-l-d. And I'm here representing the Arc of Nebraska. We are Nebraska's largest membership organization representing people with intellectual and developmental disabilities and their families. We're here because on behalf of the families who have gotten that call. I'm so glad to hear all the testimony about families who did not have a condition. But for those families on the flip side of the coin, this test process is absolutely invaluable. Otherwise, they end up further down the line seeking help, trying to find an answer as to what that diagnosis is. I've worked with those families. Those are the calls we get all the time. And it is tremendously difficult to watch as they suffer through trying to figure out, or they suffer because they didn't have an answer. And worst of all, I see some families who do have the resources, are able to go and take care of their kid with a significant disability, and it's fine until they pass away. And then what we see is that then the brothers, sisters, friends of the family who want to go and get that loved one taken care of are unable to, because most of our disability supports require that you receive a diagnosis before the age of 25. To that point, this really limits the opportunities for families to get that vital early intervention, make sure that they have the resources and knowledge that is absolutely vital to the health and safety of their kids. I want to point out that on the other side of what used to happen before we had newborn screenings, back in the 60s and 70s, was really we had massive institutionalization. If you get a chance ever, I'd encourage you, and actually, I've got the book about it here, Out of the Darkness and Into the Light, and read through. Or there's a documentary by Lee Terry about Nebraska's history of institutionalization, when we had children with disabilities who were locked to beds. That's how our state used to deal with this. And I believe part of the newborn screening was implemented to go and work on addressing some of those issues. The last thing I'll say is that one important point that I did hear today, that we would definitely be open to working with Senator Hansen and the committee on is that cost feature. That's not something that should be put at the responsibility of the parent. I think that's something that we should really look at having the state take care of. So with that, thank you. And, any questions?

HARDIN: Thank you. Any questions? Seeing none, we appreciate it. Thanks. It looks like we have another in opposition to LB1060. Hi there.

BLAIR MACDONALD: Hello. Vice Chair Harden and members of the Health and Human Services Committee, my name is Blair MacDonald, spelled B-l-a-i-r M-a-c-D-o-n-a-l-d, and I am a registered lobbyist on behalf of the Nebraska Nurses Association, or NNA, and here in opposition to LB1060. I have a letter written from Doctor Echo Koehler, who's been a registered nurse for 21 years. She was hoping to be here today, but is un-- unable to attend. Newborn screening is widely acknowledged as one of the most effective and successful public health initiatives, likely to prevent substantial harm, suffering, and or death. Through early identification and treatment, newborn screening provides an opportunity for significant reductions to-- in morbidity and mortality, which-- while reducing health care costs associated with the treatment of lifelong debilitating conditions like PKU, as we've heard. The, the concern regarding LB1060 is the greater ethical issue of beneficence, or to act for the benefit of the patient, in this case, to advocate for those unable to advocate for themselves, and around informed decision making and consent. As nurses, we are bound by a professional code of ethics. Nurses are at the forefront in patient care, with the delicate responsibility of balancing evidence-based, culturally competent health care with the ethical responsibility to promote, advocate for, and protect the rights, health, and safety of the patient. The American Academy of Pediatrics policy statement on Religious Objections to Medical Care advocates that all legal interventions apply equally whenever children are endangered or harmed, without exemptions based on parental religious beliefs. To these ends, the AAP calls for the repeal of religious exemption laws and supports additional efforts to educate the public about the medical needs of children. Others have spoken about case law. I'll go ahead and say it's the Douglas County case versus Anaya. It's a 2005 case, actually, not 2008, in which the parents of a newborn were making a religious exemption or exception for themselves. And the court ruled that while a competent adult can sacrifice their own life for religious beliefs, as a parent, one cannot refuse life sustaining treatment for a child who has not reached the age of consent and has not chosen to adhere to said religion. As elected state legislators under the legal principle of parens patriae with political authority, you carry with that the responsibility to protect citizens unable to protect themselves. The state's authority to protect the child from harm supersedes the parents' right to practice religion when those rights come into conflict. The Nebraska Nurses Association is the overarching organization for the 30,000 registered nurses in Nebraska. All nurses are bound by our code of ethics and our professional duty to our patients. Nebraskans agree that kids are our future. Therefore, together we have a moral responsibility to protect newborns from medical neglect. For these reasons, the NNA opposes LB1060. I'll be happy to answer any questions or try to.

HARDIN: Thank you. Any other questions that you can think of, committee? I'm not seeing any.

BLAIR MACDONALD: Thank you.

HARDIN: Anyone else in opposition to LB1060? Here comes one now.

ROBERT RAUNER: My lucky day.

HARDIN: Welcome.

ROBERT RAUNER: Thank you. My name is Robert Rauner, R-o-b-e-r-t R-a-u-n-e-r, and good afternoon, members of the committee. I'm speaking here today as a patient advocate. I'm also here to speak against, in opposition to LB1060, a bill to amend section 71-519 of LB301 to provide an exemption from newborn screening as prescribed, and to repeal the original section. I'm a retired from president of the United Leukodystrophy Foundation. That is a rare disease foundation that is a voice for those that cannot speak for and for and advocate for themselves. The reason why I'm here is to speak for those that cannot speak for themselves, children, and say that they want to be screened for a disease that will debilitate them and lead to an early death if they are not diagnosed and treated for that defect. This quote is from Senator Ernie Chambers in 2005, since we're going back to 2005 today. Whatever adults want to do with themselves, with their own health based on a religious belief or any other reason is fine. But there are times when the state has to look out for the interests of children. At that time he was speaking in opposition to having any opt-outs in the Nebraska newborn screening law when LB301 was passed. This is now with this bill what I'd do. I've lost two children to adrenal leukodystrophy because there was not a screening for X-ALD at that time that they were born. By the time our youngest son, Kevin, was diagnosed, it was too late for a bone marrow transplant, which was the option at that point in time. By that time, we had been on a three year diagnostic journey to find out what his health issues were, and we had no idea. So obviously, if we would have had newborn screening at that time, we could have had the option for, for our son to survive. As a parent, all we could do is find the best way to treat the symptoms, since there was really nothing else that could be done. He ended up in a nursing facility since we were not able to care for him at that time anymore. This obviously led to large expenses to the Nebraska Medicaid system because of that diagnosis, and it came so late in the disease progression. Personally, I do not want this to happen to any other family when that family has therapy options if we find out what the health issue that is identified by a newborn screening. I was kind of disappointed that there were not any conversations with the Department of Health and Human Services or the newborn screening program we have here in Nebraska, before the bill was drafted and brought before the committee. This bill as, as we're doing this, would technically be a disaster for our newborn screening program. This would effectively put our program back in the dark ages and destroy all the work that has been done over the years to save lives. We have worked hard to become one of the best programs in the country, and other states have actually come to see us and talk to us about what we've done and take that information home and use it so they can improve their programs. Having no opt-out option has allowed the state to make sure that we find all children that have a rare disease screened that can be fatal if not diagnosed at birth. By having the provision in LB1060, you are creating a potential expense to the state and Medic-- to the state Medicaid system that will end up being responsible for the medical expenses of these children, which will run into millions of dollars. This is a reason we have newborn screening. The amount of money wasted in this way will not allow us to do the other things, like property tax reductions that's very popular today. In 2016, I began to work diligently for the addition of X-ALD, Pompe disease, and MPS 1 to the Nebraska Newborn Screening panel, and I'm thankful for Robert Hilkeman, senator at that time, for his help in making this addition to our state screening panel. July, 2018, the state of Nebraska began to screen for these three diseases after the Legislature approved adding them to our state panel. So by adding these diseases to our panel, we now have the option of saving the state of Nebraska millions of dollars in Medicaid costs because these children have been diagnosed. And I just want all the children to have the same opportunity when they are born. And that is why I do not want the opt-out provision available. I do not have the dollar amounts what Medicaid would cost versus but I think those-- that information can be gathered from the DHHS. So the question is, you know, we're going to have more diseases that are going to be added to our panel with the coming years so if we can identify future babies and give them the opportunity for a life. Work that I have done in newborn screening has also given me the opportunity to become a member of the Nebraska Newborn Screening Advisory Board. Last year I received my five year anniversary as a member of that board, so I hope the committee will decide to not move LB1060 forward because of the problems that it will cause for the state of Nebraska and the children that are not screened. Thank you for listening, and I will do my best to answer any questions you might have.

HARDIN: Thank you. Any questions? Seeing none.

ROBERT RAUNER: OK.

HARDIN: Thank you.

ROBERT RAUNER: I tried to talk as fast as Doctor Tesmer, but I don't think I quite beat him, so.

HARDIN: We usually require that you pass an auctioneer test.

ROBERT RAUNER: Thank you very much.

HARDIN: Thank you. Anyone else in opposition to LB1060? Here comes one. Hi there.

ALYSSA KELLER: Hi. How are you?

HARDIN: Oh, dandy.

ALYSSA KELLER: Good. Well, good afternoon. Thank you for the opportunity to speak today. My name is Alyssa Keller, A-l-y-s-s-a K-e-l-l-e-r, and I'm here as an independent citizen to share my opposition to-- for LB1060. I work as a genetic counselor in the Inherited Metabolic Diseases Clinic, where I see patients of all ages that are-- that may be identified by Nebraska's newborn screen. I've seen the benefit that comes from identifying a baby with a metabolic condition. Those babies grow to be happy, healthy, and successful individuals. Unfortunately, I've also seen the impact when these babies are missed or they don't have a newborn screen. I see the heartbreak of these families when they realize that this diagnosis could have been made. I have seen children permanently disabled and disabled into adulthood. And unfortunately, I've seen where babies have passed away because of the failure of newborn screening. Because I've seen this deset-- this devastation. I'm incredibly grateful every time we have a patient referred to us from the newborn screening program. It means that that baby has a chance at a normal life. And when I see them back for follow up, I get to watch them do amazing things. Personally, I'm also grateful to the newborn screen. I wasn't born in Nebraska. It wasn't mandatory. And I don't know what the conversation was. But I know whether it was standard of care or something my parents opted into, they did choose to have me screened. And because of that, I was identified as having phenylketonuria or

PKU, which you've heard about earlier today. That simple heel poke done at 24 hours of age meant that I can be here as a successful, healthy adult, and not institutionalized, unable to care for myself. And it was simply implementing a low protein phe-- phenylalanine restricted diet. Just a few drops of blood mean that I get to live a normal life and not dealing with those conse-- those consequences. It is uncomfortable to say that a parent-- that the state mandates this test, that parents do not have the option to choose. However, I can't imagine that anybody is comfortable saying that the hundreds of babies diagnosed via newborn screening don't matter, and it is hundreds. In 2003-- you've heard the numbers from 2001, we recently got numbers from 2003, and it showed that approximately 457 babies were identified as having one of the conditions on the newborn screen. 412 of those were hemoglobinopathies. And I'm not great at math, but that's about 40, 50 babies that have other conditions. That's 457 babies in one year with treatable conditions that get medical care. Nebraska is a state that values its citizens and values the lives of children. To make newborn screening optional is a direct contradiction of this. The goal of the original legislation saying that all babies shall be screened was to give every baby, every child, the chance at a happy and healthy life. The chance that a child would lose due to a parent's choice is unfair and unjust. I hope and implore that this committee keeps this goal in mind as you consider this legislation. I also wanted to mention a couple of things. Cost is one thing that has come up. Looking online, you can see that the cost of this test, what the state is contracted for, the lab that does the testing is $86 per screen, and that is only for the initial screen. It's up to individual hospitals what they bill families for that. I'd also like to comment. While I don't know the legal implications of other states, in general there is a rising number of refusals of newborn screenings across the country. So I am open to your questions and thank you for your time today.

HARDIN: Thank you. Any questions? Seeing none. We appreciate it.

ALYSSA KELLER: Thank you.

HARDIN: Anyone else in opposition to LB1060? Going once. Going twice. Anyone in the neutral for LB1060? In the neutral. Seeing none, Senator Hansen, will you come back? And while you're coming back, I unfortunately have to inform you that while you were away from the Chairmanship here, we on the HHS Committee voted, and you have to do as many push ups as there were proponent letters, you had 110 of those, and as many sit ups as opponent letters, there were 95 of those, so you'll be busy for a while.

HANSEN: I already did them this morning, so we're good.

HARDIN: OK. Thank you.

HANSEN: All right. Thank you. Appreciate it. Told you it was going to be quick. I do have a few rebuttals and comments to make after hearing opposition. One was the Supreme Court case in 2008, the-- saying removal of the child-- There's some-- Let's see here, removal of the child was because of, you know, medical ne-- there could be a case of medical neglect. I think Blair brought that up from the Nebraska Nurses Association, says we do have moral authority or duty to protect children from medical neglect. That's assuming that children that we're testing have a medical condition. We don't know until they get tested, which we're not discouraging them from doing. So the case actually in 2008, where they were physically remove the child from the home, they actually end up testing the kid, and the kid was negative. Nothing was wrong with the kid, but they still removed him from the home. I'm glad you brought up the numbers from the newborn screenings from 2021. And yes, Doctor Tesmer did mention that, that DHHS, the number that they gave out, which I think the Nebraska Medical Association referenced the 57,400 samples compared to 24,000 births, the number was wrong. It was actually 28,855. And so that error was actually only found because Kelly made a phone call and asked about it. Otherwise we would not have known about that. That error would still be there. So to clarify, again. I pretty much agree with 99.8% of what everybody said in opposition. I'm not arguing the benefits of the procedure, or early detection, or treatment of testing. I'm not arguing any of that at all. I'm glad they got it. 47 other states have taken the approach of informing parents of the benefits of these tests and trusting their decision. Nebraska is taking the approach of forcing parents and infants to an invasive test that goes against the philosophical and religious beliefs of some. I venture to say most or all the people here, if they had a child or due, they'd have their child tested. It's their choice. But as much as we might disagree with it, some, for particularly religious reasons, may not want that test done. 30 states, including California and New York, allow for religious exemptions in United States. And as they were talking, the opposition, I, I-- maybe I'm wrong. Maybe somebody can correct me later. But I can't think of any other medical procedures that are forced upon infants besides this one, especially one that denies the parents a birth certificate until they get it, almost denying their identity.

HANSEN: And when it comes to, I think Senator Hardin brought this up, the idea of liberty, and this is what we struggle with. It's always tough in positions of responsibility that we're in to trust parents to make the right decision. And sometimes we feel like, based on information that's provided to us, we feel like we should be able to make decisions for them sometimes. And that's the argument that we heard here. Sometimes there's a reason government should force parents to do certain things. So with the idea of cost versus liberty that I have an issue with. People brought the idea of cost. How much is it going to cost the state of Nebraska if we don't do these tests? Some people brought up how much it's going to cost them, assuming parents won't get their children tested. I trust they're going to. And typically, from a governmental approach, I think it's our job to make sure that they're informed of this test, informed of the benefits of it, and the risks they take if they don't get it. Which we currently do for some of these tests. So I think the idea of cost is irrelevant. So I think it was-- I was glad, actually, Emily came to testify. I think she made a great argument for parents to get the test. It is compelling, emotional, and I'm glad she actually came here to testify. I disagree with one thing she said. I believe parents are the voice of the voiceless children, especially their children, not the government. That's the rub. That's the difference between what I'm proposing and what we currently have. I believe it was Robin, Emily's father-- Again, agreed with almost everything he said. Except I believe it's the parents' job to protect their child first, not the government. I believe you mentioned it's the government's job to protect children. And I believe-- Let's see here. Doctor Harney, Jenn Harney I believe actually said, and is this something I'm going to agree with her on, we are lucky to be born in a world with the ability to test for genetic diseases such as these. I think she was mentioning and some other testifiers were mentioning the idea of what the life would be like before we had these genetic tests, along with many other medical and technical innovations. We are lucky to be born, again, I just believe it should be the parents' choice to have their children tested. I believe Robert mentioned something about, he wished we would have had more discussions with DHHS beforehand. We did. We had a meeting before then, before he came to the committee. And Edison, I've always got to pick on Edison, from Arc. Him and I always fight the good fight, along with many other people here, for those with developmental disabilities. However, this, this, if this bill passes, it absolutely does not limit the parents' ability to check for these genetic diseases. He said if this bill passes, it will limit the parents' ability to check for these genetic diseases. It does not. They still have that choice. And this isn't-- this is more of an opt-out bill. So like I mentioned in my opening, even if a parent is unfamiliar with the tests, didn't even know they get tests, there's a lot of people I've talked to, many peo-- many people in, in the Legislature who didn't know that it was mandatory. So even those who don't, maybe, understand the tests, they still have to opt out of it. So the child gets it. But if they've done the research, or they have ideas about religious or philosophical exemptions, they can then opt out of it. So they still have to request to opt out of it. This isn't like everyone's opted out and the parent has to ask to opt in. It's the opposite. So I think that's it. So thank you, HHS Committee.

HARDIN: Any questions from any of you? Senator Cavanaugh?

M. CAVANAUGH: Thank you. Thank you, Senator Hansen.

HANSEN: Yes.

M. CAVANAUGH: OK. My first question is the religious exemption. You did not go that route. Can you maybe-- was there specific thinking? Because when I look at what other states have, the fact that other states have an option to not do this, it's primarily based on a religious exemption.

HANSEN: We mirrored ours after kind of what Iowa did.

M. CAVANAUGH: OK.

HANSEN: I believe Iowa and South Dakota are very similar to what this bill is.

M. CAVANAUGH: OK.

HANSEN: You have to opt out of it, I mean.

M. CAVANAUGH: So thinking through how this would work if this were to move forward, and I understand you have to opt out of it, but, I have personally been impacted by things that this Legislature has passed in the delivery room that were extraordinarily traumatic and upsetting, and it was implemented by the medical community in a way that was not the intention of this body, but resulted in me having to fill out paperwork saying that I did not want the remains of my miscarriage from nine months previous. Because there weren't remains, it was my son. And we created legislation that made the hospital community think that in order to cover themselves, that that was something, a box I had to opt out of. So you can understand how I personally am very concerned about how this would actually be implemented, because that, five years later, still traumatizes me. So what are your thoughts on that?

HANSEN: I don't know if I want to delve into that too much, because that seems like an a very emotional subject that you, that you--

M. CAVANAUGH: Well, that--

HANSEN: --that you're talking about.

M. CAVANAUGH: Yeah.

HANSEN: I think you're com--.

M. CAVANAUGH: But the reality is, is that this body, the year before I was elected, did that.

HANSEN: Yeah.

M. CAVANAUGH: Enacted that. And so I am very reticent to do anything that would translate into the medical community interpreting something that they have to basically cover their butts for--

HANSEN: [COUGHS] Excuse me.

M. CAVANAUGH: --that would somehow traumatize families. So the opting out could be presented in a way that is very complicated. So I just, maybe that's something we can talk about further--.

HANSEN: Yep.

M. CAVANAUGH: --in committee, but that sec--

HANSEN: You know, I think we're kind of comparing, we're comparing the idea of the government--

M. CAVANAUGH: Yes.

HANSEN: --and their ability to, you know, mandate certain things or not mandates certain things right? I think we're comparing kind of different things when compared to what you're talking about versus, like, a procedure such as this.

M. CAVANAUGH: Well, we did mandate. We did mandate that.

HANSEN: Yes. Yeah. And that's what [INAUDIBLE] so we're talking like kind of two different things, but similar things about the government's role in health care.

M. CAVANAUGH: Which brings me to my next question.

HANSEN: Yep.

M. CAVANAUGH: About consistency.

HANSEN: Yep, wait for it.

M. CAVANAUGH: I knew you would be. I'm sure most people are. Parents' job is to protect their children, not the government. Parents' choice in medical decision making--

HANSEN: Yep.

M. CAVANAUGH: --seems to be inconsistent statement based on what the medical issue is.

HANSEN: Yep. Which I find funny because--

M. CAVANAUGH: Do you want to address that?

HANSEN: --the opposition, right, to the certain bill, LB574. I mean, you're referencing last year--

M. CAVANAUGH: Yes.

HANSEN: --that we heard today almost said the exact opposite during LB574.

M. CAVANAUGH: I don't, I don't think most of those people--

HANSEN: Here we need to protect the children, now.

M. CAVANAUGH: I don't think most of those people were here today.

HANSEN: I believe a lot of them were.

M. CAVANAUGH: OK.

HANSEN: And so from the lobbyists and medical perspective, right? And so I think we're comparing apples to watermelons here, right? And so we're talking about the idea of mandating something that the parent has the ability to opt out of, right? A mildly invasive medical procedure. With LB574, we're talking about the ability for a parent to opt in to a, what I would term, a radical and major surgery that can have life altering implications. So we're comparing two pretty different things here. The idea that we're saying here is about protecting children in different ways.

M. CAVANAUGH: But--

HANSEN: Right.

M. CAVANAUGH: But my point to you is you trust parents judgment only in specific situations, in medical decision making.

HANSEN: Different situations, yeah, that's the thing.

M. CAVANAUGH: Yeah.

HANSEN: That's what was bringing up--

M. CAVANAUGH: That's the point.

HANSEN: --about opting out of a mandatory procedure--

M. CAVANAUGH: Right.

HANSEN: --as opposed to opting in--

M. CAVANAUGH: Right.

HANSEN: --to something else.

M. CAVANAUGH: But you're only trusting parents situationally to make medical decisions.

HANSEN: In two different situations, not the same situations.

M. CAVANAUGH: No.

HANSEN: You're--

M. CAVANAUGH: I, I know. That's what I'm saying, situationally. So your, you, your argument is it's a parent's job to protect their children and not the government this time.

HANSEN: In a totally different situation.

M. CAVANAUGH: Yes. It's not the parent's job, it is the government's job to protect children this other time.

HANSEN: Yes, in a totally different circumstance. You're trying to you're trying to put apples to apples here.

M. CAVANAUGH: But why should I trust parents in this situation, if I can't trust them when their child can actually converse with them?

HANSEN: OK. Before this conversation last 20 minutes and goes off the rails I'd much rather talk to you about it off the mic if you would like.

M. CAVANAUGH: OK.

HANSEN: Because this will devolve into something that probably, that will take--

M. CAVANAUGH: Well, I'm trying to get at--

HANSEN: --a lot longer than when we need to--

M. CAVANAUGH: I am trying to get at the root at the argument that was made by the Supreme Court. And somebody quoted our dear former colleague, Senator Chambers, was that the child can't make this decision for themselves. The child can't communicate anything. And, you want to put it in the hands of the parent to make the decision, which I'm not saying is a bad thought. It's certainly one that I think works, works to the conversation is whether or not a parent should be, having been entrusted with this decision. But, but the disparity here for me, in the incongruous thinking, is that I should trust the parent when their child can't communicate to them, but I should not trust the parent when their child can communicate to them. And I hope you can see how that is something that is difficult to reconcile.

HANSEN: Yes.

M. CAVANAUGH: And the-- and you are the person that is asking--

HANSEN: And I was expecting this conversation and I was not surprised by it.

M. CAVANAUGH: But you are the person asking this committee to reconcile those two different perspectives by bringing this bill back to the, to the committee that moved LB574.

HANSEN: I think I, I--

HARDIN: I would disagree, and I'm going to invoke Plato, sorry, because he told us that a --and a contradiction is to affirm and to deny the same thing, at the same time, in the same respect. And we are not dealing with an internal contradiction here by the rules of philosophy. I will just offer that.

HANSEN: Hard-- Senator Hardin is a conflict manager, in case you didn't know.

M. CAVANAUGH: OK. Well, I think you and I can continue this robust--

HANSEN: Yes.

M. CAVANAUGH: --conversation later. And--

HANSEN: I, I now have no-- and when this gets--

M. CAVANAUGH: --I appreciate you having it with me here.

HANSEN: This will-- especially if it gets on the floor, I will have no problem having this discussion more. But I think in essence of time--

M. CAVANAUGH: I think some people would prefer us not to have it on the microphone so--.

HANSEN: Yeah. That's true.

HARDIN: Whoever survives,we will beat them with pillows. I promise you.

M. CAVANAUGH: I, I'm finished.

HARDIN: Thank you, Senator Cavanaugh. Any other questions? Senator Walz?

WALZ: Thank you. Thank you, Senator-- Chairman Hansen. I have a question just about the, the bill itself, and maybe I'm missing something, but is there some type of agreement, a specific agreement or consent, that's signed by the parents stating they do not consent to infant screening? And then does that take away any liability for the doctor or the hospital in case something does go wrong, in case, you know, case something does happen to that child? Does that consent then say the hospital is not responsible for anything that happened to that baby because they did not have the screening?

HANSEN: Yeah. This is a discussion we had with the department beforehand too, because they have similar concerns. In my line of work, anytime a medical procedure is denied, you mean because they have the choice to, like, say, for instance, I recommend X-rays for a patient, and they deny getting any X-rays. I have a form, a legal form, that says OK, you have opted out to deny, against medical advice, to get this procedure done. And from my understanding, I'm not a lawyer, but you know, when it comes to litigious issues, that usually provides protection for the, for the hospital or somebody who is performing that procedure. Also, I would assume, and this is what they don't mention in the fiscal note, is that the-- even to get your birth certificate, then, if you opt out, I believe there has to be some kind of form filled out.

WALZ: OK.

HANSEN: We, we, we were, were just kind of discussing that right beforehand too. This, and so--

WALZ: OK.

HANSEN: --I think if I sit down with the, with the department, we can have more information about that as well.

WALZ: All right. But there's nothing in the bill right now, that's just something that's--

HANSEN: Nope.

WALZ: --in discussion.

HANSEN: Nope. This is kind of what most states did, they kind of said that, that line there, to be giving them the ability to opt out, and then we leave it up to the hospital or the facility, then, to decide what kind of form they would like to use to prevent any kind of litigious issues.

WALZ: All right.

HARDIN: Any other questions? Senator Ballard.

BALLARD: Thank you, Vice Chairman. I'm sorry if I missed it in the, in the bill in the-- Senator Walz got me thinking. Is it actually-- is it actually a box that you're checking. Or do you have to have preknowledge of-- I for-- I want this exemption?

HANSEN: Yeah. You would have to-- given, you know, there'd have to be informed consent. The patient would have to like--

BALLARD: So it's not a choice. It's not a binary like a-- it's not a yes or no choice in a form. You'd have to go in--

HANSEN: It depends on the form that's being filled out, right? You mean, you can have one that says, I choose to opt out of the genetic infant screening, and I hold no-- I hold harmless the, the hospital, whoever's performing that. And that would probably be, I'd assume, a form that the hospital would have that you sign. By signing it, you're opting out of it. I don't think it's really a box you check, yes or no, right?

BALLARD: Yeah.

HANSEN: So it'd be a form that you would fill out.

BALLARD: OK. Thank you.

HANSEN: Yep.

WALZ: OK. I was gonna--

HARDIN: Why, sure.

WALZ: --take off on what you said. So, they're being informed of all the risk and everything prior to opting out. There's, there is absolutely information given to every parent that says these are the risk if you opt out prior to signing that consent to opt out.

HARDIN: We didn't put that in statute. We left it up to the hospital or whoever's doing the testing. Yeah. Like, they, they can have a whole list. Just like I have a form, like I said, there are these forms out there, if you, if you deny a certain medical procedure against advice, I mean, you can say here are some of the risks, you mean, or you hold us harmless.

WALZ: Right. But so is that something that you're discussing that, that should be part of that consent to opt out?

HANSEN: No I'm not-- nothing in this bill that talks about what the form is going to entail and what it is.

WALZ: OK.

HARDIN: Any other questions? Thank you.

HANSEN: Yep. Thank you--

HANSEN: That will conclude--

HANSEN: --for hanging in there.

HANSEN: LB1060. And we will be moving on to LB1171. All right. Everyone got a chance to stand up and stretch your legs a little bit. All right. So now we will begin the hearing on LB1171. And welcome, Senator Hardin.

HARDIN: Thank you, Chairman Hansen, and good afternoon, fellow senators of the Health and Human Services Committee. I'm Senator Brian Hardin. For the record, that is B-r-i-a-n H-a-r-d-i-n. And I represent the Banner, Kimball and Scottsbluff Counties of the 48th Legislative District in western Nebraska. Pharmacies across the country are seeking solutions to maximize efficiencies to provide care for our communities. One solution is the utilization of off-site, closed door pharmacies to assist with data entry and verification in retail pharmacy locations. LB1171 would allow for this to occur through front end verification of prescriptions to be shared amongst Nebraska pharmacies with multiple locations that share a real time common electronic database. These off-site pharmacies utilize Nebraska licensed pharmacists and Nebraska licensed pharmacy technicians to provide data entry, data review, drug utilization review, third party resolution, and eventually phone support for local community pharmacies. These closed door pharmacies are located in Nebraska and are Nebraska licensed and not open to patients. This enhances efficiency and patient safety, since the pharmacy team members are free from distractions. There's a myriad of benefits to allowing this change to our statutes. LB1171 will help balance the workload in community pharmacies and also allow pharmacies-- pharmacists the ability to have alternative and hybrid work environments. In addition, this will benefit patients across all pharmacies in Nebraska by not only eliminating distractions for pharmacists at busy pharmacies, but by also increasing the capacity for clinician services for patients, such as immunizations and testing. It's important to note that these off-site closed door pharmacies must be located in Nebraska. For instance, this would not allow a pharmacy in Omaha to utilize a facility located in Iowa for the data entry and verification process. This ensures that jobs will be kept in our state. This concludes my opening statement. I'm prepared to answer any questions you may have. However, following me will be representatives of pharmacies who can better speak to the specifics of workflow and how this would work inside a pharmacy. Thank you.

HANSEN: Thank you, Senator Hardin. Are there any questions from the committee? Seeing none, see you at closing?

HARDIN: I shall.

HANSEN: All right. Well, welcome up our first testifier in support of LB1171. Welcome.

RICH OTTO: Thank you. Chairman Hansen, members of the Health and Human Services Committee. My name is Rich Otto, R-i-c-h O-t-t-o. I'm testifying on behalf of the Nebraska Retail Federation and the Nebraska Grocery Industry Association in support of LB71 [SIC, LB1171]. We appreciate Senator Hardin introducing this piece of legislation. I just want to quickly go over the timeline and how we arrived at LB1171. One of the Nebraska Retail Federation's pharmacy members, Walgreens, wanted to pursue the use of an off-site, closed door pharmacy in Nebraska. After discussions of the closed door pharmacy model with the Department of Health and Human Services. They determined that current law prohibited the-- prohibited this model due to verification being required to be done in the facility. Those two words: the facility. The department advised we needed a legislative change to allow for remote verification. After several conversations with stakeholders and DHHS on language, we arrived at LB1171. We also presented this language to the Nebraska Board of Pharmacy earlier this month prior to its introduction. We received positive feedback on the legislation. Currently, only three states don't allow remote verification. Those are Nebraska, Alabama, and Mississippi. One requirement of this verification change maintains that it still be done in the state of Nebraska, thus preserving jobs to the state. We have testifiers behind me that can answer questions about verification and pharm-- pharmacy related issues, but I am happy to answer any that you may have for myself.

HANSEN: All right. Thank you. Are there any questions from the committee? Seeing none, thank you very much. We'll take the next testifiers for it.

KIMBERLY WALZ: Good afternoon. I am Kimberly Walz, K-i-m-b-e-r-l-y W-a-l-z, no relation to Senator Walz, just the same last spelling. I am Regional Director of State and Local Government Relations for Walgreens, and I am joined today by Lorri Walmsley, our Director of Pharmacy Affairs and a licensed pharmacist. And we're both here today in support of LB1171. Thank you so much for your time today. As the workload continues to grow, the number of individuals entering pharmacy schools is on the decline. This is creating an imbalance inability for community pharmacies to staff enough pharmacies to meet community need. In response, Walgreens is seeking innovative solutions to provide care. One solution we have for Nebraska is the use of an off-site, closed door pharmacy to assist with data entry and verification. This is currently not allowed under Nebraska law, and

LB1171 would provide the remedy we need. Walgreens collaborated with the Board of Pharmacy and the department on the language that is proposed. Our closed door pharmacy would be located in Nebraska and would be staffed by Nebraska licensed pharmacists and Nebraska licensed pharmacy technicians. These team members would provide data entry, data review, DIR review, third party resolution, and eventually phone support for our local community pharmacies. Our closed door pharmacy would be Nebraska licensed and not open to patients. This allows the pharmacists and technicians to focus solely on supporting our community pharmacy locations. And this is how it would work. When a prescription is dropped off at our pharmacy, a pharmacy technician is able to scan the prescription, and they upload the image into a closed database system. This is then shared with our off-site location, location B. A Nebraska licensed pharmacy technician at that location or the original pharmacy is then able to enter the prescription data into the database. The data is then reviewed by either a pharmacist on site at the retail pharmacy where the prescription was dropped off, or be reviewed at the closed off-site location. If approved, the prescription is filled at the pharmacy and all final verification is done by a pharmacist on site where the patient will be picking up their prescription. Not only would this provide relief for pharmacists in busy community pharmacies, but it would allow us to create alternative work environments for our pharmacists. It also allows our pharmacists in our community pharmacies to have more time to serve the whole health of the patient, including immunizations and testing. It also allows for additional flexibilities for staffing when emergencies arise, like weather or team member illness. Thank you so much for your time today in support of-- letting me testify in support of LB1171, and Lorri and I are both here and will be able to answer questions. And since she is a pharmacist, she can speak more to the specifics and technicalities. Thank you.

HANSEN: Thank you. Are there any questions from the committee? I think so far we had testifiers whose last name was Ballard, and now we've got last name of Walz, waiting for a Cavanaugh.

M. CAVANAUGH: That's likely so.

KIMBERLY WALZ: Lorri, change your last name.

HANSEN: All right. Thank you for your testimony. Appreciate it. All right, we'll take the next testifier's work.

LORRI WALMSLEY: Good afternoon. Lorri Walmsley on behalf of Walgreens. L-o-r-r-i W-a-l-m-s-l-e-y. I'll keep my testimony short. First of all, thank you for allowing me to make comments. I'm really here just in support. I won't reiterate any of the other testimony for the sake of your time, but certainly happy to answer any questions that you might have about our process.

HANSEN: OK. Are there any questions? Well.

LORRI WALMSLEY: All right. I get off--

HANSEN: You get off easy.

LORRI WALMSLEY: I get off easy.

HANSEN: Yeah. Thank you. All right. Is anybody else wishing to testify in support? Welcome back.

HALEY PERTZBORN: Thank you. Nice to see you again. Chairman Hansen and the members of the Health and Human Services Committee, my name is Haley Pertzborn, Haley Pertzborn. I'm a licensed pharmacist and a fellow of the Nebraska Pharmacists Association. We have partnered with our grocery store and chain pharmacy leadership on LB1171. The bill aims to provide relief for pharmacists and technicians working in Nebraska pharmacies from excessive workload. By leveraging technology, a pharmacists at a site away from the dispensing pharmacy can help a colleague by performing the initial check of the prescription information as entered into the pers-- into the patient's record on the computer. This initial track ensures that the drug prescribed, prescriber, quantity, and directions for user are entered correctly. This initial check also reviews the patient's other medications, known allergies, and drug interactions for any safety issues. With the passage of LB1171, dispensing pharmacists can focus on the final verification of the prescriptions before they are dispensed to the patient, as well as counseling points and other clinical activities at the counter. As outlined, these changes will decrease workload and increase patient safety. Thank you for your time, and I will be happy to answer any questions.

HANSEN: Thank you. Any questions? There are none. Thank you for coming.

HALEY PERTZBORN: Thank you.

HANSEN: Anybody else wishing to testify in support? Anybody wishing to testify in opposition to LB1171? Anybody wishing to testify in a neutral capacity to LB1171. I wish all bills were like this. Especially mine. All right. Well, with that, we'll welcome back Senator Hardin to close if he wishes. And he waives closing. And I don't think I saw any letters to the record. So again, pretty easy. So with that, that will close our hearing for LB1171. And now we welcome Senator Ballard to open on LB1196.

BALLARD: Hopefully mine's that easy too. Good afternoon, Chairman Hansen and members of the Health and Human Services Committee. My name is Beau Ballard, for the record. That is B-e-a-u B-a-l-l-a-r-d. And I represent District 21 in northwest Lincoln and northern Lancaster County. I'm here today to introduce LB1196. LB1196 makes two changes to current law. It cuts red tape for registering med aides by allowing nursing students to work as med aides. Right now, medication aides regulation requires that the individuals applying to be medication aides have their still-- skill competency tested within six months before applying. For nursing students who may have taken classes focusing on these competencies early in their program, this could be a problem. It requires them to test again, even though they continue to use those skills throughout the rest of their nursing program. This bill would allow nursing students who have completed his or her medication aid to coursework to apply without the need to test again within six months of applying for that registration. Currently, once an application is submitted, it takes 30 days to process that application. This is a problem when hospitals are trying to get new hires started. The bill also changes current laws to allow nursing students to start as soon as their application is submitted. LB119-- LB1196 is, I guess, just a red, red tape cutting bill, creates efficiency, and helps hospitals and medical providers with their workforce. So with that, I'd be happy to answer any questions, but I do have experts behind me.

HANSEN: All right. Any questions from the committee? Seeing none, thank you.

BALLARD: Thank you.

HANSEN: We will welcome our first testifier in support of LB1196.

RUSSELL WESTERHOLD: Welcome. Good afternoon, senators. Chairman Hansen. My name is Russell, R-u-s-s-e-l-l, Westerhold, W-e-s-t-e-r-h-o-l-d as in David, I'm one of the registered lobbyists for Bryan Health. I'm here to testify in support of LB1196. We, of course, want to thank Senator Ballard for introducing this bill. I am having circulated to you a copy of the testimony of Bryan's intended witness today. Unfortunately, she is ill, and so apologies, but you'll have to suffer through me briefly. So given your workload, I think I'll not read to you what's in that handout. I'll just add maybe a couple of points to what is in there. First, absolutely want to echo what Senator Ballard said in his introduction this is a good, cutting red tape kind of bill. There's maybe another aim or purpose that I would also mention to you just a little bit. This bill is going to help us, it's going to help others integrate our nurses in training more quickly into our hospitals, our clinics, our health care facilities here in Nebraska while they're going-- while they're training here in Nebraska. Our hope, I think, in being able to better do that is to have better success once they graduate in retaining them here in Nebraska. So, that is a modest, but maybe useful, improvement to our ability to build our nursing workforce here in Nebraska. Next and last, I will acknowledge that I think the department has submitted some written comments in this, on this bill, that suggest that current regulations allow this to already be done. A couple things on that. First. I guess I'll say that was news to us. However, I will say that I have had one good conversation with the department so far on that topic. We will continue to talk to them about that. If we come to the conclusion that current regulations do allow this to be done, then I will circle back with you and certainly ask that an appropriate action be taken on the bill then. So that's all I have, Mr. Chairman.

HANSEN: All right. Are there any questions from the committee? Seeing none. Thank you.

RUSSELL WESTERHOLD: Thank you.

HANSEN: Anybody else wishing to testify in support of LB1196? Is there anybody who wishes to testify in opposition? Is there anybody who wishes to testify in a neutral capacity to LB1196? All right. So. With-- before Senator Ballard waives closing, I will mention that we did have six letters in support of LB1196, and one in a neutral capacity. So with that, Senator Ballard, waives his closing. And--

M. CAVANAUGH: Were you asking or telling?

HANSEN: No. Sorry about that. And with that we now close the hearing for LB1196, and we will open it up for LB1215, which is mine. All right.

HARDIN: Senator Hansen. We are waiting with great anticipation.

HANSEN: I feel like that little girl from Poltergeist. She says, I'm back. Except this one should be a little bit easier than the last one, and hopefully shorter. So good afternoon, fellow members of Health and Human Services Committee. I am Senator Ben Hansen and I represent the 16th Legislative District, and I'm here to introduce LB1215. LB1215 has four components related to the Department of Health and Human Services, and I will provide an outline of each element. The first part of LB1215 eliminates the required fee for any applicant or licensee requesting an informal conference with the representative Peer Review Organization. An informal conference is an option available to facilities to dispute citations after a survey of a facility has occurred. Citations can be issued for federal, state, or combination of federal and state violations. Currently, the department is required to hold two separate conferences, one for Centers for, Centers for Medicare and Medicaid Services, in which a fee cannot be charged, and one for the state with a fee. The removal of the state's fee will streamline the informal conference process for facilities and the department. The second portion of LB1215 allows, on a case by case basis and with the governor's approval, individuals with tuberculosis to be quarantined in locations other than a hospital in an outpatient setting when medically safe to do so. This change follows a national standard practice and reduces constraints placed on hospitals or health care facilities, which are utilizing more resources than are needed to treat and or monitor TB patients. The third part of the bill removes rehabilitation beds from the Certificate of Need Act to ensure rural access to health care, and allow for flexibility of facilities to meet the needs of the community, as well as reduced regulations and reporting requirements. The Certificate of Need Act requires health care facilities to meet specific criteria through an application process, with few exemptions, and receive a Certificate of Need from DHHS before additional rehabilitation beds can be added to the facility. The removal of the rehabilitation beds from the Certificate of Need Act will allow facilities to add rehabilitation beds as a need in their community arises. The final portion requires that Licensed Practical Nurses, Registered Nurses and Advanced Practice Registered Nurses register contact information with a national electronic database at no cost. The registration will allow the nurses to receive electronic notices, renewal notices, updated statuses, and provide more up to date nursing workforce data collection to the department. This will be accomplished during the license renewal process for existing licensed professionals, and upon initial licensure for future applicants. I am happy to answer any questions, or I will defer to the Department of Health and Hum-- Her-- Health and Human Services to testify regarding the need for this legislation. Thank you.

HARDIN: Thank you. Senator Cavanaugh.

M. CAVANAUGH: Thank you, Senator Hardin, I was looking at the letters, and there is, in fact, a testifier with the last name Cavanaugh.

HANSEN: Ah. See?

M. CAVANAUGH: I can't-- like I legitimately cannot believe that, so. I do have additional questions on the bill, but I hope-- I-- if the department can't answer them, I'll ask you again.

HANSEN: Sounds good.

M. CAVANAUGH: Thank you

HARDIN: Great. Any other questions? We'll see you at the end.

HANSEN: Yes.

Will the first proponent for LB1215 come on down? Welcome, Doctor Tesmer.

TIMOTHY TESMER: Thank you. It's an honor to be back again. Thank you. Good afternoon, Vice Chair Hardin and members of the Health and Human Services Committee. My name is Doctor Timothy Tesmer, T-i-m-o-t-h-y T-e-s-m-e-r, and I am the Chief Medical Officer for the Department of Health and Human Services, DHHS. I'm here to testify in support of LB1215, which proposes to make four changes important to the Division of Public Health. I would like to thank Senator Hansen for introducing this bill on DHHS's behalf. LB1215 will require Licensed Practical Nurses, Registered Nurses, and Advanced Practice Registered Nurses to register with a national electronic database at no cost, to receive renewal notices electronically, to obtain current license status, and to participate in nursing workforce data collection. Registration with e-Notify will be accomplished during the license renewal process for existing licenses, and upon initial licensure for future nurse license applicants. For the Tuberculosis Detection and Prevention Act, the proposed changes are in accordance with the centers for Disease Control and Prevention, CDC, practices. Tuberculosis patients will be provided care on an outpatient basis, and the program will coordinate with local health departments to work with patients in their homes or other appropriate settings. Patients will no longer need to be admitted to inpatient settings for tuberculosis treatment unless a directed health measure is mandated. Additionally, taking a bed and attention from licensed health care providers when not necessary exacerbates existing hospital care shortages that occur periodically.

LB1215 will eliminate the required fee for any licensed health care facility requesting an informal conference with a Peer Review Organization, PRO. An informal conferences is an option to dispute citations after a survey of a health care facility has occurred. The federal Centers for Medicare and Medicaid Services, CMS, does not allow for a collection of fees to conduct these conferences for CMS certified facilities. However, state statute requires a fee for state licensed facilities. LB1215 removes rehabilitation beds from the Nebraska Health Care Certificate of Need Act to ensure rural access to health care and allow for flexibility of facilities to meet the needs of the community. The act currently places a moratorium on the creation of new rehabilitation beds. If a hospital in Nebraska wanted to add rehabilitation beds, they could not under existing law because the occupancy rates of rehabilitation beds throughout the state do not meet current requirements for a Certificate of Need or for an exception to the moratorium on rehabilitation beds. Removing rehabilitation beds from the act will give hospitals the opportunity to create rehabilitation beds to meet consumer needs in their area of the state. We respectfully request that the committee advance the bill to General File. Thank you for the opportunity to testify today. I would be happy to answer any questions about this bill.

HARDIN: Thank you. Any questions? Senator Cavanaugh.

TIMOTHY TESMER: Yes.

M. CAVANAUGH: Thank you. Thank you, Doctor Tesmer, for being here. The rehabilitation beds is what I'm interested in, and I will be very transparent. I don't quite understand this process here, but in reading your testimony about, creating more access in the rural parts of the state, which I think is an admirable goal for us all to have, I'm looking at the statute, and I don't quite understand why having the Certificate of Need prohibits that. Because if there is a need, then there's a need. So could you maybe explain it a little bit more?

TIMOTHY TESMER: Senator, my understanding of the statute states that across the state, unless occupancy rates are 90% for rehabilitation beds--

M. CAVANAUGH: Across the state.

TIMOTHY TESMER: --across the state. Now, taking that a little bit more at a more local level, local, more health, health areas, health districts, that threshold to meet a exemption, let's say, is 80%. And currently, as it stands, there really is no health region in the state of Nebraska, and there's like 7 or 8 perhaps, that meet that 80% threshold. And certainly across the state, that 90% threshold is not met, has not been met. And that, and that all is determined by the last three consecutive quarters of reporting, which has to be done. So eliminating this Certificate of Need gives those facilities in other areas of Nebraska the ability to create rehabilitation beds within their facility for the needs of their patients in that region.

M. CAVANAUGH: So my follow up question, and I'm also wondering if my colleague next to me, I might have to ask him this question later, what is, what is the history of a Certificate of Need, then? Why do we, why do we have it?

TIMOTHY TESMER: I-- That was before my time, Senator.

M. CAVANAUGH: OK.

TIMOTHY TESMER: Now-- Not before my lifetime, necessarily, but before my time here, I do know that a-- it was back in 1979 or 1980--

M. CAVANAUGH: Well, that's just at my time.

TIMOTHY TESMER: --when--

M. CAVANAUGH: Senator Hansen and I just arrived on the scene at that time.

TIMOTHY TESMER: --certificates of need were created.

M. CAVANAUGH: OK.

M. CAVANAUGH: I don't know, honestly, the reasons for that, but it started in 1979 or 1980. There have been various amendments to that. The last one, I think, around 2013, which narrowed the scope of Certificate of Need to rehabilitation beds and assisted living facilities. This, this one that we are wanting to enact or advance takes the Certificate of Need for rehabilitation beds out of the statute.

M. CAVANAUGH: OK. Are you aware of-- is there a specific location in more rural parts of the state that are looking to create these rehabilitative beds, but aren't able to because of the Certificate of Need?

TIMOTHY TESMER: I, I'm not aware of any particular region, there may be, but I'm not aware of any right now. I think this was done to try to clean up-- clean this up a little bit.

M. CAVANAUGH: OK. Thanks for answering my questions

TIMOTHY TESMER: You're welcome.

HARDIN: Any other questions? Seeing none, thank you.

TIMOTHY TESMER: Thank you.

HARDIN: Anyone else as a proponent for 1215? Welcome.

JOHN GAGE: Thank you. My name is John Gage, that's J-o-h-n G-a-g-e. I am here on behalf of Americans for Prosperity. I'm here to testify in support of LB1215. AFP activists engage friends and neighbors on key issues and advocate for building a patient centered health care system that lowers costs, increases choice, and improves access for millions of people seeking relief. As part of this mission, we believe this bill would improve Nebraska's health care system for the better. This proposal would end the state's Certificate of Need law for rehabilitation beds, and allow health care providers to provide new bed capacity that meet the true needs of the state's families and communities. Since 1975, Nebraskans has had in place Certificate of Need laws. These laws harm providers' ability to enter new markets or make changes to their capacity without state approval. Current law is preventing health care facilities from opening new rehabilitative bed space across the state, especially in rural communities. Repealing the Certificate of Need restriction would allow health care facilities to build more rehabilitation beds to treat our state's growing health care needs. In a study done by Americans for Prosperity, we found that states that repeal Certificate of Need laws total health care spending is 7.4% lower. The study also found a 17% reduction in Medicaid spending after five years and 15% in Medicare spending. Certificate of Need repeal saves consumers money and it saves taxpayers money. Contrary to claims made by some, a Certificate of Need-- by some that Certificate of Need laws protect hospitals by limiting competition, results show that hospitals earn more money in non-Certificate of Need states, because they can add more services that generate greater revenue. The advocates for these programs will claim that repealing these laws are somehow dangerous or come with unknown risk. This is false. There are significantly more data to show that repealing these programs are beneficial to consumers, hospitals, and states. Over 100 million Americans live in states that do not have Certificate of Need laws. By passing this bill, Nebraska would join a growing number of states that have found repealing Certificate of Need lowers cost and improves levels of care. LB1215 will empower hospitals to deliver a wider variety of services, allowing them to provide more care to more customers across our state. Please support LB1215 to strengthen health care access, lower cost, and ensure patients get the right health care at the right time. Thank you.

HARDIN: Thank you. Any questions? We don't see a single question. Thank you.

JOHN GAGE: Thank you.

HARDIN: Hello, Senator [SIC].

LAURA EBKE: Senator. Vice Chair Hardin, members of the Health and Human Services Committee, my name is Laura Ebke, that's L-a-u-r-a E-b-k-e. I'm the senior fellow at the Platte Institute, a free market think tank here in Nebraska dedicated to reducing barrier-- barriers to opportunity and growth here in Nebraska. And I'm here to add yet another voice of support to LB1215, and thank Senator Hansen, for bringing this bill. My comments are related primarily to the Certificate of Need element of the bill. I'm sure you've all received a number of pieces of written testimony from national legal organizations. Senator Cavanaugh, I'd ask you to take a look at a letter that I think was sent by Pacific Legal Institute and James Manley, he gave a little bit of history-- or he sent me a copy anyhow, of one that he was-- he intended to send, a little bit of history of the Certificate of Need laws around the country. I would also point out that the Mercatus Center did a study, in cooperation with the Platte Institute back in 2020. And that study showed that Nebraska had relatively fewer Certificate of Need laws overall, than other states, but all of ours were in the health care, health care industry. And one of which is, of course, rehabilitative care that we're discussing eliminating today. Ending Certificate of Need laws does not mean a diminishment of care. OK? The Certificate of Need restrictions are in addition to standard licensing and training requirements for medical professionals, and also assorted of licensing and inspection standards required for by the states for facilities. OK? None of that changes. All this does is change the, the need to prove that there is a need. Right? Certificate of Need laws limit the supply of services rather than expanding them. They limit competition, which usually means higher prices and fewer choices for the consumer or patient in this instance. Getting rid of Certificate of Need provisions for rehabilitation beds is a good start, I think. Eliminating all

Certificate of Need requirements in the future would be even better. And I will say, as somebody who lives in a rural area, and it's all anecdotal, you know, but, we hear lots of stories about rehabilitative beds, nursing home beds, and, and things like that, that new people, new organizations want to come in, but they just can't get past the Certificate of Need requirements. So, take that for what you will. That's it.

HARDIN: Thank you. Very good. Any questions? Senator Cavanaugh?

M. CAVANAUGH: Thank you. More of a statement. Mr. Manley did submit a letter. I see it, so I will make sure to take a good look at it. Thank you.

HARDIN: Any other questions? Seeing none. Thank you.

LAURA EBKE: Thank you.

HARDIN: The next proponent for LB1215. Any opponents of LBW 1215? Welcome.

CHRIS LEE: Thank you. Good afternoon. My name is Chris Lee, C-h-r-i-s L-e-e. I'm the COO of Madonna Rehabilitation Hospitals, and I'm testifying on behalf of Madonna and the Nebraska Hospital Association. And I just would like to thank the members of the committee for this opportunity to speak before you today. Madonna and the NHA are opposed specifically to the third component of LB1215 that would repeal the Nebraska Certificate of Need Act for rehabilitation beds. I believe Nebraskans have benefited from thoughtful planning around these highly specialized services, and the repeal of the CON will exacerbate our workforce challenges in Nebraska, increase costs, and decrease quality. And I would like to respectfully take issue with some of the characterizations of the CON by Doctor Tesmer and Mr. Gage. Nebraska's CON is perhaps unique in that it is very flexible, and it allows any hospital in Nebraska to convert 10% of its beds to create a brand new rehabilitation unit any time without a Certificate of Need. It also allows any of the ten existing facilities in Omaha, Lincoln, Norfolk, Grand Island, Hastings, Kearney and Scottsbluff, across the state to add 10% more beds to their facilities every two years. And in addition to all of that, any facility can add more beds if the state occupancy level were to reach 80%. So I just want to correct that number. It's 80% for the state. We are not there. We're only running at 60% across the state of Nebraska or somewhere in that range. But it even gets more granular. If your particular health planning region is at 90%, then you could also add beds. So there are many ways for people to add beds. So I respect the arguments for repealing CN-- CON based upon reducing regulatory burdens and cost. However, the federal requirements dictating who qualifies for rehab, how care is delivered, and how that care is reimbursed won't change. So increasing competition for the small population that needs rehab doesn't decrease cost. Fragmentation drives up labor cost, reduces access to capital, and diminishes the conditions needed for quality patient outcomes. Moreover, people who have experienced life changing traumas choose services based on expertise, scope of services, and the availability of the latest technologies, and repeal of the CON will make maintaining all of those things more difficult. The shortage of nursing staff in Nebraska is expected to exceed 5,000 by 2025, and this is driving dramatic increases in labor cost in our state. Madonna's cost for contract nursing has risen by 50% over the last two years, and now totals $12 million annually. Spreading a scarce workforce across more facilities will only serve to drive costs higher as wages are further inflated and facilities are forced to rely more on contract labor. In addition, lower patient volumes make it very difficult for any individual facilities to create the capital necessary to be able to invest in the types of technologies that rehab patients truly benefit from. An influx of unneeded rehabilitation beds, which has spread patient volumes below levels needed to maintain high quality services in a highly specialized field like this one. Patient outcomes are impacted when facilities don't have the critical mass of patients to develop and maintain expertise in complex diagnoses, such as brain injury and spinal cord injury. Madonna believes repealing the CON will negatively impact Nebraskans who need rehabilitation and the facilities that provide this relatively low volume but essential medical care. We urge the committee to strike the portions of LB1215 repealing the CON, and I'd just like to thank you for your consideration today and for this opportunity to testify, and I'm happy to take any questions that you might have.

HARDIN: Thank you. Any questions? Can you maybe expound just a little bit on what you see potentially happening with contract labor as regards this situation? What if we do engage in CON activity, we jerk them, what could happen? Can you paint, paint a worst case and a probable case for us?

CHRIS LEE: Yes. Well, there is a nationwide shortage of nurses, but it's particularly acute in Nebraska. It's a scary thought to realize that we're nearly 5,000 nurses short of what we need in Nebraska. So every Nebraska hospital is currently competing for nurses, and that is driving up the cost of nursing staff, whether they're employed or contract. And it simply isn't sustainable. The cost currently for labor are far outstripping the reimbursement that we receive for caring for patients. And if we were to have even more facilities with unneeded beds when our capacity in the state is only hovering around 60%, that is just more ways to spread a very thin workforce already that will cause labor cost, I believe, to spiral even more. You know, there are only about 3,700 Nebraskans a year who require this type of highly specialized rehabilitation. It's a relatively finite number of people, and Nebraska has the facilities to do that. And again, every single one of those facilities across the state, from Scottsbluff to Omaha, are able right now to add beds periodically based upon community need without a CON. It's an exception within the CON. And, again, any community hospital could start a rehab facility if they believe that it's beneficial for them to do so in their, in their particular town. Again, without a CON as an exception.

HARDIN: OK. Any other questions? Seeing none, thank you.

CHRIS LEE: Thank you very much.

HARDIN: Anyone else in opposition to LB1215? Hi there.

JOHN WOODRICH: Hello. Thank you. I'm John Woodrich, J-o-h-n- -W-o-o-d-r-i-c-h, and I'm with Bryan Health, and I've been with them for 15 years. And I hate to admit, I was around when CON went into place. I've been in health care for 48 years, and, I don't want to repeat a lot what Chris said, but, the only section of this that I'm opposed to is the Certificate of Need. Bryan Health is probably the largest health system in the state. In the region, we take care of hundreds of thousands of patients. A subset of those do require rehab through their acute care. You know, this bill will remove the Certificate of Need for rehab beds in our state, really destabilizing a highly specialized workforce. And I think the key word here is specialized. You guys were asking about what we're spending in traveling nurses. Bryan spent $54 million last year. That's how competitive this is. You know, removing the protective administrative process for the rural and urban facilities, I think, is something we need to consider. And I'll cover that here in a little while as well. You know, I know Chris referenced the extensive training, and that's the specialized training that these nurses need to go through in order to keep up with the leading edge technology that's needed to rehab these individuals, I think, is very crucial. And I'm going to tell you, 15 years ago when I came back to Nebraska, and I'm originally from Nebraska, Madonna reached out to me and asked me to come to their facility. I was actually totally just blown away by what they offer these, these patients. We have our rehab facility within Bryan, but we work very closely with them, and you see the outcomes of being able to afford that type of technology and getting people access to that type of care. You know, maintaining that competency is very important for these nurses and these highly specialized individuals, and I don't want to see that go away in our state. You know, as he mentioned, we have key rehab facilities all the way across the state, but this doesn't include our critical access hospitals that already have the capability of providing rehab care through their swing beds. So that would be in jeopardy for all of these smaller hospitals in rural Nebraska, that oftentimes those hospitals are the economic engines for those communities. You know, I know Chris covered that there is within the current statute today, ways of organizations to go ahead and get additional rehab beds. If it's removed entirely, we do believe there will be an influx of entities that enter this market, and they're going to dilute this mass of individuals that we currently have that are specialized in, in this area. You know, we understand right now that the current purpose of this removal is that it might be a way to remove administrative burden from those wanting to expand rehab beds, but again, mentioned that we only have 60% of those beds that are filled. In the last few years, we have no indication that any filings had ever been made for a Certificate of Need for rehab beds. So even though there's an argument for removing this, there really hasn't been a burden on the department to make any judgment on anybody coming forward wanting to add additional rehab beds. I just want to end with summarizing it again. I truly believe this is going to destabilize a highly specialized workforce. It will impact the quality. It's going to continue to chip away at the rural facilities that have these swing beds that they offer rehab into. We only stand opposed to that one section of LB1215. We have attempted to work with DHHS, and we believe we've come up with some language to help compromise this that would add a little bit further flexibility to the language. But also, we-- I feel the state needs the protection of CON for its current programs. We urge you to consider this for those rehab patients, for the workforce that we have today, for the providers that will be impacted should this bill move forward. Thank you, and I'd be glad to take any questions.

HARDIN: Thank you. Any questions? You've done a magnificent job and you've left them speechless.

JOHN WOODRICH: Oh. Thank you.

HARDIN: Thank you. Anyone else in opposition to LB1215? No one else. And how about in the neutral for LB1215? Seeing no one else, Senator Hansen, would you come back? We do have three letters who are in favor, one who was opposing. And you don't have to do nearly as many sit ups and push ups.

HANSEN: That's good. I was tired and, you know. Senator Cavanaugh, there's, there's a good letter that was sent in from Matthew Mitchell in the letters that talks a little bit about the history of Certificate of Need.

M. CAVANAUGH: I see it.

HANSEN: Maybe how it was applied in Nebraska and then in some of the emp-- empirical, peer reviewed research about Certificate of Need. And, you know, back when it was first started and, and how, you know, what-- how, how good has it done since then, so. He kind of talks a little bit about that there, which I thought was pretty good. And the memorandum, they talked a little bit about the history Nebraska specifically, about when it was, when it was started and, you know, when it was introduced, all that stuff. So just some of those questions that you had earlier. Other than that, I have nothing else.

HARDIN: Any final questions, thoughts for Senator Hansen? Seeing none, thank you. This will conclude LB1215 and our hearings today. Thank you so much for being a part of it.