[LB764 LB1051]

The Committee on Appropriations met at 1:30 p.m. on Thursday, February 6, 2014, in Room 1003 of the State Capitol, Lincoln, Nebraska, for the purpose of conducting a public hearing on LB764, LB1051, and agency budgets. Senators present: Heath Mello, Chairperson; John Harms, Vice Chairperson; Kate Bolz; Danielle Conrad; Bill Kintner; Tyson Larson; John Nelson; Jeremy Nordquist; and John Wightman. Senators absent: None.

SENATOR MELLO: Good afternoon and welcome to the Appropriations Committee. My name is Heath Mello. I'm from south Omaha, representing the 5th Legislative District, and serve as Chair of the Appropriations Committee. I'd like to start off by having members do self-introductions, starting first with Senator Kintner.

SENATOR KINTNER: Well, hello everybody. I'm Bill Kintner from Legislative District 2. That's about half of Sarpy County, Cass County, and a little bit of Otoe County.

SENATOR NORDQUIST: Jeremy Nordquist, District 7, downtown and south Omaha.

SENATOR NELSON: John Nelson, District 6, central Omaha.

SENATOR HARMS: John Harms, 48th District, Scotts Bluff County.

SENATOR MELLO: Sitting to my right is Senator John Wightman from the 36th Legislative District, representing Custer and Dawson County.

SENATOR CONRAD: Hi. Senator Danielle Conrad, north Lincoln.

SENATOR BOLZ: Senator Kate Bolz. I represent District 29 in south-central Lincoln.

SENATOR MELLO: Sitting next to Senator Bolz is Senator Tyson Larson from Legislative District 40, who will be joining us later. Assisting the committee today is Anthony Circo, our committee clerk; and Matthew Ruiz, who is a senior studying international business at the University of Nebraska-Lincoln and is our committee page. On the cabinet to your right you will find some yellow testifier sheets. If you're planning on testifying today, please fill out one of the sheets and hand it to Matthew when you come up. It helps us keep an accurate record of today's public hearing. There is also a white sheet on the cabinet if you do not wish to testify but would like to record your position on a bill. When we hear testimony regarding state agencies, we will first hear from a representative of the agency, we will then hear testimony from anyone who wishes to speak on the agency's budget request. We will hear bill testimony in the following order. First will be the introducer. We will then hear those in support, followed by those in opposition, then those testifying in the neutral capacity, and we will end with

a closing statement by the introducer. If you have any handouts, please bring at least 11 copies and give them to Matthew. If you do not have enough copies, he will help make more. We ask that you begin your testimony by giving us your full first and last name and spelling them for the public record. We will be using a five-minute light system today. When you begin your testimony, the light on the table will turn green. The yellow light is your one-minute warning. And when the red light comes on, we ask you to wrap up with your final thoughts. At this time I'd ask all of us, including senators, to please look at our cell phones and make sure they are on silent or vibrate mode. Lastly, our first fiscal analyst today is Phil Hovis assisting the committee. With that, at this time we'll begin today's public hearing with Agency 14, the Public Service Commission. (Agency hearings)

SENATOR MELLO: Next up in the Appropriations Committee will be LB764 by Senator Conrad. [LB764]

SENATOR CONRAD: (Exhibit 1) Thank you, Chairman Mello, members of the committee. My name is Danielle Conrad, that's D-a-n-i-e-l-l-e C-o-n-r-a-d, and I represent, as you know, the "Fighting" 46th Legislative District of north Lincoln. I'm here today to introduce LB764, a bill that would appropriate $1.8 million to the University of Nebraska Medical Center for pediatric cancer research. And let me tell you this, friends. My staff designed and helped me craft a beautiful introduction on this legislation. But I'm just going to speak directly from my heart because that's why I brought forward LB764. Let me be very clear. This is a citizen initiative. This is not a university initiative. This is a citizen initiative. And how the legislation came to be is that many of us received an e-mail during the interim period from a dad who asked us to help raise awareness when it came to pediatric cancer. And in addition to raising awareness, he challenged us to take action. And quite simply, as a mom, it touched my heart when he shared his family's personal story with how their daughter was currently battling pediatric cancer. And in full disclosure, it probably caught my attention because I recognized the name. Mitch Ahlschwede was a high school classmate of mine from good old Seward High, class of '95 if you're interested. Yes, that may be dating myself a little bit. But it really...it touched my heart and it intrigued me to try and figure out what could we do. What steps could we take to move this issue forward? It's wonderful to pass resolutions. It's important to light up the Capitol. It's important to raise awareness. But the time for raising awareness has come, it has happened, and now is the time to take the next step. And so I started to think about, well, what could we do? And believe me, it is not an elegant approach. But roughly what this legislation represents is what if each person in Nebraska pitched in a dollar towards pediatric cancer research, and that's how we arrived at the figure of $1.8 million. And what this is, is an opportunity to take the next step, to take positive action on behalf of our kids in Nebraska and the families that need our assistance. There are many brave and inspiring stories to come behind me, and I don't want to detract from their message to you today so I will keep it short. There is an economic component to this legislation. It will help to leverage in private dollars. It will

help to leverage in research dollars, and that pays economic dividends for our state. There's also, of course, the personal component as I imagine that your hearts and minds will be equally touched by the stories that come behind us. I've heard a little opposition rumbling from some members about, well, this is nothing but feel good legislation. And so be it if people want to characterize it as such. But I say this to you. You know what doesn't feel good? Sitting on our hands and doing nothing. The citizenry has empowered us to take action on their behalf, and we have the ability to do so. This is one way that we can make a positive difference together, that we can put aside petty partisan bickering, we can put aside differences, we can come together and we can say we are going to do something positive for the kids in our state. Thank you. [LB764]

SENATOR MELLO: Thank you, Senator Conrad. Are there any questions from the committee? Senator Harms. [LB764]

SENATOR HARMS: Thank you, Senator Conrad. I appreciate you bringing this bill in. And when you just look at the amount, $1.8 million, that's not a lot of money when it comes to actual research. And so you just touched on it a little bit about using it for grant matching. Can you be a little more specific how we might use this? Because like I said, in the research world, it's not a lot of money. [LB764]

SENATOR CONRAD: Thank you, Senator Harms, and I think you're right. I'm under no illusion that this is going to magically cure cancer tomorrow. But it is indeed an important step forward in the research requisite to help us find a cure and to help us identify better treatments to improve the quality of life for children who are suffering and dealing with pediatric cancer. UNMC is going to provide testimony today in I believe a neutral capacity as is pattern and practice, but will provide very technical and specific explanations as to how their plans would be to utilize the funds if so appropriated. And I'm not trying to defer. I'm just not a medical expert and I think that they'll do a much better job getting you excited about the idea as they have been able to get us excited about it. [LB764]

SENATOR HARMS: You know, Senator Conrad, I think that anytime a child has an illness like this, if you're a parent it definitely grabs your heart. And, you know, sometimes I wrestle with how can a child so young not even get a chance to really live their life and have such a serious disease and illness. I've had a full life. I'd definitely change places. You know, you just start looking at those sort of things and it's really a tragedy. I hope that someday we can get a handle on all of this, not only for children but cancer in general. So thank you for introducing this. [LB764]

SENATOR CONRAD: Absolutely. Thank you, Senator Harms. And I failed to mention in my initial comments, you know, this body has shown great leadership when it comes to moving the ball forward in relation to cancer treatment and cancer research. Senator Harms's leadership on the Get in the Game program; I've worked to expand the Every

Woman Matters program; Senator Nordquist's effort on oral chemotherapy parity; the collective work of this body through Senator Nelson's leadership and others in putting together the funding for the UNMC Cancer Center. So this is a continuation of those investments and those policies which are good for Nebraska. [LB764]

SENATOR MELLO: Any other questions from the committee? Senator Kintner? [LB764]

SENATOR KINTNER: What does the federal government spend on this? [LB764]

SENATOR CONRAD: I don't know. We'd be happy to get you that information, but I can tell you that the information our office...I don't have the specific number. They do expend funds for research purposes. The information our offices have received demonstrate that federal funds have been declining in recent years in relation to this and other areas. [LB764]

SENATOR KINTNER: I'm trying to figure out what is the federal government spending versus what our expenditure would be. Is it a drop in the bucket or is it major? I'm trying to get a sense of relationship as to how much our money would contribute to the national effort to combat cancer. Just trying to get a relationship to that, so. [LB764]

SENATOR CONRAD: Very good. We'll be happy to get you those specific figures, Senator. [LB764]

SENATOR KINTNER: I would seriously love to have that. Thank you. [LB764]

SENATOR CONRAD: Yep, we can get those for you. [LB764]

SENATOR KINTNER: Appreciate it. [LB764]

SENATOR MELLO: Any other questions from the committee? Seeing none, thank you, Senator Conrad. [LB764]

SENATOR CONRAD: Great. Thanks. [LB764]

SENATOR MELLO: First, we will take proponents of LB764. [LB764]

KARRI SHIERS AHLSCHWEDE: (Exhibit 2) My name is Karri Shiers Ahlschwede. I am Layna (phonetic) Ahlschwede's mother and the wife of Mitchell Ahlschwede that sent the initial e-mails and probably I am the one that you can holler at for your e-mail inboxes being quite full. What I brought with me today is just a brief representation. Every child that you see on that poster is a Nebraska child, and every single one of them is either fighting cancer or has fought cancer. Some of them are still fighting, some of them have lost the fight, some of them are in remission. The little peanut with the

necklace happens to be my little one who ironically on February 6 of 2013 was diagnosed with stage 4 high-risk neuroblastoma at Children's Medical Center in Omaha. Our family has been turned upside down. Layna is the youngest of five. She was 18 months at diagnosis. She has learned to walk in the last year, pulling chemotherapy tubing and pumps behind her. Her vocabulary has expanded to know words like ouch and pain and hurt and no thank you when she sees laboratory personnel come into the room. But we're fortunate. Layna is responding to treatment and is staying on the protocol that's set forth for stage 4 high-risk neuroblastoma. Some of her friends represented on the poster are not as fortunate and have had to leave Nebraska and go elsewhere for treatment. The treatment options for refractory neuroblastoma or relapsed neuroblastoma are slim to none. In regards to federal monies, those are also slim to none. The last statistic I saw from St. Baldrick's Web site said that of all of the federal dollars given to cancer research about 3 or 4 percent of that goes specifically to pediatric cancer research. It has been decades since a new pediatric cancer drug has been developed specifically for the pediatric population. And so while Layna has suffered horribly from her disease, she has suffered just as greatly from her treatments. So what we're hoping LB764 will do is open the door to bring in people with some new ideas, bring the brightest minds in pediatric cancer to Nebraska. Nebraska is in a unique position in my opinion. We've had some national headlines, national news with regards to pediatric cancer. And it is Nebraska's opportunity right now to be a leader and step forward and say Nebraskans are family oriented, we do care about our kids, and we care about our future. And $1.8 million is a lot of money and it will give us a start and bring in the right minds, the right research dollars and hopefully some new treatments. Will it cure cancer? Maybe, maybe not. A cure has to come from somewhere. But what I'm hoping it will do is allow some of these kids some other options for treatments that they may not have elsewhere. One of Layna's friends represented on the photos is receiving treatments in Chicago. Another one will have to go to Houston. So these families, these Nebraska families are being ripped apart and sent elsewhere in the country. This $1.8 million may open the doors for some of these treatments and some of these trials to be done right here in Nebraska. Layna has received all of her treatments in Nebraska so far. Her transplant, her stem cell transplant and her radiation have all been done at UNMC. We have met kids from all over the Midwest who are coming to Nebraska for treatments. This not only benefits Nebraska but the whole Midwest. These kids need a voice, and this is the opportunity to be that voice for these kids and to say, yes, we see you. We see what you're suffering. We see what you've been through and we care and we're going to take action. [LB764]

SENATOR MELLO: Thank you for your testimony, Karri. [LB764]

KARRI SHIERS AHLSCHWEDE: Sure. [LB764]

SENATOR MELLO: Are there any questions from the committee? Senator Nelson. [LB764]

SENATOR NELSON: Thank you, Senator. Thank you, Ahlschwede is it? [LB764]

KARRI SHIERS AHLSCHWEDE: Yes. [LB764]

SENATOR NELSON: Okay. Would you point to your daughter again? [LB764]

KARRI SHIERS AHLSCHWEDE: This is Layna in the corner here. [LB764]

SENATOR NELSON: Oh, all right. Thank you. I just...I...could you elaborate on the statement that one child had to go to Chicago and another to Houston. For what reasons? Why do they have to go elsewhere? [LB764]

KARRI SHIERS AHLSCHWEDE: Let me give you a specific example. One of her friends that's actually on the poster here has the same disease Layna does, stage 4 high-risk neuroblastoma. There's a certain protocol that's set forth that each child with this same diagnosis follows this protocol, and they continually monitor through the treatment, which happens to be about a year to a year and a half worth of treatment. How is the disease responding? Are we seeing improvement? Are we seeing the disease stay status quo? Or are we getting worse? And if these kids don't respond to these treatments, the treatments that are available experimentally are not available in Nebraska. They're only available in some of the larger neuroblastoma research institutions simply because they have a research institution. They have the research dollars to get these things started. Layna's friend Sammy (phonetic) is located right in the middle of the large 8 x 10s. You'll notice there are seven 8 x 10 photos, and that is to represent the seven children that are going to die today from pediatric cancer in this country, seven that are going to die today. These are all Nebraska kids. Some of them have already lost the fight. So when I say there's not other treatment options, they're really kind of searching for will this work? No, that didn't work. Will that work? No, that didn't work. And the treatments aren't available everywhere so they kind of have to go wherever they can get the next experimental treatment or the next trial. [LB764]

SENATOR NELSON: Thank you. [LB764]

SENATOR MELLO: Is there any other questions from the committee? Senator Bolz. [LB764]

SENATOR BOLZ: I just wanted to say thank you for sharing your story. I appreciate your strength. And I think you live in south Lincoln. [LB764]

KARRI SHIERS AHLSCHWEDE: Um-hum. [LB764]

SENATOR BOLZ: And that's home for me too. And I just want you to know that door

knocking, lots of people with pink ribbons, lots of people who support you and your cause and believe in this purpose. So thank you for bringing it to our attention. [LB764]

KARRI SHIERS AHLSCHWEDE: Thank you. Thank you. [LB764]

SENATOR MELLO: Seeing no further questions, thank you, Karri. [LB764]

KARRI SHIERS AHLSCHWEDE: Thank you. [LB764]

SENATOR MELLO: Next proponent for LB764. [LB764]

ALEXA LEWIS: (Exhibit 3) Good afternoon. My name is Alexa Lewis, A-l-e-x-a, last name L-e-w-i-s. I'm not here to tell you any scary statistics or anything like that. I'm here to share our story with childhood cancer. It started in April of 2012. My youngest of three, Knox. It was a normal Thursday morning, got him out of his crib, went to change his diaper, saw what looked like a bruise, started to explore it, felt like a lump, got pretty scared, wasn't sure what we were going to be facing, called the pediatrician right away. That day was kind of a blur. We got an ultrasound that day and they thought it might be something but they weren't sure. They wanted us to follow up at Children's. I, myself, am a nurse. I thought, okay, I can go to work. I'll be distracted. I will get through this. Friday morning was awful. I couldn't think of anything but Knox, what could be going on with him. Ended up getting into Children's at noon that day after they told us we wouldn't get in till the middle of next week or even later that week. And by I think 5:30 that day on Friday our worst nightmare came true. We heard the words rhabdomyosarcoma. I had remembered hearing that during nursing school. I had no idea what it meant going forward for our seven-month-old son. They admitted us that night so that we could see a surgeon and a pediatric oncologist. I was very familiar with Children's but not as a patient or as a parent. So that night was very scary. The surgeon came in. He started talking about placing a central line and doing a biopsy, whether they would be able to take the tumor out, and it was just very, very overwhelming the terms that were used and I was in healthcare. We ended up seeing both the surgeon and the oncologist that night and got to go home that weekend. Monday is kind of when the reality sunk in. Knox went to surgery first thing in the morning, had his central line or his port placed, and they did a biopsy. They were pretty sure at that time that it was indeed cancer and would need to explore to stage it. So that week we did more testing and we did some bone marrow biopsies and some more scans. And by the following Monday we found out he was stage 2 alveolar rhabdomyosarcoma. Our initial consult with our oncologist, she said, you know, radiation is going to be really tricky because typically on this protocol that they set up they start radiation on week four but that's only if they're two years old and Knox was only seven months old. And so she was recommending that we go either to Boston or to Houston to get an opinion, a second opinion because there was nowhere around here that did any other kind of radiation that would be healthy tissue sparing radiation that hopefully wouldn't affect his growth or his development. So

we started chemo right away. He tolerated chemo wonderfully. This kid was the happiest of all of my kids. It didn't matter if I was coming at him with a needle because he needed his NEUPOGEN to bump up his white blood cells or, you know, if we were in the hospital. He was happy and he had a smile on his face. He responded to our initial treatment really well. We were very encouraged. We went to Houston for a second opinion, our radiation consult, and they were pleased with how things were responding. That was Friday. By Monday, he was showing signs of progression so that was like only 9 weeks into a 43-week treatment protocol. We had to switch things up. He didn't mind it. We went five days of inpatient chemo. He tolerated it just fine. Like I said, we had two other kids at home so our lives were turned upside down. What do we do with these two kids now that we're in the hospital five days, not to mention what are we going to do when we go to Houston for eight weeks? And Houston was one of our closest choices to go. Anyway, he continued through treatment and did really, really well. We left Houston after eight weeks of radiation or six weeks of radiation with probably the most optimism that we had had the whole time. Everybody was very encouraged how he had responded, how the tumor was responding. We came home for his first birthday to get chemo. By September 12 he showed signs that it was spreading in a lymph node in his groin. And on October 1 we did another set of scans and it had spread to his lungs and his liver. At that time, we didn't qualify for any studies or research that was open because it was considered a second relapse. So we had to go on a palliative care treatment. And to say that you have to put your one-year-old on a palliative care treatment was not an easy decision to make. We only did three weeks of that treatment before we were home on hospice. So Knox...we went home on a Wednesday and Knox earned his wings on Sunday night into Monday morning. [LB764]

SENATOR MELLO: Thank you for your personal testimony, Alexa. Are there any questions from the committee? Seeing none, thank you. [LB764]

ALEXA LEWIS: Thank you. [LB764]

GARY PETERS: (Exhibit 4) Good afternoon. Senator Mello, members of the Appropriations Committee, my name is Gary Peters, G-a-r-y P-e-t-e-r-s. I'm from Aurora, and I'm here to testify in support of LB764. I represent my son Jacob who died fighting cancer in 2011 at the age of 17. Pediatric cancer isn't just the smallest of children; it goes up to 19 years old. And like Senator Harms had mentioned, it's an absolute tragedy to see a child never be able to fulfill what possibilities they have for the rest of their lives. I'm also here because what happened to my son is unacceptable. Jacob was diagnosed with T-cell lymphoblastic lymphoma on January 31, 2011. He started his first chemotherapy treatment on February 4, 2011. He relapsed on June 3, 2011, so we started a new protocol. He relapsed again in August so we started a third protocol. He relapsed again in September so we restarted the original protocol and Jacob was told that he would need a bone marrow transplant. He relapsed again in October and this time he also had leukemia. The national study group that was following

his case gave up on him. They said there was nothing left to be done. They said we should try to keep him comfortable and prepare for his death. But his primary doctor did not give up. He recommended a radical protocol being developed at Memorial Sloan Kettering in New York that was meant for leukemia patients. But this treatment would be far worse than the chemotherapy that Jacob had previously endured. I don't have time to tell you all of the miseries that Jacob endured over the next four weeks, but believe me, it was hell. Ultimately this new chemotherapy did work for a short time. But just four days before the scheduled bone marrow transplant, test results showed that Jacob relapsed once again. The leukemia was in check but now the lymphoma was back. In the eleventh hour, Jacob's doctor wanted to try one last protocol, this last protocol one more time in hopes of moving forward with the transplant more quickly this time instead of waiting the two to three weeks that he was supposed to stay in remission. Even though Jacob was well aware of the horrific ordeal that he had just endured and the consequences of another round of his chemotherapy, he would not quit and wait to die so he chose to give it one more shot. That's the way he attacked this disease from the start. When the doctors told him what to expect and what his limitation would be during all these various chemotherapy protocols, Jacob liked to say, I'll do my job right; you do yours right. This last round of chemotherapy is what killed my son. I want to be very clear on that. He didn't die from cancer. The chemotherapy killed him. His body could not handle any more of the poison that was being injected. He died of sepsis and multiple organ failure on November 16, 2011. His mind and body had been ravaged by multiple massive infections, diabetes, neuropathy, lymphoma, leukemia, and the day he died we learned that he had developed a brain tumor. But he never quit. He died fighting. And to me and my family, there's a very distinct difference between losing the battle and dying fighting. Most cancer patients don't lose this battle. They fight until the end. And to me there's a difference. I like to say my son died fighting cancer. Cancer didn't win. He died giving his best effort. The total cost of Jacob's treatment was $2.4 million and ultimately it did not work. We are continuing to treat pediatric cancer patients with the same protocol over and over again. And I've been told that this protocol works 90 percent of the time. But what if you are one of the 10 percent that it doesn't work for? I have told people that Jacob always gave 100 percent effort in whatever he was doing. Giving 90 percent effort was never good enough on the football field or the track or the court. Getting 90 percent was never good enough in the classroom, and ultimately 90 percent was not a good enough rate for cure for his cancer. The definition of insanity is doing the same thing over and over again and expecting a different result, and that's where we find ourself--20 to 25 years with no major changes in pediatric cancer treatments, but we expect different results. We need help. Children need help. We lose enough children through accidents and natural disasters which we cannot control. This disease seems like something we should have better control over. I reject the notion that nothing else could be done. There has to be something better out there. I am not educated in the science of finding a cure, but I can find ways to fund those who are. The only way that we are going to help these children is through research. Research takes time and money. You as a committee can't give anyone more time, but you can give

money. This bill will not help my child, but it may help someone else's. New drugs take years to be tested and approved, and some cancer patients don't have years. My son had only 290 days from the day of his diagnosis. And I do not envy the job that lies ahead of you. There are a lot of bills that probably deserve to be funded that won't. There are other causes that probably carry more political clout than this one, but none are more noble than this one. This is a chance for you to take the lead and help find ways to protect children that are battling cancer. Recent headlines have swirled around the possibility of Nebraska changing the state slogan. The good life is what we want for our children, and this bill may grant someone the chance to live that good life. You can help fund the cure that gives a child a chance at a good, long life. [LB764]

SENATOR MELLO: Thank you for your personal testimony, Gary. Are there any questions from the committee? Senator Kintner. [LB764]

SENATOR KINTNER: Just have one question. When you say protocol, that's a set of treatments. Is that (inaudible)? [LB764]

GARY PETERS: Yeah. Jacob's original therapy called for eight months of chemotherapy at varying stages, started out once a week, then it was going to go to once every ten days, then once every two weeks. And after eight months, he would be on two years of maintenance that would be once a month and oral medications and a trip to the Med Center once a month. The second...when the first protocol didn't work, then they get... [LB764]

SENATOR KINTNER: So that whole set of treatments is a protocol. [LB764]

GARY PETERS: Yeah, that's a protocol. It's basically Dr. Gordon told us you're on board for three years. That's one protocol. When that one doesn't work, you don't keep going. You abandon and then you move on to something different that may or may not have worked. And his second protocol, I'm not 100 percent accurate on this, but I believe it's more of an adult cancer protocol. It didn't work either. It's abandoned after a month. And then at that point, Dr. Gordon even said that...he goes, I'm very good at curing pediatric cancer, but I really don't know what to do with relapsed pediatric cancer, you know. And he didn't. He was part of a national study group that was meeting and talking along with all the rest of the oncologists at the Med Center to decide what was the best way to go, you know, to give Jacob a chance to get to this bone marrow transplant sooner, you know, than what is typically expected. When you get to a certain point or you get a certain diagnosis and you need to have that bone marrow transplant, you're supposed to go through the radiation, go through the chemotherapy, go through all the different items necessary, and then stay in remission for a few weeks. You know, Jacob was told he needed to stay in remission for three weeks. If we had moved to transplant after a week, he would have been okay. He would have got to the bone marrow transplant. But that doesn't mean that it would have worked. You know, the

bone marrow transplant was the, you know, the last ditch, Hail Mary effort to try to save him. So, you know, there's just certain things that when you have to wait two to three weeks for the child that you know is not going to stay in remission, you know, and at that point that's off the table. So every one of these different chemotherapy treatments I call it a protocol because you follow the line item and you get to point A and you branch off this way. And if you don't...whatever results are here, you go to another one. And it's really, I mean they alluded to it, it's overwhelming. [LB764]

SENATOR KINTNER: Thank you. [LB764]

GARY PETERS: You bet. [LB764]

SENATOR MELLO: Seeing no further questions, thank you for your testimony, Gary. [LB764]

GARY PETERS: Thank you for your time. [LB764]

DAVID GATES: Good afternoon, Chairman Mello and members of the Appropriations Committee. My name is David Gates, G-a-t-e-s, and I am here to testify in support of LB764. We lost our beloved 12-year-old granddaughter, Cecelia Kathryn Duffy on August 22, 2012, to AML, acute myeloid leukemia. Cecelia's cancer was unusual in that we were told AML is not the type of leukemia that young children usually come down with. AML is more likely to be found in adult males as the risk for developing AML is thought to go up as we age. All the more puzzling that a beautiful 11-year-old girl should come down with it. Our daughter and her husband are determined to campaign for research of leukemia and other pediatric cancers. They have learned that pediatric cancer research is too far down on the priority list for funding. As you've heard, it receives only a small portion of research funding in the field of cancer. There are far too many unknowns and too many unusual cases like Cecelia's in the realm of pediatric cancer research. We want to do everything we can to progress toward that day when the causes will be found and a cure developed for pediatric cancers, including leukemia. No parent should have to suffer the loss of a child. No grandparent should have to watch their child lose a child. Senator Harms, you raised an issue that had occurred to me about the $1.8 million in the big picture is not a lot of money. It reminds me of what we are doing. We may not be able to do a lot, but we're going to do something. We've become heavily involved in promoting and encouraging people to donate blood because we saw firsthand how valuable blood products are to cancer patients. During Cecelia's ten-month ordeal, we...her father estimated that she probably used about 175 units of blood products. So we, as I said, we've encouraged people to donate blood. We volunteer at Ronald McDonald House. Ronald McDonald House was very important to us and supportive of us as we...family members tried to stay around the hospital and encourage Cecelia during her treatment. So, of course, we would like to see a lot more money, but $1.8 million will certainly help. So we ask you to please support LB764. For

those of you with children and grandchildren, we ask God to bless them with good health and long life. Thank you. [LB764]

SENATOR MELLO: Thank you for your testimony, David. Are there any questions from the committee? Seeing none, thank you again. [LB764]

KYLE ZART: Hi. My name is Kyle Zart. I am 17 years old and I'm also a 17-year cancer survivor. The reason why I'm sitting before you all today is mainly from pediatric cancer research. I believe that we need more research, and I'm in support of LB764. And if you guys have any further questions, I believe my mother, who will be coming up next, can probably answer them for you. [LB764]

SENATOR MELLO: Thank you for your testimony today, Kyle. Are there any questions from the committee? Seeing none, thanks for coming up today. [LB764]

KYLE ZART: Thank you. [LB764]

SHELLEY SAHLING-ZART: (Exhibit 5) Good afternoon, Senator Mello, members of the Appropriations Committee. My name is Shelly Sahling-Zart, S-h-e-l-l-e-y, Sahling-Zart is S-a-h-l-i-n-g-Z-a-r-t. I am a registered lobbyist, but today I'm here for me. For the first time in my 25 years of doing this, I am testifying personally on a bill. And there has been no bill in 25 years that has really meant more to me and you just met the reason why...one of the reasons why. I'm handing out a sheet. On one side you've got some pictures of a beautiful young girl, Genevieve Marie Sahling, was my niece. Genevieve was born in 1993 and she died in 2008 of osteosarcoma after a 3.5-year battle with cancer. And the gentleman talked about fighting. She was a fighter till the end. She fought pretty hard. One of the pictures there is from her Make-A-Wish trip to Hawaii, which she had to be medically evacuated back from the islands to the states. We thought we were going to lose her when she got back. But as kids do, she rallied pretty hard, fought some more. And in April in her small town of Kenesaw, she had a very wonderful senior boy who invited her to the junior-senior prom because he knew she wouldn't live long enough to see her own junior-senior prom. She was a freshman. And I was happy that they came to Lincoln and I got to help shop for prom dresses, which I'll never get to do because I have two boys. And we sent her off to the prom and she had a glorious evening. And then in September of that year she earned her wings. She was treated at M.D. Anderson. She had some treatments at the Med Center. She'd kind of been all over. But I'm going to tell you about the real reason that I think you should do this. There's lots of sad stories out there, and you just met a really good reason why you should do more research and that's my 17-year-old son, who was born August 21, 1996, and two months later on a well baby checkup we discovered a small mass in his scrotum that we thought was a hernia, and we took him in for hernia repair surgery. And the surgeon came out and told me it was not a hernia, that it was abnormal tissue, and the frozen section showed abnormal cells, and we were at the Med Center a day and a

half later and learned he had neuroblastoma. Neuroblastoma, you heard about that earlier. Neuroblastoma is a pretty deadly form of pediatric cancer for kids older than 12 months of age. We were lucky. So, Senator Harms, when you ask how this $1.8 million can be spent, one of the ways is let's figure out how to screen newborns for some of these cancers and let's treat them early. That kid is alive because it was caught early. He's alive because of a treatment protocol that was developed at St. Jude's Hospital, but it was...there were pediatricians from all over the country that participated in it. He received great care at the Med Center. There are all kinds of things, research that we can do. Newborn screening I think would be an awesome one. I checked recently. The treatment protocol, Senator Kintner, for neuroblastoma hasn't changed much in 17 years, all pretty much the same stuff. Worked for my kid. My kid was young. He was this big. Senator Mello, congratulations, by the way. You can relate to that. He was eight weeks old when he was diagnosed. And we ran, as the gentleman said, we ran poison through his veins to kill what the surgery couldn't get. And he sits here happy, healthy, strong, no residual effects from that. I am so lucky. I am so blessed. And my heart aches for those families who have been less fortunate. You all, you can't fix that but you can start. You can make a dent in it. You can't say no. You know, you asked how much funding is enough; how much funding is being done at the federal level? Not enough. There's not enough funding being done on cancer, period, anywhere. That doesn't mean we shouldn't do it. We have to start somewhere. And these kids deserve that. These kids deserve that we try to make a dent. I'd be happy to answer any questions. Thank you so much for your time. [LB764]

SENATOR MELLO: Thank you for your testimony, Shelley. Are there any questions from the committee? Seeing none, thank you. [LB764]

DR. DON COULTER: (Exhibit 6) Good afternoon. My name is Dr. Don Coulter. I'm an assistant professor of pediatrics, pediatric hematology, oncology, and stem cell transplant. I am here as a professional expert speaking for myself and not on behalf of the University of Nebraska Medical Center. I'd like to personally thank all the families who have come and shared with you today. They represent the front line of the war against cancer. It is a great honor to be the primary oncologist for some of these families and it's what I was made to do. So it's a privilege to serve them. I'd like to thank the committee for considering the bill before you. As you have heard, we have a crisis in Nebraska. It's a lack of supported childhood cancer research. This is not a crisis of our making, but it's one that we can improve through the creation of the pediatric cancer molecular biology and therapeutics program at the University of Nebraska Medical Center in collaboration with Children's Hospital and Medical Center. Pediatric cancer is the number one cause of death by disease for America's children. More children lose their battle to cancer than asthma, cystic fibrosis, and AIDS combined. On average, one of four elementary schools has a child with cancer. The average high school has two students who are current or former cancer patients. In 2010, the state of Nebraska ranked third in the United States in the incidence of cancer in children under 15 years of

age. In the 1950s, childhood cancer was almost always fatal. Today, advances in research have led to improved diagnosis and treatment, with the result that almost 80 percent of children with the most common types of cancer will survive their disease. While these statistics are wonderful news for most families, they hide a disturbing truth. Many families are still facing types of childhood cancers where progress has been slow, like neuroblastoma. And for some, there is currently no real hope for a cure. Overall, one in five children diagnosed with cancer will not survive. Over the last 25 years, only two drugs have been developed specifically for pediatric cancer patients. Pediatric patients today, as you have heard, are treated using medicines developed for adults. And as you've heard, those medications often cause significant side effects and secondary cancers later in life. Furthermore, there is a current crisis of funding of drug development in pediatric cancer research. Pediatric cancer research receives less than 5 percent of federal funding for cancer research. Senator Harms, in dollars that's $90 million. As a young physician-scientist, I can attest to the difficulty in securing adequate funding to pursue answers for children facing this disease and some of the investigations that I'm involved with. Pharmaceutical companies who provide approximately 60 percent of all funding for adult cancer drug development tend not to fund pediatric drug trials for a multitude of reasons. Research involving children is more complex than for adults and profitability is a challenge. The lack of resources supporting investigations into new therapies for children can have far-reaching implications, including national drug shortages of medicines that we've heard about on national news that are critical for treating pediatric tumors. So to me the solution is obvious: New therapies for pediatric cancer must be developed. However, the research required to identify these new drugs takes special expertise, time and money. Here in Nebraska, LB764 provides an opportunity to establish a pediatric cancer research program that will continue the work of identifying new treatments and providing new hope for families. The $1.8 million investment would augment the current work of a team of researchers, including clinicians like myself, geneticists, cell biology experts, pharmacists, and chemists who are currently utilizing existing resources at the University of Nebraska Medical Center and at Children's Hospital and Medical Center to determine how cancer cells behave and how best to eliminate them in children. This multidisciplinary team is already developing results through the existing scientific infrastructure of the university, including the colleges of pharmacy and medicine and the clinical facilities of Children's Hospital. However, the available resources are limited and the proposed support would improve those necessary resources. It would allow us to expand our team, broaden our expertise to utilize the most up-to-date technologies, and begin to develop a phase one clinical trial program to test new drugs in our state for pediatric cancer patients that many patients have to go elsewhere to receive. In 1927, H.G. Wells wrote that "...the motive that will conquer cancer will not be pity nor horror; it will be curiosity to know how and why." The families of Nebraska facing childhood cancer do not want our pity, but they deserve our support. The funding proposed in this legislation would allow us to continue unraveling the how and why of cancer, which will lead us to new medicines that can provide hope to the families of our state. I thank you for your time and

consideration, and I'm more than happy to try to answer any questions you may have. [LB764]

SENATOR MELLO: Thank you so much, Dr. Coulter, for your testimony. Any questions from the committee? Senator Harms. [LB764]

SENATOR HARMS: First, Doctor, thank you very much for coming. [LB764]

DR. DON COULTER: Yes, sir. [LB764]

SENATOR HARMS: And I guess definitely do not want my question misunderstood about the $1.8 million. Okay? I'm just saying that in the research world, as you know and I know, that's not a lot of dollars, though we can sure do a start. My question for you is that if we rank third in the nation for cancer, have we done any kind of analysis of where these children come? Is there a pocket in Nebraska where these children are born and growing up and has this kind of cancer? [LB764]

DR. DON COULTER: Senator, that's a really good question. I want to start off by saying that I meant no disrespect. I think that your question about what the money would do is incredibly important because return on investment is critical in anything like this. To answer your question, if it's okay with the Peters, I'd like to tell you that they come from Aurora, Nebraska. I treat a number of families from Aurora, Nebraska. I can list off three, four, five other families from that small town who have fought childhood cancer. We don't know why. The resources that you would supply through LB764 would allow us to use some research resources to look at the epidemiology of that to see if these pockets exist as you're saying. To be the state that has the third incidence in childhood cancer and not know the reasons why is something that we have lacked in looking at. And I think these resources would help us do that. [LB764]

SENATOR HARMS: I just don't think that...we can't accept this aspect of knowing that if Aurora has a high rate of cancer or other places have a high rate of cancer we need to deal with that issue. You know, I had a...I lost a mother of lymphoma cancer so I'm very familiar with this particular issue in our family. And I think as a family we finally drew the conclusion at the end that we're a product of what we breathe, what we drink, what we eat, and a product certainly of our genes. Where I live, there is I think a fairly high rate of colon cancer or other kinds of cancers, and that's why I was asking the question. If we can geographically get this thing identified where they seem to come in a pocket and then begin to zero in on what's really in that community or what's in that particular area, is it the water or, you know, is it what they eat, what the mother eats while she's carrying the baby, I don't know any of those answers. But... [LB764]

DR. DON COULTER: Senator Harms, you're asking questions that people have already began to investigate in other places around the country. But we are privileged in

Nebraska to have the equipment at the Fred and Pamela Buffett Cancer Center that would allow us to look at genes specifically and look at ways that what you're saying, what's the genetic part of the person who gets the cancer that then the environment adds to that causes that problem. Dr. Cowan is going to follow me and testify as well and he's the head of the cancer center and he would also be able to answer those questions. But you are hitting on something that these resources would allow us to pursue that currently we have had difficulty securing the funding for at the national level because of the sequester and other financial constraints. Childhood cancer is not as well represented as adult cancers. And also it would allow us to train physician-scientists like myself who would go into pediatric oncology and continue to work in Nebraska to find those answers about epidemiology and genetics. [LB764]

SENATOR HARMS: Thank you very much. I just always felt that that was a key; and if we're going to get a good handle on it, there's where we have to start. [LB764]

DR. DON COULTER: Yes, sir. [LB764]

SENATOR HARMS: I thank you for that. [LB764]

SENATOR MELLO: Is there any other questions in the committee? Senator Nelson. [LB764]

SENATOR NELSON: Thank you for coming, Doctor. I had hoped that maybe we might hear from Dr. Cowan afterwards. Let me start with a question or two about is it your hope if you can establish a research center or something that might be part of the new cancer research center down the road? [LB764]

DR. DON COULTER: Yes, sir. That's correct. The team that I refer to is already in position. We're already working with funds that I've garnered from a number of different private sources because government funds are so difficult to come by. With the Fred and Pamela Buffett Cancer Center being constructed, we would house the lab in sort of that facility but also be able to, with these resources, utilize the infrastructure that's there, augment that and allow other researchers who are here or recruit other researchers into that cancer center to assist in the fight. [LB764]

SENATOR NELSON: Screening was mentioned earlier. What...can you tell us a little about what type of screening, right after birth or something of that sort that might be a possibility of detecting the development of a childhood cancer? [LB764]

DR. DON COULTER: Yes, sir. That's true. When you think about the genetics of some of these things, some of our leukemias and lymphomas, it's possible that there's a genetic mutation that's there earlier that is just waiting for an environmental hit, if you will, to come along and signal the cancer to start. And so there are ways that we can

investigate if those are things that we could pick up earlier because many, many patients do better with their tumors when we treat them earlier on in life. Now there are screening protocols that have occurred with other diseases like neuroblastoma in the past that haven't been as useful. But none of them have looked at the genetic sequencing that we can do now. And I think that the future of research is there and that's something that we could support. [LB764]

SENATOR NELSON: Okay. We have a letter here from Cancer Action Network. I'm just interested in this statement, see what your comment would be: The causes of most childhood cancers are unknown and cannot be prevented for the most part, and then it talks about brain tumors and things of that sort. [LB764]

DR. DON COULTER: Yes, sir. Senator, if I may, I would agree with the first one wholeheartedly. We don't know because we don't look. And I would flatly deny the second. I think we can find out. I don't think that there's enough funding. I don't think, quite frankly, there's enough interest. I think these voices are small and they don't make as much noise as adult patients with breast cancer, colon cancer, some of the more common ones. I think that the first part of that statement is true. I think the second part of that statement is an excuse and we could do harder work to find that out. [LB764]

SENATOR NELSON: So prevention would be a good part of this research. [LB764]

DR. DON COULTER: There's a lot of research that has looked at things like obesity. Obesity is a very common issue that we talk about in pediatrics these days. There is definitely research that shows that obese children are more prone to have cancers, both in childhood and as they grow. So that's one thing that we could look at. The other thing is looking at somebody's specific genes that can trigger diseases like neuroblastoma or lymphoma or leukemia or rhabdomyosarcoma and what those are. There hasn't been enough investigation into that. And I think this research could be useful in starting the pathway down looking at those. [LB764]

SENATOR NELSON: And research would also look toward increasing the 80 percent survival rate to a higher rate. [LB764]

DR. DON COULTER: That's correct. [LB764]

SENATOR NELSON: Okay. [LB764]

DR. DON COULTER: The 80 percent survival rate I think is a little bit misleading in that, first of all, I always tell my families when I first meet them that I can't cure 80 percent of your child. I can only cure 100 percent or I can cure 0 percent. Statistics describe a population. They don't describe Layna (phonetic). So when you're dealing with that, I think that piece is hard. But I agree with you completely the more that we look at

pharmacogenomics, pharmacogenetics, exome sequencing, protein metabolism, those things are going to be important for increasing the survival rates that we have currently to even better survival rates. [LB764]

SENATOR NELSON: Thank you. [LB764]

DR. DON COULTER: Yes, sir. [LB764]

SENATOR MELLO: Are there any other questions from the committee? Senator Wightman. [LB764]

SENATOR WIGHTMAN: Dr. Coulter, either way ranking third is horrible. I agree with that. Are we talking on a per capita basis or are we talking on total numbers? [LB764]

DR. DON COULTER: Yes, sir. The statistic that we are the third in incidence is the number of new cases that come per year to the state of Nebraska. It would be difficult for me to piece out whether that is per capita specifically. It's just the number of cases that occur in the state of Nebraska ranks third in the United States when compared to other states. [LB764]

SENATOR WIGHTMAN: That almost sounds like you're talking total numbers instead of per capita, which... [LB764]

DR. DON COULTER: That's what I believe, sir, yes, sir. [LB764]

SENATOR WIGHTMAN: Thank you. [LB764]

DR. DON COULTER: Yes, sir. [LB764]

SENATOR MELLO: Seeing no further questions, thank you so much for your testimony, Dr. Coulter. Any other proponents for LB764? [LB764]

KENNETH COWAN: Chairman Mello, distinguished members of this committee, good afternoon. I am Dr. Kenneth Cowan, K-e-n-n-e-t-h C-o-w-a-n, and I serve as the director of the Fred and Pamela Buffett Cancer Center at UNMC and I'm also a medical oncologist at UNMC. I'm honored to be here today speaking in support of LB764 and thank you for the opportunity to appear before this committee. Before I begin my formal testimony, my statement, I would like to take a moment to acknowledge the many families from across our state who are facing unfathomable reality of having a child diagnosed with cancer, many of which have already testified today. And to honor these brave young women who are full of courage (inaudible) let me say that I really appreciate being able to speak here. Let me also say that I'm speaking today as a physician and a private citizen and not on behalf of the University of Nebraska Medical

Center or the University of Nebraska. Let me be clear. I want to thank the committee for considering this bill which would provide much-needed support for research in pediatric cancer in Nebraska. As you already heard from Dr. Coulter, one of our recently recruited faculty to UNMC, and you can see what good judgment we have in recruiting fine talent like Dr. Coulter, as you are aware as he said, more children die of cancer than any other disease. The incidence in childhood cancer has been increasing annually, and the incidence rate of increase in childhood cancer is actually increasing faster than in any other age population other than those people over age 65. So it's increasing every year. And in these young children, for some reason the incidence of cancer is increasing higher than in other age groups. And as Dr. Coulter mentioned, Nebraska does rank third highest in the nation in the incidence of childhood cancer, and that is per population. But still, it's a statistic that if you look on the national Web sites is out there for us to study as part of the research of why this is happening. As you know, we are very fortunate and we are currently in the process of constructing a new cancer facility at UNMC, a Fred and Pamela Buffett Cancer Center, which will integrate cutting-edge research in cancer with clinical care of cancer. With generous support provided by the state of Nebraska--and we again thank Senator Nelson for helping to lead the effort, as well as all of you who have participated in supporting that--fund-raising also for the cancer has completed and construction of the facility which is scheduled to open in 2017 is now underway. The new cancer center will actually have one research area dedicated solely to pediatric cancer research. In addition, other areas dedicated to research in cancers that are common in children, including leukemia and lymphoma and brain cancers, are also dedicated parts of the research enterprise of the new Fred and Pamela Buffett Cancer Center. Most importantly, the new cancer center will have and does have today state-of-the-art technology including next generation DNA sequencers, which will allow researchers and clinicians to analyze the cancer genome of every single patient, including pediatric cancer patients, in real time, opening up incredible opportunities and avenues to design, develop, and test new less toxic and more effective therapies than the standard chemotherapy and radiation therapy that we've been treating cancers with, including pediatric cancers, and have so many toxicities in the past. Understanding the cancer genome, the DNA sequences that are mutated in the normal cell to drive malignancies to grow, is key to developing precision cancer treatments for every patient. This technology provides specific information that will enable clinicians to prescribe specific treatment plans for each patient using agents that are custom designed to target those mutations and drive the growth of these cells. We are committed to saving lives of children diagnosed with cancer. Funding from LB764 would allow us to help build a new...recruit new faculty to UNMC and to the cancer center to expand clinical translation research in pediatric cancer and enable physicians to pursue new agents to target genetic mutations found in pediatric cancer patients here in Nebraska. Importantly, it will give hope to pediatric cancer patients and their families who are living with the devastating news that a child has been diagnosed with cancer are looking to us for hope and all that we can do. Thank you very much. [LB764]

SENATOR MELLO: Thank you so much for your testimony, Dr. Cowan. Are there any questions from the committee? Senator Kintner. [LB764]

SENATOR KINTNER: Thank you for coming and thank you for the wonderful work you do. So if we appropriate $1.8 million, can you give me an idea of what it will do? How long does that $1.8 million continue to fund the program, number one? Number two, when the $1.8 million is gone, where does the next money come from? [LB764]

KENNETH COWAN: Very, very good question. Number one, as an example of the Fred and Pamela Buffett Cancer Center and the money that was appropriated from the state to help us build this, $50 million, we are now completing construction of a $370 million building which was also the largest public-private partnership in the history of the University of Nebraska. We now raised an additional start of $26 million to help recruit additional new faculty. So we would leverage the amount of money targeted specifically to pediatric cancer if this bill passes to help recruit in the community additional funds to add to that pediatric cancer focus. But even the $1.8 million and some money that we would have appropriated, we would be able to recruit at least two new faculty, research faculty targeting this. Our research faculty at the university are expected to bring in at least $1 million to $2 million a year with the research funding per year. So we would have that sustainable for people who would come here and bring...we would hope to add additional funds to that to be able to recruit additional faculty because even with the faculty we have like Dr. Coulter and the group that he's put together we would need more than two additional people to do that. But we would commit our resources to help sustain that. [LB764]

SENATOR KINTNER: The other programs you have, where do you get funding for those programs? I don't know what programs they are... [LB764]

KENNETH COWAN: Sure. [LB764]

SENATOR KINTNER: ...but just taking a couple two or three programs, where does that funding come from? [LB764]

KENNETH COWAN: Yeah. So, for example, as you know, we are very strong in lymphoma-leukemia research at the University of Nebraska bone marrow transplant program that was started back in 1982. Over 4,500 patients have now received bone marrow transplant at the University of Nebraska. We have research funding from the federal government to help support that program, and faculty and clinical revenue from the hospital also help support some of the clinical activities and clinical research activities in that program. Pancreatic cancer is another high-profile program in the cancer center. We have five of the largest grants from the National Cancer Institute in pancreatic cancer. We have just recruited a new surgical chief of oncology who is head

of pancreatic cancer from the Massachusetts General Hospital in Boston, Dr. Sarah Thayer. She'll be arriving on our campus May 1 to help us extend this program as well. So we recruit faculty who also bring research grants with them. They bring research teams with them to Nebraska. Over 100 new faculty have been recruited to the cancer center over the last decade. We expect with the new cancer center to recruit 100 additional new faculty. We expect those faculty to lead to $100 million a year in extra revenue, both clinical revenue and research funding after...within five to ten years after the opening of the cancer center building. [LB764]

SENATOR KINTNER: Does the state fund any other programs like we would fund this? [LB764]

KENNETH COWAN: The state does provide funds to the university and to the cancer center specifically. There's a bill, LB595, that actually does provide some cigarette sales tax to the cancer center. It's been in effect since 1979 I believe, hasn't increased at all since about 1979. So we do receive some money to support the cancer center and that's helped us obviously recruit some of our faculty and sustain some of the research funds we have. [LB764]

SENATOR KINTNER: One more question. [LB764]

KENNETH COWAN: It's $1.3 million. [LB764]

SENATOR KINTNER: You're going to obviously leverage this money for other monies you can get the ball rolling. Will you be back for more money or will this do it for you? [LB764]

KENNETH COWAN: I'm a private citizen. I'm not here asking for any money right now. I'm supporting the bill. And everything helps to get us started and build a program. And whether we get this bill or not, we'll continue to work to support additional efforts in pediatric cancer research. This will help us get started and be active this year in recruiting additional faculty this year to sustain this effort in pediatric cancer research. [LB764]

SENATOR KINTNER: Point well taken. I understand. Thank you very much, appreciate it. [LB764]

SENATOR MELLO: Are there any questions from the committee? Seeing none, thank you, Dr. Cowan. [LB764]

KENNETH COWAN: Thank you very much. [LB764]

SENATOR MELLO: (Exhibits 7, 1, and 8) Any other proponents for LB764? Seeing

none, the committee received letters of support for LB764 from the Nebraska Hospital Association, the American Cancer Society Cancer Action Network for Nebraska, and a letter of support from Al Guenther to be read into the record. Is there anyone here in opposition to LB764? Seeing none, is there anyone here in the neutral capacity for LB764? Seeing none, Senator Conrad, would you like to close? [LB764]

SENATOR CONRAD: Yes, briefly. Thank you, Senator Mello. Thank you, colleagues, for your kind attention and careful consideration to this important issue this afternoon. I want to extend my extraordinary gratitude to all who came forward and shared their powerful personal stories on behalf of this effort. And I think that you will share my excitement and intrigue with all of the good things that are happening at UNMC when it comes to making gains in research and treatment in our battle against cancer. And just a very couple quick points that I just want to wrap up and make clear on the record. In the legislation, there is a reporting requirement to ensure that we can have full accountability on each of the dollars that are expended under this program and to evaluate how they were utilized. That was a suggestion from the Ahlschwede family which we incorporated into the bill. So I thank them for that effort. Additionally, this is a one-time transfer under this legislation. But again, we do have to start someplace and particularly with that shockingly high number, that number three in the country in terms of how this issue is affecting our children. You know, it's a first step. And I will rely on people like you, Senator Kintner, and people like you, Senator Bolz, Senator Mello, and Senator Nordquist, to carry on this work and this battle after some of us leave in the 2014 Session. And you heard me say many times as an eight-year veteran of the Appropriations Committee that a budget is a moral document and it sets forth what our priorities are as a state. It puts a value, it puts a price tag on what we prioritize. And in those eight years of service to this committee and to this Legislature, I'll tell you I'm not sure if there is a more meaningful piece of legislation that I've worked on. This is a moral imperative. We do have the resources available at this stage in time to take the first step. And I agree--$1.8 million is probably a small number. And if we need to negotiate upward, I'm more than happy to work with the committee in that regard. But when we were visiting about that topic in my office prior to the hearing, the families noted that it's going to take additional private dollars. It's going to take additional public investments. But $1.8 million represents a lot of bake sales and a lot of head shavings and a lot of the current ways that we're currently raising money to support pediatric cancer research that are important and not to diminish those wonderful private efforts. But I think what I want you to take away from this is something that one of the doctors noted. These families do not need our pity. They need our power. We are empowered to take positive action, to take collective action to make a difference. Let's pitch in $1 for each Nebraskan as we move the ball forward in battling cancer and pediatric cancer in particular. With that, I'm happy to answer any questions. [LB764]

SENATOR MELLO: Thank you, Senator Conrad. Are there any questions from the committee? Seeing none, thank you. [LB764]

SENATOR CONRAD: Thank you. [LB764]

SENATOR MELLO: That will close today's public hearing on LB764 and lead us to our last bill hearing of the day, LB1051 by Senator Howard. [LB764]

SENATOR HOWARD: Are you guys taking a break? [LB1051]

SENATOR MELLO: No. [LB1051]

SENATOR HOWARD: Okay. [LB1051]

SENATOR MELLO: We are ready and willing to hear LB1051. [LB1051]

SENATOR HOWARD: Okay. [LB1051]

SENATOR NORDQUIST: Do you want us to? [LB1051]

SENATOR HOWARD: (Exhibit 9) No, I'm...yes. Yes. (Laugh) All right. Okay. Good afternoon, Chairman Mello and members of the committee. For the record, I am Senator Sara Howard, H-o-w-a-r-d, and I represent District 9. Today I bring you LB1051, the Public Health Leadership and Development Act. I also bring an amendment. Are there any pages? I'll just pass it down. An amendment that substantially changes the scope of the bill, so I would first like to address the amendment. Originally, LB1051 established a pilot certification program for community health workers and provided investment in the Office of Public Health Practice. In conversations with public health professionals, after the bill was drafted, it came to my attention that the pilot program for community health workers may not be ready for prime time. It also may be ripe for a 407. And so because of those concerns, I have agreed to eliminate those sections of the bill and take a look at the community health worker certification concept over an interim study. What remains of LB1051 is an investment in UNMC's Office of Public Health Practice for the purpose of public health work force development. Public health workers are essential to our state's health infrastructure. They serve in critical capacities, preventing and monitoring the spread of disease, protecting against bioterrorism and environmental hazards, helping the state and localities respond to and recover from natural disasters, reducing injuries, and promoting healthy behaviors, to name a few. Nebraska's public health system has undergone a remarkable transformation in the last decade. Only 22 of Nebraska's counties were served by a local public health department prior to the 2001 passage of LB692 that used tobacco settlement funds to fund 16 new multicounty agencies. By 2004, all of Nebraska's counties were covered by a local or regional public health department. Nebraska's new public health system serves predominantly rural areas. I want to highlight how critical the public health work force is in this state. Many of you may not recall the serious threat that the H1N1 was in 2009. In the face of the H1

epidemic, H1N1 epidemic, Governor Heineman declared a state of emergency. He suspended any laws and regulations that would get in the way of dealing with the epidemic and made sure that Nebraska would have access to the strategic national stockpile of vaccine if needed. Discussing it now, it sounds like a doomsday scenario, and it could have been were it not for the quick and professional work of state and local public health departments and their professionals. When infected Nebraskans were discovered, local public health departments and DHHS worked with medical professionals to make sure that proper treatment was given and steps were taken to mitigate the likelihood of disease spread. When vaccine was released from the strategic national stockpile, public health officials were responsible for planning effective distribution of the vaccine throughout the state. And all of this work occurred in the very first month of the outbreak in local health departments across the state, where only 25 percent of the directors said they had enough staff to manage the current workload, which magnifies the need of work force development opportunities. This is in fact exactly what the Office of Public Health Practice does and where this funding would go. The office works with local health departments on work force development. It provides a link between local public health and academic institutions, as well as direct technical assistance for organizational improvement and development. The office works with the universities and colleges to provide public health practical experience to students, houses the Public Health Practice Council, supports practice-based collaborative projects, and puts on the region's foremost and only Institute for Public Health Leadership and development, of which myself, Senator Cook, and our Chief Medical Officer Dr. Joe Acierno are all graduates. Over the last year, the Office of Public Health Practice has offered education and training opportunities and technical assistance throughout Nebraska for the current public health work force. In the past 12 months, office faculty and staff conducted over 20 trainings with 200 individuals in state health departments, nonprofits, and FQHCs, federally qualified health centers. The office has also been intensively assisting a number of local health departments with work force development plans. This is an important activity, as local public health departments prepare for national accreditation, which will most likely be tied to federal resources in the future. And yet, for all of that important work, the Office of Public Health Practice remains critically short of the funding necessary to continue operating. There will be testifiers behind me who will speak to the Office of Public Health Practice's work and the work force need, and I appreciate you taking the time to listen to their testimony. I thank you for your consideration of LB1051 and I would be happy to take any questions you may have. [LB1051]

SENATOR MELLO: Thank you, Senator Howard. Are there any questions from the committee? Senator Harms. [LB1051]

SENATOR HARMS: Senator Howard, thank you very much for your testimony. Well, just looking at your bill, who actually is going to do the teaching? [LB1051]

SENATOR HOWARD: There are two folks at the Office of Public Health Practice and they're both trained to be educators for the public health departments and their staff. [LB1051]

SENATOR HARMS: Will these individuals that go through this become certified? Is there any way that's going to be tied in academically to the college side? I mean they got to go through this training and would it be applicable towards other kinds of certification in a postsecondary institution of higher education? [LB1051]

SENATOR HOWARD: Are you asking about the community health worker certification? [LB1051]

SENATOR HARMS: Yes. [LB1051]

SENATOR HOWARD: That portion has been removed from the bill with the amendment, unfortunately. [LB1051]

SENATOR HARMS: Oh, okay, I'm sorry. [LB1051]

SENATOR NELSON: This is all that's left here. [LB1051]

SENATOR HARMS: Oh, I got it. Okay. Thank you. [LB1051]

SENATOR HOWARD: Actually, I'm very excited about a community health worker certification program,... [LB1051]

SENATOR HARMS: Oh yes. Got it. [LB1051]

SENATOR HOWARD: ...and so it was a little heartbreaking to lose it. But I do think if it's a medical profession, it probably would need to go through a 407. And they're all great questions. [LB1051]

SENATOR HARMS: Okay. Thank you. [LB1051]

SENATOR HOWARD: Thank you. [LB1051]

SENATOR MELLO: Is there any other questions from the committee? Seeing none, thank you, Senator Howard. [LB1051]

SENATOR HOWARD: Thank you. [LB1051]

SENATOR MELLO: We'll first take proponents of LB1051. [LB1051]

BRANDON GRIMM: Good afternoon, Chairman Mello and Appropriations Committee members. My name is Brandon Grimm. I'm the director of the Office of Public Health Practice at the University of Nebraska Medical Center, College of Public Health. I'm speaking as an individual in support of LB1051, the Public Health Leadership and Development Act, and do not represent the University of Nebraska. I believe all Nebraskans should expect and demand the public health work force in our state has the capacity to protect and promote the public's health. Over the past nine years, the Office of Public Health Practice in the Great Plains Public Health Leadership Institute have assisted in meeting many of the professional development needs of public health workers throughout Nebraska. Since its launch in 2005, the Great Plains Public Health Leadership Institute, a yearlong leadership development program, has graduated 151 individuals, 119 of them from the state of Nebraska. Graduates have worked in five main areas: state and local health departments, academia, nonprofits, and healthcare. The Leadership Institute has resulted in a cadre of leaders throughout the state, including our state health officer and both of his deputies. The Leadership Institute has also resulted in a number of successful team-based projects related to obesity, STDs, maternal and child health, boards of health, dental health, and school-based health centers, among many others. The Leadership Institute is the cornerstone program of the Office of Public Health Practice, which was formally established in 2012. One of the main purposes of the office is to provide high-quality work force development opportunities for public health. In 2013 alone, the office offered education training opportunities, technical assistance, and strategic planning throughout the state of Nebraska, reaching over 200 individuals in nonprofits, local and state health departments, and federally qualified health centers. Additionally, the office coordinated student field placements for local health departments, placing 20 students in the last two years. The office is also the administrative home of Nebraska's Public Health Practice Council. The mission of this council is to establish and enhance shared partnerships between academe and practice-based partners in Nebraska in an effort to increase the capacity of public health workers to improve the public's health. In addition, over the last 18 months, the office has been assisting a number of the local health departments with creating work force development plans necessary for accreditation. The process included developing an education and training needs assessment, collecting data for health department staff, analyzing the data, and generating a report on the development needs specific to that health department. The most needed skill sets that we found were financial planning and management, cultural awareness, analytical and assessment, leadership and system thinking, and communication. LB1051 will provide work force development opportunities to our rural and urban public health professionals in the skill areas most needed in our state. Providing these services to the work force will assure they have the capacity to impact the public's health in communities where they live, work, and play. Thank you for your time and consideration. I'll be happy to answer any questions you have. [LB1051]

SENATOR MELLO: Thank you for your testimony, Brandon. Are there any questions

from the committee? Seeing none, thank you. [LB1051]

BRANDON GRIMM: Thank you. [LB1051]

SENATOR MELLO: Next proponent. [LB1051]

KERRI PETERSON: Hi. My name is Kerri Peterson, P-e-t-e-r-s-o-n, and I come representing myself as a past graduate and alumni of the institute. As Sara alluded to, public health is more than just keeping the public in good health. It really is looking systematically across our community to improve the health. When we sometimes think about public health, I don't think it's very obvious to people how and where it does impact us, from emergency preparedness, as Sara alluded to, whether it's tornado, whether it's flu epidemic, in Douglas County there's been an STD epidemic, but it's also the role that public health plays in community planning. It is public health physicians. It takes so many different angles. I'm here today not as a traditional public health worker but in my former life was an executive director of a nonprofit called Live Well Omaha, which was a collaboration of not only health agencies but over the years we also brought business aboard: Union Pacific, we brought ConAgra, the chamber of commerce. Why? Because we realized that if we really were going to improve the health of our community, it took all sectors. It took an across disciplinary approach to create health in our communities. It wasn't just going to happen if we left it only and solely to the medical care providers. As an alum, we learned that in the institute. It is so important to be able to develop those skill sets to look at health not just from our physical role but the role as a corporation, how I can create an environment that promotes health. It teaches you how to look and use data. It reaches across so many different disciplines as important. And when you look at a state like Nebraska, if you look at the United States that has poor health outcomes despite, despite all the medical resources, we have to start doing business differently and continue to invest in public health. There are over 100 alumni that can be called on at any time for public health supporting it in the state of Nebraska, and it's so important to continue to invest in that infrastructure. The institute serves a niche that is unmatched in Nebraska and I would venture to say in several other states, and it's very valuable. Any questions? [LB1051]

SENATOR MELLO: Thank you so much for your testimony, Kerri. Are there any questions from the committee? Seeing none, thank you. Next proponent for LB1051. [LB1051]

DAVID O'DOHERTY: (Exhibits 10 and 11) Good afternoon, Senators. My name is David O'Doherty, D-a-v-i-d O-'-D-o-h-e-r-t-y. I am the executive director of the Nebraska Dental Association, representing 75 percent of Nebraska's dentists. I just want to thank you again for last year's dental director appropriation. We really appreciate that. We don't have the position filled yet but we're hopeful. This testimony might be a little bit off from the...based on the amendment I just heard about, but I still think it's important

testimony supporting a community health worker that was the genesis of LB1051. We don't think it's just a good idea and hope that it will work. We know that it's a good idea and we know that it will work. But how do we know that? Access to care for the underserved populations is a complex problem. We know that improving the administrative side of Medicaid, like that of private insurance, improves access. We know that increasing provider reimbursement fees improves access. We also know that including a community health worker as part of the healthcare team improves access, and we know that because in 2006 the American Dental Association started a pilot program for a community health dental health worker. It was based on the current model of...and built upon the community health worker's proven success by layering on an oral health component with the focus on patient education, disease prevention, and patient navigation to improve access to dental care. The ADA invested more than $7 million in the CDHC pilot program. In October 2010, the first class of ten students completed their training and began working in tribal clinics, urban and rural FQHCs, Indian Health Service facilities, and other settings. Eight students graduated in the next class in 2011, and followed by sixteen students who graduated in 2012. In order to save several trees, I only printed one copy of this study that was done by the University of Alabama that evaluated the pilot program. It was completed in 2012 and includes 46 case studies. More than 11,000 patients have been served by CDHCs, generating $1.85 million in revenues at the clinics that employed them. This evaluation also determined that the CDHC model is sustainable in most clinical settings, and the CDHCs generate revenue through outreach activities. Presently, CDHCs are employed in seven states: Arizona, Wisconsin, Minnesota, Oklahoma, California, Montana, and Pennsylvania. Ongoing activities have resulted in the interest in pilot programs in several other states. In May 2013, a pilot program trainee began a sabbatical at an FQHC in New Mexico to demonstrate the skills and outreach opportunities that a CDHC can bring to the dental team. A sabbatical could bring a trained CDHC to a FQHC to work anywhere from one to four months to demonstrate how effective a CDHC can be to the clinic. Nebraska could access a sabbatical for the same purpose. The CDHC's role is proven as a financially viable form of community outreach, as an educator, a patient navigator to improve access to care significantly in areas of underutilization. The next step is to experience more widespread utilization of this model as a demonstrated answer to the access problem. LB1051, as now amended, I hope will be included in this study or in the future. Thank you. [LB1051]

SENATOR HARMS: Thank you for your testimony. Do we have any questions? Yes, Senator Nelson. [LB1051]

SENATOR NELSON: Thank you. I just want to eliminate confusion on my part. You are talking about pilot programs... [LB1051]

DAVID O'DOHERTY: This... [LB1051]

SENATOR NELSON: ...with this? Is this in existence now? [LB1051]

DAVID O'DOHERTY: This is currently in existence. It's been in existence for several years. [LB1051]

SENATOR NELSON: Okay. But is it under the...I mean is it receiving funds or is it under the supervision of the work force? [LB1051]

DAVID O'DOHERTY: It's under the supervision of someone in usually a FQHC. It's in various situations but FQHC would be a common one or an Indian tribe. In this case, it would be generally under the supervision of a dentist that might work in the FQHC. But it's not just focused solely on dentistry. It's the health of... [LB1051]

SENATOR NELSON: Okay. [LB1051]

DAVID O'DOHERTY: ...the, you know, of the patient. And one of the clinic directors said, I don't care what their clinical abilities are; I just need someone to help navigate patients into the clinics. The clinic is no different than a dental office. If the chair is empty, the clinic isn't making any money. So if they can educate patients on preventative measures and get them...to help them to navigate to a clinic for preventative health service, we all save money. And the important thing is this study shows...be happy to, if anyone would like to read it, it shows that it's profitable in a number of different clinical settings and different payer mixes: Medicaid, sliding fee scales. So it's not like it's a black hole of funding that keeps, you know, to keep this person going. They're actually making the clinic money. [LB1051]

SENATOR NELSON: All right. Thank you. [LB1051]

DAVID O'DOHERTY: Uh-huh. [LB1051]

SENATOR HARMS: Thank you, Senator Nelson. Do we have any other questions? Seeing none, thank you very much for your testimony. [LB1051]

DAVID O'DOHERTY: Thank you. [LB1051]

SENATOR HARMS: Do we have anyone else who is a proponent of LB1051? Welcome. [LB1051]

DAVID CORBIN: (Exhibit 12) Thank you. Members of the committee, my name is Dr. David Corbin, and I'm on the board of the Public Health Association of Nebraska, and I was one of the editors and contributors to the document called "The Nebraska Public Health Improvement Plan: A Statewide Plan for Public Health Partners and Stakeholders to Improve the Health of Nebraskans." This report was approved in

December of 2008, and was followed by another report entitled "The Nebraska Public Health Improvement Plan." Both initiatives convened scores of public health stakeholders to address Nebraska's public health need. LB1051 clearly addresses important needs for Nebraskans public health work force. Both reports talk about how the implementation, which you heard earlier, of LB692 in 2001, which, by the way, before that, Nebraska was, in public health, we were at the bottom of the states. And we are now looked at as a model for the way we spent the tobacco settlement dollars. Since that time, we've greatly strengthened and transformed Nebraska public health infrastructure. In addition, the creation of the UNMC College of Public Health, which I taught for at one point, has increased the public health work force and greatly expanded participatory research studies. However, there are still many gaps that need to be filled. A standardized model for assessing work force needs is needed. The public health work force requires continuing education to meet emerging public health needs. I was here for the previous testimony on the other bill and I might give a quick example. They were talking about epidemiology and now that we have health departments, district health departments that cover all the counties, this would be an excellent opportunity to do epidemiological studies to find out, well, why is there a higher incidence of pediatric cancer, for example, in certain pockets of the state and in the state as a whole. The leadership and assessment of that would be...would work greatly in complement with that bill. We also have an aging public health work force. Many of the health workers, like I have retired, will retire in the next five to seven years. While many of these workers will be replaced, some positions may not be filled or they may be replaced by staff with considerably less experience. And there are shortages of public health professionals especially in rural areas. The public health work force needs standardization training and education to meet many of the core public health competencies. The Public Health Association of Nebraska welcomes initiatives that provide work force development. PHAN has a strong partnership with UNMC and has worked collaboratively with them on providing public health work force development opportunities. In Region VII--which includes Missouri, Iowa, Nebraska, and Kansas--we work with other public health associations and universities to develop stronger work force opportunities for Nebraska by sharing resources. LB1051 will allow for greater collaboration at the local, state, and regional level to promote public health education, leadership, and assessment. Thank you. [LB1051]

SENATOR HARMS: Thank you, Dr. Corbin. Do we have any questions for Dr. Corbin? If not, thank you very much for your testimony. [LB1051]

DAVID CORBIN: Thanks for the water. [LB1051]

SENATOR HARMS: You're welcome. Do we have any other proponents? [LB1051]

LAZARO SPINDOLA: Good afternoon. [LB1051]

SENATOR HARMS: Welcome. [LB1051]

LAZARO SPINDOLA: (Exhibit 13) Thank you for receiving me today, members of the committee. For the record, my name is Lazaro Spindola, L-a-z-a-r-o S-p-i-n-d-o-l-a. I am the director of the Latino American Commission, but I am not testifying today in that position. I'm testifying as a private citizen. You've heard from academia, so I'm just going to say a little about my personal experience with public health. In 2001, Nebraska allocated tobacco settlement money to create public health departments that would cover the whole state. In that time I was the member of a local board of health and I was appalled at the fact that there was a terrible scarcity of individuals, members of those boards, who knew anything about public health. The first time...and I also was not aware of the amendment that had been done to this bill, but the first time that I functioned as a community health worker, I was a medical student and there was an equine encephalitis outbreak in Venezuela, and my job was to ride on an Army jeep with a shotgun and kill every donkey that I could see, because they were the vectors. When I got to the first village or little town and I saw a bunch of angry farmers with machetes asking me why was I killing their donkeys, which were their work animals, I began to learn about cultural competency. So it's not a matter of just enforcing public health. It's a matter of educating public health individuals on a number of competencies, on a number of activities that they need to master in order to gain the support of the population. In the case of public health workers, of community health workers, I had the chance to supervise several of them that would deal with issues such as maternal and child health, chronic disease prevention. And in this particular area we need to focus here in Nebraska because our population is aging. And I managed to supervise workers that would deal with diabetes prevention, high blood pressure prevention or limitation, asthma, etcetera. And the cost-effectiveness, I know that Senator Kintner is always concerned about cost-effectiveness, and I got me a 651-page report from the Agency of Healthcare Research (laugh) that talks about that. But I did not print it out because I didn't have the time. Somehow I lost track of the bill. I wasn't really prepared for it. Public health deals with the health of populations and this is not the same as the health of the individual. Public health deals with preserving life and health among our whole population. And in this sense, I think Nebraska has made a lot of advancements, but it also has a lot of work to do. And probably would rely on the scholars of public health for that. I urge you to consider LB1051 positively and advance it. Thank you. [LB1051]

SENATOR MELLO: Thank you for your testimony, Director. Are there any questions from the committee? Seeing none, thank you, Director Spindola. [LB1051]

LAZARO SPINDOLA: Thank you. [LB1051]

SENATOR MELLO: Are there any other proponents for LB1051? Seeing none, are there any opponents to LB1051? Any opponents? Seeing none, is there anyone here in the neutral capacity for LB1051? Seeing none, Senator Howard, would you like to

close? [LB1051]

SENATOR HOWARD: I'll be very brief because I know I'm your ticket out of here. But I just want to say thank you for listening. Public health is critical in our state and I think it's often overlooked, especially because we don't need it until we have a disaster. We don't need it until we have an epidemic. And I'm very excited at the opportunity to spend the interim working on a community health worker certification program, especially with dentists, which is a critical area of shortage for us as a state. And I appreciate your thoughtfulness in considering supporting the Office of Public Health Practice and the critical work force development work that they're doing to help public health departments receive national accreditation for their work force plans and prepare them for the potential for federal funding in the future. I'm happy to answer any questions you may have. [LB1051]

SENATOR MELLO: (Exhibits 14, 15, and 16) Thank you, Senator Howard. Is there any questions from the committee? Seeing none, for the public record the committee received a letter of support from the East-Central District Health Department, signed by Rebecca Rayman; received a letter of support from Margaret Brink, the president of Four Corners Board of Health; and received a letter in the neutral capacity from the Department of Health and Human Services for LB1051. [LB1051]

SENATOR HOWARD: Thank you. [LB1051]

SENATOR MELLO: Thank you, Senator Howard. That will close today's public hearing on LB1051 and end the Appropriations Committee hearings for the day. Thank you. [LB1051]