Judiciary Committee November 14, 2014

# [LR433]

The Committee on Judiciary met at 1:30 p.m. on Friday, November 14, 2014, in Room 1113 of the State Capitol, Lincoln, Nebraska, for the purpose of conducting a public hearing on LR433. Senators present: Colby Coash; Al Davis; Amanda McGill; and Les Seiler. Senators absent: Brad Ashford, Chairperson; Steve Lathrop, Vice Chairperson; Ernie Chambers; Mark Christensen.

SENATOR COASH: Okay. Well, that's nice, everything got nice and quiet. All right. Well, welcome to the Judiciary hearing. We are here on an interim resolution, LR433. Before we get started, a couple of housekeeping duties and introductions. If you have a cell phone...I hear a lot of people shutting those off. Please continue to do so. We are...let me introduce my colleagues who are here. I'm Senator Coash; I'm not the Chair of the committee, I'm the Vice Vice Chair, I guess today. So in Senator Ashford's absence, I'm going to chair this hearing today. To my far right is Senator Davis and we also have Senator McGill from Lincoln. We have our legal counsel, Diane, and our committee clerk, Oliver. And Senator Crawford is here to introduce the resolution. Following her introduction we do have a list of invited testimony. The first testimony will be via a call in, which we will listen to and get on the record. And then following that, I have Dr. Madhavan, Shelley Gillen, Sheriff Davis, Senator Davis is going to make a few comments as well. And then after that, we will open it up to public hearing. Can I get a show of hands of how many people intend to testify? Okay. With that in mind, we are going to use the light system, okay? And what the means is that when you see the green, you're good to testify; yellow means you've got a minute left; and when the red light comes on, we'll cut you off. I'm sure a lot of you have similar testimony. We don't want to stifle any debate, but I would ask that you keep in mind what other folks are saying and if you have something to add, please come up and testify. For those of you who want to, to get on the record you do not have to testify. You are welcome to sign in and at least show your presence for the hearing. This is not a bill, so we don't have proponents and opponents, but you can certainly indicate your presence here. And the

Judiciary Committee November 14, 2014

committee will be glad to take any materials and use those as part of the record as well. So with that in mind, Senator Crawford, we'll recognize you to open up on LR433. [LR433]

SENATOR CRAWFORD: Thank you, Senator Coash, and thank you for being here to run the hearing. Good afternoon, members of the Judiciary Committee. My name is Sue Crawford, S-u-e C-r-a-w-f-o-r-d, and I represent District 45 of Bellevue, Offutt, and eastern Sarpy County. Thank you for the opportunity to appear before you today to share the results of our interim study, LR433, regarding issues surrounding the use of cannabidiol or CBD oil to treat patients with intractable epilepsy. I first learned about this issue from Shelley and Dominic Gillen who attended a town hall meeting I held last November with their son Will. The weather that night at the town hall meeting was terrible, yet Shelley, Dominic, and Will were among those who braved the weather to attend. I invited them to share their story at the town hall and promised to do some research. Since that time I have heard many more stories of Nebraskan families like the Gillens who have a child or close family member who suffers from intractable seizures. Some of these families are here today to share their experiences. I think you will find their stories as compelling as I have. As I dug into the research on CBD and intractable epilepsy as I had promised to do, I became more convinced of the need to provide some way for patients in Nebraska with the most severe and untreatable forms of epilepsy to access CBD. After learning that a prominent pediatric neurologist from the flagship university in Utah came out in favor of a CBD bill in that state in 2013, I decided to draft a bill to submit in 2014. Bills were introduced in several other states last year as well. However, in the midst of the busy session and in the early days of the CBD debate, we did not have top neurologists from Nebraska on board yet last year. So I pulled the bill in 2014 so that we could have time to develop a sound policy and learn from other states. We have had time, thanks to this interim study and the hard work of so many in this room, to dig into the details of creating a cautious and compassionate pilot project. We are still crafting the draft that will be introduced next year. So this hearing provides an opportunity to hear suggestions and concerns as we craft that bill.

Judiciary Committee November 14, 2014

Before I continue with my testimony, I want to clearly state for the record that the focus of our interim study and the focus of legislation we intend to introduce next session, is a narrow pilot study for patients who have intractable seizures and who have tried other treatment options. These patients must receive approval by neurologists participating in the study and the only substance that the bill would authorize for these patients is a substance that contains .3 percent THC or less. Several committee members may recognize this level of THC, .3 percent or less, as the level that legally defines hemp from our discussions of Senator Wallman's industrial hemp bill that passed last year. THC is the ingredient in marijuana that creates the high. THC is also the ingredient in marijuana that has been the focus of some recent studies of the dangers of marijuana on the brain, particularly for youth. The fact that the treatment for intractable epilepsy uses CBD and not THC means that the substance has no value for recreational diversion and that it does not pose risks that may be associated with THC use. The main objection I've heard against moving forward with the CBD policy in the state is that we should not allow treatments that are not FDA approved. There is an effort to conduct clinical trials for a CBD pharmaceutical product called Epidiolex, produced by GW Pharmaceuticals. The FDA approved a limited clinical trial for approximately 300 patients out of the estimated 93,200 children in the United States who suffer from intractable seizures. Last year we checked to see if it was possible to get some of our Nebraska families in this clinical trial and learned that unfortunately Nebraska families are not able to participate in this study. The FDA approval process, as I'm sure you are aware, is a multiyear process. Meanwhile, over a very short time period of about two years now, compelling evidence for the effectiveness of CBD to treat seizures continues to mount rapidly. I do not take the risks of allowing compassionate use for CBD while FDA trials continue lightly. However, the risks that we take by acting now must be weighed against the immediate and certain risk of irreversible developmental delays and in some cases even death that these children face by waiting for FDA approval or for more research. Our program will allow parents who have tried other FDA-approved options to choose to take this risk in consultation with an epilepsy specialist. We realize that the FDA research and research in states with medical marijuana may yield findings

Judiciary Committee November 14, 2014

that open new opportunities in a few years. We need a cautious option for those kids who simply cannot wait for FDA approval and more research. Prior to the hearing we were proactive in talking to substance abuse prevention advocates who work hard in our communities to prevent marijuana use among youth. They raised three main concerns: one, that we need to proceed with caution; two, that more research is needed; and, three, that we should not send a message to youth that marijuana is safe. We agree that we need to proceed with caution and that we need more research and our program is designed to do both. It is a cautious and compassionate pilot program with an emphasis on gathering data on the use of CBD for intractable epilepsy. Finally, the emphasis of the pilot project on only allowing CBD substance that is legally equivalent to hemp reinforces the message of the danger of THC, particularly for youth. As I've already noted, there's no recreational use for low THC cannabidiol, so it does not create a diversion risk for law enforcement. We are also paying attention to clear identification of study participants, specific labeling of the CBD substance, and restrictions against smoking or vaping for participants in the study so that the pilot study does not provide cover for any illegal substances. As stated earlier, we intend to pursue legislation to create a small research pilot program that allows epilepsy specialists at the University of Nebraska Medical Center to use low THC cannabidiol oil with participants identified by these neurologists as having untreatable seizures. These university neurologists will be responsible for communicating the risks to patients or in the case of a minor patient, to their parents to ensure that they understand the medical risks involved. UNMC will also be responsible for tracking results and managing the quality of the CBD oil. This includes testing by UNMC pharmacists to ensure that the product falls under the appropriate THC level. Here with us today is Dr. Deepak Madhavan with the Department of Neurological Sciences at UNMC to discuss their interest in this project. And I appreciate their willingness to be here with us today. Also joining us via telephone is Karmen Hanson from the National Conference of State Legislatures who will provide the committee an update on CBD legislation passed in other states. Although our main focus here is on state law, I want to state for the record the importance of policy change also at the federal level. As a result of this interim study I met Jayen and his parents,

Judiciary Committee November 14, 2014

Nicole and Matt. Jayen suffers from intractable seizures. After trying 25 different medications with no long-term success--and this is just a little guy--his parents decided to try brain surgery. Unfortunately, less than a week after leaving the hospital, Jayen began to seize again. Jayen is part of a military family. Even if Jayen is able to receive treatment in Nebraska, if his family receives orders to relocate to another state, this access will be cut off unless federal action occurs. Other families may be unable to visit family or travel outside of the state with their child. It's vital that we continue to push for federal action to reclassify this low THC substance so that state efforts to explore and develop medical uses do not get restricted by strict federal-controlled substance restrictions. One of the great traditions in the Nebraska Unicameral is that anyone can testify at our hearings and we have a great crowd here today. Interim hearings provide a forum for a broad range of views on a topic. You will hear today from testifiers interested in much broader legalization policies. However, again, our proposed legislation next year will focus on a small pilot program with a strong research focus using low THC oil which has no recreational use for minors or adults. The substance's legal equivalence to hemp and the tragic consequences of inaction for children make a compelling case for the immediate creation of this pilot study. The focus on intractable epilepsy is not because I consider it more deserving than any other health condition, but instead that it happens to be a condition for which a low THC substance appears to be effective. Also, a pilot study project allows rapid implementation of compassionate care for this urgent need without the time, costs, and risks of establishing an infrastructure for broader legalization. I would like to thank Shelley Gillen and her family for their persistent advocacy for CBD access for families like hers in Nebraska. I would also like to thank the 13 parents who contacted our office to share their stories of struggling to find help for their children. Six of these parents visited Colorado with Senator Al Davis, Senator Tommy Garrett, and Dr. Ismail Dweikat, an agronomist from UNL, and me to learn about the work of the Realm of Caring Foundation. The Realm of Caring Foundation supports CBD development, particularly Charlotte's Web. I would also like to thank my intern, Addi Fairchild, for her hard work and research on this interim study. There are many people who have testimony they would like to share so I'm happy to answer some

Judiciary Committee November 14, 2014

questions if you would like but I'm going to stay and I'm happy to answer them at the end instead. [LR433]

SENATOR COASH: Okay. Thank you, Senator Crawford, for that introduction. Senator Seiler from Hastings has joined us to my far left, also a member of the committee. With that, Senator Crawford, we have a lot of people to get through so we're going to get started, okay? We're going to start with some testimony via audiconference so Karmen Hanson from the Council of State Legislatures is on the phone. Karmen, can you hear us? [LR433]

KARMEN HANSON: Yes, I can. Can you all hear me? [LR433]

SENATOR COASH: We sure can. We're going to go ahead and give you the time and please begin your testimony. [LR433]

KARMEN HANSON: (Exhibit 1) Great. Thank you, Chairman Ashford, for the invitation and opportunity to present to the committee today. I'm Karmen Hanson from the National Conference of State Legislatures' health program in the Denver office. And I have worked on health policy for 13 years and on medical marijuana policy for the last 7 or so. And today I'll provide a brief overview of the existing state medical marijuana and low THC policies and programs and include some information on the current legislative landscape. Starting with my second slide, while the discussion of using marijuana for medical use may seem like an old idea, state legislation governing its use is relatively recent. California was the first to allow for medical marijuana by a voter-approved proposition in 1996. And since then, 22 states, D.C., and Guam have followed--most of which since 2000--making for a total of 25 current programs. Thirteen of those programs were voted in by voter-ballot initiatives and 12 were approved by legislative bodies. And I've provided a link to the NCSL medical marijuana Web page here for your reference as well. And most of the information covered in this presentation comes from that page and related resources. As you may expect, no two medical marijuana laws or programs are

Judiciary Committee November 14, 2014

alike, but some similarities do exist. Most programs include provisions for the following issues: patient registries, grower or caregiver registries, dispensaries, specific conditions, recognizing patients from other states. For grower or caregiver registries, there are 17. And these are as of October of 2014 just because I haven't noticed any changes yet, but it just states that I know that this...for sure the information as of October. The limits are ... possession limits are one ounce to eight ounces and/or 3 to 12 mature plants and seedlings. These categories also vary. For example, some states don't limit the number of licensed dispensaries with a hard number. Some states restrict the number to a total number, like six in Connecticut or Minnesota is about to start their program with four. So legislation does also allow them to expand that over time if they see the need to. And when it comes to growers and dispensaries, local zoning and licensing procedures may control if they can operate legally. In Colorado, for example, many cities and counties do not allow for commercial growing or dispensaries within their jurisdiction. The process varies widely. Some programs are silent or have yet to be determined on issues like dispensaries. Or more likely, they haven't decided if they're going to recognize patients from other states. It also takes time to establish rules and regulations after these laws take effect, which is the case in Connecticut and Massachusetts from 2012 and Illinois and New Hampshire in 2013. Some items were established in the legislation or ballot measure, while in other states those details are left up to a governing board, task force, or rulemaking committee. And I also want to point out that the state health departments generally operate these programs. However, a few are run by attorneys general offices or consumer protection or public safety or justice. Of the latest issues with medical marijuana, the new low THC or CBD-only limited or research programs have come about in 2014. Eleven states passed these bills in 2014 and they vary widely. More information on them can be found on the marijuana policy page listed here and I believe you had a committee staff person also create a comparison list for you as well. As I mentioned, these new programs are very new, all of them being approved in the last six to eight months by states with no other existing medical marijuana programs. Since they are so new, no one has had an existing program model. That said, programs have some similarities and differences

Judiciary Committee November 14, 2014

and here's kind of a 30,000 foot overview. The low THC definitions vary by state. For example, I have them listed there. Some of the lowest THC limits are .3 percent and greater than 5 or 15 percent CBD by weight. Some of the highest amounts of THC allowed are 3 percent THC and/or above 10 percent cannabidiol by weight. And those conditions are kind of narrow. Some also...some of these programs require a failure of traditional treatment before gaining access to the CBD program. Identified sources of the product also vary. The most common source of the products in these programs are medical schools that managed to get a research project or a clinical trial through existing government mechanisms. Some medical schools would be able to grow their own or get it through the federal grow at the University of Mississippi, although research has shown that that process has been quite difficult and takes numerous years. sometimes up to four years unless you're in an established clinical trial or research project already under way. A few of the laws do not define where the CBD product comes from, which means that the person using the product may be put at risk of breaking federal or state laws if they transport the product through another state or through the mail. So for example, we'll use Colorado as an example. Colorado products...marijuana products in general are labeled as "only for use in Colorado." So if you drive across the border into Kansas, you can be arrested, prosecuted for having marijuana products in Kansas because in Kansas it doesn't...there's no medical program, there's nothing saying that you can bring a product from another state. Plus, you're also violating Colorado law by taking product out of the state. So none of these new CBD programs are operational yet and the details on who is to implement them aren't always clear. A few of these laws allow for a working group or a task force to finalize the details about how they will actually work or the agencies named in the legislation need to develop more rules before they can go forward. Again, for sources of the product, most of the states that...with these new programs talk about the conditions for use, which are the intractable seizure disorders such as Dravet syndrome, epilepsy, muscle spasms, different neurological disorders, cancer, pain, and a couple of others, but those are the vast majority of the conditions allowed for CBD programs. The sources vary. Like I mentioned, it's usually universities with medical schools is how it's

Judiciary Committee November 14, 2014

phrased in the legislation. And sometimes they do allow for dispensaries not affiliated with schools and those two examples are Florida and Missouri. And then the University of Mississippi is the location of the federal marijuana grow and that's, of course, in Mississippi. And it's not clearly defined in, I would say, Alabama. Even though it says universities with medical schools, but it's kind of fuzzy. Iowa, South Carolina, and Wisconsin they don't have a good, clear definition of who's allowed to produce or grow CBD products. And some of the states have included as a legal defense for the patient, some protections refer to doctors that are referring these products to folks. And some of the laws are a little vague to the point where doctors or universities or other providers may feel that they are at risk for breaking federal or state laws if they are trying to operate within the laws of the program. Sometimes there's just not enough clarity for them to feel comfortable with participating in these programs. So like anything else, the medical use of marijuana has had its advocates and critics. Shortly after California legalized medical use of marijuana, the Institute of Medicine came out with its own opinion. It found that marijuana helped some patients with pain relief and any side effect was generally short lived and well tolerated. And I want to mention that these are talking about both regular or wide strains of marijuana products and sometimes CBD specifically, but most of them are speaking to the larger use of medical marijuana with kind of considering all strains. In late 2012, the Treatment Research Institute released its own opinion based on it's addiction-related research. They do not abide using marijuana for medical use. In recent years, other disease-specific and patient advocacy groups have varied in their support of medical marijuana for treatment of pain, nausea, and other issues. Some groups that may not currently support its use but would reconsider with additional FDA and scientific research standards to support it include: The American Society of Addiction Medicine, American Cancer Society, American Glaucoma Foundation, National Multiple Sclerosis Society, American Academy of Pediatrics, American Medical Association. And note that some will not agree to full legalization of marijuana generally, but they would perhaps support it with more research. So federally, marijuana remains a Schedule I product and that means it's seen as having no acceptable medical use. However, in 2009, the Obama

Judiciary Committee November 14, 2014

administration stated that they would not actively prosecute those states adhering to the state laws for medical distribution in states with medical marijuana statutes. More recently in late August of 2013, the U.S. Department of Justice announced an update to their marijuana enforcement policy. The statement reads that while marijuana remains illegal federally, the U.S.D.O.J. expects states like Colorado and Washington to create strong, state-based enforcement efforts, and will defer their right to challenge their legalization laws at this time. The department also reserves the right to challenge the states at any time they feel it's necessary. And I can tell you firsthand, there are stories of federal agencies coming into both dispensaries and growers within Colorado and Washington and seizing materials and basically shutting them down when they find that...when they have good reason to believe there is something fishy going on, where they are not abiding by Colorado or Washington law. And there are other organizations out there that do have their opinions about if marijuana and CBD-only products are helpful or not. And I think you have folks also available today to testify that are going to speak to that. So that very briefly concludes what I have prepared for you today unless you have any additional questions. I'm glad to take those now or e-mail, so contact me with my information on the slide. So thank you very much. [LR433]

SENATOR COASH: All right. [LR433]

KARMEN HANSON: Take care. [LR433]

SENATOR COASH: Thank you, Karmen. We appreciate you phoning in to join us today. And we do have your contact information so we will use you as a resource to the committee as well as through Senator Crawford's office. So thank you again for your testimony. [LR433]

KARMEN HANSON: Thank you, Senator. [LR433]

SENATOR COASH: Thank you. Okay. We're going to move ... we're going to keep this

Judiciary Committee November 14, 2014

moving. Dr. Madhavan, would you please come on up? And one thing I neglected to say earlier, anybody that comes up to testify, if you could state your name and spell it for the record, we'll start with that. [LR433]

DEEPAK MADHAVAN: (Exhibit 2) Sure. Deepak Madhavan, D-e-e-p-a-k M-a-d-h-a-v-a-n. Good afternoon, members of the Judiciary Committee. My name is Deepak Madhavan, M.D., and I'm a physician and assistant professor at the University of Nebraska Medical Center and the director of the comprehensive epilepsy program at the Nebraska Medical Center. I'm here today speaking for myself as a physician. As part of the only comprehensive epilepsy program in the state of Nebraska, we receive referrals of adult and child patients with the most severe and intractable seizure disorders. Fortunately for most of these patients, we are able to determine a treatment regimen that is both effective and FDA approved that leads to a substantial reduction of seizures and improved quality of life. In a small subset of patients, however, their seizures are so exceptionally debilitating or severe, the standard treatment regimens are not enough to properly control their seizure activity. In this population, breakthrough seizures can result in what we call drop attacks or falls, which result in significant injury and in the pediatric population, can contribute to intellectual and behavioral regression. With these patients, we are often relegated to treating seizures with extremely powerful medications where the side effects can often rival the benefits themselves or they face risky brain surgeries which can potentially leave the patients with significant neurologic consequences. Those of us on the clinical front lines of epilepsy treatment have witnessed firsthand the devastating effects of these severe and refractory seizure disorders and have often felt powerless to help. In several case studies in small clinical trials, cannabidiol has been shown to potentially provide dramatic improvements of seizures in these individuals with severe epilepsy with a relatively benign side effect profile. It is for the above reasons that, as a physician, I am supportive of Senator Crawford's efforts to create a legal and organized method for which patients with the most severe epilepsy seen at our epilepsy center have a chance to receive cannabidiol oil. We do not harbor unrealistic hopes about the potential therapeutic effects of the

Judiciary Committee November 14, 2014

substance, but do feel that additional therapy we can offer to this most severely affected patient population allows us to at least provide further options where there were previously dead ends. I support the efforts of pharmaceutical companies that are seeking to make medications that contain cannabidiol legal and FDA approved and our senators actively seeking partnerships to test these medications in Nebraska. However, we are also aware that the time frame that is associated with the FDA approval process can take a few years. In the meantime, patients with uncontrolled epilepsy who have exhausted all other treatment options continue to be at risk for injury or intellectual damage that may be irreversible. Therefore, for these patients who have no other treatment options. I am supportive of the efforts related to sourcing and dispensing this substance through the comprehensive epilepsy program in a way that can be done with the full accordance of state and federal laws. I hope to continue working with Senator Crawford to forward this process. There would be a number of logistical and regulatory issues to work through to ensure the safe and reliable sourcing and dispensing of cannabidiol. Also decisions would have to be made about whether it is more feasible to utilize the substance in a clinical trial versus a compassionate care use. I stand ready to work with Senator Crawford and the Legislature to move forward with this planning in order to ensure another therapeutic option for those patients that suffer from the most intractable seizure disorders. Thank you and may I answer questions? [LR433]

SENATOR COASH: Thank you, Doctor. I'll start. Where would you anticipate sourcing this oil if we were...if we open up the door under this limited use? [LR433]

DEEPAK MADHAVAN: That's a very good question, Senator. We are actively discussing this. We have a number of potential options available to us. We haven't settled on one particular option quite yet. I do have a statement from our Dean of Pharmacy, Dr. Courtney Fletcher, which I'd like to submit today that discusses some of the possibilities. But we have not come to a firm decision on that at this point. [LR433]

SENATOR COASH: That would be one of the important legs of this initiative, right? Is to

Judiciary Committee November 14, 2014

have a reliable and safe source for this? [LR433]

DEEPAK MADHAVAN: Absolutely. [LR433]

SENATOR COASH: It would be medicine, is what it is. [LR433]

DEEPAK MADHAVAN: Right. Right. [LR433]

SENATOR COASH: Okay. Let me turn over IT to the committee and see if they have any questions for you. Seeing none, Doctor, thank you very much for all your work you're doing and working with Senator Crawford. I'm sure this isn't the last time this committee will hear from you. Thank you very much. Shelley Gillen, are you...come on up, Shelley. And for those of you that testify, we will have you fill out a sheet, which will be helpful for keeping a good record. The page will help you out with that. Shelley, you want to start? [LR433]

MICHELLE GILLEN: (Exhibit 10) Yes. Good afternoon, members of the Judiciary Committee. My name is Michelle Gillen, M-i-c-h-e-l-l-e G-i-l-l-e-n, and I am here today to make a plea for my 12-year-old son, Will. Will has suffered from multiple types of seizures on a daily basis since he was four months old. He has a rare diagnosis called Lennox-Gastaut syndrome. It is considered a catastrophic disorder because it is treatment resistant oftentimes. Will has failed 11 meds, special diets, a surgically implanted VNS, and in desperation on our part, alternative treatments as well, such as homeopathy, chiropractor, and neurofeedback. The meds that Will has been prescribed over the past 12 years have been very powerful ones with side effects that have been as devastating as the seizures themselves. Personally, the side effects Will has experienced have been dangerously high blood pressure, deterioration of his stomach lining, a compromised immune system, excessive weight gain, inconsolable irritability, vomiting, severely impacted bowels which required a seven-day hospitalization, excessive drooling, and behaviors that have ranged from aggressiveness to being just a

Judiciary Committee November 14, 2014

shell with no personality left at all. Some of these meds are not even FDA approved for children. And some of them are "benzos" which are completely, 100 percent addictive. At one point Will was taking 24 pills a day. As a last resort, we are now faced with a very invasive option for Will, brain surgery. A surgery that is still not a guarantee and even if it does work, the results may be temporary. This is a decision no parent should have to make, yet here we are. As a result of the thousands of seizures and the powerful meds he has been on, Will is completely nonverbal, incontinent, legally blind, and cognitively about a two-year-old. Gratefully, though, he is mobile. However, along with this blessing has come great risk factors because of falling from his seizures. In our desperate efforts to protect him, Will wears a fully padded face guard helmet at all times unless he's sleeping in his medically enclosed bed or is being transported in a medical stroller for outings. Even with all of these precautions taken, though, Will has suffered and endured horrific seizure-related injuries: multiple stitches, head staples, knocked out teeth, concussion, suspected broken nose twice, suspected broken finger, and other significant facial and mouth trauma. As you can see, epilepsy is a thief and a bully. It has robbed Will of a childhood he so deserves. It has shook our family to the core. Parents and family members of those with this diagnosis are often compared to those who have PTSD because of the horrors we have witnessed. You truly don't know how long 30 seconds is until you watch someone you love having a seizure. In the past year, though, our hopes have been renewed. They've been renewed by hearing about multiple stories in the media about the effectiveness of CBD oil for those who suffer from seizures. The oil is administered orally in food and the results have ranged from significant decrease in seizures to improved cognitive development. There are presently an estimated 21,500 people in Nebraska who suffer from treatment resistant epilepsy. Will and the other children and loved ones in this room are part of that 21,500. With that all said, in closing I would like to respectfully ask the committee to please have open hearts and open minds. Please have compassion and allow families like ours to have this treatment option, which should be decided upon between doctors and patients and not elected officials. As a mother, I have no pride in asking this. Please, please give Will and others a chance. Please give all those in Nebraska who live with epilepsy and other Judiciary Committee November 14, 2014

chronic illnesses a chance at a better quality of life. Thank you for your time and consideration. [LR433]

SENATOR COASH: Thank you very much for your testimony and for bringing Will with you so he could participate as well. Let me see if we have any questions from the committee. [LR433]

SENATOR McGILL: Thank you. [LR433]

MICHELLE GILLEN: Thank you. [LR433]

SENATOR COASH: I don't see any. We really appreciate you coming down. [LR433]

MICHELLE GILLEN: Thank you very much. [LR433]

SENATOR COASH: (Exhibit 3) Very good testimony. Sheriff Davis, come on up. While the sheriff is coming on up, I want to make sure it's reflected in the record we do have a letter from the dean and professor of the pharmaceutical college, the College of Pharmacy at UNMC, which has been submitted to the committee. Sheriff. [LR433]

JEFFREY DAVIS: Thank you. I'm Sheriff Jeffrey L. Davis, J-e-f-f-r-e-y D-a-v-i-s, I'm the Sarpy County Sheriff. I'm not here today representing any other organization, the Nebraska Sheriffs' Association or the Police Officers' Association of Nebraska yet. I want to tell you a story. Over 25 years ago a bullet was invented. It was dubbed the "cop killer" bullet. We contacted an action organization, a well-known action organization and asked them to oppose this bullet. And they told us they could not because they felt it would open the door in the future for the government to come in and start taking guns away from people or limiting the amount of ammunition that people could have. I don't know how many police officers were injured because of that decision or maybe lost their lives. But I learned a lesson back then, that you cannot stop

Judiciary Committee November 14, 2014

something that's necessary because you're afraid it's going to open a door to something else. I think that's what we have here. And I applaud Senator Crawford and her office. I think that this is certainly a step in the right direction. I pledge to her and to the Legislature to garner as much law enforcement support as I can in the future in this situation. I can tell you that I don't view it as an open door or as a door to legalization of marijuana. There might be members of the crowd here today that hope that is what's going to happen; it is not. We pledge, when we take an oath to become a law enforcement officer, to help people. We are service providers. And you can look around the room and see how many people need our or need your help through this type of legislation. That's what we're here for, that's what I get paid to do. I will tell you that I will do everything I can to make certain that that's not the direction that we go with this type of legislation. It is not to legalize marijuana in the state of Nebraska. I'm an opponent of that, as most law enforcement officers would be. And I believe given the right information pursuant to what this experiment or test is going to bring about, most law enforcement will eventually be on board and see it as necessary. With that, if you have any questions... [LR433]

SENATOR COASH: Thank you, Sheriff. Senator McGill. [LR433]

SENATOR McGILL: Sheriff, do you have a personal connection to this issue that's made you passionate about it? [LR433]

JEFFREY DAVIS: I do not. [LR433]

SENATOR McGILL: Can you tell me where that comes from? [LR433]

JEFFREY DAVIS: I know two of the members that may be here today or I know Senator Crawford knows there's one I think in the eastern part of the county and one in the western part of the county. We do a program through our office called Project Lifesaver. And in that event, we've met up with many individuals that suffer from other diseases

Judiciary Committee November 14, 2014

but that includes epilepsy. And if this is medicine that can help those people, we have to look at that and take that step and not be afraid that the media or someone else is going to look at it and say, oh, my gosh, we're opening the door to legalization of marijuana. That's not what's going to happen here. [LR433]

SENATOR McGILL: Thank you. [LR433]

SENATOR COASH: Thank you, Senator McGill. Senator Davis. [LR433]

SENATOR DAVIS: Sure. Thank you for coming today and giving this testimony, it's very important. And I'm very much a proponent of what Senator Crawford is doing and I'm going to work with her to get this done. My question is, how are we going to get...do away with the ignorance in the law enforcement community to try to get people on board, because that's going to be a big part of what we're doing? [LR433]

JEFFREY DAVIS: I think you're right. And I think that Senator Crawford and I talked about that. I don't want to put all that weight on my shoulders, but I will do my best through the organizations that I belong to to bring either Senator Crawford or members of her staff out to explain what we're talking about here and how important it is and the parameters around some of the questions you asked: Where is this going to be housed? How many people will have access to it? Those are good questions. And I'm sure law enforcement will ask those same questions but they will have those answers and I believe this is the right step. [LR433]

SENATOR DAVIS: Thank you. [LR433]

SENATOR COASH: Thank you, Senator Davis. [LR433]

JEFFREY DAVIS: Thank you very much. [LR433]

Judiciary Committee November 14, 2014

SENATOR COASH: Sheriff, thanks for coming out and testifying. From Sheriff Davis we're going to go to Senator Davis. Are you guys related? [LR433]

SENATOR DAVIS: You want me to do it from here? [LR433]

SENATOR COASH: Why don't you go on up here, Senator, and we'll...I've got some tough questions for you. [LR433]

SENATOR DAVIS: Probably a little bit unorthodox for a state senator to come testify on this bill but I am passionate about it. I'm Senator Al Davis, A-I D-a-v-i-s, from District 43. When I was 14 years old I had my first seizure. It was on the football field, I was playing in the band. And I woke up in the ambulance on the way to the hospital and had no idea what had happened to me. But my parents obviously knew what had happened and were very concerned. About two weeks later, I had another seizure. I'm a very poor piano player, but I was practicing my piano and kind of keeled over with that. My parents had the resources and the ability to take me somewhere and they took me to the Mayo Clinic and I was there for quite some time with a long diagnosis. And the physicians put me on some medication which really was guite helpful to me. At that point and with my seizure condition, preventing seizures had a big contribution to keeping me from having seizures when I got to be older, so it was important. My parents were very good about keeping me on my medications and I didn't have another one for many years. When I got to college, I was living a more free lifestyle. Doing an all-nighter one night, I had a seizure. Then I began kind of a series of having them fairly regularly then at that point. So if you've never had one, let me just talk a little bit about that process and what happens to you. Mine were grand mal seizures so you can get a sort of confused phase of your life in that particular day and collapse to the ground, seize, and then it takes a day or two before you're really kind of back because you lose memory and you lose control. And so for these particular children who have seizure conditions that happen multiple times a day, they never have a chance to catch back up. It's a bad thing. If you talk about the marijuana plant, most medications come from

Judiciary Committee November 14, 2014

marijuana. It's been almost 100 years...80-some years since the marijuana became illegal and research really stopped on the plant. But it doesn't mean that it doesn't do good things and that there aren't good things that can come from it. I think CBD oil is one of those. So I went to Colorado with Senator Crawford this summer and we toured the Stanley brothers' facility. We went to a grow lab where they start the plants, we saw how that was done, very scientifically processed. We went to the greenhouses and saw the plants growing there. And after that, we went to meet with the parents of the children who are in the Realm of Caring, one of whom is a young girl named Charlotte Figi. Charlotte's seizures have been documented by Dr. Sanjay Gupta on his CNN special on marijuana and the changing view of marijuana in the country. So when we met with the family of Charlotte Figi, the little girl was running around, she's got a cast on her arm. She'd fallen and broken her arm, but it wasn't from a seizure. She just injured herself playing like a lot of children do. Charlotte had had--and I get confused on the number, I can't remember what it was--but hundreds of seizures a month. Her parents had been told basically to kind of expect that her life would probably be ending. CBD oil has worked well for her. It can work well for people in Nebraska and we need to move forward rapidly with it. And I would urge the committee to do something with that. And just to follow up a little bit and talk about my own condition--and you heard what Michelle had to say about Will's falls and things--so I fell when I was 25 years old, dislocated my shoulder. Happened again the next seizure I had, and again, so I finally had to have shoulder surgery. And that's the kind of thing these kids deal with. If we can solve their seizure problems, even if we can't do away with them completely but you can move them down to where they're manageable, they'll have a full, real life. What a great opportunity that we have to give to them. Thank you. [LR433]

SENATOR COASH: Thank you, Senator Davis, for sharing that story. You're not getting up yet, Senator Seiler has some questions for you. [LR433]

SENATOR SEILER: Senator Davis, I may have missed Senator Crawford's statement proposed in the Legislature. How is your distribution proposed, through a pharmacy,

Judiciary Committee November 14, 2014

with medical prescription, or... [LR433]

SENATOR DAVIS: You're going to have to ask Senator Crawford that, but I think the answer to that is that the University of Nebraska Med Center will probably be the ultimate person that's in charge since this is going to be under their auspices. Correct, Senator Crawford? [LR433]

SENATOR SEILER: Thank you. That's all. [LR433]

SENATOR COASH: Thank you, Senator Seiler. Senator McGill. [LR433]

SENATOR McGILL: I just want to thank you for sharing your story. I also had seizures as a child, but nothing in comparison to you or this group; mine were partial. And I just wanted to get on the record that I'm sorry I won't be here next year to be voting on this because I absolutely would be supportive and will talk to the senator who has just been elected in my district to encourage his support. [LR433]

SENATOR DAVIS: Thank you. [LR433]

SENATOR COASH: Thank you, Senator Davis. Okay, that's all the invited testimony we have, so we're going to move on to the public's testimony. So you can come up, there's no order, and we will start to take testimony. Why don't you come on up and we are going to start the light system now so we'll ask you to keep your comments to under three minutes and then we'll see if the committee has any questions for you. We'll go ahead and let you get started. [LR433]

BECKY BUDDEN: (Exhibit 4) My name is Becky Budden, B-e-c-k-y B-u-d-d-e-n. Our daughter, Alice, is four years old. At four months of age, Alice had her very first seizure. This was on a routine surgery at Boys Town Hospital. She has continued to have seizures ever since because of the medication they gave her. Just recently Alice had

Judiciary Committee November 14, 2014

the VNS, vagus nerve stimulator inserted within her body, wired through her neck to help regulate extreme seizures. This device is known to send shock waves every five minutes for 30 seconds to the vagus nerve. My husband or I swipe her magnet to her chest. Once in a while she can feel them coming and will say, mommy, please put your magnet on me. Presently, all the medication, including the VNS, are not approved for children. Yet my daughter needs all of these adult treatments to survive. No form of treatment has been successfully identified for children for constant seizures. Many, such like our daughter, Alice, are subject to numerous forms of adult treatment physically and chemically. There is no studies out there right now giving the proper impact of what her life is going to be when she is an adult from all of this and that she has now. Nothing better exists for our daughter, Alice, on the treatment team, including my husband and I and the doctors that she goes and sees. I'm constantly worrying and struggling to not only prolong the time between Alice's seizures while attempting to lessen the magnitude of each individual seizure, but to continue to pray that the next seizure will not be the one that severely impacts or, heaven forbid, ends her life. I worry over the forms of treatment being used and the long-term effects for her health and well-being. Each time Alice has a seizure we have to reassure our six-year-old son that his sister will be okay. We don't know if this will work with the type of seizures she has, but we want to help Will and his family and every other family in the state of Nebraska get help so they don't have to move. That is it. [LR433]

SENATOR COASH: Thank you, Becky, and we have your testimony here, so I know you had some more comments and the committee has those and we appreciate you coming down. You did a great job. [LR433]

BECKY BUDDEN: Thank you. [LR433]

SENATOR COASH: Let's see if we have any questions from the committee. [LR433]

SENATOR McGILL: How old is Alice now? [LR433]

Judiciary Committee November 14, 2014

BECKY BUDDEN: She's four years old. [LR433]

SENATOR McGILL: Oh, okay. I can't see her behind the chair. [LR433]

BECKY BUDDEN: She had a tonic-clonic seizure while we were here. And now she will probably be out until Sunday or Monday before she's fully functioning again. [LR433]

SENATOR McGILL: Okay. Well, thank you. [LR433]

SENATOR COASH: Thank you for bringing her down. Any other questions for Becky? I don't see any. Thank you very much. Okay, we'll take the next testifier. Why don't you come on up. Welcome. [LR433]

DESIREE STEDNITZ: (Exhibit 5) Dear Chairman Ashford...well, Senator Coash and honorable committee members, my name is Desiree Stednitz, D-e-s-i-r-e-e S-t-e-d-n-i-t-z. I'm here today to provide testimony on the significant impact epilepsy has had on our family. My daughters Lydia and Regina were born 13 weeks premature on Memorial Day 2000. Both girls spent four months in the hospital. Lydia had collapsed lungs requiring weeks of ventilation. Reggie had many more complications. During her stay, she endured multiple surgeries on her heart, intestines, and brain. What little fighters! With lots of love, additional surgeries, great docs, wonderful teachers and coaches, physical, occupational, speech, and vision therapy, Reggie's primary diagnosis of hydrocephalus followed by cerebral palsy and developmental delay have been manageable but not easy. Reggie's secondary diagnosis of epilepsy, given after her first seizure 13 years ago today, has been our biggest struggle and heartache. Regina has had approximately 60 seizures in her lifetime. Her seizures are unusual as they are infrequent and she does not lose consciousness or her ability to speak. However, over half these seizures have been status epilepticus, a life-threatening condition where a seizure does not stop without medical intervention. We've had ones

Judiciary Committee November 14, 2014

last as long as two hours. In the first few years, she only had a few seizures, predictable during illness or upon waking. Over the past three years, though, her seizures have become more frequent and sporadic. Her heart rate rises very high during her seizures and afterwards she often vomits, sleeps for hours, wakes with a crushing headache, and fever unaffected by medicine. She is extremely drained and generally takes a few days to a week to recover, depending on the length and severity. Emotionally, Reggie's epilepsy has been very tough on the entire family. We have raced her to ER after a rescue med has not stopped the seizure. In 2006 she had a seizure on a family road trip to Dallas. We spent 20 minutes under an overpass in the driving rain waiting for an ambulance. She has been taken by ambulance from school where her twin and younger sister, Anna, attend. Two Sundays ago, she had a seizure during church. We've consulted specialists and undergone testing at the Nebraska Medical Center and Children's Hospital in St. Louis, where she's been on various medications; currently on three which all carry risks and side effects. As the risk of more unpredictable seizures has risen for Reggie over the years, we are undergoing testing to remove part of her brain as a solution. If this surgery is not successful, we will be where many families are, with no other options. Epilepsy steals time, emotion, financial resources, and even sometimes lives from families. Reggie would be here today, but she's already missed 17 days of school due to seizures, testing, and appointments. She would ask you to please give Nebraska families an additional legal weapon in the fight against epilepsy. Thank you. And I've included some pictures from recent days. [LR433]

SENATOR COASH: We have your testimony and your pictures with it; very helpful. Thank you for sharing your story. It's very helpful. Is there any questions for Desiree? Seeing none, we appreciate your testimony. We'll take the next testifier who would like to testify. Come on up. Welcome. [LR433]

MARC BOWMAN: (Exhibit 6) Thank you. Hi, my name is Marc Bowman, M-a-r-c B-o-w-m-a-n. Members of the Judiciary Committee, thank you for your time. I come to you today in support of legislation allowing the citizens of Nebraska suffering from

Judiciary Committee November 14, 2014

intractable epileptic seizures to obtain hemp oil, a/k/a cannabidiol oils, CBD-rich oil, or simply CBD as a medical treatment option. There has been much media coverage about CBD, cannabidiol, or hemp oil in the anecdotal evidence of many children with intractable epilepsy having amazing results. Most notably, Charlotte Figi from Colorado portrayed on Sanjay Gupta's documentary entitled Weed. There has been enough media such that a bill has been introduced in the House of Representatives H.R.5226, Charlotte's Web Medical Hemp Act of 2014. Studies have been performed and more underway, specifically Cunha in 1980 indicating some antiepileptic/anticonvulsant effects with minimal side effects. Studies have been done in mice, also indicating the anticonvulsant benefits. An article in The Journal of Pharmacology And Experimental Therapeutics in February 2010, Nicholas A. Jones, et al. states, "We demonstrate the potential of CBD as a novel antiepileptic drug in the unmet clinical need associated with generalized seizures." I like the indication of minimal nonlife-threatening side effects. We've tried many treatments that have failed and have included such side effects as bloating, vomiting, constipation, loss of peripheral vision, to name a few. On some occasions we have had to do blood draws on a regular basis, as much as once a week, in addition to blood pressure monitoring to avert any life-threatening side effects. While there is no guarantee of CBD's effectiveness, in our situation I think it is definitely worth a try. We have had no guarantees of any of the many other antiepileptic drugs we have tried yet. Any surgical option appears to be only palliative in nature for our daughter. Our daughter was here but she was a little loud today. Yeah, she's excited. It is estimated that there are 90,000 children, Epilepsy Foundation of America suggests, suffering from intractable epilepsy like our daughter's. We have known at least half a dozen in Omaha alone. Interestingly enough, three of these families, including ours, have children within a year of each other, all diagnosed with similar intractable epilepsy. It is agreed in the medical world that aggressive treatment should be done with childhood epilepsy because of the rapidly developing brain and the propensity of prolonged cognitive impairment. Even our education system recognizes the long-term importance of serving the zero to five-year-old population. Current medical studies suggest the brain is fully developed at 21 to 25 years of age. That being said, we have

Judiciary Committee November 14, 2014

less than ten years to impact our daughter's cognitive development for the rest of her life. It would be nice to see her walk or perhaps form a single word like "mom" or "dad" or even "no." It would be nice to see her eat food as the last time she ingested nutrition through her mouth was when she was about nine months. Seizures are a symptom that can be caused by many things: head trauma, illness, stroke, dementia, structural malformation, underlying functional disorders, and many more. One in three people have a seizure in their lifetime. Surgery can be a wonderful option if a specific focal point or a lesion can be identified. But those that do not have an identified malformation have less potential surgery options, as is our case. In my opinion, if the structure does not appear to be the cause then it must be something in the chemical balance or underlying functioning of electrical connections of the brain. With continued research and discovery of the endocannabinoid system and anecdotal evidence, perhaps the CBD-oil dependency or deficiency is the answer to allow our daughter's brain to function at its optimum and we can reach developmental milestones that are in the baby books we threw out years ago. We've been on an 11.5-year journey. We only have a few more years for a significant impact. Please don't dash our hopes. As Nebraska prepares to treat another Ebola patient, anticipating positive results again using multiple treatments. including experimental drugs not knowing what works, I think we are asking for the same all-out approach with our urgency based on the declining time line we have for optimum cognitive development. Lastly, if it were child, what would you do? [LR433]

SENATOR COASH: Thank you, Marc. Thank you very much. Any questions for Mr. Bowman. Seeing none, we thank you for your testimony and we thank your daughter for coming, too. We'll take the next testifier. [LR433]

SHARI LAWLOR: Good afternoon. [LR433]

SENATOR COASH: Good afternoon. [LR433]

SHARI LAWLOR: (Exhibit 7) My name is Shari Moreland-Lawlor. And I have a daughter

Judiciary Committee November 14, 2014

that is 21 years old. She's had epilepsy since she was 15 months. And I feel very blessed when I meet families that their children have a lot more challenges than my child has. However, I still want a better quality of life for my daughter. And I guess what I wanted to elaborate on is the trip that we made out to Realm of Caring because my curiosity just... I wanted to go out and see for myself that this was actually something that could possibly work because it just sounds too good to be true. So we traveled to Colorado last summer on kind of a fact-finding mission. And as Senator Davis says, we met the Figi family from Colorado Springs and their daughter Charlotte who was the first to try CBD oil from the nonprofit Realm of Caring. And she was having 200 seizures a week. It was on video out on Facebook. It was horrible. And her parents had signed a do not resuscitate order because they couldn't bear to see her suffer anymore. And she has had treatments now for two years with CBD oil and she is nearly seizure free. She has maybe one seizure a month. Going from 200 a week to 1 seizure a month, that's miraculous. And we talked to Heather Jackson, she's the director at Realm of Caring, and she told us she is not an isolated case. There are 73.5 percent of their clients that have started the oil who are having at least a 50 percent decrease in seizures and almost 100 percent of their clients are seeing quality of life improvements. And amazingly, 13 percent have become seizure free. And so some of the questions that come up with this new testimony from Dr. Madavan--who is my daughter's neurologist--about the research study is, you know, how is this going to roll out? What is the time line? And this hasn't been taught in medical school so who are they going to consult with? And how long will this take, I mean? And what are we to do until that time? Where are we to go? Basically, the people that are professionals in this are out in Colorado from the Realm of Caring. And it's like why reinvent the wheel when they are a source of expertise? And talking about the sheriff, about how they can protect us, I know just from our recent experience with a service dog, I carry the law with me. And this is what we could carry with our prescriptions. And I guess I would feel more comfortable about going to a state that has had years of experience with this and that would be the medical marijuana doctors out in the state of Colorado. [LR433]

Judiciary Committee November 14, 2014

# SENATOR COASH: Okay. Shari, thank you for your testimony. [LR433]

SHARI LAWLOR: Thank you. [LR433]

SENATOR COASH: I don't see any questions so we'll take the next testifier. Come on up. Welcome. [LR433]

BILL HAWKINS: Senator Crawford, senators of the Judiciary Committee, my name is Bill Hawkins, B-i-I-I H-a-w-k-i-n-s, I'm with the Nebraska hemp company this...today. And I have no idea what a seizure is like, but I've had over 40 years experience with this plant. I've been a herbalist for a lot of years. I've studied biochemistry and synthesizing of pharmaceuticals because of this plant. And I've become a spokesman for this plant. This is something that's desperately needed. We talk about studies and the need for more studies. This plant has been used "herbally" for thousands of years; it is still used in other herbal countries. We've known about the seizures since the 1800s. At the time of prohibition cannabis was in 160 medicines. We talk about safety. I have the lethal dose of marijuana here, it's a U.S. government authority. We talk about the "LD," legal dose of a pharmaceutical drug. With aspirin, over the counter safe aspirin, a dose is two tablets; a lethal dose is ten doses which is 20 tablets. The lethal dose of cannabis is approximately 1,500 pounds. And the joke around is it's only if the one-ton bale falls on you. And so there have been studies. There are over 20,000 medical studies on cannabis across the nation, across the world. Israel...a company in Israel is just joining with a company in Canada to start supplying a high CBD...their genetics from Israel. Israel has had a medical cannabis program in their hospitals, they allow vaporization in their hospitals, they have addressed this situation. So if we look at public opinion on what cannabis is doing across the nation, I have a public opinion poll. One of the questions: What do you consider the most dangerous drug? The following substances is most harmful to a person's overall health: tobacco, alcohol, sugar, or marijuana. Tobacco, as we know, kills half a million people a year is 49 percent. Alcohol, which we are suffering some real serious issues with in this state, 24 percent. They happen to

Judiciary Committee November 14, 2014

come in number third, sugar at 15 percent. Marijuana is 8 percent of the people feel that marijuana is most harmful. So as a state body, you are representative of the people so I appreciate your interest in this and we are here to answer any questions. And we are here to provide this. As a company, we are ready to start production at any time with a safe extract of high CBD, so. [LR433]

SENATOR COASH: Thank you, Mr. Hawkins. I'm sure Senator Crawford will want to hear about that and we appreciate your testimony. [LR433]

BILL HAWKINS: Okay. I thank you for your time. And thank you. [LR433]

SENATOR COASH: I don't see any questions. Appreciate it. Okay, we'll take the next testifier. Why don't you come on up. I'll tell you what, if you're clear in the back and you want to testify, come take a seat up front. That way, you'll be ready. Welcome. [LR433]

BILL ACHORD: (Exhibit 8) Hello. I'm Bill Achord, I live at...it's B-i-I-I A-c-h-o-r-d, I live at 5114 Locust. I'm here to support this CBD bill for these children, but I want to go beyond that. And I don't want anything I say to take away from how important I think this bill is. Okay? I am a combat vet, honorably discharged, 100 percent disabled. A total and permanent disability from PTSD and the effects of Agent Orange. And projectcbd.org lists 51 human conditions that are helped by CBD and lists a plethora of research. Okay? There's a lot of research on this. Of the over 50 conditions, 15 of them pretty much apply to me and I've listed this on the thing that's handed out. I won't go through them. But I have a number of medical conditions that could be helped greatly by the CBD oil. And a lot of the veterans...my brother and sister veterans have it a lot worse than I do. My dad used to say, it could be worse. And I learned that from him with a lot of other good things. And I know he'd support what I'm here to ask of you today. One of the main things I want to say is that Nebraska is different. I'm proud to be born and raised in the state of Nebraska, proud to live in Nebraska. Nebraska has got the only Unicameral in this state. I'm going to ask you not...you're all...you look like loving,

Judiciary Committee November 14, 2014

caring, concerned people. You care about people. Don't make the same mistake that other state legislators have made. I think you heard on the report, none of those...none of the...what you're going to do, none of those are being used. They can't be used yet. None of them are functioning. And if they were, if you go to Realm of Caring or you go to other suppliers...I mean, I know Mike Bowman, I know the Stanleys. There's a huge list of people waiting to get CBD oil. Okay? So you pass this today, how long is it going to...or you pass it whenever, how long is it going to be? If you do it like everybody else has done, how long is it going to be before these people here that really need it are going to get it, and my brother and sister veterans who really could use this. Think of the children first, I beg of you. But think of all of us and broaden this thing and don't do it like all the other states have done. You'll be just like them. Three years from now, four years from now, we'll be saying the same thing. Why can't we get this? And why isn't there enough? Nebraska has a feral hemp resource that's been doing natural selection for 60 to 200 years in this state. We have what they have, what the Stanleys are growing. We just need to breed it, we need to grow it. In a few years we could have what they have and we could have a lot of it. So let us go out and harvest. We've got it, it's out there in the ditches. It doesn't like to be called ditch weed, it likes to be called feral hemp. It actually likes to be called feral cannabis, which is its accurate name, right? So we're not talking about medical marijuana, we're talking about medical hemp. It's real important, so. Thank you. [LR433]

SENATOR COASH: Thank you, Mr. Achord. [LR433]

BILL ACHORD: Do the right thing. [LR433]

SENATOR COASH: We appreciate the veterans' perspective on this issue very much. [LR433]

SENATOR McGILL: Well, thank you for your service. [LR433]

Judiciary Committee November 14, 2014

# SENATOR COASH: Okay. Come on up. [LR433]

DIANE RENKER: Hi there. How are you guys this afternoon? [LR433]

SENATOR McGILL: Good. [LR433]

DIANE RENKER: Fantastic. Thank you so much for the lovely opportunity to come and speak for you today. This is overwhelming and awesome. My name is Diane Renker, D-i-a-n-e R-e-n-k-e-r, and I'm 45, married 21 years, have four kids, and in 2012...well, August 22 of 2000 was a really drastic day of my life. I was a happy dump truck driver and loved building, rebuilding, and fixing communities. Unfortunately, (inaudible) had other plans for me and I rolled my dump truck that day. I went through the windshield and bounced over what was left of my truck. I had the truck land on top of me and pin me to the ground for 51 minutes before life flight and several small town rescue squads could come and (inaudible) me and get me back to Lincoln. I broke my sternum, three ribs, fractured my pelvis in five places, scalped the back of my head, broke my collar bone and ended up with some really unique scars all over my body. Really, I shouldn't have lived. But somebody had other plans for me and I'm grateful. The problem is, I have a unique immune system and I am allergic to every prescribed medication that's legal. I can't take any of those medications. And the only three medications that I'm left able to take, I have to be hospitalized in order to take them. I can't afford that and still maintain a family. Marijuana is pain medication. It also controls the seizures that you're hearing so much about, because I'm also epileptic because of the accident. I can't take so many medications over and over and over again, because the side effects of the medication create problems with other parts of your body. Make sense? So every day that passes, I never know what my pain level is going to be, how many seizures I'm going to have. And I'm having up to three seizures a day. We need to find a medication or legalize the marijuana so I can be functioning because I don't want to be back in a wheelchair. I want a life. So please help us pass this bill so that way there we can get usage of the medications that we need for strength so we can...I don't want to have to

Judiciary Committee November 14, 2014

look at my grandchildren and say you can't come see me because I'm scared to death I'm going to seizure on top of them and hurt them. Make sense? So thank you for allowing me the chance to talk to you all. [LR433]

SENATOR COASH: Thank you, Diane. [LR433]

DIANE RENKER: Do you have any questions for me? Anything you want clarification that I might have not been clear on? [LR433]

SENATOR COASH: I don't think so, but we have your contact information through the testimony. [LR433]

DIANE RENKER: Yep. [LR433]

SENATOR COASH: We've go that as part of the record. We appreciate your testimony. Thank you. [LR433]

DIANE RENKER: Perfect. Have a great day. [LR433]

SENATOR McGILL: Thank you very much. [LR433]

SENATOR COASH: All right. Why don't you come on up and then we'll have you go next. Okay? And you can go after that. [LR433]

ALLISON HOLMES: I apologize for the cell phone, but I have my template on there, so. Technology, right? My name is Allison Holmes, A-I-I-i-s-o-n H-o-I-m-e-s, I am a social work student at the Grace Abbott School of Social Work at UNO and I am also vice president of the university's chapter for Students for Sensible Drug Policy. First of all, thank you to the Judiciary Committee for being here today and considering the perspectives of the public regarding LR433. I want to say a special thank you to Senator

Judiciary Committee November 14, 2014

Crawford for taking time to organize this hearing and for your leadership on this important study. Today I'd like to share a little information with you about multiple sclerosis and explain why it is relevant to today's legislative study. Current treatment of MS is primarily symptomatic, focusing on such problems as facticity, pain, fatigue, bladder problems, and depression. Although symptom-specific treatments exist, these are often associated with adverse effects. This has left many people suffering with pain without access to relief. I know this not only from research but also on a personal level, as my mom has been diagnosed with MS for 12 years. A multitude of studies published in peer review journals, indicates that cannabinoids have significant medical value in treating patients with serious conditions, including epilepsy. But the medicinal uses of cannabis are not limited to the treatment of epileptic seizures. Thousands of studies demonstrated that cannabis can be used as a beneficial medical treatment for AIDS, glaucoma, cancer, and chronic pain, as well as a variety of neurological disorders like multiple sclerosis, parkinsonism, and ALS. Anecdotal reports on the self medication of cannabis to treat the symptoms of MS are supported by recent advances in the understanding of the biology of cannabis and the cannabinoid receptors in the brain. As the daughter of a woman with multiple sclerosis and an advocate in my community. I want to encourage this committee to consider amending the study to include research for all profiles of cannabinoids, not just CBD. While I do have a close connection with someone suffering with MS, I don't know anyone currently suffering with ALS, cancer, or Parkinson's, but I'd venture to guess someone in this room does. It's people like them...people like my mom that could benefit from the medicinal and therapeutic effects of cannabis. That is why we must include the research for all cannabinoid properties in the study. The day may come when your neighbor, your son, your friend, your mother gets the diagnosis and you would want to do anything to relieve their pain too. By allowing this research to be more inclusive, we will ensure that their medicine of choice will be well studied by experts here in Nebraska and it will also permit patients to access effective treatment without being criminalized. Thank you. [LR433]

SENATOR COASH: Thank you, Allison. I don't see any questions from the committee.

Judiciary Committee November 14, 2014

We appreciate your testimony very much. [LR433]

ALLISON HOLMES: Thank you. [LR433]

SENATOR COASH: Why don't you come on up. Welcome. [LR433]

COURTNEY ALLEN-GENTRY: (Exhibit 9) Thank you. My name is Courtney Allen-Gentry, C-o-u-r-t-n-e-y A-I-I-e-n hyphen G-e-n-t-r-y, I'm an advanced practice public health nurse, holistic health nurse, integrative nurse coach specializing in cannabinoid science, and I am a veteran. I recently founded the center for integrative nursing and cannabinoid science here in Omaha, and my mission is to educate nurses, physicians, patients, and the public on the science of human cannabinoid system, its relationship to well-being, and the integration of exogenous cannabinoids into a holistic model of care. At the core of this debate is the ethical dilemma of whether the federal ban on the use of medical cannabis violates the basic tenets of the physician-patient relationship, patient autonomy, and patient beneficence. Patients have the right to expect full disclosure and discussion of all available treatment options from their physicians. Denying a patient knowledge of and access to a therapy that relieves pain and suffering, especially when the patient has a terminal disease or an intractable condition like epilepsy violates the basic duty of a physician and the moral obligation of society to relieve suffering. After reviewing the scientific data and grounding the issue in ethical principles like beneficence and nonmaleficence, I believe the argument for allowing physicians to prescribe the totality of exogenous cannabinoids, including cannabis oil for medical purposes is compelling. The human endocannabinoid system is a built-in network of receptors, keys, and metabolic enzymes representing the microcosm of the psychoneuroimmunology--commonly referred to as the "mind-body medicine" system--which governs self healing. Endogenous cannabinoids, CB1 and CB2 receptors are widely distributed in the central nervous system, peripheral nervous system. And CB2 receptors are present on cancer cells, thereby enabling the ability for CBDs, including THC--the psychoactive component--to bind to cancer cells, gain entry,

Judiciary Committee November 14, 2014

and program cell death. This is why high doses of concentrated CBDs taken internally can cure cancers. Like endorphins, endogenous cannabinoids provide a feeling of bliss, reduce pain, and activate healing, yet go much further to help maintain homeostasis by allowing the body to relax, eat, sleep, forget, restore, and protect. The emerging field of cannabinoid science represents opportunity for the development of novel therapeutic agents for symptom relief or control of disease progression in numerous CNS pathologies. And current research demonstrates eCBs are critical to embryologic development, neuroplasticity, neuroprotection, and a variety of other things. Indeed, eCBs are thought so important that deficiency syndrome is now linked to multiple sclerosis, irritable bowel, fibromyalgia to name a few disorders. I've listed several studies. There's over 20,000 published and peer-reviewed research articles in the National Institutes of Health, U.S. government provides clear evidence of the studies. There are a list of conditions that are here. I urge you to consider the moral obligation that you have to all the residents of Nebraska who would benefit from cannabis therapeutics in addition to epilepsy. We have a state rich in feral hemp, an abundant natural resource high in CBD which is endogenous to the state. And I believe nurses at every level need to be involved. [LR433]

SENATOR COASH: Thank you very much for your testimony. [LR433]

COURTNEY ALLEN-GENTRY: Questions? [LR433]

SENATOR COASH: I don't see any. Thank you very much. Why don't you come up and then you can come next, okay? [LR433]

TOM VALDERAZ: Hello, my name is Thomas Valderaz, V-a-I-d-e-r-a-z, just here as a regular guy trying to change things in Nebraska. Senator Davis made the comment about the Charlotte's Web with this specific person having 300 seizures. This lady had 300 seizures a week and with the CBD oil at Charlotte's Web she went down to two or three seizures a month. The government has a patent number known as 6,630,507 for

Judiciary Committee November 14, 2014

this specific CBD oil. The simple fact that the government already knows that this is a benefiting thing and we, as Nebraskans, uphold the motto "The Good Life," "The Good Life" is kind of hypocritical. So I ask you to stand by the motto you are upholding, "The Good Life" and make this possible, so. Appreciate the time, thank you. [LR433]

SENATOR COASH: Thank you, Thomas. I don't see any questions. Why don't you come on up. Welcome. [LR433]

RALPH SMITH: (Exhibit 11) Good morning. Members of the Judiciary Committee, my name is Ralph A. Smith, that's R-a-I-p-h A. S-m-i-t-h. I was born in Omaha; I live in Louisville, Nebraska. I graduated from the University of Nebraska law school, admitted to practice in 1971. I began my legal career in Omaha with the city attorney's office, assigned to the criminal division. I and one other prosecutor prosecuted all the criminal cases in Omaha in those days. One of those cases that I prosecuted was possession of less than a pound of marijuana. I prosecuted very few of these because it was used primarily as a tool by law enforcement to harass the people that were protesting the war. Since that time, it's become my life's work. I've come to understand and feel that the continued unnecessary human suffering that occurs because prosecution of patients that seek relief from disease. I also have served as a former advisor, director, and legal counsel for Patients Out of Time, a nonprofit, educational organization dedicated to educating healthcare professionals with the latest evidence-based cannabis medicine and research. During that period of time, I presented on behalf of Patients Out of Time that research to both Iowa and Nebraska Boards of Pharmacy, which led the Iowa Board of Pharmacy to recommend removal of cannabis from Schedule I, thereby recognizing the medicinal value of cannabis. In 2013, I cohosted a continuing legal education seminar to educate criminal defense attorneys in Nebraska regarding how to deal with medical cannabis prosecutions. My own father died in 1996 without the benefit of the use of cannabis just because it was against the law. My dad and I worked together for 14 years. He, by the way, was the greatest office manager ever. He saw me defend hundreds of cannabis cases. He knew what a great class of clients I

Judiciary Committee November 14, 2014

represented. My client base were primarily the working-class hippies of Omaha who would prefer to smoke marijuana than to get drunk and hurt themselves other kinds of ways. So I have looked at...while working with Patients Out of Time, we put on seminars for...since 2000, bringing recognized experts from around the world to give their take on whatever study they had done or scientific study. I have looked at this situation of CBDs. I understand how it works, I understand how the endocannabinoid system works. And I'll tell you that you, as all other vertebras, are patients. You have a system that manufactures cannabinoids and this plant happens to have something that helps you balance your body when it comes out of balance. The problem with people dying from cannabis is...it just can't happen. You can't die from getting well. I have prepared...and again...and we have some hard drives or some thumb drives here that have access to science concerning cannabis, literally thousands of studies concerning CBDs and how they would help. [LR433]

SENATOR COASH: Okay. [LR433]

RALPH SMITH: I'd like to reiterate just a second for one other thing. [LR433]

SENATOR COASH: Give you...one comment and we're going to move on. [LR433]

RALPH SMITH: We have here in Nebraska this feral hemp that is high in CBD. It's 3 percent to 5 percent CBD and .03 percent THC. We have a wonderful resource that if Nebraskans were able to juice it and/or extract this resin, it could give us no psychoactive effect whatsoever, it would help many of us. I thank you for your time. [LR433]

SENATOR COASH: Thank you, Mr. Smith. We do appreciate it. If you've got some things for the committee, the page will help us out and you can pass that out. Why don't you come on up. Welcome. [LR433]

Judiciary Committee November 14, 2014

ROXANN HAMILTON: Good afternoon, Senators. I'm Roxann Hamilton, R-o-x-a-n-n H-a-m-i-l-t-o-n, I live here in Lincoln, Nebraska. And this is my partner, Dart (phonetic.) I'm a retired college instructor and I am an advocate for persons who have disabilities. I want to commend each of you as you engage in this remarkable and compassionate endeavor. It's leaders like you that make me proud to be a Nebraskan. During my research in preparation to talk to you today, I found out many things that I had no clue about marijuana in general, marijuana used for medicine, marijuana used for the hemp oil for certain disorders, as well as the other states that have gone before you in legalizing its use, including District of Columbia. Each of those 23 states and the District of Columbia have legislated a medical marijuana just a little bit differently. But the common denominator has been to ensure that medical marijuana is an available option to patients with specific serious, horrific, painful, medical conditions. I don't have epilepsy nor do any of my adult children nor any of my grandchildren. I do have a few friends that have epilepsy and I have many clients and I've had many students that have epilepsy. It would be very helpful for them, as patients who have epilepsy that has not been treatable by traditional pharmaceuticals and other treatments, to have a medical marijuana or a hemp oil available as a treatment modality. Nebraska has an absolute rock-solid national and international reputation for delivering cutting edge healthcare to all residents and even visitors to the state of Nebraska. I strongly believe that taking on this endeavor will enhance the quality of life for people in Nebraska, further enhance Nebraska's commitment to providing the best healthcare, and eventually have significant positive fiscal impact for our great state. I support LR433. I support your work on this resolution and I'm asking that you continue the work on this resolution. After my travels and I'm coming home to Nebraska, I see the welcome to Nebraska sign at the state line. I get a huge smile on my face and nod my head and read aloud "The Good Life" and sigh with happiness to live in the great state of Nebraska. Thank you all for your time listening to my comments and thank you all for engaging in this remarkable and compassionate endeavor. Thank all of you for your continued work to indeed making living in Nebraska the good life. Thank you. [LR433]

Judiciary Committee November 14, 2014

SENATOR COASH: Thank you, Roxann. Appreciate your testimony. Thanks for bringing Dart (phonetic). [LR433]

ROXANN HAMILTON: Yep. He had a lot to say. [LR433]

SENATOR COASH: I see that. (Laughter) Okay, one... [LR433]

ROXANN HAMILTON: Just give me a second. It takes me a moment to get ambulatory. [LR433]

SENATOR COASH: Take your time. [LR433]

ROXANN HAMILTON: Let's go. [LR433]

SENATOR COASH: Welcome. [LR433]

JACOB NOWATZKE: Thank you very much. Good afternoon. My name is Jacob Nowatzke. It's N-o-w-a-t-z-k-e. I'm here today from California. I actually lived in Bellevue when my stepfather served at Offutt Air Force Base, in the Air Force, of course. And I graduated from Bellevue West High School and got my associate's at Metropolitan Community College in Omaha before moving to California where I'm studying for a bachelor's degree in cellular molecular biology. It's very nice to be back in the Unicameral, I must say. I can say that everything that has been said before me, up until right now, has very, very hard evidence to back it up. With the excuse of a little bit of terminology being mixed up along the way, everything that each person has said before me is very true. I take great pride in collecting the research on the endocannabinoid system, cannabinoids from cannabis, synthetic cannabinoids, cannabinoid research in general. I have over 13,000 references that I really enjoy reading through because it turns out that after looking at THC and CBD, which were discovered in the early '60s, that scientists came across endocannabinoid system, which you just recently heard

Judiciary Committee November 14, 2014

about. You know, very quickly, it turns out that these cannabinoids in cannabis affect this endocannabinoid system and, as was recently stated in 2013, the endocannabinoid system may prove to be effective in treating nearly all human diseases. Now, as Raphael Mechoulam, who isolated CBD and THC in the '60s, from Hebrew University in Israel, he said that even if this is 90 percent true, 80 percent true, 50 percent true, there is great promise there. I must say that Raphael Mechoulam, as they say, isolated THC and CBD, also participated in the first clinical trial of cannabidiol with epilepsy in 1980. And there were only eight patients, but seven of those eight patients receiving CBD had an improvement in their epileptic seizures. Now he said at a conference last month in Bern, Switzerland, that I attended, that for 35 years almost, no more research went into cannabidiol. And that's quite alarming, especially as we're seeing all these families that are affected and may possibly benefit from cannabidiol. Last year a paper was just published, and it surveyed parents, families who have epileptic children and their use of cannabidiol, and found that over 80 percent of them, though there were only 19, 80 percent of them had a change in or a reduction in seizures. That's very, very promising. One thing I would like to very much focus in on is the fact that cannabidiol is very similar to THC. When you look at it, it's nearly the same thing, but it doesn't have the same effects of THC. It has almost nearly the opposite effects of THC. And it turns out that cannabidiol, as Ms. Gillen mention the side effects of epilepsy, the other things that affect Will, cannabidiol can treat all of those things as well. And I must say that after meeting Raphael Mechoulam, the professor at the Hebrew University--last year I flew to Israel to meet him--and cannabidiol is a very promising thing. And to offer it to children is very amazing. As a parent of a son, I know very well what it feels like to need cannabidiol. My son passed away in my arms in 2013 from brain trauma he received from a viral infection. And I know what it feels like to want CBD more than anything else in the world to treat my offspring with. And I must tell you that if there's one thing I want you to do, it's consider this use for anything that it treats. And right now epilepsy is on the table, but I promise you there will be much more to come after that. But for right now, please, treat these children, treat these patients with this medicine that's effective and shows no side effects when compared with the drugs currently used. Thank you

Judiciary Committee November 14, 2014

very much. [LR433]

SENATOR COASH: Thank you, Jacob, for your testimony. Welcome. [LR433]

DEXTER SCHRODT: Hello. My name is Dexter Schrodt, D-e-x-t-e-r S-c-h-r-o-d-t. I am vice president of the University of Nebraska College of Law's Students for Sensible Drug Policy organization. I'm here with a story from Minnesota. Recently, a Minnesota mother was trying to get access for her child. The son had a debilitating condition with severe pain caused not at birth but due to sports injury. The mother traveled to Colorado to obtain CBD oil after the 18 prescribed medications she had tried had failed. Minnesota passed CBD, but it was not effective for the son because it was not strong enough, which begs the question of Nebraska looking into increasing the percentage available to students because the percentage considered does not treat all illnesses or debilitating conditions. The mother sought out the oil and her son improved dramatically. It wasn't until the school realized that the son had improved and was doing much better in school they became suspicious and actually turned the mother in for providing the oil to her son. This brings me to my next point which would stress, especially as if the state considers this, it's going to take years to implement. But these people back here cannot wait. People, the parents, they might be traveling to Colorado to seek the help they need, which is why, in the interim, Nebraska needs to pass an affirmative defense and get a system in place for these people to get prescriptions right away while they're waiting for the growth of marijuana in the state. I would refer the committee to Maryland's criminal code, specifically Section 5-601(c)(3)(iii). That statute says it is an affirmative defense that the defendant used or possessed marijuana because the defendant had a debilitating condition or is a parent, guardian, or caregiver of an individual who has a debilitating condition diagnosed by a physician and marijuana is likely to provide the individual with relief from the condition. It protects these parents behind me should they decide to seek help for their children in the meantime while this is being considered and the marijuana is being grown and a regulation system is being implemented. We must first seek the prescription system right away. And as soon as

Judiciary Committee November 14, 2014

that is implemented, the affirmative defense needs to happen so that they can seek the help that they need. Thank you. [LR433]

SENATOR COASH: Thank you, Dexter. Dexter, could you sit down for a second? We've got a question from Senator Seiler. [LR433]

DEXTER SCHRODT: Sure. [LR433]

SENATOR SEILER: Have you looked at the effect of a prescription, say a pharmacist licensed in Nebraska to...assume we passed a law saying they could dispense it, what effect that would have on his license regarding the federal law that's still sitting. [LR433]

DEXTER SCHRODT: To be honest, Senator, I have not looked at that issue. But I certainly can look at it for you if you want to provide me with your e-mail, and I will send you my results. [LR433]

SENATOR SEILER: Okay. [LR433]

DEXTER SCHRODT: Thank you. [LR433]

SENATOR COASH: Dexter, I'd say you want to keep in contact with Senator Crawford... [LR433]

DEXTER SCHRODT: Of course. [LR433]

SENATOR COASH: ...and make sure that she's got that information that she...this is the purpose of this hearing, is to gather that kind of information. [LR433]

DEXTER SCHRODT: Right. [LR433]

Judiciary Committee November 14, 2014

# SENATOR COASH: I'm sure she'll want to hear that. [LR433]

DEXTER SCHRODT: Thank you. [LR433]

SENATOR COASH: Any other questions for Dexter? Seeing none, appreciate your testimony. We'll take the next testifier. How about one of you come up, and then you can go after. Welcome. [LR433]

TERESA MOBERLY: (Exhibit 12) Good afternoon. Thank you for having me. My name is Theresa Moberly, T-e-r-e-s-a M-o-b-e-r-l-y. September 18, 1996, is the date that changed our family's lives forever. That's the day our daughter Molly got a four-month DPT shot and began a life of seizures. Now, at 18, Molly ranges developmentally between a one- and a five-year-old, and requires round-the-clock care. She's had thousands of seizures, been on 20 medications, two diets, and has a vagal (sic) nerve stimulator implanted in her chest. Her seizures do not stop without intervention, so someone must be with her at all times, including at night. There are many triggers for her seizures, including illness, allergies, fatigue, excitement, heat, cold, and water. Yes, water is a big one for Molly. You can imagine how difficult it is to hold onto a seizing adult in the shower. Molly has been in status epilepticus numerous times. Status is any seizure or cluster of seizures lasting longer than 30 minutes. It's considered a medical emergency, and many do not survive it. Thankfully, Molly has made it through each one, but not without loss. The medications have their own set of negatives, from bone, kidney, liver, hair, cognitive, and gait problems to taking away her voice and personality and even causing coarse facial features. One of the medicines she is on can cause aplastic anemia and death. It is not FDA approved for children, yet she started it at age five. As a baby, Molly was so full of life and loved to giggle at her brother. At three, she was completely potty trained, talking in full and very clear sentences and extremely funny. She loved posing and making faces, so we always said she was going to be an actress. Around the age of five, everything was stripped away. She quit talking. She lost her toileting skills, began to regress, and stayed there for about eight years. At 16, after

Judiciary Committee November 14, 2014

going to a specialist in Minnesota, we determined that Molly had been in a constant state of subclinical seizure activity. That's when we decided to get the VNS implanted. Our hope was that the electrical impulses would reset the electrical imbalance she was in. We saw immediate improvement. She seemed to wake up and be with it. Unfortunately, that improvement was short lived and, just like the medication, she experienced a honeymoon period with it also. We have now maxed out the VNS and truly are at the end of the line for options--for legal options, that is, in the state of Nebraska. All along there has been an amazing plant that not only could keep Molly's seizures at bay but actually restore, repair, and heal her body. This plant is cannabis. Now that I'm aware of it and have witnessed it working firsthand, I want this for Molly. She is already at the top of the waiting list and could have it right now, but the law is keeping her from it. My son asked me yesterday: What do you think Molly would be like if she had been able to use CBD from the very beginning? Wow, what a thought. Many of the medicines she has been on have actually caused more seizures. The more seizures you have, the more your brain wears a path and makes a pattern for you to have even more. I know we can't change the past. But I implore you today to think about what part you can play in Molly's future, and not only Molly but all the others. Thank you. [LR433]

SENATOR COASH: Thank you, Teresa, for sharing your story and that of your daughter Molly. Appreciate it. [LR433]

TERESA MOBERLY: Thank you. [LR433]

SENATOR COASH: Is there anybody else wishing to testify? Come on up. [LR433]

CAROL KAYTON: Hi, Senators. [LR433]

SENATOR COASH: Welcome. [LR433]

Judiciary Committee November 14, 2014

CAROL KAYTON: I'm Carol Kayton, that's C-a-r-o-l K-a-y-t-o-n. And I just want to read what I wrote. It is well documented that cannabis oil shows great promise for kids with Dravet syndrome and also for pediatric brain cancer. I happen to know someone who works in a busy neurology clinic, and she recently told me how many pediatric patients they have. And I know that she supports the legalization of any medical treatment that would help these patients. Cannabis oil should be available to these kids and for their families, as it's been documented to be effective and to be without harsh side effects. I have a form of inflammatory bowel disease, and I stay informed of advances in treatment for it. And I've seen the research recently that showed that medical marijuana put a high percentage of Crohn's disease patients in remission, and an Israeli study, and for this reason I think it should be available for adults as well. Crohn's disease is a condition for which medicinal use is legal in states that have legalized it, and it is effective. And my husband has muscular dystrophy, is quite debilitated. And there are no treatments for him other than keeping him comfortable with pharmaceuticals. But I think it should be available for him and other people like him who suffer from terminal illnesses like that. That's all I have to say. [LR433]

SENATOR COASH: Thanks, Carol. You did a great job. [LR433]

CAROL KAYTON: Thank you. [LR433]

SENATOR COASH: Okay. Come on up. Welcome. [LR433]

JESSICA NATHAN: (Exhibit 13) Hi. I am Jessica Nathan, J-e-s-s-i-c-a N-a-t-h-a-n. And I have retractable seizures. I would like to speak not only for myself but for those unable to speak. I was diagnosed with epilepsy when I was 12 years old. I'm having absence seizures. I was 17 when I went on my first pharmaceutical medication in hopes of eliminating them completely so that I would be able to drive like a normal teenager. The medications helped for a short while before I started having seizures again and had my first of many grand mals. It was...it has been a long road of many different prescription

Judiciary Committee November 14, 2014

medications that not only have all failed at keeping me seizure free but also have given me worse seizures and other health problems. I was even put on medications that made my absence seizures exponentially worse, to the point that I was having over 200 a day, which I found out was a side effect to one of the epileptic medications. Prescription medications have not seemed to be the answer, but creating a greater deficit in my case. I can tell that my energy, concentration, and motivation levels are nowhere near where they used to be. And yet I'm still having seizures. Switching medication is no easy task physically or mentally. I have felt tingly, dizzy, nauseous, and absolute carelessness about anything besides being able to make it to the next place to be able to sit down. This is not from my medication...this is from my medications, not from my seizures. All of my adolescent and adult life, all I've ever hoped and prayed for was to be seizure free, able to be able to live an independent life as my peers do, just to be able to drive myself to the grocery store instead of having to continuously rely on someone else. I cannot imagine how incredibly liberating that would feel, to achieve that seizure-free independent lifestyle that we all hope and strive for. This is why I have been through so many different medications. I am requesting the state of Nebraska to give epileptic patients like myself the option of using CBD oil. As a citizen of Nebraska, I should have the same rights as do the citizens of the other states who have access to CBD oil, which is proving better control and/or eliminating retractable seizures without the horrible side effects that medications give to me. Thank you for your time. [LR433]

SENATOR COASH: Thank you, Jessica, for sharing your story. We'll see if...don't have any questions from the committee. Thanks for coming out and testifying. You get to go next. [LR433]

JANET NATHAN: I...my...she...that's my daughter, so the papers that we gave out are also mine and my son Ryan Nathan, who is a premed student at UNL. [LR433]

SENATOR COASH: Why don't you start by giving us your name. [LR433]

Judiciary Committee November 14, 2014

JANET NATHAN: Okay. My name is Janet Nathan, J-a-n-e-t N-a-t-h-a-n. And the reason I wanted to add to my daughter's is so you know how high-functioning she was before she went on medication. Our daughter is 28. She has retract...intractable seizures. She has been having absence seizures since age 12. From age 12 to 17, we opted not to give her pharmaceutical drugs because of the side effects we were told she might have. She would go for days without any seizures, some days few; bad days, she would have several in an hour. During this time she was highly functional with no other health problems. She played the piano, saxophone, took dance lessons, participated in softball, volleyball, and track. She was a member of the Honor Society and graduated high school as valedictorian in 2005. Jessica received a B.A. from UNL in 2009. She is currently employed at the Buckle headquarters in Kearney as an assistant buyer and designer. When Jessica was diagnosed with absence seizures, we opted not to use the pharmaceutical drugs means after researching the side effects of these medications. The absence seizures were helped by our efforts but not stopped completely. We are grateful for...to have had this time. We were able to see what would stimulate her seizures and what would suppress them. We might have not realized her medications had made her seizures worse and been able to identify the side effects. We would have assumed it was from the progress of the epilepsy and not the medications. Also, Jessica would have never been able to achieve what she did academically or been able to participate in sports and dance as long as she did. Within a few weeks after her first medication, she had trouble recalling names, loss of appetite, her equilibrium was affected, she was no longer her bubbly self. Her emotions were flat at age 17. She struggled academically. This was due to her...not due to her epilepsy but the pharmaceutical medications given to prevent seizures. Since the introduction of medications, absence seizures were only controlled for the first eight months. After that, she had her first grand mal and other types of seizures. This, at times, makes small tasks very hard. Her health was...has declined. She has been in the ER with high blood pressure of 169/124. She has weekly debilitating headaches. She has lost her front tooth and part of her front jaw due to grand mal. She has been on ten different medications; all have failed her. While on medication VIMPAT, she was recorded by an

Judiciary Committee November 14, 2014

EEG to have 200 absence seizures in an hour. She was in a zombie-like state. A side effect of VIMPAT is absence seizures. Recently, she has been admitted to Barrow Neurological Institute for a week-long study, an EMU, to find out if she was a candidate for surgery. She is not. A neurologist at Barrow told us she has patients who are using CBD oil and are reporting better seizure control and feel better than they were on anti-seizure medications. We... [LR433]

SENATOR COASH: Thank you, Janet. I'm sorry to cut you off. We're... [LR433]

JANET NATHAN: That's okay. [LR433]

SENATOR COASH: Just want to make sure everybody else gets an opportunity to testify. [LR433]

JANET NATHAN: Thank you. [LR433]

SENATOR COASH: We have your testimony in writing, so... [LR433]

JANET NATHAN: Yes, and my son's, who couldn't be here. [LR433]

SENATOR COASH: And your son's, so... [LR433]

JANET NATHAN: Thank you. [LR433]

SENATOR DAVIS: Thank you. [LR433]

SENATOR COASH: Jessica has a good team behind her; we appreciate that. Why don't you come on up. I see you've been trying to sneak up here. I want to make sure you get up here. Welcome. [LR433]

Judiciary Committee November 14, 2014

TONJA PETERSON-WENDT: (Exhibit 14) Thank you. My name is Tonja Peterson-Wendt, T-o-n-j-a P-e-t-e-r-s-o-n-W-e-n-d-t. Thank you, Senators, for taking your time to consider better options for Nebraskans. I have been prescribed the same medications as those with seizures, to no avail. I use a typically epilepsy-prescribed diet to eat. I do not have epilepsy. I have a traumatic brain injury due to multiple concussions, MTHFR, Ehlers-Danlos syndrome, an uncontrolled migraine disorder, painful digestion issues, allergies, fibromyalgia, PTSD, and other issues. At the risk of alienating each of you, the conditions I have are currently under narcotic care. In fact, in addition to narcotic medications, I have to combine muscle relaxers, migraine medications, and nausea medications back to back many times, and then continue dosing all but the migraine medications to control the pain. I keep researching on my own because the medical community does not have the time or resources to spend hours upon end on the rare combination of issues that plague my everyday living. My neuro-optometrist, who was able to diagnose my brain injury, wondered how I'd made it all of these years without committing suicide. I was a puzzle he sought to help. People like me do not fit in a box, but we also need help. I need to take less damaging medications. I want access to medical marijuana, all of it, because it will likely mean gaining control of my migraines, minimizing my pain, and increasing my productivity. I know the feelings of wishing to die every day, with every agonizing breath. I'm here today not just for myself but for these children and for these adults who have various issues that are not able to thrive under today's pharmaceutical and medical current state of availability. I have some questions. I don't expect answers. Why would you focus on CBD low THC that only half of the kids with intractable epilepsy would benefit from, according to the Massachusetts GW Pharmaceuticals study? Preliminary results reported here...I've got the link for you there. Other states are already doing this, and results are having only 50 percent success. I have a friend in that study, and her child is one that does not receive any benefits. She has up to 100 seizures a day. After Nebraska would permit studies, what happens to the patients that the study helps? Do they get a pass that allows them and only them to continue on this treatment? Or are they still going to have to move to Colorado to get CBD low THC medication that works

Judiciary Committee November 14, 2014

for them? What options are you giving those who have medication-controlled seizures but whose livers are being damaged beyond repair due to their prescribed pharmaceuticals? Are you, Senators, as citizens and representatives of the state of Nebraska, going to say to yourselves, well, we've done all that we could for these kids, our conscience is clear, we don't want anything to do with THC because we don't want to have this conversation with our constituents? [LR433]

SENATOR COASH: Okay, Tonja, thank you for your testimony. You gave us a long... [LR433]

TONJA PETERSON-WENDT: Thank you very much. Yes, you have plenty more. [LR433]

SENATOR COASH: So it's all here. It's here. It's for the record. It's entered into the record. [LR433]

TONJA PETERSON-WENDT: Thank you. [LR433]

SENATOR COASH: I appreciate the enthusiasm, but the clapping interferes with our ability to get a clear record. So we'll ask you to refrain from that. Thank you, Tonja. We'll let the next testifier come on up. Sure. Welcome. [LR433]

JENNIFER ANTON: Thank you. I wasn't sure I was going to say anything today. I'm Jennifer Anton, J-e-n-n-i-f-e-r, Anton, A-n-t-o-n. I'm the baby of the family. My oldest brother is 44. He's with us today. He suffers from grand mal seizures. He had a brain tumor when he was seven, and so they removed the brain tumor. He had a stroke with a reaction from the blue dye that they injected into him and he...as a result, he had a stroke from it. He's had about seven surgeries on his brain. He's now 44. And now, as a result of his...of all the radiation that he has had as a small child, he is now having tumors growing in his brain and there's not much they can do for him. He's kind of...it's

Judiciary Committee November 14, 2014

almost like he's a helpless case. And we're so desperate. He's been living with this for 37 years. He has migraines every day of his life, and we don't know what to do. He suffers from depression badly. He watches everyone grow around him, live normal lives. And we try to explain to him, Chad (phonetic), life is hard. But he doesn't...he said, no, my life is miserable. We just, you know...so we're desperate to help him, but we don't want to go to prison to help him. We've gone to Colorado. But I have two babies. I can't cross the border and be thrown in prison for my brother. And we just want to save his life. So I'm here, I'm pleading. My mother also passed away. It will be three years. And she had cancer. And she just begged for one good day, could she just have one good day. We watched her die miserably of cancer. They finally gave her MARINOL. I don't know all the scientific studies, but it doesn't work. Absolutely not. And my mother was a woman of morals, and she wouldn't take marijuana because she didn't want to, you know...she thought maybe God wouldn't appreciate her breaking the law. Please, help my family. Thank you. [LR433]

SENATOR COASH: Thank you, Jennifer. Appreciate your testimony. Come on up. Welcome. [LR433]

KATHY SLATER: (Exhibit 15) Good afternoon. I'm very grateful and appreciative that you're taking your time to hear my testimony and that of all the other people who have been here. The one thing I have not heard is a testimony from a grandmother and... [LR433]

SENATOR COASH: Can we go ahead and start with your name? [LR433]

KATHY SLATER: All right. My name...I'm sorry. [LR433]

SENATOR COASH: That's okay. [LR433]

KATHY SLATER: My name is Kathy Slater, K-a-t-h-y S-I-a-t-e-r. William Dominic Gillen

Judiciary Committee November 14, 2014

is my grandson. When he was first born, I was on cloud nine and looking forward to watching him grow up as a healthy child with a long and happy life ahead of him. My dreams for my grandson have all been denied. When Will was four months old, my daughter, Shelly (phonetic) Gillen, witnessed him having odd jerking episodes while his eyes rolled back into his head. She took videos of the episodes to Will's doctor. An EEG was done, and Will's original diagnosis was infantile spasms, also known as IS and also known as West syndrome. The doctor explained that IS was so rare that a pediatrician might only see one case during their career, if ever. IS holds a significant risk of mortality and morbidity. The consequences of this condition are marked with severe developmental delay and mental retardation. The condition is extremely difficult to treat and can be fatal. As in Will's case, IS often develops into Lennox-Gastaut syndrome, another relentless form of epilepsy. Will's seizures are sudden, severe, and unpredictable. He falls to the floor without warning. I roll him on his side, and when my hand touches his chest I can feel his heart beating like a trip hammer. He convulses and jerks for what seems like an eternity. I try to soothe him and tell him it will be okay, although I know it will not. I pray to God to, please, make the seizures stop. Will's three siblings have witnessed his seizures all of their lives and offer him comfort when he is seizing. It is heartbreaking to watch. Our family, entire family, has been affected. Will functions at a two-year-old level. He plays with rattles and puts everything into his mouth. He has difficulty swallowing and cannot chew his food. Will's food requires hours of chopping and grinding and spoon feeding. Will is incontinent. When his parents take him out of the house, there are no changing stations to lay a growing 12-year-old child on. He has to be laid on a public rest-room floor to change his diaper. It is heartbreaking to change wet and soiled diapers on a young man not quite in his teens and take care of him as if he were a toddler. Imagine watching two generations of your own flesh and blood go through horrific seizure episodes as you stand helpless. It tears a grandparent's heart and soul in two. Will is unable to speak. I wish I could hear his voice and have a conversation with him. I am one of Will's voices. He has endured much suffering due to epilepsy, along with injuries and adverse side effects from harsh drugs, for too long. His parents have done everything they can think of to help Will have a

Judiciary Committee November 14, 2014

better quality of life. Nothing I have heard about cannabidiol oil makes me afraid to have my grandson granted the right to be treated with it. It is a lot less scary than most of the other FDA-approved medicines he has taken over his 12-year life span. CBD oil is the major non-psychoactive ingredient in cannabis, and epilepsy patients who have used the CBD treatment have shown tremendous progress with a drastic reduction in seizures. As lawmakers, you have the power to legalize what 20 other states have already accomplished for their citizens that suffer with epilepsy and other catastrophic medical conditions. Many other states are following their lead. Please work to legalize CBD oil as a medical treatment in Nebraska. Our suffering citizens deserve to have this treatment option available to them without having to pick up and move to another state to be treated. Thank you. [LR433]

SENATOR COASH: All right, thank you. Thank you very much, Kathy. I don't see any questions. Is there anybody else wishing to testify today? Come on up. Welcome. [LR433]

LEN SCHROPFER: (Exhibit 16) Thank you. Good afternoon, Mr. Chairman, members of the Judiciary Committee. My name is Len Schropfer, L-e-n S-c-h-r-o-p-f-e-r. I'm a farmer in Fillmore County. I'm handing out copies of my one-page January 15 letter to the Legislature, and also copies of a reliable history of hemp prohibition from the Internet. The Ninth Amendment of the United States Constitution says that we have rights not enumerated. And the Tenth Amendment says the powers not delegated by it to the states are reserved to the states, respectively, or to the people. The hemp/cannabis/marijuana prohibition is a clear violation of the U.S. Constitution because there has been no amendment, as there had to be with alcohol. The Eighteenth Amendment, alcohol prohibition, ratified in 1919, and the Twenty-First Amendment repealing alcohol prohibition, ratified in 1933, are of binding precedent, since it can be proved that cannabis is less harmful than alcohol. We hear a lot about overregulation, get the government off our backs. Well, this is it. Although we certainly support cannabis treatment for epilepsy, this effort, as with so-called industrial hemp, is

Judiciary Committee November 14, 2014

just nibbling at the edges of a vast unconstitutional injustice. I urge you to look at the history I've handed out. Many influential people, including the vice chancellor for research at the University of Nebraska, do not know what happened. Hemp prohibition must be ended the way it was instituted in 1937: entirely. Thank you very much. [LR433]

SENATOR COASH: Thank you, Len. Seeing no questions. Okay. Is there anybody else that wishes to testify on LR433? This is your last chance. Okay, Senator Crawford, do you want to make some final comments? [LR433]

SENATOR CRAWFORD: (Exhibit 17) Yes, please. Well, I would like to thank everyone who came to testify today. I know for many people they were tough stories to share. And I just appreciate taking the time and effort and the bravery of sharing those stories with us today, and also thank Sheriff Davis from the law enforcement community, and Dr. Madhavan from the medical community for sharing their perspectives. And both of those communities are divided on this issue, and so I appreciate their courage in stepping forward and talking about that issue as well. I would like to mention--I don't think that you've mentioned yet. Senator Coash--that also provided to the committee. just for the record, there was a letter from the Nebraska Medical Association indicating that with proper precautions they supported moving forward in this direction. And so I was very happy to see that from the Nebraska Medical Association as well. So you may have noticed many people in the room wearing purple. I don't think it's because they're all Bellevue East fans or Bellevue West fans. It's actually Epilepsy Awareness Month, and so you probably might have noticed that color theme throughout the day today. So I wanted to respond just to a couple of the comments, for the record, and also again I want to emphasize that, since this is an interim hearing, that we really have the chance to listen to what people have said and we will get a transcript to make sure we have a good record of what people have said here. And I have been listening and taking notes, and I'm just appreciative that we have the chance to do this now, before the session, so that we can think about the ideas that were presented and figure out how to respond to them well. I particularly want to respond to the comment that was made by the

Judiciary Committee November 14, 2014

gentleman saying don't do it like everyplace else because they, you know, have passed these bills and yet nothing has happened in those states yet. And I would have to say that was a serious concern that I had last year and one of the reasons that I pulled the bill last year. I saw it passing in other states, but I saw bills passing in other states that I was concerned did not consider some of these key issues we need to resolve, like supply, like federal prescription rules. And so while they were good politics, and the bills in the other states passed by wide margins for the most part, they are still...in those 11 states there are no children, as far as we know, that are benefiting from those policies yet. So my commitment in taking on the interim study was to make sure that we did the hard, detailed work first, to make sure that we tried to address the issues of supply and how to enable the doctors to actually provide the substance to the children so that we address...we asked those questions and tried to get answers to all those questions beforehand, so that when we pass something it will be something that actually will be in effect and we can actually get help to those children as quickly as possible. And I'm very grateful to UNMC, who has been helping us do some of those...ask some of those questions, answer some of those questions. We've had the pharmacy department involved as well. And I don't know if you were here when they were talking, when Dr. Madhavan was saying... I mean they're still working on a couple of different supply options to make sure that, when it passes, we can do it here. I mean, in some of the states, they have said that they'll be growing it in their universities. But obviously, it takes time for that to happen. And so the idea of a bill that is the pilot study bill is to make sure that we create something that can step in as quickly as possible. And again, a...the pilot study in which we delegate a lot of the responsibility to UNMC to manage access and quality allows us to get rolling quickly, whereas, if we were to develop a broad policy that required conversion into rules and regs, you know, that takes a long time. So I'd also like to respond to people who have mentioned, you know, the feral hemp that we have in Nebraska and their interest in making sure that we're taking advantage of that and building capacity, building this product in Nebraska, growing this product in Nebraska. And I just want to remind everyone and have on the record that we did pass a bill last year, Senator Norm Wallman...Senator Wallman's bill to allow

Judiciary Committee November 14, 2014

research on hemp. And when we went to Colorado, Dr. Ismail Dweikat with the University of Nebraska-Lincoln, an agronomist there, was very interested in developing hemp in the state that would be high in CBD and low in THC. So there is a strong interest in the University of Nebraska-Lincoln in moving forward in this area. We passed the statute to allow it, but we're still waiting for the rules and regs to be developed from the department to allow this research to go forward. But those people who are interested in being engaged in that process, I encourage you to contact Jill Brown with the University of Nebraska-Lincoln to let her know that you're interested in this project and to get involved in those discussions that are happening about developing hemp products moving forward in the state of Nebraska. One of our challenges here as state lawmakers is that we are in a federal system and there are restrictions to how far we can go on our own because there are federal laws. And we saw that last year with the hemp bill. I think there was a broad and ambitious hemp development bill that was proposed that many of us supported, but in the end we felt that we could only go as far as the federal law allowed in terms of hemp research and development. And that's why it backed off to just research and development that was available through the universities or the state as the federal farm bill allowed. So similarly, as we proceed, our effort is to try to craft a pilot project that allows access to CBD in a manner that is compliant with federal law. And that is part of why it is a much narrower bill and why we have this emphasis on the substance that is low enough in THC to be the legal equivalent of hemp. So it is in an effort to make sure that we provide access as quickly as possible and as compliant with federal law as possible that has created the narrow focus of the pilot project to just the CBD product. I again would urge people who are interested in this issue to recognize that there are many federal law restrictions, and you have federal elected officials as well that you can contact to try to help remove some of those federal restrictions that are in the way of the development of CBD research in our state, as well as the development of other research for other uses of cannabis. So I feel that we will take into account the comments that are raised today, but our...my focus next year will be to craft a pilot project that is able to be implemented as speedily as possible and as compliant as possible with federal law. Thank you. [LR433]

Judiciary Committee November 14, 2014

SENATOR COASH: Speedily? [LR433]

SENATOR CRAWFORD: Speedily, that's a technical term. [LR433]

SENATOR COASH: Just get that on the record. One...before we let you off, Senator Seiler has a question. [LR433]

SENATOR SEILER: Senator, does the federal law...I know it's a Schedule I crime. But does it have parameters of above so many...they measured them in percentages and that if you came in below that, you would not apply to federal law. Do you know what those...what the Schedule I criteria is? Is it in pounds or is it in distribution? [LR433]

SENATOR CRAWFORD: I do not know all...I don't know what you'd...I don't know...I do not know or want to put on the record incorrect information about all of the details. So one of the issues that I emphasized in my testimony was that the farm bill, you know, allowed research on hemp and it defined hemp by its THC content. And so one of the things that we stressed was keeping the substance to be in a...keeping the substance at a low enough level of THC that it was legal equivalent to hemp was an important part of that, yeah. [LR433]

SENATOR SEILER: That's why I asked that (inaudible)... [LR433]

SENATOR CRAWFORD: Yeah, yeah, yeah. So it's a percentage of THC. [LR433]

SENATOR SEILER: Okay. Maybe the Schedule I has a percentage on it. [LR433]

SENATOR CRAWFORD: I don't know. There are also federal restrictions on prescribing authorities and other things that kick in, which has been a challenge in some of those states that, instead of having a study, have...like Alabama or Iowa, there are still...you

Judiciary Committee November 14, 2014

can pass a law to tell people they can prescribe something; but if federal law prevents them from doing so, it doesn't have much effect. [LR433]

SENATOR SEILER: Thank you, Sue. [LR433]

SENATOR CRAWFORD: You're welcome. [LR433]

SENATOR COASH: Thank you, Senator Crawford. We appreciate it. [LR433]

SENATOR CRAWFORD: Thank you. [LR433]

SENATOR COASH: You can catch her after the hearing. We're going to go ahead and close the hearing on LR433. Senator Crawford, look forward to working with you next year. (See also Exhibit 18) [LR433]