MINUTES OF THE MEETING
OF THE
ASSEMBLY COMMITTEE ON HEALTH AND HUMAN SERVICES

Eighty-Second Session
May 3, 2023

The Committee on Health and Human Services was called to order by Chair Sarah Peters at 12:33 p.m. on Wednesday, May 3, 2023, in Room 3138 of the Legislative Building, 401 South Carson Street, Carson City, Nevada. The meeting was videoconferenced to Room 4406 of the Grant Sawyer State Office Building, 555 East Washington Avenue, Las Vegas, Nevada. Copies of the minutes, including the Agenda [Exhibit A], the Attendance Roster [Exhibit B], and other substantive exhibits, are available and on file in the Research Library of the Legislative Counsel Bureau and on the Nevada Legislature's website at www.leg.state.nv.us/App/NELIS/REL/82nd2023.

COMMITTEE MEMBERS PRESENT:

Assemblywoman Sarah Peters, Chair
Assemblyman David Orentlicher, Vice Chair
Assemblywoman Cecelia González
Assemblywoman Michelle Gorelow
Assemblyman Ken Gray
Assemblyman Gregory T. Hafen II
Assemblyman Brian Hibbetts
Assemblyman Gregory Koenig
Assemblywoman Sabra Newby
Assemblyman Duy Nguyen
Assemblywoman Angie Taylor
Assemblywoman Clara Thomas

COMMITTEE MEMBERS ABSENT:

None

GUEST LEGISLATORS PRESENT:

Senator Marilyn Dondero Loop, Senate District No 8
Senator Rochelle T. Nguyen, Senate District No. 3

STAFF MEMBERS PRESENT:

Diane Thornton, Committee Policy Analyst
Eric Robbins, Committee Counsel
David Nauss, Committee Counsel
Terry Horgan, Committee Secretary
Ashley Torres, Committee Assistant
Natalie Dean, Committee Assistant

OTHERS PRESENT:

Abbey Bernhardt, Youth Recovery Peer Support Specialist, National Alliance on Mental Illness
Robin Reedy, Executive Director, National Alliance on Mental Illness Nevada
Jeanette Belz, representing National Alliance on Mental Illness
Catherine Nielsen, Private Citizen, Carson City, Nevada
Elyse Monroy-Marsala, representing Nevada Psychiatric Association
Barry Cole, Private Citizen, Reno, Nevada
Alex Tanchek, representing Nevada Advanced Practice Nurses Association
Sarah Watkins, representing Nevada State Medical Association
Dora Martinez, Private Citizen, Reno, Nevada
James M. Humm, Private Citizen, Las Vegas, Nevada
Regan Comis, representing Cleveland Clinic Lou Ruvo Center for Brain Health
Lynn Chapman, Private Citizen, Sparks, Nevada; and State Vice President, Nevada Eagle Forum
Tom Dunn, Private Citizen, Reno, Nevada
Dan Musgrove, representing Nevada Donor Network
Jackie Warn, Chief Quality Officer, Nevada Donor Network
Laura D. Knight, M.D., Chief Medical Examiner and Coroner, Washoe County Regional Medical Examiner's Office
Mendy K. Elliott, Private Citizen, Reno, Nevada
Tyre L. Gray, Private Citizen, Las Vegas, Nevada
Peter Guzman, President, Latin Chamber of Commerce, Las Vegas, Nevada
Janine Hansen, State President, Nevada Families for Freedom
Melissa Clement, Executive Director, Nevada Right to Life
Cyrus Hojjaty, Private Citizen, Las Vegas, Nevada
Katrin Sienkiewicz, Private Citizen, Gardnerville, Nevada

Chair Peters:
[Roll was taken. Committee rules and protocol were reviewed.] Welcome to the Assembly Committee on Health and Human Services. We have three bills on the agenda today and will be taking them out of order. We will start today with Senate Bill 177. Welcome, Senator. We are glad to have you in our Committee today.

Senator Marilyn Dondero Loop, Senate District No. 8:
Thank you, Madam Chair. I picked up the wrong folder and just sent someone to get it, so could we be in recess for just one minute?

Chair Peters:
Yes, we will be in recess until we get those papers.

[The meeting was recessed at 12:35 p.m. and was reconvened at 12:36 p.m.]

It looks like we have everything in the room now, so we will come back to order and continue with the hearing for Senate Bill 177.

Senate Bill 177: Imposes requirements governing Medicaid coverage of certain antipsychotic or anticonvulsant drugs. (BDR 38-82)

Senator Marilyn Dondero Loop, Senate District No. 8:
Thank you so much for your patience. I am pleased to come before you this afternoon to present Senate Bill 177. This bill codifies an existing requirement that Medicaid cover antipsychotic and anticonvulsant drugs under certain circumstances and extends the requirement to health maintenance organizations (HMOs) and managed care organizations (MCOs). Additionally, this bill will authorize the Commissioner of Insurance to penalize those who do not comply.

First, I will provide some brief background on mental health in the state. In Nevada, over 20 percent of adults report having a mental health disorder, and in almost 6 percent of adults, the disorder is so severe it causes serious functional impairments in daily living activities and in the overall quality of life. This bill intends to remove barriers associated with access to mental health and other health services by protecting those individuals who rely on antipsychotics and anticonvulsant drugs, antipsychotic medications, and any pharmaceutical agent used to control the symptoms of serious mental illness such as those that occur with schizophrenia, bipolar disorder, and even some severe forms of anxiety and depression. Anticonvulsants are described as any drug used to reduce the frequency or occurrence of epileptic seizures or to terminate an ongoing seizure. Though there are protections written into the Medicaid manual regarding anticonvulsants and antipsychotics, not having these protections codified in the *Nevada Revised Statutes* (NRS) leaves room for additional barriers to be put in place. For example, many other states require more than one failure of a preferred prescription for their Medicaid patients before covering another one, leaving the individual to deal with withdrawal symptoms and other discomforts that come from gaps in treatment. Some states require the failure of two or three, and this is not something I want to see happen in Nevada.

Section 1 of this bill codifies the existing requirement for Medicaid to provide the coverage of any typical or atypical antipsychotic medication or anticonvulsant medication that is not on the list of preferred prescription drugs upon the demonstrated therapeutic failure of one drug on that list to treat the condition of a recipient of Medicaid. Section 2 of this bill clarifies that this requirement will apply to health maintenance organizations. Section 3 of this bill authorizes the Commissioner of Insurance to suspend or revoke the certificate of authority of an HMO that fails to comply with the requirement, and section 4 of this bill clarifies the requirement of section 1 that it will apply to managed care organizations.

It is my pleasure to introduce somebody here at the table with me of whom I am very fond, Abbey Bernhardt. Abbey is the former Miss Lyon County, and she is the current Miss Nevada Virginia City under the Miss America Organization and is a mental health advocate to create positive policy change. I want you to hear her story, and listen carefully because this bill is about our constituents and our Nevada residents who live next door to us. And lastly, Robin Reedy will also join me at the table. Robin is the executive director of the National Alliance on Mental Illness (NAMI) Nevada, an organization of family, friends, and individuals whose lives have been impacted by mental health. So, we will listen to Abbey's story, and then we will be ready for questions.

Abbey Bernhardt, Youth Recovery Peer Support Specialist, National Alliance on Mental Illness:
Hello. My name is Abbey. I am with the National Alliance on Mental Illness. At 3 years old, I was diagnosed with bipolar disorder. I experienced rapid episodes with manic cycling. I had so much anxiety, sadness, and anger all at once. By middle school, the mania turned to depression, and I found myself in crisis. My doctor put me on medications, hoping one would work. When it did not, he added another. My anxiety and depression increased, and I suffered from hallucinations that I had never had before and have not had since. One of the scariest memories is sleep paralysis. At this point, I was hospitalized, and a new doctor started decreasing all of the medications to start over. Now, I experienced withdrawal symptoms from medications adding additional extreme symptoms. When I first became depressed, I could deal with the pain to a certain degree. Eventually, it became harder until I could not even get through the day. I started to disassociate. I became convinced life was not real: Maybe I was drowning or in a coma, dying. I could not see a way out of my pain, and I was beyond what I could handle. I felt the weight of the world, and loneliness and sadness consumed me. At 10 years old, I attempted suicide. There was no escape. Doctors fought Medicaid trying to manage my medications but had little control over what medications were approved due to the power insurance companies have over coverage. I know the importance of medication. It gave me back my life and a way to manage my mental health. If doctors were able to choose medications based on my need, I would not have suffered so much trauma for so long. The memories of my suicide attempt left me with reoccurring nightmares when I would relive that horrible day that led me to that attempt. Now when I get depressed, I fear the nightmare I once lived. I stand with those who are struggling. There can be better days ahead. I support S.B. 177.

Chair Peters:
Thank you, Ms. Bernhardt, for sharing your story—tragic and common, unfortunately. Ms. Reedy, I believe you are next.

Robin Reedy, Executive Director, National Alliance on Mental Illness Nevada:
[The National Alliance on Mental Illness Nevada supplied additional information Exhibit C.] Thank you. I am the Executive Director of NAMI Nevada. That is the National Alliance on Mental Illness here in Nevada. I represent both those living with a mental health condition and the families who love them. Medication—a change in medication is the most dangerous time for someone living with a mental health condition and their families. I have heard story upon story with tragic outcomes because of changes, but one story I would like to tell you is much more personal. When my granddaughter was a junior in high school, she started suffering from depression, and it was serious. Her medications changed constantly trying to figure out what would work for her and dealing with the insurance companies saying, no. The National Alliance on Mental Illness believes any medication choice should be between the patient and the doctor. Period. My granddaughter eventually did not graduate high school. As she turned 18, there were more medications, and we paid cash to get the right medication for her. She is doing well now, but she lost two years because insurance companies refused to give her the medication her doctor thought would work for her; it was complicated by the fact that she was under 18. Who here wants to give up two years of their life? Who here wants to see their children or grandchildren give up two years of their lives? Please pass S.B. 177.

Chair Peters:
Thank you for sharing your stories today. Do you have any others?

Senator Dondero Loop:
No, those are my presenters, so if you have questions, please go ahead.

Chair Peters:
Great. My Committee members have let me know they have questions. I want to ask a clarifying question on this bill. The bill as written would affect only those who qualify for Medicaid. Is that correct?

Senator Dondero Loop:
Yes, it only affects those who qualify for Medicaid.

Chair Peters:
It is an existing internal policy, so this would codify it so it cannot change through regulatory and policy changes?

Senator Dondero Loop:
Correct.

Chair Peters:
Thank you very much.

Assemblyman Gray:
I have one quick question for my clarification. Just to be clear to get on the record, this is not going to be their first-line drugs. They will have to have tried other formulary drugs, and those will have to be proven ineffective before they go off formulary to be covered, correct?

Robin Reedy:
They will have to try one of the formulary drugs, and if that does not work, then they should be able to go with the drug of choice.

Assemblyman Gray:
Okay. Thank you. Do you know any reason Dr. Robin Titus in the Senate was opposed? She was the only nay vote I could find.

Senator Dondero Loop:
I cannot speak for another Senator or Assemblyman's vote. You would have to ask her.

Assemblywoman Gorelow:
Thank you for being here. I know we have been working with commercial insurance, and sometimes we have to fight to get the medication we need. I was on hold for eight hours fighting my insurance company for my son. Referring to the current list of drugs, how many are on there? Do you have any idea, and in how many instances does this happen? I assume it happens more frequently than people might think.

Senator Dondero Loop:
I checked with my phone-a-friend, and none of us are clear on exactly how many. We might be able to get you that answer, but I do not know it.

Assemblywoman Gorelow:
I was curious how many were on there.

Assemblywoman Taylor:
Thank you, Senator, and your presenters for bringing this important issue. Do you find there may be trends? Are there other states that have put something like this, where you have to try one of the formulary drugs, or something along those lines, and then you can go to the drug your doctor prescribed? It is important to go with what your doctor prescribes.

Senator Dondero Loop:
Yes, there are other states. I will let Ms. Reedy or Ms. Jeanette Belz answer that because they know other groups that have these types of bills.

Jeanette Belz, representing National Alliance on Mental Illness Nevada:
Good afternoon, Madam Chair, and members of the Committee. Thank you so much for that question. As Senator Dondero Loop mentioned in her testimony, there is a wide range across the country. One of the things that has made us concerned is the state Medicaid program changed its pharmacy benefit manager (PBM) effective July 1, 2022. There are some

programs that PBM participates in nationally with other states. Not knowing what those trends might be, it made sense to codify the current policy in statute. However, having said that, what would be lovely is if we could take that "fail one" policy away. Unfortunately, that would create a fiscal note because it is not current policy, so you weigh putting something in statute that is helpful versus something that would be really helpful. We opted not to because then there would be a fiscal note. When I was a junior lobbyist, that was the way it used to be for Medicaid. There were no restrictions on typical and atypical antipsychotics and anticonvulsants at that time. That was removed because of dollar considerations and savings to the state.

Chair Peters:
This is an important issue, especially as we are talking about destigmatizing and taking mental health and behavioral health issues more seriously. I encourage anybody who is interested in this topic to start diving in. There are several resources we can get if you are interested, but it is much more complex than just allowing patients and doctors to have their relationship, especially when it is state dollars that are involved.

Assemblyman Orentlicher:
Thank you, Chair, and thank you for bringing this bill. Does this requirement of covering any alternatives after trying one on the formulary get into the question of whether there is a generic alternative to the brand name not on the formulary? Does this say Medicaid cannot require the generic, or would Medicaid still be able to require the generic version if they go to the off-list drug?

Senator Dondero Loop:
I do not believe that is the case in this bill, and I do not believe Ms. Belz thinks there is either.

Jeanette Belz:
If you look at page 3, section 1, subsection 6, it says the Medicaid program must automatically cover any typical or atypical antipsychotic medication or anticonvulsant medication that is not on the list of preferred drugs upon the demonstration of the failure of one drug. So, I believe that would not create the restriction you are referring to.

Assemblyman Orentlicher:
Would you be comfortable if we clarified that if there is a generic version, Medicaid can require the generic version? Or would you have a problem with Medicaid saying we will let you have this medication, but we just want you to have the generic version?

Chair Peters:
Ms. Bernhardt, I think sometimes personal stories and the impact generics have had, especially on behavioral health drugs, can be helpful in understanding the complexities.

Abbey Bernhardt:
I have been on these generics, and I know when I was on lithium, at least I think it was lithium, there were so many medications over the years. Some generics I have been on have not worked as successfully. They feel different in my symptoms, and they cause different things to happen, so I do not think generics always work as effectively.

Chair Peters:
Can I clarify Senator? Did you work with Medicaid on this bill in the Senate?

Jeanette Belz:
I know I am not the Senator, but the real question was whether there was going to be a fiscal note on this or not. Since there was no fiscal note and there was no testimony in opposition, to me, that meant if there were issues, they would have been brought up.

Also, if I could briefly address Assemblyman Orentlicher's question. This is the bill in its purest form, and I would not want to inadvertently misstep with an amendment that would be unintentional in nature.

Senator Dondero Loop:
I would also address Assemblyman Orentlicher's question. With any bill, I would never say yes without seeing language. Many times, you can say yes, and then you see the language and it is a no, so I always prefer to see the language. But, we have not heard from Medicaid. Nobody has opposed this bill.

Chair Peters:
Thank you. Do you have any follow-up? All right, I have two more questions on my list. Please let me know if you have other questions.

Assemblywoman Newby:
Why the selection of antipsychotic and anticonvulsant drugs? In the treatment of mental health, patients need to try out antidepressants and other medications, and sometimes another one works better for them. Was there a particular issue with these categories of drugs versus other medications to treat mental health?

Jeanette Belz:
That would lead to the creation of a fiscal note because this codifies the current Medicaid policy of "one failed" for these particular drugs. As I mentioned earlier, a long time ago those drugs had open access—atypical and typical antipsychotics and anticonvulsants. That has been underlying in the policy for a long time because those were open access, but then they were restricted. This codifies the current policy respective to those drugs. It would be lovely to open it up.

Assemblyman Nguyen:
Thank you, Senator, for this bill. Also, thank you, Ms. Bernhardt, for your testimony. It was really moving, and I appreciate your sharing your story. It is always hard to hear it as well as

talk about it, so thank you for sharing. In terms of this bill, from a process standpoint where we enact laws, are Nevadans still having challenges getting the medication? Referring to my colleague having to spend eight hours on the phone, if this law were to pass and we need to implement this, if Nevadans have issues with folks not complying with these HMOs and MCOs, where do patients or Nevadans call—and hopefully, not have an eight-hour experience being on hold—to figure out where the help is even if there are laws in place?

Jeanette Belz:
This only applies to Medicaid. It would be the process Medicaid has in place if it has an issue with the implementation. I can tell you Medicaid is good at notifying providers. They have bulletins and notify providers of changes, and their PBM does as well. Lots of changes happen, not just related to drugs, but their PBM notifies providers relative to those. Their system is very good about that, and it would only apply to Medicaid. It would not apply to a commercial insurer; it does not apply to PEBP [Public Employees Benefit Program]; it does not apply to others, the self-insured; it does not apply to any of those. It would be whatever policy Medicaid has in place should there be challenges to how they are getting their drugs.

Assemblyman Nguyen:
My line of thought was toward making sure the community I represent—mostly those with language access issues—has the ability to navigate this process. This is a good intention where we can have more resources available, because mental health issues in the Asian community, especially coming out of COVID-19, have risen; definitely, there are a lot more who need these resources. In terms of processes that exist so language access communities that try to navigate this, and I know Medicaid is great, but in terms of data for folks accessing these resources, maybe we can raise awareness for the language access communities.

Senator Dondero Loop:
Thank you very much. That is a good reminder that we need to do those things. Hopefully, when this information goes out after the bill is passed, we have doctors who are aware and other health professionals who can assist, and all of us, right? Our constituents contact us and NAMI and other mental health organizations—of which we have many—and, hopefully, they will have that information for our fellow colleagues and constituents as well. But thank you for the question.

Chair Peters:
To that point, there is a cultural competency bill floating around the building that addresses some of those physician concerns for ensuring communication and cultural competency work is being done on the physicians' side. The state has robust policies on language access in certain areas, and I am sure Medicaid does as well; however, we do not have anyone from Medicaid in the audience today. We could follow up with them if you have additional questions on Medicaid's policies around language access. Are there any other questions from the Committee?

One of the most important issues you did not touch on, but which is worth putting on the record, is the economic impact of reducing the burden and barriers to access for these kinds of drugs and prescriptions, especially for those who are eligible for Medicaid, because they are struggling to get on their feet. The point of Medicaid and the social service structure is to help folks get back on their own feet, figure out how to support their families, figure out how to get access to the things they need to continue in some cases, without those supports. The economic burden of spending two years of your life struggling to find what makes you function properly or in a way that adds to your quality of life is a huge economic burden. I really appreciate this bill is not just a health care bill. It is about the economics and the burden of our system on folks.

Seeing no other questions, we will go ahead and move into testimony. We will start with support testimony in our physical locations here in Carson City and in Las Vegas and then move to the phones. If there are folks who would like to provide support testimony on S.B. 177, please come up to the desk.

Catherine Nielsen, Private Citizen, Carson City, Nevada:
Hello, Chair and members of the Committee. I am going to make some quick comments as a constituent today. Both my husband and I have severe epilepsy. We both spent several years in trial and error, desperate to find medications that work for us. Seizure medication can provide control of seizures in seven out of ten people. And I repeat, we spent several years, both of us did, trying to find medications that work for us, and only I was able to find one after 12 medication trials. My husband had a quarter of his brain removed to get seizure control, so it is a big deal. Medicaid does not know more than the doctors who work directly with these patients. The goal is to give back life to the individuals who have such a significant life-changing diagnoses. I urge you to listen to the patients who have gone through this and the family members who have supported people with epilepsy or mental health conditions. All we want is access to the medication that allows us to live our lives. Thank you.

Elyse Monroy-Marsala, representing Nevada Psychiatric Association:
[Elyse Monroy-Marsala supplied a letter from the Nevada Psychiatric Association, Exhibit D.] I am here today on behalf of the Nevada Psychiatric Association. As testified today, when patients have to go through those changes in medications, it is an incredibly volatile time, so ensuring providers are able to get their patients to the right medicine as quickly as possible is incredibly important. What that does is help improve and increase the patient's opportunities for a better health outcome. The most important thing is the better health outcome. We have heard talk today about the money part of this, and better health outcomes for patients on Medicaid means less money spent by Medicaid, so that is a good thing all around. To the Chair’s last comment, I will remind people that healthy people sustain a strong workforce, and a strong workforce will sustain a strong economy, so we urge your support of this bill today. Thank you.

Barry Cole, Private Citizen, Reno, Nevada:
I am a member of the Nevada Psychiatric Association, so I am glad my organization is in support. I want to testify as a psychiatrist because I have a slightly different view of how this all really happens. Twenty to thirty years ago, if you had asked me how I would pick the next medicine for the next patient, it would have been a lot of verbiage that would come down to what has been abbreviated as SWAG [stuff we all get]. If you know what that means, then you know what I am talking about. Today, it is precision. We talk about the diagnosis. We talk about which neurotransmitters we might want to modulate. We look at side effect profiles. We ask about the cost. I want to know how you will pay for the medicine because that changes what I prescribe. Each clinical trial works out to be one to three months. It takes me about a month to titrate up the medicine, at least a month to observe it, and if it is a failure, a month to take somebody off before I can start the next medicine. Now, herein lies the rub. If you look at the first episode of psychosis, each redundant psychotic break reduces the recovery rate by 10 percent. If you have ten psychotic breaks, you may become permanently psychotic, so we are trying to prevent permanency. We are trying to prevent what are called "neuroplastic changes" and get to the right medicines sooner rather than later.

Questions were asked about generics versus brand names. There is an interesting gimmick to this. The FDA [Food and Drug Administration] will acknowledge that both have the same chemical compound, but what you do not know is that a generic is allowed to have a wider range of standardization. It might only be 70 percent of the reference drug; it might be 115 percent. If you move people from one generic to another, you could have a 45 percent variance. That is why some endocrinologists say, My patients cannot take levothyroxine; they must take Synthroid. Many epileptologists will say, My patients cannot take generic phenytoin; they must take brand name Dilantin because they want consistency. If I measure a blood level and I make a dose adjustment, I can rely on that. If I am bouncing around from generic to generic, I do not know what I am dealing with.

From my perspective, we now have precision medications in terms of the antipsychotics we can give them in one-, two-, three-, and six-month injections. That is a tremendous improvement. Patient compliance is virtually 100 percent if they show up for the once-every-unit-of-time injection, and we are trying to move more people in that way. The problem is a month of that medicine is potentially $1,450. Start doing the math; you are talking about many thousands of dollars for three to six months, but then look at the price of a psychiatric hospitalization. These are not cheap—$1,000 to $2,000 a day to be in an inpatient unit. I want to encourage you to look at S.B. 177 as getting people to the right meds at the right time. The cost savings will come from what we do not do, which will not be to unnecessarily hospitalize people because they did not successfully respond while they were still outpatients. They were not getting progressively more refractory to treatment; they are staying available to us.

Alex Tanchek, representing Nevada Advanced Practice Nurses Association:
I am representing the Nevada Advanced Practice Registered Nurses Association here in support of the bill.

Sarah Watkins, representing Nevada State Medical Association:
Good afternoon, Madam Chair, and members of the Committee. I represent the Nevada State Medical Association. We are in support of S.B. 177 as it ensures continuity between the patient and the physician, and thank you to the bill sponsor for bringing this.

Chair Peters:
Seeing empty desks both in Carson City and Las Vegas, I will go to the phones for support testimony on S.B. 177.

Dora Martinez, Private Citizen, Reno, Nevada:
I am representing the Nevada Disability Action Coalition. Good afternoon, Chair, and members of the Committee. I was not prepared to testify, but I heard one of my favorite Senator's voices, so I listened to the rest of the testimonies and did some quick research. I really love this bill. People with disabilities fall into this category most of the time, and we sometimes have a hard time. We appreciate Senator Dondero Loop. We like this bill, and we support this bill.

Chair Peters:
Thank you, Ms. Martinez. Next caller, please. [There was no one.] We will move on to opposition testimony in our physical locations and then move to the phones. Is there anyone in Carson City or Las Vegas who would like to provide opposition testimony on S.B. 177? Seeing no one approaching the desks, please check the phone lines for opposition testimony on S.B. 177. [There was no one.] We will move on to neutral testimony. Is there anyone in Carson City or Las Vegas who would like to provide neutral testimony on S.B. 177? Seeing no one come up to the desks in our physical locations, we will move to the phones. Is there anyone on the phone line for neutral testimony on S.B. 177? [There was no one.] Does the bill sponsor have closing remarks? We are going to waive closing remarks today. That will close out the hearing on S.B. 177.

We will move on to Senate Bill 286. This bill revises provisions relating to health care. Welcome again, Senator. You may begin when you are ready.

Senate Bill 286: Revises provisions relating to health care. (BDR 40-84)

Senator Marilyn Dondero Loop, Senate District No. 8:
I am pleased to present Senate Bill 286 on a topic that is near and dear to my heart. This measure seeks to bring more awareness to multiple sclerosis (MS). Multiple sclerosis is defined by Johns Hopkins University School of Medicine as a long-lasting disease of the nervous system, an autoimmune disorder if you will, that causes the body to attack itself, damaging the nerves. This condition disrupts the essential communication between the brain and the body affecting everyone in different ways. Symptoms can range from blurred vision to losing the ability to communicate completely, and, in severe cases, complete paralysis. The Cleveland Clinic of Nevada, the only national multiple sclerosis-designated partner in southern Nevada, asserts there are approximately 2,500 Nevadans who suffer from this condition. As many of us know, there are challenges with diagnosing this illness for multiple

reasons such as the vagueness of symptoms and the lack of a specific test used to identify the disease. Despite these challenges, it is proven that early diagnosis yields better results and reduces disability since it allows for early intervention. Multiple sclerosis is diagnosed through a ruling-out process in which two things must be true: for an MS diagnosis, you must have two attacks at least one month apart and have more than one area of damage to the central nervous system myelin, which is a coating or layering around the nerve. This damage is often identified using MRI [magnetic resonance imaging] or a neurological exam.

Current research shows the sooner you can obtain an MS diagnosis, the sooner you can start therapy to reduce its effects. Disease-modulatory therapies (DMTs) are used to reduce the severity and number of attacks one experiences. Disease modifying therapies have been shown to be effective in reducing long-term disability. David Humm, known as one of the original [Oakland/Los Angeles] Raiders, received a diagnosis after retiring from the National Football League. When considering treatment, he opted out of receiving DMTs. That was until he noticed his sister Lori, who was also diagnosed with MS. Her treatment experience was different, as she elected to receive DMTs and responded well to treatment. Unfortunately, David lost his battle to MS in 2018. If there were more information disseminated about MS, he could have been more aware of the benefits of DMTs long before Lori's diagnosis. I went to school with David, not at the same high school, but we were in high school at the same time along with his family and my siblings as well as with a well-known lobbyist, Helen Foley. You might have heard me say on the floor at one time that Lisa Foster, our friend and longtime lobbyist here in the building, was diagnosed as well, but her delayed treatment has resulted in her now using a cane and a walker, and that is why we have not seen Lisa in the building this session.

Bringing more awareness and increasing access to information on MS could save the lives of many Nevadans, and for this reason, I chose to sponsor this bill. I am going to speak briefly to the sections of the bill, and then I am going to hand it off to my copresenters. Section 1 of this bill amends existing law and requires the Division of Public and Behavioral Health of the Department of Health and Human Services to maintain a website that provides information relating to MS and the resources available to those who are diagnosed. In section 2, the Governor must annually proclaim the third week of March to be Multiple Sclerosis Week, calling upon the media, educators, and health care professionals among others to bring MS to the attention of Nevadans. I think all of you received an MS pen and a bracelet at the end of March.

I would like to introduce Jimmy Humm. He is David Humm's nephew, and he has been a wonderful help to me telling this story. I also have Regan Comis with me today representing the Cleveland Clinic with some statistics on the disease. Madam Chair, with your permission, I would like to turn it over to Jimmy to tell the story of his uncle David.

James M. Humm, Private Citizen, Las Vegas, Nevada:
Thank you, Chair Peters, and members of the Assembly Committee on Health and Human Services. Today I am here as a private citizen to assist Senator Dondero Loop with her presentation, as this bill means a great deal to my family. Unfortunately, MS has been a big

part of our lives. In many cases, our lives revolved around it. As I sit here and reflect, there is not a day I can remember MS did not impact the lives of me and my family. I still recall seeing my cousin Courtney, when she was only 10 years old, pushing her dad in his wheelchair. Watching such a young person learn how to push and collapse a wheelchair and lift it unassisted into the back of a car was truly a sight to see. Let me quickly point out that I did assist her when I saw it. My aunt Lori was also afflicted with the disease at way too young an age. She had to navigate the raising of children while her body slowly betrayed her. Oftentimes attending their school and sporting events trying to tackle the bleachers with the use of the cane was no easy task. She continues to this day to fight this disease. Although Uncle David lost his battle, there are many others out there like Lori who continue their fight and struggle with what would seem to most of us in this room to be mundane tasks.

I outlined these struggles, but please know we have had several uplifting and incredibly positive experiences, too. My uncle received many acknowledgments and accolades during his battle and denoting his battle. My aunt has gotten help, care, and medicine she needed. We have met incredible people like Dr. Hua at the Ruvo Center for Brain Health and Regan Comis, from whom you will hear shortly, who advocate on their behalf. They are doing terrific work, and of course, there is Senator Dondero Loop who was kind enough to bring this bill forward. We are honored to be here today at her request, as the action she is taking will help raise awareness and lead to a path to something more ideal to educate and raise awareness on early detection to provide the proper diagnosis, treatment, and long-term care for those who need it, and to aid professionals in the continued research needed to battle this silent killer. I ask this Committee today, without delay, to please consider passing S.B. 286 as the first step in our journey to working together on these issues to raise awareness, prolong lives, and beat this disease. Since as Dr. Hua told us when we met with her, time equals brain. Thank you for your support and consideration of this bill.

Regan Comis, representing Cleveland Clinic Lou Ruvo Center for Brain Health:
I am here today representing the Cleveland Clinic Lou Ruvo Center for Brain Health. It is estimated that nearly one million people are living with multiple sclerosis in the United States. Multiple sclerosis is sometimes referred to as the invisible disease because many people living with MS do not outwardly exhibit symptoms. This can create a unique set of issues, and some people assume patients do not really have the disease. People with invisible symptoms must constantly adjust to the difference between how they feel on the inside and how the world reacts to them. Since they do not look sick, this can cause self-doubt or discourage some from seeking treatment, yet we know the earlier you can obtain a proper diagnosis and start the appropriate therapy, the more the risk of future disability is reduced.

While MS cannot be cured, it can be treated. One of the keys to early diagnosis is being aware of the early signs and symptoms of the disease. The onset of MS often occurs between the ages of 20 and 40 years old. Warning signs include blurred vision, difficulty walking, numbness and tingling in different parts of your body, weakness and fatigue, balance issues, problems controlling the bladder, cognitive impairment, and muscle stiffness and spasms. The Mellen Program at the Lou Ruvo Center for Brain Health is the only comprehensive

MS center in Nevada. We are currently serving around 2,000 lives, and we see over 3,500 MS patients a year. We have conducted 26 clinical trials and tested 5 newly FDA-approved drugs. Yet, we continue to turn to early detection and diagnosis to provide the best outcomes for our patients. That is why we are here in strong support of S.B. 286 to increase awareness around multiple sclerosis, provide tools for families to find assistance and the support they need, and to emphasize the importance of seeing a doctor if you or a loved one exhibits the signs and symptoms of the disease.

Chair Peters:
Thank you. Are you ready for questions?

Senator Dondero Loop
Yes, Madam Chair.

Assemblyman Nguyen:
Thank you, Senator, for being here and the copresenters as well. I want to make sure I put this on the public record as we look at different bills this session around the issue of language access and cultural competencies. In looking at things to modernize how we govern in our state as well as in the agencies and services that are available, we take this next step technologically with websites and look at an opportunity to translate this information on a website. Most of the time, it is an easy thing to add a button that says, if you speak this language, click here. Then it will convert the text into a language the user is familiar with, especially with something as complicated as MS. The district I represent has the fastest-growing language community in Nevada, and we want to be sure this information is thought of right away. Maybe you already have that in mind, but during this awareness week, I would love to see us reach out to those who truly need it because of language access. I just want to put that out there, and thank you, Senator.

Senator Dondero Loop:
Thank you very much. Duly noted, and we will make that suggestion.

Chair Peters:
I hope those who represent Google and Microsoft are listening because they have translation software, and maybe they are not marketing it in the right place. Are there other questions from the Committee?

Assemblywoman Taylor:
My colleague’s question made me think of the number of Americans who are impacted by this disease. I had no idea it was that large a number. How many in Nevada suffer from MS? Demographically, some diseases impact one group more than another or one gender more than another, and that information would also be helpful from a website standpoint. Is there anything like that? I want to see if you have anything you might be able to share.

Regan Comis:
Thank you, Assemblywoman Taylor. The exact number of Nevada citizens who have MS is hard for us to state. We guess it is around 2,500 in southern Nevada, but I do not have the data for northern Nevada. As far as the demographics, I do not have the information in front of me, but it is something I can reach out to the Cleveland Clinic and get for you.

Assemblywoman Taylor:
Thank you. That information on the website would be helpful for us. And then, if there is anything with any kind of markers or indications demographically, I think that would be helpful as well.

Senator Dondero Loop:
Ms. Lisa Foster believes she had the disease for 20 years before they diagnosed it and had the MRI. David Humm's situation was a little bit different, but still, early diagnosis is the one thing that is constant and important.

Assemblywoman Newby:
Thank you, Senator, for bringing this bill. I had the great pleasure of growing up right next door to David Humm. From seeing him as this huge, very athletic man to seeing his decline over my lifetime was really something, so I am glad you are bringing this. My question is about this website. In the implementation of it, I would hope we would also provide that information to doctors. When someone gets a diagnosis, it has to be a relief to know what is going on, but also scary to understand you have just stepped into this world. I would encourage outreach to make sure when patients get that diagnosis, they are provided that information. Dr. Google can be a scary place, so it is always nice to try and push people toward verified information.

Assemblyman Gray:
You should add as many resources as you can, like trial studies that may be going on for people to reach out to. This affects our family intimately. My wife's twin sister, in that 20-to-40 age group, was working full time as a county sheriff's dispatcher. It started with diplopia. Six weeks later, it hit her so badly that in six weeks she was bedridden. They were saying, We do not know what is going on. They wound up having to do a brain biopsy. They were not doing DMTs yet, but Copaxone was in its trial phase. They used interferon, and it did wonders. She has a 6-year-old and a 4-year-old now and is living a somewhat normal life. What we are lacking with community resources is the availability to find out the resources out there to help them cope. It caused marriage problems; it caused all kinds of things not directly related to the disease but not of a physical nature.

Senator Dondero Loop:
Thank you for that suggestion. We all three agree. One thing we are so fortunate to have in the southern part of the state is the Cleveland Clinic. It is a gift. It is a blessing for them to be in our state. So, thank you.

Chair Peters:
Thank you. Any other questions? [There were none.]. Seeing none, we will move into testimony. We are going to start with support testimony in our physical locations and then move to the phones. If you are here in support, please come up to the table, and you may begin when you are ready.

Catherine Nielsen, Private Citizen, Carson City, Nevada:
I am speaking today as a constituent only. I was 27 when I was diagnosed with multiple sclerosis. Before my diagnosis, I knew of the disease because my aunt was diagnosed as a young child. She is now completely bedbound and depends on others to help with every aspect of her life. My aunt was part of the first round of testing of DMT drugs, and because of people like her, treatments are available, and available much sooner. I received my diagnosis and treatment at the Lou Ruvo Center for Brain Health, and I applaud their hard work. Because of them, I am hopeful I will watch my three daughters walk down the aisle, and I plan to stand up on my own next to my husband when they ask who is giving them away. It is vital that this bill passes to allow for earlier access to information, and, hopefully, prolong the life and livelihood of those who receive this devastating diagnosis. Thank you.

Lynn Chapman, Private Citizen, Sparks, Nevada:
Thank you, Chairwoman and Committee. I am representing myself today. My husband's niece was diagnosed in 1989. She was 21 years old; she had just had a baby, and she was diagnosed with MS. We were all shocked. How could this possibly happen? Did we know anything about MS? We had heard the name, but we really did not understand what that meant. Along came a friend of mine I had known for about 32 years—Cathy. When I first met her at church, she was using a cane; then, shortly thereafter, she was using a walker. The next thing I knew, she was in a wheelchair. She had MS, and almost passed away. She was bedridden. It was terrible. Now, with the newer drugs, you would never know it. She walks fine. She is in really good health. You would never know she has MS. People know that multiple sclerosis is something bad, and you can end up in a wheelchair, and that is what most people know about MS. I think it would be nice to have an awareness week, and a lot more than that, because people do not realize how devastating this can be. We need to know about resources. We need to know about information and the newest meds that are available, and about the clinic in southern Nevada. I think that is important. This is a good bill and please pass it. Thank you.

Tom Dunn, Private Citizen, Reno, Nevada:
Good afternoon, Madam Chair and members of the Committee. I am testifying today as a private citizen. I have a family member who has been surviving with MS for over 20 years, and had to retire early as a public schoolteacher due to her challenges with MS. I also have a coworker who retired early from being a firefighter so that he could spend the best years of his remaining life with their small children at home. So, as a private citizen with family members and coworkers who have been surviving with MS, I highly encourage you to support this bill. Thank you.

Barry Cole, Private Citizen, Reno, Nevada:
Some of you may remember I was both a neurologist and a psychiatrist. Back in the eighties, the way we treated MS was with something called ACTH [adrenocorticotropic hormone], which was a way to stimulate the adrenal glands to give a generic immune suppression. Now we have moved on to these disease-modifying agents. It has become very precise. It is a godsend that we have the Lou Ruvo Center in Las Vegas. Dylan Wint is the medical director. He is a neurologist and a psychiatrist. One thing about MS I think is always misunderstood is it is not muscular dystrophy (MD). There is MS versus MD which are Jerry's kids—the little boys we see usually on crutches and in braces. Multiple sclerosis starts for most of the patients I have seen in their late teens or 20s, and it becomes a progressively more devastating disease. You lose vision. Maybe that is the first thing you notice, or you have what was originally called tic douloureux. Now it is called trigeminal neuralgia, and God help you if you have it on both sides. That is the diagnosis of MS even before we had things like magnetic resonance imaging (MRI) and lumbar punctures. With MRIs, we can detect this disease very early, and time is money in this condition. We really want to get to it.

I want to remind you that Nevada is a long state, and there is an MS zone that has been talked about that starts at 40 degrees north and goes north. Elko is at 40.8 degrees latitude; Winnemucca is 41; north Reno is 39.5; and Las Vegas is at 36.1, so we live in a state where we should expect to see MS. If you come from a place like Ho Chi Minh City, it is only at 11 degrees north. You would virtually not expect to see MS in Vietnam. But it is fascinating that as you go around the world and you go far north or far south, you begin to run into MS. It is probably an autoimmune disease. People have speculated about potential viruses that might be responsible.

Disease-modifying treatment saves lives, and I mean that. I have only once been told as a neurology resident that I saved a human life, and it was because I started the treatment for MS at a critical point in this person's life. We can do very well, and anything that brings attention to this disease and what it will mean for people's lives we need to get out sooner rather than later. I would even hope it comes up in a high school health class. That is how basic it should be.

Chair Peters:
Thank you for your testimony. Seeing no one else coming to the table in support in Carson City or Las Vegas, is there anyone on the public line to provide support testimony on S.B. 286?

Dora Martinez, Private Citizen, Reno, Nevada:
Good afternoon, Madam Chair and Committee. I represent the Disability Action Coalition. This is a very great bill. I say ditto to what all the people who went before me said. Thank you to the sponsor.

Chair Peters:
Is there anyone else on the line for support testimony? [There was no one.] Thank you. We will move on to opposition testimony in our physical locations. Is there anyone in Carson City or Las Vegas who would like to provide opposition testimony on Senate Bill 286? [There was no one.] Seeing no one approaching the desks, is there anyone on the public line for opposition testimony on Senate Bill 286? [There was no one.] We will move on to neutral testimony. Is there anyone in Carson City or Las Vegas to provide neutral testimony today? [There was no one.] Seeing none, we will go to the phones. Is there anyone on the public line to provide neutral testimony on Senate Bill 286? [There was no one.] I would invite the Senator for closing remarks if you have any.

Senator Dondero Loop:
Thank you very much, Madam Chair, and I thank the Committee for its indulgence today hearing two bills. Thank you for all your good questions and suggestions, and I urge your support of this bill.

Chair Peters:
Thank you so much for your presentations today. With that, we will close the hearing on Senate Bill 286.

Our last bill is Senate Bill 109. I know Senator Nguyen is on her way, and we have Mr. Musgrove here as well as a copresenter. We will take a brief recess while the Senator gets to the room and situated, and then we will begin.

[The meeting was recessed at 1:42 p.m.]

[The meeting was reconvened at 1:47 p.m.]

Welcome, Senator. We are going to open the hearing on Senate Bill 109, which revises provisions governing anatomical gifts.

Senate Bill 109 (1st Reprint): Revises provisions governing anatomical gifts. (BDR 40-453)

Senator Rochelle T. Nguyen, Senate District No. 3:
I am excited to be here this afternoon to present in front of my old Committee which is under wonderful new management. I am honored to present Senate Bill 109 today. It is official. In 2022, the U.S. reached one million organ transplants, more than any other country. Together, the organ donation and transplant community has made life-saving history, but it is only the beginning with more than 105,000 people on the waiting list in the U.S. for lifesaving transplants. Over 600 Nevadans are waiting. We are working to reach the next one million even sooner.

Critically ill patients needing organs must face the financial, physical, and emotional burdens of waiting for a lifesaving organ transplant. For Nevadans, that means traveling to neighboring states to get the care they need. Despite the continuing efforts at public education, misconceptions and inaccuracies about donations still persist today, and many of the opponents of Senate Bill 109 may be helping propagate some of those myths. We have seen that happen even on the Senate floor during the passage of this bill from that house. While specific beliefs differ, all major religions in the United States support or even encourage donation as a person's final act of love and charity in this world. If you are sick or injured and admitted to the hospital, the No. 1 priority is always to save your life. You will have heard sitting in this Committee that it is the primary mission, goal, accomplishment, creed, whatever it is, of our hospital and medical professionals that their goal is to save lives, and that is their first goal. Organ donation can only be considered after death has been declared by a physician. Senate Bill 109 does not change that, and, in fact, it does what several other states like Arizona, California, Florida, and Michigan have already done. The reason I point out those states is they have different geographical regions, they have different political heads of state, they have different political makeups, but they all have come together to enact similar legislation.

What Senate Bill 109 does is give coroners, medical examiners, and the court the ability to make decisions to save a life through donation if there is no one to speak on behalf of the deceased, or we have no indication what their last wishes might have been. We would hope that this final act of love and charity could be codified and enhanced by Senate Bill 109. There are a couple of things I am going to have my colleague, Dan Musgrove, present as well as part of the PowerPoint [Exhibit E].

Dan Musgrove, representing Nevada Donor Network:
They say any publicity is good publicity. Unfortunately, when this reached the Senate floor, that was not true. This was the headline on Channel 8 in Las Vegas saying that organ harvesting could expand in Nevada as we advance S.B. 109 [page 1, Exhibit E]. Let me tell you with complete certainty this does not provide blanket authority to procure organs. This is what was said on the Senate floor by our esteemed colleague, Dr. Senator Titus: "Sets a bad precedent. It focuses on people who tend to be homeless or foreign-born with no idea and cannot determine their true wishes [page 2]." We believe S.B. 109 tightens up the Anatomical Gift Act—a uniform law just about every state has adopted. As Senator Nguyen talked about, a number of states have gone a little bit further to make sure it is even more clear. This is a specific set of circumstances we are trying to address in S.B. 109, and I want to call attention to the fact that the Nevada Hispanic Legislative Caucus and the Latin Chamber of Commerce support S.B. 109 because there are some misconceptions out there, they wanted to make sure were not felt by this Committee.

As I said, it provides a shift in current law and tightens it [page 2]. Current law allows for about nine categories—either relatives or caregivers—who have the ability to make the determination if their loved one or the person they are taking care of is deceased and has not made a clear and present affirmation that they want to either be an organ donor or they do not want to be an organ donor. When that situation occurs, and we have done research, it only happens about once a year here in Nevada where we have not been able to find the next of kin or been able to determine whether they marked their license or told a friend they cannot be an organ donor, or that they want to be an organ donor. This gives us a very narrow ability in the case of brain death—occurrences that happen only in the hospital. That is the only time we ever transplant organs—someone who is already in a hospital, and everything has been done to try to save their life. In the case of brain death, the coroner or medical examiner could be that neutral party who says, yes, if this person is a good candidate, and we have not done anything invasive. All we have done is look at their medical records, we—the organ procurement organization—think this person who is deceased or about to die is a viable candidate for lifesaving transplant. At that time, we go to either the coroner/medical examiner or, if someone is on life support, we could go to the court, and ask them to give us permission to procure an organ for a lifesaving transplant. We believe S.B. 109 makes the law tighter. It removes one of the provisions already in law that says, "Any other person having the authority to dispose of the decedent's body." We thought that was very vague and ought to be stricken and gives us a little bit more authority to go through the process.

So, why is it important? Seventeen people each day die awaiting a transplant [page 3, Exhibit E.]. Every ten minutes, another person is added to the transplant list. Over 104,000 are waiting right now, and 600 are Nevadans who are your friends. You are going to hear from a friend who got the call, a friend of a lot of people on this Committee. These are your neighbors and your constituents. If you have the ability to save a life, would it not be worth going through this process to get one to seven or eight organs that could change people's lives forever? That is what S.B. 109 does.

As to the actual bill, we worked very closely with the coroner/medical examiner, in both Washoe and Clark Counties to make sure the provisions give them comfort and that due diligence was done. When I finish, I am going to ask Jackie Warn of Nevada Donor Network to speak, but I also have Dr. Laura Knight, Washoe County Chief Medical Examiner and Coroner, on Zoom who can talk about the process they go through to ensure that due diligence is done. The bill provides a framework for us to go through that process, both with the coroner/medical examiner and the district court. We worked with both of them and amended the bill to a degree on the Senate side. We hope this is a bipartisan-supported bill on this side and appreciate your time and attention today. If I can, Madam Chair, I will open it up to Jackie Warn in Las Vegas and then Dr. Knight in Washoe County.

Jackie Warn, Chief Quality Officer, Nevada Donor Network:
Good afternoon, Chair Peters and Assembly Committee members. I am so appreciative of Senator Nguyen’s commitment to organ donation and having the opportunity to work with her through this important piece of legislation. As Senator Nguyen stated in her earlier remarks, we believe this bill puts better protection into law, specifically for *Nevada Revised Statutes* (NRS) Chapter 451 and the Uniform Anatomical Gift Act which prescribes who has the authority to allow the lifesaving gift of life through organ donation. Nevada Donor Network is one of 56 federally certified organ procurement organizations certified by the Centers for Medicare and Medicaid Services, better known as CMS. Founded in 1987,

Nevada Donor Network's core purpose is to save and heal the lives of more than three million people in the state of Nevada and the thousands of potential transplant recipients. Our primary functions as an organ procurement organization are to coordinate, recover, and allocate these lifesaving organs and healing tissues for transplantation and research on behalf of Nevada's heroic donors.

As stated in NRS Chapter 451.566, "an anatomical gift of a decedent's body or part for the purpose of transplantation, therapy, research or education." Organ, eye, and tissue donations may be made by any member of the stated classes or persons. Senate Bill 109 further supports decision making for donation for transplantation when there is no known person able to make this decision and there is no evidence that the decedent has communicated their desire to not donate their anatomical gifts. In these circumstances, this bill is proposing the ability for the coroner and/or medical examiner to provide such authorization. Should the decedent not fall under the jurisdiction of either, the case will elevate to the court system for a decision to be made. So, S.B. 109 will make more organs available for recipients, shorten the wait for transplants, and save more lives. Again, I would like to thank Senator Nguyen for her sponsorship of this legislation, and I would like to ask for your support with S.B. 109.

Chair Peters:
Thank you, Ms. Warn, and Dr. Knight is next. Please go ahead.

Laura D. Knight, M.D., Chief Medical Examiner and Coroner, Washoe County Regional Medical Examiner's Office:
Good afternoon. I serve as Chief Medical Examiner and Coroner for the Washoe County Regional Medical Examiner's Office, and I am speaking here today in my official capacity. I thank you very much for the opportunity to appear by Zoom, as I had many autopsies to do today. Thank you for the opportunity to support this bill, S.B. 109, for reasons already stated including the long list of Nevadans awaiting a lifesaving transplant. We must do everything we can to preserve the opportunity for organ donation. My office works hard to facilitate postmortem organ donation whenever possible in compliance with the law, as Nevada law states we should collaborate and facilitate organ donation and transplantation whenever possible while maintaining our mission to determine the cause and manner of death. The occasion for the medical examiner or coroner to authorize donation in lieu of next-of-kin consent when the next of kin is not available will arise very infrequently. Such occasions where there are no next of kin available and a patient is clinically diagnosed with brain death and eligible to be an organ donor are rare. I anticipate this would be a very small number of cases, so this is not a wide-ranging change, but it is important nonetheless because every single organ potentially saves a Nevadan's life. The reason it will be a low number of cases is partially related to the small number of potential organ donors as well as the fact that my office and my counterpart in southern Nevada, the Clark County Medical Examiner's Office, go to great lengths to identify a next of kin or another suitable individual to provide the authorization.

I will go through a list of some of the techniques my office and the Clark County office use in order to locate family. First, we have a large number of resources in databases online that create or house a lot of information about people including their known associates, family members, neighbors, roommates, all previous addresses, et cetera, with contact information. We are often able to go straight into this database, which is only available to law enforcement and other investigative agencies, and immediately find people who know something about the deceased individual. We go on to contact government services, social organizations such as homeless shelters, child and adult protective services, housing and food assistance services that may have encountered the decedent and may have information such as emergency contacts. We check for arrest reports with law enforcement. We obtain medical records from hospitals including identifying information about emergency contacts which are always provided on hospitalization. We interview friends and neighbors and witnesses around the scene of the death. We have even gone so far as to canvass local homeless shelters and homeless encampments someone was known to frequent in order to find out their name and who they may be related to or know. Finally, if they have a telephone with them or personal address book, we will call all the numbers in those resources. As you can see from this laundry list, we are very resourceful. We go even as far as court and government documents, online public record databases, and then finally, online social media. Social media is a huge resource for us in identifying people connected to an individual. So, we do have a lot of access to find the next of kin. It is going to be rare that we utilize this new tool; however, I do not want to minimize the importance of it. It is important that we have the ability to authorize donations when there is no one else to do so. Those are most of my comments. I just wanted to point out the lengths we go to, to actually find the next of kin. In the majority of cases, we are going to locate the next of kin, and that would be our preference, rather than authorizing the donation ourselves. But in those rare cases where no one can be found, it will fall to us under this law, and we will take that responsibility very seriously. Thank you.

Chair Peters:
Thank you, Dr. Knight.

Senator Nguyen:
If I could just follow up for one moment. I know many of you were able to attend the Nevada Donor Network dinner at the Governor's Mansion. Dr. Knight was the Inaugural Life Award recipient of Governor Lombardo's and the Nevada Donor Network's Award of Excellence. She has an amazing career, and I am so grateful she provided that information because it is important for this Committee to understand. And again, I will make it abundantly clear that without this law, there are not these added protections. They are doing this as a part of their practice, but we want to codify these more stringent protections in place for that category (j) [subsection 1, NRS 451.566] which is, "Any other person having the authority to dispose of the decedent's body." That is current law, so this amendment in this law as a part of S.B. 109 makes it more strict, puts more protections in place to make sure procurement organizations like the Nevada Donor Network are doing that extra due diligence

in addition to working with the coroners in those rare circumstances where they are working in coordination with law enforcement and are unable to locate family members who normally would not have connections to those loved ones at the end of their lives. With that, we are ready for any questions the Committee might have.

Chair Peters:
Thank you for the presentation. We have several questions. We will start with Assemblyman Gray.

Assemblyman Gray:
Thank you, Madam Chair and Senator Nguyen. I like the bill, but I do not like the bill. I am that conflicted. We need so many organs but trampling on somebody's rights in that case without knowing creates a real conflict in me. If we do not know, then we default, even though we go to the courts. Is there a better way to do it? But let me preface that. I am not that concerned about the homeless issue or the illegal immigrant issue. I do not think that is going to happen. Two weeks ago, my homeless brother was found dead on the side of a freeway. That could have been the one time in his life of 65 years that he could have done something good for society. If he had carried a license or anything else, he probably would have signed up for it. I do not see the harm, but what I am wondering is, we have these little red hearts on our driver's licenses. Could we enact this, but could we use a black heart or something else to indicate they are absolutely in no way a donor? You can either have the red heart to be affirmative or nothing to indicate, I do not care. People's last wishes, if they can be identified, need to be honored. That is the last thing they are asking for.

Dan Musgrove:
To your point, there has been discussion throughout the country about the difference between an opt in and opt out. When you go to the Department of Motor Vehicles (DMV), you make a conscious decision to opt in to be a donor, that it would default to making you a donor unless you opted out. That has not been done in the United States. It has been tried in a couple of foreign countries, and you would think that would be a good thing. What happens now is you have made an absolute affirmation that you do not want to be a donor. If something happens and maybe on your deathbed you let family members know you changed your mind, you want to do that gift of life, we as an organ procurement organization would be hard-pressed to go against what was on the license that said you opted out; you made an affirmation that you do not want to be a donor. How often do we go to the DMV to get our license changed? What a laborious process that would be. The potential is that someone could have a change of mind and neglected to change it on their license. So, we would have to default to the no. We had a bill brought, I think last session, but it was determined that it did not work in exactly the way I described.

We certainly do not feel we are trampling on an individual's rights. As the Senator said, every religious organization supports it. They think it is more humane to be the gift of life, and if somehow with all the due diligence we did to try to find the next of kin and it came out down the road that someone came forward, I think they would feel exactly as you did. For the first time, that person had the ability to do something very precious. You will hear from a couple of folks who got that call and what their relationship to their organ donor is. It is something so meaningful that in this very narrow circumstance, I would hate to say we are trampling on an individual's rights, because we are trying to look in the best interest of the whole.

Senator Nguyen:
I would also have you look at the statute as it currently exists. Without this protection, there is no added level of having to do that due diligence. There is no added level of having to go to the court. There is not that level of definition and certainty to give those extra added protections for a process that may make people feel uncomfortable, and understandably so. What this bill does is put more protections in place and puts more responsibility on those procurement organizations to do more outreach.

Assemblyman Gray:
Having been down this road before and dealt with this, how are you going to get the intimate medical history you are going to need to identify which organs are going to be able to be used for that gift of life? As I said, I am really conflicted. We spent close to three hours on one of these calls—these interviews. How are you going to do that same due diligence with your patients receiving the organs if you do not have the history?

Senator Nguyen:
I think the Nevada Donor Network might be in the best position to talk about that.

Jackie Warn:
I do want to reemphasize the fact that when we are entertaining or pursuing an opportunity for donation as it relates to S.B. 109, these patients are under the care of a hospital, a physician, and a whole medical team. Therefore, many tests are being performed. Sometimes there are individuals who may have additional information, but we rely on the testing and the clinical outcomes from our physicians and other medical care albeit at times, there may be limited medical records available, but because of the battery of tests that are required, and especially under the umbrella of the United Network of Organ Sharing, there are criteria and testing is performed, especially for communicable diseases, to ensure, moving forward with donation, these would be safe organs for transplant for any recipient. I hope I was able to answer your question.

Assemblyman Gray:
I said this is something I am passionate about. I do believe in organ donation. Absolutely and wholeheartedly, but if you have the time to do that kind of testing and this person is already in the hospital, how is it there is no way to contact any next of kin? The timelines are not jibing, especially when we talk about patients coming in who may have been homeless or other undocumented patients—not undocumented aliens—just undocumented patients.

Dan Musgrove:
Dr. Knight outlined all we will attempt to do. And again, it is so rare that we have not been able to find that next of kin or friend or caregiver that we do not believe this will happen

more than perhaps one time a year here in the State of Nevada. But we are willing to bring this issue in front of you to debate because that one person could save one person's life. Again, we do not believe it is going to happen often, but it is worth this exercise.

Chair Peters:
The Senator said in her introductory remarks they are codifying the process of tracking folks down which right now is policy and best practice but not required under the current statute. It is not about getting around the obligation to look for next of kin or the responsible party to make the decision. It is really about codifying that process to ensure that it is best practice that is implemented.

Assemblywoman Taylor:
Thank you for bringing this forward. My colleague, Assemblyman Gray, asked a question I had pertaining to the medical records review. I want to ask a couple of clarifying questions about utilizing the data. That person is in the hospital and so, is that data going to be private or protected? How do they ensure there is some protection around that? It is great to do the work. Can you find somebody? That is clear you do the list that Dr. Knight shared and all the things that are done to try to find somebody. That is clearly important. I do not know what is left from there. That is great, but on the medical information side, how do you make sure the data is going to the place it should go? Even though this person is going to be deceased fairly soon, we want to protect their information as well.

Senator Nguyen:
This industry is not something I was familiar with until I became involved with the Nevada Donor Network where I learned about the disparities our communities of color and Nevadans of color face when it comes to organ donation and organ procurement—because it is very disproportionate. That is where my background came in. I asked some of those same questions initially when I met with them in 2019—about the process they go through in determining any organ donation. There are lots of standards to meet to be able to procure organs, even from willing and knowing donors. Ms. Warn could further highlight how those records are procured from someone who has no next of kin or if they are in the process of looking for next of kin.

Jackie Warn:
To further expand upon the medical records within the hospital under CMS's conditions of participation, organ procurement organizations such as Nevada Donor Network have contracts or memorandums of understanding (MOUs) with each of the hospitals that specifically state the sharing of medical information is for the sole purpose of evaluating and assessing an individual for transplantation. As far as sharing that information, that is part of the CMS regulations, and it is written with each one of the hospitals and the organ procurement organization to have these memorandums of understanding or contracts. With that said, every individual going in is under medical care. So, through that period, first and foremost, it is the responsibility and obligation of the care team to do all they can to help that individual, to try to save that individual, to provide treatment to that individual. While that workup is taking place, records are being created. First, care is given, but if under

certain circumstances a patient comes close to their demise, that is when Nevada Donor Network, as the organ procurement organization, is notified and provided the opportunity to assess and determine whether or not this individual would be a candidate for donation. Meanwhile, if it is a John Doe or Jane Doe, efforts by the hospital are what Dr. Knight shared. It is the same process by which we work collaboratively with the hospital and with the coroner or medical examiner to try to identify. There are many moving parts all at one time, but I wanted to emphasize how we have the ability, and that sharing of medical information is for the sole purposes of evaluating for donation.

Assemblywoman Taylor:
Thank you, Ms. Warren. That makes a lot of sense. For clarity, you mentioned four or five other states—Arizona, California, Florida, Oregon, and Michigan. Do most states have this? Can you give me an idea of where this can happen in those rare cases when you cannot find someone?

Jackie Warn:
Yes, most states do have provisions that are written in. We specifically looked at a diverse group of states so we would be able to share with all of you as Committee members that there are states of different demographics, different political leadership and oversights that have these provisions written in which is aiding donation in those states when such circumstances come up. I can share, having worked in other states and having had legislation like this in regulation, it has come into effect where it was used. But again, it was rare, it was not something of the norm, and due diligence had taken place. Most certainly, we would love to identify who those individuals' loved ones are and have that conversation. But even if donation is not a yes, for whatever reasons—maybe the result of what Dr. Knight or any other coroner/medical examiner may conclude because of the circumstances of that individual, I think we all would like to see a reuniting of someone's loved one with that individual. Most certainly, it would be most meaningful in those circumstances.

Assemblyman Hibbetts:
Thank you for the presentation. If this is simply codifying what is already being done, why not just strike section 5, subsection 1, paragraph (j)? Make it easy.

Dan Musgrove:
It is not being done because when there is not anybody who meets those categories, then the process stops. We have been very hesitant to use that provision we are striking where it talks about "Any other person having the authority." This is a very litigious society, and we certainly do not want to put ourselves in a position to err. That final category, some states allow the hospital executive to do it. That is why we looked at a number of states. For those of you who sit on the Assembly Judiciary Committee, you probably understand there are uniform acts that all states have. This is one of those—the Uniform Anatomical Gift Act—so there is a framework of things every state has adopted, but there are certain circumstances where a state can go a little bit further. We felt it was important to go two steps further: A brain death. We allow the coroner/medical examiner, and if there is no one else, we would go to the court because we want a third party to help us ensure we have done the right due

diligence, as you all talked about and questioned us about, to make sure we are not erring and making a mistake by going against someone's wishes or family members' wishes. Even if a person has a red heart on their license, if a family member comes to us and tells us, "We do not want to do it," we always yield to the family even though that person has made that conscious choice. We want this to be a welcoming experience for everybody involved, especially those who might get the organ.

Senator Nguyen:
It is important to say that section 5, subsection 1, paragraph (j) is so vague and ambiguous people could use that if they wanted to, but we wanted to have extra protection because it is such a sensitive issue. Not everyone is comfortable with organ donation. That is a fact. That is why we do not have an opt-in or opt-out situation on your license right now, but look at some of the other categories we are not even beginning to touch. If you look at section 5, subsection 1 on page 3, paragraph (h) is "An adult who exhibited special care and concern for the decedent." That is not even defined in statute. Someone could say, I have a special concern, and I am going to donate this person's organs. That person takes precedent, and that would be included already in our existing law. I really do think this gives more direction, more protections for those unknown circumstances in such a limited thing. It is a limited thing, and I think whether or not it is our policy in those limited circumstances to save just one more life or to potentially save seven more lives depending on how many organs might be there—or it could be even more than that—that is where we are. Did that answer some of your questions?

Assemblyman Hibbetts:
Thank you. It does. From what I understand, we struck paragraph (j) and put in the person appointed by the court. Fast forward to section 5, subsection 4, which is the new portion of the law. I am not a lawyer, obviously, but can you tell me how often does a judge reject an *ex parte* order? Has it ever been done?

Senator Nguyen:
I do not think we have ever had this process in place.

Assemblyman Hibbetts:
I do not mean specifically for this process; I mean, in general, an *ex parte* order.

Senator Nguyen:
Who knows. There are *ex parte* orders throughout the justice system, whether they are in civil cases, family cases, eviction cases, or criminal cases; so how many times those are rejected I would not know. I could contact the office of the courts, and they may keep those statistics. But for those of you who serve on Assembly Judiciary, they probably do not keep those statistics.

Assemblyman Hibbetts:
I doubt that they do. I was just wondering if you knew of any in your private sector employment. Thank you. I appreciate it.

Assemblyman Orentlicher:
Thank you, Chair, and thank you for your presentation. Mr. Musgrove correctly referred to the Uniform Anatomical Gift Act, and while I like the idea of this proposal for the reasons you articulated—that we need to save lives—I think it is fair to say it is a departure from the Anatomical Gift Act. The section 1 coroner provision was in an earlier version and was removed from the most recent version of the Anatomical Gift Act. In that paragraph (j) of NRS 451.566, if you look at the comments of the Act, they indicated it is going to be used in cases where too much time has passed for organs to be used. You might get eyes or tissue, but not organs. That was their expectation. Of course, states have deviated from the Anatomical Gift Act, and maybe for the reasons you have given; maybe the Anatomical Gift Act got it wrong. But one thing is important. When you look at California's authorization that we are following, as Dr. Knight said, it is important to have these very careful steps to make sure you do everything you can to find a next of kin or another spokesperson.

California codifies those steps, or many of them, and that is important because the reason why the Anatomical Gift Act took out what was proposed in section 1 is because there were coroners in Los Angeles and Cincinnati who were not as scrupulous as Dr. Knight, and that led to unfortunate court cases. We do not always know which we are going to get. Are we going to get a *Brotherton* situation or are we going to get a Dr. Knight? The *Brotherton* case was about a scandalous coroner. I think it might make more sense to follow California and put those kinds of steps in statute, so we make sure they really are followed, and careful efforts are made.

I would appreciate your thoughts about why rather than taking the California model saying you have to take reasonable steps; here are reasonable steps. We just say you have to look. Make sure that you look for a reasonably available person without saying what that means.

Dan Musgrove:
To your point, especially when it came to the coroner/medical examiner provision, we ensured that this would be for transplant only. It could not be for tissue; it could not be for research. It could not be for any other purposes to make sure we are getting into a very finite set of circumstances. We also wanted to make sure it was clear that this had to be the subject of a valid anatomical gift—so all the other questions we talked about in terms of verifying this indeed would be a transplantable organ. We also specified that not only will the coroner do her due diligence, but we will be required—both when working with the coroner, but more importantly when working with the district court—to prove we too have done our due diligence before we can even bring that request to the court to ensure no persons in the prior classes are available and that there has been no evidence of a communication by the individual of a yes or a no concerning how they feel about organ donation. I do not know if there is a state agency that regulates this or whether that would be something to put in regulation. I do not know if there are regulations that do this.

As you said, Assemblyman Orentlicher, there is proof that other states have gone a step further than the Uniform Anatomical Gift Act. I think the last time the Uniform Anatomical Gift Act was touched was in 2003 if my memory serves me correctly. We have learned a lot since then, so we are leaving it to this Committee to decide what the appropriate thing to do with S.B. 109 is.

Senator Nguyen:
I lean toward giving more discretion. Obviously, we could put every single step in here, but we have heard from our coroners what the practices are and what they would anticipate having to go through. Rather than being so prescriptive in statute about those requirements, I would tend to lean toward giving more discretion because things change, technology changes. If we put in social media, what if in five years social media was not a thing, it would be forever codified in statute that we have to go through that process. Sometimes we can be overly prescriptive in what we require people or mandate people to do in statute.

Assemblyman Orentlicher:
Yes, I appreciate that concern. And just a small correction; it was in 2006, but you are right. It has been a while, and I appreciate your thoughts about why it makes sense to be more prescriptive. As you know, our organ procurement system is built heavily on trust. We want people to donate organs, and they need to appreciate that their body will be treated as they requested. What happened with those coroners in Los Angeles and Cincinnati is they did not do what they were supposed to do, and it led to the removal of section 1. Every state had something like that; not every state law did, so it was a step backward. It seems to me we should err more on the side of doing everything we can—taking the extra steps—to assure the public that our coroners will be like Dr. Knight and not like the unscrupulous coroners. Putting stuff in statute like California is a way to preserve trust. Does that make sense?

Senator Nguyen:
I understand and appreciate that. I am sure Ms. Warn can talk about this from the perspective of the Nevada Donor Network. Much of their campaign is educating people on organ donation, educating people on long-term myths and how they can approach the people in different communities that are in need of organs to become organ donors. I trust them when they are comfortable with this language that they have come up with, that this will also feed into or help support their overall mission of educating people on proper organ donation and dispelling a lot of those myths.

Dan Musgrove:
I think there is something on NELIS from someone who will be testifying in opposition about what is going on currently with the organ donation system nationwide. There is a great deal of scrutiny. The Centers for Medicare and Medicaid Services (CMS) is reevaluating how they rank organizations and ensuring this is a process that helps procure as many organs as possible because there are certainly a number of people. I can assure you that Nevada Donor Network on any spectrum metric out there is either No. 1 or in the top five worldwide when it comes to organ procurement organizations (OPOs), and CMS has reviewed our policies and used them as a guideline for others because we are one of the best, if not the

best, in the country and in the world. Again, we have to put some trust in what they are going to do, but they believe this is one more tool they would like to have in their toolbox. It is up to this Committee to decide whether you want to amend the bill further. I would agree with Senator Nguyen. We are in a good spot right now in terms of the protections, both for family members and the individuals in the process, and we certainly would like to see it proceed as it is.

Assemblywoman Gorelow:
I want to go back to the process of looking for family members and get a little better sense of the timeline of that. Obviously, it is going to vary for each individual, but is that something you look at for a day or a couple of days, and what happens when you find family members and they disagree on whether the organs should be donated?

Laura Knight:
I can address the first part of that. That process could take anywhere from a couple of hours to multiple days depending on the difficulty of locating someone. There are times where just a quick look in the LexisNexis Accurint database accessible to investigative agencies will allow us to identify someone, make a couple of phone calls, find that we have their correct contact, and provide that information to the donor network so they may go on to have the conversation about consent. The second part, I would leave to my counterparts at Nevada Donor Network.

Jackie Warn:
I can help address the second part of that question because of the due diligence that is done and the extensive search that is made in order to identify the individual and potentially a next of kin. There is nothing hasty being done. All those avenues are exhausted before Dr. Knight or any other coroner/medical examiner or we would elevate it to the courts before a decision would be made. However, if after the fact and time has lapsed, someone has come forward as the next of kin, as an organization of organ procurement, we will have this discussion with the family. We will share with that individual the efforts that were made, and also state that we were not aware of any no to donation, and it was a good-faith effort—the final decision beforehand. With that said, we hope to bring the family some peace and solace to know that a decision was made and that good will move forward from the lifesaving gifts that were given. However, sometimes, unfortunately, it takes a while for a family member to be able to comprehend or come to terms with the final decision that was made. But as an organ procurement organization, we continue to work with that family to support them. It may be part of their bereavement and grieving process as well, so we will not walk away from anyone who has come forward, whether early in the decision-making process or after that decision has been made, and we will provide support and be there for them to answer questions and provide them with any information they would need.

Senator Nguyen:
If that person is located prior to the procurement of the organs, and that family member says, No, they will not proceed with that any further. Again, there are multiple layers and there is not only the procurement organization, there is the coroner doing the due diligence; the

hospital is also doing that due diligence. Even after everyone has agreed this is a potential candidate, it has to go to the district court for that order to be signed as well. So many different agencies and organizations are part of this that would have to have layers of protection. I think your question was if someone comes forward and you have not done the procurement yet and they say, No, I do not want this; I do not want my loved one donating now that you have located me, the organization would not seek the procurement.

Assemblywoman Gorelow:
Thank you for that. What if you found two people—you found a parent and you found a sibling—one says, Yes, and one says, No. Do we default to the no? Do we let them rock, paper, scissor it? How do we decide at that point?

Jackie Warn:
In accordance with the Uniform Anatomical Gift Act, there is an order of hierarchy by which an individual has the authority to make the decision. In the instance of what you have shared, you said a parent and then a child, the parent would be able to be the decision maker. Now, sometimes the dynamics of the family could draw out those different decisions, but we would lean on the individual with the highest authority according to the law to be able to provide that decision.

Chair Peters:
It is really interesting, but in the interest of time, could you talk about section 1, subsection 2, which is the liability immunity? Can you tell us where that comes from and the intention for that piece?

Dan Musgrove:
That was a request from both Washoe and Clark Counties specifically for the coroner or medical examiner to have that liability. The Nevada Justice Association looked at that and did not have any issue with it. It was a request by their legal counsel that they receive some kind of immunity for a decision as long as we went through all those processes.

Chair Peters:
I was just going to ask that. Is it typical in other states that have adopted measures similar to this to have that kind of liability clause in the law?

Dan Musgrove:
I do not know.

Senator Nguyen:
We can get that information for you though.

Chair Peters:
Yes, that would be helpful. Thank you so much. Are there any other questions from the Committee? [There were none.] Seeing none, we will move into testimony on Senate Bill 109. We will start in support here in Carson City and in Las Vegas and then move to the phones.

Mendy K. Elliott, Private Citizen, Reno, Nevada:
I am here representing myself today. I am on the board of the Foundation for the Nevada Donor Network, but on a personal level, on November 22, 1968, my father received a heart transplant at Stanford and was the 86th heart transplant in the world. He was 49 years old, a World War II hero, and a highly decorated colonel in the Air Force. He died at age 49. If it was not for the fact that a motorcycle accident occurred, my AB-negative father would not have had another year of life. Fast forward to five years ago where my younger sister was killed in a motorcycle accident. She was a donor, but they could not get to her fast enough. She was in rural California, and she could not donate. Fast forward to January 5, 2021. When my husband died, the nurse came in and said, Call the OPO. I knew exactly what they were saying, but at the time, I had forgotten that Steve Elliott, District Court Judge Steve Elliott, had put on his driver's license that he was a donor.

Families have a difficult time making these decisions, but we have so many people we have all known and people we have touched who have been benefactors of the fact we have these laws on the books. I am proud of the fact that Nevada does an incredible job when it comes to transplantation. The Nevada Donor Network and the OPOs around the country are doing such services and saving lives, whether it is children, whether it is adults. Nick Vander Poel, my son, was a donor for bone marrow. He went to a basketball game and as a joke got swabbed. The next thing you know, he is being flown to Arizona to save someone's life. All of us are touched by this. I understand it is a difficult and complex conversation, and I can appreciate the fact that we are cautious as we approach this bill. But personally, I want you to think about if it is your family, if it is your neighbor, if it is your child, the impact this bill will have. Thank you.

Barry Cole, Private Citizen, Reno, Nevada:
Back to being a neurologist: A tragedy could be defined as burning or burying a body with perfectly good organs. That is a tragedy. In my career, I have seen two groups of patients who could become organ donors. The first group is those who come through the emergency room. They are dead on arrival; we almost cannot get it figured out fast enough. But then there is a whole group of people who wind up in critical care intensive care units (ICUs), neuro ICUs. Over days, we determine they are brain dead. To determine you are brain dead, I have to do two electroencephalograms 24 hours apart that are flatlined, and you may not be receiving any medications that could sedate you or paralyze you, and your body temperature has to be normal. So, the notion is nobody is dead until they are warm and dead. Some of you may have heard that if you are into Boy Scouts or survival. This is really something where we can almost plan the moment of disconnection. We can almost coordinate getting somebody to the operating room to have organs procured. It is such a wonderful act. Thank you for having the red heart on your card; hopefully, every one of us has that donor heart on

our identification (ID). It is usually because somebody did not ask you to become a donor because I meet so few people in my entire life who say, I absolutely refuse to be a donor. Even my most religious in-laws want to be organ donors. So, all the debate about safeguards, I really do not see this as a high-risk endeavor. If one dying person can save a half dozen or more, that is good public policy, so I am in support of S.B. 109.

Chair Peters:
Thank you. Seeing no one else coming up to the table in Carson City, we will go to Mr. Gray in Las Vegas.

Tyre L. Gray, Private Citizen, Las Vegas, Nevada:
[Tyre Gray supplied written testimony Exhibit F.] Many of you know me as a lobbyist in that building for a number of years and/or the former President of the Nevada Mining Association. Now, I have the privilege of serving as the Chief Administrative Officer for the Nevada Donor Network, but I am coming to you in a personal capacity today because I am also a kidney transplant recipient. I really hope to put a human face on what transplant does. Many of us who have either received transplants or who are dealing with illnesses that may require transplants do not talk about it. I was 23 when I was diagnosed, and I never talked about it. I know four people who are walking around in that building right now who are organ transplant recipients. Some of them may be in the room or they may not be in the room because it is something that, unfortunately, our society still has a bit of a stigma with; I hope to help to relieve some of that stigma.

I was diagnosed at age 23 with focal segmental glomerulosclerosis, which is a lot of letters to say that my body was attacking itself. Again, I admit to not speaking about it, but that set off a process no one can imagine. You are 23, and you are usually supposed to be tackling the world, figuring out what you want to do, but every aspect of my life was impacted—where I lived, where I could work, the people I socialized with, all of that was something I had to think about. Many of the opportunities you think about taking when you are 23, I was foreclosed upon taking, and for nine years I waited on the transplant list. I was listed in California, traveled to Arizona to be listed, and was listed here in Nevada. My health began to fail, and I just had hope to hold onto. I decided to enroll in law school. I will never forget the day I got the call. It was September 12, 2012. In fact, I have a band on my wrist that says, "Donate Life 9-12-12." It was a gift to remind me of that special day, and I will never forget. I was sitting in my tax law class, and my phone rang three times from a number I did not recognize. The person said, "Is Tyre Gray there?" And I said, "This is Tyre; how can I help you?" She said, "Actually I think I can help you today. I have an organ kidney for you. How quickly can you get down to UMC?" I remember the overwhelming emotion. I talked to Dean Durant, and he said, "Get out of here. We can figure this all out later. Go get it."

This gift of life transformed my life. In the 3,885 days since my transplant, I have been able to achieve amazing things. I graduated from law school near the top of my class. I became the first African-American leader of a major trade association. But none of those things are as important as the fact that I was able to become the father of Reign and Adonis Gray. I could not have kids before this transplant, and now I have two beautiful children.

In closing, what I will say is, if you could save 900 lives over a decade, would your answer be yes? If your answer would be yes, then S.B. 109 helps facilitate that. Again, it is a clarification of processes that are happening, of law that is already in place, making sure we are able to help clear up ambiguity. Because of that ambiguity in our law, we know roughly 900 lives have not been saved or healed because one donor can impact up to 75 different lives, and that number is unacceptable in Nevada. I harp on the fact that I am one of the lucky ones. Since my transplant over 3,000 days ago, over 60,000 Americans have died while waiting on the list. In Nevada, we have an opportunity to reduce that number, to change that number by simply passing S.B. 109. I thank Senator Nguyen for her help, and I appreciate all of you on the Committee for your consideration. Again, I ask you to please support S.B. 109, because the life you save could be the next me, the next you, and/or the next president of the United States. Who knows? Thank you.

Chair Peters:
Thank you, Mr. Gray. We do not see anyone else coming to the table down in Las Vegas, so we will go to the phones. Is there anyone on the public line for support testimony on Senate Bill 109?

Peter Guzman, President, Latin Chamber of Commerce, Las Vegas, Nevada:
I have been working with the Nevada Donor Network (NDN) for the past several years in a real effort to educate the Latino community on the importance of organ, eye, and tissue donation. I am now a governing board member of NDN because I believe in it so strongly. We have been supportive of NDN since Day One when we launched Corazon de Esperanza, Heart of Hope, a campaign in an effort to spread awareness and address some of the myths surrounding organ and tissue donation among the Latino community and businesses. The NDN leadership team has been to several of our annual galas and luncheons speaking and educating families and children on this important issue.

Regarding S.B. 109, this is to clarify an existing process already codified in Chapter 451 of NRS. What we know is that there are over 100,000 Americans waiting for a transplant, and one donor can make an impact on up to 75 lives. I was blown away when I learned that. Over the past ten years, this issue has arisen about a dozen times, which is not much; however, that means 900 people were not helped because of an ambiguity in the current law. Nevada Donor Network and the government agencies that would refer a patient to NDN are fiercely dedicated to making sure the lives of our state's people are healed by the gift of transplants. Senate Bill 109 makes the process of administering the gift of life more fluid and efficient. My efforts alongside Nevada Donor Network are aimed at saving and healing lives, not taking life. We are in full support, and I ask you to do the same. I thank you for the privilege and honor of being able to testify in these chambers.

Chair Peters:
Thank you for your testimony. Is there anyone else to testify in support? [There was no one.]

[Exhibit G in support of Senate Bill 109 was submitted but not discussed and will become part of the record.]

We will move into opposition testimony on Senate Bill 109 and start in Carson City and Las Vegas.

Janine Hansen, State President, Nevada Families for Freedom:
Thank you, Madam Chair and members of the Committee. Of course, we do not oppose organ donation. We have some concerns about this particular bill and some of the issues surrounding it. It appears this bill is designed to protect procurement organizations. On page 4, line 18, it changes the basic default position in Nevada law. It changes it when it says, "No evidence exists of the decedent having communicated a desire that his or her body or part not become anatomical gifts, including, without limitation, through a refusal that has not been revoked." Essentially, it changes the automatic default position from no to yes. That is our concern, because this is where it starts, and we have concerns about what happens in the future. I really appreciated Assemblyman Orentlicher's concerns and his suggestion there should be put in this piece of legislation the specifics of what needs to happen in the coroner's office to present to the court specifically what they should do. It is wonderful to have a good coroner as in Washoe County, but we do not know what will happen in every single county. We do not know what will happen in the future. It is good to have things clearly identified in the basics of law so people can feel comfortable in what they determine to do.

As Assemblyman Orentlicher said, it has to do with trust. I read some articles, and I sent one of them to all of you by email today, about the shocking mismanagement that takes place in our organ donation system causing needless deaths [Exhibit H]. In fact, the U.S. Senate Finance Committee has done a probe into the U.S. organ transplant system. They said recent reports of lapses in patient safety, misuse of taxpayer dollars, and tens of thousands of organs going unrecovered or not transplanted, lead us to question the adequacy of the United Network for Organ Sharing. When I am using the letters OPO, it means organ procurement organization. The OPTN is Organ Procurement Transplantation Network. The federal Department of Health and Human Services has deemed that the majority of OPOs are failing key performance metrics, contributing to 33 Americans dying every day for the lack of an organ transplant. The U.S. Senate investigation of these organizations said there were serious concerns related to OPTN's role in overseeing the nation's OPOs which have been severely underperforming for decades. The OPOs have jaw-dropping tenfold variability in how well they serve Black communities. And in the past, former NAACP President Ben Jealous has written, fewer Black donors means fewer Black recipients, which means more Black deaths prompting congressional leaders to call OPO reform an urgent health equity issue. We talk a lot about equity in this building.

Organ procurement organizations have problems that run deeper than failure to recover organs. They have high-profile examples of misspent taxpayer money, criminality, and fatal lapses in patient safety prompting the bipartisan Senate investigation and the oversight committee last October to express its concerns. The higher organ donation rates in the U.S.

actually reflect higher levels of societal ills like the massive use of opioids with overdoses in the United States. In fact, while 90 percent of Americans support organ donation, a federally funded report found that the OPOs may be recovering only one in five potential donors, so there are problems in this area. The federal HHS, as Dr. Patil, former chief data scientist says, should heed the call from *The New York Times* editorial board to revisit the organ procurement transport network monopoly and pursue all options for reforms to deliver more transparent, effective, and patient-centered OPTNs. We support organ transplant. We are concerned with some of the issues of this bill, particularly changing the default and not having more specifics. Thank you, Madam Chair and members of the Committee.

Chair Peters:
Thank you. You said you had sent us those notes in an email, so we have the article [Exhibit H].

Janine Hansen:
I sent the article about the shocking mismanagement of the system to all of you in an email, and I also sent it to the committee manager, and I gave her a copy.

Lynn Chapman, State Vice President, Nevada Eagle Forum:
My favorite sister-in-law 30 years ago was the 418th person to receive a heart transplant from UCLA, and we were blessed to have her for another 13 years. When my brother was killed in 2003, he had listed on his driver's license that he wanted to be a donor, and many donations of his body were made the day he died, and in dying, he helped save many lives. Almost one-and-a-half years ago, I donated my husband's eyes, so my family has been involved in both sides of the issue—giving and receiving—so obviously, we are in support of donation, but I feel only if a person has made that decision in advance. Everyone knows the DMV has many links for information and signing up for body and tissue donation, and there are many public service announcements (PSAs) on TV and radio we have heard over the years. Most people know where to find information if they go on the Internet. They can go on websites, et cetera, and where to sign up if they are interested in doing so. I always worry about the people who are not informed at the DMV when receiving their licenses. What if people change their minds at the end of their lives? What do they do? How do they stop or want to donate?

I think we should have an awareness month. Many PSAs help people make decisions because this is an extremely important decision for people to make. I appreciate the points Assemblyman Orentlicher made; one of the most important was trust. We have to look at trust for doctors, for the coroners' offices, for organizations, for government, and for courts. Do we really trust all of them? We have to trust them to make the right decisions, so that is why I am not completely in favor of this bill because of the trust we do not always get. Please think long and hard about this. Thank you very much.

Chair Peters:
I want to thank you both for spelling out the acronyms. That really helps us, and I appreciate that.

Melissa Clement, Executive Director, Nevada Right to Life:
We are firmly in favor of organ donations. These were some of the most moving stories I have heard today, so it makes it very hard to come up here because I want to say, Go for it. But there is a part of me that is very concerned about opt in versus opt out. I would like to encourage you to really think about that and provide some safeguards. The coroner who was on was outstanding, and I would totally trust her with my body, but you have to think about everybody at every time. Gosh, you have a hard job, and thank you for doing it.

Chair Peters:
Thank you. Seeing no one else coming up to the table and no one in Las Vegas, I would go to the phones. Is there anyone on the public line in opposition to Senate Bill 109?

Cyrus Hojjaty, Private Citizen, Las Vegas, Nevada:
I will ditto the previous and future points.

Chair Peters:
Thank you for the brevity. Are there other callers on the line for opposition testimony?

Katrin Sienkiewicz, Private Citizen, Gardnerville, Nevada:
Good afternoon, Madam Chair and members of the Committee. I want to repeat what the previous folks have testified. I am not in opposition to organ donation in principle, but I do have concerns with the way this bill is written. The presenter and others who testified in favor of this bill all made the point that this is a rare situation, so my question would be, why are we legislating for one case per year, as quoted by several of the folks who spoke. The current law requires specific permission for organ donation to be given by the next of kin, and obviously that would align with the deceased person's specific wishes. Senate Bill 109 attempts to flip this and instead allows organs to be taken in the absence of evidence that the deceased was opposed and in the absence of objection by their family members. It actually takes it one step further and allows the organ procurement companies, the very companies that profit off of the organ donation, to be allowed to directly approve of an organ donation on behalf of the deceased. This is the fox guarding the henhouse. The only thing they will then need to do is make sure they cannot find any evidence that the deceased was opposed and there are no family members available to object. What kind of an incentive would these organ procurement companies have to find the next of kin? Mistakes will be made given the time-sensitive nature of organ transplantation. Furthermore, the bill then exempts the coroners and medical examiners from liability in case they make errors in granting requests made by the organ procurement companies without the approval of families. Circumventing the proper permission of the families will certainly result in cases where organs are taken against the will of the deceased and their families. Assemblyman Orentlicher made a very good point in that the due diligence steps really should be listed here and defined clearly before we move forward with legislating this change to the organ donation process. It seems to me there would be better ways to go about increasing voluntary organ donation rather than this where, once again, we are talking about the companies that stand to benefit being involved and actually granting that permission as well. Thank you very much for your time.

Chair Peters:
Thank you for your testimony. Is there anyone else on the line for opposition testimony? [There was no one.] All right, we will move into neutral testimony. Is there anyone in Carson City or Las Vegas to provide neutral testimony on S.B. 109? Seeing no one coming to the tables in either location, is there anyone on the public line who would like to testify in neutral? [There were no callers.] I would invite the bill sponsor back up for closing remarks.

Senator Nguyen:
I appreciate all the questions and the conversation. I know this is difficult and sensitive. It is our intent to put some of those added protections into the law. I am open to having discussions. I will be reaching out to Vice Chair Orentlicher to talk about some of those. I am always surprised when people want to incorporate more California laws into our *Nevada Revised Statutes*. I am open to having those conversations, obviously. Most of the determinations we made came from having local conversations with Nevadans who are practicing medicine in Nevada, who are running hospitals in Nevada, who are running organizations like Nevada Donor Network in Nevada, and transplant patients and donor families in Nevada. That is where our intention came in drafting the legislation—that this was a solution to add more protections into our existing law that really reflected our state and not those of the states surrounding us. But I am open to those conversations. Several members have already reached out and would like to have continued conversations about this, and I am definitely open to that. So, thank you for your consideration.

Chair Peters:
Thank you, Senator so much for being here. We will close the hearing on Senate Bill 109. That brings us to our last agenda item, public comment. I will start in our physical locations and then go to the phones. Is there anyone in Carson City who would like to provide public comment? [There was no one.] Seeing no one coming to the table for public comment in Carson City or Las Vegas, I would move to the phones. Is there anyone on the public line to provide public comment today? [There was no one.] We will close public comment, and with that, we are adjourned [at 3:15 p.m.].

RESPECTFULLY SUBMITTED:

____
Terry Horgan
Committee Secretary

APPROVED BY:

____
Assemblyman David Orentlicher, Vice Chair

DATE: ______________________________________

EXHIBITS

Exhibit A is the Agenda.

Exhibit B is the Attendance Roster.

Exhibit C is a document titled "SB177 – Imposes requirements governing Medicaid Coverage of Certain Antipsychotic or Anticonvulsant Medications," supplied by Robin Reedy, Executive Director, National Alliance on Mental Illness Nevada, in support of Senate Bill 177.

Exhibit D is a letter dated May 3, 2023, signed by Lesley Dickson, M.D., Nevada Psychiatric Association State Legislative Representative, submitted by Elyse Monroy-Marsala, representing Nevada Psychiatric Association, in support of Senate Bill 177.

Exhibit E is a copy of a PowerPoint presentation titled, "SB109 Misconceptions: It Does Not Provide Blanket Authority to Procure Organs," submitted by Senator Rochelle T. Nguyen, Senate District No. 8, in support of Senate Bill 109 (R1).

Exhibit F is written testimony submitted by Tyre L. Gray, Private Citizen, Las Vegas, Nevada, in support of Senate Bill 109 (R1).

Exhibit G is a letter dated May 2, 2023, signed by Senator Fabian Doñate, Senate District No. 10; Chair, Nevada Latino Legislative Caucus, in support of Senate Bill 109 (R1).

Exhibit H is a document titled "'Shocking Mismanagement' in Our Organ Donation System Is Causing Needless Death—OPTN and OPOs are mischaracterizing organ donation data to block system reform," submitted by Janine Hansen, State President, Nevada Families for Freedom, in opposition to Senate Bill 109 (R1).