MINUTES OF THE SENATE COMMITTEE ON HEALTH AND HUMAN SERVICES

Eighty-first Session
March 18, 2021

The Senate Committee on Health and Human Services was called to order by Chair Julia Ratti at 3:38 p.m. on Thursday, March 18, 2021, Online. Exhibit A is the Agenda. All exhibits are available and on file in the Research Library of the Legislative Counsel Bureau.

COMMITTEE MEMBERS PRESENT:

Senator Julia Ratti, Chair
Senator Pat Spearman, Vice Chair
Senator Dallas Harris
Senator Joseph P. Hardy
Senator Ben Kieckhefer

GUEST LEGISLATORS PRESENT:

Senator Roberta Lange, Senatorial District No. 7
Senator Dina Neal, Senatorial District No. 4
Senator Heidi Seevers Gansert, Senatorial District No. 15

STAFF MEMBERS PRESENT:

Megan Comlossy, Policy Analyst
Eric Robbins, Counsel
Norma Mallett, Committee Secretary

OTHERS PRESENT:

Layke Martin, Executive Director, Nevada Dispensary Association
Tyler Klimas, Executive Director, Nevada Cannabis Compliance Board
Kara Cronkhite, Health Program Manager, Nevada Cannabis Compliance Board
Matthew Walker, Nevada Dispensary Association
Darrell Lacy, Planet 13 Holdings, Inc.
Calvinia Williams, Founder and President, Lupus of Nevada
Chaplain Wanda Bailey Johnson, Director, Outreach for Lupus, Nevada
ShaeAnn Clements-Ojeda

Lindsay Kinsinger, Manager, Office of Public Health Informatics and Epidemiology, Division of Public and Behavioral Health, Department of Health and Human Services
Samantha Wayne
Tashe Pittman
Robert Nathan Slotnick, M.D., Ph.D., Director, Medical Genetics and Genomics
Abbi Whitaker
Tom Clark, Nevada Association of Health Plans
Cari Herington, Executive Director, Nevada Cancer Coalition
George Ross, Comprehensive Cancer Centers of Nevada
Marian Gansert
Kendahl Servino
Marlene Lockard, Nevada Women's Lobby
Erin Lynch, Social Services Chief, Division of Health Care Financing and Policy, Department of Health and Human Services
Robbin Palmer, Ph.D., Certified Genetic Counselor

CHAIR RATTI:
I will open the hearing on Senate Bill (S.B.) 168.

SENATE BILL 168: Revises provisions relating to cannabis. (BDR 56-135)

SENATOR ROBERTA LANGE (Senatorial District No. 7):
I am introducing S.B. 168 which deals with two items, cannabis curbside pickup and cannabis packaging and labeling, which I will discuss in the presentation (Exhibit B). I am joined today by Layke Martin, Executive Director of the Nevada Dispensary Association. We are presenting this bill and amendment together (Exhibit C) in cooperation with the Cannabis Compliance Board (CCB).

LAYKE MARTIN (Executive Director, Nevada Dispensary Association):
I will read from my written testimony (Exhibit D) regarding cannabis curbside pickup, cannabis packaging and labeling, and the proposed amendment Exhibit C.

SENATOR HARDY:
Is there any advertising or signage that comes with this curbside pickup?

MS. MARTIN:
I will defer to the CCB for their guidance related to what is required for curbside pickup.

TYLER KLIMAS (Executive Director, Nevada Cannabis Compliance Board):
I will ask Kara Cronkhite, who heads audit inspections in my agency, to talk about some of the restrictions for curbside that exist.

KARA CRONKHITE (Health Program Manager, Nevada Cannabis Compliance Board):
We have restrictions in place through policy that we would incorporate into regulation regarding curbside pickup. Identifications of every person in the vehicle are checked. The employees check the order and have to wear masks and gloves when handling any product or orders.

SENATOR HARDY:
Is there a limit on advertising or signage involved with the curbside pickup? Are we keeping within the bounds already existing for advertising and signage of the dispensaries?

MS. CRONKHITE:
Yes, we are keeping with the current requirements for advertising and signage.

SENATOR KIECKHEFER:
The insertion of the amended language regarding the labeling of products for sale and the removal of language as it relates to production, is this just to recognize how product flows through the production, manufacturing and distribution chain so labeling is focused on the consumer rather than every step in the process?

MS. MARTIN:
You are exactly right. It is to allow flexibility for CCB to determine how the wording should be best conveyed versus having specific stops where everybody has to apply their own labels.

SENATOR KIECKHEFER:
I refer to the amendment, top of page 8, where you are striking "a written notification with each sale of … " and replacing it with "A cannabis sales facility shall convey the following information to consumers … ." Is there anything that

says it can just be verbal? Can you just have a sign posted on the wall behind the register? Does there have to be an actual delivery of content?

MS. MARTIN:
The intention is to make sure the information is presented in the best way possible to the consumer. There is not an intent it would be on a sign or verbally conveyed. We are looking at a printout at the point of sale versus a sheet that is slipped into the exit bag versus a label on the product itself. We propose leaving it to the CCB to handle in regulation to determine what the best manner is to convey the information. I do not think the CCB has any intention of allowing those warnings to be given verbally.

MATTHEW WALKER (Nevada Dispensary Association):
I would point you to the presentation, Exhibit B, on both those questions and the manner in which something is prescribed to be on the label versus on the sticker attached to it. You can see on the smaller products what results is less information being meaningfully conveyed to the consumer. We are hoping to clear the statutory path so the CCB can comprehensively take up these regulations and ensure the information is made available, is absorbed by the consumer and can be compared among products.

CHAIR RATTI:
The intent is it would not be up to the dispensary to decide how to convey the information, but rather we are taking it out of statute and putting it into the regulatory framework. So your body would still perform the regulatory process, would give detailed instructions and would be more flexible to change because it is in the regulatory framework instead of the statutory framework. Is this the idea?

MR. KLIMAS:
Yes.

CHAIR RATTI:
Would you say for the record you do not intend to loosen the labeling or the standards in terms of the information the consumers need to stay safe?

MR. KLIMAS:
Absolutely. Core principles, public health and safety will be at the top of my list whenever we promulgate any regulations around what is conveyed as far as information.

DARRELL LACY (Planet 13 Holdings, Inc.):
We support S.B. 168 and offer a support statement (Exhibit E).

SENATOR LANGE:
This is not something new. It was already happening in curbside pickup and was successful for the business owners and patrons. The bill puts this into law. The labeling ensures these products are safe and people know what is in them when they take the products home. Products that look like candy are marked so they do not look like candy and can be kept out of the reach of children. Those kinds of things are important components in the industry.

CHAIR RATTI:
I will now close the hearing on S.B. 168. I will open the work session on S.B. 49.

SENATE BILL 49: Revises provisions relating to cannabis. (BDR 56-268)

MEGAN COMLOSSY (Policy Analyst):
I will read the summary of S.B. 49 and amendments from the work session document (Exhibit F).

CHAIR RATTI:
We had testimony on this bill, hearing from individuals who were concerned about the ability to do background checks in publicly traded companies. Stakeholders who were interested on that issue met with the CCB to see if they could mutually agree. We did not come to a 100 percent agreement, but CCB believes many of the stakeholders' concerns could be addressed through a regulatory process.

MR. KLIMAS:
That is correct. We do have a number of publicly traded companies in the industry. Nevada Cannabis Compliance Regulation 5 (NCCR 5), is a regulation dealing with publicly traded companies, background checks and waivers. Waivers of ownership under 5 percent allow for publicly traded companies with

several shareholders to continue to make day trades and purchase and sell shares. Waivers of ownership under 5 percent do not have to go through a complete registration process that any owner over 5 percent has to go through. There has been input from publicly traded companies about the 5 percent and 10 percent thresholds. There are suggestions on how to streamline that process, and the CCB understands those concerns. At the last Board meeting, it is on record CCB will hold workshops, both informal and formal whenever we make regulatory changes, so there will be plenty of opportunity to talk through NCCR 5. We encourage input from all our publicly traded companies, stakeholders and the public. We look forward to continuing to refine NCCR 5 and all our regulations as they are living documents.

CHAIR RATTI:
Would you acknowledge there could be better processes when it comes to publicly traded companies, and that is your intent by opening up those workshops on this part of your regulations?

MR. KLIMAS:
Correct. With publicly traded companies and different ownership structures, there are many scenarios and situations that go along with ownership and transfer of ownership, stock shares and selling stocks. We certainly anticipate getting into NCCR 5 and making changes that account for all those situations that arise and to help streamline the process for both regulators and members of the industry.

SENATOR HARDY:
The third amendment of the first paragraph states "The Board may employ the services of such persons it considers necessary for the purposes of hearing disciplinary proceedings." Is it subject to the Open-Meeting Law? Do we know the qualifications of those people who are employed to help or preclusions of who is not?

MR. KLIMAS:
It allows us to hire an administrative law judge. This is similar to other State agencies. The CCB does not have its own administrative law judge. We have been borrowing the Department of Taxation's administrative law judge. This is what this amendment allows us to do and is the only service we would employ under this subsection.

SENATOR HARDY:
This would not include an increase of fees for the people who are paying for the disciplinary proceeding?

MR. KLIMAS:
The administrative law judge is in the Governor's approved budget. The funds are in there.

CHAIR RATTI:
I will entertain a motion on S.B. 49.

> SENATOR HARDY MOVED TO AMEND AND DO PASS AS AMENDED S.B. 49.

> SENATOR SPEARMAN SECONDED THE MOTION.

SENATOR HARRIS:
During the hearing, I expressed a concern about the 45-day extension and its ability to be done in perpetuity. I notice the bill still says may approve one or more extensions. I encourage you through the regulatory process to put some constraints around the 45-day extension so it cannot continually be pushed out. There need to be clear instructions on when the 45-day extension will be granted or limits on how many times it can be done. At this time, I will vote the bill out of Committee but will reserve my right to change my vote on the Senate Floor.

> THE MOTION CARRIED UNANIMOUSLY.

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CHAIR RATTI:
I will open the work session on S.B. 156.

SENATE BILL 156: Revises provisions relating to crisis stabilization centers. (BDR 40-488)

MS. COMLOSSY:
I will read the summary of S.B. 156 and the amendments from the work session document (Exhibit G).

CHAIR RATTI:
The intent of this bill is to expand crisis stabilization centers from psychiatric hospitals to all hospitals, and we needed to work on the details of the wording to ensure we were getting to all hospitals. We have representatives of both amendments if you have any clarifying questions.

> SENATOR HARDY MOVED TO AMEND AND DO PASS AS AMENDED S.B. 156.

> SENATOR KIECKHEFER SECONDED THE MOTION.

SENATOR KIECKHEFER:
If we adopt amendment 2 as submitted by Mary Walker, Carson Tahoe Health, do we still need to adopt amendment 1 as submitted by Joan Hall, Nevada Rural Hospital Partners, since the intent of amendment 2 is to capture amendment 1?

CHAIR RATTI:
Our understanding from the Department of Health and Human Services (DHHS) is we need to do both to capture all of the different types of hospitals.

> THE MOTION CARRIED UNANIMOUSLY.

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CHAIR RATTI:
I will open the hearing on S.B. 175.

SENATE BILL 175: Enacts provisions relating to lupus. (BDR 40-8)

SENATOR DINA NEAL (Senatorial District No. 4):
I am presenting S.B. 175, which is a bill about lupus. I want to show a quick video about what lupus is and share written presentations (Exhibit H) and (Exhibit I) about lupus. This bill would start tracking variants associated with lupus and get data on what is happening outside of the hospitalizations that are occurring for lupus patients.

I have also submitted an amendment to S.B. 175 (Exhibit J). The most recent event around lupus funding was in 2020 when Congress authorized $8.5 million. Those funds went to the National Lupus Patient Registry indicating there was a clear interest to recognize the importance of what is going on with lupus.

CALVINIA WILLIAMS (Founder and President, Lupus of Nevada):
I support S.B. 175. The mission of Lupus of Nevada is educational awareness and advocacy. For the last 17 years, our program has consisted of nutritional workshops, support group meetings, coping strategies, educational conferences, community outreach and resources to assist our lupus community.

Individuals diagnosed with lupus face many obstacles. Some of our families and friends choose to blame us for pretending to have lupus or its symptoms. Unfortunately, they are not aware of the impact of this devastating disease so they choose to look the other way. I am a lupus survivor of 20 years. My medications are 28 pills each day just to survive.

Years ago, I was taken to the hospital as a possible stroke patient with lupus and other life-threatening problems associated with lupus. The head emergency room (ER) doctor prevented the other physicians from injecting something into me for a stroke. The ER doctor explained lupus is the great imitator, and he did not allow the injection. Instead, the ER doctor ordered other tests for me; I had been misdiagnosed. The ER doctor saved my life. How many more lupus lives have been misdiagnosed and did not make it? For those reasons, please pass S.B. 175.

CHAPLAIN WANDA BAILEY JOHNSON (Director, Outreach for Lupus, Nevada):
I support S.B. 175. I was diagnosed with pseudomonas aeruginosa, a type of bacteria. This illness came from unclean tools or equipment in the hospital. I was supposed to get a neural stimulator for my back to stimulate the pain; after changing my bandage daily, it took three months to finally clear it up and get better. We need S.B. 175 so we will not be used as guinea pigs. We need physicians to be accountable for what they do, what they give to lupus patients, and not just tell us it is a lupus flare up.

One year ago, when I was in the hospital, the doctors gave me 1,000 milligrams of prednisone for 4 days. They dropped it to 80 milligrams and sent me home. My primary doctor told me it could have killed me. You are not supposed to drop from a high dosage to a low dosage in an instant. You have to be weaned off and come down slowly off prednisone. It took my doctor weeks to get me back to the right dosage in order to treat my lupus. This bill would make the doctors accountable for giving lupus patients the right medication. Please pass this bill.

SHAEANN CLEMENTS-OJEDA:
I support S.B. 175. I am an executive board member of the Nevada State Democratic Party. I was diagnosed with lupus when I was nine years old and am on dialysis while waiting to get on a transplant list. We need more research, information and statistics to find better treatments and more resources. We also need to hold our doctors accountable. Being diagnosed so young was a lucky thing for me. The pediatric staff was more attentive than the adult medical world and, because of that, I knew who were the good doctors and nurses. When I became an adult, I came into the hospital with chest pains, severe heartburn, high heart rate and a sore left arm. I sat in the ER for two hours without any of my vitals taken or EKG with these symptoms. I kept asking the nurse when was someone going to take my vitals and EKG, and she would tell me "soon." Finally, after sitting there for a few more hours, I demanded to know why I had not had my vitals or EKG taken. I had all the symptoms of a heart attack and my family had a history of heart disease.

A nurse sat down next to me and started rubbing my left arm that I had been holding. I told her I was in severe pain. She started to explain how the demographics worked. Patients who were older and more predisposed to deadly issues would go first. Age and other things were factors for my long wait. I explained I fully understood the demographics and any patient of any age with chest pain and head injuries takes precedent after fatal bleeding wounds. I went on to say if she continued to say otherwise she would be facing violations for this hospital. Almost immediately after saying this, I did finally get my vitals and EKG taken. I eventually found out it was pericarditis, inflammation of my heart's lining, a common symptom of lupus. It truly hurt like I was having a heart attack.

Lastly, you need to know about the severity of lupus and how it is different for every patient. You could be like my friend who has painful but less deadly symptoms. You could have the severity of these two women speaking here with me today. You have me, a 27-year-old on dialysis who almost died 3 different times. You also have my mother. She was not only diagnosed as a paranoid schizophrenic and had lupus serositis her whole life, she also died not long ago as she was being diagnosed while on a dialysis machine. She died from heart failure. If not for a doctor in the psychiatric hospital she was in, who recognized me, none of us would have known she had lupus, nor would we have known what could have been causing my mother's psychosis her whole life.

She was never able to raise her children as she desperately wanted to do since before I was born as the first child. Perhaps, if we had more information regarding lupus patients in states like Nevada, maybe doctors would have caught it sooner. Maybe I would have had a mother, instead of vague memories of her being unstable and dangerous and scared of the world her whole life due to living in a false reality; which was only a symptom. Her case should be recorded and looked into and so should mine as every other lupus patient living in this State.

SENATOR NEAL:
The three presenters we just heard offer different stories about how they have been affected by lupus. Section 5, subsection 2, paragraph (a) of S.B. 175 establishes a system where we can conduct comprehensive epidemiology surveys of lupus and its variants and evaluate the appropriateness and measures for treatment. We need to understand what is happening because this disease mimics other diseases. We need to have enough data and education for physicians so they do not continue to misdiagnose lupus patients.

Section 6 of the bill continues to prescribe the kind of information we need to seek within this framework, such as the variant for cases of lupus, the method of treatment without limitation, the kind of drugs, any other diseases from which the patient suffers, and information containing the usage and access to healthcare services. If a patient is diagnosed with lupus and dies, we need to know what happened and how the patient died.

When we listen to Ms. Clements-Ojeda's testimony, if her mother was diagnosed, knowing there was a cognitive variant to lupus that would have helped her get treatment earlier. What happened with the misdiagnosis of a stroke, when Ms. Williams truly had symptoms of lupus, is something that may have happened to thousands of women. We do not know because there could have been a doctor who said a patient was having a stroke, gave the patient medication for a stroke and then effectively killed the patient.

I felt this bill was important when these presenters approached me about this legislation. The bill mimics A.B. No. 254 of the 80th Session, a bill I brought about sickle cell disease. Nevada used to be part of the registry and collected data. We fall in line with the national recommendations from 2015 from DHHS. This bill is within the general guidelines of what is being expected as the first step; to start collecting the data around patients; have the data housed and reported. This will help us understand what is going on with these lupus patients. The rest of the bill explains the analysis and confidentiality provisions of the reports that will be collected.

SENATOR KIECKHEFER:
Is there a fiscal note attached to the bill? We had issues with the Nevada Central Cancer Registry when we were trying to assess fees on the providers to report data back to the Cancer Registry. It became a significant financial burden on small doctor's offices and impeded the collection of data for the patients. In sections 7 and 8 of the bill, along the diagnosis and treatment spectrum, which people are going to be assessed fees for collection of the data and who will be required to collect the data?

SENATOR NEAL:
The majority of patients see rheumatologists in the State. There are about 13 or 14 rheumatologists who focus on the autoimmune disease portion of lupus. The other entities potentially affected are the hospitals and the ERs that are seeing the patient and transmitting the information. If the patient has a primary care physician, then that physician would also be looped in. The provision in the bill is similar to a provision I had on a bill on sickle cell, A.B. No. 254 of the 80th Session, where a fee was assessed. I recall conversations raised in the Assembly, but this has been the mechanism to get this information reported—to place the onus on the actual entity treating the individual.

SENATOR KIECKHEFER:
We have a massive shortage of rheumatologists in this State. The financial onus of the State's work being placed on a small number of providers could be problematic. I do not know the workload of collecting single patient's files from multiple providers, from a hospital to a primary care physician, and then creating an abstract for each one of those patients. It seems like a lot of work and I worry about what those fees might have to be to cover the cost of this bill.

CHAIR RATTI:
We have Lindsay Kinsinger here from DHHS. The fiscal note has not dropped yet, but the deadline has not passed, and DHHS has worked on it.

LINDSAY KINSINGER (Manager, Office of Public Health Informatics and Epidemiology, Division of Public and Behavioral Health, Department of Health and Human Services):
It would be the cost of one full-time employee to do the work within our office to manage this registry, work on the fee structure, abstract the data, collect the data, put it into our system and develop the reporting.

SENATOR KIECKHEFER:
Do you have an estimate of what the fee would be for each of the providers to generate that kind of revenue based on patients seen?

MS. KINSINGER:
It would cost DHHS about $112,000 per year for one full-time employee. I do not know how many rheumatologists there are across the State and how it would break down. I am not fully aware of what levels are in each medical provider's office the State has collected. This employee would also be responsible for developing the fee structure and who would pay what.

SENATOR KIECKHEFER:
I appreciate the need for collecting and using this information. I worry the fee structure may go against the good we are looking for in the bill.

SENATOR NEAL:
I understand there are going to be costs associated with this bill. In talking with DHHS, we could work out having one full-time employee. We have to take the first step in passing this bill because individuals are facing serious consequences of having an invincible disease.

When I look at other states that have passed legislation, they have been few and far between. California unsuccessfully attempted to pass two bills twice. Georgia has managed to form a commission on lupus. Illinois is the only state that passed a bill about lupus for individuals. Nevada is one of those states that $112,000 will save 10,000 women's lives after being misdiagnosed and provide enough data for us to get involved at the national level and obtain funding.

As I mentioned earlier, the federal government took $8.5 million, but the total amount that came out of Congress was $21.5 million; $10 million went to lupus research, $2 million went to the Office of Minority Health and $9.5 million went to the National Lupus Patient Registry. There is an opportunity, if we pass this legislation, to engage in grants and connect us from State to federal levels so we can access funding. We do not have a framework to even enter the Lupus Registry nationally because we do not have legislation that is asking for surveillance data around these patients. I understand the costs, but I also understand if this bill would get a one-shot chance of getting $112,000, we could walk into an environment where we would leverage ourselves for federal dollars.

SENATOR KIECKHEFER:
My suggestion is if we want to prioritize it, let us find a quarter of a million dollars and do it, rather than trying to create this funding mechanism.

CHAIR RATTI:
The suggestion is to take out the fee structure.

SENATOR SPEARMAN:
This is a disease mostly affecting women.

SENATOR NEAL:
Yes, 90 percent of lupus patients happen to be women.

SENATOR SPEARMAN:
Do you know what percentage of them are Black, Indigenous and People of Color?

SENATOR NEAL:
In Nevada, based on the available hospitalization data shown in Exhibit H, Black women represented 23.9 percent of the hospitalizations; 3.3 percent Hispanic; 5.7 percent Native American/Alaskan Native non-Hispanic; 3.3 percent Asian/Pacific Islander non-Hispanic; and 4.0 percent White non-Hispanic.

SENATOR SPEARMAN:
The last number for 2020 was 300,000 Nevadans that had been impacted by Covid-19. I think lupus is comorbidity when you are talking about diseases that epidemiologists track. Am I correct?

SENATOR NEAL:
I do not know if the epidemiologists are tracking the comorbidity; that is the data I am trying to obtain. I do have data as to the number of deaths. There were approximately 133 lupus-related deaths between 2017 and 2020. That was a rate of 1.1 per 100,000 in Nevada. Approximately 83 percent of the 133 deaths were female, 44 percent were white non-Hispanic and 23 percent were Black non-Hispanic. The data is based on the ICD-10 codes DHHS was able to pull for me in the summer.

SENATOR SPEARMAN:
I ask this question because if it is one of the comorbidities for Covid-19 such as asthma, high blood pressure or diabetes, I would think an autoimmune disease would be qualified as a comorbidity. Having said that, what funding is available either at the State or federal level to address this issue? The question is not if, but when will we have another pandemic. If we do not shore up those communities that are more susceptible to these things, we will see more infections and more deaths. What money is available at the State level, and what has come in for Covid-19 relief as it relates to medical diagnosis or prevention? Certainly lupus is a disease that mimics other diseases and puts individuals at a greater risk of misdiagnosis or is paid for with people's lives.

CHAIR RATTI:
The Covid-19 pandemic has shone a spotlight on the disproportionate impact on parts of our healthcare system for people of color. Asking for funds in this bill is modest to address a specific disease that disproportionately affects women and people of color.

Section 7, subsection 3, states:

> The State Board of Health shall by regulation adopt a schedule of fees which must be assessed to a healthcare facility for each case from which information is abstracted by the Division pursuant to subsection 2.

Are you committed to a fee structure where facilities pay part of the cost to collect this information? If a General Fund appropriation was available, would that suffice? As a sponsor of the bill, do you care how the funds are obtained? Is this an issue?

SENATOR NEAL:
It is not an issue. To amend the bill without the fee would be a gamble. Would we find the $112,000 going through the Senate Committee on Finance to fund the mechanism, if the fee was removed? I do not care how it gets funded. If we do this, we position ourselves for federal money that would become available in the future to help the research and establishment of a system to report information on lupus and its variants. Right now, we have no part of the landscape of lupus, not our state next door to us, not the states around us. We would be putting a step forward to say, at least in the western side of the United States, we want to help lupus patients. If you remove the fee structure and can find $112,000, I would be open to it.

CHAIR RATTI:
It seems like there is another fee in section 8, subsection 2, subparagraph (b), for anyone who wants to perform research with the data. We are a policy committee, and we are focusing on the merits of the policy. Either way, it will be forwarded to the Senate Committee on Finance for discussion if it comes out of our Committee.

SENATOR HARDY:
I understand that $112,000 would be the cost for one full-time State employee who will manage the registry, abstract and collect the data, and develop the reporting structure. Sections 5 and 6 of the bill require hospitals, medical laboratories and other facilities, and providers of health care to carry the bulk of the financial burden. They will be trying to report the information on a reporting form in a prescribed manner ensuring it is compatible with HIPAA so that names, ages and other data are not shared. It is problematic for the State and the industry. There would be questions as to who reported data, who did not report data and when it was done. Looking at section 6, subsection 2, subparagraph (a), name, address, age and ethnicity of the patient are pretty sensitive things we are trying to figure out how to report and deal with. I have challenges with the logistics. I do not feel as comfortable as I would like. How do you do it?

SENATOR NEAL:
The information on patients goes from the care facility to the Division. Section 11 states, "The Division shall not reveal the identity of any patient, physician or health care facility."

Section 12, contains the confidentiality provision which states:

> A person or governmental entity that provides information to the Division in accordance with sections 5, 6 and 7 of this act must not be held liable in a civil or criminal action for sharing confidential information unless the person or organization has done so in bad faith or with malicious purpose.

This language is similar to language in A.B. No. 254 of the 80th Session on sickle cell. These provisions in that bill passed the legislative process to make sure it is a two-way street between the provider and the Division, which is who wants this information or are designated in this legislation to get this information. The language in section 11 is the same language as in the sickle cell bill signed by Governor Sisolak. There have been no confidentiality breaches with the same exact language you see in sections 11 and 12.

SAMANTHA WAYNE:
I support S.B. 175. I have been living with lupus for 14 years. I cannot tell you how many times doctors have been hesitant to treat me. I was forced to turn to my rheumatologist who will not treat me for anything but my lupus. In 2017, I had to go to the hospital for extreme chest pains and trouble breathing. I waited hours in a hospital bed before they decided to treat me with ibuprofen. It was clear to me I was just another patient looking for pain meds rather than a 24-year-old in extreme pain. Instead, I went home with temporary pain relief and a $700 hospital bill.

In 2018, I was in the hospital again after developing autoimmune hemolytic anemia, which is a rare blood disorder that can occur with lupus. My body was attacking my red blood cells, causing me to become dangerously ill. The doctors were fearful of giving me a blood transfusion because the lupus would continue to attack the new blood cells; they were unsure how to treat me. I have been advocating for lupus since I was 15. Early on, I saw the gap in treatment and awareness. It is important to improve the care of thousands of Nevadans living with lupus every day by using research and data.

TASHE PITTMAN:
I support S.B. 175. I am a technical sergeant and retired veteran from Nellis Air Force Base. I was diagnosed with lupus in 2015 and have been a medical mystery since 2004. I had symptoms of breaking out from the sun, allergic to

sunscreen, rapid heart rate and not knowing if I was having a stroke or heart attack. There are no doctors on base, so I was sent downtown. I have been in between doctors because most of the medical doctors for military people are medical students, so most of the time my appointments are pushed downtown.

The problem I have noticed is when going to the ER I must have a referral from a doctor and they have to state it is for lupus. However, they do not know exactly what my symptoms are, so most of the time, I get a diagnosis for my lupus and am told to see a rheumatologist. The research would be vital for people in the military or people who do not know they have lupus and grow up finding out they had lupus earlier in life. This information would be vital in passing this bill.

SENATOR NEAL:
Section 10 of this bill would require DHHS to coordinate with the National Lupus Patient Registry and include in the list of purposes for which DHHS must apply for and accept any gifts, grants and donations.

The purpose of the amendment is to put DHHS in a position to use leverage to pursue federal funds since DHHS is not part of the Lupus Registry. If DHHS becomes part of the Registry and legislation is passed to start the surveillance projects going on since 2004, DHHS can be in a position to start applying for grants to help move this agenda forward around lupus patients.

SENATOR SPEARMAN:
The issue is about the money. Is it possible to add, "as money becomes available"? Would this put DHHS in a position to pursue grants?

SENATOR NEAL:
I believe so as long as DHHS, in the back of the bill, was allowed to still go after grants and donations. I have seen that language and it is a good policy. Hopefully, the Committee can find the support to get the policy out as a first step forward for it to go to the Senate Committee on Finance to find money or provide funds as they become available.

CHAIR RATTI:
Page 5, section 10, of the bill says the "Division shall apply". It directs the DHHS to apply for and accept any gifts, grants and donations specifically to support this project.

SENATOR SPEARMAN:
I did see where the bill directed DHHS to apply; however, it seems like the issue is money. I was trying to figure out a way to make sure the language in the bill is strong enough to survive, and then whatever gifts or grants are out there, DHHS can still go for them. If we have that opportunity, then money is not an issue.

CHAIR RATTI:
We are a policy committee. We will make a decision based on the merits of the policy. Since it has financial implications, if the bill passes out of our Committee, it will go to the Finance Committee and there will be another opportunity for another conversation to talk about the money. We are focused on policy in this Committee. We will not vote on the bill today. By legislative rules, there has to be some separation, typically, between the time you hear the bill and the time you vote on the bill.

I will now close the hearing on S.B. 175. The hearing on S.B. 251 is now open.

SENATE BILL 251: Revises provisions relating to genetic counseling and testing. (BDR 40-478)

SENATOR HEIDI SEEVERS GANSERT (Senatorial District No. 15):
I am joined by Dr. Nathan Slotnick, who is a medical geneticist and high-risk obstetrician. He has been practicing and seeing patients in Nevada since 1990. In 2005, he was asked to start a cancer genetics program by a local oncology practitioner group. He has also been part of a high-risk pregnancy practice with over 50,000 patients. He has been on the faculty at the University of Nevada, Reno (UNR), School of Medicine and in 2020 was named medical director for reproductive genetic medicine at Invitae Corporation. I am also joined by Abbi Whitaker, who is a well-respected and award-winning communications specialist and entrepreneur. She and her husband founded the Abbi Agency whose tagline reads "Where Chutzpah Meets Acumen," which accurately describes her.

This bill is about raising awareness and increasing appropriate screening for the most common cause of heredity breast cancer. This would be inherited duplications of cancer genes also known as breast cancer gene (BRCA) 1 and BRCA 2, which Dr. Slotnick will cover. Ms. Whitaker will tell her story. Within the past five years, I have six friends who have been diagnosed as

BRCA positive, including Ms. Whitaker. Dr. Slotnick will be able to explain the high risk of cancer if a person is BRCA positive.

The common thread with my friends is they have been fighting cancer for a while and many of them were diagnosed at an early age. The dots were never connected to show they may have had a hereditary mutation. The reason it matters if you have the BRCA genes is because women may have it as well as their children, because it is hereditary. My friends and a member of my family have been affected by this and some have children who were born positive and some negative. The key we need to remember is you have to be able to get a screening and a referral for counseling and then testing.

ROBERT NATHAN SLOTNICK, M.D., PH.D. (Director, Medical Genetics and Genomics):
I will be talking about an increasingly important component of cancer care; a subset of medical genetics. We are what we are because of what we inherit from our parents. Genes are made of a chemical called DNA which is included within the cells of our body. All human adults have in their body approximately 30 trillion cells. All of those cells are the result of many cell divisions from a single fertilized egg. Every time a cell divides, errors can occur. When those errors occur, they can accumulate. If those errors accumulate in some of the control genes of the cell, one of the possible results is cancer. I have included a presentation (Exhibit K) on Genetics and Cancer Technology which discusses in detail information on cancer risks, BRCA 1 and BRCA 2, and genetic testing. In summary, genetic testing identifies patients at risk and their families. There should be a discussion of family history, and BRCA testing should be encouraged.

ABBI WHITAKER:
I am 45 years old and have tested positive for BRCA 2. I have been getting mammograms for the last five years and this year switched to Reno Diagnostic Center. I filled out a questionnaire about my family history. When I went in for my mammogram, I was told I had been flagged to potentially take a free genetic test. A few weeks later, I was contacted by a genetic counselor who wanted to speak with me about the tests. I got busy and did not call her back; however, she kept leaving me messages so I finally called her as I thought it must be important. They told me I had tested positive for BRCA 2. I did not understand what this was and I did not know a lot about it. They told me it would increase

my chances in my lifetime from 45 percent to 75 percent that I would develop breast cancer and 45 percent for ovarian cancer.

I am already a cancer survivor. I had anal cancer, with chemo and radiation, and never was I flagged for this type of genetic testing or for BRCA. I go to the doctor all the time for blood work, and you think they would have caught this. Thankfully, the Reno Diagnostic Center decided to follow their policy and ask me those questions because now I know. I have eight brothers and sisters who are all now going through genetic testing to find out if they, too, have BRCA 1 or BRCA 2. I have ten cousins throughout the world who are also testing knowing this came from my father's side.

I decided on April 15 to have a bilateral double mastectomy, followed by a hysterectomy. I am able to make this choice because Reno Diagnostic Center asked me some simple questions about my genetic history, and I was able to find out I had the BRCA 2 gene. As women, mothers, senators, career women, we have so many things going on in our lives. The fact I now have this knowledge, can make a decision and make sure I do not die from this cancer is phenomenal.

I approached Senator Seevers Gansert about informing and educating men and women and possibly changing the law for more cancer screening. Fighting cancer is not something we want to do. If we have the knowledge, we can stop it with my daughter and son, your daughter and your son. I think this is a wonderful opportunity.

SENATOR SEEVERS GANSERT:
I have a conceptual amendment (Exhibit L) stating the screening, counseling and referral for testing is covered under preventive services based on the U.S. Preventive Services Task Force meaning the federal government covers these services. Insurance carriers are required to cover the screening, referral for counseling and potentially the testing. Section 1 requires primary care providers to screen women to determine if there is a family history indicating an increased risk for a harmful mutation in the BRCA gene, and if the screening indicates an increased risk, to take certain actions to ensure the woman receives genetic testing and genetic counseling if testing positive for the gene.

Section 2 of S.B. 251 describes the notice received with a mammogram which flags a person for genetic testing. Section 3 exempts practitioners from a category D felony to a misdemeanor for any violation of section 1.

As was described by Dr. Slotnick, when you test positive for BRCA, the odds of getting cancer are off the charts; as high as 87 percent in your lifetime. We need to raise awareness and increase the screening so people know if they are at risk and take appropriate actions. It could be pharmaceuticals or surgery, but what we want to do is make sure people can stay as healthy as possible. Ms. Whitaker mentioned her children, siblings and cousins are testing because it is a hereditary mutation. We should be testing when there is family history because it can save lives.

SENATOR HARRIS:
I am appreciative of the exemption from the felony requirement. Is there any kind of stick to this carrot to encourage doctors to comply with the law?

SENATOR SEEVERS GANSERT:
The requirement for health care providers to screen women for BRCA gene mutations and provide referrals for genetic counseling and testing is brand new. When you go to a physician, the doctor usually does a family history. It is about connecting the dots. There are tools that have been developed and are being developed to make it easy for practitioners to screen for BRCA and provide referrals for genetic counseling and testing. I hope this bill strongly encourages practitioners. I have been talking with the medical association and practitioners about trying to get this bill implemented.

SENATOR HARDY:
Sections 8 through 11 address continuing education credits for genetic instruction. Can these credits replace or be in lieu of suicide, pain management, addiction or the other requirements that physicians, whether M.D. or D.O., have a responsibility for?

SENATOR SEEVERS GANSERT:
It is not a replacement, it allows these credits to count. There are certain categories that are required, but there are more continuing medical education requirements than are categorized. It is a choice an individual can make to get credit for completing a course relating to genetic counseling and testing.

SENATOR HARDY:
The way the language in the bill reads, it looks like it could replace or be in lieu of those other requirements. Is that not your intent?

SENATOR SEEVERS GANSERT:
The intent is not to replace; it is to make it an option. There are certain required categories, but genetic instruction would be an acceptable category to fulfil part of the entire number of continuing education requirements that are in statute.

SENATOR HARDY:
Right now, I do not know of anything that would preclude you from counting genetic hours.

TOM CLARK (Nevada Association of Health Plans):
We support S.B. 251.

CARI HERINGTON (Executive Director, Nevada Cancer Coalition):
We support S.B. 251.

GEORGE ROSS (Comprehensive Cancer Centers of Nevada):
We support S.B. 251.

MARIAN GANSERT:
I support S.B. 251. My story is similar to Ms. Whitaker. I was never flagged during the course of my breast cancer history. It started 36 years ago when I was diagnosed with breast cancer and had a mastectomy on my left side. I was 30 years old and was told not much was known about breast cancer at the time. Years later, I decided to be proactive and have a preventative mastectomy on my right side. In 2015, I went to my annual gynecology appointment and was told I was eligible for genetic testing. My test came back positive. I was then told the BRCA 2 gene had a 50 percent chance of developing into ovarian cancer and a 90 percent chance of developing into breast cancer. Two months later, I had a total hysterectomy. Since I also had two mastectomies, I thought I was doing great. It did not turn out that way.

In 2017, I was diagnosed with cancer on my preventative mastectomy side. I guess a piece of breast tissue had been left behind. I had both my children tested and they tested negative. To my knowledge, my mother never had breast cancer. I do not know of anyone on my mother or father's side having breast cancer. I have a granddaughter who will be born in May, and in the back of my mind, this baby will eventually have to be tested for the BRCA gene.

KENDAHL SERVINO:
I support S.B. 251. I am a medical student at UNR and breast cancer survivor. I was diagnosed at 20 years of age; it was the biggest shock of my life and the hardest struggle I ever had to face. I received chemo, radiation and a few surgeries while finishing up my last semester of college. Losing my hair and my confidence and becoming unable to recognize myself in the mirror were the hardest parts of treatment for me. I hope none of you will ever experience or have to face breast cancer. I come here today to share the importance of BRCA genetic testing and having this bill passed. The number of lives that will be saved by passing this bill will be tremendous.

MARLENE LOCKHARD (Nevada Women's Lobby):
We support S.B. 251. This bill can and will save lives.

ERIN LYNCH (Social Services Chief, Division of Health Care Financing and Policy, Department of Health and Human Services):
We are neutral on this bill. Nevada Medicaid covers genetic screening, testing and counseling for BRCA 1 and BRCA 2 for both men and women. There is a zero dollar fiscal note on this bill.

ROBBIN PALMER, PH.D (Certified Genetic Counselor):
I am neutral on this bill and have several concerns about this legislation even though it is well intentioned. I am the only practicing genetics professional in northern Nevada. I have provided written testimony (Exhibit M).

SENATOR HARRIS:
I was reviewing the bill again and want to note a violation of section 1 would still be a misdemeanor. If it is your intention to take away all penalties, you may want to draft another amendment to exempt it as well.

CHAIR RATTI:
We had the testimony from Medicaid. There is no fiscal note because these are services already available for almost everybody in the Medicaid population. You testified earlier we are already doing this with insurance companies, and it is part of federal law and part of the essential benefits included in the Affordable Care Act by reference to preventive services. Is this your understanding?

SENATOR SEEVERS GANSERT:
Yes. It is part of the U.S. Preventive Services Task Force recommendations which is what is relied upon for preventive services.

CHAIR RATTI:
Why have the insurance components in the bill if Medicaid and insurance companies are already providing these services?

SENATOR SEEVERS GANSERT:
In speaking with the Legislative Counsel Bureau's Legal Division, I learned if we were able to put this in the bill, then we would preserve the coverage even if it were changed at a federal level. We want to make sure Nevadans have access to this counseling and testing, and this is why we want it in statute.

The federal government covers BRCA 1 and BRCA 2, and genetic medicine will be refined over the years. There are genetic mutations which we know can be lethal, and I want to have testing for those. If we can get testing for BRCA 1 and BRCA 2, and you look at the pie charts provided by Dr. Slotnick, you can see the magnitude of how many people can potentially test positive and what the outcomes can be.

We do not have enough genetic counselors, but what we do have are physicians and practitioners who can learn more about genetics. We do not have licensure as we are not at that level. Once people test positive, they are going to have relationships with their practitioners to make decisions. The decisions may be they go on birth control or have a mastectomy, but those decisions can be made between a patient and a physician. Making sure we have people screened is extremely important. We can save a lot of lives with this legislation.

CHAIR RATTI:
The hearing on S.B. 251 is now closed. Hearing no public comment, this meeting is adjourned at 6:10 p.m.

RESPECTFULLY SUBMITTED:

Norma Mallett,
Committee Secretary

APPROVED BY:

Senator Julia Ratti, Chair

DATE:

EXHIBIT SUMMARY

Bill	Exhibit Letter	Begins on Page	Witness / Entity	Description
	A	1		Agenda
S.B. 168	B	1	Senator Roberta Lange	Presentation
S.B. 168	B	1	Matthew Walker / Nevada Dispensary Association	Presentation
S.B. 168	C	1	Senator Roberta Lange	Proposed Amendment
S.B. 168	C	1	Matthew Walker / Nevada Dispensary Association	Proposed Amendment
S.B. 168	D	1	Layke Martin / Nevada Dispensary Association	Presentation
S.B. 168	E	1	Darrell Lacy / Planet 13 Holdings, Inc.	Support Statement
S.B. 49	F	1	Megan Comlossy	Work Session Document
S.B. 156	G	1	Megan Comlossy	Work Session Document
S.B. 175	H	1	Senator Dina Neal	Presentation
S.B. 175	I	1	Senator Dina Neal	Presentation
S.B. 175	J	1	Senator Dina Neal	Proposed Amendment
S.B. 251	K	1	Nathan Slotnick	Presentation
S.B. 251	L	1	Senator Heidi Seevers Gansert	Conceptual Amendment
S.B. 251	M	1	Robbin Palmer	Neutral Statement