MINUTES OF THE
SENATE COMMITTEE ON HEALTH AND HUMAN SERVICES

Eightieth Session
April 3, 2019

The Senate Committee on Health and Human Services was called to order by Chair Julia Ratti at 4:12 p.m. on Wednesday, April 3, 2019, in Room 2135 of the Legislative Building, Carson City, Nevada. The meeting was videoconferenced to Room 4412E of the Grant Sawyer State Office Building, 555 East Washington Avenue, Las Vegas, Nevada. Exhibit A is the Agenda. Exhibit B is the Attendance Roster. 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 Joyce Woodhouse
Senator Joseph P. Hardy
Senator Scott Hammond

GUEST LEGISLATORS PRESENT:

Senator Yvanna D. Cancela, Senatorial District No. 10

STAFF MEMBERS PRESENT:

Megan Comlossy, Committee Policy Analyst
Eric Robbins, Committee Counsel
Michelle Hamilton, Committee Secretary

OTHERS PRESENT:

Katie Anderson
Trudy Larson, Ph.D., Dean, School of Community Health Sciences, University of Nevada, Reno
Catherine O'Mara, Nevada State Medical Association
Melinda Hoskins, Nevada Affiliate of the American College of Nurse-Midwives
Tom Clark, Nevada Association of Health Plans
Chelsea Capurro, Health Services Coalition
Bobbette Bond, Culinary Health Fund

Todd Ingalsbee, Professional Firefighters of Nevada
Christi Cabrera, Nevada Conservation League
Rudy Zamora, League of Conservation Voters
Praveen Jayakumar, Culinary Health Fund
Joseph Douglas, Culinary Union
Jim Sullivan, Culinary Union
Crystal Munoz, Culinary Union
Stacie Sasso, Health Services Coalition
Raymond McAllister, Nevada State AFL-CIO
Chad Neanover, Culinary Union
Byron Chacon, Culinary Union
Rocky Finseth, PhRMA
Asher Lisec, PhRMA
Jay Parmer, Association for Accessible Medicines
Suzanne Bierman, Administrator, Division of Health Care Financing and Policy, Department of Health and Human Services
Amanda Khan, Progressive Leadership Alliance of Nevada
Adam Hosmer-Henner, PhRMA
Elisa Cafferata, Planned Parenthood Votes Nevada; Biotechnology Innovation Organization

VICE CHAIR SPEARMAN:
I will open the hearing on Senate Bill (S.B.) 291.

SENATE BILL 291: Revises provisions governing the testing of infants for preventable or inheritable disorders. (BDR 40-111)

SENATOR JULIA RATTI (Senatorial District No. 13):
I would like to introduce Katie and Luke Anderson, the family who brought to my attention the need for this bill and made me interested in newborn screening.

When the Anderson family received a life-changing diagnosis, they reached out to me about newborn screening. What I learned about the newborn screening process was that Nevada had fallen behind in keeping up with best practices. My first inclination was to add this one condition that you will hear about to the newborn screening process. However, there is already a public health system built around newborn screening and there are some pretty good Nationwide

processes in place. There is a uniform process where decisions are made as to which conditions belong on the newborn screening panel.

The condition we are going to talk about today is on the Recommended Uniform Screening Panel (RUSP). However, Nevada has not followed those best practices and recommendations and did not screen for that condition. Nevada needs to improve its best practices and make sure the newborn screening process is as strong as it can be.

KATIE ANDERSON:
My name is Katie Anderson and this is my eldest son Luke. Our eight-year-old son Ben was diagnosed March 9, 2018, with X-linked adrenoleukodystrophy (ALD) (Exhibit C). By then, Ben's brain was already past the point of all possible medical treatments. Following Ben's diagnosis our older son Luke was tested, and we learned that he also has X-linked ALD, but not the cerebral form.

Had there been a newborn screening for X-linked ALD, we would have immediately known about Luke immediately and we would have also been able to make an informed decision about having a second child. Conceptually, newborn screening could eliminate the spreading of these types of diseases to future generations.

SENATOR WOODHOUSE:
Thank you for sharing your story. It is important for the Legislature to know what is going on in its communities so it can make things right for families in the future.

TRUDY LARSON, PH.D. (Dean, School of Community Health Sciences, University of Nevada, Reno):
I oversee the Nevada Newborn Screening Program (NNSP). The NNSP was started in the 1990s primarily to deal with phenylketonuria (PKU). Early recognition of PKU with a special diet would offer a normal life for children who had this genetic condition.

The screening was originally done by the Oregon State Public Health Laboratory until 2014, when the program moved to the Nevada State Public Health Laboratory. Currently, the NNSP screens for 57 conditions and recently added severe combined immunodeficiency syndrome (SCID). A fatal disease early in infancy, SCID can be cured with a bone marrow transplant. The availability of

treatment is just one measure used to recommend genetic conditions for screening. There is a briefing paper (Exhibit D) by the United States Department of Health and Human Services outlining how their advisory committee of experts recommend screening tests. The outcome is the RUSP Core Conditions, (Exhibit E).

Each genetic condition brought forward for inclusion is thoroughly investigated with four overarching considerations. To be included as a primary target condition, the genetic condition must meet four conditions in Exhibit D. Each state is responsible for selecting its own screening list based on a number of factors. Nevada screens for all but three of the RUSP conditions. These three conditions are mucopolysaccharidosis type 1, X-linked ALD and spinal muscular atrophy.

These are all conditions where an enzyme does not work and there is an accumulation of material that causes destruction or where enough protein is not produced. These are all genetic conditions. We do not measure genes or look at gene mutations. We look at whether the accumulation of these materials in the blood are abnormal.

The impetus for S.B. 291 and most revisions around newborn screening are requests from families who have been impacted by genetic conditions not on the RUSP. As this applies to Nevada, S.B. 291 would add the three conditions to the NNSP already approved by the Federal Advisory Group. Nevada has the Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children (ACHDNC) composed of physicians with expertise in these genetic disorders, nurses, hospitals and support agencies. The ACHDNC has already recommended all RUSP conditions. Inherent in this action is the need to identify adequate resources to support the diagnosis, treatment and follow-up.

To support the NNSP, fees are collected from birthing hospitals and sites that are mandated to obtain specimens from every newborn. The current fee covers two testing screens. The first test is between 24 and 48 hours after birth and the second test is 2 weeks later. To add the tests for these three conditions would bring Nevada up to federal standards, but would require an increase in fees. Senate Bill 291 identifies a mechanism that will allow transparency in the development of increased fees and puts in place a means to delay adding tests if resources will not permit it. That is not just resources to do the test, it would

include resources to fund physician experts who can provide the necessary treatment for those children.

The NNSP believes it is important for Nevada to keep up with federally recommended screenings and put in place a mechanism to assist in this process. I have included a chart (Exhibit F) showing the number of conditions found since the start of newborn screening in Nevada. Of the 158,434 babies who have been screened, 235 critical conditions have been identified, allowing families to benefit from early diagnoses and treatments. Nevada is growing in numbers and resources and it needs to extend these options to all families.

SENATOR RATTI:
The easy path for this bill would be to just add these three conditions and associated fee increases and add a fiscal note. A year from now, the national RUSP may add conditions putting Nevada back in the same position.

There is also a trend where families go to Legislators with compelling stories and want their condition to be added to the NNSP. There are literally hundreds of rare disease conditions. I believe it is more effective to have a well-vetted national process to determine what conditions should be added to the panel. This is better than the Legislative Body being swayed by what might be compelling stories to add newborn screening conditions to the panel, but they do not meet the criteria for which there are not scientifically based interventions available.

What this bill seeks to do is make the standard in Nevada to keep up with the RUSP. This means Nevada will continue to follow best practices, but it will put a box or limit around it. Therefore, conditions that do not qualify for the RUSP will not be added in Nevada.

I would like to refer to section 1, subsection 2, which states the State Board of Health will set the standards for following the RUSP. This is important because Medicaid covers 55 percent of births in Nevada. For those births covered by Medicaid, Nevada will have to pay the increased screening fee to cover those conditions. Just to give you a sense of scale, the cost to add the three RUSP conditions is about $500,000. Senate Bill 291 has two important escape clauses. An example of the first escape clause would be a condition was included on the RUSP, but the cost was exorbitant. If the RUSP adds the new condition, and the amount of resources it would take for the Nevada State

Public Health Laboratory (NSPHL) to keep up with that condition was too much, the State Board of Health would be able to opt out Nevada.

The second escape clause is if the Director of the NSPHL or the Chief Medical Officer believes the resources are not available in the community to provide the support for the families to work with the diagnoses. This would also give the State Board of Health the ability to opt out Nevada.

The third part of S.B. 291 is a four-year lag. This gives Nevada four years from the time the condition is added to the RUSP to determine lab costs and resources. It requires Nevada hold a public hearing where Dr. Larson or her successor justify the rate increase. The four-year window will give Medicaid and all other payers and providers the opportunity to plan for the future.

Right now our newborn screening process is stuck in time. The current rate is $81 and that amount has not changed since Nevada adopted the program from Oregon. The NSPHL is housed at the University of Nevada, Reno (UNR). The President of UNR has the sole authority to raise fees. Currently, they could choose to raise fees and/or add conditions, but there is no public process or framework about how to do that. This puts the President of UNR in an awkward position. I am not sure he wants to make those decisions. This bill brings this back to the State Board of Health in consultation with Medicaid in regard to the fee, and gives Nevada a standard to follow. This biennium, Nevada will need to spend about $500,000 to get caught up by the addition of these three conditions. However, as new conditions come up, there is a process to adopt them, which does not freeze the newborn screening process in time at the $81 rate.

SENATOR HARDY:
I assume the lag time does not exist for the first three conditions.

SENATOR RATTI:
The bill states Nevada will do this within four years and these conditions will be added within four years. The intent would be to act immediately on these three conditions and then have four years for any new conditions.

SENATOR HARDY:
Is there an advantage to moving this back to Oregon?

MS. LARSON:
No. We have been able to improve service to the community. The results get back 24 hours faster than they did from Oregon. I believe doing this in-state provides greater service.

SENATOR HARDY:
Did we save money by moving it to Nevada?

MS. LARSON:
The fee was $81 when Nevada brought it over. Oregon was raising the rate $2 every year, and that was going out-of-state.

SENATOR HARDY:
We need to do this sooner, rather than later.

SENATOR RATTI:
In closing, I just want to let the Committee know we have been working with representatives from hospitals, insurance companies and universities to State Medicaid in order to make sure functionally this would work.

SENATOR HARDY:
Are we allowed to see if anyone is against this before I make a motion?

VICE CHAIR SPEARMAN:
I will open for support of S.B. 291.

CATHERINE O'MARA (Nevada State Medical Association):
We support S.B. 291.

MELINDA HOSKINS (Nevada Affiliate of the American College of Nurse-Midwives):
We are in support of S.B. 291. As a home birth midwife, I have some questions about reimbursement. This fee is charged to us as providers, but is not reimbursed by Medicaid.

TOM CLARK (Nevada Association of Health Plans):
Many of you might be surprised to see an insurer in support of such a mandate. I want to thank Senator Ratti for including a working group when drafting this bill. Subsection 2 of section 1 is important to us as insurers. It creates a box and makes the screening process predictive. We know when these types of

tests reach the federal level where they need to be screened; we can plan when they will come to the State. We are proud to support this bill.

CHELSEA CAPURRO (Health Services Coalition):
We are in support of S.B. 291. It is important for us to have a standard list to follow and prepare for what is coming up. This bill helps us know what we need to cover. If the fee is going to be increased, we will know how, why and when that would occur.

BOBBETTE BOND (Culinary Health Fund):
We are in support of S.B. 291.

TODD INGALSBEE (Professional Firefighters of Nevada):
We are in support of S.B. 291.

VICE CHAIR SPEARMAN:
I will close the hearing on S.B. 291.

SENATOR HARDY MOVED TO DO PASS S.B. 291.

SENATOR WOODHOUSE SECONDED THE MOTION.

THE MOTION CARRIED UNANIMOUSLY.

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CHAIR RATTI:
I will open the work session on S.B. 203.

SENATE BILL 203: Revises provisions governing programs for children who are blind, visually impaired, deaf or hard of hearing. (BDR 38-77)

MEGAN COMLOSSY (Committee Policy Analyst):
I will read the summary of the bill and the conceptual amendment from the work session document (Exhibit G).

SENATOR WOODHOUSE MOVED TO AMEND AND DO PASS AS AMENDED S.B. 203.

SENATOR HARDY SECONDED THE MOTION.

THE MOTION CARRIED UNANIMOUSLY.

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CHAIR RATTI:
I will open the work session on S.B. 258.

SENATE BILL 258: Revises provisions relating to applied behavior analysis. (BDR 39-248)

MS. COMLOSSY:
I will read the summary of the bill and the conceptual amendment from the work session document (Exhibit H).

SENATOR HARDY MOVED TO AMEND AND DO PASS AS AMENDED S.B. 258.

SENATOR SPEARMAN SECONDED THE MOTION.

THE MOTION CARRIED UNANIMOUSLY.

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CHAIR RATTI:
I will open the work session for S.B. 284.

SENATE BILL 284: Creates the Advisory Task Force on HIV Exposure Criminalization. (BDR S-742)

MS. COMLOSSY:
I will read the summary of the bill and the conceptual amendment from the work session document (Exhibit I).

SENATOR SPEARMAN MOVED TO AMEND AND DO PASS AS AMENDED S.B. 284.

SENATOR HARDY SECONDED THE MOTION.

THE MOTION CARRIED UNANIMOUSLY.

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CHAIR RATTI:
I will open the work session on S.B. 364.

SENATE BILL 364: Prohibits discrimination against and provides protection for persons who reside in or receive services from certain facilities. (BDR 40-757)

MS. COMLOSSY:
I will read the summary of the bill from the work session document (Exhibit J).

SENATOR SPEARMAN MOVED TO DO PASS S.B. 364.

SENATOR HAMMOND SECONDED THE MOTION.

THE MOTION CARRIED UNANIMOUSLY.

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CHAIR RATTI:
I will open the work session on S.B. 456.

SENATE BILL 456: Revises provisions relating to staff privileges for advanced practice registered nurses at hospitals. (BDR 40-786)

MS. COMLOSSY:
I will read the summary of the bill from the work session document (Exhibit K).

SENATOR HARDY:
I want to figure out the scope of work for the advanced practice registered nurses (APRN). For example, I do not think the APRN belongs in the hospital's

intensive care unit or on the surgical unit. I think they have been trained to do what they do and they provide valuable work. I do not think it is wise to give flat permission for the APRN to have hospital privileges. Just because they are an APRN does not mean they can or cannot do things. They have to have a scope of practice.

CHAIR RATTI:
My understanding is the enabling Legislation that allows for an APRN or any other licensed professional to have privileges in a hospital does not change their scope of practice. Their scope of practice is a combination of *Nevada Revised Statutes* (NRS), *Nevada Administrative Code* (NAC) and other regulatory and licensing processes. The act of giving them hospital privileges would not change their scope of practice, but without those privileges they cannot perform their scope of practice in a hospital.

SENATOR HARDY:
When we talked about the dieticians, we wanted to allow them to do something specific as opposed to doing everything. The dietician was not given hospital privileges to do everything. The dietician was given privileges within a scope of practice. In this bill, if we have an APRN apply for privileges at a hospital without a scope of practice, then what is there to stop an APRN from saying, "I can do whatever I want, because I have privileges at the hospital." I believe we would be remiss to give carte blanche to the APRN. According to this bill, the hospital cannot say "no" to the APRN.

CHAIR RATTI:
I will pull S.B. 456 to get clarity on this question. I would also be open to an amendment in the bill that states, "Allows an APRN to work within their scope of practice."

Can we amend S.B. 456 to state, "We give APRNs hospital privileges within their scope of practice"?

ERIC ROBBINS (Committee Counsel):
Yes, we can add such an amendment.

SENATOR WOODHOUSE MOVED TO AMEND AND DO PASS AS AMENDED S.B. 456 WITH THE CONCEPTUAL AMENDMENT PROPOSED BY CHAIR RATTI THAT STATES, "WE GIVE APRNS HOSPITAL PRIVILEGES WITHIN THEIR SCOPE OF PRACTICE."

SENATOR SPEARMAN SECONDED THE MOTION.

THE MOTION CARRIED UNANIMOUSLY.

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CHAIR RATTI:
I will close the work session and open the hearing on S.B. 262.

SENATE BILL 262: Makes various changes to provide for tracking and reporting of information concerning the pricing of prescription drugs for treating asthma. (BDR 40-55)

SENATOR YVANNA D. CANCELA (Senatorial District No. 10):
The concept of S.B. 262 will not be unfamiliar as it mirrors S.B. No. 539 of the 79th Session, intended to shed transparency on diabetes drugs. Senate Bill 262 does the same thing our State currently does for diabetes drugs, except for asthma drugs.

I want to share some numbers to show why this is important. Today 10.4 percent of all adults and 11.5 percent of all children have asthma in Nevada. In the Country, 8.1 percent of adults and 8.4 percent of children have asthma; Nevada is well above the national average. The No. 1 reason children miss school in Nevada is asthma. When children have asthma attacks, they cannot attend school. When adults have asthmas attacks, they cannot go to work.

At the same time, the cost to manage this disease is expensive. In 2015, the cost was $3,266 per person, of which $1,830 went to drug costs. Most asthma inhaler medication formulas are not new to the market, yet they are expensive. From 2013 to 2018, the cost of asthma inhalers increased about 35 percent from an average price of $280 to $380.

Senate Bill 262 intends to shed light on why asthma costs have increased and allow for a third-party unbiased look at what is happening to asthma drug costs in Nevada. Similar to S.B. No. 539 of the 79th Session, S.B. 262 will require the Department of Health and Human Services (DHHS) to compile a list of essential asthma medications. The DHHS will narrow the list to the essential asthma medications by the highest cost and highest use, among other categories, to ensure the list captures drugs that account for the majority of costs.

Once the list is compiled, drug manufactures will report certain materials such as: the cost of producing the drug, the administrative expenditures, the profits earned from the drug, the amount of financial assistance provided through prescription assistance programs, the cost associated with coupons, the wholesale acquisition cost, a history of any increase in the wholesale acquisition cost, the aggregate amount of rebates and any additional information required by the DHHS.

Additionally, manufacturers that have been subject to a significant price increase within the immediately preceding two calendar years must submit an annual report describing the reason for the increase.

Capturing the information from the drug manufacturers alone is not sufficient. The second part of S.B. 262 captures the language from S.B. No. 539 of the 79th Session that allows for a pharmacy benefit manager (PBM) to also submit information on asthma medication. That information will include the total amount of rebates the PBM negotiated with manufacturers during the immediately preceding calendar year, the amount of all such rebates retained by the PBM and the amount of all such rebates negotiated for purchase of such drugs for use by individuals with a variety of types of insurance. The bill also extends the language of NRS 439B.650 to require DHHS to analyze the information submitted by drug manufacturers and PBMs to compile a report.

It is sometimes easy to think reports or data do not create change, I want to point out some highlights since the last Session.

Today it is nearly impossible to hear policymakers talk about the high cost of drugs without including the cost of insulin. It has become the poster child for high-cost prescription drugs. Nevada helped sparked that movement by talking about the high cost of insulin and diabetes drugs in 2017. As a result, there

have been market changes for major diabetes drugs. Manufacturers have lowered the cost of some of their insulin drugs and we have seen lawmakers use Nevada's data to question the high cost of diabetes drugs. All of that affects the patients who deserve to know the answer as to why their drug costs are so expensive.

My hope is we will have the same catalyst effect in the category of asthma drugs as we have had in diabetes care.

SENATOR HAMMOND:
What has been the net effect of S.B. No. 539 of the 79th Session? It is two years later, what has been the reduction of cost in insulin?

SENATOR CANCELA:
It is hard to measure the correlation between changes in the market and the transparency created by S.B. No. 539 of the 79th Session. Just today, two PDMs announced they are going to cap the cost of insulin. I am not sure of the exact markers, but I believe they are lowering the cost of insulin because of awareness that increased cost of insulin is a problem.

Nevada now has unbiased data that show the cost of insulin has increased, along with the different reasons why it increased. That data could be used to shape public policy discussions around the need to lower the cost of insulin. In 2017, Nevada helped spark that conversation. Now there are questions being asked about insulin cost at the federal level.

CHAIR RATTI:
Is there anyone in support of S.B. 262?

CHRISTI CABRERA (Nevada Conservation League):
As an environmental organization, the connection between pollution and public health is front and center in our work. Today, people throughout Nevada with lung disease such as asthma are at greater risk from air pollution. Under no uncertain terms, air pollution has the hardest impact on low-income communities and communities of color. The American Lung Association gave Clark and Washoe Counties an "F" for ozone and particulate pollution in its *State of the Air* report. Far too many Nevadans are facing an added risk for asthma from air pollution. We support S.B. 262.

RUDY ZAMORA (League of Conservation Voters):
I am here on behalf of Chispa Nevada, a program within the League of Conservation Voters focused specifically on communities of color and low-income families in southern Nevada. As previously stated, Clark and Washoe Counties received an "F" for air quality. More than 1 in 12 kids in our State suffer from asthma, including my own 4-year-old son, William. Due to my work and service in the community, I know thousands of other families are suffering from asthma as well.

It has been painful to watch my child suffer debilitating asthma attacks. They put him in the hospital for days at a time. Just a few weeks ago, my son almost died when he went into respiratory failure and cardiac arrest. For the first 24 hours in the hospital, we were uncertain if he had suffered any long-term effects. I want my son to run and play and live a normal life.

These lifesaving medications are the only thing that will allow my son to live a close to normal life. He needs them to breath. For low-income families and communities of color these medications can become a burden. My son is on three different types of medications to control his asthma. I am fortunate to have employer-provided insurance that helps cover the cost of those medications. However, not everyone can afford $80 a month after insurance for these medications. Families without insurance can see up-front costs of $500 a month, and that does not include hospitalization or first responder costs. We support S.B. 262.

MS. CAPURRO:
On behalf of the Health Services Coalition, we support S.B. 262.

PRAVEEN JAYAKUMAR (Culinary Health Fund):
I am a primary care physician and a Medical Director with the Culinary Health Fund. I am here to testify about asthma and how to manage it (Exhibit L). This is why I am in support of S.B. 262.

JOSEPH DOUGLAS (Culinary Union):
I am 12 years old and have had asthma since I was 7 years old (Exhibit M). I support S.B. 262.

MR. CLARK:
I am here on behalf of Nevada Association of Health Plans and we are in support of S.B. 262.

MR. INGALSBEE:
I am here on behalf of the Professional Firefighters of Nevada and we are in support of S.B. 262. Firefighters receive numerous calls for kids and adults with asthma. Many of them cannot afford the medication they need and we provide them temporary relief. Sometimes we go back several times that day to provide this medication.

JIM SULLIVAN (Culinary Union):
We are in support of this bill, because it brings down the cost of health care. This issue is important to our union, because every dollar we have to spend on health care when negotiating contracts, comes out of wages, retirement and pensions.

CRYSTAL MUNOZ (Culinary Union):
I have had asthma since I was 7 years old. It is expensive to take care of my family's asthma (Exhibit N). I support S.B. 262 and increased transparency regarding the price of asthma medicine.

STACIE SASSO (Health Services Coalition):
The Health Services Coalition represents 25 employer and union self-funded health plans and roughly 280,000 lives in southern Nevada. Asthma is an expensive disease and any transparency on the prescription drugs these patients have to pay is appreciated.

MS. BOND:
Two years ago when we worked on the diabetes legislation, what we heard from the Pharmaceutical Research and Manufacturers of America (PhRMA) was Nevada would run out of drugs, manufacturers would stop selling insulin to Nevada, diabetes treatment would become more expensive, this would not save any money and they would file a lawsuit. I believe PhRMA got the last part right.

I want to remind the Committee several things happen when transparency gets going. Several other states have introduced similar legislation. Diabetes and insulin groups have grown. Eli Lilly and Company recently announced they are

cutting the price of Humalog insulin in half because they are introducing a generic insulin, and two manufacturers are going to create a product that has a $25 a month insulin cost. We have good data reporting on diabetes by DHHS.

RAYMOND MCALLISTER (Nevada State AFL-CIO):
We have 200,000 members and most of them belong to health insurance trust funds that purchase these supplies. There are a lot of bills that will make little difference in the lives of most people. There was an opportunity last Session with diabetes medication to make a real difference in people's lives. This is another one of those opportunities where you can provide transparency and start a path of better access to health care for the residents of this State.

CHAD NEANOVER (Culinary Union):
I have asthma. I was born premature, with one and a half lungs. At birth, my half lung was collapsed and I weighed one pound, nine ounces. Throughout my childhood, I was in the hospital at least once a week every month. I have never known life without asthma. I did not have health insurance from the ages of 18 to 29 years old. I could not afford to get treatment for my asthma. I took over-the-counter medications and was not able to keep my asthma under control. If I had an asthma attack, I would go to the hospital, but I would not be able to pay the $500 emergency visit copay, nor the extra cost for x-rays. I went to Tijuana to get three inhalers for under $20. In my twenties, I woke up in the emergency room. It was the most worried I have ever seen my wife. A few months later, I had a big bill from the hospital. There were times I was working two jobs and still had to forego my asthma treatments because we had to pay bills. We had to take care of not only my illness, but my wife's illness. I support S.B. 262 and increased transparency.

BYRON CHACON (Culinary Union; translator Nelson Lucero):
Byron Chacon's testimony in English (Exhibit O) is in support of S.B. 262.

CHAIR RATTI:
Is there anyone here in opposition to S.B. 262?

ROCKY FINSETH (PhRMA):
I am here on behalf of PhRMA and we are opposed to S.B. 262.

ASHER LISEC (PhRMA):
I am the Policy Director for PhRMA. We are opposed to S.B. 262 which expands the insulin transparency bill to include asthma medications. PhRMA understands the discussions about the costs and affordability of medications is important. However, PhRMA thinks transparency conversations need to be meaningful and provide information about what the consumer pays for the medicine (Exhibit P). We think this bill could be significantly improved by providing transparency across the entire supply chain.

Our second issue pertains to litigation that happened after S.B. No. 539 of the 79th Session. A product of that litigation was a set of regulations providing protection of proprietary information that was submitted to the DHHS. It is not clear whether S.B. 262 would extend those same proprietary protections to asthma drugs. We would ask the Legislature to consider an amendment to adopt the regulations from S.B. No. 539 of the 79th Session into S.B. 262 to provide the same proprietary protection for asthma medications.

CHAIR RATTI:
Is anyone here today to testify neutral for S.B. 262?

JAY PARMER (Association for Accessible Medicines):
The Association for Accessible Medicines represents the generic and biosimilar industry. The generic industry supports drug price transparency. Generic drugs reduce costs of prescriptions for consumers and Medicare and Medicaid programs. In 2005, then State Senator Dina Titus introduced a bill that became known as the "Generic Drug Utilization Act." Since that time, generic drugs have made a significant financial impact on the State. The data we have from 2017 show generic drugs saved the Medicaid program $370 million. Of the prescribed drugs for Medicaid, 82 percent were generic and they accounted for only 16 percent of total drug costs. Statewide generics were 90 percent of all prescriptions filled, but accounted for only 24 percent of total spending. This equates to about $2 billion in savings for Nevada in 2017.

SUZANNE BIERMAN (Administrator, Division of Health Care Financing and Policy, Department of Health and Human Services):
Transparency and accountability legislation help address rising pharmaceutical prices (Exhibit Q). We are neutral on S.B. 262.

SENATOR CANCELA:
One in every ten Nevadans has asthma. Nevada has a higher rate of asthma than the national average and it is expensive to treat the condition. We as a State should have neutral data to make policy decisions on this important issue. This is what S.B. 262 creates.

CHAIR RATTI:
We will close the hearing on S.B. 262 and open the hearing on S.B. 378.

SENATE BILL 378: Revises provisions relating to the pricing of prescription drugs. (BDR 40-574)

SENATOR CANCELA:
Senate Bill 378 does a number of things. It creates the Prescription Drug Affordability Board, the Prescription Drug Affordability Stakeholder Council that work with the Board and the Silver State Scripts Board.

This bill is not original to Nevada; it started as an idea in Maryland. It has gotten through the Maryland House and is now in the Maryland Senate. The Maryland Legislative Session has not ended. Currently, we do not know what the final bill is or if it passed during their session.

The reality is about one in four Nevadans struggle to deal with the high cost of prescription drugs. This bill is written to address that.

Section 12 of the bill establishes the Prescription Drug Affordability Board, which consists of five members, one each appointed by the Governor, the Majority Leader of the Senate, the Speaker of the Assembly, the Attorney General and one member jointly appointed by the Majority Leader of the Senate and the Speaker of the Assembly. The members must have expertise in the economics of health care or in the practice of clinical medicine. They must not be an employee, officer, member of the executive board or a consultant of a manufacturer or a trade association for manufacturers as defined in NRS 639.009.

Each of the appointments to the Board must reflect the ethnic and geographic diversity of the State. Before being appointed, appointees must disclose any potential conflicts of interest that may create a bias or the appearance of bias in

matters related to the duties of the Board. Members can receive a salary of $80 per day, as well as per diem and travel expenses.

Section 13 prescribes the requirement governing the procedures of the Board. The Board must meet every six weeks or at the call of the Chair. It allows for the Board to close any portion of the meeting to consider proprietary information around a prescription drug. It prohibits members from accepting financial benefits that exceed $5,000 per year from manufacturers or related people and entities. It prohibits the Board members, employees and independent contractors from accepting gifts or donations that could lead to a conflict of interest. It requires members to disclose conflicts of interest within five days of identifying the conflict.

Section 14 says the Board may appoint an Executive Director, General Counsel and other employees of the Board as needed.

Section 15 creates the Prescription Drug Affordability Stakeholder Council. This group has less appointment restrictions and allows for industry representation.

Section 16 establishes the Prescription Drug Affordability Account in the State General Fund to fund the Board.

Section 17 requires the Board to impose an assessment on manufacturers that sell prescription drugs for distribution in the State and requires the Board to deposit those assessments into the Prescription Drug Affordability Account. There are two proposed amendments. The first proposed amendment (Exhibit R) changes the word "assessment" to "fee" in this section.

Section 18 requires the Board to identify prescription drugs that meet certain criteria. Once the Board is established, these next sections answer "what does the Board do?"

Specifically, the Board must identify certain drugs and decide whether those prescription drugs should be looked at because of their costs.

The Board identifies: (1) Brand-name prescription drugs for which the wholesale acquisition cost is $30,000 per year or more and the wholesale acquisition cost has increased by $3,000 or more in any 12-month period or during the course of a treatment; (2) New biosimilar prescription drugs that have a wholesale

acquisition cost that is not at least 15 percent lower than the brand name prescription drug to which it is biosimilar; (3) Generic prescription drugs for which the wholesale acquisition cost is either $100 or more for a 30-day supply or less for one unit of the drug or has increased by 200 percent or more during the preceding calendar year; (4) Any other prescription drug the Board determines, in consultation with the Council, that the price of the drug is creating significant challenges for insurers and patients in Nevada.

For each drug the Board identifies, it must coordinate with the Council to determine whether to conduct a review of the price of the drug. The intent is the Council has industry representation that will balance the nonindustry representation within the Board to ensure the drugs under review meet this criteria and have buy-in from both sides.

Section 19 creates criteria the Board must consider when conducting such a review. This includes such information as: wholesale acquisition cost of the drug, the discount or rebates provided to health carriers and PBMs, the prices at which alternatives are sold in the State, cost to health carriers to provide the prescription drug, impact of price of the prescription drug in regard to access for the drug, and other relevant criteria.

After looking at that outlining criteria, if the Board cannot make a determination, subsection 3 outlines additional criteria it may consider.

Section 20 authorizes the Board to use certain information concerning the price of a prescription drug when conducting a review, and take certain measures. The Board may enter into a memorandum of understanding to acquire this information. Subsection 3 clarifies any proprietary information disclosed to the Board is confidential and not a public record.

Sections 13, 27 and 28 also provide for the confidentiality of the proprietary information the Board must consider.

Section 24 requires the DHHS to provide the Board any information pursuant to NRS 439B.600 through 439B.695, which requires manufacturers, PBMs and pharmaceutical representatives to submit certain information related to certain prescription drugs.

Section 21 states if, after conducting a review, the Board determines the drug price is creating significant challenges for insurers and patients in Nevada, the Board must prescribe a recommended upper payment limit for all purchases and payments of the prescription drug in the State. The first proposed amendment Exhibit R adds the language regarding payments. Purchases are made by those who take ownership of the drug, such as the wholesaler, hospital, pharmacy or patients. The payers, such as PBMs and insurers, also have to be included. The goal is to ensure the upper payment limit applies to the entire supply and financing chain.

In recommending such a limit, the Board must consider relevant information, including the cost of administering the drug, delivering the drug to consumers, and any other relevant administrative costs of the drug.

Sections 29, 30 and 32 through 36 make any upper payment limits prescribed by the Board mandatory after January 1, 2024.

Section 39 requires the Board to conduct an additional review of the price of a prescription drug for which a recommended upper payment limit was prescribed on or before December 31, 2023, and if appropriate, to prescribe a mandatory upper payment limit for that drug at the time.

Section 22 outlines the grievance procedure. In the event an entity feels the Board has made a wrong decision, this allows for a written appeal.

Section 23 allows for the Board to adopt regulations, enter into contracts and submit an annual report to the Legislature. The annual report must include trends in the prescription drugs, the number of prescription drugs reviewed, appeals submitted for judicial review and any recommendations to increase the affordability of prescription drugs in the State.

There is a conceptual amendment (Exhibit S) to expand what is already in section 31. Sections 31 and 32 establish the Silver State Scripts Program. The Silver State Scripts Program will allow DHHS to develop a list of preferred prescription drugs which must be used for Medicaid and the Children's Health Insurance Program (CHIP).

This preferred prescription drug list may be used for health benefit plans funded by a State agency, local governmental entity or nonprofit health benefit plan

that provides coverage for prescription drugs. If they choose to use the list of preferred prescription drugs. It requires that the DHHS to negotiate and enter into purchasing agreements for the drugs included in the list of preferred prescription drugs. It clarifies that DHHS has regulatory authority to develop the terms of the agreements and receive all rebates.

The conceptual amendment Exhibit S requires DHHS to manage and govern the pharmacy benefits for Medicaid and CHIP, as long as they are covered by a managed care organization (MCO) rather than have the MCO manage and govern the pharmacy benefits. This means DHHS is responsible for managing payments for prescription drugs and dispensing fees, administering all other prescription related services and costs, pharmacy benefits, data systems and drug rebates. The DHHS may select and contract with a PBM as long as the contract has significant transparency. It would also allow for the management of receiving rebates and taking appropriate action to carry out the Silver State Scripts Program.

The conceptual amendment Exhibit S requires the DHHS to report annually to the Legislature the amount of money saved through the Silver State Scripts Program.

The last part of the conceptual amendment Exhibit S replaces the existing Medicaid Pharmacy and Therapeutics Committee within DHHS with the Silver State Scripts Board. The Board will be required to identify prescription drugs for inclusion in the list of preferred prescription drugs.

The last part proposes authorizing the Board to consider the cost of a prescription drug if there is no significant difference in its clinical efficacy, safety and patient outcomes of two or more drugs. It would also allow for the Board to close any portion of the meeting in order to consider proprietary information confidential.

Finally, page 2 of Exhibit R adds audit controls of a PBM for transparency purposes. It requires a contractor to maintain certain records and documentation, cooperate with audits and submit to an annual audit.

The Silver State Scripts Program aims to expand the State purchasing power and reduce the cost for Medicaid and potentially for other State and local government health benefit plans.

CHAIR RATTI:
I would like to summarize to make sure I understand S.B. 378. There are two parts to S.B. 378. The first is the Prescription Drug Affordability Board and all of the necessary language to create and fund the Board. The Board manages drug prices in Nevada. The second part establishes the Silver State Scripts Program which gives the State the ability to create a group purchasing program for pharmaceuticals, which could include State agencies and local governments. There is also a reporting and audit process.

SENATOR CANELLA:
Yes.

CHAIR RATTI:
Does anyone want to testify in support of S.B. 378?

MS. CAPURRO:
The Health Services Coalition is in support of S.B. 378.

AMANDA KHAN (Progressive Leadership Alliance of Nevada):
I have asthma and I cannot afford the expensive prescription drugs for my asthma. I have submitted written testimony (Exhibit T). I support S.B. 378.

MS. BOND:
On behalf of the Culinary Health Fund, I want to support the idea of an affordability board, because Nevada has not had a central location to work on these issues.

MR. SULLIVAN:
The Culinary Union supports S.B. 378. I also want to point out the large groups of people wearing red shirts in this room and in Las Vegas are in support of S.B. 378.

MR. MCALLISTER:
The Nevada State AFL-CIO supports S.B. 378.

MR. INGALSBEE:
The Professional Firefighters of Nevada supports S.B. 378.

CHAIR RATTI:
Would anyone like to testify in opposition to S.B. 378?

MR. FINSETH:
I am here on behalf of PhRMA. We are in opposition to S.B. 378.

ADAM HOSMER-HENNER (PhRMA):
Senate Bill 378 proposes an imposition of price control that has potential legal vulnerabilities. These are the same legal vulnerabilities as S.B. No. 265 of the 79th Session. That piece of legislation was ultimately vetoed amid concerns about legal challenges to its imposition of price control.

First, S.B. 378 appears to violate the dormant Commerce Clause of *The Constitution of the United States* by regulating or controlling commerce in other states. The imposition of an upper payment limit affects transactions that occur entirely outside of Nevada. The amendment proposed by Senator Cancela appears to extend and exacerbate that problem by extending the reach of this piece of legislation throughout the entire supply chain.

This piece of legislation is based on a Maryland statute. The original statute in Maryland was struck down by the Fourth Circuit Court of Appeals as violating the dormant Commerce Clause after a lengthy and expensive legal battle which went to the Supreme Court of the United States. The Supreme Court of the United States declined to issue certiorari to consider and potentially reverse the decision of the Fourth Circuit Court of Appeals, leaving the bill abrogated and voided in Maryland.

The new legislation in Maryland is significantly different than the piece of legislation presented here in S.B. 378. For one thing, it only affects purchases by state entities rather than by any private health insurance plan or PBM. We believe that is an attempt to limit the potential constitutional issues with respect to transactions that occur outside the state.

Second, there is a preemption issue to this piece of legislation in the sense it affects the balance struck by the United States Congress with respect to federal patent law. The United States Congress has struck that balance with respect to the profits for an innovator to drive innovation by pharmaceutical companies and by other patent holders. A price control would restrict the goal of federal patent law. At least one federal circuit court has determined that this attempt to

set prices that can be charged by a patent holder violates that balance struck by the United States Congress, which is the ability for a patent holder to set prices (Exhibit U).

These are only two of the legal aspects raised.

CHAIR RATTI:
Does PhRMA want to add any additional remarks?

MR. FINSETH:
We have posted a written statement by PhRMA, Exhibit U.

ELISA CAFFERATA (Planned Parenthood Votes Nevada; Biotechnology Innovation Organization):
I am wearing my Planned Parenthood Votes Nevada hat. I want to address the Silver State Scripts portion of S.B. 378. I am still trying to get some feedback in terms of consolidation of prescription medication into one formulary and allowing for the consideration of the costs when it comes to the medications that are on the list. It might have an impact on the other work we have been doing this Session. For example, expanding the availability of medications such as long-acting reversible contraception, which can be expensive. We have not had a chance to finish that analysis and I want to bring up this issue.

My other hat is Biotechnology Innovation Organization. We have submitted testimony in opposition to S.B. 262 (Exhibit V) and S.B. 378 (Exhibit W).

SENATOR CANCELA:
The Attorney General in Maryland has done a lot of work, not only on the dormant Commerce Clause, but also preemption questions. They have been helpful sharing that information with Nevada.

We have crisis level problems when people cannot afford the medicine they need, and that requires bold policymaking and bold action.

CHAIR RATTI:
Seeing no further business, we are adjourned at 6:10 p.m.

RESPECTFULLY SUBMITTED:

_____
Michelle Hamilton,
Committee Secretary

APPROVED BY:

_____
Senator Julia Ratti, Chair

DATE:_____

EXHIBIT SUMMARY				
Bill	**Exhibit / # of pages**		**Witness / Entity**	**Description**
	A	2		Agenda
	B	10		Attendance Roster
S.B. 291	C	2	Katie Anderson	Testimony
S.B. 291	D	1	Trudy Larson / University of Nevada, Reno	U.S. Department of Health and Human Services Briefing Report
S.B. 291	E	2	Trudy Larson / University of Nevada, Reno	RUSP Core Conditions Chart
S.B. 291	F	1	Trudy Larson / University of Nevada, Reno	Chart of Conditions
S.B. 203	G	3	Megan Comlossy	Work Session Document
S.B. 258	H	43	Megan Comlossy	Work Session Document
S.B. 284	I	5	Megan Comlossy	Work Session Document
S.B. 364	J	1	Megan Comlossy	Work Session Document
S.B. 456	K	1	Megan Comlossy	Work Session Document
S.B. 262	L	2	Praveen Jayakumar / Culinary Health Fund	Testimony
S.B. 262	M	1	Joseph Douglas / Culinary Health Fund	Testimony
S.B. 262	N	1	Crystal Munoz / Culinary Union	Testimony
S.B. 262	O	1	Byron Chacon / Culinary Union	Testimony
S.B. 262	P	2	Asher Lisec / PhRMA	Testimony
S.B. 262	Q	1	Suzzanne Bierman / Department of Health and Human Services	Testimony
S.B. 378	R	1	Senator Yvanna D. Cancela	Proposed Amendment

S.B. 378	S	2	Senator Yvanna D. Cancela	Proposed Conceptual Amendment
S.B. 378	T	1	Amanda Khan / Progressive Leadership Alliance of Nevada	Testimony
S.B. 378	U	3	Rocky Finseth / PhRMA	Testimony
S.B. 262	V	1	Elisa Cafferata / Biotechnology Innovation Organization	Testimony
S.B. 378	W	3	Elisa Cafferata / Biotechnology Innovation Organization	Testimony