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

Seventy-Ninth Session
March 3, 2017

The Committee on Health and Human Services was called to order by Chairman Michael C. Sprinkle at 12:48 p.m. on Friday, March 3, 2017, in Room 3138 of the Legislative Building, 401 South Carson Street, Carson City, Nevada. The meeting was videoconferenced to Room 4406 of the Grant Sawyer State Office Building, 555 East Washington Avenue, Las Vegas, Nevada. Copies of the minutes, including the Agenda (Exhibit A), the Attendance Roster (Exhibit B), and other substantive exhibits, are available and on file in the Research Library of the Legislative Counsel Bureau and on the Nevada Legislature's website at www.leg.state.nv.us/App/NELIS/REL/79th2017.

COMMITTEE MEMBERS PRESENT:

Assemblyman Michael C. Sprinkle, Chairman
Assemblywoman Amber Joiner, Vice Chair
Assemblywoman Teresa Benitez-Thompson
Assemblyman Richard Carrillo
Assemblyman Chris Edwards
Assemblyman John Hambrick
Assemblywoman Brittney Miller
Assemblyman James Oscarson
Assemblyman Tyrone Thompson
Assemblywoman Robin L. Titus
Assemblyman Steve Yeager

COMMITTEE MEMBERS ABSENT:

Assemblyman William McCurdy II (excused)

GUEST LEGISLATORS PRESENT:

Assemblywoman Dina Neal, Assembly District No. 7

STAFF MEMBERS PRESENT:

Marsheilah Lyons, Committee Policy Analyst
Mike Morton, Committee Counsel
Terry Horgan, Committee Secretary
Kailey Taylor, Committee Secretary
Trinity Thom, Committee Assistant

OTHERS PRESENT:

Zippora Jones-Turner, Private Citizen, Las Vegas, Nevada
Havander Davis, Private Citizen, Las Vegas, Nevada
Kenneth Taycher, Private Citizen, Las Vegas, Nevada
Sheila L. Thorne, President and CEO, Multicultural Healthcare Marketing Group, LLC, Englewood, New Jersey
John DiMuro, D.O., Chief Medical Officer, Division of Public and Behavioral Health, Department of Health and Human Services
Kirsten Coulombe, Deputy Administrator of Administrative Services, Division of Public and Behavioral Health, Department of Health and Human Services
John Ellerton, M.D., Principal Investigator, Nevada Cancer Research Foundation
Constance Brooks, Vice Chancellor, Government and Community Affairs, Nevada System of Higher Education
Tom McCoy, Nevada Government Relations Director, American Cancer Society Cancer Action Network

Chairman Sprinkle:
[Committee rules and protocols were explained.] We will have our first work session today. This is the time for the Committee to deliver any measures that have already been heard, consider any proposed amendments, and vote on them. Additional testimony will not be taken on the measures. However, at times, I may direct a witness to answer a question or provide clarification. If any members of the public have comments related to today's work session, I would encourage you to state them during the public comment period. As is customary with this Committee and many others, we will be having public comment at both the beginning and the end of today's meeting. At this point, I would like to open public comment. Is there anyone in southern Nevada wishing to speak?

Zippora Jones-Turner, Private Citizen, Las Vegas, Nevada:
I wanted to share a comment about integrated employment. I am not originally from Nevada, and I found it difficult to find employment. As we all know, integrated employment is very important to those with disabilities. It is difficult to pay your bills and do things that are expected of normal, regular people if we do not have the same opportunities. I just wanted to let everyone know that it is great to support those who are trying to help disabled people with gainful employment.

Havander Davis, Private Citizen, Las Vegas, Nevada:
I am testifying on behalf of those with visual impairments and disabilities in regard to integrated employment. We work very hard to be a viable part of the community. Without all of the services that we can get, it is very hard to be a viable part of the community. We would implore you with any bills or anything you come up with, to make sure that we get the most services we can get, so we can be a part of the community and give back to the community, as the community gives to us.

Kenneth Taycher, Private Citizen, Las Vegas, Nevada:
I would first like to thank you for taking this time to listen to me. I would like to speak about competitive and integrated employment. I am living proof that competitive and integrated employment can be achieved. I believe that everyone deserves and is capable of making competitive wages while being employed in their community with their peers. I am 33 years old, and I have had a dual disability, hearing and vision loss, throughout my life. My family and I have had a strong desire for me to succeed in obtaining skills needed to be a successful member of the community just like everyone else. Good services including occupation and mobility-assisted technology, daily living skills, and job readiness skills are essential and crucial for this economy because everyone deserves the chance to work and wants to be self-motivated with competitive employment. There was a lack of services for me, which made me feel as though I was unemployable. My family and I never gave up. We searched out an alternative method of services. Today, I am very proud to say that I have been able to gain and obtain the skills needed to be competitively integrated and employed in my community. I am volunteering, I am engaging, and I am feeling good and productive. I could not be happier. I am very motivated, and everyone wants to be a valuable member of their community.

We all deserve to have good training regardless of whether we have a disability or not. I would like my testimony to be that the system can be better and should be better for the next generation, so they have a smoother chance for competitive, integrated employment and a smoother transition. Thank you for your time.

Chairman Sprinkle:
Is there any other public comment in southern Nevada? [There was none.] Is there any public comment in northern Nevada? [There was none.] We will close public comment for now. We will open up the work session. We will begin with Assembly Bill 20.

Assembly Bill 20: Revises provisions relating to services to assist persons with disabilities in obtaining employment. (BDR 38-225)

Marsheilah Lyons, Committee Policy Analyst:
I have been asked to walk the Committee through the various bills included in today's work session document, which is available on the Nevada Electronic Legislative Information System (NELIS). Assembly Bill 20 revises the provisions of certain employment services delivered by the Bureau of Services to Persons Who Are Blind or Visually Impaired and the Bureau of Vocational Rehabilitation in the Rehabilitation Division of the Department of Employment, Training and Rehabilitation (DETR) (Exhibit C). It defines the term "competitive integrated employment" and revises various provisions and duties relating to vocational rehabilitation services. One amendment is proposed to the bill that was presented by DETR on the day of the hearing, February 17.

Chairman Sprinkle:
Are there any questions from the Committee on this bill? [There were none.] I will accept a motion for amend and do pass.

> ASSEMBLYMAN THOMPSON MOVED TO AMEND AND DO PASS ASSEMBLY BILL 20.
>
> ASSEMBLYMAN CARRILLO SECONDED THE MOTION.
>
> THE MOTION PASSED. (ASSEMBLYMAN McCURDY WAS ABSENT FOR THE VOTE.)

Assemblywoman Joiner will take the floor statement. We will move to Assembly Bill 31.

Assembly Bill 31: Revises provisions relating to the Specialist for the Rights of Elderly Persons and the Community Advocate for Elder Rights. (BDR 38-130)

Marsheilah Lyons, Committee Policy Analyst:
Assembly Bill 31 revises the name of the Specialist for the Rights of Elderly Persons to the Attorney for the Rights of Older Persons and Persons with a Physical Disability, an Intellectual Disability or a Related Condition. It also expands the scope of the powers and duties of the attorney. Those are outlined on the cover page of the work session document (Exhibit D). No amendments are included in the work session document for this measure.

Chairman Sprinkle:
Are there any questions on this bill? [There were none.] I will now accept a motion.

> ASSEMBLYMAN YEAGER MOVED TO DO PASS ASSEMBLY BILL 31.
>
> ASSEMBLYWOMAN TITUS SECONDED THE MOTION.
>
> THE MOTION PASSED. (ASSEMBLYMAN McCURDY WAS ABSENT FOR THE VOTE.)

Assemblyman Carrillo will take the floor statement. We will move on to Assembly Bill 99.

Assembly Bill 99: Revises provisions relating to services for children. (BDR 38-144)

Marsheilah Lyons, Committee Policy Analyst:
Assembly Bill 99 requires a public or private institution or agency authorized to care for children to treat a child for whom the institution or agency is responsible as having the gender with which the child identifies, regardless of the biological sex of the child. The bill requires employees of the institution or agency who come into direct contact with the children to receive, within 30 days after being hired, at least two hours of training on working with lesbian, gay, bisexual, transgender, and questioning children. In addition to other

provisions, the bill requires the Division of Child and Family Services of the Department of Health and Human Services to establish a procedure for filing and resolving a grievance concerning a placement, a foster care agency, an agency that provides child welfare services, or an agency or institution to which a child is committed by a court.

Three amendments were submitted by Assemblyman Nelson Araujo: (1) Proposed Amendment 3029; (2) amendments for sections 37, 41, and 46; and (3) an amendment regarding the cosponsors which are all attached to this portion of the work session document (Exhibit E) for the Committee's consideration.

Chairman Sprinkle:
Are there any questions or comments on Assembly Bill 99?

Assemblyman Edwards:
I am concerned with this bill because I do not think that we, as a Legislature, have the competency to provide the training that is being talked about. We do not know what it is going to be, and we do not know if two hours is enough or too much. There has not been enough specification for what this actually is. On top of that, I think that the overall impact would be to hurt the ability of some folks who want to become foster parents. I am concerned about the children who are involved in the foster care system. I am concerned that we are trying to do something that we are not yet prepared to do. I think we need to study this a lot more before we start requiring training that we do not have prepared. I will be a no on this.

Assemblywoman Titus:
I, too, will be a no on this bill, although conceptually, I appreciate what it is that the sponsor is trying to do and the intention of this bill. Unfortunately, the unintended results of this may be negative. There is a lack of foster parenting, especially in the rural communities, and I am afraid that mandatory training, the hours required, the difficulty in obtaining the training, and the inability to identify how the training will exist will be a pushback for some otherwise qualified foster parents.

Assemblyman Yeager:
My recollection from the testimony was that this training could be subsumed in the training that is already given. This bill made a lot of sense because of the foster kids who came to testify and talked about their experiences in the system. I am a strong supporter of this bill because I think that ultimately, we need to do what is right for the foster kids. I see this as a bill that takes a small step in that direction to make sure that we are valuing everyone and making sure that kids get through the foster system.

Chairman Sprinkle:
I will now accept a motion.

> ASSEMBLYMAN THOMPSON MOVED TO AMEND AND DO PASS ASSEMBLY BILL 99.
>
> ASSEMBLYWOMAN BENITEZ-THOMPSON SECONDED THE MOTION.
>
> THE MOTION PASSED. (ASSEMBLYMEN EDWARDS, HAMBRICK, OSCARSON, AND TITUS VOTED NO. ASSEMBLYMAN McCURDY WAS ABSENT FOR THE VOTE.)

Assemblyman Nelson Araujo, Assembly District No. 3 will take the floor statement. We will now move on to Assembly Bill 108.

Assembly Bill 108: Provides for the periodic review of Medicaid reimbursement rates. (BDR 38-209)

Marsheilah Lyons, Committee Policy Analyst:
Assembly Bill 108 requires the Division of Health Care Financing and Policy of the Department of Health and Human Services to review the adequacy of Medicaid reimbursement rates every four years. If the Division finds that the rate of reimbursement for a service or item does not accurately reflect the actual cost of providing that service or item, this bill requires the Division to calculate the rate of reimbursement that accurately reflects the actual cost to provide the service or item and recommend that rate to the Director of the Department of Health and Human Services for possible inclusion in the State Plan for Medicaid. No amendments for this measure are included in the work session document (Exhibit F).

Chairman Sprinkle:
Is there any discussion on Assembly Bill 108?

Assemblywoman Titus:
I need to clarify my position on this. Although I am supportive of this bill, I am a Medicaid provider; I do not receive any direct payments from Medicaid. I am employed by South Lyon Medical Center, so this bill, if passed, would not increase my income nor would I benefit from this in a direct way, any more than any other Medicaid provider will. I wanted to clarify that, so I am clear to vote on this.

Chairman Sprinkle:
I will now accept a motion.

> ASSEMBLYMAN EDWARDS MADE A MOTION TO DO PASS ASSEMBLY BILL 108.
>
> ASSEMBLYMAN CARRILLO SECONDED THE MOTION.
>
> THE MOTION PASSED. (ASSEMBLYMAN McCURDY WAS ABSENT FOR THE VOTE.)

Assemblyman Oscarson will have the floor statement for Assembly Bill 108. That will end our work session for today. I will open the hearing on Assembly Bill 214.

Assembly Bill 214: Establishes a program to increase participation by certain demographic groups in clinical trials. (BDR 40-707)

Assemblywoman Dina Neal, Assembly District No. 7:
This bill is about promoting diversity in clinical trials and about trying to make sure that the state gets involved and tries to build collaboration around clinical trials. I wanted to start in a unique way to help you get a framework for where I am going with this bill. If the Chairman will indulge me, I have a quick three-minute clip (Exhibit G) that I thought would help encapsulate what clinical trials are about and what diversity in clinical trials means.

Thank you for allowing me to show that clip because I realized, in the process of trying to develop this bill, many people had a lot of myths around what a clinical trial is. I heard a lot about the "Tuskegee Study of Untreated Syphilis in the Negro Male" and how that was an experiment that went wrong. There is a lot of taboo around wanting to be a part of a clinical trial. There are some who think they will get sick or be used as a guinea pig. At the end of the day, it is important to understand there are biochemical differences in individuals and they are unique. Because we are different at a biochemical level, it is important that we test drugs to make sure that they will do the right thing for the right people. If I, as an African-American woman, have a particular phenotype that the drug could remedy the disease I may need to heal, this is of particular interest to me because I had a mother who had three types of cancer. She was diagnosed with breast cancer and then, 12 years later, she had lung cancer and brain cancer. When I watched her go through all of the medications, I realized the importance of drugs and getting that right so that a person can actually live the life that they choose to live.

I will now get into Assembly Bill 214. You should have a mock-up of proposed Amendment 3106 (Exhibit H). There were a series of changes that occurred from the beginning up until now. Many of the changes in this mock-up came after I talked to a principal investigator, Dr. Ellerton with the Clark County Medical Society in the southern portion of Nevada, as well as with the Department of Health and Human Services (DHHS), and other clinical trial groups in Nevada. As we go through the bill, I want to explain why

that language is there. In section 1, the United States Food and Drug Administration (FDA) is mentioned because the impetus behind this bill is to make sure that we are following the FDA action plan and guidelines, which was one of the documents (Exhibit I) that I submitted as an attachment for this bill. The FDA has been trying to get involved in improving diversity in clinical trials. One of the things they felt was important was to improve the completeness and quality of data concerning demographic groups and identify the barriers to participation. The reason I used the language "recognized by the United States Food and Drug Administration" was that some people did not know that the FDA actually had guidance and recommendation strategies around that. I wanted to make sure that if we engage in this work it is not haphazard, and we understand what the dominating theory is nationally, because they spent a lot of time getting comments around this action plan.

If you go to section 1, subsection 2(a), I had the same thought when adding in this guidance in order to make sure that, as we move forward in the collection of race and ethnicity data in the clinical trials, it is going to be a constant tool to be used by state agencies to promote awareness.

In section 1, subsection 2(a), I added the language "using existing infrastructure and tools." When I had a conversation with Department of Health and Human Services (DHHS), they suggested using existing infrastructure and tools, so that we can reduce the cost. We talked through what it would mean to use existing tools and infrastructure, and they felt that they could probably do something through the Office of Public Health Informatics and Epidemiology.

The strikeout language in section 1, subsection 2, paragraph (a), subparagraph (2), is because we do not need to be conducting conferences and training for folks who are already doing that work. Most of the people who are doing clinical trials already know what they are doing. They do not need the state to be in the actual process of doing conferences and training. They need the state to be a participant, a collaborator, and a supporter.

Currently, if you go to the state website, you would not find anything on clinical trials. You also would not find which agencies are actually doing that work. They are operating in silos. Oftentimes, I heard that they would love the state to be involved in what they do, and they would love for the state to be involved in dealing with the issue of diversity in clinical trials because in so many instances, they would print a flyer and ask for it to be posted, but they would be turned away. They would be turned away for the simple act of wanting to put up a flyer. That is a nominal thing, but what I am seeking with this bill is something much greater.

The Internet provision in the bill on page 2, line 18 is because I want the state to be a hub where links regarding clinical trials can be added into a page. I do not want us to create the link, because the links are already there. All you have to do is establish a website and make sure that the information is up-to-date in regards to the clinical trials and the drugs, so that folks can add what it is that they are doing. If you reference the snapshot page (Exhibit J) I gave you, you will see an example of what would be awesome to see in our state. This not

anything that DHHS has to do, because the agencies and the nonprofit research organizations are already doing it.

Moving further down, section 1, subsection 2, paragraph (b), promotes assistance with the Office of Grant Procurement, Coordination and Administration of the Department of Administration. We had a bill in another committee where this Office stated that they wanted agencies to use them and that there was a lack of connection and engagement. I thought that because we are adding staff to that office, we should have them be a part of this process, at least in regards to helping find grants. Most of these agencies are running by grants or private dollars. In addition, maybe they could see if there are any dollars to help DHHS maintain the website. I am trying to put some measures in the bill that will allow for financial assistance.

The reporting language that you see in section 1, subsection 2, paragraph (c), is there because when I talked to the principal investigator, Dr. Ellerton, he asked how we would know that we have actually engaged in the process of removing the barriers and creating transparency if there is no report. That is why I added that language.

The rest of the amendments continue to discuss the collaboration with community organizations who conduct clinical trials in order to make sure there is constant engagement, so we can come together and work together to reduce the barriers, create transparency, and have statewide data. I looked for statewide data. It can be found, but it is found individually by group. I would have had to upload many pages in order to show what each group was doing. The only thing I could show you was the national data, which shows demographically who is being represented in the trials. Ultimately, this is what the bill does. I do have some presenters on the phone to help answer questions as well.

Chairman Sprinkle:
Would you like to have the people on the phone give their testimony first?

Assemblywoman Neal:
Yes, on the phone is Sheila Thorne. She has the expertise in clinical trials to explain why the state's participation is important.

Sheila L. Thorne, President and CEO, Multicultural Healthcare Marketing Group, LLC, Englewood, New Jersey:
I am president and CEO of my own company, Multicultural Healthcare Marketing Group. I am also an Associate Clinical Professor at Stony Brook University School of Social Welfare. Thank you for allowing me to share my thoughts about recruiting diverse populations in clinical trials. I have been doing that for a number of pharmaceutical companies for more than a decade. It is obvious to me that as the demographics of this country change, nationally and on the state level it becomes important that we have a diverse group of participants in clinical trials. Physicians know that each racial and ethnic group responds differently to medical treatments concerning dosing, side effects, and the ultimate outcomes. If we look at the chronic diseases that affect people of color most, including

diabetes, cardiovascular disease, cancer, and human immunodeficiency virus (HIV), all of these cost a lot of money to take care of. If there were appropriate drugs or pharmaceuticals to treat or cure these diseases, it would make doctors much more confident that the drugs they are offering to these patients work in everyone. The outcome is what we are looking at in terms of quality of life as well as longevity. The whole movement of the health care industry right now is towards personalized medicine, precision medicine, and patient-centered care. There is no doubt that race and ethnicity are key factors in designing a chemical compound that will work well in these populations.

Before the middle of this century, 1 out of every 2 Americans will be a person of color, or a person of color who speaks Spanish. It behooves us to broaden clinical research. It is the foundation of the practice of evidence-based medicine. People of different races and ethnicities metabolize drugs differently, and their lifestyles are different. All of these factors affect the efficacy and safety of the drugs. Medical science has known for quite a while that each group responds differently to different drugs. It becomes problematic when you have trials that are only composed of white, middle-aged men, and you try to extrapolate that data and how it works with women of African-American, Latina, or Asian background.

Frankly, when I go into communities around the country to help the pharmaceutical client recruit a diverse population, I have found that these groups are not even asked to be in a clinical trial. Although there are barriers and obstacles, they are not insurmountable. The more good science we encourage to happen on the state level, the better the health outcomes and quality of life will be. We have made some progress, but we have a long way to go if we are going to improve the quality and longevity of life for all Americans.

Assemblywoman Titus:
Thank you for bringing this forward. I know it is emotional for you, but this is very important. I am a strong believer that we are all created equal but we are all unique, and our biochemistry is what makes us unique. Finding out what works for you is not necessarily what works for me or other people in this room. I have found it is difficult to get folks involved in some of these clinical trials. In addition, it is critical that I, as a family practice doctor who sees people from birth to age 102, of all ethnicities, know I am treating them correctly. It is work like this that helps me to do my job better.

Assemblyman Edwards:
I am trying to make sure I understand the intent and practical implementation of this. Is this bill trying to get more people to participate in a voluntary way? Alternatively, is this more a matter of the state coming up with the numbers of different folks from different communities who would be included in the clinical trials? Am I misunderstanding that the state would be determining at any point the diversity of people who would be participating, which would take away the researchers' function of deciding who should be in it?

Assemblywoman Neal:
I would say you do not understand the intent. The intent of the bill is to make sure the state is engaged in what is happening. There is currently no relationship between the people who

are doing the work and the state. My goal is to make sure that the state is a collaborator, not that they are picking who goes into the trial. That is not the goal or intent. The reason I used the FDA action plan is because the states are an integral part of making sure the conversation around barriers is happening and making sure that it is a top-down and a bottom-up conversation. It states several times that the state operates in conjunction and in collaboration with several different agencies—medical agencies, nonprofit research groups, and others.

Assemblyman Edwards:
Can you give me an example of where the state is not helping, and what impediments they would help to overcome?

John DiMuro, D.O., Chief Medical Officer, Division of Public and Behavioral Health, Department of Health and Human Services:
Diversity in clinical trials is obviously very important. Assemblywoman Titus has spoken about it as well. Even in my field of anesthesiology, you have different potencies of inhaled anesthetics for patients with red hair. Obviously, we would want a diverse clinical trial at any possible time. There are numerous ongoing clinical trials in the state, but rarely do physicians know about them. They are typically sponsored by universities such as the University of Nevada, Reno (UNR) and the University of Nevada, Las Vegas (UNLV), and Nellis Air Force Base. However, private practice physicians very rarely know about them.

Whether or not there is a true deficiency in our state about diversity, I am not sure. I have not seen that data. I know that we definitely do not have enough participation in clinical trials in this state. I have been practicing medicine for almost nine years, and it was very rare for me to come across a clinical trial. After doing research on this, I think we have a big communication problem. It is very difficult to get the clinicaltrials.gov data down to the practitioner so that the practitioner knows about it. I think the oncologists would be the most informed when it comes to clinical trials. I think Assemblywoman Titus would agree with that. To encourage diversity would be great; I do not think that Assemblywoman Neal is saying that the state would choose candidates for the trial. We would like to make sure we could educate those providers so that they are able to enter a patient into a trial.

Chairman Sprinkle:
I am not trying to break my own rule because we are not a money committee, but your amendment does address part of the fiscal note. Could you briefly touch on that?

Kirsten Coulombe, Deputy Administrator of Administrative Services, Division of Public and Behavioral Health, Department of Health and Human Services:
We will come up in neutral to discuss the fiscal note. The amendment does address those concerns. We appreciate working with Assemblywoman Neal. She referenced using the existing resources and infrastructure that we have. We think it is something that we can do viably without having the fiscal impact that we noted on the analysis of the original bill.

Chairman Sprinkle:
Just for clarification, would that eliminate the fiscal note?

Kirsten Coulombe:
Yes, the fiscal note is zero. My understanding is that it does not replace the fiscal note in the system once changed, but you are correct. For the record, our fiscal impact would be zero.

Chairman Sprinkle:
That is why I wanted that on the record. You had mentioned barriers to clinical trials as a whole. Could you describe what some of those barriers are for underserved populations in regards to this bill? Can you explain why those barriers exist as a whole in this state?

Assemblywoman Neal:
The first barrier is the myth around clinical trials. The second barrier is the wrap-around services that I have heard are usually transportation barriers. For example, let us say there is a grandmother taking care of her daughter's children and she cannot leave to go to the trial because she cannot take the time off from the child care responsibilities she has taken on. Other instances are that people cannot participate because of work. It limits their ability to earn and their ability to go into the clinical trial. Typically, you do not know how long these trials will be. The length of time could be a week, two weeks, or longer. The barriers range, but they are significant.

John DiMuro:
The two barriers that I have seen in this state are logistics and communication. Obviously, in our rural areas, it is very difficult to have people participate in the trials, and we have a very poor, if any, communication system amongst the private practice physicians to know that trials do exist. Where I come from in the Northeast, you have a very high concentration of academic centers that are always engaging in clinical trials, which is a significant draw to those institutions. Here, we do not have that. On the website, clinicaltrials.gov, there were over 3,500 clinical trials listed for Nevada, yet only 360 trials were active. The majority of those did take place at the aforementioned institutions. Two major issues were logistics and communication to the providers who would be referring out for these trials. The Division of Public and Behavioral Health can address the communication aspect fairly well. We would have to see what we could do in a neutral basis to have the logistics play out.

Assemblyman Thompson:
Thank you for bringing this forth. Will this automatically work with our medical institutions?

Assemblywoman Neal:
Yes, there is actually language in section 1, subsection 2(d) on the amendment that says, "Each State or local governmental entity that conducts clinical trials of drugs or medical devices, including, without limitation, the Board of Regents of the University of Nevada . . . ." I actually did get a chance to sit down with Dr. Brooks. They are going to come up in support of this bill because they like this idea. They did not want me to change

the language because they wanted flexibility for the Board of Regents to come up with whatever process would come into play once the medical school down south comes on board; UNR already engages in certain practices. Renown Health does as well. They thought the language was a good vehicle for them to work with.

Assemblyman Thompson:
Will that automatically include the data collection and analysis part of it? I know that we probably have to use everything in aggregate, so we do not violate the Health Insurance Portability and Accountability Act (HIPAA), but how do we know that we are trending and going in the right direction?

Assemblywoman Neal:
I see the role as collaboration and ensuring that if they do engage, there is communication among the folks that are functioning down south, and they are not doing it in isolation. What is happening right now is if you pull up clinical trials in Nevada, you will see all these little dots around the city in the south, but you do not know how they communicate with each other or what that relationship is. Ultimately, the universities will be a good tool or agent in making it more cohesive. We will have DHHS, the universities, and the entities that are performing the work. My idea is that we would see a collaboration of information, folks talking to each other and helping each other understand how to overcome the barriers. If you know where it is and have someone to help, you can leverage resources, and we will do better than what we are doing now.

Assemblywoman Benitez-Thompson:
There is amazing work being done in southern Nevada on brain science out of the Cleveland Clinic Lou Ruvo Center for Brain Health. Is there a way to capture those private institutions that may have a nexus to the universities but that are also doing private research through federal dollars, other than just a simple ask and the hope of a generous spirit?

Assemblywoman Neal:
I thought that we were trying to capture them in the bill. If we need to tighten that up, we can. We have institutions that are performing research related to drugs or medical devices. I thought that was language that would pick them up.

Assemblywoman Benitez-Thompson:
So for the record, we can know that the intent of that language is the outreach to the nongovernmental and the private sectors.

Chairman Sprinkle:
We will now take testimony in support of this bill.

John Ellerton, M.D., Principal Investigator, Nevada Cancer Research Foundation:
I am a medical oncologist and the principal investigator of the Nevada Cancer Research Foundation, which is funded by a National Cancer Institute Community Oncology Research Program grant. There are 35 of these programs in the country that provide clinical trials for

the community. In the last 30 or more years that the foundation has been funded by the National Cancer Institute, thousands of patients have been placed on clinical trials. We are the infrastructure support for the Children's Oncology Group and a number of other organizations. At the present moment, every oncology provider who wants to participate can. In fact, we have participating institutions in Carson City and Douglas County. There are also participating oncologists in Reno at Saint Mary's Regional Medical Center and Renown Health, as well as oncologists in Las Vegas; virtually everyone participates. Therefore, the protocols are made available to the oncologists and the radiation oncologists. That is the purpose of this foundation. It was one of the first ones funded in the early 1980s, and it has continuously been funded ever since.

I might mention that there were several big prevention trials in the United States—two breast cancer trials and two prostate cancer trials. Thanks to the foundation, 1,000 Nevada residents were able to participate in those trials. In our current scope of work, we have been asked to focus more on two issues; one is the diversity, and the second is cancer care and delivery research. I understand why ideas and results do not get into the general treatment community and why patients do not get into trials. This has now become a focus. We now have two or three trials open that are looking specifically at how to improve the diversity of the patients in clinical trials. Right now, we are negotiating with some national research groups to participate in some National Cancer Institute-funded bigger trials to look at diversity. It would be very nice to work with the state and have them participate in understanding how to improve diversity and how to improve the delivery of the cancer care.

I think that collaboration and cooperation are what attracted me to support the bill. We are doing the work, especially in oncology, but we need to do a better job at participant diversity and delivery of care. In the next scope of work, this will continue because this is just getting off the ground. This is very difficult to study, and I would say that the barriers secluding people from clinical trials and my colleagues are always very similar. It starts with doctors not thinking about clinical trials. About 80 percent of children with cancer go on clinical trials as opposed to only about 5 percent of adults. For those of us who do this, we feel that clinical trials are the ethical standard of care, at least to offer it to the patient. I think this is a good idea; it does not create any undue reporting burden. This bill creates a framework for us to sit down and collaborate with the state. We have wide collaboration within the hospital and doctor communities helping us to perform this research.

Constance Brooks, Vice Chancellor, Government and Community Affairs, Nevada System of Higher Education:

We would like to thank Assemblywoman Neal for bringing this legislation forward. We do feel that diversity and its inclusion within clinical trials is an imperative. As you know, we have the UNLV School of Medicine that will be starting with its first class in just a few months. We also have the UNR School of Medicine, both of which are very much in support of this bill. We do appreciate having the latitude to work within the Board of Regent's policies and procedures to develop a policy that would be applicable to this legislation. We do have a Health Sciences System Committee within the structure of the Nevada System of Higher Education. What we would like to do is work with Assemblywoman Neal as we

develop the policy aligned with this legislation to make certain that it does meet all of the requirements that would be fitting for this bill. In addition, we would appreciate her attendance at our Health Sciences System Committee as this policy is going to be brought forward and voted on within the boards.

Tom McCoy, Nevada Government Relations Director, American Cancer Society Cancer Action Network:
This is cancer awareness day at the Assembly, as you know. It is timely for me to come to the table and tell you that we support Assemblywoman Neal's efforts in this area. Clinical trials are the key to so many of our cancer patients. As we saw from the clip that Assemblywoman Neal showed us, cancer is not the only serious illness addressed by clinical trials. So are heart issues and other illnesses.

I wanted to respond to a couple of comments made about barriers. We have a transportation barrier. This is applicable to so many areas in our health care. I was talking to someone in rural Nevada who was talking about a clinical trial possibility that someone had in Salt Lake City, but this person could not take it because they could not afford to go back and forth to Salt Lake City. You might even say that in Las Vegas, Reno, and outlying areas, some people, based on their transportation challenges, may not have that opportunity.

I did want to point out something that is worth considering. We heard numbers from Dr. Ellerton in terms of participation. In 2017, we will see about 15,000 people in Nevada newly diagnosed with cancer. How many of those will be involved in clinical trials? Should there be more? This is one opportunity we have. I also wanted to mention that the American Cancer Society has something called Clinical Trials Matching Service. Anyone can call the 800-number and ask if there is a cancer clinical trial that deals with prostate cancer or any other cancer. I would hope that this can somehow be blended into our conversation about how those services can be made available and how patients can be put in touch with doctors who have been assigned to work on that particular clinical trial.

Chairman Sprinkle:
Anyone in opposition to this bill? [There was no one.] Is there anyone in neutral to this bill?

Kirsten Coulombe:
We are neutral. As you may know, Nevada is considered to have some of the lowest participation rates in the country for clinical trials. Currently, the majority of these trials are sponsored by UNLV, University Medical Center of Southern Nevada, Nellis Air Force Base, and Comprehensive Cancer Centers of Nevada. This bill would increase the visibility of trials to Nevadans. Our fiscal note related to increasing staff, a new program, and those conferences required is no longer applicable because that amendment cancels those needs and allows this to have no fiscal impact.

Assemblyman Yeager:
I heard you mention that some trials occur at Nellis, can you explain?

Kirsten Coulombe:
Yes, at the Nellis military base.

John DiMuro:
These are military trials. Typically, they will only allow military participants. Right now, there is an ongoing trial regarding back pain using an oral agent.

Chairman Sprinkle:
Assemblywoman Neal, you may come up for closing comments.

Assemblywoman Neal:
I want to thank the Chairman and the Committee for allowing this hearing to happen and indulging me with my small video. Once again, I hope the Committee understands the issue, and that you will reach out to me if you have any questions.

Chairman Sprinkle:
Thank you. I will close the hearing on A.B. 214.

[(Exhibit K) and (Exhibit L) were submitted but not discussed.]

Is there a second round of public comment? [There was none.] This meeting is adjourned [at 1:50 p.m.].

RESPECTFULLY SUBMITTED:

_____
Kailey Taylor
Committee Secretary

APPROVED BY:

_____
Assemblyman Michael C. Sprinkle, Chairman

DATE: _____

EXHIBITS

Exhibit A is the Agenda.

Exhibit B is the Attendance Roster.

Exhibit C is the Work Session Document for Assembly Bill 20, dated March 3, 2017, presented by Marsheilah Lyons, Committee Policy Analyst, Research Division, Legislative Counsel Bureau.

Exhibit D is the Work Session Document for Assembly Bill 31, dated March 3, 2017, presented by Marsheilah Lyons, Committee Policy Analyst, Research Division, Legislative Counsel Bureau.

Exhibit E is the Work Session Document for Assembly Bill 99, dated March 3, 2017, presented by Marsheilah Lyons, Committee Policy Analyst, Research Division, Legislative Counsel Bureau.

Exhibit F is the Work Session Document for Assembly Bill 108, dated March 3, 2017, presented by Marsheilah Lyons, Committee Policy Analyst, Research Division, Legislative Counsel Bureau.

Exhibit G is a copy of a video titled "Milena's Clinical Trial Story," presented by Assemblywoman Dina Neal, Assembly District No. 7.

Exhibit H is Proposed Amendment 3106 to Assembly Bill 214 presented by Assemblywoman Dina Neal, Assembly District No. 7.

Exhibit I is a document titled "FDA Action Plan to Enhance the Collection and Availability of Demographic Subgroup Data," dated August 2014, by the United States Food and Drug Administration, presented by Assemblywoman Dina Neal, Assembly District No. 7.

Exhibit J is a document titled "2015-2016 Drug Trials Snapshots: Summary Report," by the United States Food and Drug Administration, presented by Assemblywoman Dina Neal, Assembly District No. 7.

Exhibit K is a document titled "FDA Encourages More Participation, Diversity in Clinical Trials," dated January 10, 2017, by the United States Food and Drug Administration, presented by Assemblywoman Dina Neal, Assembly District No. 7.

Exhibit L is a written statement authored and submitted by the Pharmaceutical Research and Manufacturers of America, in support of Assembly Bill 214.