

Joe Lombardo
Governor



Richard Whitley,
MS
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Cody Phinney,
MPH
Administrator

Ihsan Azzam,
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Chief Medical
Officer

NEVADA RARE DISEASE ADVISORY COUNCIL

MEETING MINUTES

Date: August 4, 2023

9:33 am – 10:21 am

Meeting Locations:

Pursuant to NRS 241.020(3)(a) as amended by Assembly Bill 253 of the 81st Legislative Session, this meeting was convened using a remote technology system and there was no physical location for this meeting.

Chair Annette Logan-Parker opened the meeting at 9:33 am.

1) INTRODUCTIONS AND ROLL CALL

COUNCIL MEMBERS PRESENT:

Annette Logan-Parker (Chair); Gina Glass (Vice-Chair); Ihsan Azzam, MD, PhD; Valerie Porter, DNP, BSN, MBA; Kimberly Palma Ortega; Naja Bagner; Craig Vincze, M.D.; Christina Thielst; Amber Federizo, DNP, APRN, FNPBC (Quorum=9)

COUNCIL MEMBERS ABSENT:

Veneta Lepera; Nik Abdul Rashid, MD (excused absence); Susana Sorrentino, M.D.; Jennifer Millet, DNP, RN (excused absence); and Linetta Barnes, BSN, RN; Shirley Folkins-Roberts (excused absence); Paul Niedermeyer (excused absence)

DIVISION OF PUBLIC & BEHAVIORAL HEALTH (DPBH) STAFF PRESENT:

Kayla Samuels, *Management Analyst II, Health Care Quality and Compliance (HCQC), DPBH*

OTHERS PRESENT:

Kathleen Kingston; Amber Williams, *Executive Leadership Support, Special Projects, Cure4Kids Foundation*; Donna Laffey; Elizabeth Kessler; Jamey Felsing; Jaromy Russo, *IT Systems Analyst, Cure 4 the Kids Foundation*; Linda Anderson

Roll call was taken and is reflected above. Agenda items were taken out of order to address Informational Items first until it was determined that a quorum of the Rare Disease Advisory Council (RDAC, the Council) was present.

2) PUBLIC COMMENT

Chair Logan-Parker opened the floor for public comment.

Hearing none, Chair Logan-Parker moved on to the next agenda item.

8) INFORMATIONAL: Update the Council on the NV RDAC website. – *Chair Logan-Parker*

Chair Logan-Parker gave updates on the RDAC website noting that there have been two (2) individuals utilize the “Contact Us” button that staff were able to provide resources for. Chair Logan-Parker said it was exciting to see that the public is starting to see that RDAC has a website to offer some additional resources. Any websites or educational resources anyone would like to see included on the RDAC website are welcome. The goal is to have the website ready for “prime time.” The roll out of the needs assessment and other projects is on target for January 2024 with a big public relations (PR) push for February, which is World Rare Disease Day.

9) INFORMATIONAL: Update and discussion on Senate Bill (SB) 221 that has been signed by Governor Lombardo – *Chair Logan-Parker*

Chair Logan-Parker described SB 221 as a bill that is allowing for an additional provider type under provider type 17 to allow for an outpatient childhood cancer rare disease clinic opportunity. The bill would allow people who qualify for that particular provider type the ability to have a different methodology and different billing guide associated with the services provided. Chair Logan-Parker said it is not likely to see the long-term benefits of the bill until mid-2024 because there is a large implementation plan that needs to be worked through and ultimately the Centers for Medicare and Medicaid Services (CMS) will need to approve any changes because any increase to the rate methodology increases the federal dollars that come to the state through that program. Chair Logan-Parker said the bill passing is quite a victory and RDAC has a lot to do with helping the Governor’s Office understand the need for the bill and helping Medicaid understand as well. Chair Logan-Parker thanked the previous RDAC Chair, Amber Federizo, for starting the work early on with RDAC that has helped open the door to allowing the Council to support SB 221 through Medicaid.

Chair Logan-Parker asked if there were any questions, none heard, and asked if a quorum was established yet.

Kayla Samuels said the Council still needed two (2) more members to establish quorum, however the Council may discuss other items on the agenda without taking action.

10) INFORMATIONAL: Update on the Mercer Medicaid Study on Nevada’s System of Care for Children with Rare Disease - *Chair Logan-Parker*

Chair Logan-Parker said the Mercer study is well underway and is a result of early efforts with the Nevada RDAC and Medicaid. In 2022, the Interim Finance Committee (IFC) approved Medicaid’s request to fund a study on rare disease service delivery models and to outsource an analysis of the issues that are unique to Nevada. Chair Logan-Parker said the Governor has allowed a \$250,000 allowance for

this study and Medicaid elected Mercer, which is a national consulting organization that does a lot of work with different state Medicaid programs and CMS across the country. The final report is due to Medicaid in December 2023. Chair Logan-Parker thanked everyone who participated with the study and said she thinks the study will be very helpful.

11) INFORMATIONAL: Overview of the Needs Assessment platform in REDCap – *Jeromy Russo, IT Systems Analyst, Cure 4 the Kids Foundation*

Chair Logan-Parker said Jeromy Russo has been working on the development of the Nevada RDAC needs assessment and said the needs assessment is very self-explanatory however feels there is a need for a few additional buttons for clarification.

Mr. Russo noted in the upper right corner of the first page of the survey, there is a button for returning to an in-progress survey. Since it is a longer survey, participants are welcome to pause and come back at a later time whenever it is convenient. Mr. Russo described accessibility features such as being able to translate the survey into other languages. Currently Spanish is available as one of the languages however staff are looking to translate the survey into a few others as well. There is also an accessibility feature for changing the font size, enabling users to make it larger or smaller. Links are available at the top of the survey page for assistance. Mr. Russo said the first few pages of the survey are background information explaining the purpose of the project and survey, then is followed by the questions of the survey. The question format is checked boxes and there is usually another section where participants can type in free text. Participants must be 18 years or older to complete the survey. The survey is accessible on mobile and desktop, and is built on a platform called Project Redcap, which is a secure web application that was explicitly designed for building and managing online surveys and databases. A lot of research universities and institutions use the software, so the program has been thoroughly tested and vetted and is very secure. Mr. Russo said the URL to the survey can be customized but is now publicly accessible though is not officially launched yet. For testing purposes, however, the survey is available.

Valerie Porter said the survey looks amazing.

Chair Logan-Parker suggested showing some examples of questions from the survey. Chair Logan-Parker said the survey was based off a project being done by the Pennsylvania Rare Disease Advisory Council, who has since closed their survey and are now analyzing data to report to the State of Pennsylvania what the state's unique disease burden has been. The study collected data for a three-year period of time, so RDAC will be following Pennsylvania's footsteps and the survey is going to help to identify what are the rare diseases in Nevada as well. Chair Logan-Parker said there are a few more additions that she thinks need to be added before going live in January and will send the link to the Council to review.

Christina Thielst asked if the Council would like her to go through the survey and take it to give feedback on user design from a user capability perspective.

Chair Logan-Parker said Ms. Thielst's idea was great, and the Council should get as many people as possible who are willing to give feedback and help before going public.

Ms. Thielst said the test survey would be her submission and she would not re-take the survey in January.

Chair Logan-Parker asked Mr. Russo his thoughts on Ms. Thielst's statement.

Mr. Russo said currently the survey is anonymous so the Council would not know which submission was Ms. Thielst's, and that Ms. Thielst would likely have to retake the survey once it is live to make the submission official.

Ms. Thielst said she does not want to skew the data by submitting two survey responses.

Dr. Ihsan Azzam said the survey looks very good and very promising. Dr. Azzam asked if the survey included an explanation for the reader of what is being done with the survey and the intentions.

Chair Logan-Parker confirmed that the information described by Dr. Azzam is on the first few pages of the survey.

Ms. Porter asked how people are going to know about the survey and how providers are going to encourage patients to participate.

Chair Logan-Parker said the Council discussed a "While You Wait" campaign that will include sending posters to pediatricians, family practice, and internal medicine offices with an entire campaign that has a QR code that individuals can go to from their phone and scan to take the survey. There will also be flyers, social media campaigns, and announcements in February for World Rare Disease Day. It is going to take the entire Council to get the word out in a lot of different areas. Chair Logan-Parker said Pennsylvania had posters and other materials in waiting rooms and exam rooms and imagines that the pediatricians and physicians the Council knows in Nevada would be happy to put the poster up. People can then take the survey from there. The needs assessment will likely be open for two (2) to three (3) years to ensure there is enough time to get the word out and collect enough data.

Ms. Porter suggested getting posters out to the Veterans' Affairs (VA) clinics, which would have to go through public relations, but said she does not see that being an issue.

Chair Logan-Parker agreed with Ms. Porter and said she also spoke to David Steinberg from Steinberg Diagnostics who is willing to post it in all their facilities as well. There will be a diverse area where information about the survey will be.

The following were put in the chat:

Christina Thielst: "The survey looks great and this is exciting. I agree we need to reach out to adults. I'll share it with all of my physicians."

Gina Glass: "GINA GLASS HERE I HAD TROUBLE GETTING IN"

4) FOR POSSIBLE ACTION: Discussion and possible action to recommend to the Director if the Nevada Department of Health and Human Services the appointment of Dr. Sumit Gupta as a Council member

representing one physician who practices in the area of cardiology, emergency care, neurology, oncology, orthopedics, pediatrics, or primary care and provide care to patients with rare diseases. – *Council Members*

Chair Logan-Parker said the Council cannot take action without a quorum, however, would like to discuss the recommendation for another Council member, Dr. Sumit Gupta. Chair Logan-Parker said she thinks Dr. Gupta would be a good fit. The process is that the Council would need to make a formal recommendation to the Director of the Nevada Department of Health and Human Services (DHHS) for the appointment for Dr. Gupta and said Dr. Gupta's qualifications have already been reviewed and approved by the Deputy Attorney General's Office for consideration of a seat at RDAC. Chair Logan-Parker said Dr. Gupta is currently a member of the Nevada Newborn Screening Advisory Council and has been a full-time physician at 4 the Kids, providing specialized care to children with cancer and other rare diseases. Since 2021, Dr. Gupta has completed his pediatric hematology oncology fellowship at the University of Texas MD Anderson Cancer Center and a pediatric residency at Mount Sinai Hospital in Chicago. Chair Logan-Parker said Dr. Gupta has received several honors and awards for his work as a principal investigator for many studies that benefit children with rare diseases as well as a sub investigator for several other open studies, and currently knows academic appointments at the Kerkorian School of Medicine, Roseman University of Health Sciences, and Toro University College of Osteopathic Medicine. Chair Logan-Parker said she personally knows Dr. Gupta well and believes he would make an excellent addition to the Nevada RDAC. Chair Logan-Parker recommended Dr. Gupta with the highest recommendations possible.

Ms. Samuels stated the Council now had quorum and can consider actions at this time.

Chair Logan-Parker entertained a motion to make a formal recommendation to the Nevada DHHS to appoint Dr. Gupta as an RDAC Council Member and asked for any questions.

Gina Glass motioned to approve an official recommendation for Dr. Gupta to join RDAC to the Director of DHHS. Ms. Porter seconded the motion. The vote passed unanimously.

5) FOR POSSIBLE ACTION: Discussion and possible action to include a section on Artificial Intelligence (AI). AI is the intelligence of software or machines that is used to make the lives of humans easier. The use of AI that will be applied to the field of Healthcare will be used to assist with diagnosis and treatment options, patient engagement and adherence, and administrative activities. The AI section will be under the Awareness and Education Priority Section in the Strategic Plan for 2023-2025, which will serve to the state of Nevada and the Council Members as the initial framework for creating a collaborative approach of a comprehensive plan for the management of rare disease in Nevada. – *Council Members*

Chair Logan-Parker said the Council looked at adding additional language to the already approved RDAC Strategic Plan. Chair Logan-Parker said at the last RDAC meeting, Paul Niedermeyer had recommended an addition of language regarding artificial intelligence (AI), which has been added to page 24. A QR code leading to a study about impact of artificial intelligence on rare diseases was added to page 30. Information was also added about research and data.

Chair Logan-Parker entertained a motion to approve the addition of the new language regarding AI to the RDAC Strategic Plan and asked for any questions or comments. None heard.

Ms. Glass motioned to approve the additional language regarding AI to the RDAC Strategic Plan. Ms. Porter seconded the motion. The vote passed unanimously.

6) FOR POSSIBLE ACTION: Discussion and possible action to appoint the below Council Members into the Strategic Plan Subcommittee that will meet on the First Friday of the month at 9:30 AM PST, on odd numbered months beginning in September 2023. – *Council Members*

Chair Logan-Parker said previously RDAC had gone through the process of creating two (2) subcommittees then decided to combine into one (1) subcommittee called the Strategic Planning Subcommittee, which was voted to approve. There have been four (4) volunteers who have agreed to be members of the Nevada RDAC Strategic Planning Subcommittee which need to be voted on to approve: Anette Logan-Parker, Gina Glass, Amber Federizo, and Jennifer Millet. Chair Logan-Parker asked if there were any other Council members who would be interested in participating in the subcommittee, which would meet on a Friday every other month on months the main RDAC Council is not meeting. The subcommittee follows the same Open Meeting Law rules and would be in the same format as the main Council.

The following were put in the chat:

Christina Thielst: “I can probably join the planning committee at a later date.”

Ms. Glass motioned to approve the appointment of the four volunteer members, Anette Logan Parker, Gina Glass, Amber Federizo, and Jennifer Millet, for the Strategic Plan Subcommittee. Dr. Azzam seconded the motion. The vote passed unanimously.

Ms. Samuels stated that any members of the main Council are welcome to attend the Subcommittee meetings as members of the public. These attendees would not be considered members of the Subcommittee and thus would not be able to take action on items on the agenda, however, are welcome to participate via public comment and other avenues available to members of the public attending meetings subject to Nevada Open Meeting Law.

3) FOR POSSIBLE ACTION: Approval of minutes from June 2, 2023, Rare Disease Advisory Council Meeting. – *Council Members*

Chair Logan-Parker introduced the agenda item to approve the meeting minutes from the last Council meeting and asked the Council for a motion.

Ms. Porter said her first name was misspelled once in the minutes.

Chair Logan-Parker entertained a motion to approve the minutes from the June 2, 2023, RDAC meeting with the edit described by Ms. Porter.

Dr. Azzam motioned to approve the minutes from the June 2, 2023, RDAC meeting with the edit to correct Valerie Porter’s name. Ms. Porter seconded. The motion passed unanimously.

7) FOR POSSIBLE ACTION: Discussion and possible action to allow the NV RDAC Chair to review the NV RDAC Strategic Plan for 2023-2025 that serves as the initial framework for creating a collaborative approach of a comprehensive plan for the management of care of rare disease in Nevada, and 2023 Annual Report that will

be drafted at the end of 2023 for the Governor and Legislature that includes a summary of the Council's activities and any recommendations the Council has for Legislature or other policies in accordance with Senate Bill 315 (SB315) during the event, Rare Disease Legislative Day, the Cure 4 Kids Foundation is hosting on Rare Disease Day, Thursday, February 29, 2024. – *Council Members*

Chair Logan-Parker said the Cure 4 Kids Foundation is hosting a rare disease legislative day on World Rare Disease Day 2024, which is February 29th. The audience will be Nevada lawmakers, City Council members, mayors from across the state, members of the Governor's Office, as well as other county commissioners and members of RDAC and other advisory councils. In Nevada, there are two (2) confirmed genetic specialists speaking: Dr. Nicola Longo, who is known in Nevada and has been on staff with Cure 4 Kids Foundation for over 17 years and will be speaking on the need to improve and expand genetic and genomic testing for children and families who are searching for answers on the rare disease diagnosis, and Dr. Kyrieckos Aleck who is a clinical geneticist retired from Phoenix Children's Hospital and will be speaking on rare diseases. There are also some local physicians that are confirmed speakers. Dr. Amy Ford will be speaking on the importance of multi-specialty comprehensive clinics for people with bleeding and clotting disorders. Dr. Sumit Gupta, who was just voted to be recommended for the Council, will be speaking on the need to expand newborn screening testing menus in Nevada. Also, a parent of an adult child with a rare disease will be telling their story of their child's diagnosis odyssey on that day. There will be speakers addressing the future of gene therapy and what that means for the future of healthcare. The goal is to proactively start educating Nevada lawmakers and policymakers on the unique needs of people living with a rare disease in the state of Nevada. Chair Logan-Parker requested that the Nevada RDAC allow her, as the chair of RDAC, to represent the Council at this meeting. Chair Logan-Parker said she will be there in a professional capacity with her career at Cure 4 the Kids Foundation but would like to be able to officially present the RDAC Strategic Plan in detail and go over what will be the approved 2023 Annual Report and list of recommendations the Council will be submitting to the Governor's Office later in 2023. Chair Logan-Parker said she believes the conference is a great opportunity for RDAC to showcase the work done in this area. Chair Logan-Parker said she wants to make sure the Council is very clear on what it agrees is appropriate to represent as RDAC.

Christina Thielst said she thought Chair Logan-Parker's proposal was a great idea.

Kimberly Palma-Ortega asked if the conference would be in the north or south of the state.

Chair Logan-Parker said the conference will be located in the south on the campus where Cure 4 the Kids is located.

Ms. Palma-Ortega asked how attendance worked for the event and if tickets need to be purchased or if any members of the Council could attend.

Chair Logan-Parker said the event is completely free to anyone who would like to attend, noting the auditorium itself holds 99 people and priority would go to making sure the appropriate audience, including the lawmakers and other relevant attendees, were seated. Chair Logan-Parker said she thinks the event would be a great opportunity for RDAC members and to help lawmakers understand what the Council is working to accomplish.

Ms. Palma-Ortega said professionally she is the Public Health Liaison for the Governor’s Council on Developmental Disabilities and offered to use her position to help promote and get additional information distributed to her contacts.

Chair Logan-Parker said as the event develops there is a hope to have a call-in option as well, but that is unknown at this time.

Ms. Glass motioned to approve the request that Nevada RDAC allow Chair Logan-Parker to represent RDAC at the 2024 Cure 4 the Kids Rare Disease Legislative Day on February 29, 2024, and to specifically present about the Nevada RDAC Strategic Plan and the approved 2023 Annual Report. Dr. Azzam seconded the motion. The vote passed unanimously.

13) PUBLIC COMMENT

Chair Logan-Parker opened the floor for public comment.

Kathlen Kingston introduced herself as the parent of an adult son who has a rare disease called Tuberous Sclerosis Complex (TSC), which causes benign tumors to form throughout the body, but can also cause seizures that can cause developmental and intellectual disability. Ms. Kingston said in volunteering for the TSC Alliance for many years and learning about Alliance’s current and upcoming research opportunities, one of the current focuses is on the newborn screening aspect. The TSC Alliance wants to add the TSC screening to the newborn screening, which is very important because if an infant is discovered to have TSC, their heart can be monitored with EEGS, such that if an abnormal EEG is detected, they can get the most effective medicine that can prevent the worst seizures, which are the infantile spasms that can cause severe developmental disability and intellectual disability. It is very important to know if a baby has TSC. At World Rare Disease Day, the speakers that will be talking, it is wonderful to hear there will also be RDAC members presenting the Strategic Plan. Ms. Kingston said she is especially excited to hear that the newborn screening will be one of the subjects and would like to support in any way she can. Ms. Kingston thanked the Council for their work and for the opportunity to comment.

Chair Logan-Parker asked for any additional public comment. None heard.

12) INFORMATIONAL: Council member information sharing announcements. – *Council Members*

Chair Logan-Parker asked the Council if there was anything they would like to share.

Hearing none, Chair Logan-Parker moved to adjourn the meeting.

4) ADJOURNMENT – *Chair Logan-Parker*

Chair Logan-Parker moved to adjourn and expressed appreciation for everyone on the council.

Chair Logan-Parker moved to adjourn the meeting at 10:21 am.