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Chief Medical
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Nevada Rare Disease Advisory Council (RDAC)

Meeting Minutes

June 7, 2024

9:31 AM – 10:30 AM

Meeting Locations:

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

Chair Annette Logan-Parker opened the meeting at 09:31 am.

1) INTRODUCTIONS AND ROLL CALL

COUNCIL MEMBERS PRESENT:

Annette Logan-Parker (Chair); Amber Federizo, DNP, APRN, FNP-BC; Paul Niedermeyer; Valerie Porter, DNP, APRN, AG-ACNP-BC, MBA; Kimberly Palma-Ortega; Naja Bagner; Sumit Gupta, MD; and Kim Anderson-Mackey (Quorum=8)

COUNCIL MEMBERS ABSENT:

Gina Glass (Vice Chair); Jennifer Millet, DNP, RN; Ihsan Azzam, MD, PhD (excused); Christina Thielst, LFACHE, MHA (excused); Kimberly Palma-Ortega; Craig Vincze, PhD (excused); Brigette Cole (excused).

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

Ashlyn Torrez, *Health Program Specialist I, Office of State of Epidemiology (OSE), DPBH.*

OTHERS PRESENT:

Ofelia B. Gentscheff; Ferrari Reeder Public Affairs; Pamela White; Amber Williams; Melissa Bart-Pange; Belz-Case Government Affairs-Scribe; and Sabrina Schnur.

Roll call was taken and is reflected above. It was determined that a quorum of the Rare Disease Advisory Council (RDAC, the Council) was not present.

2) PUBLIC COMMENT

Chair Logan-Parker opened the floor for public comment.

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

3) FOR POSSIBLE ACTION: Discussion and possible action to approve meeting minutes from April 4, 2024. – Council Members

Chair Logan-Parker explained at the beginning of the meeting that since a quorum was not met the action items would be rolled over to the August meeting.

4) INFORMATIONAL ITEM: Nevada Newborn Screening Program Overview Presentation – *Ofelia Gentscheff, MA, MRC, CRC, Statewide Newborn Screening Program, Nevada State Public Health Laboratory (NSPHL)*

Chair Logan-Parker welcomed Ofelia Gentscheff and added that she has a presentation to share. Chair Logan-Parker gave the floor to Ofelia Gentscheff.

Ofelia Gentscheff presented Nevada Newborn Screening Program Overview.

Ms. Gentscheff thanked the council for their time and asked the Council for questions.

Chair Logan-Parker wanted to confirm that currently, “the State Board of Health is required by statute to adopt regulations governing the test required for the discovery of an infants of preventable or inheritable disorders.”

Ms. Gentscheff answered with an outline of adding a disorder to a screening panel, this involved a public hearing, Board of Health, a proposal for the fee increase, an outline of the advantages of adding the disorder, and a public meeting.

Chair Logan-Parker thanked Ms. Gentscheff for clarifying and asked if this method of adding disorders has been able to keep up with the state recommendations.

Ms. Gentscheff answered that with more and more being added every year that the \$81 is not enough. Ms. Gentscheff also mentioned that there is not a metabolic clinic in Nevada anymore.

Chair Logan-Parker added that the process of recruiting a metabolic geneticist to join the team full time has already begun.

Dr. Sumit Gupta asked for clarification on the process of how to increase the fee, State or Health Department.

Ms. Gentscheff answered that after a study, a proposal can be sent to Carson City.

Chair Logan-Parker asked what can be done by the RDAC to assist in pursuing additional funding.

Ms. Gentscheff answered with a plea for continued advocacy from the RDAC, and grant money being set aside in a funding pool.

Chair Logan-Parker responded with a vow to advocate on behalf of the newborn screening program. Chair Logan-Parker thanked Ophelia B. Gentscheff for her presentation.

Recording timestamp 57:01 Pamela White put into the chat: “Hi this is Pam; I will have to leave the meeting at this time. Thank you, Ofelia!”

- 5) INFORMATIONAL ITEM: Follow up on Cellular and Gene Therapy (CGT) Access Model and the State of Nevada’s current position on CGT. – *Chair Logan-Parker*

Chair Logan-Parker introduced this agenda item and provided a refresher on the topic. Chair Logan-Parker stated that during the April meeting it was discussed that supporting and recommending the Department of Health and Human Services (DHHS) and Medicaid leadership be encouraged to sign up for the cellular and gene therapy referred to as the CGT access model. Chair Logan-Parker mentioned the letter that was voted upon and written to the state. Chair Logan-Parker added that there have been no further updates since they submitted a letter of interest. Chair Logan-Parker expressed that due to this there is no real update, and it will continue to be monitored.

- 6) INFORMATIONAL ITEM: Overview and update on the Sickle Cell Disease (SCD) gene therapy Casgevy™ (exagamglogene autotemcel) and Lyfgenia™ (lvo-cel). During the April 2024 RDAC meeting, the Council voted to submit a letter of recommendation to consider gene therapies during the April 2024 Drug Use Review (DUR) Meeting. Vice Chair Gina Glass and Pamela White with Bridging the Gap Foundation spoke at the DUR meeting, and the two drugs will be on the Medicaid drug formulary. The next scheduled DUR meeting is July 18, 2024. – *Chair Logan-Parker*

Chair Logan-Parker introduced the agenda item to discuss the overview and update on the Sickle Cell Disease gene therapy Casgevy™ and Lyfgenia™ during the April 2024 RDAC meeting. Chair Logan-Parker stated that the two drugs will be added to the Nevada Medicaid drug formulary based on clinical criteria.

Chair Logan-Parker opened the floor for additional comment.

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

- 7) INFORMATIONAL ITEM: Sickle Cell Data Collection Efforts Update on the new Office of State Epidemiology (OSE) website. – *Chair Logan-Parker*

Chair Logan-Parker introduced the agenda item to discuss Sickle Cell Data Collection Efforts Update on the new Office of State Epidemiology (OSE) website. Chair Logan-Parker explained that the data collection instrument has been drafted. Chair Logan-Parker added that she was able to provide feedback to the leadership team at DPBH on any possible areas of data collection improvement. Chair Logan-Parker sighted a change in the electronic data collection platforms as a reason for current lack of data but hopes to have a more robust update on sickle cell as well as childhood cancer and lupus at the August meeting.

- 8) INFORMATIONAL ITEM: Overview of the Las Vegas, Nevada Public Broadcasting Service (PBS) Nevada Week Episode. – *Chair Logan-Parker*

Chair Logan-Parker introduced the agenda item of the Overview of the Las Vegas, Nevada Public Broadcasting Service (PBS) Nevada Week Episode. Chair Logan-Parker expressed how the *While You Wait* campaign was able to have an interview on Las Vegas PBS. Chair Logan-Parker mentioned that the interview is available on the RDAC website. Chair Logan-Parker added that the time on PBS was great publicity for not only the RDAC, but the *While You Wait* campaign.

- 9) INFORMATIONAL ITEM: Nevada Rare Disease Advisory Council (RDAC) Efforts Across the United States–
Chair Logan-Parker

Chair Logan-Parker introduced the agenda item to discuss the Nevada Rare Disease Advisory Council Efforts Across the United States. Chair Logan-Parker asked Council member Amber Federizo to speak.

Ms. Federico explained that an analysis of the RDAC had been done in the past but with the addition of more states with RDAC, it is worth revisiting. Ms. Federizo claimed that there are now 26 established RDACs across the United States, with Nevada, Utah, and Colorado being the only three on the west coast. Ms. Federizo explained that she is currently working on a report that highlights the key findings of the research and plans on presenting it at the August meeting.

Chair Logan-Parker opened the floor for additional comment.

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

10) INFORMATIONAL ITEM: Nevada Rare Disease Advisory Council (RDAC) Childhood Cancer Data Collection Efforts Update to the Council. – *Chair Logan-Parker*

Chair Logan-Parker introduced the agenda item to provide an update on the Childhood Cancer Data Collection Efforts Update. Chair Logan-Parker began with a positive report of the interface between Cure 4 the Kids Foundation and the State Central Cancer Registry. Chair Logan-Parker mentioned meeting with the Central Cancer Registry on an ongoing basis to ease the burden of collection and improve the connection with the CDC at a federal level. Chair Logan-Parker added that the historical data from the years 2019-2021 have met the minimum threshold criteria for reporting and will be added next time the CDC does an update. Chair Logan-Parker explained that the 2022 data is the next to be submitted. Chair Logan-Parker stated that data dashboards are being created now to include childhood cancer statistics, rare diseases, as well as sickle cell and lupus; these dashboards will be presented at the August meeting. Chair Logan-Parker believes that the collaboration of the RDAC with the Central Cancer Registry and the Department of Health and Human Services through annual reports has pressure to collect robust data on rare diseases.

Chair Logan-Parker opened the floor for comments or feedback.

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

11) INFORMATIONAL ITEM: Nevada Rare Disease Advisory Council (RDAC) Subcommittee on the Strategic Plan Update to the Council. – *Chair Logan-Parker*

Chair Logan-Parker introduced the agenda item Nevada Rare Disease Advisory Council (RDAC) Subcommittee on the Strategic Plan Update. Chair Logan-Parker explained that there is little to update on the efforts of the subcommittee. Chair Logan-Parker established that in the July meeting the subcommittee will be going over the strategic plan, providing updates and figuring out the next action items.

Chair Logan-Parker identified no further updates and moved on to the next agenda item.

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

Chair Logan-Parker introduced the agenda item Council member information sharing announcements.

Chair Logan-Parker opened the floor to council members.

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

13) FOR POSSIBLE ACTION: Discussion and possible action of the Council requesting lawmakers support for a bipartisan Bill Draft Request (BDR) in the 2025 Legislative Session to amend [NRS 439.5077](#) to address the recommendations listed in the 2023 annual report. – *Council Members*

Chair Logan-Parker explained at the beginning of the meeting that since a quorum was not met the action items would be rolled over to the August meeting.

14) PUBLIC COMMENT AND DISCUSSION:

Chair Logan-Parker opened the floor for public comment.

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

15) Adjournment – *Chair Annette Logan-Parker*

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

Recording timestamp 1:21:57 Valorie Porter put into the chat: “Really excited to see the data from the new dashboards to see if we can clean any information or clusters from them! Thank you so much. See you next meeting.”

Chair Logan-Parker moved to adjourn the meeting at 10:30 am.