

Joe Lombardo
Governor



Richard Whitley,
MS
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Cody Phinney,
MPH
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Ph.D., M.D.
Chief Medical
Officer

NEVADA RARE DISEASE ADVISORY COUNCIL – Subcommittee DRAFT MEETING MINUTES

Date: November 1, 2024

9:36 AM – 9:47 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 9:36 am.

1) INTRODUCTIONS AND ROLL CALL

SUBCOMMITTEE MEMBERS PRESENT:

Annette Logan-Parker (CHAIR); Amber Federizo, DNP, APRN, FNPBC (Quorum=3)

SUBCOMMITTEE MEMBERS ABSENT:

Gina Glass (Vice-Chair); and Jennifer Millet, DNP, RN

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

Ashlyn Torrez, *Health Program Specialist I (HPS I), Office of State Epidemiology (OSE), DPBH*; and Kagan Griffin, *OSE Operations Manager, OSE, DPBH*

OTHERS PRESENT:

Nadine Kienhoefer, *Ferrari Reeder Public Affairs*; Melissa Bart-Plange; Verena Samara, MD; Brian Evans; Elyse Monrey-Marsala, *Belz & Case Government Affairs*; Lea Case, *Belz & Case Government Affairs*; Joseph Filippi, *Executive Director, Director's Office, Department of Health and Human Services*; and Amber Williams, *Cure4Kids Foundation*

Roll call was taken and is reflected above. 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 agenda item number three.

- 3) FOR POSSIBLE ACTION: Discussion and possible action to approve meeting minutes from January 5, 2024. – *Council Members*

Chair Logan-Parker tabled this agenda item until the next Subcommittee meeting due to not meeting quorum.

- 4) FOR POSSIBLE ACTION: Discussion and possible action to recommend to the full Council of the Nevada RDAC to approve a letter of support for Bill Draft Request (BDR) 218 of the 83rd Legislative Session (2025), sponsored by Senator Stone, which will revise provisions to coverage and reimbursement for services provided by pharmacists. – *Council Members*

Chair Logan-Parker tabled this agenda item until the next Subcommittee meeting due to not meeting quorum.

- 5) FOR POSSIBLE ACTION: Discussion and possible action to recommend to full Council of the Nevada RDAC to approve a letter of support of Bill Draft Request (BDR) 224 for the 83rd Legislative Session (2025) sponsored by Senator Stone which will revise provisions related to the use of pharmacy benefit managers by Nevada Medicaid. – *Council Members*

Chair Logan-Parker tabled this agenda item until the next Subcommittee meeting due to not meeting quorum.

- 6) INFORMATIONAL ITEM: Update on the Nevada Strategic Plan for 2023-2025, outlining the framework for a collaborative comprehensive care management plan for rare diseases in Nevada by the Rare Disease Advisory Council (RDAC). – *Chair Annette Logan Parker*

Chair Logan-Parker combined agenda item number eight with agenda item number six. Chair Logan-Parker provided an update on the Rare Disease Advisory Council Annual Report for 2024 and stated that Ms. Ashlyn Torrez will provide the meeting minutes from the October 4, 2024, meeting. Chair Logan-Parker had no update on the Nevada Strategic Plan for 2023-2025.

- 7) INFORMATIONAL ITEM: An update on the Nevada Rare Disease Advisory Council (RDAC) survey of each of the Rare Disease Advisory Councils that are a part of the National Network of RDACs. – *Chair Annette Logan Parker*

Chair Logan-Parker provided an update on meeting with other RDACs across the nation to see how other RDACs are operating. Chair Logan-Parker added that the Pennsylvania RDAC are very active, and the Nevada RDAC can learn a lot on how Pennsylvania RDAC operates. Chair Logan-Parker stated that the Nevada RDAC will continue with the While You Wait Campaign.

- 8) INFORMATIONAL ITEM: Discuss and review the annual report that is due to Governor Lombardo and the Director of the Legislative Counsel Bureau in December 2024, pursuant to [NRS 439.5077\(2\)\(b\)\(2\)](#). – *Chair Annette Logan Parker*

Chair Logan-Parker combined agenda item number 8 with agenda item number six.

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

Chair Logan-Parker asked Melissa Bart-Plange to discuss Ms. Bart-Plange's experience at the National Organization of Rare Disease (NORD) conference.

Ms. Bart-Plange commented that the NORD conference was fun and met with Ms. Christina Thielst while in Washington, DC. Ms. Bart-Plange continued that she met with other Council members from different RDACs and found that the other RDACs are also doing a needs assessment within the other RDACs states. Ms. Bart-Plange explained that a Medicaid representative was at the conference and the Medicaid representative gave Ms. Bart-Plange a better understanding of Medicaid reimbursement and how Medicaid works in some states. Ms. Bart-

Plange felt validated that other states have the same issues that Nevada currently has like issues in receiving funding, and other RDACs within those states who are state-funded or not. Ms. Bart-Plange finished that the NORD conference was eye opening and a great experience.

Chair Logan-Parker thanked Ms. Bart-Plange for sharing and expressed her excitement that Ms. Bart-Plange and Ms. Thielst were able to attend the conference. Chair Logan-Parker felt interested how other RDACs across the nation are operating with state-funds or not funded through state-funds. Chair Logan-Parker stated that the next RDAC meeting will be a full Council meeting on December 6th and Nevada Pharmacy Alliance will discuss two Bill Draft Requests (BDRs). Chair Logan-Parker provided an update on a press release on Intermountain building Nevada's first freestanding Children's Hospital expected in 2030. Chair Logan-Parker added that Cure 4 The Kids Foundation hired a full-time geneticist who will start in December. Chair Logan-Parker asked the Subcommittee members if there are any updates to share.

Subcommittee member Amber Federizo commented that someone in New York recently launched the GUARDIAN Project, a free study where New York will be screening newborns for over 450 genetic conditions that are not currently screened as part of a standard newborn screening. Ms. Federizo added that Sana Fe Genedx a LabCorp integrated genetics facility and Ms. Federizo are co-sponsoring with a New York Presbyterian Hospital and Health System the GAURDIAN project.

Chair Logan-Parker thanked Ms. Federizo and commented that for the 83rd Legislative Session (2025), Senate Bill (SB) 123 sponsored by Senator Julia Pazina to expand newborn screening. Chair Logan-Parker asked the Subcommittee members if there are any updates to share.

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

10) PUBLIC COMMENT:

Chair Logan-Parker opened the floor for public comment.

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

11) 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 9:47 AM.