

Joe Lombardo
Governor



Richard Whitley,
MS
Director



Cody Phinney,
MPH
Administrator

Ihsan Azzam,
Ph.D., M.D.
Chief Medical
Officer

Rare Disease Advisory Council (RDAC) Meeting Agenda September 6, 2024 9:30 AM – Adjournment

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. The meeting can be listened to via telephone or viewed live over the Internet.

Meeting Links:

https://teams.microsoft.com/l/meetup-join/19%3ameeting_MWY0MGJkZGUtOGI3Mi00ZTIyLTk2YTUtZWJlOWQ0ZWm3ZjNm%40thread.v2/0?context=%7b%22Tid%22%3a%22e4a340e6-b89e-4e68-8eaa-1544d2703980%22%2c%22Oid%22%3a%22c6cbcd35-ecfc-41f0-8557-67e58ee3ad83%22%7d

Meeting ID: 292 281 778 59

Passcode: Hu4vgp

Please Note: If you experience technical difficulties connecting online, please call into the meeting to participate by phone.

Join by Phone:

+1 775-321-6111

Phone Conference ID: 345 641 736#

Please note: Agenda items may be taken out of order, combined for consideration, and/or removed from the agenda at the chairperson's discretion.

Council Members: (15) Annette Logan-Parker (Chair); Gina Glass (Vice Chair); Amber Federizo, DNP, APRN, FNP-BC; Ihsan Azzam, MD, PhD; Jennifer Millet, DNP, RN; Valerie Porter, DNP, APRN, AG-ACNP-BC, MBA; Paul Niedermeyer; Naja Bagner; Craig Vincze, PhD; Christina Thielst, LFACHE, MHA; Sumit Gupta, MD; Brigitte Cole; Kim Anderson-Mackey; Melissa Bart-Plange; and Pamela White (Quorum=9)

- 1) **CALL TO ORDER/ROLL CALL** – DPBH Staff/Chair Annette Logan-Parker
- 2) **PUBLIC COMMENT AND DISCUSSION:** (Action may not be taken on any matter brought up under this Agenda item until scheduled on an Agenda for a later meeting) Public testimony under this agenda item may be presented in person, by computer, phone, or written comment. A person may also have comments added to the minutes of the meeting by submitting them in writing either in addition to testifying or in lieu of testifying. Written comments may be submitted electronically before, during, or after the meeting by emailing Ashlyn Torrez at atorrez@health.nv.gov. You may also mail written documents to 10375 Professional Circle, 3rd Floor, Reno,

NV 89521, or fax them to (775) 684-5999. To provide public comment telephonically, dial 1 (775) 321-6111. When prompted to provide the Meeting ID, enter 345 641 736#. If providing public comment during the Teams Meeting, unmute your microphone prior to speaking. Persons making comment will be asked to begin by stating their name for the record and to spell their last name.

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

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- 4) **FOR POSSIBLE ACTION:** Discussion and possible action to approve meeting minutes from June 7, 2024. – *Council Members*

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- 5) **FOR POSSIBLE ACTION:** Discussion and possible action to recommend to the Director of Department of Health and Human Services to appoint Madison Bowe to fulfill [NRS 439.5075\(2\)](#). The Council may, by affirmative vote of a majority of its members, request the Director to appoint to the Council additional members who have expertise on issues studied by the Council. Such members serve for a period determined by the Council. – *Council Members*

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- 6) **FOR POSSIBLE ACTION:** Discussion and possible action to recommend to the Director of Department of Health and Human Services to appoint Dr. Devraj Charda to fulfill the role of a physician who practices in cardiology, emergency care, neurology, oncology, orthopedics, pediatrics, or primary care and provide care to patients with rare diseases pursuant to [NRS 439.5075\(1\)\(b\)\(1\)](#). – *Council Members*

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- 7) **FOR POSSIBLE ACTION:** Discussion and possible action to recommend to the Director of Department of Health and Human Services to appoint Dr. Verena Samara to fulfill the role of a physician who practices in cardiology, emergency care, neurology, oncology, orthopedics, pediatrics, or primary care and provide care to patients with rare diseases pursuant to [NRS 439.5075\(1\)\(b\)\(1\)](#). – *Council Members*

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- 8) **FOR POSSIBLE ACTION:** Discussion of, nomination of, and voting for a new Chair and Vice Chair of the Nevada Rare Disease Advisory Council for the next term of two years pursuant to *Article 6, Section 1 and Article 6, Section 2* of the Rare Disease Advisory Council Bylaws. – *Council Members*

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- 9) INFORMATIONAL ITEM: Overview of the Track Cancer Foundation Think Tank Event from November 2023. – *Councilmember Dr. Craig Vincze, PhD*

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- 10) INFORMATIONAL ITEM: Overview of the Healthcare Advocate Summit Event on September 3, 2024, and Vice-Chair Gina Glass' scheduled presentation on Navigating Health Equity: Tackling Rare Disease and Disparities Through Advocacy and Action. – *Vice-Chair Gina Glass*

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- 11) INFORMATIONAL ITEM: Nevada Rare Disease Advisory Council (RDAC) Childhood Cancer Data Collection Efforts update and overview of the current cancer data available in Nevada. – *Chair Logan-Parker*

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- 12) 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*

PUBLIC COMMENT AND DISCUSSION: (*Action may not be taken on any matter brought up under this Agenda item until scheduled on an Agenda for a later meeting*) Public testimony under this agenda

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- 13) **INFORMATIONAL ITEM:** Presentation on an Overview of the Office of Epidemiology Rare Disease Registries Program. – *Ashlyn Torrez, Health Program Specialist I, Office of State Epidemiology (OSE), DPBH*

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- 14) **INFORMATIONAL ITEM:** Overview on the Newborn Screening Bill Draft Request (BDR) for the 83rd (2025) Legislative Session. – *Chair Logan-Parker*

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- 15) **INFORMATIONAL ITEM:** The RDAC Needs Assessment Campaign as highlighted in the Department of Health and Human Services (DHHS) June 2024 Weekly Newsletter. – *Chair Logan-Parker*

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- 16) INFORMATIONAL ITEM: The Act4Kids and A&J Patient Advocacy Foundations sharing posters and flyers in their respective organizations for the Needs Assessment Campaign. – *Chair Logan-Parker*

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

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

- 19) PUBLIC COMMENT:

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- 20) Adjournment – *Chair Annette Logan-Parker*

NOTICES OF PUBLIC MEETING HAVE BEEN POSTED AT THE FOLLOWING LOCATIONS:

- On the Internet at the Nevada Division of Public and Behavioral Health
website: <http://dpbh.nv.gov/Boards/RDAC/RDAC/>
- On the internet at the Nevada Public Notice website: <https://notice.nv.gov>

AGENDA POSTING LOCATIONS:

- NEVADA DIVISION OF PUBLIC AND BEHAVIORAL HEALTH, OFFICE OF STATE EPIDEMIOLOGY – 10375 Professional Circle, 3rd Floor, Reno, NV 89521

This body will provide at least two public comment periods in compliance with the minimum requirements of the Open Meeting Law prior to adjournment. Additionally, it is the goal of the Rare Disease Advisory Council (RDAC) to also afford the public with an item-specific public comment period. No action may be taken on a matter raised under public comment unless the item has been specifically included on the agenda as an item upon which action may be taken. The Chair retains discretion to only provide for the Open Meeting Law's minimum public comment and not call for additional item-specific public comment when it is deemed necessary by the chair to the orderly conduct of the meeting.

Written comments in excess of one typed page on any agenda items which requires a vote are respectfully requested to be submitted to the Council at the above address five (5) calendar days prior to the meeting to ensure that adequate consideration is given to the material. We are pleased to make reasonable accommodations for members of the public who are disabled and wish to attend the meeting.

Members of the public who are disabled and require special accommodations or assistance at the meeting are requested to notify, in writing, the Division of Public and Behavioral Health, 10375 Professional Circle, 3rd Floor, Reno, NV 89521, or by calling Ashlyn Torrez at 775-447-0263 no later than three (3) working days prior to the meeting date.

10375 Professional Circle, 3rd Floor • Reno, Nevada 89521
775-447-0263 • Fax 775-684-5999 • dpbh.nv.gov

Supporting material for this meeting can be obtained from the Division of Public and Behavioral Health, by calling 775-447-0263, emailing Ashlyn Torrez at atorrez@health.nv.gov or in writing:

RDAC Attn: Ashlyn Torrez
10375 Professional Circle, 3rd Floor
Reno, NV 89521