

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 April 5, 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_MWY0MGJkZGUtOGI3Mi00ZTIyLTk2YTUtZWJlOWQ0ZWZjNm%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: 264 622 593 879

Passcode: bYt4VC

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 United States, Reno

Phone Conference ID: 447 481 106#

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: (14) 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; Kimberly Palma-Ortega; Paul Niedermeyer; Naja Bagner; Craig Vincze, PhD; Christina Thielst, LFACHE, MHA; Sumit Gupta, MD; Brigitte Cole; and Kim Anderson-Mackey (Quorum=8)

- 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 500 Damonte Ranch Parkway STE 657, Reno,

NV 89521, or fax them to (775) 684-5999. To provide public comment telephonically, dial1 (775) 321-6111. When prompted to provide the Meeting ID, enter 447 481 106#. 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 February 5, 2024. – *Council Members*

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- 4) **FOR POSSIBLE ACTION:** Discussion and possible action to recommend to the Director of Department of Health and Human Services to appoint Melissa Bart-Plange to fulfill “Parent or guardian who has experience caring for a child with a rare disease” pursuant to [NRS 439.5075\(1\)\(b\)\(7\)](#). – *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 Pamela White pursuant to [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 approve the NV-RDAC's drafting an official letter of support addressed to the Governor, DHHS and NV- Medicaid leadership regarding the support of and recommendation for the State of Nevada to sign up for the Cellular and Gene Therapy (CGT) Access Model recommended by CMS, and to allow access to Medicaid beneficiaries to both of the recently FDA approved drugs for SCD gene therapy (Casgevy™ (exagamglogene autotemcel), and Lyfgenia™ (lovo-cel), Currently using HCPCS code J3590 for unclassified biologics). – *Chair Annette Logan-Parker*

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- 7) INFORMATIONAL ITEM: Discussion of Rare Disease Day, February 28th Media Coverage. – *Chair Annette Logan-Parker*
- 8) INFORMATIONAL ITEM: Overview and discussion of Childhood Cancer Action Days in D.C. – *Council Member Brigitte Cole*
- 9) INFORMATIONAL ITEM: Overview and discussion of the next Drug Utilization Review Board (DUR) Meeting scheduled for April 18, 2024. – *Chair Annette Logan-Parker*
- 10) INFORMATIONAL ITEM: Update on the 'Wait You Wait' Needs Assessment Campaign that will evaluate the diagnosis and patient management aspects crucial for the continuation of care of individuals with rare diseases in the state of Nevada. – *Chair Annette Logan-Parker*
- 11) INFORMATIONAL ITEM: Overview and discussion of the Department of Motor Vehicles (DMV) Childhood Cancer License Plate Program Funding Report. – *Chair Annette Logan-Parker*
- 12) INFORMATIONAL ITEM: Sickle Cell Disease Data Registry Progress Update. – *Chair Annette Logan-Parker; & Ashlyn Torrez, Lupus and Other Rare Diseases Program Coordinator, Office of State Epidemiology, DPBH*
- 13) INFORMATIONAL ITEM: Overview and discussion of the 2023 Rare Disease Data that is currently available in the state of Nevada. – *Chair Annette Logan-Parker*
- 14) INFORMATIONAL ITEM: Status Report and discussion of the Mercer Medicaid study regarding rare disease service delivery models, specifically focusing on the unique issues in Nevada, which was funded by the Interim Finance Committee in December 2022. – *Chair Annette Logan-Parker*

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

16) 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 500 Damonte Ranch Parkway STE 657, 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 447 481 106#. 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.

17) 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 – 500 Damonte Ranch Pkwy, STE 657, 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.

500 Damonte Ranch Parkway STE 657 • Reno, Nevada 89521
775-447-0263 • Fax 775-684-5999 • dpbh.nv.gov

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, 500 Damonte Ranch Parkway STE 657, Reno, NV 89521, or by calling 775-447-0263 Ashlyn Torrez no later than three (3) working days prior to the meeting date.

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
500 Damonte Ranch Parkway STE 657,

Reno, NV 89521