

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 February 2, 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 (Quorum=8)

- 1) **CALL TO ORDER/ROLL CALL** – *DPBH Staff/Chair Annette Logan-Parker*
- 2) **PUBLIC COMMENT:** 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.

- 3) INFORMATIONAL ITEM: Welcome the newest Rare Disease Advisory Council Member, Kim Anderson. She will be filling the role of the Chair of the State of Nevada Advisory Council on Palliative Care and Quality of Life created by [Nevada Revised Statutes \(NRS\) 232.4855](#). – *Chair Annette Logan Parker*
- 4) FOR POSSIBLE ACTION: Discussion and possible action to approve meeting minutes from December 8, 2023. – *Council Members*
- 5) FOR POSSIBLE ACTION: Discussion and possible action to recommend to the Director of the Nevada Department of Health and Human Services (DHHS) to re-appoint Gina Glass as a member of the Council, pursuant to [NRS 439.5075\(2\)](#), for a term of 3 years. – *Council Members*
- 6) FOR POSSIBLE ACTION: Discussion and possible action to recommend to the Director of the Nevada Department of Health and Human Services (DHHS) to re-appoint Jennifer Millet as a member of the Council, pursuant to [NRS 439.5075\(2\)](#), for a term of 3 years. – *Council Members*
- 7) INFORMATIONAL ITEM: Tribute and a public thank you to Dr. Nik Abdul Rashid for her service with the Rare Disease Advisory Council, and her work providing care to patients suffering from sickle cell disease, cancer, and hemophilia. – *Chair Annette Logan Parker*
- 8) INFORMATIONAL ITEM: Presentation on the work that the National Organization for Rare Disorders (NORD) is doing with other Rare Disease Advisory Council’s across the country. – *Lindsey Viscarra, State Policy Manager, NORD*
- 9) INFORMATIONAL ITEM: Report on Rare Disease Advisory Council (RDAC) Subcommittee on the Strategic Plan from the January 5, 2024, RDAC Subcommittee Meeting. – *Chair Annette Logan Parker*
- 10) INFORMATIONAL ITEM: Discussion on media opportunities for Rare Disease Day on February 29, 2024. – *Chair Annette Logan Parker*
- 11) INFORMATIONAL ITEM: Update and discussion of the 2023 Annual Report that was due to Governor Lombardo and the Director of the Legislative Counsel Bureau in December 2023, pursuant to Nevada Revised Statutes [NRS 439.5077\(2\)\(b\)\(2\)](#). – *Chair Annette Logan Parker*
- 12) INFORMATIONAL ITEM: Council member information sharing announcements. – *Council Members*
- 13) PUBLIC COMMENT:
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.

Action may not be taken on any matter brought up under this agenda item until scheduled on an agenda for a later meeting.
- 14) 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