

Joe Lombardo  
Governor



Richard Whitley,  
MS  
Director



Cody Phinney,  
MPH  
Administrator

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

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## Rare Disease Advisory Council (RDAC) Meeting Agenda December 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\\_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](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

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:** (17) Annette Logan-Parker (Chair); Gina Glass (Vice-Chair); Amber Federizo, DNP, APRN, FNP-BC; Ihsan Azzam, MD, PhD, MPH; 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; Brigette Cole; Kim Anderson-Mackey; Melissa Bart-Plange; Pamela White; Devraj Chavda, MD; and Verena Samara, MD (Quorum=9)

- 1) **CALL TO ORDER/ROLL CALL** – *DPBH Staff/Chair Annette Logan-Parker*
- 2) **PUBLIC COMMENT:** *(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](mailto:atorrez@health.nv.gov). You may also mail written documents to 10375 Professional Circle, 3<sup>rd</sup> 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 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 October 4, 2024. – *Council Members*

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- 4) **FOR POSSIBLE ACTION:** Discussion and possible action to approve the annual report that is due to Governor Lombardo and the Director of the Legislative Counsel Bureau in December 2024, pursuant to Nevada Revised Statutes [\(NRS\) 439.5077\(2\)\(b\)\(2\)](#). – *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) **INFORMATIONAL ITEM:** Introduction of Nevada Pharmacy Alliance and an overview of current proposals for Bill Draft Requests (BDRs) 38-218 in the 83<sup>rd</sup> Legislative Session (2025) sponsored by Senator Jeff Stone that will revise provisions relating to coverage and reimbursement for services provided by pharmacists, and BDR 57-344 and BDR 40-343 in the 83<sup>rd</sup> Legislative Session (2025) sponsored by Assemblymember David Orentlicher that revises provisions relating to health care. – *Ken Kunke, PharmD, Executive Director, Nevada Pharmacy Alliance*

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- 7) **FOR POSSIBLE ACTION:** Discussion and possible action for the Council to submit a letter of support of BDR 38-218 in the 83<sup>rd</sup> Legislative Session (2025) sponsored by Senator Jeff Stone that will revise provisions relating to coverage and reimbursement for services provided by pharmacists and allow the letter of support be submitted to the Nevada State Assembly – Health and Human Services and the Nevada Senate Health and Human Services. – *Council Members*

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- 8) **FOR POSSIBLE ACTION:** Discussion and possible action for the Council to submit a letter of support of BDR 57-344 and BDR 40-343 in the 83<sup>rd</sup> Legislative Session (2025) sponsored by Assemblyman David Orentlicher that revises provisions relating to health care and allow the letter of support be submitted to the Nevada State Assembly – Health and Human Services and the Nevada Senate Health and Human Services. – *Council Members*

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- 9) **INFORMATIONAL ITEM:** Review the new Rare Disease Advisory Council Member Packet for new and upcoming Council Members. – *Chair Annette Logan-Parker*

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- 10) **INFORMATIONAL ITEM:** Presentation on Council members Melissa Bart-Plange and Christina Thielst's experiences at the National Organization of Rare Disease (NORD) 2<sup>nd</sup> Annual Rare Disease Advisory Council (RDAC) Leadership Conference that was held on October 20<sup>th</sup>, 2024, in Washington, D.C. – *Council Members Melissa Bart-Plange and Christina Thielst*

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- 11) **INFORMATIONAL ITEM:** Update on the 'While 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*

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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.

- 12) INFORMATIONAL ITEM: A comprehensive overview and discussion of the National and International RDACs that Chair Logan-Parker and team have conducted to look at various RDAC practices, needs assessments, and advocacy strategies. – *Chair Annette Logan-Parker*

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

- 14) PUBLIC COMMENT: (*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](mailto:atorrez@health.nv.gov). You may also mail written documents to 10375 Professional Circle, 3<sup>rd</sup> 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 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.

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- 15) 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, 3<sup>rd</sup> 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.

10375 Professional Circle, 3<sup>rd</sup> Floor • Reno, Nevada 89521  
775-447-0263 • Fax 775-684-5999 • [dphh.nv.gov](http://dphh.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, 10375 Professional Circle, 3<sup>rd</sup> Floor, 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](mailto:atorrez@health.nv.gov) or in writing:

RDAC Attn: Ashlyn Torrez  
10375 Professional Circle, 3<sup>rd</sup> Floor,  
Reno, NV 89521