

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 June 7, 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 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](mailto: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.

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

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- 4) **INFORMATIONAL ITEM:** Nevada Newborn Screening Program Overview Presentation – *Ofelia Gentscheff, MA, MRC, CRC, Statewide Newborn Screening Program, Nevada State Public Health Laboratory (NSPHL)*

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- 5) **INFORMATIONAL ITEM:** Target Cancer Foundation Think Tank Event Overview Presentation – *Council Member Dr. Craig Vincze, PhD*

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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.

- 6) **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*

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- 7) **INFORMATIONAL ITEM:** Overview and update on the Sickle Cell Disease (SCD) gene therapy Casgevy™ (exagamglogene autotemcel) and Lyfgenia™ (lovocel). During the April 2024 RDAC meeting, the Council voted to submit a letter of recommendation to consider gene therapies during the April 2024 Drug Use Review (DUR) Meeting. Vice Chair Gina Glass and Pamela White with Bridging the Gap Foundation spoke at the DUR meeting, and the two drugs will be on the Medicaid drug formulary. The next scheduled DUR meeting is July 18, 2024. – *Chair Logan-Parker*

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- 8) **INFORMATIONAL ITEM:** Sickle Cell Data Collection Efforts Update on the new Office of State Epidemiology (OSE) website. – *Ashlyn Torrez, Health Program Specialist I, OSE, DPBH*

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- 9) INFORMATIONAL ITEM: Overview of the Las Vegas, Nevada Public Broadcasting Service (PBS) Nevada Week Episode. – *Chair Logan-Parker*

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- 10) INFORMATIONAL ITEM: Nevada Rare Disease Advisory Council (RDAC) Efforts Across the United States– *Chair Logan-Parker*

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- 11) INFORMATIONAL ITEM: Nevada Rare Disease Advisory Council (RDAC) Childhood Cancer Data Collection Efforts Update to the Council. – *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 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 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.

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

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 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.

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

14) FOR POSSIBLE ACTION: Discussion and possible action of the Council requesting lawmakers support for a bipartisan Bill Draft Request (BDR) in 2025 Legislative Session to amend [NRS 439.5077](#) in order to address the recommendations listed in the 2023 annual report. – *Council Members*

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15) PUBLIC COMMENT:

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

16) 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 • [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, 500 Damonte Ranch Parkway STE 657, Reno, NV 89521, or by calling Ashlyn Torrez at 775-447-0263 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  
500 Damonte Ranch Parkway STE 657,  
Reno, NV 89521