

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

August 4, 2023

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:

##### **Join via Microsoft Teams Meeting:**

[https://teams.microsoft.com/l/meetup-join/19%3ameeting\\_NDZjODRkY2EtNTlmYy00NDMzLTllYWEtMjdhMjJlY2VlZDI2%40thread.v2/0?context=%7b%22TiId%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_NDZjODRkY2EtNTlmYy00NDMzLTllYWEtMjdhMjJlY2VlZDI2%40thread.v2/0?context=%7b%22TiId%22%3a%22e4a340e6-b89e-4e68-8eaa-1544d2703980%22%2c%22Oid%22%3a%22c6cbcd35-ecfc-41f0-8557-67e58ee3ad83%22%7d)

*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: 434 104 063#

*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:** (16) Annette Logan-Parker (Chair); Gina Glass (Vice Chair); Amber Federizo, DNP, APRN, FNP-BC; Ihsan Azzam, MD, PhD; Linetta Barnes, BSN, RN; Shirley Folkins-Roberts; Jennifer Millet, DNP, RN; Valerie Porter, DNP, BSN, MBA; Nik Abdul Rashid, M.D.; Kimberly Palma-Ortega; Paul Niedermeyer; Naja Bagner; Veneta Lepera, BSN, RN; Susanna Sorrentino, M.D., FACMGG, FAAP; Craig Vincze, M.D.; Christina Thielst, LFACHE (Quorum=9)

- 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. To provide public comment telephonically, dial 1-775-321-6111. When prompted to provide the Meeting ID, enter 434 104 063#. Any public testimony will be limited to three minutes per person. Persons making comment will be asked to begin by stating their name for the record and to spell their last name, and provide the secretary with written comments. 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 4150 Technology Way, Suite 300, Carson City, NV 89706, 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.

- 3) FOR POSSIBLE ACTION: Discussion and possible action to approve meeting minutes from June 2, 2023. – *Council Members*
- 4) FOR POSSIBLE ACTION: Discussion and possible action to recommend to the Director of the Nevada Department of Health and Human Services the appointment of Dr. Sumit Gupta as a Council member representing one physician who practices in the area of cardiology, emergency care, neurology, oncology, orthopedics, pediatrics, or primary care and provide care to patients with rare diseases. – *Council Members*
- 5) FOR POSSIBLE ACTION: Discussion and possible action to include a section on Artificial Intelligence (AI). AI is the intelligence of software or machines that is used to make the lives of humans easier. The use of AI that will be applied to the field of Healthcare will be used to assist with diagnosis and treatment options, patient engagement and adherence, and administrative activities. The AI section will be under the Awareness and Education Priority Section in the Strategic Plan for 2023-2025, which will serve to the state of Nevada and the Council Members as the initial framework for creating a collaborative approach of a comprehensive plan for the management of rare disease in Nevada. – *Council Members*
- 6) FOR POSSIBLE ACTION: Discussion and possible action to appoint the below Council Members into the Strategic Plan Subcommittee that will meet on the First Friday of the month at 9:30 AM PST, on odd numbered months beginning in September 2023. – *Council Members*

Chair Annette Logan-Parker  
Vice-Chair Gina Glass  
Amber Federizo  
Jennifer Millet

- 7) FOR POSSIBLE ACTION: Discussion and possible action to allow the NV RDAC Chair to review the NV RDAC Strategic Plan for 2023-2025 that serves as the initial framework for creating a collaborative approach of a comprehensive plan for the management of care of rare disease in Nevada, and 2023 Annual Report that will be drafted at the end of 2023 for the Governor and Legislature that includes a summary of the Council's activities and any recommendations the Council has for Legislature or other policies in accordance with [Senate Bill 315 \(SB315\)](#) during the event, Rare Disease Legislative Day, the Cure 4 Kids Foundation is hosting on Rare Disease Day, Thursday, February 29, 2024. – *Council Members*
- 8) INFORMATIONAL ITEM: Update the Council on the NV RDAC website. – *Chair Logan-Parker*
- 9) INFORMATIONAL ITEM: Update and discussion on [Senate Bill \(SB\) 221](#) that has been signed by Governor Lombardo. – *Chair Logan-Parker*
- 10) INFORMATIONAL ITEM: Update on the Mercer Medicaid Study on Nevada's System of Care for Children with Rare Disease. – *Chair Logan-Parker*
- 11) INFORMATIONAL ITEM: Overview of the Needs Assessment platform in REDCap. – *Jeremy Russo, IT Systems Analyst, Cure 4 The Kids Foundation*

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. To provide public comment telephonically, dial 1-775-321-6111. When prompted to provide the Meeting ID, enter 434 104 063#. Any public testimony will be limited to three minutes per person. Persons making comment will be asked to begin by stating their name for the record and to spell their last name, and provide the secretary with written comments. 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 4150 Technology Way, Suite 300, Carson City, NV 89706, or fax them to (775) 684-5999.

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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 – 4150 Technology Way, Carson City, NV 89706

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. To provide public comment telephonically, dial 1-775-321-6111. When prompted to provide the Meeting ID, enter 434 104 063#. Any public testimony will be limited to three minutes per person. Persons making comment will be asked to begin by stating their name for the record and to spell their last name, and provide the secretary with written comments. 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.

4150 Technology Way, Suite 300 • Carson City, Nevada 89706  
775-447-0263 • Fax 775-684-5999 • [dpbh.nv.gov](http://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, 4150 Technology Way, Suite 300, Carson City, NV 89706, 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  
4150 Technology Way, Suite 300  
Carson City, NV 89706