

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 October 6, 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:

https://teams.microsoft.com/l/meetup-join/19%3ameeting_NDZjODRkY2EtNTlmYy00NDMzLTllYWEtMjdhMjJlY2VlZDI2%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: 237 655 757 462

Passcode: HBGnCZ

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: (15) Annette Logan-Parker (Chair); Gina Glass (Vice Chair); Amber Federizo, DNP, APRN, FNP-BC; Ihsan Azzam, MD, PhD; 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=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 4150 Technology Way, Suite 300, Carson City, NV 89706, or fax them to (775) 684-5999.

- 3) FOR POSSIBLE ACTION: Discussion and possible action to approve meeting minutes from August 4, 2023. – *Council Members*
- 4) INFORMATIONAL ITEM: Review and discussion of the Rare Disease Advisory Council’s bylaws in regard to council member terms. – *Ashlyn Torrez, Health Program Specialist I, Office of State Epidemiology (OSE), DPBH*
- 5) FOR POSSIBLE ACTION: Confirmation of consideration to renew expired terms of RDAC members and the Chair. Recommendations will be submitted to the Administrator for consideration of submission to the Department of Health and Human Services (DHHS) Director for consideration of renewal of appointment. – *Council Members*
- 6) FOR POSSIBLE ACTION: Discussion and possible action regarding Shirley Folkins-Roberts’s resignation from the Rare Disease Advisory Council as a “organization who provides services to patients with rare disease.” Under Nevada Revised Statutes (NRS) 439.5075(1)(b)(1) and the appointment of Brigette Cole to fulfill the vacated position as a “organization who provides services to patients with rare disease.” – *Council Members*
- 7) FOR POSSIBLE ACTION: Discussion and possible action to recommend to the Director of Department of Health and Human Services (DHHS) to remove Dr. Susanna Sorrentino from the Council, pursuant to Article 4, *Membership: Section 5, Removal of a Member. Part 3 Unexcused absence from two consecutive meetings of the council. (4.5.3) of the bylaws.* – *Council Members*
- 8) FOR POSSIBLE ACTION: Discussion and possible action of the annual report that is due to Governor Lombardo and the Director of the Legislative Council Bureau in December 2023, pursuant to Nevada Revised Statues (NRS) 439.5077(2)(b)(2) . – *Council Members*
- 9) INFORMATIONAL ITEM: Discussion regarding vacancies of the Rare Disease Advisory Council (RDAC) – *Chair Annette Logan Parker*
- 10) INFORMATIONAL ITEM: Update on Dr. Sumit Gupta’s recommendation of appointment. – *Chair Annette Logan Parker*
- 11) INFORMATIONAL ITEM: Council member information sharing announcements. – *Council Members*
- 12) 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 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.
- 13) 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
- NORTHERN NEVADA HEALTH DISTRICT – 1001 E. Ninth Street, Reno, NV 89512
- SOUTHERN NEVADA HEALTH DISTRICT - 280 S. Decatur Blvd, Las Vegas, NV 89107

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.

4150 Technology Way, Suite 300 • Carson City, Nevada 89706
775-447-0263 • Fax 775-684-5999 • 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, 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 or in writing:

RDAC Attn: Ashlyn Torrez
4150 Technology Way, Suite 300
Carson City, NV 89706