

Joe Lombardo
Governor



Richard Whitley,
MS
Director



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MPH
Administrator

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

Rare Disease Advisory Council (RDAC) – Subcommittee Meeting Agenda

January 5, 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:

Join via Microsoft Teams Meeting:

https://teams.microsoft.com/l/meetup-join/19%3ameeting_MjU1YzdiNGMtM2I3Yi00NWJhLTliZTEtNDM5NTVjZWVjOGUz%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: 231 435 154 925

Passcode: akGH6i

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: 549 684 759#

Please note: Agenda items may be taken out of order, combined for consideration, and/or removed from the agenda at the chairperson's discretion.

Subcommittee Members: (4) Annette Logan-Parker (Chair); Gina Glass (Vice Chair); Amber Federizo, DNP, APRN, FNP-BC; and Jennifer Millet, DNP, RN (Quorum=3)

- 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) INFORMATIONAL ITEM: An introduction to the Strategic Plan Subcommittee. – *Chair Logan-Parker*

- 4) INFORMATIONAL ITEM: Review the Strategic Plan Subcommittee schedule. – *Chair Logan-Parker*
- 5) INFORMATIONAL ITEM: Review and discuss the Nevada 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, of the Rare Disease Advisory Council (RDAC). – *Chair Annette Logan Parker*
- 6) FOR POSSIBLE ACTION : Review and possible action to approve the While You Wait Campaign rollout. This campaign is an needs assessment asking participants with rare disease to help identify the extent of rare disease(s) in Nevada. These survey results will be used to improve quality of care and to advise state agencies on research, diagnosis, treatment, and educational needs relating to rare diseases. – *Council Members*
- 7) FOR POSSIBLE ACTION: Discussion and possible action to survey each Rare Disease Advisory Council's (RDACs) that are a part of the National Network of RDACs. – *Council Members*
- 8) INFORMATIONAL ITEM: Council member information sharing announcements – *Council Members*
- 9) 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.

- 10) 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.

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