

Steve Sisolak  
Governor

Richard Whitley, MS  
Director



**DEPARTMENT OF  
HEALTH AND HUMAN SERVICES**  
DIVISION OF PUBLIC AND BEHAVIORAL HEALTH  
*Helping people. It's who we are and what we do.*



Lisa Sherych  
Administrator

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

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**Rare Disease Advisory Council Educational Subcommittee Meeting Agenda  
June 9, 2021  
9:00 a.m. - Adjournment**

**Meeting Location:**

4150 Technology Way Room  
303 Carson City NV 89706

**Webex Meeting**

**Join from the meeting link**

<https://nvhealth.webex.com/nvhealth/j.php?MTID=mb6ef32f13aca1215de925681d0ca4308>

**Join by meeting number**

Meeting number (access code): 1876 21 0331

Meeting password: 2DYk2Fstgf9

*Once you have entered the meeting number and password you will be able to participate in the meeting virtually and comment publicly at this time prerecorded public comments are not available.*

**Tap to join from a mobile device (attendees only)**

[+1-415-655-0001](tel:+14156550001) Access code [1876210331#](tel:+14156550001) US Toll

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

Members (4) Amber Federizo, DNP, APRN, FNP-BC (CHAIR); Linetta Barnes, BSN RN; Jennifer Millett, MSN, RN; Kimberly Palma Ortega; Annette Logan

- 1) Introduction and Roll call – DPBH Staff/Chair
- 2) PUBLIC COMMENT:

Public testimony under this agenda item may be presented in person, by computer, phone or written comment. Due to time considerations, each individual offering public comment will be limited to not more than 3:00 minutes. 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 Jennie Belka at [jbelka@health.nv.gov](mailto:jbelka@health.nv.gov). You may also mail written documents to the Division of Public and Behavioral Health, 4150 Technology Way, Suite 300, Carson City, NV 89706, or fax them to (775) 687-7570.

- 3) POSSIBLE ACTION: Discussion and selection of domain name for the Nevada Rare Disease Advisory Council - Chair/Subcommittee  
Options are:
  - NVRDAC.org
  - NVRDAC.com
  - nevadararediseaseadvisorycouncil.org
  - NevadaRDAC.org
- 4) POSSIBLE ACTION: Discussion and selection of registry of diagnosis and Nevada providers for the creation of an online up-to-date database of providers who treat rare disease organized by disease state rather than the specialty - Chair/Subcommittee.
- 5) POSSIBLE ACTION: Discussion and selection of educational and organization community-based resources to be made available to consumers and providers, similar to National Organization for Rare Disorders (NORD) website for education. –Chair/Subcommittee
- 6) POSSIBLE ACTION: Discussion of content and use of National Organization for Rare Disorders (NORD) resources to feature on the RDAC website. - Chair/Subcommittee
- 7) POSSIBLE ACTION: Discussion and approval of formatting options of RDAC website design - Chair/Subcommittee
- 8) Discussion of future agenda items – Chair/Subcommittee
- 9) Discussion of future meeting dates and times – Chair/Subcommittee
- 10) 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.

- 11) Adjournment – Chair

**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  
 WASHOE COUNTY HEALTH DISTRICT – 1001 E. Ninth Street, Reno, NV 89512  
 SOUTHERN NEVADA HEALTH DISTRICT - 280 S. Decatur Blvd, Las Vegas, NV 89107  
 GRANT SAWYER BUILDING – 555 E. Washington Ave, Las Vegas, NV 89101

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) Legislative Subcommittee 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.

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, 3rd Floor, Carson City, NV 89706, or by calling Jennie Belka at 775-684-2210 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 Jennie Belka at 775-684-2210, emailing [jbelka@health.nv.gov](mailto:jbelka@health.nv.gov), or in writing:

RDAC  
Attn: Jennie Belka  
4150 Technology Way Suite  
#300 Carson City, Nevada  
89706