

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 (RDAC)  
Meeting Agenda  
September 12<sup>th</sup>, 2022  
9:00 AM – Adjournment**

Pursuant to NRS 241.023 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:**

## Microsoft Teams meeting

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*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) Amber Federizo, DNP, APRN, FNP-BC (Chair); Gina Glass (Vice Chair); Ihsan Azzam, MD, PhD; Linetta Barnes, BSN, RN; Shirley Folkins-Roberts; Jennifer Millet, MSN, RN; Valerie Porter, DNP, BSN, MBA; Nik F. Nik Abdul Rashid, M.D.; Brynlin Thornley; Kimberly Palma-Ortega; Paul Niedermeyer; Naja Bagner; Veneta Lepera, BSN, RN; Annette Logan-Parker; Suzanne Sorrentino, M.D., FACMGG, FAAP (Quorum=8)

- 1) **Call to order/roll call** – *DPBH Staff/Chair Amber Federizo*
- 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](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.

- 3) FOR POSSIBLE ACTION: Discussion and possible approval of meeting minutes from June 20, 2022 – *Council Members*
- 4) FOR POSSIBLE ACTION: Discussion of, nomination of, and voting for a new chair and vice chair of the Nevada Rare Disease Advisory Council for next term. - *Council Members*
- 5) FOR POSSIBLE ACTION: Discussion and possible action to request the Director of the Nevada Department of Health & Human Services to appoint Christina Thielst as a council member representing a patient with rare disease replacing Brynlin Thornley’s position. – *Council Members*
- 6) INFORMATIONAL ITEM: Nevada Update on Sickle Cell Registry – *Annette Logan-Parker, CEO of Cure4Kids Foundation; Ashlyn Torrez, Health Program Specialist I, Office of Public Health Informatics and Epidemiology (OPHIE), DPBH; and Nik Abdul Rashid M.D*
- 7) INFORMATIONAL ITEM: Discussion of Nevada State Medicaid Rate Survey findings case report from Cure4Kids – *Annette Logan-Parker*
- 8) INFORMATIONAL ITEM: Introduction to ALS – *Dawn Newburg, Executive Director, ALS Association for Nevada Chapter*
- 9) INFORMATIONAL ITEM: Medicaid Rate Survey for Provider Type 20 – *Chair Amber Federizo*
- 10) INFORMATIONAL ITEM: Council member information sharing announcements – *Council Members*
- 11) 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.
- 12) Adjournment – *Chair Amber Federizo*

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

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 • [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