

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  
May 27<sup>th</sup>, 2022  
9:00 a.m. to 11:00 a.m.**

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 Zoom Meeting:**

<https://zoom.us/j/99945180379?pwd=T0liTEJaSndXK0hBaGozaUxVellEUT09>

Meeting ID: 99 4518 0379

Passcode: 408252

**One tap mobile:**

+16699009128,,99945180379#,,,,\*408252# US (San Jose)

+12532158782,,99945180379#,,,,\*408252# US (Tacoma)

**Dial by your location:**

+1 669 900 9128 US (San Jose)

Meeting ID: 999 4518 0379

Passcode: 408252

*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. Due to time considerations, each individual offering public comment will be limited to not more than 2:00 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 Rex Gifford at [r.gifford@health.nv.gov](mailto:r.gifford@health.nv.gov) . You may also mail written documents to 4150 Technology Way, Suite 300, Carson City, NV 89706, or fax them to (775) 687-7570.

- 3) FOR POSSIBLE ACTION: Approval of minutes from the February 14<sup>th</sup>, 2022, Rare Disease Advisory Council Meeting. – *Council Members*
- 4) INFORMATIONAL ITEM: Discussion regarding Dr. Max Coppes’s resignation from the Rare Disease Advisory Council as a “physician who provides care to patients with rare diseases” Under Nevada Revised Statutes (NRS) 439.5075(1)(b)(1) and the appointment of Dr. Susanne Sorrentino to fulfill the vacated position as a “physician who provides care to patients with rare diseases” – *Chair Amber Federizo*
- 5) FOR POSSIBLE ACTION: Discussion and possible action to recommend to the Director of the Nevada Department of Health and Human Services (DHHS) to add Craig Vincze as a member of the Council, pursuant to NRS 439.5075(2), for a term of 3 years.– *Council Members*
- 6) FOR POSSIBLE ACTION: Discussion and possible action to recommend the Director of the Nevada Department of Health and Human Services (DHHS) to remove Brynlin Thornley 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*
- 7) FOR POSSIBLE ACTION: Discussion and possible action to recommend that the Nevada Department of Health and Human Services (DHHS) bring forward a Bill Draft Request (BDR) for the 2023 Legislative Session regarding the RDAC Annual Report policy recommendations, and possible authorization of an RDAC member to meet with DHHS to discuss proposed BDR – *Council Members*
- 8) FOR POSSIBLE ACTION: Discussion and possible action to authorize Chair Amber Federizo to draft a letter to Senator Neal to provide updates on Council budgetary and statutory constraints and request possibility of budgetary bill draft request (BDR) – *Amber Federizo, Chair*
- 9) INFORMATIONAL ITEM: Presentation of Proposed Regulation LCB File No. R107-20 Sickle Cell Reporting for Council feedback. – *Lindsey Kinsinger, Manager, Office of Public Health Informatics and Epidemiology (OPHIE), DPBH*
- 10) INFORMATIONAL ITEM: Medicaid Rare Disease Pilot Program update and discussion – *Chair Amber Federizo and Council Member Annette Logan-Parker*
- 11) FOR POSSIBLE ACTION: Discussion and possible approval of amended Council Bylaws – *Council Members*
- 12) FOR POSSIBLE ACTION: Discussion, Nomination, and voting for new chair of the Nevada Rare Disease Advisory Council. - *Council Members*
- 13) INFORMATIONAL ITEM: Council member information sharing announcements – *Council Members*
- 14) 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 2:00 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 Rex Gifford at [r.gifford@health.nv.gov](mailto:r.gifford@health.nv.gov) . You may also mail written documents to 4150 Technology Way, Suite 300, Carson City, NV 89706, or fax them to (775) 687-7570.

Action may not be taken on any matter brought up under this agenda item until scheduled on an agenda for a later meeting.

- 15) 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  
775-684-4200 • Fax 775-687-7570 • [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, 3rd Floor, Carson City, NV 89706, or by calling 775-684-4217 Rex Gifford 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 775-684-4217, emailing Rex Gifford at [r.gifford@health.nv.gov](mailto:r.gifford@health.nv.gov) or in writing:

RDAC Attn: Rex Gifford  
4150 Technology Way, Suite #300  
Carson City, Nevada 89706