

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**

**February 14, 2022**

**10:00 a.m. - Adjournment**

Join Zoom Meeting:

<https://zoom.us/j/93391022419?pwd=ZjNVcFpzakprUCtyTGIIQitSTkJwUT09>

Meeting ID: 933 9102 2419

Passcode: 937646

One tap mobile

+16699009128,,93391022419#,,,,\*937646# US (San Jose)

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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.*

Members (16) Ihsan Azzam, MD, PhD; Linetta Barnes, BSN, RN; Amber Federizo, DNP, APRN, FNP-BC (CHAIR); Shirley Folkins-Roberts; Gina Glass (Vice Chair); Jennifer Millet, MSN, RN; Valerie Porter, DNP, BSN, MBA; Nik F. Nik Abdul Rashid, MD; Brynlin Thornley; Kimberly Palma-Ortega; Paul Niedermeyer; Naja Bagner; Max Coppes, MD, PhD, MBA; Veneta Lepera, BSN, RN; Annette Logan-Parker; Suzanne Sorrentino, M.D., FACMGG, FAAP (Quorum=9)

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 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 May 19, 2021, Legislative Subcommittee, June 9, 2021, Educational Subcommittee, September 30, 2021 Educational Subcommittee, October 20, 2021 RDAC meeting. – Council Members
  - 4) INFORMATIONAL: Testimony of Council Member Naja Bagner regarding her experience with sickle cell disorder in the state of Nevada. – Naja Bagner
  - 5) INFORMATIONAL: Summary of meeting with Nevada State Medicaid, Nevada Department of Health and Human Services and the Governor’s Office regarding annual RDAC report. – Chair/Council Members
  - 6) FOR POSSIBLE ACTION: Recommendations for the development of reform criteria for pilot rare disease Medicaid administration program. – Council Members
  - 7) FOR POSSIBLE ACTION: Discuss and determine future agenda items – Council Members
  - 8) FOR POSSIBLE ACTION: Discuss and schedule future meeting dates and times – Council Members
  - 9) 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.
- 10) 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

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.

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