

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**

**Meeting Agenda**

**July 16, 2021**

**9:00-11:00am**

**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.*

Members (14) 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; (Quorum=8)

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 4150 Technology Way, Suite 300, Carson City, NV 89706, or fax them to (775) 687-7570.
- 3) FOR DISCUSSION: Review of Legislative session [SB40](#), relating to the collection of health care data; [SB175](#), enacting provisions relating to lupus; and [SB420](#), relating to health insurance. – Council Members
- 4) POSSIBLE ACTION: Discussion and possible action to approve report to include: 1) Recommendation to the Governor's Office granting authority to present at least one Bill Draft Request (BDR) per legislative session 2) Actions taken or under consideration impacting a rare disease disorder by DHHS must first be presented to the Rare Disease Council for input. – Council Members
- 5) FOR DISCUSSION: Presentation and discussion on barriers to rare disease care in the community, including discussion regarding available resources to assess financial impact of rare disease and models of care for Newborn Screening, Pediatric Cancer and inherited bleeding disorders. – Council Members
- 6) POSSIBLE ACTION: Discussion regarding the education subcommittee and website design and possible action to delegate authority to the Education Subcommittee to approve and modify website content and educational outreach, as well as apply for and receive educational grants on behalf of RDAC. – Council Members
- 7) POSSIBLE ACTION: Discussion and possible action to establish pharmaceutical industry advisory panel. – Council Members
- 8) POSSIBLE ACTION: Discussion and possible action to establish and conduct a statewide needs survey for consumers and providers and possible delegation of authority to the RDAC Educational Subcommittee. – Council Members
- 9) Discuss and determine future agenda items – Council Members
- 10) POSSIBLE ACTION: Discuss and schedule future meeting dates and times – Council Members
- 11) 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 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.

- 12) 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.

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 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