

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

NEVADA RARE DISEASE ADVISORY COUNCIL
MEETING MINUTES
Date: December 2, 2022
3:30 pm – 4:30 pm

Meeting Locations:

Pursuant to NRS 241.020(3)(a) as amended by Assembly Bill 253 of the 81st Legislative Session, this meeting was convened using a remote technology system and there was no physical location for this meeting.

Chair Annette Logan-Parker opened the meeting at 3:34 pm.

1) INTRODUCTIONS AND ROLL CALL

COUNCIL MEMBERS PRESENT:

Annette Logan-Parker (CHAIR); Gina Glass (Vice-Chair); Amber Federizo, DNP, APRN, FNPBC; Shirley Folkins-Roberts; Jennifer Millet, DNP, RN; Valerie Porter, DNP, BSN, MBA; Kimberly Palma Ortega; Naja Bagner; Veneta Lepera; Linetta Barnes, BSN, RN; Nik Abdul Rashid, MD; Craig Vincze, M.D.; and Christina Thielst (Quorum=9)

COUNCIL MEMBERS ABSENT:

Ihsan Azzam, MD, PhD; Paul Niedermeyer (excused); and Susana Sorrentino, MD.

DIVISION OF PUBLIC & BEHAVIORAL HEALTH (DPBH) STAFF PRESENT:

Lindsey Kinsinger, *Health Program Manager II, Office of Public Health Investigations & Epidemiology (OPHIE)*; Ashlyn Torrez, *Health Program Specialist I, OPHIE*; Kayla Samuels, *Management Analyst I, DPBH*; Sherry Stevens, *Administrative Assistant III, DPBH*; Vickie S. Ives, *Health Program Manager III, Child, Family, and Community Wellness*; Cassius Adams, *Health Program Specialist I, Maternal, Child, and Adolescent Health*; and Kagan Griffin, *Health Program Manager I, Maternal, Child, and Adolescent Health*

OTHERS PRESENT:

Pierron E. Tackes, *Deputy Attorney General (DAG), Attorney General Office*

Roll call was taken and is reflected above. It was determined that a quorum of the Rare Disease Advisory Council (RDAC, the Council) was present.

2) PUBLIC COMMENT

Chair Logan-Parker opened the floor for public comment.

Councilmember Linetta Barnes commented to the Council that Ms. Barnes moved out of the State of Nevada, and Ms. Barnes consulted with the Deputy Attorney General and was still qualified to serve on the Advisory Council. Ms. Barnes added that she is looking forward to continuing in her position as a parent with experience caring for a child with a rare disease.

Chair Logan-Parker thanked Councilmember Barnes.

Ms. Barnes thanked Chair Logan-Parker.

Chair Logan-Parker asked if there was anyone else on the meeting who would like to speak. None heard.

3) FOR POSSIBLE ACTION: Discussion and possible action to approve the annual report for 2022. –
Council Members

Chair Logan-Parker introduced this possible action agenda item. Chair Logan-Parker commented that the annual report has not changed much since it was reviewed during the November 14th meeting. Chair Logan-Parker added that she wanted to add additional introductory information to the report. Chair Logan-Parker wanted to make sure that the people who read it off of the internet, who would go to the RDAC site would have a clear understanding of the objectives. Chair Logan-Parker asked Ms. Torrez to scroll down through the report. Chair Logan-Parker asked Councilmember Amber Federizo if she had any comments to add.

Councilmember Federizo stated that she did not have any additional comment. Councilmember Federizo thought it was great to add the introduction section for individuals who are coming from an external standpoint. Councilmember Federizo added that the introduction section now will show how the Council was created and what the Council is planning on doing.

Chair Logan-Parker confirmed that there was no other changes done to the original document that was reviewed during the last meeting. Chair Logan-Parker opened the floor to Council to comment and discuss. None heard. Chair Logan-Parker requested a motion to approve from a Councilmember.

Councilmember Valerie Porter motioned to approve the annual report for 2022. Vice-Chair Gina Glass seconded the motion to approve. There were no objections. A quorum voted to approve the annual report for 2022.

4) FOR POSSIBLE ACTION: Discussion and possible action to approve final letter to clinicians inviting them to submit their information to NVRDAC.org, and to be entered into a drawing for a gift card. –
Council Members

Chair Logan-Parker introduced the possible action item. Chair Logan-Parker opened the floor to the Council for discussion.

Councilmember Amber Federizo stated that the final letter only has one change from the original version, when it was voted on previously. Councilmember Federizo added that the Council would have to vote again because the address for Amber Williams was not on the original. Councilmember Federizo commented that the letter would be submitted to the County Medical Society in Napa and the other groups that were originally targeted.

Chair Logan-Parker thanked Councilmember Federizo for the clarification. Chair Logan-Parker requested the Council to motion to approve.

Councilmember Amber Federizo motioned to approve the final letter to be posted to the NVRDAC.org website and gift card drawing. Vice-Chair Gina Glass seconded the motion to approve. There were no objections. A quorum voted to approve the prior meeting minutes.

5) PUBLIC COMMENT:

Chair Logan-Parker opened the floor for public comment. None heard.

6) ADJOURNMENT – *Chair Logan-Parker*

Chair Logan-Parker moved to adjourn and expressed appreciation for everyone on the council.

Meeting adjourned at 3:42 pm.