

Joe Lombardo
Governor

Richard Whitley,
MS
Director



Cody Phinney,
MPH
Administrator

Ihsan Azzam,
Ph.D., M.D.
Chief Medical
Officer

NEVADA RARE DISEASE ADVISORY COUNCIL

MEETING MINUTES

Date: 12/08/2023

09:30 am – 10:05 am

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 09:31 am.

1) INTRODUCTIONS AND ROLL CALL

SUBCOMMITTEE MEMBERS PRESENT:

(14) Annette Logan-Parker (Chair); Jennifer Millet, DNP, RN; Valerie Porter, DNP, APRN, AG-ACNP-BC, MBA; Kimberly Palma-Ortega; Paul Niedermeyer; Craig Vincze, PhD; Christina Thielst, LFACHE, MHA; Sumit Gupta, MD; and Brigette Cole; Gina Glass (Vice Chair) (Joined late) (Quorum=10)

SUBCOMMITTEE MEMBERS ABSENT:

Amber Federizo, DNP, APRN, FNP-BC; Nik Abdul Rashid, M.D; Ihsan Azzam, MD, PhD; Naja Bagner

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

Ashlyn Torrez, Health Program Specialist I, Office of State of Epidemiology (OSE); Elizabeth Kessler, Health Program Specialist II, OSE; and Kagan Griffin, OSE Operations Manager, OSE

OTHERS PRESENT:

Geodan Goebel, Deputy Attorney General (DAG); Amber Williams, Cure 4 Kids Foundation; Joseph Filippi, Management Analyst, Director's Office, DHHS

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.

Hearing none, Chair moved on to the agenda next item.

- 3) POSSIBLE ACTION: Approval of minutes from October 6, 2023, Rare Disease Advisory Council Meeting. – *Council Members*

Chair Logan-Parker introduced the agenda item to approve the meeting minutes from last Council Meeting, and asked the Council for a motion.

Dr. Craig Vincze spoke to request an edit to adjust the credential for Craig Vincze, to have the PhD, Doctor of Philosophy, instead of M.D., Doctor of Medicine.

Councilmember Valerie Porter motioned to approve the meeting minutes from prior council meeting dated 10/06/2023 with an edit to adjust Dr. Craig Vincze credentials. Council member Sumit Gupta seconded the motion to approve. There were no objections. A quorum voted to approve the prior meeting minutes with the edit adjusted correction.

- 4) POSSIBLE ACTION: Discussion and possible action to approve the finalized third annual report that is due to Governor Lombardo and the Director of the Legislative Council Bureau in December 2023, pursuant to Nevada Revised Statutes [\(NRS\) 439.5077\(2\)](#). – *Council Members*

Chair Logan-Parker introduced the agenda item to approve the third annual report and asked the Council for a motion.

Dr. Craig Vincze spoke to request an edit to adjust page 5 for the credential for Craig Vincze, to have the PhD, Doctor of Philosophy, instead of M.D., Doctor of Medicine and online Rare Disease Advisory Council website.

Christina Thielst sent an email detailing formatting focused issues which required correction, example is in the area where legislation was listed out. [SB 194](#) seemed to be listed twice.

Valeria Porter stated to include abbreviations on credentials AGACNP – BC, Adult-Gerontology Acute Care Nurse Practitioner – Board Certified. Christina Thielst stated to include MHA, Master of Health Administration, on credentials for annual report and Rare Disease Advisory Council website.

Councilmember Valerie Porter motioned to approve the third annual report 2023 with the requested edits listed in agenda item number 4 and from second public comment section. Council member Craig Vincze seconded the motion to approve. There were no objections. A quorum voted to approve the prior meeting minutes with the edit adjustment.

- 5) INFORMATIONAL: Discussion and clarification with the Council to notify Board members of unexcused absences. – *Chair Annette Logan-Parker*

Chair Logan-Parker introduced the agenda item to clarify absence process. A request for an excused absence should include an email follow-up to supporting staff Ashlyn Torrez and additionally send a carbon copy to Chair, Annette Logan-Parker and Co-Chair, Gina Glass. Open line of communication is to prevent loss of members. Reminder that bi-laws state: 2 consecutive unexcused absences, led to removal from active member status on the Rare Disease Advisory Council. The council will make its best efforts to accommodate where possible, within reason. Resource provided where individuals can see this on the Rare Disease Advisory Council website.

- 6) INFORMATIONAL ITEM: Discussion of the resignation of Veneta Lepera and her replacement Kim Anderson pursuant with [NRS 439.5075\(1\)\(a\)](#). – *Chair Annette Logan Parker*

Chair Logan-Parker introduced the agenda item to announce Veneta Lepera resignation from the council. Kim Anderson is due to hold this position pursuant to NRS 439.5075(1)(a); Chair Logan-Parker stated that Ms. Anderson is currently in the process for appointment and shall be officially on the council after paperwork is concluded.

- 7) INFORMATIONAL ITEM: Council member information sharing announcements. – *Council Members*

Chair Logan-Parker introduced the agenda item to oversee announcements and opened the floor to council members.

Council member Christina Theilst announced her participation in previously viewing a Silver State Scripts Legislation. At the meeting, Christina discovered information about Position, Navigation and timing, function, pharmacy, therapeutics function, and recommendations made to the public. Christina felt what was presented in this meeting, which was related to the rare disease community, was beneficial and worth a potential presentation.

Chair Logan-Parker invited Christina to present at the next expected meeting in February 2024.

Ms. Theilst agreed, and Ms. Theilst added that there is a new neuromuscular specialist, Verena Samara, Medical Doctor, had established care in Carson Tahoe Medical, Carson City, NV.

Dr. Vincze held the floor and stated his participation in Rare Cancer Think-Tank, located in Boston, held by Target Cancer Group, formed by an individual who had a rare cancer. Dr. Vincze stated this individual had passed away but his legacy with the group had continued for 10 years. This group found success with developing FDA approved treatments for this rare disease. Dr. Vincze expressed interest in sharing with the council at the next meeting to present his findings.

Chair Logan-Parker agreed.

Gina Glass stated an email communication from National Organization for Rare Disease (NORD) was received. NORD is holding its Virtual Stakeholder Meeting on December 14, 2023, for all Rare Disease Advisory Councils across the country.

Chair Logan-Parker requested the information be forward from Ms. Glass to support staff, Ashlyn Torrez, so it may be produced for all council members.

Chair Logan-Parker announced confirmed attendance in Washington, DC through the dates of December 12, 2023, through December 15, 2023. Chair intends to present the Annual Report, Strategic Plan, along with highlighting the Rare Disease Advisory Council to Nevada federal delegates, who are in attendance to receive information for 2025 legislative session. Chair stated her intention to report at the February Rare Disease Advisory Council meeting on her personal progress with networking.

8) PUBLIC COMMENT:

Chair Logan-Parker opened the floor for public comment.

Joseph Filippi held the floor to advise in regard to an error located on the Annual Report and the Rare Disease Advisory Council website. The error, [SB 315](#) should be [NRS 439.5077\(2\)](#). Consequently, not initiating the correction gave the appearance of current legislative session, whereas the council was previously formed in 2019.

Chair Logan-Parker concurred to modify the error.

Ms. Torrez stated that a vote needed to be held to reapprove the annual report 2023 with the edits requested by Mr. Filippi.

Chair asked the Council for a motion to reapprove agenda item number 4, the requested edits vote held unanimously.

7) ADJOURNMENT – *Chair Annette Logan-Parker*

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

Chair Annette Logan-Parker moved to adjourn the meeting at 10:05 am.