

Joe Lombardo  
Governor

Laura Rich  
Director



## DEPARTMENT OF HUMAN SERVICES



NEVADA DIVISION of PUBLIC  
and BEHAVIORAL HEALTH



Andrea R. River,  
MS  
Administrator

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

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# NEVADA RARE DISEASE ADVISORY COUNCIL – Subcommittee

## DRAFT MEETING MINUTES

Date: May 1, 2026

9:35 AM – 9:46 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 9:35 am.

### 1) INTRODUCTIONS AND ROLL CALL

#### **SUBCOMMITTEE MEMBERS PRESENT:**

Annette Logan-Parker (CHAIR); Amber Federizo, DNP, APRN, FNPBC; and Gina Glass (Vice-Chair)  
(Quorum=3)

#### **SUBCOMMITTEE MEMBERS ABSENT:**

Jennifer Millet, DNP, RN (Excused)

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

Kevin Dodson, *Administrative Assistant III, OSE, DPBH*, Ashlyn Torrez, *Health Program Specialist I (HPS I), Office of State Epidemiology (OSE), DPBH*; and Kagan Griffin, *OSE Operations Manager, OSE, DPBH*

#### **OTHERS PRESENT:**

Sumit Gupta, MD; Judith Akin; Craig Vincze, PhD; Melissa Bart-Plange; Kim Anderson-Mackey; Andela Martin.

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 Logan-Parker moved on to next agenda.

### 3) FOR POSSIBLE ACTION: Discussion and possible action to approve meeting minutes from July 11, 2025 – *Council Members*

**Councilmember Amber Federizo motioned to approve the meeting minutes from prior council meeting dated 7/11/2025. Vice Chair Gina Glass seconded the motion to approve. There were no objections. A quorum voted to approve the prior meeting minutes.**

- 4) FOR INFORMATION ONLY: Review of the 2027 Event Planning Survey results gathered from NV-RDAC Council members between April 1 and April 6, 2026. – *Chair Annette Logan-Parker*

Chair Annette Logan-Parker went over the 2027 Event Planning Survey results. The survey had been created to gather information from RDAC members regarding their interest and involvement in planned 2027 events. The results had been posted on the website, and nine Council members responded. The responses showed varied levels of interest; however, the results indicated strong support for the legislative event in Carson City and less support for the community events that had been proposed for Northern Nevada and Southern Nevada.

- 5) FOR INFORMATION ONLY: Discussion of Chair capacity, subcommittee leadership bandwidth, and realistic scope for the 2027 event calendar. – *Chair Annette Logan-Parker*

Chair Annette Logan-Parker made a recommendation to pause planning for the two community events due to limited bandwidth and the lack of commitment from other RDAC members to assist with event planning. The legislative event in Carson City was still viewed as a strong opportunity, especially within the legislative timeframe. The survey results were described as clear and straightforward, showing where members believed RDAC's efforts should be focused. An additional update was provided regarding the Southern Nevada Education Community Event. Roseman University Auditorium had originally been considered as a possible venue; however, its scheduling would not open until approximately two months before the event timeframe. That timeline was not considered sufficient to plan and prepare an event of that size and quality without confirmed venue availability.

- 6) FOR POSSIBLE ACTION: Discussion and possible action to approve the subcommittee's recommended scope, format, and proposed date window for the 2027 Carson City Legislative Education Event, for presentation to the full Council.

Chair Annette Logan-Parker stated that the subcommittee was asked to approve the recommendation to focus exclusively on the 2027 Carson City legislative event and table the two community events for possible consideration in 2028 or later.

Chair Annette Logan-Parker noted that overcommitting RDAC would not have been appropriate, particularly given the current chair term ending at the end of the year and the uncertainty around potential reelection. The limited confirmed support from other RDAC members was also cited as a reason to avoid committing the Council to multiple events.

- 7) FOR POSSIBLE ACTION: Discussion and possible action to approve a subcommittee recommendation to the full Nevada Rare Disease Advisory Council to defer the Southern Nevada and Northern Nevada Community Education Events to 2028.

Chair Logan-Parker combined agenda item number 7 with agenda item number four, five and eight

- 8) FOR POSSIBLE ACTION: Discussion and possible action to approve a subcommittee recommendation to the full Nevada Rare Disease Advisory Council to consolidate the 2027 event plan from three events to one event, focusing on the Legislative Education Event in Carson City.

Councilmember Amber Federizo stated that she agreed with the recommendation. She noted that the amount of work required for a legislative session was often significantly underestimated, especially given the scale of work involved during the 100-day session. She suggested that community events could be planned for intervening years, such as 2028, with legislative events taking place during legislative years. This approach was described as a better way to manage the bandwidth of Council members serving in a volunteer capacity. Councilmember Amber Federizo stated that she supported the proposed plan.

**Vice Chair Gina Glass motion to postpone the two educational Community events to 2028 and continue with the 2027 Carson City legislative event and moving forward we will consider those events on alternative years. Councilmember Amber Federizo seconded the motion to approve. There were no objections. A quorum voted to approve the motion.**

- 9) PUBLIC COMMENT:

Chair Logan-Parker opened the floor for public comment.

Hearing none, Chair Logan-Parker moved to adjourn the meeting.

- 10) ADJOURNMENT – *Chair Logan-Parker*

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

**Chair Logan-Parker moved to adjourn the meeting at 9:46 AM.**