Joe Lombardo
Governor

Richard Whitley, MS
Director

DEPARTMENT OF HUMAN SERVICES
NEVADA DIVISION of PUBLIC and BEHAVIORAL HEALTH

Dena Schmidt
Administrator

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

NEVADA RARE DISEASE ADVISORY COUNCIL

DRAFT MEETING MINUTES

Date: October 3, 2025
9:39 AM – 10:09 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 9:39 am.

1) INTRODUCTIONS AND ROLL CALL

COUNCIL MEMBERS PRESENT:
Annette Logan-Parker (CHAIR); Gina Glass (Vice-Chair); Valerie Porter, DNP, APRN, AG-ACNP-BC, MBA; Paul Niedermeyer; Melissa Bart-Plange; Pamela White; Dr. Verena Samara; Madison Bowe; Amber Federizo, DNP, APRN, FNPBC; Jennifer Millet, DNP, RN; Brigette Cole; Craig Vincze, PhD; and Christina Thielst

COUNCIL MEMBERS ABSENT:
Dr. Devraj Chavda; Ihsan Azzam, MD, PhD absent (excused); Naja Bagner; Sumit Gupta, MD; and Kim Anderson-Mackey

DIVISION OF PUBLIC & BEHAVIORAL HEALTH (DPBH) STAFF PRESENT:
Kagan Griffin, MPH, RD, *Operations Manager, Office of State Epidemiology (OSE), DPBH*; and Kevin Dodson, *Administrative Assistant III, OSE, DPBH*

OTHERS PRESENT:
Jennifer Glover - *Cure 4 Kids*; Amber Williams – *Cure 4 Kids*; Lea Cartwright; Cade Grogan; Karina Franco, OSE Intern; Dr. William Evans; and Linda Anderson

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

2) PUBLIC COMMENT

Chair Logan-Parker opened the floor for public comments.

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

3) FOR POSSIBLE ACTION: Discussion and possible action to approve meeting minutes from August 1st, 2025.

Chair Logan-Parker stated the minutes have not been posted on the Department of Human Services (DHS) website due to technical difficulties. She asked the Council for a motion to approve the minutes.

Councilmember Melissa Bart-Plange motioned to approve the meeting minutes from prior council meeting dated 8/01/2025. Councilmember Gina Glass seconded the motion to approve. There were no objections. A quorum voted to approve the prior meeting minutes.

4) FOR POSSIBLE ACTION: Discussion and possible action to plan a Rare Disease Advisory Council (RDAC) Community Education Event as discussed in the last RDAC Subcommittee Meeting on July 11, 2025.

Chair Logan-Parker discussed the possibility of organizing a public event in early 2027, likely in February to align with World Rare Disease Day. Options included hosting an event in Carson City for legislators, planning an education day for providers and caregivers, or exploring multiple formats such as concurrent events in Northern and Southern Nevada or a virtual option. The discussion was intended to gather feedback from the full Council and determine whether to move forward with approving a subcommittee to begin planning.

Gina Glass inquired if the event would only take place in Carson City for legislators, and Chair Logan-Parker clarified that several approaches were under consideration. It was noted that any event at the legislative building would need to be scheduled early in the 2027 session. The discussion provided an opportunity for broad input, and many expressed support for the overall concept.

Brigette Cole voiced strong support and referenced a meeting with the Parent to Parent Network, where challenges faced by families parenting children with rare diseases, particularly childhood cancer, had been a focus. She highlighted the importance of supporting families through difficult diagnoses and treatments and suggested exploring a Project ECHO (Extension for Community Healthcare Outcomes) model to address both provider and parent perspectives. Chair Logan-Parker recalled that an ECHO project had previously been presented by Dr. Mark Nunez and confirmed that it remained a strong option.

Gina Glass noted that NORD (National Organization for Rare Disorders) had consistently offered support for rare disease efforts in Las Vegas and suggested that this partnership could be valuable with sufficient lead time.

Madison Bowe emphasized the benefits for both Northern Nevada and Las Vegas, underscoring the importance of creating opportunities for families, caregivers, and providers to connect and access resources.

Christina Thielst supported the initiative and stressed the value of networking opportunities for patients with rare diseases, noting that aside from this group, she had only met one other person with a rare disease in Nevada.

Melissa Bart-Plange also expressed strong support and recommended hosting events in both the North and South to ensure wider engagement.

Gina Glass proposed holding one event for legislators and another for patients and caregivers, comparing it to a mini rare disease week in Las Vegas. Chair Logan-Parker agreed that concurrent events were feasible given the participation in both regions.

Madison Bowe added that Council member involvement would be critical to the success of the events and emphasized the need for Southern Nevada representation, as rare disease events had not previously been held in Las Vegas.

Chair Logan-Parker requested a motion from the Council to approve the concept and authorize the subcommittee to begin planning, with the intention of developing a proposal to present to the full Council for final approval.

Councilmember Gina Glass motioned to approve the subcommittee to get started on a plan to present to the full council. Councilmember Madison Bowe seconded the motion to approve. There were no objections. A quorum voted to approve the subcommittee to get started on a plan to present to the full council.

9) <u>FOR INFORMATION ONLY:</u> Review and discussion of the results received on the Rare Disease Advisory Council Member survey for feedback in drafting the next RDAC Strategic Plan for 2026-2027.

Chair Logan-Parker noted the July survey provided valuable insights that guided adjustments to the upcoming strategic plan. Results were included with the email invitation and were scheduled for posting on the DHS Nevada RDAC website once technical issues were resolved. The findings informed new action items for the plan, and appreciation was expressed to all participants.

5) FOR POSSIBLE ACTION: Discussion and possible action to approve the Nevada RDAC Strategic Plan 2026-2027, and the 2025 Annual Report that is due to the Department of Human Services (DHS), the Governor, and the Director of the Legislative Counsel Bureau (LCB) in December 2025 per NRS 439.5077.

Chair Logan-Parker noted that statewide technical difficulties beginning in August had delayed circulation of the 2026–2028 strategic plan draft, which was only emailed to Council members that morning. No vote was taken since members had not yet reviewed the draft, which remained unedited. The plan retained the zebra theme, structure, and infographics for consistency, with updated statistics to be incorporated during editing. It included a revised history section reflecting the past two years and a closing summary highlighting the impact of the current plan. The draft also introduced a strategic shift, expanding the original three focus areas—childhood cancers, inherited bleeding and clotting disorders, and newborn screening conditions—into broader categories.

The draft emphasized barriers affecting all rare diseases while maintaining the three pillars of awareness and education, care and support, and research and data, each with two priorities. It concluded with a summary and call to action, with a vote scheduled for December following additional edits, validation of statistics, and updates to the Nevada state scoreboard. Council members were invited to preview the draft and provide feedback and suggestions prior to final approval.

During discussion, Madison Bowe asked whether the document was intended to serve as a resource for patients in Nevada or strictly to outline RDAC activities. Chair Logan-Parker clarified that the plan functioned as a public document, available on the website, printed for distribution, and shared with legislators and stakeholders. She emphasized its role in highlighting RDAC's commitments and accountability. Madison suggested including resources but questioned whether this would align with the legislative purpose. Chair Logan-Parker agreed that a section could be added with a QR code linking to the resource page to increase website traffic.

Chair Logan-Parker committed to finalizing the draft by the end of October, allowing Council members in November to review and provide input before the December vote. The second half of the agenda addressed the annual report, which was still in progress but expected to be circulated within weeks. The report was planned to follow the established format, including the zebra theme, a summary of yearly activities, and a call to action for legislators and Medicaid. Council members were invited to provide feedback, with both the strategic plan and annual report identified as the most critical documents for approval this year.

6) FOR INFORMATION ONLY: Update on the social media campaign to showcase RDAC efforts, inform the public about getting involved, and highlight the 'While You Wait' Needs Assessment Campaign.

Chair Logan-Parker provided an update on the social media plan, noting revisions to include the upcoming provider survey. The plan was scheduled to launch in January 2026 with a full year of posts to be monitored and reported periodically. Council members were reminded to promote the initiative within their networks to increase visibility and impact.

7) FOR INFORMATION ONLY: Review and discuss the Nevada Rare Disease Advisory Council (RDAC) website updates.

Chair Logan-Parker stated the RDAC website was prepared for updates aligned with the new strategic plan, with a refreshed version scheduled for rollout in January. The Cure 4 The Kids Foundation creative team was expected to review the site for efficiency, optimization, and user-friendliness, while the provider needs assessment page was designed to go live the following week. Council members were asked to provide updated bios and headshots to support the improvements.

8) FOR INFORMATION ONLY: Overview of the Department of Human Services (DHS) and the Division of Public and Behavioral Health (DPBH) reclassification, organizational structure, and an update on the network issues that began August 24, 2025. – Kagan Griffin, Office of State Epidemiology (OSE) Operations Manager, DPBH, DHS

Kagan Griffin, Operations Manager for the Office of State Epidemiology, provided updates on recent state-level changes. During the latest legislative session, the Department of Health and Human Services was divided into the Department of Human Services and the newly created Nevada Health Authority. As a result, several programs shifted, including Healthcare Quality and Compliance, which moved to the Nevada Health Authority. The Division of Public and Behavioral Health also lost a deputy administrator position, previously held by Kyle Devine, who transitioned to the new authority. Melissa Bullock, State Medical Epidemiologist, assumed additional responsibilities overseeing the Office of State Epidemiology, public health preparedness, radiation control, and vital records. To manage workload, staff were directed to coordinate through Kagan Griffin or the new State Epidemiologist, Cindy Beard. The Nevada Health Authority assumed oversight of the Office of Analytics, while the Environmental Health Program moved to the Department of Agriculture. Updated organizational charts were delayed due to ongoing network issues.

On August 24, state systems were compromised by malicious actors, leading to temporary administrative leave while IT teams and the Governor's Technology Office worked on recovery. Significant progress was reported, with most systems—including email, cloud-hosted platforms, and the EpiTrax surveillance system—restored. EpiTrax resumption allowed case and laboratory reporting to continue without disruption. The primary system still offline was REDCap, which limited internal data entry but did not affect providers' ability to submit reports. Overall, the impact was operational, with provider reporting processes remaining intact.

The most significant ongoing challenge was the outage of shared drives, including the S and L drives, which prevented the Office of Analytics from accessing SAS (Statistical Analysis System) codes for data analysis. This outage delayed public-facing dashboards, including those for lupus and rare diseases. Plans to expand these dashboards were paused while the Office of Analytics managed disruptions.

A state recovery website at www.oem.nv.gov was created to provide updates and temporarily hosted the meeting agenda.

Kagan Griffin put into the chat at 10:09 AM: "https://www.oem.nv.gov/public-meetings-new/"

Kagan Griffin Friday put into the chat at 10:09AM: kgriffin@health.nv.gov

Communication channels remained active, with direct support available to triage questions and connect stakeholders with the appropriate offices. System and structural changes across agencies created additional confusion, though support was available for clarifying program placements.

Chair Logan-Parker asked whether previously approved disease categories would still appear in the state dashboard once systems stabilized. Kagan Griffin confirmed that classifications would remain but were delayed until operations normalized. Monthly meetings with the Office of Analytics continued, although the most recent session had been canceled due to ongoing challenges. A new meeting was scheduled within three weeks to establish a clearer timeline for restoring dashboard functionality.

Chair Logan-Parker concluded by tabling the dashboard review until sufficient progress was made.

10) FOR INFORMATION ONLY: Review and discussion of the results as of June 2025 from the 'While You Wait' Needs Assessment Campaign to evaluate the diagnosis and patient management aspects crucial for the continuation of care of individuals with rare diseases in the state of Nevada.

The "While You Wait" needs assessment provided 18 months of data that highlighted substantial education gaps. Respondents reported average diagnostic delays of three to five years, often after consulting five to seven providers—and sometimes more than ten—resulting in avoidable costs, duplicative testing, emergency visits, and irreversible harm. A payer-focused education campaign was proposed to promote early intervention and appropriate genetic testing, leveraging Nevada-specific data to demonstrate reduced misdiagnosis, fragmented care, and excess spending, with the aim of influencing health insurers and Medicaid.

Christina Thielst endorsed the proposal, citing personal difficulty obtaining a diagnosis despite strong insurance and system knowledge, and noting that patient navigator programs often excluded rare diseases. She emphasized that delays wasted significant healthcare dollars and that education could improve efficiency.

Madison Bowe shared similar experiences involving multiple providers and emergency rooms, underscoring increased Medicaid costs and the value of the large needs-assessment sample in demonstrating system gaps.

Chair Logan-Parker noted broad interest in refining the proposal and presenting it later, emphasizing that constituent data—augmented by upcoming provider input—would strengthen the case. Council members were reminded that Nevadans living with rare diseases could complete the needs assessment, and physicians would receive a link to the provider survey once available. In response to a question from Madison Bowe, Chair Logan-Parker confirmed that the needs assessment was available on NVRDAC.org and committed to sending a reminder with the link.

11) FOR INFORMATION ONLY: Council member information sharing announcements – Council Members.

Chair Logan-Parker opened the floor for Council Member information announcements.

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

12) PUBLIC COMMENT

Chair Logan-Parker opened the floor for public comment.

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

13) ADJOURNMENT- *Chair Logan-Parker*

Chair Logan-Parker moved to adjourn the meeting at 10:21 am.