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DEPARTMENT OF
HEALTH AND HUMAN SERVICES

NEVADA DIVISION of PUBLIC
and BEHAVIORAL HEALTH

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MS
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Ph.D., M.D.
Chief Medical Officer

NEVADA RARE DISEASE ADVISORY COUNCIL

DRAFT MEETING MINUTES

Date: December 12, 2025
10:03 AM – 11:06 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 10:03 am.

1) INTRODUCTIONS AND ROLL CALL

COUNCIL MEMBERS PRESENT:
Annette Logan-Parker (CHAIR); Gina Glass (Vice-Chair); Ihsan Azzam, MD, PhD; Valerie Porter, DNP, APRN, AG-ACNP-BC, MBA; Paul Niedermeyer; Melissa Bart-Plange; Pamela White; Madison Bowe; Amber Federizo, DNP, APRN, FNPBC; Brigette Cole; Craig Vincze, PhD; Christina Thielst; Dr. William Evan; Naja Bagner;

COUNCIL MEMBERS ABSENT:
Jennifer Millet, DNP, RN (excused); Dr. Verena Samara (excused); Dr. Devraj Chavda; Sumit Gupta, MD; Kim Anderson-Mackey

DIVISION OF PUBLIC & BEHAVIORAL HEALTH (DPBH) STAFF PRESENT:
Kagan Griffin, MPH, RD, *Operation Manager, Office of State Epidemiology (OSE), DPBH*; Ashlyn Torrez, *Health Program Specialist I;* and Kevin Dodson, *Administrative Assistant III, OSE, DPBH,*

OTHERS PRESENT:
Mallory Carvalho – *Cure 4 Kids*; Jennifer Spencer- *Senior Deputy Attorney General (HHS)*; Amber Williams – *Cure 4 Kids*; Cade Grogan.

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

Ashlyn Torrez opened the floor for public comments.

Hearing none, Ashlyn Torrez moved on to the next agenda item.

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

Chair Logan-Parker stated the minutes have been posted on the Department of Human Services (DHS) website and asked the Council for a motion to approve the minutes.

Councilmember Craig Vincze motioned to approve the meeting minutes from prior council meeting dated 10/03/2025. Councilmember Madison Bowe 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 approve the Nevada RDAC Strategic Plan 2026-2027, outlining the framework for a comprehensive collaborative care management plan for rare diseases in Nevada.

Chair Logan-Parker discussed the plan as a shift from awareness-raising to the implementation of deliverable, measurable action items that operationalized the credibility established by the prior plan. It established clear, trackable goals across policy, data, education, and access, replacing broad influence-based aims. The strategy was driven by community input and data from patients, providers, and RDAC members, including a statewide needs assessment and a council member survey. A key evolution was an expanded focus on systemic barriers affecting all rare disease patients, moving beyond the prior emphasis on childhood cancer, bleeding disorders, and newborn screening conditions.

Chair Logan-Parker continued that the surveys and statewide needs assessment demonstrated that prioritizing systemic barriers was more effective than maintaining a focus on three diagnosis categories. The plan aligned with Nevada's updated health system governance by integrating rare disease policy across the Nevada Health Authority and the Department of Human Services. Existing infrastructure, including a functioning statewide registry, an operational CNEX (Clinical Information Network Exchange) platform, and established partnerships, supported expanded statewide rare disease data collection. The plan introduced Nevada's first comprehensive rare disease care framework, creating a coordinated, multi-year roadmap uniting insurers, health systems, providers, and agencies. The plan prioritized health equity across all demographics and was the first to explicitly address rural access, minority populations, low-income families, and aging rare disease patients. It incorporated strategies for Medicaid engagement, culturally responsive outreach, social determinants such as transportation and housing, and the recruitment of diverse council members.

Council member Madison Bowe asked whether the plan included the subcommittee's request for a Rare Disease Day.

Chair Logan-Parker confirmed that the plan did include this request as part of broader outreach efforts, with further discussion planned later in the agenda.

Council member Craig Vincze asked whether the proposed creation of a BDR (Bill Draft Request) was intended to strengthen the Council's ability to secure long-term funding for the registry and whether the two efforts were related. It was explained that assigning a BDR to the Nevada Rare Disease Advisory Council would require legislation and was a long-term goal that could provide greater independence and sustainability, and this priority was included in the annual report and legislative recommendations.

Chair Logan-Parker confirmed that the proposal did not conclude immediately and would continue beyond the current timeline.

Councilmember Christine Thielst motioned to approve the Nevada RDAC Strategic Plan 2026-2027. Councilmember Gina Glass seconded the motion to approve. There were no objections. A quorum voted to approve the Nevada RDAC Strategic Plan 2026-2027.

5) FOR POSSIBLE ACTION: Discussion and possible action to 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.

The annual report was developed over several weeks and was shared with council members in advance to allow for edits, feedback, and substantive input. The final report documented a year of progress, including registry activation, statewide assessments, data infrastructure milestones, and policy achievements such as involvement in SB189 and SB348. It recorded more than 600 cases in the statewide registry, the launch of a provider needs assessment, and expanded community partnerships, including bilingual volunteer outreach. The report met statutory requirements, aligned 2026 recommendations with statewide needs, and was presented for discussion and approval.

Council member Pam White requested clarification on the scope and function of the rare disease registry.

Chair Logan-Parker explained that the registry collected data only on conditions mandated by Nevada Revised Statute, childhood cancer, sickle cell disease, and lupus, with Cure for the Kids Foundation serving as the primary pilot data contributor. The registry was described as an active, evolving initiative focused on process refinement, expanded provider participation, and integration of additional data sources through ongoing discussions with genetic specialists and major health systems. The three-year goal was to broaden both the range of tracked conditions and the number of contributing providers.

Councilmember Craig Vincze motioned to approve the 2025 Annual Report. Councilmember Valerie Porter seconded the motion to approve. There were no objections. A quorum voted to approve the 2025 Annual Report.

6) FOR POSSIBLE ACTION: Discussion and possible action to recommend to the Director of the Nevada Department of Human Services (DHS) to appoint Mallory Carvalho as a member of the Council, pursuant to NRS 439.5075(2), for a term of 3 years.

Chair Logan-Parker introduced Mallory Carvalho as a prospective Council member, with her resume and letter of intent shared in advance. She was described as completing a master's degree in social work and as a long-standing patient advocate whose experience aligned with the Council's focus areas. Her background met membership qualifications and positioned her as a strong asset to the Council. Member comments were invited prior to her introduction.

Council member Amber Federizo expressed support based on meeting Mallory Carvalho at a charity walk event, citing strong community engagement and a welcoming presence. She was described as someone who brought people together and demonstrated early leadership, with continued participation viewed as a benefit to the Council.

Mallory Carvalho identified herself as a master's-level social work student at UNLV with a concentration in management, community practice, and policy. She shared her experience as an adolescent and young adult cancer survivor with a rare form of ovarian cancer, which informed her interest in patient advocacy and policy-focused Council participation in Nevada.

Councilmember Craig Vincze motioned to approve the recommendation of Mallory Carvalho as a new Nevada RDAC member to the director of the Nevada Department of Human Services. Councilmember Ihsan Azzam seconded the motion to approve. There were no objections. A quorum voted to approve the recommendations of Mallory Carvalho as a new Nevada RDAC member to the director of the Nevada Department of Human Services.

7) FOR POSSIBLE ACTION: Discussion and possible action to approve the 2026 Nevada RDAC Blog series for social media that will provide education and outreach to the rare disease community.

An outline was developed for a proposed blog series intended to increase public understanding of the RDAC, its role, and its impact. The series emphasized Nevada's leadership in statewide rare disease policy, highlighted the best national practices in cross-state collaboration, and aimed to strengthen engagement among families, providers, and policymakers while supporting development of the next rare disease state plan. The outline included monthly Nevada-focused topics, council member profiles, and acknowledgment of Christina's contribution in providing the platform for the first published member profile.

Councilmember Gina Glass motioned to approve the 2026 Nevada RDAC Blog series. Councilmember Bridget Cole seconded the motion to approve. There were no objections. A quorum voted to approve the 2026 Nevada RDAC Blog series.

8) FOR INFORMATION ONLY: Update on the data collection efforts within the state of Nevada – Ashlyn Torrez, Rare Disease Program Coordinator, Office of State Epidemiology (OSE), DPBH

Ashlyn Torrez reported that a cyberattack in November had caused multiple system shutdowns but that the SFTP (Secured File Transfer Protocol) data upload system used by Cure 4 Kids Foundation and other providers had since been restored and was fully operational. Secure uploads into REDCap within the Division of Public and Behavioral Health were functioning, and ongoing data cleanup efforts were underway in coordination with Annette's team. Plans were shared to launch a rare disease dashboard, with sickle cell and lupus data already available on the Nevada Office of Epidemiology Rare Disease webpage and additional conditions expected in 2026, with a presentation anticipated as early as February. Staffing updates included the appointment of Laura Rich as director following the retirement of Richard Whitley and the introduction of Andrea Rivers as division administrator.

Council member Gina Glass asked about access to registry data.

Ashlyn Torrez clarified that requests for direct or detailed data should be directed to Ashlyn Torrez, while general data viewing was publicly available through the Office of State Epidemiology website and dashboard.

Chair Annette Logan-Parker asked whether technical barriers had been resolved to support broader provider outreach.

Ashlyn Torrez confirmed that most issues had been addressed, and that expanded outreach could begin in 2026. Reporting was described as statutorily supported but passive, allowing voluntary participation, with planned outreach through listservs and increased collaboration.

Council member Madison Bowe asked how individuals could be added to the registry. Clarification was provided that the registry was provider-reported, with data submitted at diagnosis, while patients and families could contribute information through the online needs assessment. Multiple data collection efforts were noted as occurring concurrently.

Council member Ihsan Azzam asked whether sickle cell reporting was mandatory.

Ashlyn Torrez clarified that current statutes supported passive reporting, allowing voluntary submission by providers and laboratories. Approximately 1,500 sickle cell cases were reported in the registry, with lupus data collection ongoing. Providers could submit cases through DPBH REDCap, and laboratory reporting through EpiTrax had been enabled to allow automatic electronic submission. Concerns were noted regarding low participation due to voluntary reporting, with future discussions anticipated to explore incentives.

Council member Gina Glass asked whether AB254 required mandatory reporting. Ashlyn Torrez explained that the statute had initially been interpreted as mandatory but was later determined to establish passive reporting. Background was provided on AB254 for the sickle cell registry.

Chair Annette Logan-Parker emphasized continued efforts to streamline reporting processes and encourage participation through outreach aligned with the next strategic plan. Reporting statutes and requirements were confirmed as posted on the Office of State Epidemiology website.

9) FOR INFORMATION ONLY: Update and balance of the DMV Childhood Cancer License Plates Reserves – Ashlyn Torrez, Rare Disease Program Coordinator, OSE, DPBH

Ashlyn Torrez reported that, as of November 17, the DMV Child Cancer license plate reserve balance was approximately $75,000. A formal spending plan, or itemized proposal, was recommended for development and submission for review and approval, noting that the governing statutes were vague regarding allowable uses of the funds.

Chair Annette Logan-Parker agreed and stated that the resources could support upcoming education and rare disease awareness efforts, including printing educational materials. The balance was noted as having accumulated due to limited prior resource needs, though future outreach and awareness activities under the next strategic plan were expected to require use of the funds.

Madison Bowe suggested including both educational materials and activity-based components when planning for Rare Disease Day and setting budget allocations.

Chair Logan-Parker directed that the item be placed on the next full Council meeting agenda, with a draft prepared for discussion and potential action, and Ashlyn Torrez confirmed that the request would be documented.

10) FOR INFORMATION ONLY: Discussion of the Rare Disease Advisory Council (RDAC) Community Education Event – Chair Annette Logan-Parker

During the October meeting, the Council held an in-depth discussion on planning a rare disease community education event for early 2027, aligned with World Rare Disease Day. Broad support was expressed, and multiple perspectives were shared. A subcommittee was approved to begin planning, though its initial meeting was canceled due to agenda and approval timing, resulting in limited progress. Feedback from the discussion supported a statewide, multi-location, and multi-audience approach. A proposed framework included a legislative rare disease education day in Carson City during the 2027 legislative session, focused on policy, data, early diagnosis, Medicaid, and newborn screening, as well as a Nevada rare disease community day. Las Vegas was identified as a feasible location, with a tentative hold placed on February 25, 2027, at the Roseman University Auditorium, a no-cost venue pending student scheduling. The potential value of a Northern Nevada community day was also noted, contingent on leadership and involvement from Northern Nevada Council members. No decisions were required at that time, and the topic was scheduled for discussion at the first full Council meeting in 2026.

Council member Madison Bowe suggested adding a virtual component to improve accessibility for patients, caregivers, and providers unable to attend in person.

Chair Annette Logan-Parker responded positively, noting that the Roseman University Auditorium supported hybrid events and that virtual options for a Northern Nevada event could be explored.

Council member Gina Glass asked about recent communication with the National Organization for Rare Disorders (NORD) regarding potential support.

Chair Annette Logan-Parker confirmed that planning was focused on February 2027 and that coordination with NORD could be reestablished as part of the planning process, noting evolving contact due to staffing changes. Future discussion on coordination with NORD was identified for an upcoming meeting.

Council member Christina Thielst shared ideas related to the legislative event in Carson City and offered support for coordination in Northern Nevada. It was suggested that legislative and community-focused activities could potentially be held on the same day to increase participation given the smaller, more dispersed population.

Chair Annette Logan-Parker responded favorably and proposed distributing a survey to Council members to gather input before the next meeting. Ashlyn Torrez confirmed assistance with survey development and distribution.

Council member Naja Bagner asked about the feasibility of creating a sickle cell license plate and potential barriers.

Ashlyn Torrez explained that a new license plate would require statutory approval and fiscal review and could not be pursued until 2027.

Chair Annette Logan-Parker clarified that the existing Childhood Cancer license plate was legislatively authorized to support Nevada Rare Disease Advisory Council activities and that funds were not restricted solely to childhood cancer, emphasizing that sickle cell initiatives were eligible for support under the Council's scope.

11) FOR INFORMATION ONLY: Update on 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. – Chair Annette Logan-Parker

The campaign was described as slow but steady, with surveys continuing to be submitted on an ongoing basis. Plans were noted to reengage the public in early 2026. The soft launch of the provider needs assessment was reported as successful and well received by providers in Southern Nevada. Both the public and provider assessments were expected to continue being promoted. Participation was encouraged by providers and individuals living with or caring for someone with a rare disease through completion of the appropriate needs assessments. Several providers had already participated, and the soft launch provided an opportunity to address issues before a broader focus in 2026 on collecting provider feedback across a wide range of medical professionals serving individuals with rare diseases.

12) FOR INFORMATION ONLY: Discussion of the 2027 Legislative Session survey that will go out to the Council for feedback on RDACs involvement. – Chair Annette Logan-Parker

A recommendation was made to distribute a legislative session survey to Council members to gather feedback on preparation for the 2027 legislative session. The intent was to ensure that the policy agenda reflected the perspectives of individuals and organizations actively engaged in rare disease work. A brief legislative priority input survey was proposed to collect feedback from families, caregivers, clinicians, nonprofit organizations, advocacy groups, and other stakeholders across Nevada, including both rural and urban areas. The objective was to identify shared concerns, opportunities for collaboration, and unified advocacy priorities to strengthen engagement with legislators. The survey was described as informational, with results to be presented for discussion and potential action later.

Ashlyn Torrez confirmed the ability to assist with survey development and distribution.

Madison Bowe asked whether needs assessments were available online for both patients and providers, and it was confirmed that the patient and family needs assessment had been posted for approximately 18 months and that a separate provider-specific assessment was active and collecting data.

13) PUBLIC COMMENT

Ashlyn Torrez opened the floor for public comment.

Hearing none, Ashlyn Torrez moved on to the next agenda item.

14) ADJOURNMENT- *Chair Logan-Parker*

Chair Logan-Parker moved to adjourn the meeting at 11:06 am.