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NEVADA RARE DISEASE ADVISORY COUNCIL

DRAFT MEETING MINUTES

Date: February 6, 2026
9:34 AM – 10:37 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 9:34 am.

1) INTRODUCTIONS AND ROLL CALL

COUNCIL MEMBERS PRESENT:
Annette Logan-Parker (CHAIR); Paul Niedermeyer; Pamela White; Brigette Cole; Craig Vincze, PhD; Christina Thielst; Dr. William Evan; Naja Bagner; Jennifer Millet, DNP, RN; Sumit Gupta, MD; Kim Anderson-Mackey; Dr. Verena Samara; Valerie Porter, DNP, APRN, AG-ACNP-BC, MBA

COUNCIL MEMBERS ABSENT:
Ihsan Azzam, MD, PhD (excused); Melissa Bart-Plange (excused); Amber Federizo, DNP, APRN, FNPBC; (excused); Gina Glass (Vice-Chair); Madison Bowe; Dr. Devraj Chavda PhD

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

OTHERS PRESENT:
Amber Williams – *Cure 4 Kids*

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 Annette Logan-Parker opened the floor for public comments.

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

3) FOR POSSIBLE ACTION: Discussion and possible action to approve meeting minutes from December 12, 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 Dr. Sumit Gupta motioned to approve the meeting minutes from prior council meeting dated 12/12/2025. Councilmember Jennifer Millet 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 recommend to the Director of the Nevada Department of Human Services (DHS) to renew Kim Anderson-Mackey, as a member of the Council, pursuant to NRS 439.5075(1)(a), for a term of three years.

Councilmember Dr. Craig Vincze motioned to approve the recommendation to renew of Kim Anderson-Mackey, as a member of the Council for a three-year term to the Director of DHS. Councilmember Dr. Sumit Gupta seconded the motion to approve. There were no objections. A quorum voted to approve the recommendation to renew of Kim Anderson-Mackey, as a member of the Council for a three-year term to the Director of DHS.

5) FOR POSSIBLE ACTION: Discussion and possible action to adopt Nevada RDAC 2027 Legislative Session Protection Plan and grant authority for Chair Logan-Parker to represent RDAC's interests and activities to protect the Council's potential consolidation during the 2027 legislative session.

Chair Annette Logan-Parker presented the proposed protection plan for Council review and noted that in 2025 the Nevada RDAC faced potential dissolution, with responsibilities possibly transferred to the Wellness and Prevention Advisory Council. Members were reminded of prior advocacy efforts, including letter writing, in response to that risk. The Bureau of Boards and Commissions indicated advisory bodies would be reviewed again during the 2027 legislative session.

Chair Annette Logan-Parker described the protection plan as a proactive framework authorizing the Chair to represent agreed-upon positions and demonstrate the Council's value to lawmakers, including considerations outside Open Meeting Law discussions.

Councilmember Jennifer Millet asked for more clarity, Chair Annette Logan-Parker stated internal strategic framework and an extension of prior authorization granted during the previous legislative session.

Brigette Cole also inquired about similar challenges in other states; Iowa was cited as having faced comparable risks, with national partners monitoring the issue.

Chair Annette Logan-Parker stated yes Iowa faced the same issues. The concerns were expressed that consolidation could diminish specialized expertise, weaken infrastructure such as the needs assessment, and disrupt the national Rare Disease Advisory Council network. With 33 councils nationwide, Nevada was identified as an early adopter. Dissolution at this stage could result in loss of momentum as significant progress had been made and the needs assessment neared completion.

The plan outlined layered activities to proactively demonstrate the value of maintaining the RDAC as a standalone council. Members were advised the item could be tabled for further review, though the importance of proactive action was emphasized. Jennifer Millet and Brigette Cole expressed support.

Kim Andeson-Mackey (Unverified) put into the chat at 9:46 AM: “Thrilled that you put this together and there is no one better to represent us.”

Christina (Unverified) put into the chat at 9:47 AM: I think being proactive is vital.

Councilmember Dr. Bill Evans motioned to approve to adopt Nevada RDAC 2027 Legislative Session Protection Plan and grant authority for Chair Logan-Parker to represent RDAC’s interests and activities to protect the Council’s potential consolidation during the 2027 legislative session. Councilmember Bridget Cole seconded the motion to approve. There were no objections. A quorum voted to approve to adopt Nevada RDAC 2027 Legislative Session Protection Plan and grant authority for Chair Logan-Parker to represent RDAC’s interests and activities to protect the Council’s potential consolidation during the 2027 Legislative Session.

6) FOR POSSIBLE ACTION: Discussion and possible action to recommend the inclusion of selected congenital heart disease (CHD) conditions be added to the data the Council collects and recommend that this subset of CHD conditions be included in the State’s Rare Disease Dashboard.

Councilmember Dr. Bill Evans expressed appreciation for the opportunity to participate on the Council and highlighted rare forms of congenital heart disease remained poorly understood by the public and policymakers. Common pediatric heart defects, such as atrial septal defects and ventricular septal defects, occurred at rates of 40 to 50 per 10,000 live births and generally did not meet the definition of rare disease. These conditions were often self-limiting or effectively treated, with favorable long-term outcomes.

In contrast, rare and complex congenital heart conditions required lifelong management. Examples included hypoplastic left heart syndrome, transposition of the great arteries, and truncus arteriosus. These conditions occurred at lower rates, about 0.1-0.5 to 1 per 10,000 live births, and required staged surgical repair and ongoing specialized care.

An even rarer condition, heterotaxy, was discussed. Heterotaxy involved abnormal arrangement of internal organs, including irregular lung lobation, displaced abdominal organs, and associated complex congenital heart defects. The condition affected multiple organ systems and carried a high risk of mortality in the newborn period without prompt intervention. Lifelong, multi-specialty care was typically required. Due to its rarity and complexity, support networks have formed several states to assist affected families.

The importance of prenatal diagnosis was emphasized. Early detection allowed delivery at specialized facilities prepared to provide immediate cardiac care. Over the past two decades, prenatal detection improved significantly, with Nevada achieving the highest detection rate in the nation. This outcome was attributed to a collaborative prenatal program involving fetal cardiologists, perinatologists, and maternal-fetal medicine specialists. Early diagnosis supported parental counseling, coordinated delivery planning, and timely intervention, leading to improved outcomes.

Councilmember Dr. Bill Evans was subsequently asked to develop a proposal following the expansion of the Nevada Rare Disease Dashboard through the Office of State Epidemiology. The dashboard had previously expanded beyond childhood cancer to include additional diagnoses such as lupus and sickle cell disease.

Chair Annette Logan-Parker extended an invitation for participation by incorporating conditions meeting the recognized rare disease definition into the dashboard. Existing data collection processes aligned with current pediatric reporting structures, allowing for integration into RDAC reporting and legislative awareness efforts.

Craig Vincze (Unverified) put into the chat at 9:59 AM: “I have to leave the meeting at 10:00am”

Annette Logan-Parker (External) put into the chat at 9:59 AM: “Thank you Craig”

Craig Vincze (Unverified) put into the chat at 9:59 AM: “Thank you!”

Valerie Porter (Unverified) put into the chat at 10:06 AM: “Presentation was great wish it would have been longer! Thank you!”

Councilmember Christina Thielst motioned to approve the recommend the inclusion of selected congenital heart disease (CHD) conditions be added to the data the Council collects and recommend that this subset of CHD conditions be included in the State’s Rare Disease Dashboard. Councilmember Dr. Summit Gupta seconded the motion to approve. There were no objections. A quorum voted to approve the recommend the inclusion of selected congenital heart disease (CHD) conditions be added to the data

the Council collects and recommend that this subset of CHD conditions be included in the State's Rare Disease Dashboard.

7) FOR POSSIBLE ACTION: Discussion and possible action to approve the 2026 Nevada RDAC blog series editorial calendar.

Chair Annette Logan-Parker recalled a prior meeting, the concept of launching a blog was discussed to highlight RDAC efforts and share ongoing initiatives with the public. The item presented served as a formal request to approve the blog series and accompanying 2026 editorial calendar previously distributed for review.

Chair Annette Logan-Parker described the blog as a community education and outreach tool aligned with the current strategic plan. Its purpose was to increase awareness of RDAC activities, foster collaboration, and encourage broader stakeholder participation across Nevada. Members were invited to provide questions or comments before moving to approve the 2026 blog calendar. Chair Annette Logan-Parker noted that the editorial calendar established a cohesive year-long theme and outlined planned activities.

Councilmember Pamela White inquired about publication frequency, noting difficulty reviewing the document by phone.

Chair Annette Logan-Parker clarified that the blog would follow a monthly theme, including Council member profiles, highlights of professional work, and perspectives on supporting RDAC, along with other relevant topics. Members would be contacted in advance to allow time for drafting and coordination.

The plan was structured to maintain content development ahead of schedule, enabling preparation months in advance to ensure consistency and alignment with identified themes.

Councilmember Valerie Porter motioned to approve the 2026 Nevada RDAC Blog series editorial calendar. Councilmember Dr. Summit Gupta seconded the motion to approve. There were no objections. A quorum voted to approve the 2026 Nevada RDAC Blog series editorial calendar.

8) FOR POSSIBLE ACTION: Discussion and possible action to approve the rollout of the Council member survey on the RDAC Community Education Event planning.

Chair Annette Logan-Parker stated that a survey had been developed to gather input from Council members regarding expectations for the 2027 education event, including preferred planning priorities and willingness to participate in various roles across northern and southern regions. The purpose of the survey was to ensure alignment, clarify member expectations, and support development of an impactful and well-coordinated event.

The survey was to be converted into a SurveyMonkey format and distributed to Council members for completion. Responses would then be reviewed by the subcommittee to determine the most effective path forward. Although the event was planned for February 2027, early preparation was emphasized due to limited meeting frequency and compliance requirements under Open Meeting Law.

Councilmember Kim Anderson-Mackey motioned to approve to send out the survey instrument to the Council members for data collection about the event planning for 2027. Councilmember Christina Thielst seconded the motion to approve. There were no objections. A quorum voted to approve to send out the survey instrument to the Council members for data collection about the event planning for 2027.

9) FOR POSSIBLE ACTION: Discussion and possible action to approve the next activities for the RDAC Community Education Event that will be presented to the Rare Disease Advisory Council for consideration.

Chair Annette Logan-Parker provided an update regarding outreach to NORD (National Organization for Rare Disorders) for support of the 2027 events, including both the community education event and the legislative awareness event in Carson City. NORD agreed to participate and expressed willingness to send representatives and provide materials or promotional items as needed.

Early coordination had successfully placed the events on NORD’s radar. No action was required, and the meeting proceeded to the next agenda item.

10) FOR POSSIBLE ACTION: Discussion and possible action to approve the rollout of the 2027 Legislative session survey to get feedback on RDAC’s level of involvement.

Chair Annette Logan-Parker discussed a second survey instrument to gather comprehensive stakeholder input before presenting future plans or recommendations to the Council. Unlike the previous survey directed at Council members, this instrument was designed for statewide distribution to stakeholders to identify priority areas for focus. The survey included 13 sections with 26 questions addressing a broad range of topics, including rare disease, childhood cancer, AYA (Adolescent and Young Adult), and policy issues.

Chair Annette Logan-Parker stated that the survey targeted multiple stakeholder groups, patients, families, healthcare providers, advocates, and researchers, and encompassed all regions of Nevada, including rural and frontier communities. The intent was to better understand regional differences in policy priorities, system gaps, and community needs in preparation for the 2027 legislative session.

Chair Annette Logan-Parker went over key themes included priority issues, system gaps, budget considerations, and workforce development, aligning with anticipated legislative priorities. The survey complemented the RDAC protection plan by supporting proactive planning and statewide representation.

Kim Andeson-Mackey (Unverified) put into the chat at 10:18 AM: “How will this be distributed?”

Chair Annette Logan-Parker replied that the survey was planned for distribution primarily via email, with links shared through social media and incorporated into the blog calendar. Outreach could also include direct email sharing by members.

Due to the size and scope of the instrument, the survey would likely be built within the REDCap system, similar to the existing needs assessment, to allow for collection of large amounts of data in a controlled environment rather than using a SurveyMonkey-style platform.

A dedicated landing page would be created on the Nevada RDAC website, featuring QR codes and direct links to guide stakeholders to complete the survey. Responses would be collected within the same data framework as the needs assessment, allowing for organized data collection, analysis, sharing of results, and identification of key insights.

Councilmember Valerie Porter motioned to approve the Nevada Statewide Stakeholder Survey instrument for deployment on behalf of the RDAC. Councilmember Jennifer Millet seconded the motion to approve. There were no objections. A quorum voted to approve the Nevada Statewide Stakeholder Survey instrument for deployment on behalf of the RDAC.

11) FOR INFORMATION ONLY: Update on the one-time expanded data pull requested by Ashlyn Torrez from the Office of Analytics for the additional CHD conditions discussed, while the Council awaits the State's Rare Disease Dashboard. – Chair Annette Logan-Parker; and Ashlyn Torrez, Rare Disease Program Coordinator, Office of State Epidemiology (OSE), Division of Public and Behavioral Health

Ashlyn Torrez provided an update on the Rare Disease Dashboard and a recent data request from the Chair. A one-time data pull had been requested from the Office of Analytics to review case counts. Complete 2025 data was not yet available; however, first and second quarter data had been finalized. Remaining data was anticipated in June or July, with updated figures expected to be distributed by email the following week. An additional update confirmed completion of the Rare Disease Dashboard. Although formal submission for inclusion of congenital heart disease (CHD) conditions was pending, the dashboard was presented to the Council.

Ashlyn Torrez provided an overview with plans to expand the introductory section to include additional details on sickle cell disease and lupus, as well as clarification regarding included rare conditions, particularly those with very low case counts.

Ashlyn Torrez went over the dashboard displayed 2024 data, including total case counts for lupus and sickle cell disease, annual hospital visits, visit rates per 100,000 population, and geographic distribution maps. Regional filters allowed data to be viewed by specific areas. Other rare diseases were grouped into categories, including cystic fibrosis and pulmonary conditions, blood disorders, immune deficiencies, metabolic and storage disorders, neurological and neuromuscular conditions, connective tissue disorders, genetic disorders, and endocrine disorders. Trend data spanning 2020 through 2024 was available, with filters for condition, year, and region. Demographic breakdowns included age, gender, race, and ethnicity.

Chair Annette Logan-Parker requested clarification regarding data sources, particularly to address discrepancies between state-level data and figures reported by individual providers or specialty programs. Ashlyn Torrez replied the dashboard primarily relied on hospital discharge data collected by the Office of Analytics. Additional sources included newborn screening data obtained through a data use agreement with the University of Nevada, Reno, and vital records data to capture mortality.

For conditions such as sickle cell disease and lupus, individuals previously identified through hospital discharge data were included in mortality counts if a death record existed, regardless of whether the condition was listed as the primary cause of death. This methodology ensured diagnosed individuals were captured even if death was not directly attributed to a rare disease.

Ashlyn Torrez continued by bringing up the three primary data sources were currently used: hospital discharge data, newborn screening data, and vital records. Future plans included incorporating data submitted through the Division of Public and Behavioral Health REDCap system, including information entered by Cure for the Kids Foundation.

Ashlyn Torrez described the dashboard as preliminary, pending approval from the Director's Office. Lupus and sickle cell data were already available on the Nevada Office of State Epidemiology Rare Disease webpage; the updated version would expand to additional rare diseases, with a third version planned to incorporate CHD conditions. Further expansion was anticipated in late 2026, subject to organizational transitions related to the transfer of the Office of Analytics to the Nevada Health Authority. Long-term goals included integrating provider-level data to allow for broader trend analysis.

Chair Annette Logan-Parker had questions regarding updates and access, Ashlyn Torrez explained that the dashboard would be hosted on the Nevada Office of State Epidemiology Rare Diseases webpage, with a direct link distributed by email. Updates were expected quarterly. While 2024 data had been finalized, 2025 complete data was projected for the third quarter, around August, due to reliance on historical data pulls.

Chair Annette Logan-Parker wanted to address whether formal authorization was required to link the dashboard from the Nevada RDAC website. Ashlyn Torrez indicated that a direct link could likely be added, with follow-up coordination to confirm appropriate procedures and obtain the official link. Public access to the dashboard was viewed as valuable for physicians, grant writers, and other stakeholders seeking statewide rare disease data.

Jennifer Millet (Unverified) put into the chat at 10:24 AM: "beautiful job!!"

Valerie Porter (Unverified) put into the chat at 10:25 AM: "Super data!"

Christina (Unverified) put into the chat at 10:25 AM: "Love the interactive nature of this. Well done."

Valerie Porter (Unverified) put into the chat at 10:25 AM: “Awesome, Love this!”

Pamela White (Unverified) put into the chat at 10:29 AM: “This is Great! Thank you!”

Kim Andeson-Mackey (Unverified) put into the chat at 10:31 AM: “Ashlyn - THANK YOU for all you do!”

Pamela White (Unverified) put into the chat at 10:35 AM “Ashlyn I would love to discuss this more”

10) PUBLIC COMMENT

Chair Annette Logan-Parker opened the floor for public comment.

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

12) ADJOURNMENT- *Chair Annette Logan-Parker*

Chair Annette Logan-Parker moved to adjourn the meeting at 10:37 am.