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DEPARTMENT OF HEALTH AND HUMAN SERVICES

NEVADA DIVISION of PUBLIC and BEHAVIORAL HEALTH

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Rare Disease Advisory Council (RDAC) – Subcommittee on the Strategic Plan Meeting Minutes

July 11, 2025

9:30 AM – 10:09AM

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 9:30 am.

1) INTRODUCTIONS AND ROLL CALL

SUBCOMMITTEE MEMBERS PRESENT:
Annette Logan-Parker (CHAIR); Gina Glass (Vice-Chair) Amber Federizo, DNP, APRN, FNPBC and Jennifer Millet, DNP, RN (Quorum=4)

SUBCOMMITTEE MEMBERS ABSENT:
None

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

OTHERS PRESENT:
Melissa Bart-Plange; Sara Stolfus, *Artia Solutions;* Cade Grogen, Kim Anderson-Mackey; Ginger Papesh, GPAP; Stefanie Abraham; Dr. Craig Vincze; and Judy Akin

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 agenda item number three.

3) FOR POSSIBLE ACTION: Discussion and possible action to approve meeting minutes from March 7, 2025. – *Subcommittee members*

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

Vice Chair Gina Glass motioned to approve the meeting minutes from prior council meeting dated March 07, 2025. Subcommittee member Jennifer Millet seconded the motion to approve. There were no objections. A quorum voted to approve the prior meeting minutes.

4) FOR INFORMATION ONLY: 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 Annette Logan-Parker

   Chair Logan-Parker reported that the internal survey had received responses from nine Council members, providing meaningful insights that informed the development of the 2026–2027 strategic plan. Although participation had been modest, the feedback contributed significantly to shaping the future direction of rare disease efforts in Nevada. The survey results highlighted three key priority themes: continued awareness and education efforts, advancement of research and data collection, and improved access to diagnostics and treatment. The findings served to evaluate the effectiveness of the previous strategic plan and guide the development of the upcoming one. Council members supported expanding efforts in areas such as data utilization, healthcare provider education, and patient navigation services.

   Notably, 90% of respondents favored broadening the Council's focus beyond its original categories to include additional conditions and underserved populations. The majority supported a shift from a diagnosis-specific model to a more systematic approach centered on equity, access, and care coordination across the rare disease landscape, prioritizing the lived experiences of individuals with rare diseases. Over half of the respondents viewed the current strategic plan as effective, while the remainder considered it somewhat effective; no one rated it as ineffective. Suggestions for improving Council engagement included forming formal work groups, establishing clear expectations, enhancing accountability, and providing more education and networking opportunities.

   Several members stressed the need for additional staff and infrastructure to fully support Council goals, and two-thirds expressed willingness to participate in advocacy efforts, such as legislative meetings and testimony. Respondents also expressed interest in exploring the use of funds generated by the specialty license plate, though accessing those funds could require navigating legislative and procedural challenges. The survey results supported prioritizing provider education, public awareness, direct patient services, and legislative advocacy. Further review was recommended to determine which priorities aligned with the appropriate use of available resources, including specialty plate funds. The findings indicated that the Council was prepared to expand its strategic efforts and pursue broader advocacy and partnerships, particularly with the Department of Health and Medicaid. The full survey results had been posted on the Department of Health and Human Services website and were to be shared with Council members ahead of the next meeting.

5) 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. – Chair Annette Logan-Parker)

   Chair Logan-Parker noted that the updated survey format had resulted in fewer responses compared to the original needs assessment, though the data collected was still regarded as valuable. A deeper review of the data remained in progress to fully understand its implications. A recommendation had been made to develop a provider-specific needs assessment to capture the perspectives of healthcare professionals caring for individuals with rare diseases. This new assessment was intended to complement the existing survey focused on the lived experiences of patients and families, with a draft expected to be presented at the next full Council meeting.

   Subcommittee member Amber Federizo expressed agreement that adding a provider-specific needs assessment represented a valuable opportunity to gather firsthand insights that were often difficult to obtain due to time limitations. Documenting these perspectives directly from healthcare providers was expected to enhance the legitimacy and impact of the identified needs.

   Chair Logan-Parker also mentioned concerns that the survey might be perceived as just another task unless it clearly demonstrated its value in improving provider education and outreach. The provider needs assessment was viewed as a meaningful tool, with the expectation that specialty providers caring for rare disease patients would be more inclined to participate.

   Kim Anderson Mackey stated that providers working with medically complex children—many of whom met the criteria for rare diseases—often spent considerable time searching for basic services such as Physical Therapy (PT), Occupational Therapy (OT), and speech therapy in their local areas. Additional challenges included navigating funding for car seats and identifying manufacturers that collaborated with Medicaid, which added to the overall burden. Capturing provider input on these persistent issues was seen as a critical step toward building a centralized resource to streamline care coordination and improve patient outcomes.

   Dr. Craig Vincze provided strong support for gathering direct input from providers to better understand their specific needs, rather than relying on assumptions. A parallel example was drawn from previous success in the research field, where asking laboratories like Dana Farber for itemized needs had uncovered unexpected barriers to progress. This direct method had proven effective not only in identifying gaps but also in enhancing fundraising efforts by presenting firsthand accounts of necessary resources. The endorsement underscored that collecting provider feedback in the rare disease field could similarly drive impactful improvements and align with broader strategic goals, including expanded research engagement.

Kim Anderson-Mackey proposed utilizing organizations with staff who were already active across Nevada to assist in disseminating information to providers. These community partners, who maintained regular contact with healthcare professionals, could be informed about the Council's goals and equipped with simple materials such as informational rack cards. A brief training session and occasional educational meetings could prepare these liaisons to effectively contribute to outreach efforts. This strategy was regarded as both cost-effective and impactful for increasing awareness and engagement within the provider community.

Chair Logan-Parker proposed hosting town hall-style events in both Northern and Southern Nevada to unveil the upcoming strategic plan. These events were intended to engage a broad audience, introduce the plan, and provide attendees with tools and resources to support the initiatives of the Rare Disease Advisory Council.

Kim Anderson-Mackey acknowledged that greater effort was needed to communicate the Council's identity, past accomplishments, and current initiatives. Despite a strong interest and willingness to help from the broader community, many individuals remained unaware of the Council's existence.

8) FOR INFORMATION ONLY: Update on the childhood cancer, systemic lupus erythematosus (SLE), and sickle cell disease (SCD) data collection efforts within Nevada. – Chair Annette Logan-Parker; and Ashlyn Torrez, Lupus and Other Rare Diseases Project Coordinator, Office of State Epidemiology (OSE), Division of Public and Behavioral Health (DPBH)

Chair Logan-Parker provided an update that, as of mid-June, 177 childhood cancer cases had been added, with 160 fully abstracted and submitted to the Nevada Central Cancer Registry. These efforts reduced the burden on the central registry and enhanced Nevada's capacity to report cases at the national level. Ten new cases for 2025 had already been entered, showing progress ahead of the typical data reporting schedule. Work remained ongoing to expand the rare disease dashboard and incorporate a comprehensive list of rare diseases into the state's data collection system, with database customization still in progress. A follow-up was planned to coordinate efforts now that the legislative session had concluded, ensuring alignment with state capabilities and timelines.

Ashlyn Torrez reported that a meeting had taken place with the individual developing the dashboard, who was in the process of adding the requested conditions identified during the legislative session. Due to low case numbers for certain International Classification of Diseases (ICD-10) codes, efforts were being made to group conditions, with a demonstration planned for an upcoming full Council meeting or by year-end.

Chair Logan-Parker stated that support had been offered to assist with grouping ultra-rare and rare conditions into broader categories to enhance data representation. It was acknowledged that some diagnoses might not appear in state data due to low incidence or lack of reporting from commercial payers.

As of mid-June, nine fully abstracted lupus cases from Cure 4 The Kids had been submitted, along with a total of 352 sickle cell cases. Additional cases were likely added since that time, and feedback had been requested on the progress of initial data collection using Research Electronic Data Capture (REDCap).

Ashlyn Torrez responded that data cleanup was required before uploading, including correcting checkbox formatting by converting true/false values to 0/1. The updated files were expected to be uploaded by the end of the day, with the process progressing well based on spreadsheet reviews. The form for sickle cell data collection had been finalized and was ready for use, signaling an appropriate time to begin outreach to providers treating sickle cell patients. A question had been raised regarding whether any providers outside of Cure 4 The Kids had submitted forms for sickle cell and lupus cases. It was confirmed that no providers had submitted paper forms yet, though the system was being checked daily for any new uploads.

[Council member sharing announcement removed at Deputy Attorney General (DAG) Request]

The Deputy Attorney General advised that any announcements Council members intended to share with the public needed to be listed as an agenda item to ensure compliance with public access requirements. Future agendas included a designated section for Council member announcements, modeled after prior agendas that listed speakers and topics. An email had been scheduled to be sent approximately one month before each meeting to collect announcement items from members. This process applied to both full Council and subcommittee meetings.

Agenda approval was required to comply with Nevada's Open Meeting Law and involved several layers of review. After gathering items from Council members and the chair, the agenda underwent review by a supervisor, followed by the chair, and then the Deputy Attorney General. The approval timeline varied, ranging from as few as three days to as many as three weeks.

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 adjourn the meeting at 10:09 AM.