Joe Lombardo
Governor

Richard Whitley, MS
Director

DEPARTMENT OF
HEALTH AND HUMAN SERVICES

NEVADA DIVISION of PUBLIC
and BEHAVIORAL HEALTH

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Administrator

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Chief Medical Officer

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

March 7, 2025

9:33 AM – 10:11AM

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 9:33 am.

1) INTRODUCTIONS AND ROLL CALL

SUBCOMMITTEE MEMBERS PRESENT:
Annette Logan-Parker (CHAIR); Amber Federizo, DNP, APRN, FNPBC and Jennifer Millet, DNP, RN (Quorum=3)

SUBCOMMITTEE MEMBERS ABSENT:
Gina Glass (Vice-Chair)

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; Iljana Gaffar; Amber Williams, *Cure4Kids Foundation;* Dr. Devraj Chavda; Kim Anderson-Mackey; Sabrina Schnur; Dr. Craig Vincze; and Pamela White

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 January 5, 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.

Subcommittee member Amber Federizo motioned to approve the meeting minutes from prior council meeting dated January 05, 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 POSSIBLE ACTION: Discussion and possible action to approve meeting minutes from November 1, 2024. – *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.

Subcommittee member Amber Federizo motioned to approve the meeting minutes from prior council meeting dated November 01, 2024. Subcommittee member Jennifer Millet seconded the motion to approve. There were no objections. A quorum voted to approve the prior meeting minutes.

5) FOR POSSIBLE ACTION: Discussion and possible action to recommend changes to the Nevada Strategic Plan for 2026-2027, outlining the framework for a collaborative comprehensive care management plan for rare diseases in Nevada by the Rare Disease Advisory Council (RDAC)

   Chair Logan-Parker introduced the upcoming strategic plan for the 2026–2027 calendar year. Plans included reviewing the current strategic plan, documenting accomplishments, and presenting a wrap-up report alongside a draft of the new plan by the fall. A survey, similar to the one conducted in 2023, was proposed to gather input from Subcommittee members, and the floor was opened for discussion regarding the Council's progress and suggestions for the next plan. The previous 2023 survey had focused on legislative tasks, priorities, and time allocation, which contributed to the development of the current strategic plan. The same process was intended for the upcoming plan, encouraging members to consider what had worked, what had not, and what should be included or excluded. Subcommittee members were invited to provide comments or proceed to the next agenda item if no feedback was offered.

   Subcommittee member Amber Federizo raised a question about the strategic plan, noting limited communication from DHHS regarding their involvement, which had not developed as expected.

   Chair Logan-Parker responded that annual reports had included recommendations for increased involvement with the DHHS team, but responses had been minimal, and outreach efforts remained limited. Although some individual DHHS staff members provided support, particularly concerning the gene therapy access model, overall input on the strategic plan and recommendations had been limited and ineffective. The need for a different approach was acknowledged, along with openness to initiating conversations to enhance engagement. Chair Logan-Parker inquired about Subcommittee member Amber Federizo's methods for approaching the process.

Subcommittee member Amber Federizo stated that efforts had been made to engage with Director Whitley and other staff to arrange meetings, though collaboration during these interactions remained limited. Consideration was given to reaching out to the Governor's office to gather feedback on the RDAC's role and share experiences, with the intention of re-establishing conversations with the Director for updates. Concerns were expressed regarding the lack of investment and feedback from both the Governor's office and DHHS.

Chair Logan-Parker commented that a meeting with the Governor's office on a separate matter had been planned, with intentions to raise concerns about engagement with the RDAC. Although reports had been sent to the Governor's office, responses had been limited to brief acknowledgments without offers for deeper involvement. The RDAC faces the possibility of being dissolved under Senate Bill (SB) 78 of the 83rd Legislative Session as part of a broader state efficiency initiative, raising concerns about the Council not being taken seriously despite national recognition for its work. Efforts to initiate outreach and schedule conversations were acknowledged, though challenges had been anticipated due to the ongoing legislative session.

Subcommittee member Kim Anderson-Mackey added despite significant progress made by the RDAC, engagement challenges persisted, as similar difficulties were experienced by the Palliative Care and Quality of Life Council, which struggled to secure meetings. A recent meeting with Gene Hesterly was marked by limited participation, emphasizing the need for continued persistence in seeking active involvement and attention from key stakeholders.

Chair Logan-Parker also talked about the conversations that took place about how the RDAC could be included in the work of the Palliative and Quality of Life Committee, which was not under consideration for dissolving. There was a commitment to continue the work regardless of RDAC's formal designation, though it was noted that future efforts, including the strategic plan and needs assessment, would be significantly impacted by these developments.

Craig Vincze shared that his foundation, established in honor of his son to support nut carcinoma research, had successfully expanded research efforts from a single institution, Dana Farber, to include Stanford, the Mayo Clinic, and the University of North Carolina. Through networking, Dana Farber provided cell lines and conducted mouse model studies at these institutions, while his wife attended a symposium at the University of North Carolina to further these efforts. She also authored an op-ed and collaborated with a PR (public relations) professional to seek publication in major outlets like USA Today or the Wall Street Journal. Concerns were raised about the impact of inconsistent NIH (National Institutes of Health) funding, noting that sudden funding stops forced researchers to make quick decisions, including potential layoffs, with some having only 30 days of salary left. The importance of public outreach through the op-ed was emphasized, and feedback was sought from the group regarding this approach. Craig Vincze inquired about potential strategies to share this information with the public.

Chair Logan-Parker mentioned that strategic plans and annual reports had been shared with legislators to build momentum, and it was suggested that revisiting outreach efforts through a social media campaign could be beneficial. The Cure 4 the Kids PR team had previously secured local media coverage, and it was proposed to engage them again to highlight the local importance of the issue. Emphasis was placed on careful messaging, considering the state's focus on efficiency and budget cuts, while highlighting RDAC's fiscal responsibility and minimal use of state resources. Suggestions were made for Subcommittee members to utilize their social media platforms to promote awareness, with plans to develop a campaign pitch, including talking points and sample emails for broader outreach. The goal was to engage representatives and leverage existing contacts, with the campaign materials to be shared with all Subcommittee members for collective action.

Craig Vincze expressed agreement with the proposed approach.

Kim Anderson-Mackey agreed and commented all councils, struggled with effectively promoting their work, and it was suggested that this should be a key focus of the 2026-2027 strategic plan. Proposals included implementing quarterly campaigns through social media or engaging directly with legislators during sessions to raise awareness about RDAC's role and importance. Emphasis was placed on the need to communicate the significance of RDAC's work to broader audiences, ensuring that its value was understood beyond those directly involved.

Chair Logan-Parker encouraged sharing ideas during the upcoming survey, focusing first on ideal outcomes before narrowing down to what is realistically achievable. Emphasis was placed on starting awareness efforts immediately, as awareness remained a significant component of the current strategic plan.

8) FOR INFORMATION ONLY: Update on the Nevada Medicaid's current position on the Cellular and Cell Gene Therapy (CGT) Access Model. – *Chair Annette Logan-Parker*

Chair Logan-Parker provided an update that Dr. Kiko Duncan, the Medicaid Pharmacy Director, had confirmed Nevada Medicaid would not participate in the CMS (Centers for Medicare and Medicaid Services)-recommended cellular and gene therapy access model. Extensive research and discussions had revealed that the high costs of sickle cell gene therapy drugs, administered exclusively in hospitals, could not be adequately reimbursed under the current Nevada Medicaid system. Adjusting the Medicaid Services Manual to accommodate these costs would have required legislative authority, making it an issue to address in the next legislative session. It was suggested that this topic be considered for inclusion in the upcoming strategic plan, with input to be gathered through the Council's survey. The issue was removed from the ongoing agenda until further legislative action could be pursued. Subcommittee members were invited to share any comments or thoughts regarding this development.

Pam White expressed appreciation for the discussion on gene therapy and showed interest in learning more about the topic. She acknowledged that it would be addressed in future legislation and appreciated its inclusion in ongoing conversations.

Chair Logan-Parker said information about gene therapy was available on the Nevada RDAC website, and additional details were offered to be shared via email. Although Nevada was not opposed to participating in the cellular and gene therapy access model, legislative steps were necessary to facilitate involvement, and further discussion was encouraged, especially regarding sickle cell initiatives in the upcoming Council Member survey.

9) 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*

Chair Logan-Parker stated the Surveys were being received through a new, more user-friendly platform, with plans for a significant social media push to promote results and encourage participation. The Cure 4 the Kids Foundation was implementing creative strategies, such as using iPads, to enhance engagement with the needs assessment. Subcommittee members were encouraged to reach out to their networks within the rare disease community to raise awareness about the needs assessment campaign, with a follow-up email planned to provide additional information.

10) FOR INFORMATION ONLY: Council member information sharing announcements – *Subcommittee members*

Chair Logan-Parker requested Kim to share the upcoming initiatives of the Palliative Council in Carson City and discuss ways to provide support.

Kim Anderson provided an update on Assembly Bill (AB) 161 of the 83rd Legislative Session, which impacted hospice and concurrent care for children, and noted that Dr. Edgeworth had introduced it. The bill, similar to SB 78 of the 83rd Legislative Session, was lengthy and contained duplicative elements, though its core focus aimed to enhance checks and balances for hospice agencies and concurrent care for children. The Assembly bill (AB) 161 sought to improve bedside care quality, with Nathan Adelson, the oldest nonprofit hospice in Las Vegas, sponsoring it. Concerns were raised about the bill's financial impact, with an estimate of 221 full-time employees (FTEs) required for manual data input, suggesting the bill might struggle in upcoming committees. Despite initial opposition to its current form, the bill gained media attention and was set to proceed to a Policy Committee, and possibly the Financial Finance Committee, where its future remained uncertain.

Kim announced a celebration event on April 16, 2025 to highlight the accomplishments of the Palliative Care and Quality of Life Council, emphasizing the importance of demonstrating their contributions. The event coincided with National Advance Decision Day and provided advanced care planning tools and samples like Nevada Pulse for end-of-life planning. The day also offered five free CEUs (Continuing Education Unit) and CMEs (Continuing Medical Education), focusing on palliative care and end-of-life topics, including a session specifically addressing children's experiences. The educational sessions aimed to support professionals in meeting Nevada-specific licensing requirements. A flyer for the event was prepared for distribution to ensure broader awareness.

Chair Logan-Parker provided an update on Senate Bill 228, which requested appropriation funds for the bone marrow transplant program in Nevada, supported by an impressive economic impact study that was nearing completion. The study, conducted by Trip Unbox, a national firm known for similar research in Nevada, aimed to strengthen the campaign for funding despite the challenging fiscal climate. Additionally, the newborn screening bill remained in the Bill Draft Request (BDR) form, with Senator Pezina actively working to advance it, and preparations were underway to launch a campaign to secure the necessary resources for the transplant program.

11) PUBLIC COMMENT:

Chair Logan-Parker opened the floor for public comment.

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

12) 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 10:11 AM.