NEVADA RARE DISEASE ADVISORY COUNCIL

DRAFT MEETING MINUTES
Date: August 7, 2026
9:36 AM – 11:16 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 9:36 am.

1) INTRODUCTIONS AND ROLL CALL

COUNCIL MEMBERS PRESENT:
Annette Logan-Parker (CHAIR); Gina Glass (Vice-Chair); Amber Federizo, DNP, APRN, FNPBC; Craig Vincze, PhD; Melissa Bart-Plange; Christina Thielst; Jennifer Millet, DNP, RN; Sumit Gupta, MD; Dr. Verena Samara; Valerie Porter, DNP, APRN, AG-ACNP-BC, MBA; Naja Bagner; Ihsan Azzam, MD, PhD; Paul Niedermeyer; Kim Anderson-Mackey; Pamela White; Madison Bowe PhD; Mallory Carvalho

COUNCIL MEMBERS ABSENT:
Brigette Cole (excused); Dr. William Evans; Dr. Devraj Chavda PhD

DIVISION OF PUBLIC & BEHAVIORAL HEALTH (DPBH) STAFF PRESENT:
Ashlyn Torrez, *Health Program Specialist I* and Kevin Dodson, *IT Business Analyst, OSE, DPBH*

OTHERS PRESENT:
Amber Williams, *Cure 4 the Kids Foundation*; Dr. Kathleen Benson, *AHVS Cardiology*; Summer Webb, *American Estate & Trust*; Kristen Hackbarth, *Communications Director, NV Cancer Coalition*; Michelle Benitez-Hernandez, *C4K Foundation*; Bella Peterson, *Ferrari Reeder*, Jennifer Glover, *C4K Foundation;* Kathryn Linnabery, *C4K Foundation*; Sierra Seda, *C4K Foundation*; Elsa Ramirez, HHS/IEA; Mark Funkhouser, *Southern Regional Behavioral Health Coordinator, Nevada Public Health foundation* (NPHF); Ann Jensen, *NV Medicaid, NHA*; Angela Lee, *C4K Foundation*; Sophia Renteria, *C4K Foundation*; Candance Dietrich, *Director of Population Health & Engagement, Carson Tahoe Health* Jennifer Glover, *C4K Foundation*; Sabrina Petrel, *Cartwright NV*; Ram K Singh, *AHVS Cardiology*; Carrie Ostrea, *Catalyst Pharmaceuticals*; Ann Ramer, *Ohio Department of Health, (ODH)*

Roll call was taken and is reflected above. It was determined that there is not 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 April 6, 2026.

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 Melissa Bart-Plange motioned to approve the meeting minutes from prior council meeting dated 4/6/2026. 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 approve meeting minutes from June 5th, 2026.

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 Valorie Porter motioned to approve the meeting minutes from prior council meeting dated 5/4/2026. Councilmember Dr. Sumit Gupta seconded the motion to approve. There were no objections. A quorum voted to approve the prior meeting minutes.

5) FOR INFORMATION ONLY: Guest presentation on NVHA/Nevada Medicaid – Ann Jensen, Administrator, Nevada Medicaid, Nevada Health Authority

Ann Jensen explained that Medicaid programs varied by state and reviewed Nevada-specific information relevant to the Council. She requested continued feedback about the experiences of Medicaid patients with rare genetic diseases to identify service challenges and improvement opportunities.

Jensen had joined Nevada Medicaid after moving to Reno two years earlier and had led the state's children's behavioral health transformation efforts. Her childhood experience receiving Medicaid coverage in Oregon contributed to her passion for the program. She had served as Nevada's Medicaid Director since July 2025.

Ann Jensen stated Nevada Medicaid operated within the Nevada Health Authority, which had been established on July 1 of the previous year with unanimous legislative approval. The authority consolidated state-administered and competitively contracted health coverage programs to strengthen negotiations with insurers and improve quality and value. It included Nevada Medicaid, Nevada Health Link, the Public Employees' Benefits Program, regulatory functions, and the Battle Born State Plan public option. Together, these programs provided coverage to one in three Nevada residents and supported individuals as they transitioned between coverage types.

Ann Jensen explained that the Nevada Health Authority had sought to ensure Nevadans were healthy and had access to affordable, reliable healthcare. Although Nevada had faced low population health rankings and rising healthcare costs, efforts had focused on using the state's purchasing power, streamlining programs, expanding affordability and access, and improving healthcare quality and outcomes.

Ann Jensen said that Nevada Medicaid had provided no-cost healthcare coverage to more than 730,000 residents, making it the state's largest single health insurance program. Unlike federally administered Medicare, Medicaid had operated as a federal-state partnership shaped by state policies and federal requirements. Some individuals had qualified for both programs. Nevada Medicaid's biennial budget had totaled $15 billion in state and federal funding, making it the largest item in Nevada's state budget.

Council member Madison Bowe put into the chat at 9:50 AM: "500"
Council member Dr. Sumit Gupta put into the chat at 9:50 AM: "1000"
Guest attendee Angela Lee put into the chat at 9:50 AM: "5,000"
Guest attendee Kristen Hackbarth put into the chat at 9:50 AM: "8500"
Council member Dr. Sumit Gupta put into the chat at 9:50 AM: 12000"

Ann Jensen used a trivia activity to provide additional context about Nevada Medicaid. She asked the question How many babies are born with health insurance coverage through Nevada Medicaid each year?

Guest attendee Angela Lee put into the chat at 9:48 AM: "50,000"
Guest attendee Kristen Hackbarth put into the chat at 9:48 AM: "5,500"
Council member Madison Bowe put into the chat at 9:48 AM: "100000
Council member Dr. Sumit Gupta put into the chat at 9:48 AM: "50%"
Council member Jennifer Millet put into the chat at 9:48 AM: "over 6000"

13,000 of Nevada's 26,000 annual births had been covered by Medicaid.

The next question was Which president signed the Federal bill that created Medicaid.

Guest attendee Kristen Hackbarth put into the chat at 9:49 AM: "LBJ"
Guest attendee Sierra Seda put into the chat at 9:49 AM: "Johnson"

President Lyndon B. Johnson had established Medicare and Medicaid by signing the Social Security Act of 1965, and Medicaid had marked its 61st anniversary that summer. As of the previous month, Nevada Medicaid had enrolled 49,500 healthcare providers, while efforts had continued to simplify enrollment and expand provider participation.

Council member Madison Bowe put into the chat at 9:51 AM: "That's a lot of providers I was just thinking doctors"

Ann Jensen asked a question about the name of Nevada's Medicaid program before it became known as Nevada Medicaid. Michelle Beneitez Hernandez gave the correct answer SAMI. Ann Jensen explained that Nevada had established its Medicaid program in 1967 under the name State Aid for the Medically Indigent, or SAMI. The program had later been associated with the Division of Health Care Financing and Policy before being rebranded as Nevada Medicaid. As part of the program's continued development a new logo has been planned.

Guest attendee Michelle Beneitez Hernandez put into the chat at 9:51 AM: "SAMI?"
Guest attendee Michelle Beneitez Hernandez put into the chat at 9:51 AM: "State Aid to Medically Indigent?"

Ann Jensen asked the next question, What percentage of Nevada Medicaid's budget goes to health services.

Guest attendee Kristen Hackbarth put into the chat at 9:52 AM: "85%"
Council member Jennifer Millet put into the chat at 9:52 AM: "70"
Council member Madison Bowe put into the chat at 9:52 AM: "95%"

Ann Jensen answered the final trivia question by explaining that 97% of Nevada Medicaid's $15 billion budget had funded health services, including provider claims and medications, while 3% had supported administrative costs. Private health plans had typically spent about 85% on services and 15% on administration. 200 employees worked within the Medicaid division, with broader support provided by 700 Nevada Health Authority employees.

Ann Jensen explained that Medicaid programs addressed eligibility, covered services, and care delivery. Although states and U.S. territories had flexibility in administering their programs, each had been required to meet minimum federal standards.

Ann Jensen continued to explain Nevada had expanded eligibility beyond federal minimums, particularly for adults and postpartum mothers, which had extended coverage to a broader population. The program included federally required benefits and optional services selected by the state. Nevada delivered care through five managed care organizations and a fee-for-service system.

Ann Jensen explained that Nevada Medicaid had served 700,000 people, with enrollment fluctuating over time. Parents and children represented 52% of members, while adults covered through Medicaid expansion accounted for 28%. Most members had lived in Clark County, with smaller populations in Washoe County, Carson City, and rural communities.

Ann Jensen stated that Nevada Medicaid had covered federally required and state-selected optional benefits, including prescription medications. Adding services required a reimbursement structure, legislative funding, and federal approval. Covered services generally had to be medically necessary and FDA-approved when applicable.

Ann Jensen used a flower analogy to explain that federal law had provided the foundation for Medicaid, while Nevada's State Plan, laws, budgets, eligibility policies, optional benefits, waivers, manuals, and contracts had shaped the state's program. Changes to the 1,200-page State Plan required federal approval and could take several months. Following the 2025 legislative session, Nevada had secured funding and federal approval to add routine adult dental services as an optional Medicaid benefit. The coverage had taken effect on July 1 and expanded dental care access to approximately 300,000 Nevadans.

Ann Jensen explained that Medicaid services are not authorized under federal law required waivers and CMS (Centers for Medicare and Medicaid Services) approval. Nevada had pursued a 1115 demonstration waiver to provide fertility preservation services for certain breast and ovarian cancer patients undergoing treatments that could affect fertility. The 1915(c) Home and Community-Based Services waiver had allowed people with disabilities to receive care outside institutional settings. Structured family caregiving had enabled qualifying relatives to be paid for supporting individuals with dementia at home.

Ann Jensen said that Nevada Medicaid had generally received 60% of its funding from the federal government and 40% from the State General Fund. Compliance with federal requirements had been essential because services provided without federal approval would have been funded entirely by the state.

Ann Jensen explained that new Medicaid benefits had undergone public review and federal approval. State Plan Amendments generally took up to a year, while waivers had taken one to four years depending on their complexity and CMS workload.

Nevada Medicaid had used fee-for-service and managed care delivery systems. 10% of recipients had received fee-for-service coverage through state-contracted providers and Gainwell. Most recipients had been enrolled in private managed care organizations responsible for provider networks, claims, care coordination, and additional benefits. Eligibility and covered services remained consistent under both systems, while administration had differed.

Ann Jensen explained that 625,000 Nevada Medicaid recipients had received coverage through managed care. A new five-year contract began in January, expanded managed care statewide, and added 60,000 to 70,000 members. Managed care organizations had been required to meet Medicaid's base reimbursement rates and could offer health-related supports, such as medically tailored meals, security deposits, and air conditioners. Nevada Medicaid monitored quality, prior authorization decisions, and required community reinvestment of some profits.

Ann Jensen mentioned that care coordination and mandatory case management had helped members, including pregnant individuals and people with complex behavioral health conditions, connect with providers and supportive services.

Ann Jensen explained that managed care organizations had maintained separate provider networks, and provider participation had generally depended on contracts with individual health plans. Certain essential providers had been required to participate to support access to coordinated care. Non-Emergency Medical Transportation had covered travel to medically necessary healthcare services, including specialized care outside Nevada. Covered assistance had included transportation for patients and caregivers by ground or air, along with lodging and meals when necessary. Care coordination teams have helped members resolve transportation access difficulties.

Council member Melissa Bart-Plange put into the chat at 10:13 AM: "How does a family get more information about traveling"

Ann Jensen advised Medicaid members to call the number on the back of their insurance card as the fastest way to receive assistance, whether they were enrolled in managed care or fee-for-service. She added that members who had difficulty reaching someone could also contact the care coordination team for additional support.

Guest attendee Ann Jensen put into the chat at 10:14 AM: "carecoordination@nvha.nv.gov"
Guest attendee Ann Jensen put into the chat at 10:14 AM: "Transportation Services"
Guest attendee Ann Jensen put into the chat at 10:14 AM: "ajensen@nvha.nv.gov"
Guest attendee Ann Jensen put into the chat at 10:14 AM: "Phone numbers for our care coordination office: Contact Nevada Medicaid"
Council member Dr. Craig Vincze put into the chat at 10:26 AM: "I have to jump on another call. Thank you Ann Jensen for the Medicade information"

Councilmember Naja Bagner raised concerns about reports that Nevada Medicaid recipients had been limited to 20 transportation vouchers and could face out-of-pocket costs afterward.

Ann Jensen stated that she was unaware of such a limit and advised affected members to contact their health plan or care coordination team. She noted that medically necessary exceptions or overrides could be available for patients requiring frequent treatment.

Councilmember Melissa Bart-Plange asked whether families enrolled through the Katie Beckett program had qualified for Non-Emergency Medical Transportation, noting that her family had traveled regularly to California for her son's care without being informed of the benefit.

Ann Jensen confirmed that Katie Beckett families had access to the same Medicaid benefits, including eligible transportation and flights. She advised families to contact their care coordination team or case worker and acknowledged that communication about available benefits needed improvement.

Madison Bowe shared a phone number, 844-879-7341, for Medicaid members seeking transportation services within or outside Nevada.

Ann Jensen explained that the number was likely connected to Medical Transportation Management (MTM), a transportation broker serving many fee-for-service and managed care members. She also noted that rural managed care members might use a different transportation broker depending on their health plan. Jensen provided a link to Nevada Medicaid's Non-

Emergency Transportation Services webpage, which contained transportation contact information and phone numbers.

Chair Logan-Parker identified a gap between available Medicaid services and public awareness of those benefits. She suggested adding answers to common Medicaid questions and links to relevant resources on the Rare Disease Advisory Council website.

Ann Jensen supported the proposal and noted that the Beneficiary Advisory Council had been developing a one-page guide explaining available benefits, how to access them, and where to obtain additional information.

Chair Logan-Parker suggested creating a dedicated Medicaid landing page or myth-busting section on the Council's website to educate people with rare diseases about available services and resources.

Ann Jensen explained that Nevada Medicaid had prioritized preparations for federal eligibility changes scheduled for 2027, including work-related requirements for certain adults covered through Medicaid expansion. Exceptions had been expected for individuals with serious illnesses, caregivers, and others facing barriers to qualifying activities. Nevada had also planned a new website that would allow residents to determine eligibility, explore financial assistance, and enroll in Medicaid or exchange coverage online.

Ann Jensen explained that Nevada Medicaid had been implementing 34 bills from the previous legislative session, including adult dental coverage and fertility preservation, while preparing for the 2027 legislative session and the 2028–2029 budget. Medicaid also offered technical assistance for proposed legislation involving coverage and services. Children's behavioral health had remained another priority. Nevada Medicaid had been developing a new delivery system to expand home- and community-based care for children with complex behavioral health needs, with procurement expected in the fall. Specialized nurses and social workers in Reno and Las Vegas had assisted families through the care coordination team.

Madison Bowe asked whether the Governor might expand newborn screenings to help identify rare diseases earlier and improve patient outcomes. Ann Jensen explained that legislation from the previous session had increased Medicaid reimbursement for certain newborn screenings. Changes to the screenings offered would likely have required legislative action, and Nevada Medicaid had been available to provide technical assistance by comparing existing policies with proposed changes.

Guest attendee Candance Dietrich put into the chat at 10:26 AM: "Are the specialized BH team available to rural communities?"
Council member Pamela White put into the chat at 10:27 AM: "I'm excited to learn of the successful push for Adult Dental Services, along with many of the new program services"
Council member Madison Bowe put into the chat at 10:28 AM: "Me tooo I didn't know that was passed so now I can do it"
Council member Madison Bowe put into the chat at 10:28 AM: "I am under FFS because of the waiver program"
Council member Naja Bagner put into the chat at 10:29 AM: "pamela white I missed the adult dental"

Guest attendee Candance Dietrich put into the chat 10:29 AM: "Thank you so much, Ann, so helpful! Great to see the progress!"

Ann Jensen clarified that specialized behavioral health support teams were available statewide, including virtually, regardless of where Medicaid members lived in Nevada. She noted that additional teams were based in Elko to support rural communities.

She also expressed enthusiasm about the newly available adult dental benefit and encouraged members seeking dental services to contact the care coordination team. For members enrolled in managed care, dental coverage was provided through Liberty Dental, which could assist with locating participating providers.

6) FOR INFORMATION ONLY: Guest presentation on NV Cancer Coalition – Kristen Hackbarth, Communications Director, Nevada Cancer Coalition

Kristen Hackbarth introduced herself as the Communications Director for the Nevada Cancer Coalition and the facilitator for development of the State Cancer Plan and the Pediatric and Adolescent and Young Adult Cancer Collaborative. She explained that although cancer broadly was not considered a rare disease, pediatric and adolescent and young adult cancers were relatively rare.

Council member Naja Bagner put into the chat at 10:30 AM: "pamela white can you give me a call after the meeting?"
Council member Pamela White put into the chat at 10:31 AM: "Yes"
Council member Naja Bagner put into the chat at 10:31 AM: "**redacted***"
Council member Pamela White put into the chat at 10:31 AM: "got it"
Council member Christina Thielst put into the chat at 10:55 AM: "Excellent program and speakers today!"

Kristen Hackbarth explained that including pediatric and adolescent and young adult cancers in Nevada's five-year cancer plan had been an important advancement because earlier plans had not addressed them. The plan served as a statewide framework for reducing cancer's impact and had been developed by more than 100 volunteers, including healthcare and public health professionals, survivors, caregivers, advocates, and policymakers. Unlike common cancers that could often be addressed through prevention and screening, pediatric and young adult cancers had generally not been preventable or detectable through routine screening. The plan had therefore focused on public health strategies to reduce their effects on Nevada patients and families.

Kristen Hackbarth explained that the Nevada Cancer Plan had promoted sustainable, evidence-based improvements through policy, systems, and environmental changes. Strategies included insurance coverage for fertility preservation, telehealth access to clinical trials, stronger referral systems, access to healthy foods, and safe spaces for physical activity. The plan had served as a statewide guide rather than a framework limited to Nevada Cancer Coalition staff. Its success had depended on collaboration among policymakers, educators, healthcare providers, survivors, nonprofits, community organizations, pharmaceutical companies, and other partners. The Pediatric and Adolescent and Young Adult Cancer Collaborative had united partners to advance the strategies outlined in the plan.

Kristen Hackbarth explained that the 2026–2030 Nevada Cancer Plan had continued to prioritize prevention, early detection, survivorship, surveillance, and research while expanding its focus on access to care and quality of life for pediatric, adolescent, and young adult cancer survivors. The plan had also addressed housing, food insecurity, rural access, public health infrastructure, environmental factors, and supportive policy changes. Objectives had been selected based on available data, measurable outcomes, stakeholder participation, feasibility, capacity, and funding. Limited data on younger cancer populations had created challenges, but growing collaboration had strengthened planning efforts. Long-term goals had been divided into achievable steps for the five-year period.

Kristen Hackbarth explained that the 2020–2025 Nevada Cancer Plan had acknowledged pediatric cancers but had not fully incorporated them into its broader strategy. Development of the next plan had included a dedicated section for pediatric, adolescent, and young adult cancers, supported by stronger partner participation, continued advocacy, and technical assistance from the American Childhood Cancer Organization. Limited statewide data had complicated planning and analysis. Pediatric cancer cases had been rare, and small numbers often had to be suppressed to protect patient privacy, particularly in rural areas. For example, Nevada had recorded 225 blood and bone marrow cancer cases over five years, compared with more than 18,000 adult cancer diagnoses annually. These limitations had restricted analysis of demographic and geographic disparities and required consideration of additional information, including workforce data.

Council member Dr. Verena Samara put into the chat at 11:05 AM: “I apologize, I have to sign off for patient care but had a question for the group that is unrelated to our excellent presentations today. Does anyone know of a clinician specializing in hypophosphatasia (adult onset)? I recently saw a patient with this genetic condition and she has many questions on how to manage her symptoms but has not been able to identify a true specialist on this disease outside of geneticists.”

Kristen Hackbarth explained that Nevada had generally fallen below national healthcare workforce and insurance benchmarks. Although the state had slightly exceeded the national rate for child and adolescent psychiatry, few professionals had been equipped to address the specific mental health needs of pediatric, adolescent, and young adult cancer survivors. Shortages had also affected pediatric subspecialties, including hematology-related care. Cancer Registry data had shown that about one in five families traveled outside Nevada for treatment over five years, while nearly two-thirds had received all treatment in the state. Partner data had indicated that 95 families traveled out of state during one year, averaging 650 to 850 miles per round trip and potentially exceeding $10,000 in annual travel costs. These burdens had not been fully captured by existing state data, demonstrating the need for improved collection and information sharing.

Kristen Hackbarth explained that a survey developed by Cure for the Kids Foundation had gathered input from pediatric oncology physicians who could not regularly attend planning meetings. An existing Nevada Central Cancer Registry childhood cancer report had also been reviewed, but outdated information had limited its usefulness. Additional information had been collected from state and community sources covering housing, food insecurity, environmental exposures, research, public health priorities, and data collection. These findings had supported the development of the Cancer Plan’s pediatric, adolescent, and young adult section, which had

aimed to improve access to quality care and supportive resources for patients and families affected by cancer.

Kristen Hackbarth explained that the Cancer Plan had included adults ages 20 to 39, who had increasingly faced cancers such as colorectal, breast, and skin cancer. This population had experienced challenges similar to pediatric patients, including limited access to care and survivorship support. The plan had prioritized achievable steps, including stronger data collection on patient and family experiences and participation in national childhood cancer initiatives. Another objective had focused on expanding clinical trial and research access through community education, telehealth enrollment, barrier identification, and improved administrative and research infrastructure in Nevada.

Kristen Hackbarth explained that strengthening Nevada's pediatric, adolescent, and young adult cancer workforce was an objective. Priorities included clinician education, coordinated transitions into adult care, expanded psychosocial and palliative care, and recruitment of more pediatric specialists and subspecialists. The next part aimed to expand patient and family support through insurance enrollment assistance, tele-navigation, caregiver services, financial assistance, and stronger connections to community resources. Implementation had already begun through quarterly collaborative meetings, expanded partnerships, a data subcommittee, Cancer Control Summit sessions, podcast episodes, and planned educational materials for legislators. These efforts had sought to reduce the burden of cancer across Nevada.

Council member Pamela White put into the chat at 11:08 AM: "I'm shocked about the lack of data collected in this State overall. Thank you for the explanation!"

Chair Logan-Parker asked how the Rare Disease Advisory Council could provide updates on changing healthcare providers, programs, resources, and data to keep the 2026–2030 Cancer Plan current.

Kristen Hackbarth encouraged ongoing communication and information sharing, including presentations at Pediatric and Adolescence and Young Adults Collaborative meetings. The State Comprehensive Cancer Control Program had evaluated the plan annually to adjust strategies and identify gaps. Although printed copies had remained unchanged, the online plan had been regularly updated with new data, strategies, and evaluation results.

Chair Logan-Parker expressed concern that workforce data had potentially overstated the number of physicians actively practicing in Nevada because some counted individuals had worked in academia, maintained licenses or provider identifiers without practicing, or had left clinical work.

Kristen Hackbarth acknowledged the limitations and explained that detailed distinctions between practicing, academic, and non-practicing physicians had not been available across all data sources. Partner organizations had therefore provided additional insight into Nevada's healthcare workforce shortages.

Kristen Hackbarth explained that Act for Kids in Nevada had been developing a statewide directory of active pediatric providers, including their specialties and subspecialties. The effort

had aimed to identify expertise relevant to rare diseases and pediatric cancer while providing a clearer picture of workforce gaps.

Chair Logan-Parker then requested guidance on improving rare disease data collection and coalition building. She noted that childhood cancer had qualified as a rare disease and that Nevada's rare disease data had remained limited, despite efforts with the Office of State Epidemiology to expand the Rare Disease Dashboard.

Kristen Hackbarth recommended assessing available data, identifying gaps and limitations, and determining which organizations collected additional information. She noted that low case counts and privacy protections had often restricted reporting, particularly in rural and frontier communities. Standardized data collection and qualitative input from patients, families, and professionals have also been important.

Chair Logan-Parker explained that ultra-rare diseases often had not met minimum reporting thresholds, creating differences between treatment-center and statewide registry data. Kristen Hackbarth noted that similar reporting limitations had affected even common cancers in sparsely populated Nevada counties.

Chair Logan-Parker asked how the Rare Disease Advisory Council could better help the childhood cancer community recognize its connection to the broader rare disease community. She noted that identifying childhood cancers as rare diseases could create additional opportunities for collaboration, advocacy, and shared resources.

Kristen Hackbarth explained that cancer represented a broad collection of many individual diseases rather than a single condition. Although cancer as a whole was common, many individual cancer types were rare, and pediatric cancers represented an even smaller portion of overall cancer diagnoses. She suggested that emphasizing this distinction could help families and advocates better understand why pediatric cancers fit within the rare disease community and how collaboration could be beneficial.

Council member Kim Anderson-Mackey put into the chat at 11:10 AM: "Kristen - I would like to see if you are willing to present to the Palliative Care & Quality of Life Council. Please give me a call at **redacted**. Thank you in advance."
Council member Amber Federizo put into the chat at 11:12 AM: "Verena Samara - Dr. Neil Braunstein in Las Vegas has a few HPP adults."

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

Councilmember Kim Anderson-Mackey motioned to approve the Recommendation of Ann Jensen, as a member of the Council. Councilmember Dr. Ihsan Azzam seconded the motion to approve. There are no objections. A quorum voted to approve Ann Jensen, as a member of the Council.

9) FOR INFORMATION ONLY- Update from Chair Logan-Parker on her presentation to the Health and Human Services Interim Committee on June 30, 2026. – Chair Annette Logan Parker

Chair Logan-Parker provided an update on her June 30 presentation to the Health and Human Services Interim Committee. She presented the Rare Disease Advisory Council's Strategic Plan and preliminary findings from the needs assessment. The committee responded positively, expressed appreciation for the information, and showed support for the Council's ongoing work.

10) PUBLIC COMMENT

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

Kim Anderson-Mackey announced that the Palliative Care and Quality of Life Council had been seeking additional members. Interested individuals could submit a CV, résumé, or letter of interest directly to her or apply through the website. Council appointments had generally been for two- to three-year terms. She encouraged individuals with relevant expertise and a strong interest in life-limiting illnesses to consider becoming involved at the state level.

Council member Melissa Bart-Plange put into the chat at 11:16 AM: "can you provide your email"

Council member Kim Anderson-Mackey put into the chat at 11:16 AM: "kanderson@amorehospicecare.com"

11) ADJOURNMENT- *Chair Annette Logan-Parker*

Chair Annette Logan-Parker moved to adjourn the meeting at 11:16 am.