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NEVADA RARE DISEASE ADVISORY COUNCIL

DRAFT MEETING MINUTES

Date: April 3, 2026
9:36 AM – 10:18 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; Paul Niedermeyer; Brigette Cole; Craig Vincze, PhD; Melissa Bart-Plange; Christina Thielst; Dr. William Evans, MD; Jennifer Millet, DNP, RN; Sumit Gupta, MD; Madison Bowe; Kim Anderson-Mackey; Dr. Verena Samara, MD; and Valerie Porter, DNP, APRN, AG-ACNP-BC, MBA

COUNCIL MEMBERS ABSENT:
Ihsan Azzam, MD, PhD; Naja Bagner; Madison Bowe; Pamela White; Mallory Carvalho; Dr. Devraj Chavda MD

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, OSE, DPBH;* and Kevin Dodson, *Administrative Assistant III, OSE, DPBH,*

OTHERS PRESENT:
Amber Williams, *Cure 4 Kids*; Jenna Doer, *Artia Solutions*; Mike Wrecker, *Intermountain Health*, Seth Andrews, *Intermountain Health*; Matt Sheffield; and Cade Grogen

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 February 6, 2026.

Councilmember Jennifer Millet motioned to approve the meeting minutes from prior council meeting dated 2/6/2025. Councilmember Dr. Sumit Gupta seconded the motion to approve. There were no objections. A quorum voted to approve the prior meeting minutes.

4) FOR INFORMATION ONLY: Intermountain Guest Presentation on strategic planning for pediatrics across Intermountain Health. – Mike Wecker, *Assistant Vice President of Strategy and Business Development, Intermountain Health*.

Ashlyn Torrez introduced Mike Wecker and Seth Andrews and expressed appreciation for their time. Mike Wecker identified himself as the leader of strategy and business development for Intermountain Children's Health and noted that Seth Andrews, who led the Children's Health Network, had joined him.

Mike Wecker provided an update on the Children's Hospital project. Land had been secured at the UNLV (University of Nevada, Las Vegas) Tech Park in southwest Las Vegas, and design work was nearing completion. That phase focused on room counts, space planning, and the hospital's overall layout. The project had since advanced into construction documentation, which involved finalizing architectural plans for general contractor handoff. Groundbreaking was anticipated in the fall, likely September or October, pending completion of construction documents and final county, state, and regulatory approvals. If the timeline were to be held, construction was expected to take approximately 44 months and finish in early 2030. An activation phase would follow for equipment installation, simulation training, and operational preparation, with the hospital expected to open to patients in the third quarter of 2030. The site was identified as the northwest corner of the UNLV Tech Park along the southwest curve of the 215 and spanned 33 acres. A brief overview of the site plan was also provided. Phase one included an inpatient tower and an attached clinic and medical office building. Combined, the hospital, medical office building, and support space totaled approximately 830,000 square feet. The hospital was planned as eight stories plus a mechanical floor, and the medical office building as four stories. The campus was also expected to include two helipads and about 1,300 parking spaces.

Mike Wecker explained that the hospital had been intentionally designed for future expansion as community needs grew. Phase one represented roughly half of the site's ultimate capacity. Future expansion areas were planned to include additional inpatient towers, expanded clinic space, and structured parking to support patients, caregivers, and staff. No timeline had been set for phase two, as it would depend on future demand and phase one performance, but the hospital was intended to grow alongside the community. Key statistics were referenced to highlight the hospital's planned services and programs, though not all details were reviewed. Supporting materials had been shared with the group for further review. The goal was for the Children's Hospital to operate as a full-service facility, offering a wide range of pediatric subspecialty care along with the ancillary and wraparound services needed to support patients and families.

Mike Wecker continued talking about the current efforts that were focused on several major areas. One priority had been to cooperate with local physicians and strengthen the workforce as needed to meet community demand and prepare for hospital staffing. Another had been developing a clinically integrated pediatric network to support shared quality goals and improve continuity of care across providers, clinics, specialties, and the hospital. Community engagement in strategic giving had also been underway to help fund the hospital and its programs, and appreciation was expressed for the support already received. Design and construction remained another major focus. Exterior renderings of the hospital were expected to be released to the community within about a month. Feedback has also recently been gathered from community physicians and family members through mock-ups of key hospital rooms, including inpatient rooms, operating rooms, and procedure rooms. Those mock-ups had been used to collect input on layout, room size, and equipment placement so the design could be refined to better serve patients, families, and providers. The hospital-specific portion of the presentation then concluded, and time was opened for questions before the discussion shifted to Seth Andrews to address personalized medicine efforts.

Seth Andrews explained that, in addition to leading population health network efforts, support for children with rare diseases had also been provided through the Center for Personalized Medicine. The center's work focused on genomic medicine and advanced technologies used to diagnose and treat rare diseases. Its three-part approach had centered on improving diagnosis through next-generation sequencing, expanding access to treatment through (Food and Drug Administration) FDA-approved therapies and clinical trials, and ensuring support reached children across all socioeconomic backgrounds and disease types. The goal had been to extend those services to the Nevada Children's Hospital and provide as many locally as possible, with an emphasis on ensuring no child was left behind.

Seth Andrews provided several examples were provided to illustrate that work. Whole genome sequencing had played a major role in diagnosing nearly every patient served, including rapid whole genome sequencing in the inpatient setting, which had been used for more than six years. That approach had produced a diagnosis in roughly 30 to 35 percent of children who received rapid hospital-based testing. Patients had also been followed over time through an integrated genetics service supported by a large team of genetic counselors and geneticists working across multiple subspecialties, including neurology and cardiology. Additional rare disease programs had included the re-seek clinic, which had reevaluated cases in which next-generation sequencing had not produced a diagnosis. A gene therapy and genomics fellowship had also supported the training and recruitment of specialists in genetics and gene therapies. Other focus areas had included telegenetics, pharmacogenomics, and novel therapeutics. It was also noted that 9 of the 14 FDA-approved cell and gene therapies had been administered at Primary Children's Hospital, with plans to expand that capability over time and increase local access for children in Nevada through the future Children's Hospital.

Seth Andrews brought up one highlighted program, Primary Children's Gene Kids, a grant-funded initiative supported by an external foundation and matched by the Intermountain Foundation. The program provided clinically indicated whole genome sequencing for all eligible patients. Efforts have also been underway to expand its reach across the Intermountain West, including through clinical partners in Nevada. For children in Nevada who needed whole genome sequencing, access had been made available through either payer coverage or study funding. The program had also supported research into family-level factors and the connection of genetic data with clinical information. This service had already been available to children in Nevada and had been presented as part of the broader effort to support personalized medicine within the future Nevada Children's Hospital.

Chair Annette Logan Parker thanked Seth and Mike for the presentation, then asked how the Utah team had worked with the newborn screening program, particularly its connection to genome sequencing through Gene Kids.

Seth explained that Utah had not yet implemented genomics-based newborn screening and had remained focused on traditional metabolic screening. A close partnership with the newborn screening program had been maintained, with Primary Children's Hospital physicians working alongside it. Although genomic newborn screening had not yet been in place, the screening panel had included about 42 or 43 conditions, and strong coordination had supported timely confirmatory diagnoses and treatment for children identified through the panel.

Chair Annette Logan Parker then asked whether efforts had been made to expand Utah's newborn screening program into genome sequencing through legislation.

Seth Andrews replied that this had not been pursued legislatively at that stage. Instead, two studies had been planned for launch that year: an inpatient study with Rady Children's called Beginnings and an outpatient study with a private company. Utah had not yet been ready to take on genomic newborn screening in-house, so a legislative approach like the one used in Florida had not yet been considered appropriate. It was explained that the state still needed to define roles and responsibilities, particularly given the challenge of serving as the lab of record. The emerging model had been viewed as a potential partnership among the state, the children's hospital, and external labs. Those studies had been intended to help demonstrate that approach while collaborating with the state continued future implementation.

Chair Annette Logan Parker then noted that close attention had been paid to developments in Florida and that it would be important to see how that effort unfolded and what precedent it might set. Ongoing collaboration and communication with the Rare Disease Advisory Council were encouraged, and support was offered wherever helpful.

Chair Annette Logan Parker raised another question about rural and frontier Nevada, noting that the Nevada Rare Disease Advisory Council served all 17 counties, only two of which were urban. Chair Annette Logan Parker asked whether plans had included clinical outreach into rural and frontier communities or whether support might instead have involved travel coordination and similar services as hospital planning moved forward.

Seth Andrews responded that the goal had been to support children as close to home as possible. Plans had included placing geneticists in Las Vegas and expanding support through a telegenetics program, since many services could be delivered through telehealth. No specific plans had yet been established for in-person rural outreach sites, but telehealth had been viewed as a major tool, while also recognizing that gaps would remain. Guidance had been requested on where outreach could have the greatest impact, particularly for children with limited access to technology who still needed support.

Chair Annette Logan Parker replied that statewide data collection had already been underway and could eventually help answer many of those questions. The needs assessment began with patients, parents, and lived experiences related to rare diseases, then expanded to include physicians and healthcare teams to better understand provider-side needs, including telehealth. It was noted that much of the data had been coming from rural and frontier communities and that, once analyzed and published, it would be made publicly available and could help guide decisions on where to focus first.

Mike Wecker then added that, because of Intermountain's large and largely rural geographic footprint, the system had developed some of the most robust telehealth services in the country across both children's and adult care.

Councilmember Madison Bowe asked whether hospital plans had included child life specialists.

Mike Wecker responded that a child life specialist program had been planned as part of the hospital. He noted that Nevada had very few child life specialists statewide compared with Primary Children's in Salt Lake, where the workforce was much larger. Child life services were described as a critical component of a fully functioning children's hospital and essential support for patients and families. Conversations had already been underway about how to build that workforce, either by training specialists in Nevada and retaining them or by recruiting them to relocate and support the Children's Hospital.

Madison Bowe – 9:54am in the chat: I would like to have more information

Councilmember Madison Bowe then asked Seth Andrews whether Intermountain had been involved with Nevada legislation related to newborn screening. Seth Andrews first asked whether the question referred to traditional metabolic newborn screening or genomic newborn screening. After Councilmember Madison Bowe clarified that the question concerned newborn screening in general, Seth Andrews explained that Intermountain and the University of Utah had maintained a clinical partnership with the state lab to support that work. He added that, to his knowledge, no legislative efforts in that area had been underway. Mike Wecker then said he was also unaware of any such efforts but noted that the matter could be checked against legislative priorities.

Seth Andrews 10:00am In the chat: Madison Bowe - do you have an e-mail you can share so we can reach out?

Brigette Cole – 10:03 am in the chat: Hello Seth and Mike, This is Brigette, CEO with Northern Nevada Children's Cancer Foundation. We serve northern Nevada families (Tonopah - north). I will email you both, as I would love to connect and learn more. My email is brigette@nnccf.org. Thank you!

Chair Annette Logan-Parker had a comment on the child life specialist issue, she explained that a coalition of child life specialists had been considering legislation to establish licensing requirements and build workforce infrastructure, similar to what had been done for genetic counselors in the previous session. She noted that a group had already been working on that effort and said introductions could be made.

Madison Bowe 10:05am in the chat: madisonbow95@yahoo.com

Chair Annette Logan-Parker shared that newborn screening has had some success during the last legislative session in expanding reimbursement for newborn screening in Nevada. She also noted that some initiatives had been removed from that bill and might be revisited in future efforts to continue expanding newborn screening in the state.

Chair Annette Logan-Parker then shared that a council member had asked about hospital staffing plans, noting that Nevada faced shortages in key healthcare professions and that staffing would likely be a major challenge.

Mike Wecker responded that staffing had likely been the biggest challenge, even more than constructing the building itself. The plan had been to work with local providers, physicians, nurses, radiology technicians, and other healthcare professionals already in the community, while also identifying areas where out-of-state recruitment would be needed to fill gaps. Efforts had also begun with local colleges and universities, particularly around nurse training, to help shape curriculum that supported pediatric care and strengthen the local workforce pipeline. The long-term goal had been to train and retain people locally rather than rely solely on outside recruitment. It was estimated that the hospital would need to hire around 1,500 to 2,000 employees, making it a significant undertaking, and foundational work had already begun in preparation for that effort.

Kim Anderson-Mackey 10:09 am in chat: Is it possible to get email address for both Seth and Mike for follow up topics?

Mike Wecker 10:09 am: Mike.wecker@imail.org

Seth Andrew 10:09 am: seth.andrews@imail.org

5) FOR INFORMATION ONLY: Update and discussion to the Nevada RDAC 2027 Legislative Session Protection Plan, that represents RDAC's interests and activities to protect the Council's potential consolidation during the 2027 Legislative Session. – Chair Annette Logan-Parker

Chair Annette Logan-Parker stated that there had not been any major new updates regarding the Nevada RDAC 2027 Legislative Session Protection Plan. It was shared, however, that the plan had been presented the previous week to the National RDACs through National Organization for Rare Disorders (NORD) after interest had grown around the council's proactive legislative effort to guard against potential consolidation under statewide efficiency initiatives. The presentation had gone well and had provided an opportunity to highlight local work on a national stage to other

RDACs. It was noted that Councilmember Christina Thilst had participated in the webinar and that the presentation had been very well received.

Madison Bowe 10:12am in the chat: I am wanting to get a recording of that webinar if possible

Chair Annette Logan-Parker said the recording could be provided. She believed it was available on the National Organization for Rare Disorders (NORD) website and stated that it would be located and sent out to everyone, adding appreciation for the suggestion.

6) FOR INFORMATION ONLY: Update and discussion and on the rollout of the 2027 Legislative session survey to get feedback on RDAC's level of involvement and initial feedback from Council members. – Chair Annette Logan-Parker

Chair Annette Logan-Parker asked Ashlyn Torrez to confirm the status of that survey.

Ashlyn Torrez responded that the survey had been sent out that week, noting that a delay had occurred and there were issues with SurveyMonkey. Ashlyn Torrez added that responses had already started coming in and that a fuller update would likely be available at the next meeting.

7) FOR INFORMATION ONLY: Update on the 2026 Nevada RDAC Blog series for social media that will provide education and outreach to the rare disease community. – Chair Annette Logan-Parker

Chair Annette Logan-Parker reported that the series had been going well, with profiles already completed for Councilmembers Christina Thielst, Dr. William Evans, and Dr. Craig Vincze, while Madison's profile was still in progress. She noted that the series had been well received in the community and thanked everyone for participating, adding that outreach would continue individually as each member's designated month approached.

8) FOR INFORMATION ONLY: Update and discussion of the Rare Disease Advisory Council (RDAC) Community Education Event. – Chair Annette Logan-Parker

Chair Annette Logan-Parker was concerned with the second survey related to the community education event planned for February 2027. Chair Annette Logan-Parker noted that the email with the survey link had gone out on April 1 and was due by April 8. Council members were encouraged to complete both surveys so the information needed for planning the 2027 Legislative Session and the 2027 educational event could be collected. Chair Annette Logan-Parker then asked whether there were any questions or comments.

Councilmember Madison Bowe asked for clarification on whether agenda item six and the current agenda item had referred to two separate survey emails or the same one, noting that only one survey appeared to have been received and that nothing had been seen regarding the community education event.

Ashlyn Torrez responded that the survey sent on April 1 had most likely been the community education event survey, while the legislative session survey should also have been sent separately. After confirming that the two were separate surveys, Chair Annette Logan-Parker stated that both links would be sent out again to make sure everyone received them. Ashlyn Torrez then said an updated email would be sent that day and that the deadline would be extended by another week.

9) FOR INFORMATION ONLY: Update on the inclusion of Congenital Heart Defects (CHD) conditions discussed at the last RDAC meeting to 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 stated that the rare disease dashboard shown at the last council meeting was now live on the Nevada Office of the State Epidemiology Rare Diseases webpage. The inclusion of the Congenital Heart Defects (CHD) conditions was still pending and that collaboration with the Maternal and Child Health Section still needed to take place, with more information expected by the next council meeting.

10) PUBLIC COMMENT

Ashlyn Torrez opened the floor for public comment.

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

12) ADJOURNMENT- *Ashlyn Torrez on behalf of Chair Logan-Parker*

Ashlyn Torrez moved to adjourn the meeting at 10:18 am.