

Joe Lombardo
Governor

Laura Rich,
Director



DEPARTMENT OF HUMAN SERVICES



NEVADA DIVISION of PUBLIC
and BEHAVIORAL HEALTH



Andrea R. Rivers,
MS
Administrator

Ihsan Azzam,
Ph.D., M.D.,
Chief Medical
Office

NEVADA RARE DISEASE ADVISORY COUNCIL

MEETING MINUTES

Date: October 2, 2026

9:35 AM – 10:51 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 9:35 AM.

1) INTRODUCTIONS AND ROLL CALL

COUNCIL MEMBERS PRESENT:

Annette Logan-Parker (CHAIR); Gina Glass (Vice-Chair); Amber Federizo, DNP, APRN, FNPBC; Jennifer Millet, DNP, RN; Valerie Porter, DNP, APRN, AG-ACNP-BC, MBA; Naja Bagner; Craig Vincze, PhD (late); Christina Thielst, LFACHE, MHA; Sumit Gupta, MD; Brigitte Cole; Melissa Bart-Plange; Pamela White; Mallory Carvalho; and Ann Jensen (Quorum=12)

COUNCIL MEMBERS ABSENT:

Ihsan Azzam, MD, PhD (excused absence); Paul Niedermeyer (excused absence); Kim Anderson-Mackey (excused absence); Verena Samara, MD (excused absence); Devraj Chavda, MD; Madison Bowe (excused absence); and William (Bill) Evans, MD

DIVISION OF PUBLIC & BEHAVIORAL HEALTH (DPBH) STAFF PRESENT:

Ashlyn Torrez, *Rare Disease Program Coordinator, Office of Epidemiology (OSE), DPBH*; Kagan Griffin, *OSE Operations Manager, OSE, DPBH*; and Jordan M. Lancaster, *Nevada Central Cancer Registry (NCCR) Program Manager, NCCR, OSE, DPBH*

OTHERS PRESENT:

Amber Williams, *Cure 4 The Kids Foundation*; Sierra Seda, *Cure 4 The Kids Foundation*; Amber Schreiber, *Cure 4 the Kids Foundation*; Whitney Glover, *Director Medicaid Policy, GeneDx Genetic Testing*; Aliyah Egan, *GeneDx Genetic Testing*; Chris Marquez, *GeneDx Genetic Testing*; Theresa Andrews, *GeneDx Genetic Testing*; Bella Peterson; Jasmin Torres; Josie Vaughn; Heidi Niedfeldt; Rachel Hoopes; Colby Gavin; Bruce Yeager; Shauna Burns; Jesse Baumgartner; and Kristen Hackbarth, *Nevada Cancer Coalition*

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 the next agenda item.

4) FOR POSSIBLE ACTION: Discussion and possible action to approve meeting minutes from August 7, 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 08/07/2026. Councilmember Brigitte Cole 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 renew terms of the below Council members and Chair Logan-Parker. Recommendations will be submitted to the Department of Human Services (DHS) Director for consideration of renewal of appointments.

Naja Bagner
Dr. Sumit Gupta
Amber Federizo
Brigitte Cole
Valerie Porter
Chair Annette Logan-Parker
Dr. Ihsan Azzam
Kim Anderson-Mackey

Chair Logan-Parker stated the above Councilmembers have expressed interest in renewing their terms to continue to serve the Council and asked for a motion to approve.

Vice-Chair Gina Glass motioned to approve the recommendation to renew the above Council members terms including Chair Logan-Parker. Councilmember Ann Jensen seconded the motion to approve. There were no objections. A quorum voted to approve the recommendation to renew the above Council members terms including Chair Logan-Parker.

3) FOR INFORMATION ONLY: Guest presentation on the Diagnostic Odyssey to Earlier Answers: Genomic Testing and Rare Disease in Nevada. – *Whitney Glover, GeneDx Genetic Testing*

Support staff Ashlyn Torrez introduced Whitney Glover with GeneDx Genetic Testing and opened the floor to Ms. Glover.

Ms. Whitney Glover thanked the Council for their time and expressed appreciation for the Council's work in Nevada. She introduced herself as the Director of Medicaid Policy at GeneDx, and noted her team works nationally to ensure Medicaid patients can access genomic testing. Her goal today is not to make everyone genetics experts, but to show how state policy and plan implementation can remove avoidable delays. She stated she is not a clinician but an advocate and fellow zebra herself and asked the Council to share questions in the chat for discussion at the end.

Ms. Glover introduced GeneDx as a national laboratory serving rare disease families for over 25 years, specializing in exome and genome testing. Their mission is to deliver actionable health insights that inform diagnosis and treatment. While rare diseases are individually uncommon, they collectively impact many families, often genetically. Genomic testing is not abstract or new but can turn years of uncertainty into a specific care plan. She shared one child's journey.

Ms. Glover introduced Amelia. From birth, Amelia experienced severe seizures and required intensive care. Ms. Glover stated Amelia's family spent years seeing specialists, undergoing hospitalizations, and trying to take medications without a diagnosis. After four years, an exome test finally provided an answer. Ms. Glover asked the Council to consider while hearing Amelia's story to think about Nevada families facing similar uncertainty, especially those traveling long distances or waiting months for specialty care.

Ms. Glover added Amelia's diagnostic journey lasted more than four years, something GeneDx likes to call an odyssey. Amelia's odyssey involved specialist visits, emergencies, procedures, and hospitalizations. After diagnosis, her care did not stop, and it became more targeted. That is the key point: earlier access to the right tool can shift care from repeated crises to informed, proactive decision-making. The goal is not less care, but the right care at the right time.

Ms. Glover stated that exome and genome sequencing are comprehensive diagnostic tools used when a child has complex or unexplained symptoms. Genome is the full book; exome is the protein-coding chapters. Both evaluate many genes at once, which is essential when symptoms overlap across many conditions. Policymakers should allow clinicians to choose the appropriate test rather than force a long sequence of lower yield tests.

Ms. Glover said for the children who need these tests, most are already enrolled in Medicaid. Many have developmental delays, seizures, congenital abnormalities, regression, or combinations of findings. These are complex cases that require more than single-gene testing. Nevada must ask whether the providers who know the child can order the test without avoidable specialty bottlenecks. The diagnostic odyssey involves years of appointments, tests, referrals, and often incomplete explanations. Families face emotional strain, lost work time, travel, and repeated costs. Nevada's focus on reducing diagnostic delay and improving specialty access makes this not just a clinical issue but a system-design issue. Fortunately, expert guidance has shifted toward using exome/genome earlier.

Ms. Glover continued that experts support exome/genome as first-line testing for developmental delay, intellectual disability, congenital anomalies, unexplained epilepsy, cerebral palsy, and autism when clinically appropriate. Coverage criteria should align with these standards. Outdated stepwise testing requirements keep children stuck in the diagnostic odyssey.

Ms. Glover discussed that Medicaid coverage has expanded to 39 states for exome/genome. Nevada remains grayed out because coverage exists on paper but not in practice. She expressed the importance of the Council playing a critical role in determining whether families experience access barriers such as inconsistent plan rules, narrow provider requirements, documentation burdens, or claim denials. Noting that commercial plans have also expanded coverage, though gaps remain. Medicaid members with complex pediatric needs have the greatest need for timely access. She noted that there was a shift from national trends to the distinction between “covered” and “accessible.” Nearly half of children with special health care needs are covered by Medicaid/CHIP (Children’s Health Insurance Program). Early and Periodic Screening Diagnostic, and Treatment (EPSDT) requires medically necessary testing, but the question is whether benefit design and plan operations allow children to actually receive it. Currently, many Nevada children who need this testing are not getting it.

Ms. Glover added that a state can intend to cover testing and still fail. Breakdowns occur at policy, prior authorization, provider availability, and claims processing. Policies may be broad at the state level but narrowed by managed care organizations. Incorrect coding edits can block payment. Consistent standards across fee-for-service and MCOs (Managed Care Association) are essential. Real-world evidence shows significant cost savings. In epilepsy, first-year savings were \$79,000 per patient. In developmental delay/intellectual disability, emergency and hospitalization use dropped dramatically. The value is not the price of the test, but it is the targeted care enabled by the diagnosis.

Ms. Glover stated Amelia’s healthcare use decreased sharply after receiving her exome results. Amelia’s events did not disappear, but they became purposeful and guided by her diagnosis. For Nevada families, especially in rural areas, this means unnecessary trips, fewer repeated tests, and more efficient care.

Ms. Glover continued to explain the three main barriers that block access: coverage misalignment, provider restrictions, and administrative friction. Nevada has only four practicing geneticists, all in southern Nevada. Policies requiring geneticist approval create a real barrier. Non-geneticists are capable of identifying appropriate patients when evidence-based criteria are used.

Ms. Glover stresses the geneticist workforce shortage is severe and requiring every child to see a geneticist turns a covered benefit into a long wait, especially in Nevada. While Telehealth helps it does not limit constraints and policies should allow qualified clinicians to order testing based on evidence and not a specialty title. Real-world data shows non-geneticists achieve diagnostic yields very similar to geneticists, demonstrating that appropriate patients are being identified. Provider criteria should be based on clinical expertise and evidence, not specialty designation.

Ms. Glover added that lack of access forces families into long delays and high costs, with rural families facing even greater burdens. Ms. Glover stated that symptoms don’t pause while the system catches up and the diagnostic odyssey continues until policy and practice improves. Nevada’s payer landscape

includes fee-for-service and multiple MCOs, creating oversight opportunities. Currently, only Health Plan of Nevada is reimbursing some tests. GeneDx has supported 320 Nevada children this year, 135 of them in Medicaid, many without reimbursement. Ms. Glover noted that biomarkers' coverage is extremely limited and there is still room for improvement.

Ms. Glover closed out the presentation with how the Council can take meaningful action by supporting exome/genome as medically necessary under EPSDT, recommend consistent implementation across fee-for-service and MCOs, allow qualified non-geneticists to order tests, and lastly measure success by patient experience. Lastly, expressing appreciation for the Council's leadership and attention.

Chair Logan-Parker thanked Ms. Whitney Glover for her presentation. She asked if Ms. Glover has seen improvement in other states, where genomic access is based on the National Provider Identifier (NPI) by granting genetic testing access to pediatricians and not only specialists. Chair Logan-Parker added that many rural Nevada providers report that they wish they could order genomic tests themselves rather than searching for a specialist, because the current NPI requirements and the long waits to see a geneticist create major bottlenecks.

Ms. Whitney Glover reported that EPSDT medical necessity review, rather than specialty restricted policy, has been the most effective method for expanding access to genomic testing. It was noted that the American Academy of Pediatrics released updated guidance in June 2025, and over the past year significant physician education efforts have taken place. As a result, an increasing number of pediatricians are now ordering exome and genome tests. Laboratories continue to support many of these orders even when reimbursement or prior authorization is not approved. Additionally, clinicians and insurance plan medical directors are often surprised that laboratories proceed with testing without prior authorization; however, pediatricians are demonstrating an ability to identify appropriate patients. Ms. Glover highlighted Indiana as a state with a policy that does not restrict ordering based on NPI specialty, instead using medical-necessity criteria to determine eligibility. A major payer is expected to issue updated policy within the next three weeks, reinforcing that NPI specialty should not prevent test approval when documentation demonstrates appropriate indications and outlines expected impacts on patient management. Ms. Glover emphasized that early access to testing allows earlier diagnosis, targeted referrals, and improved long-term management pathways. While most pediatrician-initiated orders are appropriate, some requests have been correctly denied based on medical-necessity criteria. A concern was raised regarding automated prior authorization systems, which may deny or delay testing solely because the ordering provider is not a geneticist or developmental pediatrician. Lastly noting that laboratories frequently continue supporting patient testing to avoid disrupting the diagnostic process. However, long-term sustainability requires policy alignment with current clinical practice, recognizing exome and genome sequencing as Tier 1 diagnostic tools and ensuring policy structures support access accordingly.

Chair Logan-Parker thanked Ms. Whitney Glover and asked if Ms. Glover has worked with other RDACs across the country on this particular access barrier and if Ms. Glover has seen any successes.

Ms. Glover highlighted her experience collaborating with Colorado. It was noted that Colorado's final policy outcome did not fully align with RDAC recommendations. The state initially moved toward

genome coverage but subsequently limited the benefit to EPSDT-eligible populations, creating barriers for appropriately indicated adult patients and for physicians treating unexplained epilepsy or other complex conditions. Ms. Glover noted that adults with longstanding, but complex medical needs also benefit from genomic testing, as targeted management can still improve care regardless of age. She explained, one of her colleagues on the call, oversee 24 states west of Mississippi. She noted that several states have successfully integrated advisory-council recommendations and policy reforms. Providing an example that Texas has engaged closely with GeneDx and its Medicaid leadership, the Medicaid Director and the program's physician lead, Dr. Ryan Van Ramshorst, a practicing pediatrician. Although Texas policy currently limits ordering to developmental pediatricians, state leadership acknowledged the practical barriers this creates for their own clinicians. Policy discussions are underway to expand pediatrician access to ordering genomic testing. Ms. Glover noted that national partnerships have strengthened in recent years and emphasized the value of collaboration across stakeholders. She encouraged the Council to seek input from multiple leaders in the genetic testing field and expressed appreciation for the opportunity to provide education and support. She emphasized the importance of genomic testing as a tool to send the diagnostic odyssey for patients.

Councilmember Ann Jensen introduced herself as the Medicaid Director for Nevada and expressed appreciation for the presentation and for grounding the discussion in a child-focused case study, noting alignment with Nevada's commitment to serving children and families. Ms. Jensen addressed comments regarding current policy implementation. She clarified that all Nevada MCOs are required to follow the same coverage policies as fee-for-service Medicaid. If inconsistencies occurred, she welcomed reports of specific cases and provided her contact information for follow-up. Regarding EPSDT determinations, she emphasized that Nevada applies this benefit carefully and seriously. Each authorization request is reviewed by a team of clinicians. She reminded the group that any member, family, or provider may appeal EPSDT-related decisions and noted that outcomes often depend on the documentation included with the request. She further explained that Medicaid coverage policy changes must follow the legislative process. Unlike commercial insurance, Medicaid cannot add new covered services, such as certain genomic tests without legislative approval. Because Nevada operates on a biennial legislative cycle, she encouraged stakeholders seeking expanded coverage to pursue the legislative route. Lastly, Ms. Jensen asked a question regarding the map shown during the presentation, about whether Medicaid coverage in other states was achieved through legislative bills, RDAC involvement, or alternative pathways, and requested a description of the legislative strategies used to secure such coverage.

Ms. Glover explained that not all states established coverage for exome and genome sequencing through legislation. The relevant CPT (Current Procedural Terminology) codes are already listed on the CMS national fee schedule, with established pricing for exome (81415, 81416) and genome (81425, 81426) testing. She noted that pricing concerns, particularly regarding comparator sample codes, created early national hesitation around exome coverage. She reported that in Texas, collaboration with Medicaid leadership led to administrative adoption of the exome codes onto the state fee schedule. Texas also adjusted pricing to more appropriate levels, an approach Ms. Glover fully supported. Similar support was provided in California for biomarker-related legislation and coordination with professional organizations. Ms. Glover added that while legislation is sometimes necessary, particularly for establishing biomarker mandates, it does not always create consistent or optimal implementation. Legislatively mandated coverage can outpace operational readiness, resulting in gaps in coding, fee

schedules, and medical-necessity review processes. She cited Indiana as an example where legislative action on biomarkers created a large volume of accessible codes, requiring subsequent administrative work to develop appropriate criteria and manage fiscal impact. Ms. Glover emphasized that administrative pathways, such as adopting selected CPT codes into the fee schedule, applying medical-necessity criteria, and aligning system edits are often effective for expanding access without requiring legislative action. These approaches can improve consistency and create clearer implementation frameworks. Ms. Glover asked whether Nevada operates under a “prohibition” model similar to Kansas, in which new codes or services may only be added to the Medicaid fee schedule through legislation accompanied by a fiscal note.

Ms. Jensen clarified that Nevada is not a “prohibition” state; however, the state budget structure requires legislative appropriation for any new Medicaid benefit. As a result, Nevada Medicaid cannot add coverage for services—including genetic testing—without legislation authorizing the associated funding. She agreed that having CPT codes, pricing, and operational details prepared in advance is helpful, as it streamlines the legislative process. She emphasized that legislative action is not viewed as adversarial or burdensome but is simply the established mechanism by which Nevada adds Medicaid benefits. Lastly, she reiterated that Nevada operates with lean state resources, and therefore legislative decision-making is essential in determining where funding is allocated. Medicaid stands ready to provide technical assistance during the legislative process, including guidance on calculating accurate fiscal notes and implementation costs.

Ms. Glover expressed appreciation for the prior clarification and provided additional context regarding EPSDT-related claims and operational barriers. She noted that although claims have been submitted under EPSDT, the absence of exome and genome CPT codes on Nevada’s Medicaid fee schedule prevents these claims from undergoing medical-necessity review. Without codes to anchor policy application, claims are automatically denied, and appeals cannot move forward meaningfully. She stated that GeneDx has not yet pursued State Fair Hearing in Nevada but has used that process successfully in Texas, California, and Colorado. She further explained that as a national laboratory without an in-state facility, GeneDx faces credentialing challenges in Nevada and is only granted emergent credentialing on a retroactive six-month cycle. This creates an additional barrier to consistent reimbursement despite serving Nevada patients. Ms. Glover provided clarification regarding MCO practices. She noted that while Health Plan of Nevada has applied some broader national coverage standards and occasionally reimburses for testing, other MCOs, such as Molina, do not currently apply similar coverage in Nevada, even though they do so in other states. Because Nevada Medicaid does not yet have a statewide policy covering exome or genome testing, MCOs may sometimes approve individual cases but do not provide broad or consistent coverage across their membership.

Chair Logan-Parker thanked both Ms. Jensen and Ms. Glover for their discussion. She noted that RDAC does not have any Bill Draft Requests (BDRs) assigned to the Council but is working on few BDRs through the Cure 4 The Kids Foundation for the next upcoming legislative session. She opened the floor for any other Councilmembers that might have questions.

Councilmember Amber Federizo highlighted the significant impact that limited access to genetic testing has on clinicians in Nevada. She emphasized that delays in both pediatric and adult diagnostics

contribute to moral injury among providers, particularly in a state already struggling with provider retention. When clinicians are required to repeat outdated or flow-yield diagnostic processes, despite knowing more appropriate tests exist, it leads some to leave the state for systems with better resources and support. Ms. Federizo shared her experience as a parent of a child with a rare disease, noting that she had to travel to California to obtain necessary approvals. She acknowledged that Nevada Medicaid does offer access to genetics services, but the process is difficult, and certain CPT codes remain restricted to specific ordering providers, causing additional barriers. She continued to describe the downstream effects of diagnostic days when patients cannot access genetic testing and undergo numerous unnecessary visits before reaching a diagnosis that not only incurs higher system costs but also occupies specialist appointments, contributing to waiting times of three to six months for other patients needing care. Ms. Federizo noted that accurate early diagnosis can improve outcomes to where some patients eventually transition off Medicaid and into commercial insurance as adults who are able to work and live independently. By contrast, delays perpetuate avoidance of healthcare use and strain the system. She reiterated that the moral inquiry placed on providers and the broader system impacts, urging improvement in access processes to support both patients and clinicians.

Chair Logan-Parker thanked Councilmember Amber Federizo, and asked support staff Ashlyn Torrez if there were any other comments or hands raised.

Councilmember Ann Jensen put into the chat at 10:31 AM: “*redacted*- please reach out with any questions or needs regarding current Medicaid policy!”

Councilmember Ann Jensen put into the chat at 10:31 AM: “Really appreciate that comment, Amber.”

Councilmember Ann Jensen put into the chat at 10:31 AM: “I unfortunately have to drop - thank you, all! As always, really appreciate being here.”

Ms. Torrez stated that Councilmember Ann Jensen put her email and asked anyone to reach out with any questions or needs regarding current Medicaid policy, and she also commended Councilmember Amber Federizo for her comment.

Chair Logan-Parker thanked Ms. Torrez and Ms. Whitney Glover for her presentation to the Council. She moved on to the next agenda item.

- 7) **FOR POSSIBLE ACTION:** Discussion and possible action to approve the RDAC Subcommittee recommendation to postpone the Southern and Northern Nevada Community Education Events, consolidate the 2027 event plans to one event, focusing on the Legislative Education Event in Carson City, and moving forward to consider those events on alternative years.

Chair Logan-Parker stated the Subcommittee meeting on May 1, 2026, recommended postponing the Community Education Events in Northern and Southern Nevada and to consolidate to one event and alternate future years. She asked the Council for a motion to approve.

Councilmember Dr. Sumit Gupta motioned to approve postponing the Southern and Northern Nevada Community Events, consolidating both events to one event hosted on alternate years. Councilmember Brigitte Cole seconded the motion to approve. There were no objections. A quorum voted to approve

postponing the Southern and Northern Nevada Community Events, consolidating both events to one event hosted on alternate years.

- 6) FOR POSSIBLE ACTION: Discussion of, nomination of, and voting for Chair Annette Logan-Parker and a new Vice Chair of the Nevada Rare Disease Advisory Council for the next term of two years pursuant to *Article 6, Section 1 and Article 6, Section 2* of the Rare Disease Advisory Council Bylaws.

Chair Logan-Parker asked support staff Ashlyn Torrez to address the Council for an update on Chair and Vice-Chair inquiries.

Ms. Torrez stated a survey went out to the Councilmembers earlier this month to gauge interest in both roles. However, it was noted that there was no interest in either role besides our current Chair Logan-Parker. Our current Vice-Chair Gina Glass will be stepping down from her role as she is going through a career transition within Dream Sickle Kids Foundation. Ms. Torrez stated the RDAC bylaws require a Vice-Chair and opened the floor for nominations, but the voting will be held at the next Council meeting for Chair and Vice-Chair roles. Another option presented to the Council was to amend the bylaws to remove the requirement to have a Vice-Chair.

Chair Logan-Parker thanked Ms. Torrez and stated an email that will be sent out to the Council members detailing the Vice-Chair commitment and expectations, and another survey will go out to the Council to determine interest.

- 9) FOR POSSIBLE ACTION: Discussion and possible action to approve the 2027 Rare Disease Advisory Council (RDAC) meeting schedule to meet every quarter instead of bi-monthly on the first Friday of the month at 9:30 AM PST, excluding January which will be the second Friday of the month due to a state and federal holiday.

January 8, 2027
April 2, 2027
July 2, 2027
October 1, 2027
December 3, 2027

Chair Logan-Parker introduced the agenda item to adjust the 2027 meeting schedule to be quarterly instead of bi-monthly and asked the Council for a motion.

Councilmember Dr. Sumit Gupta motioned to approve the 2027 meeting schedule. Councilmember Valorie Porter seconded the motion to approve. There were no objections. A quorum voted to approve the 2027 meeting schedule.

- 8) FOR POSSIBLE ACTION: Discussion and possible action to approve the annual report that is due to Governor Lombardo and the Director of the Legislative Counsel Bureau in December 2026, pursuant to [NRS 439.5077\(2\)\(b\)\(2\)](#).

Chair Logan-Parker briefly shared a rough draft of the 2026 Annual Report, and noted the report being similar to prior years. She stated the final draft will be made available to the

Councilmembers in advance of the next RDAC meeting and opened the floor for comments or questions.

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

10) PUBLIC COMMENT:

Chair Logan-Parker opened the floor for public comment.

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

11) ADJOURNMENT: – *Chair Logan-Parker*

Chair Logan-Parker moved to adjourn and expressed appreciation for everyone on the Council.

Chair Logan-Parker moved to adjourn the meeting at 10:51 AM.