NVRDAC

Rare Disease Advisory Council

ANNUAL REPORT 2025

www.nvrdac.org

Boldly Advancing Nevada's Rare Disease Initiatives

Executive Summary

The Nevada Rare Disease Advisory Council (NV-RDAC) continued its mission to improve the quality of life for Nevadans living with rare diseases through collaboration, education, support, and advocacy. 2025 was a year defined by action, innovation, and measurable progress. The Council strengthened statewide data infrastructure, implemented new policy milestones, and deepened partnerships across the healthcare and advocacy spectrum.

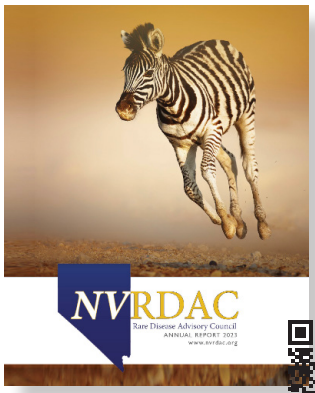
Key Highlights:

- Operational launch of the Nevada Childhood Cancer & Rare Disease Registry, housed at Cure 4 The Kids Foundation.
- Launch of the Statewide Healthcare Provider Needs Assessment to capture provider experiences and barriers.
- Policy advancements through SB 189 (Licensure of Genetic Counselors) and SB 348 (Modernized Newborn Screening).
- Expansion of the bilingual "While You Wait" awareness campaign and statewide education initiatives.
- National recognition by the National Organization for Rare Disorders (NORD) as one of the most effective RDACs in the country.

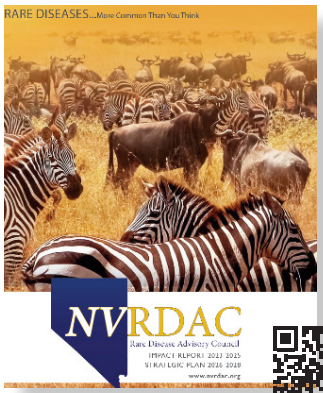
Together, these milestones reflect NV-RDAC's continued commitment to advancing evidence-based, patient-centered policy while fostering compassion and collaboration statewide.

Our resources

Scan QR Code to view each document:



NV-RDACs 2023 Annual Report



NV-RDACs Strategic Plan

NV-RDACs Needs Assessment

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A Letter from the Chair

Theme for 2025 is *Boldly Advancing Nevada's Rare Disease Initiatives*. 2025 was a year of acceleration and measurable impact for the Nevada Rare Disease Advisory Council (NV-RDAC). Guided by our mission to improve the quality of life for Nevadans living with rare diseases through collaboration, education, and advocacy, the Council built on the strong foundation of 2024 to further advance Nevada's rare disease priorities.

This year, we turned progress into performance. The Council focused on implementing key legislative wins, expanding data infrastructure, and strengthening collaboration with patients, providers, advocates, and community partners dedicated to improving care for those affected by rare diseases.

A defining achievement was the statewide expansion of data and assessment initiatives designed to turn insight into impact. The Nevada Childhood Cancer and Rare Disease Registry, housed at Cure 4 The Kids Foundation, reached full operational status—giving Nevada its first real-time system to track prevalence, outcomes, and access barriers across the state. Building on that foundation, the Council launched the Statewide Healthcare Provider Needs Assessment, expanding our focus beyond patient experience to better understand the challenges faced by front-line clinicians who care for rare disease patients. Together, these initiatives are helping Nevada listen—to families, to providers, and to communities—and translate that understanding into action.

We also celebrated key policy milestones. SB 189 established licensure for genetic counselors, and SB 348 increased the state's newborn screening program fee structure, enabling earlier detection and improving outcomes for children and families.

Nevada's leadership continues to be recognized nationally. The National Organization for Rare Disorders (NORD) again named NV-RDAC one of the most effective councils in the country. Partnerships with the EveryLife Foundation, Global Genes, and Make-A-Wish Nevada deepened our reach and impact, connecting data, advocacy, and compassion in powerful new ways.

As we continue boldly advancing Nevada's rare disease initiatives, our focus remains clear: ensuring every patient receives timely diagnosis, equitable access, and the dignity of being seen, heard, and supported.

Together, we are transforming rare disease care from fragmented to coordinated—and from unseen to understood.

Sincerely,

Annette Logan-Parker
Chair - Nevada Rare Disease Advisory Council
info@nvrdac.org

Council Membership, Governance, and Meeting Summary

The Nevada Rare Disease Advisory Council (NV-RDAC) is charged under NRS 439.5075 to advise the state on policy, data, and care coordination for individuals affected by rare diseases.

The Nevada Rare Disease Advisory Council (NV-RDAC) convened regularly throughout 2025 to oversee implementation of its legislative, data, and outreach priorities. All meetings were open to the public and maintained quorum, reflecting the Council's commitment to transparency and collaboration.

Full Council Meetings (6):

- February 7 – Legislative session kickoff; review of needs assessment progress.
- April 4 – Presentation on statewide clinical trials; registry development update.
- June 6 – Legislative debrief and mid-year report preparation.
- August 1 – Guest presentations: Orchard Therapeutics (MLD Screening) and Make-A-Wish Nevada; approval of Healthcare Provider Needs Assessment.
- October 3 – Review of registry data integration, Medicaid coordination, and strategic-plan alignment.
- December 5 (scheduled) – End-of-year wrap-up, adoption of the 2025 Annual Report, and 2026 legislative readiness.

Subcommittee Meetings (3):

- March 7 – Data Infrastructure & Registry Development Subcommittee established reporting framework and data standards.
- July 11 – Awareness & Education Subcommittee advanced the 'While You Wait' campaign and provider outreach materials.

Together, these eight sessions advanced the Council's strategic goals, ensuring alignment between policy, data, and community-based action statewide.

Key Governance Updates:

- Advance notice requirement for council announcements (DAG directive)
- Expansion of public participation and community partnerships
- Introduction of a new onboarding packet for members

Meet the Council:

Annette Logan-Parker
Chair – Founder & Chief Advocacy & Innovation Officer, Cure 4 The Kids Foundation

Georgene "Gina" Glass
Vice-Chair – Founder & Executive Director, Dreamsickle Kids Foundation

Dr. Ihsan Azzam, MD, PhD, MPH
Chief Medical Officer, State of Nevada Division of Public & Behavioral Health

Kim Anderson-Mackey
Director of New Business Development, Infinity Hospice Care • Member, Nevada Palliative Care Council

Melissa Bart-Plange
Financial Contracts Specialist Lead, Everi Holdings Inc. • Parent Advocate for Rare Diseases

Brigette Cole
Chief Executive Officer, Northern Nevada Children's Cancer Foundation (NNCCF)

Amber Federizo, DNP, APRN, FNP-BC
Advanced Practice Registered Nurse (APRN)

Dr. Sumit Gupta
Pediatric Hematology/Oncology Physician, Cure 4 The Kids Foundation

Jennifer Millet, DNP, MSN, RN
Director of Medical-Surgical Services, University Medical Center of Southern Nevada

Paul Niedermeyer
President, PN LLC – Consulting & Health Policy Advisory Services

Valerie Porter, DNP, AG-ACNP-BC, MBA
Hospitalist, VA Southern Nevada Healthcare System • Critical-Care Nurse Leader

Craig Vincze, PhD
President, Max Vincze Foundation • Biomedical Engineer & AYA Cancer Research Advocate

Pamela White
Founder & Executive Director, Bridging the Gap – Adult Sickle Cell Disease Foundation of Nevada

Christina B. Thielst, LFACHE, MHA
Healthcare Executive & Consultant • Life Fellow, American College of Healthcare Executives

Dr. Verena Samara
Neurologist & Neuromuscular Specialist, Carson Tahoe Medical Group • Clinical Assistant Professor, UNR School of Medicine

Dr. Devraj Chavda
Pediatric Neurologist & Epileptologist • Co-Founder, Neurology & Epilepsy Specialists of Las Vegas

Madison Bowe
Rare-Disease Patient Advocate • Public Speaker & Community Ambassador

Dr. William N. Evans
Founder & Co-Director, Children's Heart Center Nevada • Pediatric Cardiologist

Naja Bagner
Community Health Worker & Sickle Cell Advocate, Dreamsickle Kids Foundation

Mission: The Nevada Rare Disease Advisory Council's mission is to improve the quality of life and support care for Nevadans affected by rare diseases through collaboration, education, support, and advocacy. Our council seeks to advocate for Nevadans impacted by rare diseases as well as identify the overall impact these diseases have in our community.

Special Acknowledgement:

The council would like to recognize the contributions of our support team from the Nevada Department of Health and Human Services:
Ashlyn Torrez, Kayla Samuels, Kagan Griffin, Melissa Peek-Bullock
Cody Phinney, Jennifer M. Spencer, Geordan Goebel

The council would like to recognize the generosity and the contributions of our support team from Cure 4 The Kids Foundation:

Jamey Felsing (Vice-President of Operations) - Needs Assessment/Data Storage/Cyber Security
Mitch Koulouris (Director of Digital Content and Strategy) - Social Media
Beverly Ritzel (Clinical Applications Specialist) - Rare Disease Registry Platform Design
Jaromy Russo (Applications Specialist) - Needs Assessment/Data Storage
Amber Williams (Director of Communications) - Branding and Design/Special Assistant to the Chair

Legislative & Policy Progress – Advocacy in Action

The Nevada Rare Disease Advisory Council (NV-RDAC) continued to play an influential role in shaping health policy and ensuring that the voices of patients, families, and providers informed legislative decisions during the 2025 session. The Council's data-driven approach strengthened Nevada's framework for early diagnosis, equitable access, and sustainable care for individuals living with rare diseases.

Throughout the session, NV-RDAC provided expert testimony, data briefs, and written recommendations to legislators, helping advance bills that directly improve access to life-saving care and specialized medical services. By maintaining close collaboration with the National Organization for Rare Disorders (NORD), the EveryLife Foundation, and community partners, the Council ensured that Nevada remained at the forefront of rare disease conversation nationally.

Key Legislative Achievements

- SB 189 – Licensure for Genetic Counselors

Passed during the 2025 session, this bill established a formal licensure pathway for genetic counselors practicing in Nevada. The law ensures that families navigating rare and inherited conditions can access qualified professionals trained in genetics, counseling, and advanced diagnostics. NV-RDAC's early advocacy—including expert input from Dr. Mark Nunes, Director of Genetics and Metabolism at Cure 4 The Kids Foundation—helped shape the bill's framework and align Nevada's licensure standards with national best practices.

- SB 348 – Modernization of Nevada's Newborn Screening Program

SB 348 increased the newborn screening fee from $81 to $150, expanding the number of conditions tested at birth and strengthening the state's laboratory infrastructure. NV-RDAC strongly supported this initiative, citing the life-saving impact of early detection for many rare conditions. This legislation represents a critical investment in prevention and precision medicine for Nevada's youngest patients.

Additional BDRs and Policy Support

The Council also endorsed and monitored several key Bill Draft Requests (BDRs) aligned with NV-RDAC's mission, including:

- BDR 123 – Newborn Screening Expansion – adding federally recommended conditions to Nevada's screening panel.
- BDR 124 – Pediatric Stem Cell and Bone Marrow Transplant Program – supporting in-state access to life-saving pediatric therapies.
- BDR 38-218 – Pharmacist Reimbursement Through Medicaid – improving access to pharmacist-provided clinical services for rare disease patients.
- BDR 57-344 – Pharmacy Scope of Practice – establishing a "standard of care" framework that enables pharmacists to perform CLIA-waived testing and manage medication refills collaboratively with physicians.

- BDR 40-343 – Telehealth Expansion – ensuring reimbursement parity between telehealth and inperson visits to reach rural rare disease patients.

These legislative initiatives collectively advanced Nevada's position as a national model for data-informed, patientcentered healthcare policy. The Council's consistent engagement—through testimony, policy briefs, andcollaboration with lawmakers—ensured that rare disease patients remain visible in every stage of policy development.

"Legislative progress is more than passing bills—it's about removing barriers for families who have spent years searching for answers. Every reform we help achieve means faster diagnosis, stronger care coordination, and greater hope for Nevada's rare disease community."

— Annette Logan-Parker, Chair, NV-RDAC

Together, these accomplishments reaffirm NV-RDAC's role as a trusted partner in Nevada's legislative process—turning advocacy into measurable progress and ensuring that public policy reflects the compassion, innovation, and resilience of the rare disease community.

National Ranking In Rare Disease Support

Since 2015, the National Organization of Rare Disorders (NORD) has been engaged in its State Report Card project, aimed at assessing the effectiveness of states in meeting the requirements of their residents with rare diseases. While the report card evaluates states across eight specific and pertinent policy and access areas, it's crucial to emphasize that this grading criteria, although valuable, is not all-encompassing. Numerous significant factors affecting the lives of rare disease patients exist, even if they are not reflected in this ranking.

Nevada's Current Report Card Update

Nevada continues to make measurable progress in expanding access to rare disease care, genetic testing, and early detection programs. The 2024 NORD State Report Card shows Nevada performing near the national average overall, with high marks for Medicaid eligibility, step therapy reform, and telehealth participation. Persistent gaps remain, however, in affordability, newborn screening sustainability, and in-state diagnostic infrastructure.

The 2025 legislative session advanced two key bills — SB189 and SB348 — that collectively strengthen the state's framework for rare disease detection and support. While amendments to SB348 limited the financial modernization originally envisioned, both bills represent significant progress toward the priorities outlined in the National Organization for Rare Disorders (NORD) 2025 Policy Agenda.

Newborn Screening: B (Overall)
Nevada maintains a "B" rating in newborn screening, reflecting stable performance and a continued commitment to early detection.

- The state currently screens for 32 of the 35 Recommended Uniform Screening Panel (RUSP) core conditions.
- SB348 (2025) modestly increased the allowable newborn screening fee from $81 to $122 (2025) and $150 (2026), requiring Medicaid to reimburse newborn screening separately from delivery care

Although this represents incremental progress, the final bill removed automatic inflation indexing, lab modernization funding, and establishment of a state genetics clinic. These deletions limit the program's long-term financial stability and its ability to expand screening capacity.

2025 Outlook:
SB348 strengthens short-term sustainability but does not yet achieve full alignment with NORD's call for robust, 'well-funded newborn-screening programs in every state.'

NEVADA'S CURRENT REPORT CARD

The National Organization for Rare Disorders (NORD) publishes an annual State Report Card that evaluates how well each U.S. state supports people with rare diseases. The report covers several key areas, including newborn screening, access to medical nutrition, and the presence of Rare Disease Advisory Councils (RDACs). The latest edition of the State Report Card was compiled using data current as of November 2024.

MEDICAID FINANCIAL ELIGABILITY

B

Medicaid Eligibility for Childless adults: A
Medicaid Eligibility for Parents of a Dependent Child: A
Medicaid Eligibility for Pregnant Women: C
Medicaid Eligibility for Children: C

NEWBORN SCREENING

B

Screening for RUSP Core Conditions: D
Adding Screens: A
AC: A

PROTECTING PATIENTS IN STATE MEDICAID PROGRAMS

PASS

STEP THERAPY (FAIL FIRST)

A

Categories: F
Clinical Practice: C
Exceptions Process: A
Timeline: A

PROTECTING PATIENTS IN STATE REGULATED INSURANCE

C

Initial Plan Duration: C
Maximum Duration: C
Renewals: D

RARE DISEASE ADVISORY COUNCIL

YES

TELEHEALTH

PASS

MEDICAL NUTRITION

B

PRESCRIPTION OUT-OF-POCKET COSTS: C

Step Therapy (Fail-First): A

Nevada retains an "A" rating for Step Therapy reform.

- Following SB194 (2023), insurers must provide clear exception pathways and timely determinations. Implementation gaps remain ("F" for Categories, "C" for Clinical Practice), underscoring the need for continued oversight to ensure patients requiring complex or high-cost therapies can access care without delay.

Prescription Drug Out-of-Pocket Costs: C

- Nevada's grade improved from F to C, showing slow but steady progress in affordability. High out-of-pocket costs for specialty drugs continue to affect those with rare and chronic conditions. Further state action is needed to cap patient costs and ensure PBM reforms deliver tangible savings for rare-disease families.

Medicaid Financial Eligibility: B

- Nevada maintains strong adult coverage (A for adults and parents) but continues to lag for pregnant women and children (C), leaving key pediatric populations more vulnerable to coverage gaps. Expanding eligibility for these groups would align Nevada with NORD's equity-driven coverage goals.

Medical Nutrition: B

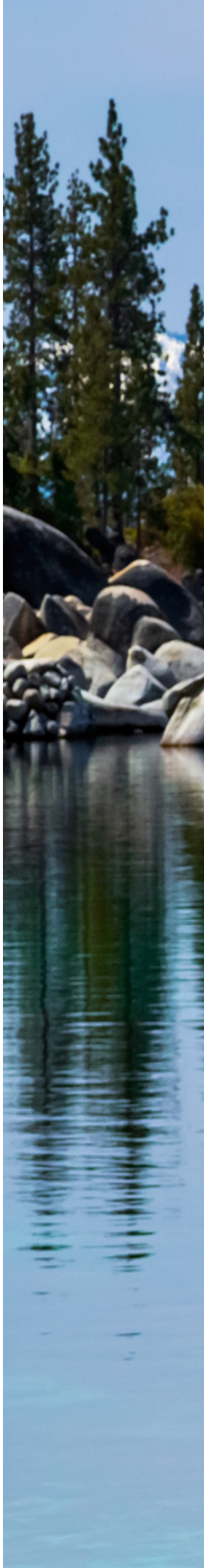
- Coverage for medically necessary foods and formulas remains moderate and inconsistent across insurance carriers. Continued advocacy is needed to strengthen statutory protections for metabolic and GI rare-disease management.

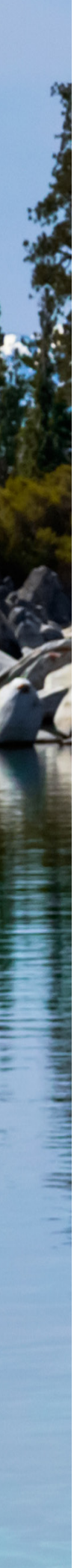
Telehealth: Pass

- Nevada's membership in the Interstate Medical Licensure Compact (IMLC) and expansion of telehealth access earns a Pass, maintaining critical cross-state connectivity for families in rural and frontier regions. The infrastructure established under SB189 now provides the clinical capacity to support these virtual care pathways.

Rare Disease Advisory Council (RDAC): Yes

- Nevada continues to lead nationally with an active and effective Rare Disease Advisory Council (NV-RDAC). The council's data-driven policy recommendations and collaboration with the Department of Health and Human Services shaped both SB189 and SB348, demonstrating the value of state-level stakeholder engagement in public-health modernization.





Legislative Integration: SB189 and SB348 (2025 Session)

- The passage of SB189 and SB348 during the 2025 legislative session represents the most comprehensive rare-disease policy advancement Nevada has achieved in over a decade. Together, they create a coordinated framework that links early detection, diagnostic interpretation, and system-wide coverage.

SB189 (2025) – Expanding Genetic Counseling and Laboratory Oversight

- Establishes licensure for genetic counselors through the Nevada State Board of Medical Examiners.
- Recognizes genetic counseling as a reimbursable medical service, paving the way for Medicaid and private-insurance inclusion.
- Defines the scope of practice for counselors, ensuring consistent patient education and test interpretation.
- Strengthens laboratory quality and ethical standards for molecular and genetic testing.

Impact:
SB189 directly supports NORD's 2025 goal to reduce the diagnostic odyssey by ensuring that every screening or test result can be followed by expert interpretation and patient navigation. It also provides the workforce foundation for Nevada's genetic-testing infrastructure — complementing SB348's system-level reforms.

SB348 (2025) – Modernizing the Newborn Screening Program

- Aligns Nevada's screening with the federal RUSP and increases the laboratory fee ceiling to sustain operations.
- Establishes Medicaid reimbursement for newborn screening separate from delivery and newborn care.
- Though scaled back, it begins to modernize a program whose fee structure had been unchanged for more than a decade.

SB348 addresses the fiscal fragility of Nevada's newborn screening system and moves the state closer to national standards for access and early detection. The bill, however, requires future legislative action to secure permanent funding and infrastructure expansion.

Overall Assessment
Nevada's 2025 policy performance demonstrates meaningful momentum toward a fully integrated rare-disease framework.

- SB189 created the professional and regulatory foundation for high-quality genetic services.
- SB348 strengthened the fiscal and administrative foundation for newborn screening.

Together, they bring Nevada closer to NORD's 2025 vision of early diagnosis, affordable access, and coordinated care.

To sustain this momentum, Nevada's next policy goals should include:

Reinstating automatic fee indexing and dedicated lab-modernization funding.

Data Infrastructure & Statewide Assessments – Turning Insight Into Impact

In 2025, the Nevada Rare Disease Advisory Council (NV-RDAC) made significant progress in its mission to transform data into action. The Council's commitment to measurable outcomes came to life through two major initiatives that now define Nevada's approach to understanding and improving rare disease care: the Nevada Childhood Cancer and Rare Disease Registry and the Statewide Healthcare Provider Needs Assessment. Together, these efforts created the state's first comprehensive data ecosystem for rare diseases—linking patient experiences, provider perspectives, and public health insights into one unified framework.

Nevada Childhood Cancer & Rare Disease Registry

Housed at Cure 4 The Kids Foundation, the Nevada Childhood Cancer and Rare Disease Registry became fully operational in 2025 after years of planning, advocacy, and collaboration among public health partners, data experts, and rare disease advocates. This registry serves as Nevada's first real-time platform for tracking the prevalence, outcomes, and care pathways for both pediatric and adult rare disease patients.

The registry integrates directly with the Nevada Central Cancer Registry, aligning local data collection with national reporting standards while ensuring accuracy and completeness in rare disease surveillance. More than 600 cases were entered during its inaugural year of reporting, encompassing childhood cancers, sickle cell disease, lupus, and newborn screening conditions. The data collected now enables state leaders and policymakers to:

- Quantify rare disease prevalence and geographic distribution across Nevada.
- Identify disparities in diagnosis and access to specialized care.
- Evaluate the economic and social impact of rare diseases on families and the healthcare system.
- Support eligibility for federal grants and research initiatives through improved reporting quality.

Beyond its analytical power, the registry represents a profound shift toward visibility. Every case recorded helps illuminate patterns once hidden in fragmented systems—allowing researchers, providers, and legislators to make informed, compassionate, and strategic decisions about Nevada's healthcare future.

Statewide Healthcare Provider Needs Assessment

Building on the registry's patient-level insights, NV-RDAC expanded its focus in 2025 to include the professionals at the heart of care delivery. The Statewide Healthcare Provider Needs Assessment was launched to understand the challenges faced by physicians, nurse practitioners, pharmacists, genetic counselors, and allied health professionals who serve the rare disease community.

Developed in partnership with healthcare and academic collaborators, the survey was built on the REDCap platform, ensuring accessibility across mobile and desktop devices. The assessment gathered quantitative and qualitative data to evaluate:

- Provider confidence in managing rare disease patients.
- Awareness and use of genetic testing, telehealth, and specialty referrals.
- Barriers related to reimbursement, care coordination, and workforce shortages.
- Opportunities for continuing education and multidisciplinary collaboration.

Initial responses have already highlighted common themes—insufficient access to specialty resources, inconsistent reimbursement for genetic testing and advanced therapies, and a growing need for structured communication pathways between community-based providers and specialists. These findings will inform the Council's upcoming 2026–2028 Strategic Plan, shaping both short-term policy actions and long-term system improvements.

Turning Insight Into Action

Together, the registry and provider assessment have laid the foundation for a data-driven rare disease framework that empowers Nevada to move from anecdote to evidence. For the first time, state policymakers and public health officials can access reliable, actionable data that connects the lived experiences of families to the structural realities of healthcare delivery.

By combining these two complementary perspectives—patient outcomes and provider experiences—NV-RDAC is ensuring that future solutions are informed by evidence, compassion, and collaboration. What was once a fragmented landscape is now a connected network, enabling Nevada to lead the nation in translating rare disease data into measurable, meaningful change.

Care & Support – Expanding Access & Equity

In 2025, the Nevada Rare Disease Advisory Council (NV-RDAC) continued advancing initiatives that strengthen the state's capacity to deliver equitable, coordinated, and compassionate care for individuals and families living with rare diseases. Building upon the foundational work of previous years, the Council focused on reducing barriers to diagnosis, expanding access to specialized services, and ensuring that patients across Nevada—regardless of geography or circumstance—receive the care they deserve.

Family & Community Partnerships

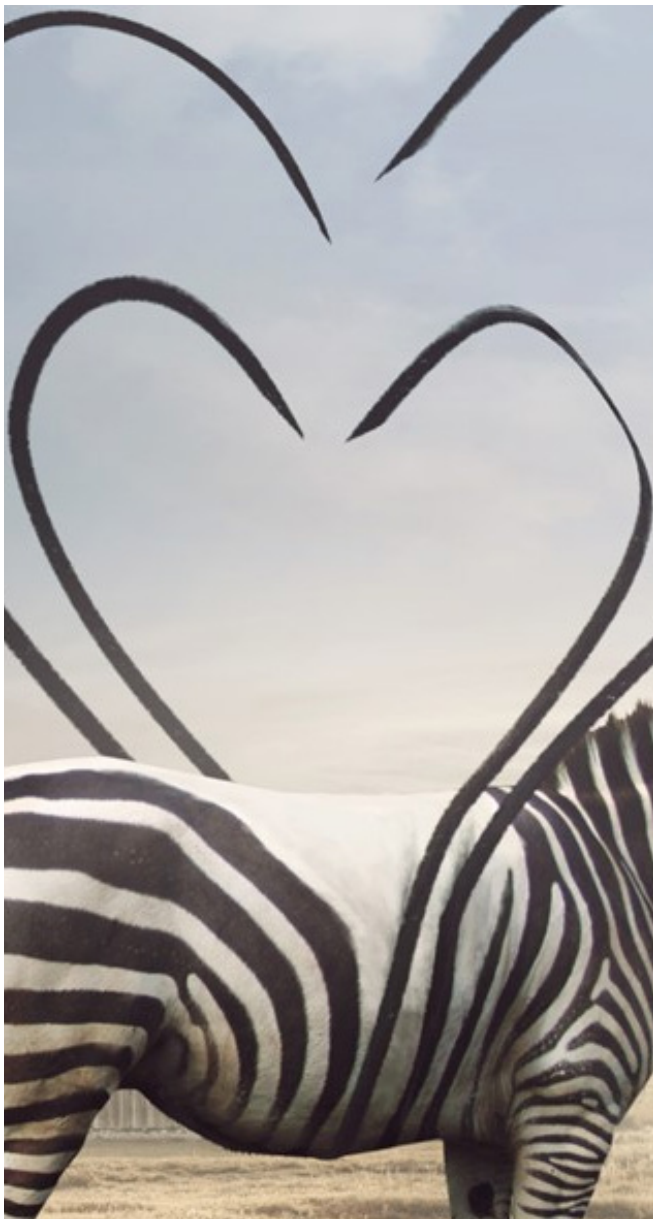
NV-RDAC recognizes that improving rare disease care requires not only policy reform but also the power of partnership. In 2025, the Council worked closely with leading community organizations whose missions intersect with the needs of Nevada's rare disease families:

- Make-A-Wish Nevada expanded its eligibility criteria to include children with rare diseases, enabling more families to experience moments of hope and relief during challenging treatment journeys. NV-RDAC supported this expansion by helping connect families through its statewide network.

- Dreamsickle Kids Foundation continued to serve as a vital partner in patient advocacy, education, and support for individuals living with sickle cell disease and other rare conditions. Their on-the-ground work in Southern Nevada continues to amplify awareness and empower families navigating complex care.

- Northern Nevada Children's Cancer Foundation (NNCCF) provided critical financial and psychosocial support to families affected by childhood cancer, aligning with NV-RDAC's mission to ensure equitable care across the state.

Through these partnerships, NV-RDAC strengthened the link between community-based services and state-level advocacy, ensuring that policy decisions are informed by the real-world experiences of those they are designed to help.

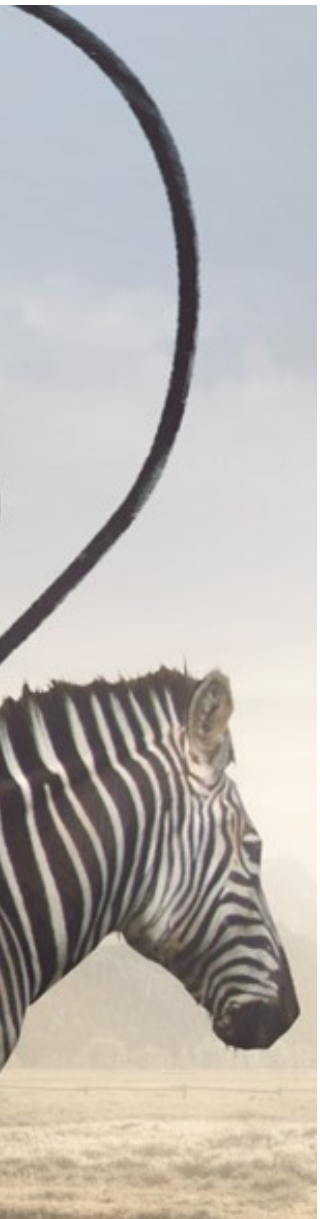


In 2025, Nevada took meaningful steps toward that vision. Families are being seen, heard, and supported like never before—and NV-RDAC remains committed to ensuring that every rare disease patient has access to comprehensive, coordinated, and compassionate care.

Awareness & Education – Building an Informed Nevada

Awareness remained at the heart of the Nevada Rare Disease Advisory Council's (NV-RDAC) mission throughout 2025. For a community as diverse and geographically spread as Nevada's, awareness is more than communication—it is connection.

The Council's education and outreach initiatives focused on empowering patients and families with knowledge, equipping providers with tools to better serve those living with rare diseases, and ensuring policymakers and the public understand the profound impact of rare conditions on individuals and communities statewide.



Expanding the "While You Wait" Campaign

The Council's bilingual "While You Wait" awareness campaign entered its second year of statewide implementation in 2025, expanding to 65 healthcare clinics, hospitals, and community centers across both Northern and Southern Nevada. Designed to engage patients and families during their time in waiting rooms and clinics, this initiative provides accessible educational materials in English and Spanish about rare diseases, early signs of genetic disorders, and available local resources for support and referral.

Through collaboration with public health agencies and clinical partners, NV-RDAC refreshed the campaign's content to include QR codes linking directly to nvrdac.org, patient advocacy resources, and registry participation opportunities. This modernized design enabled families to easily navigate information using mobile devices—making healthcare education more immediate, personalized, and actionable.

The "While You Wait" program continues to serve as a model of community-centered awareness: a low-cost, high-impact strategy that meets people where they are and turns every waiting room into a space for learning, connection, and empowerment.

NV-RDACs Healthcare Professional Needs Assessment

National Collaboration and Visibility

The Council's growing presence on the national stage was reinforced through its active participation in the National Organization for Rare Disorders (NORD) Leadership Conference in Washington, D.C. NV-RDAC representatives, including Melissa Bart-Plange and Christina Thielst, joined more than 50 delegates from other state councils to share best practices in data management, advocacy, and family engagement.

Nevada's contributions—particularly in establishing a unified registry and conducting statewide needs assessments—were highlighted as model initiatives that other states are now considering replicating.

NV-RDAC's collaboration with national partners such as EveryLife Foundation, Global Genes, and NORD continues to amplify Nevada's leadership role in rare disease advocacy.

Through shared resources, cross-state partnerships, and consistent participation in federal initiatives, Nevada's rare disease community is now seen not only as active but as innovative and forward-thinking.

Recommendations for 2026

The Nevada Rare Disease Advisory Council (NV-RDAC) concluded 2025 with a strong foundation of progress—anchored in data, collaboration, and policy advancement. As the Council transitions into its next phase of strategic planning, several key priorities have been identified to ensure that the momentum gained this year leads to long-term, systemic change.

These recommendations will guide the Council's 2026 legislative agenda, operational planning, and engagement with state partners, providers, and communities.

1. Authorize NV-RDAC to Submit Legislative Bill Draft Requests (BDRs) Independently

To sustain meaningful policy impact, the Council recommends the formal authorization to submit its own Bill Draft Requests (BDRs) each legislative session.

Currently, NV-RDAC must rely on partner agencies or legislators to introduce bills aligned with its mission. Independent BDR authority would:

- Streamline advocacy efforts and reduce administrative delays.
- Allow the Council to proactively propose legislation addressing rare disease needs.
- Strengthen Nevada's commitment to inclusive, patient-centered policymaking.

Empowering NV-RDAC with this authority mirrors the structure of other state advisory bodies and ensures the Council can act swiftly to address emerging challenges and opportunities.

2. Establish Annual Alignment Meetings with NVHA and DHS

Effective coordination across state agencies remains critical for advancing rare disease policy and care delivery. NV-RDAC recommends formalizing annual alignment meetings with the Nevada Health Authority (NVHA) and the Department of Human Services (DHS) to synchronize data collection, Medicaid reimbursement frameworks, and public health initiatives.

These meetings would:

- Strengthen communication between agencies and community stakeholders.
- Align public health goals with real-world patient needs.
- Ensure that data collected through the Registry and Provider Needs Assessment informs program planning and budget priorities.

This structured collaboration will help translate data into action, making rare disease policy more responsive and efficient statewide.

3. Secure Long-Term Funding for the Registry and Integrate with National Databases
Sustaining the Nevada Childhood Cancer and Rare Disease Registry, housed at Cure 4 The Kids Foundation, remains a top priority. Long-term funding is essential to maintain data quality, expand condition categories, and ensure interoperability with federal systems such as the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH).
A stable funding stream will:

- Support the Registry's transition from pilot phase to permanent public health infrastructure.
- Enable continued data collection on rare disease prevalence, outcomes, and care disparities.
- Position Nevada to attract national research grants and collaborative projects.

The Registry is a cornerstone of Nevada's rare disease strategy—providing evidence for advocacy, research, and resource allocation for years to come.

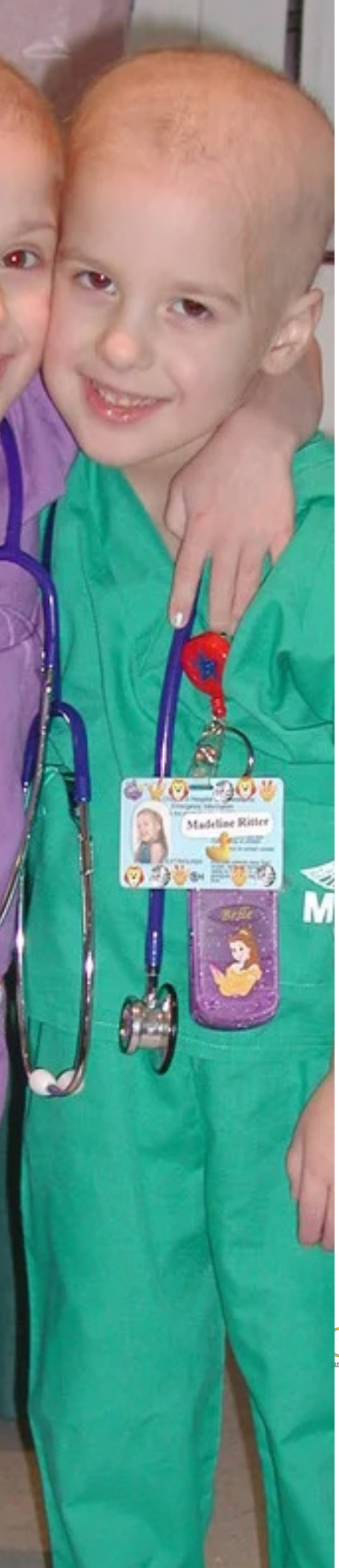
4. Develop Reimbursement Models for High-Cost Rare Disease Therapies (PAD Reform)
Access to life-saving treatments often depends on sustainable reimbursement models. NV-RDAC recommends continued collaboration with the Nevada Health Authority and Medicaid administrators to address Physician-Administered Drug (PAD) reimbursement policies that disproportionately impact providers treating rare disease patients.
Key objectives include:

- Evaluating current PAD rates and their effect on provider participation.
- Exploring value-based reimbursement models that reward positive outcomes rather than service volume.
- Ensuring that providers offering complex treatments—such as gene and cell therapies—are adequately compensated to sustain care access in-state.

Reform in this area would not only stabilize specialty care networks but also attract new providers to Nevada's growing healthcare ecosystem.

5. Integrate Rare Disease Indicators into Nevada's Health Equity Framework
As Nevada continues to expand its health equity initiatives, NV-RDAC recommends embedding rare disease metrics within the state's broader Health Equity Framework.

This integration will ensure that the unique experiences of patients with rare conditions—many of whom face intersectional challenges such as geographic isolation, racial disparities, or socioeconomic barriers—are fully represented in state health planning.



Key actions include:

- Incorporating rare disease data into annual health equity reports.
- Using Registry and Provider Assessment findings to identify underserved populations.
- Partnering with community organizations to improve outreach, screening, and support for high-need demographics.

By weaving rare disease considerations into the fabric of Nevada's equity agenda, the state can lead the nation in inclusive healthcare reform that truly serves all Nevadans.

Looking Ahead

These recommendations collectively move NV-RDAC from advocacy to sustained influence—creating mechanisms that will institutionalize rare disease priorities within Nevada's public health infrastructure.

Through legislative empowerment, data continuity, equitable reimbursement, and statewide coordination, 2026 will mark the beginning of a new chapter: one where policy, data, and compassion intersect to improve the lives of thousands of Nevadans living with rare diseases.

Acknowledgements

The Nevada Rare Disease Advisory Council extends its deepest gratitude to the many partners, advocates, and professionals who made 2025 a year of meaningful progress.

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To the healthcare providers, researchers, and policy leaders who shared their expertise, and to the families and patients whose voices guide our mission—thank you. Your courage, insight, and collaboration remain the foundation of every success we celebrate.

Dedicated to the families, providers, and advocates who make Nevada's rare disease community stronger every day.

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