RARE DISEASES...More Common Than You Think

NVRDAC
Rare Disease Advisory Council

IMPACT REPORT 2023-2025
STRATEGIC PLAN 2026-2028

www.nvrdac.org

EMPOWERING

Nevadans Living with a

Rare Disease to

Improve Their Future...

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Vision For The Future

Our vision for this next chapter is clear: to accelerate our impact and deliver systemic change for the patients and providers who depend on us. After years of building credibility, forging partnerships, and achieving meaningful wins, the Nevada Rare Disease Advisory Council (NV-RDAC) is ready to turn advocacy into measurable results.

The NV-RDAC 2026–2028 Strategic Plan builds on the foundation of our 2023-2025 plan, which created Nevada's first formal structure for rare disease advocacy and a credible voice at the policy table. We proved that focused advocacy works and we established trust among patients, providers, legislators, and state officials. Now, we move from advocacy to action.

Nevada's rare disease community still faces long diagnostic delays, insurance barriers, limited access to specialists, and a healthcare system unprepared for complex conditions. NV-RDAC exists to ensure patients and providers have not only a voice but influence that shapes healthcare policy, insurance regulations, and resource allocation.

Over the next three years, we will work with state leadership, healthcare systems, payers, and advocates to create sustainable solutions. Priorities include improving access to care, expanding telehealth, strengthening provider education, and supporting comprehensive care coordination. Rare disease management requires more than treatment—it requires integration across clinical care, insurance, navigation, research, and family support.

This plan reflects our commitment to results, not just recommendations. Our first plan proved collaboration is possible; this one will prove it can scale. The 2026–2028 Strategic Plan is designed to accelerate progress, deepen impact, and position Nevada as a national model for rare disease policy and care coordination. Together, we can make rare diseases less rare in Nevada.

Annette Logan-Parker
Chair, Nevada Rare Disease Advisory Council

To Learn More: Please join us for our regularly scheduled meetings.
Meeting schedule: We meet 12 times a year, every month February, April, June, August, October, and December on the first Friday of the month at 9:30 AM. Additional subcommittee meetings are held in January, March, May, July, September, and November on the first Friday of the month at 9:30 AM. (*Time subject to change, please confirm using the QR code below.)

Rare Disease Advisory Council Meeting Schedule (nv.gov)

For a list of current NV-RDAC members, please see www.NVRDAC.org.

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.

What is a RARE DISEASE?

In the late 1940s, Dr. Theodore Woodward, professor at the University of Maryland School of Medicine, instructed his medical interns: "When you hear hoofbeats, think of horses, not zebras." *Rare Disease Report*™ wants to encourage physicians and patients to always keep an eye out for the zebras, too, though. The rare disease community is always growing, but these uncommon conditions can sometimes be difficult to identify. It's always important to embrace your stripes.

These **5 FACTS** are a good place to start.

FACT 1

<200,000

In the United States, a disease or disorder is defined as "rare" when it affects fewer than 200,000 Americans at any given time.

FACT 2

Common symptoms can mask underlying rare diseases and lead to misdiagnosis and treatment delay.

FACT 3

50%

of rare diseases affect children.

FACT 4

The lack of scientific knowledge and quality information on a rare disease often delays a correct diagnosis and can result in heavy burdens, both social and financial, on patients and their families.

FACT 5

80%

of rare diseases have identified genetic origins, while others result from infections (bacterial or viral), allergies, and environmental causes or are degenerative and proliferative.

RARE DISEASES ARE MORE COMMON THAT YOU THINK!

1 in 10

Americans has a rare disease **+ 30 MILLION PEOPLE**

Globally, **50% of those living with a rare disease are CHILDREN**

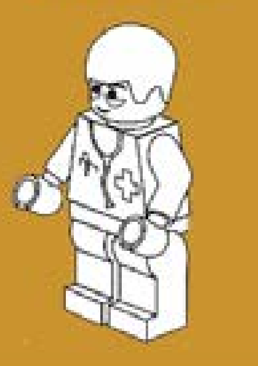
If all people affected by a rare disease lived in one country, this would make up the world's third-most populous nation - equivalent to the total US population

This means more than 300 million people around the world have a rare diseases - approximately the same number of monthyly users of Instagram

80%

of Rare Diseases are Genetically Based

Many Rare Diseases result in premature death of infants and young children or are FATAL in early adulthood



Families & private foundations provide about 3% of ALL medical research funding for Rare Diseases in the US

Introduction to Rare Diseases

In the United States, the Food and Drug Administration (FDA) defines a rare disease as any disease that affects fewer than 200,000 Americans. Our European colleagues consider a disease rare when it affects less than 1 in 2,000 people. Regardless of the contrastingly different attitudes towards what constitutes a rare disease; these numbers at first glance may seem insignificant. However, considering that there are more than 7,000 known rare diseases which affect approximately 25 million people. This is roughly translated to about 10% of the U.S. population.

Rare diseases are far more common than the term "rare disease" implies.
Rare diseases are a significant contributor of chronic illness, disability, and premature death in both children and adults. They take a disproportionate share of our health care dollars and generate an enormous administrative burden on the healthcare industry as a whole because of their complexity and the expense of, in most cases, inadequate medical interventions.
A Rare Disease Advisory Council (RDAC) is an advisory body providing a platform for the rare disease community to have a stronger voice in state government. RDACs address the needs of patients and families struggling with rare diseases by giving stakeholders an opportunity to make recommendations to state leaders on critical issues including the need to increased awareness, diagnostic tools and access to affordable treatments and cures.

In 2015, the first state advisory council on rare diseases was created in North Carolina. As of mid-2025, 33 states have established their own RDACs, and the national trend is taking hold with rare disease stakeholders across the country diligently working to establish a mechanism to allow improved representation of the this historically underserved and often misunderstood population of people.

The symbol for rare disease awareness is a black and white striped 'Zebra' ribbon.

Rare disease advocates worldwide use a the zebra stripe ribbon because of the well-known medical expression.

The formation of the Nevada Rare Disease Advisory Council “the Council” was formed in 2019 session of the Nevada Legislature. The council was assigned the following 13 specific duties:

1. Perform a statistical and qualitative examination of the incidence, causes and economic burden of rare diseases in Nevada.
2. Receive and consider reports and testimony concerning rare diseases from
3. persons, the Division, community-based organizations, providers of health care and other local and national organizations whose work relates to rare diseases.
4. Increase awareness of the burden caused by rare diseases in Nevada.
5. Identify evidence-based strategies to prevent and control rare diseases.
6. Determine the effect of delayed or inappropriate treatment on the quality of life for patients suffering from rare diseases and the economy of Nevada.
7. Study the effect of early treatment for rare disease on the quality of life for patients suffering from rare diseases, the provision of services to such patients and reimbursement for such services.
8. Increase awareness among providers of health care of the symptoms of and care for patients with rare diseases.
9. Evaluate the systems for delivery of treatment for rare diseases in place in Nevada and develop recommendations to increase the survival rates and quality of life of patients with rare diseases.
10. Determine effective methods of collecting data concerning case of rare diseases in Nevada for the purpose of conducting epidemiological studies of rare diseases.
11. Establish a comprehensive plan for the management of rare diseases in Nevada, which must include recommendations for the state and local health authorities, public and private organizations, businesses and potential sources of funding, and update the comprehensive plan as necessary.
12. Develop a registry of rare diseases diagnosed in Nevada to determine the genetic and environmental factors that contribute to such rare diseases; and
13. Compile an annual report that includes a summary of the council’s activities and any recommendations of the council for legislation or other policies.
14. A specialized license plate to support the Rare Disease Advisory Council and research and treatment for childhood cancer can be purchased through the Nevada DMV Specialized License Plates website.

The expression comes from an old saying used in teaching medical students about how to think logically regarding the process of differentiating between two or more conditions that share similar signs or symptoms. When you hear hoof-beats, think of horses, not zebras.

In the case of rare diseases- it is a zebra we are looking for and they are often extremely hard to identify in a world of horses. The zebra print ribbon seems to represent the difficulty people with rare diseases often face when seeking a diagnosis.

Our History

The Nevada Rare Disease Advisory Council was established during the 2019 session of the Nevada Legislature, making Nevada the 10th state in the nation to enact a Rare Disease Advisory Council. At that time, we were early adopters of an emerging approach to rare disease advocacy—helping to pioneer a model that has since proven its value nationwide. The NV-RDAC voted in December of 2020, that their initial focus would be on three primary categories of rare diseases: 1) All Childhood Cancers, 2) Factor deficiencies and inherited platelet disorders, and 3) Newborn screening conditions which currently, the newborn screening in Nevada screens for 46 conditions.

Over the last six years, there has been a 200% increase in RDACs nationally, reflecting growing recognition that rare disease communities need formal representation in state government. Nevada's RDAC is part of a powerful and expanding movement transforming how states address rare disease policy, access to care, and patient advocacy.

Our Mandate

The council was assigned several specific duties, including:

- Performing statistical and qualitative examination of the incidence, causes, and economic burden of rare diseases in Nevada
- Developing a registry of rare diseases diagnosed in Nevada to determine the genetic and environmental factors that contribute to such conditions
- Increasing awareness of the burden caused by rare disease among policymakers, healthcare providers, and the general public
- Improving awareness among health care providers of the symptoms and specialized care required for patients with rare diseases
- Serving as an advising body and liaison between the rare disease community and state government
- Informing, evaluating, and offering recommendations on policies and issues relevant to the rare disease community

Bridging the Knowledge Gap

Even though a significant portion of Nevada's population lives with a rare disease, state policymakers have historically lacked in-depth knowledge about the rare disease community and the unique challenges they face. This incomplete understanding has contributed to common obstacles including delays in diagnosis, misdiagnosis, lack of treatment options, high out-of-pocket costs, and limited access to medical specialists.

The NV-RDAC was established to bridge these gaps in knowledge and ensure the rare disease community has a voice in policy decisions that affect their lives. As one of the first states to establish this model, Nevada has helped demonstrate that RDACs can effectively connect patients, providers, and policymakers—a success that has inspired dozens of other states to follow suit.

Progress and Challenges

Since our formation in 2019, the NV-RDAC has made significant strides in establishing credibility, building coalitions, and advancing rare disease awareness in Nevada. We have brought together diverse stakeholders, influenced policy discussions, and elevated rare disease issues in Nevada's healthcare landscape. Our 2023-2025 Strategic Plan laid the groundwork; this 2026-2028 plan builds upon that foundation to scale our impact.

However, like many RDACs nationwide, Nevada has not yet provisioned the council with dedicated funding or resources commensurate with our legislative mandate. This remains a common challenge across the RDAC movement, as advisory councils work to demonstrate value while operating with limited resources.

We remain hopeful that emerging funding mechanisms—including the Nevada DMV Specialized License Plate for childhood cancer initiatives—will eventually grow to become a sustainable resource for the RDAC's work. For more information about the license plate initiative, please visit https://dmvnv.com/platescharitable.htm

Despite resource limitations, the NV-RDAC continues to fulfill its mandate and advance the needs of Nevada's rare disease community. As part of a growing national movement, we benefit from shared learning, best practices, and collaborative advocacy across state lines—strengthening our ability to serve Nevadans effectively.

Council Composition

Nevada statute requires NV-RDAC members to ensure balanced representation of interested parties, including:

- Physicians and nurses who care for patients with rare diseases
- Hospital administrators that provide services to people with rare disease
- Representatives from the Division of Public and Behavioral Health, Nevada Department of Health and Human Services
- Patients who have rare diseases and parents of children with rare diseases
- Administrators of organizations from both northern and southern Nevada who provide services to patients with rare diseases

This diverse composition ensures the council represents the full spectrum of rare disease experience—from clinical care to lived experience to policy implementation—reflecting the national best practice model that has proven successful across 33 states.

Join Us

If you are interested in being considered for a future council member appointment to the RDAC, please contact:

Ashlyn Torrez
Phone: 775-688-0427
Email: atorrez@health.nv.gov
Mail: 10375 Professional Circle, 3rd Floor, Reno, NV 89521

Please submit a letter of interest and a resume or curriculum vitae. Materials submitted will be forwarded to the DHHS Director for consideration for possible appointment.

Building on our Foundation
2023-2025 Strategic Plan Results

The NV-RDAC's inaugural strategic plan positioned the council as a trusted and influential voice in Nevada's healthcare policy landscape, driving measurable progress in data collection, public awareness, and legislative advocacy. This section outlines the council's key accomplishments that will guide its 2026–2028 priorities.

What We Accomplished (2023-2025)

Legislative Impact: Newborn Screening Success

The NV-RDAC's most significant policy achievements this cycle were the passage of Senate Bill 348, expanding Nevada's newborn screening (NBS) fee to modernize and enhance the state's screening panel, and Senate Bill 189 (SB 189), establishing Genetic Counselor (GC) licensure.

Through a coordinated legislative education and advocacy campaign, the council worked closely with the National Organization for Rare Disorders (NORD) and facilitated testimony from multiple NV-RDAC members, ensuring that the voices of families, clinicians, and advocates were represented in both chambers.

Following passage of SB189, the NV-RDAC has been collaborating with the Nevada Board of Medical Examiners (BOME) to assist in drafting the implementing regulations, ensuring that licensure standards align with national best practices and improve access to qualified genetics professionals statewide.

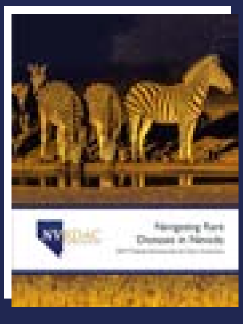
Together, these legislative successes mark a major step forward for Nevada's rare disease community—demonstrating how focused, collaborative advocacy leads to tangible policy improvements and providing a blueprint for future legislative priorities that strengthen early detection, workforce capacity, and patient access to specialized care.

Data Infrastructure: Foundation Operational

Collaboration with Cure 4 The Kids Foundation has produced measurable statewide progress in rare disease data infrastructure and reporting.

- 643 patient cases—including 210 childhood cancer and 433 rare disease cases (such as Sickle Cell Disease and SLE)—have been successfully uploaded to the State of Nevada's reporting system through this partnership.
- A research-ready registry platform is now fully available at Cure 4 The Kids Foundation.
- In collaboration with the Office of State Epidemiology, the NV-RDAC has expanded the list of conditions tracked on the State's Rare Disease Dashboard, improving visibility into prevalence and trends across Nevada.
- The statewide patient/family rare needs assessment, launched in January 2024, continues to collect comprehensive data on barriers to care through the successful "While You Wait" campaign.
- The Healthcare Provider Needs Assessment Survey entered its soft launch phase in Q4 2025, with a full statewide rollout planned for Q1 2026, designed to identify workforce gaps and system-level opportunities for improvement.

Click or scan to view
all current rare disease
data 2023-2025



Preliminary needs assessment findings revealed:

- Insurance coverage challenges and high out-of-pocket costs
- Limited access to rare disease specialists
- Significant diagnostic delays
- Care coordination gaps across systems
- Insufficient provider knowledge about rare conditions

These findings directly informed the strategic shift from disease-specific to systemic focus in this 2026-2028 plan.

Awareness & Visibility: Credibility Established

- Functional NV-RDAC website serving patients and providers
- 'While You Wait' campaign (bilingual) successfully driving needs assessment participation
- Council recognition among legislators and healthcare stakeholders
- Active participation in national RDAC network

What Worked: Proven Success Models

The NV-RDAC continues to demonstrate that collaboration, focus, and evidence-based advocacy are the cornerstones of impact. Over the course of the inaugural strategic plan, several strategies consistently produced measurable results:

1) Legislative Advocacy with Focused Asks

The passage of SB 348 (Newborn Screening expansion) and SB 189 (Genetic Counselor Licensure) clearly demonstrate the council's ability to influence state policy when advocacy efforts are strategically targeted and data-informed. By focusing on a small number of well-defined priorities each session, the council ensured clarity of message and built legislative trust, resulting in tangible outcomes that benefit Nevada's rare disease community.

2) Operational Partnerships that Deliver Impact

The data infrastructure partnership with Cure 4 The Kids Foundation (C4K) provided a critical operational backbone, enabling the successful upload of 643 patient cases into the state's rare disease reporting system and activation of a research-ready registry platform. This collaboration achieved what a volunteer advisory council could not accomplish independently—transforming recommendations into sustained, measurable action.

3) Data-Driven Recommendations that Strengthen Credibility

The statewide needs assessment and emerging provider survey have elevated the NV-RDAC's role as a data-informed advisory body. Evidence drawn directly from patient, family, and provider feedback is now guiding legislative priorities and resource recommendations, ensuring that policymaking is grounded in lived experience and verified data.

4) Member Testimony that Educates and Influences

Council members have proven to be some of Nevada's most effective advocates, delivering credible and compassionate testimony on key bills such as SB 348 and SB 189. Their participation has enhanced the council's visibility and demonstrated the power of lived experience in shaping evidence-based legislation.

What Needs Enhancement: Capacity Constraints

Despite these successes, a June 2025 council member survey revealed that accomplishments were "limited by capacity and volunteer bandwidth," even as 100% of members rated the strategic plan as effective or somewhat effective. The council's impact is strong—but its infrastructure remains fragile.

Key Resource Barriers Identified:

No sustainable funding to support ongoing advocacy campaigns, awareness programs, or data initiatives.

Volunteer-dependent model limits program execution and responsiveness to emerging needs.

Lack of structured workgroups and defined member roles reduces efficiency and accountability for follow-through.

Strategic Insight:

The NV-RDAC excels in its advisory functions—including policy recommendations, testimony, and data analysis—but requires operational partners and dedicated resources to execute broader initiatives such as provider education, awareness campaigns, and care coordination programs. Building these partnerships and securing sustainable support will be essential to expanding the council's capacity and advancing its 2026–2028 priorities.

Legislative Priorities

Building on the momentum of recent policy wins, NV-RDAC members have identified four critical legislative focus areas that align with the council's mission to improve early diagnosis, equitable access to care, and long-term sustainability of rare disease services in Nevada. These priorities will guide the council's advocacy strategy for the 2026–2028 planning cycle.

***Note on State Agency Realignment:**

In July 2025, Nevada's Department of Health and Human Services (DHHS) was restructured into two distinct entities: the Nevada Health Authority (NVHA) and the Department of Human Services (DHS).

- The NVHA now oversees healthcare-related programs, including Medicaid, the Health Information Exchange, and public health data systems.
- The DHS retains oversight of human services programs such as aging and disability, child and family services, and behavioral health supports.

The NV-RDAC will collaborate with both agencies to ensure rare disease policies are implemented across health and human service systems, reflecting the full continuum of patient and family needs.

Priority Areas

- Support for Mandatory Newborn Screening Expansion - The success of SB348 underscores the importance of continued investment in Nevada's newborn screening program. The council will advocate for ongoing modernization of the screening panel, sustained fee support to match national standards, and policies that ensure every infant—regardless of birth setting or payer—benefits from early detection and intervention.

- Improved Medicaid Coverage and Reimbursement - Access to specialized care for rare disease patients is often constrained by reimbursement gaps and administrative barriers. The NV-RDAC will continue to collaborate with the Nevada Health Authority (NVHA) to address Medicaid coverage of genetic testing, gene and cell therapies, and multidisciplinary care, ensuring reimbursement rates reflect the complexity of rare disease management.
- Legislative Support for Rare Disease Research and Data Collection - Expanding Nevada's rare disease registry infrastructure remains a top priority. The council will advocate for funding and data-sharing mechanisms that strengthen research capacity, support collaboration with academic partners, and allow Nevada to contribute to national rare disease databases. These efforts will improve surveillance, accelerate discovery, and position the state as a leader in precision public health.
- Protection of Out-of-Pocket Caps for Prescription Drugs - Financial toxicity remains a major barrier for rare disease patients who rely on high-cost therapies. The council will work to protect and strengthen existing out-of-pocket cost caps for prescription drugs and oppose any efforts to weaken patient protections. Maintaining affordability is essential to ensuring adherence to life-sustaining treatments and preventing long-term complications.

Together, these priorities reflect a comprehensive and collaborative approach to rare disease policy—one that engages both the Nevada Health Authority (NVHA) and the Department of Human Services (DHS) to integrate early detection, equitable access, financial protection, and data-driven research into a unified vision for improving outcomes for all Nevadans living with rare diseases.

Key Strategic Shifts:

From diagnosis-specific to systemic focus - 89% of members supported expanding beyond childhood cancer, bleeding disorders, and newborn screening conditions to address barriers affecting all rare disease patients.

From recommendations to measurable advocacy - Building on legislative success, this plan emphasizes specific, trackable policy goals rather than broad influence objectives.

From volunteer operations to strategic partnerships - Following the C4K model, we will identify operational partners for program implementation while focusing volunteer capacity on legislative advocacy and policy recommendations.

Rating: Strong Foundation with Measurable Impact - The 2023-2025 plan successfully established NV-RDAC credibility, built essential data infrastructure, and achieved meaningful legislative success. We proved the advisory council model works in Nevada. The 2026-2028 plan builds on these strengths by scaling proven approaches (legislative advocacy, data partnerships, focused campaigns) while addressing capacity constraints through strategic partnerships and infrastructure development.

We've built the foundation. Now we scale the impact.

Preparing for another Strategic Plan

The development of this 2026-2028 Strategic Plan was informed by comprehensive data gathered from two critical sources that provided clear direction for the council's next phase of work.

Council Member Survey

In June 2025, Nevada Rare Disease Council members participated in a comprehensive survey to assess the effectiveness of the 2023-2025 strategic plan, identify priority areas for future focus, and determine where limited resources should be applied.

The survey results confirmed that members of the NV-RDAC are not only engaged and willing to serve the state of Nevada on behalf of people with rare diseases, but they are also strongly aligned in their commitment to improve the overall landscape of rare disease management in Nevada. This includes access to high-quality medical care, improving the knowledge base of the state's healthcare providers, influencing positive change with payers who provide coverage for people with rare diseases, and educating the state's lawmakers to create new and improved regulations that positively impact people with rare diseases and the families who love them.

Key Findings from Council Member Survey:

Strategic Priorities: Council members ranked six strategic areas, with the top priorities identified as:

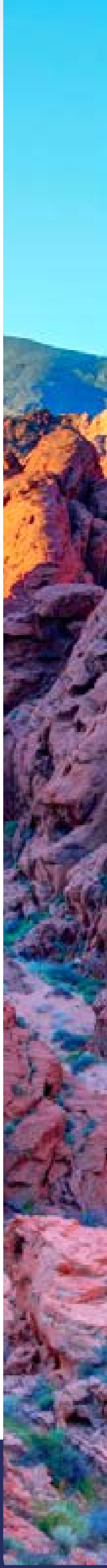
1. Awareness & Education
2. Research & Data
3. Access to Diagnostics & Treatment

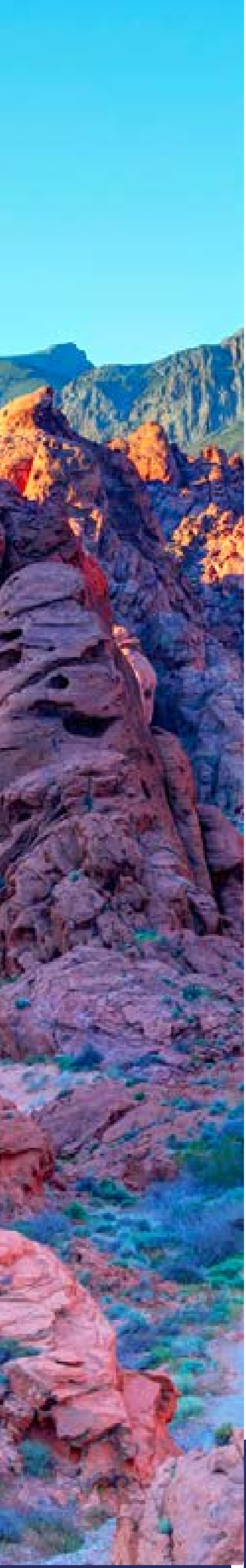
Expansion Areas: Members overwhelmingly selected the following for expansion in the next plan:

- Rare Disease Awareness Campaigns
- Improved Data Collection & Utilization
- Healthcare Provider Education & Training
- Patient Navigation & Support Services
- Partnerships with Research Institutions

Broadening Focus: 89% of respondents supported expanding beyond the current diagnosis-specific scope, with preferred strategies including:

- Shifting from diagnosis-specific focus to systemic issues (e.g., access, equity)
- Strengthening research and data infrastructure
- Focusing on care coordination and public health integration
- Partnering with academic and clinical institutions





Legislative Priorities: Members identified critical policy areas including:

- Support for mandatory newborn screening expansion
- Improved Medicaid coverage and reimbursement
- Legislative support for rare disease research and data collection
- Protection of out-of-pocket caps for prescription drugs

Perceived Barriers: Council members identified key challenges to broader impact:

- Lack of sustainable funding
- Limited administrative support and staffing
- Volunteer limitations and capacity constraints
- Need for clearer state-level engagement and buy-in

Statewide Rare Disease Needs Assessment

In 2023, the NV-RDAC rolled out a comprehensive statewide rare disease needs assessment to gather direct input from Nevada's rare disease community—including patients, caregivers, healthcare providers, and other stakeholders. This assessment sought to identify the most pressing barriers, unmet needs, and priorities from those living with and caring for people with rare diseases across the state.

Preliminary results from the needs assessment revealed critical insights into the challenges facing Nevada's rare disease community. Respondents across all rare disease categories—not just those within our initial focus areas—reported strikingly similar systemic barriers including:

- Insurance coverage challenges and denials
- Limited access to rare disease specialists
- Delays in accurate diagnosis
- Care coordination gaps
- High out-of-pocket costs
- Insufficient provider knowledge about rare conditions

These findings mirrored what council members identified in their survey: the most impactful work ahead requires addressing systemic issues that affect the entire rare disease community, rather than maintaining a diagnosis-specific focus.

Data-Driven Strategic Direction

Together, these two data sources—council member priorities and community-identified needs—provided a clear and consistent mandate for this strategic plan. Both pointed to the necessity of:

- Shifting from disease-specific advocacy to systemic issue resolution - addressing barriers that affect all rare disease patients
- Prioritizing data collection and analysis to inform evidence-based policy and demonstrate impact
- Expanding awareness and education efforts across all stakeholder groups, with emphasis on provider education
- Addressing health equity and disparities affecting rare disease patients across demographics
- Building strategic partnerships with healthcare systems, research institutions, and national organizations
- Strengthening legislative engagement on priority issues including Medicaid coverage, newborn screening, and research support
- Developing infrastructure for sustained impact including workgroups, clear member roles, and accountability mechanisms

Assessment of Progress:

Council members indicated that the 2023-2025 Strategic Plan was effective or somewhat effective (100% positive assessment), with progress noted in visibility and awareness. However, members also identified the need for more measurable impact and acknowledged that accomplishments were limited by capacity and volunteer bandwidth.

This 2026-2028 Strategic Plan reflects the priorities, insights, and evidence gathered through this rigorous planning process—ensuring our work is responsive to both council expertise and the real-world needs of Nevada's rare disease community. The plan demonstrates the council's strategic evolution from foundation-building to systems-change advocacy, supported by data and aligned with both member capacity and community priorities.

1 Our Priorities and Actions
Awareness & Education

Priority One: **Create and Develop NV-RDAC's Awareness & Education Campaign**

Building on the council's initial awareness and outreach work, this next phase broadens the focus from general visibility to targeted, impact-driven education across three primary stakeholder groups—healthcare providers, policymakers, and the public. The emphasis will shift from condition-specific awareness (e.g., single-disease campaigns) to addressing systemic barriers that affect all rare disease patients in Nevada, including diagnostic delays, access inequities, and workforce limitations.

This initiative aligns with the NV-RDAC's core mission of ensuring that every individual with a rare disease is recognized, understood, and supported through an informed and coordinated system of care.

Goals:

- Equip healthcare professionals with the knowledge and tools to identify and manage rare conditions earlier and more effectively.
- Increase legislative understanding of rare disease challenges to drive supportive policy and funding.
- Elevate public awareness to reduce stigma and highlight the shared experiences across the rare disease community.

Actions:

1) Expand Provider Education
    - Develop continuing medical education (CME) modules and training workshops in collaboration with academic partners and the Nevada Health Authority (NVHA).
    - Integrate findings from the Healthcare Provider Needs Assessment to tailor content on rare disease recognition, genetic testing, and care coordination.
    - Partner with professional medical associations to embed rare disease education into existing clinical training programs.

2) Strengthen Legislative Engagement
    - Conduct targeted legislative briefings and informational sessions on issues such as Medicaid coverage, newborn screening expansion, and data infrastructure.
    - Provide legislators with evidence-based summaries drawn from the Statewide Needs Assessment and registry data to inform future bills and budget requests.

3) Develop Statewide Awareness Campaigns
   - Create public-facing campaigns that move beyond single-disease awareness to focus on systemic barriers—such as diagnostic delays, limited specialty access, and financial hardship.
   - Highlight real Nevada families and clinicians to humanize the data and build empathy-driven understanding among the public.

4) Create Educational Materials to Support Advocacy
   - Produce concise, visually engaging resources (fact sheets, social media toolkits, legislative one-pagers) to support advocates, providers, and families in outreach efforts.
   - Collaborate with national partners to align messaging with national Rare Disease Day and awareness months.

5) Utilize License Plate Revenue to Fund CME and Outreach
   - Direct a portion of Nevada's Rare Disease Awareness license plate revenue toward continuing medical education (CME), provider training, and public engagement activities, ensuring a sustainable funding source for long-term education efforts.

By embedding rare disease education at every level—clinical, legislative, and community—the NV-RDAC aims to foster a statewide culture of awareness, empathy, and action.

Priority Two: **Leverage the Network of Rare Disease Advisory Councils for Efficiencies and Effectiveness**

The NV-RDAC recognizes that many of the challenges faced by Nevada's rare disease community—such as workforce shortages, data limitations, and fragmented policy—are shared nationwide. To accelerate progress, the council will strengthen relationships with national organizations and peer RDACs across the country to leverage shared knowledge, tools, and advocacy frameworks.

Collaboration with these partners will reduce duplication, increase access to technical expertise, and position Nevada as a leader among emerging state councils advancing rare disease policy and systems change.

Goals:

- Build a networked approach to advocacy and data collection by learning from established RDACs.
- Align Nevada's rare disease strategy with national best practices and federal initiatives.
- Maximize limited resources through shared toolkits, templates, and coordinated campaigns.

Actions:

1) Forge Strategic Partnerships with National Leaders
   - Strengthen formal partnerships with organizations such as the National Organization for Rare Disorders (NORD), EveryLife Foundation for Rare Diseases, and Global Genes to share resources and align Nevada's efforts with national priorities.
   - Collaborate with these partners on research, advocacy, and education initiatives relevant to Nevada's population.

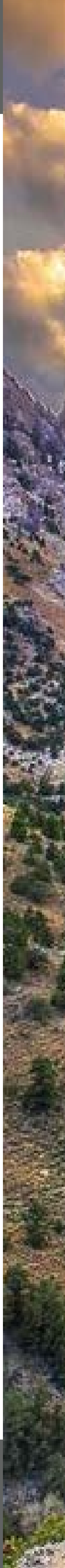
2) Network with Peer RDACs Nationwide
   - Establish an interstate RDAC collaboration group to exchange strategies, model policies, and effective advocacy tools.
   - Identify RDACs with successful programs (e.g., North Carolina, Pennsylvania, and Minnesota) and adapt proven models for Nevada's needs.

3) Participate in National RDAC Convenings
   - Engage in annual RDAC Summits and national collaborative learning opportunities to elevate Nevada's voice in the national rare disease conversation.
   - Share outcomes from Nevada's registry, needs assessments, and legislative advocacy to contribute to broader policy innovation.

4) Adopt Proven Tools and Frameworks
   - Implement data dashboards, awareness templates, and policy frameworks from successful RDACs to accelerate Nevada's infrastructure growth.
   - Collaborate with national partners to standardize outcome metrics for RDAC effectiveness and advocacy impact.

By leveraging these relationships, the NV-RDAC will transform from a state-level advisory body into an integrated part of a national rare disease ecosystem, ensuring that Nevada benefits from collective innovation, shared advocacy power, and consistent alignment with federal efforts to improve outcomes for rare disease patients nationwide.

Our Priorities and Actions
Care & Support



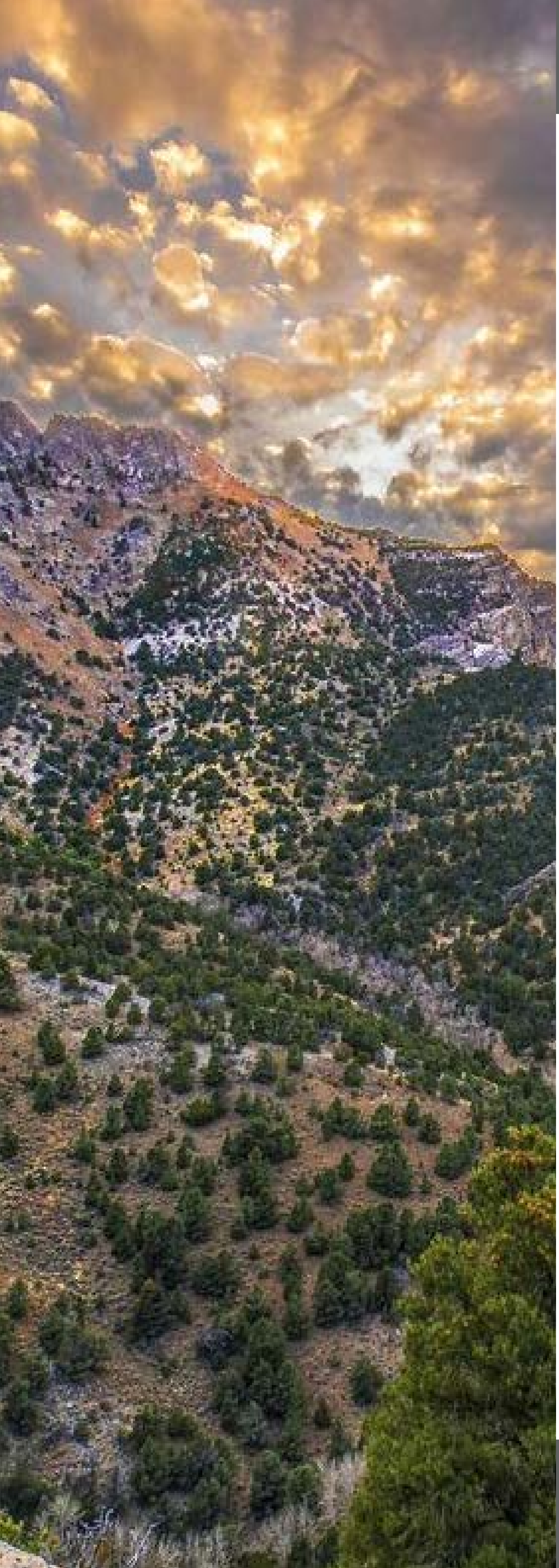
Priority One: Establish Continuity of Care Through Creation of a Comprehensive Rare Disease Plan for Nevada

Nevada's rare disease patients often experience fragmented care—moving between specialists, hospitals, and systems without coordinated support. To create true continuity of care, the NV-RDAC will lead the development of a Comprehensive Rare Disease Plan for Nevada. This plan will establish a unified framework to address barriers that affect all rare disease patients, regardless of diagnosis or age, including insurance coverage, specialist access, care coordination, and diagnostic delays.

This effort builds on the council's data infrastructure achievements, legislative relationships, and community partnerships to design systemic solutions that integrate public health, clinical care, and social supports. By aligning state policies and resources, Nevada can transition from reactive care toward a proactive, coordinated model that ensures every patient receives timely, appropriate, and connected services throughout their healthcare journey.

Goals:
- Develop a state-level roadmap that integrates clinical, policy, and public health strategies for rare disease care.
- Improve navigation, diagnosis, and treatment coordination across Nevada's healthcare ecosystem.
- Reduce fragmentation and inequities in patient experiences through consistent standards and cross-agency collaboration.

Actions:
1) Advocate for Insurance Coverage Reform
    - Document insurance denials and coverage gaps through patient-reported data and needs assessments.
    - Present findings to legislators, the Nevada Health Authority (NVHA), and the Division of Insurance to inform policy changes and reimbursement standards.
2) Identify Barriers to Specialist Access and Telemedicine Utilization
    - Use data from the Statewide and Provider Needs Assessments to pinpoint geographic, financial, and workforce barriers.
    - Develop policy recommendations for improving specialist access through telehealth expansion, cross-state licensure reciprocity, and rural provider incentives.



3) Support Development of Patient Navigation Resources
   - Partner with existing programs (e.g., C4K, Renown Health, University of Nevada, and advocacy organizations) to pilot navigation models.
   - Highlight successful frameworks from other states such as Minnesota's Rare Disease Navigator and North Carolina's Rare Disease Resource Network.

4) Strengthen Care Coordination Policies
   - Draft policy briefs and provide testimony to state agencies recommending integration of rare disease coordination into Medicaid managed care, case management, and public health programs.
   - Advocate for inclusion of rare disease metrics in state care coordination performance measures.

5) Integrate Rare Disease Considerations into Public Health Planning
   - Advise both the Nevada Health Authority (NVHA) and Department of Human Services (DHS) on incorporating rare disease data into public health preparedness, emergency response, and chronic disease planning.

6) Reduce Diagnostic Delays through Data and Education
   - Use registry and assessment data to identify diagnostic delay trends.
   - Collaborate with medical schools, CME providers, and professional societies to design training programs focused on early recognition, genetic testing, and appropriate referrals.

By establishing this comprehensive plan, the NV-RDAC will create a blueprint that unites state agencies, healthcare providers, insurers, and advocates around a shared vision—ensuring no patient falls through the cracks in Nevada's rare disease care continuum.

Priority Two: **Address Health Equity and Disparities that Impact People with Rare Diseases**

While rare diseases affect all populations, access to timely diagnosis and care is not equally distributed. Rural patients face provider shortages and long travel distances; minority and low-income populations often experience delayed diagnoses or financial barriers; and adults with rare diseases can lose access to pediatric specialists as they age.

To ensure equitable care for all Nevadans, the NV-RDAC will expand its focus to address health equity across demographics, geography, and socioeconomic status—with particular emphasis on rural communities, underrepresented populations, and aging rare disease patients. Equity will be embedded in every recommendation, ensuring that progress benefits those most affected by systemic disparities.

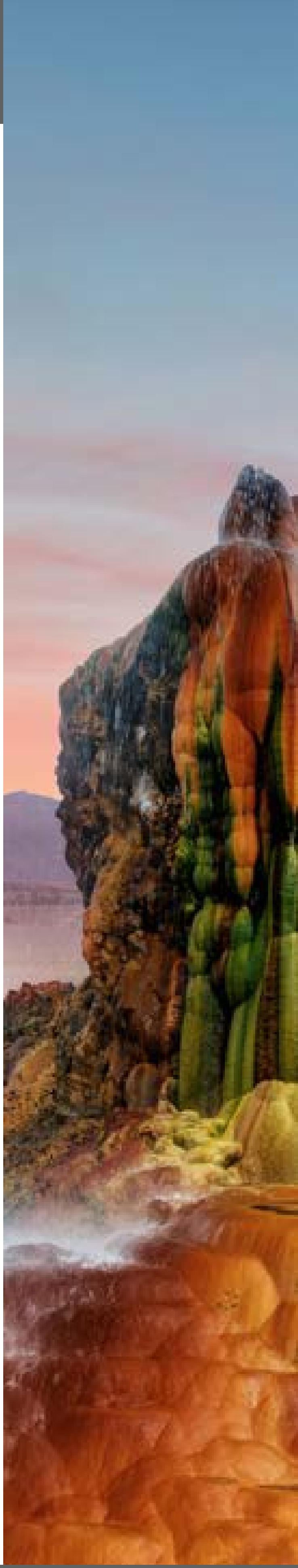
Goals:

- Eliminate geographic and demographic disparities in rare disease care.
- Ensure policy decisions reflect the lived experience of all rare disease patients, including adults and caregivers.
- Promote culturally responsive education, translation, and outreach to improve accessibility.

Actions:

1) Document Barriers for Underserved Populations
    - Expand the Statewide Needs Assessment outreach to rural, low-income, and minority populations.
    - Analyze and present findings to legislators, NVHA, and DHS to inform future resource allocation and program design.

2) Recruit and Empower Diverse Council Representation
    - Appoint adult and aging rare disease patients, caregivers, and representatives from underserved communities to council membership.
    - Establish mechanisms to ensure their perspectives actively inform policy recommendations and planning efforts.



3) Advocate for Medicaid Equity
    - Collaborate with NVHA to address coverage consistency, prior authorization reform, and equitable reimbursement for rare disease treatments.
    - Provide testimony and policy briefs highlighting inequities faced by specific populations.

4) Develop Culturally Responsive Education and Outreach
    - Partner with community organizations, tribal health programs, and nonprofit partners to co-create accessible educational materials.
    - Use license plate revenue to fund translation services, adaptive formats, and culturally appropriate outreach campaigns.

5) Address Social Determinants of Health (SDOH)
    - Utilize registry and assessment data to identify social factors—such as housing, transportation, and income—that affect patient outcomes.
    - Recommend cross-sector policy interventions in collaboration with DHS, transportation agencies, and housing authorities to mitigate these barriers.

Through this work, the NV-RDAC will position Nevada as a state leader in equitable rare disease care—ensuring that every resident, regardless of background or zip code, has access to the diagnosis, treatment, and support they need to thrive.

3 Our Priorities and Actions
Research & Data

Priority One: **Develop a Nevada-Specific Data Collection & Analysis Platform**

Building upon the successful establishment of the Cure 4 The Kids Foundation (C4K) Cancer and Rare Diseases Registry in 2024–2025, this next strategic priority focuses on expanding and institutionalizing Nevada's rare disease data infrastructure to drive evidence-based policy, measure progress, and elevate the state's position as a national leader in data-driven rare disease surveillance.

Nevada's registry work has already demonstrated that data translates into power—power to identify gaps, justify policy reform, and target interventions where they are most needed. The NV-RDAC's data-driven approach transforms anecdotal advocacy into actionable insight, aligning state priorities with verified evidence from patients, providers, and clinical partners.

In its first full operational year (September 2024 – August 2025), the C4K Cancer and Rare Diseases Registry achieved critical milestones that establish a robust foundation for continued growth and statewide integration:

- 210 childhood cancer cases captured, with 160 fully abstracted (76% completion rate).
- 433 rare disease cases documented, including 374 Sickle Cell Disease and 59 Systemic Lupus Erythematosus—achieving 100% compliance with state reporting requirements.
- Zero missed reporting deadlines, demonstrating operational excellence and data integrity.
- Direct partnership established with the Nevada Central Cancer Registry and state public health officials to ensure alignment and interoperability.
- CNExT software platform fully operational, enabling automated data collection, standardized reporting, and multi-condition integration capabilities.

These achievements position Nevada among the few states with an operational, research-ready rare disease registry connected to both clinical and public health systems.

Strategic Goals:

- Expand Nevada's rare disease data capture beyond initial conditions to reflect the state's full disease burden.
- Establish sustainable data-sharing partnerships between clinical providers, research institutions, and state agencies.
- Use registry data to produce actionable policy recommendations and measurable outcomes for patients.

Actions:

1) Advocate for Registry Expansion
    - Present data-driven recommendations to the Nevada Health Authority (NVHA) and Department of Human Services (DHS) on which additional rare disease categories should be integrated into the registry, informed by disease prevalence, burden, and needs assessment findings.
2) Promote Data Standardization and Interoperability
    - Collaborate with state health officials to establish standardized data collection protocols across healthcare systems and ensure interoperability with national rare disease registries and public health databases.

3) Strengthen Clinical Partnerships and Participation
    - Support C4K's registry operations by facilitating provider recruitment, expanding participation across hospitals and clinics, and integrating data collection workflows into electronic health records (EHRs).
    - Increase awareness of the registry among Nevada's healthcare community through targeted outreach and NV-RDAC communications.
4) Leverage Data to Inform Policy
    - Develop data dashboards and policy briefs translating registry findings into actionable insights for legislators and public agencies.
    - Use registry metrics to demonstrate measurable outcomes, cost savings, and public health impact.

This priority marks a fundamental evolution in how the NV-RDAC operates—transforming from an advisory council making recommendations based on anecdotal experience to a data-validated policy authority supported by one of the most advanced rare disease registries in the nation. Nevada is now uniquely positioned to become a national model for how states can use integrated data systems to inform and advance rare disease policy, improve patient outcomes, and guide future investment.

NVRDAC

Lend Your Expertise

Help Shape Rare Disease Care in Nevada

Are you a healthcare professional?
We need your perspective!

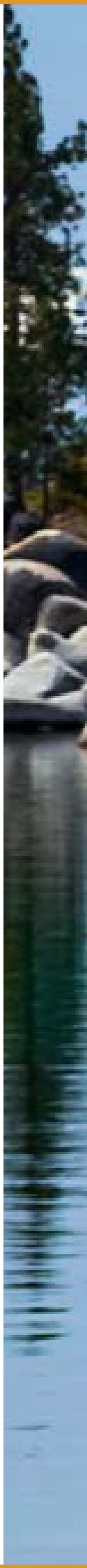
TAKE THE ANONYMOUS NEVADA RARE DISEASE NEEDS ASSESSMENT NOW

In just 10 minutes, you can help the Nevada Rare Disease Advisory Council (NV-RDAC) gain a deeper understanding of the unique challenges healthcare professionals face when caring for families affected by rare diseases across Nevada.

Your insight is essential — the knowledge you share will guide NV-RDAC in shaping policies that improve care and support for patients and families statewide.

It's EASY!
Just scan the QR code using a mobile device or visit https://redcap.link/provider-nvrdac

Healthcare Professional Needs Assessment



Priority Two: Expand and Sustain the Comprehensive Statewide Rare Disease Needs Assessment

Nevada stands at a pivotal moment in its rare disease policy evolution. For the first time, patients and families statewide have shared their lived experiences through the 2024 NV-RDAC Patient & Family Needs Assessment, offering an unprecedented view into the realities of rare disease care in Nevada. Their collective voices illuminated consistent and profound challenges:

- Long diagnostic delays and limited access to genetic testing.
- High out-of-pocket costs and inconsistent insurance coverage.
- Fragmented systems of care and limited specialist availability.

These insights have already informed council priorities and legislative action. Yet, as families have rightly emphasized, their experiences represent only one part of the ecosystem. To create sustainable change, the NV-RDAC must also capture and analyze the healthcare provider perspective—those working at the intersection of patient care and systemic constraint.

The forthcoming 2025 NV-RDAC Provider Survey expands this understanding by engaging physicians, specialists, nurses, pharmacists, social workers, and allied health professionals across the state. By pairing patient-reported challenges with provider-reported barriers, Nevada will achieve a 360° view of its rare disease ecosystem, identifying precisely where and why gaps persist—and how they can be closed.

Strategic Goals:

- Complete a comprehensive, dual-perspective assessment encompassing patients, caregivers, and providers.
- Identify aligned priorities between community experience and provider capacity.
- Translate findings into targeted policy, workforce, and education recommendations.

Actions:

1) Complete Data Analysis of the 2024–2026 Patient and Family Needs Assessment
    - Consolidate and interpret statewide data to identify recurring themes, regional disparities, and actionable insights.
2) Launch and Execute the 2025 Provider Needs Assessment
    - Engage clinical and public health professionals across pediatric, adult, and community settings to document systemic barriers and workforce challenges.

3) Expand Assessment Reach and Inclusion
    - Prioritize underrepresented populations, adult and aging rare disease patients, and rural communities to ensure full demographic representation.
4) Synthesize Patient and Provider Findings
    - Integrate both data sets to identify shared system challenges, capacity constraints, and opportunities for cross-sector collaboration.
5) Translate Findings into Policy and Legislative Recommendations
    - Develop a Nevada 360° Rare Disease Action Plan outlining clear legislative, regulatory, and funding priorities derived directly from community and provider data.
6) Disseminate Findings Across Stakeholder Networks
    - Share comprehensive results with the Nevada Health Authority, Department of Human Services, legislators, healthcare systems, and advocacy organizations to inform strategic planning.
7) Demonstrate Impact through Transparency and Accountability
    - Use combined data to guide NV-RDAC priorities, measure progress, and report on outcomes through annual updates and public dashboards.
8) Position Nevada as a National Model
    - Promote Nevada's dual-perspective assessment model at national conferences and through collaboration with peer RDACs and organizations such as NORD, EveryLife Foundation, and Global Genes.

By sustaining and expanding this two-part assessment, the NV-RDAC moves from listening to leading—using data as both a compass and a catalyst for change. This integrated approach ensures that Nevada's policies and programs are rooted in the real experiences of those who live and work within the rare disease community, creating a model for continuous improvement and accountability statewide.

Summary & Call to Action

We stand at a pivotal moment in Nevada's approach to rare diseases. Over the past few years, we've proven what's possible: we successfully advocated for newborn screening expansion, built comprehensive data infrastructure, and launched Nevada's first statewide rare disease needs assessment. We've established credibility and demonstrated measurable impact.

But our work has only just begun.

The data we've collected tells a clear story: Nevadans living with rare diseases face systemic barriers that transcend any single diagnosis. Insurance coverage challenges, limited specialist access, diagnostic delays, care coordination gaps, and insufficient provider knowledge affect families across all rare disease categories. These are not isolated problems—they are interconnected system failures that demand coordinated, strategic solutions.

The Challenge: Fragmentation to Coordination

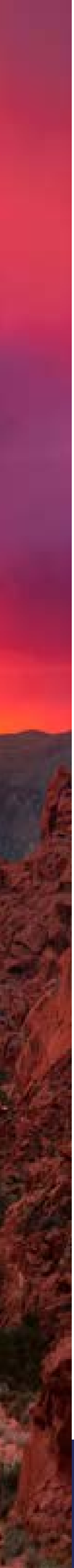
Nevada's rare disease community has dedicated advocates, committed healthcare providers, and passionate organizations working tirelessly across our state. Yet we lack the coordinated infrastructure to translate individual efforts into systemic change. Southern and northern Nevada operate largely independently. Patient advocates, providers, payers, researchers, and policymakers rarely sit at the same table. Data exists but isn't systematically leveraged for policy development.

This fragmentation limits our collective influence.

The Opportunity: United Action

This 2026-2028 Strategic Plan represents our roadmap for transforming fragmentation into coordinated action. Building on legislative success with newborn screening, we will pursue focused policy priorities backed by comprehensive data. Leveraging the C4K registry and needs assessment findings, we will present evidence-based recommendations to legislators, DHHS, Medicaid, and commercial payers. Through strategic partnerships with healthcare systems, research institutions, and national organizations, we will amplify our reach beyond what any single entity could achieve alone.

We will shift from disease-specific advocacy to systemic solutions that improve outcomes for all Nevadans living with rare diseases.



Our Call to Nevada’s Leaders

The Nevada Rare Disease Advisory Council (NV-RDAC) calls upon state leaders, agencies, and partners to join in advancing a coordinated, data-driven strategy that ensures every Nevadan living with a rare disease has access to timely diagnosis, equitable care, and sustained support. The work ahead cannot be done in isolation—it requires collective leadership, shared accountability, and alignment across systems.

To State Legislators:

We ask you to champion policies that directly address documented barriers—including Medicaid coverage improvements, expansion of specialist access, investment in provider education, and patient navigation support.

Our data demonstrates where and why gaps persist. Your leadership can translate this evidence into tangible policy and funding solutions that improve outcomes and equity for Nevada families.

To the Nevada Health Authority (NVHA):

As the state’s lead agency for healthcare delivery, Medicaid, and public health oversight, we ask the NVHA to engage regularly with this council, leverage our registry and needs assessment data to guide decision-making, and integrate rare disease considerations into program planning, quality metrics, and workforce development.

We also ask that the NVHA support ongoing rare disease surveillance, data integration, and provider education efforts that align with national public health standards.

To the Department of Human Services (DHS):

As the agency overseeing programs that impact the daily lives of rare disease families—including aging and disability services, behavioral health, and family support—we ask the DHS to collaborate with this council on initiatives that address social determinants of health, including transportation, home-based care, and service coordination.

Rare disease care extends beyond medical treatment—it requires human-centered policies that sustain families across the lifespan.

To Healthcare Systems and Providers:

We ask you to actively participate in registry data collection, needs assessment outreach, and education initiatives that improve rare disease diagnosis and care coordination.
Your collaboration in sharing data, expanding telehealth access, and implementing best practices is essential to closing Nevada’s rare disease care gaps and building a connected statewide network of excellence.

To Payers — Medicaid and Commercial Insurers:
We ask you to review documented coverage barriers, consider evidence-based reimbursement improvements, and collaborate with providers and advocates to reduce financial toxicity for rare disease families.

Transparent coverage policies and timely prior authorization processes can dramatically improve access to life-saving treatments while reducing administrative burden for providers.

To Rare Disease Organizations and Advocates:
We ask you to unite around shared systemic priorities—expanding access, equity, and education—and to amplify Nevada's rare disease voice through collaboration, storytelling, and outreach. Your partnership in advocacy, awareness, and data sharing ensures that no rare disease community stands alone, and that Nevada continues to model what is possible when lived experience and policy leadership work hand in hand.

With the establishment of the Nevada Health Authority and the Department of Human Services, we have a renewed opportunity to align healthcare delivery and human services under a shared commitment to innovation, compassion, and measurable impact.

The NV-RDAC stands ready to collaborate—providing data, expertise, and insight to help shape a future where Nevada leads the nation in rare disease care, policy, and equity.

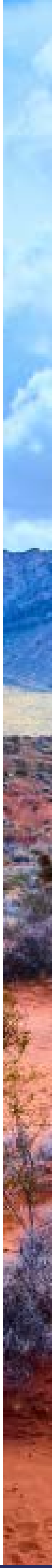
The Path Forward

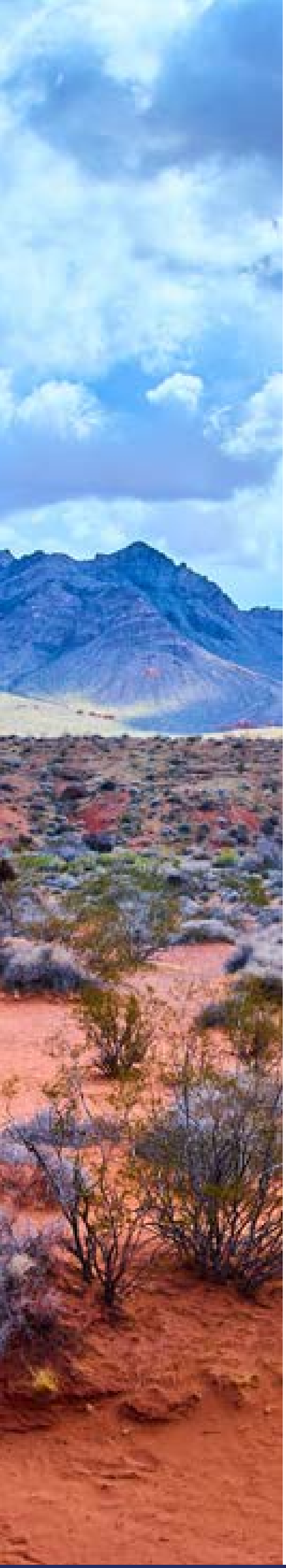
Nevada is entering a new era in rare disease care—one defined by collaboration, data-driven action, and a unified vision for equitable access across the lifespan. This 2026–2028 Strategic Plan outlines clear, measurable priorities organized under three pillars: Awareness & Education, Care & Support, and Research & Data. Each priority is rooted in the voices of patients, caregivers, and providers, and shaped by lessons learned from the council's first strategic plan.

Over the past three years, the Nevada Rare Disease Advisory Council (NV-RDAC) has established itself as a trusted policy voice and credible data partner. Through focused legislative advocacy, operational collaboration with Cure 4 The Kids Foundation, and partnerships with national organizations, Nevada has built the foundation for a more connected and compassionate rare disease system.

We now move forward with clarity about both our strengths and our needs. We know what works: focused legislative engagement, evidence-based recommendations, and operational partnerships that turn ideas into outcomes.

We know what we need: sustainable funding, administrative infrastructure, formalized interagency collaboration, and consistent engagement structures that bring every stakeholder to the table.





The restructuring of Nevada's health system in 2025 has created new opportunities for partnership. The Nevada Health Authority (NVHA) will play a central role in advancing health programs, Medicaid reforms, and data integration, while the Department of Human Services (DHS) will ensure social supports, behavioral health, and family services are accessible to those affected by rare conditions. The NV-RDAC stands ready to work alongside both agencies to ensure that rare disease care is not fragmented by systems, but unified by purpose.

The next phase of this journey demands coordination, creativity, and courage. Through strengthened data collection, cross-sector collaboration, and legislative advocacy, Nevada can become a national model for how states transform rare disease care through unified systems and measurable compassion.

Join Us

Whether you are a legislator shaping policy, a healthcare provider delivering care, a payer managing coverage, a researcher advancing discovery, an advocate building awareness, or someone living with a rare disease—your role matters.

Your voice, your expertise, and your lived experience are essential to this work. The NV-RDAC exists to ensure that every perspective is heard and translated into action that improves lives.

Together, we can make rare diseases:

- Less rare in the minds of policymakers through informed legislation and data-driven advocacy.
- Less isolating for families navigating diagnosis and care.
- Less burdensome for providers and systems striving to deliver equitable, coordinated care.

This plan is our promise—to transform insight into impact, and compassion into measurable change. Together, we can make Nevada a place where no rare disease patient stands alone and every family has a pathway to hope, care, and community.

The Nevada Rare Disease Advisory Council exists to ensure rare disease voices are heard and translated into action. This strategic plan is our commitment to you. Together, we will make rare diseases less rare in the minds of policymakers, less isolating for families navigating diagnosis, and less burdensome for those seeking appropriate care.