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ANNUAL REPORT 2024

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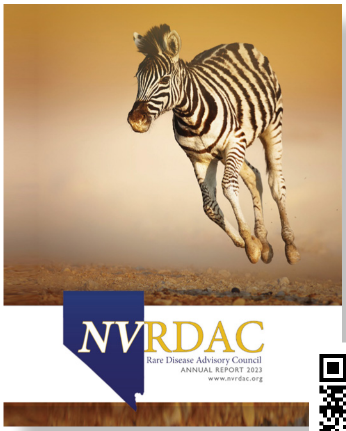

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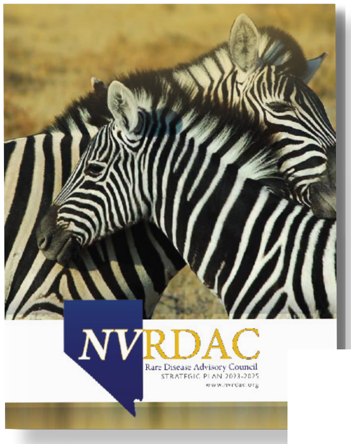
NV-RDACs 2023
Annual Report



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NV-RDACs
Strategic Plan

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A Letter from the Chair

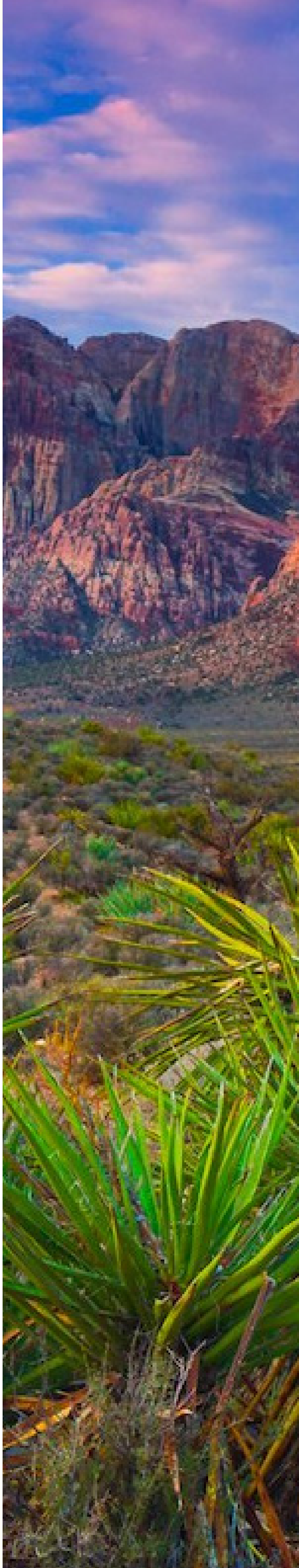
In this report, the Nevada Rare Disease Advisory Council (NV-RDAC) addresses the critical issues that continue to impact individuals living with rare diseases, alongside broader challenges within Nevada's healthcare system.

In 2023, we celebrated a major legislative achievement with the passage of SB 221, legislation focused on Medicaid reform. SB 221 required the establishment of a specific billing category and reimbursement methodology for outpatient centers primarily treating children with cancer and rare diseases. This legislation has already begun to make a positive difference for the rare disease community by improving access to specialty care. Equally importantly, it sets a new standard for legislative support of this underserved population. This success represents a key milestone in our ongoing advocacy for enhanced healthcare access, resources, and support for individuals affected by rare diseases in Nevada.

Despite this progress, significant challenges remain. Throughout this report, NV-RDAC highlights ongoing concerns, including the persistent underfunding of Nevada's Medicaid Program and the Department of Health and Human Services' (DHHS) data collection efforts. Medicaid continues to be a vital lifeline for individuals with rare diseases, many of whom face debilitating physical limitations and overwhelming healthcare costs. While we have seen promising progress in DHHS's data collection initiatives, there is still much work to be done to meet national standards and fully address the needs of our rare disease community.

We are also pleased to announce the official launch of the statewide rare disease needs assessment. This initiative is a significant step forward, and we look forward to the valuable data it will generate over the next three years. The findings from this assessment will play a crucial role in shaping the future of rare disease care in Nevada, guiding policy decisions, and hopefully leading to the improved allocation of resources to better serve those affected.

Comprehensive data collection is fundamental to understanding the prevalence, impact, and treatment outcomes of rare diseases across the state. Without ongoing investment in these efforts, Nevada will struggle to meet the unique and complex needs of its rare disease population. Insufficient data not only hampers the state's ability to make informed policy decisions, but it also limits the eligibility of Nevada's healthcare facilities for federal grants, exacerbating the challenges faced by patients and providers alike.



Looking ahead, 2025 presents an opportunity to address these challenges head-on. The NV-RDAC remains committed to advancing access to high-quality care for Nevadans living with rare diseases, while prioritizing enhanced data collection efforts within DHHS. By advocating for an increase in the Medicaid budget and creating distinct reimbursement rates for rare diseases—especially for high-cost treatments—Nevada can alleviate the financial strain on patients and address the shortage of specialists required to treat these conditions. At the same time, bolstering DHHS's data collection and analysis capabilities will provide essential insights to drive better resource allocation and evidence-based policymaking.

On a personal note, it has been an honor to serve as Chair of the NV-RDAC for the past two years (2022-2024). I am deeply grateful for the opportunity to continue in this role, having been re-elected for another two-year term (2025 - 2026). I look forward to working alongside our dedicated council members and partners as we continue to advocate for the rare disease community. Together, we can build on the progress we've made and push for positive changes in Nevada's healthcare landscape.

Together, we can make meaningful strides in improving the lives of individuals living with rare diseases and strengthening Nevada's healthcare infrastructure to meet the challenges of the future.

Sincerely,

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

On Behalf of the Council:

Annette Logan-Parker (Chair)
Georgene Glass (Vice-Chair)
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Ihsan Azzam, M.D., PhD
Naja Bagner
Melissa Bart-Plange
Brigette Cole
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Pamela White

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

Boldly Advancing Nevada’s Rare Disease Initiatives

The Nevada Rare Disease Advisory Council (NV-RDAC) is proud to reflect on a year of significant progress and meaningful accomplishments, as highlighted in this 2024 Annual Report. This year has marked a pivotal step forward in reshaping Nevada’s approach to rare disease care and advocacy. Through relentless efforts, the council has raised awareness, fostered critical partnerships, and influenced policy changes that are directly improving the lives of rare disease patients and their families across the state.

In 2024, NV-RDAC amplified its mission to serve as a vital connection between rare disease patients, healthcare providers, and state lawmakers. By addressing the unique and often overlooked challenges faced by the rare disease community, the council has played a crucial role in ensuring these voices are heard. NV-RDAC has facilitated meaningful dialogues with key stakeholders, advocating for the essential resources needed to meet the growing demands of this vulnerable population. These efforts have not only solidified the council’s position as a catalyst for positive change but also laid the groundwork for long-term improvements in Nevada’s healthcare system.

The council’s achievements this year span several key areas, including expanding outreach efforts through strategic awareness campaigns, collaborating with health authorities to enhance rare disease data collection, and driving forward critical policy initiatives aimed at improving access to care, treatments, and support services. These initiatives over time will make a signifcant difference in bridging gaps in the state’s healthcare infrastructure, with the goal of ensuring that rare disease patients receive the care and attention they deserve.

Looking ahead to 2025 and beyond, NV-RDAC remains steadfast in its commitment to creating lasting improvements for individuals affected by rare diseases. The council will continue to engage with legislators, healthcare providers, state agencies, and community organizations to advocate for comprehensive policy reforms, increased funding, and enhanced access to advanced medical care and treatments. By working together with these key partners, NV-RDAC will continue to champion the necessary changes to build a more inclusive, equitable, and patient-centered healthcare system in Nevada, where no rare disease patient is left behind.

Introduction

In the United States, a rare disease is defined by the Food and Drug Administration (FDA) as a condition affecting fewer than 200,000 Americans. While this number might seem small, the reality is that more than 7,000 rare diseases have been identified, collectively impacting an estimated 30 million Americans—nearly 10% of the U.S. population. **In Nevada alone, it is estimated that over 300,000 residents are living with a rare disease, highlighting the significant impact on our state's healthcare system.**

Despite the term "rare," collectively these conditions are actually quite common and present significant challenges. Rare diseases often lead to chronic health issues, disability, and early mortality, affecting both children and adults. The complexity of these diseases, combined with the limited availability of effective treatments, places an immense strain on healthcare systems, leading to higher costs, resource allocation challenges, and an overwhelming administrative burden for patients and providers alike. Furthermore, the rarity of each individual disease frequently delays diagnosis and limits access to specialized care, further complicating patient outcomes.

Rare diseases often fall outside the mainstream of medical research and development, leading to gaps in diagnosis, treatment options, and support systems. Many patients face a lengthy and frustrating diagnostic journey known as the "diagnostic odyssey," often waiting years for an accurate diagnosis. Even when a diagnosis is made, access to effective treatments can be limited or non-existent, leaving patients and families with few options.

To address these significant gaps, Rare Disease Advisory Councils (RDACs) serve as essential platforms for amplifying the voices of patients, families, and healthcare providers. These councils bring together diverse stakeholders—including policymakers, researchers, and advocates—to propose meaningful solutions to the unique challenges faced by the rare disease community. RDACs play a significant role in improving public awareness, promoting early diagnosis, and advocating for access to affordable and life-saving treatments.

The Nevada Rare Disease Advisory Council was created through NRS 439.5075 during the 2019 session of the Nevada Legislature. The establishment of this council marked a significant step toward addressing the unique needs of the rare disease community in Nevada. Among its many responsibilities, the NV-RDAC is tasked with providing annual reports that summarize its activities and offer recommendations for legislative and policy improvements. This document represents the fourth annual report prepared by the NV-RDAC, underscoring the council's ongoing commitment to advocating for the more than 300,000 Nevadans affected by rare diseases.

National Ranking In Rare Disease Support

Click or Scan to view NORD's Website

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

Nevada's Report Card for Rare Disease Support has shown limited fluctuations over the years with some notable improvements and ongoing challenges. **According to the National Organization for Rare Disorders (NORD), Nevada continues to face significant barriers in providing comprehensive support for individuals living with rare diseases.**

There has been ongoing improvement in the category of newborn screening, where Nevada's rating has improved due to increased utilization of dried blood spots and the expansion of screening for additional conditions. The state's rating in this category has increased from a "D" to a "B", and has remained at the B ranking for awhile, reflecting ongoing efforts to identify and address rare conditions at birth. Although Nevada has a D in the subcategory of screening for RUSP Core Conditions, the overall progress made underscores Nevada's commitment to ensuring early diagnosis for infants at risk of rare diseases. With the introduction of BDR 123 in the upcoming 2025 legislative session, we are looking forward to positive progress in the state's Newborn Screening Program.

Despite Nevada's strong overall grade of "A" for Step Therapy (Fail First) policies, there remains a significant opportunity to address deficiencies in specific subcategories that have received a failing rating. These subcategories highlight gaps in patient protections and inefficiencies in how the step therapy process is implemented. The passage of SB 194 in June 2023 introduced crucial revisions, such as the establishment of exceptions that allow patients to bypass the fail-first process in specific cases. However, the full impact of this legislation has not yet been reflected in the NORD rating. While SB 194 offers some relief by introducing these exceptions, many patients, particularly those requiring specialized or high-cost medications, continue to face delays in accessing appropriate treatments. These barriers persist due to the restrictive nature of step therapy policies, which often prioritize cost-containment over timely and effective patient care.

Nevada is one of three states currently failing in the Prescription Drug Out-of-Pocket Costs category, reflecting significant challenges in reducing the financial burden for patients. This issue disproportionately affects individuals with chronic or rare conditions, who often require expensive, long-term treatments and are at greater risk of forgoing necessary care due to high costs. Additionally, these financial pressures can lead to poor health outcomes, as patients may delay or avoid treatments, resulting in more severe health complications and higher overall healthcare costs in the long term.

NORD®
STATE
REPORT

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 2023.

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
Funding: B
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

PASS

TELEHEALTH

PASS

MEDICAL NUTRITION

B

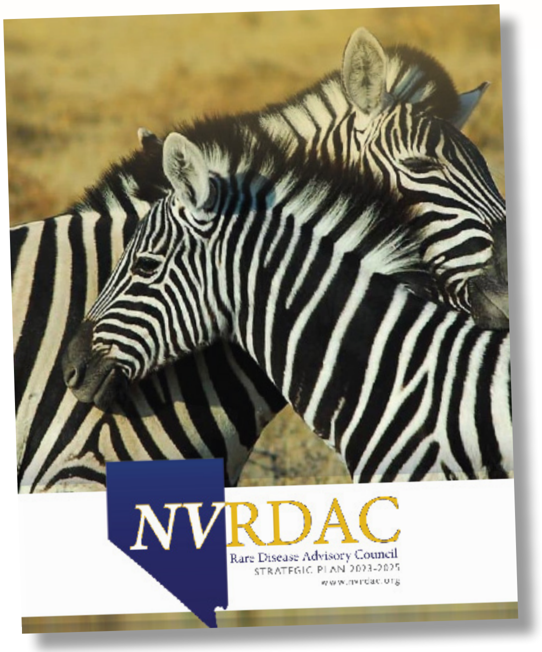
PRESCRIPTION OUT-OF-POCKET COSTS: FAILED

On a broader scale, Nevada's data reporting has historically lagged in key areas, particularly in meeting the United States Cancer Statistics (USCS) standards for data recognition within the CDC's national cancer registry, which includes childhood cancers—a crucial subset of rare diseases. The state has faced challenges due to being under-resourced, resulting in difficulties with data completeness, timeliness, and quality. However, recent collaborative efforts between state agencies, childhood cancer providers (Cure 4 The Kids Foundation), and advocacy groups have begun to show promising improvements. These partnerships are helping to enhance data reporting capabilities, positioning Nevada to make strides toward meeting national standards and improving its standing in cancer research initiatives. These partnerships are paving the way for better data management and reporting, which is crucial for Nevada's eligibility for federal research funding, particularly in childhood cancer research. Continued focus on these collaborative efforts will be essential in fully meeting USCS standards and enhancing Nevada's contribution to national cancer research initiatives.

The Sickle Cell Registry established in 2019 through AB 254 is also facing significant delays. Despite the legal mandate for healthcare providers and labs to submit data, both electronic and paper reporting forms have still not been formally introduced to the public. This delay, coupled with resource limitations, has hindered the registry's ability to function effectively, impeding progress in understanding and addressing sickle cell disease in Nevada.

In summary, Nevada's overall performance in supporting the rare disease community remains suboptimal. Despite some progress, particularly in newborn screening and recent improvements in data reporting through collaboration, there are still significant gaps in areas such as prescription drug access, data collection, and nutritional support for rare diseases.

The NV-RDAC strongly urges Nevada's leadership to prioritize the development and funding of a comprehensive statewide action plan that addresses the unique needs of individuals living with rare diseases. This plan should focus on modernizing Medicaid policies, enhancing reimbursement models, and ensuring the effective implementation of existing legislation. By committing the necessary resources, Nevada can begin to fulfill its legislative obligations and provide better support for the more than 300,000 Nevadans affected by rare diseases.



NV-RDAC Strategic Plan Update

The Nevada Rare Disease Advisory Council has established a comprehensive and collaborative strategic plan to address the complex challenges faced by individuals with rare diseases in Nevada. This strategic plan is the state's first coordinated effort, built on three foundational pillars: Awareness & Education, Care & Support, and Research & Data. The council's primary goals are to raise awareness, improve care and support, and establish a robust data collection and research framework.

Click Image or Scan to View NV-RDAC's Strategic Plan

Key Initiatives and Progress:

Statewide Rare Disease Registry

NV-RDAC is working to develop a statewide rare disease registry, in partnership with Cure 4 The Kids Foundation (C4K), to better understand the prevalence of rare diseases in Nevada. The registry, focused on childhood cancer, bleeding disorders, and newborn screening conditions, is set to launch in early 2025.

Evaluation of Treatment Systems

The council is assessing current treatment systems and advocating for improvements to increase survival rates and quality of life for rare disease patients. Testimonies in support of access to cellular and gene therapies have been delivered, and further efforts will continue through the 2025 legislative session.

Comprehensive Management Plan

NV-RDAC is actively developing a comprehensive plan to enhance rare disease management across Nevada. This plan will provide targeted recommendations to healthcare authorities, businesses, and potential funding sources, addressing critical gaps in care and support. It will be informed by key findings from the ongoing needs assessment and shaped through close collaboration with stakeholders. The anticipated completion date for the plan is yet to be determined, contingent on the assessment's final results and stakeholder input.

Progress on Awareness & Education:

- Campaigns: The important 'While You Wait' campaign has been successfully launched, providing educational materials in both English and Spanish in healthcare provider offices. NV-RDAC's social media platforms are also extremely active in promoting rare disease awareness.
- Website Expansion: The NV-RDAC's website has been continuously updated with resources for patients, families, and lawmakers. www.nvrdac.org

Click or Scan to View NV-RDAC's Rare Needs Assessment

Progress on Care & Support:

- Continuity of Care: NV-RDAC is advocating for the development of policies to ensure timely and accurate diagnoses for rare disease patients, advocating for clinical trial participation and equitable access to cutting-edge treatments.
- Health Equity: NV-RDAC is in full support of C4K's efforts establishing a fulltime genetics program focusing on children and adult genetic conditions.The NV-RDAC is committed to a coordinated statewide announcement when C4K launches their program in early 2025.

Progress on Research & Data:

- Data Collection Platform: NV-RDAC, in collaboration with C4K, is developing a statewide data collection platform, including a rare disease registry, to support research and inform decision-making.
- Statewide Needs Assessment: NV-RDAC has launched a needs assessment survey to identify barriers and gaps in care as well as inform policy changes. Data collection will continue over the next three years, with annual reports submitted to the Governor's Office.

Looking Ahead:

NV-RDAC is committed to fostering collaborative relationships with policymakers, healthcare providers, and the rare disease community. Key focus areas for the remainder of the strategic plan include the implementation of the rare disease registry, the support of the C4K genetics clinic, and continued advocacy for equitable access to diagnostics and treatment options.

2025 Legislation: Areas of Focus

As the Nevada Rare Disease Advisory Council (NV-RDAC) advances its mission to enhance the quality of life for individuals living with rare diseases, the council has identified several key areas of interest for the 2025 legislative session. These areas highlight ongoing challenges in Nevada's healthcare system and provide opportunities for targeted legislative action that addresses the unique needs of the rare disease community.

The NV-RDAC will actively monitor and support the following legislative priorities:

BDR 123 - Expansion of Newborn Screening Program

Expanding Nevada's newborn screening program is crucial for early detection and intervention in treatable rare diseases. The NV-RDAC will work to:

- Support BDR 123, the Newborn Screening Expansion initiative, which aims to broaden the conditions screened at birth, particularly those that are treatable if detected early.
- Advocate for the inclusion of additional conditions recommended by the federal Recommended Uniform Screening Panel (RUSP), ensuring more comprehensive coverage for Nevada's newborns.
- Secure funding to support the expansion and continued operation of the newborn screening program, providing essential services for early diagnosis and treatment.

BDR 124 - Access to Specialized Pediatric Care

Access to specialized care, particularly for pediatric cancer patients; a designated category of rare diseases remains a pressing issue in Nevada. The NV-RDAC will focus on:

- Monitoring and supporting BDR 124, which seeks to establish a pediatric stem cell and bone marrow transplant program in Nevada, providing essential care for children with cancer and rare blood disorders.
- Advocating for appropriate funding and infrastructure to develop this in-state Pediatric Stem Cell and Bone Marrow Transplant Program (SC-BMT) reducing the need for families to travel out of state for life-saving treatments while encouraging the reinvestment of Nevada's limited healthcare resources locally.

BDR 218 - Revises provisions relating to coverage and reimbursement for services provided by pharmacists

Allowing pharmacists to continue providing services like lab work and medication administration, expanding their role in rare disease care.

- Reducing out-of-pocket costs for rare disease medications under state-regulated insurance plans.

BDR 224 - Revises provisions relating to the use of pharmacy benefit managers by Medicaid

Affordable access to medications is vital for rare disease patients.

- Supporting the Pharmacist Payment through Medicaid - Enabling pharmacists to bill Medicaid for clinical services, improving their integration into patient care teams and enhancing care coordination.

The NV-DRAC plans to monitor and support any legislation that positively impacts the following categories:

Insurance Coverage for Rare Diseases

- Advocate for stronger patient protections in state-regulated insurance plans, ensuring that rare disease treatments are fully covered and accessible.
- Promote policies that reduce the burden of step therapy and formulary exclusions, making it easier for patients to access the treatments they need without excessive bureaucratic hurdles.

Medicaid Coverage and Reimbursement Models

- Ensuring that Medicaid provides adequate coverage for rare disease treatments is a priority for the NV-RDAC. The council will advocate for legislative actions that:
  - Establish distinct reimbursement rates for rare disease treatments, especially for high-cost, life-saving therapies, to alleviate the financial burden on families.
  - Streamline the approval processes for Medicaid beneficiaries, reducing delays caused by step therapy and prior authorization requirements, and enabling quicker access to specialized treatments.

Expansion of Telehealth Services

- Support legislative efforts to ensure parity in reimbursement for telehealth and in-person visits, with a focus on expanding access to rare disease care through telehealth services.
- Advocate for Nevada's continued participation in the Interstate Medical Licensure Compact (IMLC), increasing access to out-of-state specialists and ensuring that Nevada patients can receive care from leading experts across the country.
- Support legislative efforts that address the Telehealth needs in rural and underserved areas.

Building Relationships

NV-RDAC remains committed to driving substantial improvements in Nevada's healthcare landscape, particularly in the rare disease sector. Through proactive engagement, the council has fostered discussions with key stakeholders, including organizations such as NORD, Medical Home Portal, and Global Genes. These collaborations have expanded resources on the NV-RDAC website for rare disease patients, healthcare providers statewide, and legislators statewide.

A key outcome of these efforts has been the council's close collaboration with the Nevada Department of Health and Human Services (DHHS) to streamline data collection processes. Ongoing dialogues with the vital records and cancer registry teams within DHHS have helped identify gaps and inefficiencies, particularly in childhood cancer and sickle cell data collection. These efforts are aimed at optimizing Nevada's data infrastructure, beginning with the childhood cancer registry and expanding to sickle cell and other rare diseases.

Additionally, NV-RDAC's involvement with the Nevada Patient Protection Commission is geared toward influencing healthcare policy, ensuring that the voices of rare disease patients are heard in key decision-making processes. This relationship aims to advocate for patient protections that improve access to rare disease treatments and services. Similarly, the collaboration with the NV Pharmacy Alliance focuses on improving access to rare disease medications and therapies, working toward seamless integration of pharmacy services into rare disease care plans with the goal of improving NORD's Nevada Report Card in the prescription drug category.

These collaborative efforts represent a step forward in enhancing Nevada's rare disease care, improving data infrastructure, and ensuring that policy changes are based on national best practices and are responsive to the needs of patients and providers alike.

Key Accomplishments

Despite facing resource constraints, NV-RDAC has made some progress in several key areas:

Data Collection: NV-RDAC has initiated foundational efforts to establish a statewide rare disease registry, with particular focus on childhood cancer, sickle cell disease, and newborn screening conditions. These efforts, in collaboration with C4K and DHHS, will provide Nevada with crucial data to assess the incidence, causes, and economic impact of rare diseases. However, sustained funding is necessary to continue building these data collection systems.

Stakeholder Engagement: The NV-RDAC has made stakeholder engagement a cornerstone of its efforts to address the needs of the rare disease community in Nevada. The council has actively engaged with a broad spectrum of stakeholders, including rare disease patients, healthcare providers, advocacy groups, lawmakers, and nonprofit organizations. Through these engagements, the council has gained critical insights into the challenges faced by those living with rare diseases.

Awareness Campaigns: NV-RDAC's successful 'While You Wait' campaign and its presence on social media have significantly raised public awareness about rare diseases, supplemented by live TV appearances and print media coverage of council activities.

Policy Advocacy: In spite of the fact that the NV-RDAC does not have the authority to submit a BDR, the council has successfully collaborated with legislators to introduce the expansion of the newborn screening program (BDR 123) and access to pediatric specialized care (BDR 124) in the 2025 legistative session.

Collaborations with DHHS and C4K: Through partnerships with DHHS and C4K, the council has improved data collection processes, particularly for childhood cancer and sickle cell cases. The upcoming development of C4K's childhood cancer and rare disease registry will further streamline these efforts, ensuring Nevada's rare disease data is both accurate and efficiently managed.

Recommendations

The Nevada Rare Disease Advisory Council has made progress in addressing rare diseases, but the challenges remain ongoing and complex. The council's effectiveness will continue to evolve through collaboration with stakeholders and efforts to improve the quality of life for individuals affected by rare diseases in Nevada. Achieving this requires sustained financial support, policy reforms, and innovative approaches.

Key recommendations include:

Allocate Adequate Funding: The state must allocate sufficient, sustainable funding to ensure the staffing and resources necessary to develop and implement comprehensive rare disease strategy across Nevada. Without adequate funding, the council's initiatives cannot reach their full potential.

Policy Reforms and Innovative Funding for Rare Disease Care: Support and collaborate with Nevada legislators to lead advocacy efforts focused on implementing impactful policy reforms and innovative state-funded initiatives. These reforms should prioritize expanding insurance coverage, improving access to advanced diagnostic tests and treatments, and strengthening support services for individuals affected by rare diseases. Additionally, Medicaid's budget should be expanded to accommodate reimbursement models specifically tailored to address the unique healthcare challenges and limitations within the state. These models would link reimbursement to patient outcomes rather than the volume of services, fostering a more cost-effective and patient-centered approach. By focusing on long-term outcomes, value-based models can incentivize healthcare providers to prioritize comprehensive, effective care for rare disease patients, ensuring access to the most appropriate treatments while also optimizing healthcare resource allocation and sustainability.

Outsource Rare Disease Data Collection and Analysis: To address the limitations in current data collection, the council recommends allocating resources to outsource rare disease data collection and analysis. Outsourcing these efforts would enable more precise and comprehensive data on rare disease prevalence, treatment effectiveness, and patient experiences. By partnering with external experts, Nevada can ensure that its rare disease data is robust, actionable, and capable of informing policy and care decisions effectively. Currently, NV-RDAC relies primarily on data provided by Cure 4 The Kids Foundation. By allocating additional resources to expand these data collection efforts, the council could significantly improve both the quality and breadth of the data, enabling a more comprehensive understanding of rare disease cases across Nevada. This expanded data collection would provide deeper insights into the prevalence, treatment outcomes, and specific needs of rare disease patients statewide, ultimately enhancing the council's ability to drive informed policy and healthcare improvements.

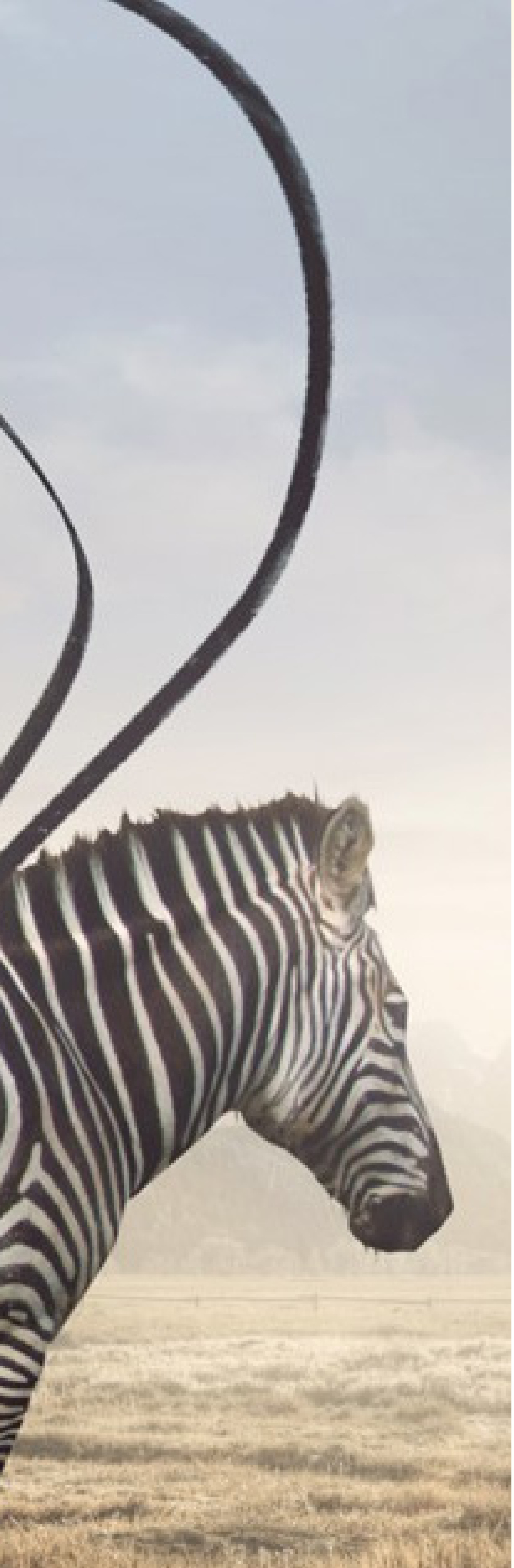
Bill Draft Requests (BDRs): The council continues to request authorization to submit one Bill Draft Request (BDR) during each legislative session. This type of legislative engagement is vital for driving meaningful reforms in Nevada's rare disease landscape and ensuring that the council's legislative priorities are addressed. To further strengthen NV-RDAC's role in shaping policy, it is recommended that the council be granted similar authorities as the Patient Protection Commission (PPC), as outlined in NRS 218D.213. Under this statute, the PPC is authorized to request up to three legislative measures related to its mission. Extending similar authority to NV-RDAC would enable the council to submit a BDR on critical issues related to rare diseases, ensuring a more proactive and impactful approach to policy development.

Increased Engagement with DHHS: Stronger and more consistent engagement is needed from the Department of Health and Human Services (DHHS), especially with state Medicaid administrators. The economic and human toll of inadequately addressing rare diseases is substantial, affecting both patient outcomes and healthcare costs. Close collaboration with DHHS is critical for developing effective strategies that better serve Nevada's rare disease community and ensuring that rare disease care is integrated into broader healthcare initiatives. It is recommended that DHHS establish an annual meeting with the Chair of the NV-RDAC to explore opportunities for collaboration on rare disease initiatives. This regular dialogue would allow for a more coordinated approach to tackling rare disease challenges, aligning state resources, Medicaid policies, and healthcare priorities to address the unique needs of this vulnerable population.

Recommendations (continued)

Address Inadequate Reimbursement for Specialty Providers: Nevada is currently facing a significant shortage of specialized physicians and facilities dedicated to rare disease treatment. To alleviate this, reimbursement rates for rare disease providers must be enhanced. Financial disincentives, burdensome student debt, and the high operational costs associated with specialized medical services exacerbate geographical disparities in care access across the state. Proposed solutions include recalibrating reimbursement rates, implementing loan forgiveness programs for specialists, advocating for telemedicine expansion, and providing incentives for specialists in underserved areas. It is also recommended that rare disease providers, particularly those qualifying under Provider Type 20-699, be excluded from the Physician Administered Drug (PAD) fee schedule. The PAD fee schedule has drastically reduced drug reimbursement rates, placing considerable financial strain on providers and potentially discouraging new specialists from practicing in Nevada. The current fee structure hinders access to critical medications for rare disease patients and contributes to the state's growing shortage of specialists willing to relocate or continue practicing here.

The council advocates for an alternative reimbursement model to the PAD fee schedule for physicians providing high-cost drug administration to patients with rare diseases, recommending a rate of 130% of the Wholesale Acquisition Cost (WAC). This approach would ensure that providers treating rare disease patients have access to essential medications while maintaining financial sustainability, allowing them to continue offering vital services without the burden of financial losses.



The Nevada Rare Disease Advisory Council is dedicated to improving the lives of individuals affected by rare diseases throughout the state. The council's key recommendations highlight the critical need for adequate funding, policy reforms, and strategic partnerships to address the unique challenges faced by Nevada's rare disease community. By implementing these recommendations, Nevada can foster a more inclusive, patient-centered healthcare system that prioritizes long-term outcomes, ensures access to essential care and medications, and supports healthcare providers in delivering specialized treatment. Through continued collaboration with legislators, healthcare stakeholders, and the Department of Health and Human Services, NV-RDAC is committed to driving meaningful change that will benefit rare disease patients and their families now and in the future.

The NV-RDAC is eager to discuss these reccomendations.
Please reach to info@nvrdac.org with any questions.

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