Nevada Rare Disease Advisory Council (NV-RDAC)

2026 Blog Series & Council Member Profiles

Purpose of the Blog Series

The Nevada Rare Disease Advisory Council is launching a year-long educational blog series titled:

**“State by State, Story by Story:

How Rare Disease Advisory Councils Are Changing Care”**

This series will:

- **Build public understanding** of what RDACs do and why they matter
- **Highlight Nevada’s leadership** in statewide rare disease policy
- **Showcase national best practices** and cross-state collaboration
- **Strengthen engagement** from families, providers, and policymakers
- **Support Nevada’s next Rare Disease State Plan** with strong, consistent messaging

Monthly topics will blend Nevada-focused work with national insights to elevate Nevada as a model for rare disease planning and policy.

Council Member Profiles

To support visibility and broaden the reach of the blog series, NV-RDAC will also create **Council Member Profiles**.

Purpose of the Profiles

- Highlight the expertise, lived experience, and unique strengths of each council member
- Personalize and humanize our collective work
- Increase public trust and awareness
- Provide ready-to-share content for your professional and organizational platforms

How It Will Work

- Each council member will receive a drafted profile
- You can edit, add details, or provide a preferred photo
- Final profiles can be shared on:
    - Social media
    - Organizational newsletters
    - LinkedIn articles
    - Public awareness campaigns

  - As supporting material for the blog series

These profiles help tell the story of *who* is doing this work—not just *what* the council produces.

Council Member Roles in the Blog Series

- Review and approve your drafted profile
- Share the blogs on your platforms when appropriate
- Offer quotes, lived experience insights, or data notes to enrich monthly posts
- Encourage your networks to participate in Nevada's needs assessments
- Support awareness around Rare Disease Day and legislative sessions
- Serve as ambassadors for Nevada's rare disease community

Your leadership and visibility are critical to ensuring our statewide message becomes a national model.

Full Year-Long Blog Outline

Below is the **12-month content framework** for the NV-RDAC blog series.

MONTH 1 — What Is a Rare Disease Advisory Council?

Introducing RDACs and Nevada's role in the national movement.

MONTH 2 — Nevada's Origin Story: How SB315 Created the NV-RDAC

The legislative beginning, early work, and why Nevada's RDAC matters.

MONTH 3 — RDACs Across America: A National Snapshot

Overview of active councils, states in development, and national trends.

MONTH 4 — Listening First: Nevada's Patient & Provider Needs Assessments

How Nevada is gathering statewide insights to shape the next State Plan.

MONTH 5 — From Recommendations to Legislation

How RDACs influence policy and how Nevada's recommendations move forward.

MONTH 6 — Centering Lived Experience: Patients & Caregivers at the Table

Why lived experience must drive statewide planning.

MONTH 7 — Clinicians, Researchers & Public Health Leadership

How provider and public health engagement strengthens rare disease policy.

MONTH 8 — Access, Coverage & the Diagnostic Odyssey

Challenges faced by rare disease families in Nevada and across the U.S.

MONTH 9 — Beyond Rare Disease Day: Building Year-Round Awareness

Developing statewide awareness efforts that extend far beyond February.

MONTH 10 — Data Drives Change: Registries, Report Cards & Metrics

How statewide data informs the State Plan and strengthens policy alignment.

MONTH 11 — How States Start or Strengthen an RDAC

Lessons Nevada can share—legislation, structure, data, and partnerships.

MONTH 12 — The Future of Rare Disease Policy in Nevada

Looking ahead to the next State Plan and long-term system improvements.

Thank You for Your Leadership

Your participation, expertise, and public presence are essential to this work. Together, we are strengthening Nevada's rare disease voice and shaping the future of statewide policy, access, and care.