Nevada Rare Disease Advisory Council

2026 Editorial Calendar (Final Draft for Sub-Committee Approval)

Executive Summary

The Nevada Rare Disease Advisory Council (NV-RDAC) has approved a year-long 2026 editorial series designed to educate the public, policymakers, providers, and partners about the role and impact of Rare Disease Advisory Councils—while highlighting Nevada's leadership in building a coordinated, data-driven rare disease system.

This editorial calendar preserves the Council's originally approved 12-month thematic framework and strengthens it by pairing each monthly focus with the lived experience, clinical expertise, public health leadership, and systems knowledge of NV-RDAC members. The result is a cohesive narrative that moves from governance and systems design, through policy development and implementation, to equity, data, and long-term sustainability.

The 2026 editorial series is intended to:

- Increase understanding of what RDACs do and why they matter
- Demonstrate how rare disease policy is shaped through collaboration across disciplines
- Elevate Nevada's model as a national example of effective RDAC engagement
- Translate complex system challenges into accessible, policy-relevant stories
- Strengthen trust and transparency by centering patient, caregiver, and provider voices

Structure and Approach

The calendar follows a monthly thematic structure aligned with the Council's strategic priorities, including:

- Systems design and governance
- Early detection and newborn screening
- Research and cross-state collaboration
- Patient and provider needs assessments
- Lived experience and equity
- Access across geography and the lifespan
- Surveillance, data, and registries
- Policy translation and long-term planning

January launches the series with a Chair's feature and a full Council overview, emphasizing the collective impact of a deliberately diverse advisory body. Subsequent months highlight individual or grouped Council members whose expertise aligns with the monthly focus. An already-published feature spotlighting Christina Beach Thielst serves as evergreen content referenced throughout the year. The series concludes in early 2027 with a forward-looking feature on next-generation leadership.

Council Member Participation

All 20 NV-RDAC members are included in the 2026 editorial plan. Participation expectations are intentionally light and supportive:

- Members are featured during a clearly identified month
- Drafts are developed centrally and shared for review and approval
- Optional interviews or quotes may be requested, but no original writing is required

Sustainability and Oversight

The editorial cadence is designed to be sustainable, with optional companion posts used only where they strengthen understanding of a monthly theme. All content will align with NV-RDAC messaging standards and be reviewed prior to publication.

Recommendation

Approval of the 2026 NV-RDAC Editorial Calendar will allow us to:

- Begin content development with clarity and lead time
- Communicate expectations to Council members in advance
- Ensure consistent, strategic public messaging throughout the year

This plan reflects the Council's shared commitment to thoughtful governance, evidence-based policy, and meaningful engagement with Nevada's rare disease community.

Member-by-Month Outline

Council Member Notification & Preparation Process

Council members will be notified well in advance of their scheduled feature month. At that time, each member will be provided with a simple preparation checklist outlining next steps and timelines.

The checklist is designed to make participation easy and supportive and will include:

- A brief overview of the monthly theme and focus
- Confirmation of the member's feature month
- A short list of optional interview or reflection prompts
- Guidance on photo preferences (if applicable)
- A review and approval timeline

Drafts will be developed centrally and shared with council members for review prior to publication. Council members are not expected to draft original content, though they may choose to provide quotes, edits, or additional context if desired. This process ensures consistency across the series while respecting council members' time and expertise.

Evergreen / Foundational Feature

1. **Christina Beach Thielst** – 1st Evergreen feature (already published, referenced throughout 2026)

January 2026

2. **Annette Logan-Parker** (Chair) – 2nd Evergreen feature- Draft under review now.
3. **Full Council Overview** – 3rd Evergreen feature -All remaining members acknowledged collectively (non-profiled)- Draft under review now.

February 2026

4. **Dr. William N. Evans, MD**

March 2026

5. **Dr. Craig Vincze, PhD**

April 2026

6. **Madison Bowe**

May 2026

7. **Dr. Devraj Chavda, MD**
8. **Dr. Sumit Gupta, MD**
9. **Melissa Bart-Plange**

June 2026

10. **Georgene' (Gina) Glass**
11. **Naja Bagner**

July 2026

12. **Dr. Verena Samara, MD**
13. **Valerie Porter, DNP, RN, AG-ACNP-BC**

August 2026

14. **Amber Federizo, DNP, MSN**

15. **Jennifer Millet, MSN, RN**

September 2026 (Dual Awareness Month)

16. **Brigette Cole**
17. **Dr. Ihsan Azzam, PhD, MD**

October 2026

18. **Paul Niedermeyer**

December 2026

19. **Pamela White**
20. **Kim Anderson**

Series Close – Early 2027

21. **Mallory Carvalho** *(intentional next-generation feature)*

2026 Editorial Calendar

Series Title: State by State, Story by Story: How Rare Disease Advisory Councils Are Changing Care

Editorial Framework: Each month highlights a system challenge, the leadership addressing it, and the statewide impact, following the Christina Thielst feature model.

1st EVERGREEN FEATURE (Already Published)

Christina Beach Thielst
When Patients Become the Experts: Spotlight on Christina Beach Thielst and Her Diagnostic Guide

- Serves as foundational content referenced throughout the year
- Not duplicated in the monthly calendar

JANUARY 2026

Theme: Designing Systems That Work

Purpose: Series launch + introduce NV-RDAC as a systems-level body

2nd Evergreen Feature

When Systems Change Because Someone Refused to Accept “Good Enough”

- Featured Council Member: Annette Logan-Parker (Chair)
- Focus: Leadership, governance, systems design, statewide vision

3rd Evergreen Feature (Planned)

One Council, Many Voices: How Diverse Expertise Is Driving Rare Disease Change in Nevada

- Full council overview (no individual profiles)
- Demonstrates how clinical, public health, lived experience, operations, research, and policy voices work together

Intent: Set credibility, orient readers, and frame the entire year as collective work.

FEBRUARY 2026

Theme: Rare Disease Month – Nevada’s Foundation

Purpose: Anchor the year in early detection and long-standing commitment

Primary Feature

- Featured Council Member: Dr. William N. Evans, MD
- Focus: Congenital and genetic disease, early diagnosis, pediatric specialty care

Companion Content

- Short explainer: *Rare Disease in Nevada: Why Early Detection Matters*

MARCH 2026

Theme: Building What Lasts – Research & Collaboration

Purpose: Show how innovation and research inform policy and care

Primary Feature

- Featured Council Member: Dr. Craig Vincze, PhD
- Focus: Biomedical research, innovation pipelines, national collaboration

Companion Content

- *From Discovery to Policy: How Research Reaches Patients*

APRIL 2026

Theme: The Human Cost of Fragmented Systems

Purpose: Highlight what happens when systems fail to coordinate

Primary Feature

- Featured Council Member: Madison Bowe
- Focus: Young adult rare disease experience, emergency care gaps, trauma-informed systems

Companion Content

- *What Happens When Systems Don't Talk to Each Other*

MAY 2026

Theme: From Recommendations to Legislation

Purpose: Demonstrate how RDAC work becomes law and practice

Primary Features (Grouped)

- Dr. Devraj Chavda, MD – Pediatric neurology, newborn screening, gene-targeted therapies
- Dr. Sumit Gupta, MD – Vice Chair, Nevada Newborn Screening Council; pediatric hem/onc
- Melissa Bart-Plange – Parent advocate; contracts and implementation expertise

Intent:
Show the full policy pipeline: clinical insight → legislation → operational execution.

JUNE 2026

Theme: Centering Lived Experience

Purpose: Reinforce that lived experience is expertise

Primary Features

- Georgene' (Gina) Glass – Founder, Dreamsickle Kids Foundation; caregiver leadership
- Naja Bagner – Sickle Cell patient advocate; community health leadership

Intent:
Highlight Sickle Cell Disease, equity, and community-driven systems change.

JULY 2026

Theme: Rare Disease Across the Lifespan

Purpose: Expand focus beyond pediatrics

Primary Features

- Dr. Verena Samara, MD – Neuromuscular specialist; academic medicine
- Valerie Porter, DNP, RN, AG-ACNP-BC – Adult/geriatric rare disease; VA population

Intent:
Show how rare disease care evolves from childhood through adulthood and aging.

AUGUST 2026

Theme: When Geography Determines Outcomes

Purpose: Address rural access and system variation

Primary Features

- Amber Federizo, DNP, MSN – Rural Nevada advocacy; vulnerable populations
- Jennifer Millet, MSN, RN – Hospital operations; navigation of complex care

Intent:
Demonstrate how location and system structure affect diagnosis and outcomes.

SEPTEMBER 2026

Theme: Childhood Cancer & National Sickle Cell Disease Awareness Month – Surveillance, Survivorship & Systems

Purpose: Elevate childhood cancer and sickle cell disease (SCD) as lifelong conditions within the rare disease landscape, with a focused emphasis on equity, survivorship, and the role of statewide surveillance systems in improving outcomes across the lifespan.

Primary Features (Dual Focus)

Childhood Cancer Focus

- Brigette Cole – Survivor perspective; patient navigation, outreach, and long-term survivorship needs

Sickle Cell Disease Focus

- Dr. Ihsan Azzam, PhD, MD – State epidemiology, surveillance, and public health strategy, with emphasis on population-level data and equity

Intent: Use September's dual national awareness observances to demonstrate how surveillance, data infrastructure, and coordinated systems of care are essential for both childhood cancer and sickle cell disease. This month connects awareness to action by highlighting how Nevada tracks outcomes, identifies disparities, and plans for long-term survivorship and system accountability—not just acute treatment.

OCTOBER 2026

Theme: Making the Invisible Visible

Purpose: Explain why rare diseases are undercounted and underfunded

Primary Feature

- Paul Niedermeyer – Systems strategy; data-driven decision-making

Companion Content

- *Why Rare Diseases Are Under-Counted — and Why It Matters*

NOVEMBER 2026

Theme: Turning Experience Into Policy

Purpose: Clarify the role and value of RDACs before legislative cycles

Primary Feature

- Council Synthesis Post (multiple member quotes)
- Focus: How advisory councils translate lived experience into actionable policy

Intent:
Reinforce NV-RDAC's credibility with policymakers and partners.

DECEMBER 2026

Theme: The Future of Rare Disease Policy in Nevada

Purpose: Close the year with continuity and vision

Primary Features

- Pamela White – Legacy SCD advocacy; adult systems and legislation

- Kim Anderson – Palliative care, quality of life, statewide systems

Intent:
Honor legacy leadership while focusing on sustainability and whole-person care.

SERIES CLOSE (EARLY 2027)

Theme: The Next Generation of Rare Disease Advocacy

- Featured Council Member: Mallory Carvalho
- Focus: Trauma-informed advocacy, workforce development, future leadership