

## Nevada Rare Disease Advisory Council (NV-RDAC) 2026-2027 Strategic Plan Planning Survey

### Introduction:

As we prepare for the next NV-RDAC Strategic Plan (2026-2027), we want to hear from council members to ensure our priorities align with the needs of Nevada's rare disease community. Your responses will help guide and directly inform the council's focus, initiatives, and advocacy efforts over the next planning period. Please take a few minutes to complete this survey.

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### Section 1: Prioritizing Key Areas

1. Rank the following areas from 1 to 6, with 1 being the highest priority, for the next strategic plan. Each number should only be used once.
    - ☐ Awareness & Education
    - ☐ Care & Support
    - ☐ Research & Data
    - ☐ Policy & Legislative Advocacy
    - ☐ Healthcare Provider Training & Workforce Development
    - ☐ Access to Diagnostics & Treatment
  2. Which of the following would you like to see expanded in the next plan? (*Check all that apply.*)
    - ☐ Rare Disease Awareness Campaigns
    - ☐ Legislative Efforts (Newborn Screening, Medicaid Expansion, etc.)
    - ☐ Improved Data Collection & Rare Disease Registry
    - ☐ Healthcare Provider Education & Training
    - ☐ Patient Navigation & Support Services
    - ☐ Partnerships with Research Institutions & Clinical Trials
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### Section 2: Identifying Gaps in the Current Plan

3. To what extent do you feel the current NV-RDAC Strategic Plan effectively addresses the needs of Nevada's rare disease community?
  - ☐ Yes
  - ☐ Somewhat
  - ☐ No
  - ☐ Unsure
4. What areas do you think need the most improvement? (*Select up to three.*)
  - ☐ Expanding the Rare Disease Needs Assessment
  - ☐ Increasing Policy & Legislative Engagement

- ☐ Enhancing Medicaid & Insurance Coverage for Rare Disease Treatments
  - ☐ Strengthening Data Collection & Research Efforts
  - ☐ Increasing Awareness Among Healthcare Providers
  - ☐ Enhancing Community Engagement & Patient Advocacy
5. What additional initiatives or programs should be considered for the next strategic plan? (*Open-ended response*)
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### Section 3: Legislative & Policy Priorities

6. Which legislative efforts should NV-RDAC focus on in the next strategic plan? (*Check all that apply.*)
- ☐ Expansion of the Newborn Screening Panel
  - ☐ Rare Disease Coverage Under Medicaid
  - ☐ Development of a Rare Disease Registry
  - ☐ Policies to Improve Access to Genetic Testing & Counseling
  - ☐ Research Funding for Rare Diseases
7. Would you be willing to participate in legislative advocacy efforts (e.g., meetings with legislators, testimonies, awareness campaigns)?
- ☐ Yes
  - ☐ No
  - ☐ Maybe, depending on availability
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### Section 4: Council Engagement & Effectiveness

8. How effective has NV-RDAC been in achieving its strategic priorities over the past planning period?
- ☐ Excellent
  - ☐ Good
  - ☐ Fair
  - ☐ Needs Improvement
  - ☐ Unsure
9. How can NV-RDAC improve member engagement and participation? (*Open-ended response*)
10. What resources or support would help you be more engaged in council activities? (*Check all that apply.*)
- ☐ More frequent updates & communication
  - ☐ Additional training & education on rare disease policy
  - ☐ More opportunities for direct advocacy & involvement

- ☐ Networking with other rare disease stakeholders
  - ☐ Other (please specify): \_\_\_\_\_
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## Section 5: Expanding the Focus of NV-RDAC

11. Should NV-RDAC broaden its focus beyond its current three categories (childhood cancers, factor deficiencies/inherited platelet disorders, and newborn screening conditions) to include additional rare diseases?

- ☐ Yes, NV-RDAC should expand to address rare diseases more holistically.
- ☐ No, the current focus areas are sufficient.
- ☐ Unsure

12. If NV-RDAC expands its focus, which approach would be most effective? (*Check all that apply.*)

- ☐ Shifting from a diagnosis-specific focus to addressing the common challenges experienced across all rare diseases.
- ☐ Developing strategies that improve overall healthcare navigation for individuals with rare diseases, rather than focusing on individual conditions.
- ☐ Expanding policy recommendations to include access to rare disease treatments, clinical trials, and multidisciplinary care.
- ☐ Strengthening research and data collection on rare disease experiences in Nevada.
- ☐ Other (please specify): \_\_\_\_\_

13. What are the biggest barriers you see in transitioning NV-RDAC to a broader rare disease focus? (*Open-ended response*)

14. Do you have any additional thoughts on how NV-RDAC should evolve in the next strategic plan? (*Open-ended response*)

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## Section 6: Engaging with DHHS and Other Stakeholders

15. What strategies should NV-RDAC use to strengthen engagement with the Department of Health and Human Services (DHHS) and other key stakeholders? (*Check all that apply.*)

- ☐ Regular meetings with DHHS leadership and staff
- ☐ Increased collaboration with Medicaid and public health programs
- ☐ Partnerships with research institutions and hospitals
- ☐ Greater involvement in statewide health policy discussions
- ☐ Other (please specify): \_\_\_\_\_

16. How can NV-RDAC expand responsibilities across its members to increase effectiveness? (*Open-ended response*)
  17. What additional partnerships or collaborations should NV-RDAC pursue to enhance its impact? (*Open-ended response*)
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## Section 7: Allocation of License Plate Funds

18. How should funds generated from the NV-RDAC specialty license plate be allocated to best support the rare disease community? (*Check all that apply.*)
    - ☐ Supporting rare disease education- CMEs for healthcare providers
    - ☐ Supporting a PR and Awareness Campaign
    - ☐ Supporting legislative advocacy for rare disease policies
    - ☐ Other (please specify): \_\_\_\_\_
  19. Do you have any additional suggestions for how these funds could be most effectively utilized? (*Open-ended response*)
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Thank You!

Your input is essential in shaping the future of NV-RDAC. Survey results will be analyzed, and key findings will be shared with the council to inform the 2026-2027 Strategic Plan. Thank you for your time and dedication to improving the lives of Nevadans affected by rare diseases!