

## **Nevada Rare Disease Advisory Council (NV-RDAC)**

### **Statewide Childhood, Adolescent & Young Adult (AYA) Cancer and Rare Disease Policy Feedback Survey**

#### ***Informing NV-RDAC Recommendations for the 2027 Nevada Legislative Session***

#### **Purpose**

The Nevada Rare Disease Advisory Council (NV-RDAC) is seeking feedback from patients, families, healthcare providers, advocates, and community partners across Nevada to inform the Council's policy and legislative recommendations related to childhood, adolescent, and young adult (AYA) cancer and rare diseases.

NV-RDAC is a statutorily established advisory body that provides guidance to state agencies and policymakers. Your input will help identify system gaps, access barriers, workforce needs, coordination challenges, equity issues, and policy and budget opportunities affecting cancer and rare disease care across the lifespan.

Survey results will be reviewed by NV-RDAC and used to guide Council discussion, priority-setting, and formal recommendations, including consideration of Bill Draft Requests (BDRs) for the 2027 Nevada Legislative Session.

This survey is advisory and informational and does not ask respondents to advocate for specific legislation.

#### **Survey Introduction**

Childhood, adolescent, and young adult (AYA) cancers and rare diseases affect thousands of Nevada families across the lifespan. Many experience challenges related to early diagnosis, access to age-appropriate specialty care, insurance coverage, behavioral health support, workforce shortages, data gaps, and coordination across systems—often during critical developmental and life transitions.

Through this survey, NV-RDAC is asking for your perspective on what changes are most needed to improve childhood and AYA cancer and rare disease care, access, equity, and outcomes in Nevada.

Thank you for taking a few minutes to share your experience and insights.

#### **Section 1: About You**

1. How do you best describe your role related to childhood or AYA cancer or rare disease?  
(Select all that apply)

- ☐ Person living with a rare disease

- ☐ Childhood or AYA cancer survivor
- ☐ Parent or caregiver of a child or AYA with cancer or rare disease
- ☐ Healthcare provider (pediatric, AYA, or adult)
- ☐ Behavioral health or social services provider
- ☐ Advocate or nonprofit organization
- ☐ Researcher or academic partner
- ☐ State or local agency representative
- ☐ Other: \_\_\_\_\_

2. Which region(s) of Nevada are you located in or primarily serve?  
(Select all that apply)

#### Southern Nevada

- ☐ Clark County (Las Vegas / North Las Vegas / Henderson)
- ☐ Nye County
- ☐ Lincoln County

#### Northern Nevada

- ☐ Washoe County (Reno / Sparks)
- ☐ Carson City
- ☐ Douglas County
- ☐ Lyon County

#### Rural & Frontier Nevada

- ☐ Elko County
- ☐ Humboldt County
- ☐ Lander County
- ☐ Eureka County
- ☐ White Pine County
- ☐ Churchill County
- ☐ Pershing County
- ☐ Mineral County
- ☐ Storey County

#### Statewide / Multiple Regions

- ☐ Statewide (serve multiple regions)
- ☐ Other (please specify): \_\_\_\_\_

2a. If you selected multiple regions, where do you see the greatest unmet need?  
(Open response)

## Section 2: Priority Issues & System Gaps

3. Which issues have the greatest impact on children, adolescents, young adults (AYA), and families affected by cancer or rare diseases in Nevada?  
(Select up to 3)

- ☐ Delayed diagnosis or misdiagnosis
- ☐ Limited access to age-appropriate specialty care (pediatric or AYA)
- ☐ Long travel distances for treatment
- ☐ Insurance coverage or reimbursement barriers
- ☐ Lack of care coordination
- ☐ Behavioral health or psychosocial support needs
- ☐ Transitions of care (pediatric → AYA → adult systems)
- ☐ Workforce shortages or lack of provider training
- ☐ Lack of data, registries, or tracking
- ☐ Other: \_\_\_\_\_

4. Are there specific gaps in Nevada's childhood or AYA cancer or rare disease systems that NV-RDAC should elevate for legislative consideration?  
(Open response)

## Section 3: Policy & Legislative Focus

5. Which policy areas should NV-RDAC prioritize when advising Nevada lawmakers on childhood and AYA cancer and rare disease issues?  
(Select up to 3)

- ☐ Early diagnosis and newborn screening
- ☐ Access to pediatric and AYA specialty care
- ☐ Childhood and AYA cancer and rare disease data, registries, and surveillance
- ☐ Workforce development and provider education
- ☐ Insurance access and affordability
- ☐ Behavioral health and family/AYA support services
- ☐ Health equity and rural access
- ☐ Research participation and clinical trials (including AYA inclusion)
- ☐ Other: \_\_\_\_\_

6. Are there specific laws, regulations, or policy changes that you believe should be *established, updated, or reconsidered* to improve childhood or AYA cancer and rare disease care in Nevada?

(Open response)

*You do not need to cite bill numbers; general descriptions are sufficient.*

7. Which issues require the most urgent action in the next 1–2 years?

(Open response)

#### **Section 4: Coordination with 2027 Legislative Efforts**

8. Are you or your organization currently working on, or planning to pursue, any policy or legislative priorities related to childhood or AYA cancer or rare diseases for the 2027 Nevada Legislative Session where NV-RDAC could help inform, coordinate, or elevate the issue?

(Open response)

*Examples may include policy concepts, research findings, data initiatives, education efforts, or system challenges—not draft legislation.*

9. If yes, how could NV-RDAC be most helpful?

(Select all that apply)

- ☐ Providing data or system-level context
- ☐ Elevating lived experience perspectives
- ☐ Coordinating across stakeholders
- ☐ Informing or refining policy concepts
- ☐ Supporting education for policymakers
- ☐ Other: \_\_\_\_\_

#### **Section 5: Budget & Investment Considerations (BDR Readiness)**

10. Which of the policy issues you identified would likely require *new or expanded state funding* to address?

(Select all that apply)

- ☐ Early diagnosis / screening
- ☐ Specialty care access
- ☐ Data, registries, or surveillance
- ☐ Workforce development
- ☐ Behavioral health supports
- ☐ Care coordination / navigation
- ☐ Unsure
- ☐ Other: \_\_\_\_\_

11. Where do you believe targeted investment could *reduce higher downstream costs*?

(Open response)

*Examples: emergency care, hospitalizations, out-of-state referrals, delayed diagnosis, crisis mental health care.*

12. In your view, would addressing these issues require:

- ☐ Small, targeted investment
- ☐ Moderate, scalable investment
- ☐ Significant statewide investment
- ☐ Unsure

13. Which state system(s) or agency(ies) would be best positioned to administer or oversee funding related to these priorities?

(Select all that apply)

- ☐ DHHS / Medicaid
- ☐ Public Health / Epidemiology
- ☐ Health and Human Services agencies
- ☐ Education or workforce agencies
- ☐ Licensing or regulatory boards
- ☐ Multi-agency collaboration
- ☐ Unsure
- ☐ Other: \_\_\_\_\_

14. Do you believe progress would require *new funding*, or could improvements be made by better coordinating or reallocating existing resources?

- ☐ Primarily new funding
- ☐ Primarily better use of existing funds
- ☐ A combination of both
- ☐ Unsure

## **Section 6: Workforce Development**

15. Which workforce gaps most affect childhood, AYA cancer, or rare disease care in Nevada?

(Select all that apply)

- ☐ Pediatric subspecialists
- ☐ AYA-focused providers
- ☐ Adult specialists with rare disease expertise
- ☐ Genetic counselors
- ☐ Nurses and advanced practice providers
- ☐ Behavioral health providers

- ☐ Care coordinators / navigators
- ☐ Rural providers
- ☐ Other: \_\_\_\_\_

16. What workforce strategies should NV-RDAC consider elevating for policy or system improvement?

(Select all that apply)

- ☐ Provider training or continuing education
- ☐ Incentives for specialty providers to practice in Nevada
- ☐ Telehealth expansion
- ☐ Fellowship or pipeline programs
- ☐ Loan repayment or recruitment incentives
- ☐ Cross-training pediatric and adult providers
- ☐ Other: \_\_\_\_\_

#### Section 7: Equity & Populations Impacted

17. Are there specific populations of children, adolescents, young adults (AYA), or families affected by cancer or rare diseases who are currently underserved or overlooked in Nevada?

(Open response)

#### Section 8: Duplication & Coordination

18. Where do you see duplication of effort, overlapping programs, or lack of coordination in childhood, AYA cancer, or rare disease services in Nevada?

(Open response)

19. What could help reduce duplication and improve coordination across systems?

(Open response)

#### Section 9: Implementation & Readiness

20. What do you see as the biggest barriers to implementing meaningful policy or system changes for childhood or AYA cancer and rare disease care?

(Open response)

21. Are there existing programs, policies, or practices in Nevada that are working well and should be protected or expanded?

(Open response)

#### Section 10: Lived Experience & Voice

22. How should NV-RDAC incorporate the experiences of children, adolescents, young adults (AYA), and caregivers into policy recommendations?  
(Select all that apply)

- ☐ Sharing stories with lawmakers
- ☐ Participating in public testimony
- ☐ Informing data collection and needs assessments
- ☐ Helping shape policy recommendations
- ☐ Educational sessions for policymakers
- ☐ Other: \_\_\_\_\_

#### Section 11: Measuring Progress

23. From your perspective, what outcomes should NV-RDAC use to measure progress in childhood and AYA cancer and rare disease care?  
(Select all that apply)

- ☐ Faster diagnosis
- ☐ Improved access to age-appropriate care within Nevada
- ☐ Better coordination across providers
- ☐ Reduced financial burden on families and AYAs
- ☐ Stronger behavioral health support
- ☐ Increased awareness and education
- ☐ Clearer pathways to services
- ☐ Other: \_\_\_\_\_

#### Section 12: Engagement & Follow-Up

24. Would you like to stay engaged as NV-RDAC refines its childhood and AYA cancer and rare disease priorities for the 2027 Nevada Legislative Session?  
(Select all that apply)

- ☐ Yes – receive updates on NV-RDAC’s 2027 policy and legislative recommendations
- ☐ Yes – provide additional input or feedback as priorities are refined
- ☐ Yes – participate in future listening sessions, workgroups, or advisory discussions
- ☐ Yes – be notified of public meetings or opportunities to engage
- ☐ No, thank you

25. If you would like to stay engaged, please share your contact information below.  
(Optional – information will be used only for NV-RDAC communication related to its advisory work.)

Name:

Organization (if applicable):

Email address:

Phone (optional):

### **Section 13: Final Thoughts**

26. Is there anything else you would like NV-RDAC and Nevada policymakers to understand about childhood or AYA cancer and rare disease care in Nevada?

(Open response)

Closing Statement

Thank you for sharing your perspective. NV-RDAC values your input and will use this feedback to inform Council discussions and recommendations aimed at improving childhood, adolescent, and young adult (AYA) cancer and rare disease care, access, equity, workforce capacity, coordination, and outcomes for Nevada's children, young people, and families.