

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

### **Legislative & Community Event Planning Survey**

Purpose: As discussed during the December 2025 NV-RDAC meeting, the Council plans to host three Rare Disease education events in 2026:

1. Legislative Education Event – Carson City
2. Community Education Event – Southern Nevada
3. Community Education Event – Northern Nevada

This survey gathers Council input to refine content, format, locations, timing, and Council involvement so planning can move forward efficiently. Results will be summarized and shared with the Council prior to final decisions.

Planning notes:

- Community events are anticipated to be in-person gatherings of approximately 100 attendees
- On-site childcare will not be available
- Virtual participation options are being considered for accessibility

#### **Section 1: Legislative Education Event – Carson City**

1. What should be the primary goal(s) of the Carson City legislative event?  
(Select up to 2)

- Educate legislators on rare disease system gaps
- Highlight data, surveillance, and registry needs
- Elevate patient and caregiver perspectives
- Inform future legislative priorities
- Build relationships with legislative staff and state agencies

2. Who should be prioritized for the Carson City event?  
(Select all that apply)

- State legislators
- Legislative staff
- State agency leadership
- Governor's Office
- Other: \_\_\_\_\_

3. In what ways could you personally support the Carson City event?  
(Select all that apply)

- Planning / advisory support

- Speaker or panelist
- Sharing lived experience or patient perspective
- Outreach to legislators or staff
- Day-of support
- Unable to support this event

## **Section 2: Community Education Event – Southern Nevada**

4. What should be the primary goal(s) of the Southern Nevada community event?  
(Select up to 2)

- Educate patients and families
- Increase public awareness of rare diseases
- Connect families to resources and services
- Educate providers and community partners
- Highlight NV-RDAC's role and recommendations

5. In what ways could you support the Southern Nevada community event?  
(Select all that apply)

- Planning / advisory support
- Speaker or panelist
- Resource table or organizational presence
- Outreach and promotion
- Day-of support
- Unable to support this event

6. Should the Southern Nevada community event include a virtual participation option?

- Yes – full hybrid (in-person + live virtual)
- Yes – limited virtual option (livestream only)
- No – in-person only
- Not sure

## **Section 3: Community Education Event – Northern Nevada**

7. What should be the primary goal(s) of the Northern Nevada community event?  
(Select up to 2)

- Educate patients and families
- Increase public awareness of rare diseases
- Connect families to resources and services
- Educate providers and community partners

- Highlight NV-RDAC's role and recommendations

8. In what ways could you support the Northern Nevada community event?  
(Select all that apply)

- Planning / advisory support
- Speaker or panelist
- Resource table or organizational presence
- Outreach and promotion
- Day-of support
- Unable to support this event

9. Should the Northern Nevada community event include a virtual participation option?

- Yes – full hybrid (in-person + live virtual)
- Yes – limited virtual option (livestream only)
- No – in-person only
- Not sure

10. Do you have suggestions for a potential location or host site in Northern Nevada?  
(Open response)

*Examples: hospitals, community centers, universities, nonprofit spaces.*

#### **Section 4: Content & Speakers**

11. What types of information should be prioritized for the community education events?  
(Select all that apply)

- Understanding rare diseases and diagnostic journeys
- Navigating the healthcare system and insurance
- Available clinical services and specialty care in Nevada
- Behavioral health and psychosocial support
- Transition of care (pediatric to adult services)
- Research, registries, and data collection
- Advocacy, policy, and patient rights
- Community resources and support organizations
- Other: \_\_\_\_\_

12. Who do you believe should deliver this information?  
(Select all that apply)

- NV-RDAC members
- Physicians or clinical specialists

- Behavioral health professionals
- Patients and caregivers with lived experience
- Community or nonprofit partners
- State agency representatives
- A combination of the above

13. For physician or clinical guest speakers, what expertise would be most valuable?  
(Open response)

*Examples: pediatric specialists, adult specialists, geneticists, neurologists, hematologists, primary care, etc.*

14. Are there specific individuals or organizations you recommend as speakers or partners?  
(Open response)

### **Section 5: Resource Partners (Not Vendors)**

15. For the community education events, which approach do you support for partner participation?

- No tables; programming only
- Limited, curated resource tables (nonprofit and community partners only)
- Limited tables including select healthcare organizations (education only, no sales)
- Not sure

16. Are there organizations you would recommend as appropriate resource partners?  
(Open response)

### **Section 6: Availability & Considerations**

#### **16. Name**

*(Required)*

#### **17. Of the three events, which are you most able to support?**

(Select all that apply)

- Carson City (Legislative)
- Southern Nevada (Community)
- Northern Nevada (Community)

#### **18. For the event(s) you selected, what role best fits your capacity?**

(Select one)

- Lead / Co-lead
- Supporting role

- Advisory / review only

**19. Are there any scheduling considerations or limitations we should be aware of?**  
(Open response)

Closing Statement

Thank you for your input. Your responses will help guide planning, clarify Council roles, identify potential locations, and ensure these events are meaningful, accessible, and aligned with statewide needs. A summary of responses will be shared with the Council prior to next steps.