

NEVADA RARE DISEASE ADVISORY COUNCIL
Community Education Event Subcommittee
Supporting Document — May 1, 2026 Meeting

2027 Event Planning Survey — Aggregated Results

Overview

This document summarizes the aggregated results of the 2027 Event Planning Survey distributed to the Nevada Rare Disease Advisory Council in April 2026. The survey was developed and approved through the Council's established process and was designed to gather Council member input on three rare disease education events being considered for 2027: a Legislative Education Event in Carson City, a Community Education Event in Southern Nevada, and a Community Education Event in Northern Nevada.

Methodology

The survey was distributed to seated NV-RDAC Council members.

Nine (9) Council members responded. Six (6) completed the survey in full, and three (3) submitted partial responses. All data submitted is included in the aggregates reported below; where individual questions were skipped by a respondent, those responses are simply excluded from that question's count.

Reporting conventions

Percentages throughout this document are calculated based on 9 total respondents unless otherwise noted. Where fewer than 9 respondents answered a specific question, the number answering is stated beneath the table.

Individual responses have been fully aggregated. Open-text responses are reported verbatim as submitted, without attribution to individual respondents. Minor punctuation and spacing cleanup has been applied where needed for readability; no substantive changes have been made to the content of any response.

Section 1 — Legislative Event, Carson City

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

Response Option	Count	% of 9
Educate legislators on rare disease system gaps	7	78%
Build relationships with legislative staff and state agencies	6	67%
Elevate patient and caregiver perspectives	2	22%
Inform future legislative priorities	1	11%
Highlight data, surveillance, and registry needs	0	0%

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

Response Option	Count	% of 9
State legislators	8	89%
Governor's Office	6	67%
Legislative staff	5	56%
State agency leadership	5	56%
Other	1	11%

"Other" open-text response: "include insurance and oncology people if possible."

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

Response Option	Count	% of 9
Outreach to legislators or staff	7	78%
Sharing lived experience or patient perspective	6	67%
Speaker or panelist	5	56%
Planning / advisory support	4	44%
Day-of support	4	44%
Unable to support this event	0	0%

Section 2 — Community Event, Southern Nevada

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

Response Option	Count	% of 9
Educate providers and community partners	5	56%
Highlight NV-RDAC's role and recommendations	5	56%
Increase public awareness of rare diseases	4	44%
Connect families to resources and services	3	33%
Educate patients and families	1	11%

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

Response Option	Count	% of 9
Outreach and promotion	6	67%
Planning / advisory support	5	56%
Day-of support	5	56%
Resource table or organizational presence	4	44%
Speaker or panelist	3	33%
Unable to support this event	2	22%

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

Response Option	Count	% of 9
Not sure	4	44%
Yes — full hybrid (in-person + live virtual)	2	22%
Yes — limited virtual option (livestream only)	1	11%
No — in-person only	1	11%

One respondent did not answer this question.

Section 3 — Community Event, Northern Nevada

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

Response Option	Count	% of 9
Educate providers and community partners	6	67%
Highlight NV-RDAC's role and recommendations	5	56%
Increase public awareness of rare diseases	2	22%
Connect families to resources and services	2	22%
Educate patients and families	1	11%

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

Response Option	Count	% of 9
Planning / advisory support	7	78%
Outreach and promotion	5	56%
Day-of support	4	44%
Speaker or panelist	3	33%
Resource table or organizational presence	2	22%
Unable to support this event	0	0%

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

Response Option	Count	% of 9
Yes — full hybrid (in-person + live virtual)	2	22%
Yes — limited virtual option (livestream only)	2	22%
No — in-person only	2	22%
Not sure	2	22%

Responses were evenly split across all four options. One respondent did not answer this question.

Question 10. Do you have suggestions for a potential location or host site in Northern Nevada?

Open-text responses, verbatim and unattributed:

- Renown Regional Medical Center, University of Nevada Reno school of nursing
- Renown
- Carson City Community Center
- Not sure
- University of Nevada, Reno (UNR) School of Medicine campus or Mathewson-IGT Knowledge Center / Innevation Center (Reno)
- University of Reno
- Not sure

Section 4 — Content and Speakers

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

Response Option	Count	% of 9
Available clinical services and specialty care in Nevada	7	78%
Community resources and support organizations	7	78%
Understanding rare diseases and diagnostic journeys	6	67%
Navigating the healthcare system and insurance	5	56%
Advocacy, policy, and patient rights	5	56%
Research, registries, and data collection	4	44%
Transition of care (pediatric to adult services)	3	33%
Behavioral health and psychosocial support	2	22%
Other	0	0%

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

Response Option	Count	% of 9
NV-RDAC members	6	67%
Physicians or clinical specialists	6	67%
A combination of the above	6	67%
Patients and caregivers with lived experience	5	56%
Community or nonprofit partners	5	56%
Behavioral health professionals	3	33%
State agency representatives	3	33%

Question 13. For physician or clinical guest speakers, what expertise would be most valuable?

Open-text responses, verbatim and unattributed:

- Pediatric and adult specialists, clinic prior authorization specialists, and social workers from complex care to highlight the outcome gaps when Nevada does not meet the necessary resources
- Pediatric specialists, ENTs, dentists, primary care
- Neuromuscular and other sub-specialists
- Hematologist
- Ideally at least one specialist in each area
- Pediatric and adult specialist, hematologist
- Pediatric and adult specialists
- Hematology/oncology, genetics

Question 14. Are there specific individuals or organizations you recommend as speakers or partners?

Open-text responses, verbatim and unattributed:

- Cure 4 The Kids Foundation team
- Named physicians affiliated with Nevada pediatric specialty care
- Council-member specialists
- Cure 4 The Kids Foundation providers
- Not sure
- Dreamsickle Kids Foundation
- Cure 4 The Kids Foundation, Candlelighters, Nevada Childhood Cancer Foundation, Make-A-Wish, Renown
- Not sure

Section 5 — Resource Partners

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

Response Option	Count	% of 9
Limited tables including select healthcare organizations (education only, no sales)	4	44%
Limited, curated resource tables (nonprofit and community partners only)	2	22%
Not sure	2	22%
No tables; programming only	0	0%

Eight respondents answered this question.

Question 16. Are there organizations you would recommend as appropriate resource partners?

Open-text responses, verbatim and unattributed:

- Managed Care Organization leadership should be present to understand the realities of front-line rare disease care
- Nevada Childhood Cancer Foundation, Renown
- Those with expertise treating adult and pediatric patients — subspecialists
- Solutions of Change, Nevada Childhood Cancer Foundation
- Renown Health, UNR School of Medicine, Nevada Childhood Cancer Foundation, NORD
- Dreamsickle Kids Foundation
- Not sure
- No

Section 6 — Availability and Considerations

Question 17. Of the three events, which are you most able to support? (Select all that apply)

Response Option	Count	% of 9
Carson City (Legislative)	8	89%
Southern Nevada (Community)	5	56%
Northern Nevada (Community)	5	56%

Question 18. For the event(s) you selected, what role best fits your capacity? (Select one)

Response Option	Count	% of 9
Supporting role	6	67%
Lead / Co-lead	2	22%
Advisory / review only	0	0%

Eight respondents answered this question.

Question 19. Are there any scheduling considerations or limitations we should be aware of?

Open-text responses, verbatim and unattributed:

- Depends on when events are ultimately scheduled
- None at this time
- Not that I am aware of at this time
- Yes, will follow up by email
- Healthcare work is often scheduled several months in advance; firm dates will support availability
- Not applicable
- Not sure
- None

Summary of Findings

Areas of Council alignment

Carson City Legislative Event:

- Seven of nine respondents identified "educate legislators on rare disease system gaps" as a primary goal.
- Eight of nine respondents indicated state legislators as the top audience to prioritize.
- Eight of nine respondents indicated they could support the Carson City event in some capacity, the highest level of commitment across the three proposed events.
- No respondent indicated they were unable to support the Carson City event.

Community events (Southern and Northern Nevada):

- "Educate providers and community partners" and "Highlight NV-RDAC's role and recommendations" were the top-ranked goals for both community events.
- One of nine respondents selected "Educate patients and families" as a primary goal for either community event.

Content priorities:

- "Available clinical services and specialty care in Nevada" and "Community resources and support organizations" were tied as the top content priorities, each receiving 7 of 9 responses.

Areas of Council uncertainty or division

- Northern Nevada virtual participation: responses were evenly split across all four options (2 responses each).
- Southern Nevada virtual participation: "Not sure" was the most-selected response, with 4 of 9 respondents.
- Northern Nevada venue: no single site received a majority recommendation; the University of Nevada, Reno and Renown Health were each mentioned three times.

Leadership and capacity

- Of eight respondents who indicated role capacity, two selected "Lead / Co-lead" and six selected "Supporting role."
- Multiple respondents noted scheduling limitations and the importance of confirming firm dates well in advance to support Council member availability.

Subcommittee Consideration

These aggregated results are provided to the NV-RDAC Community Education Event Subcommittee as a foundation for the subcommittee's review and discussion of the 2027 event plan. The subcommittee will consider these findings at its May 1, 2026 meeting, alongside considerations of available leadership capacity, scheduling feasibility, and strategic alignment with NV-RDAC's ongoing work, and will develop a recommendation for the full Nevada Rare Disease Advisory Council.

— End of Supporting Document —