

Joe Lombardo
Governor

Richard Whitley,
MS
Director



DEPARTMENT OF HEALTH AND HUMAN SERVICES



Cody Phinney,
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Administrator

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Chief Medical
Officer

Rare Disease Advisory Council (RDAC)

Meeting Agenda August 1, 2025 9:30 a.m. to Adjournment

This meeting is in being held virtually. The public is invited to attend.

VIRTUAL INFORMATION

How to participate:

Meeting Links:

https://teams.microsoft.com/l/meetup-join/19%3ameeting_OGVIM2FkNWUtZTdINi00M2VmLWExY2QtNzMyOWZlNzA5ODcy%40thread.v2/0?context=%7b%22Tid%22%3a%22e4a340e6-b89e-4e68-8eaa-1544d2703980%22%2c%22Oid%22%3a%22c6cbcd35-ecfc-41f0-8557-67e58ee3ad83%22%7d

Meeting ID: 237 259 557 090

Passcode: Mn3AU6jM

Join by Phone:

+1 (775) 321-6111

Phone Conference ID: 174 472 602#

NOTICE:

1. Agenda items may be taken out of order;
2. Two or more items may be combined; and
3. Items may be removed from agenda or delayed at any time.

1) Call to order/roll call

- 2) PUBLIC COMMENT: No action may be taken upon a matter raised under public comment period unless the matter itself has been specifically included on an agenda as an action item. To provide public comment telephonically, dial 1-775-321-6111. When prompted to provide the Meeting ID, enter 174 472 602#. Comments

will be limited to five (5) minutes per person. Persons making comment will be asked to begin by stating their name for the record, spell their last name, and provide the secretary with written comments.

- 3) FOR POSSIBLE ACTION: Discussion and possible action to approve meeting minutes from June 6, 2025.
- 4) FOR INFORMATION ONLY: Guest Presentation on Metachromatic Leukodystrophy (MLD) Atidarsagene autotemcel (Lenmeldy) & Newborn Screening.
- 5) FOR INFORMATION ONLY: Guest presentation on a new development of a statewide program for northern and rural Nevada patients through Make A Wish Foundation which includes expansion of their referral criteria to include more rare diseases.
- 6) FOR POSSIBLE ACTION: Discussion and possible action to approve the Provider Needs Assessment survey to evaluate the diagnosis and patient management aspects crucial for the continuation of care of individuals with rare diseases in the State of Nevada.
- 7) FOR POSSIBLE ACTION: Discussion and possible action to plan a Rare Disease Advisory Council (RDAC) Community Education Event as discussed in the last RDAC Subcommittee Meeting on July 11, 2025.
- 8) FOR POSSIBLE ACTION: Discussion and possible action to approve the Nevada RDAC Strategic Plan 2026-2027, and the 2025 Annual Report that is due to the Department of Health and Human Services (DHHS), the Governor, and the Director of the Legislative Counsel Bureau (LCB) in December 2025 per NRS 439.5077.
- 9) FOR INFORMATION ONLY: Update on the social media campaign to showcase RDAC efforts, inform the public about getting involved, and highlight the 'While You Wait' Needs Assessment Campaign.
- 10) FOR INFORMATION ONLY: Review and discuss the Nevada Rare Disease Advisory Council (RDAC) website updates.
- 11) FOR INFORMATION ONLY: Update on childhood cancer, systemic lupus erythematosus (SLE), and sickle cell disease (SCD) data collection efforts within Nevada. – *Chair Annette Logan-Parker; and Ashlyn Torrez, Lupus and Other Rare Diseases Project Coordinator, Office of State Epidemiology (OSE), Division of Public and Behavioral Health (DPBH)*
- 12) FOR INFORMATION ONLY: Review and discussion of the results received on the Rare Disease Advisory Council Member survey for feedback in drafting the next RDAC Strategic Plan for 2026-2027.
- 13) FOR INFORMATION ONLY: Review and discussion of the results as of June 2025 from the 'While You Wait' Needs Assessment Campaign to evaluate the diagnosis and patient management aspects crucial for the continuation of care of individuals with rare diseases in the state of Nevada.
- 14) FOR INFORMATION ONLY: Council member information sharing announcements – *Council Members*

July was Chronic Disease Month

- 15) PUBLIC COMMENT: No action may be taken upon a matter raised under public comment period unless the matter itself has been specifically included on an agenda as an action item. To provide public comment

telephonically, dial 1-775-321-6111. When prompted to provide the Meeting ID, enter 174 472 602#. Comments will be limited to five (5) minutes per person. Persons making comment will be asked to begin by stating their name for the record, spell their last name, and provide the secretary with written comments.

16) Adjournment

NOTICES OF PUBLIC MEETING HAVE BEEN POSTED AT THE FOLLOWING LOCATIONS:

PHYSICAL POSTING LOCATION

NEVADA DIVISION OF PUBLIC AND BEHAVIORAL HEALTH, OFFICE OF STATE EPIDEMIOLOGY
10375 Professional Circle, 1st Floor
Reno, NV 89521

INTERNET POSTINGS

- The Nevada Division of Public and Behavioral Health
website: <http://dpbh.nv.gov/Boards/RDAC/RDAC/>
- The internet at the Nevada Public Notice website: <https://notice.nv.gov>

This body will provide at least two public comment periods in compliance with the minimum requirements of the Open Meeting Law prior to adjournment. Additionally, it is the goal of the Rare Disease Advisory Council (RDAC) to also afford the public with an item-specific public comment period. No action may be taken on a matter raised under public comment unless the item has been specifically included on the agenda as an item upon which action may be taken. The Chair retains discretion to only provide for the Open Meeting Law's minimum public comment and not call for additional item-specific public comment when it is deemed necessary by the chair to the orderly conduct of the meeting.

This meeting is a public meeting, recorded and held in compliance with and pursuant to the Nevada Open Meeting Law, NRS 241. By participating, you consent to recording of your participation in this meeting. All voting members should leave their cameras on for the duration of the meeting and refrain from entering any information into the chat function of the video platform.

We are pleased to make reasonable accommodations for members of the public who are disabled and wish to attend the meeting. If special arrangements for the meeting are necessary, please notify, in writing, the Division of Public and Behavioral Health, 10375 Professional Circle, 3rd Floor, Reno, NV 89521, or by calling 775-447-0263 Ashlyn Torrez no later than three (3) working days prior to the meeting date.

If you need supporting documents for this meeting, notify Ashlyn Torrez at 775-447-0263, or by email at atorrez@health.nv.gov

If at any time during the meeting an individual who has been named on the agenda or has an item specifically regarding them included on the agenda is unable to participate because of technical or other difficulties, please contact Ashlyn Torrez at 10375 Professional Circle, 3rd Floor, Reno, Nevada 89521, email atorrez@health.nv.gov, or 775-687-0508, and note at what time the difficulty started so that matters pertaining specifically to their participation may be continued to a future agenda if needed or otherwise addressed.

Please be cautious and do not click on links in the chat area of the meeting unless you have verified that they are safe. If you have questions about a link in a document purporting to be from RDAC, contact Ashlyn Torrez, 10375 Professional Circle, 3rd Floor, Reno, Nevada 89521, (email address here), or 775-687-0508. Please refrain from commenting in the chat area of the meeting, unless requested to, because minutes are required to be taken of the meeting.

A person may also have comments added to the minutes of the meeting by submitting them in writing either in addition to testifying or in lieu of testifying. Written comments may be submitted electronically before, during, or after the meeting by email to: atorrez@health.nv.gov. You may also mail written documents to RDAC, Attn: Ashlyn Torrez at 10375 Professional Circle, 3rd Floor, Reno, Nevada 89521 or fax them to 775-684-5999.

Use of obscenities or other behavior which disrupts the meeting to the extent that its orderly conduct is made impractical may result in the forfeiture of the opportunity to provide public comment or removal from the meeting.

Written comments in excess of one typed page on any agenda items which requires a vote are respectfully requested to be submitted to the Council at the above address five (5) calendar days prior to the meeting to ensure that adequate consideration is given to the material.