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DEPARTMENT OF HUMAN SERVICES



NEVADA DIVISION of PUBLIC
and BEHAVIORAL HEALTH



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Rare Disease Advisory Council (RDAC)

Meeting Agenda

June 5, 2026

9:30 a.m. to Adjournment

This meeting is 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_NjdhNzQwNmMtZGU4MS00YTg5LTkyNzYtYjBhNjQ4NDZhY2Qx%40thread.v2/0?content=%7b%22id%22%3a%22e4a340e6-b89e-4e68-8eaa-1544d2703980%22%2c%22oid%22%3a%22c6cbcd35-ecfc-41f0-8557-67e58ee3ad83%22%7d

Meeting ID: 287 848 388 355 42

Passcode: 6rC9D7Ku

Join by Phone:

+1 (775) 321-6111

Phone Conference ID: 391 005 208#

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 391 005 208#. 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 April 3, 2026.
- 4) FOR INFORMATION ONLY: Guest presentation on Nevada Medicaid Coverage on IMCIVREE (setmelanotide) used to treat severe obesity and insatiable hunger caused by specific rare conditions. – *Jeff Forshey, Senior Director, Rhythm Pharmaceuticals*
- 5) FOR INFORMATION ONLY: Vice-Chair Gina Glass presentation on Sickle Cell Policy Initiative which will include proposed provisions to [NRS 439.4921](#), for the upcoming 2027 Legislative Session. – *Vice-Chair Gina Glass, Executive Director, Dreamsickle Kids Foundation, Inc., Sickle Cell Disease Association of America (SCDAA) Nevada Chapter*
- 6) FOR POSSIBLE ACTION: Discussion and possible action to approve the RDAC Subcommittee recommendation to postpone the Southern and Northern Nevada Community Education Events, consolidate the 2027 event plans to one event, focusing on the Legislative Education Event in Carson City, and moving forward to consider those events on alternative years.
- 7) FOR POSSIBLE ACTION: Discussion and possible action to RDAC’s response on Anthem Medicaid Policy Change effective July 1, 2026.
- 8) FOR INFORMATION ONLY: Update on the fiscal analysis being developed by Nevada Medicaid for submission to the Medicaid Rates, Analysis, and Development (RAD) unit. RAD will conduct a fiscal review to estimate the cost of establishing Genetic Counselors as a new provider type. – *Chair Annette Logan-Parker*
- 9) FOR INFORMATION ONLY: Update on the preliminary statewide needs assessment data discussion with Nevada Health Authority Director Stacie Weeks, JD, MPH. – *Chair Annette Logan-Parker*
- 10) FOR INFORMATION ONLY: Update on the 2026 RDAC Blog series calendar. – *Chair Annette Logan-Parker*
- 11) FOR INFORMATION ONLY: Update on 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. – *Chair Annette Logan-Parker*
- 12) FOR INFORMATION ONLY: Update on the inclusion of congenital heart disease (CHD) to the State’s Rare Disease Dashboard. – *Ashlyn Torrez, Rare Disease Program Coordinator, Office of State Epidemiology (OSE), Division of Public and Behavioral Health (DPBH)*
- 13) 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 391 005 208#. 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.
- 14) Adjournment – *Chair Annette Logan-Parker*

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

- On the Internet at the Nevada Division of Public and Behavioral Health website: <https://www.dpbh.nv.gov/boards/rdac/>
- On 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 775-688-0427 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 775-668-0427, or by email at [atorrez@health.nv.gov/](mailto: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 775-688-0427, 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, atorrez@health.nv.gov, or 775-688-0427. 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.