NEVADA RARE DISEASE ADVISORY COUNCIL

DRAFT MEETING MINUTES
Date: June 5, 2026
9:38 AM – 10:15 AM

Meeting Locations:
Pursuant to NRS 241.020(3)(a) as amended by Assembly Bill 253 of the 81st Legislative Session, this meeting was convened using a remote technology system and there was no physical location for this meeting.
Chair Annette Logan-Parker opened the meeting at 9:38 am.

1) INTRODUCTIONS AND ROLL CALL

COUNCIL MEMBERS PRESENT:
Annette Logan-Parker (CHAIR); Gina Glass (Vice-Chair); Amber Federizo, DNP, APRN, FNPBC; Craig Vincze, PhD; Melissa Bart-Plange; Christina Thielst; Jennifer Millet, DNP, RN; Sumit Gupta, MD; Dr. Verena Samara; Valerie Porter, DNP, APRN, AG-ACNP-BC, MBA; Naja Bagner;

COUNCIL MEMBERS ABSENT:
Paul Niedermeyer (excused); Brigette Cole (excused); Dr. William (Bill) Evans (excused); Ihsan Azzam, MD, PhD; Kim Anderson-Mackey; Madison Bowe (excused); Pamela White; Mallory Carvalho (excused); Dr. Devraj Chavda PhD

DIVISION OF PUBLIC & BEHAVIORAL HEALTH (DPBH) STAFF PRESENT:
Kagan Griffin, MPH, RD, *Operation Manager, Office of State Epidemiology (OSE), DPBH*; Ashlyn Torrez, *Health Program Specialist I, OSE, DPBH;* and Kevin Dodson, *Administrative Assistant III, OSE, DPBH*

OTHERS PRESENT:
Jeff Forshey, *Rhythm Pharmaceuticals*; Lea Cartwright; Keiko Duncan, *NHA, DHCFP*; Josie Vaughn; JJ Roth; and Amber Williams, *C4K Foundations*

Roll call was taken and is reflected above. It was determined that there is not quorum of the Rare Disease Advisory Council (RDAC, the Council).

2) PUBLIC COMMENT

Chair Annette Logan-Parker opened the floor for public comments.

Hearing none, Chair Annette Logan-Parker moved on to the next agenda item.

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.

Chair Annette Logan-Parker introduced Jeff Forshay from Rhythm Pharmaceuticals and explained that he had requested time with RDAC to discuss access to a specific drug for Nevada Medicaid beneficiaries.

Jeff Forshay explained that Rhythm Pharmaceuticals was a small company focused on rare neuroendocrine treatments. It was stated that its current product, setmelanotide, also known as MC4R therapy, was designed to treat neuroendocrine disease and had multiple indications, including acquired hypothalamic obesity, which had received FDA approval on March 20.

Jeff Forshay stated that acquired hypothalamic obesity and Bardet-Biedl syndrome were often misunderstood because of broader discussions around GLP-1 medications and general obesity treatment. It was clarified that these conditions involved a faulty MC4 pathway and were not expected to respond to GLP-1 medications in the same way as general obesity.

Jeff Forshay explained that acquired hypothalamic obesity often resulted from hypothalamic injury related to craniopharyngioma, hypothalamic or pituitary tumors, or surgical resection. This disruption affected the MC4 pathway in the brain and caused severe hyperphagia, rapid weight gain, and persistent abnormal food-seeking behavior.

Jeff Forshay described severe food-seeking behaviors experienced by some patients, including eating from garbage cans, dumpsters, floors, or consuming non-food items. Some children with the condition had difficulty attending school because of these behaviors, the condition often caused rapid and severe weight gain and estimated that 5,000 to 10,000 patients in the United States may be affected.

Jeff Forshay emphasized that acquired hypothalamic obesity was a rare condition caused by a faulty brain pathway and should not be confused with general obesity or overeating for pleasure. Hyperphagia was the primary issue, although it had not been formally scored in clinical trials, patient and caregiver reports showed that affected individuals could not reach a normal feeling of fullness.

Jeff Forshay explained that acquired hypothalamic obesity also caused downstream effects, including lower resting energy expenditure and increased sedentary behavior. It was stated that these factors contributed to rapid weight gain, severe obesity, and, in some cases, the inability to participate in physical activity. It was noted that because many patients were diagnosed during childhood, the condition could significantly affect their ability to function and interact with peers.

Jeff Forshay stated that diagnosis criteria for acquired hypothalamic obesity were still developing because the indication had only recently launched. It was explained that commercial payers had been adjusting their policies and utilization management requirements. It was identified hypothalamic injury, rapid weight gain, and reported hyperphagia as key symptoms used to support diagnosis.

Jeff Forshay noted that some payers required physician attestation, while others considered MRI evidence of a tumor and subsequent resection. It was cautioned that imaging requirements could be challenging because the degree of hypothalamic damage was not always easy to evaluate, the criteria for the condition were relatively straightforward and that prior experience with setmelanotide had not shown overutilization or inappropriate use because the disease state was clear and difficult to misidentify.

Jeff Forshay also provided a payer coverage disclaimer and explained that Rhythm Pharmaceuticals' patient mix included mostly commercially insured patients and Medicaid beneficiaries, with some Medicare patients included because many were younger individuals who qualified due to disability. Some patients were dual eligible and that early post-launch experience showed many patients were commercially insured, with a smaller but meaningful number in Medicaid.

Jeff Forshay stated that the affected population was extremely small, with an estimated 5,000 to 10,000 patients in the United States. It was suggested that the Medicaid population would likely represent only a small portion of that estimate. Nevada Medicaid's prior experience was also referenced with the company's previous indication, which had involved two patients, one of whom received the drug while the other case was believed to be cancelled.

Jeff Forshay discussed side effects and identified hyperpigmentation as the most commonly reported issue. He described it as whole-body skin darkening rather than a reaction limited to the injection site and stated that it typically reversed quickly after discontinuation of IMCIVREE. It was explained that the company's in-house case management team helped patients through treatment, assessed whether patients were appropriate candidates, supported compliance, and helped discontinue therapy when side effects, adverse events, or adherence concerns arose.

Jeff Forshay acknowledged that IMCIVREE was a high-cost rare disease therapy, some patients did not remain on treatment for multiple years because of challenges with daily self-injection, while others paused treatment after reaching a healthier weight. It was added that some patients later restarted therapy because of persistent hyperphagia, even when patients remained on treatment, the overall pharmacy cost impact was limited when spread across the full patient population.

Councilmember Christina Thielst put into the chat at 9:41 AM: "I made it in"

Jeff Forshay concluded by emphasizing that IMCIVREE was a highly targeted therapy and was not intended for general obesity. The treatment specifically targeted the MC4R brain pathway, which was described as the key pathway involved in helping these patients. GLP-1 medications generally had not produced effective or useful results in this patient population, and any limited response related to gut hunger typically plateaued early.

Jeff Forshay also reported that five clinical compendia had reclassified IMCIVREE over the previous two years, moving it away from the obesity category and into specialty endocrine metabolic or synthetic hormone categories. Pricing compendia, including Medi-Span and First Databank, had also reclassified the drug. It was stated that these changes better reflected how the drug worked in the body and helped distinguish it from GLP-1 medications and general obesity treatments.

Chair Annette Logan-Parker asked Jeff Forshay whether other Rare Disease Advisory Council's had become involved in similar access efforts.

Jeff Forshay responded that Rhythm Pharmaceuticals had been working with two other RDACs, including Colorado, and that Louisiana had shown interest through recent communication.

Jeff Forshay explained that Rhythm Pharmaceuticals had not sought extensive RDAC involvement but had focused on ensuring patient access to IMCIVREE through payer and Medicaid coverage. CMS's (Centers for Medicare & Medicaid Services) exclusion of general obesity medications had influenced some state Medicaid plans and contributed to coverage barriers, even though IMCIVREE was intended for rare disease treatment rather than general obesity. It was noted that approximately seven or eight state Medicaid programs still lacked a coverage pathway for the drug.

Chair Annette Logan-Parker also asked about the patient experience in Nevada and whether Nevadans outside Medicaid had been able to access the therapy.

Jeff Forshay responded that Nevada had very few patients because Bardet-Biedl syndrome, the drug's first indication, was extremely rare, patients seeking access through Nevada Medicaid had faced difficulty because no clear coverage pathway or criteria had been established, which led to denials under an exclusion and required patients to pursue appeals.

Jeff Forshay stated that he had communicated with Nevada contacts while remaining mindful of their workload. The request had been for strong utilization criteria that reflected the drug's rare disease use and classification as a rare endocrine metabolic therapy rather than a general obesity medication. It was noted that many states had reclassified the drug in their systems, which allowed coverage policies to be developed. It was also emphasized that having a coverage option would allow patients to try the therapy and discontinue it if it was ineffective or could not be maintained.

Chair Annette Logan-Parker asked Jeff Forshay to clarify how many state Medicaid programs had accepted coverage for IMCIVREE compared with those that had not.

Jeff Forshay stated that approximately 31 states had some form of written coverage criteria, either published or unpublished. He added that another 12 to 15 states covered the drug through non-published prior authorization processes without significant access issues. A smaller number of states had the drug listed on a drug list, with Texas given as an example.

Jeff Forshay explained that some large states, including California and New York, did not have formal written policies because of how their Medicaid pharmacy programs operated. The patient population was too small to make supplemental rebating practical or worthwhile for many programs.

Jeff Forshay emphasized that his goal had been to educate states about the drug, the affected patient population, and the urgency of access rather than criticize Nevada. Compendia reclassifications could help guide Nevada Medicaid and other programs as they considered how to evaluate and cover the therapy.

Vice-Chair Gina Glass put into the chat at 9:52 AM: "Gina Glass present sorry I'm late"

Chair Annette Logan-Parker also asked whether Rhythm Pharmaceuticals had data supporting potential cost savings when patients had access to IMCIVREE compared with lack of access.

Jeff Forshay responded that available information could be shared later. Many patients, especially young adults, could face significant downstream health care costs related to comorbidities, medications, procedures, and complications associated with severe obesity and hyperphagia.

Jeff Forshay explained that broader cost savings were difficult to quantify, as was often the case with rare disease therapies. Outcomes such as helping patients regain function, return to work, or contribute to society were meaningful but difficult to measure financially. Data related to comorbidities and associated health care system costs could be provided.

Vice-Chair Gina Glass put into the chat at 10:03 AM: "Hey there I'm sorry I didn't get my presentation complete so I have to post pone"

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

   Chair Annette Logan-Parker provided an update on efforts with Nevada Medicaid to establish genetic counselors as a Medicaid provider type. It was reported that progress had been made and noted that the multi-year needs assessment had consistently identified access to genetic counselors as a barrier for Nevada families living with rare diseases.

   Chair Annette Logan-Parker explained that genetic counselors were not currently enrolled as a Medicaid provider type in Nevada, which limited access to those services. Nevada Medicaid had received the needs assessment findings, along with Nevada-specific clinical data and cost projections from Care for the Kids Foundation to support the request.

   Chair Annette Logan-Parker reported that Nevada Medicaid had found the research thorough and had begun moving the issue through its administrative process. Medicaid staff were drafting a fiscal analysis report for the State's Rate Analysis and Development Unit to estimate the cost of creating the new provider type. The next steps included completing the fiscal analysis, sending the issue to Medicaid executive leadership for review and approval, and implementing the new provider type and service if authorized. Chair Logan-Parker described the fiscal analysis as an important step and noted that the administrative process appeared to be the clearest path forward and likely would not require additional legislation.

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

   Chair Annette Logan-Parker reported that she had met with Director Weeks, Director of the Nevada Health Authority, and two members of her team on May 26. The meeting was described as productive and stated that initial needs assessment findings had been shared, including results from rare disease patients, families, and providers who treated patients with rare diseases.

Chair Annette Logan-Parker stated that Nevada Health Authority representatives had been receptive to collaborating on educational and awareness efforts. They also offered to consider having a Nevada Health Authority team member join RDAC to support continued collaboration.

Chair Annette Logan-Parker reported that the Nevada Health Authority had been invited to present at the August Council meeting to provide a Medicaid 101 overview and begin an ongoing dialogue with the Council. The meeting was described as meaningful progress toward strengthening the Council's relationship with the Nevada Health Authority, which had been a primary goal of the current strategic plan.

10) FOR INFORMATION ONLY: Update to the 2026 RDAC Blog series calendar. – Chair Annette Logan-Parker

Chair Annette Logan-Parker provided an update on the RDAC blog series and noted that it was slightly behind schedule. It was reported that the posts already published had received positive feedback and had increased traffic to the RDAC website and social media platforms. The purpose of the series had been to raise awareness of RDAC's work and help people understand how to get involved.

Chair Annette Logan-Parker stated that she planned to contact remaining Council members over the next couple of weeks to help draft their profiles and stories. She also reported that the Nevada RDAC website was being upgraded because the previous theme was no longer supported. The upgrade was intended to streamline the website, modernize its appearance, and refresh the overall design. Once complete, Council members would be notified so they could review the changes.

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

Chair Annette Logan-Parker provided an update on the 'While you wait' needs campaign and noted that six months remained in the needs assessment project. Preliminary results through April 2026 had been provided to the Council.

Chair Annette Logan-Parker reported that the campaign had received 508 cumulative responses from Nevadans living with rare diseases and their families. She also reported 100 provider responses, including 69 fully completed surveys and 35 extended survey responses. It was noted that although not every provider completed every question, the level of participation was encouraging and showed that Nevada providers were eager to share information about their experiences.

Chair Annette Logan-Parker stated that another final push would take place over the next few months to increase participation. The goal was to have the final report, covering all three years of the needs assessment, ready for the legislative day planned in Carson City in February.

Councilmember Amber Federizo asked whether the genetic counselor's effort would also include a request for coverage or set-aside funding for genetic testing. Outside of newborn screening results, rare disease genetic testing could be very difficult to obtain and that access to genetic counseling would not fully address the issue without access to testing.

Chair Annette Logan-Parker agreed that the concern was valid and thanked Councilmember Amber Federizo for raising it. The current Medicaid conversations had focused on establishing genetic counselors as a provider type. Any future legislative efforts related to access to genetic testing would be monitored closely and reported back to RDAC.

Councilmember Christina Thielst asked whether the survey response rate could be compared against another benchmark to determine how closely the responses reflected the expected number of rare disease patients in Nevada. She asked whether the state's response numbers could be compared to the estimated percentage of the general U.S. population living with rare diseases.

Chair Annette Logan-Parker responded that additional inquiry with state offices would be needed to make that comparison. She explained that the information provided to Medicaid had been based on data from Cure 4 The Kids Foundation, which represented only a portion of the state's rare disease data.

Councilmember Christina Thielst noted that (National Organization for Rare Disorders) NORD may also have relevant information.

Chair Annette Logan-Parker stated that the data provided to Medicaid may have been based on approximately 35 conditions with available supporting data. She indicated that the information would be reviewed and provided back to the Council.

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)

Chair Annette Logan-Parker asked for an update on adding congenital heart disease to the State's rare disease dashboard and asked Ashlyn Torrez whether additional information was available.

Ashlyn Torrez reported that she had been working closely with the Maternal Child Health Section on the topic. She stated that efforts were ongoing to gather data and collaborate on the work. She added that the remaining details were still being refined.

13) PUBLIC COMMENT

Chair Annette Logan-Parker opened the floor for public comment.

Hearing none, Chair Annette Logan-Parker moved to adjourn.

14) ADJOURNMENT- *Chair Annette Logan-Parker*

Chair Annette Logan-Parker moved to adjourn the meeting at 10:15 am.