Steve Sisolak
Governor

Richard Whitley, MS
Director

DEPARTMENT OF
HEALTH AND HUMAN SERVICES
DIVISION OF PUBLIC AND BEHAVIORAL HEALTH
Helping people. It's who we are and what we do.

Lisa Sherych
Administrator

Ihsan Azzam,
Ph.D., M.D.
Chief Medical Officer

NEVADA RARE DISEASE ADVISORY COUNCIL

DRAFT MEETING MINUTES

Date: February 14, 2022
10:00 am – 11:02 pm

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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.
Rex Gifford opened the meeting at 10:00 am.

1) INTRODUCTIONS AND ROLL CALL

COUNCIL MEMBERS PRESENT:
Amber Federizo, DNP, APRN, FNPBC (CHAIR), Ihsan Azzam, MD, PhD; Shirley Folkins-Roberts; Gina Glass (Vice-Chair); Jennifer Millet, MSN, RN; Valerie Porter, DNP, BSN, MBA; Kimberly Palma Ortega; Naja Bagner; Max Coppes, MD, PhD, MBA; Annette Logan-Parker; Susana Sorrentino, MD (Quorum=9)

COUNCIL MEMBERS ABSENT:
Linetta Barnes, BSN, RN; Nik Abdul Rashid, MD; Brynlin Thornley; Paul Niedermeyer; Veneta Lepera

DIVISION OF PUBLIC & BEHAVIORAL HEALTH (DPBH) STAFF PRESENT:
Rex Gifford, Administrative Assistant III; Joseph Filippi, Executive Assistant; Lindsey Kinsinger, Health Program Manager II, OPHIE; Marie Curran, Management Analyst II; Antonina Capurro, Deputy Division Administrator, HCFP; Pierron Tackes, Deputy Attorney General

OTHERS PRESENT:
Katherine Nielsen, Executive Director for Governor's Council on Developmental Disabilities; Beth Slamowitz Sr. Physician, HCFP; Craig Vincze; Linda Anderson; Tyler Shaw, FRPA

Roll call was taken and is reflected above. It was determined that a quorum of the Rare Disease Advisory Council (RDAC, the Council) was present.

2) POSSIBLE ACTION: Council members' approval of minutes from October 20, 2021, meeting.

Chair Federizo provided the Council with five minutes to review the October meeting minutes and provide any comments or changes. Councilmember Max Coppes requested an alternate meeting time to approve the minutes, stating that five minutes did not seem like an adequate amount of time. Chair Federizo responded that she respects Councilmember Coppes' decision to abstain from voting to approve the minutes and that the prior minutes are posted publicly on the RDAC website for review prior to every meeting.

Chair Federizo motioned to approve the meeting minutes from prior council meeting dated October 20, 2021. Councilmember Annette Logan-Parker seconded the motion to approve. Councilmember Max Coppes abstained. There were no objections. A quorum voted to approve the prior meeting minutes.

3) PUBLIC COMMENT

Chair Federizo opened the floor for public comment.

Katherine Nielsen, Executive Director for the Governor's Council on Developmental Disabilities, provided public comment regarding information about the "Silver State Self-Advocacy Conference 2022" from August 2-4, 2022, in Las Vegas, NV. She shared that registration and speaker applications are open. She invited anyone interested in attending, presenting, or being a vendor at the conference to visit the website: https://www.nevadaddcouncil.org/2022-self-advocacy-conference/. She explained the conference is geared toward individuals with intellectual and developmental disabilities, their family members, and professionals that work in that community. Chair Federizo offered to provide a breakout session about RDAC at the conference. Katherine Nielsen said she will send the link and save-the-date flyer to the RDAC group per Chair Federizo's request.

Councilmember Pierron Tackes asked for the Council to include the aforementioned conference materials in the meeting minutes, so the information is available to members of the public. Rex Gifford confirmed he will add the materials to the RDAC website once Katherine Nielsen sends them.

There was no other public comment, so Chair Federizo moved on to the next agenda item.

4) INFORMATIONAL: Testimony of Council Member Naja Bagner regarding her experience with sickle cell disorder in the state of Nevada. – Naja Bagner

Chair Federizo introduced and opened the floor for Councilmember Naja Bagner to share a recent experience as someone with a rare disease.

Councilmember Naja Bagner started by saying she wanted to bring an issue to the table about a matter she is seeing going on in the Sickle Cell community. She shared an experience she had in October 2021 traveling for a family vacation. She was trying to receive oxygen to go on her trip, so that she was covered all the way around with medicine and other travel essentials. She found out during this process that she was denied portable oxygen because it is considered as a "luxury item" for individuals with Sickle Cell Anemia. She said she could not understand why, since there are certain things people need to maintain a healthy lifestyle with this illness. She said she feels that a lot of issues could be prevented with Sickle Cell Disease if individuals are provided with enough oxygen for their bodies to do what they need to do. She described the process for seeking emergency medical care for Sickle Cell Disease; first, providers treat with fluids, then pain meds, then oxygen. She described that when Sickle Cell patients

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are sent home from the hospital, they are told to continue with their doctor's recommended routine. She explained that patients may have everything they need at home except oxygen. She said she feels like there is a need for patients to have oxygen at home, because otherwise they are not addressing everything. She said she was told that she was denied oxygen for her trip because her oxygen levels did not drop below 88%. She explained how Sickle Cell patients' oxygen levels can change from day to day, and if they do not have oxygen at home, they will not be able to help their hemoglobin when a crisis occurs. She said it was "mind-blowing" for insurance to consider this as a "luxury item", when insurance has no problem paying for other things that are just as important as oxygen.

Chair Federizo thanked Councilmember Bagner for sharing her experience. Chair Federizo said that one of the things the Council would like to address today is the insurance criteria issue around approval for certain items. She said it can sometimes be an issue on the provider side as well, such as the hematologist using the proper wording on the prior authorization, having time to conduct the prior authorization, or having access to clinicians specialized in benign hematology from an adult perspective. Chair Federizo said she would like to have a further conversation with Councilmember Bagner regarding her insurance provider so the Council can follow-up. Chair Federizo said this will help the Council get a better idea for why the request was denied and what the criteria need to be to better support Councilmember Bagner and others with Sickle Cell, should they encounter similar issues. Chair Federizo said she will follow-up with Councilmember Bagner individually to make sure that when the Council does a roll-up to the state and addresses all the testimony and factors that led to it, in order to mitigate it. Chair Federizo told Councilmember Bagner that there are many aspects of care in the situation the councilmember described that should not have happened, and a lot of that has to do with how criteria with insurance is conducted.

Councilmember Bagner provided an example of a mother who has a child with Sickle Cell Disease. She described that if the child's breathing is low, they may be able to control it at home if they have oxygen at home. However, if they do not have portable oxygen, they may have to put their health at risk for several hours without oxygen if they need to go anywhere outside of the home. She explained that this is not treating the illness the proper way that it should be treated. She said she knows "it will be a fight and a battle because of the simple fact that COVID is going on right now", and patients are having difficulty receiving oxygen. She suggested reaching out to medical equipment companies or other places that acknowledge this as an issue. Councilmember Bagner thanked the Council for hearing her out and said she knows she is not the only one experiencing this problem, but many people are not speaking up about it.

Chair Federizo acknowledged that Councilmember Bagner is not alone in her concerns and that many patients are afraid or unable to attend council meetings to share their experiences. She told Councilmember Bagner she appreciates her courage and bravery in sharing her experience with the Council and reiterated she will follow-up to get more information about her experience with her specific insurance provider.

5) INFORMATIONAL: Summary of meeting with Nevada State Medicaid, Nevada Department of Health and Human Services and the Governor's Office regarding annual RDAC report. – Chair/Council Members

Chair Federizo introduced this agenda item by reminding the Council that in October 2021, the Council put together RDAC recommendations to the state with ways and recommendations to address their objectives. She explained that the Council sent the report to the state in November 2021, and that it took “considerable follow-up” for the state to respond and schedule a meeting. She acknowledged that Nevada Medicaid “has quite a bit on their plate” with COVID still being at the forefront of Nevada’s issues, along with other issues. During the meeting, DuAne Young conveyed that from a budget perspective the state is not sure how much they could put together for this. Chair Federizo thanked Councilmember Max Coppes for strongly conveying the council’s belief that the RDAC needs a pathway forward to making recommendations and suggestions that the Council takes time to put together. Director Whitley reached out to Chair Federizo afterward, and they had a subsequent meeting. Chair Federizo described that in that meeting, Director Whitley did “an amazing job in providing the support that is necessary to move forward with our recommendations.”

6) FOR POSSIBLE ACTION: Recommendations for the development of reform criteria for pilot rare disease Medicaid administration program. – Council Members

Chair Federizo expounded on agenda item #5 by describing the meeting in more detail. The Council met with Director Whitley and Beth Slamowitz. Chair Federizo expressed excitement that Director Whitley and Beth Slamowitz are on board with having the Council put together a comprehensive recommendation plan to address rare disease. They are looking at fiscally neutral items, which includes many of the items RDAC put forward in their original report. This would provide a roadmap on how to apply the plan. They are first looking at a pediatric pilot, so when they move to the adult side, they would have a roadmap for implementation. The expectation for this is that it would provide any providers who conduct any clinical care for rare disease an identifying qualifier for billing that would allow different administrative mechanisms to be put in place. Chair Federizo referenced Councilmember Bagner’s earlier testimony as an example for when the criteria for that disease-specific state would have an additional qualifier on it. That qualifier would allow that diagnosis state to be exempt from some prior authorizations and some pathways. She described how the state and other entities are spending much more time and revenue processing those denials and appeals. She gave the example of trying to bill a urinalysis, which is very cheap, but the appeal and prior authorization cost an individual $20 per hour to have that employee bill, appeal, and follow the claim, which is a waste of resources for the state that they do not have. Chair Federizo explained that many of the recommendations will look at evidence-based aspects that the state and Medicaid Services Manual do not address. It will take a deeper look at what some of these administrative barriers have caused in terms of cost.

Chair Federizo identified that Councilmember Annette Logan-Parker has more knowledge about the administrative aspects and has looked at this from many avenues. Chair Federizo said she expects the councilmembers with individual entities will have in-depth discussions with their contract payers and come together to present their plan before the Council for approval. Chair Federizo asked as the chair to bring Councilmembers Coppes and Logan-Parker to be part of planning what this will look like, since they are administrators of facilities where this billing primarily occurs. A lot of this work will include bringing the administrative aspects into a complete road map. Chair Federizo said she respects that not all councilmembers will not want to proceed with the time and effort required to make this comprehensive roadmap. Chair Federizo reflected that this will be the first time in the decade she has worked in Nevada that there is a path forward for rare disease to be heard. She stated this is an

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opportunity to build a pilot program that will set the stage for rare disease in Nevada for years to come. It will be built from the ground up and presented at the next RDAC meeting before it is submitted to the state to see what it will look like moving forward.

Chair Federizo opened the floor to Councilmember Logan-Parker to further discuss what the roadmap will look like.

Councilmember Logan-Parker thanked the Chair for the introduction. She explained that often the struggle is getting patients with rare diseases what they need, since the process of going about that is labor intensive and the rules are often not current evidence based. She described that they are envisioning helping the state of Nevada, and particularly Medicaid, understand that they spend a lot of time and effort advocating on behalf of patients when things get denied, then ultimately turned over and paid for. She provided an example of research being done in her facility's database to determine how much time and effort was spent during the process of denying and adjudicating denials that ultimately got turned around and paid for. This is to help the state understand that the current rules and adjudication process create an adversarial environment with so much time spent "fighting" over something that ultimately gets overturned and paid anyway. This can address the delay in getting patients what they need, as well as limit the administrative burden of the healthcare institutions that provide the care. They are envisioning that they can decide on a "modifier" for certain rare disease, which puts them into a different adjudication classification. They will help the state of Nevada determine what that adjudication process should look like.

Councilmember Logan-Parker provided an example of when a facility is giving nephrotoxic chemotherapy in an outpatient treatment environment, which requires a lot of urinalyses. So much time is spent arguing over how many urinalyses will be allowed, even though they have to do them whether they will get paid for or not. Providers have to take time away from clinical care to address these things, when there is already a healthcare worker staffing shortage in Nevada. She stated that is a simple example of what they are hoping to do. It will go more in depth about what things are currently being denied, how and why things are being denied, and whether the denials make sense based on current evidence-based practices. She reiterated Chair Federizo's point that it will be a big job, but that it will be a valuable exercise to help the state of Nevada recognize the issue. Councilmember Logan-Parker stated she believes the plan can be budget-positive for the state and the providers providing the care. She is hopeful they can influence the state to take a deep dive into how patients access care, and what that means for everyone providing the care.

Councilmember Susana Sorrentino followed up Councilmember Logan-Parker's comments by saying she thinks the conversation should include issues around genetic testing and testing for inborn errors of metabolism, such as enzyme testing. She asked Councilmember Logan-Parker what she thinks of this.

Councilmember Logan-Parker responded that she completely agrees with Councilmember Sorrentino, and they plan to cast a wide net that includes the barriers everyone can identify within their different areas of expertise.

Chair Federizo asked Councilmember Sorrentino to share recommendations that she can then incorporate from a clinician's standpoint. She wants to be sure that everything is mapped out the first

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time it is submitted to the state, because it is difficult to make amendments to the Medicaid Services Manual.

Chair Federizo asked the Council if anyone had additional questions or comments.

Councilmember Coppes commented that he is less optimistic that the project will be cost-neutral, but it is still the right thing to do for children. He reflected that it is challenging to see people adjudicate that patients should not be following standard of care guidelines when it comes to administering lethal drugs to kids. He stated he thinks there should be critical assessment and comparison to other states for how Nevada implements Medicaid.

Chair Federizo responded that she agreed with not having optimism with it being a cost-neutral program after the initial meeting with the state. She got the impression that if they did not find a cost-neutral way forward, the Council may not continue spending time on the project. She remarked that Medicaid guidelines often influence other payers, so it is a good entryway. She stated that after Director Whitley reached out, she is feeling more optimistic about a way forward. This is the first time she has heard high-level leaders in Nevada ready to move forward with this type of thing. She recognized there is a possibility it will be budget neutral, but the state does not have good data on the costs of denying things up front. She described the alternative that some patients may be going to higher cost facilities to seek care that could have otherwise been approved up front. She said it is worth an effort to move forward from a neutral cost perspective and see where it can lead.

Councilmember Ihsan Azzam asked Chair Federizo to return to the discussion of Councilmember Bagner's earlier testimony.

Chair Federizo confirmed that is appropriate, since it is relevant to the current discussion.

Councilmember Azzam commented that if a physician prescribed portable oxygen, no insurance should have the right to say "no". He suggested that the Council should try to provide recommendations to Medicaid, based on public health evidence, that insurance should not be able to deny a provider's prescription. He reflected that patients with Sickle Cell should not be denied portable oxygen, because otherwise they are unable to leave their homes.

Councilmember Bagner followed up by sharing that her insurance suggested for her to rent an oxygen machine, but that required a $2,000 financial deposit. She shared that she started her trip with a 99% oxygen level, but they went up and down during her travels- as low as 82%- and she had to see an EMT when her flight landed. She reflected that it was taking a risk to try and seek medical care in Puerto Rico, because of the language barrier and the lack of resources for Sickle Cell patients. She could tell her body was suffering from oxygen deprivation, even though she was treating the other aspects of her condition.

Councilmember Jennifer Millet commented in response to Councilmember Bagner's testimony and Councilmember Azzam's earlier suggestion. She reflected that many consumers do not know what to do when they encounter this kind of roadblock.

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Councilmember Azzam agreed with Councilmember Millet and reiterated that the Council may be able to provide standards of care based on national guidelines and advocate for patients. He stated that Medicaid and Medicare can set a standard for others to follow.

Councilmember Bagner followed up by saying that she agrees Medicaid and Medicare can provide additional barriers, because they often do not see how certain medical equipment and care are important.

Chair Federizo commented that she shared Councilmember Azzam's perspective prior to her meeting with Director Whitley, that RDAC was not given legislative authority to put forth Bill Draft Requests (BDRs). In her discussion with Director Whitley, he was on board with taking recommendations from RDAC and rolling them up to the governor's office to be included in their office's BDRs for the next legislative session. This will allow evidence-based practices and recommendations to be included in BDRs and followed-through to the legislative floor. She described that in the interim, this is an opportune time to gather their recommendations so they can be included in a BDR from the governor's office. This is the pathway of authority that the Council needed to proceed with this project.

Councilmember Azzam thanked Chair Federizo for the information.

Chair Federizo followed-up on Councilmember Millet's prior comment regarding avenues for patient support. She stated the current route in Nevada is the Office of Consumer Advocacy (OCA). She plans to reach out to them to get their input on how they address these kinds of concerns, how many people are reaching out to them, what sorts of pathways they take in addressing these concerns, and what barriers they face. She stated that she thinks this process can sometimes be intentionally time consuming, so that the patient is unable to get the necessary time-sensitive care even with proper advocacy. She speculated that even if Councilmember Bagner had eventually been approved for portable oxygen, she may not have gotten the approval until she returned from her trip. She stated that the 45-day time frame is unacceptable to come to a determination on a medical concern that medical professionals have identified. She reiterated what Councilmembers Azzam and Coppes said, that the recommendations should come from professionals with evidence-based perspectives who have seen these things happen.

Chair Federizo stated the overall plan moving forward is to have Councilmembers Coppes, Logan-Parker, Sorrentino, Azzam, and herself start meeting to work on first drafts before sending it to the Council to start working on it. This will require approval at each phase at subsequent quarterly meetings of the council, then they will present the finalized piece to the state. This will then move forward to Director Whitley with a BDR proposal recommending these changes. If Medicaid Services wants to meet and make the changes prior to the legislative authority, they can do that instead of or in addition to the BDR. As Chair, she will follow-up with Councilmember Bagner and OCA to see what the pathways for patient advocacy look like. She reiterated that she feels hopeful about how this opportunity can change things drastically for rare disease.

Chair Federizo opened the floor for further discussion on this agenda item.

Councilmember Logan-Parker asked if the Council will need to make a motion to approve the development of the reform criteria for consideration.

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Chair Federizo responded that her understanding is they can conduct conversations regarding the drafts, as long as the meetings are under quorum. Once the drafts get to the level of being deemed to be in “final state”, she will bring them to the Council in a public forum to review them in their entirety and make those votes. She asked Deputy Attorney General Pierron Tackes for confirmation.

Pierron Tackes, Deputy Attorney General, confirmed that it is compliant with the open meeting law for a group smaller than quorum to work on this then bring it to the larger group for discussion.

Chair Federizo and Councilmember Logan-Parker thanked Pierron Tackes for the clarification.

Chair Federizo commented that councilmembers can work on this asynchronously when they have time. She stated speed is of the essence so they can finalize the draft for public hearing and councilmember approval by the next quarterly meeting. She clarified this work is not limited to the aforementioned councilmembers, but they were identified because of their specific expertise. She reiterated she will need to make sure they stay under quorum in any emails and conversations.

7) FOR POSSIBLE ACTION: Discuss and determine future agenda items – Council Members

Chair Federizo stated she will move a draft review for this recommendation guidelines to the next RDAC meeting in approximately three months. She anticipates this will be the only agenda item, given the amount of time it will take to review each recommendation and proceed with a vote on how to submit it.

Chair Federizo opened the floor for other councilmembers to suggest agenda items for the next quarterly meeting. There were no further suggestions, so she moved on to the next agenda item.

8) FOR POSSIBLE ACTION: Discuss and schedule future meeting dates and times – Council Members

Chair Federizo stated they will continue sending out a Doodle poll to the Council to find the best date and time for the next quarterly meeting in May.

9) PUBLIC COMMENT:

Chair Federizo opened the floor for public comment.

Craig Vincze provided public comment. Mr. Vincze stated he was invited by Councilmember Folkins-Roberts and thanked the Council for allowing him to listen in. He stated that he has a lot of experience with insurance denying things that a doctor prescribes. He shared that his 22-year-old son recently died of a rare cancer three months after diagnosis in Reno, NV. He shared there were many times that his son’s doctor said they need a certain scan done, and insurance said there is a three-day waiting period. Mr. Vincze said, “You can watch the tumor grow in three days.” He stated he would like to be involved in future discussions about this topic. He also shared he has a colleague who survived stage IV colon cancer, and he could not get his chemotherapy medicine in Orange County, CA. His colleague had to go to the emergency room to get it, which meant that if he was getting it, someone else was not. Mr. Vincze

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stated he is optimistic about the future and he works as in biotechnology as a PhD researcher and hardware manufacturer. He has committed his career to this area, even before his son became ill. He offered to share any information with the Council that can further aid the pilot for rare disease. He asked the Council to e-mail him for any further follow-up.

Chair Federizo thanked Mr. Vincze for attending the meeting today. She stated these are the exact types of situations the Council wants to be able to prevent in the future. Chair Federizo stated she would like to send Mr. Vincze's resume to the Council to be considered for one of the two upcoming openings on the Council. This would provide him the opportunity to join as a voting member. She suggested he could also stay on in a non-voting advisory capacity, which would also be valuable. She described how it is helpful to have the voice of someone who has experienced these things first-hand, because sometimes clinicians are treated as if they make these things up and they are not taken seriously. She thanked him for coming and having the courage to speak out about his experience.

Mr. Vincze responded that he will forward his resume to the Council for review.

Chair Federizo stated that if Mr.Vincze decides to join the council, she will need to add that Council vote to the next meeting's agenda.

There was no other public comment, so Chair Federizo adjourned the meeting.

10) Adjournment- Chair

Chair Federizo moved to adjourn and expressed appreciation for everyone on the council.

Chair Federizo moved to adjourn the meeting at 11:02am.

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