

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
MEETING MINUTES
Date: May 27, 2022
9:02 am – 10:38 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.

Joseph Filippi opened the meeting at 9:02 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; Veneta Lepera; Paul Niedermeyer; Annette Logan-Parker; Susana Sorrentino, MD (Quorum=8)

COUNCIL MEMBERS ABSENT:

Linetta Barnes, BSN, RN; Nik Abdul Rashid, MD; Brynlin Thornley

DIVISION OF PUBLIC & BEHAVIORAL HEALTH (DPBH) STAFF PRESENT:

Joseph Filippi, Executive Assistant; Lindsey Kinsinger, Health Program Manager II, Office of Public Health Investigations and Epidemiology (OPHIE); Antonina Capurro, Deputy Division Administrator, HCFP; Pierron Tackes, Deputy Attorney General; Elizabeth Kessler, Health Program Specialist II; Ashlyn Torrez, Health and Human Services Professional Trainee; Aundrea Ogushi, Health Program Specialist II

OTHERS PRESENT:

Tyler Shaw, FRPA; Christina Nyren; Lara Tobias; John Bilstein; Ed Kingsley, MD, Comprehensive Cancer Centers of Nevada; David Olsen, DHCFP; Erin Guerrero

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) PUBLIC COMMENT

Chair Federizo opened the floor for public comment.

Dr. Ed Kingsley, Licensed Internist and Medical Oncologist with Comprehensive Cancer Centers of Nevada, provided public comment. He stated that he has been practicing medical oncology and hematology in Las Vegas, NV for approximately 35 years. He stated that Chair Federizo had asked him to participate in the RDAC meeting to discuss an issue with the council. He explained that his patients on Medicaid who are being treated for Chronic Myelogenous Leukemia are not being reimbursed for an essential test that assesses the effectiveness of the treatment for their Leukemia. Dr. Kingsley requested for Medicaid to reconsider reimbursing for the cost of this blood test, which costs about \$1,000.00. He explained that Medicaid is the only insurance agency he is aware of that is not reimbursing for the cost of this test. Dr. Kingsley made the comparison that not reimbursing for the cost of this test would be like prescribing an antihypertensive to a patient with high blood pressure, and then not being allowed to check that patient's blood pressure to assess the effect of that medication on the patient's blood pressure. He explained that if he does not have the results of the blood test, he cannot fully assess the response of the Leukemia to the treatment he is administering. He expressed disbelief that Medicaid will not reimburse the cost of this blood test. He stated that these patients cannot afford to pay this cost out of pocket.

Councilmember Jennifer Millet asked Dr. Kingsley if this is a coding issue or an issue with Medicaid not understanding the need for this test.

Dr. Kingsley responded that he thinks it is an issue with Medicaid not understanding the need, because it is always rejected regardless of how he codes it. He explained that it is an unambiguous, single disease entity.

Councilmember Annette Logan-Parker commented that the Cure 4 The Kids Foundation experiences similar problems with Medicaid within pediatric oncology care. She stated she is unsure of what they can do within RDAC, but she is already working on a project with Medicaid about this problem. She suggested incorporating the obstacles Dr. Kingsley brought up with their overall argument so the adult and pediatric problems can be presented together. She offered to discuss this with Dr. Kingsley.

Dr. Kingsley agreed that this discussion with Councilmember Logan-Parker would be worthwhile. He inquired if anyone within the Council could provide direction on how/with whom to address this. He had been under the impression that RDAC was the appropriate council to bring forward these concerns.

Chair Amber Federizo responded that RDAC is the appropriate forum to provide testimony on these concerns. She clarified that she and Councilmember Logan-Parker will discuss several task forces during the meeting that Dr. Kingsley may want to be included on to try and make these changes with Medicaid. Chair Federizo thanked Dr. Kingsley for his time.

Dr. Kingsley responded that he would be honored to participate in a task force to work on this issue.

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

- 3) POSSIBLE ACTION: Approval of minutes from February 14, 2022, Rare Disease Advisory Council Meeting. – *Council Members*

Councilmember Annette Logan-Parker motioned to approve the meeting minutes from prior council meeting dated February 14, 2022. Councilmember Ihsan Azzam seconded the motion to approve. There were no objections. A quorum voted to approve the prior meeting minutes.

- 4) INFORMATIONAL: Discussion regarding Dr. Max Coppes’ resignation from the Rare Disease Advisory Council as a “physician who provides care to patients with rare diseases” under Nevada Revised Statutes (NRS) 439.5075(1)(b)(1) and the appointment of Dr. Susanne Sorrentino to fulfill the vacated position as a “physician who provides care to patients with rare diseases.” – *Chair Amber Federizo*

Chair Federizo announced to the Council and the public that Councilmember Susanne Sorrentino has assumed the vacant position of a “physician who provides care to patients with rare diseases” due to Dr. Max Coppes resigning from the Council.

- 5) POSSIBLE ACTION: Discussion and possible action to recommend to the Director of the Nevada Department of Health and Human Services (DHHS) to add Craig Vincze as a member of the Council, pursuant to NRS 439.5075(2), for a term of 3 years. – *Council Members*

Chair Federizo explained that a member of the public, Craig Vincze, is interested in joining the Council. His resume was sent to the Council to be considered for a term of three years. Chair Federizo invited Mr. Vincze to provide some information about himself. However, Mr. Vincze was not present on the call.

Joseph Filippi, Executive Assistant with DPBH, confirmed that Mr. Vincze was not present on the call. Mr. Vincze’s resume was submitted to the Council and posted online prior to this meeting.

Chair Federizo opened the floor for the Council to vote on adding Mr. Vincze as a council member.

Chair Amber Federizo motioned to approve adding Craig Vincze to the Council for a term of three years. Councilmember Annette Logan-Parker seconded the motion to approve. There were no objections. A quorum voted to add Craig Vincze to the Council. Mr. Vincze will go before the DHHS Director to be approved to join the Council.

- 6) POSSIBLE ACTION: Discussion and possible action to recommend the Director of the Nevada Department of Health and Human Services (DHHS) to remove Brynlin Thornley from the Council, pursuant to Article 4, Membership: Section 5, Removal of a Member. Part 3 Unexcused absence from two consecutive meetings of the council. (4.5.3) of the bylaws. – *Council Members*

Chair Federizo introduced this agenda item by explaining that Councilmember Brynlin Thomley has not been in contact with the Council or attended RDAC meetings for approximately two years.

Chair Federizo opened the floor for the Council to vote on removing Brynlin Thornely as a council member pursuant to Article 4 of the RDAC bylaws.

Chair Amber Federizo motioned to approve removing Brynlin Thorney from the Council. Councilmember Gina Glass seconded the motion to approve. There were no objections. A quorum voted to remove Brynlin Thorney from the Council.

- 7) POSSIBLE ACTION: Discussion and possible action to recommend that the Nevada Department of Health and Human Services (DHHS) bring forward a Bill Draft Request (BDR) for the 2023 Legislative Session regarding the RDAC Annual Report policy recommendations, and possible authorization of an RDAC member to meet with DHHS to discuss proposed BDR. – *Council Members*

Chair Federizo explained that one of the challenges the Council has repeatedly faced is that the RDAC was passed as an unfunded mandate, which has made it difficult to meaningfully achieve the Council's objectives. This includes not being able to provide statistical analysis related to the prevalence and incidence of rare diseases in the state, because paying a statistician would utilize all available RDAC funds. She explained that the BDR request would be for DHHS to fund the recommendations the Council put forth to them in November 2021 and would authorize current council members to be present during discussions throughout the 2023 Legislative Session.

Chair Federizo opened the floor for questions about this agenda item.

Councilmember Susana Sorrentino asked if the Council is proposing a specific budget to DHHS or if the request is for DHHS to fund all projects.

Chair Federizo clarified that DHHS will be identifying budgets for each recommendation in the report that was brought forth in November 2021. DHHS would request funding for each of these items in the BDR. The Council is not requesting a specific dollar amount, rather that funding for at least one of the RDAC-recommended projects be included in the BDR. Chair Federizo stated that the Council would be glad if at least one project was funded.

Chair Federizo opened the floor for other questions or concerns about this agenda item.

There were no other questions or comments.

Chair Federizo motioned to approve the request for DHHS to bring forward a BDR for the 2023 Legislative Session that would allocate funding for the RDAC Annual Report policy recommendations and to authorize RDAC member(s) to meet with DHHS to discuss the proposed BDR, as long as the discussion does not meet/exceed a quorum of eight council members. Councilmember Annette Logan-Parker seconded the motion. There were no objections. A quorum voted to approve this motion.

- 8) POSSIBLE ACTION: Discussion and possible action to authorize Chair Amber Federizo to draft a letter to Senator Neal to provide updates on Council budgetary and statutory constraints and request possibility of budgetary bill draft request (BDR). – *Chair Amber Federizo*

Chair Federizo introduced this agenda item by reiterating that the Council has not had the budgetary or fundraising means to complete necessary objectives. She also identified that another challenge the Council has encountered in the last several months is that the RDAC was never given the authority required to implement the changes set forth in the November 2021 report. She compared the RDAC

authority to a report card, in the sense that the Council can advise on how things are going in an annual report. She explained that she has been in communication with other RDACs in the country have more authority to implement changes, such as approving prior authorization for drugs that are meant for rare disease. She explained that the Nevada RDAC was not given the authority to intervene on issues or recommendations related to rare disease, other than submitting the annual report at the end of the year. She stated that this lack of authority has limited what the Council is able to do. She outlined that the next steps would be for the Council to go back to the bill's sponsoring senators, including Senator Neal, to revise the legislation to provide the Council with the necessary authority.

Chair Federizo opened the floor for discussion.

There were no questions or comments.

Councilmember Annette Logan-Parker motioned to approve the authorization for Chair Federizo to draft a letter to Senator Neal and the other bill sponsors to revise the RDAC BDR in the 2023 Legislative Session to grant more authority to the Council. Councilmember Jennifer Millet seconded the motion. There were no objections. A quorum voted to approve this motion.

- 9) INFORMATIONAL: Presentation of Proposed Regulation LCB File No. R107-20 Sickle Cell Reporting for Council feedback. – *Lindsey Kinsinger, Manager, OPHIE, DPBH*

Chair Federizo introduced Lindsey Kinsinger, DPBH OPHIE Manager, to present proposed regulations regarding Sickle Cell and Lupus reporting for the Council's discussion.

Lindsey Kinsinger stated that the draft regulations had been sent out to the Council prior to the meeting and encouraged council members to have the document open while she presented. She provided some background information about the two registries. She explained the Sickle Cell Registry came into legislation in 2019, though the COVID pandemic caused the regulations to be delayed. She apologized for these delays. She explained the Lupus regulations passed the legislation in 2021. She commented that the proposed regulations for both registries are quite similar and.

Ms. Kinsinger explained that there are three ways for council members to provide feedback on the proposed regulations: (1) During the RDAC meeting; (2) By sending an email to Lindsey Kinsinger at LKinsinger@health.nv.gov; and/or (3) At a public workshop that will be scheduled in the coming months, probably around August.

Ms. Kinsinger opened the floor for questions.

Councilmember Paul Niedermeyer asked whether there are any differences between the proposed Lupus and Sickle Cell regulations, or if they are materially similar in all respects.

Ms. Kinsinger responded that they are very similar. One difference she identified is regarding the prescription of opioids for these diseases. A medical provider had brought up the point that opioids may be necessary for the treatment of Sickle Cell, whereas someone with Lupus would only use opioids as a temporary solution while working with a Rheumatologist.

Councilmember Niedermeyer thanked Ms. Kinsinger for her response.

Ms. Kinsinger stated that she has heard from various medical providers about their key concerns with the proposed regulations. One key concern is the mention of prescription of opioids in both regulations. In talking with the medical community, she has come to understand that opioids are more appropriate for treating Sickle Cell and are not a long-term treatment for Lupus. Another key concern is that the medical providers she spoke with encouraged her to engage with people who are impacted by Lupus to understand what they want most from the registry and how they think it can improve access to care. She explained that the intention of the registries is to collect data to inform programming and assist people who are impacted by these diseases. She shared that the primary topics she is aware of are increased access to Rheumatologists and the difficulties in diagnosing Lupus. Due to the differences between Lupus and Sickle Cell, she explained that it is difficult to model the two registries after one another. However, there are not many examples available to model after, particularly for Lupus. She asked the Council to provide advice on these key concerns as medical providers and individuals who have been affected by either of these diseases.

Ms. Kinsinger opened the floor for questions and feedback and reminded the Council of the other ways to provide feedback after the meeting.

Councilmember Niedermeyer suggested including special notice to various hospitals regarding these changes. This would allow hospitals to schedule necessary software updates to their electronic health record systems' (EHRs) mandatory reporting triggers. He explained that a 90-day notice prior to the changes taking affect would allow the hospitals' IT administrators to prepare accordingly.

Ms. Kinsinger thanked Councilmember Niedermeyer for his suggestion. She added that the Hospital Association provided feedback that led to a relevant provision in the regulation. Hospitals that currently report discharge data will be exempt from additional reporting because the registry information can be pulled from discharge data. This applies to most hospitals throughout the state. Ms. Kinsinger identified this provision as a method of reducing the burden of reporting on providers. The provision includes that a hospital may need to provide additional information as needed.

Councilmember Niedermeyer thanked Ms. Kinsinger for her response.

Chair Federizo asked Ms. Kinsinger if she anticipates any budgetary concerns with being able to implement the registry, since Lupus and Sickle Cell initiatives are not well-funded.

Ms. Kinsinger thanked Chair Federizo for her question. She explained that the Sickle Cell Registry came without funding, but the Lupus Registry did come with funding for a position within OPHIE. Although it has taken time to create the position within the state, they have an offer out to a candidate and expect to hire someone within the next month. This role will be dedicated to building out these registries and supporting other RDAC initiatives.

Councilmember Annette Logan-Parker asked Mr. Kinsinger about the plans for public reporting of this data. She identified that, although the current Cancer Registry data reporting has been mandatory for many years, she has not seen anything done with the pediatric cancer data. She inquired about what the plans are to make the new registry data useful and publicized, rather than just having providers report the data and never see anything from it.

Ms. Kinsinger responded that the Cancer Registry reports all data to the CDC and does quite a bit of technical data analysis, since it is such a large program. She stated she will connect with the Cancer Registry to better understand what is not being reported back to the community, because a lot of data is

sent to the federal government. She also responded that the Sickle Cell and Lupus Registries' data will not need to be reported to the CDC, and the intention is for the data to be kept within the state to improve programming for Nevadans. She expects that the data will be presented to advisory councils such as the RDAC, medical providers, public health conferences, universities, etc. She explained that the data-sharing parameters are not clear yet, but having a position dedicated to these two registries will allow for more collaboration with partners to identify what data is needed to inform programs. As OPHIE creates the case investigation and data request forms, the office will solicit feedback from the community.

Councilmember Logan-Parker responded that she understands that the Cancer Registry in the adult environment is robust. However, per the CDC's website, there is almost no childhood cancer data or analysis from Nevada. She clarified that she is more so curious about how the state plans to use the data, from the perspective of a provider who must dedicate a high volume of resources to collect data, submit data, hire a Cancer Registrar to review the data, etc., when nothing material is being done with the data. She stated that this can be frustrating, and she is challenging OPHIE to show how the data can be used in a meaningful way beyond sending it to CDC.

Ms. Kinsinger responded that she accepts the challenge and will stay in communication with the Council about the best use of the data, rather than just collecting data for collection's sake. She said she understands the councilmember's frustration.

Councilmember Logan-Parker thanked Ms. Kinsinger for her response.

Councilmember Niedermeyer provided a follow-up point. He stated that Epic and Cerner are the two primary EHR systems used in Nevada hospitals. He suggested that these two companies may be compelled to update their software to improve data collection if there are statewide regulations mandating certain reporting requirements. He suggested providing prior notice to these companies to make the necessary changes and reduce the burden of back-end reporting.

Ms. Kinsinger thanked Councilmember Niedermeyer for his comments. She shared that her office works closely with hospitals on their electronic case reporting, and she will work on Councilmember Niedermeyer's recommendations. She stated that she understands the need for prior notice and is always willing to work with reporters to make things easier on them.

Councilmember Niedermeyer thanked Ms. Kinsinger for her response.

Chair Federizo asked Ms. Kinsinger if it is possible to track the fiscal impact of adding additional disease states to the registries as the program gets up and running. She identified that Nevada tends to fragment different disease states that could be grouped together in legislation to track similar things. This should be taken into consideration as the Council talks with DHHS, bill sponsors, and other legislators in the 2023 Legislative Session. She gave the example that the Sickle Cell and Lupus Registries could have been grouped together with the RDAC when they were enacted, and they could have been used to track Sickle Cell, Lupus, and other rare diseases together. She did pose the caveat about whether it is more fiscally advantageous to incorporate additional rare diseases into a tracking system that has already been implemented for another disease, or to create a new tracking system for each distinct disease state.

Ms. Kinsinger responded that OPHIE will track time and effort costs associated with this program, so they can show the resources that go into it. She said she is happy to further discuss this topic down the line.

Chair Federizo thanked Ms. Kinsinger for her response.

Councilmember Logan-Parker commented that she just pulled up the CDC's website for Childhood Cancer Registries, and Nevada is the only state in the country that shows "data not available" for age adjusted incidents of cancer for persons less than 20 years old. She explained that this as an example for why it is challenging for providers to support registries in Nevada, when they have been submitting data for years and the information is not available on the CDC's website.

Councilmember Ihsan Azzam commented that the data is not available for the public because most providers are not submitting cancer data, not because the state is not submitting it to CDC. He explained that is why the law was changed to impose citations for noncompliance with data reporting.

Councilmember Logan-Parker responded that in southern Nevada, all board-certified Pediatric Oncologists that see childhood cancer patients are employed by Cure 4 The Kids Foundation, and the foundation submits that data regularly. They have their own Cancer Registry team onsite. She explained that for southern Nevada, which has the bulk of this information, reports are consistently submitted.

Councilmember Azzam responded that, although this information is being reported from southern Nevada, the CDC website cannot show the data because it is incomplete. He stated that, although he is not really involved in the Cancer Registry, he cannot blame the state for the incomplete data. He admitted he does not like to see Nevada as the only state where this data is not available on the CDC website, due to the providers not submitting it.

Councilmember Logan-Parker responded that she thinks Councilmember Azzam is misunderstanding the situation. She explained that six of the eight board-certified Pediatric Oncologists in Nevada practice in southern Nevada, and they all work for Cure 4 The Kids Foundation. Thus, their data is being reported regularly. She explained Cure 4 The Kids Foundation is the actual medical practice, not like other foundations.

Councilmember Azzam responded that he understands what Councilmember Logan-Parker is saying, and he hopes that there will be higher a higher level of data completeness. He reiterated that he cannot blame the state for the data being incomplete. He shared that when he was more directly involved with the Cancer Registry a few years back, they struggled to get providers to consistently report. He said that having most of the providers report is not enough, because it is still incomplete.

Chair Federizo asked Councilmember Azzam to confirm that he is saying that, although southern Nevada is fully compliant with reporting, there are still providers in northern Nevada that are not reporting data. Due to this, the data is not sufficient for the CDC to report out.

Councilmember Azzam responded that he thinks providers are underreporting statewide, not just in the north. He explained that it is not difficult for the state to submit data to CDC, there just is not enough meaningful data for CDC to analyze the data. He admitted he does not know who is not reporting, but he knows cancer providers do not submit the data on time generally. He stated that there needs to be a better way to get cancer providers to submit their data, and this has been an ongoing issue for many years. When he spoke to providers seven or so years ago, they said they did not want to duplicate

reporting if someone else in their organization is typically in charge of it. This results in no data being reported when it is not an issue for the state to identify and consolidate duplicate reporting.

Councilmember Logan-Parker responded that the irony of the conversation is that it is the same providers who are responsible for reporting on pediatric cancer will be responsible for reporting on Sickle Cell. She commented that Ms. Kinsinger has her work cut out for her.

Councilmember Azzam responded that it also applies to HIV cases that are not being reported, which puts communities at risk for further spread. He shared his opinion that there should be a campaign to improve provider reporting across the board. He stated that when the data is robust, the State Office of Analytics can do a lot with the data.

Chair Federizo highlighted one of the key issues Councilmember Logan-Parker brought up, which is that the Council does not want to go down paths that lead to the same problems from years prior. She identified one of the problems with reporting consistency is that providers are not reimbursed for their time spent on reporting. Reporting is time-intensive, on top of the time they spend fighting for tests to be reimbursed, which Dr. Kingsley brought up earlier in the meeting. She explained that the Council will be discussing which task forces need to be created within DHHS in subsequent agenda items. The state of Nevada has access to Healthy Nevada, which does link to Epic, Cerner, and some of the smaller EHRs. She explained that the data can be pulled from there to get the reports to the state. Right now, things are so fragmented that it will not do any good for the state to have a variety of different registries to track specific disease states. She shared that a centralized system such as Healthy Nevada will track data in real time. Patients have the option to opt-out of surveillance through Healthy Nevada, but she sees it as the only feasible solution to have meaningful data reported out for the state. She commented that she does not think requiring providers to report to these registries will produce meaningful data.

Councilmember Azzam agreed with Chair Federizo's comments.

Chair Federizo thanked Ms. Kinsinger for presenting. She asked Ms. Kinsinger to send out the dates of the public workshop to the Council so they can attend and provide testimony on the difficulties of registries for specific disease states.

Chair Federizo closed out this discussion and proceeded to the next agenda item.

10) INFORMATIONAL: Medicaid Rare Disease Pilot Program update and discussion. – *Chair Amber Federizo and Council Member Annette Logan-Parker*

Chair Federizo shared that she has had to balance being a rare disease provider and the Chair of the RDAC. At times, she has had to separate the two roles, because she does not have authority to speak as Chair in every setting. She explained that the RDAC had to fight very hard to have their November 2021 report recommendations heard. She stated that Director Whitley and Dr. Capurro are taking the recommendations seriously and they are moving toward meaningful change. She shared that as a councilmember, not as Chair, she has been meeting with Director Whitley and Dr. Capurro to work on a project aimed at building successful Medicaid coverage of rare disease, either via changing provider types or how the state administers Medicaid. She explained that this project will require more councilmember participation in the form of task forces, but the RDAC is not allowed to provide this type of advisement. Therefore, the Council must reach out to subject-matter experts in the community to participate in the DHHS task forces.

Chair Federizo thanked Dr. Capurro and Director Whitley for their initiative. She reiterated what Councilmember Azzam had previously stated, that these are not new problems. She shared her opinion that other RDACs in the country should have been consulted when creating the Nevada RDAC to determine the Council's authority. She provided the example of not being able to have Medicaid attend an RDAC meeting to get expert opinions and make necessary changes to prior authorizations. She explained that a task force separate from the RDAC is necessary to help DHHS solve a variety of problems that were outlined in the November 2021 report. The RDAC alone is not enough to make these changes. She had hoped the RDAC could provide the ultimate advisement on these changes but is unfortunately outside of the Council's authority.

Chair Federizo invited Councilmember Logan-Parker to provide additional updates on this topic.

Councilmember Logan-Parker explained that they have been working on getting Medicaid to understand the issues with the current adjudication process, particularly around Evaluation and Management (E&M) codes and other limitations. She gave the example of helping Medicaid understand that the level four and five limits of the adjudication process do not meet the needs of children with rare diseases, because they need to see their specialists more often. They have been reviewing scenario-based examples with Medicaid to show that required labs and diagnostic testing are not being reimbursed, such as Dr. Kingsley's previous example. She reiterated that when providers are administering chemotherapy for a patient, they need lab work to validate that they are going down the right path and not causing more harm to the patient. Councilmember Logan-Parker shared that she thinks they have finally gotten Medicaid to understand that the current rules create an undue administrative burden on the providers, which leads to delays in necessary care for people with rare diseases. She thinks Medicaid at least agrees that this is a problem and significant change must occur, whereas they used to deny that a problem existed. This has been a slow and laborious process.

Councilmember Logan-Parker explained that they are currently going through a scenario-based example with the most common type of pediatric Leukemia seen worldwide. They are walking Medicaid through the Children's Oncology Group protocol, starting with induction therapy. They are detailing that this is a five-week therapy that requires a certain amount of level five codes, procedures, lab works, port accesses, etc., so they can help Medicaid understand the unique care that is required for patients with rare diseases. They are going through this for each stage of therapy. The plan is to replicate this format with other diseases, such as Sickle Cell, to help Nevada Medicaid understand current best-practices for care. Councilmember Logan-Parker said she hopes to get to a point where Medicaid will recognize that providers of rare disease need a different set of adjudication rules to appropriately take care of their patients. The discussion with Medicaid is now focused on how to do that; whether to attach a modifier to the billing process, require a particular license or credential, implement a Medicaid Integrity Program (MPI) waiver, or create some other mechanism to identify different adjudication criteria for rare disease providers so they are less stringent. She shared that this process has been long and more laborious than she thought it would be, but she is willing to do the work to help Medicaid understand that the rules for treatment of rare diseases need to be looked at through the lens of best practice.

Councilmember Logan-Parker explained that they are working with Medicaid to make the adjudication process less adversarial. She explained that the administrative burden of appeals, denials, advocacy, and appeals management is shared by both the providers and Medicaid. She shared that she hopes to partner with Medicaid, the RDAC, and other providers in the community to form something of a joint-operating committee to come up with mutually beneficial solutions. Ultimately, patients and parents of pediatric patients should not have to be told that a necessary treatment will be delayed four-five weeks to work through the appeals process. Councilmember Logan-Parker admitted that none of this is new

information for people on the call, but it will require a lot of coordination and conversation to lead to meaningful change. She asked Chair Federizo for her input on their progress.

Chair Federizo agreed with Councilmember Logan-Parker. She shared that this is the first time in the last decade that she has felt things moving forward in a meaningful way. She explained there have been many barriers, but the leadership at the state seems open to change. She shared that, although the RDAC will serve as more of a report card for this change, she thinks it was the RDAC's November 2021 report that brought awareness to these issues and put them in writing. She said she has had to have conversations with her patients that they may need to go out of state to receive care she recommends. She is cautiously optimistic that these issues are now being taken seriously. She shared that her original intention was to have the RDAC oversee this work, but that is beyond the Council's authority.

Chair Federizo explained that next steps will involve creating task forces within DHHS to understand specific provider-type problems. This will require councilmembers to dedicate time and labor, and she will be reaching out to many councilmembers to solicit their engagement. She also asked councilmembers to suggest other providers in the community who could be involved. The Council will provide DHHS with a list of all councilmembers and their expertise to help build the task forces. She explained that this format will center providers as the direct resource for information, rather than a public forum or workshop where providers have less input. Chair Federizo emphasized that significant changes are necessary so that the RDAC is not presenting the same report to DHHS year after year. The RDAC will have regular conversations about the progress. She shared that, while these initiatives only apply to Nevada Medicaid, she expects other commercial care providers to follow suit. Other insurance providers typically do not want to provide less than the minimum care set by Medicaid.

Chair Federizo reiterated that she will be reaching out to councilmembers to participate in the task forces and asked councilmembers to send her the names of other providers who might be interested. With that, she closed out this agenda item.

11) POSSIBLE ACTION: Discussion and possible approval of amended Council Bylaws. – *Council Members*

Chair Federizo explained that it has been a difficulty for the RDAC to maintain quarterly meetings in accordance with how the bylaws are currently written. In order to provide councilmembers enough time to work on the task forces, she recommended amending the bylaws to meet a minimum of once a year, which is the legal requirement. She explained that outside of the annual report due in November, the RDAC does not have authority to work on many other activities in the meantime. This would allow the RDAC to meet as needed, in addition to the mandatory annual meeting.

Chair Federizo opened the floor for discussion.

Councilmember Bagner commented on recent experiences she has had as a person with Sickle Cell Disease. Joseph Filippi interjected that Councilmember Bagner's comments will be moved under Agenda Item #13 in the minutes.

There were no additional questions or comments.

Chair Federizo motioned to approve amending the RDAC bylaws to reduce the number of mandatory council meetings from once quarterly to once annually, with the Chair being able to call additional

meetings as needed. Councilmember Valerie Porter seconded the motion. There were no objections. A quorum voted to approve this motion.

Joseph Filippi asked the Chair if she would like to discuss now when the next annual meeting would be scheduled, or to leave it for future discussion.

Chair Federizo responded that she did not think the current meeting's agenda could be revised to include a vote on when future annual meetings would be scheduled. Her suggestion was that the annual meeting could happen in October to prepare for the annual report due in November.

Mr. Filippi said he will send a Doodle Poll to schedule the next annual meeting in October 2022.

Chair Federizo agreed with this plan and thanked Mr. Filippi.

Councilmember Valerie Porter commented that she would like the opportunity to meet with the Council face to face at the annual meetings, rather than via Zoom.

Mr. Filippi responded that future meetings could be scheduled in person with a northern and a southern location connected via teleconference, as the state has done with other boards and commissions. He said this would be an option if the Council is interested.

Councilmember Porter thanked Mr. Filippi for his response.

Chair Federizo thanked Councilmember Porter for her suggestion. Chair Federizo agreed that she would like to meet the Council in person. She posited that the Council would need to coordinate ahead of time with the state to make sure they could have state staff available at both locations.

12) POSSIBLE ACTION: Discussion, Nomination, and voting for new chair of the Nevada Rare Disease Advisory Council. – *Council Members*

Chair Federizo announced that she will no longer be able to serve as Chair starting June 1, 2022. She explained that the Council will need to discuss nominees for the new Chair. She explained that the bylaws allow for the current Vice Chair to be automatically appointed as the new Chair, but that is not required if others would like to nominate themselves or others for the Chair position.

Chair Federizo opened the floor for discussion and nominations.

Councilmember Logan-Parker asked Chair Federizo if she will still remain on the Council after stepping down as Chair.

Chair Federizo confirmed she will remain on the Council, just not as chair.

Councilmember Logan-Parker thanked her for the clarification. She commented that Chair Federizo has done a great job as Chair in leading the RDAC and getting the Council to where it is today.

Chair Federizo thanked Councilmember Logan-Parker for her comments. She explained that she came into the Chair position without much of an idea of what it would entail. She saw this opportunity as a starting point to bring awareness to what is going on. She said it has been an honor and a privilege to lead the RDAC and bring awareness to the state about the treatment of rare disease patients. Chair

Federizo explained that it was challenging to navigate some discussions with various parties who saw her as the Chair of the RDAC, rather than as a provider in the community. She explained that she hopes the RDAC can continue to serve as a report card and gauge for the changes that are being made. She said she looks forward to continuing her advocacy for rare disease patients and assisting in any way she can.

Chair Federizo moved to nominate Vice Chair Gina Glass for the position of Chair of the RDAC. She opened the floor for additional nominations.

There were no other nominations.

Chair Federizo asked Vice Chair Glass to comment on her interest in being nominated for the Chair position.

Councilmember Logan-Parker asked Chair Federizo if the Council could postpone the election to allow more time to think about potential nominations. This would also allow for discussion and nominations for the open Vice Chair role if Vice Chair Glass does assume the Chair position.

Chair Federizo responded that the Council can work with the state to coordinate a special meeting to vote for the vacant position(s). She commented that she would not like to postpone more than 30 days. She asked for other comments and suggestions.

Councilmember Gina Glass commented that she agrees with Councilmember Logan-Parker's suggestion to postpone the election.

Councilmember Porter asked if the Council could receive and review information from potential nominees as to their background and interest in the role(s) prior to the election.

Chair Federizo agreed with Councilmember Porter's idea.

Joseph Filippi commented that any discussion on the appointment of a future Chair or Vice Chair would have to be done during a public meeting. He asked the Council for clarification on how they would like to proceed.

Councilmember Logan-Parker commented that she would like to learn more about the nominees' backgrounds to make an informed decision about who to vote for.

Councilmember Porter asked Chair Federizo for clarification about whether the bylaws require the Vice Chair to assume the vacant Chair position in this event, or if it can be an open election.

Chair Federizo clarified that it could go either way. In the event the Chair steps down without notice, then it is upon the Vice Chair to resume the role. Chair Federizo explained she has been including Vice Chair Glass on correspondence related to the RDAC, so she could get an idea for what goes on behind the scenes. She clarified that the Vice Chair does not have to assume the Chair position, but it is typically one of those things that happen naturally. Chair Federizo clarified that nominations must come from within the councilmembers themselves. She offered to discuss what the Chair role entails if any councilmembers want to learn more about the time commitment and potential conflicts of interest. She suggested nominees should submit letters of interest for the Council to review, along with an optional resume.

Joseph Filippi asked Chair Federizo if the nominees' resumes and letters of interest should be sent to the Chair or to him to forward to the Council.

Chair Federizo requested for nominees to send their letters of interest and optional resumes to Joseph Filippi. She asked Mr. Filippi to then forward those submissions to the entire Council via BCC to avoid inadvertent discussion prior to the vote.

Mr. Filippi confirmed he will ensure everyone on the Council has his email address and he will send all nominees' submissions to the Council.

Deputy Attorney General Pierron Tackes commented that the resumes and letters of interest would be considered meeting materials, thus they must be available to the public.

Chair Federizo suggested that nominees may want to remove their addresses from their resumes for privacy. She confirmed the materials will be attached along with the next meeting materials.

Councilmember Logan-Parker asked whether the term for the new Chair would start a new term, or if they would only be completing the current Chair's term.

Chair Federizo responded that her understanding is that the new Chair would start a new two-year cycle.

Councilmember Logan-Parker thanked Chair Federizo for the clarification.

Chair Federizo closed this agenda item by confirming she will coordinate a special meeting agenda and date with the state. She thanked everyone for their input and the opportunity to serve as Chair of the Council.

13) INFORMATIONAL ITEM: Council member information sharing announcements – *Council Members*

Councilmember Naja Bagner shared some recent experiences from a patient's perspective. She shared that she was last hospitalized at Summerlin Hospital on April 22, 2022. She encountered that the hospital did not carry the appropriate Sickle Cell medications, Oxbyrta and Adakveo. She explained that when a Sickle Cell patient is admitted, they rely on the hospital to administer their daily medications. When the hospital does not have the patient's regular medication, it disrupts the patient's regiment. She suggested that hospitals need to ensure that new Sickle Cell medications are available for hospital patients.

Chair Federizo responded that she intends to add Councilmember to a task force where she can provide her testimony.

Councilmember Bagner thanked Chair Federizo for her response. She also shared that she would like to advocate for cancer clinics to return to allowing patients to bring a support buddy to treatment. She explained that support buddies have not been allowed since the beginning of the COVID pandemic. She has found this restriction difficult, because having someone there during treatment provides a lot of support.

14) PUBLIC COMMENT:

Chair Federizo opened the floor for public comment.

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

15) ADJOURNMENT – *Chair Amber Federizo*

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

Chair Federizo moved to adjourn the meeting at 10:38 am.