NEVADA RARE DISEASE ADVISORY COUNCIL

MEETING MINUTES
Date: June 20, 2022
3:00 pm – 4:19 pm PST

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 3:00 pm.

1) INTRODUCTIONS AND ROLL CALL

COUNCIL MEMBERS PRESENT:
Ihsan Azzam, MD, PhD; Gina Glass (Vice-Chair); Valerie Porter, DNP, BSN, MBA; Kimberly Palma Ortega; Naja Bagner; Max Coppes, MD, PhD, MBA; Veneta Lepera; Paul Niedermeyer; Annette Logan-Parker; Nik Abdul Rashid, MD; Brynlin Thornley (Quorum=8)

COUNCIL MEMBERS ABSENT:
Amber Federizo, DNP, APRN, FNPBC (CHAIR); Jennifer Millet MSN, RN; Shirley Folkins-Roberts (left early); Linetta Barnes, BSN, RN; Susana Sorrentino, MD; Paul Niedermeyer

DIVISION OF PUBLIC & BEHAVIORAL HEALTH (DPBH) STAFF PRESENT:
Rex Gifford Administrative Assistant III; Lindsey Kinsinger Health Program Manager II, Office of Public Health Investigations and Epidemiology (OPHIE); and Pierron Tackes, Deputy Attorney General (DAG)

OTHERS PRESENT:

Antonina Capurro, Deputy Administrator, Division of Health Care Financing and Policy; and Erin Lynch, Social Services Chief III, Division of Health Care Financing and Policy

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

Vice-Chair Glass did not open the floor for public comment.

3) POSSIBLE ACTION: Approval of minutes from May 27, 2022, Rare Disease Advisory Council Meeting. – *Council Members*

Councilmember Annette Logan-Parker motioned to approve the meeting minutes from prior council meeting dated May 27, 2022. Councilmember Veneta Lepera seconded the motion to approve. There were no objections. A quorum voted to approve the prior meeting minutes.

4) POSSIBLE ACTION: Discussion and possible approval of amending Council Bylaws to reflect meeting quarterly requirement, pursuant to NRS 439.5075.7 (b) – *Council Members*

Pierron Tackes, Deputy Attorney General commented that during the last meeting, it was discussed to meet less frequently as per council discussion. She noted that some staff communicated after the meeting to discuss the change to bylaws to not meet as frequently. She stated that there is a statutory requirement that the Rare Disease Advisory Council (RDAC) meets four times a year. She mentioned that the statutory requirement overrides the bylaws. She suggests amending the bylaws to reflect the statutory requirement to meet four times a year to avoid confusion.

Councilmember Annette Logan-Parker then motioned to approve amending the bylaws for the meetings to match the statutory requirement. Councilmember Shirley Folkins-Roberts seconded the motion to approve. There were no objections. A quorum voted to approve amending the bylaws to match the statutory requirement.

5) POSSIBLE ACTION: Approval of proposed quarterly RDAC meeting dates for 2022-2023 – *Council Members*

- August 2022
- November 2022
- February 2023
- May 2023
- August 2023
- November 2023

Councilmember Annette Logan-Parker motioned to approve the quarterly meeting dates for 2022-2023. Councilmember Valerie Porter seconded the motion to approve. Before the vote was finalized, Councilmember Dr. Ihsan Azzam interjected, opening the floor for discussion. He asked if this meeting was the second or third meeting of 2022.

Rex Gifford commented that he believes this meeting is the second one of 2022 and August 2022 will be the third. Dr. Azzam asked for all of 2022 the council only met in May.

Councilmember Nik Abdul Rashid commented that she thought the council met in February 2022.

Rex Gifford commented that he needed a minute to look it up. Gifford commented that the RDAC council met February 14, 2022, May 27, 2022, and today (June 20, 2022).

Dr. Azzam asked for 2022 the council would only need one more meeting to meet the requirement.

Pierron Tackes commented that is the assessment is correct per the statute requirement the council would only need to meet one more time. Dr. Azzam thanks Pierron Tackes for clarifying.

Mr. Gifford comments that he believes there is an annual RDAC letter or recommendations due to the Governor and suggested having another meeting to discuss the letter or report due to Governor.

Councilmember Annette Logan-Parker commented that she agrees with Mr. Gifford's comment that it would be beneficial to have two more meetings in the calendar year to discuss the report submitted to the Governor that is meaningful.

Councilmember Rashid proposes that the council keep the meeting dates proposed in this action item and asked if the future meeting dates in 2022 are sufficient for the report to the Governor.

Councilmember Logan-Parker commented that the two meetings in addition to the one today would be sufficient to get the letter to Governor. She also added that when the council moves into next year of 2023, it would be only the four meetings where the council is better prepared for the report.

Councilmember Rashid motioned to approve the two meetings 2022 in August and November as outlined for this action item. She added that starting in 2023, the council will have four meetings to reflect the bylaws as outlined in this action item. Councilmember Valerie Porter seconded Councilmembers Rashid's proposal. There were no objections. A quorum voted to approve the meeting dates for 2022-2023.

6) INFORMATIONAL: Presentation on proposed Nevada Medicaid initiatives and recommendations for potential long-term solutions. – Dr. Antonina Capurro, Deputy Administrator, Division of Health Care Financing and Policy and Erin Lynch, Social Services Chief III, Medical Programs Unit, (DHCFP)

Pierron Tackes noted that this item is informational, and she noted the key differences between informational items versus action items. She reminded the council when the agenda shows an informational item, no motion can be made, and no vote will be taken on this item. She stated that council members are not prohibited from having discussion and providing feedback to those presenting.

Rex Gifford asked Dr. Antonina Capurro how she would like to present the presentation? He shared the presentation with the council.

Dr. Antonina Capurro thanked the council for their flexibility and allowing them to go out of order of the agenda. She introduced herself as the Deputy Administrator of Healthcare Financing and Policy, Nevada Medicaid. Dr. Capurro introduced Ms. Erin Lynch, Social Services Chief III within the medical programs of their Division. She thanked the council for an opportunity to present Medicaid services and proposed policy initiatives for individuals diagnosed with rare diseases. Dr. Capurro stated the agenda for the presentation such as discussing the Medicaid statistics and reviewing covered services. She stated their key takeaways from the Nevada Rare Disease Advisory Council Annual Report from 2021. She commented that they will discuss Medicaid proposed policies recommendations based off the takeaways

from the annual report. Dr. Capurro asked Ms. Erin Lynch to provide background on Medicaid population, structure, and brief overview of services that they provide. She commented that while the information is limited due to time, they are willing to provide resources for future presentations.

Ms. Erin Lynch thanked everyone on the council for the opportunity to speak and introduced herself as the Chief of the medical program unit at Nevada Medicaid program. She noted that medical programs are all things medical such as primary care up to specialty care. She detailed the Division's mission to administer Nevada Medicaid and Check Up to promote a healthier Nevada by the following: purchasing and providing quality health-care services for low-income Nevadans in the most efficient manner; promoting equal access to care at an affordable cost to the taxpayers of Nevada as it is public funded; restraining growth of healthcare costs; and reviewing Medicaid and other state healthcare programs to maximize potential federal revenue. She commented it is important to remember that the Division is setup like a health plan by conducting billing with different types of codes and having procedures in place like getting prior authorization on certain things. She noted that they are not an insurance company and are considered public assistance per the Nevada revised statue NRS 422A.065. She noted that public assistance includes food stamps, temporary assistance for needy families, low energy home assistance, the program for childcare development, and Medicaid. She commented on notable statistics such as Nevadans covered under Medicaid are one in four; the Division has had a 36.2 percent growth of recipients receiving Medicaid since February of 2020, right as COVID-19 was hitting; during fiscal year 2021 (July 1, 2020 – June 30, 2021) nearly 30 percent of the state's expenditures ($4.6 billion) were spent on Medicaid. She commented that she believes it is the highest state budget. She continued listing the notable statistics like 55 percent of the births in Nevada were covered by Medicaid in 2021; 76 percent of Medicaid recipients served through Managed Care. Ms. Lynch stated that they have fees for service and managed care. She noted that managed care is mostly in urban counties and most of their recipients are on managed care where they contract out other services to other health plans such as Anthem Blue Cross-Blue Shield, Health Plan of Nevada, Silver Summit, Millennia, and Liberty Dental. She commented that the rest is fee for service. Lynch continued with the notable statistics list such as 42 percent of Medicaid recipients are aged 0-18 years old, and 6,516 children enrolled in Medicaid have a diagnosis of cancer in calendar year 2021. She reviewed the total Medicaid caseload data from the last year. She commented that the caseloads are going up each year, and by May of 2022 they have almost 893,000 individuals on Medicaid. She commented that Medicaid is a federally authorized program that each state has, and all are different which makes it difficult to compare other states to each other as they each have their own plans. She noted that Medicaid was authorized by Congress in 1965as part of the Social Security Act. Ms. Lynch stated that Medicaid is optional medical coverage program to states elect to provide to their residents. She commented that states work with CMS to provide this type of care, and a lot of federal regulations that have to be followed. She noted that Nevada covers the mandatory groups that are authorized by CMS, and there are a lot of optional services that is also covered. Ms. Lynch stated that while one person is eligible in one state, they may not be eligible in another, and services offered by one state may differ by amount, duration, or scope of services provided. She commented that state legislatures may change Medicaid eligibility, services, and/or reimbursement during the year. She noted that Medicaid is publicly financed, state dollars, and federally matched are portioned depending on the service. She commented that federally matched where the feds pick up most of the bill is highest with family plans while other services will get a lower match. She noted that Medicaid procures most of its services in private health care market by fee for services or paying premiums contracted to managed care organizations (MCOs). Ms. Lynch commented that DHCFP is under the Department of Health and

Human Services (DHHS), and the Department is made up of a lot of different divisions such as Division of Welfare and Supportive Services (DWSS) that handles the eligibility side of Medicaid. DHCFP runs the program and the services, but the Division of Welfare determines who is actually eligible for Medicaid and re-determines them to ensure that they are still eligible, and they work with NOMADS. She continued with the Division of Public and Behavioral Health that used to be known as Nevada State Health Divisions. She noted the Division of Aging and Disability Services that aids with aging and disabilities, and some are eligible for Medicaid. She continued listing the DHHS agencies such as Division of Child and Family Services and the Public Defender. She stated that DWSS eligibility information can take 24-48 hours to upload in Medicaid and another 24 hours to upload to the Pharmacy system. She commented that it is critical to be looking at EVS (Electronic Verification System) to ensure that every patient the provider sees has eligibility for Medicaid at every visit because the patient can lose coverage within the next month as on a typical basis the patients' eligibility is based off income. She commented that Medicaid Management Information System (MMIS) known as interChange (iC) is their billing system within DHCFP. She noted that their special programs are ran through Medicaid District Offices throughout the State. She continued to discuss waivers within Medicaid where they must go CMS for permission to bend the rules with Medicaid. She commented on the benefits of Medicaid that is divided into two sections, mandatory and optional. Ms. Lynch stated that within the Medicaid programs component there is an Early ands Periodic Screening, and Treatment (EPSDT) that is a federal mandate coverage plan that must be covered for recipients under the age 21 that identifies medical conditions and treatments that is medically necessary. She noted that EPSDT is known as Healthy Kids in Nevada. She commented that that for screening Medicaid follows the American Academy Pediatrics (AAP) Bright Futures screening such as physical health, behavioral health, vaccination, and all preventive screenings for kids. Ms. Lynch thanked Dr. Capurro and passed the next section off to her.

Dr. Capurro felt it was important to provide background on Medicaid and how DHCFP operates and the services they provide. Dr. Capurro commented that she reviewed the Rare Disease Advisory Councils' Annual Report from 2021 for recommendations that were specific to areas of concern for the requested evaluation of specific areas for the Department of Health and Human Services or called for action by Nevada Medicaid specifically. She acknowledged the extensive work that was done into creating this report, and it was enlightening to Dr. Capurro to read. She stated that upon reviewing the annual report there were five council recommendations in response to legislative objectives that explicitly involve the Medicaid agency that are listed in the PowerPoint for reference. She commented that The Agency focused on the objectives that called out Medicaid or the Department which were objective four to identify evidence-based strategies to prevent and control rare diseases. She continued with objective six which was studying early treatment of rare diseases on the quality of life for patients that suffer from rare diseases and the provision of services and reimbursement for services. She continued with objective eight which is the evaluation of the system of delivery and treatment for rare diseases in Nevada with recommendations to increase survival rates and quality of life. She continued to objective nine that determines the effective methods of collecting data concerning cases of rare diseases. She stated that objective ten to establish a comprehensive plan for the management of rare diseases in Nevada. She commented on the limitations identified in the report which the Division found to have as well in the Divisions' understanding to be able to provide the highest quality of services and be able to make innovative patient centered polices. She listed the limitations found as lack of an agreed-upon list of ICD-10 codes to capture all rare disease patients. She commented that there is an exhaustive list on the

National Health Institute's website which makes it very difficult to track rare diseases over time as a population. She continued with limitations found there was a lack of state directory of clinicians skilled in treating rare diseases as well as a lack of centralized registry or database. Dr. Capurro stated that some recommendations specific to the Department and Medicaid were to have public notification of policy changes. She mentioned that before any policy changes are made they are posted on their website, and they also hold public workshops and public hearings. She commented that if there is a policy change that the council may be interested in, those individuals can sign up for their list server to receive notifications and the Division encourage members of the public to come and make their voices heard when the Division is considering making policy changes. She continued with the recommendations to improve reimbursement for rare disease care. She noted that they will see how this recommendation has been incorporated into the policy recommendations. She continued with the recommendations to allow fee-for-service Medicaid providers to enroll with managed care. She commented that this is specific to a closed network and allowing multiple providers to enroll with a managed care organization. She noted that this goes back to contracting with the managed care organization and will not be covered today. She continued with the Medicaid recommendations to develop a state disease-specific reimbursement model. She noted that this will be seen in one of the proposals. Dr. Capurro stated the policy recommendations are based on the RDAC report these proposals can be viewed as a starting point for discussion, and the Division is interested in feedback today and in the future. She commented that these options will require budgetary authority, federal approval, and will have to go through the entire public workshop process. She discussed the first proposal is to create a new provider type specific to clinics that treat individuals with rare disease. She stated that a specific provider type like provider type 17 for specialty clinics could be created to allow for specific policies, billing guides, methodologies to be tailored to the unique needs of the populations that you serve, and the facilities that provide this care. She commented that there are 16 specialty clinics that are approved and listed. She stated some examples of these are federally qualified health centers, school-based health centers, and family planning. She noted that by creating this new provider type, it allows us to create a system that is specific to the needs of a specialty clinic. She noted that it could be like creating a childhood cancer and rare disease specialty clinic. She commented that this proposal will involve a State Plan Amendment which requires the Division to request federal authority to make those changes. She noted that the State Plan is the Division's state plan with the federal government, so federal approval will be needed. She stated that there will also be chapter policy changes and would also need additional fiscal authority. Dr. Capurro commented on the second policy proposal that is more of a long-term solution, and it is centered on improving a payment structure. She commented that is based off Nevada's current investigation into creating a direct to payment program. She noted that Florida's Medicaid program provides an example of this reimbursement model would be created. She stated that supplemental payments could be offered to Nevada's cancer hospitals and facilities that meet certain federal requirements, and the facility would be reimbursed based on upper payment limits. She noted that the supplemental payment program that serves as a bridge between Medicaid reimbursement rates and the actual cost of providing care. She stated that this would be a policy lever to include cancer hospitals and facilities into a directed payment program. She noted that this would be applicable to both fee-for -service and managed care to cover the entire population. She commented that proposal would involve an extensive amount of state and federal authority. She noted that a State Plan Amendment, policy changes, and need for additional fiscal authority would be needed. Dr. Capurro stated the final proposal is to create a health home. She commented that the Affordable Care Act created an optional Medicaid state plan benefit for states to establish health homes that allows the state to coordinate care for individuals with Medicaid who also

have chronic conditions. She noted that in some states the definition of chronic diseases is very broad and can also include those with rare diseases. She commented that this allows for the Division to do is create and operate a whole person care program, and the health home provides integration and coordination of primary acute behavioral health and long-term supportive services for that whole person-centered care. She noted that health home is centered on the comprehensive nature of services, offers a team-based approach, and full complement of supportive resources that is provided. She commented that there is possibility to incorporate proposal one into proposal three since there are components that are added into what is provided specifically care coordination and case management for Medicaid patients with high needs. She stated that this would also involve extensive approval process such as State Plan Amendment, policy changes, and the need for additional fiscal authority. She commented that none of these are short-term solutions, and all are long-term solutions that would be developing before the next legislative session and possibly including in the Division's budget. She noted that the Division would go through the public process to get public feedback on any one of the proposals or compliments of these ideas. She stated that we have some possible solutions we can develop and customize models of care that really focus on serving individuals with rare diseases and meeting them their unique needs. Dr. Capurro commented that she is looking forward to the council's feedback and stands prepared for any questions.

Councilmember Annette Logan-Parker thanked Dr. Capurro and Ms. Lynch for the presentation. She commented that this presentation has been very helpful to her. She stressed her concern that not all providers in Nevada who might not have that full scope available to them but would also benefit from some changes to how things are done currently. She asked if there would be layers to the Health Homes or if it would be one provider type that the providers would have to mold to.

Dr. Capurro thanked Councilmember Logan-Parker for the question. She stated that if the Division created a different provider type, a specialty clinic then that would be the provider type that would be built for these facilities to provide services under. She commented current facilities or providers enrolled under PT-20 which is the physician group which is not as tailored in its service limitations, reimbursement schedule, and prior authorizations requirements to meet the needs of populations that are served. She stated that if we are changing and creating a different provider type, then the Division would be asking providers to enroll into that provider type. She noted that the Division would have to be cognitive of all those providers that would fit under that umbrella that would make it fit for everyone.

Councilmember Annette Logan-Parker thanked Dr. Capurro for answering her question. She commented that she has a lot of thoughts that she can articulate like unintended consequences or things that may happen down the path. She asked within some of the existing provider types like 17 categories that Dr. Capurro had mentioned, are there any of those that could be amended, particularly the one with the genetic component, to incorporate some additional language to cast a wide enough net that would be capturing as many rare diseases as possible. She noted her curiosity through all these long-term proposals solutions that focus on the genetic component. She commented that majority of these rare diseases are considered to fall under that genetic umbrella.

Ms. Erin Lynch stated that whether we create a new provider type or want to amend a provider type such as PT-17167 Genetics it is going to take a lot of system hours to change the Divisions' system and update it. She commented that if there is a change to any type of reimbursement methodologies, the

Division will still need to go the federal government to get approval because the State Plan would be amending. She noted that the process will remain the same regardless of if we create a new provider type or amending current provider types to meet state authority to increase reimbursement rates, the State Plan Amendment, and all the systems changes within the MMIS, the State billing system.

Councilmember Annette Logan-Parker thanked Ms. Lynch for the clarification.

Dr. Azzam thanked Dr. Capurro and Ms. Lynch for the presentation. He commented that he does not know if Dr. Capurro or Ms. Lynch read the last RDAC Minutes from the last RDAC meeting. He noted that a physician was complaining that a certain test that is important for him to monitor treatment was not covered by Medicaid. He asked if there is a process to evaluate such a request, and who deems a test or service as necessary and should be covered. He also asked how can that process initiated?

Ms. Lynch stated that there is a policy section on laboratory testing. She noted that if the test that was being requested is not within that Chapter of Medicaid Manual Services, Chapter 800. She asked if the test was genetic?

Dr. Azzam replied that he does not recall if the test was genetic or not. He stated that this occurred during public comment section of the last meeting.

Dr. Capurro stated the Division is in touch with the physician, and they are working through the issue. She stated that if there are any other providers that have questions, they are happy to work with them one-on-one. She commented that there are policy requirements for certain codes, documentation that is needed, or a certain service limit that they might hit. She stated that they are happy to work with anyone to help them understand the system, as they know the system can be complicated. She noted that in order to add a specific laboratory code or a new CPT code, they are encouraging individuals to go through the Medicaid Care Advisory Committee. She commented that the Medicaid Care Advisory Committee has a process in which those requests can be heard and thoroughly bedded and then come to agency for evaluation.

Ms. Lynch commented that on an annual basis CMS does come out with new codes to certain procedures or add an additional code to a certain procedure. She noted that the Division does review every year, and if it is within Medicaid's coverage policy, they will add the appropriate CPT codes to the annual CMS code update. She clarified that the reason she asked if the test was genetic was because in general for laboratory testing for adults, Medicaid does not cover genetic testing unless it is the BRCA Genetic Test for breast cancer.

Dr. Azzam thanked both Dr. Capurro and Ms. Lynch.

Councilmember Naja Bagner asked if from a patient's standpoint would breathing equipment like oxygen machines fall under these proposals too.

Ms. Erin Lynch commented that within policy, there is a Chapter on durable medical equipment (DME). She notes that the medical equipment has to be medically necessary in order for Medicaid to cover

services, equipment, or medical supplies. She states that it is dependent upon the asks with that particular individual. She commented that in general Medicaid does cover DME.

Councilmember Naja Bagner commented that she has an issue with that because with Sickle Cell and Anemia, they do not carry enough oxygen in their blood cells. She noted that patients with sickle cell and anemia will have their oxygen levels at 99 one day then maybe by Wednesday their oxygen levels might be down to 90 but patients are not required oxygen. She commented that these patients are allowed to have concentrated oxygen at home, but when it comes to being out and about the insurance does not cover portable oxygen. She stated that these patients are supplied with refillable oxygen but that goes without saying that if these patients are out and they have a four-hour treatment. She noted that if these patients are going to see their families, anything can drop their oxygen levels and it happens within a split second. She stated the insurance not covering the portable oxygen for sickle cell patients can be the main things that sets off a crisis.

Ms. Lynch commented that she is unsure if Medicaid covers the portable ones. She stated that she will check with a policy specialist. She noted that in general it boils down to if DME is medically necessary for that recipient. She commented that the patient would need to work with their doctors to submit that request.

Councilmember Naja Bagner commented that she wanted to mention this because it stops patients with sickle cell from having a good quality of life because of limited access to portable oxygen when out and about. She stated that everyone needs oxygen for their blood, so for those who fall under this rare disease category such as sickle cell it is common to see patients without portable oxygen. She commented that she would like to dig deeper and provide portable oxygen to sickle cell patients.

Dr. Capurro commented that they will investigate that and provide an update back to the committee.

Councilmember Naja Bagner thanked Dr. Capurro and Ms. Lynch.

Councilmember Annette Logan-Parker commented that part of the problem with this is CMS rules for portable oxygen fall into the pre-determined criteria of people with COPD and things like that. She noted that the required testing with pulse oximetry in the physician's office and documenting that is suited best towards people with defined pulmonary conditions versus understanding that when patients with sickle cell disease have an oxygen need, that need should be based on their disease specifically not the qualifying criteria of a completely different disease.

Dr. Capurro commented that she understands and thanks Councilmember Annette Logan-Parker for the clarification.

Ms. Lynch commented that she is reaching out to the policy specialist right now and hope she will get back to her while they are still on the line.

Vice-Chair Gina Glass asked that when it comes to these updates who will be responsible for ensuring that Medicaid providers, insurers, or policy specialists are aware of the updates that occur with legislation. She commented that for example, the sickle cell bill there was a lot of different language and

policies requirements of Medicaid insurers. She noted that she is finding from patients that a lot of things that were established through the sickle cell bill are not necessary being adhered to by Medicaid. She commented that this could possibly be because they are not aware or familiar with the requirements that were established as a result of the sickle cell bill that was passed in 2019. She asked who Dr. Capurro and Ms. Lynch if they may be able to connect with that individual in charge to ensure that they are aware of the legislation and the requirements of Medicaid so that the patients do not suffer.

Ms. Erin Lynch stated that the Medical Programs Unit and the Pharmaceutical Unit did work together to ensure that the Medicaid coverage includes everything that was within that sickle cell bill. She commented that if there is anything of concern that maybe is not being covered, the council can reach out to her specifically.

Vice-Chair Gina Glass commented that she believes that Councilmember Naja Bagner was having issues with her pharmacy recently about her medication and supplements that provided to her through her provider are to be covered under Medicaid, and she is still paying out-of-pocket even though it has been three years since that bill has passed.

Ms. Erin Lynch commented to reach out to her, and she will connect them with the Pharmacy Unit Chief, David Olsen. She notes that Mr. Olsen will investigate that issue.

Vice-Chair Gina Glass thanked Ms. Erin Lynch.

Ms. Erin Lynch commented that the policy specialist on DME, Jessica replied to her about the portable oxygen for sickle cell patients. She stated that the portable oxygen is covered if medically necessary.

Councilmember Annette Logan-Parker commented that this is where we run into the defining what is medically necessary based on the disease versus the whole CMS outline on what they consider medically necessary for portable oxygen generally falls into conditions that are seen by pulmonologists, intensivists, or internists versus the rare diseases. She noted that this is an example of what is medically necessary for sickle cell patients is very different for what is medically different for COPD or some other conditions that would be routinely seen portable oxygen covered. She commented that this where the hiccup is, and it may be medically necessary for a sickle cell patient under certain situations, but it is not necessarily following into the same generalized criteria as medically necessary for a COPD patient or an individual with breathing complications.

Ms. Erin Lynch commented that there is a definition for what is medically necessary within the Medicaid Program. She noted that everything should be following that same definition. She stated that the Medicaid Services Manual, Chapter 100 would have the medically necessary definition. She commented that she is trying to location the definition.

Councilmember Annette Logan-Parker stated that will not be necessary.

Councilmember Nik Abdul Rashid commented that she would like clarification on proposal number one. She noted that the proposal involves creation of a new provider type for clinics that treat individuals with rare diseases. She asked for Dr. Capurro to explain this to her.

Dr. Antonina Capurro stated that would be a specialty clinic that the Division would create a new provider type. She commented that she had mentioned that it could be similar to a provider type that is described by childhood cancers and rare disease specialty clinic. She noted that it would be specific to the treatment of individuals with rare diseases that would allow the Division to create a new policy, billing guide, based on best practices and rate methodology that would be more in line with industry standards.

Councilmember Nik Abdul Rashid thanked Dr. Capurro for the clarification.

Dr. Antonina Capurro commented that she understands that a lot of the proposal is conceptual, and as the council and DCHFP would walk through any of these proposals or an amalgamation of these proposals there would be many decision points that would have public input to make changes.

Councilmember Nik Abdul Rashid stated her concern about one of these proposals having to fit into one of these molds as Councilmember Annette Logan-Parker expressed earlier. Rashid noted that as mentioned previously there would need to be further discussion on creating something that would encompass all the different specialties. She commented that a center for childhood cancer and rare diseases have the resources to provide all services under one roof such as social worker, physical therapy, and all the other multidisciplinary care. She stated there are other rare disease clinics that may not be able to provide that but still spend a lot of time in referrals and discussion, and all the other things that need to be done to treat someone with a rare disorder that may not fit into one of these proposed molds.

Dr. Antonina Capurro agreed with Councilmember Rashid. She commented that they would like to create a system that could be used broadly but has multiple provider types within Nevada Medicaid. She noted for example if there is an occupational therapist or a specialist did not fit into that, the specialist can enroll under their own provider type and bill separately. She stated that there will always be a mechanism to bill.

Councilmember Nik Abdul Rashid thanked Dr. Antonina Capurro for clarifying.

Dr. Antonina Capurro appreciated all the questions. She noted that contact information is listed in the PowerPoint. She asked the council to email herself and Ms. Erin Lynch with any additional questions and concerns. She thanked the council for inviting them to the meeting to present.

Ms. Erin Lynch thanked the council for inviting them to the meeting to present.

Councilmember Nik Abdul Rashid, Councilmember Valarie Porter, and Vice-Chair Gina Glass thanked Dr. Antonina Capurro and Ms. Erin Lynch with DCCFP for presenting.

7) POSSIBLE ACTION: Discussion, nomination, and voting for new chair and vice chair of the Nevada Rare Disease Advisory Council. - *Council Members*

Deputy Attorney General (DAG) Pierron Tackes asked Vice-Chair Gina Glass if she would like to move on this agenda item for the discussion, nomination, and voting of the new chair and vice-chair for the Rare Disease Advisory Council?

Vice-Chair Gina Glass commented that she would like to discuss this agenda item.

DAG Pierron Tackes stated that she will be provided an update. Ms. Tackes commented that the current Chair Amber Federizo had asked that this be put on the agenda for today's meeting, and Chair Federizo wanted to make the council aware of an employment position change. Ms. Tackes noted that Chair Federizo is working for a company called Octa Pharma, a pharmaceutical company. Tackes commented that for the record, Chair Federizo still meets the statutory requirements of her appointed position. Ms. Tackes notes that Chair Federizo's change in employment does not affect her eligibility to remain on the council and the position that she has been appointed to. Ms. Tackes states that for transparency purposes Chair Federizo did want to let the council know, and to provide that opportunity to the council to elect a different chair. Ms. Tackes states that Chair Federizo would like to remain Chair as long as the council does not want to elect someone else that has been agenized as an item for possible action.

Vice-Chair Gina Glass commented that Pierron Tackes is correct, that Chair Amber Federizo agreed to be the Chair until the end of November. Vice-Chair Glass stated that at that point a new Chair would be elected unless the council decides otherwise to elect a new Chair at today's meeting.

DAG Pierron Tackes thanks Vice-Chair Gina Glass. Ms. Tackes commented that it is her understanding that there are a few possible considerations for the council under this item. She stated that first would be to appoint a new Chair for the reminder of the term starting now until the end of 2022 and then a new Chair would be appointed for the new term. Ms. Tackes asked if this is correct.

Vice-Chair Gina Glass responded that is correct.

Councilmember Annette Logan-Parker commented that she would like to open this up for discussion. She stated that she is on-board with Chair Amber Federizo remaining in her role as the Chair for the reminder of her term. She requested that Chair Federizo voluntarily abstains from any major Pharmaceutical related discussions or votes.

Deputy Attorney General Pierron Tackes commented that all the same provisions for ethics for government will apply to her and all members of the council for all action items. She noted that if Chair Federizo's new position would present a conflict of interest she would be required to disclose that and abstain.

Councilmember Annette Logan-Parker thanked Pierron Tackes.

Councilmember Kimberly Palma-Ortega agreed with Annette Logan-Parker that Chair Amber Federizo remains the Chair until the end of term and abstains when needed.

Councilmember Valarie Porter agreed with Councilmembers Annette Logan-Parker and Kimberly Palma-Ortega to allow Chair Amber Federizo to finish her term.

Councilmember Annette Logan-Parker motioned to approve Chair Amber Federizo to remain in her role as Chair until the end of her term. Councilmember Nik Abdul Rashid seconded Councilmembers Logan-Parker's proposal. There were no objections. A quorum voted to approve Chair Amber Federizo to remain in her role as Chair until the end of her term.

Rex Gifford asked the council if the council will nominate a Chair and Vice-Chair for the next term at the next meeting.

Vice-Chair Gina Glass commented to table to nomination for Chair and Vice-Chair for next term until the next meeting.

Rex Gifford asked if the council could table the nomination of Chair and Vice-Chair for the next term.

Deputy Attorney General Pierron Tackes comments that this can be tabled until the next meeting.

Rex Gifford thanked Deputy Attorney General Pierron Tackes.

Vice-Chair Gina Glass closed this agenda item and proceeded to the next agenda item.

8) INFORMATIONAL: Update on Council vacancies appointed by the Director of the Department of Health and Human Services. – *Council Members/DPBH Staff*

- (1) One physician who practices in area of cardiology, emergency care, neurology, oncology, orthopedics, pediatrics, or primary care and provide care to patients with rare diseases;
- (1) One Division representative who provides education concerning rare diseases or the management of chronic conditions;
- (1) One person over 18 years of age who have suffered from or currently suffer from a rare disease

Vice-Chair Gina Glass stated the vacancies as listed in this informational item in the Rare Disease Advisory Council as appointed by the Director of Health and Human Services.

Councilmember Annette Logan-Parker asked what defines a Division representative.

Deputy Attorney General Pierron Tackes states that she was looking at the statue and the Division is referencing to the Division of Public and Behavioral Health. She commented that this would be a member that is representing the Division of Public and Behavioral Health. She asked for a minute to ensure that the Division is the Public and Behavioral Health is in the statue. She stated that per the statue lists out those members that are being appointed and the vacancies that we currently have of the Division. She commented that this is the Division of Public and Behavioral Health. She noted that it is interesting that another position does specify an employee of the Division, and representative is notably more broad. She commented that to an extent if there is an employee or perhaps a volunteer that volunteers within the position than that would most likely be appropriate as well.

Councilmember Annette Logan-Parker thanked Deputy Attorney General Pierron Tackes.

Rex Gifford asked Vice-Chair Gina Glass if she would like to move on to the next agenda item.

Vice-Chair Gina Glass closed out this discussion and proceeded to the next agenda item.

9) INFORMATIONAL: Council member information sharing announcements – *Council Members*

Vice-Chair Gina Glass opened the floor to the council if they have anything to announce.

There were no announcements. Vice-Cahir Gina Glass closed this agenda item and proceeds to the next agenda item.

10) PUBLIC COMMENT:

Vice-Chair Gina Glass opened the floor for public comment.

There was no public comment.

11) ADJOURNMENT – *Vice-Chair Gina Glass*

Vice-Chair Gina Glass moved to adjourn and expressed appreciation for everyone on the council.

Vice-Chair Gina Glass moved to adjourn the meeting at 04:19 pm PST.