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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: September 12, 2022
9:12 am – 10:26 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.
Kayla Samuels opened the meeting at 9:12 am.

1) INTRODUCTIONS AND ROLL CALL

COUNCIL MEMBERS PRESENT:
Amber Federizo, DNP, APRN, FNPBC (CHAIR); Shirley Folkins-Roberts; Gina Glass (Vice-Chair); Jennifer Millet, DNP, RN; Kimberly Palma Ortega; Naja Bagner; Annette Logan-Parker; Nik Abdul Rashid, MD (Quorum=8)

COUNCIL MEMBERS ABSENT:
Ihsan Azzam, MD, PhD; Valerie Porter, DNP, BSN, MBA; Susana Sorrentino, MD; Paul Niedermeyer; Linetta Barnes, BSN, RN; Veneta Lepera; Brynlin Thornley

DIVISION OF PUBLIC & BEHAVIORAL HEALTH (DPBH) STAFF PRESENT:
Kayla Samuels, Management Analyst I; Pierron E. Tackles, Deputy Attorney General (DAG); Julia Peek, Deputy Administrator; Ashlyn Torrez, Health Program Specialist I; and Autumn Blattman, Executive Assistant

OTHERS PRESENT:
Erin Lynch, Social Services Chief III, Division of Health Care Financing and Policy; Antonio Gudino-Vargas, Social Services Program Specialist III; Dawn Newburg, Executive Director, ALS Association Nevada Chapter; Linda Anderson; Tyler Shaw; and Emma Selm-Keck

Roll call was taken and is reflected above. It was determined that quorum was not met of the Rare Disease Advisory Council (RDAC, the Council). The Council was to go over informational agenda items only. However, the Council was able to meet quorum at a later time and proceeded to go through possible action items.

2) PUBLIC COMMENT

Chair Federizo opened the floor for public comment.

There was no other public comment.

3) INFORMATIONAL: Discussion of, nomination of, and voting for a new chair and vice chair for the Rare Disease Advisory Council for next term. – *Council members*

Chair Federizo commented for everyone's awareness that at the next council meeting the official voting for the chair and vice chair will occurs, as it has been two years since last vote. Chair Federizo stated that if anyone has nominations, please feel free to send them in so they will be added to the list of votes for next council meeting.

Chair Federizo moved on to the next agenda item.

4) INFORMATIONAL: Nevada Update on Sickle Cell Registry – *Annette Logan-Parker, CEO of Cure4Kids Foundation; Ashlyn Torrez, Health Program Specialist I, Office of Public Health Informatics and Epidemiology (OPHIE), DPBH; and Nik Abdul Rashid M.D.*

Chair Federizo asked councilmember Annette Logan-Parker if she would like to wait on updating the council as Dr. Rashid is running late.

Councilmember Logan-Parker stated she can provide a small update to the council. Councilmember Logan-Parker commented that Dr. Rashid and herself have been communicating a design for data collection instrument with our State partners, Lindsey Kinsinger and Ashlyn Torrez for Sickle Cell instant reporting. Councilmember Logan-Parker commented that she has reached out to colleagues in Georgia and other states to get some advice how those states are collecting data to be consistent on a national level and noted that she has not made a lot of progress, but we are clear on what we would like to see happen. She commented that there may be funding obstacles with State staffing, and she submitted a funding opportunity to Ms. Kinsinger and Ms. Torrez for a grant that is due a few months from now. She stated that the State believes this would be good timing while they are finalizing projects now. She noted that this would be a good collaborative opportunity that would provide federal resources to get the staffing needed to get the Sickle Cell Data efforts under way. She stated that Dr. Rashid, Dr. Alan, Dr. Kaida, and Joe Laskey at the Cure4Kids that have all agreed to collaboratively to define what will the data collection instrument look like for the State of Nevada. She noted that there are other things that she would like to see collected in addition to what the peer groups across the county are doing.

Vice-Chair Gina Glass asked the data collection that Councilmember Logan-Parker is speaking of, would this be something that relates to the sickle cell data registry that was created or is this separate from that.

Councilmember Logan-Parker commented that it is for sickle cell registry that was created because no one is submitting data at this time. She noted that she wants to make sure that there is a robust data collection instrument to ensure that once people start submitting data, it is very similar to what is happening in the cancer industry where there is a defined data collection system that everybody is using the same instrument and collecting the same data. She commented that it is in direct relation to the sickle cell data registry created.

Councilmember Dr. Rashid commented that she was sorry that she was late, and she missed most of what councilmember Logan-Parker had presented. She asked if they have already started the survey.

Councilmember Logan-Parker stated no, she only updated what was already known. She noted that the conversation is flowing, and that herself and councilmember Dr. Rashid had been invited to help develop that data collection instrument. She commented that there are funding issues that the state from a staffing perspective and other big projects to get over the finish line. She stated that her report was her feeling that everyone involved is headed in the right direction. She noted that she felt is going slower than what she had hoped. She commented that everyone involved is not standing still and there is progression.

Dr. Rashid commented that she contacted Julia Peek and the Centers for Disease Control and Prevention (CDC) for guidance on the surveillance of it. She stated that there is a grant opportunity through the CDC that will open next year in 2023 and she hoped that the State would apply to hire on staff for data collection.

Ashlyn Torrez commented that the State and herself are working on getting resources put together to apply for the grant that is due at the end of May of next year.

Chair Federizo asked Pierron E. Tackles if there was anything needed to be done to acknowledge that councilmember Dr. Rashid is present.

Pierron E. Tackles stated that the record will reflect that she had joined, the Council has met quorum to proceed with the voting items.

5) FOR POSSIBLE ACTION: Approval of minutes from June 30, 2022, Rare Disease Advisory Council Meeting. – *Council Members*

Chair Federizo opened the floor to discussion, comment, or changes. There were no objections.

Chair Amber Federizo motioned to approve the meeting minutes from prior council meeting dated June 20, 2022. Councilmember Annette Logan-Parker seconded the motion to approve. There were no objections. A quorum voted to approve the prior meeting minutes.

6) FOR POSSIBLE ACTION: Discussion and possible action to request the Director of the Nevada Department of Health & Human Services to appoint Christina Thielst as a council member representing a patient with rare disease replacing Brynlin Thornley's position. – *Council members*

Chair Federizo opened the floor for discussion or questions of adding Christina Thielst as a councilmember. She commented that if voted through it will go to the State for final approval and appointment. No objections heard.

Chair Amber Federizo motioned to approve the addition of Christina Thielst to the vacant position of the Council. Councilmember Shirley Folkins-Roberts seconded the motion to approve. There were no objections. A quorum voted to approve the addition of Christina Thielst to the Council.

7) INFORMATIONAL: Discussion of Nevada State Medicaid Rate Survey findings case report from Cure4Kids – *Annette Logan-Parker*

Chair Federizo commented that the Medicaid rate survey is a case report that will help the Council identify issues that the Council has seen when it comes to rare disease. The Council will include recommendations for improvement in the Council's report. She opened the floor to Councilmember Annette Logan-Parker.

Councilmember Annette Logan-Parker commented that every four years Medicaid sent out a survey that has all the different billing codes with a billing guide for the provider type 20. She noted that physicians and practitioners who provide care in an outpatient and inpatient setting. She stated that she has never participated in the survey and her team was not aware of the survey, and she reached out to 38 other medical professionals that are provider type 20 within the system. She noted that she felt that the letters sent out got lost in the shuffle of the support staff. She commented that the rates are reviewed every four years to determine appropriateness of the rates, and that majority of office do not understand their cost ratio per code. She stated that other provider type 20 listed healthcare professionals would not be able to figure this out without an intensive healthcare forensic accountant to come and do a cost analysis. She commented that majority of the healthcare professionals listed as provider type 20 felt it was to labor intensive and not worth the effort to participate in the provider type 20 survey. She noted that at Cure4Kids foundation, her team will hire the forensic healthcare accountant to go through the process, but she and her team were not able to meet the deadline to submit the survey, but she submitted her finding to Richard Whitley and Dr. Kapura at Medicaid. She stated that majority of the healthcare professionals that have the information and the authority to disclose that financial information is unaware of the opportunity to provide it, which is part of the problem. She noted that she felt that while the Council is asking members of the State to provide high quality information, but maybe the Council and her team at Cure4Kids are not communicating effectively or asking the right questions to the right individuals within an appropriate timeframe to be able to provide meaningful data. She commented that she is happy to have the opportunity to discuss the rate review with the Medicaid folks, but she felt it is ineffective information gathering process at the state level and she was hopeful that the Council can influence that. She stated that the healthcare professionals that are listed as provider type 20 felt that the fee for service Medicaid rates are inadequate and that oftentimes Medicaid do not cover their costs. She commented that the provider type 20 survey does not cover J codes, so for providers type 20 that are administered any type of medications, about 40% of those medications are reimbursed at less than acquisition cost by fee for service Medicaid. She noted that when this information was presented to Medicaid, they responded with they are not collecting data on J codes that goes through Optum. She felt that it potentially was one of the larger problems because it is one thing or the provider's time who is on your payroll to not be paid adequately but when they need to purchase a drug to give to a patient and the reimbursement is less than the acquisition cost, it puts the providers in a negative spot. She commented that it really is a challenge to get providers to want to become Medicaid fee for service providers.

Chair Federizo thanked councilmember Logan-Parker for her through discussion. She asked councilmember Dr. Rashid how the provider type 20 survey was for her and her experience with it.

Councilmember Dr. Rashid replied with she was unsure if she was aware of the survey, and she definitely did not do the survey.

Councilmember Logan-Parker commented that was the response given to her when she called other provider type 20 healthcare professionals. She commented that she is not sure how Medicaid gets any information from the provider type 20 listed because she felt that no one are taking the opportunity to submit it. She stated that Phillip Burrell mentioned that the participation rate in the survey is woefully low.

Councilmember Dr. Rashid asked about reimbursement for coverage for nurses and how would the nurses time be accounted for.

Councilmember Logan-Parker commented that the forensic accountant would come in and analyze the clinic. She noted that some of the providers do not have the resource or the desire to bring in a forensic accountant especially when the Provider Type 20 survey only wants to know what the clinic is, whether that is fee-for-service or Medicaid. She stated that this a challenge because providers do not collect their data in that format, and it is not a good way translate how the data is collected through our practice management systems and accounting system. She commented that the providers who provide care for rare diseases and oncology would skew the overall results of the data so drastically that they would be considered the outlier anyways, and that data would be excluded. She noted that she agreed with her team at Cure4Kids to hire on a forensic accountant to be prepared with the information and since Cure4Kids represents in number of volume of encounters, the largest provider of services for services for kids with rare disease, she felt responsible to solve that mystery on behalf of everyone that they are provide care.

Chair Federizo asked councilmember Logan-Parker if she knew the estimate of hiring on the forensic investigator will cost for her.

Councilmember Logan-Parker replied with an estimated $80,000.

Chair Federizo thanked councilmember Logan-Parker.

Councilmember Logan-Parker commented that at the Cure4Kids, the team are negotiating a full forensic audit that they are anticipating five staff members and at least six months to be able to do a thorough investigation and accurate analysis. She noted that since the Cure4Kids volume is so vast the forensic accountants are looking at 40,000 encounters over a three-year period. She stated that there have been 120 encounters that have an extensive line-item list in one visit to the Infusion Center, there would 16 different codes on that one claim. She commented that the forensic accountants will have thousands and thousands of transactions that would need to be audited.

Councilmember Jennifer Millet commented that it is disheartening of Medicaid State partners would want this data but make it is very cumbersome for many people and many organizations.

Chair Federizo agreed with Councilmember Millet. She commented that it is disheartening when Councilmember Logan-Parker mentioned the conversations that are occurring when it comes to the Medicaid J codes themselves. As Medicaid is moving from Optum, a Medicaid management service to Gainwell Technologies there will be another intermediate that was not there before. She stated that an institution given money by a third party would not know what was otherwise priced at, and it is giving over to Pharmacy Benefits Manager (PBM) third party to dictate across situations where they may be nationally organized, and some states might have far different resources and components to be able to come to this. She commented her concern that a provider cannot ask this particular acquisition is the way that it is in the absence of having to go through Gainwell and other pathways. She stated that she will be putting this in the Councils' recommendations report, and she will state that there needs to be clarity and transparency in terms of a provider asking a question there should be an answer or a circling back of the algorithm that was originally chosen. She commented that she is including this in the Councils' report because she felt that algorithms are derived for our state have aged out so badly that Medicaid has come to this avenue where reimbursement is still decent but does not adequately convey things for certain circumstances, and there has not been any real attempt to engage this out. She noted that the Council needs something else for rare diseases, and this is the first time in years that this is occurring for the Council, and conversations that individual Council members have had with Medicaid, but it is still frustrating. She commented that Medicaid is doing the best that they can, and she expressed her gratitude given the circumstances and the resources available to Medicaid. She stated that she became recently aware of a Spinal Muscular Atrophy (SMA) child, who unfortunately did not get identified early enough and will have irreversible damage because of Nevada Medicaid did not add that particular aspect of Phenylketourina (PKU). She noted that this situation is something that will never be good enough for her until the Council and Medicaid can prevent what is currently a preventable morbidity and mortality in children. She commented that where the var is set right now and what the Council is doing needs to be at a point where the Council and Medicaid can prevent what is actually preventable. Chair Federizo stated that the agenda item number nine Medicaid Rate for Provider Type 20 informational item will be combined with this agenda item. She mentioned that the Council knows the aspects of everything the Council has gone through with the Provide type 20 application and she came up with an analogy to summarize this. She noted that it like an independent provider trying to do taxes and in theory should be able to get on the free file system, put in their information and it should help them calculate the provider may or may not need at the end of the year. She stated that however in the circumstance the survey is so complicated that the provider would have needed to hire a certified public accountant (CPA) or an attorney to be able to navigate it and make sure that the end of year calculations are actually what you entered and then navigate through the pathway anticipated while completely disregarding the biggest cost of all, the pharmaceutical component. She stated that it is disheartening to her because the biggest cost aspects and the components the providers face from Medicaid or independent clinics actually ends up coming from lacking clarity and transparency to make as easy as it should be. Chair Federizo acknowledged Erin Lynch, who wanted to provide comment on what the Chair had previously said and let Erin Lynch know that she will call on her when agenda item

11 comes for public comment. Chair Federizo commented that she will be putting all that was previously mentioned in the Councils' recommendation. She noted that the provider type 20 survey should be more realistic and something that works for the providers that are type 20's. She commented that she the Council only came across this in last few four months when the survey only comes every four years, and there is no push to get the word out to providers to do the survey. She recommended that to address provider type 20s not receiving word about the survey is to send to the independent providers contact information from when the providers register, and not just the business office who receive a lot of emails already. She noted that form this moment now until the survey is available again in three years and some providers will need to do a three-year forensic analysis for their institutional loan such as Cure4Kids, and by that theory we will only just be ready to provide the data that the survey is asking for. She stated that this circumstance is passing people up almost intentionally and it is hard to have to wait and nothing happens where patients and providers are stuck with the same reimbursement rates that the State of Nevada has had for decades. Chair Federizo opened this discussion to members of the Council to provide any other additional experiences that can go into the Councils' letter of recommendation that the council will be reviewing in the next meeting.

Councilmember Annette Logan-Parker commented that she believed that Medicaid is doing a really good job of trying to find solutions for this. She stated that one of the obstacles that she sees when the Council reaches out to other states to get examples of what is happening in their environments, she not convinced that they are comparing apples to apples based on what other peer groups across the country. She noted that she only speaking about childhood cancer and that majority of the treatment provided for children with cancer is in an academic based environment where there is a free-standing children's hospital, and the facility is at risk for many things the nurses, pumps, pharmacist biohazard waste and all the things required to safety provide chemotherapy to children. She noted those hospitals get to enjoy different financial services incentives, 340B drug discounts, and a variety of different rebates, and the hospital has the benefit of purchasing supplies in bulk and getting different rates when doing so. She commented that when anyone looks at the cost for a leukemia patient from diagnosis to three and half years later, the total cost of care in Nevada versus how it is paid out of total cost in California or Arizona, the ratio would be different because the provide type 20s are only billing for the professional component and the facility is billing for other things. She commented that in Nevada it appears that the provider type 20 is so much more expensive than our peer groups across the country because the hospitals are at risk since they purchase the medical supplies and staff needed. She stated that this is an important part of when the hospitals and the Council look at what is appropriate reimbursement across the country. She noted that the hospitals and Council are not looking at the same institutions because all of the facility charges, outpatient facility charges in Southern Nevada are being filtered through a provider type 20 because the hospital is the only one providing the care. She commented that she spoke with her colleagues at Renown for pediatric oncology care, and they are making some of the changes on their end is going to look more like what the hospitals across the country are doing. She states that the hospitals at risk across the country are paying their physicians, medications, and drug waste that is associated. She felt that until that conversation that is open, transparent, and understanding of how things are done in Nevada versus how things are done in relation to childhood cancer in other cities, the hospitals in Nevada are never going to be comparing the same things as other states across the country. She noted that Anthem did an analysis comparing Las Vegas, Nevada to an organization that has a national footprint with all the retrospective data to be able to compare the particular type of treatment for a child from diagnosis to completion of treatment in terms of total cost of care, regardless of who or how the hospital paid for medical supplies and staff. She stated that Anthem found the total cost of care was either equal or less than the Cure4Kids in Southern Nevada than our peer groups across the country. She commented that the Cure4Kids foundation needed to identify another facility that had the data and understood the complexities because the facility themselves are billing and collecting for the same type of services out of state as a national player. She noted that the comparison that Anthem did with Southern Nevada and the other facility out of state validated what the Cure4Kids and Council already knew. She felt that the Council and Cure4Kids has gotten the right people to look at the data from a higher perspective, which leads to assumptions of how childhood cancer is treated. She stated that majority of healthcare providers assume that childhood cancer treatment is being done at Sunrise Hospital in Las Vegas, but it is not, it is done in an outpatient environment and that is one example. She commented that until the Council can everyone to come around a table and really talk about the realities of Southern Nevada about what is really happening, the state of Nevada will never get high quality data to make meaningful decisions on.

Chair Federizo agreed with Councilmember Logan-Parker. She stated that another issues that the state of Nevada faces when trying to do comparative analysis of other states is that even in similar populations, there should be some statistical outcome similarities. She commented that since Nevada statewide has many other elements that go into it. She mentioned an example of COVID deaths in Utah are half of what they were here in Nevada, despite the populations being the same. She noted that while many people are coming in and out of Nevada to visit, but that does not account for if the individual still had gotten sick in Nevada there was a higher likelihood of dying than if the individual had gotten sick in Utah. She stated that this example speaks to the fact that we have difficulties recruiting and retaining healthcare providers. She continued on with when the providers know people are sick, they can diagnose but the provider does not have the facilities and access to what the patient and provider need. She stated that is not that easy to get access to healthcare in Nevada and most would have to go out of state. She continued on to say that in a lot of other states the larger private equity firms have bought up a lot of the practices and there are not independent practices. She noted that in Nevada many of the hospitals have given up on revenue because they were losing ventures, and there used to be other groups in the past that did children's oncology, but it was decided to not something the hospital or group could continue to do because they were getting the same reimbursements from Medicaid and chose to completely shut down their oncology program. She noted that those with a passion for children oncology will continue to provide those services and be there, but the question remains for how long these hospitals can continue to provide that service realistically. She states that the Council needs to do something, and like she previously mentioned there is not a comparison to other states despite having similar populations. She continued to say that Nevada has a lot more individuals that are sick and less access to care than other states. She commented that the Council, State of Nevada partners, and stakeholders of all of Nevada need to come together to have a conversation. She expressed her frustration that individuals will say the issue is with one person or group, but it all of Nevada. She thanked the Council for sharing their thoughts and she will get everything into a comprehensive assessment of where the State of Nevada is where Nevada can be, and how to get Nevada where it needs to be. She noted that this process is going to take conversations with Medicaid and Gainwell. She expressed that Gainwell has been only working on the job for a couple of months as they have done in other states, and she anticipates not too many problems. She commented that once Gainwell is off the ground, they can start address issues specific to the state of Nevada. She was hopeful that with the Councils' report Gainwell can start looking at the Nevada specific issues. She noted that even in the absence of the survey, the changes can be made. She stated that the Council will continue to advocate for these meetings to have these conversations and this process is going to take time. She felt that Medicaid has never heard feedback regarding how convoluted the provider type 20 survey is on the provider side, and how realistically does not capture meaningful data of which to make meaningful action from. She assumed that many of the adverse outcomes the Council sees in state of Nevada are tied to the provider type 20 survey not adequately convey the composition of information that the providers need the survey to. She hoped that the Council can keep moving forward and maybe in time the provider type 20 survey can convey meaningful data. Chair Federizo opened the floor to the Council to speak. She heard none and moved to the next agenda item.

8) INFORMATIONAL: Introduction to ALS – *Dawn Newburg, Executive Director, ALS Association for Nevada Chapter*

Chair Federizo introduced Dawn Newburg with the ALS Association and opened the floor to Newburg.

Dawn Newburg expressed her gratitude for allowing her to speak to the Council. She commented that she has been with ALS Association for five months and she wanted to talk about ALS Association. She stated that she used to work at Capability Health for five years which used to be known as Easter Seals, and she worked in non-profit with Opportunity Village for eight years. She noted that ALS is commonly known as Lou Gehrig's disease, and it is a fatal neurodegenerative disease that affects individuals generally from age 40 to older. She noted that currently there are many patients in their 20s and 30s, and there is no known cause or cure for ALS, and once the individual is diagnosed with ALS the average lifespan is two to five years. She commented that ALS Association helps families and individuals that have received an ALS diagnosis with support groups, multidisciplinary clinics by bringing all of their disciplines together, and understanding where their journey is going to take them. She noted that the multidisciplinary clinics include PT, OT, speech therapy, respiratory therapy so the patient can see all their doctors and disciplines in all one spot to help the individual along their journey. She commented that ALS Association will help the families with their own support groups, and ALS Association has two nurses that conduct home visits to help with respite care. She stated that the ALS Association has a transportation program to help those ALS individuals that lost their mobility and their ability to walk, and or do not have a vehicle to get around. She added that not only does the transportation program that allows families to go not just for medical opportunities, but for vacation to Disneyland or any of those family outings. She commented that in the ALS support groups, there is discussion of the latest things happening in ALS research and other options that people may be interested in to provide hope for ALS individuals. She noted that the ALS Association has two clinics in south Nevada in Las Vegas, and one in north Nevada located in Reno. She commented that ALS Association has over 120 patients, and that is over hundreds served considering families of the patients, caregivers, and the patient themselves. She stated that ALS Association Nevada Chapter are the only non-profit organization that provides these services.

Chair Federizo thanked Dawn Newburg for her introduction of ALS. She asked if Newburg has seen any issues with coverage whether it is healthcare concerns, durable medical equipment (DME), or patients.

Dawn Newburg commented that she has a DME inventory as the ALS individuals receive their diagnosis as it is starts to progress, it happens very quickly. She noted that there is always a lag of approval for insurance coverage and a lot of things that needed are not covered by insurance which cost

$250,000 a year in out-of-pocket expenses. She stated the ALS Association wants to step in and provide some of those opportunities for their patients. She noted that there is a huge gap, and with respite care being huge, the ALS Association has a grant from the state that helps them respite for their families which plays a big factor in the reimbursement rate and being able to pay for that respite care.

Chair Federizo asked Newburg if she knows how long the prior approvals take for the ones that are successful.

Dawn Newburg commented that she is unsure and can find out and let the Council know. She noted that since the disease progresses so quickly, even if the insurance process takes six weeks, the patient might be beyond what they initially asked for at that six-week mark once it does get an approved, and then the patient is actually in a much further along phase of the disease, which is a really difficult piece of what their families face.

Chair Federizo commented that she has concerns with prior authorizations and even other specialties could take 45 days or more and then peer review which can be an additional two weeks on top of that. She stated that if ALS has the opportunity with ALS Association case managers could develop what they would like to see as the ‘pie in the sky ask’ for a patient with an ALS diagnosis, and the diagnosis code goes to the insurance for things needed that should not require prior authorization, especially if the insurance is going to approve it anyways. She noted that since this process is so delayed that by the time the patient gets what they need, they now need something else for DME. She added that she would like to include the ALS Association case managers what they would like to see as the ‘pie in the sky ask’ to put as the standard of care that is really needed for ALS patients. She commented that fixing the new standard of care will not be done tomorrow, but there is something being done. She felt that the payers at this point in Nevada have no idea what it takes because by the time patients and families go through this process, ALS Association are picking up the pieces and paying for everything for them that by the time the payer’s step in, the patient has passed.

Dawn Newburg agreed with Chair Federizo and let the Council know that ALS Association case managers will put together what they would like to see for the prior authorizations process.

Chair Federizo thanked Newburg and opened the floor to the Council for other questions.

Councilmember Shirley Folkins-Roberts thanked Dawn Newburg for the work she does and for her introduction.

Chair Federizo thanked Newburg again for her time and is looking forward to hearing from Newburg to include an ALS patient standard of care and rare disease for the State recommendation letter and the State can hopefully one day have that process in place where it needs to be.

Newburg thanked Chair Federizo.

9) <u>INFORMATIONAL:</u> Medicaid Rate Survey for Provider Type 20 – *Chair Amber Federizo*

Chair Federizo combined this agenda item with informational agenda item number seven.

10) INFORMATIONAL: Council member information sharing announcements – *Council members*

Chair Federizo wanted to update the Council on her reaching back out to Beth Slamowitz who works at the State of Nevada as the Pharmacy Policy Advisor. She noted that while the Council cannot advise or authorize any prior authorizations regarding rare disease medications, there may be a pathway that the Council can do that would be similar to how Medicaid presented their provider types that would be open to feedback. She added that some medications go through the silver drug exchange and there are no comments attached to them. She stated that RDAC website is up with all the councilmembers' bios, and she thanked the Council for sending it. She added that the registry is ready to have the invite sent out for the providers in the State to add to the provider registry. She noted that it has been some time since the Council approved the letter, but the letter is going out to Clark County Medical Society, the nurse practitioner groups, and state boards to add their provider names to monitor who is in the community as healthcare providers because the health insurance directories are out of date sometimes. She added that some practitioners that have passed on for several years but are listed on the directory as available practitioners.

Councilmember Shirley Folkins-Roberts asked if this letter would include northern Nevada.

Chair Federizo commented that yes, it is for both the north and south, and it will be a state medical board and will include licensing for all. She was hopeful that the providers will submit their information but that is always a challenge too. She noted that she may be able to reach out to some groups to push them into the putting their information on the letter to have an idea of who are providers are. She stated that the next meeting will try to let out the recommendations letter early enough prior to next meeting for the Council to add comments and suggestions to the recommendations letter which will still have items from last year that the Council does not have revenue to address or have taken some time. She added that she would like to update that items that were in last year's report and include the newer items. She opened the floor to the Council for any updates and information sharing announcements. There were no other updates, Chair Federizo moved on to public comment.

11) PUBLIC COMMENT

Chair Federizo opened the floor for public comment.

Erin Lynch apologized for joining the meeting late. She noted that Medicaid is here to provide any type of training or address any type of billing issues. She added that she would love to help any providers with the provider type 20 survey, and sometimes it an education issue. She suggested to the Council to take Medicaid up on their offer for any trainings to address the confusion or lack of education before it goes into a recommendation report. She added that Antonio Gudino-Vargas with the pharmacy unit was at the meeting to also address any education issues or any type of system issues that are happening the new pharmacy vendor, Magellan. She asked for confirmation if Magellan is the new pharmacy vendor.

Chair Federizo responded with a yes.

Lynch wanted to offer support and her help again to address the issues going on and help clear up anything so that the providers can be successful with Nevada Medicaid. She expressed her appreciation towards the Council for their positiveness about Nevada Medicaid and the differences between Nevada and other states. She added that especially with hospital-based programs and is totally different reimbursement model with other reimbursement opportunities within the hospital-based type of services such as supplemental payments. She commented that the provider survey if the providers and Council are having an issue, she can get the Council in touch with the right people like the Chief of Rates Unit, Kimberly Adams so that she can assist and receive feedback with the Provider Type (PT) 20 physicians.

Chair Federizo asked Erin Lynch to send the contact information for Kimberly Adams to State partners to send on to the Council.

Lynch replied with of course and asked if she can put it in the chat.

Chair Federizo replied with she believed so, then Ashlyn or one of the staff at the State can get it out to the Council. She asked if Lynch has had any experience with providers coming to her with issues to complete the PT20 survey.

The following was posted into the chat by Erin Lynch (Meeting timestamp 1:20:50):
"Kimberly Adams, Chief of Medicaid Rates Unit. k.adams@dhcfp.nv.gov; 775-684-3712"

Lynch commented that she is not the Chief of Rates Unit, but Kimberly Adams would have that information.

Chair Federizo asked if Lynch does the training for the PT20 survey or is it a separate department.

Lynch commented that it is a separate department, and she is the Chief over the Medical Programs Unit at Nevada Medicaid. She apologized that she did not fully introduce herself.

Chair Federizo thanked her and asked what Lynch covers specifically.

Lynch commented that as the Chief of the Medical Program Unit she covers primary healthcare up to specialty healthcare. She added including laboratory, radiology, hospitals, different types of clinics like federally qualified health centers, and Indian health clinics.

Chair Federizo asked if Lynch felt in general if a provider is having issues with prior authorizations in terms of medical care, she would have heard of the worst cases that would have ended up with her.

Lynch commented that those cases can, but it depends on what is happening there. She added that if there is a compliant or if the prior authorization goes to a hearing or brought to her attention then she gets involved to get that authorization approved. She noted that typically all of the prior authorizations on the fee for service side is handled with Gainwell technologies and they have their own requirements on how fast a prior authorization has to be reviewed and completed by. She added that earlier she thought she heard 45 days from Chair Federizo, and that is not possible.

Chair Federizo commented she understood that is not currently stated prior authorization that is listed in Gainwell. She added that with her experience as a clinician dealing with high-cost medications it becomes very problematic.

Lynch commented that might have to do with the pharmacy side, but she can always get the right people to the table to address an issue going on. She added it might be education that needs to go to the providers. She noted that she does not know the full issue at hand, but the right people can get involved to get it fixed.

Chair Federizo commented that the big issues in Nevada unfortunately when you have a peer-to-peer talking to a medical necessity, the peers are usually not in the same specialty. She expressed her frustration to have to teach a person who is going to giving the peer-to-peer approval when that person should not be giving that approval in the first place. She stated that if Lynch has the ability to have providers in the medical unit who are in the specialty that the medication is being asked for, then there would an immense improvement.

Councilmember Logan-Parker agreed. She commented that everybody follows the rules and understands that the rules are there for a reason. She added that the rules are written in a way that do not make sense. She stated that for example, a toddler receiving chemotherapy that is toxic to their kidneys and their UAs would need to be checked over and over to determine if the patient needs more migration or to lower the dose of chemo and spread the infusion longer. She added the rule book states that a one-year analysis, but to not destroy the child's kidney, the facility would need to do a ten. She noted that once the providers get the right people on the phone, they are defending the rule when the rule does not work. She commented that even with all the right people on the phone and understanding, the rules are the rules, and the patient is allowed to receive one year analysis during that time period, the facility is actively and voluntarily participating in malpractice, and the facility is not willing to do. She stated that the rulebook needs to be changed, otherwise everybody is forced to follow the rules that are no longer applicable for what the facility needs to do and then everybody's hands are tied at that intersection. She added another example where getting the right people involved with those high cost drugs, but when the reimbursement rate is A at the acquisition cost in Southern Nevada and based on the facilities ability to acquire the drug through group purchasing agreements, and B the reimbursement is less than the acquisition cost that the facility reaches the intersection and there is nothing anybody can do but care for the kids, and lose hundreds of thousands of dollars. She noted that she loved that Lynch is offering education and that many need that. She felt since she specializes in childhood cancer and that is what she is using for the examples previously provided, and what she stated may not apply to all provider types.

Lynch commented that it takes time to get the funding because Medicaid is a public assistance program and Nevada Medicaid relies on state funding. She stated that Antonio Gudino-Vargas is on the Council meeting, and he can speak to the pharmacy, since there is a pharmacy review drug board. She asked Gudino-Vargas to provide information about how the process works.

Antonio Gudino-Vargas introduced himself as the Manager for Pharmacy Services for Nevada Medicaid. He stated that in terms of the prior authorization process that has been mentioned, as far as physician administered drugs, which are drugs administered in house, there is not a prior authorization requirement for those drugs. He added that if providers are experiencing issue with the timeframes for the high-cost drugs that administered in house, Pharmacy Services would want to look into that.

Chair Federizo commented that the physician offices also dispense and this some of the issues the physicians are facing. She stated that this is point the Council is making and this does not relate to all physicians who administer in office, they also dispense. She noted that the rare diseases are unique and ask Gudino-Vargas to continue.

Councilmember Logan-Parker commented that there might not be a prior authorization required but when it comes time to pay the claim, there is some sort of nuance attached to why this drug will not be reimbursed at this particular rate and that particular scenario. She noted that the Cur4Kids Foundation and other facilities that treat rare disease do not fall victim to the no prior authorizations required anymore because these facilities have done that and in good faith provided the medication and then spent the next three to four years fighting Medicaid to get paid back for something. She added that the Rare Disease Advisory Council treats the one percent of the rarest diseases, so putting the issues faced into a bucket with provider type 20s, and the providers who need prior authorization is complicated and challenging. She noted that the rare disease experiences are very different and while it should be easy, it not what happens in the rare disease arena.

Chair Federizo expressed gratitude from a strictly fee for service presentation that was presented and is absolutely the truth for fee for service to get patients administered medications in the office and is easy, which should be done that way for rare disease. She noted that the reality is that not a lot of patients stay in fee for service, they move to MCO, and the MCO's will see those 45-day delays, thus making a patient on Medicaid is not necessarily a patient on Medicaid. She stated that she wanted to make that clarification, and asked Gudino-Vargas to continue.

Gudino-Vargas thanked the Council for the clarification, and he agrees that there might be a disconnect with the MCO. He commented that he only sees the fee for service side and only speak to that. He states that Nevada Medicaid can bring in the right people to have the discussion with MCOs to address the issues that the Council has been facing. He mentioned that the pricing of medications, Nevada Medicaid has very unique pricing for drugs that uses an algorithm that is available publicly and included in the State plan, and the Council can visit the Magellan portal where all information is contained. He added that any of the 340B drugs that is utilized or administered, there are a certain set of rules that all also included the Pharmacy Manual. He wanted to offer himself up if there is any time that providers are experiencing issues and he works closely with providers to try and resolve any of the claim's issues that Nevada Medicaid is experiencing. He added that with pharmacy there is the real time nature of the program so there is a higher urgency associated to resolve those claims. He asked the Council to please reach out to him for anything that may need to be resolved.

Chair Federizo thanked Gudino-Vargas and asked Erin Lynch and Antonio Gudino-Vargas to send their contact information to the Council because she felt that the Council would find it valuable if Nevada Medicaid could provide a presentation on the history of things, and how certain things came to be, it allows the Council to have a better understanding of how some of the decisions are made. She provided an example with the 99215 where there were improvements made. She stated that initially her thought was why were these decisions originally instituted. She wondered if Nevada was so high off the audit rails that providers were using it to fraudulently build to stay alive or what kind of initiated that pathway as to why Nevada Medicaid went about requiring prior authorizations for 99215 and no one was really able to tell me the history of why that was initiated. She stated that Nevada Medicaid said this was how this process this done, and this is the legalities, and it is legal to request prior authorization. She stated that she would have appreciated having an explanation rather than Nevada Medicaid can request prior authorization because it is legal. She noted that in terms of communication happening effectively there are still issues that the rare disease community sees when the patient becomes MCO. She added the rules change dramatically, and the patients should not be moved over to an MCO. She mentioned that she would like the Council to advocate for rare disease patients not moving over to MCO to immensely affect their outcomes from the start. She noted that the things would be so better for the rare disease community if they were on a fee for service. She asked Councilmember Dr. Rashid to speak on what she has faced in this regard.

The following what posted in the chat by Erin Lynch (timestamp 1:28:00):
“Erin Lynch, Chief of Medicaid Programs Unit. erin.lynch@dhcfp.nv.gov; 775-350-0786”

The following was posted in the chat by Antonio Gudino-Vargas (timestamp: 1:32:00):
“Antonio Gudino Vargas, Manager Pharmacy Services Unit – jgudino-vargas@dhcfp.nv.gov”

Councilmember Dr. Nik Abdul Rashid commented that patients on MCO Medicaid usually needs prior authorization for high-cost drugs, and these requirements have to be met and these requirements do not make sense. She spoke on sickle cell medication that was FDA approved in 2019 and the requirement to prove that the patient has failed several other drugs that, she as a physician felt that it would not be appropriate for those patients to be on for whatever reason. She noted that unless she can prove that those patients have been on it and failed, it is an automatic denial for this new medication that she wanted the patient to try. She stated that when she asked for a peer-to-peer, the pharmacist who goes by what is listed their policy without any further discussion because they do not understand the clinical aspect of the disease. She expressed her frustration lies with how they come up with this list of requirements, and when she looked closely at the requirements are based off the clinical trial that was run for that medication. She noted that during the clinical trials there is a lot of things excluded such as hydroxyurea or patient transfusion to ensure their medication is working. She added that she does not normally get issues with the prior authorization because usually it is not required. She commented that sometimes she would find that reimbursement does not cover the cost of the medication, and that can sometimes be restricted because her office would wait so long to get reimbursed. She noted that once the reimbursement does come, she would find out the reimbursement would not cover the cost and cannot offer the patient the medication anymore because her office would be losing thousands of dollars.

Chair Federizo asked Councilmember Dr. Rashid to correct her if she is wrong but if a child patient with a rare disease seen by Dr. Rashid would be on a great regiment, fee for service has gotten them where they need to be and on a successful path. She added that if this family were to get flipped to an MCO, their entire outcomes can change, and this child patient and family access would be removed from Dr. Rashid.

Councilmember Dr. Rashid stated that was correct.

Chair Federizo commented that a child who has been a provider since birth should not be removed from them as a provider if they would have otherwise been Medicaid eligible with the exception of the patient and family being flipped over to MCO. She noted that she would love to see a presentation from Antonio Gudino-Vargas and Erin Lynch and will place them on the agenda at the next meeting. She expressed that she would love have Lynch and Gudino-Vargas as an advocate to highlight the successes of Medicaid to the extent that she felt would see many positive outcomes will be achieved if we can keep rare disease patients under fee for services that would not increase in revenue. She expressed her appreciation to Lynch and Gudino-Vargas coming to meeting and participating in public comment. She felt that once the conversations get going there is a lot more the Council and Nevada Medicaid can do to improve. She opened the floor to everyone present at the meeting to provide comment. She heard none and moved to adjourn.

12) 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 10:26 am.