Nevada Department of Health and Human Services
DIVISION OF PUBLIC AND BEHAVIORAL HEALTH

NEVADA RARE DISEASE ADVISORY COUNCIL

MEETING MINUTES

November 6, 2020
9:00am

Meeting Locations:

- This meeting was held via teleconference only. Pursuant to Governor Sisolak's March 22, 2020, Declaration of Emergency Directive 006, the requirement contained in NRS 241.023(1)(b) that there be a physical location is suspended in order to mitigate the possible exposure or transmission of COVID-19 (Coronavirus). Accordingly, all members of the public participated by using one of the following:

Meeting number: 146 989 7455 Password: exYbm3XYw64

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Rex Gifford opened the meeting at 9:00 a.m.

1) Welcome and Opening Remarks – Dr. Ihsan Azzam, Chief Medical Officer

Good Morning Everybody and Welcome to our first meeting. We have great and diverse expertise in this council - and I am certain we will make the difference for Nevada. As you know; unfortunately, we are experiencing a significant increase in the number of cases, hospitalizations and death due to COVID-19. I must join a required urgent meeting at the Governor's office in few minutes. Sorry for that.

Thank you so much for giving me the opportunity to share with you some important opening remarks. For the record, Ihsan Azzam, Chief Medical Officer for the State of Nevada. Although everybody uses the term Rare Disease - I am not sure if that word "rare" is appropriate or even representative for such a large group of illnesses. Rare diseases, although individually - each single one of them - could be rare, and that could be of importance for healthcare providers; collectively they affect a significant proportion of the general population which is of great significance for both the public health and healthcare systems.

Medical publications and the Internet are packed with rather outdated, contradicting and inaccurate information and data; including the number of rare diseases and the estimated number of Americans who are living with them. That is not surprising as there is no clear current public health definition of what a rare disease is? And, how could such a large group of diseases be called rare; especially when more than 32 million Americans are already living with them. Seems that the cumulative prevalence of rare diseases in the population; their related morbidity; disability; hospitalization and mortality are way underestimated.

It's very concerning that rare diseases were once considered medical curiosities with little public health impact. The definition of rare diseases was not updated since the early 1980s, when they were defined as any condition that affects less than 1 in 200,000 people in the United States. Considering our current U.S. Population of more than 332 million, this corresponds to a prevalence of about 1 in 1,600 people. Although by the time when this definition was developed in 1983, the U.S. population was 235 million, which corresponds to a prevalence of about 1 in 1,200. Based on that antiquated definition; a disease that affects 1 in 1,200 people would have been considered rare in the early 1980s, but it would no longer be considered rare nowadays.

Currently, there is no consensus about an international uniform public health definition for the rare disease. And, with a frequently cited number between 5,000 to 8,000, almost 80% of those seem to have a genetic etiology. In fact, rare diseases are becoming increasingly more common, as more rare disorders are discovered;

- The U.S. Population and the world population are increasing over time;
- Medical diagnostic capabilities continue to improve.
- Additionally, better medical care for several rare diseases is leading to increased life expectancy and subsequently higher prevalence.

Although there is no consensus on the public health definition; total number of rare diseases, estimates of their genetic origin, and the cumulative prevalence, it is obvious that rare diseases represent a very serious medical, epidemiological, societal and financial burdens to individuals, families and the whole community. Despite these limitations, it seems that at least 32,000,000 American live with at least one of the 8,000 known rare diseases. This is similar or comparable to the proportion of those living with diabetes or asthma.

Remember that based on the current definition rare diseases are assumed to have extremely low prevalence, yet an estimated 32 million American living with them would certainly means that about 1 in ten Americans has a rare disease.

Again; rare diseases are increasingly common, and their heavy burden is manifest in their

- High morbidity and mortality rate,
- High Disability,
- Many years of life lost,
- High rate of hospitalization, frequent admission and readmission,
- And long-term care in skilled nursing settings.

Recent studies, show that the prevalence of rare diseases is increasing at an average rate of almost 20% a year. However, people living with rare diseases continue to face significant challenges, including diagnostic delays, lack of available treatment and difficulty in finding the right health service. Families feel isolated, under-supported, and often they face economic hardship. Of the 8,000 identified rare and neglected diseases - only about 500 have approved treatments.

Advances in diagnosis of rare diseases are gratifying. But, we can do better. Healthcare providers have a crucial role in early detecting rare diseases; making appropriate referrals, coordinating care, supporting families, and linking them with needed psychosocial and other supports.

A coordinated approach to rare diseases is extremely needed. I am confident that our council will raise valuable points of discussion among patients, families, healthcare providers, public health professionals, and with state and national leaders, and public, non-profit and private organizations dealing with rare diseases.

With this I am concluding my remarks and will be happy to answer your questions. Seeing that there are no questions. I will be disconnecting now. Thank you again and have a great and a very productive meeting.

2) Introductions and Roll call

COUNCIL MEMBERS PRESENT:
Ihsan Azzam, MD, PhD; Naja Bagner; Linetta Barnes, BSN, RN; Max Coppes, MD, PhD, MBA; Amber Federizo, DNP, APRN, FNP-BC; Shirley Folkins-Roberts; Gina Glass; Veneta Lepera, BSN, RN; Annette Logan-Parker; Jennifer Millet, MSN, RN; Kimberly Palma-Ortega; Valerie Porter, DNP, BSN, MBA; Nik F. Nik Abdul Rashid, MD; Larissa White, MPH, CPH.

COUNCIL MEMBERS ABSENT:
Brynlin Thornley

DIVISION OF PUBLIC & BEHAVIORAL HEALTH (DPBH) STAFF PRESENT:
Lindsey Kinsinger, Manager, Office of Public Health Investigations and Epidemiology (OPHIE); Rex Gifford, Administrative Assistant III (incorrectly identified as Joseph Filippi on the WebEx); Tara Van Orden, DPBH UNR MPH Student Intern.

OTHERS PRESENT:
Pierron Tackes, Deputy Attorney General; Linda Anderson; Paul Niedermeyer; Tracey Meeks; Jeanette Belz; unknown callers (3)

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.

3) Public Comment

Mr. Gifford discussed the process for the meeting and for electing a Chair, which will occur after the public comment period. Mr. Gifford then opened the floor to public comment.

- <u>Paul Niedermeyer – member of the public asked to make comment.</u>

Mr. Niedermeyer presented his background in marketing, private management and consulting, and product management. He further reported that his wife and he moved to Carson City in 2017 and he is licensed as an EMT in Nevada, is a volunteer with Carson City CERT and a volunteer with Northern Nevada Red Cross. His interest in rare diseases developed when he experienced them through close family members (a nephew and brother-in-law). He described the challenges his family members faced with the high price of medical bills, the difficulties in obtaining a diagnosis, and the resulting disabilities they experience.

Mr. Gifford recognized that Mr. Niedermeyer had reached his 3-minute limit, but did ask the floor if anyone would take issue with allowing Mr. Niedermeyer another 3-minutes. No opposition was heard, so Mr. Niedermeyer was allowed to continue.

Mr. Niedermeyer presented that he was here today to offer his experience and expertise to the RDAC, even though he does not qualify for any official council roles. He would like to request that the council considers building a rich taxonomy of current conditions. He reported that: Surprisingly there is no specialty recognized by the American Board of Medical specialties that focuses on rare diseases for physicians generally. So, if a patient is suffering from a rare disease they will go to their doctor and often get referred to a specialist without a diagnosis and then the specialist will render one, if they can. While there are rare disease advocacy groups that help identify and treat various types of rare disease, no taxonomy and no directory exists of medical personnel or diagnosticians, generally, that can offer these services within their field of expertise as a specialist in rare disease. So, finding a physician is akin to a treasure hunt. It requires time, patience, lots of money, and a bit of luck.

Mr. Niedermeyer then stated that he has lots of ideas and suggestions for the Council. The one he would like the Council to consider today and into the coming months and into the new year is to please consider a physician statement on building a rich taxonomy or directory of current physicians and other medical professionals in the state of Nevada that helps delineate their skills in diagnostic gifts. Perhaps in concert with UNR and UNLV medical school programs, they would be willing to help make this a reality. If this is done right, it could serve as a revenue source for the RDAC, help patients and caregivers more quickly find physicians they need for diagnosis and treatment as well as save many, many lives. Patients could go to a directory specific for Rare Disease or perhaps search the state medical board, board of osteopathy and other boards, to find a medical professional that could help them. Mr. Niedermeyer concluded that he appreciated the council's time and attention.

- <u>Naja Bagner – member of the Council, asked to make comment</u>

Ms. Bagner presented that she is a patient with Sickle Cell Disease (SCD) and she wanted to highlight some of the things that Mr. Niedermeyer mentioned. She reported that when dealing with SCD, patients do not have a "league of their own" as they generally have to go to cancer facilities to receive treatment. She thinks that it would be nice if there was a clinic specifically designed to treat those with SCD. For patients who need to see hematologists, they are mostly found within cancer treatment centers and SCD patients are surrounded by cancer patients where they can't relate to each other. Being able to be surrounded by others with SCD would be really helpful.

Ms. Bagner also brought up that she feels the mental illness part of the SCD is overlooked in their care and that many of those with SCD have mental illness but are not aware of it, or educated about it enough. She revealed she has been in Nevada for almost 7 years and that she moved here from OHIO for the warmer weather as her doctor explained that the cold weather affects the bones more. So, she has made the decision to up and move to Las Vegas to be able to live a healthier and fulfilled and more joyful, happier life. Ms. Bagner reported that she feels that it is a blessing for her to be on the advisory council and be able to help others with rare diseases. She likes to do patient advocating for those with SCD who might not be able to speak for themselves. They have someone to be able to help them get out what they might not be able to get out. She also mentioned that she has a small business where she creates bags to help patients during their SCD treatment at the clinic. She ended stating that she is here to be able to spread a lot of awareness on this issue and push for a lot of things that those with SCD are lacking in the health care industry.

Mr. Gifford thanked Ms. Bagner for her comments and reminded her that she had the right to vote on measures and bring up ideas for the council.

Mr. Bagner responded that she knew it was not going to take overnight, and that she knew it takes a village to get things done. But with persistence and staying active and aware of what is going on in the State of Nevada that we can get a lot done in this meeting.

Mr. Gifford thanked Ms. Bagner again and opened the floor for any other public comment.

- Veneta Lepera – member of the Council, asked to make comment

Ms. Lepera preseted that she is the Chair of the Palliative Care Council of Nevada. She thanked Ms. Bagner and Mr. Niedermeyer for joining the meeting and she highlighted that they both brought up a quality that she hopes we can incorporate into this council which is that in palliative care one of the big things we focus on is the emotional impact having a chronic disease has, not only on the individual experiencing it, but also on every single member of their family even extended family. It permeates that whole family unit and she thinks that that’s one of the things, being a palliative care expert, that is very frustrating in our traditional medical model where often we are so focused on the specific disease that we forget that there is a human being that is experiencing this. And so she wanted to mention to the council that as they develop references for the public to use to identify specialists that would benefit them, it would be important to network and have some social workers or psychologists or psychiatrists that would be willing to assist in developing programs. These programs could be similar to support groups where someone can air what is bothering them as sharing the suffering verbally with someone else can lessen that suffering.

Mr. Gifford thanked Ms. Lepera for her comments and opened the floor for other public comments.

- Linetta Barnes – member of the Council, asked to make public comment

Ms. Barnes presented that she is also part of the SCD community as a parent and in other roles as well and she wanted to add to the topic is that she is with a foundation called the Sickled Not Broken Foundation of Nevada. They focus a lot on the transition period of the teens and young adults to the adult health care side and with SCD, and all rare diseases with all people, you have to transition and that is a piece that we can incorporate into our work for our rare disease youth. Ms. Barnes stated that this population struggles when they first get into that area of health care, getting insurance, moving or going off to college and a lot times there is a loss of care during this period and higher rates of death. Ms. Barnes stated she wanted to hopefully make an impact on that population with this council.

Mr. Gifford thanked Ms. Barnes and opened the floor to other public comments.

- Kimberly Palma-Ortega – member of the Council, asked to make public comment

Ms. Palma-Ortega presented that she is a parent, her role on the Council, and that two of her children have extremely rare genetic syndromes. She reported that there are a few on this council that she is honored to work with that have been part of her children's care. She revealed that her daughter is one of 100 in the world, and her son one of 200. She is very proud to be a part of this and feels that everyone who has had a piece to say at this point really touched her life in some way. Between her two children, they have autism, IDD, blindness, childhood cancer, and other issues, so they are "dual", and don't fit in one bucket. It is often hard for them to find support. She highlighted that the family piece being talked about, with special needs and divorce (a whole other component and then the siblings shifted in between), all these things do not leave a lot of room for a parent to navigate all the services. Depending on what kind of provider you get, they are not all able to digest what is being brought to the table and it takes a long time to get services in place.

Ms. Palma-Ortega also discussed that challenges exist when physicians transfer and when there is not enough education for the extremely rare diagnoses. She stated that she is hopeful that a directory is possible and thought that this would give a "shout out" to providers that are able to help families get to where they need to be. In addition, Ms. Palma-Ortega emphasized that the transitional component is huge and that move from pediatric care to adult care is something everyone dreads and finds it painful to go through – especially when you have built a rapport with a provider. She stated that she was glad to see physicians on this panel that can help the Council create, maybe a Q & A to help those in the transition. She also pointed out that she sits on quite a few councils and boards and commissions throughout the state. From juvenile and foster care, and birth to death areas, she hopes that the Council can cross some bridges to other state identities that are currently in place. She ended with an appreciation to the rest of the Council and state she was looking forward to working with them.

Mr. Gifford thanked Ms. Palma-Ortega for her comments and opened the floor again to public comment.

- Naja Bagner – member of the Council, asked to make comment

Ms. Bagner stated that she wanted to make sure that she was keeping up to speed with everyone. She agreed with the other speakers because she feels a lot of physicians don't understand that these diseases take a toll on the whole family. She stated it was important to be able to recognize that it is not just the patient that is suffering, it is also the care givers that are suffering from the rare diseases that the patient has.

Mr. Gifford thanked Ms. Bagner for her comment and opened the floor for other public comment. Hearing no other comments, Mr. Gifford closed the public comment period and moved on to the next agenda item.

4) For Possible Action, Elect Chair

Mr. Gifford opened the floor for the Council members to discuss electing a Chair for the RDAC.

Council member Palma-Ortega asked that since the bylaws do not state whether the Chair needed to be a public identity or a parent or self-advocate, does that mean it is open for anybody? For example, on another council that I am on, it has to be a parent or a self-advocate that is the chair or co-chair, so she just wasn't entirely sure.

Mr. Gifford answered that from his understanding, anyone on the council can be the chair and everyone is eligible so anyone can nominate someone or volunteer themselves and then at that point a vote would be held to see who would be elected to be the council chair. The Chair would then lead the meetings and lead the council from that point on and it would actually be the chair's job to guide the meeting which is what he was doing. Mr. Gifford then asked if anyone would like to volunteer to be the chair or nominate someone to be chair?

Council member Folkins-Roberts asked whether the RDAC was staff supported and is the chair going to be leading primarily? She presented that she is ED of the Children's Cancer Foundation and already has a lot to do so she was looking for an idea of the workload. She mentioned that she was willing to be Vice-Chair but if no one wants to be Chair, she would consider it but does want to know what the workload looks like.

Mr. Gifford responded that as this is the first meeting of the RDAC, he could not honestly say what the workload would be. From his experience with the Board of Health, the workload can vary, but he believes the bylaws do outline what the RDAC would be doing.

Council member Palma-Ortega stated that she would agree to be the Vice Chair, if someone would agree to be the Chair.

Council member Federizo stated that she would agree to be the Chair and Ms. Palma-Ortega agreed that would work if the committee agreed.

Ms. Van Orden then advised that according to the statute, only a Chair needs to be elected, but then if other positions are wanted the Council could decide and vote on that later.

Council member Folkins-Roberts then stated that she understood that and would bow down to Amber as the Chair

Council member Coppes stated that he likes both Amber and Shirley a lot, but would have trouble with two people who work specifically with pediatric hematology and oncology. He presented that he thinks it is critically important to realize that rare diseases go beyond childhood cancer and sickle cell disorders. He repeated that he is saying this again with the utmost respect for both Shirley and Amber, but worries about the signal it would send by having both Shirley and Amber as leaders for the Council.

Council member Rashid offered her support for Amber Federizo as the Chair and clarified that she does not work with mainly pediatrics, but is actually a provider for adults with bleeding disorders.

Council member Coppes reiterated his concern that there are so many other genetic disorders and while he is a pediatric hematologist/oncologist, he worries about other disorders. He felt that the Council needs to make sure that the public feels everybody is involved and having two people in one field may be perceived wrong. Dr. Coppes further presented that the fact that there are four Council members in the hematology/oncology field already sends a challenging message. Dr. Coppes wondered where were the geneticist, the cystic fibrosis person, someone in mental health, and a representative for adult rare diseases? He cautioned being careful to be all-inclusive moving forward. He also stated that he was not able to be Chair, due to time constraints.

Council member Millet asked who was in the adult field? She stated that she was the director over med/surg at University Medical Center. Her scope includes oncology, palliative care, behavioral health, and general med/surg. She also deals with surgical issues like transplants and flaps. She reported that her plate is pretty full, and asked who else is in other fields.

Council member Lepera mentioned that as the Chair of the Palliative Care Council, there was a lot of work the first year to get things off the ground, like the website. So, though she understood Dr. Coppes's comments, she things the Council needs someone with the passion and the bandwidth of hours to put into the first year. She noted that it is labor intensive to get a council up off the ground and really get it going and the functional parts moving.

Ms. Van Orden mentioned that there is staff support from the division – not significant support, and there is also funding available (discussed later) – but there is staff support from the division.

Council member Millet then noted that there is the opportunity, as noted in the bylaws, for other positions to be added as needed, by majority vote of the council. So as Veneta mentioned it is a lot of work, she doesn't have enough time to devote to it, but can the Council could do two chairs and a vice-chair. She then asked if the Council could add people to that mix?

Ms. Van Orden answered that after the Chair is chosen, and the council gets under way, additional positions, according to the bylaws as Jennifer noted, can be added as needed.

Council member Federizo presented that though she does work in family hematology and bleeding disorders, she also works closely with NAPNA, so she has been at all the testimony and meetings for the healthcare committees. She plans on continuing this for the 2021 session. She stated that she does not see herself as only hematology.

Council member Millet then moved that Amber Federizo be voted to Chair. This was seconded by Council members Lepera and Rashid, with other members vocalizing that they were in favor. However, an official vote was not called yet.

Ms. Van Orden asked Mr. Gifford to call for an official vote. Mr. Gifford stated he would but wanted to get the poll onto the WebEx presentation. During this time, as the technical challenges were being worked on, the Council decided to take a 5- minute break.

During the break, Linda Anderson, previously of the Attorney General's office, advised Mr. Gifford to take a verbal vote. Pierron Tackes, Deputy Attorney General (DAG) agreed and advised Mr. Gifford to go through the roll call so that everyone has a chance to vote. Mr. Gifford questioned whether he should have a list on the WebEx screen to indicate each vote. DAG Tackes indicated that this was an option, but that each member still has to give a verbal vote in order to meet open meeting law requirements and to get on the record.

After the Council returned from the 5-minute recess, DAG Tackes recapped that this occurred in order for the DPBH staff to work on some technical issues. DAG Tackes then reminded that prior to the recess, the group made a motion to vote on the chair and a second and that a vote was needed on that motion.

Council member Annette Logan-Parker then presented that she would like to throw her hat into the ring for Chair. She stated that she does agree with Council member Coppes and that it is very challenging as the Council would not want the public perception that it only focuses on pediatrics. She also mentioned that she does work in pediatrics, although she represents more of a multi-specialty with rare diseases. She works with genetic disorders, liposomal disorders, as well as bleeding and clotting and childhood cancer. She stated that she really wants this council to be successful and does know that public perception is an important part of that. She stated that she would co-chair or be a Vice Chair, but also volunteers to be a chair.

Mr. Gifford then clarified that both Amber Federizo and Annette Logan-Parker have indicated they would like to be Chair. He asked if there was any other person interested.

Council member Palma-Ortega then suggested that an option would be to have a professional as chair and have a parent or self-advocate be a co-chair to assist with some of the duties and getting support. She noted that if that was not going to work, maybe a subcommittee is an option.

Mr. Gifford thanked Council member Palma-Ortega. He then presented that for now, the Council needs to vote for the Chair and then it can pursue other positions. He directed that after a Chair is chosen, then the Council would move on to the next agenda item. He again asked if anyone else, other than Amber Federizo and Annette Logan-Parker was interested in being chair. Mr. Gifford then indicated that he would gather the votes for the Chair.

DAG Tackes then briefly discussed the "Robert's Rules of Orders" for meetings and that there is usually discussion on an item and then when discussion is completed, there is a motion to vote, a second and then a vote. She then recapped that prior to the recess, there was a motion to make Amber Federizo the chair, there was a second and then there was a break to work on some technical issues. When the Council returned, there was more discussion but that motion was never voted on. DAG Tackes stated that was acceptable but suggested that the board discuss the options and then have someone on the board move for a vote. Typically, it would not be a "who would you vote for" situation, but there would be discussion, then someone would make a motion for a single person, then a vote would be counted and if didn't pass, then the process would happen again.

Mr. Gifford thanked DAG Tackes and was grateful for the advice so that the Council can make sure to follow the rules. He then asked if it was correct for the council to discuss for which of the two candidates they would make a motion. DAG Tackes concurred and stated that this is the cleanest way to do it for the record. The members can discuss who they want to be chair and a motion can be made.

Council member Dr. Coppes then stated that he would make a motion to consider more than one candidate because he likes the idea of having a choice instead of having to say Yay or Nay for one person. He did not think Robert's rules prevented him from doing this and wondered if this was correct?

Mr. Gifford yielded the question to DAG Tackes who stated that as long as there is a motion that is phrased that way and a second, then that is ok. She also clarified that there is nothing in the NRS that states that these meetings have to follow Robert's Rules of Order, but these meetings need to be clear and transparent for the public. Creating a clear record is important. So if the Council would like to proceed on a motion that is formatted like that, that's fine. It just needs to be stated clearly for the record so everyone knows what the vote is being taken on.

Council member Coppes then moved to consider more than one candidate for the chair position as the Council votes for that position.

DAG Tackes then asked for clarification on that motion. She stated that as she understood the discussion, two people have expressed interest in being chair and that Council member Coppes would like to take a vote on these two people. DAG Tackes then asked if that is the motion that is being made, for Council member Coppes to restate his motion saying "I move to take a vote between the two candidates (and state their names) to elect as chair."

Council member Coppes responded that he was happy to make that adjustment though he just wanted to make a motion to make that possible so that if there is a third person he would not have to make a new motion. He just wanted to move that the Council could vote on more than one person. If that passes and there are no other candidates, he would be happy to move for a vote between the two individuals. He wanted to make sure the Council can consider more than one individual. He then stated that he was going to keep his original motion.

Council member Veneta Lepera then stated she want to add in a motion that the candidates each take 1 minute and explain to the council members why they want to be chair and what goals they would want to achieve. Then she would make a motion that the Council decide on voting for multiple candidates.

Council member Coppes then requested that he believes his motion must be addressed prior to Council member Lepera's, and that if nobody seconded his motion, it's gone, and then she can come up with a different motion.

Council member Millet seconded Dr. Coppes's motion

Council member Millet then pointed out that a second motion was on the table from Veneta, and asks for a second. Council member Larissa White seconded that motion. Ms. Millet then asked Rex to call each candidate to give a one-minute introduction.

Council member Coppes then interjected that the Council must vote on the motion he made first and Mr. Gifford agreed. A vote was then taken on Council member Coppes's motion.

Council member Coppes made a motion to consider more than one candidate for the chair position as the Council votes for that position. This motion was seconded by Council member Millet. A verbal vote was taken and the motion passed unanimously.

Mr. Gifford then requested a vote for the motion made by Council member Lepera.

Council member Lepera made a motion that the candidates each take 1 minute and explain to the other council members why they want to be chair and what goals they would want to achieve. Council member White seconded that motion. A verbal vote was taken and the motion passed unanimously.

Mr. Gifford then presented that there are two candidates for chair, Amber Federizo and Annette Logan-Parker. Each was offered one minute to discuss their goals for Chair.

Council member Federizo presented the following:

> My name is Amber Federizo and I am a family practice nurse practitioner who is dual certified in hemostasis and family practice. I was born in rural Nevada and I currently still take care of patients across the state. My goals are to bring everyone together and not just the voices here from the urban areas, but also folks from our Indian tribes in those rural areas who also suffer with rare diseases, and to bring the entirety of the state progressing forward. Making meaningful gains towards addressing rare disease issues is not just for Las Vegas and Reno, but for all the rural areas and other cities and towns in the state. I would like to see a collaboration such as going to a comprehensive cancer center for sickle cell, so if we could collaborate and do rounds where hematologists do other rounds at other facilities and partner with the facilities to have specific goals with specific clinics. Either that could work through telehealth or for us physically going – I am very open to that. I would like to see a coordinated Nevada with Coordinated care with everyone participating and collaborating together.

Mr. Gifford then gave the next candidate the floor.

Council member Logan-Parker presented the following:

> Thank you, I am Annette Logan-Parker and I represent a multi-disciplinary program. I am the co-founder and CEO of Cure 4 the Kids foundation, and like Amber I also agree that statewide collaboration is very important. I really am focusing on making sure that children who have rare diseases have access to medical care that includes research and the socioeconomic requirements that are needed to take care of children in those situations. I myself am a parent who had a child who had a catastrophic medical situation. Research ultimately saved his life and that really helped me see the underbelly of what does not happen for children in the state of Nevada and so I would like to improve access overall. I think to multi-specialty, I think we need to bring in genetic specialists and a variety of different things to the state. I am also a trustee to Roseman University of Health Sciences where we are working aggressively to impact the curriculum for graduating health care providers educated in our state to include curriculum and

clinical rotations that relate to rare and ultra-rare diseases for children. And that is what I am about. Thank you.

Mr. Gifford then asked DAG Tackes for advise on the voting process for these two candidates. DAG responded that there still needs to be a motion to vote if there is no further discussion. Mr. Gifford then asked the Council if they needed any more discussion.

Council member Coppes then stated that he would like to make a motion.

Council member Coppes made a motion that the Council votes for either Amber Federizo or Annette Logan-Parker to be Chair. Council member Valerie Porter seconded that motion. A verbal vote was taken from each council member.

During the vote, there was further discussion as some members opted to abstain from voting.

Council member Bagner asked if the members had a right to not vote?

DAG Tackes responded that a member can always abstain to vote. She added that as a matter of public policy it is encouraged to have every member vote on matters brought before the board as that is the purpose of being appointed to a public body. Still, she reiterated that there is always the option to abstain from a vote

Council member then added that he thought that for some individuals living in Vegas, there is a conflict because both of these two candidates have a professional or patient relationship with them. He then stated that he understood the dilemma that some of the members have and he thought that given that circumstance the Council needs to accept that some members feel uncomfortable and would prefer to abstain.

Council member Bagner then voiced concern that she was worried that if some of the Council is choosing not to vote, then the Council team is not on all one accord. Further, she added that she really feels that all of the Council needs to take a chance to vote on someone because the Council needs to move as a group when it comes to being on the Council

Council member Barnes explained that the reason she was abstaining is that she has a personal connection to both candidates and she thinks that it would be fair for her to not take a part in the voting. Just for this situation. Not on everything, but on this particular voting process.

Mr. Gifford thanked Council member Barnes for her clarification and stated that since she does have a right to abstain, he will put an “A” next to her name. He then stated that if there is a tie-breaker, then it will be brought back to the council. Mr. Gifford then continued to take the vote for Chair.

Since you do have a right to abstain, I will put an A next to your name. If we have a tie breaker we will have to bring that back to the council. Do we have any other discussion on that?

Council member Coppes made a motion that the Council votes for either Amber Federizo or Annette Logan-Parker to be Chair. Council member Valerie Porter seconded that motion. A verbal vote was taken from each council member. The final vote tally indicated six (6) votes for Amber Federizo and (4) votes for Annette Logan-Parker.

Mr. Gifford then read the results indicating that Amber Federizo was elected Chair. He then asked DAG Tackes for clarification on that. DAG Tackes agreed that this was the case and that Amber Federizo was elected Chair. Mr. Gifford then moved to the next item on the agenda, item #5. DAG Tackes then interjected that she needed to take corrective action on the election of the Chair. Because there were not 8 votes to elect Amber Federizo to Chair, a new vote will need to be taken to confirm that she is elected chair and that will have to pass by a majority vote, which is 8 votes. Mr. Gifford then confirmed that 8 votes were need to confirm Amber as chair.

DAG Tackes then restated, for the record, what happened on this agenda item:

> Let me just restate what had happened on the last agenda item: First there was discussion and multiple motions and votes on that. Initially there was a motion to allow for a vote for two candidates at one time. That motion passed. Then there was a motion to allow each candidate to speak for one minute. That motion passed. Then there was a vote taken where there was a tally vote taken for both candidates. The result of that tally vote was that Amber Federizo had 6 votes and Annette had 4. So, at this time, someone would need to make a motion to confirm her as Chair.

Mr. Gifford then asked the Council to make a motion to vote for the Chair

Council member Coppes made a motion that Amber Federizo be appointed as Chair of the Council. Council member Folkins-Roberts seconded that motion. A verbal vote was taken and the motion passed unanimously. Amber Federizo is the Chair of the RDAC.

5) For Information Only - Overview of Senate Bill 315 and Bill Deliverables (Duties of the Council) – Tara Van Orden, DPBH student intern

Ms. Tara Van Orden asked Mr. Gifford to share his screen for the power point presentation that was posted for the public and the Council (included as Appendix "A"). She then thanked everyone on the Council for sticking with the Division and the Council these past few months that they've been trying to get this council together. She stated that she further appreciated all the email responses and everyone's patience. She then stated that she is going to read through a Power Point presentation on some background on rare diseases and an overview of the Rare Disease Advisory Council and their mandated deliverables.

Ms. Van Orden proceeded to share the Power Point slides with little deviation from the slides. After the presentation was complete, Ms. Van Orden added that the Council does have some funding available from the sale of the Cure Childhood Cancer license plates and that the amount collected so far was not known, but the information will be obtained for the council. Ms. Van Orden then asked if there were any questions.

Council member Bagner asked since the license plate was focused on childhood cancer, if there was funding for two license plates instead of one, in order to capture SCD.

Ms. Van Orden responded that the license plate was approved through statute and so it is not about funding, it has to be approved through the legislature and this license plate was the only one that was approved through the legislature.

Council member Bagner thanked Ms. Van Orden for the clarification.

Chair Federizo then added that another license plate would be something the Council can consider moving forward. If there are legislative changes, and bills do go through significant changes sometimes, so if it is feasible to add that as a suggestion for the future, that could happen.

Council member Bagner thanked Chair Federizo for that additional information.

Ms. Van Orden thanked Chair Federizo for the information and Council member Bagner for the question. She asked if there were any other questions and hearing none, asked Mr. Gifford to move to the next agenda item.

6) For Possible Action: Review Draft Bylaws, Amend, and Approve – Council Members

Mr. Gifford presented the next item on the agenda which is a review of the bylaws to amend and approve. The bylaws were posted for the public and the Council and are Appendix "B". Mr. Gifford invited the council members to discuss the bylaws and also posted them on the WebEx screen for viewing.

Council member Veneta Lepera started the conversation by making a motion to discuss Article 4.2 in the bylaws. The draft bylaws present that the Council must decide on whether the term of the members are either two years or three years.

Council member Jennifer Millet seconded the motion.

Council member Valerie Porter interjected this with a question about the bylaws. She asked if the 2 years or 3 years would be from when they were initially appointed, since they are starting so late in the year, or is that going to move forward to our first meeting?

Mr. Gifford deferred to DAG Tackes for this answer. DAG Tackes responded that typically the way a term will work is that it is from the appointment date. The Council has all been appointed and are currently serving their terms. These bylaws will establish what those terms will run for and that will go from the date of the appointment.

Council member Porter thanked DAG Tackes for the clarification.

Council member Millet reminded the Council that there was a vote on the table that she had seconded.

Before the vote could begin, Council member Lepera clarified that her motion was to take a vote on 2 years or 3 years, but she meant to motion that the Council vote for a 3-year term only.

Council member Lepera made a motion that the term for members will be 3-years. Council member Porter seconded this clarified motion. A verbal vote was taken and the motion passed unanimously.

The bylaws will be updated to reflect this change.

Mr. Gifford again opened the floor to the members to discuss any other changes to the draft bylaws.

Council member Porter started a discussion about adding a Vice Chair to the Council, as noted in section 6.2 in the draft bylaws.

Chair Federizo seconded that motion but was reminded by DAG Tackes that discussion of the bylaws does not necessitate a motion. Only when action is taken is a motion needed. The Council can freely discuss anything on the bylaws and only needs to take a vote if action is wanted.

Mr. Gifford and DAG Tackes then encouraged further discussion on the bylaws.

Council member Lepera presented her opinion that this is a very valuable council and she feels the duties are burdensome enough to warrant having a second person to help the chair and would support the need for a Vice Chair.

Council member Porter agreed and would also support a vice chair

Council member White then asked for a motion to approve a Vice Chair for the RDAC and this was seconded by Council member Glass.

DAG Tackes then had to interrupt to make sure that all these motions are clear for the record. She clarified that currently the agenda item that is being discussed is amending and approving the bylaws. So, the bylaws as drafted allows for the creation of a vice chair if the body so chooses. So, the next agenda item would be to elect any officers, so if the bylaws are approved, the body could elect a Vice Chair at the next agenda item, but if you'd like the bylaws to be changed so that there MUST be a Vice Chair elected then that would be appropriate to do at this time. So as drafted, it is not mandatory for a Vice Chair to be elected so if you want to change that in the bylaws the Council can do that under this agenda item.

Council member Porter then made a motion that the bylaws make it mandatory for a Vice Chair

Council member Lepera seconded the motion

Mr. Gifford then asked the DAG to clarify that this is to change the verbage in the bylaws to state in section 6.4.2 that the Council must have a Vice Chair.

DAG Tackes proposed that the change be made in section 6.1.2 which reads that the Council may include a vice, secretary or treasurer. If the Council would like it to be mandatory, she would recommend it be put into section 6.1.1 which reads that the Chair and Vice Chair shall be elected at the first meeting.

Council member Folkins-Roberts asked if it wouldn't be more efficient to discuss all the changes and then vote to approve the bylaws with the various amendments?

DAG Tackes responded that that would be great. The Council can discuss all the changes at once and then make a motion to approve the bylaws as amended. This is encouraged. What has been proposed is a vice chair, and the Council can continue to discuss this and other items and then move to approve the bylaws with the changes.

Council member Millet asked a question regarding section 9.1. She asked that since this is a huge undertaking, is every 3 months going to be enough time?

Council member Lepera responded that in her my experience, the Palliative Care Council has down that they meet a minimum of twice a year, but the first year, they really focused on developing things and they met monthly. So, she believes that if the Council elects a minimum number, they can always have more meetings, it is just in the bylaws as a minimum.

Council member Millet reported that she now understood.

Council member Palma-Ortega responded that in her past, another council she is on sits 23 people and she knows that there were meeting classified as face-to-face meetings but then there were also subcommittee meetings that would meet more regularly. She believes that the Council will need to be broken down in subcommittees that will need to meet more regularly.

Council member Lepera added that this would be at the leisure of the Chair and the Vice Chair, so does the Council want to meet as a whole 4 times a year, or more or less?

Council member Porter added that she thinks whoever initially said that the Council was required to meet 4 times per year, that if they wanted to meet more often, then they could if they wanted, but she thinks that the Council is required as a council to meet a minimum.

Ms. Van Orden clarified that the NRS does read that the council must meet “at least every 3 months” so every 3 months is the minimum but “may meet more often as needed” so the minimum is quarterly, every 3 months. The Council can still meet as often as they need to and that is what is in the bylaws.

Council member Coppes added that given how difficult it was to get a meeting, he suggested the Council meet quarterly and get those dates in as soon as possible for 2021. Then if needed, there are two options which are to meet more often or have subcommittees that meet and prepare items for the quarterlies. So that would give the Council more versatility. He then proposed that the Council agree on quarterly, and that means that we can do it more often and that we can use other means to get work done.

Council members Lepera and Millet agreed with Council member Coppes

Council member Lepera then made a motion for the Council to approve the bylaws as written with the modifications of the 3-year terms. Dr. Rashid reminded her of the change to a required Vice Chair which Council member Lepera did add to her motion. Council member Coppes seconded that motion. A verbal vote was taken and the motion passed unanimously.

*Prior to the vote, Mr. Gifford did clarify with Council member Lepera that her motion was to approve the bylaws as written with the amendments of 3 year terms and a required Vice Chair and this was seconded by Council member Coppes. Council member Lepera verbally agreed that this was correct.

Mr. Gifford then moved to the next agenda item.

7) For Possible Action: Election of Additional Members, if any (per NRS 439.5075)

Mr. Gifford presented the next agenda item which is election of additional members and discussed that this would be for the Vice Chair. He then yielded the floor to the Council for discussion.

Council member Lepera asked to make a motion to consider Annette Logan-Parker for Vice Chair

Mr. Gifford asked if anyone else would like to be considered for Vice Chair?

Council member Glass responded that she would like to be considered.

Mr. Gifford then asked the DAG for guidance on the voting for this and DAG Tackes responded that there is typically discussion on a topic. She reminded that there has been one motion already on the floor, but there has not been a second, so it sounds like that motion has fallen off. The council can continue to discuss electing a Vice Chair. Mr. Gifford then asked if the Council would have to pass a vote in order to give each candidate some time to speak. DAG Tackes responded that the action item before the Council is electing other officers so the discussion is on electing a Vice Chair and the Council can proceed how they choose. They do not have to vote to have the one-minute discussion. The Council was then directed to proceed.

Council member White then stated that she would like to hear from both Vice Chairs on why they would want to fill the position and what their background is – just one minute each.

Council member Millet concurred with this.

Council member Logan-Parker then responded that she did not think the Council needed to do this. From her perspective she believes it is important to have balance on the Council and since there is already a professional healthcare provider as Chair, she would make the recommendation that a parent or patient-advocate be in the Vice Chair role. She would therefore like to decline the nomination for Vice Chair, though she stressed that she would help in whatever way she could. For the legitimacy of the Council and for the work that is hoped to get done, she thinks that balancing the council at that juncture is very important. She again declined the nomination.

Council member Coppes responded that he so much liked what she was saying and for stepping down. He applauded her or doing that.

Council member White agreed with Council members Logan-Parker and Palma-Ortega as well, who has been addressing this and it would benefit the council to have a patient, self-advocate or patient advocate as a leader. So she agreed with that assessment.

DAG Tackes then apologized for the interruptions but advised the Council to avoid using the chat feature on the WebEx, except for mentioning technical difficulties, as those comments are still subject to the open meeting law. Keep all comments on the audio so that the public is able to capture all of the comments.

Mr. Gifford then asked if Gina Glass was the only member up for Vice Chair and if the Council wanted to discuss this any further.

Council member Glass then responded that she would be happy to share a little bit about herself if the council would like.

Council member Porter stated that she would like that.

Council member Glass presented the following:

> I'm Gina Glass and I am the founder and Executive Director of Dreamsickle Kids Foundation, which is the first sickle cell organization here in Nevada. I am also a parent with a child with SCD. Our organization has worked the past two years to spread awareness about SCD and we have had great progress in the SCD arena with a bill passing, and now we have a comprehensive SCD clinic here in Nevada. Earlier this year we expanded our focus to include all rare diseases in Nevada, because there is not much representation for the rest of the rare diseases. With Sickle Cell being rare, it seemed natural that we support those patients, and parents, and siblings affected by any rare disease in Nevada. I am also a community health worker in the state of Nevada and I have training in SCD community health work as well. We often collaborate with other organizations here in Nevada when it comes to SC awareness. My child has been and still is a patient with Cure 4 the Kids foundation and I believe that awareness for SC and rare diseases needs to increase here in Nevada and we need to have medical professionals experienced and willing to treat those with rare diseases here in the state.

Mr. Gifford thanked Council member Glass and then asked if the Council wished to make a motion or discuss the position of Vice Chair further.

Council member Palma-Ortega asked if Council member Glass was representing herself as a parent-advocate. Council member Glass answered that yes, she is a parent-advocate and that is her primary role.

Council member Lepera added that after hearing her background, she liked the idea of having Council member Glass be the Vice Chair.

Council member Logan-Parker remarked that it was just a little challenging when we don't know one another to make these votes. She knows both Amber and Gina and for those who don't know them, they will work very well together to lead this Council and Gina has been very active in a lot of ways to help those with rare diseases, as has Amber. For those who don't have the luxury of knowing them, she just wanted to really vouch for Gina and that she will do a good job, a great job and this is why she declined the nomination. She just wanted to put that out there for those that don't have the benefit of knowing them

Ms. Tara Van Orden added that she had hoped to have bios for everyone to share and had sent out emails, but did not hear back from everyone yet. She hopes to have this completed by the next meeting.

Council member Rashid then made a motion for the Council to vote Gina Glass in as Vice Chair for the Rare Disease Advisory Council. Council member White seconded that motion. A verbal vote was taken and the motion passed unanimously. Gina Glass is the Vice Chair.

8) For Possible Action: Required Rare Disease Report: Select focus of required annual report. Possible focus areas: Sickle Cell Disease, Childhood Cancer or other topic – Council Members

Mr. Gifford introduced item #8 – Required rare disease report and topics. This is for the Council to discuss.

Council member White presented that, as brought up earlier in the meeting by Dr. Coppes, that although pediatric cancers and sickle cell are just as important as any other rare diseases, the Council should discuss other possible conditions that would be covered in this report. She stated that she would add conditions that are screened for during newborn screening to the report. The majority of those are rare and considering the fact that there is also data on those disorders as far as testing and screening is concerned, it would not be difficult to obtain that information for the purposes of reporting. She then asked what the other members think about adding these conditions to pediatric cancers and sickle cell for the purposes of the report?

Council member Palma-Ortega agreed stating that that would be huge. There are some people that she knows that would be very helpful in pulling research and if the Council wouldn't mind adding a genetic component and even an undiagnosed component because there is whole group of people who are undiagnosed in this state.

Council member Rashid offered that is would be easy to get the newborn screening results as she is the hemoglobulinemia consultant for the program and a report for new diagnoses is done every quarter. She further mentioned the data is based on the newborn screening, and every patient that was not diagnosed in Nevada through newborn screening would not show up there. She then asked if anyone has ideas on how to get that information?

Council member White reported that she knew data could be obtained from claims and in-hospital billing data.

Ms. Van Orden presented that one of the issues in Nevada is getting the data for rare diseases. One related bill that was passed last year was AB254 that created a SCD registry. That is in progress but is still not projected to begin until next year. Further, there are some data acquisition problems here in Nevada. Ms. White likely knows more about this, but the data is difficult and one of the reasons this Council exists is to think about different ways to find this data.

Council member White then presented that one of the ways the Council can consider obtaining that information is talking to Healthy NV and asking if they would be open to having these institutions who represent those with rare disorders to access to their data repository for free. Then that way their patients are uploading to that system and the Council can get a better idea from some of these smaller practices who are otherwise not able to afford the access to Healthy NV and everyone kind of has access across the board. Ms. White thinks that could really improve the coordination and communication. One of the ways the Council could do that is to begin conversations with Healthy NV about that possibility.

Council member Millet added that obviously, there is a problem of gathering data and there is not one repository for the data to go to. She related this as being similar to that found in the psychology world because there is not one place to find data and "psych" patients come and go to different places without their records. So, a provider may not know if they have been in a hospital recently or what medications they are on, or taking, and the provider must call around to find these answers. Being able to go to a data repository would make this easier. Ms. Millet then asked if it would be within this group's functions to possibly make a repository with the state of Nevada to collect that data or have those different areas dump that data?

Council member Palma-Ortega then added to that question by asking if the Council was able to build a collaboration with NORD and NIH, since the State does have smaller groups of rare disease that are not necessarily known. NORD and NIH might be able to give us data on these individuals, who might live in Nevada – they even go international. The Council can see what our state has and collaborate with them and maybe open some doors that will result in creating something that maybe is not already established. This council can take that lead. Ms. Palma-Ortega then asked if anybody knew if other states have something like this now?

Vice Chair Glass responded that there are 10 states with an advisory council, but her organization is a member of NORD and a couple of other rare disease organizations. She added that she will do whatever she can to leverage that for the council.

Council member Lepera presented that part the Council's role is to make recommendations for further legislation. She thinks, referring back to one of the previous comments about having some type of depository or statewide record keeping for patients that are known to have these rare diseases, that this might be something that this council could consider as a recommendation to our legislatures – to fund the money and the people to develop that.

Council member Millet thanked Council member Lepera for that.

Council member Palma-Ortega then asked if out of those 10 states, do any of them have a data repository like what this council is talking about, that anyone knows of?

Ms. Van Orden answered that there is no comprehensive registry or data repository for rare diseases as a whole. She presented that the challenges to that are because there are so many diseases and no specific ICD10 codes, so there is no way to have a registry without definitions. One of the mandates for this council is to develop a rare disease registry, but again, without clear definitions or ways to track that, it is not feasible at this time. Still, as things are progressing, there is hope for the future and it is something to keep track of moving forward. Right now though the Council might want to sort of select something that narrows the focus for the first annual report, which could just be where they are at currently. This is just to give a little bit of guidance of where this report might go for the first one and then figure out where to go from there.

Mr. Gifford then questioned Ms. Van Orden asking if she was suggesting that the Council focus on where they are at for this annual report or go with the suggestions on the newborn screening disorders or statewide repository idea?

Ms. Van Orden answered that they are all great ideas and a good focus for the first report. She then deferred to Chair Federizo to add anything else

Chair Federizo presented that she would recommend using Healthy NV because all of the hospitals are using it. There needs to be a discussion with them. She further added that she would caution cautious against starting completely from scratch is because these repositories cost quite a bit to get going. Healthy NV would probably be the most neutral third party avenue to start putting data in, but what she would suggest is that the members of this council start making a report of what they have in their own institutions of diagnoses that they would like to see moving forward. Then the Council could pick three of those, and she would very much hesitate making those only hematology. This council should come together and decide which diagnoses we would like to see on that report. The first one could be, like Ms. Van Orden said, where the Council is starting from. For her part, she relayed that it would be easy for her to put together a report on bleeding disorders because this is already done on a state and national level. Still, she could not say what the status is for other diseases. She then asked the council members to send to the other council members what their available data is and have that data broken down by numbers. Then all members could take a look at the top 3 to 5 conditions to focus for now and then expand over the years. She also stated that she would hesitant to put everything in the report the first year because it could be overwhelming to track. She then asked for thoughts from the rest of the members.

Council member Logan-Parker agreed with Chair Federizo that “this elephant one bite at a time is probably the best way to go about this.” She presented that there are quite a few different registries that could be blended together, like the genetic patients, the oncology patients, and the SCD patients. Her foundation is in the process of creating their own special registry and would be happy to share any data with the group, but she thinks that Chair Federizo is very wise in her recommendation to say let’s pick the top 3, if that is too small the top 5, and then go from there. Working out the kinks in a statewide registry will take some time. Finally, she added that taking on all those diseases when they are not really defined as a state yet could be a challenge.

Council member White then stated that she was getting a little confused because the action item #8 is specifically talking about the report, so while a registry is a big picture goal for the Council down the line, the annual report is the priority. She then asked if the Council thinks it should only focus on the top 3 or 5 ideas, or should it be an overview or essentially a report on prevalence of conditions in our state that the Council has data access to. The report could also contain recommendations or barriers to obtaining the data.

Chair Federizo responded that it would encapture all of that and that it would end up being a more lengthy report, but it would outline some of the barriers that may not be able to be overcome. Still, she added, the report is important for the legislature because it is documentation of the things that the State needs to move forward. She added that it would be important to include all of the elements in that report.

Council member Palma-Ortega then offered that the Council could digest this a little differently, like split up newborns, adolescents, and adults. Then the diseases could be categorized differently to get a statewide view. She asked if that was an approach that could be taken that still leaves it open enough to add other components and more specifics later on?

Council member Lepera responded that she thought this was a really good idea, because it may be found that there are things more specific in the newborn range as opposed to childhood as opposed to adolescents so that might be a good way to delineate.

Council member Palma-Ortega then added that she offered this because with her other work, the way things are categorized means that a bridge is not included, especially with the transitioning ages. When each piece is then highlighted, the transition piece is missed. Including this would highlight multiple areas of interest within the state, the community, and hopefully nationally.

Chair Federizo responded that she agreed and so the focus of the report could be age cohorts rather than specific disease states. Within each age cohort there will be different needs so that report will be focused on those different age groups and the findings within those different ages

Council member Lepera responded in agreement.

Council member Palma-Ortega added that the only reason she was presenting this is because she has done a lot of legislative work and thinks that that will help the Council. This will be especially helpful it can be narrowed down. Then when it is presented for legislation, the areas that are not broken down can show the need for these areas.

Council member White added that if the Council does utilize utilize hospital patient billing and Medicaid claims data, age groups are something that could be easily produced for the report.

Mr. Gifford then asked if there was any more discussion on this issue. He reminded that this was an actionable item if the Council would like to vote on it.

Chair Federizo then responded that additional discussion was needed to define the age groups. Options given were by decades, or do 0-10, or go shorter with 0-5 or 0-1, or newborns alone, or decades, etc. She asked what the other members were thinking?

Council member Lepera add that though she is not a childhood expert, she would think that looking at psychosocial needs, when you take the 0-24 month group, that is a very different bracket than when you get to the 3- 10-year-old group. She would then propose that the groups are broken down to 0-18 months, that would make it newborn specific. Then 19 months -10 years old. And then 10 to adulthood.

Council member Palma-Ortega added that the only difference she would say was that the groups should match something already in place, which might make it easier. If there is 0-3, which is early intervention and pre-k which is 3-5, the groups could be narrowed down to match what is already pre-established and if it is narrowed down smaller than that the data may not match. There is a lot of data for the group birth to 3 that might be available able to pull from. It would be good to look at how the State works and then narrow down the groups and area breakdowns to match.

Council member Lepera agreed and asked to be educated about how the data is already broken down into groups.

Council member White supported Council member Palma-Ortega's comments and stated that for the state, the data procured for these conditions is broken down into 0-3 for the first group, then possibly 4-8 or teens sometimes, and it could be as broad as 19-21 to account for those transitionary years, and then 22 and over. However, generally after age 4, the break-down of those age groups can be modified, if needed. Definitely 0-3 when it comes to the initial age group to consider.

Council member Lepera asked whether Council member White was talking about young children, and then moving into childhood and then teenage years to 20 and then seems like early adult and then break it down to middle adult hood and then geriatric patients? Or just say 22 and up as adult?

Council member Palma-Ortega added that with pediatric care, and when you transition from pediatric to adult, most specialties say it is 21 by the absolute most. Some will be sooner, like 19, but usually 21 is the cutoff. And then with IDEA, with education, the education component is 22. So it is between 19-22 depending on the specialty.

Council member Lepera responded that she would like to a delineation for a 13-18 year old age group. She understands the transition period is important but in her experience she often sees adolescents grouped in with the 7-11 year olds and they are really at very different places mentally. The hard teen years should have some focus especially when dealing with psychosocial support and coping mechanisms.

Council member Coppes agreed with this and added that the definition of children depends on who you ask. Some of it is semantics, but looking at it practically, treating 0-12 the same way and then 12-25 should be treated in the same way and then probably over 25. Dr. Coppes then presented that while the transition is important and a 20 year old is considered an adult, he recognized at age 40 that he was not really as mature at age 20. For those with chronic disorders, they may be even more dependent than they want to be. He suggested that there would be 3 groups: the real kids, the real adults, and the rest is in between and the in between can be closer to adults or closer to children. That is how he thinks about treating and supporting these kids, adults, and families.

Chair Federizo then recommended that the Council come together with this data over the next months, and in those intervening months, collecting that data and coming to a consensus as a group as to what those age cohorts would look like in that manner. She stated that there is no need to try to force any kind of decision on reporting today.

Council member Lepera agreed with this and stated that she would like to see this council move forward with focusing on adolescents. Her argument for keeping the 13-18 group and a separate 19-25 group is that, agreeing with Dr. Coppes, she sees that those under 25 are still children, in some respects but that being said, under 18 is where parents are still responsible for their child. She sees a lot of runaways, and a lot of drug abuse – even in the home with parents. This is also seen with 20 and 21 year olds, but then it can be complicated legally as these age groups have their own right to choose.

Council member Palma-Ortega continue the conversation added that once a person turns 18, there are two platforms for how care is given in this transition period. These are guardianships and supportive decision making, which is a fairly new process. She revealed that recently she had challenges with ensuring her older daughter went through with a procedure for a life-threatening issue. Because she does not have guardianship of her daughter, the hospital was not comfortable allowing her to sign the paperwork and push for the surgery when her daughter decided at the last minute to refuse. The lack of understanding of the platforms by the hospitals resulted in hindering this needed care. Ms. Palma-Ortega then presented that the Council should also consider and understand these two legal avenues and the basis of the law of supportive decision making and how this can be filtrated to providers and the rare disease community. This would highlight something that might be hindering care.

Council member Lepera added that that may actually be a good segway for this council to encourage parents and young adults to do advance directives and do POLST because these things would help in situations like what Ms. Palma-Ortega experienced with her young adult.

Council member Palma-Ortega added that providers are not always aware of that information and neither are hospitals, so even though the legislation was passed to give individuals their right to choose, there are other avenues that are not readily apparent that do hinder quality of care. She was thankful that her daughter did the care needed but there are so many other issues. This is especially true if the person has an undiagnosed or extremely rare disorder where no one knows what they are dealing with. A quality of care is missing and this might be a component to add, especially for the transition piece that this council hopes to capture.

Chair Federizo then decided that she would like to hold any vote for this today and gather the diagnoses from everyone to discuss at the next meeting. Then the Council can collectively decide on a definitive answer for what the report will focus on. Council member Lepera agreed and there was no opposition.

Mr. Gifford then clarified that the Council was not going to take action on this item today. Chair Federizo concurred stating that she didn’t want to prematurely narrow at this point in terms of elements of the report. The Council has agreed that to do a report that is age-focused, but to not define those other areas until a consensus from the group is obtained on the diagnoses and age ranges. This will best be served if everybody has an opportunity to think about it not just from today. Mr. Gifford confirmed this with DAG Tackes, who also concurred and this item was closed.

9) Set priorities for next meeting/Recommendations for future agenda items/Accountability assignments – Council Members

Mr. Gifford opened the floor to the Council for item #9.

Chair Federizo announced that the first priority to set for the next meeting is to have a summary from each council member regarding the diagnoses they are interested in focusing on as well as their recommended age definitions so that the Council will have everyone’s input by the next meeting and a definitive decision can be made on those items.

Council member Logan-Parker then asked what the Council would think about putting together a Survey Monkey for the Council so that the information that you just requested about what everyone is working on and what their thoughts are, can be gathered. This could also ask how the Council would like to spend their time and what they want to focus on. She offered to help with that.

At this time DAG Tackes interjected in order to clarify something. She educated that this is a public body and subject to the provisions of the open meeting law. The provisions of the open meeting law are that the Council cannot have a quorum outside of a properly posted meeting. All discussions about anything that this body has authority over that has a quorum of people (so that would be 8 or more people) has to be done at a properly noticed and agendized meeting. Any communications outside of a meeting can’t exceed 8 individuals. Therefore, any sort of survey between the meetings would be a violation of the open meeting law.

Council member Barnes then asked if the Council can do something to let the community know that the Council is meeting so that they can be involved if they choose to? She stated that she believes there are a lot of families as well as providers in the community who feel they are passionate about rare diseases and will be very interested to hear about this platform.

Chair Federizo add that because it is an open meeting, all members are able to share the information through their different organizations, and those people are able to come and comment at the beginning and the end so that they can provide their thoughts on anything they want to change and provide public comment on anything that is summarized from the meeting before. She then asked the DAG to confirm that.

DAG Tackes stated that was correct and pointed out that it states on the agenda that it is posted on multiple different websites, which is a requirement of open meeting law. So before the meeting, the agenda, and the supporting materials, and the minutes from the previous meeting are posted at the websites listed and anybody is welcome to share that information with anyone they would like.

Chair Federizo then asked the DAG to clarify that if a request for information is made then council members can provide a priority list and what they have accessible to them (whether that is registry information or networking) and that would still be allowable as long as the members are not making a motion on that until the next meeting?

DAG Tackes stated that this was not correct as any outside deliberation is considered a violation of the open meeting law. What the Council could do, and what it sounds like this discussion is going, is to have everyone do their homework over the interim and if they wanted to prepare something to submit to the next meeting, they could submit those as supporting materials to be added to the agenda, so long as that item is on the agenda.

Chair Federizo thanked DAG Tackes for the clarification. She then added that those requested elements would then become that supporting documentation that is received prior to the next meeting for consideration. So each member of the council would send that in prior to the next meeting for consideration.

Council member Lepera then added that is what she has members do in the Palliative Care council, where she is the Chair. She has them send her their ideas and their summaries and their thoughts and then she summarizes those and presents those during the open meeting and then the discussion can be had. She added that one of the other things to do, once things get going, is to ask the Chair to consider using some of the funds that are available. This would be helpful in order to advertise a website or resources for parents, etc.. That is something the Palliative Care Council did where they had some things printed up and distributed within hospitals and clinics and various different places. That might be an agenda item in the future – on how to get the word out there.

Chair Federizo stated that she would like to add an overview of the financial position of the Council to the next Agenda. She does not think the Council is aware of the amount available to do these types of things and if they know, they can allocate it as they see things evolve over time. From this aspect, she agreed setting our priorities for the next meeting would be to accumulate the data and the age groups to move forward for the report.

Council member Lepera also asked Chair Federizo to email the larger group so that everyone has the contact information for the Chair and Vice Chair and can correspond with them. She then asked if the Council was free to discuss and send information back and forth with the Chair one – to one?

DAG Tackes responded that one off conversations are ok, but warned that serial communications may be a violation. What that means is that two people are talking and then that email chain gets forwarded to a third person and then a fourth and a fifth and then in this case, 8, but in the event that an email chain did include 8 people, even if it is a forwarded chain, that would be a violation. Council member Lepera is correct but the DAG would advise advise people to keep conversations one-to-one and not to relay conversations had with other additional members. The Council is always able to reach out to DAG Tackes if they have any questions about that or are worried about something they are about to do might be an open meeting law violation. Just to make sure that everyone is following the rules.

Council member Barnes then commented that she thought someone earlier said the Council might have to meet more often than the 3months? She asked if there was agreement that 3 months is enough in the beginning.

Council member Millet replied that the bylaws state that the Council has to meet at least 4 times per year, but has the authority to meet more than that.

Chair Federizo stated that it does sound that some of the elements of what they wanted to do outside of a formal meeting are not possible, so the Council would likely have to meet monthly, maybe for the first 3 months, and then go quarterly.

Ms. Van Orden added that to Council member Lepera's question earlier, if no one is opposed, she will send the Chair a directory of everyone's contact information, and she can disseminate to the rest of the Council.

Council member Lepera commented that the tricky part of the open meeting laws and being the Chair, is that all members get to bombard the Chair and they get to put it together. She added that she used to call a meeting every month and wouldn't always have a quorum, which just meant that there is not going to be a vote on anything but if it is announced in advance that there is an open meeting, even though there may not be a quorum, members can still discuss things that help move items along for the quorum next time.

Mr. Gifford stated that item #10 is to propose meeting dates for 2020, 2021, so the Council can delve into discussion about that during this item.

Chair Federizo then stated that sounds good and she thinks the members should move to get those dates. She add that she really appreciate all of that information from everyone. She stated that the next meeting would be December and asked the Council if there were dates from anyone that would be an absolute "no go", except of course, Christmas and New Year's?

Mr. Gifford asked if the Council would like to close item #9 before discussing the dates and asked if the Council wanted to make any motions before moving to item #10.\

Council member Rashid stated that she thinks the priority for the next meeting is to present our thoughts on the age group for the annual report, the different age groups and the diagnoses for each council member who is interested to make their case. She then asked if she needed to make a motion.

Mr. Gifford and DAG Tackes stated that a motion was needed.

Council member Rashid made a motion that for the next agenda, the Council will discuss the age groups and the different diagnoses. Chair Federizo seconded the motion. A verbal vote was taken and the motion passed unanimously.

10) For Possible Action: Propose meeting dates for 2020/2021, and Approve – Council Members

Mr. Gifford then opened the floor to the Council for item #10.

Council member Coppes started by stating that he would love to have the meetings be time-limited. He stated that it was very difficult for him to work from 9 until adjournment as he has many other responsibilities. In order for him to be able to manage his schedule, he would like to move that the meetings be time-limited, with a specific start and specific end time. He added that obviously, if done early, then it could stop early, but the meeting could not go over time.

Mr. Gifford then asked Dr. Coppes to clarify that he would like to propose this for the next meeting so the Council can vote on it.

Dr. Coppes responded that they probably needed to check with the legal counsel but he would like make sure that the next meeting is from a certain time to a certain time. He does not want to have the discussion at the next meeting, he does not want to have the next meeting that is until adjournment.

DAG Tackes replied that she did not have an actual answer to that right now, and that she will have to look into it. She noted that typically public meetings run until adjournment and she did not know of any that have set start and end times. That is something she can look into in the interim. If the meeting is to go over time that a public body can no longer have a quorum for, it can get adjourned and pushed to the next meeting time. The DAG apologized for not having the answer off the cuff as to whether or not a meeting can have a set end time, but agenda management will be something that is important for keeping these meeting times down, which can be difficult with a new body. She will look into that and will advise the Chair of prior to the next meeting. If setting an end time would be permissible.

Council member Coppes then explained that his dilemma was that he had his next meeting at 12 and he did not want to be impolite and leave, but knew up front that his next meeting was at 12. He wanted to make sure that he could be a valuable and active member and does not want to be the only one that continuously has to leave early. If that is the case then he noted that he may not be able to be a member of this council. He also stated that he was eally torn between wanting to contribute and being the party that has to continuously manage their time.

Council member Lepera added that as the Chair of the Palliative Chair Council of Nevada, she had this same debate and discussed with their counsel, and the Chair of the council has the authority and liberty to set a start and end time. So that is what she did for that council because she has a lot of physicians on that council. She set an hour and a half time and then moved through those agenda items really quick and then adjourn at that time. If they have not gotten through anything then she would summarize it at the end and then those items would carry over to the next meeting.

Mr. Gifford then asked the DAG if Council member Coppes could make a motion on that today or would she like to research that and push this on to the next meeting.

DAG Tackes responded that she would prefer if she could do just a little more research just so they are not doing something that would later not be permissible. She did offer that this is not to say that the Chair could propose that it is a limited time and then have a definite answer by the next meeting. She stated that it sounds like the answer is likely and that it sounds like this has already gone before the DAGs but just not her. She did not know if a vote would be appropriate right now, but did state that ultimately, it is up to the Council, though she would like the time to be sure. She stated again that the Chair can commit to making a limit. She will make sure to have the answer to that by the next meeting.

Chair Federizo replied that she was agreeable to that and definitely thinks they can limit it between 9 and 11 on the next proposed date in December.

Council member Palma-Ortega then added that on the other council she is on there are 23 people, so usually for the quarterly, or the face-to-face meeting, they have the parties available between 9-4, to be able to digest and work through everything because there is a lot of discussion. Then as long as there was a quorum, if an individual needed to step away, that was fine. If this council gets to the point of doing subcommittees, those are usually smaller, and take about 2 hours or less, depending. She also stated that typically the other council does leave that 9-4 window open for discussion and most often they are done about 1 o'clock depending on the agenda.

Chair Federizo then stated that she thinks, for predictability, if there is going to be a meeting that seems like it will be a little bit longer, she can at least afford the council that notification in advance, as opposed to today which went over more than people had anticipated. She stated that at least they could have that notification for the next meeting. She also would still propose from 9-11 for the December meeting.

Mr. Gifford then asked if the Council wanted to recommend dates and then make a motion on the dates and times or make motions separately?

Council member Palma-Ortega suggested that it might be beneficial to pick one week out of the month so as to narrow down a consistent day/time which would help people plan.

Chair Federizo agreed and suggested they choose the first Friday of the month which would make December 4th the next date. She asked if any member had any conflicts with that.

Council member Lepera stated that the only problem would be that the next meeting would be January 1 (New Year's Day) and asked if the members wanted to have a little bit longer gap between this one and the next one and move it to the 11th, or between the next one and the next one and move that?

Council member Millet responded that she liked December 11th. It works better for her and she likes Fridays.

Chair Federizo restated that it would then be the 2nd Friday of the month and then it would continue from there to January 8th. The next meeting would then be December 11th.

Council members Porter, White, Rashid, Palma-Ortega, Logan-Parker, Barnes, and Lepera all agreed that this would work for them.

Chair Federizo then asked if any member had conflicts with January 8th and none of the members did. Then the Chair mentioned that at the January 8th meeting, they can discuss whether to continue monthly or quarterly.

Mr. Gifford then asked if someone would like to make a motion on these dates so that a voted could be taken and the dates nailed down.

DAG Tackes mentioned that even though Council member Coppes had to leave a meeting, a quorum was still present and the Council can continue with the vote.

Council member Porter made a motion that for the next two dates for the RDAC meetings will be December 11 and January 8. Council member Rashid seconded the motion. A verbal vote was taken and the motion passed unanimously.

Mr. Gifford then pointed out that the proposal of 9-11 was not made, and asked if anyone wante to make a motion for that?

Chair Federizo made a motion that for the next two meetings December 11 and January 8, the time will be set for 9 am to 11 am. Council member Porter seconded the motion. A verbal vote was taken and the motion passed unanimously.

Mr. Gifford then confirmed that the next two meetings will be December 11 from 9-11 and January 8 from 9-11.

11) PUBLIC COMMENT

Mr. Gifford presented item #11 as the public comment period. He reminded that each speaker will have 3 minutes and then opened the floor for comments.

Council member Veneta Lepera made public comment

I just want to really quick congratulate Amber and Gina. I wish them the best.

Council member Larissa White made public comment

I second that.

Paul Niedermeyer – member of the public asked to make comment:

I have two questions for the Council:

1. Will there be an opportunity or process in the future for guest participants like myself to become council members?
2. What action is required for this item to be taken up as an agenda item for the next meeting? The value that I could bring to council would be related to rare disease

research, project management, and assistance with completion of action items assigned and approved by the council.

Chair Federizo responded that she believes that that can be added as an agenda item at the next meeting as the bylaws allows for a vote on addition of any council members. That can be added to the next meeting agenda for consideration and vote.

Mr. Niedermeyer thanked the Chair.

Mr. Gifford then posed the question to the DAG asking if the Chair's response was correct.

DAG Tackes responded that it was correct. And that no action was being taken by the council right now. Public comment was made and a suggestion that something be added to agenda was made for consideration by the Chair so that can be added to agenda. It is not something the council will be voting on at this moment.

Pierron Tackes, Deputy Attorney General made public comment:

I just wanted to quickly introduce myself. I am the Deputy Attorney General, one of the DAGs assigned to DPBH. I am here to assist you guys. I thank you for your patience, the many times you had questions, and when I jumped in to make corrections. But I am here to make sure your meetings run smoothly and compliant with the open meeting laws and the ethics in government provisions. I am not going to go into detail about those 2 laws but I do want to notify you all that you are all subject to those laws, so take a look at those before the next meeting and make sure you understand them and let me know if you have any questions. The AG's website has a ton of resources about the open meeting laws, so take a look at those and if you are interested I can always present something at a future meeting. But always feel free to reach out to me if you have any questions. Thanks.

Mr. Gifford thanked DAG Tackes for helping and assisting with the meeting, especially since this was the first meeting he hosted.

Council member Valerie Porter made public comment:

I just want to say congratulations to everyone and I am looking forward to working with everyone.

Hearing no other comments, Mr. Gifford closed the public comment period and moved onto item #12.

12) Adjournment – Chair

Mr. Gifford then moved on to item #12. That will be the Chair to lead the Council out.

Chair Federizo presented that the next meeting will be on December 11 from 9-11. The priorities are set for everyone to send in for the next agenda. She concluded stating that seeing how no one has any additional comment, the meeting was adjourned.

Mr. Gifford stated for the record that the meeting was adjourned at 12:22pm on November 6, 2020.

NOTICES OF PUBLIC MEETING HAVE BEEN POSTED AT THE FOLLOWING LOCATIONS:

In accordance with Nevada Governor Sisolak's Declaration of Emergency Directive 006 there will not be a physical location for the Rare Disease Advisory Council Meeting. The public is strongly encouraged to participate by phone or computer and downloading any material provided for the meeting at the website addresses below.

- As per Nevada Governor Sisolak's Declaration of Emergency Directive 006; Subsection 3: The requirements contained in NRS 241.020 (4) (a) that public notice agendas be posted at physical locations within the State of Nevada are suspended.
- As per Nevada Governor Sisolak's Declaration of Emergency Directive 006; Subsection 4: Public bodies must still comply with requirements in NRS 241.020 (4)(b) and NRS 241.020 (4)(c) that public notice agendas be posted to Nevada's notice website and the public body's website, if it maintains one along with providing a copy to any person who has requested one via U.S. mail or electronic mail.
- As per Nevada Governor Sisolak's Declaration of Emergency Directive 006; Subsection 5: The requirement contained in NRS 241.020 (3)(c) that physical locations be available for the public to receive supporting material for public meetings is suspended.
- As per Nevada Governor Sisolak's Declaration of Emergency Directive 006; Subsection 6: If a public body holds a meeting and does not provide a physical location where supporting material is available to the public, the public body must provide on its public notice agenda the name and contact information for the person designated by the public body from whom a member of the public may request supporting material electronically and must post supporting material to the public body's website, if it maintains one.

On the Internet at the Nevada Division of Public and Behavioral Health website:
http://dpbh.nv.gov/Boards/RDAC/RDAC/
On the internet at the Nevada Public Notice website: https://notice.nv.gov

Written comments in excess of one typed page on any agenda items which requires a vote are respectfully requested to be submitted to the Council at the above address five (5) calendar days prior to the meeting to ensure that adequate consideration is given to the material. We are pleased to make reasonable accommodations for members of the public who are disabled and wish to attend the meeting.

Members of the public who are disabled and require special accommodations or assistance at the meeting are requested to notify, in writing, the Division of Public and Behavioral Health, 4150 Technology Way, 3rd Floor, Carson City, NV 89706, or by calling Rex Gifford at 775-684-4217 no later than three (3) working days prior to the meeting date.

Supporting material for this meeting can be obtained from the Division of Public and Behavioral Health, by calling Rex Gifford at 775-684-4217 or emailing r.gifford@health.nv.gov.