



NEVADA RARE DISEASE ADVISORY COUNCIL
MEETING MINUTES
December 11, 2020
9:00am – 11:00am

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

Join by phone

+1-415-655-0002 United States Toll Access code: 146 989 7455

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

1) 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 (CHAIR); Shirley Folkins-Roberts; Gina Glass (Vice Chair); Veneta Lepera, BSN, RN; Annette Logan-Parker; Jennifer Millet, MSN, RN; Kimberly Palma-Ortega; Valerie Porter, DNP, BSN, MBA; Nik Abdul Rashid, MD

COUNCIL MEMBERS ABSENT:

Brynlin Thornley, Kimberly Palma-Ortega, Larissa White (resigned)

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

Lindsey Kinsinger, Manager, Office of Public Health Investigations and Epidemiology (OPHIE); Rex Gifford, Administrative Assistant III; Joseph Filippi, Executive Assistant, Tara Van Orden, DPBH UNR MPH Student Intern.

OTHERS PRESENT:

Rose Gallagher, Associate Director of Policy for the National Organization of Rare Disorders (NORD).

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

2) Welcome and Opening Remarks – Rex Gifford introduced Chair Amber Federizo who welcomed everyone to the meeting.

3) PUBLIC COMMENT

Chair Federizo opened the floor for public comment. No members of the public appeared on the WebEx or by phone. This was verified by Rex Gifford and this item was closed.

4) FOR POSSIBLE ACTION: Consideration and Approval of previous Rare Disease Advisory Council Minutes from November 6, 2020 – Chair

Chair Federizo introduced the first agenda item, to approve the minutes of the past meeting. She asked for any changes or edit. Hearing none, she moved to approve the minutes.

Council Federizo made a motion to approve the minutes of the November 6, 2020 meeting of the RDAC. This motion was seconded by Council member Coppes. A verbal vote was taken, and the motion passed unanimously.

5) INFORMATIONAL ONLY: Presentation by Rose Gallagher of NORD (National Organization for Rare Disorders, NORD)

Dr. Federizo introduced Rose Gallagher, Associate Director of Policy for the National Organization of Rare Disorders. Ms. Gallagher presented an overview of what other Rare Disease Councils are doing across the country in terms of their strategic approach as well as how Nevada’s Rare Disease Advisory Council (RDAC) can partner with other RDACs as moving forward.

Ms. Gallagher thanked the Council for the invitation and gave a brief introduction of her presentation which included what NORD is currently doing with RDACs across the country, and also a discussion of their future RDAC work. Ms. Gallagher proceeded to share her Power Point slides (Appendix A) with little deviation from the slides.

Ms. Gallagher concluded her presentation with information about NORD's inaugural Project RDAC meeting to be held via ZOOM on December 16th from 2:30 to 4:30 Eastern Time. This is for the public stakeholders where council members from Pennsylvania, Minnesota, New Hampshire, and North Carolina will discuss some of their early successes and challenges. Then there will be breakout rooms for networking depending upon where each attendee is in their RDAC journey. There is also an earlier meeting for RDAC leaders, not the public, that any of the Nevada RDAC members are welcome to attend. This will be from 12:30-2:20 EST. This will be a great opportunity to come together with other RDAC leaders across the country who are in the trenches everyday working on these councils and hearing directly from them about what's working and what's not.

Ms. Gallagher then asked the Council if they had any questions about RDACs in general or about a specific state, or anything else.

Council member Lepera introduced herself and asked Ms. Gallagher how many RDACs around the nation have palliative care physicians and nurse practitioners involved with their Council? She further asked whether the two disciplines are being weaved together or if that is something Nevada did independently.

Ms. Gallagher replied that NORD is in the process of updating their model language for the next year and that's something that (adding palliative care providers) has come up as being a good addition. She did not think that any other states have tied the two disciplines together.

Council member Lepera stated that this was a tribute to Senator Woodhouse as she was the one that decided to pull these two things together.

Ms. Gallagher then asked for any other questions.

Chair Federizo replied that the meeting link will be invaluable for this council as this was only the second formal meeting after being initiated. She further indicated that she would send the meeting link out to the other members and that she and Vice Chair Glass would be attending. She stated that she was looking forward to seeing how other councils were operating and what this council might feasibly be able to do. She then thanked Ms. Gallagher for attending the meeting and for the great presentation.

Ms. Gallagher then added one last "food for thought" which was that for councils in the early stages of getting off the ground, a community survey is very helpful for guiding future work.

Chair Federizo thanked Ms. Gallagher again and then moved on to the next agenda item.

- 6) FOR POSSIBLE ACTION: Consideration and approval of modifications made to the RDAC bylaws (Section 6.2) – Council Members

Chair Federizo presented that this agenda item was for consideration and approval of the modifications previously made to the RDAC bylaws now that they have been edited with the changes made at the first meeting. She then asked if anyone had any suggestions or changes since the last meeting.

Ms. Van Orden then asked Chair Federizo if she wanted to discuss that the time periods for the Chair and Vice Chair roles were different from the membership time periods.

Chair Federizo agreed and presented that there was an inconsistency in the bylaws and asked for the bylaws to be presented.

Council member Lepera then explained that in her palliative of care council, they have a similar situation and the reason they have a variation like that is so that the whole group doesn't get taken out or need to be renewed at the same time and so that there's always some old people that carry over to the new group. They did that by design on their council.

Chair Federizo responded that is a great idea but the way the bylaws read now is that the Vice Chair and the Chair would expire out and the rest of the council would continue and then a new Chair would have to be voted into the third year which is the last year of the rest of the council.

Council member Lepera replied that she thought Robert's Rules of Orders addressed this and that the Chair and Vice Chair's terms should expire on alternate years for that very reason.

Chair Federizo then agreed stating that the Council could leave the bylaws as-is and will just have to do an election at the end of the second year to bring in a new Chair and Vice Chair.

Mr. Filippi then asked Mr. Gifford to bring up the specific section of the bylaws that this is mentioned in which he did.

Chair Federizo clarified that the bylaw sections are 4.2 and 6.1.1. She then stated that if no changes were made, then her and Vice Chair Glass would remain as officers until 2022 when others would be voted in. She then asked for clarification that her and Vice Chair Glass would remain as council members?

Mr. Filippi answered that when it comes to board or council membership, just because you are assigned to Chair or Vice Chair position, when you are removed from that position, it does not mean that you are removed from the Council. But it is completely up to the Council how they want to draft these bylaws. The membership term limits are in statute, but it is completely up to the Council how long you want the term limit to be for the Chair/Vice Chair.

Council member Lepera then added that many councils have the co-Chair move into the Chair position and then a new Co-Chair is elected which helps with the flow of information and memory of how things started.

Chair Federizo then asked council member Lepera if she would propose that type of overlap as well for the rest of the Council because after three years all council members would fall off and leave the co-Chair with a whole new council?

Council member Lepera responded that what she had done on other councils was to amend the bylaws so it the inaugural chair sat in her position for two years and the inaugural co-Chair for three years and then it would flip flop. It was spelled out that the co-Chair would have to agree to move into the Chair position for two years and then a new co-Chair would be elected etc., etc. She further explained that this keeps the leadership with similar visions but yet still open to new ideas and change.

Mr. Filippi then clarified that just because the term limit is three years, that does not mean that anyone must leave, it is just to give everyone an opportunity to decide if they want to reapply for membership or to roll off the Council. Council members can reapply for additional term limits.

Chair Federizo replied that then she would agree with council member Lepera and would suggest removing the Vice Chair from 6.1.1 and putting the Vice Chair at three years.

Council member Lepera would second that motion, if made, if the rest of the Council would agree and then asked the rest of the Council how they felt?

Council member Rashid then asked if at the end of the two-year term for Chair, if the Council was allowed to vote in the same Chair or would it automatically flip to the Vice Chair to move to the Chair position?

Council member Lepera replied that that was up to the Council. She presented an example from her experience on the palliative care council and brought up that this type of structure also gives the Chair an opportunity to step down and just be a council member because being the Chair is a lot of work. This type of structure also allows the Council to grow and also to possibly

keep a very passionate individual as Chair for a longer term. It really is up to all of us as council members.

Council member Rashid replied that she really likes that option and also that council members can decide to remain after the three years are up.

Council member Lepera reiterated that this was the case and that all council members can decide to either step down, if they need a break, or to remain on the Council. Then if some members roll off, those positions can be filled by new people.

Council member Rashid then made a motion that the Chair term expires in two years and then the co-Chair moves into that position but with the option of the Council voting for either one. She added that she thinks somebody would need to word this correctly.

Mr. Filippi then asked, for clarity, if the overall goal is to have the option of the Vice Chair to become the new Chair automatically but it ultimately is up to the council to decide - is that accurate?

Council member Lepera answered that it is an expectation of the council that the Vice Chair will assume the chair position by vote. If the council votes to continue leadership at the same that is also up for vote. She added that in her other council, they would put it as “do we leave the Chair and Co-chair in their same positions and continue the team terms forward or do we have the co-Chair take the Chair position and the Chair step back to a member?” Then this was voted on.

Council member Barnes then asked if at in two years, if the Council chooses to have the co-Chair move to the Chair position, then another vote will be taken for a new co-Chair?

Council member Lepera replied that this was accurate, and it allows for “new blood” to come in and bring new ideas. It also allows for consistency in leadership and goals, and for knowledge transfer.

Council member Rashid agreed that she liked that option but did not know how to word it if someone could help with that.

Chair Federizo then asked if they could just take the Vice Chair out of 6.1.1?

Mr. Filippi answered that as it is ultimately up to the Council what to decide, the Council might not want to get too specific in the bylaws and just communicate as a council on the historical background. Then, when it comes to the time for a change, the Council can vote however they

choose. Even if there is an expectation that the Vice Chair will move to Chair, the Council still must vote and can vote however they choose.

Council member Lepera responded that she agreed with Mr. Filippi and then she suggested that since it sounded like the majority of the Council agreed with the theories presented of the leadership transitions, the bylaws could be redone offline and then revisited at the next meeting for final vote.

Chair Federizo agreed but did ask if any other council members were opposed to that? Chair Federizo also asked if there was a motion?

Council member Porter then added that she like the way the Chair transition and term limit option sounded because it keeps someone in the position that actually knows what's going on to kind of help mentor the new person. She agreed that rewording the bylaws in the Article 6 section would be helpful and then voting on this at the next meeting.

Chair Federizo then stated that this agenda item will be deferred to the next meeting until the revisions of Article 6 in the bylaws can be provided to all the council members for review.

- 7) FOR POSSIBLE ACTION: Consideration of recommending two (2) additional council members to the Director for appointment, pursuant to NRS 439.5075(2): Paul Niedermeyer and Susanna Sorrentino, MD. Consideration must include term length (per RDAC bylaws Section 4.3) – Council Members

Chair Federizo then presented that two people have requested to be part of the Council. Neither Mr. Niedermeyer nor Suzanna Sorrentino were able to make it to the meeting. She then asked the Council if they wanted to defer this agenda item to the next meeting and opened the floor for discussion.

Council member Lepera offered that she thought Mr. Niedermeyer presented himself at the first meeting as a very passionate and knowledgeable person. She added that she felt adding one member of the public forum, without restrictions (can be a patient, family member, or just interested party), by vote and election of the Council, would add value to discussions. She recounted that Mr. Niedermeyer reached out to her a year ago to request inclusion in the Council. She suggested that the Council do consider allowing one person from the public at large with a special interest in rare disease to be a voting member of the Council, for a three-year term. She added that she was very fond of Mr. Niedermeyer and his passion and efforts already shown to this council.

Council member Millet agreed.

Council member Porter agreed stating that she thinks it is imperative to have a member of the public on the council.

Council member Rashid agreed and also wanted to take the opportunity to discuss the other candidate for membership. At the first meeting, the Council mentioned that having a geneticist would be valuable for the Council. Dr. Susanna Sorrentino is a geneticist and has shown interest in being on the Council and providing her expertise.

Mr. Filippi then interjected that historically when recommendations are shared with the Council for review and approval, the nominees do not have to attend the meeting but what is done is that they share their resume with the council members for their review prior. Then after the Council has reviewed their resume, or letter of recommendation, then the Council can then decide based on their background and expertise if they would like to nominate them for appointment. Mr. Filippi then noted that he had not seen that this was done for this meeting. He then stated that it is up to Council if they wanted to vote on that or to table this item pending receipt of the resumes on the two nominees.

Chair Federizo then asked if the bylaws needed to be changed at 4.1.2 in order to add a member of the public-at-large.

Ms. Van Orden then answered that to her understanding, the bylaws state that anyone, including public-at-large representatives can be added. There are no exclusions noted in the bylaws.

Mr. Filippi then asked Ms. Van Orden to clarify if there was a restriction on the number of individuals that could be added to the Council?

Ms. Van Orden replied that the bylaws do not indicate a specific number or any restrictions on numbers of members that can be added.

Council member Lepera then cautioned adding too many voting members to the Council because that increases the number needed for a quorum and in her experience, as time moves on, it will be more difficult to achieve a quorum at each meeting. She suggested utilizing an “ex-officio” member type, who are not voting members, but still members able to speak and voice their opinion.

Council member Logan-Parker then added that she thought both Mr. Niedermeyer and Dr. Sorrentino would be assets to the Council, but she was concerned about the precedence set for future member evaluations if this was done without seeing resumes first. She recommended that new members must submit CVs to the Council prior to a vote on their membership.

Council member Coppes agreed with this as he thinks that following clear guidelines will ensure no one is given preferential treatment.

Council member Rashid agreed and stated that she would request Dr. Sorrentino's resume to present at the next meeting.

Council Federizo made a motion to defer this agenda item to the next meeting of the RDAC. This motion was seconded by Council member Coppes. A verbal vote was taken, and the motion passed unanimously.

8) FOR POSSIBLE ACTION: Consideration of the age cohort breakdown for the first RDAC report (see "Age and Diagnosis" document) – Council Members
Chair Federizo then presented the next agenda item as the age ranges suggested for the cohort breakdown of the RDAC report. She asked Mr. Gifford to present the draft document (Appendix B) on the screen, which he did.

Mr. Filippi interjected stating that a couple of members indicated on the "chat" function that they were no longer able to stay on the meeting and he wanted to make sure that there was still a quorum present. Valerie Porter and Jennifer Millet had to leave the meeting.

Chair Federizo did a recount and indicated that there was still a quorum of 8.

Mr. Filippi then verified the number of members and the quorum number and then advised the council members that if they do have to leave the meeting, they must make the rest of the Council aware. If the numbers drop below quorum, then the meeting can't move forward.

Chair Federizo then moved on and opened the floor to the discussion of the age cohort breakdown.

Council member Rashid asked Chair Federizo where she got this breakdown from.

Chair Federizo replied that she put this together from the datasets she uses for her registry as well as what the foundation (?) wants to use for a potential national sickle cell registry, and then she used what she received from other members. This is from what everyone emailed her from the prior meeting to be our data set for this and this would be the age ranges that we would be looking for in terms of how we report out for the conditions that we will discuss in the next item. She then asked if any member would like to break the sections down further or change one of them?

Council member Rashid brought up that the age range of 20-25 was missing.

Chair Federizo replied that this was a clerical error and it will be added back in for the final document. She then asked the Council for any other changes or discussion.

Not hearing any, Chair Federizo then made a motion to approve this age cohort breakdown, with the addition of the missing age group 20-25, as our age cohort breakdown for any of the registry and reporting considerations. Council member Glass seconded the motion. A verbal vote was taken, and the motion passed unanimously.

- 9) FOR POSSIBLE ACTION: Consideration of the first diagnoses of focus and number to be highlighted in the first RDAC report (see “Age and Diagnosis” document) – Council Members

Chair Federizo introduced the next agenda item which is the list of diagnoses for the focus of the first RDAC report. She stated that she had not received very many responses from the Council in terms of what they wanted to prioritize. She wanted to make sure the Council had a quick discussion to see if there were additional conditions in which they would attempt to focus on without getting too broad.

Council member Logan-Parker remarked that she had not had any communication from the Chair for solicitation of the requested information and did not receive any contact information for the other members in order to communicate. She requested that she get that information so that she can contribute responses moving forward. She then added that because Sickle Cell Disease is included in the Newborn Screening as Sickle Cell Trait and Sickle Cell Disease, they are both listed in that category already. She was also concerned that Childhood Cancer is not on the list. She added that since the funding that's available for this council comes from the sale of a license plate for Cure Childhood Cancer, her concern is the message that would be sent to the public by not addressing childhood cancer in the first year or two of this council when the public is providing funding under the assumption that childhood cancer is included.

Chair Federizo clarified that there were no other email notices sent out and there were instructions provided at the prior meeting to email the Chair any of the diagnoses for consideration. She did receive some suggestions from some members. She then added that more diagnoses can be added and that the list is just a draft.

Council member Folkins-Roberts responded that she agreed with Council member Logan-Parker on the addition of childhood cancer as it is the number one killer of children and was a big part of the intent of the bill and the formation of the Council as well.

Chair Federizo replied that she would add childhood cancer to the list.

Council member Rashid responded that she also agreed with Council member Logan-Parker. The Newborn Screening just include Sickle Cell Trait and Sickle Cell Disease and in addition, the AB254 has actually provisioned for the creation of a Sickle Cell Registry. She wondered if including Sickle Cell in this forum would be a duplication of efforts? She added that she is a big proponent for Sickle Cell patients, but she thinks that the Council should be advocating for other rare diseases that do not have their own bill or are being addressed in other forums.

Chair Federizo replied that Sickle Cell Disease can be taken off the list if that is the wish of the Council.

Council member Logan-Parker added that she thinks it is important to recognize that the Council should work concurrently with the folks who are addressing the AB254 and that she does not want to take emphasis away from Sickle Cell. She wants to make sure that public perception in the future doesn't become a problem for the Council when the funding for the Council or the funding that's available to the Council comes from the sale of these license plates. She is worried that could become a public relations issue for the Council in the future that she feels would be wise for everyone to avoid.

Council member Porter added that her suggestions were more based on adult diseases, or diseases that would be diagnosed more in adulthood.

Council member Lepera responded that one of the suggestions that came from Senator Woodhouse was the fact that palliative care is almost like the mission statement to improve the quality of life for all those affected by a rare disease. This could be changed to "improve the quality of life for all of those affected by a chronic life limiting illness." This is the mission statement of palliative care. council. Palliative care also, in addition to the rare disease, gets some federal attention, and she thinks there may be some benefit to drawing out the connection between the two. She sees a combination of the two in those with chronic illness, but some will know more about palliative care and some will focus more on the rare disease aspect. She would like to see if there was a way to weave these two disciplines together, with Nevada State POLST, and thinks the Council might consider that over the next month or so.

Council member Logan-Parker replied that she is concerned with the wording of "life limiting conditions" because she would not want to dilute the focus of rare and ultra-rare disease. She

added that people can end up in palliative and end of life care for a variety of reasons that are not inherently related to rare or ultra-rare diseases, such as trauma patients, etc. She does agree that the mission statement can be improved but cautions making it so broad that a significant impact cannot be made in the lives of the people that have what's considered a rare disease.

Council member Lepera then clarified her statement that she was not saying the rare disease was palliative care. She just wanted the Council to consider that as some rare diseases do lead into a palliative care scenario, this might be addressed together at some point. As far as recommendations to government, each forum could possible piggy-back on each other's movements to be even stronger.

Council member Rashid added that she thinks that one of the things the Council should look for is to highlight, or maybe add as a category, how many individuals with rare disease do end up in palliative care and/or how soon they end up needing palliative care if that is the case.

Council member Lepera added that the Council could look at whether or not individuals with rare diseases, or their family members and care givers, have access to the palliative care experts they need. She pointed out that palliative care is not hospice, and really brings chronic condition experts to patients.

Council member Rashid then responded that believes this discussion is just to decide on the diagnoses for primary focus.

Chair Federizo agreed adding that she would propose to narrow the focal diagnoses down to the three that have been mentioned and are on the draft. This would mean starting with childhood cancer and including different features within this category, like how palliative care applies, and then doing the same with the other disease categories. The Council would be limiting their view to a subset of these three to start. Chair Federizo then asked the Council how they would feel about limiting the initial focus to these three diagnosis categories, and adding in how palliative care is integrated into each of these three categories?

Council member Logan-Parker responded that she thought it was an excellent idea. Council member Lepera responded that she loved the idea.

Chair Federizo then asked if any council opposed this idea or had any other discussion.

Not hearing any other discussion, Chair Federizo then made a motion to make the Council’s **consideration list for rare disorders include childhood cancer, newborn screening conditions, and factor deficiencies and inherited plate disorders with an integration of reporting on palliative care in each category. Council member Logan-Parker seconded the motion. A verbal vote was taken, and the motion passed unanimously.**

10) FOR POSSIBLE ACTION: Consideration of a Mission and Vision Statement for the RDAC (see “Mission and Vision” document) – Council Members

Chair Federizo then introduced the next agenda item which is to consider making a mission and vision statement for the RDAC. She presented the draft that was made and stressed that it is a draft and that edits, rewrites, and revisions were encouraged. She then opened the floor for discussion and ideas.

Council member Logan-Parker stated that she liked the draft start but would add to “improve quality of life and *access to high quality medical care* for all those affected by rare diseases in Nevada”. She added that she would like to see an emphasis that people would have access to care. She further added that she could see this was articulated in the vision statement, but she would like to see it in the mission statement.

Council member Lepera added that she would like to see some mention of the whole family unit.

Council member Rashid mentioned that in the vision statement it does read to “positively impact the lives of *those affected*” which would include the family unit.

Chair Federizo added that she thinks the Council should make sure that people don't assume that that wording means only the person living with a rare disorder and not all of those around them. She thought some wording changes would help to make sure that the Council is not just working for the person with rare disease, but is also for the communities, providers, and other caregivers too.

Council member Lepera added that as the Council will eventually get to a point where they are going to be writing letters to the Nevada State Senate addressing what the Council thinks Nevada should do or change with laws, education, etc., the statements should be very inclusive of all affected.

Council member Barnes then asked if it was correct to that the main thing that the Council is trying to figure out right now is just kind of the reporting the registry part and that's what these categories are for or are these categories the focus of all movement as far as advocacy and

whatnot? Then she also asked if sickle cell disease would be included under newborn screening conditions to be also included in advocacy?

Chair Federizo answered that she believes there is some flexibility in how the Council moves forward but these would be the primary things which the Council will end up reporting on or developing a registry for. She added that sickle cell would be advocated on under the newborn screening section. Further, she commented that right now, in the beginning stages of this council, the members must take a moment to figure out what the impact is of these diseases or how much is there in Nevada and what kind of access is available. Focusing on the three categories will help in terms of getting a baseline and figuring out the resources available. She also stressed that the Council could *always* advocate for any disease that is not on the list as issues or new information arises. She then provided an example of how the Council could inform Medicaid decisions on coverage for medication or treatment for any rare disease as it comes to light.

Chair Federizo then asked what the Council's thoughts for changing the mission and vision statements and then added that she could be emailed ideas also moving forward?

Council member Coppes then responded that he felt that not too much more time should be taken on this because the Council had a lot of work to do and needed to get moving on it. He then suggested that the current statements could be approved for now and then over the next year or two, they could be revisited to see if changes were needed.

Council member Folkins-Roberts agreed with this and stated the Council would really know more in the next year or see and that it is important to move on to other work.

Chair Federizo then asked if anyone was opposed to leaving the statements as is and reminded the Council that there was time for more discussion if necessary.

Council member Lepera agreed stating that what is written already is more than adequate and descriptive for what the Council is going for and further that the Council's work will speak for itself.

Chair Federizo called for a motion to approve the Mission and Vision statements as they are written, to be changed in the future if needed. Council member Coppes made the motion. Vice Chair Glass seconded the motion. A verbal vote was taken, and the motion passed unanimously.

11) INFORMATIONAL ONLY: Presentation for review of the Sickle Cell Disease Registry Regulations (see "NAC SC Registry" document) – Council Members

Chair Federizo then introduced the next agenda item which is the presentation of the proposed regulations for the new Sickle Cell Disease Registry. She noted that this was just for informational purposes for the Council to review, and that it was under the AB 254 mentioned earlier. She then asked if any of the Council members had an opportunity to review the regulations and had any thoughts as to how the Council may utilize them or add to them?

Council member Rashid asked if the regulations were sent to all the members? Other council members stated that they had not received this prior to the meeting.

Chair Federizo apologized and stated that she would make sure it was sent out prior to the next meeting and will defer this agenda item also to the next meeting.

12) FOR POSSIBLE ACTION: Identification of future agenda items – Council Members

Council member Bagner then stated that she was having a hard time hearing the meeting.

Chair Federizo responded that it seemed like several technical difficulties were noted during the meeting and that some members had to call in by phone to hear better. She then moved on to the next agenda item, which is identification of future agenda items and asked all the members if they had any thoughts?

Chair Federizo then stated that as she had not heard any additional agenda items, she moved that the Council moves forward with the agenda items as proposed and moved from this meeting to the next meeting with no additions.

Council member Folkins-Roberts then interjected that she wanted to make sure that the Council did receive a directory of all council members.

Chair Federizo replied that she would make sure that went out that day and if each member could reply that they received it so that she could confirm the correct method of contact for each member. She then asked if there was a second to her motion.

Council member Coppes seconded the motion. A verbal vote was taken, and the motion passed unanimously.

13) PUBLIC COMMENT

Chair Federizo again opened the floor for public comment. She asked if any members of the public had joined the meeting since the beginning. No members of the public appeared on the WebEx or by phone. This was verified by Rex Gifford.

Rex Gifford and Joseph Filippi reminded the Council of open meeting law rules regarding discussion of Council activities outside of the meeting.

No other public comment was brought forth, and this item was closed.

14) Adjournment – Chair

Chair Federizo moved to adjourn the meeting at 10:34 and reminded the Council of the next meeting scheduled for January 8, 2021 from 9am-11am.