



**NEVADA RARE DISEASE ADVISORY COUNCIL
MEETING MINUTES**

January 8, 2021

9:00 am

Meeting Locations:

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 were encouraged to participate by using the web-based link and teleconference number provided in the notice.

1. Call to order/roll call – Amber Federizo, Chair

COUNCIL MEMBERS PRESENT:

Ihsan Azzam, MD, PhD; Linetta Barnes, BSN, RN; Amber Federizo, DNP, APRN, FNP-BC (CHAIR); Shirley Folkins-Roberts; Gina Glass (Vice Chair); Jennifer Millet, MSN, RN; Valerie Porter, DNP, BSN, MBA; Nik F. Nik Abdul Rashid, MD; Brynlin Thornley; Kimberly Palma-Ortega; Paul Niedermeyer;

COUNCIL MEMBERS ABSENT:

Naja Bagner; Max Coppes, MD, PhD, MBA; Veneta Lepera, BSN, RN; Annette Logan-Parker;

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:

Linda Anderson, Public Health Foundation

Rex Gifford opened the meeting at 9:00 am. Roll call was taken and is reflected above. It was determined that a quorum of the Rare Disease Advisory Council (RDAC, the Council) was present.

2. PUBLIC COMMENT

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

3. FOR POSSIBLE ACTION: Consideration and Approval of previous Rare Disease Advisory Council Minutes from December 11, 2020 – Chair

Chair Federizo introduced the first agenda item, to approve the minutes of the past meeting.

Council Folkins-Roberts made a motion to approve the minutes of the December 11, 2020 meeting of the RDAC. This motion was seconded by Council member Rashid. A verbal vote was taken, and the motion passed unanimously.

4. INFORMATIONAL ONLY: Presentation by Aimee Guarnieri, Nevada Rare Action Network

Dr. Federizo said that the presenter was delayed and would like to have her presentation to 10:00am.

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

Chair Federizo stated this agenda item was for consideration and approval of the final modifications to Article 6 of the RDAC bylaws.

Council member Rashid motioned for approval with the modifications. This was seconded by Council member Folkins-Roberts. A verbal vote was taken, and the motion passed unanimously.

6. 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 opened up the item for consideration of the two recommendations for additional council members to join. She added there is a change to this as no resume was received for Dr. Sorrentino, in time for consideration, so will not be inclusive of consideration at this time. However, the council had received Mr. Niedermeyer's resume and have that attached to our documents. She asked if anyone has had an opportunity to review that resume; or has any reservations; or suggestions; or would like to pursue with motion of passage to include Mr. Niedermeyer as a voting member of the council; the council can proceed with that. It is now open for discussion.

Council member Porter stated that she had read Mr. Niedermeyer's resume and feels he is very passionate about helping people with chronic and rare diseases. She believes it would be a good idea to have him on the council.

Council member Rashid agrees and motions to add Mr. Niedermeyer as Council member. This motion was seconded by Council member Thornley. A verbal vote was taken, and the council agreed that Mr. Niedermeyer should be admitted to the council.

Joseph Filippi clarified to the council that the Director has to appoint Mr. Niedermeyer to the council. Now that council has approved the recommendation, the council can forward a memorandum to the Director requesting his formal approval. Once the formal approval is received, the Mr. Niedermeyer would officially become a council member.

Chair Federizo thanked Mr. Filippi for clarification on the process.

7. FOR POSSIBLE ACTION: Review and discussion of Sickle Cell Disease Registry Regulations– Council Members

Chair Federizo stated that Dr. Rashid has reviewed the regulation document and asked for input from the council for changes, comments or leave as presented.

Chair Federizo had questions for Dr. Rashid, who had been involved in the early drafting of the regulations. How did the discussion go from requesting reporting from health care entities to reporting from the payors, how did that go through? She is concerned about fining facilities for potentially not reporting.

Council member Rashid stated the initial idea of the Sickle Cell Disease Registry is to identify what services patients with sickle cell are receiving. Where they are getting most of their care and whether they have primary care physicians, hematologists or are they mainly getting their care in the emergency room. When they tried to create this a couple years ago, it was to identify all the places a patient with Sickle Cell would be in contact with. That is why they are requesting hospitals, physician's offices and labs to send a report. These are quarterly reports, March, September, June and December.

Chair Federizo asked, if a smaller hematology group, a rural group, may not have enough resources to report that they end up facing fees? It might be different for a larger healthcare institution to pull a data report. She is not sure it should be a combined effort from the payer side and the provider side to ensure that these numbers, actually reconcile.

Council member Dr. Azzam stated that a hematology group would also be reporting any type of blood cancers and leukemias. He doesn't see the need to give them a break regarding the blood disorders like sickle cell, when they are required to provide other reporting. You can get the report from the clinician, Medicare or Medicaid or their insurance company. It is easy to duplicate data collection and is always better to receive it more than once than not to receive it at all.

Chair Federizo added that is correct, but that her concern would be that those with sickle cell in rural communities may not necessarily be treated by a hematologist who is reporting.

Council member Dr. Azzam then responded that regardless of who is treating the patient, they have to report the person. Because the level of missing information is extremely high, the only way to make sure all are reported is to not make an exception on reporting requirements.

Chair Federizo replied that she agrees and would love to see this level of accurate reporting. But would hate for the burden of reporting to fall entirely on the healthcare providers, while making an exception in this NAC for payors.

Council member Barnes asked if they were suggesting that they want both the providers and the payors to report? If the provider and the payor both submit, there would be duplicate reporting. But at least we have our numbers, regardless of who is reporting. She asked if that was a correct statement.

Chair Federizo responded, correct. She stated from her perspective, the punitive portion of it should apply equally to payors and healthcare facilities. She would not want the burden of it to fall entirely on a healthcare system in Nevada that is stretched to almost nothing.

Council member Azzam responded that he agrees and that he does not believe in punitive approaches.

Council member Rashid added that she believes that what the Chair is saying is that in addition to the clinics, hospitals and medical facilities, we should get this information from the insurance companies, as well?

Chair Federizo confirmed.

Council member Rashid asked if that is something that can be added.

Council member Azzam stated he did not see why not and it sounded like a good idea.

Tara Van Orden added that the regulations are not completed yet and are in review status. A small business impact survey needs to be completed. Once the regulations come from the Legislative Council Bureau, it is unlikely that they will go before the Board of Health in March because the timing has been so long. There is room for review and revision, still. That is something that can be done, after the small business impact survey, which might result in some of the issues that have been brought forth. There is still some room moving forward.

Council member Barnes stated that when the sickle cell registry was drafted, it was kind of based on the cancer registry. She asked if anyone has experience of the barriers or challenges that were faced in the beginning when that started, so the council can be aware of and be interactive in overcoming them.

Chair Federizo asked if anyone had any further discussion. She motioned to make one addition after section 4; there will be an additional section to be inclusive of insurance providers providing this data, as well, so that the council can reconcile and try to find any missing/additional patients that may be out there.

Council member Rashid agreed. Council members agreed unanimously.

Chair Federizo asked if there was anything additional with this particular NAC. If not, then the council would move on to the next agenda item.

Rex Gifford asked for clarification if this item agenda item was informational only.

Joseph Filippi replied that it was technically an informational item and the council could not make a formal decision at this time. If the council needed to make a formal recommendation or suggestions, they would have to be put as a future agenda item for action.

Chair Federizo replied that they can mark that for the next meeting. As Tara said the small business survey, that may modify this further, needs to be done. Then this recommendation can be captured and put in a draft form, then finalize the formal recommendations once we have the information back.

Joseph Filippi answered that sounded good and asked if there is anything we can do as far as bringing additional staff that might need to provide any input to let us know.

Chair Federizo replied that what they will need most is a heads up on when the meetings will be held. That is sounds like there will be a delay and it will be hard for them to track that delay.

Joseph Filippi asked if when you say those meetings, do you mean the public workshop and things regarding the regulations?

Chair Federizo answered, Yes.

Joseph Filippi responded that we will definitely make the council aware whenever those workshops are scheduled.

Chair Federizo responded that they appreciate it and that she is registered for most of the notices, but so many come through, she wants to make sure she doesn't miss it.

8. Informational Item: Discussion of possible Rare Disease Day activities (February, 2021) supported by the Council – Council Members

Chair Federizo presented the next agenda item. This is an informational only agenda item. She was hopeful that Aimee Guarnieri would be able to join the meeting at 10:00 am. She wanted to introduce herself, she is the ambassador at the Nevada level for NORD. They will be doing Rare Disease Day activities. The next one is February 28th. If you're able to provide time to volunteer, it is anticipated to be virtual this year. Last year's event was held at the Grant Sawyer building. Did anyone have any questions about Rare Disease Day or the activities?

A member asked for clarification of the date of February 28th and if they would be getting an invitation. Chair Federizo confirmed, and once they have the formal invitation, they will send it out. She anticipates that Aimee will be doing it virtually, but she did not have the information yet.

9. FOR POSSIBLE ACTION: Identification of “next steps” and assignments for Council members

Chair Federizo presented the next agenda item. Opening the discussion for this item. The primary one would be that they had discussed doing the meeting monthly to kind of get going in the first few months and they have done this. She thanked everyone for making time to do that. She believes at this juncture, it would be okay to move to quarterly meetings, placing the next meeting at April 9th. She motioned to vote to move the meetings to quarterly, with the next being April 9th.

Council member Azzam, moved to have the meeting quarterly. Council member Porter seconded. A verbal vote was taken and it was agreed unanimously to move the meetings to quarterly.

Chair Federizo responded with that they have enough to pass to move to quarterly meetings and to please send any information in the interim to herself. If something does arise as they are going into the legislative session, she can provide those updates to the council. She can provide updates after the Interim Finance Committee and the healthcare meetings get going, in terms of any legislative movement that may impact the council. Or recommend to the Legislature, anything that comes up that would be reviewed by the council before any kind of decisions move forward.

Chair Federizo presented the next agenda item of “next steps”, in terms of what they want to do, as in work, between here and the next meeting. She had thrown out some ideas of collecting the data internally from what this council was able to collect, in terms of diagnoses and described age groups. The idea is to get their numbers known because it can be a struggle with rare diseases, knowing how many patients we have in the state. The idea is for everyone to provide that data, or join up as teams to provide that data. She asked what were the thoughts on how? She stated she is aware of the limitations, that there is \$0.00

and they are limited in what they can do. But if their institutions have a way of getting this data, it may be the project they can work on for now.

Council member Rashid asked in terms of getting the diagnoses from payors, Medicaid, Medicare and insurance companies, is that something they can tap into, as well, for these diagnoses?

Council member Azzam responded that at this time most of what the Office of Analytics is doing is monitoring what is going on with COVID 19. Once we get back to something that is similar to normal, we will be able to ask for the data for them to provide all this information. Our job would be to identify what we want because as a council we need to voice our wish list, what we would like to see and will compare it with what can be done.

Chair Federizo agreed. She stated that she thought they will have to tier it, starting with their own and moving to the other analyses. Seeing if they would even allow the council to access the data to take a look at it because they don't have the time and resources either.

Council member Folkins-Roberts reported that in looking at the council's mission bylaws and noticed the legislation, in large part, was to increase awareness and identification of rare disease. She thinks the registry is extremely important, but is that something the council wants to get involved with? Is the council tracking any of the legislative activity? Is the council going to be involved in any of the legislative sessions? Is there someone tracking for the council? Is staff tracking things that might be relevant to rare disease? How is the council going to be involved?

Chair Federizo responded, Yes, to the first part, absolutely they are going to be involved. One of the thoughts she had with the awareness was to do something similar to how the opioid information has been transmitted and to create some informational materials to be distributed to the Nevada Board of Medical Examiners and the Nevada Board of Nursing. To create a CME or something along those lines. In terms of Rare Disease Day, it has always been about bringing together those individuals, organizations and consumers to increase awareness. It has worked well in Southern Nevada, but needs to be worked on in Northern Nevada. As for legislative activities, she thought that she was the only one following that at this time. But she would encourage volunteers to help and gave information of how to access the legislative website.

Council member Folkins-Roberts offered to assist with monitoring the legislative activities.

Chair Federizo thanked Council member Folkins-Roberts for her offer of assistance.

Council member Ortega stated that she Chairs the Policy Committee for Beauty Council and could sit on the board for NDOC as another avenue to use legislatively if the council wanted to look into some other options.

Chair Federizo responded that would be good.

Council member Rashid noted that the Chair said we have \$0.00, like creating a website for rare diseases.

Chair Federizo gave an update, that she did talk internally to DHHS because as it stands right now, they technically do have a website. But it is embedded within DHHS and is difficult to find and is not as open and out there. Lindsey Kinsinger is trying to find a way within DHHS to see if they could just support a creation of a website. The council would have to maintain it and add everything to it. She stated she had

agreed to pay for it, herself, to create a new website. She needed to know if it would be allowed or if DHHS was going to say no and that it has to be within the Department of Health and Human Services. They said that as long as the council maintains it, they can do what needs to be done. They do not have the resources to do that for the council. The council could create their own unique website, similar to the examples the Chair sent out for the North Carolina website. They felt that has really increased the awareness, substantially, and provided an ongoing reference for them.

Council member Ortega stated that DHHS has a Facebook page so other entities underneath them are able to post. She suggested if the council came up with a flyer and were able to post that socially, they could expand that out and get it to other places. And sharing it personally might be an option, as well.

Council member Rashid proposed the council start their own Rare Disease website for Nevada. They could add links to DHHS and Legislative pages and items, which will be more informative and easier to find than trying to find information within a big website like DHHS.

Chair Federizo liked the idea and asked if anyone else had any ideas or things that they might want to see the council move forward with, in terms of focusing?

Council member Rashid stated upon looking at the list of rare disorders, that the council decided to gather data on, based on the last meeting, is childhood cancer. She asked Council member Azzam to clarify that he had mentioned the Cancer Registry and from her understanding childhood cancer is included in the overall cancer registry, correct?

Council member Azzam responded that is correct, all cancers are included except, skin cancers, and precancerous lesions of the cervix.

Council member Rashid noted that information would be available to tap into.

Council member Azzam replied, that it should be.

Chair Federizo asked if the council had to formally vote on these ideas of which they would be working on as teamed up council members or whether they can just proceed with summarizing how they will be doing some work between now and April? So that they can get a start on some of the items.

Joseph Filippi responded that since Agenda item #10 is an action item, he would suggest that they vote on the next step items they have identified. Maybe on a future agenda the council can list an update on specific assignments that the council members are working on and have an update, quarterly, on the progress made that might be appropriate.

Chair Federizo continued, Okay, she would break the list down into individual items. Starting with the website, she motioned to move toward the creation of an individual and unique website for RDAC. Council member Rashid seconded the motion. Discussion regarding what would be involved in creation of the website, who would be assigned the project and maintenance of the website was made. A verbal vote was taken and approved to move forward with the website.

Chair Federizo presented the next agenda item. She stated the next item would be legislative monitoring and offered that both she and Council member Folkins-Roberts have indicated that they will be monitoring those. She motioned that they attend those legislatively identified meetings that may involve a rare disorder and encourage whatever the topic is to be presented to the council before finalization. It

would ensure that the council vote that, that is the path that they want to move forward with. She motioned this would be the next project.

Council member Ortega suggested that the Chair was creating subcommittees, the outreach subcommittee, which might fall under the website and then the policy/legislative subcommittee. She suggested that after this session the council could come up with a general set of subcommittees. They could get support from other people in that regard and then could meet in between the council's next set of quarterly meetings. She asked if that was something that the council could come together and if now this round, maybe it could be set as an agenda item for the next meeting?

Joseph Filippi offered that before the council moves forward with discussion about subcommittees, that from past experience, it has been difficult to ensure subcommittees comply with open meeting law. Subcommittees still have to follow the open meeting law, which means, there still has to be a quorum present, minutes have to be typed up, posted and agendas have to be posted. He wasn't suggesting that the council could not move forward with that decision, but it might be more efficient if individual council members work on specific projects and bring the items and updates back to the council as a whole.

Council member Ortega suggested if they had a chat with Joseph to understand how these work. They could maybe have more than one person work together so that they don't violate open meeting law even when they come together individually for conversation. She said that if she isn't wrong, that if more than three people are having a conversation, it would violate. And she asked if that were correct?

Joseph Filippi answered, correct, typically if these discussions are going on between council members, it has to occur during an open meeting. This would go for email, phone calls. Technically, any decisions that would affect the council as a whole, need to be made during a public meeting. This is where it gets complicated. He stated, to be honest, the Division doesn't have a lot of administrative staff assigned to this council due to lack of funding provided when it was created. So, adding additional sub groups and sub meetings will add to the burden. That being said, he leaves it up to the Chair and council to decide how they wish to move forward.

Chair Federizo said that right now, they would finish the topics that we know are agreed upon. After the council voted on the last three items they had discussed, they can talk about what a subcommittee could look like in order to clarify that. The subcommittee, as council member Ortega said, could just be identified individuals who are working on that topic, who let me know where they are in the updates. Then once they get something that needs action, they'll come to the agenda. It would be a lot of individual pathways, but at least, it would still be compliant.

Chair Federizo continued the second item would be legislative decision. As she stated before, she and Council member Folkins-Roberts have volunteered to watch the legislative items that are coming forward and present to the legislature at any time something may warrant the council's involvement. Whether they come to them to present or they present to them, they want to make sure this is an approved item. She motioned for legislative pieces to be something they begin between now and the next meeting.

Council member Rashid asked for clarification that the Chair and Council member Folkins-Roberts will monitor any legislative session and bring it to the next meeting to present and decide which ones the council are going to attend and voice opinion, correct?

Chair Federizo confirmed. The only action that she and Council member Folkins-Roberts could take with the legislature is to notify them, in public comment, that this is an item that should be recommended for review with the council. They could bring it to the next meeting or call an emergency update meeting, depending on the potential things it could involve at the time. If they present something that could drastically change rare disorder, the council may end up calling a need for another meeting, to receive quorum to receive how this council would like to respond to that involvement. But they would just be monitoring and providing the recommendation to the legislature that this should require a Rare Disease Council review.

Council member Ortega volunteered to assist with the legislative monitoring, as well. She has experience in this area.

Chair Federizo responded she would add Council member Ortega to this project if the council decided to pass it.

Council member Porter agreed and motioned to support. Council member Rashid seconded. The item was voted on and unanimously passed.

Chair Federizo presented the third item. Potentially having all council members who have access to their individual entities, collect the data they had discussed, with those age ranges and with the population of focus. That is the basic starting of identifying the numbers that the council may all have within their own institutions. She motioned that the council members start collecting the data in regard to those age cohorts and diagnoses of focus.

Council member Folkins-Roberts asked for clarification, for her nonprofit childhood cancer organization serving northern Nevada, on if it is the new numbers of children diagnosed with cancer that come to their organization this year? Or is the council looking for things going through the hospitals?

Chair Federizo said that they will start with the new numbers for this year. They can start fresh with reporting when it comes due for their report at the end of the year.

Council member Folkins-Roberts offered that her programs and service director are working with Max Coppes. He was with the Nevada Cancer Coalition before he was here and they're working on the cancer registry for pediatric cancer. Does the council want anecdotal or are they looking for medical facts?

Chair Federizo replied that hopefully they can get medical facts to back up diagnoses, but they have to start somewhere. The council could collect data from the internal council members as to what they are seeing, to have some data. She proposed that they could take a look at having everyone report what their 2020 data was and begin reporting 2021 data of how many of these diagnoses they have.

Council member Folkins-Roberts thanked her for her answer.

Chair Federizo stated what would be involved is the council asking their own entities that they are all involved with, to provide a report of the data of the age cohorts that they had decided they're taking a look at. Of each of the three diagnoses that they had, this is the data they had in 2021 so they know their internal numbers for 2021.

Council member Azzam asked if this is only from their partners, not everyone?

Chair Federizo confirmed. At this time, they have to start somewhere and they are not going to find it from everyone quite yet. Knowing their own numbers would be a place to start.

Council member Azzam stated great idea, and thanked the Chair.

Council member Rashid summarized the diagnoses that were decided at the last meeting as childhood cancer, newborn screening diagnoses, factor deficiencies and platelet disorders. Then identify how many patients with the different age cohort that they decided on, which is every ten years.

Chair Federizo confirmed that as correct with the exception of the tiny guys.

Chair Federizo motioned to approve the third item. Council member Millett seconded. A vote was taken and approved unanimously.

Chair Federizo continued that the only other item they had to discuss was the educational awareness. From her view they are going to have a lot going on. She would ask the council if they could think up ideas of how and what they want to put together. They could vote on it. The education piece would be to create flyers or pamphlets that they could distribute to the Board of Medical Examiners and perhaps the Board of Pharmacy and Board of Nursing. To update and to bring awareness to the providers within Nevada as to the numbers of rare disease disorders and of how to properly diagnose them. Where they have resources and where they can get them. This is something they will have to take some time to take a look at, what those pamphlets will look like and create them. She suggested they vote on them, thinking that they will be an ongoing project at this time.

Chair Federizo motioned for the education piece to be started. Council member Folkins-Roberts seconded.

Council member Ortega suggested that they amend it to be used legislatively as well, combining Legislative with education. And suggested that it could be sent to the schools as well.

Chair Federizo agreed that she would amend it to be more broad that education components be created and developed and distributed to all of Nevada. Because if they have a consumer group, later, that they want to present it to, then it will be captured. They will develop education for all kinds of end users. She continued with that would only apply to votes of Council members Folkins-Roberts and Glass, if the council is okay amending the educational piece.

Council member Folkins-Roberts asked if she needed a second to that amendment?

Chair Federizo replied she would.

Council member Folkins-Roberts seconded the motion to agree. A vote was taken and unanimously agreed upon.

Chair Federizo presented the next item, which was the discussion of potential for creating subcommittees. She opened the discussion as to how they might facilitate that. She asked Council member Ortega what her ideas were since she had experience doing subcommittees in the past. She asked if the thought this was feasible, either through pathways of communicating to the Chair and then adding to an agenda and what her thoughts were on how they can create them.

Council member Ortega stated typically they nominate a chair to the subcommittee and council members that would be assigned to the subcommittee. The subcommittees run similarly to the current meeting. The agenda would have to be filed, posted, etc. Education and policy are very similar and the educational component could be distributed under the legislative policy. If the council wants something like website creation, that could be for outreach. Narrowing down what they want, as the council in whole, then they could go ahead and create those very broad subcommittees. She continued that they wouldn't want too many subcommittees because it would be difficult to have people show up, but creating those subcommittees would allow for more work to be done in between the council's bigger meetings. The council would entrust those subcommittees to make those decisions and they would bring them up to the full council. If the council wants to discuss, for future agenda items, come up with a list, maybe some general areas of interest for us as a committee to work on. She thought that would be their first lead-in direction. She offered assistance in creating the subcommittees.

Chair Federizo said that would be perfect.

Council member Barnes stated that earlier someone had mentioned, although subcommittees are great, there is concern in meeting a quorum. She asked what would the quorum be? She was concerned that they had barely met quorum at the current meeting. She asked if it has to be the same amount of people for quorum for subcommittee or quorum for people that are in that subcommittee?

Joseph Filippi clarified that subcommittees have a different quorum. That however many members are assigned to the subcommittee, that as long as the majority are present then quorum would be met.

Council member Barnes thanked Joseph Filippi.

Council member Rashid asked that they could have a subcommittee with three or four people?

Joseph Filippi confirmed.

Chair Federizo said that if they consolidate them to three, they can put website and education together as they end up overlapping and requiring publication to both sides, updating a legislative one and a registry one. They could start there. She needed to know who would be interested in being a part of those. She asked Joseph Filippi, if she reaches out to Council member Coppes after the meeting, she could see if there were interest in the subcommittee.

Joseph Filippi responded that he believed the discussion would have to be made during a public meeting. He thought there should probably be members of the Attorney General's office on the call to give guidance. As far as he is aware, since it is not specifically agendaized as discussion to create specific subcommittees, it would need to be put on the agenda as an action item.

Chair Federizo asked if it would fall under assignments for council members in agenda item #10.

Joseph Filippi responded it could. If they wanted to move forward and establish the assignments for subcommittees, then take a vote on who wishes to be a member of that subcommittee, they could go ahead and make that decision in a public meeting.

Chair Federizo asked that then with Council member Coppes and the others who are unable to be present today, she would wait for the next meeting? They would wait for the next agenda to vote for them to be in a subcommittee?

Joseph Filippi continued that he was not positive if people can be assigned to be on a subcommittee if they're not present and felt it was something they would have to volunteer for.

Chair Federizo said that it would be more her, reaching out to them to see which of the subcommittees would be their preferred assignment, just the Chair to the Council members who are not present.

Joseph Filippi said that Pierron Tackes, Deputy from the Attorney General's office, was on the line and referred the question to her.

DAG Tackes asked if there is an action item right now being considered to make assignments to subcommittees?

Joseph Filippi answered that agenda item #10, one of the assignments they are discussing today, are the formation of subcommittees and they want to make sure they can do this during this meeting and so on.

DAG Tackes asked if they are going to email members who not currently present?

Chair Federizo confirmed, so they wouldn't not get to be involved in that subcommittee until the next public meeting in three months.

DAG Tackes asked if there was a quorum present for the current meeting?

Chair Federizo confirmed.

DAG Tackes asked to table this item while she looked into it and then circle back? And asked if this was the last agenda item?

Chair Federizo answered it was not. She said the council could move with the vote the decision to forward with each individual council member creating the numbers, which falls under the registry. They move the decision to create a Registry subcommittee to a future agenda. She suggested they move forward with doing two subcommittees, which would be Website/Education and Legislative at this time.

DAG Tackes said she thought that would be advisable and thanked the Chair.

Chair Federizo thanked DAG Tackes.

Council member Barnes thought she would best be suited to the Website/Education and asked if she could do that?

Council member Ortega asked if there were any other areas of interest that people were looking for subcommittees, outside of the policies, education, website and registry?

Chair Federizo answered not that anyone had conveyed.

Council member Ortega stated that without the legislative piece, she would refer it to policy which allows for other kinds of changes to fall under that category, outside of saying specifically legislative. Policy would allow the council to do local and national updates. If that were something the council would be okay with changing, it is legislative, but more of a policy name.

Chair Federizo thought that would be a good suggestion, combining them to Legislative/Policy and Website/Education, so they would only have two subcommittees.

Chair Federizo motioned to have further discussion on the two subcommittees. Council member Rashid seconded. The council members voted and passed the motion.

Chair Federizo then started with the Legislative/Policy subcommittee and asked who would like to be a part of that? Chair Federizo, Council members Thornley, Porter, Ortega and Folkins-Roberts volunteered for the Legislative/Policy subcommittee. For the second subcommittee Website/Education, Chair Federizo and Council members Millett, Ortega and Barnes volunteered.

Chair Federizo presented that at this time she would like to allow to allow Aimee Guarnieri to talk about the Rare Disease in Nevada and Rare Disease Day.

Aimee Guarnieri introduced herself and began that she is the Nevada Rare Disease Advisory/Rare Disease ambassador volunteer for the National Organization of Rare Disease (NORD). They are haveint their Rare Disease Day coming up in February. Their overview is they're going to be segwaying into the Rare Disease Advisory Council (RDAC) and are looking for people with patients, as well as, healthcare providers that would be interested in speaking on this day. It is February 24th at noon. They would like to go over the background on the RDAC, establish goals and members for frequency of meetings. They'd like to help, along with getting more people to participate and how the public can participate in these efforts. Her background is under patient, as well as, caregiver. A lot of the issues being presented today do affect her personally as well as publicly speaking to several people out there. She said that if there are any questions, she can answer on the Rare Disease data share.

Council member Millett asked if this would be a Zoom or in person meeting?

Aimee Guarnieri answered that it would be a virtual meeting this year and will be Zoom. If you are not able to make that time, we discussed with NORD the possibility of putting in a 2-3 minute video for you during that Zoom meeting, as well.

Council member Folkins-Roberts stated she is with the Northern Nevada Children's Cancer Foundation and asked if the attendees for this are typically care providers and patients?

Aimee Guarnieri answered medical providers, as well.

Council member Folkins said she would be happy to talk with Ms. Guarnieri about making a presentation what they do if that were relevant and would be happy to talk about Northern Nevada's efforts to help kids with cancer and what they do.

Aimee Guarnieri replied that she would provide her email address if it is allowed in this chat group for anyone who is interested in contacting her after the meeting.

Chair Federizo asked if she could send her digital invite and contact and she would be sure to send it out to all the council members.

Aimee Guarnieri answered that she would send it, but that they were still finalizing it.

Chair Federizo stated as soon as it is finished, she would get it out to everyone. She thought it was a good opportunity of what they had been discussing and how difficult it is sometimes to be able to include Northern Nevada in these events.

Aimee Guarnieri agreed and that they have been looking for a co-ambassador in Northern Nevada in order to have people representing the rare disease community though out Nevada and not just in Las Vegas.

Chair Federizo said she was sure Council member Coppes at Renown would want to be involved and asked if Ms. Guarnieri would like her to forward that to him as well.

Aimee Guarniere said that would be great and she would appreciate it.

Council Member Coppes stated he had joined the meeting and asked Council member Folkins-Roberts if they could talk afterwards.

Council member Folkins-Roberts agreed.

Aimee Guarnieri stated that was all that she had unless anyone else had questions.

Council member Porter asked about the gathering. She wanted to clarify that since she works with adult patients, for the data, hers would be more like the platelet disorders. She asked if they want the specific disorder and the age group they fall into, correct?

Chair Federizo confirmed correct. Stating if you're adult only and don't have kids, it would only be the adult age groups.

Council member Porter answered okay and thanked the Chair.

Chair Federizo thanks Ms. Guarnieri for taking time to connect with them and create this opportunity throughout the state. She stated she will be sure to give out the information if any other members would like to be present and present their own institution at the meeting.

DAG Tackes quickly wanted to add, about the subcommittees, the council body can do those at the current meeting and would be authorized to assign non-present members to the subcommittees. That was a way another action could be taken to keep things moving on subcommittees.

Chair Federizo state at this point they were okay with two subcommittees and the members they have. There are four in one and five in the other, which they are okay and can move forward with individual reporting. She would reach out to each individual member of the council to let them know they had voted on just trying to get the data gathered. They would keep it in mind if they decide to include another subcommittee. She thanked DAG Tackes.

DAG Tackes thanked the Chair.

Council member Ortega asked if a future agenda item could be something that is other diseases or rare conditions that we are not currently collecting data for, just to keep an oversight?

Chair Federizo answered yes, that was the intent of the beginning. There have been other RDACs that have tried to find every single rare disease up front and it became so broad they never really got any real data on any one group I participation. These three, the council has identified, were the primary ones they had the most access and the most data on. They could, as they get data on these three, move that process to the next set of rare diseases and build a more comprehensive understanding of what their numbers are.

This is a starting point for developing a way to get this data on the rest. As the council potentially includes other members, they have other genetic rare disorders and other things within the state. Then if they consider them as non-voting individuals, they are definitely going to have rare disorders out of the subset. She asked if Council member Ortega wanted to add that to the next meeting or did she want to see how the data gathering goes for three months to the next meeting? But keep this as an ongoing potential for future meetings?

Council member Ortega answered that she thought ongoing for every meeting in case they do come up with something. There are many multi-layered patients that would overlap into multiple areas.

Chair Federizo answered absolutely and that this is just a starting point in gathering data, then moving on adding additional data components as they go along.

Chair Federizo asked if there were any other agenda items for inclusion on the next meeting, keeping in mind if something comes up between now and then to feel free to email her in the interim.

Council member Barnes asked if that ongoing, they would now add on the agenda item for each subcommittee to report their work?

Chair Federizo answered yes, the subcommittees will end up having their own separate agenda piece. She asked Council member Ortega how they ran their subcommittee meetings between the main council meeting?

Council member Ortega said they typically pick a certain day. They did a subcommittee however often the subcommittee agreed to. And based it off of that.

Chair Federizo asked if they needed to set those dates or is that something on the subcommittee she can send to DHHS to approve for them to meet?

Council member Ortega said that if DAG Tackes was still on, she would refer back to her in regard that they were pre-establishing something. And they could get clarification of how they would establish their first meetings for subcommittees.

DAG Tackes asked if it was a question for getting the subcommittees started, in what regard?

Chair Federizo answered in setting the date and the chairs. And asked if that were something that they need to set up in this meeting or can it be something where the subcommittee members could send the dates that work best for them, we determine which dates and then send to DHHS which dates that those subcommittees will be meeting and an agenda?

DAG Tackes said Yes, the chair can set the dates for those and then that information can be relayed to the subcommittees.

Chair Federizo asked to confirm that isn't something that they have to vote on in the main council?

DAG Tackes confirmed that is correct.

Chair Federizo asked as it applies to the Chairs, is that something they have to do in the main council meeting?

DAG Tackes answered No, that is something that the subcommittees can vote on.

Chair Federizo, answered, Okay.

10. FOR POSSIBLE ACTION: Identification of future meeting dates and times – Council Members

Chair Federizo continued, With that, they had identified their future meeting at April 9th, Friday 9-11:00 am. The council had moved to quarterly meetings. If there is anything that requires an urgent meeting before then, she would be in touch and told the council to feel free to email if they had anything in the interim. She stated she would be in contact with the Legislative/Policy subcommittee and the Website/Education subcommittee to start those meetings off and meet with them individually. She asked if anyone had any other questions, comments or concerns before they moved to public comment?

Joseph Filippi asked that since she had advised that they were going to be quarterly meetings, going forward, did she want to schedule the rest of the meetings for 2021? Or did she want to schedule the next meeting at each individual meeting?

Chair Federizo she thought, if everyone was okay with it, that they could set the July meeting, as well, which would be July 9.

Council member Coppes stated he would be unable to attend July 9, he has a conflicting meeting in Europe.

Council member Ortega asked if members aren't able to attend if they would be able to meet quorum?

Chair Federizo wanted to clarify that with DAG. She asked if she can do a doodle poll to what date in July would work best to meet quorum. She wanted to make sure that is allowable first. They will set the April 9th date, which they had agreed upon at this juncture. Then they could set the July date once they have an idea of quorum numbers available for that date.

DAG Tackes responded, yes, that was right. The April date has been set, if approaching the April date starts to look like a quorum might not be met, it can be rescheduled. The same for July, as you get closer to the date, you can figure out who is available for that and get that date set.

Chair Federizo asked if she was allowed to send out a doodle poll to the council members to see what those days for availability would be to make sure they have a quorum? Or is that something they have to do in the meeting?

DAG Tackes replied that as long as it was restricted to availability, it is fine.

Chair Federizo answered okay. At this time the council will hold off on the July date because it may be something where the following Friday may be better to accommodate some schedules and would involve more individuals. She said they would proceed with April 9th at this point.

11. PUBLIC COMMENT

Chair Federizo presented the next agenda item, Public Comment. She asked if there was anyone from the public on the line and that they would have three minutes to make any discussions.

Linda Anderson introduced herself and stated she was from the Public Health Foundation and she would like to make a comment. She wanted to commend this group. She wanted to support what Dr. Azzam said, that they have had much more success in reaching out to providers and getting them to support a registry, than by trying to use penalties. She noted the Cancer Registry did build in some penalties for failure to report, but they did not utilize those much. She cautioned that she knew they wanted to create revenue to support the registries, but sometimes that hinders. When you're adopting regulations, providers do not want to pass those costs onto their patients. She thanked the council for all their work.

Chair Federizo thanked Ms. Anderson. She asked if there was any other public comment? Hearing none, she moved to adjourn the meeting.

12. Adjournment – Chair

Chair Federizo moved to adjourn the meeting at 11:00 and reminded the Council of the next meeting scheduled for April 9, 2021 from 9am-11am. She thanked everyone for their time and commitment. She stated she would reach out to the subcommittees and thanked them again.