

Steve Sisolak
Governor

Richard Whitley,
MS
Director



DEPARTMENT OF
HEALTH AND HUMAN SERVICES
DIVISION OF PUBLIC AND BEHAVIORAL
HEALTH

Helping people. It's who we are and what we do.



Lisa Sherych
Administrator

Ihsan Azzam,
Ph.D., M.D.
Chief Medical Officer

NEVADA RARE DISEASE ADVISORY COUNCIL
EDUCATIONAL SUBCOMMITTEE

MEETING MINUTES

July 9, 2021

1:00pm – 3:00pm

Meeting Locations:

This meeting will be held online and by phone. The online and phone meeting location was:

Meeting Link: [105936574@teams.bjn.vc](https://teams.bjn.vc/join/105936574)

Video Conference ID: 115 064 079 6

Phone: [+1 775-321-6111](tel:+17753216111), [333882452#](tel:+1333882452) United States, Reno

Phone Conference ID: 333 882 452#

Melissa Yerxa opened the meeting at 1:04 p.m.

1) INTRODUCTIONS AND ROLL CALL

COUNCIL MEMBERS PRESENT:

Amber Federizo, DNP, APRN, FNP-BC (CHAIR); Kimberly Palma-Ortega; Annette Logan-Parker (Quorum = 3)

COUNCIL MEMBERS ABSENT:

Linetta Barnes, BSN RN; Jennifer Millett, MSN, RN

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

Melissa Yerxa, Student Intern

OTHERS PRESENT:

Pierron Tackes, Deputy Attorney General Nevada

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 public comment was made.

3) POSSIBLE ACTION: Discussion of events and community outreach educational targets for committee education focus. – Chair/Subcommittee

Chair Federizo opened up the discussion by revisiting the previous RDAC subcommittee meeting. Chair Federizo stated that this agenda item will focus on coming together to develop a list of organizations and educational targets of whom the RDAC subcommittee will be inviting to participate within the website and also be able to provide education for them.

Subcommittee member Annette Logan-Parker stated that Chair Federizo would have a robust list that aligns with the other committee member's lists. Ms. Logan-Parker suggested to start with Chair Federizo's suggestions and then the committee can make further suggestions, as needed.

Chair Federizo proceeded to share her list, starting with Clark County Medical Society, Nevada Advanced Practice Association, Clark County School District, Nevada State Board of Nursing, State Board of Medical Examiners, Nevada Chronic Care Collaborative, Nevada Hospital Association, Nevada Health Care Association, Nevada State Medical Association, Nevada Primary Care Association, Health Services Coalition, and the Nevada Oncology Society. The primary goal will be to connect these providers with the awareness of the RDAC website being in development and that they will be asked to participate. If they are providers who take care of these conditions, they will be asked if they would like to provide contact information for the website - this will allow patients to connect with them. Chair Federizo suggested to potentially provide a presentation to them from our organization on upcoming meetings. She stated that she was unable to reach out to as many individual societies.

Subcommittee member Annette Logan-Parker recommended adding the State Board of Pharmacy, Association of Pediatric Hematology/Oncology Nurses (APHON), and Children's Oncology Group. Ms. Logan-Parker continued with other organizations, such as the Hemophilia Foundation, the National Center for Children and Families (NCCF), Candlelighters Childhood Cancer Foundation of Nevada. Ms. Logan-Parker asked Chair Federizo what type of providers/organizations this list will focus on.

Chair Federizo answered that the type of organizations is something that was previously discussed. One of the things that the website aims to do is include community-based organizations (CBO). Chair Federizo presented to the subcommittee if they want to target obtaining the providers' information first or to conjointly include community-based organizations simultaneously. She followed up that it may be beneficial by doing it together to save time in terms of gathering all of the information and uploading it on to the website. Chair Federizo continued by listing providers: NCCF, the National Hemophilia Foundation, Hemophilia Federation of America (HFA).

Subcommittee member Annette Logan-Parker suggested adding Candlelighters and Make-A-Wish.

Chair Federizo asked if any of the subcommittee members are aware of any newborn screening-specific foundations or related community-based organizations in Nevada. Subcommittee member Kimberly Palma-Ortega noted that Vickie Ives may be the one to contact about it as she oversees Nevada's Women's Health and Maternity and sits on the Council on Developmental Disabilities with Ms. Ortega. She reported that she can reach out to her and gain more information. Chair Federizo supported the idea

to reach out as she is not too familiar with any community based organizations for newborn screenings. She shared that this may be rolled up into other organizations and she can reach out to them.

Subcommittee member Annette Logan-Parker brought up an organization called Little Miss Hannah, which is involved with ultra-rare diseases, such as lysosomal storage diseases. She stated that they are not necessarily currently on the list, but they may provide a robust group that may be helpful to the initiative. Chair Federizo asked what type of services this organization provides because there has been talk about listing community services, like through Nevada 211. This will link patients to resources that is not disease specific, like for food insecurity. Ms. Logan-Parker answered stating that this organization provide durable medical equipment and financial resources for people with rare diseases. It is more robust than other programs in the sense that they will deliver durable medication equipment or hospital beds, etc.

Subcommittee member Kimberly Palma-Ortega shared that she knows Carrie with the Little Miss Hannah organization. She reported that Carrie has stepped away from the executive director position and started expanding further into a national-level of support. She shared that Carrie is great with connecting people and has become well-known across many resource providers nationally. Ms. Palma-Ortega advocated that Carrie would be a good asset.

Chair Federizo requested to be connected with Carrie with Little Miss Hannah. As Nevada doesn't have access, patients will be accessing out-of-state resources. The RDAC will want to have these resources accessible as well if patients aren't able to get services in the state. Subcommittee member Annette Logan-Parker will follow up and reach out to Carrie with Little Miss Hannah. Ms. Logan-Parker expressed that Carrie will be an asset and maybe at some point be someone to add the council.

Chair Federizo followed up with the subcommittee to confirm the list that was developed.

Subcommittee member Kimber Palma-Ortega followed up that she had similar providers/organizations. She additionally suggested including specialty doctors or practices, as well as include the Medical Advisory Commission. The Commission has to deal with providers that are within Medicaid and may be able to provider a direct contact list of their providers or at least be able to provide information. The RDAC can also share their information and links to the commission.

Chair Federizo stated that she liked that idea because within these organizations, there are going to be gaps and typically finding all of the specialty providers, that work with these diagnoses, are connected with Nevada Medicaid or accept Medicaid. Connecting with them would be the best global target for providers. It would be beneficial to access the Nevada Medicaid directory, much like connecting with the Board of Nursing, Board of Medical Science, Medical Association, and the Board of Pharmacy. These will be the most robust connections.

With gathering directories, Chair Federizo stated that insurance directories are not always efficient. Chair Federizo stated that they currently don't have a comprehensive list of community based organizations, but by connecting with Medicaid, the RDAC can see if they have a list of community resources for food insecurity, domestic violence, etc. If the council votes globally, they will not have to revisit to approve that heading into the website.

Subcommittee member Kimberly Palma-Ortega stated that they have a meeting on the 13th and that she can propose Chair Federizo to present to the council. These meetings involve insurance providers and other key people that be a good connection. This can introduce some of the ideas and requests that Chair Federizo is presenting and allows the Medical Care Advisory Council to become more aware. Ms. Palma-Ortega will follow up by sending that information to anyone who is interested in attending the meeting.

Chair Federizo asked the subcommittee if there are any other organizations or programs that they want to be included in the vote, other than the ones that have already been listed and the two global ones through the Nevada Medicaid Directory and any resources through the state including Nevada 211, for the website.

Subcommittee member Kimberly Palma-Ortega suggested including the juvenile system. She supported this suggestion with stating that there are children that are either undiagnosed or haven't had follow up care that meet the criteria of the individuals the RDAC serves. This includes children who may be transitioning from youth facilities into adult care, where they may not be aware or had support for their medical conditions. This can also link any family members related to those in the juvenile system. Chair Federizo appreciated Ms. Palma-Ortega's suggestion. She stated that through her experience of doing rounds at the Indian Springs prison, she is aware of developing relationships with those patients who end up becoming incarcerated still need access. Chair Federizo stated that she will add Nevada Department of Corrections on the list as it primarily encompasses most of the incarceration facilities. Ms. Palma-Ortega followed up to make sure it includes the juvenile system. Chair Federizo will list this as state level corrections, county level corrections, and city-wide corrections for both juvenile and adults. This way it will encompass on the city level for people that remain in jail or are incarcerated for a long period of time. This will include all the individuals who fall under that category, since they lose their access to having insurance and involve huge transitional problems.

Subcommittee member Kimberly Palma-Ortega also brought up the Nevada Commission for Kids, which deals with foster care children. This could connect families who go to family court with medical care. Chair Federizo followed up by stating that if it is worded that they are utilizing state resources because both of those should fall under Department of Health and Human Services (DHHS) under family services. This will include both foster care and CASA, assistance to help with court appointments. This category should fall under supervision of being under the state.

Chair Federizo moved to vote for the organizations that were previously listed at a state level, local level, and county level that covers community based organizations as well as provider directories and community resources. Chair Federizo motioned to approve the list of initial providers to reach out to. Subcommittee member Kimberly Palma-Ortego seconded the motion to approve. The Council voted unanimously to approve the registry process.

Chair Federizo continued by stating that there is a meeting on Monday to begin the website design with features that have been discussed in the last meeting. Once the website has been designed, the committee can reconvene on what is on it and bring it to the council. This will likely occur in the fourth quarter because of everything that is going on with the larger council.

4) Discussion of future agenda items – Chair/Subcommittee

Chair Federizo shared that at this time what she would like to send to the Attorney General for review and approval would consist of preliminary screenshots of what has been developed so far so this subcommittee could approve it. Chair Federizo asked the subcommittee if they had any additional items they would like added to the next subcommittee meeting.

Subcommittee member Annette Logan-Parker brought up the content of the website, asking if it needs to be very specific with the council profiles and other areas or if the screenshots are going to be more general. Ms. Parker was clarifying on what will cast a large enough net to meet what Chair Federizo has in mind. Chair Federizo responded that, if possible, she believes the best way to do a real time navigation, considering that it is contingent upon how far the committee gets as there is a lot that goes into it. Chair Federizo is looking for screenshots of some ideas of what the website will look like. If utilizing real time navigation, it would be easy to see how someone would navigate the website. Ms. Parker followed up that she has a meeting scheduled with the design team, so she will make that request with them. She will follow up with Mitch and Amber to participate so they can navigate the website and answer any questions for the whole council.

Chair Federizo reported that from the last meetings, they had every component that they wanted. Items that were discussed include how they would include the information, what it will look like, what will be included in the drop downs, and the categories that were discussed at the last subcommittee meeting. Once the subcommittee is able to look at what the website design looks like, they can change and modify it from there.

Subcommittee member Annette Logan-Parker followed up with asking about the use of stock photos for the website to make it aesthetically pleasing, will the website be required to get each stock photo approved to use because they (Cure 4 The Kids Foundation) are willing to purchase the stock photos as a part of their contribution to this. She wants to follow up on if there needs to be any approval prior. Chair Federizo responded that once the committee has an approved website, they will notify the attorney general that they are the processes and what they want to look like for approval. Then the attorney general will go in and navigate to make sure there isn't any biases towards anything. Sometimes Pharma and related programs want it to be as clean as possible so that there's nothing that violates our objectives that were passed down or anything. Once there is approval, the committee will bring it to the main council, then the main council can create authority by this subcommittee to make any foregoing changes after that point.

Chair Federizo continued stating that if there is something that the subcommittee feels like they want to add to the website, they can always resubmit it to the attorney general. As this website does represent and reflect the state, they don't want to have something on there that may need to be eventually taken down. This does slow things down a bit, but at least the subcommittee has gotten everything.

Subcommittee member Annette Logan-Parker will follow up with her team to purchase some stock photos for examples because she believes that in order to represent diversity and cast a wide net with inclusion, buying stock photos is going to be better than the subcommittee trying to create or trying to piecemeal images and things like that together. Ms. Logan stated that she believes it will accomplish the pictorial message that the council is trying to send in a good and a faster way. Chair Federizo stated that she doesn't feel as though there will be any issues with purchasing stock photos and that these photos will be approved. Ms. Logan-Parker stated that she will make sure that her team purchases something, they will document that it's on behalf of the Nevada RDAC and that all the information gets transferred

over to Chair Federizo so she is aware down the road if the website changes hands from a logistical and maintenance perspective, she will have everything she needs. Ms. Logan-Parker clarified that she typically doesn't function in such a transparent level, so she wants to make sure they don't create any objectives, unknowingly. Chair Federizo agreed with Ms. Logan-Parker about the new experience and journey with this and that she doesn't anticipate any issues with it.

Chair Federizo also shared that they do have a small amount of money in the bank due the sale of license plates. If this money needs to be accessed, Chair Federizo told the subcommittee to let her know. Ms. Logan-Parker stated that they are happy to cover the amount for stock photos.

Chair Federizo asked if there are any other agenda items to be added to the next meeting. As no one responded, Chair Federizo continued with another item that she would like to add to the agenda. She will also be bringing this up to the council. Because the RDAC is in place and meetings have been available to the public, they council is starting to get pharma interest into what the RDAC is doing and what the RDAC is looking forward to. The lieutenant governor has forwarded all of these requests that are coming to the state to the RDAC. From an educational perspective, Chair Federizo expressed that she would rather pharma individuals be in an advisory role. There are others in other states who have chosen to do voting or non-voting rights. She shared that she feels that it makes things a bit more crowded, but she opened it up to the subcommittee for ideas in terms of adding that as an agenda item for the educational subcommittee and how the committee can utilize them in an advisory role. Pharma can offer the educational committee opportunities for grants they can access to develop educational materials. Chair Federizo stated that would rather utilize them in that capacity versus adding them as a council member or a subcommittee member, which they have expressed they are okay with. Unless someone feels strongly otherwise that they should be going to the full council to do a full vote, gathering the resumes and add them entirely.

Subcommittee member Annette Logan-Parker agreed with Chair Federizo's thoughts. To maintain the integrity of the council and to make sure that the efforts that the committee does for the state to remain above that judgement kind of reproach that happens when a pharmaceutical organization sponsor big dollars can become challenging. With that, it is equally challenging because that's where money is to help us advance the work that we're doing. Ms. Logan-Parker shared that her initial instinct aligns with Chair Federizo's, allowing them involvement and participation is great, but making sure that no one could every misconstrue the work that the council is doing in a way that would be the intention of benefitting Big Pharma.

Chair Federizo stated that she agrees and will add it as an agenda item for the next educational subcommittee meeting so they can take a deeper look into how they would like to structure approaching the grant or making requirements in regard to whatever assistance received is non-branded in nature.

Subcommittee member Annette Logan-Parker brought up the topic if seeking community grants, high net-worth Family Foundation grants. Ms. Logan-Parker asked what the process is to get those types of grant requests approved because there are some local resources that could be identified to help advance the work of this organization and this council. Ms. Logan-Parker asked how it would work with the funding with funding from the state, from a nonprofit perspective. This can help her contribute by identifying some funds.

Chair Federizo noted that she is in the same boat and that there isn't a clear process with the state. Chair Federizo stated that she envisions for looking at these processes in the future, if you have someone who you think we can access through grant funding or foundational funding, they should be invited to present

to the council in terms of what it looks like and what their requirements are so that the council can decide if they want to proceed with it. From there, the council can inform the state of the grant and request approval to apply. If the council receives the grant, follow up with how they will roll it out. Chair Federizo shared that she was previously unaware that the RDAC had to file tax returns. Chair Federizo stated that she feels that as long as the council comes together to determine if they want to pursue grant funding for x, y, & z under these criteria, she doesn't anticipate or foresee any issues of the state approving the RDAC from pursuing it if the opportunity comes.

Subcommittee member Annette Logan-Parker asked about adding an agenda item about educational opportunities for the council so that they all have an understanding of how to go about presenting those opportunities, how to go about understanding how that money goes from the grant award to the council, how it's audited, and how it ends up on a tax return. This will clarify how to identify resources for the council.

Chair Federizo stated that she understands where Ms. Logan-Parker is coming from and she will put it as a heading agenda item. One of the benefits of now being a bit further from COVID is that the resources from the state have been a little bit easier to contact and easier to get ahold of. This is a huge piece that they didn't delineate out to the council, like what are these avenues, since it is new for them and new for us. Chair Federizo stated that the RDAC is finding its way together, but she understands not wanting to go down some road.

Ms. Logan-Parker shared that that was her concern and that she would like to understand the rules of engagement with funding so that they can be impactful and efficient and not problematic. Chair Federizo followed up with sharing that the council will probably be creating a lot of those rules and criteria. This way, the council will be sending it to the state for approval stating, 'this is where we are at', 'this is what we think we need.' The council will have to pull a report for the state in November, these are items that will need to be placed in there. That there was a lack of structure in terms of getting it started and an assumption that council members know what an RDAC is and know what an RDAC should do, know what other RDACs do. With Chair Federizo's work with NORD, it appears that other RDAC's feel the same that it's been a starting and learning progress, but it's difficult. Chair Federizo expressed that she feels that new members and new council members should have an opportunity to have an orientation of what an Open Meeting Law is because you don't want to violate meeting law and none of the council members were given that information prior. Subcommittee member Annette Logan-Parker agreed that it should be added as an agenda item in the future.

5) Discussion of future meeting dates and times – Chair/Subcommittee

Chair Federizo opened up the discussion for future meeting dates. This meeting will be in August, and Chair Federizo brought up that afternoons seem to be better. She suggested August 20th at the same time, 1 P.M., unless someone has a better time or date that week. Chair Federizo shared that she is open that week if anyone has any conflicts or a better time.

Subcommittee member Kimberly Palma-Ortega stated that the 20th works for her and the timeframe is good. Subcommittee member Annette Logan-Parker stated that it works for her as well.

Chair Federizo will set it with the Attorney General to block August 20th at 1PM and get it forwarded for pre-approval for the agenda.

6) PUBLIC COMMENT

Chair Federizo opened the floor for public comment. Chair Federizo asked if there was anyone from the public on the line and that they would have three minutes to make any discussions of topics discussed. No members of the public made a comment.

7) Adjournment – Chair

Chair Federizo moved to adjourn and expressed appreciation for everyone on the subcommittee and everyone’s commitment to getting everything going.

Subcommittee member Linetta Barnes shared that she was in attendance of the meeting, but was a few minutes late.

Chair Federizo asked if she was present for the votes, which Ms. Barnes reported that she was. Chair Federizo shared that she was not notified that Ms. Barnes was present, but they already met quorum, and her attendance cannot be recorded since the committee already had roll call. Chair Federizo informed Ms. Barnes that in the future to announce her arrival so her votes can count.

Chair Federizo moved to adjourn the meeting at 1:42 PM.