

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
MEETING MINUTES
June 9, 2021
9:00am – 11:00am

MEETING LOCATIONS:

This meeting will be held online, by phone, and at a physical location. The online and phone meeting location is:

Meeting Link:

<https://nvhealth.webex.com/nvhealth/j.php?MTID=mb6ef32f13aca1215de925681d0ca4308>

Meeting number (access code): 1876 21 0331

Meeting password: 2Dyk2Fstgf9

Phone: 1-415-655-0001
(Access code: 1876210331#)

Physical Meeting Location:

Nevada Division of Public and Behavioral Health (DPBH)
4150 Technology Way
Room #303
Carson City, Nevada 89706

Rex Gifford opened the meeting at 9:02 a.m.

1) INTRODUCTIONS AND ROLL CALL

COUNCIL MEMBERS PRESENT:

Amber Federizo, DNP, APRN, FNP-BC (CHAIR); Kimberly Palma-Ortega; Linetta Barnes, BSN RN; Jennifer Millett, MSN, RN (Quorum = 3)

COUNCIL MEMBERS ABSENT:

Annette Logan

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

Rex Gifford, Administrative Assistant III; Joseph Filippi, Executive Assistant; Jennie Belka, Administrative Assistant II; 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. This was verified by Rex Gifford and this item was closed.

3) POSSIBLE ACTION - Discussion and selection of domain name for the Nevada Rare Disease Advisory Council - Chair/Subcommittee

Options are:

- NVRDAC.org
- NVRDAC.com
- nevadarareadiseaseadvisorycouncil.org
- NevadaRDAC.org

Chair Federizo noted that council member Annette Logan has already allocated the domains (see list above) through Cure for the Kids. Chair Federizo stated that out of the four, the subcommittee will be voting to which of these domains will be the best for the website. Chair Federizo went through each subcommittee member to determine their vote, starting with subcommittee member Jennifer Millet. Ms. Millet voted for the NVRDAC.com option justifying that people tend to gravitate towards “dot-coms” versus “dot-org”. Subcommittee member Kimberly Palma-Ortega voted for NevadaRDAC.org, noting that previous Nevada websites tend to have the abbreviation “NV” and that by saying “Nevada” will be clearer. Ms. Palma-Ortega additionally noted that other non-profits utilize “dot-org”, so it may be easier to use a “dot-org” domain. Subcommittee Linetta Barnes shared that she is okay with either “org” or “com”, but votes for NevadaRDAC. Chair Federizo shared her concern that the “dot-com” may bring to question if the platform is legitimate and that “org” has credibility behind it. She continued stating that her vote would have been for the first option, NVRDAC.org, but that would lead to the votes being inconclusive due to no more than one vote being cast for the same domain name.

Chair Federizo revisited choosing the NevadaRDAC.org option, which is also subcommittee member Kimberly Palma-Ortega’s option. Chair Federizo followed up with the subcommittee for their input. Subcommittee member Jennifer Millet stated that she is okay with NevadaRDAC.org. Subcommittee member Linetta Barnes revisited the options noting that she is okay with the NVRDAC.org option with it being shorter/condensed. Ms. Barnes stated that the NevadaRDAC stood out to her, but she is okay with either option NVRDAC or NevadaRDAC.

Chair Federizo asked the subcommittee if NevadaRDAC.org is too long, to which Ms. Palma-Ortega responded that it may be easier for someone to spell out “Nevada” versus “NV”. Ms. Palma-Ortega continued noting that her experience has reflected that there are issues when there is a lot to spell out or

if there is a lot of abbreviations that lead to people messing up and being directed somewhere else. She noted that using the word “Nevada” may stand out and continues to choose NevadaRDAC.org, but she is open to what the rest of the subcommittee has for input and their vote.

Chair Federizo reviewed the options one more time. Subcommittee member Jennifer Millet voted for NVRDAC.org. Subcommittee member Linetta Barnes voted for NVRDAC.org but suggested that when information is shared to the public, it should state “Nevada RDAC.” Chair Federizo made the majority vote to stay with NVRDAC.org option. Chair Federizo stated that she can work with the Cure for the Kids IT to where people can use both options, NVRDAC.org and NevadaRDAC.org, to link to the program’s website. We are also able to see how many times people are attempting to use the pathways to get to the website. In the future, this can be used to determine if the domain or name needs to be changed.

At this time, the chosen domain is NVRDAC.org.

- 4) POSSIBLE ACTION - Discussion and selection of registry of diagnosis and Nevada providers for the creation of an online up-to-date database of providers who treat rare disease organized by disease state rather than the specialty - Chair/Subcommittee

Chair Federizo opened up the discussion registry of diagnosis and providers that will be attached to that. Chair Federizo continued that the idea is to speak to the IT department to develop a database where patients would search by their diagnosis rather than the provider specialty or the name of the provider specialty. This will allow patients with any disorder to type in their diagnosis and it would link to providers in Nevada who works with that diagnosis. The National Organization for Rare Disorders (NORD) website has a comprehensive listing of rare diseases, listing approximately 500 in the database. NORD is okay with Nevada RDAC utilizing their database, but Chair Federizo wanted to touch base with everyone to see if anyone has any concerns with NORD missing a diagnosis. Chair Federizo opened up the floor to this topic for the subcommittee to discuss.

Subcommittee member Kimberly Palma-Ortega shared that she has utilized NORD before, which has led to finding research and other items. Ms. Palma-Ortega stated that she believes accessing NORD is a disability-related or disease-related common practice. Ms. Palma-Ortega feels as though what Chair Federizo mentioned is appropriate. Subcommittee member Jennifer Millet agreed to utilize the NORD link. Subcommittee member Linetta Barnes additionally agreed to utilize the NORD database.

Chair Federizo followed up that the other component to agenda item four to the discussion around reaching out to those who the RDAC would like to add onto the database, to determine which hospitals they cover. Sometimes patients may not have connected with the actual facility with that provider, but may have to go to the hospital. This will help link patients to the right hospitals. When reaching out to the providers, the RDAC can determine what their capabilities include.

Subcommittee member Kimberly Palma-Ortega stated that she believes that would be helpful, especially with how difficult it is to manage and navigate medical care within our state. This will allow us to put everyone on the same page. It is important for us to pull together individuals seeking out support and have this level of communication. We are setting a new tone for awareness and acknowledgement of what our state does have to offer.

Subcommittee member Linetta Barnes followed up to summarize what was previously stated that this initiative is to incorporate the hospitals and education to the families to connect them to resources and potential hospitals. Chair Federizo responded with an example of if someone in the community is suffering with a rare disease is presented to a place, such as Desert Springs or Centennial, and has to be transferred to another location causing an inconvenience and potentially delay their care further. This can be prevented if they are aware of other hospitals that are connected with the specific hospital that can treat their rare disease. Ms. Linetta Barnes stated that all of the hospitals are connected to rare diseases, but she understands that by linking hospitals that have a trained staff to properly handle specific rare diseases, such as hemophilia, it will be beneficial to send them in the right direction. Ms. Barnes expressed concern towards people knowing that there is a choice. Chair Federizo further explained that the process will include searching the diagnosis and finding the provider, the database will share information regarding where the provider can practice. Every hospital is going to say that they are specialized in all care, but there is a concern of patients still needing to transfer out. Chair Federizo continued with not wanting to leave the onus on the hospital to say whether or not they could take this patient or not, but for the onus to be on the provider who are providing rare disease care to say, 'I'm privileged and credentialed and go around to x, y, and z hospitals.' This will allow patients to know which hospital they can go to based on the provider. Subcommittee member Linetta Barnes stated that she is in agreement.

Chair Federizo motioned to approve the registry of diagnosis to include the hospitals, credentials, the rare disease list from NORD, and the diagnosis being linked with the providers state-wide. Jennifer Millet seconded the motion to approve. The Council voted unanimously to approve the registry process.

- 5) POSSIBLE ACTION - Discussion and selection of educational and organization community-based resources to be made available to consumers and providers, similar to National Organization for Rare Disorders (NORD) website for education. – Chair/Subcommittee

Chair Federizo shared that although she likes NORD's website, it is very national. She suggested that as resources are placed in the Nevada RDAC website, they are Nevada specific. To be inclusive of that, Chair Federizo opened up the floor for discussion on including all of the community-based organizations and having them be highlighted on the website. This can include a link and location to these organizations. It can also go by diagnosis to help patients know what these organizations work with. For example, there is a National Hemophilia Foundation in Nevada and people don't realize that other diagnoses can seek support from them and it's not just for those with hemophilia disorders. By dividing up resources by diagnosis, it will help patients link to all potential community-based organizations. Chair Federizo opened up the floor for discussion on having the community-based organizations divided up similarly to what was previously determined for the providers.

Subcommittee member Kimberly Palma-Ortega stated that she feels as though it could be beneficial for the website. It will allow more traffic to the site and it will allow the site to be useful and not simply informational.

Chair Federizo added another component that this would not just be diagnosis specific, but include links to general resources, such as Nevada 211, to help with other available resources. Chair Federizo opened it up for additional discussion on this action item. Subcommittee member Jennifer Millet agreed with the additional suggestion and motioned that the subcommittee add the other resources. Subcommittee member Kimberly Palma-Ortega proposed an amendment to add a subtab for miscellaneous items, not

just community-based resources. Chair Federizo confirmed that Jennifer Millet's motion was to include all of what was previously discussed, such as food resources and community-based organizations. Ms. Jennifer Millet agreed.

Subcommittee member Jennifer Millet motioned to approve the registry of diagnosis to include community based organizations and additional state-wide resources. Linetta Barnes seconded the motion to approve. The Council voted unanimously to approve the registry process.

- 6) POSSIBLE ACTION - Discussion of content and use of National Organization for Rare Disorders (NORD) resources to feature on the RDAC website. - Chair/Subcommittee

Chair Federizo noted that she separated this topic due to the NORD resources are open to RDAC utilizing their information but expressed wanting to discuss if the information shared by them is too general in terms of education. She suggested utilizing NORD's resources as a starting point and uploading their resources. Chair Federizo opened up the discussion to the subcommittee.

Subcommittee member Jennifer Millet shared that she looked at the NORD website and feels as though the information shared is extensive. Ms. Millet believes that the information that NORD has is comprehensive and stated that she has no problem using the information from their website.

Subcommittee member Kimberly Palma-Ortega stated that she also doesn't have a problem with using their information and suggested tabling the topic to learn more.

Subcommittee member Linetta Barnes commenting that she believes it be will beneficial to utilize the NORD platform for educational and resource purposes, especially in the beginning. As more information is gathered, RDAC can keep them but maybe move the to a different section of the website. Chair Federizo stated that she likes that approach and it mirrors everyone's thought process of it being a great starting point. Chair Federizo proposed that on the diagnosis that the main council has approved the subcommittee to focus on, she will have NORD access those resources that matched the diagnosis of focus and their general content, Chair Federizo will have them utilize that as a starting point and as RDAC progresses with content, there will be more Nevada RDAC specific things.

Chair Federizo motioned to approve the use of National Organization for Rare Disorders (NORD) resources to feature on the RDAC website. Linetta Barnes seconded the motion to approve. The Council voted unanimously to approve the registry process.

- 7) POSSIBLE ACTION - Discussion and approval of formatting options of RDAC website design - Chair/Subcommittee

Chair Federizo noted that agenda item number seven will have to be tabled for another time since subcommittee member Annette Logan was not present for this discussion. Ms. Logan's IT has been working on the website, so determining the design will be pending.

Chair Federizo then stated that this agenda item will be deferred until the website if further developed.

- 8) Discussion of future agenda items – Chair/Subcommittee

Chair Federizo stated that agenda item number seven will be moved to a future agenda. Chair Federizo opened the discussion to the floor of any other future agenda items.

Subcommittee member Kimberly Palma-Ortega suggested revisiting agenda items four, five, and six to get updates and see where the subcommittee is at when it comes to verbiage, community outreach, and delegate tasks for the subcommittee to take on. Chair Federizo stated that her plan was to follow up with subcommittee member Annette Logan to see where the IT team is at with the website development and the sections they are creating first. Then Chair Federizo would reach out to the whole council with contact information to make sure that the council has their information included. As IT is able to build the website, Chair Federizo will reach out to the committee members for additional support. Chair Federizo noted that since the website is being built for free, she doesn't want to overwhelm them at once, but to focus on registry and diagnosis first. She planned on working through sections in order of agenda item four through six. Ms. Palma-Ortega agreed with that process. Chair Federizo will include revisiting agenda item four, five, and six in any future meetings as a general update on these areas.

Chair Federizo opened the discussion to any additional agenda items.

Subcommittee member Linetta Barnes brought up if there are any upcoming events that are occurring or something that can be discussed of any community events. Chair Federizo followed up that she is hoping once IT begins to add community organizations, they will be able to have a running banner of who submitted events. When it comes to upcoming events, Chair Federizo is unaware of any upcoming events. She asked the subcommittee if they are aware of any upcoming events, to which no member responded.

Subcommittee member Kimberly Ortega-Palmer brought up adding an agenda item for reaching out to community providers, such as CCSDs and nurses. This can ensure that schools are aware of the website. Chair Federizo agreed that it is a great idea, especially with school starting back up in July and August. Chair Federizo said that the subcommittee can start to think about who to reach out to and potentially what their timing may be for their education. Ms. Palma-Ortega followed up with including connections with state programs that include the medically fragile population and foster care programs. Outreach can include letting them be aware of what is going on. Chair Federizo noted that this proposed agenda item will be added.

Chair Federizo asked the subcommittee if there are any other items to propose. Subcommittee member Jennifer Millet followed up with informing medical groups, such as physicians, about the RDAC. She suggested reaching out the private practices and hospitals to let them know and see if they have any additional thoughts of the program going forward. Chair Federizo commented that labeling it as educational outreach in case they are unable to encompass something since one of the hardest things is being too specific and needing to constantly revisit the topic because it was too narrow. Chair Federizo suggested the educational outreach and shared that between now and the next meeting the subcommittee should begin to think about the clinician, medical, community, state, and government- side for educational outreach. The subcommittee can determine all the entities and how they should reach out, whether that is inclusive of whomever the committee decides and being able to reach out to them. Chair Federizo acknowledges that within the state government that there is little known of other statewide resources. Chair Federizo will make that agenda item a broad educational outreach so when the subcommittee meets again, they can streamline who to target by which section, where, and what timeframe.

Chair Federizo asked if subcommittee member Linetta Barnes if she has anything to suggest as an upcoming agenda item, to which Ms. Barnes stated that she does not.

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

Chair Federizo noted that with the Legislative Subcommittee, they decided to roll it into the main council meeting because of the legislative session has now ended. In the interim, they will still keep it on the radar. For this subcommittee, Chair Federizo prefers to keep it going to every month or every two months, depending on availability, to keep building the RDAC website.

Subcommittee member Kimberly Palma-Ortega suggested keeping the meetings monthly as they are working through the website initially and to make sure they are staying on top of the information that will be added. Ms. Palma-Ortega added she believes it will be beneficial for them to continue to work with subcommittee member Annette Logan to have a clear understanding on where the website is going and any bumps in the road that may come up.

Chair Federizo suggested July 9th and checked with subcommittee on their availability for that week.

Rex Gifford requested clarification on what subcommittee is being discussed for scheduling. Chair Federizo said that she was referencing the legislative subcommittee prior, but they are discussing the educational subcommittee as she does not intend to rolling this committee into the main RDAC committee at this time.

Subcommittee member Jennifer Millet noted that afternoons work best and clarified which week the subcommittee is looking at. Chair Federizo noted that she was looking at later in the week since it is the week after holiday. Chair Federizo shared that she is available the 9th from 12PM to 4PM. Ms. Millet responded that she is also available at that time. Subcommittee member Linetta Barnes noted she is also available at that time. Subcommittee member Kimberly Palma-Ortega said that she is open that day as well.

Chair Federizo suggested 1PM on July 9th.

Joseph Filippi checked in to see if the subcommittee is interested in having the meeting completely virtual, without having a physical location. According to AB253, the council can make a decision on if they want to meet completely virtual or if they want to do a hybrid model of meeting virtually with a physical location available for members or the public.

Chair Federizo responded that she would like to keep it hybrid in case people didn't have access to phones or have access to attend virtually. Chair Federizo would like to keep the option for people to come in. She would like there to be physical location for the July 9th meeting just in case to make sure to capture everyone.

Joseph Filippi followed up to see if the subcommittee members are interested in meeting in person and if there needs to be a location available in Las Vegas or if they would like to just keep it virtual and then have the Carson City location available.

Chair Federizo stated that this time she is okay with just having the Carson City location. It is easier to have the DHHS to go there and to have the subcommittee members stay virtually. It is easier for them to have more members attend virtually and meeting quorum.

Joseph Filippi thanked Chair Federizo for her input.

Chair Federizo continued and the time for the next Educational Subcommittee meeting was set for July 9th at 1:00 PM - 2:00 PM. Chair Federizo stated that she will try to keep the subcommittee meetings under an hour to the best of her ability.

10) 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.

11) Adjournment – Chair

Chair Federizo moved to adjourn the meeting at 9:43 AM. Chair Federizo expressed appreciation for everyone who attended and their patience. She stated she appreciated everyone's time and wished everyone a great afternoon.

DRAFT