

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
September 30, 2021
2:00pm – Adjournment

Meeting Locations:

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

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

Video Conference ID: 113 035 227 4

Phone: +1 775-321-6111,,176149675# United States, Reno

Phone Conference ID: 176 149 675#

Rex Gifford opened the meeting at 2:00 p.m.

1) INTRODUCTIONS AND ROLL CALL

COUNCIL MEMBERS PRESENT:

Amber Federizo, DNP, APRN, FNP-BC (CHAIR); Annette Logan-Parker; Jennifer Millet, MSN, RN;
Linetta Barnes, BSN, RN
(Quorum = 3)

COUNCIL MEMBERS ABSENT:

Kimberly Palma-Ortega

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.

3) POSSIBLE ACTION: Approval of prior minutes of the education subcommittee

Chair Amber Federizo introduced the approval the previous meeting minutes, dated July 9, 2021, opening the floor for feedback.

Chair Federizo motioned to approve meeting minutes from prior Educational Subcommittee meeting. Subcommittee member Annette Logan-Parker motioned to approve. Subcommittee member Jennifer Millet seconded the motion to approve. The subcommittee voted unanimously to approve prior meeting minutes.

4) POSSIBLE ACTION: Discussion and possible action to approve invitational letter for RDAC website registry inclusion for community-based organizations and providers.

Chair Federizo opened the discussion for input on the invitational letter for the RDAC website registry inclusion.

Subcommittee member Annette Logan-Parker brought up putting an emphasis on the particular conditions that the RDAC is looking for/focusing on this year, such as other rare diseases. Subcommittee member Logan-Parker suggested including examples of particular diseases that the RDAC will be looking for. Chair Federizo followed up that Subcommittee member Logan-Parker brought up a good point as some individuals may not know what is considered a rare disease. Chair Federizo asked the council and subcommittee member Logan-Parker where a good location would be to add that on the letter. Subcommittee member Logan-Parker suggested a list be an attachment to the letter. The attachment can note what the council has been focusing on in the first year, the rare diseases monitored by the newborn screenings, etc. Subcommittee member Logan-Parker noted that the letter should remain short, but there could be an attachment with a definition of rare diseases based on what the RDAC is looking for. Chair Federizo asked Subcommittee member Annette Logan-Parker to send a copy of the rare diseases that applies specifically for pediatric cancer and the conditions that are looked at, she will then follow up with Nik (Dr. Nik Rashid) in terms of newborn screening for Nevada, then include the inherited leading into the attached list for the second page.

Rex Gifford shared the invitational letter on the screen.

Subcommittee member Linetta Barnes commented on the definition used for rare disease, wondering if the definition is still under 200,000 documented patients or under. If the disease is not included on the list provided, for others to understand that the rare disease definition still applies if they are in that category. Chair Federizo shared that there is not one standardized version of that amount for the rare disease definition, so it's difficult to capture the prevalence and incidence. It's unknown what falls into those numbers since there is few of these diseases found. Chair Federizo shared that with Nevada's barriers and obstacles placed on health care, some diseases, which may not fall into the rare disease category, become methods of focus because it's so rare to find providers to care for that population. She noted that utilizing an of the definitions that are currently circulating are like one in 10,000 or one in 100,000, therefore she suggests providing a list of specific disease that the RDAC is looking for. Chair

Federizo stated that she can include all of the NORD rare diseases, but that would be over 500. It may be better to focus on the primary ones until there is a better guideline in terms of rare disease.

Rex Gifford informed the subcommittee of the letter being available on the screen.

Subcommittee member Annette Logan-Parker brought up possibly including the website address into the letter. She suggested providing an electronic version of the letter to link providers to the website. This is dependent on if the website is ready in time. Chair Federizo updated that the IT is looking at a test run going live in November so it won't be available prior to then, but it will be in beta mode. Chair Federizo agreed that including the website link will be helpful so the providers know where the information is going.

Subcommittee member Logan-Parker suggested an "under construction" message on the website. Ms. Logan-Parker emphasized the importance of providing the information for the website to make sure the community is aware that it's a resource. Chair Federizo followed up that this approach would be beneficial to have people submit information. Chair Federizo will have to follow up with Mitch and Amber (website developers) about a link for providers to submit their information, such as a link that connects to Mitch, Amber, or Chair Federizo. Subcommittee member Logan-Parker confirmed that it should be possible to have a link to provide with the letter.

Subcommittee member Logan-Parker asked about including the dollar amount for the Amazon gift card. If it is included, Ms. Logan-Parker noted that the amount should be substantial enough to stimulate people to participate. Chair Federizo shared that she cannot include the value of the card until the next agenda item, which is voting for the amount. This would need to be approved by the subcommittee for the current nominal budget.

Chair Federizo followed up noting that she feels that it's a good idea to implement a gift card to provide incentive and encourage participation.

Chair Federizo asked if there is a statewide email address for the RDAC. DPBH member Rex Gifford answered Chair Federizo that there is no state email for the RDAC. DPBH member Joseph Filippi followed up that there is a cost to create and maintain an email, which will need to come out of the RDAC budget. Subcommittee member Annette Logan-Parker suggested connecting with the website developers as this could be a component of the website platform where the website can forward messages to multiple emails. Chair Federizo agreed that that may be a more cost effective alternative.

Chair Federizo motioned to pass the letter as revised inclusive of the language with the title of the website updated after developing a statewide website gives a direct address, removing the email and instead replacing it with either a link to the website, and a second page attached for a list with example diagnoses. Subcommittee member Annette Logan-Parker approved. Subcommittee member Linetta Barnes seconded the approval. The subcommittee voted unanimously to approve the invitational letter for the RDAC website registry inclusion for community-based organizations and providers.

- 5) POSSIBLE ACTION: Discussion and possible action to approve use of gift card incentives for participation in the RDAC website registry, including possible prize lottery for registry submissions.

Chair Federizo introduced the next agenda item as the approval of use the gift cards as incentives for participation into the ARDAC website registry including possible prize lottery for registry submissions. This agenda item will approve the dollar amount assigned to the gift card and if it should apply to all participants or whether it's the first 10 submission. The current working total budget for the council is \$3,000.00.

Subcommittee member Linetta Barnes clarified the lottery specifics of how the lottery winners will be determined. Chair Federizo confirmed that this agenda item will allow the subcommittee to choose the methodology to select who to give gift cards to, whether it's all participants or a select few.

Subcommittee member Annette Logan-Parker suggested putting all participant's information into the lottery allowing everyone to have a fair chance of winning.

Chair Federizo asked the council about the amount allotted for the gift cards. Subcommittee member Annette Logan-Parker suggested a \$100 gift card. Chair Federizo agreed with Ms. Logan-Parker. Chair Federizo motioned to pass that all participants be placed into the lottery-style poll for an Amazon gift card in the amount of \$100. DPBH member Rex Gifford followed up that there may be concerns with a lottery with the Gaming Commission. Deputy Attorney General Pierron Tackes reported that this sounds more like a raffle, but she will conduct research to confirm if it may be an issue. Ms. Tackes suggested that the subcommittee vote for this agenda item and she will conduct a legal analysis and follow up before the next RDAC meeting with all council member in October.

Subcommittee member Linetta Barnes suggested referring to the lottery as a raffle instead. Chair Federizo stated that she will adjust the semantics of the original letter from "lottery" to "raffle" as the councils waits for the legal advisement.

Subcommittee member Linetta Barnes asked about determining the amount of gift cards for the raffle. Ms. Barnes followed up of keeping the exact number of gift cards and amounts off of the letter and keeping it open but determining a cut off amount. Chair Federizo clarified that Ms. Barnes suggested leaving the amounts blank and updating it will require the item to be agendized for the October meeting versus finalizing the amounts at this meeting. Mr. Barnes shared that there is a concern of a low number of participants and how it will impact the budget. Chair Federizo noted that there will need to be a cut off amount if it is not clarified. This leads to the idea of a raffle for one registration to receive the \$100 gift card since it limited the outset. Chair Federizo stated that they can always return to the letter over time and update it, possibly quarterly.

Chair Federizo motioned to pass the raffle of \$100 for one participant, once determined if the council can do a raffle. Subcommittee member Annette Logan-Parker approved motion. Subcommittee member Linetta Barnes seconded the approval. The subcommittee voted unanimously to approve the gift card incentives for participation in the RDAC website registry.

Chair Federizo revisited the agenda item to discuss the website registry format. She explained that there are three different options. DPBH member Rex Gifford shared the formats for subcommittee members to review. Chair Federizo informed the subcommittee that both NORD and Zebra gave permission to utilize their directories of diagnoses as well as connecting people with providers.

The Subcommittee reviewed the website outline examples.

Chair Federizo outlined the timeline for the website:

- Phase One: November 20th
- Basic functionality

- Who we are | Why we do what we do
- Website up and running
- Relevant core information, vision, mission, members photos, and links to all organizations
- Registry information
- Redirection from already purchased domain names
- Government session information
- Link previous meeting minutes
- Facebook and Twitter page created

Phase Two: March 2022

- Link to NORD website for searchable diagnoses
- Research link articles
- Bios on council members
- Categories
- Physician Directory Integration
- Animation
- E-Newsletter Template created

Phase Three: June 2022

- More robust and hosted searchable design
- Diagnosis finder integration

Subcommittee member Annette Logan-Parker shared that all the designs are great and stated that the first option is her favorite with a high level of professionalism. Subcommittee member Jennifer Millet agreed with Ms. Logan-Parker with a suggestion of emphasizing “RDAC”. Chair Federizo shared that she can bring feedback to the website developers based on the suggestions of the subcommittee. The subcommittee discussed color options and the RDAC logo. Subcommittee member Linetta Barnes agreed with the first option.

Chair Federizo stated that she will have the main Council authorize the educational subcommittee to make decisions on the appearance of logos.

Chair Federizo motioned to pass option one with having the website developers make some changes that the subcommittee recommends. Subcommittee member Annette Logan-Parker approved the motion. Subcommittee member Linetta Barnes seconded the approval. The subcommittee voted unanimously to approve the website design to be presented to the main council.

6) Discussion of future agenda items – Chair/Subcommittee

Chair Federizo noted that there are no topics pending.

Subcommittee member Linetta Barnes asked about any outreach opportunities, such as an event, allowing the RDAC to connect with the community. Chair Federizo noted that she is not aware of any events. National Rare Disease Day is approaching in February and to be aware of that in January. Chair Federizo will keep outreach as an ongoing agenda item.

DPBH member Rex Gifford brought up the branding guide. Chair Federizo followed up by noting that this meeting will not include a vote for the branding guide. The main council will need to authorize the educational subcommittee to work on it.

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

Chair Federizo suggested not scheduling a meeting yet since the main council is meeting in October. The subcommittee can meet up again in November, possible December. The subcommittee agreed. A Doodle Poll will be sent out for the next meeting in November.

8) PUBLIC COMMENT

Chair Federizo opened the floor for public comment. No members of the public made a comment.

9) Adjournment – Chair

Chair Federizo moved to adjourn and expressed appreciation for everyone on the subcommittee.

Chair Federizo moved to adjourn the meeting at 2:57 PM.