

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**  
**October 20, 2021**  
**12:00pm – 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: 111 682 120 6

**Phone:** +1 775-321-6111, 247 562 731# United States, Reno

Phone Conference ID: 247 562 731#

Rex Gifford opened the meeting at 12:00 p.m.

1) INTRODUCTIONS AND ROLL CALL

**COUNCIL MEMBERS PRESENT:**

Members (14) 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; Nik F. Nik Abdul Rashid, MD; Paul Niedermeyer; Max Coppes, MD, PhD, MBA; Veneta Lepera, BSN, RN; Annette Logan-Parker; (Quorum=8)

**COUNCIL MEMBERS ABSENT:**

Valerie Porter, DNP, BSN, MBA; Brynlin Thornley; Kimberly Palma-Ortega; Naja Bagner

**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 minutes from July 16, 2021 meeting. – Council Members

Chair Amber Federizo introduced the approval the previous meeting minutes, dated July 16, 2021, opening the floor for feedback.

**Council member Jennifer Millet motioned to approve meeting minutes from prior council meeting. Council member Max Coppes second the motion to approve. The Council voted unanimously to approve prior meeting minutes.**

## 4) POSSIBLE ACTION: Discussion and possible action to approve the annual report recommendations and submission, required by NRS 439.5077. – Council Members

Rex Gifford shared the annual report on the screen for the council to review.

Chair Federizo reviewed the annual report that was drafted page by page. She explained the grading system for Nevada's report card according to the National Organization of Rare Disorders (NORD). Chair Federizo opened the discussion on if the annual report should include the NORD report card and feedback from the council, which there were none.

Chair Federizo continued with the annual report. She outlined the first objective regarding performing statistical and qualitative examination of the incidence, causes, and economic burden of rare disease, which includes the development of a registry of rare diseases in Nevada. Chair Federizo noted the activities performed and the recommendations. Chair Federizo opened the discussion of Objective 1 of the annual report. No comments were made.

Chair Federizo followed up with reviewing Objective 2 of the annual report. Objective 2 tasked the Council with receiving and considering reports and testimony concerning rare diseases from persons to division community-based organizations, providers of healthcare and other local and national organizations whose work relates to rare disease. Chair Federizo noted the activities performed and the recommendations. Chair Federizo opened the discussion of Objective 2 to the Council. Councilmember Ihsan Azzam noted that there is no clear definition of what a rare disease is. Providers may not be aware of what a rare disease is. Due to the loose definition of rare disease, this may impact the incidence of rare diseases. Dr. Azzam suggested using the national incidence as a surrogate rate until the Council is able to build its own database and calculate the true incidence in Nevada. Chair Federizo responded that this was a discussion in previous educational subcommittee meetings. The National incidence could leave out some of the cancer specific items that the council may want included. The goal of the invitational letter is to link the currently known list of rare disease through both the NORD website and cancer registry to allow people to be aware of the specific disorders that the council is looking at. At this time, incentives are being reviewed to prompt participation among providers. Chair Federizo noted that she is hoping to hyperlink the NORD and Cancer Registry to provide insight on what the council is looking for. Dr. Azzam thanked Chair Federizo. No additional comments were made regarding Objective 2.

Chair Federizo continued with the next objectives, Objectives 3 and 7, which were consolidated in the report. Objective 3 focused on increasing awareness of the burden caused by rare disease in Nevada and Objective 7 is to increase awareness among provider of health care of the symptoms or and care for patients with rare disease. Chair Federizo noted the activities performed and the recommendations. Chair Federizo opened the discussion for these objectives. No comments were made regarding Objectives 3 and 7.

Chair Federizo transitioned to Objectives 4 and 9. Objective 4 focuses on identifying evidence-based strategies to prevent and control rare disease. Objective 9 was determined the effective methods of collecting data concerning cases of rare diseases in Nevada for the purpose of conducting epidemiological studies. Chair Federizo noted the activities performed and the recommendations. Chair Federizo opened the discussion for these objectives. No comments were made regarding Objectives 4 and 9.

Chair Federizo reviewed Objective 5 to determine the effect of delayed or inappropriate treatment on the quality of life for patients suffering from Rare Disease and the economy of Nevada. Chair Federizo noted the activities performed and the recommendations. Chair Federizo opened the discussion for this objective. No comments were made for Objective 5.

Chair Federizo followed up with Objectives 6, 8, and 10. Objective 6 was to study the effect of early treatment for rare disease and the quality of life for patients suffering from Rare Disease and the provision of services to such patients and reimbursement for such services. Objective 8 was the evaluation the systems for delivering treatment for diseases in place in Nevada and develop recommendations to increase the survival rates and quality of life of patients with rare disease. Objective 10 is to establish a comprehensive plan for the management of rare diseases in Nevada, which must include recommendations for the state and local health authorities, public and private organizations, businesses, and potential sources of funding and update the comprehensive plan as necessary. Chair Federizo noted the activities performed and the recommendations. Chair Federizo opened the discussion for these objectives. No comments were made for Objectives 6, 8, and 10.

Chair Federizo continued to the Summary section of the annual report. She reviewed and explained the summary page included in the annual report. This section provided explanation of activities, recommendations, and gratitude. Chair Federizo opened the discussion for feedback on the annual report.

Joseph Filippi followed up with the Council to see if there are any comments about the annual report. Councilmember Veneta Lepera noted that the annual report looks great and supports the report noting how the council will need funding to be effective. Councilmember Jennifer Millet reported that she agrees with the annual report and she is okay with submitting it as is. Councilmember Nik Rashid agreed that the report was well done. Dr. Rashid had a follow up question about the Patient Protection Commission and requested information about it. Chair Federizo answered Dr. Rashid that the Patient Protection Commission is under open meeting laws. Had the RDAC be integrated as a part of the Patient Protection Commission in the last legislative sessions, the Council would have been able to change the language in some areas. Dr. Nik Rashid followed up asking if the Council were a part of the Patient

Protection Commission, if they would still need to meet separately and then join the Patient Protection Commission meetings. Chair Federizo confirmed that the Council can meet with them and separately. She noted how it is probably better to have a group within the Commission to be able to attend meetings with both the RDAC and Patient Protection Commission to present information, meet with experts, and improve an impact statement. Dr. Nik Rashid thanked Chair Federizo.

**Chair Federizo motioned to pass the annual letter with formatting revisions. Councilmember Nik Rashid seconded the approval. Councilmembers Veneta Lepera, Ihsan Azzam, Shirley Folkins-Roberts, Max Coppes, and Jennifer Millet agreed. The Council voted unanimously to approve the RDAC annual report.**

- 5) POSSIBLE ACTION: Discussion and possible action to authorize the Education Subcommittee to develop a branding guide for future use in RDAC correspondence.

Chair Federizo introduced the next agenda item and explained what the Educational Subcommittee has done for the branding of the RDAC website. This will provide an example of what the main council will approve the Educational Subcommittee to complete.

Councilmember Nik Rashid requested clarification of what is being presented. Chair Federizo noted that what is being presented are examples of materials that the subcommittee would be creating, which will be used for pamphlets and letterheads.

Rex Gifford shared the branding guide on the screen for the council to review.

Chair Federizo explained the branding guide for the RDAC and why the Councils input is needed for approval. Three options were shown the council. Chair Federizo noted that there are some revisions pending. She explained how the website will be outlined, with a directory of the council, a link to find Zebra, NORD, and provider specific information. The timeline of what is being worked on was also presented, to which Chair Federizo explained the timeline and status of the website. Chair Federizo noted that this vote will allow the Council to provide the authority of the Educational Subcommittee to develop a branding guide. This will allow the subcommittee to make decisions without having to consult the main Council.

**Chair Federizo motioned to approve authorization of the Educational Subcommittee to move forward with approvals for the website and branding guide. Veneta Lepera seconded the approval. Councilmembers Shirley Folkins-Roberts, Nik Rashid, Annette Logan-Parker, and Gina Glass approved. The Council voted unanimously to approve to authorize the Educational Subcommittee to develop a branding guide for future use in RDAC correspondence.**

- 6) Discussion of future agenda items – Council members

Chair Federizo stated that one agenda that will need to be included in the January meeting is to vote in chairs. As the council was implemented in 2019, the two year comes up in 2022. For the next agenda meeting in January, the Council will vote for election of the next chair. At this time, she has no other

future agenda items until the response for the Annual Report. Chair Federizo opened up the discussion of any other future agenda items. No additional agenda item suggestions were made.

7) Discussion of future meeting dates and times – Council members

Chair Federizo noted a DoodlePoll will be sent out for scheduling the next RDAC meeting in January.

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 council.

**Chair Federizo moved to adjourn the meeting at 1:08 PM.**

DRAFT