



RARE DISEASE ADVISORY COUNCIL

MEETING AGENDA

December 11, 2020

9:00am to 11:00am

Meeting Locations:

- This meeting will be held via teleconference only. 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 must participate by using the following:

<https://nvhealth.webex.com/nvhealth/j.php?MTID=maa42026bcce5ea1c418b5a85b47e8d55>

Join by phone

+1-415-655-0002 United States Toll

Access code: 146 602 6115

Please Note: Agenda items may be taken out of order, combined for consideration, and or removed from the agenda at the chairperson's discretion.

Members (15): Ihsan Azzam, MD, PhD; Naja Bagner; Linetta Barnes, BSN, RN; Max Coppes, MD, PhD, MBA; Amber Federizo, DNP, APRN, FNP-BC; Shirley Folkins-Roberts; Gina Glass; Veneta Lepera, BSN, RN; Annette Logan-Parker; Jennifer Millet, MSN, RN; Nik F. Nik Abdul Rashid, MD; Kimberly Palma-Ortega; Valerie Porter, DNP, BSN, MBA; Brynlin Thornley; Larissa White, MPH, CPH.
(Quorum=8)

- 1) Introductions and Roll call – DPBH Staff/Chair
- 2) Welcome and Opening Remarks - Chair
- 3) PUBLIC COMMENT

Because there is no physical location for this meeting, public testimony under this agenda item may be presented by computer, phone or written comment. Due to time considerations, each individual offering public comment will be limited to not more than 3:00 minutes. A person may also have comments added to the minutes of the meeting by submitting them in writing either in addition to testifying or in lieu of testifying. Written comments may be submitted electronically before, during, or after the meeting by emailing Rex Gifford at r.gifford@health.nv.gov. You may also mail written documents to the Division of Public and Behavioral Health, 4150 Technology Way, Suite 300, Carson City, NV 89706, or fax them to (775) 687-7570.

- 4) FOR POSSIBLE ACTION: Consideration and Approval of previous Rare Disease Advisory Council Minutes from November 6, 2020 – Chair
 - 5) INFORMATIONAL ONLY: Presentation by Rose Gallagher of NORD (National Organization for Rare Disorders)
 - 6) FOR POSSIBLE ACTION: Consideration and approval of modifications made to the RDAC bylaws (Section 6.2) – Council Members
 - 7) 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
 - 8) FOR POSSIBLE ACTION: Consideration of the age cohort breakdown for the first RDAC report (see “Age and Diagnosis” document) – Council Members
 - 9) FOR POSSIBLE ACTION: Consideration of the first diagnoses of focus and number to be highlighted in the first RDAC report (see “Age and Diagnosis” document) – Council Members
 - 10) FOR POSSIBLE ACTION: Consideration of a Mission and Vision Statement for the RDAC (see “Mission and Vision” document) – Council Members
 - 11) INFORMATIONAL ONLY: Presentation for review of the Sickle Cell Disease Registry Regulations (see “NAC SC Registry” document) – Council Members
 - 12) FOR POSSIBLE ACTION: Identification of future agenda items – Council Members
 - 13) PUBLIC COMMENT

(Action may not be taken on any matter brought up under this agenda item until scheduled on an agenda for a later meeting) Because there is no physical location for this meeting, public testimony under this agenda item may be presented by phone or written comment. Due to time considerations, each individual offering public comment will be limited to not more than **3:00 minutes**.
 - 14) Adjournment – Chair
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NOTICES OF PUBLIC MEETING HAVE BEEN POSTED AT THE FOLLOWING LOCATIONS:

In accordance with Nevada Governor Sisolak’s Declaration of Emergency Directive 006 there will not be a physical location for the Rare Disease Advisory Council Meeting. The public is strongly encouraged to participate by phone or computer and downloading any material provided for the meeting at the website addresses below.

- As per Nevada Governor Sisolak’s Declaration of Emergency Directive 006; Subsection 3: The requirements contained in NRS 241.020 (4) (a) that public notice agendas be posted at physical locations within the State of Nevada are suspended.
- As per Nevada Governor Sisolak’s Declaration of Emergency Directive 006; Subsection 4: Public bodies must still comply with requirements in NRS 241.020 (4)(b) and NRS 241.020 (4)(c) that public notice agendas be posted to Nevada’s notice website and the public body’s website, if it maintains one along with providing a copy to any person who has requested one via U.S. mail or electronic mail.
- As per Nevada Governor Sisolak’s Declaration of Emergency Directive 006; Subsection 5: The requirement contained in NRS 241.020 (3)(c) that physical locations be available for the public to receive supporting material for public meetings is suspended.
- As per Nevada Governor Sisolak’s Declaration of Emergency Directive 006; Subsection 6: If a public body holds a meeting and does not provide a physical location where supporting material is available to the public, the public body must provide on its public notice agenda the name and contact information for the person designated by the public body from whom a member of the public may request supporting material electronically and must post supporting material to the public body’s website, if it maintains one.

On the Internet at the Nevada Division of Public and Behavioral Health website:

<http://dph.nv.gov/Boards/RDAC/RDAC/>

On the internet at the Nevada Public Notice website: <https://notice.nv.gov>

Written comments in excess of one typed page on any agenda items which requires a vote are respectfully requested to be submitted to the Council at the above address five (5) calendar days prior to the meeting to ensure that adequate consideration is given to the material. We are pleased to make reasonable accommodations for members of the public who are disabled and wish to attend the meeting.

Members of the public who are disabled and require special accommodations or assistance at the meeting are requested to notify, in writing, the Division of Public and Behavioral Health, 4150 Technology Way, 3rd Floor, Carson City, NV 89706, or by calling Rex Gifford at 775-684-4217 no later than three (3) working days prior to the meeting date.

Supporting material for this meeting can be obtained from the Division of Public and Behavioral Health, by calling Rex Gifford at 775-684-4217 or emailing r.gifford@health.nv.gov.