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## Rare Disease Advisory Council

### Meeting Agenda

April 9, 2021  
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:

Meeting number (access code): 187 693 3915

Meeting password: 7N7CuPMPbR4

#### Meeting Link:

<https://nvhealth.webex.com/nvhealth/j.php?MTID=m066b023673d480c7bc6a77c3f42ec506>

#### Join by phone:

+1-415-655-0001 United States Toll

Access code: 187 693 3915

*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 (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; Valerie Porter, DNP, BSN, MBA; Nik F. Nik Abdul Rashid, MD; Brynlin Thornley; Kimberly Palma-Ortega; Paul Niedermeyer; Naja Bagner; Max Coppes, MD, PhD, MBA; Veneta Lepera, BSN, RN; Annette Logan-Parker; (Quorum=8)

- 1) Introduction and Roll call – DPBH Staff/Chair
- 2) INFORMATIONAL: Presentation of Senate Bill (SB) 40, providing for the collection of certain data relating to health care – Sara Chohagian, Executive Director, Patient Protection Commission
- 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 Jennie Belka at [jbelka@health.nv.gov](mailto:jbelka@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.



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- 4) POSSIBLE ACTION: Consideration and Approval of previous Rare Disease Advisory Council Minutes from January 8, 2021
  
  - 5) INFORMATIONAL: Discussion and updates relating to the Bill Draft Requests (BDR) relating to rare disease policy assigned to subcommittee members for surveillance during the 81<sup>st</sup> Legislative Session which includes the following BDRs:  
  
*BDR 40-5, BDR 38-6 (SB123), BDR 40-8, BDR 38-13, BDR 53-32, BDR 54-43, BDR 50, BDR 57-54 (SB139), BDR 55, BDR 38-56, BDR 54-61 (AB177), BDR 40-62, BDR 57-71 (AB135), BDR 43-88 (SB134), BDR S89 (SB96), BDR 40-192, BDR 49-229 (AB175), BDR 40-239 (AB164), BDR 251, BDR 252, BDR 40-478, BDR 38-522, BDR 38-541, BDR 54-632, BDR 654, BDR 40-655 (AB176), BDR 40-747, BDR 40-522 (AB181)*
  
  - 6) POSSIBLE ACTION: Discussion and possible action to approve subcommittee presentation of letter testimony in support, neutral, or against proposed BDRs with discussion of possible proposed amendments to AB40 and SB175.
  
  - 7) INFORMATIONAL: Discussion of data collected by each council member accounting for the diagnosis of focus and related data breakdown for each age group.
  
  - 8) POSSIBLE ACTION: Discussion and possible action to approve final language and revisions of the National Organization for Rare Disorders (NORD) information to create a Nevada informational brochure to bring awareness to the Nevada RDAC or to allow such revisions to be conducted and approved through meetings of the educational subcommittee.
  
  - 9) POSSIBLE ACTION: Discussion and possible action to allow Cure 4 the Kids to provide website design and support for an individual Nevada RDAC website. Initial design to include registry of providers in rare disease for the state, NORD information, and subsequent additions approved by AG following submission to the educational subcommittee.
  
  - 10) POSSIBLE ACTION: Discussion and possible action to vote to add Dr. Susanna Sorrentino as a non-voting member off the council, pursuant to NRS 439.5075(2), for a term of 3 years. – Council Members
  
  - 11) Discussion of future agenda items – Council Members
  
  - 12) Discussion of future meeting dates and times – 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.
  
  - 14) Adjournment – Chair

**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 (RDAC) Legislative Subcommittee Meeting. The public is strongly**



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**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://dpbh.nv.gov/Boards/RDAC/RDAC/>

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

This body will provide at least two public comment periods in compliance with the minimum requirements of the Open Meeting Law prior to adjournment. Additionally, it is the goal of the Rare Disease Advisory Council (RDAC) Legislative Subcommittee to also afford the public with an item-specific public comment period. No action may be taken on a matter raised under public comment unless the item has been specifically included on the agenda as an item upon which action may be taken. The Chair retains discretion to only provide for the Open Meeting Law’s minimum public comment and not call for additional item-specific public comment when it is deemed necessary by the chair to the orderly conduct of the meeting.

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 Jennie Belka at 775-684-2210 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 Jennie Belka at 775-684-2210 or emailing [jbelka@health.nv.gov](mailto:jbelka@health.nv.gov).