

THE RARE DISEASE ADVISORY COUNCIL BYLAWS
Drafted 08/2020

ARTICLE 1: NAME AND DEFINITIONS

- 1.1 The name of this group shall be the Rare Disease Advisory Council, hereinafter referred to as the “Council”.
- 1.2 The term “Department” refers to the Department of Health and Human Services.
- 1.3 The term “Director” refers to the Director of the Department of Health and Human Services.
- 1.4 The term “Division” refers to the State of Nevada Division of Public and Behavioral Health.
- 1.5 The term “NRS” refers to the Nevada Revised Statutes.

ARTICLE 2: AUTHORITY

- 2.1 The Council is authorized under NRS 439.5075 – NRS 439.5077.
- 2.2 The Council is considered advisory in nature and makes recommendations to the Nevada Division of Public and Behavioral Health and the Nevada Department of Health and Human Services

ARTICLE 3: PURPOSE AND FUNCTION

- 3.1 In accordance with NRS 439.5077, the Council shall carry out the provisions, inclusive, of this act:
 - 3.1.1 Perform a statistical and qualitative examination of the incidence, causes and economic burden of rare diseases in this State;
 - 3.1.2 Receive and consider reports and testimony concerning rare diseases from persons, the Division, community-based organizations, providers of health care and other local and national organizations whose work relates to rare diseases;
 - 3.1.3 Increase awareness of the burden caused by rare diseases in this State;
 - 3.1.4 Identify evidence-based strategies to prevent and control rare diseases;

- 3.1.5 Determine the effect of delayed or inappropriate treatment on the quality of life for patients suffering from rare diseases and the economy of this State;
 - 3.1.6 Study the effect of early treatment for rare diseases on the quality of life for patients suffering from rare diseases, the provision of services to such patients and reimbursement for such services;
 - 3.1.7 Increase awareness among providers of health care of the symptoms of and care for patients with rare diseases;
 - 3.1.8 Evaluate the systems for delivery of treatment for rare diseases in place in this State and develop recommendations to increase the survival rates and quality of life of patients with rare diseases;
 - 3.1.9 Determine effective methods of collecting data concerning cases of rare diseases in this State for the purpose of conducting epidemiological studies of rare diseases in this State;
 - 3.1.10 Establish a comprehensive plan for the management of rare diseases in this State, which must include, without limitation, recommendations for the Department, the Division, local health districts, public and private organizations, businesses and potential sources of funding, and update the comprehensive plan as necessary; and
 - 3.1.11 Develop a registry of rare diseases diagnosed in this State to determine the genetic and environmental factors that contribute to such rare diseases.
- 3.2 The Council shall compile an annual report which must include, without limitation, a summary of the activities of the Council and any recommendations of the Council for legislation or other policies. The Council shall:
- 3.2.1 Post the report on an Internet website maintained by the Department;
And
 - 3.2.2 Submit the report to the Department, the Governor and the Director of the Legislative Counsel Bureau for transmittal to:
 - (a) In even-numbered years, the next regular session of the Legislature; and
 - (b) In odd-numbered years, the Legislative Committee on Health Care.

ARTICLE 4: MEMBERSHIP

- 4.1 According to NRS 439.5075, the Council shall consist of:
- 4.1.1 The Chair of the State of Nevada Advisory Council on Palliative Care and Quality of Life created by NRS 232.4855 or his or her designee; and
 - 4.1.2 The following members appointed by the Director:
 - (a) Not more than three physicians who practice in the area of cardiology, emergency care, neurology, oncology, orthopedics, pediatrics or primary care and provide care to patients with rare diseases;
 - (b) Two registered nurses who provide care to patients with rare diseases;
 - (c) Not more than two administrators of hospitals that provide care to patients with rare diseases or their designees;
 - (d) One representative of the Division who provides education concerning rare diseases or the management of chronic conditions;
 - (e) The employee of the Division who is responsible for epidemiology services;
 - (f) Two persons over 18 years of age who have suffered from or currently suffer from a rare disease;
 - (g) Two parents or guardians who each have experience caring for a child with a rare disease;
 - (h) One representative of an organization dedicated to providing services to patients suffering from rare diseases in northern Nevada; and
 - (i) One representative of an organization dedicated to providing services to patients suffering from rare diseases in southern Nevada.
- 4.2 The term for each member of the Council is **(not specified in NRS – needs to be determined by a vote of the Council? Two years? Three?)**, and members shall serve at the pleasure of the Director.
- 4.3 The Council may, by affirmative vote of a majority of its members, request the Director to appoint to the Council additional members who have expertise on issues studied by the Council. Such members serve for a period determined by the Council.
- 4.4 A vacancy in the membership of the Council must be filled in the same manner as the initial appointment.
- 4.5 Removal of a Member:

- 4.5.1 A member of the Council may be removed by a majority vote of Council members, and with approval of the Director
- 4.5.2 Reasons include malfeasance in office or neglect of duty; and
- 4.5.3 Unexcused absence from two consecutive meetings of the Council.

ARTICLE 5: VOTING

- 5.1 A majority of the voting members of the Council, eight, constitutes a quorum to transact all business, and a majority of those voting members present, physically or via telecommunications, must concur in any decision.
- 5.2 Each appointed Council member shall have one vote.
- 5.3 A concurrence of at least a majority of the members of the Council shall be required on all questions.
- 5.4 Members may abstain.
- 5.5 The Chair will count and announce the results of any vote.
- 5.6 Proxy for a Member: Should the Chair of the State of Nevada Advisory Council on Palliative Care and Quality of Life be unable to attend a meeting, he/she may designate a representative who has knowledge of the Council's activities to attend in his/her place, who shall have all the rights and privileges of the member while acting in his/her behalf.

ARTICLE 6: OFFICERS/NOMINATIONS/ELECTIONS

- 6.1 Council officers shall be elected from among its members, and include a Chair as defined by the NRS.
 - 6.1.1 The Chair shall be elected at the first meeting of even numbered State fiscal years by a majority vote of all Council members.
 - 6.1.2 Other Council officers may include a Vice-Chair, Secretary, and Treasurer, and may include others as deemed necessary by a majority vote of the Council.
 - 6.1.3 The Council's Chair shall open and close the floor for nominations.
 - 6.1.4 The Secretary shall call roll for the purposes of each member casting their vote and recording the votes.

- 6.1.5 In accordance with the Nevada Open Meeting Law all nominations and votes shall be provided orally.
- 6.1.6 Only members present during the meeting (includes teleconference attendance) may nominate and vote for officers.
- 6.2 Terms of office. The term of office of the Chair is two years.
 - 6.2.1 The Chair may serve any number of consecutive terms.
- 6.3 Vacancies. When a vacancy occurs in the office of Chair, either by reason of his/her having left the Council or office; a new Chair is elected to fill out the unexpired term.
 - 6.3.1 This shall not constitute a full term for the purposes of 6.2.
- 6.4 Duties
 - 6.4.1 The Chair shall preside at all meetings of the Council.
 - 6.4.2 If appointed, the Vice-Chair shall act for and in behalf of the Chair in all cases of his/her absence.

ARTICLE 7: COMPENSATION (NRS 439.5075)

- 7.1 The members of the Council serve without compensation and are not entitled to the per diem and travel expenses provided for state officers and employees generally.
- 7.2 Each member of the Council who is an officer or employee of this State or a political subdivision of this State must be relieved from his or her duties without loss of regular compensation so that the officer or employee may prepare for and attend meetings of the Council and perform any work necessary to carry out the duties of the Council in the most timely manner practicable. A state agency or political subdivision of this State shall not require an officer or employee who is a member of the Council to make up the time the officer or employee is absent from work to carry out duties as a member of the Council or use annual leave or compensatory time for the absence.

ARTICLE 8: STAFFING/SUPPORT

- 8.1 The Department shall provide such administrative support to the Council as is necessary to carry out the duties of the Council.

- 8.2 Staff to the Council shall be provided by the Division for purposes of secretarial, research, and other needs.

ARTICLE 9: MEETINGS

- 9.1 The Council shall meet at least once every 3 months at the times and places specified by a call of the Chair and may meet at such further times as deemed necessary by the Chair.
- 9.2 Agenda items may be submitted in writing no later than 15 working days before the meeting by Division employees and/or Council members.
- 9.3 Meetings will generally follow parliamentary procedure as contained in Robert's Rules of Order insofar as they do not conflict with the Nevada Revised Statute and these bylaws.
- 9.4 Meetings shall be open to the public and conducted in accordance with NRS 241, known as Nevada's "Open Meeting Law".

ARTICLE 10: MINUTES

- 10.1 A member of the Council, or a support staff member designated by the Division, shall act as a recording secretary for the purpose of taking minutes at each meeting.
- 10.2 Minutes of the previous meeting will be transcribed and made available for inspection by the public within 30-working days after the adjournment of the meeting.
- 10.2.1 The recording secretary will transcribe minutes from tape recording, notes taken at meeting and from agenda exhibits.
- 10.2.2 After draft of minutes is prepared, it will be submitted to the Chair for approval.
- 10.2.3 After approval, minutes will be finalized and included in meeting materials for members.
- 10.2.4 Final approval of the minutes will be done by the Council at its next meeting.
- 10.3 Minutes of each meeting of the Council are considered public record and will be maintained in the Administrative Office of the Division.

- 10.4 Copies of the minutes of the previous meeting will be made available to Committee members prior to the next meeting.

ARTICLE 11: AMENDMENTS

- 11.1 The Bylaws may be amended or changed at any regular meeting by a majority of the voting members who are present at the meeting of the Council, if the proposed amendment or change was submitted, in writing, to members of the Council and the Chair, at least 14 days before the meeting.

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