

137.68 ADVISORY COUNCIL ON RARE DISEASES.

Subdivision 1. **Establishment.** The University of Minnesota is requested to establish an advisory council on rare diseases to provide advice on research, diagnosis, treatment, and education related to rare diseases. For purposes of this section, "rare disease" has the meaning given in United States Code, title 21, section 360bb. The council shall be called the Chloe Barnes Advisory Council on Rare Diseases.

Subd. 2. **Membership.** (a) The advisory council may consist of public members appointed by the Board of Regents or a designee according to paragraph (b) and four members of the legislature appointed according to paragraph (c).

(b) The Board of Regents or a designee is requested to appoint the following public members:

(1) three physicians licensed and practicing in the state with experience researching, diagnosing, or treating rare diseases, including one specializing in pediatrics;

(2) one registered nurse or advanced practice registered nurse licensed and practicing in the state with experience treating rare diseases;

(3) at least two hospital administrators, or their designees, from hospitals in the state that provide care to persons diagnosed with a rare disease. One administrator or designee appointed under this clause must represent a hospital in which the scope of service focuses on rare diseases of pediatric patients;

(4) three persons age 18 or older who either have a rare disease or are a caregiver of a person with a rare disease;

(5) a representative of a rare disease patient organization that operates in the state;

(6) a social worker with experience providing services to persons diagnosed with a rare disease;

(7) a pharmacist with experience with drugs used to treat rare diseases;

(8) a dentist licensed and practicing in the state with experience treating rare diseases;

(9) a representative of the biotechnology industry;

(10) a representative of health plan companies;

(11) a medical researcher with experience conducting research on rare diseases; and

(12) a genetic counselor with experience providing services to persons diagnosed with a rare disease or caregivers of those persons.

(c) The advisory council shall include two members of the senate, one appointed by the majority leader and one appointed by the minority leader; and two members of the house of representatives, one appointed by the speaker of the house and one appointed by the minority leader.

(d) The commissioner of health or a designee, a representative of Mayo Medical School, and a representative of the University of Minnesota Medical School shall serve as ex officio, nonvoting members of the advisory council.

(e) Initial appointments to the advisory council shall be made no later than September 1, 2019. Members appointed according to paragraph (b) shall serve for a term of three years, except that the initial members appointed according to paragraph (b) shall have an initial term of two, three, or four years determined by

lot by the chairperson. Members appointed according to paragraph (b) shall serve until their successors have been appointed.

Subd. 3. **Meetings.** The Board of Regents or a designee is requested to convene the first meeting of the advisory council no later than October 1, 2019. The advisory council shall meet at the call of the chairperson or at the request of a majority of advisory council members.

Subd. 4. **Duties.** (a) The advisory council's duties may include, but are not limited to:

(1) in conjunction with the state's medical schools, the state's schools of public health, and hospitals in the state that provide care to persons diagnosed with a rare disease, developing resources or recommendations relating to quality of and access to treatment and services in the state for persons with a rare disease, including but not limited to:

(i) a list of existing, publicly accessible resources on research, diagnosis, treatment, and education relating to rare diseases;

(ii) identifying best practices for rare disease care implemented in other states, at the national level, and at the international level that will improve rare disease care in the state and seeking opportunities to partner with similar organizations in other states and countries;

(iii) identifying problems faced by patients with a rare disease when changing health plans, including recommendations on how to remove obstacles faced by these patients to finding a new health plan and how to improve the ease and speed of finding a new health plan that meets the needs of patients with a rare disease; and

(iv) identifying best practices to ensure health care providers are adequately informed of the most effective strategies for recognizing and treating rare diseases; and

(2) advising, consulting, and cooperating with the Department of Health, the Advisory Committee on Heritable and Congenital Disorders, and other agencies of state government in developing information and programs for the public and the health care community relating to diagnosis, treatment, and awareness of rare diseases.

(b) The advisory council shall collect additional topic areas for study and evaluation from the general public. In order for the advisory council to study and evaluate a topic, the topic must be approved for study and evaluation by the advisory council.

Subd. 5. **Conflict of interest.** Advisory council members are subject to the Board of Regents policy on conflicts of interest.

Subd. 6. **Annual report.** By January 1 of each year, beginning January 1, 2020, the advisory council shall report to the chairs and ranking minority members of the legislative committees with jurisdiction over higher education and health care policy on the advisory council's activities under subdivision 4 and other issues on which the advisory council may choose to report.

History: 2019 c 65 s 1