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State of Minnesota
HOUSE OF REPRESENTATIVES
NINETIETH SESSION

H. F. No. **2574**

04/03/2017 Authored by Dean, M.; Albright; Zerwas; Youakim; Murphy, E., and others
The bill was read for the first time and referred to the Committee on Health and Human Services Reform

1.1 A bill for an act
1.2 relating to health; establishing an advisory council on rare diseases to advise the
1.3 commissioner of health on issues related to rare diseases; proposing coding for
1.4 new law in Minnesota Statutes, chapter 144.

1.5 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF MINNESOTA:

1.6 Section 1. [144.89] ADVISORY COUNCIL ON RARE DISEASES.

1.7 Subdivision 1. Establishment. An advisory council on rare diseases is established to
1.8 advise the commissioner of health on research, diagnosis, treatment, and education related
1.9 to rare diseases. For purposes of this section, "rare disease" has the meaning given in United
1.10 States Code, title 21, section 360bb. The council shall be called the Chloe Barnes Advisory
1.11 Council on Rare Diseases.

1.12 Subd. 2. Membership. (a) The advisory council shall consist of public members
1.13 appointed by the commissioner of health according to paragraph (b) and four members of
1.14 the legislature appointed according to paragraph (c).

1.15 (b) The commissioner shall appoint the public members, including at least the following:

1.16 (1) three physicians licensed and practicing in the state with experience researching,
1.17 diagnosing, or treating rare diseases;

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

1.20 (3) at least two hospital administrators, or their designees, from hospitals in the state
1.21 that provide care to persons diagnosed with a rare disease;

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

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

2.4 (6) other public members, who may serve on an ad hoc basis.

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

2.9 (d) The commissioner of health or a designee shall serve as an ex officio, nonvoting
2.10 member of the advisory council.

2.11 (e) Initial appointments to the advisory council shall be made no later than July 1, 2017.
2.12 Members appointed according to paragraph (b) shall serve for a term of three years, except
2.13 that the initial members appointed according to paragraph (b) shall have an initial term of
2.14 one, two, or three years, determined by lot by the commissioner. Members appointed
2.15 according to paragraph (b) shall serve until their successors have been appointed.

2.16 (f) Members appointed according to paragraph (b) shall serve without compensation
2.17 except for reimbursement for actual and necessary expenses incurred in performing advisory
2.18 council duties.

2.19 Subd. 3. **Meetings.** The commissioner of health shall convene the first meeting of the
2.20 advisory council no later than September 1, 2017. The members shall elect a chairperson
2.21 from among the advisory council's membership. A majority of the advisory council members
2.22 constitutes a quorum. A majority vote of a quorum shall be required for the advisory council
2.23 to take any official actions. The advisory council shall meet at the call of the chairperson
2.24 or at the request of a majority of advisory council members.

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

2.26 (1) coordinating statewide efforts for the study of the incidence of rare diseases in the
2.27 state;

2.28 (2) advising the commissioner of health on research, diagnosis, treatment, and education
2.29 relating to rare diseases;

2.30 (3) researching and identifying priorities relating to the quality of and access to treatment
2.31 and services in the state for persons with rare diseases;

3.1 (4) developing, in conjunction with the state's medical schools, policy recommendations
3.2 relating to the quality of and access to treatment and services in the state for persons with
3.3 rare diseases;

3.4 (5) advising, consulting, and cooperating with the Department of Health and other
3.5 agencies of state government in developing information and programs for the public and
3.6 the health care community relating to the diagnosis, treatment, and awareness of rare diseases;

3.7 (6) identifying best practices for rare disease care implemented in other states and at the
3.8 national level that will improve rare disease care in the state;

3.9 (7) developing recommendations for effective strategies to raise public awareness of
3.10 rare diseases in the state; and

3.11 (8) developing recommendations for best practices to ensure health care providers are
3.12 adequately informed of the most effective strategies for recognizing and treating rare diseases.

3.13 (b) To carry out the duties in this subdivision, the advisory council shall:

3.14 (1) pursue and accept gifts, grants, and bequests of funds from individuals, foundations,
3.15 corporations, federal and state agencies, and other organizations and institutions to fund the
3.16 activities of the advisory council; and

3.17 (2) publish findings, recommendations, and reports on the diagnosis, treatment, research,
3.18 and education for rare diseases to be used by the Department of Health, other state agencies,
3.19 the medical community, and the public.

3.20 Subd. 5. **Annual report.** By January 1 of each year, beginning January 1, 2018, the
3.21 advisory council shall report to the chairs and ranking minority members of the legislative
3.22 committees with jurisdiction over health care policy on the council's activities under
3.23 subdivision 4 and other issues on which the council may choose to report.

3.24 Subd. 6. **Advisory council on rare diseases account.** An advisory council on rare
3.25 diseases account is created in the special revenue fund in the state treasury. All gifts, grants,
3.26 and bequests of funds obtained by or for the advisory council shall be deposited in the
3.27 account and are appropriated to the commissioner of health to fund activities of the advisory
3.28 council.

3.29 **EFFECTIVE DATE.** This section is effective the day following final enactment.