

1.1 moves to amend H.F. No. 2574 as follows:

1.2 Delete everything after the enacting clause and insert:

1.3 "Section 1. **[137.68] ADVISORY COUNCIL ON RARE DISEASES.**

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

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

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

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

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

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

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

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

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

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

2.4 (8) a representative of the biotechnology industry;

2.5 (9) a representative of health plan companies; and

2.6 (10) other public members, who may serve on an ad hoc basis.

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

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

2.14 (e) Initial appointments to the advisory council shall be made no later than July 1, 2018.
2.15 Members appointed according to paragraph (b) shall serve for a term of three years, except
2.16 that the initial members appointed according to paragraph (b) shall have an initial term of
2.17 two, three, or four years determined by lot by the chairperson. Members appointed according
2.18 to paragraph (b) shall serve until their successors have been appointed.

2.19 Subd. 3. **Meetings.** The Board of Regents or a designee is requested to convene the first
2.20 meeting of the advisory council no later than September 1, 2018. The advisory council shall
2.21 meet at the call of the chairperson or at the request of a majority of advisory council members.

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

2.23 (1) developing protocols for providers to use to diagnose persons in the state with a rare
2.24 disease;

2.25 (2) advising interested parties on research, diagnosis, treatment, and education relating
2.26 to rare diseases;

2.27 (3) researching and identifying outcomes assessment tools and outcomes goals to be
2.28 used when treating persons with rare diseases;

2.29 (4) developing, in conjunction with the state's medical schools and hospitals in the state
2.30 that provide care to persons diagnosed with a rare disease, policy recommendations relating
2.31 to the quality of and access to treatment and services in the state for persons with rare
2.32 diseases;

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

3.5 (6) identifying best practices for rare disease care implemented in other states and at the
3.6 national and international levels that will improve rare disease care in the state and seeking
3.7 opportunities to partner with similar organizations in other states and counties;

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

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

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

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

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

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

3.21 Subd. 6. **Annual report.** By January 1 of each year, beginning January 1, 2019, the
3.22 advisory council shall report to the chairs and ranking minority members of the legislative
3.23 committees with jurisdiction over higher education and health care policy on the advisory
3.24 council's activities under subdivision 4 and other issues on which the advisory council may
3.25 choose to report.

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

3.27 Delete the title and insert:

3.28 "A bill for an act
3.29 relating to health; requesting establishment of an advisory council on rare diseases
3.30 to provide advice on issues related to rare diseases; proposing coding for new law
3.31 in Minnesota Statutes, chapter 137."