

SENATE
STATE OF MINNESOTA
NINETY-SECOND SESSION

S.F. No. 4045

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Table with 3 columns: DATE, D-PG, OFFICIAL STATUS. Rows include dates from 03/16/2022 to 04/06/2022 and corresponding bill numbers and descriptions.

1.1 A bill for an act
1.2 relating to rare diseases; modifying provisions governing the Rare Disease Advisory
1.3 Council; instructing the revisor of statutes to renumber certain statutes;
1.4 appropriating money; amending Minnesota Statutes 2020, section 137.68.

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

1.6 Section 1. Minnesota Statutes 2020, section 137.68, is amended to read:

1.7 137.68 MINNESOTA RARE DISEASE ADVISORY COUNCIL ON RARE
1.8 DISEASES.

1.9 Subdivision 1. Establishment. The University of Minnesota is requested to establish
1.10 There is established an advisory council on rare diseases to provide advice on policies,
1.11 access, equity, research, diagnosis, treatment, and education related to rare diseases. The
1.12 advisory council is established in honor of Chloe Barnes and her experiences in the health
1.13 care system. For purposes of this section, "rare disease" has the meaning given in United
1.14 States Code, title 21, section 360bb. The council shall be called the Chloe Barnes Advisory
1.15 Council on Rare Diseases Minnesota Rare Disease Advisory Council. The Council on
1.16 Disability shall house the advisory council.

1.17 Subd. 2. Membership. (a) The advisory council may shall consist of at least 17 public
1.18 members who reflect statewide representation and are appointed by the Board of Regents
1.19 or a designee the governor according to paragraph (b) and four members of the legislature
1.20 appointed according to paragraph (c).

1.21 (b) The Board of Regents or a designee is requested to The governor shall appoint at
1.22 least the following public members according to section 15.059:

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

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

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

2.9 (4) three persons age 18 or older who either have a rare disease or are a caregiver of a
2.10 person with a rare disease. One person appointed under this clause must reside in rural
2.11 Minnesota;

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

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

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

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

2.17 (9) a representative of the biotechnology industry;

2.18 (10) a representative of health plan companies;

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

2.20 (12) a genetic counselor with experience providing services to persons diagnosed with
2.21 a rare disease or caregivers of those persons; and

2.22 (13) representatives with other areas of expertise as identified by the advisory council.

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

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

2.30 (e) ~~Initial appointments to the advisory council shall be made no later than September~~
2.31 ~~1, 2019.~~ Notwithstanding section 15.059, members appointed according to paragraph (b)

3.1 shall serve for a term of three years, except that the initial members appointed according to
3.2 paragraph (b) shall have an initial term of two, three, or four years determined by lot by the
3.3 chairperson. Members appointed according to paragraph (b) shall serve until their successors
3.4 have been appointed.

3.5 (f) Members may be reappointed for additional terms according to the advisory council's
3.6 operating procedures.

3.7 Subd. 3. **Meetings.** ~~The Board of Regents or a designee is requested to convene the first~~
3.8 ~~meeting of the advisory council no later than October 1, 2019.~~ The advisory council shall
3.9 meet at the call of the chairperson or at the request of a majority of advisory council members.
3.10 Meetings of the advisory council are subject to section 13D.01, and notice of its meetings
3.11 is governed by section 13D.04.

3.12 Subd. 3a. **Chairperson; executive director; staff; executive committee.** (a) The
3.13 advisory council shall elect a chairperson and other officers as it deems necessary and in
3.14 accordance with the advisory council's operating procedures.

3.15 (b) The advisory council shall be governed by an executive committee elected by the
3.16 members of the advisory council. One member of the executive committee must be the
3.17 advisory council chairperson.

3.18 (c) The advisory council shall appoint an executive director. The executive director
3.19 serves as an ex officio nonvoting member of the executive committee. The advisory council
3.20 may delegate to the executive director any powers and duties under this section that do not
3.21 require advisory council approval. The executive director serves in the unclassified service
3.22 and may be removed at any time by a majority vote of the advisory council. The executive
3.23 director may employ and direct staff necessary to carry out advisory council mandates,
3.24 policies, activities, and objectives.

3.25 (d) The executive committee may appoint additional subcommittees and work groups
3.26 as necessary to fulfill the duties of the advisory council.

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

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

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

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

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

4.8 (iv) identifying and addressing barriers faced by patients with a rare disease to obtaining
 4.9 care, caused by prior authorization requirements in private and public health plans; and

4.10 ~~(iv)~~ (v) identifying, recommending, and implementing best practices to ensure health
 4.11 care providers are adequately informed of the most effective strategies for recognizing and
 4.12 treating rare diseases; ~~and~~

4.13 (2) advising, consulting, and cooperating with the Department of Health, including the
 4.14 Advisory Committee on Heritable and Congenital Disorders; the Department of Human
 4.15 Services, including the Drug Utilization Review Board and the Drug Formulary Committee;
 4.16 and other agencies of state government in developing recommendations, information, and
 4.17 programs for the public and the health care community relating to diagnosis, treatment, and
 4.18 awareness of rare diseases;

4.19 (3) advising on policy issues and advancing policy initiatives at the state and federal
 4.20 levels; and

4.21 (4) receiving funds and issuing grants.

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

4.25 Subd. 5. **Conflict of interest.** Advisory council members are subject to the ~~Board of~~
 4.26 ~~Regents policy on conflicts~~ advisory council's conflict of interest policy as outlined in the
 4.27 advisory council's operating procedures.

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

4.33 **EFFECTIVE DATE.** This section is effective July 1, 2022.

5.1 Sec. 2. **APPROPRIATIONS.**

5.2 In accordance with Minnesota Statutes, section 15.039, subdivision 6, the unexpended
5.3 balance of money appropriated from the general fund to the Board of Regents of the
5.4 University of Minnesota for purposes of the advisory council on rare diseases under
5.5 Minnesota Statutes, section 137.68, shall be under the control of the Minnesota Rare Disease
5.6 Advisory Council and the Council on Disability.

5.7 **EFFECTIVE DATE.** This section is effective July 1, 2022.

5.8 Sec. 3. **REVISOR INSTRUCTION.**

5.9 The revisor of statutes shall renumber as Minnesota Statutes, section 256.4835, the
5.10 Minnesota Rare Disease Advisory Council that is currently coded as Minnesota Statutes,
5.11 section 137.68. The revisor shall also make necessary cross-reference changes consistent
5.12 with the renumbering.

5.13 **EFFECTIVE DATE.** This section is effective July 1, 2022.