

**SENATE  
STATE OF MINNESOTA  
NINETY-THIRD SESSION**

**S.F. No. 5160**

(SENATE AUTHORS: CARLSON)

| DATE       | D-PG  | OFFICIAL STATUS   |
|------------|-------|---|
| 03/21/2024 | 12530 | Introduction and first reading<br>Referred to Health and Human Services |

1.1 A bill for an act

1.2 relating to health; modifying membership of the Rare Disease Advisory Council;

1.3 appropriating money; amending Minnesota Statutes 2022, section 256.4835,

1.4 subdivisions 2, 4, by adding subdivisions.

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

1.6 Section 1. Minnesota Statutes 2022, section 256.4835, subdivision 2, is amended to read:

1.7 Subd. 2. **Public membership.** (a) The advisory council shall consist of at least 17 public

1.8 members who reflect statewide representation. Except for initial public members, public

1.9 members are appointed by the governor according to paragraph (b). ~~Four members of the~~

1.10 ~~legislature are appointed according to paragraph (c).~~

1.11 (b) The governor shall appoint at least the following public members according to section

1.12 15.0597:

1.13 (1) three physicians licensed and practicing in the state with experience researching,

1.14 diagnosing, or treating rare diseases, including one specializing in pediatrics;

1.15 (2) one registered nurse or advanced practice registered nurse licensed and practicing

1.16 in the state with experience treating rare diseases;

1.17 (3) at least two hospital administrators, or their designees, from hospitals in the state

1.18 that provide care to persons diagnosed with a rare disease. One administrator or designee

1.19 appointed under this clause must represent a hospital in which the scope of service focuses

1.20 on rare diseases of pediatric patients;

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. One person appointed under this clause must reside in rural  
2.3 Minnesota;

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

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

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

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

2.9 (9) a representative of the biotechnology industry;

2.10 (10) a representative of health plan companies;

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

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

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

2.15 ~~(e) The advisory council shall include two members of the senate, one appointed by the~~  
2.16 ~~majority leader and one appointed by the minority leader; and two members of the house~~  
2.17 ~~of representatives, one appointed by the speaker of the house and one appointed by the~~  
2.18 ~~minority leader. Members appointed under this paragraph serve until their successors are~~  
2.19 ~~appointed.~~

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

2.23 ~~(e)~~ (c) Public members appointed according to paragraph (b) shall serve for a term of  
2.24 three years, except the initial members appointed according to paragraph (b). Public members  
2.25 appointed according to paragraph (b) shall serve until their successors have been appointed.

2.26 ~~(f)~~ (d) Public members may be reappointed for up to two full additional terms according  
2.27 to the advisory council's operating procedures.

2.28 ~~(g)~~ (e) Public members may be removed as provided in section 15.059, subdivision 4.

2.29 ~~(h)~~ (f) Public members serve without compensation, but may have expenses reimbursed  
2.30 as provided in section 15.059, subdivision 3. ~~Legislative members may receive per diem~~  
2.31 ~~according to the rules of their respective bodies.~~

3.1 Sec. 2. Minnesota Statutes 2022, section 256.4835, is amended by adding a subdivision  
3.2 to read:

3.3 Subd. 2a. **Legislative membership.** The advisory council shall include two members  
3.4 of the senate, one appointed by the majority leader and one appointed by the minority leader;  
3.5 and two members of the house of representatives, one appointed by the speaker of the house  
3.6 and one appointed by the minority leader. Legislative members appointed under this  
3.7 subdivision serve until their successors are appointed. Legislative members may receive  
3.8 per diems according to the rules of their respective bodies.

3.9 Sec. 3. Minnesota Statutes 2022, section 256.4835, is amended by adding a subdivision  
3.10 to read:

3.11 Subd. 2b. **Ex officio membership.** The commissioner of health or a designee, a  
3.12 representative of Mayo Medical School, and a representative of the University of Minnesota  
3.13 Medical School shall serve as ex officio, nonvoting members of the advisory council.

3.14 Sec. 4. Minnesota Statutes 2022, section 256.4835, is amended by adding a subdivision  
3.15 to read:

3.16 Subd. 2c. **Ad hoc membership.** (a) The advisory council may include up to ... ad hoc  
3.17 members appointed by the executive committee to provide additional expertise while the  
3.18 advisory council undertakes a particular project. The initial term of appointment of an ad  
3.19 hoc member shall be for one year. Ad hoc members may be reappointed for up to two  
3.20 additional one-year terms according to the advisory council's operating procedures.

3.21 (b) Ad hoc members may be removed by the executive committee as provided in section  
3.22 15.059, subdivision 4.

3.23 (c) An ad hoc member may not serve on the executive committee of the advisory council  
3.24 and may not vote in the election of a chairperson or other officers nor on any matter related  
3.25 to the governance of the advisory council, including the appointment of an executive director.

3.26 (d) Ad hoc members serve without compensation, but may have expenses reimbursed  
3.27 as provided in section 15.059, subdivision 3.

3.28 Sec. 5. Minnesota Statutes 2022, section 256.4835, subdivision 4, is amended to read:

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

3.30 (1) in conjunction with the state's medical schools, the state's schools of public health,  
3.31 and hospitals in the state that provide care to persons diagnosed with a rare disease,

4.1 developing resources or recommendations relating to quality of and access to treatment and  
4.2 services in the state for persons with a rare disease, including but not limited to:

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

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

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

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

4.14 (v) identifying, recommending, and implementing best practices to ensure health care  
4.15 providers are adequately informed of the most effective strategies for recognizing and  
4.16 treating rare diseases;

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

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

4.25 (4) receiving funds and issuing grants.

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

4.29 (c) Legislative members and ad hoc members may not deliberate about or vote on  
4.30 decisions related to the issuance of grants of state money.

5.1 Sec. 6. **APPROPRIATION.**

5.2 \$..... in fiscal year 2025 is appropriated from the general fund to the Rare Disease  
5.3 Advisory Council to study sustainable reimbursement models for gene therapies to treat  
5.4 rare diseases and to issue recommendations to the legislature, payers, hospitals, and  
5.5 manufacturers. The general fund base for this appropriation is \$..... in fiscal year 2026,  
5.6 \$..... in fiscal year 2027, and \$..... in fiscal year 2028.