

1.1 moves to amend H.F. No. 2574, the second engrossment, as follows:

1.2 Page 2, delete subdivision 4 and insert:

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

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

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

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

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

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

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

2.1 Page 4, after line 6, insert:

2.2 "Sec. 2. **APPROPRIATION.**

2.3 \$..... in fiscal year 2019 is appropriated from the general fund to the Board of Regents

2.4 of the University of Minnesota, for the advisory council on rare diseases under Minnesota

2.5 Statutes, section 137.68."

2.6 Amend the title accordingly