

Amendment No. 1

COMMITTEE/SUBCOMMITTEE ACTION

ADOPTED (Y/N)
ADOPTED AS AMENDED (Y/N)
ADOPTED W/O OBJECTION (Y/N)
FAILED TO ADOPT (Y/N)
WITHDRAWN (Y/N)
OTHER

1 Committee/Subcommittee hearing bill: Professions & Public
2 Health Subcommittee
3 Representative Plakon offered the following:
4

5 **Amendment**

6 Remove lines 34-72 and insert:

7 members:

8 (a) As appointed by the Governor:

9 1. A representative of the Department of Health.

10 2. A representative of the Agency for Health Care

11 Administration.

12 3. A representative of the Office of Insurance Regulation.

13 4. A representative of the Department of Education.

14 5. One geneticist practicing in this state.

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15 6. One registered nurse or advanced practice registered
16 nurse who is licensed and practicing in this state with
17 experience in treating rare diseases.

18 7. One hospital administrator from a hospital in this
19 state which provides care to individuals diagnosed with rare
20 diseases.

21 8. A pharmacist who is licensed and practicing in this
22 state who has experience with drugs that are used in the
23 treatment of rare diseases.

24 9. A representative of the biotechnology industry.

25 10. A representative of health insurance companies.

26 (b) As appointed by the President of the Senate:

27 1. A representative from an academic research institution
28 in this state which receives grant funding for research
29 regarding rare diseases.

30 2. A physician who is licensed under chapter 458 or
31 chapter 459 and practicing in this state with experience in
32 treating rare diseases.

33 3. An individual who is 18 years of age or older who has a
34 rare disease.

35 4. An individual who is a caregiver of an individual with
36 a rare disease.

37 5. A representative of an organization operating in this
38 state which provides care or other support to individuals with
39 rare diseases.

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40 (c) As appointed by the Speaker of the House of
41 Representatives:

42 1. A representative from an academic research institution
43 in this state which receives grant funding for research
44 regarding rare diseases.

45 2. A physician who is licensed under chapter 458 or
46 chapter 459 and practicing in this state with experience in
47 treating rare diseases.

48 3. An individual who is 18 years of age or older who has a
49 rare disease.

50 4. An individual who is a caregiver of an individual with
51 a rare disease.

52 5. A representative of organizations in this state which
53 provide care or other support to individuals with rare diseases.
54 Any vacancy on the advisory council must be filled in the same
55 manner as the original appointment.

56 (3) The initial members of the advisory council must be
57 appointed by September 1, 2021. Each member must be appointed to
58 a 4-year term of office. However, in order to achieve staggered
59 terms, each of the initial members appointed pursuant to
60 paragraph (2) (a) must be appointed to a 2-year term. The