



381602

LEGISLATIVE ACTION

Senate	.	House
Comm: RCS	.	
03/11/2021	.	
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The Committee on Appropriations (Rouson) recommended the following:

Senate Amendment

Delete lines 34 - 72
and insert:
members:

(a) As appointed by the Governor:

1. A representative of the Department of Health.

2. A representative of the Agency for Health Care
Administration.

3. A representative of the Office of Insurance Regulation.



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- 11 4. A representative of the Department of Education.
- 12 5. One geneticist practicing in this state.
- 13 6. One registered nurse or advanced practice registered
14 nurse who is licensed and practicing in this state with
15 experience in treating rare diseases.
- 16 7. One hospital administrator from a hospital in this state
17 which provides care to individuals diagnosed with rare diseases.
- 18 8. A pharmacist who is licensed and practicing in this
19 state who has experience with drugs that are used in the
20 treatment of rare diseases.
- 21 9. A representative of the biotechnology industry.
- 22 10. A representative of health insurance companies.
- 23 (b) As appointed by the President of the Senate:
- 24 1. A representative from an academic research institution
25 in this state which receives grant funding for research
26 regarding rare diseases.
- 27 2. A physician who is licensed under chapter 458 or chapter
28 459 and practicing in this state with experience in treating
29 rare diseases.
- 30 3. An individual who is 18 years of age or older who has a
31 rare disease.
- 32 4. An individual who is a caregiver of an individual with a
33 rare disease.
- 34 5. A representative of an organization operating in this
35 state which provides care or other support to individuals with
36 rare disease.
- 37 (c) As appointed by the Speaker of the House of
38 Representatives:
- 39 1. A representative from an academic research institution



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40 in this state which receives grant funding for research
41 regarding rare disease.

42 2. A physician who is licensed under chapter 458 or chapter
43 459 and practicing in this state with experience in treating
44 rare diseases.

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

47 4. An individual who is a caregiver of an individual with a
48 rare disease.

49 5. A representative of organizations in this state which
50 provide care or other support to individuals with rare diseases.

51
52 Any vacancy on the advisory council must be filled in the same
53 manner as the original appointment.

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