

By the Committees on Appropriations; and Health Policy; and
Senator Baxley

576-02734-21

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1 A bill to be entitled
2 An act relating to the Rare Disease Advisory Council;
3 creating s. 381.99, F.S.; creating the advisory
4 council adjunct to the Department of Health;
5 specifying the purpose of the advisory council;
6 providing for staff and administrative support;
7 defining the term "rare disease"; specifying
8 application of state law governing the establishment
9 of advisory councils; prescribing the composition of
10 the advisory council; providing for initial
11 appointments to the advisory council by a specified
12 date; providing organizational and other meeting
13 requirements for the advisory council; prescribing
14 duties and responsibilities of the advisory council;
15 providing an effective date.

16
17 Be It Enacted by the Legislature of the State of Florida:

18
19 Section 1. Section 381.99, Florida Statutes, is created to
20 read:

21 381.99 Rare Disease Advisory Council.-

22 (1) The Rare Disease Advisory Council, an advisory council
23 as defined in s. 20.03(7), is created adjunct to the Department
24 of Health for the purpose of providing recommendations on ways
25 to improve health outcomes for individuals residing in this
26 state who have a rare disease. The department shall provide
27 staff and administrative support for the advisory council in the
28 carrying out of its duties and responsibilities. For purposes of
29 this section, the term "rare disease" means a condition that

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30 affects fewer than 200,000 people in the United States. Except
31 as otherwise provided in this section, the advisory council
32 shall operate in a manner consistent with s. 20.052.

33 (2) The advisory council is composed of the following
34 members:

35 (a) As appointed by the Governor:

36 1. A representative of the Department of Health.

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

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

40 4. A representative of the Department of Education.

41 5. One geneticist practicing in this state.

42 6. One registered nurse or advanced practice registered
43 nurse who is licensed and practicing in this state with
44 experience in treating rare diseases.

45 7. One hospital administrator from a hospital in this state
46 which provides care to individuals diagnosed with rare diseases.

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

50 9. A representative of the biotechnology industry.

51 10. A representative of health insurance companies.

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

53 1. A representative from an academic research institution
54 in this state which receives grant funding for research
55 regarding rare diseases.

56 2. A physician who is licensed under chapter 458 or chapter
57 459 and practicing in this state with experience in treating
58 rare diseases.

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

61 4. An individual who is a caregiver of an individual with a
62 rare disease.

63 5. A representative of an organization operating in this
64 state which provides care or other support to individuals with
65 rare diseases.

66 (c) As appointed by the Speaker of the House of
67 Representatives:

68 1. A representative from an academic research institution
69 in this state which receives grant funding for research
70 regarding rare diseases.

71 2. A physician who is licensed under chapter 458 or chapter
72 459 and practicing in this state with experience in treating
73 rare diseases.

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

76 4. An individual who is a caregiver of an individual with a
77 rare disease.

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

80
81 Any vacancy on the advisory council must be filled in the same
82 manner as the original appointment.

83 (3) The initial members of the advisory council must be
84 appointed by September 1, 2021. Each member must be appointed to
85 a 4-year term of office. However, in order to achieve staggered
86 terms, each of the initial members appointed pursuant to
87 paragraph (2) (a) must be appointed to a 2-year term. The

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88 Governor shall designate a chair and vice chair of the advisory
89 council from among its membership. The advisory council shall
90 meet for its initial meeting by October 1, 2021. Thereafter, the
91 advisory council may meet upon the call of the chair or upon the
92 request of a majority of its members. The advisory council may
93 meet via teleconferencing or other electronic means. Notices for
94 any scheduled meetings of the advisory council must be published
95 in advance on the department's website.

96 (4) The advisory council shall:

97 (a) Consult with experts on rare diseases and solicit
98 public comment to assist in developing recommendations on
99 improving the treatment of rare diseases in this state.

100 (b) Develop recommended strategies for academic research
101 institutions in this state to facilitate continued research on
102 rare diseases.

103 (c) Develop recommended strategies for health care
104 providers to be informed on how to more efficiently recognize
105 and diagnose rare diseases in order to effectively treat
106 patients. The advisory council shall provide such strategies to
107 the Department of Health for publication on the department's
108 website.

109 (d) Provide input and feedback in writing to the
110 department, the Medicaid program, and other state agencies on
111 matters that affect people who have been diagnosed with rare
112 diseases, including, but not limited to, pandemic or natural
113 disaster preparedness and response.

114 (e) By July 1 of each year, beginning in 2022, submit a
115 report to the Governor and the State Surgeon General which
116 describes the activities of the advisory council in the past

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117 year and its findings and recommendations regarding rare disease
118 research and care. Additionally, the report must be made
119 available on the department's website.

120 Section 2. This act shall take effect July 1, 2021.