

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:

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 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 the state

26 | who have a rare disease. The department shall provide staff and
 27 | administrative support for the advisory council in the carrying
 28 | out of its duties and responsibilities. For purposes of this
 29 | section, the term "rare disease" means a condition that affects
 30 | fewer than 200,000 people in the United States. Except as
 31 | otherwise provided in this section, the advisory council shall
 32 | 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 the state.

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

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

47 | 8. A pharmacist who is licensed and practicing in the
 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 the state which receives grant funding for research regarding
 55 rare diseases.
- 56 2. A physician who is licensed under chapter 458 or
 57 chapter 459 and practicing in the state with experience in
 58 treating rare diseases.
- 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
 62 a rare disease.
- 63 5. A representative of an organization operating in the
 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 the state which receives grant funding for research regarding
 70 rare diseases.
- 71 2. A physician who is licensed under chapter 458 or
 72 chapter 459 and practicing in the state with experience in
 73 treating 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
77 a rare disease.

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

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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
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 the state.

100 (b) Develop recommended strategies for academic research

101 institutions in the 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
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.