

By Senator Baxley

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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:

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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 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 appointed by the Governor:

35 (a) A representative of the Department of Health.

36 (b) A representative of the Agency for Health Care
37 Administration.

38 (c) A representative of the Office of Insurance Regulation.

39 (d) A representative of the Department of Education.

40 (e) Two representatives from academic research institutions
41 in this state which receive any grant funding for research
42 regarding rare diseases.

43 (f) One geneticist practicing in this state.

44 (g) One registered nurse or advanced practice registered
45 nurse who is licensed and practicing in this state with
46 experience treating rare diseases.

47 (h) Two physicians who are licensed and practicing in this
48 state with experience treating rare diseases.

49 (i) One hospital administrator from a hospital in this
50 state which provides care to individuals diagnosed with rare
51 diseases.

52 (j) Two individuals who are 18 years of age or older who
53 have a rare disease.

54 (k) Two individuals who are caregivers of an individual
55 with a rare disease.

56 (l) Two representatives of organizations operating in this
57 state which provide care or other support for individuals with
58 rare diseases.

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59 (m) A pharmacist who is licensed and practicing in this
60 state who has experience with drugs that are used to treat rare
61 diseases.

62 (n) A representative of the biotechnology industry.

63 (o) A representative of health insurance companies.

64
65 Any vacancy on the advisory council shall be filled in the same
66 manner as the original appointment.

67 (3) The initial members of the advisory council shall be
68 appointed by September 1, 2021. Each member shall be appointed
69 to a 4-year term of office. However, in order to achieve
70 staggered terms, the initial members appointed pursuant to
71 paragraphs (2) (a)-(i) shall be appointed to a 2-year term. The
72 Governor shall designate a chair and vice chair of the advisory
73 council from among its membership. The advisory council shall
74 meet for its initial meeting by October 1, 2021. Thereafter, the
75 advisory council may meet upon the call of the chair or upon the
76 request of a majority of its members. The advisory council may
77 meet via teleconferencing or other electronic means. Notices for
78 any scheduled meetings of the advisory council must be published
79 in advance on the department's website.

80 (4) The advisory council shall:

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

84 (b) Develop recommended strategies for academic research
85 institutions in this state to facilitate continued research on
86 rare diseases.

87 (c) Develop recommended strategies for health care

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88 providers to be informed on how to more efficiently recognize
89 and diagnose rare diseases in order to effectively treat
90 patients. The advisory council shall provide such strategies to
91 the Department of Health for publication on the department's
92 website.

93 (d) Establish a method to securely hold and distribute
94 funds solicited by the advisory council's chair and vice chair
95 to be used solely for purposes related to the advisory council's
96 mission, including, but not limited to, advancing awareness and
97 the treatment of rare diseases.

98 (e) By July 1 of each year, beginning in 2022, submit a
99 report to the Governor and the State Surgeon General which
100 describes the activities of the advisory council in the past
101 year and its findings and recommendations regarding rare disease
102 research and care. Additionally, the report must be made
103 available on the department's website.

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