

By the Committee on Health Policy; and Senator Baxley

588-01988-21

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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 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) Provide input and feedback in writing to the  
94 department, the Medicaid program, and other state agencies on  
95 matters that affect people who have been diagnosed with rare  
96 diseases, including, but not limited to, pandemic or natural  
97 disaster preparedness and response.

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.