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576-02379-21

Proposed Committee Substitute by the Committee on Appropriations  
(Appropriations Subcommittee on Health and Human Services)

A bill to be entitled

An act relating to the Rare Disease Advisory Council;  
creating s. 381.99, F.S.; creating the advisory  
council adjunct to the Department of Health;  
specifying the purpose of the advisory council;  
providing for staff and administrative support;  
defining the term "rare disease"; specifying  
application of state law governing the establishment  
of advisory councils; prescribing the composition of  
the advisory council; providing for initial  
appointments to the advisory council by a specified  
date; providing organizational and other meeting  
requirements for the advisory council; prescribing  
duties and responsibilities of the advisory council;  
providing an effective date.

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

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

381.99 Rare Disease Advisory Council.-

(1) The Rare Disease Advisory Council, an advisory council  
as defined in s. 20.03(7), is created adjunct to the Department  
of Health for the purpose of providing recommendations on ways  
to improve health outcomes for individuals residing in this  
state who have a rare disease. The department shall provide  
staff and administrative support for the advisory council in the



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28 carrying out of its duties and responsibilities. For purposes of  
29 this section, the term "rare disease" means a condition that  
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 under chapter 458 or  
48 chapter 459 and practicing in this state with experience  
49 treating rare diseases.

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

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

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



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

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

63 (n) A representative of the biotechnology industry.

64 (o) A representative of health insurance companies.

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

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

81 (4) The advisory council shall:

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

85 (b) Develop recommended strategies for academic research



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86 institutions in this state to facilitate continued research on  
87 rare diseases.

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

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

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

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