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
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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 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 The advisory council is composed of the following (2) 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. (c) A representative of the Office of Insurance 38 39 Regulation. (d) A representative of the Department of Education. 40 41 (e) Two representatives from academic research 42 institutions in this state which receive any grant funding for 43 research regarding rare diseases. 44 (f) One geneticist practicing in this state. 45 One registered nurse or advanced practice registered (q) 46 nurse who is licensed and practicing in this state with 47 experience treating rare diseases. Two physicians who are licensed and practicing in this 48 (h) 49 state with experience treating rare diseases. 50 One hospital administrator from a hospital in this (i)

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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.
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

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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 institutions in this state to facilitate continued research on 86 87 rare diseases. 88 Develop recommended strategies for health care (C) 89 providers to be informed on how to more efficiently recognize and diagnose rare diseases in order to effectively treat 90 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. By July 1 of each year, beginning in 2022, submit a (e) 99 100 report to the Governor and the State Surgeon General which

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FLORIDA	HOUSE	OF REP	RESENTA	TIVES
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2021

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.

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