

## CHAPTER 2021-122

### Committee Substitute for Committee Substitute for Senate Bill No. 272

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 carrying out of its duties and responsibilities. For purposes of this section, the term “rare disease” means a condition that affects fewer than 200,000 people in the United States. Except as otherwise provided in this section, the advisory council shall operate in a manner consistent with s. 20.052.

(2) The advisory council is composed of the following members:

(a) As appointed by the Governor:

1. A representative of the Department of Health.
2. A representative of the Agency for Health Care Administration.
3. A representative of the Office of Insurance Regulation.
4. A representative of the Department of Education.
5. One geneticist practicing in this state.
6. One registered nurse or advanced practice registered nurse who is licensed and practicing in this state with experience in treating rare diseases.

7. One hospital administrator from a hospital in this state which provides care to individuals diagnosed with rare diseases.

8. A pharmacist who is licensed and practicing in this state who has experience with drugs that are used in the treatment of rare diseases.

9. A representative of the biotechnology industry.

10. A representative of health insurance companies.

(b) As appointed by the President of the Senate:

1. A representative from an academic research institution in this state which receives grant funding for research regarding rare diseases.

2. A physician who is licensed under chapter 458 or chapter 459 and practicing in this state with experience in treating rare diseases.

3. An individual who is 18 years of age or older who has a rare disease.

4. An individual who is a caregiver of an individual with a rare disease.

5. A representative of an organization operating in this state which provides care or other support to individuals with rare diseases.

(c) As appointed by the Speaker of the House of Representatives:

1. A representative from an academic research institution in this state which receives grant funding for research regarding rare diseases.

2. A physician who is licensed under chapter 458 or chapter 459 and practicing in this state with experience in treating rare diseases.

3. An individual who is 18 years of age or older who has a rare disease.

4. An individual who is a caregiver of an individual with a rare disease.

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

Any vacancy on the advisory council must be filled in the same manner as the original appointment.

(3) The initial members of the advisory council must be appointed by September 1, 2021. Each member must be appointed to a 4-year term of office. However, in order to achieve staggered terms, each of the initial members appointed pursuant to paragraph (2)(a) must be appointed to a 2-year term. The Governor shall designate a chair and vice chair of the advisory council from among its membership. The advisory council shall meet for its initial meeting by October 1, 2021. Thereafter, the advisory council may meet upon the call of the chair or upon the request of a majority of its members. The advisory council may meet via teleconferencing or other

electronic means. Notices for any scheduled meetings of the advisory council must be published in advance on the department’s website.

(4) The advisory council shall:

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

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

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

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

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

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

Approved by the Governor June 21, 2021.

Filed in Office Secretary of State June 21, 2021.