



209168

LEGISLATIVE ACTION

Senate	.	House
Comm: RCS	.	
03/01/2022	.	
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	.	
	.	

The Committee on Appropriations (Rodriguez) recommended the following:

Senate Amendment (with title amendment)

Between lines 456 and 457

insert:

Section 4. Paragraphs (b) and (c) of subsection (2) of section 381.99, Florida Statutes, are amended to read:

381.99 Rare Disease Advisory Council.—

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

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



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

14 2. A physician who is licensed under chapter 458 or chapter
15 459 and practicing in this state with experience in treating
16 rare diseases.

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

19 4. Two individuals ~~An individual~~ who are caregivers for
20 individuals ~~is a caregiver of an individual~~ with a rare disease.

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

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

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

29 2. A physician who is licensed under chapter 458 or chapter
30 459 and practicing in this state with experience in treating
31 rare diseases.

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

34 4. Two individuals ~~An individual~~ who are caregivers for
35 individuals ~~is a caregiver of an individual~~ with a rare disease.

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

38
39 Any vacancy on the advisory council must be filled in the same



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40 manner as the original appointment.

41

42 ===== T I T L E A M E N D M E N T =====

43 And the title is amended as follows:

44 Delete line 32

45 and insert:

46 certain circumstances; amending s. 381.99, F.S.;

47 revising the membership of the Rare Disease Advisory

48 Council; amending s. 456.039, F.S.;