

South Carolina General Assembly
124th Session, 2021-2022

H. 3956

STATUS INFORMATION

General Bill

Sponsors: Rep. Howard

Document Path: I:\council\ bills\gt\6026vr21.docx

Introduced in the House on February 23, 2021

Currently residing in the House Committee on **Medical, Military, Public and Municipal Affairs**

Summary: Rare Disease Council

HISTORY OF LEGISLATIVE ACTIONS

<u>Date</u>	<u>Body</u>	<u>Action Description with journal page number</u>
2/23/2021	House	Introduced and read first time
2/23/2021	House	Referred to Committee on Medical, Military, Public and Municipal Affairs

View the latest [legislative information](#) at the website

VERSIONS OF THIS BILL

[2/23/2021](#)

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42

A BILL

TO AMEND THE CODE OF LAWS OF SOUTH CAROLINA, 1976, BY ADDING SECTION 44-1-320 SO AS TO ESTABLISH THE "SOUTH CAROLINA RARE DISEASE ADVISORY COUNCIL" WITHIN THE DEPARTMENT OF HEALTH AND ENVIRONMENTAL CONTROL, TO PROVIDE FOR THE PURPOSE, DUTIES, MEMBERSHIP, AND FUNDING OF THE COUNCIL, TO ESTABLISH CERTAIN REPORTING AND MEETING REQUIREMENTS, AND FOR OTHER PURPOSES.

Whereas, a rare disease, sometimes called an orphan disease, is defined as a disease that affects fewer than two hundred thousand people in the United States; and

Whereas, there are seven thousand known rare diseases affecting approximately twenty-five to thirty million adults and children in the United States; and

Whereas, people with rare diseases face many challenges, including delays in obtaining a diagnosis, misdiagnosis, shortages of medical specialists who can provide treatment, and lack of affordable access to therapies and medication used to treat rare diseases; and

Whereas, a state-based advisory council composed of qualified professionals and persons living with rare diseases could educate medical professionals, governmental agencies, legislators, and the public about rare diseases as an important public health issue and encourage and secure funding for research for the development of new treatments for rare diseases. Now, therefore,

Be it enacted by the General Assembly of the State of South Carolina:

1 SECTION 1. Chapter 1, Title 44 of the 1976 Code is amended by
2 adding:

3
4 “Section 44-1-320. (A) The South Carolina Rare Disease
5 Advisory Council (council) is established within the Department of
6 Health and Environmental Control in accordance with this section.

7 (B) The purpose of the council is to advise the General Assembly
8 and other governmental agencies and departments, as appropriate,
9 on the needs of individuals with rare diseases living in South
10 Carolina.

11 (C) The council shall conduct the following activities to benefit
12 rare disease patients in South Carolina:

13 (1) convene public hearings, make inquiries, and solicit
14 comments from the general public in South Carolina to assist the
15 council with a first-year landscape or survey of the needs of
16 rare-disease patients, caregivers, and providers in the State;

17 (2) consult with experts on rare diseases on the council and
18 externally, as needed, to develop policy recommendations to
19 improve patient access to and quality of rare-disease specialists,
20 affordable and comprehensive health care coverage, relevant
21 diagnostics, timely treatment, and other needed services;

22 (3) research and identify priorities related to treatments and
23 services provided to persons with rare diseases in South Carolina
24 and develop policy recommendations that include safeguards
25 against discrimination for these populations on such issues,
26 including in disaster- and public health emergency-related planning;

27 (4) publish a list of existing, publicly accessible resources on
28 research, diagnosis, treatment, and education relating to the rare
29 diseases in South Carolina on the council’s website;

30 (5) identify and distribute educational resources for health
31 care providers to foster recognition and optimize treatment of rare
32 diseases in South Carolina; and

33 (6) research and identify best practices to reduce health
34 disparities and achieve health equity in the research, diagnosis, and
35 treatment of rare diseases in South Carolina.

36 (D)(1) The Governor shall appoint the chair of the council within
37 thirty days of enactment of this section. The chair may not hold any
38 position within the government of South Carolina.

39 (2) The chair shall appoint the following members:

40 (a) one representative from the South Carolina Department
41 of Health and Environmental Control or Office of Minority Health
42 in the department;

1 (b) one registered nurse or advanced practice registered
2 nurse licensed and practicing in South Carolina with experience
3 treating rare diseases;

4 (c) one physician practicing in South Carolina with
5 experience treating rare diseases;

6 (d) at least two patients who have a rare disease;

7 (e) at least one caregiver of a person with a rare disease;

8 (f) two representatives of different rare-disease patient
9 organizations that operate in South Carolina;

10 (g) one representative of the biopharma industry;

11 (h) one representative of a health plan company; and

12 (i) one member of the scientific community who is
13 engaged in rare-disease research including, but not limited to, a
14 medical researcher with experience conducting research on rare
15 diseases.

16 (E)(1) The council shall submit a report to the Governor within
17 one year of enactment of this section and annually thereafter.

18 (2) The annual report must:

19 (a) describe the activities and progress of the council as set
20 forth in subsection (C);

21 (b) provide an update on the status of funding of the council
22 including, but not limited to, grants applied for, received, used, and
23 remaining balances; and

24 (c) provide recommendations to the Governor and General
25 Assembly on ways to address the needs of people living with rare
26 diseases in the State of South Carolina.

27 (3) A draft of the annual report must be provided for public
28 comment and discussed at an open public meeting and submitted to
29 the Governor and the ranking members of the Senate Medical
30 Affairs Committee, Senate Finance Committee, House Medical,
31 Military, Public and Municipal Affairs Committee, and House Ways
32 and Means Committee.

33 (F)(1) Members of the council may solicit funds on behalf of the
34 council.

35 (2) The council shall set up a method to securely hold and
36 distribute funds.

37 (3) The council shall report funding sources in its annual
38 report.

39 (4) There is no limit on the amount of funds the council is
40 authorized to accept.

41 (5) The council may use the funding to carry out duties set
42 forth in subsection (C).

1 (G)(1) The initial meeting of the council must occur within ninety
2 days of enactment of this section followed by in-person or virtual
3 monthly meetings for a period of time, as determined by the chair.
4 Thereafter, the council shall meet on a quarterly basis in person or
5 virtually, pursuant to a schedule determined by the chair and vice
6 chair.

7 (2) The council shall provide opportunities for the public to
8 hear updates and provide input into the work of the council, and
9 shall create and maintain a public website on which meeting notices
10 and minutes are posted and public comment may be submitted.

11 (H)(1) Initially, the Governor shall appoint a chair for an initial
12 term of three years. At the end of the chair's initial three-year term,
13 and every two years thereafter, the members of the council shall
14 appoint, by a majority vote, a new chair to serve for a two-year term.

15 (2) A council member may not serve any longer than two
16 years.

17 (3) If a vacancy on the council occurs, the members, by a
18 majority vote, shall fill the vacancy in a timely manner.

19 (I) Members shall serve without compensation and are
20 ineligible for the usual mileage, subsistence, and per diem allowed
21 by law for members of state boards, committees, and commissions.”

22

23 SECTION 2. This act takes effect upon approval by the Governor.

24

---XX---

25