

GENERAL ASSEMBLY OF NORTH CAROLINA
SESSION 2015

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HOUSE BILL 823

Short Title: Establish Advisory Council on Rare Diseases. (Public)

Sponsors: Representatives Carney, Avila, Earle, and Bishop (Primary Sponsors).

For a complete list of Sponsors, refer to the North Carolina General Assembly Web Site.

Referred to: Health.

April 15, 2015

1 A BILL TO BE ENTITLED
2 AN ACT ESTABLISHING AN ADVISORY COUNCIL ON RARE DISEASES WITHIN
3 THE DEPARTMENT OF HEALTH AND HUMAN SERVICES.

4 The General Assembly of North Carolina enacts:

5 **SECTION 1.** Article 1B of Chapter 130A of the General Statutes is amended by
6 adding a new Part to read:

7 "Part 5. Advisory Council on Rare Diseases.

8 **"§ 130A-33.52. Advisory Council on Rare Diseases; membership.**

9 (a) There is established the Advisory Council on Rare Diseases within the Department
10 to advise the Secretary on research, diagnosis, treatment, and education relating to rare
11 diseases. For purposes of this section, "rare disease" has the same meaning as provided in 21
12 U.S.C. § 360bb, as amended from time to time.

13 (b) The advisory council shall consist of the following members, who shall be
14 appointed by the Secretary:

15 (1) Up to five physicians licensed and practicing in the State with experience
16 researching, diagnosing, or treating rare diseases.

17 (2) A medical researcher with experience conducting research concerning rare
18 diseases.

19 (3) A registered nurse or advanced practice registered nurse licensed and
20 practicing in the State with experience treating rare diseases.

21 (4) One hospital administrator from each hospital in the State that provides care
22 to persons diagnosed with a rare disease, or a designee of the hospital
23 administrator.

24 (5) Two rare disease survivors over the age of 18.

25 (6) A caregiver of a pediatric rare disease survivor.

26 (7) A representative of the North Carolina Board of Education.

27 (8) A representative in the field of biostatistics.

28 (9) A representative in the field of public health.

29 (10) Up to three representatives of patient-based organizations operating within
30 the State.

31 (c) The chairpersons of the Joint Legislative Oversight Committee on Health and
32 Human Services, or the chairpersons' designees, shall be members of the advisory council.

33 (d) The Secretary, or the Secretary's designee, shall be an ex officio, nonvoting member
34 of the advisory council and shall attend all meetings of the advisory council.



1 (e) Any member of the advisory council appointed under subsection (c) of this section
2 may be a member of the General Assembly.

3 (f) All appointments to the advisory council shall be made not later than 30 days after
4 the effective date of this section. Members appointed pursuant to subsection (b) of this section
5 shall serve for a term of three years, and no member shall serve more than two consecutive
6 terms.

7 (g) Members of the advisory council shall receive per diem and necessary travel and
8 subsistence expenses in accordance with the provisions of G.S. 138-5 or G.S. 138-6, or travel
9 and subsistence expenses in accordance with the provisions of G.S. 120-3.1, as applicable.

10 (h) All administrative support and other services required by the advisory council shall
11 be provided by the Department.

12 (i) The Secretary shall schedule the first meeting of the advisory council, which shall
13 be held not later than October 1, 2015. The members shall elect the chairperson of the advisory
14 council from among the members of the council. A majority of the council members shall
15 constitute a quorum. A majority vote of a quorum shall be required for any official action of the
16 advisory council. The advisory council shall meet upon the call of the chairperson or upon the
17 request of a majority of council members.

18 **"§ 130A-33.53. Advisory Council on Rare Diseases; powers and duties.**

19 The advisory council shall exercise the following powers and duties:

- 20 (1) Coordinate statewide efforts for the study of the incidence of rare disease
21 within the State and the status of the rare disease community.
- 22 (2) Act as the advisory body on rare diseases to the Secretary on research,
23 diagnosis, treatment, and education relating to rare diseases.
- 24 (3) Coordinate the performance of the advisory council's duties with other rare
25 disease advisory bodies, community-based organizations, and other public
26 and private organizations within the State for the purpose of ensuring greater
27 cooperation regarding the research, diagnosis, and treatment of rare diseases
28 between the State and federal agencies, including but not exclusive to, the
29 United States National Institutes of Health (NIH) and the United States Food
30 and Drug Administration (FDA). Such coordination shall require, when
31 appropriate, the following:
 - 32 a. Disseminating the advisory council's research, identified best
33 practices, and policy recommendations.
 - 34 b. Utilizing common research collection and dissemination procedures.
- 35 (4) Research and identify priorities relating to the quality and cost-effectiveness
36 of, and access to, treatment and services provided to persons with rare
37 diseases in the State; and develop policy recommendations on those issues.
- 38 (5) Identify best practices for rare disease care from other states and at the
39 national level that will improve rare disease care in this State.
- 40 (6) Develop recommendations for effective strategies to raise public awareness
41 of rare diseases in the State.
- 42 (7) Determine recommendations for best practices for ensuring that the public
43 and health care providers are sufficiently informed of the most effective
44 strategies for recognizing and treating rare disease.
- 45 (8) Develop recommendations for effective strategies to aid in determining any
46 genetic or environmental contributors to rare diseases.
- 47 (9) Not later than January 1, 2016, and annually thereafter, the advisory council
48 shall report to the Joint Legislative Oversight Committee on Health and
49 Human Services on the activities of the advisory council and its findings and
50 recommendations regarding rare disease research and care in North Carolina.

1 (10) Apply for, and accept, any grant of money from the federal government,
2 private foundations, or other sources which may be available for the
3 operation of the advisory council and State programs related to rare
4 diseases."

5 **SECTION 2.** This act becomes effective July 1, 2015.