

GENERAL ASSEMBLY OF NORTH CAROLINA
SESSION 2015

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HOUSE BILL 823
PROPOSED SENATE COMMITTEE SUBSTITUTE H823-PCS10407-TA-14

Short Title: Establish Advisory Council on Rare Diseases.

(Public)

Sponsors:

Referred to:

April 15, 2015

1 A BILL TO BE ENTITLED
2 AN ACT ESTABLISHING THE ADVISORY COUNCIL ON RARE DISEASES WITHIN
3 THE SCHOOL OF MEDICINE OF THE UNIVERSITY OF NORTH CAROLINA AT
4 CHAPEL HILL.

5 The General Assembly of North Carolina enacts:

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

8 "Part 5. Advisory Council on Rare Diseases.

9 **§ 130A-33.52. Advisory Council on Rare Diseases; membership; terms; compensation;**
10 **meetings; quorum.**

11 (a) There is established the Advisory Council on Rare Diseases within the School of
12 Medicine of the University of North Carolina at Chapel Hill to advise the Governor, the
13 Secretary, and the General Assembly on research, diagnosis, treatment, and education relating
14 to rare diseases. For purposes of this Part, "rare disease" has the same meaning as provided in
15 21 U.S.C. § 360bb.

16 (b) Advisory Council Membership. –

17 (1) Upon the recommendation of the Dean of the School of Medicine of the
18 University of North Carolina at Chapel Hill, the Secretary shall appoint
19 members to the advisory council as follows:

20 a. A physician licensed and practicing in this State with experience
21 researching, diagnosing, or treating rare diseases.

22 b. A medical researcher with experience conducting research
23 concerning rare diseases.

24 c. A registered nurse or advanced practice registered nurse licensed and
25 practicing in the State with experience treating rare diseases.

26 d. One rare diseases survivor.

27 e. One member who represents a rare diseases foundation.

28 f. One representative from each academic research institution in this
29 State that receives any grant funding for rare diseases research.

30 (2) The chairs of the Joint Legislative Oversight Committee on Health and
31 Human Services, or the chairs' designees, shall serve on the advisory
32 council. A member of the advisory council who is designated by the chairs
33 of the Joint Legislative Oversight Committee on Health and Human Services
34 may be a member of the General Assembly.

35 (3) The Secretary, or the Secretary's designee, shall serve as an ex officio,
36 nonvoting member of the advisory council.



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1 (c) Members appointed pursuant to subsection (b) of this section shall serve for a term
2 of three years, and no member shall serve more than two consecutive terms.

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

6 (e) All administrative support and other services required by the advisory council shall
7 be provided by the School of Medicine of the University of North Carolina at Chapel Hill.

8 (f) Upon the recommendation of the Dean of the School of Medicine of the University
9 of North Carolina at Chapel Hill, the Secretary shall select the chair of the advisory council
10 from among the members of the council.

11 (g) The chair shall convene the first meeting of the advisory council no later than
12 October 1, 2015. A majority of the council members shall constitute a quorum. A majority vote
13 of a quorum shall be required for any official action of the advisory council. Following the first
14 meeting, the advisory council shall meet upon the call of the chair or upon the request of a
15 majority of council members.

16 **"§ 130A-33.53. Advisory Council on Rare Diseases; powers and duties; reports.**

17 The advisory council shall have the following powers and duties:

18 (1) Advise on coordinating statewide efforts for the study of the incidence of
19 rare diseases within the State and the status of the rare disease community.

20 (2) Report to the Secretary, the Governor, and the Joint Legislative Oversight
21 Committee on Health and Human Services on behalf of the General
22 Assembly not later than January 1, 2016, and annually thereafter, on the
23 activities of the advisory council and its findings and recommendations
24 regarding rare disease research and care in North Carolina, including any
25 recommendations for statutory changes and amendments to the structure,
26 organization, and powers or duties of the advisory council."

27 **SECTION 2.** All appointments to the Advisory Council on Rare Diseases,
28 established by Section 1 of this act, shall be made not later than 30 days after the effective date
29 of this act.

30 **SECTION 3.** This act becomes effective August 1, 2015.