

GENERAL ASSEMBLY OF NORTH CAROLINA
SESSION 2021

H.B. 733
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HOUSE PRINCIPAL CLERK

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HOUSE BILL DRH40421-MM-74A

Short Title: Extend Terms/NC Rare Disease Advisory Council. (Public)

Sponsors: Representative Carney.

Referred to:

1 A BILL TO BE ENTITLED
2 AN ACT TO EXTEND THE TERMS OF MEMBERS OF THE ADVISORY COUNCIL ON
3 RARE DISEASES.

4 The General Assembly of North Carolina enacts:

5 SECTION 1. G.S. 130A-33.65 reads as rewritten:

6 "§ 130A-33.65. Advisory Council on Rare Diseases; membership; terms; compensation;
7 meetings; quorum.

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

14 (b) Advisory Council Membership.

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

- 18 a. A physician licensed and practicing in this State with experience
19 researching, diagnosing, or treating rare diseases.
20 b. A medical researcher with experience conducting research concerning
21 rare diseases.
22 c. A registered nurse or advanced practice registered nurse licensed and
23 practicing in the State with experience treating rare diseases.
24 d. One rare diseases survivor.
25 e. One member who represents a rare diseases foundation.
26 f. One representative from each academic research institution in this
27 State that receives any grant funding for rare diseases research.

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

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

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



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

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

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

9 (g) The chair shall convene the first meeting of the advisory council no later than October
10 1, 2015. A majority of the council members shall constitute a quorum. A majority vote of a
11 quorum shall be required for any official action of the advisory council. Following the first
12 meeting, the advisory council shall meet upon the call of the chair or upon the request of a
13 majority of council members."

14 **SECTION 2.** This act is effective when it becomes law and applies to current
15 members of the Advisory Council on Rare Diseases.