

**GENERAL ASSEMBLY OF NORTH CAROLINA
SESSION 2021**

H

2

**HOUSE BILL 733
Committee Substitute Favorable 5/11/21**

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

Sponsors:

Referred to:

May 3, 2021

A BILL TO BE ENTITLED
AN ACT TO EXTEND THE TERMS OF MEMBERS OF THE ADVISORY COUNCIL ON
RARE DISEASES AND TO ADD TO THE MEMBERSHIP OF THE ADVISORY
COUNCIL ON RARE DISEASES.

The General Assembly of North Carolina enacts:

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

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

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

(b) **Advisory Council Membership.**

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

- a. A physician licensed and practicing in this State with experience researching, diagnosing, or treating rare diseases.
- b. A medical researcher with experience conducting research concerning rare diseases.
- c. A registered nurse or advanced practice registered nurse licensed and practicing in the State with experience treating rare diseases.
- d. One rare diseases survivor.
- e. One member who represents a rare diseases foundation.
- f. One representative from each academic research institution in this State that receives any grant funding for rare diseases research.
- g. One parent of a childhood rare disease survivor.

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

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



1 (c) Members appointed pursuant to subsection (b) of this section shall serve for a term of
2 three years, and no member shall serve more than ~~two~~three 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 and
5 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 from
10 among the members of the council.

11 (g) The chair shall convene the first meeting of the advisory council no later than October
12 1, 2015. A majority of the council members shall constitute a quorum. A majority vote of a
13 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 **SECTION 2.** This act is effective when it becomes law and applies to current
17 members of the Advisory Council on Rare Diseases.