

GENERAL ASSEMBLY OF NORTH CAROLINA
SESSION 2023

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HOUSE PRINCIPAL CLERK

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HOUSE BILL DRH30282-MG-126

Short Title: Rare Disease Advisory Council. (Public)

Sponsors: Representative Carney.

Referred to:

1 A BILL TO BE ENTITLED
2 AN ACT REVISING THE COMPOSITION AND DUTIES OF THE ADVISORY COUNCIL
3 ON RARE DISEASES.

4 The General Assembly of North Carolina enacts:

5 SECTION 1.(a) Part 6 of Article 1B of Chapter 130A of the General Statutes reads
6 as rewritten:

7 "Part 6. Taylor's Law Establishing the Advisory Council on Rare Diseases.

8 "§ 130A-33.65. Advisory Council on Rare Diseases; membership; terms; compensation;
9 meetings; quorum.

10 (a) Short Title. – This Part shall be known as Taylor's Law Establishing the Advisory
11 Council on Rare Diseases.

12 (a1) Establishment of Advisory Council. – There is established the Advisory Council on
13 Rare Diseases within the School of Medicine of the University of North Carolina at Chapel Hill
14 Department of Health and Human Services to advise the Governor, the Secretary, and the General
15 Assembly on research, diagnosis, treatment, and education relating to rare diseases. This Part
16 shall be known as Taylor's Law Establishing the Advisory Council on Rare Diseases. For
17 purposes of this Part, "rare disease" has the same meaning as provided in 21 U.S.C. § 360bb.

18 (b) Advisory Council Membership. – The advisory council shall consist of 22 members
19 to be appointed as follows:

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

- 23 a. A physician-Three physicians licensed and practicing in this State with
24 experience researching, diagnosing, or treating rare diseases. One
25 member shall serve for a term of four years, one member shall serve
26 for a term of three years, and one member shall serve for a term of two
27 years.
- 28 b. A medical researcher with experience conducting research concerning
29 rare diseases. This member shall serve for a term of two years.
- 30 c. A registered nurse or advanced practice registered nurse licensed and
31 practicing in the State with experience treating rare diseases. This
32 member shall serve for a term of three years.
- 33 d. One rare diseases survivor.
- 34 e. One member who represents a rare diseases foundation.
- 35 f. One representative from each academic research institution in this
36 State that receives any grant funding for rare diseases research.



- 1 g. ~~One parent of a childhood rare disease survivor.~~
- 2 h. Two hospital administrators representing hospitals in the State that
3 provide care to persons diagnosed with a rare disease, or their
4 designees. At least one of the hospital administrators appointed
5 pursuant to this sub-subdivision shall represent a hospital with a scope
6 of service that focuses on the treatment of pediatric patients diagnosed
7 with a rare disease. These members shall serve for a term of two years.
- 8 i. Three persons age 18 or older who (i) have been diagnosed with a rare
9 disease or (ii) are currently caregivers to a person diagnosed with a
10 rare disease. These members shall serve for a term of four years.
- 11 j. A representative of a rare disease patient organization that operates in
12 the State. This member shall serve for a term of four years.
- 13 k. A social worker licensed and practicing in this State with experience
14 providing services to persons diagnosed with a rare disease. This
15 member shall serve for a term of three years.
- 16 l. A pharmacist licensed and practicing in this State with knowledge and
17 experience regarding drugs used to treat rare diseases. This member
18 shall serve for a term of two years.
- 19 m. A licensed dentist practicing in this State with experience treating
20 persons diagnosed with a rare disease. This member shall serve for a
21 term of three years.
- 22 n. Two representatives of the life sciences industry that either focus on
23 research efforts related to the development of therapeutic products for
24 persons diagnosed with a rare disease or have a demonstrable
25 understanding of the path to commercialization of such products. At
26 least one of these representatives shall be currently employed in the
27 life sciences industry as a professional patient advocate. These
28 members shall serve for a term of two years.
- 29 o. A representative of the biotechnology industry. This member shall
30 serve for a term of two years.
- 31 p. A representative of a health benefit plan or health insurer. This
32 member shall serve for a term of two years.
- 33 q. A genetic counselor with experience providing services to persons
34 diagnosed with a rare disease or caregivers of persons diagnosed with
35 a rare disease. This member shall serve for a term of three years.
- 36 (2) The chairs of the Joint Legislative Oversight Committee on Health and Human
37 Services, or the chairs' designees, shall serve on the advisory council. A
38 member of the advisory council who is designated by the chairs of the Joint
39 Legislative Oversight Committee on Health and Human Services ~~may~~ shall be
40 a member of the General Assembly.
- 41 (3) The Secretary, or the Secretary's designee, shall serve as an ex officio,
42 nonvoting member of the advisory council.
- 43 (c) ~~Members~~ Length of Terms. – ~~All initial members appointed pursuant to subsection~~
44 ~~(b) of this section to the advisory council shall serve for a term of three years, and no member~~
45 initial member, except for the initial physician member, shall serve more than three consecutive
46 terms. The initial physician member may serve for up to four consecutive terms. Thereafter,
47 members appointed to the advisory council shall serve for the length of time specified in
48 subsection (b) of this section.
- 49 (c1) Vacancies and Removals. – Any appointment to fill a vacancy on the advisory council
50 created by the resignation, dismissal, death, or disability of a member shall be filled by the
51 appointing authority for the balance of the unexpired term. Each appointing authority may

1 remove any member appointed by that appointing authority for misfeasance, malfeasance, or
2 nonfeasance. As used in this section, the term "appointing authority" means the Secretary, in the
3 case of members appointed by the Secretary; and the cochair of the Joint Legislative Oversight
4 Committee on Health and Human Services, in the case of members appointed by said cochair.

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

9 (e) Administrative Support. – All administrative support and other services required by
10 the advisory council shall be provided by the ~~School of Medicine of the University of North~~
11 ~~Carolina at Chapel Hill~~ Department.

12 (f) ~~Upon the recommendation of the Dean of the School of Medicine of the University~~
13 ~~of North Carolina at Chapel Hill, the Secretary shall select the chair of the advisory council from~~
14 ~~among the members of the council.~~ Selection of Chair. – The advisory council members shall
15 elect a chair from among its members by a majority vote. The chair shall serve in this position
16 until his or her term expires, or until a successor is elected by a majority vote of the advisory
17 council members.

18 (g) ~~The chair shall convene the first meeting of the advisory council no later than October~~
19 ~~1, 2015.~~ Meetings and Quorum. – A majority of the council members shall constitute a quorum.
20 A majority vote of a quorum shall be required for any official action of the advisory council.
21 Following the first meeting, the advisory council shall meet at least quarterly. The advisory
22 council may meet more frequently upon the call of the chair or upon the request of a majority of
23 council members.

24 **"§ 130A-33.66. Advisory Council on Rare Diseases; powers and duties; reports.**

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

- 26 (1) ~~Advise e~~ Advise ~~coordinating the Governor, the Secretary, and the General Assembly~~
27 on all of the following:
- 28 a. Coordination of statewide efforts for the to study of the incidence of
29 rare diseases within the State and the status of the rare disease
30 community.
 - 31 b. Coordination of statewide efforts to increase public awareness and
32 understanding of rare diseases.
 - 33 c. Identification of policy issues related to rare diseases and the
34 advancement of policy initiatives related to rare diseases at the State
35 and federal levels.
 - 36 d. The appropriation of State funds to facilitate increased public
37 awareness of and improved treatment for rare diseases.
- 38 (2) Report to the Secretary, the Governor, and the Joint Legislative Oversight
39 Committee on Health and Human Services on behalf of the General Assembly
40 not later than January 1, 2016, and annually thereafter, on the activities of the
41 advisory council and its findings and recommendations regarding rare disease
42 research and care in North Carolina, including any recommendations for
43 statutory changes and amendments to the structure, organization, and powers
44 or duties of the advisory council.
- 45 (3) In consultation with accredited medical schools located in this State,
46 accredited colleges and universities located in this State with master's level
47 public health programs, and hospitals licensed to operate in this State that
48 provide care to persons diagnosed with a rare disease, develop resources or
49 recommendations regarding quality of and access to treatment and services
50 available within North Carolina for persons diagnosed with a rare disease.

1 (4) Advise and consult with the Department, the North Carolina Drug Utilization
2 Review Board, and the Medicaid and NC Health Choice Preferred Drug List
3 Review Panel in developing recommendations, resources, and programs
4 relating to the diagnosis and treatment of rare diseases.

5 (5) Identify additional relevant areas for the advisory council to study and
6 evaluate."

7 **SECTION 1.(b)** To minimize the impact of this act on the work of the Advisory
8 Council on Rare Diseases:

9 (1) By September 1, 2023, the Secretary of Health and Human Services shall
10 appoint new members to the advisory council as authorized by subdivision
11 (b)(1) of G.S. 130A-33.65, as amended by this act;

12 (2) By September 1, 2023, the cochairs of the Joint Legislative Oversight
13 Committee on Health and Human Services shall appoint any designees to the
14 advisory council as authorized by subdivision (b)(2) of G.S. 130A-33.65, as
15 amended by this act; and

16 (3) By October 1, 2023, the chair of the Advisory Council on Rare Diseases shall
17 convene the first meeting of the newly constituted advisory council.

18 **SECTION 2.** This act is effective when it becomes law.