

ADOPTED



NORTH CAROLINA GENERAL ASSEMBLY
AMENDMENT
House Bill 263

AMENDMENT NO. A24
(to be filled in by
Principal Clerk)

H263-AMQa-30 [v.4]

Page 1 of 4

Amends Title [NO]
Second Edition

Date _____, 2024

Representative Carney

1 moves to amend the bill on page 114, lines 38-39, by inserting the following new section to read:
2 **"ADVISORY COUNCIL ON RARE DISEASES**

3 **SECTION 9B.2.(a)** Part 6 of Article 1B of Chapter 130A of the General Statutes
4 reads as rewritten:

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

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

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

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

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

18 (1) ~~Upon the recommendation of the Dean of the School of Medicine of the~~
19 ~~University of North Carolina at Chapel Hill, the~~ The Secretary shall appoint
20 ~~members to the advisory council as follows:~~ the following 15 members:

- 21 a. ~~A physician~~ Two physicians licensed and practicing in this State with
22 experience researching, diagnosing, or treating rare diseases.
- 23 b. ~~A medical researcher with experience conducting research concerning~~
24 ~~rare diseases.~~
- 25 c. ~~A~~ One registered nurse or advanced practice registered nurse licensed
26 and practicing in the State with experience treating rare diseases.
- 27 d. ~~One rare diseases survivor.~~
- 28 e. ~~One member who represents a rare diseases foundation.~~
- 29 f. ~~One representative~~ researcher from ~~each~~ an academic research
30 institution in this State that receives any grant funding for rare diseases
31 research.
- 32 g. ~~One parent of a childhood rare disease survivor.~~



* H 2 6 3 - A M Q A - 3 0 - V - 4 *

NORTH CAROLINA GENERAL ASSEMBLY
AMENDMENT
House Bill 263

ADOPTED

AMENDMENT NO. **A24**
(to be filled in by
Principal Clerk)

H263-AMQa-30 [v.4]

Page 2 of 4

- 1 h. One hospital administrator, or the hospital administrator's designee,
2 representing a hospital in the State that provides care to persons
3 diagnosed with a rare disease.
4 i. Two persons age 18 or older who have been diagnosed with a rare
5 disease.
6 j. Two persons age 18 or older who are, or were previously, caregivers
7 to a person diagnosed with a rare disease.
8 k. One representative of a rare disease patient organization that operates
9 in the State.
10 l. One pharmacist licensed and practicing in this State with knowledge
11 and experience regarding drugs used to treat rare diseases.
12 m. One representative of the life sciences, biotechnology, or
13 biopharmaceutical industry that either focuses on research efforts
14 related to the development of therapeutic products for persons
15 diagnosed with a rare disease or has demonstratable understanding of
16 the path to commercialization of such products.
17 n. Two representatives of a health benefit plan or health insurer, at least
18 one of whom is a representative of a North Carolina Medicaid
19 Managed Care health plan.
20 o. One genetic counselor with experience providing services to persons
21 diagnosed with a rare disease or caregivers of persons diagnosed with
22 a rare disease.
23 ~~(2) The chairs of the Joint Legislative Oversight Committee on Health and Human~~
24 ~~Services, or the chairs' designees, shall serve on the advisory council. A~~
25 ~~member of the advisory council who is designated by the chairs of the Joint~~
26 ~~Legislative Oversight Committee on Health and Human Services may be a~~
27 ~~member of the General Assembly.~~
28 (2a) One member appointed by the President Pro Tempore of the Senate.
29 (2b) One member appointed by the Speaker of the House of Representatives.
30 (2c) One member appointed by the Governor.
31 (3) The Secretary, or the Secretary's designee, shall serve as an ex officio,
32 nonvoting member of the advisory council.
33 (c) ~~Members~~ Length of Terms. – All initial members appointed pursuant to subsection
34 ~~(b) of this section~~ to the advisory council shall serve for a term of three years, and no member
35 initial member, except for the initial physician members and the initial member representing a
36 rare disease patient organization, shall serve more than three consecutive terms. The initial
37 physician members and the initial member representing a rare disease patient organization may
38 serve for up to four consecutive terms. Thereafter, members appointed by the President Pro
39 Tempore of the Senate, the Speaker of the House of Representatives, and the Governor shall
40 serve for a term of two years and members appointed by the Secretary shall serve for a term of
41 two, three, or four years as determined by the chair of the advisory council.
42 (c1) Vacancies and Removals. – Any appointment to fill a vacancy on the advisory council
43 created by the resignation, dismissal, death, or disability of a member shall be filled by the

NORTH CAROLINA GENERAL ASSEMBLY
AMENDMENT
House Bill 263

ADOPTED

AMENDMENT NO. **A24**
(to be filled in by
Principal Clerk)

H263-AMQa-30 [v.4]

Page 3 of 4

1 appointing authority for the balance of the unexpired term. Each appointing authority may
2 remove any member appointed by that appointing authority for misfeasance, malfeasance, or
3 nonfeasance.

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

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

11 (f) ~~Upon the recommendation of the Dean of the School of Medicine of the University~~
12 ~~of North Carolina at Chapel Hill, Selection of Chair.~~ – The Secretary shall select the chair of the
13 advisory council from among the members of the council. The chair shall serve in this position
14 until the expiration of his or her term.

15 (g) ~~The chair shall convene the first meeting of the advisory council no later than October~~
16 ~~1, 2015. Meetings and Quorum.~~ – A majority of the council members shall constitute a quorum.
17 A majority vote of a quorum shall be required for any official action of the advisory council.
18 Following the first meeting, the advisory council shall meet at least quarterly. The advisory
19 council may meet more frequently upon the call of the chair or upon the request of a majority of
20 council members.

21 **"§ 130A-33.66. Advisory Council on Rare Diseases; powers and duties; reports.**

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

23 (1) ~~Advise on coordinating the Governor, the Secretary, and the General~~
24 Assembly on all of the following:

25 a. Coordination of statewide efforts for the to study of the incidence of
26 rare diseases within the State and the status of the rare disease
27 community.

28 b. Coordination of statewide efforts to increase public awareness and
29 understanding of rare diseases.

30 c. Identification of policy issues related to rare diseases and the
31 advancement of policy initiatives related to rare diseases at the State
32 and federal levels.

33 d. The appropriation of State funds to facilitate increased public
34 awareness of and improved treatment for rare diseases.

35 (2) Report to the Secretary, the Governor, and the Joint Legislative Oversight
36 Committee on Health and Human Services on behalf of the General Assembly
37 not later than January 1, 2016, and annually thereafter, on the activities of the
38 advisory council and its findings and recommendations regarding rare disease
39 research and care in North Carolina, including any recommendations for
40 statutory changes and amendments to the structure, organization, and powers
41 or duties of the advisory council.

42 (3) In consultation with accredited medical schools, accredited schools of public
43 health, and hospitals licensed to operate in the State that provide care to

NORTH CAROLINA GENERAL ASSEMBLY
AMENDMENT
House Bill 263

ADOPTED

AMENDMENT NO. **A24**
(to be filled in by
Principal Clerk)

H263-AMQa-30 [v.4]

Page 4 of 4

- 1 persons diagnosed with a rare disease, develop resources or recommendations
2 regarding quality of and access to treatment and services available within the
3 State for persons diagnosed with a rare disease.
4 (4) Advise and consult with the Department, the North Carolina Drug Utilization
5 Review Board, and the Medicaid Preferred Drug List Review Panel in
6 developing recommendations, resources, and programs relating to the
7 diagnosis and treatment of rare diseases.
8 (5) Identify additional relevant areas for the advisory council to study and
9 evaluate."
10 **SECTION 9B.2.(b)** The Department of Health and Human Services shall utilize
11 funds available to the Department to cover the administrative costs of the Advisory Council on
12 Rare Diseases authorized by this section.";
13
14 and by adjusting the appropriate totals accordingly.

SIGNED _____
Amendment Sponsor

SIGNED _____
Committee Chair if Senate Committee Amendment

ADOPTED _____ FAILED _____ TABLED _____

**The official copy of this document, with signatures
and vote information, is available in the
House Principal Clerk's Office**