



CHAPTER 130A
ARTICLE 1B - COMMISSIONS AND COUNCILS

N.C.G.S. § 130A-33.65.

Advisory Council on Rare Diseases;
membership; terms; compensation;
meetings; quorum.

SOURCE	LAST AMENDMENT IN THIS TEXT	RETRIEVED	SOURCE FINGERPRINT
General Statutes of North Carolina, as published by the General Assembly	No amendment history on record	21 September 2026, 03:44 UTC	e5fdd8c871dce4ccbd62a714 - 0f3da6a4495f6b3b216ebb68 - 1aafd9ab25668085

§ 130A-33.65(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.

§ 130A-33.65(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.

§ 130A-33.65(c) Members appointed pursuant to subsection (b) of this section shall serve for a term of three years, and no member shall serve more than three consecutive terms.

§ 130A-33.65(d) Members of the advisory council shall receive per diem and necessary travel and subsistence expenses in accordance with the provisions of G.S. 138-5 or G.S. 138-6 or travel and subsistence expenses in accordance with the provisions of G.S. 120-3.1, as applicable.

§ 130A-33.65(e) All administrative support and other services required by the advisory council shall be provided by the School of Medicine of the University of North Carolina at Chapel Hill.

§ 130A-33.65(f) Upon the recommendation of the Dean of the School of Medicine of the University of North Carolina at Chapel Hill, the Secretary shall select the chair of the advisory council from among the members of the council.

§ 130A-33.65(g) The chair shall convene the first meeting of the advisory council no later than October 1, 2015. A majority of the council members shall constitute a quorum. A majority vote of a quorum shall be required for any official action of the advisory council. Following the first meeting, the advisory council shall meet upon the call of the chair or upon the request of a majority of council members. (2015-199, s. 1; 2016-30, s. 3; 2022-74, s. 9G.5(a).)

END OF SECTION TEXT

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APPARATUS II
3 AUTHORITIES

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Authorities referenced

Every G.S. cross-reference appearing in the text of this section, in order of first appearance. Nothing is characterized; the operative language is quoted from the section itself.

REFERENCE	APPEARS IN	OPERATIVE LANGUAGE IN THIS SECTION
G.S. 138-5	(d)	<i>"in accordance with the provisions of"</i>
G.S. 138-6	(d)	<i>"the provisions of G.S. 138-5 or"</i>
G.S. 120-3.1	(d)	<i>"in accordance with the provisions of"</i>

APPARATUS III

Citation

FULL SECTION

N.C. Gen. Stat. § 130A-33.65 (2026).

PINPOINT

N.C. Gen. Stat. § 130A-33.65(a) (2026).

Pinpoint keys are set in the left margin of the text rather than line numbers: subsection designators are stable across editions and paper sizes, line numbers are not.

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