



HOUSE BILL 935: Reorganize & Fund Rare Disease Adv. Council.

2023-2024 General Assembly

Committee:	House Health. If favorable, re-refer to Appropriations. If favorable, re-refer to Rules, Calendar, and Operations of the House	Date:	June 4, 2024
Introduced by:	Reps. Carney, Lambeth	Prepared by:	Jessica Boney Staff Attorney
Analysis of:	First Edition		

OVERVIEW: House Bill 935 would transfer the Advisory Council on Rare Diseases ("Council") from the UNC School of Medicine to the Department of Health and Human Services ("Department"), revise the membership of the Council and appropriate \$250,000 in recurring funding to cover administrative costs of the Council.

CURRENT LAW: S.L. 2015-199 established the Council within the School of Medicine of the University of North Carolina to advise the Governor, the Secretary, and the General Assembly on research, diagnosis, treatment, and education relating to rare diseases. S.L. 2016-30 renamed Part 6, of Article 1B of Chapter 130A Taylor's Law Establishing the Advisory Council on Rare Diseases. S.L. 2022-74, Section 9G.5, extended the terms of the advisory council members and added a parent of a childhood rare disease survivor.

BILL ANALYSIS:

Section 1 would do the following:

- Move the Council from the UNC School of Medicine to the Department.
- Revise the membership of the Council as follows:
 - 15 of the following members appointed by the Secretary:
 - 2 State licensed physicians.
 - A registered nurse or advanced practice registered nurse.
 - A researcher.
 - A hospital administrator.
 - 2 persons age 18 or older who have been diagnosed with a rare disease.
 - 2 persons age 18 or older who are, or have been, caregivers to a person diagnosed with a rare disease.
 - A representative of a rare disease patient organization.
 - A licensed pharmacist.
 - A representative of the life sciences industry that either focus on research efforts related to the development of therapeutic products for persons diagnosed with a rare disease or have a demonstratable understanding of the path to commercialization of such products.

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- 2 representatives of a health benefit plan or insurer.
- A genetic counselor.
- 1 member appointed by the Governor.
- 1 member appointed by the Speaker of the House of Representatives.
- 1 member appointed by the President Pro Tempore of the Senate.
- The Secretary, or designee.
- Establish and amend term limits for members of the Council.
- Clarify any vacancies are to be filled by the original appointing authority and allow the appointing authority to remove a member for misfeasance, malfeasance, or nonfeasance.
- Require the Council to meet at least quarterly.
- Add the following to the Council's powers and duties:
 - Advising the Governor, the Secretary, and the General Assembly on (i) coordination of statewide efforts to increase public awareness and understanding of rare diseases; (ii) identification of policy issues related to rare diseases and advancement of policy initiatives; and (iii) appropriation of State funds to facilitate increased awareness and improved treatment.
 - Developing recommendations regarding the quality of and access to treatment and services for persons diagnosed with rare diseases in consultation with institutions of higher education and hospitals.
 - Advising and consulting with others on developing recommendations, resources, and programs relating to diagnosis and treatment.
 - Identifying additional relevant areas for the Council to study and evaluate.

Section 2 would appropriate \$250,000 in recurring funds from the General Fund to the Department to cover the administrative costs of the Council.

EFFECTIVE DATE: This act would be effective when it becomes law.