



HOUSE BILL 1166: Reorganize & Fund Rare Disease Adv. Council.

2025-2026 General Assembly

Committee:	House Health. If favorable, re-refer to Appropriations. If favorable, re-refer to Rules, Calendar, and Operations of the House	Date:	May 12, 2026
Introduced by:	Reps. Carney, Lambeth, Belk, Price	Prepared by:	Stewart Sturkie
Analysis of:	First Edition		Committee Co-Counsel

OVERVIEW: House Bill 1166 moves the Advisory Council on Rare Diseases (Advisory Council) to the North Carolina Department of Health and Human Services (NC DHHS), changes the appointment and composition of the Advisory Council, adds powers and duties of the Advisory Council, and makes an appropriation to cover the Advisory Council's operating expenses.

CURRENT LAW: The Advisory Council was established in 2015 within the School of Medicine of the University of North Carolina at Chapel Hill. Its purpose is to advise the Governor, the Secretary of NC DHHS (Secretary), and the General Assembly on research, diagnosis, treatment, and education relating to rare diseases.¹The Advisory Council currently has 12 members.

BILL ANALYSIS: House Bill 1166 would do all of the following:

- Move the Advisory Council to NC DHHS and change the appointment and number of the Advisory Council's members. The membership would consist of the following 19 members:
 - The Secretary would appoint 15 members with knowledge or experience with rare diseases, as follows:
 - Two physicians.
 - One registered nurse.
 - One researcher from an academic research institution in this State.
 - One hospital administrator from a hospital in this State.
 - Two people age 18 or older, who have been diagnosed with a rare disease.
 - Two people age 18 or older, who are, or were previously, caregivers to a person diagnosed with a rare disease.
 - One representative of a rare disease patient organization that operates in the State.
 - One pharmacist.
 - One representative of the life sciences, biotechnology, or biopharmaceutical industry that focuses on research related to developing therapeutic products for

¹ "Rare diseases" are defined as "any disease or condition which (A) affects less than 200,000 persons in the United States, or (B) affects more than 200,000 in the United States and for which there is no reasonable expectation that the cost of developing and making available in the United States a drug for such disease or condition will be recovered from sales in the United States of such drug." See 21 U.S.C. § 360bb.

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people diagnosed with rare diseases or has demonstrable understanding of the path to commercialization of such products.

- Two representatives of a health benefit plan or health insurer, at least one of whom is a representative of a North Carolina Medicaid Managed Care health plan.
- One genetic counselor.
- The President Pro Tempore of the Senate would appoint one member.
- The Speaker of the House of Representatives would appoint one member.
- The Governor would appoint one member.
- The Secretary would serve as an ex officio, nonvoting member.
- Establish the terms and term limits of members and the selection of the Advisory Council's chair. Vacancies will be filled by the appointing authority. The appointing authority can remove members for misfeasance, malfeasance, or nonfeasance.
- Require the Advisory Council to meet quarterly. The Advisory Council can meet more frequently at the call of the chair or at the request of a majority of the members.
- Provide additional powers and duties to the Advisory Council, which include:
 - Advise the Governor, the Secretary, and the General Assembly on:
 - Coordination of statewide efforts to increase public awareness and understanding of rare diseases.
 - Identification of policy issues related to rare diseases and the advancement of policy initiatives related to rare diseases at the State and federal levels.
 - The appropriation of State funds to facilitate increased public awareness of and improved treatment for rare diseases.
 - Develop resources or recommendations – in consultation with medical schools, schools of public health, and hospitals – on the quality of and access to treatment and services within the State for people diagnosed with a rare disease.
 - Advise and consult with the Department, the North Carolina Drug Utilization Review Board, and the Medicaid Preferred Drug List Review Panel in developing recommendations, resources, and programs relating to the diagnosis and treatment of rare diseases.
- Require the Advisory Council to include the Fiscal Research Division as one of the recipients of its annual report.
- Appropriate \$250,000 in recurring funds to NC DHHS to cover the operating expenses of the Advisory Council.

EFFECTIVE DATE: This bill would become effective when it becomes law.