



2025-2026 General Assembly

SENATE BILL 257: 2026 Appropriations Act, Sec. 9H.8: Transfer and Reorganization of Rare Disease Advisory Council

Analysis of: S.L. 2026-41, Sec. 9H.8

Date: August 24, 2026

Prepared by: Legislative Analysis
Division Staff

Section 9H.8 of S.L. 2026-41 (Senate Bill 257) makes the following changes to the Rare Disease Advisory Council (Advisory Council):

- Moves the Advisory Council to within the Department of Health and Human Services (DHHS).
- Expands the membership of the Advisory Council to 19 members with specified credentials. The Secretary of DHHS must appoint 15 members. The President Pro Tempore of the Senate, the Speaker of the House of Representatives, and the Governor also must appoint one member each.
- Establishes the terms and term limits of Advisory Council members. The appointing authority may (i) remove members for misfeasance, malfeasance, or nonfeasance, and (ii) fill a vacancy on the Advisory Council.
- Requires 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.
- Creates the following additional powers and duties of the Advisory Council:
 - Advising the Governor, the Secretary, and the General Assembly on (i) the coordination of statewide efforts to increase public awareness and understanding of rare diseases, (ii) the identification of policy issues related to rare diseases and the advancement of policy initiatives related to rare diseases at the State and federal levels, and (iii) the appropriation of State funds to facilitate increased public awareness of and improved treatment for rare diseases.
 - Developing 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.
 - Advising and consulting with DHHS, 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.
 - Identifying additional relevant areas for study and evaluation.
- Clarifies the terms of all members currently serving on the Advisory Council expire on October 1, 2026.

This section appropriates \$250,000 in non-recurring funds from the General Fund for the 2026-2027 fiscal year to DPH to cover the operating expenses of the Advisory Council.

This section became effective July 1, 2026.

Kara McCraw
Director



Legislative Analysis
Division
919-733-2578