HOUSE BILL 827:
Rare Disease Advisory Council.

2023-2024 General Assembly

Committee:	House Health. If favorable, re-refer to Rules, Calendar, and Operations of the House	**Date:**	April 26, 2023
Introduced by:	Reps. Carney, Lambeth	**Prepared by:**	Theresa Matula Legislative Analyst
Analysis of:	First Edition		

OVERVIEW: House Bill 827 adds members to the Advisory Council on Rare Diseases, provides additional powers and duties to the Council, requires the Secretary of Health and Human Services and the Cochairs of the Joint Legislative Oversight Committee on Health and Human Services to appoint certain members by September 1, 2023, and requires the newly constituted Council to meet by October 1, 2023.

CURRENT LAW: S.L. 2015-199 established the Advisory Council on Rare Diseases 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(a) of House Bill 827 does the following:

- Moves the Advisory Council on Rare Diseases from the UNC School of Medicine to the Department of Health and Human Services (DHHS).
- Increases the membership to 19 and provides for the staggering of term. The following are the members:
    - 3 physicians.
    - A medical researcher.
    - A registered nurse or advanced practice registered nurse.
    - 2 hospital administrators.
    - 3 persons age 18 or older who (i) have been diagnosed with a rare disease or (ii) are currently caregivers to a person diagnosed with a rare disease.
    - A representative of a rare disease patient organization.
    - A social worker.
    - A pharmacist.
    - A licensed dentist.
    - 2 representatives 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.
    - A representative of the biotechnology industry.
    - A representative of a health benefit plan or health insurer.
    - A genetic counselor with experience providing services to person diagnosed with a rare disease or caregivers of person diagnosed with a rare disease.
    - The chairs of the Joint Legislative Oversight Committee on Health and Human Services.

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  - The Secretary, or designee.
- Provide that the Council members elect the chair.
- Adds the following to the Council's powers and duties:
  - Coordination of statewide efforts to increase public awareness and understanding of rare diseases, identification of policy issues related to rare diseases and advancement of policy initiatives. Appropriation of State funds to facilitate increased awareness and improved treatment.
  - In consultation with institutions of higher education and hospitals, develop recommendations regarding the quality of and access to treatment and services for persons diagnosed with rare diseases.
  - Advise and consult with others on developing recommendations, resources, and programs relating to diagnosis and treatment.
  - Identify additional relevant areas for the Council to study and evaluate.

Section 1(b) provides that the Secretary of Health and Human Services and the Cochairs of the Joint Legislative Oversight Committee on Health and Human Services must appoint certain members by September 1, 2023, and the Advisory Council on Rare Diseases must convene the first meeting of the newly constituted Council by October 1, 2023.

EFFECTIVE DATE: House Bill 827 would become effective when it becomes law.