

GENERAL ASSEMBLY OF NORTH CAROLINA

SESSION 2017

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HOUSE BILL 808*
Committee Substitute Favorable 4/25/17

Short Title: Advisory Council Review of Rare Disease Bills.

(Public)

Sponsors:

Referred to:

April 13, 2017

A BILL TO BE ENTITLED

AN ACT EXPANDING THE DUTIES OF THE ADVISORY COUNCIL ON RARE DISEASES TO INCLUDE THE PREPARATION OF OPINIONS ON PROPOSED BILLS AND RESOLUTIONS PERTAINING TO RARE DISEASES AND REQUIRING THE OPINIONS TO BE PROVIDED TO THE BILL SPONSOR.

The General Assembly of North Carolina enacts:

SECTION 1. G.S. 130A-33.66 reads as rewritten:

"§ 130A-33.66. **Advisory Council on Rare Diseases; powers and duties; reports.**

The advisory council shall have the following powers and duties:

- (1) Advise on coordinating statewide efforts for the study of the incidence of rare diseases within the State and the status of the rare disease community.
- (2) Report to the Secretary, the Governor, and the Joint Legislative Oversight Committee on Health and Human Services on behalf of the General Assembly not later than January 1, 2016, and annually thereafter, on the activities of the advisory council and its findings and recommendations regarding rare disease research and care in North Carolina, including any recommendations for statutory changes and amendments to the structure, organization, and powers or duties of the advisory council.
- (3) Review each proposed bill and resolution pertaining to rare diseases, rare disease research, or rare disease care and prepare an opinion on the merits of the proposed bill or resolution and any recommended changes to the measure. The Advisory Council shall provide the opinion to the bill sponsor within 14 calendar days after receiving a copy of the proposed bill or resolution.

SECTION 2. This act becomes effective July 1, 2017.



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