

GENERAL ASSEMBLY OF NORTH CAROLINA  
SESSION 2017

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HOUSE BILL 808  
PROPOSED COMMITTEE SUBSTITUTE H808-PCS40556-SU-22

Short Title: Advisory Council Review of Rare Disease Bills.

(Public)

Sponsors:

Referred to:

April 13, 2017

1 A BILL TO BE ENTITLED  
2 AN ACT EXPANDING THE DUTIES OF THE ADVISORY COUNCIL ON RARE  
3 DISEASES TO INCLUDE THE PREPARATION OF OPINIONS ON PROPOSED BILLS  
4 AND RESOLUTIONS PERTAINING TO RARE DISEASES AND REQUIRING THE  
5 OPINIONS TO BE PROVIDED TO THE BILL SPONSOR.

6 The General Assembly of North Carolina enacts:

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

8 "**§ 130A-33.66. Advisory Council on Rare Diseases; powers and duties; reports.**

9 The advisory council shall have the following powers and duties:

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

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



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