

GENERAL ASSEMBLY OF NORTH CAROLINA
SESSION 2017

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HOUSE PRINCIPAL CLERK

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HOUSE BILL DRH50037-MGa-52A* (02/15)

Short Title: Advisory Council Review of Rare Disease Bills. (Public)

Sponsors: Representative Carney.

Referred to:

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 ADVISORY NOTES FOR
4 PROPOSED BILLS AND RESOLUTIONS PERTAINING TO RARE DISEASES AND
5 REQUIRING THE ADVISORY NOTE TO BE ATTACHED TO THE BILL OR
6 RESOLUTION AT THE TIME OF ITS CONSIDERATION BY THE GENERAL
7 ASSEMBLY.

8 The General Assembly of North Carolina enacts:

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

10 "§ 130A-33.66. **Advisory Council on Rare Diseases; powers and duties; reports.**

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

- 12 (1) Advise on coordinating statewide efforts for the study of the incidence of
13 rare diseases within the State and the status of the rare disease community.
14 (2) Report to the Secretary, the Governor, and the Joint Legislative Oversight
15 Committee on Health and Human Services on behalf of the General
16 Assembly not later than January 1, 2016, and annually thereafter, on the
17 activities of the advisory council and its findings and recommendations
18 regarding rare disease research and care in North Carolina, including any
19 recommendations for statutory changes and amendments to the structure,
20 organization, and powers or duties of the advisory council.
21 (3) Review each proposed bill and resolution pertaining to rare diseases, rare
22 disease research, or rare disease care and prepare an advisory note with an
23 opinion about the merits of the proposed bill or resolution and any
24 recommended changes to the measure within 14 calendar days after
25 receiving a copy of the proposed bill or resolution, as prescribed by
26 G.S. 120-30.55."

27 SECTION 2. Chapter 120 of the General Statutes is amended by adding a new
28 Article to read:

29 "Article 6E.

30 "Review of Rare Disease Bills and Resolutions.

31 "§ 120-30.55. Advisory notes from the Advisory Council on Rare Diseases on legislation
32 pertaining to rare diseases.

33 (a) Every bill and resolution introduced in the General Assembly proposing any change
34 in the law that pertains to rare diseases, rare disease research, or rare disease care shall have
35 attached to it at the time of its consideration by the General Assembly an advisory note
36 prepared by the Advisory Council on Rare Diseases established by G.S. 130A-33.66. The



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1 advisory note shall include the Advisory Council's opinion about the merits of the proposed bill
2 or resolution and any recommended changes to the measure.

3 (b) The sponsor of each bill or resolution to which this section applies shall present a
4 copy of the bill or resolution with the request for an advisory note to the Advisory Council on
5 Rare Diseases. Upon receipt of the request and a copy of the bill or resolution, the Advisory
6 Council shall prepare the advisory note as promptly as possible. The Advisory Council shall
7 prepare the advisory note and transmit it to the sponsor within two weeks after the request is
8 made, unless the sponsor agrees to an extension of time.

9 (c) The advisory note shall be attached to the original of each proposed bill or
10 resolution that is reported favorably by any committee of the General Assembly but shall be
11 separate from the bill or resolution and shall be clearly designated as an advisory note. An
12 advisory note attached to a bill or resolution pursuant to this subsection is not a part of the bill
13 or resolution and is not an expression of legislative intent proposed by the bill or resolution.

14 (d) If a committee of the General Assembly reports favorably a proposed bill or
15 resolution with an amendment that proposes a change in the law that pertains to rare diseases,
16 rare disease research, or rare disease care, the chairperson of the committee shall obtain from
17 the Advisory Council on Rare Diseases and attach to the amended bill or resolution an advisory
18 note as provided in this section.

19 (e) Copies of advisory notes prepared by the Advisory Council on Rare Diseases shall
20 be furnished to the sponsor of the bill or resolution and the chairpersons of the Rules
21 Committees."

22 **SECTION 3.** Notwithstanding the provisions of G.S. 130A-33.65(c) or any other
23 provision of law, the terms of the current members of the Advisory Council on Rare Diseases
24 are extended until July 31, 2021.

25 **SECTION 4.** There is appropriated from the General Fund to the Department of
26 Health and Human Services the sum of two hundred fifty thousand dollars (\$250,000) for the
27 2017-2018 fiscal year and the sum of two hundred fifty thousand dollars (\$250,000) for the
28 2018-2019 fiscal year. These funds shall be allocated to the Advisory Council on Rare Diseases
29 to prepare advisory notes for proposed bills and resolutions pertaining to rare diseases, rare
30 disease research, or rare disease care, as required by G.S. 130A-33.66(3), as amended by
31 Section 1 of this act, and G.S. 120-30.55, as enacted by Section 2 of this act.

32 **SECTION 5.** This act becomes effective July 1, 2017.