

GENERAL ASSEMBLY OF NORTH CAROLINA
SESSION 2019

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HOUSE PRINCIPAL CLERK

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HOUSE BILL DRH30322-MKa-136

Short Title: NC Rare Disease Council Funds. (Public)

Sponsors: Representatives Brisson, Carney, and Dobson (Primary Sponsors).

Referred to:

1 A BILL TO BE ENTITLED
2 AN ACT TO APPROPRIATE FUNDS TO SUPPORT THE ACTIVITIES OF THE ADVISORY
3 COUNCIL ON RARE DISEASES WITHIN THE SCHOOL OF MEDICINE OF THE
4 UNIVERSITY OF NORTH CAROLINA AT CHAPEL HILL.

5 The General Assembly of North Carolina enacts:

6 **SECTION 1.** There is appropriated from the General Fund to the Board of Governors
7 of The University of North Carolina the sum of two hundred fifty thousand dollars (\$250,000) in
8 recurring funds for the 2019-2020 fiscal year to be allocated to the School of Medicine of the
9 University of North Carolina at Chapel Hill to support the activities of the Advisory Council on
10 Rare Diseases (Council) established pursuant to G.S. 130A-33.65. The funds shall be used to
11 develop a rare disease network across the State for the purposes of collecting data regarding
12 regional rare disease prevalence, stimulating rare disease collaborations, and creating
13 biotechnology economic development opportunities. The Council shall partner with legislators
14 and other stakeholders in various regions of the State to increase public awareness and improve
15 diagnosis times for individuals with rare diseases. In addition, the Council shall develop key
16 strategies on increasing access to information, integrated and innovative support services,
17 translational research collaborations, educational programs, and accelerated technology, as well
18 as emphasizing economic development and retention of talented researchers. In support of these
19 activities, the funds appropriated pursuant to this act shall be allocated to the Council for the
20 following:

- 21 (1) The sum of thirty thousand dollars (\$30,000) to be used to primarily support
22 seminars on rare diseases to be held throughout the State.
- 23 (2) The sum of twenty-five thousand dollars (\$25,000) to be used to support travel
24 and per diem for members of the Council to attend conferences and other
25 partnership organization activities related to rare diseases.
- 26 (3) The sum of five thousand dollars (\$5,000) to maintain a Web site and social
27 media presence and to create material on activities of the Council.
- 28 (4) The sum of one hundred sixty thousand dollars (\$160,000) to establish
29 positions to support the Council, including contracting for temporary
30 employees to launch larger initiatives of the Council.
- 31 (5) The sum of thirty thousand dollars (\$30,000) for literature, equipment, and
32 supplies to support the Council's activities.

33 **SECTION 2.** This act becomes effective July 1, 2019.

