

**GENERAL ASSEMBLY OF NORTH CAROLINA  
SESSION 2019**

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**HOUSE BILL 720**

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

Sponsors: Representatives Brisson, Carney, and Dobson (Primary Sponsors).  
*For a complete list of sponsors, refer to the North Carolina General Assembly web site.*

Referred to: Appropriations, Education, if favorable, Rules, Calendar, and Operations of the House

April 15, 2019

A BILL TO BE ENTITLED

AN ACT TO APPROPRIATE FUNDS TO SUPPORT THE ACTIVITIES OF THE ADVISORY COUNCIL ON RARE DISEASES WITHIN THE SCHOOL OF MEDICINE OF THE UNIVERSITY OF NORTH CAROLINA AT CHAPEL HILL.

The General Assembly of North Carolina enacts:

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

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

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



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