

GENERAL ASSEMBLY OF NORTH CAROLINA
SESSION 2019

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SENATE BILL 69

Short Title: Raise Awareness of Lupus. (Public)

Sponsors: Senators Robinson, Foushee, Krawiec (Primary Sponsors); J. Davis, deViere, Garrett, Lowe, Mohammed, and Steinburg.

Referred to: Rules and Operations of the Senate

February 18, 2019

A BILL TO BE ENTITLED

AN ACT DESIGNATING THE MONTH OF MAY OF EACH YEAR AS LUPUS AWARENESS MONTH AND ESTABLISHING AN ADVISORY COUNCIL ON LUPUS WITHIN THE DEPARTMENT OF HEALTH AND HUMAN SERVICES.

Whereas, lupus is an acute and chronic autoimmune disease in which the immune system is unbalanced, causing inflammation and tissue damage to virtually every organ system in the body, including the skin, lungs, heart, kidneys, and brain; and

Whereas, lupus can cause seizures, strokes, heart attacks, miscarriages, organ failures, and even death; and

Whereas, lupus strikes mostly women of childbearing age, and African-Americans, Hispanics, Latinos, Asians, and Native Americans are two to three times more likely to develop lupus; and

Whereas, lupus can be particularly difficult to diagnose because its symptoms mimic those of many other illnesses and major gaps exist in understanding the causes and consequences of lupus; and

Whereas, there have been no new drugs approved by the United States Food and Drug Administration specifically for lupus in 52 years, and current treatments for the disease can have damaging side effects; and

Whereas, more than half of all people with lupus suffer four or more years and require three or more doctors during that time before receiving an accurate diagnosis of the disease; and

Whereas, approximately 35,000 to 40,000 North Carolinians and 1.5 million Americans are living with this chronic illness for which there is no cure; and

Whereas, lupus costs the nation \$31.4 billion annually; and

Whereas, increased public awareness, education, and research are key to winning the battle against lupus; Now, therefore,

The General Assembly of North Carolina enacts:

SECTION 1. Chapter 103 of the General Statutes is amended by adding a new section to read:

"§ 103-15. Lupus Awareness Month.

The month of May of each year is designated as Lupus Awareness Month in North Carolina."

SECTION 2. Article 1B of Chapter 130A of the General Statutes is amended by adding a new Part to read:

"Part 6A. Lupus Advisory Council.

"§ 130A-33.70. Lupus Advisory Council.



1 (a) There is established the Lupus Advisory Council in the Department. The Council shall
2 have the following duties and responsibilities with respect to North Carolina residents who have
3 been diagnosed with lupus:

- 4 (1) Make recommendations to the Governor and the Secretary aimed at improving
5 their health status.
- 6 (2) Identify and examine the limitations and problems associated with existing
7 laws, regulations, programs, and services.
- 8 (3) Examine the financing of, and access to, health services.
- 9 (4) Identify and review health promotion and disease prevention strategies
10 relating to the leading causes of death and disability.
- 11 (5) Advise the Governor and the Secretary upon any matter which the Governor
12 or Secretary may refer to it.

13 (b) The Lupus Advisory Council in the Department shall consist of 15 members to be
14 appointed as follows:

- 15 (1) Four members shall be appointed by the Governor, three of whom shall be
16 scientists with experience in lupus who participate in various fields of
17 scientific endeavor, including, but not limited to, biomedical research, social,
18 translational, behavioral, and epidemiological research, and public health; and
19 one of whom shall be an individual who has been diagnosed with lupus.
- 20 (2) Four members shall be appointed by the Speaker of the House of
21 Representatives, two of whom shall be medical clinicians with experience in
22 treating individuals diagnosed with lupus; one of whom shall represent
23 nonprofit women's organizations and health organizations, including at least
24 one state or national organization that deals with the treatment of lupus; and
25 one of whom shall be a public member who has been diagnosed with lupus.
- 26 (3) Four members shall be appointed by the President Pro Tempore of the Senate,
27 three of whom shall represent nonprofit women's organizations and health
28 organizations, including at least one state or national organization that deals
29 with the treatment of lupus; and one of whom shall be a public member who
30 has been diagnosed with lupus.
- 31 (4) Three members appointed by the Secretary, representing the Divisions of
32 Public Health and Social Services.
- 33 (5) Of the members appointed by the Governor, two shall serve initial terms of
34 one year, two shall serve initial terms of two years, and one shall serve an
35 initial term of three years. Thereafter, the Governor's appointees shall serve
36 terms of four years.
- 37 (6) Of the nonlegislative members appointed by the Speaker of the House of
38 Representatives, two shall serve initial terms of two years and one shall serve
39 an initial term of three years. Thereafter, nonlegislative members appointed
40 by the Speaker of the House of Representatives shall serve terms of four years.
41 Of the nonlegislative members appointed by the President Pro Tempore of the
42 Senate, two shall serve initial terms of two years and one shall serve an initial
43 term of three years. Thereafter, nonlegislative members appointed by the
44 President Pro Tempore of the Senate shall serve terms of four years.
45 Legislative members of the Council shall serve two-year terms.

46 (c) The Chairperson of the Council shall be elected by the Council from among its
47 membership.

48 (d) The majority of the Council shall constitute a quorum for the transaction of business.

49 (e) Members of the Council shall receive per diem and necessary travel and subsistence
50 expenses in accordance with the provisions of G.S. 138-5 or G.S. 138-6, or travel and subsistence
51 expenses in accordance with the provisions of G.S. 120-3.1, as applicable.

1 (f) All clerical support and other services required by the Council shall be provided by
2 the Department."

3 **SECTION 3.** This act is effective when it becomes law.