

GENERAL ASSEMBLY OF NORTH CAROLINA
SESSION 2023

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SENATE BILL 516

Short Title: Improve Cancer Cluster Investigations in NC. (Public)

Sponsors: Senator Sawyer (Primary Sponsor).

Referred to: Rules and Operations of the Senate

April 4, 2023

1 A BILL TO BE ENTITLED
2 AN ACT DESIGNATING THE NORTH CAROLINA COLLABORATORY AS THE LEAD
3 AGENCY WITH RESPECT TO CANCER CLUSTER INVESTIGATIONS;
4 ESTABLISHING A CANCER CLUSTER ADVISORY COMMITTEE; AND
5 APPROPRIATING FUNDS FOR THE ESTABLISHMENT OF POSITIONS TO ASSIST
6 THE NORTH CAROLINA COLLABORATORY WITH ITS CANCER CLUSTER
7 INVESTIGATION DUTIES.

8 The General Assembly of North Carolina enacts:

9 SECTION 1.(a) G.S. 130A-212 reads as rewritten:

10 "§ 130A-212. Confidentiality of records.

11 (a) The clinical records or reports of individual patients shall be confidential and shall
12 not be public records open to inspection. The Commission shall provide by rule for the use of the
13 records and reports for medical research.

14 (b) Subsection (a) of this section regarding the confidentiality of clinical records or
15 reports of individual patients applies to the North Carolina Collaboratory at the University of
16 North Carolina at Chapel Hill in the fulfillment of its duties under G.S. 116-255 and this
17 Chapter."

18 SECTION 1.(b) Part 1 of Article 7 of Chapter 130A of the General Statutes is
19 amended by adding the following new sections to read:

20 "§ 130A-212.5. Central cancer registry data remains sole property of the State.

21 The following data is and remains the sole property of the State of North Carolina:

22 (1) All data entered or stored in the Central Cancer Registry.

23 (2) All Central Cancer Registry data shared with the North Carolina
24 Collaboratory at the University of North Carolina at Chapel Hill."

25 "§§ 130A-212.6 through 130A-212.9. Reserved for future codification purposes.

26 "§ 130A-212.10. Lead agency for cancer cluster investigations.

27 (a) The North Carolina Collaboratory at the University of North Carolina at Chapel Hill,
28 established under Article 31A of Chapter 116 of the General Statutes, shall be the lead agency
29 for cancer cluster investigations in North Carolina. The North Carolina Collaboratory shall
30 oversee the coordination of State-level efforts and activities related to cancer cluster inquiries
31 and investigations, including efforts and activities by the Department of Health and Human
32 Services, Occupational and Environmental Epidemiology Branch, and the Department of
33 Environmental Quality, in a way that maximizes efficiency and effectiveness.

34 (b) The North Carolina Collaboratory shall maintain a webpage on its internet website
35 dedicated to cancer cluster investigations, which shall include the identity of, and contact



1 information for, the cancer epidemiologist selected to serve as the single point of contact for
2 State-level cancer cluster activities pursuant to G.S. 130A-212.11.

3 **"§ 130A-212.11. Cancer epidemiologist.**

4 The North Carolina Collaboratory shall employ and retain an epidemiologist with knowledge,
5 training, and experience in cancer epidemiology, including cancer cluster investigations, whose
6 primary responsibility shall be to coordinate and communicate State-level cancer cluster
7 activities. To fulfill this primary responsibility, the cancer epidemiologist shall have the
8 following duties and powers:

- 9 (1) Lead State-level cancer cluster inquiries and investigations in collaboration
10 with the Occupational and Environmental Epidemiology Branch and the
11 Department of Environmental Quality, as appropriate.
- 12 (2) Serve as the single designated point of contact for State-level cancer cluster
13 activities.
- 14 (3) Conduct routine cancer surveillance activities.
- 15 (4) Proactively monitor cancer rates statewide, including analyzing patterns of
16 cancer incidence over geographic areas and time.
- 17 (5) Lead in the development, ongoing review, and updating of the statewide
18 cancer cluster protocol established pursuant to G.S. 130A-212.12, with
19 assistance from the Advisory Committee.
- 20 (6) Developing and disseminating reports.

21 **"§ 130A-212.12. Statewide cancer cluster protocol.**

22 The North Carolina Collaboratory, in collaboration with the Central Cancer Registry and the
23 Cancer Cluster Advisory Committee created by G.S. 130A-212.13, shall establish and
24 periodically update an enhanced statewide cancer cluster protocol for addressing suspected
25 cancer clusters within the State. The protocol shall be based on the most current Centers for
26 Disease Control and Prevention (CDC) guidelines for public health agencies to assess and
27 respond to potential cancer clusters. At a minimum, the protocol shall incorporate all of the
28 following:

- 29 (1) Best practices for all phases of cancer cluster assessment, including (i)
30 surveillance for identifying new cancer cases and monitoring trends, (ii)
31 inquiries, and (iii) detection and investigation.
- 32 (2) State and local infrastructure needs.
- 33 (3) Innovative statistical methods, software tools, and analytic approaches for
34 analyzing cancer rates and detecting cancer clusters.
- 35 (4) A comprehensive plan for internal communication within the Department as
36 well as external communication with local health departments, the
37 community, the media, and other stakeholders.

38 **"§ 130A-212.13. Cancer Cluster Advisory Committee.**

39 (a) There is created the Cancer Cluster Advisory Committee of the North Carolina
40 Collaboratory. The Advisory Committee shall meet at least quarterly with the cancer
41 epidemiologist described in G.S. 130A-212.11 to provide advice and assistance to the North
42 Carolina Collaboratory on (i) the statewide cancer cluster protocol described in
43 G.S. 130A-212.12 and (ii) any State-level cancer cluster activities being conducted across the
44 State. The Advisory Committee shall be comprised of 13 individuals with expertise in cancer
45 cluster investigations, who shall be appointed as follows:

- 46 (1) Two cancer epidemiologists, one each appointed by the President Pro
47 Tempore of the Senate and the Speaker of the House of Representatives.
- 48 (2) Two environmental health scientists, one each appointed by the President Pro
49 Tempore of the Senate and the Speaker of the House of Representatives.
- 50 (3) One local health director from a rural area of the State, appointed by the
51 Governor.

- 1 (4) One local health director from an urban area of the State, appointed by the
- 2 Governor.
- 3 (5) One statistician appointed by the Governor.
- 4 (6) Two public members appointed by the Governor.
- 5 (7) The cancer epidemiologist appointed pursuant to G.S. 130A-212.11.
- 6 (8) The Director of the Central Cancer Registry or a designee of the Director.
- 7 (9) The Director of the Occupational and Environmental Epidemiology Branch
- 8 or a designee of the Director.
- 9 (10) The Secretary of the Department of Environmental Quality or a designee of
- 10 the Secretary.

11 (b) Members appointed pursuant to subsection (a) of this section shall serve for a term of
12 three years, and no member shall serve more than two consecutive terms.

13 (c) Members shall receive per diem and necessary travel and subsistence expenses in
14 accordance with the provisions of G.S. 138-5 or G.S. 138-6, travel and subsistence expenses in
15 accordance with the provisions of G.S. 120-3.1, or both, as applicable.

16 (d) All administrative support and other services required by the Advisory Committee
17 shall be provided by the University of North Carolina at Chapel Hill.

18 (e) The Executive Director of the North Carolina Collaboratory of the University of
19 North Carolina at Chapel Hill shall select the chair of the Advisory Committee from among its
20 members.

21 (f) A majority of the Advisory Committee members shall constitute a quorum. A
22 majority vote of a quorum shall be required for any official action of the Advisory Committee.
23 Following the first meeting, the Advisory Committee shall meet upon the call of the chair or
24 upon the request of a majority of the Advisory Committee members."

25 **SECTION 1.(c)** The chair of the Cancer Cluster Advisory Committee established by
26 G.S. 130A-212.13, as enacted by this act, shall convene the first meeting of the Committee no
27 later than April 1, 2024.

28 **SECTION 2.(a)** There is appropriated from the General Fund to the Board of
29 Governors of The University of North Carolina the sum of three hundred fifty-eight thousand
30 three hundred twenty-seven dollars (\$358,327) in recurring funds for the 2023-2024 fiscal year
31 and the sum of three hundred fifty-eight thousand three hundred twenty-seven dollars (\$358,327)
32 in recurring funds for the 2024-2025 fiscal year, to be allocated to the University of North
33 Carolina at Chapel Hill for the North Carolina Collaboratory (Collaboratory), to be used as
34 follows:

- 35 (1) The sum of one hundred eleven thousand four hundred fifty-seven dollars
36 (\$111,457) in recurring funds each year of the 2023-2025 fiscal biennium to
37 create one full-time equivalent Cancer Epidemiologist position within the
38 Collaboratory dedicated to cancer cluster investigations.
- 39 (2) The sum of ninety-six thousand six hundred thirty-five dollars (\$96,635) in
40 recurring funds each year of the 2023-2025 fiscal biennium to create one
41 full-time equivalent Public Health Educator II position within the
42 Collaboratory dedicated to assisting the Collaboratory with communications
43 during cancer cluster investigations and, as the results of these investigations
44 are made available, to the Department of Health and Human Services, local
45 health departments, the media, and the general public.
- 46 (3) The sum of one hundred fifty thousand two hundred thirty-five dollars
47 (\$150,235) in recurring funds each year of the 2023-2025 fiscal biennium to
48 create two full-time equivalent Certified Tumor Registrar positions within the
49 Collaboratory dedicated to coordinating outreach, communication, and
50 onboarding with physician practices to improve cancer case identification
51 across the State. These positions shall be responsible for (i) designing and

1 implementing an onboarding and training program to support increased
2 compliance with State-mandated cancer case reporting requirements imposed
3 on physician practices, (ii) providing training and, when necessary, re-training
4 on cancer case reporting when necessary to physician practice staff, including
5 case entry into a web-based application developed by the CDC and maintained
6 by the Central Cancer Registry information technology staff, and (iii)
7 monitoring compliance with State-mandated cancer case reporting
8 requirements.

9 **SECTION 2.(b)** The funds allocated in this section to create full-time equivalent
10 positions shall not be used to supplant any other source of funding for these positions.

11 **SECTION 2.(c)** This section becomes effective July 1, 2023.

12 **SECTION 3.** Except as otherwise provided, this act becomes effective October 1,
13 2023.