

GENERAL ASSEMBLY OF NORTH CAROLINA
SESSION 2025

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SENATE BILL 283

Short Title: Expand Sickle Cell Disease Programs & Svcs. (Public)

Sponsors: Senators Robinson and Lowe (Primary Sponsors).

Referred to: Rules and Operations of the Senate

March 17, 2025

A BILL TO BE ENTITLED

AN ACT APPROPRIATING FUNDS TO THE DEPARTMENT OF HEALTH AND HUMAN SERVICES, DIVISION OF PUBLIC HEALTH, TO EXPAND PROGRAMS AND SERVICES FOR NORTH CAROLINIANS WITH SICKLE CELL DISEASE.

Whereas, recent findings from the North Carolina Sickle Cell Data Collection Program funded by the Centers for Disease Control and Prevention (CDC) estimate that the number of individuals living with sickle cell disease in our State has risen to at least 7,000; and

Whereas, this represents a twenty-five percent (25%) increase from the previously estimated 5,578 persons living with sickle cell disease in our State from 2004-2008, based on the North Carolina Registry and Surveillance System for Hemoglobinopathies funded by the CDC; and

Whereas, the Department of Health and Human Services, Division of Public Health, requires additional State funds to ensure that essential services are available statewide to support the growing number of North Carolinians affected by sickle cell disease; Now, therefore, The General Assembly of North Carolina enacts:

SECTION 1. There is appropriated from the General Fund to the Department of Health and Human Services, Division of Public Health, the sum of one million six hundred seventy-eight thousand four hundred dollars (\$1,678,400) in recurring funds and six hundred twenty-nine thousand eight hundred seventy-three dollars (\$629,873) in nonrecurring funds for the 2025-2026 fiscal year; and the sum of one million six hundred seventy-eight thousand four hundred dollars (\$1,678,400) in recurring funds and six hundred thirteen thousand two hundred fifty dollars (\$613,250) in nonrecurring funds for the 2026-2027 fiscal year to be allocated and used as follows:

- (1) Funds for comprehensive sickle cell medical centers. – The sum of one million three hundred sixteen thousand three hundred sixty-four dollars (\$1,316,364) in recurring funds for each year of the 2025-2027 fiscal biennium to be distributed in the following amounts to the following comprehensive sickle cell medical centers each fiscal year to support the multifaceted needs of individuals with sickle cell disease, including social and behavioral health services and assistance for young adults transitioning from pediatric to adult care:
 - a. Atrium Health. – The sum of two hundred three thousand seven hundred thirteen dollars (\$203,713).
 - b. Duke University Medical Center. – The sum of two hundred forty-four thousand nine hundred ninety-nine dollars (\$244,999).



- 1 c. East Carolina University School of Medicine. – The sum of two
2 hundred thirty-five thousand five hundred thirty-six dollars
3 (\$235,536).
- 4 d. Mission Hospitals. – The sum of one hundred thirty-seven thousand
5 six hundred one dollars (\$137,601).
- 6 e. The University of North Carolina at Chapel Hill School of Medicine.
7 – The sum of two hundred eighty-one thousand thirty-one dollars
8 (\$281,031).
- 9 f. Wake Forest University Baptist Medical Center. – The sum of two
10 hundred thirteen thousand four hundred eighty-four dollars
11 (\$213,484).
- 12 (2) Funds for one Transition Coordinator position at each comprehensive sickle
13 cell medical center. – Of the funds allocated in subdivision (1) of this section,
14 the sum of seventy-five thousand dollars (\$75,000) in recurring funds for each
15 year of the 2025-2027 fiscal biennium shall be used by each comprehensive
16 sickle cell medical center to create one full-time, permanent Transition
17 Coordinator position at each medical center to conduct transition readiness
18 assessments and other coordination activities to ensure a seamless referral
19 process for individuals with sickle cell disease who are transitioning from
20 pediatric to adult care.
- 21 (3) Funds to provide directed grants to community-based organizations. – The
22 sum of three hundred fifty-three thousand two hundred fifty dollars
23 (\$353,250) in nonrecurring funds for each year of the 2025-2027 fiscal
24 biennium to award grants to one or more nonprofit corporations to provide
25 services to individuals with sickle cell disease. In selecting grantees, the
26 Department of Health and Human Services, Division of Public Health, shall
27 prioritize community-based, nonprofit organizations that provide a
28 comprehensive array of services to individuals with sickle cell disease, their
29 families, and the surrounding community in counties that are lacking these
30 services. Each grantee shall use a portion of their grant award to facilitate the
31 transition of individuals with sickle cell disease from pediatric to adult care at
32 the local level.
- 33 (4) Funds to support North Carolina Sickle Cell Syndrome Program operations. –
34 The following amounts to the Women, Infant and Community Wellness
35 Section of the Division of Public Health within the Department of Health and
36 Human Services to support the operations of the North Carolina Sickle Cell
37 Syndrome Program authorized by G.S. 130A-129:
- 38 a. The sum of three hundred sixty-two thousand thirty-six dollars
39 (\$362,036) in recurring funds for each year of the 2025-2027 fiscal
40 biennium to create additional full-time, permanent positions to support
41 the work of the North Carolina Sickle Cell Syndrome Program.
- 42 b. The sum of sixteen thousand six hundred twenty-three dollars
43 (\$16,623) in nonrecurring funds for the 2025-2026 fiscal year to
44 purchase office equipment and furniture to support any positions
45 created under sub-subdivision (4)a. of this section.
- 46 c. The sum of two hundred sixty thousand dollars (\$260,000) in
47 nonrecurring funds for each year of the 2025-2027 fiscal biennium to
48 disseminate an evidence-based sickle cell disease toolkit to emergency
49 department providers throughout the State and to facilitate their
50 implementation of the toolkit in order to improve emergency
51 department care for patients with sickle cell disease.

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SECTION 2. This act becomes effective July 1, 2025.