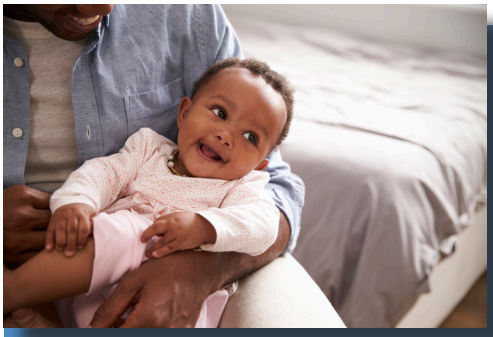

Sickle Cell Data Collection Program Brief: Births in Georgia, 2004-2016

May 2019

The Sickle Cell Data Collection (SCDC) program collects health information about people with sickle cell disease (SCD) to study trends in diagnosis, treatment, and health care utilization in the United States. Georgia is one of two states currently participating in this Centers for Disease Control and Prevention initiative.

This brief is part of a series produced using SCDC Georgia data that can inform decision-makers about how critical gaps in diagnosis, treatment, and access to care for patients with SCD can be filled through policy changes, improved health care practices, and education. This brief focuses on the number of new cases of SCD identified between 2004 and 2016 through the state's newborn screening program. Geography greatly impacts access to specialized SCD care. Understanding the distribution of SCD births can inform questions related to access, health care utilization, and quality of care during childhood.

How Is Sickle Cell Disease Diagnosed?

SCD is diagnosed with a blood test. Since early diagnosis and treatment are important, SCD is most often diagnosed at birth during routine newborn screening at the hospital, as required in every state. Follow-up testing confirms SCD and can identify which specific genetic form of SCD a patient has.

If a newborn has a positive hemoglobin screening result, the American Academy of Pediatrics recommends confirmatory testing by 3 months of age. In Georgia, the newborn screening program is run by the Georgia Department of Public Health, including initial testing and oversight of follow-up programs. For follow-up of positive results, the newborn screening program contracts with Children's Healthcare of Atlanta for newborns with positive test results in the Metro Atlanta counties, while Augusta University provides follow-up for all other counties in the state.

The teams report abnormal results to parents and the health care provider listed at birth, ensure timely confirmatory testing, and provide education and counseling to families. Confirmatory testing and additional testing of other family members for blood disorders are provided free of charge. Confirmed cases are referred to the Children 1st program at the Georgia Department of Public Health for determination of eligibility for child health intervention services.

Georgia newborn screening records do not capture individuals who move to Georgia from another state or country or individuals born with SCD in the state before implementation of universal screening in 1998.

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Georgia Health Policy Center

404.413.0314
ghpc.gsu.edu
ghpc@gsu.edu

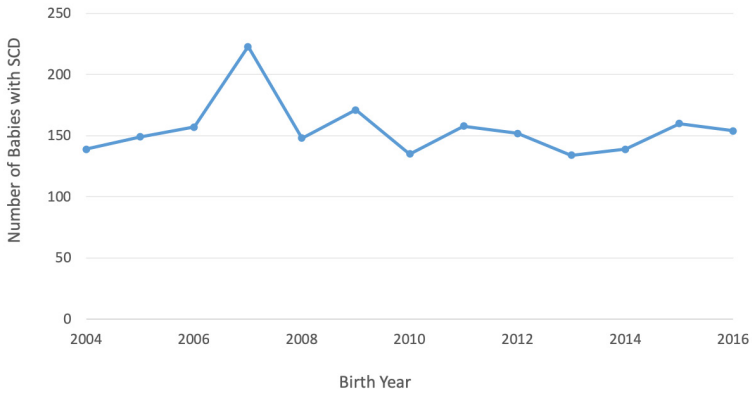
CDC Foundation

SCDC Sickle Cell Data Collection

New Cases of Sickle Cell Disease in Georgia

Georgia's newest SCDC data shows that approximately 155 babies with SCD are born in the state each year, with rates staying relatively constant from year to year from 2004 through 2016 (Figure 1). Over 95% of babies born with SCD in Georgia are black or African-American, meaning that one out of approximately every 295 black or African-American babies born in Georgia from 2004 through 2016 has SCD.

Figure 1: SCD Births in Georgia by Year, 2004-2016



As the map shows in Figure 2, babies with SCD are born in almost every county throughout Georgia. However, they are not evenly distributed throughout the state. Five Metro Atlanta counties averaged more than 10 SCD births each year, while 100 counties saw from one to 12 total SCD births over the 13-year period.

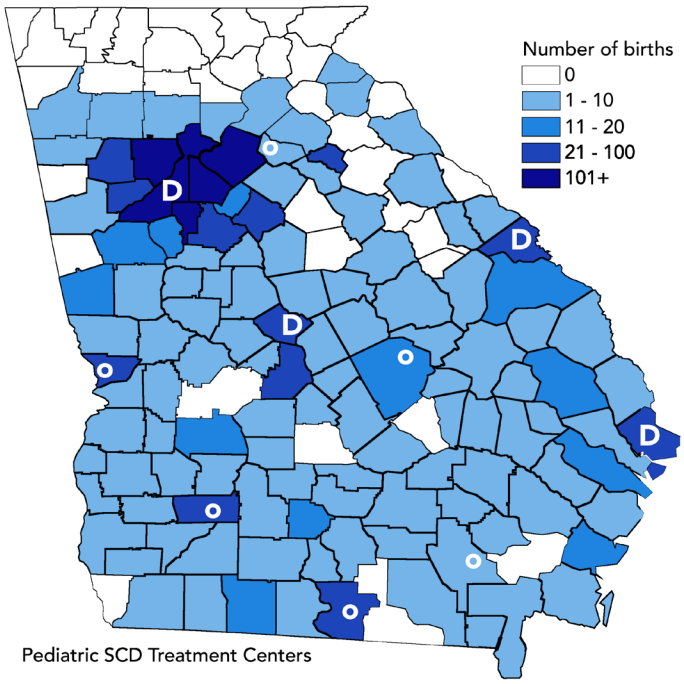
Why Is Geography Important?

SCDC data shows where patients, health care providers, and health care facilities are geographically located and can help answer questions related to access, health care utilization, and quality of care.

By overlaying SCD births in the state with pediatric SCD treatment centers, SCDC data highlights geographic challenges in gaining access to care, how far patients travel for treatment, whether they are seen at the closest facilities to their home, the ratio of identified patients to services or providers in a given region, and how these geographical factors may influence utilization by provider type (e.g., emergency department).

For instance, there were 60 SCD births in Muscogee County (where Columbus is the county seat) from 2004 to 2016. But the Columbus area is nearly a two-hour drive to the pediatric comprehensive SCD treatment center in Atlanta and a four-hour drive to the pediatric comprehensive SCD treatment center in Augusta. To better serve SCD patients in the Columbus area, the Aflac Cancer and Blood Disorders Center of Children's Healthcare of Atlanta opened an outpatient clinic in Columbus, with funding from the Piedmont Columbus Regional Foundation in March 2019.

Figure 2: SCD Births in Georgia 2004-2016 by County of Residence (N = 2,019*), with Locations of Sickle Cell Specialty Care



*Thirteen births during this period lack addresses and are not represented in the map.

At the time of writing, there are two comprehensive pediatric SCD programs in the state, with five associated pediatric outreach clinics in middle and south Georgia. There are two additional pediatric SCD treatment centers in Macon and Savannah, with plans in progress to increase outreach through specialized community health workers in several areas.

Connect with SCDC

SCDC nationally: www.cdc.gov/ncbddd/hemoglobinopathies/scdc.html
SCDC Georgia: www.ghpc.gsu.edu/project/hemoglobin-disorders-data-coordinating-center
Contact Angela B. Snyder (angiesnyder@gsu.edu) if you would like to use SCDC Georgia data for your research or planning.

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