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SICKLE CELL DATA COLLECTION PROGRAM BRIEF: ACCESS TO CARE FOR CHILDREN

September 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 data from SCDC Georgia that can inform decision-makers about critical gaps in diagnosis, treatment, and access to care for patients with SCD that might be filled through policy changes, improved health care practices, and education. This brief combines data on the number of new cases of SCD identified between 2004 and 2016 through the state's newborn screening program and geographic information on where pediatric treatment centers are located. The results highlight how geography impacts access to specialized SCD care, which has implications for health care utilization, quality of care, and short- and long-term health outcomes for children.

NEW CASES OF SICKLE CELL DISEASE IN GEORGIA

Georgia's latest 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.

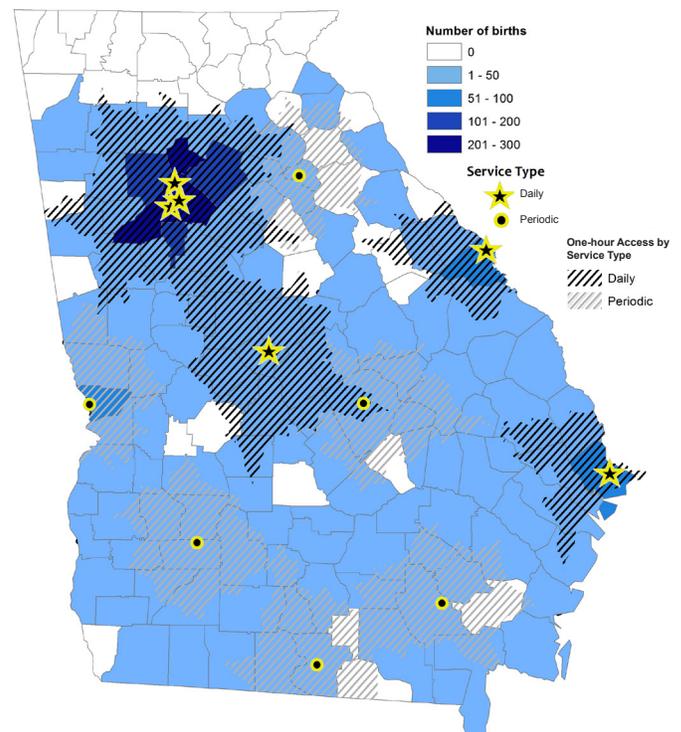
Babies with SCD are born in almost every county throughout Georgia (Figure 1). However, these births are not evenly distributed throughout the state. Five Metro Atlanta counties averaged more than 10 SCD births each year, while 100 counties in the state saw from one to 12 total SCD births over the entire 13-year period.

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Figure 1: SCD Births in Georgia 2004-2016 by County of Residence (n = 2,019*), with Locations of Specialty Care



* Addresses are missing for 13 of these patients, so they are not represented on the map.



ACCESS TO SPECIALIZED PEDIATRIC SCD CARE

SCDC researchers categorized pediatric SCD care sites as either daily or periodic based on their staffing by pediatric sickle cell specialists, and used geographic information system software to map the one-hour drive radius around these facilities.

Currently, there are two comprehensive pediatric SCD centers in the state offering daily care (Children's Healthcare of Atlanta with three sites and Augusta University with one). There are also pediatric SCD treatment centers with daily access in Macon (HOPE for Kids, Children's Hospital, Navicent Health) and Savannah (Memorial Health). Additionally, there are six sites around the state that offer periodic sickle cell specialty clinics, typically one day per month at each site, alternating in-person and via telehealth.

Children's Medical Services, a program of the Georgia Department of Public Health, operates clinics in Albany, Dublin, Valdosta, and Waycross that are staffed by specialists from Augusta University. Augusta University hosts another in Athens, while Children's Healthcare of Atlanta recently launched one in Columbus.

Of the babies born with SCD in Georgia from 2004 through 2016 —

- 76% live within a one-hour drive of a pediatric SCD treatment center with daily access
- 65% live within a one-hour drive of a comprehensive pediatric SCD center with daily access
- 14% live within a one-hour drive of a sickle cell specialty clinic with periodic access
- 10% live more than one hour from any pediatric specialty care for SCD

CONCLUSIONS

SCDC Georgia data shows that many children living with SCD and their families face the challenges of long drives and limited appointment availability to gain access to specialty care.

SCDC Georgia identified 3,509 individuals with SCD (ages 0 to 19 years) in Georgia in 2015. This translates to 351 children who live more than one hour from any specialty care option and another 491 who live within an hour of a periodic specialty clinic only. It also suggests that Children's Healthcare of Atlanta's one-hour catchment area is home to over 2,000 children with SCD.

These findings highlight locations in which specialty care access is absent or inadequate to meet the need. A number of efforts are underway to try to address these gaps: training for general practice clinicians, telehealth support for local providers under various models, and better education for patients and families. SCDC's aim is for results like these to help inform strategies that will significantly improve the length and quality of life for individuals with SCD.

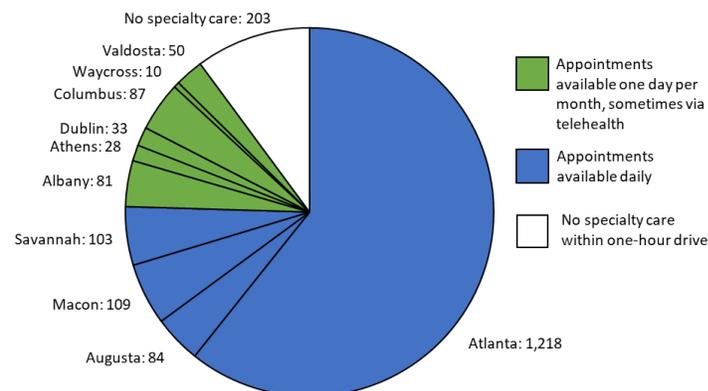
SCDC Georgia plans to further examine access issues. Research questions include these: How does access to specialty care affect short- and long-term health outcomes for individuals with SCD? How does access affect health care utilization and cost?

If you are a provider, patient advocate, or decision-maker with specific data analysis questions to improve your efforts on behalf of the SCD community, please contact us to discuss whether SCDC Georgia can help.

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.

Figure 2: Number of Children with SCD Born in Georgia 2004-2016 Who Live Within a One-hour Drive of a Daily or Periodic Pediatric SCD Specialty Care Clinic (n = 2,019*)



* Addresses are missing for 13 of these patients, so they are not included.