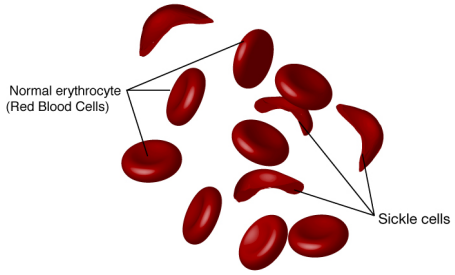
Sickle Cell Data Collection Program Brief: Sickle Cell Disease Prevalence in Georgia

March 2020

What Is Sickle Cell Disease?

SCD is an inherited blood disorder that affects hemoglobin, a protein in red blood cells that carries oxygen throughout the body. A single gene mutation causes people with SCD to have abnormally shaped hemoglobin that sticks to the walls of blood vessels, causing blockages that slow or stop the flow of blood. These blockages prevent oxygen from reaching tissues and organs and can cause severe pain and fatigue, organ damage, strokes, and even death.

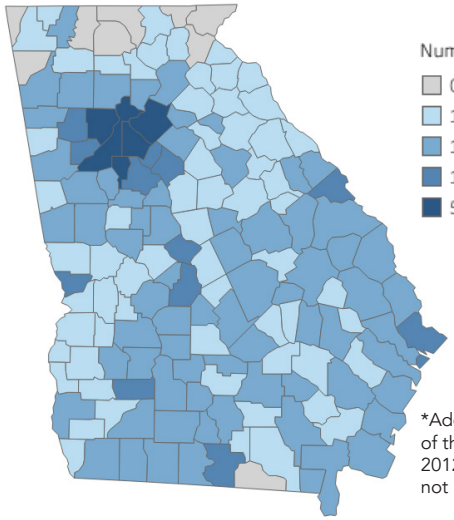


National Institutes of Health, National Human Genome Research Institute. Sickle cell disease [Photograph]. Talking Glossary of Genetic Terms.

Where in Georgia Do People With Sickle Cell Disease Live?

Georgia SCDC identified 10,396 people with SCD living in Georgia from 2012 to 2016. Of these, 60% had a diagnosis confirmed by a clinical center or through newborn screening. The rest (40%) are classified as probable cases (defined as having three or more health care encounters within five years that included an SCD diagnosis, but their confirmed SCD phenotype is not available). As the map below shows, people with SCD live in almost every county throughout Georgia.

Figure 1: SCD Prevalence in Georgia by County, 2012–2016



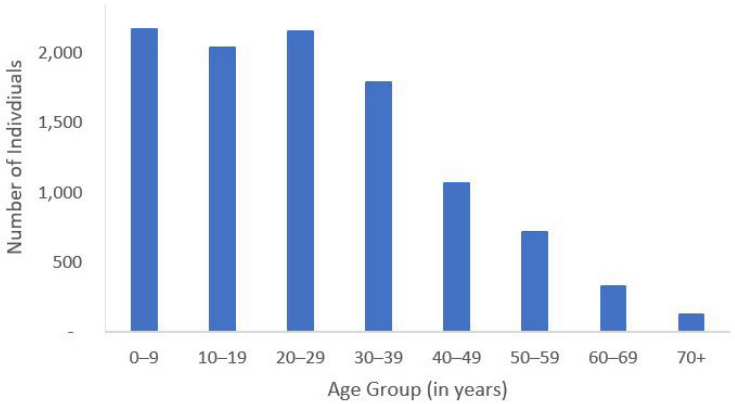
*Addresses are missing for 492 of the individuals with SCD from 2012 through 2016, so they are not reflected on the map.

Who in Georgia has Sickle Cell Disease?

SCD is diagnosed with a blood test. Since early diagnosis and treatment are important, SCD is now most often diagnosed at birth during routine newborn screening at the hospital, as required in every state. Georgia SCDC estimates that one out of every 295 black or African-American babies born in Georgia has SCD.

Georgia SCDC data confirms that SCD is no longer a "childhood disease" as it once was considered

Figure 2: Individuals Living With SCD in Georgia by Age, 2012–2016



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SCDC Sickle Cell Data Collection

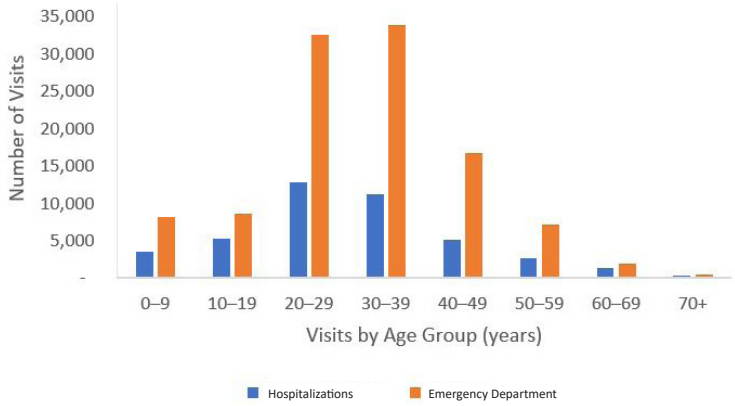
with so few children surviving into adulthood. However, data show that SCD still impacts life expectancy, but many individuals with SCD in Georgia are living well into their 40s, 50s, and beyond. (Figure 2).

Health and Health Care

Of the 10,396 people with SCD living in Georgia during this five-year period, information on health care visits is available for 9,998 (96%). Georgia SCDC shows that just under two-thirds of individuals with SCD in the state (65%) had at least one hospitalization and 79% at least one emergency department visit.

Hospital visits, especially those to the emergency department, increased considerably after childhood. While children ages 0 to 19 years averaged roughly six emergency department visits per person over five years, those ages 20 through 49 averaged more than 19 emergency departments visits per person.

Figure 3: Number of Hospitalizations, Emergency Department Visits in Georgia by SCD Age Group, 2012–2016



Aside from an increase in complications as part of the natural course of the disease, factors related to the transition from parental care to independence, from pediatric to adult medical care, and changes in health insurance coverage may explain this increase. Transition from parent-directed management to independent self-care may require some learning on the part of the individual with SCD. In addition, a break in the primary care medical home during the transition to adult care may cause discontinuity in crucial primary prevention and clinical support for patients with SCD.

What Is the Sickle Cell Data Collection Program?

The goal of the Georgia Sickle Cell Data Collection Program (Georgia SCDC) is to improve the quality of life, life expectancy, and the health of individuals with sickle cell disease (SCD) by developing and disseminating scientific evidence to inform policies and practices. To do this, the Georgia Sickle Cell Data Collection Program collects health information about people with SCD to study trends in diagnosis, treatment, and health care utilization in the United States, in partnership with the U.S. Centers for Disease Control and Prevention (CDC).

Current data-collection efforts build on 10 years of longitudinal surveillance in Georgia created under cooperative agreements with the CDC and the National Heart, Lung, and Blood Institute's Registry and Surveillance System for Hemoglobinopathies (RuSH) pilot project and the CDC's Public Health Research, Epidemiology, and Surveillance in Hemoglobinopathies (PHRESH) initiative.

Georgia's comprehensive data-surveillance system for hemoglobinopathies uses the following sources:

- State newborn screening program
- Death records
- Clinical data from the sickle cell centers in the state (Augusta University, Children's Healthcare of Atlanta, Grady Health System, and Willett Children's Hospital of Savannah at Memorial Health)
- Administrative claims data from Georgia's Medicaid, Children's Health Insurance Program, and the State Health Benefit Plan
- Hospital and emergency department discharge data

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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