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## Sickle Cell Disease in Muscogee County

Georgia Health Policy Center

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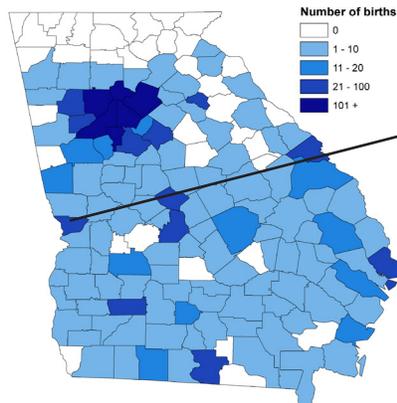
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# SICKLE CELL DISEASE IN MUSCOGEE COUNTY



## Newborn Screening, 2004-2016

Babies Born with Sickle Cell Disease in Georgia by County (n = 2,019\*)

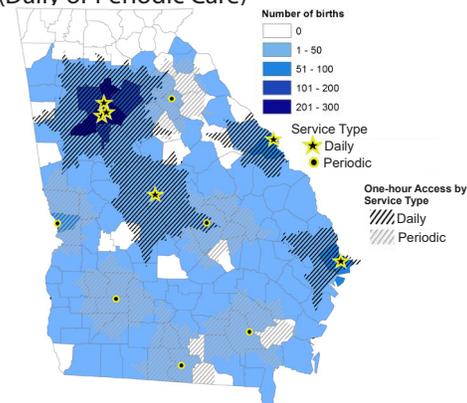


60 babies were born with sickle cell disease over 13 years in Muscogee County.

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

In total, 60 babies were born with sickle cell disease in Muscogee County from 2004 through 2016. The number of babies born in Muscogee County with sickle cell disease ranged from three to nine births per year.

## Access to Specialty Care for Babies Born With Sickle Cell Disease in Georgia: One-hour Access by Service Type (Daily or Periodic Care)



To better serve pediatric sickle cell disease patients in the Columbus area, the Aflac Cancer and Blood Disorders Center of Children's Healthcare of Atlanta opened an outpatient clinic, with funding from the Piedmont Columbus Regional Foundation in March 2019. This is a periodic clinic, with appointments available one day per month.

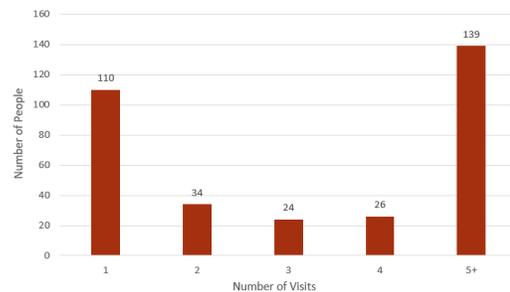


## Hospital Billing Records, 2012-2016

### Sickle Cell Disease-Related Hospital Visits

There were 333 Muscogee County residents who had at least one hospital visit (emergency department/ambulatory surgery center or inpatient stay) over the five years for a sickle cell disease-related problem. While one-third of patients only had one hospital visit, 41% had five or more visits. See the chart on the right.

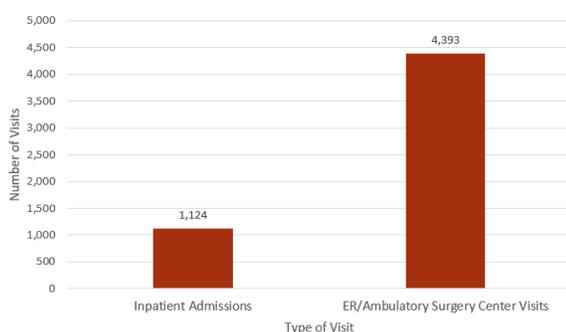
Note: We are unable to tell how many people with sickle cell disease did not have any hospital visits over this time period.



### Overnight Hospital Stays and Emergency Department Visits

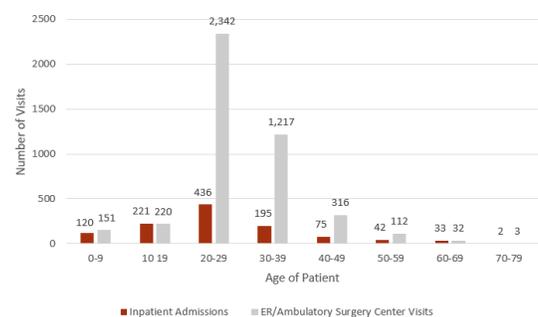
Over the five years, 333 Muscogee County residents had a total of 5,517 visits to the hospital (emergency department/ambulatory surgery center or inpatient stay) for sickle cell disease-related complications. Emergency department or ambulatory surgery center visits accounted for nearly 80% of these visits.

More than 90% of hospital visits made by Muscogee County residents for sickle cell care were made to three local hospitals. Roughly 5% of residents sought care in Atlanta.



### Hospital Stays and Emergency Department Visits by Age Group

For nearly all age groups, Muscogee County residents had more emergency department and ambulatory surgery center visits than inpatient hospital stays. Patients aged 20 to 29 years had the most hospital visits. While some negative effects of the disease are more likely as patients age (e.g., organ damage and stroke-related disability), this increase in hospital visits may also be related to the lack of insurance and access to comprehensive care that adults with sickle cell disease commonly experience. Routine and preventive care commonly can be disrupted as patients transition from pediatric to adult care.



# SURVEILLANCE IN GEORGIA

## Newborn Screening in Georgia



Every state in the United States requires that all newborns receive screening for sickle cell disease at the time of birth. In Georgia, the Georgia Department of Public Health is responsible for newborn screening, including the oversight of follow-up programs for babies who test positive for sickle cell disease. Early diagnosis and care is crucial to reducing complications, disability, and premature death.

In Georgia, the newborn screening program contracts with three teams for follow-up of positive screens. Children's Healthcare of Atlanta provides follow-up for positive results in the Metro Atlanta counties, while Augusta University provides follow-up for all other counties. The teams report abnormal results to the health care provider of record and parents, ensure timely confirmatory testing, and provide education and counseling to families. Confirmatory testing and associated family studies 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.

### Know Your Status

The Sickle Cell Foundation of Georgia is the third follow-up entity in Georgia, and it is responsible for abnormal hemoglobin results that suggest a carrier or "trait" status. Sickle cell disease is inherited when both parents pass along the sickle cell gene. Those with sickle cell trait inherit one copy of the sickle cell gene and one normal gene. These individuals are usually healthy and without any signs of the disease. However, it is still important to know about sickle cell trait status for future family planning.

## Preventing Sickle Cell Disease Complications

Pain crises are the most common complication of sickle cell disease. Most sickle cell-related complications result from the blockage of blood vessels with the abnormally shaped, sickled red blood cells. The blockage leads to a lack of oxygen and can cause organ damage, pain crises, or strokes.

Prevention is key to reducing complications. Regular checkups are recommended for all patients with sickle cell disease. Routine care may include:

- Prophylactic antibiotics to reduce life-threatening infections
- Staying current with immunizations
- Screening with transcranial Doppler to cut the risk of stroke, particularly in children
- Regular blood transfusions to lower the risk of strokes
- Treatment with hydroxyurea to decrease the number and severity of pain episodes



# ABOUT SICKLE CELL DISEASE

## About the Sickle Cell Data Collection Program



The goal of the Georgia Sickle Cell Data Collection Program (SCDC) is to improve the quality of life, life expectancy, and the health of individuals with sickle cell disease. By collecting and analyzing health information from patients with sickle cell disease over time, SCDC can identify critical gaps in diagnosis, treatment, and access to care; and can inform decision-makers about how these gaps can be filled through policy changes, improved health care practices, and education.

As the data coordinating center for SCDC Georgia, the Georgia Health Policy Center at Georgia State University is assembling a comprehensive dataset that enables surveillance of sickle cell-related diagnosis and health care utilization since 2004 for more than 10,000 patients. Data are collected from:

- Newborn screening results
- Death records
- Clinical records from sickle cell treatment centers
- Administrative claims from Georgia's Medicaid, Children's Health Insurance Program, and the State Health Benefit Plan
- Hospital and emergency department discharge data

## Be a Lifesaver – Roll Up Your Sleeve and Donate!

Many people who have sickle cell disease get blood transfusions to stay healthy. But there are risks that come with having many transfusions in a lifetime. These risks are much lower when the donated blood is a close match to their own. Blood donors are needed from all racial and ethnic groups to match the diversity of patients receiving the blood.

### What Can You Do?

**Donate.** Find a drive and give blood regularly.

**Educate.** Learn more and share with others the special reason for a diverse blood supply — to keep people with sickle cell disease and thalassemia healthy and safe.

**Motivate.** Urge your friends, family, and community to give blood and to tell others. Host a drive or recruit for one you see coming up.



**Visit [MySleevesUp.com](http://MySleevesUp.com) to learn more.**

**For more information:**

**Web:** [bit.ly/GHPC\\_SCDC](http://bit.ly/GHPC_SCDC)

**Email:** [BloodDisorders@gsu.edu](mailto:BloodDisorders@gsu.edu)