Sickle Cell Disease in Georgia

FINDINGS FROM RUSH

What is RuSH?

- Registry and Surveillance System for Hemoglobinopathies (RuSH) was a pilot project of the Centers for Disease Control and Prevention (CDC), with the National Institutes of Health's National Heart, Lung, and Blood Institute.
- The overall purpose of RuSH was to collect state-specific, population-based data on people with sickle cell disease (SCD) and thalassemia in order to provide accurate updated information to the public.
- Seven states were funded to participate in data collection: California, Florida, Georgia, Michigan, New York, North Carolina, and Pennsylvania.

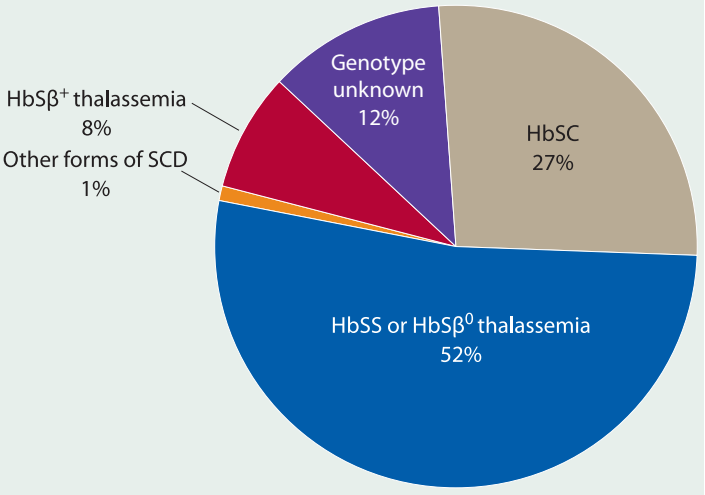
What is Sickle Cell Disease?

- SCD is a group of inherited conditions that affect hemoglobin, a protein that allows red blood cells to carry oxygen to all parts of the body.
- People with ancestry from parts of Africa, Asia and the Mediterranean are among the most likely to be born with these conditions.
- Healthy red blood cells are round, and they move through small blood vessels to carry oxygen to all parts of the body. In SCD, the red blood cells become hard and sticky and look like a C-shaped farm tool called a "sickle."
- These cells can get stuck in the blood vessels and block the normal flow of oxygen throughout the body. This leads to a variety of health problems.
- The most common types of SCD are:
  - *Hemoglobin SS Disease (HbSS)*: People who have this form of SCD inherit two sickle cell hemoglobin genes ("S"), one from each parent. This is commonly called *sickle cell anemia* and is usually the most severe form of the disease.
  - *Hemoglobin SC Disease (HbSC)*: People who have this form of SCD inherit a sickle cell hemoglobin gene ("S") from one parent and from the other parent a gene for abnormal hemoglobin called "C". This is usually a milder form of SCD.
  - *Hemoglobin S beta thalassemia (HbS beta thalassemia)*: People who have this form of SCD inherit one sickle cell hemoglobin gene ("S") from one parent and one gene for beta thalassemia, another type of anemia, from the other parent. There are two types of beta thalassemia: "0" and "+". Those with HbS beta^0-thalassemia usually have a more severe form of SCD. People with HbS beta$^+$-thalassemia tend to have a milder form of SCD.

People Living with SCD in Georgia

SCD occurs in people of all geographic and ethnic backgrounds. We estimate that 97% or more of Georgia newborns with SCD are Black or African-American, and roughly 2% overall are of Hispanic-American ethnicity. This means that about 1 out of every 295 Black or African-American babies born in Georgia from 2004 through 2008 had some form of SCD.

Types of SCD in babies born in Georgia, 2004-2008



We identified approximately 7,299 people with SCD living in Georgia in 2004-2008. Of these, 4,288 had a diagnosis confirmed by a clinical center or through newborn screening. The rest had a sickle cell diagnosis listed in another dataset and their use of health care

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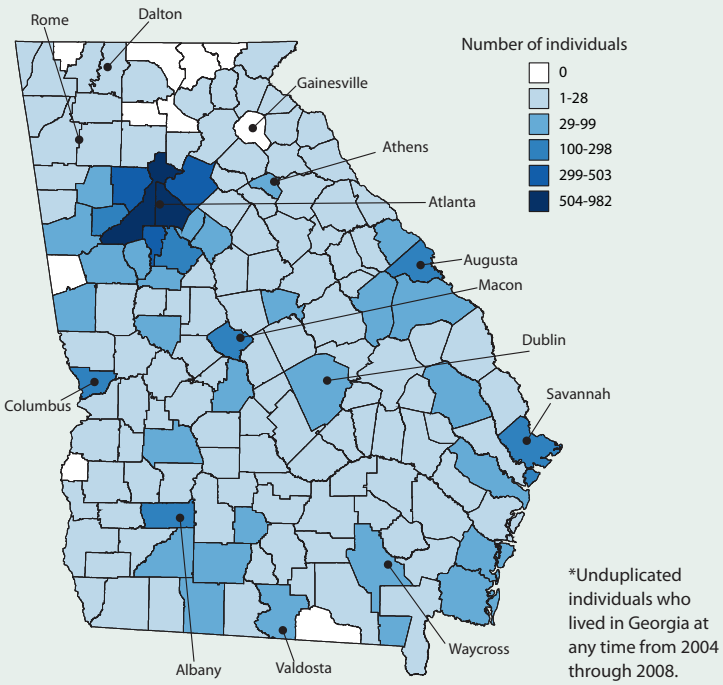
services was similar to that of someone who had SCD. As the map below shows, people with SCD live in almost every county throughout Georgia.

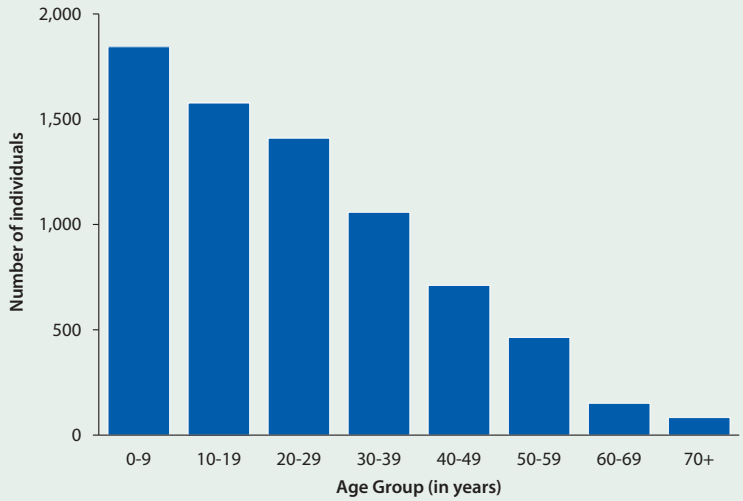
Number of individuals with SCD in Georgia counties identified by surveillance*



*Unduplicated individuals who lived in Georgia at any time from 2004 through 2008.

In Georgia, people living with SCD ranged in age from newborns to people over 70 years old. The decrease in the number of people we found to be living with SCD in the older age groups may be due to the way we identified people in datasets, not just a reflection of early death from the disease. Because our data collection methods relied heavily on information from newborn screening and public health insurance programs, we were more likely to identify children living with the disease than adults.

Age distribution of individuals with SCD in Georgia identified by RuSH



Health and Health Care

Of the 7,299 people with SCD identified, we have information on health care visits for 6,881 (94%) of them. Twenty-six percent of these had no hospitalizations during the five-year period from 2004 through 2008, and 16 percent had no emergency room (ER) visits. Hospital visits, especially those to the ER, increased considerably after childhood. While children age 0-19 averaged roughly four ER visits over five years, those age 20 through 49 had more than fifteen ER visits during the same time period. Although not assessed by our project, possible reasons for this increase, apart from the natural course of the disease, include factors related to the transition from parental care to independence, from pediatric to adult medical care, and changes in health insurance coverage. Transition to independent self-care from parent-directed management may require some learning. In addition, a break in the primary care medical home may cause discontinuity in crucial primary prevention and clinical support for patients with SCD.

Find Out More

Resources and support

- Sickle Cell Foundation of Georgia, Inc.: 404-755-1641; toll-free 800-326-5287; sicklecellga.org
- Sickle Cell Information Center website: scinfo.org
- CDC Information: www.cdc.gov/ncbddd/sicklecell

Comprehensive sickle cell centers

- Children's Healthcare of Atlanta: 404-785-1200
- Georgia Regents University: 706-721-2171
- Grady Health System: 404-616-3572

Newborn Screening Program

- Georgia Department of Public Health: 404-657-4143; health.state.ga.us/programs/nsmscd