

MAKING A DIFFERENCE ACROSS THE LIFESPAN

NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES









New! Sickle Cell Disease Annual Data Reports and Fact Sheets

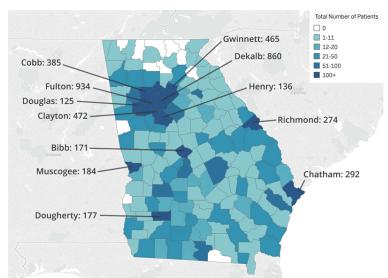
The Sickle Cell Data Collection (SCDC) program determines the number of people living with sickle cell disease (SCD) and monitors changes related to their health over time.

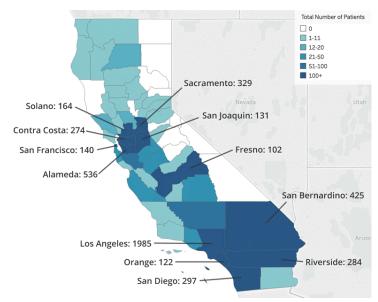
Data Reports

SCDC data reports for 2005 and 2010–2016 for <u>California</u> and 2005 and 2010–2015 for <u>Georgia</u> are now available online.

The maps and figures in these reports represent data on demographics (e.g., age, sex, and geographic information), hospitalizations, and emergency department visits for individuals with SCD living in California and Georgia.

SCDC identified 4,689 people with SCD living in California in 2016 and 8,017 people with SCD living in Georgia in 2015.





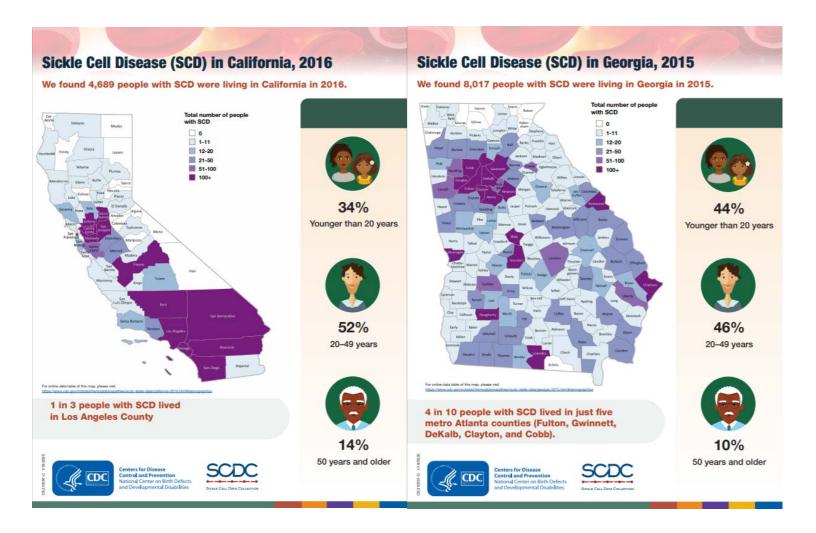
Number of patients by county of residence, California, 2016

Number of patients by county of residence, Georgia, 2015

Fact Sheets

Two new <u>fact sheets</u> highlight the most recent annual SCDC data for California (2016) and Georgia (2015):

• "Sickle Cell Disease in..." provides an overview of the demographics and healthcare utilization patterns of people with SCD and is targeted to members of the general public looking for basic information about those living with SCD.



• "Hospital and Emergency Department (ED) Utilization for People with SCD" provides additional details about healthcare utilization patterns in this population (including readmission and payer information) and is targeted to policy officials, public health professionals, and SCD organizations.

Hospital and Emergency Department (ED) Utilization for People with Sickle Cell Disease (SCD) Healthcare utilization by people with SCD, 2016 ED visits rose Age group (years) adults may be due to Overall, in 2016, people with SCD had an average of

California, 2016

The average number of hospital admissions and dramatically after age 19. This is the time when many patients transition (change) from being seen by a pediatric healthcare provider to needing a healthcare provider for adults.

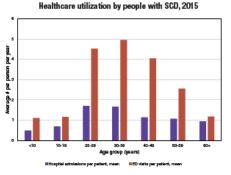
The higher number of hospital admissions and ED visits in

- More frequent and more severe SCD-related health issues; or
- Lack of access to primary care and specialty care providers for adults with SCD.

Georgia, 2015

Hospital and Emergency Department (ED) Utilization

for People with Sickle Cell Disease (SCD)



admissions and ED visits in adults may be due to Overall, in 2015, people with SCD had an average of



ital admissions: Direct hospital admissions, ill as hospital admissions that began in the ED

ED visits: ED visits that resulted in a release after

Key Terms



· More frequent and more severe SCD-related health issues; or

> Lack of access to primary care and specialty care providers for adults with SCD.

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(change) from being seen by a pediatric healthcare provider to needing a healthcare provider for adults.



Hospital admissions: Direct hospital admissions, as well as hospital admissions that began in the ED ED visits: ED visits that resulted in a release after





Recent Publications

1.3 hospital 2.3 ED admissions visits

- Tanabe P, Spratling R, Smith D, Grissom P, Hulihan M. Understanding the Complications of Sickle Cell Disease. Am J Nurs. 2019 Jun;119(6):26-35.
- Snyder AB, Zhou M, Theodore R, Quarmyne MO, Eckman J, Lane PA. Improving an Administrative Case Definition for Longitudinal Surveillance of Sickle Cell Disease. Public Health Rep. 2019 May/Jun;134(3):274-281.

Find more <u>publications</u> and <u>scientific articles</u> on <u>SCD</u>.

Additional Resources

- Sickle Cell Data Collection Brief: Births in Georgia, 2004-2016
- Sickle Cell Data Collection Program Brief: Access to Care for Children
- "Too Many Children Live Too Far From Sickle Cell Treatment They Need" (AJC article)
- CDC's Sickle Cell Data Collection (SCDC) Program
- CDC's Sickle Cell Disease Surveillance History

Share these resources with your family, friends, and colleagues!



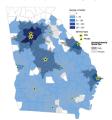
he Sidde Cell Data Collection (SCDC) program collects health information about people with sidde cell sease (SCD) to study trends in diagnosis, treatment, and health care utilization in the United States, Georgia one of two states currently participating in this Centers for Disease Control and Prevention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

This brief is part of a series produced using data from SCDC Georgia that can inform decision-maken ab-critical gas in diagnosis, treatment, and access to care for patients with SCD that might be filled through policy changes, represend health care practices, and decision. This belief combines data on the number of new cases of SCD identified between 2004 and 2016 through the state's newborn screening program and geographic finantiation on where pediatric treatment centerine are located. The results highlight brow geography impacts access to specialized SCD care, which has implicators for health care utilization, qua-case, and infort- and fong-term health courses for children.

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

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 Adlanta counties averaged mor than 10 SCD births each year, while 100 counties the state saw from one to 12 total SCD births ow the entire 13-year period.

Georgia Health Policy Center





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National Center on Birth Defects and Developmental Disabilities Division of Blood Disorders

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