

Sickle Cell Disease in North Carolina

There were approximately 5,578 people with SCD living in North Carolina in 2004-2008:

- 39% younger than 18 years
- 29% 18-35 years
- 32% 35 years and older

There were 92 babies born with SCD in North Carolina in 2008:

- 95% Black or African-American
- 1% White
- 0% Asian-American
- 1% American Indian
- 3% Other/Unknown race
- 2% Hispanic-American

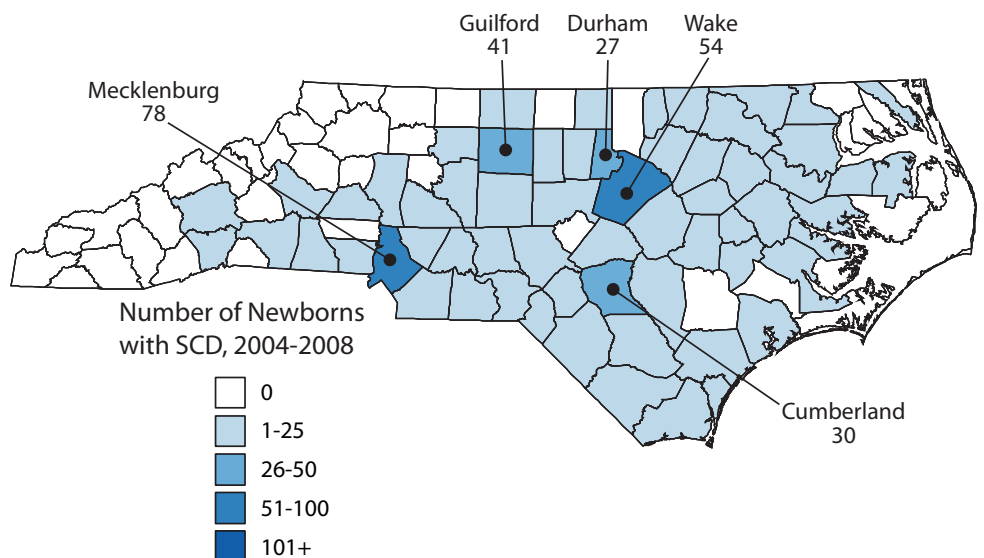
Note: There is overlap between the race and ethnicity categories.

SCD affects all races and ethnic groups. In North Carolina, SCD occurs among approximately 1 out of every

- 1,435 births
- 360 Black or African American births
- 10,800 Hispanic-American births

What is Sickle Cell Disease (SCD)?

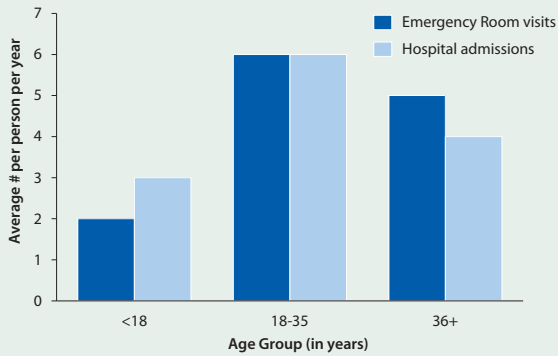
- SCD is a group of inherited conditions that affect hemoglobin, a protein that allows red blood cells to carry oxygen to all parts of the body.
- The most common types of SCD are:
 - *Hemoglobin SS Disease (HbSS)* - People who have this form of SCD inherit two sickle cell hemoglobin genes ("S"), one 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 beta⁰-thalassemia usually have a more severe form of SCD. People with HbS beta⁺-thalassemia tend to have a milder form of SCD.



This document includes information on people with a diagnosis of SCD reported by any one or more of the following data sources:

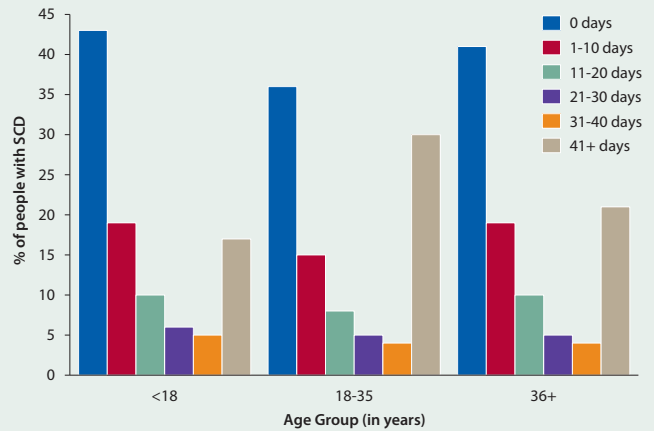
1. The results of the state newborn screening program (with or without confirmatory results)
2. A physician with documented confirmatory lab testing after the newborn period
3. An administrative data source with a sickle cell disease-related ICD* code (excluding sickle cell trait (282.5)) on two or more separate healthcare encounters PLUS one or more sickle cell disease-associated complication, treatment or procedure within a five-year period but no laboratory-based disease confirmation available.

Healthcare utilization by people with SCD, 2004-2008



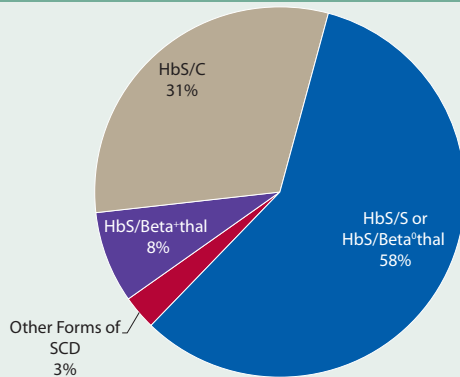
- People with SCD in the 18-35 age group had the highest healthcare utilization

Total number of hospital days for people with SCD, 2004-2008



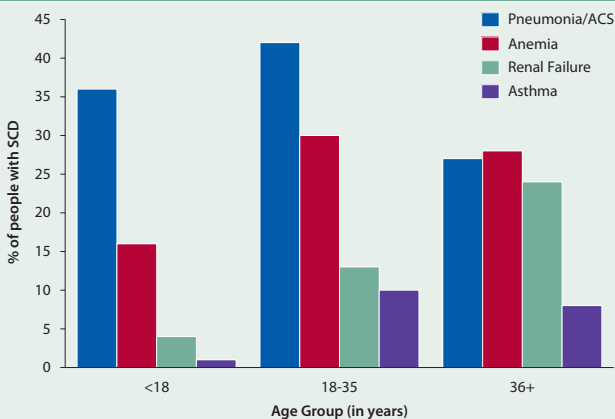
- Over 55% of people with SCD spent at least 1 day in the hospital during the 5 years

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



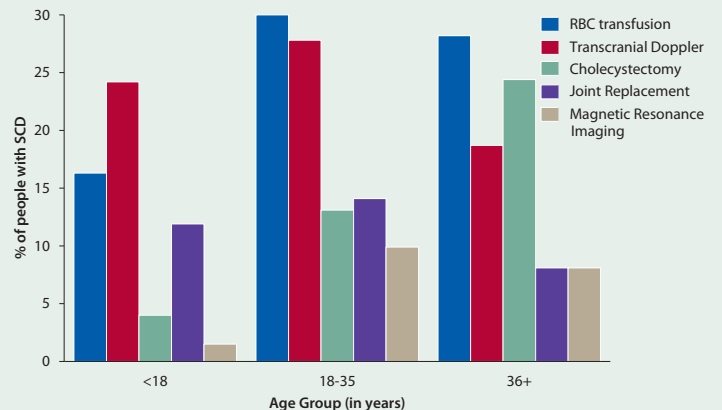
- Most of the babies born with SCD in North Carolina have Hemoglobin S/S disease or Hemoglobin S/Beta⁰-thalassemia

Most common complications among people with SCD, 2004-2008



- Pneumonia/Acute Chest Syndrome (ACS) was the most common complication for people with SCD younger than 36 years

Most common medical treatments and procedures provided to people with SCD, 2004-2008



- Transcranial Doppler was the most common procedure for people with SCD younger than 18 years. RBC Transfusion was the most common procedure for people with SCD age 18 years and older

This data was collected through the Registry and Surveillance System for Hemoglobinopathies (RuSH). RuSH was a pilot project that was implemented by the Centers for Disease Control and Prevention (CDC) in collaboration with the National Institutes for Health (NIH), National Heart, Lung, and Blood Institute (NHLBI).

For more information on the NC Sickle Cell Program, please visit www.ncsicklecellprogram.org

For more information on SCD, please visit www.cdc.gov/ncbddd/sicklecell