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.

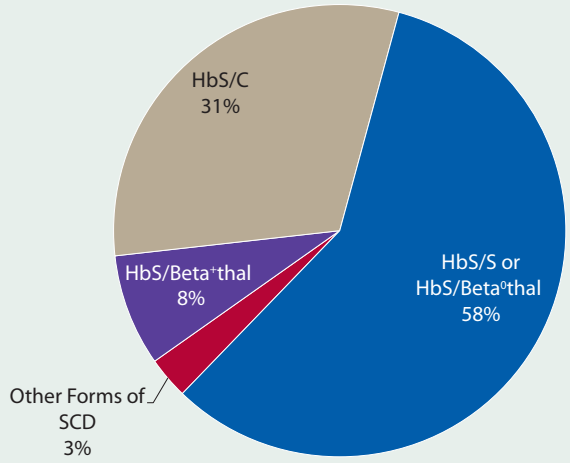
SCD affects all races and ethnic groups. In North Carolina, SCD occurs among approximately 1 out of every

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

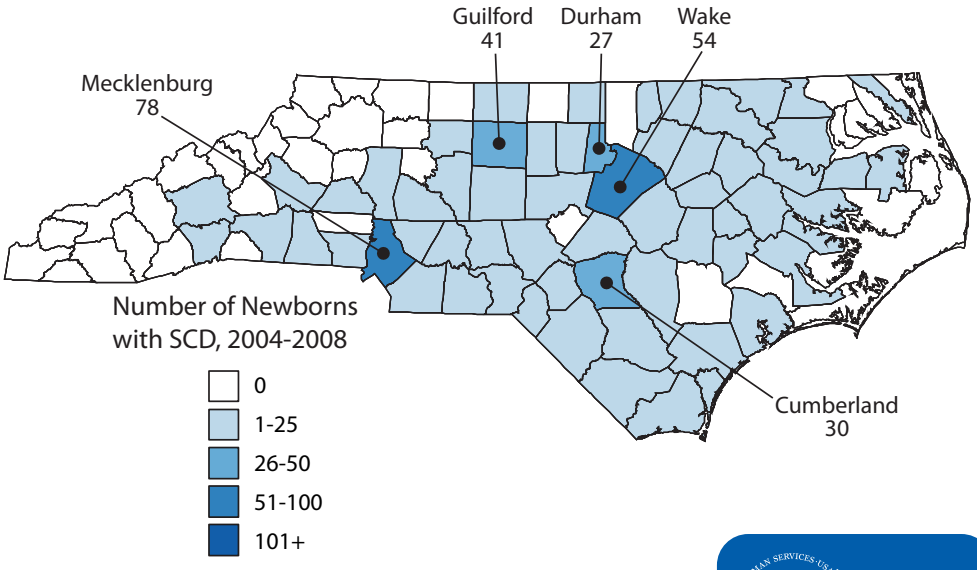
What is Sickle Cell Disease (SCD)?

- 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.
- 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.

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/Beta^0-thalassemia



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

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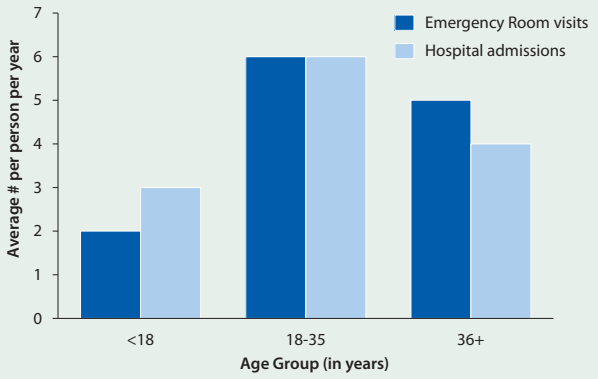
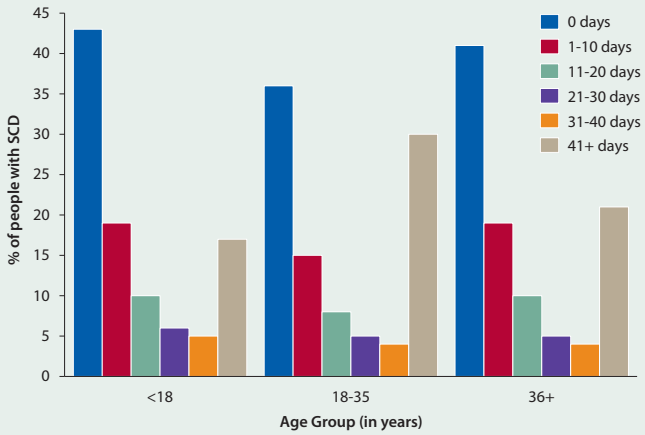
Healthcare utilization by people with SCD, 2004-2008



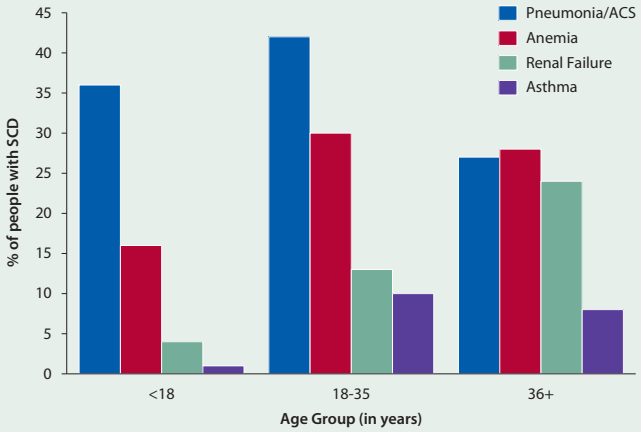
- People with SCD in the 18-35 age group had the highest healthcare utilization

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



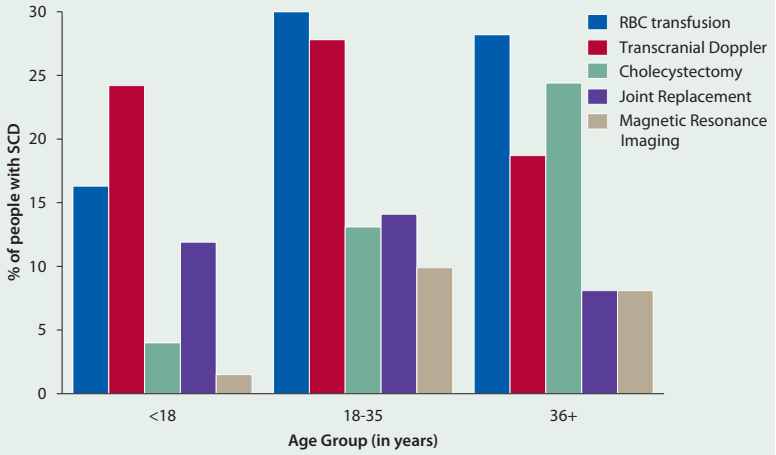
- Over 55% of people with SCD spent at least 1 day in the hospital during the 5 years

Most common complications among people with SCD, 2004-2008



- Pneumonia and/or Acute Chest Syndrome: Pneumonia is lung infection caused by a virus or bacteria that can be life-threatening in people with SCD

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

- **Anemia:** A condition in which the body does not have enough healthy red blood cells.
- **Avascular Necrosis:** Reduced blood supply causes death of bone cells, most often in the hip and shoulder.
- **Cholecystectomy:** Removal of the gall bladder by surgery. Gall stones are a common complication of SCD, beginning in children as young as toddlers.
- **Joint replacement:** A surgical procedure to replace the damaged parts of the joint with plastic or metal parts.
- **Magnetic Resonance Imaging:** A test that makes pictures of organs and structures inside the body using a magnetic field and pulses of radio wave energy.
- **Pneumonia and/or Acute Chest Syndrome:** Pneumonia is lung infection caused by a virus or bacteria that can be life-threatening in people with SCD. Acute chest syndrome is similar to pneumonia, with different diagnostic criteria.
- **RBC Transfusion:** Transfusion (putting in through the vein) of one or more units (about a pint each) of healthy RBC from a donor to lessen the symptoms of SCD.
- **Renal failure:** Includes significant forms of kidney disease, whether acute or chronic.
- **Transcranial Doppler:** This simple and painless test looks for evidence of risk of stroke in young patients with SCD, using sound or Doppler waves. As people get older, the test is less effective, so most are done on children and teens.

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