# Sickle Cell Disease in New York

### There were approximately 8,374 people with SCD living in New York in 2004-2008:

- 40% younger than 21 years
- 46% 21-50 years
- 14% 51 years and older

#### There were 197 babies born with SCD in New York in 2008:

- Race
- 89% Black or African-American
- 。8% White
- o 3% Other/Unknown race
- Ethnicity
  - o 11% Hispanic-American
- 89% Non-Hispanic

#### SCD affects all races and ethnic groups. In New York, SCD occurs among approximately 1 out of every

- 1,259 births
- 260 Black or African-American births
- 10,209 White births
- 2,714 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 (RBC) to carry oxygen to all parts of the body.
- Healthy RBC are round, and they move through small blood vessels to carry oxygen to all parts of the body. In SCD, the RBC 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.





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



 Almost 50% of people with SCD in the <21 and 21-50 year age groups had at least one emergency room visit in 2008

Most common complications among people with SCD, 2004-2008



 Pneumonia/Acute Chest Syndrome (ACS) was the most common complication across all ages

Hospital admissions for people with SCD, 2008



 Greater than 30% of people with SCD in each age group had at least one hospital admission in 2008



- Over 55% of people with SCD in each age group received at least one transfusion during the five years
- Anemia: A condition in which the body does not have enough health red blood cells.
- Asthma: A disorder that causes the airways of the lungs to swell. Symptoms include wheezing, shortness of breath, chest tightness, and coughing.
- Central Line Insertion: Insertion of a long-term access point to a vein, allowing easy blood tests and administering of medication, especially for patients who may have weak veins.
- Magnetic Resonance Imaging: a test that make 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 sickle cell disease. 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 red blood cells (RBC) from a donor to lessen the symptoms of sickle cell disease.
- 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.
- Joint Replacement: A surgical procedure to replace the damaged parts of the joint with plastic or metal parts.

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, please visit www.cdc.gov/ncbddd/sicklecell

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