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.

- 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.

There were approximately 5,100 people with SCD living in California in 2004-2008:
- 14% younger than 6 years
- 25% 6-17 years
- 22% 18-29 years
- 28% 30-50 years
- 11% 51 years and older

There were 486 babies born with SCD in California in 2004-2008:
- 89% were Black, African-American
- 8% were Hispanic, Hispanic-American
- 5% were Other

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

SCD affects all races and ethnic groups. In California, SCD occurs among approximately 1 out of every:
- 5,644 live births
- 452 Black, African-American, live births
- 35,454 Hispanic-American live births

Number of Newborns with SCD, 2004-2008

![Map showing number of newborns with SCD in California by county]

- **Alameda** 32
- **Kern** 31
- **Los Angeles** 166
- **Orange** 45
- **San Bernardino** 82
Healthcare utilization by people with SCD, 2004-2008

- The number of hospital admissions and emergency room visits rises dramatically after age 18

Most common medical procedures provided to people with SCD on Medi-Cal, 2004-2008

- Over 40% of people with SCD in each age group received at least one transfusion during the five years

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

- Over 60% of people with SCD, age 6 and older, spent at least 1 day in the hospital during the five years

Most common complications and comorbidities among people with SCD on Medi-Cal, 2004-2008

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

Age at death for people with SCD, 2004-2008

- Over 40% of deaths in people with SCD during the five years were 40 years old and younger

These data were 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).