



## SICKLE CELL DISEASE

# FACTS AND STATS

### WHAT?

Sickle cell disease (SCD) is an inherited blood disorder in which red blood cells may become sickle-shaped and harden. For a baby to be born with sickle cell disease, both parents must carry a sickle cell trait or genes for another hemoglobin like HbC, HbE or beta thalassemia. Sickle cell disease is not contagious, and there is no universal cure.

### The Facts

- About **1 in 13** African Americans carry the sickle cell trait, and many do not know they have it.
- An estimated **100,000** people in the U.S. have SCD.
- Approximately **2,000** babies are born with SCD annually in the U.S.
- On average, diagnosis is made at **birth**.
- People of many ethnic **backgrounds** can have SCD.
- Latinos have the **second** most common incidence in the U.S.

### The blockage of blood flow caused by sickled cells leads to complications including:

- Chronic severe and unpredictable pain
- Anemia
- Frequent infections
- Swelling in extremities
- Fatigue
- Delayed growth
- Vision problems/blindness
- Lung tissue damage
- Kidney disease
- Stroke
- Shortened life expectancy
- Damage to hip joint

### WHERE?

- Sickle cell disease is a global health problem.

### WHAT YOU CAN DO

- Donate blood to support transfusions.
- Advocate for better treatment, education and research.
- Educate others about sickle cell disease and sickle cell trait.
- Get tested for sickle cell trait if you are of African descent and do not know your status.
- Support SCDA as we search for a universal cure.



# STAYING WELL

## HOW?

People with SCD can live full lives by being proactive in their care. Here are some tips to help you or someone you know with SCD stay as healthy as possible.

### Staying healthy with sickle cell disease involves:

- Pain management
- Preventing infections from common illnesses such as the flu
- Self-care including eating well, exercising and staying hydrated
- Medications to reduce the severity of sickle cell disease
- Regular preventive care including vaccinations and health and dental check ups
- Quality medical care from doctors and nurses who are educated about SCD
- Building a support system of friends and family
- Connecting with a patient support group or a community-based SCD organization for information and assistance

## TREATMENT OPTIONS

- **Over-the-counter pain relievers** are commonly used to treat chronic pain.
- **Hydroxyurea (Siklos, Droxia)** and **Oxbryta (Voxelotor)** are prescribed medications that can decrease some complications of SCD.
- **Endari (Glutamine)** and **Adakveo (Crizanlizumab)** are prescribed medications that can reduce the number of sickle cell pain crises.
- **Blood transfusions** can help relieve symptoms of SCD and potentially prevent complications.

## SCREENING TESTS

- **Newborn screening** can help identify SCD and expedite early management and treatment.
- **Adult screening** can help identify if someone has SCD or is a carrier for the SCD trait.
- **Sickle stroke screening**, also known as **Transcranial Doppler (TCD) screening**, can help identify people with brain abnormalities as a result of SCD who are at high risk for ischemic stroke and brain injury.
- **Organ screening** can help identify damage to organs such as the kidney, eye and heart in adults.

## THE SEARCH FOR A CURE...

**Bone marrow (stem cell) transplants** can, in some cases, cure sickle cell disease, but not all individuals are eligible for this procedure, and there are associated risks. Read more about this NIH initiative:

**[www.curesickle.org](http://www.curesickle.org)**

*This information is for educational purposes only and does not serve as medical advice or as an endorsement by SCDA. Talk to your doctor about the screenings and treatments that may be right for you.*