

# What is Sickle Cell Disease?

Sickle cell disease (SCD) is a genetic disease that is passed from parents to their children. The abnormal genes related to Sickle Cell Disease cause red blood cells to become sickle-shaped (like a crescent moon) instead of round and flat. When they are shaped like sickles, they get stuck in tiny blood vessels and die. This keeps the blood from flowing properly throughout the body, and causes tissue damage and pain.

A pain episode or “sickle cell crisis” is the most common symptom of SCD. Other symptoms and complications are anemia (shortage of red blood cells), vision problems, acute chest syndrome (difficulty breathing, chest pain, fever), swollen hands or feet, pooling of blood in the spleen, fever, infections, stroke, and jaundice.

SCD affects millions of people throughout the world. If your ancestors came from these parts of the world, your chances of having the abnormal sickle cell gene are greater: sub-Saharan Africa; South America, Cuba, and Central America; Saudi Arabia; India; and Mediterranean countries (Turkey, Sicily, Greece, and Italy). SCD is the most common inherited blood disorder in the United States.

## Who is affected by SCD in Connecticut?

- In Connecticut every baby born in a Connecticut hospital is tested for sickle cell disease and sickle cell trait. From 1990 through 2011, newborn screenings in Connecticut identified over 570 babies with the disease and 17,475 with the trait.
- In Connecticut, the number of inpatient hospitalizations with a SCD diagnosis has increased 22% from 2007 to 2010 (from 1,269 to 1,543). The number of Emergency Department (ED) visits has increased 43% (1,285 in 2007 to 1,840 in 2010).

Data Source: *Connecticut Health Information Management Exchange Data, 2012*

## Why is it important to know if you have a family history of SCD?

If anyone in your family has sickle cell disease or sickle cell trait, all family members should be tested. This is especially important if you are planning to have children. Children are born with sickle cell disease only when they inherit abnormal genes from both parents. If they inherit the gene from just one parent, they have “sickle cell trait” (SCT). If one parent has sickle cell disease and the other has normal genes, all the children will have sickle cell trait. People with SCT usually have no symptoms, but they are “carriers” and can pass the gene to their own children. SCD is related to many chronic conditions, and its complications can cause death. People with SCD must be watched closely and treated by doctors throughout their lives as daily life can consist of pain, multiple visits to emergency rooms, and a reduced quality of life.

## Your Family Health History

Know your past. Act in the present. Protect your future.

### **Why is it important to know about SCD?**

Early identification and treatment of SCD can prevent complications. Newborns with abnormal test results are referred to a Sickle Cell Treatment Center. To prevent serious infections, they receive penicillin every day plus all scheduled vaccinations. It is important for people of all ages with SCD to follow their doctors' advice, get regular health screenings, know the signs and symptoms of complications, and know when and where to go for medical help.

You can be tested for sickle cell disease and sickle cell trait no matter how old you are. All it takes is a blood test. Ask your doctor for more information.

## **SCD Resources:**

**Infoline 2-1-1** ... [www.infoline.org](http://www.infoline.org)

### **Centers for Disease Control and Prevention**

[www.cdc.gov/ncbddd/sicklecell/index.html](http://www.cdc.gov/ncbddd/sicklecell/index.html)

### **The Sickle Cell Disease Association of America**

[www.sicklecelldisease.org](http://www.sicklecelldisease.org)

(800) 421-8453

### **SCD Association of America - Northern Connecticut Chapter Citizens for Quality Sickle Cell Care (CQSCC)**

[www.cqsc.org](http://www.cqsc.org)

(860) 223-7222

### **SCD Association of America - Southern Connecticut Chapter**

[www.scdaaofsouthernct.org](http://www.scdaaofsouthernct.org)

(888) 745-2327