What is Sickle Cell Disease (SCD)?

Sickle cell disease (SCD) is a genetic disease that is passed from parents to their children. The abnormal genes 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 also 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.

Who is affected by SCD?

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).

In Connecticut:

- Every baby born in a Connecticut hospital is tested for sickle cell disease and sickle cell trait.
- Newborn screening has identified more than 334 babies with sickle cell disease and nearly 12,000 with sickle cell trait.
- In 2005, the hospitalization charges for treating SCD patients was $21 million.

Data Sources: Connecticut Department of Public Health.
State Plan to Address Sickle Cell Disease and Trait, and *2005 Hospital Discharge and Billing Data*

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 get 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.

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

Centers for Disease Control and Prevention
www.cdc.gov/ncbdd/sicklecell/

The Sickle Cell Disease Association of America
www.sicklecelldisease.org

The Sickle Cell Information Center
www.scinfo.org

The Sickle Cell Society
www.sicklecellsociety.org

Connecticut Children's Medical Center
www.ccmckids.org
(860) 545-9630

Yale-New Haven Hospital
www.ynhh.org
(203) 785-4641 or (203) 785-4144

Citizens for Quality Sickle Cell Care (CQSCC)
www.cqscc.org
(860) 223-7222

SCD Association of America - Southern Connecticut Chapter
www.scdaaofsouthernct.org
1 (888) 745-2327

American Pain Foundation
www.painfoundation.org

March of Dimes
www.marchofdimes.com/connecticut

CONNECTICUT DEPARTMENT OF PUBLIC HEALTH
Keeping Connecticut Healthy

Connecticut Department of Public Health - State Health Planning Section
J. Robert Galvin, MD, MPH, MBA, *Commissioner*
www.ct.gov/dph

FHHSCD 04/08