

Sickle Cell Disease / Sickle Cell Trait

Categories : [Health Issues](#)

The following information is extracted from the Centers for Disease Control and Prevention.

Sickle Cell Disease

Sickle cell disease is the most common genetic blood disease in the United States. The Centers for Disease Control statistics for sickle cell disease in the United States are as follows:

- Approximately 100,000 people have sickle cell disease
- 1 in 365 Black or African Americans has sickle cell disease
- 1 out of 16,300 Hispanic Americans has sickle cell disease
- About 1 in 13 Black or African American babies is born with sickle cell trait (SCT)

Sickle cell disease affects almost all races. It especially affects people with ancestry from Africa; Central and South America; the Middle East; India; the Caribbean; and Mediterranean nations like Italy, Greece, and Turkey.

Sickle cell disease is a very serious chronic blood disease. It can be life threatening. It can lead to anemia (a shortage of red blood cells), causing fatigue and possibly damage to blood vessels and vital organs. And it often causes severe pain that can last for hours or days.

Sickle Cell Trait

Millions of people have sickle cell trait, including approximately 8% of African Americans. However, many people do not know their trait status.

CDC statistics for the U.S. are as follows:

- 2.5 million people in America have the sickle cell trait.
- 1 in 13 Black Americans has sickle cell trait.

Having the trait means you carry only one sickle cell gene and you do not have the disease. Sickle cell trait will not turn into the disease and usually you won't feel sick. However, it is possible to have symptoms of the disease under extreme conditions of physical stress or low oxygen levels. In some cases, people with the trait have gotten very sick or even died during rigorous exercise or sports. There are precautions you can take to avoid this, so be sure to speak with your health care provider about risk factors.

Precautions for People with Traits

It is possible for a person with sickle cell trait to experience complications of sickle cell disease, such as splenic sequestration, "pain crisis", and, rarely, sudden death.

This can happen under extreme conditions of:

- High altitude (flying, mountain climbing, or cities with a high altitude)
- Increased pressure (scuba diving)
- Low oxygen (mountain climbing or exercising extremely hard, such as in military boot camp or when training for an athletic competition)
- Dehydration (too little water in the body)

Know Your Status/Know Your Risk

It's possible to have the trait and not know it. If someone in your family has the trait or the disease, you might have it too. If you have the trait, there is a 50% chance that you could pass the trait on to your children. If your partner also has the trait, your children will have a 25% chance of having sickle cell disease. **This is true for every pregnancy.**

This is why it's very important to know your "sickle status." The easiest way to find out if you have sickle cell trait or disease is to have a blood test. Tests are available through your primary care provider, your ob-gyn doctor, or [sickle cell disease community based organizations](#).

If you have the trait, talk to your health care provider to find out what you can do to protect your health. If you and your partner both have sickle cell trait and you wish to have a baby, a health care provider can tell you about your options. You may wish to speak with a genetic counselor or a sickle cell counselor at one of the community based organizations. These counselors can help determine your risks for having a child with sickle cell disease.

Managing Sickle Cell Disease

If you have sickle cell disease but aren't under a doctor's care, speak with a medical professional so you can learn about the treatment options available to you. You should also be aware of situations that can lead to a sickle cell episode. These situations include infections, stressful environments at home and in the workplace, dehydration, sudden temperature variations and overexertion.

Fact Sheets on Sickle Cell Disease and Sickle Cell Trait

For comprehensive information about the disease and the trait, how they affect your health, treatment options, and tips for healthy living go to the Centers for Disease Control web site: <https://www.cdc.gov/sickle-cell/data/index.html>

Newborn Testing in Connecticut

Starting in 1990, all babies born in Connecticut are screened for sickle cell disease and sickle cell trait.

Connecticut Resources:

The following two community based organizations (CBOs) in Connecticut provide information to individuals and families about treatment providers, support groups and advocacy, and free sickle cell trait testing and counseling for people of all ages:

- Citizens for Quality Sickle Cell Care: (860) 223-7222, <https://www.facebook.com/Citizens-for-Quality-Sickle-Cell-Care-SCDAA-Northern-Chapter-Inc-CQSCC-90198330048/>
- Sickle Cell Disease Association of America Southern Connecticut Facebook page: 203-859-5355, <https://www.facebook.com/scdaaofsouthernct.org/>
- Connecticut Department of Public Health: <https://portal.ct.gov/DPH/Family-Health/Sickle-Cell-Disease/Sickle-Cell-Disease-Home>

There are three Sickle Cell Treatment Centers in Connecticut:

- Yale New Haven Hospital Sickle Cell Program- 203-785-4640
- Connecticut Children's Medical Center Sickle Cell Program – 860-545-9630
- University of Connecticut Health Center Adult Sickle Cell Treatment Center – 800-579-7822 or 860-679-2100

SOURCE: Connecticut Department of Public Health; Sickle Cell Disease Association of America

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