What is Sickle Cell Disease (SCD):

Cause, Diagnosis, Complications, Treatment

What causes SCD?

Sickle Cell Disease is a red blood cell disorder that can cause significant discomfort for those with the disease and even shorten a person's life expectancy when not managed by healthcare professionals. Sickle Cell is a genetic condition inherited from both parents who carry the recessive sickle cell trait, similar to how eye color and hair texture are inherited. People with sickle cell find out their diagnosis as soon as birth through a blood test.

How is SCD diagnosed?

Sickle cell is diagnosed with a simple blood test. In children born in the United States, it most often is found at birth during routine newborn screening tests at the hospital. In addition, sickle cell can be diagnosed while the baby is in the womb.

Routine newborn screening occurs when a health care provider pricks a baby's heel to get a few drops of blood. The blood is collected on special paper and is sent to a lab for testing. Diagnostic tests before the baby is born, such as chorionic villus sampling and amniocentesis, can check for chromosomal or genetic abnormalities in the baby. Chorionic villus sampling tests a tiny piece of the placenta, called chorionic villus. Amniocentesis tests a small sample of amniotic fluid surrounding the baby.

Because children with sickle cell are at an increased risk of infection and other health problems, early diagnosis and treatment are important.

What complications come with SCD?

People with sickle cell start to have signs of the disease during the first year of life, usually around five months of age.

Symptoms and complications of sickle cell are different for each person and can range from mild to severe. People with sickle cell can experience different complications, but some of the common ones are listed below:

- Acute Chest Syndrome
- Anemia
- Avascular Necrosis (Death of Bone Tissue)
- Blood Clots
- Dactylitis (Hand-Foot Syndrome)
- Fever
- Infection
- Stroke
- Splenic Sequestration
- Liver Problems
- Kidney Problems
- Leg Ulcers
- Organ Damage
- Pain
- Priapism (Painful Erection of the Penis)
- Pulmonary Hypertension (High Blood Pressure in the lungs)
- Sleep-Disordered Breathing
- Vision Loss

For more information and resources please visit:
https://ldh.la.gov/page/SickleCellDisease_SCD_Louisiana

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Is there a cure for SCD?

The only therapy approved by the FDA that may be able to cure SCD is a bone marrow or stem cell transplant. Bone marrow is a soft, fatty tissue inside the center of the bones, where blood cells are made. A bone marrow or stem cell transplant is a procedure that takes healthy cells that form blood from one person—the donor—and puts them into someone whose bone marrow is not working properly.

Bone marrow or stem cell transplants are very risky and can have serious side effects, including death. For the transplant to work, the bone marrow must be a close match. Usually, the best donor is a brother or sister. Bone marrow or stem cell transplants are most common in cases of severe SCD for children who have minimal organ damage from the disease.

Can you live a healthy life with SCD?

People with sickle cell disease can live full lives and enjoy most of the activities that other people do. The following tips will help you, or someone you know with sickle cell disease, stay as healthy as possible.

- **Find good medical care:** SCD is a complex disease. Good quality medical care from doctors and nurses who know a lot about the disease can help prevent some serious problems. Often the best choice is a hematologist (a doctor who specializes in blood diseases) working with a team of specialists.
- **Get regular checkups:** Regular health checkups with a primary care doctor can help prevent some serious problems.
- **Prevent infections:** Common illnesses, like the flu, can quickly become dangerous for a child with sickle cell disease. The best defense is to take simple steps to help prevent infections.
- **Learn healthy habits:** Children can, and should, participate in physical activity to help stay healthy. However, it's important that they don't overdo it, rest when tired, and drink plenty of water.
- **Look for clinical studies:** New clinical research studies are happening all the time to find better treatments and, hopefully, a cure for sickle cell disease. People who participate in these studies might have access to new medicines and treatment options.
- **Get support:** Find a patient support group or community-based organization that can provide information, assistance, and support.

Information adapted from: www.cdc.gov/ncbddd/sicklecell/index.html

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