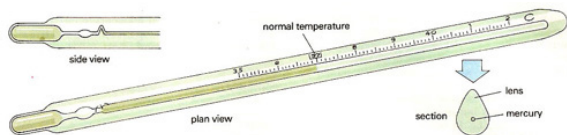


Calling the physician:

It is important to establish a relationship with your doctor and nurse so that you get to know and trust each other. This relationship will make it easier for the doctor to take care of your baby, whether in the home or hospital.

When calling the doctor, he or she will need to know:

1. Is there a fever? If so, how high is it? You must keep a thermometer on hand and learn how to read it so that you can give your doctor the exact temperature readings. This is very important for your baby's health.



Thermometer

2. Have you given your baby any medication? If so, what kind, how much and when was the last dose given?
3. Is the baby eating and/or drinking fluids? It is very important that people with sickle cell anemia drink lots of fluids. You should pay close attention to the amount of fluid intake. If your baby is not drinking fluids, please let the doctor or nurse know.
4. Is there vomiting?
5. Is there pain? If so, where? Have you given your baby any pain medication? If so, how much, and what kind? When was the last dosage?
6. Does your baby have any of the symptoms listed previously?

Preparing for emergency room or hospitalization:

If you need to take your baby to the emergency room or have your baby admitted to the hospital, here is what you will need:

Proof of insurance: Medicaid card, Medicare card, and/or private insurance card.

Clinic Card: LSU Health Science Center, Tulane, Sickle Cell Center or other.

Sweater or blanket: to keep you and your baby warm (*emergency rooms are usually cooler than home*).

For further information, contact the Sickle Cell Center in your area, your private physician or your local health clinic.

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For: State of Louisiana Genetic Diseases Program

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Program (Title V Social Security Act), Health Resources and Services Administration, Department of Health and Human Services

There are even more ways to get up-to-date health information, news and emergency updates from LDH.

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Hemoglobin SC Disease



What Every Parent Should Know

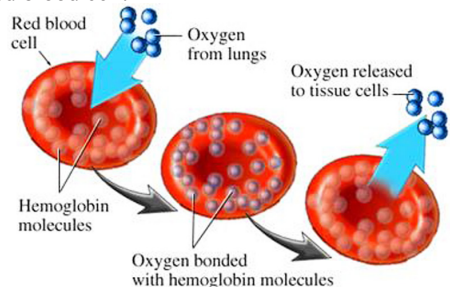


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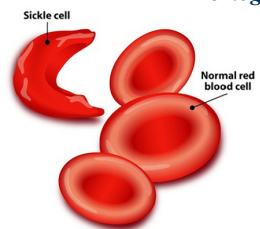
This disease is tested by newborn screening in Louisiana. FIND IT EARLY!

What is hemoglobin SC disease?

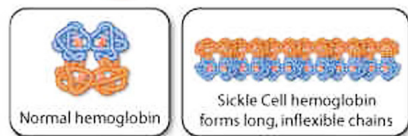
Hemoglobin SC (HSC) disease is a form of sickle cell disease. It is an inherited disorder of the hemoglobin in red blood cells. Hemoglobin is the oxygen-carrying portion of the red blood cell.



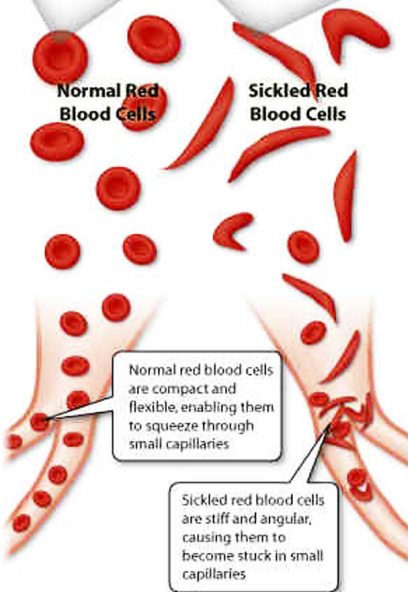
Hemoglobin Function



Red blood cells (RBCs) transport the oxygen from the air we breathe to all parts of our body. RBCs are usually round, soft and pliable.



In sickle cell anemia, RBCs can sometimes become distorted and block off blood vessels. They also do not live as long as RBCs in individuals without sickle cell anemia do.



Normal red blood cells are compact and flexible, enabling them to squeeze through small capillaries

Sickled red blood cells are stiff and angular, causing them to become stuck in small capillaries

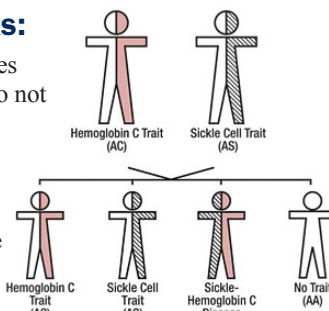
How did my baby get hemoglobin SC disease?

Hemoglobin SC disease is inherited from both parents. Like hair color, general body build and other physical characteristics, this was passed down from the parents through genes.

Genes come in pairs; for each characteristic there is one gene from the mother and one from the father. One pair of genes determine hemoglobin. Most people inherit hemoglobin A. Some people inherit a changed hemoglobin, such as S or C. If your baby has hemoglobin SC disease, it means that the baby has inherited a gene for changed hemoglobin S from one parent and a gene for changed hemoglobin C from the other parent. The baby did not inherit genes for the usual Hemoglobin A. Your baby has S and C hemoglobins and is affected with hemoglobin SC disease.

Here is how it works:

Most people who carry genes for changed hemoglobins do not have a disease. They are carriers. This means that they have inherited both one gene for the usual hemoglobin A and one gene for a changed hemoglobin, such as S or C, but they have A hemoglobin or AC hemoglobin in their blood. However, if one parent has AS hemoglobin and the other parent has AC hemoglobin, they can each pass the changed hemoglobin to their child, thus giving the child SC hemoglobin.



With each pregnancy there is a 25-percent chance that the child of carrier parents will inherit hemoglobin SC disease, a 50-percent chance that the child will be a carrier (either AS or AC), and a 25-percent chance that the child will have normal hemoglobin (AA).

Caring for your baby with hemoglobin SC disease:

Even though your baby has a serious, chronic disease, he or she will behave like most babies who do not have a medical problem. As such, your baby should be cared for as any other newborn baby. In general, hemoglobin SC disease is not as severe as sickle cell anemia (hemoglobin SS disease), although many of the same problems can occur. However, there are some signs you should be aware of so that quick medical care can be obtained as soon as possible when needed.

Fever: If your baby feels warm, you should take his or her temperature. If the temperature is 100 degrees, you should immediately call the physician or nurse. If the temperature is 101 degrees or above, take the baby to your doctor or emergency room for treatment immediately. This may require that your baby be hospitalized and placed on intravenous antibiotics. Fever in babies with hemoglobin SC disease may indicate very serious, life-threatening infections.

Splenic sequestration: As blood is filtered through the spleen, sometimes sickled cells may become trapped in the spleen and keep the blood from moving out of the spleen. Symptoms of this are swollen stomach, unusual sleepiness or irritability (fretfulness). This is a serious, life threatening problem. Go to an emergency room immediately. Have them call your baby's doctor. Your doctor or nurse can show you how to recognize this problem during your regular clinic appointment.

Anemia: Because sickle cells do not live as long as normal cells, your baby will be anemic. That is, your baby will have a low blood count. This is usually nothing to be concerned about; the baby's body will adjust to this lower blood level. However, the baby may have less energy than other babies. If the baby appears listless, contact the doctor immediately, as this may indicate a sudden and severe worsening of the anemia.

Jaundice: When cells are destroyed they produce products in the blood that are carried off as waste. Sickle cells are destroyed at a much faster rate than regular red blood cells, so more of these waste products are found in the blood stream of individuals with HSC disease. These products can cause jaundice, giving a yellowish tint to the white of the eyes or an orange tint to the skin. Call your baby's doctor if this yellowish tint becomes more pronounced than usual.

Swollen hands and feet: One of the first symptoms of hemoglobin SC disease in babies may be swollen hands and feet. The hands and feet feel warm and are sensitive to the touch. Contact your doctor for instructions on how to make your baby comfortable. This is NOT an emergency

Skin problems: Breaks in the skin or untreated insect bites can sometimes lead to serious problems in patients with hemoglobin SC disease. Sores, cuts and insect bites should be cleaned and treated with a mild antiseptic. If the area is not healing or begins to get swollen or reddish, contact the baby's doctor or nurse.