

Positive Result:

Blood Spot Screen Result Notification



Hemoglobin S, no A (sickle cell disease)

What was found on the newborn screen?

The newborn screen that was collected at birth found that your baby only had hemoglobin S (S stands for sickle) and was missing normal hemoglobin (hemoglobin A).

What does this mean?

When only hemoglobin S is found, it is likely that your baby has sickle cell (SS) disease.

What happens next?

Your baby's doctor or a specialist (pediatric hematologist) familiar with sickle cell disease will help arrange for more testing.

What is sickle cell disease?

Sickle cell disease is a disorder which affects the hemoglobin/blood. Hemoglobin is a protein in the red blood cells. The job of hemoglobin is to carry oxygen throughout the body.

Red blood cells containing normal hemoglobin (hemoglobin A) are round and flexible. People with only hemoglobin S have red blood cells that contain no normal hemoglobin. Their red blood cells become sickle (banana) shaped instead of round (donut) shaped.

Sickle-shaped red blood cells can be rigid and can get trapped in blood vessels and block blood flow. Tissues and organs that do not get normal blood flow can become damaged. This can be painful and cause health problems.

What health problems can it cause?

Sickle cell disease is different for each child. Sickle cell disease is a lifelong condition that may result in serious health problems. If untreated, it can cause:

- Drop in red blood cell count (anemia)
- Enlarged spleen
- Infections
- Painful crises
- Serious lung disease
- Stroke

Children with sickle cell disease can benefit from prompt and careful treatment.

What treatment options are available?

Sickle cell disease can be treated. Possible treatments throughout childhood can include:

- Antibiotics to prevent infection
- Blood transfusions
- Hydroxyurea medication (a medicine which helps the body produce normal red blood cells)
- Immunizations
- Medications for pain
- Stem cell transplant

Children with sickle cell disease should see their regular doctor and a doctor who specializes in blood disorders.

Resources

Genetics Home Reference:
<http://ghr.nlm.nih.gov>

Save Babies Through Screening Foundation:
www.savebabies.org

Baby's First Test:
www.babysfirsttest.org