

Family action sheet for sickle cell disease

If a newborn blood screening result shows that your baby could have a serious condition called sickle cell disease, your baby needs more testing, as soon as possible, to know for sure if they really do have the disease. Your baby should be seen by their medical provider and a sickle cell disease specialist.

Why was your baby screened?

All babies born in California have a routine blood test shortly after birth to find medical conditions. The goal of this newborn screening is to find those at risk for serious medical conditions.

Babies can look healthy at birth and still have one of these conditions. Babies with these conditions benefit from early diagnosis and treatment.

What is sickle cell disease?

Sickle cell disease affects the body's ability to have healthy red blood cells. It affects protein inside of red blood cells called hemoglobin that carries oxygen from the lungs to all parts of the body.

Symptoms for sickle cell disease can vary a lot and people can have very different experiences living with sickle cell disease.

Your child may have one of these common types of sickle cell disease:

- Sickle cell anemia
- Sickle "C" disease
- Sickle beta thalassemia

Where can you get more information?

Your baby's medical provider and sickle cell disease specialist are the best people to teach you about sickle cell disease.

Is there treatment for sickle cell disease?

Yes. There are many treatments that help people manage and live well with the disease. With proper information and treatments, people with sickle cell disease can enjoy happy, productive lives. Your medical providers should discuss treatment options with you.

Sickle cell disease is a life-long condition. You will need to make sure your baby has regular medical care. Your baby should be followed by a medical team at a sickle cell disease center.



Next steps

1. Your baby needs more testing as soon as possible to find out what type of sickle cell disease they have

The medical provider may also ask one or both parents to take a blood test.

2. Your baby's medical provider will help arrange an appointment with a sickle cell disease specialist

The specialist will review test results and recommend treatment. Babies with sickle cell disease are treated with penicillin twice a day to help prevent serious infections. They also get other supportive care.

3. Work closely with your baby's medical provider and follow recommendations

Baby's First Test

(<https://www.babysfirsttest.org>). Type "Sickle" into the "Find a Condition" Box. Follow the link. For Spanish, click on the top right black box marked "en Español"

