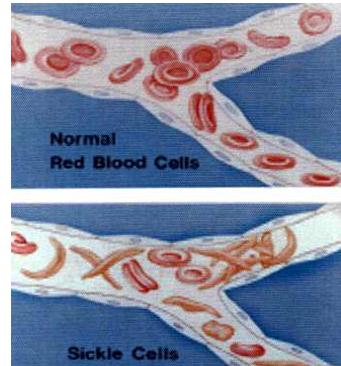


What to Know If You Have a Child with Sickle Cell Disease

Sickle Cell Disease

► What It Is

Sickle cell disease is a disease of the red blood cells. It is called sickle cell disease because the person's red blood cells can become shaped like a "sickle". A sickle is a tool that farmers have used to cut their crops, and it is shaped like the letter C. Normal red blood cells are round and soft. Sickle cells are not round, may look like the letter C and they are sticky and rigid, instead of soft and smooth. Because they are sticky and rigid, sickle cells cannot move easily through a person's body. These cells can get stuck in blood vessels and cause a number of problems.



► How You Get It

Sickle cell disease is a condition that people get in the same way that they get the natural color of their eyes, skin, and hair. A person with sickle cell disease is **born** with it. This means that people cannot catch sickle cell disease from being around a person with sickle cell disease. And, it is no one's fault. There is nothing you did that caused your baby to have sickle cell disease.

► What to be Concerned About

Sickle cell disease is a serious disease that can be very painful. It can also cause a number of serious complications. For some people, it has even caused death.

No parent of a young child wants to hear this. But it's important to know. Your child will need to count on you to be informed and to make good decisions. And, good medical care will help.

► What to be Happy About



Children with sickle cell disease are adorable, just like everyone else. They can grow to be good students, just like everyone else. They can sometimes drive their parents crazy as teens, just like everybody else.

And they can become well-educated successful adults. They can get married and have children of their own. They can even grow into old age with sickle cell disease. So, plan to enjoy your little one - or your little ones, if you have more than one child with sickle cell disease. There are many good times ahead.

Know What Good Health Care Is

Care that Follows a Plan

Check (✓) to make sure these happen:

Right After Birth

- ___ Baby has a primary care doctor



By 2 Months of Age

- ___ Baby should be referred to a Pediatric Comprehensive Sickle Cell Clinic or to a Pediatric Hematologist (a baby doctor who is a specialist in blood diseases)

■ Primary care doctor will see child every 2 months for immunizations.

■ Hematologist may also see child every 2-3 months.

Birth to 6 Months

- ___ The type of sickle cell disease is confirmed.
- ___ Parents are offered testing for themselves.
- ___ Baby starts getting penicillin 2 times a day.
- ___ Baby starts getting baby shots (immunizations).

6 Months to 1 Year

- ___ Baby keeps on getting penicillin 2 times a day.
- ___ Baby still sees the doctor every 2-3 months.
- ___ Doctor gets a blood count done every 2-3 months to find out what the baby's usual Hemoglobin level is.
- ___ Doctor gets other blood tests done to check the baby's liver and kidney function.
- ___ Doctor checks size of the spleen and teaches family members and other caregivers to do the same.
- ___ Baby keeps on getting baby shots.
- ___ Baby gets a flu shot.

1 to 2 Years

- ___ Baby keeps on getting penicillin 2 times a day.
- ___ Baby keeps on getting baby shots.
- ___ Baby starts getting a flu shot every year in the Fall.
- ___ Baby gets scheduled (soon after turning two) to have a special study called TCD to see if he or she is at risk for stroke (if your baby has a certain type of sickle cell disease).
- ___ Once a year, baby gets other blood tests to check his or her liver and kidney function.

3 to 5 Years

- ___ Increase dosage of penicillin and continue to take 2 times a day.
- ___ Continue baby shots (immunizations).
- ___ Continue getting yearly flu shot.
- ___ Continue getting a TCD (for children with certain types of sickle cell disease).
- ___ Continue yearly blood tests to check liver and kidney function.

Care that is Comprehensive

Check (✓) to make sure this happens.

Baby sees a doctor regularly

- to get checked for symptoms of the disease
- to see if referrals to other specialists are needed
- to see if special treatments are needed

Parents get information, support and advice

- About the disease

Parents get information about the disease, what to be aware of and what to do.

- About parenting

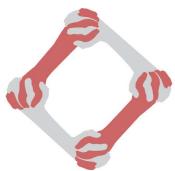
Parents get emotional support and advice on parenting.

- About other issues of importance

Parents get support on issues concerning insurance, transportation, housing, child care, when needed.



Credits



**National Coordinating
and Evaluation Center**

Sickle Cell Disease and Newborn Screening Program



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