

Sickle Cell: Basic Facts

This booklet explains what sickle cell disease is and how you can keep your child healthy.



**INDIANA
HEMOPHILIA &
THROMBOSIS
CENTER, INC.**

8326 Naab Road, Indianapolis, IN 46260
Tel: 317-871-0000 | Toll Free: 1-877-256-8837 | Fax: 317-871-0010
www.ihtc.org | <http://www.facebook.com/IndianaHemophilia>

©2014 Indiana Hemophilia & Thrombosis Center, Inc.

Rev 12/14



What is sickle cell disease?

Inside your blood are red blood cells that carry oxygen all through your body. Most people have red blood cells that look like these below.



The blood cells of people with sickle cell disease are different from normal red blood cells. These abnormal blood cells are called sickle cells.

When a person has sickle cell disease, their red blood cells look like this one below.



How do you get sickle cell disease?

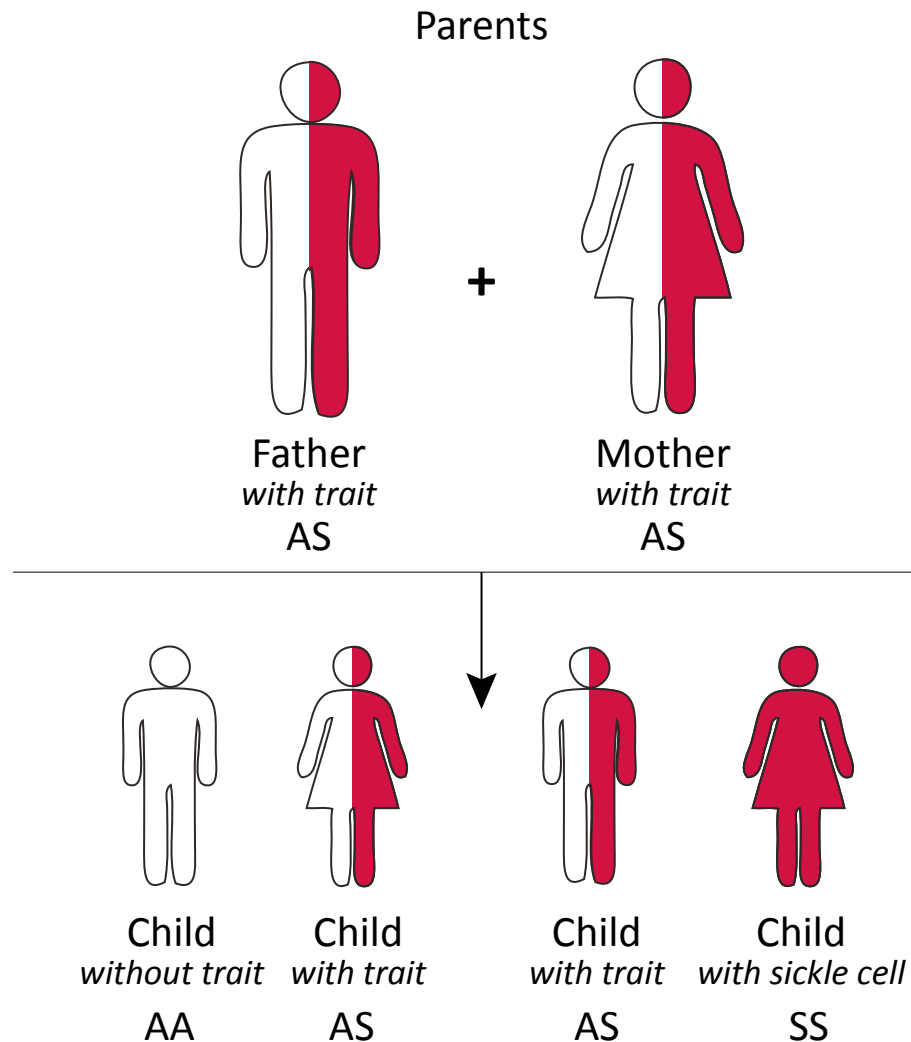
Sickle Cell Disease is passed down from parents to children, the same way that eye color and hair color are passed down.

When a person has a trait, this means they have one gene for sickle cell disease.

If both parents have a sickle cell trait, they can have a child with sickle cell disease.

This picture shows two parents with sickle cell trait and the types of children they can have.

If both parents have a sickle cell trait, EVERYTIME THEY HAVE A BABY, he or she has a 25% chance of having sickle cell disease.



What problems can my child have if he or she has sickle cell disease?

- » fever and infection
- » spleen problems
- » pain
- » acute chest syndrome
- » stroke
- » priapism
- » tiredness
- » delayed growth



Fever & Infection

Children with sickle cell can get infections easier than other children so a fever can be dangerous. If your child has a fever it could mean they have an infection in their blood.

Call your child's sickle cell doctor if they have a fever of 101 degrees or higher. They may need to be taken to the hospital.

When your child has a fever, do not give your child pain medicine to reduce the fever unless your doctor tells you to do so. Pain medicine can make it hard for your doctor to tell what is wrong with your child.



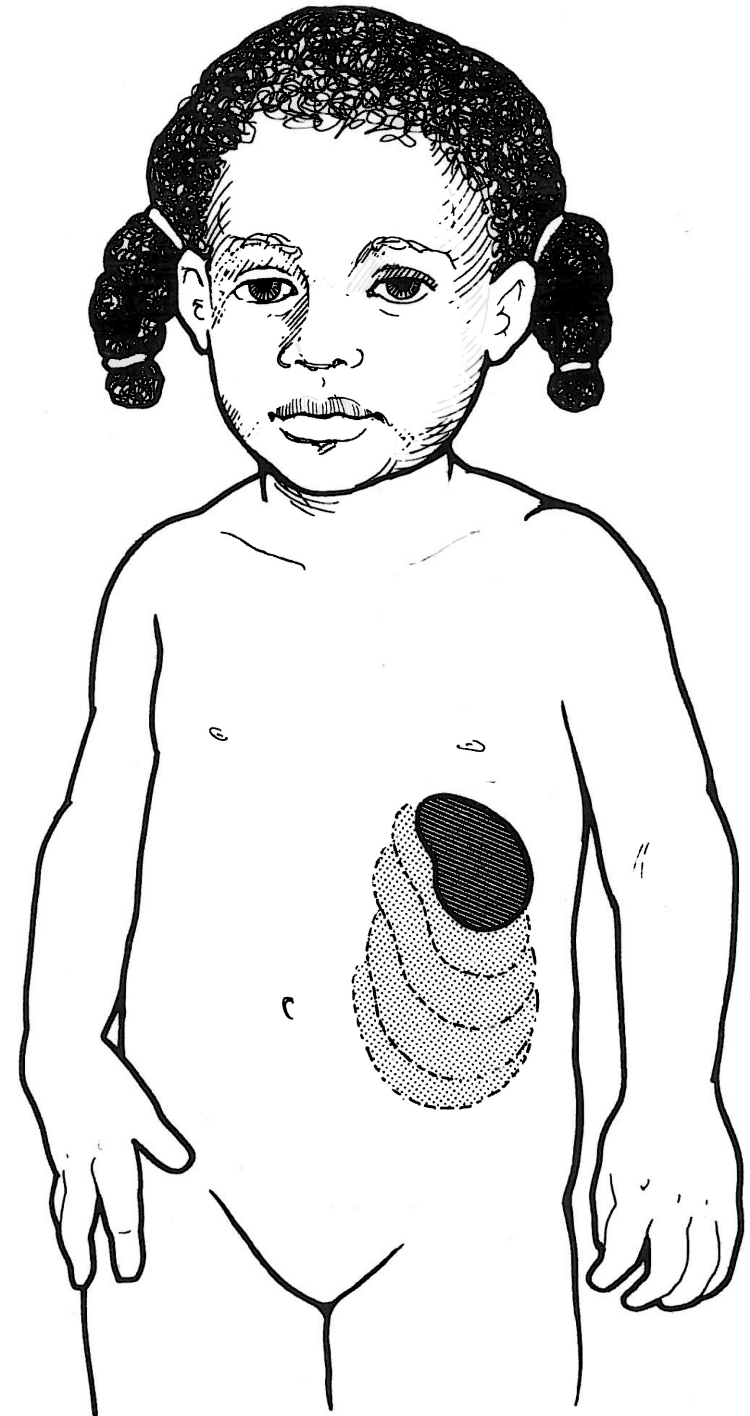
Spleen Problems

The spleen is an organ that helps fight infection and keeps your body fluids in balance. It is very common for sickle cells to get caught in the spleen. When this happens, the spleen can fill up with blood and get very large. Your child's doctor should teach you to feel for your child's spleen so you know if it is suddenly getting bigger.

When the spleen gets bigger and bigger, this is called splenic sequestration. This can be very dangerous for your child.

Call your child's doctor if:

- » your child is very tired and cranky
- » his or her skin is pale or lighter in color
- » he or she seems weak
- » his or her heart is beating fast
- » his or her spleen is bigger than normal
- » he or she is having pain on the left side of his or her stomach



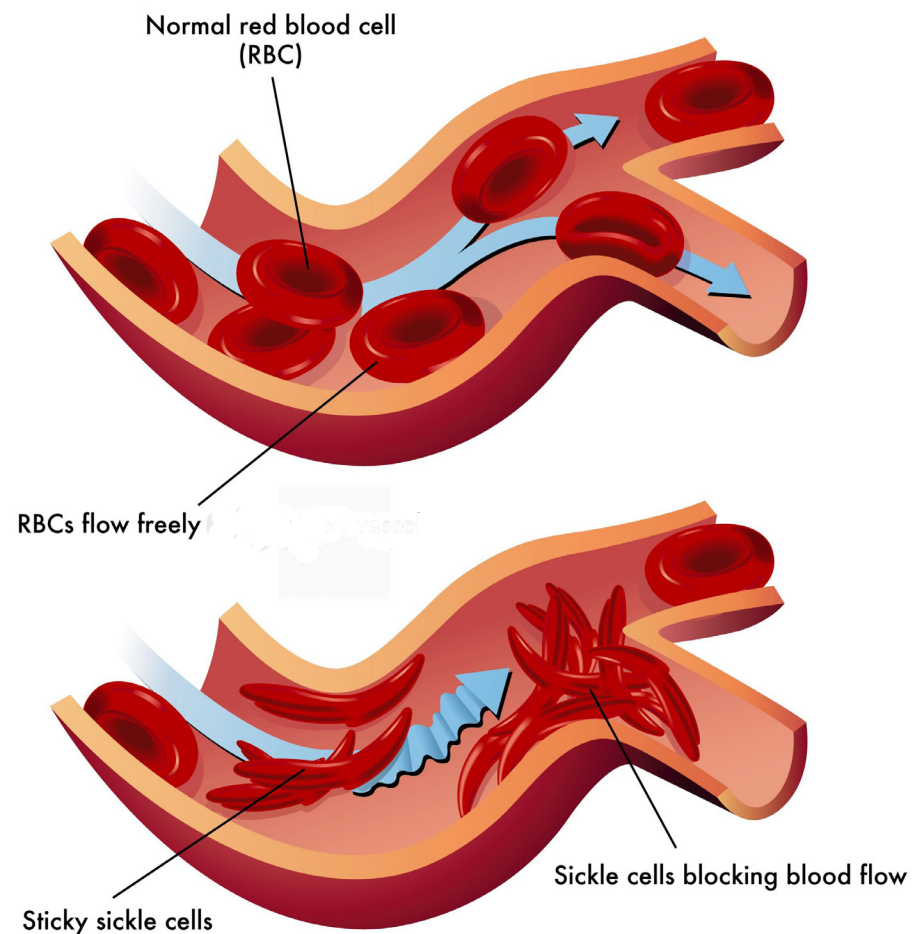
Pain

People with sickle cell disease will sometimes have pain. This may be called a pain crisis. Pain can be located in different parts of the body, including the:

- » bones
- » arms or legs
- » stomach
- » chest
- » back
- » hands and feet

If your child is in pain, you can do several things to help him or her. You may:

- » put a warm cloth or heating pad on the painful area
- » massage the part of the body that hurts
- » give the child a warm bath
- » give him or her lots of water or juice and help them relax
- » give him or her pain medicine from the doctor
- » and if the pain doesn't go away, call his or her sickle cell doctor or take them to the hospital



Acute Chest Syndrome

Sometimes, sickle cells can get caught in the lungs. This causes something called Acute Chest Syndrome. Acute Chest Syndrome can be caused by an infection like pneumonia. It can also happen right before, during, or after a pain crisis.

Watch for these signs:

- » chest pain
- » fast breathing
- » coughing
- » fever
- » difficulty breathing

Call your child's doctor right away if you notice these signs.



Stroke

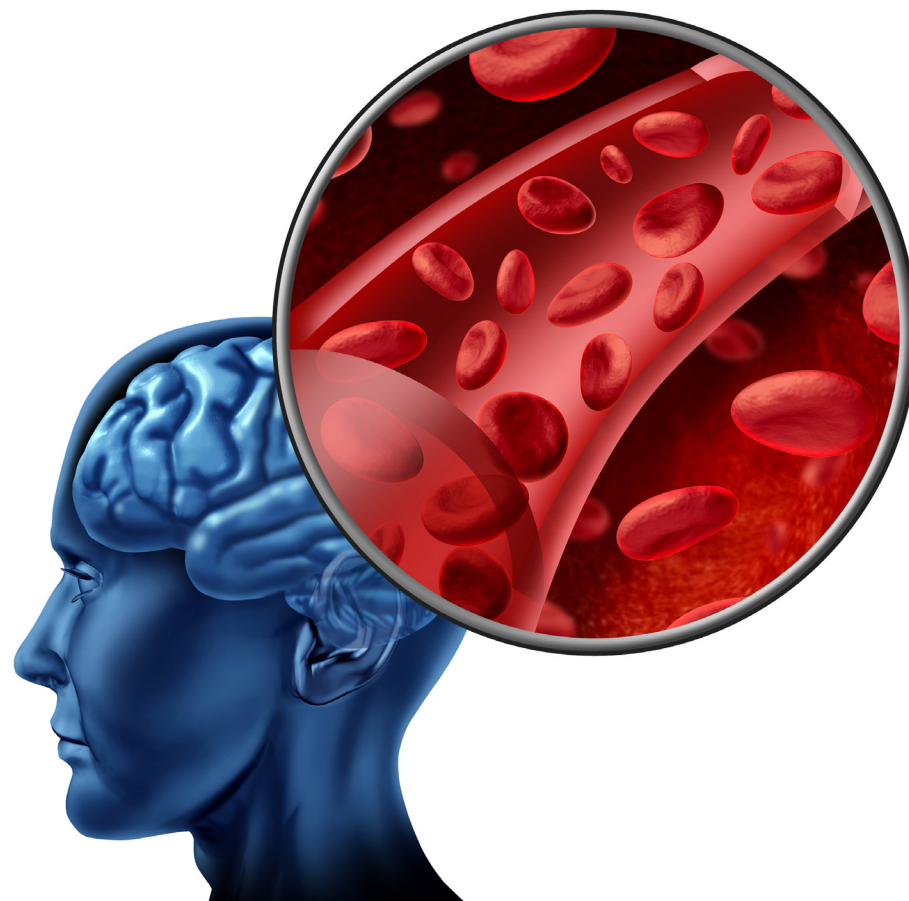
Sometimes sickle cells can get stuck in the brain. This can cause a stroke.

This picture shows how blood is supposed to move through the brain. When blood does not move properly through the brain, it can cause a stroke.

Watch for these signs:

- » if your child can not talk as well as usual
- » if your child is having trouble walking
- » if your child can't remember things
- » if your child can't move part of his or her body
- » if your child complains of a very bad headache

If your child has any of these signs, you should call his or her doctor right away.



Priapism

Sickle cells can get stuck in the penis. When this happens, it can hurt and become erect. This is called priapism.

Sometimes this erection will only last for a few minutes, but sometimes it lasts longer. ***If it lasts more than 30 minutes, you need to call your child's doctor right away.***

If this happens to your child, you can help him by:

- » giving him a warm washcloth or heating pad to put in his lap
- » giving him extra water or juice
- » putting him in a warm bath or shower
- » giving him pain medicine from the doctor



Feeling Tired

It is normal for people with sickle cell disease to be tired more often than other people. Feeling tired is usually not a sign that your child is sick, but there are some signs you should watch for if your child is tired.

Watch if your child:

- » seems pale or lighter in color than normal
- » has been very tired for several days
- » has a headache
- » faints or passes out

Call your child's doctor. It is possible that your child might have an infection.



Delayed Growth

Sometimes children with sickle cell disease grow slower than other children without sickle cell disease. Your child may be small or thin for his or her age. It may also take longer for him or her to reach puberty. If you are concerned about how much your child is growing, talk to his or her doctor.

What you can do:

- » Encourage your child to eat a healthy diet with plenty of fruits, vegetables, and protein
- » Be active with your child and encourage them to exercise and have a healthy lifestyle
- » If your child is upset at being shorter or smaller than his or her friends, reassure your child that they will catch up to other children



Sickle Cell Resources

Indiana Sickle Cell Clinics

Indiana Hemophilia and Thrombosis Center
8326 Naab Road
Indianapolis, IN 46260
317-871-0000
www.ihtc.org

Lutheran Hospital Pediatric Hematology/Oncology Clinic
7910 W. Jefferson Blvd. Ste. 217
Fort Wayne, IN 46804
260-435-2501
www.lutheranchildrenshosp.com

Riley Hospital for Children Hematology/Oncology
705 Riley Hospital Drive Ste. 3300
Indianapolis, IN 46202
317-944-2143
www.iuhealth.org/riley

Memorial Children's Hospital Pediatric Hematology/Oncology
615 N. Michigan Street, 6th Floor
South Bend, IN 46601
574-647-6892
www.beaconhealthsystem.org

Pediatricians Specializing in Sickle Cell Care

Dr. Clark Kramer
300 W. 80th Place
Merrillville, IN 46410
219-736-1400
www.medspecindiana.com

Indiana Sickle Cell Initiatives

Martin Center
3545 N. College Ave.
Indianapolis, IN 46205
317-927-5158
www.themartincenter.org

North Central Indiana Sickle Cell Initiative
307 N. Michigan Street
South Bend, IN 46601
574-647-1370
1-877-647-1370
<http://www.qualityoflife.org/memorialcms/index.cfm/che/chronic-conditions/sickle-cell-education-support/north-central-indiana-sickle-cell-initiative-ncisci/>

SCACURE Networks, Inc.
815 John Street, Ste. 110
Evansville, IN 47713
812-549-3593
www.scacurenetworks.org

Regional Sickle Cell Clinics

Kosair Children's Hospital Comprehensive Sickle Cell Program
231 E. Chestnut Street
Louisville, KY 40202
502-629-7755
www.kosairchildrenshospital.com

Ann and Robert H. Lurie Children's Hospital of Chicago Sickle Cell Disease Program
225 E. Chicago Ave.
Chicago, IL 60611
1-800-543-7362
www.luriechildrens.org

Comprehensive Sickle Cell Center at University of Illinois Health
1740 W. Taylor Street, Ste. 5E
Chicago, IL 60612
312-413-8666
http://hospital.uillinois.edu/Patient_Care_Services/Sickle_Cell.html

La Rabida Children's Hospital
6501 Promontory Drive
Chicago, IL 60649
773-753-8626
<http://www.larabida.org/page-sickle-cell>

Regional Sickle Cell Initiatives

Sickle Cell Disease Association of Illinois
8100 South Western Ave.
Chicago, IL 60620
773-526-5016
www.sicklecelldisease-illinois.org

Important Contacts

Primary Care Doctor

Name _____

Phone Number _____

Hematologist

Name _____

Phone Number _____

Emergency Room/Hospital

Name _____

Phone Number _____

Address _____

Emergency Contact 1

Name _____

Phone Number _____

Emergency Contact 2

Name _____

Phone Number _____

Pharmacy

Name _____

Phone Number _____

Other Specialist

Name _____

Phone Number _____

Other Specialist

Name _____

Phone Number _____

Notes

Notes