

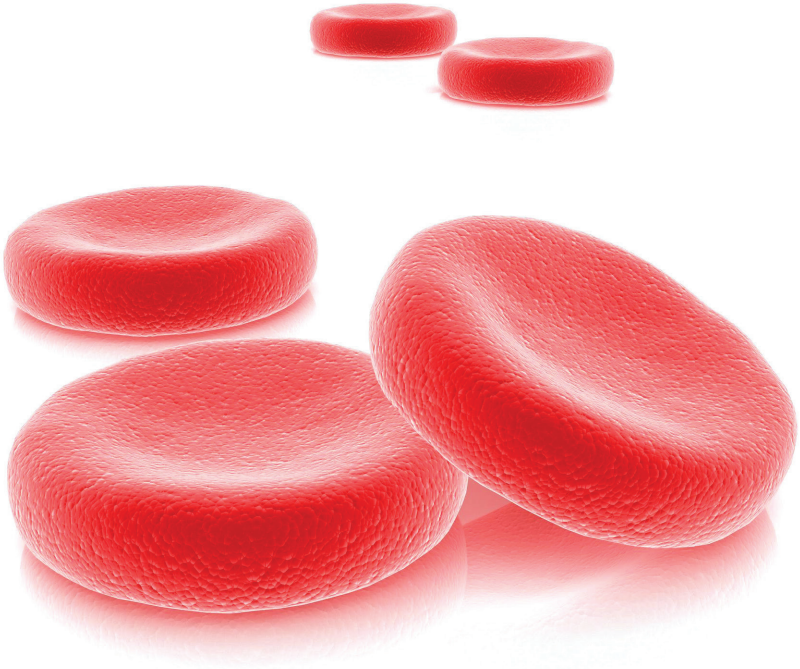
# Sickle Cell: Basic Facts

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



# *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.

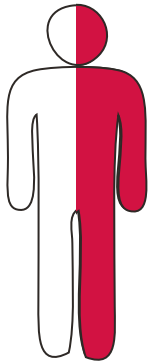
If both parents have a sickle cell trait, they can have a child with sickle cell disease.

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.***



Parents

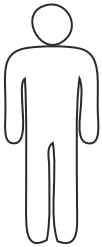


Father  
*with trait*  
AS

+



Mother  
*with trait*  
AS



Child  
*without trait*  
AA



Child  
*with trait*  
AS



Child  
*with trait*  
AS



Child  
*with sickle cell*  
SS



# *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*

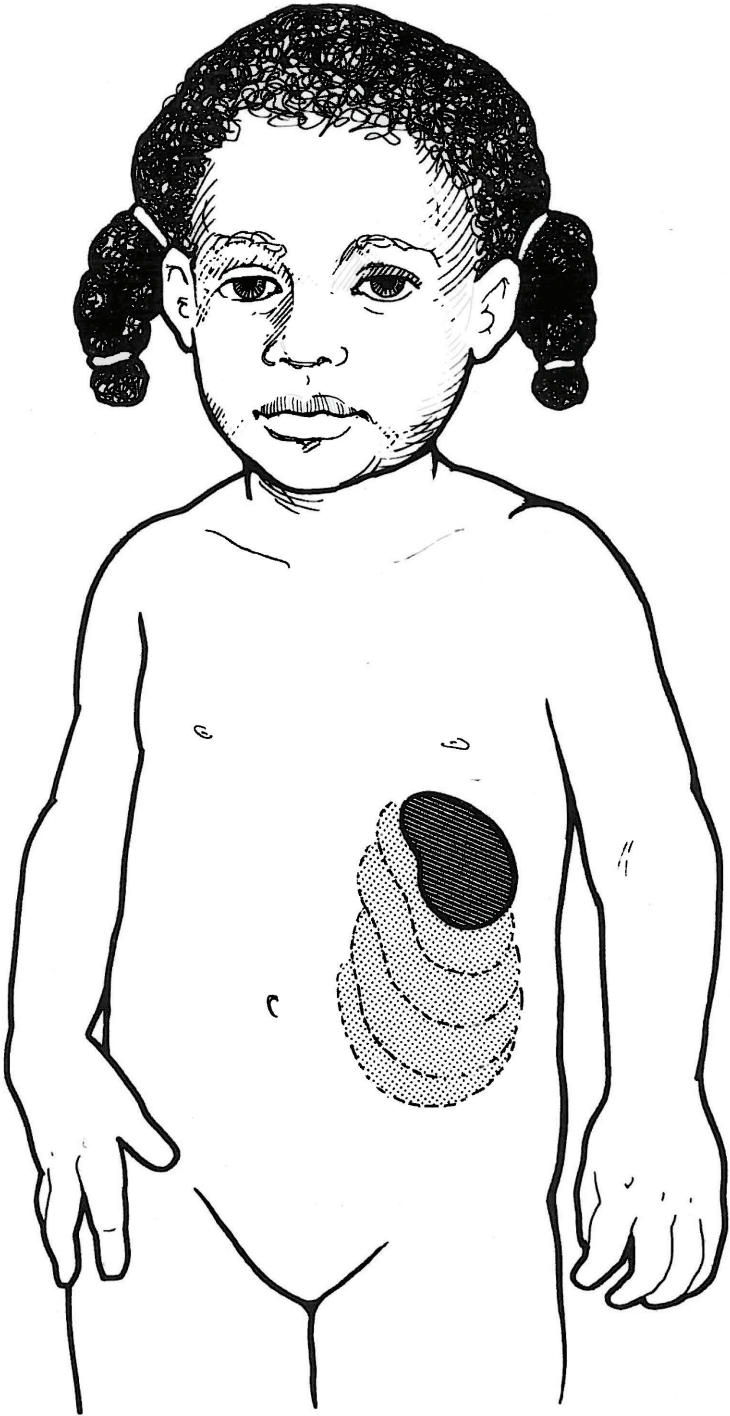
The spleen is an organ that helps fight infection and keeps your body fluids in balance. It is very common for sickle cells to get caught in the spleen. When this happens, the spleen can fill up with blood and get very large. Your child's doctor should teach you to feel for your child's spleen so you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





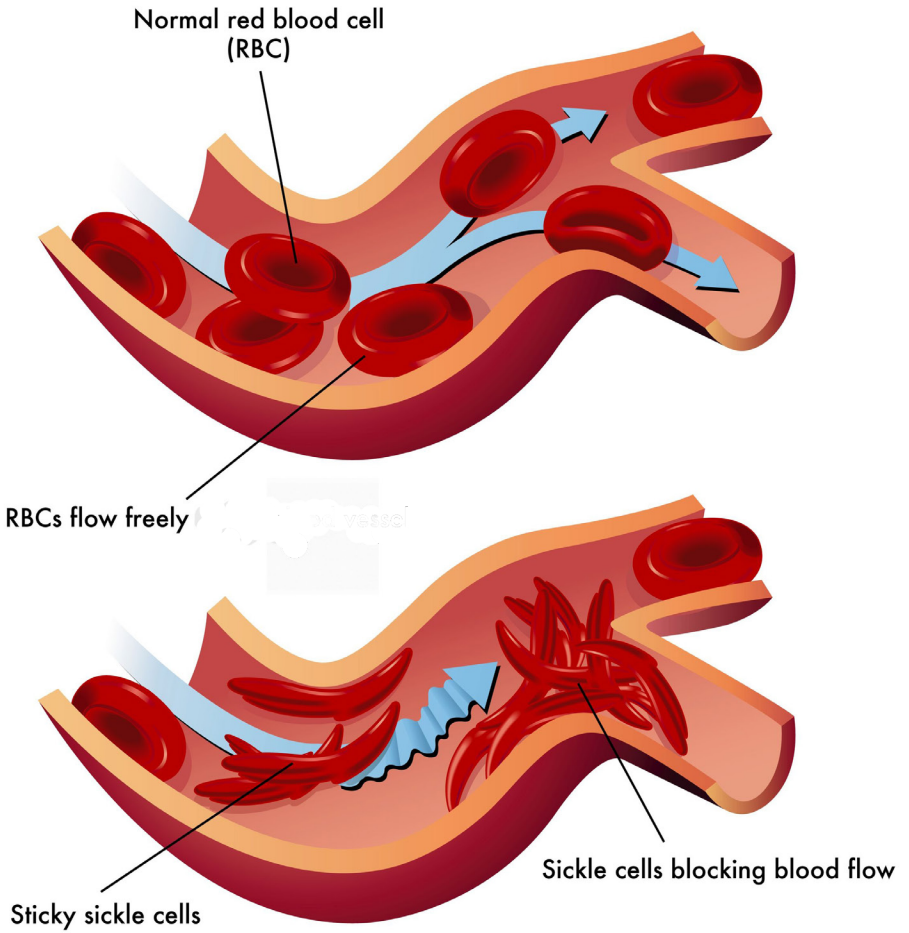
# *Pain*

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.

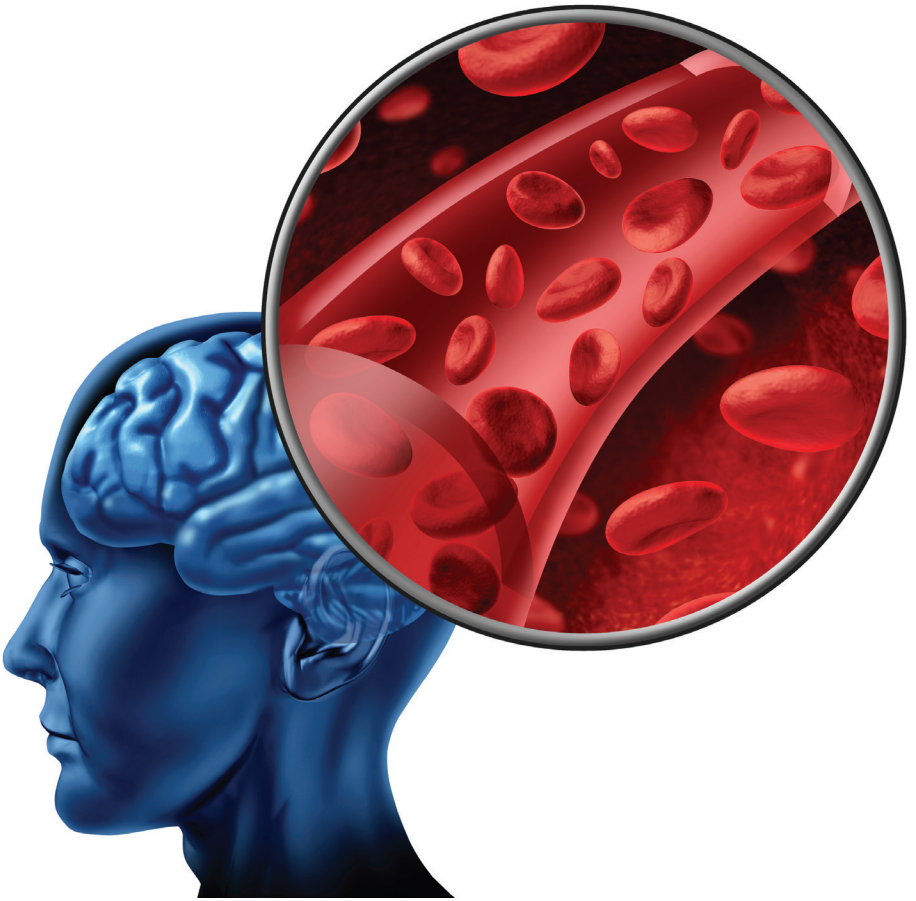
This picture shows how blood is supposed to move through the brain. When blood does not move properly through the brain, it can cause a stroke.

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](http://www.ihtc.org)

Parkview Hospital  
Pediatric Hematology/Oncology Clinic  
11104 Parkview Circle Drive, Ste. 050  
Fort Wayne, IN 46845  
260-425-6712

Riley Hospital for Children Hematology/Oncology  
705 Riley Hospital Drive Ste. 3300  
Indianapolis, IN 46202  
317-944-2143  
[www.iuhealth.org/riley](http://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](http://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](http://www.medspecindiana.com)

## **Indiana Sickle Cell Initiatives**

Martin Center  
3545 N. College Ave.  
Indianapolis, IN 46205  
317-927-5158  
[www.themartincenter.org](http://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](http://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](http://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](http://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](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](http://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*





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.ihtc.org) | <http://www.facebook.com/IndianaHemophilia>

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