

Helping Your Child to Stay Well

Advice for Parents of Young Children with Sickle Cell Disease

► Get Good Providers and Hospitals

Find doctors who:

- Know about sickle cell disease or who are willing to learn.
- Can admit your child to a hospital that has experience in treating children with sickle cell disease.

► Keep Appointments with Your Child's Primary Doctor

- Make sure that your baby gets all his or her baby shots (immunizations) on time.
- Talk about your child's growth and development.
- Have your child's hearing and vision checked.

► Keep Appointments with Your Child's Hematologist

- Take your baby to the hematologist even when your child is well. **Don't skip these appointments.**
- This helps doctors know what your child is like when he or she is well. It can help them to make better decisions about what to do when your child is sick.

► Give Your Child Penicillin – Twice A Day, Every Day

- Penicillin helps prevent certain kinds of dangerous infections.
- Children with sickle cell disease cannot fight off infections as well as other children. They can become very sick, very quickly.
- The infections can be serious and can even cause death.
- **Giving penicillin every day can truly make the difference between life and death.**

► Make Sure Your Child Gets His or Her Baby Shots (Immunizations) on Time

- Be sure to keep **all** of your child's immunization appointments.
- Your child will also get a flu shot every year.
- Bring your immunization card with you to keep track of your child's baby shots (immunizations).

► Make Sure Your Baby Stays on Breast Milk or Formula for the First Year

- Breast milk or formula is important for your baby's growth and development.
- Give your baby the amount of formula your doctor recommends. Do not give other types of fluids instead of formula or breast milk.

► Let Your Child Drink Enough Fluids

Give your child extra fluids:

- when your child has a fever or pain episode
- when your child is active
- when it is a hot, humid day
- when he or she is traveling



► Help your child to eat healthy

- Children with sickle cell disease need more calories so they need to eat more healthy foods than other children.
- A healthy diet for your child is one that includes:
 - lots of fruits and vegetables
 - whole grains (like wheat)
 - lean meats like chicken, turkey, fish, beans, eggs, and nuts
 - fat-free or low-fat milk and milk products, like cheese.
- Most of the time, children under two years of age should be given full fat milk. Talk with your baby's doctor about this.

A healthy diet is low in saturated fats, trans fats, cholesterol, salt and sugars.



It can sometimes be hard to know what a healthy diet looks like. The government has a website designed for parents and their children. The website helps explain what types and amounts of foods children should be eating. You can find this website at <http://www.mypyramid.gov/kids/index.html>.

► Give your child vitamins

- Even a healthy diet can benefit from extra vitamins.
- Your child's doctor may prescribe daily **follic acid** to help your child make new red blood cells.
- Children with sickle cell disease should take regular daily vitamins, especially if they do not eat well.
- More children with sickle cell disease have low zinc, Vitamin D, and Vitamin A. Check with your child's doctor to find out whether your child needs more of these.

► Avoid Letting Your Child Get Chilled

- Dress your child warmly when the weather is cool, or when the child is going to be in an air conditioned room for a long time.
- Don't let your child swim in very cold water, even when the weather is warm.
- Dry your child off quickly after a swim and be sure to wrap him or her in a dry towel to keep warm.



► Avoid Temperature Extremes

Your child may be more likely to have a pain episode when it is very hot and humid (over 80 degrees) or very cold (less than 32 degrees) outside. Sudden changes in weather conditions can cause the child to develop a pain episode.

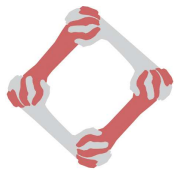
► Let Your Child Rest When Needed

► **Learn How to Tell if Your Child Is Getting Sick**

Call your doctor right away if you see any of these symptoms.

- Fever higher than 101° (Never Ignore This!)**
- Pain**
- Swollen hands and/or feet**
- Paleness**
- A swollen belly or one that is tender to the touch (enlarged spleen)**
- Cannot move their hands, arm or leg or cannot wake up**
- Limping (especially when there is no pain)**
- A change in behavior**
- Unusual tiredness**
- Loss of appetite**
- Trouble breathing**

Credits



**National Coordinating
and Evaluation Center**

Sickle Cell Disease and Newborn Screening Program

**Sickle Cell Disease and
Newborn Screening Program**



**SCDAA National Headquarters
2008**

This booklet is made available through grant number U38MC00217-07-03
from the Genetic Services Branch of the Maternal and Child Health Bureau