

Make Sure You Know the Answers to These Questions

- Here is a list of questions that the parents of a baby or child with sickle cell disease may ask.
- By talking with your child's Primary Care Doctor, Hematologist, and the other health care providers that you see, you should **know the answers** to the questions below.

From Birth to 6 Months

You should know the answer to questions about:

The symptoms of sickle cell disease you can expect to see in your baby.

- ___ What you should do if you notice these symptoms.
- ___ How to tell if your baby has a fever.
- ___ How to take your baby's temperature.
- ___ What doctors appointments, including specialists, you should set up for your child.
- ___ If there are any community-based sickle cell programs in your area.
- ___ If they can put you in touch with other families who have children with sickle cell disease.

From 6 Months to 1 Year

You should know the answer to questions about:

- ___ Why it is important to give your child enough to drink.
- ___ What foods, vitamins and minerals are best for your child.
- ___ How to respond to fever as a medical emergency.
- ___ How to know if your baby is having pain.
- ___ How to manage pain at home.
- ___ What to do if your baby's hands and feet are swollen.
- ___ What the spleen is and how to tell if it is enlarged.

When Your Baby is 1 to 2 Years

You should know the answer to questions about:

- ___ How to manage your child's pain.
- ___ Why eyes get yellow and what to do.
- ___ How to tell if there are problems with your child's lungs (Acute Chest Syndrome).
- ___ How to tell if there are problems with the spleen (Splenic Sequestration).
- ___ The signs and symptoms of a stroke.

When Your Baby is 3 to 5 Years

You should know the answer to questions about:

- ___ How to make sure your child is getting plenty of liquids and a proper diet.
- ___ How your child might grow and develop.
- ___ How to manage your child's pain.
- ___ Materials you can use to teach your child's pre-school teacher or staff about sickle cell disease.
- ___ Why it is important to have an educational plan for your child.

Questions?

You can ask your child's doctor, nurse, or other healthcare workers any questions you may have about your baby and sickle cell disease.

Write your questions down here.

Resources: Where to Turn to Find Out More

Where to Call:

► **Sickle Cell Disease Association of America**

231 East Baltimore Street
Suite 800
Baltimore, Maryland 21202

(410) 528-1555 Office
(800) 421-8453 Toll Free
(410) 528-1495 Fax

Comprehensive Sickle Cell Center:

Address

Phone Number

Community-Based Sickle Cell Program:

Address

Phone Number

Websites to Visit:

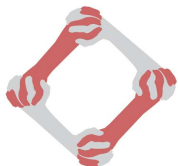
- You can find a lot of information on the Internet, but keep in mind that some information you find may not be correct.
- You should ask your doctor or nurse about Internet sites that contain information about sickle cell disease that you can trust.

Sickle Cell Disease Association of America
<http://www.sicklecelldisease.org>

Sickle Cell Information Center
<http://www.scinfo.org/>

National Coordination and Evaluation Center (NCEC)
<http://www.sicklecelldisease.net>

Credits



National Coordinating and Evaluation Center

Sickle Cell Disease and Newborn Screening Program

Sickle Cell Disease and Newborn Screening Program



SCDAA

"Break The Sickle Cycle"

**SCDAA National Headquarters
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