

## 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.**

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**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:**

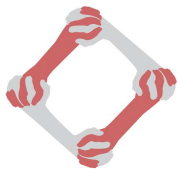
- You can find a lot of information on the Internet, but keep in mind that some information you find may not be correct.
- You should ask your doctor or nurse about Internet sites that contain information about sickle cell disease that you can trust.

**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**



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