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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________________________________________________________________________
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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

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