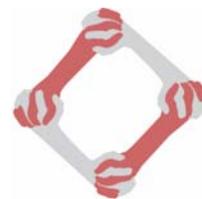


MCHB
Sickle Cell Disease
Newborn Screening Follow-up Program
Educational Tools



**National Coordinating
and Evaluation Center**

Sickle Cell Disease and Newborn Screening Program

Objectives

- Provide an overview of Sickle Cell Disease (SCD) & Sickle Cell Trait (SCT)
- Overview of State Newborn Screening Programs
- Introduce the HRSA funded National Coordinating and Evaluation Center (NCEC) & Newborn Screening Program (NBS)
- Discuss the educational needs of parents and healthcare providers related to newborn screening for SCD & SCT
- Describe NCEC educational products designed to address some of these educational needs
 - *SCT Materials for Healthcare Providers/Families Toolkit*
 - *SCD Toolkit*
 - *Welcome Kit*

Sickle Cell Disease

- Sickle Cell Disease is a disease of the red blood cells.
- It is called Sickle Cell Disease because many of the person's red blood cells are shaped like a "sickle". A sickle is a tool that farmers have used to cut their crops, and it is shaped like a big C.

Sickle Cell Trait

- Sickle Cell Trait
 - usually a mild condition
 - blood in the urine from time to time
 - some pain or discomfort at high altitudes
 - problems with extreme exercise in hot humid weather, when not drinking enough water

State Newborn Screening for SCD

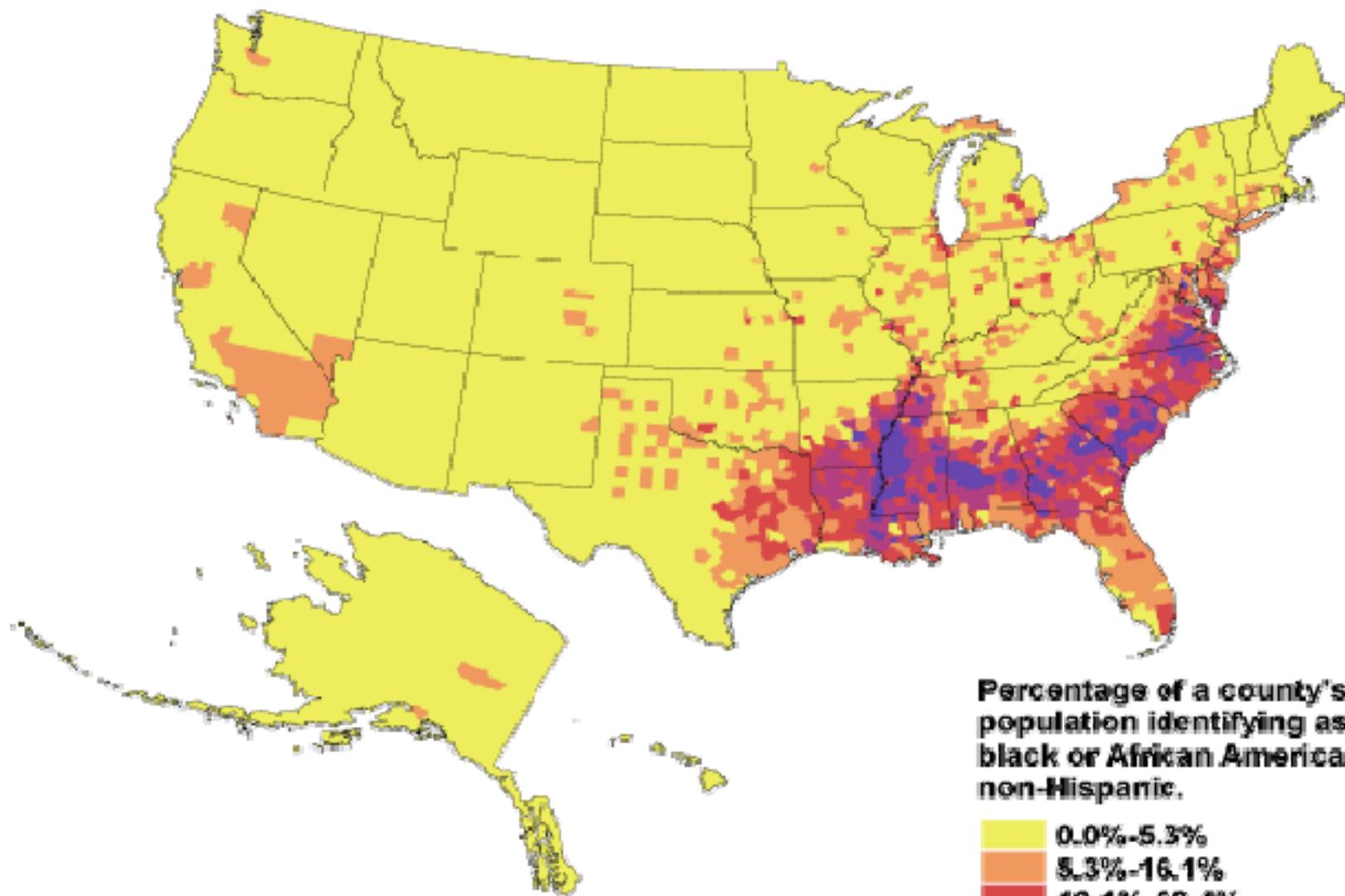
- Historically newborn screening (NBS) for sickle cell and other Hemoglobinopathies has been a joint effort among
 - State Newborn Screening Programs
 - Tertiary/ Comprehensive Care Centers
 - Community-Based SCD programs
 - Primary Care Providers

State Newborn Screening for SCD

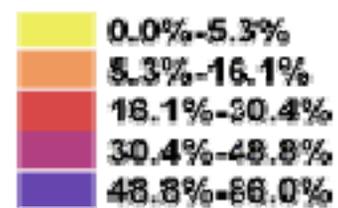
- For over three decades the outcome of NBS work has been a better understanding of
 - the epidemiology of sickle hemoglobinopathies in newborns
 - consequent life saving care protocols
 - effective provider & public education about SCD and SCT
 - who is affected

State Newborn Screening for SCD

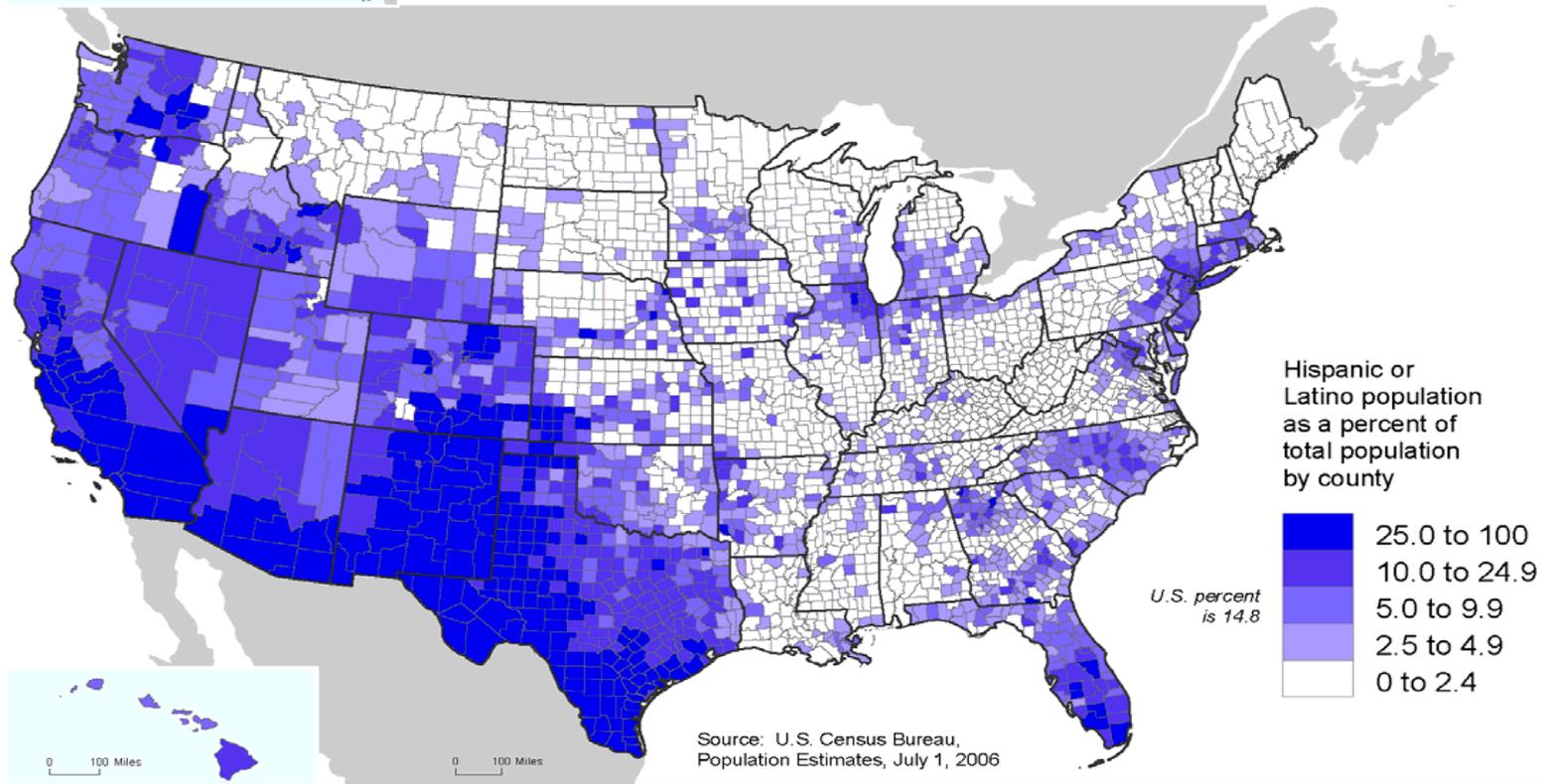
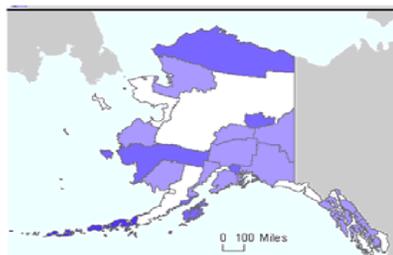
- Populations who are affected
 - African Americans, Italians, Greeks, Portuguese, Spanish, French Corsicans
- Populations typically targeted
 - African American
- Populations that have emerged
 - Caucasians, Hispanics, Latinos



Percentage of a county's population identifying as both black or African American and non-Hispanic.



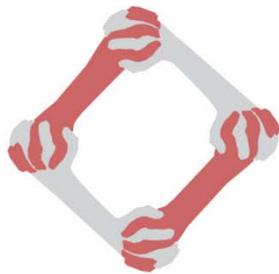
Percent of Population 2006 Hispanic or Latino



State Newborn Screening for SCD

- HRSA funded pilot projects have identified continuing concerns in the areas of:
 - parent and provider education
 - contacting and counseling of parents of infants identified as carriers
- Follow-up efforts have remained problematic
- Very little has been documented about the effectiveness of efforts to improve follow-up of NBS

National Coordinating and Evaluation Center (NCEC)



**National Coordinating
and Evaluation Center**

Sickle Cell Disease and Newborn Screening Program

HRSA Funded Newborn Screening Program for Sickle Cell Disease

Purpose:

- Increase the capacity of the HRSA funded SCD newborn screening community-based programs
- Increase the capacity of partners & 17 funded community-based programs (new funding cycle began 6/1/2008) through the development of networks
- Provide model education, counseling and follow-up services to families with babies identified with SCD, or as carriers of SCD and other hemoglobinopathies.

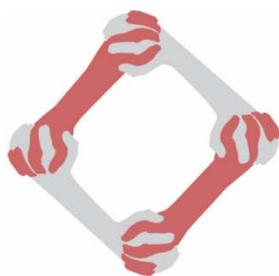
NCEC Outcomes

1. Increase knowledge about SCD for families with babies identified with SCD, as carriers of SCD or other hemoglobinopathies, and of their providers who are served by the HRSA funded SCD community-based programs
2. Strengthen partnerships between HRSA funded SCD community-based programs, State NBS programs, comprehensive SCD centers, Primary Care Physicians (PCP) and Title V Programs

NCEC Outcomes

3. Improve SCD newborn screening and carrier follow-up activities of HRSA funded SCD community-based programs.
4. Develop, assess and disseminate educational materials for providers, families and individuals with SCD and SCT

NCEC Educational Materials



**National Coordinating
and Evaluation Center**

Sickle Cell Disease and Newborn Screening Program

Needs Assessment

- What parents need to know
 - Focus groups
- Review of existing materials
 - Readability
 - Appeal
 - Content

Materials development process

- Develop reader-friendly materials
- Review by content experts
- Field testing and evaluation (target populations)
- Lessons learned

Reader-Friendly Materials

- User friendly layout
 - Font is 12-point or higher.
 - Avoids use of all CAPS, *italics*,
 - Use ample white space
 - Limits paragraphs to 4 to 5 lines in length
 - Use bullets, boxes, indentations, bolding, short lists

Reader-Friendly Materials

- Illustrations that carry the message
 - Serve a purpose
 - Clear and realistic
 - Familiar and likely to be understood
- Clear messages are easy to pick out
 - Begins with cover, title, headings
 - Reader will be clear about what he or she needs to DO

Reader-Friendly Materials

- Information manageable
 - Shorter words and shorter sentences
 - Conversational tone and personalized approach
 - Limit the number of messages
 - Limit use of graphs or statistics

Materials for Healthcare Providers

Purpose:

- Shortages of sub-specialists, a lack of knowledgeable providers and reliance of clients on emergency rooms for care demonstrate importance of educating healthcare providers about sickle cell disease and trait.

Materials for Healthcare Providers/Families

- Materials for healthcare providers include:
 - Information about SCD/ SCT
 - Treatment protocols
 - Assistance in offering information to families of newborns diagnosed with SCD or SCT
- Materials for patients/ families should:
 - Be accurate
 - Provide information that is easy to read and understand
 - Give a clear sense of what they can and should DO with the information



National Coordinating
and Evaluation Center

Sickle Cell Disease and Newborn Screening Program

SICKLE CELL TRAIT NOTIFICATION TOOLKIT FOR PROVIDERS

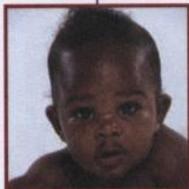


This tool kit is made available through grant number U38MCOO217 from the Genetic Services Branch of the Maternal and Child Health Bureau.

SCT Materials for Healthcare Providers/Families

- **Materials to guide health care providers**
 - 5 Things Parents Want to Know
 - Checklist and Guide for Creating Reader-Friendly Materials
- **Materials to use with consumers**
 - Template notification letters
 - Sample brochure for trait notification
 - Sample brochure for getting tested
 - “What If – Future Babies Card”
 - Bookmark

Your New Baby Has
Sickle Cell Trait



**National Coordinating
and Evaluation Center**

Sickle Cell Disease and Newborn Screening Program



**Find Out What You Should
Know and Do for Your Family**

Purpose

- To provide parents of newborns with sickle cell trait with understandable and useful information that they may not otherwise receive

Getting Tested For Genes That Can Cause Sickle Cell Disease

Find Out Why and How to Get Tested



**National Coordinating
and Evaluation Center**

Sickle Cell Disease and Newborn Screening Program

Purpose

- To help consumers understand why they may want to consider getting tested and how to do so, if they choose

Content

- Provides 5 main points on why and how to get tested
- Includes another 5 points to let people know what they can DO

SCT Materials for Healthcare Providers/Families

What If – Future Babies Card

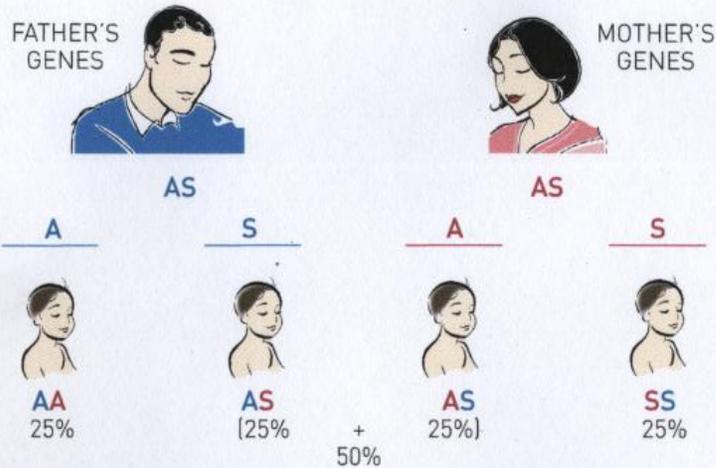
Purpose

- To help professionals counsel interested couples and individuals about their chances of having a child with Sickle Cell Disease
- Attempts to clarify misconceptions that information about probabilities has often caused by adding explicit and concrete information about actual possibilities that can occur as people go on to have children
- To translate numbers (%ages) and genetic symbols (AS,SS) into common language that lay people are most likely to understand

Your Future Babies: Can Any of Them Have Sickle Cell Disease?



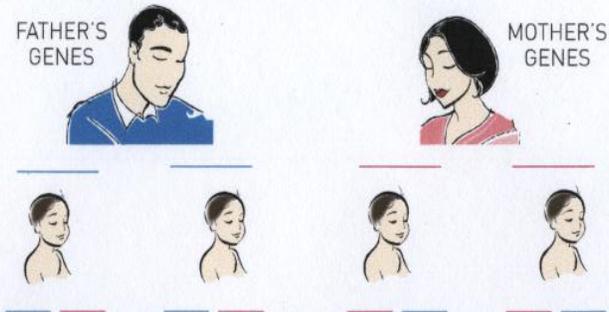
Find out how to tell. For example:



If you have **AS** and the other parent has **AS**

- Here is what can happen with **EACH** baby you have:
 - He or she can have **AA** and have **NO** Sickle Cell Trait (AS) and **NO** Sickle Cell Disease (SS)
 - He or she can have **AS** and have only Sickle Cell Trait (AS)
 - He or she can have **SS** and have Sickle Cell Disease (SS)
- It is all a matter of chance. So, that means if you have several children in the future:
 - They can **ALL** have AA
 - They can **ALL** have AS
 - They can **ALL** have SS
 - You can have one or several of each
- Keep this in mind if you have children in the future.

Find out how to tell.
Fill in your own gene test results here.



Your chances are:

% Chance
 % Chance
 % Chance
 % Chance

This means that your baby may have:

To Find Out More

Contact your local Sickle Cell Disease organization or clinic at:

or
Contact our national office at:



**National Coordinating
and Evaluation Center**

Sickle Cell Disease and Newborn Screening Program

Contact National Coordinating and Evaluation Center at SCDA National Headquarters
231 E. Baltimore Street Suite 800 Baltimore, MD 21202
410-528-1555 (Phone) 410-528-1495 (Fax) 1-800-421-8453 (Toll Free)
www.sicklecelldisease.net

This brochure is made available through grant number U93MC00217-02-00 from the Genetic Services Branch of the Maternal and Child Health Bureau.

SCT Materials for Healthcare Providers/Families

Advice at a Glance Bookmark

Purpose

- Designed to be given to adults and teens who have sickle cell trait and want to know what it means for them and what, if anything, to do about it.

ADVICE At-a-Glance

For People Who Have Sickle Cell Trait (AS)

BE INFORMED: Here are **5** things to know

- 1** You have one Sickle gene (S).
 - **Genes** are what cause parents to pass traits (like eye color) or health conditions (like Diabetes) along to their children. The Sickle gene (S) affects the red blood cells.
 - **Sickle Cell Trait (AS)** occurs when a person inherits a Normal gene (A) from one parent, and a Sickle gene (S) from the other.
- 2** Sickle Cell Trait is usually a very mild condition.
 - **Sickle Cell Disease** is a serious blood disease that can be very painful.
 - **Sickle Cell Trait is NOT Sickle Cell Disease.** It does not make people sick the way Sickle Cell Disease does.
- 3** Problems with Sickle Cell Trait are RARE.
 - **Most people with Sickle Cell Trait (AS) cannot tell that they have it.** Millions of people have Sickle Cell Trait (AS). They are fine, and they lead active lives.
 - **A few people with the Trait (AS) may have:**
 - Blood in the urine, from time to time
 - Some pain and discomfort at high altitudes (like in the mountains or in certain cities that are high above sea level)
 - Problems with extreme exercise in hot, humid weather, when not drinking enough water

IMPORTANT: See other side

4 The Sickle gene (S) runs in many families.

The Sickle gene (S) is found in people from many different countries. It is found in:

- Africans, African-Americans, West Indians
- Latinos, Brazilians and in other people from Central and South America
- Italians, Greeks, and other people from other Mediterranean countries
- East Indians, Asians and people from countries in the Middle East

5 MOST IMPORTANT: You CAN have a baby with Sickle Cell Disease, in the future

- **You can pass your Sickle gene (S) along** to any of your children in the future.
- **So, find out if your partner also has a gene that can cause Sickle Cell Disease.** It could be an (S) gene or another gene. If so, any of your children can be born with the disease. Ask him or her to be tested to find out.

Contact your local Sickle Cell Disease organization or clinic at:

or

Contact our national office at:



**National Coordinating
and Evaluation Center**

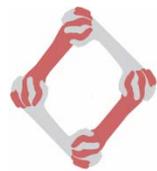
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410-528-1495 (Fax)
1-800-421-8453 (Toll Free)
www.sicklecelldisease.net

This brochure is made available through grant number U38MC00217-05-01 from the Genetic Services Branch of the Maternal and Child Health Bureau.

Sickle Cell Disease Tool-Kit

- **Materials to guide providers**
 - 5 Things Parents Want to Know
 - Tips for explaining risk information (under development)
- **Materials to use with consumers**
 - Template notification letters
 - Sample brochure for SCD notification
 - Sample brochure for SCD Symptoms and Management
 - “What If – Future Babies Card”

Caring for your Baby with Sickle Cell Disease



National Coordinating
and Evaluation Center

Sickle Cell Disease and Newborn Screening Program

Find Out What You Should Know and Do for Your Baby

Purpose

- Provide an overview of features of SCD
- Include messages of encouragement
- Provide Action Messages
 - Keep appointments
 - Penicillin
 - Treat fever as medical emergency
 - Calling doctor if baby is sick
 - Ask questions

Content

- Introduction to SCD
- 5 Things You Should Know
- 5 Things You Should Do

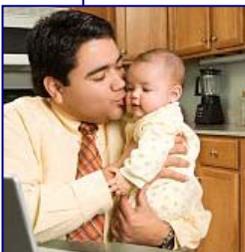
What You Need to Know About Sickle Cell Disease



National Coordinating
and Evaluation Center

Sickle Cell Disease and Newborn Screening Program

This brochure will help you learn about sickle cell disease and steps you can take to help your baby.



Purpose

- Provide more detail about features and management of SCD
- Include messages of encouragement
- Provide Action Messages
 - Learn what you can do to keep your child healthy
 - Keep Appointments
 - Learn how to tell if your baby is getting sick
 - Treat fever as medical emergency
 - Ask questions

Content

- Symptoms and Management
- 5 Things You Should Know
- 5 Things You Should Do

Materials for Parents of Newborns with Sickle Cell Disease

Welcome Kit

Purpose:

- Review of symptoms and management
- Provides health care system navigation tools
- Outlines what to know and where to find out more
- Highlights what documents to keep on hand
- Provides information for child care providers and teachers

Getting the most from the *Welcome Kit*

- Ask doctor, nurse or other healthcare provider any questions about the information in this book.
- Use the book to keep track of child's visits to the doctor and other information.
- Keep this book on hand at all the time including when taking the child to see *any* doctor.
- Ask doctors to keep notes about visits with child in this book. This will help doctors communicate with each other.
- Use the plastic cardholders and pocket folders to keep important information in one place.

About Your Child



- A place to record important information about your child.
- A place to keep your child's health insurance information.
- A calendar and a place to keep track of your child's appointments.

Whom to Call
**People Who Care for
Your Child**



- Medical Home
- Information about the people who will help you take care of your child.
- How to contact your child's doctors and other healthcare providers.
 - A place to record contact information
- A place to keep business cards you get from your doctor or other healthcare provider.

When to Call the Doctor Or Go to the Emergency Room



- What to do if your child has a fever or other signs of illness.
- When you need to take your child to the emergency room.
- Notes about how to get to the emergency room when you need to.
- What to do if your child gets sick when you are traveling away from home.

Key Messages



- When to seek care **Immediately**
 - Symptoms to watch for
 - Treating fever as a medical emergency

Make sure you tell any doctor that sees your child that your child has sickle cell disease.

DOCTOR'S NOTES



- A place for doctors who see your child to keep notes about the visit

What to *KNOW*
If You Have a Young Child
with Sickle Cell Disease
From Birth to 5 Years of
Age



- Information about sickle cell disease.
- Information about how your child will develop.
- Checklists about good health care.

Topics

- Information about good healthcare
 - Care that follows a plan
 - Care that is comprehensive

- Checklists



Topics

- **Symptoms and Management Information**

- Anemia
- Infection
- Pain
- Swollen Hands and Feet
- Problems with the Chest
- Problems with the Spleen
- Stroke
- Yellow Eyes

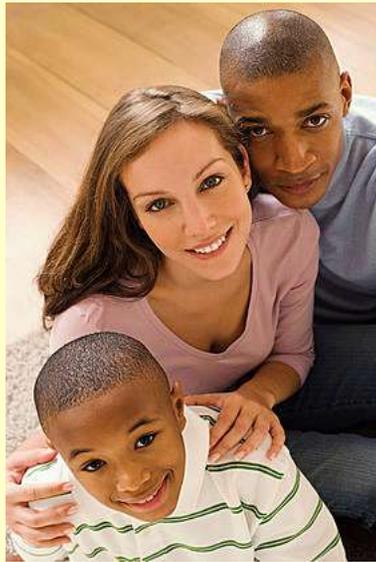
- **Action Messages**

- What you need to KNOW
- What you need to DO



What to *DO*
If You Have a Young Child
with Sickle Cell Disease

From Birth to 5 Years of Age



- Advice for taking care of your baby or child with sickle cell disease.

Make Sure You Know the Answers to These Questions



- A list of questions you should know the answer to
- A place to write down questions you have

Records to Keep



- A list of records you should keep.
- A place to keep track of your child's medical tests.
- A place to keep track of medicines your child needs to take.
- A place to keep notes about your child's pain episodes.

Information for Child Care Providers and Teachers



- Information you can share with people who help take care of your child.
- Information to give to your child's teachers.

Key Messages for Child Care Providers

- Child care providers can learn what they need to know about taking care of a baby or young child with sickle cell disease including:
 - how to tell if the child is getting sick
 - what to do if about fever and other symptoms
 - know how to contact the family and/or health care provider

Resources

Where to Turn To Find out More



Where to Call

- SCDA
- Comprehensive Sickle Cell Center
- Community-Based Sickle Cell Program

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

Developing a “Welcome Kit”

- Welcome Kit Concept
 - Easy to read content
 - Useful format – 3 ring binder
 - Action messages
 - System navigation tools
 - Other useful tools (e.g. tote bag, thermometer, pill crusher)
- Drafting content based on health literacy principles
- Input from Focus Groups
 - Parents of young children with SCD
 - Physicians
 - Health Care Providers



Lessons Learned - Terminology

- Trait, AS, Carrier
- “The Sickle gene (S)”
- “Genes that can combine to cause Sickle Cell Disease”
- “Runs in families”
- “Genes are what cause parent to passed along traits like...”
- “Sickle cell disease is a serious disease of the red blood cells”
- “Detailed test results”
- “Useful” tests

Lessons Learned – Main Messages

- What to tell parent first –Not to worry?
- The need to emphasize the implications of having a child with the trait has for the parents and future pregnancies
- The need to better explain to lay people what Sickle Cell Trait is in a way they can best understand it

Lessons Learned – Main Messages

- The need to consider the Sickle Cell Trait as being a “condition” based on what we now know about it and in spite of the need to not alarm lay people
- The need to tell people what SCD is in a way that will help them to understand what they may need to worry about
- The need to give more specific information about how to get tested and about the possibility of getting misleading results

Lessons Learned – Accuracy and Avoiding Misconceptions

- The need to avoid implying that there is only one type of SCD and that there are only 2 or 3 genes that can combine to cause SCD
- The need to avoid implying that there is only one way for 2 parents to have a child with SCD
- Unless explained verbally by a trained genetic counselor, to reconsider showing quantitative probabilities when giving printed information to families

Lessons Learned – Accuracy and Avoiding Misconceptions

- The need to stress that the (S) gene can be present in people with family roots in the Middle East, India and the Mediterranean, so that they are not overlooked
- The need to stress that there is no fault involved and that it takes BOTH parents to have a child with a particular combination of genes

Next Steps – Materials Development

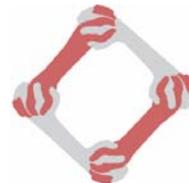
- Obtain feedback from multiple stakeholders
- Final Review and Editing
- Field testing in the community
 - Opportunity to find out if and how tools are used by parents and healthcare providers
 - Information about how tools can be improved
- Revise as needed prior to broad dissemination

Dissemination

- Dissemination
 - Community based programs
 - Title V programs
 - SCDAAs member organizations
 - NCEC grantees
- Access
 - Making educational materials available electronically
 - HRSA – SCD Website (under development)
 - NCEC and SCDAAs Websites

Acknowledgements

- HRSA – Maternal Child Health Bureau - Genetic Service Branch
- SCD Newborn Screening Program Grantees
- Advisors, Consultants, Consumers & Partners
- NCEC Staff
- Sickle Cell Disease Association of America (SCDAA) and the Medical and Research Advisory Committee (MARAC)



National Coordinating
and Evaluation Center

Sickle Cell Disease and Newborn Screening Program

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