Parent's Guide to Sickle Cell and School

Children's Mercy
KANSAS CITY

Table of Contents

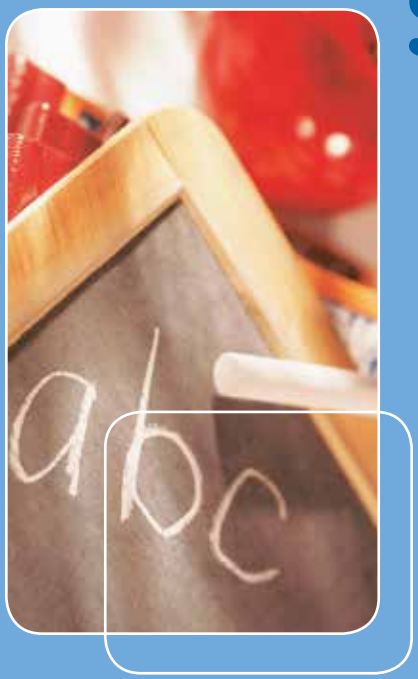
Introduction

This book is to help you and your child with the school system. As you know, learning is very important. Sometimes this disease will get in the way of your child's education. You know the most about your child, but here are some helpful hints for school.

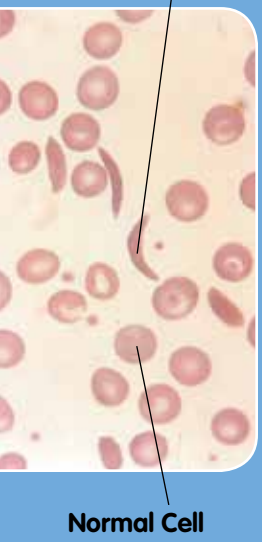
Included in this book are common things about sickle cell disease that may be helpful to talk about when meeting with teachers and staff about your child's disease.

Children's Mercy
KANSAS CITY

Understanding Sickle Cell



What is Sickle Cell Disease?



Sickle cell disease is a group of disorders that affects the red blood cells in the body. Normal red blood cells are soft and round, like a donut, and travel through the body without any problems. The main job of red blood cells is to carry oxygen. When exposed to certain triggers, red blood cells affected by sickle cell disease can become hard, sticky and curved in shape, like a banana. Sickled cells are not as soft and flexible, so they may get stuck in small blood vessels. If this happens, some parts of the body do not get enough oxygen. Pain or damage may occur.

Other facts about sickle cell disease

- It is genetically inherited, one gene passed from each parent.
- It is usually identified at birth through mandatory newborn screening.
- It affects one out of every 400 African Americans.
- The disease also affects people of Mediterranean, Caribbean and Asian descent.
- The disease is characterized by chronic anemia, increased susceptibility to infections and painful episodes.

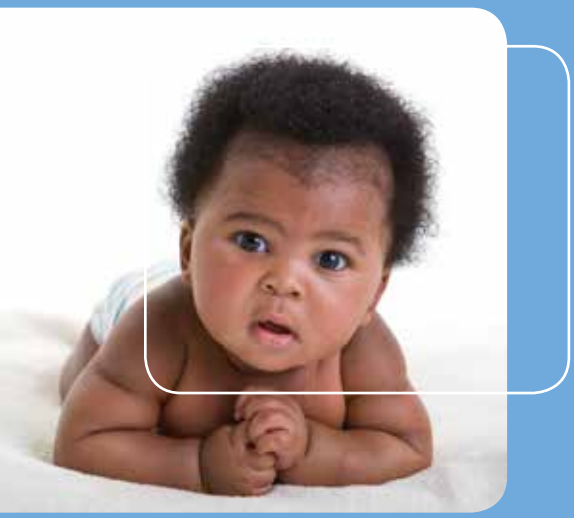
Types of Sickle Cell Disease

- Hemoglobin SS Disease
  (Sickle Cell Anemia)
- Hemoglobin SC Disease
- Sickle Beta Zero Thalassemia
  (Sickle β° Thalassemia)
- Sickle Beta Plus Thalassemia
  (Sickle β+ Thalassemia)
- Sickle Hereditary Persistence of Fetal Hemoglobin (S/HPFH)
- Other types

Sickle cell affects one out of every 400 African Americans

Sickle Cell Trait

Sickle cell trait is passed on from a child's parents. Children who get one normal hemoglobin gene from one parent and one sickle hemoglobin gene from the other parent will have sickle cell trait. A child born with sickle cell trait will have it all of his life, but it will never turn into sickle cell disease. Sickle cell trait is found in one out of every 10 to 12 African Americans. It can also be found in people of Mediterranean, Middle Eastern, Indian, Caribbean and South American descent. People with sickle cell trait usually do not have any medical problems. The normal hemoglobin that was passed on by one parent keeps them from having sickle cell disease. **People with sickle cell trait should live normal, healthy lives and have a normal life expectancy**.



Common Characteristics of Sickle Cell Disease

- **Anemia** is a lower number of red blood cells (oxygen-carrying cells) in the body. This results in a lower hemoglobin level.

- **Infection** may occur due to the spleen not working properly. Sickled red blood cells get trapped in the spleen causing damage. The spleen normally filters bacteria out of the blood to help reduce infection.

- **Pain** occurs when red blood cells "sickle" (change their shape) and become trapped in small blood vessels in the body. Once trapped, blood cannot flow normally. The area where the blood cells are trapped does not get enough oxygen, therefore pain may occur.

- **Decreased urine concentration** causes frequent trips to the restroom.

- **Delayed growth and development** is common in children with sickle cell disease.

Less Common Complications of Sickle Cell Disease

- **Stroke** occurs when there is decreased oxygen to parts of the brain due to sickle cells blocking blood vessels.

- **Gallstones** happen more often in people with sickle cell disease because sickle red blood cells break down much faster than normal red blood cells. When these break down, they release bilirubin which collects in the gallbladder and can form a sludge or gallstones.

- **Aplastic Crisis** is a sudden drop in the hemoglobin usually caused by a virus called parvovirus or Fifth Disease.

- **Splenic Sequestration** is an enlargement of the spleen and a sudden drop in the hemoglobin.

- **Avascular Necrosis (AVN)** is a change in the shape of the hip or shoulder bones which can cause pain.

- **Priapism** is a painful, unwanted erection due to trapped sickle cells in the penis. It is treated like a painful episode with fluids and pain medicines.

Anemia

Most children with sickle cell disease will be anemic. This means that the child will have a lower amount of red blood cells in the body and have a lower hemoglobin level. Normal red blood cells (without sickle cell) usually live 120 days. Sickle red blood cells only live 10 to 20 days. **Being anemic may cause the child to tire more easily and need to rest more frequently.**

Infection

Children with sickle cell disease (especially sickle cell anemia and sickle beta zero thalassemia) are at higher risk for infection than people who do not have sickle cell disease. Infection is the leading cause of death in young children with sickle cell disease. **It is very important for infections to be treated quickly**. Some common infections children with sickle cell disease may get include meningitis (infection of the spinal fluid), pneumonia (infection of the lungs), osteomyelitis (infection of the bone) and sepsis (infection in the blood).

Painful Episodes

One common occurrence in children with sickle cell disease is pain. Pain can happen at any time of the day or night. It may last a few hours, a few days or even a few weeks. The pain can range from mild to severe and is different in each child. Sickle cell pain can be anywhere in the body, but the most common sites are the arms, legs, back and stomach. **Some pain can be treated at home or during the day at school, but sometimes the pain becomes severe enough to need hospitalization.**

Common Triggers of Sickle Cell Pain:

- Exposure to extreme hot or cold temperatures
- Dehydration (extra fluids are needed to prevent dehydration which can cause pain)
- Overexertion
- Infection
- Stress
- High altitudes
- Shivering (if wet or cold)

Decreased Urine Concentration

Children with sickle cell disease urinate frequently because they are not able to concentrate their urine. Occlusion from sickle cells may cause small amounts of damage to the kidneys, therefore causing the inability to concentrate the urine. **More fluid intake is required to prevent sickling, therefore more restroom breaks are needed.**

Growth and Development

Children with sickle cell disease may be thinner and smaller than other children their age. The child's metabolism is usually increased due to the chronic anemia causing him to burn off more calories and put on less weight. **Children will usually "catch up" later in teen or early adult years**.

Jaundice/Yellow Eyes

Children with sickle cell disease sometimes have yellowing of the eyes. Red blood cells in the body break down quickly in these children. As this occurs, bilirubin is released causing the white part of the eye to turn yellow. The yellow color may come and go, but some children may always have yellow eyes. **This is not a contagious condition or one that requires medical intervention.**

What Should You Do?

What Should You Do for Your School-Age Child?

- **Discuss your child's illness with his teacher.**

- **Make a plan for if your child gets sick at school:**
  - » Give home and emergency numbers.
  - » Provide medication to school nurse with instructions.
  - » Tell the teacher/school nurse what to look for (for example, "John puts his head down when he doesn't feel well.")

- **Make a plan for when your child is sick at home or in the hospital:**
  - » Call the school when he is sick.
  - » Make arrangements to pick up homework.
  - » Return homework when done.
  - » If needed, ask the nurse, doctor, or social worker for a letter about the hospitalization.
  - » Update the school every three days.

- **Encourage your child to have a positive attitude about school.**

(continued on next page)

What Should You Do (cont'd)

- **Help your child with school work.**
- **Support your child's academic and other interests.**
- **Praise your child for hard work.**
- **Help your child know who to go to if he has a problem (i.e. teacher, nurse, counselor).**
- **Encourage open, honest communication about the disease, school performance and peer relationships.**
- **Teach your child how to deal with school bullies and teasing by:**
  - » Ignoring hurtful statements.
  - » Telling a teacher.
  - » Explaining the disease to other students (for example: why "my eyes are yellow").
  - » Learning positive coping skills.

Things to Do When Meeting with Your Child's School

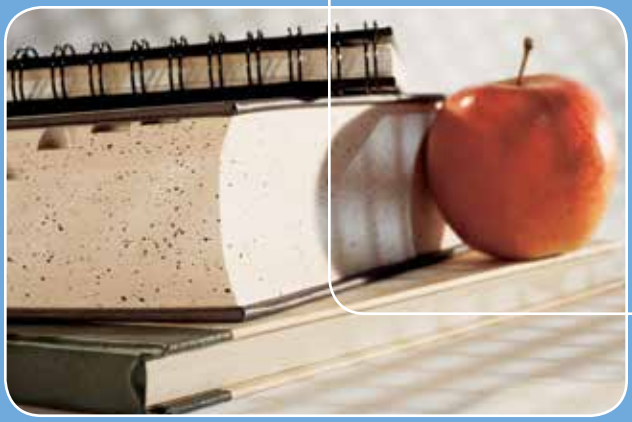
You might find the following "checklist" helpful to remind you of things to discuss with your child's teachers.

- ❒ Give the school your home, cell, work and/or emergency phone numbers.
- ❒ Inform the school of signs or symptoms of pain, fever and fatigue.
- ❒ Provide your child's medicine(s) to the school nurse.
- ❒ Provide a letter from your child's doctor or nurse stating that the child can take the medications you brought from home.
- ❒ Give the school the *Educator's Guide to Sickle Cell and School* or a letter from your child's doctor describing your child's medical needs.
- ❒ Plan a meeting with your child's school to talk to them about sickle cell disease.
- ❒ If your child has difficulty walking to the school bus stop, plan a meeting with the school nurse to arrange door-to-door transportation.

Ways You Can Help Your Child

Creating a unique educational plan can assist in your child's academic success.

Comprehensive Educational Plans



504 Plans

A 504 plan protects students with disabilities from discrimination. The plan is for students with physical and mental impairments that limit one or more of their life activities. An example would be a student with sickle cell disease who has difficulty learning because of prolonged pain/hospitalization.

How your child can obtain a 504:

- Call the school counselor, teacher or principal and request a 504 plan.
  - » Send a follow-up letter confirming your request.
- Call the school in two weeks after a verbal or written request has been made.
- Make sure the 504 plan is completed in writing.
- Make sure each teacher has a copy.

(continued on next page)

504 Plans (cont'd)

Here's a sample 504 plan:

504 ACCOMMODATION PLAN

Student:
School:
Grade:
Today's Date:

Student ID Number:
Teacher(s):

Date of Birth:

Instructions: Check the accommodations required for the student. Indicate the date(s) the accommodations will be initiated/completed to adapt to the student's area(s) of concern:

- ◯ evaluate on mastery of subject instead of the number of assignments completed
  Date Initiated_____ Date Completed_____
- ◯ provide/assign a peer note taker
  Date Initiated_____ Date Completed_____
- ◯ provide extra time to complete assignments including time after the quarter
  Date Initiated_____ Date Completed_____
- ◯ provide a second set of books for home
  Date Initiated_____ Date Completed_____
- ◯ modify tests as needed
  Date Initiated_____ Date Completed_____
- ◯ provide weekly assignments in an assignment book
  Date Initiated_____ Date Completed_____
- ◯ allow restroom breaks as needed
  Date Initiated_____ Date Completed_____
- ◯ allow a water bottle at all times
  Date Initiated_____ Date Completed_____
- ◯ allow an open pass to the school nurse for rest and/or medications
  Date Initiated_____ Date Completed_____
- ◯ provide teachers with information regarding student's health problems
  Date Initiated_____ Date Completed_____
- ◯ modify the length of the assignments
  Date Initiated_____ Date Completed_____
- ◯ provide study guides
  Date Initiated_____ Date Completed_____

TEAM MEMBERS DEVELOPING THE PLAN

Name/Position _____ Signature _____

Review Date(s) _____

IEP Plans

An IEP is an **I**ndividualized **E**ducation **P**rogram. The IEP is for students with medical and educational difficulties. Some schools may not be as familiar with the process for a child who has sickle cell disease, but children with sickle cell disease do qualify for an IEP under the category Other Health Impaired (OHI). According to the Missouri Department of Elementary and Secondary Education, Other Health Impairment means "having limited strength, vitality, or alertness…with respect to the educational environment that is due to chronic or acute health problems…and adversely affects a child's educational performance."

How your child can obtain an IEP:

- Call the school district to request your child be reviewed for an IEP plan.
  - » Send a follow-up letter confirming your request.
- Call the school in two weeks after a verbal or written request has been made.
- Make sure the IEP plan is completed in writing.
- Make sure each teacher has as copy.

Homebound Instruction

Homebound instruction is a portion of a 504 or IEP plan. Homebound instruction can be utilized when your child is frequently absent from school. Homebound instruction provides instruction in the child's home or in the hospital. The homebound instructor coordinates with your child's school to obtain the student's necessary schoolwork and to assist with instruction.

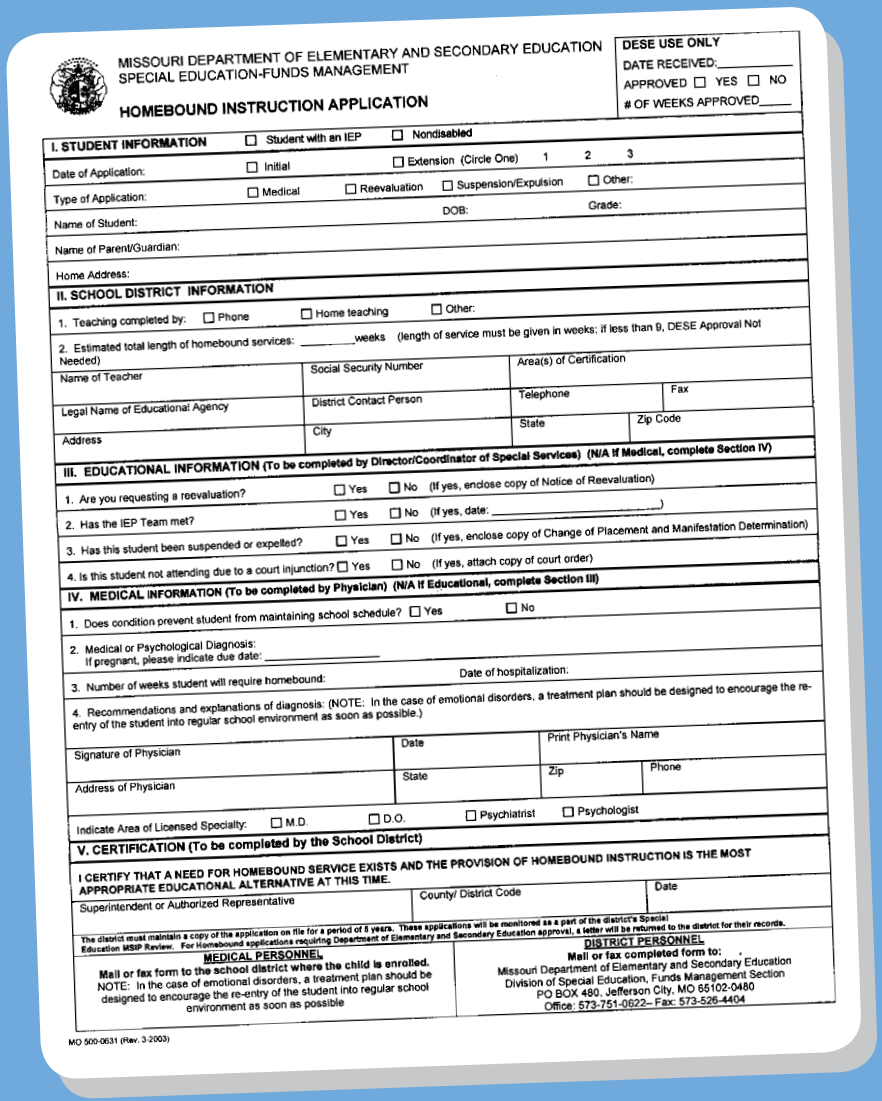
How your child can obtain Homebound Instruction:

- Discuss your request with your child's sickle cell team.
- The team will complete the Homebound request form.
- Once homebound instruction is arranged, coordinate with the instructor by notifying him your child is ill and not attending school.

(continued on next page)

Homebound Instruction (cont'd)

Here's a sample Homebound Request form:



MISSOURI DEPARTMENT OF ELEMENTARY AND SECONDARY EDUCATION
SPECIAL EDUCATION-FUNDS MANAGEMENT

HOMEBOUND INSTRUCTION APPLICATION

DESE USE ONLY
DATE RECEIVED:_____
APPROVED ☐ YES ☐ NO
OF WEEKS APPROVED_____

I. STUDENT INFORMATION ☐ Student with an IEP ☐ Nondisabled

Date of Application: ☐ Initial ☐ Extension (Circle One) 1 2 3

Type of Application: ☐ Medical ☐ Reevaluation ☐ Suspension/Expulsion ☐ Other:

Name of Student: DOB: Grade:

Name of Parent/Guardian:

Home Address:

II. SCHOOL DISTRICT INFORMATION

1. Teaching completed by: ☐ Phone ☐ Home teaching ☐ Other:

2. Estimated total length of homebound services: _____weeks (length of service must be given in weeks; if less than 9, DESE Approval Not Needed)

Name of Teacher	Social Security Number	Area(s) of Certification	
Legal Name of Educational Agency	District Contact Person	Telephone	Fax
Address	City	State	Zip Code

III. EDUCATIONAL INFORMATION (To be completed by Director/Coordinator of Special Services) (N/A if Medical, complete Section IV)

1. Are you requesting a reevaluation? ☐ Yes ☐ No (If yes, enclose copy of Notice of Reevaluation)
2. Has the IEP Team met? ☐ Yes ☐ No (If yes, date: _____)
3. Has this student been suspended or expelled? ☐ Yes ☐ No (If yes, enclose copy of Change of Placement and Manifestation Determination)
4. Is this student not attending due to a court injunction? ☐ Yes ☐ No (If yes, attach copy of court order)

IV. MEDICAL INFORMATION (To be completed by Physician) (N/A if Educational, complete Section III)

1. Does condition prevent student from maintaining school schedule? ☐ Yes ☐ No
2. Medical or Psychological Diagnosis:
   If pregnant, please indicate due date: _____
3. Number of weeks student will require homebound: Date of hospitalization:
4. Recommendations and explanations of diagnosis: (NOTE: In the case of emotional disorders, a treatment plan should be designed to encourage the re-entry of the student into regular school environment as soon as possible.)

Signature of Physician	Date	Print Physician's Name	
Address of Physician	State	Zip	Phone

Indicate Area of Licensed Specialty: ☐ M.D. ☐ D.O. ☐ Psychiatrist ☐ Psychologist

V. CERTIFICATION (To be completed by the School District)

I CERTIFY THAT A NEED FOR HOMEBOUND SERVICE EXISTS AND THE PROVISION OF HOMEBOUND INSTRUCTION IS THE MOST APPROPRIATE EDUCATIONAL ALTERNATIVE AT THIS TIME.

Superintendent or Authorized Representative	County/ District Code	Date

The district must maintain a copy of the application on file for a period of 5 years. These applications will be monitored as a part of the district's Special Education MSIP Review. For Homebound applications requiring Department of Elementary and Secondary Education approval, a letter will be returned to the district for their records.

MEDICAL PERSONNEL

Mail or fax form to the school district where the child is enrolled.
NOTE: In the case of emotional disorders, a treatment plan should be designed to encourage the re-entry of the student into regular school environment as soon as possible

DISTRICT PERSONNEL

Mail or fax completed form to:
Missouri Department of Elementary and Secondary Education
Division of Special Education, Funds Management Section
PO BOX 480, Jefferson City, MO 65102-0480
Office: 573-751-0622– Fax: 573-526-4404

MO 500-0631 (Rev. 3-2003)

Developmental Recommendations

Developmental Recommendations

We recommend that learning begin at birth. Below are some recommendations that will assist with your child's school success.

Birth to 3 years of age

It is recommended that you enroll your child in Parents as Teachers. Parents as Teachers is an early education program that provides specially trained parent educators.

To obtain a Parents As Teachers Educator, call the school district that you live in.

3 years of age to Kindergarten

It is recommended that your child participate in Head Start or an Early Education Program.

To enroll your child in Early Education or Head Start, discuss this with your child's Parents As Teachers Educator or call the school district that you live in.

(continued on next page)

Developmental Recommendations (cont'd)

Kindergarten to 6th Grade

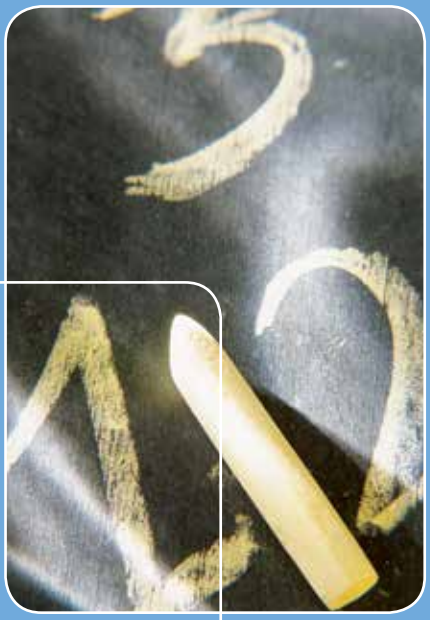
Enroll your child in school and consider participation in extracurricular activities (dance, music, after-school clubs, etc.).

7th Grade to 12th Grade

Have your teen obtain information about adolescent issues from a primary care provider or the Children's Mercy Teen Clinic. The teen should learn about the impact of drugs, alcohol and smoking.

Review with the teen his school requirements for graduation and explain the importance of maintaining a C average to earn graduation credits.

There is Help



Who Can Help You?

The Children's Mercy Sickle Cell Team is available to help you and your child with the educational system.

The Sickle Cell Nurse Can:

- Answer your questions about sickle cell disease.
- Talk to the school nurse about symptoms, medications and a plan of care.
- Provide letters about your child's disease.
- Help with school-requested forms regarding giving medications.
- Assist with the development of a 504 or IEP plan.

The Sickle Cell Social Worker Can:

- Explain the 504 or IEP process.
- Coordinate with school representatives to develop 504 or IEP plans.
- Attend school meetings as needed.
- Provide letters for missed school days when your child is hospitalized.
- Assist children with the emotional stress of school and peer relationships.

Children's Mercy Kansas City
Hematology/Oncology/Bone Marrow Transplantation
2401 Gillham Road
Kansas City, Mo. 64108
(816) 234-3000
www.childrensmercy.org

This publication is supported by funds from
the Missouri Department of Health and Senior Services

04/15