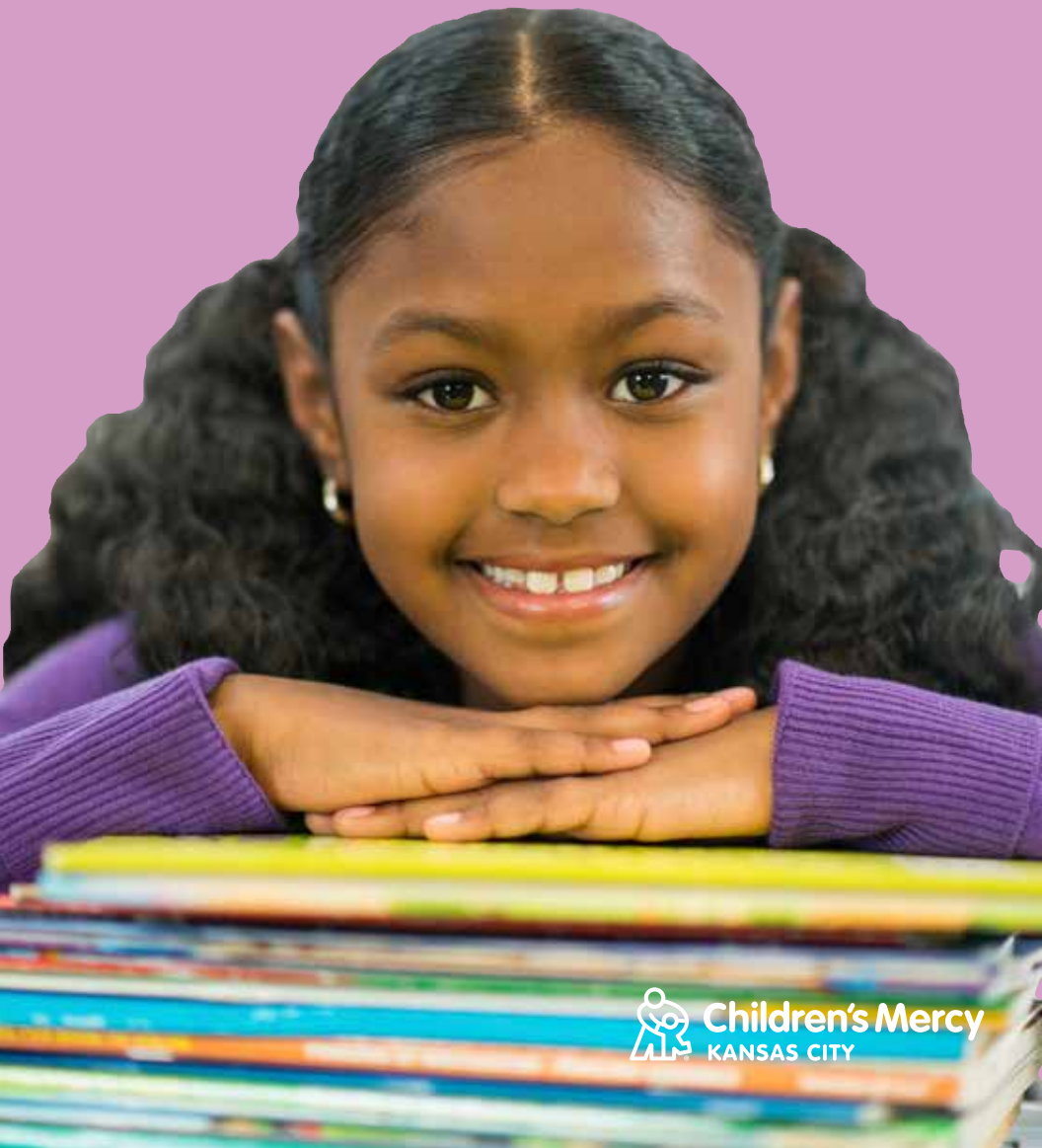




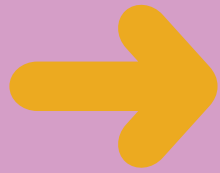
# Educator's Guide to Sickle Cell and School



**Children's Mercy**  
KANSAS CITY



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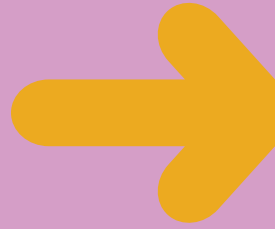
# Introduction

It is our hope that this book will provide insight and/or information to schools that educate students with sickle cell disease. An important goal of the sickle cell team is to work closely with the student, family, and school to achieve school success. If there are any concerns regarding the student, medically or academically, please contact the student's parent/guardian first. We are more than happy to assist once the parent has been notified.



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# 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  $\beta^0$  Thalassemia)
- Sickle Beta Plus Thalassemia  
(Sickle  $\beta^+$  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.**





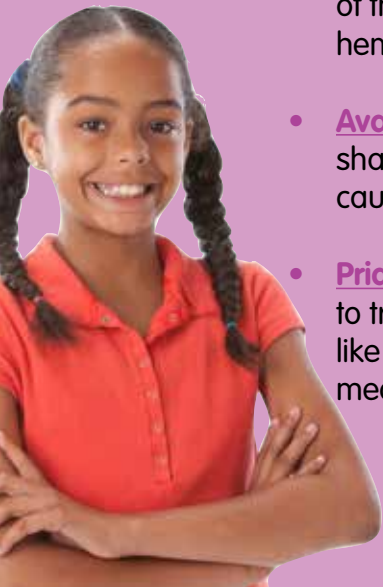
# Common Characteristics of Sickle Cell Disease

- **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 important)
- 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.**

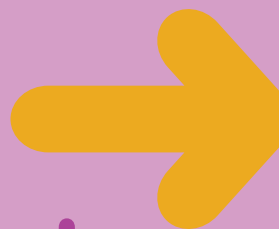
# Growth and Development

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 them 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.**

# Tips for the Educator



# Here's How You Can Help

## **Tip #1: Collaborate with the student's parent/guardian.**

- Always include the family in educational planning.
- Call the family with any questions or concerns.
- Help the family advocate for the student's educational success.

## **Tip #2: Discuss with the parent/guardian and student their wishes for disease disclosure.**

- Do not assume the student wants other students to know about the disease.
- Always obtain parent/guardian/student permission to share information with the student's classmates.

## **Tip #3: Assist with missed classroom instruction.**

- Follow established educational plans.
- Allow additional time to complete missed assignments and exams.
- Coordinate with the family on how they can help the student to catch up.
- Consider asking the school to establish a 504 or IEP plan.

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# Here's How You Can Help (cont'd)

## Tip #4: Hydration

- Encourage frequent trips to the water fountain.
- Allow a water bottle at the student's desk.

## Tip #5: Bathroom privileges

- Provide an open pass to the restroom.
- Remember that students with sickle cell disease cannot concentrate their urine, therefore they need frequent bathroom breaks.



## Tip #6: Activities

- Allow the student to participate in all activities, as she is able.
- Allow rest during activities as needed.
- Modify activities to include, instead of exclude the student from her peers.
- Swimming may cause painful episodes due to cold water. Provide an alternate activity for the student as needed.
- Allow extra fluid intake during times of increased physical activity.

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# Here's How You Can Help (cont'd)

## Tip #7: Nutrition

- Offer a well-balanced diet (there should be no food restrictions related to sickle cell disease unless instructed by the parent).
- Encourage extra fluid intake, preferably avoiding caffeinated drinks, to prevent dehydration.

## Tip #8: Transportation

- Assist the parent in establishing bus transportation to and from school if needed.
- It is important for the student not to walk long distances in the cold or heat.

## Tip #9: Fostering Self-Esteem

- Encourage the student's strengths and assets.
- Provide positive reinforcements as much as possible.
- Encourage creativity and imagination instead of emphasizing limitations.
- Treat the student as normal as possible.



# Managing a Student Through Pain

- Encourage fluids.
- Allow rest.
- Escort the student to the school nurse.
- Dispense pain medications as instructed by the parent.
- Apply heating pad or warm pack to painful area.
- Notify the parent of the student's condition.
- Provide emotional support.
- Utilize relaxation or distraction techniques.

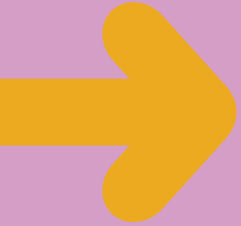
# Managing a Student Through a Fever

- Notify the parent immediately.
- Monitor temperature.
- Give Tylenol as directed by the parent.
- Encourage extra fluids.

## **Notify the student's parent immediately for:**

- Fever of 101.5 degrees Fahrenheit or greater
- Moderate to severe pain
- Paleness
- Excessive fatigue
- Slurred speech
- Inability to use an arm or leg
- Vision changes
- Shortness of breath

# What Can You Do to Help?



# What You Can Do as the Teacher



- Help the family maintain a comprehensive assignment notebook with clear instructions.
- Identify when a 504, IEP (other health impaired), and/or homebound instruction is needed.
- Communicate frequently with the family.
- Clearly explain the parent's responsibility to pick up and turn in homework while the student is out.
- Be familiar with sickle cell disease and its characteristics.
- Allow the student to have water breaks and/or a water bottle at his/her desk.
- Provide additional passes to the restroom and school nurse as needed.

**Communicate frequently with the family.**

# What You Can Do as the Principal

- Encourage staff involvement in learning about sickle cell disease.
- Collaborate with parents and teachers in the development of a 504 or IEP.
- Designate a staff person to monitor the student's 504 or IEP.
- Communicate with the parent about your school's willingness to assist in the student's physical health and intellectual development.

(Sample 504 plan)

**504 ACCOMMODATION PLAN**

**Student:** \_\_\_\_\_ **Student ID Number:** \_\_\_\_\_ **Date of Birth:** \_\_\_\_\_  
**School:** \_\_\_\_\_ **Teacher(s):** \_\_\_\_\_  
**Grade:** \_\_\_\_\_  
**Today's Date:** \_\_\_\_\_

**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) \_\_\_\_\_

# What You Can Do as the Guidance Counselor

- Facilitate staff development by hosting an educational session on sickle cell disease.
- Evaluate students with sickle cell disease to determine the need for a 504 or an IEP. Often the parent(s) may not be aware the student qualifies for special education or 504 accommodations. If a teacher shows concern about a student, assess the student's absences and days spent in the nurse's office.



- If an IEP or 504 evaluation process is requested by the school or the parent(s), coordinate with school representatives to see that this process is timely.
- Designate a staff person to monitor the student's 504 or IEP.
- Provide emotional support to the student with sickle cell. Welcome the student back when there has been a prolonged illness at home or in the hospital.
- Provide educational resources, such as information about summer school, after-school sessions and tutoring to assist and enhance the student's learning.

# What You Can Do as the School Nurse

- Become educated about sickle cell disease including its characteristics and treatments.
- For every student with sickle cell disease, maintain a plan that includes information on warning signs, complications, “as needed” medications, routine medications and things to do in an urgent situation.
- Communicate with the parent for any questions or concerns.
- Ask the student what she usually does at home for treatments or things that work best for her.
- Have all necessary paperwork in place to administer medications as needed.
- Monitor response to pain management interventions.

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# School Nurse (cont'd)

- Coordinate educational sessions for other school staff members.
- Notify the parent of any painful episodes, fevers of 101.5 degrees Fahrenheit or greater, increased lethargy, increased paleness or any other concerns.
- Provide necessary treatments for painful episodes:
  - Rest
  - Increased fluids
  - Heating pad
  - Pain medications  
(as instructed by the parent)
  - Notify parent for further directions





# What You Can Do as the Physical Education Instructor/Coach

- Be familiar with sickle cell disease and its characteristics.
- Encourage participation in all activities as tolerated.
- Communicate with the parent about the student's ability to fully participate in activities and note any restrictions.
- Allow the student to rest as needed. Children with sickle cell disease may tire more easily than others. Prolonged strenuous activity may lead to a painful episode.
- Provide an alternate activity that includes other students when the scheduled activity is too strenuous for the student with sickle cell disease.

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# Physical Education Instructor/ Coach (cont'd)

- Be supportive if the student is unable to complete the scheduled activity.
- Allow frequent use of the water fountain as children with sickle cell disease can become dehydrated quickly.
- Avoid exposure to extreme temperatures (hot, cold, damp).



# Closing

Many students enjoy academics and go on to graduate, attend college, and pursue a career or vocation. Your role as a teacher, mentor, or friend will assist the student in becoming a successful adult. With your support, the information in this booklet will help a student with sickle cell disease succeed.



# Can You Pass the Test?

## FUN QUIZ

- Sickle cell is a disease that affects the red blood cells.**  
 True     False
- What are ways you can assist with the student's educational success:**
  - Allow bathroom privileges
  - Communicate with the student's parent/guardian
  - Create a notebook with classroom assignments
  - All of the above
- Circle the common characteristic(s) of sickle cell disease:**
  - Mild to moderate pain
  - Contagious disease
  - Anemia
  - Impairs cognitive ability
  - Infection
- Students with sickle cell disease can graduate and lead normal lives.**  
 True     False



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