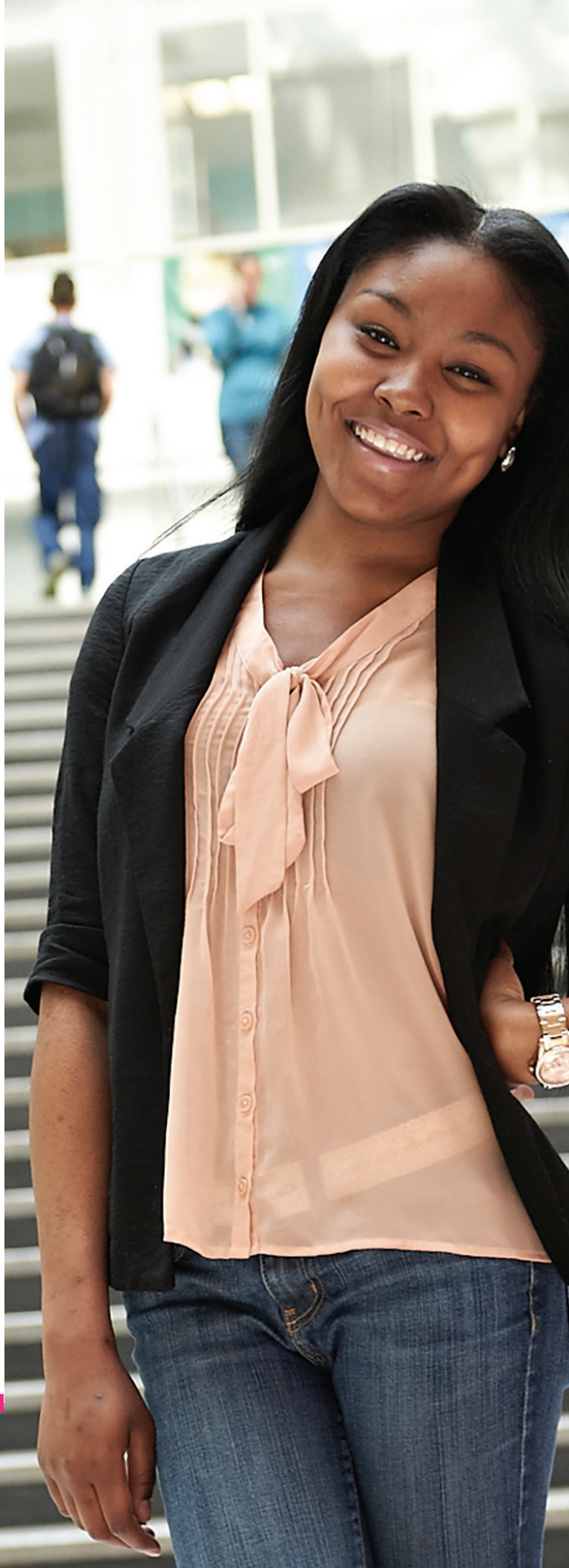
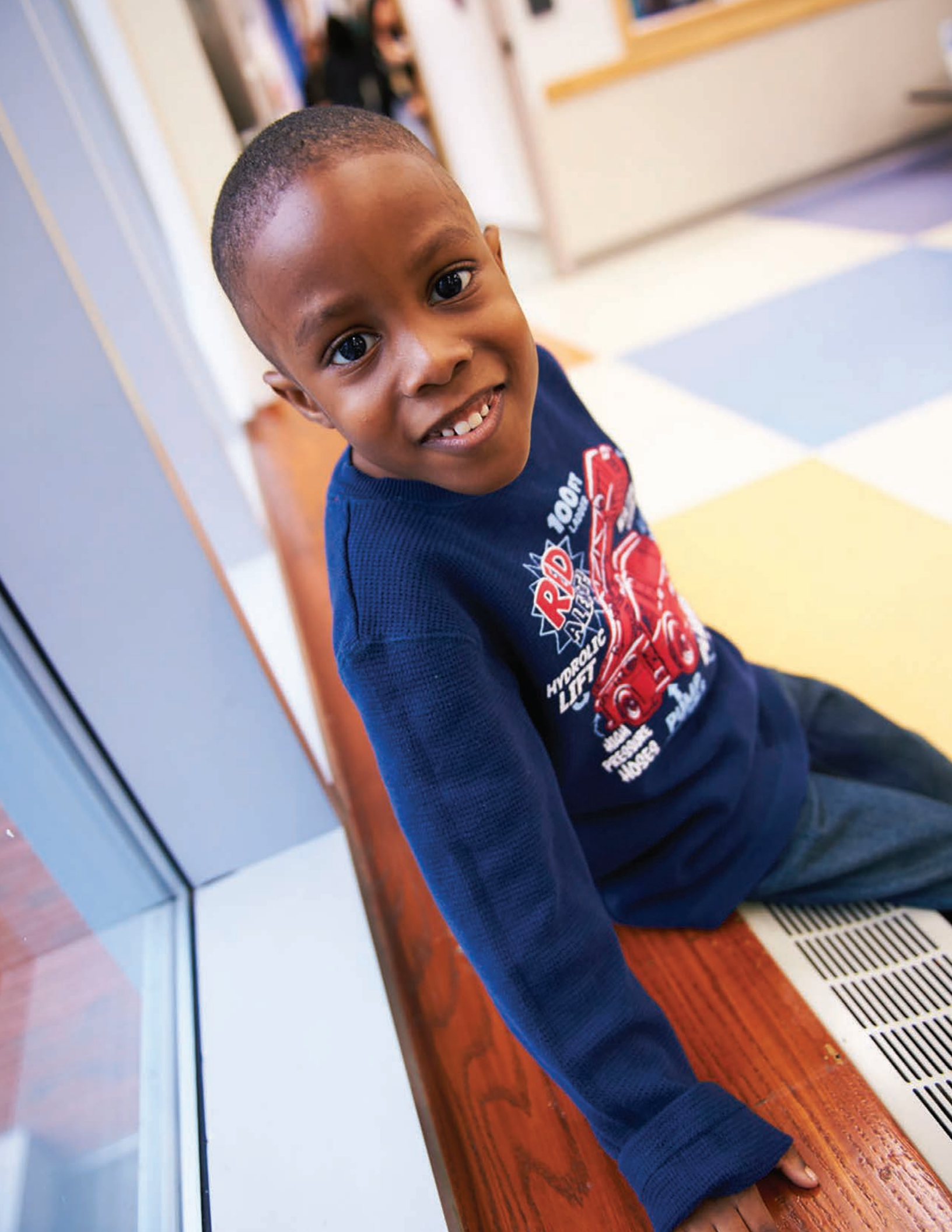
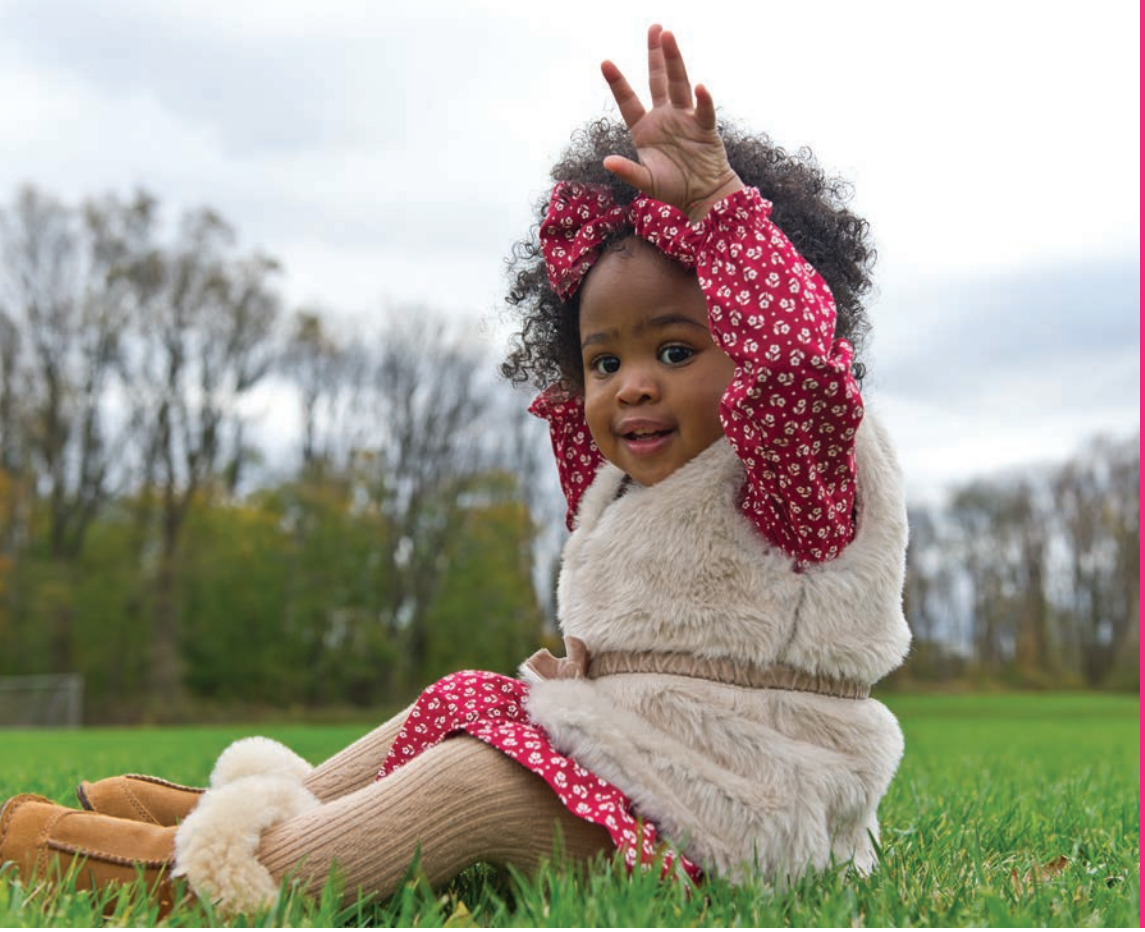
SUPPORTING THE STUDENT WITH SICKLE CELL DISEASE

A Comprehensive Handbook for Your School Community



Children's Hospital of Philadelphia®
Breakthroughs. Every day.®


100ft
HYDROLIC
LIFT



AUTHORS

Trudy Tchume-Johnson, MSW, LSW, Hematology Social Work Manager, CHOP Comprehensive Sickle Cell Center

Kaitlin Murtagh, M.Ed., Outpatient Education Coordinator, CHOP Comprehensive Sickle Cell Center, New Jersey Section of Hematology/Oncology Voorhees Specialty Care Network Center

Renee Cecil, RN, MSN, Clinical Nurse Coordinator, CHOP Comprehensive Sickle Cell Center

Jennifer Brereton, PsyD, Psychologist, CHOP Comprehensive Sickle Cell Center

Tahirah Austin, MPH, Outpatient Community Health Worker, CHOP Comprehensive Sickle Cell Center

Colleen Cerebe, BA, Inpatient Education Coordinator, CHOP Hospital School Program

Elisa Olson, M.Ed, Education Coordinator, CHOP Pediatric Stroke Program

TABLE OF CONTENTS

THE PURPOSE OF THIS HANDBOOK

To support teachers of students with sickle cell disease

This handbook was developed to support access to readily available sickle cell disease related information in most academic and extracurricular settings. We understand that many school staff members, including teachers, wear many hats. The role that teachers and other supporting staff play in the care of students with sickle cell disease is incredibly important.

To assist caregivers and providers in supporting teachers

This handbook is one method that can be very useful to caregivers and providers when conveying this information to teachers and other supportive school staff. The intent was not for teachers to sit and read the document in one session but for them to feel supported with easily accessible resources to promote ongoing communication with students, their families and healthcare providers.

NOTE TO EDUCATORS

If you have a student with sickle cell disease

You may have recently been told that a student in your class has sickle cell disease, and it may seem like there is a great deal to learn. It is important to us that you have a reliable, user-friendly resource that contains the latest information on sickle cell disease and how this chronic illness might impact your student's academic functioning. Our goal is to support the development of an academic action plan that can be tailored to the individual student's needs and that supports proactive planning for an optimal school year experience.

This resource is designed for you

We know that schools are communities where each person should feel cared for and supported. This material has been organized to serve as a reference that can be accessed and implemented during each stage of the student's academic career.

Please share the information

We hope that you will share this handbook with your colleagues so that they can also learn about sickle cell disease. We encourage you to take an active role within your school community and have conversations that will promote ongoing and open communication between school personnel, the student and family, and their healthcare team.

ACKNOWLEDGEMENTS

We are especially grateful to our caregivers, students, and school communities who shared their experiences. Their insight was the catalyst for developing a handbook that supports the balance of their specific education and healthcare needs.

We would like to thank our CHOP Comprehensive Sickle Cell Center reviewer, Kim Smith-Whitley, MD, Director, Janet Ohene-Frempong, MS, of J.O. Frempong & Associates Inc., and Symme Trachtenberg, Director, Community Education, CHOP, for providing invaluable input, feedback and contributions to this handbook.

We appreciate Donna Wasik, MSS, LSW, Hematology social worker at CHOP Specialty Care Center in Voorhees, N.J., for her thoughtful review and feedback during the development of this handbook.

We would also like to thank the following contributors: the Pediatric Stroke Program and the Center for Rehabilitation at Children's Hospital of Philadelphia for providing specific guidelines for working with individuals in an educational setting who have experienced a stroke.

OVERVIEW

What is sickle cell disease?

Sickle cell disease (SCD) is an inherited, lifelong condition. SCD is inherited in the same way that people get the color of their eyes, skin and hair. So it is not contagious. You cannot catch it.

In SCD, red blood cells can change from being soft and round to being stiff and misshapen. This can cause many problems, especially pain.

Who is born with sickle cell disease?

SCD is estimated to occur in about 1 of every 365 African-American births and about 1 of every 36,000 Hispanic-American births in the United States.

SCD affects millions of people throughout the world and is particularly common among those whose ancestors come from sub-Saharan Africa and certain regions in the Western Hemisphere including South America, the Caribbean and Central America. SCD also affects people in Saudi Arabia, India, and Mediterranean countries such as Turkey, Greece and Italy.

Is there only one type of sickle cell disease?

No. There are several types of SCD. These are the most common types in the United States:

- sickle cell disease, type SS, also known as sickle cell anemia
- sickle cell disease, type Sß^0 thalassemia
- sickle cell disease, type SC
- sickle cell disease, type Sß$^+$ thalassemia

What is sickle cell trait?

- People who inherit one normal gene (A) and one sickle cell gene (S) have a trait condition (AS). They are said to have sickle cell trait (SCT).
- SCT is not SCD.
- People with SCT usually do not have many of the symptoms of SCD, but they can pass the trait on to their children. If they have children with another person with sickle cell trait, sickle cell disease or another hemoglobinopathy trait or disease, they can have a child with sickle cell disease. Because most people do not have symptoms from sickle cell trait, they do not know they have it unless they had blood tests for it. Although pain is not a feature of SCT, kidney problems such as blood in the urine can occur.

What are the physical complications of SCD?

Individuals with SCD can experience complications. Sickled cells can get stuck in small blood vessels and block the flow of blood and oxygen to organs in the body.

These blockages can cause any of the following problems:

- Repeated episodes of severe pain
- Stroke and other organ damage
- Higher risk of serious infections

Symptoms indicating that sickle cell complications are occurring include:

- Fever (temperatures of 101°F and higher)
- Pain including headache
- Fatigue
- Weakness and slurred speech

Sickle cell disease complications cannot be predicted. A student may be fine in the doctor's office for a routine physical in the morning and become sick later that same day. Pain episodes can last for a week or even longer if there are additional complications.

IF ACUTE MEDICAL ATTENTION IS NEEDED:

- Contact the caregiver.
- Be prepared that the next steps could also include contacting emergency medical services/911.

For additional information regarding physical complications, please refer to the School Health Services section on page 11 of this handbook.

SCHOOL PROGRAMMING GUIDELINES

Students with sickle cell disease meet the criteria for additional school programming due to the nature of this chronic illness.

- The most common programming needs are 504 Plans, Individual Education Plans (IEPs) and transportation services.
- It is important to have a meeting with the student's caregiver(s) in the beginning of each school year to proactively address potential barriers that would prevent the student from having a successful school year and to re-evaluate appropriate accommodations or modifications in the student's 504 Plan or IEP.

School Health Services Action Plan

Each student is unique, and therefore a health action plan should be created in consultation with the caregiver, as well as the student if possible. This action plan should address the health problems the student might encounter while in school. For example, if the student has frequent pain, this provides an opportunity for the caregiver to share how they would like the pain handled while at school and when it is appropriate for the student to be sent home.

This plan should include the school emergency protocol when signs or symptoms occur. This plan should be available in the classroom along with the appendix sample templates such as the "Teacher/Substitute Teacher Personalized Action Plan."

A template for a School Health Services Action Plan begins on page 26 of this booklet.

Transportation

Extreme changes in temperature, such as prolonged exposure to cold, chilly or wet conditions, can precipitate painful episodes for students with SCD. Prolonged exposure to heat can lead to dehydration, which can also precipitate painful episodes.

- If the student's residence is more than a half of a mile walking distance from school, bus transportation should be provided to reduce exposure to extreme temperatures and inclement weather.
- The student's bus stop should be no more than one block from their home.

504 Plans

Students with sickle cell disease have been identified as eligible via Section 504 of The Rehabilitation Act of 1973.

- A 504 Plan is a good tool that helps the student receive needed instruction both inside the classroom and during times of absence due to complications.
- 504 Plans can make a significant difference in the student's learning experience.

Individual Education Plans

Some students with sickle cell disease may already be classified under the Individuals with Disabilities Education Act (IDEA) as having a disability that requires special education and related services.

- For those students, the IEP will include accommodations or modifications related to the classification of disability.
- In addition to those accommodations or modifications, there may be additional suggestions made by the student's physician.

Common accommodations/modifications incorporated in 504 Plans and IEPs for students with sickle cell disease should include, but are not limited to:

Category of Accommodation or Modification	Examples
Environment and Setting	**Protection from weather** • Prolonged exposure to extreme hot or cold weather should be avoided. • If residence is more than a half of a mile walking distance from school, bus transportation is to be provided to reduce exposure to extreme temperatures and inclement weather. Bus stop should be no more than one block from home. • The school should incorporate a plan to keep the student safe from overexposure to extreme hot or cold weather during fire and disaster drills. For example, student should be able to have outerwear according to the weather. • Shared decision-making with the caregiver(s) is recommended. **Access to water** • The student should be allowed access to water (water bottle at desk). **Access to the bathroom** • This student should be allowed to go to the bathroom as needed without being penalized. **Management of complications** • The school should have a plan in place for the student in the event they experience complications in school.
Scheduling	**Excused absences** • All absences due to medical appointments, hospitalization or medically documented illness should be excused.
Instructional	**Provisions for:** • **Rest**: The student should participate in physical education class, but they should be allowed to rest when needed. They should be encouraged to stay well hydrated. • **Homework**: The student should be provided with homework to keep them up to date with what is going on in the classroom when absent due to complication(s). • **Deadline extensions**: In case of absences due to complication(s), the student should have extensions on deadlines for completion of assignments. • **Extra books**: Provide an extra set of books for the student to keep at home to minimize the need to carry books to and from school. This also means that books will always be available at home when the student is ill and needs to stay up to date with assignments. • **Homebound instruction**: A plan for intermittent or extended homebound instruction should be established. This plan should include options such as in-school tutoring to address missed school hours and hospital-based bedside instruction. An example of this is the Hospital School Program at CHOP.
Test Procedure	**Make-up testing:** • If the student is ill or absent during standardized testing, the student, when fully healthy, should be permitted to make up tests.
Communication	**Provisions for:** • **Caregiver involvement**: Caregiver(s) should be a major participant in the development and implementation of the 504 Plan and IEP. • **Regular communication**: Regular communication should be established between the school and home. • **Consistent communication**: The school should establish a designated member of its staff who will communicate with the caregiver(s) and with teachers to ensure assignments are being sent home during periods of absence due to SCD-related complications. • **Caregiver notification**: The caregiver(s) should be notified if fatigue seems to be excessive — for example, falling asleep in class.

SCHOOL HEALTH SERVICES

School nurses and administrators play a vital role in helping students remain healthy and active members of their school community. It is important to be well informed about the physical signs and symptoms that a student with SCD may exhibit and how to respond quickly in the event of a potentially life-threatening complication. We encourage you to work with the student's caregiver(s) to create an emergency plan.

Important Sickle Cell Disease Problems You Should Be Familiar With

Prompt Medical Attention Is Needed for These Signs and Symptoms

- Fever of 101°F (38.3°C) or higher
- Severe headache
- Vision changes such as sudden loss of vision
- New painless limp
- Weakness or inability to use extremities
- Facial asymmetry
- Difficulty speaking or slurred speech
- Chest pain
- Difficulty breathing
- Rapid heartbeat and/or breathing
- Nausea, vomiting and/or diarrhea

If acute medical attention is needed, contact the caregiver immediately. Be prepared that the next steps could also include contacting emergency medical services/911.

Common SCD Complications

Bacterial Infection/Fever

- **Fever is considered a medical emergency because it may be the only sign of a life-threatening bacterial infection.**
- Children with sickle cell disease are more susceptible to certain serious infections.
- A digital thermometer needs to be available in your setting and staff needs to be proficient in using it and interpreting the results.
- Fever of 101° F (38.3° Celsius) or greater in a child with sickle cell disease may indicate a life-threatening infection.
- **DO NOT GIVE FEVER-REDUCING MEDICATIONS** until the temperature has been recorded and fever is documented. If fever-reducing medication is given for low-grade fever, the student should then be referred to an emergency department. In either situation, the caregiver or you must consult the student's healthcare provider immediately.

Stroke

- **Stroke is considered a medical emergency.**
- Stroke could be indicated by severe headache or new onset of a painless limp, numbness, weakness of extremity, or vision or speech difficulty.

You must consult the student's caregiver or the student's healthcare provider immediately.

Acute splenic sequestration (enlarged spleen)

- **Acute splenic sequestration is considered a medical emergency.**
- This occurs when a large amount of blood becomes trapped in the spleen, which then becomes enlarged. The student may go into shock because of the loss of blood from the body's circulation.
- Symptoms of acute splenic sequestration include increasing paleness, lethargy, extreme drowsiness and difficulty breathing. An older child may complain of abdominal pain.

You must consult the student's caregiver or the student's healthcare provider immediately.

Painful episodes or crises

- **Painful episodes are unpredictable**. Most individuals with sickle cell disease cannot predict when an episode will occur, nor can they usually identify a precipitating factor.
- **They occur in many places in the body**. In young children, the pain occurs mainly in the hands and feet, but pain can be experienced in other parts of the body. In addition to pain in hands and feet, swelling and redness may be present.
- **They can be caused by changes in temperature**. Extreme changes in temperature, such as prolonged exposure to cold, chilly or wet conditions, can precipitate painful episodes for students with sickle cell disease. Prolonged exposure to heat can lead to dehydration, which can also precipitate painful episodes. The student should be dressed warmly before activities in cool environments and dried quickly when wet.
- **They may not always require hospitalization**. There may be times when painful episodes are severe enough for a child to stay home from school but not need to be hospitalized. Additionally, it is not uncommon for students to return to school while still experiencing pain.
- **Please be supportive of a student in pain**. Please be mindful to discuss with the student and caregiver(s) ways in which the school staff can support the student as they recover.

Pain Management at School

Mild painful episodes may be managed in school. Routine medications should be available in the school.

1. First, take the student's temperature. If temperature is greater than or equal to 100°F, medication should not be given and temperature should be reassessed in **ONE** hour.
2. If temperature is below to 100°F, give medication, per the school's medication authorization form.
3. Apply heat to the painful area and increase fluid intake.
4. Allow the student to rest in the nurse's office.
5. If condition worsens or fails to improve, please update the caregiver(s).

Increased Fatigue

- **What can cause it?** Due to the chronic anemia, children with sickle cell disease may tire more easily than their peers.
- **What to do?** If fatigue seems to be excessive, such as unusual falling asleep in class, please call the caregiver(s) so that you can discuss whether the student needs immediate medical attention.

FOSTERING EMOTIONAL WELL-BEING

Possible risk for depression and/or anxiety

Many students with SCD cope fairly well with their illness. However, children with chronic illnesses, such as SCD, are more at risk for developing some social-emotional issues such as depression and/or anxiety.

Reasons might include:

- **Vulnerability to teasing or bullying**. Some students with SCD have a shorter stature, may experience jaundice (yellowing of the eyes) and may reach puberty at a later time than their peers. In addition, children with SCD may have bed-wetting issues. These physical differences, along with the fact that children with SCD sometimes are absent from school on a fairly frequent basis due to pain episodes and medical appointments, can make students with SCD feel alienated or be a vulnerable target for teasing or bullying.
- **Vulnerability to alienation**. Regardless of physical appearance, some students with SCD may feel embarrassed or ashamed of their illness, and may not be comfortable sharing their condition with others. Sometimes embarrassment or shame can lead to changes in behaviors. In addition, the fact that some students miss a significant amount of school sometimes prevents them from establishing strong connections with their peers.
- **Vulnerability to low self-esteem**. As previously noted, students with SCD may also have cognitive impairments that negatively affect academic functioning. They may also experience academic difficulties due to the loss of instructional time due to pain, medical appointments or treatment. These academic challenges may also negatively impact students' self-esteem and/or their motivation and concentration, as well as further alienate them from their peers.

How You Can Help

Take the following issues into consideration:

1. **Normal treatment**. Treat the student with SCD as normally as possible.
2. **Group or partner projects**. Foster group and partner projects to help student improve connections with others and build social skills.
3. **Identification of strengths**. Help student to identify their strengths.
4. **Support for self-esteem and competence**. Assign student special tasks to assist with building self-esteem and competence.
5. **Support after extended absences**. After extended absences, welcome the student back. Talk to the student and family about what information, if any, they want shared with the class.
6. **Social skills and peer interactions**. Refer to school guidance counselor (if available) if there are concerns regarding social skills or peer interactions.
7. **Concerns about mood and behavior**. Communicate concerns regarding student's mood and behaviors to caregiver(s) as early as possible. Encourage caregiver(s) to seek treatment for their child. A child or adolescent psychologist or therapist can assist the student with learning effective coping skills to manage sadness and anxiety, teach pain management skills, and help the student learn appropriate ways to respond to their peers.

EARLY CHILDHOOD EDUCATION

School personnel and caregivers play an important role in a student's health and academic success. For students living with a chronic health condition like sickle cell disease, communication between caregivers and school officials is essential in supporting positive academic outcomes beginning at an early age.

Students in this age range may not have the verbal skills to describe their pain or discomfort. We encourage you to trust your instincts and to address any concerns and changes in behavior with the student's caregiver(s) immediately.

School-related issues for students with SCD

Here are a few situations in which special consideration may be necessary:

Physical appearance. In general, children with sickle cell disease do not look or act differently than other children and should be treated the same as the other children in the childcare/ preschool setting. However, some may be smaller than the other children of their age group and their eyes may become slightly yellow or jaundiced. Mild jaundice of the eyes should not be of much concern.

Activity. In general, children with sickle cell disease can tolerate normal physical activity. They may, however, tire more easily than other children, and prolonged strenuous activity may lead to a painful episode. These children should be encouraged to participate in all activities up to their own limits and be permitted to stop and rest when they feel tired.

Hydration. Because of an inability to produce concentrated urine, children with sickle cell disease urinate more often than other children and also become thirsty more often. They are more prone to dehydration.

- All children with sickle cell disease should be encouraged to drink plenty of fluids, especially after exercise and on warm days.
- You may find it necessary to change diapers more frequently.
- Toilet-trained children should be given unlimited bathroom privileges.

See appendix of this handbook for daily water consumption guide recommendations.

Weather. Extreme changes in temperature and prolonged exposure to cold, chilly or wet conditions can precipitate painful episodes for students with SCD. Prolonged exposure to heat can lead to dehydration, which can also precipitate painful episodes. The student should be dressed warmly before activities in cool environments and dried quickly when wet. Shared decision-making with the caregiver(s) is recommended.

Important Sickle Cell Problems You Should Be Aware of as an Early Childhood Educator

Please see the School Health Services section of this handbook beginning on page 11 for a list of complications and symptoms. Caregiver(s) should be contacted immediately if you notice any of the complications.

ELEMENTARY SCHOOL, MIDDLE SCHOOL AND HIGH SCHOOL

We encourage you to have open communication about the importance of self-advocacy with students, especially on the topic of their comfort level with having their health history shared with their classmates, and their preferred method of communicating their health history with other staff.

Special considerations for high school staff: High school staff will have additional factors to consider in supporting high school juniors and seniors as they begin preparing for college or vocational training. For more information, please refer to the appendix titled "High School Staff and Guidance Counselor Reference for the College- and Career-Bound Student."

Three Major Barriers to Continued Academic Success

1. Absenteeism

Absenteeism is one of the largest obstacles to school success and a leading cause of compromised academic skills.

You may see that the student ...

- misses a significate number of school days due to hospitalizations, doctor visits or at-home care

What can you do?

A. Consistently communicate
   - The school should establish a designated member of your staff who will communicate with the caregiver(s) to ensure assignments are being sent home during periods of absence related to illness.
   - Make sure the student and caregiver(s) are aware of your expectations for your class and missed assignments. Please remember they are making up several assignments from different teachers.
   - Make sure the student and caregiver(s) are aware of and understand the school's absentee policy and truancy guidelines.
   - Communicate often with caregiver(s) about academic performance, including excessive absences.
   - Encourage the implementation of homebound instruction to help with missed assignments.

B. Make a plan for completing or making up missing assignments
   - In the beginning of the year, involve the student in the development of a personalized action plan to complete assignments missed due to absences.

C. Prioritize
   - Please prioritize assignments and have students complete only what is necessary in order to master the concept being taught.
   - When returning to school from absence related to illness, be mindful that the student may still not have been able to complete all assignments missed while absent.
   - The student should have extensions on deadlines for completion of assignments.

D. Identify peer helpers
   - Recruit capable peers as study partners or note takers for the student during an absence.

E. Send work
   - If aware of hospitalization, reach out to the student's caregiver(s) and discuss next steps including, communicating with hospital school teachers or designated healthcare team member and send assignments to be completed.

2. Academic performance

Proactive planning in order to maintain continued academic success is crucial for all students. This is especially important for students with SCD whose academic performance is often compromised by difficulties associated with missed instruction during periods of absence and lack of reinforcement of subject matter that builds on previous knowledge.

You may see that the student ...

- Has inconsistent performance from one subject to another
- Has difficulty with effective time management, particularly with long-term assignments

What can you do?

A. Maintain realistic expectations
   - Realistic expectations should be maintained in relation to the student's situation.
   - Create opportunities for the student to exhibit independence and emphasize progress as a positive intervention.

B. Break down assignments
   - Breaking assignments down into smaller parts will help the student gain a sense of accomplishment and likely decrease feelings of being overwhelmed. Approaching assignments in more manageable "chunks" will likely reduce the tendency to put off projects until the last minute.

C. Create outlines
   - Help the student to develop outlines for reports/essays.
   - Help the student to plan out an approach for tasks, assignments and projects.
   - Develop a calendar with a plan for when and how each step of long-term projects and assignments will be completed. Have someone frequently review the plan, the steps required and identify materials needed.

3. Physical complications

Physical complications can present in several ways and impact the student's needs in the classroom. As teachers, you are adept at developing creative ways to provide students who may need additional accommodations with the support they need in a way that does not draw attention to their differences. Please communicate with the student and their caregiver(s) about what is necessary to best support the needs of the student with SCD in the school setting.

You may see that the student ...

- Experiences painful episodes.
- Needs to drink large amounts of fluid.
- Needs to use the restroom more frequently than their peers.
- May become fatigued more easily than their peers.
- Is more sensitive to extreme changes in temperature.

What can you do?

A. Respond to complications quickly
   - If acute medical attention is needed, refer to the action plan and contact the caregiver immediately. Be prepared that the next steps could also include contacting emergency medical services/911.

B. Encourage the student to increase fluid intake.
   - Allow frequent trips to the water fountain or allow student to have a water bottle.
   - Allow the student to go to the bathroom as needed without being penalized.

C. Be flexible
   - Allow the student to participate up to their level of tolerance that has been discussed with the family prior to the beginning of the school year.
   - The student should not be required to participate in strenuous exercises.
   - Include the student's guidance counselor if the student needs additional supports.

For additional information regarding physical complications, please refer to the School Health Services section of this handbook beginning on page 11.

SUPPORTING A STUDENT WHO HAS HAD A STROKE

Students with SCD who have a history of stroke have an increased need for additional academic support. There are seven common school-related issues for students with SCD who have a history of stroke:

1. Decreased attention
2. Learning and memory difficulties
3. Fine motor difficulties
4. Executive functioning difficulties
5. Reduced mental processing speed
6. Sensory impairments
7. Specific learning challenges

Here are strategies to address them:

1. Decreased attention

You may see that the student ...

- Makes careless errors
- Has difficulty remaining in seat
- Seems to forget things
- Loses assignments
- Has difficulty listening to instructions
- Is distractible
- Cannot complete tasks without taking breaks
- Performs inconsistently on tests and quizzes
- Has difficulty following multi-step commands
- Needs help from an adult to stay on task

What can you do?

A. Arrange for priority seating
   - Seat the student in the center-front of the classroom, if teacher stays in front of the class.
   - For teachers who tend to move around the classroom, efforts should be made to establish eye contact to keep student on task.
   - Seat the student away from a window.
   - Also, seat the student next to peers who have adequate attention skills

B. Gain the child's attention
   - Have the student's attention before giving instructions
   - Use verbal and nonverbal cues to direct attention to tasks
   - Say the student's name
   - Touch student on their shoulder
   - Point to the activity or task
   - Use a phrase (e.g., "Listen") or turn off the lights when the student is expected to attend to instructions

C. Schedule breaks. Provide frequent, regularly scheduled breaks that are routine.

D. Give directions. Directions should be given in one- or two-step commands — the shorter, the better. Check to make sure the student has heard and understood the instructions by having the child repeat them back to you.

E. Help the child to focus. Help the student maintain attention in conversation and remain on topic by requesting structured verbal output. "Tell me three things about the Incas." "What are the two main points of the story?"

F. Avoid unneeded material. Keep worksheets free from extraneous material. Students with attention problems can become easily overwhelmed with too many problems on a single page. For math computations, have the child circle the final answer.

G. Break information into smaller parts. Break multiple-step directions into short, manageable bits. Give the student one direction at a time and wait for completion before proceeding to the next step.

H. Break assignments into smaller parts. Break down large assignments into small and manageable segments. Students with attention problems can become easily overwhelmed by large tasks. Provide an incentive for completing each segment.

I. Draw attention to what is most important. Find ways to emphasize the important aspects of assignments or changes in directions (e.g., underline or bold text, highlight with different colors). On math computation sheets, have the student circle the operation sign before beginning the problem.

J. Remove visually distracting material. Block out material by covering or removing from the visual field the material that you don't want students to focus on. Remove distracting clutter from the board or screen.

K. Possibly use a timer. Consider using a timer for students who work well with a "beat the clock" system for work completion.

2. Learning and memory difficulties

You may see that the student ...

- Forgets things
- Gets lost easily
- Can't follow more than one- or two-step directions
- Has trouble telling details from a story
- Has difficulty grasping new concepts
- Has inconsistent school performance

What can you do?

A. Teach strategies to assist memory skills.
   - Chunking information: Reduce the information to be learned into smaller segments. For example, learning a Social Security number can be "chunked" into three segments and then rehearsed.
   - Associative learning: Teach mnemonic strategies to recall information based on association. For example, using the phrase "Roy G. Biv" (red, orange, yellow, green, blue, indigo and violet) to recall colors of the rainbow.
   - Rehearsal: Improve recall by rehearsing new information by reciting it out loud or paraphrasing. Writing the material to be remembered may also be helpful.

B. Emphasize essential details. Reduce the amount of information presented.

C. Present in small blocks. For rote learned facts (spelling words, math facts, vocabulary), items should be presented in small blocks (4-6 units), with rehearsal of the block to mastery prior to the introduction of another block.

D. Use recognition cues. Rather than relying on the student's rote memory, use recognition clues such as providing true/false or multiple choice options rather than fill-in-the-blank or essay tests.

E. Use repetition. REPEAT, REPEAT, REPEAT! This is essential.

F. Use external aids.
   - Multicomponent organizational devices: These include devices such as PDAs, memory notebooks or computers, which would allow the student a space to organize, store and retrieve a relatively significant amount of information. A student should receive training on how to use these devices and be encouraged to use them on a regular basis.
   - Simple prospective memory devices: These include simpler tools, such as a calendar or alarm watches, that remind a child to perform a particular activity at a specific time.

G. Enhance meaningfulness. Find ways to relate the content being discussed to the student's prior knowledge.
   - Parallels: Draw parallels to student's own life.
   - Examples: Bring in concrete, meaningful examples for students to explore to provide an experiential experience.
   - Alerts to caregiver(s): Inform caregiver(s) about upcoming topics so that they can talk about topics and provide related background activities at home or make a trip to the library.

H. Provide a focus point. Before presenting new material, provide the student with a topic for them to focus their attention on (for example, the main characters of a story or the story's setting).

I. Check for attention. Make sure that the student is attending to the source of information (for example, eye contact is being made, hands are free of materials, and the student is looking at the assignment).

J. Use visualization strategies, experiential learning and multisensory presentation. For example, if the student is learning about George Washington crossing the Delaware, the student could hear a story about it, draw a picture about it, and imagine what it would feel like to be George Washington. When later asked to retrieve that information, the student has multiple pathways (e.g., verbal, visual, sensory) by which this information could be retrieved.

K. Provide a schedule. List daily activities, locations and materials needed for each class. Use pictorial cues to enhance memory.

L. Communicate with caregiver(s). Daily or weekly communication between teacher and caregiver(s) is important to ensure that necessary information (which the student may have forgotten) is conveyed. Journals or weekly progress notes are examples of written communication techniques.

3. Fine motor difficulties

You may see that the student ...

- Does not anchor a piece of paper while writing on it
- Takes a long time to produce written work
- Has difficulty copying or writing information that is seen
- Misspells many handwritten words
- Has sloppy handwriting or drawings

What can you do?

A. Check for appropriate seating. Make sure the student's seating is supportive with the desk or table at elbow height.

B. Promote hand-strengthening exercises. Provide opportunities for hand strengthening prior to handwriting tasks.

C. Compensate for poor fine motor control.
   - Allow larger-scale writing.
   - Provide the student with paper that has boxes on it (i.e., graph paper) that would allow them to write one letter per box.
   - Allow wide-ruled paper.
   - Allow the student to write on every other line.
   - Allow students to print rather than write in cursive.
   - Allow the use of a clipboard or tape paper to the desk if a student has difficulty anchoring paper.

D. Establish realistic expectations of neatness. Realistic and mutually agreed upon expectations for neatness should be established and care should be taken to avoid pressuring the student to consistently meet standards at the limit of capacity of motor control.

E. Take breaks from handwritten paper-and-pencil tasks.

F. Use verbal rather than written responses. When possible, allow the student to respond verbally when writing is not the focus of instruction.

G. Provide copies of class notes. Assignments or other information written on the board should be provided to the student in written form, rather than having them copy it down.

H. Assign a note-taking buddy. A buddy checks their notes against that of another student to ensure there is a full record of information presented in class. This can help make sure a student is not penalized for the inability to rapidly record information.

I. Allow for audio recording. Recording class lectures or dictating class assignments can be very helpful to the student.

J. Allow the student to type information on a computer instead of writing by hand.

K. Give alternatives to handwritten assignments. Along with typing and dictation, theatrical presentations, video presentations or oral reports can be used.

L. Shorten assignments. Assign truncated assignments for writing (i.e., having the student copy down only half or the spelling words, then having the others provided for the student to study).

4. Executive functioning difficulties

You may see that the student ...

- Has difficulty completing long-term projects
- Has good ideas but cannot get them on paper
- Underestimates time needed to finish tasks
- Starts assignments at the last minute
- Turns in written work that is poorly organized
- Has difficulty thinking of alternative ways to complete a task
- Has difficulty getting started with directions or assignments
- Has difficulty getting started on a task despite being able to tell you the instructions
- Routine tasks are not finished without assistance or reminders

What can you do?

A. Assist with planning. Help the student to plan out an approach for tasks, assignments and projects.
    - Outline: Develop a calendar with a plan for when and how each step will be completed. Help the student to develop outlines for reports and essays.
    - Review: Have someone frequently review the plan, assess the steps required and identify materials needed.

B. Provide incentives. Incentives for timely completion of work may help the student transition from one task to another.

C. Chunk information. Breaking assignments down into smaller parts will help the student gain a sense of accomplishment and likely decrease feelings of being overwhelmed. Approaching assignments in more manageable "chunks" will likely reduce the tendency to put off projects until the last minute.

5. Reduced mental processing speed

You may see that the student ...

- Asks for directions to be repeated
- Spends more time on tasks or homework than other students
- Fatigues easily
- Performs poorly on timed tests
- Appears confused when instructions are given
- Appears inattentive
- Does not complete work

What can you do?

A. Emphasize essential details. Keep instructions short and simple. Instructions should be simplified by breaking them down into steps requiring one or two actions at a time.

B. Be specific. Specify a time commitment for homework (for example, one hour per night) or indicate a reduction in the number of problems per assignment that the student is required to complete (for example, half of the math problems).

C. Add in extra time. Allow extra time for test-taking and assignments. Some students may benefit from taking tests in a quiet resource room rather than among peers.

D. Give breaks. Allow frequent breaks. Mix up higher-interest with lower-interest tasks, less active with more active tasks, and individual with group activities.

E. Create focus. Ensure that you have the student's attention (e.g., eye contact) before giving instructions.

F. Break down assignments. Classroom assignments should be broken into a sequence of subtasks involving shorter work periods. The number of concepts introduced during a class period or lesson may need to be reduced.

G. Supplement oral directions. Provide the student with annotated outline of lectures. Students with processing deficits often have difficulty with auditory information, such as a teacher's lecture, while trying to keep up with note taking. Written instructions are also helpful so that the student has something tangible to refer to if they become confused.

Please remember: It is very important not to penalize a student who has slowed processing speed for not completing assignments as quickly as their peers. If a student requires extra time, allow them extra time during study halls or shorten the requirements rather than have them miss out on a fun activity, such as recess.

6. Sensory impairments (vision or hearing difficulties)

You may see that the student ...

- Complains of headaches
- Complains of double vision
- Appears to be squinting while reading from the board
- Holds reading materials close to his face or puts face close to desktop while writing
- Forms letters poorly or overlapping with each other
- Reads quickly to self but has difficulty answering comprehension questions
- Looks confused when given oral instructions
- Appears to "zone out" during lectures
- Asks for repetition of instructions
- Speaks loudly
- Ends up with notes taken during lectures that are "spotty" and missing essential details

What can you do?

A. First, review concerns with the student's family and/or school nurse to determine if a sensory deficit has already been identified. If these are new concerns, the student may need to have an evaluation.

B. For vision impairments: Use visualization strategies, experiential learning, and multisensory presentation.
   - Place a ruler under sentences being read for better tracking.
   - Adapt worksheets by using LARGER type (or enlarge on a photocopier) and good contrast between print and background.
   - Provide worksheets with fewer items per page.
   - Allow student to use all capital letters when spelling to reduce confusion among similar appearing lower-case letters (e.g., "d," "b" and "p").
   - Encourage the student to wear their eye patch if it is a part of their treatment plan to address double vision or blurriness.
   - Position the student in the room according to his visual field cut (left side if student has right visual field cut).
   - Place a magnifier over computer monitors.

C. For hearing impairments: Use visualization strategies, experiential learning, and multisensory presentation.
   - Seat student in front of the classroom.
   - Use an FM system (microphone attached to the teacher).
   - Voice record class.
   - Provide student with a copy (either of teacher's or classmate's) of class notes to check for missed information.
   - Encourage student to ask for clarification.
   - Check understanding of task instruction by asking the student to repeat them back before beginning a task.

7. Specific learning challenges

You may see that the student ...

- Has assessments that reveal weaknesses in specific academic areas
- Shows poor performance on quizzes and homework
- Seems unable to keep up with peers during class

What can you do?

A. First, review concerns with caregiver(s) and/or school nurse to determine if a sensory deficit has already been identified. If these are new concerns, the student may need to have an evaluation.

B. In math:
   - Allow the student to use a calculator without penalty.
   - Group similar problems together (e.g., all addition problems in one section).
   - Provide fewer problems on a worksheet (e.g., 4 to 6 problems on a page, rather than 20 to 30).
   - Require fewer problems to attain passing grades.
   - Use graph paper to write problems to help the student keep numbers in columns.
   - Tape a number line to the student's desk.
   - Provide a table of math facts for reference.
   - Use pictures and graphics.
   - Teach the student to break down lengthy word problems into smaller parts.
   - Use visual aids such as an abacus, blocks, number lines, graphs, and fraction wheels.

C. In reading:
   - Highlight key words with a colored marker.
   - Use a lone marker (a strip of paper or ruler) to keep place while reading.
   - Ask the student to summarize what they have read in short intervals.
   - Use a lower-level test as alternative reading material in subject areas.
   - For classes not specifically teaching reading (e.g., science or social studies), allow books on audiotape to accompany written textbooks. Such audiotapes can be obtained free of charge through services such as Reading for the Blind and Dyslexic (rfbd.org). The student can utilize the tape during the class by using headphones.
   - Encourage the student to read aloud or subvocalize, rather than silently, to help increase comprehension.
   - Provide the student with a set of textbooks to be kept at home to make notes in and highlight.
   - To aid comprehension and retention, provide outlines and periodic review questions during lengthy reading assignments.

On the following pages, you will find templates for action plans that can be copied and filled out by school health services, teachers, early childhood education providers, athletic departments, guidance counselors and summer camps.

SCHOOL HEALTH SERVICES ACTION PLAN
FOR THE STUDENT WITH SICKLE CELL DISEASE

Student's Last Name: _____ Student's First Name: _____

Date of Birth: _____

Grade: _____ School Year: _____

Classroom Teacher: _____

Caregiver(s) Contact Information

Last Name: _____ First Name: _____

Address: _____

Home Phone: _____ Work Phone: _____ Cell Phone: _____

Email: _____

Last Name: _____ First Name: _____

Address: _____

Home Phone: _____ Work Phone: _____ Cell Phone: _____

Email: _____

Additional Authorized Emergency Contact:

Last Name: _____ First Name: _____

Address: _____

Home Phone: _____ Work Phone: _____ Cell Phone: _____

Email: _____

CLINICAL INFORMATION

Hematology Provider:

Last Name: _____ First Name: _____

Street Address: _____ City: _____

State/Province: _____ Mailing/ZIP Code: _____

Telephone Number: _____

Hospital of Choice: _____

Primary Care Physician:

Last Name: _____ First Name: _____

Street Address: _____ City: _____

State/Province: _____ Mailing/ZIP Code: _____

Telephone Number: _____

MEDICATIONS

Drug(s) and Dosage Time:

_____

_____

Major Complications This Student Has Experienced:

_____

_____

Most Recent Hospitalization:

_____

What to Do if Symptoms Occur

Prompt Medical Attention Is Needed for These Signs and Symptoms

- Fever of 101°F (38.3°C) or higher
- Severe headache
- Vision changes such as sudden loss of vision
- New painless limp
- Weakness or inability to use extremities
- Facial asymmetry
- Difficulty speaking or slurred speech
- Chest pain
- Difficulty breathing
- Rapid heartbeat and/or breathing
- Nausea, vomiting and/or diarrhea

If acute medical attention is needed, contact the caregiver immediately. Be prepared that the next steps could also include contacting emergency medical services/911.

Common SCD Complications

Bacterial Infection/Fever

- **Fever is considered a medical emergency because it may be the only sign of a life-threatening bacterial infection.**
- Children with sickle cell disease are more susceptible to certain serious infections.
- A digital thermometer needs to be available in your setting and staff needs to be proficient in using it and interpreting the results.
- Fever of 101° F (38.3° Celsius) or greater in a child with sickle cell disease may indicate a life-threatening infection.
- **DO NOT GIVE FEVER-REDUCING MEDICATIONS** until the temperature has been recorded and fever is documented. If fever-reducing medication is given for low-grade fever, the student should then be referred to an emergency department. In either situation, the caregiver or you must consult the student's healthcare provider immediately.

Stroke

- **Stroke is considered a medical emergency.**
- Stroke could be indicated by severe headache or new onset of a painless limp, numbness, weakness of extremity, or vision or speech difficulty.

You must consult the student's caregiver or the student's healthcare provider immediately.

Acute splenic sequestration (enlarged spleen)

- **Acute splenic sequestration is considered a medical emergency.**
- This occurs when a large amount of blood becomes trapped in the spleen, which then becomes enlarged. The student may go into shock because of the loss of blood from the body's circulation.
- Symptoms of acute splenic sequestration include increasing paleness, lethargy, extreme drowsiness and difficulty breathing. An older child may complain of abdominal pain.

You must consult the student's caregiver or the student's healthcare provider immediately.

Painful episodes or crises

- **Painful episodes are unpredictable**. Most individuals with sickle cell disease cannot predict when an episode will occur, nor can they usually identify a precipitating factor.
- **They occur in many places in the body**. In young children, the pain occurs mainly in the hands and feet, but pain can be experienced in other parts of the body. In addition to pain in hands and feet, swelling and redness may be present.
- **They can be caused by changes in temperature**. Extreme changes in temperature, such as prolonged exposure to cold, chilly or wet conditions, can precipitate painful episodes for students with sickle cell disease. Prolonged exposure to heat can lead to dehydration, which can also precipitate painful episodes. The student should be dressed warmly before activities in cool environments and dried quickly when wet. Shared decision-making with the caregiver(s) is recommended.
- **They may not always require hospitalization**. There may be times when painful episodes are severe enough for a child to stay home from school but not need to be hospitalized. Additionally, it is not uncommon for students to return to school while still experiencing pain.
- **Please be supportive of a student in pain**. Please be mindful to discuss with the student and caregiver(s) ways in which the school staff can support the student as they recover.

Pain Management at School

Mild painful episodes may be managed in school. Routine medications should be available in the school.

1. First, take the student's temperature. If temperature is greater than or equal to 100°F, medication should not be given and temperature should be reassessed in **ONE** hour.
2. If temperature is below to 100°F, give medication, per the school's medication authorization form.
3. Apply heat to the painful area and increase fluid intake.
4. Allow the student to rest in the nurse's office.
5. If condition worsens or fails to improve, please update the caregiver(s).

Increased Fatigue

- **What can cause it?** Due to the chronic anemia, children with sickle cell disease may tire more easily than their peers.
- **What to do?** If fatigue seems to be excessive, such as unusual falling asleep in class, please call the caregiver(s) so that you can discuss whether the student needs immediate medical attention.

School Health Service Staff Notes: Changes in behavior that may indicate the student has a fever, is experiencing pain and/or another complication:

_____

_____

EARLY CHILDHOOD EDUCATION PROVIDER ACTION PLAN FOR THE STUDENT WITH SICKLE CELL DISEASE

Student Name: _____

Classroom: _____

Sickle cell disease (SCD) is an inherited, life-long condition, which affects red blood cells. It is not contagious. In general, children with sickle cell disease do not look or act differently from other children and should be treated as the other children in the daycare setting.

Situations for Which Special Consideration May Be Necessary

Physical Appearance: In general, children with sickle cell disease do not look or act differently from other children and should be treated as the other children in the childcare/ preschool setting. However, some may be smaller than the other children of their age group and their eyes may become slightly yellow or jaundiced. Mild jaundice of the eyes should not be of much concern.

Activity: In general, children with sickle cell disease can tolerate normal physical activity. They may, however, tire more easily than other children, and prolonged strenuous activity may lead to a painful episode. These children should be encouraged to participate in all activities up to their own limits and be permitted to stop and rest when they feel tired.

Hydration: Because of an inability to produce concentrated urine, children with sickle cell disease urinate more often than other children and also become thirsty more often. They are more prone to dehydration.

- All children with sickle cell disease should be encouraged to drink plenty of fluids, especially after exercise and on warm days.
- You may find it necessary to change diapers more frequently.
- Toilet trained children should be given unlimited bathroom privileges.

See appendix of the handbook "Supporting the Student with Sickle Cell Disease" for daily water consumption recommendations.

Weather: Extreme changes in temperature, such as prolonged exposure to cold, chilly or wet conditions can precipitate painful episodes for students with sickle cell disease. Prolonged exposure to heat can lead to dehydration, which can also precipitate painful episodes. The student should be dressed warmly before activities in cool environments, and dried quickly when wet. Shared decision-making with the caregiver(s) is recommended.

What to Do if Symptoms Occur

Prompt Medical Attention Is Needed for These Signs and Symptoms

- Fever of 101°F (38.3°C) or higher
- Severe headache
- Vision changes such as sudden loss of vision
- New painless limp
- Weakness or inability to use extremities
- Facial asymmetry
- Difficulty speaking or slurred speech
- Chest pain
- Difficulty breathing
- Rapid heartbeat and/or breathing
- Nausea, vomiting and/or diarrhea

If acute medical attention is needed, contact the caregiver immediately. Be prepared that the next steps could also include contacting emergency medical services/911.

Common SCD Complications

Bacterial Infection/Fever

- **Fever is considered a medical emergency because it may be the only sign of a life-threatening bacterial infection.**
- Children with sickle cell disease are more susceptible to certain serious infections.
- A digital thermometer needs to be available in your setting and staff needs to be proficient in using it and interpreting the results.
- Fever of 101° F (38.3° Celsius) or greater in a child with sickle cell disease may indicate a life-threatening infection.
- **DO NOT GIVE FEVER-REDUCING MEDICATIONS** until the temperature has been recorded and fever is documented. If fever-reducing medication is given for low-grade fever, the student should then be referred to an emergency department. In either situation, the caregiver or you must consult the student's healthcare provider immediately.

Stroke

- **Stroke is considered a medical emergency.**
- Stroke could be indicated by severe headache or new onset of a painless limp, numbness, weakness of extremity, or vision or speech difficulty.

You must consult the student's caregiver or the student's healthcare provider immediately.

Acute splenic sequestration (enlarged spleen)

- **Acute splenic sequestration is considered a medical emergency.**
- This occurs when a large amount of blood becomes trapped in the spleen, which then becomes enlarged. The student may go into shock because of the loss of blood from the body's circulation.
- Symptoms of acute splenic sequestration include increasing paleness, lethargy, extreme drowsiness and difficulty breathing. An older child may complain of abdominal pain.

You must consult the student's caregiver or the student's healthcare provider immediately.

Painful episodes or crises

- **Painful episodes are unpredictable**. Most individuals with sickle cell disease cannot predict when an episode will occur, nor can they usually identify a precipitating factor.
- **They occur in many places in the body**. In young children, the pain occurs mainly in the hands and feet, but pain can be experienced in other parts of the body. In addition to pain in hands and feet, swelling and redness may be present.
- **They can be caused by changes in temperature**. Extreme changes in temperature, such as prolonged exposure to cold, chilly or wet conditions, can precipitate painful episodes for students with sickle cell disease. Prolonged exposure to heat can lead to dehydration, which can also precipitate painful episodes. The student should be dressed warmly before activities in cool environments and dried quickly when wet. Shared decision-making with the caregiver(s) is recommended.
- **They may not always require hospitalization**. There may be times when painful episodes are severe enough for a child to stay home from school but not need to be hospitalized. Additionally, it is not uncommon for students to return to school while still experiencing pain.
- **Please be supportive of a student in pain**. Please be mindful to discuss with the student and caregiver(s) ways in which the school staff can support the student as they recover.

Pain Management at School

Mild painful episodes may be managed in school. Routine medications should be available in the school.

1. First, take the student's temperature. If temperature is greater than or equal to 100°F, medication should not be given and temperature should be reassessed in **ONE** hour.
2. If temperature is below to 100°F, give medication, per the school's medication authorization form.
3. Apply heat to the painful area and increase fluid intake.
4. Allow the student to rest in the nurse's office.
5. If condition worsens or fails to improve, please update the caregiver(s).

Increased Fatigue

- **What can cause it?** Due to the chronic anemia, children with sickle cell disease may tire more easily than their peers.
- **What to do?** If fatigue seems to be excessive, such as unusual falling asleep in class, please call the caregiver(s) so that you can discuss whether the student needs immediate medical attention.

Caregiver Notes: Changes in behavior that may indicate the student has a fever, is experiencing pain and/or another complication:

_____

_____

TEACHER/SUBSTITUTE TEACHER ACTION PLAN FOR THE STUDENT WITH SICKLE CELL DISEASE

Student Name: _____

School Year: _____ Grade: _____

Student has 504 Plan: Yes/No (explain): _____

Student has an IEP: Yes/No (explain): _____

SCD-Related Classroom Accommodations/Modifications for this student:

_____

_____

_____

Anticipated number of days per month the student will miss this class for scheduled clinic visits: _____

Changes in behavior that may indicate the student has a fever, is experiencing pain, and/or another complication are:

_____

_____

The school staff members responsible for assisting this student in the event of a SCD complication:

1. Name: _____ Position: _____

   Contact Number: _____

2. Name: _____ Position: _____

   Contact Number: _____

The student's caregiver(s) emergency contact information:

1. Last Name: _____ First Name: _____

   Address: _____

   Home Phone: _____ Work Phone: _____

   Cell Phone: _____

   Email: _____

2. Last Name: _____ First Name: _____

   Address: _____

   Home Phone: _____ Work Phone: _____

   Cell Phone: _____

   Email: _____

Additional authorized emergency contact:

3. Last Name: _____ First Name: _____

   Address: _____

   Home Phone: _____ Work Phone: _____

   Cell Phone: _____

   Email: _____

What to Do if Symptoms Occur

Prompt Medical Attention Is Needed for These Signs and Symptoms

- Fever of 101°F (38.3°C) or higher
- Severe headache
- Vision changes such as sudden loss of vision
- New painless limp
- Weakness or inability to use extremities
- Facial asymmetry
- Difficulty speaking or slurred speech
- Chest pain
- Difficulty breathing
- Rapid heartbeat and/or breathing
- Nausea, vomiting and/or diarrhea

If acute medical attention is needed, contact the caregiver immediately. Be prepared that the next steps could also include contacting emergency medical services/911.

Common SCD Complications

Bacterial Infection/Fever

- **Fever is considered a medical emergency because it may be the only sign of a life-threatening bacterial infection.**
- Children with sickle cell disease are more susceptible to certain serious infections.
- A digital thermometer needs to be available in your setting and staff needs to be proficient in using it and interpreting the results.
- Fever of 101° F (38.3° Celsius) or greater in a child with sickle cell disease may indicate a life-threatening infection.
- **DO NOT GIVE FEVER-REDUCING MEDICATIONS** until the temperature has been recorded and fever is documented. If fever-reducing medication is given for low-grade fever, the student should then be referred to an emergency department. In either situation, the caregiver or you must consult the student's healthcare provider immediately.

Stroke

- **Stroke is considered a medical emergency.**
- Stroke could be indicated by severe headache or new onset of a painless limp, numbness, weakness of extremity, or vision or speech difficulty.

You must consult the student's caregiver or the student's healthcare provider immediately.

Acute splenic sequestration (enlarged spleen)

- **Acute splenic sequestration is considered a medical emergency.**
- This occurs when a large amount of blood becomes trapped in the spleen, which then becomes enlarged. The student may go into shock because of the loss of blood from the body's circulation.
- Symptoms of acute splenic sequestration include increasing paleness, lethargy, extreme drowsiness and difficulty breathing. An older child may complain of abdominal pain.

You must consult the student's caregiver or the student's healthcare provider immediately.

Painful episodes or crises

- **Painful episodes are unpredictable**. Most individuals with sickle cell disease cannot predict when an episode will occur, nor can they usually identify a precipitating factor.
- **They occur in many places in the body**. In young children, the pain occurs mainly in the hands and feet, but pain can be experienced in other parts of the body. In addition to pain in hands and feet, swelling and redness may be present.
- **They can be caused by changes in temperature**. Extreme changes in temperature, such as prolonged exposure to cold, chilly or wet conditions, can precipitate painful episodes for students with sickle cell disease. Prolonged exposure to heat can lead to dehydration, which can also precipitate painful episodes. The student should be dressed warmly before activities in cool environments and dried quickly when wet. Shared decision-making with the caregiver(s) is recommended.
- **They may not always require hospitalization**. There may be times when painful episodes are severe enough for a child to stay home from school but not need to be hospitalized. Additionally, it is not uncommon for students to return to school while still experiencing pain.
- **Please be supportive of a student in pain**. Please be mindful to discuss with the student and caregiver(s) ways in which the school staff can support the student as they recover.

Pain Management at School

Mild painful episodes may be managed in school. Routine medications should be available in the school.

1. First, take the student's temperature. If temperature is greater than or equal to 100°F, medication should not be given and temperature should be reassessed in **ONE** hour.
2. If temperature is below to 100°F, give medication, per the school's medication authorization form.
3. Apply heat to the painful area and increase fluid intake.
4. Allow the student to rest in the nurse's office.
5. If condition worsens or fails to improve, please update the caregiver(s).

Increased Fatigue

- **What can cause it?** Due to the chronic anemia, children with sickle cell disease may tire more easily than their peers.
- **What to do?** If fatigue seems to be excessive, such as unusual falling asleep in class, please call the caregiver(s) so that you can discuss whether the student needs immediate medical attention.

REFERENCE FOR THE COLLEGE- and CAREER-BOUND STUDENT WITH SCD

Consider the student's growing need for autonomy: As high school staff members, you understand that students need to feel a sense of autonomy in their daily lives. It is the same for the student with a chronic illness, such as sickle cell disease (SCD). It is important to continue to foster a sense of independence in students with SCD as they prepare to move toward the next steps in their life paths.

How staff and counselors can help: During proactive planning meetings, we encourage the student to take initiative as an advocate for themselves during the development of their personalized action plan with their teachers. We ask that you continue to guide them in this process, ask prompting questions, and help the student take ownership of a plan that will allow them to maintain employment and academic success throughout the school year and beyond.

The special need for guidance with college and career planning: In addition to the information high school guidance counselors typically provide for college and career preparation, keep the following items in mind when working with college- and employment-bound students with SCD.

- Proximity to a SCD treatment center is a crucial component that students with SCD should consider when searching for colleges. Students are encouraged to attend colleges within a one-hour drive of a SCD treatment center in order to help them more easily manage their complications and be closer to care when needed.
- Location can play an important role in determining which college or where to seek employment. The student with SCD should research the location and consider whether they want to reside in a rural area, a suburb or a city and be mindful of the healthcare access related to the different settings. Size and layout of a campus or work setting can also be important. Some students with SCD have physical limitations that would make a great deal of walking or traveling through hilly terrain difficult.
- Weather can be a critical factor for those with SCD to consider when searching for employment or higher education. A student with SCD should be aware of typical weather patterns throughout the year to anticipate potential complications that may occur as a result of extreme changes in temperature.
- Access to and quality of public transportation can be an important factor in understanding how they will get to and around a work site or college.

Other Considerations

- **Encourage self-advocacy**: One of the major shifts students face when graduating high school and beginning college or seeking employment is learning to be a self-advocate. This shift is particularly important for students with chronic illnesses, like SCD, to understand. We encourage you to have open communication about the importance of self-advocacy with students, especially on the topic of whether or not to share their health history with employers, college personnel and other students.
- **Specific arrangements and health records**: Encourage the student to have conversations with their healthcare providers about any SCD-related accommodations they may need to help them remain healthy and active members of their college or employment communities. Remind them to create a comprehensive medical summary with medications, doctors' names and contact information, preferably on official healthcare provider letterhead, to support their needs, especially in an emergency.

- **Assistance in making plans for colleges**: Review the process for applying for accommodations and steps to take in identifying ways the college's disability services can assist in securing appropriate accommodations, particularly regarding sharing this information with professors and residence life staff.
- **Assistance in making plans for the workplace**: The career-bound student should connect with the Human Resources office to secure appropriate accommodations at the employment site and to learn how to apply for Family and Medical Leave to protect their employment. In addition, discussing their needs with their direct supervisors can aid in the creation of a proactive plan to address concerns if the employee is unwell or needs specific SCD treatments during work hours.

Disability Law

- **Possible need for more information**: Students with SCD who have Individual Education Plans may need more information about the shift in education law from being covered under the Individuals with Disabilities Education Act (IDEA) to Section 504 of the Rehabilitation Act of 1973 and the American with Disabilities Act of 1990 (ADA) once they graduate high school.
- **The need for additional guidance**: Work with these students to help them better understand that IEPs do not "follow" them to college and offer information on how to apply for accommodations through the college disability services center.
- **Employment**: For students seeking employment, the Americans with Disabilities Act of 1990 also offers protection for those seeking a career path. The ADA protects employees from discrimination based on a disability. The ADA prohibits employers from discriminating against employees or applicants with disabilities in all aspects of employment including hiring, pay, promotion, firing and more.

ACTION PLAN FOR THE STUDENT WITH SCD

Participating in sports and activities are an important part of the day for most students. For children and teens with sickle cell disease (SCD), playing sports and participating in recess activities can be just as enjoyable. Most children with SCD can participate in both, and taking precautions and preventative measures are the most important factors to safeguard against complications. Below are some tips to assist you as a physical education teacher or coach when working with students who have SCD.

Physical activity: Students with SCD can tolerate normal physical activity and can participate in routine physical education classes and playground games. However, they can tire more easily than their peers due to their state of chronic anemia and impaired pulmonary function.

Rest and recovery: Students should be provided adequate rest and recovery between activities and at their request. Discuss alternatives for play and required activities that best fit students' physical abilities.

Weather: Students should avoid extremely cold temperatures, but can undertake outdoor activities when dressed appropriately. Students should avoid extreme heat due to risk of dehydration. Shared decision-making with the caregiver(s) is recommended.

Hydration: Students should be encouraged to drink plenty of fluids. Because of an inability to produce concentrated urine, students with sickle cell disease urinate more often than other students and also become thirsty more often. They are more prone to dehydration. Students should refrain from consuming high-energy drinks as they may contribute to dehydration. *See appendix of the handbook "Supporting the Student with Sickle Cell Disease" for daily water consumption recommendations.*

Swimming: Swimming, especially in cool water, may lead to painful episodes in some students with SCD. The student should be given the option to refuse swimming and provided with alternative activities if the swimming tips cannot be provided.

Swimming Tips

- It is ideal for students to swim in a heated pool.
- Before getting in the pool, the student should perform warm-up exercises, such as jumping jacks or briskly rubbing the skin.
- After swimming, students should dry themselves immediately to prevent sudden changes in body temperature.

Prompt Medical Care

Stop activity immediately if a person is experiencing symptoms or struggling. Seek prompt medical care when experiencing physical distress.

- Fever
- Fatigue and/or breathlessness
- Severe headache
- Muscle pain
- Chest pain
- Severe abdominal pain
- Painless limp, numbness, weakness of extremity, visual or speech difficulty
- Nausea or vomiting

ATHLETIC DEPARTMENT STAFF NOTES

Student's name: _____ Class level: _____

Changes in behavior: _____

The athletic department staff members responsible for assisting this student in the event of a SCD complication:

Name: _____ Position: _____

Contact Number: _____

Name: _____ Position: _____

Contact Number: _____

The student's caregiver(s) emergency contact information:

Last Name: _____ First Name: _____

Address: _____

Home Phone: _____ Work Phone: _____

Cell Phone: _____

Email: _____

Last Name: _____ First Name: _____

Address: _____

Home Phone: _____ Work Phone: _____

Cell Phone: _____

Email: _____

Additional authorized emergency contact:

Last Name: _____ First Name: _____

Address: _____

Home Phone: _____ Work Phone: _____

Cell Phone: _____

Email: _____

ACTION PLAN FOR THE STUDENT WITH SCD

Your role is essential and important to parents and guardians due to the amount of time students spend in your care. This valuable time can help this student's teacher and caregivers stay informed about any potential changes that take place academically, socially, physically and emotionally. Below are some tips that can assist you when working with a student with sickle cell disease.

Important Sickle Cell Disease Problems You Should Be Familiar With

Prompt Medical Attention Is Needed for These Signs and Symptoms

- Fever of 101°F (38.3°C) or higher
- Severe headache
- Vision changes such as sudden loss of vision
- New painless limp
- Weakness or inability to use extremities
- Facial asymmetry
- Difficulty speaking or slurred speech
- Chest pain
- Difficulty breathing
- Rapid heartbeat and/or breathing
- Nausea, vomiting and/or diarrhea

If acute medical attention is needed, contact the caregiver immediately. Be prepared that the next steps could also include contacting emergency medical services/911.

Common SCD Complications

Bacterial Infection/Fever

- **Fever is considered a medical emergency because it may be the only sign of a life-threatening bacterial infection.**
- Children with sickle cell disease are more susceptible to certain serious infections.
- A digital thermometer needs to be available in your setting and staff needs to be proficient in using it and interpreting the results.
- Fever of 101° F (38.3° Celsius) or greater in a child with sickle cell disease may indicate a life-threatening infection.
- **DO NOT GIVE FEVER-REDUCING MEDICATIONS** until the temperature has been recorded and fever is documented. If fever-reducing medication is given for low-grade fever, the student should then be referred to an emergency department. In either situation, the caregiver or you must consult the student's healthcare provider immediately.

Stroke

- **Stroke is considered a medical emergency.**
- Stroke could be indicated by severe headache or new onset of a painless limp, numbness, weakness of extremity, or vision or speech difficulty.

You must consult the student's caregiver or the student's healthcare provider immediately.

Acute splenic sequestration (enlarged spleen)

- **Acute splenic sequestration is considered a medical emergency.**
- This occurs when a large amount of blood becomes trapped in the spleen, which then becomes enlarged. The student may go into shock because of the loss of blood from the body's circulation.
- Symptoms of acute splenic sequestration include increasing paleness, lethargy, extreme drowsiness and difficulty breathing. An older child may complain of abdominal pain.

You must consult the student's caregiver or the student's healthcare provider immediately.

Painful episodes or crises

- **Painful episodes are unpredictable**. Most individuals with sickle cell disease cannot predict when an episode will occur, nor can they usually identify a precipitating factor.
- **They occur in many places in the body**. In young children, the pain occurs mainly in the hands and feet, but pain can be experienced in other parts of the body. In addition to pain in hands and feet, swelling and redness may be present.
- **They can be caused by changes in temperature**. Extreme changes in temperature, such as prolonged exposure to cold, chilly or wet conditions, can precipitate painful episodes for students with sickle cell disease. Prolonged exposure to heat can lead to dehydration, which can also precipitate painful episodes. The student should be dressed warmly before activities in cool environments and dried quickly when wet. Shared decision-making with the caregiver(s) is recommended.
- **They may not always require hospitalization**. There may be times when painful episodes are severe enough for a child to stay home from school but not need to be hospitalized. Additionally, it is not uncommon for students to return to school while still experiencing pain.
- **Please be supportive of a student in pain**. Please be mindful to discuss with the student and caregiver(s) ways in which the school staff can support the student as they recover.

Pain Management at School

Mild painful episodes may be managed in school. Routine medications should be available in the school.

1. First, take the student's temperature. If temperature is greater than or equal to 100°F, medication should not be given and temperature should be reassessed in **ONE** hour.
2. If temperature is below to 100°F, give medication, per the school's medication authorization form.
3. Apply heat to the painful area and increase fluid intake.
4. Allow the student to rest in the nurse's office.
5. If condition worsens or fails to improve, please update the caregiver(s).

Increased Fatigue

- **What can cause it?** Due to the chronic anemia, children with sickle cell disease may tire more easily than their peers.
- **What to do?** If fatigue seems to be excessive, such as unusual falling asleep in class, please call the caregiver(s) so that you can discuss whether the student needs immediate medical attention.

Hydration: Students should be encouraged to drink plenty of fluids. Because of an inability to produce concentrated urine, students with sickle cell disease urinate more often than other students and also become thirsty more often. They are more prone to dehydration. Students should refrain from consuming high-energy drinks as they may contribute to dehydration.

See appendix of the handbook "Supporting the Student with Sickle Cell Disease" for daily water consumption recommendations.

BEFORE AND AFTERCARE STAFF NOTES

Student's name: _____ Class level: _____

Changes in behavior: _____

The before and aftercare staff members responsible for assisting this student in the event of a SCD complication:

Name: _____ Position: _____

Contact Number: _____

Name: _____ Position: _____

Contact Number: _____

The student's caregiver(s) emergency contact information:

Last Name: _____ First Name: _____

Address: _____

Home Phone: _____ Work Phone: _____

Cell Phone: _____

Email: _____

Last Name: _____ First Name: _____

Address: _____

Home Phone: _____ Work Phone: _____

Cell Phone: _____

Email: _____

Additional authorized emergency contact:

Last Name: _____ First Name: _____

Address: _____

Home Phone: _____ Work Phone: _____

Cell Phone: _____

Email: _____

SUMMER CAMP

ACTION PLAN FOR THE STUDENT WITH SCD

Summer camp can be exciting for all children, but extra precautions and preventative measures might be needed for children who have SCD. These campers can and should participate in most summer outdoor and indoor activities. Camp counselors and staff should be aware that variables such as temperature, whether hot or cold, can have a serious effect on campers with SCD, and it's necessary for them to stay hydrated at all times. Below are some tips to keep everyone healthy, happy and having fun.

Important Sickle Cell Disease Problems You Should Be Familiar With

Prompt Medical Attention Is Needed for These Signs and Symptoms

- Fever of 101°F (38.3°C) or higher
- Severe headache
- Vision changes such as sudden loss of vision
- New painless limp
- Weakness or inability to use extremities
- Facial asymmetry
- Difficulty speaking or slurred speech
- Chest pain
- Difficulty breathing
- Rapid heartbeat and/or breathing
- Nausea, vomiting and/or diarrhea

If acute medical attention is needed, contact the caregiver immediately. Be prepared that the next steps could also include contacting emergency medical services/911.

Common SCD Complications

Bacterial Infection/Fever

- **Fever is considered a medical emergency because it may be the only sign of a life-threatening bacterial infection.**
- Children with sickle cell disease are more susceptible to certain serious infections.
- A digital thermometer needs to be available in your setting and staff needs to be proficient in using it and interpreting the results.
- Fever of 101° F (38.3° Celsius) or greater in a child with sickle cell disease may indicate a life-threatening infection.
- **DO NOT GIVE FEVER-REDUCING MEDICATIONS** until the temperature has been recorded and fever is documented. If fever-reducing medication is given for low-grade fever, the student should then be referred to an emergency department. In either situation, the caregiver or you must consult the student's healthcare provider immediately.

Stroke

- **Stroke is considered a medical emergency.**
- Stroke could be indicated by severe headache or new onset of a painless limp, numbness, weakness of extremity, or vision or speech difficulty.

You must consult the student's caregiver or the student's healthcare provider immediately.

Acute splenic sequestration (enlarged spleen)

- **Acute splenic sequestration is considered a medical emergency.**
- This occurs when a large amount of blood becomes trapped in the spleen, which then becomes enlarged. The student may go into shock because of the loss of blood from the body's circulation.
- Symptoms of acute splenic sequestration include increasing paleness, lethargy, extreme drowsiness and difficulty breathing. An older child may complain of abdominal pain.

You must consult the student's caregiver or the student's healthcare provider immediately.

Painful episodes or crises

- **Painful episodes are unpredictable**. Most individuals with sickle cell disease cannot predict when an episode will occur, nor can they usually identify a precipitating factor.
- **They occur in many places in the body**. In young children, the pain occurs mainly in the hands and feet, but pain can be experienced in other parts of the body. In addition to pain in hands and feet, swelling and redness may be present.
- **They can be caused by changes in temperature**. Extreme changes in temperature, such as prolonged exposure to cold, chilly or wet conditions, can precipitate painful episodes for students with sickle cell disease. Prolonged exposure to heat can lead to dehydration, which can also precipitate painful episodes. The student should be dressed warmly before activities in cool environments and dried quickly when wet. Shared decision-making with the caregiver(s) is recommended.
- **They may not always require hospitalization**. There may be times when painful episodes are severe enough for a child to stay home from school but not need to be hospitalized. Additionally, it is not uncommon for students to return to school while still experiencing pain.
- **Please be supportive of a student in pain**. Please be mindful to discuss with the student and caregiver(s) ways in which the school staff can support the student as they recover.

Pain Management at School

Mild painful episodes may be managed in school. Routine medications should be available in the school.

1. First, take the student's temperature. If temperature is greater than or equal to 100°F, medication should not be given and temperature should be reassessed in **ONE** hour.
2. If temperature is below to 100°F, give medication, per the school's medication authorization form.
3. Apply heat to the painful area and increase fluid intake.
4. Allow the student to rest in the nurse's office.
5. If condition worsens or fails to improve, please update the caregiver(s).

Increased Fatigue

- **What can cause it?** Due to the chronic anemia, children with sickle cell disease may tire more easily than their peers.
- **What to do?** If fatigue seems to be excessive, such as unusual falling asleep in class, please call the caregiver(s) so that you can discuss whether the student needs immediate medical attention.

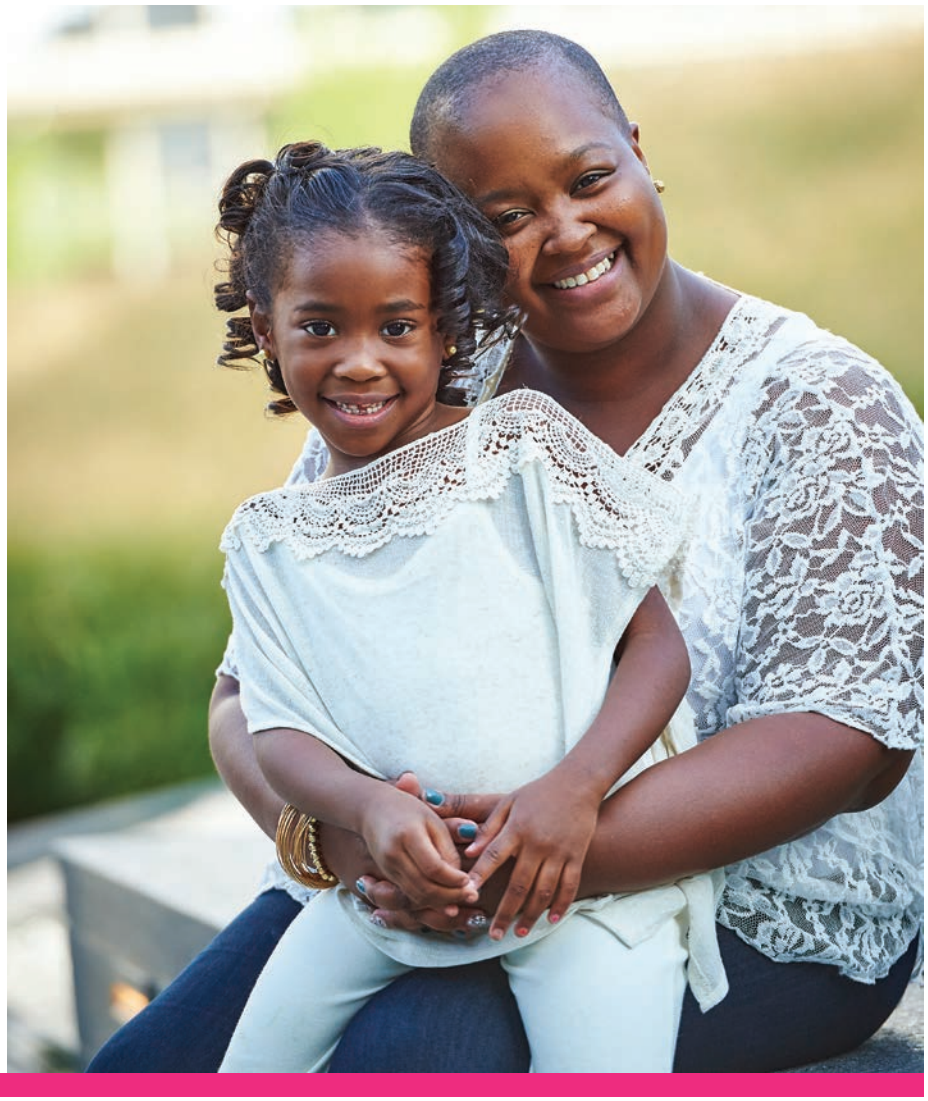
Hydration: Students should be encouraged to drink plenty of fluids. Because of an inability to produce concentrated urine, students with sickle cell disease urinate more often than other students and also become thirsty more often. They are more prone to dehydration. Students should refrain from consuming high-energy drinks as they may contribute to dehydration.

See appendix of the handbook "Supporting the Student with Sickle Cell Disease" for daily water consumption recommendations.

Swimming: Swimming, especially in cool water, may lead to painful episodes in some campers with SCD. The camper should be given the option to refuse swimming and provided with alternative activities if the swimming tips cannot be provided.

Swimming Tips

- It is ideal for campers to swim in a heated pool.
- Before getting in the pool, the camper should perform warm-up exercises, such as jumping jacks or briskly rubbing the skin.
- After swimming, campers should dry themselves immediately to prevent sudden changes in body temperature.



CAMP STAFF NOTES

Student's name: _____ Class level: _____

Changes in behavior: _____

The camp staff members responsible for assisting this camper in the event of a SCD complication:

Name: _____ Position: _____

Contact Number: _____

Name: _____ Position: _____

Contact Number: _____

The camper's emergency contact information:

Last Name: _____ First Name: _____

Address: _____

Home Phone: _____ Work Phone: _____

Cell Phone: _____

Email: _____

Last Name: _____ First Name: _____

Address: _____

Home Phone: _____ Work Phone: _____

Cell Phone: _____

Email: _____

Additional authorized emergency contact:

Last Name: _____ First Name: _____

Address: _____

Home Phone: _____ Work Phone: _____

Cell Phone: _____

Email: _____

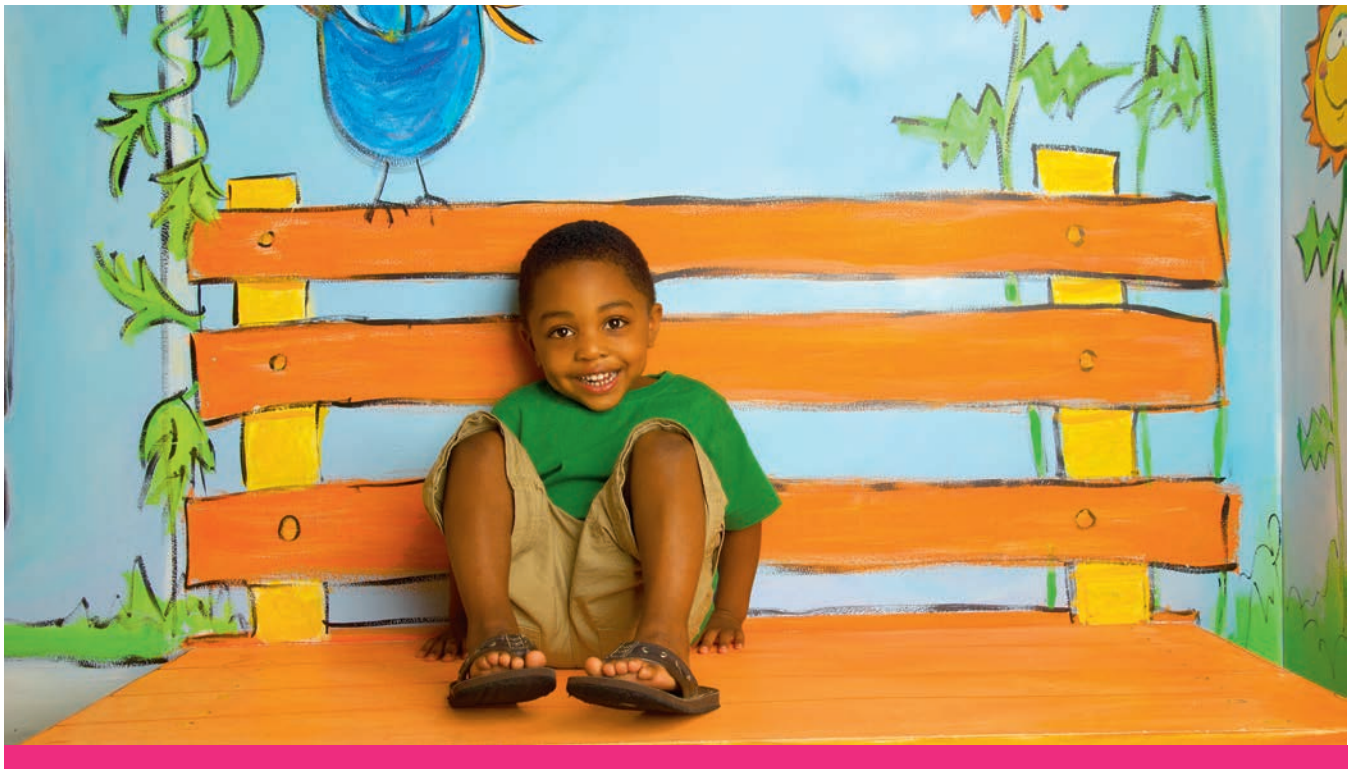
CAREGIVER BACK-TO-SCHOOL CHECKLIST

FOR SCHOOL STAFF REFERENCE PURPOSES

As part of our ongoing commitment to promoting communication between school staff and caregivers, we recognize that the student and their caregiver(s) have a responsibility to provide you with important school-related documentation and consents, which allow you to collaborate with the student's medical team.

The checklist below is given to caregivers prior to the beginning of each school year. Please review the information provided in this checklist during meetings you have with the student and his/her caregiver.

- ❑ Schedule a meeting with school administration to discuss your child's needs.
- ❑ Make sure a 504 Plan is in place and updated for the current school year.
- ❑ If your child has an IEP, make sure you are reviewing to sickle cell disease-related accommodations during their IEP annual review meeting.
- ❑ Complete and sign updated school-related consent forms (Family Educational Rights and Privacy Act [FERPA] and healthcare release of information forms) and school medication authorization forms to communicate about your child's healthcare needs.
- ❑ Update all emergency contacts with the school along with physician contact information. Establish whether you prefer that the school contact you along with or before contacting the healthcare team when possible.
- ❑ Inform school of upcoming appointments and admissions immediately.
- ❑ Obtain documentation from your medical team when you have an appointment or an admission.
- ❑ Inform the medical team if you are concerned about any learning or academic challenges.



APPENDIX

DAILY WATER CONSUMPTION RECOMMENDATIONS

English units version

Body Weight (pounds)	Recommended Range per Day (8-ounce cups)
10	2 to 3 cups
25	4 to 6 cups
30	5 to 8 cups
45	6 to 9 cups
55	7 to 10 cups
75	8 to 11 cups
100	9 to 13 cups
130	10 to 15 cups
150	11 to 17 cups
175	12 to 18 cups

Metric units version

Body Weight (kilograms)	Recommended Range per Day (liters)
5	0.5 to 0.7
10	1.0 to 1.4
15	1.2 to 1.8
20	1.4 to 2.2
25	1.5 to 2.3
30	1.7 to 2.5
35	1.8 to 2.7
45	2.0 to 3.0
55	2.3 to 3.4
65	2.5 to 3.8
75	2.8 to 4.1

Platt, A. F., Eckman, J., & Hsu, L. L. (2016). *Hope and destiny: The patient and parents guide to sickle cell disease and sickle cell trait* (3rd ed.). Chicago, IL: Hilton Publishing Company.

ADDITIONAL RESOURCES

CHOP Comprehensive Sickle Cell Center Sickle Cell School Outreach
https://www.chop.edu/health-resources/sickle-cell-school-outreach

Centers for Disease Control and Prevention (CDC) Tips for Supporting Students with Sickle Cell Disease
https://www.cdc.gov/ncbddd/sicklecell/documents/tipsheet_supporting_students_with_scd.pdf

U.S. Department of Education (DOE): A Guide to the Individualized Education Plan (IEP)
https://www2.ed.gov/parents/needs/speced/iepguide/index.html

U.S. Department of Education (DOE): Parent and Educator Resource Guide to Section 504 in Public Elementary and Secondary Schools
https://www2.ed.gov/about/offices/list/ocr/docs/504-resource-guide-201612.pdf

REFERENCES

(2018). Retrieved from **https://www.ncaa.org/sites/default/files/NCAASickleCellTraitforSA.pdf**

(2018). Retrieved from **https://www.cdc.gov/ncbddd/sicklecell/documents/tipsheet_supporting_students_with_scd.pdf**

Cdc.gov. (2018). [online] Available at: **https://www.cdc.gov/ncbddd/sicklecell/documents/SCD-factsheet_What-is-SCD.pdf** [Accessed 2 Aug. 2018].

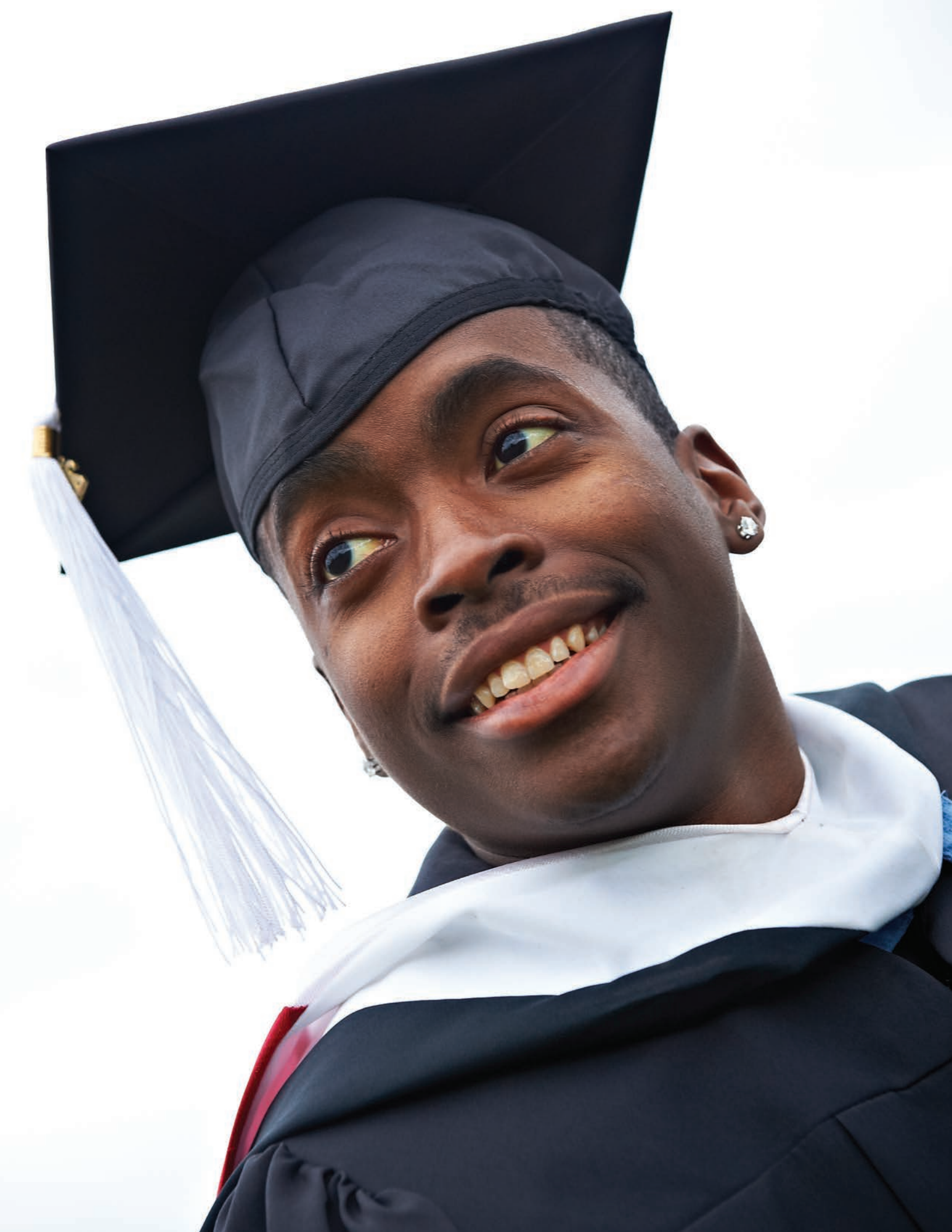
Disability Discrimination. (2018). Retrieved from **https://www2.ed.gov/about/offices/list/ocr/frontpage/faq/rr/policyguidance/disability.html**

Fithian, J. (2000). *Sickle Cell Disease; Handbook for the School Nurse (2nd ed.).* Philadelphia.

Fithian, J. (2000). *Sickle Cell Disease; Handbook for the Physical Education Teacher (2nd ed.).* Philadelphia.

Fithian, J. (2000). *Sickle Cell Disease; Handbook for the Teacher (2nd ed.).* Philadelphia.

Platt, A. F., Eckman, J., & Hsu, L. L. (2016). *Hope and destiny: The patient and parents guide to sickle cell disease and sickle cell trait (3rd ed.).* Chicago, IL: Hilton Publishing Company.



Every day, teams at Children's Hospital of Philadelphia make breakthroughs that transform children's lives. Since our founding in 1855 as the nation's first children's hospital, we have made extraordinary discoveries, trained generations of leaders, and advocated for children everywhere. Our pediatric research program, one of the largest in the country, has set a new standard for scientific innovation around the world. As a nonprofit charitable organization, we rely on the generous support of donors who are inspired by our work — and our mission.

Children's Hospital of Philadelphia®

Breakthroughs. Every day.®