Handbook for Patients and Families

Sickle Cell Disease Program

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Welcome

About the Aflac Cancer and Blood Disorders Center

- Is ranked as 1 of the leading childhood cancer and blood disorders programs in the country.
- Serves babies, children, teens and young adults with cancer and blood disorders.
- Has a team of childhood cancer and blood disorders specialists.
- Supports advanced medical care and research.
- Provides a complete program to work with children who have:
  - Sickle cell disease
  - Hemophilia and other bleeding disorders
  - Cancers
  - Blood and marrow transplants (BMT)

The Aflac Cancer and Blood Disorders Center and its programs are located at:

- Children's Healthcare of Atlanta at Arthur M. Blank Hospital
- Children's Healthcare of Atlanta at Hughes Spalding

Your child's provider will decide which location is best for you. We will ask you to choose one campus as the main site for your child's treatment and follow-up care.

Our mission

To provide complete care to children and teens with cancer and blood disorders through:

- Caring for your child's physical and emotional needs.
- Teaching you what you need to know about sickle cell disease.
- Taking part in research to help find the best way to treat and cure sickle cell disease.

About the handbook

Our sickle cell disease team created this handbook to help you and your family learn about sickle cell disease and:

- How it is treated.
- How to care for your child.

This handbook should not replace any instruction from your child's healthcare team. It is not meant to be medical advice or a complete resource. Your child's care team is the best source of information about what is best for your child.

To help you learn about your child's care more easily:

- Bring this handbook with you to each clinic visit.
- Write down any treatment changes or questions in the notes section.
- Plan to bring this handbook with you if your child needs to stay in the hospital.

Our promise to you

At the Aflac Cancer and Blood Disorders Center, our priority is to provide you and your child with high-quality, family-centered care. Together, our team will support you throughout your treatment journey. At each hospital stay and clinic visit, we want you to have a nurturing, caring environment.

Our mission is to provide you and your family with the finest in cancer and blood disorders treatment. We are honored that you have placed your child in our care. We will work every day to help live up to that trust.

We Want to Hear from You

We work to improve our programs and renew our mission to provide the best care possible for your child. If you have concerns during your time at the Aflac Cancer and Blood Disorders Center, we want to hear from you. Please call 404-785-1200 with any questions or concerns during your time at the Aflac Cancer and Blood Disorders Center.

In the hospital	
For urgent issues or concerns	Ask to speak with the family experience liaison or the nurse in charge.
For matters that need an administrator	Ask for the department manager, then inpatient clinical director of the Aflac Cancer and Blood Disorders Center if needed.

In the clinic	
For immediate issues or concerns	Speak with your primary outpatient nurse. If the matter cannot be resolved by your primary outpatient nurse, ask to speak with the nurse in charge.
For matters that need an administrator	Ask for the outpatient manager, then outpatient clinical director of the Aflac Cancer and Blood Disorders Center if needed.

This handbook should not replace instructions given to you by your child's doctor and healthcare team. It is not meant to be medical advice or a complete source of all information about this subject. Your child's doctor is the best source of information about what is best for your child's treatment and care. ***Call 911 or go to the nearest emergency department right away in case of an urgent concern or emergency. Also call your child's sickle cell disease clinic at one of the phone numbers listed on page 9.***

Sickle Cell Disease Clinic Information

Children's Healthcare of Atlanta at Arthur M. Blank Hospital
2200 North Druid Hills Road NE
Atlanta, Georgia 30329

Sickle Cell Disease Clinic	8 a.m. to 5 p.m. Monday to Friday
Appointments and daytime questions (leave a message if not urgent)	404-785-1200
After hours (including weekends and holidays)	404-785-1200
Outpatient clinic	404-785-1200

Children's Healthcare of Atlanta at Hughes Spalding
35 Jesse Hill Jr. Drive
Atlanta, Georgia 30303

Sickle Cell Disease Clinic	8:30 a.m. to 5 p.m. Monday, Wednesday and Thursday
Appointments and daytime questions (leave a message if not urgent)	404-785-9800
After hours (including weekends and holidays)	404-785-9800
Outpatient clinic	404-785-9800

Your Child's Sickle Cell Disease Team

Child's name: _____

Health condition: _____

There are many people who will care for you and your child. Write down the name and phone number of each person you meet. Ask them how to spell their name and what they do.

- **Sickle cell disease doctor:** A hematologist who receives special training in caring for children with sickle cell disease.
- **Advanced practice provider (APP):** A pediatric nurse practitioner or physician assistant with advanced medical training who coordinates medical and nursing care for your child. They help care for your child with the doctor.
- **Nurse:** A registered nurse (RN) in the hospital or clinic who provides and coordinates daily nursing care, phone advice and teaching.
- **Respiratory therapist:** A professional who helps your child breathe well by giving breathing treatments during your child's hospital stay.
- **Physical therapist:** Works with your child to maintain a level of fitness through therapy and exercises.
- **Psychologist:** A professional with training to help you and your child cope with feelings about sickle cell disease. They work with other members of the care team to help focus on your child's emotional needs.
- **Social worker:** Provides guidance and counseling to help you and your family. They can help find the services and resources your family needs while in and out of the hospital.
- **Chaplain:** Helps meet your family's spiritual needs. They can work with your pastor or religious leader to provide spiritual support. Our chaplains also lead interfaith services in the hospital.
- **Case manager:** A registered nurse (RN) who is part of the care team. They work with home health companies and insurance companies to provide families with resources, such as medical supplies and medicines.
- **Nurse coordinator:** A registered nurse (RN) who helps children and families as they receive care from different specialists.
- **Child life specialist:** Helps your child cope with illness through play and other activities. They can answer questions, teach you ways to cope with fear and pain, prepare your child for a procedure and teach you, your child and their siblings about the hospital stay.
- **School teacher:** A certified teacher who helps your child keep up with schoolwork to bridge the gap between hospital, home and school. They often work closely with your child's classroom teachers and offer classes during hospital stays.

Notes

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About Sickle Cell Disease

What is sickle cell disease (SCD)?

Sickle cell disease is a blood disorder that affects red blood cells (RBCs) in the body.

- RBCs contain a protein called hemoglobin. Hemoglobin allows the RBCs to carry oxygen from the lungs to all parts of the body.
- Most people have the same type of hemoglobin. It is made up of a pattern of building blocks.
- The RBCs of a person with sickle cell disease contain sickle hemoglobin. It is made up of a different pattern of building blocks.

Normal red blood cells are round and smooth

Sickle red blood cells look like a banana or sickle

Why are sickle cells a problem?

Normal RBCs are round and smooth. They flow through blood vessels very easily.

RBCs that carry sickle hemoglobin:

- Change their shape after they deliver oxygen to the body.
  They look like a banana or a sickle. This is how the disease got its name.
- Sickle cells are hard and sticky. This is because the sickle hemoglobin sticks together inside the blood cell.
- The sickle shape makes it harder for the sickle cells to flow smoothly through the blood vessels.
- The sickle cells may block blood flow to parts of the body.
- Areas of the body that do not receive normal blood flow can become damaged. This is what causes many of the problems from sickle cell disease.

Problems from blocked blood flow can happen quickly, such as sudden pain. Other problems happen more slowly and can damage the body's tissues and organs over time.

Another problem with sickle cells is that they do not live as long as normal RBCs.

- Normal RBCs live for about 120 days (4 months). Sickle cells live for about 20 days (2 to 3 weeks).
- This causes anemia. Anemia means a low RBC count or low hemoglobin level.

What symptoms could my child have?

Babies are born with normal RBCs. In a child with sickle cell disease, symptoms start only after enough sickle cells are made. Most often, this takes about 4 to 6 months.

We do not know when or why some children have certain symptoms.

- Sickle cell symptoms change from child to child and from mild to severe.
- Some symptoms are chronic and last throughout life. Other symptoms come and go.

Your child's sickle cell disease provider will talk with you about any problems your child may have.

Sickle cells break down quickly

Your child may feel tired, feel weak or have low energy. When the cells break open, they release a yellow substance called bilirubin into the blood. This can cause:

- Jaundice or a yellow color of the eyes and skin.
- Gallstones or solid clumps in the gallbladder.

Blocked blood vessels can cause pain

Pain happens when sickle cells block the blood vessels.

- This can happen anywhere in the body. It often happens in the arms, legs, chest, back and stomach area.
- This is called a vaso-occlusive episode (VOE). It used to be called a pain crisis. These may last from hours to days or sometimes weeks. It can happen many times throughout your child's life.

Your child may need to stay in the hospital to get stronger pain medicines if the pain is very bad.

Blocked blood vessels can cause problems in the body's organs

Sickle cells can block blood vessels inside organs, such as the spleen, kidneys, brain and lungs.

- When blood vessels in the spleen are blocked, blood fills the spleen instead of flowing through it. This causes the spleen to get very large. This is called splenic sequestration.
- This is a serious problem for children with sickle cell disease. It is a medical emergency.

Infections are more common for children with sickle cell disease.

- Infections can happen more often and can be more severe
- Your child may have a fever or other problems. This depends on where the infection is in the body.
- The chance of getting an infection never goes away. It gets less common as children get older.

Your child's sickle cell disease provider can talk with you about:

- The type of sickle cell disease your child has.
- Their plan of care.
- Tests, medicines and treatments they need.

Please feel free to ask us any questions you have about your child's care.

What tests could my child have?

All children born in the United States are screened for sickle cell disease at birth. Check with your child's primary doctor (pediatrician) if you do not have your child's test results.

- If your baby's newborn screening shows sickle cell disease, they will need more blood tests (labs) to make sure.
- If you cannot find out the results of your baby's screening, they may need other tests. One of these tests is called **hemoglobin electrophoresis**.

How can I help my child?

Your child needs your help from the time they are born. Some tips about how you can help your child are listed below.

Keep your child healthy

- Take your child for regular visits with their primary doctor and their sickle cell disease team.
- Make sure your child gets vaccines to help prevent disease.
- Know and understand the results of your child's blood tests and other tests.
- Learn about sickle cell disease symptoms, treatment and other problems your child may have.

- Ask your child's doctor about treatments for sickle cell disease.
- Teach your child healthy habits and good nutrition. Make sure they drink lots of fluids.

Help prevent infections

- Clean your hands often. Wash them well with soap and water for at least 20 seconds or use an alcohol-based gel or foam. Teach your child and anyone who cares for them to clean their hands often.
- Give your child penicillin each day as their doctor directs. Penicillin is an antibiotic medicine used to help prevent or treat infections.
- Dress your child properly for the weather that day. Avoid exposing them to severe weather changes.

Build a good family support

- Learn how to cope and manage stress. Be a role model for your child.
- Teach other family members and close friends about sickle cell disease and your child's needs. They may be a source of support and help in times of need.
- Find other sources of support you can use through your employer or community agencies.

Will my child need special care?

Your child will need regular care from their primary care doctor and special care from a team of sickle cell disease providers.

- This may include:
  - Exams, blood tests and X-rays on a regular basis to help prevent or check for problems.
  - Special medicines to help prevent or treat problems.
  - Vaccines to help prevent certain serious infections.
  - Other special treatments are based on your child's needs.
- Your child may go to any of the Children's sickle cell disease clinics and hospitals.

Types of sickle cell disease

The 4 most common types of sickle cell disease are:

- Hemoglobin SS (Hb SS or sickle cell anemia)
- Hemoglobin SC
- Hemoglobin S Beta + Thalassemia
- Hemoglobin S Beta 0 Thalassemia

Each one of these types is due to a different gene and each one can cause different problems.

Hemoglobin SS (HbSS)

This is the most severe form of sickle cell disease. Children with HbSS are more likely to have problems. (Figure 3)

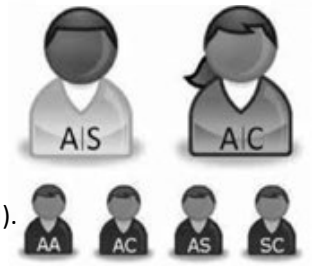
- Sickle cell disease is when a child gets 2 abnormal sickle cell genes, 1 from each parent.
- The abnormal genes are S and S (SS).
- This form of sickle cell disease is sometimes called homozygous or hemoglobin SS disease.
- A child with this type of sickle cell disease may keep some of their fetal hemoglobin**.**
- Your child's sickle cell disease provider will refer to this as "baby hemoglobin."
- High fetal hemoglobin often helps to protect your child from the more severe problems seen with HbSS.
- Very high fetal hemoglobin may be a milder form of sickle cell disease called S-HPFH (hereditary persistence of fetal hemoglobin).
- Your child's sickle cell disease provider can give you more details about S-HPFH.

Figure 3

Hemoglobin SC (HbSC)

- HbSC is when a child receives 2 abnormal genes, 1 from each parent. (Figure 4)
- The abnormal genes are S and C (SC).
- Children with HbSC may have moderate to severe problems with sickle cell disease.
- Often, symptoms may not be as severe until the second decade of life (10 to 20 years old).
- These children are at increased risk for eye, *spleen*, and bone problems.

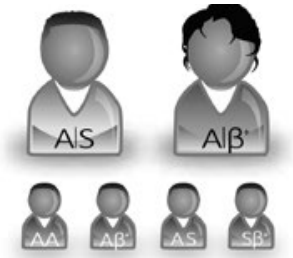
Figure 4



Hemoglobin Sickle Beta Thalassemia (HbS BetaThal)

- Beta (β) Thalassemia is another type of gene a child receives from a parent who has the Thalassemia trait (Aβ).
- This gene affects the amount of hemoglobin made by the body.
- Sickle Beta (β) Thalassemia is when a child receives both the Beta (β) Thalassemia gene and the sickle cell disease gene, 1 from each parent.

Figure 5

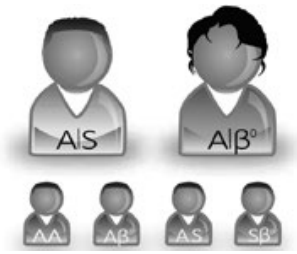


Thalassemia (Sβ+)

There are 2 forms of HbS Beta Thalassemia:

- (+) Thalassemia (Sβ+): Children with HbS Beta + Thalassemia have a small amount of normal hemoglobin A1. This protects them from some of the problems that can happen with sickle cell disease. They often have mild disease. (Figure 5)
- (0) Thalassemia (Sβ0): Children with HbS Beta 0 Thalassemia have no normal hemoglobin A1 and higher hemoglobin A2 and S values. They often have more severe problems. (Figure 6)

Figure 6



Thalassemia (Sβ0)

Newborn screening

Step 1

All states complete a special type of blood test called a newborn metabolic screening to find out if a baby has the sickle cell disease gene.

Step 2

The results of the screening are sent to the state health department and your baby's primary care provider in about 6 weeks. The test results are also sent to the Sickle Cell Foundation of Georgia to confirm the results if an abnormal gene is found.

Step 3

Your provider will review your baby's screening results and will refer your baby to our Sickle Cell Disease Clinic for more tests.

Step 4

During your first visit to the Sickle Cell Disease Clinic, we will do other blood tests to confirm if your baby has sickle cell disease. These tests may include:

- Hemoglobin electrophoresis is a blood test that checks different types of hemoglobin.
- Complete blood cell count is a test that measures the number of white blood cells, red blood cells and platelets in the blood.
- Reticulocyte count is a test that measures the number of new red blood cells.

Our sickle cell disease team will check your baby and ask you questions. We need to know about your baby's birth, checkups, general health, and family history. You will be able to ask questions and share your concerns at each clinic visit.

Step 5

It may take several days to get the results of the blood tests. Your child's sickle cell disease provider will talk with you about the results and give you a chance to ask questions.

Things you can do to help your child

You can learn to manage your child's health. Our sickle cell disease team is ready to help you. With excellent care, your child can live a long and productive life.

Penicillin and infection

Your child will begin penicillin prophylaxis soon after birth.

- Penicillin is a type of antibiotic. Antibiotics are most often used to treat infections.
- Penicillin prophylaxis helps prevent infection.

Give your child their dose of penicillin 2 times each day to help prevent a serious blood infection. Your child will not become resistant to this antibiotic. Follow the directions carefully. Do not stop giving your child penicillin without talking with the provider first.

After age 5, you may not need to give penicillin to your child unless they:

- Has a blood infection caused by a germ (bacteria).
- Had their spleen removed in surgery.

Folic acid

Your child will begin taking folic acid, a B vitamin, soon after they are 6 months old. Give your child this medicine every day. It is a pill that can be crushed in food. Ask your child's provider about how much to give.

- Normal red blood cells live for about 120 days.
- Sickle red blood cells live for about 20 days. This results in anemia (low red blood cell count).
- Folic acid helps produce red blood cells.
- Your child will take folic acid for the rest of their life.

Clinic visits

Take your child to their scheduled clinic visits. We will check to make sure they do not have any problems. They must have regular checkups and tests to stay as healthy as possible. With good care, your child can live a long life.

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Sickle Cell Disease Complications

This chapter has basic information about sickle cell disease problems.

Acute chest syndrome

What is acute chest syndrome (ACS)?

Acute chest syndrome (ACS) is a lung problem that happens in children who have sickle cell disease. It looks like pneumonia on a chest X-ray. It can be caused by 1 or more of these:

- Sickle red blood cells blocking blood vessels in the lungs, like a sickle cell crisis
- An infection in the lung
- Fat droplets in the lungs caused from a sickle cell bone pain or crisis
- Extreme sleepiness from medicine being used to treat pain

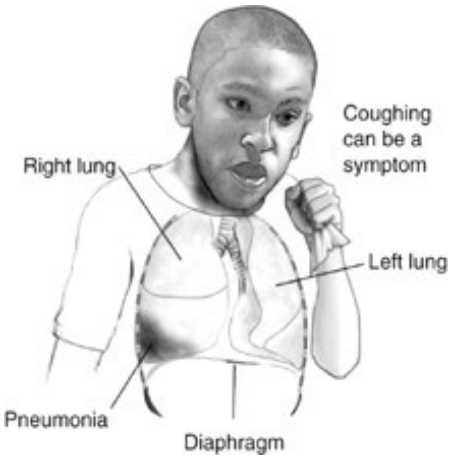
Children with sickle cell disease who have ACS may develop it again. If your child has asthma, the risk for ACS again is even higher. Repeated ACS can cause lasting lung damage.

- ACS can get worse quickly and become life-threatening.
- It is important for you to know about symptoms of ACS so you can get medical help **right away**.

What are the symptoms?

Your child may have 1 or more of these:

- Trouble breathing (fast or heavy breathing)
- Fever or temperature of 101°F or higher
- Cough
- Chest pain
- A low oxygen level
- Back pain or belly pain



What should I do if my child has symptoms?

If your child has any of these symptoms:

- **Get medical help right away.** Your child needs treatment as soon as possible.
- Call the Sickle Cell Disease Clinic and take your child to the emergency department (ED).

What tests could my child have?

Your child will need:

- A physical exam.
- A chest X-ray.
- Blood tests (labs), including blood counts.
- Their blood oxygen level measured.
- Blood cultures or other tests to check for bacteria.

What is the treatment?

Your child will need treatment in the hospital. This may include:

- Intravenous (I.V.) fluids.
- Incentive spirometry (breathing exercises) to help to keep the lungs open.
- Breathing treatments and chest physiotherapy (CPT) to help loosen mucus and thick fluids in the lungs.
- Checking blood oxygen levels by using a pulse ox (a soft probe that is attached to your child's finger or toe using a piece of tape).
- Treatment with oxygen if oxygen levels are low.
- Antibiotics to help kill germs.
- Pain medicine if needed.

Your child may also need:

- A blood transfusion to help the lungs heal and improve oxygen levels.
- BiPAP or CPAP (breathing machines to help get more air into the lungs if oxygen levels are too low or if your child has trouble breathing).
- An intensive care unit (ICU) stay where the care team can watch them more closely and provide more serious treatments if needed.

What follow-up care does my child need?

Your child needs a clinic visit after they go home from the hospital. It is very important that your child goes to their visit to make sure the lungs are healing and to help prevent further damage to the lungs.

During the visit, your child may need:

- A physical exam.
- Blood tests, including blood counts.
- Their blood oxygen level measured.
- A chest X-ray to see if the lungs are getting better.

Many children also need to see a pulmonologist (lung doctor).

- They may need other medicines or treatments to help prevent ACS from happening again.
- A visit with the lung doctor is important for those children with asthma or other lung problems.

When can my child return to school or day care?

Your child may be able to go back to school or day care soon after leaving the hospital if they feel better. It could take up to 1 week for your child to feel back to normal.

How can I help prevent ACS?

To help prevent ACS from happening again:

- Follow-up with the Sickle Cell Disease Clinic and lung doctor as advised. **This is very important**.
- You help avoid infections when you:
  - Clean your hands often. Wash them well with soap and water for at least 20 seconds or use an alcohol-based gel or foam. Teach your child and anyone who cares for them to clean their hands often..
  - Keep your child's vaccines (shots) up to date, including the Influenza (flu) vaccine.
  - Give your child antibiotics if the doctor prescribes them. Do not skip doses. The infection could return if you skip doses or do not finish the medicine.
- Give your child:
  - Any prescribed breathing treatments, such as inhalers or nebulizers.
  - Other medicines as prescribed to help treat or prevent problems.

What should I do if my child is sick?

- Follow your child's sickle cell disease provider's advice.
- Call your child's provider and **get medical care right away** anytime your child has a fever of 101°F or higher.
- When the clinic is closed (between 5 p.m. and 8 a.m. during the week and on weekends and holidays), call the hematologist on call before going to the hospital. They will call the emergency department (ED) and help with your child's care.
- **ALWAYS** tell the ED doctors and staff that your child has sickle cell disease. Also tell them which sickle cell disease clinic they visit.

Anemia

Most children with sickle cell disease have some anemia (low red blood cell count or low hemoglobin). This means the body has fewer red blood cells to carry oxygen. Anemia can cause your child to feel tired when they exercise or do physical work.

What are the symptoms?

Your child may have 1 or more of these:

- Pale lips, gums or nails
- Weakness
- Feels more tired than normal
- Sleeps longer
- Headache
- Does not want to eat or drink as much as normal
- Irritability

Call the Sickle Cell Disease Clinic **right away** if your child has any of these symptoms. Be prepared to take your child to the hospital or clinic.

Aplastic crisis

What is sickle cell disease aplastic crisis?

Aplastic crisis happens when the body stops making red blood cells (RBCs) for a short time. This causes a drop in your child's hemoglobin level (red blood count) for a short time.

- The word aplastic means "unable to form."
- In aplastic crisis, the RBCs are unable to form.

With sickle cell disease, many RBCs are broken down each day. This means that many more RBCs need to be made each day.

- Infections may cause the bone marrow to stop making RBCs for a few days. Most often, this is not a problem for people who do not have sickle cell disease.
- In children with sickle cell disease, severe anemia (very low hemoglobin) can happen if the bone marrow stops making RBCs, even for a few days.
- Your child may need a blood transfusion if the hemoglobin level is too low. A transfusion helps deliver oxygen to the body so it can keep working well.

What causes it?

Several types of infections can prevent bone marrow from making RBCs. Most happen when children are old enough to go to school.

Parvovirus B19 is one of the main causes. It spreads easily from person to person. If your child has parvovirus B19, they will need to be "isolated" from others to help prevent spreading the virus. They should stay away from:

- Children with sickle cell disease or children with other types of chronic illness.
- Pregnant women.
- People who have weak immune systems.

What are the symptoms?

Many of the symptoms come from a low RBC count. This may include:

- Pale lips, gums or nails.
- Feeling weak all over.
- Feeling very tired or sleepy.
- Fever or a recent fever (temperature of 101°F or higher).
- Fast heartbeat.
- Headache.
- Feeling short of breath.
- Being cranky.

How do I know if my child has it?

Your child needs to see a doctor if they have any of the symptoms listed in this handbook. Your child could have aplastic crisis if their:

- Hemoglobin falls below your child's baseline level.
- Reticulocyte count (newly made RBCs) is low.

Your child may need:

- A physical exam.
- Blood tests (labs), such as:
  - Blood counts.
  - Parvovirus B19 test.
  - Blood type and crossmatch in case they need a blood transfusion.
  - Blood culture to check for any germs.
- A chest X-ray to look for problems in the lungs.

What is the treatment?

Treatment depends on how sick your child is. Often, the drop in hemoglobin lasts for only a short time. The doctor will watch your child's blood counts (hemoglobin and reticulocyte counts) closely.

Treatment may include:

- A blood transfusion to help raise the RBC count to a safe level.
- A hospital stay if they are very sick.
- I.V. fluids, oxygen, antibiotics or pain medicines.

If your child has parvovirus B19:

- They may not visit with others or leave their hospital room.
- The care team and other staff will wear masks, gowns and gloves to help prevent the spread of the virus.

What follow-up care does my child need?

After your child goes home from the hospital, they will need:

- Frequent blood count checks to see if their blood counts are back to normal.
- A clinic visit as advised by your child's sickle cell disease provider.

If you have other children with sickle cell disease, be sure to check them for any symptoms. They will need to have their blood count checked for aplastic crisis.

How can I help prevent aplastic crisis?

It is rare for aplastic crisis to happen more than 1 time, but here are some tips to help prevent it:

- Avoid contact with people who have colds or other types of infection.
- Clean your hands often. Wash them well with soap and water for at least 20 seconds or use an alcohol-based gel or foam. Teach your child and anyone who cares for them to clean their hands often, too.
- Talk with your child's doctor about whether there is a vaccine to help prevent parvovirus B19.

Avascular necrosis (bone changes)

What is avascular necrosis (AVN)?

Avascular necrosis (AVN) is a well-known complication of sickle cell disease. AVN:

- Affects up to 10 percent of people with sickle cell disease.
- Can happen with all sickle cell types
- Can also be called osteonecrosis.

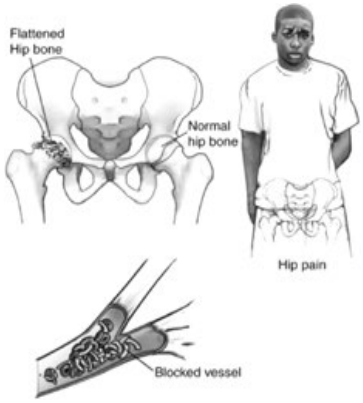
AVN is a type of bone damage that most often happens during the teen years. It is caused by a lack of blood supply to the bone.

- Avascular means no blood flow.
- Necrosis means death and decay of certain tissues in the body.

What causes it?

The exact cause for this type of bone damage is not clear. It is thought to be linked to abnormal blood flow from sickled red blood cells.

- This can cause damage and swelling of the blood vessels.
- Without a good blood supply, the bone tissue starts to die. This causes weakness that worsens over time and changes the normal shape of the bone.
- AVN can cause pain and loss of bone function.



In sickle cell disease, AVN mostly affects the joints of long bones like the hip and shoulder. AVN may also affect other small bones in the body like the sternum (breastbone) or vertebrae (spine).

- When AVN affects the hip joints, the round, smooth surface of the bones becomes flat and rough.
- These changes make it hard for the joints to move freely.
- This causes the area to get very sore, swollen and tender.
- Your child may have pain when they walk, climb stairs or move.

What are the symptoms?

Many children with early AVN may not have any symptoms. As AVN gets worse, your child may have some or all of these:

- Swelling, tenderness and soreness in the involved bone or joint area
- Pain that is sharp, dull or aching
  - It may be different than a regular pain episode.
  - It could worsen by putting weight on the area involved (weight bearing) or moving (such as walking, climbing stairs or sitting for long periods of time).
- Stiffness or tightness in the involved joint
  - AVN can feel like arthritis pain.
  - Your child may limp when they walk.
  - There may be less movement of the joint that is in pain.

How do I know if my child has it?

If your child has bone or joint pain often, please call their sickle cell disease provider who can begin to check for AVN. This may include:

- A complete exam and questions about your child's health history.
- X-rays of the involved bones or joints. This may include the hips, shoulders or spine.
- An MRI, or detailed imaging study, to take pictures of the involved bones or joints.

What is the treatment?

Treatment for AVN is more helpful when started early. It may depend on how severe your child's symptoms are and the extent of bone or joint damage. Treatment may include:

- Anti-inflammatory medicines for joint pain and swelling, such as ibuprofen (Motrin or Advil), naproxen (Aleve) or celecoxib (Celebrex).
- Stronger pain medicines called opioids, such as hydrocodone (Norco or Lortab) or oxycodone (Roxicodone), if anti-inflammatory medicines do not work well.
- Bed rest and crutches or braces to help decrease pressure at large joints like the hip and shoulder.
- Physical therapy (PT) and exercises to help improve muscle strength around the affected joints.

If these treatments do not provide enough pain relief, your child may need to see a bone specialist (orthopedic surgeon).

- The bone specialist can complete an exam, view X-rays and MRIs, and decide if surgery is needed to remove some of the damaged bone.
- In severe cases of AVN, surgery may be needed. This could involve joint replacement, bone reshaping (osteotomy) or core decompression (removal of necrotic tissue).

How can I help prevent AVN?

The exact cause of AVN in sickle cell disease is still not known.

- Regular physical activity may help your child. Mild, weight-bearing activities like walking can help improve bone health.
- Helping your child maintain a healthy weight and normal body mass index (BMI) can decrease stress on the joints, especially the hips.
- It may also decrease your child's chance of having AVN when you help them follow their sickle cell treatment

  plan to avoid other problems like pain crises and acute chest syndrome.

Jaundice and gallstones

What is jaundice?

Jaundice is when the white part of the eye and skin turn yellow.

- Bilirubin is a yellow substance normally found inside red blood cells.
- When fragile, sickle red blood cells break open and bilirubin leaks out into the bloodstream.
- As blood travels throughout the body, bilirubin pigment causes the eyes and skin to turn yellow (jaundice).

What are gallstones?

Gallstones are small stones that form when bile hardens into a solid form.

- Bile is most often a liquid. It is used to help break down (digest) fats that we eat.
- Bile is made by the liver and stored in the gallbladder.

The gallbladder is a sack or pouch under the liver. It is in the upper right part of the belly.

- Children with sickle cell disease have more bile than the gallbladder can hold.
- The extra bile forms a thick sludge and causes stones to form (gallstones).

Gallstones are most often not harmful. Pain may happen if they get stuck in the tube that leaves the gallbladder.

- Infection can happen if the tube gets blocked by stones.
- This can affect other organs nearby like the pancreas.
- About 1 in 3 children with sickle cell disease can have gallstones.

What symptoms can gallstones cause?

Your child may have 1 or more of these:

- A yellow color of the skin or whites of the eyes
- Sudden, sharp belly pain mostly on the upper right part of the belly. The pain gets worse after eating fatty foods.
- Upset stomach or vomiting (throwing up)
- Fever (temperature of 101°F or higher)
- Pale lips, gums or nails
- Weakness
- Feels more tired than normal
- Not wanting to play or take part in normal activity

What should I do if my child has symptoms?

Call your child's sickle cell disease provider if your child has any of these symptoms.

- Call your child's provider and **get medical care right away** anytime your child has a fever. **Fever is always a medical emergency for your child**.
- Be prepared to take your child to the Sickle Cell Disease Clinic or emergency department (ED).
- Give your child clear fluids like water, Powerade or Gatorade if they can drink without vomiting.

What is the treatment?

Your child will need to go to the Sickle Cell Disease Clinic or ED. They may need 1 or more of these:

- A physical exam
- A vital sign check (temperature, blood pressure, pulse and breathing rate)
- Blood tests (labs) to check their blood count, bilirubin level and other body chemicals
- Pain medicine
- Intravenous (I.V.) fluids to keep them from getting dehydrated
- Antibiotics if they have a fever
- An ultrasound of the belly to check for gallstones or infection

If your child has gallstones, they may also need:

- Surgery to remove the gallbladder with gallstones. This is called a cholecystectomy. It will be a scheduled surgery. It is one of the most common types of surgery in children and adults with sickle cell disease.
- Your child may need a blood transfusion before surgery. Blood transfusions before surgery help to reduce side effects after surgery.

What follow-up care does my child need?

After going home from the ED:

- Give your child plenty of fluids to drink.
- Avoid feeding your child fatty foods, such as pizza and fried foods. Fatty foods increase pain.
- Follow-up in the Sickle Cell Disease Clinic for a checkup and blood tests.
    - Your child may need an ultrasound of the belly if they did not have one in the ED.
    - Your child's provider will talk with you about surgery if your child has gallstones.

After going home from surgery:

- Be sure to follow the discharge instructions given when your child goes home from the hospital.
- Once your child goes home, they will need follow-up care in the Sickle Cell Disease Clinic.
- They will also need to follow up with their surgeon.

Chronic pain

As children get older, sickle cell disease pain can become chronic (long-term).

- When tissue damage happens, nearby nerves send signals to the brain that are felt as pain.
- Some children have pain every day.
- Chronic pain is treated in both the hospital and at home.

What is the treatment?

Chronic pain is treated in a different way than acute (short-term) pain. We will give your child a treatment plan to deal with chronic pain. This plan may include:

- Regular and frequent visits with your child's sickle cell disease provider.
- Anti-inflammatory medicine.
- Strong pain medicines taken by mouth (swallowed).
- Muscle relaxers.
- Meeting with a pain specialist.
- Visits with a psychologist.
- Physical therapy (PT) and TENS units.
- I.V. fluids and I.V. anti-inflammatory medicines in the hospital or clinic.

Pain medicine is not the only thing your child should use for pain. Your child's sickle cell disease provider will work with you to develop the right treatment plan for your child.

Fever and infection

What is a fever?

- A fever for children with sickle cell disease is when their temperature is 101°F or higher. Please check your child's temperature by using a thermometer and not by touch alone.
- A fever is often the first sign of an infection. It is important to treat **infections quickly.**

What is an infection?

An infection happens when germs (bacteria or viruses) are not recognized by the body. These germs continue to grow and spread. This causes an infection. Infections are a big danger to children with sickle cell disease. Children with sickle cell disease:

- Have a higher chance of getting infections than those who do not have sickle cell disease.
- Can have any infection at any time during their lives.
- **Can die from infections caused by bacteria if not treated quickly.**

What type of infection can my child have?

Your child can have an infection in the:

- Lungs (pneumonia).
- Blood (bacteremia or sepsis).
- Bowel (gastroenteritis).
- Bladder or kidneys [urinary tract infection (UTI) or pyelonephritis].
- Bone (osteomyelitis).
- Brain (meningitis).
- Ears and throat.

Why is my child at higher risk for infection?

- The spleen is one of the organs in the body that helps fight infection. In sickle cell disease, the spleen does not work like it should. This is due to damage from the sickle red blood cells.
- When there is damage to the spleen, it cannot fight off infections well.
- Damage to the spleen starts when a child is younger than 1 year old.
- Children with sickle cell types HbSS and HbS beta zero thalassemia have lower spleen function than children with other types of sickle cell disease

What should I do if my child has a fever?

- Take your child's temperature anytime they act or look sick.
  - **Have a thermometer at home and know how to use it**.
  - Make sure that others taking care of your child know how to use it, too.
  - If your child has a fever of 101°F or higher, call your child's doctor **right away**.
- **Fever is a medical emergency.** Do not wait until the next day to call the clinic or your primary care doctor. Call the on-call doctor if it is after hours for the clinic.
- Be ready to take your child to the emergency department (ED) or clinic.
- If your child has a fever, do **NOT** give them acetaminophen (Tylenol or less costly store brand), ibuprofen (Motrin, Advil or less costly store brand) or any other medicines with acetaminophen or ibuprofen in them.
  - These medicines can bring down the fever. They do not treat the cause of the fever.
  - **Always** check your child's temperature before giving them pain medicine.

What other symptoms could my child have?

If your child has a fever, they may also have 1 or more of these:

- Cough
- Chills
- Cold symptoms like a stuffy or runny nose
- Body aches
- Does not want to eat or play
- Feels weak or tired (fatigue)
- Headache
- Vomiting (throwing up) or diarrhea (loose stools)

What is the treatment for a fever?

Most often, fever is a sign of infection. Infections caused by bacteria can be very serious. **Getting treatment for your child right away can help to save their life.**

If your child has a fever, take them to see a doctor **right away**. Your child will need:

- A complete physical exam.
- Blood tests (labs) to check their blood count and find out if they have any germs in their blood (a culture).
- Other tests that depend on your child's symptoms. These tests may include a chest X-ray and urine test.

What happens if my child has to stay in the hospital?

Your child may have to stay in the hospital for more care. Most often, children younger than 6 months old with fever stay for at least 1 day. If your child's tests show they have an infection, they will need to stay longer.

In the hospital, your child may need:

- Strong antibiotics given through a vein (I.V.) or into the muscle (a shot) to help fight the infection.
- I.V. fluids.
- Medicines to help treat their fever.
- Vital signs (temperature, blood pressure, pulse and breathing rate) and oxygen level checks.
- A physical exam each day.
- Blood tests.

Your child may go home when they:

- Are feeling better.
- Have no fever.
- Have blood tests that show no signs of an infection.

What happens when my child goes home?

- Make sure you understand and follow your child's discharge instructions.
- **Take your child to the clinic for follow-up care as advised by the doctor**.
- If your child is still taking antibiotic medicines, do not stop giving them when they start to feel better. Give the total amount of antibiotics that your child's doctor prescribed.
- Ask your child's doctor about whether it is OK to give acetaminophen (Tylenol or less costly store brand) or ibuprofen (Motrin, Advil or less costly store brand) for fever. **DO NOT:**
  - Give your child more than 5 doses of acetaminophen in 24 hours.
  - Give acetaminophen to babies younger than 3 months of age without a doctor's order.
  - Give ibuprofen to babies younger than 6 months of age without a doctor's order.

How can I help prevent fever and infection?

To help prevent infection, follow these guidelines:

- Your child's doctor may order an antibiotic to help prevent infections caused by bacteria (germs).
  - It does **not** prevent all infections.
  - **Give the medicine as your child's doctor directs. This is very important**.
- Have your child get immunizations (vaccines) to help protect their body from harmful germs.
  - Keep your child's vaccines up to date.
  - Your child will also need other vaccines as advised by their sickle cell disease provider.
- Clean your hands often. Wash them well with soap and water for at least 20 seconds or use an alcohol-based gel or foam. Teach your child and anyone who cares for them to clean their hands often.

Hepatic sequestration (liver problems)

Hepatic sequestration is a problem sometimes seen in older children with sickle cell disease. When this happens, red blood cells get trapped inside the liver instead of the blood.

What are the symptoms?

Your child may have 1 or more of these:

- Pale skin color

- Belly pain
- Yellowing of the eyes (jaundice)
- Nausea (upset stomach) and vomiting (throwing up)

What is the treatment?

If your child has any of these symptoms:

- Your child needs to be seen **right away**.
- Call the Sickle Cell Disease Clinic or go to the nearest emergency department (ED) **right away.** In severe cases, your child may need a blood transfusion.

Iron overload

What is iron overload?

Iron overload means your child's body has stored more iron than it needs.

- We all need iron to grow and develop.
- It can cause health problems when too much iron builds up to a level that overloads the body.

What causes it?

Blood transfusions are used to treat many different types of sickle cell problems. This means some children with sickle cell disease may need many blood transfusions to stay healthy. Children who receive blood transfusions over a long period of time can have a buildup of extra iron.

- Each unit or pint of blood contains iron.
- The body can only store a small amount of iron safely.
- The body does not have a natural way to get rid of the extra iron.
- The extra iron builds up in the body over time.
- It is stored in major organs like the liver and heart.
- The body cannot function like it should with extra iron.

What are the effects of iron overload?

Most often, there are no symptoms in the early stages of iron overload. For this reason, children who receive frequent blood transfusions will have their iron levels checked regularly. It is important to treat high iron levels because the extra iron will cause organ damage. Iron stores itself on the:

- Liver.
- Heart.
- Skin.

- Pancreas.
- Reproductive organs (ovaries in girls, testes in boys).

What are the symptoms?

Your child may have 1 or more of these:

- Weight loss
- Fatigue (feel very tired)
- Bronze or gray skin
- Joint pain
- Shortness of breath
- Swelling of ankles
- Abdominal (belly) swelling or pain
- Blood in the stool
- Stunted growth
- Delayed puberty
- Diabetes (increased thirst and increased urinating)

Ask your child's sickle cell disease provider for more details about problems with iron overload.

What tests could my child have?

Your child may have 1 or more of these:

- A blood test called a ferritin level
  - It tells how much iron is stored in the body.
  - If your child gets blood transfusions often, their sickle cell disease provider will order this blood test to check for iron overload.
- FerriScan: this is a special type of MRI that measures iron levels in the liver.
- Cardiac MRI: this is an MRI of the heart that can measure iron levels in the heart.
- Liver biopsy: the doctor takes a sample of tissue from the liver and sends it to the lab. The lab checks it for iron levels and checks for any damage to the liver tissue.

What is the treatment?

There are medicines to help remove extra iron from the body. They are called iron chelators. They can be taken:

- By mouth (to swallow).
- Under the skin by subcutaneous injection (shot).
- Through an I.V. in the hospital with a continuous infusion.

Most children with iron overload will take iron chelators by mouth. Some children will need more than 1 type of chelator to treat high iron levels. Your child's doctor will give you instructions based on your child's needs.

Other ways to treat or prevent iron overload are:

- Phlebotomy – a certain amount of blood is removed based on your child's weight and hemoglobin level. This helps to rid the body of extra iron.
- Exchange transfusion – this is done to remove sickle red blood cells and replace them with normal red blood cells. It can help stop the buildup of iron in the body and keep the excess iron levels down.

Kidney problems

Sickle cell disease can also affect the kidneys. Kidney problems can start early in life and get worse over time.

What is sickle cell nephropathy?

Sickle cell nephropathy happens when there is damage to parts of the kidney.

- The kidneys are filters for the blood. They make urine, which allows your body to remove salts, waste and extra water from your blood. They also help your body to keep the important parts of your blood like proteins and cells inside the blood.
- In sickle cell nephropathy, parts of the kidney are damaged by sickle cells. This does not cause pain. You may not know there is any damage to your child's kidneys unless it is found in blood or urine tests.
- Sickle cell nephropathy happens very slowly. If it starts in childhood, it may slowly cause more damage over several years and become more severe in teens and adults.

What happens from sickle cell nephropathy?

When the kidneys are damaged by sickle cells:

- Small amounts of protein in the blood can leak out of the blood and be lost in the urine. One of these proteins is called albumin. Having too much protein in urine is called proteinuria or albuminuria. This is an early sign that kidney damage has started.
- Blood can sometimes appear in the urine when the kidneys are damaged. This is called hematuria. The bleeding can last for a few hours or a few days.
- As damage to the kidneys gets worse over years, the kidneys may stop working (kidney failure). A person with kidney failure may not be able to make urine. People with kidney failure need dialysis (a machine to help the body get rid of waste) a few times each week to survive. They may also need a kidney transplant if the condition is not improved with dialysis.

What are the symptoms?

Your child may not have any symptoms. **Early signs of kidney damage often show on a routine urine test done in clinic.**

Your child could have 1 or more of these:

- High blood pressure
- Protein in the urine
- Blood in the urine

What should I do if my child has symptoms?

Call your child's sickle cell disease provider if your child has any symptoms.

If your child has blood in their urine, call the Sickle Cell Disease Clinic. If after-hours, leave a message with the on-call service and ask to talk with the hematologist on call.

What tests could my child have?

Your child will need a complete physical exam and blood pressure check. They may also need:

- A urine test to look for blood and protein in the urine.
- Blood tests (labs) to check blood counts and kidney function.
- An appointment with a kidney doctor (nephrologist).
- A kidney biopsy. This test uses a tiny sample of kidney tissue. It tells doctors how much kidney damage has happened and the type of treatment needed.

What is the treatment?

Your child's treatment may include:

- Intravenous (I.V.) fluids if there is blood in the urine.
- An appointment with a kidney doctor.
- Medicines to treat sickle cell disease, such as hydroxyurea.
- Medicines to decrease protein in the urine, such as losartan, lisinopril or similar medicines.
- Medicines to treat high blood pressure if needed.

Your child's sickle cell disease provider will talk with you about other treatments your child needs. Please ask questions.

What follow-up care does my child need?

Your child will need continued care after they leave the clinic, emergency department (ED) or hospital. Make sure to follow all discharge instructions.

- Take your child to a follow-up clinic visit as their provider directs.

- Give your child plenty of fluids to drink each day. Ask your child's provider how much fluid your child needs.
- Make sure your child is urinating well. Look at the urine to make sure there is no blood in it. The urine should be a clear, pale, yellow color.
- Follow other instructions as the provider directs.

How can I help prevent kidney damage?

To help prevent kidney damage:

- Give your child plenty of fluids to drink each day.
- Know what your child's normal blood pressure is and when the numbers may be too high.
- Avoid medicines that can harm the kidneys. Ask your child's provider or pharmacist about the medicines your child takes. This includes over-the-counter medicines.
- Ask your child's provider about how nephropathy is treated.

Pain episode

What is a pain episode?

Pain and other sickle cell problems happen when the red blood cells (RBCs) become sickle shaped. The sickle shaped cells are sticky and clump together. These clusters of sickle cells block blood flow and oxygen to parts of the body. This can cause pain to the affected area.

A pain episode (also called a vaso-occlusive episode) is the most common problem for children with sickle cell disease. A pain episode can happen anywhere in the body. Some of the more common areas are the bones, lungs, spleen, brain, eyes and kidneys.

- When tissue is damaged, the injury causes nearby nerves to send electrical signals to the brain. The signals are felt as pain.
- Pain can continue for some time until the tissues start to heal and the nerves calm down.
- In some children, pain can last longer because the nerves do not calm down.

What are the symptoms?

Everybody feels pain in a different way. This depends on many things, such as:

- How well the body repairs itself.
- How the body and mind react to pain.
- Past experiences with pain.
- How well pain medicines work.

Pain episodes can happen:

- Sudden and without warning.
- With some warning signs.
- With other sickle cell problems, mainly in the lungs.
- As a result of another sickle cell problem, such as gallstones.

Sometimes people can have pain for a short period of time. This type of pain is called acute. It can last anywhere from a few hours to a few weeks. There are other children who have pain that stays all the time. This pain is called chronic. Acute pain and chronic pain have different treatments. Your child's doctor will tell you how to best treat your child's pain.

In babies and toddlers

A more common type of pain for younger children is hand-foot syndrome or dactylitis. This means the symptoms are mostly in the hands or feet and include:

- Swelling, warmth or change in movement.
- Pain or upset.

Young children often have trouble telling where the pain is, what it feels like and how much they hurt. Some signs of hand-foot syndrome are when a child does not want to hold their bottle or have socks and shoes on their feet. They may also avoid walking or putting weight on their feet.

In older children and teens

Pain can happen anywhere in the body and in more than 1 place at the same time.

- The most common sites of pain are the arms, legs, joints, back and belly
- Swelling, warmth and increased pain with movement or touching can happen.
- Sometimes the pain can be deep in the body or bones without these other signs.

Older children and teens learn how to tell where the pain is and how much they hurt. They often say their sickle cell pain feels "different" than other pain, such as headache, sore throat, or muscle sprains.

What tests could my child have?

Pain can happen with any type of tissue injury or damage, such as after surgery or an accident. Pain in a person with sickle cell disease can be caused by many different things. This includes:

- Exposure to cold.
- Higher levels of stress.
- Illness.
- Extreme changes in the weather.

There are no medical tests that check for pain or a pain episode. There are no tests that can tell when sickle cells are causing a blockage. This means that pain is not easy to confirm. It is important that providers listen to what your child says about their pain.

There are triggers that can start a pain episode. Some tests can check for triggers. This includes:

- A complete blood count (CBC) to check for anemia (low red blood cell count or low hemoglobin).
- Blood chemistries to check for dehydration.
- A chest X-ray to check for pneumonia or sickle cell crisis in the lungs (acute chest syndrome).

What is the treatment?

The goal of treating a pain episode is to help make your child more comfortable and allow for as many normal activities as possible.

- This does not always mean being without pain.
- Having a positive outlook, taking control and not giving up are helpful life skills that can help your child cope with pain.

Most pain episodes are similar each time. Your child's provider will talk with you about specific care for your child. This includes pain medicines based on your child's weight and normal level of pain. Work with your child's provider to help choose treatments for mild or severe pain.

Things you can do at home

Most pain can be managed at home with pain medicine, drinking extra fluids and rest. Make a plan that works best for you and your child's level of pain.

This includes:

- Massage or heat on the painful area for 15 minutes every hour. Be sure to place a cloth cover on the skin before you apply heat to help prevent skin burns. **Do not use ice packs**. They could make the pain worse.
- Help your child find a quiet place where they can relax, rest and be comfortable. Many pain medicines cause children to feel sleepy.
- Use distraction to help take your child's mind off their pain. Some ideas include:
  - Playing cards and video games.
  - Reading.
  - Watching TV.
  - Listening to music
  - Talking with friends on the phone.
- Some children find quiet meditation or prayer helpful.

- Give your child plenty of extra fluids, such as water (best choice) or juice, to help prevent getting dehydrated.

For mild pain or pain that is just starting

- Give your child acetaminophen (Tylenol or less costly store brand) or ibuprofen (Motrin, Advil or less costly store brand).
- Be sure to check your child's temperature **before** giving these medicines.
- **DO NOT:**
  - Give more than 5 doses of acetaminophen in 24 hours.
  - Give more than 4 doses of ibuprofen in24 hours.
  - Give more than the advised dose each time.
  - Combine acetaminophen with other medicines that also have acetaminophen in them like Lortab (hydrocodone + acetaminophen). This is too much acetaminophen and can cause liver damage.

For more severe pain

- Give your child a stronger opioid pain medicine, such as Lortab, or similar medicine prescribed by your child's doctor.
- Opioid pain medicines can cause side effects. If these are problems for your child, talk with their provider about things you can do to help prevent or reduce them. Some side effects include:
  - Constipation.
  - Sleepiness.
  - Upset stomach.
  - Itching.

When should I call the clinic about my child's pain?

Call your child's provider when you cannot handle your child's pain at home. Your child may need other types of pain treatment. Also, be sure to call the clinic **right away** anytime your child has a fever of 101°F or higher.

When should I take my child to the hospital for pain?

You may need to take your child to the hospital to get stronger pain medicines. They are:

- Most often given through an I.V. (into a vein).
- Often work better when given with I.V. fluids.
- May be given in the clinic, emergency department (ED) or hospital. This is based on how severe the pain is. Your child's provider will let you know where to go for treatment.

Take your child to the hospital if they have other serious symptoms, such as:

- Fever.
- Trouble breathing.
- Weakness.
- Loss of consciousness (passes out).

What do I need to know about pain medicines?

- Make sure you do not run out of pain medicine. Your child's provider may not be able to call in a prescription for opioid pain medicines. You may need to give a written prescription to the pharmacy.
- Be sure to keep medicines in a safe place. It is dangerous for children to take too much.
- Do not wait to see if the pain goes away by itself. Pain can get very strong. This makes it harder to treat.
- When your child needs medicine for pain, give it on a **set schedule**.
    - Most pain medicines only work in the body for 4 to 6 hours.
    - Follow the medicine directions carefully for how much to give your child and when to give it. This is very important when your child needs more than 1 medicine to control the pain.

Providers most often use a step-up or "ladder" approach with pain medicines. Ask them what this means for your child.

What follow-up care does my child need?

After your child goes home from the ED or hospital:

- Give pain medicines and fluids as directed.
- Make sure you know when to stop the pain medicines. If opioid pain medicines are stopped too quickly, your child could have problems with withdrawal symptoms.
- Have your child return to their normal activities and schoolwork as soon as possible.
- Follow-up with your child's provider as advised. They can talk with you about how well the medicines worked and make changes as needed. You will also be able to get new prescriptions for medicines to use in the future.
- Your child's provider can make a Pain Action Plan. This will be a list of set treatments that have worked to help treat your child's pain in the past.

How can I help prevent pain episodes?

It is not fully understood what causes a person to have a pain episode. For that reason, it is hard to find ways to prevent them. People have their own triggers or patterns. Some things that seem to play a role include:

- Physical and mental stress.
- Changes in the weather.

- Being very tired.
- Dehydration.
- Infections.
- For some older girls and women, pain episodes happen around their monthly period.

Healthy lifestyle habits can help prevent some pain. Try to help your child:

- Drink enough water.
- Sleep 7 to 8 hours each night.
- Reduce or treat their stress.
- Avoid cold water on their skin and ice packs.

For some children, pain is a part of their sickle cell disease. If this is true, there are a few things that may help reduce how en a pain episode happens. This may include:

- Blood transfusions.
- Medicines like hydroxyurea, L-glutamine or crizanlizumab (Adakveo).
- A bone marrow transplant.

Priapism

Priapism is a long-lasting, unwanted, painful erection (firmness) of the penis.

- It results from sickle cells blocking the blood vessels in the penis.
- Priapism can happen as early as age 5, but more often affects older boys and men.
- It often happens late at night or early in the morning.

What is the treatment?

Priapism is very uncomfortable and needs treatment **right away**. Home treatments include:

- Taking pain medicine.
- Taking a warm shower or bath.
- Drinking plenty of fluids.
- Taking a medicine like pseudoephedrine (Sudafed). Talk with your child's sickle cell disease provider if you have questions about this medicine.

If priapism lasts longer than 2 hours, call the Sickle Cell Disease Clinic **right away** or go to the nearest emergency department (ED).

- Your child will need to be seen in the Sickle Cell Disease Clinic or the nearest ED.

- They will get I.V. fluids and I.V. pain medicines.
- They may also need a blood transfusion.
- Your child's sickle cell disease provider may want your child to see a urologist (doctor who specializes in care of urinary tract and penis).

If not treated, priapism can lead to problems with sexual function or fertility problems (difficulty having children). Make sure your child tells you **right away** if they have symptoms.

Pulmonary hypertension (lung problems)

Pulmonary hypertension can happen in people with sickle cell disease. It is caused by increased blood pressure in the blood vessels that carry blood from the heart to the lungs.

- The high pressure can lead to narrow arteries (blood vessels). This can cause the heart to work harder as it pumps blood.
- It is most often found by doing an ultrasound of the heart (echocardiogram).
- It is more common in adults than children.

Pulmonary hypertension can be caused by:

- The breakdown of an excess number of red blood cells (hemolysis).
- Having low oxygen levels for a long time.
- Repeated blockage of the blood vessels by sickle red blood cells and clots.

What are the symptoms?

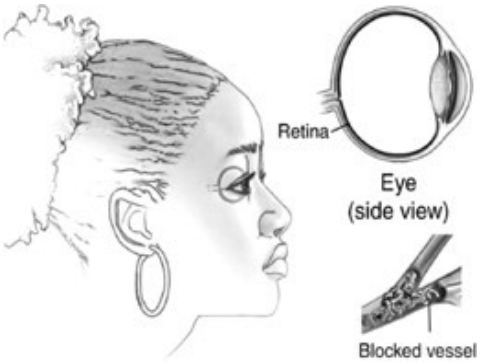
Symptoms of pulmonary hypertension are also common in other conditions like asthma. They can be mild to severe and may include:

- Dizziness
- Trouble breathing
- Fatigue (feels very tired)
- Chest pain

Without treatment, pulmonary hypertension may lead to heart failure and death in adults with sickle cell disease.

- Because of this risk, we advise that your child have an echocardiogram (echo) and other heart tests by the time they turn 10 years old.
- Finding this problem early and starting treatment are the best ways to treat it.
- Take your child to the clinic for regular checkups and care to help prevent these kinds of problems.

Retinopathy (eye problems)



What is sickle cell retinopathy?

Retinopathy is damage to the retina in the eyes. The retina is the "seeing" part of the eye. It is in the back of the eye and:

- Contains nerves and small blood vessels.
- Captures light and images so we can see.

Eye problems are more common in older children and adults with HbSC and HbS Beta + Thalassemia.

- This is may be due to a higher hemoglobin level in patients with these types of sickle cell disease. This makes the blood thicker.
- As this "thicker" blood travels through the small blood vessels in the eyes, it causes damage to these vessels and can lead to vision loss if not treated early.

What causes it?

Sickled red blood cells can get trapped inside the small blood vessels in the retina. This can cause:

- A decrease in blood flow. This can lead to damage of the retina. The damage may be permanent.
- Bleeding in the eye.
  - When blood vessels get blocked, the eye makes new vessels to replace the blocked vessels.
  - The new vessels are thinner and weaker. They may break open and bleed.
  - The bleeding causes damage to the retina. Bleeding can also cause the retina to loosen from the rest of the eye. This is called a detached retina. Damage to the retina can cause changes in eyesight. If the damage is not treated, blindness may happen.

What are the symptoms?

At first, there may be no symptoms. **This is why an eye doctor must check your child's eyes every year.**

When retinopathy worsens, your child may have these problems:

- Flashes and dark shadows in some parts of their vision (floaters)
- Blurred vision
- Sudden loss of vision
- Pain in the eyes

What should I do if my child has vision changes?

Call your child's doctor **right away** if your child has vision changes.

- If your child already has an eye doctor (ophthalmologist), call them **right away**.
- **If your child cannot see an eye doctor right away, take your child to the nearest emergency department (ED).**

Vision changes can also happen with a stroke. Either way, your child needs to be checked **right away.**

What tests could my child have?

Your child needs a complete eye exam by an eye doctor who knows about sickle cell disease.

- The eye doctor will put drops in your child's eyes. This helps the doctor see the entire eye better.
- **ALWAYS** tell the eye doctor that your child has sickle cell disease. Your child needs a more careful exam.

What is the treatment?

Your child will need treatment if their retina shows signs of damage.

- If caught early, your child's eye doctor can treat most problems.
- Your child may need eye exams more often.
- Some problems can be treated with a laser.
- Others may need to be treated with surgery.

What follow-up care does my child need?

- Make sure you understand and follow the instructions the eye doctor gives you. Always ask questions if the instructions are unclear.
- Your child needs regular follow-up care with the eye doctor and their sickle cell disease provider.

How can I help prevent retinopathy?

Early stages of sickle cell retinopathy most often do not cause changes in eyesight. You can help prevent eye problems by doing these things:

- When your child is 9 or 10 years old, start scheduling them for an eye exam with an eye doctor **every year.** Treatments work better if eye changes are found early.
- Your health insurance may need a referral from your child's primary doctor (pediatrician) before they can see an eye doctor. Talk about this with your health insurance company (including Medicaid) ahead of time.
- Follow treatments as advised by the eye doctor.
- Give your child plenty of fluids to drink each day. Do this from the time they are 6 months old. Fluids help keep the sickle cells from sticking together and causing problems.

- Ask your child often if they have any vision changes. If they do, schedule an eye exam **right away** even if they are younger than 9 or 10 years old.
- A simple vision screen using the eye chart is different from a full eye exam by an eye doctor. Ask your child's sickle cell disease provider if you are unsure of the type of eye exam that your child needs.

Splenic sequestration (spleen problems)

What is a splenic sequestration crisis?

Splenic sequestration crisis is a problem that sometimes happens in children who have sickle cell disease. The name means:

- Splenic – the problem happens in the spleen.
- Sequestration – the blood in the spleen is separated from the rest of the blood in the body.
- Crisis – the problem is an emergency.

The spleen is an organ to the left and slightly above the stomach. It is protected by the ribs. The spleen helps to:

- Fight infection.
- Make and store red blood cells (RBCs).
- Clean the blood.

Splenic sequestration crisis:

- Can happen as early as 6 to 9 months of age.
- Often happens before 5 years of age.
- Can happen in older children with hemoglobin SC disease and sickle beta+ thalassemia.

What happens with splenic sequestration crisis?

With splenic sequestration crisis, the spleen suddenly gets swollen and big because:

- The spleen is the first organ injured by sickle cells in the blood. The sickle red blood cells block the blood vessels inside the spleen. This prevents the blood from leaving the spleen.
- When this happens, a large amount of blood gets trapped in the spleen. This causes the spleen to get swollen.
- Since the blood cannot get back into the bloodstream, the hemoglobin level (RBC count) can go down to very low levels.
- There may not be enough blood left in the bloodstream for vital organs to work as they should.
- **This can lead to shock and is a medical emergency**.
- This is one of the most common causes of death in children with sickle cell disease.

What are the symptoms?

The spleen gets very big and easy to feel. Your child's care team will teach you how to feel for your child's spleen. Get help for your child **right away** when you feel a big spleen.

Your child may also have 1 or more of these:

- Pale lips, gums or nails
- Fast breathing
- Fast heartbeat
- Weakness
- Pain in the area around the spleen
- Feels more tired than normal
- Does not want to play or take part in normal activity
- Sleeps longer
- Does not feed or eat like normal

NOTE: Fever or infection can sometimes happen. Your child may or may not have fever when their spleen is swollen.

What should I do if my child has symptoms of a crisis?

If your child has any of these symptoms:

- **Get medical help right away.** Your child needs treatment as soon as possible.
- Call the Sickle Cell Disease Clinic or go to the emergency department (ED).

Call 911 right away if your child is:

- Very limp or pale.
- Having trouble breathing.
- Not responding well.

What tests could my child have?

Your child will need many of these tests:

- A physical exam
- Blood tests (labs), including blood counts
- A blood type and crossmatch in case your child needs a blood transfusion
- An ultrasound test to see how big the spleen is or if there are any other problems
- Frequent checks of the spleen size to make sure it is not getting bigger

What is the treatment?

The spleen can get big very quickly. This can cause serious problems. A child with splenic sequestration crisis most often needs treatment in the hospital. Sometimes a splenic sequestration crisis may not be as bad and can get better without treatment.

If your child needs treatment, it may include:

- Intravenous (I.V.) fluids.
- Blood transfusion.
- Oxygen.
- Antibiotics.

Your child may be able to go home if their red blood cell (RBC) count is not too low and you know how to feel for the spleen.

After going home from the ED:

- Feel the spleen as you have been taught. Watch closely for any increase in size.
- **Call the Sickle Cell Disease Clinic or return to the ED right away if you feel the spleen getting bigger.**
- Follow-up in the clinic within 1 or 2 days, or as your child's doctor directs. They will check your child's RBC count and spleen size.

After going home from the hospital:

Take them to their follow-up clinic visit as advised. The follow-up may include:

- A physical exam.
- Blood tests.
- Teaching you how to feel for your child's spleen if you do not know how.
- A blood transfusion on a regular schedule if your child had very bad splenic sequestration. This can help prevent a crisis.

Call the Sickle Cell Disease Clinic or return to the ED right away if you feel the spleen getting bigger.

If your child's spleen stays swollen:

- This is called chronic splenomegaly (enlarged spleen).
- You may need to limit your child's activity to help prevent injury to the spleen. Your child should avoid contact sports like football, basketball and soccer.
- Your child may need a blood transfusion if their spleen gets bigger and their hemoglobin drops too low.

If your child had severe splenic sequestration crisis or has had it more than 2 times, they may also need:

- Surgery to remove the spleen (called a splenectomy).
- Blood transfusions on a regular schedule if your child is younger than 2 years old. Children under 2 are not old enough for this surgery because they have a higher risk of infection.

What follow-up care does my child need?

Your child will need frequent clinic visits to check their red blood cell (RBC) count and spleen size.

How can I help prevent splenic sequestration crisis?

A splenic sequestration crisis can happen more than 1 time. A child who has it 1 time is likely to have it again. You can help decrease the chance of it happening when you:

- Keep all your child's follow-up visits in the Sickle Cell Disease Clinic. This is very important.
- Follow the sickle cell disease provider's advice for your child's treatment. This includes making sure they get blood transfusions when needed.
- Learn how to feel for your child's spleen so you can tell **right away** if it is getting bigger.

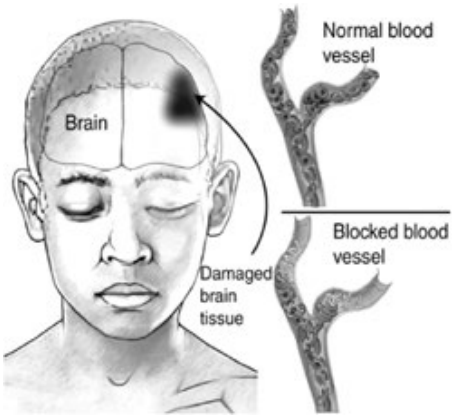
Stroke

What is a stroke?

A stroke is the loss of blood supply to part of the brain. A stroke is caused when either a blood vessel in the brain is blocked or there is bleeding of the blood vessels inside the brain. Strokes are more likely to happen in children with sickle cell disease because:

- Blood vessels can get blocked by sticky sickle red blood cells (RBCs).
- Sickle cells cause the blood vessels in the brain to become narrow. This makes it easier for the sickle cells to get stuck.
- Blood vessels damaged by sickle cells can bleed more easily.

Strokes are more common with hemoglobin SS but can also happen in other types of sickle cell disease. They also happen more in children ages 2 to 5 years old but can happen at any age.



What happens from a stroke?

A stroke cuts off the normal blood and oxygen supplies to part of the brain. This causes brain cells to die and brain damage to happen.

- The damaged part of the brain does not work like it should.

- The parts of the body the damaged brain area controls do not work well either. This is why an arm or leg can be weak or not able to move after a stroke.
- A stroke may also cause problems with memory and learning.

What are the symptoms?

Strokes can happen without warning. They can also happen with other sickle cell problems.

A stroke can cause 1 or more of these:

- Slurred or confused speech (when speech was clear before)
- Muscle weakness or unable to move 1 side of the body (face, arm or leg)
- Unsteady walk (when walking was normal before)
- Numbness or tingling of the arms or legs on 1 side of the body
- Very bad headache that does not go away
- Confusion
- Seizures (jerking or twitching of the face, arms or legs)
- Loss of consciousness (passing out)
- Changes in vision (seeing)

Rarely, stroke symptoms may last for a short time and then get better. **Call your child's sickle cell disease provider right away.** Sometimes, a more severe stroke can happen soon.

What should I do if my child is having a stroke?

- **Call your child's sickle cell disease provider right away if they have any symptoms of a stroke.**
- Take your child to the nearest emergency department (ED).

Call 911 right away if your child:

- Has trouble breathing.
- Does not respond to you or passes out (is unconscious).
- Has a seizure.

What tests could my child have?

Your child will need tests to see if a blood vessel in the brain is blocked or if bleeding has occurred. Tests may include:

- A physical exam.

- Blood tests (labs), including a blood type and crossmatch for a blood transfusion.
- CT scan or MRI of the brain.
- An exam to check how well the brain, nerves and muscles are working.

What is the treatment?

Treatment may include:

- Intravenous (I.V.) fluids.
- Medicines to help prevent or treat seizures.
- Oxygen treatment if oxygen levels are low.
- Blood transfusions help get more oxygen to the brain through the blood.
- An exchange transfusion to replace the sickle cells with normal RBCs. This may help the damaged brain tissue recover more quickly.
- Surgery to relieve pressure from bleeding inside the brain. This is most often not needed.
- Treatment with specialists, such as neurologists (doctors who treat problems with the brain and nerves).
- Treatment of fever and infection as needed.

What follow-up care does my child need?

Follow-up care is very important. Your child will need more treatment and care, which may include:

- Checkups, exams, blood tests and a treatment plan in the Sickle Cell Disease Clinic.
- Physical, occupational and speech therapy to help retrain and strengthen parts of the body affected by the stroke.
- Follow-up with a neurologist to check your child's progress and watch for any problems.
- Follow-up with a psychologist (a doctor who helps with problems with learning and behavior) to find out if other treatments are needed.
- Working with teachers and other learning specialists to get special help with schoolwork. A stroke can damage parts of the brain that control learning, reading, language or math.

How can I help decrease the risk of another stroke?

Seventy percent (7 out of 10) of children with sickle cell disease who have had a stroke will have another stroke if they do not get proper treatment. Treatment to help prevent another stroke may include:

- Blood transfusions each month to help decrease the number of sickle cells that block blood vessels in the brain.
- Exams, tests and MRI scans to check the nerves and brain.
- Brain blood vessel surgery to go around blockages in the brain.
- A bone marrow transplant (BMT), which can cure sickle cell disease.

How can I help prevent my child from having a stroke?

- A brain ultrasound test called a transcranial doppler (TCD) can show if your child is at a higher risk of having a stroke.
  - If your child has SS or S beta zero thalassemia, they should get a TCD at least 1 time every year from the time they are 2 years old until they are 16 years old.
  - TCD screening has decreased the number of children with sickle cell disease who have strokes. It is very important to make sure your child gets this test at least 1 time each year. In some cases, the doctor may want your child to have the test more often.
- Your child may need blood transfusions each month to help prevent a stroke if TCD results are not normal.
- Hydroxyurea treatment may decrease your child's risk of stroke.
- Bone marrow transplant to cure sickle cell disease can also prevent stroke.

What is a "silent stroke"?

A silent stroke is seen on an MRI in a person who has not had symptoms of a stroke. Silent strokes are common in children with sickle cell disease and may cause learning problems. Research is being done to better understand how to help prevent and treat silent strokes.

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Tests and Procedures

Abdominal ultrasound

An abdominal ultrasound is a test that looks for problems in the abdomen (belly). It is often done when children with sickle cell disease have 1 or more of these symptoms:

- Belly pain
- A swollen belly or a feeling of pressure inside the belly
- Enlarged spleen
- Yellowing of the eyes or skin (jaundice)
- Nausea (upset stomach) or vomiting (throwing up)
- Low platelet count
- Abnormal liver enzymes

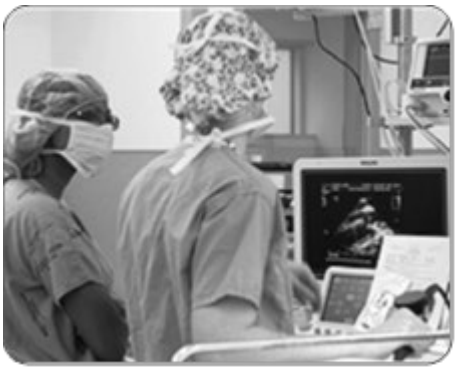
Common findings may include:

- Gallstones
- Sludge (small bits of semi-liquid stones) in the gallbladder
- Enlarged spleen or liver
- Small area of damaged tissue in the spleen or kidneys
- Cysts on the ovaries

Note: Do not allow your child to eat or drink anything for at least 4 hours before an abdominal ultrasound. Food and gas in the belly can cause the test to be cloudy. If this happens, you may need to reschedule your child's test.

Echocardiogram

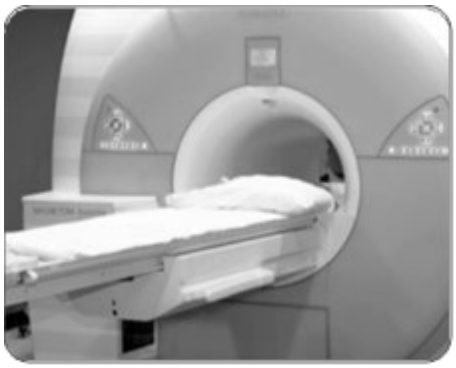
An echocardiogram (echo) is a medical test that takes pictures of the heart using sound waves (sonogram). It is helpful because children with sickle cell disease may have heart problems.



To do the test, a technologist spreads warm gel on your child's chest. The technologist then moves a wand across the skin to take pictures of the heart on a computer screen. It is not painful. A cardiologist (heart doctor) reviews the pictures and sends the results to your child's provider.

Your child will have an echo at 10 years old and again before they change to adult care. We will let you know if your child needs a repeat test sooner based on their results.

MRI



An MRI uses a large magnet, radio waves and a computer to take pictures of the inside of your child's body. The provider can see a more detailed picture of your child's brain, belly, joints and more.

The MRI looks like a tunnel. It has a special bed that slides in and out. It makes a loud noise, but does not hurt your child. If your child is not able to stay still for the test, they may need medicine (sedation) so they can be calm, sleepy and lie still during the test.

A radiologist (X-ray doctor) reviews the pictures and sends results to your child's sickle cell disease provider.

Transcranial doppler ultrasound (TCD)

What is a transcranial doppler (TCD)?

A transcranial doppler (TCD) is an ultrasound of the brain.

- It measures the blood flow speed in the main blood vessels of the brain.
- It is safe and painless.
- Your child does not have to do anything special to prepare for it.

Why is a TCD used?

A child with sickle cell disease (SCD) has a much higher chance of having a stroke than a child who does not have sickle cell disease. A TCD helps to find out which child has a higher chance of having a stroke.

What is a stroke?

A stroke happens when 1 or more blood vessels inside the brain are blocked.

- A stroke can happen without warning. The damage may never go away. It causes damage to the brain and nerves.
- The less damage there is, the better the chance of a full recovery.
- The TCD helps your provider learn if your child has a higher chance of a stroke before the stroke happens.

Who should have a TCD?

Children with Hb SS and S Beta 0 Thalassemia between the ages of 2 and 16 years should have the TCD test 1 time each year.

- A stroke can happen as early as 2 years of age. Your child should start the screening test at the age of 2.
- Your child's sickle cell disease provider will talk with you about the test.

How does the TCD work?

TCD measures the speed of the blood flow through the blood vessels in the brain. It shows areas that have high or low blood flow speed.

- Blood flow speed depends upon the size of the vessels. It is more difficult for blood to travel if the blood vessels are narrow. The body uses more pressure to push the blood through the small space. This makes the speed of the blood flow through that area higher than normal.
- Higher blood flow speed and smaller blood vessels can increase the chance for a stroke at any time.

What should I expect when my child has a TCD?

The TCD is done in the outpatient Sickle Cell Disease Clinic when your child is feeling well. Your child may eat, drink and take their medicine as usual. The TCD does not cause pain or discomfort and takes about 30 to 45 minutes.

During the test:

- Your child may wear their own clothes.
- A clear gel is put on their head. A small wand is placed on your child's head to measure the blood flow speed.
- Your child will be awake, but needs to lay still and stay quiet. The test results of the TCD will not be as accurate if your child is moving around or sleeping.

After the test, the area on their head is cleaned, and they can return to their normal activities.

What do the TCD results mean?

Your child's test may show 1 of the results below:

- **Normal TCD** means your child has average blood flow speed.
  - Your child needs to have a TCD **1 time each year**.
- **Conditional TCD** means your child's blood flow speed is higher than average.
  - Your child should have a repeat TCD **in 3 to 4 months** to see if their blood flow remains conditional.
- **Abnormal TCD** means your child's blood flow speed is too fast or too slow.
  - This type of blood flow puts your child at risk for having a stroke. They need to have a repeat TCD **within 2 to 4 weeks.**

- If the TCD is still abnormal, your child will need further treatment to help prevent a stroke.
- Your child's sickle cell disease provider may also order an MRI (magnetic resonance imaging) of the brain if the TCD results are abnormal.

- **Inadequate TCD** means your child's test results cannot be read.
  - If this happens, your child will need to repeat the TCD or have a different test.

When do I get the results?

A pediatric radiologist, a doctor specially trained in children's X-rays, will look at the pictures. They send a report and may talk with your child's sickle cell disease provider.

- Your child's sickle cell disease provider will contact you with the test results.
- Call your child's sickle cell disease team if you have not received the test results after 5 business days.
- Please make sure we have a **working phone number** for you.

Other common imaging studies

Because sickle cell disease affects many body organs, your child will have other tests to check them. Some of these tests may include:

- **Chest X-ray:** A test that looks for problems in your child's lungs, such as pneumonia or acute chest syndrome.
- **CT scan:** A test to provide clearer views of body organs that cannot be seen with a regular X-ray. If your child's doctor is concerned about bleeding in the body, they may order a CT scan of a certain area. A CT scanner is a round-shaped machine with a special bed that moves in and out. It is not painful. The test takes a few minutes.
- **Doppler ultrasound:** An ultrasound used to check for blood clots in the blood vessels.
- **FerriScan:** A special type of MRI used to measure the amount of iron in the liver. The test may take up to 20 minutes. If your child is not able to stay still, they may need medicine (sedation) so they sleep through the test.

Pulmonary function test (PFT)

Many children with sickle cell disease have lung problems, such as acute chest syndrome, hypoxia and asthma. A PFT checks how well your child's lungs work (lung capacity). It is completed at the time of your visit and may be done in the clinic or in the pulmonary lab.

- The test takes about 15 to 20 minutes and is done by a trained technician.
- It is not painful and does not include blood work or shots.
- Your child will breathe through a mouthpiece in different ways.

A pulmonologist (lung doctor) reviews the results and gives them to your child's sickle cell disease provider. Based on the PFT results, your child may need treatment. You will have a chance to talk about the results with your child's provider and ask questions.

Liver biopsy

The doctor removes a small piece of tissue from the liver using a special needle. Children with iron overload from chronic transfusions will sometimes have a liver biopsy to find out how much iron is in the liver and to look for liver damage.

- Your child will get medicine (anesthesia) that will put them into a deep sleep for the test. They will not feel any pain while asleep.
- Your child will get extra I.V. fluids.
- Your child may need a blood transfusion before the test. The test takes a short time. It may take up to 24 hours before your child feels well enough to go home.

After the test, the tissue is sent to the lab. The results are then sent to your child's sickle cell disease provider, who will let you know if your child needs any other treatment.

Overnight sleep study

Some children with sickle cell disease may need an overnight sleep study, which can:

- Check your child's breathing, heart rate, oxygen levels, sleep patterns and movement while they sleep.
- Detect extreme snoring or enlarged tonsils.
- Measure brain waves with special probes and wires placed on your child's head.

This test is not painful. It takes all night to complete. It is done in a Children's sleep lab. Your child can go home early the next morning. One parent needs to stay with them through the night.

A pulmonologist (lung and sleep medicine doctor) will review the results and then send them to your child's sickle cell disease provider. You will have a chance to talk about the results with your child's provider and ask questions.

Blood tests (labs)

Your child will have blood work checked at every appointment, both well checkups and sick visits. A complete blood count (CBC) will be checked. It is normal for people with sickle cell disease to have results outside of the normal range. It is important to know what your own child's normal lab values are, especially their normal hemoglobin level.

White blood cells (WBCs)	4,500 to 15,000	Fights infection. If low, your child is at risk for infection. If high, your child may have a serious infection.
Reticulocyte count (Retic)	0.5% to 3.0%	New red blood cells. If low, your child may not be making enough red blood cells.
Hemoglobin (Hgb)	11.5 to 15.5	Hemoglobin transports oxygen. If low, your child may be pale, tired, weak, dizzy, have a headache or have a fast heartbeat.
Platelets	150,000 to 450,000	Help blood clot. If low, your child may have bruising, petechiae (small, red pinpoint spots on the skin) or bleeding. A low platelet count could also be a sign of an enlarged spleen.
MCV	Varies based on the type of sickle cell disease; MCV increases when taking hydroxyurea	Size of each red blood cell.
ANC	1,500 to 8,000	Number of special white blood cells that fight infection. If low, your child is at risk for infection.

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Clinical Information

Clinic visits

Scheduled clinic visits

Children with sickle cell disease are most often seen every 3 months for a full physical exam and lab tests. Children younger than 1 year old are seen every 2 months.

- Most lab tests are done during this visit. Your child's sickle cell disease provider will talk with you about the results.
- You will have a chance to ask questions and talk with your child's care team at each clinic visit.

Your child may need a clinic visit more than every 3 months. This depends on your child's treatment. In general:

- Children on hydroxyurea need clinic visits every 1 to 2 months.
- Children with HbSS or HbSβ0 Thalassemia and who are not taking hydroxyurea need clinic visits every 3 months.
- Children who get chronic blood transfusions need clinic visits every month.
- Children in research studies need clinic visits based on study guidelines.
- After age 5, children with HbSβ+ Thalassemia and HbSC need clinic visits about every 4 to 6 months based on how severe their disease is.

What to bring to clinic

Bring these items to every clinic visit:

- A list of your child's medicines. It may be helpful to bring the medicine bottles and a list of the refills you need.
- The address and phone number of your pharmacy.
- A snack or lunch if you expect to be at the clinic for a long time.
- Videos or electronic devices for your child to watch while receiving treatment.

If your child has not had chickenpox or the chickenpox vaccine, or if you suspect your child has chickenpox, tell the staff before you enter the clinic. Also tell the staff if there are any cases of chickenpox in your child's school or daycare.

Clinic check-in

All children younger than the age of 18 must have a parent or guardian stay with them for the whole visit. You will sit in the waiting room until your child's name is called. A patient care technician or medical assistant will take you to a triage room. A care team member will check your child's vital signs, height and weight, and draw blood work. Then you go to a room to wait for your child's nurse or sickle cell disease provider.

Unscheduled clinic visits and infusion center visits

Call the clinic to schedule a sick visit if your child has symptoms of a complication. The sickle cell disease team may be able to see your child during normal clinic hours. If not, your child may be sent to the nearest emergency department (ED). It is important that you call the clinic to get instructions from a sickle cell disease team member before leaving home. Our team will call the ED and let them know about your child. The ED staff will be ready for your child when you get there.

- A care team member will check your child when you get there.
- Treatment may include blood tests (labs), I.V. fluids, I.V. medicines (antibiotics and pain medicines) and breathing treatments.
- Your child may go home if treatment in the ED helps. Or the doctor will admit your child to the hospital. Your child may go home if they improve with treatment. Your child may be admitted to the hospital if they need more treatment.

Specialty clinics

Sickle Cell Disease Pulmonary Clinic

This clinic is for children who have a problem with acute chest syndrome, asthma or other lung diseases. Your child may see a sickle cell disease provider and a pulmonologist (lung doctor) if they need to.

In this clinic, your child will have:

- Blood oxygen measurements (pulse oximetry)
- Physical exams
- Lung function tests, such as a PFT for children over 5 years old

Some children may also need further testing. This may include:

- **Echocardiogram:** ultrasound of the heart
- **Polysomnogram:** sleep study
- **Exercise testing:** test for breathing difficulties

Our providers can advise on treatments and medicines to help improve your child's heart or lung function and sickle cell disease.

Sickle Cell Disease Pain Clinic

This clinic is for children with sickle cell disease who have chronic pain. Your child will see a sickle cell disease provider, pain specialist, social worker and psychologist if needed. They may also see a physical therapist.

Care team members will talk with your child to learn more about their pain. They will then:

- Meet with you and your child to develop a treatment plan to help manage their chronic pain.
- Schedule follow-up visits as needed.

Sickle Cell Disease Gastroenterology Clinic

This clinic is for children with constant belly pain, constipation, reflux, poor weight gain or poor growth. Your child will see a sickle cell disease provider and gastroenterologist (stomach doctor) if needed. They will also get a routine exam for their sickle cell disease.

Sickle Cell Neurology Clinic

This clinic is for children who have had a stroke, abnormal TCD or brain MRI, constant headaches or school problems. Your child will see a sickle cell disease provider, neurologist (nervous system doctor) and psychologist if needed.

In this clinic, your child may:

- Have a complete check of their nervous system.
- Get their routine sickle cell disease care.
- Have recent brain scans reviewed.

Care team members will also advise treatments and medicines to help improve nervous system function and sickle cell disease.

Transition program

What is a sickle cell transition?

Transition is the period of evolving from a teen to an adult. You will begin to prepare for transition around 13 years of age. Transition is:

- A normal part of growing up.
- Preparing you for adult health care, 1 step at a time.

- Learning and gaining independence to take care of your health and manage your sickle cell disease.

Why is sickle cell transition needed?

- By the time you finish high school or by the time you turn 18, you should be ready to transfer your routine sickle cell care to an adult sickle cell disease provider of your choice.
- Adult health care providers are trained and specialized in treating sickle cell issues and concerns that may happen during the late teen years and into adulthood.

To stay healthy and have a successful transition to adult care, you must learn to be responsible for your own health and for your own body. You must learn about the healthcare system and you own health needs. This means:

- **Become informed** – know about your specific sickle cell type, your usual lab values and past issues you have had due to your sickle cell disease.
- **Find an adult sickle cell disease provider** – talk with your pediatric sickle cell disease provider and ask for help with this. Your care team has a list of local adult sickle cell disease providers and can also help you find out-of-state providers.
- **Learn to make your own clinic appointments** – know the right provider to call when needed.
- **Take charge of your daily medicines** – make sure you know the names of the medicines you take and each medicine's purpose, dose, how often to take it and side effects. Also know when and how to get refills.
- **Know your local sickle cell resources** – learn about the types of resources in your area and how to access them. Your sickle cell disease care team can help you find these.
- **Know about your insurance** – make sure you have proper coverage for all your medical needs. There are resources to help you with this. Insurance is required to get medical care and prescription coverage.
- **Learn to manage finances** – know how to pay for your sickle cell disease care, living costs, medicines, and getting to and from appointments.
- **Plan your career** – set goals to finish high school, possibly go to college or a vocational program, earn a living and begin a career.

How do I prepare for sickle cell transition?

- Sickle cell transition is not always easy. It needs to be planned and needs to happen over time.
- Leaving your pediatric sickle cell disease providers is a huge life change. Your Children's Healthcare of Atlanta Sickle Cell Disease team will help you and your family prepare for your journey.
- We have many programs and community resources to help with this process.

At Children's, we offer the **Teen Scene** activities listed below. Ask your sickle cell disease provider for more details about these programs and events.

Clinic Education Program (Teen Clinic). This is encouraged for patients 1 to 2 times each year from age 13 until ready for transition at about 18 years of age.

- Get prepared for the transition process while in your usual clinic setting.
- Meet and talk with other teens with sickle cell disease and their families in separate teen and parent groups.
- Talk with your sickle cell disease providers about your sickle cell disease and care plan. Spend time reviewing the skills you need to prepare yourself for transition and adult care.
- Learn about transition in small amounts every year during your teens. This will help you feel confident, prepared and ready when the time comes for transition.

Transition Education Day (for 17 and 18 year olds). This happens 2 times a year for teens and their families at a local adult sickle cell facility.

- Get a list of local adult sickle cell disease providers. You may also meet some local adult sickle cell disease providers and get a tour of an adult clinic.
- Meet other adults with sickle cell disease. Learn about how they moved to adult care and how they live with sickle cell disease on a daily basis.
- Discuss tips for successful transition and other life topics, such as reproductive and sexual health, social and emotional challenges, college-career options, and lifestyle concerns for adults living with sickle cell disease.
- Hear social workers discuss topics, such as getting and maintaining health insurance, social security, community resources, planning for college-vocation, scholarship opportunities and financial planning.

Where do I go for adult sickle cell care?

- Talk with your sickle cell disease provider about adult care in your area.
- If you plan to go to college away from home, you must plan ahead.
  - Ask for a referral to an adult sickle cell disease provider near your campus.
  - Ask the Office of Disability Services at your college to help you.
  - Get a letter from your sickle cell disease provider to give to the Office of Disability Services.

You are not alone. Your doctor, nurse, social worker, parents and the rest of your care team are here to help with your transition to adult health care. You will be in charge of your health care as an adult so be strong, ask questions, and be part of the plan.

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Hospital Information

Staying in the hospital

Providers may need to admit children with sickle cell disease to the hospital for many reasons. This may include:

- Pain not controlled by home medicine, fever, acute chest syndrome, stroke or surgery.
- Other problems, such as severe anemia, splenic sequestration crisis and priapism.

A hospital stay can be hard for you and your child. Your child's care team will do all that they can to help make it as comfortable as possible.

Your child may go to the Sickle Cell Disease Clinic or Day Hospital before going to the hospital. Or they could go right to the hospital or nearest emergency department (ED).

If your child goes to an ED, tell the staff:

- Your child has sickle cell disease
- Your child's symptoms
- Any medicines they take
- Any allergies they have

Your child could have several tests or treatments while in the clinic, Day Hospital or the ED. This may include:

- Blood tests (labs)
- I.V. fluids
- I.V. antibiotics and other medicines
- X-rays
- Breathing treatments

If your child needs to stay in the hospital, they will be transferred to a hospital unit.

Tips for your child's hospital stay

We know being in the hospital is not like being at home. To help make your child's stay in the hospital easier, here is a list of items to bring with you:

- Comfort items for your child from home, such as a favorite pillow, blanket, DVDs or electronic device

- Clothes and pajamas. This helps keep things normal and makes your child feel like a child first and a patient second.
- Journal or notebook to keep track of treatment, blood counts and questions you want to ask your child's care team
- List of your child's medicines and their doses
- Cell phone and charger if you have one
- Things to entertain you and your child, such as crossword puzzles, movies and books
- Favorite snacks
- Sweatshirt (room temperatures can change)
- Relaxing music to help relieve stress and get more restful sleep

Try to take 1 day at a time. Your needs are important, so do not be afraid to ask a question. Our staff is here for you.

Daily routines

While your child is in the hospital, your child's providers and nurses have things they will do each day to help ensure your child gets the care they need. Some of these include:

- **Vital signs:** A care team member will take your child's temperature, blood pressure, pulse and breathing rate throughout the night and day. In special cases, such as when your child has a fever or needs a transfusion, they will check vital signs more often. Vital signs tell the care team how your child's body is responding to treatment or an illness.
- **Weight:** Your child's weight may be checked as often as 2 times each day. It is important to know if your child is losing weight. This may mean that your child is not eating or drinking enough. In some cases, your child may gain weight from too many fluids. It is important to know how your child's weight changes during treatment.
- **I and O:** Intake (I) means how much fluid your child takes in by mouth (drinks) and by I.V. (fluids and medicines). Output

  (O)means how much fluid comes out (urine, vomit and stool). I and O are measured every day. The care team needs your help to keep track of what your child drinks and how much your child puts out.

  (P) If you change your child's diaper, do not throw it away. A care team member will weigh it to see how much urine is in the diaper.

  (Q)If your child uses the urinal or bedpan, do not flush the urine down the toilet until it has been measured.

Inpatient unit

Once in the hospital, your child will have a nurse assigned to them. The nurse will:

- Help with their care.
- Follow providers' orders for treatments and medicines.

A sickle cell disease provider will check your child every day while they are in the hospital. Each morning, all members of the sickle cell disease team will provide family-centered rounds, giving you and your child a chance to ask questions and hear details about your child's progress.

Parents can most often stay with their child except in our pediatric intensive care unit (PICU). The PICU is an area specializing in the care of critically ill babies, children and teens. PICU staff may ask you to step out of the unit:

- If an emergency happens.
- When they need to give certain kinds of care.
- When your child needs rest to help them get better.

Talk with your child's nurse if you have any questions or concerns about your child's care. The nurse can help make sure you and your child get the help you need.

You must give a working phone number so the care team can call you if you leave the hospital. They may need to:

- Get your consent (permission) for a blood transfusion, special test or surgery.
- Talk with you about a change in your child's condition.

Before you leave the hospital unit:

- Make sure your child will not have any tests that require you to stay.
- Leave your phone number in your child's room.
- Give your work, cell and home phone numbers to the nurse.
- Write down your child's room number and the unit phone number. Take it with you so you can call the hospital with any questions.

Visitor and sibling guidelines

Visiting hours for other family members and friends are 8:30 a.m. to 8:30 p.m.

- All visitors must wash their hands when entering and leaving your child's room.
- It is best for your child that a parent spends the night.
- Anyone who has a fever, rash, diarrhea (loose stools), vomiting (throwing up) or other illness cannot visit.
- All visitors, including brothers or sisters, must stop at the nurses' station for screening before going to your child's room.
- Anyone who may have been exposed to chickenpox or shingles may not visit.
- All visitors younger than 18 must always have adult supervision. This includes siblings.

If your child is admitted to the hospital, try to arrange childcare for their siblings. If you are not able to find childcare for siblings, discuss this with your care team **right away**.

Daily schedule

Once your child begins to feel better, the care team will create a daily schedule for them. The schedule can help your child become more active and get better faster. Be sure to learn about your child's schedule and take part in it as much as possible.

Here is an example of a daily schedule for a school age child:

Time	Activity
8 a.m.	Wake up and get out of bed. Turn on lights and open window shades.
8 to 10 a.m.	Eat breakfast, bathe and get dressed
10 to 11:30 a.m.	Go to physical therapy (PT). Visit the activity room. Take part in an activity with Child Life.
11:30 a.m. to 1 p.m.	Return to your room. Eat lunch and have quiet time.
1 to 3 p.m.	Go to the School Program.
3 to 4 p.m.	Return to your room. Read, listen to music, watch TV or have quiet time.
4 to 5 p.m.	Go to the library.
5 to 6:30 p.m.	Eat dinner.
6:30 to 9 p.m.	Enjoy free time by watching TV or a movie, playing video games or working on the computer.
9 to 10 p.m.	Have quiet time. Read and get ready for bed. Lights out.

Tests and treatments

Your child's provider will order tests, treatments and medicines to help them get better so they can go home. These sometimes happen at night.

- Blood tests (labs) are often drawn early in the morning to compare with results from the day before.
- Your child may need some treatments day and night so they can get better.

Do not refuse blood tests and treatment. These are vital in helping us treat your child.

Discharge planning

The care team begins planning for your child's discharge as soon as they are admitted to the hospital. You may need to take part in a family conference to help us create a treatment plan for your child at home.

Along with inpatient care team members, other people who may help your child return home include a:

- Case manager
- Social worker
- Pharmacist
- School teacher
- Child life specialist
- Chaplain
- Financial counselor

Help us with discharge planning by answering questions about:

- Your insurance plan.
- Parent or caregiver work schedules.
- Your child's school schedule.
- People who can help support you at home.

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Caring for Your Child

Talking to your child about sickle cell disease

It is very important to talk with your child about sickle cell disease at an early age. It may be hard. Not telling your child the truth can have harmful effects. Children know when something is wrong. Here are some resources that can help you talk with your child:

Websites

- Children's Healthcare of Atlanta: choa.org/sicklecell
- Sickle Cell Kids: sicklecellkids.org

Books

- Hope and Destiny: A Patient's and Parent's Guide to Sickle Cell Disease and Sickle Cell Trait
- Hope and Destiny Jr.: The Adolescent's Guide to Sickle Cell Disease
- Just Like Me: A Story for Beginners with Sickle Cell Disease
- Be the Boss of Your Pain
- Help Children with Sickle Cell Disease Succeed at School

As your child grows older, they will need more information about sickle cell disease. Talk with your child's sickle cell disease provider about resources for older children.

Helping your child cope

Sickle cell disease offers many challenges for your child and family. As a parent or caregiver, you may ask:

- What does my child know about sickle cell disease?
- How will my child feel about treatment?
- How can I support my child?

How your child deals with their disease depends on their:

- Age.
- Personality.
- Coping style.

- Support from family and friends.
- Treatment plan.

When children have stress, their normal behaviors may change. They may act younger than their age. Your child may not know how to handle all of their feelings.

You are an important part of your child's life for many reasons.

- You know what your child has gone through in the past and how they handle stress.
- You can help the sickle cell disease team learn about your child.

The care team will work together with you to find new ways to help your child cope with sickle cell disease.

Child life specialists can:

- Help you learn more about your child's reactions to being in the hospital.
- Help your child and any siblings learn about and cope with the disease.

Stages of your child's development

This section provides some guidelines to help you learn how to support your child through different ages and stages.

Babies (birth to 12 months)

- Look to their parents to meet their needs.
- Rely on adults for food, comfort, play and care.
- Learn about the world around them through their senses, such as smelling and tasting.
- Trust people and things that are familiar.
- May fear being separated from you.
- May fear strangers.
- Respond to the new people and places around them.

Some issues and fears	How you can support your baby
• Separation from familiar people	• Be with your baby as much as possible. • Leave a shirt with your smell on it if you need to leave. • Rock or hold them. • Keep familiar blankets and toys nearby.
• Fear of strangers	• Have the same people care for your baby when possible. • Limit the number of people and voices in the room.
• Development	• Allow your baby to explore toys with their hands and mouth. Be sure toys are clean and there are no small pieces that they could choke on. • Use gentle touch and massage to comfort them. • Talk to them and play games, such as peek-a-boo, like you would at home.
• Sense of safety	• Keep your baby's crib a safe space - ask if the staff can use the treatment room for painful procedures; this is not always possible. • Wake your baby before a painful procedure. • Try to keep normal feeding, bathing and bedtime routines as much as possible.

Toddlers (12 months to 3 years)

- Start to do more on their own. Your toddler's favorite words may be "me do" or "no."
- Do some things by themselves. Allow them to do this because it gives them a sense of control.
- Use actions to show you how they feel because they do not have the words to describe their feelings.
- Have a hard time understanding how the inside of their bodies work.
- Think they make things happen. They may create ideas about how they got sick and what happens to them.

Some issues and fears	How you can support your toddler
• Fear of separation • Fear of strangers	• Be with your child as much as possible. • Have the same people care for your child when possible. • Provide security objects, such as a blanket or stuffed animal. • When leaving, tell them where you are going and when you will be back. • Leave something of yours, such as a picture or shirt, for them to keep until you return.
• Loss of control	• Allow your child to make choices when you can (like choosing apple or orange juice). • Do not offer a choice when there is not one. "Are you ready for your medicine," is not a choice. • Give them a job to do, such as holding a bandage or Band-Aid. • Allow them to play and be in control of the game or activity.
• Loss of normal routine	• Try to keep normal eating, sleeping and bathing routines as much as possible. • Let them play with their favorite toys.
• Behavior changes	• Give them safe ways, such as painting and building blocks, to express anger and other feelings. • Tell them it is OK to feel mad or sad. • Spend time with them, and reassure them. • Set limits and give discipline when needed. Your child needs limits to feel safe. • Praise them whenever possible.
• Fear of treatment (like medicine, vital signs and tests)	• Ensure them that they did nothing wrong. • Keep security objects nearby (like a blanket, pacifier or stuffed animal). • Use simple words, pictures or books to tell what will happen. • Tell them what will happen just before the treatment.

Preschoolers (3 to 5 years)

- Take pride in being able to do things for themselves: “I can do it.”
- Know more words to tell you what or how they feel. They still use actions to tell you things.
- May see the hospital, treatment and pain as punishment for “being bad.”
- Get confused by adult words and make up reasons for the things that happen.
- May fear being separated from you.
- May fear a new environment.
- May fear needles.
- May act younger than normal.

Some issues and fears	How you can support your preschooler
• Magical thinking (make up reasons for what happens) • Medical words they may not understand (like thinking a CT scan has to do with a cat) • Fear of harm to their bodies • Fear of the unknown	• Use simple words, pictures or books to tell them what will happen. • Tell your child what will happen a little before the treatment. • Let your child play with doctor kits and safe medical supplies, such as a blood pressure cuff.
• Loss of control	• Allow your child to make choices when you can (like choosing apple or orange juice). • Do not offer a choice when there is not one. “Are you ready for your medicine,” is not a choice. • Give them a job to do, such as holding a bandage or Band-Aid.
• Loss of normal routine • Behavior changes	• Praise your child for doing things for themself (like dressing, brushing teeth and feeding). • Give them time to get used to new changes. • Use play to help your child show their feelings.

School-age children (6 to 12 years)

- Take pride in doing most things by themselves.
- Enjoy school because it helps them learn and get good at new things.
- Think friends are important.
- Think about cause and effect. They have a better sense of time.
- Learn more words to describe their bodies, thoughts and feelings
- Understand more of how their bodies work. They may still have a hard time understanding medical words.
- May fear loss of control.
- May worry about pain.

Some issues and fears	How you can support your school-age child
• Loss of control	• Allow your child to make choices when you can (like choosing apple or orange juice). • Do not offer a choice when there is not one. "Are you ready for your medicine," is not a choice. • Give your child a job to do, such as holding a bandage or Band-Aid. • Let them practice things that are new or scary. • Let them go to school or do schoolwork. • Provide games, play and activities.
• Being away from friends and school	• Have your child write letters or call friends. • Let friends visit when they feel well enough.
• Fear of harm to their bodies • Fear of the unknown	• Use simple words, pictures or books to tell them what will happen. • Tell them what will happen a few days before the treatment, if possible. • Let your child play with safe medical supplies, such as a blood pressure cuff).

Teens (13 to 18 years)

- See themselves as individuals in the world. They want to be independent.
- Worry about how others see them. Illness and treatment cause teens to be different when they are trying so hard to be the same.
- Understand cause and effect but also see things from many points of view.

Some issues and fears	How you can support your teen
• Loss of control • Loss of independence	• Allow your teen to make choices when you can. • Let your teen be active in social and school activities. • Involve them in the treatment plan. Include them when talking to the care team about the plan of care. • Have them do their own self-care as much as possible (like washing and going to the bathroom).
• Body image • Self-esteem	• Give your teen chances to talk about physical and emotional changes. • Tell them it is OK to have many different feelings about illness and treatment. • Point out things they do well. • Allow your teen to do things that make them feel good about themself.
• Loss of privacy	• Respect that they may need to do some things by themself (like going to the bathroom and making phone calls). • Knock before entering your teen's room. • Offer them private time.
• Separation from peers	• Encourage time with friends. • Allow friends to visit and call.
• Concern for the future	• Answer questions openly and honestly. • Help your teen plan for the future. • Encourage them to keep doing normal things, such as going to school.
• Behavior changes	• Give your teen safe ways to express their feelings, especially anger. They may do this through physical activity, talking or writing. • Assure them that their feelings are normal (like guilt, fear and sadness).

Disciplining your child

From the time you find out that your child has sickle cell disease, the way your family reacts to each other may change.

- Your child with sickle cell disease may become the center of attention. This makes it easy for them to get used to being special since other siblings may not need as much of your time.
- Once your child feels better, discipline problems may happen. This happens because special attention stops as normal routines begin again.

Your child's illness can also slow discipline. Pain and other problems of sickle cell disease can put any child in a bad mood. Your child may act more helpless when they feel sick. This can make it hard to know what to expect from your child.

You may feel helpless when you see your child suffer. You may want to help your child by giving special rewards. These feelings are normal. Children need adults to provide rules and limits. Structure helps children feel safe.

If you do not expect your child to follow the same rules that are in place for your other children, you can:

- Set clear limits that your child can understand.
- Know that the limits may need to change when your child does not feel well.
- Praise them and reward good behavior.
- Try to discipline your child without spanking. Spanking can bring on a pain episode. Try using a time out or taking things away instead.

Keeping your child healthy

There are many ways to help keep your child healthy. Some of these ideas are needed for every child. Others are specific to children with sickle cell disease.

- Visit your child's provider and dentist regularly.
- Make sure your child:
  - Drinks plenty of water so they do not get dehydrated.
  - Avoids sodas, juice drinks, energy drinks and alcohol.
  - Brushes their teeth every morning and night. They should also brush their teeth after each meal.
  - Takes baths regularly.
  - Takes medicine as advised by healthcare providers.
  - Eats a healthy diet that includes fruits and vegetables.
  - Dresses properly for major weather changes. Have them wear layers of clothing for cold weather.
  - Avoids swimming pools with cool water and dries off completely.

- Talk with your child's sickle cell disease provider before giving vitamins, herbs or other natural products to your child. These products may react with medicines your child takes for sickle cell disease.
- Be sure to pace your child's activities. They should not do too much at a time.

Medicines

Some common medicines your child may take include:

- **Penicillin:** An antibiotic that helps fight off certain bacteria in the body.
- **Folic acid:** A type of vitamin B that helps promote new, healthy blood cell growth. It is found in many foods like green leafy vegetables and meats like liver.
- **Hydroxyurea:** A medicine used to reduce sickle cell problems by increasing fetal hemoglobin.
- **Ibuprofen:** A medicine used to reduce pain.
- **Opioid:** Stronger medicines used to reduce severe pain. Examples include oxycodone and morphine.

Vaccines

Vaccines (immunizations) can help protect your child from harmful infections. This is very important for children with sickle cell disease since they are at a higher risk for harmful infections. Ask your child's provider about what vaccines your child should have. Besides their regular vaccines, the provider may advise these:

Vaccine	What it does	Age your child should receive it
Pneumococcal	Helps protect against infections caused by certain germs	2 to 7 years old
Influenza (flu)	Protects against the flu	6 months and older (every year)
Meningococcal	Protects against meningitis	After 2 years old (at least 4 vaccines)

Surgery

Why is surgery a problem for patients with sickle cell disease?

Patients with sickle cell disease can have certain problems during or after surgery. One reason is because less oxygen gets to the tissues. This is because:

- Patients with sickle cell disease often have low hemoglobin. This is called **anemia.** Anemia means the red blood cells are less able to carry oxygen to the tissues.
- During surgery, blood flow may change because your child receives anesthesia (medicines to put your child to sleep). This can lead to less oxygen going to the tissues.
- Some surgeries may cause bleeding. This also leads to less oxygen going to the tissues.

Sickle cell problems, as well as the stress of surgery, may cause:

- A sickle cell vaso-occlusive episode (VOE) or pain episode (called a pain crisis in the past).
- A serious crisis in the lungs called acute chest syndrome (ACS). ACS is a lung problem (infection and/or fluid in the lungs) with fever, low oxygen levels or chest pain.
- Slower healing time.

Why might my child need surgery?

Some children with sickle cell disease may need the same types of surgery as other children, such as:

- Putting tubes in the ears to help prevent ear infections.
- Taking out tonsils and adenoids to help prevent throat infections.

Surgeries for sickle cell problems may include:

- Taking out the spleen if it gets too large from blood being trapped inside (called splenic sequestration crisis).
- Taking out the gallbladder if gallstones happen.
- Repairing or replacing a damaged hip joint.

How should I schedule surgery if my child needs it?

Most surgeries need to be scheduled like any other clinic visit or test. This depends on:

- The type of surgery and if it is needed right away.
- Your schedule.
- The surgeon's schedule.

Most of the time, you may schedule surgery in advance. This helps you to:

- Complete forms or make phone calls to arrange things.
- Work with your employer, insurance company or your child's doctor's office.

What happens before surgery?

Here are some guidelines for what to expect before your child's surgery:

- Your child's providers will talk with you about why your child needs surgery. They will tell you what will happen and how to help prepare your child.
- Your child may need several clinic visits for exams and tests before surgery.
- Your child will need a consult visit with the surgeon before the care team can schedule surgery. The Sickle Cell Disease Clinic team will work with the surgeon's team to schedule the surgery date.

- Your child will most likely need to be admitted to the hospital the day before surgery. They may get I.V. fluids, breathing treatments or blood transfusions.
- Your child may need certain vaccines before surgery. This depends on their age and the type of surgery they need.

Some things to know about blood transfusions include:

- Your child may need **at least 1** blood transfusion before surgery. This can be done in the clinic or hospital. The transfusion helps to:
  - Avoid sickle cell problems after surgery.
  - Reduce the amount of sickle hemoglobin by replacing it with blood that has normal hemoglobin.
  - Raise the blood count (hemoglobin) to a higher level so oxygen can be carried throughout the body easier.
- Children who have problems with blood transfusions may need other treatments before surgery.
- Children who have high hemoglobin levels or who have minor surgery may not need a transfusion.

What tests could my child have before surgery?

Some tests may include:

- A physical exam.
- Oxygen checks (oxygen saturation level).
- Blood or urine tests.
- Echo and EKG to check the heart.
- Chest X-ray to check the heart and lungs.
- Other X-rays or an ultrasound to look at certain organs depending on the type of surgery.
- Breathing tests to check the lungs.

Some tests can be done at your child's doctor's office. Others need to be done at the clinic or hospital. Talk with your child'scare team to schedule any tests.

What happens after surgery?

Your child's surgeon will talk with you about your child's surgery and what type of care they will need. Your child may need to stay in the hospital for at least 1 night after surgery. Some care may include:

- I.V. fluids until your child can drink on their own.
- Pain medicine as needed. Your child may only need strong pain medicine for 1 to 2 days. This depends on the type of surgery and how your child reacts to pain.
- Oxygen checks. Your child will need extra oxygen if their oxygen levels are low.

- Breathing treatments and using an incentive spirometer or blowing bubbles to help the airways and lungs stay open and work better.
- Getting out of bed and taking short walks to help prevent complications. Your child's care team will let you know when this is OK for your child.

Your child's providers will let you know when your child may go home and what kind of care they need at home.

What follow-up care will my child need?

Your child will need a follow-up visit with the surgeon and their sickle cell disease provider within 4 weeks after surgery or as advised. This is to make sure your child is healing well and that their sickle cell disease is under control. They will talk with you about:

- The care your child needs.
- When your child may return to normal activities and go back to day care or school.

Packed red blood cell transfusion

What is a blood transfusion?

A blood transfusion is when your child gets blood from another person. When a person donates blood, the blood is separated into different parts, including the red blood cell (RBC) part. When your child gets a RBC transfusion, they get just the RBC part of the blood.

Transfusions are given:

- In a vein through an I.V.
- 1 or more times.

RBC transfusions are given to children with sickle cell disease for different reasons. Some of those reasons are:

- To treat urgent sickle cell problems in the hospital.
- To help prevent sickle cell problems by getting scheduled transfusions in the clinic.
- Before surgery or anesthesia to help prevent sickle cell-related problems.

When does my child need a blood transfusion?

Blood transfusions are often used to treat children with sickle cell disease. Normal RBCs carry oxygen to the entire body. Sickle RBCs do not carry oxygen very well. Sickle cells can also get stuck in the blood vessels and block the flow of blood.

A blood transfusion gives your child healthy, normal RBCs. This can help get more oxygen to the body and to unblock the blood vessels. Your child may need a blood transfusion:

- To improve anemia if their hemoglobin is very low.
- To treat many problems in sickle cell disease, such as:
  - Stroke.
  - Enlarged spleen (splenic sequestration) or enlarged liver (hepatic sequestration).
  - Long-lasting or frequent pain episodes.
  - Acute chest syndrome.
- To help prevent future problems from sickle cell disease, such as:
  - Sickle cell-related problems with surgery or anesthesia like acute chest syndrome.
  - Stroke or other serious sickle cell problems.

How often will my child need a blood transfusion?

The number of times your child will get a transfusion depends on the type of sickle cell disease they have. Most children with sickle cell disease get a blood transfusion at least 1 time in their life. A child with hemoglobin SS or Sβ° may need a transfusion more often than a child with hemoglobin SC or Sβ° thalassemia.

Acute blood transfusions are:

- Given 1 to a few times. This depends on your child's needs.
- Needed to treat acute sickle cell problems like acute chest syndrome or aplastic crisis.
- Used before surgery to help prevent sickle cell problems.

Chronic blood transfusions are:

- Given every month for several months to many years, or for their entire life.
- Given to increase the number of healthy RBCs in your child's blood and to lower the amount of sickle RBCs. Your child's sickle cell disease providers measure the amount of sickle hemoglobin (hemoglobin S) in your child's blood to know how well the chronic blood transfusions are working.
- Given to children who have had a severe problem, like a stroke, or those at high risk for having a severe problem.
  - If your child has had a stroke, they may need a transfusion every month for their entire life. This helps lower the risk of another stroke.
  - If your child has had an abnormal TCD ultrasound test, they will need chronic transfusions for at least 1 year. This helps to prevent a stroke. Your child may be able to stop transfusions if they have a normal TCD ultrasound test.

Using a port-a-cath for chronic blood transfusions

If your child needs a transfusion regularly, sometimes their veins may get weak from so many blood draws and I.V. lines. This can make it hard to start an I.V.

- Your child may need a special I.V. called a port-a-cath (port). This will provide easy access for your child to get blood and to have blood drawn for tests.
- The port may stay in for years.
- Please ask your child's sickle cell disease provider for more details.

What kind of blood transfusion will my child get?

There are 3 types of RBC transfusions a child with sickle cell disease may get.

Simple blood transfusions

- Your child gets a blood transfusion into their vein. They do not have any of their blood removed by the transfusion.
- The blood comes in a unit. A unit is a pint-sized bag of blood that takes from 2 to 4 hours to infuse (go into the I.V.).
- Your child may get 1, 2, 3 or more units of blood. This depends on how big your child is and how low their hemoglobin level is.
- The purpose is to raise your child's hemoglobin level and to lower the amount of sickle hemoglobin.

Exchange blood transfusions (erythrocytapheresis)

- This removes sickle RBCs and replaces them with normal, healthy RBCS.
- It is done with a special machine. Your child will need a special type of port or I.V. to remove their blood and to give them new blood at the same time.
- It is a faster way to lower the sickle hemoglobin level.
- It can help stop the buildup of iron in the body.

Partial manual exchange transfusions

- Your child will have some of their sickle RBCs removed through an I.V. before getting a regular blood transfusion.
- Less sickle RBCs are removed than with an exchange blood transfusion.
- It helps to lower the sickle hemoglobin level and slow the buildup of iron in the body (but not as much as an exchange blood transfusion).
- It can be done without a special port.

Please ask your child's sickle cell disease provider for more details about the kind of transfusion your child needs.

How safe is a blood transfusion for my child?

- Blood transfusions are proven to help children with sickle cell disease.
- Special testing is done to make sure the blood type matches your child and that your child will not react against the blood.
- The U.S. Food and Drug Administration (FDA) regulates all U.S. blood banks. All blood centers must pass regular inspections.
- Each unit is carefully screened to help prevent infections, such as HIV and hepatitis. This is done to make sure the blood is as safe as possible for your child.

What are the risks of blood transfusions?

Although blood transfusions can help treat sickle cell disease, problems may happen.

Blood transfusion reactions

- Your child's immune system may react against the donated blood. This can cause swelling, itching, trouble breathing, fever or pain. These reactions could happen during the transfusion or at the end of the transfusion.
- Your child's body may make antibodies against the donor blood. These antibodies may show up a few days or weeks after apheresis. If your child forms antibodies, it may be harder to find blood to give them.

Iron overload

- This happens when there is too much iron in the body.
- Each unit of blood contains iron. When your child gets a blood transfusion, that iron stays in the body.
- Your child's body cannot get rid of extra iron. Iron levels increase with each transfusion.
- Too much iron can be harmful to the body, especially to the liver.
- If your child gets many blood transfusions, their iron levels will be tested.
- If your child's iron levels are too high, they will need medicine to lower their iron level. This may be a medicine that they will need to swallow every day.

Infection

- The chance of getting an infection from a blood transfusion is very low.
- All donor blood is tested for infection.
- The chance of getting HIV from a blood transfusion is less than 1 in 2 million.

Please talk with your child's sickle cell disease provider for more details about problems that may happen.

Red blood cell exchange (apheresis)

What is red blood cell exchange?

Red blood cell (RBC) exchange, or apheresis, is when a special machine removes your child's blood through a needle or catheter and gives them new RBCs from a blood donor.

- The machine uses sterile tubing that is thrown away after apheresis to help prevent infection.
- Your child's blood goes through the sterile tubing, into the machine, and is separated into parts:
  - Red blood cells (RBCs)
  - White blood cells (WBCs)
  - Platelets
  - Plasma
- The machine removes your child's RBCs and gives your child new RBCs.
- Your child's WBCs, platelets and plasma are returned to them.

How is the blood removed and put back?

Your child will need any of these to get apheresis:

- 2 intravenous (I.V.) lines.
  - An I.V. in each arm: 1 to take blood and 1 to give blood.
- A special port-a-cath called a Vortex port.
- A central venous access device (CVAD). This is also called a central line.

Why does my child need apheresis?

Apheresis removes sickle RBCs and replaces them with healthy RBCs. It is a faster way to lower the amount of sickle RBCs in your child's body. Apheresis can:

- Help prevent extra iron in your child's body.
- Help decrease the side effects of sickle cell disease.
- Improve your child's oxygen levels.
- Improve blood flow to your child's organs.

When could my child need apheresis?

Your child's care team may suggest apheresis 1 time or on a regular schedule.

- It may be used for children who have serious problems like stroke or acute chest syndrome.
- If your child has an abnormal MRI or transcranial doppler ultrasound (TCD), they may need apheresis on a regular basis.

If your child needs apheresis on a schedule, you can expect:

- Apheresis every 3 to 6 weeks (about 1 and a half months).
- Outpatient blood tests (labs) before each visit.
  - These labs measure the amount of sickle hemoglobin (hemoglobin S) in your child's blood to see how well the apheresis is working.
  - The team will also watch your child's iron levels (ferritin).
- Your child's care team will decide how long your child needs apheresis. Some children will still need apheresis as adults.

What happens before apheresis?

- Please come to your visit on time.
  - Call your child's social worker if you need help with transportation.
  - Call the apheresis team if you must reschedule or be late.
- Your child will get labs 24 to 72 hours before their apheresis visit. The Blood Bank needs this time to make sure they have enough blood to match your child's blood.
- Give your child extra fluids to drink the day before and the day of the apheresis.
  - Fluids may include water, sports drinks and juice.
  - Your child should drink 24 to 32 ounces (oz) each day.
  - Do not give your child any drinks with caffeine.
- Put numbing cream on your child's arms or Vortex port site before the visit.
  - The doctor will give you a prescription for numbing cream. The care team will show you during your first visit where the needles will be placed and where to put numbing cream.

What happens during apheresis?

- A care team member will check your child's vital signs (temperature, blood pressure, pulse, breathing rate and oxygen levels).
- A nurse will place 2 I.V. lines or access your child's Vortex port. The nurse will clean your child's skin before putting the needle into the skin.
- Your child cannot walk around after they are connected to the machine. Take your child to the bathroom before it starts.
- Apheresis most often takes 2 to 4 hours. A nurse will check your child's vital signs and manage the machine during this time.

What happens after apheresis?

- A nurse will take out the I.V. lines or port needle and put a bandage over each site. Keep the bandages on for 3 to 4 hours.
- Your child should sit for at least 30 minutes after apheresis. They should not get up and walk around during this time. Some children have nausea (upset stomach) or dizziness.
- A nurse will check your child before they can go home. This includes taking their vital signs and drawing labs to check their progress.
- Your child may have snacks and juice before they go home.
- Check your child's I.V. or Vortex port sites when you get home. Put pressure on the sites if you see any bleeding. The bleeding should stop quickly.
    - Call the Aflac Cancer and Blood Disorders Center team if the bleeding does not stop within 5 minutes.

For 24 hours after apheresis, your child should:

- Avoid lifting heavy objects.
- Take the elevator, not the stairs.
- Drink 24 to 32 ounces of caffeine-free drinks.
- Avoid heavy exercise.

What are the side effects?

Apheresis helps treat sickle cell disease, but your child may have side effects. Talk with your child's doctor for more information about these possible problems.

Blood transfusion reactions

- Your child's immune system may react to the donor blood.
- This can cause swelling, itching, trouble breathing, fever or pain.
- Reactions can happen during or after apheresis.
- Your child's body makes antibodies against the donor blood. These antibodies may show up a few days or weeks after apheresis. If your child forms antibodies, it may be harder to find blood to give them.

Anticoagulant reaction

- During apheresis, the nurse gives an anticoagulant (blood thinner) medicine to help prevent blood from clotting in the machine. Some children have side effects from the blood thinner for a short time. Tell your child's nurse **right away** if your child:
    - Has tingling in their fingers or toes.

- Has numbness around the lips, nose or mouth.
- Feels cool when you touch them.
- Has nausea (upset stomach).

- Side effects most often come and go quickly. Your child's nurse can pause the apheresis machine and give your child medicine to help stop the side effects if needed.

Infection

- The chance of getting an infection from apheresis is very low.
- All donor blood is tested for infections.
- The chance of getting HIV from a blood transfusion is less than 1 in 2 million.

When should I call the doctor?

Call your child's doctor if your child has any of these:

- Fever of 101°F or higher
- Chills that start within 4 hours of apheresis
- A new rash or itching
- Back pain
- Urine that looks brown or bloody
- Wheezing or trouble breathing

The Sickle Cell Disease Clinic is open Monday through Friday from 8 a.m. to 5 p.m. The clinic is closed on weekends and holidays. If you need to talk with a doctor after hours, call the Aflac Cancer and Blood Disorders Center and ask to speak with the doctor on call.

In case of urgent concern or emergency, call 911 or go to the nearest emergency department (ED) **right away**. ALWAYS tell the ED doctors and staff that your child has sickle cell disease.

Effects of the weather

Could my child's pain be related to the weather?

- Changes in weather can affect children with sickle cell disease more than people without sickle cell disease.
- Extreme temperature changes, either hot or cold, may cause a vaso-occlusive episode or VOE (called a pain crisis in the past).

- Keep a jacket or sweater nearby, even in the summer months. This is helpful when your child is indoors with air conditioning for long periods of time and gets too cold.

- Drinks enough fluids to stay hydrated.
  - Most often, it is OK to give your child at least one 8-ounce (oz) cup of water for every year of age. For example: a 7 year old can have seven 8 oz cups of water each day.
  - After 10 years old, your child should not drink more than 10 to 12 cups of water each day.

In hot weather

Make sure your child:

- Drinks enough fluids to:
  - Stay hydrated.
  - Keep up with water lost through sweating. They should increase the amount of fluids they drink when sweating more than normal.
- Takes breaks in the shade or goes inside often. At least every 20 minutes is advised.
- Avoids going into cool air conditioning when very sweaty.
- Dresses in layers so they can take off clothes if they get too hot and start to sweat.
- Does not swim in water that is too cold. Limit their time in the water so they do not get chilled.
- Dries off their entire body **right away** after getting out of the pool or playing in the water. Have them change into dry clothes **right away.**
- Has extra towels to avoid being wrapped up in a wet towel.

When does my child need more fluids?

Your child needs more fluids when they:

- Have pain.
- Are very active.
- Travel.
- Are in hot weather.

Use the chart below to know how much water to give your child. Talk with your child's care team if you have questions.

Child's weight in pounds (lbs)	Child's weight in kilograms (kg)	Number of 8 ounce (oz) cups each day
10 to 20 lbs	4 to 5 kg to 9 kg	2 to 4 cups
20 to 30 lbs	9 to 14 kg	4 to 6 cups
30 to 40 lbs	14 to 18 kg	5 to 7 cups
40 to 60 lbs	18 to 27 kg	7 to 9 cups
More than 60 lbs	More than 27 kg	10 or more cups

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Research and Advances

What is clinical research?

Research means doing a study to learn something new or answer a question and then sharing the answers with others. New research studies build on the results of past research studies and current treatments. Research studies are the building blocks of medical breakthroughs and cures.

Clinical research is research on human patients. Doctors rely on clinical research to make advances in treating diseases, such as sickle cell disease. Without families willing to take part in clinical research studies during treatment, we would not know how to best treat children with blood disorders.

Why is research important?

Research studies can help improve the health, medical care and quality of people's lives. Research into sickle cell disease is very promising.

- Sickle cell disease once caused death in most children.
- It is now a chronic illness found in adults, many of whom are leading long and productive lives.

Clinical trials

A clinical trial is a research study that involves a medical treatment.

- Clinical trials provide a standard way (protocol) to treat a disease. They also collect information about how well the treatment works.
- A clinical trial tries to learn more about the safety or success of a drug, device, or medical procedure.
- The goal is to use what is learned from a clinical trial to help improve care, or even find a cure for an illness.

There are many clinical trials that have taken place or will take place in the future. The care team may ask you to allow your child to take part in one. These studies are not intended to harm your child in any way. A team of providers and research experts at Children's must approve them before they can be used.

You and your child have a choice

You and your child have a choice about whether to take part in clinical research. Your child does not have to take part in a clinical research study to get treatment. Your choice will not affect how our staff feels about or treats you or your child. Your child will still get the same quality of care.

You may talk with your child, your child's provider, your family or others before you decide to take part in a research study.

- You and your family can ask questions at any time during the study.
- You can take your child out of the research study at any time.
- During the study, researchers will review what is learned from the study. They will tell you if they find that it is not safe for your child to stay in the study. If this happens, the care team will take your child out of the study.

Clinical researchers at the Aflac Cancer and Blood Disorders Center take part in several clinical trials focused on sickle cell disease. Some of these are national studies, while others are local.

Advances in sickle cell disease

There have been several advances made in sickle cell disease. Your child's provider will talk with you about these treatments if they are right for your child.

Blood and marrow transplant (BMT)

What is a blood and marrow transplant (BMT)?

- A BMT helps to restore blood stem cells that are damaged, missing or not working.
- It replaces unhealthy sickle cells with healthy blood cells.
- It is the only cure for sickle cell disease right now.
- BMT is not surgery. It is a medical treatment that takes place over many months.
- Most often, at least the first month is spent in the hospital.

What is bone marrow?

Bone marrow is the soft, spongy tissue and liquid found inside bones. Marrow is where blood cells are made.

The cells in bone marrow are called blood forming stem cells. These stem cells form 3 major types of cells in the body:

- White blood cells that fight infection
- Red blood cells that carry oxygen
- Platelets that help the blood to clot

How does a BMT help children with sickle cell disease?

BMT can be a cure for sickle cell disease when the normal red blood cells from a healthy donor replace the sickle red blood cells in your child.

What are the risks of a BMT for children with sickle cell disease?

BMT is the only cure for sickle cell disease now, but there are risks. These risks include:

- Infection.
- Low blood counts, which can lead to anemia.
- Bleeding, stroke and other problems.
- A weakened immune system for some time.
- Rejection of the transplant.
- Graft versus host disease [when the donor's cells (graft) attack your child's body (host)].
- Infertility (not being able to get pregnant or father a child).
- Death.

Your child will need:

- Antibiotics to help prevent or treat infection.
- Platelet transfusions to help prevent or treat bleeding that may happen.
- Blood transfusions to treat anemia.
- Medicines that lower the immune system for several months.

A BMT can put a lot of stress on children and their families because it is such a long process.

What is the process for having a BMT?

Finding a donor

The best donor is a full sibling (brother or sister) who:

- Does not have sickle cell disease.
- Has the same tissue type as your child.

Another name for tissue type is HLA. HLA stands for human leukocyte antigens. These are proteins found on the surface of the cells in the body.

- Each full sibling has only a 1 in 4 chance (25%) of having the same HLA type.
- Half siblings would not make a good donor because they do not have the same HLA type.
- The donor does not need to have your child's blood type but must have the same HLA or transplant tissue type.
- The donor **can** have sickle cell **trait** and still donate.

Preparing for transplant (treatment plan)

- Your child's treatment plan is based on their condition.

- Your child will get chemotherapy (chemo) and other medicines that make their immune system weak.
- The medicines get rid of your child's old bone marrow cells. They also prepare the body to get the new, healthy blood stem cells from the donor.
- The medicines may cause temporary side effects, such as :
  - Nausea (upset stomach) and vomiting (throwing up).
  - Hair loss.
  - Mouth sores
  - Poor appetite (does not want to drink or eat like normal)
  - Diarrhea (loose stools).
  - Low blood counts.

The transplant

- Blood stem cells are taken from the donor during BMT.
- Your child gets the blood stem cells from the donor through an intravenous line (I.V.). It is like getting a blood transfusion.
- A BMT can take a few minutes to a few hours.

After the transplant

- The new blood stem cells travel to your child's bone marrow.
- It may take up to 2 to 4 weeks for your child's body to produce new healthy cells.
- Your child could stay in the hospital for 4 to 6 weeks.
- After leaving the hospital, your child may take several medicines for many months.
- Your child will make many visits to the BMT clinic as they recover.
- Your child will have to stay out of school and follow special infection rules for a time.

Can my child get a BMT?

Due to the serious risks, a BMT is offered to younger patients with more severe sickle cell disease. These patients are at the highest risk for disability or death.

The most common reasons for a BMT are:

- Stroke or a high risk for stroke.
- Frequent acute chest syndrome.
- Frequent pain episodes.

Many children with severe sickle cell disease are not able to have a BMT because they do not have a healthy matched sibling donor. The risks of a BMT are higher, so a transplant is an option only in rare cases.

Notes

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Resources

Special programs and events

Sickle Cell Education Day

- Full day of activities and learning for people who have been affected by sickle cell disease.
- For patients, parents, family members, friends of the family, teachers and healthcare workers.
- Happens 1 time each year (most often on a Saturday).
- Includes an overview of treatments, updates, new clinical advances and school health issues.
- Also includes activities for sickle cell disease patients and their siblings.

404-785-0873

choa.org/SCED

Camp New Hope

- Hosted each year by the Sickle Cell Foundation of Georgia.
- Overnight camp designed for children with sickle cell disease, starting at age 6.
- Lasts 6 days.
- Takes place at a camp in Atlanta.

sicklecellga.org

Camp Crescent Moon

- Hosted each year by Children's Healthcare of Atlanta.
- Overnight camp designed for children with sickle cell disease, starting at age 6.
- Takes place at a camp in Atlanta.

choa.org/camps/camp-crescent-moon

Annual Holiday Toy Breakfast

- Hosted each December by the MTS Sickle Cell Foundation, Inc.
- Holiday event for families affected by sickle cell disease.

mythreesicklers.org

Financial assistance programs

Do not let insurance or Medicaid coverage lapse. This can cause problems and hardship for you and your family. Talk with our financial counselors if you have any questions or concerns. They are here to help.

Family and Medical Leave (FMLA)

Parents who need to miss work to care for their child may be able to take family and medical leave.

- Ask your employer how you should make the request.
- If approved, FMLA allows for up to 12 weeks (about 3 months) of unpaid leave in 12 months. It allows you to care for a child with a serious health problem. Your job, or one like it, must be open to you once you return to work.
- You may take FMLA all at 1 time or spread out in short amounts of time.
- FMLA may not apply if you work for a small company.
- Ask your employer for more details.

Your sickle cell disease social worker and medical team can assist you with completing FMLA forms. Note: It takes at least 2 weeks to complete the forms.

Supplemental Security Income (SSI)

SSI is a Social Security program.

- To enroll, a child must meet certain disability standards and the family must meet income guidelines.
- Once enrolled, children receive a cash amount each month, plus Medicaid coverage.

800-772-1213

Helpful resources

Georgia Medicaid

Georgia Medicaid provides free health insurance for children and families who qualify.

- Whether you get coverage depends on the family's income.
- Call your county Division of Family and Children Services (DFCS) to apply.

PeachCare for Kids

PeachCare for Kids is a Georgia program that offers health insurance benefits to children up to age 19 for a fee.

- Whether you get coverage and the fee are based on the family's income.
- It is for families whose income is too high to receive Medicaid. You must still meet income limits, but they are higher than those for Medicaid.

877-GA-PEACH (877-427-3224)

Georgia Division of Family and Children Services (DFCS)

Georgia DFCS provides information and help for:

- Temporary assistance for needy families (TANF).
- Food stamps.
- TEFRA/Katie Beckett Medicaid Program.
- Childcare needs.
- Medicaid.
- Energy bills.
- Housing.

404-657-3433 or **800-869-1150**

dfcs.georgia.gov

dfcs.georgia.gov/services/low-income-home-energy-assistance-program-liheap

Heating Energy Assistance Team (HEAT)

HEAT provides help with energy bills for Georgians in need.

678-406-0212

heatga.org/about-heat

Project Share (Salvation Army)

Project Share provides help with energy bills for families based on financial need.

770-441-6200

southernusa.salvationarmy.org/georgia/project-sharehttps://southernusa.

Lifeline Assistance Program & Link-up Georgia

The Lifeline program provides some financial support for home phone service. Whether you get support depends on the family's income. Call your local phone company for more details.

psc.ga.gov

Community Action Agency

Community Action Agency provides needy families in certain areas with financial help or refer them to other resources. georgiacaa.org

Travel and housing

Ronald McDonald House Charities

Ronald McDonald House Charities provides lodging for patients and families during medical treatment.

- There are guidelines you must meet to stay at the Ronald McDonald House like living a certain distance away from the hospital.
- Families must be referred by a social worker to stay at the house. Call your sickle cell disease social worker with questions.

rmhc.org

Medicaid nonemergency transportation

Medicaid offers nonemergency transport services for Medicaid patients who need help traveling to and from healthcare visits.

- You must arrange transport 3 business days before your child's appointment.
- Call the phone number they give you when your appointment is over.
- You will need your child's Medicaid number to use this service.
- Call your sickle cell disease social worker or county DFCS office for more details.

Hospital resources

School program

School is a very important part of every child's life. Children with chronic illnesses, such as sickle cell disease, may face problems at school. They may miss a lot of school and have pain or other symptoms that affect their learning. It is important for your child to have medical information on file at school. The sickle cell disease providers in our clinics can fill out a school packet for you, which will explain your child's medical and school needs.

The School Program at Children's helps support the learning needs of our patients. Patients with a chronic illness who are staying in the hospital can come to our hospital classroom for instruction. Hospital teachers can help parents get support for their child at school. They can also assist with the documents needed for school services, such as homebound instruction.

Our hospital school rooms have state-approved textbooks, computers and learning tools.

Family library and business center

Your child and family may use our family libraries for health information and leisure materials. Leisure materials may include books, magazines and movies for all ages. They also offer these services for patients in the hospital:

- Help create Care Pages
- Laptop computer program for long-term patients
- Computers with internet access and Microsoft Office programs
- Copier, fax machine, notary and printers
- Digital camera checkout (only for use in the hospital)

CarePages

CarePages is a secure and private website. It allows you to create your own webpage. It helps your family and friends learn about your child's progress, share messages of support and offer help. The service is free. You can use it before, during and after your child's hospital stay.

Sickle cell transformative therapies resource list

Be The Match

This organization, along with the National Marrow Donor Program (NMDP), helps patients find a matching donor and provides education, support and advocacy for those considering any blood stem cell or marrow transplant.

- Visit BeTheMatch.org or follow them on social media. See education on sickle cell transplant or request free information to be mailed.
- Contact Be The Match Patient Support Center at patientinfo@nmdp.org or 888-999-6743.
- Visit sicklecellconnect.com to learn about the Sickle Warrior program and order a free Warrier Package.

Peer Connect Program

Connects possible Curative Therapies patients with families who have been through BMT and gene therapy in the past. They are trained as volunteers to share their experience.

BMTInfoNet.org

An organization that provides education and support of those going through transplant.

Sickle Transplant Advocacy and Research Alliance (STAR)

A group of doctors, researchers and advocates that aims to make transplant safer and available to more patients with sickle cell disease.

curesicklenow.org.

Sickle Cell Disease Association of America

Provides information about medical advances in the treatment of sickle cell disease.

- Visit sicklecelldisease.org.
- Sign up for their distribution list for news about bone marrow transplant and gene therapy treatments.

The Sickle Cell Disease Coalition

The American Society of Hematology (ASH) provides education and resources about sickle cell disease.

- Visit scdcoalition.org.
- Subscribe to their newsletter at scdcoalition.org/get-email-updates.html.
- Sign up for the "Bringing Sickle Cell Disease to Life" podcast at hematology.org/about/podcasts-and-apps/scd-podcast-sign-up-form.

Clinical research

Transplant is sometimes offered as standard of care (without taking part in a clinical trial) and sometimes as part of a clinical trial. It is helpful to learn more about clinical trials and other types of research. The Office for Human Research Protections (OHRP) offers short videos.

- hhs.gov/ohrp/education-and-outreach/about-research-participation/informational-videos
- hhs.gov/ohrp/education-and-outreach/about-research-participation/informational-videos/index.html

Gene therapy

Gene therapy is a new and, in some cases, still experimental treatment.

- **Bluebird Bio**

  A company that makes a gene therapy product (Lyfgenia). It was FDA approved in December 2023 for sickle cell disease patients 12 years and older.

  mybluebirdsupport.com

- **Vertex**

  A company that makes a gene therapy product (Casgevy). It was FDA approved in December 2023 for sickle cell patients 12 years and older.

  casgevy.com/sickle-cell-disease

- **American Society of Gene & Cell Therapy (ASGCT)**

  Has information about gene therapy in general, as well as for sickle cell disease.

  patienteducation.asgct.org/disease-treatments/sickle-cell-disease and youtube.com/watch?v=Ro18vRnk6JI

- **OneSCDvoice**

  onescdvoice.com/gene-therapy

- **The Cure Sickle Cell Initiative of the National Institutes of Health (NIH)**

  Aims to speed development of gene therapy for sickle cell disease.

  curesickle.org and genome.gov/research-at-nhgri/Projects/Democratizing-Education

- **The Gene Home Resource Center**

  thegenehome.com/resources

- **Sickle Cell Disease and Blood and Marrow Transplant (BMT) 101: What You Need to Know**

  youtube.com/watch?v=Pj6mqkKiFyo

Connect with a family

- Ask your child's doctor or assigned coordinator (if you have one) how to connect with families who have been through transplant for sickle cell disease.
- Be The Match also has a Peer Connect program.

  bethematch.org/patients-and-families/support-for-you-and-your-family/peer-connect-program

Events

- **Atlanta Sickle Cell Education Day**

  An event for families of children with sickle cell disease that includes a session on donor transplant and gene therapy. choa.org/SCED

- **STELLAR**

  An event for families of children who have had a transplant for sickle cell disease. It is also open to families thinking about it. Meet and hear from families who have been through transplant.

  stellarbmt.org

Fertility and reproductive genetics

- **Sickle Cell Disease Reproductive Education Directive:**

  A non-profit started by a woman who went through transplant for sickle cell disease.

  sicklecellred.org

- **Aflac Fertility Team Consult**

  Encouraged if you are thinking about Curative Therapy treatment for your child. The team can counsel you on your child's expected risk of infertility based on their proposed treatment. They can provide options to preserve fertility. Ask your BMT doctor or coordinator to make the referral.

Neutrophil's Guide to Stem Cell Transplant for Kids

Book by Robert Henslin that you can order on Amazon or through your local bookstore.

Cord blood storage

If you are planning to grow a family using a full sibling cord blood transplant, learn more about umbilical cord storage through The Sibling Connection.

viacord.com/cord-banking/sibling-connection

For more questions or to request a consult with one of our BMT doctors:

Email scdcurativetheapies@choa.org and our Curative Therapies nurse coordinator will reach out to you.

Sickle cell disease related websites

Aflac Cancer and Blood Disorders Center

choa.org/sicklecell

Centers for Disease Control and Prevention (CDC)

cdc.gov/ncbddd/sicklecell/index.html

FOCUS + Fragile Kid

This organization provides support to parents of children with disabilities or with ongoing medical needs.

focus-ga.org

Georgia Department for Public Health: Newborn Screening for Metabolic and Sickle Cell Disorders Program

dph.georgia.gov/nbs-screening-metabolic-and-sickle-cell-disorders

Make-A-Wish Foundation

This foundation offers a wish for children with life-threatening illnesses who qualify. Call your social worker or child life specialist for more details and to see if your child qualifies.

wish.org

MTS Foundation, Inc.

This foundation is a local advocacy group started by a mother of 3 children with sickle cell disease. The mission is to increase public awareness of sickle cell disease and support families affected by this life-threatening disease.

404-925-4369

mythreesicklers.org

Lockhart-Morgan Sickle Cell Foundation

This parent-run support program is for families facing the challenges of sickle cell disease.

404-375-032

new2.lockhartmorganfoundation.org

National Coordinating and Evaluation Center: Sickle Cell Disease and Newborn Screening Program

This program provides support to families whose babies screen positive for sickle cell disease and sickle cell trait.
sicklecelldisease.net

National Heart, Lung, and Blood Institute

nhlbi.nih.gov

National Organization for Rare Disorders (NORD)

This organization helps people with rare diseases and the organizations that serve them.

rarediseases.org

National Pain Foundation

thenationalpainfoundation.org

Parent to Parent of Georgia

Parent to Parent of Georgia provides support and information to parents of children with disabilities.

p2pga.org

Sickle Cell Disease Association of America, Inc.

This association provides education, screening and awareness programs for patients with sickle cell disease at a national level.

800-421-8453

sicklecelldisease.org

Sickle Cell Foundation of Georgia, Inc.

This foundation provides education, screening and counseling programs for patients with sickle cell disease and other abnormal hemoglobins in Georgia.

404-755-1641

sicklecellga.org

info@sicklecellga.org

Sickle Cell Information Center

This center provides education, news, research updates and links to worldwide sickle cell disease resources.

scinfo.org

Sickle Options

This website provides details on sickle cell disease and helps patients and families find out information about different treatments.

sickleoptions.org/en_us

(Insert Appendix Tab page after this page – delete text before printing)

Glossary

Anemia: A condition that happens when there are fewer healthy red blood cells (RBCs).

Avascular necrosis: Happens when there is a lack of blood supply to the bone, most often the hip or shoulder. It may cause pain and result in bone damage.

BiPAP or CPAP: Breathing machines that help get more air into the lungs. They are used if oxygen levels are too low or if a child has trouble breathing.

Bone marrow: The soft, inner part of large bones that makes blood cells.

Blood and marrow transplant (BMT): A procedure that replaces bone marrow cells that have been destroyed with new, healthy bone marrow stem cells.

Cardiologist: A doctor with special training and skill in finding, treating and preventing diseases and problems of the heart and blood vessels.

Chelator: A medicine used to remove excess iron from the body.

Clinical trial: A carefully designed medical study of drugs or other treatments. Each trial is designed to answer 1 or more questions and to find better ways to help prevent or treat disease.

Complete blood count (CBC): A blood test that measures the number of blood cells in the body, such as white cells, red cells and platelets in the blood.

Dactylitis: Painful swelling of the fingers or toes.

Dehydration: Loss of too much body fluid.

Echocardiogram (echo): A test that takes pictures of the heart and looks at how the heart is working.

Folic acid: A vitamin that helps the body make new blood cells.

Gastroenterologist: A doctor who cares for and treats people with problems of the digestive (GI) tract.

Graft versus host disease (GVHD): This can happen after a BMT. The donor's cells (graft) attack the body (host).

Hematologist: A doctor who treats people with disorders of the blood.

Hemoglobin: A protein found in red blood cells that carries oxygen to different parts of the body.

Hemoglobin electrophoresis: A blood test that detects the different types of hemoglobin in the blood.

Human leukocyte antigen (HLA): Proteins or markers found on white blood cells (WBCs). They are used to match patients and donors for BMT (blood and marrow transplant) and transfusions. A perfect HLA match happens only with identical twins.

Hydroxyurea: A medicine used to help reduce sickle cell disease problems in children and adults with sickle cell disease.

Iron chelators: Medicines used to help rid the body of excess iron due to repeated blood transfusions. These include Exjade, Jadenu and I.V./subcutaneous Deferral.

Infusion: Giving fluids or medicines through a vein.

Intravenous (I.V.) line: A narrow plastic tube put into a vein. It is used to give different types of fluids or medicines into the blood.

Newborn screening: A process that tests newborns for sickle cell disease and other diseases.

Parvovirus: A type of virus that causes infection and prevents the temporary production of red blood cells. This is a dangerous problem for children with sickle cell disease since their red blood cells have a shorter life cycle.

Pediatrician: A doctor who cares for and treats children and teens.

Pediatric intensive care unit (PICU): A unit in the hospital that provides specialized care for critically ill

children. **Platelet:** A type of blood cell that helps the blood clot.

Pneumococcal infection: An infection caused by a type of bacteria (pneumococcus). It can cause infections like sinus, ear and more serious bloodstream infections, such as pneumonia and meningitis. Sickle cell disease patients are at a higher risk of getting this infection.

Polysomnogram: Overnight sleep study.

Protocol: A written outline that lists drugs, dosages and timeframe for treating a certain disease. It also includes the dates for procedures.

Providers: Professionals with special training to care for children with sickle cell disease. They direct the medical care of your child. Providers are made up of doctors, nurse practitioners and physician assistants.

Pulmonologist: A doctor who cares for and treats people with lung disease and breathing problems.

Pulse oximetry: A machine that measures blood oxygen levels. It consists of a soft probe that is connected to your child's finger, toe or earlobe using a piece of tape and a small computer. It is also called pulse ox.

Radiologist: A doctor who has special training in reading medical images.

Reticulocyte count: A test that measures the production of new red blood cells.

Sickle cell trait: An inherited condition in which both hemoglobin A and S are produced in the red blood cells. It is not a type of sickle cell disease.

Spleen: An organ to the left and slightly above the stomach and under the ribs. It helps fight infection, make and store red blood cells, and clean the blood.

Transfusion: An infusion of a blood product, such as red blood cells, in children who are anemic.

Urologist: A doctor who cares for and treats problems of the urinary organs in females and the urinary tract and sex organs in males.

Vaso-occlusive event: A form of a sickle cell disease crisis that happens when sickle cells block blood vessels. It can cause pain, organ damage, leg ulcers and stroke.

This handbook should not replace instructions given to you by your child's doctor and healthcare team. It is not meant to be medical advice or a complete source of all information about this subject. Your child's doctor is the best source of information about what is best for your child's treatment and care.

Health-related information changes frequently, and therefore information contained in this handbook may be outdated, incomplete or incorrect. This handbook may contain printed material that has been updated by Children's Healthcare of Atlanta. Please talk with a member of your child's healthcare team if you need an up-to-date copy.

Children's Healthcare of Atlanta has not reviewed all of the sites listed as resources and does not make any representations regarding their content or accuracy. Children's Healthcare of Atlanta does not recommend or endorse any particular products, services or the content or use of any third-party websites, or make any determination that such products, services or websites are necessary or appropriate for you or for the use in rendering care to patients. Children's Healthcare of Atlanta is not responsible for the content of any of the above-referenced sites or any sites linked to these sites. Use of the links provided on this or other sites is at your sole risk.

Call 911 or go to the nearest emergency department right away in case of an urgent concern or emergency.

Notes

Notes

Children's Healthcare of Atlanta Nondiscrimination Statement

Discrimination is against the law. Children's complies with applicable federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability or sex. Children's does not exclude people or treat them differently because of race, color, national origin, age, disability or sex.

Children's Healthcare of Atlanta:

Provides people with disabilities reasonable modifications and free appropriate auxiliary aids and services to communicate effectively with us, such as:

- Qualified sign language interpreters.
- Written information in other formats (large print, audio, accessible electronic formats).

Provides free language assistance services to people whose primary language is not English, including:

- Qualified interpreters.
- Information written in other languages.

If you need any of these services, contact Children's Civil Rights Coordinator at **404-785-4545**.

If you believe that Children's has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability or sex, you can file a grievance with:

Children's Civil Rights Coordinator
1575 Northeast Expressway NE
Atlanta, GA 30329
404-785-4545
section1557coordinator@choa.org

If you need help filing a grievance, Children's Civil Rights Coordinator is available to help you.

You can also file a civil rights complaint with the U.S. Department of Health and Human Services Office for Civil Rights electronically through the Office for Civil Rights complaint portal, available at **ocrportal.hhs.gov/ocr/portal/lobby.jsf**, or by mail or phone at:

U.S. Department of Health and Human Services
200 Independence Ave. SW
Room 509F, HHH Building
Washington, DC 20201
800-368-1019
800-537-7697 (TDD)

Complaint forms are available at:
http://www.hhs.gov/ocr/office/file/index.html

This notice is available at **choa.org**.

Created in 2024

Language Assistance Services and Auxiliary Aid Services

English

ATTENTION: If you speak English, free language assistance services are available to you. Appropriate auxiliary aids and services to provide information in accessible formats are also available free of charge. Call 404-785-4545 or speak to your provider.

Spanish

ATENCIÓN: Si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. También están disponibles de forma gratuita ayuda y servicios auxiliares apropiados para proporcionar información en formatos accesibles. Llame al 404-785-4545 o hable con su proveedor.

Vietnamese

LƯU Ý: Nếu quý vị nói tiếng Việt, chúng tôi cung cấp miễn phí các dịch vụ hỗ trợ ngôn ngữ. Các dịch vụ và phương tiện hỗ trợ phù hợp để cung cấp thông tin theo các định dạng dễ sử dụng cũng được cung cấp miễn phí. Vui lòng gọi theo số 404-785-4545 hoặc trao đổi với người cung cấp dịch vụ của quý vị.

Korean

주의: 한국어를 사용하시는 경우 무료 언어 지원 서비스를 이용하실 수 있습니다. 이용 가능한 방식으로 정보를 제공하는 적절한 보조 기구 및 서비스도 무료로 제공됩니다. 404-785-4545 번으로 전화하거나 서비스 제공업체에 문의하십시오.

Chinese

注意：如果您说[中文]，我们将免费为您提供语言协助服务。我们还免费提供适当的辅助工具和服务，以无障碍格式提供信息。请致电 404-785-4545 或咨询您的服务提供商。

Gujarati

ધ્યાન આપો: જો તમે ગુજરાતી બોલતા હો તો મફત ભાષાકીય સહાયતા સેવાઓ તમારા માટે ઉપલબ્ધ છે. સુલભ ફૉર્મેટમાં માહિતી પૂરી પાડવા માટે યોગ્ય સહાયક સાધનો અને સેવાઓ પણ વિના મૂલ્યે ઉપલબ્ધ છે. 404-785-4545 પર કૉલ કરો અથવા તમારા પ્રદાતા સાથે વાત કરો.

Language Assistance Services and Auxiliary Aid Services

French

ATTENTION : Si vous parlez français, des services d'assistance linguistique gratuits sont à votre disposition. Des aides et des services auxiliaires appropriés pour fournir des informations dans des formats accessibles sont également disponibles gratuitement. Appelez le 404-785-4545 ou parlez à votre fournisseur de services.

Amharic

ማሳሰቢያ፡- አማርኛ የሚናገሩ ከሆነ፣ የቋንቋ ድጋፍ አገልግሎት በነፃ ይቀርብልዎታል። መረጃን በተደራሽ ቅርጸት ለማቅረብ ተገቢ የሆኑ ተጨማሪ እገዛዎች እና አገልግሎቶች እንዲሁ በነፃ ይገኛሉ። በስልክ ቁጥር 404-785-4545 ይደውሉ ወይም አገልግሎት አቅራቢዎን ያናግሩ።

Hindi

ध्यान दें: यदि आप हिंदी बोलते हैं, तो आपके लिए निःशुल्क भाषा सहायता सेवाएँ उपलब्ध हैं। सुलभ प्रारूपों में जानकारी प्रदान करने के लिए उपयुक्त सहायक साधन और सेवाएँ भी निःशुल्क उपलब्ध हैं। 404-785-4545 पर कॉल करें या अपने प्रदाता से बात करें।

Haitian

ATANSYON: Si'w pale Kreyòl, sèvis assistans lang ou disponib pou ou gratis. Èd ak sèvis oksilyè apwopriye pou bay enfòmasyon nan fòma aksesib yo disponib gratis tou. Rele nan 404-785-4545 oswa pale avèk founisè ou.

Russian

ВНИМАНИЕ: Если вы говорите на русском, вам предоставляются бесплатные услуги языковой поддержки. Также бесплатно предоставляются соответствующие вспомогательные средства и услуги по предоставлению информации в доступных форматах. Позвоните по телефону 404-785-4545 или обратитесь к своему поставщику услуг.

Arabic

تنبيه: إذا كنت تتحدث اللغة العربية، فستتوفر لك خدمات المساعدة اللغوية المجانية. كما تتوفر وسائل مساعدة وخدمات مناسبة لتوفير المعلومات بتنسيقات يمكن الوصول إليها مجانًا. اتصل على الرقم 404-785-4545 أو تحدث إلى مقدم الخدمة.

Language Assistance Services and Auxiliary Aid Services

Brazilian Portuguese

ATENÇÃO: Se você fala português do Brasil, serviços gratuitos de assistência linguística estão disponíveis para você. Auxílios e serviços auxiliares, apropriados para fornecer informações em formatos acessíveis, também estão disponíveis gratuitamente. Ligue para 404-785-4545 ou fale com o seu provedor.

Telugu

గమనించండి: మీరు తెలుగు మాట్లాడితే, మీకు ఉచిత భాషా సహాయ సేవలు అందుబాటులో ఉంటాయి. యాక్సెస్ చేయగల ఫార్మాట్‌లలో సమాచారాన్ని అందించడానికి తగిన సహాయక చర్యలు మరియు సేవలు కూడా ఉచితంగా అందుబాటులో ఉంటాయి. 404-785-4545 కి కాల్ చేయండి లేదా మీ ప్రొవైడర్‌తో మాట్లాడండి.

German

ACHTUNG: Sie haben Anspruch auf kostenlose Sprachdienste, wenn Sie Englisch sprechen können. Kostenlose Dienstleistungen und Hilfsmittel, die geeignet sind, Informationen in zugänglicher Form zu vermitteln, werden ebenfalls angeboten. Sprechen Sie mit Ihrem Anbieter oder rufen Sie die Nummer 404-785-4545 an.

Tamil

கவனிக்க: நீங்கள் ஆங்கிலம் பேசுபவராக இருப்பின், இலவச மொழி உதவி சேவைகள் உங்களுக்கு வழங்கப்படும். எளிதில் அணுகக்கூடிய வகையில் தகவல்களை வழங்குவதற்கான பொருத்தமான துணை உதவிகளும் சேவைகளும் இலவசமாகக் கிடைக்கின்றன. இந்த சேவையை பெற 404-785-4545 என்ற எண்ணிற்கு அழைக்கவும் அல்லது உங்கள் வழங்குநரிடம் கலந்துரையாடவும்.