

Sickle cell disease (SCD): 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.
- When too much iron builds up to a level that overloads the body, it can cause health problems.

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 for a long 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 as 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 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 provider for more details about problems with iron overload.

In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away.

Sickle cell disease: iron overload, continued

What tests could my child have?

Your child could have a:

- Blood test called a ferritin level.
 - It tells how much iron is in the body.
 - If your child gets blood transfusions often, their sickle cell 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 too much iron.
- Exchange transfusion. This is done to remove sickle red blood cells and replace them with normal red blood cells. It can help stop a buildup of iron in the body and keep the excess iron levels down.

What should I do if my child is sick?

- Follow your child's sickle cell provider's advice.
- Call your child's provider and **seek medical care right away** anytime your child has a fever of 101°F or higher. Do not give iron chelator medicines if your child has a fever.
- 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 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 clinic they visit.

For more details on sickle cell disease and services, visit the Children's Healthcare of Atlanta website at choa.org/sicklecell.

This teaching sheet contains general information only. Talk with your child's doctor or a member of your child's healthcare team about specific care of your child.

In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away.