

# Sickle cell disease: red blood cell exchange (apheresis)



## What is red blood cell exchange (apheresis)?

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 the following to be able 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 more efficient way to lower the amount of sickle RBCs in your child's body.
- It can help prevent the buildup of iron in your child's body.

Children with sickle cell disease often need blood transfusions to increase the oxygen in their blood and lessen sickle cell complications. Simple RBC transfusions can cause side effects like iron overload (too much iron in the blood).

- Healthy RBCs carry oxygen to the entire body. Sickled RBCs do not carry oxygen well.
- Sickle cells can get stuck in the blood vessels, organs or joints and decrease blood flow to parts of your child's body.
- Donor blood contains iron. Iron from the donor blood stays in the body and your child's body cannot get rid of extra iron.
- Your child's iron levels may increase with each RBC transfusion. Your child may need medicine to help lower your child's iron level (such as Jadenu).
- Too much iron can harm your child's liver and heart.
- Apheresis helps prevent buildup of iron in the body.

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

## **Sickle cell disease: red blood cell exchange (apheresis), continued**

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### **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 a stroke or acute chest syndrome.
- Your child may need scheduled apheresis if they had an abnormal MRI or transcranial doppler (TCD) ultrasound test.

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

- Apheresis every 3 to 6 weeks.
- The care team to check your child's blood tests (labs) before each visit.
  - The 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 continue it into adulthood.

### **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 have to reschedule or will be late.
- Your child will get labs 24 to 72 hours before their apheresis visit. This is to make sure there is donor blood that matches your child's blood.
- Give your child 24 to 32 ounces (oz) of liquids to drink the day before and the day of their apheresis visit. Liquids may include water, sports drinks and juice. Do not give your child any caffeine.
- Give your child balanced meals before their visit. Avoid high fat foods.
- 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.
  - Ask your child's nurse for the numbing cream teaching sheet for more information.

### **What happens during apheresis?**

- A care team member will check your child's vital signs (temperature, heart rate, blood pressure and oxygen levels).
- A provider will ask you to sign a consent form for permission to do apheresis. Please talk with your child's doctor if you have any questions.
- Your child cannot walk around after they are connected to the machine. Take your child to the bathroom before it starts.
- 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.

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- 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 will 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 (stomach upset) 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 your Aflac 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 problems:

#### 1. 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.

#### 2. 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.

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- Feels cool when you touch them.
- Has nausea.
- Side effects most often come and go quickly. Your child's nurse can pause apheresis and give your child medicine to help stop the side effects if needed.

### 3. 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 every 2 million transfusions.

## **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 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 talk to the doctor on call at your campus.

**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 and 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/medical-services/cancer-and-blood-disorders/blood-disorders/sickle-cell-disease](http://choa.org/medical-services/cancer-and-blood-disorders/blood-disorders/sickle-cell-disease).

**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.**

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