

## Iron overload evaluation

Your doctors have asked you to come to St. Jude for an iron overload evaluation. People who receive red blood cell transfusions frequently can have too much iron in their bodies. The doctors want to make sure the iron levels are not causing damage to your body. The doctors use many different tests for this evaluation. No one test is the best, and the doctors will look at the results of all of the tests together to see how your body is tolerating the iron received from transfusions. If you have had these tests before, the doctors will compare the new results with old results.

If you are taking Desferal (a medicine to help get rid of iron), the doctors will look for side effects of that medicine, too. People who use Desferal will be asked to continue using this medicine as they normally would at home.

This list is to help you understand some of the tests you may be having. Not every patient has every test. Your doctor will decide which tests are needed at this visit. Always ask the doctor or nurse if you have questions about the tests.

### Appointment type

#### Assessment and Triage

### Purpose

Vital signs, weight and height will be measured. Most blood tests will be collected here (see individual test name). Ask the nurse whether you ought to leave an IV catheter in place for other tests you may have scheduled. This appointment is scheduled first thing in the morning. Please do not eat or drink for 8 hours before this blood draw, because it will affect the results.

#### Hematology follow up

You will see your primary doctor, who will ask about your health history since your last visit. The doctor will also perform a physical exam. You may want to write a list of questions you want to ask the doctor at this time.

#### Echo/EKG

This is a painless test to measure the size of your heart and how well it is working. The echocardiogram (Echo) is an ultrasound of the heart so the staff can take pictures and measurements. The electrocardiogram (EKG) is a measure of the electrical activity of the heart and its rhythm. Too much iron in the heart muscle can cause it to grow in size, work too hard, have irregular rhythms, or pump blood less effectively. The doctors will compare these results to earlier tests if you have had this done before.

*This document is not intended to take the place of the care and attention of your personal physician or other professional medical services. Our aim is to promote active participation in your care and treatment by providing information and education. Questions about individual health concerns or specific treatment options should be discussed with your physician.*

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### Appointment type

### Purpose

#### X-ray (chest and bone age)

The bone age X-ray shows the doctors whether your bones are growing properly for your age. People with too much iron sometimes have changes in their growth patterns. The chest X-ray shows the doctor the size of your heart and the appearance of your lungs.

#### Audiology visit

Audiology is the study of hearing. Patients using Desferal may have changes in the nerves for hearing, but iron can also damage the hearing nerves.

#### Eye Clinic visit

An eye doctor will examine your eyes for any vision changes or changes to the structure of his eyes. People who use Desferal may have changes to their retinas over time. If you have diabetes, there may also be retinal changes that can affect your vision.

#### Endocrine Clinic visit

This clinic has doctors who specialize in the growth and hormones of children and adolescents. They will measure your height and weight, and ask questions about growth and development. They will look at the results of many of the blood tests to see if you have normal amounts of hormones for proper growth and development. Some people with too much iron have delayed growth or delayed onset of puberty, or changes in insulin production and use (diabetes). If you are 18 or older, your appointment may be at an office outside St. Jude with an endocrinologist, who specializes in adults

#### CT bone density

This is a CT or CAT scan to look at the thickness of your bones. People who have excess iron can have thin bones that break easily. It is a painless test (like an X-ray). The doctors will compare the results to other bone density tests you may have had. Desferal can also increase calcium loss from the bones.

#### Nuclear medicine (MUGA scan)

During this test, a dye is injected in your veins. Using special scanning equipment, the doctors will watch the flow of blood through your heart to see how well it is pumping. This should be a painless test.

#### Abdominal ultrasound

If you have hepatitis, you will probably have this painless evaluation to look at the size and shape of the organs in your abdomen, especially your liver.

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#### Liver biopsy

### Purpose

This test requires a special consent to be signed and is not done with every iron overload evaluation. For this test, you will be given medicine (anesthesia) to help you sleep. The doctors take a small sample of liver tissue using one of two methods: transjugular (through a vein in the neck) or percutaneous (with a needle through the abdomen directly over your liver). The doctors will decide which method is best for you. You will need to stay in the hospital all day so the doctors and nurses can watch for any side effects of the procedure. You will probably not have an incision or stitches, but you may feel a little tired or sore. Everyone's liver stores iron and this test will measure how much iron is in your liver. This test also shows if any damage has been done to the liver by hepatitis or iron deposits. The doctors will compare this to past results.

### Laboratory tests

Listed below are some of the laboratory tests your doctor may order. You may not need every test. Some of the results will be available the same day, but others may take several days or weeks. You should talk to your doctor about what the results mean.

#### CBC (complete blood count)

This blood test measures the number, size and type of cells in your blood. From this test, the staff can learn the amount of hemoglobin you have, and decide whether you need a transfusion of blood or platelets.

#### Chem 18

This blood test measures the amount of 18 different chemicals and electrolytes in your blood, such as sodium, potassium, magnesium, or liver function tests.

#### Ferritin

Ferritin is an iron-storage protein produced in the body. It usually corresponds to the total amount of iron stored all over the body.

#### 2-hour glucose and insulin test

Staff will ask you to note when you have a big meal, and then they will draw blood 2 hours after that meal. Some people with too much iron develop diabetes mellitus. This blood test tells how well your body uses up its sugar with the hormone insulin, and whether you are at risk for diabetes.

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# *Do you know...* continued

## **Iron overload evaluation**

### **Coagulation screen**

The liver makes the proteins that help the blood clot when you are injured. The doctors want to make sure your liver is producing the right amount. We will have to use a needle (a fresh stick) to collect this blood sample even if you have a central line, such as a subcutaneous port.

### **Free T4, TSH, PTH, FSH, etc.**

All of these chemicals are hormones. Since iron overload can affect your growth and development (see Endocrine Clinic visit above), this is one way the doctors can measure your development.

### **24-hour urine collection**

For this laboratory test, the staff will ask you to collect all of your urine for 24 hours, and keep it in a container that they will give you. Please keep the urine cold (on ice). After 24 hours, the laboratory measures how much of several chemicals, such as iron, glucose, or protein, are in your urine. They compare this amount to the amount in blood to see if the kidneys are filtering the blood well and getting rid of the harmful chemicals correctly. You will do this 2 days in a row, and if you use Desferal, you should use it during these 2 days.

### **Hepatitis panel/HIV screen**

The staff screens every patient for these viruses. Very rarely, people who have received blood transfusions have contracted one of these viruses. Furthermore, hepatitis can damage the liver, the main organ of iron storage.

### **Hepatitis C PCR**

If you have hepatitis C, this test will measure the amount of hepatitis virus living in your body. The doctors will watch how this increases or decreases over time.

### **Alpha fetoprotein**

If you have hepatitis C, the staff will also test for this protein that can be an early warning sign of liver cancer.

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