

Hi there, my name is CR Hume. I am the IDI mascot. My job is to raise awareness about the importance of blood donation and to remind you to keep your “ferritin in range”! *Today I am introducing our...*



Starter Kit for Hemochromatosis Patients

Your KIT includes the basic information about iron tests, therapy, genetics, informing family members, and diet.

**Your KIT also includes
the Iron Disorders Institute (IDI)
Personal Health Profile form Test-Results page**

More information is available on our websites

www.irondisorders.org

or

www.hemochromatosis.org



FIRST STEPS: getting diagnosed

1. Ask your doctor for all THREE of these tests:

• **Fasting Serum Iron**

Fasting is nothing by mouth except water or prescribed medications 8 hours prior to lab-work; also avoid sugary juices and supplements, especially iron.

• **TIBC or UIBC**

TIBC or UIBC plus fasting serum iron will provide your transferrin-iron saturation percentages or TS% which gives you information about how much iron you are loading.

• **Serum Ferritin**

Measures contains (stored) iron.

2. Get a copy of the results.

3. Compare results to our ranges.

Note: ferritin ranges differ for age and gender but levels below 25 or above 75 might need to be watched for possible iron balance problems. TS% is usually 25 - 35%.

4. If the test numbers are high, your doctor may want to confirm the diagnosis of hemochromatosis.

Some ways that are recommended by our medical advisory board:

• **Genetic testing**

This test can be done by your doctor or through home testing.

• **Trial phlebotomy**

Phlebotomy is blood removal, which is the treatment for hemochromatosis. Patients with high body iron can undergo several phlebotomies without becoming anemic. Read more about phlebotomy on our web site [www.irondisorders.org] or call us if you have questions.

• **Liver biopsy**

No longer recommended to diagnose hemochromatosis; however, liver biopsy is needed to assess liver damage, especially in patients with a serum ferritin higher than 1,000ng/mL. Read more about liver biopsy on our web site [www.irondisorders.org] or call us if you have questions.

5. Contact Iron Disorders Institute toll-free 1-888-565-4766

For information about genetic counselors, resources, workshops, services and literature.

Hemochromatosis (HHC) is an inherited condition; blood relatives of people diagnosed with HHC are at risk and should be tested early to prevent disease. People with hemochromatosis absorb extra iron from the diet, which collects in major organs such as the heart, brain, joints, liver, gall bladder and pancreas. If not treated, hemochromatosis can be fatal. Early detection and treatment are key to living a normal, healthier lifespan.

Iron Disorders Institute is a national advocacy partner with the US Centers for Disease Control and Prevention.

For more information about hemochromatosis, visit these sites:

www.irondisorders.org | www.hemochromatosis.org | www.cdc.gov | www.niddk.gov



NEXT STEPS: getting treatment

Treatment includes phlebotomy, diet changes and tracking your numbers.

Phlebotomy is blood removal; it is the same thing as blood donation except that a phlebotomy requires a doctor's written order. Phlebotomy or blood donation is the treatment for hemochromatosis. Patients with high body iron can undergo several phlebotomies without becoming anemic, but patients who have too many phlebotomies can become iron deficient and have many unpleasant symptoms such as shortness of breath, Restless Legs Syndrome, tiredness and poor sleep. Keeping track of numbers is one way to assure quality treatment.

1. Get a copy of our *Personal Health Profile*.

This form is on our web site or your can call us and we will mail you one. The form has reference ranges and a place to record important test results. There is room for notes and important phone numbers.

2. Arrange for blood removal.

Blood removal might be done in your doctor's office, at a hospital or at a center that has special permission to use hemochromatosis blood once it is tested like all other donated blood.

3. Make sure the doctor's order is written so that you are not OVER-bled.

Our medical advisory board recommends a pre-phlebotomy hemoglobin of 12.5g/dL

4. Make simple diet changes.

Cut back on red meat, animal fats and sugar; cut back on alcohol; avoid raw shellfish, limited vitamin C supplements to 200mgs per dose. For more detailed information about diet visit our web site [www.irondisorders.org] or call us **1-888-565-4766**

5. Give a copy of the Iron Disorders Institute's *Physician Hemochromatosis Reference Chart* to your doctor.

Contains charts, guidelines for diagnosis, treatment and management of hemochromatosis including genetic information.

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NEXT STEPS: family

The most common type of hemochromatosis runs in families.

If you have been diagnosed with hemochromatosis, you need to take the steps to inform blood relatives.

1. Get a copy of CDC's letter to family members.

This letter is online or you can us for a copy.

2. Mail or give this letter to all blood relatives OR ask us to send a letter on your behalf.

IDI will contact each family member with a letter signed by the Executive Director. Basic information about FIRST and NEXT STEPS will be included in the information packet sent to each family member.

3. If you have children, notify the pediatrician.

Tell the doctor of your children that hemochromatosis has been diagnosed in your family. Classic hemochromatosis is not known to cause iron loading in children; however a bench mark iron panel is recommended—keeping in mind that at some ages the iron levels and some liver enzymes are naturally elevated and may not be a sign or iron loading but preparation for a growth spurt.

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diet information for patients with hemochromatosis

- 1. Don't take iron pills, nutritional supplements, or multivitamins with iron.**
 - If you are taking a multivitamin, read the label to make sure it does not contain iron.
- 2. Don't take pills with more than 500 mg of vitamin C per day, vitamin C increases the amount of iron your body absorbs.**
 - Eating foods that contain vitamin C is fine.
- 3. Don't eat raw fish or raw shellfish.**
 - Cooking destroys germs that are harmful to people with iron overload, so it is okay to eat well-cooked fish and shellfish.
- 4. Drink very little alcohol, if you choose to drink.**
 - Women should have less than one drink a day. Men should have less than two drinks a day.
 - If you have liver damage, do not drink alcohol.
- 5. For more information on iron and iron supplements, go to:**
 - www.cc.nih.gov/ccc/supplements/iron.html
 - www.irondisorders.org

Hemochromatosis cannot be treated by diet alone.

Phlebotomy is important to the successful management of hemochromatosis.



Department of Health and Human Services
Centers for Disease Control & Prevention



phlebotomy information for patients with hemochromatosis

What is a phlebotomy (pronounced: flee-bot-o-me)?

It's the same procedure as when you donate blood. A nurse takes about a pint of blood from a vein in your arm. The procedure takes about an hour. A phlebotomy is simple, safe, and effective.

How often must I have a phlebotomy?

For about a year or more, you will probably have phlebotomies once or twice a week. How many phlebotomies you have and how often you have them depends on how much iron has built up in your body and what your doctor recommends.

Must I have phlebotomies for the rest of my life?

Yes. But after the iron is first lowered to a safe amount, you will have phlebotomies less often, usually a few times a year.

Does a phlebotomy have side effects?

Most people feel just fine. Others feel tired afterward and like to rest for an hour or so. It's a good idea to drink water, milk, or fruit juices before AND after a phlebotomy.

Where can I get a phlebotomy?

Therapeutic phlebotomy can be made in many places; including hospitals, clinics, and bloodmobiles (mobile blood drives on specially equipped buses). People can also donate at community blood centers and hospital-based donor centers. Many people donate at blood drives at their work places. Verify that the blood donation center can withdraw blood for your phlebotomy treatments at the frequency prescribed by your doctor. If you need help finding a blood donation center, check with your doctor.

The donation process

The donor lies down or sits in a reclining chair. The skin covering the inner part of the elbow joint is cleansed. A new, sterile needle that is connected to plastic tubing and a blood bag is inserted into an arm vein. The donor is asked to squeeze his or her hand repeatedly to help blood flow from the vein into the blood bag. Typically, one unit of blood, roughly equivalent to a pint, is collected. Collected blood is sent to the laboratory for testing. The donor is escorted to an observation area for light refreshments and a brief rest period.

Before treatment

- ♦ Drink water, milk, or fruit juice; liquids such as these will help increase blood flow and therefore shorten the amount of time a phlebotomy will take.

After Your Treatment

- ♦ Drink water, milk, or fruit juices after treatment.
- ♦ Avoid vigorous physical activity for 24 hours after treatment.
- ♦ Continue phlebotomy treatments as needed.

Without phlebotomies, iron overload may cause illness and premature death. Treatment is worth the effort.



Department of Health and Human Services
Centers for Disease Control & Prevention



Dear Family Member,

One of our family members is under medical care for hemochromatosis [*pronounced he-mo-kro-ma-TOE-sis*], a genetic condition that causes the body to absorb too much iron. Because you are a family member related by birth [blood relation], you may have inherited the genes that can cause this disease.

During the early stages of hemochromatosis, most people do not feel sick and cannot tell they have the disease. Without treatment, however, iron can build up in the heart, joints, or pancreas and cause permanent damage. The good news is that complications from hemochromatosis can be prevented if it is found and treated early.

To find out if you have this condition, have your iron status evaluated by your family doctor within the next few months. Two simple blood tests can determine if you have too much iron in your blood: transferrin saturation and serum ferritin. If test results show that you have too much iron, you will need to begin phlebotomy [*pronounced flee-BOT-o-me*] treatment. This is a safe, simple, and very effective treatment. On a regular basis, patients have blood taken from a vein in the arm, just like donating blood. With proper treatment, people with hemochromatosis can lead long, healthy lives.

Please do not ignore this letter. The special blood tests you need are very simple. Remember, many people who have hemochromatosis feel fine. Finding the disease EARLY is important. Be sure to ask your doctor for these blood tests and talk with your doctor about the results.

Sincerely,

You can learn more about hemochromatosis on the Internet at the website provided by the Centers for Disease Control and Prevention:

<http://www.cdc.gov/nccdphp/dnpa/hemochromatosis/index.htm>

[Free access to the Internet is available at your local public library.]



Department of Health and Human Services
Centers for Disease Control & Prevention



DNA RESULTS

LAB TEST RESULTS

| DATE | DATE | DATE | DATE | DATE | DATE |
|------|------|------|------|------|------|
|------|------|------|------|------|------|

NAME _____

| | TEST | TYPICAL REFERENCE RANGES | | | | | |
|--------------------|---|---|---|--|--|--|--|
| IRON PANEL | OVERLOAD | Serum Iron (SI) | 40-180 mcg/dL | | | | |
| | | Transferrin Iron Saturation Percentage (TS%) <small>TS% is a calculation of SI/TIBCx100%</small> | 25-35% | | | | |
| | ANEMIA | Total Iron Binding Capacity (TIBC) Unbound Iron-binding Capacity (UIBC) | 250-450 mcg/dL | | | | |
| | | Ferritin | Refer to Reference Ranges Below... | | | | |
| | | Hemoglobin (Hgb) Adult female: 12.0-16.0 g/dL male: 13.5-17.5 g/dL Adolescents, Juveniles, Infants & Newborns: Age 6-18 yrs 10.0-15.0 g/dL Age 2-6 mos 10.0-17.0 g/dL Age 1-6 yrs 9.5-14.0 g/dL Age 0-2 weeks 12.0-20.0 g/dL Age 6 mos-1 year 9.5-14.0 g/dL Newborn 14.0-24.0 g/dL | | | | | |
| BLOOD COUNT | Hematocrit (Hct) is expressed as a percentage that is generally 3X hemoglobin | | | | | | |
| | Red Blood Count (RBC) | 5-10 million/uL | | | | | |
| | White Blood Cell (WBC) | 4-10,000/uL | | | | | |
| | Red Blood Cell Distribution Width (RDW) | 12-16 % | | | | | |
| | Mean Corpuscular Volume (MCV) | 82-98 fL | | | | | |
| | Mean Corpuscular Hemoglobin (MCH) | 27-33 pg | | | | | |
| | Mean Corpuscular Hemoglobin Concentration (MCHC) | 31-36 g/dL | | | | | |
| GENERAL | Platelet Count* | 140,000-450,000/uL | | | | | |
| | Blood Pressure | <140 over 90 | | | | | |
| | Heart Rate (at rest) | <100 bpm | | | | | |
| | Body Mass Index | 20-25 ideal 25-27 overweight >27 obese | | | | | |
| LIPIDS | Height* | | | | | | |
| | Cholesterol (Total) | <200 mg/dL | | | | | |
| | HDL | >35 mg/dL Males >40 mg/dL Females | | | | | |
| KIDNEYS | Triglycerides | <400 mg/dL | | | | | |
| | BUN | 8-20mg/dL | | | | | |
| BIOPSY: | LIVER | Uric Acid | 2-6mg/dL | | | | |
| | | AST (SGOT) | 10-40 IU/L | | | | |
| | | ALT (SGPT) | 10-40 IU/L | | | | |
| | | GGT | 0-85 IU/L | | | | |
| ENDOCRINE | HORMONE LEVELS | ALP | 25-125 IU/L | | | | |
| | | Testosterone (total) | Males: 270-1,070 ng/dL Females: 6-86 ng/dL | | | | |
| | | TSH (thyroid stimulating hormone) | 0.5-3.5 mU/L | | | | |
| | | T4 (Total) | 4.5-12.0 mcg/dL | | | | |
| | | T3 (Uptake) | 24-39% | | | | |
| PANCREAS | HORMONE LEVELS | Free Thyroxine Index (T7) | 1.2-4.5 ug/dL | | | | |
| | | Glucose (fasting) | 65-115 mg/dL | | | | |
| | | HbA1C | 4.2-5.9% | | | | |
| | | Amylase (Blood) | 25-130 IU/L | | | | |

PERSONAL HEALTH PROFILE

DOB _____

ID # _____

* Labs vary with respect to ranges. The values listed are only approximate. Normal ranges not provided should be supplied by attending physician.

| | | | | | | |
|---|-------------------|-----------------|-------------------|-------------|---------------------|-------------|
| Ferritin Important Reference Ranges | Adult Males | up to 300 ng/mL | Male Ages 10-19 | 23-70 ng/mL | Infants 7-12 Months | 60-80 ng/mL |
| | In Treatment | below 100 ng/mL | Female Ages 10-19 | 6-40 ng/mL | Newborn 1-6 Months | 6-410 ng/mL |
| | Ideal Maintenance | 25-75 ng/mL | Children Ages 6-9 | 10-55 ng/mL | Newborn 1-30 Days | 6-400 ng/mL |
| | Adult Females | up to 200 ng/mL | Children Ages 1-5 | 6-24 ng/mL | | |
| | In Treatment | below 100 ng/mL | | | | |
| Ideal Maintenance | 25-75 ng/mL | | | | | |

**For the definition of "In Treatment," see note on "treatment" page to follow.