Mission:
Iron Disorders Institute (IDI) exists so that people with iron disorders receive an early, accurate diagnosis, appropriate treatment and are equipped to live healthy lives.

For more information about iron:
Books:
- Guide to Hemochromatosis
- Guide to Anemia
- Exposing The Hidden Dangers of Iron
- The Hemochromatosis Cookbook

Newsletter:
nanograms for patients

At-a-Glance Desk Reference Charts for Physicians:
- Hereditary Hemochromatosis
- Iron Overload with Anemia

Web sites: www.irondisorders.org
           www.hemochromatosis.org

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For more information about iron, visit our website
www.irondisorders.org
1. Hemochromatosis is not a blood disease. It is an inherited metabolic condition that causes a person to absorb extra iron from the diet. The body has no natural way to get rid of excess iron except through blood loss or in some cases with medications formulated to remove iron.

2. The treatment for hemochromatosis is therapeutic phlebotomy (TP). TP is just like a blood donation, except that therapeutic phlebotomy requires a physician’s prescription.

3. Hemochromatosis patients with very high iron levels can give blood as often as twice a week without becoming anemic! Regular blood donors can only give blood every 56 days.

4. Hemochromatosis patients might give as many as 75-80 units of blood in their first year of treatment.

5. Blood donation is a life-long commitment for people with hemochromatosis. Although once their iron levels are in a healthy range, they may need to donate only occasionally.

6. A unit of blood donated by a person with hemochromatosis contains NO MORE IRON than a unit from any other donor! The excess iron is stored in the organs in ferritin. Each 500cc unit of blood contains about 250 milligrams of iron regardless of the donor.

7. Hemochromatosis blood is tested in the same way as all donor blood.

8. Hemochromatosis blood may have more new red blood cells, which makes it a superior blood product for transfusion.

9. In April 1999, the Food & Drug Administration (FDA) declared that hemochromatosis blood is safe to use for transfusional purposes.

10. Blood Centers can apply for a variance and offer Hemochromatosis Donor Programs. Donors must obtain a physician’s order. Centers will provide instructions about the order form. Programs include standard phlebotomy; some centers also offer double red cell apheresis.

As of 2010, more than 150 blood centers in the USA offer hemochromatosis donor programs—Iron Disorders Institute helped make this program possible.

Hereditary hemochromatosis can be confirmed with a genetic test. Excess iron is determined with an IRON PANEL:
- fasting serum iron (nothing by mouth after midnight except prescription medications)
- TIBC (total iron binding capacity)
- serum ferritin
- hemoglobin

*To avoid overbleeding, IDI recommends that physician orders for TP specify a pre-treatment hemoglobin of 12.5g/dL for the majority of patients.

Visit our websites:
www.irondisorders.org
www.hemochromatosis.org