

Hereditary Hemochromatosis (HHC)

What is Hereditary Hemochromatosis?

HHC is an inherited (genetic) disorder which can cause the body to absorb too much iron from foods you eat. This extra iron can injure vital organs such as the heart, liver, pancreas, skin and joints. Early diagnosis and treatment can prevent damage to these organs. Approximately 1 in 10 people carry the gene and 1 in 300 can potentially develop the condition. You would only have the diagnosis of "Hereditary Hemochromatosis" if and when you develop iron overload.

How would I know I had it?

Symptoms usually don't develop until after age 40 and they can be different from one person to another. People who have a very high iron level may have skin with a bronze or gray color. Their liver may get bigger and become scarred. Other signs of hereditary hemochromatosis include painful joints, diabetes, a weak heart, and problems with glands that produce hormones.

How is it diagnosed?

The first step is a blood test. The blood will be checked using two different measures of the iron in your body—a "serum ferritin" and either a "transferrin saturation" or an "unsaturated iron binding capacity". If the tests show that you have too much iron in your system, your chance of having hemochromatosis is increased, and your doctor may recommend genetic tests (also done with a sample of your blood).

What is the treatment?

No genetic disorder can be "cured", but hemochromatosis can be safely treated if the iron levels become too high. Because it is the build-up of excess iron that causes damage to organs in your body, sessions to remove iron-rich blood can help prevent this damage. These treatments are like donating blood. In fact, becoming a regular blood donor is one way to help prevent iron overload.

Consult with your doctor about your diet. Drastic changes are **not** recommended, but it is advisable to *avoid* vitamin supplements that contain iron or vitamin C. As well, too much alcohol can damage your liver, and raw seafood increases your chances of getting a serious infection.

Should my family be tested?

Yes, once the diagnosis has been made, it is recommended that siblings and perhaps other family members (including children over age 18) be tested for the hemochromatosis gene. If two people who are 'carriers' of the gene have children, their children are at risk for developing the disorder.

Where can I learn more?

The Canadian Hemochromatosis Society: concise informative pamphlet available; toll free phone 1-877-BAD-IRON or visit their website at www.cdnhemochromatosis.ca

The Centers for Disease Control: two excellent booklets are available free on their website:

- Questions and Answers for hemochromatosis—many issues covered; discusses pros and cons of diagnosis, including potential harms from genetic testing
www.cdc.gov/genomics/info/factshts/faqhemo.htm
- Harms of iron overload— a 12 page booklet with many details
www.cdc.gov/hemochromatosis/pdf/IronOverload_508.pdf
- American Academy of Family Physicians www.aafp.org/afp/20020301/865ph.html provides general information and links to other organizations in the U.S.

Adapted from: Hemochromatosis (HHC): Iron Overload—Too much of a good thing can kill you. Canadian Hemochromatosis Society www.cdnhemochromatosis.ca; Hereditary Hemochromatosis. American Academy of Family Physicians. www.familydoctor.org/x2423.xml?printxml

