

# Hemochromatosis IRON ZONES

*A Guide for Iron Reduction & Diet*

“The Hemochromatosis IRON ZONES Guide can be helpful to someone newly diagnosed. Some of the most common first questions are about diet or are based on the fear of dying or concern for the children. If people are left without hope, believing only with the worst possible outcomes, then they might go to extremes or completely withdraw. IRON ZONES was created not as a rigid, exact science, but to help families be less fearful of this very manageable iron disorder and to provide some measure of self-help strategies—so that they can live a normal life-span, hopefully disease free.” Cheryl Garrison, Executive Director, Iron Disorders Institute

Hereditary hemochromatosis—type 1 is a leading cause of iron overload, which is an excessive build up of iron in vital organs leading to disease and organ failure. Type 1, also called classic hemochromatosis (HHC) is attributed to changes in the HFE gene. These changes are called mutations. Abnormal iron absorption is experienced by individuals who inherit mutated copies of HFE.

People with normal iron metabolism absorb about 1 milligram of iron per day from the diet; whereas, people with type 1 hemochromatosis can absorb four-times this amount. The body has no natural way to get rid of excess iron. Therefore over time, the extra iron builds up in vital organs resulting in iron overload. If excess iron is not removed, symptoms, disease or death will result.

According to the preliminary results of the 2010 National Hemochromatosis Patient survey, the top three areas of interest to patients include: preventing complications of hemochromatosis (iron overload), self-care tips and diet. Obviously people desire some degree of control over disease management. Hemochromatosis is the poster child for disease prevention; a patient can play a prominent role in managing the condition.

Prevention of complications of hemochromatosis depends on several things: the extent or stage of iron overload at the time of diagnosis, therapy compliance (how well a person sticks to the treatment), behavior (alcohol consumption) and diet—including supplements. For the majority of hemochromatosis patients who are not anemic, no drug is needed for iron reduction. This places the responsibility of iron reduction squarely on the shoulders of the patient who can choose to keep a scheduled phlebotomy or skip it. Non-compliance with blood donation will certainly impact the degree of organ damage; in some cases the damage may be irreversible. On the other hand, one should not go to extremes and over-donate. Giving too much blood (over-bleeding) will lead to unnecessary iron deficiency and most likely anemia.

Many doctors still follow out of date guidelines that dictate forced-sustained anemia to achieve iron reduction. In this practice patients are bled when hemoglobin values are below normal. Although iron reduction is achieved with this method the patient trades one iron disorder for another. Forced sustained anemia for iron reduction is an outdated approach. If your doctor is using this approach in your therapy, share with him or her the Iron Disorders Institute Physician’s Hemochromatosis Reference chart where the most current best practice guidelines are provided.

Iron levels and health status will dictate iron reduction or iron replenishment strategies and diet guidelines.

The first step is in knowing your iron levels. You can accomplish this by obtaining a complete iron panel, which consists of hemoglobin, fasting serum iron, total iron binding capacity (TIBC) and serum ferritin (SF). The serum iron and TIBC are used to calculate the transferrin-iron saturation

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percentage (TS%) which is normally 25-35%. For adults, the ideal range for serum ferritin is 50-150ng/mL. With few exceptions, prior to phlebotomy the ideal hemoglobin value is 12.5g/dL or greater, but still within normal limits—not too low or too high. High hemoglobin levels indicate another health issue because typically hemochromatosis patients have normal hemoglobin levels. Other factors such as smoking, dehydration, blood loss or diseases of the bone marrow (polycythemia vera) cause abnormal hemoglobin.

Once iron levels and health status are defined, a physician will establish a therapy schedule noting that serum ferritin will decline about 30-50ng/mL with each full unit of blood removed. Note also that serum ferritin can be elevated if inflammation is present.

The four zones indicate a stage of iron overload and predict to some degree an anticipated phlebotomy schedule and diet modifications. Because each person is unique, there will always be exceptions to any set of guidelines and therefore whatever diet and supplement plan you choose, including this one, you should first discuss these approaches with your health care provider.

**IRON-ZONE 1; IDEAL ZONE:** Zone one is defined as a time in which one may have been diagnosed with genetic hemochromatosis, early, prior to symptoms, and iron levels are not yet above or below the Ideal Range for serum ferritin or TS%. This zone can also include individuals with a history of excess iron levels, but who have successfully achieved iron reduction without complications (no consequential disease) and whose iron levels are within a similar ideal range. In this zone, a hemochromatosis patient can be a routine blood donor, giving blood every 3-4 months or less—for life. As long as blood loss (by donation or menstruation) is taking place, there are no diet restrictions (except for the generally accepted healthy diet and behavior choices) for hemochromatosis patients in the IDEAL ZONE;. Consuming a healthy balanced diet is recommended. Even moderate red meat or alco-

hol consumption (for HHC patients in this zone) is permitted—so long as the liver remains healthy and the patient is being monitored routinely by a qualified physician who can modify restrictions if warranted. For prevention of further build up of iron, see key strategies below.

**Ideal Iron Range for Adults:** serum ferritin 50-150ng/mL, TS% 25-35%, hemoglobin  $\geq$ 12.5g/mL for males;  $\geq$  11.0g/dL for females (but not in excess of the upper range of normal).

**IRON-ZONE 2; LOW MODERATE ZONE—** Zone two is defined as a time in which the person is in an early stages of iron overload but has no symptoms; he or she may have silent symptoms, such as inflammation of organs—especially the liver. In zone two, the SF is above 150ng/mL but below 500 ng/mL with a TS% above 45. This individual may require an initial round of therapeutic phlebotomies (if so directed by the physician) until the SF is below 300ng/mL. After this level is reached an individual could choose to continue therapeutic phlebotomy every other month or they can become a routine blood donor, donating blood every 8-10 weeks unless anemia develops. If the liver is healthy and the patient is compliant with the iron reduction program (routine blood donation, therapeutic phlebotomy, iron chelation therapy), he or she can impact iron balance greatly with the diet and behavior and disease prevention strategies (see key strategies below)

**IRON-ZONE 3 HIGH MODERATE—**Zone three is defined as a time when the person has iron overload with symptoms. Symptoms will vary depending upon the distribution of iron; for most, chronic fatigue and joint pain (will vary) in the hips, knees, ankles or knuckles—iron fist—are the first symptoms realized by the patient. In zone three, SF is might be above 500ng/mL but below 1,000ng/mL with TS% above 45. If the SF level is closer to the 500 level, initial (induction) therapy could require weekly phlebotomy. If the SF is closer to the 1,000ng/mL level, twice weekly phlebotomies could be required—if inflammation is ruled out as a contributor to elevated serum ferritin. Once the SF is lowered to below 300ng/



mL and the TS% is below 45, zone 2 steps, followed by zone one steps can be considered. If the liver is healthy and the patient is compliant with the iron reduction program (routine blood donation, therapeutic phlebotomy, iron chelation therapy), he or she can impact iron balance greatly with the diet and behavior and disease prevention strategies. (see key strategies below)

**Iron-ZONE 4: THE CRITICAL ZONE:** Zone four is defined as a time when iron overload is present along with severe symptoms and organ damage. Serum ferritin is well above 1,000ng/mL at the time of diagnosis. Organ damage may or may not be reversible.

Induction therapy is weekly or twice weekly phlebotomy. Diet restrictions include: no foods high in heme iron such as red meat (beef, venison, lamb, bison) or blue fin tuna. Do not consume raw shellfish and abstain from alcohol. If the liver is healthy\*, drink one serving of tea or coffee with meals. Encouraged is the consumption of lean low-heme-iron meats (white meat), fresh fruits that are low in sugar (berries), vegetables (including spinach), high fiber grains and cereals (including oatmeal) and eggs. Hemochromatosis patients with diabetes should discuss the hemochromatosis diet limitations with a qualified diabetes nutritionist so that the recommendations for the HHC diet are compatible with recommendations for the diabetes diet. When in doubt, the diabetes diet takes priority over the hemochromatosis diet. Remain compliant with iron reduction program (therapeutic phlebotomy, iron chelation therapy).

\*healthy liver: no inflammation, no fatty infiltrates, no cirrhosis/fibrosis, liver enzymes within normal range for age and gender.

**Key strategies** for disease prevention can include blood donation to keep iron levels in an ideal range; limiting consumption of red meat to three or fewer servings per week; consuming a cup of tea or coffee once daily, generally with the main meal—so long as the liver is healthy. Tea

and coffee contain tannins, which can impair the absorption of iron but tannin in excess can harm the liver. If alcohol is desired and permitted by the physician, limit consumption to moderate intake. Alcohol will speed up iron absorption, therefore, if you choose to drink, make certain to let your doctor know so that liver health can be assessed, monitored and maintained. If any iron level is elevated, do not consume raw shellfish, which can contain a bacteria that is deadly to people with elevated iron levels. Avoid supplemental vitamin C at mealtime; supplemental vitamin C is fine when taken in the AM or mid afternoon but not at mealtime because vitamin C enhances absorption of iron. Eat freely of low sugar fresh fruits (apples, berries, kiwi) and fresh vegetables including spinach. Include high fiber nuts and grains, eggs and an occasional piece of dark chocolate.

“Some may grow weary of phrases such as ‘consult with your physician’; however, it is imperative that you do so. It is my experience that some patients will become obsessive in their efforts to control iron levels. They may consume excessive amounts of green tea (capsules especially), or take antacids, or calcium supplements with every meal. These products do in fact impede iron absorption, but at the same time, they restrict the absorption of many other nutrients. I would also urge people to avoid over-the counter products that claim to ‘remove iron’ from the body. These substances may be able to impede iron absorption, but none can remove iron from ferritin. Further, some of these products can cause side effects such as itching, rashes, thin blood and can shut down a liver if a person takes too much. I do encourage people with hemochromatosis to take a one-daily multi-vitamin without iron—but I feel strongly that supplementation beyond this is a medical issue and should be addressed jointly by the patient and his or her healthcare provider.” Cheryl Garrison, Executive Director Iron Disorders Institute



## Resources:

**Iron Disorders Institute** Physician Hemochromatosis Reference Chart

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**Iron Disorders Institute** Guide to Hemochromatosis SourceBooks 2009

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