“Every man dies. Not every man really lives.” — William Wallace Scottish patriot

Fourth Quarter 2009
Dear Reader,

We estimate that 90 million Americans experience some problem with iron balance at least once in their lifetime. Although most of these cases can be corrected with diet, blood donation or short term iron supplementation, about 4 million of these individuals have a life-long problem with iron. Iron disorders such as hemochromatosis are not well known. Other iron disorders such as iron deficiency are well known but often mismanaged where supplemental iron is taken only on the basis of low hemoglobin.

Awareness and education of the public and the medical community are key to early detection and appropriate treatment of iron imbalances.

The education commitment seems daunting when we consider that there are more than* 660,000 MDs in the US plus nearly 80,000 physician’s assistants (PA’s), two and half million nurses, nearly 50,000 chiropractors, more than 656,000 clinical laboratory technologists and more than 60,000 dietitians and nutritionists!

How will we ever reach all of them? The answer is with time, money and dedicated, passionate people.

Very soon, we will be activating our grassroots efforts to reach US Representatives and state Senators to deliver our important message. Did you know that the congressional budget for hemochromatosis provides a mere nickel per doctor or patient for awareness and education programs? Yep, that’s it: 5 cents!

Evidence is substantial that Iron-Out-of-Balance™ is a risk factor for diabetes mellitus, liver disease, heart failure, joint disease, gall bladder disease, hormone imbalances, impaired cognitive development or ability. Mismanaged iron in the brain occurs in the brains of people with early onset Alzheimer’s, Huntington’s, ALS (Lou Gehrig’s disease), multiple sclerosis and epilepsy, especially when the person has mutated copies of iron regulating genes.

With early detection of an iron imbalance, if action is taken, the risk of these life-altering diseases is lowered. Through screening which we can do for a few dollars, we can give every single American at least one disease prevention tool and a chance at better health.

Just this past September, US Supreme Court Justice Ruth Bader Ginsburg was taken to hospital. It was reported that she got dizzy and felt ill after receiving a treatment for iron deficiency. I wondered about that iron treatment. I wondered if Justice Ginsburg got a full iron panel before she got the full iron treatment. I hope so.

Take care, Cheryl Garrison, Executive Director


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**Acknowledgments:**

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**Fourth Quarter 2009**
Blood Center Focus: New York Blood Centers

Hemochromatosis patients who live in Manhattan, New Brunswick, NJ area, the Bronx or Hudson Valley, Brooklyn or Staten Island, Long Island or Queens, can participate in the New York Blood Center (NYBC) Hemochromatosis Phlebotomy Program, which provides for standard whole blood unit or “double” red cell apheresis (DRCA).

New York Blood Center Hemochromatosis Phlebotomy Program has been in existence since 2001, when the center received its variance from the Food and Drug Administration (FDA) that allows them to use HHC blood for transfusion purposes.

Debra Kessler, RN, MS Director of Special Donor and Community Health Services coordinates the program. According to Debbie, the program is a success, generating about 2.00 transfusable units of blood per month. She comments, “Hemochromatosis patients typically are drawn as frequently as once a week or two for 3-4 months. Once the iron levels are within a normal range, they may continue at the same frequency as any other blood donor or, if they don’t meet the requirements to qualify, they may continue on a maintenance program established by their physician.” As per FDA guidelines, whether or not they are eligible to have their units transfused for patient’s, there is no change for the phlebotomy.

According to Stephanie Clary, Blood Services Coordinator, “Maintenance is a critical time. If a patient waits too long to donate, their iron can build up to levels where therapeutic phlebotomy has to be reinstated. We urge patients to establish a 2, 3 or 4 times a year blood donation to avoid this problem.”

For Information about NYBC visit: http://live.nybloodcenter.org/
To enroll in the NYBC program, contact Debbie Kessler Debra Kessler RN, MS
Director, Special Donor and Community Health Services
New York Blood Center
310 East 67th St.
New York, NY 10065
ph. 212-570-3021
fax 212-288-8464
dkessler@nybloodcenter.org

CR HUME Facts about Hemochromatosis blood

1. Hemochromatosis is not a blood disease. It is an inherited condition that causes a person to absorb extra iron from the diet. It is not catching, but it is inherited, so it runs in families.

2. The treatment for hemochromatosis is therapeutic phlebotomy, which is just like a blood donation, except that therapeutic phlebotomy requires a physician’s prescription, which allows blood removal to be done more often than routine blood donors.

3. Some hemochromatosis patients can give as many as 75-80 units of blood in the first year of treatment without experiencing anemia. Thereafter, these patients can continue to give blood several times a year for the rest of their life.

4. A unit of blood donated by a person with hemochromatosis contains NO MORE IRON than a unit from any other donor!

5. Hemochromatosis blood is tested in the same way as all donor blood and has the same discard rate as other donor blood.

6. The FDA declared in April, 1999 that hemochromatosis blood was as safe to use for transfusion. Blood centers that wish to offer a hemochromatosis donor program can apply for a special variance.

7. Centers that are offering hemochromatosis blood donor programs report that their usable blood supply is increased as a result of this program.

8. Once the iron levels are down to normal, the hemochromatosis patient will still need to donate periodically because their genes will continue to step up iron absorption. Blood donation is a lifelong commitment for someone with hereditary hemochromatosis.

In Memory of Graydon Funke, MD

If you would like for us to honor the memory of someone who is suffering or who has lost the battle with a deadly iron disorder, or you would like to make a prayer list request, call us toll free 888-565-4766 or email Peggy Clark: pclark@irondisorders.org.
For children, iron needs fluctuate considerably, temporarily dropping when an infection is present, and rising markedly in preparation for a growth spurt. Growth spurts are most remarkable while in the womb. A Mother’s iron requirements are less than 1 milligram (mg) per day in the first trimester but increase to between 4 and 5 mg in the second trimester, and more than 9 mg in the third trimester. This steady rise in the Mother’s iron needs is nature’s way of assuring that the offspring has an abundance of iron during this intense period of fetal growth and development, especially of the lungs and the brain.

Once born, a newborn’s iron levels are naturally very high and remain so for several months. Without the presence of infection, when infants are breast-fed or given low-iron fortified formulas and introduced to meat and other iron rich foods at the appropriate ages, iron deficiency is not generally an issue. When children get older and consume excessive amounts of cow’s milk, chocolate, tea or coffee, the risk of iron deficiency rises. These substances dramatically reduce iron bio-availability so that the child might be getting enough dietary iron, but not absorbing much of it.

Eating an iron-fortified cereal may not deliver adequate dietary iron since the ability of calcium in milk will override the body’s ability to absorb the additive iron. Whole grain cereals such as oatmeal or cream of wheat or even cereal bars that are not eaten with milk and served with a piece of whole fresh fruit are better ways to assure better iron absorption from these breakfast foods. For lunch and dinner meals, one or two servings a week of lean red meat will likely keep iron levels adequate for most growing children. Tacos, “Sloppy Joes” and pizza are great ways to provide meat meals to children.

Trendy coffees served as iced beverages, chocolate flavored frappés or shakes, energy boosters and green tea have rapidly emerged as drinks of choice for youths who can afford it. These popular beverages are marketed as “social status symbols” or healthy choices. Truths about herbs, vitamins and amino acids are not fully disclosed in marketing campaigns promoting green tea, energy drinks fortified with taurine, ginsing, etc. Instead, the message is that these natural herbal supplements will deliver improved health—Facts taken out of context can easily support marketing claims by misleading parents into thinking that their children are getting benefit from such “herbal enriched” beverages. Case in point: for adults green tea consumption can reduce heart disease and help in weight reduction. Energy drinks can lower the threshold for pain also in adults. But these findings do not make these drinks suitable for youths. More to the point, when consumed in certain combinations the additives in these drinks, change the ability to absorb iron, increase the risk of strokes, insomnia, anxiety attacks and even a fatal heart attacks in children.

Another issue that is not emphasized is that these commercially sold beverages are as a rule are heavily sweetened packing a wallop of empty calories. Teen women already at risk for iron deficiency may allow such drinks to serve as meal replacement and thereby reduce the amount of nutritious foods eaten during the course of the day.

Bioavailability is the level of which a nutrient is able to be absorbed.

Select foods that lower iron bioavailability: dairy, tea, coffee or chocolate
Select foods that increase iron bioavailability: red meat, vitamin C

A growing number of young children have become vegetarians because of their concern that animals must be killed to provide meat. When properly balanced with good variety and especially so that complete proteins are created the vegetarian diet can be ideal. Vegan adults have a lower incidence of heart attacks, strokes, and obesity.

Most younger children on a vegetarian diet, may not comprehend the types of vegan diets or the importance of the combinations of vitamins and nutrients that they need. For example, vitamin B12 is only gotten from meat or dairy products. Meat also provides heme iron, the most absorbable form of iron. Anemia (low red blood cell count) can result in children if they are not monitored and guided to make good food choices. These children will underperform in school and play as a result of inadequate oxygen to fuel their bodies. They may also have lower test scores. Therefore, strict parental guidance is imperative to assure that variety of proper food combinations and supplemental nutrients (if needed) are part of the child’s vegan diet. Vitamin C rich foods can boost the amount of iron absorbed. Fresh whole vegetables (carrots, tomatoes, leafy greens) and fruits (oranges, kiwi, strawberries, blueberries) or juices that are not made from concentrate are the better choices for vitamin C rich foods.

Read more about vegan diets in children on the American Academy of Pediatrics website: http://www.healthychildren.org Read about foods that decrease or increase iron bioavailability on page 10.

resources:
Four Important Tests Where Ranges for Normal Vary

The right test can often solve health mysteries and bring about a complete diagnosis. Some of these tests are not routine, and must be requested. Compounding the issue is that one might get the test, but because ranges for normal vary from lab to lab, the diagnosis continues to be missed. Serum ferritin (SF), Thyroid Stimulating Hormone (TSH), gamma-glutamyl transpeptidase (GGT—a liver enzyme) and Vitamin D are among the tests that can be extraordinarily helpful, but often declared normal because results are “within range” when, for the individual, the levels are actually abnormal.

Serum ferritin (SF): Ferritin is a protein produced by the body to contain iron. Low serum ferritin detects iron deficiency, (low hemoglobin detects “anemia”; SF determines iron deficiency); high serum ferritin is present with inflammation or excess tissue iron. Serum ferritin reference ranges differ by age and gender. Newborns and infants have very high levels of ferritin, whereas adult measurements range from about 15 – 200 ng/mL for women and 20 – 300 ng/mL for men. Elevated SF can be present in people before the onset of chronic conditions such as diabetes mellitus, bone and joint disease, cardiovascular disease, liver/gallbladder disease, hormone imbalances and some cancers. Serum ferritin distinguishes “defense anemia” (anemia of inflammatory response) from iron deficiency anemia. Donating blood will lower serum ferritin. Ferritin levels can be increased with supplemental iron, blood transfusion, iron infusion or diets rich in heme iron found in meat, especially red meat. Presently the Iron Disorders Institute Medical and Scientific Advisory Board members are discussing the issue of establishing an ideal serum ferritin range of 50-150ng/mL for adults.

gamma-glutamyl transpeptidase (GGT) is a liver enzyme that has traditionally been measured to detect liver health and function. The normal biologic role of GGT is to reconstitute glutathione, the body’s master antioxidant. Glutathione provides natural protection against harmful oxidative stress. When GGT concentrations are above “low-normal” ranges, excess GGT can catabolize (break down) glutathione causing critical depletion of this very important antioxidant. When glutathione is depleted, and only insufficient amounts remain to protect the body’s organs from oxidative stress, damage starts to occur. Excess levels of uncontained metals such as iron contribute to this destructive process. A harmful combination is elevated iron with low GGT. Over time, oxidative stress can lead to a vicious cycle of irreversible cell, tissue and DNA damage, and ultimately to severe impairment of vital organ function. In recent years, elevated GGT measurements have proved to be effective early warning signs of other health risks such as atherosclerosis, stroke, type 2 diabetes, kidney disease and even cancer. Large population studies conducted in the US and around the world have identified increased risks of metabolic syndrome, including cardiovascular disease and diabetes, as well as all-cause mortality in both men and women, when GGT concentrations exceeded the lowest 25% of normal population ranges. Fortunately, an inexpensive blood test can determine GGT concentrations. GGT levels can be lowered through a balanced diet that includes ample portions of grains, fruits, nuts and vegetables; this bolsters the body’s natural antioxidant defenses. Several studies have shown that blood donation reduces GGT and other enzymes often associated with liver diseases. Coffee and tea consumption help to lower GGT levels; excessive alcohol consumption can increase GGT. Elevated GGT depletes glutathione and impairs antioxidant protection. The high end of “normal” GGT laboratory ranges are generally 65 – 70 U/L for men and 40 – 45 U/L for women.

thyroid stimulating hormone (TSH): is an indirect way to determine under-active or over-active thyroid function. When thyroid function is over-active (hyperactive), the TSH is low. When thyroid function is under-active (hypoactive), the TSH is elevated. People with diseases or conditions that cause iron overload are prone to hypothyroidism, possibly due to iron related injury to the anterior pituitary. These individuals may suffer with many symptoms before they are properly diagnosed and treated. Depression, infertility, irregular or heavy menstruation, hair loss, poor concentration or poor memory, loss of interest in sex, elevated body fat, irregular slow heart beat, dry itchy skin, heat or cold intolerance, and muscle pain can be attributed to low thyroid function.

Many doctors use 0.5-5.0 mU/L reference range for TSH; The Iron Disorders Institute provides a reference range for TSH of 0.5–3.5mU/L but considering its reference range to be compatible with the American Association of Clinical Endocrinologists (AACE) guidelines for TSH of 0.3–3.0mU/L. These tighter ranges help detect hyper or hypo active thyroid sooner.

Vitamin D: Adequate levels of vitamin D protect us against osteomalacia, osteoarthritis, high blood pressure and possibly type 1 or2 diabetes, some cancers (prostate, colorectal) or multiple sclerosis. We get vitamin D from foods or sunshine, but studies demonstrate that people with adequate exposure to sunshine have insufficient levels of vitamin D. According to the Office of Dietary Supplements, National Institutes of Health: supplemental intakes of 400 IU/day of vitamin D are insufficient and that daily intakes of approximately 1,700 IU are needed to raise these concentrations to more healthy levels.

At risk for low levels of D are people with liver disease, or who have taken anti-tuberculosis or anti-convulsant medications for prolonged periods of time. Also at risk are individuals who have conditions that interfere with absorption (short bowel syndrome, gastric-banding, celiac disease) or problems of fat malabsorption syndromes such as cystic fibrosis or inflammatory bowel disease such as Crohn’s disease.

According to clinical researcher vitamin D expert B.W. Hollis, MD, Department of Pediatrics, Medical University of South Carolina, Charleston current adult recommendations for vitamin D, 200-600 IU/day, are very inadequate when one considers that a 10-15 min whole-body exposure to peak summer sun will generate and release up to 20,000 IU vitamin D-3 into the circulation

The 25-hydroxy vitamin D test is the most accurate way to measure how much vitamin D is in your body.

<10-11ng/mL <25-27.5 nmol/L
Associated with vitamin D deficiency, leading to rickets in infants and children and osteomalacia in adults

<10-15 ng/mL <25-37.5 nmol/L
Generally considered inadequate for bone and overall health in healthy individuals ≥15 ng/mL ≥37.5 nmol/L Generally considered adequate for bone and overall health in healthy individuals

Consistently >200 ng/mL Consistently >500 nmol/L
Considered potentially toxic, leading to hypercalcaemia and hyperphosphatemia, although human data are limited. In an animal model, concentrations ≥400 ng/mL (≥1,000 nmol/L) demonstrated no toxicity

* Serum concentrations of 25(OH)D are reported in both nanograms per milliliter (ng/mL) and nanomoles per liter (nmol/L). ** 1 ng/mL = 2.5 nmol/L

References:


Hypogonadism

Exceeding for diabetes mellitus, hypogonadism is the most common endocrine complication of hemochromatosis (HHC). Persons with HHC may suffer multiple symptoms before the underlying cause of hypogonadism is revealed.

Hypogonadism is a condition in which the gonads (ovaries in women, testes in men) produce below normal levels of hormones needed for healthy sexual function. Hypogonadism may be “primary,” due to damage or failure of the gonads themselves, or “secondary,” due to damage or failure of the pituitary gland, the master endocrine gland, located at the base of the brain. The normal pituitary gland makes and secretes several hormones, including follicle stimulating hormone and luteinizing hormone that normally stimulate the gonads to produce estrogen and testosterone. When the pituitary is inflamed or damaged by iron, it may not produce the messenger hormones needed to stimulate gonad function. This condition is called hypogonadotrophic hypogonadism; it is more common than primary gonadal failure in HHC.

Signs and Symptoms of hypogonadism include:

—Erectile dysfunction
—Infertility
—Lack of menstrual periods
—Decrease in beard and body hair growth
—Decrease in muscle mass
—Undersized testicles
—Development of breast tissue (gynecomastia) in men
—Loss of bone mass (osteoporosis) in both men and women

Hypogonadism can also cause mental and emotional changes. As testosterone decreases, some men may experience symptoms similar to those of menopause in women. These may include fatigue, hot flashes, difficulty concentrating or decreased sex drive.

Tests that help diagnose hypogonadism include estrogen levels in women or testosterone levels in men. Your physician might also order tests for the follicle stimulating hormone (FSH) and luteinizing hormone (LH), thyroid stimulating hormone (TSH), sperm counts, and prolactin levels. Additional investigation can include semen analysis, pituitary imaging studies, genetic studies, bone densitometry, testicular ultrasonography, testicular biopsy, and specialized hormonal dynamic testing. An iron panel will provide insight as to the cause of hypogonadism.

The Association of Clinical Endocrinologists recommends that physicians evaluate the cause of hypogonadism before they commence therapeutic steps. The recognition, evaluation, and treatment of hypogonadism in male patients are often dismissed by the patients and overlooked by physicians. “The symptoms and signs of hypogonadism should be identified through appropriate questioning of the patient and a directed physical examination.” [AACE Medical Guidelines]

The age at diagnosis and the start of phlebotomy are critical for prevention and reversal of organ damage. Phlebotomy treatments will help unless glandular destruction has progressed too far. One of the first symptoms of severe damage is infertility. HHC is a major cause of secondary hypogonadism. The iron overload that occurs secondary HC, due to frequent blood transfusions, can also result in secondary hypogonadism.

HHC is one of the most common autosomal recessive disorders affecting mainly Caucasians. About 80% of the cases HHC have a genotype predictive of HHC. These individuals are generally progeny of Northern or Western European ancestry. Several U.S. population and prevalence studies have shown that there are about three individuals with HHC genotype per 1,000 people randomly tested. Most of the HHC affected patients are homozygous for the main HFE gene mutation (C282Y).

Researchers estimated the prevalence of hypogonadism in a large group of HHC patients diagnosed in a single center over 20 years. The period of follow-up spanned the time before and after widespread screening was introduced and the HFE gene was recognized. Abnormally low plasma testosterone levels, with low LH and FSH levels, were found in nine of 141 (6.4%) male patients tested. Eight of nine (89%) had associated hepatic cirrhosis; three of nine (33%) had diabetes mellitus. Inappropriately low LH and FSH levels were found in two of 38 females (5.2%) in whom the pituitary-gonadal axis could be assessed. [McDermott JH et al]

This was the largest detailed study of hypogonadism reported in HHC. The lower prevalence of hypogonadism in this study compared with other reported series likely reflects the earlier diagnosis of HHC in an unselected group of patients. Patients with lesser degrees of hepatic siderosis at diagnosis are unlikely to develop hypogonadism.

Suggested reading:


American Association Of Clinical Endocrinologists (AACE) Medical Guidelines For Clinical Practice For The Evaluation And Treatment Of Hypogonadism In Adult Male Patients—2002 Update Endocrine Practice Vol 8 No. 6 November/December 2002

Fertility & Sterility. 2009 91(5):1793-800.
IRON; “A FAVORITE” IN RESEARCH

Iron is often the choice of clinical researchers because iron is a tiny molecule and coupled with oxygen, iron can reach targeted tissues more swiftly than other transport vehicles.

More recently, iron has gained favor in the emerging field of medical technology known as nanomedicine.

Nanomedicine is the application of nanotechnology for medical purposes. Approaches in nanomedicine include the use of nanomaterials or nanoparticles such as iron for the delivery of drugs to target tissues in the brain, heart, lung, joints, arteries and liver. The technology has enormous potential—but when iron is the chosen nanocarrier concerns arise about the toxicity to these target organs.

Superparamagnetic iron oxide nanoparticles (SPIONs) are used as magnetic resonance imaging (MRI) contrast agents because these particles can be maneuvered to reach a specific location such as a tumor. Sungho Jin a professor of materials science at the University of California studied this approach. He found that once attached, these nanoparticles can be heated up and selectively kill cancer cells in a process he describes as magnetic hyperthermia.

In an 2007 interview with Science Daily, professor Jin warned, “…there are recent reports that this type of nanoparticle can be toxic in some cell types, and our discovery of their nano-toxicity in yet another type of cell suggests that these particles may not be as safe as we had once thought.”

It has been known since 1936 that inhaled iron oxide can cause lung cancer. Now there is overwhelming evidence that excess/misplaced iron can enhance oxidative stress and is a risk factor for cardiovascular, endocrine, gastrointestinal, infectious, neurologic, oncologic, orthopedic and pulmonary diseases as well as for aging.

Key concerns for nanomedicine involve the coupling of any form of iron (zero valent, ferrous, ferric) to items that are to be inhaled, ingested, injected or applied directly onto the skin. Few yet significant studies have been conducted to investigate in vivo toxicological testing of these iron coupled materials.

Investigators demonstrated that zero-valent iron is toxic; magnetic ferric iron causes oxidative stress; ferrous iron and zero valent iron is cytotoxic (cell killing).

Smart drugs use nanotechnology and are reported to be highly successful in reaching target tumors, infarcts caused by strokes and neuroblastomas. Smart drugs are also being studied in the treatment of malaria and human immunodeficiency virus (HIV).

Another type of nano-delivery system is liposomal encapsulation. A liposome is a type of vessel comprised primarily of fat, such as the fatty acid phosphatidylcholine derived from lecithin. Manufacturers claim that this type of system delivers more product to the cell. Presently liposomal encapsulated vitamin C is commercially available. Experiments are underway to study the efficacy of iron oxide-loaded liposomes, which may become the next super iron supplement.

These systems focus on using iron as part of a delivery system. In contrast iron chelators remove iron from the cell. Iron chelators coupled with nanoparticles are being studied as potential therapeutic agents for Alzheimer’s disease (AD) and may be promising. Mismanaged or misplaced iron is present in the brains of persons with Alzheimer’s. Used as a treatment for AD, these substances must cross the blood brain barrier to mop up excess or mismanaged iron. However the same concern for toxicity must be considered in these studies. The human body is highly efficient for impeding substances from crossing the blood-brain-barrier.

The degree of iron mediated toxicity (IMT) when iron oxide is employed as a nanocarrier is not well known. Investigators are encouraged to visit the National Nanotechnology Initiative web site and pursue funding opportunities posted on the site.

“Few yet significant studies have been conducted to investigate in vivo toxicological testing of these iron coupled materials.”

—Eugene Weinberg, Ph.D.

Nano-bytes (bits of info about iron & nanotechnology)

Nanotechnology: structures of the size 100 nanometers or smaller in at least one dimension A nanometer (nm) is one-billionth of a meter, smaller than the wavelength of visible light and a hundred-thousandth the width of a human hair source: Berkeley Labs

Natural iron oxide pigments are derived from hematite, which is a red iron oxide mineral; limonites, which vary from yellow to brown, such as ochers, siennas, and umbers; and magnetite, which is black iron oxide. Synthetic iron oxide pigments are produced from basic chemicals. Three major methods for the manufacture of synthetic iron oxides are thermal decomposition of iron salts or iron compounds; precipitation of iron salts, usually accompanied by oxidation; and reduction of organic compounds by iron (Podolsky and Reid, 2006, p. 1458).

Potential uses for nanosized (less than 0.1 micron or 100 nanometers) iron oxides include catalysts and ferrofluids. Uses for ferrofluids include computer disk drives and high performance loud speakers; other applications are in biology and medicine, including nuclear magnetic resonance imaging (Vollath, 2008, p. 2, 5)
David: my diet made a difference

As a teenager my doctor attributed my chronic fatigue to “teenaged laziness”. My joint pain, ashen gray-green skin color, abdominal pain, severe weight loss or lack of enthusiasm for school or friends did not prompt this doctor to investigate any further.

Eventually with the help of a new doctor more tests were run which revealed high blood sugar and high iron. Juvenile diabetes was suspected.

At the time, my parents owned a family restaurant, where my mom often prepared special dishes for people with health issues. Because of conversations with these special needs customers, mom learned basic information about diseases such as diabetes. So when the doctor suggested further testing for juvenile diabetes, mom was puzzled because she knew I lacked key symptoms of this disease.

Next to the results of my serum iron level the doctor had noted “wildly high” prompting mom to ask: “What about that high iron?”.

The doctor replied “That goes along with diabetes”—and later, we learned that it does, but mom was still curious. Because of the diabetics she met in the restaurant she learned from them about their symptoms of excessive thirst and urination, and blurred vision. I did not have any of these symptoms.

Somewhat intimidated by “getting online” mom went to the medical libraries and read all she could find about “high iron”—most of what she read was grim. The Merck Manual flatly stated that high iron was fatal. When she finally did brave the Internet, what she read there was equally scary.

Many of you know this story and how my mom went on to become one of the founders of Iron Disorders Institute (IDI) but what you may not know is how I am doing today, 13 years later.

Having been genetically tested, I carry one mutation of H63D, which I inherited from my Dad. I had begged my Dad to get tested and to learn about iron but he trusted his doctor who did not think the iron tests were needed. My Dad died in 2007 of a heart attack at the age of 65. This type of loss is only understood by someone who has experienced it. I have learned from my years at IDI that getting family members to take this seriously can be next to impossible. I understand the helplessness one feels when they know something that could save a loved one’s life but not be able to convince them of the dangers.

After discussion with various experts including the late Dr. Ernest Beutler, it is decided that I undoubtedly load iron. They believe that I very likely have some combination of gene mutations possibly one of the juvenile hemochromatosis, transferrin receptor or hepcidin mutations.

My initial phlebotomies helped lower my iron levels to normal. Thereafter, I was very careful with my diet: no alcohol, no red meat were the two most significant steps I took to control my iron levels. I have used this strategy for most of these 13 years and kept my iron levels in check. Recently, because of my grandfather’s severe iron deficiency anemia my mom fed him more beef. Since I was eating the same diet as my grandfather, within a short time my iron levels shot up like a rocket. I began to combat these rising levels with supplements of Vitamin C (as an antioxidant) and Vitamin D along with a diet with low iron.

Today I believe my levels to be lower, I am healthier, and have had a tremendous increase in my energy levels. High iron is fatal, but it is also preventable with a good diet, phlebotomy, and the helpful addition of supplements that combat free radical activity of iron.

After earning a degree in economics, David chose to start his own business. He is the owner and operator of WebSpeak Media, a Greenville, SC based company which designs websites and companion printed material for businesses of all sizes. www.webspeakmedia.com
If you haven’t joined the online discussion group or posted a question in our forum, we invite you to do so.

The LIST is made up of hundreds of people who have experienced problems with iron. Some of the LIST members are long time participants who know the ups and downs of dealing with iron related issues.

The purpose of the LIST is to offer support, not medical advice. When medical concerns do arise the FORUM is a good place to post a question, resolve a debate or to ask what IDI’s policy or opinion is of an issue. Both venues are monitored regularly by volunteers and staff of Iron Disorders Institute.

Join our CIRCLE of patients, family members, educators, students, and healthcare professionals on the EXCESS IRON online discussion list. One click on our website gets you on the list and in the CIRCLE. Here you can listen, share, ask questions and get help.

Very soon a new feature “Iron Blog” will be added to the IDI website.

We encourage you to join the discussion and learn from sharing with others.

Instructions for joining the LIST or posting to the FORUM are on the website www.irondisorders.org.

If you have questions, you can email Stephanie Clary sclary@irondisorders.org.

What is your Question?

One way for new patients to learn about iron disorders is from other patients on the Excess Iron Discussion List. Join NOW!

If you need help getting on the LIST send us an email. SClary@irondisorders.org

SUSTAINING MEMBERSHIP SUPPORTS STAFF AND SERVICES WITH A RECURRING MONTHLY DONATION.

CAN YOU GIVE TEN?

888-565-4766; email: pclark@irondisorders.org or visit our websites: www.irondisorders.org and www.hemochromatosis.org

We need you! Become a Volunteer!

Among my many passions is volunterrism. Now, more than ever we need to strengthen our volunteer network to help us reach treatment centers and members of the medical community.

Awareness and education is vitally needed to close up knowledge gaps so that every patient gets an early diagnosis, the appropriate treatment and the best information to stay current with trends and news.

Sign up today! Go to: irondisorders.org Click on the Volunteer tab. Fill out the form! We will contact you and discuss the volunteer program.

Excess Iron in the Body Systems

In his highly informative book Exposing the Hidden Dangers of Iron Dr. Eugene Weinberg provides several strategies to prevent excessive iron levels.

Alliances Around the World

Helping us to increase awareness around the world are alliances such as The Irish Haemochromatosis Association. Their website provides basic information leaflet, articles and events. Margaret Mullett, the driving force and inspiration behind the establishment and growth of the IHA was motivated to do so because of family. Margaret’s husband of 30 years George died at the age of 63 of a heart attack due to hemochromatosis. Margaret’s concern for her five children and for other Irish families fueled her passion for education and awareness.

Margaret has attended Iron Disorders Institute’s (IDI) conferences and corresponds regularly with several people at IDI. We encourage you to visit the IHA website and if you live in Ireland, join this fine organization.

www.haemochromatosis-ir.com/

Map courtesy of: Worldmapsonline.com

What is your Question?

One way for new patients to learn about iron disorders is from other patients on the Excess Iron Discussion List. Join NOW!

If you need help getting on the LIST send us an email. SClary@irondisorders.org

SUSTAINING MEMBERSHIP SUPPORTS STAFF AND SERVICES WITH A RECURRING MONTHLY DONATION.

CAN YOU GIVE TEN?

888-565-4766; email: pclark@irondisorders.org or visit our websites: www.irondisorders.org and www.hemochromatosis.org

We need you! Become a Volunteer!

Among my many passions is volunterrism. Now, more than ever we need to strengthen our volunteer network to help us reach treatment centers and members of the medical community.

Awareness and education is vitally needed to close up knowledge gaps so that every patient gets an early diagnosis, the appropriate treatment and the best information to stay current with trends and news.

Sign up today! Go to: irondisorders.org Click on the Volunteer tab. Fill out the form! We will contact you and discuss the volunteer program.

Excess Iron in the Body Systems

In his highly informative book Exposing the Hidden Dangers of Iron Dr. Eugene Weinberg provides several strategies to prevent excessive iron levels.

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October, November and December: The Eating Zone!

Beginning with Halloween candy, we segue into Thanksgiving feasts, Christmas and Hanukkah Celebrations—then we punctuate the year with New Year’s Eve Festivities. No wonder January is filled with new exercise programs and weight loss resolutions!

One approach to making it through the “Eating Zone” without picking up too many extra pounds is to train your tummy to be satisfied with “less”. If you begin early in September or October, working to shrink your stomach size by gradually downsizing your portions, you will arrive at the beginning of the “Eating Zone” armed with the best defense: a desire for less.

Be persistent and you will step into the new year with your wardrobe in tact!

The recipe featured in this issue is nourishing, low in “bad fats” and sugar—it is suitable for any one of these holiday occasions.

**recipes for iron balance**

**“Holiday Apple Crisp”**

<table>
<thead>
<tr>
<th>Ingredients</th>
</tr>
</thead>
<tbody>
<tr>
<td>4 cups peeled, cored, sliced granny smith apples (~3-4 medium apples)</td>
</tr>
<tr>
<td>½ cup coarsely chopped English walnuts</td>
</tr>
<tr>
<td>1 tablespoon white sugar</td>
</tr>
<tr>
<td>2 teaspoons fresh lemon juice</td>
</tr>
<tr>
<td>1/4 cup whole wheat flour</td>
</tr>
<tr>
<td>2/3 cup “Old Fashion” rolled oats</td>
</tr>
<tr>
<td>1 tablespoon extra virgin olive oil</td>
</tr>
<tr>
<td>1 tablespoon melted butter</td>
</tr>
<tr>
<td>½ teaspoon ground cinnamon</td>
</tr>
<tr>
<td>⅛ teaspoon sea salt</td>
</tr>
</tbody>
</table>

Spray the inside of 9X12 Pyrex baking dish or iron skillet (see TIPS) with olive oil spray. Place apples evenly in the bottom of the dish. In a separate medium sized bowl, blend together the remaining ingredients until it has the texture of coarse meal. Add nuts and stir. Bake in a preheated oven at 350° for ~25-30 minutes.

**Optional topping:**

In a small saucepan simmer for 10 minutes ½ cup of apple liquor, 2 tablespoons light brown sugar, 1/2 teaspoon cinnamon and 2 tablespoons butter. Cream liquid mixture together with one 8oz. block of Neufchatel (low fat version of cream cheese) until smooth. Place a dollop of topping on serving of Apple Crisp dessert.

**TIPS:**

# 1: If your iron levels are high, bake your Crisp in a Pyrex Dish.

# 2: If your iron levels are low, bake your Crisp in an iron skillet!

# 3: The iron in apples is not easily absorbed. Apples is an excellent source of antioxidants, which are important regardless of your iron levels!

**FOODS AND SUBSTANCES THAT IMPAIR IRON ABSORPTION**

---BETA-CAROTENE
---SUGAR
---ACIDIC FOODS OR BEVERAGES
---ALCOHOL
---VITAMIN C SUPPLEMENTS
---RED MEAT

**FOODS AND SUBSTANCES THAT IMPROVE IRON ABSORPTION**

---COFFEE
---TEA
---EGGS
---FIBER
---CHOCOLATE
---CALCIUM SUPPLEMENTS

---VITAMIN C
---Calcium
**IRON SMART!**

C.R. Hume is IDI’s mascot; he is a health-minded ferret, who helps raise awareness about the benefits of maintaining a healthy ferritin level. His name “CR HUME”, when run together with the word ferret sounds a bit like serum ferritin.

**GET all 3!**

**IRON in Use:** determined by measuring hemoglobin.

**IRON Being Transported:** determined by measuring serum iron and IBC

**IRON Contained:** determined by measuring serum ferritin.

**YOU NEED ALL THREE VIEWS** for a complete picture of your iron levels.

**IN YOUR GENES?**

Some iron disorders are inherited; that means it’s in your genes. If you are diagnosed with an inherited iron disorder, even if you are just a carrier, be sure to tell all your blood relatives: your parents, brothers and sisters, cousins, aunts and uncles. They need to know!

If it is in their genes too, knowing might save their life!

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**Important Ranges**

**Hemoglobin** measures the amount of iron in the blood that is carrying oxygen to vital organs. Hemoglobin will be within normal range unless you are iron deficient or have anemia of chronic disease.

**Ferritin** (serum) is a measure of contained iron. Ferritin will be elevated if you have too much iron in your body or if you have inflammation. Ferritin will be low if you are iron deficient.

**Hemoglobin**

<table>
<thead>
<tr>
<th>Normal Range</th>
<th>Adult Males</th>
<th>Adult Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>13.5-17.5 g/dL</td>
<td>12.0-16.0 g/dL</td>
<td></td>
</tr>
</tbody>
</table>

**Adolescents, Juveniles, Infants & Newborns**

<table>
<thead>
<tr>
<th>Age 6-18 years</th>
<th>10.0-15.5 g/dL</th>
<th>Age 2-6 mos</th>
<th>10.0-17.0 g/dL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age 1-6 years</td>
<td>9.5-14.0 g/dL</td>
<td>Age 0-2 weeks</td>
<td>12.0-20.0 g/dL</td>
</tr>
<tr>
<td>Age 6 mos-1year</td>
<td>9.5-14.0 g/dL</td>
<td>Newborn</td>
<td>14.0-24.0 g/dL</td>
</tr>
</tbody>
</table>

**Ferritin**

<table>
<thead>
<tr>
<th>Normal Range</th>
<th>Adult Males</th>
<th>Adult Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>up to 300ng/mL</td>
<td>up to 200ng/mL</td>
<td></td>
</tr>
</tbody>
</table>

**Adolescents, Juveniles, Infants & Newborns**

<table>
<thead>
<tr>
<th>Male ages 10-19 23-70ng/mL</th>
<th>Infants 7-12 months 60-80ng/mL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female ages 10-19 6-40ng/mL</td>
<td>Newborn 1-6 months 6-410ng/mL</td>
</tr>
<tr>
<td>Children ages 6-9 10-55ng/mL</td>
<td>Newborn 1-30 days 6-400ng/mL</td>
</tr>
<tr>
<td>Children ages 1-5 6-24ng/mL</td>
<td></td>
</tr>
</tbody>
</table>

*Therapeutic phlebotomy for people without anemia*
Our books are available online and in major bookstores.

For more information visit our website: www.irondisorders.org

PO Box 675 Taylors, SC 29687

Help Support our MISSION:

Iron Disorders Institute