Late last year the Food & Drug Administration (FDA) posted in the Federal Register a proposed rule change for Requirements for Human Blood and Blood Components Intended for Transfusion. During the past decade, blood centers applied for a variance with the FDA. For some of the earlier applicants the paperwork was a bit daunting—but eased up over the years as blood centers such as The Blood Connection in Greenville, SC; Medic in Knoxville, TN and The Ozarks, AR assisted other blood centers with the application process through IDI.

According to Gerry Koenig, member of the Iron Disorders Institute board of directors and advocate for promotion of hemochromatosis blood use, “This move should bring us a step closer to accessing hemochromatosis blood; however, the lack of variance applications in the past few years suggests that economic and knowledge barriers discouraging many currently non-participating establishments will still persist.”

What does this mean for patients? This proposed rule would eliminate the need for a variance request and permit all collecting establishments to use a donation from an individual with hemochromatosis (HHC) as a source of whole blood and not affix a disease label for HHC, if the following conditions are met:

* The donor with hemochromatosis otherwise meets the same eligibility requirements under proposed § 630.10 as for other allogeneic donors whose blood would be used for transfusion; and
* The collecting establishment does not charge a fee for any phlebotomies performed on individuals with hemochromatosis, including those who do not meet the eligibility requirements proposed under § 630.10.

The center must also have in place standard operational procedures (SOP) to allow for blood donation more frequently than every 56 days.

Patients are encouraged to contact the FDA with comments about the proposed change. IDI will submit a statement to the FDA before the deadline, which is now August 2008. Watch for updates on this important matter in the newsletter and on IDI’s websites. If you wish to send your comments to IDI, please email to Cheryl Garrison cgarrison@irondisorders.org
Dear Reader,

You notice that our newsletter has a new name. We have been considering this change for sometime now, because the name “In Touch” is widely used and we wanted a name that is more unique to iron disorders. Nanograms works because nanograms is a unit of measurement for serum ferritin, a key test used to determine the level of contained body-iron.

Most of you know that we used nanograms as the name of a mailer we distributed for over a year. Feedback from distribution of this mailer helped us assess its outreach potential for planning especially 2008, which is uniquely important.

2008 marks the second decade of IDI publications. Our boards, which guide us on issues of mission, funding, development, ethics and service are pleased with the plans we will implement over the next ten years including the consolidation and new direction for publications. Our newsletter will be published quarterly and printed for IDI members. ID-Insight will become a once a year “state of the sciences” report about iron disorders.

2004-2007 were especially important for IDI as a time of reflection and evaluation of mission, programs and services for 2008-2018. Challenges for IDI during this time were met balancing flexibility for change with delivering consistency of service. During this period of time, our governing board gave us a new vision, which you will see unfold over the next years. To realize our vision, the board gave us a new mission:

IDI exists so that people with iron disorders receive early, accurate diagnosis, appropriate treatment and are equipped to live in good health.

It was agreed that for the past decade IDI has done an exemplary job reaching the Caucasian population with hemochromatosis literature, programs and services. In late 2006, IDI established a minority health division so that we can carry out our mission in the Hispanic-Latino, African American, Asian and other minority populations living in the U.S..

During our years of service, we hope that you and your family are among ones that we have helped. If you are, we appeal to you to help us with your continuance and contributions.

Take care,

Cheryl Garrison, Executive Director
MINORITY HEALTH ISSUES
ADVISORY COUNCIL IN PLACE

On December 12th, 2007 the Kick-Off meeting for members of the Iron Disorders Institute (IDI)/South Carolina Minority Health Advisory Council was held. Prominent South Carolinians gathered at IDI headquarters to discuss the framework for a statewide plan to carry out the mission of Iron Disorders Institute to the minority population of South Carolina.

“South Carolina is an excellent place to form a council and develop this plan,” says Executive Director, Cheryl Garrison. “IDI is headquartered in Greenville, SC and the state has the unfortunate distinction of being among the lowest ranked states in the USA for poor healthcare, especially among minorities, which make up about one-third of the state’s population.”

The state by state health rankings chart illustrates the southeast region of the US, Region IV of the Department of Health and Human Services (DHHS). South Carolina is nearly at the bottom ranking #48th, down from #47th last year.

According to results of the Centers for Disease Control and Prevention (CDC), Behavioral Risk Factor Surveillance Survey (BRFSS) South Carolina is above the national average in deaths or risk factors for diabetes, cardiovascular disease, cancer and obesity. All of these are conditions where an iron imbalance could be the direct cause or a contributing factor.

The minority population is especially at risk. Of the 1,276,500 minorities who reside in South Carolina, nearly one-half million (425,500) are at risk for an iron disorder. These disorders include iron deficiency anemia, anemia of chronic disease, iron overload or iron overload with anemia. Since South Carolina is part of DHHS Region IV, this seemed the most logical place for IDI to begin its efforts by forming the council and implement the plan.

In late 2006, IDI started a division to focus on minority iron related health issues. Inspired by SC DHEC’s Department on Aging approach of forming a council to develop a statewide plan, IDI began to look for funds to support a council. Local prominent businessman Fred Gibbs provided the first dollars with his generous donation and agreed to serve of the council. After that, a proposal was submitted to the US Department of Health and Human Services (DHHS) Office of Minority Health requesting seed money for the project.

“We were thrilled when we got the news of the award. We knew that this council would be important first step. We had identified the iron-related health issues of minorities in SC and needed to address the barriers to carrying out our mission to this population. For this we needed a plan,” Cheryl Garrison remarks.

Invites to the council graciously agreed to take on this task and are now in the midst of structuring the first draft for full council review. The plan will include strategies and tactics to improve the health of minorities suffering and dying prematurely from iron related disease. The final plan is due to be completed by June, 2008.

“I also want to point out that our SC legislators are aware of Iron Disorders Institute’s efforts and sees our work as a state priority. They share the concern about South Carolina. We need to move this state out of its terrible low ranking. With a strong statewide plan for our minority citizens, who are at greatest risk for iron related deaths, we have the basis for a regional and national plan.” Garrison concludes.

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**clinical trials**

*If you have hemochromatosis, you may be eligible for a study of the: oral iron chelator EXJADE®*

<table>
<thead>
<tr>
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<td>Laura Braggins</td>
<td>Age 18 or older; No HIV infection; No chronic hepatitis B or C; No symptomatic or trouble some problems with cataracts.</td>
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My Iron Story: Precious Gamble

How ironic for a little girl to be given a name that just months later would hold more meaning than anyone could have known.

Precious Gamble was indeed a precious little girl who needed transfusions every month to prevent strokes from sickle cell disease. Diagnosed at 3 months, Precious was in and out of the hospital many times in her short life. Her illness became so serious she eventually needed monthly transfusions to prevent strokes.

“Each transfusion took two - three hours. It was hard, but I knew her life depended on it,” said Precious’ mom Priscilla. There was something else about Precious that was rare: her blood. Because of the multiple transfusions, she developed a number of antibodies in her blood that required the donor’s blood to be an exact match. It was not as simple as just matching the blood type. And there were very few donors who matched. Since Precious was African-American, African-American donors were more likely to match. But, African-Americans make up only 10% of blood donors.

“I hate to think what would have happened if there weren’t people like those who donated for Precious. One of her transfusions had to be delayed four days because a matched donor wasn’t available. I encourage all minorities to donate,” said Mrs. Ketter. Precious’ family thanks those who donated each month for Precious. Each day her life was a precious gamble.

Most recently, at a health fair, Priscilla met Angie Cole, Iron Disorders Institute Member Services Coordinator. From Angie, Priscilla learned something about sickle cell disease that she did not know. She was unaware of the complications with iron overload and sickle cell disease. And she did not know that with every unit of whole blood contains about 250 milligrams of iron. Excess iron is stored in the body; over time excess iron will cause damage to the heart, the liver, the pancreas and other vital organs.

Precious did receive iron chelation therapy, which is the only way to remove excess iron in patients who are anemic. But the iron overload was never fully understood by Priscilla or her family. To help with the iron overload, Precious was put on Desferal chelation therapy, which lasted about a year and a half. With the lack of compatible blood donors, Precious’ family began to look into alternative treatments like Hydroxy Urea and a stem cell transplant, but her Precious Gamble lost her fight with the deadly iron disorder.

Priscilla urges all minorities to donate blood regularly. They may be saving another precious life. If you live in South Carolina, contact The Blood Connection 864-255-5005.

Cherished and remembered, forever...

In Memory of Mr. Burnett “Tom” Conner
From: Mr. and Mrs. David Wolf
Mr. and Mrs. Jason Keilb
Barbara C. Norris  (My Wonderful Brother)

In memory of Mr. John D. Burren
From Todd and Karen Roscoe

In Memory of Mr. Phil Barton
From Mr. Patrick McKeever

In Memory of Sandra Anne Herr
From Emma E. Sakmar Columbus, Ohio; Doug, Newark, OH; Wesley and Donna Sargent, Granville, OH.

In Memory of Chris Main
From Wesley and Donna Sargent

In Memory of Mr. Kevin Patrick Hyland
from Ms. Mary Ann Pass
from Ms. Rita A. Cahill

In Honor of Ms. Sarah L. Parker
from Gregson Parker

In Loving Honor Of...

In Honor of Ms. Sarah L. Parker
from Gregson Parker

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.

OUR MISSION

“I encourage all minorities to donate blood; it truly is the gift of life.” Priscilla Ketter, Donor Resources, Special Recruiter; The Blood Connection, Greenville, South Carolina

“Iron Disorders Institute exists so that people with iron disorders receive early, accurate diagnosis, appropriate treatment and are equipped to live in good health.”
My Iron Story: Janelle Nicolo

Janelle Nicolo is a 26 year old resident of Massachusetts. Not only is Janelle a national level fitness and bikini competitor, as seen on ESPN, but she has hemochromatosis. However, Janelle has not let the disease disable her; in fact, she decided to take 100% complete responsibility for her health and how she was feeling. Since starting to compete in 2005, she has entered a total of 12 competitions and has place in the top spots in every one. Nationally, she placed 9th in the Fitness Universe competition in Miami Fl., last summer, and has also placed 2nd in Ms. Bikini Universe and 9th in Ms. Bikini America. In 2007 Janelle won the coveted ESPN’s Miss Bikini title.

Along with her accomplishments on stage she’s been featured in Oxygen Magazine (three times), Muscular Development, Fitness & Physique Magazine, and also had a story about her fight with Hemochromatosis in Complete Women Magazine.

It all started when Janelle was feeling tired all the time, having joint pain and digestive problems at the age of 11, her mother feared something was wrong. She was an active pre-teen, participating in sports and not overweight. She went to many doctors and specialists and a year later learned she had hemochromatosis (iron overload).

Since learning she had the hereditary disease along with many of her family members, Janelle has been able to monitor her iron levels, and get regular phlebotomy’s, but only since turning to a completely healthy and active lifestyle has she been able to ease her symptoms she had suffered from for many years. “Although I still have joint problems that can become inflamed due to overuse, I no longer feel fatigue or get the stomach and digestive problems I used to before switching to a clean diet. A clean diet, active lifestyle, and combined with regular blood lettings (phlebotomies) helps me keep my iron levels in a safe zone and enables me to live my best life!”

Janelle is happy to join Iron Disorders Institute in order to help aid in the fight for Hemochromatosis Awareness by launching her ‘Calories For A Cure’ campaign on her website. People can download a form on her website (www.janellenicolo.com) and make a direct pledge to her goal of burning 9,000+ calories a month on an ongoing basis.

“Since competing nationally in fitness gets expensive, I wanted to find a way for me to be able to continue my fitness goals, while helping raise money for Hemochromatosis Awareness.” Says Janelle. “When someone pledges to my Calories For A Cure Campaign I will personally donate 20% of all proceeds directly to the Iron Disorders Institute’s Hemochromatosis Health Promotion Programs, Services and Research in honor of Dr. Margit Krikker, who founded the Hemochromatosis Foundation in 1982.”

More good news! A second addition of Janelle’s cookbook will be available this year. Ten percent of all proceeds from books purchased through her website will be given to the Iron Disorders Institutes’ Hemochromatosis Programs!

If we’ve helped you, please help us by donating.

BECOME A Volunteer and a MEMBER

With your membership dues you will receive your handsome IDI membership pin and a printed copy of nanograms.

For details about membership please call Angie Cole, Member Services Coordinator 888-565-4766 or visit our websites: www.irondisorders.org and www.hemochromatosis.org
In the June 19, 2002 issue of JAMA (Journal of The American Medical Association) the AMA published its review: “Vitamins for chronic disease prevention in adults: scientific review.” Investigators concluded that some groups of patients are at higher risk for vitamin deficiency and suboptimal vitamin status. They also concluded that some people are at risk of taking too many supplements and may do themselves harm. The latter point of the review was not as highly publicized as the “recommendation that we take a daily multi-vitamin.”

Some degree of supplementation has proven benefit for certain groups such as folic acid (synthetic form of folate) for women of child-bearing age. The problem is that most people overdo it, thinking that if something is good for us, more must be better. Evidence is surfacing that warns folic acid could actually do harm if taken in excess by certain groups.

Iron Disorders Institute board recommends fluids and a daily multi-vitamin without iron for people with hemochromatosis (HHC) undergoing phlebotomy. With the removal of blood, not only iron is removed, but so are other nutrients. Someone undergoing frequent phlebotomies could be at increased risk for deficiencies, especially if their diet is also lacking in variety of nutritious foods.

Some multi-vitamins are better than others for the hemochromatosis patient. Vitamin C, which enhances iron absorption, also helps with the absorption of other nutrients. HHC patients need to limit supplemental vitamin C to about 200 milligrams per dose—unless otherwise recommended by their physician. If the daily multi has vitamin C in excess of this amount, there’s probably no need to toss the bottle. The pill can be taken mid-morning with a snack until the supply is used up.

Vitamin A probably poses more of a problem for hemochromatosis patients than does Vitamin C. Most multi-vitamins have dangerously excessive amounts of vitamin A. Some multi’s have A content as high as 20,000 IU; where 10,000 IU could shut down a liver under certain circumstances. Look for daily vitamins that have low vitamin A levels, preferably around 2,500 IU to 4,500 IU.

And do one more thing: let your doctor know what supplements you are taking. The assumption that over-the-counter supplements are safe because they do not require a prescription is flawed thinking: consider iron for example.

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Iron depends on copper and copper binding proteins to maintain iron homeostasis. Both metals can trigger free radical activity by oxidizing lipids (fats). Both metals are tightly regulated by the body with numerous binding and transport proteins, enzymes and genes. Copper is a component of ferroxidase, an enzyme that changes iron from one form (ferrous) to another (ferric) so that iron can be absorbed. Ceruloplasmin is a copper containing protein that influences the transport and storage of iron and copper. Low ceruloplasmin impairs iron’s transfer into plasma resulting in anemia, even though iron stores may be normal. Inadequate amounts of ceruloplasmin causes a disruption of the incorporation of iron into heme. This disruption leads to inappropriate iron distribution in the red blood cells or sideroblasts. People with sideroblastic anemia have this type of red blood cell. These cells can be seen under a microscope when stained with a substance such as Perls’s iron stain. People with iron overload (hemochromatosis) or copper overload (Wilson’s disease) have low levels of ceruloplasmin. With both diseases serum ferritin can be elevated. Even though hereditary hemochromatosis is 200 times more common than Wilson’s, it seems reasonable to check the iron levels in patients with Wilson’s disease in order to detect possible iron overload. Hemochromatosis is mainly treated with therapeutic phlebotomy. Wilson’s disease requires a pharmaceutical chelator that binds with copper restoring balance of the metal.

**DYK?** While iron increases the growth of bacteria (Weinberg), copper inhibits bacterial growth. ([www.copper.org](http://www.copper.org))

<table>
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<th><strong>TESTS</strong></th>
<th><strong>WILSON’s Disease Typical Findings</strong></th>
<th><strong>HEMOCHROMATOSIS Typical Findings</strong></th>
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**RESEARCH:**
Investigators discovered that when two mutations of the Ceruloplasmin (Cp) gene and two mutations of the Hemochromatosis gene (HFE) were present in mice, these mice deposited more iron in the liver than mice defective for either one or both genes. In contrast, mice that had two Cp mutations but normal or single mutation of HFE showed 30% decrease in liver iron when compared with mice that had only one Cp mutation. **CONCLUSIONS:** This study highlights the existence of complex interactions between Cp and HFE and represents the first example of a modifier gene with a protective effect, in which heterozygosity reduces the iron load in the context of HFE deficiency.


Studies demonstrate that estrogen significantly raises the level of serum ceruloplasmin and can mask ceruloplasmin deficiency.


**KEY WORDS:**
ceruloplasmin (SIR-RULO-PLAZZ-MEN) copper containing protein
ferric (FAIR-ICK) form of iron that cannot be absorbed; needs to be changed into ferrous form by acid such as stomach acid or ascorbic acid
ferrous (FAIR-US) form of iron that can be absorbed
ferroxidase (FAIR-OX-EH-DACE) copper and ceruloplasmin containing enzyme
heme (heem) iron containing portion of hemoglobin
hemochromatosis (HEE-MOW-CROW-MOW-TOE-SUSS) disorder of iron metabolism; person absorbs more iron than needed
homeostatis (HOE-MEO-STAY-SIS) balance and proportion
Perl’s Prussian blue classic stain used to demonstrate iron in tissues
sideroblast (SID-ER-OH BLAST) Wilson’s disease disorder of copper metabolism; person absorbs more copper than needed
Dr. Bonkovsky is world renowned for his work in digestive and metabolic diseases. His expertise covers a wide range of conditions including liver damage caused by alcohol, drugs or iron. Hepatic porphyrias, porphyria cutanea tarda, viral hepatitis, cirrhosis, fatty liver and liver cancer are also areas that Dr. Bonkovsky has investigated and reported significant findings. The National Library of Medicine lists nearly 200 publications authored or co-authored by Dr. Bonkovsky on these and other topics relevant to the liver.

According to Dr. Bonkovsky, “The liver is not only the body’s clearinghouse affecting all body systems, but it serves to maintain blood glucose levels, makes most of the proteins that circulate in the blood, helps fight infections, and now with the discovery of hepcidin, the liver may hold the key to managing body iron levels.”

Dr. Bonkovsky is the inventor of a method of specialized MRI for assessing liver-iron levels that inspired today’s technology for non-invasive methods of qualifying and quantifying hepatic iron. He has served on numerous editorial panels and consensus committees addressing issues about liver disease and formulating treatment policies that remain the gold standard today. His greatest love is clinical research where diagnosis and treatment methods learned in research are translated immediately to the patient.

“Dr. Bonkovsky is one of the kindest men I know. He cares deeply for his patients, going out of his way to help even in dire cases. His guidance both as a medical advisor and now as a member of IDI’s board of directors is valued beyond words.” C. Garrison, Executive Director

Dr. Bonkovsky recently accepted the position as Vice President for Research, Carolinas Healthcare System. He is also Adjunct Professor for the University of North Carolina and Professor, University of Connecticut. Visit www.carolinash health.org for more on The Cannon Research Center and work of Dr. Bonkovsky.

Dr. Caplan is the inventor of a method of specialized MRI for assessing liver-iron levels that inspired today’s technology for non-invasive methods of qualifying and quantifying hepatic iron. He has served on numerous editorial panels and consensus committees addressing issues about liver disease and formulating treatment policies that remain the gold standard today. His greatest love is clinical research where diagnosis and treatment methods learned in research are translated immediately to the patient.

“Dr. Caplan is one of the most approachable and down-to-earth people I know. His sense of humor which subtly underlies his passionate voice for bio-ethics makes everyone want to sit up and listen.” C. Garrison, Executive Director, Iron Disorders Institute

**Definition of Bioethics:** “The discipline that considers the morality of applications of biotechnology and medicine to humanity.” Francis S. Collins The Language of God: Simon and Schuster 2006. Read news, projects and events of the Center for Bioethics: http://www.bioethics.upenn.edu/
Rusty Curmudgeon Retires as IDI’s Newsletter Editor

After four years as editor on IDI’s newsletter, Jim Hines AKA The Rusty Curmudgeon retires. The newsletter, then called id-In Touch became a very popular item under Jim’s direction. On average, more than 1,000 visitors a month visit our website and link to id-In Touch to read articles about Iron-Out-of-Balance”.

According to Cheryl Garrison, Executive Director, Iron Disorders Institute, “Jim had many challenges as editor—often having to write articles from scratch. But nothing stood in his way of missing a deadline. Graphics, text, links, web loading, you name it, Jim always came through in his meticulous way and on time—which is the biggest challenge when resources are limited. His attention to detail never failed to amaze me. Every link worked; every word was properly spelled and used correctly. He is to be commended for these years of dedicated work.” Garrison concludes.

Personal dedication to people with hemochromatosis was the driving force behind Jim’s years of volunteerism. He not only helped IDI with its publications but he helped other organizations too. Jim says that he will consider doing a “Rusty Curmudgeon” column when he can, but for now he and his wife Ruth are pursuing a business venture that is doing well and requiring more of Jim’s time. Presently, the two are on their way to Massachusetts, where Jim and Ruth have family.

A letter of thanks from our board of directors and Gene Weinberg, Chair of Publications is on its way to Jim; highlights of comments and signatures include:

“Jim’s work has been a superb model for our continuing newsletters. He has gotten us off to a fine start. We hope we can continue to call on him from time to time for advice.” Gene Weinberg, Chair Publications

“This note is to add my word of thanks to you for your efforts these past 4 years on behalf of IDI. The Newsletters have been excellent, and we will miss your work. We wish you and yours well in coming months and years.” Herb Bonkovsky, M.D. Chair, Medical & Scientific Board

“When the crowd enjoys a beautiful and well-orchestrated Broadway play, most applaud the actors on stage, even calling for encores’. But the folks who really know the business and are regular fans understand that the curtain could not come up and the lights would never be turned on if it weren’t for the talented and dedicated ones who are “behind the scenes.” So, for those of us on the stage of IDI, and the many in the audience, I stand and cheer you for the steadfast and persistent commitment in doing your part to bring a better quality of life to thousands and laying the groundwork that will someday, hopefully, render IDI useless. As a former Navy Master Chief, picture an enemy warship, numbered C282Y, captured and refitted as a cruise ship for all to enjoy. Now that’s an encore. We pray that you and Ruth enjoy your days in Virginia Beach and never sail too far that we can’t reach out and touch you as you have touched us.” Tim Roberson, Chairman, Board of Directors

“I not only thank you for the years of doing this work, but also for years of friendship. ” Cheryl Garrison, Executive Director

Q: Is the compound heterozygote at risk of iron loading?
A: Not enough is known about the loading patterns of heterozygotes to discount the potential risk of morbidity/mortality in this population. Until more evidence is available, Iron Disorders Institute (IDI) recognizes the compound heterozygote (C282Y/H63D) in the same risk group for iron loading as the C282Y homozygote, although iron loading may be less severe in the compound heterozygote, IDI suggests monitoring with periodic measurement of iron levels.

Q: Do I have to become anemic to be de-ironed?
A: Forced-sustained anemia is outdated and can be harmful. IDI recommends a pre-phlebotomy hemoglobin of 12.5g/dL (Approx HCT 37.5%) to avoid overbleeding. There are exceptions, which are emphasized in IDI’s Physician’s Hemochromatosis Reference Chart. IDI’s recommendation against overbleeding is shared by Principal Investigator, Susan Leitman, M.D.; National Institutes of Health Hemochromatosis Protocol, Bethesda, MD.

Q: Do I need a liver biopsy?
A: Liver biopsy is no longer used to diagnose hereditary hemochromatosis; but is recommended for HHC patients with serum ferritin 1,000ng/mL at the time of diagnosis. Serum ferritin is an important part of the treatment and iron reduction management, dropping ~30ng/mL per 500cc of blood removed. Serum ferritin is also an acute-phase reactant and can be elevated in conditions of inflammation or ingestion of certain drugs such as nicotine, alcohol or estrogens. This should be taken into account for individuals whose ferritin drops in large increments.

Q: What about my children?
A: In families where HHC is diagnosed, for children under the age of 18 but no younger than age 3, IDI recommends a benchmark iron panel (fasting serum iron, TIBC or UIBC and serum ferritin) at the first opportunity to draw blood e.g., back to school physicals. Diet changes need not be made; but observation with periodic iron level measurements is encouraged.

Q: What about diet and supplements?
A: For people with high iron levels, reduction of consumption of alcohol, red meat, fats and sugars is recommended. Raw shellfish should be avoided. Supplemental vitamin C should not exceed 200mg per dose and calcium supplements which are known to reduce heme and non-heme iron absorption but should not be used in place of phlebotomy. A daily multiple vitamin without iron and with a vitamin A content less than 4,500 IU and fluids are recommended for patients undergoing phlebotomy. Fresh fruits and vegetables including spinach are encouraged regardless of vitamin C content. Read more about diet on page 11 and 12.
Chip Sullivan

My Iron Story:

Forty-two year old professional golfer Chip Sullivan was diagnosed with hemochromatosis (too much iron in the body) in late 2006. Chip was told he also had diabetes, a common result for people with hemochromatosis, but a real shocker to Chip who thought that diabetes was found only in overweight people who didn’t take care of themselves. Chip’s 44 year old sister Kerry lost a battle to the consequences of undiagnosed hemochromatosis in 2004; Kerry died of liver failure, complicated by diabetes. Chip’s early detection of hemochromatosis has spared him and an older sister; both are now being treated with routine phlebotomies to lower iron levels.

Chip’s iron story began in December 2005 during an annual check up with his family physician, Dr. Todd Palmerton. Chip was 40 at the time; everything came out fine except for mild thrombocytopenia (decreased platelet count). Chip was referred to a hematologist, Dr. Padmaja Mallidi for further testing. Dr. Mallidi found that Chip had a slightly enlarged spleen and liver. A hepatitis test was done and the results were negative. Further testing showed mildly increased serum ferritin (499ng/mL). A liver biopsy was recommended but postponed. Chip later developed increasing ferritin levels and was started on phlebotomies. Chip was then referred to a gastroenterologist, Dr. Dennis Weiserbs for additional evaluation. Dr. Weiserbs told Chip that he was a “borderline” candidate for a liver biopsy. “We decided to wait a year and see if the extra iron would come out.”

Because Chip also has diabetes, he must also keep a close check on his sugar levels as well as his iron levels. “My most recent A1C was 6.7. My endocrinologist seemed pleased and recommended no changes. My diabetes is managed with 2 types of insulin that I inject: 20 units of Lantus® (once a day) and 5-10 units of Novolog® (before meals when needed). I also take Janumet® daily which is a combination of 50 milligrams of Sitagliptin® and 1000 mgs of Metformin®. Additionally, I take 5 mgs of Lisonopril® for my kidneys and Tricor® for high triglycerides.”

Most of the diet changes Chip has made are for the diabetes. He tries to drink more water now, and drinks diet drinks rather than regular. He also eliminated potatoes and French fries. He has also vowed to work out more but adds, “With three children at ages 3, 6, and 9, it is never easy to find time, but I am starting this week and getting on a new golf fitness plan the first of February.”

Chip’s victory over these two potentially deadly diseases was highlighted when this June Chip won the 2007 PGA Professional National Championship. His win qualified him for the fourth time to compete in the PGA Championship against giants such as Tiger Woods. According to a PGA of America website article about Chip, he remarks “With what’s going on with every thing else in my life, time is limited. You have to pinch me that I won.” Chips win earned him an exemption; he will be playing in six PGA Tour events starting in February, 2008.

Since his victory in the PGA, Chip says that he wants to help Iron Disorders Institute raise awareness about hemochromatosis. To do that, he will host a golf tournament this October 2008 at the Ashley Plantation, Daleville, Virginia.


Dick Main has already signed up to play! If you have an interest in participating by playing or helping us promote the event, contact Laura Main 888-565-4766.
misconception: If you have hemochromatosis (HHC) you can no longer eat red meat. Though avoiding or reducing the amount of red meat an HHC patient consumes is good advice when iron levels are above normal, there are ways to eat red meat, such as beef while iron levels are elevated. Beef can be marinated in coffee or tea and cooked well-done. Once iron levels are within normal range and as long as phlebotomies are continued (as needed), the HHC patient can enjoy red meat: venison, beef or lamb.

misconception: Spinach is high in iron and should be eaten by people who are iron deficient but avoided by people with hemochromatosis. The iron in spinach is not easily absorbed, if at all. Spinach is rich in many nutrients including folic acid and is loaded with antioxidants. Eaten fresh or steamed, spinach is recommended for everyone, regardless of their iron levels.

misconception: Eggs are high in iron; good for people who are iron deficient but should be avoided by people with hemochromatosis. Eggs contain about 1 milligram of non-heme iron, a form that is not easily absorbed. Eggs also contain a compound that reduces iron absorption by as much as 30%.

misconception: Vitamin C should be avoided by people who have hemochromatosis. For hemochromatosis patients with high body iron, supplemental vitamin C should be limited to 200 milligrams per dose. Vitamin-C rich foods should not be eliminated from the diet regardless whether a person has high iron or not enough iron. Natural sources of vitamin C contain antioxidants and numerous nutrients needed for healthy metabolism. Best choices are low sugar fruits such as apples, kiwi and berries. C-rich vegetables must be eaten raw as cooking destroys vitamin C.

misconception: Cooking in an iron skillet is a good way to get iron. Prolonged cooking (sauces, stews) allows iron filings to get into the food source and can increase the amount of iron absorbed. This extra iron can be a problem for people with high body iron but can help those who are iron deficient.

misconception: The iron contained in well water is in a form that is not easily absorbed and drinking this water will not likely lead to iron overload. However, when you see iron streaks in the sink or tub, that is generally an indication of contaminants in the water. Begin to look for a dump or landfill nearby that is filled with rusting items. State health agencies will test well water. Begin to look for a dump or landfill nearby that is filled with rusting items. State health agencies will test well water.

misconception: Well water high in iron is dangerous. The iron contained in well water is in a form that is not easily absorbed and drinking this water will not likely lead to iron overload. However, when you see iron streaks in the sink or tub, that is generally an indication of contaminants in the water. Begin to look for a dump or landfill nearby that is filled with rusting items. State health agencies will test well water for a modest charge.

misconception: People with hemochromatosis should not drink alcohol. If a person has high iron and drinks, even modest amounts can damage the liver. When iron levels are lowered to normal and if there is no liver damage, a person with hemochromatosis can have alcohol. Moderation is recommended; some alcoholic beverages such as red wine have a health benefit, possibly because of the high tannin content.

recipes for iron balance

Hot BEEF Stew
for those who need more iron
serves 4
heme iron 1.1 mgs
non-heme iron 3.5 mgs

1 lb sirloin cut into chunks
1 medium onion
6 red skinned potatoes (washed but not peeled, cut in half
4 carrots (washed but not peeled; cut into chunks)
1 cup beef broth
1 cup red wine (burgundy or merlot do not use a sweet wine)
2 T whole wheat flour
2 T olive oil
1 small can tomato sauce
red pepper flakes (from shaker about 10 “shakes” worth)
salt to taste
In a large iron skillet with medium heat, saute onions in oil, until done (about 15-20 minutes). Drop beef cubes into plastic bag along with flour. Shake until meat is coated. Add meat to simmering onion, stirring occasionally. Add broth and red wine; simmer covered for two hours. Add potatoes, carrots, tomato sauce, salt and red pepper. Simmer 30 minutes or until carrots and potatoes are tender. Serve with crusty garlic toast, leafy green salad with fresh squeezed lemon juice/olive oil dressing.

Hot BEEF Stew
for those who need less iron
Follow the same recipe, except marinate beef overnight in two cups of coffee or tea. Use this marinade in place of beef broth. And cook in a glass or ceramic (Corningware® skillet.)

Steps for planning a meal to balance your iron intake
• Estimate the amount of heme (animal source) and non-heme (plant source) iron in your meal.
• Determine what to substances to add or substitute to improve iron absorption— if you need more iron, or impair iron absorption— if you need less iron. See page 12 for substances that improve or impair iron absorption.
• Plan ahead! If you plan our menus in advance and use a shopping list, you will be less prone to impulsive eating and processed foods.

Get a FREE copy of the Iron Disorders Institute (IDI) MENU PLANNER FORM. You can also download this form from our website www.irondisorders.org
Or if you are a member, you can request we send you a printed copy. Call us toll free: 888-565-4766!
C.R. Hume says, “Let us help you remain...
IRON SMART!”

ABOUT IRON
Iron is mineral that we get from food. All living things must have iron to survive. Humans need about 1 milligram of iron a day to have enough energy to function. People lose about 1 milligram of iron per day in sweat, skin flakes or tears. Most people get enough iron from the diet, but some have Iron-Out-of-Balance™. This is any condition where iron levels in the body are not normal.

TESTS TO DETECT
Iron-Out-of-Balance™ is detected with blood tests. The most common tests include:
--serum iron
--total iron-binding capacity (TIBC)
--serum ferritin
Other tests or procedures are needed to determine the cause of Iron-Out-of-Balance™. Examples include complete blood count, retic count, B12 or folate, genetic testing, liver biopsy, and bone marrow aspiration. Our books are excellent resources for understanding iron disorders such as hemochromatosis, anemia of chronic disease, iron overload with anemia and iron deficiency.

C.R. Hume is IDI’s mascot; he is a health-minded ferret, who helps raise awareness about the benefits of blood donation. His name is suggestive of “serum”. Together, his name and genre sound like serum ferritin.

IN YOUR GENES
Many 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!

THERAPY TO CORRECT
People with normal hemoglobin and high body iron can have therapeutic phlebotomies. If they cannot tolerate the phlebotomies, they may be candidates for iron chelation therapy. This form of therapy is usually used with iron overload patients who are anemic. Iron chelators are pharmaceuticals that will specifically bind to iron.

TIPS TO MANAGE

SOME ITEMS THAT KEEP YOU FROM ABSORBING IRON:
--COFFEE
--TEA
--EGGS
--FIBER
--CHOCOLATE
--CALCIUM SUPPLEMENTS

SOME ITEMS THAT HELP YOU ABSORB IRON:
--BETA-CAROTENE
--SUGAR
--ACIDIC FOODS OR BEVERAGES
--ALCOHOL
--VITAMIN C SUPPLEMENTS

DYK?
“If you laid 260 million atoms of iron end to end in a line, how long would the line be?”

THREE VIEWS OF IRON

IN USE: determined by measuring hemoglobin.
BEING TRANSPORTED: determined by measuring serum iron and TIBC (total iron-binding capacity)
CONTAINED IN STORAGE: determined by measuring serum ferritin.
YOU NEED ALL THREE VIEWS for a complete picture of your iron levels.

In treatment

Important Ranges

hemoglobin

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<tr>
<th>Age</th>
<th>Normal Range</th>
<th>Adult Males</th>
<th>Adult Females</th>
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<tbody>
<tr>
<td>Age 0-2 weeks</td>
<td>12.0-20.0 g/dL</td>
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<td>Age 2-6 mos</td>
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<tr>
<td>Age 6 mos-1 year</td>
<td>11.0-15.0 g/dL</td>
<td>12.0-16.0 g/dL</td>
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</tr>
<tr>
<td>Adolescents, Juveniles, Infants &amp; Newborns</td>
<td>13.5-17.5 g/dL</td>
<td>12.0-16.0 g/dL</td>
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Ferritin

<table>
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<th>Age</th>
<th>Normal Range</th>
<th>Adult Males</th>
<th>Adult Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age 6 mos-1 year</td>
<td>11.0-15.0 g/dL</td>
<td>up to 200ng/mL</td>
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<td>Adolescents, Juveniles, Infants &amp; Newborns</td>
<td>up to 300ng/mL</td>
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Important Ferritin Reference Ranges