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About IDI Page Two
Dear Reader,

This has been an exceptionally busy period of time—Three of our books are now available as second editions!

Our transfusional iron overload awareness program is underway. We are moving on plans for next year’s patient conference in Charlotte, NC. July Hemochromatosis Awareness activities have increased over last year’s events. More and more physicians are including the topic of hemochromatosis in *Grand Rounds* and other medical seminars. In the upcoming American Society of Hematology Annual meeting in New Orleans, one of our board members, Dr. Gordon McLaren has been invited by ASH to present on the topic of hemochromatosis. Highlights will be included in the next issue of nanograms.

The Internet has exploded with references to hemochromatosis; so we know that awareness is on the rise. There are over 900,000 medical doctors in the USA, many still need to be reached. What we have accomplished so far has only been possible because of terrific and dedicated volunteers, staff and the power of our web-sites.

Which brings me to the next point of good news. Our website www.irondisorders.org is getting an overhaul—by the time this newsletter is fully distributed, our new look should be launched.

After months of hard work, testing and re-testing the site, asking lots of questions, we feel we have developed a site that gets you to the information faster—hopefully, within 3 clicks.

If you haven’t been there lately, check it out: www.irondisorders.org

Let us know what you think by browsing the site and then taking our survey. Be sure to add some comments to your review!

Take care,

Cheryl Garrison
Executive Director
IDI Blood Center Focus:
Indiana Blood Centers

Hemochromatosis patients who live in Indiana can arrange to donate blood at any one of the Indiana Blood Centers (IBC) fixed sites. As of 2009 the IBC has 10 fixed sites. Five are located in Indianapolis proper; other locations include: Avon, Muncie, Columbus, Lafayette and Terre Haute. The IBC received its FDA variance to use hemochromatosis blood in August 2003.

Presently more than 250 hemochromatosis (HHC) patients are enrolled in the IBC’s program. According to Felecia Nichols, Manager of the Donor Patient Services Department, “The program has had a positive impact on the community. People tell us that they are happy their blood is being used.”

To enroll in the program a doctor’s order is required. The Center prefers that patients use the IBC order form because it contains more information about the patient. However, they will accept an order on the doctor’s form so long as it contains the diagnosis of hemochromatosis, frequency of blood removal and a pretreatment hemoglobin level.

The Central Indiana Regional Blood Centers variance allows for an order to be written with a hemoglobin as low as 11.3g/dL; 12.5g/dL is the standard pre-treatment hemoglobin for these orders.

An appointment is required for hemochromatosis donors. This can be arranged with the nono patient services department. The direct number is 317-916-5290; toll free 800-632-4722 #2.

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 volunteer blood donations.

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 5-10 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 announced in April, 1999 that hemochromatosis blood was as safe to use for transfusion and invited blood centers to apply for the variance to accept this blood.

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

Is there a blood center in your area that does not take hemochromatosis blood? Encourage them to call IDI to learn how they can increase their blood supply with an endless resource of donors.

In Memory of Dave Vercontaire
by the Foley Family

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

“Iron Disorders Institute exists so that people with iron disorders receive early, accurate diagnosis, appropriate treatment and are equipped to live in good health.”
Iron Balance—from Conception to Birth

Iron is mandatory for all life—but too much iron is harmful and can be fatal. Women are especially vulnerable to iron imbalances and subsequently are at risk for the inability to conceive, multiple miscarriages, pre-eclampsia, gestational diabetes, premature and low birth-weight babies or babies that do not survive. Barriers to conception, a healthy pregnancy and normal birth can include inherited or acquired iron disorders, such as hereditary hemochromatosis, von Willebrand Disease, sickle cell disease and thalassemia. Other influences or risk factors contributing to problems of conception or poor pregnancy outcomes include health of the spouse, gestational alloimmunity, behavioral—environmental conditions such as chronic exposure to toxins, use of tobacco products, poor diet or eating disorders, alcohol abuse, use of certain medications or herbal/nutritional supplements or teen pregnancy.

Classic hereditary hemochromatosis (HHC) is a genetic condition that increases the amount of iron absorbed from the diet. Women with undiagnosed HHC can experience loss of period, multiple miscarriages or extreme difficulty getting pregnant. Some of these women miss out on the opportunity to have children because of delayed or missed diagnosis. When hemochromatosis is discovered early and steps taken to restore iron levels to a healthier range, the chances are dramatically increased for conception, normal pregnancy and giving birth to healthy babies. Although in some cases, hormone replacement therapy may be necessary. Compounding the problem are the spouses who also may have hemochromatosis. These men can experience impotence or low sperm quality or count.

Sickle cell disease (SCD) is an inherited hemoglobin disease where the red blood cells become sickle-shaped following an event that triggers a “sickling crisis”. The missshapen cells cannot pass through the small blood vessels, causing severe pain. SCD patients become anemic (insufficient hemoglobin) while accumulating toxic levels of iron due to chronic hemolysis or blood transfusion. Women with SCD are able to become pregnant, but in about 50% of cases, these women experience “sickling-crisis” in the third trimester. Judicious management of anemia early in the pregnancy reduces the risk of a sickling crisis.

Thalassemia is a complicated hemoglobin disease. Like SCD the patient can experience both anemia (insufficient hemoglobin) and excess levels of tissue iron (high serum ferritin). These chronic excessive levels of iron damage the heart, liver and endocrine system causing impaired function and disease. In recent decades medical advances have enabled women with thalassemia to conceive, carry to term but not without intervention and careful management. Hormone therapy is sometimes used to induce ovulation; judicious and programmed use of blood transfusion is used to address anemia. Still, rates of low-birth weight and premature births remain high in patients with hemoglobin diseases.

Congenital bleeding disorders such as von Willebrand Disease historically has been under-diagnosed in women as the underlying cause of the menorrhagia (heavy periods) and subsequent iron deficiency anemia. As many as 20% of women with menorrhagia are found to have undiagnosed VWD.

Gestational alloimmunity is well established as the cause of neonatal hemochromatosis, an often fatal disorder. Newborns with NH die of liver failure due to iron overload. When women with a history of neonatal hemochromatosis deaths who are subsequently given immunoglobulins at 18 weeks of gestation and weekly thereafter, a large majority of these women give birth to normal healthy babies.

Behavioral and environmental factors can cause iron imbalances such as anemia of inflammatory response or iron deficiency anemia. Examples of these factors include infection, chronic exposure to toxins, such as pesticides; eating disorders, alcohol abuse, use of tobacco products; chronic use of certain medications or herbal/nutritional supplements. Also, age at conception is a consideration. Compared to a 20-year-old pregnant woman, teenaged mothers are in a higher risk group for fetal death, low birth weight and premature babies and anemia.

Oxidative Stress is a result of the body’s production of free radicals, a normal function of metabolism. Iron is a catalyst for free radical production but when iron is excessive and this activity unchecked, the outcome is harmful. Delicate tissues and DNA can be permanently damaged by uncontrolled free radical activity and oxidative stress. During pregnancy oxidative stress peaks by the second trimester, indicating a means of protection for the fetus. Maintaining a healthy iron balance during the course of pregnancy is paramount in the timing of mechanisms in place to assure a normal pregnancy and birth. Studies on the influence of iron supplementation schemes on oxidative stress are greatly needed.

Iron Supplementation:
During conception, pregnancy and birth, Nature provides elaborate, elegant systems to assure that sufficient amounts of iron are present for each period of development.

As early as 1975, investigators without fully understanding the mechanism or its purpose, described what could be The Iron Withholding Defense System in early pregnancy—the investigators reported this finding, but declared a lack of understanding the phenomenon. What these investigators observed was a slight drop in iron absorption during the first trimester of pregnancy. During the second and third trimesters, iron absorption increased to 4-5 milligrams in the second trimester and 6-7.5 milligrams in the third. Some experts attributed the first trimester modest slight drop in iron to the absence of menstruation, others were not so certain. On the side of caution, some simply stated the fact that iron absorption rises naturally following this first trimester drop in iron absorption. Others averaged the iron needs over the three months, indicating permanent damage by unchecked free radical activity and oxidative stress. During pregnancy oxidative stress peaks by the second trimester, indicating a means of protection for the fetus. Maintaining a healthy iron balance during the course of pregnancy is paramount in the timing of mechanisms in place to assure a normal pregnancy and birth. Studies on the influence of iron supplementation schemes on oxidative stress are greatly needed.

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Another component of this natural protective mechanism might be the nausea and vomiting experienced by most women early in their pregnancy. Could vomiting be serving as a means of suppression of a teratogenic risk?

In 2008 1-4% of all births were abnormal. Can this be due to increased awareness or increased environmental factors? Emerging evidence supports iron to be teratogenic in mice.

In the USA, there are no clear guidelines for iron supplementation of pregnant women. American women who become pregnant are routinely advised to take a daily supplement of 30-40mg iron. According to government reports, an extensive review of controlled trials failed to demonstrate that this practice improves clinical outcome of mother or newborn. Still it is highly probable that the iron prescribed these women will be far in excess of this 30-40 milligram amount.

Unpublished work carried out in Mexico City with nonanemic women at mid-pregnancy indicates that 60 milligrams/daily of iron increases the risk of hemoconcentration (a decrease in fluid and an increase in red blood cells—high hemoglobin), low birth weight and premature birth and produces a progressive decline in plasma copper. These risks are not observed in women supplemented with 120 mg iron once or twice per week.

If a woman is iron replete (has sufficient iron) supplementation could be harmful—yet if a woman is marginally iron deficient or her iron stores are on the low side, it is appropriate to supplement with oral iron. Iron deficiency anemia during pregnancy is a risk factor for preterm delivery and low birth weight. The challenge lies in making certain that a woman is in fact iron deficient and not experiencing anemia of inflammatory response. This requires at least the measurement of serum ferritin,

The American College of Obstetricians and Gynecologists and the Iron Disorders Institute recommend screening and monitoring of the iron levels in pregnant women using both the serum ferritin and hemoglobin. It is highly likely that of these two tests, serum ferritin is not being routinely performed for pregnant women.

Until public health policy guidelines can be clearly defined and enforced, Iron Disorders Institute provides the following iron supplementation protocol based on serum ferritin levels:

**Women whose serum ferritin is**
- greater than 70ng/mL: no iron supplements
- 30-70ng/mL: 40 mg ferrous iron daily
- <30ng/mL: 80-100 mg ferrous iron daily

In addition to iron supplements, increasing consumption of lean red meat in the diet can boost iron levels faster. Red meat contains heme iron, a type of iron that is highly bioavailable (easily absorbed). Iron supplements should not be taken with calcium, dairy, tannin or high fiber foods all of which inhibit the bioavailability of iron. Women taking iron supplements should take precaution to keep them out of the reach of small children.

A toxic dose of elemental iron is 30 mg/kg of body weight for infants and children, and doses as low as 60 mg/kg have proved fatal (CDC, 1993).

**Iron Absorbed in Pregnancy**

<table>
<thead>
<tr>
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<th>12</th>
<th>24</th>
<th>36</th>
<th>18 months after delivery</th>
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<tr>
<td>Milligrams of iron absorbed daily</td>
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<td>8.6*</td>
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*Mean milligrams of iron absorbed daily from a balanced diet containing 13 milligrams of iron.


Postpartem—(after giving birth)—iron deficiency anemia can result from heavy blood loss during birth. Some blood loss so severe that blood transfusions, iron infusions and iron pills are needed. Again hemoglobin and serum ferritin are important measures during this timeframe.

Breastfeeding is encouraged for all who can do so. Mother’s milk is superior to formulas in that it contains unique properties that cannot be duplicated synthetically. When breastfeeding is not possible, iron fortified formulas are widely available.

Read more about breastfeeding in the Iron Library under articles.

For a complete bibliography, contact us with your request: publications@irondisorders.org

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Family Reunions—Great Opportunities for Hemochromatosis Awareness

“Enclosed is a donation check for $250.00 to help further your work with iron disorders,” writes Janice Sullivan who sent this photo to us for National July Awareness Hemochromatosis Month. Her family meets once a year and raises money for awareness with a silent auction. This year, the family selected Iron Disorders Institute (IDI) to be the recipient of their fundraising efforts.

“We were delighted to have been chosen,” comments IDI Executive Director, Cheryl Garrison. "I marvel at the incredible outreach and education potential of these family reunion get-togethers.”

Several members of Janice’s family suffer with consequences of hemochromatosis. Family reunions allow them to share their experiences with one another.

Reunions are also a time to find new case of hemochromatosis. Following the Carpenter family reunion in April 2009, four other family members have obtained a complete diagnosis and are now donating blood and watching their diets. One member of the Carpenter family who was diagnosed is a medical doctor and also a film-maker. Inspired by events surrounding his brother’s diagnosis, his own diagnosis and finding out that several other family members have hemochromatosis, Dr. Carpenter decided to make a film about the condition. His family’s story is the basis for the film’s content. The film is due out in 2010; look for details on the IDI websites.

If you are planning a family reunion, please contact us; we will provide posters and brochures for your event.

888-565-4766

Pictured here are Chris & Harry Kieffer’s family, their daughters and families, Chris’s parents, brother (next to Chris) and his boys in the middle. Chris is one of the founding directors of Iron Disorders Institute and a motivated and highly successful individual raising awareness about hemochromatosis. “When Harry was diagnosed, we knew that our daughters needed to be tested, but what we never counted on was finding out that one of our son-in-laws has a grandmother who was diagnosed with HHC in her 80’s! That means our grand sons on both sides of this family may have the condition!”

“Family reunions can be a great time to learn about this condition. We just have to remember to plan some event that centers on awareness.” Chris comments. “Personally, I carry information with me everywhere! I never know who I will meet or where, but one thing for certain, if you have a crowd of people, someone in that crowd has genetic hemochromatosis!”
Cancer & Iron Deficiency——

accelerated significantly by administering DSS (dextran sulfate sodium) in combination with a known colon carcinogen… or iron.

In one major study of iron reduction therapy (phlebotomy), investigators found that iron reduction was associated with lower cancer risk and mortality. Findings included that the risk of new visceral malignancy was lower in the iron reduction group than in the control group and, among patients with new cancers, those in the iron reduction group had lower cancer-specific and all-cause mortality than those in the control group. Mean ferritin levels across all 6-monthly visits were similar in patients in the iron reduction and control groups who developed cancer but were lower among all patients who did not develop cancer than among those who did.

Clearly, it is in the best interest of the cancer patient to restore hemoglobin so that they can function, but how one goes about it can result in a battle to achieve a healthy iron status, while impairing the cancer cell’s ability to obtain iron.

How this can be achieved must be addressed in a case by case approach. Much will depend upon the patient’s age, general health, weight, stage and type of cancer and prognosis.

Cancer patients can become iron deficient, either as a direct association with their disease or as a result of therapy. Regardless of the mechanism, an iron deficient patient can suffer symptoms such as weakness, chronic fatigue, shortness of breath, headaches, sensitivity to cold, restless legs syndrome, depression and a general disinterest or inability to perform in day-to-day activities. The challenge is to address the iron need without increasing the potential for cancer growth.

One case example: 85 year old male, obese, colon cancer with liver metastases, no symptoms except those related to anemia, which upon investigation was found to be caused by blood loss due to hemorrhoids.

At the time of anemia diagnosis his iron levels were as follows:

Hemoglobin 10.0g/dL
Serum ferritin 8.0ng/mL

This patient declined chemotherapy or surgery to treat his cancers; he declined iron pills (ferrous sulfate 325 mgs 3X daily) because of the side effects. He chose instead to alter his diet, avoiding foods and substances that impaired the absorption of iron, while consuming three small servings of lean red meat per week, accompanied by fresh vegetables.

Within 6 weeks his iron numbers were:

Hemoglobin 16.2g/dL
Serum ferritin 7.0ng/mL

Notice that this person is still iron deficient but no longer is anemic.

Without benefit of MRI or PET scan technology, it cannot be determined whether the cancer growth has accelerated or diminished during this approach.

The question: Should the doctor strive to build up serum ferritin or allow the patient to continue on course with periodic lab work or procedures to evaluate iron levels and disease progression?

Resources:

-FASEB J. 2007 21(2):564-76. Consequences of expressing mutants of the hemochromatosis gene (HFE) into a human neuronal cell line lacking endogenous HFE. Lee SY, Patton SM, Henderson RJ, Connor JR.
Pumping Iron
My Life With Thalassemia
by Laurice Levine, MA, CCLS
Thalassemia Outreach Coordinator and Patient
Children’s Hospital & Research Center at Oakland

Have you ever heard of thalassemia (also called Cooley’s anemia)? You are not alone if you have never heard of this genetic disorder. Despite being one of the most common genetic diseases in the world, the severe form of thalassemia is quite rare in the United States. People with thalassemia major are unable to make hemoglobin, which is the protein in red blood cells that carries oxygen to all parts of the body. This lack of hemoglobin production causes severe anemia. Consequently, the primary treatment for thalassemia major is routine blood transfusions every two to four weeks.

I was diagnosed with thalassemia at 14 months of age. During my childhood, I was frequently sick with colds, ear infections, respiratory problems, and general malaise. I had an enlarged spleen, so I could not roller skate with my friends or wear pants—I always had to wear dresses. I could not run laps during P.E., and I was teased because I had jaundiced skin. I had congestive heart failure at age 9; a splenectomy at age 10; a tonsillectomy at age 13; and my gall bladder removed when I was 22. By the time I reached 25, a lifetime of severe anemia finally caught up with me. I went into congestive heart failure a second time and was diagnosed with severe pulmonary hypertension. I was given a choice—begin receiving routine blood transfusions, or die before I was 30. Clearly, this was not a difficult choice to make!

I am now 37 years old and in very good health. Since I was 25, I have become very proactive in my own health care, and I have found doctors who specialize in thalassemia to provide me with the quality, comprehensive care that I require to live a fit, active life. My treatment regimen is intense and time-consumming. I receive one to two units of A+ blood every two weeks. I have had 254 blood transfusions, which amounts to approximately 550 units of lifesaving blood. As a result of blood transfusions, people with thalassemia, like me, are at risk for iron overload. In one unit of blood, there is about one year’s worth of the iron needed by the human body. Most people get the iron they need through an adequate diet, but I get all that extra iron through blood transfusions. Iron is released when blood cells die (after 120 days), and since the human body only needs a certain amount of iron, the excess iron saturates the blood and eventually gets stored in the vital organs such as the heart, liver, and pancreas.

Before the 1970s, people with thalassemia were dying of iron overload. Iron toxicity can cause heart failure, liver cirrhosis, and damage to the pancreas that leads to secondary problems such as diabetes (luckily, I have managed to avoid this). In the 1970s, a drug called Desferal was made available. Desferal is administered subcutaneously (in the fatty tissue) using a needle attached to a small pump. Desferal is infused into the body, where it binds to and rids the body of excess iron. I wear my pump six to seven days a week for 12 to 24 hours a day. Compliance with Desferal therapy, although challenging, is the key to health and long-term survival with thalassemia.

There is now an oral chelator called Exjade that has recently been FDA approved. Unfortunately, it was too expensive for me—my insurance co-pay would have been approximately $3,000 a month. Exjade also upset my stomach, so it was not an option for me. There is another drug, L1, which has long been approved in Europe and other countries, though it is not approved for use in the United States. L1 has been proven to be very effective in removing cardiac iron. I took L1 on a compassionate-use basis for over a year before I became neutropenic (having a low white-cell count, and therefore being prone to infection) and had to stop taking it. I was one of the first patients in the United States to experiment with combination therapy—Desferal and L1 together. During the time that I was on this dual therapy, I was fortunate to be able to completely clear my body of all excess iron, and I am still relatively iron-free. My continual compliance is vital, because as long as I receive blood, I will need to chelate iron.

Thalassemia is a part of my life—when people hear about it, they wince and tend to feel sorry for me. But no patient wants to be pitied. The best way to help is to donate blood or put on a fundraiser for thalassemia so that we can get much-needed money for more medical research. If it were not for research and better treatments, I would not be here writing this article. I encourage people to educate the community and support health-care reform so that those of us with chronic conditions do not get denied health-care coverage. The biggest challenge in my life as a patient, along with the loss of loved ones to thalassemia, has been battling insurance companies.

It is important for my mental health to strive for positive outcomes and prevail over challenges. A childhood riddled with medical hardship helped me grow into a capable and compassionate adult. Knowing that my time on earth may someday be cut short, I try to live each day to the fullest and with passion. This is not to say that I do not have my share of bad days, but I try very hard to make these few and far between. I am fortunate that despite some very serious health issues during my twenties, I was still able to persevere and earn my master’s degree at the same time. I went on to become a child life specialist and a thalassemia outreach coordinator, and I work in a hospital environment, where my understanding enables me to be more empathetic.

The best part of my life is that even though I always thought my chronic illness would keep me from finding true love, I am entering into my fifth year of marriage to my husband, who actually had heard of thalassemia before I met him. He supports me every day, and I made a promise to him that although I could not guarantee longevity, and might not even be able to become pregnant (we are hoping to adopt), I would do everything in my power to be compliant and remain healthy. As long as I get my blood and pump my iron, I can stay strong and keep my promise. I treasure the time we have together, along with our loving corgi, Jozz, and our parakeets, Moose and Thor.

Getting tested for thalassemia trait is an easy process with a simple blood test. Ask your provider to check the following:

- Hemoglobin electrophoresis with quantitative hemoglobin A2 and hemoglobin F.
- Complete Blood Count (CBC).
- Iron studies (free erythrocyte protoporphyrin, lead, ferritin, and/or other iron studies.)

If you have any questions about thalassemia, please feel free to visit the following websites:

- www.thalassemia.com (Comprehensive Thalassemia Center at Children’s Hospital Oakland)
- www.helpthals.org (Thalassemia Support Foundation)
- www.cooleysanemia.org (Cooley’s Anemia Foundation)

Also, feel free to contact me at (510) 428-3885 x 5427; or e-mail LLevine@mail.cho.org.
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 to the information you need to get on the list and in the CIRCLE. Here you can listen, share, ask questions and get support.

access, thick blood, joint pain, diet and Nifedipine research.

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 Iron Disorders Institute.

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

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 a problem with iron. Some of the LIST members are long time participants who know the ups and downs of dealing with iron related issues.

Some of the topics discussed during this period of time include: Iron oxide coating on Advil and generic ibuprofen products; scar tissue with phlebotomy, iron avidity, serum ferritin ranges and the importance of diet. Participants on the LIST also discussed reactions and problems with phlebotomy; suggestions for how to eat and hydrate prior to phlebotomy; symptoms experienced during de-ironing process, genetics, vein

For More Information About Thalassemia
National Center on Birth Defects and Developmental Disabilities at CDC http://www.cdc.gov/ncbddd/index.html
Click on the “T” in the index at the top of the page.

Iron Disorders Institute’s Guide to Anemia Book devotes a chapter to thalassemia contributed by the Cooley’s Anemia Foundation.

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.

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 Peggy Clark, Member Services Coordinator 888-565-4766; email: pclark@irondisorders.org or visit our websites: www.irondisorders.org and www.hemochromatosis.org

Alliances Around the World
Helping us to increase awareness around the world are alliances, such as, The Canadian HEMOCHROMATOSIS Society. Their newsletter Iron Filings provides information, awareness and support along with patient stories, opportunities to donate time and make financial contributions. Iron Filings opens with a great message from the Executive Director Bob Rodgers and is unique in that half the newsletter is in English; the other half is the translated into French!

The Canadian HEMOCHROMATOSIS Society and Iron Disorders Institute have similar missions. Working together, we help each other to carry out our missions in the USA and Canada. Recently, both IDI and CHS have launched new websites. We encourage everyone to visit both sites and let us know what you think!

www.toomuchiron.ca
www.irondisorders.org
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 the list below of substances that improve or impair iron absorption.

- Plan ahead! If you plan your menus in advance and use a shopping list, you will be less prone to impulsive buying of low nutrient, 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

Got questions? Join the Excess Iron Online Discussion List or go to our Forum and enter your question. Instructions on ways to participate are on the irondisorders.org website.

Spinach Lasagna

1 cup cooked fresh spinach, drained
24 lasagna noodles
2 eggs
1 cup ricotta cheese
4 cups Marinara Sauce
2 cups mozzarella cheese
1/2 cup Parmesan cheese

Squeeze the excess water out of the spinach by pressing with an absorbent paper towel. Set aside.

Cook the lasagna according to the package directions. Drain and rinse with cool water.

In a medium bowl mix the eggs, ricotta, and spinach together.

In a shallow glass casserole dish begin to layer the lasagna noodles, then spinach mixture, marinara sauce, mozzarella cheese, and Parmesan cheese. Continue to layer, ending with lasagna, reserving some marinara, mozzarella, and Parmesan. Spread a thin layer of marinara sauce over the noodles. Top with mozzarella and parmesan. Bake uncovered at 350° for 45 minutes to 1 hour.

Let stand 15 minutes before serving

Serves 6

TIPS:

- # 1: If your iron levels are high, cook your noodles in water with one cup of brewed tea.
- # 2: If your iron levels are low, cook your marinara saue in an iron skillet!
- # 3: The iron in spinach is not easily absorbed. Fresh spinach is an excellent source of antioxidants, which are important regardless of your iron levels!
All ABOUT IRON
Read all about iron—what it is, where it comes from, how much we need—on the updated versions of our website: www.irondisorders.org

IRON Panel TESTS
Iron-Out-of-Balance™ (too much or too little iron) detected with blood tests. The most basic tests include:

—hemoglobin
—serum iron
—IBC (iron binding capacity: TIBC total iron-binding capacity UIBC unbound iron binding capacity)
—serum ferritin

Read about other tests and procedures in the IRON Library www.irondisorders.org

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!

C.R. Hume says, “Let us help you remain...

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.

Our Books
Second Editions
now available online and through major bookstores. See a list on our website.

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.

Important Ranges
Hemoglobin
Normal Range
Adult Males: 13.5-17.5 g/dL
Adult Females: 12.0-16.0 g/dL

Adolescents, Juveniles, Infants & Newborns
Age 6-18 years: 10.0-15.5 g/dL
Age 1-6 years: 9.5-14.0 g/dL
Age 6 mos-1 year: 9.5-14.0 g/dL
Age 2-6 mos: 10.0-17.0 g/dL
Age 0-2 weeks: 12.0-20.0 g/dL
Newborn: 14.0-24.0 g/dL

Ferritin
Normal Range
Adult Males: up to 300ng/mL
Adult Females: up to 200ng/mL

In treatment*
Adult Males: below 100ng/mL
Adult Females: below 100ng/mL

Ideal maintenance
25-75ng/mL

Adolescents, Juveniles, Infants & Newborns
Male ages 10-19: 23-70ng/mL
Female ages 10-19: 6-40ng/mL
Children ages 6-9: 10-55ng/mL
Children ages 1-5: 6-24ng/mL

*Therapeutic phlebotomy for people without anemia

DYK?
Consuming excessive amounts of green tea can increase the risk for iron deficiency—Read about this in the next issue of nanograms!

Third Quarter 2009
Our books are available online and in major bookstores.

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

Our mission is to offer affordable treatment and to make people with iron disorders more aware of their condition.

Help Support our Mission:
Iron Disorders Institute (IDI) exists so that people with iron disorders receive early, accurate diagnoses, and appropriate treatment and are equipped to live in good health.

Iron Disorders Institute
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