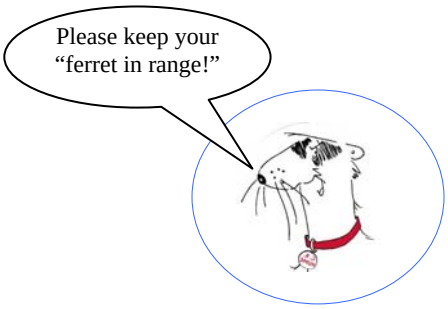
idi in Touch newsletter

IDI's way of keeping in touch with you!



JANUARY/FEBRUARY, 2006 | IRON DISORDERS INSTITUTE | VOLUME 6, ISSUE 1

INSIDE THIS ISSUE

NEXT ISSUE

IRON PATIENTS – THEIR OWN STORIES
The Randall Family

PLAN NOW TO ATTEND!

Iron 2006 USA

May 18-19, 2006

National Institutes of Health, Bethesda, MD

"Achieving Iron Balance in Men and Women with Hemochromatosis"

FEBRUARY IS NATIONAL AMERICAN HEART MONTH

IDI Headquarters, Greenville, South Carolina

Heart disease is the leading cause of death in the United States. It affects men and women of every age and race. During American Heart Month, we, at Iron Disorders Institute, encourage all Americans to join the fight against heart disease and to learn more about how to prevent it.

Having a sibling with a history of cardiovascular disease carries the same or greater risk as having a parent with a history of the disease, according to a new report from the long-standing Framingham Heart Study conducted by the National Heart, Lung, and Blood Institute (NHLBI), a part of the National Institutes of Health (NIH). **(See Important Heart Links, page 5.)** Personal risk of having a cardiovascular event, such as a heart attack, stroke, or peripheral artery disease, may be raised by as much as 45 percent in middle-aged people whose brother or sister has had such an event.

Heart disease is responsible for the deaths of one in three women in the United States. To make women more aware of the danger of heart disease, the National Heart, Lung, and Blood Institute of the National Institutes of Health has joined with the Department of Health and Human Services and other national organizations to launch a nationwide campaign called "The Heart Truth." **(See Important Heart Links, page 5.)** This important campaign encourages women to learn more about heart health, to lead healthier lives, and to talk with their doctors about their risk for developing heart disease.

Ladies of all ages: Wear your red dress and participate in Go Red for Women, which is The American Heart Association's Campaign to raise awareness that heart disease is the # 1 killer of American women**.** (See Important Heart Links, page 5.)

IRON IN THE HEART

(Excerpt from book: *Exposing the Hidden Dangers of Iron* – ED Weinberg) To read more about iron in the cardiovascular system we suggest: *Exposing the Hidden Dangers of Iron* – ED Weinberg

"Regardless of whether iron overload in human beings results from transfusions

Please see **Heart**, page 5, column 1.

IRON Disorders Institute

Post Office Box 675
Taylors, SC 29687

Place Stamp Here

- Hemochromatosis
- Acquired Iron Overload
- Sickle-Cell Anemia
- Juvenile Hemochromatosis
- African Siderosis
- Thalassemia
- Porphyria Cutanea Tarda
- Sideroblastic Anemia
- Iron-Deficiency Anemia
- Anemia of Chronic Disease

If you can read this, you are not on IDI's mailing list for future issues. To contact IDI, see page 8,

IRON PATIENTS – THEIR OWN STORIES

"Education is the most powerful weapon which you can use to change the world."
Nelson Mandela, Statesman

RALPH AND SYLVIA ROSS: Hemochromatosis Lineage

How much unnecessary pain and suffering has gone on because of undiagnosed hereditary hemochromatosis? For how many has the diagnosis come too late – at autopsy? We have the opportunity to get the word out about the medical effects caused by hemochromatosis and to make a difference. So what if your slight acquaintances say, "Oh no, here comes that woman that talks about iron!" Disregard those folks. You'll save some lives along the way.

My husband, Ralph, had an easy diagnosis. After retirement in 1991, he didn't get a physical until 1995. After seeing the test results, his doctor said Ralph's iron level was 219$_{mcg/dL}$. He wanted to repeat the test as well as TIBC and % saturation. Ralph's second iron test result was 195$_{mcg/dL}$ and Tsat% was 100%. He told us he was reasonably sure it was HH and referred us to a gastroenterologist. The gastroenterologist repeated the iron test, adding a serum ferritin test. After seeing the results, he performed a liver biopsy. There was no serious damage and a diagnosis of hereditary hemochromatosis was made and weekly phlebotomies were begun.

How beneficial it would be if serum iron was still included in routine physicals and hospital admissions. When MetPath Laboratories included iron to their standard Chem-20 Screen during the 90s, the diagnosis of HHC immediately increased by tens of thousands!

The next few years our thoughts were on phlebotomies, then quadruple bypass surgery and, in 1999, Type 1 diabetes arrived. We were dealing with hemochromatosis, but not the "hereditary" part of the overall picture. When we learned in 2000 that DNA was available, we got busy discovering the overall picture. (See chart 1.)

Ralph is C282Y/C282Y and I am negative for both the C282Y and H63D mutations; therefore, our 3 grown children are obligate C282Y heterozygotes. Their DNA didn't need to be done, but that of their mates just blew us away. Our three heterozygous children had each married a heterozygous mate!

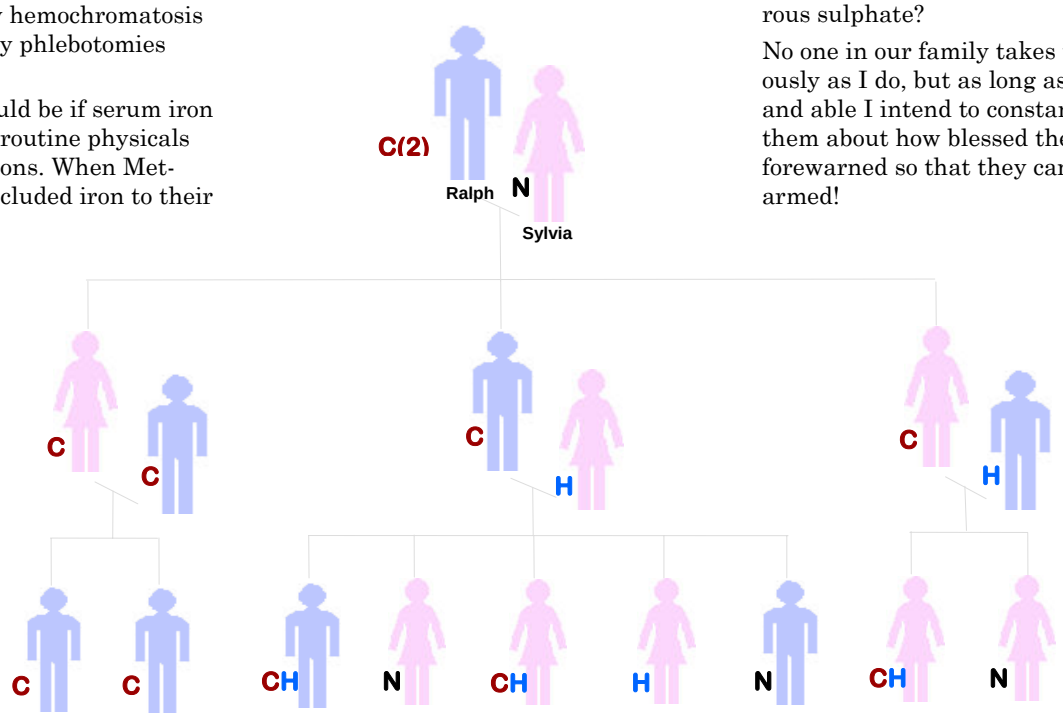
Does that sound like a RARE disorder to you?

Then the fun and games began with our 9 grandchildren: 3 are normal, 3 are heterozygous (one C282Y, two H63D) and the remaining 3 are compound heterozygous C282Y/H63D. We are thankful that no one is homozygote for C282Y like Ralph.

Iron profiles have been done and no one is elevated; it's interesting to notice that the compound heterozygotes have the highest results. I encourage the boys to start giving blood once they turn 17 and we are just keeping tabs on the girls right now. The youngest compound heterozygote granddaughter got so tired/weak this past spring that I told her mom to be sure they checked her iron level when she went to the doctor. Guess what? Hgb of 10, iron 11 and ferritin 3.3!! No wonder she couldn't keep up on cross country when she was used to winning.

Who would have thought I'd be eager to see a compound heterozygote taking ferrous sulphate?

No one in our family takes this as seriously as I do, but as long as I am alive and able I intend to constantly remind them about how blessed they are to be forewarned so that they can be forearmed!



Legend

C (2)	=	Cy282, double mutation
C	=	Cy282, single mutation
H	=	H63d, Single mutation
CH	=	1 mutation of each gene
N	=	Normal

76%

of the Ross family has been affected by hemochromatosis genes!

Chart 1: Ross Family HHC Gene Inheritance.

Summary

Homozygote	1
Heterozygote (Cy282)	6
Heterozygote (H63d)	3
Compound Heterozygote	3

JASON'S GIFT — A CHRISTMAS STORY

By John F. Waldron
Virginia Beach, VA

Just three days after receiving a lifesaving liver transplant at Shands Hospital at the University of Florida, I was taking phone calls and assuring family and friends that "the reports of my death were greatly exaggerated." I don't recall that I gave Mark Twain credit for the line.

After my return home, it wasn't a week before I began to anxiously wonder about my organ donor. A male or a female? White or black? A roofer? A dancer? An accountant? Maybe from Florida? Georgia? Alabama?

I composed a letter to my unknown donor's family and turned it over to my transplant coordinator. Such correspondence is encouraged, but must be anonymous, with no last names or addresses. Ever. That's the deal.

I wrote that I had received a healthy liver, apparently from within their family, and I thanked them. I mentioned that I had recently retired after working hard all of my life, and I attached a photo of our family (three generations) at the beach. I immediately felt better for having done so.

That winter, as I worked through rehab and followed my weekly lab schedule, I often thought about my donor. All I knew was that the blood type had to have been B negative, the same as mine.

Blood. It was blood that caused most of my problems in the first place. Without warning, I had become seriously ill with acute hemochromatosis, a genetic condition that causes the body to produce excess iron. It was destroying my liver. Doctors put me on the waiting list for a transplant.

For a year and a half, I was a floppy rag doll. Hospitalized twice, I almost died when my immune system failed. I plodded through a therapeutic phlebotomy every Thursday. I became jaundiced, a difficult condition for a vain man. I suffered three painful compression fractures of the spine. Eventually, biopsies showed that my liver had become cancerous. Not unexpected.

It was during that period of depression, gray pain and prayer that my special phone call came through: "We have a liver for Mr. Waldron. How soon can you get him here?" My indomitable wife said, "I'll have him there in 90 minutes."

Just hours later, I was in the big room with the high ceiling and more lights than Yankee Stadium. A dozen masked angels looked down on me. I sang to myself — an old hymn I knew as a choirboy. I was not afraid. Peace!

That was Sept. 26, 1999. My recovery was remarkable. My energy level is more than acceptable, and I happily play golf just as poorly as ever. I spend wonderful, fun-filled hours at the beach with my grandchildren, the youngest of whom was heard to say, "Look! Poppa can do! Poppa can do!" All that fuss because her grandfather can now carry his own beach chair.

Then one day I received a brown envelope from my transplant coordinator. When I opened it, snapshots fell into my lap. Each was of a handsome, strapping young man; he was hefting large fish to the camera; he was hugging a young girl next to a Christmas tree; he was looking "cool" behind wraparound sun glasses. Instantly I knew that I was looking at photos of my donor and that the attached letter was from his father.

He thanked me for my letter of a year before, wished me continued good health and explained that the pictures were of his only son, Jason, who was 25 when he died of massive head injuries. "As you can see," he wrote, "Jason was a fisherman. He made his living fishing, and his friends say when it came to grouper and red snapper, his charters were the best." He proudly remarked that everybody in the port knew his name, and more than 300 came to his funeral service.

He spoke of Jason's younger sisters and how proud they were of their brother "who agreed to be an organ donor at 16 when he got his first driver's license." The father closed with these words: "His mother and I were truly blessed to have been his parents." The letter was signed, "Jason's family."

Often, when I get up in the morning, I sit on the edge of the bed, clasp my hands around my belly just below the rib cage, and rock back and forth like an expectant mother. And I say aloud, "Jason! Wait till you see what we do today."

It's generally unspectacular. We may work in the garage, sit on the porch, hit a bucket of golf balls or just putt around. Maybe write some e-mails.

On these chilly December mornings, we may drive over to the ocean to be with the early morning crew at the Sandbridge Fishing Pier. At the far end, where the big boys cast, it's nice to see a three-foot striped bass come wriggling up and over the railing and loudly slap onto the deck.

Jason loves those moments. I can tell.

DREW WILSON

Editor's Note: John's story originally appeared in the Commentary section, Sunday Forum of *The Virginian-Pilot* on December 25, 2005. John is a retired advertising writer. Jason's Gift is reprinted here with permission of the author.

17,274

The number of candidates waiting for a liver transplant as of 01/06/2006

Source: Untied Network for Organ Sharing
http://www.unos.org/

The United Network for Organ Sharing (UNOS) administers the Organ Procurement and Transplantation Network (OPTN) under contract with the Health Resources and Services Administration of the U.S. Department of Health and Human Services. OPTN was established by the United States Congress under the National Organ Transplant Act (NOTA) of 1984.

BACTERIA, VIRUSES AND IRON

(Excerpt from Spring-Summer 2003 *id Insight*)

Bacteria and viruses are very different in structure and each has its own relationship with iron. When these invaders get into our body, often an infection is the consequence. Pathogens enter our body through the skin or mucous membranes. These membranes are located in the lining of the mouth, eyes, nasal passages, lungs, gastrointestinal tract, vagina, and urethra. If the immune system is challenged in any way, the body cannot defend itself against some of the invading organisms and symptoms such as fever, vomiting, diarrhea, headache, nausea, joint pain, heart problems and anemia can result.

BACTERIA

Every surface of the human body is host to some type of bacteria. Mostly these bacteria are friendly; they are called normal flora. Normal body flora is part of our defense system that keeps harmful bacteria under control. These friendly bacteria assist the immune system.

Bacteria are single cell organisms with a nucleus that is amorphic, meaning without specific shape. There are three different shapes of bacteria: spherical-round like a ball, spiral or rod shaped. Bacteria can divide, synthesize DNA and RNA, and they can adapt to hostile environments and grow resistant to antibiotics. Staphylococcus is one of the best illustrations of the ability of bacteria to adapt to antibiotics.

Disease producing bacteria can be transmitted sexually, by contaminated food or water, by insect bites, or by casual contact such as touching, kissing, drinking after or breathing air exhaled by an infected per-son. Harmful pathogens are able to infiltrate the body by attaching directly on the surface of cells of an organ or by secreting toxins, which can cause disease locally or systemically by getting into the bloodstream of the host.

Some virulent microorganisms can be harmful in one part of the body but not in other parts. To survive, regardless of where they are in the body, nearly all of these bacteria need iron and each obtains the metal in its own way. For example, bacteria that cause tuberculosis can enter a macrophage, a cell that is intended to destroy the harmful germ.

Macrophages, a type of white blood cell, engulf old red blood cells so that the iron in the hemoglobin of these cells can be recycled. When bacteria enter the macrophage, they ingest the iron, which insures their survival.

Other ways bacteria can get iron is from heme in hemoglobin or transferrin, an iron-transport protein found in the blood. Other bacteria can get iron directly from lactoferrin, a defense iron binding protein found in body fluids such as saliva, tears, breast-milk, vaginal and seminal (semen) secretions. Helicobacter is an example of a pathogen that can get iron from lactoferrin. Helicobacter (*H. pylori*) is the leading cause of stomach ulcers and stomach cancers. This pathogen can be present in a person for decades before symptoms are noticed. Often symptoms of *H. pylori* infection will be attributed to stress or diet.

Bacteria such as Vibrio vulnificus can enter the body by ingesting contaminated raw shellfish or walking barefoot over contaminated beaches. V. vulnificus can become highly virulent in an iron rich environment. Persons with excessive body iron who become infected with *V. vulnificus* can die within hours due of sepsis. Sepsis is the spread of an infection from its initial site to the bloodstream.

VIRUSES

Structurally, viruses are less complex than bacteria. Unlike bacteria, viruses do not require iron to survive or proliferate. Viruses highjack cells and inject their DNA or RNA into these cells. Then the virus uses the overtaken cells to reproduce. Once inside a cell, viruses alter DNA or RNA and here they are nurtured and multiply.

When enough virulent material has replicated within the cell, the cell bursts and the contents gets released into other tissues. Viruses are highly efficient at reproduction, but they cannot evolve or thrive without a specific host cell. For example, the Influenza virus can only proliferate in cells of the respiratory system. Herpes Simplex survives in tissues of the mouth.

Antibiotics, which work on bacterial infect-ions, do not work on viral infections. Specific antiviral drugs are now available for many viral infections. Viruses are vulnerable outside the body if a surface has been disinfected with some product such as common household bleach. Some of the better known viruses include AIDS, viral Hepatitis A, B & C, Poliovirus and Rubella, which causes German measles.

REFERENCES:

Weinberg, E.D. "Roles of metallic ions in host-parasite interactions." Bacteriological Reviews 30 (1966):1336-51.

Weinberg, E.D. "Iron and susceptibility to infectious disease." Science 184 (1974):952-6.

Weinberg, E.D. "Patho-ecological implications of microbial acquisition of host iron." Reviews in Medical Microbiology 9 (1998):171-8.

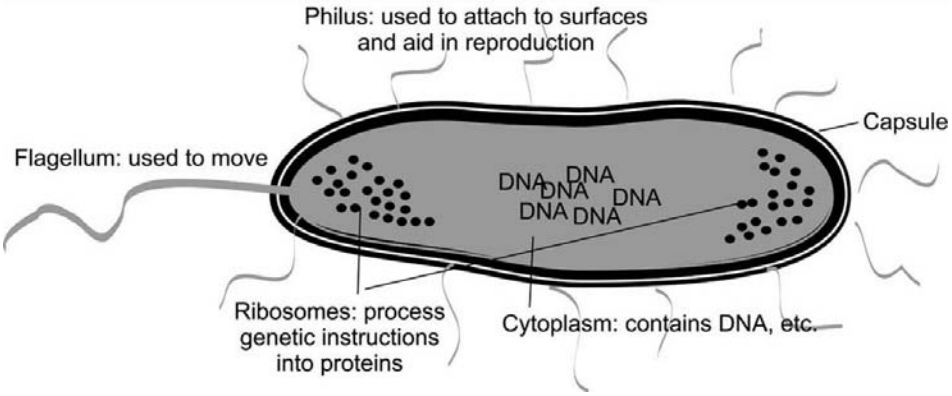


Exhibit 1: Bacterium Structure

Heart (continued from page1.)

in patients with thalassemia major, hereditary hemochromatosis or other causes, it (iron overload) impairs cardiac function and is a major cause of death."[1]

Heart muscle is a prime target for iron deposition. Even with a small quantity of extra iron deposition in the heart, the muscle cells degenerate to result in loss of electrical conductivity and muscle function. Capillary bleeding can occur also. Untreated excessive amounts of iron (iron overload) in the heart will lead to heart damage and possibly death.

To better understand iron overload induced cardiomyopathy investigators at The Rammelkamp Center for Education and Research, Cleveland, studied the effects of daily doses of iron on Mongolian gerbils. To produce iron overload, the gerbils were given iron dextran subcutaneously in amounts ranging from 200/mg/kg/wk) to 800 mg/kg/wk Deferrioximine (DFO), an iron chelator was administered at a dose of 200mg/kg/day to the high-iron dose subjects.

Electrocardiograms (EKG) tracked the cardiac response for more than 70 weeks while iron injections continued to be administered. Observations included that the Q-T interval prolongation was of utmost significance.

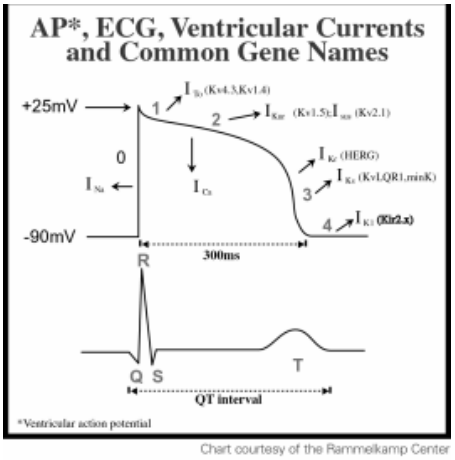


Figure 1: Elongated "Q-T" wave

The "Q-T" wave is usually not prominent on EKGs of persons with normal healthy hearts. **(See Figure 1)** However, in patients with iron-induced cardiomyopathy, the Q-T wave is extended or elongated. An elongated Q-T wave frequently accompanies congestive heart failure. **(See Figure 2)**

Survival was dose dependent, with median survival 68 and 14 weeks for low dose and high dose periods respectively. Bradycardia in the early stages, premature ventricular contractions, variable degrees of atrioventricular block, changes in the ST segment and T-wave inversion at later stages coincided with death. DFO prevented death and EKG changes during the 20-week high dose period.[2]

[1] Yang , Dong, Kuryshev , Obejero-Paz, Levy , Brittenham, Kiatchoosakun, Kirkpatrick, Hoit, Brown. Rammelkamp Center for Education and Research, Cleveland, Ohio "Bimodal cardiac dysfunction in an animal model of iron overload." Journal of Laboratory Clinical Medicine 140 (2002):263-71.

[2] Obejero-Paz, C., T. Yang, W. Q. Dong, M. N. Levy, G. M. Brittenham, Y. A. Kuryshev, A. M. Brown. "Deferoxamine Promotes Survival and Prevents Electocardiographic Abnormalities in the Gerbil Model of Iron-Overload Cardiomyopathy." Journal of Laboratory Clinical Medicine 141 (2003): 121-130.

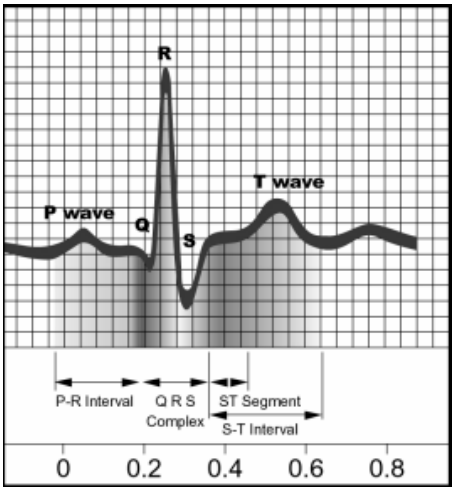


Figure 2: Normal "Q-T" wave

Important Heart Links

"Go Red for Women" ..... http://www.americanheart.org/

"Framingham Heart Study"... http://www.nhlbi.nih.gov/new/press/05-12-27.htm

"The Heart Truth" ..... http://www.nhlbi.nih.gov/health/hearttruth/

Raising Awareness for Iron-Out-of-Balance™

Q. How can I participate in increasing awareness of Iron-Out-of-Balance™?

A. The most obvious way is by becoming a member of IDI and making a donation to one of our programs.

The less obvious and equally important way is by sharing your knowledge with others who are now walking in your footsteps – those most recently diagnosed with an iron imbalance.

Q. How can I share my hard-earned experience and knowledge?

A. You can share your invaluable experience with others by scheduling a few minutes of your valuable time in contributing to one of several programs IDI has developed in the past 2 years.

Q. I'd like to share my experience. What programs are available?

A. They are:

1. Enroll in our on-line discussion group, **Excess Iron List**.
2. Submit a **Haiku** to our newsletter.
3. Submit your "**Magnetic Experience**" or humorous short story to the newsletter.
4. Submit a personal story for inclusion in our newsletter "**Iron Patients: Their Own Stories**" section.
5. Sponsor a student for an iron-related school health/science project and publication under the **Youth Awareness Recognition Program.**
6. Submit local iron-related topics of interest for the **Ambassadors' Corner.**

Q. Where can I find out more about IDI's programs?

A. On IDI's web site and previous issues of our on-line newsletter, ***id-in Touch***.

The Truth about Heart Disease

#1	80%	53%
Heart disease kills more American Women than any other disease	The number of American women who do NOT identify heart disease as the greatest women's health problem	The percentage of Coronary Heart Disease (CHD) among all cardiovascular diseases

Source: National Heart, Lung, and Blood Institute, National Institutes of Health (NHLBI-NIH)

The Rusty Curmudgeon

Jim Hines was diagnosed with hemochromatosis in 1978. He is living testimony that an early diagnosis and participatory iron management will provide longevity along with improved quality of life. Jim can be contacted at jedwhines@cox.net

"*If you have knowledge, let others light their candles with it.*"
Winston Churchill, *British statesman*

Ponderings

Consider for a moment the statistics with respect to liver diseases on page 5 in the November/December issue, the number of candidates waiting for a liver transplant on page 3, and heart disease in American women on page 5 of this issue.

One has to wonder how much did excess iron contribute to these stats?

If so, would the statistics decrease proportionately if excess iron had been identified as an underlying factor much sooner than the onset of heart or liver problems and treated accordingly?

It goes without saying, that there are a number of medical reasons for this level of morbidity besides iron. Nevertheless, one has to pause and wonder!

Fatigue: A Proverbial Mask

Symptoms associated with hemochromatosis; such as fatigue, or lack of energy, can often be the same symptoms associated with other dissimilar medical conditions. In many instances, a similar symptom resulting from different problems may occur simultaneously. As patients, diagnosed with disorders of excess iron, we must constantly be alert for this situation where one symptom masks another. To do otherwise could possibly jeopardize our health.

In fact, it is wise to discuss this dilemma and the symptoms with your physician so that he or she will also be alert to discern the underlying cause or causes, which may not iron-related.

About a year or two after I had been deironed, my wife remarked that as I approached a regularly scheduled phlebotomy I became extremely tired, exhibiting little or no energy. She also noticed that several days after a phlebotomy, my energy levels increased dramatically. I was on a monthly phlebotomy schedule at the time.

It took only several more phlebotomies before realizing the validity of my wife's observations. Thus, I began to use my level of energy and the intensity of my fatigue as a barometer to recognize the possible need for a phlebotomy. However, blood tests have always been the determining factors as to whether or not I would be phlebotomized.

I used this gauge confidently until about 5 or 6 years ago when I was diagnosed with benign prostatic hyperplasia, or BPH. One of the symptoms of BPH is frequent nightly urination. Waking up 3 and 4 times every night because nature is unnaturally calling really puts a damper on one's energy level. Now, I was always tired during my every waking hour, not just when I needed a phlebotomy.

Needless to say, a barometer I had relied on for years was no longer reliable.

As you can see, this is an example of one symptom – frequent urination – causing another symptom – tiredness – which was similar to the symptom – tiredness – I had been experiencing when I needed a phlebotomy. Add to the mix, the aging process and the cause of fatigue become indistinct. Fatigue resulting from BPH was masking my iron loading.

I can't emphasize enough to discuss symptoms, especially vague ones, with your doctor. The more information you provide your doctor increases the possibility of isolating and treating a specific cause.

Fatigue

can be a normal and important response to physical exertion, emotional stress, boredom, or lack of sleep. However, it can also be a nonspecific sign of a more serious psychological or physical disorder. When fatigue is not relieved by enough sleep, good nutrition, or a low-stress environment, it should be evaluated by your doctor. Because fatigue is a common complaint, sometimes a potentially serious cause may be overlooked. Source: MedLinePlus

Bizarre Experiences

Browsing through the *Guide to Hemochromatosis*, I came across a quotation of **Dr. Weinberg's** that reminded me of the many bizarre experiences I have heard of or read about from patients with hemochromatosis or other disorders of excess iron.

Experiences; such as wristwatches that stopped keeping time while being worn, yet kept perfect time when removed from the person's wrist; airport metal detectors setting off alarms when subsequent body searches reveal no indication of what may have triggered the alarm; and extreme cases of static electricity build-up observed in persons by sparks when one touches a metal door knob or tries to pet the family cat with the animal taking off in a fit of howling.

> ***"What sets of airport metal detectors is the metal itself. Iron is after all, a metal."***
>
> –Eugene Weinberg, Ph.D., Professor of Microbiology, Indiana University, Iron Disorders Institute Scientific Advisory Board Member.

Navy Master Chief **Art Callahan** experienced several instances with airport metal detectors. (See the "*Guide*", page 16.) Art's personal experience of iron overloading as a result of *glucose-6-phospahte dehydrogenase deficiency* or G6PD deficiency appeared in the Spring/Summer 2002 issue of IDI's magazine *idInsight*, "In Their Own Words…"

Anecdotal stories, like Art's are more often than not a method of rationalizing in retrospect certain experiences resulting from an individual's diagnosis of excess iron, such as hemochromatosis. However, these events are certainly valid to the individuals experiencing them.

I'd like to share one of mine with you. "The Phantom Itch" is my favorite. To this day, I do not really know if the itching was triggered by iron in the body and my exposure to a magnetic field, or not. (See page 7). I'll leave that for your imagination!

But let me ask you this:

Have you ever experienced extreme static electricity?

Have you had problems with metal detectors?

Did your watch start ticking when you took it off?

If so, IDI invites you to share your strange or humorous iron-related experiences story with our *id-in Touch* readers. Jot down some notes; such as time, circumstances, etc.

Send your particular story and details with contact information to:

Iron Disorders Institute
C/O Bizarre Experiences
PO Box 675
Taylors, SC 29687.

The Phantom Itch

My strange itching symptoms began in Newport, RI at the Naval Base where I was stationed during the period 1968 through 1970. I was assigned to a computer installation located in a building on one of the two main piers jutting out into Narragansett Bay.

Naval warships and utility vessels were berthed on both sides of the pier, many for various repairs and maintenance. Periodically, one or more of these ships underwent a deguassing process. This is a preventive measure; whereby the entire ship, because it is largely metal, is demagnetized to minimize the attraction of magnetic mines.

One morning at work, I felt this extremely itchy sensation all over my torso, mainly on my back. No amount of scratching or wiggling or rubbing would relieve the itch. I even rubbed my back against a doorjamb like bears do against trees to ease the itch. That didn't help either. There was no skin discoloration or rash except that caused by my scratching and rubbing. The more I scratched, the more excruciating the itch became. I had scratched myself so much in the first hour that I was certain I was going to remove my skin clear down to the bone. The itching became so distracting; I was unable to focus on my duties. Meanwhile my co-workers, somewhat disbelieving my discomfort, were having a tremendous time laughing at my predicament.

I tolerated the itchiness for several more hours before I succumbed, deciding to go home for a change of clothes. Fortunately, I only lived about 2 miles from work; thus, a trip home wouldn't take too long. Once off the pier and inside my Volkswagen camper, I began tearing my tie, white shirt and tee shirt off; while at the same time attempting to drive a 4 speed stick shift. I still can vividly recall driving through the Navy base going through all types of contortions, completely naked from the waist up in the middle of a Newport November. I'll tell ya', it was cold and VW heaters in those days didn't produce much heat. My itch had become so intense by that time I reasoned (irrationally, maybe) that the cold and any embarrassment I might endure would be the lesser evil.

Was my wife ever surprised when this half-naked man came bounding through the front door with scratch marks all over his chest and back and half his uniform draped over his arm. More so, when I began stripping off my remaining clothes just inside the front door. Realizing whom it was, my wife was convinced more than ever that her mother had always been correct: she had definitely married a madman. Believe me, at that moment I felt that being mad would have been preferable.

My wife took my clothes so I could continue undressing. But when she did, she received a shock of another kind – my white blended-cotton dress shirt was electrically charged as if it had just came out of a clothes dryer. I returned to work after completely changing clothes, but my relief was only temporary. Several hours later, the same sensation returned with what seemed like a vengeance. You guessed it. Home again! This time I also took a shower and covered my entire body with lotion.

My itch sessions repeated themselves several times a month throughout my tour of duty in Newport, regardless of the season. (Retrospectively, I have a notion that they were more severe during the colder months.) The relief process had become second nature. Showering followed by a generous application of body lotion and a complete change of clothes seemed to ease my suffering more than Benadryl or similar antihistamines. Our next door neighbor was truly ecstatic to see me suffer, as she was able to keep me continuously supplied with body lotion. "Avon calling!"

My co-workers in the computer installation would never let me handle magnetic computer tapes after my first itching episode, especially after I described to them how my wife received a shock from my shirt. However, once I left Newport for warmer climes the itching episodes never occurred again.

I dismissed the incidents from my mind until after I had been diagnosed for hemochromatosis in 1979, when my wife reminded me how crazy I had been during those itching attacks, both of us wondering if there was a connection between "the phantom itch" and hemochromatosis.

Not too humorous at the time, but now we enjoy a reminiscent laugh every now and then. The "phantom itch" has never returned even though I've lived in cold weather climes since. Furthermore, I handle magnetic disks and tapes all the time now without incident.

I've been de-ironed for more than 27 years now.

Sky Diving Trustee

"I can't believe I actually did it!" exclaims **Tim Roberson**, Iron Disorders Institute Board of Trustee member. As a birthday present, Tim's wife Beverly gave him a certificate to sky dive.

At 10,300 feet above Oconee County, South Carolina tumbling and floating groundward, Tim remembers out loud expressions of awe and wonder at the beauty of the landscape below: Whiteside Mountain, Table Rock, The Blue Wall, Lakes Jocassee, Keowee, Hartwell, Clemson University Tiger Stadium and the Greenville horizon.

Tim landed like any novice, on his knees. Standing, still a bit awestruck, he greets Beverly with a hug, kiss and thanks for one of the most memorable experiences of his life. For those of us who might get such a certificate, Tim offers these words of advice: "You're never too young to be old... and you're never too old to be young."

Marathon Des Sable Beckons Trustee

Aran Gordon, Iron Disorders Institute Board of Trustee member Iron Disorders Institute Board of Trustee member will compete once again this coming spring in the *Marathon Des Sables*, the world's most challenging marathon.

The *Marathon des Sables* is a 140 mile, 6 day race across the Sahara Desert in Morocco.

Last year, Aran finished 373rd out of 777 runners. He is an inspiration to others who have hemochromatosis.

Read more of Aran's personal achievements with hemochromatosis and the *Marathon Des Sables* at IDI's web site.

Aran Gordon in the Sahara Desert during the *Marathon Des Sables*, April, 2005

IRON DISORDERS INSTITUTE

OUR MISSION: reducing pain, suffering and unnecessary death due to disorders of iron through awareness, education and research.

OUR GOVERNING BOARDS: A complete list of IDI's governing and scientific advisory board members, including links to our alliance's and partner's web sites can be viewed online:

Board of Trustees

Scientific Advisory Board

Institutional Review Board

OUR PUBLICATIONS:

Periodicals:

id-inTouch – online bi-monthly newsletter

nanograms – bi-monthly bulletin

iron bytes –repository for iron research

idInsight – quarterly magazine

Books:

Guide to Hemochromatosis

Guide to Anemia

Cooking with Less Iron

Exposing the Hidden Dangers of Iron

OUR PROGRAMS:

July Hemochromatosis Awareness

IRONUSA Patient Conference

Patient Advocacy

Educational Materials

Patient Information Series

Physician Reference Charts

Personal Health Profile Booklet

Web Site – www.irondisorders.org

Patient Surveys

Youth Awareness Recognition

OUR CONTACT INFORMATION:

Mail: Iron Disorders Institute
2722 Wade Hampton Blvd.
Suite A
Greenville, SC 29615

Or:

Iron Disorders Institute
Post Office Box 675
Taylors, SC 29687

Phone: 864-292-1175

Fax: 864-292-1878

Web: www.irondisorders.org

OUR EMAIL:

General Support:
PatientServices@irondisorders.org
Printed Materials Assistance:
Publications@irondisorders.org
Member Support:
Membership@irondisorders.org
General Comments:
comments@irondisorders.org

OUR EDITORIAL STAFF:

Cheryl Garrison, Editor

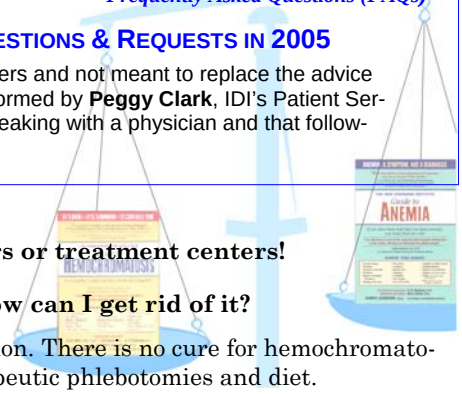
Peggy Clark, Circulation

Jim Hines, Technical Assistant

Iron Disorders Institute is a 501(c)3 voluntary health public interest organization with headquarters in Greenville, South Carolina.

MOST FREQUENTLY ASKED QUESTIONS & REQUESTS IN 2005

Please note that these are abbreviated answers and not meant to replace the advice of a physician. In each case the patient is informed by **Peggy Clark**, IDI's Patient Services representative that the patient is not speaking with a physician and that follow-up with a physician is recommended.



Requests from patients for local doctors or treatment centers!

How did I get hemochromatosis and how can I get rid of it?

Hemochromatosis is an inherited condition. There is no cure for hemochromatosis; iron levels are controlled with therapeutic phlebotomies and diet.

Do I have to have a liver biopsy to see if I have hemochromatosis?

A liver biopsy is normally done to check for damage to the liver. There are other non-invasive ways to confirm hemochromatosis such as genetic testing.

Do I need a liver biopsy to find out how much iron is in my liver?

Liver biopsy is the most used method for determining the amount of iron in the liver; however there are other technologies such as SQUID and FerriScan. Read more about these technologies on our web site.

I am anemic, but iron pills make me sick; what can I do?

You can cut back on the dose, change the form of supplemental iron you are taking to a heme- based pill such as Proferrin®, or increase consumption of red meat (lean cuts of beef, venison or lamb). Red meat is one of the best sources of iron and contains other nutrients such as B12, zinc and protein.

I am a vegetarian and anemic; what can I do?

Avoid foods that inhibit the absorption of iron such as tannins and calcium; increase vitamin C and beta carotene rich foods. An oral iron supplement is likely necessary. Some of the liquid forms with gluconate may be considered.

If iron levels are high, how long before my liver is damaged?

If your diagnosis occurs before serum ferritin is over 1,000ng/mL, there is less than 1% chance of liver damage such as fibrosis or cirrhosis. Talk with your doctor about palpating (gently pressing on the area of the abdomen where the liver is located) the liver to determine if the liver is larger than normal. A liver biopsy may be necessary to confirm liver damage.

My (Hemochromatosis patient) ferritin is low but my transferrin-saturation percentage (Tsat %) is very high; what should I do?

We call this condition iron avidity. You are actually iron deficient and need to get iron levels back in balance. See our newsletter May/June, 2005 issue for details about iron avidity and suggested treatment.

How can I get the new pill EXJADE®?

This drug is an oral iron chelator that is mixed with juice and taken once a day. Few side effects were reported in clinical trials. Read information about EXJADE® on our website and then link to the Novartis website for more information. EXJADE® is currently only approved for use in transfusion-related iron overload. Otherwise use of this drug would be considered "off-label".

IRON Disorders Institute

All Iron Disorders Institute periodicals and books can be ordered online or by contacting Iron Disorders Institute. If you do not have access to a computer, then please visit your local library or use a friend's computer.

For program information, please contact IDI.