Life is something like this trumpet. If you don’t put anything in it, you don’t get anything out.

W.C. Handy, blues musician

IDI's way of keeping in touch with you!

SEPTEMBER/OCTOBER, 2006  IRON DISORDERS INSTITUTE  VOLUME 6, ISSUE 5

JULY HEMOCROMATOSIS REGIONAL SYMPOSIUM
AN EDUCATION AND OUTREACH COLLABORATIVE
Rochester, NY
July 27, 2006

The Mary Gooley Hemophilia Center (MGH), Rochester, NY and Iron Disorders Institute (IDI), Greenville, SC team up for hemochromatosis education and outreach in the Rochester community.

People living with hemochromatosis (iron overload) were treated to an informative hemochromatosis update and discussion by world-class expert, Dr. Prad Phatak. His talk was upbeat, informative and the audience enjoyed his humorous video clips about iron overload. Following Dr. Phatak’s presentation was an inspirational talk given by the Iron Disorders Institute Chairman, Aran Gordon. (See story “Tri-buddy” on page 3.) These two dynamic speakers combined to make this year’s Hemochromatosis Symposium truly outstanding.

Aran, chronicled his struggles to complete the Marathon des Sables this year using a dramatic slide presentation showing clips of the 5-day race.

Recorded 130 degree heat in the Sahara Desert - unusually high humidity - and a tremendously difficult 150 mile marathon course challenged Aran to do what he feared might be impossible ... finish! But finish he did, somehow propelled by

See MGH continued on page 11.

WHO WE ARE

Mary M. Gooley Hemophilia Center
Founded in 1959 by Mary M. Gooley with the help of the Rochester Chapter of the National Hemophilia Foundation (NHF), the Mary M. Gooley Hemophilia Center, located in Rochester New York, has been serving people who suffer from bleeding and blood-related disorders for over 45 years. Our Center was one of the first chartered NHF chapters, and the first free-standing comprehensive care clinic in the nation. We are in fact one of very few combined treatment centers and chapters in the country.

Some of the diseases/disorders we treat:
• Hemophilia • Von Villebrand Disease •
• Hemochromatosis • Other Single Factor Deficiencies •
• Gaucher’s Disease • Trombophilia • Hepatitis & HIV •
• Genetic Info about each Disease •

http://www.hemocenter.org/
**WORKING TOGETHER**

Editor’s note: Lisa Kessler, a certified genetic counselor with DNA Direct, has graciously agreed to contribute a column on genetics. Lisa will undoubtedly be an invaluable genetic resource for IDI member patients and their families. In this issue, Lisa introduces herself.

My name is Lisa Kessler and I am a certified genetic counselor at DNA Direct, a web-based genetic testing service that provides pre-test education, informed consent, results interpretation, post-test support and resources. Before joining DNA Direct, I had the privilege of working with lots of individuals and families with hemochromatosis at the University of Pennsylvania. Currently at DNA Direct, I am the Clinical and Advocacy Coordinator and we continue to have excellent collaborations with the IDI.

In the spirit of working together and promoting hemochromatosis and genetics education, we will have a regular column with some background information.

The HFE gene, associated with Hereditary Hemochromatosis, was identified in 1996. This gene makes a protein that regulates how much iron is taken from the food we eat. A genetic change (called a mutation) in this HFE gene causes the protein to work incorrectly, and the body absorbs too much iron.

Everyone has two copies of the HFE gene – one inherited from their mother and one from their father.

There are 3 key changes in the HFE gene called: **C282Y**, **H63D** and **S65C**.

We will focus on the first two. There are 3 important terms that come up when thinking about genetic testing:

- **Heterozygous** – carrying one gene mutation (i.e. C282Y and no mutation). This is also called being a “carrier”
- **Homozygous** – having two copies of the same gene mutations (i.e. C282Y/C282Y)
- **Compound Heterozygous** – carrying 1 copy of each gene mutation (i.e. C282Y/H63D)

If you are interested in learning more or pursuing genetic testing for hereditary hemochromatosis, IDI recommends DNA Direct, www.dnadirect.com or call 877-646-0222 to speak with one of our genetic experts, 9:00 am - 5:00 pm Pacific Time.

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**A VOLUNTEER AND FRIEND REMEMBERED...**

Iron Disorders Institute mourns the loss of Jason Christopher Clark. Jason served as a volunteer for the Patient Services Department. He was also a dear friend to all working and volunteering at IDI.

Jason was known for his warm spirit, kind heart, hard work, and his “Hollywood smile.” He was generous, always willing to help, and he made everyone feel welcome and appreciated for the work they were doing.

Jason began volunteering for IDI in March of 2006. His sister Jennifer is also a volunteer. His father, Jerry is an engineer with Hanson Aggregates. His mother, Peggy is the sweet southern voice you hear when you call IDI.

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**IF TOMORROW NEVER COMES**

If I knew it would be the last time that I’d see you fall asleep, I would tuck you in more tightly and pray the Lord your soul to keep.

If I knew it would be the last time that I see you walk out the door, I would give you a hug and kiss and call you back for one more.

If I knew it would be the last time I’d hear your voice lifted up in praise, I would videotape each action and word, so I could play them back day after day.

If I knew it would be the last time, I could spare an extra minute or two to stop and say “I love you,” instead of assuming, you would KNOW I do.

If I knew it would be the last time I would be there to share your day, well I’m sure you’ll have so many more, so I can let just this one slip away.

For surely there’s always tomorrow to make up for an oversight, and we always get a second chance to make everything right.

There will always be another day to say our “I love you’s”, and certainly there’s another chance to say our "Anything I can do’s?"

But just in case I might be wrong, and today is all I get, I’d like to say how much I love you and I hope we never forget. Tomorrow is not promised to anyone, young or old alike, and today may be the last chance you get to hold your loved one tight.

So if you’re waiting for tomorrow, why not do it today? For if tomorrow never comes, you’ll surely regret the day that you didn’t take the extra time for a smile, a huge or a kiss and you were too busy to grant someone what turned out to be their one last wish.

So hold your loved ones close today, whisper in their ear, and tell them how much you love them and that you’ll always hold them dear.

Take time to say “I’m sorry”, “please forgive me”, “thank you” or “it’s okay”. And if tomorrow never comes you’ll have no regrets about today.

Author Unknown
I am very happy to provide a summary version of when I was diagnosed with HH etc. I was 45 years old, an accountant and married with one child. My wife and I returned to Ireland after having worked in New York City for 4 years and in London for 14 years to live in a small town called Monaghan, which is in midland Ireland in the border region. I come from quite a large family of eleven, 2 brothers and 8 sisters. (There was no television in Ireland in those days!)

In July 2003, I went to the day ward in my local hospital with symptoms of numbness and pins and needles in my right arm. As part of the numerous blood tests they decided to take one for my ferritin level. Subsequently, an MRI established that I had a prolapsed disk which explained the symptoms in my arm, but surprisingly I was diagnosed with HH and had a level of 3,500mg/l*.

When I was told what I had, my first reaction was that of despair as I had never heard of HH before and thought “my God is this the big one?” Ignorance is a dangerous thing.

Fortunately, through some research and help in the form of information from my hospital my worst fears were alleviated. I have since become quite knowledgeable of HH and now know that it is easily and painlessly treatable as long as it is caught in time. The medical staff and my consultant expressed great surprise that I had not shown any symptoms of HH such as joint pains, lethargy, etc. But I guess I was just very lucky that my hospital had a program in place and good working knowledge of HH. The rest of my family was checked out and only one sister was diagnosed with HH and she is a carrier.

Bovine Tuberculosis Meningitis

Tuberculosis (TB) is a contagious disease of both animals and humans. It is caused by three specific types of bacteria that are part of the Mycobacterium group: Mycobacterium bovis, M. avium, and M. tuberculosis.

Bovine TB, caused by M. bovis, can be transmitted from livestock to humans and other animals. No other TB organism has as great a host range as bovine TB, which can infect all warm blooded vertebrates.

Source: US Department of Agriculture, Veterinary Services, National Center for Animal Health Programs [http://www.aphis.usda.gov/vs/nahps/tb/]

Meningitis is usually caused by a bacterial or viral infection that invades the cerebral spinal fluid (CSF). CSF is the fluid within the open spaces of the brain that protects and cushions the brain and spinal cord. A fungus or parasite may also cause meningitis.

Source: Children’s Hospital of Philadelphia

According to the Children’s Hospital of Philadelphia tuberculosis (TB) may cause meningitis. [http://www.chop.edu/consumer/your_child/condition_section_index.jsp?id=9204]

In a 2001 study of humans, elevated dietary iron was associated with a 3.5 fold increase in cases of active tuberculosis. Pg. 145

Legionella pneumophila and Mycobacterium tuberculosis require iron-loaded macrophages for bacterial multiplication. Pg. 110

Source: E.D. Weinberg, "Exposing the Hidden Dangers of Iron"; 2004

From July through to February I had venesection almost every week to bring down my iron levels. Unfortunately, in February, 2004, I contracted a disease called TB Meningitis and the treatment of HH was postponed for two years until such time as this disease was eradicated from my system.

It is believed I contracted Bovine TB Meningitis through drinking unpasteurised milk as a child, which in the sixties would have been quite common in country areas throughout Ireland. Unfortunately with me, the bug lay dormant in my system and reappeared in the form of a full blown disease and was triggered off by stress etc. from work - so the theory goes!!

In August 2005, I got the all clear for my disease and despite residual problems left over from scarring tissue caused by the disease; I am trying to get my life back in order again.

In September 2005, I resumed my venesection treatment and am glad to say that I now have a reading of 15mg/l. I only have a venesection every three or four months and it is very easy to maintain my iron levels.

I am now a director on the Irish Haemachromatosis Association and very much involved in all issues concerning HH in Ireland.

Would you know of any TB Meningitis centres in your part of the world that I could possibly contact with the view to obtaining any information from other people who had the same disease? All I get in Ireland is that because the disease is so rare - they have nobody to compare me to - I would appreciate if you could help in any way.

IDI’s CHAIRMAN INSPIRES “TRI-BUDDY” IN FINGER LAKES TRIATHLON

In the Rochester Democrat and Chronicle, an article on September 7, 2006, highlighted Brian Reh’s participation in the fourth annual Finger Lakes Triathlon held in Canandaigua, NY. Brian who is relatively new to triathlons was not knowledgeable about bleeding disorders until he agreed to become a Tri-Buddy to a young patient at the Mary M. Gooley Hemophilia Center.

For the past 3 years, Train for Treatment program has paired triathlon participants with young hemophilia patients.

“Coupling my personal desire to perform well in the Finger Lakes Triathlon with the sponsorship of a child has made training for this race quite special,” Reh says.

Brian was also inspired by Aran Gordon of Baltimore, who has twice completed the 150-mile Marathon des Sables, a six-day run across the Sahara Desert, despite suffering from the blood-iron disorder hemochromatosis. To Reh, this showed how places like the Mary M. Gooley Hemophilia Center have “made it possible for people with bleeding disorders to achieve seemingly unattainable goals.”

Read more about Sharing the gift of health

Preventing Disease Caused by Iron-Out-of-Balance™
In Their Own Words...the Margaret Kennedy Story

Editor's Note: Margaret Kennedy’s personal story first appeared in the Winter 2003 issue of IDI’s magazine, idInsight. In many patients hemochromatosis may be a precursor to arthritis. Margaret reveals how serious arthritis can affect quality of life issues when hemochromatosis is not diagnosed in a timely manner.

Margaret Kennedy has genetic hemochromatosis (HHC), an inherited metabolic disorder where iron absorption is abnormally regulated resulting in the accumulation of toxic levels of iron within the body’s vital organs. For more than 14 years, Margaret has experienced frustration in both getting diagnosed and locating a doctor that would recognize the importance of treating the results of her disorder. What has made her experience even more infuriating is that Margaret has been a dedicated registered nurse for more than 30 years and never in her wildest imagination expected to witness such a knowledge void by her profession about the diagnosis and treatment of hemochromatosis.

“As a registered nurse for more than 30 years, never in my wildest imagination did I expect to witness such a knowledge void by the medical profession about the diagnosis and treatment of hemochromatosis.”

Margaret Kennedy

Margaret’s 14 year odyssey began when her younger brother, Charles, was diagnosed with dysentery upon his return from a temporary job assignment in the Middle East during the late 1980s. While undergoing tests to determine the cause of his dysentery, his physician noticed his ferritin level was over 4,000 ng/mL. The doctor recommended a liver biopsy to confirm his suspicion that her brother may have hemochromatosis. When the biopsy results confirmed hemochromatosis, along with early stage cirrhosis, her brother was astonished and told his doctor “That is what my father-in-law died from!” His wife’s father had been diagnosed prior to his death.

“My sister-in-law, Carol, had never been informed that she should have been tested for hemochromatosis. Neither were her siblings.” Nevertheless, it was decided then and there that Carol should also have a liver biopsy, which coincidentally resulted in a diagnosis of hemochromatosis. Charles and Carol immediately began therapeutic phlebotomies to reduce their iron to more manageable levels.

Margaret paid little heed to her brother’s diagnosis until 1987 when she attempted to donate blood. She noticed that her blood was thick and very dark. It was then that the stark realization struck her that she too may also have hemochromatosis. Margaret presented her concerns to her doctor, but he informed her that there was no indication of the disorder from her blood tests, except for elevated hemoglobin, which would drop provided Margaret quit smoking. “I did! And my hemoglobin never dropped.”

Three years later, after being plagued with symptoms of fatigue, dry itchy skin, hair loss and weight gain, Margaret was diagnosed with hypothyroidism and prescribed Synthroid. “My mother had been taking Synthroid for years so I wasn’t too overly surprised by a similar diagnosis and treatment.” Still concerned about hemochromatosis, Margaret pestered her doctor to order a ferritin blood test, which indicated her ferritin was hovering around 400 ng/mL; however, “My doctor insisted I had no symptoms because my liver function studies were normal.”

The following year, Margaret, after having surgery, requested her doctor monitor her ferritin every few months. He placated her, but by late 1992, Margaret’s ferritin has risen to 800 ng/mL, well over the upper range of 200 ng/mL for a female. Frustrated, Margaret insisted that she be referred to a gastroenterologist. This specialist did nothing more than repeat the same diagnosis I’ve been hearing for several years now, “You have no symptoms.”

“What more do these doctors want? My brother has hemochromatosis. My ferritin has risen from 400 ng/mL to 800 ng/mL in two years and my hemoglobin has been consistently high!”

Finally in January, 1993, her gastroenterologist ordered a liver biopsy. “Much to everyone’s amazement, but mine, my hepatic liver index (HII) was 3+.” (See Liver Iron Assessment) Margaret immediately began phlebotomy treatments every 2 weeks for hemochromatosis. After several phlebotomies, her regimen was changed to once a month. “This doctor saw me every three months, ordered infrequent blood tests relying only on liver enzymes, continuously said my lab work looked good and never once palpatated my liver.” “I was once again frustrated and completely dissatisfied with his treatment.” Disillusioned, Margaret decided it was time for a change of doctors.

Early in 1994, Margaret located a hematologist who determined that her liver was enlarged during his initial examination. Based on his exam along with the results of her previous liver biopsy and blood tests, he scheduled Margaret for phlebotomies twice a week. “I had 3 units drawn in 10 days. On the 11th day, I passed out and I was taken to the Emergency Room where my blood pressure dropped whenever I stood and my electrolytes were totally out of whack, so I was admitted overnight for observation where I was re-hydrated.” Thereafter, Margaret was phlebotomized once a month; however the same blood pressure and hydration problems persisted, not to mention that she felt terrible for the next several days. “It wasn’t unusual for my phlebotomy to take an hour because my blood was very thick and clotted frequently. It was really a horrible time.” Her doctor determined that it

Continued on next page.

LIVER IRON ASSESSMENT

Hepatic iron index (HII) = hepatic iron concentration (µmole/g dry weight) divided by patient’s age in years. HII values greater than 1.9 is a diagnostic for hemochromatosis.

Hepatic iron content (HIC) greater than 4500 mcg (80 mcmol) per gram of dry weight or 3+ iron stain substantiates elevated liver iron stores.

The liver biopsy remains the most widely accepted means of establishing the extent of liver damage, such as cirrhosis or fibrosis. Also, it is recommended that for individuals with serum ferritin (SF) greater than 1,000 ng/mL, liver biopsy be considered.
would be wiser to admit Margaret for observation after every
phlebotomy and have a liter of fluids administered intravenously. “This helped me generally to feel better.” “This
procedure lasted for about 2 years, but I just couldn’t get over
the feeling that this was an inappropriate use of valuable
hospital bed space. That’s just the nurse in me.”
Margaret eventually located a company that specialized in “in
home infusions” where a nurse would come to her home to
administer a liter of fluids. She napped during this procedure
and always felt better afterwards. The “in home infusions”
continued until the end of 2001.
Soon after being diagnosed, Margaret’s diet became an
important part of her life. “I threw away the iron skillet,
avoided spinach and iron-fortified foods and consulted with a
dietician.” After 2 weeks of following the dietician’s
recommendations, Margaret realized that the recommended
foods were high in iron. “Needless to say, I got a refund for her
services!” After that episode, Margaret followed her own
judgment and common sense.
“Sometime during the late 1990s, I located the Iron Disorders
Institute and Founder Randy Alexander. He agreed to send
me all sorts of literature on hemochromatosis, which I
devoured.” “Randy informed me that I should avoid eating
beef because beef was one of the greatest sources of absorbable
iron. I couldn’t help recall how little that nutritionist knew
back in ’93.” “Up until I became aware of the Iron Disorders
Institute, I had been pretty much on my own.”
In the fall of 2000, Margaret and Jim attended the Patient
Iron Conference in Greenville, South Carolina sponsored by
the Iron Disorders Institute. “This conference was a turning
point in my life!” It was at this conference that Margaret met
Chris Kieffer who introduced her to the myriad of joint issues
associated with hemochromatosis. This knowledge increased
her pent up frustration, while at the same time increasing her
resolve to become more knowledgeable. In retrospect,
Margaret realizes that the severity of her medical problems
could have been lessened, if not prevented entirely, had she
been diagnosed for hemochromatosis much earlier and treated
accordingly. This is especially true for her several bouts with
arthritis as indicated in the table – Margaret’s
Hemochromatosis Related Medical Problems.
Margaret is extremely grateful for the support she
receives from her husband, Jim, whom she married in June, 2000. Jim
accompanies Margaret to all the iron conferences and has
changed all the faucets and several door handles in their home
to lever handles to compensate for the arthritis in her hands.
Kidding, Margaret says one of the nice treats about Jim was
that “he brought a computer to their marriage”, which has
made her research efforts much easier. “I previously did all
my research at the local public library.”

<table>
<thead>
<tr>
<th>Year</th>
<th>Diagnosis</th>
<th>Treatment</th>
<th>Relationship to HH</th>
</tr>
</thead>
<tbody>
<tr>
<td>1989</td>
<td>Hemochromatosis</td>
<td>Phlebotomy</td>
<td>Brother &amp; Sister-in-law diagnosed</td>
</tr>
<tr>
<td>1990</td>
<td>Hypothyroidism</td>
<td>Synthroid</td>
<td>Mother also, Heterozygous</td>
</tr>
<tr>
<td>1991</td>
<td>Endometrial Ablation</td>
<td>Surgery</td>
<td>Increased iron stores</td>
</tr>
<tr>
<td>1993</td>
<td>Hemochromatosis</td>
<td>Phlebotomy</td>
<td>Decrease iron stores</td>
</tr>
<tr>
<td>1996</td>
<td>Arthritis, right thumb</td>
<td>Cortisone</td>
<td></td>
</tr>
<tr>
<td>1999</td>
<td>Trapezium reconstruction, right hand</td>
<td>Surgery</td>
<td></td>
</tr>
<tr>
<td>2002</td>
<td>Failed joint replacement, right hand</td>
<td>Surgery</td>
<td>Self-explanatory</td>
</tr>
<tr>
<td>2002</td>
<td>Bunion with arthritis</td>
<td>Surgery</td>
<td></td>
</tr>
<tr>
<td>2002</td>
<td>Arthritis, left thumb Arthroplasty</td>
<td>Surgery</td>
<td></td>
</tr>
<tr>
<td>2003</td>
<td>Heel spurs &amp; planter fasciitis Orthotics, Cortisone</td>
<td>Physical Therapy</td>
<td>Often the result of arthritis</td>
</tr>
<tr>
<td>2003</td>
<td>Arthritis, neck</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>


Margaret has acquired “Dr. Grip” pens to make writing less
painful and “Big Grip” utensils by OXO for her use in the
kitchen. She highly recommends these tools for folks suffering
from arthritis of the hand. (See House Aids, next page.)
Although disillusioned in the past by the medical treatment
she received by her profession, Margaret takes solace in the
fact that in her current capacity representing the Iron
Disorders Institute as a volunteer Ambassador in the
Fayetteville, North Carolina area, she has the opportunity to
educate both her profession and the public about diagnosing
and treating of iron overload and the effects of excess iron on
the human body – a challenge she has undertaken vigorously
and with an extremely positive attitude.
For example, this past May, Margaret and Jim attended the
International Patient Hemochromatosis Conference 2003 at
the National Institute of Health, Bethesda, MD. One of her
most memorable moments during this
conference was meeting Margaret
Mullett, Chair, Irish
Haemochromatosis
Association and Margaret
Rankin, the President,
Haemochromatosis Society
Australia.
Margaret was also
instrumental in staff writer,
Rebekah Sanderlin of The
Fayetteville Observer
publishing “Blood is Thicker” in August, an
article about hemochromatosis and how Margaret has dealt
with her disorder. A synopsis of her story also appeared in the
Irish Haemochromatosis Society’s newsletter.

* “Trapezium refers to the wrist. The procedure is considered
  major surgery involving a general anesthetic. Recovery
  involves physical therapy for about 6 – 8 weeks. An
  orthopedic surgeon performs this procedure.
  Involvement of the second and third fingers of the hand is a
  pattern often seen in HHC-arthritis and referred to as “Iron
  Fist.”

Continued on next page.
More recently, Margaret submitted a suggestion to her local blood bank requesting the director to file for an FDA variance to use the blood of hemochromatosis patients who are otherwise qualified donors. The suggestion was rejected as not being cost-effective, but Margaret is determined to redress the issue with the blood bank director.

For Margaret, this has truly been a family affair. Not only has her brother and sister-in-law been diagnosed with hemochromatosis, but one of her nieces and a nephew are also. Her brother and sister-in-law have been diagnosed with the issue with the blood bank director.

The suggestion was rejected as not being cost-effective, but Margaret is determined to redress the issue with the blood bank director. For Margaret, this has truly been a family affair. Not only has her brother and sister-in-law been diagnosed with hemochromatosis, but one of her nieces and a nephew are also having therapeutic phlebotomies. A 3rd niece has been diagnosed, but not yet having phlebotomies because of her age. Furthermore, Margaret believes hemochromatosis was part culprit in the death of her aunt in 1961 from liver cirrhosis. After her diagnosis in 1993, her parents, who are at the very least carriers, have had their iron checked with good results.

Margaret has been genetically tested, confirming that she has the double mutation gene, Cys282Tyr, for hemochromatosis. Margaret’s youngest son has a single Cys282Tyr mutation and her plans are to have the remaining children genetically tested by the end of this year. They have yet to have their iron levels tested, but Margaret is continually badgering them. She believes it is imperative that they are tested for excess iron because their father passed away in 1996. “To my knowledge, he never had his iron checked.” “The uncertainty worries me.”

The good news is that Margaret recently reached a new plateau when informed by her doctor that she was now de-ironed and could now anticipate maintenance phlebotomies every 10 weeks. “It only took 10 years!”

Please see Margaret Kennedy’s Update, next page.

"Besides chronic fatigue, joint pain is a leading complaint of hemochromatosis patients."
Joanne Jordan, M.D., MPH, Associate professor of medicine and orthopaedics, University of North Carolina Chapel Hill Iron Disorders Institute Scientific Advisory Board Member

FACTS ABOUT HEMOCHROMATOSIS ARTHRITIS
Arthropathy was first described as a potential complication of HHC in 1964 by Dr. H.R. Schumacher and Dr. Margit Krikker.
HHC arthritis is degenerative rather than inflammatory as seen in rheumatoid arthritis (RA)
Both RA and hemochromatosis arthritis are symmetrical but each has distinctive characteristics. In HHC arthritis there is bone enlargement, joint narrowing and joint damage (erosion, pitting); whereas in RA, inflammation and synovial thickening is more prominent. In HHC arthritis, the second and third metacarpals, wrists, shoulders, hips, knees, and ankles are the joints most typically affected; whereas in RA, joint involvement is more global.
Transferrin-saturation percentage (TS%) is found to be higher among osteoarthritic patients who are heterozygous for C282Y compared to those who lack both HFE mutations

References:
Barton, JC, Edwards, CQ. (Editors) "Hemochromatosis: Genetics, Pathophysiology, Diagnosis and Treatment." 2000 Cambridge University Press

Percentage Of Persons In General Population And In Those With HHC Who Reported Arthritic Symptoms

<table>
<thead>
<tr>
<th>Age in years</th>
<th>General Population</th>
<th>HHC</th>
<th>General Population</th>
<th>HHC</th>
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<tr>
<td>17-39</td>
<td>5.9</td>
<td>10.3</td>
<td>5.2</td>
<td>8.9</td>
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<tr>
<td>40-59</td>
<td>23.4</td>
<td>34.9</td>
<td>14.7</td>
<td>22.2</td>
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<tr>
<td>60-84</td>
<td>51.1</td>
<td>42.8</td>
<td>33.8</td>
<td>31.5</td>
</tr>
</tbody>
</table>


SUGGESTED HELPFUL HOUSEHOLD AIDS FOR ARTHRITIC SUFFERERS

- "Dr. Grip" pens make writing less painful.
  Available from officeworld.com

- "Big Grip utensils by OXO are for use in the kitchen.
  Available from amazon.com

- Light switches that slide or toggle are easier to use. Switches are available from most major electrical supply houses.

- Bathroom accessories, which facilitate easier use, are available through most hardware companies such as Lowe’s or Home Depot.

- Kitchen accessories, which facilitate easier use, are available through most hardware companies such as Lowe’s or Home Depot.

ADDITIONAL RESOURCES
For more information about arthritis or dexterity problems, visit the following web sites:
- National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) www.niams.nih.gov
- Arthritis Foundation www.arthritis.org
- Arthritically Correct™ www.arthriticallycorrect.com

Arthritically Correct products have been ergonomically designed to reduce or eliminate any pain or discomfort that might accompany performing our everyday tasks or chores.
- Dynamic Living® www.dynamic-living.com

Dynamic Living offer hundreds of kitchen products, bathroom helpers and unique daily living aids.
MARGARET KENNEDY’S UPDATE

Much has occurred since the article was printed 2 years ago. After 10 years of phlebotomies, my veins were not cooperating and neither was the local blood bank. For 2 years, Tru, a dear lady, did my phlebotomies with a 21 butterfly needles and 70 red top tubes while Jim handed her the tubes until we hit 70. Unfortunately, all good things come to an end and my veins would no longer cooperate. I had a Port-a-Cath® catheter put in Sept of 2005, now I go to the hospital’s Peripheral Access Department for my phlebotomies, which has worked well. It helps to be in the medical profession.

I’ve also had all 3 of my children genetically tested because their father is deceased. I’m real glad I did because they all have a single C282Y gene. Gratefully, they are frequent blood donors. Later, I discovered after talking with my deceased husband’s sister, that there is HHC in her family.

In 2005, 2 toes just dislocated, which forced me to cease walking 20 miles per week. My resourceful husband, Jim, bought us bikes, now I have the option to either ride or walk. When my podiatrist performed corrective toe surgery after I retired that year, I requested a biopsy of what was removed. The pathology report returned indicating the presence of iron, making a firm believer of this physician.

Also during that year, Jim had to take me to the ER at 5:00 a.m. with severe abdominal pain where an abdominal CAT scan revealed pancreatitis, as my pancreas was surrounded by fluid. I returned home 36 hours later. It was probably the worst pain I have ever experienced.

This past summer I had a Hida Scan* and it showed that my gall bladder functioning at only 17%. I asked the surgeon to have it stained for iron. The surgery will be this September. The surgeon feels it was the gallbladder problem that caused the pancreatitis.

In addition to all this, Jim and I have had to provide home care for my 83 year old mother because of a fractured hip, subsequently arranging or care in an assisted living facility. The logistics involved has dramatically changed our lives.

On a very positive note, I am finally deironed, having only required 7 phlebotomies in the past 20 months with a few being only a half unit. My latest labs were: serum ferritin (SF) - 14.7ng/mL; transferrin iron saturation (TS%) - 17%; and hemoglobin (Hgb) - 14g/dL.

Until I got educated by IDI, the physician I was seeing was going on Hgb and really not looking at saturation. I changed doctors!

*Lasix is used in the treatment of high blood pressure and other conditions that require the elimination of excess fluid (water) from the body.

LETTERS TO THE EDITOR

August 17, 2006

Dear Editor,

My ferritin got up to 305. Thought I might get to try Exjade. You have to be registered by a doctor to get it. Iron ferritin has to be up above 1000 to get on it and they stop it when it gets below 500. None of my doctor's patients have been able to handle it due to BAD side effects. Seems like the 5 per cent ill effects I see on the internet may be wrong.

Two nurses mentioned all the side effects I had read on the internet and they didn't recommend it in my case.

I went to my doctor’s chemotherapy room to try another phlebotomy yesterday. I had stopped my lasix* and drank a lot of water. I had two sticks in one arm and got blood just to the bag and when it stopped. We got over a unit of blood in a rather unorthodox manner in my other arm. Nurse stuck me with an IV needle this time and attached big syringes to it and helped it with a little vacuum pull resulting in 5 full big syringes along with several smaller ones.

This was the first unit of blood taken from me in a long time. Made my day!

I'm still surviving here in Memphis.

Art Callahan
Memphis, TN
P.S. A Bravo Zulu to you and everyone at IDI. Thanks for the rewrite.

*Lasix is used in the treatment of high blood pressure and other conditions that require the elimination of excess fluid (water) from the body.
September was Gynecologic Cancer Awareness Month, but women should always be aware of this category of cancers, not just in September.

Gynecologic cancers include those of the female reproductive tract, such as ovarian, uterine, vaginal, cervical, vulvar, and tubal cancer. Gynecologic cancers are the fourth most common cancer group in American women today.

Ovarian cancer being the most serious is sometimes referred to as the "whisper" disease. Most women experience some or all of the symptoms associated with it during their lives.

Iron’s role in gynecologic and estrogen-dependent cancers has not been greatly investigated. One recent Russian study provides that women who carry the H63D mutation of HFE, the gene for hemochromatosis have greater than 4 fold increased risk for breast and ovarian cancer especially after the age of 57. The same risk does not appear to exist for those who carry the C282Y mutation of HFE. (See abstract next column.)

More research is needed to support these findings. Also, research is needed to investigate whether or not serum ferritin is elevated in individuals with breast cancer and women with ovarian cancer. We think that serum ferritin is likely to be elevated in these cases, but no evidence known to us is available to support this concern.

In the meantime, we encourage women to be aware of all cancers, but in this month we emphasize the gynecologic cancers especially ovarian cancer. Another important action is to get serum ferritin levels checked every two years, especially if you no longer menstruate or your menstrual cycle has been diminished with birth control pills.

Abstract Excerpt

Odds ratios for breast cancer risk associated with the H63D mutation increased significantly with age: 0.5 in women below 48 years old, 1.0 in a range of 48-57 years, and 4.4 in older women (P(trend)=0.002). The latter value was statistically significant (95% CI, 1.4-14.1), indicating that women bearing the H63D mutation may be at an increased breast cancer risk at an age above 57 years. Preliminary results obtained in patients with two other estrogen-dependent malignancies revealed the same tendency to OR increase with age in ovarian cancer patients

Source: Frequency of hemochromatosis gene (HFE) mutations in Russian healthy women and patients with estrogen-dependent cancers.

For more information about Gynecologic Cancers check out the following links:
- US Department of Health and Human Services, Office of Women’s Health
  http://www.4women.gov
- Gynecologic Cancer Coalition of Greater Washington/Rhonda’s Club
  http://www.cancer-ovarian.org
- Gynecologic Cancer Foundation
  http://www.thegef.org
  http://www.wcn.org

10 DISEASES DOCTORS MISS
The Reader’s Digest for October 2006 listed 10 diseases most often missed by doctors resulting in – you guessed it – unnecessary suffering.

- Heart disease
- Chronic obstructive pulmonary disease (COPD)
- Hepatitis C
- Sleep apnea
- Chlamydia
- Hemochromatosis
- Celiac disease
- Lyme disease
- Hypothyroidism
- Lupus

Pick up a copy of the October issue of Reader’s Digest issue for more detail. Or, view on line: 10 Diseases Doctors Miss.
As a student, Bonnie Hayes recalls receiving a rather cursory once-over on the topics of hemochromatosis/iron overload and iron deficiency anemia; two issues, not particularly linked to one another. Fast forward twenty-two years, and Dr. Bonnie Hayes has more than a cursory interest in iron out of balance. “As a Chiropractor, I became sensitized to iron imbalance several years ago” says Dr. Hayes, “when I received a telephone call from the husband of one of my long-term patients. This particular patient is one I had become fond of over time. She is a very high-functioning, intelligent, stable, and interesting post-menopausal woman, and I very much enjoyed treating her as well as the conversations we have shared during her visits. When her husband notified me that his wife had been committed to a psychiatric ward for severe depression, I was stunned. Although I knew some patients can be masters at masking depressive feelings – in this case, I felt sure something just did not fit.”

“A few months later” Dr. Hayes continues, “I received a call from my patient who was now back at home. Being the inquisitive type, she had spent her afternoon browsing through her local Barnes & Noble. She could barely contain her excitement.”

“I found it” she told me. “You always told me I had too much iron. I saw the cover of this book, picked it up and started reading, and I brought it home – THIS IS ME!”

“I was so intrigued that on my way home that night, I stopped at Barnes & Noble and I purchased that book – Guide to Hemochromatosis from the Iron Disorders Institute”, says Dr. Hayes.

“As a Chiropractor, my specialty area of interest is neurology, specifically – neurodegenerative dysfunction” states Dr. Hayes. “I am continuing my education as a student at the Carrick Institute for Graduate Studies where I am involved in a very exciting and captivating program of study in Clinical Neurology with an emphasis on neurological function. There has been a good deal of research which potentially links mismanagement of iron in the brain to diseases such as Alzheimer’s, Amyotrophic lateral sclerosis, Huntington disease, Multiple Sclerosis, Parkinson’s disease and more.”

According to the Iron Disorders Institute’s Guide to Hemochromatosis edited by Cheryl Garrison, “Iron is stored in the brain in ferritin and is transported to the brain and within the brain by transferrin. So the players in the management of brain iron are the same as in other organs. Serum ferritin levels in the body are measured in a blood sample taken from the arm. However, brain ferritin levels are determined from fluid obtained from a spinal tap. The signals that are used between the brain and its blood vessels to determine how much (and when) iron should be transported into the brain must be discovered before we can directly test this idea. A grant from the National Institutes of Health supported research for scientists James Connor and John Beard to investigate this brain signal function. They proposed that the amount and timely delivery of iron to the brain in hemochromatosis is disrupted as the brain tries to read signals regarding the amounts of iron in the blood. Poorly timed or inappropriate amounts of iron delivery to the brain would directly affect the synthesis rates of the chemical communicators for nerve cells, and inappropriate levels of chemical communicators can be associated with depression. The data supporting the idea that the levels of iron or iron-associated proteins (transferrin or ferritin) in blood can correlate with depression and other psychological illnesses are growing.”

“What is the “metabonome”? Genomics measures the entire genetic makeup of an organism, while proteomics measures all the proteins expressed under given conditions. Metabonomics is no different. As the name might imply, metabonomics is defined as measurement of the complete metabolic response of an organism to an environmental stimulus or genetic modification. ”

“The metabonome for every organism is different, and it changes with age,” says Jeremy Nicholson of Imperial College London, whose group coined the term. (The metabolome, by contrast, is the full complement of metabolites in a given cell.) There are 600 to 700 known major metabolites, leading to vast numbers of potential combinations and different sets in each cell. “The metabonome is so big, we may never know how big it really is,” Nicholson says. His group has developed a metabonomics blood test that can non-invasively diagnose coronary heart disease (Brindle, J.T. et al. Nature Medicine 8, 1439-1444: 2002)
The paradigms of the past no longer apply. Today’s educated patient not only has a desire, but an obligation to be an active participant in his own health care. “Until fairly recently conventional medical professionals and healthcare consumers alike have readily accepted the “allopathic model” in diagnosis and treatment, which generally is reflective of treating disease with remedies that produce effects different from those caused by the disease itself, focused treatment - with focus on the end stage disease”. Chiropractic is a natural method of health care that treats the causes of physical problems rather than just the symptoms. Chiropractic is based on a simple but powerful premise: With a healthy lifestyle and normally functioning nervous system: the brain, spinal cord, peripheral nervous system which includes the spinal joints and nerves etc.; your body is better able to heal itself. That’s because the spinal cord, which is protected by the spine, is the main pathway of your nervous system. It controls movement, feeling, and function throughout your body.

As a Doctor of Chiropractic” Dr. Hayes says, “it is rewarding to see more and more frequently consumers as well as various medical disciplines embracing what I believe Chiropractors have always known — it is vital to address the intermediate level of metabolism.”

Disorders of iron metabolism, presently providing us with a groundswell of emerging data serve as an excellent model for development of screening, diagnosis and treatment plans that truly utilize all disciplines in medicine – with the patient squarely seated as an equal member of the team.

It's an exciting time in the healing arts.

WHAT IS CHIROPRACTIC?

By definition of the American Chiropractic Association, Chiropractic is a health care profession that focuses on disorders of the musculoskeletal system and the nervous system, and the effects of these disorders on general health. Chiropractic care is used most often to treat neuromusculoskeletal complaints, including but not limited to back pain, neck pain, headaches and pain in the joints of the arms or legs.

Doctors of Chiropractic, often referred to as chiropractors or chiropractic physicians, practice a drug-free, hands-on approach to health care that includes patient examination, diagnosis and treatment. Chiropractors have broad diagnostic skills and are also trained to recommend therapeutic and rehabilitative exercises, as well as to provide nutritional, dietary and lifestyle counseling. Doctors of chiropractic may assess patients through clinical examination, diagnostic imaging and other diagnostic interventions to determine when chiropractic treatment is appropriate or when it is not appropriate.

Chiropractors will readily refer patients to the appropriate health care provider when chiropractic care is not suitable for the patient’s condition, or the condition warrants co-management in conjunction with other members of the health care team. Within the chiropractic profession, there are specialists in various disciplines including radiology, sports injuries, orthopedics, neurology, pediatrics, internal disorders and physical rehabilitation.

WHAT CAN ALTERNATIVE PRACTITIONERS DO?

By Cheryl Garrison, Executive Director, in consultation with Dr. Hayes

A complete diagnosis can often be missed because the symptoms of hemochromatosis are non-specific and vague. Heart failure, diabetes, cirrhosis, arthritis, hypothyroidism, impotence or infertility is among the consequences of untreated hemochromatosis.

In a 1999 patient survey conducted by the US Centers for Disease Control and Prevention, input from 3,000 respondents revealed that it took on average three physicians as long as nine years to get a complete diagnosis of hemochromatosis. Another survey is greatly needed to determine if the discovery of HFE, the gene for hemochromatosis along with increased education and outreach programs have had time to positively impact this important concern.

People with multiple symptoms who are not getting relief with conventional medicine will often seek the help of alternative health professionals. Because the alternative health care provider generally spends more time with each patient, (insert: physicians on average spend 7-10 minutes with a patient, in contrast the alternative health care provider spends 20-30 minutes with a patient) additional key information, especially about family history, might get revealed in these longer sessions and hemochromatosis suspect sooner. Many medical doctors support and encourage alternative approaches; likewise, chiropractors support conventional medicine. According to Atlanta chiropractor Bonnie Hayes “We are obliged to refer patients back to his or her primary care physician for further testing when we see something that is not adding up.”

Signs and symptoms that might help an alternative health-care provider identify hemochromatosis in time to impact a person’s quality-of-life are listed below.

When patients report any combination of the following:

- Irregular heart beat
- Chronic fatigue
- Pain, especially in the first two knuckles of the hands, ankles and knees
- Pain in the gut (in some cases the back)
- Odd color to the skin: ashen gray-green or bronzing
- Hair loss (total body can be involved)
- Loss of interest in sex
- Depression
- Inability to get pregnant or repeated miscarriages
- Women who no longer have a period (for any reason including hysterectomy, menopause or taking birth control pills)
- Frequent thirst or urination,
- Unexplained weight gain or loss
- Family history of hemochromatosis, too much iron, some relative having to give blood often, or early death by heart attack

WHAT IS COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM)?

Health care practices and products that are not presently considered to be part of conventional medicine are called CAM. Complementary medicine is used together with conventional medicine. Alternative medicine is used in place of conventional medicine. National Institutes of Health, National Center for Complementary and Alternative Medicine http://nccam.nih.gov/
his sheer guts and determination to spread the word about hemochromatosis!

The Iron Disorders Institute (IDI) co-sponsored this year’s event. IDI Executive Director, Cheryl Garrison and long-time active members, Chris & Harry Kieffer were in attendance. The seminar, held at the Lodge at Woodcliff was sold-out. Part I included dinner and Dr. Phatak’s presentation and was attended mainly by patients and their spouses, Part II was for both patients and athletes and featured super athlete and hemochromatosis patient Aran Gordon.

Also in attendance were: Ronald Sham, MD - the Center’s medical director, Yvonne Ace-Wagoner - Board Chairman, Tricia Oppelt, LMSW - Social Worker, Linda Miller - Director, Special Events and Rona Wyner - Director, Development & Communications.

Evaluations and comments from the attendees were exceptionally helpful. Speakers received the highest praise and marks; attendees indicated that they would definitely attend should the event be repeated next July.

Prompted by this enthusiasm, Bob Fox, Aran Gordon, Cheryl Garrison and Tricia Oppelt met the following month to begin planning for next year’s event, which will likely take place in July.

A special thanks to the MGH Center’s Rona, Tricia and Linda who organized and supervised this highly successful event.

Additionally, IDI representatives enjoyed a tour of the Mary Gooley facilities. (See tour photos this page.)

Prior to IDI’s departure, Rona Wyner shared one of the hemochromatosis posters she has designed for MGH’s hemochromatosis program.
# Iron-related Non-profit Health Organizations (USA)

<table>
<thead>
<tr>
<th>Organization</th>
<th>Name</th>
<th>Acronym</th>
<th>Founded</th>
<th>Type</th>
<th>Mission</th>
<th>Dedication</th>
<th>Scope</th>
<th>Governance</th>
<th>Contacts</th>
<th>Publications</th>
<th>Educational Programs and Projects</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Hemochromatosis Society, Inc.</td>
<td>AHS</td>
<td>AHS</td>
<td>1998 in Florida</td>
<td>501c3 non-profit health organization</td>
<td>The mission of the American Hemochromatosis Society (AHS) is to educate and support the victims of HFE-associated hereditary hemochromatosis (genetic iron overload) and their families as well as educate the medical community on the latest research on Hereditary Hemochromatosis (HH). AHS aims is to identify through genetic testing, the 43 million+ Americans who unknowingly carry the single or double gene mutations for HH which puts them at risk for loading excess iron.</td>
<td>...to hemochromatosis.</td>
<td>National</td>
<td>Board Of Directors</td>
<td>4044 W. Lake Mary Blvd., Unit #104, PMB 416</td>
<td>The Blood Letter - latest issue - 1/2000</td>
<td>Children Helping Children Screening &amp; Awareness Project</td>
</tr>
<tr>
<td>Iron Overload Disease Association, Inc.</td>
<td>IOD</td>
<td>IOD</td>
<td>1980 in Florida</td>
<td>A 501 (C) 3 Charity and Non Profit Medical Association</td>
<td>To lead the search for the millions of Americans and other nationals who have undiagnosed iron overload; to promote adequate treatment and to prevent the severe health problems and avoidable deaths that results from neglect of iron overload.</td>
<td>...to diseases that result from iron overload, mainly hemochromatosis.</td>
<td>International</td>
<td>Board Of Directors</td>
<td>433 Westwind Drive P.O.</td>
<td>Ironic Blood - latest issue 6/2006 (bi-monthly)</td>
<td>Senior Helping Senior Screening &amp; Awareness Project</td>
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<tr>
<td>Iron Disorders Institute, Inc</td>
<td>IDI</td>
<td>IDI</td>
<td>1996 as Common Ground, 1998 as IDI in South Carolina</td>
<td>501(c) 3 national voluntary health public interest organization</td>
<td>Iron Disorders Institute's (IDI) mission is to reduce pain, suffering and unnecessary death by disorders of iron through education, awareness and facilitating research.</td>
<td>... to disorders of iron imbalances: anemia and iron overload.</td>
<td>National</td>
<td>Board of Trustees</td>
<td>2722 Wade Hampton Blvd., Greenville, SC 29615</td>
<td>Id-in Touch - latest issue 8/2006 (bi-monthly)</td>
<td>Families Helping Families online discussion support group</td>
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<th>Membership</th>
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<tbody>
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<td>Books</td>
<td>The Iron Elephant; Roberta Crawford; 1990</td>
<td>Tick...tick...tick...; Roberta Crawford; 1994</td>
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<tr>
<td></td>
<td>Cooking With Less Iron; Cheryl Garrison; 2001</td>
<td>Exposing The Hidden Dangers of Iron; Dr. Eugene Weinberg PhD; 2004</td>
</tr>
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<tr>
<th>Educational Programs and Projects</th>
<th>For more information, click on underlined links</th>
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<tr>
<td>Children Helping Children Screening &amp; Awareness Project</td>
<td>Annual International Symposium</td>
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<tr>
<td>Senior Helping Senior Screening &amp; Awareness Project</td>
<td>Local area support groups organized by volunteers</td>
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<tr>
<td>Families Helping Families online discussion support group</td>
<td>Marathon Des Sables - Aran Gordon fundraiser</td>
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<tr>
<td>Physician Referral Program</td>
<td>Library Outreach Program</td>
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<td>Bi-annual IRON USA Conference</td>
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<td>Regional workshops</td>
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<td>Physician Referral Program</td>
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<td>Physician Reference Charts developed by Scientific Advisory Board</td>
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<td></td>
<td>Local area support groups organized by volunteers</td>
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<td></td>
<td>Youth Awareness Recognition Program (YARP)</td>
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<td></td>
<td>Excess Iron List online discussion support group</td>
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<td></td>
<td>Helpful forms available on line, or contact IDI headquarters</td>
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**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 jehwhines@cox.net

“If you have knowledge, let others light their candles with it.”

Winston Churchill, British statesman

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**Iron-related NPOs**

In the United States, patients diagnosed with diseases or disorders characteristic of iron imbalances have the good fortune to have not one, but three non-profit public health organizations (NPOs) dedicated to educating the medical community, patients and the public-at-large about the insidious effects that iron can have on one’s health if left untreated. The American Hemochromatosis Society (AHS), Iron Overload Disease Association (IOD), and the Iron Disorders Institute (IDI) provide an aggregate plethora of information with respect to iron overload and anemia.

All this information can be obtained without cost; however, each organization does solicit membership for a reasonable fee to defray the expenses incurred in locating and publishing credible medical information about iron, along with providing patient services. There is no such thing as a free lunch.

To simplify locating which services are applicable to your particular situation, I’ve created a chart on the previous page, which provides a basic description of the three organizations, along with most of the programs they provide.

I’ve found it extremely useful to have this chart at my fingertips (actually, my mouse) when searching for information with respect to iron, thus I thought this would be a good time to share it with you, the readers of *id-in Touch*, so you could have it at your fingertips. My copy had become dog-eared, so I improved its appearance and added links to each item on the chart where ever a web page exists on an organization’s web site. In other words, you now have a bird’s eye view for non-profit sources of information relating to iron and its insidious manifestations.

The chart’s information has been gleaned from newsletters and web sites of the respective organizations. If I have inadvertently failed to include information that is considered significantly important, I will be more than glad to update the list in the newsletter and repost it with the corrections.

One note of caution, the value of having the chart’s included links will be greatly diminished if any of these organizations upgrade their web sites. The reason I remind you of this is because I understand that there are dynamic changes being made to IDI’s and IOD’s web site, which may possibly affect the links in this chart. Irrespective of this potential flaw in this chart, the information should remain valid, and I will endeavor to provide future updates, accordingly.

**Reader’s Digest Article** (see page 8)

It came as no surprise to many hemochromatosis patients, including myself, that our disorder was listed in the recent *Reader’s Digest* article, “10 Disease Doctors Miss”.

My curiosity was piqued when I recognized that several of the other diseases in RD’s list had a documented relationship to iron. So to satisfy my curiosity, I used my favorite search engine to identify those specific diseases. Basically, I searched the internet for articles containing the name of each disease.

See Rusty continued on next page.

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**Recognition, Diagnosis and Management of Hereditary Hemochromatosis**

By Cheryl Mellan, Excess Iron List Moderator

Hereditary hemochromatosis is a disorder of iron metabolism, which occurs as a result of excess iron accumulation in tissues and organs. If left undiagnosed and untreated, iron overload can cause serious and sometimes fatal health problems. Early detection of iron overload and hemochromatosis treatment can delay or prevent irreversible complications and prolong life.

Early non-specific symptoms of hemochromatosis (e.g., fatigue, arthralgias, weakness, depression, weight loss, abdominal pain) often resemble symptoms of various other diseases. According to a 1996 U.S. Centers for Disease Control and Prevention Survey, chronic fatigue and arthritic pain in joints were the two symptoms most frequently experienced by individuals with Hemochromatosis. Any actual arthritis of the ankle, knuckles, or the first joint of the second and third fingers should suggest testing for HHC. The x-ray finding of a white line of chondrocalcinosis in any joint is another tip-off. Other symptoms, findings, or diseases associated with iron overload include arthritis, diabetes mellitus (especially type II), heart trouble or arrhythmia, liver disease, and mildly elevated liver enzymes – especially ALT. Also associated with iron overload are amenorrhea, anterior pituitary failure, impotence and loss of libido, inappropriate increase in skin pigmentation, depression, hypothyroidism, infertility, viral hepatitis, liver cancer, NASH and porphyria cutanea tarda (PCT).

The diagnosis of hemochromatosis is often missed, especially when the disease is in its early stages. Delay in diagnosis results in an increase of related health problems, including permanent organ damage.

Hemochromatosis can be detected with simple blood tests. Specific tests include: fasting serum iron (SI), total iron binding capacity (TIBC), hemoglobin (Hgb)/hematocrit (Hct), and serum ferritin (SF). Both serum ferritin and transferrin-iron saturation percentage (TS%) will be elevated if tissue iron levels are excessive.

The treatment of choice, phlebotomy, is relatively easy and inexpensive.

For more information, medical professionals can contact the Iron Disorders Institute for a “Physician’s Reference” guide which includes a diagnosis and treatment algorithm. (See page 7 for additional details.)

Medical professionals can visit the Centers for Disease Control and Prevention to earn free CME credits by participating in the online tutorial “Hemochromatosis: What every clinician and health care professional needs to know” – an online training course for primary care providers describing the pathophysiology, epidemiology, diagnosis, treatment, and management of patients with adult onset hemochromatosis.

Go to [http://www.cdc.gov/hemochromatosis/](http://www.cdc.gov/hemochromatosis/) then click on Training for Professionals.

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**What is conventional medicine?**

Conventional medicine is medicine as practiced by holders of M.D. (Doctor of Medicine) or D.O. (Doctor of Osteopathic Medicine) degrees and by their allied health professionals, such as physical therapists, psychologists, and registered nurses. Other terms for conventional medicine include allopathy; Western, mainstream, orthodox, and regular medicine; and biomedicine.
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 – http://www.irondisorders.org
- Patient Surveys
- Youth Awareness Recognition

OUR CONTACT INFORMATION:

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

Or: Iron Disorders Institute
Post Office Box 675
Taylors, SC 29687

Phone: 864-292-1175
Fax: 864-292-1878
Web: http://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:

- Jim Hines, Editor
  jedwhines@cox.net
- Peggy Clark, Circulation
  pclark@irondisorders.org

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

Laura Main, Lorei Reinhard, and Cheryl Garrison have a photo op with Licking Memorial Health Systems’ mascot SCRUBS, an irresistible hound who is always on the lookout for opportunities to improve health. Scrubs gives Lorei an affectionate hug and agrees to send health fair attendees to the booth where she is screening people for hemochromatosis as part of the Licking Memorial Health Systems/Iron Disorders Institute July Hemochromatosis Awareness Outreach Program.

Rusty continued from previous page.

plus iron, i.e., Chlamydia+iron. Was I surprised! And I only looked at the 1st or 2nd hit from my search queries.

I’m certain many of you had similar thoughts, but here are the results of my search:

- Heart disease: “Iron and Heart Disease”, 10/1/2006, American Heart Association
- Chronic obstructive pulmonary disease (COPD): “Oxidative Stress in Chronic Obstructive Pulmonary Disease”, American Journal Respiratory Critical Care Medicine, 8/1997
- Sleep apnea: No direct connection to iron; however restless leg syndrome (RLS) is a closely related sleeping disorder and is associated with iron.
- Hemochromatosis: No need to elaborate
- Lyme disease: “UGA Research Shows For the First Time That Lyme Disease Bacterium Does Not Require Iron To Infect Host”, 6/31/2000, University of Georgia

A simple summary of the 10 diseases listed: 5 have a direct relation to iron overload; while 3 are directly relation to iron-deficiency anemia; and sleep apnea has an indirect relationship via other related sleep disorders, like RLS. Ironically, it has been shown that unlike most other bacteria, iron has no effect on Lyme disease.

Nine out of ten of the most often missed diagnoses appear to be iron-related, either directly or indirectly. Although my internet search does not reach the same plateau as scientific research, it appears to me that these results would justify having a complete panel of iron blood tests conducted on patients as a matter of routine by first-line medical care providers – perhaps, not as frequently as a CBC, but definitely on an annual basis. It looks to me as if this is a good definition of a “twofer”; the same blood tests series that can help to diagnose either anemia or iron overload.