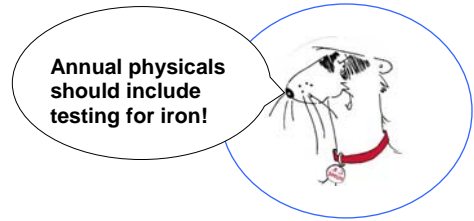


“Education is not the filling of a pail, but the lighting of a fire.”

William Butler Yeats, poet

id in Touch newsletter

IDI's way of keeping in touch with you!



JANUARY/FEBRUARY, 2007

IRON DISORDERS INSTITUTE

VOLUME 7, ISSUE 1

IDI ATTENDS ASH EXPOSITION

Orlando FL
December 9-12, 2006

Held annually in December, the American Society of Hematology (ASH) annual meeting provides hematologists from around the world a forum for discussing critical issues in hematology. More than 21,000 clinicians, scientists, and others attend the four-day meeting, which consists of a superb educational program and cutting-edge scientific sessions. The annual meeting features oral and poster presentations that are chosen by peer-reviewers from abstracts submitted prior to the meeting and contain the latest and most exciting developments in scientific research. Source: www.hematology.org



IDI Booth at the Orlando ASH Conference attended by **Cheryl Garrison** (l.) and **Sheila Dogan** (r.).

During the annual meeting, attendees can also visit the state-of-the-art exposition, which features exhibits from pharmaceutical companies, medical suppliers, clinical diagnostic and research-based companies, publishers, and nonprofit organizations. Iron Disorders Institute exhibited at this year's meeting, which enabled IDI staff and volunteers to make direct contact with 288 physicians. Each physician was given a copy of the IDI Physician Reference Charts and responded favorably about the content. All practicing physicians said that they would use the charts in their practice.



IDI's booth at the Orlando ASH Conference attended by **Darlene Mitchiner** (l.) and **Sheila Dogan** (r.)

The Society has over 14,000 members many of whom are hematologists or oncologists. ASH members are from all over the world with 77% of its members in the USA. The mission of the American Society of Hematology is to further the understanding, diagnosis, treatment, and prevention of disorders affecting the blood, bone marrow, and the immunologic, hemostatic and vascular systems, by promoting research, clinical care, education, training, and advocacy in hematology.

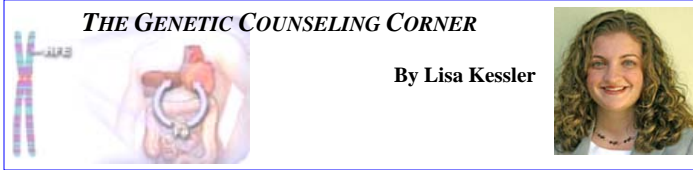
Visit the ASH web site to locate a physician specializing in hematology: <http://www.findahematologist.org>



Cheryl Garrison discussing iron overload with a physician during the Orlando ASH Conference.

THE GENETIC COUNSELING CORNER LISA KESSLER PAGE 2	GENETIC INFORMATION NONDISCRIMINATION ACT PAGE 2	STAFF & VOLUNTEER PROFILES SHEILA DOGAN & DARLENE MITCHINER PAGE 3	RAISING HEMOCHROMATOSIS AWARENESS CREATIVELY WENDY HUHN PAGE 4
IDI BOARDS: AN INSIGHT HIGHLIGHTS PAGE 6	SICKLE CELL DISEASE FAQ PAGE 8	2007 IRON-RELATED HEALTH EVENT CALENDAR PAGE 9	THE RUSTY CURMUDGEON SPEAKING OUT PAGE 10

IDI's mission is to reduce pain, suffering and unnecessary death by disorders of iron through education, awareness and facilitating research

THE GENETIC COUNSELING CORNER

By Lisa Kessler

SEEKING OUT GENETICS INFORMATION

In the January 8, 2007 issue of US News and World Report, genetic testing was the cover story. The article was titled [Unraveling Your DNA's Secrets: Do-it-yourself genetic tests promise to reveal your risk of coming down with a disease. But do they really deliver?](#)

<http://www.usnews.com/usnews/health/articles/061231/8genes.htm>

DNA Direct was one of 2 companies that offered genetic counseling with the testing services. As many of you know, interpreting genetic test results can be complex. Understanding lots of terminology like genes and mutations requires input from someone who can put these results in context for each individual such as a geneticist or genetic counselor.

The following describes some of the genetic counseling questions that have recently come up about hemochromatosis. For example, one common question is about what it means to be compound heterozygous. This means someone has one copy of 2 different mutations in their HFE genes, such as H63D and C282Y. Individuals with this test result have an increased risk to develop iron overload, but this result must be looked at in conjunction with other details such as their biochemical testing (i.e. percent transferrin saturation). For many, finding out that they have an increased risk for a particular disorder is different than finding out that they have that condition. This is where input from a genetic counselor can be helpful.

As we talked about in the last issue, genetics has implications for our family members, and a patient's genetic test results can impact our families. Finding out that you have 2 copies of the C282Y mutation generally means that you inherited one copy from your mother and one copy from your father. This tells us that they are each at least carriers for HH. This is another topic that frequently comes up in interpreting test results.

All of these questions lead me to think about where patients and their families go to find out genetic information. There are some great websites out there, and some were mentioned on the excess iron listserv this month. The DNA Direct website has some information about genes and HH as well:

http://www.dnadirect.com/resource/conditions/hfe/GH_Hemo_Genes_Cause.jsp

In addition, I am available to answer genetics questions, too. So, please feel free to contact me at 877-321-0077 or lkessler@dnadirect.com. We can all learn from each other.

Best Wishes for the New Year!

lkessler@dnadirect.com

Or

1-877-321-0077

*Lisa Kessler is a certified genetic counselor with DNA Direct;
<http://www.dnadirect.com>*

GENETIC INFORMATION NONDISCRIMINATION ACT

From: coalitiongeneticfairness@listserv.galists.org
Subject: **Time to move into high gear - Genetic Information Nondiscrimination Act**

January 17, 2007

Dear all,

This has got to be the most exciting year of the 12 years we have been working on genetic nondiscrimination - we see things happening quickly already, and expect the momentum to increase!

Last night the House introduced H.R. 493, with 143 cosponsors!

Today, President Bush toured the NIH and said:

I had a fantastic experience today with some smart docs talking about how they can use genetic research, which Francis will talk about, to create cures for a lot of diseases. We particularly focused on kidney cancer today. And I strongly believe that it makes sense for us to progress and take advantage of the research that the Human Genome Project has yielded.

However, I really want to make it clear to the Congress that I hope they pass legislation that makes genetic discrimination illegal. In other words, if a person is willing to share his or her genetic information, it is important that that information not be exploited in improper ways -- and Congress can pass good legislation to prevent that from happening. In other words, we want medical research to go forward without an individual fearing of personal discrimination.

We think that the Senate will introduce the same Bill (these are all identical to S. 306 and H.R. 1227) in the next few days and then pass it quickly as it has in previous Congresses.

We need you to sign up for the Coalition for Genetic Fairness right away - so that you can continue to be at the hub of all that is happening - we appreciate your support and want you to celebrate success with us this year!

To rejoin the Coalition, simply go to this URL:
<http://www.geneticfairness.org/registration.html>

Join us at the Coalition's 110th Congress inaugural meeting on January 25, in Washington, DC. We have invited the Bill's sponsors from both the House and the Senate to address us. We will strategize at the meeting. Go to here for information:
<http://www.geneticfairness.org/index.html>

You will receive a couple of action alerts from us shortly - we are working to increase the number of cosponsors in both the House and the Senate, and we will be getting letters from all of you to take to the Hill for our supporters to use on the floor.

Thanks so much - here we go - let's do it this year!

Sharon F. Terry, MA, LHD
President and CEO
Genetic Alliance
4301 Connecticut Avenue, NW,
Suite 404
Washington, DC 20008
Phone: 202.966.5557 x201
www.geneticalliance.org

Iron Disorders Institute National Headquarters Staff and Volunteers

IRON PROFILES

"What makes a person extraordinary? It's what they do, not how they're born"

Jody Williams, 1997 Nobel Peace Prize recipient

**Sheila Dogan,
Director, Minority Health Issues**



"Approximately 70,000 Americans have SCD and approximately 1,800 American babies are born with the disease each year"

Hi readers, my name **Sheila** and I am really excited to be a part of the Iron Disorders Institute. My role with IDI is to promote wellness by educating the minority community about Iron-Out-of-Balance™. My area of focus will be on any iron related illness or disease. Mainly now my area of concentration is on sickle cell iron overload.

As the Director of Minority Health Issues by goals are:

- To Increase awareness and provide an organized voice for sickle cell iron overload & African American siderosis patients in South Carolina
- To help the communities have a clear understanding of the signs and symptoms of the diseases through understandable language instead of technical jargon.
- To aggressively solicit funds from public and private sources to support the organization's sickle cell iron overload & African Americans siderosis prevention, treatments, cures and complications community education programs.
- To encourage the legislature to enact public policies, research funding, address racial and ethnic disparities in health care whether in insurance coverage, access, or quality of care for these diseases.
- To collaborate with local healthcare agencies to develop a tracking/monitoring system for statistical data pertaining to sickle cell, sickle cell iron overload & African American siderosis disease.

Questions often arise as to "**What is sickle cell disease?**" and "**How do sickle cell patients get iron overload?**" Please see side the bar on the page 8 for answers to these questions.

As a life long resident of South Carolina, I know that with the support of the community the above goals will be accomplished. Thanks in advance for your help and enjoy reading.

Finally, I would like to give a special thanks to **Conway Rice**, owner of the **Tire Corral** in Spartanburg for his generous donation to IDI.

**Darlene Mitchiner
Volunteer**



Darlene was a volunteer IDI representative at the American Society of Hematology. (See story on page 1.)

Darlene is a resident of Rutherford County, NC. She has worked in law enforcement for almost 11 years, where she first began her career as a

Correctional Officer. She is now a Probation/Parole Officer with the NC Division of Community Corrections. She is also a certified instructor in unarmed self-defense, pepper spray, and CPR.

Darlene became interested in Iron Disorder Institute after reading IDI's mission and realizing that she knows so many people who live with some form of iron disorder. Darlene stated that after attending the ASH Conference where she learned about all the needed work, she is now more eager now to help IDI achieve their mission by educating people of the importance of iron overload, early detection, and how to treat it, with special emphasis towards African Americans.

**Joe Wills
Volunteer**



"My awareness of hereditary hemochromatosis (HHC) sprang from an NPR program that caught my wife's ear in August 2000 and directly led to my self-diagnosis via the do-it-yourself services of HealthCheckUSA whose analysis of my DNA indicated an endowment of two

C282Y genes thus pinpointing the cause of my malaise. The steep learning curve that naturally ensued included the first two IDI conferences held in 2000 and 2001. My "new lease on life" motivated an adjustment of priorities that led to volunteer activities which include AmeriCorps and Habitat for Humanity in addition to IDI. I recently assisted IDI staff at the ASH conference in Orlando. (See story on page 1.)

I am engaged in a continuing personal renaissance which now focuses on the pursuit of a degree in building construction that will supplement my somewhat vintage degrees in engineering and business."

Raising Hemochromatosis Awareness Creatively

Editor's Note: Wendy Huhn's personal story was first published in IDI's magazine, *idInsight*, Winter issue 2001.



Wendy

Wendy Huhn had never heard of the word hemochromatosis, much less iron overload. Eight years after a complete hysterectomy, and during a routine gynecological exam, Wendy was told by her physician, **Dr. Jackie Barbour** that her serum ferritin was elevated. A year earlier in 1996, Dr. Barbour had measured serum ferritin and at that time, her ferritin levels were within normal range. One year later, in 1997 her ferritin was now elevated. Dr. Barbour told Wendy that she suspected hemochromatosis. Barbour explained that if not treated the consequences of hemochromatosis could be fatal.

"I can't repeat the first words out

my mouth," says Wendy. "But I will say that Dr. Barbour got my attention."

An assistant professor at the University of Oregon, Wendy knows her way around a medical library. Her husband Tom, a dentist was helpful directing her to respected scientific journals.

"I poured over publications like the New England Journal of Medicine, JAMA and any others that I could find. There just wasn't much reliable information in print about hemochromatosis." Wendy then turned her search to the Internet and found Iron Overload Diseases information helpful, but she still had questions

Meanwhile because of HMO restrictions Dr. Barbour had to refer Wendy back to her primary physician, **Dr. Kathleen Hirtz**, who had never had a hemochromatosis patient. Wendy was her first. In the best interest of her patient Dr. Hirtz referred Wendy to an internist, a specialist.

"The internist was perfectly awful!" Wendy describes her experience. "He immediately wanted to do a liver biopsy to confirm the diagnosis of hemochromatosis. I refused; he ordered more blood tests, but I have no idea what these were. It took weeks to get the results. I was furious. When he finally did call to say that I indeed had hemochromatosis, he commented that it (HHC) was '...not a big deal and nothing to get concerned about.' I told him in so many words that "...this is my life and it certainly was a big deal to me!" remarks Wendy. Then she adds, "I can understand how the internist might have thought I was not in any danger."

"He was still thinking about hemochromatosis as he learned about in med school. To him hemochromatosis was an older male's disease; the patient gets diabetes, bronze skin and liver disease or dies. Obviously, this didn't describe me. I had no symptoms; by his standards of knowledge, my ferritin of 373 and saturation percentage of 75% were not that high. Also, Mom and Dad were in their 80's and in good health. Doctors are looking for symptoms, abnormal blood-work and

"Hemochromatosis is not a blood disease; it is an inherited disorder of iron metabolism."

Dr. Michele Reyes, Former Hemochromatosis Team Leader, US Centers for Disease Control and Prevention

family history of disease. My levels were in fact, high enough to warrant phlebotomy, but lacking symptoms and family history, I didn't appear to be sick or in need of kind of therapy. I guess I wasn't the typical hemochromatosis patient profile," Wendy continues.

"If I had stopped with this doctor's casual attitude about my iron levels; however, I might be the sacrificial sibling of my family. I decided to take charge of my health. I fired the internist and eventually found a terrific physician."

Dr. Andrew Monticelli at the Willamette Valley Cancer Center in Springfield, OR began treating Wendy. He tested her genetically; she was positive for both mutations of C282Y. "Dr. Monticelli explained that I was a homozygote for this disorder and at highest risk for disease. He started me on phlebotomies. Initially I had trouble; my blood was so thick, it wouldn't flow. Dr. Monticelli's staff was simply wonderful. They sat with me during these uncomfortable phlebotomies, 'milking' the tube to try and draw out the blood. Eventually, they used a butterfly needle and this helped immensely."

Wendy has fibromyalgia, which she did not attribute to iron overload until now. She takes a non-narcotic prescription pain reliever and says it helps somewhat. She is not a smoker; eats meat in moderation, and no longer drinks, even casually.

"This is just part of my therapy. Sure, I used to enjoy a glass of wine now and then but giving that up to save my liver is a small sacrifice."

"What we put in our bodies is the one part of managing this condition that we can control."

Immediately after Wendy was given a suspect diagnosis of hemochromatosis from Dr. Barbour, Wendy contacted everyone in her family. She urged her two sisters **Leslie** and **Nancy** to talk with their doctor. Nancy was able to get a diagnosis right away and enrolled in a Kaiser Permanente study funded by the National Heart Lung and Blood Institute and The National Human Genome Research Institute. Nancy is a carrier of the C282Y mutation. She received



Nancy



Leslie

excellent counseling from **Roberta Foxley**, MS genetic counselor of Kaiser and knows to check her iron levels periodically.

Wendy's other sister, Leslie, who lives in Hawaii, spent 11 months trying to get a diagnosis. Even though her sister Wendy had a firm diagnosis of this inherited condition, Leslie could not persuade a physician to check her for hemochromatosis.

Once she located a physician to help her, Leslie found her numbers were almost identical to her sister Wendy. Her ferritin was 320 and her TS% 79%.

Teaching classes in surface design as far from home as Guatemala, and The Netherlands, Wendy is dedicated to educa-

Continued on the next page.

tion and art. She decided to use her love of education, her experience with iron overload and her talent as an artist to raise awareness about hemochromatosis. Her quilt “**Silent Killer**” was premiered at “Comments on The American 20th Century” at the Connell Gallery in Atlanta, GA, November, 1999. Details in her meticulous design all have meaning and were inspired by her experience with iron overload disease.

Her choice of the color pink was intended to represent blood cells; the clock and the bomb remind us that prevention of chronic disease from hemochromatosis is all about timing, early detection, that is. When undetected iron overload is a “time bomb” ready to destroy without notice. Wendy chose a female for her central subject because she feels physicians need to look for HHC in women and not take for granted that this disorder only shows up in men. Leeches, arms with tourniquets and a scattering of butterflies are all symbolic of therapeutic blood removal.



“**Silent Killer**”
1999

Handmade quilt by artist Wendy Huhn tells the story about iron overload disease.

“I see myself as a visual storyteller,” concludes Wendy. “The phrase ‘*chi non cera non trotra*’ I found in the book *Tick, Tick, Tick*, by **Roberta Crawford**; translation ‘he that does not seek does not find’, which is so very true with hemochromatosis. I spent a lot of time searching for information and trying to get educated about HHC. Today, people have the Iron Disorders Institute *Guide to Hemochromatosis* a comprehensive reference book written for patients and families. The Guide bibliography provides excellent scientific references for any physician interested in hemochromatosis.”

Visit Wendy’s website for other examples of her exceptional talent. <http://www.wendyhuhn.com>

To obtain a copy of *Tick, Tick, Tick*, contact Roberta Crawford at: Iron Overload Diseases; 433 Westwind Drive; North Palm Beach, FL 33408-5123.

To obtain a copy of the *Guide to Hemochromatosis*, telephone IDI at **864-292-1175**. Or visit the Iron Store at <http://www.irondisorders.org/Store>.

Editor’s Note: Wendy Huhn’s Dad passed away on November 28, 2006, surrounded by his family, at home. Wendy read this tribute to her father at the funeral.

THE FINAL LESSON

What I would like to talk about today is the final lesson my Father taught me. It is probably the most important thing I have ever learned.

It is not an easy subject to talk about and most people would rather not. The subject is dying.

Two months and 7 days ago Dad was diagnosed with primary liver cancer, his prognosis wasn’t good – 2-4 months to live. He used that time wisely making sure that his affairs were in order and that Mom would be all right

Dad said he felt he had lived a good life, had a great family and most of all spent 59 years married to the love of his life. Dad made his decision and Mom honored his choice to return home. Dad felt that with the help of Mom, family and hospice it would be the best way to die.

I will spare you the details of the past 2 months, as it was bittersweet. Dad was a good, no, a great patient, much to our surprise as he had a stubborn nature.

He handled all the indignities of a terminally ill person with such grace. He was always in good humor no matter how bad things got. He always had a funny comment during the most stressful of times.

I asked him if he found all this dying business scary; if he was afraid of dying.

He answered, “No I think it will be interesting.” And so it was.

During his final days he told me things that will stay in my heart forever.

The greatest gift my Father gave me was the privilege to participate in his passing. Dad showed me how to depart from this life with grace, dignity and humor. I don’t fear death now as I know it will be an “awfully big adventure.”

Thank you, Dad. I love you

**Your daughter,
Wendy**

SISTERS THREE UPDATE

Wendy has not needed a phlebotomy in 4 years because her ferritin level has stabilized.

Leslie, Wendy’s older sister continues to have phlebotomies every four months.

Nancy, Wendy’s younger sister does not have hemochromatosis, but is participating in a sibling study at Oregon Health Science University in Portland, OR.

IRON DISORDERS INSTITUTE'S BOARDS: AN INSIGHT

Headquarters, Greenville, SC
January, 2007

Iron Disorders Institute's (IDI) organizational structure consists of three boards at the organization's apex, which provide organizational and mission governance, scientific and medical literature oversight and research review.

Learn more about board members and their iron expertise by visiting <http://www.irondisorders.org/about.asp>

Board of Trustees

The Board of Trustees (BOT) is the governing board; the members set policy and assure that the IDI is able to carry out its mission.

Board members include:

Tim Roberson, Chairman

Chad Bortle

Tom Gallagher

Cheryl Garrison

Aran Gordon

Laura Main

George Whittenburg

Kris Kowdley, M.D.

University of Washington, Seattle, WA
Expert: **Liver**

John Longshore, Ph.D.

Carolina Medical Center, Charlotte, NC
Expert: **Laboratory Genetics**

Robert Means, M.D.

University of Kentucky
Expert: **Anemia of Chronic Disease**

David Meyers, M.D.

Kansas University College of Medicine
Expert: **Cardiology**

Mark Princell, M.D.

Spartanburg Regional Health Systems
Expert: **Occupational Therapy & Emergency Services**

Barry Skikne, M.D.

Kansas University Medical Center
Expert: **Iron Overload with Anemia**

Eugene Weinberg, Ph.D.

Indiana University
Expert: **Cancer and Infectious Disease**

Lewis Wesselius, M.D.

Mayo Clinic, Scottsdale, AZ
Expert: **Pulmonary Disease**

Mark Wurster, M.D.

Ohio State University
Expert: **Internal Medicine**

Scientific Advisory Board

The Scientific Advisory Board (SAB) members provide scientific and medical oversight of IDI's literature and serve as Directors of IDI Centers of Excellence (COE).

Presently IDI has one operating COE at Penn State University.

Board members include:

Herbert L. Bonkovsky, M.D., Chairman,
University of Connecticut Health Center
Expert: **Metabolic Disease**

Pradyumna D. Phatak, M.D., Vice-chairman,
Hematology/Oncology
Rochester General Hospital
University of Rochester
Expert: **Hematological Diseases**

Ann Aust, Ph.D.,
Utah State University
Expert: **Inhalation of Iron**

John Beard, Ph.D.,
Pennsylvania State University
Expert: **Nutrition**

George Bartzokis, M.D.
University of California, Los Angeles
Expert: **Brain Iron**

Arthur L. Caplan, Ph.D.
University of Pennsylvania
Expert: **Bioethics**

James R. Connor, Ph.D.
Penn State University
Expert: **Neurodegenerative Disease**

James Cook, M.D.
Kansas University Medical Center
Expert: **Anemia**

Joanne Jordan, M.D., M.P.H.
Thurston Arthritis Research Center
UNC Chapel Hill
Expert: **Arthritis**

Institutional Review Board

The Institutional Review Board (IRB) members review research funded by IDI to assure the protection of people who participate in the research projects. All IDI research activities that involve the public are reviewed by this board to assure the protection of human subjects.

In cases where the public may be involved but no invasive tests are conducted, the project can be exempted from review by the IRB Chairman.

Board members include:

Arthur Caplan, Ph.D., Chairman

Matt Anderson

Cheryl Garrison

Laura Main

Prad Phatak, M.D.

Melissa Robinson

Vera Tanner

Gene Weinberg, Ph.D.

George Whittenburg

See **Board Member Highlights**, next page.

IRON DISORDERS INSTITUTE BOARD MEMBER HIGHLIGHTS



Herbert L. Bonkovsky, M.D.
Chairman,
Scientific Advisory Board



Arthur L. Caplan, Ph.D.
Chairman,
Institutional Review
Board



James R. Connor, Ph.D.
Member,
Scientific Advisory
Board



P. D. Phatak, M.D.
Vice-chairman,
Scientific Advisory
Board



Tim Roberson
Chairman,
Board of Trustees

- **Dr. Herbert L. Bonkovsky** is Director, Liver-Biliary-Pancreatic Center at the University of Connecticut Health Center. He has served as Chairman of the IDI's Scientific Advisory Board for eight years. Read more about Dr. Bonkovsky at: <http://lbpcenter.uhc.edu/aboutus.htm>
- **Dr. Arthur I. Caplan** is the Chairman of IDI's Institutional Review Board. He writes a regular column for MSN. His commentary can be read at: <http://www.msnbc.msn.com/>. Read more about Dr. Caplan by visiting the University of Pennsylvania web site: <http://www.bioethics.upenn.edu/>
- **Dr. James R. Connor** is the Director of the IDI's Center of Excellence (COE) at Penn State University, where research is conducted to investigate iron's role in neurodegenerative disease. Read more about Dr. Connor's work on Penn State's web site: <http://www.hmc.psu.edu/neurosurgery/team/jconnor.htm>
- **Dr. Pradyumna D. Phatak** is Chief of Hematology/Oncology and Director of Oncology at the Lipson Cancer Center, Rochester General Hospital, Rochester, NY. He serving as Vice-chairman of IDI Scientific Advisory Board. Read more about Dr. Phatak at: http://www.viahealth.org/body_lipson.cfm?id=37
- **Tim Roberson** was recently elected as Chairman of IDI's Board of Trustees. Read more about Tim on IDI's web site at: <http://www.irondisorders.org/Board/TimRoberson.asp>

FACTS ABOUT OUR LIVER

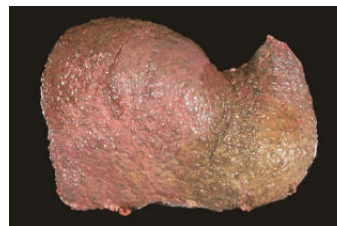
- When the liver loses its ability to make the protein albumin, water accumulates in the leg (edema) and abdomen (ascites).
- When the liver slows or stops production of the proteins needed for blood clotting, a person will bruise or bleed easily.
- Jaundice is a yellowing of the skin and eyes that occurs when the diseased liver does not absorb enough bilirubin.
- A damaged liver cannot remove toxins from the blood, causing them to accumulate in the blood and eventually the brain. There, toxins can dull mental functioning and cause personality changes, coma, and even death. Signs of the buildup of toxins in the brain include neglect of personal appearance, unresponsiveness, forgetfulness, trouble concentrating, or changes in sleep habits.
- If cirrhosis prevents bile from reaching the gallbladder, a person may develop gallstones.
- Bile products deposited in the skin may cause intense itching.



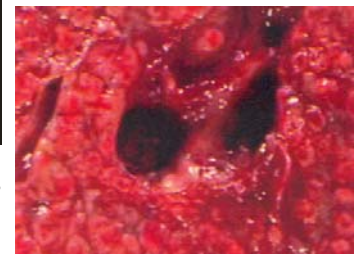
Healthy liver



A pre-hepatic alcoholic liver disease or "Fatty Liver" appears yellow in color and swollen



A cirrhotic liver due to alcohol consumption, with small nodules



Microscopic view of a cirrhotic liver

What is Sickle Cell Disease?

Sickle cell disease (SCD) is an inherited blood disorder that affects red blood cells and occurs mainly in the minority population. People with sickle cell disease have red blood cells that contain mostly hemoglobin* S, an abnormal type of hemoglobin. Sometimes these red blood cells become sickle-shaped (crescent shaped) and have difficulty passing through small blood vessels. When sickle-shaped cells block small blood vessels, less blood can reach that part of the body. Tissue that does not receive a normal blood flow eventually becomes damaged. This is what causes the complications of sickle cell disease. Approximately 70,000 Americans have SCD and approximately 1,800 American babies are born with the disease each year. SCD also is a global problem with close to 300,000 babies born annually with the disease. There is currently no universal cure for sickle cell disease.

How Do Sickle Cell Patients Get Iron Overload?

Patients with sickle cell disease get iron overload in two ways, chronic hemolysis or repeated blood transfusion.

1. Chronic hemolysis is the breakdown (destruction) of red blood cells. The sickle shaped cell cannot be used for hemoglobin, so the body destroys the misshapen cell. Iron from the destroyed cell is thrown back into the body and collects in organs such as the liver and the heart.

2. Blood transfusion is the therapy used to prevent and treat the complications of sickle cell disease. Blood transfusions help sickle cell disease patients by reducing recurrent pain crises, risk of stroke and other complications, but each unit of blood contains 250 milligrams of iron. The body has no way to get rid of the excess iron, so in time patients who receive repeated blood transfusions can accumulate iron in the body until it reaches toxic levels. Removal of the excess iron is done with medication that is specially formulated to remove iron from the body through a process called chelation.

Read about sickle cell anemia and iron chelation in our book, *Guide to Anemia* or on our Web site, www.irondisorders.org.

(Click on disorders and then on sickle cell anemia)

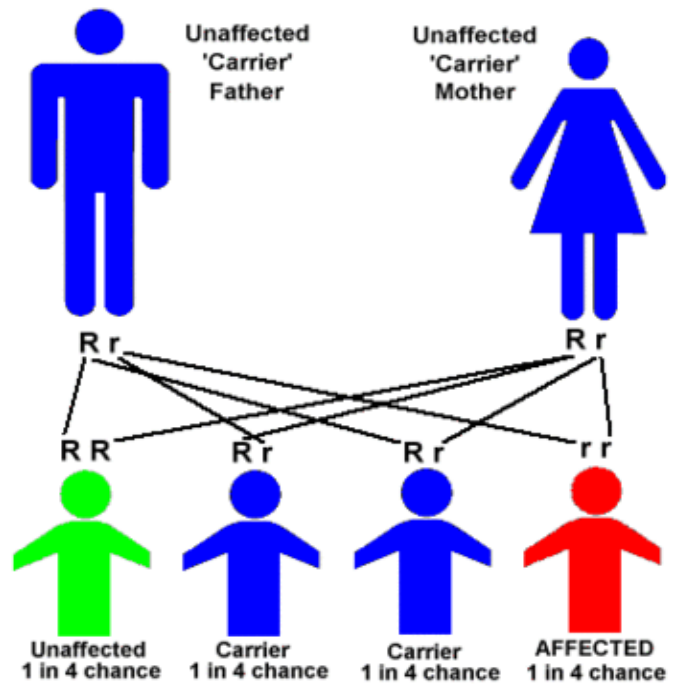
For more information on SCD, please contact:

Sheila Dogan,
 Director, Minority Health Issues
 Telephone: (864) 292-1175
 Email: sdogan@irondisorders.org

Or, visit the Sickle Cell Disease Association of America's (SCDAA) website: <http://www.sicklecelldisease.org/>

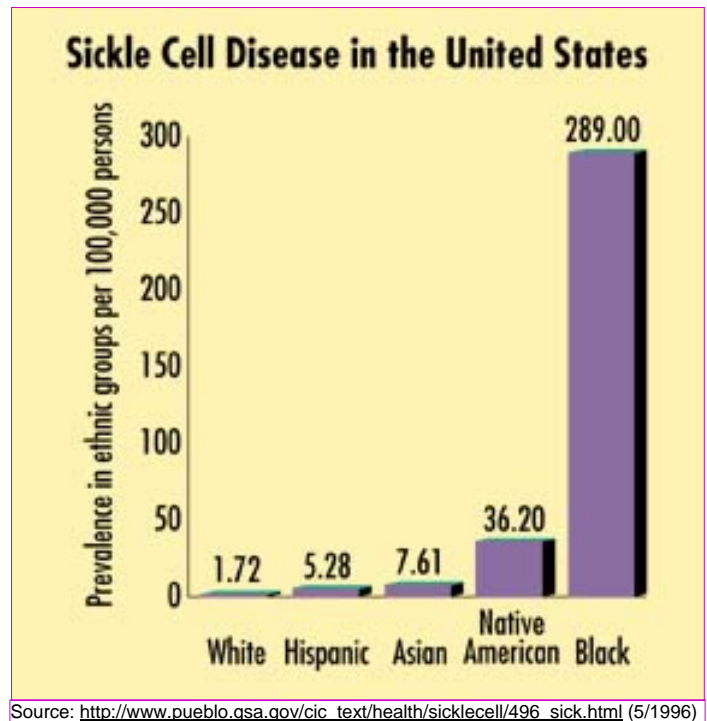


SICKLE CELL DISEASE INHERITANCE CHARACTERISTICS



Sickle-cell disease is inherited in the autosomal recessive pattern, depicted above.

Source: www.wikipedia.org



Consider donating to Iron Disorders Institute as a memorial to your loved one

You can obtain more information from our web site:

<http://www.irondisorders.org/Donate/>

Your contributions are fully tax-deductible to the amount allowed by law.

Iron Disorders Institute Health Observance Planner

2007 Iron-related Health Event Calendar *

January

S	M	T	W	T	F	S
	①	2	3	4	5	6
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January

- 1** Thyroid Awareness Month
- 8** National Folic Acid Awareness Week

February

- 1** American Heart Month
- 2** National Wear Red Day 2007
- 11** Cardiac Rehabilitation Week
- 14** National Donor Day
- 16** National Women's Heart Day
- 18** National Porphyria (PCT) Week

February

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March

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March

- 1** National Colorectal Cancer Awareness Month
- National Kidney Month
- National Nutrition Month®
- 27** American Diabetes Alert Day

April

- 1** Alcohol Awareness Month
- IBS (Irritable Bowel Syndrome) Awareness Month
- National Donate Life Month
- 2** National Public Health Week
- 5** National Alcohol Screening Day
- 15** National Volunteer Week
- 25** DNA Day

April

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May

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May

- 1** Better Sleep Month
- Clean Air Month
- National Osteoporosis Awareness and Prevention Month
- 13** National Alcohol- and Other Drug-Related Birth Defects Week
- 31** World No Tobacco Day

June

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June

- 3** National Cancer Survivors Day

July

- 1** Hemochromatosis Awareness Month
- TBD - Regional Iron Conference, Columbus, OH
- TBD - Regional Iron Conference, Greenville, SC
- TBD - Regional Iron Conference, Rochester, NY

July

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August

- 1** National Minority Donor Awareness Day

August

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September

- 1** Healthy Aging® Month
- National Food Safety Education Month
- National Pain Awareness Month
- National Sickle Cell Month
- Ovarian Cancer Awareness Month

September

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October

- 1** Healthy Lung Month
- National Celiac Awareness Month
- National Medical Librarians Month
- 5** Regional Iron Conference; Sacramento, CA
- 6** Regional Iron Conference; Sacramento, CA
- 24** Lung Health Day

October

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November

- 1** American Diabetes Month
- 15** Great American Smokeout
- 18** Gastroesophageal Reflux Disease Week

November

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December

- 1** National Aplastic Anemia and MDS Awareness Week

December

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TBD = Actual dates to be determined

* Marked dates indicate beginning of a period.

Source: <http://www.healthfinder.gov/>

Last updated on 2/7/2007

THE RUSTY CURMUDEON

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@irondisorders.org



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

Winston Churchill, *British statesman*

Speaking Out

Many of you are aware that I have genetic hemochromatosis, an iron overload disorder. In 1978, when I requested blood testing from a Navy doctor, his initial response was "You don't have any overt manifestations." I often see and hear similar experiences today from other patients. As a result, I've taken responsibility for becoming more knowledgeable about this insidious disorder, as many of you have also. If you haven't, I encourage you to do so. What has become increasingly obvious to me and many others also, is that blood tests for serum iron, total iron binding capacity (TIBC), and ferritin (stored iron) and are not routinely employed as a diagnostic tool. I'm convinced they should be, at least by age 18.

Iron is necessary to make the proteins hemoglobin and myoglobin. Hemoglobin binds with oxygen for delivery to all parts of the body, while myoglobin is used by our muscles for all of our movements, such as walking or running. Too little iron can result in anemia, while too much iron can result in severe morbidity, even death. What I have learned in the past twenty-nine years since being diagnosed is that balancing iron is not only fundamental, but essential to and necessary for good health, which begs the question, if iron is so important to life, why are medical providers not monitoring our iron levels?

For years after I was diagnosed, there was very little published in medical journals about iron overload, while many physicians clung to the now disproved myth that hemochromatosis was "an old man's disease." That's not to say that this particular myth doesn't rear its ugly head now and then.

"...if iron is so important to life, why are medical providers not monitoring our iron levels?"

However, the tide has turned. Today, medical science in all fields has shown, and published, that there is an unquestionable iron relationship to many diseases that were heretofore unknown. By comparison to my earlier attempts at locating information, this is a fantastic development. Iron overload is no longer considered an "old man's disease" by the majority of health care providers. Although, the available data about excess iron is often overwhelming to many patients, the message is clear. ***Excess iron can debilitate, even kill.***

In the [September/October newsletter](#), I pointed out that in a recent *Reader's Digest* article "10 Diseases Doctors Miss", 9 of the 10 diseases listed were iron-related. I can only assume that one of the reasons that doctors are not diagnosing these 9 diseases, and probably many more iron-related diseases, is that blood tests; such as TIBC and serum iron, are not routinely ordered by examining physicians. To a certain degree, I partially understand why these blood tests are infrequently requested: the symptoms of excess iron are similar to many other non-iron related medical problems; doctors' patient loads are often excessive; they are inundated with paperwork, which distracts from practicing medicine; and in many cases, doctors, are often looking for overt manifestations, rather than vague symptoms. However, there is likely another more pro-

found reason for the lack of iron testing – ***Government intervention compounded by government inflexibility!***

In the mid-nineties, the Health Care Finance Administration (HFCA) modified their reimbursement guidelines for the Medicare/Medicaid programs as a result of perceived overcharging by a few providers. Other insurers quickly followed suit. One of the unfortunate casualties of this policy change was iron testing. I can certainly appreciate HFCA auditing to ferret out improper billing and unnecessary procedures, indicating good stewardship of our tax dollars. On the other hand, auditing procedures should also exist to determine if current policy continues to be valid, which would suggest good stewardship of good health and prolonged life through more germane diagnostic testing.

Testing for iron is a case in point. The two iron blood tests are considered to be a "twofer." In other words, a single test can determine if either or both anemia and excess iron is present. Considering the humongous knowledge base that exists today, resulting from medical scientists' untiring efforts towards discovering the effect of iron and its relationship to a myriad of diseases and disorders, one would think that common sense would prevail allowing modification to this particular reimbursement policy.

Discounting the bureaucratic impact, this would seem to be relatively simple and sensible change yielding significant and positive results. I am not suggesting that iron testing be included with other existing blood testing like the notorious Executive Panel that caused iron testing to become collateral damage back in the mid-nineties, nor am I suggesting that iron testing be used diagnostically as frequently as the Complete Blood Count (CBC) is now used.

What I am suggesting is that iron testing (TIBC and serum iron) becomes a routine component of an annual physical, as a minimum and not less than every 18 months: simply another tool to monitor a patient's health progressively. The benefits are numerous.

For example, when doctors identify patients with slightly raised ferritin levels, they can recommend to the patient that they donate blood serving two purposes: provide an additional blood source for blood centers, and reduce their patient's risk associated with many of the iron-related diseases as identified in our available medical knowledge database. Additionally, a provider can delineate some of the risks associated with excess iron, much like what is done today regarding smoking.

Are there other benefits? Certainly! Lower iron levels are very important in maintaining good health.

Consider that ferritin is iron that your body is not using and is stored until you have an extreme need to create more red blood cells. Meanwhile, iron is stored in many of your vital organs, such as the heart, liver, pancreas, to name a few. An excess of stored iron has the capacity to destroy these organs. (Some would say rust.) The result may be liver cirrhosis, as one example.

Please see **Rusty** on the next page.

IRON DISORDERS INSTITUTE

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

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id-inTouch – online bi-monthly newsletter
iron bytes – repository for iron research
idInsight – journal

Books:

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Guide to Anemia
Cooking with Less Iron
Exposing the Hidden Dangers of Iron

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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

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Rusty continued from the previous page.

Thus, reducing iron to a balanced level or maintaining balance ferritin levels has the advantage of lowering the risk for many diseases, such as liver disease, in some instances reversing some or all of the associated debilitating effects. Medical science is now revealing that lower ferritin may also lower the risk for Alzheimer's disease. Other diseases include, but are not limited to diabetes and heart disease. Iron is usually removed from the body through bleeding.

Blood donation and phlebotomy therapy are the simplest and most economical methods for removing excess iron.

Please don't make the mistake that I am implying that iron is the root of all medical problems. I'm not! What I am saying is that the evidence indicates that a higher incidence of iron-related diseases is occurring that has only recently been recognized. Better testing and monitoring of serum iron and TIBC can only serve to identify the patient-at-risk earlier, justify the expense of testing for serum ferritin, and further reduce morbidity and death rates across the board.

To understand more about iron-related disease and increase your ability to communicate with your elected and government officials, along with your medical providers about the need for improving iron monitoring, visit the Iron Store and purchase IDI's *Guide to Hemochromatosis* and *Exposing the Hidden Dangers of Iron* by Eugene Weinberg, Ph.D.

<http://irondisorders.org/Store/>

AN ENLIGHTENED AUTHOR

I recently purchased several Clive Cussler novels at my local library's Friends of the Library book sale. While reading *Valhalla Rising*, I came across this very interesting paragraph:

"Thomas uttered a quiet laugh. "I'm sixty-five years old, Mr. Pitt. I have diabetes, acute arthritis, an iron overload disease called hemochromatosis, and cancer of both the pancreas and the liver. I'll be lucky to walk the earth five years from now. What would I do with a billion dollars?"

Josh Thomas, a minor character;
Valhalla Rising: A Dirk Pitt Novel;
 Clive Cussler; 2001

The author, Clive Cussler, is either very well versed in this metabolic disorder, or he, maybe someone in his family, has hemochromatosis. Then again, this may have simply been the result of good research for building a minor character.

Farcus

by David Waisglass
 Gordon Coulthart



"The doctor wants to run a few more blood tests."