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FAMILY-BASED DETECTION FOR HEMOCHROMATOSIS
 Headquarters, Greenville, SC

A hemochromatosis diagnosis identifies a patient who needs treatment and a family potentially at risk. Encouraging hemochromatosis patients to urge family members (blood relatives) to have biochemical tests for iron overload (fasting transferrin saturation and serum ferritin) is an important disease prevention opportunity. A patient who has hereditary hemochromatosis is often highly motivated to speak to family members about this preventable disease. Family-based detection is an efficient way to identify those who have an increased risk of developing hemochroma-

tosis, but it requires careful attention to patient confidentiality and preferences.

- Health care providers can facilitate family detection by counseling patients about the value of informing family members.
- A common approach is to give patients printed information about hemochromatosis and a letter for family members that will encourage them to be tested for iron overload by their regular health care providers.

The Center for Disease Control and Prevention (CDC) has more information about family-based detection.



FAMILY-BASED: PATIENTS AND THEIR FAMILIES
http://www.cdc.gov/hemochromatosis/training/family_detection/patients_and_families.htm



How can you get a Marathon Des Sables T-shirt?
 (See details, page 6)

NEXT ISSUE – MAY/JUNE, 2006

“Iron Patients – Their Own Stories” – The Nora Walker’ Story
“The Heart and Soul of Iron Disorders Institute” (See details, page 6)

PLAN NOW TO ATTEND!



May 18-19, 2006
National Institutes of Health, Bethesda, MD
“Achieving Iron Balance in Men and Women with Hemochromatosis”
 More details, column 3, page 5

The information provided in this newsletter is intended for your general knowledge only and is not a substitute for professional medical advice or treatment for specific medical conditions. You should NOT use this information to diagnose or treat a health problem, disease or disorder without consulting a qualified healthcare provider. Please consult your healthcare provider with any questions or concerns you may have regarding your condition.



Post Office Box 675
 Taylors, SC 29687

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

Place Stamp Here

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

IRON PATIENTS – THEIR OWN STORIES

“Education is the most powerful weapon which you can use to change the world.”

Nelson Mandela, Statesman



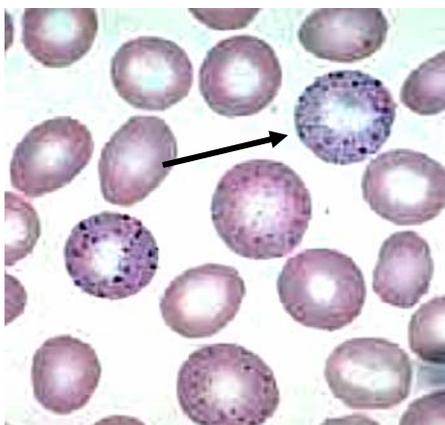
DONNA MARIE O'DONNELL

SIDEROBLASTIC ANEMIA AND HEMOCHROMATOSIS

In 1994, my primary doctor informed me from routine blood work that I was anemic and perhaps I should see a hematologist. I told myself, “What for? I feel fine. I’ll just make sure I’m taking my multi-vitamins with iron.”

Isn’t that the first thought for most people who are told they are anemic?

In 1996, a new primary care physician told me the same thing, as well as ordering a colonoscopy and further blood work. He concerned me enough to follow through. So began my journey into learning much more about anemia. My hematologist said that I had a sideroblastic anemia (SA), probably an “MDS”¹ of sorts. She also told me that I should stop taking iron because my ferritin was higher than normal. A subsequent bone marrow biopsy confirmed adequate iron stores in the marrow, “ringed sideroblasts” in the marrow, and all chromosomes in the marrow were fine. (Not fine would mean trouble). Thereafter, I saw my hematologist every 6 months and I was considered “stable”.



The bone marrow aspirate from a patient with sideroblastic anemia in this photomicrograph was stained with Perl's Prussian blue. The arrow indicates a normoblast with a greenish halo of material stained by Perl's Prussian blue surrounding the nucleus. Electron microscopic examination would show these to be iron-laden mitochondria.

In February, 2003, I was feeling much more tired than usual, so I called my hematologist. She had me come in to her office right away. There was a sig-

nificant drop in my hemoglobin (Hgb) and a rise in my Mean Corpuscular Volume (MCV). She ordered an iron panel, a hepatitis workup, and liver function studies. My ferritin had climbed to 600ng/mL, my percent transferrin saturation (Tsat %) was in the low 90's, and my hepatitis workup was totally negative. Also, my liver functions studies (LFT) and alpha-fetoprotein (AFP) blood tests were normal. I found out that I wasn't immune to hepatitis B, so I got a booster at my place of employment. (Good call – I'm a registered nurse).

My hematologist asked me if I'd ever heard of hemochromatosis (HHC), and that she'd like to run a DNA test, also recommending I have a liver MRI done. The DNA test confirmed I was a compound heterozygote with 2 gene mutations associated with HHC (C282Y/H63D). My liver MRI confirmed a significant amount of iron consistent with HHC. My hematologist recommended I see a gastroenterologist for consultation. I found one who recommended a liver biopsy. After much research, I was able to share with my hepatologist and hematologist information I obtained through IDI about the possibility to quantify liver iron content non-invasively through a SQUID² in Oakland, California. (See Liver and Tissue Iron Measurement Methodologies, page 8.)

To make a long story short, I had a significant amount of iron in my liver. Unable to do therapeutic phlebotomies due to anemia, I began iron chelation therapy with the drug Desferal®, which is kidney toxic. My anemia is also an iron-storing anemia, and I am NOT deficient in iron.

After 2 months of every night infusions, I had lost my appetite and was losing weight. We discontinued the Desferal® and tested my creatinine³, which had jumped 30%. After it normalized, I resumed the Desferal at 4 nights a week, and my creatinine has remained within normal range (WNL) range. I have also been on Procrit® injections since December, 2003 to stimulate my marrow to produce more red blood cells. It has been beneficial, keeping my Hgb above 10g/dL. I have my eyes examined

every 6 months now as well.

Family education has been paramount. Diet has been a priority, without going nuts. Sharing knowledge with my care providers has been empowering, and humbling. It's been quite a journey, one that I've gained so much from and hopefully can continue with a healthy, positively framed future.

Last April, I returned to Children's Hospital and Research Center (CHORI) in Oakland, CA for another SQUID. It measured a significantly lower amount of iron in my liver as compared to the previous year, and it was thought that I might be able to discontinue the Desferal® by the end of the year. When December rolled around, my Ferritin was down to 55ng/mL. After 18 months, I was able to discontinue Desferal treatment. I'm waiting to hear from my visit last week what my blood work looks like.

I hope to return to Oakland this coming spring for my 3rd SQUID, along with a liver MRI.

Meanwhile, I'm thriving.

DEFINITIONS

1. MDS: Myelodysplastic syndromes are a group of diseases in which the bone marrow does not make enough healthy blood cells. Normally, the bone marrow produces stem cells (immature cells) that develop into mature blood cells. In myelodysplastic syndromes, the stem cells do not mature into healthy red blood cells, white blood cells, or platelets. The immature blood cells, called blasts, do not function normally and either die in the bone marrow or soon after they enter the blood. This leaves less room for healthy white blood cells, red blood cells, and platelets to develop in the bone marrow. When there are fewer blood cells, infection, anemia, or easy bleeding may occur.

2. SQUID: The **S**uperconducting **Q**uantum **I**nterference **D**evice detection system combined with a superconducting magnet provides an accurate measurement of iron concentration in the liver and spleen for adults and children. (See more on SQUID, page 8.)

3. creatinine: A waste product of protein metabolism; It is excreted in the urine; measurements of excretion rates are used as diagnostic indicators of kidney function.

IRON PATIENTS – THEIR OWN STORIES

“Knowledge is to be acquired only by a corresponding experience.”

Henry David Thoreau, Author & Naturalist

“It never ceases to amaze me to hear physicians ask what Kelly and Sierra’s symptoms were. Don’t they get it?”

Linda Randall, Wife & Mother



THE RANDALL FAMILY’S JOURNEY WITH HEMOCHROMATOSIS

Our story began in June, 1997 when my husband was diagnosed with hereditary hemochromatosis (HHC). Little did I know that a journey beginning with fear and frustration would turn into one of purpose and determination?

Kelly was 43 years old and completely symptomless. We had decided to increase our life insurance coverage because of Kelly’s motorcycle riding, but were puzzled when the company denied us increased coverage due to elevated liver enzymes. Being the nagging wife that I am, I insisted that he follow up with a doctor. Upon his first visit with the doctor, he was told to quit drinking beer and return in one month. Seemed simple enough! After following doctor’s orders he returned to have the lab results come back the same.

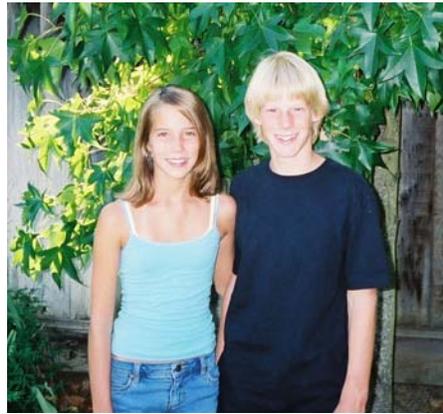
This time the doctor followed up by running more extensive labs and found his ferritin to be 2200. He ordered an ultrasound of Kelly’s liver, which showed enlargement, followed by a liver biopsy as he suspected the “rare disease” hereditary hemochromatosis. The biopsy confirmed iron overload. Kelly’s doctor referred him to a Hematologist to start phlebotomies. Kelly endured phlebotomies weekly for 1 ½ years until he reached a ferritin of less than 50. He maintains this level now by going for phlebotomies every 3 months.

Being a protective wife and mother, I asked Kelly’s primary physician, his gastroenterologist, and his hematologist if we should be concerned about our children as this was “hereditary”. The answer from all three was the same. They told us it was a “rare disease”, not common among women, and as long as I, the mother, didn’t have elevated iron levels that our children didn’t have it. I went along with that answer for awhile; after all, these were doctors telling me this.

Then one day as fate would have it, I read an article to Ann Landers from **Sandra Thomas** of the American Hemochromatosis Society, stating that HHC was more common than had been disclosed to me and that genetic testing

was available. Hmm, no one ever told me there was DNA testing for this. I decided maybe there was more to learn about HHC than I first thought.

As I started educating myself about the DNA testing and HH the more frightened I became for my children. I pursued the DNA testing for both of my



Sierra (CC) and Brendan (Bing) Randall

children and learned that my daughter, **Sierra**, who was four years old at the time was homozygous for the C282y gene and my son, **Brendan**, age 7 was heterozygous. Sierra’s iron levels, saturation, ferritin, and liver enzymes were all elevated but would not have been enough evidence to confirm HHC on their own. Once Sierra was diagnosed, panic set in. I found myself desperately trying to find foods without iron only to come home with empty grocery bags.

My desperation turned to hope when I joined the **Excess Iron List**. The education and advice I received started to calm my fears. The rest of my family members were tested but Kelly’s side of the family was less concerned and not very proactive. Some members were tested while others were given the same typical misinformation by their doctors that they had nothing to worry about. It is a battle I will continue to fight as I am sure there are cousins out there where HHC has reared its ugly mutation in.

People always ask whether I recommend the DNA testing and my answer

is “It is a very personal choice which can lead to insurance company discrimination, so give it careful thought.” In our own case, I’m glad I had it done as it was the only way to confirm Sierra’s diagnosis. Without those results, I doubt that I would have been allowed to have Sierra’s iron panels tested each year nor any phlebotomies. The insurance company and the doctors probably would have deemed them unnecessary. Truly a double-edged sword!

We had a wonderful pediatrician, **Dr. Robin Gilleland**, now retired, who was supportive and sent us to Children’s Hospital in Oakland, CA. Our first appointment was with **Drs. Elliott Vichinski** and **Paul Harmatz**, both very well versed in caring for iron overload because of the patients they treat for Thalassemia and Sickle Cell. When a liver biopsy was suggested for Sierra, I refused to take the risk with a child so young. From my education on the Excess Iron List, I had read enough to know that phlebotomies were going to be her treatment and she had a confirmed diagnosis through DNA. The two doctors at Children’s Hospital told me that the future hopefully would hold a new piece of equipment which could non-invasively scan the liver for iron. They said there was one in Germany and one non-working one in New York called a Ferritometer, sometimes called SQUID. I told them I would fly to the ends of the earth to prevent surgery on Sierra. With that response, they asked if we would help share our story and help raise funds for a Ferritometer of their own. Needing to raise 1 million dollars, Sierra’s story was used to show how children would benefit from this equipment. She was photographed for their calendar, and was even flown to San Diego where she was able to meet the inventors of the Ferritometer, an incredible group of people, including **Drs. Robert Fagaly** and **Roland Fischer**.

We spent the day learning about and observing the Ferritometer that would

Please see **Randall**, Page 6, column 3.

IRON DISORDERS INSTITUTE HONOR ROLL

"stars, in our eyes"



For the past 7 years, Iron Disorders Institute has honored two individuals for their unwavering support of IDI's mission. Annually, the Board of Trustees selects one lay person and one member of the scientific/medical community for their outstanding and unique contribution of time and effort during the past year towards advancing awareness of Iron-Out-of-Balance™. (Active Board members and IDI staff are not considered for either award.) Recipients of the "stars, in our eyes" award and "Making a Difference" award are generally announced each year at IDI's annual patient conference.

2006 recipients will be announced during IRON USA 2006 Medical Conference.

"Making a Difference"



Past Recipients of "stars, in our eyes" Awards

1999

Kristen Hill

Kristen, a television news reporter for WALB in Albany, GA, worked with Chris Kieffer, one of IDI's founders, on a four-part special about hemochromatosis, which was re-broadcast in television markets across the United States and in Mexico. Kristen's story is featured in the premiere issue of *id-In Touch* newsletter 1999.

2000

Bonne Ritter

As a result of her husband Jack's hemochromatosis, Bonne started the first support group in Pennsylvania where IDI volunteers such as John Haile and several doctors attended. She began modestly in her living room and saw participation increase. Bonne's story is featured the *Guide to Hemochromatosis* and in a 2002 issue of the newsletter.

2001

Dolores Foreman

Dolores is considered one of the pioneering women for HHC. Dolores and Bob lost their precious daughter, Rhonda, to juvenile hemochromatosis. Rhonda's complete diagnosis was made after the discovery of the hemojuvelin gene. Dolores has also accompanied doctors on "grand rounds" at University of Alabama at Birmingham (UAB) Hospital.

2002

Jim Hines

Jim has served on several IDI conference committees, providing technical assistance. He has contributed to the web content of both IDI's and IOD's web site. Jim is Editor of IDI's online newsletter, *id-in Touch*.

2003

Cheryl Mellan

Cheryl saw the importance of the Internet and online discussion as a way to offer patient support. She moderates the IDI Excess Iron Discussion list. Cheryl has been a positive influence and proactive in both her assistance at and contributions to several patient conferences.

2004

Missie Kendall

Missie edited and produced the first CD Rom about hemochromatosis on behalf of IDI and her sister Laura Main, who serves on IDI's board of Trustees.

2005

Chris Kieffer

Chris was selected for this award after retiring with ten years of service on the IDI's Board of Trustees. Chris was one of the founders of IDI. Her accomplishments are legendary. She served as IDI's first Executive Director, IDI Board of Trustees (1998-04), as President, Board of Trustees (2001-03), as President of International HHC Societies and as a speaker at the International Conference in Sydney, Australia. Chris's story is featured in the *Guide to Hemochromatosis* and the May/June 2005 issue of the online newsletter, *id-in Touch*.

Past Recipients of "Making a Difference" Awards

1999

Vincent Fellitti, M.D.

Dr. Fellitti was among the first to conduct US studies about hemochromatosis. As Director of Kaiser Permanente in San Diego, Dr. Fellitti established one of the first patient screening programs and was instrumental in the successful application of the hospital system's variance to use hemochromatotic blood for transfusional purposes.

2000

Corwin Q. Edwards, M.D.

Dr. Edwards was among first to conduct US studies about the prevalence of hemochromatosis providing physician education on this subject.

2001

Joseph DeStephano, M.D.

Dr. DeStephano was among the first physicians in upstate South Carolina to screen patients for hemochromatosis. He was responsible for identifying more than 30 families in one year.

2002

Tom Clayton, M.D.

Dr. Clayton founded and moderated the online Excess Iron List discussion list until he generously gifted the list to Iron Disorders Institute in 2002.

2003

Victor Herbert, M.D., J.D.

Awarded posthumously

Dr. Herbert's efforts to raise awareness about iron fortification of US foods are still recognized by the industry.

2004

Susan F. Leitman, M.D.**Charles D. Bolan, M.D., Col. (Retired), USA**

Dr. Leitman began the hemochromatosis protocol at the Warren G. Magnuson Clinical Center, National Institutes of Health as principle investigator. Dr. Bolan works closely with Dr. Leitman. Findings from this protocol helped substantiate IDI's recommendation against overbleeding the HHC patient. Both physicians give generously of their time to review publication articles, answer questions from the public, attend and present at IRONUSA conferences.

2005

Mark W. Wurster, M.D.

Dr. Wurster was one the first family practice physicians in the state of Ohio to establish a hemochromatosis screening and treatment program. Dr. Wurster developed the design whereby practitioners refer patients with abnormal iron indices to him. In turn he establishes the complete diagnosis of HHC; provides the patients with IDI literature, which they carry back to their primary physician for ongoing treatment. Dr. Wurster is the most recent member of the IDI's Scientific Advisory Board (SAB).

THE RUSTY CURMUDGEON

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

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

Winston Churchill, *British statesman*



"Jason's Gift — A Christmas Story" was a truly remarkable first person account of survival with a liver transplant necessary due to damage resulting from undiagnosed hemochromatosis. (See *id-in Touch*; January/February, 2006; page 3.)

Further reflection on John's and Jason's story raised several questions in my mind.

Could John Waldron's liver damage and resulting liver transplant have been prevented?

Of course, had his hemochromatosis been diagnosed much earlier in his life and his having been treated with therapeutic phlebotomies! I'm only preaching to the choir with this answer, as almost every who has been diagnosed with HHC is aware that this is indeed true. After 28 years of treatment, I can personally attest to the answer's validity. But the first question and obvious answer led me to consider another. I bet my bottom dollar that many of you have wondered the same!

What would be the cost difference between a liver transplant and a lifetime treatment of therapeutic phlebotomies?

According to Transplant Living (<http://www.transplantliving.org>) the estimated U.S. average total billed charges per liver transplant as of July 1, 2005, including transplant procurement, hospital, physician, evaluation, follow-up and immuno-suppressants costs is a majestic sum of \$392,800.

Earlier, the United Network for Organ Sharing (UNOS) (<http://www.unos.org/>) estimated first year charges and estimated follow-up charges for a liver transplant in 1996 dollars as a modest sum of \$336,500.

In 1995, the costs related to hemochromatosis at Kaiser Permanente in San Diego were informally studied by a Center for Disease Control and Prevention (CDC) medical economist who concluded that it costs us \$1,100 to diagnose a case. The analysis supposed that neither liver biopsy nor genetic analysis was used as a diagnostic method. Lifetime treatment cost was calculated at \$6,400 per patient. ("Hemochromatosis: A Common, Rarely Diagnosed Disease: Clinical

and Economic Benefits of Screening" Vincent J. Felitti, M.D.)

Comparing the UNOS cost estimate of \$336,500 for a liver transplant in 1996 dollars with Dr. Felitti's estimate by CDC economists of \$7,500 (diagnosis and treatment) in 1995 dollars, one can only conclude that there is a net difference of \$329,000. It doesn't take an economist to arrive at a similar conclusion.

I realize, of course, that using a liver transplant as a comparison to the standard treatment for hemochromatosis is an extreme case, but I would venture that a comparison of almost every other malady associated with iron overload would result similarly. They may not be as dramatic, but nevertheless there could be a significant savings.

By my calculations, this degree of savings could be redirected towards prevention of organ damage by diagnosing and treating more than 40 individuals with iron overload, using 1995/96 dollar estimates. I suspect that within this potential group of 40, there may be one or two that a similar transplant could be avoided; thus accruing additional savings.

But why, why is this happening?

The reasons are many and varied, which have been eloquently voiced before by patients repeatedly! One can only wonder sometimes, if anyone is even listening other than those affected directly. At least, the CDC has recognized, partially, the extent of the problem, along with several other medically oriented institutions.

In CDC's 2003 reported in *Genomics and Population Health: United States 2003*:

Patients reported that they saw an average of 5 physicians before receiving a diagnosis of hemochromatosis, on average 9.5 years after the onset of symptoms. Reducing this time lag by increasing physicians' awareness of the early symptoms of hemochromatosis is clearly an important disease prevention opportunity.

Iron Disorders Institute (IDI), and other non-profit health organizations, such as the Iron Overload Disease As-

sociation (IOD) and the American Hemochromatosis Society (AHS), in addition to several international organizations are making major inroads towards increasing awareness about the insidious effects of iron imbalances. There are moments when it seems as if this educational progress is extremely slow, as in one doctor, or one patient at a time. Still, it is progress, which is extremely important, and must continue. The educational tempo has to increase if we are to stand a chance of changing "sick-care" into true "health-care".

This requires more proactive participation by many more folks like YOU.

Get involved!

One way to become involved is to attend IDI's Patient and Physician's conference, IRON USA 2006 and network with involved patients, volunteers, scientists, and physicians.

IRONUSA 2006 is a seminar hosted by Iron Disorders Institute (IDI); it is open to the public, representatives of our government health agencies, public interest groups and members of IDI. This event brings investigators, clinicians, and patients together to inform and discuss diagnosis, treatment and management of Iron-Out-of-Balance™. IRONUSA features members of the Iron Disorders Institute Scientific Advisory Board and invited colleagues.

IRONUSA 2006, the main event is May 18th with a half day Friday, May 19th for patients and members of IDI. This year's focus is on **"Achieving Iron Balance in Men and Women with Hemochromatosis"**. Patients and physicians will have an opportunity to gain cutting edge information about hemochromatosis and to ask questions of experts in this field.

May 18-19, 2006



Visit www.irondisorders.org to register.

IRON PATIENTS – THEIR OWN STORIES

“Even as wisdom often comes from the mouths of babes, so does it often come from the mouths of old people. The golden rule is to test everything in the light of reason and experience, no matter from where it comes.”

Mohandas Gandhi, Soldier of Peace

PHYLLIS' STORY: THE CART BEFORE THE HORSE

An unusual family-based detection story submitted by the IDI Excess Iron Online Discussion List Moderator, Cheryl Mellan.

I was diagnosed with hemochromatosis in December of last year. I had given a child up for adoption in 1970 and found him in April of last year. One of his first questions to me was, “Have you ever heard of hemochromatosis?” Of course, I hadn't. He told me that he had been diagnosed with it in 2004 after having kidney stones and having blood work done. Thank goodness he had a smart doctor who knew about elevated liver enzymes and what that meant. My son told me about the disorder, and that I had to be at least a carrier for him to have it. I told him I would be checked.

I started having some right side pain in September and after being passed around between five different doctors who couldn't find out what was wrong with me, I finally decided to tell one of them to check my ferritin level. It was high, so we did the genetic test. So here I am. I feel that my birth son saved my life. All the doctors that I was going to were clueless. I'm sure that eventually one doctor would have hit on what was wrong with me, but who knows when.

I have had very painful feet for several years and my ankles sometimes hurt

badly. I can move my feet a certain way and the pain in my ankles sends me through the ceiling. Ouch! My knees and hips have just started giving me trouble. My pointer fingers and middle fingers are showing signs of arthritis. Some days they are painful but most of the time they don't bother me. I also have mild liver damage. I had a liver biopsy after I was diagnosed with HHC. The hepatologist called it fatty liver with mild fibrosis. My hepatic iron index was 5.0.

I had a hysterectomy when I was 33 so I have had quite a while to build up a good supply of iron in my body, me being 50 years old. I have been easily fatigued most of my life but I just thought I was lazy. I hate it that I have HHC, but I am glad that I am not just lazy.

This is all new to me and I sure appreciate having a place to come to and learn about the disorder from people who are going through what I am. I have been reading everything I can get my hands on but sometimes I feel so alone in all this.

Thanks for being here.

ARAN IS GOING TO “DO IT AGAIN.”

Yes, Aran is going to participate once again in the 2006 Marathon Des Sables in April. And you can support him and IDI in their effort to raise funds to provide educational materials to raise the awareness of Iron-Out-of-Balance™.

If you make a donation of **\$35 or more** to Iron Disorders Institute, you will receive a **FREE** Marathon des Sables T-Shirt. However, donations of any amount will be graciously accepted. Donations can be made on-line or by mail. (See page 8 on how to contact IDI.)

Visit IDI's web site where you can learn more about how Aran Gordon successfully overcame his battle with hemochromatosis and his achievement of finishing 373rd in a field of 777 participants in last year's grueling 245 kilometers (approximately 152 miles) marathon over an unbelievably hostile terrain. 

We, at IDI, are rooting for Aran to better himself this year. He departs for Morocco on Monday, April 3, 2006.

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

**THE HEART AND SOUL
OF
IRON DISORDERS INSTITUTE**

Beginning with the May/June, 2006 issue, this newsletter will initiate a new series portraying the altruistic character and noble spirit of the volunteers and staff who strongly believe that IDI's mission and their contributions of time and effort will overcome the trials and tribulations that many patients and their families have experienced to obtain a correct diagnosis with respect to an iron imbalance.

May/June, 2006 Issue

**“The Staff and Volunteers
of IDI Headquarters”**

Randall (continued from page 3.)

be sent to Torino, Italy where it now resides. Sierra met more PhD's, doctors, and scientists, than I had in a lifetime. Many extraordinary people were involved with the fundraising effort and today the dream has been realized – Children's Hospital now has their own Ferritometer, thus eliminating the need of liver biopsies for many. (See Liver and Tissue Iron Measurement Methodologies, page 8.)

Sierra had two phlebotomies when she was five with the help of Emla Cream, her “magic medicine” as she calls it. She didn't mind them at all. Sierra is now eleven and we monitor her levels annually. Her ferritin hangs around 26 and her saturation is 97%, a definite concern to us but we also know her body is using the iron differently than an adult's. There is still so much to learn about hereditary hemochromatosis, especially where children are concerned. We are very fortunate to have **Dr. Flanzbaum** as our pediatrician who is open to studying and learning.

One of my dear friends always states, “The universe meant for it to happen”, and I truly believe that now. Our HHC diagnosis has led us to meet wonderful people and let us hopefully contribute to saving lives. What a gift that is for us! Sierra and Brendan have both used every chance to help educate others by doing school reports and science projects on HHC.

It never ceases to amaze me to hear physicians ask what Kelly and Sierra's symptoms were. Don't they get it? Waiting for symptoms to appear can mean being too late in some cases. This always inspires me to speak up and share our story. If we all continue to inform those we can, our doctors, friends, family, blood banks, and teachers, hopefully HHC will be caught before it can adversely affect any more lives.

Editor's Note: “Chip” Randall's school science project, “Disease Project Report”, was published in the January/February, 2005 issue of *id-in Touch* in the column, “THE AWARE GENERATION.”

<http://www.irondisorders.org/Newsletter/jf05.pdf>

**Want One?
See column 1.**



Iron Disorders Institute Health Observance Planner

2006 Iron-related Event Calendar *

January						
S	M	T	W	T	F	S
①	2	3	4	5	6	7
8	⑨	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				

February						
S	M	T	W	T	F	S
			①	2	③	4
5	6	7	8	9	10	⑪
12	13	⑭	15	16	⑰	18
⑱	20	21	22	23	24	25
26	27	28				

March						
S	M	T	W	T	F	S
			①	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	⑳	29	30	31	

April						
S	M	T	W	T	F	S
2	③	4	5	⑥	7	8
9	10	11	12	13	14	15
⑱	17	⑱	19	20	21	22
23	24	⑳	26	27	28	29
30						

May						
S	M	T	W	T	F	S
	①	2	3	4	5	6
7	8	9	10	11	12	13
⑭	15	16	17	⑱	19	20
21	22	23	24	25	26	27
28	29	30	⑳			

June						
S	M	T	W	T	F	S
				1	2	3
④	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	

January

- 1 National Blood Donor Month
Thyroid Awareness Month
- 9 National Folic Acid Awareness Week

February

- 1 Heart Month
- 3 National Wear Red Day 2006
- 11 Cardiac Rehabilitation Week
- 14 National Donor Day
- 17 National Women's Heart Day
- 19 National Porphyria (PCT) Week

March

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

April

- 1 Alcohol Awareness Month
IBS (Irritable Bowel Syndrome) Awareness Month
National Donate Life Month
- 3 National Public Health Week
- 6 National Alcohol Screening Day
- 23 National Volunteer Week
- 25 DNA Day

May

- 1 Better Sleep Month
Clean Air Month
National Osteoporosis Awareness and Prevention Month
- 14 National Alcohol- and Other Drug-Related Birth Defects Week

May

- 18 IRON USA 2006 Medical Conference (2 days)
- 31 World No Tobacco Day

June

- 4 National Cancer Survivors Day

July

- 1 Hemochromatosis Awareness Month

August

- 1 National Minority Donor Awareness Day

September

- 1 Healthy Aging Month
National Food Safety Education Month
National Pain Awareness Month
National Sickle Cell Month

October

- 1 Healthy Lung Month
National Celiac Awareness Month
National Medical Librarians Month
- 25 Lung Health Day

November

- 1 (Gastroesophageal Reflux Disease)
American Diabetes Month
- 16 Great American Smokeout

December

- 1 National Aplastic Anemia and MDS Awareness Week

July						
S	M	T	W	T	F	S
						①
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9	10	11	12	13	14	15
16	17	18	19	20	21	22
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30	31					

August						
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September						
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October						
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22	23	24	⑳	26	27	28
29	30	31				

November						
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26	27	28	29	30		

December						
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						①
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24	25	26	27	28	29	30
31						

* Marked dates indicate beginning of a period.

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

Last updated on 3/9/2006

IRON DISORDERS INSTITUTE

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

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

Board of Trustees

Scientific Advisory Board

Institutional Review Board

OUR PUBLICATIONS:

Periodicals:

id-inTouch – online bi-monthly newsletter
nanograms – bi-monthly bulletin
iron bytes – repository for iron research
idInsight – quarterly magazine

Books:

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

OUR PROGRAMS:

July Hemochromatosis Awareness
IRONUSA Patient Conference
Patient Advocacy
Educational Materials
Patient Information Series
Physician Reference Charts
Personal Health Profile Booklet
Web Site – www.irondisorders.org
Patient Surveys
Youth Awareness Recognition

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

LIVER AND TISSUE IRON MEASUREMENT METHODOLOGIES

IDI Headquarters, Greenville, SC

The quantification and monitoring of tissue iron concentrations play important roles in the clinical management of patients with iron overload diseases such as thalassemia and hereditary hemochromatosis. Although blood tests such as serum ferritin and transferrin saturation are used for assessing the degree of iron overload in these patients, these tests can be confounded by factors such as the presence of infection and inflammation. In order to make a definitive measurement of the degree of iron overload, the widely accepted method has been chemical analysis of iron from liver needle biopsy specimens.

However, liver iron concentration (LIC) measurements by needle biopsy have several associated problems. Primarily there is a sampling error owing to the large variation in LIC from site to site within the liver. This error increases as iron loading increases. Secondly, liver needle biopsy is an unpleasant procedure for the patient and carries some degree of risk. These latter two factors limit the frequency with which measurements can be made. The Iron Disorders Institute Scientific Advisory Board does not recommend liver biopsy for patients whose serum ferritin is below 1,000ng/mL at the time of diagnosis.

A second, very accurate method of measuring iron is through a radiologic study performed by a machine called SQUID, the Superconducting Quantum Interference Device. The SQUID or Ferritometer devices, available from Triston Technologies, Inc. of San Diego, CA use magnetic fields to measure the

amount of iron stored in the liver.

The procedure is non-invasive and takes less than 15 minutes to complete. Non-invasive liver iron measurements are currently available at two locations in the United States: Columbia-New York Presbyterian in New York (SQUID) and Children's Hospital & Research Center (CHORI) in Oakland, California (Ferritometer). There is also Ferritometer equipment in Torino, Italy and Hamburg, Germany.

Editor's Note: Donna O'Donnell, (see page 2) and Linda Randall, (see page 3) have had iron assessments using the Ferritometer at CHORI. Both families were informed of the Ferritometer's existence by Cheryl Mellan, the moderator of IDI's Excess Iron List.

A third method is now available. FerriScan™ is a novel, non-invasive diagnostic test of the iron content of a patient's liver to assist clinicians in the detection and treatment of iron overload disorders such as thalassemia and hereditary haemochromatosis. This diagnostic test is available through Resonance Health Ltd, an Australian Healthcare company. The FerriScan™ diagnostic test service uses existing MRI (magnetic-resonance imaging) machines at radiology facilities worldwide which can be configured to provide a suitable scan of the liver that is subsequently analyzed at the centralized image analysis centre to quantify iron loading using proprietary software. The FerriScan™ test provides a safe alternative to liver biopsy and will become a valuable adjunct to gene testing for iron overload diseases.



The Biomagnetic Liver Susceptometer (BLS)
Source: Triston Technologies, Inc



Preventing Disease Caused by Iron-Out-of-Balance™

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

For program information, please contact IDI.

IMPORTANT METHODOLOGY LINKS

IDI Physician's Reference Chart

<http://www.irondisorders.org/Forms/phyref.pdf>

Triston Technologies, Inc.

<http://www.tristantech.com/>

Resonance Health Limited.

<http://www.resonancehealth.com>

<http://www.ferriscan.com>

Children's Hospital & Research Center

http://www.thalassemia.com/chelation_2.html