

stars in our eyes... MAKING A DIFFERENCE 2006 AWARDS PAGE 2	ADOLESCENT HEMOCHROMATOSIS KATE WALKER PAGE 3	IRON USA 2006 PICTORIAL PAGE 4 - 6	IRON USA 2006 HIGHLIGHTS PAGE 7	100 MILE CLUB DEBUT PAGE 7
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## HEMOCHROMATOSIS AWARENESS AND SCREENING MONTH

IDI Headquarters, Greenville, SC

July is **National Hemochromatosis Awareness and Screening Month**, noted on medical calendars\* throughout the USA, thanks to the efforts of **Dr. Margit Krikker**, who passed away August 2004. Her work continues with the help of IDI volunteers who are organizing activities ranging from patient workshops to distribution of books and the 2006 IDI **Physician Hemochromatosis Reference Chart**.

If you attended **IRONUSA 2006**, or you are a member of IDI you have already seen the new expanded 2006 chart. It is a real accomplishment and includes: a diagnosis algorithm, treatment options, phlebotomy frequency, diet, genetics, and our "at a glance" charts comparing different iron disorders. Thanks to educational grants, IDI can distribute these charts to your community for July Awareness Month, **FREE** of charge.

**How can you help?** Contact the Continuing Medical Education (CME) director at your local hospital(s); ask if he or she would write a letter to all the physicians working in their system and attach the reference chart. A sample letter might include the following:

Enclosed is a complimentary copy of 2006 Iron Disorders Institute **Physician Hemochromatosis Reference Guide**. Please consider screening for this potentially fatal condition by checking your patient's serum iron levels. If their iron levels are elevated, refer to the diagnosis algorithm in the "guide" to determine what additional tests and treatment may be necessary.

Send your request to Peggy Clark by email ([pclark@irondisorders.org](mailto:pclark@irondisorders.org)) indicating how many charts you need and your shipping address. It's easy and will help to spread the word. You may also ask for extra charts to provide to your local blood center or your own healthcare providers. There is no limit on how many you can request, but we do ask for a follow-up report with details. [Accompanying photos would be terrific!](#)

**HELP US TO RAISE YOUR CAREGIVERS' IRON AWARENESS!**

\* See IDI's Health Observance Planner in the March/April, 2006 newsletter.

**IRONUSA 2006 speaker presentations and associated audio will soon be available on our website.**

## JULY AWARENESS ACTIVITY IN CORDELE, GA

Cordele, GA

*"The number of people diagnosed in Cordele began with my husband Harry and has grown to more than 50! Out of a total population of about 11,000 in Cordele, we are ahead of the average 1 in 50. You can do the same in your town because I know that NO community escapes hemochromatosis. It is common and guaranteed to affect someone close to you."* Chris Kieffer, retired IDI Board of Trustees member and former President

July Hemochromatosis Awareness and Screening Month will be recognized here in Cordele for the 11th year by **Crisp Regional Hospital**, Cordele, GA. Each year the hospital advertises "Test of the Month" offered every Friday during the month of July. Testing is to check iron levels, which includes the transferrin-iron saturation percentage (TS%) and serum ferritin (SF) for \$25.00. A doctor's order is not required. Patients will receive their test results in the mail, which can be taken to their doctor for follow-up.

**Chris Kieffer** will help promote this event with the local media, where she is a celebrity as she is often referred to as the "**Iron-Lady**." Chris has also convinced local businesses to donate to IDI. The **Cordele Lions Club's** ongoing program has resulted in IDI books being donated on their behalf to the doctor's lounge at Crisp Regional Hospital. In addition, IDI's updated "**Physician Hemochromatosis Reference Chart**" will be put in each of the doctor's mail boxes at the hospital and a notice will be posted in their in-house computer message system.

### REGIONAL IDI WORKSHOPS SCHEDULED FOR THE FOLLOWING LOCATIONS

Facility	Location	Dates	Facilitator
Mary M. Gooley Hemophilia Center	Rochester NY	7/26/07	
Ann Arundel Blood Center	Rockville, MD	TBA*	Debbie Doss
Lexington Memorial Hospital	Columbia SC	TBA*	Cheryl Garrison
The Blood Connection	Greenville SC	TBA*	Cheryl Garrison
Licking Memorial Hospital	Newark, OH	TBA*	Laura Main

\*TBA – To be announced

**Check IDI's website frequently for workshop updates.**



## IRON DISORDERS INSTITUTE'S 2006 AWARDS

National Library of Medicine, Lister Hill Auditorium, Bethesda, MD

Each year Iron Disorders Institute recognizes outstanding volunteer effort with two awards: **Making a Difference**, and **stars in our eyes...**

The **"Making a Difference"** award is given to a medical doctor that has demonstrated outstanding efforts to educate the medical community about iron.

The **"stars in our eyes..."** award is given to a lay person who has made a unique contribution to the vision and mission of Iron Disorders Institute and especially to raise awareness about potentially deadly disorders of iron, such as hemochromatosis.

### Making a Difference

Drs. **David H. Lehman** and **Christopher J. Gresens** were both recognized with the 2006 "Making a Difference Award". Drs. Lehman and Gresens have demonstrated their dedication and willingness to work with Iron Disorders Institute by providing physicians throughout the local Northern Californian medical communities with IDI hemochromatosis educational materials.



**Dr. Lehman** is Board-certified, Internal Medicine and Rheumatology and has been in private practice in Sacramento, since 1976; he remains Caroline's physician.

His *curriculum vitae* include:

B.A., University of California, Berkeley, 1966  
M.D., University of California, San Francisco 1970

Internship, Yale University, New Haven, 1971  
Residency, University of California, San Diego 1972  
Fellowship, Scripps Clinic and Research Foundation, La Jolla, 1975  
Fellowship, University of California, San Francisco, 1976  
Chairman, Continuing Medical Education, Sutter Medical Center, 1987-1999  
Phi Beta Kappa, 1966  
Trudeau Award, California Thoracic Society, 1969  
Alpha Omega Alpha, 1970  
Humanitarian Award, Sacramento Arthritis Foundation, 1996  
Heroes in Healthcare Award, 1996  
Heroes in Healthcare, Lifetime Achievement Award, 1999



**Christopher J. Gresens, MD** is BloodSource's Medical Director of Clinical Operations. Dr. Gresens is a 1991 graduate of the UCLA School of Medicine. In 1996, he completed his internship and residency in pathology at UCLA Medical Center. He is board certified in Anatomic Pathology, Clinical Pathology, and Blood Banking/Transfusion Medicine, and is an experienced transfusion medicine special-

ist who has committed his career to ensuring that all patients within his practicing sphere have access to the highest quality blood products and related services available. He holds an assistant clinical professorship at the University of California, Davis School of Medicine, and directs BloodSource's medical education program for all visiting doctors-in-training.

Dedicated to improving international transfusion practice and blood safety, he also is director of BloodSource's International Services Department, which currently is fully funded by the Centers for Disease Control to assist four countries in



### stars in our eyes...

This year's award goes to **Caroline Alexander**, an Iron Disorders Institute volunteer from California.

Caroline graduated University of California (UC Davis) with degree in Human Development/BioScience; she was diagnosed with hereditary hemochromatosis in 1996 and remarks on the irony of her background in the sciences and medical field all the while HHC was unknowingly wreaking havoc with her health in the form of chronic fatigue and painful arthritis.



Caroline wanted to make certain that others would not have to wait until debilitating and painful symptoms were present before getting a complete diagnosis. She had enjoyed her career as a pharmaceutical representative, but chronic fatigue and painful hands had kept her from doing her job completely. Eventually she found a physician who correctly diagnosed her HHC.

Once diagnosed and with treatment underway, Caroline felt anger and frustration that HHC disease can be prevented with early diagnosis and treatment. She talked with her physician, **David Lehman** about helping her with physician education in California. There was no hesitation.

Caroline then recruited another physician **Dr. Chris Gresens**, medical director BloodSource; Sacramento, CA. Together these three began a concerted effort to raise awareness about HHC with physician education in the Sacramento area. With the help of IDI published materials, Caroline, Dr. Gresens and Dr. Lehman contacted hospital systems to schedule a CME credit presentation about hemochromatosis. Letters of invitation to colleagues were personally composed and signed by Dr. Gresens. Dr. Lehman presented the clinical aspects of HHC and Dr. Gresens presented the more technical material.

Among their successes was a broadcast of the program from the main Kaiser Hospital site to 13 satellite clinics throughout the Kaiser system. Nearly 200 practitioners participated. For the balance of the year 2005, this dedicated team made presentations at seven other hospitals in California further raising awareness. They continue this effort today, revisiting hospital systems by request or conquering new ground at other hospitals in the area. For this sustaining effort to raise awareness among the medical community,

sub-Saharan Africa and Guyana as they strive to improve the quality of their national blood banking systems.

We wish this team the very best and continued success to heighten awareness and improve early diagnosis and treatment of hemochromatosis. They serve as an inspiration to all of us striving for the same goal.

KATE WALKER

## ADOLESCENT HEMOCHROMATOSIS

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

When I read the invitation to submit personal stories to this newsletter, I thought it would be a perfect opportunity to share a story about the adolescent side of hereditary hemochromatosis (HHC). I have read many accounts of adults struggling to have this disorder diagnosed, and treated by doubting doctors who believe HHC is very rare. Let me tell you, the skepticism triples in the medical community when you start talking about iron overload in children. There seems to be a preconceived notion that iron loading can't begin before the age of 18, particularly in females.

*I have a feeling children are at least as under-diagnosed as adults, if not more so.*

My name is **Nora Walker**. I live with my husband **Pat** and daughter **Kate** in Langley, British Columbia, Canada. Our journey began about five years ago when I began to have some joint pain in my fingers, which was diagnosed as age related aches and pains – when tests for arthritis came back negative. Over the next couple of years I returned to the family doctor with various symptoms including fatigue, low thyroid function, pseudo gout and hair loss. Eventually I was referred to a dermatologist for the hair loss. He recommended an iron panel to see if anemia might be a factor.

The iron panel showed my ferritin was 502 and my saturation 44%. According to medical guidelines and protocols in British Columbia, “Serum ferritin is not a reliable screening test for iron overload because it may be nonspecifically elevated as an acute-phase reactant. It is useful only for monitoring response

to phlebotomy.” Further testing for hemochromatosis is only recommended when fasting transferrin iron saturation percentage (Tsat %) is consistently over 45%. It took a few months of testing for other possible causes before a genetic test was done in order to prove the elevated ferritin was not caused by HHC. I tested positive for a single C282Y mutation. In my doctors medical opinion a single mutation was not sufficient for a diagnosis of hemochromatosis for me, but he did recommend iron screening for my daughter, Kate. This recommendation turned out to be a potential life saver.

In August 2004 at the age of 15 Kate's iron panel showed her ferritin to be 601 and her saturation 52%. She was referred to an internist for genetic testing and official diagnosis. I have to mention this internist by name because he is perhaps the best doctor I have ever encountered. His name is **Dr. Barry Kassen** and he works at St. Paul's Hospital in Vancouver, B.C. He was extremely knowledgeable, thoughtful, caring and attentive during the diagnostic phase. Dr. Kassen thought it would be best to put her treatment in the hands of a pediatric hematologist once Kate's genetic testing revealed she was a C282Y homozygote. I wish Kate had remained in Dr. Kassen's care.

The pediatrician we saw two months later started our appointment by stating he had never treated HHC but did regularly treat children with iron overload acquired through transfusion. Most of the children he treated had iron levels much higher than Kate's and he wasn't convinced Kate's iron levels indicated a need for phlebotomies. In the time leading up to this appointment I had done a lot of reading and I was convinced that phlebotomies were necessary and the potential consequences of not doing them scared the living daylights out of me. In addition to my own research I had the benefit of the collective knowledge of the IDI discussion group. Cheryl Mellan, the group's moderator, was for me proof that angels do indeed walk among us on earth. I told this doctor everything I had learned and he was very dismissive, he said he would do another iron panel before considering treatment.

Kate was finally scheduled for her first phlebotomy at the end of November, 2004. Her first 3 phlebotomies did not go well. The phlebotomist's primary job involved autologous blood collection for children with impending surgeries; this meant every last drop of blood was a precious necessity. She was determined to get every last drop from Kate and if this meant moving the needle constantly, then so be it. I'm sure everyone reading who has given blood will shudder at the thought of constant needle adjustment during the procedure.

After 3 months of once a month blood withdrawals Kate and I had another face to face meeting with the pediatrician. I wanted to discuss the Mean Corpuscular Volume (MCV) method of de-ironing to learn what iron levels would be appropriate for Kate's age. I needed a goal. I was stunned to learn the pediatrician had not even looked at any of Kate's blood work until we entered his office, he had not decided, nor was he willing to tell me what an appropriate iron level might be. When I attempted to discuss anemia and or iron avidity with him he said he had never heard of “Iron Avidity” and anemia was not a concern for someone with HHC. The pediatrician suggested I find another doctor for Kate. For the first time, I was in total agreement with him.

I was unable to find a local doctor willing to take responsibility for Kate's de-ironing treatment; every doctor I spoke with felt something so “VERY RARE” should be treated by a specialist. There were a few interesting and sometimes humorous side comments such as “Gee, she really doesn't look very bronze.” I was amazed how many doctors were dubious of a hemochromatosis diagnosis without there being evidence of iron related damage. I explained to many doctors that waiting for organ damage before diagnosing HHC is a little like waiting for a coma before diagnosing diabetes.

We finally found a naturopath willing to try the MCV method of de-ironing. Much to Kate's relief his phlebotomist used a 20 gauge butterfly needle and syringes for the blood withdrawal. After

Please see **Walker**, page 8 Column 2.



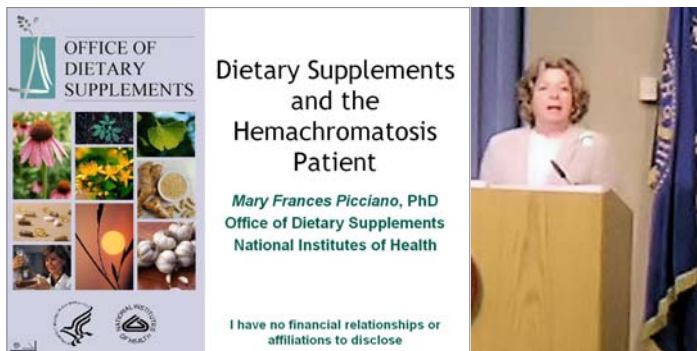


**IRON USA 2006 PICTORIAL**

**IDI's 4<sup>th</sup> Bi-annual Medical Conference**

*"Achieving Iron Balance in Men and Women with Hemochromatosis"*

**Thursday, 11:00 a.m.** Mary Francis Picciano, Ph.D. provided attendees with a bit of humor *"Is it a food or dietary supplement?"* Supplements **ARE** regulated. She recommending that we shop for known and trusted brands. Dr. Picciano incorporated IDI's recommendations for a daily multi-vitamin, which includes limiting vitamin A to ~3,500 IU because high doses of vitamin A can potentially damage to the liver.



**NOTICE:** Speaker presentations and audio from the **IRONUSA 2006** Medical conference will **SOON** be available on-line.

**Heath-care Providers**  
**Visit IDI's web site to see how you may earn**  
**Continuing Medical Education Credits (CME)**

▼ **Thursday, 1:30 p.m.** Professor Gene Weinberg provided an in-depth view of the impact that human pathogens have on the human body through their use of iron.



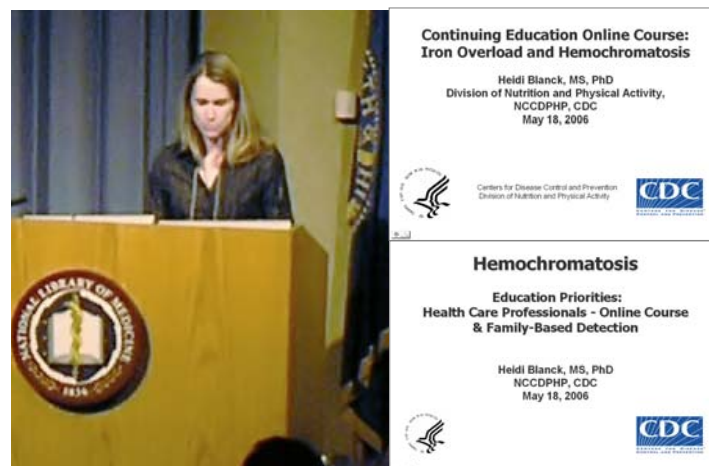
▲ **Thursday, 3:00 p.m.** Aran Gordon pointed out that not everyone is a candidate for a marathon. He encouraged HHC patients to take on small activity projects such as walking. He chose the Marathon Des Sables because it was (and is) the toughest race to complete.

Attendees' Evaluation Comments

**"Hope the California meeting becomes a reality, but I will come wherever you are!!!!"**

**"Very useful information!"**

**Thursday, 11:40 a.m.** Heidi Blanck, Ph.D. presents CDC's views on hemochromatosis. In addition, Dr. Blanck explained the availability of Continuing Medical Education (CME) credits on CDC's website, encouraging healthcare providers to take advantage of the on-line hemochromatosis education program. The on-line training is available to patients, also.



▼ **Thursday, 2:00 p.m.**  
**"Compound Heterozygotes: More Common, Less Understood."**

Eric Gregory elaborated on his observations regarding manifestations of morbidity with compound heterozygotes (H63d/Cy282). He noted that this is truly anecdotal medicine based on his own experiences but that there appear to be trends that require further medical investigations

His main points were:

1. Medical problems associated with iron overload seem to appear at an earlier age and with different manifestations than with homozygotes. They are often ignored because they are not acute, but more chronic in nature.
2. Additionally, these medical problems appear to occur with lower iron levels than similar conditions occur in homozygotes.
3. Progression seems to continue regardless of iron management intervention.



**IRONUSA 2006 was sponsored by:**  
**Iron Disorders Institute (IDI);**  
**National Heart, Lung and Blood Institute (NHLBI);**  
**U.S. Centers for Disease Control and Prevention (CDC);**  
**American Board of Quality Assurance; and**  
**Utilization Review Physicians**

**IRON USA 2006 PICTORIAL**

**IDI's 4<sup>th</sup> Bi-annual Medical Conference**

*"Achieving Iron Balance in Men and Women with Hemochromatosis"*

**Thursday, 3:45 p.m.**

**Award Announcements**

Recipients of this year's awards "Making a Difference" and "stars in our eyes..." were announced. (See page 2.)

**Certificates of Appreciation**

Volunteers who assisted with making this year's conference a success were presented with Certificates of Appreciation by IDI's Executive Director, Cheryl Garrison:

- |                      |                     |
|----------------------|---------------------|
| <b>Faye Bass</b>     | <b>Deb Doss</b>     |
| <b>Jim Hines</b>     | <b>Dave Kitzman</b> |
| <b>Art Smith</b>     | <b>Lorrie Smith</b> |
| <b>Fran Weinberg</b> |                     |



▲ **Thursday, 3:45 p.m.** Cheryl Garrison, IDI's Executive Director, delivers the 2005 "Making a Difference" award to Mark Wurster, M.D., Ohio State University. (From left) Chad Bortle, HHC patient; Cheryl Garrison; Dr. Mark Wurster; and Laura Main, IDI Board of Trustees member.

**Special Thanks**

IRONUSA 2006 Conference photos contributed by

**Lorrie Smith**

**Friday, 8:30 a. m.** P.D. Phatak, M.D. presented clear comparisons of different chelators in treating iron overload. **NOTE:** Dr. Phatak's presentation will be used for a web-based physician education module.



**Use of Iron Chelators in Iron Overload**

Prad Phatak MD FACP  
May 19<sup>th</sup> 2006

**Noninvasive Measurement of Liver Iron Content**

Kris V. Kowdley MD  
University of Washington  
Seattle, WA



▲ **Friday, 9:10 a.m.** Kris Kowdley, M.D. presented an enlightening comparison of technology used to measure liver iron content without invasive procedures. **NOTE:** Dr. Kowdley's presentation will be used for a web-based physician education module.

**NATIONAL LIBRARY OF MEDICINE  
LISTER HILL CENTER**



▲ **Friday, 9:45 a.m.** Forum: Discussion of Iron-Out-of-Balance™ as a Risk Factor for Acute and Chronic Disease. (From left to right) Vera Tanner, facilitator; Panel: Scientific Advisory Board members, Eugene Weinberg, Ph.D., Chair, Publications; Mark Wurster, M.D., Chair, Physician Material Review; P.D. Phatak, M.D. Vice Chair, IDI's SAB and Conference Chair.

**Common Sense**

A Simple Strategy for Iron Balance

Jim Hines, HHC Patient



▲ **Friday, 9:45 a.m. Guest Center:** Jim Hines relates his 27 year's experience of undergoing phlebotomy treatment for hemochromatosis. In his opinion, "...it's simply a matter of applying common sense."

**"I have terrible veins and really appreciated knowing about the tips of how to access veins"**

**Tim Roberson**  
IDI Board of Trustees Member

**IRON USA 2006 HIGHLIGHTS****IDI's 4<sup>th</sup> Bi-annual Medical Conference**

*"Achieving Iron Balance in Men and Women with Hemochromatosis"*

**IRONUSA 2006 Attendance****40%**

The percentage of  
healthcare providers\*

**60%**

The percentage of  
patients and family  
members

\* includes physicians, physicians assistants, nurses, phlebotomists, and dieticians.

**How did you first learn of hemochromatosis?****28%**..... from another patient**14%**..... from a family member**10%**..... from the internet**10%**..... from a colleague (MD)**21%**..... from medical school**How long have you known about hemochromatosis?****82%**

Had "years" of  
knowledge

**5%**

Had only recently  
heard about it

**What prompted you to attend IRONUSA 2006?****24%**..... have patients with HHC**48%**..... patients diagnosed with HHC**21%**..... concern for a family member**7%**..... having difficulty with treatment**10%**..... for educational credits (CME)**What topic was most helpful?**

**Highest Individual  
Scores**

HHC – Dr. Wurster  
Supplements – Dr. Picciano

**Overall - 41%**

"All" of the pres-  
entations were  
helpful

**100-MILE CLUB DEBUT**

By Erika Spinelli

As a fitness instructor teaching 12 classes a week, **Monica Brummer** knew the pain and exhaustion she was experiencing was well beyond her realm of daily physical activity.



**Monica Brummer  
and her son, Alex**

A trip to her nurse practitioner resulted in a prescription for anti-depressants, which only worsened her symptoms, making her more tired, depressed, and unable to function as she knew she was capable.

"It's frustrating because, as a fitness instructor, everyone assumes that I know how to eat right, and that I'm healthy and in optimal shape," she said. "And I'm the worst eater. I love Doritos and tea, and with a four-year-

old, everything's eaten on the run."

She took advantage of her insurance company's offer of a full blood panel test, which showed high levels of iron. She made a note of it, but continued for several more months on the same course, experiencing more pain and exhaustion. She returned to the nurse, who reviewed her blood test results. Immediately the nurse recognized the symptoms coupled with the test results and diagnosed her with hemochromatosis. Monica hadn't even heard of it. The nurse told her to do some internet research on the condition, and not to be scared, but warned her that what she read would be true.

Thinking back, Monica recalled the life and death of her grandmother. When surgeons operated on her colon cancer, they discovered damaged and non-functioning kidneys, and the family thought back to their jokes about her hidden Indian heritage in relation to her dark skin color; Monica deduced the classic symptoms of undiagnosed hemochromatosis. Even Monica had noticed in her own blood work through the years that her iron level was high, but had never paid it much attention.

Just before Christmas 2005 she received the official diagnosis, and has been adjusting to a new diet, a new exercise regimen, and a new treatment plan. She and her family are learning to eat healthier; she's cut down on her teaching schedule and slows down when her body talks to her through aches and pains; and she puts into perspective her now monthly phlebotomy procedures.

"I don't beat myself up anymore," she said. "I know why I'm tired and sore and I pull back...and I know I have no right to complain. I'm seeing an oncologist for my monthly phlebotomies, and most of the other patients are there for chemotherapy. It helps me keep things in perspective."

Monica is also using her experience and enthusiasm for exercise to encourage others with chronic conditions to utilize exercise as a means to improve their overall health. Her "100-Mile Club" began, however, with a group of preschool moms she meets with monthly.

"As a mom of a preschooler, you never have time for yourself," she said. "But being a fit mom can make you a better and definitely healthier mom."

So she encouraged her friends to start exercising, and developed a tracking system for them. Every 20 minutes of exercise – cycling, weights, walking and aerobics – earns one mile.

Please see **100-mile Club**, page 8 Column 3.



## 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](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:** [www.irondisorders.org](http://www.irondisorders.org)

## OUR EMAIL:

General Support:

[PatientServices@irondisorders.org](mailto:PatientServices@irondisorders.org)

Printed Materials Assistance:

[Publications@irondisorders.org](mailto:Publications@irondisorders.org)

Member Support:

[Membership@irondisorders.org](mailto:Membership@irondisorders.org)

General Comments:

[comments@irondisorders.org](mailto:comments@irondisorders.org)

## OUR EDITORIAL STAFF:

Jim Hines, Editor

[jedwhines@cox.net](mailto:jedwhines@cox.net)

Peggy Clark, Circulation

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

**Walker** (continued from page 3.)

a few phlebotomies six weeks apart Kate's blood work revealed an MCV drop from 93 to 89; we stopped blood withdrawals and her next iron panel showed her ferritin had dropped to 77 her saturation to 42%. Because there is no medical literature to indicate an appropriate maintenance level for an adolescent, we decided to let the drop in MCV values be our guiding factor. All of Kate's blood values were well within reference ranges, and we hoped 77 was the appropriate amount of ferritin for her current needs.

Kate has a standing order at the local blood lab for an iron panel every 3 months. She does slowly load additional iron, but she is now 17 and is eligible to donate blood to the blood bank so there is no need for doctor authorized phlebotomies. For the moment we feel aware of enough basic information to be comfortable proceeding into maintenance with confidence instead of fear.

I am a strong believer that an ounce of prevention is worth a pound of cure, and I would recommend iron panels for all children of hemochromatosis patients. I have a feeling children are at least as under-diagnosed as adults, if not more so.

**100-mile Club** (continued from page 7.)

Monica tracked the miles for the group over the winter, and soon they had collectively exercised more than 2,000 miles.

"I thought, WOW! Think if we could get paid 10 cents for every mile we exercised," she said. "We could raise a lot of money."

She uses the financial equivalent as a motivator for her moms, and now for hemochromatosis patients through the Iron Disorders Institute. No money changes hands – yet – but it's a great motivator, she said.

"The money comparison just helps to put it in perspective," she said. "It's just another way to look at what you've accomplished and not focus so much on the scale."

Monica is hoping more Iron Disorders members will participate in the "100-mile Club" through the website. Her goal is to encourage others to exercise, however and whenever they can.

"I've enjoyed reaching out to the hemochromatosis patients who've emailed me," she said. "Exercise just makes you feel better when you're facing all this stuff. I don't even care about the miles...I just hope people get up and get moving."

Look for more details on the 100-mile Club this fall on the Iron Disorders Institute website.

### **SPECIAL NOTICE**

#### **Hemochromatosis Support Group**

Iron Disorders Institute will hold its first Hemochromatosis Support Group meeting July 25th, 7-8:00 p.m. at IDI Headquarters, 2722 Wade Hampton Boulevard, Greenville, SC.

**Lauren Smith-Nagle** will facilitate; she has offered to establish this first model in Greenville, which will become available to other communities interested in having a local support group.

The model will include purpose and expected outcomes.



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.

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.

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