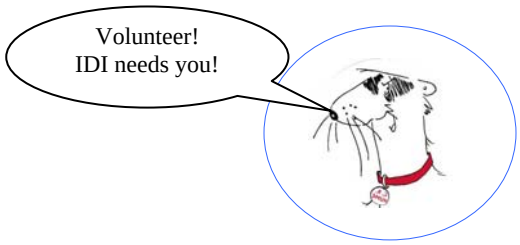
*Service to others is the rent you pay for your room here on earth.*

Muhammad Ali, *boxer*


# id in Touch newsletter

*IDI's way of keeping in touch with you!*



JULY/AUGUST, 2006 | IRON DISORDERS INSTITUTE | VOLUME 6, ISSUE 4




## A TRIBUTE TO *id-in Touch's* UNSUNG VOLUNTEERS

***There is no higher religion than human service. To work for the common good is the greatest creed.***

Woodrow Wilson, *28th president of US (1856 - 1924)*

### COLUMNISTS

**L. to r.** Dick Blum, David Garrison, Chris Kieffer & Sylvia Ross

**Dick Blum**

Dick graciously assumed responsibility for keeping IDI Ambassadors informed of support programs available for the purpose of spreading the word about IDI's mission in the column, "Ambassadors' Corner."

**David Garrison**

David explained the inner workings of patient services provided by IDI in his column titled, "Patient Services." The information he provided enabled iron patients and their families to obtain the latest information about hemochromatosis and other disease or disorders related to Iron-Out-of-Balance™.

**Chris Kieffer**

Chris, in her column, "Reaching Out," was the impetus behind an outpouring of support for Vester Cox while he was waiting for a liver transplant. Chris also related her various success stories in getting several national organizations; such as the American Society of Hematology, to be more aware of iron as a significant detrimental factor to health.

**Sylvia Ross**

Sylvia contributed considerable information of interest to patients in the "National Physician Registry Update" column. She did more than simply outline the Physician's Registry; she also introduced iron-related subjects that were dear to many patients of iron imbalance.

### COMMUNITY ACTIVISTS

Top l. to r. Caroline Alexander, Rita Berasley & Aran Gordon
Bot. l. to r. Margaret Kennedy, Chris Kieffer, Laura Main & Jody Williams

**Caroline Alexander**

Caroline's efforts to encourage her doctor, Dr. David Lehman and Dr. Chris Gresens, Medical Director BloodSource; Sacramento, CA to raise iron awareness through physician education resulted in a very successful program.

**Rita Berasley**

Not only did Rita establish an Iron Disorders Institute booth at the Manatee County, FL health fair, but she contributed a great story about her experience in such a way that anyone could duplicate her method.


See **Tribute** continued on next page.

**Tribute** (continued from previous page.)

**Aran Gordon**

Aran has raised the international community's awareness of iron through his visibility of competing in not one, but two *Marathon Des Sables* marathons. Aran is also President of IDI's Board of Trustees.

**Margaret Kennedy**

Margaret presented a workshop on iron and arthritis to nurses in her North Carolina community. Her presentation was co-branded with the Arthritis Foundation. Her personal experience with HHC and arthritis was portrayed in the IDI's magazine, *idInsight*, Spring 2004.

**Chris Kieffer**

Chris actively instigated and participated, along with her husband, Harry, in conjunction with the Lions Club and Crisp Regional Hospital to conduct FREE iron testing in her community. This free testing has been ongoing for eleven years in her community of Cordele, GA.

**Laura Main**

In addition to Laura's many other endeavors involving iron awareness, Laura has been instrumental in ensuring IDI has a place in health fairs conducted both at the Licking Memorial Hospital, Newark, OH and Ohio State University. Laura is a member of IDI's Board of Trustees.

**Jody Williams**

Jody has been working with the Blood Centers of the Pacific to increase awareness of their services (and HHC) within Northern California.

## PATIENTS

**Editor's Note: The date following each contributors' name is a link to the online issue of id-in Touch at IDI's web site containing their respective story. To view each experience, click on the link.**

**Caroline Alexander**; Jan/Feb '05, p5
Carol explained how she has had to deal with severe arthritis as a result of hemochromatosis.

**Phyllis Brady**; Mar/Apr '06, p6
Phyllis has a unique story how her son was first diagnosed with hemochromatosis and was subsequently able to inform her about HHC.

**Joe Brinkley** (See page 8 in this issue.)
Joe's story brings to light the possible association between hemochromatosis and the gallbladder problems.

**Patrick McKeever**; Nov/Dec '04, p3
Patrick described his experience with iron avidity. He has also been instrumental in several other items being published in the newsletter.

**Dawn Marie O'Donnell**; Mar/Apr, '06, p2
Dawn Marie relates her experience in dealing with both hemochromatosis and sideroblastic anemia.

**The Randall Family**; Mar/Apr, '06, p3
The Randalls discussed how their family has been affected by hemochromatosis and the use of a Ferritometer in diagnosing their daughter, Sierra.

**Ralph and Sylvia Ross**; Jan/Feb, '06, p2
Ralph and Sylvia outlined how their family has been affected genetically by hemochromatosis.

**Art and Lorrie Smith**; Sep/Oct, '05, p2
Art and Lorrie described their experience using Double Red Cell Apheresis at the National Institutes of Health.

**John Waldron**; Jan/Feb, '06, p3
John's story was first published in *The Virginian-Pilot*. He describes his liver transplant, a result of hemochromatosis, and Jason's gift of a liver.

**Kate Walker**; May/Jun, '06, p3
Kate's mother, Nora, describes how hemochromatosis can also affect adolescents.

## FREELANCE CONTRIBTORS

L. to r. Monica Brummer, Cheryl Mellan, Bing Randall, & Lorrie Smith
Photos Unavailable: Bud Brown, Marcia Christensen & Erica Spinelli

**Mardi Brick**

Mardi's contribution of "how to organize a support group" can read on page 6 of this issue.

**Bud Brown**

Bud contributed a concise book review on "The Iron Disorders Institute Guide to Hemochromatosis", which raised the book's value to "must read" and certainly enhanced book sales.

**Monica Brummer interviewed by Erica Spinelli**

Between Monica's enthusiasm for "the 100 Mile Club" and Erica's writing skill, the "Club" was described, which will hopefully encourage patients and their families to become involved.

**Marcia Christensen**

Marcia contributed her poem, "My HH Song" which can be sung to the tune of "Supercalifragilisticexpialidocious."

**Cheryl Mellan**

Cheryl contributed a rave book review on IDI's book, *Cooking With Less Iron*, reflecting the educational value of the book, along with her personal experience in using several diet suggestions in her own home.

Cheryl also interviewed Joe Brinkley to write his story, which appears in the issue.

Cheryl's "full-time" volunteer position as the moderator of the Excess Iron List consumes much of her time, yet she has found time for the aforementioned contributions.

**Bing Randall**

Bing was the first and only student to submit his school health project for publication in the "Aware Generation" column. Strictly speaking, Bing is not a Freelance Volunteer, but his entrée in the Youth Awareness Recognition Program warrants recognition for his efforts. Hopefully, IDI volunteers will surface to encourage more students to participate in this worthwhile program. (Nov/Dec/ '05)

**Lorrie Smith**

Lorrie has willingly volunteered to take photographs during the past 2 bi-annual conferences, which contributed immensely to the quality of past conference articles.

**Editor's Note:** There were many other dedicated individuals who contributed their personal photos for publication. To those unnamed members of the iron imbalance community, you are very much appreciated and I thank you from the bottom of my heart.

***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*

You must have realized by now, after reading the "tribute to *id-in Touch's* volunteer contributors on the front page this column's theme is about volunteerism. It was extremely appropriate to pay tribute to the many volunteers that have helped to publish our newsletter, *id-in Touch* on schedule (most of the time) every two months for the past 16 issues.

As you are aware, Iron Disorders Institute is a voluntary organization with only a couple of meagerly paid employees. Thus, the preponderance of our growing visibility and credibility with the medical, scientific, and patient communities is a direct result of the dedicated efforts of enthusiastic volunteers, who believe strongly in IDI's mission – to reduce pain, suffering and unnecessary death by disorders of iron through education, awareness and facilitating re-search.

Individuals, like yourself, with an unwavering sense of responsibility to share their knowledge, their personal experiences and their involvement in local activities about raising iron awareness have "stepped up to the plate" and contributed their time and effort towards bringing id-in Touch to you. Mind you now, their commitment was in addition to their myriad responsibilities to their families and employers. Their motivation has always been altruistic, never having asked for anything in return. This praise and honor for their generosity is long overdue.

Its human nature to classify people, places and things, based on our experiences; therefore, I'll continue to express my gratitude in that vein by identifying individuals in alphabetical order for credit in major categories where their contributions lay. You're certain to see the same name show up in several categories.

### COLUMNISTS

It was these individuals that initially and unselfishly volunteered to help by writing a column for id-in Touch. This was the beginning of my technical involvement with IDI's newsletter when I assumed Julie Cole's desktop publishing responsibilities when she returned to college. In fact, without the untiring efforts of these columnists, the newsletter may have faltered. At the very least, the newsletter would have consisted of only several pages rather than the customary robust eight pages since January, 2004.

### COMMUNITY ACTIVISTS

The individuals in this category and their contributions were instrumental in raising the awareness levels of iron in their respective communities. Then, they took the time to share their experience with other iron patients and their families through our newsletter with the hope that a similar spirit would be kindled in many communities across the country

### PATIENTS

Personal stories were originally published in IDI's magazine, idInsight. It was felt that individual challenges that were faced and overcome in dealing with excess iron should continue to be an inspiration to others that will inevitably follow in their footsteps. Thus, the decision was made to begin publishing these remarkable stories of how individuals and families overcame adversity and challenges in the face of wanting knowledge within the medical community.

Patients often feel their personal experience in dealing with an imbalance of iron is not significant enough to warrant sharing. I can assure you that each individual tale adds to the cornucopia of knowledge, which in turn affords all of us, similarly afflicted, the opportunity to deal with iron maturely.

It goes without saying that each of these stories reflects the true courage that it takes to open one's innermost fears and frustrations for the altruistic purpose of educating others. One could say the decision for each of these patients to come forward was the result of serious soul searching.

In earlier times the actions of our patient contributors would be considered "true grit."

### FREELANCE CONTRIBUTORS

Recently, we are having volunteers who interview iron patients, write their stories and submit these stories for publication. These are magnanimous examples reflecting the essence of volunteerism. These individuals gave of their time and talent when called upon to develop a contribution to our newsletter.

You have been given a bird's eye view of the many individuals who have contributed unselfishly to this high quality newsletter. Like the people portrayed in the tribute beginning on page 1, I have a personal interest in the continuing value of this newsletter being able to increase a patient's knowledge of iron. If that sounds biased, so be it!

The highest praise I can bestow is by casting light on their many contributions or accomplishments and by associating them all together as a single entity – an extremely valuable asset to the iron community.

Wouldn't you want to be a member of this high caliber group of patients and their families who have been willing to give of their time, energy, and often their own funds towards educating the medical community and the public by increasing awareness of how iron can adversely affect your lives and the lives of your families?

Wouldn't you like to tell your children, your family or your friends that you have made a difference in someone's life?

It simply a matter of being willing to share!

**Share** a thought by writing a haiku about iron, genetics, insurance, organs, or what ever suits you're fancy.

**Share** an hour or so by sending us your personal experience during your diagnosis and treatment of an iron disorder. If you've never done something like this before, don't worry, we'll assist in every way possible. As you can see, there are several folks who have shared their personal experiences, so you are not alone.

**Share** your time with a student by mentoring and help them

See **Curmudgeon** continued on page 10.

## In Their Own Words...

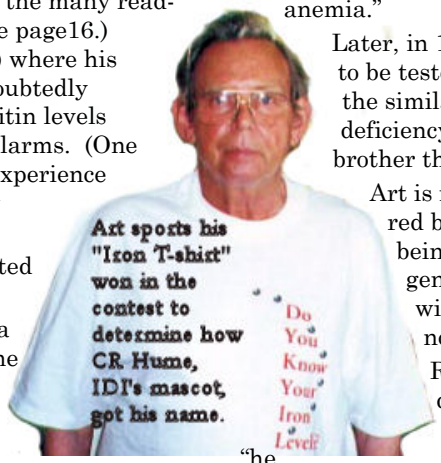
**Editor's Note**: Art Callahan's personal story first appeared in the Spring/Summer 2002 issue of IDI's magazine, ***idInsight***. Recently there has been an interest in anemia that can also load iron. IDI staff thought that this particular column would share insights to both an iron loading anemia along with the side effects of using an infusion pump for Deferoxamine to mange iron.

Many iron overloading disorders are rarely diagnosed early enough to preclude the onset of serious morbidity primarily because of the non-specific symptoms that can be associated with a myriad of medical conditions. More difficult is diagnosing an anemia that also stores excess iron. This has been especially true for Art Callahan of Memphis, TN who was diagnosed with Glucose-6-phosphate dehydrogenase (G6PD) deficiency in 1989 even though several early warning signs had presented themselves and gone unnoticed prior to Art's retirement from the United States Navy in 1974.

Art Callahan needs very little introduction to the many readers of IDI's ***Guide to Hemochromatosis*** (See page16.) and ***Cooking with Less Iron*** (See page 233.) where his airport experiences have been published undoubtedly raising awareness of how extremely high ferritin levels have the potential to set off airport detector alarms. (One can only imagine the humiliation Art would experience at an airport today given the present security awareness in effect.)

It was several years later before Art appreciated the significance of his airport episode.

In 1988, Art was treated for discoid lupus by a dermatologist who was administering Atrabine Winthrep, a trademark for *quinacrine hydrochloride* used primarily to treat malaria. During treatment, his doctor discovered that Art was undergoing hemolysis, a condition where red blood cells are prematurely destroyed. Art refers to Atrabine as the "offending malaria drug." Needless to say, the drug was discontinued in an effort to prevent severe hemolytic anemia. "I kept assuming my fatigue was coming from lupus." All along hemolysis had been the underlying cause Art's extreme tiredness.




**Hemolytic anemia** is one of the red blood cell destruction disorders, where red blood cells are destroyed prematurely. Consequently, an enlarged spleen will be seen along with a tendency for ferritin stores to be increased in organ tissues; a condition called hemosiderosis. **Hemolytic anemia** can also occur in hemoglobin apathies such as thalassemia and sickle cell anemia, or in conditions such as sideroblastic anemia, renal disease and vitamin deficiencies and in reaction to some medications.

Since then, Art has learned that there are many anti-malarial drugs, antibiotics, alcohol and infectious illnesses that can precipitate hemolysis for individuals with G6PD deficiency.

When Art returned to his family doctor for further testing he discovered that his ferritin level was 2,480$_{ng/mL}$, his percent saturation was 70 percent and his red blood cells were larger than normal. Art discussed the existence of G6PD deficiency within his family tree with his doctor. Art's older brother, Paul, had been diagnosed with G6PD deficiency more than 20 years ago. But Art's theory was summarily dismissed because "most all cases of G6PD in the Memphis area are African descendents and your name doesn't sound Italian or Greek." Art explained, "My doctor couldn't see the relationship between the extremely high ferritin levels and the ongoing hemolytic anemia."

### WHAT IS G6PD DEFICIENCY?

Glucose-6-phosphate dehydrogenase (G6PD) deficiency is a hereditary condition estimated to affect about 400 million people worldwide. The highest prevalence rates are found in tropical Africa, the Middle East, tropical and sub-tropical Asia, Papua New Guinea and some parts of the Mediterranean; such as Italy and Greece.

G6PD deficiency is an inherited X-linked recessive genetic trait; therefore, there is no cure for this condition. This means that males are more likely to be affected by this condition than are females. Genetic testing is available to identify a deficiency in G6PD in both males and females.

G6PD is an enzyme that protects red blood cells from oxidizing substances. When the red blood cells are deficient of G6PD, oxidizing substances produced by infections or oxidant drugs damage hemoglobin molecules resulting in cellular destruction of red blood cell, or *hemolysis*.

Later, in 1989, Art's sister-in-law, Martha, urged him to be tested for G6PD deficiency after pointing out the similarities between his test results and G6PD deficiency. "You have more in common with your brother than you realize," she said.

Art is in a constant state of hemolysis because his red blood cells are continually and prematurely being destroyed along with hemosiderosis, the generalized deposition of ferritin (iron stores) within his body tissues because his body does not use iron efficiently.

Recognizing that he would be living with a double-edge sword, Art jokes that his early research on G6PD deficiency indicated that "he should simply stay away from offending drugs and have a good life." Nevertheless, he's serious about his new objectives in life to ensure his iron levels are kept under control and to avoid oxidizing substances. For someone with Art's temerity and self-discipline that's hardly a challenge!

Phlebotomy treatments to remove the excess iron were begun on a bi-weekly basis 6 months after a G6PD deficiency diagnosis. After 10 phlebotomies, Art's ferritin dropped from 2,480$_{ng/mL}$ to 1,390$_{ng/mL}$, but 11 subsequent phlebotomies had little or no effect on his ferritin levels and his percent saturation remained well above 50 percent. "My veins dried up after 21 pints," Art commented. His phlebotomist nurse also noticed that his heart was skipping during one of the last phlebotomies. As a result, Art began chelation therapy with Desferal® about a year later.

Deferoxamine, the generic name for Desferal®, binds to some metals and carries them out of the body. It is used to treat acute iron intoxication, chronic iron overload, and aluminum accumulation in people with kidney failure. The recommended method is slow subcutaneous infusion over 8 to 12 hours, of a 10 percent Desferal® solution, using an infusion pump for a period of 8 weeks.

Art's first infusion pump was a "World War II model, the size of a brick and as heavy and cumbersome." "Not something you would wear to work." He eventually graduated to the much lighter battery operated Graseby Syringe Pump. The therapy is self-administered after the patient is indoctrinated and certified by a nurse. For each therapy cycle, Art receives a 14

See **G6PD** continued on next page.

**G6PD** (continued from previous page.)

day supply of materials every 2 weeks, consisting of 14 syringes containing 8cc of Desferal®, Butterfly Intravenous kit (IV), 36" extension, Veni-prep Kits and Tegderm dressings. The Desferal® is delivered in an icepack, thus he keeps 7 syringes in the refrigerator because Desferal® is stable at room temperature for only 1 week.

Art's chelation therapy infusion lasted for 8 or 9 hours, on a daily basis, generally for a 4 week cycle, which Art admits is when he stopped treatment because he had reached a severe anemic state. "Knowing my life was at stake, I developed a big threshold for pain and anemic conditions." He repeated the 4 week cycle 4 times a year for 7 years when he returned to phlebotomy therapy to manage his iron levels.

During this time, Judy, Art's wife, was his caregiver, because he had not "mastered" the art of self-injecting his arms. Art selected the site where Judy would insert the butterfly needle after the IV setup was attached to the infusion pump. He rotated the injection site among six areas: left and right arms, left and right stomach and left and right legs.

The Callahans were vigilant to avoid previous injection sites identified by "frogs", a childhood term referring to a large swelling or welt. His wife Judy reminds everyone to "Think frog, think lump. Think lump, think pineapple." Art also consumed large amounts of Benadryl to offset his reactions to the Desferal®.

He wore the pump to bed in a waist holster after setting the timer for 8 hours. Sometimes, the infusion pump shut down because of a crimped tube from turning over in his sleep. As a result, Art had to wear the pump to work the next day to complete the daily infusion.

About the same time Art began chelation therapy, he decided that he needed to change his diet because he realized, "My steak and potato meals were increasing my iron stores."

Art's determination to modify his diet increased dramatically when a physician informed him that, "diet wouldn't matter." He has since learned that diet can be a very big deal. "I believe a low-iron diet has to be adhered to in my case."

Art went back to phlebotomy treatments to manage his iron rather than continue with chelation therapy as it began to take a toll on him, both physically and emotionally. His regimen is approximately 4 phlebotomies per year.

Art strongly believes in keeping his relatives informed about G6PD deficiency because of its genetic characteristics. He has written to everyone in his genealogical tree advising them of the possibility of their offspring inheriting this particular gene. "If inheritance is possible, I recommend all males be checked at birth for G6PD deficiency," Art writes.

"My brother's grandsons, Christopher and Matthew were diagnosed at birth by an alert doctor."

"Several years ago, Christopher informed me he had been diagnosed with iron overload at age 27. He is now on an iron maintenance cycle of 3 or 4 phlebotomies a year. His daughter is a G6PD deficiency carrier. I'm thankful I've been able to alert Christopher to have his iron level checked."

Matthew enlisted in the Army for 3 years, but had to have a medical waiver because of his G6PD deficiency. He finished his enlistment and has since gone on to the University of Illinois. Last time Art heard from Matthew his iron levels were good.

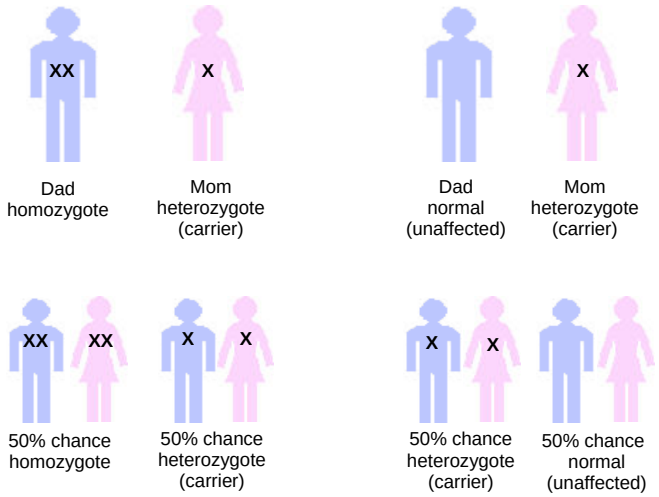
Art thinks it is fantastic that the military is routinely screening for G6PD deficiency because often overseas duty requires anti-malaria treatment.

"Last year was a bad one for me," said Art. "I've had a couple of heart attacks, also congestive heart failure. In addition, I've had a "balloon job", a stent inserted and a lot of new medication for my heart." As a result, he has stopped his phlebotomies because his red blood count was low and his ferritin level is climbing, but is still under 200$_{ng/mL}$.

Although Art has had some heart damage, he walks 2.5 miles each day. There is no question in Art's mind that his heart problems are directly related to iron overloading.

Considering that Art has only recently become "wired to the Web", his prowess in acquiring information essential to inform his kin, modify his diet and become well-versed on G6PD deficiency without the benefit of technology is quite remarkable.

### Chances of Passing the G6PD Deficiency Gene to Children




### Art Callahan Update

July, 2006

Art is still up to his old tricks of setting off security alarms. His most recent occurrence was in a police station rather than in an airport. (He was there on official business.) This event was not the result of his iron instead the alarm was triggered by his pacemaker/defibrillator, which was implanted two years ago.

Art can't take Desferal treatments for iron overload any longer due to a reaction from the drug. However, his doctor will prescribe Exjade® when it is needed to manage his ferritin levels, which he has been able to maintain below 300$_{ng/ml}$ by following an almost iron-free diet.

"I just hope my body will take Exjade® when the time comes around. That is truly a miracle break through in the iron overload world."

When notified that his story about G6PD deficiency was going to be reprinted, Art's immediate response was "It's great to hear I can be recycled."

### Links Relating to this Article

Exjade®.....http://www.irondisorders.org/News/ExjadeFDA.asp
G6PD.....http://www.g6pd.org/
.....http://rialto.com/g6pd/

## HEY – HOW ABOUT STARTING A SUPPORT GROUP?

(*Lots of questions and a couple of answers*)
By **Mardi Brick**, volunteer
Santa Cruz County, CA

Have you ever thought of joining a Hereditary Hemochromatosis (HHC) Support Group? What? No support group in your area? Well then, why don't you organize one? – But, wait a minute. Where do you start?

Let's just think about this. First of all, how do you find other HHC patients? You can't call doctors and ask them to give you their patients' names and addresses. (Would you want your doctor to give some stranger your name and address?)

You could try writing a "Letter to the Editor" column of your local paper – or if you know someone at the paper, perhaps you could ask for an interview and get the story that announces your new support group on the Meeting Page. Or, you might get a response by putting the information on the internet.

Well, dear friends, this has become quite tedious with all these questions. It might be best if I tell you what approach I took two years ago when I decided to "try" to organize an education and support group in Santa Cruz County, CA.

Here is my five step action plan. Let's hope these suggestions will get you started.

**The rest is up to YOU**.

**Editor's Note:**

**Mardi Brick** was introduced to me at the IRONUSA 2006 conference in Bethesda, MD this past May where I learned she was instrumental in forming a support group for hemochromatosis patients in California under the aegis of the Iron Overload Diseases Association.

Mardi graciously agreed to provide a "How To" article for this issue. She has been successful in many endeavors: as a teacher, as a writer/journalist and as volunteer for several organizations, including being the founder of several community organizations. She has also been a proactive advocate for the use of hemochromatosis blood by the Red Cross Blood Collection Program. Last, but not least, she is the former mayor of Los Gatos, CA.

## MARDI BRICK'S FIVE STEP ACTION PLAN for ORGANIZING A HEMOCHROMATOSIS SUPPORT GROUP

**Step I: The Invitation List**

A. Personal visit to President of local Medical Society to explain objectives and get permission to buy Society mailing list.
   1. Cull list for specialties that would most likely see HHC patients, i.e. cardiologist, endocrinologist, family and general practitioner, fertility specialist, gastroenterologist, hematologist, internist, rheumatologist, etc.

B. Compose two explanatory form letters 1) to doctors, 2) to potential patients. **(See sample patient and professional letters, next page.)**
   1. When composing, leave room at the top of the text to hand-address a salutation to each doctor.
   2. Xerox copies of letters using good quality stationary and envelopes for doctors' letter; use contrasting color for patient letter.
   3. Personally sign each letter.
   4. Mail both letters in the same envelope addressed to the doctor (having printed "PERSONAL" in red to the left of the address.)

**Step II: Legible Records**

A. Keep records in relevant categories
   1. Dates: mailings; phone follow up; date invitation was delivered to doctor's office.
   2. Reactions: staff assistants; name; supportive or other.
   3. Delivery of patient invitations; how many needed by each doctor. **Important: Respect patients' anonymity at all times!**

**Step III: Time Allotment**

A. Personal assessment
   1. Be realistic, each one of these steps will consume an inordinate amount of time, especially dealing with doctors' staff in Step II.
   2. Is dependable help available?

B. Response time
   1. Your phone line must be free for you to take time each respondent professional or patient.

C. Persistence takes time (and discipline.)
   1. Phone relationships: professional, not chatty.
   2. Adjust proper time span for rechecks with medical personnel, this requires delicate balance between your "helpful reminder" and their "pain-in-the-neck" attitude.
   3. Keep careful records of recheck results.

**Step IV: Publicity**

A. When
   1. Approximately 30 days after mailing the original letters to doctors, start publicizing the first meeting of support group.

B. Where
   1. Media coverage, newspapers, medical journals, church and synagogue bulletins, TV health news.
   2. Hospital, neighborhood bulleting boards.
   3. Internet, other.

C. What
   1. Choose attention-grabbing name for group (I came up with The Ironic Family.)
   2. Select a central, non-threatening location.
   3. Select a convenient time for people in the work force.
   4. In anticipation of a small group, find a cozy, welcoming setting.
   5. List the foregoing arrangements in all publicity.

**Step V: Meetings**

**The sky's the limit.**

# SAMPLE LETTER TEMPLATES
## BY MARDI BRICK

### PATIENT LETTER

**[LOCAL CHAPTER OR BRANCH NAME] [NATIONAL ORGANIZATION]**

**[DATE]**

When the mythical Pandora opened her box so long ago is it possible that among all of the ills of mankind hereditary hemochromatosis escaped as well?

We'll probably never know, but there are other things that we can discover about hereditary hemochromatosis (HHC) that will be helpful in managing the disease.

I would like to propose that those of us in the **[LOCAL AREA]**, who have been diagnosed as HHC patients, get together for sharing knowledge and support. We might even come up with some ideas on increasing the awareness of this hereditary condition among the general public.

Hereditary hemochromatosis has been called the most common genetic disorder in the United States by the Centers for Disease Control and Prevention (CDC) in Atlanta, GA. They estimate that HHC occurs in 1 of every 200 Americans.

The **[NATIONAL ORGANIZATION]** in **[LOCATION]** is a/an **[ORGANIZATION'S PRIMARY FUNCTION]** for information on iron overload conditions. It is a major repository of news from physicians, scientists and patients.

The **[NATIONAL ORGANIZATION]** mission is **[ORGANIZATION'S MISSION STATEMENT]**.

I have chosen the name "**[LOCAL CHAPTER OR BRANCH NAME]**", in the hope that we might work together as a family here in our area. We would be an affiliate of [National Affiliation], which is a non-profit organization founded by **[FOUNDER(S) NAME(S)]** over **[NUMBER OF YEARS]** years ago. They publish a bi-monthly newsletter called ***[NEWSLETTER NAME]*** and hold annual national meetings each year.

Won't you join me in learning more about iron overload and how we can help other potential victims to get an early diagnosis?

An organizational meeting has been scheduled for **[DAY, DATE & TIME]**. Our meeting will be held at **[LOCATION, ADDRESS AND ROOM #, as applicable]**. Refreshments, plus maybe a cookie or two, will be waiting for you.

These are my contact numbers for further information:

Email: **[EMAIL ADDRESS]**
Phone: **[TELEPHONE NUMBER]**

Hope to welcome you on the **[DATE]**

Sincerely,

[**SIGNATURE**]

### DIRECTIONS FOR LETTER TEMPLATES

Replace information inside the square brackets [ ], including the brackets with your particular information. For example: **[NATIONAL ORGANIZATION]** should be replaced by Iron Disorders Institute. **Note**: Remove the brackets and bold attributes when replacing keywords.

Rewrite any paragraph relating to your personal situation that you deem fit.

We have provided links to each of the letters in text format, which can be copied and pasted into your favorite word processor, or saved to your computer as text; then opened with your favorite word processor.

### PROFESSIONAL LETTER

**[LOCAL CHAPTER OR BRANCH NAME] [NATIONAL ORGANIZATION]**

**[DATE]**

**[PERSONALIZED GREETING]**

I am a hereditary hemochromatosis patient who has lived in **[CITY/TOWN]** for the past **[NUMBER]** years. I became a member in **[NATIONAL ORGANIZATION]** in **[CITY, STATE]** because I wanted to learn more about managing my condition.

However, I have found that even though I attended their annual **[SYMPOSIUM/CONFERENCE]** and I received their monthly newsletter, ***[NEWSLETTER NAME]***, it didn't quite meet my need for interaction with other people in my same boat.

Soon after we moved here from **[CITY/TOWN]**, my **[RELATION]** was diagnosed with **[DISEASE NAME]**. Serving as a caregiver for six-plus years was tiring and frustrating. It also entailed a bit of a sacrifice of my own needs.

I joined a **[DISEASE NAME]** support group and found that the interaction with others, who had many of the same problems, made all the difference in the world to my own mental health.

Since my **[RELATION'S]** death I have been considering trying to organize a hereditary hemochromatosis support group, but I wasn't able to solve the problem of how to reach other members of this select group. I think I may have stumbled upon a solution, but I will need a little assistance in order to observe the important privacy issue of each patient.

Attached you will find a letter of invitation to your hereditary hemochromatosis (HHC) patients to join me in organizing an education support group. If you could possible request a member of your staff to help I would be most grateful.

I would only need two things: 1) the number of patients you are treating (so I can give you the right number of invitations and 2) a few minutes of staff time to insert this letter and the attached letter at the top of each patient's file.

As each patient comes in for an appointment it can be handed to them. In this way the patient will be notified of the meeting date and can decide whether they want to join us and you will not be involved in their decision. The invitation will explain the "why" plus the "where" and "when with my contact number for further inquiries.

When I was diagnosed **[NUMBER]** years ago, I thought that HHC was a rare disease because I had never heard of it. As I mentioned in the attached letter, I later learned that the Centers for Disease Control and Prevention has labeled it the most prevalent genetic disease in out country. In 1999 their estimate: 1 in 200 Americans.

Because I had thought the disease was rare, I felt very much alone. At that point, I would have welcomed some friendly support.

I do hope you or your staff will not feel overburdened with just one more thing to do. However, I believe that this support group may make a difference in many patients' lives.

Thanking you in advance for your help, I remain sincerely,

**[SIGNATURE]**

**[TELEPHONE NUMBER]**

### WEB LINKS TO A TEXT VERSION OF EACH LETTER

Text files have been provided so you won't have to retype each letter. You will, however, have to save the file to your computer as a text (.txt) file and format the letter to meet your needs.

Professional Letter: http://www.irondisorders.org/Newsletter/proltr.txt

Patient Letter: http://www.irondisorders.org/Newsletter/patltr.txt

*IRON PATIENTS – THEIR OWN STORIES*

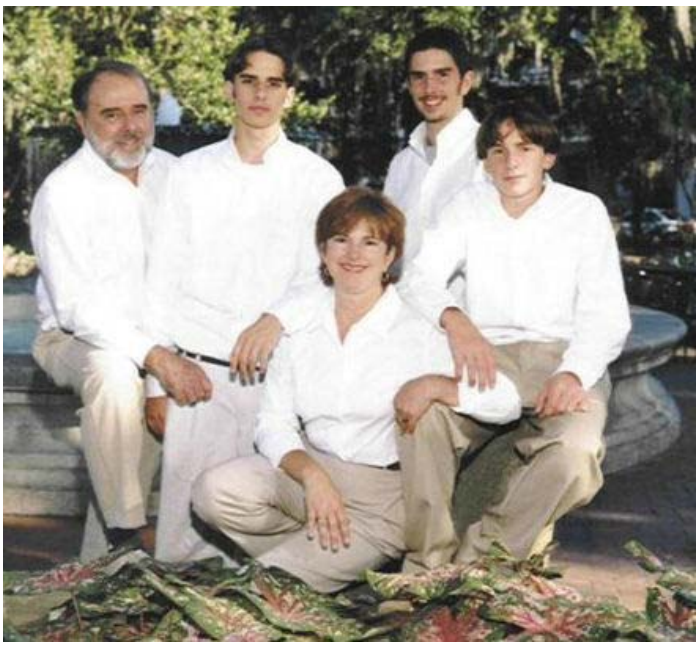
***"Education is the most powerful weapon which you can use to change the world."***
***Nelson Mandela, Statesman***

## JOE BRINKLEY

## "STICKING IT OUT IN THE SOUTH"

Interviewed by **Cheryl Mellan**, Excess Iron List Moderator and volunteer

I am happy to report the rumors of my death have been greatly exaggerated. I am alive; living in Savannah with my lovely young bride and three terrific sons and at long last, feeling in good health. There was a time when I felt like the poster child for "*Everything You Always Wanted to Know About Hereditary Hemochromatosis, But Were Afraid to Ask.*"



**The Brinkley Family**

**From l. to r: Joe, Casey, Tammie, Will and Ben**

For several years prior to the summer of 2003 I knew I was not well. I didn't know what it was, and the doctors didn't seem to see a thing. I felt bad all the time. I was plagued with a string of various symptoms, some vague and some not so vague. The most pronounced were constant fatigue, joint pain, bad moods and abdominal pain that came and went. In view of the fact that I'd had elevated liver enzymes for several years, I was referred to a Gastroenterologist by my primary care physician for additional testing that would complete my physical exam. As I left my doc's office that day he handed me a copy of my blood work and asked me to see what the second physician thought about my elevated enzymes.

At my first visit with the Gastroenterologist additional blood tests were ordered. I received a call the following day from the physician's nurse. The doctor wanted one more test – this time genetic, "the doctor thinks you have hemochromatosis." The results of that genetic test did indeed reveal that I am a homozygote for the C282Y mutation of HFE. On July 1, 2003 my serum ferritin was $2700_{ng/ml}$, TS% 89%. Therapeutic phlebotomies were scheduled immediately. I was told it was a strong possibility I had cirrhosis of the liver.

I went home and gravitated at once to the Internet for information. I found a "hemochromatosis organization" that did a fine job of convincing me that my condition was terminal. As luck would have it, my wife was out of town on a business trip at the time. I remember just sitting and staring at the screen that was telling me I was going to die. I joined their on-line support group, and promptly decided to refuse the offer of a liver biopsy suggested by my physician. I didn't want a needle stuck in my liver; I wasn't particularly fond of needles to begin with. The patient feedback I was receiving was not very positive. Being not very well educated in medical matters, in the absence of having anything that I could read, I took what I was handed. I recall feeling numb, not even discussing what I knew so far with the people who meant the most to me in the world.

**CIRRHOSIS**

When cirrhosis is present at the time of diagnosis of hemochromatosis the risk of liver cancer can be as high as two-hundred-fold. Cirrhotic tissue provides a fertile ground for the initiation and promotion of cancer cell growth. Iron is a well-recognized mutagen and can cause development of liver cancer even in nonfibrotic tissue.

*Exposing the Hidden Dangers of Iron,* E.D. Weinberg, PhD

One good thing that did come of that experience is that a fellow list-member forwarded one of my posts to Cheryl Mellan, the Moderator of the Excess Iron Discussion Group provided by the Iron Disorders Institute. Cheryl answered my questions privately, invited me to IDI's website, and to join her discussion group. I'm glad I took her up on that offer.

The first indication of a problem arose shortly after beginning phlebotomies. My original phlebotomy order indicated I could have a therapeutic phlebotomy weekly if my hematocrit was 37% or above. From the start, I was unable to sustain a hematocrit of 37%. That number was repeatedly reduced, eventually ending with 32%. Many times I did a phlebotomy with an Hct of 32.5%. The additional blood loss would leave me feeling washed-out for several days. Weekly injections of Aranesp were begun. Aranesp is an erythropoietin drug that stimulates your bone marrow to produce more red blood cells. With more red blood cells I might have more energy; more importantly phlebotomies could continue. Despite my faithfulness to the phlebotomy schedule the ferritin continued to bounce up and down, but by February 2004, it had declined to $451_{ng/ml}$. About half-way through the de-ironing process it was as if a curtain was lifted and the gloom went away. My wife commented to the kids "The old Dad is back." I was happy with my progress and feeling somewhat better, I could see a light at the end of the tunnel.

**ERYTHROPOIESIS**

The use of Epoietin (EPO) is suitable for some patients with iron overload, especially if they have anemia. EPO is expensive and not approved for use with hemochromatosis. Benefits of EPO for persons with iron overload should be limited to those who cannot tolerate routine phlebotomy and who have ineffective erythropoiesis, such as patients with sideroblastic anemia, CDAII, red cell enzymopathies, autoimmune hemolytic anemia, myelodysplastic syndromes, or kidney disease. Iron-overload patients with cardiomyopathy or cardiac arrhythmias are also possible candidates for EPO.

*Exposing the Hidden Dangers of Iron,* E.D. Weinberg, PhD

See **Brinkley** continued on next page.

**Brinkley** (continued from previous page.)

Throughout that summer, fall and into winter I continued to be plagued with intermittent abdominal pain which I attributed to my long-standing hiatial hernia. In early February I had an attack of pain that did not go away, and this time the pain was worse than ever. I was admitted to the hospital to have my badly infected (gangrenous is the specific word) gall bladder and the 10 black stones it held removed. I was in the hospital for six days with IV pain medication; it was another six weeks recovering before I even considered phlebotomies. It must be true that "every dark cloud has a silver lining." While removing my gall bladder the surgeon did a liver biopsy, this time with my blessing. I have no cirrhosis. When I was tested prior to my scheduled phlebotomy I was really pleased to learn the ferritin had fallen from $451_{ng/ml}$ to $61_{ng/ml}$ *without blood loss.*

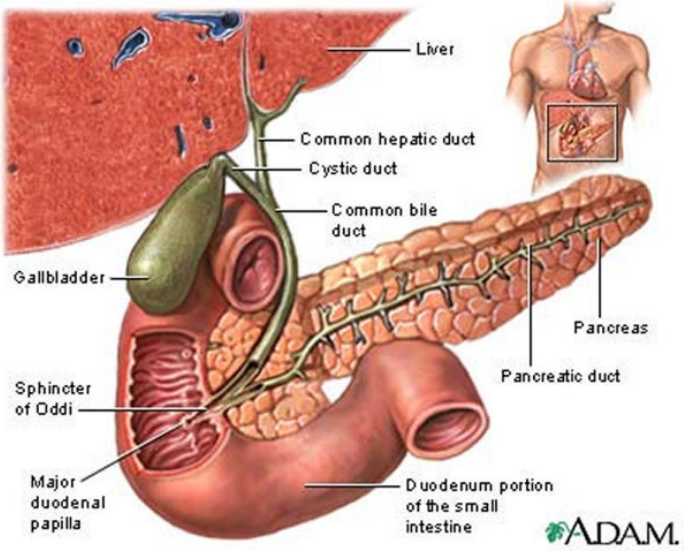
Just three more phlebotomies and my ferritin was $26_{ng/ml}$, TS% 39%.

### GALLBLADDER AND IRON

The exact mechanism of how the gallbladder is affected in patients with iron overload is not widely studied. Gallbladders of HHC patients are often removed because of cholelithiasis . According to the Iron Disorders Institute Patient Database, some HHC patients who have had their gallbladders removed report that the stones are "variable in size and black in color," possibly indicating the presence of iron in the bile. In a 1996 US Centers for Disease Control and Prevention survey where 2851 hemochromatosis patients responded, liver and gallbladder disease was reported by 9.5 percent of males age 17-39 years and 5.2 percent in females of the same age range; 17.7 percent in males and 20.0 percent of females age 60-84.

With special attention to the spincter of Oddi, French scientists examined 109 consecutive autopsies. These investigators concluded that chronic pancreatitis (which can be a consequence of excessive iron or chronic alcohol abuse) was more frequently associated with an abnormal spincter of Oddi. At the University of Milan, 350 patients with alcoholic cirrhosis and hemochromatosis were studied. The incidence of cholelithiasis (gallstones) was 3 times higher in these patients than in nonalcoholic, iron-normal controls.

*Exposing the Hidden Dangers of Iron,* E.D. Weinberg, PhD.




Source: MedlinePlus, a service of the National Library of Medicine (NLM) and the National Institutes of Health (NIH)

I have to agree with my doctor who told a friend of mine that "Joe Brinkley is one lucky man." I'm grateful for a family who couldn't have been more supportive – a wife who never complained about my two-day naps and sons that cut the lawn while I did. There were days when our lawn was the worst one on the block, but somehow things that needed to be done got done eventually. I'm grateful for my two adult daughters and my grandchildren, none of which probably will ever know the influence they have, or the inspiration they have been. I'm grateful to have found IDI, and for the information and education I've received there. I'm grateful that the level and quality of information received is such that I can share it with my physician and phlebotomists. I remember my blood bank telling me they had applied for "a program" that would allow them to take my HHC blood and use it for transfusion to patients in need. It felt good to say "Yeah, the variance for collection of blood from HH patients, I know about that!" It's nice not to feel "lost." I have often said that had it not been for the Iron Disorders Institute, I probably wouldn't have continued the de-ironing process to the end.

If I could make newly diagnosed persons absorb only one thing, it would be that they need to stick it out, see it through to the end. Hemochromatosis is not a death sentence; you CAN tolerate sticking out being "stuck." That diagnosis was not my end, I feel like my life began with hemochromatosis. There was a time when my mental state was so affected that I could not pick up one foot and put it in front of the other. I could interact with someone one-on-one for a short while, but only for a short while. I could sit at the front of a row of cars at a major traffic intersection and wait for the light to change; when it did I would think about whether or not I was making the right decision to move. I don't know at what point it got better. I feel better today than I have felt in twenty years. It feels good not to feel bad.

Now if only I could improve my golf swing!

The Florida Georgia Blood Alliance has eight donation centers located throughout the greater Northeast Florida/Southeast Georgia area. Three of those centers - Jacksonville, Florida, Camden County, Georgia and Savannah, Georgia are designated "Special Donation Centers" where blood of HHC patients is accepted under the "Variances for Blood Collection from Individuals with Hereditary Hemochromatosis" guidelines.

For more information, or to schedule your appointment at the Savannah Community Blood Bank at Market Walk, contact Willie Cherry at 912-355-0271.

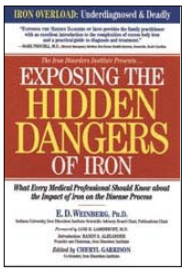
For more information on the Jacksonville, Florida or Camden County, Georgia facilities, contact Lorrie Ballasso at 800-447-1479.

THE BLOOD ALLIANCE

http://www.fgba.org/

***Exposing the Hidden Dangers of Iron***, E.D. Weinberg, PhD can be purchasd at IDI's Iron Store.

http://www.irondisorders.org/Store/



## 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:

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**Institutional Review Board**

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**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

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Personal Health Profile Booklet

Web Site – http://www.irondisorders.org

Patient Surveys

Youth Awareness Recognition

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

get their school health or science project published. It could be your child, the child of a relative, even your next door neighbor's child. Know this! Almost every child in America has to do school projects at one time or another during the formative education. The opportunities are boundless. Why not an iron-related subject; such as genetics, blood, iron overload disorders, anemia, et al? There are countless topics. Try it you will experience intense satisfaction.

**Share** with others by attending the next bi-annual conference. Lasting friendships have been made with folks like yourself, evidence that you do not have you bear the burden of treatment alone. You'd be surprised how much you can learn about iron from other patients in attendance, as well as from the presenters.

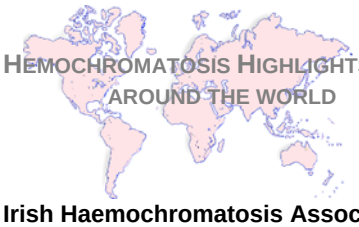
**Share** your talents, experience, knowledge, or time with IDI. There are many one-time essential tasks, other than those I have suggested that go uncompleted because there are not enough hands to make light work.

Just be willing to share.

We will all personally profit by it in gained knowledge of how to manage Iron-Out-of-Balance™.

I would also like to take this opportunity to thank all of you beforehand: those of you who are reading this and are going to follow in the footsteps of the dedicated people in this tribute.

Finally, to each and every one of you who has contributed to id-in Touch during my tenure, you have my sincerest gratitude and a well earned international **"Bravo Zulu."**




### Irish Haemochromatosis Association
### Dublin, Republic of Ireland

The Irish Haemochromatosis Association (IHA) played a prominent role in developing recommendations to increase recognition and improve treatment of haemochromatosis in Ireland.

The Working Group established by Ms Mary Harney, TD*, Tánaiste** and Minister of Health and Children, in February, 2006 was charged with examining and reporting all issues relating to haemochromatosis in Ireland.

This committee submitted their report to Tánaiste June, 2006 along with 20 recommendations addressing the problems caused by haemochromatosis.

The Working Group membership was comprised of:

**Dr. Maurice Manning** (Chairperson)

**Dr. William Murphy**, National Medical Director of Irish Blood Transfusion Service

**Dr. Suzanne Norris**, Consultant Hepatologist, St James's Hospital

**Ms Margaret Mullett**, Irish Haemochromatosis Association

**Mr. Brendan Gallagher**, Irish Haemochromatosis Association

**Ms Mary Jackson**, Principal Officer, Blood Policy Division, Department of Health and Children

* A member of the Dáil is known as a *Teachta Dála* (often abbreviated TD), or deputy.

** Deputy Prime Minister, Republic of Ireland

**Links Relating to Irish Haemochromatosis Association (IHA)**

Irish Working Group Report can be viewed at:

http://www.irondisorders.org/News/IrishReport.pdf

IHA's Spring 2006 newsletter is available online:

http://www.haemochromatosis-ir.com/newsletters.html

**Links Relating to Rusty's Column**

How to write and submit your Haiku

http://www.irondisorders.org/Newsletter/nd05.pdf

Youth Awareness Recognition Program

http://www.irondisorders.org/Newsletter/nd05.pdf