

“Don’t hurry. Don’t worry. Your only here for a short visit. So don’t forget to stop and smell the roses.”
 H.G. Wells, writer



IDI's way of keeping in touch with you!



MAY/JUNE, 2007

IRON DISORDERS INSTITUTE

VOLUME 7, ISSUE 3

CONGRESSIONAL BRIEFING HEARS FROM IDI

By Marilyn Baker
 Washington, D.C.

Aran Gordon, Hemochromatosis survivor and IDI board member, and **Marilyn Baker**, new IDI outreach programs director, recently attended a congressional briefing held by the National Center on Birth Defects and Development Disabilities (NCBDDD). The briefing was held in the Hart Senate Building, the largest of three office buildings designated for U.S. Senators.

Aran and Marilyn attended this gathering of patient groups to learn more about the NCBDDD’s activities for patients while advocating for assistance in fighting iron imbalance disorders.

Aran was able to directly tell his inspiring story to many legislative personnel, senatorial aides, and representatives from the Centers for Disease Control and Prevention.

It was learned at this meeting that blood disorders receive only 16% of the NCBDDD budget with birth defects receiving 43%, and human disability receiving the other 41%. It is hoped that by such outreach efforts IDI can increase awareness of the dangers of iron imbalance and the importance of accurate diagnoses and treatment thereby increasing our percentage of the NCBDDD budget.

The External Partners Group is a coalition of government and private sector participants who work together to enhance the

Hart Senate Building; Washington, D.C.



mission and activities of the National Center on Birth Defects and Developmental Disabilities (NCBDDD) in promoting child development; preventing birth defects and developmental disorders / disabilities; and enhancing the quality of life and preventing secondary conditions among people who are living with mental or physical disabilities, or a combination thereof. Iron Disorders Institute is one of the newest members to this group.

If anyone is interested in assisting IDI in advocacy and awareness activities, please contact Cheryl Garrison:

cgarrison@irondisorders.org

Reminder!  **Check your mail!**

IDI will be sending you a very important letter in the next few weeks.

If you do not receive this letter, you may have overlooked adding your name to our mailing list.

To have your name and mailing address added, please contact IDI.

In the meantime, this letter is available on page 10.

JULY
 IS
HEMOCHROMATOSIS SCREENING
 &
AWARENESS MONTH

Volunteers are needed to distribute information about Continuing Medical Education credits (CME) to medical providers

Contact:
patientservices@irondisorders.org

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

THE GENETIC COUNSELING CORNER

By Lisa Kessler



HEREDITARY HEMOCHROMATOSIS GENOTYPES AND STROKE RISK

What is a “genotype?”

This is a term commonly used in genetic counseling for hereditary hemochromatosis. Genotype describes a person’s genetic makeup, the actual genetic code. For example, for someone who has 2 copies of the C282Y mutation, the genotype would be homozygous for C282Y, also referred to as C282Y/C282Y.

What is a “phenotype?”

A phenotype describes the clinical features of a condition. For example, the phenotype for someone who is homozygous for the C282Y mutation may be iron overload and its associated features, such as fatigue, joint pain, and skin bronzing.

On the other hand, not all people who are homozygous for the C282Y mutation develop symptoms. These people are said to have the genotype associated with hemochromatosis, but they do not have the phenotype (iron overload). That is because having 2 copies of the C282Y mutation puts someone at increased risk for developing iron overload, but does not guarantee that they will develop iron overload or associated complications.

What does this have to do with risks for stroke? A new article came out in *Neurology* on March 30, 2007 which demonstrated that a particular genotype associated with hereditary hemochromatosis increased the risk for ischemic stroke (this type of stroke is due to a blockage within a blood vessel that is supplying blood to the brain).

The authors of the study looked at individuals with 5 different genotypes to see if any could be connected with symptomatic carotid atherosclerosis, ischemic cerebrovascular disease (ICVD), and ischemic stroke.

Specifically, those in the study with the genotype of H63D/H63D (homozygous for the H63D mutation) were found to have a 2-3 times greater risk of ICVD and ischemic stroke compared with the other genotypes in the study. Interestingly, as you may know, this particular genotype is associated with a lower risk of developing iron overload compared to the C282Y/ C282Y genotype. At this time, the authors can only speculate about this relationship and what it has to do with iron overload.

Do you have questions about the differences between genotype and phenotype?

Please don’t hesitate to contact me about this topic or other genetic counseling questions at

877-321-0077

or

lkessler@dnadirect.com

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

CORDELE’S IRON OVERLOAD AWARENESS TRADITION CONTINUES

By Chris Kieffer
Cordele, GA

Iron overload awareness began in Cordele, GA when **Harry Kieffer** was diagnosed with hemochromatosis in 1992. In 1993 hemochromatosis awareness programs started on WSST-TV’s Phil Streetman show. Later, WALB-TV Albany, GA and the Cordele Dispatch joined the campaign. Soon after, Crisp Regional Hospital and the Cordele Lions Club joined with other organizations in a long standing relationship helping Iron Disorders Institute make a difference in the Cordele area. Cordele was used by IDI as a pilot program for July HHC Awareness Month program.

Recently Chris and Harry Kieffer manned an IDI booth at the Crisp Regional Hospital Health Fair. It was exciting talking to the people especially one man of Irish heritage who recognized 9 HHC symptoms listed on the Guide to Hemochromatosis book cover.

Each year, the Lions Club presents a check to IDI to support our iron awareness efforts in Cordele



Chris Kieffer, a founder and past board member of IDI receives a check from **President Earl Hamilton** of the Cordele Lions Club for iron awareness educational activities.

We have distributed Physician Reference Charts to all area physicians at their hospital mailboxes and donated IDI books with labels recognizing the support of the Cordele Lions Club. Also, this year we will be providing plexiglass displays in doctor’s offices, urgent care facilities and other locations with IDI’s brochure, Do YOU Suffer From. Each display will also have a sticker recognizing the Lions Club’s contribution to raising iron awareness. The Lions Club mission is preventing blindness and if we diagnose HHC early enough we do just that, so in the beginning years we saw common missions.

During Hemochromatosis Awareness Month in July we have hosted awareness/ fundraising activities with Wal-Mart. and have also received grant money in past years. The Lions, TV stations and the newspaper have all been involved in different events including raffles with a week-end get-away and other prizes donated from local merchants and held at Wal-Mart.

Each year during July, Crisp Regional Hospital offers blood tests for ferritin and ferritin-iron saturation percentage (TS%) for \$25.00 total promoting the tests with newspaper and shopper ads. The TV station promotes it also throughout the month of July. These relationships that started so long ago continue today in making a difference in the cause for raising the awareness of hemochromatosis. As a result of Harry Kieffer’s diagnosis in 1992 the effects of the community programs have been far reaching and we estimate over 50 people have been diagnosed.

Iron Disorders Institute National Headquarters Staff and Volunteers

IRON PROFILES

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

Jody Williams, 1997 Nobel Peace Prize recipient

**Isabelle Bedell, M.P.H.
Volunteer
Researcher**



"When you give blood, the life you save may be your own"

"Public Health is caring about people before you even meet them."

At age 70, Isabelle Bedell, M.P.H. is making great strides researching iron disorders and breast cancer. She has a deep passion for others, and wants to raise awareness of iron metabolism disorders. "Everyone should know their ferritin and transferrin saturation percentage levels just like they know their cholesterol levels", Mrs. Bedell stated with firm conviction. Conversant in 10 different languages by having traveled to 30 different countries, Mrs. Bedell has connected herself with as many researchers as she can to more fully understand the effects of iron metabolism disorders and breast cancer. Thus far, she has found almost 100 articles linking iron loading disorders to breast cancer.

When funding becomes available, and approval by the ethics board is received, Mrs. Bedell and her colleague, Dr. Cheryl D. Ortel in Easton, MD, will initiate a prospective clinical trial and enroll women and men with previous breast cancer. The study participants will periodically donate blood (therapeutic phlebotomies) and modify their diets, as necessary, to reduce or maintain their ferritin and transferrin saturation percentage levels. The objective will be to keep the ferritin slightly below 50 and the transferrin saturation percentages slightly below 45%. By reducing the intake of red meat or other high iron foods along with avoiding vitamin C in pill form and doing periodic phlebotomies it may be possible to reduce the recurrence of breast cancer in some people.

Mrs. Bedell has many motivations for getting involved in this area of research. One motivator is Mrs. Bedell's graduate study of Public Health at Hunter College, New York City, NY. Another very important factor is that she herself has an iron disorder and may be more susceptible to breast cancer because of the H63D gene, ethnicity and age. For years she suffered from depression, joint pain and other physical symptoms. Finally she began searching for answers as to what was wrong with her. She faced many barriers getting a correct diagnosis because many physicians are not familiar with iron disorders. Her quest for a diagnosis included one physician who diagnosed her as having a blood disease instead of an iron metabolism disorder. Yet another doctor refused to give her a prescription for a therapeutic phlebotomy. Armed with medical

Please See **Bedell Profile** on page 6.

**Marilyn Baker, M.B.S., LLC
Director of Outreach**



Iron Disorders Institute welcomes **Marilyn Baker**, M.B.S. LLC, as our new Director of Outreach.

Coming from her term as President of the Aplastic Anemia & MDS International Foundation, Marilyn has a strong background in patient support and advocacy. She will help IDI in several ways including promotion of hemochromatosis, advocating on the Hill with Aran Gordon, working with members of the board of directors to securing new sources of funding to support research and help patients fighting iron imbalance disorders.

Partnership with IDI supporters is crucial if we are to achieve our life-saving mission: to assure that people with iron disorders receive early, accurate diagnosis, appropriate treatment and are equipped to live in good health.

At the recent board of director's meeting all members present agreed unanimously with the comment made by Dr. Herbert Bonkovsky, Chairman of IDI's Scientific and Medical Advisory Board "Marilyn will be a great addition to IDI and a wonderful help to Cheryl."

Adds Cheryl Garrison, Executive Director, "I am delighted to have Marilyn on board; her experiences with growth and challenges of a non-profit will be invaluable to us. She has already helped me tremendously."

Marilyn emphasizes that financial resources must be found for IDI to fund medical research studies and continue to provide valuable updated medical information to patients. She is interested in talking with any supporter who would like to help IDI identify major donors, create corporate allies, and locate other sources of donations.

Please contact Marilyn by telephone at 443.607.8302 or email her at mbaker@irondisorders.org

IRON PATIENTS – THEIR OWN STORIES***“Education is the most powerful weapon which you can use to change the world.”******Nelson Mandela, Statesman*****DAN WILSON****NON-ALCOHOLIC FATTY LIVER DISEASE AND HEMOCHROMATOSIS*****“This may just be normal for me.”*****In retrospect, I wish I had never heard those words.**

The American Liver Foundation estimates anywhere between 10-20 percent of all Americans live with a condition formally known as steatohepatitis. In layman terms, this condition is a fatty liver. In 2-5 percent of Americans, steatohepatitis is accompanied by inflammation leading to a more serious condition called non-alcoholic fatty liver disease or NASH.

My journey with NASH started nearly nine years ago when I made an appointment for a routine physical before a possible deployment to the Middle East. These types of assignments come up occasionally when working in the field of aviation maintenance for a Department of Defense contractor. Remembering what the medical facilities were like from a previous tour, I figured it would be wise to get checked out prior to departing. I was feeling well at the time and didn't expect anything out of the norm. Two days later I was called by the doctor's office asking me to come in for a consultation. Apparently one of the blood tests revealed elevated liver enzymes (ALT & AST). Total protein was also higher than the normal range. A second liver function test was completed as well as hepatitis screening which came back negative but the liver enzymes and protein were still elevated. "This may just be normal for me." In retrospect I wish I had never heard those words.

My primary care physician (PCP) wasn't completely comfortable with my blood tests so he referred me to the local cancer center for more tests. For the next six weeks I underwent a series of tests to find out what the cause of the enzymes and protein levels were. This was probably the most stressful time in my life. Each appointment resulted in another blood test with no answer for the results. Total protein was higher with each test and the liver enzymes remained elevated. Eventually they came to the conclusion that I was cancer free and sent me home with what I thought was a clean bill of health. I was feeling well so I figured my PCP was right when he stated this could be normal for me.

Over the next several years my health was noticeably degrading, prompting me to visit my PCP on many occasions for various illnesses, aches and pains. With each blood test the ALT and AST enzymes were flagged. Fortunately, the proteins fell back into the normal range. Whenever a doctor mentioned them I explained what my PCP had told me, detailed all the previous tests and stated no follow up tests were ever performed. After all, those results were "normal for me."

In 2003, my PCP retired from the medical profession and I was assigned a new doctor. By this time fatigue was setting in and I was attributing it to the stress from a big project I was overseeing at work.

I started to see my new doctor for a chronic cough in 2004. After several office visits without any success in treating the cough, he asked me to come in for a routine physical. Once again the liver enzymes were elevated and I tried to explain how that was normal for me. This time my explanation fell upon deaf ears and he ordered more blood test over the next couple of weeks. One revealed elevated iron levels and then a ferritin level of 719 with a transferrin-iron saturation percentage (TS%) of nearly 97%. He suspected hereditary hemochromatosis (HHC) and ordered a genetic test which revealed I was an H63D heterozygote and he formally diagnosed me with HHC.

Phlebotomies were immediately started with a hematologist to treat HHC along with the normal blood work that goes with them. While my ferritin level was dropping, my liver enzymes remained elevated. There was also a persistent dull pain in the upper right quadrant of my abdomen.

Now taking a more assertive approach to my health care I began to ask questions and research on my own. An ultrasound was ordered, after pushing the right buttons, and I was diagnosed with an enlarged or fatty liver. I began to ask about a liver biopsy to see what the extent of damage was done from the iron. Both the PCP and hematologist said a biopsy was not necessary since my ferritin level did not go over 1000. My research verified this if the patient is under the age of 40. I, on the other hand, was in my mid forties, had liver enzymes out of the norm for several years, and was not comfortable with the possibility my liver could have an even more serious problem, like cirrhosis.

Thirteen phlebotomies later I was declared de-ironed. The cough went away but the ALT and AST enzymes were still well above the normal range and my concern was as elevated as the enzymes.

A couple of follow-up appointments later I was finally able to convince my PCP to refer me to a Gastroenterologist. Upon reviewing my records and hearing the story he agreed to perform the biopsy.

The diagnosis of non-alcoholic steatohepatitis (NASH) came in April 2005. There was no evidence of cirrhosis or fibrosis. My big boned liver had inflammation which was causing the enzymes to stay high. He informed me the treatment was a slow weight loss coupled with lowering cholesterol and controlling my glucose level. Losing weight too fast can worsen the condition. I managed to drop twenty pounds, my cholesterol has dropped from 249 to 149 and my glucose levels remain under control. The enzymes slowly fell back into the normal range and have stayed there for the past 14 months.

Please see **Wilson** on page 6.

IRON PATIENTS – THEIR OWN STORIES**“Education is the most powerful weapon which you can use to change the world.”****Nelson Mandela, Statesman****RICK KAUFMANN
HEMOCHROMATOSIS HEALTH FAIR**

Fifty year-old **Rick Kaufmann** was diagnosed with hemochromatosis three years ago. His story is typical of the wild ride many patients take to get the complete diagnosis. Often said by Chris Kieffer, a founder & past board member of Iron Disorders Institute, “Most people with an illness wait for a cure; people with hemochromatosis wait for a diagnosis!”

Rick was no exception. He was a regular blood donor, donating 1 to 3 times a year in

response to blood drives at his place of work the Veterans Hospital, Reno Nevada. Though at the time, he had several vague symptoms of fatigue, headaches, irregular heart beat, and weight gain, it was not until he was told that he could no longer donate blood that he began to investigate matters.

“Since I had been working at the VA hospital for 16 years, repairing medical equipment, I told a friend who was a cardiac R.N. that the blood mobile refused my donation. She asked me a few questions and offered to perform a calibration check of an EKG machine on me. She did a 12 lead exam, we showed the print-out to a cardiologist, also a friend, who took a quick peek. His response was you are now over 50, you are overweight, and it has been over 3 years since your last physical. Start there!

Taking his advice, I made an appointment with my family doctor who gave me a complete physical including lab work. After a few days I was called by his office and asked to go back to the lab for another test. After that test I received another phone call to go back to the lab for a third test. I just thought my blood was being either lost, contaminated, or I had something in the results that baffled the doctor.”

The latter must have been closer to the mark, since my doctor made an appointment for me to see an internal medicine doctor. It was a good call, because that doctor gave me of the diagnosis of hemochromatosis (HHC). He recommended I have a cardiac workup with a cardiologist, a liver biopsy, and scope of my colon to evaluate the damage that may have been caused by the HHC.

A liver biopsy revealed elevated iron (+1.5) and a genetic test was ordered. Genetic testing confirmed the diagnosis of classic, type I hemochromatosis, which is the presence of two copies of the C282Y mutation of HFE.

Rick and his wife Marge thought immediately of their two children. Their son Scott, age 22, was away at college swimming for the University of Florida and their daughter Karen, age 19, was on her way to New Mexico State University also a swimmer. The decision was made to monitor the iron levels for Scott and Karen, which were found to be within normal range. Both children will consider genetic testing when they are ready to start a family of their own.

Rick was helped by the Iron Disorders Institute books Guide to Hemochromatosis and Cooking with Less Iron. In fact,

Marge has created some recipes of her own based on favorites in the book. He is now a regular visitor to the web site iron-disorders.org and to the toll-free patient information request line.

After 39 phlebotomies in 44 weeks, Rick is now dealing with iron avidity, which is iron deficiency in hemochromatosis patients who have been over-bled. His ferritin is improved but still hovers around 12_{ng/mL}. He was delighted to hear that the IDI approach to correcting iron deficiency in over-bled hemochromatosis patients is to eat lean red meat, since this is a favorite food he has done without for over a year and a 1/2. “I was grateful for the helpful articles in the online newsletter, *id-in Touch*, about iron avidity and the diet to correct this condition. These articles are ones that I can easily share with my doctors.”

On behalf of other hemochromatosis patients who have undergone many phlebotomies Rick shares a tip: “I wear a special medical alert bracelet noting hemochromatosis”. Initially one might be puzzled by this, but has a very good reason for doing so. After several phlebotomies his nurse made a passing comment that if he were brought into the hospital under an emergency and were unconscious, she and probably others would assume that he was an abuser of drugs. The outcome could have devastating consequences if this assumption were made.

Because of these experiences and being helped by IDI, Rick has become a motivated advocate wanting to reach out to others who may be at risk for hemochromatosis, but also who may be struggling with maintenance issues such as over-bleeding and diet. This year in May Rick provided literature about hemochromatosis to more than 250 employees at the VA Hospital in Reno.

“We must all work very hard to raise awareness in our communities; if we make one bit of effort, we will find people with hemochromatosis and doctors will take notice!”

“My hospital was having an employee health fair. All the departments were setting up informational booths that would be helpful to the employees. The eye clinic was doing eye testing; pharmacy was providing flu shots; etc. I asked if I could do an information booth on my condition HHC and the education coordinator thought it would be a great idea. I called the director, Cheryl Garrison, at IDI. She offered to provide me with pamphlets and posters. I decided I wanted to get something that could be used as a screening poster and try to catch attention using humor from some of the miserable symptoms that I had. With Jeff Foxworthy as my inspiration I came up **“You might have HHC if...”** (See page 8.) The poster went over well especially with the employees with the mental health department who had no idea that an iron overload could cause mood swings and other mental problems. It started a lot dialogue among the medical professionals at my

Please see **Kaufmann** continued on page 6.

Bedell Profile (Continued from page 3.)

journal articles, she finally found a physician who was willing to give her a prescription for phlebotomy therapy. These are just two examples illustrating the lack of awareness and knowledge about iron overload disorders.

Isabelle has two mottos that she fervently believes in and lives by: **“When you give blood, the life you save may be your own”**, and **“Public Health is caring about people before you even meet them.”**

After educating women on managing money and budgeting in addition to helping entrepreneurs pursue their dreams, Mrs. Bedell has dabbled in the stock market. Now, she hopes to soon partner with a non-profit organization or gain funding in some other way to enable her to educate the public about hemochromatosis and reduce recurrence of breast cancer. Without research funding and approval, very little can be done, except give lectures to the public at large and distribute Iron Disorders Institute brochures on hemochromatosis, anemia and iron overload.

Wilson (Continued from page 4.)

NASH and fatty liver are becoming more prevalent in today's world. Diabetes, hypertension, high cholesterol, and obesity make up a condition known as metabolic syndrome. When linked with NASH, the fat content in the liver tends to be higher than those without metabolic syndrome. Studies have also shown the prevalence of heterozygosity of H63D or C282Y to be much higher in NASH patients.

The American Liver Foundation states in their web site that NASH differs from a simple accumulation of fat in the liver. It is accompanied by inflammation that causes damage to the liver cells. This damage is usually detected in ALT and AST enzymes. People with iron overload should keep a wary eye on these enzymes.

After all, they could be trying to tell you something.

Kaufmann (Continued from page 5.)

hospital. I understand that Cheryl shared the poster with people at CDC who responded that it was nice to see patients having fun.

Rick's efforts to raise awareness about hemochromatosis do not end with just the employees. Rick has gained the attention of the medical director at the VA who is enthusiastic about promoting hemochromatosis awareness and training for the 40 healthcare providers and 30 medical students associated with the facility. IDI will supply the educational materials and arrange for training and continuing education credits.

“Many of the hospital staff I work with still believes this is a rare condition. My motivation is to educate medical professionals that this condition is not rare and that people can die without treatment. My years of regular blood donation probably helped saved my life, but still, I was headed toward health-disaster without the complete diagnosis.

“We must all work very hard to raise awareness in our communities; if we make one bit of effort, we will find people with hemochromatosis and doctors will take notice!”

BOARD OF DIRECTORS MEET

Charlotte, NC

The Iron Disorders Institute (IDI) Board of Directors meeting was held at the Embassy Suites, Charlotte NC May 25. Attending the meeting were Tim Roberson, Chairman; Aran Gordon, immediate past chairman; Herbert Bonkovsky, Chair Scientific & Medical Advisory Board; Chad Bortle; Laura Main; Cheryl Garrison and guest Marilyn Baker.

The meeting focused on the board governance policy, which was crafted and approved at a February 2007 board training and meeting in Greenville, SC. For two days in February, 2007 board members Chad Bortle, Laura Main, Cheryl Garrison and Tim Roberson attended board training which included structuring the first 150 policies for IDI, new by-laws, initiating invitations to new board members and changing from Board of Trustees to Board of Directors.

The May meeting was the board's first time to experience the dynamics of a board meeting focusing on the newly adopted board governance policy. Everyone actively participated demonstrating the power of this tool to focus a board and realize exceptional outcomes from the meetings. Executive Director Cheryl Garrison comments on the model “This first report was more challenging than I thought it would be, I am very grateful to Reid for his help guiding me through my first report of this type. Overall, I cannot imagine the future of IDI without the policy governance in place; it clearly allows freedom and flexibility of the Executive Director with oversight that does not micro-manage or rubber stamp. The board members role is well defined and evaluated through ENDS statements. The Executive Director's role is defined by limitations. Tim is to be commended for helping us navigate through our first board meeting with the new policies. Twice during the meeting, he was able to flex his muscle of experience using this tool and bring the board back to task—of course with smiles and Tim's usual sense of humor. In a few years and with more practice, we should have a solid foundation of policy to assure the sustainability of IDI and the very best board performance.”

We wish to thank Kristen Bortle, Chad's wife for making hotel arrangements which was no simple task, since it was race-week in Charlotte and brimming with race fans. Also, we wish to thank again, Reid Lehman who facilitated the board training this past February and for providing Cheryl with some pointers and tips on monitoring reports.

The next board meeting is tentatively scheduled for October, 2007.



Rick Kaufmann explaining iron and hemochromatosis to a veteran at the Veterans Hospital health fair in Reno, NV.

SHAVINGS & FILINGS

OUR NEW HOME AT CDC

Hemochromatosis' location on the Centers for Disease Control website has recently been modified due to a change in the CDC's organizational structure. Hemochromatosis is now under the Division of Blood Disorders, whereas it used to be featured in the Nutrition Division. The Division of Blood Disorders is found under the CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD).

<http://www.cdc.gov/ncbddd/hemochromatosis/>

Please write or email to let us know your opinion on this new development, as we are interested in the effect this change has on patients.

The RESEARCH ADVOCATE

May 2007

* * *

The Iron Disorders Institute's Aran Gordon was featured on the Discovery Health's "Mystery Diagnosis" in April. After diagnosis and treatment of hemochromatosis, Gordon rallied to run a 150-mile footrace in the Sahara twice. For more information about the IDI, a Research!America member, visit www.irondisorders.org.

* * *

THE IRONIC FAMILY SUPPORT GROUP MEETING NOTICE

The Ironic Family, a support and education group for iron overload in the Monterey Bay Area of California will be addressing the issue of do-it-yourself DNA home test kits at their next meeting at 9:30 am on June 2, 2007 at 2395-59 Delaware Avenue, Santa Cruz, CA.

This meeting will focus on Genetic Testing Awareness Month.

Rick Tozer, CLS Supervisor for the Hemochromatosis Program at Dominican Hospital Clinical Lab, will be the featured speaker. Our members and guests will also learn about do-it-yourself DNA kits.

Please contact the Ironic Family Coordinator, **Mardi Brick**, for more information about this and future meetings:

Telephone: 831-459-9459 or 831-429-5949.

Email: marbrik@sbcglobal.net

It's Your Turn to Write a Book

IDI is happy to announce that we have sold the very last of our cook book, *Cooking with Less Iron*. Because the book was so popular and helpful to patients, we have elected to do a second edition. This edition will be a little bit different and exciting. This time around, we invite you to submit recipes that you've found enjoyable and low in iron. We will be choosing recipes to be included in the book from recipes that are sent in. If you are interested in sending your recipes, please send us your name, a short story or explanation about your recipe, and the detailed recipe instructions.

ANOTHER IRON SCIENTIST TO THE RESCUE



Hiromi Gunshin joined the School of Public Health and Health Sciences, Department of Nutrition at the University of Massachusetts in Amherst, MA, in September as an Assistant Professor. Dr. Gunshin holds a Ph.D. in Nutritional Bio-

chemistry from The University of Tokyo and an M.S. in Nutritional Biochemistry from Hiroshima University. Her research will use knockout mouse models to determine whether iron absorption affects liver and heart iron accumulation, and to investigate how iron absorption is regulated, and how the liver and heart cells take up iron. The long term goal is to develop strategies to diagnose, prevent, and treat iron overload in the liver and heart.

Hiromi Gunshin is an Assistant Professor of Nutrition, with research interests in iron metabolism, anemia, and iron overload. Dr. Gunshin received her M.S. in Nutritional Biochemistry from Hiroshima University and Ph.D. in Nutritional Biochemistry from the University of Tokyo. She is setting up a cell culture facility in the Department, and will utilize knockout mice to examine iron's roles in different tissues.

STAFF AND VOLUNTEER FAMILY NEWS

Jennifer Clark, daughter of Peggy and Jerry Clark was married to Kris Cassidy on May 19th in Cheraw, SC.

Angela (Angie) Cole graduated received her Bachelor of Arts in Psychology from the University of South Carolina, Columbia, SC.

Damisha Dogan, daughter of Sheila Dogan graduated from Boiling Springs High School; Boiling Springs, SC. Damisha was awarded her school's Athletic Scholar Award. She will attend Virginia State in the fall.

David Garrison, son of Cheryl Garrison received his Bachelor of Arts in Economics from Winthrop University, Rock Hill, SC.

Christina Hines, daughter of Jim and Ruth Hines, received her Bachelor of Science in Liberal Studies from Excelsior College, Albany, NY while serving as a Lieutenant in the United States Navy.

It's Not So Rare!

Hereditary Hemochromatosis (HHC)

You might have HHC,

if your ancestors are from Australia,



Canada,



or Europe!



You might have HHC,

if your knees and hips feel 25 years older than you are!



You might have HHC,

if rust is a new skin tone for you!

You might have HHC,

if your head hurts so much that Advil has become a new food group for you!



You might have HHC,

if sleeping more than 4 hours at a time, is a thing of the past!



You might have HHC,

if you can go from "Mr. Nice Guy" to a "Cranky Old Man" in a millisecond!



You might have HHC,

if you need an afternoon nap more than a kindergartner!



You might have HHC,

if you can't walk by a restroom with out stopping in!



You might have HHC,

if your annual flu or cold is a quarterly flu or cold!



You might have HHC,

if you have started your own kidney stone collection!



And you might have HHC,

if you can set off an airport metal detector in the nude!



Photo Not Available

Submitted by Rick Kaufmann, Reno, NV

Based on his experience with HHC.



MINORITY HEALTH ISSUES UPDATE

By Sheila Dogan
Director, Minority Health Issues



April was observed as National Health Month across the nation and the goals of the observance include raising and expanding awareness about health disparities in minority communities and implementing strategies to address these disparities. Minorities often have less access to care; receive lower-quality care; and have higher rates of illness, injury and premature death than does the general population, according to the Institute of Medicine's 2003 report "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care. National Minority Health Month was established in 1998 by the National Minority Health Month Foundation to increase awareness about health disparity issues affecting minority population.

Life expectancy and overall health have improved in recent years for most Americans, thanks in part to an increased focus on preventive medicine and dynamic new advances in medical technology. However, not all Americans are benefiting equally. For too many racial and ethnic minorities in the United States, good health is elusive, since appropriate care is often associated with an individual's economic status, race, and gender. While Americans as a group are healthier and living longer, the nation's health status will never be as good as it can be as long as there are segments of the population with poor health status. Even with outstanding progress in the overall health of the Nation, there are continuing disparities in the burden of illness and death experienced by blacks or African Americans, Hispanics or Latinos, American Indians and Alaska Natives, and Native Hawaiian and Other Pacific Islanders, compared to the U.S. population as a whole. For those of us who are not aware of the disparities the following information source is the website, **Healthy People 2010**:

<http://www.healthypeople.gov/>

"Even though the Nation's infant mortality rate is down, the infant death rate among **African Americans** is still more than double that of whites. Heart disease death rates are more than 40 percent higher for African Americans than for whites. The death rate for all cancers is 30 percent higher for African Americans than for whites; for prostate cancer, it is more than double that for whites. African American women have a higher death rate from breast cancer despite having a mammography screening rate that is nearly the same as the rate for white women. The death rate from HIV/AIDS for African Americans is more than seven times that for whites; the rate of homicide is six times that for whites."

"**Hispanics** living in the United States are almost twice as likely to die from diabetes as are non-Hispanic whites. Although constituting only 11 percent of the total population in 1996, Hispanics accounted for 20 percent of the new cases of tuberculosis. Hispanics also have higher rates of high blood pressure and obesity than non-Hispanic whites. There are differences among Hispanic populations as well. For example, whereas the rate of low birth weight infants is lower for the total Hispanic population compared with that of whites, Puerto Ricans have a low birth weight rate that is 50 percent higher than the rate for whites."

"**Asians and Pacific Islanders**, on average, have indicators

of being one of the healthiest population groups in the United States. However, there is great diversity within this population group, and health disparities for some specific segments are quite marked. Women of Vietnamese origin, for example, suffer from cervical cancer at nearly five times the rate for white women. New cases of hepatitis and tuberculosis also are higher in Asians and Pacific Islanders living in the United States than in whites."

"**American Indians and Alaska Natives** have an infant death rate almost double that for whites. The rate of diabetes for this population group is more than twice that for whites. The Pima of Arizona have one of the highest rates of diabetes in the world. American Indians and Alaska Natives also have disproportionately high death rates from unintentional injuries and suicide."

Iron-Out-of-Balance™ is often related to many disorders that affect minority populations to a greater degree; such as heart disease, cancer, diabetes, tuberculosis, HIV, low birth rates, high blood pressure. Although the prevalence of iron-deficiency anemia has remained stable over the last decade in the general U.S. population, it continues to be highest among minority and poor children. Anemia diagnosed early in pregnancy is associated with increased risks of low birth weight and preterm delivery. IDI's minority health issues education program can be instrumental in helping to reduce those numbers by educating minorities on the role that iron plays in these focus areas.

I know these facts are distressing but unfortunately they are true, and knowing that iron imbalances play a role in some of the diseases listed is what motivates me. Your help is very important to the work that we do, and I am calling out to all to help us. Our programs are developing around these issues; our success depends upon funding, as is always the challenge of any non-profit. If you have an interest in helping us get the word out to the minority population with either a donation, sponsorship or by volunteering time, contact me.

Now it's time to thank the South Carolina Human Affairs Commission for inviting IDI down to share and educate the staff on iron disorders. I would also like to thank Gardenia Ruff for meeting with me, and discussing ways we could partner together to address the serious issue around iron disorders in the minority communities.

IDI thanks the following contributors for their donations to our **Minority Health Program**:

Mr. Patrick Wright (Toyota of Greer, SC), **Mr. Bobby Foster**, **Professor Ron Romine**, **Mr. Larry Geter** and **Mr. Fredrick D. Gibbs**

Mr. Fredrick D. Gibbs is President and CEO of Banc Capital & Financial Services, Inc., a financial intermediary company that provides commercial real estate loans through a number of bank and non-bank lenders. Mr. Gibbs donates his time with several organizations in Spartanburg County, and is the IDI's largest supporter of the minority program this month.





Dear Friend of IDI:

Over the past 10 years the Iron Disorders Institute (IDI) and thousands of patients, families and friends have forged a powerful partnership. Together, we have built a remarkable institute of programs and services focused on providing information about iron-related disorders and advocating for better diagnosis and treatments.

I am extremely proud to report to you that as a result of our partnership, IDI has grown to the edge of a new level of productivity. Soon we will offer an improved website featuring additional resources and services. We have increased our advocacy to fight for more medical research. And we have created more awareness about iron disorders. Unfortunately, we have gone as far as we can with our current resources and will only grow further with additional support.

This is why I am asking you to invest in IDI and help us grow into a higher level of service and advocacy.

We CAN get there with your support, so please make a generous tax-deductible contribution to IDI today. Your donation will enable us to do a better job in helping more patients, providing more medical information, creating more awareness, and funding more research to find better treatments.

Your **\$50** donation will provide one patient with one year of IDI educational materials and newsletters.

Your **\$75** donation will supply one doctor's office with IDI educational materials for their patients.

Your **\$100** donation will buy one month of postage used to mail information to newly-diagnosed patients.

Your **\$500** donation will pay for one month of IDI's toll-free hotline used to answer patient's questions.

Your **\$1,000** donation will print one year's supply of one medical information brochure.

Your **\$2,000** donation will distribute one issue of our Bi-monthly News Bulletin.

Your **\$5,000** donation will give patients one additional informational service on our website.

Your **\$10,000** donation will promote the need for more research funding for better diagnosis and treatments.

We have made donating EASIER for you by offering our ***IDI MONTHLY GIVING PROGRAM***. This is a convenient way for you to spread your donations comfortably throughout the year instead of making one large contribution during the holiday season. For less than a cup of coffee a day, you can provide us with the financial foundation we need to help more patients and to find more treatments. Simply return the enclosed IDI Monthly Giving Enrollment Card - an easy way to have your tax deductible contribution made by the end of the year!

Please, let's continue our partnership every month of the year and I pledge to you a GREAT return on your investment. On behalf of the thousands of patients ones who will directly benefit from your gift, thank you.

Sincerely,

Cheryl Garrison
Executive Director

Marilyn Baker, MBS
Director, Outreach Programs

P.S. REGISTER your family members, friends, interested co-workers, and medical contacts to help us spread the word about the importance of iron disorders awareness and invite them to join our efforts! Include your list of contacts along with your donation and completed Monthly Giving Enrollment Card in the enclosed envelope!

2722 Wade Hampton Suite A, Greenville, South Carolina 29615
Phone: 864-292-1175 • Fax: 864-292-1878 • www.irondisorders.org

Iron Disorders Institute is a registered 501(c)3 non-profit charitable organization incorporated in South Carolina, USA; FEIN 57-1054474