Great news for patients

**May 2008:** FerriScan® arrives at Carolinas Medical Center, Charlotte, NC.

Herbert Bonkovsky, M.D., is gearing up to accept patients for liver iron measurements using FerriScan®. Dr. Bonkovsky is Chairman, Iron Disorders Institute Medical & Scientific Advisory Board; Vice President for Research, Carolinas Medical Center, Professor of Medicine, University of Connecticut, and Adjunct Professor, University of North Carolina.

FerriScan® is software that allows for a non-invasive (does not puncture the skin) way to measure the amount of iron in the liver (hepatic iron concentrations). The technology works with standard magnetic resonance imaging (MRI) equipment. In a very simplistic description, MRI uses a powerful magnet and radio-frequencies (signals, pulses) which are sent through the person’s body producing a reading that is sent to a computer. Using a specialized technique a trained radiologist can demonstrate differences in the rate at which a signal/pulse transverses (passes through) the body. A reading is taken of these rates (proton transverse relaxation rates, or (R2)) which yield the relaxation time (recovery time) of the signal/pulse. If nothing stands in the way of the signal/pulse, the relaxation time is normal and the output or reading of the organ scanned demonstrates no abnormalities. When the signal is interrupted by a tumor or in this case, iron, the relaxation time is “shortened”. If iron is present in the liver, the output reading shows a “black” area where the signal/pulse recovery time was abbreviated. A radiologist must have additional training to perform this specialized imaging technique. Dr. Herbert Bonkovsky is one of the inventors of this approach.

**Arch “Chip” Mainous III, Ph.D. joins Iron Disorders Institute’s Medical and Scientific Advisory Board.** Dr. Mainous obtained his Ph.D. from the University of Texas and spent 8 years as director of research in the Department of Family Medicine there before joining the Department of Family Medicine at Medical University of South Carolina (MUSC) in 1998. He currently serves as director of research in the department. Dr. Mainous’ research interests are in diabetes and cardiovascular health, treatment of respiratory infections, continuity of care and biostatistics. Dr. Mainous has published several articles that report important iron related findings, including that biochemical markers for iron overload, alone and when combined with other risk factors, can increase the potential for premature death, cancers and Alzheimer’s disease.

**Nancy C. Andrews, M.D., Ph.D.** is one of four new members appointed to the Advisory Council of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) by Health and Human Services Secretary Mike Leavitt. Dr. Andrews is an emeritus member of the Iron Disorders Institute (IDI) Advisory Board. Her early contributions to IDI’s Physician Reference Charts and other publications remain current and vital to IDI’s education programs. Currently Dr. Andrews is dean and vice chancellor of Academic Affairs at Duke University School of Medicine in Durham, N.C. She is the first woman to be appointed dean of Duke’s School of Medicine and is the only woman to lead one of the nation’s top 10 medical schools. Prior to her appointment at Duke, she served as dean for Basic Sciences and Graduate Studies at Harvard Medical School in Boston. She is also an internationally renowned researcher in the fields of pediatric hematology and oncology. Dr. Andrews’ research interests include the study of iron absorption and its role in hereditary hemochromatosis.
DearIDI Member,

This advanced printed copy of nanograms, IDI’s newsletter, is made possible in part by your membership dollars. We hope it provides helpful information for you and your family. PDF versions will be placed on our website at a later date, so that you can download it for friends; however as a member, you can request additional FREE hard copies of nanograms (while supplies last) for up to six family members. We will do the mailing!

We are very proud to announce the most recent addition to our Medical & Scientific Advisory Board, Dr. Chip Mainous. His work is highlighted on the cover page but I must add a personal note; besides being a very gifted scientist, Chip is kind and generous. He has already demonstrated his willingness to help IDI carry out its mission with the highest level of professionalism.

In spite of flight delays, soaring gas prices, speaker scheduling challenges, we all had an amazing time at the April Midwest Regional Hemochromatosis Conference, Hilton at Easton, Columbus, OH! Conference organizers Dr. Mark Wurster, Laura Main, Missie Kendall, Chad Bortle, Kristen Bottle; support personnel, staff and volunteers Sam Kendall, Erica Passarell, Gretchen Herr, Debbie Clegg, Bob Clegg, Beth Gwynn, Evie Stark, Linda Hover, Nancy Graham, Peggy Clark, Angie Cole, David Garrison are to be commended for a job well done. Laura Main gained the distinction of M.D. (Most Determined) for her efforts. Accommodations at The Best Western Port Columbus and The Hilton at Easton received high marks by attendees, guests and board members. Laura Main reports that 91 people were registered for the conference; although some attended only the AM or PM sessions. See pages 8-9 for conference highlights and comments; they’re impressive! Board of Director members Gerry Koenig, Tim Roberson and I are especially grateful to Jason Stilwell for his expert driving to and from Ohio (despite Tim’s side trips—translated: we got lost!)

To maximize resources, the IDI Board of Directors met at the Best Western, Port Columbus, OH. (Thank you Chad & Kristen for arranging this—we appreciate it.) The board had a lively and productive meeting thanks to Tim Roberson’s board exercise and a major presentation by newest board of director member Gerry Koenig. Besides me, members present at the meeting were: Tim Roberson, Laura Main, Chad Bortle, Gerry Koenig, Herb Bonkovsky and guest Missie Kendall.

We are always in need of volunteers! Key activities during the upcoming three months where volunteers could help tremendously include helping with the Western Regional Hemochromatosis Patient Conference (more details page 10); health-fairs, July Hemochromatosis Awareness Program; distributing IDI’s 2008 Physician Hemochromatosis Reference Charts, conducting surveys, reviewing or contributing to IDI publications such as nanograms, websites, and the second edition of our books: Guide to Anemia and Guide to Hemochromatosis. Most volunteer work can be done online (from home) or with limited travel. If you are interested, contact me directly: cgarrison@irondisorders.org

Have a great summer and thank you so much for your continued support of IDI’s mission!

Take care,
Cheryl Garrison, executive director
Calcium and Iron

Understanding calcium’s role in absorbing iron

Calcium and iron are essential minerals. Neither is made naturally by the body and must be gotten from the diet. Calcium is a macronutrient, where greater amounts are needed daily as compared to iron, which is a micronutrient, where only tiny amounts are required daily. Absorption of these nutrients depends on sufficient acid in the stomach, substances consumed with these nutrients and which form of the nutrient is taken.

Calvin citrate for example may be more easily absorbed than calcium carbonate, because the “citrate” provides the acid environment needed to make a nutrient more soluble. This is especially helpful for elderly people who might not have low levels of stomach acid. If you eat chocolate or consume a large amount of fiber or do not have adequate amounts of vitamin D, the calcium is not as efficiently absorbed. CDC recommends “3-a-Day” servings of dairy for adequate amounts of calcium and vitamin D, now a major deficiency for many adults.

Heme iron, the form that comes from animals is easily absorbed. By contrast non-heme iron, the form that comes from plants, is not so easily absorbed. Non-heme iron depends upon acid (stomach or ascorbic) to change it from ferric iron (which cannot be absorbed) to ferrous iron (which can be absorbed). Very little interferes with the absorption of heme iron, but a number of substances can impair the absorption of non-heme iron. Tannin in coffee or tea, oxalates in spinach or chocolate, fiber (phytates) and calcium supplements can lower the bioavailability* of iron.

Calcium is often prescribed for women to lower the risk of osteoporosis, even though evidence suggests that other approaches, such as supplemental vitamin D may work better to lower this risk of this disease. Recent reports of increased heart attacks among post-menopausal women brings an added concern for older women. In a study of 1471 postmenopausal women (mean age 74): 732 were randomized to calcium supplementation (how much?) and 739 to placebo. Those who were taking calcium supplements had a 47 percent higher risk of having any one of three “events” (heart attack, stroke or sudden death) than women in the placebo group.

When taken with iron, calcium supplements in amounts greater than 500 milligrams can impair both heme and non-heme iron absorption, increasing the risk of iron deficiency anemia. This approach might be helpful for patients with excessively high body iron, such as a person with hemochromatosis. But Iron Disorders Institute does not recommend taking calcium supplements in lieu of blood removal to lower body iron levels. This approach could be incorporated into an overall strategy for lowering iron levels if one’s physician is recommending calcium supplementation.

Regardless of one’s iron status, unless otherwise prescribed by your physician, calcium supplementation should not exceed 500 milligrams daily if taken at all. The primary source of calcium in our opinion is best gotten from whole foods such as green leafy vegetables, low-fat yogurt, oranges, almonds and sesame seeds.

Second Quarter 2008

3

www.irondisorders.org

©2008 Iron Disorders Institute

Resource:
http://ods.od.nih.gov/
Tordoff MG, Alleva AM. “Effect of drinking soda sweetened with aspartame or high-fructose corn syrup on food intake” 1460-5.


Resource:

Resource:

Resources:
http://ods.od.nih.gov/

Resource:
www.ncbi.nlm.nih.gov/ pubmed/9568093

Summary of Relevant Research (based on NHANES data): Arch G. Mammus III, Ph.D.; Medical University of South Carolina (MUSC); IDH MKSAB and Gerry Kunig, member IDI BOD.

Summary of Relevant Research (based on NHANES data): Arch G. Mammus III, Ph.D.; Medical University of South Carolina (MUSC); IDH MKSAB and Gerry Kunig, member IDI BOD.

Summary of Relevant Research (based on NHANES data): Arch G. Mammus III, Ph.D.; Medical University of South Carolina (MUSC); IDH MKSAB and Gerry Kunig, member IDI BOD.

Summary of Relevant Research (based on NHANES data): Arch G. Mammus III, Ph.D.; Medical University of South Carolina (MUSC); IDH MKSAB and Gerry Kunig, member IDI BOD.

Summary of Relevant Research (based on NHANES data): Arch G. Mammus III, Ph.D.; Medical University of South Carolina (MUSC); IDH MKSAB and Gerry Kunig, member IDI BOD.

Summary of Relevant Research (based on NHANES data): Arch G. Mammus III, Ph.D.; Medical University of South Carolina (MUSC); IDH MKSAB and Gerry Kunig, member IDI BOD.

Summary of Relevant Research (based on NHANES data): Arch G. Mammus III, Ph.D.; Medical University of South Carolina (MUSC); IDH MKSAB and Gerry Kunig, member IDI BOD.
My Iron Story:
Vashti Ray

I was first diagnosed with anemia after the birth of my daughter, who is now 18. Because I am in the healthcare field, I knew that my anemia was not life threatening. However, as I have now learned by experience anemia does affect the quality of your life. Anemia is related to not only lack of energy, but may also include symptoms such as weakness, dizziness, depression, rapid heartbeat and difficulty in thinking. I was beginning to suffer from rapid heartbeat and shortness of breath even though I was able to perform my every day tasks without any problems.

Each year at my annual checkup, my family doctor and I would discuss my anemia and treatment options. I would try a new medication each time with the same result—taking it for a few days before quitting. Iron preparations are known to have very unpleasant side effects including constipation, black tarry stool and cramping. Each year my hemoglobin level would decrease more. Finally at my annual checkup in 2006, my level was below 7.0 (normal level for women 12-15). My family physician became concerned at my dropping levels and referred me immediately to a hematologist to ensure that I did not have a blood disorder.

The hematologist performed a complete blood count as well as checked my iron stores. My iron stores were low, but treatable by methods not involving intensive intravenous therapy. Before leaving my family physician, again we tried a new medication called Tandem Plus. The hematologist decided to continue this therapy and monitor my levels monthly.

It has almost been a year since my first visit with the hematologist. My hemoglobin levels are within normal and my iron stores are improving. I no longer have the shortness of breath or the rapid heartbeats. I am by no means cured for I continue to take my medication and keep my appointments for monitoring of my levels. As my family physician often says to me regarding my anemia and energy, “why live your life at a 6, when you could be at a 10!”

Cherished and remembered, forever...

In memory of Jewel Dale Lambert, Sr.
by Shelby Bruce, Laura Clapp, Diane King, Lou McDaniel, Belinda McKinley and Debra Stafford
the Faculty of Florence Elementary School.

In memory of Jewel Dale Lambert, Sr.
by The Thomas B. and Doris Laverne Clark
Kennedy Family.

In memory of Mr. Kevin Patrick Hyland from Caliper Life Sciences
from Mr. and Mrs. Charles Duc, Steven Wojtal and Wendy Koziel, Paul Wojtal, Michael Wojtal and Ann Withington.

In Loving Honor Of...

Cheryl Mellan
By Peggy Queen

OUR MISSION

“My Iron Disorders Institute (IDI) exists so that people with iron disorders receive early, accurate diagnosis, appropriate treatment and are equipped to live in good health.”

If you would like to honor the memory of someone who is suffering or who has lost the battle with a deadly iron disorder, or you have a prayer list request, call us toll free 888-565-4766 or email Peggy Clark: pclark@irondisorders.org.
Acupuncture by Dr. Benjamin Zappin

Traditional Chinese Medicine (TCM) is a safe and effective system of both diagnosis and treatment of illness and imbalance in the body that has been experiencing rapid growth and acceptance around the world. The goal of this article is to expose the reader to the theoretical nature of TCM, its history, and various medical/healing modalities and their possible role in providing relief for many secondary complications of hemochromatosis. There are many imbalances for which TCM is indicated from which individuals living with iron overload disorder often suffer, including depression, irregular heart beat, osteoarthritis, impotence, infertility, hypothyroidism, and diabetes mellitus. This article explores how TCM balances the body and how an individual might safely go about finding relief from their ailments related to hereditary hemochromatosis (HHC).

TCM originated in Chinese societies several thousand years ago and has developed continuously to the present day. Contemporary Chinese medicine has benefited from the validation and refinement of modern scientific research both in China and abroad. Chinese medicine is a comprehensive medical system that utilizes a variety of methods of treatment including acupuncture, Chinese herbal medicine, massage, heat therapy, and lifestyle recommendations. Acupuncture is the modality that has received the most attention in Western medicine, being implemented in many American hospitals and being subjected to research in the West. Acupuncture is a form of treatment that employs thin, solid, metallic needles at specific anatomical points in the skin, manipulated either manually or electrically, to effect different healing responses from the body.

The basics concepts of TCM diagnosis and treatment involve balancing the body in reference to a variety of pattern discrimination methods that describe the body in relation to the natural world. TCM takes into account heredity and the individual’s relationship to nature, as well as considering a Western-defined disease diagnosis. If someone has a deficiency of vital energy and fluids, the therapeutic objectives and tools for recovery are going to be very similar for an individual with depression as they are for someone recovering from a cold or flu as long as they present with the same energetic pattern. Thus, TCM can bring the body into balance with a focus on health rather than focusing on the cellular processes of disease.

The practitioner determines what is out of balance in the body via a series of four standard diagnostic modalities. First, the practitioner asks a series of questions to gain information about signs and symptoms of imbalance and to get a detailed history of the development of the pathology. Next, the practitioner will do a visual inspection, inventoring skin color and tone, posture, and other characteristics of the face and body. He or she will also carefully inspect the tongue and its coating. The sound of the voice and any relevant smells emanating from the patient will be taken into account during the diagnostic inquiry. Finally, different areas of the body including the abdomen, any areas related to the body’s imbalance, and especially the pulse at both wrists will be felt. The information from these examinations is used to form a diagnosis followed by a treatment plan.

TCM as it is practiced today involves the integration of information from advances in modern medicine. TCM is part of the hospital systems of many countries around the world. Research into the value of acupuncture is increasingly taking place in the West often motivated by the relatively low costs and ease of implementation in relieving different health concerns. The World Health Organization (WHO) and the U.S. National Institutes of Health (NIH) have completed a large body of literature and research corroborating the traditional use of Chinese medicine for a wide range of disorders. It is increasingly the standard for TCM practitioners in the United States to receive a solid foundation in Western medical diagnostic procedures and pathology, thus enabling them to read laboratory tests, various imaging systems, and to perform other physical diagnostic tests. In California, Licensed Acupuncturists are considered primary health care physicians meaning that they are licensed to diagnose and treat illness, order lab tests, and have hospital privileges in many cases. Many health plans now provide acupuncture coverage.

There are many common complications of hemochromatosis that are commonly benefited by acupuncture and other TCM modalities. The value of acupuncture in the treatment of osteoarthritis, depression, and infertility has all been established in several research studies in the United States. Courses of therapy vary from one imbalance or disease to another. Sometimes patients can resolve an issue with lifestyle changes alone.

The pain and inflammation of arthritis that often occurs as a result of iron overload disorder can often be quickly remedied by acupuncture. Sometimes patients can obtain significant relief in one treatment. Generally patients begin receiving one to three acupuncture treatments per week for a few weeks. A standard course of therapy consists of 10-12 treatments after which the need for frequency of regular treatment.

TCM should not be a substitute for regular Western medical care for individuals with iron overload disorder, but rather provides a highly effective complementary modality for alleviating the suffering from the secondary complications of this disease. Patients should discuss adjunctive therapies such as TCM with their physician. It is also important for patients to educate their acupuncturist about the details of their particular condition. By balancing the body through natural therapies TCM can reduce patients’ dependency on multiple pharmaceuticals to treat these secondary complications, limiting harmful side-effects and promoting the healing process.

To locate a TCM practitioner see www.nccaom.org

Benjamin Zappin, L.Ac., Herbalist, practices in Santa Cruz, Ca. Benjamin is on the faculty of Five Branches University and operates Five Flavors Herbal Pharmacy. Please see www.fiveflavors-herbs.com.
River Rock Valley Blood Center (RRVBC), Rockford Illinois obtained its FDA variance December 10, 2007. The FDA variance allows for use of hemochromatosis (HHC) blood for transfusional purposes. Staff at RRVBC invite hemochromatosis patients to participate in their program. RRVBC services the needs of eight hospitals in the northern Illinois and southern Wisconsin area. RRVBC welcomes any HHC patient that feels like traveling to the downtown Rockford facility.

Hemochromatosis patients need to obtain an order from the doctor to participate in the program. For physicians unfamiliar with special services of this type, Iron Disorders Institute (IDI) Medical Advisory Board provides a sample order (see blue box in next column) and evidence-based illustrated Physician Hemochromatosis Reference Charts.

To request a FREE copy of the Iron Disorders Institute Physician Hemochromatosis Reference Chart contact Peggy Clark at IDI toll free 888-565-4766 or by email: pclarke@irondisorders.org

If you have ever participated in the online Excess Iron Discussion Group (List Serve provided by IDI), you know List Moderator Cheryl Mellan. Cheryl took on the demanding job as moderator of the list in 2002, when she encouraged IDI’s board to take ownership of the unique open discussion forum. Since participation allows for open iron-related discussion Cheryl has weathered many discussion storms (some of them a category 5!). Undaunted, she continued to deliver reliable health information to patients and healthcare providers looking for answers. Her well written exchanges with list participants were charged with passion and determination.

Cheryl is the IDI 2003 recipient of IDI’s “Stars in Our Eyes” award for her outstanding efforts on behalf of patients. She has been a strong promoter of IDI events and publications, getting the word out to visitors on the List. Earlier this year, Cheryl landed a dream job with the national forestry service. Now she enjoys commuting from her home (where she checks in on list members from time to time) into the woods to contribute to another worthy cause: beautifying and protecting our natural resources of Ohio. “Cheryl Mellan has always been passionate and determined whatever the issue. She loves people of any age and will go to great lengths to reach out to those she cares about. She is absolutely one-of-a-kind and we know that many will miss her zeal and lively responses on the list.” Cheryl Garrison, executive director, Iron Disorders Institute.

“We will miss you; good luck!” Gene Weinberg, Chair IDI Publications

“We are all a bit envious, but glad to hear that your energies will be going to a great cause: protecting our precious natural resources. Thank you for your years of service.” Tim Roberson, Chairman, IDI Board of Directors.

Enrollment is as easy as 1, 2, 3!

1. Contact IDI toll free 888-565-4766 to get educational materials about hemochromatosis (HHC) and iron management

2. Obtain a doctor’s order (see sample order below) that the blood center must have to enroll you in the program

3. Contact the RRVBC Special Services Coordinator Diane Mortenson or Audrey Green (877-778-2299) to set up your visits. Remember, you must have a doctor’s order to donate more often than every 56 days.

RRVBC has three donation centers but only the downtown location offers the hemochromatosis program.

RRVBC Downtown Donor Center and Headquarters
419 N. 6th Street
Rockford, Illinois 61107

Phlebotomize* 500cc so long as hemoglobin is ≥ 12.5g/dL or spun hematocrit is ≥ 37.5%

*Frequency will vary based on iron indices TS%** and serum ferritin (SF)

**TS% is derived by fasting serum iron divided by total iron binding capacity (TIBC) X 100%

RRVBC is a not-for-profit organization, governed by an eleven member Board of Directors. We are regulated by the Food and Drug Administration; accredited by the American Association of Blood Banks; and a member of America’s Blood Centers.

FerrisScan® is a novel magnetic-resonance image analysis technology that has been developed to facilitate a non-invasive measurement of the iron concentration within the liver. The technology is based on the quantitative image measurement of a fundamental physical parameter of magnetic resonance known as transverse relaxation rate (R2). An R2 image is calculated for the largest axial image slice of the liver, following which a transformation is applied to convert the average R2 value for the liver slice to an estimate of the average liver iron concentration (LIC).

The key components for the FerrisScan® liver iron concentration measurement technology are:

1. The use of a specific imaging protocol for acquisition of the raw image data
2. A patented analysis methodology for performing the R2-M image analysis
3. A clinical study calibration curve that enables transformation of the average R2 value in the liver to a liver iron concentration.

To facilitate the FerrisScan® liver iron concentration measurement, the analysis methodology and calibration curve are incorporated into a custom image analysis software platform. To read more about this software visit: www.ferriscan.com

You may also contact Iron Disorders Institute for details.
888-565-4766

©2008 Iron Disorders Institute
Iron-Related Bone & Joint Disease

Excessive stored iron can be predicted to be a direct cause of osteoporosis, and is reported in approximately 50% of patients. Regardless of the cause of iron loading, too much stored body iron can inhibit the production of important hormones in the anterior pituitary, a small gland located in the central region of the skull. Depressed hormonal production will tend to cause iron loaded persons to become osteoporotic. Impaired production of the gonadal hormones estrogen and progesterone has been reported to suppress bone regeneration activity (as well as diminish sexual drive and function). Excessive stored iron can cause or contribute to these conditions.

Most people are surprised to discover that even in adulthood about 10% of the human skeleton is remodeled or replaced every year. This process is accommodated by cells that absorb existing bone material, osteoclasts, and different cells, osteoblasts, serve to remodel and replace bone that is lost through resorption. Some individuals first become aware of this in the area of dental health. Bones that support healthy teeth can be lost (or resorbed) leading to failing dental health and tooth loss. A number of different factors can contribute to this type of bone loss. It is now known that too much stored iron can accelerate or contribute to this painful condition.

Bone resorption coupled with factors affecting bone regeneration is the primary cause of age-related bone loss and can result in osteopenia, which is the precursor to osteoporosis. Eugene Weinberg PhD, a member of IDI’s Medical and Scientific Advisory Board, recently published an article covering excessive stored iron as a factor in osteoporosis. Dr. Weinberg reasons that, “Iron binding agents that specifically could withdraw excess skeleton iron, and be excreted as the iron chelate, might have therapeutic utility.”

The combination of bone resorption and reduced bone mineralization (formation) can weaken skeletal structure and lead to possible bone fracture. As in other conditions affected by excess stored body iron, too much iron can accelerate this process causing it to commence at an earlier age than in those not affected by iron catalyzed oxidative damage. Osteoporosis associated with aging is generally experienced by women following menopause. This is called “primary” osteoporosis, while the same condition resulting from, or exacerbated by, some medications or factors such as iron overload is referred to as “secondary” osteoporosis. Secondary causes can result in osteoporosis in men and premenopausal women and can also contribute to primary osteoporosis in as many as a third of the women affected by this ailment. Recent studies of bone density in men affected by hemochromatosis have shown that osteopenia and osteoporosis occur in fairly significant numbers of men with iron overload. The seriousness of these conditions appear to correlate with age and amount of stored iron. Bone mineral density decreases as iron excesses stored in the liver increase.

Osteoarthritis develops in a fairly high percentage of the population. This condition is also referred to as degenerative joint disease or degenerative arthritis. As in osteoporosis, osteoarthritis can be worsened when iron catalyzed oxidative damage becomes a secondary factor. The disease process can often be debilitating as joints become inflamed and cartilage breaks down. Other genetic factors and normal (or unusual) wear and tear can start the process, which by itself is considered part of the normal aging process.

Arthritis of the hand and the joints of the first two fingers is often a symptom of hemochromatosis. Several types of arthropathy seem to affect both these joints in similar fashion to the processes described directly above. Although when crystals form in the synovial fluid surrounding the major joints in the hand, the condition is called “calcium pyrophosphate dihydrate crystal deposition disease;” the short name is CPPD; and it is sometimes called pseudogout. This often painful condition is normally associated with secondary metabolic causes such as hemochromatosis.

Another condition affecting bone health is osteomalacia. This bone softening conditioning in adults is similar to rickets in children. Iron imbalances and other metal and vitamin deficiencies or surpluses can be primarily responsible for about osteomalacia, which is often observed in patients undergoing chemotherapy and other transfusion therapies.

Traditional phlebotomy therapy can be affective in preventing the onset of the above conditions, but unfortunately once bone and joint involvement reach critical stages, this traditional therapy has not been shown to be able to reverse permanent bone damage.

For more information about bone and joint disease detection and management, visit The Arthritis Foundation website: www.arthritis.org

Resources:

Key Definitions:

Osteoporosis: a disease occurring especially in women after the menopause in which the bones become very porous, break easily, and heal slowly. It may lead to curvature of the spine after the vertebrae collapse. (Encarta Dictionary)

Osteopenia: Osteopenia refers to bone mineral density (BMD) that is lower than normal peak BMD but not low enough to be classified as osteoporosis. (WebMD)

Osteomalacia: a disease occurring mainly in women that results from a lack of vitamin D or calcium, causing softening of the bones and resulting pain and weakness. (Encarta Dictionary)

Osteoarthritis: a form of arthritis characterized by gradual loss of cartilage of the joints, usually affecting people after middle age. (Encarta Dictionary)
Ohio Regional Hemochromatosis Conference ’08
One in 250 Americans have genetic hemochromatosis.
Are you the ONE?

Conference attendees listen intently to identical twins Alison and Meredith C282Y/C282Y homozygotes share details of their compelling stories.

YOU helped make it possible....
We deeply appreciate and wish to acknowledge sponsors who provided educational grants or donations to help make this event possible: Novartis Oncology, MedBen, Licking Memorial Health Systems, Park National Bank and Iron Disorders Institute Members. We also wish to thank Ohio State University, Conference Organizers: Mark Wurster, Laura Main, Missie Kendall, Chad Bortle, Kristen Bortle and Volunteers: Sam Kendall, Erica Passarell, Gretchen Herr, Debbie Clegg, Bob Clegg, Beth Gwynn, Evie Stark, Linda Hover, Nancy Graham, Fran Weinberg, Angie Cole, Lee Woods, Peggy Clark and David Garrison.

Meredith O’Connor Collins stands by her sister Alison O’Connor Dinning as she makes her presentation.

Amy Sturm, after swapping name signs with Dr. Weinberg, listens to his response to a question from a patient.

Weinberg

Bonkovsky

Koenig

Cairns

Garrison

Roberson

Kendall

Mark Wurster, M.D., FACP; OSU and IDI Medical Advisory Board Member

Amy Sturm, MS, CGC, Ohio State University pauses her presentation to take a question about HFE gene from the audience.

Laura Main presents Craig Cairns, MD, MPH, Licking Memorial Health Systems with the 2008 Making a Difference Award, which is given by IDI to an MD for outstanding contributions that further the mission of Iron Disorders Institute.

Laura also presents Lorei Reinhard, BS, MT (ASCP) SH, Licking Memorial Health Systems with the 2008 Stars in Our Eyes, which is given by IDI to an individual for outstanding dedication to patients with iron disorders.

Dr. Bonkovsky responds to questions from attendees. Seated on the left: Gerry Koenig

Amy Sturm, after swapping name signs with Dr. Weinberg, listens to his response to a question from a patient.

Dr. Bonkovsky responds to questions from attendees. Seated on the left: Gerry Koenig

Laura Main presents Craig Cairns, MD, MPH, Licking Memorial Health Systems with the 2008 Making a Difference Award, which is given by IDI to an MD for outstanding contributions that further the mission of Iron Disorders Institute.

Laura also presents Lorei Reinhard, BS, MT (ASCP) SH, Licking Memorial Health Systems with the 2008 Stars in Our Eyes, which is given by IDI to an individual for outstanding dedication to patients with iron disorders.

Mark Wurster, M.D., FACP; OSU and IDI Medical Advisory Board Member

Amy Sturm, MS, CGC, Ohio State University pauses her presentation to take a question about HFE gene from the audience.

Laura Main presents Craig Cairns, MD, MPH, Licking Memorial Health Systems with the 2008 Making a Difference Award, which is given by IDI to an MD for outstanding contributions that further the mission of Iron Disorders Institute.

Laura also presents Lorei Reinhard, BS, MT (ASCP) SH, Licking Memorial Health Systems with the 2008 Stars in Our Eyes, which is given by IDI to an individual for outstanding dedication to patients with iron disorders.

Dr. Bonkovsky responds to questions from attendees. Seated on the left: Gerry Koenig

Ohio Regional Hemochromatosis Conference ’08
One in 250 Americans have genetic hemochromatosis.
Are you the ONE?

Conference attendees listen intently to identical twins Alison and Meredith C282Y/C282Y homozygotes share details of their compelling stories.

YOU helped make it possible....
We deeply appreciate and wish to acknowledge sponsors who provided educational grants or donations to help make this event possible: Novartis Oncology, MedBen, Licking Memorial Health Systems, Park National Bank and Iron Disorders Institute Members. We also wish to thank Ohio State University, Conference Organizers: Mark Wurster, Laura Main, Missie Kendall, Chad Bortle, Kristen Bortle and Volunteers: Sam Kendall, Erica Passarell, Gretchen Herr, Debbie Clegg, Bob Clegg, Beth Gwynn, Evie Stark, Linda Hover, Nancy Graham, Fran Weinberg, Angie Cole, Lee Woods, Peggy Clark and David Garrison.
Conference Comments

“Wonderful Program! Not too technical for those of us who are not in the medical field.”
—P. Queen, Niles, MI

“...There is so much information that I know I’ve missed or misunderstood some... Not being from the healthcare industry, some information I didn’t understand.”
—C. Miller, Ostrander, OH

“The more I learn, the more I realize our medical system is woefully uninformed. Awareness & advocacy seem essential to catch this (hemochromatosis) before severe physical damage occurs.”
—S. Walker, MS, RN; Zanesville, OH

“Excellent Conference! Worth the trip from Florida to Attend”
—M. J. O’Brien, Sebring FL

“Kudos! Great Program, Thank you”
—K. Wilster, Brookfield OH

“Very well put together, looking forward to other conferences.”
—T. Noble, Reynoldsburg, OH

“My hope is that the public will be made more aware of hemochromatosis. Thanks for all your diligent work.”
—M. Berger, Gahanna, OH

“This has been informative and eye-opening. Thank you! I am a real novice!!”
—Name not given

“Excellent Program!”
—J. Pantalos, Columbus, OH

Conference Evaluations

Breakdown of Attendees
- 50% Patients
- 25% Spouse or Friend of Patients
- 25% Healthcare or related professional

Level of Knowledge of Hemochromatosis Prior to Conference
- 61% Known of HHC for years
- 32% Heard of HHC only recently

Level of Knowledge of Hemochromatosis After the Conference
- 7% Never heard of HHC before conference
- 24% Some Knowledge
- 62% Very High Knowledge
- 14% High Knowledge

Evaluation of Presenters Expertise and Delivery Receive High Ratings
Expertise (knowledge of material presented) was rated: 61% Excellent; 39% Very good
Delivery by Presenters was rated: 55% Excellent, 44% Very good
My Iron Story: Mary Jane O’Brien

My journey into the world of hereditary hemochromatosis (HH) took a most unusual path. Until January 2005, I had never heard the word “hemochromatosis”. I had just undergone a routine colonoscopy in Miami, where my gastroenterologist, Dr. Marc Lederhandler found that I had arteriovenous malformations (AVM’s) which are abnormal collections of blood vessels. Suspecting that I might be anemic, as these tend to bleed microscopically, he ordered an iron panel. The results were surprising to him as well as to me a few days later when he told me the results of the blood tests. He surmised that I had hereditary hemochromatosis as indicated by a ferritin level of 713. To confirm this he ordered the gene test which proved positive for the H63D mutation. This particular mutation accounts for less than 1% of those with HH! How can a woman at age 64, with no history of fatigue or other common symptoms have known? The answer is quite simple. I had menstrual periods until I was 60 years old at which time I had a hysterectomy. Over the next 3 ½ years, unbeknownst to me, my iron levels began to rise. Had it not been for a colonoscopy and a very astute gastroenterologist, my outcome may have been quite different.

Dr. Lederhandler immediately sent me to Dr. Peter Citron, a Miami hematologist who again counseled me in great detail about the implications of HH, if not treated. He ordered a liver MRI which was normal. For several months my iron levels were monitored and my ferritin began to decrease at times. It was not until my ferritin reached 854 that I began phlebotomies. Initially, my prescription was for every 2 weeks unless my hematocrit level went below 36. Since I was donating at a licensed Blood Center, twice they were able to use my blood for donation when the hematocrit level was at or above 38. I felt good knowing someone would benefit from my donation. I would return to the Blood Center every 2 weeks and many times my hematocrit level was below 36, so they were unable to proceed. In February 2008, Dr. Citron was dissatisfied that my ferritin level was not decreasing quickly enough so he lowered the target hematocrit level to 32. Now I was able to have phlebotomies every 2 weeks, and did so for the next eight weeks. I’m happy to report that last week my ferritin level was 34. At Dr. Citron’s direction, I have stopped the phlebotomies for now and will have additional blood work in 3 months. Hopefully, I will then be on maintenance with a phlebotomy every 3-4 months.

On April 19th I had the pleasure of attending the Hereditary Hemochromatosis Patient Conference in Columbus, Ohio, sponsored by the Iron Disorders Institute. There, for the first time I met others with HH. The conference was outstanding! I learned that the irregular heartbeats (PVC’s) I have experienced since I was a teenager could be attributed to HH as well as a recent onset of arthritis in both index fingers. After hearing other’s stories of misdiagnosis and/or mismanaged care, I feel fortunate to have a gastroenterologist with knowledge of HH and a hematologist that is caring and compassionate.

As a result of information gained at the conference, I now believe with certainty that my father’s death of a heart attack at age 44, when I was just 13, was due to HH. My mother died the year before at age 43 of heart disease, when I was 12. She had suffered from rheumatic fever as a child, so I am less certain whether she, too had HH or only the HH gene.

I am thankful for the medical care I have received since being diagnosed and for the Iron Disorders Institute and their commitment to educate doctors, patients and unsuspecting others who may need to be tested for hereditary hemochromatosis.

JULY is National Hemochromatosis Awareness and Screening Month!

On the National Health Observances Calendar (healthfinder.gov) hemochromatosis (HHC) is among the daily, weekly and monthly national health observances. Hemochromatosis is an inherited disorder; people with this condition absorb extra iron from the diet. The body has no efficient way to excrete iron, so over time, excesses build in vital organs of the liver, heart, pancreas, pituitary and joints. Iron burdened organs eventually fail to function and disease or premature death occurs. Excess iron levels can be reduced with blood donation (phlebotomy). Simple tests can define body iron levels. Is your iron elevated? Find out by requesting an iron panel: fasting serum iron, TIBC and serum ferritin. If your iron is elevated, you may want to get a DNA test, but reducing your iron levels is most important! Contact IDI to see what you can do to raise awareness in your community: pclark@irondisorders.org or Call 888-565-4766.

WESTERN REGIONAL PATIENT CONFERENCE VOLUNTEERS NEEDED!!!

If you live near Reno, NV and are interested in helping with the upcoming event: Western Regional Hemochromatosis Patient Conference Reno, NV; October 3-4, 2008

Contact: Lee Woods 888-565-4766 or by email: lwoods@irondisorders.org

If we’ve helped you, please help us by donating.

BECOME A Volunteer and a MEMBER

With your membership dues you will receive your handsome IDI membership pin and a printed copy of nanograms.

For details about membership please call Peggy Clark, Member Services Coordinator 888-565-4766; email: pclark@irondisorders.org or visit our websites: www.irondisorders.org and www.hemochromatosis.org
5

Little Known FACTS about ANEMIA

Anemia is a symptom not a complete diagnosis: When a person is diagnosed with anemia, the reason behind the anemia must be determined. To take iron pills without knowing the cause of anemia could result in more symptoms and possibly death. Causes of anemia are numerous but they usually will fall into a few categories: nutritional deficiencies or excesses, problems of absorption, bleeding, (blood loss from menstruation, fibroids, cancer, tumors), increased demand for iron (growth spurts); abnormal hemoglobin management (making hemoglobin or premature destruction of red blood cells—hemolysis); enzyme imbalances.

Hemoglobin alone will not provide the full iron status picture: There are three different ways to determine iron status. One is hemoglobin, which measures the amount of iron in the blood; this iron is called functional iron because it picks up oxygen from the lungs and delivers the oxygen to cells so that they can function. After it delivers the oxygen, it then picks up carbon dioxide from the cells and delivers this waste product to the lungs to be exhaled from the body. The cycle begins again. Another way to look at iron status is in transport or “on the move”. The iron bound to transferrin is being transported primarily to the liver and the bone marrow or to storage in ferritin. Ferritin is like a big sink; it holds iron that the body does not need at the time. A person could have a low hemoglobin but very high ferritin. This is not a true anemia, but a form that occurs when a person is sick and has inflammation somewhere in the body. Specific tests are needed to determine a complete iron status picture. These are: hemoglobin, TS% (transferrin-iron saturation percentage, which is calculated by measuring fasting serum iron and total iron binding capacity) and serum ferritin. When you are told that you are anemic make certain that all three tests have been performed.

A person can be iron deficient but not anemic: In functional iron deficiency the hemoglobin is normal but the stored iron in ferritin is low. Stores are used up first before hemoglobin is lowered.

Anemia of chronic disease is often confused with iron deficiency anemia: Anemia of Chronic Disease (ACD) will demonstrate low (to low normal) hemoglobin and an elevated serum ferritin. Serum ferritin reacts to inflammation due to disease and will increase in the presence of even modest inflammation. For example serum ferritin in a child with an ear infection can jump by 50 points! SF will return to normal when the disease is cured. People with ACD should not take iron pills.

Anemia can be fatal: If a person’s hemoglobin goes too low, they can die from heart failure. A hemoglobin of 5.0g/dL is the lowest hemoglobin known where the patient survived. Complicated conditions such as thalassemia or sickle cell disease can result in death also, but ironically it is due to excess iron. These patients are anemic because of hemoglobin diseases; they have to get blood transfusions to survive. Ironically, the blood transfusions carry 250 milligrams of iron with each unit of blood. This iron builds up to excesses and has to be removed with special medicines or the patient can die of a heart attack.

Hemoglobin-requiring anemics: Anemia of chronic disease is often confused with iron deficiency anemia: Anemia of Chronic Disease (ACD) will demonstrate low (to low normal) hemoglobin and an elevated serum ferritin. Serum ferritin reacts to inflammation due to disease and will increase in the presence of even modest inflammation. For example serum ferritin in a child with an ear infection can jump by 50 points! SF will return to normal when the disease is cured. People with ACD should not take iron pills.

Anemia can be fatal: If a person’s hemoglobin goes too low, they can die from heart failure. A hemoglobin of 5.0g/dL is the lowest hemoglobin known where the patient survived. Complicated conditions such as thalassemia or sickle cell disease can result in death also, but ironically it is due to excess iron. These patients are anemic because of hemoglobin diseases; they have to get blood transfusions to survive. Ironically, the blood transfusions carry 250 milligrams of iron with each unit of blood. This iron builds up to excesses and has to be removed with special medicines or the patient can die of a heart attack.

Steps for planning a meal to balance your iron intake

• Estimate the amount of heme (animal source) and non-heme (plant source) iron in your meal.
• Determine what to substances to add or substitute to improve iron absorption--if you need more iron, or impair iron absorption--if you need less iron.

Get a FREE copy of the Iron Disorders Institute (IDI) MENU PLANNER FORM. You can also download this form from our website www.irondisorders.org

Or if you are a member, you can request we send you a printed copy. Call us toll free: 888-565-4766!
ABOUT IRON
Iron is a mineral that we get from food. All living things must have iron to survive. Humans need about 1 milligram of iron a day to have enough energy to function. People lose about 1 milligram of iron per day in sweat, skin flakes or tears. Most people get enough iron from the diet, but some have Iron-Out-of-Balance™. This is any condition where iron levels in the body are not normal.

TESTS TO DETECT
Iron-Out-of-Balance™ is detected with blood tests. The most common tests include:
- Fasting serum iron
- Total iron-binding capacity (TIBC)
- Serum ferritin
Other tests or procedures are needed to determine the cause of Iron-Out-of-Balance™. Examples include complete blood count, retic count, B12 or folate, genetic testing, liver biopsy, and bone marrow aspiration. Our books are excellent resources for understanding iron disorders such as hemochromatosis, anemia of chronic disease, iron overload with anemia and iron deficiency.

IN YOUR GENES
Many iron disorders are inherited; that means it’s in your genes. If you are diagnosed with an inherited iron disorder, even if you are just a carrier, be sure to tell all your blood relatives: your parents, brothers and sisters, cousins, aunts and uncles. They need to know; if it is in their genes too, knowing might save their life!

THERAPY TO CORRECT
People with normal hemoglobin and high body iron can have therapeutic phlebotomies. If they cannot tolerate the phlebotomies, they may be candidates for iron chelation therapy. This form of therapy is usually used with iron overload patients who are anemic. Iron chelators are pharmaceuticals that will specifically bind to iron.

TIPS TO MANAGE
SOME ITEMS THAT KEEP YOU FROM ABSORBING IRON:
- Coffee
- Tea
- Eggs
- Fiber
- Chocolate
- Calcium supplements

SOME ITEMS THAT HELP YOU ABSORB IRON:
- Beta-carotene
- Sugar
- Acidic foods or beverages
- Alcohol*

*Red wines contain tannins that will impair iron absorption. IDI is not encouraging the use of alcohol to improve iron bioavailability.

THREE VIEWS OF IRON IN USE:
Determined by measuring hemoglobin.

BEING TRANSPORTED:
Determined by measuring serum iron** and TIBC (total iron-binding capacity)

CONTAINED IN STORAGE:
Determined by measuring ferritin.

YOU NEED ALL THREE VIEWS
For a complete picture of your iron levels.

**Serum iron is best done fasting.

Important Ranges
Hemoglobin measures the amount of iron in the blood that is carrying oxygen to vital organs. Hemoglobin will be within normal range unless you are iron deficient or have anemia of chronic disease.

Ferritin (serum) is a measure of contained iron. Ferritin will be elevated if you have too much iron in your body or if you have anemia of chronic disease. Ferritin will be low if you are iron deficient.

hemoglobin

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Adult Males</th>
<th>Adult Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal Range</td>
<td>13.5-17.5 g/dL</td>
<td>12.0-16.0 g/dL</td>
</tr>
<tr>
<td>Adolescents, Juveniles, Infants &amp; Newborns</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age 6-18 years</td>
<td>10.0-15.5 g/dL</td>
<td>10.0-17.0 g/dL</td>
</tr>
<tr>
<td>Age 1-6 years</td>
<td>9.5-14.0 g/dL</td>
<td>12.0-20.0 g/dL</td>
</tr>
<tr>
<td>Age 6 mos-1 year</td>
<td>9.5-14.0 g/dL</td>
<td>Newborn 14.0-24.0 g/dL</td>
</tr>
</tbody>
</table>

ferritin

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Adult Males</th>
<th>Adult Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal Range</td>
<td>up to 300 ng/mL</td>
<td>up to 200 ng/mL</td>
</tr>
<tr>
<td>In treatment*</td>
<td>below 100 ng/mL</td>
<td>below 100 ng/mL</td>
</tr>
<tr>
<td>Ideal maintenance</td>
<td>25-75 ng/mL</td>
<td>25-75 ng/mL</td>
</tr>
<tr>
<td>Adolescents, Juveniles, Infants &amp; Newborns</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male ages 10-19</td>
<td>23-70 ng/mL</td>
<td>Infants 7-12 months 60-80 ng/mL</td>
</tr>
<tr>
<td>Female ages 10-19</td>
<td>6-40 ng/mL</td>
<td>Newborn 1-6 months 6-410 ng/mL</td>
</tr>
<tr>
<td>Children ages 6-9</td>
<td>10-55 ng/mL</td>
<td>Newborn 1-30 days 6-400 ng/mL</td>
</tr>
<tr>
<td>Children ages 1-5</td>
<td>5-24 ng/mL</td>
<td></td>
</tr>
</tbody>
</table>