Board member John L Beard, Ph.D. Dies—February 2009

We are saddened by the loss of John Beard, who served on the Iron Disorders Institute Medical & Scientific Advisory Board for more than a decade. Dr. Beard was 61; his death was sudden.

Dr. Beard joined the Penn State faculty in 1984. His research influenced how scientists consider iron in neurology, in particular the correlation between iron and brain function. In addition, he examined the public health implications of iron deficiency. According to Centre Daily Times, John was considered to be one of the most influential and well-respected experts in the world today on the nutritional impact of iron on the brain and cognitive function. In a distinguished career spanning more than three decades, his research has created a paradigm shift in the way scientists think about the way the brain uses iron, has influenced approaches to dietary supplementation in third-world countries, and has offered fresh perspectives for the treatment of clinical disorders.

Dr. Beard provided the oversight for all nutritional information published by IDI. Although his expertise leaned toward iron deficiency, he had a keen understanding of the importance of too much iron in the human body. He was a colleague of James Connor, Ph.D, also a member of IDI advisory board. Together Drs. Beard and Connor published several papers on iron balance in the brains of people with Alzheimer’s. Dr. Beard presented at IRONUSA 2006, National Institutes of Health Campus, Bethesda MD where he talked about the benefits and concerns of fortifying foods with iron, especially in developing countries. His final contribution to our publications included reviewing articles about iron deficiency anemia, iron avidity and sections of the Guide to Anemia book. He is survived by his wife Diane, two sons Zachary and Matthew and a brother, Dennis.

Sources:
www.centredaily.com
www.psu.edu

In This Issue

“Everything outside my physical life is designed to cause my death.” —Oswald Chambers

GGT: Find out why this liver enzyme should be a routine test for all adults—page 6

Misunderstood-Misinformed: Dealing with the frustrations of family members who won’t listen....page 7

Cyberchondria: is the Internet making you sick?....page 9

Men’s Health: Wyoming man tells his story. Screening provides all the right clues but the diagnosis is still delayed....page 5

Delayed Cord Clamping: One of nature’s best but little known strategies for iron balance...page 8

Talk on the “LIST” and in the “Forum”

Iron: Sufficient, Deficient or Excessive? Find out who is most at risk—learn strategies that work—and surprising facts...page 4

Also in this issue

ABOUT IDI
PAGE 2

MESSAGE FROM EXECUTIVE DIRECTOR
PAGE 2

HONORARIAUMS AND MEMORIALS
PAGE 3

FEATURED BLOOD CENTER
PAGE 3

IRON SMART CHARTS AND TIPS
PAGEx 11

IN THE NEXT ISSUE: Reno Conference Highlights; Phlebotomy: Different for Everyone; Dementia and Iron; Transfusional Iron Overload; BioIRON Report; Misunderstood-Misinformed: Pitfalls of Self-diagnosis; Ideas for JULY Awareness

If we have your email address, we will send you a reminder that nanograms is available. Printed copies will be mailed to IDI MEMBERS. Join today and get your printed copy of nanograms.

www.irondisorders.org
Dear Reader,

During 2009 we anticipate challenges to continue our efforts to raise awareness and educate the public about Iron-Out-of-Balance™. The economic status has already begun to impact giving. But we are dedicated to carry out our mission and prevail in spite of challenges which all health charities are facing. Later this year, Dee Dawkins, our Director of Minority Health Issues will address the National Institutes of Health (NHBLI) about these challenges.

In spite of these challenges, we will press on because our mission is so vital to the health outcomes of millions.

“90 MILLION AMERICANS ARE AT RISK, SUFFERING OR DYING PREMATURELY WITH AN IRON DISORDER”

Iron disorders are wide spread throughout the world affecting numbers that are nearly impossible to comprehend. When Gerry Koenig first joined our board of directors he challenged our statement “90 million Americans”. Confident that these numbers are solid, the seasoned board members tasked Gerry with disproving the statement. Within four weeks Gerry was able to report back to the board that “90 million” is not only solid but very conservative. Inspired by his discovery, Gerry began compiling evidence with members of our advisory board that support our claim. His data were presented it to top directors at the Centers for Disease Control and Prevention (CDC), The National Institutes of Health and members of Congress resulting in total agreement: iron disorders represent a huge public health issue worldwide. Early detection and prevention are key goals we must achieve to lower and eliminate the risk of an iron disorder. Iron Disorders Institute plans to achieve earlier detection with screening and to educate a larger population with increased capacity to continue proven programs. Our partners will help us attain our goals.

Iron disorders include: Insufficient iron or anemia, which has multiple causes and presents as a symptom in every major and many rare diseases. In our second edition of Guide to Anemia, due out this June, a number of these diseases are featured chapters that include ways to address the iron imbalances. Among these is a chapter on anemia of inflammatory response (anemia of chronic disease), which is not really anemia per se, but a natural defense mechanism used by nature to protect us against nourishing harmful invaders.

Excess iron or iron overload (hemochromatosis) presents in millions of Americans and is a major explanation for premature death. Hereditary hemochromatosis classic type I (HHC) is common. An estimated one million Americans have the genetic makeup for HHC. Our data suggest that as many as four million Americans including minorities are at risk for excess iron.

Excess iron or iron overload (hemochromatosis) presents in millions of Americans and is a major explanation for premature death. Hereditary hemochromatosis classic type I (HHC) is common. An estimated one million Americans have the genetic makeup for HHC. Our data suggest that as many as four million Americans including minorities are at risk for excess iron.

FACT

EACH YEAR 375,000 AMERICANS WILL DIE OF CONSEQUENCES (COMPLICATIONS) OF HEMOCHROMATOSIS (HHC)—HEMOCHROMATOSIS KILLS MORE AMERICANS THAN BREAST CANCER AND AIDS COMBINED.

Help us to raise awareness by volunteering to distribute educational literature to hospitals and healthcare facilities in your community. One pamphlet in the right hands could save hundreds of lives.

Be well and take care,
Cheryl Garrison, Executive Director
IDI Blood Center Focus: Community Blood Center of the Ozarks (CBCO)

—Contributors Chris Kieffer; Stephanie Clary

Community Blood Center of the Ozarks (CBCO) obtained its FDA variance to accept Hemochromatosis (HHC) donors in 2000. As part of this exemption, CBCO does not charge hemochromatosis donors even if they are unable to use the blood.

According to Johnelle Hargis, CBCO special collections coordinator, the center has 100 hemochromatosis donors. In the last year, CBCO has received 376 donations from HHC patients.

Community Blood Centers of the Ozarks offers their hemochromatosis donor services at all three locations and their mobile unit that travels to different area hospitals once a week. Appointments can be made to have blood drawn from any of these locations including the mobile unit. To find out more about donation sites or to make an appointment, call (417) 227-5000 and ask for the Special Collections Coordinator, Johnelle Hargis.

Community Blood Centers of the Ozarks
2230 S. Glenstone
Springfield, MO 65804

CBCO
Northpark Mall
101 N, Range Line Rd.
Joplin, MO 64801

CBCO
3503 S. Thompson
Springdale, AR 72764

Is there a blood center in your area that does not take hemochromatosis blood? Encourage them to call IDI to learn how they can increase their blood supply with an endless resource of donors.

Common misconceptions, myths and a bit of history about HHC blood:
Prior to the FDA variance, which Iron Disorders Institute (IDI) helped to bring about, hemochromatosis patients experienced a range of emotions as they saw their blood labelled “hazardous waste” and tossed. In fact, hemochromatosis blood is actually preferred stock. Because HHC patients can donate more frequently, their blood contains more young blood cells—a good thing for transfusion recipients. In a 2008 issue of New England Journal of Medicine, post surgery transfusion patients receiving newer blood had fewer post operative problems. Also, blood centers that promote IDI’s pre-treatment 12.5g/dL hemoglobin realize more useable units. Patients often do not know that blood taken from a donor whose hemoglobin is below 12.5g/dL must be destroyed. The IDI guideline for phlebotomy (with some exceptions) is compatible with the National Institutes of Health Hemochromatosis Protocol guidelines. The pre-treatment 12.5g/dL hemoglobin can protect the patient from being overbled, a serious issue with HHC patients AND, the blood can be used provided it meets other eligibility criteria.

A common belief is that HHC blood contains more iron than other donor blood. This is a myth; the excess iron in a hemochromatosis patient is not in the blood but in containment in ferritin. With each unit of blood the donor gives up ~250 milligrams of iron regardless if he or she has hemochromatosis or not. In rare cases the hemochromatosis blood will be thick and difficult to extract, but this is generally due to other factors such as lack of hydration, smoking or a condition called polycythemia, which if often miscategorized as an iron storage disease. The therapy for both diseases is phlebotomy, but HHC is a metabolic disorder where polycythemia is a condition of abnormal blood production, where the bone marrow makes excessive amounts of red blood cells (myeloprolific.)

In the next issue: centers that offer Double Red Cell Apheresis as part of their hemochromatosis program.

OUR MISSION

“Iron Disorders Institute 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 for us to honor the memory of someone who is suffering or who has lost the battle with a deadly iron disorder, or you would like to make a prayer list request, call us toll free 888-565-4766 or email Peggy Clark: pclark@irondisorders.org.

Cherished & Remembered, Forever...
Laura & Dick Main made a contribution in memory of:
Jonas Bryan “JB” Blanton, age 86 who died of unknown cause, January 4, 2009 at Lookout Mountain, TN. He is the 2003 Guinness World Records holder as the world’s oldest solo hang glider pilot still active. His 2009 flight was an attempt to reclaim his title; it marked his 65th consecutive year of flying. He is survived by his wife of 55 years, Elsa, his sons Victor, Wes and Paul and one daughter Cheryl Garrison.

Patrick McKeever made a contribution in memory of:
Elizabeth “Beth” Turner McGinnis, age 60. Elizabeth died late December of complications of hemochromatosis. She is survived by her husband Roger McGinnis; her daughter, Adrienne McGinnis; gransson, Turner Toliuszis; Mother, Marguerite Turner; brother, Joseph Turner; sister, Judith Tyson, sister-in-law, Carol McGinnis Beachy; brother-in-law, Tim McGinnis and several nieces and nephews.
Iron: Sufficient, Deficient or Excessive?

Any condition of Iron-Out-of-Balance™—that is too much or too little iron to function normally—results in an iron disorder, a critical risk factor for many serious symptoms, disease advancement and premature death. As a prevention against these costly and life threatening possible outcomes, iron should be maintained at a sufficient level throughout life. However, sufficient levels iron will not be achieved in the same way for everyone.

Without iron we would suffocate and die—but iron needs do not fall into the “One-Size-Fits-All” category. Iron needs vary depending on many things, such as overall health status, whether a person is male or female; infant, toddler, juvenile, adolescent, adult or elderly—and ethnicity can be a factor. Evidence supports lower hemoglobin to be sufficient for some minorities, especially African Americans. Older patients and patients with some forms of infection may actually benefit from mild iron deficiency. Typically given iron supplements are pregnant women, infants, children and older people. If their iron stores are adequate, they could be harmed rather than helped by indiscriminate large doses of supplemental iron.

We need to better understand nature and the elaborate measures we have to naturally balance iron in the human body. Hemoglobin is a measure of functional iron, but a low hemoglobin is not always an indication of iron deficiency. Hemoglobin will be naturally lowered in inflammatory states—a condition called anemia of inflammatory response. Key tests are needed to differentiate between these two iron disorders: anemia of inflammation or iron deficiency anemia.

Deficient iron: No question, there is ample evidence to support that iron deficiency anemia can result in symptoms of weakness, fatigue, shortness of breath, heart arrhythmia, restless legs syndrome and headache. Decades of evidence demonstrate that during certain periods of growth iron deficiency will result in behavioral and cognitive delays in children. People with cancer or poor kidney function often become iron deficient and have major challenges bringing iron up to normal levels while dealing with the seriousness of the cancer or kidney failure. Tests that help determine true iron deficiency anemia include: hemoglobin and serum ferritin. Other more sophisticated tests include: serum transferrin receptor, which is used more in research settings and reticulocyte hemoglobin content (CHr) which is a newer and more precise way to predict iron deficiency in children younger than six.

Anemia of inflammatory response can be determined with tests such as serum ferritin, C-reactive protein or the serum transferrin receptor.

Excess iron: too much iron (iron overload/hemochromatosis) is a serious risk factor for liver, heart, bones and joints, endocrine, infectious, malignant, neurodegenerative, respiratory diseases and premature death. We estimate as many as four million Americans could be at risk for genetic iron overload (not due to repeat blood transfusion). Many if not most are completely unaware. Excess iron generally builds slowly over time, silently rising to toxic levels permanently destroying health tissue in vital organs. Some of this damage is irreversible by the time symptoms are present. For this reason, early detection should be a high priority for public health agencies. Detection of excess iron can be revealed by measuring fasting serum iron, total iron binding capacity and serum ferritin.

Presently guidelines for sufficient, deficient and excess iron differ greatly depending on the laboratory or the reporting agency. Iron Disorders Institute offers ranges that are evidence and expert based; these ranges are compiled by IDI’s Medical & Scientific Advisory board. Meanwhile, Iron Disorders Institute is working diligently to bring consensus between stakeholders so that all guidelines for iron are uniform—assuring that people with iron disorders receive early, accurate (complete) diagnosis.

See page 11 for The Iron Disorders Institute normal ranges for hemoglobin and serum ferritin.
**Hemochromatosis: Screening provides important clues that are downplayed and dismissed**

In June/July of 2007 David attended a job sponsored wellness program. The program is designed to keep employees healthy by screening them for risk factors of potential diseases especially hypertension, diabetes, and heart and liver health. David was motivated to participate in the program because of the monetary incentive offered to any employee who took part.

The program included measuring blood pressure, body mass index and having some routine blood work. Among the blood tests were cholesterol, triglycerides, blood sugar, liver enzymes and serum ferritin. David tells about receiving a copy of the wellness report.

“When I received my lab results some things were a little high some a little low especially in the cholesterol area. They weren’t that out of whack, so, I didn’t give much thought to it and said that I would just cut down on the margarine a little. Not eat so much junk food and try to adjust my caffeine intake. Simple, I thought. Then I read at the bottom of the lab result that this thing called ‘Ferritin’ was quite a bit higher than the normal high.”

He continues. “My ferritin number was somewhere in the 1500-1600 range. I had never heard of ferritin and noticed that the normal top end of the range was 244ng/mL. Mine, was 1600+. There was no note on the lab result indicating that I should take the results to my physician immediately so I basically ignored it. I filed it in the trash.”

In June/July of 2008 David again attended the same wellness program and again received the blood work with an even higher ferritin. This time it was around 1,900ng/mL.

“Again, there were no notes telling me to go to my doctor. This time however I called ‘Ask a Nurse’ hotline and asked them what ferritin was and my results. I also asked if I should be concerned and go to the doctor’s office. I was told and I quote “it has something to do with iron. Do you eat a lot of green vegetables? If there was not notation on your lab results, you don’t have to be too concerned.”

David was relieved. “Great, I thought, not a big deal, just as I thought. Contrary to what I had read and what my ferritin was, they only told that it was a condition where my body retains too much iron which could lead to organ damage. If DNA confirmed that I had hereditary hemochromatosis, the treatment was to bleed every once in a while, probably for the rest of my life.”

Wanting to learn more, David got on the Internet. He remembers thinking that the information given to him by the healthcare professional made him feel like hemochromatosis was “no big deal”. What he read on the Internet made him feel the opposite was true.

Eventually David joined the Iron Disorders Institute sponsored Excess Iron Support Group where he was able to get answers to many of his questions.

His DNA test results were positive C282Y/C282Y. “I was set up to give my first phlebotomy on January 6, 2009, nearly two weeks after my diagnoses. Contrary to what I had read and what my ferritin showed, I felt it (treatment) was too late.”

In the course of 14 months, David saw several doctors, most left him feeling like they knew very little about hemochromatosis. “They were so cavalier. I was obviously getting sicker and possibly facing organ damage that could have been prevented. This infuriates me! Why don’t doctors know more about hemochromatosis?”

David learns later that he has a leaky heart valve. At first he is given all sorts of precautions and warnings but on his return trip his heart arrhythmia and leaky valve are downplayed by the doctor.

David finally connects with a hematologist who promises to stick with him and learn as much as she can about hemochromatosis. As a result of his case, the hematologist Dr. Tracy Coe contacted Iron Disorders Institute, purchased multiple copies of the Hemochromatosis Cookbook; several copies of the IDI Physician Reference Chart were sent—one each for her colleagues.

Dr. Tracy Coe at the Welch Cancer Center writes, “David had such impressive non-specific symptoms that it drove me to do a literature review. The IDI actually gave me more helpful information than my old internal medicine textbooks, and provided a great springboard to further my own education. Since we live in such a huge HHC area, I hadn’t been previously exposed to such large numbers of patients before moving here and needed to start somewhere. The cookbook has the most amazing introduction, and even as a specialist I learned loads, which helped me further help David and the other less-severe cases in our state.”

David closes his story with this thought. “I hope my story helps others. I do appreciate the support I got from IDI and feel that I can go back to them for answers.”
Gamma Glutamyltransferase or GGT is a liver enzyme that has traditionally been measured to detect liver health and function. Historically, elevated GGT was suggestive of alcohol abuse.

In recent years, elevated GGT measurements have proved to be effective early warning signs of other health risks such as atherosclerosis, stroke, type 2 diabetes, kidney disease and even cancer. Large population studies conducted in the US and around the world have identified increased risks of metabolic syndrome, including cardiovascular disease and diabetes, as well as all-cause mortality in both men and women, when GGT concentrations exceeded the lowest 25% of normal population ranges.

In other words, substantial numbers of people (75%+) incurred increased disease risk when GGT was above the “normal low” range. Medical researchers describe this phenomenon as a “dose-response relationship,” essentially, the higher the GGT concentration, the greater the risks of future diseases and premature mortality.

The high end of “normal” GGT laboratory ranges are generally 65 – 70 U/L for men and 40 – 45 U/L for women. Although GGT correlates with other risk factors, most research has demonstrated that elevated GGT, even when well within normal ranges, independently predicts increased disease and mortality.

Researchers have concluded this by studying large apparently healthy populations from which they accumulated and analyzed data covering multiple known risk factors. Years later they compared outcome data gathered from health, hospital and death records. When the populations were stratified into smaller groups according to similar factors like age, sex, body mass index, smoking, alcohol consumption, diet and exercise, the researchers were able to calculate that elevated GGT presented a significant additional risk, independent of those shared by members of the smaller groups with similar health profiles.

The mechanism behind these findings is generally described as follows: The normal biologic role of GGT is to reconstitute glutathione, the body’s master antioxidant. Glutathione provides natural protection against harmful oxidative stress. When GGT concentrations are above “normal low” ranges, excess GGT can catabolize (break down) glutathione causing critical depletion of this very important antioxidant. When glutathione is depleted, and only insufficient amounts remain to protect the body’s organs from oxidative stress, damage starts to occur. Over time, this process can lead to irreversible cell, tissue and DNA damage, and ultimately to impairment of vital organ function.

Fortunately, an inexpensive blood test can determine GGT concentration. GGT levels can be lowered through a balanced diet that includes ample portions of grains, fruits, nuts and vegetables; this bolsters the body’s natural antioxidant defenses.

Several studies have shown that phlebotomy reduces GGT and other enzymes often associated with liver diseases. Interestingly, moderate to high coffee consumption has been universally shown to reduce GGT; and by doing so, effectively enhance the protective antioxidant capabilities of glutathione.

On the other hand, excessive alcohol consumption has been demonstrated to increase GGT, which depletes glutathione and impairs antioxidant protection.

For some people it might be important to test GGT periodically. An Austrian study of 76,000 people followed over seven years demonstrated that not only were the initial GGT testing levels important, but also, the direction and degree of change over time modified the initial risks significantly. Irrespective of the original GGT measurement, although lower initial GGT always indicated less risk than higher, individuals whose GGT concentrations increased over time were subject to heightened disease and mortality risk, while those whose GGT went down faced diminished risks. As in the studies based on one-time GGT measurements, the degree of change over time (up or down) also followed a “dose-response relationship.” An interesting common finding of almost all of the research in this area indicated the strength of these relationships, and therefore the risks, were significantly greater among men and women less than 60 or 65 years of age than they were for older people.

The following is a sample of two population research studies:

**Study Relative Risk (RR)**

<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Relative Risk</td>
</tr>
<tr>
<td><strong>Males:</strong> (U/Ls)</td>
<td></td>
</tr>
<tr>
<td>Normal low &lt; 14</td>
<td>1.04</td>
</tr>
<tr>
<td>Normal high 14-27</td>
<td>1.28</td>
</tr>
<tr>
<td>Moderately elevated 28-41</td>
<td>1.39</td>
</tr>
<tr>
<td>Increased 42-55</td>
<td>1.66</td>
</tr>
<tr>
<td>Highly elevated &gt; 56</td>
<td>1.66</td>
</tr>
</tbody>
</table>

**Gamma Glutamyl Transferase and Metabolic Syndrome, Cardiovascular Disease, and Mortality Risk Population: 3,451 American Adults**


<table>
<thead>
<tr>
<th>Gender</th>
<th>Relative Risk</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Males and Females:</strong> CVD Event Rates (adjusted)</td>
<td></td>
</tr>
<tr>
<td>1st Quartile</td>
<td>1.0 (reference)</td>
</tr>
<tr>
<td>2nd Quartile</td>
<td>1.26</td>
</tr>
<tr>
<td>3rd Quartile</td>
<td>1.40</td>
</tr>
<tr>
<td>4th Quartile</td>
<td>1.67</td>
</tr>
</tbody>
</table>

---

Contributing author Gerald Koenig
Grant was fifty-three when he got his diagnosis; he had been genetically tested and was homozygous for C282Y. His serum ferritin at the time was 630 ng/mL and his TS percentage was 78 percent. He was relieved to get his diagnosis because he had suffered with terrible fatigue and joint pain for a while. After learning that his condition was inherited, he first went to the Internet to read what he could about the condition. He got worried when he read that hemochromatosis could be fatal. The more he read, the more concerned he got for his two brothers and sister. He called his sister first; she listened but did not sound convinced. He wanted to call his brothers, but unfortunately he did not get along well with either one, and he wasn’t sure just how to go about letting them know that they might also have this condition. Their father had died at fifty-eight of heart failure, and Grant wondered whether this cause of death could have been a consequence of hemochromatosis. The more he read, the more concerned he became. His concern made him very outspoken, something that was not appreciated by his siblings. He begged his mother for help, but she declined. (Later it was learned that his mother felt shame for having given her children a potentially deadly disease.) Grant kept trying. He called his sister, who told him that she had talked with her doctor and had been told that women don’t get hemochromatosis and that she did not need to be tested. This frustrated Grant even more because he knew that his sister had gone through menopause and so her risk of loading iron was increased. Grant wrote letters and sent cards and e-mail but his brothers refused to pursue help. At a holiday gathering, Grant gave it one more try. His two brothers grew angry and walked away. For six more years, Grant tried to get his siblings to seek help and be tested. By now, one brother was experiencing heart arrhythmia, his sister was diagnosed with hypothyroidism, and the other brother was impotent. Even still, none of Grant’s siblings would pursue testing to see whether they had hemochromatosis.

Grant’s story, which is based on a real case history, is one of many similar such stories where blood relatives are unimpressed by the urging of a diagnosed family member. His case is almost identical to others where the males do not want to hear about potential disease or females who are told by doctors that “hemochromatosis does not occur in women”—the matter gets dismissed until symptoms arise. Even then, perhaps because of personal pride, some siblings refuse to ask their diagnosed sibling for support.

At an Iron Disorders Institute family workshop for patients with hemochromatosis, a twenty-six-year-old son of a man diagnosed and receiving phlebotomies remarked without hesitation that he wasn’t going to give blood. At the time, this young man’s serum ferritin was over 600 ng/mL and his TS percentage was greater than 70 percent. He went on to say that his dad looked OK, discounting the fact that his dad was receiving therapy. The son announced that he would be just fine; after all, he had no symptoms. He said he was not concerned that his iron levels were very high.

In a US Centers for Disease Control and Prevention family-based detection survey of hemochromatosis patients and siblings, investigators identified three key barriers to a sibling’s diagnosis. These included a lack of concern because of the absence of symptoms or their belief that their doctors would inform them if there was a risk, or they thought the condition was rare (their chances of inheritance low).

When hereditary hemochromatosis (HHC) is diagnosed in a blood relative, all other blood relatives are at risk of disease or premature death.

Portions of this article are from Guide to Hemochromatosis 2nd edition, 2009 Cumberland House a division of SourceBooks, Chicago, IL.

M. Reyes; Dunet, DO; Isenberg, KB; Trisolini, M; Wagener, DK. Family-based detection for hereditary hemochromatosis. Journal of Genetic Counselors 2008; 17 (1): pp 92-100

“Why anyone would dismiss having three relatively inexpensive blood tests to save themselves from pain, suffering and possible early death is something that baffles me still to this day!”

—Chris L. Kieffer, Founding Director, Iron Disorders Institute
Delayed Cord Clamping: One of Nature’s Strategies for Iron Balance in Newborns

Shortly after a child is born the umbilical cord is clamped and cut freeing the newborn to thrive on its own. Timing of umbilical cord clamping remains a controversial issue. In Western medicine the cord is clamped within the first 10 to 15 seconds after birth. This immediate cord clamping provides a more viable source of stem cells for research purposes. However, there has been no sound evidence in favor of immediate clamping for health benefits to the infant compared to the benefits of the older practice of clamping the cord between 1 and 3 minutes after birth.

Delayed cord clamping protects against iron deficiency in the first six months of life, delivers more oxygen to the newborn’s brain, reduces the need for blood transfusions of premature babies and lowers the risk of intra-ventricular hemorrhage. Intraventricular hemorrhage (IVH) is bleeding inside or around the spaces in the brain containing the cerebral spinal fluid. IVH is most common in premature babies, especially very low birth-weight babies weighing less than 3.5 pounds.

Multiple elaborate natural mechanisms are in place to assure that humans achieve iron balance in the first years of life. In cases where genetics or man impairs these systems, an iron disorder results.

Although iron deficiency is the better known iron disorder, there are lesser known iron disorders that result in pediatric iron overload. Some conditions of iron overload are compounded with anemia and require regular blood transfusions to survive. Rare conditions that can cause iron overload in infants include allogeneic disorders (neonatal hemochromatosis); erythrocyte disorders, enzyme deficiencies and membrane defects: Diamond-Blackfan anemia, Schwachman-Diamond syndrome, and Congenital Dyserythropoietic Anemia; pyruvate kinase (PKD) or glucose-6-phosphate dehydrogenase deficiency (G6PD) and hemoglobinopathies, (hemoglobin diseases) thalassemia and sickle cell disease.

Except in these rare disease states, throughout the pregnancy, iron delivery is managed by elaborate systems that nourish and withhold iron with impeccable precision. During the first trimester, iron is slightly withheld from the developing fetus—possibly to protect against potential infection, which would surely threaten survival.

During the second trimester the iron delivery is stepped up and finally in the last trimester of pregnancy, the mother delivers a vast amount of iron from the placenta to the baby just prior to birth. Following birth, the umbilical cord continues to pulse sending an extra final supply of iron-rich blood to the infant.

In our contemporary society with unprecedented advances in science and medicine, combined with pressures of time constraints and busy schedules we have abandoned or replaced many of these natural systems. We over-supplement iron-replete mothers, excessively deliver babies surgically by Cesarean section (C-section) and immediately clamp the umbilical cord—perhaps so that researchers can use the embryonic stem cells.

As early as the late 1950’s the benefits of vaginal birthing and delayed cord clamping were widely known and practiced. Vaginal birth promotes blood flow from the placenta to the fetus, whereas delivery by C-section usually has the opposite effect. The umbilical cord was then allowed to stop pulsing before it was clamped and cut. Generally the cord was clamped 1-3 minutes after delivery.

Very-low-birth-weight (VLBW) infants often require blood transfusions for anemia VLBW infants whose cords were clamped at least one minute after birth had less need for transfusion and fewer incidence of intra-ventricular hemorrhage. Moreover, delayed clamping of the umbilical cord improves cerebral oxygenation in preterm infants in the first 24 hours.

“Another benefit of delayed clamping would be the increase of hematopoietic stem cells transfused to the newborn, which might play a role on different blood disorders and immune conditions... The advantages of umbilical cord clamping at least at 1 minute after birth could decrease the prevalence of iron-deficiency anemia in the first year of life, especially in populations with limited access to health care.” José M. Ceriani Cernadas, MD, from the Hospital Italiano de Buenos Aires in Argentina Pediatrics. April 2006;117:e779-e786 http://cme.medscape.com/viewarticle/530352

“Delivering the clamping of the umbilical cord for 2 min can increase body iron content by approximately 33% (75 mg), and results in greater iron stores at 6 months of age. Iron status during preg-
nancy, the iron provided from stores and breast milk is sufficient for >/=6 months, but before this time higher-risk infants may become iron deficient. Iron supplementation can be beneficial for high-risk infants, but can have adverse effects on growth and morbidity of iron-replete infants. After 6 months most breast-fed infants will require complementary foods that are rich in iron.” —Dewey, KG; Chaparro, CM. Proceedings of the Nutrition Society 2007 66(3):412-22. Session 4: Mineral Metabolism and Body Composition Iron Status of Breast-fed Infants.

Dr. Benjimin Ononeze, Consultant in Obstetrics & Gynaecology, Darlington Memorial Hospital, Darlington, England conducted a survey based on the 2004 recommendation to delay cord clamping. The survey was intended to measure the attitude of obstetricians toward the approach and to determine barriers to adopting the procedure in clinical practice.

Questionnaires were given to obstetricians from 43 different obstetric units in The United Kingdom, USA, Canada, and Australia. From the responses it was learned that 53% had adopted the recommendation to delay cord clamping on occasion, whereas 37% had never delayed cord clamping. The main reasons stated by responders for not adopting delayed cord clamping were: 1. Difficulty with implementation in clinical practice 2. Lack of being aware of the benefits of delayed cord clamping.

“Although iron deficiency is rare in newborns, delaying clamping of the cord until it ceases to pulse is highly beneficial to a newborn and especially a premature or low birth weight baby.”
—Roshni Kulkarni M.D. Professor & Director Pediatric and Adolescent Hematology/Oncology Michigan State University
What is your Question?

One way for new patients to learn about iron disorders is from other patients on the Excess Iron Discussion List. Join NOW!

If you need help getting on the LIST send us an email. SClary@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

Cyberchondria

Microsoft Research investigators Ryen W. White and Eric Horvitz performed a study of how people search the Internet for health information. They wanted to know the extent to which symptoms could escalate the person’s search to rare diseases that might include some of these symptoms. Their research showed that the Internet also called the World Wide Web can indeed escalate medical concerns. Further, post session anxiety was a persistent finding.

The Internet provides unprecedented amounts of information available almost instantaneously. In some cases, we know that complete diagnosis is achieved by things found on the net. Yet this place remains a high risk zone for mistakes, unnecessary worry and conflicts between patients and their doctors.

People are easily influenced by symptoms that are not necessarily specific. Eugene Weinberg, Ph.D. recalls that his medical students frequently were convinced that they had contracted some horrible microbial disease just simply by discussing the symptoms or consequences of infection.

According to White and Horvitz who coined the term cyberchondria”...the Web has the potential to increase the anxieties of people who have little or no medical training, especially when Web search is employed as a diagnostic procedure. We use the term cyberchondria to refer to the unfounded escalation of concerns about common symptomatology, based on the review of search results and literature on the Web."

The full article is well worth reading. Cyberchondria: Studies of the Escalation of Medical Concerns in Web by Ryen W. White and Eric Horvitz Microsoft Research can be accessed by visiting: http://research.microsoft.com/
**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*. See the list below of substances that improve or impair iron absorption.
- Plan ahead! If you plan your menus in advance and use a shopping list, you will be less prone to impulsive eating and processed foods.

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!

---

### Antioxidant Wake-Ups

**One serving**

**INGREDIENTS**

- 1 four-ounce CARTON OF LOW FAT VANILLA YOGURT (look for brands with live cultures)
- 1 CUP OF FRESH BLUEBERRIES
- 4 OUNCES OF Northland Brand* Blueberry with Pomegranate Juice (Diabetics should substitute 4 ounces of apple juice)

**Directions**

Measure juice and pour into blender  
Add yogurt and fruit

*Northland Brand juices are available at your local Walmart stores and come in many varieties.

**BLUEBERRIES**: are native to America and Canada—they are in season in late summer and can be frozen for later use. Blueberries have a high ORAC (Oxygen Radical Absorbance Capacity) which protects us against free radical damage. They contain fiber and are loaded with properties that reduce our risk for cancer and heart disease and help our brains work better. Blueberries also contain polyphenols, which can impair the absorption of iron. Read more about this powerful and delicious fruit: [http://www.blueberry.org/nutrition.htm](http://www.blueberry.org/nutrition.htm) [http://www.cdc.gov/nccdphp/dnpa/5aday/](http://www.cdc.gov/nccdphp/dnpa/5aday/) [http://www.ars.usda.gov/Services/docs.htm?docid=15866](http://www.ars.usda.gov/Services/docs.htm?docid=15866)

---

### FOODS AND SUBSTANCES THAT Improve Iron Absorption

- BETA-CAROTENE
- SUGAR
- ACIDIC FOODS OR BEVERAGES
- ALCOHOL
- VITAMIN C SUPPLEMENTS
- RED MEAT

### FOODS AND SUBSTANCES THAT Impair Iron Absorption

- COFFEE
- TEA
- EGGS
- FIBER
- CHOCOLATE
- CALCIUM SUPPLEMENTS

---

**In Our Opinion**: except in extraordinary cases, iron balance is best achieved with whole foods rather than supplements. Blueberries featured in this issue is a great example. When eaten in its natural form, it is difficult to overwhelm the body. When consumed as a concentrated form, the kidneys could be harmed.
C.R. Hume says, “Let us help you remain...
IRON SMART!”

ABOUT IRON
Iron is 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:

-- 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.

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 serum ferritin.

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

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!

Healthy adults absorb about 10% to 15% of iron that they consume; people with hereditary hemochromatosis absorb up to 4 times that amount!

DYK?
Hemochromatosis COOKBOOK

*therapeutic phlebotomy for people without anemia

<table>
<thead>
<tr>
<th></th>
<th>hemoglobin</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>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Adolescents, Juveniles, Infants &amp; Newborns of normal height and weight for their age and gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age 6-18 years 10.0-15.5 g/dL</td>
</tr>
<tr>
<td>Age 1-6 years 9.5-14.0 g/dL</td>
</tr>
<tr>
<td>Age 6 mos-1 year 9.5-14.0 g/dL</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ferritin Reference Ranges</th>
<th>ferritin</th>
<th>Adult Males</th>
<th>Adult Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal Range</td>
<td>up to 300ng/mL</td>
<td>up to 200ng/mL</td>
<td></td>
</tr>
<tr>
<td>In treatment*</td>
<td>below 100ng/mL</td>
<td>below 100ng/mL</td>
<td></td>
</tr>
<tr>
<td>Ideal maintenance</td>
<td>25-75ng/mL</td>
<td>25-75ng/mL</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Adolescents, Juveniles, Infants &amp; Newborns of normal height and weight for their age and gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male ages 10-19 23-70ng/mL</td>
</tr>
<tr>
<td>Female ages 10-19 6-40ng/mL</td>
</tr>
<tr>
<td>Children ages 6-9 10-55ng/mL</td>
</tr>
<tr>
<td>Children ages 1-5 6-24ng/mL</td>
</tr>
</tbody>
</table>

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 inflammation. Ferritin will be low if you are iron deficient.

Suggested Range

Adult Males

<table>
<thead>
<tr>
<th>Iron-Out-of-Balance Reference Ranges: Other Test Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal Range</td>
</tr>
<tr>
<td>In treatment*</td>
</tr>
<tr>
<td>Ideal maintenance</td>
</tr>
</tbody>
</table>

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 inflammation. Ferritin will be low if you are iron deficient.
Our mission: Iron Disorders Institute exists so that people with iron disorders receive early, accurate diagnosis, appropriate treatment, and are equipped to live in good health.

HELP SUPPORT
Iron Disorders Institute
PO Box 675, Taylors, SC 29687

Iron Disorders Institute
promoting wellness through iron-balance
PO BOX 675 • TAYLORS, SC 29687