“Alone we can do so little. Together we can do so much.”
Helen Keller, lecturer

IDI’s way of keeping in touch with you!

Hoxworth Blood Center
Cincinnati, OH

Our Purpose Is...
To enhance the well-being of patients in our service area by assuring a reliable and economical supply of the safest possible blood, by providing innovative hemotherapy services, and by promoting research and education programs in transfusion medicine.

Hoxworth Blood Center, University of Cincinnati Academic Health Center, is the only blood center for the greater Cincinnati area.

Serving a 17-county area in Ohio, Kentucky and Indiana, Hoxworth collects, tests, processes and distributes blood and blood components to 28 hospitals and medical centers.

Hoxworth’s purpose is to enhance the well-being of patients in our service area by assuring a reliable and economical supply of the safest possible blood. Hoxworth is licensed and regulated by the U.S. Food and Drug Administration and accredited by the American Association of Blood Banks. Hoxworth is also a member of America’s Blood Centers.

Founded by Dr. Paul I. Hoxworth in 1938, the Blood Center has grown to be an internationally recognized leader in transfusion medicine. Today, Hoxworth has a staff of more than 250 full and part-time employees in 26 departments and a compliment of more than 300 volunteers committed to serving our community.

Hoxworth’s variance to phlebotomize and reuse hemochromatotic patient blood was approved by the FDA on 6/7/2001.

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We are looking for our next RISING INVESTIGATOR - a young girl or boy pursuing an iron-related career. Please send in profiles of your children who are interested in science, medicine, and iron-related problems. Please include a picture and a profile of your child to be considered a candidate for the next rising investigator.

IDI's mission is to reduce pain, suffering and unnecessary death by disorders of iron through education, awareness and facilitating research.
Direct-to-Consumer Genetic Testing and Genetic Privacy

A number of questions have been raised recently about direct to consumer (DTC) genetic testing. Instead of going to the doctor for a test, people can order tests on the Internet, have specimen collection kits sent to their homes, and receive test results directly. Some companies, such as DNA Direct, also provide genetic counseling as part of the testing process.

There are several potential advantages to this type of testing, including increased access to genetic testing. However, not all companies offering DTC genetic testing do so in a responsible manner. If you are considering DTC testing, it is important to look for a company that uses Clinical Laboratory Improvement Amendments (CLIA) certified laboratories, offers tests that are scientifically valid, and is staffed by genetics professionals including certified genetic counselors and medical geneticists. Genetic test results are complicated, especially those related to iron disorders. Test results often need to be interpreted in the context of personal and family medical history. Not understanding what the genetic information means for a specific person and his/her family is not helpful, and may even be harmful.

Some people have raised questions about privacy and whether or not there is a way to keep the information out of their medical record. As a genetic counselor, I am very aware of how private genetic information is, and I encourage people to be cautious with whom you share this information. Privacy is an advantage of testing with a DTC or direct-access. In fact, this is one of the reasons DNA Direct was started and why we have gone to great efforts to ensure privacy and confidentiality as well as the most current genetic information. Our extensive privacy policies address both security on the Web and HIPAA (The Health Insurance Portability and Accountability Act) compliance within our own doors. We ensure that no one has access to genetic testing results or the Personalized Report that DNA Direct provides each tester by using personal order ID numbers instead of names, and maintaining all our information under the strictest safety regulations. You can see our privacy policy and our standards on our website, www.dnadirect.com. (Just click the links at the bottom of the home page)

In order to help with concerns about genetic discrimination, genetic counselors often discuss some of the current laws that are in place to help protect us from genetic discrimination. HIPAA protects those with group health insurance from being denied insurance or having their insurance cancelled. HIPAA has many limitations, including not protecting those who are individually insured and, not offering protection for disability and life insurance. HIPAA does not prohibit using genetic information as a basis for charging a group more for health insurance.

Because of the limitations of HIPAA, several states have enacted their own laws to provide additional protection against

Genetic Corner continued on last page.
A resident of York, Pennsylvania, a brilliant artist, and a hemochromatosis patient, Melvin Conrad is intently trying to weave his way through the medical field to find answers concerning his disorder.

Mel was diagnosed with hemochromatosis in 2004 after a lingering year of uncertainty, tests and a liver biopsy. Before Mel got sick he was a full-time freelance artist, but when he got sick he had to take a break from his work. Melvin was suffering from several key symptoms of HHC including chronic fatigue, depression, and heart arrhythmia. But, like many hemochromatosis patients, Melvin found it hard for his physician to take him seriously about his illness. After finally having the liver biopsy, Mel was diagnosed with the disorder.

Mel still suffers from chronic fatigue even with his blood lettings. “The hardest thing is getting up in the morning...what do hemochromatosis patients do to alleviate some of these symptoms?”, he asks himself.

Explaining these symptoms to others is sometimes frustrating as well. Melvin conveyed how most people just reply with suggestions of drinking coffee and taking naps when he tries to share his struggle with chronic fatigue.

At age 45, a new and primary concern of his is connecting with other hemochromatosis patients. “I never thought I was the type of person to want to be in a support group for anything...until now”, says Melvin. He states that he can relate to others with the disorder and feels “normal.” Even within the last couple weeks, Melvin has been able to meet with two other hemochromatosis patients in his area and converse about the disorder.

For now, Mel has a full time job and does caricature work on the side, and will continue to try to raise awareness about his disorder.
ABSTRACT: The purpose of this paper is to show that hemochromatosis which means too much iron or iron overload, is the cause of many - far too many cases of irritable bowel syndrome (IBS) and may be the leading reason to test for iron overload or hemochromatosis in patients presented with IBS. Until now there hasn’t been a cause of IBS stated, the way I understand it. Now in more and more cases, iron overload will be determined to be the cause of very many cases of IBS and a lot can be done about this iron problem in these patients to what most would call a complete ‘cure’, if too much iron is found to be the cause - and then a diagnosis of the cause will be known. This should prove that in many cases, there is a specific cause of IBS and that is iron overload where the entire body is overloaded with iron or it could be where the lumen of the gut itself is overloaded with iron.

We can see the wave on the ocean, but we don’t see the wind behind it, and we can see the pathologies that too much iron causes, but we have failed to see the iron that cause them in far too many cases. The velocity of the wind can be and is now measured. The amount of iron in our body tissues can now be measured and it can even be seen if properly stained for - the problem is that neither of these procedures is done as they should be. Testing for too much iron or even giving it consideration for it being done and the problems that too much iron causes, is neglected or never thought of in treating disease conditions much too often; or even taken into consideration how much iron is in the diet or medications (supplements) that the patient is taking.

People having been treated for hemochromatosis have taught us a lot about iron and what removal of excess iron from the body will do to improve one’s health and greatly prolong their lives and the lack of proper treatment for iron overload has shown the deadly results of the neglect to do so.

It is rather strange that the symptoms or pathologies of both hemochromatosis and IBS overlap almost completely.

The chronic fatigue symptom may be the first to show up in either of these two conditions - I prefer to call hemochromatosis a condition for if not diagnosed in time and properly managed, it will lead to all kinds of pathologies, and the same could be for IBS if iron overload is found to be the cause of IBS.

Actually, if you have been diagnosed for IBS, you have only been told you have a bunch of symptoms and together they are called IBS with no specific cause. Now if you can prove that you have too much iron, you do have a cause and something can be done about your IBS – and the number of people with IBS would no doubt be found to have a much higher percentage of hemochromatosis or iron overload, than would be found in the general population.

It is rather strange that the symptoms: fatigue, diarrhea and sometimes constipation, chronic abdominal pain, bowel disturbances of bloating, cramps and nausea; dumping syndrome, mental distress, depression, hysteria, obsessive compulsive traits, loss of appetite, heart burn, hypothalamus - pituitary - (glands) axis, back pain, weakness, faintness, palpations, diagnostic confusion, physical deteriorations, myalgia, lactase deficiency which may masquerade as IBS, sleep difficulty, white blood cell influence and immune dysfunctions are all symptoms of IBS and hemochromatosis also. This is rather strange to have so many overlapping symptoms and there not be a connection between the two - there is in very many cases. These are of course not all of the symptoms or problems associated with both.

FATIGUE: This is a lot of times the very first presenting symptom of both H and IBS. This is enough in itself to warrant testing for iron OVERLOAD or iron deficiency.

ABDOMEN: Bloating, nausea, and severe cramps are common to both.

HEARTBURN: Very common to both - Dyspepsia, very common to both.

DUMPING SYNDROME: Common to both

DIARRHEA: Of course this is the name of the game for IBS and H; although sometimes the patients will complain of constipation. This is where we find that hemochromatosis is America’s most hereditable disease, for it works just like the cowboy diarrhea, it runs in the genes, and literally this is the way it works. You can't believe the very explosive and painful diarrhea with both conditions.

ABDOMINAL PAIN: This is very common in both conditions; H patients complain of pain in the upper right quadrant but the pain can be from any part of the abdomen for both conditions.

MENTAL: Depression, mental distress and hysteria, are common to both. Vertigo is common in H

LOSS OF APPETITE: Common to both.

PITUITARY GLAND: No doubt about this most important gland being involved and iron is known to be the culprit in at least the case of H. The pituitary is very sensitive to iron and is damaged severely by too much iron and the damage does not repair itself even after the patient is de-ironed in too many cases - by association, iron has to be involved with the pituitary in IBS.

BACK PAIN: Common to both.

WEAKNESS, FAINTESS AND PALPATIONS: All are common to both.

DIAGNOSTIC CONFUSION: The patient will have so many and confusing symptoms that the doctor may want to send him or her to a shrink. This happens frequently - and lots of times before any iron studies are done - what neglect to fail to test any patient for iron levels.

MYALGIA: common to both and you can also add fibromyalgia and chronic fatigue syndrome (CFS) to this list

LACTASE DEFICIENCY: This is very common to both and is a most interesting aspect of both to connect the two together.

SLEEP DIFFICULTY: Common to both IBS and H, and you can add CFS and fibromyalgia to this also.
**THERMAL REGULATION:** Night sweats may be common - low grade infections enhanced by iron probably plays an important role in this.

**WHITE BLOOD CELL INFLUENCES AND IMMUNE DYSFUNCTIONS:** Common to both.

It is amazing that the incidences of H, fibromyalgia and chronic fatigue syndrome increase with age and patients with these three conditions much too often complain of IBS symptoms. Iron buildup in the body also increases with age.

**LACTOFERRIN:** This is a very important iron binding protein found from the eyes, nose, mouth, and all the way through the alimentary canal; also in some white blood cells. This is what helps to keep iron bound up and manageable until it is properly utilized or passes through the alimentary canal. The supply or amount of lactoferrin is limited and if there is too much iron in or added to the diet, this leaves free unbound iron to play havoc all the way through the canal. If you didn't have lactoferrin in your tears, how long do you think your eyes would last from being overwhelmed by infection? - and the same goes for your gut.

**INFECTION IN THE GUT:** Let us start with the stomach or duodenal ulcers. We use to think that ulcers were caused by a bad wife or a bad job; a bad husband couldn't have anything to do with them! Well, iron is the culprit for the cause of too many ulcers. I take my hat off to Dr. Barry Marshall from Australia who discovered that *Helicobacter pyloric* is the germ that causes the ulcers or causes the infections of ulcers. Which comes first, the ulcer or the infected ulcer? I say the ulcer comes first and *Helicobacter pyloric* being the opportunist that it is just takes over the opportunity presented to it. *E. coli* lives in the gut of most people and I think *Helicobacter pyloric* does the same, both taking advantage of available opportunities. I take my hat off to Dr Marshall for his work about ulcers, but in all his writings that I have read, I never found one mention of iron being involved with the gut physiology, good or bad, in his writings. Iron is necessary for nearly all infective organisms to grow and cause infection. *Vibrio vulnificus*, the shell fish poisoning germ, is a prime example of this. Those people with full blown iron overload (hemochromatosis), would be lucky to make it to a hospital if the body is overloaded with iron, it cannot do this and they are exposed to this germ. The body must be able to withhold iron from infective organisms to combat infection. - if the body is overloaded with iron, it cannot do this and infection takes over.

Iron is necessary for nearly every cell in our bodies up to a point. Up to a point, iron stimulates and maintains - after that it retards, causes mutant changes, causes break down of the cells and death of the cells. Iron is the principal catalyst involved in the production of detrimental free radicals.

Nearly all of the bacteria, friendly and unfriendly, that inhabit the gut are stimulated by iron. One exception are the lactase producing bacteria in the gut. You see, these lactase producing bacteria do not use iron for their vital functions as most other cells use iron; they use cobalt and manganese. This is where iron plays havoc with these important and friendly bacteria. Iron is much stronger metal than either cobalt or manganese in a chemical reaction, the stronger metal will take over and mess up everything in this case. - - Iron also influences the unfriendly bacteria in the gut supplying them with the most important nutrient they need and they grow and prosper, and are able to also influence your lactase producing bacteria - this is the case of unfriendly bacteria taking over and killing off your much needed lactase producing and friendly bacteria - just because there is too much iron present for these germs to take advantage of. Without an adequate supply of lactase, you really have problems, especially if you are going to eat ice cream or drink milk - I mean very serious and painful problems. I know several people who were `cured' of milk intolerance by being de-ironed down to normal levels - just as simple as that.

I have three very well written medical books on my shelf that were thrown out of a very good near by medical library of a major hospital. The deal is, the surgical procedures described in these books to treat IBS symptoms DIDN'T WORK EITHER. I never saw iron mentioned in these books one time.

As mentioned, iron enhances the growth of unfavorable bacteria in the gut also and if the body cannot withhold iron from these germs, then you can have all kinds of problems including gut and systemic infections. This could account for a lot of the night sweats that go along with H and IBS - and many sicknesses caused by infection. Too much iron deposited within the gut wall, can and does influence all of the cells there in and especially your host defense cells (some of your WBCs.) They become overloaded with iron and dysfunctional.

Iron taken into the gut can stay suspended in the ingesta, it can ADSORB to the gut lining, it can be ABSORBED into the gut wall and it can pass on into the blood stream and from there to all parts of the body. Problems can be had from any place or part of the body that has a concentration of too much iron.

In the lumen of the gut excess iron causes disturbances in the bacterial (micro flora) flora usually in a detrimental way to the body. When adsorbed to the gut lining, iron is causing free radical production (oxidation/reduction) that affects the gut cells just like the hot sunshine shining on your tender skin. Then when it gets into the gut lining, the same process occurs if this iron is not bound (controlled) and is in too much abundance.

The gut lining is shed off or exfoliated and rebuilt completely about every 10 days the way I understand it. Too much iron can speed up this process to our detriment. Shed off enough stomach lining cells, fast enough and deep enough, and down to the blood vessels, and then you have a bleeding ulcer.

**IRON DOES CAUSE SOME ULCERS.** In a study of about 5000 cases (specimens) of ulcer tissue, stainable iron was found in about 10 percent (500) of these cases. It was also found that adding iron salts to a culture of *Helicobacter pyloric* enhanced the growth of this bacterium, and several others in the same experiments. All of these organisms tested were unfriendly to the gut and to the body.

Iron plays a very important role with the pancreas. It influences the production of digestive enzymes and the production of the bicarbonate radicals (acid neutralizers) produced by the parietal cells lining the ducts from the pancreas to the gut. Without the proper amounts of pancreatic digestive enzymes and the bicarbonate (acid neutralizers), I would say you will have all kinds of digestive problems including abdominal pain, diarrhea, constipation, vomiting, dumping syndrome, and you name it. From this one aspect, the term IBS (irritable bowel syndrome) could be born. The iron causing this aspect of IBS would have to be absorbed and deposited in these pancreatic cells mentioned and in excess to cause these problems.
You will be told that if there is excess iron in the lumen of the gut that it will not hurt you for you will not absorb it unless you need it. The fact is, the more iron there is in the diet, the more iron that will be absorbed. Once absorbed, the body does not lose iron unless there is bleeding - one milligram a day excepted. As explained, if not absorbed, the iron is still in the gut until it passes through that most posterior aperture causing problems all the way along the entire length of the gut. A lot of the problems come from the free radical production and in the colon I can’t think of a better place for free radical production then in the colon. What goes on in the colon reminds me more of a political convention that winds up being a big political blow out - you know, kinda on the democratic side.

Excess iron in the colon sure would not help colitis or diverticulitis. Infective organisms must have iron to function.

You don't have to have full blown H to have an iron problem that would cause IBS symptoms; just too much iron floating around in the gut can do it or elevated iron levels in your body between what is considered normal and what is considered diagnostic for full blown H can do the trick. If your IBS symptoms are caused by too much iron in the gut from iron supplements or iron rich food, it will take time for this iron to get out of the gut before improvement is shown even if corrective measures are taken.

I can see absolutely no reason for any IBS or fibromyalgia or chronic fatigue syndrome patient to take any iron supplement what-so-ever. The only exception to this would be if the patient had a full blood work up and found to be iron deficient before doing so. A simple hematocrit or hemoglobin reading would not do the trick. Serum iron, TBIC and or UIBC, ferritin, and hematocrit or hemoglobin readings would be necessary to determine the need for iron supplements.

People get these conditions and think they need vitamins; so what do they do, they go get a multiple vitamin or mineral tab that is loaded to the hilt and especially with iron. The pill will usually have 18 mgs of iron in each. Eighteen mgs of iron is 100 percent of the USRDA (or daily value) for some people, but for most of the people taking this much iron, it is 180 percent of the USRDA for iron. The USRDA for iron for men above 19 and women above 50 years of age is 10 mgs. The same applies to a lot of the breakfast cereals you eat. To put it simply, you don’t have to have full blown H to have an iron problem. It is very serious warnings that should accompany such products SHOULDN'T BE CONSIDERED A HEINOUS CRIME.

How does one find out if iron may be the cause of these problems - IBS, fibromyalgia, and chronic fatigue syndrome? A blood work up including serum iron, TBIC and or UIBC, and ferritin tests are necessary. If you just have too much iron in your gut floating around causing the problems, then you would have to check on what you are taking or eating. This would get you started. You need a doctor who is at least interested in the iron subject. If your doctor tells you this is not necessary or that you don't need all of this, then I suggest you change doctors - pronto.

These iron tests mentioned are necessary in any blood work up for any patient for any condition now days - more important than your cholesterol tests and they are important too!

It would be most interesting to know what percentage of people who have been diagnosed for IBS, chronic fatigue syndrome, or fibromyalgia have none or either one or both of the genes for hemochromatosis as is compared to the general population. This would be real easy to find out now that the genetic test for hemochromatosis is available and really is not too expensive. All it would take is to run these genetic tests on one hundred (500 would be better) people diagnosed with IBS and ditto for CFS and fibromyalgia and compare these findings with the same tests run on a group of people from the general population. I am 'sure' the results of this research would be astounding. The genetic test for the hemochromatosis genes cost about $135.00 per person and this times 500 is only $67,500.00, and compared to most research, this is chicken feed. The thing is, most people with the symptoms of any of these conditions, should have all of these tests run at any rate - regardless.

The treatment for iron overload is donating blood (phlebotomy) and you may think to yourself: being sick and donate blood? - yes, dat is de way it is. To get rid of that excess iron that you have that is causing so many of your problems.

How many cases of IBS, CFS, and fibromyalgia are just cases of full blown hemochromatosis just waiting to be diagnosed.? Have your iron levels checked and then donate blood to keep from ever developing full blown hemochromatosis. Keep your ferritin levels down below 50 and your percent of saturation of your transferrin below 30.

There are about 1,250,000 people in our country who have the double genes for hemochromatosis and the potential of developing full blown hemochromatosis. There are about 30,000,000 people in our country who have the single gene (carriers) for hemochromatosis, and some of these do develop full blown hemochromatosis. It would be very interesting to know what percentage of those people who have CFS, IBS, and fibromyalgia also have either one or have the double genes for hemochromatosis and compare these with the population who have neither gene for hemochromatosis.

Why the copyright? I had a paper stolen from me and plagiarized to the tune of about 99 percent, and that person attached his name to it, and he didn't give any credit. Permission is granted for use of part or all of this paper for quotes or reproduction if you desire. Please leave my name on it so that I can be in on the cussing and discussing of what comes from it.

This is really just one narrow aspect of the iron (hemochromatosis) topic.

My best selected references for this paper are:

1. Weinberg, Eugene D., Ph. D., Cellular Iron Metabolism in Health and Disease, Drug Metabolism Reviews, 22(5):531 - 579 (1990)

I thought about making a fitness movie, for folks with hemochromatosis, and call it "Pumping Rust." -- Anonymous
**Genetic Corner** (Continued from page 2.)

genetic discrimination. To learn more information about this topic, go to [www.genome.gov](http://www.genome.gov), and look under the heading, “Privacy and Discrimination.”

In addition to the current laws, there is legislation underway to increase protections against genetic discrimination called “The Genetic Information Nondiscrimination Act” (GINA). GINA has already been passed by the House of Representatives, but has not yet been voted on by the Senate. The act will protect individuals against discrimination based on their genetic information when it comes to health insurance and employment.

It is reassuring to know that some protections against genetic discrimination exist. For those with concerns about this topic, it can help to talk with your doctor or a genetic counselor. Also, I am always available to help with genetic counseling questions.

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

877-321-0077 or lkessler@dnadirect.com

Lisa Kessler is a certified genetic counselor with DNA Direct; [http://www.dnadirect.com](http://www.dnadirect.com)

**FAQ**

**How can I be certain about the diagnosis of an iron disorder?**

To assure a complete and proper diagnosis of the various disorders of iron, several different measures of iron must be examined: iron in hemoglobin, bound iron and stored iron.

To learn more about the different views of iron, visit our online Iron Library:

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**OUR MISSION:** IDI exists so that people with iron disorders receive an early and accurate diagnosis, appropriate treatment and are equipped to live in good health.

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

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**Genetic Corner (Continued from page 2.)**

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