Iron Filings

Canadian HEMOCHROMATOSIS SOCIETY

Providing information, awareness and support

FALL | 2009

What was happening to me?

HOW HEMOCHROMATOSIS AFFECTED MY LIFE

William James Brinnen

It was 1983, I was 41 years old and I was starting to feel like I was 70.

I was tired all the time, my joints were stiff, my stomach felt bloated, my eyes tired easily and I was having erectile dysfunction.

I was not one to go running off to a doctor for the least little ache; however I went to a doctor in Terrace, BC, regarding my eyesight and erectile dysfunction. He referred me to specialists, one who prescribed glasses, the other testosterone shots. My condition did not get better, it worsened. I was told to take 6 months off work. Instead I worked out of my home, thanks to an understanding boss. Finally, I went to my GP, Dr. Eastwood. He wanted to know every little problem that I had that I would not necessarily take to a doctor. At the end of that session, he sent me to the lab for a ferritin test. The very next day I was on a plane to Vancouver for a liver biopsy where it was confirmed that I had a very advanced stage of hemochromatosis and that my ferritin count was up in the thousands.

The only reason my doctor picked it up was because just months before, he had a new patient come to him with the disease. He would never have heard of it otherwise. He told me that I needed treatment immediately if I was going to survive more than a year.

Back to Vancouver again to meet with a liver specialist who put me on a regime of twice weekly phlebotomies. I thought I was tired before, think again. They wanted my hemoglobin count down to approximately 10 to leech the iron out of my system. At this time I was told that because of the effects of hemochromatosis; one testicle had atrophied and I would need testosterone injections for the rest of my life; that I needed to be treated for arthritis; that iron deposits had lodged in the muscles of my eye so I would need glasses; and that my liver was badly compromised.

I went on a regime of 2 phlebotomies a week. With a hemoglobin count around 10 it was a real effort to put in a full day's work. Because my job required me to drive 35 miles to work every day, I could only come home and sleep.

As my ferritin levels dropped over the next couple of years, the frequency of the phlebotomies gradually reduced to weekly, bi-weekly, monthly, and finally a maintenance frequency of every three months. Years went by with me continually having phlebotomies and blood tests with periodic visits to a specialist for ultrasounds and blood work to keep check on the condition of my liver. Most nurses or doctors I visited had never heard of hemochromatosis and the few that did had questions like "do you eat out of iron pots?."

CONTINUED ON PAGE 2

"The question was asked '*how has Hemochromatosis affected my life*' and the answer would have to be... profoundly."

CONTINUED FROM COVER

What was happening to me?

In January of 2008 I suffered a major gastric bleed and nearly died on the way to the hospital with a dangerously low blood pressure due to loss of blood.

After several incorrect diagnoses, it was finally determined that my liver was poisoned by the many years of taking Diclofenac, an anti-inflammatory drug used to treat hemochromatosis induced arthritis. The poison in my liver also caused me to be delusional. Once my liver was flushed out and I went off Diclofenac and onto morphine, my health improved but I was tired and weak and had lost 34lbs.

While undergoing CT scans and MRI's to determine the cause of the bleed, several small cancerous tumors in my liver were discovered. A PET scan in November 2008 reported that the cancer in my liver had metastasized to my lung, negating conventional treatment. I was put on an experimental chemo drug that caused me to be weak, tired, not wanting to eat, and nauseous. In March 2009 further tests showed the cancer was still growing and the experimental chemo drug was not working. There was nothing more to be done except enjoy what life I had left.

It has been made clear by the doctors that the root cause of my problems is hemochromatosis.

The question was asked "how has hemochromatosis affected my life?" The answer would have to be that it has affected me profoundly; emotionally, financially, physically and sexually.

Living with a disease that very little was known about in the early 80's, and the effects of the disease restricting the activities that should be normal for one in their early 40's – my mortality was ever present on my mind. My life was controlled by this disease, hospital/doctor visitations, phlebotomy schedules, lab work, and physical restrictions.

One of the worst emotional problems to deal with was the loss of my virility. It affected my previous marriage and it affected my self esteem because I had to use enhancements such as penile injections, or recently Viagra.

It has been a financial drain for 25 years with the cost of pharmaceutical treatments for the side effects of the disease, plus the cost and time of travel for phlebotomies and tests, ambulance charges, work time loss, hospital stays and walkers etc.

Hemochromatosis has been attributed as the root cause of my impending demise from cancer, so to anyone who may suspect they have the disease, I urge you to get tested. If you have it, get your family tested. If a family member has it, get yourself tested. One of my siblings is currently under treatment and past members of our family are suspected of having it.

If detected early, treated and maintained with phlebotomies, one can live a long and healthy life.

William James Brinnen 1942 - ?
Parksville, BC

Undiagnosed and untreated hemochromatosis causes heart disease, cancer, diabetes (type 2), arthritis and other serious crippling diseases

FROM THE DESK OF BOB ROGERS, EXECUTIVE DIRECTOR

Bob Rogers

Inside this Issue

In this issue of Iron Filings, we are introduced to two wonderful people who live in Canada: Bill, who lives on Vancouver Island and Diane, who lives in Ottawa. They come from two different ethnic backgrounds; Bill is from Irish stock and Diane's ethnicity is French. Both have hemochromatosis. They tell you their story to make you aware of the consequences of letting iron build up in their bodies.

From coast to coast in Canada, over 100,000 people from Northern European and Celtic descent have hemochromatosis and over 3 million have one gene copy of the mutation associated with this disorder. In the lives of all these people hemochromatosis is important, however, most don't know they or their offspring have the potential for iron overload. The horrible effects of iron overload are completely preventable with early testing, diagnosis and treatment.

You can help us reach others before it's too late. Learn as much as you can about iron overload. Talk to your friends. Go to our website at www.toomuchiron.ca. Get involved. Consider volunteering your time and energy to help us spread the word and, if you are able, give generously to the Canadian Hemochromatosis Society.

Your action will reduce suffering and save lives. Thank you.

French Canadians are at risk for hemochromatosis. This story explains why.

Around 800 AD: Back in a time in Europe when dietary iron was scarce and plagues were beginning to kill great numbers of Europeans, the human body altered itself to adapt to this harsh environment. The body adapted through the alteration of the HFE gene into what is now called the C282Y mutation. This mutation predisposes the body to absorb increased amounts of iron. Bacteria normally thrive in iron-rich environments, but strangely enough the hemochromatosis mutation prevents at least some bacteria from gaining access to the iron in the body. One of these bacteria is the one that caused the Bubonic Plague that would kill millions of Europeans in the 14th century.

At the time, Vikings were raiding along the coasts of several northern European countries. They invaded Normandy, France, and conquered the land. The Vikings continued on with their conquest by raiding the neighbours further south down the coast: the province of Brittany. The people of Brittany put up a good fight, but eventually surrendered to Viking rule.

In all probability, a raiding male Viking who carried a C282Y gene met a female Breton who also carried a C282Y-altered gene, and together they had a child. This child was fortunate enough to receive the C282Y gene from each parent, protecting him from the Bubonic Plague and most likely other plagues as well. Whether the spread of the C282Y gene began with this original couple, or whether the spread began with several couples similar to the one written here, the high societal ranking of Vikings and inter-marriages helped to concentrate the gene in Brittany and offered protection from the Plague for all those affected.

To this day there is an extremely high frequency of the C282Y gene in Brittany's population, and thus a high prevalence of hemochromatosis. However, the hemochromatosis gene doesn't offer quite the advantage it did 700 to 1200 years ago, with the near-eradication of the Plague and the current abundance of iron-rich foods. Instead, those with the genetic markers for hemochromatosis are at risk for overloading their organs, joints and tissues with iron, causing illness and disease, even early death.

The French eventually colonized several countries around the world. Many settled in the part of the world that is now known as Canada. Not only did they settle in an area that was eventually named Quebec, but also throughout the rest of Canada.

History has made French-Canadians a group that is at risk for hereditary hemochromatosis. If you are French-Canadian and are experiencing symptoms of the disorder, get tested for it. You could save your life and the lives of others in your family.

References:

Moalem S. and Percy M.E. HFE gene: the positive side. Epidemic Pathogenic Selection (EPS) as an Explanation for Hereditary Hemochromatosis. Insight Spring/Summer 2003.

Milman N. and Pedersen P. Evidence that the Cys282Tyr mutation of the HFE gene originated from a population in Southern Scandinavia and spread with the Vikings. Clinical Genetics 64(1): 36-47 July 2003.

New! Website

Have you visited our website lately? To coincide with the start of this year's May Awareness Month, we relaunched our website on May 1st with a new look and feel which capitalizes on our re-branded print materials. Visit our site at www.toomuchiron.ca to learn more about hemochromatosis, find valuable links, sign up to our email list, or make an online donation. Send us an email at office@toomuchiron.ca to tell us what you think of the new website. We'd love to hear from you.

President's Message

Ross Gilley, President

This edition of Iron Filings marks a special occasion in the society's evolution. For the first time we are extending our reach to the 6.7 million Canadians whose mother tongue is French.

Why is this significant? Research indicates an unusually high incidence of Hemochromatosis among the Quebecois, Acadians and other French peoples living in Canada. In order to spread the essential messages of hemochromatosis awareness in Canada, we absolutely need to communicate in both official languages.

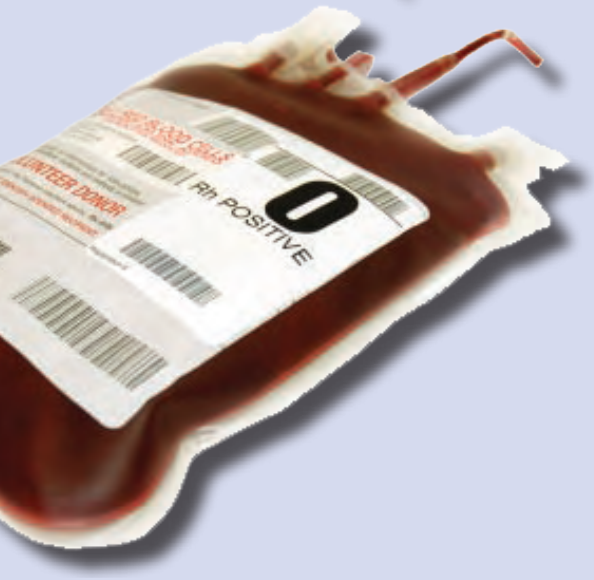
This is why all our future issues of Iron Filings will be in French and English. We are also currently working on a project to translate and design our website in French by December of this year. Our message, in both languages, will continue to stress early testing, diagnosis and treatment of iron overload. Only through constant communication will we achieve our key objectives:

- to extend the lives of Canadians threatened by iron overload-related diseases.
- to reduce the suffering that many experience from hemochromatosis-related symptoms.
- to proactively assist the Canadian health system by saving health care dollars through the prevention of iron overload related diseases
- to save the lives of others by encouraging individuals in treatment for hemochromatosis to donate their blood to the Canadian Blood Services

These realities drive our daily passion to inform all Canadians of the ravages of iron overload, and with your past support we have been able to expand our reach. As we move forward, new and ongoing support can help thousands of others and save lives.

Thank you sincerely for your past support, spreading the word and helping this cause. We look forward to strengthening our relationship with you in 2010.

"Research indicates an unusually high incidence of hemochromatosis among the Quebecois, Acadians and other French peoples living in Canada."



Canadian Blood Services

The Canadian Hemochromatosis Society is a member of Canadian Blood Services' "Partners for Life" program. If you are in the maintenance phase, you can team up with the Society to save more lives. Here's what you need to do to donate your blood through the Canadian Hemochromatosis Society:

1. Have the Canadian Hemochromatosis Society Partner ID # ready. This # is CANA002257.
2. Register online by going to our website at www.toomuchiron.ca and clicking on the link that says: **CBS Partners for Life Registration F orm** found in the column to the right of the home page. This is a "one time" process. Once you are registered, your blood donations will automatically be tracked with no further action on your part.
3. Call 1 888 2 DONATE to book an appointment to donate blood.

If you don't have internet access, all clinics should also have a registration form on hand to fill out.

Are You Iron Avid?

Believe it or not, a hemochromatosis patient can become iron deficient with their treatment. This condition is termed “iron avidity”, and occurs when a patient’s ferritin level is in the low to low-normal range (15-40 ng/mL) and the transferrin saturation percentage is elevated (>50%). In an iron avid person, the danger is increased for all symptoms of iron deficiency including fatigue, malaise and restless legs syndrome. There is also a risk of bacterial infections, since bacteria will grow in the presence of a high transferrin saturation percentage.

Why does iron avidity happen and how do you correct it?

Hemochromatosis is a scary diagnosis for many people. Often, hemochromatosis patients will immediately start an iron-reduced diet to counteract their body’s abnormal ability to absorb four times the amount of dietary iron as a person without hemochromatosis. Iron removal via therapeutic phlebotomies then begins, often on a weekly basis, becoming less frequent until the patient is de-ironed. During the maintenance phase, many hemochromatosis patients are over-bled and this, in combination with a reduced-iron diet, places them in an iron avid situation.

Researchers believe that iron avidity is the condition that results from over-bleeding, where the body’s mechanisms start to send more iron to the bone marrow than is really required. A key to hemochromatosis management is to keep the iron in your body in balance – not too much, and not too little. Dr. Siegfried Erb, a Vancouver-based gastroenterologist who treats many hemochromatosis patients, stated in the Fall 2007 issue of Iron Filings, “When you are stable, you should have a normal hemoglobin, TS less than 50 percent, and ferritin less than 50 ng/mL.” The optimal ferritin levels are between 25 and 50 ng/mL. Once too much iron has been removed, it can be difficult to regain the balance.

What can an iron avid patient do to get his/her iron back in balance?

Monitor ferritin and transferrin saturation levels and track them on a chart. Eat an iron-rich diet to help replenish the body’s iron stores. Discontinue phlebotomies until the ferritin reaches a minimum level of 50 ng/mL. The transferrin saturation percentage should be close to or within the normal range of 30-40% at this point.

What can a hemochromatosis patient do to prevent becoming iron avid?

Once in maintenance, monitor and chart ferritin and transferrin saturation levels routinely to determine when a phlebotomy is required. The hemoglobin (Hgb) and mean corpuscular volume (MCV) should remain in their normal ranges. The normal range for Hgb is 12 – 16 g/dL for adult females and 13 -18 g/dL for adult males. The normal range for MCV is between 80 and 100 fL. Don’t base your decision to have a phlebotomy just because the calendar tells you that it is time.

Acknowledgements:
The Canadian Hemochromatosis Society thanks Dr. Gershon Growe, Medical Director at Canadian Blood Services, BC/Yukon Region, for editing this article.

References:
Iron Disorders Institute. Iron Avidity… Common phenomenon seen in hemochromatosis patients. idInTouch. May/June 2005.

UPDATE ON

Awareness Month

This year, May proved to be a very busy month for activities raising awareness of hemochromatosis. Highlights of the month included:

Left to right: Amanda Bennett, Julie Cormack, Anne Stang

↑ Volunteers Anne Stang, Amanda Bennett and Julie Cormack hosting an information booth at the Seniors' Resource Fair in Calgary's City Hall.

Bryan Allen with Bob Rogers

↑ CHS Executive Director, Bob Rogers, being interviewed with Dr. Paul Adams, Chief of Gastroenterology at London Health Sciences Centre and leading hemochromatosis researcher, on CKNX AM 920's "Talk Show with Bryan Allen" out of Wingham, Ontario. The show was heard around the world via the online streaming on CKNX's website. If you missed the broadcast, a recording of the lively one hour show can be heard over 6 videos on our YouTube channel, found at this URL: www.youtube.com/toomuchiron.

- Bob Rogers was interviewed on Hamilton's CHML AM 900 Radio. Bob spoke about hemochromatosis in a ten minute segment of the talk show, "Health Matters with Jamie West". This show was heard around the world with the station's online streaming. Go onto our YouTube channel to listen to a recording of this show.

Brenda Ohara and Ashley Mitchell

← Volunteers and staff hosting an awareness booth at the European Festival in Burnaby, BC. We recorded a video of Bob Rogers interviewing people of northern European descent, and posted the video to our YouTube channel.

Hats Off Day with The Thunderbirds Barbershop Quartet

← Volunteers and staff hosted an information table at North Burnaby's Hats Off Day celebrations. The Thunderbirds Barbershop Quartet volunteered to sing at the venue to draw attention to our display. In addition, Top Barbers donated partial proceeds from the day's haircuts to CHS.

← Bob Rogers meeting with members of CHS.

These activities do much to advance the awareness of hemochromatosis in communities all across the country. A big THANK YOU goes out to everyone who made this year's Awareness Month flourish with activity

What everyone should know about FERRITIN.

Is ferritin the best test for iron in the body?

Ferritin is the best test for adequate iron in the body. However, it is not the best test for iron overload.

Why is ferritin not the best indicator of iron overload?

Ferritin is an acute phase reactant. An acute phase reactant will go up when the body is ill with acute or chronic infection, inflammation or neoplasm. Ferritin will also go up naturally with age.

Is there a better test for iron stores in the body?

The best test is percent iron saturation (% iron sat). One is suspicious for possible genetic hemochromatosis if the saturation is greater than 50%. A direct iron is also a good test.

Why don't doctors order direct iron and % iron sats rather than ferritin?

Often ferritin is the only measure of iron on a standard requisition because doctors are more commonly looking for iron deficiency. Direct iron and % iron sat need to be written on the requisition.

Is the ferritin level useful in iron overload?

Yes. When % iron sat, direct iron and ferritin are all elevated, the level of ferritin can indicate how much iron is stored.

How high can ferritin get?

Fortunately, organ damage in hemochromatosis seldom occurs under a ferritin of 1,000 ug/L. Damage can occur earlier if a target organ, such as the liver, is sick for other reasons eg. hepatitis.

In most individuals with genetic hemochromatosis, it takes years to reach truly toxic levels of iron. Genetic diagnosis in early adulthood can prevent problems when iron levels are kept low. Ferritin as an acute phase reactant can reach into the thousands without any iron overload at all. Such levels occur in the setting of serious illnesses such as cancer or acute inflammatory conditions such as Crohns or rheumatoid arthritis.

How can iron studies be interpreted?

Result 1

High % iron sat, normal or high direct iron and normal ferritin. This is an individual who may well have genetic predisposition to hemochromatosis but has not yet stored enough iron to be in danger. This is the best time to prevent iron overload by becoming a regular blood donor.

Result 2

High % iron sat, high direct iron and high ferritin. This individual almost certainly does have genetic hemochromatosis and has accumulated too much iron. Phlebotomy will likely be necessary.

Result 3

Normal direct iron, normal % iron sat and high ferritin. This could be any number of things – age alone, an acute illness such as pneumonia, or a serious chronic illness such as cancer. It sounds like we need all three measurements to assess for genetic hemochromatosis. That is the message we need to get out to physicians and patients.

Dawna Gilchrist MD FRCPC FCCMG DHMSA
Professor and Clinical Geneticist
Medical Genetics, University of Alberta

YouTube

New! YouTube Channel

We now have a YouTube Channel! This is another tool that we can use to spread awareness of hemochromatosis. We have already posted several videos on our new channel, and plan to post many more. Watch our channel at www.youtube.com/toomuchiron and make a comment or rate the videos. You can also send the videos to all your contacts, or share the videos with friends on FaceBook.

Hemochromatosis

VERY COMMON • VIRTUALLY UNKNOWN • POTENTIALLY FATAL • EASILY TREATABLE

What is it?
The excess storage of iron in the body.

What is the cause?
Primarily hereditary.

Most common symptoms
Chronic fatigue, joint pain, irregular heart beat, mood swings, confusion, bronzing of the skin, loss of libido and abdominal pain.

Most common complications
Liver and heart disease, diabetes, arthritis and hormonal irregularities.

Tests required for diagnosis
Serum ferritin, transferrin saturation percentage and genetic testing.

Treatment
Phlebotomy treatments (bloodletting) which are ongoing for life.

Reference reading
The Bronze Killer; Ironic Health; Iron Disorders Institute Guide to Hemochromatosis

Hereditary Hemochromatosis (HHC) is a genetic disorder that affects over 3,000,000 people in Canada.

There is a cure. Awareness.

Please forward this newsletter onto your family and friends

Newsletter Design by Hallographix

Support CHS and help prevent needless suffering and early death

Donation $_____

Annual Membership

- ☐ Regular ____ @ **$30**
- ☐ Senior ____ @ **$20**
- ☐ Family *(same address)* ____ @ **$45**

☐ Yes, please renew my annual membership automatically by using my credit card info

- ☐ Senior's Lifetime (55 +) ____ @ **$295**
- ☐ Lifetime ____ @ **$500**

Books & Accessories

- ☐ The Bronze Killer ____ @ **$20**
- ☐ Ironic Health ____ @ **$22**
- ☐ Wristband ____ @ **$8**
- ☐ Hemochromatosis DVD ____ @ **$21**
- ☐ Too Much Iron DVD ____ @ **$10**

Total $_____

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(use credit card info area to the right)

- ☐ I have Hemochromatosis (HHC)
- ☐ I have a blood relative with HHC

- ☐ I would like my support acknowledged in the newsletter
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