FALL 2012

Canadian HEMOCHROMATOSIS SOCIETY
Société canadienne de l'hémochromatose

Iron Filings

Providing information, awareness and support

Ironians Live Amongst You

BY MARCEL MORIN, GATINEAU, QUEBEC.

My name is Marcel Morin, I am 50 years old and I live in Gatineau, Quebec. My wife's name is Lyne and together, we have two wonderful children, Rosalie, 17, and Xavier, 15.

Despite the clear fact that I live on planet Earth, it had been evident to me for a very long time that my origin was not that certain. Before I received a diagnosis of hereditary hemochromatosis (homozygous for C282Y HFE gene mutation) in April 2009, I had some doubts about my planet of origin for about fifteen years.

At the beginning, these doubts started with joint pain to my right foot and ankle, and burning sensations on my legs. As a result, it was even difficult to run after my kids when they were young. I experienced other symptoms too: swelling legs, bronzing of the skin and a lot of difficulty walking. With all these symptoms, I consulted my family doctor who informed me that, after careful consideration, I was just getting old. I was only 36 years old at the time, so this was a bit surprising to hear, to say the least. The only thing to do was to silently suffer and accept and live with the pain. Through all that time, a voice inside of me was telling me that there was something wrong, but I was able to keep it silent and life went on.

Later on, I became more and more tired, to the point where it was difficult to participate in family activities and undertake small projects at home. Then, along with the chronic fatigue, anger and depression periods set in. It was clear that there was something wrong. For that whole period, I was very lucky to have a wife who, although she had difficulty understanding what was happening to me, stayed with me for better or for worse. I would say that for a long time for her, it was for worse.

Just before I received the diagnosis, periods of fatigue were more and more frequent. I lost at least 40 pounds and with the greying of my facial skin, I was frightening to look at. My colleagues and friends were too shy to ask what was wrong with me but they saw that I was declining at a very fast pace. At work, I needed twice the time to accomplish very simple tasks. My diabetes type 2 diagnosis was confirmed when I renewed my temporary life insurance contract in Fall 2008. It wasn't until my family doctor registered me in a workshop on diabetes management that I started to see the light at the end of the tunnel.

After a battery of medical tests prescribed by an endocrinologist, in addition to my diabetes situation being confirmed, the results showed that I had a serum ferritin of 3200 ng/mL. That night, I came back home with a prescription of insulin as well as the knowledge that I had a very high level of iron in my blood. A new life was beginning and my first reaction was to thank, from the bottom of my heart, the endocrinologist who was able to find the right diagnosis. It was such a weight off of my shoulders; all these symptoms were not in my head. They were real and I suddenly received the confirmation of my real origins; I was not from the planet Earth but instead from the planet "IRON". Many Canadians are from this very special planet but many of them as well as many doctors are not aware of it. As a result, many people suffer silently for so many years and many of them have permanent after effects.

April 2009 was the beginning of the second step of my fight: the therapeutic phlebotomies. For the first nine months, phlebotomies were every two weeks and weekly for the next 15. What an adventure! It has been a very exhausting process but the results are there. On June 30, 2011, my serum ferritin was at 95 ng/mL. Fourteen months later, my ferritin is at 82 ng/mL. Saturation is still high (100%) but I feel so well. I have to accept that some of the damages are permanent, diabetes and joint pain to name only a few. Apparently, the preliminary symptoms of liver cirrhosis are blurring. Phlebotomies are now once every six weeks, a huge improvement for me.

Ironians Live Amongst You (CONTINUED)

On the family side, Lyne had the genetic test done and received confirmation that none of her genes which stop excess iron absorption were defective. This means that our two children have only one defective gene and they should not develop the disease. My oldest sister received the same diagnosis as I with a serum ferritin of 700 ng/mL. Two years later, she is at 40 ng/mL. The damages for her are mainly related to joint pain and legs feeling tight. My two brothers have only one defective gene while my youngest sister has been the luckiest with no defective genes at all.

Today, I am feeling well, but my biggest challenge remains to accept that I have suffered in silence for so many years without knowing that the "silent killer" was having devastating effects on me. It is an ongoing challenge that I am able to fight every day with the precious help of my family, my friends and colleagues.

To conclude, never forget that as a person with genetic hemochromatosis, you are your own hemochromatosis specialist. So, have confidence in yourself and invest in managing this disorder. Through information you can find on the Canadian Hemochromatosis Society's website or their Client Support line, and with the assistance of the incredible hemochromatosis specialists, you will reap the rewards.

Looking Back for Answers
French Canadian History and Hemochromatosis

Hereditary hemochromatosis is Canada's most common genetic disorder, and it can lead to organ damage and premature death if left untreated. Historically, this condition affects mainly those of Northern European descent. So why should nearly 8.5 million French Canadians be concerned about hemochromatosis? As we turn back the hands of time and return to history for an explanation, the answer may surprise you.

In the past, increased iron absorption was a desirable trait due to iron-poor diets. Iron was also essential in compensating for blood lost during battle. The human body adapted to these distinct conditions by altering the HFE gene into what is now called the C282Y mutation.

Commonly referred to as the "Celtic Curse," scientists hypothesize that the genetic mutation leading to hemochromatosis originated from one single Celtic or Viking ancestor. In 1000 B.C, the Celts colonized parts of Europe north of the Alps, from parts of the United Kingdom down to Northern Italy. The term "Celtic" is often used today to describe those of Irish, Scottish, Welsh or Breton (French) origin.

Later in history, the Viking warriors invaded large parts of Europe which were previously under the influence of the Celts. Between 911 and 916 AD, the Norsemen seized control over Normandy and Brittany. It is likely that intermingling occurred, and the C282Y mutation became further concentrated in the gene pool of the Norman and Breton peoples.

French colonization of modern day Canada began in the 16th century, and in 1604, attracted by the abundance of natural resources, French settlers set up the first colony of Port Royal in Acadia, New France, now a national historic site in Nova Scotia. According to the Canadian Encyclopedia, most of the settlers in these areas were from French provinces including Normandy, Maine, Touraine, and Brittany. As more colonists arrived, Acadia began to expand inland and westward into modern day Quebec. Many French Canadians today can trace their heritage back to ancestors that have warred and intermixed with the Celtic and Scandinavian peoples.

The most common gene related to iron metabolism is called HFE (Human + Fe, the symbol for iron). The majority of hemochromatosis patients have a combination of the two most common mutations of the HFE gene, the C282Y and H63D mutations. Various studies have suggested that frequency of the hemochromatosis gene in the population of Brittany remains high. For example, recent research found two copies of the C282Y mutation (homozygosity) in every 1 in 200 people. These historical events help explain why the French Canadian population is at risk for hereditary hemochromatosis. Excess iron absorption can lead to buildup in vital organs, but when diagnosed early, complications caused by the disorder are completely preventable. If you have French Canadian or Northern European roots, you are part of the population at high risk for iron overload. If you are experiencing symptoms, get tested for hemochromatosis. Support the Canadian Hemochromatosis Society in its mission for greater public awareness, and you could save lives.

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Why are accidental findings transcending sound medical practice?

BOB ROGERS,
CANADIAN HEMOCHROMATOSIS SOCIETY - EXECUTIVE DIRECTOR AND CEO

I often speak to clients, members, sponsors and individual donors in my role as Executive Director of the Society. Our clients tell me about their long, wearisome and frustrating journey of suffering, sickness, and disease they experienced until they chanced upon a doctor who was knowledgeable and took enough time to assess their symptoms, make a connection between their several symptoms and excess iron levels, and arrive favourably at a clinical diagnosis of hemochromatosis. This substantial diagnostic delay has caused too many individuals to experience irreversible organ damage that leads to needless suffering and early death. This is completely unacceptable and irresponsible. It has to stop!

A few years ago I received a phone call from a lawyer in Calgary who posthumously represented a 35 year old male. An autopsy revealed he had a serum ferritin level of 7500 ng/mL. This individual had frequently visited several doctors to investigate his many health issues but none of his attending physicians diagnosed his overload of iron (likely a contributing cause of the health problems) which led to his early death.

A few months later, a vibrant, apparently healthy 33 year old male applied for extended health insurance benefits through his employer. The insurance company performed various blood screening tests to determine his insurability. When his ferritin result came back at an astounding 9500 ng/mL, they declined coverage. His insurance company participated in a finding of hemochromatosis. His situation was not discovered previously by his doctor. No matter how fortuitous this discovery was, in the light of the first example of what a severely elevated ferritin can produce, you can see how dangerous it is to leave an important diagnosis to chance.

Sound medical practice must question why an individual is suffering from their health conditions and investigate all the possibilities, including the possibility of an underlying genetic reason. If a patient is in the hereditary risk group (white, northern European or Celtic ethnicity) and the patient has two or more of the symptoms or diseases associated with too much iron in the body, then it is prudent for the physician to test transferrin saturation and serum ferritin levels by indicating on the lab form they suspect hemochromatosis. If the result of these tests is positive for iron overload, a genetic test can confirm the diagnosis. Until this clinical procedure becomes more common place, too many people will suffer because they lack the medical care they deserve.

The Canadian Hemochromatosis Society was established to create awareness about this little-known, but very common disorder so that early diagnosis would become the rule rather than the exception and needless suffering and premature death from undiagnosed hemochromatosis would become a thing of the past. The Society, its members, its staff and volunteers will not rest until this mission is achieved. When you donate to this Society with your time, talents and/or contribute financial resources you enable us to execute our programs throughout Canada, particularly to those affected by hemochromatosis, the healthcare professions and the general public. Please give thoughtfully and generously to the Canadian Hemochromatosis Society. Thank you.

Chondrocalcinosis: A Valuable Indicator

The American College of Rheumatology notes that approximately 50% of hemochromatosis patients with arthritis also have associated chondrocalcinosis. Arthritis is one of the symptoms of hemochromatosis, particularly in the knuckles, ankle, or first joint of the second and third fingers (also known as the iron fist). Chondrocalcinosis (kon"dro"kal sĭ-no´sis) is a form of arthritis characterized by the accumulation of calcium pyrophosphate dihydrate crystals in connective tissues (CPPD). Crystal deposits found in CPPD can affect any joint.

Chondrocalcinosis is similar to gout, an inflammation of the joints caused by uric acid crystals. Therefore, the term "pseudo-gout" was coined to describe inflammation caused by CPPD. CPPD crystals can also cause inflammatory joint effusions, a condition where abnormal fluid builds up in the joints. Through a process called joint aspiration, the fluid can be examined in order to differentiate between pseudo-gout and gout.

The discovery of a white line of chondrocalcinosis in an x-ray can also be evidence of underlying hemochromatosis. In a 1988 study done by Dr. H. Ralph Schumacher, and published in Arthritis and Rheumatism, the cartilage of hemochromatosis patients was analyzed. On the surface of the eroded cartilage, CPPD crystals and iron deposits were found in addition to degenerative alterations.

Marie Warder, founder of the Canadian Hemochromatosis Society, is a carrier of the gene mutation for hemochromatosis. She was diagnosed with chondrocalcinosis in 2011, and now relies on a voice recognition device to aid her in her work as an author. In her blog, Marie mentions that CPPD has been reported by many homozygotes (those who carry two identical gene mutations) as having been the presenting symptom of hemochromatosis. Marie also writes, "Over the years I have learned, however, that that it is also possible for heterozygotes (persons carrying only one gene) to be afflicted. I have known some with knees so swollen that the fluid has had to be aspirated." Today, the mechanism through which iron overload causes arthritis remains unknown, but the presence of CPPD and chondrocalcinosis should not be overlooked as a valuable indicator to get tested for hemochromatosis

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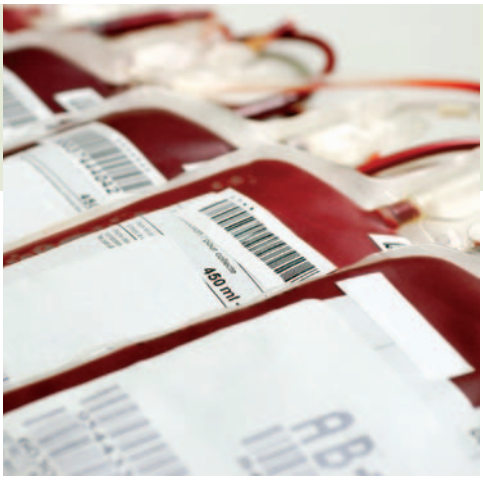
Partner in Focus: Héma-Québec

Combining forces for increased hemochromatosis awareness



In August 1997, the Red Cross announced that "it was relinquishing all control over Canada's blood programs as of September 1998." At that time, Québec's Health Minister Jean Rochon was left with the option of joining the new blood supplier about to be created (now Canadian Blood Services), or to establish a new local bank. In light of the Minister of Health's goal to bridge the gap between the provincial healthcare system and its blood supplier, Héma-Québec (HQ) was founded in March of 1998. As a non-profit organization, HQ is now governed under special legislation (Bill 438), which was adopted by the National Assembly in June of 1998.

Since its establishment, the mission of Héma-Québec has been to efficiently provide adequate quantities of safe blood components, human tissues, and stem cells to meet the needs of all Quebecers. It has also endeavored to provide specialized services and develop expertise in the fields of transfusion medicine and tissue transplantation. At the heart of their mission, Héma-Québec is a community-focused agency, with its Board of Directors "[representing] all stakeholders in the transfusion chain, from donor to recipient." The organization has also developed a Sustainable Development Action Plan, which reaffirms their commitment towards implementing core principles such as public awareness, training, and prevention.

Due to the complexity of its components and associated defense mechanisms, research still has not discovered a viable substitute for blood. This life-saving resource must therefore be collected through blood donations. An hour is all that is needed to save up to three lives. In spite of that, statistics from Héma-Québec show that the mean number of blood donations per donor has remained stable at 1.6 for the last 10 years, and the percentage of the population donating blood is 3%. Though this situation is similar to the one observed elsewhere in North America, it has been a constant challenge for Héma-Québec to maintain the blood supply at an adequate level. The blood bank must continuously adjust its recruitment strategy in order to increase the number of blood donors. A common misconception is that blood from hereditary hemochromatosis (HHC) donors contains excessive amounts of iron, and is therefore discarded. In truth, blood from patients with hemochromatosis contains normal iron levels, with the added advantage of having a greater number of young red blood cells. In 1991, the Canadian Red Cross deemed blood taken from people with HHC safe for transfusion. Héma-Québec confirms that HHC donors in the maintenance phase of their treatment are accepted at regular 56 day intervals if they satisfy the initial selection criteria predetermined by Health Canada.

Héma-Québec strives to promote blood, blood stem cells, and human tissue donations, in addition to fostering durable relationships with hospitals and other non-profit societies, such as the Canadian Hemochromatosis Society (CHS). It is the objective of both HQ and CHS to offer efficient and improved services to HHC sufferers in Quebec through regular blood donation. Preparation, training, and a working strategy with local physicians and specialists are underway to ensure that HHC donors receive the highest quality of service and treatment. Together, HQ and CHS have united their missions and goals into one voice, working together strategically in order to raise greater public awareness of hereditary hemochromatosis while simultaneously increasing the number of blood donors.

donor clinic

To learn more about donating blood in Quebec, visit www.hema-quebec.qc.ca.

CHS Snapshots

Karin Calford of Haemochromatosis Australia (l) met with Frank Berto and Brenda Ohara, both of CHS

Karin Calford, Haemochromatosis Australias's New South Wales contact and committee member, met with CHS staff in July while in Vancouver visiting her son. Karin, along with Frank Berto, CHS Event Coordinator, and Brenda Ohara, Director of Communications, discussed activities of both societies and discovered many similarities. Haemochromatosis Australia, a volunteer run society, organized their first National Haemochromatosis Awareness Week this past August 13th – 19th. The week was touted as a great success with the extra publicity and awareness raised and many attendees at their country-wide information sessions.

CHS Executive Director Bob Rogers with WiseQuacks Dr. Robert Sealey (l) and Dr. Dave Hepburn (r)

In July, Bob Rogers spread awareness of hemochromatosis on the entertaining and upbeat radio health show, WiseQuacks. The show was broadcast over the airwaves across Canada.

Among Ourselves

This column appears regularly in every issue of Iron Filings and features stories about our dedicated volunteers.

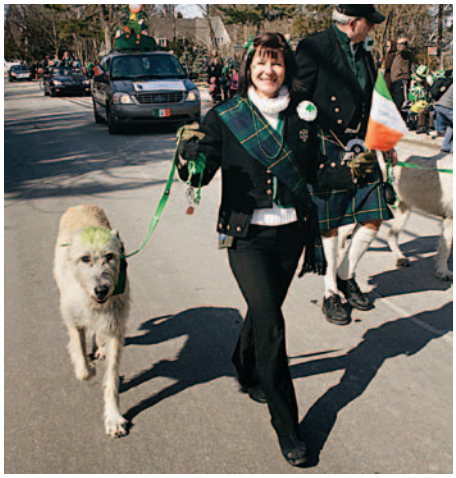
Montreal Chapter

The Canadian Hemochromatosis Society (CHS) is getting stronger every day, and much of the credit can be attributed to our volunteers – wonderful, giving people who take on tasks like answering the phone in the national office and conducting vital public awareness and fund raising activities. Volunteers also help us to extend our influence across Canada by joining local Chapters.

Chapters are formed when a person committed to spreading the word about hereditary hemochromatosis (HHC) takes on the role of Regional Organizer, responsible for establishing a Chapter in their home community and maintaining communication with the national office about the Chapter activities. Regional Organizers have a leadership role, and work with the national office to recruit Chapter members and facilitate training so that volunteers can participate in awareness-raising events in their home community. Many of our volunteers have been touched by hemochromatosis, either directly or through a family member. Others are attracted to the CHS because of the diversity of volunteer opportunities and the camaraderie and friendships that develop as people come together to support an important cause.

One of our newest Regional Organizers is Juliana Pavelka-Johnston, who stepped forward to organize the newly formed Montreal Chapter. Juliana is a classic example of the old adage: "if you want something done, be sure to ask a busy person". Since becoming involved in CHS she has enthusiastically embraced the many tasks involved with setting up a Chapter while, at the same time, running a household, tending to aging parents, and participating in activities of the Montreal Irish Society and the Irish Wolfhound Club of Canada. Juliana is keenly aware of the importance of raising HHC awareness because her father is suffering from many symptoms resulting from a delayed diagnosis of HHC. She wants to send the message to health care professionals and the general public, that early diagnosis of HHC may prevent the onset of symptoms that could cause disability and even early death.

Another new volunteer, one of the first members of the Montreal Chapter, is Mark Johns. When asked why he chose CHS to support, he responded, "I have hemochromatosis and would like more people to become aware of the health problems that it can cause. Even though I had to undergo bilateral hip replacement last fall at the age of 47, I consider myself lucky to have a family doctor who diagnosed my hemochromatosis so that I could get treatment and prevent worse complications down the line. I strongly believe that with greater awareness of hemochromatosis, much unnecessary suffering can be avoided – particularly when the treatment for the disorder itself is so simple."



Juliana Pavelka-Johnston with her Irish Wolfhound, Kuri

We are indeed fortunate to have a core group of dedicated people supporting the work of CHS, but we need more help to extend our reach even further. If you would like to organize a Chapter in your community, join an existing Chapter, or find out more about CHS volunteer opportunities, check out our website at www.toomuchiron.ca, send an email to program@toomuchiron.ca, or call us at 1-877-BAD-IRON (1-877-223-4766). We look forward to hearing from you!

Attendees at the Prince George Information Session

Information sessions were held across British Columbia in July and August, with CHS Executive Director Bob Rogers presenting in stops along Northern BC, Vancouver Island, the Lower Mainland, the Okanagan Valley, and the Thompson-Shuswap. Attendees enjoyed Rogers' presentations and many have signed up to become volunteers for CHS, signifying the beginnings of many Chapters being formed in BC. Read more about Chapters and volunteering in the "Among Ourselves" column in this newsletter and the "Get Involved" section of the CHS website www.toomuchiron.ca.

CHS President and Chair of the Board Patrick Haney (l) with Executive Director Bob Rogers and CHS founder Marie Warder

Marie Warder recently blessed the CHS office with a visit in August, sharing stories of the early days of the Society.

DNA 101: The Genetics of Hemochromatosis

BY JUNE WONG, PHD, VICE PRESIDENT, LABORATORY OPERATIONS, GENETRACK BIOLABS INC.

The HFE gene was first discovered as the causative gene for hemochromatosis in 1996. This discovery allowed DNA testing for the diagnosis of HFE associated Hereditary Hemochromatosis.

The HFE gene is responsible for regulating the amount of iron that is absorbed from the food that we eat. We all have two copies of the HFE gene, one copy inherited from our mother and one copy inherited from our father. Our chances for developing hemochromatosis depend on whether we have inherited the normal or the defective HFE gene from our parents.

Hereditary hemochromatosis can occur when a person inherits two defective copies of the HFE gene, one from each parent. Men and women have the same chance of inheriting two copies of the defective HFE gene.

A person who has inherited one defective HFE gene and one normal HFE gene usually does not develop the symptoms of hemochromatosis as the normal gene can balance out the defective HFE gene. In a small number of cases, inheriting only one defective gene may still eventually lead to iron overload. In these people, the iron overload may be triggered by a precipitating factor, such as hepatitis (inflammation of the liver) or alcohol abuse.

After taking the hemochromatosis DNA test, there are three possible categories of results: normal, carrier, and affected. The following table lists the phenotype associated with each genotype:

Normal

A person is considered normal if the results do not detect any of the three known mutations of the HFE gene. A normal result finding means that the person is not at risk of developing hereditary hemochromatosis and will not pass a defective HFE gene to further generations.

Carrier

A carrier is an individual who has inherited one defective HFE gene and one normal HFE gene. Carriers may pass the defective gene to future generations but usually do not develop the disease themselves. However, carriers of the C282Y mutation may still have higher than average iron absorption. There is a 50% chance that a carrier will pass the defective gene to their children.

Affected

An affected individual is one who has inherited two copies of the defective HFE gene, one defective gene from each parent. People who have two defective HFE genes (C282Y/C282Y, or C282Y/H63D) are at risk of absorbing too much iron and developing hemochromatosis. Although people with two defective genes have a significant risk of eventually developing some type of iron overload, not everyone with two copies of the defective HFE gene develops the disease. There is a 100% chance that an affected individual will pass a defective HFE gene to their children.

To order a hemochromatosis DNA test or for more information on HFE gene testing, go to www.hemochromatosisdna.org.

What are the chances....?

This chart gives the cumulative probabilities of having affected and unaffected children based upon the two parental crosses that typically concern hemochromatosis sufferers for passing on the defective HFE genes.

Heterozygote: an individual who has inherited one defective HFE gene and one normal HFE gene

Homozygote: an individual who has inherited two identical defective HFE genes

	Heterozygote x Heterozygote Probability of:			Heterozygote x Homozygote Probability of:		
	all children unaffected	at least one affected	all children affected	all children unaffected	at least one affected	all children affected
1 Child	75.0%	25.0%	25.0%	50.0%	50.0%	50.0%
2 Children	56.3%	43.8%	6.3%	25.0%	75.0%	25.0%
3 Children	42.2%	57.8%	1.6%	12.5%	87.5%	12.5%
4 Children	31.6%	68.4%	0.4%	6.3%	93.8%	6.3%
5 Children	23.7%	76.3%	0.1%	3.1%	96.9%	3.1%
6 Children	17.8%	82.2%	0.0%	1.6%	98.4%	1.6%
7 Children	13.3%	86.7%	0.0%	0.8%	99.2%	0.8%
8 Children	10.0%	90.0%	0.0%	0.4%	99.6%	0.4%
9 Children	7.5%	92.5%	0.0%	0.2%	99.8%	0.2%
10 Children	5.6%	94.4%	0.0%	0.1%	99.9%	0.1%

Synchronistic Life Events **Bring Blessings**

BY MANON PELLETIER, SAINT JOHN, NB

I was adopted and knew nothing about my family's health history. My biological brother and I had been Facebook "friends" for a year but never connected—until I was being tested for hemochromatosis and felt the urge to find out if it ran in our family. We met this summer and joyfully talked for hours about things we have in common. He shared his own journey and reassured me that treatment for iron overload is non-invasive and that I can expect to regain my vitality. Two blessings in one shot!

My first complaint of extreme fatigue was 10 years ago. I was 31—two years after I was happily married, and four years since I began my career as an executive assistant in a corporate world I thrived in. Because I worked in a high-profile position, I was told to take a vacation and antidepressants. I took the vacation to sleep it off, but threw out the prescription.

As time progressed, my life revolved around my fatigue. I would get home at dinner-time and go straight to bed. I could no longer travel—something that my husband and I loved to do. I was losing friends because I could no longer keep up. I hit rock-bottom in 2008, after six years of being told there was nothing wrong with me. I was not sleeping due to restless legs and getting worse each day. On the advice of my doctor, my last day of work was November 14, 2008.

The customary insurance benefits forms followed, along with prescriptions for antidepressants and sleeping pills. I spent hours seeing therapists—all telling me that I do not have a mental health issue and that I seem happy and centered. Five months into my sick leave, I was still too weak to return to work. Without a diagnosis, my application for disability benefits was declined, and I felt I had no choice but quit my job voluntarily. I was heartbroken—but not depressed.

With the support of my loving husband, and my retirement savings, I was able to stay home and manage life around my fatigue. I began practicing yoga and meditation. I have spent the last 3 years learning about healthy living, reading hundreds of books and attending workshops.

In the fall of 2011, I undertook training for women entrepreneurship. After the four-month program, I did not have the energy or enthusiasm to pursue my dream. I began seeing a therapist to discuss my issues. I told him how frustrated I was with my low energy. I was inspired to work, but my body did not follow. He clarified things for me, candidly saying: "your problem isn't mental, it's physical. Go see a good doctor and push until this is resolved."

By then, I was down to 79 pounds, and green as an olive. I called my doctor (the third in eight years) to schedule an appointment. I began the blood-work routine and taking a prescription drug to manage my restless legs at night.

I also began seeing a Nurse Practitioner. She listened to all my complaints and symptoms for more than an hour. I recall vividly her expression when she paused, and said: "let's get you tested for hemochromatosis—iron is high." I still remember the emotional charge I felt at that moment. I knew that my life was about to change.

A few months passed, I went for more blood work and I felt fantastic without knowing why. This past June, my doctor confirmed that I was homozygous for the C282Y mutation of the HFE gene. Recent results also indicated that I was loading iron, with a transferrin saturation above normal limits at 70%– explaining my weight loss, low testosterone, abdominal pain, arrhythmia, hip pain, chronic fatigue, and restless legs. The reason I felt so good was that I was having blood work done. I recently learned that phlebotomy brings relief in most cases, but because I am under the 110-lbs protocol, I cannot donate blood. I have an appointment to see a hematologist this fall to begin treatment, and I am looking forward to it.

I believe that all events in our life are interconnected and intended for our self-realization. Recent events have been enlightening and a blessing. I have had the opportunity to meet my biological brother and a get a diagnosis. After ten years of silent suffering, social stigma and financial hardship, I can put my frustration to rest. I am tremendously grateful for the Nurse Practitioner who took the time to study the whole of my case—going beyond the traditional one-complaint-per-visit protocol. This is the primary reason I accepted to share my story. I hope that it will help promote awareness of hereditary hemochromatosis within the medical community, and highlight the role of Nurse Practitioners in the maintenance of good health (prevention) and early detection.

Meditation has transformed my life. It has allowed me to be peaceful, content and resilient. I am ready to explore the wonders of modern science.

CHS Updates

New Board

The 2011 Annual General Meeting was held on June 27th at the Richmond Caring Place in Richmond, BC.

A new Board of Directors was elected at the meeting, and includes Patrick Haney of Vancouver, British Columbia as President and Chair of the Board, Frank Erschen of Toronto, Ontario as Past President, Kelly McQuiggan of Vancouver as Treasurer, Ryan Howe of Vancouver as Secretary, Dr. Sam Krikler of Richmond, British Columbia, Warren Funt of Vancouver, David Lloyd of Vancouver, Shannon Haney of Okotoks, Alberta, and Pat McParland of Vancouver.

Returning directors are Patrick Haney, Frank Erschen, Kelly McQuiggan, Dr. Sam Krikler, Warren Funt, David Lloyd, Shannon Haney and Pat McParland.

Patrick Haney returns as President and Chair of the Board

Facebook

The CHS Facebook page has 573 Likes and counting. Keep updated on the Society's events and hemochromatosis information by "Liking" our page: www.facebook.com/TooMuchIron.

Go Green

If you would like to receive future Iron Filings newsletters by email, please let us know at office@toomuchiron.ca.

Il Sono Benefit Concert

On Saturday, April 28, 2012, Il Sono Men's Vocal Ensemble of Calgary, Alberta, gave a benefit concert for the Canadian Hemochromatosis Society. They titled the concert "His Sound: a concert celebrating the male voice", and a celebration it was.

They covered 400 years of "the manliest music from Giovanni Palestrina to Billy Joel". There was even a local composer, Georgina Craig, who accompanied her pieces on the flute.

After intermission, Anne Stang, Regional Organizer of CHS' Calgary Chapter, gave a brief presentation about hemochromatosis. It was a timely concert because one of the singers was diagnosed with hereditary hemochromatosis just two weeks before. At the reception after the concert, Anne and the others, Carolyn O'Connor and Amanda Bennett and some of her relatives, answered more questions for individual audience members. Again the comment, "I've never heard of this condition" was frequent.

Many thanks to Il Sono for their support.

Support CHS While You Buy Groceries

Everyday shopping can be an easy way to raise additional funds for CHS!

CHS is one of the charities that you can support with your purchase through DonateNaturally.com. DonateNaturally.com provides all of your favourite natural and organic groceries delivered conveniently to your front door, Canada-wide. For customers outside of the Greater Toronto area, your groceries are sent via Canada Post at no extra charge.

With every purchase, 15% of the value of your order goes to the cause of your choice. You are not charged an additional 15% on top of your order, and items are competitively priced with those at your local store.

First time buyers are eligible for a special promotion. At the checkout, enter promo code 'TRYIT30' to receive 30% off your first order.

You already shop for your groceries on a weekly basis; why not raise money for CHS while you do so? We thank you!

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THE EVERYDAY FUNDRAISING GROUP

New Blood Donors Needed

Every minute of every day, someone in Canada needs blood. Most often, it takes more than one donor to save a hospital patient's life. A single car accident victim may require 50 units of blood and blood products to survive injuries. That's why communities, groups and families across the country are encouraged to rally together to donate blood.

In order to help meet the needs of hospital patients during 2012-13, Canadian Blood Services needs to collect 915,000 donations and to recruit 90,000 new donors across Canada.

Why the need to recruit so many new donors? As the loyal blood donor base ages not only do donors leave the system, but they can potentially become users of the blood system. New donors are needed to ensure that a safe and sufficient supply of blood products is available for Canadian hospital patients when and where needed.

As a proud Partner For Life, members of the Canadian Hemochromatosis Society (CHS) are joining together to help Canadian Blood Services do their job to meet this need.

At CHS, we currently have 86 members donating to reach our lifesaving goal of 150 donations by December 31, 2012. As of the end of August, our organization has already made 112 donations, so we are at 75% to our pledge!!

If you are in the maintenance phase of your treatment for hemochromatosis, please consider donating on behalf of CHS to help improve or save the lives of hospital patients so they can return home to their family and friends.

If you haven't yet registered with the CHS Partners for Life group, you can do so from our website www.toomuchiron.ca or in person at the blood donor clinic. The Partner ID# to use is CANA002257 (four letters and six numbers).

Canadian Blood Services
it's in you to give

For Canadian Blood Services donor clinic locations and schedules, visit www.blood.ca/clinics. Check your eligibility at www.blood.ca/eligibilty.