



Iron Filings

Providing information, awareness and support

Our Vision

An end to suffering and premature death related to hemochromatosis in Canada

Hemochromatosis: What Everyone Should Know

BY PATTY HECKMAN, MOTHER OF FOUR, GRANDMOTHER TO FIVE, COUSIN TO 30

"Eric is dead! Aunt Patty, Eric is dead!"

It all began the night of October 24, 2012. First, my sister called and she was screaming so hysterically I couldn't understand her. A minute later my niece called and stated, "Aunt Patty, Uncle Eric is dead." I immediately thought, "Oh God no, there's been a mistake." My son, James, drove me to my brother's house and sure enough there was the paramedic truck, an ambulance, and police. The police wouldn't let me in; they wouldn't let me see my brother. His identical twin was out front with our sister and we were being held off by the police. I couldn't believe what I was hearing. "If only I could see my brother," I thought, "Then everything would be alright."

I can't remember a worse night in my life. There was no reason, no explanation. The coroner would have to give us answers. We were told it would be months because they were short-handed and back logged. John, Eric's twin, and I headed home to tell our father. More disbelief. His second child, dead.

As family and friends gathered to celebrate Eric's life, we decided to have a second autopsy. That decision literally saved our lives. The coroner had come back to us in January with a cause of death of diabetes and ketoacidosis. A week prior to his death, Eric had lab work done for a doctor's visit on October 23rd. He had a blood sugar of 292 mg/dL and 4+ Ketones. He was given Metformin and told to take half a pill. He left work early because he didn't feel well, and died early the next morning. We were left with more questions and no real answers.

In February we got the results from the second autopsy. Eric had iron deposits in his pancreas, liver, adrenal glands, thyroid, heart and lungs. He had hereditary

hemochromatosis. Doesn't the name mean we all could have it? There was a good chance another one or two or three of us have it. There were 6 of us after all. Not only us, but our 30 cousins could also have it. Have they had problems? Has anyone else died? Wait, cousin Jimmy died of liver cancer. I remember from Nursing School that hemochromatosis is a condition where the body retains iron in the organs. I needed to get the word out. I called those I had phone numbers for; I emailed others and Facebooked as many as I could. At one point I spoke with Aunt Dorothy, my Dad's sister, who told me she got checked. She stated that her doctor said her hemoglobin is 14 g/dL and she is fine. I tried to explain to her that she may be fine, but her two boys could be at risk.

All of my siblings are carriers except for John, Eric's identical twin. John is positive for two copies of the C282Y mutation on the HFE gene. He was found to have a ferritin level of over 6000 ng/mL. A normal ferritin range for men is 20-220 ng/mL.

I believe the first signs my brothers encountered were the bronzing of their ankles and toes. They each went to a dermatologist and they were each given "salve" to put on the rashes. The first doctor I spoke with about hemochromatosis was my dermatologist. I gave him two books I found very revealing on the subject. He stated to me he read about hemochromatosis during his medical training, but hadn't given it much thought until



Patty Heckman (far left) with family members. "Of vital importance is that future generations learn early on about this disorder."

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Hemochromatosis: What Everyone Should Know (Continued)

he saw me reading *The Bronze Killer* by Marie Warder. This was a very common statement from physicians to which I have spoken about this disorder

Eric was 47 when he died. Weeks before his death, he had complained of fatigue, thirst, and shortness of breath when climbing stairs. He saw his physician and had labs drawn one week before he died. I wonder...if his physician had put the symptoms together, ...if he had noticed the blood sugar and ketones, the elevated liver functions, could he have done something to save him? Probably not. I am resigned to this outcome, but can I wake up others in time? This is a recurring theme in my mind and in many of the stories I've read and heard. My brother was not in poor health and had no history of medical issues. I believe that by adding a serum ferritin test to the standard blood test (also known as a CBC, or Complete Blood Count), Eric's death could have been prevented.

I want to raise awareness, educate physicians and patients, and inform families of this disorder, and how it can take a life, devastate a family, and go unnoticed time after time. It is apparent to us the symptoms are attributed to destruction of the organs. In other words, diabetes, cancer, cirrhosis, and other diseases are diagnosed instead of the underlying cause, which is hereditary hemochromatosis.

Fortunately for my family, Eric's identical twin is doing well. His ferritin is down to 80 ng/mL after 19 months of weekly phlebotomies. His liver functions and glucose are normal. His hemoglobin has changed from 16 to 14 g/dL, but has not varied any further. He has continued to work a full time job, engage with family members, and live life as an active participant. He looks great and we never thought he looked ill, but of note is that the gradual change in appearance and degradation of health can be easily dismissed as normal affects of growing older. We are all

being tested for iron levels every 6 months to 1 year. Even though my sister and I are only carriers, we have noticed that our ferritin and iron saturation levels are higher than last year. We are going to donate blood. We are testing our children and grandchildren to see if they carry the mutated genes. Of vital importance is that future generations learn early on about this disorder.

As for Aunt Dorothy, I explained to her hemoglobin is not an indicator for hemochromatosis. Physicians repeatedly have used this test to put family members at ease. John's hemoglobin after a year of weekly phlebotomy has not strayed from 14. We have found physicians don't know what tests to order. Please don't let your physician off the hook by telling you that you are fine after a normal hemoglobin test was performed. Ask specifically to test for serum ferritin and a transferrin saturation percentage.

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Working to serve you better

Plans are underway at the Canadian Hemochromatosis Society to develop and staff an outreach and client support position based in the Greater Toronto Area to better serve individuals and families in Eastern Canada. The position will focus on providing client support, facilitating community outreach programs, collaborating with related not-for-profit organizations and cultural groups, and fostering corporate partnerships and sponsorships.

The person filling this new role will be fluently bilingual in French and English as we work to provide the best service we can for all Canadians impacted by hereditary hemochromatosis.

The board and staff at CHS are excited with this new opportunity. Be sure to keep an eye on our website www.toomuchiron.ca for further announcements in the coming weeks.



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Follow us on Twitter at @IronOutCanada

Senator pays tribute to Marie Warder

During the February 19th Senate Sitting, Senator David Wells of Newfoundland and Labrador paid tribute to the late Marie Warder and shone a light on hereditary hemochromatosis in the Senate. He spoke of the avoidable complications caused by iron overload, and the work of the Canadian Hemochromatosis Society to bring awareness to the condition and support to individuals and families affected. Senator Wells himself has hereditary hemochromatosis. The following is a portion of Senator Wells' statement:



Honourable Senators, I rise today to pay tribute to Marie Warder and to bring awareness to a common genetic disorder that remains relatively unknown: hemochromatosis. It is a genetic disorder where there is excessive and potentially

toxic accumulation of dietary iron in the body. This iron overload can be fatal. I know this all too well because I, too, suffer from this condition.

Marie Warder founded the Canadian Hemochromatosis Society in British Columbia 35 years ago. The Canadian Hemochromatosis Society is her legacy. In 1992, hemochromatosis took the life of Marie's husband Tom. Tom suffered from liver disease resulting from hemochromatosis and, sadly, Canada lost Marie Warder this past October.

Hemochromatosis is Canada's most common genetic disorder. Those with hemochromatosis are genetically unable to metabolize iron absorbed from their diet. Men and women are equally affected. Harmful

iron overload occurs in joints, the liver, pancreas, heart, brain and endocrine glands. Left unrecognized and undiagnosed, the consequences of too much iron can be prolonged, severe and fatal.

One in 300 Canadians has the condition. One hundred and twenty-five thousand people in Canada have the genetic potential to suffer severe organ damage due to iron overload. It's believed that only 20 per cent of those with hemochromatosis know they have it.

Hemochromatosis cannot be cured, however, early testing, diagnosis and treatment for the disorder can reduce or eliminate most of the severe complications, which include arthritis, diabetes, heart failure, cirrhosis of the liver and cancer. Diagnosis is made through blood tests and genetic testing. Treatment is

simple: frequent and regular removal of blood. This blood is suitable for donation.

Hemochromatosis is most prevalent in Canadians of European and Celtic descent. The incidence in Newfoundland and Labrador is significantly higher than the national average, and there are instances where an entire family has the condition. Those affected in rural and remote regions must travel hundreds of kilometres to receive treatment.

The burden of undiagnosed hemochromatosis in Canada results in avoidable costs to the health care system of premature chronic diseases, the financial loss to families due to disability and the preventable loss of loved ones.

The Canadian Hemochromatosis Society strives to create awareness of hemochromatosis and provide support for those affected. The society has helped many Canadians avoid the progressive suffering, disability and premature death from chronic diseases prompted by hemochromatosis. A small dedicated staff, a national board of volunteers, regional volunteer chapters and a medical advisory board champion the work that Marie started 35 years ago.

“ Colleagues, awareness is the cure to hemochromatosis. As Marie so accurately stated, “Find us one victim, and we will save a whole family.” ”



“I want hemochromatosis to be made history. I really want that to happen. People don't have to die when all they need is a simple diagnosis. I founded the society so that people who needed to know this, would know. We cannot stop until everyone at risk for hemochromatosis is found and treated before it is too late, until all family doctors are aware of the disorder.”

– Marie Warder

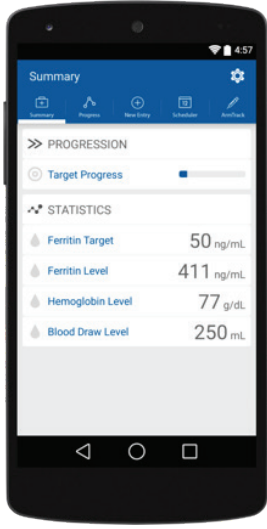
In her memory, Marie Warder wanted the Canadian Hemochromatosis Society to be her legacy, to continue the work she began. Please give in support of the Marie Warder Legacy Fund, and help us reach our goal of \$100,000 in 2015. A lasting, sizable amount in the Legacy Fund will honour Marie's work. You may donate online at www.toomuchiron.ca or by completing the enclosed donor form.





Get the FREE Iron Tracker App

www.irontracker.ca



**Keep track of
your records!**



**See your
progress!**

READY TO START MANAGING YOUR TREATMENT?

The Iron Tracker App gives patients a single place where treatment and life-long progress can be tracked, combining appointment management with tracking and visualization of bodily hemoglobin and ferritin values, providing a clear visualization of this data to better understand and share progress with friends, family and physicians. The app also tracks phlebotomy appointments and details, helping patients manage their lifestyle and wellness.

"Iron Tracker nails it! Great little app for those with haemochromatosis. Nicely designed and very easy to use. Simple and effective and adaptable to users in any country, not just Canada."

— Tony Moorhead - Haemochromatosis Australia

"Excellent design. I'm a gastroenterologist. I have two patients that have the app and it runs smoothly; is well designed, easy to understand and is a great tool in the management and follow up of my patients. They are excited to follow their progress in their smartphones and they are happy not to carry a ton of lab results to the office. Great job!"

— Harry Ruiz

Think it's time for your phlebotomy?



Have your serum ferritin levels checked first before deciding to have a blood-letting, and avoid creating iron levels that are too low.

Many people with hemochromatosis have a standing order from their doctor for blood tests. Ask your doctor to write you one.

Hereditary Hemochromatosis Often Presents As A Rheumatic Problem

Its Clue Is An Unexplained Hind Foot Complaint

BY DR HENRI A MÉNARD, PROFESSOR OF MEDICINE AND RHEUMATOLOGIST, MCGILL UNIVERSITY HEALTH CENTER, MONTREAL, AND MEDICAL ADVISOR TO THE CANADIAN HEMOCHROMATOSIS SOCIETY

My deepest conviction as a rheumatologist is that patients have all the questions and all the answers. My job in a university-hospital is that of a clinician-scientist (physician, teacher and researcher) looking for insightful clues given by patients and for explanatory answers in the library or in the laboratory.

Hereditary hemochromatosis (HHC) is currently understood to be a genetically-determined and slowly-progressive accumulation of iron with resulting organ failure. The rheumatology textbooks describe HHC arthritis as a slowly progressive degenerative type of arthritis, i.e. osteoarthritis (OA), typically involving the 2nd and 3rd knuckles and calcium pyrophosphate dihydrate (CPPD) crystals deposition in unusual places, i.e. in joints other than the wrists, pubis and knees. The textbook further states that phlebotomies do not help HHC arthritis. Most doctors are not particularly aware of HHC when seeing new OA patients. In fact, I for one rarely if ever made a diagnosis of HHC based on EARLY, vague and general rheumatic symptoms. On the other hand, I readily made the diagnosis of late HHC arthritis in patients referred to me with known HHC. That is not good medicine. Given what we now know, that part of the textbook on

HHC OA needs to be rewritten not only textually but also conceptually. What brought about my change of mind?

I started changing about 10 years ago because of an HHC patient I had the privilege to care for. Like in many others, her HHC diagnosis was serendipitous. Her husband had to go to work in the USA and all his family had to undertake a general health assessment. Except for an “annoying ankle” problem, she was “apparently healthy”. Still, laboratory results showed high serum iron levels, high % transferrin saturation, high serum ferritin and HFE gene mutations. Although the liver function tests were normal, liver biopsy confirmed early liver involvement. She underwent regular phlebotomies until her ferritin level was normal for one year. She then stopped phlebotomies as ferritin remained normal. During that phase, % transferrin saturation remained



at the upper limit of normal or was intermittently mildly elevated. She complained more and more of her “ankles”. That pain was specific to her hind foot, more precisely her sub-talar joint – not the real ankle (See Figure A and B). She kept insisting that it was due to HHC. Because there were no CPPD crystals identified, and because the hind foot was not mentioned in our textbook, I was reluctant to agree! Not anymore!

At about the same time, Dr. Graeme Carroll in Australia stressed the frequent early localization to the hind foot of HHC arthritis even in patients having the so-called “silent” H63D HFE mutation and a normal iron profile. From that time on, I started to systematically test for HHC in all unexplained hind foot complaints. I further became a strong believer after I played golf with someone whom I never had much social interaction before. As we walked around

(Continued to next page)

FIGURE A

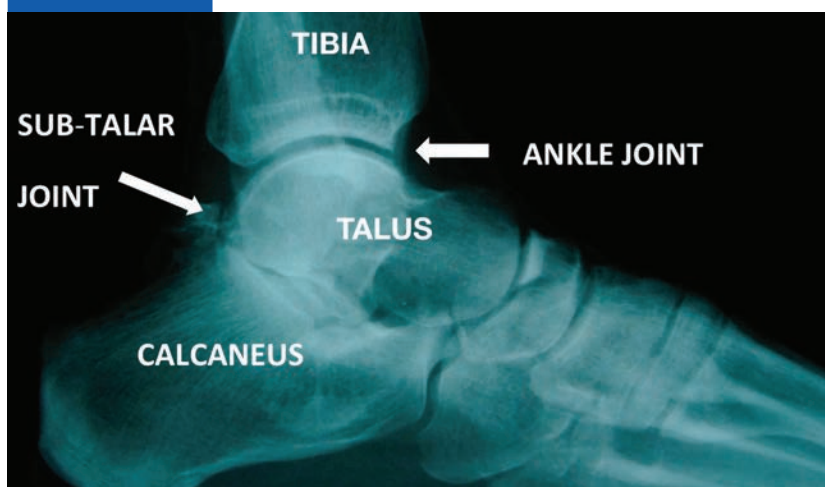


FIGURE B



Hind foot complaint in two different patients due in A, to mildly/moderately severe sub-talar joint HCC arthritis (between the talus and calcaneus) and due in B to very advanced ankle joint HCC arthritis (between the tibia, fibula and talar bones).

Hereditary Hemochromatosis Often Presents As A Rheumatic Problem (Continued)

the course, I noticed that he was limping intermittently. When asked why, he answered "because of my ankle," but neither he nor I could find a reason why. I invited him to drop by the office to sort this out, trying not to alarm him because he felt "generally fine, thank you". His hind foot appeared normal in X-rays. The hind foot clue was a long shot, but the lab results showed all the biochemical and genetic markers of HHC: high iron and ferritin, 99% fasting transferrin saturation and homozygous C282Y HFE mutations. Even though "apparently" healthy, he agreed to have weekly phlebotomies. After two years, he is on a quarterly maintenance schedule at Héma-Québec. Six months after his iron levels were corrected, his hind foot complaints disappeared and did not recur. Further, he "felt much healthier and energized, more than in a long time" – enough to play golf and walk 9 of his daily 18 holes at 69 years of age!

Focusing on hind foot complaints, we easily found new patients with H63D HFE mutations. Most had normal X-rays: no OA, no crystal deposits. Nevertheless, in some it was the earliest and only subjective complaint. This meant that we could use that clinical feature to predict the presence of HFE mutations before any serious disease

or damage developed and that there may be a window of opportunity when phlebotomies, if required, could help prevent HHC disease. Further, this suggested that iron overload is not the only effect in one with HFE mutations! We presented those findings at the 2011 American College of Rheumatology (ACR) meeting in Chicago and they were highlighted by the organizers.

We have since collected arguments to explain why the hind foot is targeted. Controlled and reproducible laboratory experiments suggested that there is more to HFE mutations than just excess iron. The H63D mutations may be silent from the iron perspective but they appear to be far from silent in their effects on cartilage as well as factors in other diseases. Because of the potential impact of those findings in the general population, we have treaded very cautiously to confirm and re-confirm the lab data. Our first application to get research support in 2012 was denied as is usual when the ideas are novel and/or against the grain. To perform and repeat the lab experiments, we had to divert funds obtained for other research projects. We feel it was a productive investment and we are planning to reapply for funds in 2015 with more preliminary supportive data. The hind foot clue was confirmed at the November 2014 American College of

Rheumatology meeting in Boston. Dr Patrick Kiley sent a questionnaire to 1300 members of the UK Haemochromatosis Society and found that the hind foot area was the most frequently involved area, often years before the biochemical or genetic HHC diagnosis was made. Strikingly, few if any of the HHC diagnoses were primarily made by rheumatologists. The rheumatologists only recognized the arthritis of the known HHC patients, usually referred by the liver specialist i.e. the advanced cases where phlebotomies are indeed not very useful for the joint failure. Overall, it would appear that like me ten years ago, rheumatologists are not much more aware than general practitioners of the fact that often, HHC first presents as a (hind foot) rheumatologic condition significantly interfering with quality of life. If they would recognize that, an early or even pre-disease diagnosis could be made and appropriate treatment would make the known organ failures things of the past. It would also help identify those HFE carriers with a normal iron profile as candidate for further research into the other potential roles of HFE mutations.

[Read the full article online at
www.toomuchiron.ca](http://www.toomuchiron.ca)

May is National Hemochromatosis Awareness Month CALENDAR OF EVENTS



MAY 2015 Bring a Friend to Iron Out Hemochromatosis Campaign

CHS is pleased to work with Canadian Blood Services throughout May on our Bring a Friend to Iron Out Hemochromatosis campaign! Together our two organizations will provide awareness opportunities at blood donor clinics in Ottawa, Edmonton, Calgary and all permanent donor clinics in BC while helping to increase the nation's blood supply. Visit our website [calendar www.toomuchiron.ca/events](http://calendar.www.toomuchiron.ca/events) for updates and details on these activities.

Partners
For Life

Canadian Blood Services
it's in you to give

iron out
Hemochromatosis

FRIDAY, MAY 1, 1 PM – 8 PM Awareness Blood Drive with Héma Québec

Les Galleries Des Sources
3237 Des Sources,
Dollard-des-Ormeaux, Quebec

Email montreal@toomuchiron.ca for details or to volunteer at this event.



We can save more lives together!

A successful year for Canadian Hemochromatosis Society as we celebrate our Partners for Life achievement!

Partners
For Life

Canadian Blood Services
it's in you to give

The Canadian Hemochromatosis Society is proud to celebrate another successful year of saving lives together as a member of Canadian Blood Services' Partners for Life program. Our members contributed 301 blood donations across the country in 2014, which is a significant contribution toward saving patients undergoing surgery, cancer treatment and treatment following accidents. Thank you to everyone who donated!

Half of all Canadians will either need blood or know someone who will need blood at some point in their lives. That's 17.5 million reasons why it's time to save a life! That's why Canadian Blood Services relies on the support of organizations, companies, groups and communities across the country to come together and show that blood donations make a positive impact on someone's life. Someone in your community appreciates the generosity of Canadians rallying together to donate blood.

Meet Cindy, who is alive today thanks to people who give blood and organs. She urgently needed a new liver and many units of blood to survive. Watch her inspirational story at youtube.com/18882DONATE.

Canadian Hemochromatosis Society is committed to saving lives again in 2015, with a goal of at least 400 donations again year. "I can think of no better example of "we give where we live" than the 301 blood donations your team made this past year in communities across the country, saving the lives of Canadians who live in those same communities. On behalf of the patients whose lives you saved, thank you. I look forward to setting another record for donations as a Partner for Life in 2015!" – Bill Coleman, Director of Partnership Development.

Every member – as well as friends and family – are welcome to join the team by registering online with our Partner ID # CANA002257 (four letters, six numbers) at www.blood.ca/joinpartnersforlife. By registering just once, all donations will be counted towards our team's goal.

To find a blood donor clinic near you and book an appointment, call 1 888 2 DONATE (1-888-236-6283) or visit www.blood.ca.



"The only words I really have are thank you... and I really wish it could be so much more..."
— Cindy



Irons for Iron

You are invited to take part in one of our annual Irons for Iron Golf Events this May and June! Irons for Iron is a fun day of golf with friends to support CHS programs which

create awareness and provide support to those affected by hereditary hemochromatosis. Players of all skill levels are invited to participate. Early registration is encouraged, as spots are limited.

For details or to register for Irons for Iron events, please visit www.toomuchiron.ca or phone 1-877-223-4766

THURSDAY, MAY 21, 11:00 AM Irons for Iron Toronto Event

\$200/person
Royal Woodbine Golf Club
195 Galaxy Boulevard, Toronto, ON
Lunch with golf to follow

FRIDAY, MAY 29, 12:00 PM Irons for Iron Cape Breton Event

\$200/person
The Lakes Golf Club
5101 Highway #4, Ben Eoin, Cape Breton, NS
Lunch with golf to follow

FRIDAY, MAY 29, 12:00 PM Irons for Iron Ottawa Event

\$120/person
Casselview Golf and Country Club
844 Aurele Road, Casselman, ON
Box lunch and golf, with dinner to follow

THURSDAY, JUNE 4, 12:00 PM Irons for Iron Vancouver Event

\$200/person
Quilchena Golf & Country Club
3551 Granville Avenue, Richmond, BC
Golf with dinner to follow

MAY | NATIONAL HEMOCHROMATOSIS AWARENESS MONTH

Among Ourselves

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

Ottawa

By Kate Lalumiere

The CHS Ottawa Chapter is comprised of a group of passionate, dedicated volunteers who came together under a unique set of circumstances. After two of the founding members attended an awareness seminar in Québec it became apparent that Ottawa lacked the necessary resources for those who suffered from Hereditary Hemochromatosis (HHC). Quickly, the founding members of the Ottawa Chapter put the wheels in motion to host an awareness seminar that would eventually bring together the chapter's core volunteers. Together, over the course of the last 15 months, the chapter has worked to serve two mandates: to offer information to those who have Hemochromatosis and to bring greater awareness to a disease that can be fatal.

The newly established Ottawa chapter has seen a very successful inaugural year and looks forward to the challenges that lie ahead. Meeting on a monthly basis, the CHS Ottawa Chapter has established a core group of nine dedicated volunteers who make possible our events, seminars and monthly meetings. It is due to the commitment, perseverance and diversity of our volunteers that we have been able to reach and surpass our goals for the year. In our first year, the chapter hosted two awareness

seminars with CHS CEO and Executive Director Bob Rogers. The seminars, which we promote through local publications, serve as crucial information sessions for those who may have questions about HHC. The seminars also act as an efficient channel to target new audiences. In May 2014, the chapter organized Ottawa's first Irons for Iron golf tournament - a successful fundraiser that was enjoyed by volunteers and attendees alike. Other events that we have participated in over the course of the last year include the Maxville Highland games - a cultural fair that targets Scottish and European descendants. The chapter has also attended two health and wellness expos where the CHS booth piqued the interest of patients and health care professionals. As a result, the chapter has made great inroads with health care professionals and has established a relationship with the Ottawa Hospital's Head of Haematology. The Ottawa Haematology department, as well as several other clinics in Ottawa, now display the CHS pamphlet.

The chapter also works to leverage innovative methods of communication through social media channels and more traditional media outlets. At



our quarterly events the chapter often live-tweets and connects with an online audience. We have also published two articles about HHC in a local newspaper which serve to bring awareness to the community at large.

Going forward, we hope to bring greater awareness to HHC and see notable participation in our Irons for Iron golf tournament which we plan to hold in May, 2015. Along with the mandated chapter initiatives, we plan to organize a bonspiel fundraising event that will take place in the winter of 2015.

Many exciting challenges lie ahead as we work together to raise awareness about Hemochromatosis here in Ottawa.



Mailbag

"I am a Ghoul" (Iron Filings - Fall 2014) misleads about diet

In the article, there was the comment regarding his delight in no longer having 'kale and spinach' on his plate. This is not what I understand to be true of spinach. Yes spinach, eggs and red meat are high in iron. However on reading the Hemochromatosis Cookbook by Cheryl Garrison, it is stated that; red meat contains the most absorbable form of iron (heme iron), whereas spinach contains a compound that actually impairs the absorption of iron; so do eggs. These do not need to be removed from the diet.

I hope that some of these dietary notes can be clarified in order help others who may be removing foods from their diets that could be beneficial.

Sincerely,
J.H. Fenelon Falls, ON

In this article Peter Dueck made a statement about spinach and kale are no longer on his plate. This is very disturbing as these are non-heme irons. They should be on his plate. Now the people think they need to avoid spinach and iron! Please inform the public and him of this error!

Thank you!
K.S. Mississauga, ON

Note: It is impossible to completely avoid iron in one's diet and it is not advisable in any case. Many foods rich in iron also have other essential vitamins and minerals. In the active de-ironing phase, reducing iron intake is almost insignificant compared to the 225 mg of iron that are being removed with each phlebotomy. In the maintenance phase, restricting iron intake may increase the time between phlebotomies but at no time will reducing iron in the diet replace phlebotomies as effective therapy. Visit our website at www.toomuchiron.ca for more information and dietary precautions.

--Editor