

Iron Filings



The Curse and the 'cure'

THE CELTIC CONNECTION:

EARLY DIAGNOSIS OF LITTLE-KNOWN DISORDER KEY FOR CELTS

Kelly Bromley suspected something was wrong when she experienced chronic fatigue, but she never suspected the Celtic Curse was the culprit.

"I was tired all the time — I had two kids playing trombone and trumpet and I fell asleep right in front of them," Bromley says with a laugh.

Now living in North Vancouver, Bromley is one of seven siblings raised in Schreiber, Ontario, a little town of 900 on the northernmost point of Lake Superior.

As tired as she was day and night, Bromley wrote it off as a common symptom of motherhood.

"I drank coffee all the time to stay awake," she remembers.

Then, 10 years ago she got a call from her sister, living in Australia. Bromley's sister was so fatigued that she saw a doctor, and was

diagnosed with hereditary hemochromatosis, a common yet little-heard-of disorder manifested with too much iron stored in the body.

Common symptoms are joint pain, bronzing or greying of the skin, loss of libido, thyroid problems, elevated glucose and triglyceride levels, enlarged liver and cirrhosis and irregular heartbeat. Without treatment, hemochromatosis can be deadly.

Complications caused by excess iron storage can include diabetes, liver disease, arthritis and congestive heart failure.

Hemochromatosis is Canada's most common genetic disease, with one in 300 having both mutated genes that cause the disorder. But surprisingly, for those with Irish roots, the ratio jumps to one in 83, hence the moniker Celtic Curse.

Bromley's sister suggested she get tested. She did, and like six of seven siblings in the family, she tested positive for hemochromatosis. But there was good news. With early diagnosis, the heart murmur Bromley had developed as a result of the disorder was successfully treated.

"I was lucky but a lot of people that didn't get tested in time will have to live with problems," she says.

Continued on next page

Kelly Bromley and
Pat McParland



The Curse and the 'cure'



Bromley's brother Pat McParland was even luckier. He's the only sibling not carrying both genes for hemochromatosis, although he carries one of the genes. One in nine of the general population carry one hemochromatosis gene, which means they may also store too much iron. (One in six from Celtic ancestry carry one hemochromatosis gene.)

"I really dodged a bullet," McParland says. His extended family has been affected though. His father-in-law from Belfast went undiagnosed and died of the disorder, with much suffering. McParland's wife was not diagnosed, but died of cancer. McParland says there's no way to know for sure, but it's possible his wife was also affected by hemochromatosis. If he didn't have enough reasons to fight hemochromatosis, McParland just found another.

He recently joined the Board of Directors for the Canadian Hemochroma-

tosis Society, seeking to raise awareness about the disorder and eliminate needless suffering and premature death from undiagnosed hemochromatosis.

"There are a lot of family reasons for me to join the society but there's the larger cause," McParland says. "Early diagnosis can save a lot of lives. People should do this — it's just a simple blood test but it could save your life."

And diagnosis is easier than ever. Unlike 10 years ago when a liver biopsy was needed to test for iron deposits, modern diagnosis only requires a blood sample. Plus, with advances in genetic screening, families with high risk for hemochromatosis incidence can be tested for the DNA mutations that cause the disorder.

The harm of excess iron in the body can be reversed with the regular removal of blood in treatment called a phlebotomy. As the body makes new blood cells

to replace those lost during phlebotomy, iron is pulled out from storage from the organs, tissues and joints, bringing iron levels down to a safe level.

So all that's needed is increased awareness to make the ravages of hemochromatosis a thing of the past.

"Within five years we want to make sure people are much more aware," McParland says.

Canadian Hemochromatosis Society Executive Director Bob Rogers points out a "win-win" situation that can be realized as more people get tested and treated for hemochromatosis — over a lifetime blood removed from the body in treatment can be used in the blood supply through the Canadian Blood Services.

For more information on hemochromatosis, go to their website at www.toomuchiron.ca

Have you been diagnosed with HHC and are starting treatment?

HERE ARE SOME TIPS TO PREPARE YOURSELF FOR YOUR PHLEBOTOMIES

- Educate yourself – learn about the treatment procedure and form realistic expectations.
- Keep a record of every phlebotomy treatment.
- Drink water (500 ml) before and after each treatment. In hot weather, drink more.
- Alternate treatments between arms to give the veins a rest (there are also other sites that can be used).
- If you are squeamish, keep the blood bag out of sight and do not watch the puncture.
- After removal of the phlebotomy needle, apply pressure to the puncture for a good 5 minutes to avoid bruising.
- Rest quietly after each treatment for 15 minutes.
- If you feel faint, sit down right away and put your head between your knees.
- Leave a bandage on for 8 hours as leakage can occur.
- If bleeding occurs after treatment, elevate the arm and apply pressure to the vein until the bleeding stops.
- Avoid physically hard work for 24 hours.
- Each unit of blood removes about 80 g of protein, so when more than one or two units are taken each week, increase the dietary protein you consume accordingly.

Treatment should not be suspended because of difficult bleedings. If you have difficulty with your phlebotomy treatments try:

- Applying a hot pack to the area if your veins are difficult to access.
- Applying a local anaesthetic to the area to reduce trauma and assist blood flow.
- Asking your health care provider to use 19 or 21 gauge needles. MacoPharma manufactures and supplies phlebotomy bags to hospitals across the country. One of their products (Ref VSL7000YQ) is a phlebotomy bag with a male luer that can fit any sized needle with a female luer. Visit MacoPharma website at: www.macopharma.com
- Adjusting the volume of blood removed during each treatment in cases where 500 cc is not tolerated.



UPCOMING EVENTS

May is National Hemochromatosis Awareness Month

Read more on May Awareness Month events in the April issue of our e-newsletter, "The Magnet".

If you don't already receive "The Magnet", send us an email with your full name, city, province and email address to office@toomuchiron.ca, and we will add you to our email list.



Host A Party Ideas

Hosting a Party is a fun way to entertain your friends, raise awareness of hemochromatosis, and support CHS at the same time. We have brochures and information pieces that we can send to you for your party.

Are you having a hard time coming up with an idea for your "Host a Party" party? Well, here's a host of ideas that will take advantage of the good weather that surely will be coming your way.

- Invite friends over for a summer solstice party
- Have a games night. You can hold a Rummy/Crib/Whist Bridge/Hearts tournament, or play Scrabble/Rumoli/Snakes & Ladders/Crokinole
- Host a barbeque and challenge your guests to:
 - a horse shoe tournament
 - croquet
 - bocce
 - a putting competition

Tell your guests that you are hosting a party to raise funds and awareness for the Canadian Hemochromatosis Society. When your guests ask what they can bring to the party, invite them to make a donation to

Ottawa, ON

Capitalizing on the great response and energy from 2008, our volunteer Regional Coordinator Marjorie Louder and fellow volunteers will once again be hosting information booths in malls around Ottawa during May Awareness Month. Keep an eye on our website and the Ottawa Citizen for dates and locations.

Calgary, AB

Anne Stang, our volunteer Regional Coordinator in Calgary, along with volunteers Amanda Bennett and Colleen O'Brien, will have a table at the Seniors' Resource Fair at Calgary City Hall on Saturday, May 30 from 9:30 am – 2:30 pm. This will be the second year in a row that Anne has set up an awareness booth at this fair. Calgary City Hall is located at 800 Macleod Trail SE.



Burnaby, BC

Top Barbers will be donating partial proceeds to the Canadian Hemochromatosis Society from all haircuts during North Burnaby's Hats Off Day on June 6. Volunteers will be on hand to host an information table at the shop. Thank you Jim and Sam for your generosity!

Canada-Wide

CHS Public Service Announcements will once again be heard on radios across the country, informing all listeners of the dangers of untreated and undiagnosed hemochromatosis.

CHS instead of bringing wine, flowers or food. Or charge a "Pay to Play" fee for the games, with a prize for the winner. Hereditary hemochromatosis is the most common genetic disorder in Canada, and the cause is important to you. Your guests will want to support you, so don't be afraid to ask.

Funds raised will support the Society's efforts to promote awareness throughout Canada, to prevent the needless suffering and early death caused by untreated and undiagnosed hemochromatosis. The Canadian Hemochromatosis Society appreciates any size of donations and any amount of funds raised. Every dollar counts.

If you are more comfortable selling items for the cause, how about the following ideas? While you barter with your "customers", you can tell them about hemochromatosis and spread the awareness.

- Hold a Garden Party and Perennial Sale
 - Divide your perennials to make room in your garden, and sell them to raise funds for CHS
- Sell your unwanted household items

in a Garage Sale with proceeds going to CHS

- Sell guesses to a "guess the number of items in a jar" and offer a prize to the winner
- Sell drinks and snacks to raise additional funds

If you have other great ideas, we would love to hear them. During your event, be sure to take photographs and email them to us. We will include your ideas and photos in "The Magnet" and "Iron Filings".



President's Message



Ross Gilley, President

“... any contribution helps extend and improve the quality of countless Canadians well into the future.”

Have you seen that cheesy TV commercial playing on all the networks this winter? It features “Vince” extolling all the features of the “Shamwow” cloth. There’s nothing really special about the message. After all, it’s just a low budget “in your face” commercial like so many before it. Yet every time it’s on, I watch in fascination as Vince exclaims, “**But wait, there’s more!**” He’s got me convinced. That thing really is amazing!

That got me thinking what the CHS has in common with the Shamwow (stay with me here!). After all, I don’t know of another organization that delivers greater value for a low price. Sure, we’re the Canadian Hemochromatosis Society, but what other national organization accomplishes as much with just 2 part-time staff and a small cadre of committed volunteers? Together, they deliver more than seems possible every day of the year.

But wait, there’s more! Our Board of Directors came together in November to map out our strategic plan for the next few years. These talented and selfless volunteers travelled at their own expense and committed 2 days to the process because they believe that the CHS can play an influential role

in Canadian Public Health initiatives over the next decade. Already, the Board and staff have embarked on new communication and alliance efforts that are sure to harvest tangible benefits over time.

Vince says the Shamwow soaks up 12 times its own weight. **Amazing!** You might say the CHS does the same. After all, if we succeed in our quest to identify Hemochromatosis in every afflicted Canadian early in life, we can prevent Diabetes, Arthritis, Heart Disease, and even Cancer later in life. **Amazing!** Your Society really is the One-Stop Prevention Superstore.

My new friend Vince wanted me to send in \$20 to see for myself. I just about did it. But then I considered where my investment would really pay dividends in today’s uncertain world.

I pretended to buy a few Shamwows for my family and instead addressed my envelope to the CHS, secure in the knowledge that any contribution helps extend and improve the quality of countless Canadians well into the future. As much as I was tempted, Vince will just have to wait.

I wish you all the very best this spring.

OFFICIAL NOTICE

Canadian Hemochromatosis Society Annual General Meeting

Wednesday, April 8th, 2009

6:00 pm
Richmond Caring Place
Room 340, 7000 Minoru Blvd.
Richmond, BC V6Y 3Z5

Presentation of our annual report and plans for the future. Election of our new Board of Directors (by members only). Recognition of retiring Board Members *Refreshments will be served.*

Can’t make the meeting? Be part of the proceedings on our special conference call phone line! Contact our office for the phone number prior to April 1st, and enjoy the AGM from the comfort of your own home.

Not a member yet? Support our efforts, stand by our mission, and have a say in the direction of CHS – Join now at www.toomuchiron.ca.

RSVP by end of the day April 1st, 2009 | 604 279 7135
1 877 BAD IRON | office@toomuchiron.ca

Prevention is worth more than Millions of Dollars spent on Cures



Bob Rogers, Executive Director

Undiagnosed and untreated hemochromatosis (HHC) can lead to liver disease & cancer, heart failure, diabetes, arthritis and Alzheimer's disease. These diseases cause terrible suffering and early death. According to recently published data, the organizations that work for a cure when people become afflicted with these diseases received several millions of dollars in donations and other income:

150,000 people in Canada have hemochromatosis. Over 3 million carry one of the genes that can cause this disorder. **In 2008, our goal was to reach 1000 new families who have hemochromatosis.** We implemented changes to programs, communications, awareness efforts, chapter development, staff & volunteer resources, board skills and experience, social enterprise programs and fund development. In 2008, we reached several hundred people in Canada who have this disorder. We made significant progress; many were reached, many were diagnosed, many treated and we rejoice in these successes. **Still, CHS needs to increase its awareness efforts to save more lives and reduce suffering.**

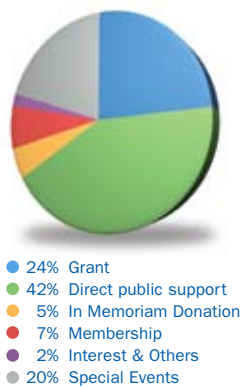
CHS manages its resources very carefully. However, in 2008, our income fell short of our operating expenses. **All the work of CHS in Canada is done with only two part-time staff and several volunteers.**

If the Canadian Hemochromatosis Society is to accomplish its mission, it needs your support to effectively save people's lives. The Canadian Hemochromatosis Society wishes to thank every member and donor who gave generously to the Society in 2008. Your thoughtfulness for others is a blessing. However, many individuals and families across Canada still remain uninformed, undiagnosed, untreated and at risk for the diseases induced by hemochromatosis. You can make a difference!

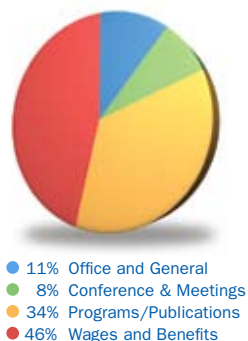
The Canadian Hemochromatosis Society has already received significantly lower donations in the first two months of this year compared to the past two years. You can put your charitable dollars to better use through the prevention of liver cancer, heart attacks, arthritis, Alzheimer's and diabetes and other serious medical illnesses caused by hemochromatosis. **Please give generously and save lives.**

Yearly Donation Totals for several Canadian Organizations	
Canadian Liver Foundation	\$ 6,959,000
Heart & Stroke Foundation	\$ 141,883,000
Canadian Diabetes Association	\$ 77,682,000
Arthritis Society of Canada	\$ 34,163,111 (2006)
Alzheimer's Society of Canada	\$ 11,288,649 (2007)

CHS 2008 REVENUES Total \$152,912



CHS 2008 EXPENSES Total \$176,250



Millions of government health-care dollars are spent for the treatment of these diseases too.

In comparison, the **Canadian Hemochromatosis Society**, whose mission is the **prevention** of liver and heart disease, diabetes, arthritis and Alzheimer's when caused by hemochromatosis, receives a small fraction of these amounts:

Canadian Hemochromatosis Society	
2008	\$ 152,000
2007	\$ 99,000

We all know the saying, **“An ounce of prevention is worth a pound of cure.”** The mission of CHS is to promote early testing, diagnosis and treatment of hemochromatosis which, if done effectively, would result in the elimination of all the above listed diseases induced by hemochromatosis. **Clearly, your support and donations provided to CHS for prevention is money well saved.**



NEW! **Donate Through Our Secure Online Donation Page**

Visit our website at www.toomuchiron.ca and click on the “Make A Contribution – Make A Difference” icon to the right of the screen. You will be taken to our donation page where you can make secure online donations conveniently and easily using Visa, MasterCard or American Express. On this page you can also make tribute donations, purchase our books, DVDs and wristbands, purchase or renew memberships, and coming soon you will be able to purchase tickets to our special fundraising events.

NEW! **Buy Your Fair Trade Coffee at Costa Cana and Support CHS**

CHS has partnered with Costa Cana Import Inc., a Canadian company that supports not-for-profit organizations with fundraising projects. Costa Cana offers Fair Trade gourmet arabica coffee from Costa Rica at competitive prices. With each purchase, a large percentage of sales goes towards CHS.

Tannins contained in coffee inhibit the absorption of iron. Studies have shown that drinking one cup of strong coffee within two hours of consuming

a meal will impair up to 60% of iron absorption. Since arabica coffees offer half the caffeine of robusta types, and yet deliver a full flavour and aroma, coffee lovers can now support CHS and enjoy the benefits of premium arabica coffee. Visit Costa Cana’s website to learn more and to shop online at www.costacanaimport.com. At the “Checkout”, be sure to select Canadian Hemochromatosis Society as the organization to support.

NEW! **Find Us On Facebook**

We have created a group on Facebook, entitled “Canadian Hemochromatosis Society”. Join our group and help spread awareness of hemochromatosis and CHS. While on Facebook, you can also join the cause, “Hearts for Hemochromatosis” and feature this cause on your profile page.

NEW! **Number to Donate Your HBC Reward Points**

Help us by donating your reward points from Zellers, The Bay and Home Outfitters. Our new Public ID # is 4275683. You will need this number when you want to donate your points

online or in person at a store. Any HBC rewards numbers that we have given previously will not be recognized.

Sign Up

Sign up for The Magnet, our e-newsletter that is issued five times a year with timely news and updates. Look for May Awareness Month events in the next issue. Send your email address, first and last names, city and province to office@toomuchiron.ca.

Leave a Legacy™

CHS is a member of the Canadian Association of Gift Planners and is a partner in the Leave a Legacy™ program. If you would like to make a difference in the lives that follow, please speak with us and we can provide you with information to get you started.

When sending money...

...such as a cheque or credit card number, be sure to let us know what it is for. Money will be automatically entered as a donation unless you specifically tell us it is for a membership or in memory of a loved one.

TREATMENT FOR HEMOCHROMATOSIS IS PHLEBOTOMIES (BLOOD-LETTING)

Blood-letting in the olden days!



For six centuries the barbers of Europe practised surgery. This custom began with the papal decree of 1163 which forbade the clergy to shed blood. Monks were required to undergo blood-letting at regular intervals and some of them had been performing this task themselves along with minor surgery. After the papal decree these duties were turned over to the barbers. The arrangement was satisfactory to the doctors of the era who considered that blood-letting was beneath their dignity. They were glad to relegate to the barbers other physical tasks as well, such as lancing of abscesses and treatment of

wounds. The barbers of London were granted a charter as a trade guild in 1462. This guild was amalgamated with that of the surgeons in 1540. Blood-letting reached its peak in the eighteenth and nineteenth century. According to medical texts of the time, if you went to your doctor with a fever, hypertension or dropsy; you would be bled. If you had an inflammation, apoplexy or a nervous disorder; you would be bled. If you suffered from a cough, dizziness, headache, drunkenness, palsy, rheumatism or shortage of breath; you would be bled. Even if you were haemorrhaging blood; you would be bled.

The barber’s shop was the place to go. The barber’s pole originated as

a symbol for bloodletting. The brass bowl at the top represented the bowl where leeches were kept. The bowl at the bottom represented the bowl for collecting blood. The red and white spirals had their origins in the medieval practice of hanging bandages on the pole to dry after they had been washed. When George Washington was ill with a throat infection, doctors treating him conducted at least four bleedings in 24 hours. It is unclear today whether he actually died from the infection or from shock caused by blood loss. Patients were routinely bled until they fainted. This was taken as a sign that the right amount of blood had been removed. Fortunately times have changed!

Among Ourselves Again

This is part two of Looking Back, which contains information from previous editions of *Among Ourselves* and *Iron Filings*. These answer many of the frequently asked questions that the CHS office receives each week.

Blisters

Hemochromatosis often complain about an allergy to watches, rings and other jewellery which is worn constantly. Small blisters form which, when they pop, cause such discomfort that the sufferer is obliged to remove this cause. If it happens to be a wedding band, this can perhaps lead to problems and misunderstandings, so show this to your spouse, if this has been your experience, as proof that you are not just imagining things.

"Among Ourselves" Fall 1983,
Volume 1 Number 1 (the first newsletter)

Confusion with Polycythemia

Polycythemia is a disorder in which there are too many red cells in circulation and this gives rise to a high hemoglobin and hematocrit. The hemoglobin is normal in hereditary hemochromatosis and, therefore, it can be easily distinguished from polycythemia. There are very rare reports of polycythemia occurring in Hemochromatosis so perhaps we might suggest that the member who inquired about this should discuss it with his doctor.

Confusion with Lupus

Perhaps this occurs because non-specific symptoms such as fatigue and stiffness of the joints are features of the disorder. Apart from these symptoms, the two conditions do not appear to have much in common.

"Among Ourselves" Spring/Summer 1984
Volume 2 Number 1

What were your first symptoms?

"Good health until thyroidectomy in 1946," reports E.C. of Ontario. "From then on, not energetic. Hysterectomy 1974 – downhill faster, with fatigue inertia; 'mildly diabetic' 1968-71. From 1975, 'colitis' returned and even worsened. Depression, 'nerves', worsening arthritic pains. Got weaker and more shaky, fatigue worsened. Liver enlarged. Treated for Lupus, but this could not be confirmed. Ever worsening digestion, bowel cramps, diarrhea, bloating. Severe fatigue by now, weakness, racing, irregular heart. Felt I was dying but didn't care. Couldn't concentrate much, not cope at all. Insomnia. Lived on baby food... severely sensitive, sore eyes. Got up and stayed alive by sheer force and was frustrated by so many doctors' diagnosis of just nerves and depression. Can't stand heat."

First symptoms: "Tired, loss of weight, red eyes, leg and foot cramps. Felt shaky, lethargic and not interested in things. Thinning hair. Diagnosed as hyperthyroidism. Given a radioactive capsule and put on thyroid pills. As a child, and through the years, doctors always put me on iron – since my hemoglobin was always low.
C.L.B. Ontario

Among the symptoms listed by J.C. of Alberta, are: arthritis, thyroid, memory loss, bad nerves, depression, itching, insomnia, headaches, arthritis and an intolerance to heat or cold.

"Frequent nausea, bouts of depression, abdominal pain – possibly from spastic colon, which has been diagnosed. Mood swings, " is P.S. of Alberta's reply to "first symptoms". "Tests were being conducted for a spastic colon when doctor discovered too much iron in my blood."

Constant headaches – chest pains – legs ache right down – swollen, painful left breast – fatigue – occasional dizziness – arthritic pain in hands – lots of sore throats – abdominal pain – very poor hearing. R.G. Ontario
"Among Ourselves" January 1990
Volume 5 Number 1

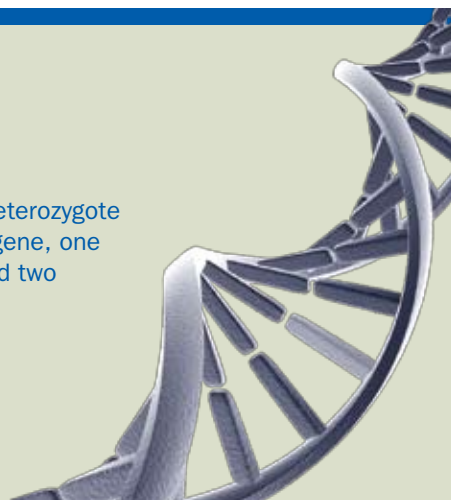
Did you know...

...that coffee contains tannins that help inhibit the absorption of iron?

...that iron loading may still occur in heterozygotes and compound heterozygotes? A heterozygote is an individual who inherited one normal gene and one mutated version of the same gene, one on each of their chromosomes. A compound heterozygote is an individual who inherited two different mutated versions of a gene, one on each of their chromosomes.



...that hemochromatosis can occur in 1 in 83 people in Ireland?
– from the Irish Haemochromatosis Society



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



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 \$ _____

- Credit card Cheque/Money order
(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
- I would like to receive the E-Newsletter, The Magnet
- Send me information about planned giving or leaving a bequest in my will.

Contact Information

Name: _____

Address: _____

City: _____ Province/State _____ PC/Zip: _____

Tel: _____ Email: _____

Official Revenue Canada receipts are issued for all memberships and donations.

Donation Options

I would like to make a Monthly Quarterly Annually Other _____
donation in the amount of \$

- Charge my VISA MC American Express

Card Number: _____ Expiry date: _____

Signature: _____

- I am enclosing _____ postdated cheques in the amount of \$ _____ to the Canadian Hemochromatosis Society.

Please mail this form to:

Canadian Hemochromatosis Society

272 - 7000 Minoru Blvd. Richmond, BC V6Y 3Z5

Tel: 604 279 7135 | Toll Free: 1 877 BAD IRON

