Canadian HEMOCHROMATOSIS SOCIETY

Spring, 2008

Iron Filings

Member in the Spotlight

Newfoundland Coordinator Spreads the Word

On "the Rock," the Society's regional coordinator Linda Oldford hopes to make hemochromatosis a common household term.

Newfoundland regional coordinator Linda Oldford and husband Tom

I first heard of hemochromatosis in the late 1980s when I watched a CBC program on which Marie Warder was discussing the disorder and her book *The Bronze Killer*. I remember writing down the details and being intrigued that such a potentially fatal disease could go undiagnosed. When my brother was diagnosed in 1994, I immediately recalled the television program and the hemochromatosis society that Marie had started.

In 1995, the *Readers Digest* printed an article about hemochromatosis. I encouraged family members to read it and promote testing in order to find out from which side of the family we had inherited hemochromatosis. I suspected my father's side because three of his brothers had died in their 60s from stomach or liver disease. As well, that side of the family had cases of early diabetes and arthritis. My suspicions were confirmed when my father's sister's son (my cousin) was diagnosed next. I come from an immediate family of 14 and now five of us have being diagnosed since my brother's initial diagnosis. Now more than 100 extended family members have been tested. For me, that confirms why awareness is so important.

At first, I thought it was unlikely that I would have it as I was having blood tests and check-ups every couple of months after treatment for breast cancer. I have had arthritis for years and now I was also feeling chronically fatigued, had irritable bowel, mood swings, and my hormones

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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; The Iron Elephant; Iron Disorders Institute Guide to Hemochromatosis.

From the President

Volunteers Hold the Key to Our Success

Hemochromatosis Awareness Month is almost upon us again, bringing into sharp focus the real heroes of our organization, our volunteers. They constantly amaze me with their creativity in developing new strategies to be affective ambassadors no matter what their personal health circumstances or how remote their geographic locations.

Our Member in the Spotlight, Linda Oldford from Newfoundland, is a great example. The Members Corner article highlights the activities of several more of our volunteers and exhorts us all to find a way to contribute not just in Awareness Month, but all through the year.

The value of volunteerism came home to me recently in a very personal way. The person who has most inspired me over my years as a volunteer is my own mother. I have had much occasion to think of her of late as she recently passed away, suddenly and unexpectedly.

At the time of her death at 81 she was an active member of at least 12 different organizations including CHS; the president of one, the secretary of another and the treasurer of still another. As my siblings and I have been sorting through her things, the sheer volume of her 50 plus years of volunteer activity with countless organizations has been staggering.

We have also been moved many times by stories people have shared with us about some positive affect my mother has had on their lives. It has made us all realize that the true secret of immortality is to touch the lives of others and I have been humbled and inspired all over again.

When I took on the presidency four years ago, I was acutely aware of both the responsibility and of the legacy of my predecessors, Marie Warder and Charm Cottingham. They had used their passion

Elizabeth Minish, President CHS

and dedication to make CHS an effective agent for change. They knew theirs was a huge task that would take many years to accomplish and that successes would be measured by small victories along the way.

CHS had come as far as it could with a small group of volunteers. I set out to professionalize the organization with the ultimate goal of increasing our capacity and expanding our reach.

As I step down as president, I am proud of how much we have accomplished and thankful for the opportunity I have had to lead the organization through this exciting period of change. As I look back on my 24 years as a volunteer with the CHS, I am amazed at how far we've come and excited by how far we may still go. I am also mindful that no matter how our fortunes may improve and how big we may become, there is no substitute for the contribution and passion brought to an organization by its volunteers.

I would like to thank all the volunteers who have given so much to the Society over the years, especially those who have served on our board. Special thanks to Julie Mohaseb for her work on this newsletter, even during her recent pregnancy and the arrival of her little girl.

Last, I'd like to thank Ross Gilley for his constant support. I wish him and the new board every success as the work of CHS goes forward.

Iron Filings

Iron Filings is the newsletter of the Canadian Hemochromatosis Society
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The Disorder

Hemochromatosis is the most common genetic disorder afflicting Canadians. It is a crippling, potentially fatal condition caused by iron overload in organs, joints and tissues. The complications caused by the disorder are preventable.

Our Purpose

The society is dedicated to preventing the unnecessary suffering and death caused by hemochromatosis by promoting awareness and early diagnosis while supporting those affected by the disorder.

Why we do what we do: Working with you to get the word out

Bob Rogers, Executive Director, CHS

Almost every day, I learn something new about the needless suffering individuals and families experience due to hemochromatosis. In a recent email from one of our regional coordinators, I read about the hurt and pain that continues for the family members who lost their beloved father. If he had been screened and diagnosed earlier in his life and received treatment, his iron levels would have been controlled and the second stage disease, which took hold, would have been avoided.

A few months ago, I received a telephone call from a woman in Toronto. She had been experiencing tenderness in her abdomen. Her doctor was alert and ordered the necessary tests for hemochromatosis. The tests results were positive for hemochromatosis and this woman is now undergoing regular treatment.

Many doctors still believe hemochromatosis is rare. At CHS, we inform physicians that the prevalence for hemochromatosis is one in 300 in the general population and provide them with the important information they need to know. Considerable effort is underway in Ontario to ensure a medical protocol is developed like the ones that currently exist in British Columbia and Alberta.

The purpose of the Canadian Hemochromatosis Society is to ensure the best information about hemochromatosis is made known to everyone who needs to understand and diligently act to preserve the quality and length of life. In Canada more than 100,000 individuals are at risk to develop hemochromatosis.

In 2008, our goal is to reach 1,000 new families and provide them with the necessary information to act and prevail over the ravages of hemochromatosis.

We continue to seek your financial support and volunteer assistance to achieve our goals. I am looking forward to growing relationships with you so that together we can "iron out" hemochromatosis in Canada.

At the AGM on April 2, departing president Elizabeth Minish presents retiring board member, Ruth Doll, with a certificate of appreciation for her work with CHS. Longtime board member Anna Kyle, Ottawa Ontario, also retired. The new board, seen pictured on page 8 of the newsletter, was sworn in during the meeting.

Contact us!

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Hemochromatosis and Your Heart

Your heart is one of the many organs in your body that can be affected by iron loading caused by hemochromatosis. Heart problems are not typically one of the first symptoms to arise in adult-onset hemochromatosis because it takes a lot of iron buildup and time for the heart to become affected. The buildup of iron is known to be toxic as cardiac function characteristically worsens or improves in proportion to the degree of iron accumulation in the heart muscle cells, however the exact mechanism of its toxicity is not known. Current research indicates that the generation of oxygen-free radicals causes the damage

With time and no preventative treatment, the damaged heart muscle develops such cardiac problems as *cardiomyopathy, arrhythmias*, and *congestive heart failure*. In severe cases where there has been significant iron buildup in the heart, multiple cardiac conditions can occur.

Arrhythmia

Usually, the heart beats between 60 and 80 times a minute in a regular rhythm. When the heart beats abnormally in any way, this is referred to as an arrhythmia. Arrhythmia may cause the heart to beat too slowly (*bradycardia*, which is less than 60 beats per minutes) or too quickly (*tachycardia*, which is more than 100 beats per minute), or cause uncoordinated contractions (*fibrillation*).

Cardiomyopathy

Cardiomyopathy refers to disease of the heart muscle and occurs when the heart muscle becomes inflamed and can't work properly. *Dilated cardiomyopathy* is the most common form where the damage to the heart muscle causes a loss of muscle tone. This allows the heart cavity to stretch and enlarge which reduces its ability to pump blood to the rest of the body which can lead to congestive heart failure.

Congestive heart failure

When the heart does not pump as strongly as it should, the body does not get the right amount of blood and oxygen it needs to work properly. Congestive heart failure can cause a backup of fluid in the lungs and other parts of the body, which is referred to as *edema*. Patients with congestive heart failure are typically short of breath and cannot lie flat due to the fluid in the lungs.

How are heart problems in hemochromatosis diagnosed?

Physicians will conduct a clinical history and examination, including a history of irregular heart beat, palpitations, shortness of breath and chest pain. Examination for signs of heart failure include looking for evidence of an enlarged heart and murmurs as well as for signs of edema like swelling in the lower legs, or fluid on the lungs.

Special diagnostic tests can assist in determining the degree of heart function. The non-invasive echocardiogram (ECG) can show rhythm, chamber size and thickness of the heart wall, all features that can be important in heart failure. Magnetic resonance imaging (MRI) can quantify the amount of intramyocardial iron levels, and this is obviously quite important to those with hemochromatosis in order to determine the amount of iron accumulation. Biopsies of the myocardial tissue may still be performed to determine the presence of iron, but since this is invasive, ECGs and MRIs are now more widely used.

Can the amount of ferritin signify possible cardiac problems?

More than 1000ng/ml is the value for cirrhosis and liver problems; there does not seem to be a definitive equivalent value for heart. Any value of heart iron is not good and one should aim for no iron in the heart.

Can phlebotomies prevent heart damage caused by too much iron?

With regimented phlebotomy treatment, becoming de-ironed may prevent cardiac complications from arising. There was a reported case where a 36 year old woman had dilated cardiomyopathy and underwent a cardiac transplant. A biopsy revealed significant iron overload in her excised heart. Six months after receiving her new heart, iron buildup was noted again; this finally instigated the diagnosis of juvenile hemochromatosis and now she is being successfully treated with phlebotomies *(J Heart Lung Transplant. 2006 Jan; 25(1):144-7)*.

Juvenile Hemochromatosis

Unlike adult-onset hemochromatosis,in cases of juvenile hemochromatosis, heart conditions such as cardiomyopathy seem to be one of the cardinal features at diagnosis. In some severe cases, the patient is diagnosed when they present with heart failure. Juvenile hemochromatosis is caused by defects in a different gene (called *hemojuvelin*) and iron buildup in these patients is much faster and more severe, so organs such as the heart are affected much earlier.

Can intensive phlebotomy therapy reverse or improve existing heart conditions caused by too much iron?

Phlebotomy may help, especially if the heart condition is detected early. However, it does depend on the underlying condition and whether the condition is really due to the excess iron. Even if it is not due to the excess iron, the removal of iron may lead to some degree of improvement. In juvenile hemochromatosis, where more patients have heart conditions at a much earlier age, if detected early, intensive phlebotomy therapy (2 times a week for 12 months) has been shown to bring serum ferritin values back down to normal range and normal cardiac function noted (Eg. Article*: Internist (Berl). Jan 23, 2008).*

If the condition is already quite severe before phlebotomies start, then it is much more difficult to deplete sufficient iron stores and reverse disease. A report of a 47 year old man with hemochromatosis and cirrhosis developed symptoms of congestive heart failure and was found to have dilated cardiomyopathy 7 months after receiving a liver transplant. His heart failure worsened, and 3 years later required a heart transplant. So despite best efforts with phlebotomy, it did not reverse his cardiac conditions *(A J Clin Pathol 1993 Jan:99(1):39-44).*

Iron Reference

Normal Serum Ferritin Levels

Adult Males 20-300 ng/ml

Adult Females 20-120 ng/ml

Normal transferrin saturation values are between 30-40 per cent.

Normal Hemoglobin Range

Adult Males 13-18 g/dL

Adult Females 12-16 g/dL

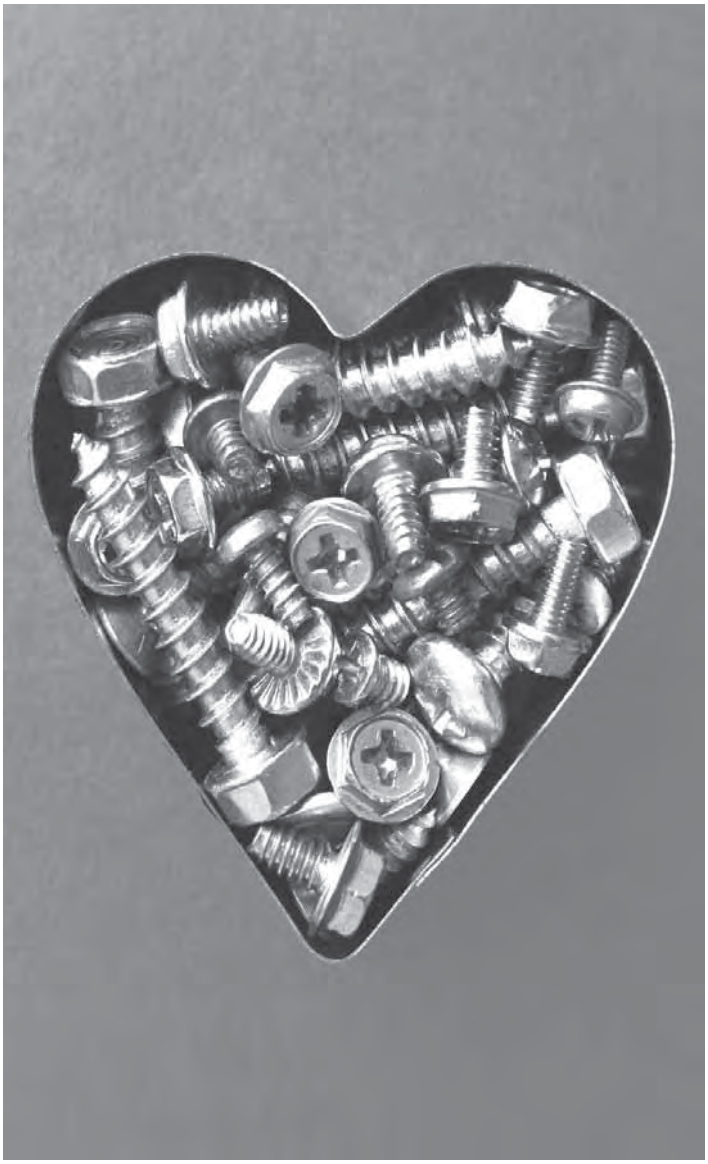
Does Canadian Blood Services refuse to take blood donations from patients with heart conditions?

Any person who has a heart condition is ineligible to donate blood via the CBS. Hemochromatosis patients with diagnosed heart conditions must have phlebotomies performed at hospitals, outpatient clinics or at doctors' offices.

What is the typical management for a hemochromatosis patient with a heart condition?

Depending on the heart condition, lifestyle changes (diet, exercise, limiting alcohol) can help. As well, many different medications and surgical procedures are available.

As always with our newsletter articles, we try to provide accurate but general information and by no means feel this is sufficient for any kind of medical interpretation. It is important to talk to your doctor about your specific treatment and management of hemochromatosis and cardiac conditions.



Members' Corner

by Ross Gilley

Around the middle of February we had a chance to chat with a number of folks around the country about recent happenings and ideas for the upcoming **Awareness Month in May**. We call them regional coordinators, but really they are members who take an uncommon interest in helping others diagnose and treat hemochromatosis. Besides plans for Awareness Month, hot topics included the growing use of the website forum for useful discussion, and the quest for medical protocols in each province.

Bob MacLeod of Kingston, Ontario facilitates the website forum subjects and conversations in a highly professional manner. A recent check-in to the forum revealed several discussions taking place, including notice of recent seminars held in Toronto and Vancouver, and input from forum participants about ferritin and iron saturation levels during de-ironing.

The forum includes contributors from around the world, and provides a support structure for those seeking a road map around the murky world of hemochromatosis. If you haven't yet checked out the forum, you can access it by going to www.toomuchiron.ca and clicking on the third tab from the right. If you have difficulties getting there, give us a call at the office and we'll point you in the right direction.

Bob MacLeod has been gathering information on symptoms for future use in developing medical protocols for Ontario. **Ben McEwen** in Edmonton is our local resource on this subject, as he took part in a campaign last year to introduce Alberta guidelines to supplement the existing BC protocols. Protocols are important in the medical community as reference tools. They add legitimacy and ease access to treatment in provincial medical systems for CHS members. According to Ben, some of the key steps to getting protocols in place include:

- Contacting the provincial medical association to recommend that guidelines be developed.
- Aligning with a committed medical professional who can act as a champion and assist in getting on the agenda of the protocol committee. Ben was greatly aided by **Dr. Dawna Gilchrist**, who did an incredible job of raising the issue within the Alberta Medical Association.
- Establish a working group of physicians and CHS members to establish guidelines and present them to the members of the provincial medical association. This is where it really pays to be a CHS member, as larger numbers mean more clout for these efforts!

This challenge took just over a year to complete, and he reports that the task gets easier when the local medical association has access to the work of another province. In this case, both the BC and Alberta guidelines are posted for all to examine on our www.toomuchiron.ca website.

Ross Gilley, CHS President Elect

Thanks for joining CHS! Why not check out the Web Forum (under "Events") to trade good ideas about Awareness Month activities in May.

Share your story

Sadly, many in Canada know little or nothing about hemochromatosis. CHS would like to change this. We are asking you to share your story. How does hemochromatosis affect you or a member of your family? Send your story to: mystory@toomuchiron.ca. We will publish these stories in our newsletter, on our website, or our other publications. If you would like to remain anonymous, just tell us and we will ensure you or your family are not identified. Your story will increase awareness and may help thousands of Canadians avoid suffering and premature death.

May Awareness Month

CHS has recruited a wonderful woman to help coordinate May Awareness Month activities from our head office. Mary Gavan, RN, MA, started in March to put together an Awareness Month plan. She will use the suggestions and list the activities the regional coordinators have recently contributed.

Mary brings knowledge of hemochromatosis, a delightful ability to communicate through storytelling, and a strong desire to serve. Mary can be reached at mgavan@toomuchiron.ca. More information about May Awareness Month is available on the CHS website!

Staff Changes and Updates

Dalila Bekkaoui, our Office Manager at CHS, will soon be taking a maternity leave. During this leave, Brenda Ohara will be fill her shoes. Brenda is just coming off a maternity leave and is looking to use her administrative and marketing skills to help the work of CHS move along smoothly. Brenda can be reached at bohara@toomuchiron.ca.

Lynda Oldford: Member in the Spotlight

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were abnormal, all of which I blamed on the chemotherapy and radiation treatment. But I was wrong. Instead, these were all symptoms of hemochromatosis. I had genetic testing done in 2003 which discovered the common C282Y mutations on the HFE gene. My ferritin level was 586 ng/ml, and following investigations and a visit to a hematologist, I began phlebotomies to bring my ferritin down to 50 ng/ml. I am now maintained on phlebotomies 3-4 times a year through the hospital system as I am unable to donate at CBS clinics because I had breast cancer. My four children have been tested and do not have hemochromatosis.

I talked about hemochromatosis at my check-up at the cancer clinic, and on my next visit, the doctor told me, because of what I had told him, a colleague of his got tested and was diagnosed.

In 2004, one of my brothers, who initially did not have the genetic testing, started experiencing severe arthritis. He remembered the family history and symptoms of hemochromatosis and so he had his iron levels checked. His ferritin level was measured at 3100 ng/ml and obviously started phlebotomies right away. He thankfully is now down to a healthier level of 50 ng/ml.

With the family looked after, I set about to inform whomever I could about this disease. I felt that everyone needed to know about hemochromatosis and get tested because if diagnosed early, simple treatment via phlebotomies could prevent the secondary damage.

I joined the CHS and received all the educational literature. I started my awareness campaign at the local hospital where I worked as a nurse. I found few staff who knew what hemochromatosis was, so I developed an information package for all the medical staff. It was well received. Last year, we had a display table in the hospital lobby too hand out brochures.

I talked about hemochromatosis at my check-up at the cancer clinic, and on my next visit, the doctor told me, because of what I had told him, a colleague of his got tested and was diagnosed.

I then moved on to the community putting up posters during hemochromatosis awareness month in May and leaving brochures in clinics, doctors' offices, malls, and anywhere else that I could think of! Now I am happy to report that our local radio station plays the hemochromatosis public service announcement during May awareness month, the local newspaper has printed the article *Hemochromatosis Should Be A Household Word* and our provincial newspaper interviewed me and published an article on hemochromatosis. Two years ago, I joined an on-line book club "Bookcrossing" and use toomuchiron.ca as my home page. I get several messages a year from people all over the world who check it out and thank me for providing hemochromatosis awareness.

With my role as CHS regional coordinator for Newfoundland, I hope to continue to spread awareness whenever and wherever I can.

Donors, Sign in Please

When you go to the Canadian Blood donor clinic on Oak St. in Vancouver, be sure to sign the *Partners for Life* book at reception under "Canadian Hemochromatosis Society."

The Society is listed in the book, and we want to qualify to have CHS posted on the *Partners for Life* board in the Clinic.

Enjoy your newsletter!

Please pass it on. Our newsletter is also available online on our website. If you would rather read it electronically, or if you don't want future newsletters, let us know and we'll take you off the list.

Speak Up!

When leaving a message on our toll-free line, 1-877-BAD-IRON, leave your full name and address (spell them out) and your 10-digit number.

Do You Collect HBC Points?

Did you know that you can donate your HBC Reward Points to CHS? The Society can redeem the points for merchandise and supplies for the office.

When shopping at any of the stores that accept the HBC Rewards Card, tell the cashier that you wish to credit your points to CHS. The card number is: 600294593471099. Keep this number with your HBC Reward Card. Don't forget to tell them that you wish to keep your points account open or they may close it.

Thank you for supporting CHS!

Buy Gas at Husky!

Every time you make a purchase at a Husky/Mohawk gas station, store or restaurant, and have your loyalty card swiped, CHS will receive 2 per cent of your purchase. A gas fill of $45 means 90 cents is paid to CHS. Contact our office for your card today. Lottery and tobacco products, of course, are not eligible.

CHS Board, 2008~2009

The new Board of Directors was sworn in at the AGM on April 2, 2008 From left to right: Dr. Siegfried Erb; Chris Petty; past president Elizabeth Minish; treasurer Randy Pratt; president Ross Gilley; Cyrus Ameli; Frank Erschen; and Pam Sinclair. Not pictured: Ben McEwan, Gloria Haché, Julie Mohaseb, Greg Shyba.

Support CHS and help prevent needless suffering and early death

Annual membership $30	_____
Senior $20, family $45,	
professional $55, lifetime $500	
Books: *The Bronze Killer* $20	_____
***Ironic Health* $22**	_____
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For international prices, contact office.

❑ **I have HHC** ❑ **A blood relative has/had HHC**

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❑ I am a new member ❑ Renewal

❑ As a member/donor, I grant permission to publish my name in the CHS newsletter.

❑ Do not publish my name in any CHS media.

Send me___brochures and _ information packages.

❑ Payment enclosed ❑ Please charge my VISA

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THANK YOU!

Spring, 2008