Iron Filings

The Newsletter of the Canadian Hemochromatosis Society **Spring, 2003**

The Disorder

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

Our Purpose

The society is dedicated to the dissemination of information about the disorder, and its early diagnosis and treatment.

Inside

Member in the Spotlight: Katherine Koper

Managing HHC for the Good Life

I guess I'm one of the lucky ones. I discovered that I had HHC in the very early stages before organ damage. I was and still remain asymptomatic.

I'm an elementary teacher. I didn't have any serious health problems, or at least none that couldn't be fixed if I'd lost some weight. I'd tried every diet known. I even tried to be anorexic for a short time. Then I happened to watch Roseanne tell about her gastric by-pass surgery and realized that I was included in the group called "morbidly obese." Our small town had a very compassionate and understanding doctor. She understood obesity can affect one physically and emotionally, even changing a person's personality. She referred me to her best choice of surgeon. Even though I lived in northern Ontario and the surgeon was in Toronto, he agreed to schedule me for surgery sight unseen.

So, I turned 50, and in the summer of 1999 I began the next half of my life. Gastric by-pass is serious major surgery and something not to be entered into lightly.

My recovery was fast and uncomplicated. My doctor worked closely with the hospital dietician and both required patients to take liquid iron after surgery. The iron made me sick, but in about 18 months I lost 110 lb and felt great. No more arthritic knees and ankles, high blood pressure or fear of diabetes. The surgeon required blood tests every 3 months. The dietician became extremely concerned about my high ferritin levels, as I was registering 689. Through her efforts, she finally convinced the surgeon to schedule me to see a hematologist. The genetic blood test revealed that I am "homozygous for the Cys282Tyr mutation" and had inherited hemochromatosis.

By switching to a multi vitamin without iron, avoiding cold cereals and liver and drinking more tea and less orange juice, I was able to reduce my ferritin level to 200

Katherine Koper

within a year. The hematologist continued to monitor me. Meanwhile, my younger brother in southern Ontario had to wait almost a year to see a specialist who confirmed that he also has HHC (ferritin levels of 2400!). This explained his early onset arthritis. We realize now that our father probably had HHC, which helps us understand his depression, change of personality and early death. Our mother is a carrier. Only two of the four siblings have HHC.

I asked the hematologist on one of my visits about two lumps in my neck. This is when I learned that cancer tends to grow in an iron rich environment.

It's been a year now since my radiation and chemotherapy treatments ended. I had been 231 and now I was 89 lbs! The doctors encouraged me to drink liquid meal replacements. Most of these contain iron (there are two brands that don't but they are more expensive and less easily obtained). My ferritin jumped to the mid 800s last December. By the end of January it was 214. A

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From the President

Our Future is Bright

Our appeals in the last newsletter were definitely heeded. We received a very generous donation from Janet Campbell, which enabled us to purchase a new slim-line computer and fund some of the costs of this newsletter. Your HBC points put a new black and silver desk in our office. Also from Lloyd Kitchen we received a good used computer, monitor and colour printer, as well as a used laptop computer from Skip Young. So we now have three working computer stations, where many programs can be opened and used at the same time. It certainly makes it easier and more efficient for everyone in the office.

As you may have noticed, we have a new look to our newsletter. Chris Petty has volunteered his services to produce it, which allows us to cut our costs and free our office staff to do other things.

Maggie Campbell, one of our new Board members, has become the Fundraising Director and is keeping us all on our toes, coming up with information to run her programs more efficiently. She has already obtained some large donations, with plans to obtain many more. Check out our insert for an upcoming event she has planned with Canadian Blood Services. We continue to lobby CBS to make the regulations for hemochromatosis patients more user-friendly, such as a shorter period of time between donations and the use of smaller size needles.

The medical history form survey by Dr. Chris Whittington has not yet been completed. She had a bit of a setback when her husband and children were not well, and she hopes to get it done in the next two months. I encourage you to read her new book, *Ironic Health*. It tells of her experiences in an Australian phlebotomy clinic and how hemochromatosis affects people in all walks of life. We are selling this book from our office. You will find it listed on our membership form at the end of this newsletter.

The support groups in Ottawa and Richmond are meeting regularly and planning many activities. I encourage other cities and towns to form support groups. It can start small with just three or four people (ie: sufferers and their families) and then grow. We will give you all the help we can but it takes a dedicated person on the spot to give it the enthusiasm that is required.

Arie Boom, our world traveling Dutchman, is planning to arrive in Florida this spring and is now hoping to travel by land across the United States and into Canada. He is looking for funding and support. One of our new Board members, Dr. Erb, has offered him the loan of his camper from October 2003 to April 2004. Can anyone else offer anything?

We have just had 5000 new brochures printed so please order what you will need for Awareness Week and start delivering them to doctors offices, pharmacies, libraries, etc. We had a letter from one of our contacts, who informed us that her pharmacist, Murray Grossman in Scarborough, Ontario has been distributing our brochures for over three years now and does so with enthusiasm. So lets all of us try and find another Murray Grossman.

Two of our longstanding directors have had to resign because of work pressures. So we are searching for enthusiastic people who would like to give us four evenings a year and a Saturday afternoon. We especially need a new Treasurer. Please search among your family and friends to find us one. We have an accountant who comes in one day a month and does the financials. We just need someone to present these figures in an understandable way to the rest of the Board and to keep an eagle eye on expenses.

At present our future is looking very bright. We have two new enthusiastic Board members, our expenses are not exceeding our income and the office is working very efficiently under the guidance of Candace, with the help of Natasha.

Charm Cottingham, National President

Thanks for Our New Desk

Thanks to all those generous people who donated their reward points. We now can work on a space saving desk instead of the fold up table we had before.

Zellers, The Bay and Home Outfitters now have the new HBC Rewards points. You can help out CHS by donating your points to the Society. Use our card # 850 639 047.

Please advise the rewards center that you want to keep your card active when donating points, or they will cancel it.

Iron Filings

Canadian Hemochromatosis Society
#272 - 7000 Minoru Boulevard
Richmond, BC Canada V6Y 3Z5
604-279-7135
fax 604-279-7138
email office@cdnhemochromatosis.ca
Toll Free 1-877-BAD-IRON

Member of the International Association of Hemochromatosis Societies
Charitable Donation #11921 9160 RR 0001

Volunteer Contacts

Volunteers distribute materials, contact media, answer phone queries, etc. We need contacts in outlying areas. We have no contacts in PE, NT, or NU, so call our offices if you want to help. Thanks for your support.

MEETINGS

Ottawa Support Group
March 13, April 10, May 8, June 12
7-9 pm, Boardroom,
Ottawa Hospital, Riverside Campus
Call Marjorie 613-739-9277
or Elaine 613-521-5897

Richmond Support Group
March 29, 1-3 pm
6220 Blundell Blvd, Richmond
Call Howard 604-277-5905 or
chsrich@vcn.bc.ca
This will be a pot luck with guest speaker.
Please phone the office at 604-279-7135 for future dates.

Newsletter produced by Chris Petty

www.cdnhemochromatosis.ca

Katherine Koper

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drop of that amount in one month without any dietary change seemed incredible and suspicious. No one has been able to give me a reasonable explanation for it, but they always add that radiation and chemotherapy drugs can do strange things to our bodies.

I started corresponding with CHS and learned that a ferritin level of 200 is NOT normal once you have been labeled HH. The society sent the hematologist their doctors' information package and he scheduled me to get three phlebotomies three weeks apart before the school year began. My ferritin level now registers 32!

Since I continue to have no symptoms, the hematologist no longer needs to see me. We have a new doctor in our community, and he will be able to schedule three or four phlebotomies a year for me, which should keep the ferritin below 50.

I am most fascinated by hereditary hemochromatosis. It seems incredible that so few people, including doctors and hematologists, know so little about this condition. How wonderful that we have the great persistence and knowledge of the founding members of the Canadian and American HH societies to rely on.

Hemochromatosis in the News

Cois Tine-Irish Community News, Fall 2002: Hemochromatosis: The Celtic Curse

Sunday Sun, Toronto, Oct. 2002: *Genetic disease is little-known* by Dr. Gifford-Jones

Brantford Expositor, ON, Oct. 2002: *Iron overload can damage organs, by Dr. Gifford-Jones*

Good Housekeeping (UK), *It took 17 years to find out why I felt so tired all the time, by Lucy Harding*

Edmonton Journal, AB, Aug., *Excess iron can scar the liver, by Dr Paul Donahue*

BC Medical Journal, Dec, 2002 *Genetics of HHC* by Dr. C Whittington

Physicians Newsletter, MDS Metro Lab Services, January 2003, *Genetic Testing for Hemochromatosis*

Marie Warder interviewed on radio, Oct. 2002

In Memoriam

Donald Taylor: A Good Friend Passes

I have not been able to remain very active in the CHS for some years now due to a variety of health problems, but I have never ceased to be passionate about Hemochromatosis, and I still care very deeply about the affairs of the society and the people connected with it. Because those who work in the Richmond office know this, they are extremely kind and tolerant about my bouts of interference, and because they know that I long for news of old friends, they graciously photocopy and send me any letters they feel would be of interest to me.

One of the letters I have grown to expect would be from Don Taylor, my old friend from Victoria, BC. His periodic notes and messages to me were of the utmost value because, apart from my family, Don was the very first registered member of the CHS! It will take some getting used to the fact that Don will not write and encourage us any more.

Those of you who have read *The Bronze Killer* only need to look in the index to find the account of how Don Taylor walked into our lives – Tom's and mine – one day late in 1980. I have told about my desperate search to create awareness and to find enough people to incorporate a society. I have told about people who were helpful in this regard and how "almost simultaneously," Leigh and Tom found another good friend in Dorothy Found of the Ambulatory Day Care Unit. Dorothy undertook to tell patients about the proposed society and to direct them to where they could find us.

"What an exciting day it was when Don Taylor first walked into the piano and organ store where Tom and I were working and said: "Dorothy sent me to you. I have hemochromatosis!"

I have gone on to write: "It was five years since Tom had been able to compare notes with anyone. I guess Don had never had the opportunity to do so; and the two of them nearly talked their heads off." Today, 21 years later, Don's signature on the formal application for incorporation of the Canadian Hemochromatosis Society remains a lasting record of his enthusiasm.

After the society was finally incorporated in Victoria in 1982, Vancouver and the Lower Mainland became the first branch of the society, and even after, when by a formal motion passed at a special meeting of the society in 1983, the headquarters were moved to Richmond, it seemed quite natural at that time to continue to hold the AGM in Victoria. To organize this, at long-distance from Richmond, would have been impossible were it not for the ever-available help of Don and his lovely wife Fay, and Tom Rogerson – another of the charter members.

My family and I are deeply saddened by the news of his passing, and our hearts go out to Fay – in sympathy and gratitude!

Marie Warder, Founder and President Emeritus of CHS

Hemochromatosis

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 and confusion, bronzing of the skin 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; The Iron Elephant; Ironic Health; Iron Disorders Institute Guide to Hemochromatosis.

Welcome New Members

Barbara Baker, Bagley MN
William Bloomfield, Victoria BC
Melvin Bowen, Port Alberni BC
David Campbell, Mississauga On
Canadian Porphyria Foundation, Neepawa MB
Larry Chambers, Lloydminster AB
Leona Chatwood, Burnaby BC
Gregory Cleveland, Lunenburg NS
Donna Craig, Chilliwack BC
Diane Denham, Wetaskiwin AB
Thomas Doucette, Port –Cartier QC
Bruce Edwards, Saanichton BC
Pat & Don Findlay, Sudbury ON
Janice Fleming, Turner Valley AB
Sue Furlong, Enderby BC
Margaret Gelle, Brantford ON
Dave Greenall, North Vancouver BC
Martin Guest, Toronto ON
Margaret Hawkins, Surrey BC
Keir Hay, Wairton ON
Bob Hickey, Dundas ON
Pauline Hughes, New Westminster BC
Marleen Humphries, Kelowna BC
Joan Kamel, Saint Bruno QC
Dennis Kilmer, St Thomas ON
Lorraine Lapointe, Maxville ON
Georges Lauzon, Powell River BC
Vera Lima, Mississauga ON
Annabelle Marsh, West Vancouver BC
Susan Mather, Petrolia On
Keith McLean, Richmond BC
Ralph McLean, Vancouver BC
Catherine Moore, Bracebridge ON
Cherie Newton, Nanaimo BC
Jonathan O'Hara, Edmonton AB
Evelyn O'Sullivan, Prince George BC
Donald Owen, Kamloops BC
Janet Parson, Peterborough ON
Therese Perry, Vancouver BC
Nils Primdahl, Lindsay ON
Maureen Reid, Hamilton ON
Chuck Rendell, Blind River On
Gordon Ross, Gibson BC
Thomas Ross, Brampton ON
Freda Sather, Vancouver BC
Barbara Seldon, Burlington ON
Barry Singleton, Calgary AB
Brenda Thompson, King City ON
Laurie Townsend, Calgary AB
Dave Turk, Peterborough On
Lauretta Vik, Cobble Hill BC
Mary Waldrum, Parry Sound ON
George Waldrum, Parry Sound ON
Elizabeth Winter, Point Edward ON
Dorothy Yackulic, Saskatoon Sk
Bruce Young, Richmond BC

Professional memberships are $50; lifetime memberships are $500. Those donating $500 or more will automatically become lifetime members.
Thanks to Stanley Wales, Janet Campbell, Marjorie Lounder, and Gordon & Fay Smith for becoming lifetime members.

Our Readers Speak Out

Letters

We appreciate and welcome your letters. In order to fit as many in our newsletter as possible, we must edit for space. Our apologies if our editors took out your best lines.

My story describes the problems I've had getting a diagnosis and the on-going problems I've had finding a doctor to treat me. I should note that I am 46 years old.

Ever since I was a baby, my mother gave me Gravol for nausea and vomiting and children's aspirin for headaches. As a young child, I always had a wrist or ankle wrapped in elastic bandages because they were swollen from being sprained. When I was 12, my mother took me to the hospital to check for appendicitis because I constantly complained about abdominal pain. The hospital found nothing wrong.

I became a registered nursing assistant in the Hamilton General Hospital. When I was 21 my right wrist gave out as I was lifting a tiny old woman. After 6 months of doctors not believing anything was wrong, they finally did an arteriogram and discovered that the right triangular ligament was torn.

Throughout the years, I have struggled with severe migraine headaches. I tried several medications but nothing seemed to work. My first child was born 2 months before my 22nd birthday, and within about 6 months my periods became very erratic. An ultrasound showed an ovarian cyst, which was removed.

In 1996, I was feeling very weak and my Hbg was 53. Doctors did a bone marrow and every other test they could think of. Then one day my Hgb dropped to 41. I was immediately transfused with 2 units of whole blood. By the time my Hgb was back in the 70s I was sent home with numerous bottles of pills, iron supplements among them.

After about 6 months my family doctor phoned me and said my blood tests showed liver damage. He said I was abusing alcohol and asked how much I drank every day. When I told him, he accused me of lying and said I needed to admit I had a problem abusing alcohol and to get help. I said I didn't have a problem. He said if I refused to get help there was nothing more he could do for me. Then he hung up.

In October, 2000 I had an ultrasound and later that day I received a phone call saying I had a 17 cm. ovarian cyst and an appointment with an oncologist gynecologist who booked me for surgery. As I waited to go into the OR the surgery was cancelled because my platelets were so low they felt I would bleed to death. They asked me, "How much do you drink a day?" I insisted I was not an alcoholic. They said I was in denial.

The hematologist said she'd test me for something but it was rare and she doubted very much if I had it. I had it. Hemochromatosis. In February, 2001, I had a liver biopsy that showed I had end stage liver cirrhosis. I made an appointment with another hematologist. He admitted to being a bone marrow transplant specialist and knew only the basics about hemochromatosis.

I've had 3-4 phlebotomies, the last one over a year ago, though my iron levels are never taken. In July, the cyst was removed. I was hospitalized for 3 weeks and was unable to take anything by mouth. I am currently on the organ transplant list at the Toronto General Hospital.

I am seeing a hepatologist here, in Hamilton, and a hepatologist at the Toronto General Hospital. Both of these doctors have admitted that they know very little about hemochromatosis, and my transplant coordinator said I was the first hemochromatotic she'd seen in the transplant program.

A hepatologist in Hamilton told me that my anemia in 1996 was caused by a vitamin deficiency. They checked me out thoroughly and if my liver was damaged I would have thought they'd have noticed it. Instead it showed up in blood work after several months of iron supplements.

We'd like to have a doctor that we can have confidence in.

M.C., Hamilton, ON

On January 20, I had the pleasure and opportunity to go to the town of Grandview, MB with my niece to speak to the family of a newly diagnosed hemochromatosis sufferer, Devey Barnett. Early in January, Devey's sister Maggie Barnett asked me to set up an information meeting in Grandview for the family members. They wanted more information about my husband Mervyn's experience with this genetic disorder.

While we have from time to time heard from people being diagnosed, this was the first time a family has requested any feedback and further communication as well as group support. About 20 people attended the meeting, and we passed out brochures from the society and showed their video. I told them how Mervyn was diagnosed incidentally because of testing done related to a cancer on his nose and of the years of phlebotomies required to bring his body's iron stores into line. I told of his bilateral hip replacements and of his need for a pacemaker because of a 3rd degree heart block, and of his declining health, which has been affected through the years.

I stressed the positive aspects of dealing with stress and illness in that it brought our family closer together. We developed a feeling of hopelessness after our first attempts to inform our local doctors and friends of the implications of hemochromatosis. It seemed to have had no impact. Without the perseverance of Marie Warder and others we would not have the society, which is now affiliated worldwide. We would not have the knowledge and research presently being done without the persistent efforts of those founders of our society. I know how fragile our fledgling society is and so ended with a plea for support with awareness efforts and money.

Following the presentations we had a discussion on the effects on various family members and the need for genetic testing. My feeling was that the motto of the society, "Find us one person with hemochromatosis and we will be able to save a family," certainly could be said of this family.

We hope to plan another gathering in the future. The word is getting out that hemochromatosis is far more prevalent and more devastating to families than we could have imagined. Thank you for your efforts at the Canadian Hemochromatosis Society.

D. M., Swan River MB

This is my third donation for this year, but you are doing good work, and I would like you to keep going. So I hope it will help.

A friend of mine who is a retired chiropractor asked for some of the literature you sent me. He now says he has some of the symptoms, and has gone for the test. So please keep going.

J.C., Saskatoon, SK

Please send your letters to:

Canadian Hemochromatosis Society
Richmond Caring Place
#272 - 7000 Minoru Boulevard
Richmond, BC Canada V6Y 3Z5

A Gene Pool for Hemochromatosis Research

For the incidence of the C282Y mutation to have flourished it must have conferred an advantage. The advantage was likely preservation and repletion of iron stores in susceptible individuals. Such individuals include those with an iron poor diet, an otherwise decreased ability to absorb iron, or those losing large amounts of iron through injury, menstruation and childbirth. The C282Y mutation may be at least one hundred generations old. In modern times with iron rich diets, supplements and blood transfusions, this evolutionary advantage may be a disadvantage.

A high incidence of the C282Y mutation has been reported in Celtic populations, with the highest incidence occuring in the Irish. Up to 1 in 4 persons in Ireland may carry one copy of C282Y, and more than 1 in 100 may carry two copies and have a predisposition to HHC. One copy of C282Y has been cited as predisposing to the skin disorder porphyria cutanea tarda, non-alcoholic steatohepatitis and increasing the risk of complications of liver disease if infected with hepatitis B or C.

The cloning of C282Y has been especially important for persons of Irish extraction. Recent work done in Ireland by the "Irish Origins" committee of the Royal Irish Academy points to the C282Y mutation as possibly having come to Ireland with the mesolithic settlers. A small rapidly breeding population may have allowed the gene to reach a high frequency. From Ireland the gene likely spread out to many parts of the world. It may have been taken to Scandinavia by Irish, captured as slaves by the Vikings. In more recent times the gene spread to the New World.

The Great Famine of the 1840s and the other smaller famines that occurred in Ireland likely contributed to the high frequency of Irish with one or more C282Y mutations. In times of famine iron deficiency soon causes a marked decrease in fertility as women may cease menstruating and miscarry more frequently. Women of childbearing age with two C282Y mutations have a distinct advantage during times of famine, as they are more resistant to such a decrease in fertility. Women who carry two C282Y mutations pass one mutation to each of their children. Even those who have one C282Y mutation have a higher hemoglobin level and a greater protection against anemia than those with no C282Y mutations. The carriage of one C282Y mutation is also a positive selecting factor in times of famine. The very existence of the C282Y mutation may have helped the Irish people to survive repeated famines. This remarkable survival capacity may have allowed the mutation to become very common in the Irish population.

In Australia the state of Queensland in particular has a high concentration of persons of Irish heritage. This base population combined with the excellent medical researchers and facilities in Queensland has led to much valuable research on HHC which has benefited, and has the potential to continue to help, not only Australians but also Irish nationals and the millions of persons of Irish extraction scattered throughout the world.

Chris Whittington, Clinical Assistant Professor, department of Family Practice, faculty of Medicine, UBC. For references contact CHS

Iron-Related Heart Arrhythmia

Excessive accumulation of iron in any vital organ can lead to life-threatening disease. But in the heart, excess iron can precipitate heart failure that can end in sudden death because of the development of cardiac arrhythmias. People with chronic iron loading disorders such as hemochromatosis and transfusion dependent iron overload are especially at risk for heart problems. These individuals must be diligent with de-ironing therapy and keep iron levels within a safe range to protect their hearts.

De-ironing patients with hemochromatosis is straightforward. Therapeutic phlebotomy or periodic blood extraction to reduce iron level is generally safe, though each patient is different. Variation of frequency and amount of blood removed is best when individualized, taking into consideration a patient's health profile.

Ferritin, an iron storage protein, traps iron; this mechanism somewhat protects organs against the destructiveness of the metal. Ferritin is contained in nearly every cell of every organ in the human body. The liver produces the greatest amounts of ferritin. The heart also produces ferritin but in lesser quantities than other organs – possibly because the heart it a muscle.

It is thought that during the iron loading process, accumulating iron destroys heart cells by movement of large numbers of iron atoms, that in great quantities, are suspect of tearing cells. More likely high levels of iron contribute to free radical activity, which will contribute to destruction of heart cells.

What happens during the de-ironing process is also speculative. It is reasonable to conclude however, that if myocytes, or cells of the heart, can be damaged when iron is accumulating, perhaps the heart can also be damaged when this iron is being mobilized and removed-especially if iron is removed too rapidly.

For decades, physicians who have successfully diagnosed patients with iron overload conditions have employed a standard de-ironing regimen. Patients, which are usually adult males, are bled until hemoglobin remains at 10.0g/dl for at least three weeks. At this point these patients are considered to be de-ironed.

Therapy depends greatly on a patient's condition, age, gender, overall health and habits such as smoking, drinking, diet and their willingness to comply with therapy. Youths, post-menopausal females and males over the age of 65 might be better served with therapy that involves slower, smaller extractions, which can offer added protection for the heart-especially when there is a family history of heart disease, if the patient has a history of heart problems.

Individuals with this type history or who have small veins that create an access problem might ask about use of a butterfly needle with a vaccum bag and small portion extraction. It is important to know that ferritin might be elevated due to other disorders such as inflammation, infection, kidney disease, viral hepatitis, AIDS, and other conditions. Therefore it is always important to be sure that the raised ferritin is due to iron overload.

From *ID Insight* For complete article contact CHS office

Maggie's Message

by Maggie Campbell

I was diagnosed two years ago at the age of 28. During a routine physical my doctor noticed elevated liver enzymes. I stopped drinking alcohol for three months and he ran the tests again but the enzymes were still elevated. He then tested my ferritin levels which were elevated as well. He started my de-ironing process before the results of the genetic test were on his desk.

I am so lucky. I have no long term problems relating to hemochromatosis. I can prove to you and the rest of the world the benefits of early testing and diagnosis. I give blood to Canadian Blood Services twice a year and my doctor regularly checks my ferritin. I will live a normal life and others can as well. This is why I became involved with CHS. There is no need for anyone to suffer from hemochromatosis!

As the board member responsible for fundraising, I'm going to use this column to tell you what's happening in that department.

First of all, thanks to all of you who gave last year. CHS relies on you for both time and money: we simply cannot do without you! You can hold your own events to help us through 50/50 draws, sales and other initiatives. One member wrote their MP for a list of federal government funders and had an information table at their community wellness fair. There are so many ways you can help! I will hold an information evening during Awareness Week.

Dennis Kilmer, above, with his 1970 Jeepster Commando. The HHC info board is part of his classic car display.

Dennis Kilmer of St Thomas, Ontario, displays an information board about hemochromatosis at the antique car shows he attends with his stock 1970 Jeepster Commando Convertible. As well as raising awareness for HHC he also got a runner-up award in his class. Congratulations Dennis!

It feels good to help others, and it helps you, too. You will receive a federal tax credit equal to 16% of the first $200 you give, and you will also get a tax credit equal to 29% for donations over $200. The more you give the more tax credit you receive. The tax credit value changes depending on which province you live in, so check it out.

Our most pressing need is money for operating costs, but you can always tells us what you want us to do with your donation. It is always a good idea to plan your spending but did you know you can plan your giving? Contact the office for more information on monthly and long term giving.

Exciting things are going on in the development department and we will keep you informed of the changes and how they will affect you. If you have any questions or you would like to discuss giving options please contact me through the office.

See you all in the fall!

Maggie Campbel is the CHS board member responsible for fundraising.

Enjoy your newsletter!

When you have finished with it, please pass it on. Let us know if you don't want future newsletters, 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 phone number. Please talk clearly, as it's very hard to understand some messages.

Good Donations

You can now donate online through our website. Visit www.canadahelps.org. Search "hemo," then click "Donate now." This is a secure site. You can use your credit card and all your donation comes to our society.

When sending money . . .

. . . such as a cheque or Visa 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.

Save Your Life While Saving Others

To help us celebrate National Hemochromatosis Awareness Week, we will hold a one day Hemochromatosis Awareness event on **Saturday, May 24**, from 9:00 am – 3:00 pm at the Canadian Blood Services (CBS) Oak Street clinic in Vancouver, located at 4750 Oak Street.

The Canadian Hemochromatosis Society is working with CBS to promote healthy persons with Hemochromatosis to donate blood at CBS clinics and to increase the awareness of this genetic disorder with the public and media.

All members of the CHS family in the Lower Mainland should come out and donate blood during the week. You will help save lives through blood donation and attract media attention. In addition to those great cookies at the clinic, Grimm's Meats has graciously donated hotdogs for a BBQ from 11:30am – 1:00pm!

You can book an appointment in advance by calling 1-888-236-6283 (1-888-2DONATE), or call if you're not sure you are eligible to donate blood.

So, come out and support two great causes on May 24! If you would like to volunteer a few hours of your time on May 24 contact Maggie at 604-279-7135 or office@cdnhemochromatosis.ca

Q&A

Can you help? Share your experience with other members.

I WOULD BE interested to know if anyone has been able to dispense with hearing aids after their iron index has been lowered. I started wearing hearing aids this year in July although they were recommended two years ago when I was diagnosed with a 30% loss in each ear with no explainable cause. My iron index is only 242, so I don't know if that is severe enough to even cause such a loss. Has anyone else with HHC ever complained about hearing loss?

C. H., Nanaimo, BC

IS ANYONE SUFFERING from leg pains after phlebotomies, stinging pain when standing, or having to take slow, short steps because of cramping legs muscles?

G. K., Halifax, NS

If you have some personal knowledge to share, send it to us and we'll publish it in the next newsletter.

Canadian Hemochromatosis Society

Annual General Meeting

Saturday April 26, 2003
1:00 pm
Caring Place
7000 Minoru Boulevard
Richmond BC

Come and voice your opinion and participate in a question and answer period with one of our medical advisors.

Help us promote

Hemochromatosis Awareness Week

May 25 ~ 31, 2003

Help us get the word out. Members can distribute posters and brochures to local libraries, pharmacies, doctors' offices, hospital, community events boards, etc. Send information to your local media, or talk to them yourself.

Contact our office for your supplies NOW.

Contact us!

Post	#272 - 7000 Minoru Boulevard Richmond, BC Canada V6Y 3Z5
Phone	604-279-7135
Fax	604-279-7138
E-mail	office@cdnhemochromatosis.ca
Toll Free	1-877-BAD-IRON

www.cdnhemochromatosis.ca

Support CHS and Raise Awareness of Hemochromatosis

Annual membership _____
($25, senior $15, family $40, professional $50 lifetime $500)
Books: *The Bronze Killer* $18* _____
Ironic Health* $20 _____
Hemochromatosis Video $19* _____
Lapel Pin —— @ $5 _____
Donation _____
TOTAL _____

* US dollars for US orders.
For international prices, contact office.
Charitable Tax #11921 9160 RR 0001

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

Name _____

Address _____

_____

_____ Postal Code _____

Email _____ Tel _____

❑ I am a new member
❑ Please acknowledge my support in the newsletter.
❑ Please release my name to my local contact person.

Send me ___ brochures and __ posters for Awareness Week.

❑ Payment enclosed ❑ Please charge my VISA

Card # _____ Expiry Date _____

Cardholder signature: _____

Please return to:
Canadian Hemochromatosis Society
#272 - 7000 Minoru Boulevard
Richmond, BC Canada V6Y 3Z5

THANK YOU!

March 2003