Iron Filings

The Newsletter of the Canadian Hemochromatosis Society Fall, 2004

Elizabeth Minish, CHS President

Inside

Member in the Spotlight: Elizabeth Minish

New CHS President got involved after father's diagnosis

In 1981 during treatment for skin cancer on his nose, Mervyn Minish's doctors discovered that his liver enzymes where abnormal. Mervyn, then 59, had spent most of his life farming in Manitoba which explained the skin cancer, but the reason for the elevated liver enzymes was not so obvious. Knowing Mervyn was a tea-totaller, his doctor ordered a liver biopsy to confirm his suspicion that the underlying cause was hemochromatosis. Mervyn was lucky, because few doctors at the time had much experience with the disease.

As a girl, Elizabeth remembers how her father complained about arthritis in his hands, especially the knuckles on the index and middle fingers. He used to have her squeeze them to relieve the pain. She also remembers how sensitive his stomach was to spicy foods and how very little body hair he had. It was always a bit of a family joke that it was lucky that all seven of his chest hairs were strategically placed so they showed at the collar of his shirts. In retrospect, Mervyn had several symptoms consistent with hemochromatosis, including arthritic hips, which forced him from farming, but no one ever put these symptoms together with hemochromatosis. As Elizabeth says, getting cancer probably saved his life. The discovery of his hemochromatosis and subsequent phlebotomy treatments added years to his life and he is alive today because of this timely diagnosis.

Elizabeth was living in Calgary when, shortly after her father's diagnosis, she saw a small ad in the newspaper placed by the Canadian Hemochromatosis Society based out of Victoria, BC. They were looking for members. A name like "hemochromatosis" really stands out once you've been made aware of it and she sent the clip to her father who became a member. By the time she moved to Vancouver in 1984, so had the CHS and, thankful for the help her father had received, she contacted Marie Warder to get involved. She wanted to help ensure that other families might experience the same good fortune brought about by early diagnosis that hers had. She became an expert in envelope-stuffing for newsletters and donor letters, and after an article in the Readers' Digest in

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Hemochromatosis

heem-ah-chrom-ah-TOE-sis

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

From the Editor

The theme of this Fall newsletter was supposed to be "Thanksgiving," or more correctly about giving thanks — to our donors in our new once-a-year separate page format, for advances in knowledge that have changed lives, and to our members who share their stories with us, some tragic, some hopeful. But as the newsletter took shape and I reflected on this past year, what struck me more than anything was the amount of change the Society has undergone.

The Society has been in existence for 22 years and much has happened in all those years. Back then, the CHS was one of the first organizations of its kind in the world to deal with hemochromatosis. Now, there is an International Association of Hemochromatosis Societies made up of societies from countries all over the world. Another of the early pioneers was the Hemochromatosis Foundation, Inc., founded by Dr. Margrit Krikker. We are saddened to hear of her recent passing.

Newsletters which were once labouriously typed on typewriters and mailed are now produced on desk-top computers and posted on websites. The internet has completely changed the way we get our information and raised our expectations for the speed it comes to us and the amount we feel we need.

We take the opportunity on the back page to invite your comments on our newsletter. Let us know what you like and dislike. What you'd like to see more (or less) of.

Hemochromatosis was confirmed as a genetic disorder in the 1960s. By the 1980s, HLA testing was available, and in 1996 scientists isolated the gene they thought was the cause of most hereditary hemochromatosis. This year, Xenon Pharmaceuticals (formerly Xenon Genetics) has been awarded a grant to fund research on a drug to address iron absorption using a target gene as the groundwork.

Unfortunately, some things haven't changed enough since we started our work, reminding us that we can never become complacent about our important mission. Missed diagnosies are still leading to suffering and untimely death creating very real and personal tragedies for families all over the country.

For that reason, we continue to do the work of the Society, and change it to take advantage of new opportunities. And, we continue to ask for your support to make it all happen. Thank you.

I hope you enjoy our newsletter.

~ Elizabeth Minish, editor

Volunteer Contacts

We need contacts in outlying areas. We have no contacts in PE, NT, or NU, so please call us if you can help.

MEETINGS

Ottawa Support Group

Nov. 10, Dec. 9, Jan.12, 2005, Feb. 10, Mar. 10, Riverside Hospital Boardroom, 1967 Riverside Dr., Ottawa. Parking is $4.50. Call Marjorie 613-739-9277 or Elaine, 613-521-5897

Toronto Support Group

Meetings are held at K. Easun's home in downtown Toronto. Call 416-598-5248 for more information.

Richmond Support Group

The Richmond Support Group requires a new leader. Please contact our offices..

Newsletter produced by Chris Petty

New Tests and Treatments On the Way

Xenon Pharmaceuticals Inc. has been awarded $4.7 million in funding from Genome Canada and Genome British Columbia to develop improved screening, diagnostic tests and therapeutic treatments for common iron metabolism disorders like hemochromatosis. Matching funds for the three-year project will be provided by Xenon.

The primary goal of this project is to deliver innovative clinical approaches that will transform the way physicians treat disorders of iron metabolism, including both iron deficiency and overload.

The Canadian Hemochromatosis Society wrote a letter in support of Xenon's grant application early in 2004. Dr. Michael Hayden, chief scientific officer with Xenon, was a medical advisor to CHS in the 1980s, and is a world-renowned expert in genetic illness.

Iron Filings

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

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.

Newsboards Answer Hemochromatosis Questions

Wouldn't it be great to be able to sit down with other hemochromatosis sufferers or their family members and talk about things among knowledgeable, helpful friends?

Not only is it possible, it's happening: people are doing it every day on the news board on the CHS website.

When you visit our website (www.cdnhemochromatosis.ca), simply click on "Newsboard" in the left hand frame, and you'll see a page that looks something like the one at right.

Click on any of the headlines and you'll see a message with links below it to go to comments on the message or new messages that further the discussion. Topics range from joint damage and liver problems to medical services in Australia, things to tell your doctor and nutritional concerns. Of course, you should consult your physician on all aspects of your health, remembering that the participants on the newsboard are not professionals. But the conversations are lively, the chat informative and the tone friendly. No wonder people get hooked on the internet! Here is a sample thread:

Transferrin saturation

Posted by Kathy on 9/23/2004, 7:30 pm

I just received my latest blood results. It is the first time the transferrin saturation has been tested for a long time. As the phlebotomies are not going well - I have some questions to ask those of you who know more than I.

My ferritin was 291 (the first time it has been under 300) with the TS at 88%. Are these levels I should be concerned about? I am a postmenopausal female in my 50s.

Thanks for any information you can offer.

Re: Transferrin saturation

Posted by Bill on 9/24/2004, in reply to "Transferrin saturation"

Kathy - - Every case is unique of course. That said. if I were you, yes, I would be a bit concerned. Both of your two key HH indictors are near or above the upper end of normal. Normal TS is about 15-60%. As I understand it, transferrin is the protein that more or less scavenges excess iron. Once its capacity to do so is exhausted (100% saturation) the iron has to go somewhere where it could do damage (liver, heart, etc). At 88% saturation your ability to scavenge excess iron is approaching its limit.

At 291 your ferritin is not at the level usually associated with organ damage, but the upper end of normal is 300 so you are nearing the upper limit.

A lot would depend on the trend and the rate of change. But just given what you say in your post, I would keep a very close eye on things and probably look for a way to get your iron stores down a bit.

I'm not a health care professional. What does your doc say?

Re: Transferrin saturation

Posted by Kathy on 9/24/2004, in reply to "Re: Transferrin saturation"

It has been really interesting. My Dr. is trusting my info and research as he doesn't appear to know that much.

The hemotologist said that she wouldn't worry unless my ferritin goes above 400...and the endocronologist just watches and contacts the hemotologist every so often.

My Dr. is considering an A-V Fistula so that they can easily access the blodd for phlebotomies. I am currently trying to find out everything I can before I go to see the surgeon in November. I want to make an informed decision. (I have the public health nurse doing some research for me.)

This is all a quandry for me....

Re: Transferrin saturation

Posted by Bill on 9/28/2004, in reply to "Re: Transferrin saturation"

Kathy - - I have no experience whatsoever with A-V fistulae, so I can be of no help whatsoever in that vein, so to speak. Over the years I have spoken with fellow patients, more often than not women, who have great difficulty with phlebotomies. Generally they say their doctors attributes this to either thick blood, which is prone to clot in the needle, or to small or "wobby" veins that are difficult for the needle to penetrate.

Have all your phlebotomies been attempted in your arm opposite your elbow? I do recall one instance when after two unsuccessful attempts in each arm, the phlebotomists used the vein in my hand. It was a real gusher and delivered a pint of the best in record time. I inquired why they don't use the hand routinely since it was easier to see the target and gave such good results. She replied that the hand was not used rouinely because the hand had more nerves and was therefore more pain sensitive. Also, cosmetically, people didn't like the black and blue on their hand. All of which is to suggest you might ask the phlebotomist to try a hand stick. It might be worth a try.

Our Readers Speak Out

Mail Bag

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.

This message is excerpted from a presentation made during Awareness Week. Ed.

In December 2001 I lost my husband, Doug, to hemochromatosis.

It really started in the late spring of 2000. Over a 15-year period we developed a successful construction business. He was a carpenter and very much a hands-on builder. He designed and built many custom homes and commercial buildings, while I was the real estate broker and keeper of the books.

We were at the point of enjoying long winter holidays before the onslaught of busy spring starts. When I look back, that winter he did seem a little more tired than usual but he worked so hard during building season that I thought he just needed a rest.

As spring ran into summer, he seemed more and more worn out at the end of the day, but insisted it was just the workload. In August, on a family vacation to Nova Scotia, Doug did all the driving and once again he was very tired but put it down to overwork. He had also begun to lose weight. He was always a very big man at 6'2" and around 250 lbs.

I had been pushing him to go to the doctor without any success but when we returned from the east coast I made an appointment for him and insisted he come with me. In early September he went to see the doctor. After about 5 minutes he was back out. The doctor had checked his blood sugar level and told him he was diabetic. So with prescription in hand, we left feeling that once we got his blood sugar level down, all would be well.

For the next month nothing changed. The doctor increased his prescription every week, but the pills were doing no good. In early October, the doctor decided that the oral medicine was insufficient and Doug started needle insulin. This again started with a low dose and was gradually increased over the next month with no results.

By now he was becoming a little disoriented and saying some rather odd things. He was always a very fast worker and now jobs were taking much longer to complete and seemed to be an effort for him. His hands were beginning to cramp and show real signs of arthritis. His skin was bronze, but as he worked outdoors he always had a tan so it wasn't a cause for concern.

One morning in early November he got up and was totally incoherent, hallucinating, saying and seeing strange things. I took him to the hospital. He was there for a week, most of the time totally unaware of where he was or why. It seemed to me they were treating him like an alcoholic with the D.T.'s as I was asked several times how much he drank. Even though Doug had always enjoyed a drink socially, he was by no means an alcoholic. In fact for several months he hadn't felt like drinking at all. I know they didn't believe me and at that time I insisted he see a specialist – a gastroenterologist, who ran some tests.

> "He was put in the hallway with an IV to monitor his fluids. There was no output and by 6 p.m. he had a massive breakdown and was gone by early evening. He was 47."

Two weeks later, he had an appointment with the specialist to get the results, but somewhere between the hospital and the doctor's office his file was lost. They were now very concerned with his liver, but this was the first time anything other than diabetes had been discussed.

The first part of December was very busy with the birth of our grandson and the company Christmas party. By this time he was down to 210 lbs but he was still able to enjoy himself. During the next week he started to retain fluid and saw his own doctor and the specialist. He was prescribed diuretics but by December 10th he was feeling terrible and could hardly walk for the swelling and he asked me to take him to the hospital around noon. Peterborough's hospital, like so many others now, was overcrowded. He was put in the hallway with an IV to monitor his fluids. There was no output and by 6 p.m. he had a massive breakdown and was gone by early evening. He was 47.

The next day, the doctor who had cared for him in the hospital at the end (who coincidentally was Irish) called me and suggested that I ask for an autopsy as he felt Doug's death could have been caused from an hereditary disease. The assumption had been cirrhosis of the liver caused by alcohol but the autopsy confirmed hemochromatosis.

We all assumed that Doug's parents had died from heart disease, both in their fifties. Now we realize there was another hidden disease there. If anything at all good has come from this, the family is now aware of the gene and will be tested.

I don't feel that Doug got the medical care he should have. I asked that doctor if it would have made a difference if Doug had been diagnosed when he started to feel ill in the spring. He said he would have needed to know about it 20 years before to stop what had happened to his organs. Hopefully this story will help to bring awareness for the need to lobby to have iron levels included in routine the blood work done with annual checkups to catch this hidden killer before it's too late.

M.W., Peterborough

We know you enjoy the **Letters** section. You can also share your stories and questions via our website. Many people are finding this "cyber support group" a big help. Check out the forum at: **www.cdnhemochromatosis.ca** and click on the News Board link.

Please send your letters to:

Canadian Hemochromatosis Society
Richmond Caring Place
#272 - 7000 Minoru Boulevard
Richmond, BC Canada V6Y 3Z5
or email:
office@cdnhemochromatosis.ca

Why I am a Life Donor

Today I still bear the scars on both my ankles from the incisions that were made on the day that I was born.

In 1946 some babies that died at birth were called "blue babies." Those practising medicine at that time had come to consider cases where one parent had the Rh factor and the other not as the reason. This was true with my parents. The pattern of successful births and failures also matched. My

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Iron in the Diet: Hemochromatosis and the Food You Love to Eat

Every year we receive a number of questions from readers about dietary recommendations.

Human nutrition is complicated and "rules" often seem contradictory, especially for people who tend to load iron. For instance, red skinned grapes and soy beans are high in iron, but contain phytic acid, which inhibits iron absorption. Other foods are high in iron but also contain antioxidants, which are good for iron loaders. Red wine is high in phytic acid and antioxidants, but alcohol tends to enhance iron absorption and should be avoided in any case when liver function may be compromised. As in all things, moderation is the key.

We publish a list of general nutrition and dietary guidelines on our website. But, depending on your particular situation, these guidelines may be more or less applicable.

Confused? We'll try to shed some light on the issue.

Anyone with iron loading issues should avoid iron in supplemental form, including the iron added to many multivitamins. This iron is more easily absorbed than that found naturally in food and can be dangerous. Iron loaders should also avoid foods that are highly fortified with iron such as breakfast cereals, fortified breads and pastas. Check the package for ferrous sulphate.

Avoiding iron in most natural foods is impossible, and not really necessary. Even if you could cut out all foods containing iron, you would also be eliminating essential nutrients from your diet, probably causing more harm than good.

Dietary iron is divided into heme iron from animal sources and non-heme iron from vegetable and fruit sources. Heme iron is more readily absorbed and is present in higher quantities in red meat (this includes venison and most other wild game), which is why we recommend limiting red meat consumption.

High-iron vegetables such as spinach and broccoli are on the recommended list because the iron is bound up by other nutrients and is not easily absorbed. This is true, generally, of all high-iron fruits and vegetables.

Hemochromatosis sufferers who are actively de-ironing — that is, undergoing frequent phlebotomies — don't need to restrict their iron intake from unfortified foods. One phlebotomy removes 250 milligrams of iron from the body, while a normal day's intake of food results in only 2 to 3 milligrams of iron absorbed.

Once maintenance phlebotomies begin, however, restricting dietary iron is a good idea since it may increase the length of time between phlebotomies.

Those with a genetic predisposition to load iron, but who currently have normal or only slightly elevated iron levels could donate blood regularly to avoid dietary restrictions. But if you don't qualify as a donor for some other reason, then you should take particular care to avoid dietary iron as much as possible.

Each of us, regardless of our condition, should pay attention to the food we put in our bodies. Hemochromatosis sufferers need to avoid highly refined foods not just because they tend to be fortified, but because they tend to be unhealthy.

Visit our website and click on "Nutrition Guidelines" in the blue box on the Home Page. For additional information, check out the National Institute of Nutrition website at www.nin.ca

Enjoy your newsletter!

When you have finished with it, please pass it on. Our newsletter is also available online at 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. And please speak clearly.

The Great Sushi Debate

A controversy erupted recently in Ontario about sushi. No, not about which restaurant had the best or the freshest, but whether raw fish should be served at all. There's even talk of a total ban on serving raw fish in Ontario.

Hemochromatosis sufferers, or anyone with an iron loading problem, should avoid raw fish or raw shellfish, and not just because they are high in iron (which they are).

More important is the fact that raw fish and shellfish are susceptible to contamination from the bacteria that causes paralytic shellfish poisoning. This bacteria is toxic to everyone, but it is especially toxic to iron loaders because it thrives particularly well in an iron-rich environment — like the blood of an iron loader. Paralytic shellfish poisoning is potentially fatal to iron overloaded persons.

This doesn't mean hemochromatosis sufferers should avoid Japanese restaurants. Many menu items contain no aquatic protein whatsoever, and most are fully cooked. And delicious, we might add.

Iron loaders should also take extra care when handling fish and shellfish (wear gloves), and avoid walking barefoot on the beach. It's just as romantic wearing sandals.

Cliff Abraham, 1957-2004

Sheldon Clifford Abraham died in Toronto on July 2, 2004. He succumbed to cancer which was precipitated by hemochromatosis.

Cliff was the President of Northern Transportation Company Ltd. which ships goods across Canada's Arctic. Cliff, his two brothers and one sister, were grandchildren of Gordon Leitch of Toronto who died in 1954 as a result of hemochromatosis.

He and his siblings had been urged by their parents to have a hemochromatosis test, but three of them did not follow through. Cliff requested the test in early 2000, and although his medical records indicate his doctor's intention to request the test there is no indication that it was performed.

In March of this year, when Cliff was in Calgary on business, he experienced severe swelling in his legs. He went to an emergency ward where he was examined and told "not to worry" because the swelling was probably due to the warm temperature in the meeting room and also due to the fact that Cliff had been sitting there for several hours. He was told to keep his feet elevated as much as possible and it would go away. Cliff continued to experience swelling and increasing weakness, so just before Easter his family physician in Hay River, NWT requested a liver function test which determined that his liver was extremely cirrhotic.

At this point, Cliff mentioned that his grandfather had died of hemochromatosis. As Cliff was to be in Calgary on business the week after Easter, his doctor arranged for him to go to the Peter Lougheed Centre to have the hemochromatosis test performed. In the days following, Cliff's health deteriorated markedly with several days of constant diarrhea. His family physician arranged for Cliff to be seen by a liver specialist in Yellowknife and when he arrived there on April 14th he was admitted immediately and underwent several tests. He was told that he had inoperable cancer of the liver and that possible surrounding organs and several lymph nodes were also cancerous.

Cliff was flown to Toronto on April 19th where the diagnosis was verified. A biopsy of his liver indicated cancer and toxic iron overload. By this time, the test results of the hemochromatosis test performed in Calgary (a week prior) were still not available.

After several follow-up phone calls made by Cliff and his physician from Hay River to the Lougheed Centre, it was discovered that the wrong test had been administered and the diagnosis of hemochromatosis had never been officially confirmed. Subsequently, Cliff's brothers and sister as well as his children have been tested for hemochromatosis. His sister and one brother are negative, but one brother who lives near Boston did test positive and is currently in the process of treatment and further tests. Cliff's son has been tested and, fortunately, does not have hemochromatosis but is a carrier. His daughter is presently in the process of being tested. During the weeks of his illness, Cliff's wife and family used the internet to do some research on hemochromatosis and learned that it is much more widespread than they had originally thought. It was their desire, as well as Cliff's, that as many people as possible should be made aware of hemochromatosis and of its prevalence and deadly potential. One way to do this was to ask for donations to the Canadian Hemochromatosis Society. Cliff had many friends and business associates across Canada and in the United States and over 500 people attended his funeral. So many of these people have kindly responded to the appeal for donations and many more are now aware of what hemochromatosis is and what it can do.

In Memoriam

In Memory of Sheldon Clifford Abraham
Wendy Lodge, Robert Falby, Mary Jane Tuthill, Dr. Edward Turner, Very Rev. S. Duncan Abraham, Mary Kurdydyk, Natalie Kurdydyk, Joan Jones, Barbara Smith, Weldco-Beales Mfg. Alberta Ltd., Algoma Central Corporation, SMT Services, Norterra Inc., St. Paul's L'Amoreaux Centre, Groupe Desgagnes

In Memory of Shirley Barnes
Kathy & Dennis Morris

In Memory of Milton Jowsey
John D. Kanerva; Gary E. Johnson; Elizabeth Holmes

In Memory of Peter Charles Stanley Cook
J.W. Cook, Kamloops Naval Veterans Assoc.

In Memory of Lawson Kaake
Lorraine Kaake

In Memory of Mary McNab
Ian Martin

In Memory of Reggie Morais
Pat and Lee Rogers

In Memory of Margaret Parise
Jean M. Parise

In Memory of Fred Settle
Debbie Settle

Dr. Margit Krikker

With regret and deep respect we announce that Dr. Margit Krikker, founder of The Hemochromatosis Foundation of Albany, New York, has died.

No formal organized hemochromatosis groups existed until the late 1970s, and few people had actually been diagnosed. Mayo Clinic had only 13 confirmed cases of hemochromatosis by the mid-1960s. The condition was thought to be rare — an older male's disease.

Early on, through the efforts of individuals like Marie Warder, Dr. Margit Krikker and Roberta Crawford, people with hemochromatosis had a source of information. We owe these pioneers, and others like them, our gratitude.

Dr. Krikker was a tireless advocate for those with hemochromatosis and championed efforts to cut the amount of excess iron in our diet. She dedicated herself to hemochromatosis research and education after her husband was diagnosed with the disease.

Elizabeth Minish: Member in the Spotlight

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1987, helped handle some 8,000 letters from concerned readers.

Over the years she became involved in other aspects of the society, serving on the board in various positions. In 1994, after Egene Boyko spearheaded the move to the Caring Place, Marie Warder was forced to step down as president due to ill health just as the CHS moved into the new facility. Charm Cottingham took over as president, and Elizabeth became vice president in 1996.

As vice president she attended conferences and various government meetings, all the while helping to promote the society and aid its members. She was also narrator of the CHS video *Hemochromatosis, The Story*, produced by Nancy Cottingham-Powell, Charm's daughter. The video was sent out to more than 500 libraries across the country when it was first produced in 1999, and is still in demand.

In 2003, Elizabeth chaired a strategic planning committee that recommended, among other things, that the Society hire an executive director to guide the society's work, and to increase fundraising. In January, 2004, Agnes Papke was hired as executive director. After serving as president of the Society for nearly 10 years, Charm stepped down and Elizabeth was acclaimed as president at the AGM in April of this year.

Elizabeth's goals as president are to maintain the work of the Society. To do this, she feels we must focus on increasing financial support for the society to insure our continued survival.

"It's also important that we keep evaluating our performance and learn from the experience of other hemochromatosis societies around the world, many of which we helped establish" she says. "We have accomplished a lot in the last 22 years, and I want to maintain our momentum".

In 1998, when genetic testing became generally available, Elizabeth discovered that she was a compound heterozygote and had elevated transferrin saturation making her involvement with the Society even more personal. She gives blood regularly through the Canadian Blood Service to reduce the increased risk of infections that this can cause.

Elizabeth, who is self-employed as an interior design consultant, has another passion: singing. She is a member of the Sweet Adelines International "Lions Gate Chorus," and "Velocity" quartet. Lions Gate placed 11th in the world last year in Phoenix. "Velocity," as the top quartet in western Canada, will compete in Indianapolis this fall against 50 other quartets from around the world.

Please contact Elizabeth through the CHS offices.

Mail Bag

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brother was born in 1941 with no problems and then there were two other children who did not make it. So the doctors arranged for me to begin my life with a blood transfusion. Shortly after birth my blood was drained and I was given new blood compatible with my mother's blood type. So I may owe my life to a blood transfusion.

As soon as I was old enough, over forty years ago, I started to donate.

I haven't always been able to donate as I moved from one community to another but when I could I did and I continue to give blood regularly.

Later in life my father was diagnosed with hemochromatosis. My father died unexpectedly young and spent his last years with a number of chronic ailments associated with hemochromatosis. Furthermore, my brother was identified as a carrier. Therapy mainly calls for blood donations or regular blood-withdrawals (phlebotomies), another motivation for me to donate regularly. But the main reason why I donate is the obligation I feel to help others whatever their condition, age or situation that warrants blood transfusions.

RW, Gatineau, PQ

Progess . . .

In 1992, CHS convinced the Red Cross to accept blood from otherwise healthy HHC patients. Now, a just-published MA thesis in Public Policy makes the case for Canadian Blood Services to waive the 56-day wait for those HHC patients undergoing the de-ironing phase of their treatment.

"Why CBS should solicit blood from Canadians with hemochromatosis" was prepared by Charles Randall at UVic, with the support of CHS.

CHS Development

Maggie's Message

by Maggie Campbell

To all of you who donated during our successful spring mail out, thank you! Your gift is appreciated and used to help people with hemochromatosis. Keep your eyes peeled for the upcoming holiday mail out!

I recently had a phlebotomy at Canadian Blood Services. I want to remind those of you who can donate every 56 days to please do so at CBS. It helps save the lives of others and it is a great way to spread the word about hemochromatosis. For more information about CBS go to their website (you can follow the link from our site) or call 1-888-2-DONATE.

If you have any questions or comments about how the CHS raises money for its work or to discuss donation possibilities, please contact us, we are happy to help you.

Donate Your HBC Reward Points

Zellers, The Bay, and Home Outfitters now issue HBC Rewards points. Help us by donating your points to the Society. Use our card #850 639 047. Be sure to tell the rewards centre that you want to keep your own card active when donating points, or they will cancel it.

Good Donations

You can 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 with confidence.

Matching Gifts

Does your employer have a matching gift program? If so, please indicate the company name on your donation. If you aren't certain, just send us your employer's name and we can follow up. Many firms will match some portion of their employee's charitable donations.

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.

Reader Response

Help us make this the best newsletter possible. Just answer a few questions and send your response in to our offices, attention Newsletter Editor.

How much of the following would you like to see in ***Iron Filings***?

	More	Same	Less
Member profiles	❑	❑	❑
New Research	❑	❑	❑
Basic HH Information (symptoms, treatment options)	❑	❑	❑
Nutrition Tips	❑	❑	❑
Basic Health Info.	❑	❑	❑
FAQs	❑	❑	❑
Mail Bag	❑	❑	❑
Expanded Obituaries	❑	❑	❑
Fundraising Info.	❑	❑	❑
Web site links	❑	❑	❑
Genetics	❑	❑	❑

	Yes	No
Do you read ***Iron Filings***?	❑	❑
Do you use the CHS website?	❑	❑
Do you read ***Iron Filings*** online?	❑	❑
Have you ever donated to CHS?	❑	❑

Comments (or use separate sheet) _____

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Contact us!

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Fax 604-279-7138
E-mail office@cdnhemochromatosis.ca
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#272 - 7000 Minoru Boulevard
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THANK YOU!

October, 2004