25th ANNIVERSARY 1982 ~ 2007
Canadian HEMOCHROMATOSIS SOCIETY

Fall, 2007

Iron Filings

Member in the Spotlight

Regional Coordinator Charms the Media

Pryna Koberstein of Lacombe, Alberta is one of the many dedicated CHS' Regional Coordinators. This year, she has been a media mogul in her province, attracting much attention for hemochromatosis during our May Awareness Month campaign. Here, we highlight her story.

Picture a group of ten people. Did you know that, on average, one of those people will be a carrier of the gene that causes hemochromatosis? Now imagine a gathering of 300 people. On average, one of those people will develop hemochromatosis, though they will likely never know it. If left untreated, hemochromatosis can cause diabetes, cirrhosis and liver cancer, and congestive heart failure. Symptoms of hemochromatosis can be chronic fatigue, joint pain and arthritis, mood swings, bronzing of the skin and an irregular heartbeat. Treatment is effective and simple and, if started early enough, can prevent both the symptoms and the life threatening diseases associated with hemochromatosis.

I live in Lacombe, Alberta. I am a Regional Coordinator for the Canadian Hemochromatosis Society. Why did I volunteer to take on that job? Hemochromatosis has had a big impact on my family. If my husband, Ed, and I had only known earlier, we could have avoided the life threatening and life altering damage that my husband has suffered as a result of undiagnosed hemochromatosis. He suffered considerable damage from arthritis to his hands and joints prior to being diagnosed at age 40. He has since had both hips replaced and in November of 2006 had one hip re-done.

Pryna Koberstein and husband **Ed**, in Lacombe, Alberta

To develop hemochromatosis, a person has to inherit two hemochromatosis gene copies, one from each parent. When my husband was diagnosed more than 20 years ago, we were naturally concerned for our young children. Because at that time the condition was considered very rare (one in thousands), and because nobody on my side of the family seemed to have symptoms of hemochromatosis, we assumed that our children would not be at risk. They would be carriers only, inheriting one gene copy from my husband. In 2001, our daughter, now married and contemplating starting a family, decided to pursue the matter and had genetic testing done. It was a shock to find out that she was at risk of developing hemochromatosis because she had inherited two gene copies. As a result of her genetic diagnosis, our adult son was tested and found also to have inherited two gene copies. Though he did not show any symptoms of hemochromatosis, his iron levels indicated that he was already in need of treatment (phlebotomies). Because our children had two gene copies, it meant

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INSIDE

The Newsletter of the Canadian Hemochromatosis Society

From the President

Advancing Our Message: Next Steps for CHS

Elizabeth Minish, President CHS

Twenty five years goes by fast when you're trying to get a big job done and our big job isn't simple. We want to make hemochromatosis a household word, as well known as, say, "cholesterol," so that its ravages will become a thing of the past. Our method isn't simple, either. We need to raise the awareness of hemochromatosis in the medical community and the general public through direct contact, word-of-mouth, advertising and any other way that gets the message out.

Most worthwhile endeavors take time and money, and our society has spent a lot of the former and not much of the latter to accomplish many worthwhile things. We have made a vital difference in the lives of many hemochromatosis sufferers and we have saved lives. You can read about some of the victories we have celebrated just this year in our first expanded Awareness Month in both the Member in the Spotlight article and in the stories from across the country in the Members Corner feature. Even our feature article on treatment was an outgrowth of the Q&A at the end of our first-ever information night held in Vancouver in mid-May.

> "To go where we have never gone before we must do what we have never done before."

But after 25 years, I am struck by how far we still have to go before we reach our goal. It occurs to me that time alone is not going to get us there. What will it take to move us to a place where we can shut the doors of the Canadian Hemocrhomatosis Society and say, "Mission Accomplished"?

In a word, money and quite a lot of it. In mid September, our board members held a strategic planning session to analyze our current situation and to set a course for the future. We realized that the CHS has done about as much as it can with the present level of funding and staffing, and that we need to raise serious money to conduct the kind of information campaign that we have only dreamed of in the past: national advertising; professional print and electronic vehicles; and a focused, strategic communications plan.

To paraphrase a motivational quote I recently read: "To go where we have never gone before we must do what we have never done before."

We were inspired by some new faces around the table in the persons of our two newest board members from southern Ontario (See side bar) and by our new Executive Director, Bob Rogers. A bio of Bob appears in this newsletter.

I would also like to take this opportunity to thank Agnes Papke, our very first Executive Director, for three and a half wonderful years. She left CHS in May of this year to take an opportunity with the Delta Hospital Foundation. She applied a calm and expert hand in helping us get our organizational house in order, and made it possible for us to take the steps we are now taking to achieve our goals. We wish her every success for the future.

As we contemplate the next exciting phase in the life of our society, we would once again like to take the opportunity to thank all of our members and donors without whom we could never have come this far. We hope you will continue to support us in our vital work and that we may even inspire you to find new ways to use your personal networks to help us reach our goal of making hemochromatosis a household word well before we celebrate another 25 years.

Iron Filings

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Member of the International Association of Hemochromatosis Societies
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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.

New Executive Director Brings Heart and Experience to the Job

Bob Rogers was born in Toronto in 1951 into a single parent family with three brothers and one sister. The family had its share of troubles, and Bob learned that poverty too often led to sadness and despair. But the economic and social adversity he experienced as a child moved him, years later, to seek employment in areas that advocated and ministered to others.

Bob's family moved to Vancouver for a few years during his early teens, and though they moved back to Toronto, he fell in love with the westcoast lifestyle and determined, one day, to move back.

After college in Ontario, he used his outgoing personality and gift for the gab to work in various sales positions from vacuum cleaners to automobiles, and as a placement consultant for an employment agency. This early work provided him with a basic understanding of marketing, commerce and networking, and throughout this period he kept an eye open for opportunities that would allow him live out his personal mission.

In 1978, he was hired by Wood Green Community Centre, an inner-city agency in Toronto, as a program supervisor in its Elderly Person's department. This experience led him, in 1982, to take a position as Administrator and COO with a mission of the Presbyterian Church that provided affordable, social housing to senior citizens. He met Brenda at this time, and they married in 1990. They honeymooned in British Columbia. Later on, he and Brenda adopted her late sister's son Justin, who has recently married and lives in Ontario.

In 1993, Bob took a position as manager with the Salvation Army's first housing project in Toronto. In 1998, he was promoted to Regional Director for Ontario, and in 2000, for all their projects in Canada.

The events of September 11, 2001 destabilized the operations of many organizations, including the Salvation Army. Donations declined and the charity laid off hundreds of employees nationwide. In 2003, Bob's position was eliminated and he and Brenda seized the opportunity to relocate to Vancouver. Here, he landed a one-year contract with the Harvest Project in North Vancouver, an agency that serves people caught in poverty and at risk of homelessness. Bob built a strong financial base for the project, and was nominated as Business Person of the Year in 2006 in the North Vancouver Chamber of Commerce Business Excellence Awards competition.

Bob Rogers, Executive Director, CHS

Now, Bob brings his extensive experience and sense of social responsibility to the Canadian Hemochromatosis Society. We are extremely happy to welcome him to the fold, and look forward to working with him to build awareness of hemochromatosis through information and education and increase the financial sustainability and access of the organization throughout Canada.

Two Canadian Blood Services employees make off with their free hot dogs and pamphlets about hemochromatosis on May 29th during Hemochromatosis Awareness month at the Oak St. donor clinic. CHS volunteer **Pam Sinclair** (weilding the tongs in the background) answered all their questions.

E. Minish photo.

Treating Hemochromatosis

Phlebotomies, De-Ironing and the Secrets of Canadian Blood Services

During this year's National Hemochromatosis Awareness Month in May, the CHS hosted an information night in Vancouver with a panel of health experts. Many of the questions from the audience during the session involved treatment for hemochromatosis, so for this issue of Iron Filings, *we have asked two of the panel experts – Dr. Siegfried Erb and Dr. Gerry Growe – to answer more questions related to phlebotomies and donating at the Canadian Blood Services.*

Q: After a diagnosis of hemochromatosis is made, how often should I have phlebotomies?
A: Usually you start with one a week. One phlebotomy is the equivalent of extracting 500ml of blood which contains approximately 225mg of iron. If after eight phlebotomies (eight weeks), the hemoglobin is still normal, it's best to go to twice a week. The evidence indicates that individuals who are de-ironed sooner have a better long-term outcome.

Q: What blood tests do you monitor in the de-ironing phase?
A: There are many protocols. Many physicians monitor the ferritin every few months to predict when it will be under 50 ng/ml. I simply do a hemoglobin on the drawn blood. When hemoglobin is less than 11g/dL for a man and 10g/dL for a woman, I stop the phlebotomies. I also stop when the patient develops significant fatigue. The fatigue is not caused by the anemia (lack of red blood cells), but rather by the iron deficiency, as iron is needed to run many other biochemical reactions in the body. Then I repeat all the iron tests and usually wait for three months to allow the hemoglobin to get back to normal, and then resume phlebotomies again.

Dr. Siegfried Erb fields a question at the information session during National Hemochromatosis Month in May.

Q: What else can I do to speed up the de-ironing phase or decrease iron absorption?
A: The only thing that you should do, at all times, is avoid multivitamins which contain iron. Multivitamins without minerals are OK, but those with minerals, may contain iron. Read the label carefully. Almost any grocery store carries multivitamins with minerals but without iron. Apart from that, don't take high doses of vitamin C, which increases iron absorption, but which has also been shown independently to be bad for you. As well, don't drink more than four alcoholic drinks per week. Red wine is OK, however, as the tannins bind the iron preventing it from being absorbed.

Q: Are there things I can do to make the phlebotomies more tolerable?
A: The first phlebotomy is the worst. After that it's usually OK. It's very unusual to have any problems with the subsequent ones. Unfortunately, pain and bruising can occur, and some patients find that smaller gauge needles can help, or try rotating your phlebotomy site. Some patients complain of fatigue after phlebotomies so it's recommended to rest and not do vigorous exercise for the first day after a phlebotomy. If your ferritin was less than 1,000ng/ml at the start, ask your doctor if you can decrease the frequencies of the phlebotomies. Also the Center for Disease Control in the US recommends lots of fluids be taken before and after a phlebotomy. Water, milk, and fruit juice can help increase blood flow and therefore may shorten the amount of time a phlebotomy takes.

Q: During the de-ironing phase, why can't I just go to the Canadian Blood Services (CBS) and donate every week?
A: The CBS has to follow the regulations of Health Canada in regards to who can and who can not donate. There are many reasons why hemochromatosis patients are unable to donate at CBS during the acute de-ironing phase. Firstly, all hemochromatosis patients should be checked for hepatitis A, B and C. If they have been exposed to hepatitis B or C, they cannot donate at the CBS. Secondly, their hemoglobin may be too low during the de-ironing phase to qualify for blood donation. Thirdly, CBS can only draw blood from healthy individuals every 56 days and during acute de-ironing of hemochromatosis patients, phlebotomies could be happening weekly.

Q: But if my phlebotomies are being performed at a hospital or clinic, then

all the collected blood just goes to waste then?
A: Yes, the blood collected at a hospital or clinic is wasted. Blood drawn at a hospital is not collected according to Health Canada guidelines and so therefore can not be used for transfusion via CBS.

How will I know when I'm past the deironing phase?
A: Most physicians will stop when the ferritin is less than 50ng/ml. At that point, you will get phlebotomies every three months either in a hospital/clinic setting or with CBS. As I check hemoglobin levels, I'll know when someone is iron deficient when his/her hemoglobin suddenly drops while on stable phlebotomies, or he/she becomes significantly fatigued. Then, I would check the iron levels to confirm iron deficiency, and wait three months to let the hemoglobin go back to normal. After that, I would recommend the patient have phlebotomies every three months which would then be called the maintenance phase of treatment.

Q: Where should my iron levels be during the maintenance phase?
A: This is a bit controversial. The provincial guidelines recommend that your ferritin be measured once a year and be kept under 50ng/ml. I'm not convinced that is the right answer. No one knows how long it takes to get the iron out of the heart. It's easy to get iron out of the liver. If you start with a ferritin of less than 1,000ng/ml, it suggests that your total body iron stores are not that high. You'll be OK no matter what you do. If your ferritin is much higher, you may have deposited much more in your other tissues. My rule is that for each one thousand ferritin, you should keep your levels really low for one year. If your ferritin is four thousand, keep your levels very low for four years. My targets are transferrin saturation (TS) levels less than 40 per cent and ferritin levels less than 15ng/ml. Remember, TS always goes up before ferritin. Check your TS and ferritin every six months for the period as mentioned above, then check them once a year thereafter. When you are stable, you should have a normal hemoglobin, TS less than 50 per cent, and ferritin less than 50ng/ml. It doesn't matter when you check your iron levels, but I suggest not doing it in the first month after a phlebotomy.

Q: Will I need phlebotomies all my life?
A: Yes. Some patients need only one a year; others need six per year. It depends on your age, gender and iron intake.

Q: Are there any serious side effects to phlebotomies?
A: If the hemoglobin drops too low, it's possible to get angina (which is chest pain because the heart is not getting enough blood). However, the lowered hemoglobin may actually be beneficial as it is less likely for the blood to clot. Depending on the patient's ferritin at the start, we would usually do ten phlebotomies and then reassess a patient with cardiovascular disease.

Dr. Gerry Growe makes a point during the session.

Q: During the maintenance phase when my iron levels are more stable, can I donate at the CBS then?
A: Yes, if the hemochromatosis patient meets all of the CBS requirements for routine blood donation. As mentioned above, this means donating every 56 days, and values for hemoglobin and blood pressure, for example, are within normal range.

Q: I called CBS and they said I couldn't donate but I was not sure why. My doctor tells me that I've never been exposed to hepatitis B or C. Why would they refuse me?
A: Hemochromatosis donors may be turned away either for related or unrelated conditions. For example, if they have diabetes which requires insulin, they are ineligible. If they require only diet or oral agent diabetic control, they are acceptable. As well, any person who has traveled to a malaria-risk area is disqualified for a year, and those on certain medications or who have heart disease would also be ineligible.

Q: Is there anything other than phlebotomies that would keep my irons low? I've heard of chelators. Would they help?
A: For types 1, 2 and 3 hemochromatosis, phlebotomy is the best therapy. Chelators have a specific role in patients who can't readily tolerate phlebotomies. These include patients with a primary bone marrow problem, those with thalassemia or hemolytic anemia, or anyone who requires recurrent transfusions. For more than thirty years we have been using a chelator called desferrioxamine each time we transfuse someone with Blackfan-Diamond syndrome. This is a congenital condition in which the body does not produce red blood cells. These patients therefore have a lifelong dependency on transfusions, and chelators. Chelators are unlikely to be of much benefit to most patients with hemochromatosis.

Dr. Siegfried Erb is a gastroenterologist at Vancouver General Hospital
Dr. Gerry Growe is a hematologist with Canadian Blood Services

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

Members' Corner

Highlighting the dedicated CHS Regional Coordinators and their efforts during Hemochromatosis Awareness Month

In this, the first edition of *Iron Filings* after our inaugural Awareness Month, it seems appropriate that we review some of our members' successes in getting the word out to those unwashed masses who have yet to be educated about hemochromatosis. Heck, let's be honest, we're thrilled whenever we find that people have even heard of the term hemochromatosis, let alone spell it correctly!

Awareness is really all about getting the right information into the hands of people who can use it to better their own health or the health of those close to them. May 2007 proved a watershed month in providing timely information across Canada.

On the Burin Peninsula of Newfoundland, **Linda Oldford** convinced the hospital administration to allow her to set up a display table in the front lobby and talk to people as they passed by. In her spare time, she placed posters in the shopping mall, and handed out plenty of brochures. Linda curiously awaits the level of local feedback she hopes to receive over the coming months in order to measure the success of her effort.

In Moncton, NB, a team led by **Therese Dupuis** organized a public conference involving **Dr. Bader El Safadi**, a local gastroenterologist. The event was publicized through local radio announcements, media interviews, and an information table at the hospital the week prior. Although the event was well-attended, what surprised organizers the most were the numerous questions which led Dr. Safadi to commit to working towards changing the protocols in New Brunswick. Therese passed along the BC protocol guidelines for Dr. Safadi to use as a starting point.

Awareness is really all about getting the right information into the hands of people who can use it to better their own health or the health of those close to them.

Kay Easun set up a booth at the Sherway Gardens Mall in Toronto and talked to 170 people in just two days. **Mark Garner** did the same at the Kitchener/Waterloo, Ontario Farmers Market where about 5,000 people come to shop each day. In what turned out to be an amazing domino effect, Mark also did an interview on Rogers Cable TV following an article published in the Kitchener/Waterloo Record, which was itself based on a previous article written about **Ed Koberstein** in the Red Deer Advocate. Ed's wife, **Pyrna Koberstein** initiated the Alberta newspaper articles and is highlighted in the this *Iron Filings* "Member in the Spotlight" story. Mark also successfully formed a corporate partnership with a local furnishing store and presented a "Lunch and Learn" seminar to approximately 100 staff.

In Swift Current, Saskatchewan, **Diane Nelson** wrote a letter to the local newspaper editor. Radio Public Service Announcements were heard in Halifax and Port Hawkesbury NS, on CHAM in Hamilton ON, and on CKNW and CKWX in Vancouver. **Bev** and **David Creighton** continued their good work in the Parksville area on Vancouver Island, with their annual booth at the Wellness Fair, and **Dalila Bekkaoui**, from the CHS office based in Richmond, BC, approached a number of high schools in the Vancouver area.

It's a big country, so no doubt there were other events we have not mentioned here. Many, many thanks to all who participated this year; for the first time, we really had a national presence. We can all take a deep breath and be proud of what we have accomplished before we start preparing for...next year!

– Ross Gilley, Vice President, CHS

Ross Gilley, far right, CHS National Vice President, hosted awareness events at the Canadian Blood Services clinic in Kelowna. **Donal** and **Sylvianne Morgan,** centre and left, volunteered to help get the word out.

Pryna Koberstein: Member in the Spotlight

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that I must, at minimum, be a carrier of the hemochromatosis gene. Genetic testing confirmed that I was a carrier only.

After my husband's diagnosis and during the period when he was going through the process of blood letting to get his iron levels down, we were made aware of the Canadian Hemochromatosis Society. We joined, and somewhere along the line indicated that we would be willing to be active members. Two years ago, I agreed to be one of the Regional Volunteer Coordinators for the Society. Under the guidance of Ross Gilley, Elizabeth Minish and the Society office staff, the Regional Coordinators have worked to promote hemochromatosis awareness across Canada during the month of May.

This year, I decided to target the local and regional newspapers. I went to the local newspaper office armed with a brief information paper about my husband, hemochromatosis and the Society. I was able to meet personally with the editor who was quite captivated by our story and immediately agreed to do an article. She not only wrote a story that appeared in the April 16, 2007 issue of the *Lacombe Globe*, but she wrote an editorial about the need for increased awareness about the disease as well.

Flushed with success, I contacted the editor in charge of community interest stories for a regional newspaper. This editor was also very receptive and invited us to come to his office in Red Deer for an interview. This resulted in a story in the *Red Deer Express* and the *Red Deer Advocate*. The story was also picked up in eastern Canada by an on-line news service.

I was able to meet personally with the editor who was quite captivated by our story and immediately agreed to do an article.

As a result of this publicity, Ed and I have received many phone calls for information. People we meet still comment on the stories and the shocking fact that there is so little awareness about hemochromatosis.

We are very thankful to those newspaper editors for the excellent stories they published creating more awareness about hemochromatosis in our area. I am also very grateful to the Canadian Hemochromatosis Society, its board members, and the office staff for the encouragement they give to the Regional Volunteer Coordinators and for the hours of hard work they put in promoting hemochromatosis awareness. It is an uphill battle but we are making progress!

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.

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 Donor 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, just 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, otherwise 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.

Thanks to the panel members who participated in our information night during Awareness Month. The session was televised across the province.

Left to right: Dr. Gerry Growe, hemotologist, Canadian Blood Services; Dr. Brett Casey, director molecular genetics lab, Children's Hospital; Dr. Siegfried Erb, internal medicine, VGH; Dr. Chris Whittington, family physician; Dr. Paul Goldberg, geneticist, Xenon Pharmaceuticals; Dr. David Koehn, genetic counsellor, Children's Hospital; Elizabeth Minish, moderator, president CHS.

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** _____

Hemochromatosis Video $21 _____

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Bill my credit card monthly for a donation of: _____

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❑ I am a new member ❑ Renewal

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❑ 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!

Fall, 2007