

Iron Filings

The Newsletter of the Canadian Hemochromatosis Society

Autumn, 2002



The Disorder

Hemochromatosis is the most common genetic disorder afflicting Canadians. It is a crippling, potentially fatal condition caused by iron overload in the blood and tissues. 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.

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Member of the International Association
of Hemochromatosis Societies

www.cdnhemochromatosis.ca

Member in the Spotlight: Howard Cordick

Athlete, volunteer, father

I was born in Cumberland on Vancouver Island in 1944. Shortly after my birth, my mother died and my father packed up my two sisters, my brother and me and headed to Vancouver. My father remarried and we were blessed with three sisters.

As a young man I worked as a cook and baker, then I tried construction and bartending until my eyesight failed. Then I went into the family upholstery business.

I was born with Axenfield Syndrome, which caused glaucoma in both eyes. While I was still a young man the doctor told me I also had an underactive thyroid and a ruptured esophagus. In 1981 I was declared legally blind. Then I developed arthritis in the top three vertebrae of my neck and in my wrists and hands. To this day, the arthritis in my neck causes me pain every waking moment. In 1998 my doctor asked me to have a stress test. It showed that I had heart damage, which was produced from a heart attack suffered in 1992, and angina. Prior to this I had been diagnosed with enlarged prostate.

In 2000 I still complained of fatigue, light-headedness, dizziness, frequent urination and weight loss of more than 30 pounds in a short time. I had a series of X-rays, ultrasounds and blood tests which showed I had Hepatitis C, but because some symptoms still did not seem to point to my other health problems, they did more tests. That is when I was diagnosed with hemochromatosis. My ferritin count was 2100 and I started phlebotomies twice a week for 6 weeks, then once a week for 6 weeks, bringing my ferritin down to 100.

By the time I was down to phlebs once a month I was told I was now a good candidate for the latest treatment for Hepatitis C. I went on my first 6 month treatment this past winter and it was successful. I am now free of the virus in my blood and I am



Howard Cordick at the HCC office.

continuing treatment for six months to get it out of my liver and other organs. I haven't been able to have phlebotomies during this time, so I'm looking forward to starting again so I can get my iron levels down to 20.

I took up lawn bowling in 1993 and I am now the Canadian Gold Medalist in World Blind Bowls. Since 1995 I have represented Canada in World Blind Bowls in England and Scotland, as well as at the Paralympics in Atlanta. I was Richmond's Disabled Athlete of the Year in 2001. I volunteer as a counselor at the Richmond Crisis Centre and have started speaking to young children in the grade schools about suicide prevention.

I also volunteer for the Canadian Hemochromatosis Society. I started working in the office, and they helped me start a support group for people in the Vancouver area. We hope to do great things to increase awareness about hemochromatosis. Our first meeting was very successful with about 30

Continued page 2

We Need Your Help

In our last newsletter we asked for your immediate financial help. Sadly, we had to release our Education and Development Co-ordinator, Marguie Nordman as a cost saving measure. We have yet to assess the impact that this has had on our society. Candace and Natasha have taken on more responsibilities so we have continued to keep our office running smoothly. However, we know that liaising with other organizations has suffered plus we have been unable to do extra fundraising.

In spite of our plea, donations and memberships have not increased. If we don't get some large donations soon we may well have to close our doors and the services that so many of you have come to rely on will no longer be available.

Many thanks to those of you who have renewed your memberships and given us a donation, but we continue to need your assistance. Please look at contacting your local service clubs and ask to speak to them. You can show them our video and tell them your story. We would remind you that you can also make us your designated charity through your office or United Way. Many fundraising suggestions have been given to us, such as selling roses, T-shirts, bumper stickers, fridge magnets. Please let us know

Howard Cordick

Continued from page 1

people and during the summer we had a barbeque at Dr. Erb's home. He has become very interested in helping our Society and has offered to sit on our board of directors. At the AGM meeting last spring I was elected to the board. Together with Dr. Erb and others, I hope to be able to raise money and bring more awareness to our Society. My own family doctor, Scott Garrison is now giving HHC blood tests to all his patients. If we can get all the doctors in Canada to do this we will be well on our way.

Oh, I almost forgot the most important bit of news. At the age of 57 years, my wife Julia (35 years) and I are expecting our first child in November. She will be a girl and we will name her Shailyn. So not everyone affected with hemochromatosis becomes impotent.

what you think of any of these ideas.

Arie Boom, the Dutchman, sailed August 31st on his trip around the world to publicize Hemochromatosis. His full story is elsewhere in this newsletter.

In June there was a meeting held at the Kelowna Health Centre. Those present were from Kelowna, Vernon, Vancouver, Winfield, Westbank, Tappen, Okanagan Falls and Anglemont. Charlie Smedley, our contact in that area, organized and ran the meeting. All present felt that they had benefited from the exchange of information.

The Ottawa and Richmond support groups will be meeting regularly this fall. The Richmond group held a barbeque in July.

Thank you all for your response to our mailouts regarding the medical history forms and Dr. Adams survey. We will print the results in future newsletters.

Dr. Chris Whittington in Abbotsford has written a book about her experiences in a phlebotomy clinic in Australia. She spoke at our AGM in May about how hemochromatosis has affected her family, so she is very enthusiastic about helping our society in any way she can. Marie Warder also spoke at our AGM and told us about the past 20 years of the society.

So I leave you with the double challenge of helping to spread our awareness message and helping us to increase our revenue.

Charm Cottingham, President

Computer Needed!

Anyone willing to donate a new computer to CHS would be a Godsend. Our current one is on its last legs and our tech man says it is costing us more to fix it than to buy a new one.

We Are Just So Close!!

We would also like to let our members know that we are only 235,521 Zeller Points away from being able to purchase a new computer station for the office! Please Donate your Zellers, Bay, and Home Out Fitters Points to the Hemochromatosis Society; card # 850 639 047.

Iron Filings

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.

New Volunteer Contacts

Linda Oldford, NF – April 2002
Brenda Devine, BC – April 2002
Betsy Cowan, YK – May 2002
Katherine Koper, ON – May 2002

Volunteers help us in their communities by distributing materials, contacting media, answering phone queries, etc. We need contacts in outlying areas. At present, 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

September 12 and October 10, 7-9 pm
Boardroom,
Ottawa Hospital, Riverside Campus
Call Marjorie 613-739-9277 or Elaine 613-521-5897
Everyone is welcome!

Richmond Support Group

October 5, 1-3 pm
Caring Place, Richmond
Call Howard 604-277-5905 or
chsrich@vcn.bc.ca
Come spend a couple of hours with your friends and have a coffee and a chat with someone who's been there.
Please phone the office at 604-279-7135 for future dates.

The Role of Your Liver in Nutrition

The food you eat is broken down in your stomach and intestine. The nutrients from the food pass through your intestine where they are absorbed in the bloodstream and transported to the liver.

Here they are either stored or broken down further, ready for your body to use, depending on your needs at the time. When someone has a liver problem these processes continue but may not be carried out as well as in a healthy person.

Food is made up of three main sources of energy or calories: carbohydrate, fat and protein. Carbohydrate and fat are the main sources of energy and protein is used by the body for growth and repair.

Carbohydrate in our diet comes from starch and sugar and is found in food such as bread, potatoes, fruit and sweets. Carbohydrate is broken down in the liver to glucose. Any glucose not used immediately for energy is stored as glycogen in the liver

and some in the muscles.

The liver converts glycogen back into glucose when the body needs extra energy. The liver also helps to control the level of glucose in the blood and prevents it from rising and falling too far.

Fat in our diet comes from butter, cheese, cooking oil, animal fat and from many invisible sources such as crackers, pastry, chips and cakes.

Fat cannot be digested without bile, which is made in the liver and stored in the gall bladder. Bile is released when needed into the small intestine and acts as detergent, breaking fat into tiny droplets so it can be absorbed into the body. Fat can be used as a long-term energy store.

Protein in our diet comes from food such as meat, fish, cheese, eggs and nuts. Protein is made up of units called amino acids and once they reach the liver they provide building blocks to make cells and tissues.

Cirrhosis

People with cirrhosis need more protein and energy and should eat a diet that provides 60 to 80 gms of protein and 2000 to 3000 calories a day. The damaged liver may be unable to store glycogen, the carbohydrate that provides short-term energy. Eating every 2 to 3 hours may help.

Although many people with cirrhosis do not need to follow a special diet, changing your diet may be necessary if complications, such as fluid retention or mental slowness or confusion develop.

Hyperglycemia

Some people with cirrhosis have hyperglycemia, or high blood sugar levels, and may be advised to follow a diabetic diet which involves eating a well balanced diet but avoiding foods high in sugar. People with hyperglycemia have different needs and will need individual advice from a dietician.

Enjoy what you eat

It is important to enjoy what you eat and to discuss any problems you may have with your doctor or dietician.

Adapted from a British Liver Trust booklet.

Thanks to Our Donors

Special thanks for our large donations from West Coast Energy and The Christopher Foundation.

Cathy Allen
Hugh Andrews
Mireille Aubry
Shirley Baines
Violet Ball
Effie Bates
BC Hydro Employee Fund
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Patrick Wright
James Wright
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Joyce Zintel

I Want to be a Blood Donor!!

Two years ago I did something I'd never done before. I donated blood. It took me forty-five years to get to it because until then I did not meet the minimum weight requirement of 110 lbs. As it turns out, there are a number of reasons why a person might not be able to donate blood, but having hemochromatosis (HHC) is not one of them.

In the past, Canadian Blood Services (CBS) and the Red Cross before them were on record as accepting blood donations from otherwise healthy people with HHC, however, the policy was not uniformly applied and many people were turned away. Since last year when CHS and

CBS teamed up to do an awareness campaign about the advantages of donating blood through CBS, it has become much easier for people with HHC to donate their blood and we have received a number of queries about how to go about it.

Using CBS for phlebotomies is not an option for everyone. Currently, they can only take your blood every 56 days and not if you are older than 71 (65 for a first-time donor). Also, if you have other health issues, related

to HHC or otherwise, you may not be eligible to donate. (To find out if you are eligible, one of the easiest ways to check is through the CBS website which has a link from ours if you have access to the Internet or by telephone at 1-888-2 DONATE if you don't.)

If you do meet the criteria, you may find this a welcome alternative to going to a

Myth

"People with HHC have more iron in their blood than regular people so when they donate blood it's like high octane fuel."

Fact

"Blood can only carry a finite amount of iron. When it can't carry any more, it stores the surplus, hence the amount of iron in a pint of blood is roughly the same for everyone."

hospital for at least some of your regular phlebotomies. (Check with your doctor to confirm how appropriate iron level testing will be carried out.) CBS clinic hours are often more convenient because they offer some evening hours and it is not only possible but encouraged that

you book an appointment to keep waiting time to a minimum. To further enhance the experience, the whole facility is geared to the specific procedure of blood donation complete with extremely comfortable chairs, well trained staff, and of course, cookies and orange juice served afterwards. The real bonus is that instead of being thrown out, your blood gets used to help save another life!

Elizabeth Minish, Vice-President, 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; Iron Disorders Institute Guide to Hemochromatosis.

Welcome to Our New Members

Betty Aldred, Uxbridge ON
Monique Allen, Calgary AB
Hugh Andrews, Alford Lincolnshire England
Lavina Batryn, Mission BC
Jack Beeching, Comox BC
Sheila Bell, Montreal QC
Kathryn Berditch, West Vancouver BC
Betty Brant, McKellar ON
Jean Brown, Cobble Hill BC
Margaret Campbell, Vancouver BC
Janet Campbell, Vancouver BC
Matti Cathcart, Anmore BC
Susan Cumberland, Willowdale ON
Helmut David, Qualicum Beach BC
Ann Donald, Halifax NS
Shirley Douglas, Mitchell ON
Jeannine Ducharme, Montreal QC
Lorna Esouloff, Grand Forks BC
Catherine Ewing, Vancouver ON
Venu Fitzgerald, Salt Spring Island BC
Brian Gallery, West Bolton QC
Michael Garvey, Parksville BC
Dorothy Gates, Calgary AB
Ross Gilley, Kelowna BC
Paul Godin, Petit Rocher NB
Debbie Goodwin, McCord SK
Martin Graham, Scotsburn NS
Ian Grant, Surrey BC
Gary Grant, Bay Roberts, NF
Norah Johnson, Vancouver BC
Gordon Kent, Halifax NS
Jack Kergan, Fort Langley BC
B.R. Kergan, Moose Jaw SK
Joyce Knapp, Brantford ON
Katherine Koper, Pickle Lake ON
David Leetham, Oakville ON
Lawrence Lessing, Agassiz BC
Hazel Marr, Courtenay BC
Carol McArthur, London ON
Kerry McDevitt, Vancouver BC
Karen McGoldrick, Cobble Hill BC
Joseph McNeil, Vancouver BC
Betty McPherson, Nanaimo BC
Daniel McWilliams, Lakefield ON
Dr Darrell Morin, Lloydminster AB
Marguie Norman, Vancouver BC
Dianne Pukanski, Edmonton AB
Elizabeth Ratz, Calgary AB
Ruth Seeber, Dunnville ON
Irene Shore, Victoria BC
Henry Tukendorf, Cobourg ON
Elaine Van Veenendaal, Surrey BC
Raymond Webb, Victoria BC
David Wells, St. John's NF
Holly Wondell, Calgary AB
Elsie Young, Woodbridge ON

We would like to announce that we now have professional memberships for \$50 and lifetime memberships for \$500.

Special thanks to Dr William Saywell, Dr Siegfried Erb, Marlene Stasyk, and Tom Cigolotti for becoming lifetime members.

Letters

A few years ago my husband was diagnosed with hemochromatosis in screening, because his brother had been diagnosed. Both have had a congenital form of cardiomyopathy called IHSS. This is apparently unproven in linkage to hemochromatosis, though I cannot understand why 2 brothers would have both. At the time I emailed your organization and was so impressed with the immediate response and assistance. Your newsletter has been informative. Sadly, despite rigorous management of both conditions, my husband died, at 50 years old, last year while undergoing heart surgery. Thank you for the work you do and please accept my donation in memory of my husband.

D. S., Ottawa, ON

Thanks for the website. My mother died from complications of HHC two years ago, after years of no diagnosis. My 18 year old daughter has HHC as do several of my mother's siblings and my eldest sister's son. It is incredible to realize the widespread affect of HHC and the apparent lack of knowledge and concern on the part of the medical establishment. Keep up the good work

G. C., Anmore, BC

One good thing that came out of my appointment was that the consultant asked me to lecture one of his medical students on hemochromatosis, as apparently I now know more about it than anybody in the hospital. That is to a large extent thanks to your website. So once again thank you.

H. A., Alford, Lincolnshire, England

Thank you for your prompt response to my inquiry. We have found the info very helpful. We have been able to change the phlebotomy protocols as a result. They are now using #20 Teflon catheters for the procedure instead of #15 steel needles. Apparently the patients find the procedure much more comfortable and it is certainly easier on their veins.

S. B., St. Joseph's Hospital, Comox, BC

Up until March 8, 2002 I had been taking Vioxx for my osteoarthritis. My phlebs had brought me from a ferritin over 2800 to

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.

1643 and I decided to find out how much relief I was getting from the Vioxx. Instead of the pain going up, it dropped considerably. The constant ache and pain is still there with spikes but, for the most part, reduced.

N. J., Elmvale, ON

I have had 92 phlebotomies from September/95 to May/00. Since May 15 my body apparently has commenced metabolizing ferritin. I have not required phlebotomies for almost 2 years. Serum ferritin levels have remained at 10-11 (started at 1540). In August of 2000, I had a femoral-popliteal bypass as the femoral artery had become constricted. This entailed (I believe) 2 pints of blood transfusion. In April 2000, due to graft scarring, the original graft was bypassed with more transfusions. I am currently on Coumadin. I have a ferritin blood test every 6 months and am keeping my fingers crossed, particularly as both copies of HLA-H are mutated.

R. D., Calgary, AB

I was investigated for low platelets, when the DNA confirmed HHC. I received phlebotomies once a week from June 2000 to May 2001 to bring my ferritin level from 2000 to 151. Just finished reading "The Bronze Killer" and noticed similarities to my condition in many case histories. When I retired as a lab technologist (talk about ironic irony) I did a few lab tests on myself. Liver enzymes slightly elevated probably meant I should limit alcohol consumption, although I didn't think I drank excessively. Other observations: My vibrant thick hair is thinning and dull. My head feels "empty" and a few years ago I went to a throat specialist because of black/brown spots under my tongue & back roof of mouth.

D. H., Windsor, NS

In August of 1998 my father-in-law (after many trips to the doctors) was diagnosed with hemochromatosis. His ferritin level was 2170 at the time. The past 5 years he'd aged 20 yrs. His siblings then were sent for testing. His brother too had 2170 ferritin level at the time of his testing. He had had an emergency appendectomy 10 yrs earlier.

Because of a blood test both he and his wife were questioned at length about the amount of alcohol he drank. Had the doctors at that time decided to investigate other reasons why his blood would be like that, maybe Vern would be alive today, my father-in-law wouldn't have gotten so sick before being diagnosed. Both of them would have had 10 yrs. less damage to their organs.

R.D. Weyburn SK

In the spring of 1999, my husband Garry had a ferritin test and it came back at 1248. He was referred to a doctor in Moose Jaw to start all the steps his dad & uncle went through. I took him off the Vitamin C pills and cut down on beef as well. I found out a way to get genetic testing done and on July 27/00 approximately 8 vials of blood were sent to Winnipeg. I have 2 normal chromosomes and Garry has one of each of the chromosomes that cause hemochromatosis-H63D and C282Y. We can now relax though; knowing none of our 4 children will get it.

B. S., Eyebrow SK

Thanks again for providing me with the volunteer info kit. It was bitter sweet to see the Video. Looking at Jack Cottingham reminded me of my own dear father who passed away from this disorder. Tears were running down my face remembering how Dad looked and what he suffered. At the same time if it weren't for my father and his diagnosis in 1975, the rest of our family would be looking at the same devastating implications and early death. The Cottingham story brought it all back and it made me realize the importance of early detection to prevent others from going through this pain. So far the 100 Mile area has been very receptive and to date 2 medical clinics, hospital, pharmacy, library and many stores have accepted the CHS info and posters. Radio and newspaper will run the PSA and article during Awareness Week. I am pleased with all the positive attitude.

B.D., 00 Mile House BC

Letters continued page 8

Please send your letters to:

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

Endocrine Damage and Hemochromatosis

Endocrine System

The system consists of a network of ductless gland and other structures. The endocrine or hormonal system is composed of eight major glands that secrete chemical substances called hormones. These are transported to all parts of the body in the extra cellular fluid to help regulate function.

The endocrine system includes the hypophysis (pituitary), thyroid, parathyroid, suprarenal, pancreatic islets in the pancreas, ovaries, testes, pineal body and placenta (during pregnancy).

Endocrine organs potentially affected by hemochromatosis

| Organ | Disease |
|--------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------|
| Pancreas | Diabetes |
| Pituitary Gland | Gonadal Failure (Testes/Ovary) <i>Loss of libidolimpotence</i> <i>Infertility</i> <i>Loss of periods (Amenorrhoea)</i> Osteoporosis Anemia |
| Gonads (Testes/Ovary) | As above, but rare for iron to have a direct effect |
| Thyroid Gland | Hyperthyroid (overactive) Hypothyroid (under active) |
| Bones | Osteoporosis |

Prevalence:

Hypogonadism invariably affects the younger person with loss of libido, or menstruation in women can cease, and men can become impotent.

Sexual dysfunction (hypogonadism) is the most common endocrine dysfunction in men with hemochromatosis. Occurs in 10-40% of cases, and is often an early symptom.

Sexual impotency in hypogonadic men can be restored with i.m. testosterone replacement. Androgens are usually efficient but should be avoided in liver damage.

In women menstruation and successful pregnancy can be obtained with gonadotrophic and hormonal therapy.

Hypogonadotropic Hypogonadism (Males)

This is due to iron deposition in gonadotroph cells in the pituitary. This can lead to a reduction in testosterone and sperm production in the testes leading to loss of libido, partial/complete impotence or loss of ejaculate. This problem usually does not respond to treatment, but phlebotomies can restore pituitary and gonadal function in those patients with endocrine abnormalities of recent onset. Phlebotomy therapy can produce results, and testosterone replacement may be of benefit.

Thyroid Disease in Hemochromatosis

Hypothyroidism more common than hyperthyroidism. Males are more susceptible.

For under active thyroid medication is required (thyroxine).

Bone Disease in Hemochromatosis

Osteopenia (bone thinning) and osteoporosis both occur. This condition can be associated with:

- Hypogonadism
- Chronic liver disease/cirrhosis-inflammation-low Vitamin D
- Iron damage to parathyroid gland
- Direct toxic effect of iron on the bone

Improvement with phlebotomies, calcium replacement, and testosterone for men.

Relevant tests for hormonal problems

- Testosterone
- Growth hormone IGF-1
- Free T4
- Thyroid stimulating hormones
- Prolactin (fertility hormone)
- ACTH (Adrenal Studies)
- Cortisol (synacten stimulation test)

Depression and mood swings

There is no actual evidence or scientific work done on the dysfunction of the pituitary gland. It can be assumed that excess iron is accumulated in this area of the brain if there are hormonal imbalances.

With this type of dysfunction in the pituitary gland, the disturbance to the secretions in hormones then can interfere with behavior in general, produce mood swings, question sexuality and stunt growth.

Presented by Dr. Mike McCullen, Senior Fellow, Princess Alexandra Hospital, Brisbane Australia

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My hemochromatosis was found by sheer accident. I went to see a specialist who was filling in for one who was on holiday. I told him my hair was falling out a fair bit. He thought I was anaemic, so he ordered some blood tests. I never heard back from him. Last October I had to go back for another prescription. When my doctor saw my chart and realized I had high ferritin she sent me for another blood test, which had the same result. She sent the blood work on and it finally ended up at Children's Hospital for DNA testing. It came back positive for hemochromatosis. My ferritin level was 1,553 then. I have been receiving weekly phlebotomies ever since and my ferritin is now 158.

After sending the papers back home to my brothers and sister, my youngest brother has tested positive for HHC. He is fortunate not to have any symptoms yet. He has started phlebotomies and I have a very good feeling that he is going to be all right.

My rheumatologist has taken this condition very seriously. She has read all about HHC from the doctor's package I asked you to send her. She has been testing the ferritin levels from many of her patients who she suspects might have hemochromatosis.

P. D. Coquitlam BC

Memorial Remembrance of Loved Ones

In Memory of Marion Arthur

Keith & Marlene Bradley; Irene Hancock; Gordon & Lorraine Wright; Patricia MacLeod; Michael Roche; Lois Lamourie; Ross Bradley; Marilyn Sullivan; Donna Keenan; Marion & Ron Taylor; Caw Local 4266; Joyce White; Mr. & Mrs. Herb Banning; Mr. & Mrs. Alvin Arthur; Cindy & George Bradley; Roland Chabot; Jean Bradley; Shoppers Drug Mart; Pearl Arthur; Dennis & Doralen Amesbury

In Memory of Gerald Brennan

John Burke; Dorothy & Donald Adams; Wayne & Leora Gratton; William & Ann Graham; Ian McKellar; Myrna Darling; Elizabeth Giroux & Glen Seymour; Patrick & Carolyn Morris; Dr. Krystyna Wojakowski & Dr. Bruce Murray; Jack Arnold; Michael & Sandra Henderson; Murray & Chris McClure; Allan & Evelyn Hayman; Dr. Robert Houston; Raymond & Lillian Lupasko; Michael & Catherine Quinlan; Clarence & Elizabeth Brennan; Patrick & Muriel O'Neill; Alf & Astrida Udris; Barbara & Allan Glover; Steven & Susan Luciani; Pauline Rowland; The Partners of Ernst & Young

In Memory of Ronald Charbonneau

Berlex Canada Inc.

In Memory of Jack Crellin

Don & Mary Pifer; Margaret & Harry Erickson; Sheila Dutka; Beverly Hlady; Melva Isley; Barbara Langla; Shirley Anne Mexter; Majorie Henry; Doug & Bev Whittle; Joan & Earl Fenner; Margaret Upton; Cathy Hollingsworth & Family; Zion Lutheran Church; R. Halldorson; Ruth Crellin; Gordon & Lorraine Smith; Gail Mullock & Family

In Memory of Carl Doyle

Cheryl McNaughton

In Memory of Edward & Darcy Drab

Beatrice Drab

In Memory of Ernest Gilmore

Donna Stroud

In Memory of John Kemp

Nettie Kemp

In Memory of Helen Kirkwood

C.U.P.E. Local 2280

Our deepest condolences to the families and friends who have lost loved ones and our thanks to the many listed below who have sent memorial gifts.

In Memory of T. Gordon McGrath

Jane McGrath

In Memory of David McIntyre

Avva Light Corp.; Edith & Charlie Sutherland; Janice Main; Allan Denis; Burnaby Emergency Dept Nurses; Carolyn Williams; Leah Rishaug; Merle Taylor; Linda Youell

In Memory of Mary Frances McKnight

Gladys Stuart

In Memory of Keith Meadows

Yolande Mara

In Memory of Bill Moss

Donna Stroud

In Memory of Hellen Nowak

Diagnostic Imaging

In Memory of Lester Pomeroy

Muriel Menzies

In Memory of Art Preston

Lesile Coummings

In Memory of Hillel Schwartz

Corinne & Jerry Frank; Renee Peal & Daniel Sigler; Stanley & Isabel Rubel; Gerry Rosen; Daisy & Jack Hendelman; Phyllis Goodman; Loretta Shefner; Sheila & Marvyn Kussner; Barbara Hendelman; Ariela Braun; Felice & Simon Strauss

In Memory of Ralph Sandberg

Muriel Menzies

In Memory of Jim Walker

The Doug Johnson Family; Lillian & Lloyd Grover; Parlee McLaws; Jane Colcy; Marion & Ed Lorentz; Debbie & Kieran Doetzel; Ann Ridgedale; Ella & John Kisser; Dells & Willy Raessler; Lois Ballinger; Clara Sorensen; Hardy Galster; Palsy Sorensen; Mary Sorensen; Agnes & Audy Sorensen; Arthur & Dorothy Wasdal; Debra & Vernon Brockman; Margaret Groat; Richard Rempel

Hemochromatosis in the News

Toronto Globe & Mail

"Gene test too expensive, US labs say"
Feb 7, 2002

Toronto Star

"Science friction, greed versus public good"
Feb 16, 2002

Ottawa Citizen

"Iron Overload"
Feb 19, 2002

The Expositor, Brantford ON

"Genetic Rust featuring Joyce Knapp"
May 7, 2002

The Hinton Parklander

"Hemochromatosis awareness week,
May 25-31"
June 3, 2002

The Parksville Star, BC

"High iron levels are harmful" featuring
Bev Creighton and her husband
June 5, 2002

The BC Medical Journal of March 2002 published two articles:

*Prevalence of iron overload in the Lower
Mainland of British Columbia*
by Dr Sam Krikler.

The study of 1905 male volunteers
found a lower prevalence than expected
for a typical North American
population.

*Screening for hemochromatosis: Should
we do the last test first?*

by Dr Paul Adams.

Population screening for HHC before
symptoms develop has begun in research
studies around the world, including BC.
Screening is controversial because of the
uncertainties surrounding the natural
history of untreated disease, the cost of
screening programs, and the potential
hazards of widespread genetic testing.

Contact us!

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E-mail office@cdnhemochromatosis.ca

Toll Free 1-877-BAD-IRON

www.cdnhemochromatosis.ca

Around the World for Hemochromatosis

In our last newsletter we wrote about Arie Boom (40 years old) who suffers from hemochromatosis. Diagnosed incurably ill he has decided to take one last sailing voyage to bring awareness to hemochromatosis. This incredible man left on August 31, 2002 from Harlingen, the Netherlands, to go around the world by himself in a 32 foot sailing vessel.

The trip will take two years and he will sail with the seasons. In order to avoid hurricane seasons in the tropics, he went to the Dutch Meteorology Institute and planned the whole journey with maps of the weather over the last 150 years.

His first stop will be Brest in the north of France, then Vigo in the north of Spain, the Canary Islands, Caribe, Panama Canal, Galapagos Islands, French Polynesia, Fiji, East Australia, by plane New Zealand, Northern Australia, South Africa, St. Helena, Caribbean, and maybe if he has enough time left, Florida, or the Azores and back to

Harlingen again.

For those who are interested in this exciting trip, you will be able to follow it on Arie's website www.ironoverload.nl. He can send email and phone home by satellite.

Arie's wife, Marjon, will be taking care of the website during his absence. "I intend to write a lot but am not sure yet about how often. Time will tell, he says."

You can email him at info@ironoverload.nl during his trip. When going onto the website click on "kart" and you will find a map with his route around the world. He tells us that everyone is working very hard to get everything changed on the English and French website. Therese Dupuis (one of our members) from New Brunswick is busy translating the site into French.

Arie says, "Since the 22nd of August we are officially a foundation. Stichting Ironoverload



Arie's voyage will take him to the Galapagos Islands, where these blue-footed boobies wait patiently.

= Iron Overload Foundation! Bank account number stays the same! We do still need money."

Arie asks that we invite people and, of course, companies to donate and to show their support in anyway possible.

"Thank you for including an article about me and my trip," he says. "I truly hope there will be (a little) more awareness about hemochromatosis when I return."

Support CHS and Raise Awareness of Hemochromatosis

Annual membership _____
(\$25, senior \$15, family \$40,
professional \$50 lifetime \$500)
Book: *The Bronze Killer* \$18* _____
Hemochromatosis Video \$19* _____
Lapel Pin ___ @ \$5 _____
TOTAL _____

* US dollar for US orders
For international prices, contact office.
Official Revenue Canada tax receipts are issued
for all memberships and donations.

I have HHC A blood relative has/had HHC

Name _____

Address _____

_____ Postal Code _____

Email _____ Tel _____

- I am a new member
- Please acknowledged 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!

Oct. 2002