

# Iron Filings



Ross Gilley, President

FROM THE BOARD

## President's Message

Welcome to the new Iron Filings, where you will find the latest on happenings within the world of Hemochromatosis. Bob Rogers gives you his take on the current fundraising and membership drives, we issue a challenge for new fundraising ideas, and we walk down memory lane with a look at awareness from years past.

**Did you know that every single Canadian likely knows someone with undiagnosed Hemochromatosis?**

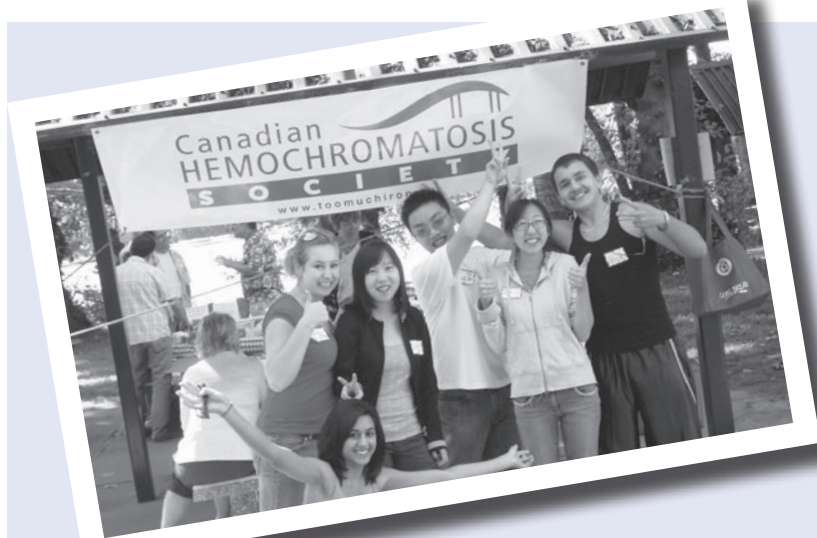
We absolutely need to help these unsuspecting victims and their families live longer lives free of pain and suffering. Why not pass this issue of Iron Filings on to friends and neighbours after you have finished with it? You never know whose life you will help save!

This issue of Iron Filings is a little lighter and brighter than previous newsletters. In today's high-tech environment, we know that Canadians get their information from many different sources. Iron Filings is just one part of our greater conversation with our members and supporters that integrates the newsletter with our website, our personal support tools, and our upcoming E-Newsletter, The Magnet.

It has never been more true that when it comes to Hemochromatosis, **Awareness Is The Cure**. Thank you for partnering with us on this most important journey of awareness.

Ross Gilley was elected President of the Canadian Hemochromatosis Society at the Annual General Meeting held on April 2, 2008.

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### VOLUNTEERS

## Student BBQ for Awareness

In September, a group of college and high school students organized a BBQ to raise awareness about Hemochromatosis in the Vancouver-Burnaby area. It was well attended by members and volunteers alike. BBQ's are a fun and easy way to promote awareness for our cause. Top marks to these students for doing a great job.

Thank you.



Bob Rogers, Executive Director

FROM THE NATIONAL HEAD OFFICE

## Executive Director's Message

Our offices in Richmond, BC are across the street from a high school. The school has a large soccer pitch and frequently students are practicing or playing. Watching them recently I was reminded how team sports rely on everyone working together with one goal in mind. Without everyone joining in, working together and contributing, the game is lost for one of the teams.

The Canadian Hemochromatosis Society depends upon Canadians to join our organization as members and support our cause with their time, energy and finances. In 2007, more than 80 percent of our income was donated by our membership. So far, our 2008 income from individual contributors is down from last year and

short of our budget projection. If we are to inform 1000 new families about hemochromatosis this year and next, we need to increase our resources to get it done, to score the goal and win the game.

If you are not a member yet of our Society, would you please consider joining now. We are purposefully keeping our membership rates low to allow as many people as possible to join our cause of creating awareness about Hemochromatosis. If you are already a member, we truly need your support. To learn about several ways that you can help, please read our articles in this newsletter about the Host a Party challenge, Community Awareness events and our National Fundraising Campaign.

If you are not a member yet please consider joining the Canadian Hemochromatosis Society

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## An Awareness Activity in Calgary

ANNE STANG, REGIONAL COORDINATOR, CALGARY, AB

It's a good thing I've been active with my ethnic group, the Germans from Russia. They have frequently taken part in the Senior's Resource Fair in Calgary, so I knew what to expect and it was not completely daunting. Registration for the day was easy; once that was confirmed, I prepared a table top tri-fold just using the information from the poster. I also put "Canadian Hemochromatosis Society" in the largest letters that would fit across the top of the display board. (Thank God for computers and copy machines.) Taking that and a box of pamphlets and then setting up in the city hall atrium was easy too.

Business was fairly steady most of the day – 9:30 to 2:30. Sometimes I was bold and stepped out from the table to hand out brochures; sometimes I could easily start talking to passersby because they were trying to pronounce "Hemochromatosis". If people had

time, especially if they said something like "My cousin has it.", I would talk of the possible consequences for them. Non-Caucasians were assured it was rare in their group.

The day's most rewarding experience came from the woman who said "I'm so glad you're here. I was diagnosed this week." Further conversation revealed that her two sons were also affected. She also called a few days later to say thanks, and promised to join the society, and help with future activities in Calgary. She took some extra brochures as did a few others if they had affected relatives or friends.



Anne Stang helps a gentleman learn more about Hemochromatosis

Would I do this again? Definitely! If even a fraction of the people read the brochures and several people are moved to be tested, it will have made the day more than worthwhile.

# Thank You for your Donations

Allen, Cathy  
Ashton, Catherine  
Baines, Shirley  
Barker, Alice  
Barnett, E. Maggie  
Batho, Peter  
Belanger, Larry & Janet  
Belland, Denise  
Billich, Sam  
Blouin, Pierre  
Bradley, Keith & Marlene  
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Brown, Ivy B.  
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Brown, Leslie  
Buchanan, Rosemary P.  
Button, Ray  
Cameron, Keith  
Cameron, Vern  
Cerilli, Alma and Albert  
Christian, Pauline E.  
Church, Russell and Grace  
Cigolotti, Tom  
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Conway, Reginald B.  
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Croll, S. Catherine and Alex  
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Ensign-Langin, Geneva  
Evans, Donald  
Fate, Kenneth & Helen  
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Friesen, Sherry  
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Gallery, Brian  
Gardner, Roy  
Gelpke, Norman H.  
Gillespie, Neil  
Gilley, Ross  
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Harwood, Rick

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Korchinski, Gwen  
Kwinter, Shelley  
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Lapointe, Lorraine  
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Lenfesty, Rosanna  
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MacEwen, Shirley  
Mara, Yolande  
Marshall, Donald  
Martin, Kathleen  
Massong, Shirley  
McKay, Barbara  
McKean, Thomas Graham & Muriel  
McLean, Irene M.  
McLean, William and Linda  
McLelland, Elizabeth  
McMannis, Marie  
McNeil, Joseph  
Meadows, Kerri Lynette  
Milling, May E.  
Minish, Elizabeth  
Morin, Lillian  
Morris, Dennis & Kathy  
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Neary, Hilary  
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Charity Trust  
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Perkins, Linda A.  
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Phillips, Janice  
Pinsonneault, Johanne  
Potts, Gail Suzanne  
Prytulak, Stephen & Laura  
Pukanski, Dianne  
Reece, Fred

Rennie, William & Shirley  
Robertson, D.W. & V. Joyce  
Robidoux, Peter  
Rogerson, Tom  
Schon, J. Carol  
Semchyshyn, Tony & Eileen  
Serdula, Kenneth  
Simpson, Joyce  
Smith, Carol  
Smith, Gordon & Fay E.  
Sponagel, Christa & Karl  
Staples, Brian & Marjorie  
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Stevenson, June  
Stroud, Donna M.  
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Swain, Ken & Joan  
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Tsougrianis, Maria  
Tull, Glen  
Turk, David R.  
Valgardsson, Norman & Joanne  
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Van Zoelen, Gerrit  
Veilleux, Sheila Anne  
Villeneuve, Judy Ann  
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Walker, Elsie  
Walker, Ronald E.  
Waring, John  
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Wight, Douglas A.  
Williams, Donald L.  
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Worobey, Maureen  
Wozney, Lynne D.  
Wright, Bernadette  
Wright, Dale D.  
Wright, Michael  
Wright, Patrick J.  
Zeiler, Lorraine & Percy  
Zintel, Joyce

**By supporting  
the Canadian  
Hemochromatosis  
Society our donors  
save lives. It's as  
simple as that.**

Their contributions make a difference by enabling us at CHS to inform more people of the ravages of hemochromatosis, leading to more Canadians being tested, diagnosed and treated.

**We thank all our  
donors and members.**

If you have made a donation and your name isn't on this list, please let us know.

**We would also like to  
graciously acknowledge  
all those who  
contributed to CHS  
through the Allan and  
Lynn Day party.**



# Awareness is the Cure

In the life of a non-profit organization there are different times and growing points when it must do things bigger and better to fulfil its mission and goals.

CHS is at one of these key growing points. Every day we are made aware of the large number of people who learn they have hemochromatosis because they have started to suffer from a hemochromatosis-induced disease. Or, even sadder, we find out that someone has needlessly died, early in life, from a heart attack or cancer caused by hemochromatosis.

CHS is now positioned to make a difference in Canada and get the word out about this silent killer. Through new materials, the internet, radio and

television, magazines and local and national events, CHS will reach out to individuals and their families bringing awareness about this disorder. All we need to begin this new work is the financial support of our members, foundations, corporations and others. The Board of Directors has set a target to raise Five Hundred Thousand Dollars (\$500,000) by March 31, 2009. They have been supplied with a resource kit to promote the awareness of hemochromatosis and the work that CHS will do with this level of support. We need your help to spread the word. In



the New Year, we will be contacting you to tell you about a new and informative booklet that you can share with your family, your colleagues, people in your workplace and friends. Save thousands of lives across Canada from needless suffering and early death. CHS thanks you in advance for your continued help and support. **You can make a difference.**



## A MEMBER CHALLENGE

# Host a Party for Hemochromatosis in 2009

One of the most exciting activities in 2008 was a member-inspired party in Toronto at the Rosedale Golf Club. **Allan and Lynn Day** hosted the party and asked their guests to donate to the Canadian Hemochromatosis Society. Over 200 people attended this event and donated nearly \$20,000. In addition,

Elizabeth Minish and Bob Rogers attended the party, meeting most of the Day's friends and sharing information about hemochromatosis. Thank you Allan, Lynn and all your special friends for the care and contribution each of you continue to give to support awareness about hemochromatosis in Canada.

Allan and Lynn Day challenge all readers to hold a fundraising party for Hemochromatosis in 2009. CHS can arrange to issue a tax receipt to those who make a donation at the party and to the host for the costs associated with holding the event. Contact our office for more details.



Allan and Lynn Day hosted the party and asked their guests to donate to the Canadian Hemochromatosis Society. (L-R) Kay Easun, Elizabeth Minish, Lynn Day and CHS Executive Director Bob Rogers

# Among Ourselves Again

Here are some newsy tidbits from previous editions of *Among Ourselves* and *Iron Filings*. These answer many of the frequently asked questions that the CHS office receives each week.

## What were your first symptoms?

Fall/Winter 1986 Volume 3 Number 1  
"Among Ourselves"

**Neilene R. Nutting:** Feeling very tired all the time.

**M. Laurie McColl:** Fatigue, low resistance. In early teens developed a severe rheumatism in ankles, knees, wrists and shoulders. Later Dr. Halparin examined my sister, who was first diagnosed, and requested me to have bloodwork done also.

**James Jennings:** Extreme thirst, loss of sight (Diabetes)

**Maureen Jeannette Woroby:** Began about 22 years of age. General tired feeling, ankles stiffening in the morning began about 24 years of age. Knees sore and making grinding sounds about 25 years of age. When I was 34, my brother was diagnosed and my sister and I had blood tests done.

**Frederick (Tom) Warder:** "Tanned" skin for many years. Classic symptoms of Diabetes at age 42. Doctors did not

diagnose this for over a year, despite thirst, impaired memory, disorientation, personality change, weight loss. Severe headaches. Leg and foot cramps. Diarrhea so bad that I was tested for parasites. Rapid onset of Diabetes, progressively resistant to insulin. Loss of eye lashes and body hair.

**Leigh Ann van der Schyff:** Headaches and tiredness led me to go for tests, but were not necessarily related to HH. I was prompted to go mainly through knowledge of possible heredity.

**Martha Duck:** Weakness, unsteady, confused mentally. Fell twice.

**Helen Cameron:** Tiredness, bad headaches, a lot of pain in the muscles. Very weak spells.

**Frank Koenders:** Weakness, fatigue.

**Clyde P. Jaques:** Tired; liver pain and cramps in abdomen and chest. Loss of memory. Dark ankles.



Spring 2004

### Omega Oils Provide Relief

I was having left knee pain, but after taking a blend of Omega 3-6-9 oil for a month the pain suddenly vanished and has not returned! When I saw my doctor recently, he said there is no problem with me taking this. I believe it is available at any health food store. I expect I'll be taking it for the rest of my days!

V.B. Edmonton, AB

Fall 2002

### Not in Vein

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

## Office Staff & Volunteer Updates



Brenda Ohara

**Dalila Bekkaoui**, our office manager, began a maternity leave in May of this year. On May 27th, she gave birth to a beautiful baby boy, Zacharia. While Dalila is away, **Brenda Ohara** has

joined us and has quickly learned much about hemochromatosis. Brenda brings marketing, sales and customer service skills to CHS and this is proving to be of great

assistance to our Executive Director in the growth and development of CHS.

We are also very fortunate to have several key volunteers assisting in the office operations of CHS this year. Here is **Ross Gilley**, CHS President, presenting volunteer appreciation certificates to **Henry Chen** and **Vicky Tse**, who are helping in the administration, data entry and accounting every day in the CHS office; **Vincent Tang**, our computer systems engineer; and **Patricia Lambert**, our 2007-2008 strategic coach and mentor... they are all very dedicated and we couldn't do all that we do without them. Thank you everyone.



Henry Chen



Vincent Tang



Patricia Lambert



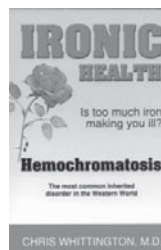
Vicky Tse

## May 2008 Awareness Events

This year, May Awareness Month was a tremendous success. We had activity in every area of Canada through local information booths, special projects and public service radio announcements. **Elizabeth Minish** and **Lynn Ravnat** were interviewed nationwide on 'Canada AM' by **Beverly Thomson**, and **Ross Gilley** was interviewed by **Mi-Jung Lee** in Vancouver. **Barbara Louder** was interviewed by **CTV** in Halifax. Our other regional coordinators and volunteers circulated materials, held meetings and were interviewed in their local newspapers, helping to spread the word. More information going out has resulted in many more inquiries from across Canada. May Awareness Month 2008 proved to be great for CHS. Let's make 2009 even better.

# The Magnet - Drawing You Closer to What's Happening Across Canada

In November, CHS is launching The Magnet. This E-Newsletter will bring you more frequent up-to-date activities of CHS, awareness events across the country, and any new information and its significance to those with Hemochromatosis. Watch for our special sale coupon in the upcoming edition of The Magnet to purchase Dr. Chris Whittington's book, *Ironic Health*, for a very special price ... ONLY in The Magnet.



We are accepting submissions for The Magnet. If you have an event you would like us to include in an upcoming issue, email us and tell us about it. We will be sending out our first issue in November to our current email group. If you wish to receive The Magnet in your Inbox, please send us your email address, contact name, city and province at [office@toomuchiron.ca](mailto:office@toomuchiron.ca).

The Magnet is an environmentally-friendly way of creating awareness.



## Support CHS and help prevent needless suffering and early death

### Annual Membership

- Regular \_\_\_\_\_ @ **\$30**  
 Senior \_\_\_\_\_ @ **\$20**  
 Family (same address) \_\_\_\_\_ @ **\$45**  
 Yes, please renew my annual membership automatically by using my credit card info  
 Lifetime \_\_\_\_\_ @ **\$500**

### Books & Accessories

- The Bronze Killer \_\_\_\_\_ @ **\$20**  
 Ironic Health \_\_\_\_\_ @ **\$22**  
 Wristband \_\_\_\_\_ @ **\$8**  
 Hemochromatosis DVD \_\_\_\_\_ @ **\$21**  
 Too Much Iron DVD \_\_\_\_\_ @ **\$10**

**Total \$** \_\_\_\_\_

- Credit card  Cheque/Money order  
 (use credit card info area to the right)

- I have Hemochromatosis (HHC)  
 I have a blood relative with HHC

- I would like my support acknowledged in the newsletter  
 I would like to receive the E-Newsletter, The Magnet  
 Send me information about planned giving or leaving a bequest in my will.

### Contact Information

Name: \_\_\_\_\_  
 Address: \_\_\_\_\_  
 City: \_\_\_\_\_ Province/State \_\_\_\_\_ PC/Zip: \_\_\_\_\_  
 Tel: \_\_\_\_\_ Email: \_\_\_\_\_

*Official Revenue Canada receipts are issued for all memberships and donations.*

### Donation Options

I would like to make a  Monthly  Quarterly  Annually  Other \_\_\_\_\_

donation in the amount of \$

- Charge my  VISA  MC  American Express

Card Number: \_\_\_\_\_ Expiry date: \_\_\_\_\_

Signature: \_\_\_\_\_

- I am enclosing \_\_\_\_\_ postdated cheques in the amount of \$ \_\_\_\_\_ to the Canadian Hemochromatosis Society.

Please mail this form to: Canadian Hemochromatosis Society  
 272 - 7000 Minoru Blvd. Richmond, BC V6Y 3Z5  
 Tel: 604 279 7135 | Toll Free: 1 877 BAD IRON

Canadian  
**HEMOCHROMATOSIS**  
**SOCIETY**