25th ANNIVERSARY 1982 ~ 2007
Canadian HEMOCHROMATOSIS SOCIETY

Spring, 2007

Iron Filings

Member in the Spotlight

Forum Moderator Shares Expertise

Fitting for Spring, this issue of Iron Filings highlights our new activities, growth and heightened awareness of hemochromatosis in 2007, starting with our newly appointed CHS website forums' moderator, **Bob McLeod**, *as our* Member in the Spotlight. *Bob has been active on the website forum since its inception just over a year ago, sharing information and his own stories.*

"We think you might have Hemochromatosis." Those ominous-sounding words echoed off the walls of my doctor's office. I am 50 years old, live in Kingston, Ontario, and I hadn't been feeling right for the last couple of years. These words were the culmination of numerous tests and visits to my doctor. We had been trying to determine why I had been feeling sick for so long. I was feeling totally de-energized and had lost interest in just about everything. We suspected cancer at first, but regardless of what I told my doctor, she just didn't seem to hear what I was saying and it was very frustrating.

"I may have what?" I asked, quite concerned. I had never heard of this before.

"Hemochromatosis," she said again. She went on to say that it wasn't yet life threatening and luckily was easily treatable. I would have to have more blood work and possibly a few more tests done to confirm the diagnosis. This was the first positive reaction I had received from seeking out answers for all my health problems.

My wife Susie and I went home and sat down to discuss the news. At first, I was bewildered. I didn't have a clue of how to deal with this. I did know however that I needed to get information that was reliable and up to date because my doctor admitted that she knew very little about this and couldn't tell us much. We searched the internet and found the new CHS website and forum. It was there that I would make contacts and start finding answers.

I read the *Bronze Killer* and couldn't put the book down. I shook my head as I read, relating first hand to a lot of the problems described. I knew about the unexplainable rages and the depressions. I knew about having no energy and how everything could become a major chore, and how interaction with friends, family and co-workers was almost impossible. I had other symptoms that have all too often been tied into hemochromatosis, but never been totally accepted or recognized as disease features. Between Susie and me, we were able to document distinct symptoms for well over ten years. The most bothersome of the physical symptoms was very similar to I.B.S. (inflammatory bowel syndrome). Having to make frequent trips to the washroom every day of the week isn't fun.

My doctor then sent me to a hematologist. The whole process made me feel as if I was wasting his and my time. The genetic testing hadn't been done and I was told that a transferrin saturation level of 64% was nothing to worry about.

Continued page 6

CHS Celebrates 25 years of Awareness.
CHS founder Marie Warder, president Elizabeth Minish and past president Charm (Cottingham) Moul gathered for the 2007 Annual General Meeting and celebration for the society's 25th Anniversary at the Richmond Caring Place on April 5.

INSIDE

The Newsletter of the Canadian Hemochromatosis Society

25 Years: Looking Back and Looking Forward

At the AGM on April 5th we were reminded of how important volunteers have been to our success over the years when our founder, Marie Warder, shared with us a brief recounting of our history. She drew our attention to some milestones, like the first Awareness Week 20 years ago in 1987. It was set for May 25–31 each year in honour of her husband Tom's birthday on the 25th.

Most notably, she pointed out how important people have been in the history of the society and how often a seeming coincidence led people to us who turned out to make key contributions. Marie doesn't believe in coincidence, preferring to give credit to divine intervention, but whatever one believes, there is no denying that we are certainly in the debt of our volunteers and we continue to marvel at how often people with just the right skills show up when we need them most.

A good case in point is this month's member in the spotlight, Bob McLeod from Kingston, Ontario. So is Ben McEwen, our board member from Edmonton, who put his skills and experience in government to work on our behalf when he helped spearhead the committee that developed the Alberta Medical Association's protocol for the treatment and management of hemochromatosis. This is just the second such protocol in Canada, following our own here in BC.

We are very proud of the fact that the original BCMA protocol developed in 2001 with input from Drs. Sam Krikler, Sigfried Erb and Gillian Lockich, who have past and present associations with the society, was the first of its kind in North America. It has been used outright as the protocol in other jurisdictions and as a blueprint for developing new ones, as was the case with the Alberta protocol. Our BC protocol was updated at the end of 2006 and both will be posted on our website. The impact of these protocols, including information about their similarities and differences, is the subject of our feature article.

Events planned for the newly expanded Awareness Month are listed and hopefully will act as inspiration for your ideas of ways you might expand awareness of hemochromatosis in your little corner of the world. We are particularly pleased to be attempting our first annual information night here in Vancouver based on the successful model used in Halifax for the past three years. We hope roll this out across the country in the future.

When I first met our founder, Marie Warder back in 1984, I certainly never imagined the society would be celebrating its 25th anniversary with me at the helm as president. My early years as a volunteer with the society were unremarkable except perhaps for my ability to stuff large volumes of envelopes in a short period of time. I guess it all goes to show that one never knows from where the next president will come.

With this experience as my guide, and as I accepted the nomination for another term as president this year, it was with the stipulation that it would be my last. I will be stepping aside next year to create an opportunity for renewal of our leadership and I am confident that whatever that person brings to the CHS will be part of an exciting new chapter in our history.

As we celebrate our successes this year after 25 years in existence, my fondest hope for our future is that by the time we get around to celebrating our next 25 years, we won't be necessary at all. Until then, we thank you for your continued interest and support of our vital work.

Enjoy your read, and as usual, pass your copy along when you're finished. ■

Elizabeth Minish, President

Iron Filings

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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.

Protocols
in Diagnosing and Treating Hemochromatosis

by Julie MacFarlane

Diagnostic Protocols

In order to find out if a person has a particular disorder, clinicians follow a specific set of procedures and guidelines as outlined by boards of medical experts. These sets of procedures, called *protocols*, are based on scientific evidence and expert clinical opinion.

In this issue we report on the BC and Alberta protocols currently used to screen for and diagnose cases of hemochromatosis, and compare and contrast them to what is used in the USA and UK.

The establishment of protocols for particular disorders sets a baseline health management plan and is essential to ensure consistent patient care. It also alerts physicians to the existence of the disorder, and that he or she should be on the lookout for it. While hemochromatosis was recognized as a specific disorder many years ago, guidelines for diagnosing and treating it have only recently appeared.

Still, hemochromatosis remains a mystery to the general public and to some medical practitioners. The Canadian Hemochromatosis Society works hard to raise the awareness of this disorder and to publicize the existence of the protocols.

British Columbia Protocol

The hemochromatosis protocol was revised by Dr. Max Zahir (chair – retired), Dr. Samuel Krikler (Hematological Pathology and current medical advisor to the CHS), Dr. Bakul Dalal (General Pathology), and Dr. Abram Karrel (Medical Consultant, BC Ministry of Health).

The BC protocol for *"Investigation and Management of Iron Overload"* was originally developed in 2001 and revised in December 2006. Until Alberta's protocol was introduced, BC's was the only one in Canada and was used in other jurisdictions. It takes the clinician through a step by step process of recommendations for who should be tested for iron overload, how they should be tested, who should be offered DNA testing, appropriate follow-up of DNA testing results, and management of hemochromatosis including details on therapeutic phlebotomy.

When a new or revised protocol is introduced, the BC Medical Association and Ministry of Health Services mail the new version to all the province's GPs, specialists and specialty departments relevant to the particular disorder.

Most of the 2006 revisions result from updates in the literature and some clarification to terminology. Two additions to the hemochromatosis management section is to recommend that patients be thoroughly assessed for possible end organ damage (arthritis, liver dysfunction, diabetes, heart disease) prior to initiation of a phlebotomy program, and that patients with a serum ferritin level greater than 1000 ug/L should have liver function tests because of increased risk of cirrhosis and liver cancer.

Another change in the 2006 version reflects current population screening research into why some individuals with HFE mutations do not go on to develop hemochromatosis while others do. Compound heterozygotes C282Y/H63D are now considered to have less than a 3% chance of developing iron overload, reduced from 5% in the 2001 protocol. Despite hemochromatosis being considered the most common autosomal recessive genetic disorder in persons of European descent, with an estimated prevalence of 2-5 / 1000, less than 10% of these individuals actually manifest the clinical features of hemochromatosis.

These numbers are controversial however, because "clinical features" are defined differently by different researchers. Some researchers only consider end-stage organ damage such as liver fibrosis/cirrhosis and heart problems as "clinical features." Many patients with HFE mutations will not go on to develop these features, so many researchers will not consider them to be "affected individuals with hemochromatosis." But in some cases, these patients were identified before irreversible damage occurred and phlebotomies have reduced their iron loading. They may never develop end-stage organ damage because they are being properly treated for the disorder, and therefore may never be included in the statistics for "clinically affected" hemochromatosis patients.

If the definition of "clinical features" was broadened to include initial biochemical iron overload (ie. high serum ferritin and high transferrin saturation), then the number of "affected individuals" would be much higher than the quoted 10%. The UK protocol, discussed below, states that of persons with HFE mutations, 95% of men and 80% of women over 40 will experience biochemical iron overload. This numbers game has been an issue for the medical community and the CHS because it makes it difficult for clinicians to agree on an appropriate screening model. It will continue to be a problem until further research can really sort out the reasons why some individuals with HFE mutations go on to load iron and possibly manifest hemochromatosis, while others do not.

Alberta Guideline

Dr. Dawna Gilchrist, medical geneticist from Edmonton's University of Alberta Hospital, convinced the Alberta Medical Association that a protocol was needed, and she headed the protocol committee. CHS Board member Ben McEwen was also involved in developing the protocol.

The Alberta *Guideline for the Diagnosis and Management of Hemochromatosis,* posted in 2007, is shorter that BC's (2 pages vs 8), and as such is more generalized. One advantage of this is that it does not downplay the possibility of C282Y / H63D and H63D/H63D individuals loading iron and experiencing symptoms, as does BC's. The Alberta protocol suggests that other genetic factors may play a role in modifying an individual's clinical features which currently are beyond our ability to identify. Alberta also mentions possible consequences of genetic testing including insurance discrimination and genetic counselling referrals.

Continued page 4

Protocols

continued from page 3

BC's protocol is much more specific around ferritin and transferrin saturation screening first, and more detailed on ranges and cut-offs, even recommending repeat screening one month after a positive result. Alberta's protocol appears to move quickly from serum screening, focussing more on genetic testing. Neither is wrong: one just places more emphasis on one or the other, probably reflecting the kind of specialists that sit on the protocol committees.

Importantly, both BC and Alberta encourage contact with the CHS.

American Clinical Guidelines

The American Clinical Guidelines for hemochromatosis were developed by the American College of Physicians in 2005. They provide a two-part document: one for physicians discussing the screening of primary care patients for hemochromatosis; the other, a one page summary for patients.

The American guideline breaks down its testing section into what it considers diagnostic testing of people who have symptoms of iron overload and screening testing of people who have no symptoms. It focuses attention on the risks and benefits of screening and whether using blood tests or genetic testing is most appropriate. Since early diagnosis might help prevent organ damage, advocates of screening in all primary care patients support serum iron levels being checked when doing routine blood work in order to enhance the pick-up rate. The use of genetic screening is more controversial because not all people who have the HFE gene mutations develop hemochromatosis and organ damage. A "positive genetic HFE" result, and the labelling of people who may never get sick can lead to anxiety and health insurance problems.

The American College of Physicians concludes that there are no identified benefits of routinely removing blood from HFE positive but asymptomatic individuals. The protocol does not endorse HFE genetic screening unless there is a reason to do it such as increased serum iron levels, obvious symptoms, or family history, much like the BC protocol.

> . . . the need for and the success of using guidelines can only help us in our quest for better and earlier screening and detection and therefore earlier treatment of hemochromatosis.

UK Best Practices Guidelines

Since hemochromatosis primarily affects the Northern European population, it is definitely on the medical radar in the UK. Over the years, most UK countries developed their own hemochromatosis testing and reporting practices. In 2006, the UK Clinical Molecular Genetics Society hosted a workshop in Ireland to develop a common hemochromatosis protocol. The resulting protocol encompasses diagnostic, predictive and carrier testing, and deals with reporting the results of such testing. Guidelines for phlebotomy treatment are considered separate, published by The British Committee for Standards in Haematology.

The UK guideline focuses on the genetic testing of the HFE gene and the interpretation of the test results, with genetic testing indicated once a patient's transferrin saturation level has reached 45% or greater. No differences are noted from BC and Alberta's protocol when it comes to interpreting the biochemical iron overload and hemochromatosis disease risk of C282Y / C282Y individuals. They do mention that 5% of hemochromatosis patients will instead have the compound heterozygote C282Y / H63D combination, but interestingly, 2% of the UK general population is also walking around with this genotype, healthy, and not affected with hemochromatosis, so interpretation is complicated with this combination test result.

The UK protocol states that 25% of carriers of one C282Y mutation have an increased risk of mild to moderate biochemical iron overload, but are not at risk for hemochromatosis complications. In contrast however, when a patient with just one detectable HFE mutation (an HFE carrier) develops the disease, it is likely that other genetic and environmental factors are playing a role. In clinical practice, the common C282Y and H63D variants are the only HFE variants tested. Many other rare variants in the HFE gene exist, as do other iron related genes which could cause a so-called "HFE carrier" to develop hemochromatosis. But testing all these variants in practice is prohibitively expensive and tends only to be done at the research level.

The H63D/H63D homozygous combination is considered common in the UK population (2%) and its significance to hemochromatosis is uncertain. It has been suggested that these individuals are at a slight risk of biochemical iron overload.

The UK guidelines also discuss management of individuals identified before they manifest any rise in serum iron levels or disease symptoms (ie. an asymptomatic sibling of an affected sibling). The guidelines recommend an annual test of serum iron levels for those with the C282Y/C282Y genotype, stressing that it is not accurate to state that they have hemochromatosis or will develop it, only that they are at an increased risk. They recommend testing once every 3 years for those unaffected individuals found to have the C282Y/H63D genotype. They recommend that minors (under 16) not be tested for carrier status. Approximate risk can be calculated for each child, but the child should be allowed to choose to have their carrier status investigated when they reach consenting adult age.

The UK guidelines are broader than the Canadian guidelines, providing interpretation and recommendations for each kind of test result. However, the entire protocol assumes a level of understanding only health professionals and patients knowledgeable in hemochromatosis would be able to follow. It doesn't appear to be reader-friendly for the local GP who would be the front line person in screening and diagnosing HH.

Limitations of Protocols

Unfortunately, these protocol are not able to include all the nuances, exceptions and new

Continued page 7

WEBLINKS

Read the BC and Alberta protocols on the CHS website
www.toomuchiron.ca

BC Ministry of Health, Medical Services Plan website
www.hlth.gov.bc.ca/msp/protoguides

Alberta Medical Association – Towards Optimized Practice program website
www.topalbertadoctors.org/top/

From the CHS Mail Bag….

Dear CHS
I have been a registered nurse for 24 years and recently I took a leave of absence to go back to school to become a primary care nurse practitioner in Ontario.

Part of the program involves taking a clinical placement one day a week. Two weeks ago, when I was doing a placement in a small rural office with another nurse practitioner and her wonderful physician consultant, a hemochromatosis patient came in for a phlebotomy. The doctor asked if I knew anything about it, and I had to honestly answer no, I had only heard of it. I don't think I had even said the name before.

We talked a bit about the patient. I looked at her family history and the doctor gave me the book "The Bronze Killer" to read. Before I had even finished it, I researched this condition non-stop. This past week I wrote a paper for my pathophysiology course outlining the role of hepcidin in hemochromatosis. It is fascinating to me. I can't believe I didn't know anything about this most common condition.

This week when I went back to my placement, the doctor had a newly diagnosed hemochromatosis patient in for her first phlebotomy. The doctor had done some blood testing on her based on her skin color. That was so interesting. Having just finished all my hemochromatosis literature research, I was happy to be able to answer questions for this lady as she endured her first treatment. She had a bracelet on from your Society and had received some information from you which she had read and we were able to discuss. She had lots of questions.

We talked about her family members and it will be interesting to see if her son also has the condition. It sounds like he certainly has some of the early symptoms.

Thanks so much for your great website and keep up the great work! CHS founder Marie Warder will be happy to know that one more primary care practitioner is now knowledgeable about hemochromatosis. I will be taking this to my class at university this week and sharing with other nurse practitioners there. Thanks Marie for enlightening the world! ■

Anne Douglas RN, BScN, RN(EC) student

Members' Corner

A welcome addition to *Iron Filings* this spring is our *Members' Corner*, a new section devoted entirely to the good work underway by CHS members across Canada. We will still continue to highlight the *Member in the Spotlight*, but at the rate of one member per newsletter issue, it's going to take an awfully long time to get through us all.

In particular, the *Members' Corner* allows us to introduce you to and keep you informed of the new CHS regional coordinators living across Canada who together are creating another layer of networking, guidance, and information for the Society.

A question we often hear at the Society is **"Why become a member in the first place?"** Why not just donate to the Society? The answer is that while we will never turn down a donation, we would really prefer to have as many members as possible, and here are just a few of the many good reasons:

A large membership gives us clout!

It is important to have numbers on our side when we apply for grants or lobby on your behalf with various medical bodies and governments. A common misconception we fight every day is that hemochromatosis is a rare disorder, so the more members we have to confirm the reported statistics, the easier the communication becomes.

The Society headquarters are based in Richmond, BC, because this is where CHS founder Marie Warder lived. But we really ***are*** a National Society with members in every province. We are increasingly discussing hemochromatosis with provincial medical organizations, and when we can demonstrate that our members live in every nook and cranny of the country, we achieve speedy credibility.

Members are more knowledgeable about the disorder.

The fact is that we need people to spread the word about hemochromatosis, and the best sources are the people directly affected by it. When you are a member, you open yourself up to a world of vital information that you can pass on to others in a manner that will still get you invited to parties! Most members can honestly say they have lengthened and improved the quality of at least one person's life. That is a powerful testament to the impact of each of us as individuals.

Membership makes it easier for us to track you.

Don't worry, this statement is not as sinister as it sounds! The fact of the matter is that we care about our members and want to provide assistance in any way possible. Membership info provides us with better information about who we are, where we live, and what has motivated us to become aware of hemochromatosis. This allows us to focus our efforts more effectively as a Society. We are entirely volunteer-driven and governed, and membership growth and activity provides all of us with the feedback we crave to keep moving forward!

The bottom line is that membership sows benefits far beyond its nominal annual cost. If you're not already a member, won't you consider joining us?

Next Issue: Read all about our Fantastic 14 Regional Coordinators across Canada making a difference for the CHS.
Ross Gilley, CHS Vice-President

Contact us!

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Bob McLeod: Member in the Spotlight

continued from page 1

Member in the Spotlight, Bob McLeod

Normal was right around 60%. A ferritin level of "only" 840 ng/ml wasn't anything to be concerned about either because it wasn't serious until it was into the thousands. (Ferritin levels can change daily and having a meal can lead to inaccuracies. I had been on a sixteen hour fast prior to this blood test.)

The genetic testing was finally done, and my results showed that I was a carrier (HFE C282Y). I was told that there was nothing to worry about since carriers very rarely load iron, and that was the end of it.

Susie had accompanied me and spoke up: "How do you explain all his symptoms if it's of no concern?" The doctor stopped and thought for a couple of minutes.

"Here's what I want you to do," he said. "I want you to do three blood donations at CBS and keep a diary of how your symptoms change. If they improve and your numbers stay up, we'll consider putting you into the phlebotomy clinic to get the numbers down."

I donated the next day. I had read how people had ached the day after a phlebotomy but nothing prepared me for being as sore as I was. I mentioned that on the CHS website forum and received valuable advice from other members which helped a lot. Within a week, most of my physical symptoms had undergone major improvements. Within two weeks, my moods had stabilized and I was much easier to get along with. (I had always thought that I was pretty easy to get along with. Now I know otherwise.)

My abdominal swelling went down and my frequent trips to the bathroom were drastically reduced to the point that I could start to get on with a reasonably normal life. I wasn't constantly stiff and having as much trouble sleeping. My energy and interest levels were back up. These improvements lasted for about five weeks before the whole cycle started over again. This was the pattern that proved to be the norm for me up until late November, six months post diagnosis. Then I went to the hospital with chest pains and while I hadn't had a heart attack, they felt I was in danger of congestive heart failure and that I should get this checked out.

> I haven't been quiet about hemochromatosis. I tell anyone who will listen and do my best to stay informed about it.

On December 5 I tried donating at CBS again, but couldn't because the possible heart problems hadn't been cleared. I was instead booked to go to the hospital-based phlebotomy clinic. On January 5 I saw my family doctor and made arrangements to have an ultrasound of my liver and to have an echocardiogram for my heart. (I have been cleared of possible heart problems.) I am very pleased to be able to say that since my diagnosis, my family doctor has diagnosed five more patients through routine testing. On January 25, I had my first phlebotomy at the hospital and was happy to be there. I'm on a six week schedule with a target ferritin of about 100 ng/ml, providing everything is balanced. I'm prepared to adjust my schedule either way as required.

I haven't been quiet about hemochromatosis. I tell anyone who will listen and do my best to stay informed about it. A few friends from different regions tell me they've been diagnosed. If I can help others get diagnosed and avoid seeing them fall through the cracks in the system, I'll be doing it very happily. ■

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!

Need a Laugh?

The Daily Show with Jon Stewart puts its tongue in its cheek about nearly everything, including hemochromatosis. Visit this url – **www.ifilm.com/video/2830706** – and listen to Jon's interview with Dr. Sharon Moalem, a neurobiologist who has just written *Survival of the Sickest, or Why We Need Disease*.

He tells us why hemochromatosis evolved as a protection against the Bubonic Plague, and how "living until tomorrow" is preferable to living to be one hundred.

Hemochromatosis Awareness Month
May, 2007

National Hemochromatosis Awareness Week, usually held in the last week of May, has been transformed into National Hemochromatosis Awareness Month. From now on, the Canadian Hemochromatosis Society will help coordinate a month-long long effort to get the word out on Canada's most common genetic disorder. Here are some of the activities planned.

Hemochromatosis Information Night

Wednesday May 16th, 2007 @ 5-8 pm, UBC Telestudios, 2329 West Mall, UBC Campus. Go to www.maps.ubc.ca for a printable map.

Featuring the premiere of the new CHS video, presentations from an expert panel of heochromatosis health professionals, and a Q&A session. Patients, family members, interested public, and health professionals are invited to attend.

Contact the CHS office for information and registration.

Canadian Blood Services Blood Donor Drives

Our CBX program has been expanded to include sites across Canada. Call 1-888- 2 DONATE (1-888-236-6283) to make an appointment. Be sure to sign the *Partners for Life* book on the CHS page, so we will know how many supporters donated during May. Anyone can give blood during Awareness Month, so bring your friends!

We need volunteers at all locations to hand out brochures and greet clinic visitors. Come support patients with hemochromatosis and donate a pint of blood on behalf of the CHS. Book your appointments at the following CBS locations. Light refreshments and hemochromatosis information will be available.

CBS Hemochromatosis Awareness Month Drives

CBS Kelowna
Tuesday May 8, 3:00 to 5:00 pm, 1865 Dilworth Drive .

CBS Kamloops
TBC, either Thursday, May 10, noon to 6:30 pm or Friday May 11, 9 to 3:45. Call Calvary Community Church, 1205 Rogers Way in early May.

CBS Prince George
Thursday, May 17, 2:00 to 4:00 pm, location TBC. Call our office.

CBS Penticton
Friday, May 25, noon to 6:15 pm, Seniors Drop In, 2965 South Main St.

CBS Vancouver Oak Street
Tuesday May 29, 4:00 to 7:00 pm,

Around Ontario
Contact CHS Ontario member Jeannette Gibson *jeannettecgibson@yahoo.ca* for more information.

Toronto will host three CBS sessions

- At the downtown clinic on College St.
- In Square One Mall
- Hillcrest Mall

Ottawa, Location TBC

Awareness Month Information Tables at Hospitals and Shopping Centres

Another great way to get the word out about hemochromatosis is to directly solicit health professionals in the hospital and the public at shopping malls. Our diligent CHS members will be at information tables at the following locations:

North Vancouver–Information Table at Lion's Gate Hospital, Thursday, May 24, 9:00 to 4:00 pm.

Ottawa-Gatineau–Info table at Carlingwood Shopping Mall on Sunday, May 20, and St. Laurent Shopping Mall on Friday, May 25.

Visit our website often for the latest updated information
www.toomuchiron.ca

Corporate Community Support

Are you a current employee or retiree of a company with community support programs? Linda Perkins of Toronto is. She works for BELL who support their employees' volunteer commitments with cash! Linda has logged many volunteer hours over the years for CHS, and has discovered that she can apply for a $500 grant for her charity of choice (CHS of course) for 50 hours of annual volunteer service.

It is certainly worth checking into. Retirees of BC Hydro are regular contributors to CHS, and many companies offer a matching gifts program, matching employee charitable contributions, or a portion of the contribution.

Please check with your employer. There are many ways to support the Canadian Hemochromatosis Society.

Protocols

continued from page 4

discoveries involved in a disorder as complex as hemochromatosis, especially when revisions only take place every five years. But overall, the need for and the success of using guidelines can only help us in our quest for better and earlier screening and detection and therefore earlier treatment of hemochromatosis. ■

References

Schmitt et al., Screening primary care patients for hemochromatosis with transferrin saturation and serum ferritin level: systematic review for the American college of physicians. Clinical Guidelines. *Annals of Internal Medicine 2005; 143: 522-536.*

King, C. and Barton, D.E. Best practice guidelines for the molecular genetic diagnosis of Type 1 hereditary hemochromatosis. *BioMed Central Medical Genetics. 2006; 7(81): 1-7.*

MARIE WARDER CUTS THE 25TH ANNIVERSARY CAKE.
Our society was registered in 1982 by Marie Warder, a fierce and persistent lobbyist for awareness about hemochromatosis. Her energy and spark have helped save countless lives over the years. She is also a prolific author, having published more than 20 books of fiction and non-fiction, including "The Bronze Killer." Thanks, Marie.

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.

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* _____
Lapel Pin _____ @ $5 _____
Wristband _____ @$7.50 _____
Donation
Bill my credit card monthly for a donation of: _____
TOTAL _____
* US dollars for US orders.
For international prices, contact office.

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

Name _____

Address _____

City _____ Prov. ___ PC _____

Email _____ Tel _____

❑ I am a new member ❑ Renewal

❑ As a member/donor, I grant permission to publish my name in the CHS newsletter.

❑ Do not publish my name in any CHS media.

Send me____brochures and _ information packages.

❑ Payment enclosed ❑ Please charge my VISA

Card # _____ Expiry Date _____

Cardholder signature: _____

Please return to:
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THANK YOU!

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