SPRING 2014

Canadian HEMOCHROMATOSIS SOCIETY
Société canadienne de l'hémochromatose

Iron Filings

Providing information, awareness and support

Our Vision

An end to suffering and premature death related to hemochromatosis in Canada

"I consider myself privileged"

ROBERT ARSENAULT, SHEDIAC, NEW BRUNSWICK

From left to right : Robert Arsenault, his wife Hélène, their daughter Nathalie, her husband Mike Gison and Serge, Robert and Hélène's son. This photo was taken on the wedding day of their daughter Nathalie, in November 2013.

In May 1992, I was placed in a hospital isolation room at the age of 43, because of jaundice. After an ultra sound of my liver, my gastroenterologist was convinced that I was an alcoholic, even though I did not drink alcohol, except for a little sip of wine, as a Christian, on Sunday during the Lord's Supper. These groundless remarks made me sad, because the doctor didn't believe my word. A biopsy revealed that there was ten times more iron in my liver than normal. That hepatic biopsy showed that I had a moderate fatty liver, with the beginning of an arachnoid fibrosis and a few Mallory bodies. Fortunately, there was no cirrhosis of the liver. The level of ferritin in my blood was high, at 600 ng/mL. These tests indicated, according to the specialist, that I had hemochromatosis.

Before my hospitalization I was often tired and my thoughts were sometimes unclear. This had an effect on my work, family and community life. To eliminate the excess of iron, I had initially a bloodletting every two weeks, then once a month. These bloodlettings helped regain my energy. In 1999, the level of my ferritin had decreased to 20.6 ng/mL. When the genetic test for hemochromatosis became available, my test came back stating that I was homozygous for the C282Y gene. My wife also had a genetic test that revealed no sign of hemochromatosis. Since the quantity of ferritin gradually diminished, the number of bloodlettings decreased to twice a year around the year 2000. Strangely, I had no bloodletting for the past two years. My doctor, a hematologist, explained to me that the acceptable level of ferritin in the blood has slightly increased according to the new medical standards. My last blood test, in October 2013, indicated that my level of ferritin was 110.0 ng/mL and my transferrin saturation was at 31.8%.

Before my departure from the hospital, my gastroenterologist, suggested I contact the Canadian Hemochromatosis Society for more information and moral support. The publications of the Society, as a semi-annual bulletin, helped me to understand my excess of iron. The testimonies of persons affected by this genetic problem, that I read, encouraged me to accept my medical condition. I learned also to reduce my consumption of food that contain a high quantity of iron, such as red meat and barley green, a product rich in iron that would have, according to my doctor, contributed to provoking my jaundice. At first, I was greatly preoccupied by my hemochromatosis, but today, I consider myself privileged that this genetic disease did not bring about important effects for me. I thank the Lord for this.

To end the suffering and premature deaths caused by hemochromatosis, the Canadian population should be genetically tested and have their level of ferritin and transferrin measured, all this paid by Medicare. Thank goodness the Canadian Hemochromatosis Society has demanded this preventive measure for a long time now. The family doctors should request these tests for all their patients. Some government officials say that this measure would increase the public health costs, but the well-being and life of our citizens has no price.

INSIDE THIS ISSUE

Up Close with the Chair of the Medical Advisory Board – Dr. Sam Krikler

CHS has a Medical Advisory Board comprised of physicians from across Canada with specialities related to the body's physiological systems affected by iron overload. Here, we get up close and personal with the chair of the Advisory Board, Dr. Sam Krikler.

Q. How did you first become involved with hereditary hemochromatosis?
A. I was asked to participate in the Hemochromatosis clinic set up at Shaughnessy Hospital (in Vancouver) in 1990. Three patients with HH had been coming to Shaughnessy Hospital for their phlebotomies and a former colleague asked me if I would be prepared to look after them. I was happy to agree because I enjoyed the clinical interaction and I was quite comfortable doing the procedure. Word spread in the hospital that I had both interest and expertise and that is how I came to be approached by the Hemochromatosis clinic during the planning stages.

Q. Are you currently working on research related to hemochromatosis?
A. Dr. Chris Whittington (in Abbotsford, BC) and I have an interest in non-HFE hemochromatosis in the Mennonite community in the Fraser Valley.

Q. Please describe the findings from this study.
A. We have found a mutation in the gene which regulates the breakdown of heme (the iron containing pigment in red cells) in 2 individuals; we would like to look for this mutation in others who have "unexplained" non-HFE hemochromatosis. The significance of this finding is that it may explain the mechanism of iron overload in others within the Mennonite community. We have to remember that non-HFE (inherited) iron overload is much less common than HFE. Nevertheless, looking for a specific mutation (such as heme-oxygenase) might spare a patient (and the health care system) from time-consuming and expensive investigations.

Questions **Answers**

Q. As chair of the Canadian Hemochromatosis Society's Medical Advisory Board, you must have a passion for the cause. What drives this passion?
A. My passion for Hemochromatosis is 99% due to the influence of Marie Warder (the founder of the Canadian Hemochromatosis Society) whom I was privileged to meet for the first time over 20 years ago. One percent is my intellectual curiosity about certain aspects of the disorder.

Q. Please explain the roles and activities of the Medical Advisory Board.
A. To advise the society regarding new scientific and therapeutic developments;

To help develop and evaluate national and international guidelines;

To provide guidance regarding references in the medical and scientific literature;

To act as a resource for patients and physicians.

Q. How will these roles and activities help those with hemochromatosis?
A. By keeping the Society current and providing resources for patients and physicians.

Q. Fun Facts time! Who is your greatest role model and why?
A. Within the hemochromatosis community it is absolutely Marie Warder. Her amazing knowledge, enthusiasm and optimism are inspiring.

Q. What is your favourite movie and why?
A. "Out of Africa." I was born in Zimbabwe and the sweeping vistas of East Africa in that movie combined with Meryl Streep's superb acting and all the themes which the film touches on have left an indelible impression.

CANADIAN HEMOCHROMATOSIS SOCIETY MEDICAL ADVISORY BOARD

Dr. Sam Krikler, Chair (BC) Hematopathology; Director of the Department of Laboratory Medicine at Surrey Memorial Hospital

Dr. Siegfried Erb (BC) Gastroenterology; Liver Specialist with Vancouver General Hospital, BC

Dr. Paul Adams (ON) Gastroenterology; Professor of Medicine and Chief of Gastroenterology at the University of Western Ontario

Dr. Heather Flynn (NL) Family Medicine; Assistant Professor of Family Medicine at Memorial University

Dr. Gail Graham (ON) Medical Genetics; Chief of the Regional Genetics Program at Childrens's Hospital of Eastern Ontario

Dr. Barry Kassen (BC) Internal Medicine; Clinical Associate Head of Medicine at St. Paul's Hospital, Head of the UBC Division of General Internal Medicine

Dr. Jeff Patterson (AB) Hematology; Assistant Professor in the Division of Hematology at University of Alberta Department of Medicine

Dr. Kevork Peltekian (NS) Hepatology; Acting Head and Interim Chief for the Division of Digestive Care & Endoscopy at Dalhousie University Department of Medicine

Dr. Henri Menard (QC) Rheumatology; Professor of Medicine at McGill University and Master of Rheumatology of the Pan-American League of Associations of Rheumatology

Dr. Robert Turner (AB) Hematology; Clinical Professor of Medical Oncology at University of Alberta Cross Cancer Institute

Dr. Philip Welch (NS) Medical Genetics; Retired professor of Pediatrics at Dalhousie University and past Head of Clinical Genetics Division at IWK Hospital (1992-1994)

To learn more about the Medical Advisory Board, please visit www.toomuchiron.ca/about/medical-advisory-board.

BOB ROGERS, CANADIAN HEMOCHROMATOSIS SOCIETY – EXECUTIVE DIRECTOR AND CEO

The Colour of Hemochromatosis is Blood

What if every Canadian knew that the majority of BLOOD in Canada's blood system came from those affected by hereditary hemochromatosis (HHC)? What a change it would make! Do you realize that if 25% of those at risk for HHC registered and donated at least two units of blood with the Canadian Hemochromatosis Society's Partners for Life group, over 50,000 units of blood would be made available to help hospital patients? Can you imagine the level of awareness in Canada about hereditary hemochromatosis that would be created? The Canadian Blood Services would likely want to find more people with HHC. The same case can be made regarding blood donations with Héma-Québec. No longer would we need to fight to tell people this IS NOT a blood disease. No longer would there be the devastating ignorance about this disorder amongst healthcare professionals and the general public. Early testing, diagnosis and treatment would be commonplace and people would live healthy vibrant lives with their families in their communities. Throughout Canada and very likely around the world, hereditary hemochromatosis would be well known and the fight to promote awareness would be won.

Several years ago I was standing curbside watching a Canada Day parade make its way through town. Far away in the distance I saw a huge throng of women all attired in PINK t-shirts. Without a moment's hesitation I knew at a glance the cause these marchers represented. PINK ribbons, t-shirts and insignias were everywhere. The breast cancer movement has built a strong association with the colour PINK. Through the colour PINK they have helped countless women learn to fight and overcome the ravages of breast cancer. They chose their colour and took the steps to promote it everywhere.

Therapeutic phlebotomy or blood-letting is the classic treatment for HHC and most everyone with the disorder needs to have 500cc of BLOOD withdrawn approximately every 3 to 4 months. Further, since no one wants to see BLOOD wasted, those affected by HHC can donate this BLOOD to the Canadian Blood Services (Héma-Québec in Quebec). The Canadian Hemochromatosis Society is a national participant in the Partners for Life program. When a person donates blood to Canadian Blood Services, the donor may register their BLOOD donation towards the Canadian Hemochromatosis Society's Partners for Life group. Remember, if 25% of those at risk for HHC registered and made two blood donations per year with our Partners for Life group, Canadian Blood Services would collect over 50,000 blood donations from these members alone. This would significantly supply the blood needed in Canada. Yet, in 2013, only 198 units of donated blood were registered in our Partners for Life group. While we are grateful for the 198 donations, it isn't enough to be an important marker for HHC. We believe many more people with HHC give blood to Canadian Blood Services, but the donation isn't being registered. Can we change this please?

I want to challenge every reader and their family members to give blood to Canadian Blood Services and register their donation with the Canadian Hemochromatosis Society's Partners for Life group. All you need to do is register at www.blood.ca/joinpartnersforlife and use ID number CANA002257 (four letters, six numbers). Register once and all donations made at any Canadian Blood Services clinic will be tracked toward the hemochromatosis group. Any donations already made in 2014 will be counted retroactively to January 1, 2014.

Please do your part to create a very visible awareness marker for hereditary hemochromatosis. Let BLOOD be our colour to move awareness ahead and save lives.

May is National Hemochromatosis Awareness Month

FRIDAY TO SUNDAY, APRIL 25 TO 27

Canadian Home Builders' Association of Northern BC Home Show
Prince George Kin Centre
Corner of 18th Ave and Ospika Boulevard
Prince George, British Columbia

Stop by our booth to learn more about the disorder, including screening, diagnosis, treatment and management.

FRIDAY, MAY 2

Blood Drive with Héma-Québec
Les Galleries Des Sources
3237 Des Sources,
Dollard-des-Ormeaux, Québec

Come out to donate blood and help raise awareness of hereditary hemochromatosis! What better way is there to spend a Friday afternoon than by helping hospital patients with your blood? The exact time of the blood drive will be announced on our website.

donor clinic

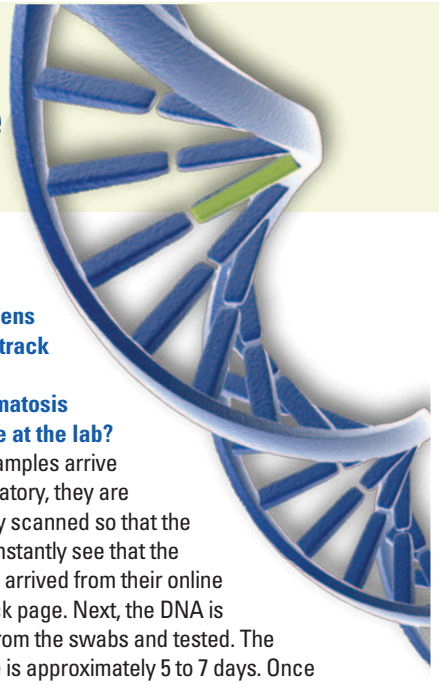
***Irons for Iron* Golf Events**
Have fun playing a round of golf with friends in support of CHS programs. Golf events are planned in cities across the country. For more information, please see your invitation on page 8 of this newsletter.

Letters to Newspapers
Volunteers will be sending Letters to the Editor in their local papers to promote hemochromatosis awareness month in May. If you would like a template of a letter to send to your local newspaper, please email office@toomuchiron.ca with your request.

Keep an eye on www.toomuchiron.ca/events for events happening throughout May and the rest of the year.

DNA 101: A look at possible future tests, lab accreditations, and what happens to your test sample

By June Wong, PhD, Vice President, Laboratory Operations, Genetrack Biolabs Inc.



Here are answers to some frequently asked questions we receive:

Will there be more hemochromatosis mutations to test for in the future?
While 88% of individuals of European origin with HFE hereditary hemochromatosis are either homozygous for the C282Y mutation or compound heterozygous for the C282Y and H63D or S65C mutations, not all individuals who have these mutations will go on to eventually develop clinical hemochromatosis. Since the penetrance of C282Y, H63D and S65C is not 100%, it is possible that there may be yet undiscovered genetic markers which may act together with these mutations to cause the clinical symptoms of hemochromatosis. Recently, a study by Stickel et. al. suggests that a mutation in the PCSK7 gene (proprotein convertase subtilisin/kexin type 7 gene) which is associated with iron metabolism may be a risk factor for cirrhosis in hereditary hemochromatosis patients who have tested homozygous positive for the C282Y mutation. If other mutations are identified in the future which are proven to contribute to or enhance HFE hemochromatosis, an announcement will be posted to www.hemochromatosisdna.org and additional test options will be provided.

What accreditation standards should one be looking for in a trusted genetics testing lab?
Accreditation and proficiency testing are important for ensuring the highest quality testing services from a laboratory. Recognized accreditations in the industry include ISO17025 for DNA identification testing, AABB (American Association of Blood Banks) Accreditation for genetic testing, CAP (College of American Pathologists) Accreditation for genetic testing, and CLIA certification (Clinical Laboratory Improvements Act) for medical genetic testing. Genetrack is ISO17025 accredited, Standards Council of Canada Accredited to ISO17025, AABB accredited, CAP accredited, and CLIA certified. Genetrack performs routine proficiency testing and is currently the only genetic testing laboratory in Canada for private hemochromatosis testing.

What happens once Genetrack receives a hemochromatosis test sample at the lab?
Once the samples arrive at the laboratory, they are immediately scanned so that the client can instantly see that the sample has arrived from their online status check page. Next, the DNA is extracted from the swabs and tested. The testing time is approximately 5 to 7 days. Once the test is complete, the final test report is generated and sent to the client by mail, email or both.

Reference:
1. Evaluation of genome-wide loci of iron metabolism in hereditary hemochromatosis identifies PCSK7 as a host risk factor of liver cirrhosis. Stickel et. al. Hum Mol Genet. March 2014

Canadian HEMOCHROMATOSIS SOCIETY
Société canadienne de l'hémochromatose

CHS Updates

New Website
If you have yet to check out toomuchiron.ca this year, now's the time! In January, the CHS website received a facelift to increase its usability and functionality. Some of the new information you will find includes a self-assessment tool to determine if you are at risk for hemochromatosis, the latest news, an events calendar, and more stories from people who have hemochromatosis. While you're on the site, remember to connect with us on Facebook, Twitter, LinkedIn and YouTube.

Health Care Professionals Referral Network
To support our growing list of clients, we maintain a Health Care Professionals Referral Network which is a network of general practitioners, specialists, nurse practitioners and other medical professionals who are knowledgeable in the diagnosis, treatment and management of HHC and its associated medical conditions. The purpose of this Referral Network is to help clients find informed health care professionals who can provide the best route of care for the testing, diagnosis and treatment of HHC. By developing and maintaining this network, our clients gain access to proper care and can return to contributing to the vibrancy of their families and communities.

Do you have a physician who you find to be knowledgeable in the diagnosis and treatment of hereditary hemochromatosis? If so, please pass his/her name along to us and we will contact them to determine their ability to belong to the Referral Network. CHS is continuously working to increase the number of medical professionals in the Network so that clients in every region in Canada can be well looked after.

8 easy ways to be involved

By supporting CHS programs which foster health promotion, disease prevention and health education related to hereditary hemochromatosis, you will create healthier lives and vibrant communities. While direct financial contributions are greatly appreciated, there are many other ways to be involved in raising the profile of hereditary hemochromatosis:

1 Come out to information and awareness events

Attending a hemochromatosis awareness or information event in your area is a show of public support. Large turnouts at these events evidence the need for CHS programs, and clearly demonstrates to granting agencies and local, provincial and federal governments the need for their added support in the mission of CHS. Your participation in CHS sponsored events strengthens the Society's case for support as it seeks program funding, the creation of provincial and national screening and management protocols, the addition of hemochromatosis screening tests to the standard blood panel, and other similar initiatives.

2 Join or start a local volunteer Chapter

Volunteer to be a point person in your region, and help CHS recruit others to help spread awareness of hemochromatosis and provide leadership within your community. Chapters are being formed across the country, and we are seeking new volunteers to fill roles of Regional Organizers who will lead their local Chapter, and Local Volunteers who will be part of a team that supports the activities of their local Chapter.

If you would like to become a volunteer for an existing Chapter, please contact the Regional Organizer directly. A list of current Chapters and Regional Organizers can be found at www.toomuchiron.ca/support/chapters.

If you are interested in becoming the Regional Organizer for a new Chapter, or if you would like to plan awareness events in your area where there are currently no Chapters, please contact our Volunteer Coordinator at program@toomuchiron.ca.

3 Donate blood to Canadian Blood Services and Héma-Québec

If you've read the message from Bob Rogers, the Executive Director and CEO, earlier in this newsletter, you will see why it is important to donate blood to our Canadian blood collection agencies. People with hereditary hemochromatosis have the potential to significantly contribute to the country's blood supply and raise the awareness level of hemochromatosis through the roof. Won't you help? If you haven't already done so, please read Bob's column on page 3 for a very inspirational message.

4 Become a DUCA member

DUgood is DUCA Credit Union's way of giving back to communities. When you join DUCA, they will give you $50, plus they will give the Canadian Hemochromatosis Society $50 as a charity of your choice. This is another great way to raise funds for CHS and raise awareness of hereditary hemochromatosis. To join DUCA, visit dugood.ca.

5 Donate Extra Aeroplan Miles

You can donate Aeroplan Miles to CHS at any time of year. Collected Aeroplan Miles will be used to offset travel costs associated with bringing CHS programs to cities and towns across Canada. Each donated mile will allow money to be directed toward activities which increase awareness of hereditary hemochromatosis such as hosting community outreach events, supporting CHS clients and dedicated volunteers, and engaging the country's medical professionals to understand the protocols for testing, diagnosing and managing the disorder. To support healthier lives and stronger communities through CHS programs, please donate your extra Aeroplan Miles at beyondmiles.aeroplan.com/eng/charity/452.

March 1st kicked off the month for CHS' Aeroplan Contribution Campaign which is when CHS set a goal of raising 50,000 Aeroplan Miles in the first 30 days of the month. If CHS reached within 90% of this goal, Aeroplan would top up with 10% to help CHS meet its goal.We are happy to announce that we raised a total of 51473 Miles! Thank you to our donors and Aeroplan for giving their Miles for hemochromatosis!

6 ChangeIt®

The Canadian Hemochromatosis Society has partnered with ChangeIt®, a new and unique way to automatically round up your debit and credit card purchases to create Virtual Change® for CHS. You have complete control over your rounding preferences and can set a maximum monthly donation. For example, if you have purchased a morning coffee and muffin for $4.63 on your debit card, Virtual Change® of $0.37 is created (it does not show up on your purchase receipt) and summed up monthly along with other round-ups. The sum is charged to your card as a single amount and forwarded in full to CHS and other charities of your choice. Every dollar donated through ChangeIt® is eligible for a charitable tax receipt. For more information and to become a ChangeIt® donor, please visit changeitcanada.com.

7 Shop at DonateNaturally.com

Many people have already taken advantage of raising additional funds for CHS while doing their everyday shopping at the same time. With every purchase at DonateNaturally.com, 10% of the value of your order goes to CHS. You are not charged an additional 10% on top of your order, and items are competitively priced with those at your local store. DonateNaturally.com provides all of your favourite natural and organic products delivered conveniently to your front door, Canada-wide. For orders outside of the Greater Toronto Area, DonateNaturally.com offers immediate shipping of non-perishable items via Canada Post. Orders over $100 will be shipped free! Find out more about this great service at – you guessed it – DonateNaturally.com.

8 Take part in Irons for Iron Golf Events

Irons for Iron is a fun day of golf with friends to help support CHS programs and build awareness of hereditary hemochromatosis. Players of all skill levels are invited to participate. Read more about Irons for Iron on page 8 of this newsletter.

Excerpted from original open letter which can be viewed at www.toomuchiron.ca

I am preparing this document for the following two reasons:

1. To ask those health care professionals who provide therapeutic phlebotomies to patients with hemochromatosis to consider the substantial benefits of using an 18 gauge IV catheter for phlebotomies, instead of the commonly used 15 or 16 gauge metal needle attached to standard blood bags.

2. To inform HHC patients of this alternative so they can initiate the necessary dialogue with their health care providers.

The equipment needed to use an 18 gauge IV catheter is a blood bag with no attached needle, just a luer lock that allows you to easily attach any size needle. Such a blood bag is readily available in the market. All it takes is an awareness of the benefits and an interest in providing care that is best adapted to a specific patient's needs.

. . . Estimates indicate there are probably over 100,000 Canadians and one million Americans with Hereditary Hemochromatosis. Many of these people will not be fortunate enough to have been born with easily accessible large elbow or lower arm veins and for them, therapeutic phlebotomies can be a nightmare, as they were for me. That's a lot of people whose lives can be improved with a few simple changes. Using the techniques I describe in this paper can greatly facilitate phlebotomizing these folks and have a significant impact on their quality of life. This was, and still is, my situation and the techniques described here were used over and over in my case with great success.

Background

I am a patient, not a doctor or nurse, who has Hereditary Hemochromatosis. I was diagnosed at the age of 59, with a double C282Y mutation, and fairly significant levels of ferritin, as well as hemosiderin deposits in the liver, which were visible via MRI. Given my condition, my hematologist recommended aggressive de-ironing, and initial phlebotomies were scheduled once a week.

Patients with Hereditary Hemochromatosis are often diagnosed only after they become symptomatic, and have accumulated significant levels of iron in their bodies. The usual course of action is to "aggressively de-iron" the patient to remove such accumulations and then place the patient on a maintenance program for the rest of their lives.

The aggressive de-ironing phase can involve phlebotomies as frequently as one to three times a week, for a year or even two years, depending on how much iron is stored.

Clearly, it is most important to maintain vascular access to perform all these phlebotomies. Using a standard blood bag with an attached 15 or 16 gauge metal needle is neither ideal, nor necessary, for many patients. A far better option is an 18 gauge teflon coated IV catheter.

Before discovering the possibility of using smaller IV catheters, I was initially phlebotomized with 16 gauge needles. Every time, my arm was sore afterwards for a couple of days, and finally the one elbow vein I had that could accommodate such a large needle collapsed and stopped giving blood. If it were not for the realization that smaller gauge IV catheters could be used in the smaller veins of the hands and lower arms, I would undoubtedly have a Port-a-cath installed in my upper chest now. . . .

> "Using the techniques I describe in this paper can greatly facilitate phlebotomizing these folks and have a significant impact on their quality of life."

The shortcomings of the 15 or 16 gauge metal needle

The metal 16 gauge needle has several drawbacks, by comparison with the IV catheter:

- It limits the number of veins that can be used (typically elbow veins provide enough volume for such a large needle, but veins in the hands or lower arms do not).

- It scars the veins to a greater extent than the smaller and more flexible IV catheters do, and hence reduces the usable life of veins. A steel needle held steady by a phlebotomist, in an ideal world, would be stationary inside your vein and hence not be scratching the inside of the vein. In the real world, there are many distractions that occur over the course of a phlebotomy and the phlebotomist invariably moves the needle to some degree. The tip of the needle is very sharp and hence there is the potential to scratch the inside of the vein. When an IV cathether is used, after the initial venipuncture, the needle is withdrawn and only a flexible plastic tube remains inside the vein, with most certainly a far lesser propensity to do damage to the inside of the vein.

- It results in more post procedure pain and hematoma than the smaller IV catheters. This is significant when the patient is being phlebotomized one, or more, times a week. Their arms hurt for a number of days, each week, week in and week out, and this potentially for a year or more.

- It results in substantially more post procedure bleeding and hematoma for patients who are anti-coagulated (on warfarin, etc)

Equipment needed to use an IV catheter

The simplest arrangement is to use a 600 ml blood bag that comes with no needle attached to it. In place of the needle, there is a luer lock, to which any needle can be attached. The only supplier of such a bag that I have

found so far is MacoPharma Inc and the bag model number is VSL 7000YQ (or just ask for the "therapeutic phlebotomy blood bag equipped with a luer lock"). This bag also has a port to insert vacuum tubes for taking blood samples. A most excellent bag for the hemochromatosis patient. . . .

If the MacoPharma bag is unavailable for any reason, it is possible to attach an IV catheter to a standard blood bag with attached 16 gauge needle, by using an extension set. Such an arrangement is described in Appendix B of a document entitled HFE-Associated Hereditary Hemochromatosis Investigations and Management, found on the website of the Ministry of Health of the Province of British Columbia in Canada, at the following web address: http://www.bcguidelines.ca/pdf/hemochromatosis.pdf

Disclaimer: The information and opinions expressed in this article are not those of a health care professional. They are those of a patient with no formal medical training, and are simply based on his direct experiences and observations as a hemochromatosis patient. The intent of the document is to request the medical profession to consider these experiences and observations, and respond by adapting the treatment delivered to hemochromatosis patients where appropriate, and to inform HHC patients that there is an alternative procedure that will help preserve their veins – veins they will need for the rest of their lives.

Among Ourselves

This column appears regularly in every issue of Iron Filings and features stories about our dedicated volunteers.

Ottawa

Dynamic mother and daughter duo Jackie and Kate Lalumiere, were featured in February in the Orleans Star, a local newspaper, helping to raise awareness of hemochromatosis and an upcoming information event. Jackie's husband and Kate's father died prematurely from complications related to hemochromatosis. Together, Jackie and Kate, along with fellow volunteer Mary Lennox (whose story can be read on the cover of the Spring 2013 Iron Filings), are establishing a Chapter to further the mission of the Canadian Hemochromatosis Society in the nation's capital. As a Chapter, they plan to hold awareness events and fundraisers, including the Irons for Iron Golf Event this spring. With this group's passion for the cause, those in Ottawa will be sure to hear lots more on hereditary hemochromatosis in the near future!

You too can join the efforts of the Ottawa Chapter by volunteering for as little as a few hours a month. To learn more about volunteering or about future events, please email Mary at ottawa@toomuchiron.ca.

Montreal

Regional Organizer Juliana Pavelka-Johnston is planning a blood drive in partnership with Héma-Québec this coming May in celebration of Hemochromatosis Awareness Month in Canada. Juliana hopes to see blood donors with hemochromatosis out in full force on May 2nd to help out hospital patients and themselves at the same time. Of course, all eligible blood donors are welcome and encouraged to attend the blood drive, as this is an excellent opportunity to raise awareness of hereditary hemochromatosis. See page 3 for details.

Cape Breton

Volunteers of the Cape Breton Chapter have a booth at the Y's Men's Home Show in April, will be doing a major presentation at the Cape Breton 50+ Lifestyle Show, has established a permanent partnership with

Attendees of the Ottawa Information Session held in February.

The Gaelic College to promote awareness of hemochromatosis, and with the cooperation of the Community Health Boards, will be making a number of presentations in rural communities. As hereditary hemochromatosis is essentially unique to people of Celtic and Northern European background, Cape Breton is "Ground Zero" for those at risk.

Bravo to these and all our volunteers for making a difference!

Special Acknowledgements

The Canadian Hemochromatosis Society gratefully acknowledges its current Gold, Platinum and Diamond level corporate and provincial sponsors for their generous support of our programs.

- Can-Am Geomatics
- Ivanhoé Cambridge II Inc.
- Keir Surgical Ltd.
- Miller Thomson LLP
- Ontario Power Generation Inc.
- RBC Foundation
- Government of Alberta
- Province of British Columbia

Cape Breton: Annual run held in honour of Myles Burke

To honour the late Cape Breton Regional Police Chief Myles Burke, the second annual Myles Burke Memorial Run is being held on Sunday, September 14, 2014 at the Joan Harriss Cruise Pavillion (Big Fiddle) in Sydney.

Myles Burke was an extremely dedicated community leader and family man, and well known in the policing community across the country. He was a recipient of the police Exemplary Service Medal and in 2007 was awarded the Member of the Order of Merit of the Police Forces in Canada.

Burke passed away suddenly in 2011 from a heart attack. Although Myles had not been diagnosed with hereditary hemochromatosis, iron overload may have been a factor in his death as several members of the Burke family have this disorder.

All funds raised from the 2014 run will be donated to the Canadian Hemochromatosis Society to further awareness efforts of hemochromatosis in Cape Breton and Nova Scotia.

Stay tuned to the Canadian Hemochromatosis Society website at **toomuchiron.ca** for updates and details of the upcoming run.

You are invited!

The Canadian Hemochromatosis Society (CHS) is proudly hosting its second annual IRONS for IRON golf events in cities across the country this spring.

To register, please visit www.toomuchiron.ca or call 1-877-223-4766.

Irons for Iron
Des fers pour le fer
Canadian HEMOCHROMATOSIS SOCIETY
Société canadienne de l'hémochromatose

IRONS for IRON is a fun day of golf with friends to help support CHS and build awareness of hereditary hemochromatosis. Players of all skill levels are invited to participate. Your registration fee of $200 will cover greens fees, a meal, and door prizes. A donation receipt will be provided for the portion of the registration fee that is in excess of the golf fees, meals, and event charges. Early registration is encouraged as spots are limited.

Toronto Event
Thursday, May 22, 2014 – 12:30 pm
Royal Woodbine Golf Club, Toronto, ON
Golf with dinner to follow

Ottawa Event
Monday, May 26, 2014 – 12:00 pm
Hylands Golf Club, Ottawa, ON
Lunch with golf to follow

Calgary Event
Tuesday, May 27, 2014 – 12:00 pm
Blue Devil Golf Club, Calgary, AB
Golf with dinner to follow

Moncton Event
Tuesday, May 27, 2014 – 1:00 pm
Moncton Golf & Country Club, Riverview, NB
Golf with dinner to follow

Halifax Event
Wednesday, May 28, 2014 – 1:00 pm
Glen Arbour Golf Course, Hammonds Plains, NS
Golf with dinner to follow

Cape Breton Event
Friday, May 30, 2014 – 12:00 pm
The Lakes Golf Club, Ben Eoin, Cape Breton, NS
Lunch with golf to follow

Vancouver Event
Thursday, June 5, 2014 - 1:00 pm
Quilchena Golf and Country Club, Richmond, BC
Golf with dinner to follow