FALL 2015

Canadian Hemochromatosis Society 35 Years/Ans
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

New Self-Diagnostic Mobile App to Honour CHS Founder Marie Warder

The Canadian Hemochromatosis Society is launching a fundraising campaign to mark the passing one year ago of a remarkable Canadian woman who single-handedly launched a nation-wide battle to alert Canadians to the dangers of hereditary hemochromatosis (HHC).

To honour the memory of Marie Warder and to continue her work, the Society which she founded 35 years ago is seeking to raise $10,000 to fund the development of a simple self-diagnostic mobile app to help people of Celtic or Northern European descent determine if they may be among the estimated 80,000 Canadians who have the disorder but are unaware of it. Please consider giving a donation in her memory by using the donation form enclosed with this newsletter. You may also donate online through our website (www.toomuchiron.ca).

HHC impairs the body's ability to eliminate excess iron and affects about 1 in 300 Canadians. If undiagnosed and untreated, this excess iron accumulates in the organs or joints and often results in debilitating and sometimes fatal diseases, including cancer, heart disease, liver cirrhosis, diabetes, and arthritis. Tragically, three-quarters of the Canadians who have HHC have never been diagnosed and do not realize that their health is acutely at risk. And because too many doctors still consider hereditary hemochromatosis a relatively rare disorder, the diagnosis is often missed.

When Marie Warder's husband Tom was diagnosed with HHC, his body had suffered irreversible damage, and he eventually died of hemochromatosis-related cancer in 1992. Marie made it her lifelong mission to ensure others would not needlessly suffer the same way. She founded the Canadian Hemochromatosis Society, the Hemochromatosis Society of South Africa, and the International Association of Hemochromatosis Societies. She wrote a ground-breaking book on hereditary hemochromatosis, "The Bronze Killer," more than 300 articles on the subject, and patient literature for individuals, hospitals and other medical facilities that has gone to more than 16 countries. She appeared on local and national TV and radio and persuaded the Canadian Red Cross (now Canadian Blood Services) to accept blood donations from people with HHC. She also convinced Consumer and Corporate Affairs Canada to clarify language regarding iron content on food labels.

"It is incredible how Marie helped open people's eyes to this common yet surprisingly little-known disorder, both among the general public and medical professionals," says Dr. Sam Krickler, Medical Director of the Clinical Laboratory at Surrey Memorial Hospital in BC. "We urgently need to continue her work given the thousands of Canadians who still don't know they have this potentially deadly, yet easily treated condition."

Society President Ian Hilley is appealing to Canadians to acknowledge the anniversary of Marie Warder's passing by making a donation in her memory so the Society can develop a self-diagnositic mobile app to help Canadians decide if they should visit their physician to determine if they may be at risk of having HHC.

VERSION FRANÇAISE DU IRON FILINGS
Lorsqu'il fut temps d'imprimer ce bulletin d'information, la traductrice bénévole de la SCH travaillait fort pour traduire plusieurs articles importants. Afin de permettre l'envoi de la version papier, nous publierons la version française de ces articles sur le site internet seulement (www.toomuchiron.ca/support/newsletter). Merci de votre compréhension. L'édition du printemps 2016 sera publiée en français et en anglais.

You can help **iron out Hemochromatosis** in Canada.
Find out more at www.toomuchiron.ca

200 Canadians with Hereditary Hemochromatosis Donate Blood to Canadian Blood Services

The Canadian Hemochromatosis Society's partnership with Canadian Blood Services has resulted in 197 blood donations during the first nine months of 2015. Almost 200 people who have hereditary hemochromatosis (HHC) have donated their blood through the Society which is a member of the Canadian Blood Services "Partners For Life" program. The Society has set a target of 400 donations for 2015. CHS is urging individuals with hereditary hemochromatosis and who are in the maintenance phase to donate their blood to CBS.

The first step is to register online by visiting the following CBS webpage www.blood.ca/en/blood/how-do-i-join-team. CHS's partner ID# is CANA002257. This is a one-time process. Once you register, your blood donations will be tracked automatically with no further action on your part. To book an appointment to donate blood, call 1-888 2 DONATE.

CHS estimates that 110,000 Canadians are affected by HHC. CHS Chief Executive Officer Bob Rogers says, "People with HCC have the unique and staggering potential to meet the needs of hundreds of thousand of hospital patients in Canada. Unfortunately, many medical practitioners are unaware that their HHC patients can give blood to Canadian Blood Services. For example, a recent issue of the Canadian Medical Association Journal (CMJ) carried an article on a hereditary hemochromatosis case authored by three physicians. The article did not mention that the patient in question has the option of giving blood through CBS as part of his maintenance program."

Dr. Mindy R. Goldman, CBS's Donor and Clinical Services Medical Director, sent a letter to the editor of the journal pointing out that the authors of the article missed an opportunity to educate physicians about HHC and voluntary blood donations. Dr. Goldman wrote, "Patients with hereditary hemochromatosis who meet all other blood donor eligibility criteria may donate blood at Canadian Blood Service or at Hema Quebec. Donors may donate every 56 days which is the usual minimal interval for whole blood donations. If more frequent phlebotomies are needed, there must be a minimum one-week interval between a therapeutic phlebotomy in a hospital clinic and a donation at Canadian Blood Services. Currently, our volunteer blood system relies on approximately 4% of the eligible Canadian population who donate blood and iron deficiency is a common condition in high frequency donors. We therefore urge readers to discuss possible blood donations with individuals diagnosed with hereditary hemochromatosis, benefiting patients in need and saving scarce health care resources."

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Iron Fillings is published twice a year. If you have an article suggestion or a personal story about your experience with hemochromatosis please contact us at: office@toomuchiron.ca

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Former Member of Parliament and Cabinet Minister John Duncan Urges Early Diagnosis of Hereditary Hemochromatosis

John Duncan, a former BC Member of Parliament and Cabinet Minister, didn't know he had hereditary hemochromatosis until he was treated for another serious genetic disorder in 2010.

He was born with a bicuspid aortic valve which meant he has two leafs instead of three. Inevitably these valves calcify and fail over time. In December 2010, he received a new aortic value during open heart surgery.

"As part of his recovery, he was prescribed iron supplements. He had never taken iron supplements before and didn't like his body's reaction. After a few weeks, he decided to stop taking them. Only later did he realize why his body was reacting so badly to the iron supplements.

Eleven months later he was admitted to Emergency in Comox to treat an endocarditis infection from bacteria which had established a colony on his new valve.

As part of the diagnosis, his doctor ticked the ferritin box on his blood test form. "I do not know to this day what my status would have been if my doctor had not done this," he said. "The number came back at 7000 PPM or 70 times the normal level. The diagnosis was hereditary hemochromatosis." He started a full course of phlebotomies in the spring of 2013 to reduce the iron in his system. After 90 weekly treatments (about double the predicted number), he is now normalized at 100 PPM and is on a maintenance regime of just one phlebotomy per month.

"I have lifetime cirrhosis of the liver from iron build up and I have some affected joints that can make some things difficult," he said. "But I feel blessed to be otherwise healthy."

Mr. Duncan was a featured speaker at a Hemochromatosis Awareness reception on Parliament Hill last spring. His main message was: Simple routine testing for hereditary hemochromatosis makes sense.

He told the gathering that medical costs attributed to his hemochromatosis are adding up. His phlebotomies are in the order of $350 each occasion. He must also see a hematologist each year and has an annual ultrasound of his liver to ensure cirrhosis has not developed into cancer. He also said that he was fortunate that he did not develop other conditions which iron build-up is known to cause, including Depression, Type II Diabetes, Hypothyroidism and disease of the heart muscle.

"Given the prevalence of this inherited generic disorder in our population," he said. "It makes sense in every way to diagnose the disorder in the early stage. This will be cost effective and prevent irreversible damage. I congratulate the Canadian Hemochromatosis Society for their advocacy and Senator Wells for hosting this first meeting of the Hemochromatosis Society in this place. Today is a good start to effect change."

DUCA
Come bank with us.

DUCA Credit Union President and CEO Richard Senechal (centre) recently received an award to recognize the company's generous ongoing support of the Canadian Hemochromatosis Society. The award was represented by Josie St. Hilaire, CHS's newly appointed Ontario Regional Coordinator (left). CHS Executive Director and CEO Bob Rogers (right) also attended the presentation. Bob was in Toronto to attend CHS Awareness and Information events in North York and Kitchener/Waterloo. Bob also gave a hereditary hemochromatosis presentation to physicians and medical staff at Toronto East General Hospital.

CTV Report Alerts Thousands of Atlantic Canadians to the Prevalence of Hereditary Hemochromatosis

Thousands of Eastern Canadians recently learned about hereditary hemochromatosis (HHC) for the first time when CTV News Atlantic broadcast a story on the Iron Tracker app featuring an associate professor of computer science at Mount Allison University, who co-created the app in partnership with the Canadian Hemochromatosis Society which has been downloaded 5,000 times.

"If there is too much iron, it gets converted to a long term systemic form and is stored in the organs of the body," Andrew Hamilton-Wright said in an interview. "So it will end up in the heart; it will end up in the liver; it will actually end up in the tendons."

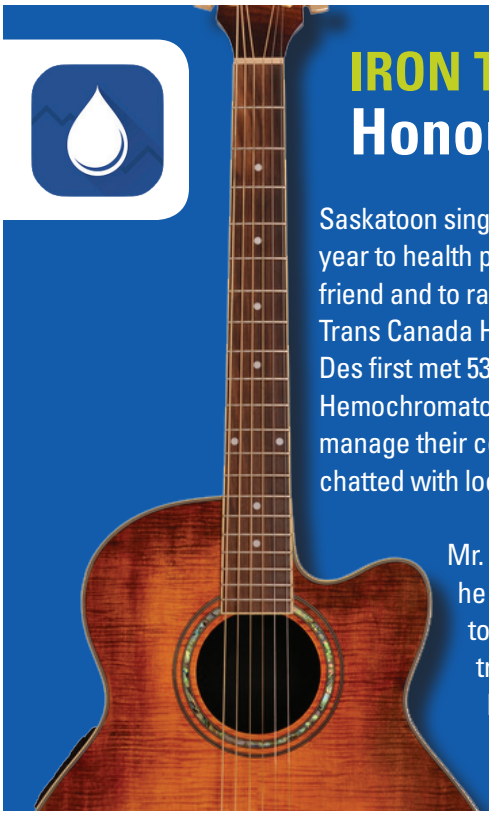
Professor Hamilton-Wright said roughly one in 300 Canadians of northern European ancestry have the condition. However, for people of Celtic descent, of which there are thousands in the Maritimes, the rate is higher. "I have seen numbers as high as one in seven for people who have ancestry from Ireland, or from Scotland, or north of England," he said.

The app which was co-created by Dr. G. Grewal of the University of Guelph allows those with HHC to track their iron levels and record medical appointments and observe progress over time. Professor Hamilton-Wright said there are even bigger benefits from the app–voluntary data collection. The data collection extension of the app will be rolled out over the next few months. "We now have this audience of the thousands of people who have downloaded the app and are using the app to improve their treatment," he said. "(Hopefully) some fraction of those people will be willing to share their data with us."

Ian Hilley, president of the Canadian Hemochromatosis Society was also interviewed for the story and said the ability to collect user information has huge implications. "We might be able to advocate for better services, better support, better partnerships with the Canadian Blood Services. So that is why it would be useful to use the mobile phones and the app as a source of information collection," he said.

CHS has posted a link to the CTV interview in the news section of its website (www.toomuch Iron.ca).

GET IT ON Google play Download on the App Store



IRON TRACKER TOUR
Honours One Life to Save Many

Saskatoon singer/songwriter Jack Walton lost his long-time friend Des Browning earlier this year to health problems caused by hereditary hemochromatosis (HHC). To honour the life of his friend and to raise awareness about the disorder, Mr. Walton took a musical journey along the Trans Canada Highway from Saskatoon to Des' hometown of Sudbury, Ontario where Jack and Des first met 53 years ago as high school students. The tour in partnership with the Canadian Hemochromatosis Society took its name from the Iron Tracker app which helps HHC suffers manage their condition. The tour also made stops in Ottawa and Orillia. At each stop Jack chatted with local media to share the message of early detection and treatment.

Mr. Walton said, "Des was very supportive and an influence on my music and he was active in the community so it seemed a fitting combination. I hope this tour raised awareness of the disorder and will result in early diagnosis and treatment for other Canadians who are presently unaware they have hereditary hemochromatosis."

Hereditary Hemochromatosis Makes It to Prime Time TV

The new CBS television series "Limitless" featured hereditary hemochromatosis in its pilot episode which aired September 22.

A member of the US-based Iron Overload Action Network was able to obtain a copy of the script, part of which is reprinted below. The plot is about the main character taking a drug that allows him limitless abilities for a period of time while he's on it. In the first five minutes of the show, he plays guitar and chess and basically a montage of him doing brilliant things he couldn't do before. Then he diagnoses what his father has been suffering from – Here's the dialogue straight out of the script:

BRIAN: My brother's medical school textbooks were still at my parents' place. Nobody else could figure out what was wrong with my father. Why can't I? Suddenly, I knew exactly what I was looking for...

(He looks at a picture of his grandparents on their honeymoon.)

Her eyes, they're the same as Dad's. It runs in the family.

BRIAN phones his father:
Good morning, Dad...
I think you've got something called, um hemochromatosis. It's caused by a trait that runs in our family. Uh, Grandma Helen had it, your cousin Scott. You've got it the worst out of anybody though and, um it's 'cause your body can't process iron.

DAD: All right, stop! Just stop. You spend one night on the floor and suddenly you're a doctor, Brian?

BRIAN: Dad, listen to me for a second, okay? Now, the inherited version of hemochromatosis is-is one of the most misdiagnosed diseases that there is. Doctors mistake it for dozens of other things.

DAD: And if they can't find it, how could you?

BRIAN: It's a long story. But there is a test that they can run called a, uh, transferrin saturation test. And, um I-I think you guys should take that.

Today: (cell phone rings)

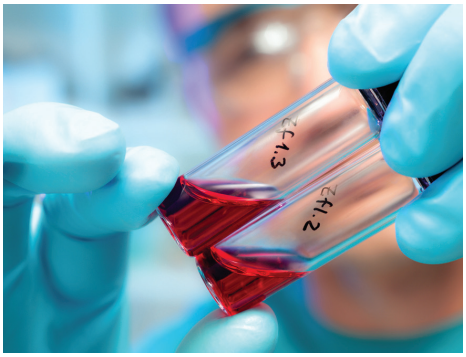
FEMALE ELECTRONIC VOICE: You have one new message.

MOM: Brian, uh, I don't know how you knew, but you were right. Your father has hemochromatosis.

New Drug to Treat Hereditary Hemochromatosis Approved for Testing in US

A US pharmaceutical company has received clearance from the Federal Drug Administration (FDA) to begin a Phase 1 study of LJPC-401, a novel formulation of hepcidin which is a naturally occurring regulator of iron absorption and distribution. By regulating the absorption and distribution of iron, hepcidin prevents excessive iron accumulation in tissues, such as the liver and heart, where it can cause significant damage and even result in death.

La Jolla Pharmaceutical is developing LJPC-401 for the treatment of iron overload, which occurs as a result of diseases such as hereditary hemochromatosis (HHC). HHC is a disease caused by a genetic deficiency in hepcidin that results in excessive iron accumulation. HHC is the most common genetic disease in Caucasians and causes liver cirrhosis, liver cancer, heart disease and/or failure, dementia and diabetes. LJPC-401 has been shown to be effective in reducing serum iron in per-clinical testing. Specifically, La Jolla has completed animal toxicology studies that demonstrated a dose-dependent reduction in serum iron levels in all species tested. La Jolla expects to release preliminary results from a Phase 1 clinical trial of LJPC-401 by the end of 2015.



It is estimated the 80,000 Canadians have hereditary hemochromatosis but are unaware they have the condition.

Meet the 2015-16 Board of Directors and Council of Advisors

Canadian HEMOCHROMATOSIS SOCIETY
Société canadienne de l'hémochromatose

The Canadian Hemochromatosis Society elected a new Board of Directors at its Annual General meeting in June.

The new president is **Ian Hilley**. Ian graduated in Pharmacy from the University of Bradford and has over 30 years experience working in global pharmaceutical companies. He lives in King City, Ontario with his spouse and daughters and is a keen fan of cycling and soccer.

The Treasurer is **Mark Jordan**. He is a Chartered Accountant working within a Canadian top 10 accounting practice. Mark has 10 years experience providing accounting services in Europe, Asia and North America. He lives in Vancouver and is a keen hiker, runner and skier.

Dr. Carlyn Volume-Smith is a licensed pharmacist who possesses a Master of Science degree in Health Promotion and a Ph.D. in Pharmaceutical Sciences. Carlyn is responsible for departments that adjudicate extended health, travel, dental and drug claims for Alberta Blue Cross benefit plans. She works closely with a Ministerial advisory committee that provides advice on drug formulary coverage.

Dr. Samuel Krikler is Medical Director of the Clinical Laboratory at Surrey Memorial Hospital. Sam is a hematopathologist with a long standing interest in hereditary hemochromatosis. Sam's research is community-based and recently it has focused on non-HFE iron overload in the Mennonite community residing in the Fraser Valley. He helped to develop the provincial guideline for the investigation and management of iron overload. He is a Clinical Associate Professor within the UBC Department of Pathology and Laboratory Medicine.

Stephen Bromley is an actuarial analyst in the pension department of the consulting company Morneau Shepell.

Steve Mitchell has 35 years experience as a communications professional with major Canadian companies and is an independent communications consultant. He is currently Senior Strategic Communications Advisor to Kinross Gold Corporation, the world's fifth largest gold producer. He studied at the University of British Columbia and the University Of York (UK) and holds a BA in English (Honours).

The Board is supported by a Council of Advisors made up of the following individuals

Andrew Hamilton-Wright is an Associate Professor in the Department of Mathematics and Computer Science at Mount Allison University, a public liberal arts and sciences school in Sackville, New Brunswick. He pursues research into information management and decision-making as it pertains to the management and understanding of biomedical data problems. Current projects include the IronTracker hereditary hemochromatosis treatment management app, and electromyographic signal processing, information management and visualization.

Gary Grewal is a Computer Science Professor at the University of Guelph, where he is contributing to raise awareness about hereditary hemochromatosis internationally through the development, maintenance and advertising of the Iron Tracker mobile application which he co-developed with Andrew Hamilton-Wright.

John Lee has worked for the Alberta Government for 35 years and has also been operating a successful life coaching /first aid business for the last 10 years. He enjoys traveling, working with developmentally disabled adults in an art setting, reading and learning.

Geneviève Myhal is a Business Analyst at Héma-Québec where she is contributing to raise awareness about hereditary hemochromatosis within the medical community and eventually helping to improve access to blood donation for people with hereditary hemochromatosis. She is member of the CHS Board's Medical Education & Awareness Committee.

Pat Haney is a Partner in Pacific Surgical Holdings Ltd., and serves as president of its Keir Surgical division. Keir Surgical is a Canadian distributor of surgical products, with a specialty in surgical instruments. Patrick has B.Sc. in Genetics from the University of Alberta and an MBA granted jointly from Queen's University and Cornell University. Pat is a Past President of the Canadian Hemochromatosis Society (2012-2015)

Scott Bissessar is an Ex-CFO with global experience in energy, financial services and health; private sector and NFP director experience with focus on enterprise risk, talent, succession and executive compensation.

Gordon Sutherland is a co-owner and director of Copol International Ltd, an extruder of polypropylene film, in North Sydney, NS. Gordon has been removed from the daily activities of the company for 12 years and spends his time traveling and volunteering with local organizations. He lives in Nova Scotia in the summer and Florida in the winter.

Jean-François Granger graduated from Concordia University with a Bachelor's Degree in Commerce and then obtained a Master's in Business Administration (MBA) from Université de Montéal's HEC. He has over 20 years of experience in the medical/surgical industry and currently holds the position of General Manager at Galen Medical Ltd. "JF" as he likes to be called lives in Montréal and has a daughter.

Deborah Storlien-Cundy is a health facilities capital planner and has worked in the Government of Alberta for over 26 years. Deborah lives in the Edmonton region and is married with a teenage son.

MRI Effectively Measures Hereditary Hemochromatosis Iron Burden

Magnetic resonance imaging (MRI) is an accurate and safe tool for the detection of low levels of iron overload in patients with hereditary hemochromatosis, according to a letter to the editor published online in the American Journal of Hematology.

Magnetic resonance imaging (MRI) is an accurate and safe tool for the detection of low levels of iron overload in patients with hereditary hemochromatosis, according to a letter to the editor published online in the American Journal of Hematology.

Reijâne A. Assis, M.D., from Hospital Israelita Albert Einstein in São Paulo, Brazil, and colleagues examined all medical records of consecutive patients with iron overload seen in a tertiary hospital in Brazil (159 patients; 2008 to 2012) in order to correlate MRI T2* with HFE genetic profiles.

The researchers found that mutations in the HFE gene were identified in 68.6% of patients. Of the 3 patients (out of 126) with positive T2* MRIs, 2 had the H63D mutation (1 homozygous and 1 heterozygous). Of the 61 patients with liver overload, 27.9% were C282Y carriers and 50.8% carried the H63D mutation. The C282Y mutation (in either homozygosis or heterozygosis), compound heterozygous (C282/H63D), and H63D in homozygosis were significantly associated with a higher frequency of iron overload in the liver as measured by T2* ($P = 0.001$).

"Given the observation that MRI is an accurate and safe tool to measure iron stores in these organs, we believe that this technology should be incorporated in the investigation of suspected cases of hereditary hemochromatosis and contribute to guide therapeutic decisions such as phlebotomy," the authors write.

Jack Swanson Memorial Golf Tournament Raises $4,000 for CHS

The 10th Annual Jack Swanson Memorial Golf Tournament held this September near Edmonton raised $4,000 for the Canadian Hemochromatosis Society. Jack Swanson was an avid golfer who passed away suddenly in 2005. Steve Melin, who was a lifetime friend of Jack Swanson and family has hereditary hemochromatosis. So the proceeds of this tournament went to our Society. A member of the Swanson family, Susan (Swanson) Brayford, said Steve and his employer Northgate Chevrolet in Edmonton have supported our different causes every year. Therefore, it is with pleasure that a Society that supports Steve will benefit from this year's tournament.

2 Percent of Canadians with Type 2 Diabetes Have Hereditary Hemochromatosis

Representatives of the Canadian Hemochromatosis Society attended a Canadian Diabetes Association information and awareness event in Toronto this November to inform attendees that two percent of type 2 diabetics have hereditary hemochromotatosis.

Attendees of Celtic or Northern European descent we given a short self-diagnostic quiz and encouraged to consult their physician if they had any two of the symptoms listed below. If hereditary hemochromatosis is suspected, your physician will need to order a FASTING iron saturation percentage (TSat) and a serum ferritin test. If both test results are elevated, the next step is a HFE genetic test to clinically confirm the diagnosis of hereditary hemochromatosis. All the tests are covered by your provincial medical plan.

Canadian Diabetes Association

- chronic fatigue or tiredness
- pain and stiffness in the joints of the hand particularly the small joints at the base of the thumb, index and middle fingers
- abdominal pain and bloating in the upper right region
- loss of libido and/or erectile dysfunction in men
- loss of libido and irregular periods and/or early menopause in women
- pigmentation of the skin resembling a sun tan or slate grey colour
- onset of diabetes (type 2) insulin resistant diabetes
- an irregular heartbeat
- thyroid problems
- elevated liver enzymes
- personality changes, mood swings; anger and depression

A 10-minute Radio Clip "Required Listening" for Every Canadian of Celtic or Northern European Descent

Calgary radio talk show host Danielle Smith whose father-in-law had hereditary hemochromatosis interviewed CHS Executive Director Bob Rogers in October when he was in Calgary to attend a CHS Information and Awareness Event. A 10-minute clip of the interview is an excellent primer on Canada's most common genetic disorder. All Canadians of Celtic or Northern European descent should listen to it. The clip is posted in the news section of the CHS website (www.toomuchiron. ca)

HEREDITARY HEMOCHROMATOSIS

VERY COMMON • UNDER-DIAGNOSED • POTENTIALLY FATAL • EASILY TESTED • EASILY TREATED

Your support helps fund our programs

Community Outreach
Prevention of hemochromatosis-induced suffering begins with awareness. By raising awareness through community outreach, affected individuals can recognize the disorder and receive the proper tests and treatment for hemochromatosis before damage is done. When detected and treated early, individuals can avoid the pain and diseases associated with undiagnosed hemochromatosis, and have a normal life expectancy.

Patient Support
CHS provides support for hereditary hemochromatosis sufferers and their families to help them understand and manage the disorder. As part of this program, CHS also provides information to physicians and other front-line medical personnel to share available treatment information related to hemochromatosis. This program helps affected individuals receive the best route of care and management for their iron overload and related illnesses.

Medical Referral Network
CHS maintains a network of medical professionals who are recommended for their knowledge and capacity to treat hemochromatosis as recognized by CHS medical advisors, members and supporters. These medical professionals include general medical practitioners, medical specialists, dieticians, naturopathic doctors, therapists and genetic counsellors from across Canada.

Awareness Month
May is recognized as National Hemochromatosis Awareness Month. During Awareness Month, volunteers and staff of CHS concentrate their efforts to plan and implement awareness activities across Canada, enabling stronger messages about hemochromatosis to reach the public.

Be Aware and Volunteer
Volunteers are the heroes of the Canadian Hemochromatosis Society. Through their passion and dedication, they are inspiring ambassadors of the organization and contribute greatly to the many successes of CHS. Volunteer recruitment, coordination, training and management are activities that keep volunteers engaged and challenged as they help CHS with its mission and programs.

Hereditary Hemochromatosis is a genetic disorder that affects over 3,000,000 people in Canada. Help us reach them with the cure: Awareness.