

# Iron Filings

Providing information, awareness and support

## Our Vision

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

## Rob Ross's Hereditary Hemochromatosis Nightmare

Rob Ross, who runs a catering business in Port Albert, Saskatchewan was suffering from a host of health problems, including seizures, memory loss, unexplained weight gain and aching joints. Despite numerous visits to a variety of medical practitioners, it took almost two years to find a doctor who agreed to order a genetic test on the recommendation of a nurse practitioner who suspected that Rob may have hereditary hemochromatosis. The test confirmed her suspicion: Rob has the disorder.

After his diagnosis, Rob urged his family members to be tested, too. "Nearly my entire family, on both my parents' sides, either have hereditary hemochromatosis or are carriers,"

Rob said. "If I had not been diagnosed when I was, my doctors say I would not have lasted a year. I was having severe seizures due to iron being deposited in my brain."

Rob is now certain his father died of HHC at the age of 53. He also believes his grandfather's early death was related to the disorder. "My dad's brother has also tested positive," he said. "But it has advanced far beyond any point of repair. He is now in a care home at the age of 66."

Rob's mother, Alana, is a registered nurse and helped Rob through his ordeal. "He was always so tired," she said. "He was retaining fluid to



Rob Ross and his mother Alana in healthier times. (inset shows Rob's weight gain caused by HHC)

the degree that his clothing size could change 2-3 sizes in course of a week. His legs were like tree trunks and he ended up in compression wraps with an ulcer on one leg." (continued on page 2)

## Senator David Wells Hosts Second Parliamentary Reception to Boost HHC Awareness

Members of Canada's House of Commons and the Senate will be learning more about the risks of hereditary hemochromatosis to Canadians and its steep costs to Canada's health care system as part of hereditary hemochromatosis month in May.

Senator David Wells of Newfoundland and Labrador will be hosting the second annual Parliamentary reception in Ottawa May 31 in

support of the Canadian Hemochromatosis Society (CHS).

All 338 Members of the House of Commons and 82 Senators will be invited to the gathering. CHS will be supported by volunteers from the Montreal, Ottawa and Toronto Chapters. At last year's reception, Senator Wells, former Minister John Duncan from British Columbia, and CHS Past President Pat Haney

all shared their personal HHC stories with the assembled guests.

"We are delighted that Senator Wells is building on the success last year's reception as a great way to raise awareness of HHC among members of our Federal Government," said CHS President Ian Hilley.

(continued from page 1) Alana said Rob was referred to a urologist who took a history and told him to go home and lose weight.

"We persisted with numerous visits to doctors and the ER," she said. "One nurse practitioner who suspected hereditary hemochromatosis sent Rob to an internist who was certain it was something other than HHC, despite Rob's high ferritin levels."

"It was a nightmare for two years even after the diagnosis. Rob looked like he was dying before my eyes. Thankfully, I was familiar with the system and had good support from my colleagues. I do not know what I would have done otherwise," she said.

Rob still has a lot of joint pain and has permanent problems with his blood pressure, heart, and kidneys. He also suffers from

diabetes and arthritis – all told, a very steep price to pay for a lack of knowledge about a treatable disorder.

"The area where I was born and grew up has a large population of people with HHC and our local clinic and practitioners have very little knowledge of the disorder," Rob said. "My mother and I would be very interested in establishing a CHS chapter in the area."

## Undiagnosed Hereditary Hemochromatosis Costs Health Care System Millions



Canada's health care system could save many millions of dollars each year if every Canadian with hereditary hemochromatosis (HHC) was diagnosed and treated, according to a position paper just released by the Canadian Hemochromatosis Society. HCC, Canada's most common genetic disorder, causes the body to store excess iron in various unintended parts of the body, including the liver, heart, pancreas and joints. Left untreated, this overload of iron can have devastating consequences.

The paper entitled "The Economic Burden of Undiagnosed Hereditary Hemochromatosis" was prepared by Dr. Sam Krikler, a Hematopathologist who is the Director of the Department of Laboratory Medicine at Surrey Memorial Hospital and an Associate Clinical Professor in the Department of Pathology and Laboratory Medicine at the University of British Columbia. Dr. Krikler is also the Chair of the Canadian Hemochromatosis Society's Medical Advisory Board. The paper states that the prevalence of the most "common" (C282Y) form of HHC is approximately 3 per 1,000 in Canadians of Northern European heritage.

Large population studies have shown that 70 percent of affected individuals will load iron and 10 percent of these will develop severe complications of iron overload, including diabetes, arthritis, cirrhosis and hepatocellular carcinoma (primary liver cancer). The latter two conditions are the most serious complications of untreated HHC and are responsible for the highest direct costs to the health care system; and general societal costs for lost economic productivity. Based on the above statistic, it is estimated that approximately 80,000 people in Canada are at risk of developing HHC. Early diagnosis (by iron chemistry tests and the confirmatory genetic test) and treatment by phlebotomy (blood-letting) prevents these serious diseases which rob people of their health and also add avoidable expenses to the health-care system.

A recent comprehensive report prepared by the Canadian Liver Foundation points out the economic impact of liver disease in this country. According to the report, average annual costs for inpatient diagnostic and therapeutic procedures alone (e.g. endoscopy

and paracentesis) for liver disease amount to \$50 million. This does not include costs related to hospitalization (nursing care, drugs, laboratory tests and imaging studies). Out-patient costs (doctors visits, etc.) must also be considered. The societal cost for lost productivity and the toll borne by care-givers cannot be ignored. Based on a conservative assumption that approximately 5% of cirrhosis and liver cancer is caused by undiagnosed HHC, the total cost runs into many millions of dollars. Two other common diseases associated with HHC add multiples to any base amount attributable to the condition. It is estimated that 30% people with HHC will develop some form of arthritis and that two percent of insulin resistant type-2 diabetics have HHC.

The paper concludes that there is a strong business case to allocate resources for the early diagnosis and treatment of HHC in addition to the ethical imperative to prevent and minimize suffering which is the **raison-d'être** of the Canadian Hemochromatosis Society.

## We Need Your Email Address To Stay In Touch

The Canadian Hemochromatosis Society is always looking for ways to reduce costs, work more efficiently and direct the most donor dollars towards our public awareness and client support programs. That includes finding the most cost-effective ways to stay in touch with our community.

With widespread use of the internet, email, and social media, more and more

not-for profit organizations are switching to electronic newsletters to eliminate the significant costs of printing and mailing, save trees, and allow more timely contact with subscribers.

We are considering switching Iron Filings to an electronic format and delivery, both to take advantage of these cost savings and enhance our communications with you.

**But to do that, we need your email address.**

If you want to be sure to stay in touch through Iron Filings, the law requires that you actively invite us to contact you. Please send your email address today to [program@toomuchiron.ca](mailto:program@toomuchiron.ca) stating: "Yes, I authorize you to contact me via email if you decide to switch Iron Filings to an electronic format."

# Bob Rogers Retires As CHS Executive Director

Through media interviews, workshops, open houses, and countless one-on-one conversations, Bob helped to build awareness of hereditary hemochromatosis in Canada and save lives by spreading the message of early diagnosis.

After over eight years as a passionate advocate and spokesperson for Canadians with hereditary hemochromatosis, Executive Director Bob Rogers is retiring from the Canadian Hemochromatosis Society.

Bob was dedicated to furthering the vision and legacy of Marie Warder throughout his tenure with the CHS. Through media interviews, workshops, open houses, and countless one-on-one conversations, he has helped to build awareness of hereditary hemochromatosis in Canada and save lives by spreading the message of early diagnosis. He enhanced the reach of the CHS message by developing a high-quality website and through the Society's newsletters, social media, and other channels.

Under his leadership, CHS broadened its national network of regional chapters, volunteers and activities, while still maintaining its strong B.C.

base. All the while, Bob helped thousands of Canadians with hereditary hemochromatosis to better understand and manage their disorder and get connected with the right medical professionals and services. Last but by no means least, Bob developed important sources of revenue support for CHS programs while managing the Society's finances carefully.

"On behalf of the CHS board, staff, and volunteers, I want to thank Bob for all he achieved for our Society and wish him the very best in retirement," said CHS President Ian Hilley.

"As a board, we remain strongly committed to furthering the CHS mission to save Canadians from needless suffering and death as a result of hereditary hemochromatosis. We will be re-doubling our efforts in the coming weeks and months to deliver on the many programs and events we have planned for 2016, including a



busy roster of activities during Hemochromatosis Awareness Month in May," he said.

"Let me take this opportunity to extend a heartfelt thanks to our donors and volunteers for their continued generosity and time in helping us to deliver on the vital CHS mission," he said.

## Pharmacists Urged To Help Identify HHC Sufferers

By Dr. Caryln Volume-Smith, CHS Vice President and Licensed Pharmacist

Often individuals with Hereditary Hemochromatosis (HHC) who are suffering from the effects of iron overload remain undiagnosed until irreparable organ damage has occurred, affecting their longevity and quality of life. Community pharmacists are often one of the first health care providers who are approached by patients suffering from

tiredness, aches and pains and general malaise in an effort to self-treat before proceeding to their family physicians. Unfortunately, some remedies for such symptoms could end up harming HHC sufferers over the long term. For example, advising regular dosing of acetaminophen (e.g. Tylenol®) could harm an already damaged liver. Recommending iron supplements or multivitamins with iron can create even more iron overload in an already dangerous situation.

In an effort to ensure that potential HHC sufferers are identified at the pharmacy counter, the Boots pharmacy chain in the United Kingdom, in cooperation with the Haemochromatosis Society of the UK,

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has created an educational program for pharmacists. This program is aimed at increasing pharmacists' knowledge about the causes, symptoms, risks and management of HHC. The Canadian Hemochromatosis Society (CHS) believes that a similar program in Canada would also prove helpful for Canadian pharmacists and is actively working to increase awareness of HHC in the Canadian pharmacy profession.







## Irons for Iron

You are invited to take part in one of our annual Irons for Iron Golf Events this May and June! Irons for Iron is a fun day of golf with

friends to support CHS programs which create awareness and provide support to those affected by hereditary hemochromatosis. Players of all skill levels are invited to participate. Early registration is encouraged, as spots are limited.

**For details or to register for Irons for Iron events, please visit [www.toomuchiron.ca](http://www.toomuchiron.ca) or phone 1-877-223-4766.**

**THURSDAY, MAY 19, 2016, 12:00 PM**

## Irons for Iron Toronto Event (\$200)

Royal Woodbine Golf Club  
195 Galaxy Boulevard, Toronto, ON M9W 6R7  
Deluxe patio BBQ lunch with golf to follow

**THURSDAY, JUNE 2, 2016, 1:00 PM**

## Irons for Iron Vancouver Event (\$215, dinner only \$100)

Quilchena Golf & Country Club  
3551 Granville Ave, Richmond, BC V7C 1C8  
Golf with deluxe BBQ dinner to follow  
Dress code in effect (No jeans, please.)

**FRIDAY, JUNE 3, 2016, 1:00 PM**

## Irons for Iron Ottawa Event (\$120, dinner only \$45)

Cassellview Golf and Country Club  
844 Aurele Road, Casselman, ON K0A 1M0  
Box lunch and golf, with dinner to follow

# New Jersey Considers Testing All Infants for HHC Genetic Mutation

The New Jersey State Legislature is considering a Bill that would require all infants born in the state to be tested for the genetic mutations associated with the development of hereditary hemochromatosis.

Under the Bill, if an infant is found to have one or more of the genetic mutations associated with hereditary hemochromatosis, the medical care provider overseeing care of the infant would provide the parents with genetic counseling and information concerning the risk factors, symptoms, screening procedures, and the treatments available for hereditary hemochromatosis. The parents would also be provided with information concerning the risk that they, their parents, and their children may carry one or more of the genetic mutations and information about genetic testing. If an infant is found to carry two mutated genes associated with the development of hereditary hemochromatosis, the bill would permit the medical care provider to retain the genetic test results until such time as the tested infant turns age 18. At that time, the hospital, birthing facility, or medical facility would provide that person with information concerning the risk that the person may develop hereditary hemochromatosis, the symptoms of hereditary hemochromatosis,

the procedures for, and benefits of, periodic screening for the development of hereditary hemochromatosis, and the available treatments for hereditary hemochromatosis.

The Bill cites the federal Centers for Disease Control and Prevention (CDC) which reports that the greatest risk factor for developing hereditary hemochromatosis is inheriting two copies, one from each parent, of a mutated HFE gene. Not every person who inherits two copies of the mutated HFE gene will develop hereditary hemochromatosis; however, a person with two copies of the mutated gene has a much greater risk of developing the disease and should undergo periodic blood screening to detect signs of excess iron buildup. Similarly, a person who inherits one copy of the mutated gene will usually not develop hereditary hemochromatosis; however, the person is said to be a "carrier" and may pass the gene on to their children. If both parents are carriers, there is a risk their children will inherit two copies of the mutated gene and potentially develop hereditary hemochromatosis. Additionally, when a person is found to carry one or more of the mutated genes, that person's parents and siblings may carry one or two copies of the mutated gene and may be at risk for developing hereditary hemochromatosis.

According to the CDC, the symptoms of hereditary hemochromatosis rarely appear before adulthood. Symptoms may vary depending on which organs are affected by the excess iron buildup, and early symptoms often resemble those of other common diseases, which may make the condition difficult to detect before irreversible organ damage has occurred.

Once detected, hereditary hemochromatosis is highly treatable by periodically drawing blood from the arm, a process known as phlebotomy, until the person's iron levels return to normal. Once iron levels return to normal, periodic phlebotomy sessions may be necessary to maintain proper iron levels. The CDC suggests that, if treatment begins before organ damage occurs, the person can expect to live a normal lifespan.

