

Iron Filings

Providing information, awareness and support

SPECIAL REPORT ON AWARENESS MONTH

Radio Shows and Info
Sessions and Golf
Events.... Oh May!

The month of May kept volunteers and staff across the country busy providing radio show and television interviews, presenting public information sessions and hosting golf events. The feedback on all this activity has been extremely positive and encouraging. This special edition of Iron Filings aims to share with our readers the excitement and momentum that May Awareness Month has brought to the Canadian Hemochromatosis Society | Société canadienne de l'hémochromatose (CHS), its members, supporters, volunteers and those affected by hemochromatosis.

Getting the Job Done

BOB ROGERS, CANADIAN HEMOCHROMATOSIS SOCIETY CEO | EXECUTIVE DIRECTOR

My recent trip to the Maritimes this May proved truly productive and inspiring. Information sessions were packed with individuals wanting more information to help them understand the disorder. Our first annual Irons for Iron Golf Event in Cape Breton was a successful fundraiser. Media outlets in Atlantic Canada bent over backwards to make sure our message was heard on their programs and read in their newspapers. New volunteer Chapters are being formed.

Atlantic Canadians understand the impact that undiagnosed hemochromatosis makes in their local communities and none more so than a

significant donor in Nova Scotia, whose support made this trip possible. Results from this trip will fill some key priorities for CHS: ensuring individuals get tested, diagnosed and treated early; informing family doctors of the prevalence of hereditary hemochromatosis and thus raising their level of suspicion for the disorder; and getting provinces to work with us to establish protocols. All of these priorities were advanced by my trip this year. Still, more needs to be done. With 110,000 Canadians at risk for iron overload, our job is to reach each one of these individuals and their families. With the support of Canadians coast to coast, we will get this job done.



Bob with Scott Simpson of News 95.7 in Halifax, NS

Awareness in Atlantic Canada Reaches New Heights

Those on the East Coast would have had a hard time missing hemochromatosis-related awareness activities this past May.

Five information sessions were held across the Maritime Provinces, including one each in Moncton, NB; Charlottetown, PE; Sydney, Sydney Mines and Halifax, NS. Turnouts for these sessions were outstanding, with 80 people alone coming to the Moncton information session to learn more about the disorder,

meet others affected by hemochromatosis and discover ways to raise awareness of hemochromatosis in their community.

To promote these information sessions in advance, newspapers ran stories on locals who suffer from hemochromatosis. Joanne Lagacé relayed her personal hemochromatosis story in the *Moncton Times & Transcript*, Seana Evans-Renaud's story appeared in *The Guardian* in PEI, and Kevin MacInnis was featured in the *Cape Breton Post*.

CHS Executive Director Bob Rogers was interviewed on five CBC radio shows, including *Information Morning Moncton*, *Mainstreet PEI*, *Information Morning Cape Breton*, *Maritime Noon* and Radio Canada's *Libre échange*. Joanne Lagacé and Ivan Doncaster shared their personal stories with listeners in Moncton and Cape Breton, respectively. Bob also provided a radio interview with *Maritime Morning* on News 95.7.

On television, Sara Fraser of *CBC News: Compass* reported a story on the state of hemochromatosis testing and diagnoses on PEI, and featured Seana Evans-Renaud, physician

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



Bob Rogers listens to a question at the Moncton Information Session

Dr. Terry Magennis, and PEI Health Minister Doug Currie.

To top off all the publicity and information events, newly diagnosed Melita Paul in Newfoundland and Labrador gave a radio interview on CBC Radio One's *Labrador Morning Show*. Melita provided listeners with insight into a typical individual's journey towards diagnosis, as well as sharing her particular challenge in her treatment regime: having to drive 500 km each week to travel back and forth from the closest clinic that performs phlebotomies – a task made even more difficult due to fatigue caused by the blood removal.

In addition to the public events, Bob Rogers met privately with PEI Health Minister Doug Currie to discuss adding hemochromatosis screening tests to the standard blood tests, and creating screening and treatment protocols. Bob was encouraged by the discussion, and will keep in contact with Minister Currie to ensure medical screening and treatment protocols are in place in PEI, and eventually in the rest of the Atlantic Provinces. Investigation and management of hemochromatosis protocols in every Canadian province is a key objective and priority for CHS.

Hemochromatosis strikes a chord with many individuals and families in Atlantic Canada. CHS would like to thank the donor from Nova Scotia whose major contribution allowed CHS to make significant strides in heightening awareness in the Maritimes in May. Through donor and volunteer support, we can – and will – end the suffering and death caused by hemochromatosis.



A few of the stunning views we saw while promoting awareness

My Call to Action

By Sharon Spencer, River Ryan, NS

It was January 2012 when I was diagnosed with hereditary hemochromatosis. Unfortunately, like many others, the diagnosis came too late. I have been told that the iron got into my pancreas and that is why I am now a diabetic.

I'm not quite sure where in my family's history that this disorder began, but I believe it may have been on my father's side of the family. Looking back, I see now that a lot of my father's symptoms were hemochromatosis-related which brought him to an early death 18 years ago – he was 65. Then his sisters died of a liver complication and heart troubles. All were bad diabetics, and all of their deaths were more than likely related to hemochromatosis. My brothers and I are now in our 50's and just recently diagnosed with this disorder.

My request would be that every person in the risk population would be checked by the age of 30 for their transferrin saturation and ferritin levels, and if elevated, then checked for the genes. This would save unnecessary suffering for many people, not to mention the expense on health care due to complications.

I recently found an article in Reader's Digest dating back to 1995, regarding a story about a husband whose wife fought to gain awareness of hemochromatosis and its early diagnosis so people like her husband would not have to suffer when a simple blood test could



Sharon Spencer

have helped. Her story was an eye opener on just how much hemochromatosis should be addressed with medical authorities. This woman was Marie Warder, who founded the Canadian Hemochromatosis Society in 1980.

In closure, I would like to sum up in one word my feelings towards this misdiagnosed genetic disorder: disgust. I am disgusted that too many people are suffering and dying early because a simple blood test is not routinely done to detect this disorder. We need action now.

Among Ourselves

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

NEW FACES, NEW CHAPTERS

CHS is pleased to welcome the new volunteers who form the **Sydney Chapter in Nova Scotia**, the latest Volunteer Chapter to be created! Sydney's next Chapter meeting is planned for Tuesday, September 17th, 7pm at the Dobson Yacht Club, 600 Westmount Rd, and they are looking for more volunteers. If you can help with awareness or fund-raising activities in the Sydney area and would like to attend the meeting, please contact Gordon Sutherland at jgsutherland@live.com.

In **Ontario**, Kelly Walters is the new volunteer Regional Organizer of the Toronto Chapter, aided by Co-Regional Organizer and long-time volunteer, Kay Easun. To join Kelly and Kay in Toronto Chapter activities, please email Kelly at toronto@toomuchiron.ca.

The **Prince George Chapter** in British Columbia has been up and running since January, with Jim Owen taking on the role of Regional Organizer. Jim and his volunteer group were busy in March and April, with Jim being featured in awareness stories in the Prince George Free Press and on CKPG TV, and the group helping organize a public information session at the Civic Centre and

hosting an information booth at the Home Show. If you yearn to help spread the word on hemochromatosis in Prince George and surrounding areas, please contact Jim at princegeorge@toomuchiron.ca.

Plans are underway for **Moncton, NB** and **Halifax, NS** volunteer chapters to soon be operational. Other chapters in locations across the country are also being developed. Watch our website and Facebook page www.facebook.com/TooMuchIron for announcements and local contact details.

MONTREAL HAPPENINGS

Regional Organizer Juliana Pavelka-Johnston initiated a radio interview for the Canadian Hemochromatosis Society on The Right Chemistry with Dr. Joe Schwarcz. The interview aired on April 28 on CJAD 800 in Montreal, with CHS Executive Director Bob Rogers being heard over the airwaves. Juliana is currently organizing a Montreal Information and Awareness Event, being held in October. Details of this event can be seen on page 4.



Jim Owen with Bob Rogers at the Prince George Home Show

Where can I catch those interview?

To listen to the recorded radio show interviews and view the television interviews mentioned in this newsletter, please visit www.toomuchiron.ca/about/media.php.

DUgood in Your Neighbourhood

As a community minded credit union, DUCA Financial Services aims to do good at every opportunity. Introducing DUgood, a program that connects community banking with community giving. By joining DUCA through the DUgood program new members receive \$50 and can designate \$50 to their charity of choice. The Canadian Hemochromatosis Society is pleased to be one of the charities supported by the DUgood program.

DUCA tracks what has been donated to CHS through the DUgood program and if CHS has the most donations by 12/31/2013, DUCA will match the amount.

It's a great way to raise funds and boost CHS' profile. So get out there and rally people to DUgood.ca and watch the donations grow.



DUCA is a diamond level sponsor of the Canadian Hemochromatosis Society. For more information about DUCA visit duca.com.



On May 6th, CHS Executive Director Bob Rogers (r) presented DUCA Financial Services Credit Union with a Diamond Level Sponsorship Plaque in appreciation of their generous corporate support. DUCA president and CEO, Richard Senechal, accepted the gift and presented Bob with a cheque.

Blue skies made for two wonderful days at our inaugural *Irons for Iron Golf Events* held in Vancouver, BC and Cape Breton, NS. With the success of these two events, we will be holding our second annual *Irons for Iron* golf tournaments next year, with additional event locations across the country being planned.



Patrick Haney Speaks
at Irons for Iron
Vancouver



Donna MacInnis wins
closest to the pin at the
Cape Breton event

VANCOUVER

Thank you to all our participants and event organizers who helped make our Vancouver Golf Event on May 16th at Quilchena Golf & Country Club a success. The sun made the day perfect for a round of golf, as everyone had a great time on the course and at dinner afterward. Special thanks to Quilchena Golf & Country Club and our sponsors Rowland & Company Barristers & Solicitors, Metropolis at Metrotown, Alexander Holburn Beaudin & Lang, and Harrison Hot Springs Resort & Spa. Together, we raised a net total of \$6,125 that will go toward ending suffering and death related to hemochromatosis in Canada.

CAPE BRETON

On May 20th, as the sun shone down on golfers at The Lakes Golf Club in Ben Eoin, irons were swinging away to raise money for the Canadian Hemochromatosis Society. Together, our participants and sponsors helped us raise a net total of \$4,299! A great big THANK YOU goes out to our participants, event organizers, National Bank Financial, Copol International and The Lakes Golf Club.

Canadian
HEMOCHROMATOSIS
SOCIETY
Société canadienne de l'hémochromatose

Awareness Event in Montreal, QC



Royal Victoria Hospital
687 Pine Avenue West
JSL Browne Amphitheatre, M.3.01

Thursday, October 24th, 2013
7:00 – 9:00 pm

You are Invited

This event will connect hemochromatosis sufferers and their families to others afflicted with the disorder in the local community. Representatives of the Canadian Hemochromatosis Society (CHS) will provide information on the treatment and management of the disorder and updates on the activities of the Society locally, provincially, and nationally. Medical professionals, students and other guests are welcome. As space is limited please RSVP early!

This event is part of CHS' Community Outreach Program and is provided free of charge.

RSVP by October 1st to Juliana Pavelka-Johnston at montreal@toomuchiron.ca

Questions? Contact Regional Organizer:
Juliana Pavelka-Johnston T: 450-732-1103 or the
CHS Head Office at 1-877-223-4766

Attention: All Family Physicians in the Maritimes

As a result of appearing on the radio show *Maritime Noon* with Norma Lee MacLeod, Executive Director Bob Rogers has been invited to present a webinar for family physicians in Nova Scotia through Dalhousie University's Continuing Medical Education webinar program. If you are a family physician located in Nova Scotia and would like more information on the webinar, please contact the CHS head office at 1 877-223-4766 or email office@toomuchiron.ca. Many thanks go to Dr. Jean Cameron for spearheading this opportunity to create more awareness of hemochromatosis in the medical community.