

My Husband Died of Iron Overload

By Jackie Lalumière

In January 2010, my usually healthy, energetic 72 yr. old husband began to feel unwell, unable to describe the feeling except to say that he felt very tired. During several physicals, his doctor had noted a rise in ferritin levels. The doctor said there was no cause for alarm as he had seen much higher ferritin levels in other patients. There was no mention of iron overload; my husband and I assumed all was well.

By summer the ferritin levels had risen to 935 ng/mL. The doctor thought it may be iron overload and ordered more blood tests, but there still was no definitive diagnosis. During the next two years, without diagnosis or treatment, my husband began to show definite signs of what I now know to be hereditary hemochromatosis. He developed a bronze skin tone, and his friends would ask if he had been down south. He was constantly tired and lost his appetite. His ferritin was now 1,793 ng/mL.

Finally, in 2012, my husband was referred to a hematologist and a gastroenterologist. An MRI disclosed severe liver damage. Phlebotomies were ordered and iron levels decreased, but so did the white cell count. Following several inconclusive bone marrow tests, my husband was unable to continue with phlebotomy therapy due to his low white cell count. The only available treatment now was a chelation medication, but his damaged liver was

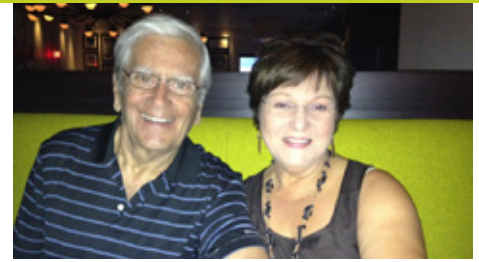
unable to filter this strong medication. His ferritin levels rose and he began to suffer many of the associated illnesses of hemochromatosis.

On Friday, April 19th 2013 I called the ambulance to take my husband to hospital. He died on May 3rd from complications of hemochromatosis due to an untimely diagnosis.

One important point to note is that at no time during my husband's consultation with doctors was there any mention that his family, siblings or children should be tested for this hereditary genetic condition.

My daughter and I could not believe that someone so healthy and full of life could pass from this world due to high iron levels. We researched the condition and discovered the Canadian Hemochromatosis Society (CHS). We also learned that ours was not the only case of a late diagnosis ending so tragically. We attended an information session in Montreal, and soon after we started the Ottawa Chapter for CHS. Our first information session drew a small number of attendees, but we found volunteers who were willing to help build the chapter.

Since those early days of starting up the chapter we have had several successful information sessions. We attend the Highland Games to help bring information



Tom and Jackie Lalumière

"My daughter and I could not believe that someone so healthy and full of life could pass from this world due to high iron levels."

to the Celtic population who are often affected by hereditary hemochromatosis. The chapter has organized four fundraiser golf tournaments and we attend health shows in the area, bringing awareness and information. The cure for hemochromatosis is awareness.

In our small group of eight volunteers, we have among us two who have hereditary hemochromatosis, my daughter and one of her friends are carriers of one of the mutations, and the father-in-law of one of our volunteers has just been diagnosed with the disorder. It is easy to believe that 1 in 300 Canadians is at risk of this genetic hereditary condition!

Annual Report – your generosity helped us make a difference on many fronts

The Canadian Hemochromatosis Society makes sure every dollar you donate works extra hard to fight hemochromatosis: 85% of revenues go directly to funding programs. These programs include Community Awareness & Outreach, Healthcare Professionals Referral Network, Client Support, Healthcare Professionals Awareness, and Volunteer & Chapter Development.



Our Facebook campaign reached 118,833 people per month

Community Awareness & Outreach

This program has the largest mandate: to reach individuals in all corners of this country who are at risk for hereditary hemochromatosis. Thanks to the generous support of our donors, we've had a busy year developing new resources and avenues for information and awareness including:

- **A 3-minute explainer video which has been viewed over 4800 times** on our website www.toomuchiron.ca and YouTube channel www.youtube.com/user/toomuchiron since May, and shared across the UK and Australia
- Three 30-second social media videos
- Three 30-second audio files for radio ads and public service announcements

- **A targeted Facebook campaign that ran from May (Awareness Month) to July and reached an average of 118,833 individuals each month in British Columbia alone.** This campaign leveraged videos, statistics and personal stories to reach and engage the audience. Over 94,800 users had watched the videos to completion by the end of the three month campaign
- **Guiding targeted Facebook users to our online Self-Assessment, which averaged 1400 visits per month during the campaign.** Each visit lasted over 3 minutes, indicating viewers are taking the time to assess their risk
- **Running 200 radio ad spots during the first quarter of the year, reaching over 1 million listeners,** and again as free public service announcements throughout May in 97 spots

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Annual Report Continued

- **Eight new information videos featuring Dr. Paul Adams of the University of Western Ontario, a leading global authority on hemochromatosis**, covering topics ranging from ancestral links to research to serum ferritin and diet
- Providing editorials and placing ads in targeted media
- **Hosting our annual “Hemochromatosis on the Hill” day, raising awareness amongst MPs and Senators on Parliament Hill.** Several MPs went on to inform their constituents about hemochromatosis using social and conventional media
- Twelve web pages (and counting!) of hemochromatosis information in French language to support our French community

Volunteer & Chapter Development

We welcomed and trained new volunteers from the West Coast through to the Atlantic Provinces while continuing to support existing volunteer chapters. Volunteers have appeared as guests on radio talk shows in Winnipeg, Moncton and Vancouver, hosted information sessions in Ontario and New Brunswick and staffed awareness booths on both sides of the country to promote awareness and speak on their personal experiences dealing with hemochromatosis. Many others answered the call to distribute brochures and posters in their communities during May Awareness Month and to promote awareness through social media using our online resources. The Ottawa Chapter held another fun and successful Irons for Iron golf event and fundraiser in June.



Members of the Ottawa Chapter

Healthcare Professionals Awareness

We participated at the Family Medicine Forum (FMF), an annual meeting of some 3500 of Canada’s 35,000 family physicians, to help raise hemochromatosis awareness and promote early diagnosis. A team of CHS volunteers from Vancouver staffed our booth which drew many physicians – thanks in part to the presence of our own “Iron Man”!



The opportunity for selfies with Iron Man at our booth was a main attraction at the forum

Client Support and Healthcare Professionals Referral Network

We are continuously updating our Healthcare Professionals Referral Network and working to improve the effectiveness of this program so that we can better support clients looking for the best route of care for their testing, diagnosis and treatment of iron overload. During the past 12 months, staff and volunteers have personally answered more than 280 client support calls and emails, providing much needed guidance and counselling for hemochromatosis patients, their families, and those who believe they may be at risk.

Help us “Iron Out” Canada!



How you can help launch an exciting new awareness campaign coast to coast

This year we tested new ground by running a hemochromatosis awareness campaign targeting potential at-risk Facebook users in British Columbia. The goal: to see how many people we could reach using social media.

The results were staggering. We reached an average of 119,000 people per month, with 1400 individuals taking the time monthly to perform our self-assessment, and 94,800 people viewing our videos to completion during the total campaign.

Imagine how many we can reach if we targeted the rest of Canada! With the population of Canada 7 ½ times greater than that in BC, our target is to reach 893,000 Canadians each month through social media, and have 10,500 of them use our self-assessment tool to evaluate their risk.

We need your help to make it happen. Only the support of donors like you will give us the funds we need to duplicate our success in BC across all of Canada.

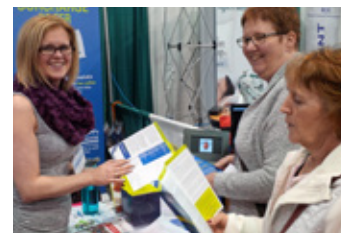
Think of the impact you could make on someone’s life.

Please consider providing monthly gifts to help us achieve our monthly targets. A donation of just \$15 per month or whatever amount you can afford could help ensure that at-risk Canadians where you live are learning about iron overload before it’s too late.

Spreading the word in Atlantic Canada

Jo-Anne Legacé shares her story

The first thing I did after I received my hemochromatosis diagnosis was ask my doctor for literature – she had none. I looked at the blood clinic – same story! That’s when I turned to the internet and came across www.toomuchiron.ca, the website of the CHS.



Jo-Anne Lagacé providing information at the Moncton Wellness Expo

The team at the Society is full of dedicated individuals who create awareness of hemochromatosis throughout Canada. A+ to them for sharing their invested interest in educating physicians, patients and volunteers on hemochromatosis. They were able to answer my questions and address my concerns. I knew one day I would work with the Society, although I wasn’t ready to become a volunteer at the time. Instead, I made periodic donations by pressing the “DONATE NOW” button on their site. It was the least I could do to thank them for their support.

It’s been three years since my diagnosis. Blood work and treatments vary between three to four times a year and it’s going well. I have a lot more energy, I walk a minimum of 6 kilometres a day, in the summer I train for 5 and 10 kilometers runs, I’ve successfully completed a college program, and I manage a fundraiser.

This year I have committed to build a volunteer Chapter for the CHS in Moncton, New Brunswick, to support the Maritimes. As a hemochromatosis sufferer, I know that local Chapters are key to bringing awareness and support to those who need these resources.

I’m looking for volunteers to help me spread the word here in New-Brunswick. If you’re looking for a great volunteer opportunity, please write to me at moncton@toomuchiron.ca.

Read more of Jo-Anne’s story and the stories of others affected by hemochromatosis on our website www.toomuchiron.ca/iron-chronicles