

## IRON TEEN

By Carimé Lane

Whenever I tell someone familiar with hereditary hemochromatosis (HH) about my diagnosis, they're always surprised – not because of sky high ferritin levels or condition – but because I was diagnosed at such an early age: 19-years-old. I was diagnosed because I went to the doctor with a history of arrhythmia, but I remember telling the doc I had been feeling a bit fatigued and sluggish as well.

At the point I was initially diagnosed, I had a fasting iron saturation of 90 per cent. Another blood test confirmed similar levels, so they had genetic testing done in a larger center near my hometown. This revealed that I carry two copies of the C282Y HFE mutation. My first phlebotomy was done in 2004.

I am of Dutch/French and German ancestry, so my diagnosis was also helpful in getting others in my family tested.

The last time I was in touch with a doctor about my condition specifically was more than few years ago, I'm afraid. At that point, the doctor informed me that, as a menstruating woman, I wouldn't need to be in touch with a doctor regarding HH until I reach menopause. Despite this advice, I have had tests done at intervals, and my iron levels have been found to be healthy, or even slightly lower, than they should be.

Beyond visiting the doctors, getting in touch with the Society has been the most helpful to me. I'm a freelance writer, who often reports on health and wellness, so the first time I reached out to the Canadian Hemochromatosis Society was to find people to interview for a story I was hoping to publish. The first story didn't end up selling, but the second story – a piece on Marie Warder, the founder of the Society – did! The story has been published in Folks magazine online - please feel free to follow the link below and share! Finding out about Marie, and her fight to inform the public and medical community about HH has also been helpful to me. It made me realize that many have been dramatically affected by the disorder, which is an especially good reminder to me since I am still healthy (despite having HH). Also, writing about Marie was a good reminder to stay on top of my condition, since we are becoming more informed about HH as the years go by. In fact, a couple of 2019 studies highlight the fact that HH is far more serious than was once thought (link below).



I'm currently a 36-year-old law school student in my second year (and still freelance writing as well), hoping to practice criminal law. Although these endeavours do put me in a chair more often than I'd like, I am pretty active and feel healthy. I feel grateful to the work of the Canadian Hemochromatosis Society for informing Canadians about the disorder, so that I can be in this position, where I'm aware of HH, and have the opportunity to care for my health with this knowledge.

Link to 2019 study:

University of Exeter. *Common gene disorder causes serious "stealth" disease, but could easily be treated.* Updated January 16, 2019. [www.exeter.ac.uk/news/archive/2019/january/title\\_700061\\_en.html](http://www.exeter.ac.uk/news/archive/2019/january/title_700061_en.html)

Link to my article:

[folks.pillpack.com/what-it-takes-to-fight-a-stealth-killer](http://folks.pillpack.com/what-it-takes-to-fight-a-stealth-killer)

## We are stronger together!

### Be a Member

Help us reach our goal of 500 members! A member can be anyone who has been affected directly or indirectly by hemochromatosis and cares about early diagnosis and treatment for all. We offer Lifetime Memberships for \$500 as well as Annual Memberships for \$36/year. The Canadian Hemochromatosis Society is your voice to create awareness of iron overload. As we continue to work to create awareness of hereditary hemochromatosis and promote the early detection and treatment of the disorder, we are confident that awareness is strengthened when you add your voice to ours. Join today! [www.toomuchiron.ca/membership](http://www.toomuchiron.ca/membership)



### Canadian Hemochromatosis and Canadian Blood Services are Partners for Life!

Have you registered with our Partners for Life team? Please register here [www.blood.ca/en/ways-donate/donate-partner/becoming-partner/team-member-registration](http://www.blood.ca/en/ways-donate/donate-partner/becoming-partner/team-member-registration) and your blood donation (and any other blood donations you have made this year) will be added to our annual team pledge. Use our partner ID # CANA002257 when registering. Our team total demonstrates how people with hemochromatosis are important contributors to the blood supply in Canada.



Canadian Blood Services Société canadienne du sang

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# 2019 – Year in Review

Over the past year, we have been privileged to hear more stories of people that have been affected directly and indirectly by hemochromatosis, to be a resource to people who have just been diagnosed with iron overload and to reach out to people all across Canada as we create awareness of one of the most common genetic disorders that people have never heard of. With every new member, we are growing the voice of people affected by hemochromatosis and people are becoming more aware of the benefits of early diagnosis and treatment for the disorder. Awareness is important and key to preventing the negative consequences of inherited iron overload. The Canadian Hemochromatosis Society strives to inform all Canadians about the signs, symptoms and treatment of iron overload.

Here's how we've been raising awareness in 2019:



## Awareness Through Multiple Channels

Building on the multi-media campaign utilizing Facebook, Google and YouTube in 2018, this past year we ran a series of creative bilingual Facebook campaigns in BC and Ottawa featuring patient stories, our new podcasts, and links to our *Learn More* downloadable pdf. We measured the engagement with the targeted audiences over the 1 ½ months of these campaigns, and continue to track other metrics.

- **151,264** average 28-day reach on Facebook, the highest number yet since we began our social media campaigns in 2017.
- **13,274** average 28-day engagement on Facebook, another all-time high.
- **19,357** clicks to our website during the 2019 campaigns.
- **1,679** total plays in the first four months of our new Too Much Iron Podcast series. These podcasts can be found at [www.toomuchiron.ca/support/too-much-iron-podcast](http://www.toomuchiron.ca/support/too-much-iron-podcast).
- **45** downloads of the *Learn More* pdf to date. The pdf can be found at [www.toomuchiron.ca/learnmore](http://www.toomuchiron.ca/learnmore) and is provided to help start a conversation with one's doctor about their risk for iron overload.
- **4** more personal stories from our members added to our webpage: [www.toomuchiron.ca/iron-chronicles](http://www.toomuchiron.ca/iron-chronicles).

## Awareness Through Grassroots Activities

2019 saw a number of community outreach activities, spearheaded by an amazing group of volunteers, including these highlights:

- Members meeting other members at Coffee Meet-ups in Montreal and Vancouver
- Volunteer Ambassadors providing awareness at Mobile Blood Donation locations in BC during May Awareness Month
- Group Blood Donation events in Vancouver BC, Victoria BC and Toronto ON hosted by our members and volunteers
- Ottawa Information Session – using Facebook Live for the second time to broadcast session
- Hemochromatosis information posters in 79 medical clinics across BC for 5 weeks
- Digital ads in select BC medical clinics for 5 weeks March - April
- Facebook Fundraisers – members are using Facebook to create awareness and raise funds for the Canadian Hemochromatosis Society
- Scotiabank Charity Challenge at the Tamarack Ottawa Race Weekend fundraiser – Kate and Mitch Carkner and Adam Weiss
- Awareness booth at the Family Medicine Forum in Vancouver to connect with 3,500 attending family physicians
- Volunteer Hellen Huang coordinates and delivers presentation at her local Seniors Centre

### Please Give

Help us reach our goal of \$25,000 this season. Your generous donations of money and securities support the good work of the Canadian Hemochromatosis Society throughout the year.

### Stronger Together Continued

#### Organize a Group Blood Donation Event near you and experience 3x the benefits!

1. Receive treatment. Invite others to join you when you “treat” yourself at a Canadian Blood Services or Héma Québec blood donor clinic near you.
2. Know that you are not alone. Meet others who are affected directly and indirectly by hemochromatosis.
3. Be a part of Canada’s Lifeline. Share your blood and save lives!

We are looking for people willing to organize Group Blood Donation Events in cities across Canada. Please consider this opportunity to volunteer 3-5 hours a month to organize monthly, bimonthly or even quarterly events in your area. The Canadian Hemochromatosis Society office staff and volunteers will help you promote the event and will shower you with appreciation! Please contact us at [chs@toomuchiron.ca](mailto:chs@toomuchiron.ca) or call 1-877-223-4766 (Tuesdays and Wednesdays).

#### Coffee Meet-Up Near You!

People are doing it! They are meeting up with others who have been affected directly or indirectly with hemochromatosis. Some of them have put a free ad in their local newspaper, some have advertised on Facebook, some have asked the CHS office to send out a targeted email to people in their area inviting them to meet. How about you? Would you like to meet people in your area that have experience with hemochromatosis? Create a Coffee Meet-Up, or let the office know where you live and we will help you organize one. Email us at [chs@toomuchiron.ca](mailto:chs@toomuchiron.ca) or call 1-877-223-4733.

