

## RETURNING FROM THE SHADOW OF ONE'S SELF

*Karine is a member of the Canadian Hemochromatosis Society and our newest volunteer who is helping us reach out to Canadian Francophones by posting on our Facebook page in French and providing translation. Karine exemplifies how we are truly stronger together! You too can help strengthen awareness of hemochromatosis by joining our membership at [toomuchiron.ca/membership](http://toomuchiron.ca/membership).*

My name is Karine and I'm 43 years old. I live in the "belle province", Quebec. Here is how I discovered the Canadian Hemochromatosis Society (CHS).

At the age of 36, I started feeling ankle stiffness in the morning. I couldn't go downstairs normally! I also started to feel bad in general. I was thinking to myself: wait, this is going to pass, this is how life is with a full-time job and 2 children... Then I had stiffness in my fingers, toes and back. Next was constant tiredness before I was 40.

Many naps punctuated the following months (years). I had become a shadow of myself. The energetic woman, always ready with a lot of projects in mind, spent her spare time sleeping. Physiotherapist, kinesiologist and chiropractor were consulted. Though, my life was perfect: I had the job of my dreams, two beautiful, adorable and healthy children, and their father, my partner of the past 10 years, had just proposed to me.

***"Alas, on my wedding day, during the photo shoot, all I wanted was ... a place to lie down and doze off!"***

It was around this time that my doctor decided to investigate further. A year later (!) I met a rheumatologist. She was the one who suggested the ferritin and transferrin saturation tests after ruling out other diagnoses. I remembered an uncle had had bloodletting. I made the connection. A blood test later, I cried with joy when I knew ... I finally had answers.

While researching the internet, I came across the CHS website where I found a lot of practical and quality information. I ordered Marie Warder's book, "The Bronze Killer," which I read with great interest. I became a member and was contacted by some people from the CHS who were looking to reach the francophone population of Canada, especially Quebec. I found that the people who worked at the CHS were empathetic humans, with a deep desire to help and to know the members.

It took seven years, three specialists and a lot of tenacity to find out. Today, naps are no longer part of my daily life and I have returned to a (almost) normal life. I donate blood as often as possible and try to educate as many people as possible about this little-known condition, which is like so many others. It will be a great pleasure for me to assist Liz and Brenda at CHS in order to meet the needs of francophones in Canada!



## Uncovering the Needs of the Hemochromatosis Community

By Caitlyn Vas

I started volunteering with the Canadian Hemochromatosis Society (CHS) in 2019. I joined CHS as a summer student after graduating from the University of British Columbia in May 2020 and was excited to work with the Society in a new capacity.

This year, CHS has focused on increasing its membership numbers, and therefore wanted to learn how it can better meet the needs of the people it serves. Thus, the Needs Assessment Project was brought to life, and I began working on this important research.

I met and spoke with some individuals affected by hemochromatosis, using Zoom, to gather preliminary data surrounding their opinions of the Society. The interviewees not only shared their personal stories, experiences and connections to hemochromatosis, but they also shared how much CHS has meant to them, as a source of information, connection and support. With the interview stage complete, we created the 2020 Needs Survey. You can access and complete this 10-minute survey using the QR code at the end of this article.

***"Please take the time to participate in the survey as your answers will help shape the Society's activities and ultimately make it stronger for you."***

As my time as CHS's summer student comes to an end, I want to express my gratitude for this amazing opportunity. I have learned and gained a lot through my time with CHS over the summer. I got a sense of what a strong community CHS has, and the potential it has going forward as it develops and grows.

I look forward to continuing my involvement with the Canadian Hemochromatosis Society in the next chapter of my life. Thank you to all my mentors and to CHS for your support, encouragement and positive experience I had working for you.



## Take the 2020 Needs Survey Now!

Go to [toomuchiron.ca/2020survey](http://toomuchiron.ca/2020survey) to complete the survey and provide us with your feedback on how we can meet your needs.

**Or scan the QR Code® alongside using your smartphone:**



# 2020 – YEAR IN REVIEW

This has been a year of global challenges with the COVID-19 pandemic. However, the year also provided new opportunities for the Canadian Hemochromatosis Society (CHS) to innovate and adapt. Our staff continue to support programs using tools such as Zoom and Microsoft Teams which have enabled us to reach more Canadians at low cost by connecting through online meetings and events. We have continued to increase our membership numbers and raise awareness of hereditary hemochromatosis in Canada. Now is the time to get involved with our awareness efforts by becoming a member, joining or starting a local Chapter and participating in local events either online or in-person. Now, more than ever, we are stronger together!

Here's a review of this past year's activities:

## Outreach Events

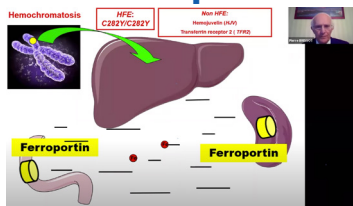
Prior to the pandemic, we hosted a booth at the Vancouver Wellness Show in February. This event was an opportunity for staff and volunteers to interact with people, distribute information and brochures and promote the CHS website and podcasts.

## Awareness Campaigns

Google search and display ads that ran mid-February to mid-March generated 8212 visits to the self-assessment page on our website, alerting visitors to their potential risk for hemochromatosis.

In May, our Awareness Month campaign featured a row of postcards with artwork from some of our creative members which were distributed to over 1100 people. These postcards were created as gifts to keep in touch with friends and family during the pandemic while raising awareness of hemochromatosis at the same time.

## Membership Lecture Series



A new lecture series was created for our members and offered to the public. The series featured renowned academic and medical professionals Prof. Pierre Brissot from Rennes, France in June, and Canada's own Dr. Paul Adams in July. Over 100 people participated in the live online Membership Lecture Series. If you missed the live events, be sure to watch their recorded lectures at [toomuchiron.ca/video](https://toomuchiron.ca/video).

## E-Newsletters



The Magnet is published monthly and is distributed to over 900 email mailboxes. This newsletter features upcoming events, stories and articles of interest for people affected directly and indirectly by hereditary hemochromatosis. Visit our website at [toomuchiron.ca](https://toomuchiron.ca) to subscribe to our emails and stay up to date on CHS happenings.

## Connections

### Coffee Meet-Ups

were held in person in Vancouver, Toronto and Edmonton early in the year. Once the pandemic hit, coffee meet-ups went virtual via Zoom, and we saw participation from



around the country and even internationally. We continue to invite people from across Canada to join or host meet-ups virtually or safely in person in their local cities and towns.

**Local Chapters** are being recharged in Toronto, Ottawa, Edmonton, Calgary, Vancouver and Vancouver Island. Members from across the country stepped forward to participate in the newly formed Chapter Development Committee. The goal of the committee is to facilitate opportunities to engage individuals in every province and territory across Canada to further grass-roots awareness and support. The committee is off to a strong start and is developing a structure to sustain and support Chapters. If you are interested in starting a Chapter in your area or want to join an inspiring team of people to share ideas, contact Liz Charyna at [lcharyna@toomuchiron.ca](mailto:lcharyna@toomuchiron.ca).



### Group Blood Donation

**Events** continue in person with masks and precautions. They have been coordinated in Victoria, Vancouver,

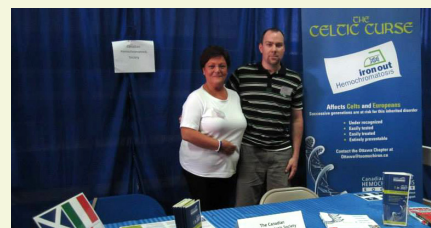
Edmonton and Toronto and we would like to see them in more places over the next year.

## Query Support

Each year over 200 people are assisted by Brenda Ohara in the CHS office by phone, email and on Facebook. Brenda answers questions and recommends resources and peer-reviewed information to people affected directly and indirectly by hereditary hemochromatosis. If you have a question regarding hemochromatosis, contact [bohara@toomuchiron.ca](mailto:bohara@toomuchiron.ca).

# Show Your Support

## Local Chapters



Join people in your area to create awareness of the symptoms and treatment of hereditary hemochromatosis and help save lives! Make a local impact in your community by hosting coffee meet-ups, group blood donations, information sessions or a booth at a community event. Direct people to [toomuchiron.ca](https://toomuchiron.ca) where they will find resources and support. Fundraise to support your Chapter activities. By participating with your local Chapter in these and many other ways, you make it possible for people to connect with others who have experience with hereditary hemochromatosis, support people who have recently been diagnosed, and inform people who have never heard of the complications that too much iron can have on overall health. Each Chapter contributes to help all Canadians be more aware of hereditary hemochromatosis. Friends and family interested in meaningful and fun volunteer opportunities can help spread awareness by joining a Chapter in their area.

Please contact Liz Charyna at [lcharyna@toomuchiron.ca](mailto:lcharyna@toomuchiron.ca) if you wish to join or start a Chapter!

## Membership



Annual Memberships are an important source of recurring revenue and contribute to a stronger

organization that is better positioned to apply for grants and advocate for early detection. We currently have 272 members.

The goal of the Canadian Hemochromatosis Society is to have 500 members by Dec 31, 2020! Please show your support, and tell your family and friends that they too can show their support, by becoming a member today at [toomuchiron.ca/membership](https://toomuchiron.ca/membership). Help strengthen awareness of hereditary hemochromatosis!

## More Ways to Show Your Support

- Answer our calls for volunteers to help at events, assist with Chapter activities, or sit on committees!
- Use the Donate Now button on our website: [toomuchiron.ca/donate](https://toomuchiron.ca/donate)
- Save on your taxes and donate Securities here: [toomuchiron.ca/donate/donate-securities](https://toomuchiron.ca/donate/donate-securities)
- Donate your old car! Find out how here: [toomuchiron.ca/donate/donate-car](https://toomuchiron.ca/donate/donate-car)
- Leave a gift in your will to the Canadian Hemochromatosis Society.
- Use the enclosed donation form and mail in a cheque or your credit card information.