



Celebrating Extraordinary People

Volunteer Spotlight: Tara Johnson-Ouellette

Tara Johnson-Ouellette

“It’s all about keeping my mom’s spirit alive and working hard to give hope to the next generation”

I was 20 when my mother, Janice, was diagnosed with Huntington disease. In the months that followed, we both cried ourselves to sleep each night. The disease progressed quickly. While others my age were going to parties and making plans for the future, I became my mother’s caregiver.

At the same time, I was going through the emotional wringer of genetic testing. I remember the discrimination I faced from my insurance company, the fear of finding out if I inherited the disease and the survivor guilt that hit me minutes after learning I was gene-negative.

I don’t know how I would have gotten through that period without the support and services of the Huntington Society of Canada. It’s your lifeline. It is literally your lifeline.

Those were dark times. But amidst the pain and sorrow, **I also found purpose. I promised myself that I would do everything I can to help other families affected by the disease.** It was a turning point in my life.

For the past 20 years, I have contributed in many ways. I set up the Janice Johnson Family Fund in support of HSC. **I raised awareness and pioneered new fundraisers with the Calgary Chapter.** I have secured generous donations to launch our YPAHD program and built strategic partnerships with Parkinson’s Alberta and the Alberta Council of Healthpartners.

I also served on HSC’s national board, **where I gained a deeper appreciation of how important it was to have a dependable stream of donations coming in on an ongoing basis.**

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We’re definitely a leader, it’s phenomenal what we’ve accomplished.

Thanks to our supporters and volunteers we’ve expanded services across the country. We created YPAHD to better serve youth. We spearheaded the Canadian Coalition for Genetic Fairness, advocating for an end to genetic discrimination.

For me, it’s all about keeping my mom’s spirit alive and working hard to give hope to the next generation. For me, there’s no excuse, it’s my responsibility to give back.

NATIONAL VOLUNTEER WEEK IS APRIL 6 -12

Help Celebrate our Extraordinary People!

"HSC's volunteers are the heart and soul of this organization. It is our volunteer core that makes real differences in the lives of individuals and families affected by Huntington disease. Actively raising awareness in their communities, advocating for the rights of those affected by HD, and raising funds that contribute to groundbreaking research triumphs, are just some of the inspiration that our volunteers provide us to continue our march toward a reliable treatment for HD."

Devin Bonner, National Chapter Development Manager

