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Meet Lindsay. She lives with Huntington Disease.

May is Huntington Disease Awareness Month and Lindsay wants to tell her story.

(Kitchener, ON) April 27, 2016 – For Lindsay Groot, Huntington disease is devastating. Over time, Huntington disease (HD) breaks your brain down and you start seeing symptoms that are behavioural, cognitive and emotional. Lindsay’s grandmother died from the disease, her father is symptomatic, and now she has the gene - which means it’s only a matter of time before she too will develop symptoms.

Lindsay’s family is supportive, she comes from a small rural community, so neighbours and friends have seen first-hand the impact Huntington disease has had on generations of her family. They watched her grandparents live through Huntington disease and now they are witnessing the struggles that Lindsay’s parents are facing.

Even knowing what her fate will bring, Lindsay considers herself lucky. Her parents helped Lindsay and her husband go through in vitro fertilization (IVF) to make sure that their children are free from Huntington disease. Now they have a little girl who doesn’t have the Huntingtin gene.

“I am the first member of my family to open up about going through IVF for the reasons of HD. We have no fertility issues and only did it so our kids wouldn’t have to live through the same fears as I did. I was always terrified whether or not my dad would turn out like my Oma, dwindling away and becoming someone we didn’t recognize. When he was diagnosed, that fear shifted to my generation and life seemed hopeless,” says Lindsay “When I was diagnosed, I was shocked. I truly believed I was going to be negative, but in case I was positive, I had prearranged my IVF paperwork so that the ball could get rolling even while I was not able to deal with such a complicated adventure.”

Lindsay opened up about her status and IVF so others could learn from her experience and talk to her if they were struggling to decide if getting diagnosed or doing IVF was for them. “If I wasn’t having kids, I wouldn’t have found out until I thought I was symptomatic or there was a cure, or I could be of use to research. I would be involved in [research] if I could be, and I will be when I can.”

To Lindsay, a positive diagnosis for HD is a huge challenge to overcome for so many reasons. There are days that the diagnosis alone gets her so down that she isn’t sure she wants to get out of bed and deal with anything. Recently, Lindsay was told by friends that she is the person they think about in their hard times, because of what she has been through.

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“My struggles give people strength and that is something that I can hold onto and use when I have bad days. I can give others hope in their life in regards to things other than HD, and that's an invaluable thing,” says Lindsay. “IVF isn't an easy process to go through for so many reasons — financially, with all the hormones, time off work, and pressure. It definitely puts a strain on your relationship with your spouse and anybody in your life,” says Lindsay. “But there's nothing that makes me happier than looking at my daughter and knowing that she's gene-negative. It kind of makes me forget about my own diagnosis.”

For Lindsay, participating in clinical trials once qualifying is important. She feels it's the only way that research is going to progress, and the only way researchers are going to be able to stop the disease.

On May 1, 2016, the Huntington Society of Canada is launching a new PSA campaign: *What is Huntington Disease?*, coinciding with the start of Huntington Disease Awareness Month. For Lindsay, participating in the new PSA campaign for the Huntington Society of Canada gives her strength and courage. “The more people that know about Huntington disease, the better. Huntington disease is devastating, it impacts generations of families and strikes during the best years of a person's life. We need to make sure people know about this disease and how far the research has come. The research that is being done now may create a 'domino' effect and provide answers to Alzheimer's, ALS, Parkinson's, and other neurological diseases. That work is exciting to me and why I volunteer and push the Huntington message each and every day.”

“We are so fortunate to have individuals like Lindsay in our community. Individuals who choose to get involved and want to make a positive impact,” says Bev Heim-Myers, Chief Executive Officer of the Huntington Society of Canada. “It takes courage to stand up for what you believe in and we are very grateful to Lindsay for her commitment and dedication to helping increase awareness of Huntington disease in Canada.”

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Huntington disease (HD) is a debilitating brain disorder that is fatal and incurable. About one in every 7,000 Canadians has HD and approximately one in every 5,500 is at-risk of developing the disease. Many more are touched by HD, whether as a caregiver, a family member, or a friend. HD causes cells in specific parts of the brain to die. As the disease progresses, a person with Huntington's becomes less able to manage movements, recall events, make decisions and control emotions. The disease leads to incapacitation and, eventually, death.

The **Huntington Society of Canada (HSC)** is a respected leader in the worldwide effort to end Huntington disease. HSC is the only Canadian health charity dedicated to providing help and hope for families impacted by Huntington disease across Canada.

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