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Niagara man raises awareness for Huntington disease ***May is Huntington Disease Awareness Month***

(KITCHENER, ON) May 7, 2015 – John Stainsby has the genetic mutation that means he will one day develop Huntington disease (HD). John has chosen to help raise awareness for HD this May during Huntington Disease Awareness Month by sharing his story.

John and his siblings had never heard of Huntington disease when their mom was diagnosed with the fatal illness. They quickly learned how devastating it is, destroying the brain cells required to walk, speak and swallow. They also learned they each had a 50 per cent risk of heading down that same path.

John wanted more certainty, so he opted for genetic testing. Shortly after his mother's death, he received the results: he had inherited the HD gene. For the next six months, he walked around in a fog, trying to come to terms with the news.

Despite the hand he has been dealt, John counts himself lucky. For most people, HD appears in their 30s or early 40s. At age 59, he has not yet begun showing symptoms. On top of that, both of his children have tested negative for the gene.

Of course, he still lives with fear – fear of when HD will strike and how he will cope with the steady erosion of his abilities. Of what the future holds for his siblings. Of the emotional and physical stress on his caregivers.

However, he knows the Huntington Society of Canada will be there for all of them, just as the organization (national and local) helped John deal with his mother's illness and his own genetic test results. "They were just wonderful resources," he says.

In return, John has given back to HSC. He served as president of his local Chapter and president of the national Board of Directors. He has organized fundraisers and run several half-marathons for HD.

Through HSC, John draws strength from thousands of others across Canada facing the same situation. "There are many people dealing with this disease in their own way," he says. "It's inspiring to me. It just keeps you going."

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May is Huntington Disease Awareness Month. This year it comes on the heels of *Inside the O'Briens*, the newly released novel by award-winning, New York Times bestselling author and neuroscientist, Lisa Genova. Released on April 7, 2015, it is a poignant portrayal of the devastating impact of HD on Joe O'Brien, a 44-year-old police officer from the Irish Catholic neighborhood of Charlestown, Massachusetts. A devoted husband, proud father of four children in their twenties, and respected officer, Joe begins experiencing bouts of disorganized thinking, uncharacteristic temper outbursts, and strange, involuntary movements. He initially attributes these episodes to the stress of his job, but as these symptoms worsen, he agrees to see a neurologist and is handed a diagnosis that will change his and his family's lives forever: Huntington disease.

The novel is a good way to gain a better understanding of the impact of HD on generations of families. The Huntington Society of Canada is truly grateful to Genova for raising awareness of HD in Canada and across North America. To support the HD community and people like Erin, through the Huntington Society of Canada, visit www.huntingtonsociety.ca.

The Society is registered at Chapters Indigo fundraising initiative, visit ow.ly/LFcJS to purchase a Chapters Indigo gift card that can be used to purchase *Inside the O'Briens* or another book of your choice. Chapters Indigo will donate 10% of the value of your card to the Society.

Huntington disease is a debilitating brain disorder that is fatal and does not have a cure. The symptoms, which may include uncontrollable jerking movements and relentless cognitive and emotional impairment, usually present between the ages of 30 and 50 and gradually worsen over the 10-25 year course of the disease. Eventually they lead to total incapacitation and death. About one in every 7,000 Canadians has HD and approximately one in every 5,500 is at-risk of developing the disease.

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 dealing with Huntington disease across Canada.

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