Huntington Society of Canada
HUNTINGTON
Société Huntington du Canada

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Ontario woman raises awareness for Huntington disease

May is Huntington Disease Awareness Month

(KITCHENER, ON) May 7, 2015 – Huntington disease (HD) claimed the lives of Marion Genoe's father and three of her siblings. Marion has chosen to help raise awareness for HD this May during Huntington Disease Awareness Month by sharing her family's story.

Marion Genoe never knew her father. When she was just six months old, he was hospitalized with Huntington disease, a fatal, inherited neurodegenerative illness. His diagnosis catapulted her mother into a nervous breakdown. Marion and her four siblings were parcelled out to foster care. Eventually, the three youngest returned home, but HD was not something they discussed.

"Back in those days it was all put in the closet," she says. "But I sure opened it up." After her mother died, Marion got in touch with the then fledgling Huntington Society of Canada, organized fundraisers, launched a support group and talked to the media.

She also grappled with the fact she had a 50:50 chance of developing the same disease that killed her father. "The minute you drop a cup in the morning, you think 'oh gosh, I've got it,'" she says. At that time, the test for the HD gene had not been developed. All her doctor could suggest was living life to the fullest, so Marion did just that.

Today, at age 68, she volunteers with the local hospital auxiliary, the Day Away senior's program and the Legion. She line dances, plays cards, knits, crochets and bakes up a storm. Although HD has sidestepped her, she continues speaking about the disease that has killed three of her siblings and is now taking its toll on the next generation.

Amidst the illness and loss, Marion takes solace in how much has changed. Health-care professionals know much more about HD, and care has improved significantly — you don't see patients in straightjackets anymore, says Marion. Many families speak openly about the disease. And while there is still no cure, potential treatments are now in clinical trials.

"It has really come a long way," says Marion. And for that, she can take some of the credit.

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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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