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

(KITCHENER, ON) May 6, 2015 – Hedley Cullen has Huntington disease (HD). Hedley has chosen to help raise awareness for HD this May during Huntington Disease Awareness Month by sharing his story.

Growing up in Moncton, New Brunswick, Hedley Cullen knew that his grandmother was sick. She had a short temper, yelled frequently and seemed to be very clumsy. Shortly before his first tour with the Canadian Armed Forces, Hedley’s grandmother passed away. That was when he learned of Huntington disease, a fatal genetic neurodegenerative disorder.

As Hedley continued his Navy career, married his wife Kate and raised two step-children, HD raised many questions. With a 50 per cent chance of getting the disease, what did his future hold? At the time, a Navy regulation allowed for immediate dismissal if he tested positive for HD. So he postponed genetic testing in order to provide for his growing family – he and Kate had two children together.

When the regulation changed in 2005, Hedley was finally able to undergo testing. The results would change his life: he had the HD genetic mutation.

“My world and the world of my family had just been changed,” says Hedley.

Eight years later, after moving to Victoria, B.C., Hedley’s symptoms had progressed and he was no longer able to work for the Armed Forces. He took this setback in stride. His growing involvement with HSC’s Victoria Chapter allowed him to connect with people with shared experiences.

After attending his first HD Retreat, Hedley felt inspired to give back to the HD community in his own way. He emblazoned the tailgate of his truck with “Please Help Find a Cure for Huntington Disease” and an appeal for donations. He also organized a “Tats for a Cure” fundraiser at a local tattoo parlour last summer. The event was a huge success, raising over \$2,000 and a lot of awareness.

Why does he do it?

“I am hopeful for a cure so that my children and all other affected people can one day be free of this disease.”

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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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