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Newfoundland man raises awareness for Huntington disease to help his wife ***May is Huntington Disease Awareness Month***

(KITCHENER, ON) May 7, 2015 – Rich Wheeler’s wife, Ruby, has Huntington disease (HD). Rich has chosen to help raise awareness for HD this May during Huntington Disease Awareness Month by sharing his family’s story.

Every hour on the hour throughout his work day, Royal Newfoundland Constabulary Sergeant Rich Wheeler calls home to make sure his wife is OK. Ruby has Huntington disease (HD), a fatal hereditary disease that is slowly destroying parts of her brain. Right now the 50-year-old can still manage on her own, but she is a little unsteady on her feet and has cut herself a few times chopping vegetables. So Rich worries. He calls. And whenever he can, he pops home at lunch to see how she is doing.

The couple knew this day might come. Because Ruby’s dad had the disease, she and her siblings each faced a 50:50 chance of inheriting the fatal gene. As it turned out, Ruby lost that coin toss. These days, she has been forced to quit working. She and Rich wonder whether their 24-year-old son has inherited the gene. And they know that if he has children, Ruby probably will not be around to see them grow up. “We live one day at a time,” Rich says.

They focus their energies on raising money to fund services for people with HD and to support research. “It is our hope that a cure is right around the corner,” says Rich. “It may be too late for Ruby, but it may help others who are at-risk.”

Their first event — a four-kilometre walk in 2014 — raised close to \$15,000. The previous year’s event was just as successful, and for 2015 they’re also organizing a climb up Gros Morne’s Killdevil Mountain. To boost awareness about HD, Rich launched a Facebook page called Ruby’s Battle.

Mostly, he manages to stay philosophical about the curveballs life has thrown them. But when it comes to his son’s future, Rich has one hope: “I wish that pitcher called life would get a sore arm.”

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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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