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Winnipeg woman hopes conference will draw attention to fatal disease

(Winnipeg, MB) [October 20, 2014] — Sylvia and Jay Mclsaac had been married four years when he learned he carried the gene for Huntington disease (HD) — an incurable, progressive neurological disorder. Because his mother had the disease, the couple knew Jay had a 50 per cent chance of inheriting the fatal gene. Still, the news came as a huge blow.

“It was horrifying,” Sylvia recalls. “I thought I was prepared for a bad result, but I don’t know if you ever really can be.” While the Mclsaacs’ friends were getting married and starting families, Sylvia and Jay were facing a very different future. Once the symptoms start to appear — likely in Jay’s 30s or 40s — the disease will slowly destroy parts of his brain. In the process, it will take away his ability to walk, speak and even swallow.

“It was very scary, very isolating,” says Sylvia. “We felt like we had just been fast-forwarded into a completely different time of our lives where we were facing mortality.”

That’s why she and Jay are excited to be attending the Huntington Society of Canada’s national conference taking place at Winnipeg’s Holiday Inn Airport West on October 24th and 25th. The sold-out event brings together participants from across the country, including world class researchers, social workers, healthcare professionals and families affected by HD.

This year’s topics range from the latest research breakthroughs to genetic discrimination to better patient care. Speakers include Emmy award-winning TV journalist Charles Sabine, who carries the gene; Order of Canada recipient and Killam prize-winning geneticist Dr. Michael Hayden; and globally renowned U.K. neurologist Dr. Ed Wild. A pre-conference day for youth focuses on the challenges of growing up in families affected by HD.

“We are so pleased to be in a position to present cutting edge research topics, coping strategies and management techniques for Huntington disease to Winnipeg,” says Chapter President Vern Barrett. “The Huntington Society of Canada and the Winnipeg Chapter are proud to feature a number of notable professionals recognized internationally for their progressive contributions to Huntington disease research and care. This is an excellent opportunity for Winnipeg and I am honoured to be partnering with HSC to host this national event.”

For Sylvia and Jay, the conference offers a chance to learn more about HD and to connect with others facing the same issues. In addition, Sylvia hopes it will bring more attention to just how hard this disease is on families. “If someone’s affected, that means they’ve watched their parent and grandparent or aunts or uncles suffer through it,” she explains. “I’m hoping other Canadians will see that and be touched by that and be driven to help.”

She also hopes Canadians will be inspired to support the search for treatments for Jay and thousands like him — treatments such as highly promising gene-silencing drugs expected to begin clinical trials next year. “I know there’s hope,” says Sylvia. “I know they’re close, but all that help is driven by money.”

The Society has been working to make sure trials of any potential treatment proceed as quickly as possible. “For the past two years the Society has played a key role in bridging the relationship between clinician scientists and individuals, by educating Canadians on the importance of the clinical trial process,” says Huntington Society of Canada’s CEO, Bev Heim-Myers. “It is vital that we ensure people know how they can get involved; and why their participation is so crucial. The HSC National Conference brings the Canadian HD community together and provides a key opportunity to share the most up to date research, clinical and family services information. ”

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The 2014 Huntington Society of Canada’s national conference is supported by many generous sponsors, including The Winnipeg Foundation and Winnipeg based Reider Insurance, Enroll-HD, and the Saskatchewan Mutual Insurance Company.

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 become 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 dealing with Huntington disease across Canada.

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