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**“Now is the most exciting time in the history of Huntington Disease Research.”
*May is Huntington Disease Awareness Month and Tam wants to tell her story.***

(Kitchener, ON) May 9, 2016 – And Tamara Mauri ought to know, not only is she working on finding a treatment to unlock the mystery of Huntington disease (HD), she also comes from a family who is impacted by the disease. “My grandfather had Huntington disease, so we have known about the disease in our family for a long time. Now, my mom is starting to show symptoms.”

For Tamara Maiuri, Huntington disease is twofold, it’s in her family and it’s her job. She works at an HD research laboratory at McMaster University, alongside other researchers who are working in earnest to find a treatment for HD. “There are a lot of people working on this [disease], and they are working really hard. Research is a very slow process — it has been 20 years since they identified the gene — but things are finally coming to light,” says Maiuri.

Maiuri believes that this is the most exciting time in the history of HD research because so many drugs are going into the clinical trials testing phase. She emphasizes that what is required now is people, and lots of them, as so many drugs need to be tested.

“HD is a major focus in my life, it’s in my family, and I work on trying to find a solution for HD every day,” says Maiuri. In her spare time, she and her husband play in the band, Eli and The Strawman. The band is working with the Huntington Society of Canada to raise awareness for HD. This past April, the band toured and incorporated information about HD in their marketing materials. The lead singer wrote a song called *No One*, which talks about coming out of the fog, specifically about HD. “I think that’s what’s happening. Coming out of the fog, not only in HD research, but also with all the resources and support services that are now available to families,” says Maiuri. “We have spent a lot of time and a lot of hard work trying to find a solution to HD, and its coming. I really believe it is coming.”

On May 1, 2016, the Huntington Society of Canada launched a new PSA campaign: *What is Huntington Disease?* coinciding with Huntington Disease Awareness Month. For Tam, participating in the new PSA campaign for the Huntington Society of Canada gives her strength and courage. “We need to work towards ending this disease together. Researchers, volunteers, families and community members – we have to come together to end this disease. Huntington disease is terrible, it impacts generations of families. The research that is being done now may create a ‘domino’ effect, accelerating our findings in the near future. It’s important to raise awareness so that we have the public support we need to get the best possible studies done and find a treatment as soon as we can.”

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“We are so fortunate to have individuals like Tam in our community. Individuals who choose to get involved and want to make a positive impact,” says Bev Heim-Myers, Chief Executive Officer of the Huntington Society of Canada. “It takes courage to stand up for what you believe in and we are very grateful to Tam for her commitment and dedication to helping increase awareness of Huntington disease in Canada.”

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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 becomes 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 impacted by Huntington disease across Canada.

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