

MEMBERS:

Brain Injury Canada

Brain Tumour
Foundation of Canada

Canadian Epilepsy
Alliance

Canadian Neurological
Sciences Federation

Dystonia Medical
Research Foundation
of Canada

Huntington Society
of Canada

Hydrocephalus Canada

March of Dimes Canada

Ontario Federation
for Cerebral Palsy

Ontario Neurotrauma
Foundation

Ontario Rett Syndrome
Association

Parkinson Canada



NHCC

NEUROLOGICAL HEALTH CHARITIES CANADA

4211 Yonge Street, Suite 316
Toronto, Ontario M2A 2P9
Phone: 416-227-9700, ext. 3314
Fax: 416-227-9600
Web: www.MyBrainMatters.ca

NHCC announces 2018 Change-Maker Awards for three outstanding individuals impacted by brain conditions

Toronto, ON, April 29, 2019 - A young man who has transformed his life following a brain injury and two women whose commitment to caregiving has enriched their respective mothers' lives while inspiring their communities are the winners of the 2018 NHCC Change-Maker Awards announced today.

Neurological Health Charities Canada's (NHCC) Change-Maker Award recognizes individuals who have made a meaningful difference in improving the quality of life for Canadians living with brain conditions. Organizations can also receive the award.

Honoured this year are: **Enrico Quilico** of Montreal, QC, Change-Maker Award for person living with a brain condition; **Shaunacy De Jong** of Sauble Beach, ON, Future Champions Award for a young caregiver; and **Jenna** of Toronto, ON, Change-Maker Award for a caregiver. (*Jenna prefers not to have her last name used because of privacy concerns.*)

"NHCC is thrilled with the opportunity to present 2018 Change-Maker Awards to three outstanding individuals. Enrico, Shaunacy and Jenna all characterize the creativity and courage of Canadians affected by brain conditions, those who live with the conditions and those who are caregivers. They are truly inspirations to us all," said Joyce Gordon, NHCC chair.

NHCC is a coalition of organizations that represent millions of Canadians living with brain diseases, disorders and injuries (brain conditions). They affect mobility and dexterity, while impairing memory and the ability to think. These conditions can make it hard to see, speak and communicate; and tend to be painful and debilitating. See more information at: www.mybrainmatters.ca or www.moncerveaumavie.ca.

Enrico Quilico of Montreal, QC – Enrico was just 23 when he was severely injured in a motorcycle-automobile collision in 2006. His injuries included a traumatic brain injury as well as a shattered pelvis and other broken bones. He was in intensive care for five weeks. Months of challenging rehabilitation followed as he struggled to come to terms with living with a brain injury. He credits his involvement with Think First Quebec (now part of Parachute Canada) as a turning point in his recovery. He started to tell his story about the injury and recovery to students in schools in the Montreal area.

Enrico decided to return to university and also qualified as a fitness instructor and personal trainer as a "fall back" career. He also started competing in triathlons and used his interest in athletics and fitness to pursue a master's degree in kinesiology and physical education at McGill University.

Brain injury and exercise soon became his research focus, and he led a study in Montreal that explored benefits and barriers to exercise for adults living with severe traumatic brain injury,

Enrico was accepted into the PhD program in rehabilitation sciences at the University of Toronto in 2014, but had to put his studies on hold because of burn-out. During this time, he became involved with Brain Injury Canada including raising funds for the organization by completing his first full Ironman competition. It was a way to commemorate the tenth anniversary of the accident and to celebrate his new approach to life.

During this time, Enrico also returned to his interest in helping people with traumatic brain injury rebuild their lives through exercise. He launched a pilot project in Quebec to involve individuals with traumatic brain injury with exercise and sport. Nine of the 12 project participants competed in the YMCA Indoor Triathlon with two of the teams awarded gold and bronze in their categories. He continues to run the program each year.

Enrico is now back at the University of Toronto pursuing his PhD, this time leading a Sport Participation Research Initiative with funding from the federal Social Sciences and Humanities Research Council insight grant program. He still competes in triathlons every season and runs community traumatic brain injury programs in Montreal every week.

“At many points after my injury, I doubted that I would be able to resume such a functional and meaningful life. I am grateful to all the people who helped me along the way: those in health care like physicians, nurses and rehabilitation specialists; those in organizations like the YMCAs of Quebec, the Quebec TBI Association, Think First Quebec, Parachute Canada and Brain Injury Canada; my mentors and advisors at Concordia University, McGill University and the University of Toronto, and of course, my dear family and close friends. I am indeed very fortunate and will continue to give back to the community in any way that I can,” said Enrico.

Brain injury is the leading cause of death and disability for Canadians under the age of 40. Approximately 1.5 million Canadians live with the effects of an acquired brain injury. Research focuses both on the mechanisms of brain injury, improving approaches to early diagnosis, treatment and more diversified care and rehabilitative strategies.

Enrico was nominated for the award by Brain Injury Canada. <https://www.braininjurycanada.ca/>

“Enrico is so deserving of this award. He has survived near-death, disability, depression, doubt and has demonstrated such resilience. His spirit of determination and drive, like so many others living with acquired brain injury, personifies that acquired brain injury doesn't have to be the end of the road,” said Michelle McDonald, Executive Director, Brain Injury Canada.

Shaunacy De Jong, Sauble Beach, ON – Shaunacy has been a caregiver since she was 17-years-old for her mother who lives with Huntington disease. When she took on the carer's role, Shaunacy realized she had to balance caring for her mother, learn more about Huntington disease (HD) and continue her own studies. She took action to find support for herself, her mother and the rest of the family by reaching out to the Huntington Society of Canada.

Being matched with a mentor from the Society's Youth Mentorship Program helped Shaunacy deal with her mom's difficult symptoms and navigate the process of getting her own genetic test. Later, at Huntington Disease Youth Organization camp, she discovered a whole circle of peers who understood what she was going through and had her back.

Shaunacy soon found that she was giving back as well as receiving support. She and her sibling are active fundraisers for the Huntington Society. In 2015, they organized a BBQ and raffle that raised more than \$8,000.

This year, they are holding a benefit dance in May featuring four live bands, a raffle, a silent auction and plenty of food and drink with the goal of raising \$10,000.

Shaunacy has also joined Huntington Disease Coalition for Patient Engagement (HD-COPE), a 20-person international advisory group that includes caregivers, people with HD and family members. Last year, Shaunacy travelled to London, England to learn about clinical trials: their processes, those involved in setting up a clinical trial and the important role that community plays in those clinical trials. Importantly, HD-COPE also provides advice to the pharmaceutical companies conducting the clinical trials to ensure that their design takes into account what could make it less of a burden for volunteers to participate, to enable recruitment and ensure retention in clinical trials.

It all adds up to a big sense of purpose for Shaunacy. "I can only do so much for my mom so becoming involved with HD-COPE and the Society fills that void because I'm able to help other individuals. It has definitely shaped me into a person who is more hopeful for the future," she said.

Huntington disease is a genetic disorder. The HD gene is dominant, which means that each child of a parent with HD has a 50 percent chance of inheriting the disease and is said to be at-risk. Males and females have the same risk of inheriting the disease. HD occurs in all races. Symptoms usually appear between the ages of 35 and 55.

Shaunacy was nominated for the award by Huntington Society of Canada
<https://www.huntingtonsociety.ca/>

"Currently, there is no treatment for the root cause of Huntington disease. While this fact can be daunting, Shaunacy's spirit and courage provide continued hope and vital support to the HD community. Shaunacy is a shining example of facing adversity with courage and selflessness," said Robin Markowitz, CEO, Huntington Society of Canada.

Jenna, Toronto, ON – Jenna is a caregiver for her mother who lives with Huntington disease (HD). Although HD is hereditary, there was no one in Jenna's family who had shared they had the gene for the disease.

Following the medical diagnosis and with the help of a Huntington Society of Canada (HSC) social worker, Jenna helped her family navigate the process of the diagnosis and learned how best to support her mother. With that in place, Jenna starting thinking about the implications for herself especially prior to having children.

She again turned to HSC and decided to become a youth mentor so she could give back to others facing a parent's diagnosis of HD. As an educator, Jenna has seen how complicated home situations can hurt students socially and academically and that even one positive role model can make a huge difference. Following the HSC training session, she was matched with a young person whom she has been supporting since 2015.

Jenna has shared her story through HSC community publications and fundraising campaigns. A member of Young People Affected by Huntington Disease (YPAHD), Jenna has attended annual YPAHD days offered through the Society. During these sessions, youth connect to learn more about the HD, living at risk, the young carer role and current HD research. Jenna also represented YPAHD at the American HD youth day in Baltimore.

Jenna has become not only a source of knowledge for her family and a support to her mentee on a regional level, Jenna has also become an essential advocate for caregivers of those living with HD within the national and international clinical trial discussion.

Jenna joined Huntington Disease Coalition for Patient Engagement (HD-COPE), a 20-person international advisory group that includes caregivers, people with HD and family members. A key meeting last year in London, England was with one of the pharmaceutical companies now conducting a clinical trial of an HD treatment. The purpose was to provide advice to ensure that the clinical trial design enables people with HD to participate as easily as possible, boosting recruitment and retention. Since then, Jenna has also attended numerous other advisory board meetings with various companies and clinical trial groups.

“It’s fantastic to be able to interact with these people and know them by their first name and be able to share your story and to know that they’re listening,” she says. “I think that this is really the start of something that’s going to be quite strong and quite powerful.”

Huntington disease is a genetic disorder. The HD gene is dominant, which means that each child of a parent with HD has a 50 percent chance of inheriting the disease and is said to be at-risk. Males and females have the same risk of inheriting the disease. HD occurs in all races. Symptoms usually appear between the ages of 35 and 55.

Jenna was nominated by Huntington Society of Canada. <https://www.huntingtonsociety.ca/>

“Jenna has represented the HD community in numerous settings and continues to be a clear and confident voice ensuring that the HD experience is heard. Jenna has a passion for research and her enthusiasm is contagious. We are so fortunate to have a strong leader like Jenna as part of our HD community,” said Angèle Bénard, Director of Family Services and Community Development, Huntington Society of Canada.

Contacts:

Deanna Groetzinger, Manager
Neurological Health Charities Canada
E - deanna.groetzinger@mybrainmatters.ca
T – 647-993-8429

Michelle McDonald, Executive Director
Brain Injury Canada
E – mmcdonald@braininjurycanada.ca
T – 6130878-6861

Robin Markowitz, CEO
Huntington Society of Canada
E – rmarkowitz@huntingtosociety.ca
T – 1-800-998-7398