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Pandemic spurs on NHCC 2020 Change-Maker award winners to greater efforts

Toronto ON – April 8, 2021: Neurological Health Charities Canada is honouring two women who continued to support others living with brain conditions despite the pandemic. Receiving 2020 NHCC Change-Maker Awards are Chantale Boivin of Longueuil, QC, who lives with dystonia, and Halina (Lin) Haag of Kitchener, ON, who lives with an acquired brain injury.

NHCC Change-Maker Awards recognize individuals who have made a meaningful difference in improving the quality of life for Canadians living with brain conditions.

Chantale Boivin of Longueuil, QC: After receiving a diagnosis of cervical dystonia over 15 years ago, Ms. Boivin vowed to make a difference in the lives of the estimated 50,000 Canadians living with dystonia. Immediately after diagnosis and experiencing severe neck pain, she had to stop work and became increasingly isolated.

Once she found a treatment that helped with the severe pain, she was able to return to work and also decided to organize a support group where people could share their experiences. In 2014, she founded Dystonie-Partage, the only francophone support group of the Dystonia Medical Research Foundation Canada (DMRF Canada).

Ms. Boivin said of Dystonie-Partage, “this group has a lot of impact on the physical and mental health of people. Being able to meet and discuss with people who have the same disorder brings a lot of comfort.” One group member added, “thanks to this group, I gained confidence, I came out of isolation and I accept myself much more. I am no longer ashamed. It saved my life!”

Currently, Dystonie-Partage cannot hold in-person events, but Ms. Boivin has pivoted to online support group meetings, allowing members to still have access to their large network of support. She also organized a virtual mental health conference with a registered psychologist to help people gain better coping mechanisms to navigate the mental health challenges that have been intensified during the pandemic.

Her dedication to the dystonia community goes beyond Quebec and Canada. Since the start of the pandemic, she has collaborated with AMADYS France on four virtual webinars connecting the French-speaking dystonia community in Quebec with the dystonia community in France.

“The dystonia community and DMRF Canada are lucky to have Chantale as a leader and as an advocate. She has persevered through the physical pain and mental health challenges that dystonia has caused her and made life better for many,” said Archana Castelino, National Director.

Dystonia is a movement disorder that causes the muscles to contract and spasm involuntarily. There are approximately 13 forms of dystonia, and dozens of diseases and conditions include dystonia as a major symptom.

Halina (Lin) Haag of Kitchener, ON: As a survivor of a traumatic brain injury, Ms. Haag is using that personal experience in her ground-breaking work in brain injury in the intimate partner context. A Ph.D. candidate in Social Work at Wilfrid Laurier University and the Acquired Brain Injury Lab at the University of Toronto, she is one of the leaders of a project to empower women experiencing brain injury and intimate partner violence with respect to employment.

Intimate partner violence has escalated worldwide during the pandemic; it has been called the shadow pandemic. Although it is known that up to 92 percent of abusive hits are to the head, the intersection of traumatic brain injury and intimate partner violence has not been widely recognized. While there has been an enormous focus on concussions in sports, the occurrence of brain injuries among abused persons who are primarily women has garnered little attention to date despite the numbers of women affected world-wide that dwarf the number of athletes affected.

Ms. Haag's work tackles this issue in several ways. She took a leadership role in putting together a toolkit for front line providers and service users that addresses the intersection of intimate partner violence and traumatic brain injury. The toolkit provides practical information, educational resources, research and community resources. It is used in Canada and internationally.

Responding to needs raised by the pandemic, Ms. Haag took a leadership role in the fall of 2020 in organizing a COVID-related Canada-wide emergency summit with 30 stakeholders from across Canada. She continues to be a highly sought-out research partner, speaker and collaborator in this important, but too-often ignored area.

"Lin uses her lived experience of disability to enrich her research, practice, and teaching. She brings a unique combination of authenticity and academic preparation to her research, combined with a commitment to privileging the voice of a traditionally marginalized group of women through their inclusion in all aspects of the research process," said Dr. Angela Colantonio, Professor, Rehabilitation Sciences Institute, University of Toronto, and Ms. Haag's thesis co-supervisor.

NHCC is a coalition of organizations that represent millions of Canadians living with brain diseases, disorders and injuries (brain conditions) that affect mobility and dexterity, while impairing memory and the ability to think. See more information at: www.mybrainmatters.ca or www.moncerveaumavie.ca.

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