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Dystonia Advocate Recognized for Raising Awareness for Disorder

TORONTO, ON – April 17, 2018 – The Dystonia Medical Research Foundation (DMRF) Canada, is pleased to announce that Casey Kidson, Founder of *Dyfying Dystonia*, has been recognized as the 2017 recipient of the Change-Maker Award by Neurological Health Charities Canada (NHCC); a coalition of organizations that represent people with brain diseases, disorders and injuries in Canada.

The NHCC Change-Maker Award, first launched in 2011, aims to recognize outstanding contributions and leadership in inclusion, innovation and integration for the benefit of Canadians living with brain conditions.

"We're thrilled that Casey is getting the recognition she deserves – as a dystonia warrior who has done so much to inspire the 50,000 Canadians who are currently suffering from dystonia, and to raise awareness for a condition that is still largely unknown", said Stefanie Ince, Executive Director of the Dystonia Medical Research Foundation (DMRF) Canada. Dystonia is a chronic neurological condition characterized by persistent or sporadic muscle contractions, causing abnormal repetitive movements or postures, at times resembling a tremor. Depending on the severity of the condition, patients are faced with varying degrees of disability or pain.

Casey was diagnosed with myoclonus dystonia in 2003 at the age of 15, and launched *Dyfying Dystonia* in 2017, with a goal to raise awareness of dystonia through her running campaign. Throughout the year, Casey participated in over 30 runs and raised close to \$10,000.00 for dystonia awareness programs. In addition, Casey was featured in iRun magazine, and appeared in newspaper articles and television spots promoting her campaign. In 2018 Casey is continuing to *Dyfy her Dystonia* – and will log 7,471 km, representing the distance across Canada, through races, triathlons, at least two Ironman events, and training.

"I am absolutely honoured and beyond grateful to have been selected as the 2017 Change-Maker recipient", said Casey; "when your goals are driven through your passion, it is incredible the difference you can make without even realizing the ripple of change you are creating. My *Dyfying Dystonia* campaign continues to lead me through an incredible journey presenting opportunities and challenges I once only dreamt of achieving"

"NHCC is delighted to present the 2017 Change-Maker Award to Casey. She epitomizes the creativity and courage of the millions living with brain conditions. Casey is truly an inspiration to others living who have dystonia and other brain conditions," said Joyce Gordon, NHCC chair.

Now - Casey has issued a challenge to the dystonia community – she's asking the 50,000 Canadians who suffer from dystonia in Canada to defy dystonia in their own way – either getting fit, or taking a course, or raising awareness of dystonia in their communities. Visit: www.dystoniacanada.org/dyfydystonia to learn more about Casey and her campaign.

About the Dystonia Medical Research Foundation (DMRF) Canada

The Dystonia Medical Research Foundation was founded in 1976 by Samuel and Frances Belzberg of Vancouver, after their daughter was diagnosed with generalized dystonia. The mission of the DMRF Canada is to advance research for more treatments and ultimately a cure; to promote awareness and education; and to support the needs and well being of affected individuals and families. DMRF Canada is a registered non-profit Canadian charity governed by a volunteer <u>Board of Directors</u>.

About Neurological Health Charities Canada (NHCC)

Neurological Health Charities Canada (NHCC); a coalition of organizations that represent people with brain diseases, disorders and injuries in Canada. NHCC provides leadership in evaluating and advancing new opportunities for collaboration specific to advocacy, education and research to improve the quality of life for people affected by brain conditions.

For more information, please contact: Stefanie Ince Executive Director, DMRF Canada stefanieince@dystoniacanada.org 416.488.6974