

FOR IMMEDIATE RELEASE

**Join the Dystonia Community to do Your Race – Your Way
Introducing: Freedom to Move: Run, Walk, and Wheel for Dystonia
Taking Place Across Canada June 1 – 30, 2021**

TORONTO, (June 1, 2021) The Dystonia Medical Research Foundation (DMRF) Canada is pleased to announce that the 2021 Freedom to Move: Run, Walk and Wheel for Dystonia in memory of Chuck Saundercook has officially launched. The virtual event will run from June 1-30 with all proceeds benefitting dystonia research and support programs. Participants across Canada can run, walk, or wheel at their own pace, for any distance, and on their own schedule.

Dystonia, the third most common movement disorder behind **Essential Tremor** and **Parkinson's Disease**, is a relatively unknown neurological disorder that causes uncontrolled muscle spasms, twisting, and pain. Dystonia affects an estimated **50,000 people in Canada**.

To date, DMRF Canada's Freedom to Move events have raised over one million dollars for DMRF Canada's research and support programs and is the organization's largest fundraiser.

This is the second time the event will take place virtually across Canada. "Even though we cannot meet in person again for this year's event, the modification to a virtual event has allowed us to expand our reach across every part of Canada, uniting the dystonia community coast-to-coast. We can still come together, safely, as a community and raise critical funds for dystonia research and support programs" shared Archana Castelino, National Director, DMRF Canada.

This year's Freedom to Move Ambassador is Paralympic swimmer - Shelby Newkirk. This summer, Shelby will be achieving a lifelong goal of representing Canada in the upcoming 2021 Tokyo Paralympic Games, but she is just as passionate to join hundreds of others in the dystonia community for this event. "I'm incredibly proud to be this year's Freedom to Move Ambassador. Over the next 30 days, we will walk, run, and move anyway we want – with a common goal: to raise funds and awareness for dystonia," said Shelby.

In 2010, at age 13, Shelby was diagnosed with generalized dystonia, a form of dystonia that affects multiple muscle groups throughout the body.

For Shelby, in addition to raising funds and getting active, Freedom to Move: Run, Walk and Wheel for Dystonia, is also opportunity to connect with others with dystonia. "One thing that I've come to realize over the past year is the value and importance of community. This event is a great way to raise money - and awareness, but to also show people that they are not alone and that we are all in this together," shared Shelby.

DMRF Canada is the only organization dedicated to supporting the dystonia community in Canada. With just two full-time staff members, the organization is tremendously resourceful, working with dedicated volunteer board members, support groups leaders, interns, volunteers, and impacted patients and families who are passionate about finding a cure.

This year marks 45 years of service to the dystonia community. Thanks to DMRF Canada's supporters, dystonia research and scientific insight into the disorder is progressing more quickly than previously thought possible. Funds raised through this event remain a critical resource to fulfilling our mission of advancing research, improving awareness and education, and supporting affected individuals and their loved ones. "Thank you to our sponsor, Ipsen Biopharmaceuticals Canada Inc., for your support of this event. Your efforts help change the lives of the 50,000 Canadians living with dystonia" said Archana.

To find out more about the DMRF Canada, and to register for Freedom to Move, visit: www.dystoniacanada.org/freedomtomove.

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