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NHCC

NEUROLOGICAL HEALTH CHARITIES CANADA

NHCC 2022 Change-Maker Award recipient has passion for helping dystonia community self-advocate

Toronto ON – May 24, 2023: Neurological Health Charities Canada has awarded its Change-Maker Award to a young woman whose journey as a disability activist began with her birth.

Sarah Anderson of Winnipeg received the 2022 NHCC Change-Maker Award for her advocacy as a University of Winnipeg student for increased accessibility for people with disabilities. She spearheaded the More Than a Door Campaign at the university as accessibility director of the Students' Association Board of Directors.

The campaign focused on increasing the number of automatic doors on campus. So far, the campaign has successfully installed more than 70 automatic doors in 18 campus buildings, enabling students and staff living with mobility issues more independence as they navigate the campus.

It is such a logical solution, but as Ms. Anderson explained, "Barriers exist in a way you might not see. Something as simple as a door can be a challenge for a person with a disability as it can hinder their independence."

Originally diagnosed as having cerebral palsy following a difficult birth, Ms. Anderson was diagnosed as having generalized dystonia as a pre-teen following significant changes in her symptoms. She could no longer use a walker, her tremors progressed and her legs started to twist to the left.

Despite decreased mobility and the pain associated with generalized dystonia, she graduated high school as an honour roll student and enrolled at the University of Winnipeg. There she realized that to continue to excel, she would have to advocate for herself. "Once I entered university, it was up to me to tell the university or my professor what I needed. The essential skill of self-advocacy was something I had to learn through experience," she said.

Ms. Anderson shares the lessons she has learned about self-advocacy as a guest lecturer at the university and with her work with the Students' Council. She also is a disability advocacy point of contact to help others in the dystonia community sharpen their self-advocacy skills. As she tells her life story as someone with dystonia, she stresses that is not about her and that her main point in is the power of community and the role everyone can have in creating a more equitable world.

Ms. Anderson's advocacy work has been recognized by the Rick Hansen Foundation when she became a Teen Ambassador in 2016. She was also named the first Teen Ambassador in 2017 by Dystonia Medical Research Foundation Canada.

Sarah's passion for disability advocacy and increased accessibility will not end once she leaves university. After graduation, she plans to become a high school teacher. For her and thousands of other Canadians living with disabilities, it is vital that they see people like them in leadership positions as it helps dispel the incorrect notion that they are not qualified to do the same tasks as able-bodied people.

“Sarah is an incredible asset to DMRF Canada and to the dystonia community,” said Archana Castelino, National Director. “She has not only persevered through the challenges generalized dystonia has given her, she has also triumphed in the face of adversity. Through her awareness efforts, she has championed the needs of her community and has helped further the public profile of dystonia. Her dedicated advocacy work has resulted in a more equitable environment for future generations at the University of Winnipeg.”

According to the Dystonia Medical Research Foundation Canada, dystonia is a neurological disorder that causes excessive, involuntary muscle contractions. These muscle contractions result in abnormal muscle movements and body postures, making it difficult for individuals to control their movements. The movements and postures may be painful.

The NHCC Change-Maker Award recognizes individuals or organizations that have made a meaningful difference in improving the quality of life for Canadians living with brain conditions. 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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