MUSCULAR DYSTROPHY CANADA
DYSTROPHIE MUSCULAIRE CANADA

Newsletter
SPRING 2025

Breaking Down Barriers
FOR THE CANADIAN NEUROMUSCULAR COMMUNITY

BREAKING DOWN BARRIERS: ADVANCING ACCESS TO EARLY DIAGNOSIS, TREATMENTS, AND ESSENTIAL EQUIPMENT THROUGH ADVOCACY

For many Canadians with neuromuscular disorders, the journey to diagnosis is long and frustrating, marked by uncertainty, misdiagnoses, and delays. Myotonic dystrophy type 1 affects not only mobility but also the heart, cognition, and the gastrointestinal system, yet many individuals spend years searching for answers before finally accessing genetic testing. These delays result in missed opportunities for early intervention, symptom management, family planning, and access to clinical trials and emerging treatments.

Recognizing the need for earlier, more equitable access, Muscular Dystrophy Canada has launched a nationwide initiative to improve genetic testing for myotonic dystrophy.

A timely and accurate diagnosis is more than just an answer—it unlocks specialized care, clinical trials, and innovative treatments that could slow disease progression and improve quality of life. Through a landscape analysis, Muscular Dystrophy Canada is identifying testing barriers, reimbursement challenges, and long wait times while also offering no-cost genetic testing and counselling for Canadians with a suspected diagnosis or family history of myotonic dystrophy.

Addressing Delays in Treatment Access

Canadians face delays due to regulatory approvals and reimbursement barriers. Even after Health Canada approves a therapy, provincial funding decisions can take months or even years, leaving patients waiting for treatments that could preserve mobility, independence, and quality of life.

Muscular Dystrophy Canada continues to advocate for faster access to diagnosis, treatment approvals, and reimbursement policies that put persons impacted first.

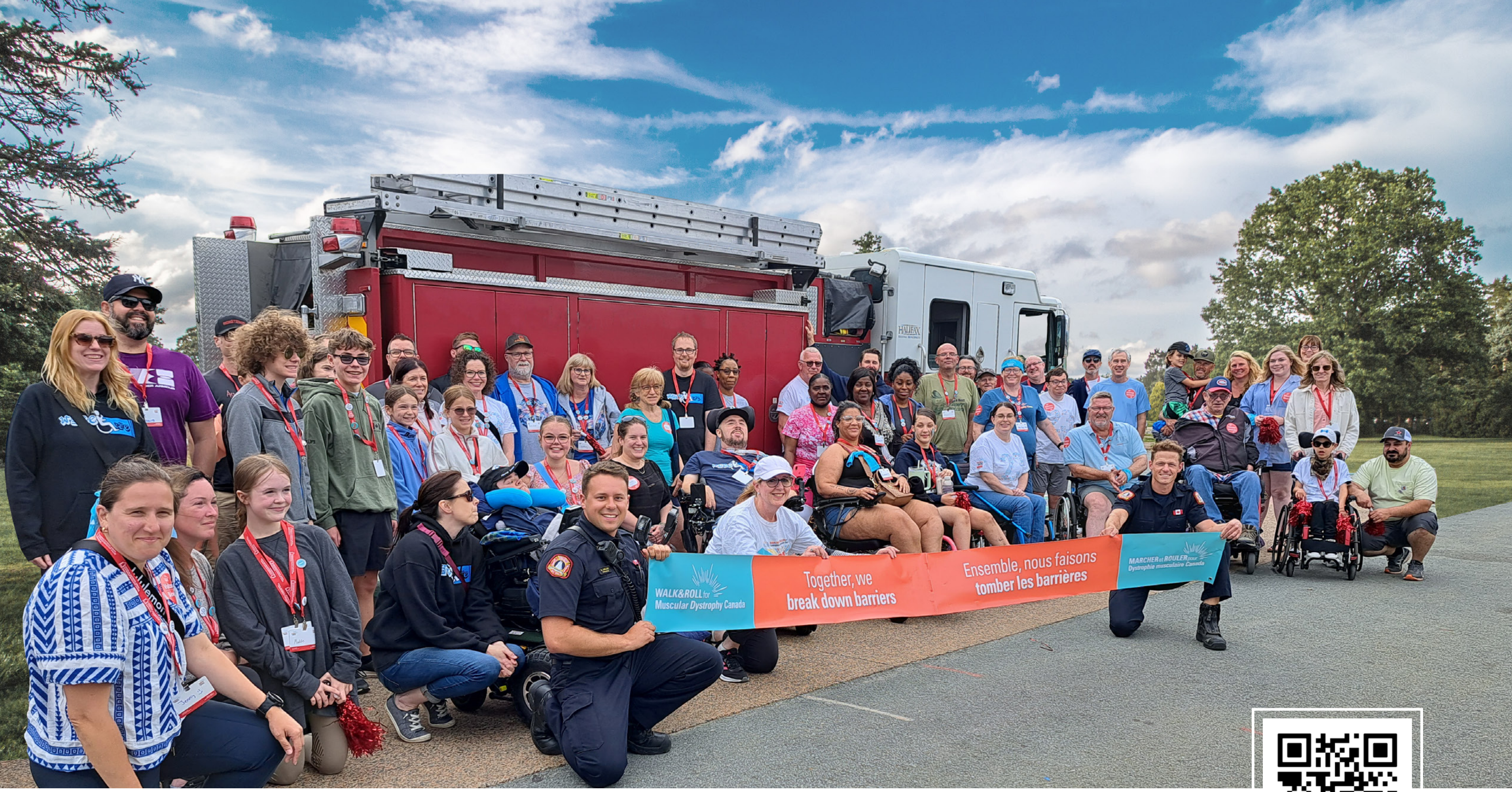
Breaking Down Financial Barriers: Ensuring Access to Essential Equipment

For individuals with neuromuscular disorders, mobility aids, assistive devices and medical equipment are essential to safety, independence, and quality of life. Yet, Hoyer lifts, wheelchairs, hospital beds, and pressure-relieving mattresses—critical for mobility, caregiver safety and daily living—are not consistently covered by provincial health programs and/or private insurance.

Without adequate funding, many individuals are left paying out of pocket, waiting years for partial assistance, or simply going without. Thanks to generous donors, Muscular Dystrophy Canada's Equipment Program helps bridge some gaps, but demand far exceeds available resources. Through #YourDevicesYourRights, Muscular Dystrophy Canada is working with like-minded community partners advocating for improvements in funding with provincial programs.

While governments cannot cover everything, some equipment—like Hoyer lifts or wheelchair adaptations—is essential. No one should be denied access because of where they live or their financial situation. Ensuring consistent, needs-based funding across Canada is a matter of dignity, safety, and human rights.

Through your support of Muscular Dystrophy Canada, you are making an impact. Join us in breaking down barriers to ensure that all Canadians with neuromuscular disorders receive the diagnosis, treatment, and support they need—when they need it.



REGISTRATION IS NOW OPEN FOR THE 2025 WALK & ROLL FOR MUSCULAR DYSTROPHY CANADA!

Join us at one (or more!) of 30 in-person Walk & Roll events taking place across the country! At each event, you can look forward to an amazing, fun-filled day complete with games, snacks, crafts and interactive activities, the chance to connect with other members of the neuromuscular community, and opportunities to hear stories and updates from community members, Muscular Dystrophy Canada staff and researchers. All registered participants will also receive a lanyard that can be customized with collectable pins!

And by registering today, you can also get a head start on raising critical funds that will help break down barriers for the neuromuscular disorder community! The funds you raise will ensure that all Canadians living with a neuromuscular disorder have timely access to treatments, healthcare and community supports, enabling them to live their best lives and achieve their goals, whatever they may be! Join us in making an impact today! Register now!

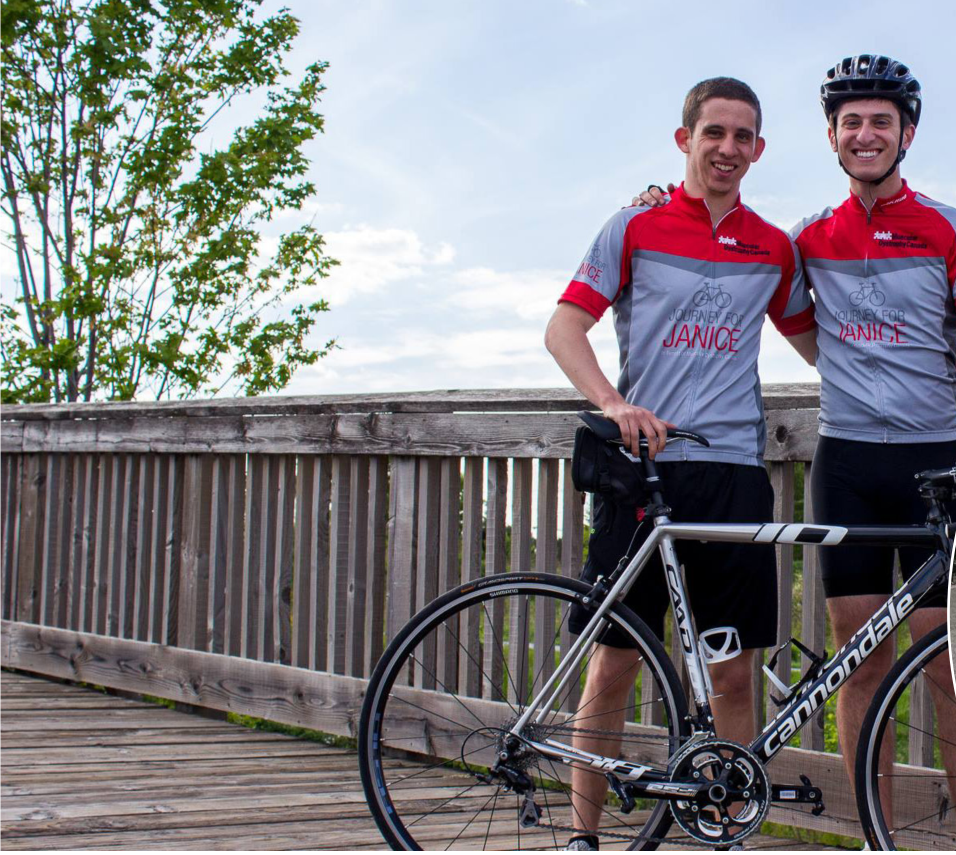
Visit WalkRollMDC.ca today for more information including event locations, dates and to register or donate.

WALK&ROLL for Muscular Dystrophy Canada

Can't participate this year but still want to help break down barriers? Please consider donating or hosting your own Walk & Roll event. To make a gift or for more information on hosting your own event visit: WalkRollMDC.ca

Did you know that our equipment application form is now completely online?

To learn more about the form, or for support with use please contact Veronique Painchaud, Manager of Programs & Services at Veronique.Painchaud@muscle.ca.

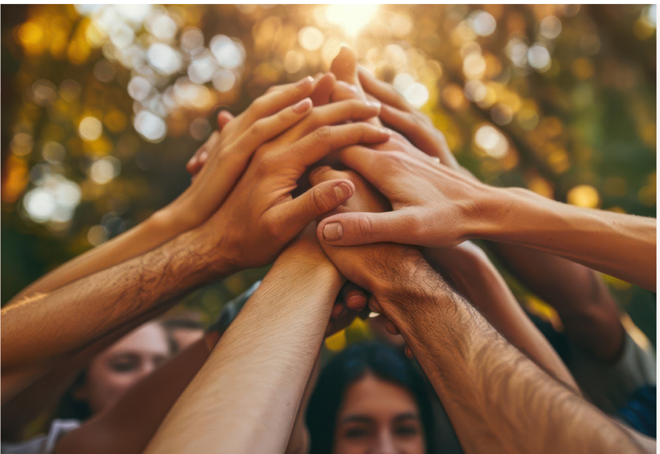


COMMUNITY MEMBERS MAKE A DIFFERENCE IN WAYS THAT MATTER MOST TO THEM

Every year, individuals and groups across the country raise money to support Muscular Dystrophy Canada in their own way by hosting their own special events, including everything from bake sales to bike rides, golf tournaments, dances, auctions, and head-shaving challenges. Each year our community has fun while giving back in all sorts of ways!

Community members like François Bernier, who in the summer of 2024 rolled from Montreal to New York City in his wheelchair! Over the course of 10 days, Francois travelled more than 600km by wheelchair, raising more than $20,000 for the neuromuscular community. Through this unique and bold challenge, Francois was able to break down barriers for all Canadians affected by neuromuscular disorders.

Making a difference can be as simple as riding a bike! In 2014, Jordan Freedman and Hartley Ruch created a cycling event called "Journey for Janice" in honour of Jordan's mother, Janice Freedman who passed away in 2012, from complications related to polymyositis. For the last nine years, Journey for Janice has grown, raising over $200,000 and hosting close to 90 riders in recent years. Jordan and Hartley have stepped up, year over year, to support the neuromuscular community in ways that matter most to them!



Are you feeling inspired?
There's no time like the present to get fundraising.

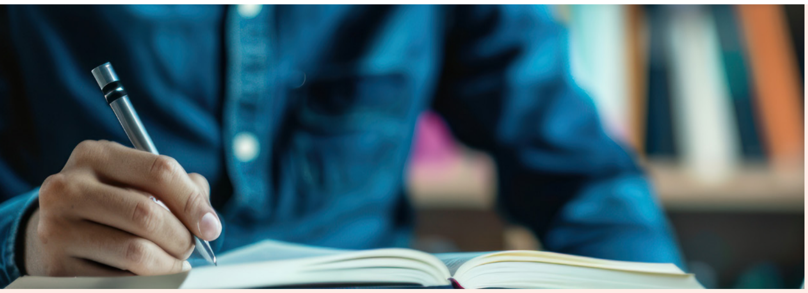
Hosting your own fundraiser can be a fun and meaningful way to give back to the neuromuscular community. With careful planning, you can help make a real difference in the lives of people with neuromuscular disorders. With commitment and dedication, it is easy to make a difference. For more information, or to get support with your fundraiser, contact Jennifer Williams at Jennifer.Williams@muscle.ca.

BRINGING THE NEUROMUSCULAR COMMUNITY TOGETHER TO CONNECT, REST AND SHARE EXPERIENCES

Breaking Barriers: Building Bonds

Thanks to generous supporters, like you, Muscular Dystrophy Canada is thrilled to be hosting more than a dozen retreats in 2025. From Caregiver Retreats to Family Retreats and new this year, hybrid retreats there is something for everyone to enjoy. Caregiver Retreats offer anyone taking care of someone affected by a neuromuscular disorder a relaxing weekend away, while Family Retreats are open to the entire family to come together and meet other families from their area, while enjoying various activities and entertainment. Hybrid Retreats will offer a combination of both, with opportunities for family activities, as well as caregiver-only sessions. For more information, or to complete the online registration form, please visit muscle.ca.

"At retreats, families encourage and support each other and there is an unspoken bond that melds us all together. Even though there are many diverse circumstances, we know during that weekend we are all equal; all supporting each other and recharging one another's batteries. There's joy and laughter from people whose lives are often an uphill battle. As a family with two young men in wheelchairs, we value the reprieve more than most people will ever realize." — Jody and Doyle, who attended a recent retreat with their sons, Jon and Ty.



TOGETHER, WE ARE BREAKING DOWN BARRIERS FOR POST-SECONDARY GOALS!

Thanks to the generosity of our donors, supporters, and Canadian Fire Fighters, students affected by neuromuscular disorders are now one step closer to achieving their dreams of higher education and building meaningful careers. This type of support makes a profound impact, enabling students to attend post-secondary institutions and overcome barriers that might have previously seemed insurmountable.

We are excited to announce that eligible students can now access funds to support their academic journey. These funds can be used for a wide range of essential expenses, including tuition, books, transportation, equipment (such as laptops and iPads), and even attendant fees.

This initiative is not just about financial support—it's about creating opportunities for individuals to thrive in their education and career paths, regardless of barriers. If you are a student or are enrolling in post-secondary education, we would love to hear from you! Please contact Veronique Painchaud at 1-800-567-2873 ext. 4291, or via email at Veronique.Painchaud@muscle.ca.

We are proud to be part of a community that believes in inclusion, empowerment, and the power of education. Thank you for your continued support in making these goals a reality! We are so excited for the students embarking on their academic journeys and for the future they are building.

MUSCULAR DYSTROPHY CANADA
familyretreat

Upcoming Family Retreats 2025:

BC: May 23, 24 & 25
AB: September 5, 6 & 7
QC: September 12, 13 & 14
ON: September 19, 20 & 21

MUSCULAR DYSTROPHY CANADA
caregiverretreat

Upcoming Caregiver Retreat 2025:

QC: April 4, 5 & 6

NOTE: More event dates and locations will be announced as they are confirmed.

UPCOMING EVENTS

Various Dates: Walk & Roll for Muscular Dystrophy Canada —visit WalkRollMDC.ca for more info.

April 12, 2025: Champions of Change Conference in Ontario

May 16, 2025: Deadline for student bursary applications

May 24, 2025: Champions of Change Conference in British Columbia

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