

## MDC AND PARTNERS LAUNCH CENTRAL HUB FOR NMD SPECIALISTS – A CANADIAN FIRST!

Have you ever looked for a healthcare professional who specializes in the specific neuromuscular disorder (NMD) affecting you or a loved one? If your response is 'yes', you share a common experience with many Canadians who frequently seek healthcare professionals experienced in their specific condition. In fact, the second most frequently asked question to MDC's Research Hotline in 2023 was about finding physiotherapists, occupational therapists, physical medicine and rehabilitation physicians, speech-language pathologists, surgeons, and respirologists with expertise in neuromuscular conditions. This valuable information wasn't centralized in one location—until now!



Canadian Neuromuscular  
Community of Practice

Communauté de pratique canadienne  
sur les maladies neuromusculaires

For the first time ever all healthcare professionals in neurology or other disciplines focused on NMDs in Canada can connect. The new **Canadian Neuromuscular Community of Practice** not only helps identify healthcare professionals involved in neuromuscular care, but it also makes it easy for all professionals to learn together, exchange information and broaden their overall knowledge of NMDs!

### THANKS TO MDC'S DONORS AND PARTNERS, THE COMMUNITY OF PRACTICE WILL BREAK DOWN BARRIERS FOR THE NMD COMMUNITY BY:

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| <ul style="list-style-type: none"> <li>• Making it easy to share information on NMDs</li> <li>• Continually training and educating</li> <li>• Opening access for peer-to-peer support</li> <li>• Allowing for collective problem solving and faster access to experts for advice</li> <li>• Providing access to more NMD experiences</li> <li>• Improving Canadian clinical trial readiness and access</li> </ul> | <p><b>WHICH WILL ...</b></p> <ul style="list-style-type: none"> <li>• Provide timely references to appropriate specialists</li> <li>• Improve Canadians access to reliable information</li> <li>• Strengthen the level of NMD expertise in the Canadian medical community</li> <li>• Reduce the time it takes to receive effective care</li> <li>• Improve access to clinical trials in Canada</li> </ul> |
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Are you a client looking for neuromuscular disorder information or specialists? Are you a healthcare provider looking to join the community of practice or share information? The Canadian Neuromuscular Community of Practice team is happy to help! Contact [research@muscle.ca](mailto:research@muscle.ca)!

The community of healthcare professionals supporting the Canadian Neuromuscular Community of Practice are (pictured from left to right) Dr Warman-Chardon, Dr Lochmüller, Dr Gagnon, Dr Campbell, Dr Schellenberg, Dr Mah, Dr O'Connell, Dr Rodrigue and Dr Plamondon.

# TOGETHER, WE'RE HELPING BREAK DOWN BARRIERS FOR CHILDREN WITH NMDS



During a time when being understood, included and involved is critical, classroom environments can be a daunting place for anyone affected by a neuromuscular disorder (NMD). Did you know Muscular Dystrophy Canada (MDC) offers tools to help educate a wide range of audiences on specific NMDs? These activities are tailored to open the conversation around disability and inclusivity.

- 'Why are children with NMDs often tired?' 'Why use a scooter in the schoolyard, but not inside?' **Muscle Facts presentations** provide schools with a better overall understanding of neuromuscular disorders. MDC staff join students and teachers to share information about NMDs and specific conditions experienced by students in the community, symptoms, equipment and why it's used, and so much more! This presentation is a great opportunity for open discussion to improve the classroom experience for all.
- Not all educational staff have experience teaching students affected by NMDs. It can be overwhelming and you might not know where to start or how best to support that student. Don't worry! MDC staff are here for educators too. **Lunch and Learn sessions** offer a great opportunity to learn about an NMD affecting a student and brainstorm ideas to promote an inclusive school environment. These sessions also help staff adapt their teaching, activities, or school to ensure the child's needs are met.
- Every child has their own way of doing things. **AccessAbility workshops** promote awareness and understanding of people with disabilities by focusing on their abilities, using games and adapted communication techniques. Sponsored by the Canada Post Community Foundation, these workshops address not only NMDs but any type of disability, and focus on six main areas of development: function, family, fitness, fun, friends and future.



## ARE YOU A HEALTHCARE PROFESSIONAL?

MDC offers Outreach presentations for healthcare professionals and community agencies, providing useful information to better understand, support and care for people affected by NMDs. These presentations bring awareness of MDC as an organization, the disorders we cover, the scope of our programs and services, research initiatives, funding opportunities and more.

Email us at [info@muscle.ca](mailto:info@muscle.ca) to schedule a presentation or learn about other education opportunities.



*"It truly takes someone who understands not only NMDs but also a young student's mind to be able to speak with them in a relatable and understandable way. My main concern going into this presentation, at my son Neema's school, was how he would react and feel. But it was unfounded because the presentation focused on neuromuscular disorders, and how it affects every day life," shared Natalija Manigoda. "I like how the students were completely engaged because the presentation was fun and interactive. I was pleasantly surprised by how many students had great questions. It was an incredible teaching moment that clearly explained how these disorders affect student life."*

Connect with MDC to set up a presentation that works for you! Email us at [info@muscle.ca](mailto:info@muscle.ca) or call toll free at **1-800-567-2873**.














You can also find an MDC Service Specialist near you by visiting: [muscle.ca/services-support/need-help](https://muscle.ca/services-support/need-help) or scanning the QR code.



# WE HEARD YOU: BREAKING DOWN THE BARRIERS OUR COMMUNITY EXPERIENCE MOST

At the 32 Walk & Roll events that took place across the country last year, we surveyed participants to learn more about the barriers persons affected by NMDs face every day. From this feedback, it was clear our community encounter many challenges when it comes to receiving an accurate and timely diagnosis, accessing equipment and treatment, and finding specialists knowledgeable about the specific NMD that affects them or their family member.

Armed with feedback directly from the Canadian NMD community on what barriers impact them most, this year we are focusing our advocacy efforts on:

 <b>Early diagnosis and newborn screening</b>	 <b>Equitable and timely access to treatments</b>	 <b>Improved access to specialized healthcare providers and clinics</b>	 Did you know on average for Canadians it takes <b>5 years</b> and at <b>3 healthcare professionals</b> before receiving a final diagnosis?
 <b>Equitable access to assistive devices and equipment</b>	 <b>Financial assistance for expenses related to health and community needs</b>	 <b>More opportunities to participate in clinical trials and registries</b>	 Not fun fact: <b>40%</b> said they have difficulty finding the right doctors, specialists and clinics.
 <b>Improving access to NMD information and raising awareness</b>	 <b>Comprehensive person-centered supports prioritizing the right to choose</b>	 <b>Accessible public spaces and experiences</b>	 <b>78%</b> said they can't afford equipment, assistive devices, repairs, physiotherapy, rehabilitation or home/vehicle modifications without funding support.
			 A staggering <b>70%</b> of participants said they had difficulty accessing clinical trials and research opportunities.

## YOU CAN HELP BEAK DOWN BARRIERS AT THE WALK AND ROLL



Register for the 2024 Walk and Roll for MDC today!

By participating in the Walk and Roll for Muscular Dystrophy Canada and raising funds, you're helping individuals affected by neuromuscular disorders get the right diagnosis and access treatment as early as possible. You're advancing research that will lead to cures, and helping Canadians find the right resources at the right time.

This year we need to raise \$1.3 million through the Walk and Roll to continue this essential work.

Will you help us? Register now at [WalkRollMDC.ca](https://WalkRollMDC.ca).



*"My favorite thing about Walk & Roll is everyone coming together as one. I love seeing all the smiling supportive faces of everyone around! For me, this day is all about raising awareness, sharing my story, and being with family and friends who have supported me throughout my DMD journey." – Christopher Mino.*

## YOU ARE BUILDING THE FUTURE OF RESEARCH AND CARE

MDC together with the Neuromuscular Disease Network for Canada (NMD4C) are thrilled to announce the recipients of the National Clinical and Post-doctoral Fellowships competition.



These fellowships are made possible by YOU. They are funded by generous donors and incredible partners like Fire Fighters across the country. Congratulations to Dr Yassine Ouahdi, Dr Cedric Happi-Mbakam, Dr Yiu-Chia Chang, Dr Mark Krongold, and Dr Bram De Wel.

Scan the QR code to learn more or visit [muscle.ca/researchers/fellowship-awards](https://muscle.ca/researchers/fellowship-awards)



## FIRE FIGHTERS IGNITE JOY AND MAKE LASTING CONNECTIONS

Fire Fighters go above and beyond in more ways than we can count!



For almost seven decades, dedicated and passionate Fire Fighters across Canada have been supporting the neuromuscular community in a variety of ways. They raise important funds through boot drives, rooftop campouts, stair climbs and other activities. But, did you know they also give their time at MDC events to connect with the community throughout the year?

In 2023, local Fire Fighters and their service dogs volunteered for MDC's Alberta Family Retreat, putting a huge smile on everyone's face! At our Quebec Family Retreat, families enjoyed various activities and entertainment, including Fire Fighters showing kids of all ages (even kids at heart) their truck. Fire Fighters also took part in several Walk and Roll for MDC events last year.

These are only a few examples of the incredible support, dedication and interest Fire Fighter partners offer the neuromuscular community year-round. We are so grateful for their commitment and all they help accomplish! To learn more about how Fire Fighters support the NMD community visit [filltheboot.ca](https://filltheboot.ca)



#FillTheBoot  
[filltheboot.ca](https://filltheboot.ca)

## CELEBRATING VOLUNTEERS AS THEY CHAMPION CHANGE ACROSS CANADA

MDC is incredibly thankful to have volunteers who demonstrate extraordinary commitment to raising funds, increasing awareness and advocating for the NMD community, and supporting continued research. Volunteers give so much, in so many ways, it's hard to express how appreciative we are for their dedication. One way MDC shows our gratitude and celebrates the contributions of all volunteers is with the annual Dr David Green Awards. Last year, we were very excited to celebrate some of these amazing people and organizations in front of their peers at MDC's Champions of Change conference in November 2023 with the presentation of their awards. Thank you to every single person who gives their time, thought, skills, connections and passion to help support the Canadian neuromuscular community.

Want to change a life? Consider volunteering at MDC today!

Visit [muscle.ca/take-action/volunteer/](https://muscle.ca/take-action/volunteer/)



## UPCOMING EVENTS

- SMA Masterclass: register at [surveymonkey.com/r/MDCSMAmasterclass](https://surveymonkey.com/r/MDCSMAmasterclass)
- High Rise Challenge: registration opens in May 2024
- Walk & Roll for MDC: registration is open!  
[WalkRollMDC.ca](https://WalkRollMDC.ca)



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