

RESEARCH BRINGS HOPE FOR A BETTER FUTURE

Muscular Dystrophy Canada (MDC) knows the incredible hope research brings for a better future. With many treatments, therapies and trials coming into Canada, partnerships and collaboration are key to funding innovative discoveries and improving health outcomes. That's why MDC works with researchers and clinicians across the country to move research forward so better treatments, and ultimately a cure, can be found for neuromuscular disorders (NMDs).

Last year, MDC invested more than \$2 million in research and leveraged an additional \$3.5 million by working with partners like the Canadian Institute for Health Research (CIHR) to match donors' funding. We invested in three partnered grants including a new pan-Canadian network of neuromuscular disorders stakeholders to make it easier for Canadian researchers, clinicians and advocates to improve research and clinical care. We invested in nine translational and clinical health research seed grants that were disorder-specific (e.g., Duchenne Muscular Dystrophy, Spinal Muscular Atrophy, Myotonic Muscular Dystrophy, Myopathies) and cross-cutting, meaning the findings can apply to multiple NMDs. While we support important research projects taking place across the country, thanks to donors we're also able to invest in research activities at MDC.

Through education and information sessions, MDC supports individuals affected by NMDs to gain a deeper understanding of their disorder and for healthcare providers to better manage NMDs. With help from generous donors, like you, MDC helps ensure research is well understood, available and accessible for all.

Recently MDC, in partnership with the NMD4C, launched a Royal College of Physicians & Surgeons accredited webinar series to share up-to-date information on NMDs so clinicians across the country are better able to serve clients. The webinars have been hugely successful with more than 50 researchers and clinicians in attendance each month.

We also have two research experts working at MDC, and this past year, with their support, we launched a Research Hotline to answer questions from the NMD community and a Canada-wide study on the Economic Impact and Quality of Life of Living with a NMD.



Dr. Daria Wojtal, PhD, is our Director of Research at MDC. Dr. Wojtal's PhD is in Molecular Genetics. As the Director of Research, she oversees research investments including the design, implementation and monitoring of the Research Grant Competitions. She works closely with the Medical & Scientific Advisory Committee to ensure high-quality NMD research is being funded. Dr. Wojtal also provides

her expertise on NMDs and data analysis within MDC, ensures accurate research information is available for all clients and works closely with donors to assist with investigating research opportunities that best align with donor's interests.

Dr. Homira Osman, PhD, is our Director

of Knowledge Translation & External Engagement. Dr. Osman is a clinician-scientist with a PhD in Neuroscience and specialized training in Knowledge Translation/Patient Education. She provides leadership to a broad range of education and research initiatives including the Research Hotline, #LetsTalkNMD

webinars, Research Spotlights and the Economic Impact and Quality of Life of Living with a NMD study. She works closely with all MDC stakeholders to help build connections, tools and resources. Dr. Osman also engages with federal and provincial governments and like-minded organizations to represent the voices and experiences of the neuromuscular community.



Do you have a research or disorder related question and don't know where to turn for answers? Dr. Wojtal and Dr. Osman have a dedicated hotline! Call **1 800 567-2873 ext. 9037** or email research@muscle.ca and they'll provide you with accurate and timely answers from a panel of medical and scientific experts.



TD BANK GROUP (TD) PROVIDES OPPORTUNITY FOR YOUTH TO CONNECT AND LEARN

Atlantic Canada youth affected by a neuromuscular disorder now have more opportunities than ever to form valuable connections. Thanks to generous support from TD, Muscular Dystrophy Canada (MDC) has launched the TD - MDC Let's Connect Atlantic Youth Network meeting series. These virtual network meetings will connect Atlantic Canada Youth in the neuromuscular community and offer an opportunity to learn and grow together as a group and as individuals.



This network series offers opportunities to share, listen to others' experiences, focus on self-care and meet guest speakers who will share their expertise on a wide range of topics such as; health and wellness, stress management, transitioning from pediatric care to adult care, and community involvement.

MDC thanks TD for their generous support of the TD - MDC Let's Connect Atlantic Youth Network. We are so pleased to be working together to make a difference for Atlantic Canadian Youth affected by neuromuscular disorders!

THANK YOU FOR HELPING CANADIANS LIVE FULL, SAFE LIVES



Friends of MDC, like you, provide essential equipment to individuals affected by neuromuscular disorders. You help ensure they have technology to communicate, home modifications so they can come and go freely and the right equipment for the stage of their disorder. MDC client, Maurice Richard, recently experienced an emergency in his home and thanks to you he received the help he needed quickly.

"It must be said that I am living alone and I have Spinal Muscular Atrophy (SMA) type 3. One afternoon, last June, I returned from an outing. I sat down at my kitchen counter to quench my thirst and the control button of my motorized wheelchair got stuck under my counter. The armchair started up and threw me under the counter and crushed me against the table. I managed to stop the engine, maneuvering the rocker of the chair, but there I was—really stuck. I heard noises coming from my neighbour's home, so I cried for help, but they didn't hear me. After a few minutes of panic, I remembered that I was wearing a remote-monitoring bracelet, so I pressed the button," shared Maurice.

He continued, "a few seconds later someone from the emergency call centre called me to help, and then two kind police officers arrived and managed to get me out of there. Without this call button, I would have to wait several hours for the CLSC attendant (local community service centre) to come in the evening.

Several years ago, I spent seven hours leaning in my chair without being able to sit up. In this awkward, painful position, I crushed a nerve in my leg. Since then my foot has remained partially paralyzed. The need for a remote monitor was evident, but not having the means to pay for this service, MDC was able to help with the costs of the monitoring service. Thank you!"

MDC's equipment program can only provide vital equipment to clients across Canada thanks to very generous donors. For those affected by neuromuscular disorders, accessing essential equipment is a high priority, especially since provinces and programs vary drastically in what they are able to provide.

Unfortunately, compared to last year we've seen a 46 per cent decrease in revenue and have had to reduce funding to all programs including the Equipment Program. If you're in a position to help, please make a donation today, to ensure Canadians like Maurice have the equipment and support they need: muscle.ca/donate

WELCOME TO 2021

I want to take this opportunity to thank each and every donor, client and their family members, Fire Fighter, healthcare professional, researcher, volunteer, staff member and partner who connected and worked with us in 2020 to help us deliver on our mission. You inspire us each and every day. We couldn't do it without you.

It was a challenging year for all, but your support directly impacted thousands of Canadians across the country.

I'm also pleased to announce Muscular Dystrophy Canada recently received Imagine Canada accreditation under its Standards Program for excellence in non-profit accountability and transparency, governance and fundraising. I want to thank our dedicated Board of Directors and MDC team for their hard work in making this accreditation possible. To learn more, visit imaginecanada.ca.

While it is wonderful to acquire this prestigious Trustmark, our goals and practices have always been about doing our best to support the neuromuscular community. As such, donations from supportive Canadians, like you, are put to work right away to support families and to fund research.

While we continue to be optimistic during the pandemic, charities like ours are still being impacted by its effect on our traditional fundraising activities and the economic realities for so many. However, we are committed to finding innovative and creative opportunities to meet the diverse, challenging needs of the neuromuscular community. And, with you by our side, all things are possible.

We hope you can continue your support for 2021. Because, like us, I know you too are ignited by passion and fueled by hope.

Stacey Lintern,
CEO, Muscular Dystrophy Canada



THE TENAQUIP FOUNDATION WALK4MD UNITES THE NATION

Canadians from coast, to coast, to coast came together virtually on September 12, 2020 for The Tenaquip Foundation Walk for Muscular Dystrophy. Thanks to supporters like you, the event raised \$776,521, which will be invested in research, programs and services, and advocacy for the neuromuscular community.



Thank you to all the participants who registered and fundraised, to our amazing donors, our sponsors, and everyone who helped us put the show together! We could not have done this without you!

Stay tuned for news on The Tenaquip Foundation Walk for Muscular Dystrophy 2021. Did you miss livestream event in 2020? No problem! You can watch it now on [Youtube.com/muscular dystrophy can](https://www.youtube.com/muscular dystrophy can).

HIGH RISE CHALLENGE TAKEN TO NEW HEIGHTS

On September 26, 2020, Muscular Dystrophy Canada (MDC) held its first-ever virtual High Rise Challenge and raised more than \$195,000!

A huge thank you goes out to all of the incredible participants who demonstrated creativity, endurance, and great strength in completing their challenges and raising vital funds for the neuromuscular community.

To the 2020 High Rise Challenge Organizing Committee, your hard work and dedication to the cause does not go unnoticed. This event would not be possible without you. Thanks also go out to our generous sponsors: Cadillac Fairview, APM - L'Association des pompiers de Montréal, SPQ - Syndicat des pompiers et pompières du Québec, Firebag MTL, and Espace VERRE.

FIRE FIGHTERS GET CREATIVE TO FILL THE BOOT

Fire Departments and Associations can now sign up as a team or individual on filltheboot.ca and promote their own fundraising pages! You can support your local Fire Fighters in their efforts to Fill the Boot in support of individuals affected by neuromuscular disorders.

Thank you to all of the dedicated Fire Fighters who have been fundraising online, holding events safely in their communities, and raising awareness.

Visit FILLTHEBOOT.CA to learn more, donate or sign up today!