

## DONOR SUPPORT PREPARES OTTAWA FAMILY FOR ONSET OF DUCHENNE MUSCULAR DYSTROPHY

In 2019, Linda and Tony Morabito packed up their family home in Smithville, Ontario and moved to Ottawa so they would be prepared for the inevitable.

Their 6-year-old son, Aidan, was recently diagnosed with Duchenne Muscular Dystrophy. And, though he doesn't have any symptoms yet, Linda and Tony know it's only a matter of time before they need to be closer to the children's hospital, as well as live in a one-level home to make things easier once Aidan requires a wheelchair to get around. Thankfully, they had donors like you to help them!

Because of you, Linda was able to pick up the phone and call a Muscular Dystrophy Canada (MDC) service specialist who, Linda says, made the process of acquiring a wheelchair a very "smooth experience."

MDC has service specialists located across the country to help individuals and families navigate a diagnosis, answer questions, and connect them with programs and services, like our equipment program, Family and Caregiver Retreats, and educational resources.



**"Being connected with a service specialist makes us feel like we're no longer alone."**  
— Linda Morabito



**"Being connected with a service specialist makes us feel like we're no longer alone,"** says Linda.

Your support makes the relationship between our service specialists and clients possible.

It was also through a service specialist that the Morabito's heard about MDC's Muscle Fact Presentations.

These presentations help school-aged children understand differences in disability, provide an opportunity to learn about neuromuscular disorders and how it impacts their classmate, and allows peers and teachers of the child impacted to ask questions.

Linda and Tony were thrilled that their son's new classmates and teacher were able to learn about Duchenne, and have scheduled a second presentation with the remaining staff at Aidan's school. Your gifts and ongoing support are breaking down barriers for Canadians impacted by neuromuscular disorders.

**If you need support, please call our toll-free number 1-800-567-2873 to speak to a service specialist or email [info@muscle.ca](mailto:info@muscle.ca)**

INTERESTED IN HELPING FAMILIES LIKE THE MORABITO'S? VISIT [WWW.MUSCLE.CA/DONATE](http://WWW.MUSCLE.CA/DONATE)



## ENHANCEMENTS TO MDC VOLUNTEER PROGRAM COMING SOON

who are impacted.” Volunteers, like Danny, are truly priceless.

As a volunteer-driven organization, volunteers have a big impact at MDC. Our volunteers are respected individuals of the MDC team and play a vital role in the delivery of our fundraising campaigns, programs, and services. MDC strives to provide our volunteers with an opportunity to succeed, contribute, and be recognized using best practices outlined by Imagine Canada.

Muscular Dystrophy Canada (MDC) has the best volunteers. They are dedicated, enthusiastic, diverse, dynamic; and we couldn't help Canadians impacted with neuromuscular disorders without them.

Of course, some of our volunteers, like Danny Morris, have been diagnosed with disorders themselves so they know all too well the important role they play at MDC. Danny is 52-years-old and lives in Halifax, Nova Scotia. Growing up, he was always strong, fit and athletic, but when he started to slow down in his 30's, he realized something was wrong.

He was diagnosed with Facioscapulohumeral muscular dystrophy (FSHD), and recently transitioned from walking to using a wheelchair. Danny is a dedicated MDC volunteer, who is actively involved in the Halifax Chapter leadership, and sits on the Halifax Walk for Muscular Dystrophy committee. "I enjoy volunteering at the Walks—I love the group of people I volunteer with," he says. "The volunteer committee and the staff are like family."

His walk team, "The Sole Mates," fundraise an incredible \$10,000 each year. "I love volunteering," he says.

"It's a way for me to raise awareness about neuromuscular disorders and help others

Volunteers are key partners in the delivery of MDC's support programs, client services, fundraising efforts and governance. Our volunteers play important roles in the Walk for Muscular Dystrophy, Chapters, Networks, supporting Fire Fighters, participating in other special events, Board of Directors and Committees, Advocacy, and Mission events including Family and Caregiver Retreats, Educational Sessions and sharing personal stories.

To better serve our volunteers and provide a rewarding and meaningful experience, the enhancements listed to the right are being made to our volunteer engagement program.

To each and every one of our volunteers, thank you from the bottom of our hearts for the incredible work that you do.

**If you are interested in volunteering at MDC please email [info@muscle.ca](mailto:info@muscle.ca) or call us toll-free at 1-800-567-2873.**

### New volunteers with MDC will be supported in the following ways:

- Will undergo a screening process, interview, and a background check to ensure that the needs of the volunteer match those of the organization, and that all of our stakeholders are protected.
- Complete the organization orientation and training on disability sensitivity, diversity, and neuromuscular disorders, as well as any type of training specific to the volunteer role.
- Ongoing support and communication with MDC staff partners and leadership volunteers, including regular check-ins and opportunities for volunteers to provide feedback.
- Tracking of volunteer activities so that we can communicate and demonstrate the impact of their work on individuals affected by neuromuscular disorders.
- Recognition for outstanding contribution.



## NEW NETWORK TO IMPROVE OUTCOMES AND ACCESS TO THERAPIES



MDC is very excited and proud to announce that, in partnership with the Canadian Institutes of Health Research (CIHR), we are funding a grant entitled, **“NMD4C: An integrated research network for patients, scientists, and clinicians to improve outcomes and access to therapies for individuals with neuromuscular disorders in Canada.”**

The goals of the new NMD4C Network are to:

- Build and sustain a new network of neuromuscular disorders stakeholders to make it easier for Canadian researchers, clinicians and patient advocates to improve research and care.
- Train and educate the next generation of neuromuscular disorder-specific clinicians, scientists, and patient advocates to improve the quality of care and research.
- Raise the standard of care for neuromuscular disorders and access to therapies across Canada, by developing and providing the right information, to the right

audience, at the right time.

- Expand access to research resources and build research capacity by uniting local efforts across Canada and linking to international activities.

In addition to helping fund this three-year grant, MDC will be an equal partner to the NMD4C Network and serve as the knowledge translation lead. MDC will

be responsible for the coordination and management of knowledge translation activities.

We hope to raise the standard of care for neuromuscular disorders by developing, disseminating, and implementing clinical care guidelines tailored to different audiences; use a variety of methods to share knowledge with individuals impacted by neuromuscular disorders, clinicians, and researchers about network activities, clinical trial opportunities, and educational and training events.

In line with our goal of increasing the understanding and awareness for neuromuscular disorders, MDC is very happy to be organizing its first-ever nationwide **Neuromuscular Conference** set for November 7–8, 2020 at the Sheraton Centre in Toronto. Registration and full website will open in the spring.

### NEUROMUSCULAR CONFERENCE 2020

#### MARK YOUR CALENDARS

#### PRE-CONFERENCE- NOVEMBER 6, 2020

##### MDC Medical and Scientific Summit

*Open to scientists, healthcare professionals and pharmaceutical industry partners*

#### CONFERENCE- NOVEMBER 7-8, 2020

##### MDC Neuromuscular Conference

*Open to all individuals impacted by neuromuscular disorders and professionals who work with the neuromuscular community*

##### Sheraton Centre Toronto Hotel

123 Queen St W, Toronto, ON

Registration Opens February 2020

[research@muscle.ca](mailto:research@muscle.ca)





## REGISTRATION IS NOW OPEN FOR THE 2020 WALK FOR MUSCULAR DYSTROPHY!

The Walk for Muscular Dystrophy (Walk4MD) is a fully accessible community event that's fun for families, friends, and community members! Walk events take place in more than 40 locations across Canada—we hope to see you at an event near you! Join us, as we Walk as One to support Canadians impacted by neuromuscular disorders!

At #Walk4MD you will build a network of support, fundraise for a good cause, and get to know your community and neighbours a little better.

So, what are you waiting for? Head on over to [www.walk4md.ca](http://www.walk4md.ca) now to register!

## BREAKING DOWN BARRIERS: FOCUS OF NEW MDC STRATEGIC PLAN

Muscular Dystrophy Canada (MDC) is in the process of developing a new five-year strategic plan that will be a significant evolution of our organization, and that builds upon the solid foundation we created with our previous plan. This solid foundation and successful growth were made possible thanks to supporters like you! Thank you for all you do to support our mission and the neuromuscular community.

The 2020–2025 strategic plan will see MDC investing in more research initiatives with potential for the greatest impact; adapting programs and services to fill the critical gaps that currently exist; and advocating with, and for, the neuromuscular community for meaningful changes to public policy.

Your continued support of MDC will be instrumental as we implement this plan. Together, we can break down barriers for Canadians impacted by a neuromuscular disorder. We can't wait to get started with you by our side once again.

The 2020–2025 Strategic Plan is expected to be finalized this spring, and will be available on our website [www.muscle.ca](http://www.muscle.ca). Stay tuned to see what we're up to!

## UPCOMING EVENTS

**February – April**  
Rooftop Campouts

**March**  
Buck 4 Luck

**May– October**  
Walk for Muscular Dystrophy

**April 11**  
Atlantic Easter Fill the Boot

**May 30**  
High Rise Challenge

**November 6 – 8**  
Neuromuscular Conference

To stay up to date on all upcoming events, please visit [muscle.ca/events](http://muscle.ca/events).

## CONNECT WITH US!



MUSCLE.CA | 1-800-567-2873