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Muscular Dystrophy Canada's (MDC)
2023–2028 Strategic Priorities

Breaking Down Barriers

FOR THE NEUROMUSCULAR COMMUNITY

Muscular Dystrophy Canada's (MDC) strategic priorities represent a continuing evolution for our organization. They build upon the outcomes and learnings over the last three years, during which time our organization continued to meet the needs of clients through our programs and services, equipment, and system navigation; successfully encouraged governments to change public policy; and, supported translational and clinical research, in addition to, expanding Canadian neuromuscular research infrastructure.

Our investments in research have helped create exciting changes in the Canadian landscape. Whether it was working with our researchers and clinicians facilitating educational webinars, developing resources so our clients have access to credible and clear information, or through our shared work with the Neuromuscular Disease Network for Canada (NMD4C) – our clients are benefiting from early screening and diagnosing, new treatments, trials, and standards of care.

Extending into the next five years, our unwavering focus is on expanding our base of clients to ensure we assist more Canadians with neuromuscular disorders and their families. As well, we remain committed to fiscally responsible spending - ensuring funds raised go to our organization's mission, and to increasing our fundraising activity to meet the needs of the neuromuscular community.

In addition to our commitment to reach more Canadians affected by a neuromuscular disorder over the next five years, the strategic priorities enable our commitment to ensuring we are innovative, efficient, and inclusive by providing our community the support and information they need to make informed decisions. We will expand our programs and services to engage further with remote and underserved communities, and will provide services in the languages that make up the fabric of our country.

Government policies at the federal, provincial, territorial, and local levels have a daily impact on our community. The next five years will see MDC expand our direct advocacy efforts working in partnership with our community, other like-minded organizations, industry, partners, clients, and government.

Over the next five years we will continue to work with researchers and clinicians to enhance collaborative and proactive strategies to support infrastructure development, capacity building, develop centres of excellence and the sharing of research outcomes that benefit our community.

We will respect that as a diverse community representing a wide spectrum of cultures and experiences, there are different ways of knowing, and of approaching health. We will incorporate this understanding and a respect for the whole person – mind, body, and spirit — in all that we do. We will continue to ensure that all organizational planning and decisions align with our strategic priorities, in addition to ensuring the right measurements are in place to monitor our performance.

Finally, we will not give up the search for more and better ways to work with all our stakeholders. Our clients and their families, staff, donors, supporters, partners, and volunteers are essential members of our community and we are grateful for their support every day.

We are excited about the impact MDC will have during the next five years.

Stacey Lintern,
Chief Executive Officer

David Crawford,
Board Chair

To read our 2023-2028 Strategic Plan visit:

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CHANGEMAKERS

VALUE OF A *monthly gift*

Did you know that every month, you have the opportunity to change the life of someone affected by a neuromuscular disorder?

Making a monthly donation, and becoming an MDC Changemaker is an important and rewarding way to show your support for the neuromuscular disorder community. By pledging a few dollars each month, you can provide ongoing and meaningful support, which makes a huge difference in the lives the persons affected. MDC Changemakers are part of the fabric of the neuromuscular community and their support plays a vital role in driving our work forward and ensuring that Canadians affected by neuromuscular disorders have the tools and resources they need to live rich, full lives.

"Over the years, as my equipment needs have changed, Muscular Dystrophy Canada's (MDC) support has been indispensable. With the support of donors, MDC helped me get an elevating wheelchair and even provided funding support so my family could afford a van with a power lift. And getting back some independence through this equipment has been life-changing for me. MDC made that possible."
– Alex Harold

1 It's convenient: Set it and forget it!

Monthly giving is a great way to include charitable donations in your budget. Smaller donations that occur throughout the year, are generally more manageable for your personal budget. Plus, MDC issues a single, consolidated tax-receipt to all Changemakers for the full amount of their yearly donation so you don't have to keep track of each individual gift.

2 Compounded impact: A little goes a long way!

A regular gift made over a longer period of time stacks up in terms of total impact. Recurring monthly gifts provide MDC with regular and predictable support that allows us to fund our life-changing programming throughout the year and better predict future cash flows.

3 Join an exclusive community

At MDC, our monthly donors are Changemakers; a community dedicated to breaking down barriers for the neuromuscular community. Becoming an MDC Changemaker comes with some exclusive benefits, including:

- ✓ A dedicated MDC staff member to answer your questions and provide support whenever you need it;
- ✓ Members-only webinars, focused on research updates;
- ✓ Email-only quarterly updates to share impact statistics and good news stories;
- ✓ An annual report highlighting how your support of MDC has impacted the neuromuscular community;
- ✓ The feeling of pride at being a part of one of the most important communities within MDC.

Become an MDC **CHANGE**MAKER today, and help
break down barriers for people affected by neuromuscular disorders.

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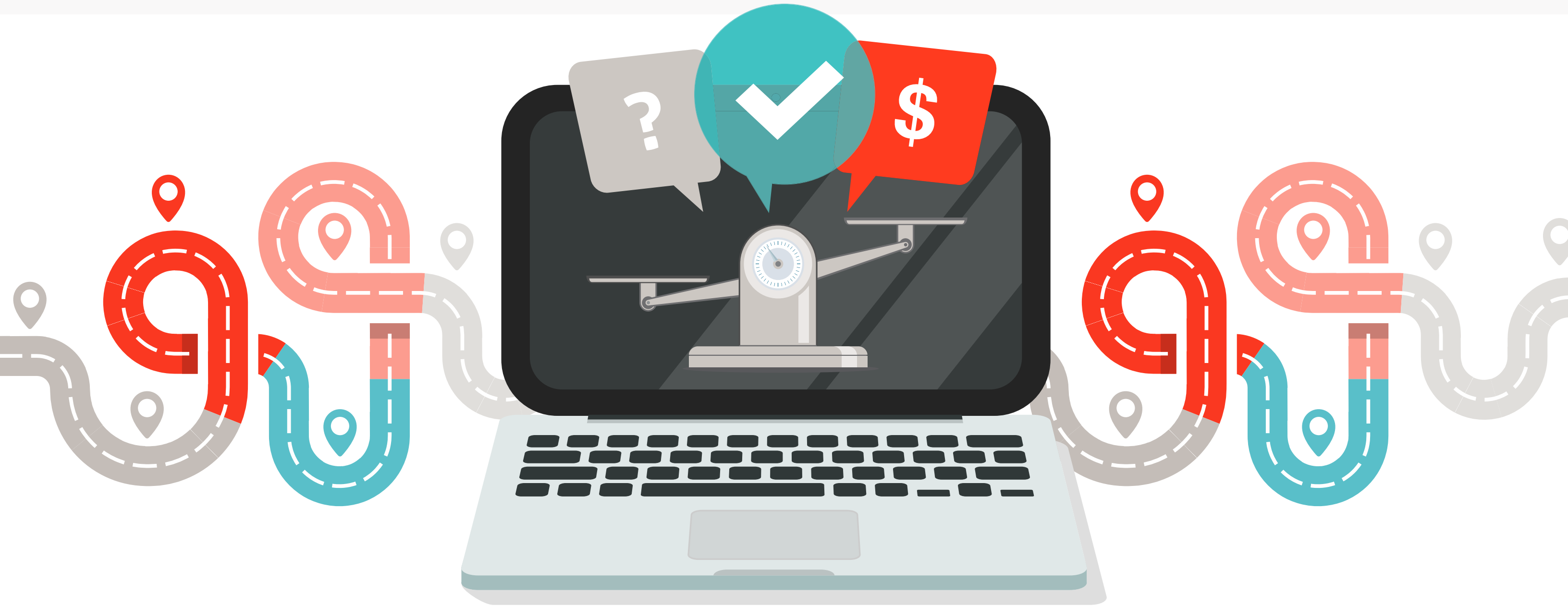
Newsletter
SPRING 2023



GETTING A CLOSER LOOK AT THE SOCIAL AND ECONOMIC COSTS OF NEUROMUSCULAR DISORDERS

Muscular Dystrophy Canada is proud of our significant contributions to understanding the costs related to living with a neuromuscular disorder (NMD) in Canada. In fact, thanks to your support, we led the first study to examine the societal cost in Canada for six common types of neuromuscular disorders: Duchenne muscular dystrophy, spinal muscular atrophy, myotonic dystrophy, facioscapulohumeral muscular dystrophy, Charcot-Marie-Tooth disease, and myasthenia gravis.

What we learned is although neuromuscular disorders are rare, the total number of people with one of the six disorders mentioned above is considerable, and the total annual cost to society is substantial ($4.6 billion). It also left us wondering, what are the indirect costs for individuals affected and their families: how much time is spent in clinics and hospitals, away from work and school, and how much time and money is spent on travel, medications, rehabilitation, assistive devices and equipment, diagnostics, home therapies and other aspects of life with an NMD.

BIND, is a comprehensive new study funded by CIHR and led by Dr Jodi Warman-Chardon from the University of Ottawa, which will collect information about the hidden and indirect costs of living with any neuromuscular disorder, at any age.

Watch now: Dr Jodi Warman-Chardon leads BIND study

With new treatments and therapies becoming available in the near future, the BIND study will be leveraged to make informed decisions to influence public policies and healthcare system planning, as well as to shape Muscular Dystrophy Canada's programming, inform our advocacy work, and help provide information to decision-makers about what families affected by neuromuscular disorders need most.

MDC is also calling on people with myasthenia gravis (MG) to help us map the Patient Journey: What were the first signs and symptoms of MG? How long did it take to get a diagnosis? How is MG managed today?

To participate in **BIND** or **Myasthenia Gravis: The Patient Journey in Canada**, please email *research@muscle.ca* or call 1-800-567-2873 ext 1114.

TOGETHER WE ARE BREAKING DOWN BARRIERS TO IMPROVE ACCESS TO THERAPIES FOR CANADIANS AFFECTED BY FSHD

Canadians affected by facioscapulohumeral muscular dystrophy (FSHD) could face substantial delays in accessing clinical trials and any Health Canada approved life-changing treatments and therapies when they become available. Muscular Dystrophy Canada (MDC) is working with the Canadian Neuromuscular Disease Registry (CNDR) and the Neuromuscular Disease Network for Canada (NMD4C) to help prevent that from happening.

“Studies show that Canadians have less frequent and timely access to therapies for rare diseases, like FSHD; that very few therapies approved elsewhere in the world are even submitted to Health Canada for regulatory approval; and, that if treatment is approved there is a vast difference in who has access across the provinces and we are working hard to change this,” said Stacey Lintern, CEO, Muscular Dystrophy Canada.

There are more than a dozen FSHD therapies currently in development. The work that MDC is leading will help introduce a patient registry and collect information to build a Canada-wide core dataset for FSHD to speed up development, approval and access to treatments regardless of where a person lives in Canada.

“We know from our experience with spinal muscular atrophy therapies that our government requires Canadian data when reviewing a treatment. With this FSHD dataset and registry, MDC wants to get out ahead of the treatments being developed and address the challenges and barriers to access so that Canadians can access treatments as soon as possible. We’re also hopeful more biopharmaceutical companies will establish sites, and conduct clinical trials in Canada,” added Lintern.

“The CNDR is dedicated to working in close partnership with Muscular Dystrophy Canada and NMD4C to promote opportunities to participate in cutting-edge clinical trials for patients affected by FSHD but to also collect data towards ensuring access to future therapies once approved,” said Dr Lawrence Korngut, National Principal Investigator and neurologist at the University of Calgary.

"Enabling Canadians living with FSHD to register in a single national system allows them to signal their interest in participating in clinical trials, provide the essential Canadian baseline data that the regulators want to see, and be contacted when new treatments become available,” said Dr Hanns Lochmüller, NMD4C Investigator and FSHD clinical trialist.

By engaging partners, MDC is committed to breaking down barriers that prevent Canadians from accessing life-changing treatments, not just for FSHD, but for all neuromuscular disorders and investigating additional opportunities that would benefit our community.

Would you like to help determine what is included in the FSHD dataset and share your Canadian experience? Join us for a virtual roundtable by emailing

research@muscle.ca

RAISING THE BAR FOR NEUROMUSCULAR DISORDER RESEARCH AND CLINICAL CARE IN CANADA

Thanks to Muscular Dystrophy Canada's (MDC) incredible supporters, when opportunities arise to improve the care, research and treatment of neuromuscular disorders (NMD) for Canadians, we're able to act. Such was the case with the Neuromuscular Disease Network for Canada (NMD4C).

Launched in January 2020, with funding from MDC and the Canadian Institutes of Health Research (CIHR), NMD4C was created to provide a comprehensive, inclusive, open and enduring network through which Canadian stakeholders can share expertise and data, and collaborate on joint activities and research. In addition to helping fund the network, MDC also became an equal partner and helps support knowledge translation.

Three years later, MDC has worked with NMD4C to:

- introduce support for clinical and post-doctoral research fellows;
- provide up-to-date clinical and research education through monthly accredited webinars, and forums for dialogue and exchange;
- create a national competency standard that recognizes advanced neuromuscular training;
- develop an accredited and standardized Canadian neuromuscular fellowship curriculum;
- build a virtual Canadian neuromuscular disorder biobank catalogue;
- update the Canadian Neuromuscular Disease Registry by adding two new disease datasets;
- establish NMD clinical trials, as well as clinical trial capacity;
- and, launch 'imPORTND', the first patient-oriented training platform developed specifically for neuromuscular disease research.

imPORTND

To learn more about imPORTND, visit ***www.muscle.ca/research/importnd***

"Being a patient partner enables me to have meaningful input into research, to increase its relevance to quality of life and ensure that among its measures are things that are important to patients," said Corinne Kagan, Patient Research Partner and co-developer of the imPORTND training modules.

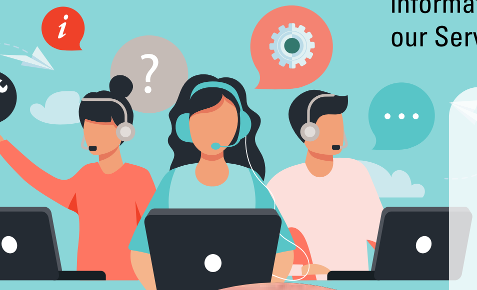
"As a partner and funder, MDC has ensured that Canadians affected by neuromuscular disorders remain at the forefront of NMD4C's decision making, activities and outcomes. From investing in early career researchers and clinicians and developing a virtual biobank, to strenghtening the clinical landscape, the goal has always been to positively influence the NMD healthcare experience in Canada and to build research capacity and knowledge about these rare disorders," said Dr Homira Osman, Vice President of Research and Public Policy, Muscular Dystrophy Canada. "We (MDC) remain committed to the network, and to working together to raise the bar for clinical and research standards in Canada and build upon the momentum currently taking place in research."

NMD4C

To learn more about NMD4C and how you can support or become involved, contact ***research@muscle.ca***

MDC IS HERE FOR YOU!

Whether you live on the east coast, the west coast, the Prairies or central Canada, MDC is here to support you. We have Service Specialists across the country who will be happy to work alongside you, ensuring you have the information and support you need. Meet Ryanne, our Service Specialist in Atlantic Canada.



"As a Service Specialist I am able to work directly with clients and their families to support them in achieving a wide range of goals and navigation of the healthcare system. When we are able to provide funding towards an essential piece of equipment, we are not only supporting our clients with the financial strain that accompanies living with a neuromuscular disorder, but we are also providing hope for the possibilities of what they will accomplish with this equipment. Being able to provide this kind of support and making positive connections with our families truly is my favorite part about working at MDC."

"The majority of the disorders we cover are so rare that it can make you feel isolated. It is so important for our clients to understand that is why MDC is here, to ensure you do not have to navigate living with a neuromuscular disorder alone."

Are you or someone you know living with a neuromuscular disorder? MDC has a wide range of programs and services designed to meet you where you are. Whether it is information on your disorder, helping you with accommodation needs at work or school, navigating the healthcare system, housing or financial issues, or helping you secure equipment – we're here to help. Visit **https://muscle.ca/services-support/need-help/** to find a Service Specialist near you, or call us at **1-800-567-2873**.

If you wish to make a gift, you can do so by visiting us online at **muscle.ca/donate** or calling **1-800-567-2873.**

Check out our 2023 clinical and translational research grant recipients

UPCOMING EVENTS

muscle.ca/events

- **High Rise Challenge – September 30, 2023** *(registration COMING SOON!)*
- **Walk & Roll for MDC in-person events:**

MAY

Niagara, ON – May 13, 2023
Surrey, BC – May 20, 2023
Moncton, NB – May 27, 2023
Montreal, QC – May 27, 2023

JUNE

Edmonton, AB – June 3, 2023
Windsor, ON – June 3, 2023
Summerside, PE – June 4, 2023
Waterloo, ON – June 4, 2023
Gatineau, QC – June 10, 2023
Halifax, NS – June 10, 2023
London, ON – June 10, 2023
Peel, ON – June 10, 2023
Saint John, NB – June 10, 2023
Saskatoon, SK – June 10, 2023
Hamilton, ON – June 11, 0223
Ottawa, ON – June 11, 2023
Regina, SK – June 11, 2023
York, ON – June 11, 2023
Pictou County, NS – June 17, 2023
Quebec City, QC – June 17, 2023
Winnipeg, MB – June 17, 2023
Fredericton, NB – June 24, 2023
North Bay, ON – June 24, 2023
Sydney, NS – June 24, 2023
Toronto, ON – June 24, 2023
Durham, ON – June 25, 2023

JULY

St. John's, NL – July 8, 2023

SEPTEMBER

Jonquière, QC – September 9, 2023
Burnaby, BC – September 16, 2023
Vancouver Island, BC – September 23, 2023
Belleville/Kingston, ON – September 24, 2023
Westman, MB – September 24, 2023

OCTOBER

Calgary, AB – October 7, 2023

For more information, or to register for an event, visit www.WalkRollMDC.ca.

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