

2022-2023 YEAR IN REVIEW: ANNUAL REPORT HIGHLIGHTS

Accomplishments
you made possible
last year!



BOARD OF DIRECTORS

"I'm excited to welcome **Fanny Chagnon, Liz Stirling, Lise Poulin, Nicole Cote and Michael Low** to the MDC Board of Directors. Their wealth of knowledge, talents and familiarity with neuromuscular disorders will be invaluable for providing strategic guidance as we continue to break down barriers for the neuromuscular community this year. I am also extremely pleased that Debra Chiabai has stepped into the Chair position," said Stacey Lintern, CEO, Muscular Dystrophy Canada.



New Board Chair Debra Chiabai added, "It has been a great pleasure to be a member of the Board as a Director for the last 13 years, and I am

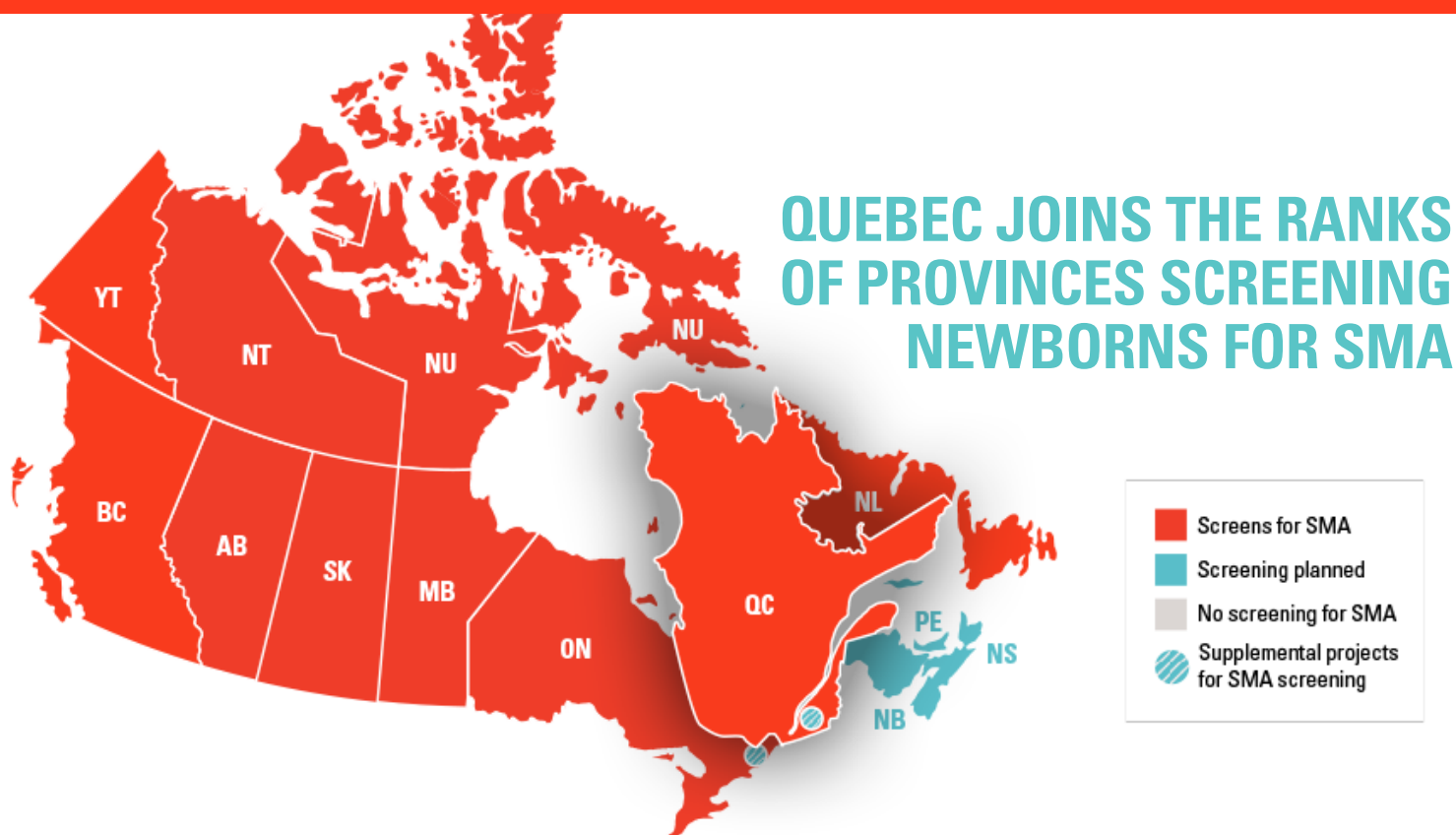
looking forward to stepping into a new role to help guide MDC through the next few years."

At its annual general meeting, the Muscular Dystrophy Canada Board of Directors officially issued its 2022-2023 Annual Report and what's abundantly clear, is that thanks to your support we accomplished so much and broke down even more barriers for the neuromuscular community. Thank you!

- We invested \$2 million to fund: nine new clinical and translational science research projects through our **Neuromuscular Research Grant Competition**; six fellowships; two collagen 6-related dystrophy (Col6-RD) research projects in partnership with CureCMD; and, other projects to ensure the momentum we are seeing in research continues.
- We partnered with Independent Living Canada, People First Canada, Inclusion Canada, Eviance, the Canadian Association of the Deaf, and the Canadian Council on Rehabilitation and Work to produce **Shaping Canada's Disability Inclusion Action Plan (DIAP)**, a report that will inform the federal government's national Disability Inclusion Action Plan.
- **491 individuals affected by neuromuscular disorders registered** with MDC, an increase of 17% over the previous year. To accommodate this growth and provide support, we increased the funds directed towards Mission activities by 11%.
- We diversified our fundraising by meeting new donors and better understanding their interests, and ensured all donors were being stewarded in ways that were meaningful for them. As a result, MDC **increased its total fundraising by \$2.6 million** over the previous year for a total of \$10.7M in revenue.

All of this was possible, because of people like you! Thank you for your commitment to MDC's mission. We're breaking down barriers for the neuromuscular community, together, so that sometime soon a breakthrough is made that leads to cures.

Check out the entire report at:
[muscle.ca/discover-mdc/
financial-statements/](https://muscle.ca/discover-mdc/financial-statements/)



We are thrilled to announce that spinal muscular atrophy (SMA) has been added to the newborn screening panel in Quebec, a significant milestone for the province and Muscular Dystrophy Canada (MDC). Screening is being integrated now, with full implementation to take place by the end of 2023.

Extensive conversations, collaboration and financial contributions (\$583,778) towards the lab program at CHU de Québec-Université Laval, equipment, and building an evidence-based pathway for the early initiation of disease-modifying therapy for individuals with SMA across Quebec, led to this exciting change in policy.

"We couldn't be happier with the recent news", said Stacey Lintern, CEO, Muscular Dystrophy Canada. "The addition of SMA to the panel means that infants and families in Quebec will now equitably benefit from the same opportunities as the majority of other Canadians, gaining access to early detection possibly before the onset of symptoms."

In neuromuscular disorders like SMA, early diagnosis and prompt access to treatments are critical to achieving the best possible outcomes.

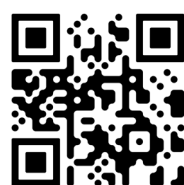
"For families, what matters is for their child to have the best chance in life, to be able to do as much as they're able to do. That is what we can offer with newborn screening for SMA", said Dr Hugh McMillan, Professor of Pediatrics at the University of Ottawa, Pediatric Neurologist and Neuromuscular Specialist at the Children's Hospital of Eastern Ontario

(CHEO) and Clinical Investigator at the CHEO Research Institute.

We thank our partner Novartis Pharmaceuticals Canada Inc. as well as donors, clinicians, researchers, families affected by SMA, and Fire Fighters who collaborated with MDC to advocate for the inclusion of SMA on the newborn screening panel.

MDC is currently working with the Maritime provinces to bring newborn screening for SMA to that part of the country. For more information on MDC's efforts in ensuring all Canadian babies are screened for SMA, visit muscle.ca/services-support/newborn-screening/

Scan the QR code to watch Dr McMillan's video:



If you or a loved one was diagnosed with SMA, MDC has a variety of programs and services for you. Please contact us at 1-800-567-2873 or email info@muscle.ca for personalized support.

MYASTHENIA GRAVIS JOURNEY MAPPING: AN INSIDE LOOK

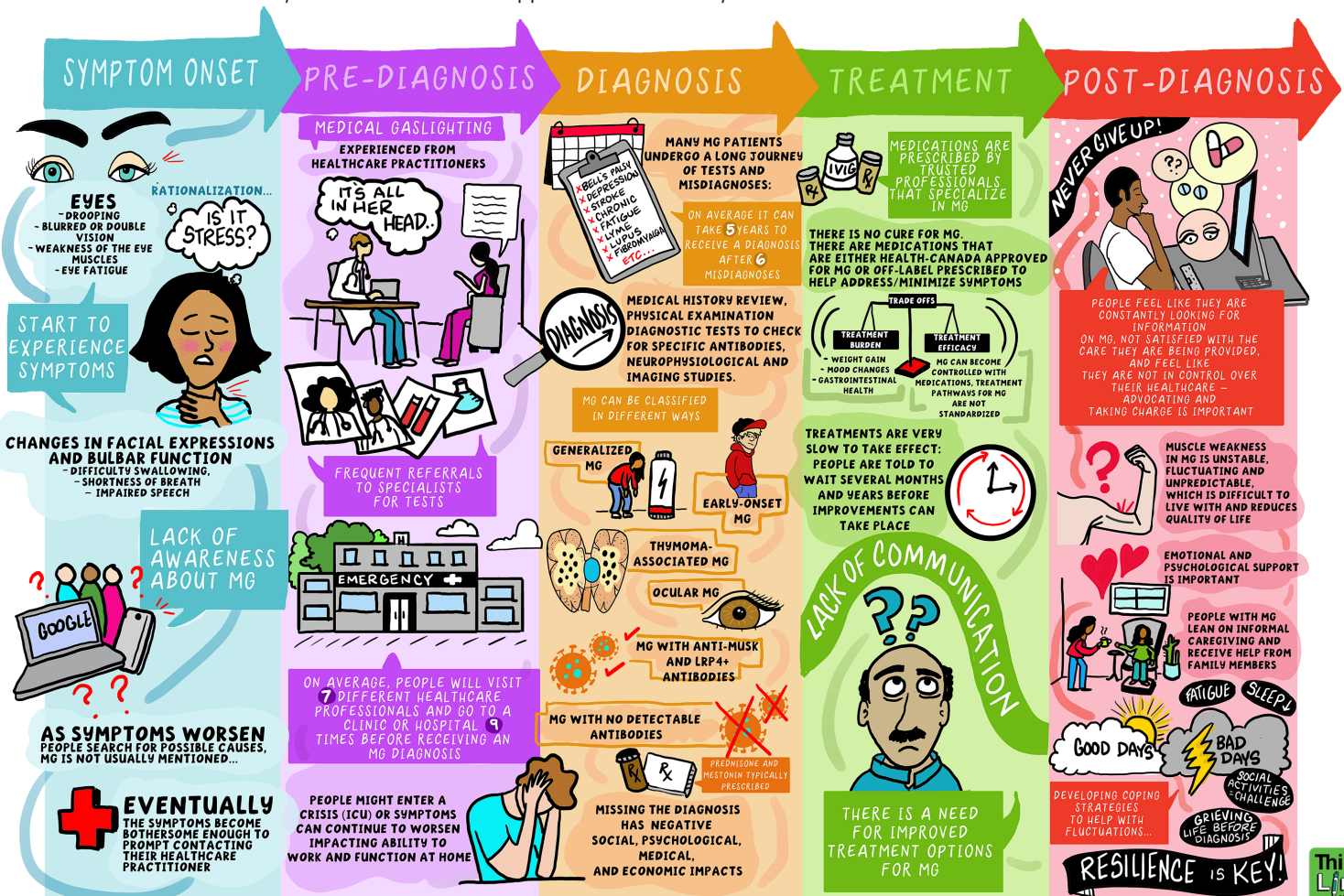
In 2023, Muscular Dystrophy Canada (MDC) conducted a journey mapping initiative for Canadians with myasthenia gravis (MG), a rare autoimmune neuromuscular condition. While some treatments are available for MG in Canada, there remains many challenges and unmet needs. We recognized these recurring roadblocks and difficulties in the diagnosis process for our MG clients, and wanted to capture this information so we would know how best to support this community.

We sought to examine the journey from time of most bothersome symptoms, to diagnosis, to treatment, to post-diagnosis. So, we asked individuals affected across Canada to participate in surveys, interviews and roundtable discussions related to their experiences with their diagnosis, treatment, information provided and day-to-day life.

Our goal was to capture the clinical, attitudinal, cost and informational journey including time to diagnosis, diagnostic experience, treatment, emotions during each stage of their journey, and pressure points. The MG journey map below illustrates a person's needs, processes they follow, and perceptions and emotions they have throughout their healthcare journey. Information is key, knowing where the challenges are means we know exactly where we need to support our community!

Want to learn more about the MG Journey Mapping project?

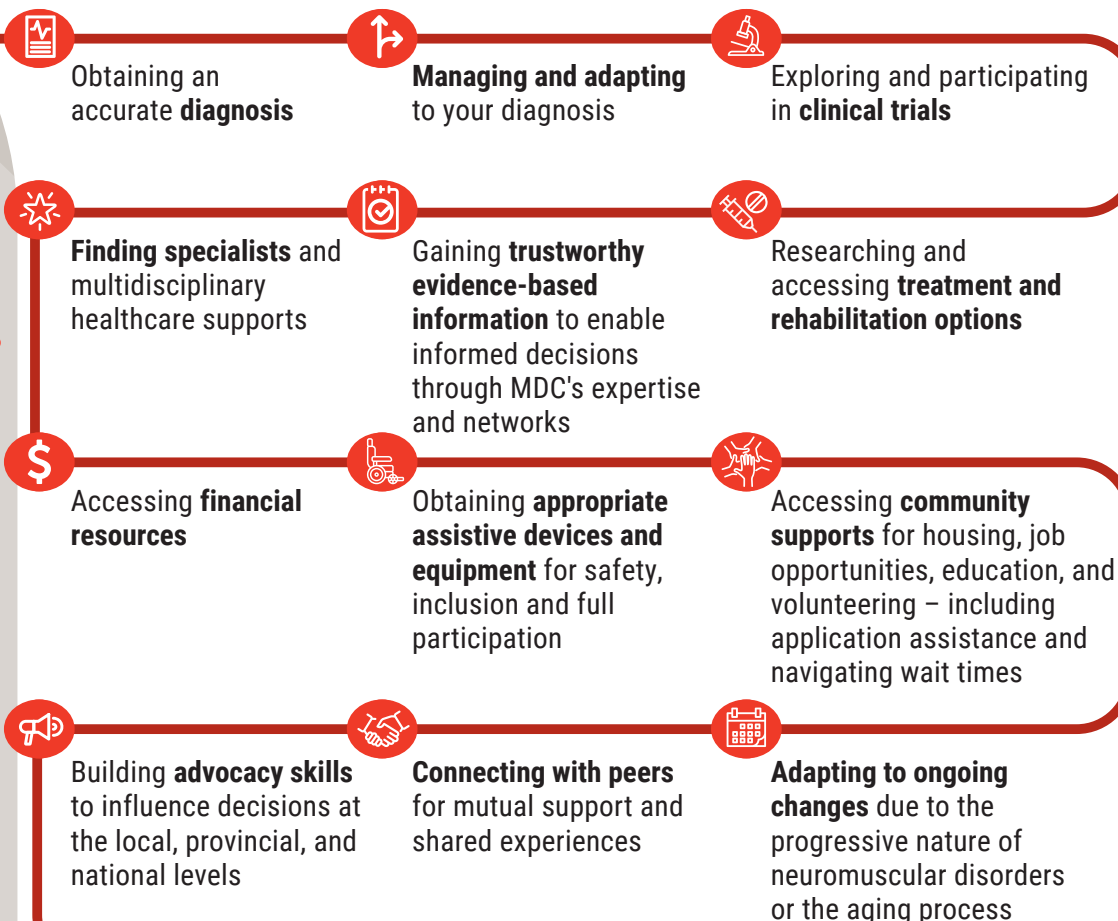
Visit: muscle.ca/services-support/advocacy/mg-journey-mapping-project/ to watch the results video and access a full sized version of the image below, or scan the QR code:



LET'S FIND YOUR PATHWAY OF POSSIBILITIES

Regardless of the NMD, MDC is here to help! The image below illustrates where along your journey MDC's services will be able to support, guide and inform you and your families.

ACHIEVE YOUR PERSONAL GOALS WITH OUR SERVICES. WE CAN SUPPORT YOU WITH:



OUR IMPACT:

- Enhanced **healthcare outcomes** and experiences (↓ time to diagnosis and treatment, ↓ admissions to hospitals, ↓ serious complications)
- Enhanced knowledge for **informed decision-making**
- Enhanced access to **options and solutions**
- Enhanced **safety** and independence
- Enhanced **quality of life**

If you or someone you care for has questions or would like to access any of the individualized, adaptable and person-centred services offered, please contact 1 800 567-2873 or research@muscle.ca



imPORTND



RESEARCH TRAINING IS AVAILABLE FOR YOU!

**Did you know you could guide research and maximize its findings?
It's true! When you become a patient research partner you will inform
research findings and make a difference for the NMD community!**

Many incredible NMD community members have generously participated in research initiatives as participants. But now, you can be part of the team and direct research from the inside!

Canadians affected by NMDs, their families, and advocates are often asked to take part in research, but they often feel unprepared to do so. To help you feel ready to become a research team member, Muscular Dystrophy Canada (MDC) in partnership with the Neuromuscular Disease Network for Canada (NMD4C) offers online, self-directed, free training modules through the imPORTND Patient-Oriented Research Training program.

With a 'nothing about me, without me' approach, MDC has been working with parent and patient partners on different projects. Most recently MDC, together with researchers from McMaster University, and research teams from Germany and Italy, were selected to conduct a collaborative research project looking at the transition experiences from pediatrics to adult care for people with Duchenne muscular dystrophy (DMD) and their families. This project team includes incredible partners with lived experience such as: Doyle Steinke, Nicola Worsfold, Mark Liam Arouza Pai, Gurvir Singh Shergill, Stacy Theofilopoulos, and Andrea Cleary. Become an MDC research partner today, to participate in projects that will have a direct impact on the NMD community.

Interested in becoming a research partner? Contact us at info@muscle.ca, call 1-800-567-2873 or scan the QR code below to learn more!



Gurvir Singh Shergill



Nicola Worsfold



Mark Liam Arouza Pai



Andrea Cleary



"As parents of adults with DMD and developmental disabilities, we have lived through a very frustrating transition regarding our boys' care. From the medical side, the transition to adult care has been reasonable but from the side of caregiving and our role as caregivers, we are not being looked after like we were when the boys were minors. This is a gap that seems to plague the care system. Too many adults with complex needs fall through the cracks during the transition to adulthood. Being directly involved in this research project gives me the opportunity to make positive changes for others in similar situations." – Doyle Victor Steinke, patient research partner

Doyle and Jody Steinke with their sons, Jonathan and Ty Razor.

THE 2023 WALK & ROLL FOR MDC WAS A HUGE SUCCESS THANKS TO YOU!

WALK&ROLL
for
MDC

The Walk & Roll for MDC 2023 season is officially over and it was a huge success! Despite a few bumps in the road, including several wild fires and floods that caused many events to be re-scheduled, we were thrilled to host more than 1,000 registered participants at in-person events across the country. We wish to thank all participants, donors, sponsors, ambassadors, and everyone who supported this year's Walk & Roll for MDC events. Thanks to you, we raised \$1,281,674 in support of breaking down barriers for the neuromuscular community! For more information on the Walk & Roll for MDC, visit WalkRollMDC.ca

If you participated in the Walk and Roll for MDC in 2023, we need your input to make the event even better! Please complete our survey at: surveymonkey.com/r/VVNY929



FIRST RESPONDERS MAKE A DIFFERENCE FOR THE NEUROMUSCULAR COMMUNITY

The 2023 High Rise Challenge took place on September 30 in Shawinigan, Quebec. For the 26th year, Fire Fighters, paramedics, Muscular Dystrophy Canada families, as well as police, military, and community members, took on the challenge. Over 250 participants joined us on site to climb the 36 floors of La Cité de l'énergie tower, twice – a total of 1,190 steps – to raise funds that will be used to support individuals and families affected by a neuromuscular disorder. Thank you to all of the participants, volunteers, donors, organizing committee, our amazing sponsors 3M Scott Fire & Safety, Desjardins Caisse du Réseau municipal, and everyone who supported the 26th High Rise Challenge. Thank you for helping to break down barriers for the neuromuscular community. We could not have done this without you! For more information on the High Rise Challenge, visit HighRiseChallenge.ca

FIRE FIGHTERS CONTINUE TO BREAK DOWN BARRIERS



#FillTheBoot
filltheboot.ca

Across Canada, dedicated and passionate Fire Fighters help #FillTheBoot in a variety of ways. Through events taking place across the country such as boot drives, rooftop campouts, stair climbs, truck pulls, pancake breakfasts or sporting events, Fire Fighters are breaking down barriers and making a difference in the lives of countless Canadian families who are affected by neuromuscular disorders. Muscular Dystrophy Canada (MDC) is extremely proud of the long-standing partnership we have with Fire Fighters across Canada. Check our events page for dates and locations or support your local Fire Fighters by making a donation online at FilltheBoot.ca!



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We can't do this study without you!

Help shape MDC's programming, inform advocacy work, and educate decision-makers about what Canadians affected by NMDs need most. If you, or someone you know, are affected by one of these disorders, we need your participation in our BIND study: oculopharyngeal muscular dystrophy, myasthenia gravis, Charcot-Marie-Tooth, facioscapulohumeral muscular dystrophy, limb-girdle muscular dystrophy, Duchenne muscular dystrophy, spinal muscular atrophy, Becker muscular dystrophy, Friedreich ataxia, myotonic dystrophy, or Pompe.

To participate
scan the QR
code or visit:
[omc.ohri.ca/
BIND/](https://omc.ohri.ca/BIND/)



On-demand DMD Masterclass available for all practitioners

If you or someone you love has Duchenne muscular dystrophy (DMD), chances are it took many doctor visits before you received a diagnosis. With the goal of shortening the journey to a diagnosis and improving follow-up care for those affected by DMD, Muscular Dystrophy Canada is hosting a DMD Masterclass. This educational opportunity is open to all general practitioners, pediatricians, specialist nurses, therapists and multidisciplinary team members who would like to improve their understanding of DMD.

DMD Masterclass is now available on demand so you can review the content on your own schedule. Please share this opportunity with your healthcare team!

To register: [surveymonkey.com/r/
MDCDMDMasterclass](https://surveymonkey.com/r/MDCDMDMasterclass)