

BREAKING DOWN BARRIERS

FOR THE CANADIAN NEUROMUSCULAR COMMUNITY



MUSCULAR
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CANADA

Annual Report | 2023-2024



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“Bloom” by Kiana Randi Bergen

Dr David Green Awards

Volunteers are the backbone of our organization. Dr David Green Awards are presented annually to individuals and groups that show extraordinary commitment to raising funds, creating awareness and advocating for people affected by neuromuscular disorders, supporting research, engaging other community members and building positive connections. Muscular Dystrophy Canada is very grateful to have such amazing individuals and groups committed to supporting our mission and the Canadian neuromuscular community. Learn more about our [2024 award winners](#).

MISSION STATEMENT

Muscular Dystrophy Canada’s mission is to enhance the lives of those affected by neuromuscular disorders by continually working to provide ongoing support and resources while relentlessly searching for cures through well-funded research.

STRATEGIC PRIORITIES

Expanding research infrastructure

Improving public access to healthcare, information, education and other community resources

Increasing accessibility to expanded programs and services

Driving revenue generation to meet the needs of our community

MESSAGE FROM THE CEO & BOARD CHAIR

This is our second year of the launch of our updated five-year strategic priorities, “Breaking Down Barriers.” In 2023-24, Muscular Dystrophy Canada broke down barriers for our community thanks to our donors, Fire Fighters, volunteers, partners, staff and community. Together, we’ve made the second year of our plan a huge success.

One highlight from this past year was fighting for – and getting – Canada-wide newborn screening for spinal muscular atrophy (SMA), which means early diagnosis, treatment access, and better health outcomes for all families. Now, every province and territory offer SMA as part of their newborn screening programs.

This is huge. And we couldn’t have done it without you.

Breaking down innovation barriers

Our Research team also used this past year to investigate the challenges of living with neuromuscular disorders, accessing treatments, and receiving accurate diagnoses. Their findings helped move decision-makers across Canada. Now, Alberta, British Columbia, Ontario and Quebec have changed several health policies and practices, which means more Canadians will get the right diagnosis, treatments and resources earlier for better health outcomes.

We also continued to fund translational research, which bridges lab discoveries with clinical applications. Our investment accelerated new gene therapies, personalized treatments, and advanced diagnostic tools that can improve quality of life and bring us closer to cures for neuromuscular disorders.

Breaking down financial and accessibility barriers

We recognize the efforts of our Canadian healthcare system, but we also know where it ends and where Muscular Dystrophy Canada begins. So, this year, we continued to fund essential equipment, assistive devices, and services not covered by government or other funding programs. We also offered affordable family and caregiver retreats, networking events, and educational sessions to strengthen connections and knowledge in our community. Huge thanks to our Research Hotline staff and dedicated Service Specialists who worked in partnership with clients and their families to reduce delays in accessing healthcare and community services, improve timelines in diagnosis, treatment and therapies, and help them cope, adjust, and enhance their overall quality of life. Their work helped our clients and their families achieve their goals by finding creative ways to break down barriers in our healthcare and social systems.

Breaking down barriers together

It takes a community to break down barriers. That’s why we’re so grateful to our Fire Fighters, donors, volunteers, staff, partners and community supporters. Their incredible work helped Muscular Dystrophy Canada land more individual donor support this past year than ever before. Our fundraising has never been more diverse and exciting.

Muscular Dystrophy Canada walkers and rollers and our Canadian Fire Fighter heroes also raised funds and awareness through fun-filled community events



across Canada. Although last year's wildfires created safety challenges to some events, we overcame them together. We kept everyone safe, and Muscular Dystrophy Canada used its reserves while enhancing its operations.

Our volunteers and partners also made a massive difference. Volunteers played a leading role in everything from planning Walk and Roll events to supporting research, public engagement, and education sessions. Meanwhile, our partnerships helped us give essential access to treatments, clinical trials, healthcare services, and early diagnoses. Together, their dedication, collaboration, and sponsorship helped enhance the quality of life for Canadians affected by neuromuscular disorders.

Breaking down the barriers ahead

All of this is wonderful news, but at the same time, we know we still have more to do. That's why Muscular Dystrophy Canada is committed to strong governance and responsible decision-making so we can continue to break down barriers for our community.

In the coming years, we want to make sure that more of the neuromuscular treatments in Canada's pipeline are approved, so our community has access to more clinical trials and treatment options. We want to help make sure that more Canadians get the right diagnoses earlier and get the healthcare, community supports, and resources they need to live their best lives on their own terms. And we also want to be sure Canada has the most advanced neuromuscular research infrastructure possible, producing innovations that lead to cures.

These are the barriers we're working hard to break down for all Canadians — and your support helps us do that.

Thanks to everyone who helped our mission this past year. Your continued support—along with the support of our clients, families, staff, Fire Fighters, donors, volunteers, and partners—makes all of this possible.

You made a difference.

Sincerely,

Stacey
Stacey Lintern,
CEO



DEChiabai

Debra Chiabai,
Chair of the
Board of Directors



BOARD OF DIRECTORS



Debra Chiabai,
Chair



Nicole Coté,
Vice Chair



David Cluff,
Treasurer and Chair,
Finance, Audit & Risk
Management Committee



David Crawford,
Past Chair and Chair,
Governance & Nominating
Committee



Kerry Zado,
Secretary



Alfred Breton-Paré,
Director



Fanny Chagnon,
Director



Michael Kaye,
Director



Michael Low,
Director



Stefanie Marinich-Lee,
Director



Scott Marks,
Director



Donna Nixon,
Director and Chair,
Fundraising Committee



Lise Poulin,
Director



Kara Reid,
Director



Liz Stirling,
Director



Dr Jodi Warman Chardon,
Director

YEAR IN REVIEW 2023-2024

STRATEGIC PRIORITY #1 – EXPANDING RESEARCH INFRASTRUCTURE

- More than 1,200 Canadians participated in our Canadian Institutes of Health Research-funded study in 2023-24. Our study captured the direct and indirect costs of living with neuromuscular disorders and identified policies that must change for the betterment of our community nationwide. We're using these findings to fuel several focused advocacy initiatives.
- Muscular Dystrophy Canada invested \$240,000 to fund 3 clinical fellows this year. The funding provided specialized training for physicians, equipping them with the expertise to diagnose, treat, and manage neuromuscular disorders. Our investment helps to ensure our community can access specialized care Canada-wide from a continuous supply of skilled clinicians dedicated to this complex field.
- We invested \$80,000 to fund 2 post-doctoral research fellows. Our funded post-doctoral fellows are at the forefront of cutting-edge research projects that increase understanding of neuromuscular diseases and explore new therapies and diagnostic tools. This year's investment brings us closer to effective treatments and cures.
- We achieved greater participation in research, clinical trials, and studies, with approximately 1,800 Canadians joining research studies conducted by our Research team.
- Muscular Dystrophy Canada invested \$960,000 into clinical and translational research projects focused on managing healthcare, understanding diagnosis and disease progression, enhancing care, and discovering novel treatments and therapies. We're proud that our investment helped more breakthroughs move from the lab to the clinic at an unprecedented pace.
- Researchers and clinicians gave over 355 hours this year to grant reviews, webinars, and the Neuromuscular Disease Network for Canada (NMD4C). Their work increased volunteer participation in our grant review process by 27%, significantly strengthening our process and the overall quality of our assessments.

STRATEGIC PRIORITY #2 – IMPROVING PUBLIC ACCESS TO HEALTHCARE INFORMATION

- After years of Muscular Dystrophy Canada's advocacy, more than 90% of Canadian newborns have access to screening for spinal muscular atrophy (SMA) through newborn screening programs. This year's win for our community ensures more families gain the early diagnoses and life-saving interventions they need.
- Muscular Dystrophy Canada increased access to education and resources for our neuromuscular community by delivering 12 new webinars.
- Muscular Dystrophy Canada's Research Hotline answered a record 2,800 questions throughout 2023-24. The hotline's work increased participation in research and clinical trials while improving people's access to evidence-based and up-to-date information for greater decision-making about neuromuscular disorders.
- Muscular Dystrophy Canada continued to influence policy decisions on behalf of the neuromuscular community. We influenced decisions that increased air travel accessibility for those with disabilities, access to treatments, and the Canadian Disability Benefit. We also played a significant role in influencing Canada's National Rare Disease Strategy. More work is needed on this strategy, and we will continue to advocate for our community.
- Muscular Dystrophy Canada increased the number of opportunities for our clients, families and friends, educators, and health care professionals to learn more about neuromuscular disorders, our services and various quality-of-life topics with a 57% increase in education sessions, a 100% increase in retreats, and our continued network events and clinic visits.



STRATEGIC PRIORITY #3 – INCREASING ACCESSIBILITY TO EXPANDED PROGRAMS AND SERVICES

- Muscular Dystrophy Canada received funding requests for assistive devices, medical equipment, and other support that other funding bodies couldn't fulfill—but we did! We funded more applications than last year, delivering \$2,117,417 in funding support to our community, up 4% from the year before.
- We increased our community impact by engaging more clients with system navigation support. System navigation interactions with clients rose by 1%, to 26,550, compared to 26,196 last year. Muscular Dystrophy Canada clients can use this service to support any part of their neuromuscular journeys, including building advocacy skills or accessing housing, information, funding, or other resources.
- We earned more engagement across many of our client events this year. As a highlight, our retreat participation grew by 56%, and our network participation increased by 39%, allowing Muscular Dystrophy Canada to support more of our community for more positive outcomes.
- We delivered more direct support to clients this year. Muscular Dystrophy Canada gained a 16% increase in client registrations, a 6% increase in support to family members, and overall, 34% increase in in-person events and client events like retreats and education sessions. Our increased events also gave our clients more opportunities to connect with the wider community.

STRATEGIC PRIORITY #4 – DRIVING REVENUE GENERATION TO MEET THE NEEDS OF OUR COMMUNITY

- The Mesachie Group reached a milestone of \$1,000,000 raised for Muscular Dystrophy Canada. This Fire Fighter fundraising team from British Columbia held its annual slow pitch tournament and auction, bringing Fire Fighters from the region together for a weekend of competition and heroic fundraising.
- We gained the support of 24 new major donors. We're grateful for their investment in our mission and our community.
- The fundraising initiative Journey for Janice raised \$200,000 in support of Muscular Dystrophy Canada and in memory of Janice Freedman. This initiative ensures Janice's legacy continues to impact the neuromuscular community significantly. Her son Jordan and co-organizer Hartley Ruch led the initiative with the support of many friends and family members.
- We are grateful to the 14 supporters who bequeathed a portion of their estates to Muscular Dystrophy Canada this past year. Their legacy gifts of over \$1,500,000 will support our community's highest priorities.
- Muscular Dystrophy Canada monthly donors — our Changemakers — increased their generous giving by 13% this year! Their support continues to make positive changes for our community.
- This year's Walk and Roll events raised over \$1,200,000 nationwide thanks to our community members' incredible fundraising efforts— congratulations to all!
- Our dedicated volunteers drove our overall success this year. They helped us secure sponsorships, manage fundraising and event logistics, recruit research participants and assist other research needs, engage with clients and share their inspiring stories—all to drive our mission of enhancing the lives of people affected by neuromuscular disorders.

Condensed Statement of Revenue and Expenses

Year ended March 31, 2024

	2024	2023
REVENUES:		
General campaign and donations	10,159,262	10,575,589
Other revenue	251,000	243,461
	10,410,262	10,819,050
Investment and sundry income	500,450	370,742
	10,910,712	11,189,792
EXPENDITURES:		
Fundraising	2,079,056	2,071,979
Operations support	1,897,756	1,959,969
	3,976,812	4,031,948
Volunteer support and governance	263,271	278,043
	4,240,083	4,309,991
NET FUNDS AVAILABLE FOR PROGRAMS & SERVICES	6,670,629	6,879,801
PROGRAMS & SERVICES		
Research programs	1,990,474	2,011,697
Services	2,711,581	3,144,257
Education and information services	1,355,179	1,268,336
Other programs	448,185	430,243
Services operating support	178,675	216,982
	6,684,094	7,071,515
(Deficiency) excess of revenues over expenditures before the undernoted	(13,465)	(191,714)
Amortization of capital assets	(25,824)	(31,955)
Change in fair value of investments	(200,898)	(405,967)
DEFICIENCY OF REVENUE OVER EXPENSES FOR THE YEAR	(240,187)	(629,636)

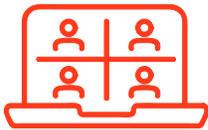
Condensed Statement of Financial Position

As at March 31, 2024

	2024	2023
ASSETS		
Cash and investments	7,168,926	8,720,341
Capital assets	29,122	54,613
Other assets	793,838	592,350
TOTAL ASSETS	7,991,886	9,367,304
LIABILITIES		
Accounts payable and accrued liabilities	1,296,668	1,590,186
Deferred revenue	119,338	211,142
Deferred lease inducements	38,282	77,476
Commitments for research grants	1,299,666	1,320,423
Long term commitments for research grants	445,239	440,899
	3,199,193	3,640,126
DEFERRED CONTRIBUTIONS RELATED TO:		
Neuromuscular research	247,323	543,802
Services	1,446,906	1,766,185
Education	704,093	785,771
British Columbia gaming	10,792	7,654
	2,409,114	3,103,412
TOTAL LIABILITIES	5,608,307	6,743,538
NET ASSETS		
Net assets restricted for endowment purposes	1,217,136	1,162,451
Net assets invested in capital assets	29,122	54,613
Unrestricted net assets	1,137,321	1,406,702
	2,383,579	2,623,766
	7,991,886	9,367,304

Note: Complete audited financial statements available upon request or online at muscle.ca.
Certain comparative figures have been reclassified to conform to the current year's financial statement presentation.

YOUR IMPACT IN 2024



12 webinars | 586 participants



63 education presentations | 1343 participants



322 retreat participants



10 of research projects funded



1500+ volunteer hours



1474 pieces of assistive devices funded
for a total cost of over \$6 million leveraged

"I am leaving with a lot from this retreat. It has given me a strong sense of belief that my son has great ability to live his best life. For the first time I can see that he wants to go beyond the limitations that others have determined he may have because of his neuromuscular disorder. For the first time, he had the opportunity to socialize with a whole group of people that understand his experiences. He has always loved sports, however, before the retreat, didn't have the opportunity to play. This is an eye opener for me. I don't have enough words to express my feelings and gratitude. So, I am just ending with THANK YOU Muscular Dystrophy Canada!"



"I volunteer for Muscular Dystrophy Canada because every effort we make helps light the path toward hope and progress for those affected by a neuromuscular disorder. Having a neuromuscular disorder at times steals my joy. Volunteering gives me my joy back. Volunteering for Muscular Dystrophy Canada allows this incredible organization to continue the work they do. Together, we build a network of support, drive crucial research, and foster inclusivity, enhancing the lives of people and families affected by a neuromuscular disorder."



"I wanted to share this photo of our family during our daily walks in our neighborhood. We had an unsuitable stroller and Raphaël did not have the necessary support. As we already have a wheelchair for him, the government will not reimburse an adapted stroller. Although we often use his wheelchair, we need a suitable stroller when Raphaël is more tired and when we go on longer outings. This stroller allows us to store his suction machine. It will last for many years to come! Huge thanks to Muscular Dystrophy Canada for your generosity towards our family. The assistance the equipment program offers, allows us to enjoy life without the financial worries that are too present for families who have children with a neuromuscular disease. It's one less worry in our lives and Raphaël is comfortable when we go out. Thank you!"

"I am proud to uphold the Fire Fighter tradition of supporting Muscular Dystrophy Canada. As a father with a son affected by a neuromuscular disorder, I experience the positive effects of our contributions firsthand. The strides being made in research are inspiring, and it's clear that we're making a difference every day. "

"I am living my best life. I am grateful that I have access to a treatment that slows down the progression of my neuromuscular disorder. This would have not been possible without Muscular Dystrophy Canada's outstanding research and advocacy efforts!"



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To read more about Muscular Dystrophy Canada or
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