BREAKING DOWN BARRIERS

FOR THE CANADIAN NEUROMUSCULAR COMMUNITY

MUSCULAR
DYSTROPHY
CANADA

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CANADA

ANNUAL REPORT

2022-2023

“Deep Shadows” by Dawn Mitchell

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 the neuromuscular disorder (NMD) community, supporting research, engaging other community members and building positive connections. MDC is very grateful to have such amazing individuals and groups committed to supporting our mission and the Canadian NMD community. Learn more about our 2023 award winners.

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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

In 2022-2023 Muscular Dystrophy Canada (MDC) launched its updated strategic plan to guide the organization's direction for the next five years. The Breaking Down Barriers 5-year strategic plan was originally developed in 2020 but put on "pause" to adjust and plan for the pandemic. In 2022, we revisited the plan and used our learnings over the previous three years to develop MDC's strategic directions for 2023-2028.

With the strategic plan guiding our activities, last year Muscular Dystrophy Canada (MDC) met the needs of the neuromuscular community by offering its basket of programs and services, supporting the neuromuscular community in navigating and accessing health care, providing community and clinical trial resources, facilitating networking and funding essential equipment and assistive devices. We also successfully partnered with government decision-makers to change public policy; and, funded translational and clinical research, while we continued our efforts to ensure Canada is better equipped with research and clinical resources to conduct the best neuromuscular research and promote innovation. These activities encompass the role we play in removing barriers across the broad spectrum of Canada's neuromuscular community.

For instance, in 2022-2023 we increased our investments in research by working with researchers and clinicians to facilitate educational webinars and develop knowledge translation tools so the neuromuscular community has access to credible, relevant and clear information to make informed decisions. As a co-lead of the Neuromuscular Disease Network for Canada (NMD4C), MDC worked directly with leading clinical, scientific, technical and patient experts to improve Canada's neuromuscular care, research and collaboration in neuromuscular disorders. At the same time, we carried out our own research focused on an individual's lived experience with a neuromuscular disorder, and the financial cost of a disorder on an individual, healthcare and community services. MDC utilized these types of research to influence public policy. As a result, the neuromuscular community has better-diagnosing experiences, access to new treatments, clinical trials, and better standards of care.

We continued our commitment to "getting back to growth" with our fundraising efforts. We worked in collaboration with major donors, foundations and sponsors to help fund our mission activities. We brought events like our Walk and Roll and High-Rise Challenge back to local communities. Canadian Fire Fighters hosted fundraising activities while increasing neuromuscular awareness nationwide. Our early success makes us very optimistic that we will hit our goal and grow fundraising 25% by working in partnership with the neuromuscular community over the next five years, so we can continue to break down barriers for the neuromuscular community.

We still have a great deal of work to do to ensure that we address all barriers faced by the neuromuscular community so that, as we search for cures, individuals and their families have access to treatments and therapies, clinical trials in Canada, healthcare and community resources, financial resources and will receive a correct and timely diagnosis. But over the last year, we have many learnings that we can leverage. We will ensure that all organizational planning and decisions align with our strategic priorities, the right measurements are in place to monitor our progress and we continue to invest additional funds in our mission.

Finally, we want to express our sincere thanks to each and every person who supported MDC's mission last year. Our clients and their families, staff, donors, supporters, partners, sponsors and volunteers are essential members of our community and we are grateful for your support every day.

Sincerely,

Stacey Lintern,
CEO

David Crawford

David Crawford,
Chair of the
Board of Directors

BOARD OF DIRECTORS

David Crawford,
Chair

Debra Chiabai,
Vice Chair

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Director

Kara Reid,
Director

Dr Jodi Warman Chardon,
Director

Kerry Zado,
Director

BREAKING DOWN BARRIERS BY INCREASING OUR MISSION ACTIVITIES

With our 2023-2028 Strategic Priorities guiding our activities over the past year, we continued to meet the needs of the neuromuscular community through a basket of programs and services; we worked with government to change public policies; and, we funded translational and clinical research – in addition to conducting our own research studies – to expand the Canadian neuromuscular research infrastructure.

48% ↑

increase in funds directed towards research initiatives to build upon collaboration, outcomes, and research program continuity; increase opportunities for translational research; and expand strategic research development with a focus on early diagnosis.

24% ↑

increase in funds directed to Systems Navigation to curate knowledge and resources available in the community in a way that facilitates their effective and efficient use by individuals affected and families.

18% ↑

increase in informational webinars and roundtable conversations to build a vibrant online community, as well as to engage and connect individuals, families and caregivers affected by neuromuscular disorders with health care providers.

17% ↑

increase in individuals with neuromuscular disorders registering with Muscular Dystrophy Canada to access our programs and support services.

11% ↑

increase in funds directed to mission activities such as equipment funding, opportunities for connection, research initiatives and meaningful changes to public policies to improve the quality of life for individuals and families affected by neuromuscular disorders.

YEAR IN REVIEW 2022-2023

STRATEGIC PRIORITY #1 – EXPANDING RESEARCH INFRASTRUCTURE

- 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 developments continues.
- MDC partnered with Génome Québec and Ataxia Canada to create a funding program for **research on hereditary ataxias.** This program supports the objectives of government by accelerating therapeutic innovation and by presenting an alternative to creating new drugs for the treatment of rare diseases.
- Partnered with Neuromuscular Disease Network for Canada (NMD4C) to launch **'imPORTND',** the first patient-oriented training platform developed specifically for neuromuscular disease research. This program is grounded in a "nothing about us, without us" inclusive approach to research.
- In 2023, **MDC conducted research** to create a journey map for Canadians affected by myasthenia gravis (MG), a rare autoimmune neuromuscular condition. The results of this study are being used to influence public policies and healthcare system planning; and, as Canadian evidence to improve access and decisions related to timely diagnoses, clinical trials, drugs and therapies.

STRATEGIC PRIORITY #2 – IMPROVING PUBLIC ACCESS TO HEALTHCARE, INFORMATION, EDUCATION AND OTHER COMMUNITY RESOURCES

- MDC and the NMD4C worked together to fund **$360,000 in fellowships** to help train and educate the next generation of neuromuscular researchers and clinicians. Three post-doctoral fellowships will help strengthen neuromuscular research capacity, and the three clinical fellowships will **strengthen the specialist care available** to the neuromuscular community.
- Educational sessions also saw a dramatic rise in 2022-2023. To ensure the neuromuscular community has access to information and learning resources, we increased our Lunch and Learn, Outreach, MuscleFacts and AccessAbility presentations by 71%, and went from 308 participants in 2021-2022 to 1,461 participants this past year.
- There are now more than 600 genes that contribute to neuromuscular disorders (NMD), so we **expanded our disorder list** to ensure even more Canadians affected by an NMD receive the support they need.
- We continue to work with key decision-makers, like-minded organizations, partners and supporters to ensure **newborn screening for spinal muscular atrophy** (SMA) is a reality for all Canadians. Currently, only Quebec and the Maritime provinces are not screening for SMA but planning is underway.
- Partnered with Independent Living Canada, People First Canada, Inclusion Canada, Eviance, 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.
- MDC partnered with the Canadian Neuromuscular Disease Registry (CNDR) and the NMD4C to 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.

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

- **491 individuals affected by neuromuscular disorders registered** with MDC, rising 17% over the previous year. To accommodate this growth and provide support, we directed more funds (11%) towards Mission activities.
- More registrations and demand for our programs and services, also meant we had more people to connect with so our **touch-points with clients expanded** by 53%, and inquiries through our Research Hotline went up by 89%.
- MDC added a substantial list of **Assistive Technology** to its equipment funding list to help people affected by neuromuscular disorders improve their health, safety, and independence, as well as their ability to actively participate in education, the workforce and their community. These devices include (but are not limited to) items such as smart watches or wearables for fall detection and medical alerts, smart home technologies and gaming accessories.

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

- 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's **fundraising total went up by $2.6 million** over the previous year for a total of $10.7M in revenue in 2022-2023. Gifts from major donors, planned giving donors and Foundations increased by 20%. MDC will continue to learn from these fundraising activities and investigate new opportunities in partnership with the neuromuscular community.
- **Funds raised through the High Rise Challenge grew by 20%** helping us meet the needs of the neuromuscular disorder community and rebuild toward pre-pandemic fundraising revenue totals.
- **The boots were back this year, with Fire Fighters** across the country hosting Fill The Boot campaigns and increasing their fundraising revenue by 95%! MDC greatly appreciates its Fire Fighter partners who have been dedicated to the NMD community since 1954.
- Our friends at Shad's R&R broke an impressive fundraising milestone in 2022-2023. Through their annual golf tournament in support of Muscular Dystrophy Canada, they have now raised over $5 million for the neuromuscular community. We extend a big thank you to Shad's R&R and all the tournament participants for their long-time commitment and dedication to raising funds in support of fellow Canadians.

HOW IT HAPPENED

All of this was possible, because of people like you!

Industry partners
Sponsors
Staff
Volunteers
Family members
Board of Directors
Fire Fighters
Event participants
Researchers
Chapter
Like-minded organizations
Clients
Caregivers
Community partners
Healthcare professionals
Donors

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.

Condensed Statement of Revenue and Expenses

Year ended March 31, 2023

	2023	2022
REVENUES:		
General campaign and donations	8,693,373	6,778,265
Other revenue	1,882,217	880,484
	10,575,590	**7,658,749**
Investment and sundry income	614,203	807,921
	11,189,793	**8,466,670**
EXPENDITURES:		
Fundraising	2,071,979	1,779,292
Operations support	1,959,969	1,816,138
	4,031,948	**3,359,430**
Volunteer support and governance	237,344	195,356
	4,269,292	**3,790,786**
NET FUNDS AVAILABLE FOR PROGRAMS & SERVICES	**6,920,501**	**4,675,884**
PROGRAMS & SERVICES		
Research programs	2,011,697	1,355,964
Services	3,144,257	3,427,222
Education and information services	1,268,336	977,850
Other programs	430,243	429,621
Services operating support	216,982	169,785
	7,071,515	**6,360,442**
(Deficiency) excess of revenues over expenditures before the undernoted	(151,014)	(1,684,558)
Amortization of capital assets	(31,955)	(33,925)
Investment management fees	(40,700)	(54,418)
Change in fair value of investments	(405,967)	(215,163)
DEFICIENCY OF REVENUE OVER EXPENSES FOR THE YEAR	**(629,636)**	**(1,988,064)**

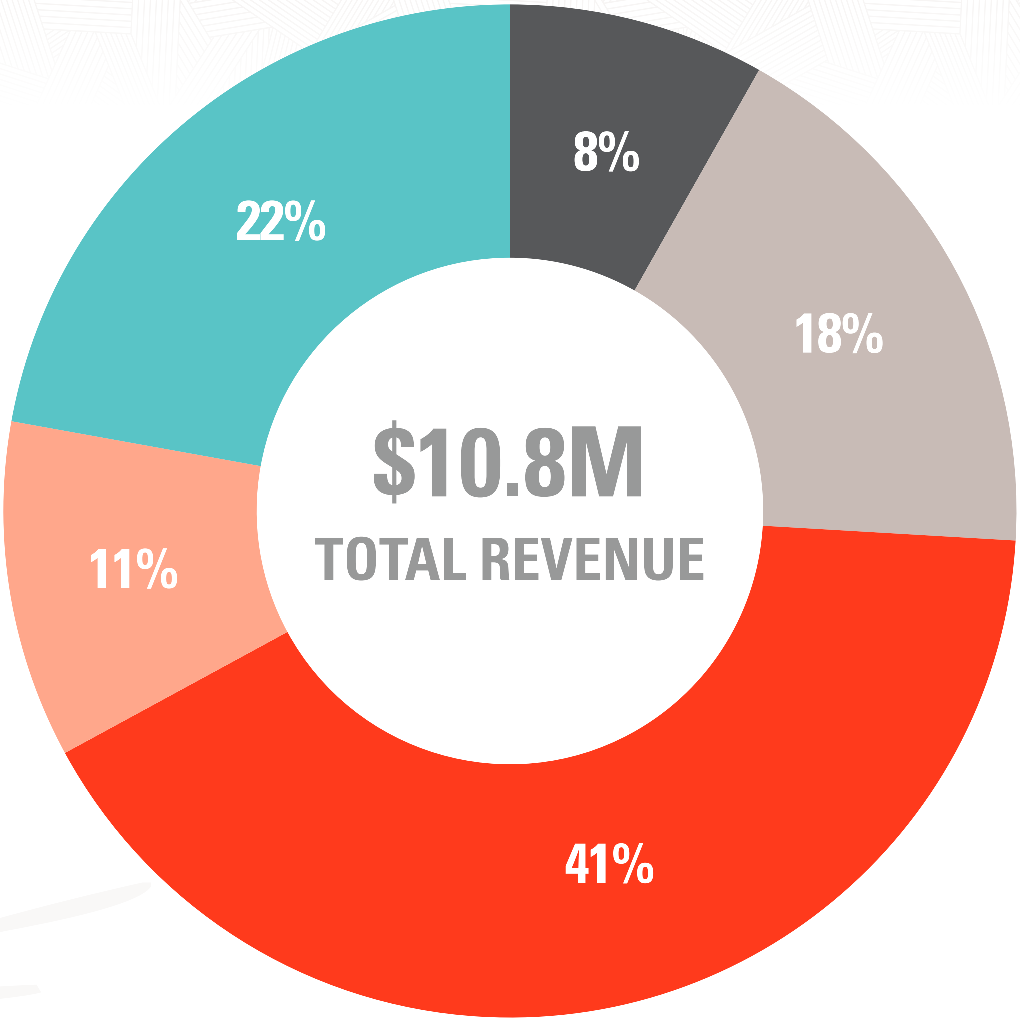
Condensed Statement of Financial Position

As at March 31, 2023

	2023	2022
ASSETS		
Cash and investments	8,720,341	9,174,316
Capital assets	54,613	59,987
Other assets	592,350	538,928
TOTAL ASSETS	**9,367,304**	**9,773,231**
LIABILITIES		
Accounts payable and accrued liabilities	1,590,186	876,315
Deferred revenue	211,142	169,503
Deferred lease inducements	77,476	92,287
Commitments for research grants	1,320,423	1,062,100
Long term commitments for research grants	440,899	390,000
	3,640,126	**2,590,205**
DEFERRED CONTRIBUTIONS RELATED TO:		
Neuromuscular research	543,802	382,866
Services	1,766,185	3,057,795
Education	785,771	483,392
British Columbia gaming	7,654	5,571
	3,103,412	**3,929,624**
TOTAL LIABILITIES	**6,743,538**	**6,519,829**
NET ASSETS		
Net assets restricted for endowment purposes	1,162,451	1,096,832
Net assets invested in capital assets	54,613	59,987
Unrestricted net assets	1,406,702	2,096,583
	2,623,766	**3,253,402**
	9,367,304	**9,773,231**

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.

FINANCIAL SUMMARY



FUND DEVELOPMENT BREAKDOWN

- 🟥 MAJOR GIFTS, FOUNDATIONS, AND GRANTS
- 🟦 FIRE FIGHTERS
- 🟫 PLANNED GIVING, DIRECT RESPONSE
- 🟧 GENERAL ANNUAL
- ⬛ WALK & ROLL FOR MUSCULAR DYSTROPHY CANADA

"Freya is a happy and healthy child, and I could not imagine what our life would look like if she were not given genetic, SMA-testing at birth," Taylor says. "The challenges Freya and our family face because of her disorder are very minimal, thanks to early diagnosis and treatment. And while we have had many questions since her diagnosis, the support and information we received from Freya's doctors and MDC have helped us tremendously."

"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," said Alex Harold.

"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.

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