BREAKING DOWN BARRIERS

FOR THE CANADIAN NEUROMUSCULAR COMMUNITY AND MOVING FORWARD ON OUR PATH TO GROWTH.

Reset. Rebuild. Reignite.

MUSCULAR
DYSTROPHY
CANADA

DYSTROPHIE
MUSCULAIRE
CANADA

ANNUAL REPORT
2021-2022

We greatly appreciate each and every

Advisory & Committee Member
Family Member
Fire Fighter
Researcher
Chapter
Volunteer
Client
Donor
Partner
Healthcare Professional

who worked with us in 2021 – 2022. Your support is helping Muscular Dystrophy Canada reset, rebuild and reignite so we can continue breaking down barriers for the Canadian neuromuscular community and moving forward on our path to growth.

Thank You

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We are strongest when we work together.

MESSAGE FROM THE CEO & BOARD CHAIR

In 2021-2022, Muscular Dystrophy Canada (MDC) was guided by its commitment to “break down the barriers” faced by the Canadian neuromuscular disorder (NMD) community. Unfortunately, there are far too many barriers and the pandemic has only exacerbated the challenges that exist. As always, and perhaps even more so now, MDC is committed to finding innovative ways of continuing to enhance the lives of people affected by neuromuscular disorders by working to provide ongoing support and resources, while relentlessly searching for cures through well-funded research.

To continue breaking down barriers and move forward on a path to growth, MDC first had to *reset, rebuild and reignite.*

We thoroughly examined our programs and services and reset their delivery to ensure we could meet the current and future needs of the NMD community. Simultaneously, our supporters, volunteers, Fire Fighters and staff were reigniting each other’s passion and rebuilding our fundraising streams.

These activities allowed us to make the very important decision to increase our spending on mission activities that would break down barriers. We were able to advocate for better clinical standards of care, and access to treatments and ultimately cures; alleviate financial pressures while other funding sources for assistive devices and supports declined as a result of the pandemic; invest in fellowships to ignite the Canadian research infrastructure; and, work with the NMD community so they could navigate and access the right resources at the right time.

Fundraising and passion, alone, were not enough to make all of this incredible work happen so we also worked tirelessly to leverage partnerships with government, industry and like-minded organizations to share resources, reduce costs, expand capacity and facilitate greater research and advocacy outcomes to make our generous donor dollars go even further.

Of course, none of this would have been possible without the incredible efforts of our volunteers, partners, supporters, donors, and staff who all played critical roles in helping to break down the barriers. We know we have work left to do, but we also know that because of the decisions made in 2021-2022, together, we are on a path to growth.

Sincerely,

Stacey Lintern,
CEO

David Crawford

David Crawford,
Chair of the
Board of Directors

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.

BOARD OF DIRECTORS


David Crawford, Chair


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


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Kara Reid, Director


Dr. Jodi Warman Chardon, Director


Kelly Zacharias, Director

BREAKING DOWN BARRIERS BY INCREASING OUR MISSION SPENDING

Through roundtable consultations with people affected by a neuromuscular disorder (NMD), submissions to our research hotline and conversations with our Service Specialists, in 2021-2022 it became abundantly clear that the barriers faced by Canadians in the NMD community were growing. External funding for items such as NMD research grants and infrastructure, as well as assistive devices were depleted as a result of the pandemic, new treatments were unobtainable for many, and gaining access to health care support was increasingly difficult. So, in 2021-2022 Muscular Dystrophy Canada increased its mission spend to meet the growing needs of the NMD community.

54%↑ in funds directed to mission activities to improve the quality of life for individuals and families affected by neuromuscular disorders, invest in research initiatives and advocate for meaningful changes to public policies.

115%↑ in funds directed towards research initiatives to ensure collaborative and proactive support of infrastructure development, capacity building and knowledge translation.

18%↑ 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.

61%↑ in assistive devices/equipment provided to individuals affected by neuromuscular disorders.

85% of provinces and territories are currently screening or are in the stages of putting processes in place to implement newborn screening for spinal muscular atrophy.

YEAR IN REVIEW
2021-2022

Research

- Invested $1.3 million to fund: nine new clinical and translational science research projects through our **Neuromuscular Disorder Research Grant Competition**; five fellowships (see next bullet); and, other projects so talented and dedicated Canadian researchers can develop new methods for disease diagnosis, uncover novel insight into disease pathogenesis, and develop new treatment options.

- Partnered with the Neuromuscular Disease Network for Canada (NMD4C) and the Canadian Society of Clinical Neurophysiologists, to fund three **national clinical fellowships** in neuromuscular medicine and electromyography, and two **national post-doctoral fellowships** in neuromuscular research ensuring top-ranked researchers receive funding and early-career scientists can conduct studies focused on NMD research.

- MDC partnered on multiple national and international team research studies, namely the **BIND study** with researchers and health economists in Ottawa and Calgary to study the indirect socio-economic cost of living with inherited NMDs; and, the GrowDMD study with teams from Canada, Germany and Italy to study patient experiences and systems to optimize care for transition to adulthood.

Advocacy

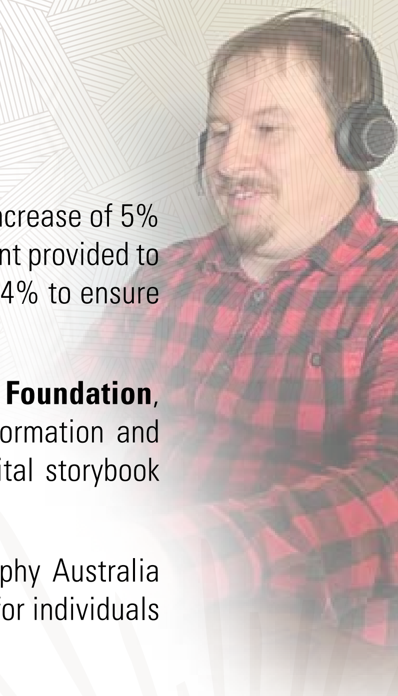
- Spearheaded an **Advocacy Advisory Committee** by bringing together 19 stakeholders from the neuromuscular community to help us work towards inclusive policies that reflect and respect Canada's diversity, value the neuromuscular experience and are accessibility-focused.

- Thanks to a partnership with **Novartis Canada** and our unwavering supporters, our advocacy efforts resulted in Alberta, Saskatchewan, Manitoba, Yukon, and Nunavut joining Ontario in screening newborns for spinal muscular atrophy (SMA); Quebec, New Brunswick, Nova Scotia and Prince Edward Island are in the planning stages.

- Funded a first-of-its-kind project to evaluate the cost-effectiveness of newborn screening for SMA in Canada, including early treatment. The innovative national project, led by a team at the **Children's Hospital of Eastern Ontario,** will provide vital evidence for policy and decision-makers.

- Partnered with **Independent Living Canada** to equitably consult with individuals, organizations and stakeholders across disabilities to help inform the development of Canada's first Disability Inclusion Action Plan.

Programs & Services



- **420 individuals** affected by neuromuscular disorders registered with MDC, an increase of 5% over the previous year; there was a 61% increase in assitive devices and equipment provided to Canadians; and, we increased the funds directed towards mission activities by 54% to ensure programs and support services were available for everyone who needed them.
- Launched the AccessAbility Program, sponsored by the **Canada Post Community Foundation**, to shift the classroom setting for students and educators by incorporating information and resources on disabilities, accessibility, inclusion and equity, and develop a digital storybook through which students can share their personal neuromuscular stories.
- Signed a **Statement of Intent** with Muscular Dystrophy UK, Muscular Dystrophy Australia and Muscular Dystrophy Foundation of South Africa to help break down barriers for individuals living with neuromuscular disorders, worldwide.

Philanthropy

- **Events continue to be hosted virtually** with much success thanks to our committed event participants, donors, sponsors and volunteers.
- **Funds raised increased by 20%** helping us rebuild toward pre-pandemic fundraising revenue totals and ensured the needs of the NMD community continued to be met.
- **Fire Fighters** started rebuilding community Fill The Boot campaigns to increase funds raised, and are well on their way to pre-pandemic fundraising levels. MDC is hugely grateful for the dedication and commitment of Canadian Fire Fighters.

HOW IT HAPPENED

Put simply, Muscular Dystrophy Canada has amazing supporters, volunteers, donors, sponsors, partners, Fire Fighters, staff and board members. The passion that these people have for breaking down barriers for the neuromuscular community is unapparelled, and we count ourselves very lucky to be on this mission, together, with them.

In 2021-2022, we:

- ***Teamed up*** with NMD4C, and the Canadian Society of Clinical Neurophysiologists to offer fellowships and research grants for the most-promising studies, and ensure incredible advances continued to take place.
- ***Collaborated with*** local, provincial and federal governments, industry partners, healthcare and Canadians affected to identify inefficiencies, inconsistencies and gaps in policies and programs so that sustainable solutions and meaningful positive change for the neuromuscular disorder community could be created.
- ***Partnered with*** like-minded organizations, government and healthcare professionals to coordinate expertise and develop shared infrastructure to lower administrative costs, increase our mission expenditures and positively impact the lives of more Canadians affected by neuromuscular disorders.
- ***Worked with*** Fire Fighters, volunteers and supporters to find new ways to raise funds and lower administrative costs, to have the greatest impact possible on the neuromuscular community.

Condensed Statement of Revenue and Expenditures

Year ended March 31, 2022

	2022	2021
REVENUES:		
General campaign and donations	6,778,265	4,569,469
Other revenue	880,484	1,816,636
	7,658,749	**6,386,105**
Investment and sundry income	807,921	441,920
	8,466,670	**6,828,025**
EXPENDITURES:		
Fundraising	1,779,292	1,723,909
Operations support	1,816,138	1,773,706
	3,359,430	**3,497,615**
Volunteer support and governance	195,356	120,580
	3,790,786	**3,618,195**
NET FUNDS AVAILABLE FOR PROGRAMS & SERVICES	**4,675,884**	**3,209,830**
PROGRAMS & SERVICES		
Research programs	1,355,964	630,855
Services	3,427,222	1,911,404
Education and information services	977,850	1,031,012
Other programs	429,621	352,287
Services operating support	169,785	233,078
	6,360,442	**4,158,636**
(Deficiency) excess of revenues over expenditures before the undernoted	(1,684,558)	(948,806)
Amortization of capital assets	(33,925)	(42,877)
Investment management fees	(54,418)	(53,594)
Change in fair value of investments	(215,163)	941,153
(DEFICIENCY) EXCESS OF REVENUE OVER EXPENSES FOR THE YEAR	**(1,988,064)**	**(104,124)**

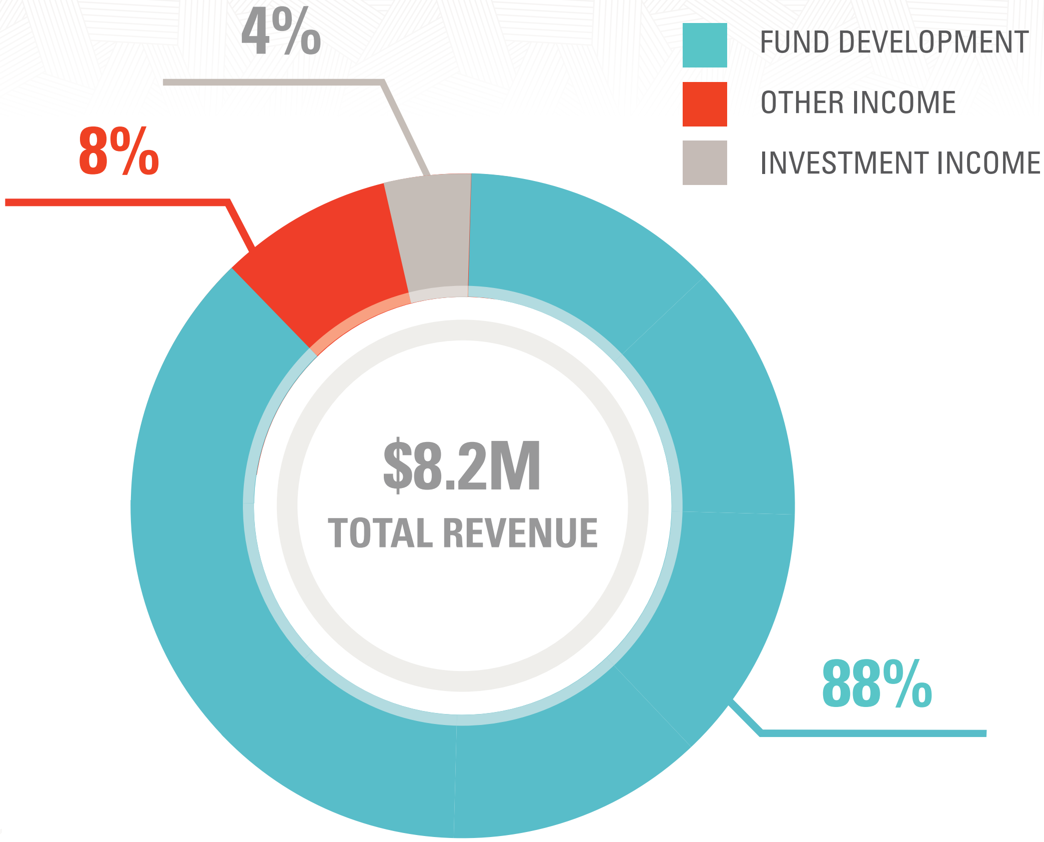
Condensed Statement of Financial Position

As at March 31, 2022

	2022	2021
ASSETS		
Cash & investments	9,174,316	10,831,863
Capital assets	59,987	93,621
Other assets	538,928	872,297
TOTAL ASSETS	**9,773,231**	**11,797,781**
LIABILITIES		
Accounts payable and accrued liabilities	876,315	663,201
Deferred revenue	169,503	156,921
Deferred lease inducements	92,287	118,205
Commitments for research grants	1,062,100	970,733
Long term commitments for research grants	390,000	392,099
	2,590,205	**2,301,159**
DEFERRED CONTRIBUTIONS RELATED TO:		
Neuromuscular research	382,866	866,800
Services	3,057,795	2,926,109
Education	483,392	443,373
British Columbia gaming	5,571	18,874
	3,929,624	**4,255,156**
TOTAL LIABILITIES	**6,519,829**	**6,556,315**
NET ASSETS		
Net assets restricted for endowment purposes	1,096,832	1,036,809
Net assets invested in capital assets	59,987	93,621
Unrestricted net assets	2,096,583	4,111,036
	3,253,402	**5,241,466**
	9,773,231	**11,797,781**

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

"It's impossible to not find reward in supporting MDC. My favourite part is meeting the children who participate in events like the High Rise Challenge. Seeing their shy smiles, seeing it change to not so shy when they get to sit in the fire truck. That's why I raise funds – to help moms and dads who are going through what my parents experienced so that their stories have a different ending." – Will Truman, Fire Fighter

"Through providing fellowship opportunities for residents to pursue high-quality clinical training in the field of neuromuscular medicine and electromyography, we will create a path to practice for talented clinicians with a passion for neuromuscular disease, raising the standard of treatment and access to care for all Canadians affected by neuromuscular disease."
– Dr. Hanns Lochmüller, Lead Investigator, NMD4C

"As the mother of an infant with SMA who was not screened at birth, I know first-hand the devastating implications of delayed diagnosis. Someday soon, no matter where they live all families will have the opportunity to make critical healthcare decisions and realize their child's full developmental potential from the very beginning."– Laura Van Doormaal, Newborn Screening Advisory Committee member

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To read more about Muscular Dystrophy Canada or make a donation, visit muscle.ca or call 1-800-567-2873.

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