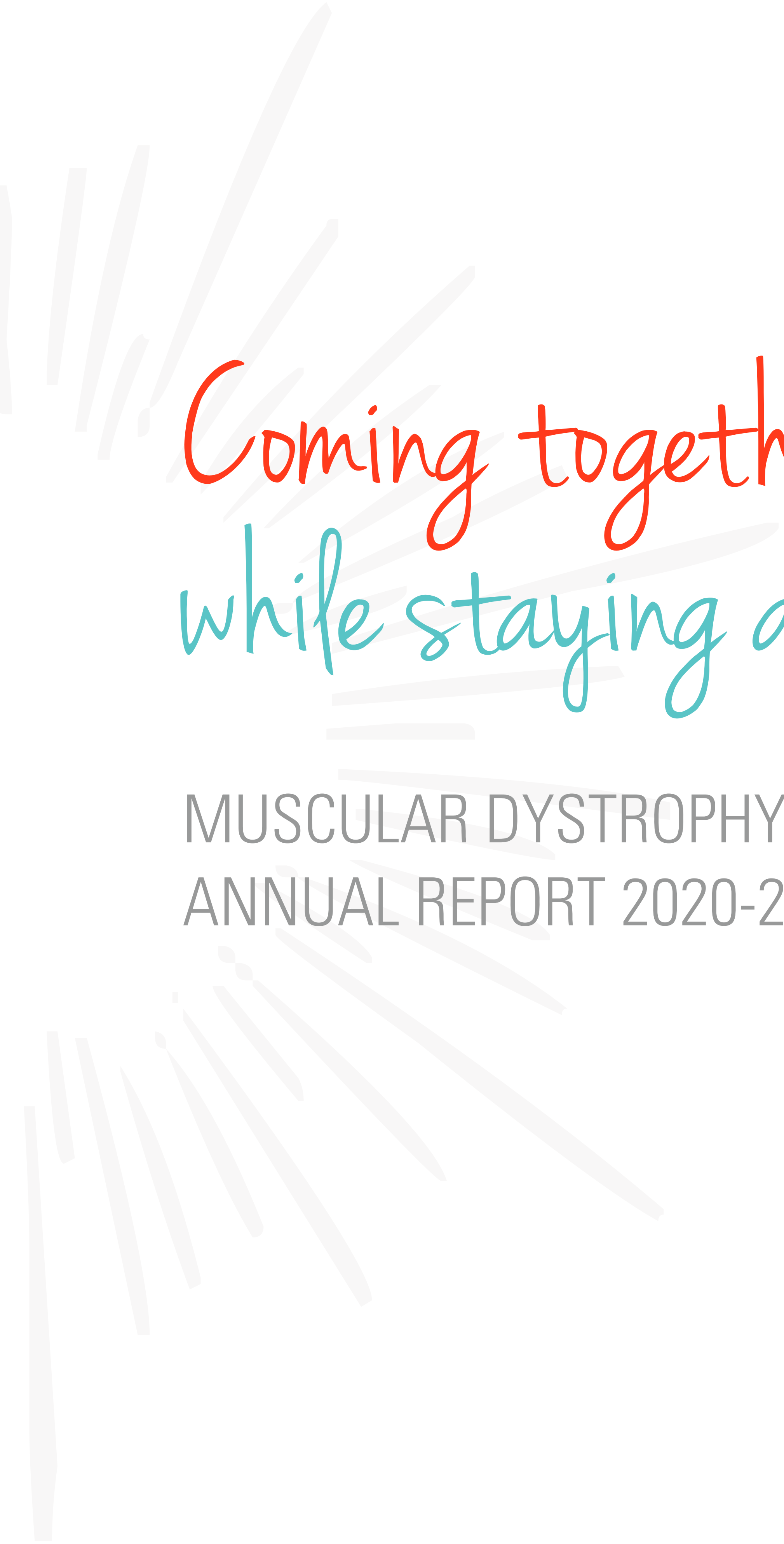

Coming together, while staying apart.

MUSCULAR DYSTROPHY CANADA ANNUAL REPORT 2020-2021

MUSCULAR
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CANADA

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CANADA

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> *"Due to the global pandemic, we are isolated from our friends and family. Our routines have completely changed. We aren't able to do the things we love and visit our favourite places. This is what life is like, every day, for many individuals affected by neuromuscular disorders.*
>
> *Because of MDC supporters, I am able to participate in virtual network meetings. These meetings give me a chance to connect with others who understand my situation and frustrations. It also gives me the chance to help others and be a support system for new friends across the country."*
>
> **Warren Jones,**
> **MDC client**

MESSAGE FROM CEO & BOARD CHAIR

It will come as no surprise that the global outbreak of COVID-19 presented some unique challenges for Muscular Dystrophy Canada (MDC) as it did for many other organizations, particularly those in the charitable sector. Fortunately, our family of supporters along with pandemic recovery programs offered by the federal government, and a modest increase in the value of our investment portfolio helped offset a steep decline in our fundraising revenue.

It has been a year marked by uncertainty and considerable change. While some tough decisions had to be made, we are immensely proud of the way the neuromuscular community came together to support one another. Despite fundraising challenges, we continued to prioritize the critical needs of clients, safeguarded their health and well-being and connected 26,375 times to offer support, programs and services throughout the public health crisis. Additionally, we invested $600,000 in new and exciting areas of research that hold tremendous promise.

We are also pleased to report that we achieved another milestone in the past year. MDC received accreditation for excellence in non-profit accountability and transparency, governance and fundraising under the Imagine Canada Standards Program. This was a lengthy and rigorous process, and we thank our dedicated colleagues on the Board of Directors, volunteers and the entire MDC staff team for their contributions towards this accomplishment.

MDC has learned a lot over the last year. The pandemic required us to adapt quickly and pushed everyone to think outside the box. It also showed us what we can do when we work together, inspired by and focused on our clients, their families and caregivers. Looking ahead, we are already preparing for the next "normal". We are connecting with our key stakeholders in new and meaningful ways and we have a plan in place that will ensure MDC continues to grow and thrive well into the future.

We want to take this opportunity to thank all of our generous donors and supporters. Your dedication has helped sustain MDC through a difficult period and we hope you will be there for us in the future as we continue to work toward our goal of finding cures!

Sincerely,

Donna Nixon

Stacey Lintern,
CEO

Donna Nixon,
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


Donna Nixon,
Chair


David Crawford,
Vice Chair


Michael Kaye,
Past Chair and Chair,
Governance Committee


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


Dave Ferguson,
Secretary


Alfred Breton-Paré,
Director


Debra Chiabai,
Director


Buzz Green,
Director


Yazmine Laroche,
Director


Kara Reid,
Director


Dr. Jodi Warman Chardon,
Director


Kelly Zacharias,
Director


Kerry Zado,
Director

FUNDS INVESTED IN MISSION

Because of our incredible supporters, we were able to invest over $4.1 million into mission activities including research and knowledge translation supports, advocacy efforts, and programs and services.

$2.6 MILLION

invested in providing our Systems Navigation program to clients across Canada, including equipment funding

1,889 INDIVIDUALS

received support through the Research Hotline

31 #LETSTALKNMD WEBINARS

were delivered to share up-to-date information on a number of critical topics for the neuromuscular community

4 ADVOCACY PARTNERSHIPS

formed with like-minded organizations to accelerate advocacy initiatives

$600,000 INVESTED IN RESEARCH

with an additional $1.7million leveraged by working with partners like the Canadian Institute for Health Research (CIHR).

Thank you

We greatly appreciate each and every

CLIENT,
FAMILY MEMBER,
DONOR,
FIRE FIGHTER,
CHAPTER,
HEALTHCARE PROFESSIONAL,
RESEARCHER,
VOLUNTEER,
PARTNER,
ADVISORY AND COMMITTEE MEMBER

who connected and worked with us in 2020 – 2021 to help us deliver on our mission.

Your support directly impacted thousands of Canadians across the country.

Thank you for *coming together* to support the neuromuscular community!

Coming together to...

PROPEL RESEARCH FORWARD & SHARE INFORMATION

Muscular Dystrophy Canada (MDC) knows the incredible hope research brings for a better future. With many treatments, therapies and trials coming into Canada, partnerships and collaboration are key to funding innovative discoveries and improving health outcomes. Never was this more relevant than in 2020-2021.

Despite the challenges brought on by the COVID-19 pandemic, MDC continued to support researchers and clinicians across the country to move research forward so better treatments, and ultimately cures, can be found for neuromuscular disorders (NMDs). Thanks to our donors and supporters, we were able to fund seven new grants and continue our support of 12 existing grants to maximize positive outcomes for the NMD community.

MDC is proud to support life-changing neuromuscular research in the following areas:

UNDERSTANDING DIAGNOSIS AND DISEASE PROGRESSION

DISCOVERING NOVEL TREATMENTS AND THERAPIES

ENHANCE CARE

MANAGE HEALTHCARE

Not only did we invest in research projects, we also conducted one of our very own. The Economic Impact Study focused on gathering information and experiences from the neuromuscular community on the overall cost of living with a NMD. The final report, which is in development, will help us, researchers, healthcare providers, drug regulators and health technology assessment agencies better understand the cost of living with a NMD and the impact it has on individuals, their families, the healthcare system and society as a whole.

The NMD community required timely, relevant information during the pandemic to make informed decisions so MDC worked with partners to share information and knowledge.

We *came together* with the Neuromuscular Disease Network for Canada (NMD4C) to launch a continuing professional development webinar series, accredited by the Royal College of Physicians and Surgeons of Canada, to share up-to-date information on NMDs so clinicians across the country were better able to serve clients. We also launched the #LetsTalkNMD webinar series to educate Canadians about NMDs and share trusted, and timely information on topics including COVID-19. A panel of experts including clinicians, researchers, and people with lived experience presented at each webinar, and participants were encouraged to ask questions and share experiences.

The popularity of these webinars reaffirmed what we had known for some time, Canadians need reliable NMD information in plain language from trusted sources. By offering opportunities for our community to connect directly with experts across the country, as well as MDC's internal experts via the Research Hotline, we were able to provide relevant, credible information during a time of great uncertainty.

> *"Despite an unprecedented time, MDC staff and the Board of Directors worked relentlessly to explore all options to invest in research in Canada, recognizing the need to maintain momentum. Through careful consideration and planning, we were able to ensure the incredible advances currently taking place in research are accelerated."*
>
> **Stacey Lintern,**
> **CEO, Muscular Dystrophy Canada**

Coming together to...

ADVOCATE FOR POSITIVE CHANGE

Muscular Dystrophy Canada's (MDC) priority when it came to advocacy in 2020-2021 was ensuring the wellbeing and safety of the neuromuscular disorder (NMD) community in a time of crisis. First and foremost, that meant working with provincial governments to ensure prioritization of persons affected by NMDs in vaccine roll-outs, by sharing evidence-based information, clinical consensus statements and input from the community. We worked to ensure the COVID-19 response by government and other agencies was inclusive across all provinces and territories, and was in the best interest of the NMD community by providing evidence-based feedback directly from the neuromuscular community.

MDC approached health policies and issues in a strategic and evidence-based manner and represented our community across Canada on critical issues such as:

- equitable access to intensive care units as outlined in provincial pandemic triage protocols;
- use of virtual assessments for the Ontario Assistive Devices Program; and,
- working towards health policies and financial supports for people with disabilities to ultimately achieve better health outcomes and improved quality of life during the pandemic.

In 2020, Ontario became the first (and only) Canadian province to screen babies for spinal muscular atrophy (SMA). To ensure newborn screening for SMA becomes a national reality, we proudly embarked on a multi-year initiative that will see up to $2 million invested by Novartis Pharmaceuticals Inc. We initiated the project in a step-wise manner, with the first step being an assessment to understand each province's needs, barriers and readiness from clinical infrastructure and public health perspectives. Upon completion of the assessment, we launched our initial call for projects that can accelerate inclusion of SMA on newborn screening panels. The investment to-date, coupled with support from major donors and partners, will fuel the goal of making newborn screening for SMA a reality from coast-to-coast-to-coast in the future as well as generate critical evidence and best-practices.

> *"People across the country affected by neuromuscular disorders are experiencing challenges no one should have to go through alone. That's why MDC is so fortunate to have supporters, like you, who recognize the importance of providing opportunities for connection – whether that's bringing individuals together virtually, or ensuring they have someone like me to reach out to for support."*
>
> **Courtney Stearns,**
> **MDC Service Specialist**

Coming together, while staying apart.

A YEAR IN REVIEW

Received **Imagine Canada** accreditation under its Standards Program for excellence in non-profit accountability and transparency, governance and fundraising.

Strategically revised our business plan in response to the pandemic, which led to the organization successfully meeting the needs of the NMD community. We did this by making investments to **diversify our revenue programs, and increase opportunities for community support that would serve us now and in the future.**

Partnered with Children's Hospital at London Health Sciences Centre, and Children's Health Foundation to offer the **Shared Decision Making** pilot project, an innovative service that helps paediatric patients and families make informed decisions throughout their care journey.

Postponed all in-person events and fundraising to protect the health and wellbeing of clients, staff, and volunteers. Together with our community, we quickly pivoted and found creative, safe ways to raise funds.

Through a partnership with Technology for Living, MDC provided eight **CoughAssists** to adults in British Columbia affected by neuromuscular disorders, who did not have access to this critical piece of respiratory equipment. This pilot program assessed the benefits and impact of a **CoughAssist** for individuals and caregivers. These outcomes will be critical for key decision makers to promote coverage of this vital respiratory equipment in the future.

Hosted our first **virtual fundraising events** with outstanding support from the NMD community, and broadened our reach as many clients were unable to attend in-person events.

2020-2021

Worked with our community to urge provincial governments to **prioritize access to the COVID-19 vaccine** for persons with NMDs and reduce the time between doses.

26, 375 interactions with clients (phone calls, emails, meetings).
978 pieces of equipment funded to increase quality of life.
400 individuals with NMDs and **61 family members** registered with MDC.

Provided timely and important information during the pandemic so our community had access to reliable, plain-language information from experts and individuals with lived experience so they could make informed decisions about their wellbeing and care.

Specialists offered emotional support, provided information and helped develop contingency plans to address issues like attendant care, caregiver burnout and cancelation of home supports.

Embarked on a multi-year initiative with up to $2 million invested by Novartis Pharmaceuticals Canada Inc. to make nationwide **newborn screening** for spinal muscular atrophy (SMA) a reality in the near future.

Conducted The **Economic Impact Study** – the largest Canadian NMD study of its kind on cost-of-illness and economic impact. This study will help everyone better understand the cost of living with a NMD and the impact it has on individuals, families, the healthcare system and society.

Coming together to...

SUPPORT EACH OTHER

New research confirmed that the increased psychological distress caused by the pandemic was greater among those with chronic health conditions.

This really came as no surprise to us. In 2020-2021, we experienced an increased demand for mental and emotional well-being supports, evidence-based information and life-changing equipment – the majority of these being complex requests related to the pandemic.

There was a 76 per cent monthly increase in total interactions with clients; a 400 per cent increase in requests for emotional support; and, a 280 per cent increase in requests for educational materials and answers to COVID related questions.

Thanks to generous donors and supporters, we were able to quickly adapt our services and programs to “virtually” support priorities and address some of the challenges being faced by the neuromuscular community.

We prioritized the funding of assistive devices to ensure our clients had the equipment they needed to live their daily lives; Service Specialists, connected with clients, virtually, to provide assistance with non-medical needs; and, we launched the “MDC Let’s Connect Virtual Networks” via Zoom to provide an opportunity for individuals of all ages, located across Canada, to come together, form friendships, share learnings and support each other.

Thanks to our many supporters, MDC was able to address the critical needs of the NMD community over the past year and continue to invest in the right supports to broaden our reach and impact in the future.

“The MDC Let’s Connect Virtual Network gives me something to do since I’m stuck at home and alone in these times. It also gives me a chance to connect and meet other people, like me, who have neuromuscular disorders which is something I’ve always wanted to do. It makes me feel like I have a part in all of this.”

Alexandra LeBoeuf,
MDC client

Coming together to...

RAISE MUCH NEEDED FUNDS

To ensure the safety of all stakeholders, in March 2020 Muscular Dystrophy Canada (MDC) made the decision to postpone in-person fundraising events. Recognizing the impact of our work, MDCs supporters still came together in a big way to assist the NMD community and raise much-needed funds. Due to careful and strategic planning by staff, the leadership of our Board, gifts from generous donors, virtual event participants, support from government and smart investments, we wrapped up the year in very good financial standing.

With so much change, we had the opportunity to re-evaluate our mission priorities and reassess our revenue development opportunities. We remain committed to always putting the needs of our clients first. We successfully funded support programs and services throughout 2020-2021 by focusing on major and leadership giving, and re-inventing our signature fundraising events and campaigns as virtual events.

Thanks to a supportive community and amazing volunteers, we moved our Walk4MD and High-Rise Challenge from local venues and came together online, while maintaining the “in-person” feel our community looks forward to each year. Both events were incredible successes and raised a combined total of over $970,000!

Even our long-time supporters, Canadian Fire Fighters, went virtual with their fundraising efforts in 2020-2021. Filltheboot.ca was launched to offer an online alternative to placing donations in an actual Fire Fighters boot. Thank you to all of the dedicated Fire Fighters who have been fundraising online, holding events safely in their communities, and raising awareness.

I helped #filltheboot

THE TENAQUIP FOUNDATION
WALK FOR MUSCULAR DYSTROPHY

High Rise Challenge

Thank you

Thank you to all the Fire Fighters, event participants, amazing donors, sponsors and volunteers who helped us fundraise in 2020-2021 and ensured the needs of the NMD community continued to be met!

Condensed Statement of Revenue and Expenditures

Year ended March 31, 2021

	2021	2020
REVENUES:		
General campaign and donations	4,569,469	7,585,135
Other revenue	1,816,636	1,340,769
	6,386,105	**8,925,904**
Investment and sundry income	441,920	462,130
	6,828,025	**9,388,034**
EXPENDITURES:		
Fundraising	1,723,909	2,387,697
Fundraising operating support	1,773,706	1,683,181
	3,497,615	**4,070,878**
Volunteer support and governance	120,580	309,570
	3,618,195	**4,380,448**
NET FUNDS AVAILABLE FOR PROGRAMS & SERVICES	**3,209,830**	**5,007,586**
PROGRAMS AND SERVICES		
Research programs	630,855	2,034,022
Services	1,911,404	2,443,018
Education and information services	1,031,012	1,190,638
Other programs	352,287	351,693
Services operating support	233,078	209,367
	4,158,636	**6,228,738**
(Deficiency) excess of revenues over expenditures before the undernoted	(948,806)	(1,221,152)
Amortization of capital assets	(42,877)	(60,152)
Loss on disposal of capital assets	-	-
Investment management fees	(53,594)	(64,808)
Change in fair value of investments	941,153	(38,810)
(DEFICIENCY) EXCESS OF REVENUE OVER EXPENSES FOR THE YEAR	**(104,124)**	**(1,384,922)**

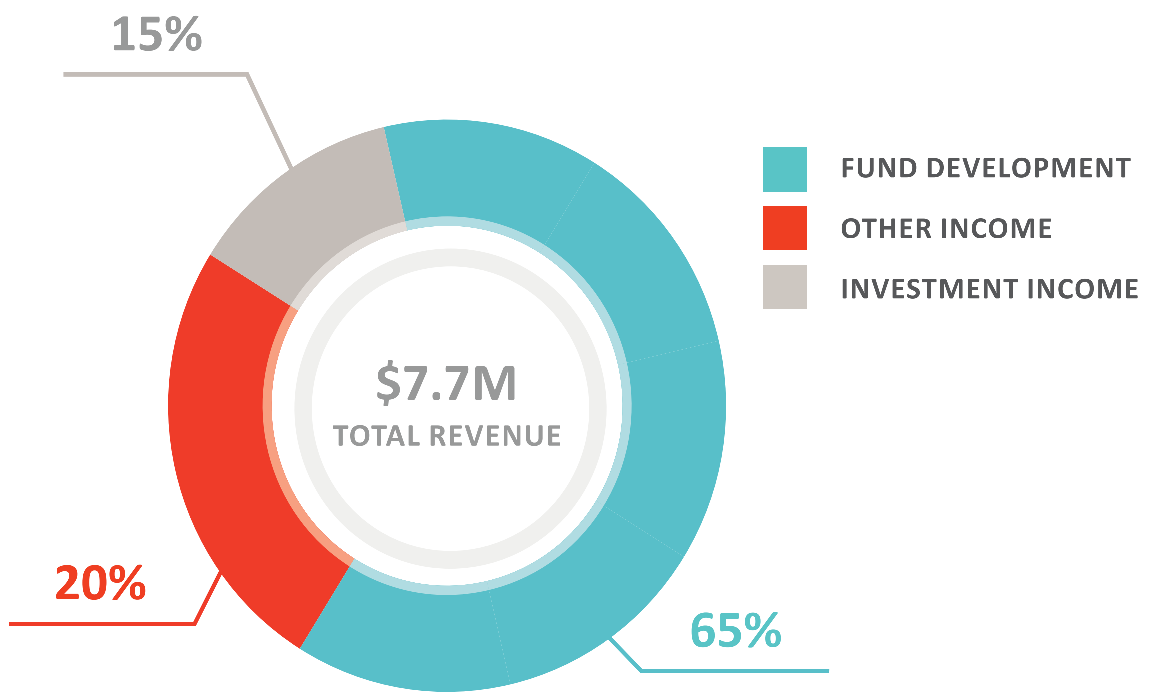
Condensed Statement of Financial Position

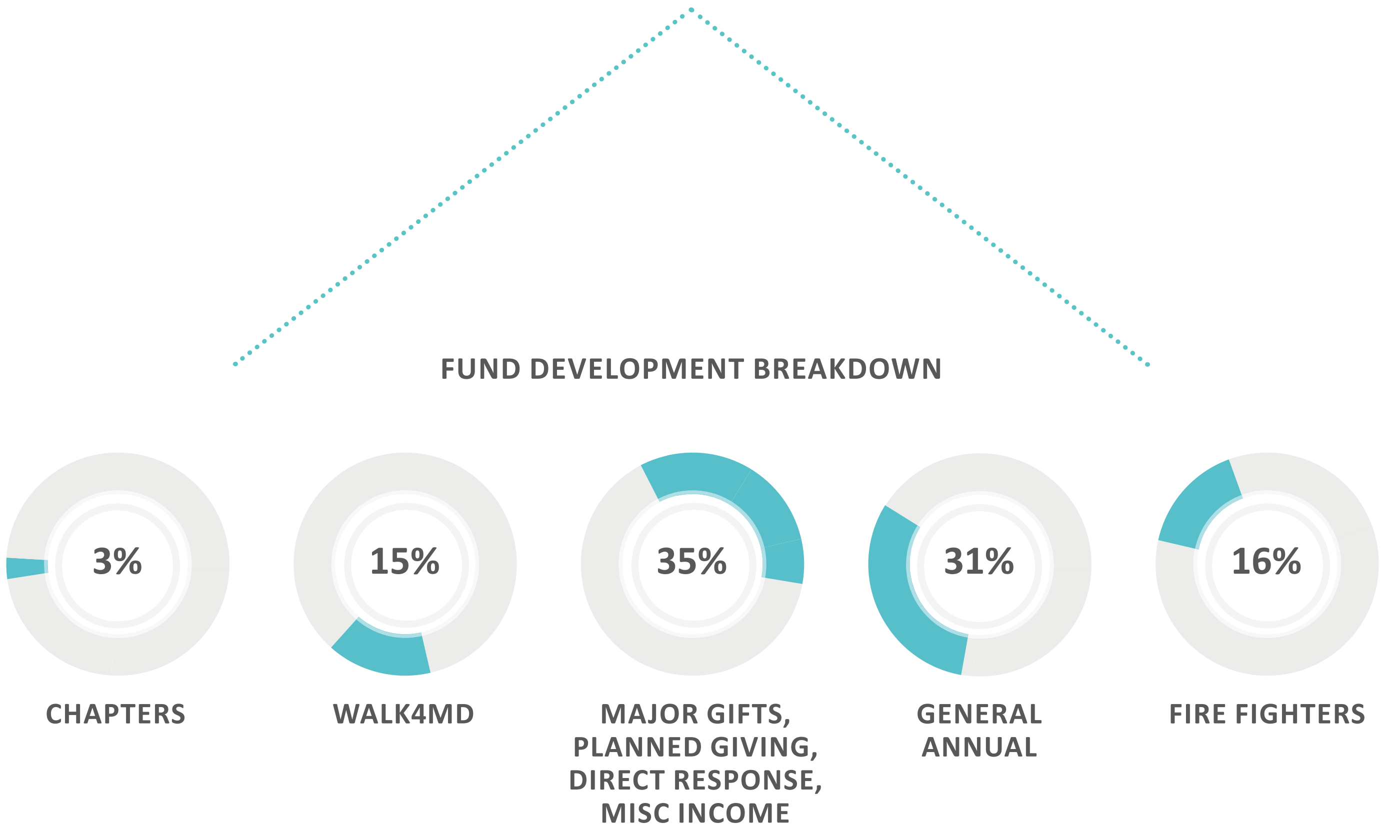
As at March 31, 2021

	2021	2020
ASSETS		
Cash & investments	10,831,863	10,474,440
Capital assets	93,621	136,186
Other assets	872,297	1,106,552
Total assets	11,797,781	11,717,178
LIABILITIES		
Accounts payable and accrued liabilities	663,201	989,121
Deferred revenue	156,921	359,978
Deferred lease inducements	118,205	129,613
Commitments for research grants	970,733	1,238,440
Long term commitments for research grants	392,099	569,500
	2,301,159	3,286,652
DEFERRED CONTRIBUTIONS RELATED TO:		
Neuromuscular research	866,800	909,447
Services	2,926,109	1,687,596
Education	443,373	376,698
British Columbia gaming	18,874	111,195
	4,255,156	3,084,936
TOTAL LIABILITIES	**6,556,315**	**6,371,588**
NET ASSETS		
Net assets restricted for endowment purposes	1,036,809	992,909
Net assets invested in capital assets	93,621	136,186
Unrestricted net assets	4,111,036	4,216,495
	5,241,466	**5,345,590**
	11,797,781	**11,717,178**

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





Nolan Caskanette, who was diagnosed with spinal muscular atrophy (SMA) type 1, has a tracheotomy and requires 24-hour care and support. Because of his respiratory challenges, Nolan was particularly vulnerable during the pandemic.

“This is a difficult time for everyone, but especially for families living with neuromuscular disorders. We are grateful for the support of MDC and their Service Specialists. They have been absolutely amazing in providing support and guidance during this very scary time.”

Kerri,
Nolan’s mother

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STRONG NONPROFITS. STRONG COMMUNITIES.
ACCREDITED
SINCE 2020
IMAGINE CANADA

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