ANNUAL REPORT
2019-2020

MUSCULAR
DYSTROPHY
CANADA

DYSTROPHIE
MUSCULAIRE
CANADA

We call it...

IGNITED BY PASSION, FUELED BY HOPE.

...a neuromuscular disorder.

Muscular Dystrophy Canada (MDC) supports individuals affected by neuromuscular disorders.

Neuromuscular disorders (NMDs) are a group of genetic and immune-mediated disorders of the muscle, neuromuscular junction, peripheral and lower motor neurons. Neuromuscular disorders include:

- muscular dystrophies
- myopathies
- neuromuscular junction disorders
- peripheral nerve disorders
- lower motor neuron disorders

The causes, symptoms, age of onset, severity and progression can vary depending on the specific diagnosis and the individual. Muscle weakness is experienced in various degrees by individuals living with NMDs, which can affect their arms and legs, but also the muscles needed for eating, speaking and breathing.

For some individuals, their disorder is life-limiting. There are no cures for any NMDs. However, advances in care are improving quality of life and individuals are living longer. Life changing therapies and treatments are in development, in clinical trial, and others are in the approval process and available for some NMDs.












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MISSION

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

IGNITED BY PASSION, FUELED BY HOPE.

MESSAGE FROM THE CEO AND BOARD CHAIR

Muscular Dystrophy Canada (MDC) thanks each and every supporter, donor, client and their family members, Fire Fighter, health care professional, researcher, volunteer, staff member and partner who connected and worked with us throughout 2019-2020 to help us deliver on our mission. You inspire us each and every day. We couldn't do it without you.

With your support, we raised more than $8.9 million to invest in critical programs and services, continue important advocacy work and fund innovative research in support of Canadians impacted by neuromuscular disorders (NMDs).

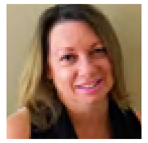
In 2019-2020, the Board and the Executive Leadership Team at MDC made a conscious decision to increase our investment in mission in order to respond to increased requests for programs and services from our clients, and to provide additional funding for cutting-edge neuromuscular research. While this decision resulted in MDC running an annual deficit, it enabled us to support more clients nationwide and increase our investment in critical research.

Thank you for sharing your time, energy and ideas for raising funds, influencing positive change and promoting greater awareness of NMDs and the support MDC offers. Unfortunately, the 2019-2020 year did not end as we had planned. The neuromuscular community needs us now more than ever as we continue to navigate the impact of the COVID-19 pandemic. We are in this together. And, with your ongoing commitment, we will persevere and continue to be there in meaningful ways for the Canadian neuromuscular community.

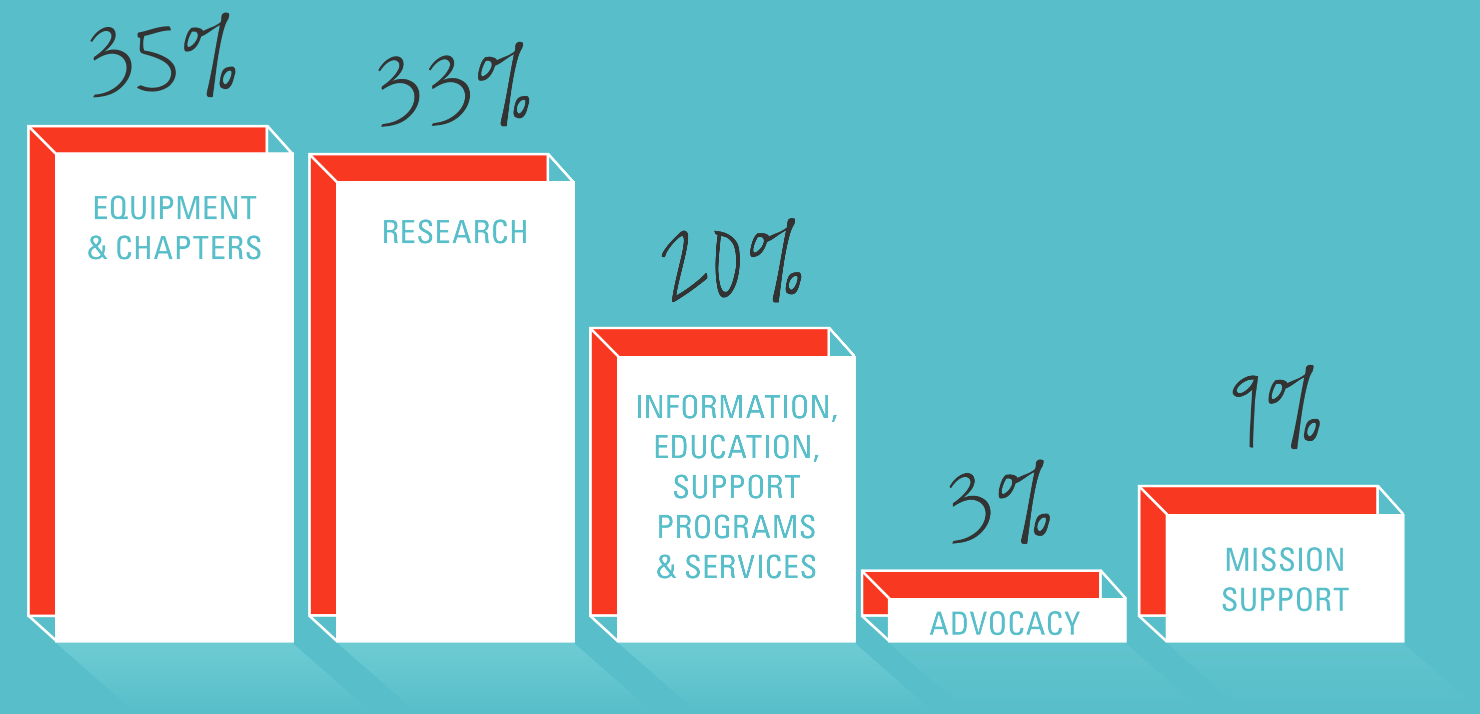
THANK YOU.

Stacey Lintern
CEO

Donna Nixon
Chair of the
Board of Directors



FUNDS INVESTED IN MISSION



Thanks

To the 25,000 donors, hundreds of volunteers and the dedicated staff members who supported our mission in 2019-2020.

More than

$2 million

invested in research plus an additional

$3.5 million

leveraged

9

Seed Grants funded

3

Partnerships funded

RESEARCH

MDC invests in research that focuses on improving diagnosis, developing new treatments, improving clinical care and promoting collaboration among different Canadian researchers and clinicians. We know that neuromuscular disorders (NMDs) are individually rare but collectively common. We aim to support research that is disorder-specific but also where the findings of a study can be applied to different NMDs.

In 2019-2020 we supported research with broad applicability to all NMDs as well as those focusing on a specific disorder such as Congenital Myopathy, Spinal Muscular Atrophy (SMA), Myotonic Dystrophy, Duchenne Muscular Dystrophy, Myasthenia Gravis and Charcot-Marie-Tooth Disease. For the first time ever, we funded a research study focused on immune mediated NMDs (Myositis/ Dermatomyositis /Chronic Inflammatory Demyelinating Polyneuropathy).

With your help we have also been able to support initiatives aimed at network building, which helps to translate these important research discoveries into practice.

MDC, together with the Canadian Institute of Health Research, supported a new pan-Canadian network called NMD4C (Neuromuscular Disease Network For Canada). This network brings together the country's leading clinical, scientific, technical and patient expertise to improve care, research and collaboration in neuromuscular disorders. MDC believes that working together with like-minded organizations, coordinating expertise and developing shared infrastructure at a national level is essential to making progress for Canadians impacted by NMDs.

We held our first ever SMA Research Summit in November 2019. The day was filled with learning and discussing new research, clinical trial developments, and the changing treatment and regulatory landscape in Canada.

With many treatments, therapies and trials coming into Canada, partnerships and collaboration will be key to not only fund ground-breaking research but also to improve health outcomes of Canadians affected by NMDs.

Did you know MDC has a Research Hotline?
Call 1 800 567-2873 ext. 9037 or email *research@muscle.ca* with any research related questions!

Meet Michael

He calls it Facioscapulohumeral Muscular Dystrophy (FSHD). We call it a neuromuscular disorder.

Michael Gottlieb's journey with Facioscapulohumeral Muscular Dystrophy (FSHD) began when he was four years old and his kindergarten teacher called his parents to tell them he couldn't run. But, he didn't receive an official diagnosis until the age of 38. Over the course of his life there have been several other missed opportunities for diagnosis – an experience sadly shared by many. While he says the road to diagnosis was challenging, it was ultimately a relief to know the symptoms were not in his head. He was happy to finally have a road map for moving forward and managing his symptoms.

Michael's life is a full one. He has a wonderful family, a strong social circle, and a career he's proud of in the healthcare industry. He wants you to know that although diagnosis comes with a lot of anxiety and fear there are great resources out there, including MDC, who can help connect you with the support you need.

ADVOCACY AND SUPPORT

MDC recognizes that people are often advocating for themselves and their loved ones. MDC is here to work in partnership to support individual advocacy efforts but also to positively influence policies within all levels of government that will have a meaningful impact today and in the future. Through partnering with like-minded organizations, sharing evidence-based information and consensus building, we have become the trusted voice for the neuromuscular community in Canada.

In 2019-2020, fair and timely access to affordable medicines and therapies was the cornerstone of our advocacy initiatives. We worked directly with local, provincial and national governments, drug system regulators and industry partners to understand how inefficiencies, inconsistencies and gaps in policies, programs and the healthcare system impact people with NMDs.

By emphasizing problems identified by the neuromuscular community and working with decision-makers to identify sustainable solutions, we can continue the momentum for meaningful positive change.

1
CADTH patient drug submission

5
Consultations with the Patented Medicine Review Board

Meet Eve

She calls it Myotonic Dystrophy Type 2. We call it a neuromuscular disorder.

It was just two years ago that Eve Rozen began experiencing tingling in her right leg. Initially her symptoms were dismissed as a typical part of the aging process and it wasn't until recently that she was diagnosed with Myotonic Dystrophy Type 2.

Eve is a passionate theatre goer and traveller and as her symptoms increased she found, more and more, that her world was closing in around her. Fortunately, Eve was able to connect with MDC and receive the support she needs to continue to live her life on her own terms. She wants to encourage anyone who is newly diagnosed to be as positive as possible, and take one day at a time.

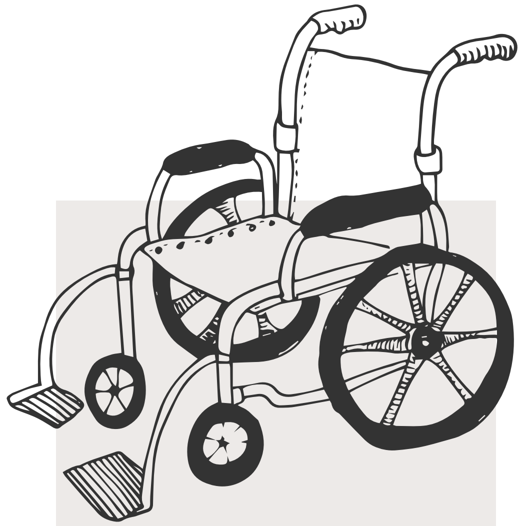
PROGRAMS, SERVICES AND EDUCATION

MDC is dedicated to delivering the right supports, at the right time, throughout an individual's neuromuscular journey in a holistic 'person and family centered' approach. MDC's System Navigation program focuses on collaboration to meet the individual's specific needs and goals. In fact, Service Specialists work directly with individuals and their family members from coast-to-coast-to-coast to help with non-medical needs such as housing, transportation, and access to mobility aids, assistive devices and other life-changing equipment.

This past year we worked with healthcare professionals and neuromuscular clinics nationwide to broaden awareness of the System Navigation supports available to individuals with NMDs no matter where they reside. We had 1,695 new clients register with MDC.

In partnership with clients, Service Specialists also help to address barriers, make connections with others in the community, share education materials and resources, enhance life skills and self-coping strategies, and embrace inclusion. In 2019-2020, MDC provided numerous opportunities for the neuromuscular community to learn, connect and share through: seven Muscle Facts presentations for 460 students, 12 network meetings with 116 participants, five lunch and learn presentations, and five Retreats with 293 attendees. This was the first year we held a Family Retreat in British Columbia – and it was a huge success!

TO LEARN MORE ABOUT OUR BASKET OF PROGRAMS AND SERVICES, VISIT **MUSCLE.CA/ACCESS-HELP.**



More than

$1.7m

invested

to help purchase more than 1,400 pieces of vital equipment with a retail value of approximately $4.4million

19,074

calls, emails, meetings and interactions with clients

Meet Stefanie

She calls it Spinal Muscular Atrophy. We call it a neuromuscular disorder.

“I CALL IT... **Spinal Muscular Atrophy**”

Stefanie Marinich-Lee was just 17 months old when she was diagnosed with type 3 Spinal Muscular Atrophy (SMA). As Stefanie got older, she slowly lost the ability to walk. In junior high and high school, she remembers friends pushing her to class in her wheelchair.

It wasn't until she was 19 where she felt true independence. She got her first scooter and she was able to attend her classes and make her way around the University of Waterloo. She went on and chased her dreams to become a lawyer. However, each day becomes a little more difficult as her disorder progresses.

She wants you to know that MDC is here to help people impacted by NMDs. She wants to reassure those impacted that “people with disabilities can do anything.”

“MDC has helped me since I was a teenager. If it wasn't for MDC, my parents wouldn't have been able to afford my wheelchair, and then later my scooter—and the different things around the house that help make each day a bit easier.”

FIRE FIGHTER PARTNERSHIP

$2.9 MILLION

across 640 Departments and Associations

This past year marked the 65th anniversary of the remarkable tradition of Fire Fighters across the country supporting MDC. In 1954 Fire Fighters first showed their support for MDC and the many families impacted by neuromuscular disorders, and have pledged to continue this support until there is a cure!

In 2019–2020, thousands of dedicated and passionate Fire Fighters nationwide raised an incredible $2.9 million through Fill the Boot, rooftop campouts, stair climbs, ladder sits, truck pulls, car washes, raffles, sporting events and so much more! Fire Fighters have been, and continue to be, MDC's largest network of supporters and we are incredibly thankful for their ongoing commitment and enthusiasm.

345

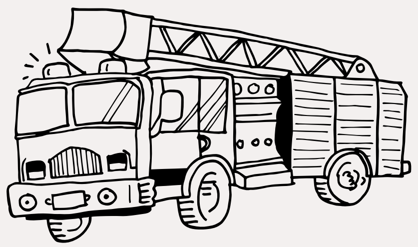
Departments & Associations helped Fill the Boot by raising over

$1.7 million

19

Departments & Associations held a Rooftop Campout or Ladder Sit and raised more than

$360,000



43

Departments & Associations held a Truck Pull and raised over

$36,000

High Rise Challenge

22nd EDITION

87	**650**
teams	participants

$300,000

raised

CHAPTERS AND VOLUNTEERS

MDC is extremely grateful for the hundreds of volunteers who selflessly give their time, talents and support to help achieve our mission. Thank you for everything you do!

In 2019-2020, there were 17 Chapters across the country, made up of individuals living with neuromuscular disorders, family members, friends, caregivers, and other community-minded supporters, that helped to raise funds and awareness! These Chapters also provide amazing peer support and foster connections.

Congratulations and thank you to all of the incredible individuals who contribute to the Board of Directors, Finance Audit and Risk Management Committee, Volunteer Engagement Advisory Committee, Medical and Scientific Advisory Committee, and the National Fire Fighter Relations Committee for providing valuable advice and helping drive the strategic direction and priorities for the organization!

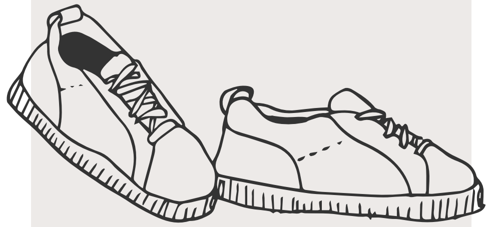
MDC CHAPTERS

Calgary | Central Alberta/Red Deer | Central NB/Fredericton | Edmonton | Fraser Valley/Abbotsford | Fundy/Saint John | Grand Prairie | Halifax | London | Ottawa | Outaouais/Gatineau | Saguenay/Jonquiere | South Okanagan/Penticton | Southern Manitoba/Winnipeg | Southern Saskatchewan/Regina

RAISING FUNDS

$1.1 MILLION

raised through Walk for Muscular Dystrophy



2624

Participants

347

Teams

43

Walk Events

MDC's signature event, the Walk for Muscular Dystrophy, is a wonderful opportunity to connect with others and come together as a community.

WALK FOR Muscular Dystrophy

Not only is this event a major fundraiser for MDC, it is also a chance for clients to form new friendships and networks of support. Whether you're a person with a neuromuscular disorder, a family member, caregiver, health care professional, researcher, Fire Fighter or community supporter—you are always welcome at the Walk.

Independent fundraising events hosted by community members, just like you, raised an incredible amount of support for individuals impacted by NMDs. More than $690,000 was raised through creative fundraising events— like bike rides, sports tournaments, auctions, and concerts, just to name a few.

A huge thank you goes out to the incredible participants, leaders and donors who contribute to MDC fundraising efforts all year long.

Thank you to every MDC staff member for your dedication, commitment and passion.

You've made an incredible impact in the lives of those impacted by NMDs.

3

Galas with

700

attendees

$400K

raised

STATEMENT OF FINANCIAL POSITION

For the year ended March 31, 2020

Assets	2020	2019
Cash & Investments	10,474,440	10,981,393
Capital Assets	136,186	160,489
Other Assets	1,106,552	599,190
Total Assets	11,717,178	11,741,072

Liabilities		
Accounts payable and accrued liabilities	989,121	734,329
Deferred Revenue	359,978	151,280
Deferred Lease Inducements	129,613	156,825
Commitments for Research Grants	1,238,440	300,000
Long Term Commitments for Research Grants	569,500	258,333
	3,286,652	1,600,767

Deferred Contributions related to:		
Neuromuscular research	909,447	1,407,385
Services	1,687,596	1,528,661
Education	376,698	271,684
British Columbia gaming	111,195	202,063
	3,084,936	3,409,793
Total Liabilities	**6,371,588**	**5,010,560**

Net Assets		
Net assets restricted for endowment purposes	992,909	950,691
Net assets invested in capital assets	136,186	160,489
Unrestricted net assets	4,216,495	5,619,332
	5,345,590	**6,730,512**
	11,717,178	11,741,072

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

STATEMENT OF REVENUE & EXPENDITURES

For the year ended March 31, 2020

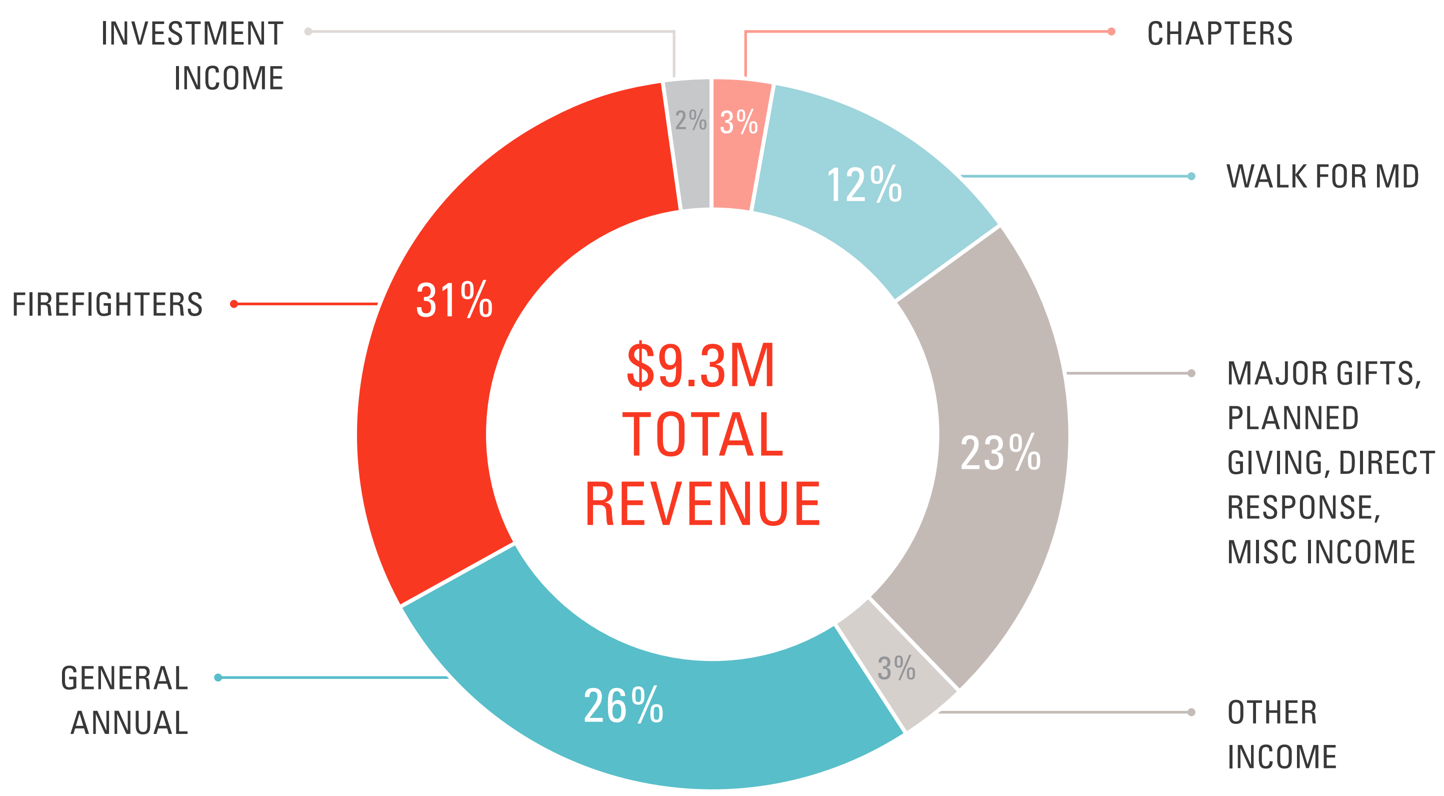
Revenues	2020	2019
General campaign and donations	7,585,135	7,740,931
Other revenue	1,340,769	1,191,581
	8,925,904	8,932,512
Investment and sundry income	462,130	409,521
	9,388,034	9,342,033

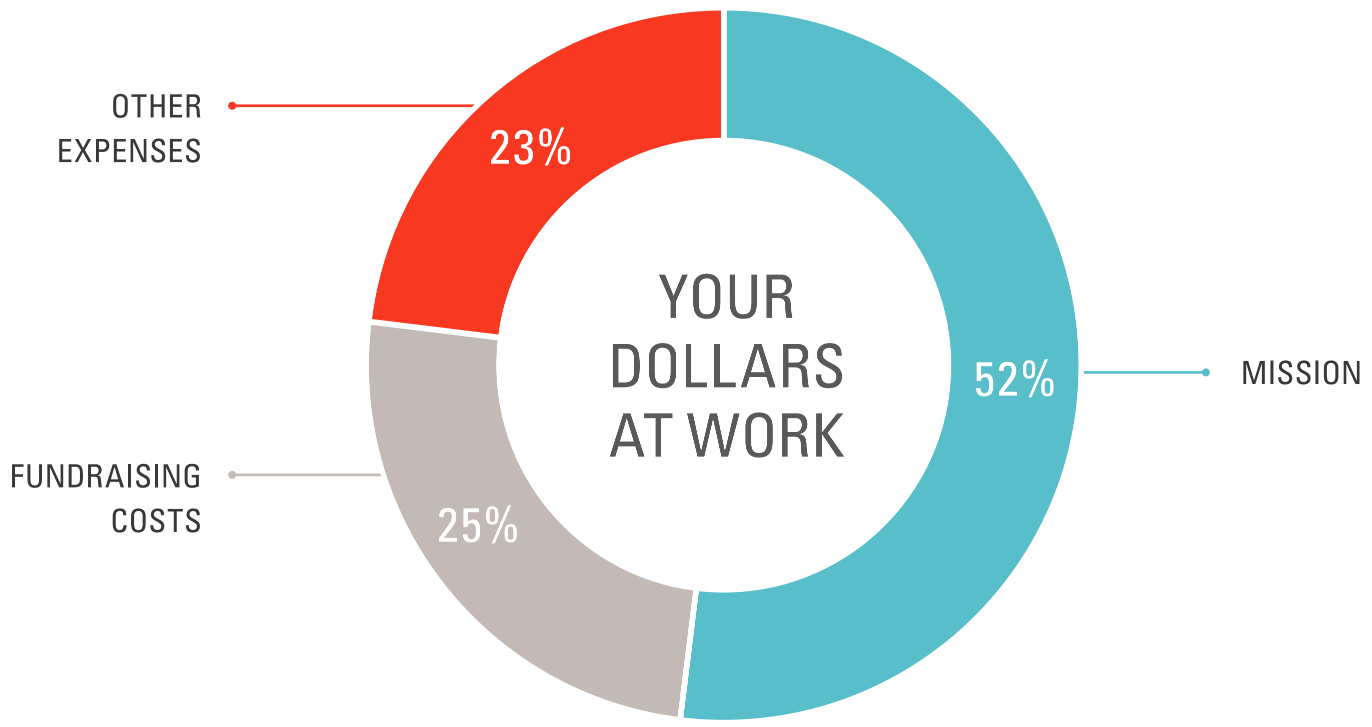
Expenditures		
Fundraising	2,387,697	2,425,343
Fundraising Operating Support	1,683,181	1,534,515
	4,070,878	3,959,858
Volunteer support and governance	309,570	287,756
	4,380,448	4,247,614
Net Funds Available for Programs & Services	5,007,586	5,094,419

Programs and Services		
Research Programs	2,034,022	1,142,189
Services	2,443,018	1,918,371
Education and information services	1,190,638	975,284
Other Programs	351,693	316,972
Services Operating Support	209,367	194,533
	6,228,738	4,547,349
(Deficiency) excess of revenues over expenditures before the undernoted	(1,221,152)	547,070
Amortization of capital assets	(60,152)	(93,781)
Loss on disposal of capital assets	-	(53,454)
Investment management fees	(64,808)	(39,111)
Change in fair value of investments	(38,810)	258,424
(Deficiency) excess of revenue over expenses for the year	**(1,384,922)**	**619,148**

FINANCIAL STATEMENT

For the year ended March 31, 2020





Meet Alex

He calls it Duchenne. We call it a neuromuscular disorder.

Alex Harold is a new university graduate. He loves to play video games and cheer on his beloved Raptors and Leafs and he has Duchenne Muscular Dystrophy. Diagnosed at the age of four, Alex demonstrates every day that a diagnosis does not define you. He has fought tirelessly for the accessibility he needed to finish his degree and his hard work has helped others dealing with their own accessibility challenges.

He's empowered every day by advocating for others and working to change the minds of people he encounters about how valuable the contributions of those living with a NMD can be. Although each person's experience of their disorder is individual, in the neuromuscular community they often encounter the same initial judgements and prejudices where people only see their disability.

He wants you to know that while you may have another diagnosis or a different genetic condition that he is here with you to fight all forms of NMDs.

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TO READ MORE, VISIT:

Muscle.ca

1-800-567-2873

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