



we work as  
**ONE**

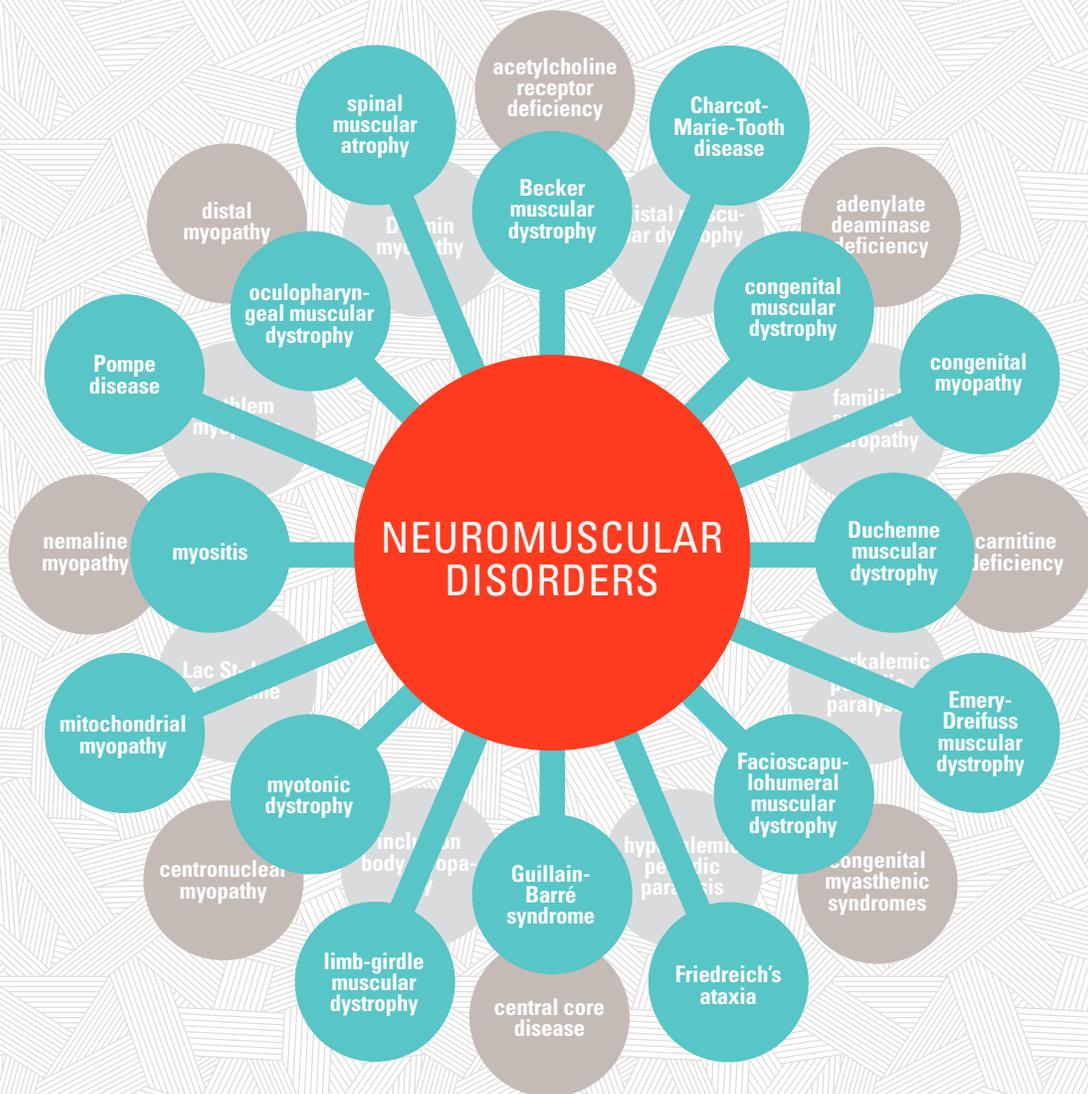
ANNUAL REPORT  
2018|19



MUSCULAR  
DYSTROPHY  
CANADA  
DYSTROPHIE  
MUSCULAIRE  
CANADA

## MISSION

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



\*This diagram shows just a fraction of the neuromuscular disorders covered by Muscular Dystrophy Canada. Disorders in teal are more prevalent than those in grey. All neuromuscular disorders are considered to be rare or "orphan" diseases.

*Throughout this report, you will find red banners like this one featuring Canadians we've honoured in 2018–2019 for their outstanding commitment to the neuromuscular community.*



## NEUROMUSCULAR DISORDERS

Muscular Dystrophy Canada supports Canadians diagnosed with 160-plus known neuromuscular disorders.

Neuromuscular disorders are a group of diseases that weaken the body's muscles or the nerves sending signals to muscles. The causes, symptoms, age of onset, severity and progression vary depending on the individual and the exact diagnosis.

While some types of neuromuscular disorders are first evident in infancy or early childhood, other types may not appear until later in life. The severity of symptoms, the age at which the symptoms appear, how fast the symptoms progress, and what pattern of inheritance the disorder follows, are all factors that differ among the various forms of muscular dystrophy.

In general, neuromuscular disorders are progressive, causing the muscles to gradually weaken over time. People diagnosed

with a neuromuscular disorder may lose the ability to do things that most people take for granted, like brushing their teeth, feeding themselves or climbing stairs. Some people will lose the ability to walk or breathe on their own.

Neuromuscular disorders don't discriminate.

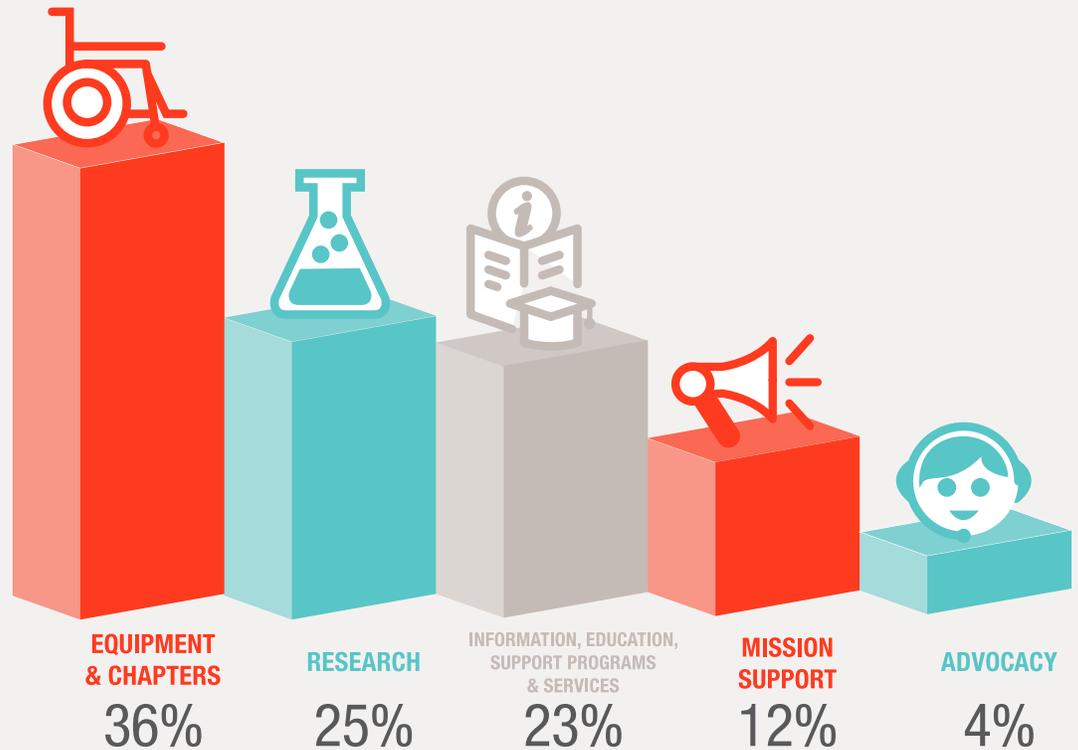
All they really care about is robbing you of muscle strength, making it hard to run, play, communicate and remain independent. They may progress quickly, or very slowly. They don't care about your age, your lifestyle or about you at all.

For some individuals, the disorder is fatal. Currently, there is no cure.

# IGNITED BY PASSION, FUELED BY *commitment*

## FUNDS INVESTED IN MISSION

Thank you to the more than **29,598 donors** and **hundreds of volunteers** who helped us work towards our mission in 2018-2019.



# Thank you!

*"I wish to thank Muscular Dystrophy Canada and all the people who donate money. The donations help Muscular Dystrophy Canada provide funding for the expensive equipment people with disabilities rely on to make their lives easier and independent."*

*"Thanks to generous donations to Muscular Dystrophy Canada, we have a new wheelchair accessible shower and a shower chair. Our son has now been able to have a proper shower, something he has not been able to do for years. He had his hair washed properly for the first time in years. He said he has never felt so clean. Words cannot express how thankful we are to all who have donated. Thank you from the bottom of our hearts."*

# MESSAGE FROM THE *CEO* AND *Board Chair*

## **WE WORK AS ONE.**

It's as simple as that. Muscular Dystrophy Canada (MDC) couldn't exist without generous donors, passionate Fire Fighters, committed volunteers, inspirational clients and amazing partners who work with us every day to enhance the lives of those impacted with neuromuscular disorders.

By working together, we've made a tremendous impact on the neuromuscular community in 2018-2019.

Thank you for standing by our side, sharing our vision and keeping Canadians impacted, at the heart of everything you do. Thanks to you, we raised more than \$9 million to invest in much-needed programs and services, continue important advocacy work and fund life-changing research in support of all Canadians living with this disorder.

Your ongoing support clearly demonstrates, that like us, you are Ignited by Passion and Fueled by Hope.



A handwritten signature in black ink, appearing to read 'BSC'.

**Barbara Stead-Coyle, CEO**



A handwritten signature in black ink, appearing to read 'Michael Kaye'.

**Michael Kaye, Chair**

we work as



**ONE**

# IGNITED BY PASSION, FUELED BY hope

## FUNDING CUTTING EDGE RESEARCH

Funding cutting-edge neuromuscular research has always been a priority for Muscular Dystrophy Canada, and this year we took another step towards growing this important work by appointing a MDC Director of Research, Daria Wojtal. Daria comes to us from Dr. Ronald Cohn's team at the Hospital for Sick Children and the University of Toronto, where she worked on her PhD in developing CRISPR gene-editing technology for the treatment of neuromuscular disorders.

This is a very exciting time in the neuromuscular community as more new treatments than ever before are in development. One of the biggest milestones this year, was US Food and Drug Administration's approval for the first gene therapy for a neuromuscular disorder, Spinal Muscular Atrophy (SMA). This marks a changing era and will open doors for other gene therapies in the pipeline. In fact, positive early findings are being published from clinical trials for Limb-girdle and Duchenne (DMD) Muscular Dystrophies gene therapies.

Over the years, MDC has supported research that will lead to improved quality of life and future life-altering therapies. Research published this year from laboratories that MDC

donors helped fund, includes Dr. Michael Rudnicki and team at The Ottawa Hospital who discovered how to help muscles make new muscle cells, delaying progression; and, Dr. Toshi Yokota (MDC's Friends of Garrett Cummings Research Chair) and team at the University of Alberta who studied a potential therapeutic use of CRISPR gene-editing. These proof-of-concept studies give new insight into neuromuscular disorders and brings us another step closer to developing new treatments.

Improving access to a life-changing treatment was at the heart of our advocacy efforts this year. We encouraged governments to expand access to SPINRAZA, a treatment for SMA. Our advocacy efforts, in partnership with the SMA community, resulted in the expansion of access to this drug in Quebec, Ontario, Alberta and Saskatchewan.

*"This is a time of hope. What's so exciting are the number of new therapeutics that are in the pipeline. The support that patients, donors and families give to MDC is what's helping us move forward. We've had so many breakthroughs and the funding from MDC is what is really helping us move therapies to the next level." – Dr. Jodi Warman Chardon, Director, The NeuroMuscular Centre, The Ottawa Hospital*

**DR. GEORGE KARPATI**  
**RESEARCHER OF THE**  
**YEAR AWARD**  
*Dr. Robin Parks*



Muscular Dystrophy  
Canada funded  
**9 Research  
Grants**  
to support the  
most promising  
neuromuscular  
research

**We focused our  
advocacy efforts  
on access to**

- clinical trials
- new treatments
- affordable medication

**\$1.1M**  
WAS INVESTED IN  
RESEARCH ACROSS  
CANADA

# IGNITED BY PASSION, FUELED BY support

## SUPPORTING LIVES: PROVIDING PERSONAL FREEDOM

Adjusting to living with a neuromuscular disorder can be overwhelming. There's so much to learn about adjusting to life with a complex disorder. To make things even more complicated, no two people experience the disorder the same way. A custom approach is needed every time.

In order to more effectively and efficiently meet the support and equipment needs of MDC clients, we implemented our Nationwide Equipment Program in Quebec this past year. After extensive review and consultation with healthcare professionals and clients, it was determined that our Quebec clients would be better supported and have access to more services through the nationwide program, as opposed to the provincial program they had been supported by previously. This change has allowed us to serve our clients more efficiently and provide access to even more services and supports.

In fact, this year we helped purchase 1,192 pieces of vital equipment for our clients. Of course, this would not have been possible without the generosity of our amazing MDC donors.

**EXCELLENCE IN SERVICE  
DELIVERY AWARD**  
*GF Strong Centre  
Neuromusculoskeletal  
Outpatient Team*

**LEADERSHIP IN  
ADVOCACY AWARD**  
*Victoria Lacey*

**DR. KATIE MANDERS COURAGE  
TO INSPIRE AWARD**  
*Jenna Keindel*

**NATIONAL OUTSTANDING  
HEALTHCARE PARTNER AWARD**  
*Dr. Hugh McMillan*

*"It has been a long, wild ride since Elisa was diagnosed with muscular dystrophy more than six years ago. Starting from her very first customized Ankle Foot Orthosis to her most recent Power Wheelchair, Muscular Dystrophy Canada has always been the first organization we turn to for financial assistance. I don't really know what we would have done all these years considering the financial hardship we face every single day as a family of six with one of us having special needs. Thank you."*



**175** Canadians participated in Family and Caregiver Retreats across the country



**13,458** calls, emails, and interactions with clients



**>\$1.3M** was invested to help purchase **1,192** pieces of vital equipment with a retail value of approximately **\$4M**

# IGNITED BY PASSION, FUELED BY *dedication*

## FIRE FIGHTER PARTNERSHIP

Fire Fighters have supported Muscular Dystrophy Canada since 1954, delivering an impact that has been felt for decades. And, this past year was no exception. In 2018–2019, Fire Fighters across the country raised an incredible \$3,122,076 to support Canadians impacted by neuromuscular disorders.

The signature fundraiser of our Fire Fighter partners is the Boot Drive. This year supporters helped “Fill the Boot” with donations at more than 400 events raising an incredible \$1,689,212 across the country! In addition to boot drives, our dedicated Fire Fighters hosted 24 Rooftop Campouts & Laddersits raising \$451,204, and nine truck pulls raising \$32,129 for Canadians impacted by neuromuscular disorders.

This year also marked the 21st edition of the Défi Gratte-Ciel, or High-Rise Challenge, in Montreal. This event sees

more than 600 participants including Fire Fighters, police, paramedics, and the public climb the 1,188 steps (46 floors) of the Deloitte Tower. Together, they were successful in raising \$251,474.

Fire Fighters are Muscular Dystrophy Canada’s largest network of supporters and we are incredibly thankful for their ongoing dedication and passion.



**DR. DAVID GREEN  
IMPACT AWARD**  
*International Association  
of Fire Fighters*

**FIRE DEPARTMENT  
OF THE YEAR AWARD**  
*Fredericton Fire Fighters’  
Association, IAFF Local 1053*

**FIRE FIGHTER  
OF THE YEAR AWARD**  
*Tony Rose*

Fire Fighters from **614** fire departments raised over **\$3M** across the country



**614**

*“A few years after being diagnosed with muscular dystrophy, I reached out to Muscular Dystrophy Canada with the desire to get involved and raise awareness about neuromuscular disorders. I quickly discovered the impact that Canadian Fire Fighters have had on the organization and families impacted, and to say it repaired my broken spirit following my diagnosis is an understatement. Thank you Fire Fighters.”*

**– Christina Massad, client**

# IGNITED BY PASSION, FUELED BY *community*

## RAISING FUNDS AND BUILDING FRIENDSHIPS

At the heart of everything we do here at Muscular Dystrophy Canada are the volunteers, partners, donors, sponsors and event participants who share our commitment to helping Canadians impacted by neuromuscular disorders.

This year, volunteers and supporters walked, biked and ran thousands of kilometres; hopped like bunnies; and danced the night away at fundraising events across the country to raise funds for MDC programs and research. But these events are so much more than just fundraising efforts, they are community-driven events that bring individuals and families together to build friendships and networks of support.

Our signature event, Walk for Muscular Dystrophy, saw 1,944 people participate in 44 events this year to raise over \$1.2 million. From May to September friends, family, staff and clients came together in communities big and small to enjoy time together, catch up with old friends and make new ones.

Seven hundred of our friends attended Galas and Cabarets in Montreal and Toronto this year raising an incredible \$630,000. These events are always an amazing time with fabulous food, entertainment, and prizes.

But it was the independent fundraising events hosted by community members, just like you, that really blew us away. More than \$563,000 was raised through fundraising efforts—like bike rides, bake sales and car races just to name a few.

Thank you to the incredible leaders who organize these fundraising events, and the supporters who participate and give generously. You've made an incredible impact in the lives of people living with neuromuscular disorders this year.



Over **\$1.2M** raised at **44** events with **1,944** participants nationwide

**DISTINCTION IN CHAPTER LEADERSHIP AWARD**  
*Edmonton Chapter*

**MARY ANNE WICKHAM AWARD FOR VOLUNTEER OF THE YEAR**  
*Kerry Zado*

**FRED SHADDICK COMMUNITY SPIRIT AWARD**  
*Rumble the Road*

**CARING CORPORATE PARTNER OF THE YEAR AWARD**  
*PTC Therapeutics*

*"The events MDC organizes, especially the Walk for Muscular Dystrophy, are important to my family. The Walk is an event that my children have grown up being a part of. They love to spend time with the Fire Fighters at the Walk and I have always been inspired meeting other families like mine, who bring hope and courage to my struggles. But most of all the funds raised help all of us."*

**– Sakina Mustan, MDC client**

# WHAT OUR Clients ARE SAYING



Family Retreat

“Thank you so much for your assistance. I honestly don’t know what I would have done, as my old scooter had quit completely! The funding from MDC came through quite quickly, and helped me regain and improve my mobility. I will be forever grateful for your help!”

“We highly recommend having Muscular Dystrophy Canada come and educate your son or daughter’s school team with a lunch and learn. Our two sons have Duchenne Muscular Dystrophy and the experience was so valuable. It really helped his teachers understand the impacts of Duchenne.”

“It’s difficult to put into words what the generosity of Muscular Dystrophy Canada really means to our family and the hope it provides for our daughter’s future. It offers more than the prospect of better mobility but also the opportunity for her to have more meaningful experiences during her formative years.”

“Before coming to the Family Retreat, it was like my daughter and her husband were on an island, dealing with Muscular Dystrophy in isolation. I am so glad they came. They have met so many people and are really sharing. They have exchanged contact numbers and will continue to connect. This is exactly what I had hoped would happen. Thank you for including us.”



# BOARD OF Directors



**Michael L. Kaye**  
Chair



**Alfred Breton-Paré**  
Director



**Debra Chiabai**  
Chair, Volunteer Engagement  
Advisory Committee



**David Cluff**  
Treasurer



**David Crawford**  
Vice-Chair



**Dave Ferguson**  
Secretary



**Buzz Green**  
Chair, Governance  
& Mandate Committee



**Elizabeth Ivey**  
Director



**Dr. Lawrence Korngut**  
Director



**Yazmine Laroche**  
Director



**Donna Nixon**  
Vice-Chair



**Kara Reid**  
Director



**Tony Rose**  
Chair, National Fire Fighter  
Relations Committee

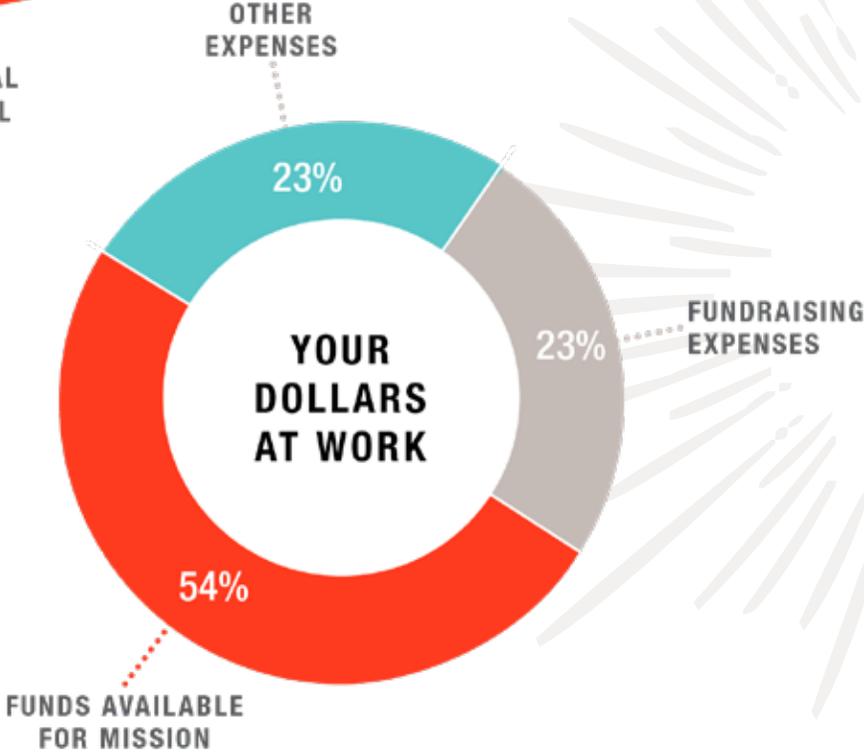
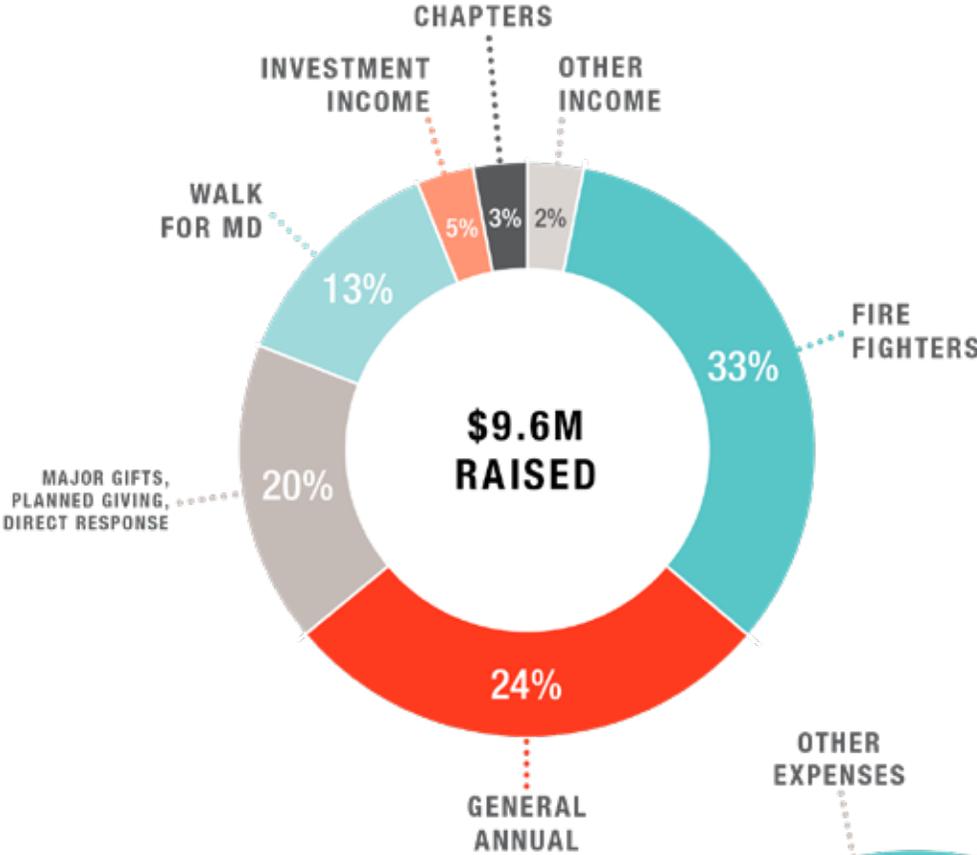


**Kelly Zacharias**  
Director



**Kerry Zado**  
Director

# Financial SUMMARY



# Statement of Revenue & EXPENDITURES

For the year ended March 31, 2019

	<b>2019</b>	<b>2018</b>
<b>Revenues:</b>		
General Campaign & Donations	\$7,740,931	\$8,577,182
Other Revenue	1,191,581	757,286
	<hr/>	<hr/>
	8,932,512	9,334,468
Investment & Sundry Income	409,521	237,094
	<hr/>	<hr/>
	<b>9,342,033</b>	<b>9,571,562</b>
<b>Expenditures:</b>		
Fundraising	2,425,343	2,795,300
Fundraising Operating Support	1,534,515	1,531,252
	<hr/>	<hr/>
	3,959,858	4,326,552
Volunteer Support and Governance	287,756	285,268
	<hr/>	<hr/>
	<b>4,247,614</b>	<b>4,611,820</b>
<b>Net Funds Available for Programs &amp; Services</b>	<b>5,094,419</b>	<b>4,959,742</b>
<b>Programs &amp; Services:</b>		
Research Programs	1,142,189	918,519
Services	1,918,371	1,804,302
Education & Information Services	975,284	811,697
Other Programs	316,972	327,075
Services Operating Support	194,533	183,342
	<hr/>	<hr/>
	<b>4,547,349</b>	<b>4,044,935</b>
Excess of revenue over expenses before the undernoted	547,070	914,807
Amortization of capital assets	(93,781)	(109,358)
Loss in disposal of capital assets	(53,454)	-
Change in fair value of investments	219,313	78,347
	<hr/>	<hr/>
Excess of revenue over expenses for the year	<b>619,148</b>	<b>883,795</b>

# Condensed Statement OF FINANCIAL POSITION

As at March 31, 2019

	2019	2018
<b>Assets:</b>		
Cash & Investments	\$10,981,393	\$10,735,286
Capital Assets	160,489	210,306
Other Assets	599,190	453,006
<b>Total Assets</b>	<b>11,741,072</b>	<b>11,398,598</b>
<b>Liabilities:</b>		
Accounts Payable & Accrued Liabilities	734,329	687,649
Deferred Revenue	151,280	170,188
Deferred lease inducements	156,825	29,286
Commitments for Research Grants	300,000	460,000
Long-term Commitments for Research Grants	258,333	258,333
<b>Deferred Contributions related to:</b>		
Neuromuscular Research	1,407,385	1,923,858
Services	1,528,661	1,304,409
Education	271,684	182,684
British Columbia Gaming	202,063	270,827
	<b>3,409,793</b>	<b>3,681,778</b>
<b>Total Liabilities</b>	<b>5,010,560</b>	<b>5,287,234</b>
<b>Net Assets:</b>		
Restricted for Endowment Purposes	950,691	909,300
Invested in Board Approved Priorities	—	983,085
Invested in Capital Assets	160,489	210,306
Unrestricted	5,619,332	4,008,673
	<b>6,730,512</b>	<b>6,111,364</b>

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



MUSCULAR  
DYSTROPHY  
CANADA  
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MUSCLE.CA • 1-800-567-2873

*Ignited by passion, fueled by hope.*

