

# Ware's Lace by Bev England

The beautiful image on the cover is entitled "Nature's Lace" and was created by Bev England, a Muscular Dystrophy Canada client.

Bev was diagnosed with Spinal Muscular Atrophy (SMA) four years ago. Doctors now feel strongly that her sister and mother, who passed away, also had muscular dystrophy.

Bev is a life-long artisan of many mediums. She started doing photography eight years ago. One of her favourite techniques is 'macro photography'. Her images are primarily captured at her home and are of everyday things that would normally be overlooked. When you look at a weed or water droplet through a macro lens it takes on a completely different appearance.

"Nature's Lace" is a macro photo of a leaf and water bead. This image captures the delicate nature of the plant's skeletal system and reminds Bev of the intricacies of the nervous system and our own neuromuscular functions.



Since 1954, Muscular Dystrophy Canada has been the leading voice of the neuromuscular community in Canada. Our vision is to find a cure for neuromuscular disorders in our life-time and, while we continue to fund ground breaking research, we also understand the importance of ensuring the daily lives of our clients are as rich and full as possible.

Funded by Canadians from coast to coast, our support of the Research community is advancing the development of new treatment and clinical trials. Our programs and services play a critical role in informing and supporting members of the neuromuscular community. These programs and services include funding equipment to improve daily life, family and caregiver retreats, providing emotional and educational support, along with access to vital resources and support systems. Our advocacy efforts focus on enhancing public policy at all levels of government to bring about positive change.

## Vision

To find a cure for neuromuscular disorders in our lifetime.

### 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.

Values

**Determination** – We are resolute. No matter what the obstacle, we will not be deterred.

**Courage** – We bravely move forward even when we are afraid or unsure where the road will lead.

**Passion** – Our enthusiasm and our appetite to learn, grow and make a difference is insatiable.

Caring – We have genuine human concern for others that is never contrived and without a hint of pity or sympathy.

## Message from the CEO and Chair

Every day, we are inspired by the people we meet and the stories we hear. Stories of commitment, courage, determination and caring. Stories that encourage us and ignite our passion to work harder ensuring we can deliver on our promise to our community.

In this report, you will have the opportunity to meet some amazing people. People who are fueled by hope — for a cure and for empowering the lives of others.

This past year has been one of great success, as you will see on the pages that follow. Together, and because of the commitment of all of you, we have been able to significantly lower our fundraising and administration costs. As part of our strategic plan — we set a goal of hitting the Canadian Revenue Agency guideline of 28 cents in 3 years. We did it in 1 year.

Why is this important? Because it means more of your dollars are invested in what matters to you the most — research, programs and services, and advocacy.

Our work would not be possible without all of you who raise funds, donate, volunteer and truly care about our collective mission. Thank you.

While we have much to celebrate, we are always faced with the reality of those who are no longer with us on this journey. We remember them and carry their spirit forward as we continue to push beyond possible and never giving up until there is a cure.

It is the sense of community that connects us to each other and makes our lives richer. In the words of Helen Keller, "Alone we can do so little; together we can do so much."



Barbara Stead-Coyle, CEO

Mully
Michael Kaye, Chair

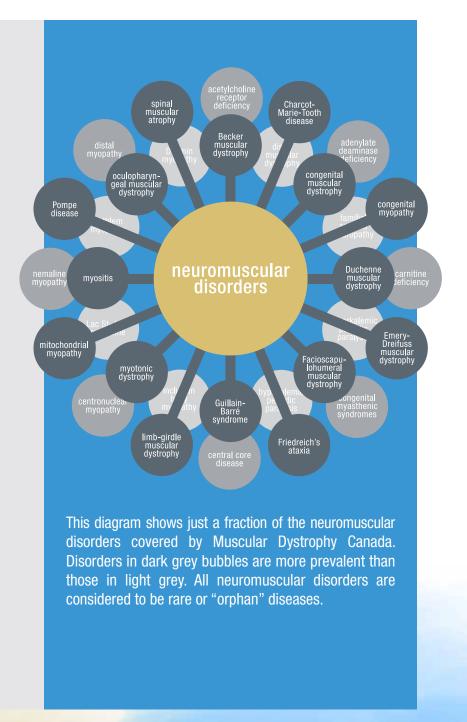


## Neuromuscular Wisorders

Muscular Dystrophy Canada (MDC) supports individuals affected by muscular dystrophy and related muscle diseases. Together, these rare conditions are referred to as neuromuscular disorders. Neuromuscular disorders weaken the body's muscles. The causes, symptoms, age of onset, severity and progression vary for each individual.

Anyone can be affected. Contrary to popular belief, neuromuscular disorders do not exclusively impact children. While some types of neuromuscular disorders are first evident in infancy or early childhood, other types may not appear until later in life.

Most 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 are often taken for granted, like brushing their teeth, feeding themselves or climbing stairs. Some people will lose the ability to walk or breathe on their own. For some individuals, the disorder is fatal. Currently, there is no cure.

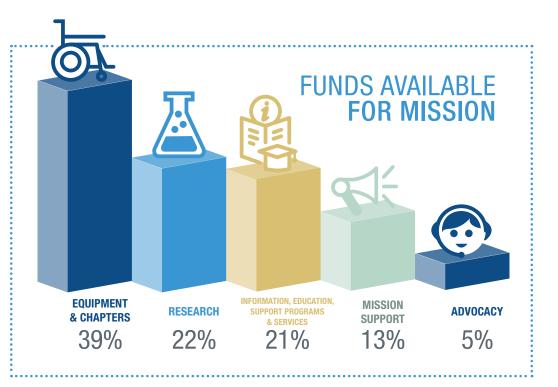


## Thank you!

Thank you to the more than **35,000 donors** and approximately **800 volunteers** who helped us work towards our mission in 2017-2018.

7<u>813</u>

\$1.2M was invested to help purchase 813 pieces of vital equipment with a retail value of \$4.9M



231 Canadians participated in Family and Caregiver Retreats across the country







"Words can not describe what an amazing organization Muscular Dystrophy Canada is and how much they have made possible for our family. We can not express how thankful we are to them and their wonderful supporters." - MDC client



SPECIAL & THIRD-PARTY EVENTS RAISED MORE THAN

IN SUPPORT OF
MUSCULAR
DYSTROPHY
CANADA

Muscular Dystrophy Canada funded

**7 Seed Grants** 

to support the most promising neuromuscular research



### Műscülar Dystrophy

\$1.4M raised at 48 Walk for MD events with 3,409 participants nationwide MORE THAN
\$900,000
WAS INVESTED IN
RESEARCH ACROSS
CANADA

We focused our advocacy efforts on access to



clinical trials



new treatments



affordable medication



611

Fire Fighters from **611** fire departments raised **\$3M** across the country

Until there's a cure. There's us.



Distinction in Chapter Leadership Award

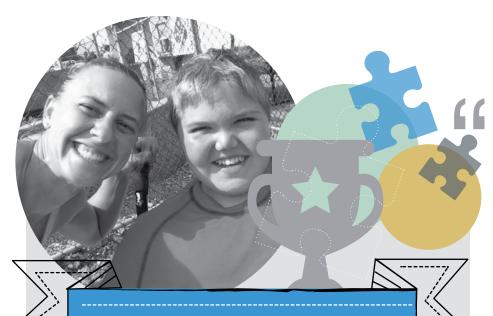
The Central NB Chapter has been consistently committed to supporting all clients in their area and ensuring they are connected to the resources they need most. The Central NB Chapter are exceptional volunteers and valued members of the MDC community.

Being a volunteer for Muscular Dystrophy Canada has given me a chance to give back and help others affected by neuromuscular disorders. I have a neuromuscular disorder and relate to everyone else who also has a disorder. My hope is to raise funds that will one day find a cure and purchase equipment to give people a better quality of life. We have already lost too many people to this terrible disease. For me and many other volunteers, the goal is to hopefully stop neuromuscular disorders so no one else will have to suffer.

Everyone involved in the Chapter is united by either having a neuromuscular disorder or knowing someone who does. Our hope as a Chapter is to influence big positive changes in the neuromuscular community in our area.

When we come together as a Chapter we are able to share stories, ideas and support everyone involved. We are able to make much more impact when we work together as a Chapter then we would be able to do alone. We are excited to see more of the positive changes we are able to create in the future!

Accepted by Richard Steeves, Chapter President
Fredericton, NB



**MaryAnn Wickham Award** for Volunteer of the Year

Kim has organized a trail run event called Muscles in Motion for eight years, and three years ago she also started a Hip Hop for MD event. She is also an avid advocate for the neuromuscular community. Kim lost her nephew to muscular dystrophy and is committed to raising as much funds and awareness as she can so that others won't have the same experience in the future.

It is important to me to volunteer for Muscular Dystrophy Canada so I can be an advocate for those that fight these disorders every day. Volunteering allows me to spread awareness of neuromuscular disorders and the effect they have on individuals and their families. Through the events I run, I'm able to educate the general population about neuromuscular disorders to give them a better understanding of what many individuals are going through and why it is so important to donate and raise funds.

My hope is to continue to create awareness and support those currently living with neuromuscular disorders. My goal is to keep an optimistic and positive attitude by running ongoing fundraising events that create hope for the future which will ultimately lead to a cure. Making sure that all those affected are supported fully and know that they are not alone is top priority.

Sylvan Lake, AB

Kim Reinhart



Outstanding Healthcare Partner Award

Gale always takes the time to listen to families, address their needs and advocate for them to other healthcare professionals. Gale often refers clients to Muscular Dystrophy Canada and helps spread awareness of the programs and services MDC offers. Gale is a passionate, caring and dedicated partner and always goes above and beyond to ensure her clients have what they need.

Working with an amazing multidisciplinary team, which includes the families and our Muscular Dystrophy Canada representative, to provide the best service we can is extremely rewarding. The families are central to the care we provide. We get to know the families so well and are there with them through the good times, which are many, as well as the not-so-good times.

The children and families living with muscular dystrophy are faced with and overcome many challenges in life. I am inspired by their determination and commitment to their loved ones. I have learned to appreciate the small things in life, how important family and friends are and not to take the life I have been given for granted. Seeing things from their perspective has impacted the care I provide to families.

Rehabilitation Centre for Children, Winnipeg, MB

Cafe Bonin



Joe and Rami have been dedicated supporters of Muscular Dystrophy Canada for 20 years. They raise vital funds to support SMA research through Muscular Dystrophy Canada and the Ilsa Mae Research Fund. Joe and Rami are incredible philanthropists who have garnered the support and dedication of communities and companies around them to support our cause.

Our daughter, Ilsa Mae, passed away from Spinal Muscular Atrophy Type 1 in March 2000. As parents who have lost a child to this devastating disease, we vowed to continue supporting Muscular Dystrophy Canada in their quest to find a cure for muscular dystrophy and support families affected by this disease. During the time that Ilsa was with us, Muscular Dystrophy Canada gave us both emotional and monetary support which was essential for Ilsa to have the best life possible. As well, there have been great strides in treatments since 2000 for Spinal Muscular Atrophy and Duchenne muscular dystrophy. We know that the funds we have helped raise over the years both support families in coping with this disease and bring the likelihood of a cure that much closer.

By being willing to share our story with anyone who will listen, we have increased the number of people who understand the effects of muscular dystrophy and hopefully are motivated to donate funds or volunteer. We hope that our continued efforts on behalf of Muscular Dystrophy Canada eventually lead to a cure.

Joe and Rami Chougnies

Edmonton, AB



Dr. Katie Manders Courage to Inspire Award

Richard spent countless hours playing the video game, Guitar Hero, and then picked up the real instrument! Playing music became a way for Richard to express himself. He now uses this talent to inspire others and raise funds and awareness for charities near and dear to his heart.

Being part of Muscular Dystrophy Canada is like being part of a big community. I get to make connections with other people and families that are also living with muscular dystrophy, and I know that I am not alone. It makes me feel more encouraged and hopeful that we will be able to find a cure one day! It lets me know that someone cares about what I and others like me, are going through.

I want to raise awareness beyond just the neuromuscular community about the severity of muscular dystrophy, and the fact that it is terminal. I want people to change the way they think of the word "disabled". To me, being disabled doesn't mean "not being able". I think a lot of people are scared of that word, but I think it's important to call myself disabled because it lets people know what obstacles I've conquered and what I've had to go through. People sometimes think that because I'm not sad all the time it means that I don't know Duchenne's muscular dystrophy is terminal, or that I don't want to talk about it. I don't sugar coat what's happening to me. I understand what having a terminal illness means, but that doesn't ever stop me. Having Duchenne muscular dystrophy is part of what makes me who I am, but it doesn't define what I can do. Don't let anything or anyone dictate what you do with your life. I don't just have muscular dystrophy, I LIVE with it.

Mard Lyan
Vancouver BC



We are proud as a school to support Muscular Dystrophy Canada through the Walk for Muscular Dystrophy. We are dedicated to this cause because of the Mino family who are part of our school community and have two amazing children at our school. Christopher, who is in Grade 8, was diagnosed with Duchenne muscular dystrophy when he was four years old.

The entire school community came together to raise awareness and funds for the Move it for Mino campaign! We raised \$1,565.25 in support of the Niagara Walk for MD.

St. Ann Catholic School

Accepted by Principal Mr. Root St. Catharines, ON



## Fire Fighters

As an organization, Muscular Dystrophy Canada is extremely fortunate to have an unparalleled relationship with Fire Fighters across the country. Fire Fighters have supported Muscular Dystrophy Canada since 1954, delivering an impact that has been felt for decades. This relationship continues to strengthen. Canadian Fire Fighters have a goal of raising \$100 million by 2020 to support Muscular Dystrophy Canada's mission and they have already surpassed \$85 million. We are incredibly thankful for their ongoing dedication and passion for the cause.

Until there's a cure, there's us.





#### Dr. David Green Impact Award

The Smithers Fire Rescue truly embodies the Fire Fighter mantra "Until there's a Cure, there's us". They have reached a major milestone of \$1 million raised. Which is an incredible feat for any fundraising group, not to mention, a small volunteer fire department in a community of 5,500. They are an extremely motivated group of supporters who continue to grow their events and support the entire neuromuscular community.

Smithers Fire Rescue has supported Muscular Dystrophy Canada since 1964. The impact we hope our fundraising efforts have is to free individuals and their families from the effects of muscle debilitating disorders. By working together with Muscular Dystrophy Canada and other partners, we hope to continue to enhance the lives of those affected by

neuromuscular disorders and work to provide ongoing support and resources, while relentlessly searching for a cure.

What fuels our drive to continue supporting MDC is seeing the advancements in research, watching persons affected live more independent lives, getting to know the clients individually and seeing the person, not the disability. Until there's a cure there's us!

Smithers Fire Rescue
Smithers, BC



Dan has been a leading force in growing the truck pull fundraising events across the country. His dedication, perseverance and enthusiasm for the cause is contagious and noticed by staff, volunteers and clients everywhere he goes.

#### Volunteering with Muscular Dystrophy Canada over the past number of years has brought me pure joy.

It's an incredible feeling knowing you are raising not only funds but much needed awareness of neuromuscular disorders. Being able to bring together fire departments across multiple provinces to find new ways to help raise funds and make a difference has been very inspiring. It's always a good day when you can share good news stories with fellow Fire Fighters about how the monies they helped raise made a difference for someone living with a neuromuscular disorder.

Building continued support with Fire Fighters and Muscular Dystrophy Canada staff, seeing the smiles from families when we help them even with a small gesture, and continuing the different fundraising events held throughout the year are just a few of the things that motivate me to continue my involvement. Also, it is a great honor to participate in the National Fire Fighter Relations Committee and represent Fire Fighters from the province of New Brunswick and work with members from across Canada to make changes that could impact the way Fire Fighters interact with Muscular Dystrophy Canada for years to come.

Sussex, NB

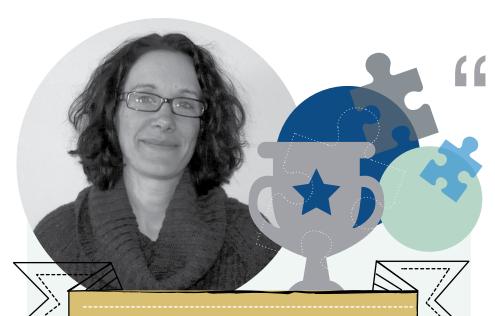


What motivates us the most is getting to know the families and individuals living with neuromuscular disorders. Seeing firsthand, clients get the help that they need and deserve is extremely rewarding. It is truly rewarding to see the difference that we are able to make in these families' lives. A bad day for us is nothing compared to a bad day for them.

Fire Fighters continue to support Muscular Dystrophy Canada because of the path that has been paved by well-respected colleagues that have supported this organization for so long.

Watching the impact it has made on other leaders' lives has been infectious for future volunteers and it makes everyone want to get involved. Fire Fighters also thrive on tradition. We've been supporting Muscular Dystrophy Canada since 1954 and it is something that we are very humbled and proud to support.

Edmonton Fire Department
Accepted by Courtney Polson
Edmonton, AB



Dr. George Karpati Researcher of the Year Award

Dr. Gagnon has been a volunteer on the Medical and Scientific Advisory Committee (MSAC), a speaker at many events and a supporter of the Quebec Research Symposium. She is a very dedicated researcher and clinician devoted to improving the lives of her patients.

Working with the neuromuscular community is so rewarding because you feel like you're part of an extended family and everyone is concerned about each other's wellbeing. I have the unique opportunity of having our research team located within a neuromuscular clinic and a regional office of Muscular Dystrophy Canada. This means that I am able to have ongoing interactions with my extended family including patients, families, clinicians, trainees, administrators, research professionals, students and Muscular Dystrophy Canada representatives.

As a researcher, I feel extremely privileged to be able to work with my team on important and significant issues that affect patients and families such as; gaining a better understanding of disease evolution, working to address their daily struggles by providing evidence-based interventions and optimizing trial readiness. My neuromuscular extended family takes such good care of my research team by providing terrific patient engagement in more than 13 current research projects, clinicians sharing their unique knowledge and research professionals and students being dedicated and enthusiastic! In addition, our Canadian research community is strongly united to enhance collaborations between basic and applied research to make sure that we are rapidly bringing solutions to Canadians affected by neuromuscular disorders.

Vr. Cynthia Gagnon



Alfred is a tireless supporter of Muscular Dystrophy Canada. He never misses an opportunity to raise awareness for patients and families and constantly promotes Muscular Dystrophy Canada's programs and services.

**Advocacy Award** 

#### My involvement with the neuromuscular community started in 2012 with the High-Rise Challenge event.

It was this event that triggered my desire (and my family) to be supporters of this cause, following the Duchenne muscular dystrophy diagnosis of our son Eloi.

Right from the start, we've worked closely with Fire Departments in Montmagny and Berthier-Sur-Mer. I want to continue using the High-Rise Challenge to raise awareness for the cause; while raising as much money as possible in order to fund research and services for clients. I hope this support will help many families.

In Fall 2017, I was offered the opportunity to be a member of MDC Board of Directors. I accepted with much enthusiasm, hoping to use my experience in the Pharmaceutical Industry to benefit MDC and its clients. With respect to clinical trials, I want to impact the organization so we can provide the most up-to-date information to families. That way, they can discuss with their physicians the different studies, make an informed decision; and potentially have a shot at receiving a promising new medication. I would also like to contribute to MDC being the leader in the neuromuscular community.

When you witness how a simple gesture can impact someone; it gives you a great sense of accomplishment. Most importantly, it fuels your motivation to do more. Eloi and others affected by neuromuscular disorders are courageous, resilient and certainly deserve our involvement.

Quebec, QC

Alfred Breton-Paré





The Canada Post Community Foundation for Children's generous contribution to the System Navigation program will help hundreds of clients across the country access the support and resources they need, when they need it most!



Fondation communautaire de Postes Canada

## The Canada Post Community Foundation for Children is dedicated to improving the lives of children across

**Canada.** By building the capacity of registered charities, as well as local initiatives and school programs, the Foundation can help caring communities develop happier, healthier children.

Muscular Dystrophy Canada's application for a \$50,000 grant from our Foundation resonated with us. Muscular Dystrophy Canada's System Navigation program is helping families of more than 1,800 children with neuromuscular disorders access high-quality services no matter where they live. We're pleased to see it expand so it can support more children and families.

Canada Post, Community
Foundation for Children



## Excellence in Service Delivery

The staff at the BC Children's Hospital
Neuromuscular Clinic goes above and beyond
for clients to ensure they are informed and
supported. They regularly attend information and
training sessions to increase their knowledge.
They are dedicated to offering cross collaboration
opportunities such as volunteerism, professional
development and fire fighter integration.

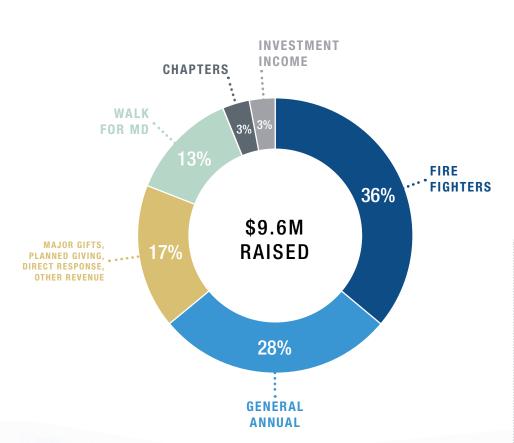


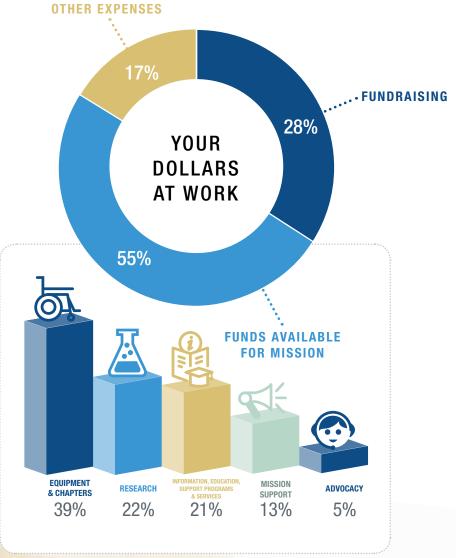
It is essential that we are able to give family-centred care and as we serve families throughout the province of British Columbia and the Yukon, that we can ensure that our families access supports within their local communities for ongoing care.

We want to support our family's medical care, education, and psychological support, and give them the hope and resources to ensure their child reaches their potential. Additionally, they should have access to clinical care, clinical trials and studies where appropriate. We want to encourage education and knowledge for improving health outcomes, and quality of life. We are constantly striving to improve the quality of care we provide to our families in the Neuromuscular Clinic, and we are honoured to receive this award.

BC Children's Hospital - Neuromyscular Clinic Vancouver, BC

## Financial Symmary







#### & EXPENDITURES

For the year ended March 31.2018

	2018	2017
Revenues:		
General Campaign & Donations	\$8,577,182	\$8,638,328
Other Revenue	757,286	1,608,157
	9,334,468	10,246,485
Investment & Sundry Income	237,094	231,306
	9,571,562	10,477,791
Expenditures:		
Fundraising	2,795,300	3,835,983
Fundraising Operating Support	1,531,252	1,441,053
I dildiability Operating Support	4,326,552	5,277,036
Volunteer Support and Governance	285,268	486,832
	4,611,820	5,763,868
Net Funds Available for Programs & Services	4,959,742	4,713,923
Programs & Services:		
Research Programs	918,519	863,512
Services	1,804,302	1,573,781
Education & Information Services	811,697	925,746
Other Programs	327,075	288,180
Services Operating Support	183,342	647,429
	4,044,935	4,298,648
Excess of revenues over expenditures before the undernoted		415,275
Amortization of capital assets	(109,359)	(119,386)
Change in fair value of investments	78,347	408,535
Excess of Revenue Over Expenditures	883,795	704,424
for the year before restructuring costs		
Restructuring costs	-	(724,000)
Excess (deficiency) of revenue over expenditures for the year	883,795	(19,576)

## Condensed Statement

#### OF FINANCIAL POSITION

As of March 31, 2018

	2018	2017
Assets:		
Cash & Investments	\$10,735,286	\$10,628,619
Capital Assets	210,306	296,311
Other Assets	453,006	434,062
Total Assets	11,398,598	11,358,992
Liabilities:		
Accounts Payable & Accrued Liabilities	687,649	1,356,424
Deferred Revenue	199.474	113,083
Commitments for Research Grants	460,000	260,000
	1,347,123	1,729,507
Language Committee and for Documents County	050,000	000 000
Long-term Commitments for Research Grants	258,333	360,000
<b>Deferred Contributions:</b>		
Neuromuscular Research	1,923,858	2,257,877
Services	1,304,409	1,327,357
Education	182,684	179,597
British Columbia Gaming	270,827	277,085
	3,681,778	4,041,916
Total Liabilities	5,287,234	6,131,423
Net Assets:		
Restricted for Endowment Purposes	909,300	869,420
Invested in Board Approved Priorities	983,085	983,085
Invested in Capital Assets	210,306	296,311
Unrestricted	4,008,673	3,078,753
	6,111,364	5,227,569

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.

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Dave Ferguson Secretary



David Cluff Treasurer



Buzz Green Chair, Governance & Mandate Committee



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Relations Committee



**Debra Chiabai**Chair, Volunteer Engagement
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David Crawford
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Nancy E. Cumming Director



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Donna Nixon Director



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Kerry Zado Director

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Trace McCandless

Mike Nicholson

**Bruce Porter** 

Kerry Zado

Jeremy Dixon\*

Dave Ferguson\*

Dave religusoii

Kelly Zacharias\*

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**Peter Arnburg** 

Shanon Brausen

Alfred Breton-Paré

Cathy Cunningham

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<sup>\*</sup> Non-Voting















Join us. To be part of the solution!

For more information or to get involved, please contact us.

Toll-free: 1.800.366.8166 info@muscle.ca





www.muscle.ca



@muscle.ca



@MD\_Canada