



“ WE CALL IT A NEUROMUSCULAR DISORDER. ”

ALEX CALLS IT DUCHENNE; MICHAEL CALLS IT FSHD; EVE CALLS IT MYOTONIC. WE CALL IT A NEUROMUSCULAR DISORDER.

Muscular Dystrophy Canada (MDC) is on a mission to demystify muscular dystrophy and neuromuscular disorders; and, make Canadians aware that we are here to support them whether they, or a family member, have been diagnosed with a disorder and regardless of what they call it.

To do that, we launched a new campaign aptly named “We call it NMD,” which includes disorder support and research information on our new muscle.ca website, as well as videos featuring MDC friends and clients.

The stories shared in the campaign echo sentiments we hear time and time again from the neuromuscular community: challenges being diagnosed, frustration navigating the healthcare system, and lack of support. That’s why it’s so important that we spread the word that MDC is here to help!

You can find the campaign, and watch the videos here: muscle.ca/wecallitnmd. But first, let us introduce you to Alex, Michael and Eve and then you can get better acquainted with them online.



“ I CALL IT...
Duchenne
muscular
dystrophy ”

“If I can help one more person know what muscular dystrophy is then that’s one more person in the fight.”
— Alex Harold



“ I CALL IT...
Facioscapulohumeral
muscular dystrophy ”

“We need to do better as a community at helping people get answers. Muscular Dystrophy Canada is in a great place to help direct that future.”
— Michael Gottlieb



“ I CALL IT...
Myotonic
dystrophy ”

“Fortunately, I was connected to MDC and now have them and donors like you helping me all the way.”
— Eve Rozen

JOIN THE CONVERSATION AND HELP US SPREAD THE WORD USING THE HASHTAG #WECALLITNMD ON SOCIAL MEDIA.



IGNITED BY PASSION, FUELED BY COMMUNITY



Muscular Dystrophy Canada extends a heartfelt thank you to the many foundations that support our mission to enhance the lives of Canadians impacted by neuromuscular disorders. Your continued support ensures MDC is able to fund life-changing research, advocate for better public policies, and provide support services to ensure individuals impacted are able to live full, rich lives. Thank you!

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| United Way Estevan | Eric T. Webster Foundation |
| The Harold E. Ballard Foundation | Fred North Charitable Foundation |
| North Shore Municipal Community Grants | The Slight Family Foundation |
| Victoria Foundation | The Holt Foundation |
| Colleen Kiers Memorial Fund at the Niagara Community Foundation | The Hamber Foundation |
| Shoppers Drug Mart Life Foundation | Stephen and Michelene Worobetz Foundation |
| Danbe Foundation Inc. | Zeller Family Foundation |
| The Hylcan Foundation | Edmonton Oilers Community Foundation |
| The Windsor Foundation | Mr. and Mrs. P.A. Woodward's Foundation |
| Harry & Martha Cohen Foundation | Ladysmith Healthcare Auxiliary |
| The Lorne and Evelyn Johnson Foundation | The Birks Family Foundation |
| CIBC Miracle Foundation | Gary Bluestein Charitable Foundation |
| Edmonton Civic Employees Charitable Assistance Fund | |

MUSCULAR DYSTROPHY CANADA / DYSTROPHIE MUSCULAIRE CANADA

Join us for the **SMA RESEARCH SUMMIT** November 14-15, 2019
Toronto, Ontario



Register now to secure your spot! Spaces are limited.

Costs to attend the SMA Research Summit are covered by our sponsors. Please email laura.willman@muscle.ca for details.

SMA SUMMIT SET TO KICK-OFF IN NOVEMBER

Muscular Dystrophy Canada is hosting the National SMA Research Summit November 14-15, 2019 in Toronto, Ontario. This exciting event will bring Canadian and international experts in SMA research and the medical community together to discuss new research, clinical trial developments, and the changing treatment and regulatory landscape in Canada.

Thanks to our sponsors, Biogen, Novartis, and Roche for helping us bring this important summit to the neuromuscular community.

If you are interested in attending, please visit:
muscle.akaraisin.com/ui/SMAResearchSummit
to register today, as only a few spots remain.



SPINRAZA NOW AVAILABLE TO MORE CANADIANS BUT WORK LEFT TO DO

Thank you for supporting Muscular Dystrophy Canada as we continue our advocacy work to encourage government to expand access to SPINRAZA for all Canadians.

We've made great progress! MDC congratulates the provinces of Quebec, Ontario, Alberta, Saskatchewan, New Brunswick and Nova Scotia for their leadership in expanding access to SPINRAZA, a lifesaving treatment for those impacted by Spinal Muscular Atrophy (SMA).

Thank you to everyone across the country who signed our petition, reached out to their MPs' and political

representatives, and signed advocacy postcards at the Walk for Muscular Dystrophy.

While we've made tremendous progress there are still provinces who have not yet approved broad access to SPINRAZA. And, there are many patients, like our friend Zoe Koontz from British Columbia, whose access is either nonexistence or at risk of being revoked if we do not continue to push for access.

We're fighting for SPINRAZA for all, so families like Zoe's don't have to worry about how they will access this life-changing treatment.

JOIN US AND THE DAMATAN-KOONTZ FAMILY IN THE FIGHT FOR EQUAL ACCESS TO SPINRAZA

Zoe and her family are feisty. Since her diagnosis when she was just two years old they have successfully fought to gain access to SPINRAZA through private insurance, becoming the first to do so in British Columbia.

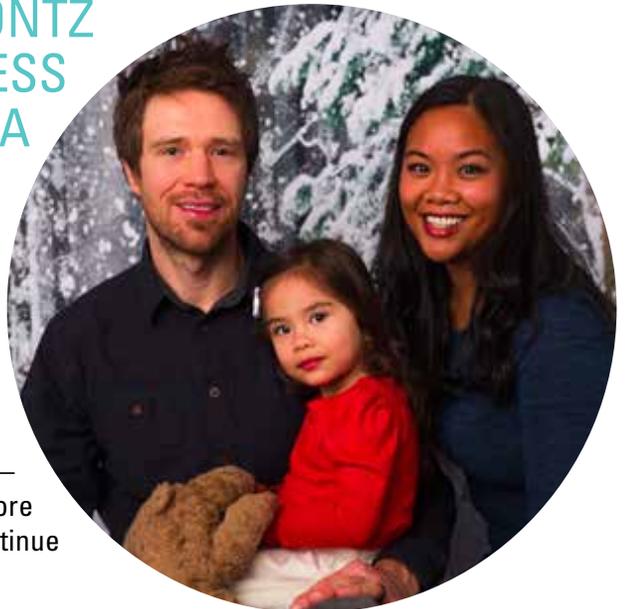
The impact this treatment has had on Zoe's life cannot be overstated. Her mom, Vivienne remembers the time between her diagnosis and the start of her treatments as, "the longest few months of my life," and shares that the transformation in Zoe since treatment began has been, "incredible, she just exudes joy."

She also acknowledges how lucky their family is to have gained access to this life saving treatment, "We know in

the community that there are people who have been waiting their entire lives for this and still don't have access."

Zoe and her family will lose access to SPINRAZA in 2020 if the BC government does not approve broad access—leaving Zoe and her parents more determined than ever to continue the fight.

Please join us. Call your MP, reach out to your Health Minister, host a letter campaign. Our representatives need to know that this is important to our community, provinces and country as a whole.



As Vivienne put it, "right now people are dying—plain and simple—and we have the tools to do something about that."



MUSCLE.CA IS ALL NEW!



AND WE'RE LIVE!

Did you know that after months and months of hard work behind the scenes, our new website is live!

With a new look, easier navigation and up-to-date information about all our support services, events and stories, we know the new and improved muscle.ca will be a great resource for you.

Be sure to check it out!

UPCOMING EVENTS

October 1 – December 11
Atlantic Fall Raffle

November 28
Application Deadline
Research Grants

December 3
Giving Tuesday

To stay up to date on all upcoming events, please visit muscle.ca/events.

CONNECT WITH US!

MUSCLE.CA | 1-800-567-2873

NEW BURDEN OF ILLNESS STUDY TO HELP RAISE AWARENESS

Muscular Dystrophy Canada (MDC) is excited to share with you that we are currently working on a Burden of Illness Study. We know that living with a neuromuscular disorder is expensive and our community experiences a tremendous financial burden. This project will highlight the economic burden associated with the direct and indirect costs related to living with a neuromuscular disorder. This study will enhance awareness and education for key decision makers related to Canadian health care and research policy and will assist MDC and partners to influence positive change.

The study will explore the data related to the number of people living with Spinal Muscular Atrophy, Duchenne, Myotonic Dystrophy, Facioscapulohumeral muscular dystrophy (FSHD), Charcot-Marie-Tooth disease (CMT), and Limb Girdle. The project focus will also include the economic burden on family members and caregivers. The study will include the economic burdens associated with access to treatments, therapies, as well as, resources that enhance quality of life such as assistive devices.



EXCLUSIVE HOLIDAY ORNAMENTS – AVAILABLE NOW!

A perfect gift for loved ones, family members and friends! Spread some holiday cheer by gifting an exclusive one of a kind hand-crafted pewter ornament.

Each ornament purchased helps Muscular Dystrophy Canada provide essential equipment, support programs and services, and funding for ground-breaking research to help the neuromuscular community!