

Message from the CEO



Barbara Stead-Coyle, CEO

We are pleased to present our new quarterly newsletter! We hope you enjoy getting to know us better, staying informed and receiving exciting news about Muscular Dystrophy Canada and the clients we serve. Over the last two years, Muscular Dystrophy Canada has made great strides in creating greater alignment nationwide for our people, moving more money to mission activities and raising the profile of our cause with those who can make a difference. I would like to thank you for your ongoing support and dedication as we continue to make progress, Pushing beyond Possible and striving to serve more Canadians dealing with the realities of a neuromuscular disorder. We could not do it without you, our loyal donors and supporters. Thank you and enjoy!

Navigating a neuromuscular disorder diagnosis needs personalized support efforts

“It seems like only yesterday, my son Ryan was at taekwondo and another parent, who was a neurologist, approached me. He had been watching the class and noticed Ryan was having trouble getting up off the floor. He suggested that we have him tested for muscular dystrophy,” says Ryan’s mother, Allison Belme.

A muscular dystrophy diagnosis can be a rollercoaster ride of emotions. Because it is a rare disorder, many parents and individuals are unfamiliar with its progression, the resources available, and what daily life will look like post diagnosis.

“After Ryan was diagnosed with Duchenne Muscular Dystrophy (DMD) when he was five and a half, we felt lost and alone – we did not know where to turn for help. Then we met Karen from Muscular Dystrophy Canada (MDC),” says Allison.

“I relied on MDC to help me advocate when the school administrators decided Ryan needed to be in his wheelchair at all times. And again, when they decided he couldn’t go canoeing on his graduation trip.”

After a diagnosis, things continuously change. There are many stages of emotions as you discover new challenges. No two people experience a diagnosis the same way which is why MDC provides clients with personalized support.

“MDC calls what Karen and others across Canada do – System Navigation – I call it being a life saver. One thing I can always count on when things get overwhelming is that Muscular Dystrophy Canada will be there to help me solve problems and put things into perspective.”

“Now, as Ryan turns 15, I look at him and see a young man who is growing in confidence and independence, someone who is trying new things and learning to advocate for himself. As he connects with others, through sport - his powerchair hockey team just won nationals last summer (pictured above), through camp and through fundraising events and walks, I can see how far we’ve come since kindergarten. **I share our story, as a chance to say thank you to everyone who donates to Muscular Dystrophy Canada – your support has made such an impact on our lives!**”



Your gifts to Muscular Dystrophy Canada make a difference. Thank you!

Online: muscle.ca/donate

By phone: 1-800-884-6322

Mail in the included donation slip.

Advocating for Access: SPINRAZA's Affect on SMA



Dominic was a happy, healthy and strong baby, meeting all his milestones with flying colors. It wasn't until he was about 10 months old that his mom, Stéphanie, started to notice some changes. "He wasn't advancing as quickly as he had been. Having an older child, I just knew that something was off," says Stéphanie. "The doctors were telling me that everything was fine and not to compare his progression to anyone else's but I knew in my heart that there was something else going on."

Stéphanie continued to push the doctors, insisting for more tests and referrals to specialists. By the time Dominic was 18 months old, he was diagnosed with Spinal Muscular Atrophy (SMA). SMA is a disorder that robs people of physical strength by affecting the motor nerve cells in the spinal cord, taking away their ability to walk, eat,

and in severe forms, breathe.

"I think this is one of the most heartbreaking diseases. You have to just sit there and watch your child deteriorate before your eyes and there's nothing you can do about it," says Stéphanie.

"You feel like you've lost all control. For me, the only way I was able to feel like I still had some control over what was happening was to be as informed as possible. I did a lot of research, I still do a lot of research, I spoke to groups like Muscular Dystrophy Canada and Cure SMA, I connected with support groups on social media, I went to conferences and I talked to researchers and clinicians."

Since SMA is a rare disorder, many medical teams don't see it or have to deal with it on a regular basis. Stéphanie worked with Dominic's medical team

to brainstorm new ideas, search for treatments and to provide them with information on the most recent findings and ways of thinking for SMA treatment. About two years ago, Dominic joined a clinical trial for a drug called SPINRAZA™.

"I couldn't believe the results, and how fast we saw progress."

"With SMA, it's never supposed to get better, only worse. After only two months on SPINRAZA™, we saw Dominic begin to progress. He hadn't been able to sit up by himself and within the first two months of the trial, he could bend over to pick up a toy and lift himself back up. We were blown away", shared Stéphanie. "We also noticed a huge difference with his sleeping. Before taking SPINRAZA™ we would have to wake him up 10 or more times a night to change his position because he couldn't

roll over himself. Now we don't have to wake up and he can roll and move comfortably while he sleeps. Depending on the type of SMA and the age and physiology of the individual, the results may vary but SPINRAZA™ does stop the progression of this degenerative disease which is the ultimate goal!"

In early January, the CADTH announced that they are now recommending SPINRAZA™ for use in treating a subset of SMA Type 1 patients who meet specific criteria. We know there is a lot more work to be done. Muscular Dystrophy



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Canada will continue to advocate on behalf of the neuromuscular community.

“Access to and coverage for SPINRAZA™ means everything to us. We were very frustrated and disappointed with the recommendation and feel that it will be very costly for those who are affected by all types of SMA. SPINRAZA™ is an effective treatment for SMA, it works, it is safe and this should have been reflected in the recent recommendation. It is completely necessary and so far is the only treatment approved and available worldwide! We have seen the results first hand and are communicating with families around the world who have also witnessed results. We feel strongly that this treatment needs to be available to all patients affected regardless of age or type of SMA,” says Stéphanie.

“Muscular Dystrophy Canada is currently working on behalf of our SMA families and actively asking both INESSS and CADTH to reconsider their positions regarding the use of SPINRAZA™ for the treatment of SMA. MDC’s position is that fair, affordable access to this medication is crucial to clients and a basic right of Canadians. This treatment has the potential to extend and improve the lives of SMA sufferers.” - Barbara Stead-Coyle, CEO, Muscular Dystrophy Canada.

If you or someone you know is dealing with a neuromuscular disorder diagnosis, please visit muscle.ca

The Central Okanagan Foundation impacts British Columbia families

Equipment funding is an extremely important part of Muscular Dystrophy Canada’s mission. Access to equipment increases clients’ freedom, independence and their overall quality of life.

The Central Okanagan Foundation has been a generous supporter of Muscular Dystrophy Canada’s BC Equipment Program. Over the last two years, they have awarded a grant of \$30,000 which supported individuals to receive vital equipment.

Without the dedication of funders like the Central Okanagan Foundation, we would not be able to fund equipment requests for clients. We are very grateful for the support of the **Central Okanagan Foundation**.

If you or a loved one is interested in learning more about equipment funding, please visit muscle.ca/we-can-help/financial-assistance/

Connect with Muscular Dystrophy Canada!



Upcoming events:

March 22 – Montreal Gala

May 3 & 4 – Neuromuscular Symposium in Quebec

May 4 & 5 – Caregiver Retreat in Quebec

May 23 – Montreal Cabaret

May 20 – Defi Gratte Ciel

Join us for the 2018 **Walk for Muscular Dystrophy**. Visit muscle.ca/walk-for-muscular-dystrophy/ to find a walk location near you!

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

Thank you, Edmonton Civic Employee Charitable Foundation!

We are so grateful for the dedicated donors, sponsors and supporters who generously contribute to Muscular Dystrophy Canada's mission of supporting individuals living with a neuromuscular disorder. Since 2006, the Edmonton Civic Employee Charitable Foundation has been a longstanding dedicated supporter, contributing more than \$200,000.00.

Specifically, the Edmonton Civic Employee Charitable Foundation supports the Edmonton Rooftop Campout with funds being directed toward a Family Retreat in Alberta!

Family Retreats offer a weekend 'away from it all' in a safe, welcoming, and natural setting. These retreats are a critical component of the holistic approach to



For more information on Family and Caregiver retreats, visit muscle.ca

Above: Junior Schilbert-Cutarm (client), Courtney Polson (MD Edmonton Fire Fighter Chair), Grady Polson (family member) and Wes Bauman (Edmonton Fire Fighter).

care offered by Muscular Dystrophy Canada. Family Retreats provide an opportunity to learn, connect, reflect and relax while in the company of others with similar experiences.

Because of generous donors, like the Edmonton Civic Employee Charitable Foundation, clients have access to vital programs like retreats. We can't thank the Edmonton Civic Employee Charitable Foundation enough for their continued generosity to our clients!

Canadian Neuromuscular Summit

From February 20 to 22, Muscular Dystrophy Canada and the Starratt Family Foundation were pleased to sponsor the 2018 Canadian Neuromuscular Summit in Montreal. The goal for the Summit was to connect Canada's leading researchers, clinicians, industry partners and patient organizations in one room to talk about how, together, we can continue to accelerate advances to benefit Canadians impacted by neuromuscular disorders.

Covering issues related to research advancements, access to new treatments and clinical trials and many other topics, the two day summit was a wonderful opportunity to ensure that we continue to work together on behalf of our neuromuscular community.



Fire Fighters supporting Canadians



Since 2005, Rooftop Campouts have been a major fundraising event for Muscular Dystrophy Canada and annually, raise more than \$375,000. Passionate Fire Fighters brave the elements and camp out on rooftops for more than 70 hours to raise awareness and funds for Canadians affected by neuromuscular disorders. These events bring Fire Fighters and local families together to raise awareness of the programs provided to Canadians needing support. Since 1954, the biggest supporters and champions of our mission have been Fire Fighters. We thank those who endure snow, frigid temperatures and wind-chills to support programs and services provided to our clients.

Thank you for believing in our mission and being our largest supporter.

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