



**YOU CAN  
BREAK DOWN  
THE BARRIERS**



MUSCULAR  
DYSTROPHY  
CANADA  
DYSTROPHIE  
MUSCULAIRE  
CANADA

**CASE FOR SUPPORT**

## WHY MDC?

**“EVERYTHING  
IS FINE.  
GO BACK  
HOME.”**

Elizabeth is affected by  
spinal muscular atrophy

**That’s what doctors told Julie Trubiano when she went to the hospital with her daughter, Elizabeth, to find out why her toddler had gone from walking to barely being able to hold herself upright. But Julie refused to go home. “This is clearly not normal,” she kept insisting.**



# Every dollar matters. Every donation is powerful.

For a whole week of 16-hour days, Julie kept bringing Elizabeth back to the hospital to be examined by stumped doctors and medical students. Then, finally, a neurologist was called, and a blood test was given.

“Go home, Mrs. Trubiano, and wait.”

A month later, Julie received a phone call from the hospital.

“Your daughter has spinal muscular atrophy – a degenerative disease,” the doctor said.

Julie was shocked and confused. “You need to come back to the hospital,” the doctor continued, “because there’s almost zero chance that your current pregnancy won’t be affected in the same way.”

Julie was six months pregnant and couldn’t believe what was happening to her and her family. And she was shocked by how few answers and treatment options the hospital was giving her.

## Where the Healthcare System Stops, Muscular Dystrophy Canada Begins

We’re grateful for our amazing Canadian healthcare system, but it can only do so much. It just doesn’t have all the information on diagnoses, treatment options, and support services for neuromuscular disorders (NMDs) that people need.

That’s where we come in.

Muscular Dystrophy Canada (MDC) is a recognized authority on all neuromuscular disorders, which includes muscular dystrophy and hundreds of other conditions classified as NMDs. We are a sophisticated network of informed professionals, service specialists, and

volunteers who deeply understand neuromuscular disorders. We can also give people the non-medical services and emotional support they need to help deal with their disorder.

When a Canadian is diagnosed with a neuromuscular disorder, we know they will need a lot of support and services. But the systems around us – provincial healthcare, private insurance, and government policy – aren’t set up to give that kind of full support. These systems are also difficult for people to navigate. So that’s why we’re here – to fill in the healthcare gaps and help people find their way through these systems.

MDC has a full spectrum of programs, services, and supports for the thousands of Canadians of all ages living with a neuromuscular disorder. Plus, we invest in transformative research to work towards more answers, therapies, and hopefully, potential cures.

**But we need your help to continue this essential work.**

“I was so grateful. I don’t know how many hours I spent filling out forms, sending forms, and making sure doctors and insurance offices got the forms. Having a service specialist at Muscular Dystrophy Canada hold my hand and help me walk through all the steps – that is worth a lot of money. I would give her everything for all the help that she gave me.” – Julie

## How You Make a Difference

Because of our donors, Julie Trubiano was connected to one of our service specialists, who helped her fast-track through the healthcare system and find physiotherapy for her daughter. Julie’s MDC service specialist also helped educate her daughter’s daycare about her disorder and how best to provide support, and stood by Julie as a compassionate and proactive ally throughout it all.



RESEARCH

# FUNDING CUTTING-EDGE RESEARCH

**Who do you call after getting the difficult news that you or someone you love has been diagnosed with a neuromuscular disorder? Your mind races between practical concerns and anxious thoughts: What treatments are available? What does this disorder look like in five or 10 years? Who can give you answers you can trust?**

Your donation makes sure Dr Warman Chardon and people living with an NMD can keep finding hope – in the present and future.

Thanks to generous giving, Muscular Dystrophy Canada (MDC) is a leader in funding ground-breaking research for all neuromuscular disorders (NMDs). This does two things: first, it lets us advance the global understanding of NMDs and the advancement of more treatments, therapies, and potential cures. And second, our deep involvement with these research projects means we can get people the most up-to-date information they need.

Through regular webinars, workshops, seminars or phone calls, we give people the latest information about their condition to help them make the most informed decision about their health. We also connect them to the most current treatment options, specialists, therapies, and clinical trials.

Your donation will save lives by fueling future discoveries and ensuring Canada is prepared to provide access to new life-changing treatments, while also filling the immediate need for advanced treatment and care options.

### Working Together for World-Class Care

MDC is a funding partner of the Neuromuscular Disease Network for Canada (NMD4C), an integrated research network for patients, scientists, and clinicians focused on improving patients' health outcomes by improving healthcare, research and treatments. Through NMD4C, we can connect people living with a neuromuscular diagnosis to advancements in world-class care and some of the latest treatments being developed within the network.

**When you give to MDC, you are helping thousands of Canadians right now – while also giving hope to future generations.**

“For many disorders, there isn't a treatment yet, but the ability to participate in MDC-funded research gives people true hope. We've made incredible discoveries in the last few years, and they're just going to accelerate.”

– Dr Jodi Warman Chardon



Dr Jodi Warman Chardon is a Clinical Scientist in the Department of Medicine at the Ottawa Hospital, and a Muscular Dystrophy Canada Board of Directors Member.

Dr Warman Chardon follows, assesses, and diagnoses patients with rare and ultra-rare neuromuscular disorders who live across Canada and around the world. Patients with these rarer disorders often need sophisticated and complex forms of testing to get a diagnosis and start looking for treatment options.

“Patients who don't have a diagnosis are doubly disadvantaged. Not only do they not know what's happening to them, but they don't know how it could be potentially treated. So we need more resources and more research to help get more answers.”

Dr Warman Chardon has seen firsthand how MDC's funding directly advances neuromuscular research.

“Muscular Dystrophy Canada has been a fantastic partner to help move research forward. They also invest in our future superstars – basic scientists coming through post-doctoral fellowships or new clinical neuromuscular disease fellows that will help us further develop potential cures.”

Clinical Scientists like Dr Warman Chardon, and the thousands of other people who have dedicated their lives to researching neuromuscular disorders, are vital to our community – and you can help them.



A young boy with short brown hair and glasses is looking upwards and to the right. He is wearing a white polo shirt with blue and green stripes on the collar. The background is a blurred outdoor setting.

EQUIPMENT

# PROVIDING FUNDING FOR LIFE CHANGING EQUIPMENT

Alex is affected by  
Duchenne muscular dystrophy

**Canadians with neuromuscular disorders have the same talent, goals, and ambitions as any other Canadian. Your donation can help eliminate the barriers that keep them from reaching their full potential.**

# Every dollar you give makes sure that nothing holds people like Alex back.

When Alex was four, he was diagnosed with Duchenne muscular dystrophy, a severe form of muscular dystrophy that's characterized by progressive muscle deterioration and weakness. It eventually affects the heart and lungs.

Alex says that living with his condition impacts every aspect of his life, but he is fiercely determined not to let it hold him back.

"Over the years, as my equipment needs have changed, Muscular Dystrophy Canada's (MDC) support has been indispensable. With the support of donors, MDC helped me get an elevating wheelchair and even provided funding support so my family could afford a van with a power lift. And getting back some independence through this equipment has been life-changing for me. MDC made that possible," said Alex.



## The Costs of a Neuromuscular Disorder

All neuromuscular disorders (NMDs) affect muscle function and lead to a range of mobility challenges. So having the right equipment like motorized scooters, bedside slings, ramps, handrails, and more, is critical for daily activities like going to school, work, and recreational activities. In cases where peoples' respiratory systems are affected or their balance is unsteady, equipment like breathing aids and emergency alert systems can save their lives and protect them from serious injury.

But the cost of equipment adds up. It isn't fully covered through private health insurance, and government support varies from province to province. In fact, even where people are fortunate enough to have an additional amount of coverage, out-of-pocket costs can still be high.

Sources:

1. Osman H., Wojtal D., Lintern S., Economic Impact and Health-Related Quality of Life of Patients and Caregivers Affected by Neuromuscular Disease. Poster Presentation at CADTH Symposium 2021.

For example, Ontario covers just 25% of the cost of devices like new wheelchairs. But wheelchairs can cost upwards of \$60,000, so that can still mean a \$45,000 out-of-pocket expense.

When MDC totals the costs of paid caregivers, assistive devices, home and vehicle modifications, and allied healthcare providers as an average for all Canadians living with an NMD diagnosis across all disorders, it can easily be more than another \$25,000 out-of-pocket expense, per person per year.<sup>1</sup> That's a lot. Especially when you consider that the median after-tax income for Canadian families is \$66,800.00.<sup>2</sup>

This can create an overwhelming financial burden for families and for individuals— and the costs are only going up. But you can help these individuals and families.

With the help of our donors, MDC's long-standing equipment program has helped thousands of people buy the costly equipment they need. In one year alone, we invested \$2 million to help buy 1,400 pieces of life-changing equipment.

**When you give to MDC, you're breaking down barriers. You're making sure that when someone needs vital equipment to help them get around, live independently, participate in school and work fully – or even help save their life – they won't have to do without it.**

"It's important to know that people with neuromuscular disorders have goals and dreams of their own. We just face a few more physical challenges. But your donation to MDC can help remove some of the obstacles we face." – Alex

2. Statistics Canada. Canadian Income Survey, 2020. <https://www150.statcan.gc.ca/n1/en/daily-quotidien/220323/dq220323a-eng.pdf?st=H2rnenpS>. Published March 23, 2022.



COMMUNITY,  
EDUCATION  
& ADVOCACY



# ENGAGING THROUGH COMMUNITY, EDUCATION, AND ADVOCACY

Fanny is affected  
by Friedreich ataxia

**A neuromuscular disorder diagnosis can make you desperate for answers and send you searching for solutions. Unfortunately, most people living with a neuromuscular disorder (NMD) have to overcome a lot of barriers just to get the information and options they need. Your donation to MDC helps break down those barriers.**



## Your donation ensures that people like Fanny will always have access to the support that's right for them.

We know every diagnosis and situation is unique, complex and personal. Thanks to our generous donors, we can deliver all kinds of targeted non-medical services for all kinds of people in communities right across Canada.

We're proud to deliver community-wide educational programming or one-on-one information sessions on specific conditions, treatments, therapies, and other care options. We also lead informed support groups for caregivers and people living with a neuromuscular disorder (NMD) that can be customized to life circumstances and specific disorders. These groups help people connect, share experiences, and support each other. We also host family and caregiver retreats, where people can come together for activities, to relax, and make new friends.

### Championing Customized Support Through Our Service Specialists

Muscular Dystrophy Canada's (MDC) service specialists are experts who are a compassionate lifeline for Canadians affected by an NMD diagnosis. They can help people navigate the unique requirements of systems and institutions across our country. They can also help people advocate for themselves when they need support at school or work. Or, if they want, a service specialist can come into schools and workplaces to run tailored education sessions for them, informing peers, teachers, colleagues, and employers about the specifics and related challenges of a person's condition. But importantly, our service specialists also provide the emotional support that many people so often need.

**Service specialists are often our clients' greatest champions. Your giving makes their work possible.**

In 1995, Fanny was diagnosed with an unknown form of ataxia, a degenerative disorder of the nervous system that affects the parts of the brain that coordinate movement. Neurologists and specialists followed Fanny's progress for over 20 years without being able to give a more specific diagnosis.

Recently, Fanny finally got a diagnosis of Friedreich ataxia. This rare inherited form of the disease leads to progressive nervous system damage, mobility impairments, and can even mean a shorter life.

"The diagnosis was a shock to me because it is more serious than what I thought I had. I wish I had known 20 years ago. But if I had known, I probably would not have done my Ph.D., and I probably would not have had children—I have two boys, they are 16 and 14. So, in the end, all is well, but still, it was a shock. Thankfully, MDC is always there if I need something. I can call my service specialist at MDC, ask her anything, and she'll direct me to the right resources, so it's really reassuring."



"I tell anyone I meet with a neuromuscular disorder, 'Call MDC.' Because even if you don't know anyone at the organization, MDC will welcome you and be there for you. If you talk to MDC and tell them what you need, they'll organize a meeting with people in the same situation, direct you to the right doctor or neurologist, link you to support groups, or just listen – sometimes, you just need to be listened to." – Fanny

# LEADING POLICY CHANGE

Annabelle is affected by spinal muscular atrophy

When doctors told Julie Trubiano her unborn child would likely share the same diagnosis of spinal muscular atrophy as her daughter Elizabeth, she was terrified. When Julie gave birth to Annabelle, doctors performed a newborn screening test to confirm the diagnosis and were able to start her on treatments right away. Now, a year later, Annabelle is symptom-free. A miraculous difference in outcomes can be possible when some NMDs are caught early.



# You can help make the *positive change* our country needs.

Early diagnosis, at any age, can dramatically reduce people's symptoms and create better health outcomes for them at a reduced cost. Newborn screening and other early diagnosis initiatives for some NMDs are currently possible but aren't always available across Canada's healthcare system.

This needs to change. And you can help.

When you donate to MDC, you give people living affected by an NMD a voice and access to politicians and other key decision-makers who need to know more about NMDs, see the costs to families and the healthcare system, and hear how they directly affect Canadians. We believe this will influence leaders to address gaps in the healthcare system.

Right now, MDC is funding, leading, and facilitating projects to collect the data and recommendations needed to fix outdated policies and create new ones. We're also advising and building partnerships with health care centres and leaders at all levels of government to address the unique needs of people living with neuromuscular disorders.

## Positive Change Happening Right Now

### The Disability Inclusion Action Plan

As an authority on all neuromuscular disorders, MDC is working with the federal government to create the first *Disability Inclusion Action Plan*. We are co-leading this important work and getting Canadians living with a disability to share their experiences with government leaders. We want to make sure the Action Plan is inclusive and effective.

### The Canadian Rare Disease Strategy

Canada doesn't have policies to properly address all the healthcare issues that are related to rare diseases. This directly affects our community because ALL NMDs are considered rare. That's why MDC is championing research to inform a much-needed rare disease strategy. This strategy will improve diagnosis, access to therapies, and medical coverage for treatments and equipment.

**We're working hard to bring positive change to our community. But we need your help. It takes just one generous act to change our country – and our future – for good.**

Julie Trubiano says she went through “months of agony” fighting to get her daughter Elizabeth’s diagnosis and then working through the ensuing maze of securing financial coverage for the therapies and equipment her daughter would need.

But when Julie connected with MDC, she discovered a group of people who could fight with her.

“I’m not as strong as people think. People see me fighting for medication for my daughter, so they tend to think I’m very strong. People don’t see how crushed I am. Taking action is my way of making sense of everything that has happened. It’s why I am part of support groups, and I’m going to host fundraising events.”

As a woman of action, Julie values the commitment MDC has shown her family and others. She hopes you will stand with us by supporting our work for all Canadians affected by neuromuscular disorders.





**FIRE FIGHTER  
PARTNERSHIP**

# **BREAKING DOWN BARRIERS**

**More than 60 years ago, the co-founder of MDC, Dr David Green, knocked on his local fire station's door. He needed to raise money to research his son's (and others') muscular dystrophy. Dr Green asked the Fire Fighters to help him. From that day onward, thousands of career and volunteer Fire Fighters have kept answering Dr Green's call for help. Will you join them?**



# Every dollar is powerful. Every donation matters.

Through high-rise challenges, boot drives and tolls on the local roads, community barbecues, rooftop campouts, car washes, raffles – you name it – more than 600 fire departments and associations all across our country work with MDC every year to give all neuromuscular disorders “the boot” in this lifetime.

## See the Difference You Make

The events that are hosted by Fire Fighters raise funds to support Canadians living with neuromuscular disorders. These events also let Fire Fighters meet those Canadians and see the many ways they’re helping transform lives.

“One family– their daughter was diagnosed at an early age,” says City of Edmonton career Fire Fighter, Courtney Polson. “They were told that she wasn’t going to walk again. As a parent, that would just be heartbreaking. But these parents ended up getting a chair for their daughter when she was about seven or eight. Instead of sitting, the chair would prop her upright so she could be as tall as her peers and tippy toe her way around instead of using her hands. And at eight years old, she walked for the first time. I couldn’t imagine being those parents – how that would feel being told she wouldn’t walk, and now she is.”

## Inspiring Community Relationships

Organizing a fundraising event is also an excellent opportunity to build rapport with a station’s community, says volunteer Fire Fighter with Middlesex County, Launie Fletcher. “The community sees us, and we get a chance to talk and visit, so that’s a big thing for us, too.”

Launie has been fundraising with MDC for 40 years and is still moved by the generosity boot toll events inspire in his community. “One father drove through the boot toll in the morning and then came back again in the afternoon. And he commented, ‘You know, my son said he had some more money and that we’ve got to put it in the Fire Fighter’s boot.’ So, they drove back by because

they knew that the Fire Fighters needed the money. Whether it’s fifty cents or five dollars, I don’t know, and I don’t really care. But that they drove by twice to help us collect money for our charity. That makes me want to grab my boot and go out into the street right now.”

## Breaking Down Barriers

The funds raised by Fire Fighters are essential for our community, because MDC doesn’t get a lot of government funding.

We know organizations’ time and resources are always tight. But Launie and Courtney see how much more could still be done – and they’re doing their best to urge other fire departments and associations to get involved.

**“Just try it,” says Courtney. “Do one event and see how you feel. It’s easy to say, ‘I’m too busy,’ but for fellow Fire Fighters, we need to make it a priority to help where we can. Every dollar matters.”**

Launie couldn’t agree more that the need is urgent. “When it’s Fire Fighters and MDC together, we’re a family, and we know they need our help. So, when it comes to fundraising, I say, ‘give me a challenge, and I’ll give you my best.’”

Join Launie, Courtney and the many other Fire Fighters across this country who are giving their best by organizing a fundraising event at your station or workplace.

Give us a call or send an email, and you will have MDC’s staff support every step of the way as you plan and run your event.

To get your Fire Department or Association involved, or to organize a fundraising event for your workplace, contact us at [info@muscle.ca](mailto:info@muscle.ca) or 1-800-567-2873.

“Events are just so rewarding for everybody because we see the difference they make. With Muscular Dystrophy Canada, I’ve seen firsthand where the money goes – how it makes a difference in people’s lives.” – Courtney, Edmonton Fire Fighter

## ABOUT MDC

### 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.

### VISION

To find a cure for neuromuscular disorders in our lifetime.

### 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.



# NOW IS THE TIME TO BREAK DOWN BARRIERS

Join as a *monthly donor* or give a *one-time gift*.

Any amount you can give will help make sure that Canadians living with a neuromuscular disorder can reach out to MDC and get the information, equipment, treatment options, and personalized support they need at any time.

It takes just one act for you to change someone's life.

**To donate, visit [muscle.ca/donate](https://muscle.ca/donate)**

Fundraise with your *coworkers*.

There are lots of ways you and your coworkers can come together to fundraise for Muscular Dystrophy Canada and change the lives of thousands of people living with a neuromuscular diagnosis.

**Assemble a team by visiting [muscle.ca/events](https://muscle.ca/events)**

Become a *corporate sponsor*.

Create a legacy of giving at your organization by sponsoring MDC in our crucial work. Your gift will improve health outcomes, financial support, and public policies for all Canadians living with a neuromuscular disorder.

**To learn more about becoming a corporate sponsor, contact us toll-free at 1-800-567-2873 or email us at [info@muscle.ca](mailto:info@muscle.ca).**



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