The disease doesn’t control you, you can control it!

“I spent many years of my life not knowing why I felt different. It wasn’t until I was in my twenties that I was actually diagnosed with Charcot Marie Tooth (CMT) disease,” says Dave Waters.

The reality is that because CMT is difficult to diagnose, many individuals go through life not knowing they have it and not being able to receive the support and resources they need to live their best life.

“I tried every sport out there when I was younger but was really bad at them all. After my diagnosis, I had surgeries on my ankles to help with stability and pain,” continues Dave. “In my forties, my wife suggested I try sports again. I became heavily involved in Para Canoe, Para Athletics and sledge hockey.”

“With muscular dystrophy, it’s important to recognize that there will always be challenges but you have to find something that helps you push through it all and keeps you motivated,” says Dave. “It’s all about finding something that speaks to you. Once you do, it can make a world of difference!”

Dave has competed on the national team for Para Canoe from 2010 to 2018 and has placed 2nd at the world championship, 3rd at the World Cup and 2nd at the Pan American Championship. Being involved in group sport has been incredibly inspirational for him and he encourages anyone interested to give it a try!

As an active individual and a multi-sport athlete, it is important that Dave has access to the equipment and resources he needs to be able to continue his participation.

“In 2018, Muscular Dystrophy Canada (MDC) helped fund my new ankle braces. They are a huge help in my day-to-day life as well as with enabling me to continue in my athletics,” says Dave.

Because of generous donors, MDC is able to support clients, like Dave, when they need it most. For many individuals living with a neuromuscular disorder, access to equipment funding is a top priority and can drastically improve their quality of life.

“My advice to anyone living with a neuromuscular disorder is to ask lots of questions, find others with similar experiences and ask them about what worked for them,” says Dave. “If one thing doesn’t work for you, try something else! Don’t let the disease control you. You can control it.”

To learn more about Muscular Dystrophy Canada’s Equipment Program and how you can make a difference, please visit muscle.ca.
Your support pushes research even further!

Five research projects will be funded by Muscular Dystrophy Canada (MDC) through the Seed Grant Program this year thanks to the ongoing and generous support of donors!

“Muscular Dystrophy Canada is committed to finding a cure for neuromuscular disorders, and the only way to accomplish that goal is through cutting-edge research,” said Barbara Stead-Coyle, CEO, Muscular Dystrophy Canada. “Because of our generous donors, there is promising research taking place in our country to uncover a cure.”

Muscular Dystrophy Canada is honoured to support Canada’s leading researchers as they continue to uncover more effective treatments, and ultimately a cure, for neuromuscular disorders.

- **Interventional study of expiratory muscle strength training as a treatment for muscle disease.**
  Dr. Gerald Pfeffer, University of Calgary.

- **A better trunk and lower limb control for a better mobility: Assessment of a re-entrainment program in Autosomal recessive spastic ataxia of Charlevoix-Saguenay.**
  Dr. Cynthia Gagnon, Université de Sherbrooke.

- **Quand attendre est synonyme de meilleurs services: Création d’une salle d’attente interactive pour informer les personnes atteintes de maladies neuromusculaires des enjeux de la recherché.**
  Dr. Cynthia Gagnon, Université de Sherbrooke.

- **Denosumab for the Treatment of Osteoporosis in Boys with Duchenne Muscular Dystrophy: A Pilot Study.**
  Dr. Leanne Ward, Children’s Hospital of Eastern Ontario.

- **A Population-based Cohort Study of Pregnancy Outcomes in Women with Myasthenia Gravis.**
  Dr. Ari Breiner, Ottawa Hospital Research Institute/University of Ottawa.

Learn more about Muscular Dystrophy Canada’s commitment to research by visiting [muscle.ca/research](http://muscle.ca/research)

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Welcome Daria Wojtal to the Muscular Dystrophy Canada team!

We are pleased to announce that Daria Wojtal has joined Muscular Dystrophy Canada as the new Director of Research. Daria comes to us from the Hospital for Sick Children and the University of Toronto, where she worked under the leadership of Dr. Ronald Cohn on her PhD in developing CRISPR gene editing technology for the treatment of neuromuscular disorders.

Daria is also a long-time volunteer for Muscular Dystrophy Canada as a Planning Committee Member where she acted as a liaison between MDC and a team of scientists from SickKids.

We are excited about the work that Daria will be focusing on and the level of neuromuscular research background she brings to the organization. **Welcome to the team, Daria!**
Personal Empowerment Program offers Canadians more support and resources

Generous support from donors across Canada has made it possible for Muscular Dystrophy Canada to expand and refine programs and services offered to Canadians.

Over the last year, Muscular Dystrophy Canada has consulted with clients, family members, health professionals and community members to get a sense of where the gaps in support are and realign our programs and services to best meet the needs of all those impacted by neuromuscular disorders.

Our existing Systems Navigation program has been improved and is now referred to as the Personal Empowerment Program (PEP). The PEP focuses on three key areas that have been identified by clients as priorities:

1. Personal Freedom - Muscular Dystrophy Canada’s Equipment Program
2. Community Connections - Family and Caregiver Retreats and MDC Chapters
3. Knowledge Transfer - Accessible Information and Education, Conferences and Symposiums

“We were on a walk the other day, and Doug wanted to pick some blackberries. Of course the good ones were up high. He went for it and said “this is why man is in love with machine”.

He said that driving his power wheelchair off the paved surface towards a thorny blackberry bush was scary but worth the risk! And the berries were delicious. Thank you to Muscular Dystrophy Canada for all of your help with the extra features on the chair. They make moments like this possible,” says MDC client Cam Penner.

Because of dedicated and passionate donors, like you, we are able to focus more time, funds and efforts into ensuring our programs and services increase the independence, mobility and overall quality of life for clients across the country. For more information on how you can impact others, visit muscle.ca/donate.

Upcoming events


- Registration is now open for Walk for Muscular Dystrophy events across the country. Visit walk4md.com to learn more.

Connect with Muscular Dystrophy Canada on social media!
We have a new look!

At Muscular Dystrophy Canada, it is important to us to pay tribute to our history while looking forward to the future. With that in mind, we completed a brand re-boot and we can’t wait to share our new look with you!

We took a lot of time and consideration into each decision, we consulted with stakeholders internally and externally and tried to create an updated brand that represented all of you.

Our new tagline is “Ignited by passion, fueled by hope”. We love the tie this tagline has to our longstanding relationship with fire fighters and how it highlights our continued passion and dedication to finding a cure.

We will be slowly rolling our new branding out and using up existing materials to be as efficient as possible. We hope you love our new look as much as we do! For more information on our new brand, visit us on Facebook at facebook.com/MuscularDystrophyCA.

East coast vs. west coast fire truck pull raises awareness across the country

As a friendly competition, Mission Fire and Rescue in British Columbia and Hampton Fire and Rescue in New Brunswick challenged each other in an East vs. West National Truck Pull. The two departments raised funds and awareness leading up to their events and shared videos of the events on social media.

Each team had to pull a 34,500 lb fire truck 100 feet twice. The official times were Mission Fire and Rescue with a time of 37.20 seconds and Hampton Fire and Rescue with a time of 39.05 seconds. Mission Fire and Rescue won the competition by 1.85 seconds!

Thank you to everyone who participated and raised funds and awareness for Muscular Dystrophy Canada. Both New Brunswick and British Columbia Fire departments are hoping to see others jump on board with nationwide competitions in 2019.

Hampton Fire and Rescue during their truck pull event. Mission Fire and Rescue after their triumphant truck pull event.

We value your preferences! If you wish to receive this newsletter electronically or wish to unsubscribe from receiving this publication, please contact communications@muscle.ca. If you unsubscribed after the last mailing and are still receiving communications from us we may have crossed paths! Sorry for the inconvenience. Your unsubscribe will be processed.