MOVING MOUNTAINS IN SUPPORT OF MUSCULAR DYSTROPHY CANADA

In September 2018 Paolo DiEmanuele stood on the summit of Mount Kilimanjaro. He thought about his cousin Dino Giannetti who had set him on this path, and how happy he would be to know families would get the support they needed because of it.

Dino was a shining light who inspired everyone he met. Diagnosed with Duchenne Muscular Dystrophy at the age of five, he never let his diagnosis slow him down. Incredibly warm and fun-loving, Dino was fiercely committed to raising awareness for people impacted by neuromuscular disorders.

He was a part of the Muscular Dystrophy Canada (MDC) community for many years and brought his passion to our Chapters, Walk for Muscular Dystrophy events, and retreats. Dino never let any barriers slow him down; he went to university, became a sommelier, played ice hockey and travelled as much as possible.

His passing in December 2017, at the age of 29, was devastating for his family and the MDC community. It was the memory of Dino and his spirit that led Paolo to embark on his own adventure in honour of his cousin.

Dino had always wanted to go to Africa but was unable due to accessibility challenges.

“When the chance came up for me to take the same trip, I saw it as an opportunity to honour my cousin and help others impacted,” said DiEmanuele.

He set out to use his climb to raise much-needed funds for Muscular Dystrophy Canada and the thousands of Canadians it supports every year by providing equipment, support programs and education. Thanks to his efforts, the support of Fred and Nadia Giannetti and the MDC community he was able to raise $3,225—funds that will directly help other families impacted by neuromuscular disorders.

Paolo, thank you for your incredible passion and dedication to helping others! And, thank you to everyone who made donations in honour of Dino. You are truly making a difference in the lives of families across Canada by helping provide much-needed support services and programming.

If you would like to support families impacted by neuromuscular disorders, visit our website at muscle.ca to make a secure online donation.

Paolo DiEmanuele sits at the summit of Mt. Kilimanjaro, holding his cousin Dino’s signature bow tie. Paolo set out on this journey to raise funds for families impacted by muscular dystrophy. Canadian families need your support too!
RESEARCH & TECHNOLOGY

HOW YOUR DONATIONS ARE REVOLUTIONIZING TREATMENT AND CARE

One of the most exciting research areas that your donations support is the implementation of technology in treatment and care for people impacted by neuromuscular disorders.

Over the last few years, thanks to your support, we’ve funded several projects that explore the use of new technology towards diagnosis, treatment development, caregiver support and quality of life.

In 2017 you funded Dr. Jodi Warman-Chardon and her collaborators to support their evaluation and implementation of a web-based Muscle MRI database that will help doctors use Muscle MRI to its fullest potential as a diagnostic tool. We know the road to obtaining a diagnosis is a long one, and sometimes even when a diagnosis is made, it may not be accurate. This delay may have serious health consequences as an accurate diagnosis informs medical treatment options, eligibility for clinical trials and access to medication. Muscle MRI could be a game-changing diagnostic tool that will increase the accuracy of diagnosis and decrease the need for painful and often futile muscle biopsies.

A treatment-based technology with incredible promise is Dr. Ellen Roche’s work to develop an artificial diaphragm. Diaphragm failure is common in many types of muscular dystrophy, making it difficult for a patient to breathe. This results in low oxygen and, in the most severe cases, respiratory failure. Your support has brought this research team one step closer to developing an ‘implantable ventilator’ that will help the patient’s diaphragm continue to operate normally.

Research is not just about science in the typical lab setting. It’s about finding ways to improve the full scope of factors that affect people’s quality of life. A prime example of this is Dr. Louise Rose’s online peer support program for family caregivers. Building community and providing online support for caregivers may be less measurable but no less impactful. By supporting this research, you’ve helped build connections across Canada that would have been impossible in the past.

Community engagement and recreation are also powerful tools that support a better quality of life for those impacted by neuromuscular disorders. Dr. Oldford and Dr. Bleau are taking a look at how assistive technology can improve quality of life for individuals with neuromuscular disorders. They are using robotic toys modified with assistive devices to help people overcome the challenges they face in accessing activities independently.

The landscape of research is changing but thanks to the support of donors like you, researchers are able to explore how new technologies and robotics can advance the care and treatment of neuromuscular disorders for all Canadians impacted. Thank you for your continued support!
TREATING DUCHENNE MUSCULAR DYSTROPHY
THE FOCUS OF NEW RESEARCH PARTNERSHIP

Thanks to the support of donors, like you, Muscular Dystrophy Canada (MDC) and The Foundation for Gene & Cell Therapy (Jesse’s Journey) are joining forces to accelerate ground-breaking research focused on new treatments for Duchenne Muscular Dystrophy to the sum of $600,000.

The two research projects you’ve enabled us to fund are:

- Dr. Anthony Gramolini: Non-viral, immune-modulatory nanoparticles for delivery of CRISPR/Cas9 as a treatment intervention for Duchenne Muscular Dystrophy.

- Dr. Michael A. Rudnicki: Exosomal Delivery of Wnt7a for Treating Duchenne Muscular Dystrophy.

“For anyone impacted by a neuromuscular disorder, research offers hope that better treatments will be uncovered, and ultimately, cured. Both of these research projects show very promising initial results and we are thrilled that this investment will help move the research forward”, said Barbara Stead-Coyle, CEO, Muscular Dystrophy Canada. “We are thrilled to be working with Jesse’s Journey to fund this promising research and thankful to our donors who made this partnership possible. We can’t wait to see what positive impacts it has on our clients and families.”

Both projects focus on improving an essential component of gene therapies, the delivery vehicle that carries the genetic pieces of the therapy into cells where we need them to be in order to work. If successful, the results could have broader applicability to other types of neuromuscular conditions.
The Walk for Muscular Dystrophy is back and it’s better than ever. Running from May to September, Canadians from coast to coast are taking to the streets to Walk as One! Come and join us!

The Walk for Muscular Dystrophy is more than a fundraiser. It is a fully accessible community event that is fun for family, friends, colleagues and community members. Walks offer an opportunity to come together, support, honour and create a world of understanding and compassion. Your support and involvement help Muscular Dystrophy Canada reach its mission to support individuals and families impacted by neuromuscular disorders while continuing to invest in research.

Since the Walk began on May 4, Canadians have already taken to the streets to Walk as One in Manitoba, Ontario and Quebec. But we still need your support.

Find a location near you at walk4md.ca and join us today! If you can’t join us this year, please consider donating. Last year, 1,944 people raised $1.25 million to help Canadians impacted by neuromuscular disorders access equipment, lifesaving treatments and support. We need your help to surpass that amount this year!

UPCOMING EVENTS

**June 25**
Hamilton Network Meeting
6:30–8:30pm
Bennetto Community Centre
450 Hughson St North

**September 18**
Toronto Network Meeting
6:30–8:30pm
Holland Bloorview,
Room 2W625
150 Kilgour Rd

**September 12**
Toronto Cabaret
For more info visit:

To stay up to date on all upcoming events, please visit [muscle.ca/events](http://muscle.ca/events).