

Tomesch family encourages others to live their best life and pursue their dreams



Above: Jason Tomesch

“When our son Jason was just two and a half years old he was diagnosed with Duchenne Muscular Dystrophy, a degenerative disease where your muscles continually deteriorate and daily tasks become more difficult as your body weakens,” says Jason’s mother, Sue.

Due to the progressive nature of neuromuscular disorders, families often experience a lot of bad news and have to overcome new challenges regularly. Five years ago, Jason was critically ill with aspiration pneumonia and spent six months in the hospital. He cannot eat, drink or talk loudly as he has a trache and feeding tube. He also relies on oxygen and a ventilator to breathe.

These circumstances do not define him as a person. Jason is now 25 and has a very important message to share with others who face similar challenges: Don’t be afraid to live.

“We so often focus on the negatives, the things we can’t do, the fear. But there is so much more than that. Get out there and live the life you want,” says Jason. “I still do so many of the things that I love and I want to encourage other individuals with neuromuscular disorders to continue to pursue their passions as well!”

“What we love about working with Muscular Dystrophy Canada is that they really want to help you have the best life that you can! And they provide you with the information and resources to do that,” says Jason.

“Connecting with others who have similar experiences or have faced similar challenges has been very helpful and inspiring for me. I hope others who are facing a new diagnosis or are struggling will reach out to these communities for support and friendship,” says Jason.

“Muscular Dystrophy Canada has helped us with many things since my diagnosis but specifically over the last five years. They helped us purchase a much needed track lift and other vital equipment, they helped us advocate for coverage that we weren’t receiving. They have supported us by providing information about grants, funding, and possible treatments which we weren’t aware of,” says Jason. “They have also provided me with opportunities to share my experiences with others. I have been asked to present to numerous groups including Walk participants. I’ve really enjoyed being able to share my story with others and connect with other members of my community.”

Jason and his parents, Sue and Dave, are very involved with the Walk for Muscular Dystrophy. Jason’s team has been one of the top fundraisers each year. They have raised an incredible contribution of more than \$35,000 over the years which helps Muscular Dystrophy Canada continue providing critical support, funding and resources to all those affected by neuromuscular disorders in Canada.

“We know how hard it is to face a neuromuscular disorder diagnosis, which is why we continue to be so involved in events like the Walk for Muscular Dystrophy,” explains Jason. “We don’t want to see others go through the same struggles that we have faced. Any chance we have to bring more awareness to muscular dystrophy, the better.”



Above: Sue, Jason and Dave Tomesch at the Walk for Muscular Dystrophy.

If you’re looking for support or information or are interested in being connected with the neuromuscular community near you, please visit muscle.ca/contact-us to contact your local Muscular Dystrophy Canada staff.

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

Online: muscle.ca/donate
By phone: 1-800-884-6322
Mail in the donation slip

Pilot Project uses song and dance to improve quality of life for those living with neuromuscular disorders

During a Firefighter conference in Edmonton, Danielle Peers and Dr. Janice Richman-Eisenstat happened to be presenting on the same day. Both of their presentations touched on the need to support meaningful opportunities for recreation and physical activity for people living with neuromuscular conditions. This chance encounter was the beginning of a wonderful partnership.

Danielle and Janice decided to join forces, along with Dr. Hernish Acharya and Dr. Kelvin Jones, to start a pilot project, *Moving to Breathe, Breathing to Move*. They received funding for this pilot project through the Muscular Dystrophy Canada Seed Grants.

There are many barriers that restrict individuals living with neuromuscular disorders to participate in physical activity including inaccessible infrastructure, financial barriers, and lack of programming available for Canadians with a wide range of abilities.

“Our goal was to create a program that would welcome individuals with a wide range of neuromuscular conditions, at a wide range of stages which removes barriers they’ve previously encountered. We hope this pilot project will support our community to come and move together in ways that are more meaningful, safe, and beneficial,” says Danielle Peers.

“After my own health complications ended my

Paralympic career, I spent years

looking for physical activities that would be more suitable to my energy output, but would still give me the personal and social fulfillment that sports did”, says Danielle. “That is when I accidentally stumbled on integrated dance”.

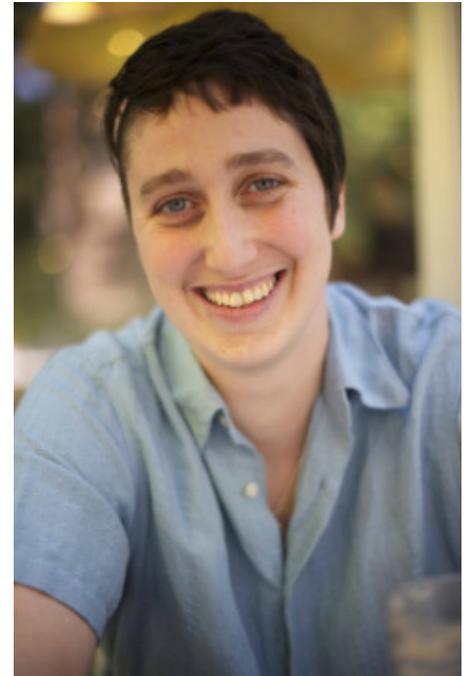
“Through our research we have found that singing and dancing have similar health benefits to other physical activities, with extra quality of life benefits tied to self-expression, creativity, cultural engagement, and listening to music,” continues Danielle.

Danielle and the research team have now completed two of the three months of their pilot choir and dance program in Edmonton. Participants and researchers have learned a lot over the last two months about what makes the most fulfilling, safe, beneficial, and meaningful dance and singing classes.

“We have been playing with choreographed dance elements like space and time, and have been working through singing techniques like how to use less breath by using more vibration of vocal cords,” explains Danielle.

Researchers are learning a lot by having participants wear a vest called a Hexoskin during the program. The Hexoskin measures how the individual is breathing both from the belly and from the chest. They are working to see if tracking breath through the Hexoskin can help them identify or even predict optimum levels of activity and fatigue.

At the end of this pilot project,



Above: Danielle Peers

the research team will create a video. Through artistic expression, they will share experiences and outcomes from the pilot and explore what it meant to each individual. They will also share a new protocol for a singing and dancing program that can be adapted across Canada and beyond to improve access to safe and meaningful programming for individuals living with neuromuscular disorders!

For updates and findings from the *Moving to Breathe, Breathing to Move* project, please visit www.mediainmotion.ca/projects.

To learn more about current research projects or open funding opportunities, please visit muscle.ca/research.

A night to remember at the Montreal Cabaret!

On May 23rd at Le Windsor in Montreal, clients, community members and supporters came together for the Muscular Dystrophy Canada Cabaret presented by The Tenaquip Foundation. More than 200 guests attended and raised more than \$266,000! A wonderful time was had by all and proceeds will support programs and services for Canadians living with neuromuscular disorders.

A special thank you goes out to the sales committee which was chaired by Glenn Watt and George Alexopoulos. This event would not have been such a success without your hard work.

Thank you to all the wonderful sponsors; Tenaquip Foundation, Lisa and Mark Smith, KCMN Foundation and Velan Family, Azrieli Foundation, Belden Canada, Bell, Charles River Labs, BMO, Delmar, Encore Travel, and La Presse who made this event possible!



Left: George Alexopolous and Glenn Watt address the crowd.
Right: Wonderful entertainment provided by Manina World.

Making a difference in Alberta

Muscular Dystrophy Canada received a \$30,000 gift from the **Calgary Flames Foundation** in support of the Equipment Program in Alberta.

For many clients, next to finding a cure, the highest priority is equipment funding. Access to items such as scooters, wheelchairs, stair lifts, and more increase the quality of life for clients by providing access to school, post-secondary education, employment opportunities and community engagement.

We are so grateful for the support from the Calgary Flames Foundation in ensuring our clients in Alberta have access to the vital equipment they need. **Thank you Calgary Flames Foundation! You are making a big difference.**



To stay up to date on the latest news and events, visit muscle.ca or connect with us on social media!



Upcoming events:

September 13 – Toronto Cabaret

September 21-23 – Alberta Family Retreat (contact Fraser at 1-780-489-6322 ext. 5103)

September 28-30 – Quebec Family Retreat (contact Ivy at 1-514-393-3522 ext. 3108)

September is Muscular Dystrophy Awareness Month!

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.

Annual High Rise Challenge raises an incredible \$275,000

The 21st annual High Rise Challenge took place this spring at the Deloitte Tower in Quebec. More than 80 teams answered the challenge of climbing more than 1100 stairs to raise funds and awareness for Muscular Dystrophy Canada. Participants had the opportunity to make the climbs in full firefighter bunker gear connected to a respirator adding a total of 50 pounds of equipment.

An incredible total of \$275,000 was raised in support of programs, services and research through Muscular Dystrophy Canada.

The team with the highest fundraising total was **Montmagny - Éloi - Berthier-sur-mer** for the seventh year in a row! Thank you for your continued dedication and passion.

This event would not be possible without the support of our generous sponsors; Cadillac Fairview, Scott Safety, and Cage aux Sports. Thank you!



Above: Elise Lefebvre receives the ambassador helmet for her hard work, dedication and inspiration. (Photo credit: Étincelle photographe)

Successful neuromuscular disorder research symposium hosted in Quebec City



Above: Symposium participants gather for opening presentations.

The first ever nationwide and bilingual research symposium took place this May. Two hundred participants from across the country gathered in Quebec for the two-day symposium which included more than 40 presentations, 12 of which were simultaneously translated to be bilingual.

Participants and speakers alike had a wonderful time sharing ideas and forming connections. The symposium offers an excellent opportunity to meet with neuromuscular specialists and learn about new research, treatments, improved standards of care and best practices.

The first Caregiver Retreat in Quebec took place following the symposium. The Caregiver Retreat offered 20 participants the opportunity to rest, reflect, learn about new research and clinical trials, talk to healthcare professionals, and connect with individuals who are sharing similar life experiences.

A big thank you goes out to our Symposium and Retreat sponsors: Sanofi Genzym, Biogen, PTC and Keeogo.

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