

MUSCULAR DYSTROPHY CANADA DYSTROPHIE MUSCULAIRE CANADA

COMMUNITY

SUMMER 2024



YOU'RE MOVING RESEARCH FORWARD

Muscular Dystrophy Canada is the only dedicated source of funding for neuromuscular research in Canada. Because of donors, volunteers, Fire Fighters and incredible supporters, like you, we invested \$900,000 into nine clinical and translational research projects through the Neuromuscular Research Grants Competition this year. Thanks to your generosity, we also invested \$63,630 towards an innovative study led by Dr Gonorazky on Charcot-Marie-Tooth disease, bringing our research investment for this year closer to \$1 million.

In recent years, neuromuscular research has undergone significant transformations, leading to changes in clinical standards, improved diagnoses and breakthroughs in treatment discovery. Continued investment in research is key to keeping and accelerating this momentum moving forward.

"We want to thank the clinicians and researchers on our Scientific Review Panel, as well our Lived Experience Readers who volunteered their time and expertise in selecting this year's recipients." - Stacey Lintern, CEO, Muscular Dystrophy Canada.

Scan to see the full announcement:



DID YOU KNOW...

20 volunteers generously give 200 hours to make this grant competition possible each year?

Visit muscle.ca/volunteer to learn more about Muscular Dystrophy Canada's incredible community of volunteers across the country.

CONGRATULATIONS **TO THE 2024-2025 GRANT RECIPIENTS:**



Dr Haim Abenhaim Maternal and neonatal outcomes of cesarean deliveries in women with muscular dystrophy



Dr Krista Best Efficacy of wheelchair skills training to improve mobility for people with ARSACS and DM1



Dr Nathalie Bier Understanding the impact of central nervous system impairments on daily life in myotonic dystrophy



Dr Rageen Rajendram Utilizing AI to predict noninvasive ventilation need in neuromuscular disorders: a proof of concept



Dr Karine Choquet Elucidating DYSF premRNA splicing to inform therapeutic avenues for dysferlinopathies



Dr Lisa Hoffman Angiopoietin-1 enhances microdystrophin replacement therapy for Duchenne muscular dystrophy



Dr Rashmi Kothary Maternal transfer of AAV vectors: a minimally invasive approach to deliver SMN-gene therapy for SMA



Dr Keir Menzies A new in vitro eccentric muscle contraction assay for drug repurposing for muscular dystrophy



Dr Gerald Pfeffer Single nucleus RNAseq biomarkers in adult-onset muscle diseases



UNWAVERING COMMITMENT: FIRE FIGHTERS AND MUSCULAR DYSTROPHY CANADA CELEBRATE 70[™] ANNIVERSARY

Through boot drives and tolls on local roads, community barbeques, rooftop campouts, car washes, stair climbs and raffles - you name it more than 600 fire departments, locals and associations across our country work with Muscular Dystrophy Canada every year so they can give all neuromuscular disorders "the boot" in this lifetime.

Fire Fighters have hosted these Canadians affected by neuromuscular people affected by neuromuscular transform lives. disorders.

"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," said volunteer Fire Fighter with Middlesex County, Launie Fletcher. Launie has been fundraising with Muscular Dystrophy Canada for 40 years!

Fundraising events also provide Fire Fighters with an opportunity to meet

fundraising events for 70 years to support disorders and see how they're helping

City of Edmonton career Fire Fighter, Courtney Polson added, "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."

To learn more about our 70-year partnership with Fire Fighters or to make a gift of appreciation, visit **FilltheBoot.ca**



Muscular Dystrophy Canada's partnership with Fire Fighters started in

1954

Total amount raised by Fire Fighters over

70 years: \$103,607,542

2023: ***2.5 million**

2024 goal: ***3.2 million**

LET'S PARTNER TO ACHIEVE EVEN MORE! TOGETHER, WE HAVE ACCOMPLISHED SO MUCH AND WE KNOW THERE IS MORE TO DO

At Muscular Dystrophy Canada we understand that every community is diverse in its needs and priorities.

Help shape your community's priorities, set goals, and create important action plans that we can achieve together. We're inviting people affected by neuromuscular disorders, family members, caregivers, Fire Fighters, donors, healthcare professionals, researchers, and supporters to tell us what is most meaningful in your local community!

Register and join a town hall meeting near you. If you don't see a location that is close to you... don't worry we are only getting started. More communities will be added after these initial consultations are completed. Have questions? Contact us at community@muscle.ca.



Scan to access the registration form and all key dates:





Scan below to register or learn more about retreats:







BRINGING THE NEUROMUSCULAR COMMUNITY TOGETHER TO CONNECT, **REST AND SHARE EXPERIENCES**

Thanks to generous supporters, like you, Muscular Dystrophy Canada offers two types of retreats. Caregiver Retreats offer anyone taking care of someone affected by a neuromuscular disorder a relaxing weekend away. And Family Retreats bring the entire family together to meet other families from their area and enjoy various activities and entertainment.

"This retreat changed my life and allowed me to make many new connections." I won't miss any future retreats. They are so important and life-changing for those of us who have loved ones that struggle with daily life." - 2023 Muscular Dystrophy Canada Caregiver Retreat attendee.

Upcoming Family Retreats:

Quebec: September 20-22 | Camp Papillon, Saint-Alphonse-Rodriguez

Ontario: September 20-22 | Camp Fire Circle, Rosseau

British Columbia: October 4-6 | Camp Shawnigan, Shawnigan Lake

Alberta: Date and location coming soon!

Upcoming Caregiver Retreat:

Ontario: October 18-20 | Ramada, Bellville



WALK & ROLL SEASON HAS OFFICIALLY STARTED



Sherbrooke, QC

Surrey/Burnaby, BC

Grande Prairie, AB

A huge thank you to everyone who participated in one of the 23 events this Spring. Whether you donated, volunteered, hosted your own event, or attended an event as a participant, THANK YOU for supporting the Walk & Roll for Muscular Dystrophy Canada and for helping to break down barriers for the neuromuscular community. And while we might be halfway through the season, there is still plenty of time to register for the Fall events.

Upcoming Walk and Roll's include:

September 7 — Jonquiere, QC September 8 — Belleville/Kingston, ON September 22 — Calgary, AB & Vancouver Island, BC September 29 — Toronto, ON

At each Walk & Roll you'll enjoy an amazing day filled with fun, community, and support for the neuromuscular community. Join us and help break down barriers for Canadians affected by neuromuscular disorders. Register today at **WalkRollMDC.ca**

Can't participate this year but still want to help break down barriers?

Please consider making a donation. You can make a pledge to an individual or team participating or a general gift to the event. To make a gift or for more information visit: **WalkRollMDC.ca**

UPCOMING EVENTS

muscle.ca/events

High Rise Challenge

Quebec: September 28 – Cité de l'énergie, Shawinigan

Join us as we celebrate 27 years of the High Rise Challenge! Register at highrisechallenge.ca

Family Retreats

Québec: September 20-22 Camp Papillon, Saint-Alphonse-

Rodriguez

Ontario: September 20-22 Camp Fire Circle, Rosseau British Columbia: October 4-6 Camp Shawnigan, Shawnigan Lake

Caregiver Retreat

Ontario: October 18-20 *Ramada, Belleville*

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