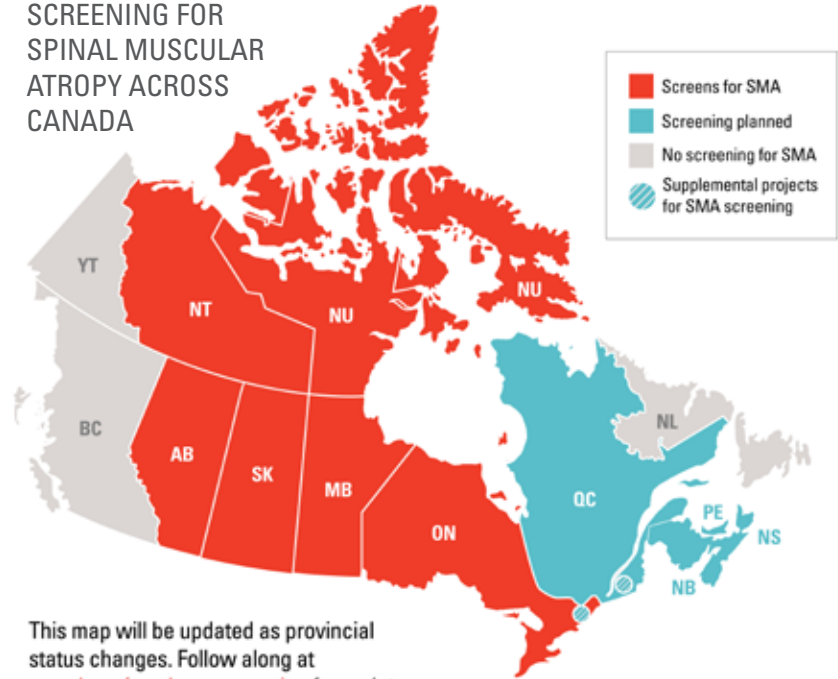


TEN DOWN, THREE TO GO: Manitoba and Quebec latest provinces to embark on newborn screening for SMA

It's been one year since we started working on making newborn screening (NBS) for spinal muscular atrophy (SMA) a reality for all Canadian babies. Thanks to a partnership with Novartis Canada and your unwavering support – there are only two provinces and a territory left to commit to this life-changing test. This spring, Quebec started planning for newborn screening for SMA, and Manitoba announced it moved from the planning phase to officially screening all babies.

NEWBORN SCREENING FOR SPINAL MUSCULAR ATROPHY ACROSS CANADA



This map will be updated as provincial status changes. Follow along at muscle.ca/newborn-screening for updates. [#screenforSMA](https://twitter.com/screenforSMA)



Watch now:
Newborn
screening
progress

Stacey Lintern, CEO, Muscular Dystrophy Canada, is certain with your continued support, families in Newfoundland and Labrador, as well as British Columbia/ Yukon will soon have access to screening and early treatment.

"These governments understand the importance of newborn screening and that treatments are available for newborns diagnosed with SMA. We are working with them to determine how MDC can support them in making this a priority," said Lintern.

Dr. Hugh McMillan, Pediatric Neurologist at McGill University Health Centre, has worked in a province that screens and one that didn't until recently.

"I used to see children who were born with SMA and had developed symptoms.

By offering therapies, I could stop the progress of their disease and offer modest clinical benefit. But I was not able to offer them the same chance to sit, walk or run that they would have had the diagnosis taken place shortly after birth," said Dr. McMillan.



Watch now:
Impact of
newborn
screening

Our focus is on full-implementation of screening and providing information to support long-term sustainability projects across Canada. Thanks to supporters like you, MDC is funding a first-of-its-kind project to evaluate the cost-effectiveness of newborn screening for SMA in Canada, including early treatment. The innovative national project led by a team at the Children's Hospital of Eastern Ontario (CHEO) will provide policy and decision makers with evidence to make NBS for SMA a national standard.

"Generating this data will also foster collaboration and information sharing across the country and can ultimately inform Canada's Rare Disease Strategy," added Lintern.



Watch now:
Beyond
newborn
screening



If you or a loved one was diagnosed with SMA, or another neuromuscular disorder, Muscular Dystrophy Canada has a variety of support programs and services for you. Please contact us at **1-800-567-2873** or email info@muscle.ca and one of our Service Specialists would be happy to help.

RESEARCH FUNDING IS CHANGING NEUROMUSCULAR LANDSCAPE IN CANADA

Because of generous supporters, like you, nine new clinical and translational science research projects received funding this year. These projects are excellent examples of the high quality, exciting research taking place right here in Canada! We wouldn't be able to support research like this without YOU.



Dr. Jodi Warman Chardon

"I am so excited and honoured to receive a Neuromuscular Clinical and Research Grant. Because of this funding, we're going to be able to look very carefully at how Oculopharyngeal Muscular Dystrophy (OPMD) progresses with muscle MRI. We will be looking at the percentage of how the dystrophy changes, which will allow us to get the population of OPMD patients ready for when there are new therapies coming out," says Dr. Jodi Warman Chardon. "We will be able to use this imaging technique for many different NMDs, which will position us better in Canada to have more studies on OPMD and other neuromuscular disorders (NMD). We're really excited about how this is going to change care, enhance our ability to assess patients and how it can be used for other therapies and trials in the future."

2021-2022 RECIPIENTS:

Building a screenable human 3D neuromuscular junction model for neuromuscular disorders

Dr. Thomas Durcan

The Royal Institution for the Advancement of Learning/McGill University

Mitochondrial-targeted therapies to improve Duchenne muscular dystrophy outcomes

Dr. Christopher Perry

York University

Genome-wide DNA methylation profile in Duchenne muscular dystrophy

Dr. Craig Campbell

London Health Sciences Centre (Lawson Health Research Institute)

Measuring balance in chronic inflammatory demyelinating polyneuropathy

Dr. Michael Berger

University of British Columbia

Endurance training as a novel therapeutic strategy for myotonic dystrophy type 1

Dr. Bernard Jasmin

University of Ottawa

QP-OPMD: Quantitative MRI imaging to assess progression in oculopharyngeal muscular dystrophy

Dr. Jodi Warman Chardon

Ottawa Hospital Research Institute

Exploring the impact of spinal bulbar muscular atrophy on persons self-identifying as Indigenous

Dr. Kerri Schellenberg

The University of Saskatchewan

The transition of TEENagers with spinal muscular atrophy to a multi-disciplinary adult program

Dr. Reshma Amin

The Hospital for Sick Children

Motor network connectivity in spinal muscular atrophy: new pathways for intervention

Dr. Maryam Oskoui

The Research Institute of the McGill University Health Centre



	ANNUAL NEUROMUSCULAR RESEARCH GRANTS		NEUROMUSCULAR FELLOWSHIPS	
	Translational Science Research Grant	Clinical Research Grant	Postdoctoral Research Fellowship	Clinical Fellowship
Funding Type	Project	Project	Fellowship	Fellowship
Funding Amount (Total/grant)	\$100,000	\$100,000	\$40,000	\$80,000
Anticipated Number of Awards	8		2	3
Competition Opens	September 1, 2022	September 1, 2022	September 1, 2022	September 1, 2022
Competition Closes	November 14, 2022	November 14, 2022	October 18, 2022	October 18, 2022
			*in partnership with NMD4C	*in partnership with NMD4C and CSCN



GET IN TOUCH!

Visit muscle.ca to learn more about these and other research projects. If you have a specific research question, our dedicated Research Hotline is here to help! Call 1-800-567-2873 ext 1114 or email research@muscle.ca and our research team will provide you with accurate and timely answers.



YOU'RE HELPING MAKE CLASSROOMS A SAFE AND ACCEPTING PLACE FOR ALL



Imagine being the only child in your class who has a neuromuscular disorder. Imagine being the only one who even knows what a neuromuscular disorder (NMD) is.

During a time when being understood, included and involved is critical, classroom environments can be a daunting place for anyone affected by an NMD. Muscular Dystrophy Canada's AccessAbility program, graciously funded by donors like you, and the Canada Post Community Foundation, is working to change that for students.

Muscular Dystrophy Canada's (MDC) Service Specialists work with students to develop an accessibility presentation

focusing on their unique needs and abilities. This empowers the student to share their abilities with classmates and teachers, provide information to educators so they can expand their knowledge on enhancing accessibility and inclusion in schools, and decrease the negative stigma associated with disabilities.

"It truly takes someone who understands not only neuromuscular disorders but also a young student's mind to be able to speak with them in a relatable and understandable way. My main concern going into this presentation, at my son Neema's school, was how he would react and feel. But it was unfounded because the presentation focused on neuromuscular disorders, and how it affects every day life," shared Natalija Manigoda. "I like how the students were completely engaged because the presentation was fun and interactive. I was also pleasantly surprised by how

many students had great questions. It was an incredible teaching moment that clearly showed how these disorders affect student life."

While many children and youth affected by NMDs have a physical disability, they can also experience sensory, development, hearing and learning disabilities. The unfortunate reality is that a large percentage of students who have disabilities feel like they do not fit in with their peers. This program educates teachers and peers, creates a more inclusive environment and celebrates the unique abilities of all students.

Amazing donors like you, and the Canada Post Community Foundation have made this program a reality! To ensure programs like this can continue, expand and help more youth, like Neema, feel accepted in their learning environments, please consider making a donation at muscle.ca/donate.



Neema and his family were relieved to have MDC inform his classmates and teachers about NMDs.

AccessAbility Program

To learn more about the AccessAbility program or to speak to a Service Specialist about facilitating a presentation please visit muscle.ca/services-support/need-help.





Are you up for the challenge?

STEP UP FOR THE NEUROMUSCULAR COMMUNITY

The 25th High Rise Challenge takes place **Saturday, October 8, 2022**. Join us, and hundreds of Fire Fighters, paramedics, police officers and members of the community, as they climb the 36 floors of La Cité de l'énergie in Shawinigan, Quebec – twice – for a total of 1,190 steps.

Raphaëlle Gagnon-Blais (pictured above), a Fire Fighter from St. Cesaire, Quebec, started participating in the challenge four years ago. "When I learned about the High Rise Challenge, I immediately thought the cause was honourable. So, I signed up with my dog, who charmed people to raise donations. We work as a duo," she said.



Through this exciting event, participants raise funds to advance life-changing research, provide support programs and services, and advocate for positive policy changes on behalf of the neuromuscular community.

Help us make the 25th year a huge success by registering or donating now at highrisechallenge.ca.



The Boots are Back

Help Fire Fighters
#FillTheBoot

THE BOOTS ARE BACK AND WE NEED YOUR HELP!

No one has missed seeing Fire Fighters out in the community supporting individuals affected by neuromuscular disorders more than Fire Fighters themselves.

"We are so happy to be in a position where we can bring the boots back out into the community to raise funds and awareness."
– Dan Hamel, Chair of the National Fire Fighter Relations Committee

Fire Fighters have been enduring partners and supporters of Canadians affected by neuromuscular disorders and Muscular Dystrophy Canada (MDC) for more than 67 years. They give their time and help Fill the Boot by organizing various events like boot drives, rooftop campouts, stair climbs, ladder sits, car washes, raffles, sporting events and truck pulls.

As provinces progressively reopen, Fire Fighters are back in their communities, holding boots to raise funds in support of Canadians affected by neuromuscular disorders. You can help keep the tradition going by supporting Fill the Boot events across Canada! For more information, visit filltheboot.ca.

UPCOMING EVENTS | muscle.ca/events

- June 11, 2022 • Walk4MD season opens
- September 1, 2022 • Research grant competitions opens
- September 10, 2022 • Walk4CMT
- October 8, 2022 • High Rise Challenge

