

## STUDY FINDS COSTS OF LIVING WITH A NEUROMUSCULAR DISORDER ARE SIGNIFICANT

*“A neuromuscular disorder (NMD) can affect everything - 100 percent of our lives. How we plan our day, working full-time, caregiver commitments and responsibilities, stress, and concern for overall mental and physical health. It impacts our finances, emotions... everything. We are fortunate he is a smart, strong-willed, resilient, independent young man, but the NMD still gets in the way, in some form, every day.”*

**- Parent of a child affected by spinal muscular atrophy**

In 2020, Muscular Dystrophy Canada (MDC) launched a study to look at the costs related to living with a NMD for not only the person impacted, but family members and society as a whole.

### WHY DID WE COMPLETE THIS STUDY?

As new treatments and therapies emerge with potential for impacts on individuals affected by NMDs, it is important the current economic impact of these NMDs is known and shared. The results of this study will help drug regulators and Health Technology Assessment agencies, insurance providers, and society have a better understanding of the costs associated with NMDs. These findings will help inform future analyses for therapies, screening programs, and planning of health services and community supports.

### HOW WAS THE STUDY CONDUCTED?

In collaboration with neuromuscular clinicians and academics from our Medical and Scientific Advisory Committee, we launched three surveys designed for children, adults, and family members/caregivers. Thanks to the participation of community members across the country, we received over 1,500 responses making this the largest comprehensive study of this kind to be produced in Canada with a focus on NMDs. While Canadians with different NMDs responded, we focused our study on six common NMDs: Duchenne muscular dystrophy (DMD), spinal muscular atrophy (SMA), myotonic dystrophy (DM), facioscapulohumeral muscular dystrophy (FSHD), Charcot-Marie-Tooth disease (CMT), and myasthenia gravis (MG). Together with Eversana, a provider of commercial services to the life science industry, we took your responses and applied a detailed approach to determine the direct and indirect costs of living with NMDs.

Initial results point to one very clear message: NMDs cause a large economic load for the person affected, their family, and society as a whole. Specifically, the need for equipment and assistive technologies; home and vehicle modifications; time away from the workforce for the person affected and family member; and in-patient stays due to falls, injury, or other health complications can be costly.

This reinforced delivery of programs and services, specifically as it relates to the Equipment Program – enables MDC to provide funding support for bathroom aids, wheelchairs, lifts, home and vehicle modifications and other critical equipment. It also helps inform our advocacy efforts to ensure there is a Rare Disease Strategy, so that innovative and life-changing therapies are approved and available in a fair and timely manner across the country.

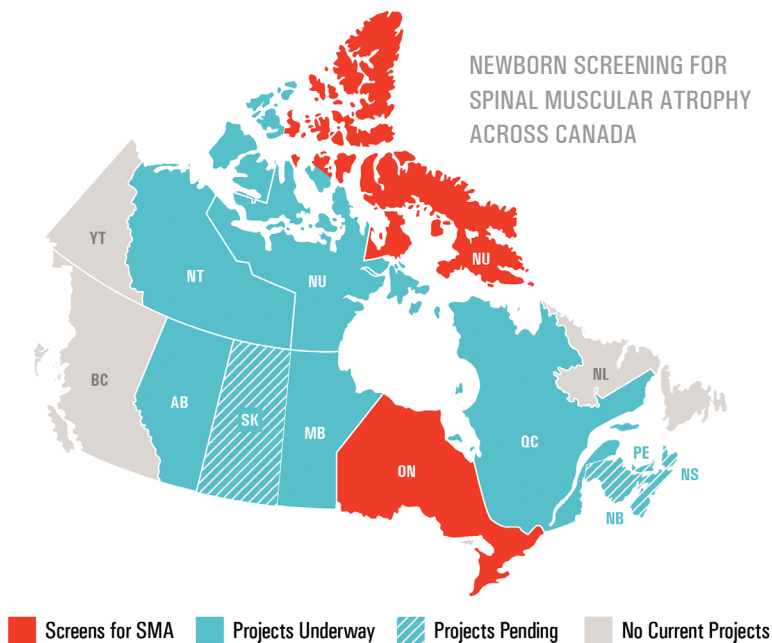
### THIS STUDY WAS PROUDLY SUPPORTED BY:



If you need help, whether it is with equipment funding, navigating and securing community and healthcare resources, emotional support for you or your family, or forming connections with others in the NMD community, please contact your MDC Service Specialist – [muscle.ca/services-support/need-help](https://muscle.ca/services-support/need-help)

To learn more about the study, please email [research@muscle.ca](mailto:research@muscle.ca)

## SMA SCREENING: A NATIONAL COLLABORATION



Thanks to your support, MDC is a step closer to making newborn screening for spinal muscular atrophy (SMA) a reality across Canada.

This summer we announced funding for newborn screening projects focused on SMA for Alberta, Manitoba and Quebec. These are the first provinces to be awarded funds as part of our collaboration with Novartis Pharmaceuticals Canada Inc. (Novartis), which will see up to \$2 million invested to help make newborn screening for SMA a national reality. Ontario is currently the only province screening for SMA.

*"In a neuromuscular disorder like SMA, where time is of the essence, early diagnosis and prompt access to treatments are critical to achieving the best possible outcomes. Unfortunately, this is not the reality for most Canadian children born with SMA,"* said Stacey Lintern, CEO, Muscular Dystrophy Canada. *"With the unparalleled commitment of government leaders, Novartis, the SMA community and MDC's dedicated Board of Directors, Fire Fighters, clients, donors and supporters, we are one step closer to ensuring all Canadian newborns are screened for SMA."*

*"As the mother of an infant with SMA who was not screened at birth, I know first-hand the devastating implications of delayed diagnosis,"* said Laura Van Doormaal, Newborn Screening Advisory Committee member. *"This announcement means that one day soon, no matter where they live, all families will have the opportunity to make critical healthcare decisions and realize their child's full developmental potential from the very beginning."*

MDC is currently working with British Columbia, Saskatchewan and the Maritimes to accelerate newborn screening in those provinces.

For more information visit: [muscle.ca/newborn-screening](https://muscle.ca/newborn-screening)

## HONOURING COMPASSION, DEDICATION AND ACTION

Muscular Dystrophy Canada (MDC) recognizes the contributions of individuals and groups who champion our mission with courage, determination, and passion with the Dr. David Green Awards.

These supporters show extraordinary commitment to raising funds, increasing awareness, engaging other community members and building positive connections.

The National Dr. David Green Awards for 2020-2021:

### EXCELLENCE IN SERVICE DELIVERY AWARD

Neuromuscular Shared Decision-Making Team -  
Bonnie Wooten

Neuromuscular Shared Decision-Making Team -  
Dr. Craig Campbell

### DR. GEORGE KARPATI AWARD FOR RESEARCHER OF THE YEAR

Dr. Hanns Lochmüller

### FIRE DEPARTMENT OF THE YEAR AWARD

Williams Lake Fire Department

### FIRE FIGHTER OF THE YEAR AWARD

Steven Achterberg

### DISTINCTION IN CHAPTER LEADERSHIP AWARD

Calgary Chapter

### LEADERSHIP IN ADVOCACY AWARD

ARCH Disability Law Center

### OUTSTANDING HEALTHCARE PARTNER AWARD

Dr. Colleen M. O'Connell

### CARING CORPORATE PARTNER AWARD

CIBC

### DR. DAVID GREEN IMPACT AWARD

The Martin Family

### FRED SHADDICK COMMUNITY SPIRIT AWARD

The Gottlieb Family

### DR. KATIE MANDERS COURAGE TO INSPIRE AWARD

Owen McGonigal

### MARY ANN WICKHAM AWARD FOR VOLUNTEER OF THE YEAR

William Truman

### OUTSTANDING PHILANTHROPIST AWARD

Laura and Scott Van Doormaal



## INVESTING IN THE NEXT GENERATION OF RESEARCHERS AND CLINICIANS

Imagine this – you or your loved one has been diagnosed with a neuromuscular disorder (NMD) that is so rare that you may be the only person in your geographical area with the condition and your local health care provider is not familiar with it. This is the reality for many Canadians and it affects their ability to receive an accurate and timely diagnosis, tailored health care and more.

That is just one of the reasons Muscular Dystrophy Canada (MDC), in partnership with the Neuromuscular Disease Network for Canada (NMD4C), are excited to share that for the first time we are adding research and clinical fellowships to our existing initiatives aimed at investing in the next generation of NMD researchers and clinicians.

MDC and the NMD4C are committed to supporting both researchers and clinicians to build successful careers in the NMD field and will be awarding \$240,000 of funding in Postdoctoral Research and Clinical Fellowships this fall!

Both MDC and NMD4C, which is also co-funded by MDC and the Canadian Institutes for Health Research (CIHR), play a direct role in nurturing the next generation of clinical and research professionals through mentoring, skills development and networking. In addition, we also offer continuing education and awareness opportunities for professionals through all stages of their careers for all specializations.

In addition, MDC's Annual Research Grant Competition also launched earlier this fall. We look forward to the continued momentum of this program in supporting innovative NMD clinical and translational research.

Recipients of Fellowships will be announced in the new year and the annual research grant awardees will be announced in May 2022.

Learn more about research opportunities and investments by visiting [muscle.ca/services-support/research](https://muscle.ca/services-support/research)

## YOU CHANGE LIVES

Muscular Dystrophy Canada (MDC) is incredibly grateful for the many foundations that support our mission to enhance the lives of Canadians affected by neuromuscular disorders. Your generous support ensures MDC is able to fund programs and services, life-changing research, and advocacy initiatives for positive policy changes to best support the neuromuscular community. Thank you!



- Birks Family Foundation
- Bourassa Savaria Foundation
- Calgary Flames Foundation
- Chamandy Foundation Fund at the Foundation of Greater Montreal
- City of North Vancouver
- Colleen Kiers Memorial Fund at Niagara Community Foundation
- Edmonton Civic Employees Charitable Assistance Fund
- Eric T. Webster Foundation
- Fondation Denise et Robert Gibeau
- Gary Bluestein Charitable Foundation
- Harry & Martha Cohen Foundation
- MacMurray Foundation Inc.
- Morris and Rosalind Goodman Family Foundation
- Our Lady of the Prairies Foundation
- R. Howard Webster Foundation
- SaskTel TelCare Saskatoon District Assembly
- SaskTel TelCare Regina and District
- The Alice and Murray Maitland Foundation
- The Azrieli Foundation
- The Hamber Foundation
- The Hamilton Golf & Country Club Foundation
- The Harold E. Ballard Foundation
- The Henry and Berenice Kaufmann Foundation
- The Hensen Foundation
- The Holt Foundation
- The Hylcan Foundation
- The Slight Family Foundation
- The Thomas Sill Foundation Inc.
- The Windsor Foundation
- TELUS Friendly Future Foundation
- United Way Estevan
- Victoria Foundation
- Winnipeg Goldeyes Field of Dreams Foundation
- Youth Endowment Saskatoon at Saskatoon Community Foundation

If you wish to make a gift, you can do so directly by visiting us online at [muscle.ca/donate](https://muscle.ca/donate) or calling us at 1-800-567-2873.



## WALK AND ROLL: 2021 TENAQUIP FOUNDATION WALK4MD A SUCCESS



The 2021 Tenaquip Foundation Walk4MD took place virtually on June 19. More than 40 members of the neuromuscular disorder community shared their stories about how your support positively impacted their lives. To date, the 2021 Tenaquip Foundation Walk4MD has raised more than \$940,000 with 712 participants, 186 teams, and 7,916 donations!

Musicians Mark and Sergey Krutik, singer/songwriter Liliana Wilde and Midnight Village, and Fire Fighter band Dirt Road shared their talents with performances. We put the spotlight on research with the 2021 Walk4MD research champions. Dr. Reshma Amin, MD; Dr. Bernard Brais, MD, PhD; Dr. Nicolas Chrestian, MD; Dr. Robin Parks PhD; Dr. Gerald Pfeffer, MD, PhD; and Dr. Martine Tétréault, PhD, were selected because of their scientific contributions to the neuromuscular community and the MDC family.

Congratulations to the Top 3 fundraising teams: Team Trekin' For Deccan, Team JRun, and Team Moving Muscles, who will have the opportunity to participate in a meet and greet with a researcher this fall.

Each year we take time to reflect on what this event means to everyone involved – teams, participants, donors, sponsors, volunteers, and staff – and are humbled by what the neuromuscular community is able to accomplish together. This year was no exception. Thank you!

## FIRE FIGHTERS STEP UP AGAIN FOR THE HIGH RISE CHALLENGE



The on-site event for the 2021 High Rise Challenge took place on October 9 and 10 at La Cité de l'énergie in Shawinigan. Participants had a unique opportunity to reserve a 1-hour block with their team to climb the 595 steps of the tower. Participants who could not attend the on-site event did "their challenge, their way". They selected from the 19 suggested provincial or territorial challenges and completed them – or an equivalent - in their neighbourhood.

For 24 years, Fire Fighters, Paramedics, Police, Military, MDC families and members of the community have been participating in the High Rise Challenge. We are so grateful for their continued engagement and partnership with MDC! Their support helps provide better access to programs, services and research needed to increase overall quality of life.

The virtual celebration for the 24th edition took place on Saturday, October 30, 2021.

To learn more, watch the show or donate, visit [highrisechallenge.ca](http://highrisechallenge.ca)

## CONFERENCES

**"If I Knew Then What I Know Now": A Focus on Transition to Adulthood** – November 20, 2021 – email [research@muscle.ca](mailto:research@muscle.ca) to register

**Defeat Duchenne Canadian Conference** – December 3-4, 2021 – register at [dmdcanadianconference.com](http://dmdcanadianconference.com) (for health professionals only)

## TD ATLANTIC YOUTH NETWORKS

Learn more or register at [muscle.ca/services-support/td-mdc-lets-connect-atlantic-youth-networks](http://muscle.ca/services-support/td-mdc-lets-connect-atlantic-youth-networks)

**Luca 'Lazylegz' Patuelli** – November 13, 2021 at 3pm ATL

**The World of Gaming, where will you go? with Ghaasan Akl** – December 11, 2021 at 2pm ATL

**The Paralympic Journey with Ben Brown** – January 15, 2022 at 2pm ATL

To stay updated on our upcoming events, visit [muscle.ca/events](http://muscle.ca/events)

