Montréal, Canada

2026 MDF & MDC Regional Conference

May 30th

A One-Day Event to Unite Community, Care, and a Cure for Myotonic Dystrophy

Myotonic Dystrophy FOUNDATION

IDMC15 Meeting 2026

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Table of Contents

Myotonic Dystrophy FOUNDATION

MDMC MUSCULAR DYSTROPHY CANADA DYSTROPHIE MUSCULAIRE CANADA

2026 MDF & MDC Regional Conference

May 30th in Montréal, Canada

MDF's Vision

We envision a world with treatments and a cure for myotonic dystrophy.

MDF's Mission

MDF's mission is Community, Care, and a Cure.

We support and connect the DM community.

We provide resources and advocate for care.

We accelerate research toward treatments and a cure.

MDC's Mission

Muscular Dystrophy Canada's mission is to enhance the lives of those affected by neuromuscular disorders by continually working to provide ongoing support and resources while relentlessly searching for cures through well-funded research.

Welcome to the 2026 MDF and MDC Regional Conference in Montréal, Canada!

On behalf of the Myotonic Dystrophy Foundation (MDF) and Muscular Dystrophy Canada (MDC), welcome to the 2026 MDF & MDC Regional Conference in Montréal, Canada. We are honored to gather with more than 100 community members from across 22 states, provinces and territories. Your presence strengthens our shared community and underscores the importance of collaboration across borders.

For nearly two decades, MDF Conferences have created opportunities for individuals and families affected by myotonic dystrophy (DM) to come together, learn from experts, share experiences, and build lasting connections. We are especially proud to partner with MDC this year to bring the Canadian and U.S. communities together in Montréal. This is a uniquely meaningful location: Québec not only plays a vital role in global DM research, clinical care, and patient engagement, but also experiences one of the highest prevalences of myotonic dystrophy in the world.

We are deeply grateful to the many volunteers, advocates, clinicians, researchers, industry partners, and supporters whose dedication and expertise made this conference possible. Regional Conferences are designed to bring our community closer together by creating space to connect, ask questions, and learn about progress toward improved care, treatments, and ultimately a cure. Today's program reflects community input and is tailored to meet the diverse needs of individuals and families affected by DM. We encourage you to visit the registry and community engagement tables today to learn more about opportunities to participate and stay informed.

This conference also highlights the strength of collaboration across the myotonic dystrophy community. Together, MDF, MDC, clinicians, researchers, industry partners, and advocates are working more strategically to advance research, strengthen care, and ensure that the voices of people living with DM are heard. There is real reason for hope as we move closer than ever to the first approved treatments, and community participation—through registries, research, and engagement opportunities—remains critical to shaping the future of care.

We encourage you to stay connected beyond today through the many programs, resources, and opportunities offered by both organizations. MDF invites you to explore our educational resources and events, including Myotonic Dystrophy In Motion Month this July, celebrating movement, wellness, and community engagement (learn more at www.myotonic.org/in-motion). MDC offers programs and services across Canada, including advocacy initiatives, research updates, clinical trial matching, equipment support, webinars, and community events (learn more at www.muscle.ca).

Thank you for being here, for supporting one another, and for being part of the progress ahead. If there is anything we can do to enhance your experience today, please do not hesitate to reach out. Enjoy the conference—we are glad you are here.

Tanya Stevenson, EdD, MPH
Chief Executive Officer
Myotonic Dystrophy Foundation

Stacey Lintern
Chief Executive Officer
Muscular Dystrophy Canada

Agenda for Saturday, May 30th

Time	Drummond	Salon 6-7	Salon 4-5	Salon 1	Salon 2	JOA Lounge (Musset)
8:30 - 10:00 AM	Check In Opens					
9:00 - 10:00 AM	Breakfast					
10:00 - 10:45 AM	Welcome & Introduction				Quiet Space	
10: 45 - 11:00 AM	Break					
11:00 - 11:45 AM	IDMC Overview Clinical Trials & Emerging Treatments	IDMC Broadcast **[French/Français]**			Quiet Space	JOA Welcome and Get to Know You Session
11:45 AM - 12:00 PM	Break					Let's Get Moving: Exercise & DM
12:00 - 12:45 PM	DM1 & DM2: What You Need to Know	Community Panel: Life Hacks **[French/Français]**	Community Panel: Life Hacks	Living Better with DM: Tools & Services of Occupational Therapy	Quiet Space	JOA Focus Group & Activities
12:45 - 1:45 PM	Lunch					
1:45 - 2:45 PM	Industry Updates	JOA Parents Focus Group			Quiet Space	Community Panel: JOA
2:45 - 3:00 PM	Movement Moment					
3:00 - 3:15 PM	Break					
3:15 - 4:00 PM	Exercise & DM: Moving Safely Toward Strength & Function	Living Well with DM: Addressing Energy, Motivation, & Mental Health	Managing Dietary Needs & Swallowing with DM	Navigating the Canadian Health System	Quiet Space	Stump the Doctor: JOA
4:00 - 4:15 PM	Break					
4:15 - 5:00 PM	Stump the Doctor: DM1 & DM2				Quiet Space	Karaoke and Games
5:00 - 7:00 PM	Reception, Dance Party, & Networking					

General Sessions

General sessions are for everyone! All general sessions are located in Drummond.

10:00 - 10:45 AM
Welcome and Introduction to DM Resources

The Myotonic Dystrophy Foundation & Muscular Dystrophy Canada

This session will provide an overview of the conference and a summary of the work of MDF & MDC, including the readily available tools and resources for the community.

11:00 - 11:45 AM
IDMC Overview: Clinical Trials & Emerging Treatments


Andy Rohrwasser, PhD, MBA, Chief Scientific Officer, MDF
Darren Monckton, PhD, Professor, University of Glasgow
MDF Medical and Scientific Advisory Committee

This session will start with a brief summary of key takeaways from the 15th International Myotonic Dystrophy Consortium Meeting. Next this talk will provide an overview of clinical trials and help attendees think about how to prepare for upcoming trials and studies.

1:45 - 2:45 PM
Industry Updates

Representatives from biotechnology and pharmaceutical companies will provide updates on their drug development efforts in the DM field.

2:45 - 3:00 PM
Movement Moment

Isabelle Demers, PT, PhD, Pediatric Physiotherapist & Postdoctoral Fellow
Université de Sherbrooke, GRIMN

Join for a short, interactive movement demonstration for all conference attendees to gently get moving, stretch, and break up a full day of sessions.

4:15 - 5:00 PM
Stump the Doctor: DM1 & DM2

Mayra Aldecoa, MD, Adult Neurogentic Clinical Fellowship
Montreal Neurological Institute-Hospital

Stump the Doctor is an opportunity for community members to meet a leading expert in myotonic dystrophy and ask their most persistent challenging questions. Can you stump the doctor?

Note, this session will not be recorded.

Breakout Sessions

Breakout Sessions at these Regional Conferences serve a variety of community interests and needs. They have been designed with community input and have a universal focus for all people affected by DM1 or DM2 and their families.

12:00 - 12:45 PM *(Drummond)*

DM1 & DM2: What You Need to Know

Cam-Tu Nguyen, MD, Pediatric Neurologist, CHU Sainte-Justine

This session is for those new to the DM1 & DM2 communities and those seeking a refresher. Join for an overview of DM1 & DM2 including genetics, symptoms, self-management, and working with your clinical care team to ensure the best quality of life.

12:00 - 12:45 PM *(Salon 4-5)*

Community Panel: Life Hacks

Jeannine DeSoi, David Kugler, and Robin Miles

Join MDF volunteer community leaders in a discussion on everyday victories through useful tips, tricks, and adaptive devices.

Please note, this session will not be recorded.

12:00 - 12:45 PM *(Salon 1)*

Living Better with DM: Tools and Services of Occupational Therapy

Catherine Desautels, B.Sc, M.Sc Applied in Occupational Therapy
Christine Morais, MSc, Occupational Therapist
Neuromuscular disorders program, Centre de réadaptation Marie Enfant du CHU Sainte-Justine

This session highlights how occupational therapy (OT) can improve the daily lives of those living with DM1 or DM2. Experts will discuss common mobility and self-care challenges and offer practical solutions through adaptive equipment and environmental modifications.

1:45 - 2:45 PM *(Salon 6-7)*

JOA Parents Focus Group

Isabelle Demers, PT, PhD; Isabelle Gaudet, D.Psy, PhD

This focus group for parents of children, adolescents and young adults living with pediatric myotonic dystrophy type 1 (DM1) invites participants to share their perspectives, experiences, & concerns related to daily life, health, & well-being. Insights from this group will help researchers better understand what really matters to young people living with DM1 and will contribute to a longitudinal research study and future clinical trials. These sessions are part of an ethics-approved research project (Approval no. 2026-774).

Breakout Sessions

Breakout Sessions at these Regional Conferences serve a variety of community interests and needs. They have been designed with community input and have a universal focus for all people affected by DM1 or DM2 and their families.

3:15 - 4:00 PM *(Drummond)*

Exercise & DM: Moving Safely Toward Strength & Function

Isabelle Demers, PT, PhD, Pediatric Physiotherapist & Postdoctoral Fellow
Université de Sherbrooke, GRIMN, CIUSSS de la Capitale Nationale

Join this session to learn how moderate exercise can be safe and helpful for people with myotonic dystrophy. Learn about the latest studies on DM and exercise, how to choose exercises with your healthcare team, and some examples of DM-friendly exercises.

3:15 - 4:00 PM *(Salon 6-7)*

Living Well with DM: Addressing Energy, Motivation, & Mental Health

Isabelle Gaudet, D.Psy, PhD, Neurologist & Professor
Université du Québec à Chicouti, GRIMN

This session explores the challenges of apathy, fatigue and sleep-related issues, and mental health in individuals living with DM. Participants will learn how these symptoms may present in DM, how they impact daily life and relationships, and practical strategies to improve quality of life.

3:15 - 4:00 PM *(Salon 4-5)*

Managing Dietary Needs & Swallowing with DM

Catherine Desautels, B.Sc, M.Sc Applied in Occupational Therapy
Christine Morais, MSc, OT

In this session, experts discuss how DM1 & DM2 impacts nutrition and swallowing. Attendees will learn about the latest research on these issues and gain practical advice on managing symptoms.

3:15 - 4:00 PM *(Salon 1)*

Navigating the Canadian Health System

Homira Osman, PhD, Vice President, Research, Public Policy & Programs
Muscular Dystrophy Canada

This session provides a practical overview of navigating the Canadian health care system for individuals and families affected by myotonic dystrophy. Participants will explore approaches to accessing specialty care, coordinating services and supports, understanding available coverage and funding programs, and navigating provincial health systems and resources across Canada.

Séances en français

Les séances ci-dessous seront données en français. Toutes les autres séances seront données en anglais, avec sous-titres en direct en français.

11:00 - 11:45 AM *(Salon 6-7)*

Diffusion de la conférence de IDMC

Rejoignez cette session pour regarder une diffusion en direct de la Journée des familles en français, organisée par la Clinique des maladies neuromusculaires, le Groupe de recherche interdisciplinaire sur les maladies neuromusculaires (GRIMN) et Dystrophie Musculaire Canada (DMC) dans le cadre du congrès IDMC-15

12:00 - 12:45 PM *(Salon 6-7)*

Panel communautaire : Astuces du quotidien

Julie LeBoeuf, Marie-Claude Sauvé

Rejoignez les responsables bénévoles de la communauté MDF pour une discussion sur les petites victoires du quotidien grâce à des conseils, des astuces et des aides pratiques.

Veuillez noter que cette session ne sera pas enregistrée.

1:45 - 2:45 PM *(Salon 6-7)*

Groupe de discussion des parents <<JOA>>

Isabelle Demers, PT, PhD; Isabelle Gaudet, D.Psy, PhD

Ces session prendront la forme de groupes de discussion destinés spécifiquement aux parents de jeunes vivant avec une forme pédiatrique de DM1. Les parents seront invités à partager leurs points de vue, leurs expériences et leurs préoccupations liées à la vie quotidienne, à la santé et au bien-être. Les échanges permettront aux chercheurs de mieux saisir les priorités des jeunes vivant avec la DM1 et contribueront à une étude de recherche longitudinale ainsi qu'au développement de futurs essais cliniques. Cette session s'inscrit dans le cadre d'un projet de recherche approuvé par un comité d'éthique (no d'approbation : 2026-774).

Ressources MDF en français

Ressources pour les professionnels de santé

- Recommandations de soins basées sur le consensus pour les adultes atteints de Dystrophie Myotonique de Type 1
- Prise en charge anesthésique des patients atteints de dystrophie myotonique – risques et recommandations

Ressources pour les personnes touchées par la DM

- Guide Pratique
- Alerte Médicale et Antécédents Médicaux
- La dystrophie myotonique et le coeur: Guide Communautaire
- Conseils pratiques pour l'anesthésie destinés aux personnes atteintes de dystrophie myotonique et à leurs familles

Juvenile-onset Adult (JOA) Sessions

Juvenile-onset DM is often defined as someone living with DM1 whose symptoms manifested in childhood or early adulthood, usually before age 21. All JOA sessions are located in the Musset Room.

Please note that these sessions are not recorded and are only intended for JOA individuals.

11:00 - 11:30 AM

Getting to Know You & Ice-Breaker Games

Josée Goulard

Get to know each other with some fun team building games. Work together to list the group rules for the JOA Lounge, which will be open to throughout the day so plan to stop by & chill out whenever you need to relax!

11:30 - 12:00 PM

Let's Get Moving: Exercise & DM

Isabelle Demers, PT, PhD

This session is a great opportunity to learn about exercise & DM and move. This movement session is for all levels and experiences.

12:00 - 12:45 PM

JOA Focus Group/Activities

Isabelle Demers, PT, PhD; Isabelle Gaudet

During this optional focus group, participants will share their experiences and priorities to help researchers better understand what matters most to young people living with DM1 and inform future research and clinical trials; other activities will be available for those who do not wish to participate.

1:45 - 2:45 PM

Community Panel: Navigating Life as a JOA

Luke Desforges, Alex LeBeouf

This JOA community panel brings together young adults living with DM to share real-life experiences, challenges, and strategies for navigating work, school, mental health, and physical health in daily life.

3:00 - 4:00 PM

Stump the Doctor: JOA

Mayra Aldecoa, MD

Adult Neurogentic Clinical Fellowship, Montreal Neurological Institute-Hospital

An opportunity for JOAs to meet a leading DM expert and ask their most persistent and challenging questions. Can you stump the doctor?

4:15 - 5:00 PM

JOA Games & Karaoke

Josée Goulard

Join the final JOA session of the day for fun activities and karaoke! Learn new games or share your favorites with the group. Don't miss this chance to strengthen your connection with the JOA Community!

Myotonic Dystrophy at a Glance

Myotonic dystrophy is the most common form of adult muscular dystrophy and considered the most variable of all known conditions. Do your part to help start conversations and educate your family, friends, and care providers about the basics of myotonic dystrophy (DM).

Myotonic dystrophy is a rare, multi-systemic, inherited disease that may affect as many as 1 in 2,100 people, or over 3 million individuals across the world.

Myotonic dystrophy is inherited - people living with myotonic dystrophy have a 50% chance of passing on the mutated gene to their children.

Millions of people are living with DM globally, yet millions of people do not know they have the disease and are in need of care.

People living with myotonic dystrophy experience varied and complex symptoms, from skeletal muscle problems, to heart, breathing, digestive, hormonal, speech and swallowing, diabetic, immune, excessive daytime sleepiness, early cataracts and vision challenges, and cognitive difficulties.

Myotonic dystrophy is the most common form of adult muscular dystrophy and considered the most variable of all known conditions.

Myotonic dystrophy is commonly referred to as DM, an abbreviation of the Latin name used by doctors and researchers worldwide: dystrophia myotonica. Other names for DM include myotonic muscular dystrophy (MMD), Steinert's Disease for DM1, and proximal myotonic myopathy (PROMM) for DM2.

Myotonic dystrophy doesn't always look the same. The different body systems affected, the severity of symptoms, and the age of onset of those symptoms vary greatly between individuals, even in the same family.

Myotonic dystrophy symptoms usually become more severe with each generation, yet there is currently no cure and there are no approved treatments.

Delays in diagnosing myotonic dystrophy are common. Despite the availability of simple genetic tests, a lack of familiarity with the disease on the part of healthcare providers can allow misdiagnoses to persist for decades.

Mutations prevent genes from carrying out their functions properly, which can impact multiple body systems. Myotonic dystrophy type 1 is caused by a mutation in the DMPK gene, while myotonic dystrophy type 2 is caused by a mutation in the CNBP gene.

Over 30 biopharmaceutical companies are leading promising research which may result in new treatments for myotonic dystrophy, and, one day, a cure.

Learn more at www.myotonic.org/at-a-glance

MDF Resources for Individuals Affected by DM

These publications are for a general audience to help understand the condition and various aspects of life with DM. You can access them all for free on the MDF website or email us at info@myotonic.org to get a hard copy mailed to you.

*An * indicates this resource is available in more than one language.*

Practical Advice for Anesthesia for Individuals with DM & their Families*

People living with DM may have severe and life-threatening reactions to anesthesia. This resource equips individuals living with DM and their families with crucial information to help navigate the anesthesia process.

Myotonic Dystrophy & the Heart: A Community Guide*

For individuals living with myotonic dystrophy, heart or "cardiac" issues can pose a serious threat to their health. This resource aims to help people living with DM understand heart health risks and how they are managed.

My Clinic Visit Planner*

This planner enables families to discuss upcoming clinic visits and jot down important questions and information to help ensure it is covered at the appointment.

Exercise Guide & Exercise Infographic for Individuals with Myotonic Dystrophy*

This guide includes information on the benefits of exercise for DM, recommendations on aerobic activity, types of exercise, monitoring exercise, exercise strategies & finding motivation.

Nutrition Guide for Individuals with Myotonic Dystrophy*

Developed by nutritionists experienced with DM, this guide covers information on diet and DM, managing constipation, being overweight/underweight with DM, managing swallowing problems, feeding tubes, supplements, and sample meals.

Applying for Social Security Disability Benefits Toolkit

The toolkit is designed to assist those affected by DM in navigating the application process for Social Security Disability Insurance (SSDI) benefits and Supplemental Security Income (SSI) benefits. (US Health System only)

Mental Health Handbook*

This resource highlights the social and emotional impact of DM, offering an overview of potential mental health challenges and available supports.

Medical Alert Card*

Patients with myotonic dystrophy often exhibit adverse reactions to sedatives, anesthetics, and neuromuscular blocking agents. Ensure your emergency responders follow these critical guidelines.

Going to School with DM: A Guide to Understanding Special Education & IDEA

This comprehensive resource helps parents and family members take advantage of the Individuals with Disabilities Act (IDEA).The Guide covers services and mandates for ages newborn through 21.

Health Insurance Considerations for People Living with DM in the US

MDF created this resource to help you navigate the process of making sure your medical treatments and medications are covered, and how to appeal your claim if it is denied.

Guide for Adults Affected by Juvenile-onset (JOA) DM & their Caregivers

This Guide is specifically designed to help families affected by juvenile-onset DM understand how to manage their lives, especially at transition points in development and education.

Employment Access Toolkit*

This Toolkit helps individuals navigate employment, covering how DM may affect work, job readiness, applications, resumes, interviews, and more (U.S. job system only).

Planning for Adulthood: A Guide for Families & Caregivers of Children with CDM

This guide covers key steps in preparing for the transition to adulthood for children living with CDM, including legal, educational, healthcare, and financial planning.

Learn more at www.myotonic.org/resources

MDF Resources for Healthcare Professionals

These publications are for professional audiences – especially doctors and nurses – who treat and care for individuals living with DM. You can access them all for free on the MDF website or email us at info@myotonic.org to get a hard copy mailed to you.

*An * indicates this resource is available in more than one language.*

Care Guidelines for Speech and Language Pathologists Treating Adults and Children with DM

This guide is written and reviewed by an international group of speech and language pathologists who are specialized in working with adults and children with DM.

Clinical Care Recommendations for Cardiologists & Pulmonologists Treating Adults with DM Type 1*

Two separate resources for cardiologists and pulmonologists that provide care recommendations for treating adults with DM1.

Occupational Therapy Suggestions for the Management of a Myotonic Dystrophy Patient

A quick reference excerpt for clinicians from the full MDF Toolkit.

Respiratory Care Recommendations for Myotonic Dystrophy Patients During the COVID-19 Pandemic*

This guide includes tips for patients, caregivers, and medical providers on the use of noninvasive positive pressure ventilation (NIPPV) if you have been exposed to or have symptoms of COVID-19.

Clinical Care Recommendations*

Resources to improve and standardize care developed by more than 65 leading DM clinicians in Western Europe, the UK, Canada, and the US. Resources include recommendations for DM1 in adults and children, and adults with DM2.

Clinical Recommendations for People of Pregnancy Potential with Myotonic Dystrophy*

This resource is designed to provide clinicians with an overview of risks and care recommendations for individuals living with DM who are pregnant or considering pregnancy.

Practical Suggestions for the Anesthetic Management of a Myotonic Dystrophy Patient*

Regardless of the form of DM or the severity of DM symptoms experienced, severe and life-threatening reactions to anesthesia are possible and should be monitored whenever anesthesia is administered.

The Role of Physical Therapy in the Assessment and Management of Individuals with DM

These Physical Therapy Guidelines for myotonic dystrophy address the role that the physical therapist plays in DM care.

Learn more at www.myotonic.org/resources

About Muscular Dystrophy Canada and DM

Muscular Dystrophy Canada is the national charity dedicated to improving the lives of Canadians affected by neuromuscular disorders through research, advocacy, programs, services, education, and community connection. For more than 70 years, Muscular Dystrophy Canada has worked alongside individuals and families, clinicians, researchers, industry, and community partners to accelerate progress toward better care, improved quality of life, and ultimately cures.

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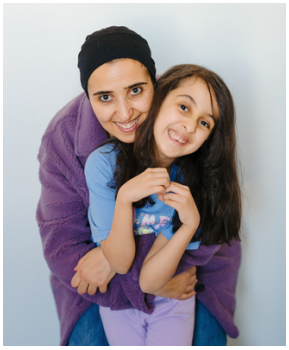
Canada and particularly Québec holds a unique and internationally recognized leadership role within the myotonic dystrophy (DM) community. Due to a well-documented founder effect within French-Canadian populations, Québec has one of the highest prevalences of Myotonic Dystrophy Type 1 (DM1) in the world. Over generations, this contributed not only to a greater understanding of the disease within Canada, but also positioned the country as a global leader in DM research, clinical expertise, registries, and innovation.

Canada has helped shape the international understanding of myotonic dystrophy for decades. In 1992, Canadian researchers in Ottawa played a key role in the landmark discovery of the gene mutation responsible for DM1 — a breakthrough that transformed diagnosis, genetic testing, research, genetic counselling, and therapeutic development worldwide. Since then, Canadian researchers, clinicians, patient organizations, and advocates have continued to drive advancements in natural history studies, standards of care, clinical trial readiness, registries, and patient engagement initiatives. Today, Canada is recognized globally for its collaborative, patient-centered approach to advancing neuromuscular care.

About Muscular Dystrophy Canada and DM

At Muscular Dystrophy Canada, we are proud to work alongside world-leading Canadian researchers, neuromuscular clinics, community advocates, industry partners, and international collaborators who are helping move the field forward. Through partnerships with organizations such as the Myotonic Dystrophy Foundation, the Neuromuscular Disease Network for Canada (NMD4C), and the Global Alliance for Myotonic Dystrophy Awareness, Canada continues to strengthen its role as a leader in neuromuscular research, care, and therapeutic readiness.



While remarkable progress is being made, individuals and families affected by DM continue to face challenges related to diagnosis, access to specialists, treatment availability, and navigating complex healthcare systems. At the same time, we are entering an unprecedented era of momentum in genetics, clinical trials, precision medicine, and emerging therapies. This is a moment of real hope for the DM community and reinforces the importance of ensuring Canadians are not left behind as innovation advances globally.

Muscular Dystrophy Canada's work is guided by strategic priorities focused on accelerating research and innovation, improving access to information and supports, advancing advocacy and public policy, strengthening community engagement, and helping individuals and families navigate the healthcare system with greater confidence and equity.

Across Canada, Muscular Dystrophy Canada provides programs and services designed to support individuals and families at every stage of their journey, including:

- Advocacy and public policy initiatives
- Research funding and knowledge translation
- Clinical trial awareness and matching support
- Equipment funding and assistive device support
- Educational webinars and conferences
- Peer and community connection opportunities
- Information and system navigation supports
- Collaboration with clinicians and neuromuscular clinics across Canada

About Muscular Dystrophy Canada and DM

One of Muscular Dystrophy Canada's key advocacy efforts is the "What About Canada?" initiative, a national campaign focused on addressing delays and inequities in access to neuromuscular therapies and care across Canada. The initiative highlights the need for Canadians living with neuromuscular disorders to have timely and equitable access to diagnosis, clinical trials, specialized care, and innovative therapies.

Building on this work, Muscular Dystrophy Canada has also launched its "Time to Access" initiative, which highlights the lengthy and complex pathway Canadians often face between scientific breakthroughs, regulatory approvals, and actual access to treatments through public drug plans. Through evidence generation, policy engagement, awareness campaigns, and lived experience storytelling, the initiative is helping shine a light on the real-world impact of delays in access to therapies and the urgent need for faster, more equitable access across Canada. This work reinforces Muscular Dystrophy Canada's commitment to ensuring Canadians are not left behind in an era of rapidly advancing neuromuscular innovation.

Muscular Dystrophy Canada is also advancing initiatives to improve diagnosis and clinical trial readiness within the DM community. In 2025, Muscular Dystrophy Canada launched a national initiative focused on improving access to genetic testing for myotonic dystrophy across Canada. Through this program, individuals with suspected DM accessed no-cost genetic testing and post-test genetic counselling to support earlier diagnosis, informed decision-making, improved access to specialized care, and participation in research and clinical trials.

As research accelerates and the therapeutic landscape continues to evolve, Muscular Dystrophy Canada remains committed to ensuring Canadians affected by myotonic dystrophy are informed, supported, connected, and represented. Together with researchers, clinicians, advocates, partners, and families, Muscular Dystrophy Canada continues working toward a future where Canadians affected by DM have equitable access to timely diagnosis, high-quality care, innovative therapies, and ultimately cures.

Learn more about Muscular Dystrophy Canada at www.muscle.ca.

Myotonic Dystrophy Drug Development Pipeline

Below is a partial snapshot of drugs for myotonic dystrophy that are currently in clinical trials. The DM Drug Development Pipeline was developed by MDF and continues to evolve based on publicly available information. Academic institutions are not included. To view the full pipeline, scan the code to the right or visit www.myotonic.org/pipeline.

Company	Program	DM Subtype	Clinical Phase		
			1	2	3
AMO PHARMA	Tideglusib	CDM / DM1			
AVIDITY BIOSCIENCES A Novartis Company	AOC 1001 del-desiran	DM1			
LUPIN NEUROSCIENCES	Mexiletine	DM1 / DM2			
Dyne THERAPEUTICS	Dyne 101 z-basivarsen	DM1			
ARTHEx biotech	ATX-01	DM1			
HARMONY BIOSCIENCES	Pitolisant	DM1			
PepGen	PGN-EDODM1	DM1			
Juvena THERAPEUTICS	JUV-161	DM1			
VERTEX	VX-670	DM1			
sanofi	--	--			
SAREPTA THERAPEUTICS	SRP-1003	DM1			

International Myotonic Dystrophy Awareness Day

MDF is proud to be a founding member of the Global Alliance for Myotonic Dystrophy Awareness, a group of organizations and institutions from around the world working together to raise awareness of myotonic dystrophy. Learn more at: www.myotonic.org/international-dm-day

Make the Most Out of Your Conference Experience

First Time at an MDF or MDC Event?

Staff members will be wearing white lanyards and will be happy to answer any questions you may have about the conference. Look for the MDF Support Group Facilitator exhibitor table as well to learn more about supports and resources and meet community member attendees committed to helping ensure your first Conference experience is a complete success!

Make the Most of Breaks

There are many breaks built into the conference agenda so you can take care of personal needs. Use this time to snap a photo, rest in the Quiet Space in Salon 2, connect with others, or visit exhibitor booths.

Take A Photo!

Don't let your conference memories fade away: share your experience. Post on social media, tag Myotonic Dystrophy Foundation (@MyotonicStrong) and Muscular Dystrophy Canada (@md_canada) and use #MyotonicDystrophy to help raise awareness and stay connected with the community.

Don't forget to stop by the MDF step-and-repeat backdrop near registration for a fun photo background.

Keep in Touch!

Stay connected after the conference with MDF's monthly e-newsletter, the MDF Dispatch, and MDC's e-newsletter. Sign up at www.myotonic.org/sign-up and muscle.ca/subscribe/

Continue Learning with MDF

MDF Digital Academy

Watch hours of educational and inspiring videos from DM experts whenever you like. Browse by category and interest at: www.myotonic.org/digital-academy

Meet the DM Drug Developers Webinar Series

Since 2021, MDF has hosted biotechnology and pharmaceutical partners working on treatments and cures for myotonic dystrophy in special presentations for the community. In these sessions, they share progress and answer questions. View the complete series at: www.myotonic.org/meet-dm-drug-developers

Explore the Updated Find a Doctor Map

Finding medical professionals who understand myotonic dystrophy is one of the most important ways to help manage its symptoms. With input from the community, MDF has compiled a database of healthcare providers with experience caring for people living with DM. Find a medical professional in your area at: www.myotonic.org/find-a-doctor-map

Ask the Expert Series

MDF's virtual Ask the Expert series is available online, featuring DM experts across many body systems. Experts in digestion, brain, heart, speech and swallowing, mental health, lungs, and more share information and answer questions. View the complete archives at: www.myotonic.org/ask-expert-series

Need additional support? Get One-on-One Support at 415.800.7777

July is DM In Motion Awareness Month!

Movement makes connections, and we're excited to bring the DM community together through weekly Movement Monday programming, Movement and Meeting Happy Hours, and more! Special thanks to our Movement Committee for their continued support and development of this initiative!

Now through the end of July - order your limited-edition DM In Motion Awareness Month gear at www.myotonic.org/in-motion

Thank You to MDF's Amazing Volunteer Leaders!

2026 MDF Board of Directors

Thank you to our 2026 Board of Directors which is comprised of volunteer leaders from the public and private sectors, most of whom are either living with myotonic dystrophy or have loved ones living with the disease. The Board works closely with the MDF Staff and Scientific Advisory Committee. To learn more about MDF Board of Directors, visit: www.myotonic.org/board-directors

Jeremy Kelly • Martha Montag Brown • Elizabeth Florence, Esq • David Herbert • Andy Berglund, PhD
Rob Campagna, MD • Belen Esparis, MD • Charles Thornton, MD • David Berman, MBA
John Cooley, Esq • Peter DesForges • Haley Martinelli, Esq • John W. Day, MD, PhD • Tom McPeek

2026 MDF Support Group Facilitators

MDF support programs, led by trained community volunteers, create safe spaces to network, learn, and share. We would like to specially thank our Support Group Facilitators for donating their time and energy to create these unique opportunities. Learn more about our SGFs at: www.myotonic.org/sgfs

Alexandra LeBoeuf • Anke Klein • Ann Woodbury • Annette Rnjak • Araceli Mera • Bernhard Rogg
Beth Feigenblatt • Bill Nuttall • Caroline Easterling • Carolyn Valek • Chuck Hunt • Cindy Hubert
David Kugler • Emily Jones • Erin Beucler • Guillermo Zubillaga • Haley Martinelli • Jeannine DeSoi
Jim Dolan • Jodie Howel • John Cooley • Julian Easterling • Julie LeBoeuf • Kathie Thorsland • Kathy Coletta
Kelsey Freedman • Kim McPeek • Kim Reynolds •Kristen McClintock • Kyle Dunson • Lois Schenk
Luke Desforges • Lynn Schneider • Marie-Claude Sauvé • Mark Coplin • Mark Planco • Mindy Kim
Nathan Beucler• Patricia Gibson • Peggy Melton • Rob Besecker • Rose Albanese • Ryan Vogels
Samantha Welsh • Sarah Berman • Shaun Moore • Suzanne Perkins • Ted Salwin • Tom McPeek

Advocate for the DM Community: Your Voice Matters!

By raising awareness, we help influence research funding, therapy development, clinical trials, and care for people living with myotonic dystrophy.

Help change the future of DM today:

- Educate Policymakers – Learn how to engage officials to protect and expand research funding.
- Advocate with Confidence – Get tools to speak with representatives about DM research and care.
- Share your Story – Your experience can drive change.
- Strengthen DM Support – Celebrate advocacy wins and build relationships with key decision-makers.

www.myotonic.org/Advocate

DM INSIGHT Survey Results

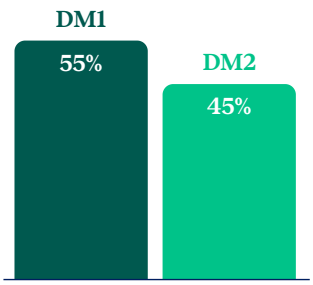
In 2025, the Myotonic Dystrophy Foundation completed DM INSIGHT, a community-informed study to better understand the real-life experiences of people affected by myotonic dystrophy. This work was made possible by members of the DM community who shared their perspectives.

This infographic highlights key findings related to daily life with DM, access to care, and support for caregivers. As new treatments move closer to reality, these insights can help guide healthcare providers, researchers, advocates, policymakers, and payors to support meaningful improvements in everyday life.

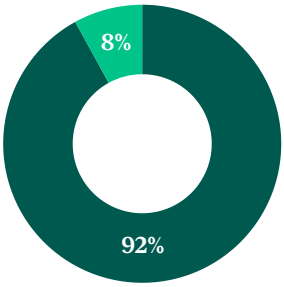
Who Participated?

447
People Living with DM

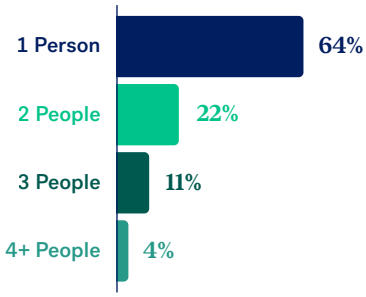
238
Caregivers



% of Respondents Diagnosed with DM1 or DM2



% of Respondents by Country (US. vs. Canada)



% of Caregiver Respondents by Number of People They Care For

Access to and Satisfaction of Healthcare

People with DM & their caregivers felt their medical care was average, with differences between DM1 & DM2.

DM1: Slightly more satisfied

DM2: Slightly less satisfied

Most Helpful Healthcare Professionals

45% Neurologists

38% General Medicine

What Drives DM Healthcare Satisfaction?

Your confidence in knowledge of anesthesia & cardiac risk.

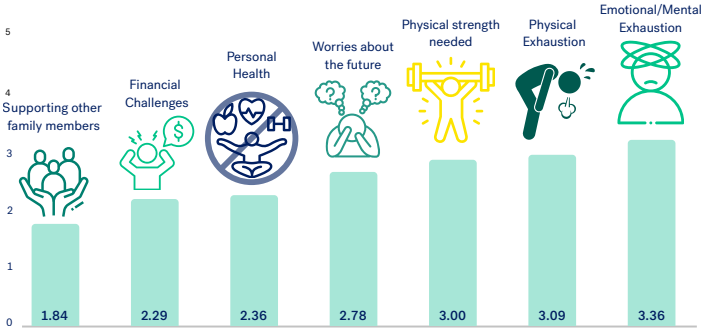
Confidence in your doctor's expertise in DM.

Seeing your doctor more frequently.

Shorter wait times to see your doctor.

Aspects of the Caregiver Experience

How Caregivers Rated Their Challenges: 1 = Low, 5 = High



All seven aspects of caregiver burden are strongly connected. Struggles in one area often spill over to others.

What are Predictors of Caregiver Burnout?

- Higher care needs means higher burden
- Fewer breaks mean higher burden

The Biggest Challenges for Caregivers

49% Addressing emotional or behavioral changes

45% Supporting daily activities or mobility

Myotonic Dystrophy Family Registry

Living with Myotonic Dystrophy?

We need to hear from you!

Join the Myotonic Dystrophy Family Registry (MDFR) today and help support DM research.

By Joining the Registry, You Will:

- Provide critically needed information to researchers pursuing treatments & a cure for myotonic dystrophy
- Make it easier for MDF to connect you with researchers recruiting trial & study participants
- Be informed about the latest news on DM research
- Gain access to anonymous data on symptoms, demographics, & other summary information

IT'S EASY • IT'S CONFIDENTIAL • THERE IS NO COST TO JOIN

Your voice counts and we need to hear from you!

Questions?

Contact the MDFR coordinator:

Sofia Olmos, PhD

415-800-7777

coordinator@myotonicregistry.org

www.myotonicregistry.org

Log in now!

www.myotonicregistry.org

Myotonic Dystrophy IN MOTION
www.myotonic.org

Movement Matters

Join MDF's third annual Myotonic Dystrophy In Motion Awareness Month this July and stay active and connected with the DM community.

- Movement classes each Monday in July.
- Learn safe, practical movement from DM experts.
- Community happy hours to connect with others.

The first 100 community members who register by June 1 will receive an In Motion water bottle (U.S. only).

www.myotonic.org/In-Motion

Raise DM Awareness on September 15th!

Join a global movement to drive research, improve care, and accelerate treatments for DM.

Will you celebrate International DM Awareness Day?

- Wear green and share your support on social media.
- Share the DM-At-A-Glance poster at school or work.
- Display an awareness sign in your community.
- Educate healthcare providers with MDF resources.

Together, we can make myotonic dystrophy more visible and build a future with better care and treatments.

SCAN ME!

www.myotonic.org/International-DM-Day

Myotonic Dystrophy FOUNDATION

Fundraise Your Way!

Are you celebrating a special occasion, participating in a fitness challenge, or hosting a community event?

You can make a difference with a fundraiser for MDF!

Your DIY (Do It Yourself!) Fundraiser empowers our work to support the DM community, provide essential resources, and accelerate research toward treatments and a cure.

www.myotonic.org/DIY

SCAN ME!

Myotonic Dystrophy FOUNDATION

Community Connections

Send a Letter, Share a Smile!

The DM community can use your support. Many people living with myotonic dystrophy experience social isolation and may find it hard to connect. Send a heartfelt letter, drawing, or story to brighten someone's day.

- Nominate a community member to receive letters.
- Write a letter, share a joke, or draw a picture.
- Mail or email your message, and MDF will forward it in a special care package!

Your words can make a difference—reach out today!

www.myotonic.org/community-connections

Together With YOU...

Loraine
DM1 Advocate and her family

It is humbling and inspiring to be part of this important gathering, and to witness the tireless work and thoughtful leadership of the Myotonic Dystrophy Foundation throughout the year. **We want to recognize and thank anyone who has participated in or inquired about our studies.** You have helped propel pioneering research forward for those living with myotonic dystrophy.

Together with you, we are advancing the understanding of this rare disease with the goal of bringing critically needed therapies to those who are waiting.

...Our Work Continues

Avidity is now part of Novartis, and we are excited to bring our global resources, passion for novel science, and relentless commitment to serving patient communities to you. **Thank you for inspiring us with your stories, educating us by sharing experiences,** and working with us to move our research program for myotonic dystrophy forward.

With gratitude,

AVIDITY®
BIOSCIENCES
A Novartis Company







Myotonic Dystrophy FOUNDATION

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