

Myotonic Dystrophy Foundation 2025 Sponsorship Opportunities





www.myotonic.org



About MDF

The Myotonic Dystrophy Foundation (MDF) is the leading global advocate helping patients and families navigate the myotonic dystrophy (DM) disease process, and is often the first resource contacted by newly-diagnosed patients, their families, their social workers and their physicians around the world.

Our Vision

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

Our Mission

The mission of the Myotonic Dystrophy Foundation is Community, Care, and a Cure.

- We support and connect the myotonic dystrophy community.
- We provide resources and advocate for care.
- We accelerate research toward treatments and a cure.





2025 Sponsorship Opportunities

MDF is dedicated to creating transformative experiences for individuals and families affected by myotonic dystrophy. Our robust roster of programs offers our community diverse ways to connect, learn, seek support, and build community.

We are proud to offer our partners more opportunities than ever before to support and connect with the DM community through the Sponsorship of any number of the following initiatives in 2025:

- 2025 MDF Conference
- Clinical Education Initiative
- Warmline Support Program
- Support Group Program
- Community Education Webinar Series
- Myotonic Dystrophy In Motion Program & Awareness Month (July 2025)
- Drug Access & Coverage Initiative
- Communication About Studies and Trials



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2025 MDF Conference

The Myotonic Dystrophy Foundation (MDF) invites you to partner with us as a sponsor for the 2025 MDF Conference, taking place May 1-4, 2025, in Indianapolis, Indiana. This event is the largest gathering of the myotonic dystrophy (DM) community, bringing together over 500 attendees, including families, researchers, clinicians, and industry professionals. The conference offers a unique opportunity to showcase your commitment to advancing research, care, and support for the DM community.

Program Highlights:

- **Community Workshops:** Practical 1:1 workshops with experts in genetic counseling, family planning, insurance and more, designed to empower those affected by DM and their families with knowledge and resources to manage their condition.
- **Networking Opportunities:** Special events, including welcome reception, First-Timer's Tea, Networking Buddy lunch and activities designed to foster connections among attendees, particularly those between professional and community groups.
- Wellness Room: A quiet space for attendees to take a break from the business of the conference, as well as a room dedicated to wellness sessions such as yoga and chair yoga, breathing techniques, and mediation.
- Fireside Chats: Small group sessions designed to allow community members an informal opportunity to discuss topics of interest with leading experts.
- **Cardiac Endpoints Workshop w/DMCRN:** Thursday before the conference Professional Track attendees will have the opportunity to engage in a workshop and discussions focused on cardiology care standards, neuromuscular cardiology, electrophysiology and cardiac imaging.
- **Pharma Day w/ Euro-DyMA:** Thursday before the conference Professional Track attendees will have the opportunity to talk with invited pharma/biotech partners.
- Young Investigators Workshops: Mentor sessions for the next generation of leading DM researchers will take place on Saturday afternoon.
- Professional Track & Poster Awards: Sessions led by leading researchers and clinicians in the field of myotonic dystrophy, sharing the latest advances in research and treatment. For the first time ever, MDF will host a scientific poster award competition for young investigators in the Poster Showcase!

Sponsorship levels and benefits begin on the following page.



2025 MDF Conference, May 1-4

Sponsorship Overview



Sponsorship Benefits	Lead \$75,000	Diamond \$35,000	Platinum \$25,000	Gold \$15,000	Silver \$10,000	Bronze \$5,000
Sponsor of DM Networking and Social Hours on Friday (Only 1 available)						
Host a Sunday Breakfast for up to 25 community members or Sponsor Sunday Community Workshops*	Choice of breakfast or community workshop	Breakfast				
Option to include a flyer or swag in Attendee Bag**	Flyer or swag	Flyer				
Exhibitor Table	•		•			
Industry Updates Plenary Session Presenter (optional)***	First Presenter					
Professional Registrations	10	6	4	2	1	
Ad in Printed Program	2-page spread	1 page	1/2 page	1/2 page	1/4 page	1/4 page
Logo Size & Placement	Large; Attendee Bag, Website, Signage, Printed Program	Medium; Attendee Bag, Website, Signage, Printed Program	Medium; Attendee Bag, Website, Signage, Printed Program	Small; Website, Signage, Printed Program	Small; Website, Signage, Printed Program	Small; Website, Signage, Printed Program
Acknowledgement in Communications	Press Release, MDF newsletter, minimum of 5 social media posts	MDF newsletter, minimum of 3 social media posts	MDF newsletter, minimum 1 social media post	MDF newsletter	MDF newsletter	

*Workshops do not include any industry-community activity opportunities.

Swag or flyer inclusion in Conference Attendee Bag is subject to deadlines; shipping of materials to conference venue is not included. *Industry Updates presentations have limited spaces. Sponsors with this benefit are guaranteed the opportunity to present.

Please confirm selections by February 1st to receive maximum benefits.

2025 MDF Conference, May 1-4

Sponsorship Add-On Opportunities



Add-on Opportunity	Additional Cost	Description
Exhibitor Table	\$1.5k	6' table, two chairs, power strip, wastebasket.
Professional Track Pharma Day (Presented in partnership with Euro-DyMA) Sponsor	\$5k	To help cover the cost of audio visual and space rental, sponsors of Pharma Day will receive recognition on Pharma Day materials, including in the conference printed program, specific Pharma Day signage, and the MDF website.
Professional Track Cardiac Endpoints Workshop Sponsor	\$5k	To help cover the cost of the workshop lunch, audio visual, and space rental, sponsors of the Cardiac Endpoints Workshop will receive recognition on Cardiac Workshop materials, including in the conference printed program, specific Cardiac Workshop signage, and the MDF website.
Named Friday Dinner Sponsor (Only 1 available)	\$40k	Sole Sponsor of the Friday Night Murder Mystery Dinner! Sponsor will receive recognition on dinner-related materials, including in the conference printed program, slides shown at dinner, specific Murder Mystery Dinner signage, and the MDF Website. Sponsor will be provided 5 minutes on stage ahead of the dinner to welcome the conference participants to dinner, thank them for their role in DM research, and to share about the progress of their DM drug development program.
Virtual Event Sponsor (Only 1 available)	\$30k	Covers the cost of the virtual conference platform. Includes opportunity to feature prominent logo placements on the virtual site and ad placement on homepage banner.
Named Breakfast or Lunch Sponsor (Only 2 available)	\$25k	Named host of a breakfast or lunch on Friday or Saturday (May 2nd and 3rd) for all in-person Conference attendees. Covers the cost of the meal and includes the opportunity to share branded swag, play a short promotional video (up to 3 min), and feature a logo on the presentation screens during the meal.
Cocktail Hour Sponsor (Only 1 available)	\$10k	Named sponsor of the cocktail hour on Saturday (May 3rd).
Movement Sponsor (Only 1 available)	\$5k	Named host of Movement Moments, which are short exercise and movement demonstrations for all conference attendees. Includes opportunity to share branded exercise swag.
Community Financial Aid Sponsor	\$15k	Help fund the MDF Scholarships for the 2025 MDF Annual Conference. Scholarships fully cover recipients' hotel stays, event registration, and conference meals and provide partial or total reimbursements for transportation. Includes recognition in conference printed program and the MDF website.
JOA Program Sponsor (Only 1 available)	\$15k	Covers the cost of the JOA (Juvenile Onset Adult) program activities at the conference, potentially including an off-site field trip. Includes opportunity for branded signage and handouts to attendees.

Please confirm selections by <u>February 1st</u> to receive maximum benefits.

2025 MDF Conference, May 1-4

Sponsorship Add-on Opportunities



Add-on Opportunity	Additional Cost	Description
Childcare Sponsor (Only 1 available)	\$12.5k	Covers the cost of the childcare room and childcare services. Includes opportunity for branded signage and handouts to parents & guardians.
Fireside Chat Sponsor (Only 1 available)	\$5k	Covers the cost of the room for our Fireside Chats, small group discussions with leading experts covering a wide range of topics. Includes opportunity for branded signage.
Wellness Room Sponsor (Only 1 available)	\$5k	Named sponsor of the Wellness Room. Includes opportunity for branded signage and handouts to attendees.
Young Investigator Workshop Sponsor (Only 1 available)	\$5k	Covers the cost of room for the workshop. Includes opportunity for branded signage.
Community Workshop Sponsor (Only 1 available)	\$5k	Covers the cost of training MDF Conference community panelists and advocates on storytelling for impact during multiple virtual training sessions leading up to the conference. Includes program highlight and logo included on select training materials.
Refreshment Break Sponsor (Only 4 available)	\$5k	Named sponsor of a refreshment break. Covers the cost of snacks and beverages during scheduled break.
Breakout Session Sponsor (Limited availability; subject to approval)	\$5k	Helps cover the cost of the rooms for breakout sessions. Includes opportunity for branded signage at room entrance.
Entertainment Sponsor (Only 1 available)	\$1k	Covers the cost of a DJ for Saturday night post-dinner event. Includes opportunity for branded signage.
Poster Award Sponsor (Only 5 available)	\$1k	Covers costs associated with Young Investigator's Poster Award. Includes recognition with all Poster Award Sponsors on presentation screen at introduction of awards presentation.

Contact MDF at <u>development@myotonic.org</u> for additional details on Sponsorship Add Ons.

Please confirm selections by <u>February 1st</u> to receive maximum benefits.

Myotonic Dystrophy Foundation 2025 Sponsorship Opportunities

Clinical Education Initiative - Year 1

MDF has made significant strides in equipping healthcare professionals with essential care guidelines, high-quality resources, and events to support individuals affected by myotonic dystrophy. Building on these successes, this proposed initiative aims to take a multi-pronged and multi-phased approach to deepen DM awareness, improve diagnosis, and enhance access to high-quality care that promotes well-being and hope for those with DM.

As DM research progresses toward new treatments, MDF's collaboration with healthcare providers and institutions is crucial to shift perceptions and encourage clinicians to recognize DM as a treatable condition. Recognizing the opportunity to expand and enhance our clinical education resources, this initiative is designed to elevate the knowledge and expertise of healthcare providers. By doing so, we aim to significantly increase the number of high-quality, knowledgeable healthcare professionals in the DM field to further elevate patient care, reduce diagnosis delays, and keep professionals informed with the latest research.

This initiative includes a multi-year three-tiered strategy to boost general awareness, enhance support for current DM providers, and move towards developing standards to promote and support Centers of Excellence to offer in-depth training. The first year will focus on a community survey/needs assessment in 2025 and a build out of our Find-A-Doctor map with a database of DM providers, whom we can share information about MDF with. Resource dissemination to clinical care teams will begin with results of the needs assessment. In year one we will also launch an Early Career Clinical Scholar Grant Program.

Sponsorship Opportunities:

Supporter Sponsor - \$25,000

We invite you to fund the Clinical Education Initiative as a Supporter Sponsor.

Early Career Clinical Scholar Grant Program Partner Sponsor - \$200,000 (exclusive sponsor)

This special sponsorship opportunity includes co-branding of the 2-year Early Career Clinical Scholar Grant Program for the 2025-26 grant year.



Warmline Support Program

The MDF Warmline provides critical, personalized support for individuals and families impacted by myotonic dystrophy (DM). Through phone and email interactions, MDF connects community members with tailored resources, answers questions, and offers support. MDF also mails DM resources both domestically and internationally, ensuring our community has access to the latest information and tools for managing DM.

By sponsoring the Warmline Support Program, you will be helping make a direct and positive impact on the lives of individuals and families affected by myotonic dystrophy. Your support will help us provide the resources and personalized support they need to feel empowered and have a better quality of life.

Sponsorship levels and benefits are on the following page.



2025 Warmline Support Program

Sponsorship Overview



Sponsorship Benefits	Platinum \$25,000	Gold \$15,000	Silver \$10,000
MDF Annual Report inclusion Dedicated impact statement on your support of Warmline	•		
Acknowledgment once per quarter MDF digital newsletter			
Warmline webpage recognition	Logo placement	Recognition of support	Recognition of support
Social media communications	Four (4) dedicated social media post acknowledging support for Warmline	Two (2) dedicated social media post acknowledging support for Warmline	One (1) dedicated social media post acknowledging support for Warmline
Recognition at 2025 MDF Conference Community Resource Hub The Community Resource Hub is where attendees can access printed resources and receive personalized guidance from MDF Staff.			

Support Group Program

MDF believes in the power of community and support to transform the lives of people living with myotonic dystrophy and their families. We have been dedicated to enhancing the quality of life for these individuals through our support groups for more than five years. Our Support Group Program is the heart of our mission, providing a lifeline for those affected by DM. We invite you to become a beacon of hope and support by sponsoring our peer-led Support Group Program.

MDF provides a safe, inclusive, and empathetic environment through our peer-led support groups, where people can connect, share their experiences, and learn to manage the challenges they face due to this disease. DM presents unique and often isolating challenges for both those affected and their families. Our support groups offer a vital lifeline where individuals living with DM and their caregivers can find understanding, share coping strategies, and build connections. However, we need your support to continue to provide this critical service.

With great success, MDF expanded our 2024 Support Group Programing bringing on 12 new Support Group Facilitators (SGF) serving 2 new locations, and 2 special groups. Through in-person, virtual, and social media group discussions, **this program hosted over 250 sessions** in the first three quarters of 2024, reaching more than 1,500 participants. MDF aims to continue to expand and refine this programming in 2025, increasing the number of Support Group Facilitators and locations, as well as implementing robust evaluation tools. MDF provides continual training for our support group facilitators, including introducing discussion guides for community resources, and training on how to choose, invite, and host a guest speaker. Monthly trainings and professional development for our SGFs ensures they are prepared for the socioemotional challenges that arise in their support groups and are knowledgeable about which MDF resources and toolkits to share and when to share them.

By sponsoring the Support Group Program, you will be helping make a direct and positive impact on the lives of those affected by myotonic dystrophy. Your support will help us provide the connection, resources, and support they need to feel empowered and have a better quality of life.

Sponsorship levels and benefits are on the following page.



2025 Support Group Program

Sponsorship Overview



Sponsorship Benefits	Platinum \$25,000	Gold \$15,000	Silver \$10,000	Bronze \$5,000
Social Media announcement highlighting partnership				
Prominent logo placement in program materials, including Support Group Facilitator manual, group modules, and discussion guides	•			
Recognition in support group promotional materials, MDF newsletters, and on MDF website				
Recognition in support group meetings and events			•	
Recognition on MDF webpage dedicated to Support Groups				
Recognition in program materials, including Support Group Facilitator manual, group modules, and discussion guides				

Myotonic Dystrophy Foundation 2025 Sponsorship Opportunities

Community Education Webinar Series

MDF's commitment to making a positive impact in the lives of those affected by myotonic dystrophy extends to providing valuable education and expert insights. We believe that knowledge and information are essential tools in managing the challenges posed by this complex condition. We also understand that not everyone will have access or availability to attend the 2025 MDF Conference. As part of our mission to empower individuals and families living with DM, we are thrilled to introduce our Community Education Webinar Series. This series includes our Ask-the-Expert webinars and our Meet-the-DM-Drug-Developers webinars.

Myotonic dystrophy presents a unique set of challenges, and individuals affected by this condition, as well as their families, often have questions that demand expert guidance. Our **Ask-the-Expert** webinars are designed to bridge this knowledge gap. By sponsoring this series, you will play a vital role in ensuring individuals affected by DM, no matter where they are, have access to the most up-to-date information and expert advice.

- Clinical Trial readiness
- Medical advancements in relevant specialties across all phenotypes (GI, Physical Therapy, Swallowing, Sleep, etc.)
- Young and emerging adult topics (Intimate relationships, young professionals, etc.)
- Quality of life enhancements for those living with DM

Our **Meet-the-DM-Drug-Developers** webinars provide our biotechnology and pharmaceutical partners working on treatments and a cure for myotonic dystrophy the opportunity to sit down with our community to share their progress and answer questions in real time.

By sponsoring our Community Education Webinar Series, you will directly contribute to improving the lives of individuals and families affected by DM. Your support will help us provide valuable educational resources, connect participants with leading experts in the field, and create a platform for individuals to ask questions and seek guidance.

Sponsorship levels and benefits are on the following page.



2025 Community Education Webinar Series



Sponsorship Overview

Sponsorship Benefits	Platinum \$25,000	Gold \$15,000	Silver \$10,000	Bronze \$5,000
Opportunity to introduce and thank the expert speaker at each Ask-the- Expert Webinar	•			
Guaranteed Meet-the-DM-Drug-Developer Webinar in 2025	•			
Logo placement on all promotional materials for entire Community Education Webinar Series, including Ask-the-Expert and Meet-the-DM-Drug Developers				
Opportunity to provide 5-minute introduction to one Ask-the-Expert webinar topic of choice (subject to availability; offered to sponsors in order of Platinum, Gold, Silver).				
Recognition as sponsor for entire Community Education Webinar Series				
Logo placement on Webinar Series landing pages				

Myotonic Dystrophy in Motion Program and Awareness Month *(July 2025)*

At MDF, we are passionately committed to improving the lives of individuals and families affected by myotonic dystrophy. We believe in the transformative power of staying active and engaged. That is why we are thrilled to introduce the Myotonic Dystrophy in Motion (MDIM) Program and Awareness Month.

DM presents a wide range of challenges, and remaining active, both physically and mentally, is a key component of managing this condition. The MDIM Program and Awareness Month is designed to provide participants with opportunities for physical activity, education, and community connection. By sponsoring this program, you can help us promote physical and mental well-being, and bring individuals and families affected by DM closer together.

The MDIM Program and Awareness Month offers various activities, opportunities and will cover a diverse array of topics, including (but not limited to):

- Insights into the latest research and advancements in exercise and movement for people with DM
- Strategies for maintaining physical and emotional well-being
- Adaptive exercise classes tailored to the needs of individuals with DM
- Educational webinars on nutrition, adaptive techniques, and overall well-being
- An annual MDIM Awareness Month, an international event to promote physical activity and raise awareness

By sponsoring the MDIM Program and Awareness Month, you will directly contribute to enhancing the quality of life for individuals and families affected by DM. Your support will help us provide access to physical activities, educational resources, and supportive community that empowers participants to lead active and fulfilling lives on their own terms.

Sponsorship levels and benefits are on the following page.



2025 Myotonic Dystrophy in Motion Program and Awareness Month



Sponsorship Overview

Sponsorship Benefits	Platinum \$25,000	Gold \$15,000	Silver \$10,000	Bronze \$5,000
Sponsorship acknowledgment on all program materials	•			
Opportunity to introduce and thank participants an MDIM event (e.g. webinar) of choice	•			
Social media announcement highlighting partnership		•		
Opportunity to provide an introduction at an MDIM event (e.g. webinar) of choice (subject to availability)	5-minute introduction	5-minute introduction	2-minute introduction	
Recognition as sponsor for MDIM Program and Awareness Month				•
Logo placement on MDIM Program landing page		•		•

Drug Access & Coverage Initiative (DACI)

MDF's DACI works to ensure that all individuals living with DM have affordable coverage and access to new DM treatments. Over the next 12-18 months, MDF will launch a series of surveys, meetings, and listening sessions with patients, clinicians, payors, and other interested stakeholders to gather data and information to guide our efforts. These efforts will lead to a MDF white paper that outlines the challenges and opportunities with the anticipated approval of new DM treatments and recommendations on how MDF and our partners can help ensure appropriate coverage for these treatments.

- Making the Case For Coverage: Understanding the payor landscape and gathering data on the DM patient experience. Here we will: Review Existing Data, Conduct DM Community Survey/Needs Assessment, and 3) Build insurance coverage profile to complement the other existing publication data.
- Assess Private Payor Perspectives and Motivations: What data is most important and will influence payors to cover new DM treatments? Here we plan to: Meet with payors and related groups to better understand their interests.
- **State Medicaid Drug Utilization Review.** New CMS guidelines that will require patient representation on DUR panels. MDF will monitor and help train community members as needed.
- **Prepare for Possible FDA Advisory Committee "***Ad Comm***" Meetings on DM Drugs.** Frequently, the FDA convenes a panel of independent technical and scientific experts to serve on advisory committees (Ad Comm) to provide advice on regulatory decision making including certain drug approval decisions. While we do not know if any of the DM treatment applications will necessitate an Ad Comm, MDF will begin to prepare to utilize these forums to build awareness and educate the FDA on patient preferences and lived experiences.
- Train DM Community on Public Advocacy on Access/Coverage Issues. As we get closer to a DM drug coming to market, MDF will plan to develop a web-based training curriculum to help the community to participate in these forums and be effective communicators. These trainings can be focused on participation at FDA Ad Comms, meetings with payors, and public forums.

Sponsorship Opportunity:

\$10,000 - Supporter Sponsor

All sponsors receive recognition of support in our DM community survey/needs assessment, which will be sent to approximately 13,000 community members.



Communication About Studies and Trials

We believe in helping ensure the DM community is part of the development of study and trial design. We are also committed to encouraging the DM community to participate in research about the disease. Through newsletters, email, and social media, we will share information about studies and trials with the 13,000 people active in our database. This sponsorship will help to cover the cost of staff time and computer software needed to create and distribute the communication.

Sponsorship Opportunity:

\$5,000 - Supporter Sponsor





2025 MDF Sponsorships

Confirm your selection by February1st to receive maximum benefits!

Conference Sponsorships & Add-ons



MDF Initiative Sponsorships

Clinical Education Initiative	Supporter \$25,000	Early Career Cl	inical Scholar Grant Pr	ogram \$200,000
Warmline Support Program	Platinum \$25,000	Gold \$15,000	Silver \$10,000	
Support Group Program	Platinum \$25,000	Gold \$15,000	Silver \$10,000	Bronze \$5,000
Community Education Webinar Series	Platinum \$25,000	Gold \$15,000	Silver \$10,000	Bronze \$5,000
Myotonic Dystrophy In Motion Program & Awareness Month	Platinum \$25,000	Gold \$15,000	Silver \$10,000	Bronze \$5,000
Drug Access & Coverage Initiative	Supporter \$10,000			
Communication About Studies and Trials	Supporter \$5,000			



2025 MDF Sponsorships

Confirm your selection by February1st to receive maximum benefits!

Contact Information Sponsor Name **Contact Name Mailing Address Phone Number** E-Mail **Payment Details** Total Pledge Amount \$ Check - Please make payable to the Myotonic Dystrophy Foundation and mail to the address below. Electronic Funds Transfer - Please contact MDF at development@myotonic.org for additional instructions.

Authorized Signature

Date

By signing this form you are committing your organization to contribute the above amount to MDF in 2025.

Myotonic Dystrophy Foundation

663 13th Street, Suite 100 0 Oakland, CA 94612



(415) 800-77777

Community, Care, and a Cure.

Thank you for helping advance our work to improve the quality of life and find treatments for those living with myotonic dystrophy.

www.myotonic.org (\square)



Thank You!

Phone Number
Email Address
Website
Location Address

+415-800-7777

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