

Community Track: Friday, May 2nd

As of April 8th



Please Note: Agenda times and speakers are subject to change. Find the latest details at www.myotonic.org

Time	General Sessions	Fireside Chats	JOA Lounge	Wellness Room
8:00 - 9:00 AM	Check-in Opens			
9:00 - 10:00 AM	First Timers' Tea			Morning Self-Guided Meditation
10:00 - 11:00 AM	Community Breakfast			
11:00 - 11:45 AM	Welcome & State of the Foundation			Quiet Space
11:45 AM - 12:00 PM	Break & Movement Moment		JOA Lounge Opens	
12:00 - 1:00 PM	Community Breakouts (see pg. 2)	You've Just Been Diagnosed, What's Next?	JOA Session: Welcome and Get to Know You Games	Chair and Stand Up Zumba
1:00 - 1:15 PM	Break			Quiet Space
1:15 - 2:15 PM	Lunch & Networking Buddies Lunch			
2:30 - 3:30 PM	Community Breakouts (see pg. 2)	Affected Men's Real Talk: Managing Intimacy and Sexual Health Challenges with DM	JOA Session: Building Connections	Movements for Everyday Life
3:30 - 3:45 PM	Break			
3:45 - 4:45 PM	Industry Updates Part 1		JOA Lounge Karaoke/Craft Time/Games	Quiet Space
4:45 - 5:00 PM	Break & Movement Moment			
5:00 - 6:00 PM	Community Breakouts (see pg. 2)	European Patient Organizations: A Unique Opportunity to Share and Collaborate	JOA Movie Night	
6:00 - 6:30 PM	Break		JOA Lounge Closes	Wellness Room Closes
6:30 - 8:30 PM	Dinner & Entertainment: Murder Mystery			

Community Breakouts: Friday, May 2nd

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Time	Community Breakouts					
12:00 - 1:00 PM	Unraveling DM1: From Genetics to Care and Everything in Between	DM2 Essentials: Understanding, Managing, and Thriving with DM2	Adulthood Ahead: Essential Planning for Parents of Children with CDM	Finding Relief: Exploring Medications and Tools for Managing Pain in DM2	Your Guide to Clinical Trials: From Phases to Participation	Nourishing Solutions: Managing Dietary Needs and Swallowing with DM
1:00 - 1:15 PM	Break					
1:15 - 2:15 PM	Lunch & Networking Buddies Lunch					
2:30 - 3:30 PM	Genetics Unveiled: Understanding Testing, Counseling and Family Conversations about DM1	Mind Matters: Navigating Cognitive and Memory Challenges in DM2	Building Resilience: Family Dynamics and Support in the DM Journey	Keeping Your Heart in Check: DM1's Impact and Care Tips	Life Works: Landing the Job: Building Resumes and Acing Interviews	
3:30 - 3:45 PM	Break					
3:45 - 4:45 PM	Industry Updates Part 1					
4:45 - 5:00 PM	Break & Movement Moment					
5:00 - 6:00 PM	DM1: Networking & Social Hour	DM2 Networking & Social Hour	Caregiver Networking & Social Hour	CDM Family Networking & Social Hour	Living Better with DM: Tools and Services of Occupational Therapy and Home Health	
6:00 - 6:30 PM	Break					
6:30 - 8:30 PM	Dinner & Entertainment: Murder Mystery					

■ ■ ■ ■ ■ All Attendees
 ■ DM1
 ■ DM2
 ■ CDM Families
 ■ Caregivers
 ■ JOA / Young Adults

Community Track: Saturday, May 3rd

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Time	General Sessions	Fireside Chats	JOA Lounge	Wellness Room
8:00 - 9:00 AM	Check-in Opens			
9:00 - 10:00 AM	Community Breakfast			Morning Self-Guided Meditation
10:00 - 11:00 AM	Welcome & Stories of Inspiration		JOA Lounge Opens	
11:00 - 11:15 AM	Break & Movement Moment			
11:15 AM - 12:15 PM	Community Breakouts (see pg. 4)	Affected Women's Real Talk: Managing Intimacy and Sexual Health Challenges with DM	JOA Session: Let's Get Moving!	Quiet Space
12:15 - 12:30 PM	Break			
12:30 - 1:30 PM	Exhibitor and Research Poster Showcase		JOA Session: Snack Smart!	Afternoon Gentle and Chair Yoga
1:30 - 1:45 PM	Break			
1:45 - 2:45 PM	Lunch			
2:45 - 3:45 PM	Industry Updates Part 2	There's Hope: The Future of DM2 Research		
3:45 - 4:00 PM	Break & Movement Moment		JOA Karaoke/Free time	Quiet Space
4:00 - 5:00 PM	Community Breakouts (see pg. 4)	Voices for DM: Open Discussion on Advocacy		
5:00 - 5:15 PM	Break			
5:15 - 6:15 PM	Community Breakouts (see pg. 4)		JOA: Stump the Doctor	
6:15 - 6:30 PM	Break		JOA Lounge Closes	Wellness Room Closes
6:30 - 8:30 PM	Closing Dinner & Dance Party			

Community Breakouts: Saturday, May 3rd

As of April 8th



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Time	Community Breakouts					
11:15 AM - 12:15 PM	DM1 Community Discussion Panel: Sharing Hope and Life Hacks	DM2 Community Discussion Panel: Stories of Hope and Helpful Tips	Unaffected Male Caregivers Community Panel: Self Care	CDM Community Discussion Panel: Sharing Everyday Victories Through Useful Tips, Tricks, and Assistive Services	Unaffected Female Caregivers Community Panel: Self Care	
12:15 - 12:30 PM	Break					
12:30 - 1:30 PM	Exhibitor and Research Poster Showcase					
1:30 - 1:45 PM	Break					
1:45 - 2:45 PM	Lunch					
2:45 - 3:45 PM	Industry Updates Part 2	There's Hope: The Future of DM2 Research - Fireside Chat				
3:45 - 4:00 PM	Break & Movement Moment					
4:00 - 5:00 PM	Breathe Easy, Sleep Sound: Managing Sleep and Pulmonary Health with DM1	Genetics Unveiled: Understanding Testing, Counseling and Family Conversations about DM2	Unaffected Caregivers: Love in Transition: Balancing Romantic Connections and Caregiving in DM	Empowering Adult Children: Managing Care, Service Delivery, and Living with CDM	Securing Tomorrow: Financial Strategies and Planning for Your and Your Family's Future	Thriving Under Pressure: Managing Mental Health in Everyday Life
5:00 - 5:15 PM	Break					
5:15 - 6:15 PM	DM1: Stump the Doctor	DM2: Stump the Doctor				
6:15 - 6:30 PM	Break					
6:30 - 8:30 PM	Closing Dinner & Dance Party					

■ ■ ■ ■ ■ All Attendees
 ■ DM1
 ■ DM2
 ■ CDM Families
 ■ Caregivers
 ■ JOA / Young Adults

Over three days, the 2025 MDF Conference will delve into critical topics shaping myotonic dystrophy (DM) research and care. Sessions will cover cardiac care, clinical trial endpoints, and cutting-edge advancements in gene editing, diagnostics, and patient-centered research. The program includes expert-led discussions, insights from the French Registry, and fast-paced presentations of groundbreaking studies during the Lightning Round.

As of April 8th

View the Community Track:
www.myotonic.org/community-sessions-2025-mdf-conference

Young investigators can participate in career workshops offering tailored guidance on academia, industry, and funding opportunities. The event concludes with a celebration of progress and community at the Closing Dinner & Dance Party, offering a chance to connect, collaborate, and reflect on the strides being made in DM research and care.

Thank you to our sponsors, **Avidity Biosciences**, **Dyne Therapeutics**, **PepGen**, **Vertex**, **Sanofi**, **Lupin Neurosciences**, and **Arrakis Therapeutics** for helping make the Cardiac Endpoints Workshop possible and for supporting Pharma Day at the 2025 MDF Conference Professional Track.

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Thursday, May 1st		
Time	Topic	Session Speakers
9:00 AM	Check In Opens	
12:00 - 2:30 PM	Cardiac Phenotypes and Clinical Trial Endpoints in DM & Lunch	Nicholas E. Johnson, MD, MSci, FAAN, Virginia Commonwealth University William J. Groh, MD, MPH, Medical University of South Carolina Tom Cooper, MD, Baylor College of Medicine Jordana Kron, MD, Virginia Commonwealth University Greg Hundley, MD, Virginia Commonwealth University Amy Ladd, PhD, Pauley Heart Center Jennifer Jordan, PhD, MS, FSCMR, Virginia Commonwealth University
2:30 - 3:00 PM	Break	
3:00 - 5:45 PM	Pharma Day	Presented in Partnership with Euro-DyMA Speakers to be announced
5:45 - 6:00 PM	Break	
6:00 - 8:30 PM	Early Arrivals Welcome Reception (For All Conference Attendees)	

2025 MDF Conference: Professional Track



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Friday, May 2nd

Time	Topic	Session Speakers
8:00 - 9:00 AM	Professional Track Breakfast	<i>MDF Research Fellows & Career Scholars Breakfast (Private)</i>
9:00 - 10:55 AM	Professional Session 1: Progress & Possibilities for DM Research	Andy Berglund, PhD, University of New York at Albany Andy Rohrwasser, PhD, MBA, Myotonic Dystrophy Foundation Nadine Ann Skinner, PhD, Myotonic Dystrophy Foundation Maurice Swanson, PhD, University of Florida Guillaume Bassez, MD, PhD, Institut de Myologie Antoine Mangin, PhD, Cardiff University/ UK Dementia Research Institute
10:55 - 11:00 AM	Break	
11:00 - 11:45 AM	Welcome & State of the Foundation	
11:45 - 11:50 AM	Break	
11:50 AM - 1:15 PM	Professional Session 2: Innovations in Genomics and Diagnostics	Darren Monckton, PhD, University of Glasgow Paul Kruszka, MD, GeneDx Andreas Roos, PhD, University of Duisburg-Essen
1:15 - 2:15 PM	Lunch & Networking Buddies Lunch	
2:15 - 3:40 PM	Professional Session 3: Patient Perspectives & New Tools	Nicholas E. Johnson, MD, MSci, FAAN, Virginia Commonwealth University Jeannine DeSoi, BSN, RN, MDF Support Group Facilitator Belen Esparis, MD, MDF Board of Directors Charles Thornton, MD, University of Rochester
3:40 - 3:45 PM	Break	
3:45 - 4:45 PM	Industry Updates	<i>Industry presenters to be announced</i>
4:45 - 5:00 PM	Break	
5:00 - 6:00 PM	Professional Networking & Research Poster Showcase	
6:00 - 6:30 PM	Break	
6:30 - 8:30 PM	Dinner & Entertainment: Murder Mystery!	

2025 MDF Conference: Professional Track



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Saturday, May 3rd

Time	Topic	Session Speakers
7:30 - 8:30 AM	Professional Track Breakfast	<i>MDF Scientific Advisory Committee Breakfast (Private)</i>
8:30 - 10:00 AM	Professional Session 4: DM & Body Systems	Eric Wang, PhD, University of Florida Belinda Pinto, PhD, University of Florida Paloma Gonzalez-Perez, MD, PhD, Massachusetts General Hospital Auinash Kalsotra, PhD, University of Illinois Urbana Champaign
10:00 - 11:00 AM	Welcome & Stories of Inspiration	
11:00 AM - 12:30 PM	Young Investigators' Poster Presentation Lightning Round Showcase	Moderator: Tom Cooper, MD, Baylor College of Medicine
12:30 - 1:30 PM	Exhibitor & Research Poster Showcase	
1:30 - 1:45 PM	Break	
1:45 - 2:45 PM	Lunch	<i>Global Alliance for DM Awareness Member Lunch (Private)</i> <i>Young Investigators' Mentor Lunch (Private)</i>
2:45 - 3:45 PM	Industry Updates	<i>Industry presenters to be announced</i>
3:45 - 3:50 PM	Break	
3:50 - 6:30 PM	Young Investigators' Workshop	Lukasz Sznadjer, PhD, University of Nevada, Los Vegas Johanna Hamel, MD, University of Rochester Jana Jenquin, PhD, Senior Scientist, Novartis Ranjan Batra, PhD, Lexeo Therapeutics Andy Rohrwasser, PhD, MBA, Myotonic Dystrophy Foundation
6:30 - 8:30 PM	Closing Dinner & Dance Party	