



2021

Virtual MDF Annual Conference

SEPTEMBER 10 & 11



A Virtual Event to
Unite Community, Care, and a Cure for Myotonic Dystrophy



2021 Virtual MDF Annual Conference

SEPTEMBER 10 & 11

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Welcome!



Dear MDF Community,

It is my great privilege to welcome you to the 2021 Virtual Myotonic Dystrophy Foundation (MDF) Annual Conference! On behalf of the MDF Board of Directors and staff, thank you to the over 1,000 people who weighed in to help us develop this year's program. Your feedback from MDF Warmline calls and emails, strategic planning surveys and interviews, focus groups, support groups, as well as past conference evaluations, helped our team design a program to help meet the diverse needs of our community.

While we wished and hoped to see you all in San Diego, California this month, the last year had something different in store for the world. In response, MDF has once again shifted gears to a virtual format for the health and safety of our community, and we remain committed to connecting you to the latest in myotonic dystrophy (DM) research, DM clinical experts, biotechnology and pharmaceutical partners working toward treatments and a cure, resources for families and healthcare providers, and of course, one another.

This year's conference offers three Community Tracks designed for families and individuals living with DM1, with DM2, and their Caregivers. We are proud to announce this year's conference will also feature a carefully crafted Professional Track for DM researchers, clinicians, and industry professionals. While these four Tracks were designed to act as a guide for your conference experience, we invite you to attend any session that best meets your needs, regardless of Track. Thank you to the unbelievable DM experts who helped make all of this possible by generously sharing their time, energy, and expertise with our community this month!

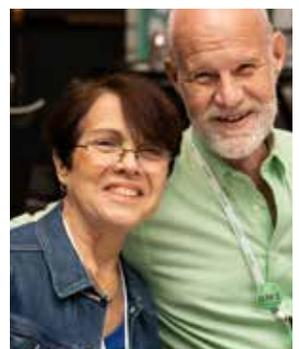
I hope you will take advantage of this opportunity to connect with our community, as well as the wide variety of phenomenal programs offered each day! Stay active, attentive, and get your blood pumping with our Movement sessions; explore the sponsor and exhibitor booths; learn about new clinical trials; review DM research posters and discuss groundbreaking work with their authors and MDF Research Fellows; attend a concert by singer-songwriter Eric Hutchinson; and bring your hardest questions to stump our DM1, DM2, and Health Insurance experts! And for those of you who are new to the MDF Community, we invite you to meet the MDF Board of Directors, Support Group Facilitators, and staff at our favorite pre-conference tradition, the First Timers' Tea!

I look forward to connecting with you over the next few days and hope you enjoy this year's virtual event.

With respect and appreciation,

A handwritten signature in black ink that reads "Tanya Stevenson".

Tanya Stevenson, EdD, MPH
Chief Executive Officer





Use the checklist below for the best conference experience possible!

Suggested setup:

- [Google Chrome](#) or [Microsoft Edge](#) web browser
- Laptop or desktop computer
- At least 1.5 mbps internet connection (check your internet speed: <https://www.speedtest.net/> or <https://fast.com/>)
- Webcam, microphone + headphones or speakers
- Zoom video conferencing app (you don't need an account but do need Zoom downloaded)
 - Download Zoom <https://zoom.us/>
 - Camera and lighting tips <https://support.pathable.com/hc/en-us/articles/360055411231-Presentation-Pro-Tips-and-Best-Practices>



If the above options aren't available, check out these alternatives:

- Smartphone or tablet
- Other internet browsers (Safari, Firefox, etc.)
- Slower internet speeds - we suggest keeping your camera turned off if your internet is less than 1.5 mbps



Extra credit setup:

- Build your personal conference agenda:
 - In the conference website, go to **Agenda > Full Agenda**
 - Select the + next to sessions you want to attend to add them to **My Agenda**
 - Review your schedule under **Agenda > My Agenda**
- Get to know attendees, speakers, sponsors and exhibitors
 - View everyone attending the conference under the **Attendees** tab
 - Learn more about individuals by clicking their name and reading their profile
 - Schedule video meetings, or send messages to get in touch with other attendees!



At the Conference:

- When it's time, join sessions you have selected by going to **Agenda > My Agenda** and clicking **Join Live Meeting**
- Chat with others in the chat box on the right side of any session page
- Take notes during sessions by clicking **Notes** on any session page (download these later by exporting from the **Agenda** page)
- Visit the exhibitor and sponsor booths during Showcase hours by visiting **Exhibitors > Exhibitors by Type**
 - Read about exhibitors and sponsors just as you would a session
- Talk to the hosts live during the Showcase hours: **11:30 AM – 12:45 PM** and **5:00 - 6:00 PM** on Friday and **12:00 - 12:50** and **5:00-6:00 PM** Pacific Time on Saturday by clicking Enter Live Showcase Booth



Enjoy the Conference!

Agenda for Thursday, September 9, 2021



Time*	Session
9:00 AM - 5:00 PM	Exhibitor Preview
3:00 PM - 4:00 PM	Ask-the-MDF-Staff-Live
4:00 PM - 5:30 PM	First Timers' Tea

Agenda for Friday, September 10, 2021



Time*	Track 1: DM1	Track 2: DM2	Track 3: Caregivers & Self-care	Track 4: Professional
8:00 AM - 8:50 AM	Adaptive Yoga			
9:00 AM - 9:50 AM	Opening Session: Welcome & State of the Foundation			
10:00 AM - 11:15 AM	DM1: Disease Development, Symptoms, & Management	DM2: Disease Development, Symptoms, & Management	Acceptance & Commitment: Strategies for Good Mental Health	Repeat Instability & Stabilization
11:15 AM - 11:30 AM	Break			
11:30 AM - 12:45 PM	Adaptive Strength Training	JOA: Getting to Know One Another	Exhibitor Showcase	Research Poster Showcase
12:45 PM - 1:00 PM	Break			
1:00 PM - 1:45 PM	Industry Updates Part 1			
1:45 PM - 2:00 PM	Break			
2:00 PM - 3:15 PM	State of DM1 Research & Ways to Engage	State of DM2 Research & Ways to Engage	Talking about DM to Children, Family Members, & Doctors	Mechanistic Aspects of the Heart & CNS
3:15 PM - 3:30 PM	Break			
3:30 PM - 3:50 PM	Special Performance by Singer-Songwriter Eric Hutchinson!			
4:00 PM - 5:00 PM	Facilitated Networking DM1 DM2 Caregivers CDM Families JOA Professionals			Exhibitor Showcase

****All times Pacific Daylight Time (Pacific).***

The conference website should adjust the online program agenda to read in local time zones.



Agenda for Saturday, September 11, 2021



Time*	Track 1: DM1	Track 2: DM2	Track 3: Caregivers & Self-care	Track 4: Professional		
8:00 AM - 8:50 AM	Exercise & Movement Activity		Exhibitor Showcase			
9:00 AM - 10:15 AM	Day 2 Welcome: Stories of Inspiration					
10:15 AM - 10:30 AM	Break					
10:30 AM - 11:45 AM	Clinical Trial Readiness Workshop	Clinical Trial Readiness Workshop	Advocacy & Awareness Workshop - Get Ready for International DM Awareness Day	Gene Editing & DM		
11:45 AM - 12:00 PM	Break					
12:00 PM - 12:50 PM	Sit Fit	JOA: Games & Networking	Exhibitor Showcase	Research Poster Showcase		
12:50 PM - 1:00 PM	Research Updates on DM2 & RAN Proteins as a Therapeutic Target					
1:00 PM - 1:45 PM	Industry Updates Part 2					
1:45 PM - 2:00 PM	Break					
2:00 PM - 3:15 PM	Stump the Expert - DM1	Stump the Expert - DM2	Stump the Expert - Health Insurance	Clinical Updates: Cardiac Management, DM Clinical Research Network, & Brain Manifestations of DM1		
3:15 PM - 3:30 PM	Break					
3:30 PM - 4:45 PM	Living Your Best Life: Community Panels					
	DM1	DM2	Caregivers	CDM Families	JOA	Veterans
4:45 PM - 5:00 PM	Break					
5:00 PM - 6:00 PM	Dance Party!		Networking Lounge	Exhibitor Showcase		

****All times Pacific Daylight Time.***

The conference website should adjust the online program agenda to read in local time zones.



Track 1: DM1

This track was designed for individuals and families seeking to learn more about DM Type 1. Sessions include:

- **DM1: Disease Development, Symptoms, and Management**

Jacinda Sampson, MD, PhD

Learn about genetic factors causing DM1, the different body systems affected, the most common symptoms, and how best to manage and provide care for the disease from a leading expert. Appropriate for newly diagnosed and those living with DM1 for many years.

- **State of DM1 Research & Ways to Engage**

Jeffrey Statland, MD

Myotonic dystrophy type 1 (DM1) is a complex disease caused by a rare genetic mutation which can affect many systems of the body, producing symptoms that can vary considerably in type and degree from person to person. Learn about the broad range of basic science, studies, clinical trials and other research approaches that are currently being explored to reduce the burden of DM1 for individuals and families.

- **Clinical Trial Readiness Workshop**

Jodie Howell, LPN; Nicholas Johnson, MD, MSCI, FAAN; Christy Newman; Alissa Peters

A panel of experts will explain what a clinical trial is, what it takes to develop a trial, which trials are currently enrolling, and how members of the DM community can participate to advance research.

- **Stump the Expert: DM1**

John Day, MD, PhD

Meet a leading expert in DM1 and ask your most persistent, challenging questions. Can you stump the expert?

- **Living Your Best Life: A Community Panel for Individuals Living with DM1**

Laura Gershenson; Mindy Kim; Bill Nuttall

Hear from a panel of individuals with DM1 about how they live their best life, and share your own experiences.

Track 2: DM 2

This track is intended for individuals and families seeking to learn more about DM Type 2. Sessions include:

- **DM2: Disease Development, Symptoms, and Management**

Johanna Hamel, MD, Lindsay Baker, PT; Araya Puwanant, MD

Learn about genetic factors causing DM2, the different body systems affected, the most common symptoms, and how best to manage and provide care for the disease from a leading expert. Appropriate for newly diagnosed and those living with DM2 for many years.

- **State of DM2 Research & Ways to Engage**

Laura Ranum, PhD

Myotonic dystrophy type 2 (DM2) is a complex disease caused by a rare genetic mutation which can affect many systems of the body, producing symptoms that can vary in type and degree from person to person. Learn about the broad range of basic science, clinical studies, and other research approaches that are currently being explored to reduce the burden of DM2 for individuals and families.

- **Stump the Expert: DM2**

Charles Thornton, MD

Meet a leading expert in DM2 and ask your most persistent, challenging questions. Can you stump the expert?

- **Clinical Trial Readiness Workshop**

Jodie Howell, LPN ; Nicholas Johnson, MD, MSCI, FAAN; Christy Newman; Alissa Peters

Experts in DM will explain what a clinical trial is, what it takes to develop a trial, which clinical trials are currently enrolling, and how members of the DM community can participate to advance research.

- **Living Your Best Life: A Community Panel for Individuals Living with DM2**

Haley Martinelli ; Tom McPeek; Lorraine Piechota; Louis Vinnyey

Hear from a panel of individuals with DM2 about how they live their best life, and share your own experiences.





Track 3: Caregivers & Self-care

This track was designed for family members, caregivers, or those who are their own caregiver; also appropriate for individuals living with DM1 or DM2. Sessions include:

- **Acceptance and Commitment: Strategies for Good Mental Health**

Christopher D. Graham, PhD, DClinPsychol

Life with DM can contribute to emotional and mental stressors. This session focuses on strategies and tools for maintaining good mental health, and an explanation of Acceptance and Commitment Therapy (ACT) and how it can be applied by individuals living with DM and their families.

- **Talking about DM with Children, Family Members, and Doctors**

Rebecca Axline, LCSW-S, APHSW-C;

Reagan Shivitz, BSN, RN-BC; Sheetal Shroff, MD

Talking with family, medical providers, and others about DM can be a huge challenge. Join a discussion with a medical team and community member to enhance your communication about DM in different settings, and add your voice to the discussion with comments and questions.

- **Advocacy and Awareness Workshop - Get Ready for International Myotonic Dystrophy Awareness Day**
Kate Beck; David Brand; Lauren S. Brand, MS, CCC-SLP; Teresa Buffone

International Myotonic Dystrophy Awareness Day is September 15. This is the first year of the global event, so learn how you can raise awareness online, in your community, and around the world. Hear from successful advocates and Team MDF so that you can be inspired and empowered to change the future of myotonic dystrophy.

- **Stump the Expert: Health Insurance**

Erin Bradshaw; Amy Jackson, Patient Access

Specialist; Erin Springer, MSN, BSN;

A Representative from the Social Security Administration

A panel of experts will provide important tips for navigating health insurance and will answer your questions. The panel focuses on the U.S. health insurance system.

- **Living Your Best Life: A Community Panel for Unaffected Caregivers**

John Cooley, JD; Lois Oppenheim, PhD;

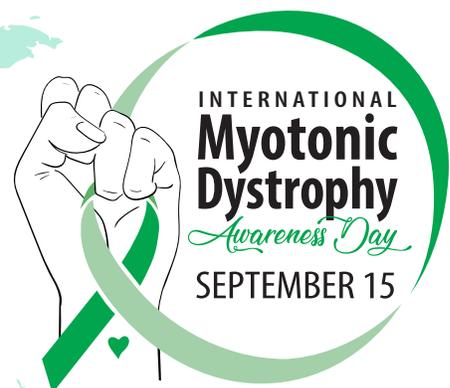
Suzanne Perkins, PhD

Hear from a panel of unaffected spouses, partners, parents, and other unaffected caregivers about how they live their best life, and share your own experiences.

You Can Help Raise Awareness About Myotonic Dystrophy!

International Myotonic Dystrophy Awareness Day aims to garner the attention of the wider general public, policy makers, regulators, biopharmaceutical representatives, researchers, health care professionals, and anyone with an interest in changing the future of myotonic dystrophy. Raising awareness of myotonic dystrophy will help improve service provision, basic research, drug development, and policymaking related to the disease. Increased funding for myotonic dystrophy research will improve health outcomes, reduce disability, and increase life expectancy for individuals living with the disease, and holds great promise for helping individuals with diseases with similar genetic bases, such as Fragile X syndrome and Huntington's disease.

Learn more at www.myotonic.org/interational-dm-day





Track 4: Professionals

This track is intended for clinicians, researchers, and industry experts. Session topics were developed based on direct feedback from DM professionals. Sessions include:

- **Repeat Instability & Stabilization**

Peter Bialek, PhD; Darren Monckton, PhD; Christopher Pearson, PhD

Repeat instability is the crux of myotonic dystrophy disease. Join three leading researchers for a panel presentation of research addressing possible opportunities for repeat stabilization. Dr. Pearson presents recent research into mouse model repeat stabilization for Huntington's with a discussion of implications for DM. Dr. Monckton discusses somatic CTG repeat expansion in DM1, with respect to dynamics, consequences, and therapeutic opportunities. Dr. Bialek discusses the work of Triplet Therapeutics in utilizing ASOs and siRNAs to stabilize repeat expansion.

- **Mechanistic Aspects of the Heart & the CNS**

Thomas Cooper, MD; Eric Wang, PhD

This session will cover the current understanding of mechanisms that affect the central nervous system and heart functions in DM.

- **Gene Editing & DM**

Vincent Dion, PhD; Nan Zhang, PhD

Gene editing is state of the art technology with implications for DM. Learn about the research of Dr. Zhang, who will describe his work targeting pathologically expanded RNA using CRISPR-Cas13 and DNAzyme in neurodegeneration, and Dr. Dion who will discuss his laboratory's research using Cas9 for DM.

- **Research Updates on DM2 & RAN Proteins as a Therapeutic Target**

Monica Banez Coronel, PhD; Matthew Disney, PhD

Dr. Banez Coronel describes how RAN proteins accumulate in DM1 brains and discusses prospective implications for DM treatments. Dr. Disney will present on DM2 Research from his lab at Scripps.

- **Clinical Updates: Cardiac Management, DM Clinical Research Network, and Brain Manifestations of DM1**

Nick Johnson, MD, MSCI, FAAN;

Pradeep Mammen, MD; Peg Nopoulos, MD

Innovations that lead to treatments and cures are essential, but so are innovations in clinical care. Dr. Mammen provides an overview of the latest and most crucial elements of cardiac care for the DM patient including screening, monitoring, treatments, and procedures. Dr. Johnson focuses on the activities of the Myotonic Dystrophy Clinical Research Network (DMCRN), including the adult natural history study and upcoming pediatric study. He will provide early demographic and clinical characteristics of the enrolled population. Dr. Nopoulos discusses new research that distinguishes psychological problems that arise due to brain changes from DM1, from those that arise from psychological triggers, and the implications in treatment from this discovery.

- **NIH Research Funding Opportunities & First Look at New DM Data from CDC & Marigold Foundation**

Emily Carifi, PhD ; Sarah Howe, MBA;

Glen Nuckolls, PhD; Natalie Street, MS, CGC

MDF is pleased to present special research, data, and funding opportunity updates for DM professionals. The Marigold Foundation presents findings of a recent study of health resource utilization from claims data. Ms. Street will present an overview of MD STARnet, sociodemographic and clinical description of the myotonic dystrophy population in four U.S. States, and the direction of current and future MD STARnet research. Glen Nuckolls and Emily Carifi will supply an overview of NINDS and NIAMS supported DM research and describe the different areas of disease research NIH supports, and give a brief overview of NIAMS specific research areas and a brief primer of NIH opportunities for investigators.



The Conference incorporates many traditional events and activities, including:

- **Exhibitor Showcase**

Learn about our amazing sponsors and other exhibitors. Step into a virtual booth to learn and connect. Virtual booths will be accessible throughout the Conference, but exhibitors may not be live. You can always post comments to the discussion board so that exhibitors can answer your questions or respond to your comments at another time.

- **Ask-the-MDF-Staff Live**

Log in to the Conference site to explore the navigation, layout, and resources ahead of the official program. MDF staff will be available live through chat to answer your questions about the platform and the program at 3:00 PM PT. Checking out the site ahead of scheduled programming will give you greater confidence during live sessions to find your way around and make the most of all that Conference has to offer, plus MDF staff will be on hand to help. At 4:00pm PT, head to the First Timers' Tea to meet the Board, staff, and other Conference attendees.

- **First Timers' Tea**

All attendees are welcome to attend the First Timers' Tea, an MDF Conference tradition. Board members and volunteers will welcome you to the Conference and provide a simple tutorial about the Conference virtual platform. Then, break out into Zoom rooms to meet other attendees. Note: The First Timers' Tea is part of the "soft open" on Thursday before the official Conference opening Friday.

- **Welcome and State of the Foundation**

Welcome! MDF leadership and Board of Directors are eager to share exciting updates about the state of Foundation, International Myotonic Dystrophy Awareness Day, and the MDF strategic plan.

- **Industry Updates:**

**Avidity Biosciences • Harmony Biosciences
Dyne Therapeutics • AMO Pharma •
PepGen ARTHEX biotech • Expansion
Therapeutics NeuBase Therapeutics**

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

- **Adaptive Yoga**

Basma Gale

Wellness coach and yoga teacher Basma Gale will lead a session of breathing, stretching, and movement with adaptive instructions so that anyone may participate.

- **Adaptive Strength Training**

Rach Kahn, NCPT, CSCS, CMT

This class will begin with a warm-up including a body scan, breath work, active-stretching, and joint/spinal mobility work. The intensity will build as we layer on full-body strength training with functional, task-oriented movements, and some balance and coordination exercises. We will wrap up with some grounding movements to calm your nervous system and send you on your way!

- **Sit Fit**

Nathan Perkins, EdD, ACSM-CIFT

The exercise session/workout will consist of a 45-minute non-weighted upper body sit-down exercise routine that will focus on cardiovascular and strength training and range of motion movements through all major joint structures and ligaments.

- **Juvenile-onset Adult Programs**

Carolyn Valek, Ann Woodbury

Juvenile-onset adults (JOAs) connect and get to know one another, connect over fun activities, and network. For JOAs and family members only.

- **Poster Showcase**

Learn about different topics in DM research. View poster presentations and meet the researchers.

- **Special Performance by Eric Hutchinson**

Eric Hutchinson

Singer-songwriter Eric Hutchinson performs for the DM community.

- **Facilitated Networking**

Join facilitated conversations for special DM populations: individuals living with DM1, individuals living with DM2, parents of congenital DM (CDM) children, juvenile-onset adults (JOA), unaffected caregivers (family or other caregivers who do not have DM); DM professionals.



General Sessions *(continued)*



- **Day 2 Welcome: Stories of Inspiration**

Lisa Harvey-Duren, MBA; Alexandra, Julie & Michel LeBoeuf; Tanya Stevenson, EdD, MPH; Paul, Angie & Glen Wiggans

Start Day 2 off with a celebration of the DM community, including the 2021 Kayla Vittek Memorial Award for Outstanding Community Advocate presented by Lisa Harvey-Duren, plus hear from two bold families committed to changing the future of myotonic dystrophy.

- **Living Your Best Life: A Series of Community Panels for CDM Families, Juvenile-onset Adults, and Veterans**

CDM: Lorraine Dressler, Maricela Delgado, Johnathan Jones

Veterans: Laura Root, Nick Coplin, Chuck Hunt
JOA: Terry Cohen, Carolyn Valek, Ann Woodbury, Scott Valek

Hear from a panel of parents or other caregivers of congenital DM (CDM) children, of juvenile-onset adults (JOA), parents, and other caregivers, and of military veterans with DM (all types), about how they live their best life, and share your own experiences.

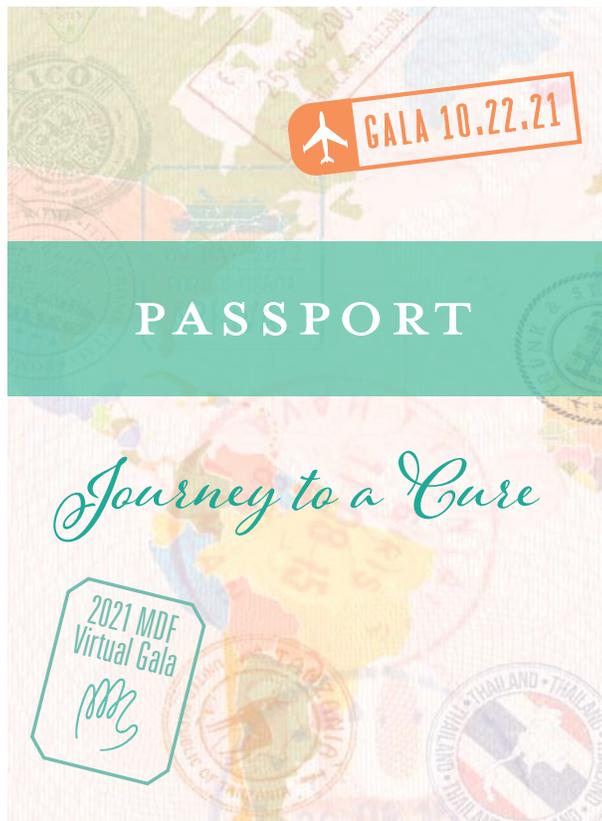


- **Dance Party!**

Join us for a virtual dance party! Our DJ is playing everyone's favorite dance numbers. Keep your camera on so we can see your cool moves!

- **Networking Lounge**

Connect with old friends and make new ones at this closing session of networking. All are welcome!



MYOTONIC DYSTROPHY FOUNDATION

2021 Virtual Gala

Register for the 2021 Virtual Gala!

Friday, October 22, 2021

5:30 PM Pacific / 8:30 PM Eastern

We hope you can join us to celebrate and help raise funds for the Myotonic Dystrophy Foundation's critically-important work on behalf of individuals and families living with myotonic dystrophy. Everyone is welcome so mark your calendar for our 2021 Virtual Gala! *Invite your friends and family!*

Learn more at www.myotonic.org/Gala



Conference Speakers



Rebecca Axline, LCSW-S, APHSW-C
Clinical Social Worker
Houston Methodist
*Talking About DM to Children,
Family Members, and Doctors*



Lauren S. Brand, MS, CCC-SLP
MDF Community Member
Advocacy and Awareness Workshop



Monica Banez Coronel, PhD
Assistant Scientist
Center for NeuroGenetics, Ranum Lab
University of Florida
*Research Updates on DM2 & RAN
Proteins as a Therapeutic Target*



Teresa Buffone
MDF Canada Support Group Facilitator
Advocacy and Awareness Workshop



Lindsay Baker, PT
Physical Therapist
University of Rochester Medical Center
*DM2: Disease Development, Symptoms,
and Management*



Emily Carifi, PhD
Program Director
Muscle Disorders & Therapies Program
National Institute of Arthritis &
Musculoskeletal & Skin Disorders.
*NIH Research Funding Opportunities &
First Look at New DM Data from CDC &
Marigold Foundation*



Kate Beck
Special Projects Manager
Myotonic Dystrophy Foundation
Advocacy and Awareness Workshop



Terry Cohen
MDF Community Member
*Living Your Best Life: A Community
Panel for Juvenile Onset Adults (JOAs)*



Rob Besecker, MBA
MDF Illinois Support Group Facilitator
DM2 Facilitated Networking



John Cooley, JD
Kansas Support Group Facilitator
*Living Your Best Life: A Community
Panel for Unaffected Caregivers*



Peter Bialek, PhD
Head of Translational Sciences
Triplet Therapeutics, Inc.
Repeat Instability and Stabilization



Thomas Cooper, MD
Professor & Director of the Cooper Lab
Baylor College of Medicine &
MDF Scientific Advisory Committee
*Mechanistic Aspects of the Heart &
the CNS*



Erin Bradshaw
Chief of Mission Delivery
Patient Advocate Foundation
Stump the Expert - Health Insurance



Nick Coplin
MDF Community Member
*Living Your Best Life: A Community
Panel for Veterans*



David Brand
MDF Community Member
Advocacy and Awareness Workshop



Valerie Cullen, PhD
Senior Vice President, Research
Expansion Therapeutics
Industry Updates



Conference Speakers (continued)



John Day, MD, PhD
Prof. of Neurology, Pediatrics & Pathology
Director, Neuromuscular Medicine,
Stanford Neuroscience Health Center
MDF Board of Directors & Scientific
Advisory Committee
*Professionals Facilitated Networking
Stump the Expert – DM1*



Laura Gershenson
MDF Community Member
*Living Your Best Life: A Community
Panel for Individuals Living with DM1*



Jeffrey M. Dayno, MD
Chief Medical Officer
Harmony Biosciences
Industry Updates



Christopher D. Graham, PhD, DClinPsychol
Clinical Psychologist, Senior Lecturer in
Clinical Psychology & Academic Director,
Clinical Psychology Training Program
Queen's University, Belfast
*Acceptance and Commitment:
Strategies for Good Mental Health*



Maricela Delgado
MDF Community Member
*Living Your Best Life: A Community
Panel for CDM Families*



Johanna Hamel, MD
Assistant Professor of Neurology,
Pathology & Laboratory Medicine
University of Rochester
*DM2: Disease Development,
Symptoms, and Management*



Vincent Dion, PhD
Professor, Dementia Research Institute
Cardiff University
Gene Editing & DM



Jodie Howell, LPN
Certified Clinical Research Coordinator
Nurse
Virginia Commonwealth University
Clinical Trial Readiness Workshop



Matthew Disney, PhD
Professor at Scripps Research Institute
& Founder Expansion Therapeutics
*Research Updates on DM2 & RAN
Proteins as a Therapeutic Target*



Eric Hutchinson
Performing Artist & MDF Community
Member
Virtual Concert



Lorraine Dressler, former RN, CPHQ
MDF Southern California Support
Group Facilitator
*Living Your Best Life: A Community
Panel for CDM Families*



Lisa Harvey-Duren, MBA
Founding Executive Director
Myotonic Dystrophy Foundation
Day 2 Welcome: Stories of Inspiration



Ashish Dugar, PhD
SVP & Global Head of Medical Affairs
Dyne Therapeutics
Industry Updates



Sarah Howe, MBA
Program Manager
Marigold Foundation
*NIH Research Funding Opportunities &
First Look at New DM Data from CDC &
Marigold Foundation*



Basma Gale
Wellbeing Coach & Yoga Teacher
Adaptive Yoga



Chuck Hunt
MDF Georgia Support Group Facilitator
*Living Your Best Life: A Community
Panel for Veterans*

Conference Speakers (continued)



Amy Jackson
Patient Access Specialist
Patient Services Inc.
Stump the Expert - Health Insurance



Jane Larkindale, PhD
Senior Director, Clinical Science
PepGen
Industry Updates



William Jacobson, PhD
Senior Director, Clinical Development
Harmony Biosciences
Industry Updates



Alexandra LeBoeuf
International DM Awareness Day Logo
Designer & MDF Community Member
Day 2 Welcome: Stories of Inspiration



Nicholas Johnson, MD, MSCI, FAAN
Associate Professor & Vice Chair of
Research, Neurology
Virginia Commonwealth University
Clinical Trial Readiness Workshop
*Clinical Updates: Cardiac Management,
DM Clinical Research Network, & Brain
Manifestations of DM1*



Julie LeBoeuf
MDF Community Member
Day 2 Welcome: Stories of Inspiration



Johnathan Jones
MDF Community Member
*Living Your Best Life: A Community
Panel for CDM Families*



Michel LeBoeuf
MDF Community Member
Day 2 Welcome: Stories of Inspiration



Rach Kahn, NCPT, CSCS, CMT
Nationally Certified Pilates Teacher,
Certified Strength & Conditioning
Specialist, & Certified Massage Therapist
Adaptive Strength Training



Beatriz Llamusi, PhD
Chief Executive Officer
ARTHEX biotech
Industry Updates



Jeremy Kelly
Chair, MDF Board of Directors
Welcome & State of the Foundation



Ibraheem Mahmood
Chief Executive Officer
AMO Pharma
Industry Updates



Jae Kim, MD, FACC
Chief Medical Officer
Avidity Biosciences
Industry Updates



Pradeep Mammen, MD, FACC, FAHA, FHFA
Assoc. Prof., Internal Medicine Division
of Cardiology & Medical Director of
Neuromuscular Cardiomyopathy Clinic
UT Southwestern Medical Center
*Clinical Updates: Cardiac Management,
DM Clinical Research Network, & Brain
Manifestations of DM1*



Mindy Kim
MDF North Carolina &
Facebook Support Group Facilitator
*Living Your Best Life: A Community
Panel for Individuals Living with DM1*



Haley Martinelli
MDF Community Member
*Living Your Best Life: A Community
Panel for Individuals Living with DM2*



Conference Speakers (continued)



Tom McPeck
MDF Board Member & DM2 Support Group Facilitator
DM2 Facilitated Networking Session
Living Your Best Life: A Community Panel for Individuals Living with DM2



Nathan Perkins, EdD, ACSM-CIFT
Adapted Physical Education Instructor
De Anza College, Cupertino, California
Sit Fit



Darren Monckton, PhD
Professor of Human Genetics
University of Glasgow
MDF Scientific Advisory Committee
Repeat Instability and Stabilization



Suzanne Perkins, PhD
MDF Michigan Support Group Facilitator
Living Your Best Life: A Community Panel for Unaffected Caregivers



Christy Newman
MDF Community Member
Clinical Trial Readiness Workshop



Alissa Peters
Director, Patient Advocacy & Corporate Affairs
Avidity Biosciences
Clinical Trial Readiness Workshop



Peg Nopoulos, MD
Professor of Psychiatry, Pediatrics & Neurology, Chair of the Dept. of Psychiatry
University of Iowa Hospitals
Clinical Updates: Cardiac Management, DM Clinical Research Network, & Brain Manifestations of DM1



Lorraine Piechota
MDF Community Member
Living Your Best Life: A Community Panel for Individuals Living with DM2



Glen Nuckolls, PhD
Program Director
National Institutes of Health
NIH Research Funding Opportunities & First Look at New DM Data from CDC & Marigold Foundation



Araya Puwanant, MD
Assistant Professor of Neurology,
Wake Forest University
DM2: Disease Development, Symptoms and Management



Bill Nuttall
MDF Facebook Support Group Facilitator
Living Your Best Life: A Community Panel for Individuals Living with DM1



Laura Ranum, PhD
Professor of Genetics & Research Director
Ranum Lab, University of Florida
MDF Scientific Advisory Committee
State of DM2 Research & Ways to Engage



Lois Oppenheim, PhD
Professor & Chair of the Dept. of Modern Languages & Literatures
Montclair State University
Living Your Best Life: A Community Panel for Unaffected Caregivers



Laura Root
MDF Community Member
Living Your Best Life: A Community Panel for Veterans



Christopher E. Pearson, PhD
Senior Scientist
The Hospital for Sick Children
Full-Professor, University of Toronto
Canada Research Chair, Disease-Associated Genome Instability
Repeat Instability and Stabilization



Jacinda Sampson, MD, PhD
Clinical Associate Professor
Stanford University
DM1: Disease Development, Symptoms, and Management

Conference Speakers (continued)



Reagan Shivitz, BSN, RN-BC
Nurse Coordinator, Neuromuscular &
Myotonic Dystrophy Clinic
Houston Methodist Texas Medical Center
*Talking About DM to Children,
Family Members, and Doctors*



Carolyn Valek
MDF Ohio Support Group Facilitator
*Juvenile-onset Adult Programs &
Networking Session*
*Living Your Best Life: A Community
Panel for JOAs*



Scott Valek
MDF Community Member
*Living Your Best Life: A Community
Panel for JOAs*



Louis Vinnyey
MDF Community Member
*Living Your Best Life: A Community
Panel for Individuals Living with DM2*



Eric Wang, PhD
Assistant Professor
Dept. of Molecular Genetics & Microbiology
University of Florida
*Mechanistic Aspects of the Heart &
the CNS*



Angie Wiggins
Above & Beyond Award Recipient &
MDF Community Member
Day 2 Welcome: Stories of Inspiration



Glen Wiggins
MDF Community Member
Day 2 Welcome: Stories of Inspiration



Paul Wiggins
MDF Community Member
Day 2 Welcome: Stories of Inspiration



Ann Woodbury
MDF Mountain West & JOA Connections
Support Group Facilitator
*Juvenile-onset Adult Programs &
Networking*
*Living Your Best Life: A Community
Panel for JOAs*



Nan Zhang, PhD
Assistant Professor of Neurology, Houston
Methodist Research Institute & Weill Cornell
Medical College
Gene Editing & DM



Sheetal Shroff, MD
Co-director, Myotonic Dystrophy
Multidisciplinary Clinic
Houston Methodist Hospital
*Talking About DM to Children,
Family Members, and Doctors*



Erin Springer, MSN, BSN
Nurse Clinical Specialist
University of Iowa Hospitals & Clinics
Stump the Expert - Health Insurance



Jeffrey Statland, MD
Professor of Neurology
University of Kansas Medical Center
State of DM2 Research & Ways to Engage



Dietrich A. Stephan, PhD
Chief Executive Officer & Chairman
NeuBase Therapeutics
Industry Updates



Tanya Stevenson, EdD, MPH
Chief Executive Officer
Myotonic Dystrophy Foundation
Welcome & State of the Foundation
Day 2 Welcome: Stories of Inspiration



Natalie Street, MS, CGC
Health Scientist
National Center on Birth Defects &
Developmental Disabilities
Centers for Disease Control & Prevention
*NIH Research Funding Opportunities &
First Look at New DM Data from CDC &
Marigold Foundation*



Charles Thornton, MD
MDF Board Member & Scientific Advisory
Committee
University of Rochester
Professionals Facilitated Networking
Stump the Expert - DM2



 **AMO Pharma** will be on hand to discuss results seen in the clinical studies to date and future clinical studies for DM, including the recently launched REACH-CDM Clinical Trial for AMO-02 (Tideglusib).

 **Asklepios BioPharmaceutical (AskBio)** is developing life-saving AAV gene therapy in partnership with patients, families, medical societies, and patient advocacy groups that is focused on neuromuscular and central nervous system conditions including myotonic dystrophy.

 **Astellas** develops genetic medicines with the potential to deliver transformative value for patients and is currently exploring three gene therapy modalities: gene replacement, exon skipping gene therapy, and vectorized RNA knock-down.

 **Avidity Biosciences** is working to improve the lives of people living with DM by advancing a new class of targeted RNA therapies, called AOCs (Antibody Oligonucleotide Conjugates) with their Phase 1/2 MARINA™ trial of AOC 1001 in adults with DM1.

 **Biogen** was founded in 1978 as one of the world's first global biotechnology companies and has led innovative scientific research with the goal over the last decade to defeat devastating neurological diseases. Our booth will focus on patient centered drug development and clinical endpoints for DM1.

 **Dyne Therapeutics** is focused on innovative life-transforming therapeutics for patients with genetically driven diseases utilizing their proprietary FORCE™ platform to overcome the current limitations of muscle tissue delivery to advance modern oligonucleotide therapeutics. Dyne is targeting muscle tissue with the goal of stopping or reversing progression in a broad range of diseases including DM1.

 **Expansion Therapeutics** Visit the Expansion Therapeutics booth to learn about their DM program and recent study results.

 **Harmony Biosciences** Come explore the Harmony Biosciences booth to learn about their DM program and recently announced clinical trial, Safety and Efficacy of Pitolisant on Excessive Daytime Sleepiness and Other Non-Muscular Symptoms in Patients with DM1.

 **LocanaBio** Our mission is to create transformational therapies that will improve the lives of patients with devastating genetic diseases.

 **Lupin Neurosciences** is a specialty pharma division of Lupin with an initial focus on meeting the unmet needs of patients with myotonic disorders.

 **Neubase Therapeutics** has a synthetic genetic medicines platform and is developing a new treatment option for patients with DM1. The lead candidate (NT-0200) is designed to engage with the hairpin on just the mutant copy of the DMPK RNA molecule and restore normal cellular function, potentially stopping or slowing disease progression. Other genetic disease therapies, including DM2, are in the pipeline.

 **PepGen** is harnessing the power of our Enhanced Delivery Oligonucleotide technology to solve the challenge of getting oligonucleotides to where they need to be to work, and to realize the clinical potential of oligonucleotide therapies to transform the lives of people living with neuromuscular diseases.

 **Pfizer** Our purpose is grounded in our commitment to fund programs that provide public benefit, advance medical care and improve patient outcomes.

 **Syros** is redefining the power of small molecules to control the expression of genes. Our myotonic dystrophy program goal is to develop an oral medicine that decreases the expression of the mutated copy of the DMPK gene, lowering levels of toxic RNA, to provide a therapeutic benefit for patients with DM1.

 **Vertex Pharmaceuticals, Inc.** is an American biopharmaceutical company based in Boston, MA. It was one of the first biotech firms to use an explicit strategy of rational drug design rather than combinatorial chemistry.

Exhibitor Showcase



Check out our Conference Exhibitor's Virtual Showcase booths any time by clicking on the menu **Exhibitors > Exhibitors by Type** and then click on their images. Interact live with representatives during the Conference from **11:30 AM - 12:45 PM and 4:00 - 5:00 PM Pacific on Friday** and **8:00 - 8:50 AM, 12:00 - 12:50 PM and 5:00 - 6:00 PM on Saturday**.



Adaptive Yoga Live An online seated yoga class created for the disabled community in response to COVID-19. All ages and abilities welcome.



Ann S. Woodbury is an MDF Support Group Facilitator for 10 years and a full-time caregiver for her husband and four children (now adults) who all live with DM. She will be on hand to discuss her book, "Surviving Myotonic Dystrophy: A Mother's Struggle to Care for her Family with a Rare Disease".



Cure DM UK Our aims are to preserve and protect good health among, and relive the needs of, people living with Myotonic Dystrophy, their families and carers.



DMCRN In 2011, MDF awarded a grant to support the establishment of the first-ever Myotonic Dystrophy Clinical Research Network (DMCRN). There are now 17 sites around the world enrolling patients in studies and trials.



Houston Methodist Department of Neurology The mission of the Stanley H. Appel Department of Neurology at the Houston Methodist Neurological Institute is to pioneer the future by translating advances in basic science research into meaningful therapies for diseases of the nervous system.



Leslie Krongold, Ed.D. is the MDF Northern California Support Group Facilitator and host of Glass Half Full Podcast, Blog & YouTube channel for people with chronic health conditions and/or disability.



Meet the MDF Board of Directors Our Board of Directors is comprised of leaders in science, finance, fundraising, advocacy and non-profit leadership. Their expertise helps our work, assess our impact, and guide our pursuit of patient-relevant outcomes.



Muscular Dystrophy Association USA is an American 501(c)(3) umbrella organization that works to support people with neuromuscular diseases.



Muscular Dystrophy Canada is a Canadian non-profit organization that strives to find a cure for neuromuscular disorders.



MyPaTH Story Booth brings together patients and researchers who are interested in improving health and health care. If you are a patient or caregiver, we want to hear your story, in your voice.



National Institutes of Health are a part of the U.S. Department of Health and Human Services. NIH is the largest biomedical research agency in the world.



NORD and **NORD Rare CA** are 501 (c)(3) non-profit patient advocacy organizations dedicated to individuals with rare diseases and the organizations that serve them.



Patient Advocate Foundation (PAF) is a national 501 (c)(3) non-profit organization which provides case management services and financial aid to Americans with chronic, life threatening and debilitating illnesses.



Patient Services, Inc. was founded by a patient for patients. We know the challenges of chronic illness. We're here to help pay for your medication, provide health insurance premium and copay assistance, navigate health insurance plans, give legal advice, and be there every step of the way.



Rach Kahn is a movement teacher for bodies of all abilities who has been practicing for the past 9+ years. They specialize in working with people who have neurological conditions including (but not limited to) spinal cord injuries, Cerebral Palsy, and strokes.



Rare New England (RNE) Our mission is to bring together New England patients, families and providers touched by rare and complex disorders.

Exhibitor Showcase (continued)



Rob Besecker is an award winning inspirational writer whose books include “Everest Strong: Reaching New Heights with Chronic Illness” and “Overcoming Obstacles and Challenges in Life and Pursuing Goals and Dreams”. He is also an inspirational speaker, healthcare professional and MDF’s Illinois Support Group Facilitator.



Sit Fit with Nathan Perkins, a certified inclusive fitness instructor and former Paralympic Athlete, leads 30 minute classes that is a combination of stretches, strength and cardio exercises all done in a seated position with or without weights.



Stanford Dr. John Day’s research team will be available to describe the studies we have ongoing at Stanford University. Visit our booth to learn how to enroll in our Recruitment Database for studies and trials, and learn more about our Myotonic Dystrophy Biobank.



TREAT-NMD is a global network for the neuromuscular field that provides an infrastructure to ensure that the most promising new therapies reach patients as quickly as possible.



University of Rochester’s myotonic dystrophy team conducts research and provides clinical care for people with DM. Our 22 person team is dedicated to finding better treatments for both DM1 and DM2 and we partner with patients and families to understand more about these complicated conditions.



Virginia Commonwealth University (VCU) is conducting the largest study of myotonic dystrophy so far, END-DM1, which is representing cooperation of families and researchers from six countries in North America and Europe, and is also partnering with biotechnology companies that are working on myotonic dystrophy. VCU also leads DMCRN activities.



5 Tips to Help Maximize Your Conference Experience

- 1. Divide and conquer.** If you are attending the Conference with multiple family members or friends, consider attending different sessions when multiple sessions occur at the same time.
- 2. Use the breaks.** Feedback from last year suggests that attendees wanted more time between sessions, and more frequent breaks, so there is a lot of room between sessions. Use these breaks to stretch, check out other Conference activities, message a new friend, or just rest.
- 3. Network.** The Conference platform allows each attendee to contact every other attendee, including speakers, sponsors, and exhibitors. If you have a question for a speaker, or you just want to say hello to a friend, network throughout the Conference.
- 4. Take notes.** Sessions are jam-packed with information, and it would be impossible for anyone to memorize everything that’s discussed at the Conference. Take notes so you can revisit things again after the Conference.
- 5. Don’t worry** – everything is being recorded. Every session, except for the Community Panels and Networking Sessions, will be recorded and posted to MDF’s Digital Academy after the Conference. So if you miss a session, or you have to choose one session over another that looks equally interesting, don’t worry – you will see it soon!





MDF Digital Academy



View hours of educational and inspirational videos by DM experts wherever and whenever you would like. Videos are categorized by areas of interest, for example, clinical trials and drug approval, DM2, congenital and childhood onset, genetics, and more! <https://www.myotonic.org/digital-academy>

Ask-the-Expert



MDF's 2021 virtual series with DM experts is available online. Experts in GI, brain, heart, speech and swallowing, mental health, lungs, and other specialties related to DM share information and answer community questions. View the complete archives at: <https://www.myotonic.org/ask-expert-series>

Myotonic Dystrophy Family Registry



**Myotonic
Dystrophy**
Family Registry

The Myotonic Dystrophy Family Registry (MDFR) is a web-based database of information provided by families to aid researchers in developing treatments for DM and identifying participants for research studies and clinical trials. The MDFR enables MDF and others to review community-reported statistics and data about their experience of living with DM to aid advocacy and education efforts. Learn more and register here: <https://myotonicregistry.patientcrossroads.org/index.php>

Meet the DM Drug Developer



Throughout 2021, MDF invited biotechnology and pharmaceutical partners that are working on treatments and cures for myotonic dystrophy to sit down with our community, share their progress, and answer community questions. View the complete series here: <https://www.myotonic.org/meet-dm-drug-developers>

Toolkits & Publications



MDF has convened world experts in DM – specialists, researchers, and those living with the disease – to create publications, toolkits, and clinical care recommendations that guide health care providers and families in the care and management of DM. Publications include clinical care guidelines for DM1, DM2, congenital DM, anesthesia, cardiology, and more. View the full range of toolkits and publications here: <https://www.myotonic.org/toolkits-publications>

Support Programs



Due to the variable nature of DM, one can sometimes feel isolated, frustrated, and confused. Many families benefit from connection and community with others who share their experiences. MDF facilitates local support groups, virtual meetings for special populations, and even social media communities to ensure that no one affected by DM ever feels alone. Check out MDF's support programs here: <https://www.myotonic.org/find-support>

MDF Support Group Facilitators



The Myotonic Dystrophy Foundation is the world's largest myotonic dystrophy (DM) patient advocacy organization, connecting people living with DM in more than 80 countries around the world. What helps make this organization so meaningful is your role in it – your advocacy to advance “Care and a Cure” and your support of us and of one another. We're thrilled that so many of you have found each other through the Foundation and are building support groups. We would like to specially thank our Support Group Facilitators for donating their time and energy to create these support opportunities.

Find our virtual support options here: <https://www.myotonic.org/find-support>.

Learn more about our Support Group Facilitators here: <https://www.myotonic.org/support-group-facilitators>.

Find out about upcoming support groups and events on our calendar: <https://www.myotonic.org/calendar/month>.

Aside from reaching out directly, you can also share your contact information with our support group facilitators.

If you are interested in volunteering as a Support Group Facilitator, please contact MDF at info@myotonic.org.



Rob Besecker, MBA
Chicago, IL, USA



Teresa Buffone
Ottawa, Canada



Barry Cohen, PhD
Florida, USA



John Cooley
Kansas City Area, USA



Mark Coplin
Portland, Oregon, USA



Paul Dillon
Worthington, OH, USA



Loraine Dressler
Orange County, CA, USA



Jonathan Freedman
Seattle, WA, USA



Patricia Gibson
Kansas City Region, USA



Kay Hayes
Denver, CO, USA



Tim Haylon
Worcester, MA, USA



Chuck Hunt
Atlanta, Georgia, USA



Support Group Facilitators (continued)



Emily Jones
Rochester, NY, USA



Mindy Kim
North Carolina, USA &
Adult Facebook Chat



Anke Klein
International German
Speakers



Leslie Krongold, EdD
Northern California, USA



Tom McPeck
DM2 Virtual Support
Group



Sherry Morris
Dallas, TX, USA



Bill Nuttall
Adult Facebook Chat



Suzanne Perkins
Michigan, USA



Bernhard Rogg
International German
Speakers



Ted Salwin
Indianapolis, IN, USA



Carolyn Valek
Worthington, OH, USA



Patrick Welker
Dallas, Texas, USA



Ann Woodbury
Utah & Mountain West
Region, USA

Learn more about our Support Group Facilitators here:
<https://www.myotonic.org/support-group-facilitators>.

MDF Research Fellows



Introducing the 2021 MDF Pre- and Postdoctoral Research Fellows! Trainees applied for support for projects focused on basic, translational, or clinical research in myotonic dystrophy (DM). This program not only supports meritorious research, but also helps continue to build a critical mass of researchers engaged in working on DM. To learn more about our MDF Research Fellows go to <https://www.myotonic.org/myotonic-fellows-grant-recipients>. Be sure to visit the Fellows' exhibit booths at the conference during Showcase hours to talk with them live about their research!



Raphael Benhamou, PhD
Scripps Research Institute



Talita Conte, PhD
University of Montreal



Kamyra Simone Edokpolor
Emory University
School of Medicine



Maya Gosztyla
UC San Diego



Benjamin M. Kidd
University of Florida



Sarah Overby
University of Valencia



Rong-Chi Hu
Baylor College of Medicine



Subodh Kumar Mishra, PhD
The RNA Institute,
University of Albany

MDF Staff



To learn more about MDF staff go to <https://www.myotonic.org/staff>.



Kate Beck
Special Projects Manager



Kleed Cumming
Communications &
Technology Manager



Allison Formal, MBA
Senior Science Advisor



Mike Knaapen
Program Director



Sara Littlefield
Development Associate



Nadine Skinner, PhD, MPA
Research Coordinator



Tanya Stevenson, EdD, MPH
Chief Executive Officer



MDF Scientific Advisory Committee



The MDF Scientific Advisory Committee is comprised of individuals who collectively have devoted more than ninety years to studying muscle diseases, specifically myotonic dystrophy. Read more here: <https://www.myotonic.org/scientific-advisory-committee>.



Tetsuo Ashizawa, MD
Houston Methodist
Neurological Institute



Guillaume Bassez,
MD, PhD
Institut de Myologie



Kathie Bishop, PhD
Acadia Pharmaceuticals



Thomas A. Cooper, MD
Baylor College of
Medicine



John W. Day, MD, PhD
Stanford University



Douglas Kerr, MD, PhD,
MBA
Generation Bio



Darren Monckton, PhD
University of Glasgow



Richard Moxley III, MD
Emeritus Member
University of
Rochester



Laura Ranum, PhD
University of
Florida



Charles Thornton, MD
University of Rochester

MDF Board of Directors



The Myotonic Dystrophy Foundation's Board of Directors is comprised of volunteer leaders from the public and private sectors, most of whom are either living with myotonic dystrophy or have loved ones with the disorder. The Board works closely with the MDF Staff and Scientific Advisory Committee. To learn more about MDF Board of Directors go to <https://www.myotonic.org/board-directors>. Visit the Board in their virtual Exhibit Booth during Conference Showcase hours.



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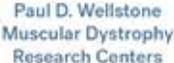
BRONZE



Our Global Alliance



MDF is proud to be a founding member of the Global Alliance for myotonic dystrophy awareness! Comprised of dozens of organizations and institutions around the world dedicated to helping raise awareness about DM, all members of the Global Alliance will be celebrating International Myotonic Dystrophy Awareness Day on September 15th. Learn more and join the Alliance here: <https://www.myotonic.org/international-dm-day>

 Australia	 Belgium	 Canada	 Canada	 Denmark
 Europe	 France	 Germany	 Greece	 Italy
 Japan	 Netherlands	 Netherlands	 New Zealand	 Spain
 Switzerland	 United Kingdom	 United Kingdom	 United Kingdom	 United Kingdom
 United Kingdom	 USA	 USA	 USA	 USA
 USA	 USA	 USA	 USA	 USA
 USA	 USA	 USA	 USA	 USA
 USA	 USA	 USA	 USA	 USA
 USA	 USA	 USA	 USA	 USA
 Worldwide				



Keep in touch! The MDF monthly e-newsletter, the MDF Dispatch, provides you with up-to-date information on research advances, DM daily living strategies, upcoming events and stories from community members. It is the best way to stay current on news in the DM community.

Sign up here: <https://www.myotonic.org/news-and-events/newsletter-archive>



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