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

Welcome ................................................................. 1
Conference Checklist .................................................... 2
Agenda for Thursday, September 9, 2021 ............................. 3
Agenda for Friday, September 10, 2021 .............................. 3
Agenda for Saturday, September 11, 2021 ........................... 4
Conference Tracks
  Track 1: DM1 .......................................................... 5
  Track 2: DM2 .......................................................... 5
  Track 3: Caregivers & Self-care ...................................... 6
  Track 4: Professionals .................................................. 7
General Sessions ......................................................... 8
Conference Speakers .................................................... 10
Sponsor Showcase ....................................................... 15
Exhibitor Showcase ..................................................... 16
Continue Learning With MDF .......................................... 18
MDF Support Group Facilitators ..................................... 19
MDF Research Fellows .................................................. 21
MDF Staff ............................................................... 21
MDF Scientific Advisory Committee ................................. 22
MDF Board of Directors ............................................... 22
Thank You to Our Sponsors .......................................... 23
Our Global Alliance ..................................................... 24
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,

Tanya Stevenson, EdD, MPH
Chief Executive Officer
Conference Checklist

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

<table>
<thead>
<tr>
<th>Time*</th>
<th>Session</th>
</tr>
</thead>
<tbody>
<tr>
<td>9:00 AM – 5:00 PM</td>
<td>Exhibitor Preview</td>
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<tr>
<td>3:00 PM – 4:00 PM</td>
<td>Ask-the-MDF-Staff-Live</td>
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<tr>
<td>4:00 PM – 5:30 PM</td>
<td>First Timers’ Tea</td>
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</tbody>
</table>

## Agenda for Friday, September 10, 2021

<table>
<thead>
<tr>
<th>Time*</th>
<th>Track 1: DM1</th>
<th>Track 2: DM2</th>
<th>Track 3: Caregivers &amp; Self-care</th>
<th>Track 4: Professional</th>
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</thead>
<tbody>
<tr>
<td>8:00 AM – 8:50 AM</td>
<td>Adaptive Yoga</td>
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<tr>
<td>9:00 AM – 9:50 AM</td>
<td>Opening Session: Welcome &amp; State of the Foundation</td>
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<tr>
<td>10:00 AM – 11:15 AM</td>
<td>DM1: Disease Development, Symptoms, &amp; Management</td>
<td>DM2: Disease Development, Symptoms, &amp; Management</td>
<td>Acceptance &amp; Commitment: Strategies for Good Mental Health</td>
<td>Repeat Instability &amp; Stabilization</td>
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<tr>
<td>11:15 AM – 11:30 AM</td>
<td>Break</td>
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<tr>
<td>11:30 AM – 12:45 PM</td>
<td>Adaptive Strength Training</td>
<td>JOA: Getting to Know One Another</td>
<td>Exhibitor Showcase</td>
<td>Research Poster Showcase</td>
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<tr>
<td>12:45 PM – 1:00 PM</td>
<td>Break</td>
<td></td>
<td></td>
<td>NIH Research Funding Opportunities &amp; First Look at New DM Data from CDC &amp; Marigold Foundation</td>
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<tr>
<td>1:00 PM – 1:45 PM</td>
<td>Industry Updates Part 1</td>
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<tr>
<td>1:45 PM – 2:00 PM</td>
<td>Break</td>
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<tr>
<td>2:00 PM – 3:15 PM</td>
<td>State of DM1 Research &amp; Ways to Engage</td>
<td>State of DM2 Research &amp; Ways to Engage</td>
<td>Talking about DM to Children, Family Members, &amp; Doctors</td>
<td>Mechanistic Aspects of the Heart &amp; CNS</td>
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<tr>
<td>3:15 PM – 3:30 PM</td>
<td>Break</td>
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<tr>
<td>3:30 PM – 3:50 PM</td>
<td>Special Performance by Singer-Songwriter Eric Hutchinson!</td>
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<tr>
<td>4:00 PM – 5:00 PM</td>
<td>Facilitated Networking</td>
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<td>Exhibitor Showcase</td>
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*All times Pacific Daylight Time (Pacific). The conference website should adjust the online program agenda to read in local time zones.*
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<th>Track 4: Professional</th>
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<tr>
<td>8:00 AM - 8:50 AM</td>
<td>Exercise &amp; Movement Activity</td>
<td>Exhibitor Showcase</td>
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<tr>
<td>9:00 AM - 10:15 AM</td>
<td>Day 2 Welcome: Stories of Inspiration</td>
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<tr>
<td>10:15 AM - 10:30 AM</td>
<td>Break</td>
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<tr>
<td>10:30 AM - 11:45 AM</td>
<td>Clinical Trial Readiness Workshop</td>
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<td>Advocacy &amp; Awareness Workshop - Get Ready for International DM Awareness Day</td>
<td>Gene Editing &amp; DM</td>
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<td>11:45 AM - 12:00 PM</td>
<td>Break</td>
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<tr>
<td>12:00 PM - 12:50 PM</td>
<td>Sit Fit</td>
<td>JOA: Games &amp; Networking</td>
<td>Exhibitor Showcase</td>
<td>Research Poster Showcase</td>
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<tr>
<td>1:00 PM - 1:45 PM</td>
<td>Industry Updates Part 2</td>
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<tr>
<td>1:45 PM - 2:00 PM</td>
<td>Break</td>
<td></td>
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<tr>
<td>2:00 PM - 3:15 PM</td>
<td>Stump the Expert - DM1</td>
<td>Stump the Expert - DM2</td>
<td>Stump the Expert - Health Insurance</td>
<td>Clinical Updates: Cardiac Management, DM Clinical Research Network, &amp; Brain Manifestations of DM1</td>
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<td>Break</td>
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<tr>
<td>3:30 PM - 4:45 PM</td>
<td>Living Your Best Life: Community Panels</td>
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<tr>
<td>4:45 PM - 5:00 PM</td>
<td>Break</td>
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<tr>
<td>5:00 PM - 6:00 PM</td>
<td>Dance Party!</td>
<td>Networking Lounge</td>
<td>Exhibitor Showcase</td>
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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: DM2

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.

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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.
General Sessions

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.
Join us for an evening with our families and friends from around the world for our MYOTONIC DYSTROPHY FOUNDATION 2021 Virtual Gala.

Friday October 22, 2021
5:30–6:30 pm PT / 8:30–9:30 pm ET

PROGRAM TO INCLUDE
Voices from the global myotonic dystrophy community
Live auction  •  Paddle raise

To register or donate, please visit MYOTONIC.ORG/GALA

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

Gala Committee

Martha Montag Brown (Co-Chair)
Erica Kelly (Co-Chair)
Leslie Lynch
Elizabeth Florence

MDF Board of Directors

Jeremy Kelly (Chair)
Martha Montag Brown (Vice-Chair)
Elizabeth Florence
David Herbert
David Berman
John Fitzpatrick
Joel Revill
John Day, MD, PhD
Charles Thornton, MD
Thomas McPeek

Journey to a Cure
Conference Speakers

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

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

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

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

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

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

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

David Brand  
MDF Community Member  
*Advocacy and Awareness Workshop*

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

Teresa Buffone  
MDF Canada Support Group Facilitator  
*Advocacy and Awareness Workshop*

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*

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

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

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

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

Valerie Cullen, PhD  
Senior Vice President, Research  
Expansion Therapeutics  
*Industry Updates*
## Conference Speakers (continued)

<table>
<thead>
<tr>
<th>Name</th>
<th>Title</th>
<th>Institution/Role</th>
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<tbody>
<tr>
<td>John Day, MD, PhD</td>
<td>Prof. of Neurology, Pediatrics &amp; Pathology Director, Neuromuscular Medicine, Stanford Neuroscience Health Center</td>
<td>MDF Board of Directors &amp; Scientific Advisory Committee</td>
</tr>
<tr>
<td>Jeffrey M. Dayno, MD</td>
<td>Chief Medical Officer, Harmony Biosciences</td>
<td>Industry Updates</td>
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<td>Maricela Delgado</td>
<td>MDF Community Member</td>
<td>Living Your Best Life: A Community Panel for CDM Families</td>
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<tr>
<td>Vincent Dion, PhD</td>
<td>Professor, Dementia Research Institute, Cardiff University</td>
<td>Gene Editing &amp; DM</td>
</tr>
<tr>
<td>Matthew Disney, PhD</td>
<td>Professor at Scripps Research Institute, Founder Expansion Therapeutics</td>
<td>Research Updates on DM2 &amp; RAN Proteins as a Therapeutic Target</td>
</tr>
<tr>
<td>Lorraine Dressler, RN, CPHQ</td>
<td>MDF Southern California Support Group Facilitator</td>
<td>Living Your Best Life: A Community Panel for CDM Families</td>
</tr>
<tr>
<td>Ashish Dugar, PhD</td>
<td>SVP &amp; Global Head of Medical Affairs, Dyne Therapeutics</td>
<td>Industry Updates</td>
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<tr>
<td>Basma Gale</td>
<td>Wellbeing Coach &amp; Yoga Teacher</td>
<td>Adaptive Yoga</td>
</tr>
<tr>
<td>Laura Gershenson</td>
<td>MDF Community Member</td>
<td>Living Your Best Life: A Community Panel for Individuals Living with DM1</td>
</tr>
<tr>
<td>Christopher D. Graham, PhD, DClinPsychol</td>
<td>Clinical Psychologist, Senior Lecturer in Clinical Psychology &amp; Academic Director, Clinical Psychology Training Program</td>
<td>Queen’s University, Belfast</td>
</tr>
<tr>
<td>Johanna Hamel, MD</td>
<td>Assistant Professor of Neurology, Pathology &amp; Laboratory Medicine, University of Rochester</td>
<td>DM2: Disease Development, Symptoms, and Management</td>
</tr>
<tr>
<td>Jodie Howell, LPN</td>
<td>Certified Clinical Research Coordinator Nurse, Virginia Commonwealth University</td>
<td>Clinical Trial Readiness Workshop</td>
</tr>
<tr>
<td>Eric Hutchinson</td>
<td>Performing Artist &amp; MDF Community Member</td>
<td>Virtual Concert</td>
</tr>
<tr>
<td>Lisa Harvey-Duren, MBA</td>
<td>Founding Executive Director, Myotonic Dystrophy Foundation</td>
<td>Day 2 Welcome: Stories of Inspiration</td>
</tr>
<tr>
<td>Sarah Howe, MBA</td>
<td>Program Manager, Marigold Foundation</td>
<td>NIH Research Funding Opportunities &amp; First Look at New DM Data from CDC &amp; Marigold Foundation</td>
</tr>
<tr>
<td>Chuck Hunt</td>
<td>MDF Georgia Support Group Facilitator</td>
<td>Living Your Best Life: A Community Panel for Veterans</td>
</tr>
</tbody>
</table>
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*

Beatriz Llamusi, PhD  
Chief Executive Officer  
ARTHEx biotech  
*Industry Updates*

Ibraheem Mahmood  
Chief Executive Officer  
AMO Pharma  
*Industry Updates*

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

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, FHFS  
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)

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

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

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

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

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

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

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

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

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

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*

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  
*NIDH 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*

Carolyn Valek  
MDF Ohio Support Group Facilitator  
*Juvenile-onset Adult Programs & Networking*  
*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 Wiggans  
Above & Beyond Award Recipient & MDF Community Member  
*Day 2 Welcome: Stories of Inspiration*

Glen Wiggans  
MDF Community Member  
*Day 2 Welcome: Stories of Inspiration*

Paul Wiggans  
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*
**Sponsor Showcase**

**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.
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 relieve 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.
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](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](https://www.myotonic.org/ask-expert-series)

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. Lean more and register here: [https://myotonicregistry.patientcrossroads.org/index.php](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](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](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](https://www.myotonic.org/find-support)
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](https://www.myotonic.org/find-support).

Learn more about our Support Group Facilitators here: [https://www.myotonic.org/support-group-facilitators](https://www.myotonic.org/support-group-facilitators).

Find out about upcoming support groups and events on our calendar: [https://www.myotonic.org/calendar/month](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](mailto:info@myotonic.org).
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 McPeek
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.
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!

MDF Staff

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

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

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.

Jeremy Kelly
Board Chair &
Lifetime Trustee

Martha Montag Brown
Vice-Chair

Elizabeth Florence
Secretary

David Herbert
Treasurer

David Berman, MBA
Board Member

John W. Day, MD, PhD
Board Member

John Fitzpatrick
Board Member

Thomas “Tom” McPeek
Board Member

Joel Revill
Board Member

Charles Thornton, MD
Board Member
Thank You to Our Sponsors

PLATINUM

GOLD

SILVER

BRONZE
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
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.