

Welcome!

2024 MDF Support Group Facilitator Training

Chicago, IL

Tanya Stevenson, EdD, MDF
Chief Executive Officer



Our Vision

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

Our Mission

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

We support and connect the myotonic dystrophy **Community**

We provide resources and advocate for **Care**

We accelerate research toward treatments and a **Cure**

Founded in 2007

Invested over \$25million in DM research and programs.

MDF is now the largest DM-focused patient advocacy organization in the world, serving tens of thousands of individuals and families across the US and 139 countries.

Areas of Focus

Programs/Resources for Individuals/Families:

- Strengthen our community

Clinical Education

- Educate the healthcare community, including clinicians, insurance companies, and other healthcare providers, for improved access to quality care and diagnostic tools

Advocacy

- Increase federal funding for DM research, educate FDA, advance policies to improve QOL

Accelerate Drug Development

- Fund new research projects to evolve our understanding of DM, develop the next generation of DM researchers, support clinical trials

Meet Team MDF



Tanya Stevenson, EdD, MPH
Chief Executive Officer



Andy Rohrwasser, PhD, MBA
Chief Scientific Officer



Kate Beck
Director of Development



Mindy Buchanan
Director of Programs



Kleed Cumming
Director of Communications
& Technology



Lucie Shiffman
Senior Manager of
Community Engagement



Emily Romney, MPA
Community Education Manager



Nadine Skinner, PhD, MPA
Research Grants Manager



Sofia Olmos, PhD
Myotonic Dystrophy Family
Registry Coordinator



Genevieve Wiegler
Communications Associate

Our Consultants



Mindy Kim
Registry Outreach Specialist



Ruth Sheldon, MPH, MSW
Health Resources Coordinator



Kevin Brennan
Advocacy Consultant

MDF Board of Directors



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MDF Scientific Advisory Committee



Andy Berglund, PhD
Committee Chair



Charles Thornton



Cynthia Gagnon, MD



Darren Monckton, PhD



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Guillaume Bassez, MD, PhD



Jacinda Sampson, MD, PhD



John W. Day, MD, PhD



Kathie Bishop, PhD



Laura Ranum, PhD



**Nicholas E. Johnson, MD,
M.Sci, FAAN**



Thomas Cooper, MD



Richard Moxley III, MD
Emeritus Member



Tetsuo Ashizawa, MD
Emeritus Member

Today: MDF Support Group Facilitators



Alexandra LeBoeuf • Anke Klein • Ann Woodbury
Araceli Mera • Bernhard Rogg • Bill Nuttall • Carolyn
Valek • Chuck Hunt • Cindy Hubert David Kugler •
Emily Jones • Guillermo Zubillaga Janis Jaffe •
Jeannine DeSoi • Jodie Howell • John Cooley •
Jonathan Freedman • Julie LeBoeuf • Kay Hayes • Kim
McPeek • Kristen McClintock • Mark Coplin • Mindy
Kim • Patricia Gibson • Rashid Kassir • Rob Besecker
Samantha Welsh • Sarah Berman • Susan “Glenda”
Winson • Suzanne Perkins • Ted Salwin • Haley
Martinelli • Scott Virgo • Thomas (Tom) McPeek

10 New Today!

Annette Rnjak • Barbara Ochoa • Beth Feigenblatt •
Caroline Easterling • Jim Dolan • Kathie Thorsland •
Lois Schenk • Rose Albanese • Ryan Vogels •
Shaun Moore

Support Group Program: Brief History

2007	<i>MDF Founded</i>
2007	<i>SGFs migrated from other organizations to begin hosting DM-only groups</i>
2012	<i>Official launch of MDF SG program under Leslie Krongold's leadership</i>
2012-18	<i>First SGF Manual Developed and more SGFs recruited</i>
2018	<i>Launch of German-speaking SG (3 countries via phone)</i>
<i>Continued growing slowly until 2020: moved to virtual</i>	
2021	<i>Strategic Plan Development</i>
2022	<i>Held Community Meetings around the US to assess high need areas</i>
2022	<i>SGF Recruitment Campaign = 15 new SGFs + 8 new groups launched!</i>
2022	<i>Launch of Spanish-speaking SG (5+ countries)</i>

Where are MDF Support Groups Now?

#s	Details
30	Support Groups
45	SGFs (a record!)
5	Facebook Groups
7	Facebook Moderators
200	Average # of Support Meetings/Activities/yr
7	Average # of Participants/Meeting

Who is Here?

- Over 40 attendees
- 2 Countries
- 19 US States
- SGFs w/ 0 to 18 years experience
- Ann, Carolyn, Chuck: 15+ yrs each!
- 154 years of cumulative SGF experience!!



YOU
are the
HEART
of our
Community!



Characteristics of Strong Community Leaders

- Open-minded
- Empathetic (with boundaries)
- Self-aware
- Optimistic
- Ability to improvise and be flexible
- Clear communication
- Possess Organizational and Time Management skills
- Problem solving and conflict management

- **Support for yourself!**

Additional Characteristics of Strong Support Group Facilitators

- Welcome and embrace those struggling AND thriving
- Self-less
- Brave
- Share stories, vulnerabilities
- Create and foster a safe space for all

- **You cultivate hope!**

Support Groups and the MDF Strategic Plan

- Development of the Plan
 - SGFs Served on the Planning Committee (1/4 of committee; Loraine, Leslie, Tom)
 - Updated mission: **Community, Care and Cure**
 - Creation of MDF's Theory of Change: Community is 1/3 of that Framework
- Some of the Related Plan Priorities
 - Pilot New Support Groups
 - New Geographies and Diverse Stakeholders (started w/Comm Meetings)
 - Develop Continuum to Define Community Engagement
 - Re-engage Those Who Have Drifted
 - Find and Welcome New Community Members
 - Develop New Resources
 - Build awareness, empower and self-advocate
 - Invest in our **Community Leaders**
 - Provide Training for SGFs
 - Dedicated Support Staff (Mounica → Lucie)
 - Virtual technology
 - Funding to Travel to Essential Events

Why are We Here Today?

This training is an investment in **you** as a community leader, a connector.

MDF believes you change people's lives. You make people feel seen, heard, valued.

You ensure people are not alone on their journeys. And that they know that.

We want to help you do your chosen job well, and continue to grow stronger.

We believe in you.

Housekeeping Items

- In this room together for all day programming (**West Ballroom**)
- Meal tickets at registration
- Bar (before dinner) in foyer
- Dinner will be behind the air wall (**East Ballroom**)
- Sunday will have additional breakout rooms
- Bring your computers with you today (not likely needed Sunday)
- Bathrooms down the hall; Family Bathrooms around the corner

Thank You to Our SGF Training Sponsor



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Thank You!

We Appreciate You!

We are Grateful You are Here!