



Join TeamMDF!

Are you looking to make a more sustained commitment in the fight against myotonic dystrophy? Are you interested in joining forces with MDF to create resources that will serve more members of the DM community and drive research? If you are, **TeamMDF** needs you!

TeamMDF volunteers agree to:

- A formal volunteer commitment (depending on volunteer role, activities include time spent moderating the MDF Community Forum, providing phone Peer-to-Peer Warmline support, helping coordinate medical professionals referral lists, planning and executing fundraising efforts, etc.);
- Receive training from our Community Engagement Manager and Outreach Director to ensure the DM community is being served in the best way possible;
- Participate in monthly webinars and other training opportunities as available;
- Distribute MDF communications (e.g. articles, invitations, referral lists, MDF Toolkit, etc.) to increase awareness of DM in your area;
- Share experiences, ideas, best practices, and solutions with other **TeamMDF** volunteers and the MDF community;
- Promote the MDF calendar of events, including fundraising or awareness campaigns, regardless of volunteer role;
- Participate and encourage others to join the Myotonic Dystrophy Family Registry, tissue donation programs, and other research efforts;
- Identify local medical professionals, social service professionals, services providers, and other organizations that currently provide services to the DM community, for recommendation to our Medical Professionals Referral List and global resources database;
- Provide feedback to MDF on the impact and quality of **TeamMDF** programs and objectives.

TeamMDF volunteers receive ongoing support and resources from the MDF staff.

Our available volunteer roles are:

ADVOCACY

- Advocate for increased rare disease funding and critical legislation;
- Respond to calls-to-action using our online system;
- Attend in-person meetings with local legislators and members of Congress when they are in town;
- Help obtain proclamations for Rare Disease Day in February.

EDUCATION & OUTREACH

- Distribute packets to healthcare professionals and promote the Myotonic Dystrophy Family Registry;
- Discuss myotonic dystrophy with healthcare professionals and medical students;
- Seek out and volunteer at health fairs to raise public awareness about myotonic dystrophy;
- Refer your local medical professionals to our Medical Professionals Referral List, and find new doctors in the area who have treated others with DM.

FUNDRAISING

- Plan and execute events and fundraisers, on a small or large scale;
- Help spread the word about our existing fundraising campaigns and events;
- Provide input about what type of events we should pursue on an annual basis in your area.

MEDIA & SOCIAL MEDIA

- Notify the media about local fundraising and awareness efforts, and tell your story and other DM community members' stories to the local media;
- Promote national campaigns, such as Rare Disease Day and our national Dine Out for DM day;
- Write letters to the editor using approved templates;
- Re-post social media posts to your networks (Facebook, Twitter, Instagram, YouTube). Engage your social media networks using approved hashtags.

SUPPORT GROUPS & WARMLINE

- Lead local support group meetings, on a quarterly or monthly basis, and promote support group meetings in your community;
- Keep track of meeting attendees and report them to the Outreach Director after meetings;
- Promote MDF campaigns at meetings, such as local fundraisers or national programming (Rare Disease Day, Grandparents Campaign, etc.);
- Staff our Peer-to-Peer Warmline and answer phone calls and emails from the DM community.

For questions and more information, please contact Aly Galloway, MDF Community Engagement Manager, at 415-800-7640 or alyssa.galloway@myotonic.org.