

MDF Support Group Facilitator Requirements

Support group facilitators (SGFs) for the Myotonic Dystrophy Foundation (MDF) are essential for achieving the MDF mission: 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.

SGFs act as the foundation of the community component by bringing families together. By sharing your time and talent, and with the resources of the Foundation – especially its website, contact lists, and up-to-date information about DM – your volunteerism can help individuals living with DM and their families end isolation, understand DM and how to live with it, join a community, and learn how to empower themselves and fight back.

The goal of SGFs is to bring together individuals diagnosed with DM and their families for mutual support and information sharing. They achieve this goal by:

- Holding regular support group meetings focused on the needs of individuals diagnosed with DM and their caregivers.
- Facilitating meetings that foster mutual support and information sharing among attendees, ensuring that privacy and confidentiality are respected, and making space for every member to be heard and to hear others.
- Directing attendees to accurate, up-to-date information and resources about DM from MDF.

All MDF SGFs agree to:

- Advance the mission of MDF.
- Plan, promote, and run a minimum of four support group meetings each year.
- Seek assistance from MDF if experience difficulty planning or running meetings.
- Read, understand, and implement the guidelines outlined in the MDF support group facilitator manual and other guidance issued by MDF.

- Submit meeting information, such as the date, time, and location (if virtual, the link and/or call information), and special guests such as subject matter experts, to MDF at least one month in advance.
- Report to MDF after meetings about attendance, any issues that arise, or other relevant information.
- Establish confidentiality as a guideline during meetings.
- Never give medical advice¹ but encourage attendees to seek medical advice from their own healthcare provider(s).
- Refer attendees to MDF for resources and information.
- Perform all duties on a voluntary basis.
- Notify MDF about ending the volunteer agreement or taking a break from service.
- Work with an MDF Support Group co-facilitator or back-up facilitator to maintain continuity and consistency for the group.
- Attend MDF SGF meetings each month. When unable to attend, check in with MDF within one week of the meeting.
- Attend at least one SGF group meeting with the MDF Social worker per year.
- Attend annual training in-person or virtually.

Questions?

Have questions about the duties of an MDF Support Group Facilitators? Contact MDF Senior Manager of Community Engagement, Lucie Shiffman, lucie.shiffman@myotonic.org.

¹ “Medical advice” is defined as a professional, formal opinion about what someone must do to preserve or improve health based on the best available medical science. It is perfectly appropriate for group members and facilitators to share opinions and experiences, but it is never appropriate to represent them as medical advice