

Support Group Facilitator Agreements 2025

SGF Role

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 are often a friendly face that community members turn to with questions and to help them navigate their day-to-day journey.
- The SGF team plays a vital leadership role within the DM community. SGFs are volunteer community leaders who receive training and support from the MDF to create spaces for those living with DM, and their caregivers to confidentially share their experiences, learn from others impacted by DM, and access resources and information to help improve quality of life.
- SGFs provide leadership for support groups that are sponsored by the MDF. SGFs make a two-year commitment and agree to follow the SGF roles, responsibilities, and support group policies provided by the MDF. All SGFs must host a minimum of four support groups per year to remain in the position.

Support Group Management:

- Collaborates with support group co-facilitator (if you have one).
- Coordinates support group meeting logistics either in-person or virtually, including frequency of meetings and meeting date.
 - For in-person: identifies appropriate location, secures meeting fees, and procures snacks and/or refreshments.
 - For virtual meeting: works with MDF to establish Zoom.
- Communicates meeting date and time to group participants either via phone or email.
- Attends and leads support group meetings as scheduled.
- If meeting guests are desired, generates topic ideas for support group meetings and recruits, or works with MDF to recruit guest speakers.
- Follow the MDF Support Group Guidelines on page 31 of the SGF handbook
- Communicate the group norms and agreements to group members
- Ensure group members are following norms and agreements
- Ensure that group members are not giving medical advice, or speaking about their participation in clinical trials.

Technology:

- SGFs should have access to adequate technology necessary to perform their volunteer work.

- SGFs will need to be able to join Zoom Meetings, either for their own groups, or for monthly SGF Meetings
- For virtual support groups: SGFs are encouraged to check their Zoom registration, send out registration reminders through Zoom
- SGF Webpages: SGFs agree to verify the information on the SGF website
- SGF Email Account (@sgf.myotonic.org)
 - SGFs need to be able to log in and access their MDF email accounts regularly
 - SGFs are expected to use their SGF email to send correspondence to their support groups
 - SGFs agree to use and keep the correct MDF branded Signature
 - When emailing their support group, SGFs should follow the following guidelines:
 - SGFs should use BCC (Blind Carbon Copy) when emailing their community members. This helps us keep our community safe by protecting their private information.
 - SGFs should email their support groups with reminders about Support Group events
 - Want to send other resources or information? We appreciate you keeping your support group up to date, please follow these guidelines, and if you have any doubt, ask MDF Sr. Manager of Community Engagement before sending.

Share with your group	Check with Sr. Manager of Community Engagement
MDF resources and toolkits	Invitations to participate in research
MDF Articles and Announcements	Information shared from local partners or group members
MDF events	Invitations to participate in focus groups, registries, or similar
Connecting a group member with another SGF (using their MDF email address)	•

Finance

- SGFs will receive up to \$500 in expense reimbursement for travel to an MDF Conference. This can be used for airfare, mileage reimbursement (\$.67/mile), or other travel related expenses (meals while traveling).
- In person Group Event reimbursement:
 - SGFs can receive up to \$50 reimbursement per in-person support group event.
 - This money can be used for:
 - Refreshments: healthy snacks, non-alcoholic drinks, paper plates, napkins etc. (note: MDF will not reimburse for alcohol)
 - An activity (arts & craft, game night, etc.): craft supplies, or a game.
 - This money is limited and will be reimbursed on a rolling basis.

- SGFs can receive reimbursement for event space up to \$100, if the cost of a space rental exceeds \$100, please discuss with Sr. Manager of Community Engagement before reserving.
- SGF reimbursement requests must be received no later than 6 months after purchase, and must include receipts for all items to be reimbursed
 - To submit a reimbursement request, email the required receipts, and event information to Sr. Manager of Community Engagement.
 - If tipping is included for reimbursement, please note that MDF reimburses up to 15% tip. Anything over this percentage is covered by the SGF.
- SGFs may request to receive MDF one pagers to share with community members at in person events, these requests must be made at least one month prior to the date of the event.
- SGFs may request to receive MDF one-pagers to share with their clinicians or clinic offices. Please expect up to 2 weeks for shipments to arrive.
- MDF Support Group activities are a free resource to the community. SGFs should not receive dues or any money from community members for any reason, such as funding in-person events, etc. SGFs are not allowed to open bank accounts to keep funds from community members.
 - If community members are interested in giving funds to support the group, they can provide snacks or refreshments. If they are interested in fundraising for MDF we can connect them with the Director of Development
 - If a community member is ill, loses a loved one, or is celebrating a life change (marriage, child etc) you can send them an SGF greeting card.

Representing MDF

- Raise awareness of current MDF educational initiatives, including resources available at www.myotonic.org, special events, and conferences.
- Share relevant MDF resources and toolkits, utilize SGF discussion guides to encourage community members to use resources.
- SGFs are asked, but not required, to attend an MDF Conference each year.

Communicating with MDF

- Ensures MDF has correct meeting dates and times set up for promotion and events calendar.
- Provide MDF with up to date meeting information such as date and time at minimum once every six months.
- Communicate special speaker or topics 3 weeks in advance of meeting date.
 - Speakers secured by SGFs should be shared with MDF prior to confirming their speaking engagement for the group.
- Communicate special and/or difficult situations or incidents which arise during a support group meeting within 48 hours.

- Reporting attendance: If your support group does not use Zoom registration or is in person, you must report attendance of support group members. For your first reporting, you must provide the following information:
 - First and Last Name
 - State, City
 - Email address
 - Topic of interest (DM1, DM2, JOA, CDM)
 - Relationship to DM.
- Should an SGF plan to host a group in a private home or business, he/she/they must first seek MDF's approval, as well as provide documentation of insurance.

Training, Check-ins and Support

- Attend monthly SGF virtual meeting, at least quarterly
- Attend, either in-person or virtually, Annual SGF training
- Attend SGF support group with Vanessa Zinke at least twice per year or schedule two 1-1s with her.
- Schedule at least 4 check-ins per year with Sr. Manager of Community Engagement. Either 1-1, or with your co-facilitator.

Leave

- It is recognized that SGF's may need to step away from their role due to personal situations, either temporarily or permanently. In this case, SGF's should contact the Senior Manager of Community Engagement as soon as this need arises so that a smooth transition may occur for both the SGF and their support group participants.
- After completing each 2-year commitment as a volunteer, SGFs will be asked to take at least 2 months off from responsibility, or one meeting if their group meets quarterly.
 - This process will start during a check in with the Sr. Manager of Community Engagement.
 - During this check in we will make a plan for when the break is being taken, and when/if it will end.
 - SGFs are welcome back into their role after this break and check in with the Sr. Manager of Community Engagement.
- After this break, veteran SGFs will be asked to check in with the Sr. Manager of Community Engagement and discuss capacity, energy, and future plans and schedules.

Confidentiality:

As an MDF Support Group Facilitator activities may be performed which may require disclosure of confidential or proprietary information (confidential information is any information of any kind, nature, or description concerning any matters affecting or relating to the services for Foundation, business or operations, donors, data, researchers, clinicians, and/or those served by Foundation.)

- SGF will hold the confidential information received from MDF or anyone it serves in strict confidence and shall exercise a reasonable degree of care to prevent disclosure to others.
- SGFs will not disclose or divulge either directly or indirectly the confidential information to others unless authorized to do so in writing by MDF.
- SGFs will not reproduce confidential or proprietary information, resources or tools, nor use this information commercially for any other purpose other than the performance of his/her/their duties for MDF.
- SGF will, upon the request, or upon exit or termination, deliver to MDF any notes, documents, and materials received from MDF or originating from their activities for MDF.
- The obligation to protect information confidentiality will survive SGF's term in their role, and will last indefinitely unless otherwise stated.
- SGFs will create a safe space for their community members and agree not to share notes and community member experiences after meetings.

MDF reserves the right to take disciplinary action, up to and including termination from the volunteer SGF role for violations of this agreement.