

Support Group Facilitators and Patient Days Guidelines

What is a Patient Day?

- A Patient Day is an event hosted by a clinic or academic institution. It provides an opportunity for people living with DM, their families, and caregivers to learn more about research and treatments related to DM and/or other neuromuscular diseases.

Does MDF participate in Patient Days?

- MDF is excited so many clinics are interested in supporting and educating the DM community! Due to capacity and the work needed to host a successful Patient Day, MDF Staff does not initiate Patient Days, nor does MDF help facilitate the planning or execution of a Patient Day.
- MDF is happy to share printed resources that the community can utilize and give out during these days.
 - Resources include: DM and the Heart Community Guide, Mental Health Guide, Exercise Infographic, Anesthesia Guide for Community Members, and Quick Reference Consensus Based Care Recommendations. If additional resources are requested, the host clinic or institution may consider ordering a DM Essentials Box for Community Members.
- If a clinic or institution wants to partner with MDF on an event, the institution must reach out to MDF directly. These conversations take many months of planning and should not be initiated by SGFs.

Patient Days and Support Groups:

- Because Patient Days are not MDF affiliated events, sharing them with your support group must go through the same process of sharing other resources.
 - Please send all information to the Senior Manager of Community Engagement to make sure this event is appropriate to advertise to your support group.
- The host clinic or institution may reach out to members of the community for feedback or brainstorming for the event. However, this may not take place at the official MDF support group. SGFs may not share support group contact information with the institution. However, if members of the support group are interested in participating, SGF may choose to give the host clinic/institution contact information to the interested member of the group.

How can SGFs be involved in a Patient Day?

- SGFs can participate in Patient Days in a multitude of ways:
 - **As community members:** show up and participate in the day with your friends and families, learn from experts, and connect with the community.
 - **As volunteer leaders:** SGFs can help coordinate or plan a patient day with their clinic if they are interested. It is not an obligation or expectation for SGFs to support these events, and if you chose to volunteer your time for planning, it is in a separate capacity from your SGF duties. SGFs should not be in charge of planning or facilitating these days *as an MDF Support Group Facilitator*; the brunt of the responsibility will be on the local Clinic.
 - **Note:** As many of us know, clinics are often very busy, and they will appreciate all of the support they can get. It is important to pay attention to your capacity and make sure you aren't taking on too much work!
 - **In your official role as an SGF:** MDF encourages SGFs to host a table at Patient Day Events, if they are interested. This is not an official SGF obligation. If you are interested, you would order a box of MDF Resources at least 3 weeks in advance, and commit to sitting at a table and sharing these resources, along with information about MDF and our support group program with other community members.
 - **Note:** Often, these Patient Days are not DM exclusive, so be sure focus on sharing these resources and groups with the DM community.
 - SGF Resource Box:
 - SGFs can order a box of resources to give out free of charge. This box contains printed resources from our website.
 - SGFs can order a box of MDF tabling materials. This box will include resources, as well as a tablecloth .
 - **Note:** Because the tablecloth is an asset MDF uses regularly, SGFs will be responsible for ensuring the materials are returned. If there is a lost or missing item, the SGF will be responsible for covering the cost of replacing it. MDF will cover postage.