

5: ROLE DESCRIPTION - DMRF CANADA SUPPORT GROUP LEADER

Dystonia Medical Research Foundation (DMRF) Canada aims to provide support for the thousands of individuals who are affected by dystonia in Canada through the establishment and management of local support groups. Volunteer support group leaders help us to achieve this goal.

Support group leaders work with DMRF Canada to:

- Increase awareness of the condition and DMRF Canada in their local community.
- Provide an opportunity for persons affected by dystonia to meet others similarly affected.
- Offer relevant, valid, and reliable sources of educational information.
- Expand fundraising potential.
- Develop and enhance a relationship between DMRF Canada and the local community.

Location:

All volunteering is based within your local community or online. This could include the organization of regular (quarterly/semi-annual/annual) meetings or gatherings where individuals with dystonia can come together – either virtually or in person - to talk about their experiences, discuss challenges and successes, share stories and meet others with dystonia. It could also include the organization of other events, fundraisers, or any other opportunities that would allow an opportunity to raise the profile of dystonia and the DMRF Canada.

Key Responsibilities:

Distribution of responsibilities amongst the co-leaders is highly recommended. To ensure a well-functioning group, DMRF Canada encourages having multiple co-leaders to help support the different functions of the group based on co-leaders individual strengths.

1. Phone/email contact for support in your local area
 - a. Respond to patient support queries – over the phone and by email.
 - b. Provide feedback to DMRF Canada about the needs of the group, including additional support and training requirements.
2. Organizing meetings
 - a. Maintain an active support group with at least one meeting taking place each year and keeping DMRF Canada informed about meetings dates, times and locations.
3. Liaison/Ambassador
 - a. Distributing materials/connecting with the dystonia treaters/clinics in their area to ensure awareness and support is available.
 - b. Connect with local movement disorder clinics/dystonia treaters to ensure they are aware of - and referring patients to the local support group or DMRF Canada for

- resources and support.
- c. Build relationships with local physicians, health care professionals, government and community representatives, in order to increase dystonia awareness and group membership.
 - d. Circulate dystonia and DMRF Canada literature to support group members, health care providers, and others as needed.
 - e. Act as a local dystonia and DMRF Canada ambassador for their community. Promote the Support Group within their network.
 - f. Leverage DMRF Canada to ask for support in raising awareness of upcoming events as needed.

All leaders are encouraged to participate in DMRF Canada led training programs on opportunities and responsibilities of DMRF Canada Group Leaders via Webinar/conference (when required).

Length of Appointment /Time Commitment:

- Minimum commitment of one year.

Qualifications and Characteristics:

- Strong leadership skills;
- Strong organizational skills;
- Passionate about making a difference in the lives of others affected by dystonia;
- Comfortable speaking with individuals about their dystonia experience;
- General understanding of the various forms of dystonia;
- Flexibility, ability and interest in meeting with others in person or over the phone;
- Ability to understand and comply with DMRF Canada policies as described in the support group manual;
- Possesses good judgement, and an ability to maintain privacy and confidentiality.

Note: You do not need to have dystonia in order to be considered for this position.

Interested parties should email info@dystoniacanada.org