DYSTONIA
MEDICAL
RESEARCH
FOUNDATION
CANADA

FONDATION DE
RECHERCHE
MÉDICALE SUR LA
DYSTONIE
CANADA

serving all dystonia-affected people
désservant toutes personnes atteintes de dystonie

SUPPORT GROUP MANUAL

Dystonia Medical Research Foundation Canada
550 St. Clair Ave W, Unit 209,
Toronto, Ontario M6C 1A5

https://dystoniacanada.org/
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DYSTONIA MEDICAL RESEARCH FOUNDATION
SUPPORT GROUP MANUAL
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INTRODUCTION

Dear Support Group Leader,

Thank you for your willingness to form a DMRF Canada support group. You are now part of the foremost national organization dedicated to providing support to those with dystonia. This manual was created to provide assistance with the formation and development of affiliated support groups. We stand ready to assist you in your efforts to represent the organization on the local level.

Support group leaders often have to wear many hats. In addition to hosting meetings and responding to inquiries from patients, you may also have to work with the media to raise awareness or coordinate grassroots advocacy on a timely issue. This manual was created to assist you with all aspects of running a support group.

You will find that this manual is broken up into broad sections which focus on the main areas of support group leadership. Within each of these larger sections is more specific information and tips to help you quickly identify important tasks, organize more easily, and ensure that the support group runs smoothly. This format was used to make sure that you have accurate information on everything from planning a meeting to leading one of the meeting's discussions, and beyond.

The DMRF Canada may send you additional ideas and updated information on running support groups that can be added to this manual. The Manager of Community Engagement is available as the primary contact for support group leaders: offering guidance on starting, maintaining, and strengthening support groups. We hope you will continue to add information from the DMRF Canada, and details about your support group, to this manual so it remains a useful reference tool for you and future leaders of the support group.

Thank you again and please consider the DMRF Canada a willing and helpful partner as you work to lead and grow your support group.

Sincerely,

Stefanie Ince
Executive Director

About the Dystonia Medical Research Foundation Canada

The Dystonia Medical Research Foundation Canada was founded in 1976 by Samuel and Frances Belzberg of Vancouver, after their daughter was diagnosed with generalized dystonia.

The mission of the Dystonia Medical Research Foundation Canada (DMRFC) is to advance research for more treatments and ultimately a cure; to promote awareness and education; and to support the needs and well being of affected individuals and families. DMRFC is a registered non-profit Canadian charity governed by a volunteer Board of Directors.

DMRF Canada works in partnership with the Dystonia Medical Research Foundation in the United States to ensure funding of the best and most relevant dystonia medical research worldwide and partners with the Canadian Institute of Health Research (CIHR) and other like-minded research organizations to fund excellent dystonia research in Canada.

The Critical role of Support Groups

Coping with a chronic illness can take anyone outside of his or her comfort zone. Pre-diagnosis can be frightening and uncertain, while the loss of health or independence can be frustrating and stressful. Furthermore, serious personal issues can present themselves as patients struggle through changes in self-image and self-esteem presented through loss of independence or quality of life.

Peer support can help dystonia patients recover and thrive. By sharing knowledge and feelings, dystonia patients can learn from each other and take comfort in knowing that they are not facing an uncertain future alone. Support groups can help alleviate feelings of depression and promote a healthy mental attitude and better physical outcomes.

Support groups offer patients, family members, and friends a venue for discussing and validating their changing needs and feelings. They call upon Foundation resources and the experiences of members, offer companionship, and lessen feelings of loneliness and isolation. In addition, the support group serves as a trusted resource for accurate information. This is critical service as media and the Internet offer easy access to inaccurate or misleading information from unqualified or unchecked sources. As a patient’s needs change, so will their participation and interest in the support group and what it offers. It is important that the support group remains informal and welcoming so that all dystonia patients and their families can attend, share, and engage in the ways in which they are most comfortable.

While the support group can be many different things to dystonia patients, it should not be considered an alternative to appropriate medical treatments or therapies. The support group is a resource to address the needs of mind, body, and spirit, but it cannot be an alternative to a structured treatment plan prescribed by a medical professional.

The key function of the support group is support and education, and this can go beyond holding a regular meeting. E-mail, Facebook, and other technology makes it easier than ever for the group to stay in contact or for you to correspond with group members about upcoming events and activities. Your support group can be a valuable resource for all dystonia-affected individuals in your area.

The purpose of a DMRF Canada support group is to improve the member's quality of life by acting as a resource for information, an exchange for sharing coping strategies, and a forum to share experiences and knowledge. This manual will assist you with forming, coordinating, and operating an effective DMRF Canada support group. In addition, it will provide you with helpful information

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Dystonia Medical Research Foundation Canada Support Group Agreement

Congratulations on your decision to become a part of a national support network of dedicated persons working to support those affected by dystonia. Through your efforts as a support group leader, you will serve as a valuable resource for your community on dystonia. Thank you for your willingness to join the DMRF Canada and take on this important role.

The following agreement defines what is expected of DMRF Canada support groups and what you can expect from the Foundation. Please review this information. If you have questions, please do not hesitate to contact the DMRF Canada office.

Once you have carefully reviewed this agreement, please complete the authorization form and submit it to the DMRF Canada Office. The contact information for the National Office is:

Dystonia Medical Research Foundation Canada
550 St. Clair Ave W, Unit 209,
Toronto, Ontario M6C 1A5
Phone: (416) 488-6974
Toll Free: (800) 361-8061
E-mail: info@dystoniacanada.org

The Dystonia Medical Research Foundation Canada Agrees to:

1. Provide technical assistance and act in an advisory role in all aspects of operating the support group.
2. Supply Foundation materials at no charge for authorized support group use.
3. Keep the support group informed of all current DMRF Canada programs including: research grants, research contracts, awareness efforts, support programs, advocacy efforts and other activities that may be of interest to support group members.
4. Provide assistance in securing speakers, when appropriate, and topics for meetings.
5. To assist in the promotion of meetings/activities of the group.
6. Confer the use of its logo to the support group.
7. Maintain regular communications with the support group leader through routine and special mailings, electronic communications, and telephone calls.
8. Respond in a timely manner to all requests for assistance, serve meeting notices as requested, and post meeting information on the DMRF Canada web site.
9. Assist with group fund raising efforts, including but not limited to: providing gift acknowledgments/tax receipts, tracking gifts, providing indirect support for approved events, assisting in the promotion of approved events, and providing materials for approved events/activities
10. To highlight support group activities, as space allows, in issues of the Dystonia Canada Report and the Foundation's web site.

Our DMRF Canada Support Group Agrees to:

1. Be open to all persons, affected by all forms of dystonia.
2. Operate in a confidential manner. The group leader agrees to announce this at the start of each meeting as a reminder to participants that confidentiality is a critical component of the group since privacy is a concern of many participants.
3. Not discriminate against people attending meetings on the basis of race, color, religion, sex, national origin, disability, age, sexual orientation, marital status, or any other basis prohibited by law.
4. Provide dystonia information and dystonia-oriented programs free of charge to patients. (The group may decide to ask for contributions to cover the operating costs of the support group but it is understood – contributions are not required.)
5. Not to provide medical advice relating to diagnosis, treatments, or alternative therapies.
6. Not endorse institutions (such as hospitals), individuals (such as physicians) or products.
7. Recognize that the Dystonia logo is the property of the Foundation and the support group shall have the right to use the logo as long as it remains an authorized support group and the logo use is authorized by the national office.
8. If the group has a website or social media page, to comply with the DMRF Canada Support Group Website & Social Media Guidelines, as well as provide the URL for all sites to the National Office and add the DMRF Canada as an administrator to any group-run site or page.
9. Maintain the privacy of support group members and guest speakers in online spaces by obtaining verbal or written permission before posting pictures, videos, or audio recordings.
10. To respond appropriately and promptly to calls and emails from the public asking for information on the group, local dystonia resources and meetings; to understand that support group leaders will be temporarily removed from the DMRF Canada website and the group will be considered inactive if

the DMRF Canada has reached out to a support leader or contact several times within a 30-day period and has not received a response.

11. To respond appropriately and promptly to requests for information (such as membership lists and financial data) from the DMRF Canada office.
12. Should the support group decide to host a fundraiser, to comply with all accounting and fundraising guidelines, including but not limited to: informing the DMRF Canada office of their intent, providing names of donors to the national office so tax receipts can be produced, providing a complete accounting of the event that is audit ready, and forwarding the proceeds to the national office within 30 days following the day of the event or last day of the activity.
13. Provide the name of the leader and contact person, if different from the leader, and their contact information for use on the DMRF Canada website and support group promotional activities.
14. Report and communicate with the DMRF Canada National Office in Toronto, Ontario; promptly inform the DMRF Canada of any changes in contact information, such as phone numbers, mailing and email addresses.
15. Comply with and be bound by the policies & standards of the Foundation, and comply with all applicable laws.
16. Complete an annual reporting form as provided by the DMRF Canada national office.

Group Leader Information:

Name: ____

Address: ____

City: _______________________Province: _________________ Postal: ________________

Phone: _____________________ E-mail: ____________________________________

Group Leader Contact Information:

The contact information you provide below will be made available on the DMRF Canada website and will be listed on support group meeting promotions made through the DMRF Canada, including email, mail and Facebook.

Name: ____

City: ________________________State:____________________________________

Phone: ____________________Email: _____________________________________

I, ______________________________, the undersigned, acting for the Group to be known as the Dystonia Support Group of:

____ ,
(Name of the Group)

understand that the contact information provided will be made available to the public through the DMRF Canada website and support group meeting promotions. I understand that if I am deemed to be unreachable within a 30 day period my contact information will be removed from the DMRF Canada website and the group will be considered inactive until I have renewed contact with the National Office. I understand that the support group shall conform to all regulations and policies of the Dystonia Medical Research Foundation Canada, and that the Board of Directors of the Foundation, upon notice, reserves the right to alter the terms of this agreement and maintains the right to cancel authorization to operate the support group for any reason deemed by the Board to be sufficient. The parties agree to be bound by the agreement.

Group Leader's Signature: _______________________________ Date: ____________

DMRF Canada Executive Director: _______________________________ Date: ____________

Organizing a DMRF Canada Support Group

Recruiting members

From the very beginning it will be important to work with others who share your desire to form a support group. This will help establish a core of leadership for the support group which is necessary for the support group to be able to grow and thrive. Please consider enlisting the support of friends, family, and medical professionals as you work to establish this core group. You can also work to raise local or regional awareness to try and attract other highly motivated individuals who can assist you with forming this core group.

Finding Like Minded People – Enlist the cooperation and assistance of neurologists, movement disorder specialists, other healthcare providers and their staffs. The physicians will know of others who are interested in sharing common feelings and perceptions. Names of patients are confidential so this initial process may take time for the physician to ask others of their interest, but people will eventually respond.

The DMRF Canada is another resource for finding the names of helpful contact persons. These are people who have consented to have their names open to calls and inquiries. They may know of other persons in your geographic who wish to be part of the group. The Foundation is happy to help with meeting promotions by reaching out to individuals and organizations in your area to announce the establishment of a local support group as well as upcoming meetings and events. Many dystonia patients across the country receive the DMRFC's e-news and mailing updates. Reaching out to the individuals in your area through mailings, emails, and social media can greatly increase interest and participation in support group activities.

Defining the Purpose of the Support Group – After learning who shares your interests in having a support group, the members of the organizing group will want to talk about the reasons why they want to start a support group, such as:

- Supporting one another, offering companionship, and guiding one another in learning to cope with lost health and independence.
- Calling upon medical resources for their strategies in dealing with dystonia and to receive information about treatments or therapies.
- Learning what medical advances are being made and how you as a group can contribute to the medical research efforts through fundraising and other activities.
- Keeping up to date on laws, regulations, and policies that impact the dystonia community and working to address these issues through participation in coordinated advocacy activities.
- Increasing awareness about dystonia in the medical and lay communities.

Host an Initial Meeting for the Organizing Group – If you are able to identify other interested individuals and helpful healthcare providers or other community members, consider inviting this core group to a planning meeting. These individuals can provide valuable input and perspective for creating a support group and making sure it caters to all dystonia patients. They may even be interested in helping run the meetings and share the work, or assisting with regular administrative tasks. As the discussion moves forward and addresses topics like when and where to meet, it is important to remember that you will not be able to please everyone, but you should always be open and willing to try working with everyone to collaboratively identify the best courses of action.

Initial Meeting Objectives – Some critical topics should be discussed at this initial meeting and some important issues should be addressed to ensure that the group moves forward, including:

- What should the structure of the group be?
- What tasks are group members willing to take on?
- What responsibilities would group members like?
- What needs should we focus on addressing?
- What community resources are available to us?
- What experiences, expertise, and skills can group members apply to critical areas like raising awareness and recruiting additional members?
- What should the time, place, program, etc., be for your first official, widely announced DMRF Canada support group meeting?

Tips for Leaders – To follow are a few general tips that can assist you with many aspects of support group leadership:

- Never provide medical advice or counsel members of the group.
- Continually remind members that all conversations and discussions are to be kept confidential.
- Whenever possible, make contact with new participants and work to make sure they feel comfortable within the group.
- Always speak in a loud, clear voice.
- Be patient.

The DMRF Canada helps to promote Support Group Meetings in the following ways:

DMRF Canada Calendar Events

This includes all of the details for your support group meeting, including date and time, location, and leader contact information. This can also include specifics such as guest speaker information/biography, parking and transportation directions, etc.

Mailings

These consist of postcard with your meeting's date & time, location, guest speaker, topic, and contact information. Mailings are sent to people in your area, and the search radius we use will be dependent on your meeting location.

E-mail Blasts

DMRF Canada will send multiple emails with your meeting information: usually an initial blast and then at least one reminder a few days before the meeting. Depending on the location of the meeting, there may be more notices if there are several support groups in the same state.

Facebook

The DMRFC's Facebook page will have an event with the meeting information available on the website calendar. If you have a Facebook account or group page, our administrators will list you as a co-host so that you can make edits and share the event.

Foundation policies and guidelines

DMRFC Policies and Practices:

Inclusion – The Dystonia Medical Research Foundation Canada asks that all support groups be open and welcoming to people with all forms of dystonia. It may be that there will be subgroups with different interests composed of individuals with blepharospasm or spasmodic dysphonia or torticollis or generalized dystonia, and specific sessions on topics of interest to different groups; but the policy of the Foundation remains to always be inclusive and never discriminatory. Our aim is to serve all dystonia-affected persons and their families. Furthermore, DMRF Canada support groups must prohibit discrimination against people attending meetings on the basis of race, color, religion, sex, national origin, disability, age, sexual orientation, marital status, or any other basis prohibited by law. This extends to respecting other's beliefs and making sure that everyone feels accepted and welcomed into the dystonia support group.

Confidentiality – Confidentiality must be an issue for all support groups, and we ask that you operate in a confidential manner. Groups should discuss the need for confidentiality and assume this as a policy in all its activities. This means that any information which might individually identify a group member cannot be released outside the group. Since privacy may be a concern of many participants, this policy should be stated as one of the ground rules (along with time for speaking and other rules) at the beginning of every meeting. A good rule of thumb is: you can repeat what you said during a meeting, but do not repeat what others said or how they reacted to your comments. In other words, "What you see and hear at a meeting, leave at the meeting."

Furthermore, if a news release about a group activity includes pictures, videos, or names, a news/video release permission form should be signed by the group members who will be identified. If pictures are taken or media people attend a meeting, members should be advised beforehand about what is happening and why so they can decide whether or not to participate.

DMRF Canada Support Group Website & Social Media Guidelines:

DMRF Canada support group leaders are empowered representatives of the organization, and the Foundation strives to provide resources to help them serve their members. DMRF Canada support groups are not required to maintain a website or social media page (such as Facebook), but for those that do we offer the following guidelines.

Purpose – The purpose of the website or social media page should be to:

- Promote support group meetings and activities
- Serve as a local resource to share information such as DMRF Canada research updates, events, and advocacy and awareness activities
- Refer users to the information on the DMRF Canada website (www.dystoniacanada.org) for questions on treatment, research, diagnosis, and resources
- Stay in-touch with support group members during those interims between meetings
- Attract new membership to continue building local support communities

Content –Web page and social media content should adhere to all DMRF Canada policies outlined in the Support Group Agreement.

- Clearly state the name of the support group and the group's affiliation with the DMRF Canada, incorporating the DMRF Canada logo where possible.
- Suggested content for a support group website or social media page may include:
    - Contact information for the support group
    - Dates and details of upcoming meetings and events
    - News from the DMRF Canada website, social media pages, and e-blast announcements
    - A link to the DMRF Canada website: www.dystonia-foundation.org
    - Links to DMRF Canada online support forums: www.dystonia-foundation.org/online
- Photos from support group meetings and activities can be included (see below for more information on processes for consent and permission).
- Keep in mind that dystonia support groups cannot provide medical advice relating to diagnosis, treatments, or alternative therapies. Groups must not endorse medical institutions (such as hospitals), individuals (such as physicians), or products.
- DMRF Canada support groups and leaders should avoid disparaging or promoting certain therapies and/or treatments based on personal experiences or circumstances. It is always best to encourage members to consult with their doctor with questions regarding treatment, products, methods, or techniques.

Confidentiality – As with in-person support group meetings, website and social media pages must maintain the confidential nature of the support group.

- Refrain from posting other member's comments or concerns discussed during a meeting (What you see and hear at a meeting, leave at the meeting).
- Obtain written permission from guest speakers and lecturers before recording, filming, or posting information regarding topics discussed or presented-on during support group meetings and events (contact the National Office for the appropriate release forms).
- If you plan to post online any videos or audio recordings from a support group meeting or group related event, obtain written permission before recording/posting.
- When taking pictures, respect the privacy of support group members and attendees at meetings and support group related events, such as lunches, educational symposiums, or awareness events.
    - Inform group members of your intention to post pictures online before photographing and respect their privacy if they choose to not be in group or event photos.
    - Before taking a picture at a support group meeting or related event, give attendees the opportunity to opt out of being in the picture.
    - When in doubt, obtain written consent before posting online (contact the National Office for the appropriate release forms).
- If you are photographing or recording any content which includes children to be used on any support group related website or social media page, obtain signed permission from a legal guardian and specify where on the Internet it will be posted/used (consent is implied if you are posting content of your own children).

Privacy is a priority, and the DMRF Canada does its best to maintain the confidence of dystonia community members; we ask that support groups do the same by following these guidelines. Website and social media pages are an important platform for groups to celebrate and share their accomplishments, as well as to assist in raising dystonia awareness.

Images and videos posted anywhere on the Internet can easily spread much farther than the original poster intended, and the Foundation seeks to ensure that everyone who is included in content made public through the DMRF Canada and affiliated support groups is comfortable with its usage. Attention to these important details help all individuals involved in support activities feel that they are in a safe space and be secure in knowing that their privacy will be maintained.

SAMPLE

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SPEAKER RELEASE FORM

I hereby authorize and release the Dystonia Medical Research Foundation Canada and the ___________ [name of support group] to photograph and video/audio record my presentation. I also grant the DMRF Canada permission to use, edit, digitize, transmit, and display the video or audio or other presentation materials of my participation as well as to use my name, voice, photograph, likeness, biographic information, and ancillary material in connection with such video or audio.

I understand these images/recordings may be used in awareness, educational, and promotional materials, electronic or in print, produced or endorsed by the DMRF Canada.

Name____ _________________________
Please Print First Name Middle Initial Last Name

Phone__________________________ E-mail address________________________________

Signature:

____

Responsiveness and Accessibility Policy:

As outlined in the DMRF Canada Support Group Agreement, one of the primary responsibilities of a support leader is to be responsive to those in need of support. Leaders may decide that they need to take a temporary break from group leadership due to burn out, health issues, family emergencies, and so on.

The DMRF Canada understands that leading a support group can be a challenging task, and that support leaders often have to manage many of their own personal challenges in addition to those of leading a support group. The Foundation always recommends identifying someone who can help you manage the support group, such as a co-leader. Running the group with another person can alleviate some of your responsibilities and allow the group to remain active even if you need to take a break. If you decide to take a step back from running the support group, we ask that you please inform the National Office of your concerns as soon as possible so that we can best support you. The DMRF Canada understands that self-care comes first.

The Foundation actively stays in touch with leaders to offer them support. If the DMRF Canada has reached out to a leader several times without response, this can be cause for concern. Every day dystonia-affected individuals reach out to the National Office looking for sources of support, and if the DMRF Canada cannot reach a support group leader there is potential for others to have a similar experience. Reports from the public that leaders are unreachable will be taken into consideration and prompt the DMRF Canada to check in with the leader.

If the DMRF Canada is unable to reach a support group leader after numerous contact attempts within a 30 day period, the Foundation will take the step of temporarily removing the leader’s contact information from the DMRF Canada website and the group will be considered inactive. In the event that a leader is deemed unresponsive and removed from the website, the DMRF Canada will inform the leader of the action through the most effective means and encourage them to contact the National Office, Manager of Community Engagement.

Your support group is an invaluable resource for those in the dystonia community, and you as a leader are an important representative of the DMRF Canada. When referring individuals to our support network, the Foundation wants to be confident that our contacts respond in a timely manner to those in need. Support leaders volunteer their time and energy to this important cause, and the DMRF Canada aims to ensure that the best interests of the leader, as well as the public, are adhered to as much as possible.

Leading a Dystonia Support Group

Running the Organization

Leading a support group can be a demanding task. Support group leaders are expected to be knowledgeable, good listeners, good organizers, non-judgmental, and capable of managing difficult personalities in addition to managing the organization. Most importantly, an effective leader is aware of their limitations. Do not hesitate to ask others for help or work to delegate responsibility amongst interested individuals. You may find that a team approach that plays to multiple group members' strengths is the best way to lead the organization.

Most support groups are informal. The leader is responsible for orderly, pleasant meetings, encouraging others to participate, and recognizing that people come and go as their interests and needs are met. The leader makes attendees comfortable with flexible membership requirements and uses an "open door" policy for members and their families.

Ideas for Meeting Locations and Time - It is generally best to enlist the assistance of your neurologist and/or his/her staff members and have meetings in a Conference Room of a hospital, thus having handicapped accessible entrances and toilet facilities and avoiding any liability insurance which private establishments will require. You may wish to investigate university and college facilities, which are also often available and accessible. Libraries and banks are another popular choice.

Please be mindful of your surroundings when choosing a location. Security issues, bathroom access, and convenient parking should all be taken into consideration. Also, more subtle issues should be considered as well. For example, some dystonia patients might not feel comfortable meeting in a religious establishment even if it is during a time when religious services are not being conducted.

Generally, meetings are best on a Saturday or Sunday afternoon when driving is relatively light, and families and/or friends can easily attend with the dystonia-affected person. Some dystonia support groups choose to meet weekday evenings, finding their members and speakers like that particular time. Every group is different, and it is important to check-in with members to find the right day, time and month that works for the most people.

Management of the Support Group - To ensure the success of the support group, it is imperative that all group members feel accepted as equals and have support dealing with the issues at hand. Each person has his or her own unique experiences and his or her own way of dealing with issues. One person is not necessarily better or worse at handling his or her problem than another person. Members of the group must feel that they have equal status within the group.

It is also important to promote contact between old and new members of the group. A person who has extensive experience at successfully dealing with a particular problem can reassure a newcomer that the issue can be managed and will be able to give pointers. In this regard, it may be a good idea to have a welcoming session for new members before the official meeting begins. Sharing experiences also reminds the long-standing members of why they originally joined the group. Most importantly, this kind of sharing helps people feel good about themselves and about the group. Some established groups have a "buddy system" to encourage communications. The strictly observed rule about confidentiality will encourage members to be more open than they would otherwise be.

There is usually an expectation that the group leader be knowledgeable about the various types of dystonia. Keeping up-to-date on articles and media attention to areas like dystonia research, treatment options, and advocacy activities, can be very helpful. You may want to consider asking group members to discuss or provide on a regular basis any new dystonia information they have come across. This information may help you answer questions or identify a good program topic for an upcoming meeting.

Frequently Asked Questions - You receive a call from a person who has just been diagnosed with dystonia. The caller has many questions – how do you respond?

- "*Am I receiving the correct treatment*?" It's important to support the caller. Dystonia is a complicated disorder and what works for one individual may not work for another. Instead of giving advice, tell a story about yourself or a friend. It also depends on what the treatment is – encourage them to speak with their doctor if they are concerned about their treatment.
- "*What doctor should I see?*" Tell them that it is important that they find a doctor who will listen to them and with whom they trust and feel comfortable. If they are part of an HMO, they may contact their HMO for a list of specialists. They may also wish to contact the NIH. The Foundation maintains a list on their web site of neurologists and other healthcare professionals who specialize in movement disorders. The Foundation can provide assistance over the telephone for anyone looking for a physician in their area.
- "*Will this get any worse?*" Give them hope—they need to allow time to pass after the initial diagnosis is made. Tell them with proper medication it may improve. It's very unpredictable and all medications work differently on different people. Also, tell them this is a question they should ask their doctor and encourage them to talk with their doctor.
- "*Where did it come from?*" Respond that it's a disorder from the part of the brain called basil ganglia which is responsible for movement. It may affect one or many parts of their bodies. The cause is not yet known.
- "*Will it be passed onto my children?*" Let them know that it may be passed on if they have a genetic form. Suggest they seek genetic counseling or contact the DMRF as we have helpful information in this area.
- "*What medications should I take?*" Finding the right medications is a trial-and-error situation. To find the right one and develop a treatment plan, you must work with your doctor.
- "*Life is changing and it isn't fair*." Reassure them it may take time for balance to return to their life. Suggest they join a support group to foster a better understanding of dystonia and to learn coping techniques. Although life isn't fair, remind them that they are strong enough to work through this and that it is very possible to live well with dystonia.

If a Member is in Crisis - It is important to note that at some point you may have a support group member who is going through a particularly difficult time. Feelings of anxiety and depression are not uncommon in the dystonia community, and as a support leader you may find yourself in a situation where a support group member or individual from the community is in need of professional help. If this situation arises, know that the DMRF is here to support you. The role of DMRF Canada support group leaders is to offer peer support – you are not expected to fill the role of a mental health professional.

For resources and more information to help navigate these potential challenges, please see Appendix C for a link to the DMRFC's recorded webinar "Resources to Assist Members in Crisis" along with the accompanying handout which offers a Mental Health Resource List, Tips for Supportive Listening & Communication, and tips for Compassionate Communication & Self Care.

Voluntary Support Group Newsletters – The only support that many people receive is through the Dystonia Canada Report, e-communications with the DMRF Canada and the local newsletter some groups provide. While the newsletter is optional, it can be an effective means of informing group members and interested individuals of important developments in the dystonia community and upcoming activities. If you chose to do a newsletter, below are some tips to keep your newsletter supportive, informative, and stimulating membership activity.

- Use humor, cartoons, or life-affirming statements so readers come away with a good feeling.
- Use questions or comments from members as the basis of your articles.
- Include an upcoming calendar.
- Use articles from Dystonia Dialogue or other support group newsletters.
- Have members share their experiences.
- Make sure the newsletter reflects the support group.
- Make sure you properly credit or cite any sources.

Facilitating a Meeting

The major challenge of support group meetings is making sure they satisfy the needs and expectations of group participants. Having multiple members of the group fill different roles during a meeting can be helpful in meeting this challenge. For example, someone could greet new members and help introduce them to the group. Feedback materials, such as comment cards and suggestion sheets, can provide timely information on the thoughts of support group members.

Staying organized is a great way to make sure meetings run smoothly. Beginning your preparations for a meeting well in advance is a key to success. Furthermore, arriving early the day of the meeting and utilizing the meeting checklists in this manual can help ensure that no detail is overlooked.

You may want to have general dystonia material available at your meeting or information specific to the topic of your meeting. The DMRF Canada has a wide range of literature, pamphlets, and informative materials that are available to you through the National Office.

(For a full list of materials, see Appendix C.)

Tips for Effective Meetings.

- Make the atmosphere friendly, cooperative, and pleasant; help new members easily fit into the discussion and the activities.
- Encourage all members to participate and communicate, not just a few. And ensure that there is no fighting for status or hidden agendas.
- Work to see that the group uses the abilities of all members rather than relying on a few.
- Help the group adjust to changing needs and situations.
- Provide an environment where members feel safe speaking out; neither ideas nor people should ever be ridiculed or belittled. Individuals or situations that negatively affect this safe space should be addressed quickly and sensitively. Leadership feels shared.
- Keep members well informed and up-to-date.
- Remember that decision-making is carried out in a consensus-building manner.
- Remind attendees that all discussions are kept confidential.
- Ensure that group members who are not medical professionals do not provide medical advice or counsel to others.
- Schedule the meetings on a regular set date so group members can maintain a consistent calendar.

Suggested Programs

1. Overview of Dystonia

Synopsis:
Many dystonia patients have general medical questions and require additional background information on the condition. Learning about dystonia and recent advancements in our understanding of the condition can lead to better management of symptoms and improved quality of life and self awareness.

Recommended Speakers:
Neurologists; Physicians who administer Botox/Myobloc; Movement Disorder Specialists

Purpose:

- To answer questions of a medical nature.
- To provide information concerning the origins of dystonia, what is known, what is not known.
- To promote understanding of the genetic and nongenetic factors.
- To review current research and discuss the state of the science.
- To understand how a Dystonia Clinic and/or a Movement Disorder Clinic operates.
- To explain the process by which dystonia is diagnosed.
- To better understand dystonia treatment options.

2. Physical Therapy

Synopsis:
Exercise and physical therapy are important to everyone who wishes to maintain an active lifestyle, but dystonia can be physically disabling and make even simple activities more difficult and risky. Posture assistance, safe exercises, and strategies for avoiding fatigue can help dystonia patients better manage their physical activities.

Recommended Speakers:
Physiotherapists; Psychologists

Purpose:

- To improve independent function and address the treatment of pain, as well as provide advice on exercise and posture.
- To share information about short-term relief (moisture, heat, ice, etc.).
- To offer guidelines on exercise and posture.
- To suggest safety and mobility devices.

3. Occupational Therapy for Dystonia Patients

Synopsis:
Occupational therapy can be an effective non-drug therapy for dystonia patients. Learning useful or innovative techniques for staying active can be an empowering experience as well as one that helps dystonia patients achieve greater awareness and control over their bodies.

Recommended Speakers:
Occupational Therapists

Purpose:
- To promote, maintain, and restore task related proficiency, performance, health, and emotional well being.
- To offer guidelines to control fatigue and maintain good posture, and to maintain good nutrition.
- To assist patients in the choice of medical equipment and materials, as well as adaptive equipment.

4. Speech Therapy

Synopsis:
Learning strategies and conversation techniques to communicate more effectively can educate and empower dystonia patients. Tips regarding diet, chewing and swallowing, and nutrition are also viewed as valuable by many dystonia patients.

Recommended Speakers:
Speech-Language Pathologist

Purpose:
- To improve communication, individualized therapy programs can help develop specific techniques. Speech therapy may be more effective in combination with other specific therapies such as medications. (If speech is severely impaired, a communication aid may be required.)
- To make speech intelligible.
- To help improve chewing and swallowing.
- To recommend diets which ensure proper nutrition.

5. Psycho-Social Aspects

Synopsis:
Many dystonia patients are interested in advice concerning adjusting to lifestyle changes and managing associated stress. Dystonia patients may also be interested in counseling services or other available coping resources.

Recommended Speakers:
Social Workers; Counselors; Psychotherapists; Psychologists; Psychiatrists; Quality of Life Specialists

Purpose:

- To validate and normalize the reactions persons with dystonia and their families experience.
- To use the group process to recognize, identify, and develop coping strategies.
- To utilize the expertise of professionals in improving quality of life for the dystonia patient and their family.
- To enhance the self-confidence of the individual participants in their ability to cope actively and constructively with issues which confront persons with dystonia and their families.

6. Community Resources

Synopsis:
Dystonia patients may have questions or be interested in additional information about the local, state, and federal resources which are available to them. In addition, there may be some questions about helpful local services, such as policies or programs available within the community or local hospitals.

Recommended Speakers:
Social Workers; Social Security Specialists; Government Representatives; Insurance and/or Legal Specialists

Purpose:

- To educate dystonia patients and their families about availability and accessibility of community resources.
- To receive the latest information on federal and state assistance.
- To make known what entitlements or financial assistance may be available.
- To ease anxieties and discomforts which may accompany the effect of having dystonia.

7. Nutrition/Well-Being

Synopsis:
A proper diet can boost energy levels and feelings of personal satisfaction for anyone. Furthermore, adequate nutrition can aid dystonia patients in controlling their weight, even as physical ability is reduced, and avoid the complicated health issues that arise with significant weight gain.

Recommended Speakers:
Dietitians; Nutritionists; Physicians who specialize in weight problems

Purpose:

- To educate dystonia patients and their families about the importance of diet.
- To alert patients to possible allergic reactions and the effects of chemical reactions with medication.
- To dispel misconceptions.
- To understand how foods affect us.

8. Caregiver’s Meeting

Synopsis:
Many individuals are impacted by dystonia due to the constant support and aid they provide for a loved one who has the condition. These dystonia-affected individuals have their own unique issues and perspectives to discuss and share.

Recommended Speakers:
If this is an occasional caregivers-only meeting, a social worker is usually an appropriate facilitator.

Purpose:

- To give caregiver’s the opportunity to share feelings with one another.
- To help caregivers cope more effectively with dystonia.
- To be emotionally supportive in relation to the disorder.
- To provide a safe place for caregivers to vent their feelings.
- To encourage self-care for the caregiver.

9. Back-up Programs

Purpose:
Unforeseen events can occur at the last minute to disrupt a planned support group meeting. Speakers can cancel without any notice or programs may be missing an overlooked component. Since many individuals look forward to and rely on these meetings, and since there may not be time to provide sufficient notice, an alternative meeting may need to take place instead. Below are some ideas which you may want to have prepared as possible back-ups to a scheduled event.

1. Show a video.

2. Group Exchange (to elicit a positive response by discussing a topic and then returning as a whole, reporting your findings).

Examples:

- How to build a community event
- Sharing of personal stories
- How to write a news story
- How to avoid burnout as a caregiver
- How to be sensitive to family needs

Pre-Meeting Checklist

Speaker/Program Decided. (6 weeks prior to meeting)

_______ Speaker invited and confirmed well before meeting.

_______ Speaker's A/V needs confirmed.

_______ Speaker's introduction prepared.

_______ Notify DMRF Canada if help is needed for sending out meeting announcements.

Preliminary Communications Completed. (4 weeks prior to meeting)

_______ Flyers/notices sent out.

_______ Telephone tree and listserv used to raise awareness.

_______ Press releases sent out to local media.

Materials Obtained. (2 weeks prior to meeting)

_______ Brochures received from Foundation (if needed).

_______ Posters, displays, informational literature, advertising, exhibits ready.

_______ Agenda drafted and available.

_______ Reminder call to individual(s) responsible for refreshments.

Surroundings Prepared. (1 hour prior to meeting)

_______ Refreshments available.

_______ Sign-in sheet and nametags available

_______ Lighting, temperature, seating, parking, coat racks, etc. taken care of.

Meeting Checklist

_______ Placard designating the meeting room and directional signs to meeting room.

_______ Front desk aware of meeting location (if applicable).

_______ Host to welcome and introduce guests as they arrive.

_______ Start meeting on time and finish on time in accordance with agenda.

_______ Time for Q and A after presentation(s).

_______ Ground rules for meeting established.

_______ Encourage all to participate and reach out to new members.

_______ Delegate responsibilities for the next meeting through discussion.

_______ Announce when and where the next meeting will be held.

_______ Remind everyone to add their contact information to the sign-in sheet.
(Please see sample sign-in sheet)

_______ Prepare a summary immediately following the meeting or take notes.

Post-Meeting Follow-up

______Evaluate the meeting regarding location, timing, convenience, speaker, discussion, and identify what went well and what needed work.

______Send out thank you letters to speakers.

_____ Call/contact new members or first time meeting attendees.

______ Consider and address outstanding organizational issues that have been highlighted at meetings and identify solutions to persistent issues that continually arise, such as a logistical problem or inconvenience with the meeting space.

_______ Keep searching for new members and interesting ideas, themes, and speakers.

_______ Think about ways to attract new members such as by using a new meeting location.

_______ Send out follow-up information through the phone tree and/or e-mail listserv. Consider using a Newsletter.

_______ Identify upcoming birthdays as an opportunity to personally reach out to members and use other opportunities to stay in touch with the group.

_______ Track or report to the DMRF Canada office number of attendees at the meetings

This can be managed by the support group leader, co-leader, or a responsible member of the group to assist with delegating and sharing responsibility.

Consider having an annual meeting review with group members to ensure that the schedule, format, and programs are supported by the group. Refrain from getting discouraged if the group dwindles in size. It is very important to continue with meetings. Some participants may need to know the group will last before they wish to commit more time and energy.

Facilitating a Discussion

Keeping the discussion on track can be a necessary and complicated task for a support group leader. You continually have to balance priorities like maintaining a focused discussion with making sure everyone gets to participate. It is also important to remember that not everyone will know how to appropriately participate in a support group discussion and you may have to steer the conversation through some strong personalities.

Developing ground rules can help ensure a structured environment where group members feel comfortable attending and sharing. Rules can be drafted by the group leader with input from group members and then posted at every meeting. Before a discussion, new members should be made aware of the rules, and the option of opening any of the rules for modification should always be available to group members. Below are some sample ground rules:

- What is said and discussed during support group meetings is confidential.
- Participants will refrain from judging one another or making disparaging comments.
- No interrupting—everyone will patiently listen to the views of all support group members.
- Participants will not pressure one another or make anyone feel compelled to participate.

Ensuring Participation - Discussion is greatly affected by the number of people in the group. The best size for personal discussion is between 6 and 10 people. Too few limits the diversity of experiences while too many may mean that not everyone gets the opportunity to participate.

If your group is large, or wishes to break up into specific dystonia groups, there could be smaller groups for discussion which get back together for activities the whole group is interested in. Having "reporters" of the individual smaller sessions reporting back to the whole group affords the opportunity for more people to become involved.

You may experience individuals who monopolize or take the conversation into uncomfortable areas. We have all come across individuals who attempt to dominate a conversation, refuse to participate, or are perpetually negative, and the support group setting will be no different. Anticipate these situations and have some strategies ready to immediately mitigate them and move the conversation along in a manner that the entire group will be comfortable with.

Responsibilities – While support group members will be participating, as the leader you may need to steer the conversation or move it along. Below are some areas to be mindful of during a discussion:

- Opening up discussions
- Broadening participation
- Limiting participation
- Moving along
- Evaluating
- Reaching a decision on a group issue
- Lending continuity to the discussion

Moving a DMRF Canada Support Group Forward

Maintaining momentum

Support groups tend to go through a process where participants grow increasingly accustomed to one another and begin to participate more. From a leadership perspective, it is important to make sure no one dominates early discussions and that possible personality conflicts are immediately resolved. Moving forward, it will be important to ensure that strong personalities have a role in the organization which suits their interests. Establishing a leadership core by assigning tasks to group members can ensure they stay involved and help the support group grow.

Leadership – There are different styles of leadership which are effective in different situations. For example, an assertive leader might be required to get a group moving on a problem, but that personality may be less effective when encouraging compromise. The Support Group is stronger when it realizes that no single person possesses all leadership skills such as facilitating, organizing, motivating, planning, and delegating. Different members can therefore perform different leadership roles and share in the responsibilities of the group.

Publicity – You are providing an important service to the community and you should work to publicize it. Getting the word out about meetings will ensure robust participation and a steady stream of new participants. Widely disseminating meeting notices and public service announcements through local newspapers, community bulletin boards, radio stations, and relevant newsletters is an excellent way to raise the profile of your support group.

Group Development – Support groups rely on cooperation among members. All groups have needs that must be met if the group is to stay lively and effective. One need is to get its job done—work towards its purpose. Other needs are being met when members get the meeting started, arrange for speakers, help keep the meeting moving, give information, or summarize events. Typically though, a support group is more focused on the social and emotional needs of its members to ensure that members are compromising, adding humor when appropriate, participating openly, and receiving encouragement and validation.

Structure – Support groups are usually quite informal. Generally, the organizer is designated as the leader. It may be that you, as the organizer, or your group would feel more comfortable with co-leaders or rotating leaders. Sometimes the need for structure can be met through a system of rotating responsibilities among various group members. For example, have someone act as the chairperson for one month and then have someone else in that role the next month. A system of rotation helps keep members involved with group activities and is also a way that members learn more.

Informal groups are often better at meeting emotional and physical needs while more formally structured groups are often better at accomplishing specific tasks. It is important to add more structure as the group's needs progress and, ultimately, strike the appropriate balance between a formal organization and one that is unstructured.

Each support group should cultivate a core group to implement Foundation goals as well as to offer personal comfort and medical education for members and families. As the group becomes more established these individuals who want to take on a larger role in the group could be responsible for certain tasks. Such responsibilities might include:

Awareness/Public Education:
To publicize success stories, make contact with media outlets, and distribute news items--particularly during Dystonia Awareness Week.

Development:
To monitor the group's changing needs and identify opportunities to improve the group or advance its goals.

Children's Education:
To reassure families that there are treatments and to aid them in obtaining education rights and put them in touch with other parents.

Advocacy:
To disseminate grassroots information from the Foundation which informs dystonia-affected persons about legislative efforts of interest to the patient community.

Medical Education:
To distribute educational brochures and materials to physicians and hospitals so they will refer patients and their families to the Foundation and local support groups.

Fundraising:
If the support group decides to undertake fundraising activities, these individuals should interface with the Foundation and work collaboratively on fundraising events.

Keeping People Involved – The effectiveness of any group depends partly on how people feel about being members of the group. It also depends on how they feel about taking part in its activities. One meeting may be warm, informal, and exciting, while the next may seem formal and relatively quiet. This "climate" depends on who is present, what the activities are, and on the behavior of the facilitator.

The physical surroundings are important; attention to details such as room temperature, comfortable chairs, and quiet surroundings makes a difference. Seating arrangements are also important. Arranging chairs in a circle will make it more likely that all members will see each other and participate, while classroom style seating would be appropriate for a particular speaker.

The leader's mood and personality also greatly contribute to the setting. A leader who is cheerful, approachable, and enthusiastic will encourage others to act in a similar, productive manner.

Maintaining Self-Care – Maintaining self-care is paramount for every support leader. While you are providing support to others, the DMRF hopes that you will remember to take care of yourself first. If you are starting to feel overwhelmed or burnt out with running the support group, the Foundation has some suggestions that may help:

Delegate Responsibilities:
While it is ideal to find a co-leader, there is not always someone available who is willing to divide the responsibilities of running a group. This does not mean that you have to do everything yourself. Call on your support group members to share in the responsibilities of running a group and give them smaller, more manageable tasks that can offer you some relief but not feel overwhelming to members.

Create a list of things that need to be done (whether it be getting snacks and refreshments, helping with set-up, sending out the newsletter, maintaining a group Facebook page, etc.) and ask for volunteers to sign-up. Asking others to be involved in running the group will not only help you as the leader, it will also serve to build-up a community of support and ensure that members are invested in the group and its activities.

Find Volunteers:
If you are having trouble finding support group members to step up and take on some of the responsibilities of running the group, try contacting volunteer organizations or people who are retired and ask for help. Give volunteers specific tasks and ask what they would like to do.

Set Boundaries:
Support leaders not only give their time, but also much of their energy, in being a support and resource for others. Fielding calls and inquiries from support group members and the general public can become draining. It is important to set boundaries and maintain a balance in supporting others and yourself.

While leaders are expected to be responsive to outreach from the public and the DMRF, you are not expected to be available 24/7. Set limits on when you receive calls and respond to emails. Having a separate phone number and email address can help you maintain your privacy and ensure that you do not feel as if you are constantly “on-call”.

It is also important to remember that you are not responsible for the wellbeing of your support group members. You are not a therapist or a doctor and may sometimes need to remind others that you are their peer. As a volunteer who truly cares about others, it can be difficult to say “no”, especially to a person who is not only a group member but also a friend. Again, remember to take care of yourself first and understand that setting boundaries will help you to continue being a successful support leader.

Build Your Personal Support Network:
While you take on the task of being a support and resource for others, you should also make sure that you have your own network of support. Building and maintaining relationships with family, friends, neighbors, and other DMRF leaders is essential for self-care.

Take a Break:
If you ever need to take a break from leading the support group, you should do so. Self-care is important for every leader and will always come first. Let the DMRF know that you need to take some time away from the group, and know that you can always return when you feel ready and refreshed.

The DMRF is here to support you and help you navigate leading a support group. If you are feeling overwhelmed, please do not hesitate to reach out to the Foundation and share your concerns and frustrations.

Expanding activities

Once your support group has grown and established itself, you may want to consider taking on additional activities beyond hosting a meeting. At this point, it is likely additional members will have taken an interest in being involved in planning and executing the support groups activities. These individuals and the support group itself may want to discuss ways in which the group can move into new areas and expand its role in the future. Two opportunities which will engage and empower support group members and raise the profile of the support group in the community are:
(1) help advance the dystonia community's legislative agenda by becoming advocates; and
(2) help directly support critical research and education initiatives by fundraising.

Advocacy – As legislative issues emerge, the Foundation will send through information on how your support group and its members can make an impact. You may want to consider sharing this information with your support group, discussing its importance, and encouraging politically minded members to become patient advocates. Please note that the Foundation avoids partisan issues, wedge issues, or controversial issues.

The DMRF Canada is available to answer any questions on legislative issues your support group might have, as well as to provide you with any additional advocacy or legislative information if you contact the National Office.

Setting an Annual Agenda – As you set the calendar for the upcoming year, you strive for an interesting and varied collection of meetings and programs that will stimulate attendance. Below are some tips to on how to plan meetings: frequency, location, day/time, etc.

- Have comment cards available at all meetings and events so that you can easily identify the programs and activities that support group members are interested in.
- Select a core group that will set the agenda. Note holidays and sporting events because you don't want your meetings to compete with special occasions.
- Decide where to meet and try to keep that location for one year.
- Pick topics that reach out to the total group and decide which speakers you want to invite. Topics do not have to be medically related. One group shared a successful meeting where a policeman spoke to the group about personal safety.
- Plan seasonal events like a picnic in the summer, a holiday party, and Dystonia Awareness Month activities.
- When planning, think about your members—do they come for education, support, or both? Also think of weather conditions and if there are any limitations for your members. You may want to refrain from a January meeting if the winter is typically harsh and creates travel problems.
- Have on-line information about events.

Fundraising – The DMRF Canada relies on financial contributions and funds raised by individuals and groups to continually support dystonia patients by advancing research, producing helpful materials, conducting informative events, and hosting other activities.

Support groups are not expected to raise funds for research, but it can be a meaningful group activity. As a condition of using the Foundation name, logo, 501(c)(3) tax exemption, literature, and services, all funds raised are the property of the Foundation and must be delivered to the Foundation within 30 days after the fund-raising event. The National Office must be informed of any planned fundraising activities well before they are held.

Reasonable expenses depending on the event are allowable for such items as printing, duplicating, postage, decorations, entertainment, unusual telephone tolls and/or faxes. (In-kind donations by local businesses and/or member underwriting can minimize these expenses.)

If clerical help is needed for large events, such temporary hourly pay is deducted from the gross receipts. In order to be cost-effective, the Foundation authorizes no salaried positions and/or persons who receive permanent hourly pay except at the Foundation office.
The DMRF Canada is available to provide support, guidance, and assistance with any fundraising activities if you contact the National Office. If you are planning to conduct any fundraising activities, please complete the form on the following page.

Dystonia Medical Research Foundation Canada Fundraising Guidelines Agreement

Thank you for your interest and dedication in raising money for dystonia-specific research. The following guidelines have been developed as a tool to assist you with your project and clarify the assistance that the Foundation staff and volunteer boards can provide for you.

____agree(s) to:
(Name of individual or support group)

1. Comply with and be bound by the policies and standards of the Dystonia Medical Research Foundation Canada and comply with all applicable Federal and State laws;
2. Work with the Development staff of the Dystonia Medical Research Foundation Canada to create and adhere to an agreed upon event budget and an event plan;
3. As a condition of using the Foundation name, logo, 501 (c) (3) tax exemption, literature and services, all funds raised less reasonable expenses are the property of the Foundation and should be delivered to the Foundation by the individual in charge of the event within 30 days after the fundraising event;
4. Submit a detailed financial accounting of the event, including bank statements, gross income, net income, expenses, and any in-kind donations;
5. Advertise clearly on all materials related to the fundraiser that all proceeds are raised on behalf of the Dystonia Medical Research Foundation Canada and proceeds will be applied to medical research;
6. On all advertisement materials, the Dystonia Medical Research Foundation Canada campaign number will be clearly identified, and provide the Foundation with copies of all materials used to advertise the event; and
7. Maintain regular contact with the staff at the Foundation on progress of the event.

____understand(s) that: (Name of individual or support group)

1. Support groups are not incorporated separately and are membership units of the Foundation. Groups may charge dues to cover operating expenses (costs of mailings and incidental expenses). Funds raised for research should be recorded separately and sent to the Foundation. The Foundation will issue receipts to the individual donors for contributions received;
2. Reasonable expenses (depending on the event) are allowable for such items as printing and duplicating, postage, decorations, entertainment, unusual telephone tolls, faxes, and/or e-mails. (In-kind donations by local businesses and/or member underwriting can minimize these expenses);
3. Donations forwarded to the Foundation will be issued tax receipts according to generally accepted policies.

Support Group Name:

Name:__________________________ Address:__________________________

Phone:__________________________ E-mail:__________________________

I, the undersigned, acting for the individual, committee, or group holding the fundraiser, understands that such individual(s) shall conform to all regulations and policies of the Foundation and that the Board of Directors, upon notice, reserve the right to alter the terms of the Agreement and maintains the right to cancel authorization to operate the fundraiser for any reason deemed by the Board of Directors to be sufficient. The parties agree to be bound by this agreement.

Signed:______________________________ Date:__________________________________

DMRF Canada authorization to operate a fundraiser on behalf of the Foundation:

Signed:_________________________________ Title:__________________________________ Date:_______________________

Campaign Name:____ Campaign Date:_______________________

Participating in Foundation Activities

Dystonia Symposium – The Foundation may host Symposiums. These multi-day event covers a number of areas and brings dystonia patients and families together from across the country. The age sensitive programs help introduce dystonia-affected youth to a supportive, nationwide peer group.

Your support group may want to consider raising awareness of this event or helping send interested members.

Dystonia Awareness Month – September is Dystonia Awareness Month. The DMRF and affiliated support groups use this opportunity to raise awareness of the issues affecting the dystonia community. The U.S. Senate passed a Congressional Resolution recognizing the month and promoting dystonia awareness and the impact of the disorder on patients and their loved ones.
Your support group may want to take this opportunity to raise awareness for dystonia issues in the community, and interested group members can ask their Members of Congress to support the annual Congressional Resolution.

Appendix A

DYSTONIA
MEDICAL
RESEARCH
FOUNDATION
CANADA

FONDATION DE
RECHERCHE
MÉDICALE SUR LA
DYSTONIE
CANADA

serving all dystonia-affected people
désservant toutes personnes atteintes de dystonie

PATIENT CARD

I would appreciate having more information about dystonia and being placed on the mailing list to receive the Dystonia Canada Reports.

Name: ____

Address: ____

City: ____________________ State: ___________________ Zip: _______

Phone: _________________________ E-mail: __________________________

Referred by (physician's name): ____

Hospital (if any): ___________________ Form of Dystonia: __________________

_____________________________ I would like to find out about a dystonia support group in my area.

_____________________________ I would like to be contacted by the support group in my area.

Comments: ____

____

____

Return completed forms to:
Dystonia Medical Research Foundation Canada,
550 St. Clair Ave W, Unit 209, Toronto, Ontario M6C 1A5

Appendix B

MEETING AGENDA (Sample)

Toronto Support Group
An Overview of Dystonia

Saturday, January 10, 2018
1:00 PM
Johnson Memorial Medical Center
123 Main Street
Any Town, Toronto, A1A 1A1

1:00 PM	Welcoming Remarks and Facilitator Introduction
1:05 PM	Group Announcements DMRF and Dystonia News Personal News
1:15 PM	Participant Introductions New Attendee Introductions
1:20 PM	Introduction of Speaker and Topic
2:00 PM	Question and Answer Session
2:15 PM	Sharing Time Comments about the Program How have Members been since the Last Meeting? How are Members Feeling Now?
2:45 PM	Closing Remarks Topic of Next Meeting Next Meeting Date and Time Other Outstanding Items
2:55 PM	Refreshments and Social Time

SIGN-IN SHEET

Date: ______________________________ Time: ________________________________

Program: ____

NAME	ATTENDED BEFORE?	PHONE	E-MAIL

COMMENT CARD/SUGGESTION SHEET

The members of this dystonia support group welcome you. Please feel free to share any comments or suggestions with us. Your thoughts and feedback help this support group grow and better serve the needs of its members.

Areas of Interest (Speakers/Topics, etc.):

____

____

____

____

____

____

Areas of Concern (Issues/Potential Problems, etc.):

____

____

____

____

____

____

General Comments/Suggestions:

____

____

____

____

____

Please list the names and contact information for anyone you think may be interested in this support group:

____

____

____

You are a (*required*): Patient Relative Friend Other

Your contact information is (*optional*):

Name:

____

Address:

____

Phone: ____

E-mail: ____

SUPPORT GROUP MEMBER QUESTIONNAIRE

DYSTONIA
MEDICAL
RESEARCH
FOUNDATION
CANADA

FONDATION DE
RECHERCHE
MÉDICALE SUR LA
DYSTONIE
CANADA

serving all dystonia-affected people
désservant toutes personnes atteintes de dystonie

DMRF Canada Support Group Member Questionnaire

This questionnaire is administered by Support Group Leaders of the Dystonia Medical Research Foundation to better assess the needs and opinions of their members. All responses are anonymous. Thank you for your time in taking this survey. Your leaders greatly appreciate your feedback!

1. What do you look for in a support group? (You can select more than one)

☐ Discussion and sharing
☐ Research updates and new information
☐ Activities
☐ A strong community
☐ Guest speakers
☐ Social activities
☐ People who understand what I'm going through
☐ To better understand my loved one's disorder
☐ Community or fundraising activities and events
☐ Other (please specify)

2. Where would you like to have support group meetings? (You can select more than one)

☐ Hospital/Medical Center
☐ Public Park
☐ Restaurant
☐ Community Center
☐ Library
☐ Current meeting venue
☐ Someplace else (please specify)

3. How often would you like to have meetings?
   - ☐ Twice a year
   - ☐ Three times a year
   - ☐ Four times a year
   - ☐ Every other month
   - ☐ Every month
   - ☐ Other (please specify)

4. In general, what do you think are the best months to have support group meetings? When are you most likely to be available?

5. What would be the best day to have meetings?

6. When would be the best time to have meetings?
   - ☐ Mornings
   - ☐ Afternoons
   - ☐ Evenings
   - ☐ Other (please specify)

7. For you, how important is it to have food/refreshments available at support group meetings?
   - ☐ Very important
   - ☐ Somewhat important
   - ☐ Hardly important
   - ☐ Does not matter

8. What topics would you like to explore at future support group meetings?

9. Which guest speakers would you be most interested in having your leader invite to support group meetings? (You can select more than one)
   - ☐ Neurologists
   - ☐ Physical Therapists
   - ☐ Occupational Therapists
   - ☐ Alternative Therapists
   - ☐ Psychologists

☐ ENT Specialists
☐ Other (please specify)

10. Would you be interested in remote participation for support group meetings?

☐ Yes, I can do video conferencing
☐ Yes, I can do telephone conferencing
☐ No, I'm not interested
☐ Other (please specify)

11. What, if anything, hinders you from regularly attending support group meetings? (You can select more than one)

☐ Transportation
☐ Access and/or cost of parking
☐ Scheduling conflicts
☐ Dystonia or other health issues
☐ Meeting location
☐ Meeting day and/or time
☐ Not interested in meeting topics
☐ Negative experience at a previous meeting
☐ I don't feel the need to go to meetings at this time
☐ N/A
☐ Other (please specify)

12. What is the best way to inform you about upcoming meetings and events? (You can select more than one)

☐ Phone
☐ Email
☐ Mail
☐ Facebook
☐ Other (please specify)

13. Additional Comments?

Appendix C

DYSTONIA
MEDICAL
RESEARCH
FOUNDATION
CANADA

FONDATION DE
RECHERCHE
MÉDICALE SUR LA
DYSTONIE
CANADA

serving all dystonia-affected people
désservant toutes personnes atteintes de dystonie

Materials and resources

The DMRF Canada is here to support you. We have a wide variety of printed materials and online resources at your disposal.

Printed Materials:

- Going Forward Patient Package
- What is Dystonia Brochure
- Focal Hand Dystonia / Writer’s Cramp Brochure
- Blepharospasm Brochure
- Spasmodic / Laryngeal Dystonia Brochure
- Cervical Dystonia Brochure
- Functional Dystonia (Psychogenic Dystonia) Brochure
- Generalized Dystonia Brochure
- ‘Never Look Down’ Picture book to help your child's friends and peers understand dystonia
- ‘Real Patients Real Answers’ Dystonia Canada Survey Report
- Dystonia Canada Report (Newsletters)
- Promise and Progress Report
- ‘What is Dystonia?’ wallet cards
- ‘Do you have Dystonia?’ Posters
- ‘Going Forward’ Posters

Online Resources:

DMRF Website:
https://dystoniacanada.org/

Website for Support Group Leaders:
https://dystoniacanada.org/support

Resources for Support Group Leaders and Area Contacts:
https://www.dystoniacanada.org/resourcesforleaders

Social Media:
https://dystoniacanada.org/support-us-find-us-social

Online Support Forums:

Winnipeg Dystonia Support Group is here.

London Dystonia Support Group is here.

Alberta Dystonia Support Group is here.

Calgary Dystonia Support Group is here.

Montreal Dystonia Support Group (French) is here. / Ici pour le groupe de soutien Dystonie-partage de Montréal.

Montreal Dystonia Support Group (English) is here.

Vancouver Dystonia Support Group is here.

Online Dystonia Bulletin Board

Musicians with Dystonia Bulletin Board

Benign Essential Blepharospasm Research Foundation Bulletin Board

Patient and Family Run Online Dystonia Groups:

Dystonia Parents and Families in Canada Support Program: We recently received the much-needed funding to launch a support program specifically for parents of children and teens who have dystonia, as well as the children and teens who are affected by the disorder. Click here to find out more information.

Facebook Group: "Dystonia Awareness Canada"

Facebook Group: "Parents of Canadian children with Dystonia"

Facebook Group: "Cervical Dystonia Support Forum"

Facebook Group: "Oromandibular, Blepharospasm & Cranial Dystonia Support Forum"

Facebook Group: "20/30 Dystonia Group - A Forum for People in Their 20s and 30s"

Facebook Group: "Support4Parents of Children with Dystonia"

Facebook Group: "Generalized Dystonia Support Forum"

Facebook Group: "Parenting with Dystonia Support Forum"

Facebook Group: "Dystonia Spouses & Loved Ones"

Yahoo Group: "DBS for Dystonia"

Compassionate Communication and Self Care

Compiled by Karen K. Ross, PhD

How to say no with empathy and kindness:

1. I am sorry I cannot do this for you.
2. No, I am sorry.
3. No, that won't be possible.
4. I understand that you are having a difficult time.
5. What you are asking of me is beyond my scope of expertise.
6. I would like to help you in this, but I can't. However, I have a list of referrals for you.
7. What do you think would help you at this point?
8. I am not a therapist, but I can refer you to some that I know others have used.
9. Yes, I know you have been to therapists before and I wish I could help you, but it is not my role as a support group leader to be a therapist.
10. I would like us to find some ways to work on this issue together.
11. I am not available for calls in the evening and on weekends.
12. Let's find another time to sit down and talk about this, right now I have other things I need to do.
13. I understand you don't like your doctors, but I am not a professional and I cannot help you in this area.
14. I understand you are feeling depressed, please discuss this in detail with your neurologist.

Setting limits and boundaries:

- Setting boundaries means knowing what you are responsible for and what you are not.

- You are not responsible for another person's feelings, mental health, well-being or life.

- You are responsible for your feelings, your mental health and your well-being.

- Setting limits and holding your boundaries with members or with anyone else for that matter, has a big payoff; you continue to build your own self-esteem and feel more empowered. Always take care of your own well-being first.

TAKE CARE OF YOURSELF FIRST