

WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION OF CANADA

SUPPORT GROUP LEADER JOB DESCRIPTION

Responsibilities

Be available for contact from other Waldenstrom's patient(s) and/or caregiver(s)

Your contact information (phone and email address) will be listed on the WMFC website. You will be expected to take calls from WM patients in your area. You should be an active listener showing empathy, encouragement and support. Discussions will focus on symptoms, diagnosis, treatment, physician experts and WMFC services such as Support Groups, Educational Forums, WM literature and WMFC website. Veteran WM patients may call regarding their personal journey with WM. If they would like to connect with another WM patient in the area, with permission, it is fine to facilitate the connection. Try to determine the local WM physicians so that you are aware of your members' personal oncologists. This is very helpful information for new members.

Plan and facilitate two or more Support Group meetings per year

Frequency of meetings may depend on interest level, travel requirements and weather conditions. Ideally, meetings should be in locations that do not charge a fee, such as community centres, libraries, hospitals, churches, cancer centers or member's homes. However, financial support from WMFC may be available if needed. To stimulate interest among members, we recommend that you offer a range of program formats. Suggestions include guest speakers, educational sessions via internet or DVD, themed discussions or general Group sharing. Every meeting should include an opportunity for members to share experiences, questions and concerns even if it is for a limited time following a presentation by a guest speaker. At all meetings, new members should be introduced and offered the chance to share their personal story, if desired. You may want to collaborate with local cancer organizations for additional support (i.e. Leukemia and Lymphoma Society or Lymphoma Canada)

Communicate/Publicize your meetings

Please connect with Daniel Zlatin (WMFC web administrator) to post your meeting information (date, time, location, map, meeting agenda) on the WMFC website. You should also send out a notice to your group, using the bcc option.

Manage the WMFC member list for your Support Group area

Please recognize the importance of keeping your list of WM patients and caregivers current...and inviting them to your Support Group meetings.

If you are aware of loss of members, please advise the web administrator so our mailing list can be updated. New attendees should be encouraged to join the WMFC via our web

site (<https://www.wmfc.ca/membership/membership-form/>). Support Group Leaders are encouraged to ask attendees to update their member information (address, phone number, WM doctor, etc.) on the web site, or to collect the information and either add it for them or forward it to the web administrator so the membership list can be kept up to date.

The web administrator will notify Support Group Leaders of any new WMFC members (patients and/or caregivers) in your area that have contacted the WMFC directly, so you can reach out to them, invite them to your next meeting, and so they can be added to your list.

Note that we intend to periodically exchange membership information with the IWWMF, so that WMFC members can also benefit from IWWMF membership.

Communicate with your Support Group members

Please send Support Group meeting notices several weeks in advance so that members can plan ahead. Reminders can be sent closer to the meeting date. You may share news of interest to your Group, such as a local cancer-related meeting or a link to a key WM presentation. When emailing your Group, please use the Bcc option to protect the privacy of your members' email addresses. REMINDER: please make sure that your meetings/events have been sent to the web administrator prior to sending meeting notices to your members, so they can refer to the WMFC website if they would like.

Stay informed about new WM-related developments and patient issues

If possible, please consider joining the internet based forum IWWMF Connect to participate and connect with other WMers in discussions on all aspects of WM and sharing of concerns and positive experiences...these discussions are in English. A number of International Affiliates also have internet based forums, some in languages other than English. You can find all internet based forums at www.iwwmf.com/get-support/iwwmf-connect-and-online-discussion-forums.

If you are able, plan to attend the annual IWWMF Educational Forum and/or the WMFC bi-annual Educational Forum or the bi-annual IWWMF International Doctor-Patient Forums. These events, like Support Group meetings can be found on our website: www.wmfc.ca

The educational forums are a wonderful opportunity to learn about the latest WM developments from hematologists/oncologists who are experts on WM and network with others who have WM. In addition, you are encouraged to attend a WMFC/IWWMF Support Group Leader Workshop.

Assistance from the WMFC is available.

Thank you for thinking of taking on such an important role for the WM community. We sincerely appreciate your interest in serving others.