

ONLINE SUPPORT GROUP POLICIES

Content on Defeat MSA/Vaincre AMS/Vaincre AMS Canada associated charity websites and social media pages are contributed by volunteers and other users and thus, cannot be regarded as medical advice. The contents of associated pages and social media (such as text, graphics, images, information obtained from third parties, etc.), and other material contained on its websites (hereinafter "Content") are for informational purposes only. The Content is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified healthcare provider with any questions you may have regarding a medical condition. Never disregard professional medical advice or delay in seeking such advice because of something you have read on any social media platform or any Defeat MSA/Vaincre AMS/Vaincre AMS Canada associated website.

Reliance on any information and/or Content provided by Defeat MSA/Vaincre AMS volunteers, moderators, administrators or others appearing on Defeat MSA/Vaincre AMS associated websites and social media platforms at the invitation of the Defeat MSA/Vaincre AMS administrators or other visitors is solely at your own risk. Defeat MSA/Vaincre AMS volunteer staff takes no responsibility for, does not expressly or implicitly endorse, and does not assume any liability for, any content on any Defeat MSA/Vaincre AMS website or associated social media platform. Further, there are no representations or warranties of any kind, express or implied with respect to any content.

Participation in any research studies that one may learn about via perusing a Defeat MSA/Vaincre AMS associated website or social media platform is completely optional. Defeat MSA/Vaincre AMS/Vaincre AMS Canada's only function is to disseminate information. It cannot recommend any course of treatment or any particular diagnosis.

Our Data Collection Policy

For our privacy policy, please refer to this page on [our privacy guidelines](#).

If you have any questions about our privacy policy, please contact: info@msacanada.ca

Your Privacy Choices

Before posting a message, every user should be aware that posting might share possibly confidential information to be linked to personal identifiers (the username and Facebook profile information a member chooses to provide). This information will become available to others, and no one knows the identity or the motivation of those accessing the information. Posted messages can also be found by search engines (e.g., Google). It is therefore important to be careful when disseminating personal information (for example name or phone number) or when it concerns the privacy of relatives, especially children. In addition, every member should be aware that some of their own posts can be included in the responses of other participants, and can, therefore, could

be impossible to remove from Facebook data collection processes. It is advisable to weigh the potential benefits of participation in this online community with attendant risks to the confidentiality of information. Careful consideration should be given by users before agreeing to disclose location any information. Due to the nature of the diseases as being rare and the possible isolation of members, by disclosing location information, it may be possible that users can be identified.

Your Commitments to Defeat MSA/Vaincre AMS associated charities:

We are committed to keeping Defeat MSA/Vaincre AMS associated websites and social media platforms, a safe and supportive environment for everyone, so in using any of these websites or platforms, you are making the following commitments:

- **You will not act under a pseudonym in any of the groups or on any pages.**

- **You will not offer medical advice:**

Messages on groups or on pages must be for informational purposes only. You must not offer, or be perceived to be offering, medical advice. The information posted by users is often partial and may only cover one aspect of a person's illness(es) or experience(s). You will do your best to avoid generalizing from personal experience(s) and will clearly indicate if and when you are sharing your own personal story. Any information relating to therapy or diagnosis, even if it comes from users who could be considered to have 'expert knowledge' of a disease, must be received with caution. Only your physician is authorized to offer and/or confirm medical diagnosis and/or advice.

- **You will not recommend treatments:**

Treatment options should only be provided by a qualified physician and should depend on the particulars of everyone's medical history. The treatment choices of other users must be respected, and group members should never claim that a specific treatment is the only one that is effective for a particular disease. Group members must also be careful when sharing their experience(s) with products and/or practices that have not been properly evaluated for the disease or symptom that is the subject of discussion within the group.

- **You will not post any unauthorized advertising messages:**

Any form of advertising is not allowed in the groups. This applies with respect to treatments, clinical trials, registries, physicians, care facilities, etc.

- **You will be respectful of other group members. You will do this by:**

- respecting the opinions, beliefs, and differences of other members.
- being polite and keeping a measured tone in all exchanges.
- refraining from undermining the morale of other members.
- not posting hateful, threatening, violent or otherwise inappropriate content.
- not spreading rumors or content that may harm or endanger the health and safety of others.

- **You will not post content or engage in behavior that is illegal:**

All members must comply with the laws of their country. Particular emphasis must be on avoiding the spread of illegal content, respecting the privacy of other members, and protecting copyright and other intellectual property laws.

- **You will not collect users' content or information from this website for your own personal or commercial use. This applies to any and all means of collection (e.g. manual, automated, direct and/or indirect).**

Administrators and other volunteers reserve the right to delete postings or remove any member or participant who violates these restrictions and commitments, and this may be done in their sole and exclusive discretion. Administrators may, in accordance with their legal obligations, act quickly to remove data or make access impossible when they have knowledge from a third party that a member has circulated illegal content via Defeat MSA/Vaincre AMS/Vaincre AMS Canada associated groups or pages.

PURPOSE: The MSA Caregivers Video SGS ("Support Group Session") aims to provide a regular way for Caregivers Journey members to come together to support one another. This is a PRIVATE messenger room chat. No conversation is recorded, available after the chat or available to others outside the group.

All discussion in this group is confidential. No images or recordings may be taken.

For a list of those groups, visit here: <https://msacanada.ca/patient-programs/facebook-online-groups/>
OR call us: 1 855 KICK-MSA (1 855 542-5672)

GROUP GUIDELINES:

1. All comments must be respectful of all members. Participation in the group is at the discretion of the group administrators, moderators or other volunteers coordinated by Defeat MSA/Vaincre AMS. We have zero tolerance for any form of bullying whatsoever.
2. This forum may not be used for personal fundraising, sales, solicitation by individuals or groups, other than official Defeat MSA/Vaincre AMS sponsored activities.
3. Members may not lobby others in the group to fund a specific researcher, his/her particular type of research or his/her lab over others. Postings that excessively support particular researchers, their research or their lab may be removed at the discretion of group admins, Defeat MSA/Vaincre AMS staff or volunteers.
4. While Defeat MSA/Vaincre AMS/Vaincre AMS Canada appreciates the good intentions of the MSA community, the sharing of prescribed medication or treatments, in most jurisdictions, violates the law, thus this group cannot be used for such activity.
5. Participation in and/or admission to the group is entirely at the discretion of group administrators. Group admins are not obligated to provide reasons for not admitting an invitee, terminating a member or removing a post. However, due process will be followed in all cases.
6. Please avoid advertising, promoting other groups, suggesting members join other groups, using the group to fundraise for other organizations or to fundraise privately for individuals, for specific researchers or for the selling of their books, their treatment plans or diet plans.
7. None of the administrators or group members are trained professionals, thus, we cannot provide personal, marriage or family counseling.
8. Your participation in any of our support group sessions implies that you consent to all our support guidelines listed here:

Disclaimer: The material in this group is for informational purposes only and should not be used to diagnose or recommend treatment. Defeat MSA/Vaincre AMS/Vaincre AMS Canada makes no warranty as to the accuracy or relevance of the information in this group. Every member should consult with a doctor or other health care professional for diagnosis and/or treatment.

If you find that you are experiencing depression, then we strongly recommend that you to seek help. Anyone that posts anything that gives any hint that they may harm themselves or other people, that posting/individual will be referred to appropriate authorities.

We are all in this together! Let's speak as a true family - with one voice and one heart!

Group Sponsors: [Affiliated Charities of MSA United Research Consortium](#)