

The Society manages relationships with pharmaceutical, medical device, and research companies as well as with other MS organizations. **These types of organizations are not to directly contact and support Society affiliated self-help groups.** If a representative from an outside organization contacts you directly with a request related to your group, please refer the request to your staff partner and let the representative know you have done this.

Frequently Asked Questions

There are times when a pharmaceutical company sales representative contacts me, or a group member, directly and offers to arrange for speakers and refreshments for upcoming meetings. Is this an acceptable practice?

No, it is not. Pharmaceutical and medical device sales representatives may find and fund speakers for support group meetings, as well as pay for and provide refreshments. Your Society staff partner is to coordinate these types of requests and should approve of the speaker and proposed content first. When introduced, an approved speaker must fully disclose that he/she has been paid an honorarium by the pharmaceutical company. If the speaker plans to use handouts provided by the company, the Society must review the handout in advance. The representative is not allowed to be present at the meeting.

We have a local pharmaceutical sales representative who would like to attend our meetings. Is this allowed?

While the sales representative may be a genuinely caring and generous person, their presence at the support group is ultimately to promote the company's product. This goes against Society policies, in some cases against the pharmaceutical company's policy, and it may send a message to the group's members that the Society supports this company's product. Your staff partner should speak to the sales representative and advise them that their attendance is not permitted at meetings. Other employees of pharmaceutical companies, such as a nurse educator, may attend support group meetings but should not promote a particular treatment to the group.

I receive emails or phone calls from researchers or research companies asking for me to promote recruitment for different MS research studies. Can I share this information with my group members or forward a list of names to them for possible participation?

No, you should not. You should first contact your staff partner to find out if the

research study has been vetted and approved by the Society. If it has been, you can share that information with your group members. If it has not, you should not share the information with your group members. You should never release information about your group members to any outside individual or group.

I have started receiving calls and contact from local medical marijuana dispensaries. Can I have a speaker talk to our group about medical marijuana or cannabis?

Yes, you can, but the same guidelines apply as those we use with other pharmaceutical industry partners. Consult with your staff partner should you receive this type of request. To be consistent with our guidelines, if approved by the staff partner, only medically qualified personnel (physicians, nurses, pharmacists, etc.) should speak at group meetings and materials or content delivered should be approved beforehand. Representatives from the medical marijuana industry (such as sales representatives, or staff from the dispensary or grower) are not acceptable speakers. The agenda should only focus on medical use, even in states where recreational use is approved.

I had another MS organization reach out to talk to me about affiliating my group with them as well as with the Society. Is this something I can do?

Self -help groups are encouraged to utilize community resources through formal or informal affiliations, provided attention has been given to the focus and integrity of the other organization and the outcomes that will be achieved through the association. Reach out to your staff partner to talk through the request you received.

Sometimes support groups are approached by other organizations, including other MS organizations, to form affiliations or working partnerships. When considering the pros and cons of affiliating with another organization, **group leaders and Society staff collaborate** to investigate the mission, reputation, credibility, and activities of that organization. Before an affiliation is forged, both Society staff and the group leaders need to be certain that there is no intent on the part of the other organization to exploit the Society or its members. Affiliations are forged only when doing so will strengthen, not interfere with, the fulfillment of our mission. Other organizations may have different requirements and standards. Groups must adhere to those requirements and standards of the Society to have dual affiliation.