



SUPPORT GROUP LEADER GUIDELINES

OVERVIEW

The goals of the Facial Pain Association's Support Group Program are to:

1. Promote and support the mission, vision, and priorities of FPA
2. Be a resource for anyone affected by facial pain
3. Promote awareness of FPA
4. Promote public awareness of facial pain

The Support Group program is an important part of FPA's commitment to substantially increase the number of people we reach in the facial pain community including those living with neuropathic facial pain, their caregivers, and the medical community. FPA believes personal contact with others affected by facial pain is critical, and will promote the Support Group program through all its communication channels.

FPA Support Group Leaders are volunteers who coordinate regularly scheduled Support Group meetings for those in their local area affected by facial pain. Support Group meetings may include face to face meetings, video conferencing, or a hybrid of both aimed at providing access to as many participants as possible. Meetings will be held no fewer than twice a year, and may be held as often as the group decides.

Support Group Leaders will strive to provide upbeat meetings that create connections between people, provide consistent, comfortable environments, and promote networking and learning. Support Group Leaders will strive to communicate with empathy, honesty, and reassurance.

Support Group Leaders are expected to share FPA announcements, information, and resources at all meetings. FPA will provide announcements periodically.

Support Group Leaders are encouraged to provide FPA information to healthcare professionals in their area.

FPA welcomes Support Group Leader volunteers from varied backgrounds, life experiences, and medical histories. No specific skills, educational background or experiences are required to serve as a Support Group Leader. However, successful applicants are asked to meet the requirements listed in these Guidelines.

FPA MISSION, VISION and PRIORITIES

MISSION: To serve those with neuropathic facial pain, including trigeminal neuralgia, through support, education, and advocacy.

VISION: To be the most reliable and comprehensive resource on facial pain conditions for patients, their families and healthcare professionals.

PRIORITIES:

1. Substantially increase the number of people with neuropathic facial pain, their caregivers and the medical community who the FPA reaches



2. Improve the value of FPA's work by significantly improving the alignment and delivery of information and support to the needs of our constituents
3. Expand the healthcare community's awareness, involvement with, and support of FPA's work to better serve our community
4. Substantially expand FPA's strength by developing a large volunteer corps and aligning their activities with our mission and plan
5. Increase FPA's revenues to enable it to fully fulfill its mission and implement this plan

BENEFITS of VOLUNTEERING

1. Connect with others with shared experiences
2. Help others by sharing information and tips on dealing with specific issues, overcoming disabilities, and reassurance of better times ahead
3. Reduce the isolation, and frustration felt by many affected by facial pain

APPLICATION PROCESS

1. Complete and return the application
2. FPA will contact applicants, if appropriate, to schedule a telephone interview
3. Feedback given by FPA to applicants with next steps, as needed
4. FPA leadership may approve or decline any applicant at their discretion

HOW IT WORKS

FPA is contacted daily by members of the facial pain community seeking support and information. FPA responds by providing requested information along with a list of resources including a list of Support Groups. The Support Group list includes contact information for Support Group Leaders. It is then up to the individual to reach out to one or more group from the list.

It is ultimately the responsibility of the Support Group Leader to create a vibrant, engaged group. However, FPA is committed to promoting Support Groups, and assisting Support Group Leaders.

FPA WILL:

1. Promote all groups on the Association website, through emails, social media channels, and the twice monthly email newsletter Bulletin
2. Promote all meetings
3. Provide education, training, and information to Support Group Leaders.
4. Provide a dedicated Volunteer Coordinator
5. Assist in finding meeting locations
6. Assist in finding speakers
7. Periodically publish a Support Group Leader email newsletter
8. Provide resource material
9. Notify Support Group Leaders of upcoming programs, including webinars and conference events
10. Provide the QUARTERLY-Journal of the Facial Pain Association
11. Maintain an accurate database with contact information for all FPA Support Group Leaders, meeting attendees, and members of the facial pain community.



VOLUNTEER REQUIREMENTS

General:

1. Possess good communication skills
2. Ability to speak objectively with different types of people
3. Reflect positively on FPA in all interactions including conversation, in writing, and on social media
4. Be knowledgeable about FPA programs and services
5. Respect the privacy and confidentiality of attendees
6. Never share information for any purpose inconsistent with FPA policies
7. Commit to a two-year term as Support Group Leader volunteer

Communication with Your Group:

1. Be accessible by email and/or telephone
2. Respond to inquiries in a timely manner
3. Do not speak on behalf of FPA on any media unless part of an official FPA activity

Keep in Touch with FPA:

1. Grant permission to FPA to disclose contact information provided on the Support Group Leader Application
2. Update contact information with FPA, as needed
3. Update your personal information with FPA including any treatment updates, as needed
4. Inform FPA if you will be unavailable for an extended time
5. Coordinate information requests with FPA Volunteer Coordinator
6. Provide FPA with meeting schedule and details 4-6 weeks in advance
7. Provide regular reports to FPA on recent meetings to include: number of attendees, topics discussed, and speakers hosted

Upon approval, new Support Group Leaders will receive a Welcome Package to include:

1. Letter or email confirming participation and effective dates of participation
2. List of FPA Support Groups with leader contact information
3. Peer Mentor list
4. Information and Resources List

FPA DISCLAIMER

All volunteers are approved by FPA, and may be removed any time at the discretion of FPA. Volunteers may share personal experiences in an effort to increase awareness and educate participants about their diagnosis and treatment experience. When sharing experiences, volunteers must be clear they are sharing personal stories as someone else might have a different experience.

Support Group Leaders may not give medical advice. Opinions expressed, or information provided, by FPA Support Group Leaders is not a substitute for medical advice. Support Group Leaders must always encourage those they communicate with to contact their own doctor, or other professional healthcare provider, with questions concerning their or their family's health.

FPA STATEMENTS



FPA is a secular organization and respects all spiritual beliefs. There shall be no discrimination in the recruitment, selection, placement, training, retention, and recognition of volunteers regardless of race, color, religion, ethnicity, age, socio-economic status, disability, sexual orientation, gender identity, gender expression or national origin.

Revision May 2022