

How to stay connected to SPF members

Be a listener! Give suggestions and know who to contact for different requests. Be well versed in the SPF website. Visit it often to see what's new.

Be a liaison! Know whom to contact. And make sure to follow-up!

Be a conduit! Especially newly diagnosed people don't know where to begin or what to ask. "Where do I start?"

Be an example! (Practice what you preach!) If you are recommending stretching or other forms of exercise, make sure you are doing it too.

Send out periodic emails. However often—you decide. Be excited! Send pictures and short videos. Share what's happening with you.

Update your contact information at least once a year. Let SPF know of a change. It costs money, in returned postage, that could be spent on research.

Hold periodic group meetings. This can be formal (a connection with an agenda or speaker) or informal (a simple "let's meet for coffee!") as you like!

Please maintain respect for everyone with HSP or PLS in your area at all times, hold the Spastic Paraplegia Foundation in high regard and follow the guidelines presented by the Board of Directors.

HSP and PLS must both be represented equally at all times. Please use hashtag #hspandpls when posting online.

If you are asked any questions by your membership group that you are not confident in answering, please direct them to the Board of Directors by emailing the question to volunteer@sp-foundation.org

Facebook:

<https://www.facebook.com/SpasticParaplegiaFoundation>

LinkedIn:

<https://www.linkedin.com/company/spasticparaplegiafoundation/>

Twitter:

<https://twitter.com/SpasticWorld>

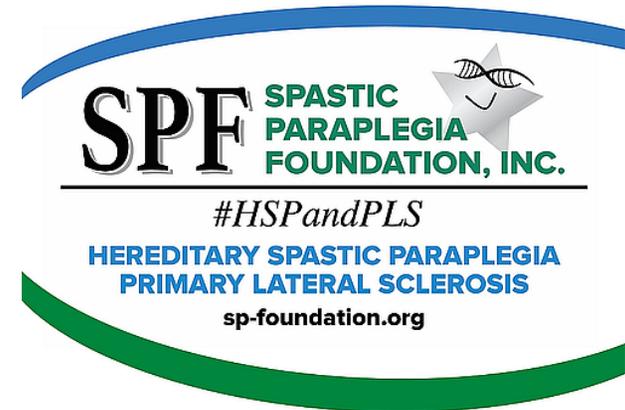
Instagram:

<https://www.instagram.com/spasticparaplegia/>

YouTube:

<https://www.youtube.com/channel/UCsZIM577T5rKs8hRjToucZA>

SPASTIC PARAPLEGIA FOUNDATION
<https://sp-foundation.org/>
(877) 773-4483



SPF Ambassador Volunteer Information

SPF VISION: The day when all individuals with HSP or PLS are diagnosed, treated and cured.

Ambassador Volunteer Description

Ambassadors raise awareness about our disorders as well as enhance community building and industry relationships. You can assist with media relations, share your story, speak at local groups, or help with grassroots advocacy.

Establish a network and locations of people

Ambassadors can receive an Excel spreadsheet of contact information for people in their state known to have HSP, SP, or PLS. The number of people will range from a few to many and the information will range from just names and emails to full mailing addresses

Your Role as an Ambassador

Ambassadors will receive information of new people in their area who join our community and send out "Welcome" emails to them. Depending upon the area, this may be 1-12 people over the course of a year.

Let people who live within reasonable proximity to one another know they are "neighbors" and encourage them to meet.

Send out periodic emails as needed to maintain the regional network.

Hold periodic group support meetings or more formal events

Try to get current contact information if the information provided on the original spreadsheet is incorrect. Report updated information to SPF database coordinators at volunteer@sp-foundation.org

Encourage participation in annual conferences and monthly meetings.

Criterion for Ambassadors

Have an SPF disorder (HSP, SP, or PLS), related to, or a caregiver to, someone who does.

Are people who seek to enhance the quality of life for individuals and bring energy and commitment to the program.

Are comfortable with email, internet searches and Excel and Word applications.

Can make a commitment of one year.

Will respect and maintain the confidentiality of our members and not share personal information outside of SPF initiatives. Additionally, Ambassadors will respect the desire of individuals who do not want any further contact.

Resources on the Website

Ways to donate:

<https://sp-foundation.org/get-involved/donate-here/>

Ambassador Resources:

<https://sp-foundation.org/get-involved/ambassadors.html>

Member Resources:

<https://sp-foundation.org/news-resources/>

How to reach out to members in your state/region

Reach out to volunteer@sp-foundation.org to obtain a list of members in your region. Then use the sample welcome letter to send an email to the members in your state, which is found at: <https://sp-foundation.org/get-involved/join-the-spf-ambassadors.html>

What to expect as an Ambassador

Participate in the monthly SPF Education Committee and Ambassador Meetings, held on the third Wednesdays of the month, starting at 7:00PM CST via Zoom.

Send a monthly email to members in your region with high level updates from the monthly education committee and ambassador meeting.

Stay connected to members in your region as a liaison and support member giving them info they may need to feel connected in the community.