

## Connections Resource Book

Step-by-Step Guide  
To A Successful Connection event

Spastic Paraplegia Foundation, Inc  
PO Box 1208  
Fortson, GA 31808-1208

(877) 773-4483  
[events@sp-foundation.org](mailto:events@sp-foundation.org)



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*Research / Education / Support*

## Contacting SPF

Web	<a href="http://www.sp-foundation.org">http://www.sp-foundation.org</a>
State Ambassadors	<a href="http://www.sp-foundation.org/State_Ambassadors.htm">http://www.sp-foundation.org/State_Ambassadors.htm</a>
Email	<a href="mailto:events@sp-foundation.org">events@sp-foundation.org</a> or <a href="mailto:information@sp-foundation.org">information@sp-foundation.org</a>
State Ambassadors National Coordinators	Linda Gentner <a href="mailto:lkgentner@aol.com">lkgentner@aol.com</a> (510) 651-5676  Annette Lockwood <a href="mailto:annette.lockwood@verizon.net">annette.lockwood@verizon.net</a> (703) 493-8779
Telephone	(877) 773-4483 (877) SPF-GIVE
Mail donations to	Spastic Paraplegia Foundation, Inc. PO Box 1208 Fortson, GA 31808-1208
SPF National Legal Advisor	Mark Weber, Esq. <a href="mailto:markw732@yahoo.com">markw732@yahoo.com</a> ( 860) 354-7071
SPF Tax ID	04-3594491

# 1 Connections Resource Book

Connections are special events that bring our community members together to share stories, resources, treatment programs and concerns as well as learn about treatment therapies and research. Connections can range from small, casual get-togethers to formal events with one or more featured programs or speakers. The type of Connection depends upon the Connection organizer's interests, abilities and geographic location (i.e., how many other community members are in the organizer's area). This resource book provides suggestions to help you in organizing and hosting a successful Connection.

People with HSP or PLS began organizing meetings and conferences in the late 1990's, before the Spastic Paraplegia Foundation (SPF) was founded. At that time, there was no organization dedicated to our conditions so people began to organize meetings and do fundraising as individuals or with researchers. As closely related motor neuron disorders, the two communities merged over time and ultimately decided to form the SPF as an incorporated organization dedicated to both conditions.

*Connections  
bring people  
together*

After the founding of SPF in 2002, the term "Connection" began to be used as the broad term for all types of community events. The popularity of Connections continues to this day because people have found there is no substitute for meeting in person to share common experiences and concerns.

Connections are commonly organized by State Ambassadors; however, anyone can work with the State Ambassador to organize one. An active regional area generally has at least one Connection per year as well as a TeamWalk (a special Connection with a fundraising focus).



2010 New England Spring Forward Connection

## 2 Casual Connections

At Casual Connections the focus is on sharing and getting to know one another. That's usually easier and more comfortable for the participants if done in connection with a snack or mid-day meal. These casual events are often small under 12 people so they are commonly held in coffee shops, restaurants or similar places where no one has to think about meal preparation.

- Coffee Shop
- Restaurant
- Hotel restaurant - these are actually the best because you can linger there
- Home - Potluck and Picnic Connections on people's patios work well

We have found that both distance to travel and expense of the event are significant considerations when community members are deciding whether or not to attend a Connection. Hold a Casual Connection in an easy-to-reach place where the density of community members is high such as near a major city. When finalizing the specific facility for the event consider accessibility. The room itself, obviously, has to be accessible, but also check to see that there's sufficient accessible parking, accessible washrooms and that the seating can accommodate wheelchairs and/or scooters.

### Getting Started

As with any project in life, the most difficult step is getting started. Talking over the need for a Connection with a close friend is a great way to start. Considering some options for location and a date should be done early on. Once you decide on the date and location, you are on your way. Publicize your event by using the various electronic services SPF has to offer. Posting an invitation to your event using the on-line support forums, PLS-Friends and HSP ListServ, is a great way to start. Alternatively you could send a broadcast email to all those in the area of your event. Or, you could pick up the phone and start calling.

The general concept for a Connection as opposed to meeting a few close friends is to make it an open invitation to all SPF community members in the area of the event. If you are unfamiliar with the use of the SPF on-line

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forums, contact the SPF National State Ambassador Coordinator. See Resources, page 2.

If you already are familiar with use of the on-line forums, just go ahead and use them to announce your event. If your event becomes much larger than 12 people you might think about organizing it as a Seminar type Connection as discussed in Section 3.

After the Casual Connection, if possible send a brief email report to the SPF National State Ambassador Coordinator along with a few digital photos taken at the event. You will likely see your article in the next issue of Synapse.



### 3 Seminar Connections

Seminar Connections have a dual purpose – socializing (sharing experiences and getting to know other members of the SPF community) and education (learning of new therapies, helpful exercises or advances in research into the causes of HSP and PLS). Usually this involves inviting a speaker, so it's worth sharing with a larger audience. The larger the group the more opportunities people will have to make new friends.

Similar to the Casual Connection, socializing at Seminar Connections is usually easier and more comfortable for the participants if done in conjunction with a snack or mid-day meal at tables of six to eight. As a result Seminar Connections are usually held in a hotel or assisted living function rooms, church fellowship halls, hospital or medical center meeting rooms, vendor conference rooms, or outdoor picnics in state parks (weather permitting).

#### Suggested Locations

The following is a listing of locations for past successful Seminar Connections:

- Coffee Shop
- Restaurant
- Hotel restaurant - these are actually the best because you can linger there
- Parks – a park with some type of shelter is best in case of rain
- Tourist venues (these usually offer an interesting activity as well as a place to meet and linger)
- Library - very easy to book a room, but sometimes food or drink is an issue
- Hospital Cafeteria or meeting room
- University cafeteria or meeting room
- Health Clinic meeting room (physical therapy places are usually pleased to host us)
- Durable Medical Goods Store meeting room
- Work place meeting room
- Church or temple meeting room

We have found that in general SPF community members are willing to travel more than a few hours for a Seminar Connection because of the added value of the program coupled with the opportunity for social interaction. But as with the Casual Connection both distance to travel and expense of the event tend to be significant considerations when SPF members are deciding whether or not to attend a Connection. Therefore it's recommended to hold a Seminar Connection in an easy-to-reach place where the density of community members is high such as near a major city. When finalizing the specific facility, as with the Casual Connection,

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consider accessibility. The room itself, obviously, has to be accessible. Also check to see that there's sufficient accessible parking, accessible washrooms and that the seating can accommodate wheelchairs and/or scooters.

### Suggested Themes and Speaker Topics

A recent survey of SPF community members demonstrated that the overwhelming majority want Connections that inform them on advances in research, therapies or treatments for their disorders. Accordingly a neurology researcher or a clinician, a physical therapist, an advocate for the disabled or a social worker all make good choices for a speaker. We have found that having some form of stretching or exercise led by a physical therapist is a great activity in addition to the main speaker.

Here are some additional speaker sources:

- Physical Therapist - may be found through Yellow Pages or by calling PT Sports Clinics or universities that have PT programs
- Alternative Medicine - there are often small organizations that offer specialties such as massage, acupuncture
- Counselor/therapist to speak on topics such as Mind/Body, Stress, Progressive Disease, Relationships - call hospitals to inquire about their Speaker Program or just use the Yellow Pages
- Independent Living Centers have people who can do Motivational Talks and talk about ILC services
- Elder Services Organizations often have people who can talk about programs of interest like safety in the home, modifications, etc
- Neurologist or MD: the Connection Organizer often asks their neurologist to be keynote speaker
- Pharmacists - talk about spasticity drugs and other remedies for our disorder symptoms
- Medtronic reps – have been willing to speak about Baclofen pumps
- Rep from durable medical goods store – usually are willing to demo products. It would be good to have an OT at the same time





- Disaster Preparedness - Red Cross is a good source for such speakers

Experience has shown it helps a lot to have some or all of the above as it makes the Connection more valid and interesting. Titling your event as a Lunch Connection or Picnic Connection is appealing. Your event announcement should include a tag line after the title to better describe the event. Providing an event agenda that lists the topics or activities that will be included at the meeting is helpful.

For example,

- *Meet, Share, & Learn*
- *Best Practices*
- *Meet the Experts*
- *Quest for the Cure*
- *Tips, Tools & Techniques*
- *Ask the Experts*
- *Balancing Act*
- *Sit Wise*
- *Making Lemonade*
- *Silver Linings*
- *A Family Affair*
- *Just Between Us (breakout for caregivers and helpers to meet separately)*

These are easy programs to do that are just "us" and giving them a "name" makes them more intriguing. All of the above could be just "us" doing a round table or could be featuring a Special Guest talking about something pertinent to that topic.

### How to Organize

Taking the first step, as with the Casual Connection, is a challenge for organizing the Seminar Connection. Here, because more details need to be considered and implemented it's important to have helpers. Talking over some ideas for a seminar topic, location and date with a friend is an



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effective way to start. Simply follow the five steps outlined below in Section 4. It is important to share your tentative plan with the SPF National State Ambassador Coordinator to be sure there are no conflicts with other SPF events in your area. Getting others to help is especially important here because of the number of details to work out – finding a speaker, figuring out what to charge, checking the location you have picked for handicapped accessibility, negotiating the function room price and meal charge, accepting reservations and MCing the event. You will find that if you can share the load with others the event organizing and running can actually be an enjoyable enriching experience!



## 4 Steps to Success

A successful Connection requires that people hear about it soon enough that they have time to seriously consider attending. We have outlined a five step process that smoothes the entire activity for you, from planning on day one through to the Connection event itself.

### 1) Contact SPF

Start by contacting the SPF National State Ambassador Coordinator. She or he will supply you with all the information you need, guidance and assistance as needed in organizing your event. (See a list of some of the material available in Section 5).

### 2) Get Others to Help

It's more fun and easier if you have others working with you. Consider family members, friends and people you have met at prior SPF events and the SPF State Ambassador, if there is one for your state. Between publicity, coordinating with the event location manager, collecting registrations and arranging for a speaker, there is plenty of work to go around. The SPF National State Ambassador Coordinator may be able to help find some people in your region to help as well.

### 3) Select a Location, Date and Calculate Cost

The first activity will be to draw up a list of possible locations for the event. The goal is to offer an event that is so appealing that it encourages SPF community members, some of which might be reluctant to attend events for the first time, to attend. Select a date that does not interfere with a Christian or Jewish holiday weekend.

Each Connection is intended to be self-supporting that is the expenses are paid by the SPF members attending, so carefully consider the expenses. If it's a casual connection then the bill can be divided among the participants or each can order separately. For a seminar connection it's best to announce a cost per person with the invitation. This means you need to estimate those expenses - meal and tip, function room cost (if any), gift for a speaker (if any) and any mailing expenses you might have - well in advance of the event. Appoint someone as the registrar for the event so that all registrations come to their address including checks made out to SPF to cover their registration and any donation they wish to make.

SPF is a charitable non-profit 501 C(3) organization. Our Federal Tax ID is listed under resources on page 2.

Retain receipts for all expenses, so that you or the appointed registrar can be reimbursed by the SPF Treasurer after the event. (See the financial report that should accompany the receipts and checks in Section 5, Financial Responsibility) If the expenses of holding your event appear to be significant it's worth checking to see if the expenses, such as catered

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lunch, facility use charge, etc. are tax exempt in your state. Contact the SPF legal advisor to see if SPF has a tax exemption in your state.

### 4) Spread the Word

Publicizing your Connection to SPF community members in your area is the most critical step in making your event a success. Make your initial event announcement at least 8 weeks before your event, which you might do through SPF's on-line support groups PLS-Friends and HSP ListServ. Early on you should also contact the SPF National State Ambassador Coordinators. They will reformat your draft announcement and use SPF's database and broadcast service to send a Save-the-Date email broadcast message to all the SPF members in your state or regional area. (See the sample email in Section 6)

SPF will help you promote your event through listings on the SPF Website, in SPF e-News and in the SPF Synapse newsletter as well as promotion through the SPF email support groups. If you wish SPF can also set up an on-line registration form and payment using a credit card or PayPal. Follow-up reminders via email, or more effectively, personal calling to SPF community members in your area by members of your committee are a critical second step. This step in the process is usually the most challenging, but perseverance pays off. Just think of the positive reaction so many have after attending their first Connection.

### 5) Hold Your Event

Divide the responsibilities associated with running the event, receive registrations before the event, assign someone to MC the event and enjoy your Connection! After the event there are two reports you need to complete:

1. Financial report: Fill out the financial reporting form in Section 6 and send it to the SPF Treasurer so that your checks are cashed promptly and you are promptly reimbursed for the event expenses.
2. Event report: Also take time to briefly summarize the event in an email to the SPF State Ambassador National Coordinator. Send the email along with a few digital photos as attachments so it can be included in the Events section of the next Synapse.

Now sit back and relax, you are done!

## 5 Available SPF Resources

### National Ambassador

The SPF National State Ambassador Coordinators are listed on the Resources Page (page 2). They can provide you with:

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Guidance	Find out what other SPF events are already scheduled for your region or area.
History	Get the history of team walks in your area, how much was raised, when and how.
Contact information	Obtain a listing of SPFers in your area including mail and email addresses, phone numbers and whether they are patients or caregivers
Area wide email instructions	Obtain assistance in preparing and sending a broadcast email to SPF community members in your area. The SPF email broadcast system maintains privacy by showing only that individual's email address on each email received.

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### Financial Responsibilities

The SPF maintains a database of all donors. It does this for various legal, tax, and marketing purposes. Periodically, the SPF must report all donations received to each respective Secretary of State office.

Donors expect all donations to be processed as soon as possible. To accomplish this, all donations received must be sent to the SPF National Treasurer.

Every two weeks, send all checks received, along with the donor name, address, telephone number, and email address (if available) to the donation address below. The SPF will send them a thank you email.

It is appropriate to make a photocopy of each registration form received. If this option is not available to you, use the reporting sample form attached in Section 6.

### Reimbursement for Expenses

Keep all receipts. After you have completed your event, send all expenses and all final donations received. The SPF will reimburse you for valid and approved expenses. You can work with the SPF National State Ambassador to determine if an expense is appropriate and reimbursable. Any expense over a \$yyyy must have prior SPF approval.

To request a reimbursement, complete the form below, mail your Connection receipts and expenses along with the completed financial report to the SPF National Treasurer at:

Spastic Paraplegia Foundation, Inc.  
PO Box 1208  
Fortson, GA 31808-1208

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Event Date and Location

Total Donations Received

#### **Expenses**

Meals and tip

Function room

Speaker gifts

Other expenses

Total expenses to be  
reimbursed

Make check payable to

## 6 Sample Email and Flyers



### The New England Spring Forward Connection

Saturday, April 10, 2010

11a.m. – 3:00 p.m.

Brooksby Village, Peabody, MA 01960

Please plan to -

**Join us** to greet old friends and meet new friends.

**Enjoy** lunch in Brooksby's Garden Room

**Exercise** in your chair, led by Liz Wroblewski, PT

**Learn** from Dr. Nazem Atassi of MGH

Our speaker this year is **Dr. Nazem Atassi, MD**, a neurologist at MGH in Boston. His talk will be on "Trends in Research and Therapies for Motor Neuron Diseases." We think both those with HSP and those with PLS will find Dr. Atassi's talk easy to understand and very relevant to our situations. Those of you who attended the 2009 Fenway Park TeamWalk will remember **Liz Wroblewski**, a PT, who led our stretching exercises there.

**Driving directions:** From Rt. 95 take Exit 47A (Route 114 East towards Peabody); travel 0.5 miles east on 114 to Brooksby Village Drive on the right. Tell the guards at the gate you are going to the SPF meeting at Renaissance Gardens; they will direct you. Park in the back of the building and enter through the front door. Follow the signs to the Garden Room.

If you have any questions, please call the event chairman, Jim Campbell.

Phone: 508-653-5246

Email: [jimthurza@comcast.net](mailto:jimthurza@comcast.net)

\*\*\*\*\* cut here and mail \*\*\*\*\*

**Registration Form (Deadline: March 31)**

**Registration is \$15 per person.** Make checks payable to "Spastic Paraplegia Foundation" and mail with your registration to: Joel Seidman 304 Brooksby Village Drive, Unit 210, Peabody, MA 01960-8582

Name(s) of attendees:

Lunch wrap selection(s): Roast Beef\_\_\_\_; Tuna\_\_\_\_;Turkey\_\_\_\_;Vegetarian\_\_\_\_

Enclosed is also a donation to the SPF Research Fund: \$\_\_\_\_\_.

Total enclosed: \_\_\_\_\_

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Or you can go to the following Webpage to learn more details and to register:

<http://sp-foundation.org/events/neconnection-2010.htm> At bottom of that Webpage you can register on-line. You have the option of using a credit card to pay the meeting fee including lunch or mailing a check.



## Tampa Bay SPF Lunch Connection

For people concerned with *Hereditary Spastic Paraplegia* or *Primary Lateral Sclerosis*



Sunday, February 15, 2009

12:00 p.m. – 3:00 p.m.

5559 97th Way N, St. Petersburg, FL 33708

Gather with others concerned with HSP or PLS at the home of Jeff and Diana Litt. Note: Jeff is a registered pharmacist and will present our Special Feature program.

*Exchange stories, concerns and resources. Participate in our  
“Top T’s” session: share a helpful tip, tool or technique*

*“Ask the Pharmacist” with Jeff Litt, RPH – learn about drugs  
helpful with spasticity, anxiety/depression, and bladder/bowel  
issues  
Lunch*

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**Advance registration is necessary!** The cost is \$10 per person, which covers your lunch and the program. Please clip this section and enclose it with your payment (check to SPF) and mail to: Kathi Geisler, 1 Dornoch Circle, North Chelmsford, MA 01863. Questions: call Kathi Geisler at 978-204-7432 or email at [kathi@kgeisler.com](mailto:kathi@kgeisler.com).

I am attending the Tampa Bay Lunch Connection:

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