



## **SPD-Parent Connections Host Information and Application**

Thank you for your interest in starting a Sensory Processing Disorder-Parent Connections (SPD-PC) group in your community. This application contains information about how we at the SPD Foundation and you as a parent volunteer can work together to help sensational families.

### **SPD-PARENT CONNECTIONS**

SPD-PC is a parent/volunteer activity of the Sensory Processing Disorder (SPD) Foundation, a nonprofit 501(c)3 charity dedicated to SPD research, education, and advocacy.

SPD-PC groups exist to provide a geographically diverse source of local support, information, and understanding to anyone who has SPD or lives with someone who has SPD. Parents served by SPD-PC benefit directly by learning from hosts and sharing their experiences with one another. To the extent that these parents become better informed and more effective advocates for their children, they help raise general awareness of SPD to the benefit of "sensational families" everywhere.

### **ROLE OF THE PARENT CONNECTIONS HOST**

SPD-PC hosts act as facilitators for Parent Connection groups operating under the auspices of the SPD Foundation. Hosts typically organize support for parents of children with sensory issues by:

- Scheduling group discussions, guest speakers, special events, and/or other activities.
- Distributing information to parents about SPD, community resources, and other topics.
- Conducting fundraising activities on behalf of the SPD Foundation.

### **ROLE OF THE SPD FOUNDATION**

SPD Foundation supports SPD-PC hosts by:

- Referring parents who contact us in search of local support to SPD-PC groups in their areas.
- Publishing your contact and meeting information on our web site.
- Providing handouts, templates, and other forms and information that can be downloaded and printed or be downloaded, customized, and printed to promote SPD awareness and SPD-PC activities. (Soon to be posted on the web site.)
- Maintaining a private bulletin board on our web site where you may network with other hosts to exchange information, ideas, questions, and answers. (Currently under re-construction.)
- Providing a designated mailbox (parents@spd.foundation.net) where you may submit questions, requests, problems, and other matters for our handling.
- Designating an SPD Foundation parent coordinator to answer questions, supply materials, and otherwise support our Parent Connections hosts.

### **MEMBERSHIP**

Membership is a formal way of affiliating with and showing support for the SPD Foundation. As a parent host, you will receive a free membership and all membership benefits as long as you host. Making announcements at your meetings or in your emails promoting membership within your SPD-PC group is a valuable to support the Foundation and is strongly encouraged.

## MEETINGS

**Hosts are strongly urged to consult the SPD-PC mission statement (see page 4) for guidance in choosing appropriate guest speakers for SPD-PC meetings and activities for their group.**

### General meeting guidelines

- Meetings are generally held once a month or quarterly. It is the prerogative of each group to determine the frequency of meetings.
- Group meetings are free of charge. (Fees may be charged only to cover a speaker's fee or for similar extraordinary costs.)
- While we recommend inviting professionals who treat people with SPD in your community to present at your meetings, hosts may use their own discretion and creativity to develop the programs that best meet the needs and interests of their groups.
- Hosts are free to operate independently or with a committee, whichever arrangement is best for you and your group.
- **No** children are permitted at SPD-PC meetings. It is the host's responsibility to communicate and enforce this policy to parents. The SPD Foundation expressly denies any responsibility or liability arising out of SPD-PC meetings.

### Helpful meeting tools

- Name tags
- Sign-in sheet for names, addresses, phone numbers, email addresses, name/age of children
- A sample copy of *Sensational Kids* by Lucy Jane Miller, PhD, OTR
- A sample copy of *The Out of Sync Child* by Carol Stock Kranowitz
- A sample copy of Diana Henry's *Tool Chest: For Teachers, Parents & Students*
- Catalogues from Abilitation/Integrations, Southpaw, Sensory Resources, Flaghouse, and other sensory product manufacturers and distributors
- Books and tapes you have personally found useful
- A list of local community resources you and your members develop from your experiences

**Meeting policies:** Hosts agree to observe the following meeting policies:

- Hosts may not sell any products or services at their meetings.
- Hosts may not represent particular companies or types of therapy.
- Meetings are to be held in public venues.
- Hosts should state clearly at each meeting that they are not providing medical advice.
- Hosts will not charge for monthly meetings except for payment to a guest speaker or to cover similar extraordinary costs.
- Hosts will inform guest speakers that they may not use SPD-PC meetings as a venue for recruiting new clients or promoting products.
- Hosts will state and enforce the prohibition on children attending meetings.

## DUAL HOSTING

The SPD Foundation recognizes the value of all parent-hosted networks in spreading awareness of SPD and realizes that some parent hosts may wish to participate in more than one support system. We encourage parents to participate in whichever support networks they find helpful. At the same time, we believe that taking on the responsibility of *hosting* a group may at times include significant time and effort. Because acting as host for more than one network may result in excessive stress on the host, we request that SPD-PC hosts refrain from hosting for other support networks.

**By submitting this application, you agree to undertake the following:**

1. Public Knowledge:

- To set up an SPD-PC group in your community.
- To maintain a current email address on the SPD Foundation website where people may contact you (www.SPDFoundation.net).
- To be available by email and/or telephone to respond to questions and comments from parents in your service area.

2. Communications:

- **To visit** the SPD-PC Host Post bulletin board at least once weekly to read alerts and other bulletins for hosts from the SPD Foundation and to stay up-to-date on activities by other SPD-PC groups.
- **To protect** the Host Post bulletin board as a limited-access SPD-PC host activity by never giving its password to anybody who is not an SPD-PC host.
- **To refer elsewhere** questions that are clinical in nature (e.g., about SPD symptoms, causes, prevalence, treatment, and other). For example, you might refer people to the "About SPD" pages of our web site, to Our Library at www.SPDFoundation.net, and/or to Dr. Lucy Jane Miller's book, *Sensational Kids: Hope and Help for Children with Sensory Processing Disorder (SPD)*.
- **To respond** to parent and other questions about SPD and resources in your community within a reasonable period of time at your convenience.
- **To include** the following disclaimer whenever communicating information in print or in email:  
*Please note: SPD-Parent Connections groups are run by parents. Parents share their personal experiences related to SPD. All comments or advice are the opinions of parents and are not recommendations. Advice of a qualified clinical professional should be sought for diagnosis and treatment.*
- **At your own discretion**, to write/distribute a general letter/email to provide meeting time/location information.

3. Time Commitment: Time commitment will vary depending on your schedule. Some hosts only host meetings and respond to emails. Others have set up their own web sites or blogs and organize benefits for the SPD Foundation. The degree of commitment you make beyond sponsoring regular meetings is entirely at your own discretion. Start small and build!

4. Meeting Times and Locations: You will arrange for a meeting place and set meeting times. We recommend public venues, such as libraries, community centers, or schools. This is for insurance purposes: Most public buildings carry liability insurance for those who utilize their facilities. **We advise against holding meetings in private homes.** Meetings should be on a regular date and time (e.g., the second Tuesday of the month at 7 p.m.).

5. Fundraising: As a non-profit charity, the SPD Foundation relies heavily upon donations to support its SPD research, education, and advocacy programs, including SPD-Parent Connections. As a SPD-PC host, you may be asked on occasion to organize, facilitate, and/or support fundraising in your community. Fundraising ideas, supporting handouts, and other information will be supplied by the SPD Foundation. Initiating fundraising events, campaigns, and/or activities on your own is highly encouraged!

6. Community Resources: Your group members may find it helpful if you develop a list of community resources to bring to your meetings. We recommend including occupational therapists, pediatricians, neurologists, psychologists, speech therapists, dentists, and any other professionals parents frequently seek out. You can start a list by going to "Find Providers" on the SPD Foundation web site and entering your city and/or state into the search function. Expand your resource list at each meeting by soliciting input from other parents in attendance. Print the resulting list as a handout or forward to members of your group. *Always cut and paste the **Disclaimer Statement** located on the Find Services page into any information you distribute about resources.*

7. **Expansion:** You may grow your membership in any way that works in your community, e.g., list your group in the local newspaper or parenting magazine, in your PTO newsletter or church bulletin, on local listserves, on your MySpace page if you have one, and wherever other sensational parents might come across it. Provide your local school system, health care systems, and others with informational flyers.

## **THE SPD FOUNDATION MESSAGE**

Research conducted by the SPD Foundation has validated occupational therapy with a sensory-integration approach as an effective intervention for SPD. **No** other approach has been validated by research conforming to rigorous scientific protocols.

We respect the right of parents to pursue all interventions that they personally feel are the most appropriate for their child, and we do not judge or criticize others for making those choices. Professionals from other fields may be invited to present information related to Sensory Processing Disorder at SPD-PC meetings from time to time, but they must be informed of the policy against using the meetings to recruit new clients or promote products.

## **SPD FOUNDATION MISSION STATEMENT**

The mission of the SPD Foundation is to enhance the quality of life for children with SPD and their families by

- conducting rigorous **research** into the causes, diagnosis, and treatment of SPD.
- providing **education** for those with SPD and for families, health care providers, policy makers, and the public.
- conducting **advocacy** for recognition of SPD.

The SPD Foundation is a Colorado 501(c) (3) public charity. Contributions are tax-deductible.

## **SPD-PARENT CONNECTIONS MISSION STATEMENT**

The mission of SPD-Parent Connections (SPD-PC) program is to support the mission of the SPD Foundation by

- establishing an international network of support groups where parents can help other parents meet the challenges of raising children with Sensory Processing Disorder.
- providing support to the SPD Foundation in implementing its mission.

## **BENEFITS OF BEING AN SPD-PC HOST**

- Being an active part of the SPD Foundation, the only organization committed full-time to the triple mission of SPD research, education, and advocacy
- The satisfaction of improving the lives of other families living with SPD
- The ability to network with other host parents nationwide and around the world to share ideas, stories, and ask questions.
- Access to an SPDF staff member dedicated to parent support.

**Don't hesitate to contact us if you have questions, comments, or suggestions that may help other hosts.**

## **CONTACT INFORMATION:**

SPD Foundation  
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303.794.1182

