

SB Connect Facilitator Training

Welcome! And thank you for your time, work, and dedication to help build a better and brighter future for all those affected by Spina Bifida in your community!

Objective of SB Connect

- To foster connections among people with spina bifida and their families
- In a relaxed environment
- On a consistent basis.

Goals:

- Increase friendships
- Networking
- Finding others who understand
- Sharing practical information
- Helping all to thrive and grow.

Purpose and features

- Intended for areas unserved or underserved by other spina bifida organizations.
- Facilitated by volunteer members of the spina bifida community.
- Free of cost.
- Inclusive of the entire intergenerational community.

Common characteristics of successful facilitators

- They have a can-do, take-charge personality.
- They already have good connections to people with Spina Bifida in their communities.
- They are social, start conversations easily, and enjoy meeting new people.
- They have reliable transportation and a fairly reliable schedule.
- They have some experience with Facebook groups, or they are willing to learn the platform.
- They are willing to spend 4-5 hours per month facilitating their group.

The SB Connect Steering Committee will help you every step of the way!

Let's Get Started!



Define your service area

- Not so small that it limits the population
- Not so large you cannot accommodate most people in the group by hosting gatherings at one central location.
- Will vary depending on whether your area is urban, suburban, or rural, and other factors.
- The steering committee will help you narrow your focus based on our experiences.
- SB Connect groups are always inclusive and welcoming of children and adults with SB and their families.

Start your Facebook group

- Each SB Connect group has its own Facebook group to help you locate and gather local community members, provide online space for people to get to know each other, and create and promote upcoming events.
- A steering group member can assist you with starting your group.
- Name it “SB Connect of (your service area)”
- Use the settings, images, and “about” section copy provided to you.
- Keep your group active by posting conversation starters, SB/disability-related articles, and local resources.
- Prepare members for upcoming meetups by posting helpful info such as parking suggestions, nearby attractions, and potential conversation topics.

Get the word out

- Invite people you know from the SB community in your service area to your Facebook group.
- Introduce your group in other spina bifida social media channels. (Make sure the group you post in does not have a rule against promoting other groups, or ask the administrator for permission.)
- Let your local spina bifida clinic coordinator, specialists, therapists, and teachers who work with people with spina bifida know about your group.
- You can also use our PDF flier that is customizable for your group and event information to give providers and post in areas such as therapy or clinic waiting rooms.

Select a location

- Don't let the momentum from adding people to your group slow down by waiting too long to have your first in-person gathering.
- One challenge is finding a cost-free space for your group. Some ideas are fast casual dining restaurants, coffee shops, mall food courts, community centers, library meeting rooms, and YMCA recreational spaces.
- Look for these important factors:
 - Central location
 - Convenient parking
 - Accessible entrance and bathrooms
 - Accessible by public transportation
 - Family friendly for those with young children
 - Relaxed atmosphere to encourage conversation

Choose a meeting time

- Think about a day and time to meet routinely that would be convenient for yourself and others.
- A two-hour timeframe on weekends or evenings works best.
 - For example, “every third Saturday from 2-4 p.m.” or “the first Sunday of the month from 3-5 p.m.’
- Consistency helps people plan for events.
- Ask or poll people in your group for what times and days work best.
- The steering committee requests all SB Connect groups meet in person or virtually a minimum of 6 times per year, but some groups meet monthly.

Stay connected to the steering committee

- The steering committee meets the second Tuesday of every month at 8 p.m. eastern time.
- All facilitators are highly encouraged to attend.
- This is your time to share your progress, learn from others, discuss challenges you're having, and give other ideas.
- Staying connected to this group is one of your best bets for success in building your group.
- We also have a private Facebook group just for facilitators and steering committee members to ask questions and share with each other between meetings.

Feedback form

For SB Connect to expand and become more successful, we need to collect data to assess its impact. The steering committee asks that you share some basic information such as attendance numbers and other outcomes in a Google Form reporting tool each month. This information will also help individual groups and the program as a whole track trends that can help us improve.

SBA Chapters

- If your service area falls within an SBA affiliated or corporate chapter service area, you will also need to stay in regular communication with its executive director or chapter manager.
- They can help you promote your group, keep you in the loop on chapter activities, and more.
- SBA corporate chapters require SB Connect group facilitators in their areas to also be members of their chapter advisory committee to improve communication.

Other Helpful Tips



Other helpful tips

- Identify a co-facilitator, if possible. Life happens, especially for people in our particular community. In the case that you or a family member experience a particularly difficult day, week, or season, it is helpful to have another person to fill in for you so the group does not lose steam.
- Respect others' privacy. Get permission before taking and posting photos at gatherings. Remember that information shared in the group should stay in the group unless the person asks you to share it.
- Attend! Even if it seems like no one will be able to come, go anyway. Scope out the location, take a photo of yourself there to post in your group, and be there in case someone shows up.

Other helpful tips

- Be persistent. Every group has a “mulligan” every now and then. It doesn’t mean the group is not needed or wanted; it might have just been a fluke that day, or bad timing. Ask for feedback and keep going.
- Keep it inclusive. If some families of little kids want to meet up at a playground, or some adults want to go to a bar together, that’s great! But encourage these smaller meetups outside of SB Connect time and keep those as intended.
- You’re not expected to have all the answers. As leader of the group, members may come to you for advice and answers. You are not responsible for solving everyone’s problems. If you have experience with the issue and want to share, go for it. Otherwise, you can suggest resources or just listen.

Other helpful tips

- Keep it positive. Sometimes a group member specializes in complaining, arguing, or badmouthing. Try to redirect the conversation and focus on the positive so it doesn't bring everyone down.
- You're a leader! As a volunteer SB Connect facilitator, you actually are a representative of SBA. Try to stay up to date with SBA happenings and keep your group informed. As you meet families and professionals in your community, represent SBA in a positive light.
- Keep everyone engaged. At a meetup, look for the quiet ones and try to engage them in the conversation as much as they are comfortable. Some might prefer one-on-one conversations, or you might be able to introduce them so someone else with common interests.

Other helpful tips

- Consider the children. You might want to bring games, toys, or coloring books to keep young children busy and entertained, or suggest their parents do so.
- Don't fundraise. Money-handling can become very messy, and this program should be free of cost (or low optional cost, such as at a coffee shop) for you to lead and others to participate.

Good Luck!

We wish you much success with your SB Connect group, and the steering committee is always happy to support you along the way. Thank you for your willingness to help us connect individuals and families affected by Spina Bifida across the nation, one community at a time.