



## **SBA PARENT ADVISORY COUNCIL CHARGE**

### **Purpose**

The Parent Advisory Council serves as a critical community champion of the Spina Bifida Association and parents of individuals with Spina Bifida. Members of the Advisory Council share their gifts in service to our mission by providing our organization with their expertise; their diverse knowledge of constituent perspectives; their connections to local, national or international resources, colleagues or peers; their philanthropic support or other forms of needed assistance.

### **Composition**

Five to fifteen (5-15) people, who:

- Are parents of individuals of all ages with Spina Bifida
- Possess relevant expertise and experience
- Represent the Association's diversity

### **Method of Appointment**

Council Members—selected and appointed by SBA staff. Nominations will be solicited from the community to support the selection.

### **Term of Appointment**

Two-year term

### **Frequency of Meetings**

As needed via conference call

### **Qualifications**

#### ***Advisory Council members should:***

- Be parents of individuals of all ages with Spina Bifida and be familiar with SBA programs and services;
- Be able to participate effectively in a collaborative group process, which requires ability to listen to and work well with other Council members;
- Be able to provide feedback in a respectful manner;
- Be open to a diversity of ideas; and
- Be able to keep required information confidential

### **Responsibilities**

- Be informed about SBA's mission, services, policies, and programs
- Allow the SBA to publish council member names as members of the Advisory Council.

- Make recommendations on SBA programs and services and marketing efforts.
- Conduct outreach to inform community members about the SBA's work, solicit their input, and identify additional forums for reaching people affected by Spina Bifida.
- Identify, discuss, and rank issues of concern to members. Each Advisory Council will review and analyze information related to issues of concern obtained from stakeholders.
- Advise the SBA staff on issues that need to be considered as SBA engages in planning
- Provide advice on issues the SBA staff or Board of Directors brings to the Advisory Council
- Participate in the peer review of SBA programs and projects as needed
- Review and comment on programs, projects, and policies as needed
- Engage in activities and conduct discussions throughout the year via electronic communication tools
- Attend and participate in meetings of the Advisory Council
- Support SBA's advocacy efforts

### **Expected Outcomes**

1. The programs and services offered by the Association and its marketing efforts will be enhanced through the input of critical community input into the needs, implementation, and evaluation of such work.
2. Relevant topics relating to parents of individuals with Spina Bifida are identified, necessary policies are developed, and recommendations to the staff and Board are made. Necessary tools to achieve SBA goals are developed. Association efforts are communicated and explained by the Council.
3. Topics for short- and long-term action, which reflect consideration of stakeholder input, are developed and presented to the staff and/or Board of Directors as required.

### **Expectations**

#### ***It is expected that members of the Council will:***

- Perform their volunteering role to the best of their ability.
- Abide by the *SBA Operating Principles*.
- Follow the SBA's procedures and standards in relation to its staff, volunteers and constituents.
- Maintain the confidential information of the SBA and of its constituents.
- Keep required or embargoed information confidential until such time as the SBA determines it should be shared.
- Meet time commitments and standards agreed to and give reasonable notice so other arrangements can be made when this is not possible.
- Maintain an unwavering focus on the SBA's mission and the people we serve.

- Listen, analyze, and think strategically and creatively, and work well with people individually and in a group.
- Consider multiple viewpoints about controversial issues and communicate the SBA's perspective effectively with members and stakeholders.
- Have a willingness and ability to prepare for and attend meetings, and engage effectively and responsibly in discussions.
- Act in significant ways to support the SBA's mission.
- Keep informed about plans, activities and needs of the SBA.
- Support SBA's messages as articulated by its staff and/or Board of Directors.
- Allow the SBA to publicize Council member name and participation on the Council.

### **Scope of Work**

The primary function of the Parent Advisory Council is to provide support and guidance to both the Board and staff pertaining to issues of parents of individuals with Spina Bifida. The Council does not have fiscal oversight and is not ultimately responsible for the health and well-being of SBA, but it takes an active role in helping the organization implement its goals and objectives. The Advisory Council has no governing function within the organization; however, it provides a direct link to various insights into the Spina Bifida community.

The Council shall not:

- Implement recommendations in the absence of prior Board of Director appropriate approvals.
- Develop recommendations that impinge on or restrict the authority of the CEO.

### **Communications**

The Council may use customary or special communications methods to inform the staff and/or Board and Association of its progress to seek input on pertinent parent matters.

### **Available Resources**

The Council will be staffed by the Director of Research and Services. If deemed necessary to the discharge of its responsibilities, the Council may create issue-specific Work Groups, which will conduct their work by teleconference. Sufficient financial resources will be allocated to support the Council's work.