



RESEARCH ADVISORY COUNCIL CHARGE

Purpose

The Research Advisory Council helps provide resources and guidance to support our research efforts. Made up of clinicians, adults, parents, and caregivers, Council members contribute to our mission by providing their diverse knowledge; their connections to local, national and/or international resources, colleagues or peers; or provide other forms of needed assistance.

Composition

The Council will be made up of ten to twelve (10-12) people who possess relevant research expertise and experience and represent the Association's diversity, including:

- Two physicians, including a member from the PAC Science and Research subcommittee
- Two adults with Spina Bifida
- Two parents of children with Spina Bifida (1 parent of an adult/1 parent of a child)
- Two advanced practice nurses
- Two health care professionals such as social workers, physical therapists, or others.

Method of Appointment

The Council chair and members are selected by SBA staff. Nominations will be solicited from the community.

Term of Appointment

Two-years

Frequency of Meetings

At least six meetings per year via conference call

Qualifications

Advisory Council members should be:

- Parents of and individuals with Spina Bifida who are interested in improving the lives of people with Spina Bifida through research;
- health care professionals with experience in research methods;
- able to provide feedback in a respectful manner;
- open to a diversity of ideas;
- knowledgeable about research funding sources and willing to identify them; and
- willing to educate new researchers about the research needs in Spina Bifida.

Responsibilities

- Be informed about SBA's mission, services, policies, and programs;
- allow the SBA to publish their name as a member of the Advisory Council;

- make recommendations on SBA research priorities and strategies;
- 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;
- through the Council Chair, advise the SBA staff on issues that need to be considered as SBA engages in research planning;
- provide advice on research issues the SBA staff or Board of Directors brings to the Advisory Council;
- participate in the peer review of SBA involved research as needed;
- review and comment on programs, projects, and policies as needed;
- attend and participate in meetings of the Advisory Council; and
- support SBA's advocacy efforts.

Expected Outcomes

- The programs and services offered by SBA will be enhanced through critical community input about the identification and prioritization of research projects;
- relevant research topics for people with Spina Bifida are determined, funding is identified, implementation plans are developed, and recommendations to the staff and Board are made, and
- 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.

Expectations

It is expected that members of the Council will:

- Attend and participate fully in the work of the Council;
- allow the SBA to publicize Council member name and participation on the Council;
- maintain the confidential information of the SBA and of its constituents;
- meet time commitments and standards agreed to and give reasonable notice so other arrangements can be made when this is not possible;
- 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;
- prepare for and attend meetings, and engage effectively and responsibly in discussions.
- keep informed about plans, activities, and needs of the SBA; and
- maintain an unwavering focus on the SBA's mission and the people we serve.

Scope of Work

The primary function of the Spina Bifida Association Research Council is to provide resources and guidance to the research efforts of the SBA. The 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 without SBA Board approval or develop plans that impinge on or restrict the authority of the President & CEO.

Communications

The Council may use customary or special communications methods to inform SBA staff and/or Board of its progress.

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 workgroups.