



OUR MISSION

We promote the prevention of Spina Bifida and enhance the lives of all affected.

The SBA achieves its mission through the work of volunteers—adults with Spina Bifida, family members and caregivers, and healthcare providers—throughout the nation.

Through its website, activities and events, and network of Chapters, SBA works collaboratively with volunteers nationwide and touches thousands of people each year through:

- Research
- Education & Support
- Community Building
- Advocacy
- Resource Development

OUR VISION

We envision a world in which no pregnancies are affected by Spina Bifida. People living with Spina Bifida thrive in a barrier-free world that offers ready access to an array of effective treatment options and uniformly excellent medical care. Their individual life choices are not impeded by Spina Bifida and all experience rich and personally fulfilling lives.

OUR CORE VALUES

Visionary Leadership

We lead with hope and serve with passion toward our vision for the future.

Integrity

We pursue our mission with honor, fairness and respect for all individuals while we act as good stewards of our mission and the public's trust.

Commitment to Excellence

We aspire to hold ourselves to the highest standards and serve as champions of our cause, striving to be the best in all that we do.

Collaboration

We value mutual respect and honesty as the cornerstones of all of our relationships. We employ teamwork and transparency to guide our efforts.

Effective Voice

We work together to affect change and encourage knowledgeable advocacy on a personal, community and global level.

Inclusiveness

We represent varied cultures, ethnicities and backgrounds, embracing diversity of thought, innovation and creativity.

KEY TRENDS

Efforts to decrease the number of births affected by Spina Bifida have resulted in a decrease of births affected by it; however, an estimated 166,000 people are living with it in the United States. Every year, babies are born with Spina Bifida and more children grow into adulthood. The clinical setting at the pediatric shrunk over the last decade while few adult clinics exist. There are no standards of care for people with Spina Bifida and no standards for healthcare providers, centers of excellence, or clinics in Spina Bifida Care.

The number of adults with Spina Bifida is not documented or known at this time. SBA estimates that adults with Spina Bifida make up anywhere from 40 – 60% of the 166,000 people living with Spina Bifida in the United States. Increasingly, adults are reporting their inability to find qualified and willing healthcare providers to treat them and progressively more intricately complex and life-threatening conditions which are incorrectly diagnosed and treated, or simply left untreated. The result all too often is death.

Through anecdotal self-reports, Adults with Spina Bifida tell SBA that they also face multiple, intertwined challenges in their living conditions, the employment market, and social interactions. They articulate an inability to find adequate housing to meet their mobility and financial needs resulting all too often in placement in nursing homes at ages as early as in their twenties. Adults with disability are living at the poverty level across the United States and face employers who do not understand their abilities or talents, and adults are less likely to advocate or share issues about their health to employers which can have life-threatening impact on their health. Increasingly adults report feelings of isolation and depression due to a complex situation created by their cognitive challenges, urologic and bowel issues, and small social connection.

These trends have led the SBA on new paths and focus. We will continue to support quality of life efforts and parents of children with Spina Bifida and their children. But we must concentrate on adults. With this in mind, SBA built a Strategic Framework to guide our efforts over the next three years. With laser focus, we will use the strategic framework set forth in this document.

STRATEGIC FRAMEWORK 2016-2018

Goals	Strategies
RESEARCH <p>SBA drives Spina Bifida research and treatment through the Spina Bifida Collaborative Care Network.</p>	<ul style="list-style-type: none"> • Expand and strengthen the quantity and quality of Spina Bifida research to accelerate new discoveries and treatment for people with Spina Bifida across the lifespan. • Heighten awareness of the National Spina Bifida Patient Registry and using its findings to impact treatment of people with Spina Bifida. • Elevate Healthcare Guidelines to a level closer to Standards of Care. • Discover and document the status of healthcare for adults with Spina Bifida.
EDUCATION AND SUPPORT <p>SBA develops, delivers and leverages resources to enhance care for people with Spina Bifida and quality of life for those affected by the condition.</p>	<ul style="list-style-type: none"> • Provide timely, accurate, and comprehensive information for people affected by Spina Bifida. • Connect people affected by Spina Bifida with their communities, information, resources, programs and services, and each other.
COMMUNITY BUILDING <p>SBA leads the Spina Bifida movement, mobilizing people to get involved with improving the lives of people affected by it.</p>	<ul style="list-style-type: none"> • Heighten awareness of Spina Bifida to facilitate understanding, engagement, and action to fuel movement on Spina Bifida. • Expand the impact of SBA through new and enhanced community collaborations and partnerships.

ADVOCACY	<p>SBA advocates for people with Spina Bifida.</p> <ul style="list-style-type: none"> • Advocate for federal, state, and local policies essential to people affected by Spina Bifida and disabilities. • Engage people affected by Spina Bifida to take on leadership roles in advocacy at all levels of government. • Join forces with organizations and coalitions to advance mutual goals.
RESOURCE DEVELOPMENT	<p>SBA aligns business and financial resources to achieve our goals.</p> <p><i>Revenue</i></p> <ul style="list-style-type: none"> • Develop sustainable revenue growth of 15% over three years to support the organizational programs and services. • Develop a strong corporate and major donor giving program. • Increase grassroots fundraising. <p><i>Infrastructure</i></p> <ul style="list-style-type: none"> • Streamline operational processes throughout the organization to increase capacity to do more. • Maximize process efficiencies through the use of standardized systems. • Embrace innovation allowing new processes and tools to elevate our work.