



**SPINA BIFIDA  
ASSOCIATION**

**2023-2025  
Strategic Plan**



### **Our Mission**

To build a better and brighter future for all those impacted by Spina Bifida.

### **Our Vision**

A world where everyone impacted by Spina Bifida is accepted and thrives.

### **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.



## 2023-2025 Strategic Goals

### 1. People with Spina Bifida will have greater access to quality health care providers, equipment, medication, and supplies.

*Evidence:*

- Lists of SB knowledgeable providers grow in particular in geographies where there are gaps.
- Individuals with SB report lower costs and availability of equipment, medication, and supplies.

#### **Objectives**

- A. Increase the number of adult providers available who are knowledgeable in the care of individuals with Spina Bifida across the lifespan.
- B. Advocate for reform of insurance payment policies to make equipment, medications, and supplies more affordable.
- C. Collect and share information about providers and equipment to provide effective and speedy referrals and connections for families and individuals with Spina Bifida.

### 2. Expectant and new parents of children with Spina Bifida will get off to the right start.

*Evidence:*

- Number of OB/GYNs using SBA-approved Spina Bifida diagnosis protocols increases
- Number of babies born with Spina Bifida connected to a Spina Bifida clinic by three months increases

#### **Objectives**

- A. Improve the way the diagnosis of Spina Bifida is delivered to reduce maternal/family stress and ensure potential parents have all the options available.
- B. Connect more newborns with Spina Bifida to qualified clinical care.

**3. People with Spina Bifida, their families, and care partners will be better connected to one another for support, education, and access to resources.**

*Evidence:*

- *Individuals with Spina Bifida report having multiple opportunities to connect with other individuals and support groups.*
- *Number of people with Spina Bifida in SBA and/or chapter-supported networks increases*

**Objectives**

- A. Connect more individuals with Spina Bifida and their care partners to peer groups for to information, education, and support.
- B. Increase the sharing of information, research, and support within and across Spina Bifida peer groups.

**4. The Spina Bifida community will have access to better quality, more comprehensive, community-centered research and data**

*Evidence:*

- *More research on Spina Bifida being published and presented at conferences*
- *More funded Spina Bifida research*
- *More patient data being tracked in Spina Bifida registries*

**Objectives**

- A. Expand data gathering efforts to supplement the CDC Registry and support additional research.
- B. Generate funded research that advances the SBA community-centered research agenda.
- C. Facilitate robust sharing and dissemination of research at conferences, in online resources, and with other outreach activities.

**5. Clinicians, researchers, federal and state policymakers, and potential investors will have an increased understanding of Spina Bifida as a rare condition and the everyday reality of living with Spina Bifida.**

*Evidence:*

- *Increase in direct response campaign engagement*
- *Increase in earned media on Spina Bifida*
- *More Spina Bifida content being presented at conferences and other thought leader convenings*

**Objectives**

- A. Increase thought leadership by generating media coverage of Spina Bifida; presenting on Spina Bifida at conferences and other convenings; and by placing more thought pieces in targeted publications.
- B. Increase direct educational outreach to federal and state elected officials and policymakers through additional meetings, lobbying events, and legislative and regulatory agency briefings.
- C. Increase direct educational outreach to clinicians and researchers.

**6. SBA (national and chapters) will achieve greater alignment in its execution of mission priorities and operations.**

*Evidence:*

- *Pilot "integration" projects completed with lessons learned and shared*
- *Areas of integration identified and implemented with efficiency and effectiveness achieved*

**Objectives**

- A. Develop and, if feasible, implement recommendations on systems, processes, and governance for joint constituent relationship management.
- B. Better coordinate and align Walk-N-Roll and virtual events to create a higher quality and more consistent brand experience for participants.
- C. Coordinate more closely on the execution of priority mission initiatives requiring joint execution at the national and local level.

**7. SBA (national and chapters) will grow system-wide revenue with a focus on higher-margin revenue channels and a diversified and more sustainable revenue mix.**

*Evidence:*

- *Greater system-wide gross and net revenue*
- *A more diversified revenue mix with greater emphasis on higher-margin sources of revenue*
- *Improved acquisition and retention of donors*

**Objectives**

- A. More effectively coordinate fundraising and sponsorship opportunities with national and global companies and foundations to generate more revenue.
- B. Coordinate with local chapters to ensure a high-quality donor experience.
- C. More actively share best practices, strategies, and tools to enable chapters and SBA as a whole to collectively generate more resources.

**8. SBA (national and chapters) will benefit from a more externally facing, community-driven culture and the recruitment and retention of a more diverse, higher-performing workforce.**

*Evidence:*

- *Increase in the number of volunteers and advocates*
- *Improved employee retention and performance measured through reviews*
- *Increased workforce diversity that better reflects individuals served*

**Objectives**

- A. Grow the Spina Bifida movement by recruiting and retaining more volunteers and advocates.
- B. Modernize and develop new systems and processes for engaging and managing relationships with volunteers and advocates to increase impact and improve their brand experience.
- C. Develop, implement, and share strategies to improve workforce recruitment and retention.