



**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.