



SPINA BIFIDA  
ASSOCIATION

# 2023-2025 Strategic Plan

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



# 2023-2025 Strategic Plan

## External

-  1. People living with Spina Bifida will have greater access to quality health care providers, equipment, medication, and supplies.
-  2. Expectant and new parents of children with Spina Bifida will get off to the right start.
-  3. People with Spina Bifida, their families, and care partners will be better connected to one another for support, education, and access to resources.
-  4. The Spina Bifida community will have access to better quality, more comprehensive, community-centered research and data.
-  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.

## Internal

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

# Goal 1: Adult Care Gaps

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

- 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.



## Key Components:

- Spina Bifida 101 training for clinicians
- Clinicians on-call for consultation
- Advocacy for increased telehealth options
- Advocacy for better insurance coverage
- Enhanced information & referral services

# Goal 2: Diagnosis to Three Months

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

- 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.



## Key Components:

- New diagnosis protocols for clinicians
- New tools and resources for expectant parents
- Advocacy for changes in medical school curricula
- Additional partnerships with Spina Bifida clinics

# Goal 3: Building Community

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

- 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.



## Key Components:

- Community engagement and needs assessment
- Networking opportunities at conferences and workshops
- Additional peer-to-peer engagement training
- SB Connect Groups

# Goal 4: Better Evidence

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

- 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.



## Key Components:

- SBA Patient-Reported Outcomes Registry
- Funded research to advance community-centered research agenda
- Advocacy for increased funding for CDC's Spina Bifida Program
- Online research hub to connect and engage the Spina Bifida research community

# Goal 5: Raising Awareness

**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.**

- 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.



## Key Components:

- Increased direct response engagement
- More robust policymaker, regulatory agency engagement
- Congressional briefings
- Targeted media engagement

# Goal 6: Alignment for Impact

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

- 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.



## Key Components:

- Demonstration projects with affiliate chapters to model alignment and integration
- Joint national-local mission execution on key initiatives
- Greater integration of fundraising efforts

# Goal 7: Resource Generation

**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.**

- 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.



## Key Components:

- New donor stewardship processes
- Additional learning opportunities for chapters
- Systemized approach to corporate sponsorships
- Additional capacity to support corporate and individual, and direct response fundraising

# Goal 8: People and Culture

**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.**

- 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.



## Key Components:

- Systemized approach to recruiting, engaging, and retaining volunteers
- Best-practice sharing with chapters
- Higher-quality brand experience at high profile events (i.e. Walk-N-Roll)

For more information:



**SPINA BIFIDA  
ASSOCIATION**

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