2023-2025 Strategic Plan

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

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 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

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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)