



STRATEGIC PLAN 2020-2022

OUR MISSION

The mission of the Spina Bifida Association is to build a better and brighter future for all those impacted by Spina Bifida.

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, clinical care, education and support, network building, and advocacy.

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.

Spina Bifida Association Strategic Plan 2020-2022



Goal

1. Research: SBA, through the *Spina Bifida Collaborative Care Network*, leads research to enhance the quality of life for people living with Spina Bifida.

Strategy	Key Performance Indicators
1.1. Create Research Agenda: Define, share and seek funding to support a prioritized national research agenda to address the gaps identified in the Guidelines for the Care of People with Spina Bifida (Guidelines).	<ul style="list-style-type: none"> ● Research agenda finalized by end of 2019 ● One national research priority funded by the end of 2022
1.2 Support and continue to be key influencer of the agenda for the National SB Patient Registry.	<ul style="list-style-type: none"> ● One staff member attend each NSBPR meeting
1.3 Translational Research: Develop and implement a continual process to review and update the Guidelines.	<ul style="list-style-type: none"> ● Guidelines are fully updated at least every 5 years ● Maintain inclusion of the Guidelines in the ECRI Institute ● SBA provides clinics and providers regular updates to Guidelines
1.4 Research & Study Requests: Review, approve and share information about IRB-approved research studies.	<ul style="list-style-type: none"> ● Number of requests for support for external research increases (2019=X) by two annually ● Ensure annual reports on external research progress/results is published
1.5 Conduct Research: Conduct discrete research projects/needs assessments to better understand the SB community	<ul style="list-style-type: none"> ● Conduct and report results on at least one SBA research project annually
1.6 Summarize Research: Begin a regular process of summarizing and sharing currently published information about SB. (LIPTAK)	<ul style="list-style-type: none"> ● Development of processes ● Number of articles summarized to establish baseline (2020); targets established for 2021 & 2022



Goal

2. Clinical Care: SBA spearheads, through the *Spina Bifida Collaborative Care Network*, efforts to improve clinical care for all people living with Spina Bifida

Strategy	Key Performance Indicators
2.1. Clinics/Health Care Providers: Expand and strengthen SBA’s relationship with clinics and health care providers to advance their knowledge about caring for individuals with SB.	<ul style="list-style-type: none"> ● 50 Clinical Care Partners by 2022 ● 450 attend World Congress in 2022 ● 150 attendees at Clinical Care meetings annually
2.2 Translational Research: Ensure the Guidelines are understood being implemented by clinics and care providers to inform care.	<ul style="list-style-type: none"> ● Method to measure uptake on Guidelines determined by 2020 ● Number of views of Guidelines from the website to establish baseline (2020); targets established for 2021 & 2022 ● Number of downloads of the Guidelines app to establish baseline (2020); targets established for 2021 & 2022
2.3 Outcomes: Use NSBPR data to understand differences in patient outcomes in different clinical settings.	<ul style="list-style-type: none"> ● Clinic Benchmarking process developed by 2020 ● Clinics with best and worst outcomes identified by 2020 ● Clinics are informed of their standings in 2020 ● Implement Benchmarking Process to understanding difference in outcomes in 2021 and 2022
2.4 Transition Support: Improve the transition of care from pediatric clinics to adult care system.	<ul style="list-style-type: none"> ● Implement the process to develop a transition toolkit for providers published by 2022
2.5 Adult Care: Improve Access to Adult Care	<ul style="list-style-type: none"> ● Baseline of clinicians serving adults established by end of 2022
2.6 Partnership: Network with other organizations/specialist Societies to identify and build on shared education and advocacy priorities.	<ul style="list-style-type: none"> ● Increase partnerships with one organization annually. (Baseline: 9)



Goal

3. Education & Support: SBA empowers members of the SB community with information and support to improve their quality of life.

Strategy	Key Performance Indicators
3.1. Information & Support: Provide timely, accurate, and comprehensive information for people affected by Spina Bifida.	<ul style="list-style-type: none"> ● Finalize SB Connect Support Group model ● SB Connect is introduced/launched in 5 new states annually ● Participation in SB-You webinars increases 10% annually (Baseline 2019) ● Report on number of social media groups and key topics annually (Baseline 2019)
3.2. Education: Provide education on topics related to SB to people with SB and their families	<ul style="list-style-type: none"> ● Host 8 Education Days reaching a minimum of 600 people by 2022 ● 12 SB-YOU sessions held annually by 2022 ● Each Corporate Chapter hosts one work shop annually by end of 2022 ● SB info sheets updated by 2022 ● Development of a plan to update the Living Well series and old Preparations website by 2021; begin plan implementation 2022
3.3. National Resource Center: Expand the visibility and utilization of the National Resource Center.	<ul style="list-style-type: none"> ● Report on the number, type, and complexity of inquiries annually (Baseline 2020) ● Development of a quarterly FAQ format for the NRC in 2020; begin plan implementation in 2021



Goal

4. Network Building: SBA serves as a hub to connect Chapters, clinics, and the broader community to improve the quality of life of people living with Spina Bifida.

Strategy	Key Performance Indicators
<p>4.1 Strengthen SBA Chapters</p>	<ul style="list-style-type: none"> ● Assessment of Corporate Chapter service areas to see if the current service area aligns with community needs ● Develop a plan to assure that all Corporate Chapters have paid local staff in place by the end of the plan ● 100% of Affiliate Chapters meet Affiliation Agreement Standards by the end of the plan (50%: year 1, 75%: year 2, 100%: year 3) ● 100% of Corporate Chapters attend training on the Chapter Manual annually (50%: year 1, 75%: year 2, 100%: year 3) ● 100% of Corporate Chapters submit annual budgets for programs aligned with programmatic standards (50%: year 1, 75%: year 2, 100%: year 3) ● 100% of Chapters participate in annual Leadership Retreat ● 75% of Chapter EDs and Field Relations Committee members attend the Monthly Calls ● Chapters meet at least once a year with leadership of the local SB clinic or SB providers (where applicable) ● Creation of guidelines for Chapter/clinic engagement established by Q4 2022
<p>4.2 Communications: Strengthen awareness and understanding of SBA activities and resources for all audiences</p>	<ul style="list-style-type: none"> ● Website baseline metrics established in 2019; targets establish for 2020-2022 ● SB Update open rates and click throughs established in 2019; targets establish for 2020-2022 ● Increase Twitter engagement by 10% by 2021 (2019 baseline =X) ● Increase Facebook engagement by 10% by 2021 (2019 baseline =X) ● Increase Instagram followers by 15% by 2021 (2019 =X) ● Creation of a clinician newsletter by 2020 ● Development of a Linked In plan to increase engagement by 2021; implementation begins in 2022



Goal

5. Advocacy: SBA advocates for positive change to the issues impacting the lives of people living with Spina Bifida.

Strategy	Key Performance Indicators
<p>5.1. Appropriations: Advocate to increase funding for the National Spina Bifida program at CDC and Spina Bifida research at NIH.</p>	<ul style="list-style-type: none"> ● Meet with 90% of the members of House and Senate LHHS Appropriations Committees annually ● Spina Bifida Caucus grows to 40 by 2022 ● 25% of registry clinics participate in advocacy efforts on appropriations in Spring by 2022
<p>5.2 Teal on the Hill Event: Engage members of the Spina Bifida community in face to face advocacy to to increase funding for the National Spina Bifida program at CDC and Spina Bifida research at NIH.</p>	<ul style="list-style-type: none"> ● 50% increase in Teal on the Hill event by the end of the plan (2019 baseline = X) ● 50% increase in Virtual Teal on the Hill event by the end of the plan (2019 baseline = X)
<p>5.3 Grassroots Advocacy: Engage members of the SB community to meet with their Representatives and Senators in their district offices on issues related to appropriations and advocacy coalition work.</p>	<ul style="list-style-type: none"> ● Development of Grassroots Advocacy plan by end of 2020. Baseline on Grassroots advocacy participation in 2021; targets established for 2022 and 2022.
<p>5.4 Advocacy Coalitions: Continue to join or lead coalitions to advance “global” issues related to health and disability rights.</p>	<ul style="list-style-type: none"> ● CEO presents report on coalition advocacy in Q4 annually
<p>5.5 State Advocacy: Work with SBA Advocacy Committee to develop and implement a plan to engage local SB communities in advocacy with their state legislatures.</p>	<ul style="list-style-type: none"> ● Development of State Advocacy plan developed by end of 2020. Baseline on State Advocacy participation in 2021; targets established for 2022 and 2022.



Goal

6. Fiscal Health: SBA raises funds from diverse streams and responsibly manages its financial resources to achieve organizational strategies.

Strategy	Key Performance Indicators
6.1. Fiscal Oversight: Ensure that budgeting and financial operations are conducted in accordance with nonprofit standards	<ul style="list-style-type: none"> ● Balanced budget annually ● Clean audit annually
6.2. Development: Raise funds to expand the delivery & impact of SBA’s mission	<ul style="list-style-type: none"> ● Corporate and foundation giving increased by developing 3-5 new corporate partnerships annually and securing an overall growth in corporate/foundation funding by 15% by 2022 ● Overall individual giving revenue increased by 5% annually (Baseline=2019) ● Major donors (\$1K+) increased 5% annually (Baseline=2019) ● Monthly donors increased by 3-5% annually (Baseline=2019) ● Launch Planned Giving outreach campaign in 2020 ● Walk revenue metrics established by end of 2019 baseline; targets are established for 2020-2022. ● Corporate Chapters raise at least \$2000 annually beyond Walk-N-Roll



Goal:

7. People & Operations: SBA aligns human, business, and operational resources to achieve organizational strategies.

Strategy	Key Performance Indicators
7.1. Staff: Recruit, train, and retain actively engaged and talented staff.	<ul style="list-style-type: none"> ● Succession plans in place for staff ● Staff is cross-trained
7.2. Board: Recruit, develop, and retain actively engaged diverse board members who are passionate about the mission, committed to effective governance, and ensure that the organization has the resources and relationships to advance and support the mission.	<ul style="list-style-type: none"> ● Succession plans in place for Board members and leaders. ● Board Members attend all scheduled Board meetings ● Board Members sit on at least one committee and attend 80% of scheduled committee meetings ● 100% of BOD Members make a personal financial contribution annually ● 100% of BOD Members connect the organization with resources, funders and/or volunteers ● Board Assessment completed annually in Q4 ● 100% of new Board Members participate in an orientation ● 100% of Board Members rate their experience on the board as 4.0 + on a 5-point scale. ● 100% of Board Members rate their committee experience as 4.0 + on a 5-point scale ● 100% of Board Members in an SBA formal advocacy event
7.3. Volunteers: Increase the engagement of volunteers in supporting the SBA mission	<ul style="list-style-type: none"> ● Volunteer needs across the organization identified by 2020 ● Corporate Chapter leadership model rolled out by Q4 2020 ● Job descriptions developed for all volunteer positions by 2021 ● 100% of Walk-N-Roll Chairs participate in annual national training by 2022