We’re On A Mission

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

Our Priorities

Research
We identify the needs of people with Spina Bifida, bring health care professionals together to share the latest in treatment and care, identify clinics with the best outcomes, and inform and encourage future Spina Bifida research.

Advocacy
In addition to advocating for funding for Spina Bifida programs at the CDC, disability rights, and affordable, accessible health care, we empower those with Spina Bifida to share their stories to create change in their communities.

Education
Through in-person and online education programs featuring medical experts, parents, and adults, we help individuals with Spina Bifida learn to live safely and successfully with a disability.

Support
We provide resources and referrals in English and Spanish to individuals and families in need.
Our Board of Directors
Nicole Gower, Chair
Mike Harty, Jr., Chair-Elect
Megan Sorensen, RN, BSN, CEN, Immediate Past Chair
Maria Bournias, Esq, CPA, Secretary/Treasurer
Marie Thoming, PE, Member-at-Large
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David Morrissey
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Chase Phillips
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Advisors to the Board
Timothy J. Brei, MD, FAAP, Medical Director
Stephanie P. Hales, Partner, Legal Counsel

Our Staff
Sara Struwe, President & CEO
GlenRae Brown, Chief Operating Officer/Controller
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Christina Berlin
Sherita Brace
Samantha Greenberg
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Tynia Lewis
Elizabeth Merck
Juanita Panlener
Libby Riordan
Sheliah Roy
John Smith
Judy Thibadeau
Kristi Wass
Our Programmatic Highlights

Thanks to the generous support of friends like you, we were able to accomplish some amazing things in 2019. Here are a few highlights:

- 115 Spina Bifida advocates from 27 states held 75 meetings with Members of Congress at our second annual Teal on the Hill advocacy day in Washington, DC.

- More than 200 individuals and families attended four Education Days in California, Nevada, Texas, and Tennessee to learn more about bowel and bladder care, nutrition, orthopedics, physical activity, and other issues.

- Our SB-YOU webinars on taking care of your mental health, getting fit and staying healthy, and bowel management were viewed more than 400 times.

- We reached 1.5 million people during our Spina Bifida Awareness Month campaign in October.

- 150+ healthcare providers attended our inaugural Clinical Care Meeting in Chicago to improve communication and collaboration among clinics across the country and the care of people with Spina Bifida across the lifespan.
Our Financials

Expenses: $2,239,325

Revenue: $1,885,525

Note: Financial information was compiled utilizing SBA’s 2019 Audited Financial Statements.
A Thank You to Our Supporters

Thank you to the many individuals, corporations, and foundations who supported our work in 2019, and our Board of Directors, Advisory Councils, and other committees and volunteers who donated their time and energy. SBA is a 501(c)(3) charitable, nonprofit organization, and we depend on your donations. Your tax-deductible gifts allow us to serve the more than 166,000 individuals living in the United States today with Spina Bifida, their families, and the health care professionals who care for them.

To use resources wisely, we have opted not to publish a list of our supporters in this report. However, a list of corporate contributions can be found on our website. If you have additional questions or would like information on ways to give, visit www.spinabifidaassociation.org or contact Elizabeth Merck, Director of Development, at emerck@sbaa.org or (202) 618-4754.

SPINA BIFIDA ASSOCIATION

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