



# 2019 ANNUAL REPORT



SPINA BIFIDA  
ASSOCIATION





# 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

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Mike Harty, Jr., Chair-Elect

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Wilson Neyland

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McKay Tolboe

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Timothy J. Brei, MD, FAAP, Medical Director

Stephanie P. Hales, Partner, Legal Counsel

## Our Staff

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GlenRae Brown, Chief Operating Officer/Controller

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Nora Henle

Tynia Lewis

Elizabeth Merck

Juanita Panlener

Libby Riordan

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# Our Programmatic Highlights

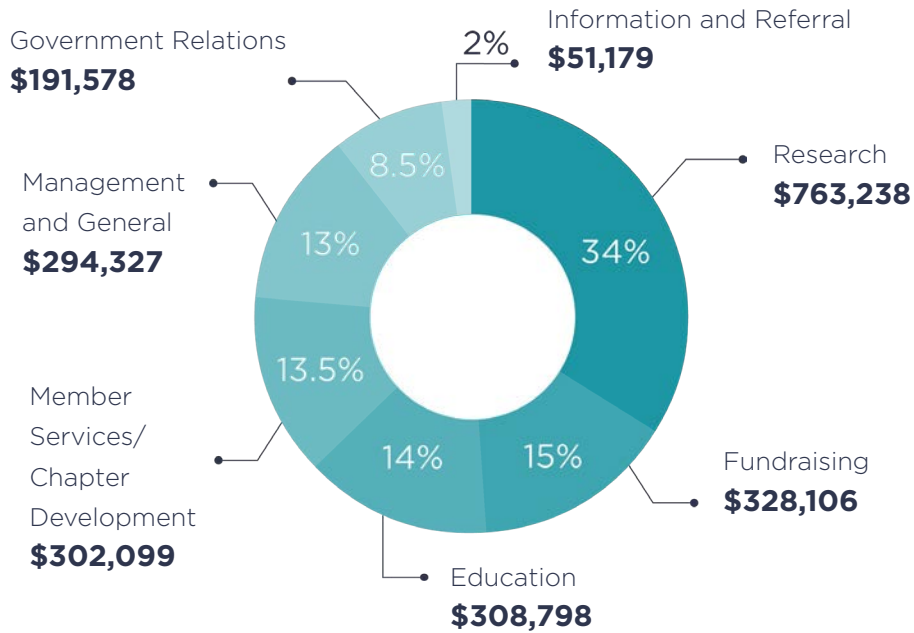
Thanks to the generous support of friends like you, we were able to accomplish some amazing things in 2019. Here are a few highlights:



- 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**

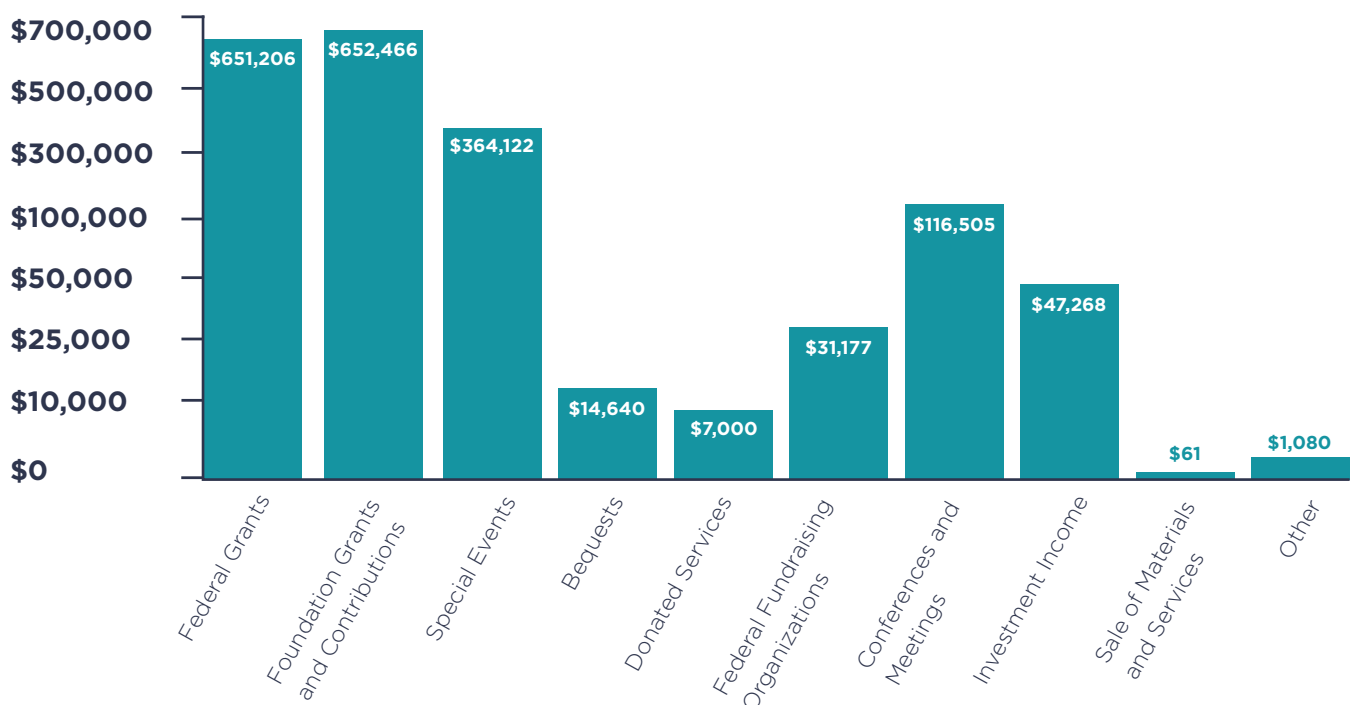


Net Assets Beginning of Year:  
**\$1,763,040**

Net Assets End of Year:  
**\$1,409,240**

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](http://www.spinabifidaassociation.org) or contact Elizabeth Merck, Director of Development, at [emerck@sbaa.org](mailto:emerck@sbaa.org) or (202) 618-4754.



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