

ANNUAL REPORT

2021



SPINA BIFIDA
ASSOCIATION



800-621-3141



sbaa@sbaa.org



spinabifidaassociation.org



1600 Wilson Blvd, Suite 800, Arlington, VA 22209

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

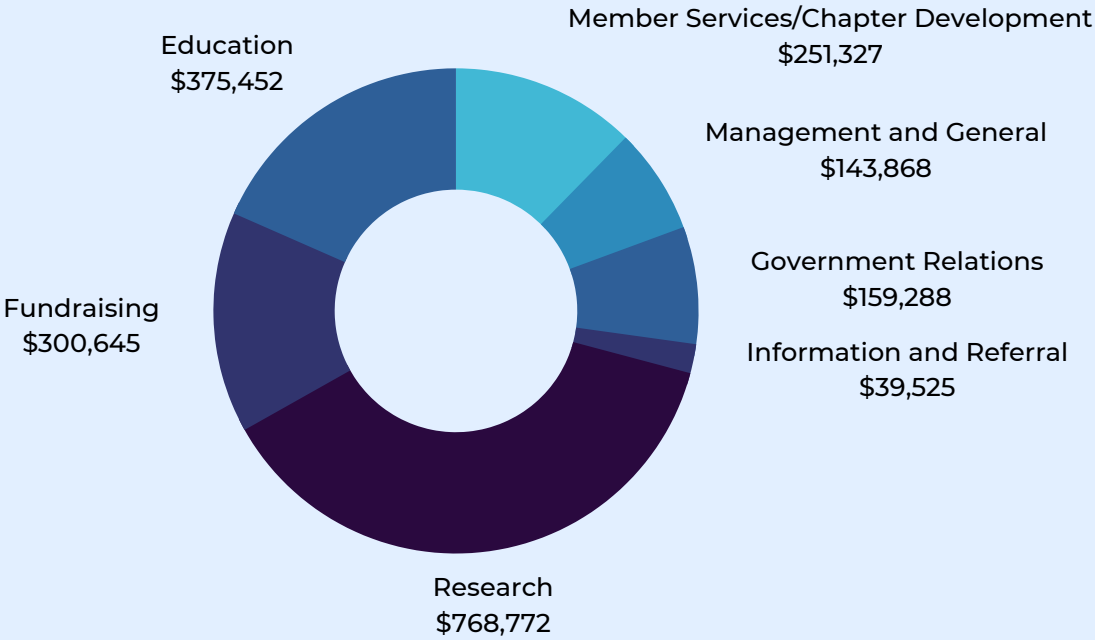
Through in-person and online education programs featuring medical experts, parents, and adults, we help individuals with Spina Bifida learn to live safely and successfully with a disability.

Support

We provide resources and referrals in English and Spanish to individuals and families in need.

Our Financials

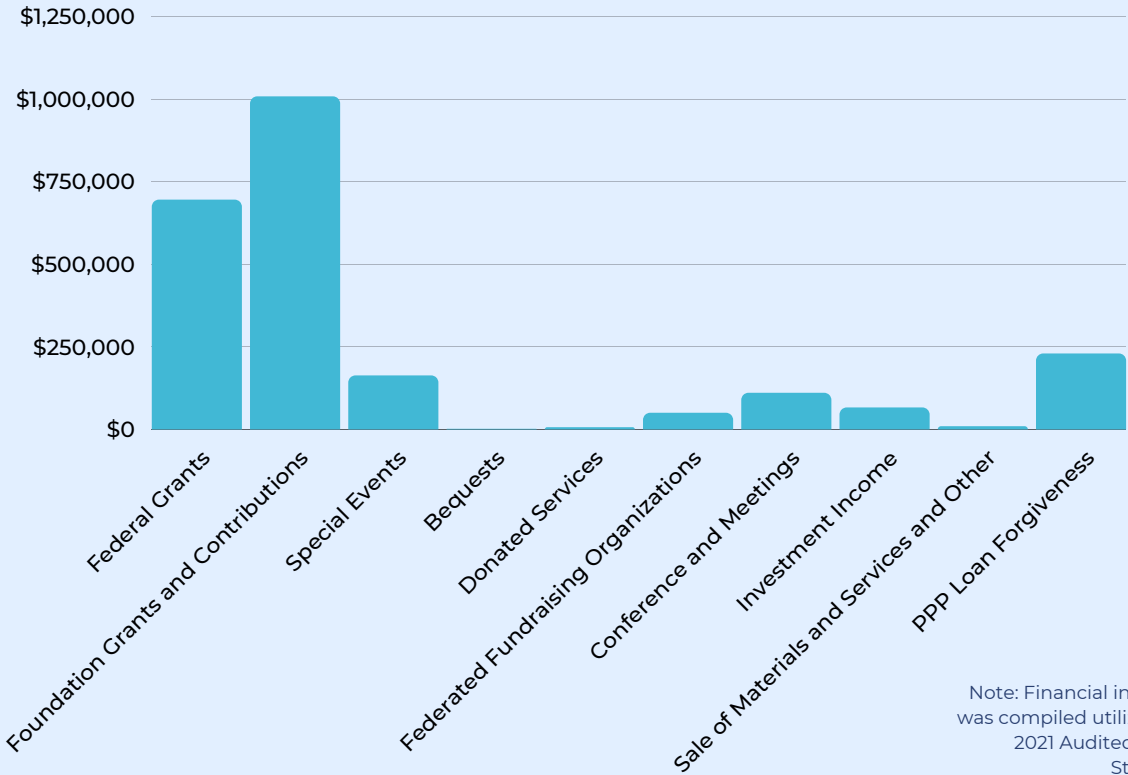
Expenses: \$2,038,877



Net Assets Beginning of the Year: \$910,095

Net Assets End of the Year: \$1,206,001

Income: \$2,334,783



Note: Financial information was compiled utilizing SBA's 2021 Audited Financial Statements.

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Our Programmatic Highlights

- Received over 1,500 catheter survey responses that are currently being used to advocate for health insurance companies to change catheter reimbursement policies.
- Over 40 children took part in the first-ever Virtual Kids Adventure Week. From adapted fitness sessions and toy-boat building to a virtual scavenger hunt, this event provided a way for kids in the Spina Bifida community to connect with others during a time when world went virtual.
- Expanded our Adapted Fitness Club providing a place for community members to get their body moving and help benefit their overall health through weekly classes and monthly wellness sessions.
- Created nine “Spina Bifida: Your Guide to a Healthy Life” guidelines, in English and Spanish, to help people with Spina Bifida better understand their health and arm health care professionals with accurate information when it comes to treating our community members.
- Held nearly 90 congressional meetings with almost 200 Spina Bifida advocates across the country during Teal on the Hill. Advocates spent hours pushing for an increase in funding for the National Spina Bifida Patient Registry.

Our Programmatic Highlights

- Launched a new Ask the Expert program which offered a new way for people to receive information and ask questions live to experts in the field.
- Almost 300 clinicians from across the globe attended the first Spina Bifida Community-Centered Research Workshop. Breakout groups were created to dive into potential research topics that will better the lives of the Spina Bifida community.
- Over 500 people attended the four SB-YOU webinars held throughout the year. SB-YOU is a webinar series created specifically for adults with Spina Bifida, giving them a place to hear directly from experts.
- Added 35 new Clinic Care Partners. These clinics meet 10 standards identified as best practices to care for people with Spina Bifida. These clinics have dedicated health care professionals who partner with people living with Spina Bifida and their families to provide expert care and help identify research priorities.
- Provided support to seven research projects, adding our community voice and experiences to these projects, compared to four projects in 2020.
- Raised over \$10,000 through our efforts during Spina Bifida Awareness Month.

Thank You



Thank you to the many individuals, corporations, and foundations who supported our work in 2021, 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.

If you have additional questions or would like information on ways to give, visit www.spinabifidaassociation.org or contact Jenna Brown, National Director of Development, at jbrown@sbaa.org.



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