



SPINA BIFIDA ASSOCIATION OF KENTUCKY

Annual Report 2020



Mission

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

History

The Spina Bifida Association of Kentucky's (SBAK) mission is to build a better and brighter future for all those impacted by Spina Bifida. SBAK was founded in 1983 by two mothers of children affected by Spina Bifida, who were searching for a support and resource network for families. Over the past 37 years, SBAK has evolved into a thriving and successful organization helping both children and adults affected by Spina Bifida in every corner of The Commonwealth and Southern Indiana, with offices in Louisville and Lexington Kentucky.

Because The Spina Bifida Association of Kentucky is the only organization in the state that focuses solely and deeply on all issues related to Spina Bifida, we are highly effective in reaching a receptive audience.

The accomplishments and growth of SBAK are the direct result of the commitment, enthusiasm and dedication of many supporters. In 2021, SBAK looks forward to reaching more individuals living with Spina Bifida, their families' caregivers and supporters. The Spina Bifida Association of Kentucky can accomplish all that we do because of the donation of time and dollars from individuals like you.

Spina Bifida Facts

- Spina Bifida means "split spine."
- Spina Bifida is a neural tube defect that happens in the first 28 days of pregnancy.
- One out of every 1,300 babies born in the United States each year have Spina Bifida.
- In Kentucky, more than two out of every 1,300 babies are born with Spina Bifida.
- Spina Bifida is the most common permanently disabling birth defect.
- The effects of the Spina Bifida vary from minor back problems to paralysis, hydrocephalus, learning issues and bowel and bladder dysfunction.
- Research studies indicate that if a woman takes 400 mg of folic acid, a B vitamin, daily before becoming pregnant and during the first three months of pregnancy, the number of births involving Spina Bifida could be reduced by 70 %.

ACCOMPLISHMENTS

The arrival of the Covid-19 pandemic in 2020 forced SBAK to suspend in-person programs and events for most of the year. We were able to hold limited outdoor and drive-thru events, but the year posed great challenges to all non-profits and we were no exception.

During 2020, SBAK has:

- Utilized Zoom virtual meetings and programming to stay in touch with our families. Newborn outreach visits were replaced with phone calls and information sent by mail.
- Collaborated with other organizations and other interested partners to serve the needs of the Spina Bifida Community.
- Supported families impacted by spina bifida and helped them learn to advocate for their families.
- Operated support services to assist individuals with Spina Bifida, their families and caregivers.
- Advocated for public policies that increase government funding for Spina Bifida research, education programs, and support services.

2020 Year In Review

SPINA BIFIDA ASSOCIATION OF KENTUCKY

- Attended the virtual Teal on the Hill advocacy day hosted by the Spina Bifida Association of America
- Hosted Walk-n-Roll Awareness fundraiser campaign drive-thru events at three locations in Kentucky
- Delivered Summer Fun activity baskets to 30 families in the Kentucky and So. Indiana area
- Hosted four virtual meetings with families for the Growing up with Spina Bifida program
- Hosted a drive-thru Holiday Party in Louisville where each child received a gift from Santa. Gifts and activities were shipped to families who could not attend the drive-thru event.



5

Newborn Outreach
Visits

10

Programs hosted
across the state

36

Volunteers
supporting programs
and events

Financial Report*

2020 Income: Where does the money come from? (audited)	
Fund Raising Events	\$16,406
Grants and Partnerships	\$53,522
General Donations	\$117,761
In-Kind Donations	\$28,520
Federal PPP Forgivable Loan	\$24,800
Interest Income and Merch Sales	\$108
Total	\$241,117
2020 Expenses: Where does the money go? (audited)	
Programs & Services	\$116,725
Fundraising	\$59,387
General/Administrative	\$39,512
Total	\$215,624
Net Assets Beginning of 2020	\$82,898
Net Assets end of 2020	\$112,869

***Complete copy of our audited financial statements is available on request.**

A special Thank You to all our individual, corporate, and foundation donors during the past year. Without you none of our work is possible!

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Spina Bifida Family Camp at Center for Courageous Kids

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The Spina Bifida Association of Kentucky is a registered 501 (c) 3 organization.
You can donate at sbak.org. All donations are tax deductible to the extent allowed by law.
SBAK is supported by generous individual donors, corporate sponsors, matching gifts, grants and fundraising events.



Supported Organization