



SPINA BIFIDA ASSOCIATION OF KENTUCKY

Annual Report 2019



Teal on the Hill – National Advocacy Day



Walk N Roll

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 36 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.

Over the past eight years, SBAK has grown as an organization to meet the growing and ever-changing needs of our families across Kentucky. In 2011, the addition of an SBAK Lexington office allowed us to increase program outreach efforts in Eastern Kentucky where the rate of neural tube defects is the highest in the nation.

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 2020, 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

In this year the Spina Bifida Association of KY intensified efforts to support individuals living with Spina Bifida, their families, friends, caregivers and the professionals who work with them. In addition, SBAK also seeks to educate the public about Spina Bifida. During 2019, SBAK has:

- Collaborated with other organizations and other interested partners to serve the needs of the Spina Bifida Community.
- Educated the public, physicians and other health professional about Spina Bifida.
- 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.

2019 Year In Review

SPINA BIFIDA ASSOCIATION OF KENTUCKY

- Over 100 attendees at the Spina Bifida Association of Kentucky Regional Conference.
- Provided financial assistance to 25 individuals to attend the SBAK Regional Conference.
- Funded 34 families to attend Camp for Courageous Kids - a camp specifically for children with special needs - for a weekend retreat.
- 1,300 individuals, families, and professionals received the quarterly SBAK Newsletter.
- Hosted 12 playgroups for children ages 0-6 with Spina Bifida and their families across Kentucky and Southern Indiana.
- Hosted 7 Giving Back Group Programs in Louisville and Lexington
- Hosted 8 Growing Up with Spina Bifida programs for school aged children and their parents and siblings in the Louisville and Lexington area.
- Hosted 3 Walk-n-Roll Awareness Fundraising Campaigns across the state with over 600 people in attendance.
- Attended the National Advocacy Day at Teal on The Hill in Washington D.C. with 7 representatives from Kentucky including SBAK staff, adults with Spina Bifida, and parents of children with Spina Bifida.
- 300 attendees at the 5 Holiday Parties across Kentucky with every child receiving a gift from Santa.
- 4 Appearances by staff on local news stations to spread awareness and promote SBAK's mission



10

Newborn Outreach
Visits

40

Programs hosted
across the state

103

Volunteers
supporting programs
and events

Financial Report*

2019 Income: Where does the money come from? (unaudited)	
Fund Raising Events	\$66,035
Grants and Partnerships	\$66,466
General Donations	\$38,661
In-Kind Donations	\$14,880
Program Revenue – Conference	\$2,732
Interest Income and Sales	\$575
<i>Total</i>	\$189,349
2019 Expenses: Where does the money go? (unaudited)	
Programs & Services	\$170,233
Fundraising	\$24,967
General/Administrative	\$31,777
<i>Total</i>	\$226,977
Net Assets Beginning of 2019	\$127,574
Net Assets end of 2019	\$89,946

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

Make a Donation to Support SBAK

www.sbak.org

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

2019 Board of Directors

Amy Sugg

Board Chair

Norton Children's Hospital - 231 E Chestnut St, Louisville, KY 40202
Director of Operations

Lance Williams

Board Treasurer

Blue and Co. - 2650 Eastpoint Pkwy Suite 100, Louisville, KY 40223
Senior Accountant

Cindy Pryor

Board Secretary

Program Committee Chair

Administrative Assistant II
Humana – 515 W. Market Street, Louisville KY 40202

Erin Straub

Board Member

Summit Financial Group

Operations Process Director/Manager

3108 Setting Sun Court, Crestwood, KY 40014

Colleen Payne

Board Member

6612 Rockview Way, Louisville, KY 40299

MS, MRC

Beth Bryant

Board Member

Adult with Spina Bifida

Michelle Gerken

Board Member

Eastern Kentucky University - 521 Lancaster Ave, Richmond, KY 40475

Associate Professor, ECU

Belinda Coyle

Board Member

Coloplast - Traveling Sales (no office)

Territory Manager KY/IN



Spina Bifida Family Camp at Center for Courageous Kids

Spina Bifida Association of Kentucky
982 Eastern Parkway, Box 18 Louisville, KY 40217
Office: 502-637-7363 Fax: 502-637-1010

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



Supported Organization