



# SPINA BIFIDA ASSOCIATION OF KENTUCKY

Annual Report 2021



## 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 38 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 2022, SBAK looks forward to returning to in person programming and events. 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 is a neural tube defect that happens in the first 28 days of pregnancy. 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 60 %.
- One out of every 2,758 babies born in the United States each year have Spina Bifida.
- Kentucky's Spina Bifida rate is more than twice the national average.
- 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.

## ACCOMPLISHMENTS

In 2021 the continuing Covid-19 pandemic forced SBAK to limit in-person programs and events for most of the year. Outdoor events became the order of the day, and many meetings and group events were held online.

During 2021, SBAK:

- 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.

## Financial Report\*

<b>2021 Income: Where does the money come from? (audited)</b>	
Fund Raising Events	\$93,244
Grants and Partnerships	\$50,984
General Donations	\$24,802
In-Kind Donations	\$21,760
Federal PPP Forgivable Loan	\$28,906
Interest Income and Merch Sales	\$813
<b>Total</b>	<b>\$220,509</b>
<b>2021 Expenses: Where does the money go? (audited)</b>	
Programs & Services	\$96,861
Fundraising	\$45,499
General/Administrative	\$66,905
<b>Total</b>	<b>\$209,265</b>
Net Assets Beginning of 2021	<b>\$112,869</b>
Net Assets end of 2021	<b>\$124,285</b>

\*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!**

## 2021 Board of Directors

**Colleen Payne, Board Chair**

6612 Rockview Way, Louisville, KY 40299  
MS, MRC

**Jonathan Evans, Treasurer**

Thornton's, LLC Assistant Category Manager  
107 Third St., Simpsonville, KY 40067

**Cindy Pryor, Board Secretary**

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

**Amy Sugg**

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

**Beth Bryant**

Adult with Spina Bifida  
7416 Arapaho Dr., Louisville, KY 40214

**Belinda Coyle**

Coloplast - Sales Territory Manager KY/IN  
4912 Merton Square  
Louisville, KY 40241

**Jeffrey White, MD**

Norton Community Medical Associates, Pediatric Urologist  
4123 Dutchman's Ln., Louisville KY 40207

**Christi McKim**

National Seating & Mobility, Inc., OT/ATP  
207 Franck Ave.  
Louisville, KY 40206

**Marcello Girao**

Transcend Orthotics & Prosthetics, Practice Manger, CO/LO  
10285 Champion Farms Dr.  
Louisville, KY 40241

# 2021 YEAR IN REVIEW

## SPINA BIFIDA ASSOCIATION OF KENTUCKY

- Hosted in-person Walk-N-Roll Fundraiser Awareness Campaigns in Louisville, Lexington, and Paducah
- Introduced the new Park Hop Play Date program, where we gather with our spina bifida families at various accessible parks in Kentucky
- Provided adaptive ride on toys to 15 children with spina bifida through the Financial Assistance Fund Pick Your Play program
- Hosted 11 families at the annual Spina Bifida Family Camp at the Center for Courageous Kids
- Hosted in-person December holiday events in Louisville, Lexington and Paducah, providing a gift for every child who attended



**4**

Newborn Outreach  
Visits

**127**

Families Helped by the  
Financial Assistance Fund

**49**

Volunteers Supporting  
Programs & Events





2021 Spina Bifida Family Camp at Center for Courageous Kids

Spina Bifida Association of Kentucky  
982 Eastern Parkway, Ste. 18 Louisville, KY 40217  
sbak@sbak.org  
502-637-7363

[sbak.org](http://sbak.org)

The Spina Bifida Association of Kentucky is a registered 501(c)(3) organization.  
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.

