

















Ready. Set. Walk-n-Roll!

The 2020 SBAK Walk-n-Roll for Spina Bifida will be wherever you call home!

The WNR is SBAK's largest fundraiser, but it also celebrates the accomplishments of the families living with spina bifida in Kentucky. All the proceeds raised are used for the Spina Bifida of Kentucky's FREE programs and services.

To prioritize the safety of our community, this year the walkn-roll will be a virtual event. While we can't all come together as planned in Louisville, Lexington, Paducah and Bowling Green, we CAN come together in spirit and spread spina bifida awareness far and wide!

As always, our WNR will be held during October in recognition of Spina Bifida Awareness Month! The entire month will be full of social media posts including; pictures, individual stories, videos, challenges, and so much more!

Kentucky Virtual WNR Saturday, October 24th

Visit sbakwalk.org to start a fundraising page today!



Like & follow Walk-N-Roll for Spina Bifida
Kentucky on Facebook for fundraising tricks and
tips and weekly updates!

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A Move to Virtual

SBAK responds to a changing landscape during Covid19 Pandemic

With March, came upheaval and change in everyone's lives. Everyone has been affected differently over the past several months, but everyone has felt the effects of this pandemic.

One of the greatest experiences in our community is the chance to build relationships and connections with other people that share many of the same challenges. With social distancing, our great plans for the 2020 program year came to a staggering halt. SBAK program staff seamlessly transitioned to virtual programming utilizing ZOOM.

The disability community is no stranger to isolation and social distancing. For many, this is a way of life and not just a response to a once every 100 years pandemic, and using virtual platforms we have been able to connect to individuals and families more than ever before!

As we move forward, remaining connected is still of utmost importance! We will continue hosting kids' programming that allow children with spina bifida and their siblings to have a fun break in routine by playing educational games, practicing socialization skills, and building friendships. Regular Parent Chats give parents a safe space to connect to other parents that face the same daily struggles and successes. Adult chats and panel discussions also provide respite from solitude and a way to further connect.

We hope to see all your smiling faces in person soon, but until then, follow social media to see all the ways SBAK is still tirelessly serving our community!



EXECUTIVE DIRECTOR'S LETTER

Dear Friends,

Let me introduce myself to you. I have been your Executive Director since October 2019. I have over 35 years of experience in the nonprofit sector. A native of Cincinnati, my family, wife Lorie, and two children, Nick and Lindsey, moved to Louisville in 1991 to become the Executive Director of the American Diabetes Association, Kentucky Affiliate.

After 12 years with ADA in various regional and national office positions following 8 years as Kentucky ED, I worked for the National MS Society, Diabetes Exercise Sports Association, the American Cancer Society, and The V Foundation for Cancer Research, all as Executive Director here in Louisville.

I enjoy spending time with my granddaughter, Brinlee (almost 4 years old) and I have a new granddaughter, Olivia, who lives in Memphis with mom and dad, Rachel and Nick. You can find me watching the Cincinnati Reds and Bengals, the Louisville Cardinals (Go Cards!), and my beloved Louisville City FC, as often as possible.

In my short 9 months on the job, I have met many interesting and dedicated volunteers, parents, and kids and adults with Spina Bifida. The last 3 months have been very trying and difficult for all of us. We all look forward to the day that we can see all of you live and in person.

It does look like Covid-19 is going to continue to wreak havoc on all face-to-face gatherings for some time to come. Walk-N-Roll will now be a virtual event. More info to come on that. Programs will continue for the foreseeable future to be conducted virtually. I hope more of you will join Sarah and Mary Beth as they continue to work hard on your behalf to bring the information you crave and the opportunity to interact with others. Stay the course, we will get through this together.

We are hoping to have our Annual SBAK Golf Scramble and the new Bifida Bash in person; however, we are making plans to hold both events virtually if necessary. Again, stay tuned for updates in July for both events.

I encourage everyone to follow our local and state guidelines for staying safe and healthy during these challenging times. I look forward to seeing you all very soon.

Doug Dressman Executive Director





SBAK Annual Golf Scramble

Friday, August 21, 2020

Weissinger Hills—Shelbyville, KY

12pm/Registration 12:30pm/Lunch 1:15 pm/Shotgun Start

Team Registration \$600 per foursome **Individual Registration** \$150 per player

Registration Includes

Green Fee / Cart / Gift / On-Course Games & Goodies / Silent Auction Raffle Prizes / Lunch / Prizes for 1st, 2nd & 3rd Place Teams

Beat the Pro \$5 / Mulligans \$10 each



Visit www.sbak.org to register.

Contact Doug Dressman at ddressman@sbak.org with any questions or if you are interested in becoming a sponsor for this event.

2019 Year In Review

SPINA BIFIDA ASSOCIAITON 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

SEPTEMBER 12

GET YOUR TICKETS NOW WWW.SBAK.ORG

314 EXCHANGE, PEWEE VALLEY, KY







Live Music with JD Shelburne

KENTUCKY







Meet the Team

Each newsletter will feature some of our board members, staff, and community volunteers so you can meet the team that serves the spina bifida population.



Colleen Payne has a 14 year old son, Nate, who was born with spina bifida, and two younger children, Georgia and Bo. She formerly worked for SBAK as program coordinator and executive director until 2015 and recently graduated with a master's degree in rehabilitation counseling from the University of Kentucky. Colleen joined the board in 2019 and is currently the Board Development Chair. She lives in Louisville with her husband, Blake, two dogs and two kittens.



Belinda Coyle graduated with Bachelor's of Science in Nursing from University of Louisville; GO CARDS!!!! She began her career at Frazier Rehab, where she became passionate about helping patients affected by spinal cord impairment/injury. She now works as a Senior Territory Manager & Field Sales Trainer for Coloplast in the Continence Care division, where she markets & promotes the Speedicath brand of urinary catheters & a transanal bowel irrigation system called Peristeen. Belinda has been an active member of the SBAK Board for 4yrs and is currently serving as Golf Committee Chair. In her spare time she loves traveling, concerts & sporting events (especially UofL football & basketball); working out/playing sports; and spending quality time with family (especially her 2 nephews & niece) & her amazing friends.



Erin Straub is a Louisville native and first became involved with SBAK while working at Norton Children's Hospital as part of the Spina Bifida Multidisciplinary Clinic. After having her son, Erin wanted to remain involved with the organization so she joined the SBAK Board of Directors in 2018. Currently she serving as the Bifida Bash Committee Chair. She enjoys family trips to Nolin Lake with her 2 dogs.



Beth Bryant is an adult born with Spina Bifida. She has been part of the Spina Bifida of Kentucky since 1983 when she first started her volunteer career. She is an advocate in the spina bifida community, traveling both to Frankfort, Ky and Washington D.C. to push for change and promote the agenda of the disability community. She was Ms. Wheelchair Kentucky in 2017 and continues to act as Ms. Wheelchair Kentucky State Coordinator. Beth is always willing to help out SBAK in any capacity she can.





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Christmas in July





SBAK's annual holiday parties are one of our most popular programs. This end of year celebration of all our families is held in multiple cities across the bluegrass every December.

We ensure that every child affected by spina bifida and all siblings receive a gift from Santa, because we recognize that the entire family is affected by spina bifida. Spreading this holiday joy goes a long way towards our mission to make the world a brighter place for all those impacted by spina bifida.

We would not be able to carry on this cherished holiday tradition without the generosity of others. Please visit **sbak.org/how to help/wishlist** to purchase a gift for a child and have it delivered directly to SBAK.



