



Spina Bifida Family Camp

APRIL 29 - MAY 1, 2016

THE CENTER FOR COURAGEOUS KIDS CAMP

Camp is an experience of a lifetime and now the whole family can enjoy it together! SBAK is partnering with the Center for Courageous Kids in Scottsville, KY, to provide a FREE Spina Bifida family camp on the weekend of April 26-28. Children with Spina Bifida ages 3-17 are eligible for the camp, and parents and siblings are invited! (Even if your child is not quite 3, you can still apply.) The Center for Courageous Kids is a world class medical camping facility providing a safe and fun camping experience for kids with disabilities and special needs. The Center for Courageous Kids is one of just a handful of medical camps of this caliber nationwide. At camp, families will enjoy horseback riding, fishing, archery, campfire sing-a-longs and so much more. Each and every child (including siblings) is assigned a well trained volunteer buddy to help them do whatever activities they are interested in. Parents have a chance to participate in all the activities, and also to have a kid-free evening.

This is an amazing opportunity for the whole family – and it's free! There are 30 spots for families to participate, so if you are interested, you need to apply soon. To get the application and learn more about the camp, go to www.thecenterforcourageouskids.org, call CCK at (270) 618-2900 or contact Erin at egillespie@sbak.org.



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SBAK Staff

Executive Director
 Shannon White
Associate Director
 Erin Gillespie
Program Coordinator
 Cindy Pryor
Administrative Assistant
 Kenzie Carden

Contact Us:
sbak@sbak.org
 Louisville: 502-637-7363
 Lexington: 859-268-5798



SBAK's Featured Program

Growing-Up with Spina Bifida

Open to all ages, focused on children with Spina Bifida 5-15 years old and their families.

This mini-series will address the greatest needs and issues our kids face as they grow up with Spina Bifida. Parents are encouraged to join us for an opportunity to learn and discuss these important topics, while the children get to experience hands on learning about their Spina Bifida.

February 27th: Let's talk about Spina Bifida - Louisville

March 12th: Let's talk about Spina Bifida - Lexington

Parents will privately discuss how we talk with our kids about Spina Bifida and answer their tough questions. Children will learn more about how to explain Spina Bifida to friends and grown-ups, which is the foundation for self-advocacy.

May 14th: Making Friends (Social Skills) - Louisville

Many children with Spina Bifida have difficulty developing meaningful friendships and picking up on unspoken social rules. Children will learn important social rules for making and keeping friends. Parents will privately discuss how to support our children in developing quality friendships.

August. 20th: Learning Differently (Executive Functioning) - Louisville

Children with Spina Bifida are often very intelligent but have difficulty paying attention, staying organized, and being flexible. If this sounds familiar, come learn more about how to build these skills for success in academics and life.

November 12th: Talking care of our bodies (Nurturing Independence) - Lexington

November 19th: Taking care of our bodies (Nurturing Independence) - Louisville

Parents are experts on caring for our children's complex needs, but as our children grow, they must learn how (and why) to begin the baby steps of managing their own medications, appointments, and hygiene.

Please contact Cindy at cprior@sbak.org or call 502-637-7363 for more information or to RSVP.

If you are interested in Lexington Programs, please contact Erin at 859-268-5798 or egillespie@sbak.org.

Thank You



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Executive Director's Letter

Dear friends,

Happy New Year from SBAK!

We hope everyone is having a great start to the New Year!

SBAK has so many exciting things going on right now and we are planning for 2016 to be even more awesome than 2015!

We have streamlined scheduling some of our programs, and are excited that for busy families, planning ahead will be simple this year. For example, Play Pals is set for the third Saturday every other month. And, our Transitioning Webinars are set for the first Thursday evening every three months. We hope that by planning ahead, we can have even more families involved throughout the year. Look for your annual SBAK program magnet in the mail soon!

We are also really excited about our new four part mini series, "Growing Up with Spina Bifida". This series is for all ages, and will address the greatest issues facing our families. We are thrilled to have national expert, Dr. Peg Dawson, author of *Smart But Scattered*, join us in August to tackle executive functioning. Please help us spread the word about this amazing new series!

We have also added new members to the SBAK Board of Directors, and are thrilled to have Erin Hinson, "Henry's Mom", lead the Board as Chairwoman. Her passion for SBAK is infectious!

Lastly, we are expanding the 2016 Walk-N-Roll to FOUR locations this year. Since we help families affected by spina bifida in all corners of the state, expanding the WNR to Eastern Kentucky is a high priority. We will continue to host walks in Louisville, Lexington and Paducah on October 1st, 2016, and are looking forward to celebrating with our Eastern Kentucky families this fall.

Please remember we are just a phone call away if you ever need a shoulder to cry on, a double high five, an answer to a "silly" question or support finding a new resource for your family.

Hope to see you at an SBAK program or event sometime soon!

On behalf of those we serve,

Shannon White



New SBAK Board of Directors Chairwoman

Erin Hinson is a native of Louisville, KY. She graduated from Fern Creek High School and went on to double major in Public Relations and Political Science at Western Kentucky University. She is currently serving as the Legislative Assistant to Councilwoman Angela Leet who represents the roughly 26,000 constituents living in Louisville Metro Council District 7. Erin first became involved with SBAK when her unborn son, Henry, was diagnosed with myelomeningocele around 20 weeks gestation. Henry will be 3 at the end of February and is an amazing little boy who is changing the conversation about Spina Bifida one smile at a time. Erin, and her husband Nathan are also the proud parents to Oliver, who is 5, and the best big brother around. Erin is excited to begin her work as the chairwoman of the SBAK board and serving the many families across Kentucky who are part of the SBAK Community. Erin is passionate about our mission as she lives with the ups, downs, twists and turns that can be life with Spina Bifida every single day. In her free time Erin loves to cheer on the Denver Broncos, watch HGTV, win every game of Uno played in her house and she bakes a mean sugar cookie! Erin would love to hear from you -- you can email her any time at ErinRHinson@gmail.com.





Have you moved or changed your email address?

Call or email us at 502-637-7363 or sbak@sbak.org to update your information. With updated info, you will receive program invites, education workshop opportunities, and much more!!

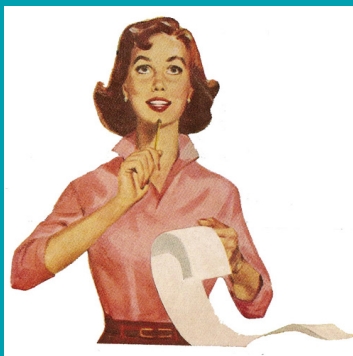


2015 SBAK HOLIDAY PARTIES



2015 SBAK Van Grant Winner

The Smith family was so excited to hear they were the 2015 SBAK Van Grant recipients. Braiden (seen below) tells everyone about the ramp. They said they have never seen a kid so excited about a van!



SB-Abby Advice Column

Dear SB-Abby,

We are looking to transition my daughter out of her crib. She's a full time wheelchair user. What kind of bed would be safe for her and give her a chance to get in and out on her own?

Advice...

We were allowed a KAYSERBETTEN bed through our insurance. It is still like a crib BUT sides open completely and it lowers all the way to the ground so she can now get in and out on her own too. It's a twin size as well. - *Amanda Blas*

Our son went from a crib to a twin bed with those mesh rails you can buy at Babies R Us. Then he went from that to a full size bed when we moved into our new house when he was 3yrs old. He is now 6yrs old and he's still in the same full size bed and we still have the mesh railings on so he cannot roll off the bed. The railings don't go down all the way to the foot of the bed so he has plenty of room to get in and out of his bed. He never gets out of his bed to the floor always into his chair. - *Keishia Vincent*

I had a mattress on the floor most of my childhood!! I loved it cause I could get out of it easily and crawl around if I wanted to!!! - *Kristina Hornback*



Put your running shoes on for Team Spina Bifida!! Was your New Year's resolution to be more active? Well, be active with us and help raise money for a great cause!

If you or someone you know is interested in participating in the Kentucky Derby Marathon or Mini-Marathon on April 30, consider running for Team Spina Bifida! You will be raising Spina Bifida awareness and funds for SBAK! SBA will provide you with fundraising tips, ideas, forms, a web page, and constant support along the way. Many with Spina Bifida can't run or walk a mile, but you can do it for them! Online registration is now open. For more information, visit

spinabifidaassociation.org and click on Team Spina Bifida or contact Shannon White at swhite@sbak.org.

Spina Bifida Association of Ky

2016 Program Schedule

Play Pals (0-6yrs)

January 16	PTs/OTs - Louisville
January 16	OT - Lexington
March 19	EASTER - Louisville
March 19	EASTER - Lexington
March 20	EASTER - London
March 20	EASTER - Western KY
May 21	Bowl Management - Louisville
May 22	Bowel Management - Lexington
July 16	Summer Picnic / Back2School Blast
July 16	Summer Picnic/ Back2School Blast
July 23	Summer Picnic/ Back2School Blast
September 17	Pumpkin Patch - Louisville
September 17	Pumpkin Patch - Richmond
December 2	Holiday Party - Lexington
December 3	Holiday Party - Louisville
December 3	Holiday Party - London
December 4	Holiday Party - Pikeville
December 4	Holiday Party - Western KY

Transitioning Webinars (6:00- 8:00pm)

March 3	Intro: Pre-Employment Transition Services
June 2	Self Advocacy
September 1	Workplace Rediness
November 3	Job Exploration

Growing Up with Spina Bifida (7-15yrs)

Mini Series

February 27	Let's Talk About Spina Bifida - Louisville
March 12	Let's Talk About Spina Bifida -Lexington
May 14	Social Skills/Making Friends - Louisville
August 20	Executive Functioning - Louisville
November 12	Taking Care of our Bodies - Lexington
November 19	Taking Care of our Bodies - Louisville

Newborn Outreach Mentor Training

February 20	Mentor training - Louisville & Lexington
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Teen/Adult Socials (16+yrs)

January 8	Freezer Meal Workshop
February 19	Giving Back Group - Lexington
April 8	Wine & Paint
April 8	Giving Back Group - Lexington
August 5	Giving Back Group - Lexington
October 22	Ghost Bowl/ Halloween Party - Louisville & Lexington

Special Events

April 29-May 1	Spina Bifida Family Camp
March 24	Many Faces Luncheon
May 5	Oaks Eve Gala
June 25 - 28	National Conference - Minneapolis
October 1	Walk-N-Roll - Lexington, Louisville, Paducah & E. KY

New Arrivals

**Maria and Nictoriano welcomed Hannah on
January 21, 2016**

**Kayla and Christopher welcomed Paisley on
February 3, 2016**



**SPINA BIFIDA ASSOCIATION
OF KENTUCKY**

Kosair Charities Centre
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**SPINA BIFIDA ASSOCIATION
OF KENTUCKY**

FINE PRINT

NEW Fisher-Price Power Wheels Ford F-150: Blue
12-Volt Battery-Powered Ride-On
Drives on hard surfaces, wet grass and rough terrain
2 speeds forward (2.5 and 5.0 mph) plus reverse (2.5 mph)
Maximum speed: 5 mph
Real FM radio & MP3 jack
Roomy truck bed with working lift-and-lower tailgate
Pretend seat belts
High-speed lockout option for beginners
Power-Lock brakes
Requires one 12V battery (battery and charger included)
Requires 4 C batteries for radio (not included)
Maximum weight capacity: 130 lbs.

This truck has been modified so a child can use the floor
petal or two buttons that are located on the steering wheel!

VALUED OVER \$350!!!



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