



SPINA BIFIDA ASSOCIATION
OF KENTUCKY

January/February 2017



Adult Spina Bifida Camp

JUNE 2 - 3, 2017

CAMP HORSIN' AROUND

Camp is an experience of a lifetime and now adults with Spina Bifida can do it together! SBAK is partnering with ECU Parks and Recreation and Camp Horsin' Around in Perryville, KY, to provide a FREE Adult Spina Bifida camp on June 2-3. Adults with Spina Bifida ages 18 and up are eligible for the camp. Camp Horsin' Around is an amazing camping facility providing a safe and fun camping experience for kids and adults with disabilities. At campers can enjoy fishing, archery, swimming, rock climbing and so much more.

This is an amazing opportunity for any adult with Spina Bifida in Kentucky or Southern Indiana – and it's free! There are 18 spots available for participants, To get the application and learn more about the camp, contact Erin at egillespie@sbak.org.

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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 18th: Chores - Lexington

February 24th: Chores - Louisville

One of the best things we can do to help prepare our kids with SB for greater independence in adulthood sounds very simple: Chores. But in reality, chores are not always simple for kids with mobility challenges and executive dysfunction, are they? Come hear from our expert panel of adults with SB about how they adapt chores and how their parents helped them toward independence. They will also do a demonstration for the kids and encourage them to help out around the house.

June 24th @ Regional Conference: Student Involvement in IEP Meetings - Lexington

A great way for students to learn to advocate for themselves is to participated in their own IEP meetings, starting with minimal involvement in elementary school with the potential to run their own meetings in high school. Parents will learn how to facilitate this involvement, while kids learn more about IEP's.

August. 26th: Kids Taking Over- Louisville

As our kids get older, they need to start taking a bigger role in their own doctor appointments, with the goal of them managing their own health in adulthood. We will talk about how to encourage kids to get more involved in every aspect of their appointments from the paperwork to follow up questions. We will also hear from an expert in transitioning patients from pediatric to adult doctors. Meanwhile, the kids will test their knowledge of their medical care and practice new skills.

November 11th: What do you want to do when you grow up? - Louisville

November 12th: What do you want to do when you grow up? - Lexington

It's never too early to start planning for transition to adulthood. Kids and parents will talk about their dreams for the future and plan how to get there.

Please contact Cindy at cpryor@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.

Executive Director's Letter

Dear friends,

I have some exciting news to share with you! In the coming weeks, I will leave my role as Executive Director of SBAK to take on a different role at Centerstone (formerly Seven Counties Services). While I am looking forward to the next chapter in my life, I am also sad to leave this position, and a job I have cherished for the past 4 years. Not many people get to work with a staff and families that are so loving, enthusiastic and supportive, not only to me, but to each other. I have sincerely had a ball, and thank you for the trust you have placed in me to lead SBAK!

I am extremely proud of the work we have accomplished to make SBAK the thriving and successful organization it is today. A few of my highlights include passing The Delivering the Diagnosis Law, opening The new Norton Children's Hospital Pediatric Spina Bifida Multidisciplinary Clinic, expanding Walk-N-Roll to four locations, increasing adult programs, surviving The KDF Mini-Marathon for Team Spina Bifida (picture below) and securing additional funding to help ensure that SBAK is sustainable for generations to come.

At the same time, I am thrilled to welcome Erin Gillespie as SBAK's new Executive Director! Over the past five years, Erin has established a strong

Giving Back Group in Lexington, designed the first Spina Bifida awareness project in Eastern Kentucky, launched the new SBAK website, updated the bimonthly newsletter, collaborated with strategic programs such as Build Inclusion's AIM! Program and recruited hairy dudes to support SBAK at the Annual Beard and Loathing event in Richmond.

She has been an incredible family advocate and these sincere relationships will make SBAK bigger and better in the years to come.

I will be sure to stay involved and stay in touch. And, I will always be a strong advocate for families affected by Spina Bifida!

So, from the bottom of heart, thank you for your support and friendship. It has been such an honor to lead SBAK, and I can't wait to see what the future holds for our organization.

Cheers!

Shannon
White



SBAK's New Staff Member - Amy Muth

Amy has over 16 years of accounting experience primarily in the nonprofit and healthcare industries. In addition to time spent as a stay at home mom, she has worked for Seed Capital Kentucky, Boys & Girls Clubs of Kentuckiana, Columbia/HCA and Frazier Rehabilitation Center in the Louisville area. While living in Nashville from 1995 to 2004 she worked for Dialysis Clinic, Inc., Deloitte & Touche LLP and Healthsource Tennessee, Inc. Amy earned her Bachelor of Science in Accounting from the University of Louisville and was a licensed CPA in Kentucky from 1999 to 2003.

Her most challenging and rewarding job is raising five boys that range in age from fourteen to seven. Amy and her husband spend most of their "free" time with their children. The most rewarding part of being a mother to her five boys is watching the four older boys interact, teach, and protect their youngest sibling with Down Syndrome – a child who brings a ray sunshine to everyone he meets.

She enjoys working for nonprofit organizations and is proud to join Spina Bifida Association of Kentucky in hopes of contributing to the mission. In her experience, nothing is more important than advocating for those with challenges to become successful, independent, productive, and integrated members of society.



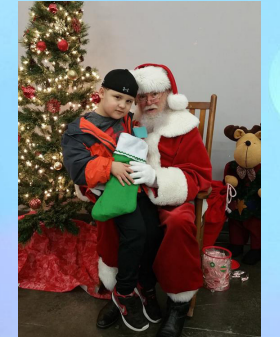


Have you moved or changed your email address?

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!!

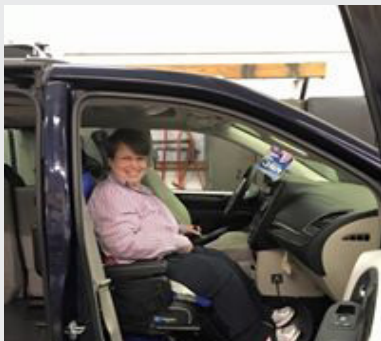


2016 SBAK Holiday Parties



2016 SBAK VAN GRANT WINNER

Congratulations to the Shepard family for winning the SBAK Van Grant! Thank you to Superior Van and Mobility for your partnership and support. The Shepard's are so excited about their new van.



SB-Abby Advice Column

Dear SB-Abby,

Question for those who have waivers--if you or your employee makes a minor mistake on your timesheet, like put an am for a P.M. or something simple and don't catch it--does your support broker allow you to fix it and get paid or just send it back and you have to wait until the next pay period?

Advice...

We are with seven Counties and all of our time sheets are done online. The program they use actually catches if you make those sorts of mistakes. Also, I happen to have a really good caseworker right now and she actually alerts me if there's a problem in my documenting. We have never had to wait out a pay period.

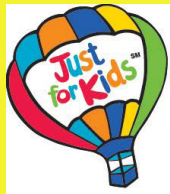
- Kellie Mitchum

We are notified of errors and are allowed a certain amount of time to fix them and still be paid on time. If we miss that deadline, we have to wait. - Amy Foster

KIPDA used to let us fix stuff and return and still get paid, but they changed the rule because they said it was the same people making the same mistakes. - Colleen Payne

2017 Miss Wheelchair Kentucky Congratulations, Beth Bryant!





NORTON
Children's
Hospital

Norton Children's Hospital Opens Spina Bifida Clinic

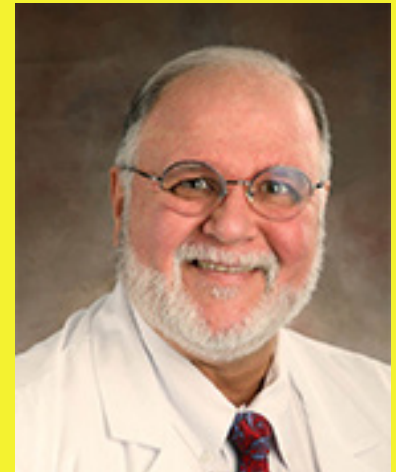
Norton Children's Hospital, in conjunction with the Kentucky Commission for Children with Special Health Care Needs, celebrated the opening of the Norton Children's Hospital Spina Bifida Clinic on Oct. 19. The clinic is held on the third Wednesday of each month in Norton Medical Plaza II – Brownsboro, Suite 205, 9880 Angies Way.

The clinic brings together in one place a multidisciplinary team, which includes pediatric specialists in orthopaedics, neurosurgery, spine surgery, urology, gynecology, physical therapy and occupational therapy, as well as brace shop technicians, nutrition counseling and care coordination for patients and their families.

"We saw a need for our families to have a single location on a single day per month to see all their providers," said Dennis Peppas, M.D.,

pediatric urologist, Norton Children's Urology. "By opening this clinic, our hope is that we are providing care that is not only convenient and personalized to each child's needs, but also that we are saving time for our parents and caregivers that they can now spend having fun with their families."

For information on the clinic or to schedule an appointment, call (502) 559-SBAK (7225).



Dennis Peppas, M.D.
Norton Children's Urology

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1-800-458-8267 | superiorvan.com

Eastern end of the city. Be on the look-out for our Grand Opening announcement and Open House.

In the mean-time, please make plans to attend our Ribbon Cutting Ceremony and reception, performed by the Jefferstown Chamber of Commerce on February 23, 2017, at 11 am. It will be a great time to see the new 2017 Pacifica and other wheelchair accessible vans in our new showroom! Completely redesigned, the new Pacifica features many safety upgrades, and advance features including added interior space for both the driver and passenger. Don't forget that our website, www.superiorvan.com, is a great place to flip through our current inventory of both new, pre-owned, and used wheelchair accessible vans. In addition, if you click on the Resources Tab of our website, you can review some of the Funding and Financing options currently available. Please contact one of our mobility consultants today with any questions!

We're moving! Superior Van & Mobility will be opening a new, state-of-the-art Mobility Center in Louisville, KY in early February. Our new address will be 1506 Lakeshore Court, Louisville, KY 40223, but our main phone number will remain the same, 1-800-458- 8267. This new location is conveniently located just 1.4 miles from the I64 / Hurstbourne Lane exit on the





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SAVE THE DATE!



In the Heart of the Bluegrass...

2017 SBAK Regional Conference

June 23 - 25 / Clarion Hotel / Lexington, Kentucky

