



SPINA BIFIDA ASSOCIATION
OF KENTUCKY

July/August 2017



Walk Locations & Dates:

Iroquois Park, Louisville // October 14th

Shriners Hospital, Lexington // October 14th

Noble Park, Paducah // October 21st

Hazard City Park, Hazard // October 21st

This family-friendly, leisurely walk creates awareness about Spina Bifida, raises funds for SBAK, and celebrates the accomplishments of families living with Spina Bifida in Kentucky. All proceeds are used for SBAK's free programs and services.

Registration for the 2017 Walk-N-Roll will begin at 9:30am on Saturday at all locations. During this time, we will collect all pledged and new donations.

Go to sbakwalk.org for more information!

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Meet the team: Ann Muth, APRN, Norton Children's Urology

Ann Muth, APRN is the newest addition to the Norton Children's Urology practice. As part of the Norton Children's Hospital Spina Bifida clinic, multiple specialty providers, including urology are able to care for your child in one coordinated visit. We sat down to learn a little bit more about Ann and her connection to the area and the Spina Bifida community.

A Louisville native, Ann Muth knows the River City just about as well as she knows pediatric urology. She grew up here and attended Mercy Academy before enrolling in Bellarmine University, where she earned a degree in biology. She went on to attend Spalding University in order to begin her career as a nurse practitioner. After graduating from Bellarmine, she began to take care of her mother who was dealing with sickness. In hindsight, Muth believes that caring for her mother helped her realize that she wanted to find a job where she could help others.

Starting off at Norton Children's Hospital, Muth has worked in many different environments and has received a great amount of experience collaborating with a variety of doctors. She spent 7 years in oncology, and then 10 years in the operating room. Muth knew she wanted to focus on a specific field and became interested in pediatric urology when an opportunity in a practice presented itself. She quickly fell in love with caring for children.

"Kids are resilient," she said. "They also say the funniest things."

Her passion is being able to see kids with stigmatizing issues, such as bed-wetting, come back to see her with their issues resolved.

Spina bifida has been an important focus for Muth for 14 years. The birth defect affects the way the bladder works. "Spina bifida used to be life threatening because kids couldn't empty their bladders," she said. "The introduction of catheters meant that babies with spina bifida could overcome the urinary system challenges." Urology is a vital component of spina bifida treatment, and Muth loves helping her patients get on a healthy path.

Heavy lifting isn't how Muth describes her day-to-day duties. It's actually a hobby of hers. She enjoys Olympic weightlifting in her free time, focusing on lifts such as the clean and jerk, snatch and power clean. She's even participated in several powerlifting competitions, deadlifting over 300 pounds! Muth also enjoys traveling in her off time. She's vacationed in Puerto Rico and is currently looking forward to a trip to the Baltic Sea.

Muth's one health tip is to maintain a healthy body weight. Many health issues are a direct result of poor weight management, so it's very important to eat well and exercise.



Catherine Ann Muth, APRN

Looking for a pediatric urologist?

Norton Children's Urology is a member of the Norton Children's Hospital Spina Bifida Clinic and is accepting patients. Find more information at NortonChildrens.com/Urologists or call (502) 559-1670.



Executive Director's Letter

Dear Friends,

The FIRST SBAK Regional Conference in Lexington was incredible, with over 100 people in attendance. There were families from Ohio, Illinois, Minnesota, Missouri, and all over Kentucky!

Conference gives individuals in the SB community the opportunity to learn about the newest trends, latest treatments, and innovative procedures to help make the lives of those living with SB as independent and productive as possible. Not only do the classes provide more information than you can imagine, the networking and friendships created leave an incredible impact.

Saturday's sessions were packed with education, work responsibility, advocacy, medical awareness, and recreation. Many people raved about the No Work - No Money and the Bowel Management sessions, but the Ask the Specialist with Dr. Peppas, Dr. Meier, and Dr. Moriarty, was the most engaging session I was able to attend. The Norton Children's Hospital SB Clinic doctors held a Q & A session and the information shared was invaluable.

We were so happy to see so many of our SB families there and look forward to the next Regional Conference in 2019!

Update From Spina Bifida Association of America (National)

As many of you know, SBA was due to hold its next National Conference in 2018. After a very extensive search for an affordable and accessible location, SBA's Board of Directors has made the decision not to hold a National Conference next year.

We know that this is very sad news for some of you, and we want you to know that we did not make this decision lightly. Here are some of the factors that influenced this decision:

- It has become increasingly difficult to find a hotel that can accommodate a conference of our size and with our accessibility needs at rates that are reasonable for our constituents.
- Hotel, food & beverage, and rental costs have continued to rise, making National Conference less and less affordable for SBA and for our Spina Bifida families.
- With an average of 700 attendees at each conference, many of whom come every year, we are not reaching the majority of nearly 177,000 people within the Spina Bifida community. We've tried to increase the number of people attending over the past decade, and we have not been able to do so. We believe that this is due, in large part, to the cost of the conference.

In response to the overall health needs of our community and the current political environment, SBA has begun shifting its priorities to focus more on research and advocacy. - Megan Sorenson, SBA Board Chair

Best Wishes,

Erin Gillespie



SBAK Walk-N-Roll...Are you Ready?

Ever wonder how you can make a difference?

Your decision to join us for the Walk-N-Roll for Spina Bifida will do just that.



Walk-N-Roll for Spina Bifida is a one day walk dedicated to raising funds for the Spina Bifida Association of Kentucky's free programs and services to benefit those living with Spina Bifida. This inspiring event also gives families and friends the opportunity to raise awareness in their communities. Participants share an incredible experience and take pride in their efforts to make a difference in the lives of families facing Spina Bifida.

Why Walk-N-Roll as a Team?

Ever heard the expression, "two heads are better than one"? The same is true for walking. You'll have more fun, and enjoy your Walk-N-Roll experience more, if you Roll as a Team!

What are the benefits of forming a Walk-N-Roll for Spina Bifida team?

- Enhances employee morale and builds team spirit
- Provides an opportunity to benefit a cause with your friends, family, and coworkers
- Provides a wellness activity to employees; healthy employees are more effective employees
- Provides an opportunity to build relationships with customers
- Provides business-to business marketing opportunities

Register Your Team

Visit sbakwalk.org to register your team online for the Walk-N-Roll for Spina Bifida in your area and take advantage of easy-to-use online fundraising tools. As a team leader you can create your own team Web page, send personalized emails to recruit and motivate team members, and track your team fund raising progress.

Using Social Media

Are you on Facebook, Instagram, LinkedIn or some other type of social media network? These can be valuable tools for recruiting team members and raising funds!

Download the Walk-N-Roll logo from the Web site and post it to your social media page. Update your status frequently with information and be sure to send out the link to your personalized fundraising page!

Fundraising Tips

- Dedicate your efforts to an individual living with Spina Bifida and raise funds in their honor. By sharing your honoree's story, you are sharing why you are so personally invested in this cause!
- Provide information about Spina Bifida to your contacts. Let your donors know what exactly their donations will be helping.
- Be enthusiastic and positive. The Walk-N-Roll is intended to be a fun event demonstrating our passion and dedication to this worthy cause. Enthusiasm is truly contagious!
- Ask, ask, ask! And aim high. If you know your donors are capable of making a large donation, do not be afraid to ask for a specific amount.
- Don't forget to thank your donors.



Fast Facts about Spina Bifida

- Spina Bifida is the most commonly occurring complex birth defect in this country affecting over 177,000 individuals.
- It occurs when the spine of the baby fails to close during the first month of pregnancy, leaving an opening in the spinal column.
- Those who are born with Spina Bifida must learn to live with conditions such as hydrocephalus (fluid on the brain), full or partial paralysis, bladder and bowel complications, learning disabilities, and latex allergy as well as social issues.
- There is no known cause of Spina Bifida and each of the 65 million women of childbearing age in this country are at risk for an affected pregnancy.
- It is estimated that up to 70 percent of birth defects like Spina Bifida can be prevented with a daily dose of 400 micrograms of folic acid every day prior to pregnancy.
- The average total lifetime cost to society for infants born with Spina Bifida may well exceed \$1,000,000.
- Children who have Spina Bifida have medical expenditures 13 times greater than other children.
- Adults who have Spina Bifida had medical expenditures 3 to 6 times greater than other adults.

It's easy to raise \$200

Here are a few ideas:

- Give something up—a movie, manicure or dinner at an expensive restaurant—and contribute what you would have spent to Walk-N-Roll for Spina Bifida.
- Host a fundraising party and ask attendees to pledge their support.
- Create a buddy system. Ask someone who cannot join you on walk day to help you collect donations.
- Ask your company and other companies to conduct a Dress Down Day for their employees and ask for donations to participate.

- Hold a garage sale and donate the proceeds.
- Take your fundraising letter and Walk-N-Roll for Spina Bifida information everywhere you go.
- Ask one person a day to sponsor you in Walk-N-Roll for Spina Bifida.
- Ask your friends to contribute to Walk-N-Roll for Spina Bifida instead of purchasing a gift for your birthday, anniversary or any occasion.
- Promote yourself—call your local newspaper and let them know what you are doing. Offer to send a photo. Publicity generates donations.
- Approach your company. Many companies will give a flat donation and many others have matching gift programs.

Who to ask?

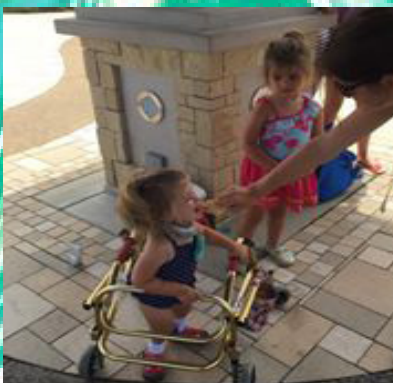
Here is a list of ideas for asking others to support you.

- Send an email or a letter to everyone in your address book
- Friends
- Family
- Co-workers
- Favorite local restaurant owner
- Any favorite local shop that you frequent often
- Your doctor, dentist or lawyer
- Your teammates or gym buddies
- Your hairdresser or barber
- People at your place of worship

Continue to ask your team members to invite their friends, family members, neighbors, and business associates to walk with you until you reach your recruitment goal.



SBAK SUMMER FUN!!!



Save the Date!

Spina Bifida Awareness Month

SB INK - October 28th

Get INK and raise awareness
and funds for Spina Bifida!

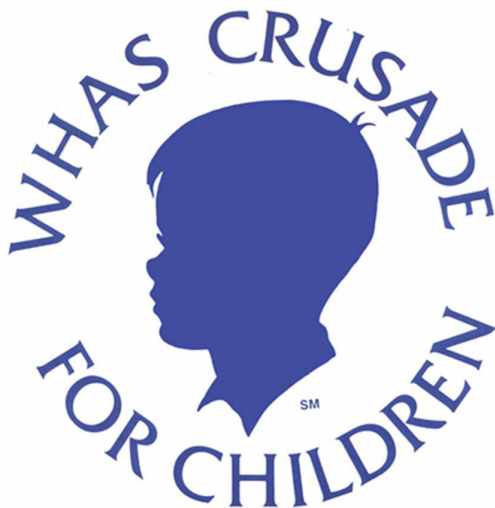


Presented By:
Tattoo Charlie's

Lexington and Louisville Locations

Applause!

The 2017 WHAS Crusade for Children
Grant of \$23,000 will allow SBAK to
continue serving individuals across KY!



Thank you Beard and
Loathing for your continued
support! This year's *Beard
On* raised over \$2,400!





Kosair Charities Centre
982 Eastern Parkway, Box 18
Louisville, KY 40217
www.sbak.org
(502) 637-7363

Upcoming Events and Programs

September

Sept. 23rd

FALL FESTIVAL

Location: Gallern Farms
Shelbyville, KY
Time: 11am - 1pm

Sept. 24th

FALL FESTIVAL

Location: Baldwin Farms
Richmond, KY
Time: 2pm - 4pm

October

Oct. 14th

SBAK WALK-N-ROLL

Location: Lexington and Louisville
Time: 9:30am - 1pm

Oct. 21st

SBAK Walk-N-Roll

Location: Paducah and Hazard
Time: 9:30am - 1pm

October 27th

SB Adult Halloween Party

SBAK Program Rm. - Louisville
Time: 6pm - 8pm

October 28th

SB INK

Location: Lexington and Louisville
Time: All Day

