



## *Tis the Season for Holiday Celebrations!*

### **Holiday Party Locations**

*Lexington*

*Friday*

*December 1st, 6-8pm*

*GattiTown*

*Louisville*

*Saturday*

*December 2nd, 3-5pm*

*Beechland Baptist*

*London*

*Saturday*

*December 2nd, 1-3pm*

*Old Town Grill*

*Bowling Green*

*Sunday*

*December 3rd, 3-5pm*

*Ryan's Buffet*

*Pikeville*

*Sunday*

*December 3rd, 1-3pm*

*GattiTown*

Once again, SBAK will be hosting five holiday parties across the state! These celebrations are intended for those affected by Spina Bifida and their immediate family. Don't forget to RSVP.

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## Monthly Spina Bifida Clinic coordinates care

*Kids can visit several doctors in a single day at Norton Children's Hospital*

Avery Richardson will turn 3 in December, but the Shelbyville, Kentucky, girl has already been through a lot. Avery has undergone six operations, including two in the days immediately after her birth.

Avery has spina bifida, a birth defect that causes the structure enclosing the spinal cord to fail to form properly in the womb.

"It's incredible to watch the resilience that Avery and other kids have that are going through the exact same thing," Richardson said.

Avery sees a pediatrician, urologist, gynecologist, orthopedic surgeon, neurosurgeon and spine surgeon for her spina bifida. That can mean a lot of appointments, which can be taxing on the entire family.

To ease the burden, Norton Children's Hospital offers a special Spina Bifida Clinic on the third Wednesday of every month, allowing Avery and others with the condition to see their doctors in a single day.

"It's a good way for families to see all the people they need to and get all the tests done," said Avery's pediatric neurosurgeon at the clinic, Thomas M. Moriarty, M.D., Ph.D.

Before the clinic opened in 2016, getting Avery to her doctor appointments was difficult. Her mother recalled one seven-day stretch in which Avery had seven appointments.

Dr. Moriarty said the clinic also has the advantage of making it easy for physicians to coordinate care. Getting another specialist's opinion is as easy as walking down the hall.

"A lot of these concerns are overlapping, so we can get together and talk," he said. "I think it's working really well."

Richardson agreed.

"I prefer the clinic setting, because there are so many things with spina bifida," she said. "It's not just one doctor that takes care of it. The team approach is so important."

In April, Richardson left a management job to become program coordinator for Louisville and Western Kentucky

for the Spina Bifida Association of Kentucky. On Norton Children's Hospital Spina Bifida Clinic days, she brings "survival snack bags" to help the patients — and their siblings — get through the long day.

Since it began in 2016, the clinic has served 61 different patients with 320 appointments. Each patient typically sees three to four specialists during a visit. It normally would require more than 1,100 separate specialty appointments for the same care.

This clinic has provides convenient coordinated care to these families and will continue to positively impact the lives of children with spina bifida in this region, which is particularly hard hit by the condition.

"They come out with a real problem," Dr. Moriarty said. "During the first day or two of life, they typically have one or two operations."

Like Avery, Dr. Moriarty said children with spina bifida are incredibly resilient.

"These children tend to be some of the most tough, outgoing, survivor kind of kids," he said. "Some might think these children are at a disadvantage in life having this condition. That's not the way these kids see themselves."

Richardson sees her daughter's willful nature as an asset in the long run.

"There's nobody that's ever going to tell her she can't do something in life — because she'll find a way to prove them wrong."

Norton Children's Hospital Spina Bifida Clinic has services provided from the following specialty practices and support services:

- Norton Children's Gynecology
- Norton Children's Neurosurgery
- Norton Children's Orthopedics of Louisville
- Norton Children's Urology
- Norton Children's Hospital rehabilitation and social services
- Family support services by Spina Bifida Association of Kentucky
- Kentucky Commission for Children with Special Healthcare Needs

The Norton Children's Hospital Spina Bifida Clinic offers care planning for expectant mothers with a diagnosis and immediate and long-term care to children of all ages. For more information, call **(502) 629-7225**.



# EXECUTIVE DIRECTOR'S LETTER

Dear Friends,

We all look forward October for many reasons, but for the SB community, October gives us the opportunity to celebrate together, share our stories, and raise awareness for a cause that means so much to all of us. SBAK's staff, friends, and families worked incredible hard to make this year record-breaking! We are very proud of everyone for their hard work and dedication.

All four Walk-N-Rolls in Lexington, Louisville, Paducah and Hazard were filled with celebrations, laughs, triumphs, cheers, and support! With over 700 attendees, this was one of the best years yet! It was amazing to see so many people come together to help support those affected by Spina Bifida throughout the state.

As we wrap up the month, I thought it would be nice to share how much we have accomplished in such a short time.

- Radio show with WQXE in Elizabethtown
- Walk-N-Roll TV appearance on WKYT Lexington
- Spina Bifida Awareness Month TV appearance on WKYT Lexington appearance for Spina Bifida Awareness Month
- Kosair Charities Crystal Ball
- Walk-N-Roll and Spina Bifida Awareness Month TV appearance on WPSD Paducah
- Louisville WNR
- Lexington WNR
- Hazard WNR
- Paducah WNR
- SB Ink - Spina Bifida Awareness Month Tattoo Benefit
- Louisville Spina Bifida Awareness Month Proclamation by Councilwoman Angela Leet
- Kentucky SB Stories (Nate Payne and Bethany Curry) posted on the SBA (National) Facebook page and Blog
- Norton Children's Hospital article starring our own, Sarah and Avery Richardson!
- Halloween All Disabilities Event

Again, we thank you for making October so incredible! We hope you have a wonderful holiday season and we look forward to seeing you at one of our FIVE holiday parties!

Best Wishes,

*Erin Gillespie*

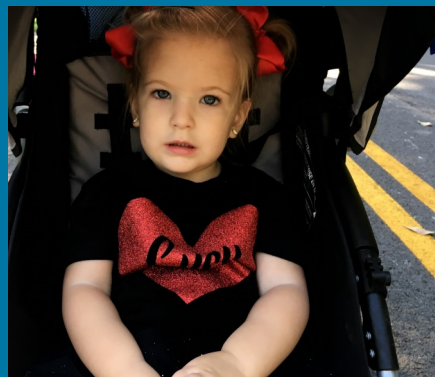




# 2017 SBAK WALK-N-ROLL LOUISVILLE LEXINGTON HAZARD PADUCAH







The 2017 WNR  
raised over  
\$60,000!!

Thank you!! We  
couldn't have done  
it without you!

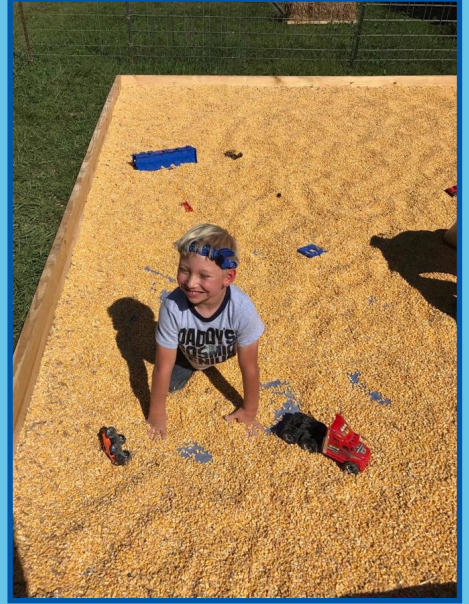
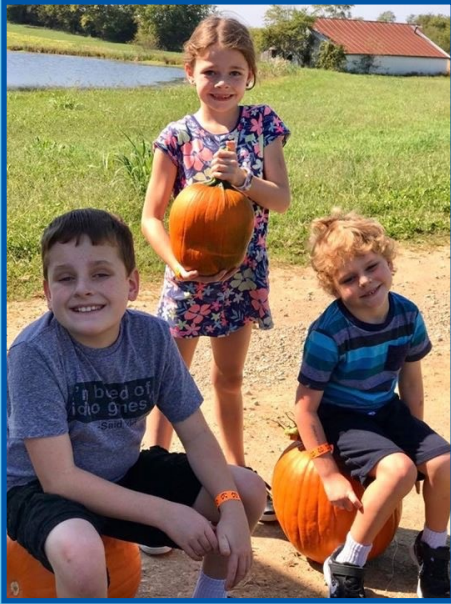




# Thank you to our 2017 WNR Sponsors!







**SBAK**  
**Fall Fun!!**





**SPINA BIFIDA ASSOCIATION  
OF KENTUCKY**

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