



SPINA BIFIDA ASSOCIATION
OF KENTUCKY

March/April 2016



beyond all limits

June 25, 2016 - June 28, 2016

Spina Bifida National Conference *JUNE 25 - JUNE 28TH*

The Spina Bifida Association (SBA) is hosting their 41st National Conference in Bloomington, Minnesota. Children and adults with Spina Bifida, their families, physicians, nurses, and other clinicians will have the unique opportunity to gain information on the latest medical care and network on various topics which affect their lives and professions.

- Learn up-to-the-minute information about urology, orthopedics, neurology, neurosurgery treatment, adult specific care, and much more!
- Attend practical workshops and special programs that address your own interest areas.
- Network with various groups – from others living with Spina Bifida to health professionals and product manufacturers.
- Find out how researchers are paving the way for more knowledge about Spina Bifida.
- Hear from leading Spina Bifida partners about the important role advocacy plays in our Community's success.

If you are interested in attending, SBAK can help. The National Conference Scholarship is limited to conference registration and hotel stay only. Scholarships are available for adults or children born with Spina Bifida and parents of children under eighteen born with Spina Bifida who reside in Kentucky or Southern Indiana.

Contact Erin at egillespie@sbak.org or 859-268-5798 if you have any questions or would like an application.

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Preventing pressure ulcers in teens with spina bifida

Kosair Children's Hospital, Chief of Pediatric Plastic surgery, Mark Chariker, M.D. gives tips and his recommendations for preventing pressure ulcers.

As a pediatric plastic surgeon, I treat children with spina bifida in two phases. The initial encounter is usually at birth, when a neurosurgeon repairs the neural tube and a plastic surgeon reconstructs the skin and muscle to cover the nerve repair. The second usually occurs during the teenage years, when patients who lack sensation in the lower torso and legs develop pressure ulcers.

These pressure injuries result from a variety of factors. Blood flows to the buttocks while we are sitting, but is reduced over bony prominences called pressure points. We tend to shift our weight due to pain or discomfort, which helps blood circulate to these pressure points and prevents injury to the skin, muscle and fat. However, some children can't feel pain. As these children gain weight, pressure-point injuries develop more rapidly.

Teenagers often sit on critical pressure points for extended periods, which can result in pressure ulcers. Incontinence, leading to prolonged skin moisture, can also contribute to the softening and breaking down of skin, which may be the start of an open wound or ulcer. Using advanced pressure reduction materials while sitting is key to prevention.

Tissue injuries are often hard to recognize. The initial signs are usually redness or bruising of the skin. Later, an open wound or ulcer forms, and surgical treatment and wound care are required. When a pressure wound occurs, it is essential to keep all weight off the injured area. A balanced plan that includes weight-gain management, moisture control, immobilization, weight shifting and advanced pressure relief materials can help prevent pressure ulcers.

I advise teenagers with spina bifida to adopt measures for preventing and treating pressure ulcers. These strategies include:

- **Weight management** – This is a long-term endeavor. The more you weigh, the harder it becomes to shift your weight with your arms, so strengthening your arms and shoulders may help prevent damage by allowing you to self-shift your weight.
- **Moisture control** – Moist skin is subject to injury either from pressure or shearing. A frank discussion about incontinence with a pediatric surgeon and urologist is vital to long-term ulcer prevention.
- **Pressure-relief shifting** – A critical injury can occur over a bony prominence in as little as 15 minutes of immobilization, leading to an open wound. Pressure-relief materials and the patient's weight are important factors. Patients should shift their weight every five to 10 minutes or arrange for a caregiver to assist in the process. If this is not feasible for an extended period, the patient should be placed in a face-up or face-down position. There are a number of mobile phone apps that can assist with position timing. The Bit Timer or Interval Timer are both free apps.
- **Protective pressure pillows and pads** – A good seat cover may give you an extra few minutes of sitting and prevent a complex wound. There are many advanced materials provided by rehabilitation centers, but these break down over time and can give a false sense of protection. Be sure to replace materials when they begin to show signs of wear.
- **Frequent skin inspection** – Frequent or daily inspection of pressure points on the buttocks or bottoms of the feet is a good way to prevent pressure injuries. Some patients need a mirror to examine these and other areas. If redness or bruising appears, complete pressure relief may allow the injury to recover. If you are not sure how to treat the injury, see a clinician



To find a Kosair Children's Hospital physician in any specialty call **(502) 629- KIDS.**



**KOSAIR
CHILDREN'S
HOSPITAL**
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Executive Director's Letter

Dear Friends,

Recently, at a family hospital visit, a parent of a child with spina bifida said, “WOW! I didn’t know SBAK did that!” which got me thinking. As a staff, we work so hard behind the scenes on so many things at once, that a quick refresher on exactly what SBAK does, might be a good idea!

So, here are the top 5 things SBAK does and continues to work on throughout the year:

1. SBAK answers the phone - This may seem simple, but on a daily and weekly basis, SBAK receives calls from nervous expectant moms, concerned toddler parents, social workers, case managers, adults with spina bifida and more. Each of them are looking for a shoulder to cry on, a friendly hello, a reassuring conversation or a connection to helpful resources. People from all over the region call us just to talk to someone who “gets it”. Answering the phone is one of the most important things we do every day.

2. SBAK sends 30 families to CCK Camp - Every spring, usually the last weekend in April, The Center for Courageous Kids (CCK) hosts the annual Spina Bifida Family Retreat. SBAK sponsors up to 30 families to attend this world-class camp for free, and it is absolutely amazing. At camp, for once, kids with Spina Bifida are in the majority. They can look around and see all the other children who also wear braces or use equipment—and some who don’t at all. There’s a dance party after every meal, and fun opportunities like fishing, archery, horseback riding and swimming. It is an awesome weekend filled with laughter, support and friendships.

3. Playgroups, Seminars, Webinars, Social Events, Conferences and More – SBAK offers countless ways for families, children, teens and adults to connect to each other throughout the year. From holiday parties to bowel management webinars there are so many ways to get together all across the state. We often refer to spina bifida as a snowflake condition, because it affects everyone so uniquely, and the same could be said for our programming. Sometimes there is a program in your neighborhood, while other times, you can connect online in your pjs. We try to make each program fun, interesting and worthwhile for attendees.

4. Financial Assistance Fund (FAF) – SBAK helps support families by offsetting some of the costs of equipment, travel



expenses, accessibility needs and more. In the past year alone, SBAK has helped provide zip zacs, adaptive bikes, hotel accommodations, travel expenses, wheelchairs, walkers and an accessible van. Most people don’t realize that The FAF Committee is made up of committed volunteers that are completely separate from SBAK. They remain completely unbiased in their review of applications, and spend a ton of time double checking documentation and making recommendations.

5. Big picture Initiatives – Two huge projects SBAK is working on include developing a Spina Bifida Clinic with Kosair Children’s Hospital and spreading awareness about The Delivering the Diagnosis Law. Currently, Kentucky does not have a multidisciplinary spina bifida clinic and we are trying to change that for families across the state. In a nutshell, an SB Clinic would allow our families to spend one day, all day, at one location, and have doctors (Nuero, Ortho, Uro, etc) visit them in one clinic appointment. This would allow families to consolidate testing, reduce travel times, and streamline doctor visits. In addition, we are trying to spread the word within the medical community about the Delivering the Diagnosis law to eliminate “Your child will be a vegetable” horror stories. We have partnered with other organizations across the country to find innovative and effective ways to communicate with OBGYNs and MFMs. We hope that we will change the perception of spina bifida one mailing, one email blast and one doctor at a time across Kentucky.

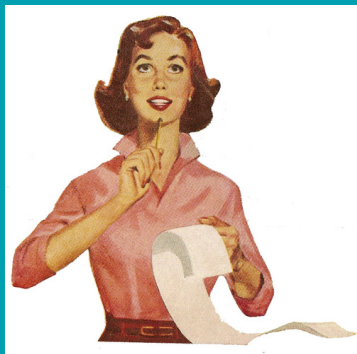
Overall, SBAK serves families affected by spina bifida. We are here when you need us – on the phone, by email, through Facebook or at an SBAK event. All of us involved want to be the best support system possible. If you need us, we are here to help!

Please let us know how we can help and hope to see your family soon,

Shannon







SB-Abby Advice Column

Dear SB-Abby,

I'm a young adult with SB and want to travel to the national Spina Bifida Association conference this summer. But I've never traveled on my own and I haven't flown in years. Any tips for a wheelchair user in the airport, or for finding accessible transportation when I get there, or anything else I should think about?

Advice...

Just need to make sure they tell the folks at the airport they need assistance. Make sure they take as much of their medical supplies as they can onto the plane with them. Also, have them take a photo of their chair before leaving it. Take clothing guards and seat cushion onto the plane too.

-Beth Bryant

Let them know when you check in, that you will need an aisle chair. *- Matt Davis*

Dear SB-Abby,

My husband and I have one child, and he has Spina Bifida. We have thought about having another child, but we are concerned about all the time a baby would take away from his needs. What are the pros and cons of growing up with Spina Bifida and having a sibling?

Advice...

It will only take a little time away for a short time, which may be a good thing as they learn they're not the only person in the world and the pros of siblings are endless-built in best friends!

-Shawna England

As an adult with SB and having an older sibling without SB, I have to say I could not imagine life without her. My parents raised us both the same (same rules, expectations, chores, etc.) a sibling becomes your first best friend and one you can almost always rely on. My older sister taught me how to fight for myself when she was being selfish, she gave me tough skin when we had those sibling rivalries but has always been there for me through break ups, surgeries, marriage and plenty of memories. *-Bethany Adams Curry*

Growing Up with Spina Bifida Guest Speaker - 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.

Peg Dawson, Ed.D., NCSP, received her doctorate in school/child clinical psychology from the University of Virginia. She worked as a school psychologist for 16 years in Maine and New Hampshire, and since 1992 has worked at the Center for Learning and Attention Disorders in Portsmouth, New Hampshire, where she specializes in the assessment of children and adults with learning and attention disorders. She has many years of organizational experience at the state, national, and international level, and served in many capacities, including

president, of the New Hampshire Association of School Psychologists, the National Association of School Psychologists, and the International School Psychology Association.

SAVE the DATE

4 Walk-N-Roll's!

October 1st, 2016

Louisville WNR
Iroquois Park

Lexington WNR
Shriners Hospital for
Children

Paducah WNR
Noble Park

October 8th, 2016

Whitesburg WNR
River Park



New Arrivals

Justine and Andy welcomed
Charles on 2/1/2016

Free Service Dogs for the Louisville Area

Paws with Purpose trains and places assistance dogs for adults and children with physical disabilities within a 35 mile radius of the Louisville Metro area. It takes at least two years to train a dog and on completion of training they are valued at \$20,000, yet Paws with Purpose does not charge the recipient for the dog. These dogs help with retrieving items, opening and closing doors and drawers. They can assist with taking off shoes and socks and do other tasks that would be difficult or impossible for someone with a mobility disability. For more information please visit our



website www.pawswithpurpose.org, email info@pawswithpurpose.org or call 502689-0804.



The 5th Annual Bluegrass Beard On in fantastic Richmond Kentucky, hosted by Beard & Loathing KY to benefit Spina Bifida Association of Kentucky.

Location: Paddy Wagon Irish Pub,
Richmond KY

Registration 4:00 to 6:00

Competition Begins at 6:30

For more information search for the
Bluegrass Beard-On on Facebook or go to
beardandloathing.org



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sbak.org or call
1-502-637-7363.**

May	
May 5	Oaks Eve Gala Louisville
May 14	Growing Up with SB Louisville
May 21	Play Pals Louisville
May 22	Play Pals Lexington
June	
June 2	Transition Webinar
June 11	Giving Back Group Lexington
June 18	Beard On Richmond
June 25-28	National Conference Bloomington, MN

