



SPINA BIFIDA ASSOCIATION  
OF KENTUCKY

May/June 2017



**In the Heart of the Bluegrass...**

## **2017 SBAK Regional Conference**

**June 23 - 25 / Clarion Hotel / Lexington, Kentucky**

# **SBAK REGIONAL CONFERENCE**

**JUNE 23 - 24, 2017**

### **COME LEARN ABOUT:**

- Bowel Management
- Spina Bifida World Congress
- Transition
- Adaptive Sports
- and more!

### **FEATURING:**

- Learning track for adults with SB
- Learning track for parents of children with SB
- Kids Camp for children newborn to 18, siblings welcome!

### **EVEN MORE FUN!**

Meet and Greet Opening Reception!

Friday, June 23rd

Saturday Night Social - Staycation!

Saturday, June 24th

**Register Today at [sbak.org](http://sbak.org) or call (502) 637-7363**

- Registration: \$50 for adults, \$30 for children. Registration covers the cost of breakfast and lunch Saturday and breakfast Sunday.
- For hotel reservation at a discounted \$99/night, call 859-233-0512.
- Financial Assistance is available on a first come, first serve basis. Please contact Mary Beth at [mlong@sbak.org](mailto:mlong@sbak.org) or 859-268-5798.

### **THIS ISSUE**

Meet the Doc pg. 2

Executive Director's Letter pg. 3

Easter Pictures pg. 4 & 5

SB - Abby pg. 6

Louisville Adaptive Rowing pg. 7

Upcoming Programs pg. 8

### **SBAK Staff**

*Executive Director*

Erin Gillespie

*Program Coordinator - Lexington*

Mary Beth Long

*Program Coordinator - Louisville*

Sarah Richardson

*Accountant*

Amy Muth

**Contact Us:**

[sbak@sbak.org](mailto:sbak@sbak.org)

Louisville: 502-637-7363

Lexington: 859-268-5798

# Meet the doc: Dennis Peppas, M.D.

In his own words, Dennis Peppas, M.D., pediatric urologist, Norton Children's Urology, started in health care to get back at his pediatrician and it turned into a passion that took him around the country. Dr. Peppas joined the Army and learned many of the skills he uses today. We asked him a little bit about the path that led him to Louisville and Norton Children's.

## **Why did you become a doctor?**

My first recollection to become a physician was early in my life. It was for the most notable of reasons and that was to get back at the pediatrician who was giving me shots. As I got older I became fascinated with how the human body works. I loved children and thought that I wanted to be a pediatrician. Once I got into college, I realized that being a physician was more than just caring for people and that I wanted to be a part of that.

## **You served in the Army for more than 25 years. How did you go down that path in life?**

I was in the Army from July 1979 until October 2004. I originally joined the military as a way of receiving my medical education without incurring a huge debt. In return for my four years of medical school, my military commitment was seven years. I was able to do my residency in the Army and my fellowship in pediatric urology at the Johns Hopkins Hospital. In 1999, I was the chief of urology at Walter Reed Army Medical Center. At that point, I made the decision to remain until I became a colonel and retire in that grade. What I carried on from my time in the military is the fact that a team can accomplish far more than any individual. I also gained the confidence in myself to begin and build two separate practices in pediatric urology; first in San Antonio, Texas, and the other here in Louisville.

## **Do you have a motto for caring?**

Treat every patient as if they were your family member. By remembering this, we can never go wrong in the care of our patients. In addition, by using humor, I can help make a frightened child often not as scared.

## **Why did you decide to specialize in urology?**

Pediatric urology is the perfect balance of pediatrics and surgery. There is no other specialty that I am aware of where you can care for patients over a prolonged period of time with nonsurgical issues, and at other times take care of children to correct their birth defects.

## **If you weren't a doctor, what would you be?**

If I was not a physician I would either be a teacher or a restaurant owner. I really enjoy the interaction with children in their process of learning. My father was a chef and passed on some of his recipes and cooking secrets to me.

## **Who are your heroes?**

My father came to America with only a fourth-grade education and taught himself to cook and to learn English. He left the house every day at 9 a.m. and returned home around 11 p.m. He had only one day off per week and that was Sunday. I watched and modeled my work ethic from him.

Gen. George S. Patton Jr. is a hero of mine. He was a straightforward soldier who said what he meant and meant what he said. He also believed that there was only one direction to go in life and that was straight ahead.

Lastly, John Wayne was of a hero of mine. As an actor, he played so many roles, almost always of a strong-willed person. He was gentle when he needed to be, comedic when he needed to be and tough when he needed to be.

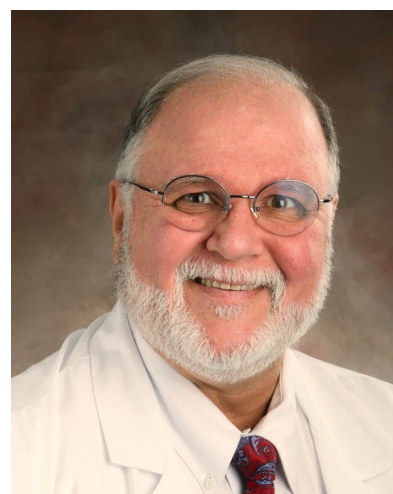
## **What is the most challenging part of your job?**

The most challenging part of my job is also one of my most satisfying parts of my job, which is building a sustainable pediatric urology practice for Louisville and the surrounding areas. We started this practice with two providers and by the beginning of June 2017, we will have two additional nurse practitioners. We are in the process of trying to find a third physician to join us next summer. This is an exciting time for pediatric urology and for Norton Healthcare.

## **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](http://NortonChildrens.com/Urologists) or call (502) 629-KIDS.



**NORTON**  
**Children's**  
Hospital

## Executive Director's Letter

Dear friends,

SBAK has been busy with a few transitions and gearing up for the 2017 Regional Conference!

I am excited to announce two new staff members have joined the SBAK team! Sarah Richardson and Mary Beth Long. Both have been active members of SBAK and are parent's of children with Spina Bifida. Since April, they have hit the ground running with playgroups, prevention and awareness projects and meeting new families at Shriners and the Spina Bifida Clinic at Norton Children's Hospital. We are very lucky to have them part of the team!

SBAK is hosting our Regional Conference June 23rd-25th in Lexington, KY. It is our first conference in this area, and we are eager to welcome new and familiar families. Conference is an amazing opportunity to learn about new and inventive healthcare, recreation, community resources and much more! If you haven't yet, register at [sbak.org](http://sbak.org) and join us for a weekend of education and FUN!

Cheers!

Erin Gillespie



Hello SBAK families and friends!

My name is Sarah Richardson, I am the new Program Coordinator for the Louisville and Western Kentucky region. I live in Shelbyville Kentucky with my husband, Shawn and our three little girls; Olivia (5), Avery (2), and Emery (5 months).

I attended the University of Kentucky and received my Bachelor of Arts degree with a focus in creative writing. The only creative writing I get to do these days are posts on Social Media about my kids. This requires little creativity. My kids do all the work and I just share their hilarity with the world. Avery was born in December of 2014 with Spina Bifida. I embraced my new life as a special needs mom and advocate. I planned all my vacation time at work around SBAK events and when people asked, "How do you do it?" I had no good answers. I'm just living life. The position as Program Coordinator allows me to support and learn from other families like my own. After all, this is our life. - Sarah Richardson

Hi my name is Mary Beth Long, Program Coordinator for the Lexington and Eastern Kentucky areas. Currently I am on the move, quite literally from Nicholasville to soon Georgetown, Kentucky. I am joined in this journey by my most awesome husband Brian. We have two girls, Kaitlyn (19) and Abbie (9), as well as our sweet niece from Texas, Ashley (17), who will be joining us in the fall.

I attended the University of Kentucky, focusing on Elementary Education and Special Education. Abbie was born with Spina Bifida L5 to S1. I can tell you that I have been exactly where most of you have been. Though some of my experiences may have been different than yours, I have cried in anger, sadness and joy.

My hobbies include spending time with family friends, crafting, reading, shopping and couponing. My passion, is what I am doing when I am planning programs for SBAK. I am here to help, listen, talk, and build you up. Let's join in together and make our community, state, and world more aware about Spina Bifida! - Mary Beth Long







# 2017 Easter Egg Hunts









## Save the Dates!

Louisville

October 14th

Lexington

October 14th

Paducah

October 21st

Hazard

October 21st

**Start your  
team TODAY!  
sbakwalk.org**



## SB-Abby Advice Column

Dear SB-Abby,  
At what age did your kids go to their IEP meetings?

### Advice...

Makayla started going in the 3rd grade...it was just for a few minutes to start with, asking her what she was comfortable with, now at age 12, she sits through the whole meeting and I do very little. She answers all the questions and tells them if something isn't working! I love how independent she is becoming! That's what I wanted for her! - *Melissa Mullins*

I went to an IEP advocacy class a couple of weeks ago and they said age 16. One of the other parents suggested that they come in towards the end of the meeting to make sure the kids understand and have some input. - *Mary Beth Long*

Nate started participating in meetings in 4th grade in a very limited role--we just prepared something for him to read at the meeting about what he likes about school, what is hard for him, any concerns he had about the next year, and what he wanted to be when he grew up.

We are actually going to talk about how to include kids in their IEP meetings at our next Growing Up With Spina Bifida program, which will be at the SBAK regional conference on June 25. - *Colleen Payne*



**SBAK Golf Scramble**

Spina Bifida Association of KY

Fore...for good!

## SAVE THE DATE!

**SBAK GOLF SCRAMBLE**

**PERSIMMON RIDGE, LOUISVILLE KY**

**SEPTEMBER 11TH, 2017**

# LOUISVILLE ADAPTIVE ROWING (LAR)

Louisville Adaptive Rowing (LAR) offers competitive and recreational adaptive rowing opportunities on and off the water for people with disabilities. LAR's Winter Indoor Rowing Program allows adaptive athletes to receive a great cardio row workout while "erging" on an indoor rowing machine. Coach Bob will teach you the basic rowing technique during your indoor workout. You will become prepared to row in a boat "skull" when the Outdoor Rowing Program begins.

For wheelchair users, a modified fixed seat is attached to the rowing machine. This fixed seat can also be used in the boats, while rowing in the skulls. A transfer box is provided for those who need additional assistance transferring from the wheelchair to the skull. The traditional slide seat is available for non wheel chair users.

LAR encourages non-wheelchair users to become Partner Rowers. The Partner Rowers will be trained to row with an adaptive rower. Adaptive Rowers and Partner Rowers can choose to row for recreation or competitively. Partner Rowers will be allowed to row with their adaptive rower at regattas (rowing competitions)!

## **LAR's Winter Indoor Rowing Program**

When: November to April

## **LAR's Summer Outdoor Rowing Program**

When: May to October

**Cost:** \$100/year for Adaptive Rowers

\$25/year for Partner Rowers without a disability

**Age:** Youth and Adults (7 and up), along with family and friends.

**Where:** Louisville Community Boathouse located at 1325 River Road, Louisville, KY 40206

(Waterfront Park-Yellow Parking Lot on River Road-Next to the UofL Boathouse)

For more information contact:

Louisville Adaptive Rowing Club

Randy Mills, Program Director

Phone: 502-419-0033

Email: Randy.mills0033@yahoo.com

Website: <http://www.louisvillerowingclub.org/adaptive.html>



## **Have you moved or changed your email address?**

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



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

## Upcoming Events and Programs

### June

#### June 23rd -25th

SBAK CONFERENCE

Location: Clarion Hotel,  
Lexington KY

#### June 25th

GROWING UP WITH SB

Location: Clarion Hotel,  
Lexington KY

Time: 10:30am - 11:45pm

### July

#### July 23rd

LEX/ LOU SUMMER PICNIC

Location: Juniper Hills Aquatic Center,  
Frankfort

Time: 1pm - 3pm

#### July 23rd

OWENSBORO SUMMER PICNIC

Location: Smothers Park

Time: 12pm- 2pm

#### July 30th

EASTERN KY SUMMER PICNIC

Location: Jenkins Public Pool

Time: TBD

