



**SPINA BIFIDA ASSOCIATION  
OF INDIANA**

# *SBAIN Newsletter*

## **SBAIN IN TOUCH**

**Spring 2014**

### **TABLE OF CONTENTS**

<b>LETTER FROM THE EXECUTIVE DIRECTOR</b>	Page 1
<b>PICNIC</b>	Page 2
<b>WALK N ROLL</b>	Page 3
<b>QUALITY OF LIFE STUDY</b>	Page 4
<b>NATIONAL CONFERENCE</b>	Page 5
<b>WINE AT THE LINE</b>	Page 6
<b>CALENDAR OF EVENTS SBAIN CONTACT INFORMATION SBAIN MISSION STATEMENT</b>	Page 7

SBAIN OFFERS PARENT PLAY GROUPS IN VARIOUS AREAS OF THE STATE. THIS TIME ALLOWS CHILDREN TO PRACTICE SOCIALIZATION AND LEARN FROM EACH OTHER. WHILE THE CHILDREN PLAY, PARENTS ARE DEEP IN DISCUSSION ABOUT ISSUES THEY ARE FACING, SHARING INFORMATION AND ADVICE, LEARNING FROM EACH OTHER, AND INSPIRING ONE ANOTHER. SIBLINGS ARE ALSO INVITED TO JOIN THE GROUPS.

SBAIN'S WOULD LIKE TO PROVIDE VOLUNTEERS STATEWIDE TO ORGANIZE AGE-APPROPRIATE PLAY GROUPS FOR CHILDREN WITH SPINA BIFIDA, THEIR SIBLINGS AND FAMILIES. PLEASE EMAIL SHALON @ [SHALON.SBAIN@GMAIL.COM](mailto:SHALON.SBAIN@GMAIL.COM) IF INTERESTED IN VOLUNTEERING OR FORMING A GROUP IN YOUR AREA.

Sincerely,  
  
Shalon Perez,  
Executive Director



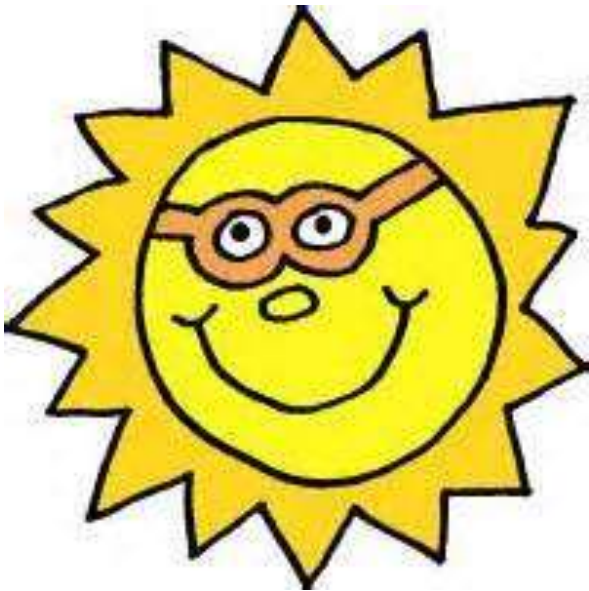
**1**

### **SBAIN Board of Directors**

<b>Chair</b>	Joyce Jones
<b>Secretary</b>	Heather Zetzl
<b>Treasurer</b>	Cynthia Bogan
<b>Membership/ Outreach</b>	Rachel Stotts
<b>Members at large</b>	Kerstin Sobus Lori Lowe Angie Eugenio Hope Wooldridge Bobbie Rowland

### **Executive Director**

Shalon Perez



## **MARK YOUR CALENDARS FOR THE SBAIN PICNIC**

**WASHINGTON TOWNSHIP PARK  
AVON INDIANA  
CARDINAL SHELTER**

**SATURDAY AUGUST 9TH  
TIME: 11:00 AM**

The physical location of the Park is 115 South Co Rd 575 East, Avon, Indiana 46123.

For those GPS users, the coordinates of the Pavilion Center are 39°45'09.78"N 86°25'09.02"W.

***THIS PARK HAS A HANDICAP ACCESSIBLE SPLASH PAD SO PLEASE BRING BATHING SUIT,  
TOWELS, AND SUNSCREEN IN ADDITION TO:***

**Chairs and/or blankets to sit on**

**A side dish to share**

**If your last name begins with:**

**A thru M: bring a salad/vegetable**

**N –Z bring a dessert to share.**



**SBAIN WILL PROVIDE CHICKEN AS WELL AS FUN & GAMES**

Please RSVP by to [shalon.sbain@gmail.com](mailto:shalon.sbain@gmail.com) or 765.490.6979 so we can plan appropriately.

In case of questionable weather, check our web site – [www.sbain.org](http://www.sbain.org) for weather update or call

Shalon at 765.490.6979

**The 2014 Walk-N-Roll is gearing up!  
New Location in 2014!**

**Register for a team, start a team or support a team  
now! Visit [www.sbain.org](http://www.sbain.org)**

**Saturday September 27, 2014**

**Zionsville Lions Park**

Join us for the Third Annual Walk-N-Roll for SBAIN  
on a NEW date at a NEW location!

**[REGISTER NOW](#)**

It's a New Day & Location! Plan to  
join us for the fun!

The Walk is still the same! A  
morning of fun, family,  
friends, festivities, food and a mile-  
long, wheelchair accessible, family-  
friendly walk all dedicated to  
raising funds for programs and  
services to benefit those living with  
Spina Bifida.



# Will my child's life be better after this surgery? Quality of life in children with Spina Bifida.

Konrad M. Szymanski, MD MPH, Rosalia Misseri, MD, Benjamin Whittam, MD, Shelly King, RN CPNP, Katherine C. Hubert, MD MPH, Martin Kaefer, MD, Richard C. Rink, MD, Mark P. Cain, MD  
*Division of Pediatric Urology, Riley Hospital for Children at IU Health, Indianapolis, IN*

Doctors have a perception of what might make children and families happy. But our real desire is to find out how happy children and families really are. We would like to investigate children's feelings further, to see if the care and surgeries we provide are enhancing their quality of life. In order to properly assess a person's quality of life, special questionnaires are necessary. Asking: "Are you feeling better or happier?" is just not enough. Questions for patients need to be understood and answered by the patients and families. The questions need to focus specifically on what is important to the patients. But, this process takes time... and help from patients and their families.



The Division of Pediatric Urology at Riley Hospital for Children has developed a questionnaire for children, teens, and adults with Spina Bifida to allow us to measure the quality of life of our patients. This questionnaire will help us understand if patients are doing better in certain areas of their life, or struggling in others. We want to improve the quality of life of our patients. You can help!

We are looking for children 8 years old or older, teens and adults with Spina Bifida. Ultimately, we hope this will help others with Spina Bifida. Helping with this important project would require people with Spina Bifida and their parents or caregivers to complete a 20-minute online questionnaire on a secure website. We do not keep patient information and all information is anonymous. We will ask for a few general medical details, as well as questions about how the child, teen or adult with Spina Bifida feels.



**If you are interested in  
participating in this project,  
please go to:**

**[www.surveymonkey.com/s/QSB](http://www.surveymonkey.com/s/QSB)**

**to fill out the questionnaire.**





Discover the Magic!

June 29th - July 2nd  
Disneyland Hotel, Anaheim, CA

The 40th National Conference is being held at the *Disneyland*® Hotel (Anaheim, California). This magical place is steeped in history and full of modern luxuries — located steps away from the parks and accessible via the world-famous monorail.

## There is still time to register!

Please join the Spina Bifida Association (SBA) for the **40th National Conference to be held at the *Disneyland*® Hotel (Anaheim, California)**. Children and adults with Spina Bifida, their families, physicians, nurses, and other clinicians have the unique opportunity to gain information on the latest medical care and network on various issues which affect their lives and professions.

- Learn up-to-the-minute information about urology, orthopedics, neurology, neurosurgery treatment, and much more!
- Attend practical workshops and special programming that address your own interest areas.
- Network with various interest 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.**

**Register today at <http://www.spinabifidaconference.org/>**

Find out why the SBA National Conference has earned its place as the world's premier educational event for the Spina Bifida Community.

## **Mallow Run Winery Presents the 5th Annual Benefitting SBAIN**



### **A 5 mile Run & 5K Run/Walk**

Saturday, October 4th, 2014  
@ 4pm

2 Course Options: 5 Mile Run & 5K Run/Walk  
Courses will start and end at Mallow Run Winery

Run through the scenic (and sometimes hilly!) countryside and past Mallow Run vineyards

## **Registration opens June 1, 2014!**

### **Registration Includes:**

- chip timing for both events
- long-sleeved race t-shirt
- Wine at the Line commemorative wine glass
- food and drink to replenish your hungry body
- post-race celebration with wine tasting, food and musical entertainment

**Come for the run, stay for the fun!**

**August 9**  
**September 27**  
**October 4**  
**December 7**

Picnic  
Walk N Roll  
Wine at the Line 5K Run/Walk  
Holiday Party

Washington Township Park, Avon  
Lions Park, Zionsville  
Mallow Run Winery, Bargersville  
St. Andrew Presbyterian, Indianapolis

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**SPINA BIFIDA ASSOCIATION  
OF INDIANA**

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**317-592-1630**  
[www.sbain.org](http://www.sbain.org)

**E-mail: [shalon.sbain@gmail.com](mailto:shalon.sbain@gmail.com)**

**Shalon Perez**

Our Mission is *To promote the prevention of Spina Bifida and to enhance the lives of all affected.*

Information

- Newsletter
- Web site
- Chapter Meetings

Education

- Visiting Speakers

Support

- Medical assistance/equipment fund
- Camp scholarship
- Conference scholarship
- Members

Recreation

- Holiday parties
- Social meetings

Advocacy

- Work with SBA