



SPINA BIFIDA ASSOCIATION
OF INDIANA

SBAIN Newsletter

SBAIN IN TOUCH

May 2012

LETTER FROM THE BOARD PRESIDENT

By Pat Wyman

What a spring we have had here at the Spina Bifida Association of Indiana. In all of my years involved with the chapter, I don't think we have ever been this busy.

As most of you know, we now have a new part time Executive Director. Her name is Shalon Perez and she is working 20 hours a week as a paid staff member. Please feel free to contact her if you have anything you want to talk about related to our chapter. Her e-mail is shalon.sbain@gmail.com. Please welcome her at any of our events.

Our new website is UP and RUNNING. It is www.sbain.org. It has been a long time in coming but we finally accomplished this. Feedback would be welcome.

You all know that the Walk-N-Roll is coming up May 12. Please see the article on it in this newsletter (page 2). We expect to see all of you that morning rain or shine with your walking shoes on. Ok...wheelchairs also. Our goal is \$30,000 so please help us meet that goal. All of us benefit by the success of this event. Also, please thank the three main chairs of this event when you see them on May 12. They are Lori Antony, Bobbie Rowland, and Joyce Jones. All three of them and their committees have spent many, many hours on the Walk and each of us needs to thank them for all their efforts in supporting our chapter. **Kudos to Lori, Bobbie, and Joyce.**

Every year the National Spina Bifida Association holds a conference for all of the Spina Bifida community throughout the United States. This year we are so lucky! It will be here in Indianapolis June 28-July 1. The last one that was held in Indianapolis was in 1994. This is a fantastic opportunity for us to learn, network, and share with others from the Spina Bifida world. We do need volunteers to help with the conference. If you help at least one day, you will receive a discount on your registration fee. Please contact Shalon if you are interested.

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SBAIN Board of Directors

President	Pat Wyman
Ex. Director	Shalon Perez
Secretary	Heather Zetzel
Treasurer	Cynthia Bogan
Membership/ Outreach	Rachel Stotts
Newsletter	Elizabeth Gregory
Member at large	Lisa Jones Lori Lowe Angie Eugenio
Website Administrator	Jim Zetzel Lori Antony



**Still time to register for the 1st Annual Indiana
Walk-N-Roll
Saturday, May 12, 2012, Fort Harrison State Park**

Registration begins at 9:30 a.m.
Walk begins at 10:30 a.m.
Fun & Festivities all morning!

The Walk-N-Roll for Spina Bifida is a family-friendly, 1-mile walk event being held to raise money for and awareness about Spina Bifida and celebrate the accomplishments of the over 166,000 Americans living with it. All proceeds are used for programs and services for people living with [Spina Bifida](#) in Indiana.

The Walk-N-Roll is being held in over 16 [locations](#) across the country. Proceeds from the Indiana Walk-N-Roll benefit the SBAIN, the sole voluntary health agency working to improve the lives of people living with Spina Bifida and promoting the prevention of it in future generations in Indiana.

The name "WALK-N-ROLL" was selected because it embodies a sense of inclusiveness and invokes the sense of empowerment which the Spina Bifida Community embraces in all that it does. A belief in a better tomorrow is our vision and the steps taken in this walk represent steps on a path to realizing that dream.

Your support for this cause means the world to the over 166,000 Americans living each day with the complications of this birth defect. With the funds you help raise, the Spina Bifida Association of Indiana can deliver valuable programs and services to help make better tomorrows for people with Spina Bifida TODAY. Walk-N-Roll comments or questions can be sent to SBAINWalkNRoll@gmail.com

Letter from the Board President
By Pat Wyman
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We have a new member on our Board who just joined in April. Her name is Angie Eugenio and she is a physical therapist. She brings a wealth of experience to our board and we look forward to her involvement in the chapter.

Finally, I invite each one of you to become active in our organization. You tell us what you would like to do and we will try to make it happen. We welcome your ideas! Our chapter is made up of all of you. Please help us meet your needs and continue to make 2012 the best year ever for our Spina Bifida families.

National Spina Bifida Conference **June 28-July 1 in Indianapolis**

This year's National Conference will feature findings from the Second World Congress on Spina Bifida Research and Care, SBA's international meeting of Spina Bifida health care providers and researchers that concluded in March 2012. Be the first to hear about the latest in care treatment and what is on the horizon for this challenging condition!

Attend educational sessions covering the latest information on Spina Bifida health care approaches including bladder management, weight management, adult-specific health concerns, independence, tethered cord, and accessibility. Kids can enjoy the only national camp designed for children with Spina Bifida and their siblings. Adults with Spina Bifida can participate in an "adult-only" day dedicated to issues challenging this population. During the day, attendees can visit exhibitors' booths filled with the latest products and innovations

designed to ease the challenges of life with Spina Bifida.

These are just some of the many reasons the 39th National Conference is a "can't miss." Scheduled from June 28 to July 1 in Indianapolis, Indiana, the Conference is an unforgettable experience of learning, sharing, and fun. Each year, the locale, sessions, theme, and even the attendees may vary, but the Conference always retains certain essential qualities: friendliness, discovery, warmth, knowledge, and most of all, support.

For more information or to register for the 39th National Conference, please visit www.spinabifidaconference.org. If you are interested in volunteering for the conference please contact Shalon Perez at shalon.sbain@gmail.com or 765-490-6979.

Center for Courageous Kids 2012 Summer Camp

The Center for Courageous Kids in the rolling hills of Scottsville, Kentucky has extended an offer for children in Indiana to attend the Physical Disabilities Summer Camp July 3-7. This is an independent summer camp for children ages 7-15. Activities such as swimming, fishing, bowling, woodshop, boating, horses, basketball, cooking, arts and crafts and much more are featured.

For more information contact the Office of Camper Recruiting at 270-618-2912 or apply at www.courageouskids.org

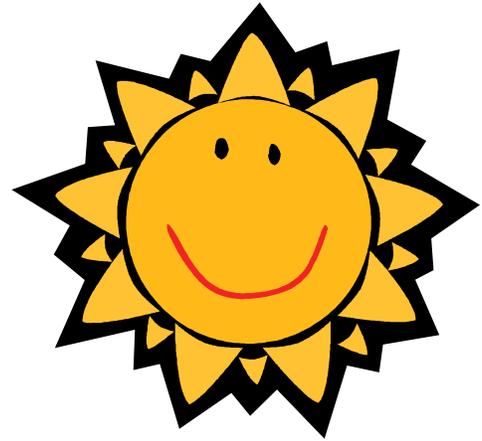


2012 Camp Riley Dates

Camp Riley applications for 2012 for the five different summer sessions are now available! Every summer, children ages 8-18, prove to themselves and others that their strength and will power define them—not their physical circumstances.

The theme this year is **Mysteries of the Woods**. By day, experience traditional camp activities such as swimming and waterfront fun, creative arts, adventure challenge, music, sports, camping, and horseback riding. By night, explore camp and help solve the latest mystery of the woods!

To receive application information, please visit the Camp Riley website at www.rileykids.org/about/camp_riley/ or for questions please call 877.867.4539 (toll-free) or email campriley@rileykids.org



Caring for your Skin

People with Spina Bifida can develop sores, calluses, blisters, and burns on their feet, ankles, and hips. However, they might not know when these develop because they might not be able to feel certain parts of their body.

Ways to help protect the skin:

- Check the skin regularly for redness, including under braces.
- Try to avoid hot bath water, hot irons and hot or unpadded seatbelt clasps that may cause burns.
- Make sure to wear properly fitting shoes at all times.
- Use sunscreen and don't stay out in the sun too long.
- Do not sit or lie in one position for too long.

Taken from the Centers for Disease Control and Prevention

Calendar of Events

MAY

May 12

First Annual SBAIN Walk-n-Roll

Fort Harrison Park, Indianapolis

SUMMER

June 28– July 1

39th Annual Spina Bifida National Conference Indianapolis

Come Join Us!

We are now recruiting new members across the state and beyond! I would like to extend an invitation to you and any friends or family members who may wish to join the organization.

SBAIN has been in existence for over 40 years and there have been many changes to the lives of people affected by Spina Bifida since its inception in 1971. Our core foundations have remained solid as we continue to make a difference in the lives of people daily.

If you have any questions or require additional information, please do not hesitate to contact me at shalon.sbain@gmail.com or 765-490-6979. I look forward to welcoming you as a member.

Yours sincerely,
Shalon Perez, Exec. Director

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Pat Wyman
Shalon Perez
Heather Zetzl
Cynthia Bogan
Rachel Stotts
Lisa Jones
Lori Lowe
Angie Eugenio

Our Mission is "To promote the prevention of spina bifida and to support the needs of all people affected by spina bifida." To fulfill this mission, SBAIN provides information, education, support, recreation, and advocacy through the following services:

- Information
 - Newsletter
 - Web site
 - Chapter Meetings
- Education
 - Visiting Speakers
- Support
 - Medical assistance/equipment fund
 - Camp scholarship
 - Conference scholarship
 - Members
- Recreation
 - Holiday parties and social meetings
 - Play groups
- Advocacy
 - Work with SBA