



**SPINA BIFIDA ASSOCIATION
OF INDIANA**

SBAIN Newsletter

SBAIN IN TOUCH

Summer 2013

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Not even the early morning temperature of 44 degrees and overcast sky could keep 700+ family & friends from coming out to spend a cold morning at Fort Harrison State Park playing games, dancing, decorating mini-horses, and Walking-N-Rolling for the 2nd Annual walk benefitting SBAIN. Together we raised almost \$59,000. Thank you for a fantastic event and to all the people who drove from near and far, we are grateful for each and every one of you!

Many thanks to our sponsors: Coloplast, 180 Medical, Capital Analysts of the Midwest, Soul Hitz Entertainment, Occasions Photography, Kellogg's, Index Traub, Walgreen's, Hollister, ABC Medical, Woodfield Printing, 3R Products and Services, and Allisonville Animal Hospital. Thanks to our many volunteers who helped things run smoothly on Saturday! We couldn't have done it without you!

A link to the video and pictures is available on our website at www.sbain.org or our photographer, Chriss Payton, has photos available at <http://www.occasionsphotography.net/p405204278>

SBAIN Board of Directors

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Executive Director

Shalon Perez

Shalon Perez,
Executive Director



4th Annual Who Knows Why Golf Outing

SBAIN would like to specially thank the VanGordon Family, Andrew, Michelle, Olivia, and Ean. For the past four years, the VanGordon's have put together a fundraiser in order to support two organizations that are near and dear to their hearts. Their son Ean has Spina Bifida and one of the goals of the golf outing is to raise awareness about SB as well help fund various scholarships that SBAIN distributes to families in the form of camp, medical expenses, college, or conference expenses.

Their daughter Olivia is passionate about two things outside of school; her brother and soccer. Proceeds of the outing also assist St. Francis Lady Storm soccer families with scholarships and needed equipment. On Wednesday, June 19th the outing was held at Morningstar Golf Club and raised a record total of more than \$8,000 to be shared equally between the two organizations. Thank you again to the VanGordon's as well as all the sponsors and volunteers to bring this event together!



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



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 is currently developing 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 telephone interview or a 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 our project, please contact us at: sjking@iupui.edu. We look forward to hearing from you.

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

New Camp Riley Mentor Program

Camp Riley has developed a new program for their Venture campers called “Beyond the Woods” that will launch this summer. This program will allow the campers to take what they learn at camp “beyond the woods”, back with them into their communities. They are hoping to equip campers with a mentor and with self-determination, allowing them to dream about what their future might look like.

They have about 40 Venture campers, these are the campers they are focusing on for the “Beyond the Woods” program. Their goal is to offer a 1-on-1 mentoring program. They have campers that come from all across the state. Anyone that is interested in serving as a mentor please email Shalon at shalon.sbain@gmail.com



Why become a mentor?

Mentors will play a positive role in providing the support campers need when they return home and need to deal with school, peers, family issues and decisions about college, training and employment. Having a mentor who has personal experience dealing with a physical disability has the potential to make an important difference in these young people’s lives and futures.

What are a mentor’s responsibilities?

We ask that all mentors make a commitment to do the following:

- Make a minimum of a one-year commitment
- Communicate with camper by phone or e-mail at least twice a month
- Provide ongoing support and encouragement
- Be a resource
- Check-in monthly with Riley Children’s Foundation Events/Camp Manager
- Make an effort to meet face-to-face with camper at least once a year at an event held at Bradford Woods
- Read Franklin Covey’s *The 7 Habits of Highly Effective Teens* (provided by RileyChildren’s Foundation)

What are the qualifications to be a mentor?

To be a mentor it is necessary to:

- Be over 21
- Be employed or a student
- Have personal experience dealing with a physical disability

How can I apply to be a mentor?

- Complete application and questionnaire attached to this flyer
- Provide two written personal references
- Pass criminal background check
- Participate in a phone interview

What Camp Riley Means to Brenna

By Lori Delaney, Brenna's mother

Camp Riley has been such a positive opportunity for Brenna. Brenna is 17 years old and has Spina Bifida. She has been attending Camp since she was 8 years old and has been attending the 2 week camp since 14. Every year camp time comes around Brenna is a little apprehensive leaving the comforts of her home (family, friends, cell phone, facebook and her diet coke) but always returns from camp with a smile on her face and stories to share.

Camp gives her the opportunities to do things she would not normally get to do at home. She has been able to swim, ride horses, 4 wheel, pontoon, cardiac hill, water ski and attend the formal dance. Not only does she get to do many awesome things she gets to meet many awesome people too. These awesome people are those folks who volunteer their time to spend the summer with these special kids to make their dreams a reality. She has gained many friends over the years she has attended camp. It saddens me to realize that next summer (2014) will be her last year to attend camp unless she can somehow attend by helping at camp.

Camp gives Brenna the opportunity to come back and share stories with her family and friends. I know when she comes home we always look forward to hear about what she has done and who she has met. We look forward to looking at the pictures each day when they post them on the web site. Camp gives Brenna the chance to feel like she doesn't have a handicap. If it gives her even a moment of happiness to shine and not worry about her handicap it is worth a million bucks to me.

The ironic coincidence is that when my middle sister was in College she spent a summer working at Camp Riley. This was many years before knowing we would have a special little girl in our lives that would benefit from this opportunity to spend a summer at camp as one of the participants.

Brenna is a special young lady who doesn't ask for much and appreciates all that she has. So each year it is my priority to make sure she gets to camp. Our thanks go out to the Spina Bifida Association who lends some financial assistance to make this priority a reality. In all of the years that Brenna has attended Camp we have never had one negative experience. I can't enough positive things about Camp and do the program and those who run it justice.



Brenna age 17

A special thank you to Corvette Indy who made a donation to SBAIN for two children to experience the amazing opportunities that Brenna has enjoyed all these years at Camp Riley!





**MARK YOUR CALENDARS
FOR THE SBAIN PICNIC**

**SATURDAY AUGUST 24TH
Time: 11:00 - ?**

INDEPENDENCE PARK REMC SHELTER

(2450 South Morgantown Road, Greenwood)

THIS BEAUTIFUL PARK HAS ACCESSIBLE PLAYGROUND EQUIPMENT.

DIRECTIONS:

From I-465: Take I-465 to south side of town and exit on S.R. 37 South. Turn off exit heading south. Follow S.R. 37 South to Smith Valley Road. (Indy RV on Right and Speedway Gas Station on Left) Turn left on Smith Valley Road. Follow to first stop light at Morgantown Road. Turn right (south) on Morgantown. Follow Morgantown approximately 1 ½ to 2 miles. You will pass Walnut Grove Golf Course on the left. Park is on the Right after golf course. If you get to Center Grove High School, you have gone too far.

What to Bring:

Chairs and/or blankets to sit on

Your own drinks/coolers and side dishes.

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 August 9th to 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 for weather update or call

Shalon at 765.490.6979

Congratulations and Good Luck to Dr. Brei on your new opportunity, Indiana will certainly miss you. Another Congratulations to Dr. Turner on your retirement. We appreciate your years of service to the Spina Bifida community.



Save the Date



More information to come on the come on the Spina Bifida Association of Indiana's 1st Annual Ride N Roll for the Ribbon Motorcycle Run to be held on Saturday September 21st The ride will begin at Mann's Harley Davidson in Columbus and continue through Morgantown, Bloomington, and end at House of Thunder in Nashville Indiana. If you are interested in participating, volunteering, or sponsorship please email Shalon at shalon.sbain@gmail.com or call 765.490.6979.

Special Thanks to our wonderful sponsor:

Making Life Easier for People with Intimate Healthcare Needs

Learn more at <http://www.us.coloplast.com/>



P.O Box 19184
Indianapolis, IN 46219-0814
317-592-1630
www.sbain.org

E-mail: 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