



SPINA BIFIDA ASSOCIATION
OF CENTRAL INDIANA

SBAIN Newsletter

SBAIN IN TOUCH

January 2012

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LETTER FROM THE BOARD PRESIDENT WELCOME TO THE YEAR 2012! By Pat Wyman

I hope all of you will have a healthy and prosperous 2012.

I have so much to share with you about our chapter. We truly cover the state of Indiana so we want to try to get everyone involved from all over the state to become active members. We want to serve all of your needs. Please make your needs known to the board.

Starting the week of January 16th, we have a new part time executive director. Her name is Shalon Perez and she will be working 20 hours a week as a paid staff member. She resides in Lafayette and will be working out of her home. She is so excited to be a part of our organization and we know she will help our organization grow. Welcome Shalon. Please feel free to contact her if you have any concerns. She may be contacting you for your input!

Tired of our old website? Shortly, you will be seeing a new and improved website. We received a grant from the national office and we are putting this money towards the development of a new website. This is easier said than done but I want to thank Jim Zetzi, Doug Stotts, and Lori Antony for leading this effort.

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SBACI Board of Directors

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

WELCOME TO THE NEW EXECUTIVE DIRECTOR



SBAIN is taking the Indiana Chapter to the next level! After years of success and tremendous passion as a volunteer board and member driven chapter, the association has hired a part-time Executive Director. Shalon Perez joined the organization in January with fifteen years of progressively responsible positions in various areas in the non-profit, healthcare, and for profit sectors. Key areas of expertise include growing programs and organizations, developing relationships and partnerships, building awareness and fundraising. Shalon will be engaged in all of these roles in her new position.

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WALK-N-ROLL FOR SBAIN

By Lori Antony

We Need You!

Want to help with the largest fund raiser of the year for SBAIN?

I am pleased to announce a WALK-n-ROLL for SBAIN will be held on May 12, 2012 at Fort Harrison State Park, 9:30am Registration, 10:30am Walk, *with your help!* The planning process is underway. We have a date and a location but we are in need of volunteer committee members to bring the walk to life. Please talk to your family, friends & co-workers to see if anyone would like to help. Forward names to Lori Antony (LoriAntony10@gmail.com) or Pat Wyman (pjwyman1@aol.com).

What is a WALK-n-ROLL?

The WALK-n-ROLL is a family-friendly walk event being held to raise awareness about spina bifida and celebrate the accomplishments of the over 166,000 Americans living with it. There will be a 1-mile walk & roll and entertainment after the walk. Money is raised by Sponsors, Corporate Teams, Friends & Family Teams, and Individuals. Spina Bifida Chapters across the nation have been conducting WALK-n-ROLLS for years with huge success, some chapters raising up to \$50,000.

Committees

Strong committees are essential to the success of a WALK-n-ROLL. Please review the committees and volunteer for one that best fits your talents!

1. Friends & Family Teams - assist in recruiting Friends & Family Teams which represent a significant source of income for the event
2. Corporate Teams - assist in recruiting businesses to sponsor & participate as corporate teams
3. Logistics - Day-of-event details, in-kind donations, refreshments, entertainment, etc
4. PR & Media - publicity & PR

Together we can make the 2012 WALK-n-ROLL for SBAIN a huge success!
Volunteer for a committee!

New Executive Director Continued from Page 1

Of her appointment she states, "I am very excited about the future of SBAIN. I am looking forward to further development of the chapter and the great things to come there." This year SBAIN will host its inaugural Walk-N-Roll, a family-friendly walk being held at Fort Benjamin Harrison State Park on May 12th to raise awareness and funding to be used for programs and services for those affected by Spina Bifida. In 2012, the 39th annual conference will be held in Indianapolis from June 28th to July 1st.

Shalon holds an undergraduate degree from Purdue University in Individual and Family Development.

A lifelong Hoosier, originally from La Porte, Shalon lives in Lafayette with her husband, Ed and has two sons, Brennan, a student at Purdue University and Quentin a Sophomore at McCutcheon High School.

Letter from the Board President

By Pat Wyman

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Do you have your walking shoes ready or your wheelchair ready? Our chapter will be holding our first ever Rock-n-Roll fundraiser on May 12th at Fort Harrison in Indianapolis. Lori Antony and her committee are very busy putting together the event and it will be a great time for young and old. If you would like to be on the committee or help out the day of the event, please email with your name and phone number and what you would like to do. Even if you have friends that aren't able to participate, they can still support you by pledging money. You will definitely be hearing about this in the next month or two. We will hold it later in the morning so those from out of town will also be able to attend. Who is going to have the most team members? We shall see??????

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 from June 28th through July 1st. 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. You will be hearing more about this later but put it down on your calendar right now to save the dates.

Every year I talk about our Board and how much I appreciate all the work that they do. This past year, two of our Board members "retired". They were Sara Farmen and David Dornfeld. They did a fantastic job while on our Board and we will really miss their passion. However, we now have two new Board members. They are Holly Mortlock (member-at-large) and Cindy Bogan (treasurer). Please welcome them to our board.

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 make 2012 the best year ever for our Spina Bifida families.

NEW WEBSITE!

By Jim Zetzi

Over the past several months, a small committee has been working on replacing our current web site. The goals of this project include:

- making the site easy for the board members to update as needed so that it will stay current
- creating tools to allow for event planning, sign-ups, and communication
- providing the ability to take payments online
- complying with the standards of SBAA, our national organization
- giving SBAIN a home

This site will help us to have a place to check-in, to see what is going on, to communicate, and to belong. We will be able to tie into social media sites, such as Facebook, LinkedIn, and Twitter. We hope that this will help us to stay in touch and to reach more members in Indiana.

This year, we will have a major new fundraiser, the Walk-n-Roll. The new site is essential to being able to coordinate this event and make it a success. The Walk-n-Roll together with the new site are critical to growing SBAIN, allowing us to do more for our members and to reach out to potential new members throughout the state.

In late September, we signed a contract with Global Cloud to provide some of the basic capabilities. We have been hard at work ever since. We have had design meetings, we are setting up a merchant account and payment gateway, and we are getting trained on the new tools. Our goal is to complete the site before the end of the year.

Thanks to Pat Wyman and the board for their support, and to the committee members, Lori Antony, Doug Stotts, and Jim Zetzi.

39th National Spina Bifida Conference

JUNE 28 – JULY 1, 2012

INDIANAPOLIS

By Joyce Jones

This is your opportunity to attend the National Spina Bifida Conference right in your own back yard whether this is your first conference or you have attended previously. Listed below is a general overview of how the Conference works.

Who should attend? Children and adults with Spina Bifida, Parents of children with Spina Bifida, siblings, medical professionals, corporate sponsors of the Spina Bifida Association (SBA).

Opening Night Reception. The Conference officially kicks off on Thursday night with an Opening Reception in the Exhibit Hall. You will be able to meet other attendees, exhibitors, and sponsors at this very popular kickoff event. Entertainment, food, and beverages add to the festivities.

Plenary Session. On Friday morning the Conference sessions will open with a Plenary Session. This session is most frequently set up as a panel presentation and offers a question and answer period. Following the Opening Plenary is a luncheon in the Exhibit Hall which is open to all paid Conference attendees.

Breakout Sessions. Friday afternoon through the close of the Conference on Sunday offers a series of breakout sessions in a layperson format on a range of topics from which attendees can select.

Celebration Luncheon. Sunday also features the Celebration Luncheon. Come celebrate the best of the best as the SBA Annual Awards are presented at this festive luncheon (Additional charge applies).

Adult Day. Adult Day is programming offered to adults with Spina Bifida focused on issues important to them – from health challenges associated with aging to employment, relationships, advocacy, and more.

Kids!Camp. SBA's Conference has a place for children of all ages with and without Spina Bifida. This is the only national camp specifically designed for children with Spina Bifida. It offers programming for kids with Spina Bifida and their siblings. Kids!Camp teaches self-reliance, confidence, socialization skills, and independence. It helps attendees to feel empowered as individuals and become valuable team players while engaging in activities such as swimming, rock climbing (walls), and more. Attendees are placed in the program by age group and are lead through activities by counselors. Nurses are available to help with cathing throughout the day and parents may stop in at any time to check on children.

Please make plans to attend the 39th National Conference in Indianapolis from June 28 to July 1, 2012 at the Indianapolis Marriott Downtown. Registration and additional information will be available in early 2012 on the SBA Web site.

Start making your plans to attend. Don't miss this great opportunity. In addition to attending the Conference, there will be opportunities for people to volunteer both before and during the Conference. More information will follow.

Calendar of Events

MAY

May 12 First Annual SBAI Walk-n-Roll Fort Harrison Park, Indianapolis

SUMMER

June 29 – July 1 39th Annual Spina Bifida National Conference Indianapolis



SPINA BIFIDA ASSOCIATION
OF CENTRAL INDIANA

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

E-mail: president@sbaci.org
E-mail: shalon@sbaci.org
E-mail: secretary@sbaci.org
E-mail: treasurer@sbaci.org
E-mail: membership@sbaci.org
E-mail: lisa@sbaci.org
E-mail: board2@sbaci.org
E-mail: board3@sbaci.org

Pat Wyman
Shalon Perez
Heather Zetzl
Cynthia Bogan
Rachel Stotts
Lisa Jones
Lori Lowe
Holly Mortlock

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, SBACI 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