



**SPINA BIFIDA ASSOCIATION
OF INDIANA**

SBAIN Newsletter

SBAIN IN TOUCH

Winter 2012

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On December 1st, SBAIN held its Annual Holiday Party. More than 100 people of all ages gathered for the yearly event that included food, fun, games and of course a visit from a special guest!

Not only was this a special way to celebrate the holiday season, but families got to meet new friends and catch up with old! If you missed the Holiday Party this year, we hope that you will try to fit it in to your busy holiday schedule in 2013!

It is always a great time for all!

Thank you to our Elves: The Jones-Pepiot Family, The Tillman family, The Waggoner Family as well as the Albright family for the special photography

Special Thanks to Santa

Shalon Perez,
Executive Director

SBAIN Board of Directors

Chair	Joyce Jones
Secretary	Heather Zetzi
Treasurer	Cynthia Preuss Bogan
Membership/ Outreach	Rachel Stotts
Members at large	Lisa Jones Lori Lowe Angie Eugenio

Executive Director

Shalon Perez



Please join the CDC's National Center on Birth Defects and Developmental Disabilities in commemorating National Birth Defects Prevention Month during January 2013! There will be activities throughout January that will highlight the latest information about birth defects as well as feature stories of families and people affected by these conditions.

Birth defects affect us all.



What effect will YOU have on birth defects?

Learn more about birth defects. Visit www.cdc.gov/birthdefects. 

National Birth Defects Prevention Month, January 2013

Special Web features

A series of web features will be posted on the CDC website this month. The first one, in honor of National Folic Acid Awareness Week, highlights the importance of consuming 400 micrograms of folic acid daily before and during early pregnancy to reduce the risk of neural tube defects. Check back each week to see new features on birth defects, including a story of a family affected by birth defects and an interactive quiz to test your knowledge about birth defects.

Family Stories & Photos (Flickr)

Birth defects don't just impact the lives of the children who are affected. They are conditions which impact the entire family. Throughout January, we'll be featuring the photos and stories of several families and individuals whose lives have been changed by birth defects. The album will be posted in early January. To view the album, please visit: <http://www.flickr.com/photos/cdcsocialmedia/>. For more information, please contact Kara Polen at 404-498-3914 or fvc1@cdc.gov.

National Birth Defects Prevention Month Tweet-Up

During the entire month of January, we will be sharing a fact a day on Twitter to raise awareness of birth defects. Each daily fact will be marked by the hashtag: #1in33. We encourage you to participate by following and re-tweeting the facts! Feel free to add content that is more specific to your priorities or customize them to incorporate your state data—just remember to use hashtag #1in33. **Please share with your colleagues and other groups who might be interested in participating.**

Social Media Buttons

We have created buttons to increase awareness of birth defects. You can help by posting a button to your website, blog, or social networking site (e.g., Facebook page). These buttons are available at <http://www.cdc.gov/ncbddd/birthdefects/multimedia.html>.

Morbidity and Mortality Weekly Report (MMWR) Announcement

We've included an announcement on National Birth Defects Prevention Month and Folic Acid Awareness Week in the January 11th issue of MMWR.

National Birth Defects Prevention Network Educational & Promotional Materials

The National Birth Defects Prevention Network has educational and promotional materials available via their website: <http://www.nbdpn.org/bdpm2013.php>. Feel free to use these materials to promote birth defects awareness and prevention.

Please visit the NCBDDD's birth defects website at www.cdc.gov/birthdefects for more information, including the latest research, data & statistics, podcasts, and more!

Zoo Happenings Christmas at the Indianapolis Zoo Christmas at the Zoo 2012

Discount Christmas at the Zoo Tickets

Spina Bifida group sales code at login screen is **izsba**

Direct link: <http://goo.gl/hLTZF>

Discounted group rate

Adult - \$7.50

Child (2-12) \$6.00

5-9pm • Wednesday-Sunday • through December 30th

5-9pm • Wednesday-Sunday • Nov. 23-Dec. 30

Get into the holiday spirit with our annual light spectacular, Christmas at the Zoo presented by **Donatos** and **Teachers Credit Union**. Join us to make memories too big to fit in a box while you visit animals that love cooler weather, walk the Zoo grounds covered in lights, and enjoy holiday cheer. The fun starts ever earlier this year, so make your holiday plans today! The Zoo opens at noon, with holiday activities from 5-9pm each night we are open. Christmas at the Zoo is free for Zoo members and included with regular Zoo admission. A trip to Christmas at the Zoo is unlike any other time of the year. As dusk sets over the White River State Park, the Zoo begins to glow with Christmas lights creating peaceful, yet magical nights. You'll find yourself eager to celebrate everything the holidays should be ... plus animals! Several of the Zoo's hardiest will stay up late to enjoy the cooler nights, including the sea lions, polar bear, walrus, tigers and brown bears. You and your loved ones can keep warm as you dash between Oceans, the Dolphin Dome, Deserts, Santa's Village, Café on the Commons, Santa's Sweet Shop and two campfires. Grab some hot chocolate and come join in the fun!

Santa's Village • Santa visits (great photo packages available*) • Cookie decorating* with Mrs. Claus • Letters to Santa

Energy Efficient Holiday LED Lights sponsored by **Wells Fargo Advisors, LLC** • We Three Trees presented by **Indianapolis Honda Dealers** • All-A-Glow Light Show • All-new lights throughout **Encounters**

Animals • Holiday-themed Dolphin Show • Five animal keeper chats

Carolers (before Christmas) • Performances by local school choirs (at Café on the Commons) • Traditional carolers singing around the campfire

Find the Mistletoe • Be on the lookout for up to 10 mistletoes and register to win one of two **Dolphin In-Water Adventures**. (Not all mistletoes need to be found in order to register.)

Rides* • **Holiday Train Ride** presented by Marathon • **Carousel** • The Wizard of Oz 4-D Experience in the **4-D Theater** presented by Yellow Pages

* Requires additional charge



SBAIN CARES

by Lisa Jones

What is SBAIN Cares? SBAIN Cares gives the Spina Bifida Association of Indiana the opportunity to share something special like Mylar balloons, flowers, stuffed animals and of course good wishes with a child or adult with Spina Bifida when he or she is in the hospital. We want them to know that we are thinking about them and wish them well. We need your help to carry out this special opportunity to share with others.

If you know of someone with Spina Bifida who is in the hospital or going into the hospital, please contact me. I can be reached by phone at 317-475-9571 or by email at ljoneshome@att.net. Please provide the following information:

Name and age of child or adult
Hospital and room #
Anticipated length of stay
Parent name and phone #

Thank you for helping SBAIN Cares.



SBAIN TREASURER - CYNTHIA PREUSS BOGAN

Cindy graduated from New Castle High School and attended Indiana Business College in Muncie, IN. She moved to Indianapolis in 1967 and has two sons, Dean and Steven Darling.

Cindy has owned and operated Preuss Business Services since 1982, a small accounting and tax firm on the far eastside of Indianapolis. Her oldest son, Dean joined the firm about ten years ago.

She married Frank Bogan 12 years ago and between them they have 16 grandchildren.

Her youngest son, Steven and wife Kathleen are the parents of Charlie, who is 3 and Madison, who is 16 months old. Madison was born with Spina Bifida. Cindy attended last year's Christmas party with her family and heard the board chair make a plea for someone to take over the upcoming vacancy of treasurer, so Cindy graciously volunteered to serve and was appointed to serve in that capacity. Cindy had not planned to attend the event, however felt like that was the reason she was there. Cindy desired to make a difference in the organization and help families dealing with Spina Bifida.

Cindy is involved with several other organizations, including Indiana Society of Accountants, serving as the State Treasurer since 2002, and Cumberland G.A.P. a far-eastside neighborhood association working to preserve historic buildings and the small-town presence of Cumberland.

SB Tween2Teen

A place for Tweens and Teens living with Spina Bifida. Blogs, videos, Ask the expert, real stories and Fact Sheets. Visit www.sbaa.org and click on the SB Tween2Teens Logo.SB Tween2Teen

SBAIN Receives \$2,000 from SB Genetics

Thank you to all of those who participated in the study. SBAIN received a check for \$2,000. Congratulations to California for winning the grand prize of \$10,000 for the greatest number of participants.

Have you recently moved? Has your email address or phone number changed?

Please email us and let us know so we can update our membership directory!!



On May 11, 2013, the Spina Bifida Association of Indiana will be hosting its 2nd annual

Walk-N-Roll® for Spina Bifida event in Indianapolis at Fort Harrison State Park. The purpose of the Walk is to raise funds to support our mission and to celebrate the successes of those living with Spina Bifida.

With enough public, corporate and philanthropic support, we can expand upon the success of the inaugural year. What if everyone secured at least one sponsor or held a fundraiser for the walk in their community?

We greatly appreciate your consideration of our request. If you have any questions or need sponsorship forms and/or letters, please feel free to contact Shalon Perez at 765.490.6979 or shalon.sbain@gmail.com



Follow us on Facebook and Twitter **Under Spina Bifida Indiana**

Items for Sale, Donation or Trade

Several members have recently mentioned that they have equipment, toys and gadgets related to spina bifida that they're looking to sell, trade or give away. So, here's your chance. If you have an item that you'd like to list, please describe the item, whether you want to sell, trade or give it away, and send it to shalon.sbain@gmail.com

Special Thanks to our wonderful sponsor:

Making Life Easier for People with Intimate Healthcare Needs

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



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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