

# Kaleidoscope

*changing . . . adapting . . . growing*



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# Kaleidoscope

*changing... adapting... growing*

Spring 2013

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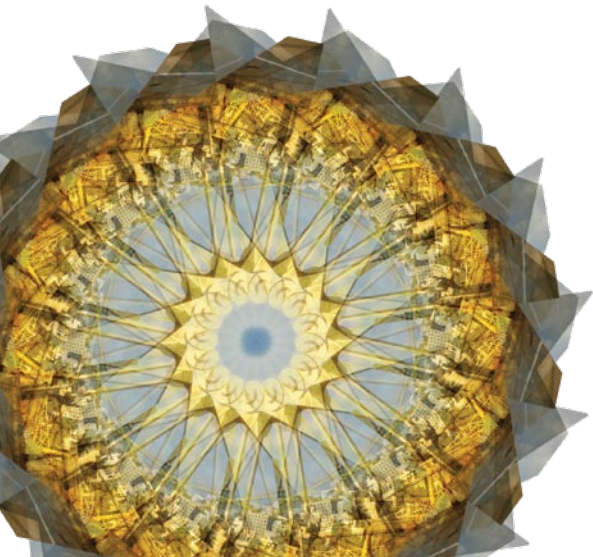
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**Spina Bifida**

Spina Bifida Association of  
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Mars, PA 16046  
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[www.sbawp.org](http://www.sbawp.org)  
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Donations may be made on line at:  
[www.sbawp.org](http://www.sbawp.org) or by check made payable to  
"Spina Bifida Association of Western PA"  
and mailed to:

Spina Bifida Association of Western PA,  
1158 Dutilh Road, Mars, PA 16046-9448

#### Our Mission

The Spina Bifida Association of Western Pennsylvania is committed to improving the quality of life for people with Spina Bifida and their families by providing a continuum of support services, education and advocacy.

## TRICIA REESMAN, SBAWP CAMP DIRECTOR

by Mike Foley

Tricia Reesman, SBAWP's new Camp Director, first heard of the Spina Bifida Association of Western Pennsylvania at a job fair held at Slippery Rock University. She began working as a counselor for the Firefly Camps and Retreats program in 2011, and in 2012 she was promoted to cabin leader. She enjoyed her work, and grew attached to many of the campers with whom she worked

Therefore, she was "extremely excited and blessed" to accept the job of Camp Director for SBAWP, which she began on January 15, 2013. Her new position will include overseeing staff members to make sure that campers receive quality care while having fun and enjoying the camp experience. Her goal is to continue making the Firefly Camps and Retreats Program a success.

Reesman is currently a senior at Slippery Rock University where she is getting a Bachelor's Degree in Social Work. She will graduate in May.

While growing up, Reesman worked at a family-owned berry farm in her hometown of Scottdale, PA. When Reesman was in college, she worked on campus and was a member of AmeriCorps, a government organization focused on community service.

Reesman resides in Freeport, Pa. with her husband (who supports her work at the Firefly camps program) and their two dogs. They want to move closer to Cranberry Township so that she is closer to where she works. In her free time, Reesman enjoys scrapbooking, watching movies, and volunteering. ■







# CAMP ROCK wish List

## **Toiletries**

Spray Deodorant (Male/Female)  
Shampoo  
Body Wash  
Baby Wipes (No Scent)  
Clear Hand Soaps  
Kleenex  
Paper Towels  
Towels/Wash Cloths  
Bedding  
Twin Vinyl Mattress Covers (25)  
Twin Sheet Sets  
Blankets  
Pillows

## **Art Supplies**

RIT Tie Dye Colors  
Construction paper  
Glue  
Markers  
Crayons  
Glitter  
Stickers  
Modeling Clay  
Plaster of Paris  
Acrylic and Tempera Paints  
Modge Podge  
Large rolls of White Paper  
Painters Tape  
Foam Art (Shapes, Letters, etc.)  
Sponge Paint Brushes  
Colorful Duct Tape

Empty Pringles Containers  
Empty Coffee Can Containers  
Latex Free Rubber Bands  
Play Doh

## **Miscellaneous**

S'mores Supplies  
Cooking Spray  
Garbage Bags  
Batteries (AA,D, AAA)  
Flashlights  
Disposable Table Cloths  
Ziplock Bags (Small and Large)  
Sharpie Markers  
Glow Sticks  
Wax Paper  
Dish Soap  
Bug Spray  
Sun Screen (SPF 30)  
Allergy Pills  
Children's Liquid Allergy Medicine  
Mesh Laundry Bags  
Old Newspapers  
Dish Sponges  
White Bandannas (75)  
Any Music Themed Items  
Musical Instruments  
Decorations  
Games  
Party Supplies  
Etc.....

# TheraDance



Monday, March 18, 2013 was a day I will never forget. That was the day when my 7 year old daughter, Elizabeth, proved to us that she would never accept the limitations of Spina Bifida. Instead, she stepped “on stage” and performed her little heart out at her first dance recital.

Elizabeth was born with the myelomeningocele form of Spina bifida, hydrocephalus, and symptomatic Chiari II malformation. After she underwent several major surgeries and lengthy hospitalizations my husband and I resigned ourselves to thinking that her physical limitations would make it virtually impossible to participate in a dance class. This was particularly difficult to accept because Elizabeth has always loved music and moving to the rhythm. Her former PT, Pat Smith-Martin, recently commented, “I can remember this kid shimmying before she could even sit!” And now, after 7 years of hard work

in physical therapy, our beautiful daughter was given the opportunity to “get her groove on.”

Elizabeth would never have had this opportunity

***I can only hope that by spreading the word, more children will be able to experience the magic and excitement of performing for their family.***

if not for the development of an exciting new “TheraDance” program created by her current PT, Jamie Barnhill, DPT. I can’t tell you in this brief message how much this has meant to our family. I can only hope that by spreading the word, more children will be able to experience the magic and excitement of performing for their family.



TheraDance is a group physical therapy program designed for children with physical limitations, such as impaired balance, body awareness, coordination, flexibility, strength and endurance. The program is offered by the Center for Independence at Children’s Hospital of Pittsburgh of UPMC at their Pine Center location in Wexford. The sessions are 10 weeks in length and culminate in a choreographed routine to music. For more information, call the Center for Independence at 724-933-9286.

# Runner with a Disability Wins Marathon *by Mike Foley*

A marathon can be a hard race for anyone, able-bodied or disabled, to run without adequate preparation and training. If you walk with crutches, the necessary conditioning can be even harder. However, these obstacles didn't dissuade Ashli Molinero from participating in a marathon in Pittsburgh, Pa in May 2012.

This was a significant milestone for Molinero because she was born with spina bifida, a birth defect where a hole at the base of the spine doesn't fuse. This can leave exposed nerves at the base of the spine vulnerable to infection. Patients with this condition can experience a lack of circulation of blood to their legs and feet along with a lack of sensation in these areas.

Molinero was born in Pittsburgh, Pa. She is 41 years old and has two sisters. Growing up, her disability was not an issue in her family though because Molinero's parents had the same expectations for her that they had for her siblings. In fact, her parents were "exceptional role models" for Molinero during her childhood.

They taught Ashli to be as independent as possible at an early age. They encouraged her to self-advocate and solve problems. Instead of not being able to do things because of her spina bifida, her family helped her determine ways she could.

Molinero's parents knew that people around her would tell her that she would be unable to do certain things. To help their daughter deal with this, Molinero's parents would often tell her to articulate about what she wanted to participate in or achieve. Also, important for her was how she envisioned herself accomplishing a task or achieving a goal.

During her childhood, Molinero received services at the Children's Institute of Pittsburgh. There clinicians—doctors who work directly with patients instead of just doing research—taught her how to get into and

out of a car, board a school bus, and go up and down stairs as well as on to and off of curbs.

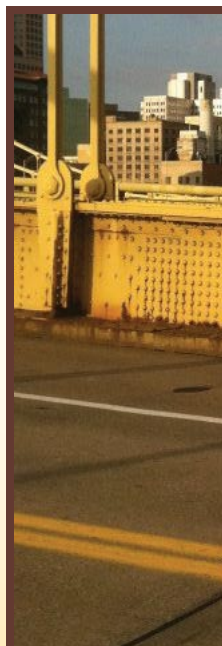
When Molinero was really young, she would have to go to doctors for regular checkups. During one of these appointments, her orthopedic surgeon, Dr. Wissinger, said to her, "Ashli, baby, do your thing!" He was basically telling her to do whatever it was she wanted to do and not second-guess herself because of her physical limitations.

During her high school years, Molinero did pretty much the same things that able-bodied high school kids do. She even went with her friends on a trip abroad to Europe.

After graduating high school, Molinero attended Robert Morris University in Pittsburgh, Pa. There she earned a Doctor of Science degree in Information Systems and Communications. When she graduated from Robert Morris, she earned another degree, a Masters in Education Design and Instruction from the University of Pittsburgh. Her third degree is a B.A. in Communications with a minor in Political Science from Chatham College.

After getting her bachelor's degree, she got a job at UPMC's Center for Assistive Technology. While there, professors from University of Pittsburgh's Department of Rehabilitation Sciences and Technology inspired Molinero to use her degree to help others achieve goals. She did this through helping evaluate the needs and goals of individuals who wanted to improve their lifestyles. The three areas that assistive technology can be used in are mobility, communication, and comfort.

Today, Molinero attempts to





encourage others in much the same way as her doctor did when she was young. She is an assistant professor in the Department of Rehabilitation Science and Technology at the University of Pittsburgh, School of Health and Rehabilitation Sciences. For her, time management is the most difficult thing to work on because “It is hard to carve out time for everything I want to do,” said Molinero.

For her prioritizing was, and still is, important. Exercising and eating healthy became difficult for Molinero due to her busy

**Dr. Wissinger, said to her, “Ashli, baby, do your thing!” He was basically telling her to do whatever it was she wanted to do and not second-guess herself...**

schedule. Lack of exercise hampered her mobility, which made daily tasks difficult. To improve her health and mobility, Molinero decided to compete in the marathon. Because she walked with crutches, the extra weight was impacting her mobility. Molinero felt that training for the marathon and changing her diet would help her get in shape. The changes worked and since she

started training for the marathon in January 2012, Molinero has lost 35-40 pounds and feels much better.

Molinero did not let her disability and its physical challenges prevent her from attempting what many people might think is impossible. Instead, she participated in the Pittsburgh marathon in May 2012 and won her division.

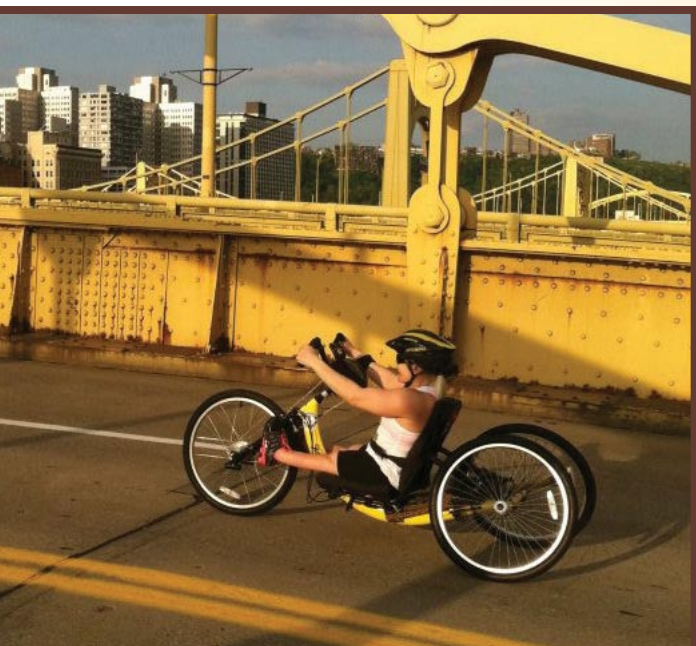
For Molinero, training for the Pittsburgh marathon was no different for her than it would be for an able-bodied runner. The only difference was that she hand-cycled all 26.2 miles. To train for the marathon, Molinero worked out with a trainer at a gym, and attended weekly yoga and cycling classes.

Molinero completed all 26.2 miles, the same distance as everybody else, on her hand cycle. She and other hand cyclists, along with wheelchair racers got a five-minute head start ahead of the 19,000 runners.

All her hard work and dedication paid off. Not only did she finish the marathon, but she also won her division. Her goal was to complete the race in three hours or less. She finished the marathon in an impressive 2:15.

Just like when she was a young child, she envisioned herself accomplishing a task—training—and achieving a goal—running the marathon. Her attitude and motivation helped her achieve her goal and inspire others in the process.

Her only regret is that she was the only woman competing in her division. Molinero hopes this will change as more women learn about this marathon division. Along with working, she continues to train and looks forward to the 2013 Pittsburgh Marathon as well as the New York Marathon in the fall. I hope to be a spectator this year to cheer for Molinero.



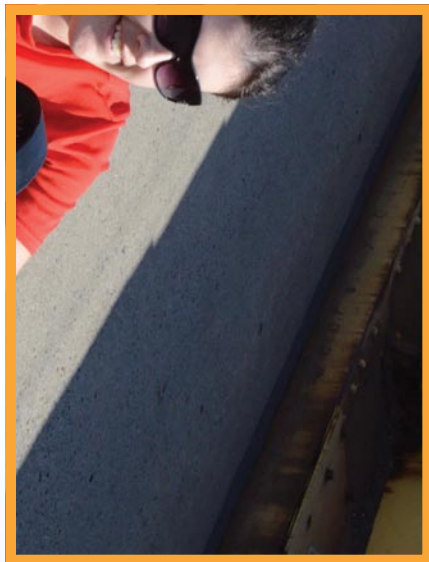
## HIGHMARK WALK FOR A HEALTHY COMMUNITY



### HOW TO WALK THE HIGHMARK WALK FOR SBAWP

Join SBAWP in the 2013 Highmark Walk for a Healthy Community, a 5K Walk from the North Shore to downtown Pittsburgh (or one-mile Fun Walk) to raise money for SBAWP.

SBAWP is one of 69 organizations participating in this year's Highmark Walk, which will take place on Saturday, May 18th at Stage AE on Pittsburgh's North Shore. Registration begins at 7:45 a.m. and the Walk is at 9 a.m. 100% of the money we raise comes back to SBAWP, because Highmark Blue Cross Blue Shield underwrites all the cost of the event.



There are lots of ways you can support SBAWP in the Highmark Walk. Just follow this link: <http://highmark.towercare.com/Markslist/site/displaySite.do?siteIdCode=NGRXLCK8> and then:

- Register to sign up to participate in the Walk (5K or One Mile Fun Walk)
- Register as a virtual walker if you are unable to walk "in person."
- Create or join a team (you must register as an individual or virtual walker first).
- Search for Participants to support an individual or team in the Walk.
- Donate to make a donation directly to SBAWP.
- Send an e-mail, share through Facebook or Twitter or collect money in person to ask friends and family to sponsor you in the Walk.
- Hold a fundraiser to support an individual or team in the Walk.

If you have any questions, or need help registering or making a donation, call 724-934-9600.

***So, get those walking shoes ready, and see you on May 18th!***





# 2013 SUMMER FESTIVAL

Plans are well underway for SBAWP Fifth Annual Summer Festival presented by Seubert and Associates to be held on Saturday, August 10, 2013 at Blueberry Hill Park in Franklin Park from 1 p.m. to 8 p.m. This family-friendly summer event will feature games and activities for all ages, live music, and great food. Tickets are only \$10 (and children 5 and under free), and all proceeds benefit SBAWP

There will be something for everyone at the 2013 Summer Festival, including bounce houses, games and arts and crafts for the little ones and sports like horseshoes, archery, and a corn hole toss for all ages. Bingo and Karaoke are again planned for some of the bigger “kids” in attendance. Festival goers will be able to buy a chance to win lots of auction baskets and prizes.

Live music will again fill the air throughout the Festival this year, featuring headliners Midlife Crisis wowing the crowd with their classic rock. The North Star Kids will be back again this year for a special performance.

You don't want to miss the fun – so mark your calendars for the 2013 Summer Festival now!

We are still looking for Corporate Sponsors, donations of auction items and prizes, and volunteers. For more information about attending or getting involved in the Festival, please contact Sharon Wolf at 724-934-9600 or [swolf@sbawp.org](mailto:swolf@sbawp.org).

Special Thanks to the 2013 Summer Festival Corporate Sponsors (as of March 20, 2013): Seubert and Associates (Presenting Sponsor), NexTier Bank, Coloplast, Chuck Foley Memorial Foundation, Fifth Third Bank, Harkel, First Choice Mortgage Services, and Settlements, Ltd. and Quest Energy Solutions.



# *12th Annual Pittsburgh Smoker Event*

Once again, SBAWP is pleased to be partnering with the Men In Christ-Pittsburgh Smoker Ministries for their 12th Annual Gentlemen's Night - The Pittsburgh Smoker dinner and charity event to be held at the IBEW Circuit Center in the South Side on June 13, 2013.

Special guests will include Bill Hillgrove, voice of the Pitt Panthers and Pittsburgh Steelers, as well as, Jay Caulfield of the Pittsburgh Penguins along with several other Pittsburgh sports celebrities to be announced at a later date. Local area businessmen and women will unite with Pittsburgh sports figures for dinner, talk, entertainment, prize drawings, and a chance to bid on some great silent auction items, including sports memorabilia.

Proceeds from this event will benefit SBAWP and several other local charities. Partners, such as the Pittsburgh Smoker Ministries, the Boilermaker's and the Blue Thong Society help raise funds needed to support SBAWP programs.

*June 13, 2013  
IBEW Circuit Center*





# Luan Fundraiser

blue thong society

**On Saturday, August 24, 2013**, the Bell Bottom Blues – the Springdale, PA Chapter of the Blue Thong Society – will be holding a Luau fundraiser from 8 p.m. to 11 p.m. at the Springdale Township Firehall in Harwick, PA, with all proceeds benefitting SBAWP programs.

The Luau is going to be an Island-themed evening of dinner and entertainment featuring the band The Businessmen, speakers from SBAWP, a basket auction and 50/50 raffle, all for \$20 per person.

The Blue Thong Society is a unique women's organization that connects, inspires and mobilizes women to make a difference in their communities and around the globe. They're modern, confident, professional and philanthropic- they connect socially, but with the purpose and intent to make the world a better place. They do good works by adopting local charities (like SBAWP) and supporting their work. Their slogan is it's cool to be blue™! For more information about the Blue Thong Society, check <http://www.bluthongsociety.com>.





# Summer Festival

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## Towels & Cup Sales

Show your support of the Firefly Camps and Retreats by purchasing a beach towel or tumbler! Our beach towels are 100% mid weight cotton and are 60"X30" with the Firefly logo printed on them. Towels sell for \$15. Our tumblers are insulated double walled with screw on lid and straw. The Firefly logo is pressed between the walls of the tumbler. Tumblers sell for \$8. We are running a special – buy both for \$15! Call 724-934-9600 to purchase yours today!



## Firefly Retreats are Springtastic!


We have been having a blast at the winter and spring retreats. We have had dances and crafts galore. We even had a visit from the Pittsburgh Zoo with animals from the Rain Forest and a volunteer firefighter who also has spina bifida. Firefighter Larry showed us that we can be whatever we want to be! Our February retreat showed that love was definitely in the air as we ate a quaint little dinner by candlelight.

We are looking forward to our upcoming retreats and hopefully some weather that will let us get to the pond for some fishing! Don't forget that the May retreat hosts our annual Mother's Day brunch! We hope to see you all there!

Just a quick reminder that all paperwork for the camps and retreats is now online with Campdoc! If you have not completed yours or need access to Campdoc please call us at the office so we can get you set up! We are very excited about using this online program!



## BluePrints Support Group



We have been very fortunate to have developed a relationship with the wonderful people at National Rehab who cosponsor all the support group meetings. With them and the fantastic families that attend we have been having some pretty amazing discussions at support group.

The spring support groups are all at the Fithian House and are going to be run by the PEAL Center as they continue to present their mini-series on Developing Strong IEP's and Working with School Teams. Part 1- Developing a Strong IEP was on February 12th. Part 2- Working Effectively with Your School Team will be held on April 9th and Part 3- Your Parental Rights and IEP Clinic will be held on May 14th. You don't need

to have attended the prior session to attend but you must register online at [www.pealcenter.org](http://www.pealcenter.org). We send a sincere thank you to the PEAL Center for their support in putting on this mini-series. BluePrints sessions will be held during the mini-series but you must call Kelly Mayer at 724-934-9600 to request a spot for your child.

Support group is open to anyone who has a child with spina bifida or related disability. Each month we offer a different topic/speaker as requested by the parents that attend and we rotate between Wexford and Moon Township for meetings. A BluePrints session is always going on during support group so that kids can come with their siblings and have a great time while their parents get the information and support they need.

### UPCOMING SEMINAR

We are so excited to be putting together a seminar on Sepsis Prevention! We are working with Dr. Brad Dicianno and Dr. Michael Ost to be presenters. Please check the website for details about date, time, and location as we will post information there as soon as we have it available.







## Calendar of Events

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### April, 2013

- 6 | **Pancake Breakfast Cranberry Community United Presbyterian (CCUPC)** – 8 a.m. – 11 a.m.
- 9 | **Support Group for Caretakers 6:30 to 8:30 p.m.** 134 Shenot Road, Wexford, PA 15090
- Peal Center Part 2: Working Effectively with Your School**
- 12-14 | **Adult Weekend Retreat Family Retreat Center**

### May, 2013

- 10-12 | **Youth and Teen Weekend Retreat** Family Retreat Center
- 14 | **Support Group for Caretakers 6:30-8:30 p.m.** 134 Shenot Road, Wexford, PA 15090
- 18 | **Highmark Walk for a Healthy Community**

### June, 2013

- 13 | **Pittsburgh Smokers** – The IBEW Circuit Center, South Side 6 p.m.

### July, 2013

- 5-12 | **CampRock** - Youth and Teen Family Retreat Center
- 8, 10-11 | **BluePrints Mini-Day Camp** - Family Retreat Center
- 13-20 | **Camp Rock** - Adults Family Retreat Center
- 29 | **Boilermakers Golf Tournament**  
Hickory Heights Golf Course, Bridgeville

### August, 2013

- 3 | **Special Needs Family Fun Day** – Blueberry Hill Park, Franklin Park, 1 p.m.
- 10 | **Annual Summer Festival** presented by Seubert and Associates  
Blueberry Hill Park, Franklin Park, 1 p.m. to 8 p.m.
- 24 | **Blue Thong Society Luau Fundraiser** - Springdale Township  
Fire Hall 8 to 11 p.m.

**Save the Date!**  
**Highmark Walk**  
**Saturday, May 18th**  
**Stage AE on Pittsburgh's**  
**North Shore.**

*See page 8 for more details*



**2013**  
**SUMMER**  
**FESTIVAL**

**Save the Date** for the SBAWP Fifth Annual Summer Festival presented by Seubert and Associates to be held on **Saturday, August 10, 2013** at **Blueberry Hill Park in Franklin Park** from **1 p.m. to 8 p.m.** This family-friendly summer event will feature games and activities for all ages, live music, and great food. Tickets are only \$10 (and children 5 and under free), and all proceeds benefit SBAWP **See you there!**



Phone: 1-800-243-5787

Fax: 724-934-9610

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