

Kaleidoscope

changing . . . adapting . . . growing



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Kaleidoscope

changing... adapting... growing

Spring 2011

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Spina Bifida

Spina Bifida Association of
Western Pennsylvania
1158 Dutilh Road
Mars, PA 16046
Phone: 1-800-243-5787
Fax: 724-934-9610
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info@sbawp.org

Donations may be made on line at:
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.



The Crossing Point

As I was driving out of my neighborhood the other day, I saw three deer crossing the road from one ravine to another. I slowed to allow them to continue and just as the third one headed down the hillside, a fourth one appeared and charged after the group. I continued on and when I was at the point of crossing, I looked to my left and there stretching his neck as far as he could was the head of deer number five looking at me as if to say, “Hey! Where did everybody go?”

And so, we too here at SBAWP have arrived at a crossing point – the point at which one Executive Director heads into a different area only to be replaced by a new person to lead. By the time you read this, my retirement will be well underway but my thoughts will continue to be with the Association and those we serve each and every day.

Now, I can help the Association the same way that many of you do – by contributing to the special events that happen throughout the year and by membership in the Association. We have made it easy to do that either on-line or by dropping a check in the mail to the address shown on the Kaleidoscope inside of the front cover.

It is our donations that provide the dollars to support the array of programs that we offer. It is our donations that determine how many people we can serve and the level that we can serve them. Many of the people that we serve live independently and count on SBAWP to be there to assist with those chores and living assistance that they need. Our donations and attendance at special events helps to ensure that SBAWP will be there in the future!

So now, in celebration of my retirement, join me in making that donation today to SBAWP! And find someone to support in the Highmark Walk for a Healthy Community on May 21st! And watch the Kaleidoscope and our website for more ways that you can give back to this community of individuals!

Unlike deer number 5, we don’t want anyone to have to ask, “Hey! Where did everybody go?”

A handwritten signature in black ink that reads "Dick Lynch".



PJ'S FUNDRAISER



What do you get when you have an outstanding retreat counselor and 30 high school students?!!?

Recently at SBAWP, we have introduced a way for our staff to show appreciation for their peers. Known, as the "You Lit Up A Life" award, staff have the opportunity to nominate a fellow staff person who has gone the extra mile to help out. Firefly Camps and Retreat Counselor PJ Ruetschi deserves this award and so much more! PJ is a graduate of First Love Christian Academy in Washington, PA, where he helped lead a fundraiser in support of SBAWP.

Throughout March 2011, First Love Christian Academy in Washington, PA held two events in support of Spina Bifida Association of Western Pennsylvania. The 9th-12th graders began raising money by having a coin war. Later in the month, the school decided to hold a dress-down day for SBAWP, otherwise known as "Down with SBAWP". Between both of the fundraisers the school donated a total of \$605.00 to SBAWP! This donation is going to assist in the continuing to provide quality entertainment during our monthly adult retreats, specifically April's event- Ferris Bueller's Revenge. SBAWP is so incredibly grateful and cannot thank First Love Christian Academy enough for all the support!

PJ began working at retreats last fall and has since become an outstanding addition to our team! PJ is currently a freshman at West Liberty University majoring in Social Work and minoring in Psychology, with concentrations in developmental disabilities and mental illness. PJ continues to volunteer at Elkhorn Valley Christian Service Camp as a camp counselor serving children and adults with special needs in his spare time. Thank you PJ! ■



Grades 9-12...Kaitlyn Moore, Jeremiah Campian, Zach Ruetschi

BluePrints



“Ready, Set, Gooooo”! is what 2-year old, Braden Ernhardt, says each week when he attends SBAWP’s BluePrints Program at Positive Steps Therapy in Renfrew, PA. Shannon Barnes, parent of 2-year-old Natalee says, “We, as a family could not have been anymore blessed to have such a wonderful program so close to home.”

In the last twelve weeks, it is quite evident that BluePrints has made a significant impact on both the parents

tried before. The kids have a great time playing with their new friends and always are asking when it’s time to go to play group. BluePrints understands the importance of being flexible and offering groups during both afternoon and evening times. The next evening session will be offered every Wednesday beginning May 4th until June 22 from 6:30-7:30pm at SBAWP’s office location in Mars, PA. There will also be a group every Tuesday afternoon

BluePrints is not just for children with spina bifida but for children of all abilities.

and children served. Barb Levandoski, BluePrints Program Coordinator enthusiastically shares, “It is so amazing to have parents telling me how much they appreciate this program and how each time their child comes, he/she reaches a milestone, whether it is trying a new food for the first time, participating in new sensory activities, or something just as simple as sharing toys with a new friend.”

BluePrints is not just for children with spina bifida, but for children of all abilities. BluePrints offers children and their parents the opportunity to participate in both structured and unstructured play time. Homemade play-doh, slime, clean mud, blowing bubbles, planting flowers are some of the fun and new activities that the children and parents do which they may have never

at The Baierl Family YMCA from 1:30-2:30 beginning May 3rd.

“We even get together and go on field trips! Our most recent get-together was at the Children’s Museum in March! The kids had a blast!”, says Barb. Don’t forget to check out our website at www.sbawp.org. to see what fun get-togethers may be planned in the future or call 724-934-9600 ext. 26 for more info! Find BluePrints on Facebook, too! ■





SBAWP CAMPS & RETREATS PROGRAM



The SBAWP camps and retreats program has been offering developmental opportunities to individuals with spina bifida and related disabilities for almost 30 years. Every year, we sit down and attempt to design our programs specifically around camper growth and development. Our primary focus for every program is to have campers reconnect with old friends, make new friends, and explore a world where “I can” is more powerful than “I can’t.” Part of this experience is ensuring that our campers have a variety of experiences from going on outings in the community to learning how to maneuver and adapt to new environments. We have discovered that the facility where we have been conducting our current program is a wonderful place for teaching new real world skills

vide an opportunity that no other program can - to be around and with people who not only know us, but also understand us.

We want to ensure that not only our staff, but also our campers have a positive experience while attending our programs and we rely on the conversations and surveys we have to help us ensure we are doing our job well. We cannot emphasize enough that our campers’ and their parents’/guardians’ feedback matters; so, if you have not done so already please take a few minutes to complete and return the survey we mailed to you.

We have been having a blast at our fall retreats; we hope that you will join us for all the fun we have planned for the spring and summer! For the past year, we have been

We have learned to overcome obstacles, believe in ourselves, and understand that although our communities are not always accommodating for those of us in wheelchairs that we still can and will go out and be an active part in them.

to all those who attend. Our campers have learned that life is full of graded paths and smaller spaces that can be transformed from obstacles to opportunities. We have learned to overcome obstacles, believe in ourselves, and understand that although our communities are not always accommodating for those of us in wheelchairs that we still can and will go out and be an active part in them. These experiences culminate in the realization that those who participate learn real life skills, develop self esteem, and gain a real sense of independence and community. Our campers make friends and memories that last a lifetime. The Firefly Camps and Retreats pro-

taking our youth/teen into the community. We have gone to the aviary, a pumpkin patch, movies, bowling, and swimming at the Baierl YMCA, just to name a few. We are committed to ensuring that we experience some new fun places with our friends in the spring. New to the adult retreats is our Saturday night entertainment. We have had a ventriloquist, a magician, and some carolers. We are excited about the spring and the new opportunities it will bring.

Our theme for the summer is Greek Week and we will begin actively recruiting staff in the new year. At Firefly Camps and Retreats we have the sky aglow with our possibilities. ■

What are you doing this summer?

With summer fast approaching, camp is just around the corner. Plans are well underway for another great summer at Firefly Camps and retreats, and we want you to be part of the fun! The programs this summer have something for everyone: there are arts and crafts, games, skits, songs, and time to just be yourself with good friends - new and old. There are exciting activities outdoors like swimming, fishing, cookouts, and campfires. All of this fun and excitement is offered within the context of our Greek Week theme.

So as the days get longer and the days get warmer start thinking about all the good times and good friends we have at summer camp. Our staff is excited to give you a new summer experience, one about overcoming challenges, learning new skills, and having fun with our friends. So grab your suitcase and join us. Don't forget your toga!

There is still time to register for a summer that you will never forget - so many lives have been enriched and changed by a camp experience. Camp brochures are available at the Association office or online at www.sbawp.org. Online registration is fast, easy, and provides instant confirmation that you are registered for camp. Camperships are available. We look forward to growing and glowing with you this summer!

Here are just a few of the things we need to grow and glow together. Will you please consider donating an item or two on this list to ensure that we have a safe and enjoyable summer camp? ■

- | | |
|----------------|--|
| Washcloths | Batteries- assorted sizes |
| Shampoo | Large stackable bins- need 40 |
| Soap | Garbage cans- need 8 |
| Toothbrushes | Laundry baskets- need 8 |
| Toothpaste | Tension rods- need 24 |
| Wipes | Solid cloth non-transparent shower curtains- need 24 |
| Lysol | Shower curtain hooks- need 24 sets of 10 |
| Hand sanitizer | Mattress covers- need 45 |
| Hand soap | Sheets-White top sheets- need 10 twin or full size |
| Trash bags | Command hooks- need 60 |
| Bug spray | Portable Radios/CD players- need 8 |
| Sunscreen | Digital camera |
| Flashlights | Ipod speaker/docking station |
| Towels | |



E-mail your friends, twitter, Facebook take us viral!



Meet the BluePrints Program Coordinator at SBAWP Barbara Levandoski

Barbara Levandoski started employment at SBAWP in March of 2008. Barb has held so many positions in the Association that she could serve as the spokesperson for SBAWP programs.

As a Life Skills Instructor, Barb was responsible for providing training and support to the participants in the Adult Services Programs. Barb assisted with the health, care, safety, life management, community integration, household management, employment and educational needs of SBAWP program participants.

As an Academic Support Coordinator, Barb provided professional level leadership and coordination of the academic program components for both SBAWP staff and participants. Barb was responsible for the development and implementation of training and support systems to enable SBAWP participants to perform well within post high school training programs. She provided care, training and supervision for participants to ensure academic success.

As a Vocational Coordinator, Barb developed and implemented community based training related to employment and integration. She was responsible for providing care, training and supervision for participants. Barb assisted in the assessment and implementation of the vocational needs for all participants. Additionally, she served as an instructor of curriculum material related

to employment, community integration, and work related skills.

Barb is currently the BluePrints Program Coordinator. (See page 5 for program details.) She is responsible for leadership in the on-going development, refinement and delivery of the BluePrints Program. She interfaces with clients, parents, instructors, and agencies who promote the program. Barb actively markets the program through networking, site visits and advertising. She literally and figuratively takes the BluePrints Program wherever it is needed! She is forever loading and unloading her car with food, crafts, soft play equipment and more.

In addition to her position as BluePrints Program Coordinator, Barb is also a Camp & Weekend Retreat Co-leader. As such, she participates in the programming and

If you saw her in action at a BluePrints session, you would see for yourself how enthusiastic and passionate Barb is about her work.

delivery of the summer camps and weekend retreat programs. Her job is to ensure that all participants

reside in a healthy and safe environment while attending the camp and weekend retreats and that all participants' needs are met while participating in the camp and weekend retreat programs. She provides overall support to the weekend retreat program and continues to foster each participant's development in all areas that will be carried over from the summer camp program. Barb's biggest challenge is to

provide an environment where everyone is not only safe, but also has a great time.

Prior to working at SBAWP, Barb attended Westminster College and graduated with a Bachelor of Arts in Elementary Education. She is currently attending Slippery Rock University in order to obtain a Master's Degree in Special Education.

Barb has worked with children and adults with special needs since May 2003. Barb says, "I love working with children and helping others." If you saw her in action at

a BluePrints session, you would see for yourself how enthusiastic and passionate Barb is about her work.

Summer is Barb's favorite season. She loves going swimming, sitting by fires and having barbecues. Coincidentally, these are some of the same things that Barb gets to do and enjoy in her additional position as Camp/Retreats Coordinator.

Thanks Barbara Levandoski for all that you do at SBAWP! ■

Books and Resources

At Your Fingertips

In addition to our many programs for the benefit of individuals with disabilities, there are also other programs and resources that people with disabilities and their families can turn to for help and education. Consumers can find some of these, on our Resources page at www.sbawp.org

On the Resource Page of our website, you will find a link to **the SBAWP Resource Library**, which provides links to books in seven categories:

Childrens Books
Sports and Recreation

Parenting

Living with a Disability

For Educators

Medical Professionals

Products

When you find a title you wish to buy you can ***purchase it online through the library page.***

SBAWP partners with a number of organizations in the community to deliver services to its consumers. On the "Partners" page of our Resources section of the SBAWP website, we provide the link to the websites of 16 organizations and companies with whom we work to provide the very best services to our consumers and their families.

Please check out our Resources page at www.sbawp.org today, and check back often as the information is updated as necessary.

Make sure you tell your friends and families about our selection of books on Spina Bifida and related topics.

Email – Twitter - Facebook make us viral!

 **LIGHT UP A LIFE WITH SONG CABARET
RAISES SPIRITS AND MONEY FOR THE SBAWP**

An engaged audience filled the seats and enjoyed an evening of sparkling song and entertainment, all for the benefit of SBAWP, when the Light Up a Life with Song Cabaret took the stage on April 2nd.

The CAPA Cabaret, located at the Pittsburgh Creative and Performing Arts High School, provided the perfect backdrop for the Cabaret which featured talented local singers performing popular show tunes and songs of hope and inspiration. Music director Matthew Wolf also acted as accompanist for the evening.

Emcee Dennis Bowman, KDKA-TV meteorologist, engaged the audience with his wit and humor. Adding to the fun he elicited chuckles with his ventriloquist and musical routines.

Legendary Jazz vocalist Etta Cox lit up the night with her renditions of “Accentuate the Positive,” “I’m Beginning to See the Light,” and “You Light Up My Life.” Cox returned to some familiar territory to perform in the Cabaret, which was built by the Pittsburgh School District on the site of the former nightclub Dowe’s on Ninth, which was co-owned by Cox and Al Dowe.

Betsy Lawrence impressed us with her first public performance of Dolly Parton’s “Light of a Clear Blue Morning,” and Hugh Rial hit some impossible notes while performing “The Impossible Dream.”

Anna McTiernan moved the audience

with her rendition of “Somewhere” while Mike Goffus and Korey White performed a lively “All for the Best.” Carl Hunt soared as he took us to his “Corner of the Sky,” and Frank Klingensmith charmed us with “Sunny Side of the Street.” Barbara Burgess Lefebvre belted out “Everything’s Coming Up Roses.”

Holly Bryant Scott dazzled with “The Light in the Piazza,” while Cara Walkowiak brought down the house with “If My Friends Could See Me Now.” Sharon Wolf, SBAWP’s director of development, joined Matthew Wolf (her husband) for “They Were You.”

The performers, staff and audience had such a great time; many expressed a desire to do this again next year!

The evening was a great success and raised thousands for the kids and young adults we serve. ■





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Family Fun * Arts & Crafts * Athletic Contests
Children's Activities & Inflatables * Food & Beverages
Live Entertainment: Midlife Crisis & Southern Comfort

SUN 7th AUG | Blueberry Hill Park in Franklin Borough
Fun Begins 2:00-8:00pm

TICKETS & DETAILS: WWW.SBAWP.ORG

ADMIT ONE 10.00
Children Under 5 Free

Mark the date now for the **SBAWP Annual Summer Festival** presented by **Seubert and Associates**. This fun-filled event will be held on Sunday, August 7, 2011 from 2 to 8 p.m. at the Blueberry Hill Park on Nicholson Road in Franklin Park, with all proceeds benefitting the Spina Bifida Association of Western Pennsylvania (SBAWP). Tickets are \$10 a person, and children under 5 get in free. Food will be available to purchase from Food Vendors throughout the day.

For more information, or to reserve tickets, call 724-934-9600 or check our website at www.sbawp.org.

Email your friends, Twitter and Facebook our events – take us viral!



Have fun! Get involved! Support SBAWP in the 2011 Highmark Walk for a Healthy Community

Get your walking shoes ready, BUT.... You don't even have to walk unless you want to!

Now is the time to register to raise money to support the Spina Bifida Association of Western Pennsylvania (SBAWP) in the 2011 Highmark Walk for a Healthy Community presented by Highmark Blue Cross Blue Shield on Saturday, May 21, 2011 at Heinz Field.

SBAWP is one of 67 non-profit organizations in the Pittsburgh area participating in the Walk, which has a two-fold purpose – to allow local health and human service agencies to raise money to support their missions, and to promote healthy activity in our communities. Highmark Blue Cross Blue Shield underwrites the cost of the Walk so that 100% of the

money SBAWP walkers raise will support SBAWP programs that help individuals with spina bifida and other disabilities to live happy and healthy lives.

There are several ways you can help to support SBAWP through the Highmark Walk.

Log onto <http://sbawp.dojiggy.com/>, then do one of the following:

- Click "Register" to sign up to join 5K (3.02 miles) or One Mile Fun Walk, then get your friends and family to sponsor you,
- Click "Make a Pledge" to sponsor a registered walker or to make a general donation to SBAWP.

For more information, call 724-934-9600 or 866-620-WALK.

E-mail, Facebook and Twitter your friends, and family, tell them to meet you there, make us viral, start a team at the office, have fun and help us help the kids.



Summer Festival

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Wish List

SBAWP is always in need of new or gently-used furniture and equipment for our residential programs. Please consider a donation of the following to SBAWP:

- 4 Saucepans w/lids *
- 4 Fry pans 10"*
- 2 Fry pans 8" *
- 2 Stockpots (dutchoven)*
- 2 Small frypans *
- 1 Coffee pot
- 1 Handmixer
- 8 Serving bowls
- Serving plates
- 4 Anti-slide mixing bowls
- 2 Microwaves
- 3 Cooking utensils sets
- 3 Serving utensils sets
- 20 Plastic drinking cups (not white, various sizes)
- 4 Sets casual dishes – non breakable, not white
- 4 Full sets flatware
- 2 Knife blocks
- 4 Sets dishtowels
- 4 Sets hot pads/mitts
- 3 9X12 baking pans
- 3 8X8 baking pans
- 2 Muffin pans

- 2 Loaf pans
- 4 Cake pans
- 3 Casseroles w/ lids
- Pie pans
- 3 Blenders
- 4 Cutting boards
- 2 Sets measuring cups
- 2 Sets measuring spoons
- 8 Sets broom/dustpan
- 4 Steak knives sets
- 4 Room dividers/privacy screens
- 1 Couch (vinyl or leather – not fabric)
- 9 Single (twin) beds with mattress – drawers or storage below
- 2 Full beds with mattress –Drawers or storage below
- 11 Night-stands w/drawers
- 2 Vacuums

*Restaurant Quality preferable, Non-rusting



Calendar of Events

May, 2011

- 3, 10, 17, 24 & 31 | **BluePrints** Program - Baierl Family YMCA-1:30 pm
- 4, 11, 18 & 25 | **BluePrints** Program - at SBAWP Offices - 6:30 pm
- 6-8 | **FireFly** Youth/Teen Retreat - Family Retreat Center
- 21 | **Highmark Walk** for a Healthy Community

June, 2011

- 1, 8, 15 & 22 | **BluePrints** Program - at SBAWP Offices - 6:30 pm
- 7, 14 & 21 | **BluePrints** Program - Baierl Family YMCA-1:30 pm
- 26-30 | **FireFly** Camp Staff Training
- 28 | **Kennywood Park** - Community Participants

July, 2011

- 1-8 | **FireFly Summer Camp** - Adults/Family Retreat Center
- 9-16 | **FireFly Summer Camp** - Youth & Teens/Family Retreat Center
- 12, 13, 14 | **BluePrints** Day Camp/Family Retreat Center

August, 2011

- 7 | **Summer Festival** at Blueberry Hill Park





Saturday, May 21
Heinz Field

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Spina Bifida Association of Western Pennsylvania invites you to our

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Family Fun * Arts & Crafts * Athletic Contests
Children's Activities & Inflatables * Food & Beverages
Live Entertainment: Midlife Crisis & Southern Comfort



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Spina Bifida Association of Western Pennsylvania

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