

Kaleidoscope

changing . . . adapting . . . growing



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Kaleidoscope

changing... adapting ... growing

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Spina Bifida Association of Western Pennsylvania

1158 Dutilh Road, Mars, PA 16046
Phone: 1-800-243-5787 • Fax: 724-934-9610
www.sbawp.org • info@sbawp.org

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"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.

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Kevin Smith – A Transition Success Story

Kevin Smith is a familiar face at the SBAWP. Kevin is a fun-loving 25 year old who loves to play pranks on his friends. You can usually find him hanging out with his friends in

his new apartment at the Fithian House watching sports or playing video games.

Kevin was born in Florida, but he primarily grew up in Ohio. Kevin first moved into the Gatehouse in 2010 to participate in the Gatehouse Transitional Living Program for young adults ages 18 and older. He attended Community College of Allegheny County (CCAC). Kevin was learning life skills at the Gatehouse, but he was homesick. After about a year, he chose to move back to his parents' home in Ohio. After moving home, Kevin grew bored. He held several volunteer positions, but he was unable to find a job that he really enjoyed. In 2014, Kevin decided he had a plan and was ready to move back into the Gatehouse to develop his own personal goals and learn the self-care skills necessary to live independently.

Through the Gatehouse Program, Kevin found a volunteer position at Vincentian Nursing Home in the North Hills. He was charged with escorting patients to and from physical therapy and other activities during his shifts. He felt like this might be his life's calling. In the meantime, he started looking into going back to school, and he learned about the Vocational Programs with Learning Supports at CCAC. There were several to choose from and Kevin found that there were two he was interested in – Resident Aide and Nursing Assistant. Kevin chose the Nursing Assistant Program. In January 2015, Kevin became a full time student at the CCAC North Campus. In addition to attending classes four days per week, Kevin was required to volun-

teer one day a week, as well. He was able to keep volunteering at Vincentian while he was attending school.

As school started and Kevin was excelling in his classes, it appeared that Kevin didn't have the upper body strength to do the lifting needed to be a Nursing Assistant. Fortunately, Kevin was still eligible to keep taking classes and earn the Resident Aide Certificate, instead. Kevin finished his first semester on the Dean's List.

As the August 2015 semester approached, Kevin was excited to go back and finish his program. He was also getting ready to move out of the Gatehouse and into his own apartment at the Fithian House. Unfortunately, the weekend before classes were to start, Kevin was attending the wedding of a friend where he took a bad fall and shattered his femur in ten places. The injury required surgery, the insertion of a steel rod into his leg and months of

Kevin decided he had a plan and was ready to move back into the Gatehouse to develop his own personal goals

rehabilitation and physical therapy. Kevin was in a wheelchair for the first time since childhood.

Kevin worked hard to overcome his injury. He never let the surgeries, pain or circumstances get him down. He went into the hospital in August and from there, he went straight into the rehabilitation center. In October, he was finally able to move into his new apartment at the Fithian House where he strives to put into practice the self-care skills he learned at the Gatehouse to live independently with minimal assistance.

Additionally, Kevin was able to continue his classes at CCAC in January 2016. He has already passed the Pennsylvania certification exam for his program. He is finishing his classes and internship and expects to graduate in May of 2016 with a Certificate in Residential Aide. Way to go Kevin!



University of Pittsburgh Partners with SBAWP to Provide Interns

SBAWP has maintained a relationship with the University of Pittsburgh School of Health and Rehabilitation Sciences for over 10 years. Field work education is a crucial part of professional preparation for students in the Master of Occupational Therapy (MOT) program and is integrated as a component of the MOT curriculum. Megan Shaffer and Hanna Morris are two MOT students who chose to complete their field work as interns at the SBAWP Gatehouse Transitional Living Program.

Megan's undergraduate degree is in Kinesiology. She decided to be an Occupational Therapist because a friend of hers had a traumatic brain injury and she was able to see firsthand how occupational therapy made a difference in the life of a person with a disability. Hanna originally majored in Marketing, but decided to switch to Occupational Therapy in order to help people achieve their goals.

Megan and Hanna began their internship at the Gatehouse in January 2016 and will continue through April 2016. As interns, they observe and assist the Gatehouse program participants with healthy menu planning, grocery shopping and food preparation. Hanna and Megan make learning fun by conducting cooking classes and developing individualized strategies related to each program participant's abilities in order to enhance their independence.

Program participants enjoy spending time with the interns because they are always ready and willing to help, and they plan educational group outings, such as a luncheon at Max and Erma's Restaurant in Cranberry.

New Board Members



Jeryl Rauluk was elected Treasurer for the SBAWP Board of Directors on September 18, 2015. Jeryl is currently employed as Vice President Treasury Management at Fifth Third Bank where she is responsible for providing consulting services and treasury expertise to middle market and large corporate companies. Jeryl has a Business Administration and Management degree from La Roche College and a master's degree in Business Administration from Joseph M. Katz Graduate School of Business. She is active in the Pittsburgh Association for Financial Professions, Chatham University Center for Women's Entrepreneurship, and Fifth Third Bank Professional Women's Network.

When Jeryl is not busy handling banking business, she enjoys spending time with her husband, Tad, her son, Pate (22), and her daughter, Rae (19). Tad is one of 8 children and half of them still live in Southwestern, PA with their families. According to Jeryl, "We love to get together on holidays. It's an instant party. As a family, we like to travel and explore. We've been to Aruba, Jamaica, Mexico, Canada, France, Italy and Spain." SBAWP is blessed to have Jeryl's 25 years of banking experience, a genuine concern for the very special individuals we serve and assistance with the annual fundraisers to raise dollars for SBAWP programs.



Joseph Cieply was elected as a Director to the SBAWP Board of Directors on November September 18, 2015. Joe is currently employed as Senior Labor Affairs Consultant for Highmark, Inc. Joe has over 20 years of human resources experience in the private, non-profit and public sector.

In addition to serving on the SBAWP Board, Joe uses his leadership and management skills, high level relationship building expertise, sound communication and analytical abilities to serve on the DePaul School for Hearing and Speech, on the Advisory Board of Variety the Children's Charity and the Palermo Heart to Heart Foundation. When he is not busy at work and volunteering, Joe spends quality time with his wife, Kathleen, and their three adult children and four grandchildren. Joe is never too busy to spend time with his grandson, Max (pictured with Joe at the recent Afternoon Jamfest at Jergel's). Max has participated in the SBAWP BluePrints Program. Joe's ability to network and develop positive relationships will assist SBAWP in increasing awareness and expanding programs. Joe, like the other members of the SBAWP Board, believes in giving back to the community, and SBAWP appreciates his willingness to give back to "our" very special community.



Kenneth Nickel was elected to the SBAWP Board of Directors in March 2015. Ken, a Pittsburgh native, began ballet training at the age of eleven. Ken has had an illustrious ballet career that has won him many awards and taken him from the Pittsburgh Ballet Theatre to Dallas to Moscow to Florida and back to Pittsburgh. As Artistic Director of Performing Arts at LaRoche, he established a B.A. Degree for Performing Arts in Dance, developed a public school arts program for dance, Resource Education Arts Development for

Youths (R.E.A.D.Y) and started a program with the Very Special Arts of Pennsylvania, in which children with disabilities went to the college to learn different art forms.

Ken has been Ballet Master for the Lincoln Park Performing Arts Charter School in Midland Pa. He has created and developed an Associate Arts Degree in Dance Education in conjunction with the Community College of Beaver County that dancers can earn in their junior and senior years in High School. Ken currently serves as Artistic Director of the program for the Community College of Beaver.

Ken has been a volunteer firefighter for the past 10 years with the Bradford Woods Volunteer Fire Company where he serves as Assistant Fire Chief. Ken has a "heart for service", and he is a welcome addition to the SBAWP Board!



A SPECIAL AWARD FOR A VERY SPECIAL WOMAN



Linda Ernhardt, a friend and program participant of the SBASP BluePrints Networking Group, recently received a very special award from the AK Steel Foundation.

Linda was selected as the area's seventh annual Steel Magnolia Award honoree. The award honors women who have overcome obstacles to positively impact their community. The Middletown Community Foundation administers the award program and is funded by the AK Steel Foundation. The award was presented to Linda by AK Steel representative Brandon Adkins, Manager of Steelmaking, Butler Works.

"The AK Steel Foundation is proud to fund the Steel Magnolia Awards to honor women who have overcome adversity and serve as a shining example to others," said Roger K. Newport, Chief Executive Office of AK Steel.

Linda and her husband, Barry, began fostering infants with special needs more than 20 years ago when their own children were 4 and 5 years old. In that time, they have fostered 59 infants, including one born six years ago with spina bifida and drug addictions whom they adopted, caring daily for him through seizures and catheterizations every four hours. They assumed the responsibility for doctors' appointments, therapies, therapeutic riding, adaptive swimming and Miracle League Baseball for their very special child, Braden. Braden is a very familiar face at

the BluePrints Networking Play Group. Braden is now in school and was chosen as Pennsylvania's Elks Child of the Year for 2014.

"Her strength of character and positive attitude have carried her through good times and bad," wrote her nominator, Cindy Harbison of Butler.

Each recipient of the Steel Magnolia Award is able to designate an eligible charity of her choice to receive a \$1,500 donation in honor of her selection. SBASP is blessed because Linda chose the SBASP to receive the donation for the BluePrints Networking Group program which is open to families and caregivers of children with spina bifida or a related disability up to age 18.

BluePrints Family Networking Group is the new name for the former BluePrints Support Group. SBASP changed the name to grow the program. The goal of the BluePrints meetings is to be educational for parents and fun for children. Through the activity of "play", BluePrints helps children learn about and interact with their world, and gain the mental, physical and social skills necessary to succeed while providing families with the resources they need to help their children succeed.

girlfriends
for good



2nd Annual Girlfriends for Good Purse Bash

A group of women came together for a cause on Saturday, November 7, 2015 at the Pine Community Center in Wexford, PA. The Girlfriends for Good Purse Bash is an annual event to support children and young adults with spina bifida and related disabilities. This year's event had over 150 attendees and raised over \$5000.

The Purse Bash provides attendees with the chance to win designer purses or accessories every 5 minutes. The benefit included sangria's, heavy hors d'oeuvres, vendors, and auction items. Thank you to all who attended and to Karen Brackett and Norma Liebenguth for entertaining us as emcees. We hope to see you at this year's Girlfriends for Good Purse Bash on Saturday, November 5 at the Pine Community Center!



SAVE THE DATE

Annual Wellness Conference
will be held on **August 13, 2016**,
10AM-3PM, at the DoubleTree by Hilton
910 Sheraton Dr. Mars, PA 16046

This extraordinary conference will provide multiple learning opportunities on how to improve the health and wellness of individuals with spina bifida. Attendees will also have the opportunity to mingle with vendors that provide services and products related to individuals with spina bifida. Lunch and childcare are both provided.

This event is free, however, RSVP is required.

Please call Tricia Reesman at 724-934-9600 or email reesman@sbawp.org for more information.

Do you have interest in learning more on how to improve the health and wellness of yourself or a family member with spina bifida? Join us for our Annual Wellness Conference on August 13, 2016.



Find us on:  

Clara's Tea Party

The Ambridge Performing Arts Academy,
directed by new SBAWP board member

Kenneth Nickel, presented

Clara's Tea Party

and excerpts of the Nutcracker

to benefit SBAWP

at Grazie restaurant in Wexford

on Sunday, November 29th.

The event included a special tea reception

with the Sugar Plum Fairies,

Mother Ginger, Drosselmeyer,

Clara, and all their friends.

Attendees enjoyed excerpts of the Nutcracker,

met the performers, and snapped photos

with their favorite characters.



Sara McCarrell with
Columbine Doll
(Elizabeth Miller)



Light up a Life!

Support SBAWP in the Highmark Walk for a Healthy Community

NOW is the time to register to participate with the Spina Bifida Association of Western PA (SBAWP) in the Highmark Walk for a Healthy Community presented by Highmark Blue Cross Blue Shield on **May 14, 2016** at Stage AE in Pittsburgh.

BE A WALKER, START A TEAM



Go to:
<http://hcf.convio.net/sbawp>

SHARE YOUR STORY



Personalize your page. What does SBAWP mean to you!

MAKE A SELF DONATION



Invite family and friends to follow your lead and kick start your fundraising by donating to yourself

SEND EMAILS



Send emails to family and friends to support you, be sure to include the link to your personal page.

INVITE OTHERS TO JOIN YOU



Ask friends, family, and coworkers to join you in walking or rolling for SBAWP

FUNDRAISE WITH SOCIAL MEDIA



Share your passion online and ask for donations from family and friends

THANK YOUR DONORS



Tell those who give to you how thankful you are for their support

The Highmark Walk for a Healthy Community is a fundraiser that benefits 72 local nonprofits including SBAWP.

Highmark Blue Cross Blue Shield underwrites the cost of the walk so that **100% of the money raised goes directly to support SBAWP.**

HIGHMARK®

WALK FOR A HEALTHY COMMUNITY



AFTERNOON JAMFEST

Hundreds of SBAWP supporters came together at Jergel's Rhythm Grille in Wexford for the guarantee of great music and a great time.

The Afternoon JamFest returned for the 3rd year on Saturday, March 7th. This annual event has evolved into the largest and most anticipated fundraiser to support SBAWP programs. This year's event had over 350 attendees and raised over \$30,000.

The JamFest has become SBAWP's signature event, replacing our annual Summer Festival, and highlights the musical talent of two great local bands. Jaywalker and Government Cheese, generously provided attendees with the music for the event. The bands played something for everyone and kept the crowd singing and dancing all afternoon.

Keith Quinn (guitarist/vocalist), Adam Meyers (vocalist/guitarist), Trevor Oliver (bassist), and Jake Locke (drummer) make up the band Jaywalker and their music involves hints of several genres

such as reggae, punk, and rock. Check out their Facebook page for their schedule-this is a group you will want to see in action.

Government Cheese comprised of band members, Corey Logo (guitar), Ted Dunham (guitar and keys), Kevin Sprinkle (drums), and Rich Rodemoyer (bass) plays classic rock and hits from the '80s and '90s — including the era's most popular dance tunes. Check out their Facebook page for their schedule and venues-we promise you will not be disappointed.

The event could not have been successful without the support of the bands, SBAWP Board, staff and families, sponsors, our emcee Chaz Kellem, and the Jergel's staff. Thank you to all who attended and we hope to see you at next year's JamFest!





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Family



Board members



Emcee



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Spina Bifida Association of Western Pennsylvania

Thank you to everyone who attended FireFly's Fall Retreats. We hope that you had a fun time reuniting with friends from summer.



Get ready, 2016 summer camps are quickly approaching.

The theme is FireFly's Amazing Race. You can brush up on your skills by watching the actual television show on CBS, Fridays at 8pm. Just like the show, teams will immerse in physical and mental challenges, deduce clues, navigate themselves in foreign areas, interact with new people, and perform physical and mental challenges. Registration information will be mailed out in April. In the meantime, **mark your calendars, youth/teen camp is July 2-9 and adult camp is July 10-17.**

Are you interested in helping to make camp a success? We're looking for donations. FireFly Camps and Retreats is in need of the following items for the 2016 summer camp season!

- | | | |
|---------------------------------|-------------------------|---------------------------|
| Spray Deodorant (Male/Female) | Smore supplies | Musical Instruments |
| Clear Hand Soaps | Garbage Bags | Gift Cards - |
| Kleenex | Batteries (AA, D, AAA) | Michaels, Target, JoAnns, |
| Paper Towels | Flashlights | Wal-Mart, Home Depot, |
| Twin Vinyl Mattress Covers (25) | Disposable Table Cloths | and Pat Catans) |
| RIT Tie Dye Colors | Ziplock Bags (Small and | |
| Construction paper | Large) | |
| Glue | Sharpie Markers | |
| Markers | Glow Sticks | |
| Modge Podge | Bug Spray | |
| Large rolls of White Paper | Sun Screen (SPF 30) | |
| Painters Tape | Old Newspapers | |
| Sponge Paint Brushes | Dish Sponges | |
| Latex Free Rubber Bands | White Bandannas (75) | |





Calendar of Events

April, 2016

- 1-3** Adult Retreat - Family Retreat Center
- 10** BluePrints Family Networking Group

May, 2016

- 6-8** Youth & Teen Retreat
- 14** Highmark Walk

June, 2016

- 11** Noll-Spratt Senior Project Golf Benefit
- 27-30** Staff Training - Summer Camp

July, 2016

- 2-9** Youth and Teen Summer Camp
- 10-17** Adult Summer Camp

August, 2016

- 13** Wellness Conference

Come Walk or Roll With Us!

**Saturday, May 14, 2016 at Stage AE
on Pittsburgh's North Shore.**

SBAWP is one of 72 health and human service organizations participating in this year's Highmark Walk for a Healthy Community.

Registration begins at 7:45 AM and the Walk is at 9 AM.

<http://hcf.convio.net/sbawp>



Highmark is an Independent Licensee of the Blue Cross and Blue Shield Association

The Gatehouse

Celebrating 25 years of service to young adults with disabilities. Join the celebration this summer- details to be announced!



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Fax: 724-934-9610

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Noll-Spratt Senior Project Golf Benefit

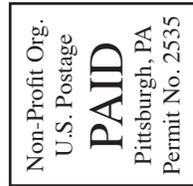
Brandon Noll and Tanner Spratt, seniors at Rochester High School, were inspired to organize a golf outing as their senior project to support the efforts of the SBAWP in the hopes of bringing light to something that many people may not know about in honor of Abby (cousin of Brandon) and Nick (friend of Tanner's family).

Saturday, June 11, 2016

Beaver Valley Golf Club
725 6th Avenue
Beaver Falls, PA 15010

The outing is open to anyone who wishes to participate. To register, sponsor, or donate please visit:

<https://www.sbawp.org/events/noll-spratt-golf-benefit/>



Spina Bitida Association
of Western Pennsylvania
1158 Dutilh Road
Mars, PA 16046