

Kaleidoscope

changing. . . adapting. . . growing

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Kaleidoscope

changing... adapting ... growing

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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.

Executive Committee

Chairperson | Joe McCormick
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Vice President | Stephanie L. Schneck-Jacob, M.D.
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Kenneth Nickel
Nikki Mason
Susan Lanzel
Archie Leonard III
Christine Shambach
Richard L. Smith
Chelsea Weston

Emeritus Board of Directors

Peter Kochis

Changes in Leadership and Board Structure in 2017

In January 2017, the SBAWP Board of Directors promoted **Sally Bayuk**, part time in-house Accountant, to the position of Executive Di-



rector. Sally has been with SBAWP since April 13, 2010. In her role as Accountant, Sally was responsible for developing the annual operating budget and consulting with departmental leadership on the fiscal aspect of

program planning, state and regulatory requirements and other administrative actions.

Over the past several years, Sally has taken on increased responsibility and a leadership role in working with SBAWP staff in the areas of budgeting and programming. She was instrumental in assisting the former Executive Director on financial matters on a regular basis. Sally has both the knowledge and skills to grow the programs and services that SBAWP currently provides.

In her seven years at SBAWP, Sally and her family have taken an active part in annual fundraising events by volunteering at the Summer Festival, the Girlfriends for Good Purse Bash and the Jergel's Jamfest events. Sally has been married to her husband Doug for 26 years. They have four children who are willing to give back to the community. Adam, the oldest is a senior at St. Vincent College; Nate is a sophomore at Villanova University; Will is a senior at Mars Area High School and Kristin is in 7th grade at the Mars Area Middle School. Adam, Will and Nate are familiar faces as they have volunteered with maintenance projects at the SBAWP office location over the years.

Sally enjoys spending time with family and friends. Her hobbies include spectator at her children's many games and activities, skiing and giving back to the community.

When asked about her new role as Executive Director, Sally was quick to reply, "I look forward to the opportunity to work every day

to make a positive difference in the lives of the individuals we serve. SBAWP's employees are truly a wonderful, dedicated and passionate team of individuals whom I look forward to working with."

Sally holds a Bachelor of Science Degree in Accounting from Clarion University of Pennsylvania.

.....

Chelsea Weston, was elected as a Director to the SBAWP Board of Directors on January 19, 2017. Chelsea is currently employed as a Marketing Specialist for McKesson Patient Care Solutions in Moon Township, PA. She has



a strong background in Journalism and Marketing. Her expertise and experience with social media will be beneficial to SBAWP in promoting our programs, services and fundraisers.

Chelsea graduated from Robert Morris University with a degree in

Communications. She started working at McKesson in August of 2014 and immediately began attending Support Group meetings with a co-worker and fell in love with the McKesson Partners in Care Program. The following spring, the opportunity came to Chelsea to take over the marketing for the program and she was very excited to accept! Chelsea said, "I love interacting with everyone who comes to the support groups, camps and education days".

In her spare time, Chelsea enjoys spending time with her boyfriend, friends and family, going to her family camp in the summer, and traveling. Chelsea has such a passion for traveling that she recently became a part time travel agent. Her favorite vacation spot is Disney World and that can be readily verified as she has visited the Walt Disney World Resort nearly 30 times! Chelsea also enjoys making Swarovski jewelry which is her other business interest although

continued on page 4

she views it as more of a hobby than a business. Chelsea has two dogs, Lilly who is a Goldendoodle and Daisy who is a Pekinese. She also has two younger siblings, McKenzie who is 16 and Luke who is 14.

Chelsea is a welcome addition to the SBAWP Board of Directors although she has been a familiar face at SBAWP since 2014 volunteering her time, talents and treasures at SBAWP fundraisers and the BluePrints Networking group.

.....

Effective February 8, 2017, SBAWP was saddened to accept the resignation of **Steve Shivak**, Director on the SBAWP Board of Directors since June 2013. Steve's knowledge and networking skills have proved invaluable in the areas of fundraising, foundation connections and strategic planning. Steve has a heart for



service and is passionate about helping nonprofits achieve their goals. SBAWP was blessed to have Steve's assistance during his tenure on the Board as we continued to make our mission - to improve

the quality of life for people with disabilities, especially those with spina bifida, and their families by providing a continuum of direct services, education and advocacy – a reality. Steve has taken on a new position as Executive Director for the Pittsburgh Chapter of Autism Speaks. We wish him continued success! Although Steve will no longer serve on the SBAWP Board due to his change in employment, we know Steve will continue to be a part of "our" community in other ways.

Community Outings



Gatehouse outing to the movies at Cinemark North at McCandless Crossing. The movie was great, but the time with friends was amazing!

Community outing to Dave and Busters. A fun time was had by all!



Fine Art Miracles, a nonprofit organization, specializes in classes for those faced with life's challenges, whether physical, intellectual, emotional or circumstantial, who want the



freedom to explore their creativity in a safe and fun environment. Classes are scheduled at the Gatehouse throughout the year. These are a few of the masterpieces!

Community outing to Dots and Doodles. The creative juices were flowing!





BluePrints

The SBAWP's BluePrints program offers children with spina bifida and other related disabilities the opportunity to develop social, motor, sensory and cognitive skills by interacting with peers in a fun and stimulating environment. This program meets on a monthly basis with dates and times determined by each event. These sessions include structured and unstructured play time with peers. Parents can listen to outside professionals involving a topic related to their child. We also go on outings to places like the zoo and Idlewild. Recently we met up at PartyLane in Mars and Dots and Doodles in Wexford. On April 23rd, a school psychologist will speak to our group about traditional versus neuropsychological evaluations.

McKesson Patient Care Solutions



Special thanks to our volunteers who continue to help make our BluePrints program a success. We truly appreciate their dedication to our program and compassion towards our participants and their families. These individuals are all employees of McKesson Patient Care Solutions and help at almost every BluePrints event that we have. With the generosity of their time and McKesson Match Program they have helped bring in almost \$2,500 to SBAWP programming. This is HUGE and we cannot thank them enough.

Fun facts about our McKesson volunteers...

Courtney Tedford is an Accounts Receivable Commercial Payer Liaison.

What was your favorite event that you volunteered for? My favorite event that I've volunteered for was the Symposium- We got to spend the day with all the children, while the parents got to relax and learn. All of the children are so wonderful and full of their

own personality! We also got to spend some time with their siblings and get to know them as well!! Just such a wonderful event and I'm just so grateful to be a part of it.



Jenna Nicoletti is a Tier 3 Insurance Specialist.

What do you enjoy most about volunteering with us? I love watching the kids grow and seeing how great they are doing. Each time they are all taller!

Margie Mayewski is a Contract Coordinator 2.

What do you enjoy most about volunteering with us? Being with the kids, they inspire me and

Adele Duffy Retired from SBAWP

After 8 years of tireless dedication to SBAWP, Adele Duffy retired on January 16, 2017. Her unselfish commitment to SBAWP will be greatly missed. Adele states, "Resigning as Executive Director was not an easy decision to make as I feel very strongly about the work we do and the services we provide to our very special program participants and families."

Adele started with SBAWP in 2008 as Executive Secretary. Her knowledge and work ethic was recognized and her responsibilities quickly grew. She was promoted through the organization and became Executive Director in June 2012. In that leadership role, Adele did a wonderful job of using her business acumen and kindhearted personality to further the mission of SBAWP.

During her tenure, SBAWP has expanded its programming, provided quality care and maintained a high level of fundraising and contributions. Adele played an integral part in developing the Wellness Program and worked to institute new

fundraising ideas including the Jamfest and Purse Bash. Both of these events have become critical to the fundraising budget. In addition to her incredible competence and skill, she has been a friend to all with her thoughtfulness and quiet encouragement. We are indebted to her vision and commitment for propelling us into the future.

Adele wishes to express the following, "I want to extend a very special note of thanks to friends, family and staff that have supported me over the years in my role as Executive Director. It has been a pleasure and definitely a learning experience."

In her retirement, Adele plans to travel and enjoy quality time with friends and family. We wish Adele all the best as she retires from SBAWP!

Adele will continue working part-time with SBAWP Housing, Inc. as Property Manager for the Fithian House. We are thankful for Adele's ongoing commitment and friendship as she continues to be part of the SBAWP family. We know Adele will never be very far!



show me that you can do anything. They are a wonderful group of young people.

Chelsea Weston is a Marketing Specialist

What was your favorite event that you volunteered for? I would have to say my favorite event is Kennywood! I enjoy riding rides with the campers and taking them out for a fun day! One of the things I enjoy most is being able to interact with our patients.



special events



We at the SBAWP are tremendously grateful to everyone who sponsored, attended, or contributed to the 4th Annual Afternoon JamFest on Saturday, March 4th at Jergel's Rhythm Grille in Wexford. Thanks to your support we raised \$30,000 to support SBAWP programs.

Special thanks to Jaywalker for donating their time and talents again this year to entertain attendees with their musical stylings. Jaywalker's music involves hints of several genres such as reggae, punk, and rock and the band is made up of 4 truly remarkable young men: Keith Quinn (guitarist/vocalist), Adam Meyers (vocalist/guitarist), Trevor Oliver (bassist), and Jake Locke (drummer). Jaywalker truly plays something for everyone and have garnered a number of new fans while performing at the JamFest. Check out their Facebook page for their schedule- they are a group you will want to follow.



The Afternoon JamFest has become SBAWP's signature event, raising the most funds to annually support SBAWP programs. The event could not have been successful without the support of the bands, SBAWP board, staff and families, sponsors, and the Jergel's staff. Thank you to all who attended and we hope to see you at next year's JamFest!

Mark your calendar now for the 5th Annual JamFest on Saturday, March 3, 2018.





AFTERNOON JAMFEST

Chairman's Award Presented to Gynni Gorman

SBAWP has been annually presenting its Chairman's Award to an individual, or group who has demonstrated extraordinary generosity to the improvement of the quality of life for individuals with disabilities since 1996.

On March 4, 2017 at our 4th Annual JamFest, Joe McCormick, Chairman of the SBAWP Board of Directors, presented Gynni Gorman with 2016's Chairman Award.

Gynni Gorman is the mother of Marissa Courtney, an SBAWP program participant. Gynni is a familiar face at both the SBAWP office and the Gatehouse, where Marissa currently lives. Gynni gives generously of her time to plan, organize and solicit for SBAWP events like the soup and salads, JamFest, Highmark Walk, in addition to selling candy bars and raffle tickets. Gynni and her family raise over

\$3000 to support SBAWP programs each year. We admire her spirit and commitment not only to her daughter but all of our program participants. SBAWP is blessed to have the support and friendship of Gynni Gorman and her family!



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FireFly Camps and Retreats New Location

FireFly Camps and Retreats is moving to a NEW LOCATION. Our new home for the summer of 2017 will be at Camp Guyasuta in Sharpsburg (which is right outside of Pittsburgh).

Change can be scary, we know! However, it can also show us new strengths that we never knew we had. In the poem "Welcome to Holland" by Emily Perl Kingley she references what it's like to experience change.

"...it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guidebooks and make wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting. After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland." "Holland?!!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy." But there's been a change in the flight plan. They've landed in Holland and there you must stay. The important thing is they haven't taken you to a horrible, disgusting, filthy place full of pestilence, famine and disease. It's just a different place. So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you never would have met. It's just a different place""But after you've

been there for a while and you catch your breath, you look around...and you begin to notice Holland has windmills...and Holland has tulips. Holland even has Rembrandts. But everyone you know is busy coming and going from Italy...and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned." "...If you spend your life mourning the fact that you didn't get to go to Italy, you may never be free to enjoy the very special, the very lovely things...about Holland."

There are many new and exciting things for us to experience at the new location. We can either mourn the loss of the old location or embrace what the new one has to offer. We're sure this will be one unforgettable fun and enriching summer no matter what. We will get to shoot on a BB gun range, do low ropes courses, participate in STEM activities, climb a rock wall, and maybe even take a zip line across the camp. We'll still be taking our annual Kennywood trip during youth/teen week and meeting up with our adults there. During adult camp week we'll also be going on a pontoon boat in the river.



On May 6th you will have the opportunity to look at our new summer camp home and check out what exciting things we will be doing. You'll be able to tour the activity spaces, sleeping corridors, and outdoor amenities. We hope to see you there! We hope the open house will be able to answer that one most important question, "How will this work?" Just like the poem and arriving

to Holland we'll work together and make this one outstanding summer.

Please note:

***The dates of camp have changed.
Our adult camp week will run from
July 1-8 and our youth/teen camp
week will be from July 9-16.***

JOIN US.....

FireFly Camps and Retreats

OPEN HOUSE

Saturday, May 6th 11AM-2PM

AT THE NEW 2017 CAMP LOCATION

—Camp Guyasuta—

Address: 300 23rd Street, Sharpsburg, PA 15215



Pennsylvania Treasurer Joe Torsella is pleased to announce that the Pennsylvania ABLE Savings Program (PA ABLE) is open for enrollment.



PA ABLE is an extraordinary, new, low-cost saving vehicle that allows people with disabilities and their families to have greater control of their finances and to plan for a more financially secure future.

Saving with a PA ABLE account helps people to save for a wide range of disability-related expenses without jeopardizing government benefits. Plus, savings benefit from several great tax advantages, including tax-free growth when used for a wide range of qualified disability expenses.

If you want to learn more about the features and benefits of the PA ABLE Savings Program, read important disclosures and enroll, visit PAABLE.gov or call 855-529-ABLE (2253).

The Pennsylvania ABLE Savings Program is administered by the Pennsylvania Treasury Department. Before investing, please carefully read the disclosure statement (available at PAABLE.gov or by calling 855-529-2253) to learn more about the program, including its effect on federal and state benefits, investment objectives, risks, fees, and tax implications.

PA ABLE Savings Program | PAABLE.gov | 855-529-ABLE (2253) | Joe Torsella, State Treasurer 607 South Drive, Suite 529 | Harrisburg, Pennsylvania 17120

3rd Annual Girlfriends for Good

Purse Bash

When women come together in community, they make a powerful impact. The Girlfriends for Good Annual Purse Bash is a testament to the impact women can make. This year's Purse Bash on November was bigger, better, and busier than ever before. Attendees enjoyed an assortment of spirits, hors d'oeuvres, vendors, auction items, mystery grab bags, and wine pulls in addition to the chance to win designer purses and accessories. There was truly something for everyone and the day was bustling with smiles, laughter, and friendship.

"When women come together with a collective intention, magic happens." - Phylcia Rashad. Special thanks to everyone who helped be a part of the magic with us and to make this event such a great success. Extra special thanks to Karen Brackett and Norma Liebenguth for entertaining us as emcees again this year and to Patty Stolar and Kathy Wittman for the amazing hors d'oeuvres and also to our beautiful purse models Kristin Bayuk, Amanda Chizmar, Taryn Campion, and Kate Mathieu.

Mark your calendars for next year's Purse Bash on Saturday, November 4, 2017.



Make a Difference One Step at a Time!

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 13, 2017** 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 78 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.**

Calendar of Events

April

23 | BluePrints - Location TBD

May

12-14 | Youth & Teen Retreat

14 | Mother's Day Brunch Family Retreat Center

13 | Highmark Walk

20 | Pittsburgh Zoo (BluePrints)

June

26-29 | Staff Training

28 | Kennywood (Adults)

July

1-8 | Adult Camp

12 | Kennywood (Y & T)

9-16 | Youth & Teen Camp

August

Wellness Conference TBD

Save the Date

SBAWP is one of 78 organizations participating in this year's Highmark Walk, which will take place on **Saturday, May 13th** at Stage AE on Pittsburgh's North Shore. Registration begins at 7:45 a.m. and the Walk is at 9 a.m.

See page 15 for more information or visit: www.walkforahealthycommunity.org



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