Spring 2018

Kaleidoscope changing ... adapting ... growing.

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Kaleidoscope

changing...adapting...growing

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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, 3000 Stonewood Dr., Suite 100, Wexford, PA 15090

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

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Emeritus Board of Directors Peter Kochis

in our community

SBAWP Housing, Inc. – Change in Board Directors



Effective December 8, 2017, SBAWP Housing, Inc. was saddened to accept the resignation of Dr. Ashli Molinero, Director and Chairman of the Program Committee from the SBAWP Housing, Inc. Board of Direc-

tors. SBAWP Housing, Inc. is a SBAWP related nonprofit that is responsible for overseeing the Fithian House in Wexford where 14 young adults with spina bifida reside.

Thank you Ashli for your 8 years of service as a Director and Chairman of the Program Committee. As a person with spina bifida, your knowledge and dedication to helping others with disabilities is greatly appreciated.

Dan McCoy.....

Dan McCoy, a Cheswick resident, was elected to the SWAWP Housing Board of Directors in December of 2017. Dan and his parents were active participants in the SBAWP. Dan attended SBAWP summer camp when he was younger. Dan is a 2017 graduate of the University of Pittsburgh with a Bachelor of Arts Degree in Communication and Rhetoric. He plans to earn his Master's degree in Wellness & Human Performance at the University of Pittsburgh. Dan is a Certified Personal Trainer. As an athlete with a physical disability, Dan's career objective is to improve the physical well-being of individuals with disabilities through motivational presentations, research, clinical support and personal fitness training.

Ever since he was eight years old, Dan dreamed of competing in the Paralympics.



In 2014, at the age of 20, he fulfilled his dream as a member of the 2014 US Paralympic Sled Hockey Team that finished 1st place at the 2014 Paralympic Games in Sochi, Russia. Dan continues his love for sled hockey as Captain of the Mighty Penguins Senior Sled Hockey Team. He is also a Mentor and Assistant Coach for the Mighty Penguins Sled Hockey, Inc. As such,



he mentors individuals with disabilities in the sport of sled hockey during novice, junior and intermediate team practices. He assists the head coach during weekly senior practices to develop players' skills

through drills and scrimmages. Additionally, Dan is the Director of Player Development. He develops off-ice training plans/schedules for intermediate and senior level players to improve on-ice performance. And, he assists the executive team with management of social media accounts to increase community awareness.

Dan is a member of the Connecting Children with Champions. He visits children undergoing cancer treatment to give encouragement and share his gold medal. He talks to them about



their hopes and dreams.

> In addition to sled hockey, Dan is an avid

participant in adaptive sports such as kayaking and hand cycling. Dan's and Ashli's paths have crossed as they both enjoy kayaking and hand cycling, a bike powered by a hand crank rather than foot pedals. They both plan to participate in the 2018 Pittsburgh Marathon. SBAWP Housing, Inc. is blessed to have board members like Dan and Ashli who have spina bifida and can provide a first person perspective that is invaluable. They both model for "our" community and others that it is about our abilities and not our disabilities.

Community Outings and Activities Sponsored by SBAWP

SBAWP is grateful to have such a wonderful dedicated staff in Community Services and Gatehouse Programs who provide opportunities to our participants for outings and activities.



Participant's Volunteering and Giving Back



Celebrating the Holidays at the Fithian House







A Journey in Their Own Words



Journey of Travis Wheeler in his Own Words

I moved into the Gatehouse on June 15, 2013. Before that, I lived at home with my parents and two brothers. I was very nervous to move into the Gatehouse at first because I was not sure what the atmosphere would be like. After my first six months, I started to feel comfortable living there. I made friends and we went on many outings and just hung out which was a lot of fun. I learned life skills, which has helped me to live independently now.

I moved into my own apartment at the Fithian House on October 12, 2017. I was nervous but very excited. I knew that I worked hard at the Gatehouse and wanted to start using my skills to live inde-

pendently. I enjoy living at the Fithian House. I like shopping for myself, doing my own laundry, and cooking for myself. I am proud of how far I have come in living independently.

While at the Gatehouse, I began working at the Department of Motor Vehicles as a greeter and still enjoy working there. In 2016, I started taking Adaptive Driving lessons and I passed my driver's license on December 5, 2017!! I am currently looking to purchase my first vehicle, which will give me even more independence.

Minimize Risk. Maximize Potential.®





3rd Annual Noll-Spratt Golf Scramble

Consider joining us for a great day of Golf and Fun!

The 3rd Annual Noll-Spratt Golf Scramble will be held on **Saturday**, **June 9**, **2018** at the beautiful Beaver Valley Golf Club in Beaver Falls, PA. Players will have the chance to win numerous prizes and participate in a Chinese Auction for a variety of themed baskets. All donations will benefit SBAWP's programs for children and adults.

Each player's entry fee of only \$100 includes:

- Lunch & Snacks
- Beverages during play
- Giveaways & Prizes
- Dinner

Business Sponsorships and Tee Sponsorships are available!

Call Sally Bayuk at 724-934-9600 for more details.

We are looking forward to another fantastic event to carry

on Tanner Spratt and Brandon Noll's commitment to community and pay tribute to two exceptional young men!

SAVE THE DATE for SBAWP's First Ever Sporting Clay Shoot!



This is an event you aren't going to want to miss. New this year, SBAWP will be hosting its first ever Sporting Clay Shoot at Seven Springs Mountain Resort, which has been rated one of the best facilities in the county.

What is sporting clays you ask? Patience.

Precision. But mostly exhilaration! Often times described as "golf with a shotgun." Clay shooting is taking off as a favored western PA hobby.

Unlike trap and skeet, sporting clays are thrown in a great variety of trajectories, angles, speeds, elevations and distances, which stimulates actual hunting conditions. It's great for novice and competitive shooters of all ages.

Hope to see you there on **Wednesday**, **September 12th**. The event will run from 11AM to 5:00 PM and will include Ammo, Gun rental, the "flight," and a buffet dinner. More details, registration, and sponsorship opportunities will be available soon!



You make a difference!

Simply put, if it wasn't for faithful supporters like you, we couldn't continue the work we do. So thank you for helping us to make a difference in the lives of individuals with spina bifida right here in our community by supporting SBAWP's signature event- The Afternoon JamFest.

The 5th Annual Afternoon JamFest was held on Saturday, March 24, 2018 and with your tremendous support raised almost \$30,000 to support individuals with spina bifida and disabilities.



Special thanks to Madeline Rae & The Daisy Chain for donating their time and talents to entertain attendees with their musical stylings.

The Afternoon JamFest has become SBAWP's signature event, raising the most funds to annually support to SBAWP programs. Every year, this event gets bigger and better and it could not be without the support of the band, SBAWP board, staff and families, sponsors, our emcee and Executive Director Sally Bayuk, and the Jergel's staff. Thank you to all who attended and we hope to see you at next year's JamFest!

Jr. Chairman's Award Presented to Gracie Crim

SBAWP began awarding the Jr. Chairman's Award in 2016 to recognize students or youth that contribute to the SBAWP community through service.



This year's award was presented to Gracie Crim at our 5th Annual JamFest.

Gracie is the daughter of SBAWP's Director of Development Rebecca Crim. Often times, kid's today are characterized as apathetic and self-centered. If we hold to this description then Gracie is from another time period in history, as these would be the last words ever used to describe Gracie. Most accurately, Gracie is a quality young woman defined by characteristics such as a willingness to serve, empathy, consideration, altruism, and confidence. Gracie is a familiar and friendly face at FireFly Camps and Retreats and fundraisers- she has volunteered over 400 hours to support SBAWP individuals. Thank you Gracie for your spirit and your laugh!









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camps & Retreats

The retreats this year have been a blast! We did new crafts and a lot of new and exciting activities. During the fall, our adults had a casino night where, if they played their cards right, they won some great prizes. Tom Kelly, a reptile guy, stopped by with some exotic animals!

During the spring retreats, magician Seth Neustein showed us many cool tricks and even read our minds! We even got to meet staff member Brennan's fury friend.

With Easter and spring time right around the corner, egg hunts and egg races were part of the fun during the March and April retreats. May 11-13, 2018 is our last retreat before summer camp. Thank you to everyone who attended FireFly's Fall and Spring retreats and to all our special guests.











Summer camp is right around the corner and we are so excited to see everyone! The dates for this years camps are:

Adult camp - July 1, 2018-July 7, 2018 Youth and Teen camp - July 8, 2018-July 13, 2018.

Kennywood will be an adult only event this year, however, McKesson is planning a carnival day during the Youth and Teen camp and they have lots of fun activities and snacks planned. We have so many amazing activities planned for this summer we hope you will join in our fun! Packets should be coming out in the next few weeks! Have any questions, please contact the office and ask for Trisha Pipchok- our new Camp Director.

Wish List

Are you interested in helping to make camp a success? We are looking for donations! FireFly Camps and Retreats is in need of the following items for the 2018 summer camp season!

- □ S'mores Supplies (110 People)
- □ Sunscreen
- Painters Tape
- Sponge Paint Brushes
- Paper Plates
- Dish Soap
- Latex-Free Rubber Bands
- □ Lysol Wipes
- Personal Wipes
- Tall Kitchen Size Garbage Bags
- □ Paper Towels
- Toilet Bowl Cleaner
- □ Gallon/Sandwich Size Zip-Lock Bags
- □ IV Poles (4)
- □ Folding TV Trays (8)
- Travel Size Deodorant, Shampoos
- Gift Cards (Lowes/Home Depot, Michaels, Wal-mart)
- Conditioners, Toothpastes, and Body Washes

















When women come together with a collective intention, magic happens and the 4th Annual Girlfriends for Good Purse Bash is a testament to that magic. Every year this event gets bigger and busier. In addition to the opportunity to win a designer purse or accessory every 5 minutes, there were various vendors, fabulous food, spectacular spirits, a bountiful basket auction, winning wine pull, and a marvelous mystery table. This year's event held at the Pine Community Center in Wexford, PA on November 4th had over 150 attendees and raised over \$7,000 to support the SBAWP community.

Special thanks to all of our "girlfriends" who helped be a part of the magic with us and to help make this event such a great success.

Save the date for the 5th Annual Girlfriends for Good Purse Bash on November 3, 2018!











Local Sing Sing Sing! Owners, Jacqueline (Jacki) Rudolph Smathers and Melody Molinaro are two amazing women who give back to the community through their annual Sing Sing Give! Benefit Concert.

This year, the benefit was held in memory of Richard (Ricky) Rudolph, the late brother of Jacki with the proceeds benefiting SBAWP. Ricky was a graduate of SBAWP's Gatehouse Program.

The Concert was held on November 19, 2017 and was a great success! It was such a special, inspiring day filled with lots of fabulous music, fun, and countless touching moments. Performers included Sing Sing Sing!'s amazing students and SBAWP's very own talented young ladies, Abby McCormick, Ann Marie Suski, and Krista Lamison - they all ROCKED IT!



Thank You!

We are very thankful to NexTier Bank for their ongoing support of SBAWP participants and programs. NexTier and their employees give generously of their time, talents, and resources. Thank you!

Calendar of Events

<u>May 2018</u>

- 11-13 Youth & Teen Retreat
- 13 Mother's Day Brunch (Camp Guyasuta)
 12 Uighmark Walk
- 12 Highmark Walk

June 2018

9 Noll Spratt Golf Outing26-29 Staff Training28 Kennywood (Adults)

July 2018

1- 7 Adult Camp 8-13 Youth & Teen Camp

September 2018

12 Clay Shoot Seven Springs







(see page 7 for details)

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