

# Kaleidoscope

*changing ... adapting ... growing*



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changing... adapting ... growing

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**Spina Bifida Association of Western Pennsylvania**  
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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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Peter Kochis

## Participant Spotlight

### “Don’t Be Afraid to Fail”

*By Willie Dudash, Resident and Participant of the Gatehouse Program*

You learn more from failure than from success. No matter what I go through in life, I will NEVER give up on my dreams or goals I want to set and achieve. I will push myself to the limit until I feel I’ve accomplished that specific goal. If I fall I will ALWAYS find a way to get back up and try again. I will always stay positive and keep a positive outlook on life, I want to be the reason someone smiles every day and is inspired but also motivated by seeing what I am capable of doing even while being in a wheelchair. The only limitations I will ever have are the ones I put on myself, which is why I will NEVER stop trying new things, the smallest step in life can be those that lead me in the right direction. As Jimmy Dean said, “I like to think of my life as a sailboat, I can’t change the direction of the wind, but I can always adjust the sail” to lead me in the right direction to reach my goals I want to accomplish in life.

Every day I go through a different obstacle that I have to adapt to in order to find my own way to get through it. Being in a wheelchair isn’t easy but you have to make the most of what you’ve got and every day I tell myself to think positive and tell myself I CAN and I WILL. Every day I will continue to push myself and I always find a way to defeat the obstacles I go through in everyday life. Every day I wake up, jump out of bed and set a goal I want to achieve for that specific day. I’ll never change any-

thing about my life, I love the life I have and I am blessed to be alive and well. I always tell myself that everything will work out just fine, my time is now, I am strong and I can do anything I want I just have to keep myself motivated every single day.



*I will NEVER stop trying new things, the smallest step in life can be those that lead me in the right direction.*

Being in a wheelchair will never put limitations on me. I’m never ashamed to tell my life story and how my disability helps motivate me to stay positive and never give up. By telling other people about my life and the obstacles I face every day, I hope that my disability and the way it helps me get through life obstacles inspires and also shows others that no matter what you go through in life don’t give up and don’t ever say you can’t do something, stay positive and NEVER GIVE UP.

## New Team Member

We are excited to announce that Brennan McMahon has joined our team as Youth Services Manager. Brennan will lead the FireFly Summer Camps and Weekend Retreats, Family School Partnership and BluePrints Programs. Brennan has a passion for making a difference in the lives of others and we feel fortunate to have him on board.



Brennan started working at FireFly Summer Camp in 2014 as the Sports Instructor and Counselor during his college summer break. He attended Clarion University of Pennsylvania and graduated in 2015 with a degree in Early Childhood and Special Education.

After graduation, he taught in Annapolis, MD at a special education school and subsequently for the Pre-K Counts Program in McKeesport, PA.

With summers off from teaching, Brennan has continued to work for SBAWP in Firefly Summer Camps and Weekend Retreats. He has held leadership roles at each summer camp by working as the Co-Leader and then progressing to the Assistant Manager in 2018. He has also worked part-time in our Community Services Program providing direct care to individuals we serve in the community. He has been a proven leader over the past 4 years and this experience will serve him well in his new role. Brennan always has a smile and encouraging words for our campers. He brings a great energy and a fresh perspective to the position.

Brennan met his fiancé at Firefly summer camp and they are getting married this May. He is an outdoor enthusiast and enjoys golfing, hunting, fishing, and all sports.

Welcome Brennan!

## Chairman's Award Presented to Randall Crim

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 3, 2019, at our 6th Annual Jamfest, Joe McCormick, Chairman of SBAWP Board of Directors, presented Randall Crim with 2018's Chairman Award with our sincere appreciation of his outstanding support and tireless dedication to the Association.

Randy is the husband of Rebecca Crim, Development Director of SBAWP. The two met while working for SBAWP as camp counselors and have been married for 20 years. Randy has worked in many capacities for SBAWP, starting as a camp counselor in 1995 and ending in 2004 as Manager of the Villa Program when he left to pursue a career in nursing. He is a Registered Nurse and is currently working on his Doctorate of Nursing Practice.

In the fall of 2010, Randy began volunteering as the nurse at FireFly Weekend Retreats and Summer Camp and has not missed a retreat or camp. He willingly makes time in his busy schedule to come each day to change the dressings on wounds and is available for any



other nursing issues that may arise. He has been an invaluable resource since, without a nurse visit each day, some campers would not be eligible to attend. Also, each year, as a nurse, Randy is involved with training new summer camp staff during orientation week. The volunteer hours he has committed and the monetary savings help keep weekend retreats and summer camp a possibility for all who attend. The campers always look forward to Randy's visits as he has known some for over 20 years and he has a personal connection and history with so many. He really cares about each and every participant and it shines through when you see him in action!

Randy is also a familiar face at all of SBAWP's fundraising events along with his amazing family. We are grateful to have such dedication from a volunteer. He has truly made a difference and impacted so many at SBAWP! Thank you Randy for being such an integral part of SBAWP over 20 years!

# SBAWP Local Grassroots Golf Outing Fundraiser Event Celebrates 30th Year

For 30 years, the Boilermakers Local 154, Steamfitters Local 449 and Ironworkers Local 3 have been golfing together around the Pittsburgh area for the Spina Bifida Association of Western Pennsylvania (SBAWP). In that time, they have raised almost \$1 million dollars to help send thousands of children and teens with spina bifida and related disabilities to the local FireFly Summer Camp.

Coincident with last year's momentous 30th year celebration, held on July 30, 2018 at Hickory Heights Golf Course in Bridgeville, SBAWP changed the name of the event from Tony Yakemowicz Spina Bifida Annual Golf Tournament to the John L. Moroney III Memorial Golf Classic. The name change is in memory of John L. Moroney III, longtime SBAWP program participant, who passed on August 18, 2017. John was the son of retired Boilermaker, John L. Moroney, Jr. and his wife Patricia.



John attended summer camp and weekend retreats for many years with old friends and new friends. He was a graduate of the SBAWP Gatehouse Program where he learned to live independently. He was employed at Heinz Field for over a decade despite intermittent health issues.

Dan Quinn, retired Financial Secretary-Treasurer/Business Agent for the Boilermakers and personal friend of John L. Moroney III and John L. Moroney, Jr, has continued in his role of Honorary Chairman to lead the preparation for this very successful event for 30 years!

The 2018 outing had over 90 sponsors and donors! The day started out with a few rain showers, but that did not dampen the golf-

ers' spirits as they enjoyed a delicious brunch, fresh grilled sandwich choices from the break cart and, as always, an amazing steak dinner. Golfers had a chance to win \$1 million on a hole-in-one, a set of golf clubs, autographed Matt Murray jersey and other door prizes. Dino Guarino generously donated a framed



Sidney Crosby painting as a special raffle item. Skill prizes and awards were also presented. Kelly Timms and Johnathan Dulemba assisted Dan Quinn with the drawings for the 50/50 raffle and Chinese auction items. (Photo of Kelly, Dan and Jonathan)

SBAWP gives a BIG, heartfelt "THANK YOU" to Dan Quinn, the dedicated sponsors and golfers who have contributed to the success and longevity of this local grassroots fundraiser. The relationship between the SBAWP and the Boilermakers, Steamfitters and the Ironworkers local unions has been a rich history of members, families and friends who continue to give back to their community and the SBAWP community. Their generosity continues to pave a path for a strong future and a stronger community as we begin preparations for the 31st Annual John L. Moroney III Golf Classic scheduled for Monday, July 29, 2019 at Hickory Heights Golf Course in Bridgeville. Come join us!



# In Community



**Heinz History Museum**



**Tour of  
Old Pittsburgh Jail**



**Monkey Business at the  
Gatehouse After Class**



**Wahlburgers Outing ... Good  
Food and Good Friends!**



**Visit to Pittsburgh  
Wintergarden**



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**Intern Rachael Nickell's Therapy Dog Project at Fithian House**



**Intern Ali Machi's Stress Free Seminar**



**Supporting the Highmark Walk**

## Health and Wellness Program

The SBAWP Housing, Inc. Board of Directors/Program Committee has implemented a new Health and Wellness Program available to all residents at both the Fithian House and the Gatehouse. Board members Theresa Crytzer, Assistant Professor University of Pittsburgh Rehabilitation Science and Technology and Dan McCoy, ACE-Certified Personal Trainer are in charge of the new program.

**Program Description:** Provide an opportunity for residents to learn more about ways to improve and maintain their health and wellness. Residents will be able to communicate with personal trainer, Dan McCoy and determine their individual goals.





# SBAWP TURNS 50!



The Spina Bifida Association of Western PA (SBAWP) was established in 1969 by a group of parents representing the first infant survivors of spina bifida and hydrocephalus in significant numbers. The parents focused on supporting one another and advocating for better health care. Today, 50 years later, the SBAWP still focuses on supporting one another. We are proud of the progress we have made and as we reminisce about all the great times, the good times, and the hard times we see the contented faces of all those impacted but also see the continued struggle and pain of families living with spina bifida. We have only come this far with the support of people like you, whether it's attending a program, sponsoring or attending a fundraiser, providing a grant, or making a donation.

Allison used to cry herself to sleep almost every night, trying to figure out why she couldn't fit in. David's lack of self-confidence over his awkward body was devastating to his social development, making him feel different and less worthy. Sam's disability prevented her from being part of the fun and games at school with the other children. John's family wept inconsolably in grievance for their beloved son, whom they lost to complications of spina bifida and they miss dearly. It's hard to find comfort knowing how many children and parents have cried themselves to sleep.

For hundreds of families just like these, SBAWP is changing those tears to a community of support, a strong shoulder to lean on through programs and ac-





tivities that make them strong. Allison has found a place of belonging and a group of people who accept her for who she is. David is learning that bodies come in every shape, and it's up to each of us to take care of our own through a healthy, balanced, and active lifestyle. Sam is gaining self-esteem and an eager spirit for life and is connected to a circle of friends that will not only be there for her today but

## *SBAWP paves a path for a brighter, stronger future by building strong kids, strong families, and a strong community.*

for years to come. John's family, while still grieving, is adjusting to the loss of their beloved son knowing that John was able to live his best life.

SBAWP paves a path for a brighter, stronger future by building strong kids, strong families, and a strong community. This was the vision by Dr. Donald Reigel and Gay Simpson-Reigel when they began SBAWP, 50 years ago. We continue this vision through the generosity and support of people like you, who have been an integral part of our mission.

As a friend of the SBAWP, you have been an integral part of helping individuals with spina bifida and related disabilities find a place to belong-to renew their enthusiasm, build character, and overcome obstacles on their journey to become thoughtful, active, and successful members of society! THANK YOU!

We look forward to the next 50 years!



# AFTERNOON JAMFEST



**We are tremendously thankful to everyone who braved the weather forecast and attended the 6th Annual Afternoon JamFest!**

The JamFest continues to be SBAWP's signature event, raising the most funds to annually support SBAWP programs. This year's event raised just over \$31,000 and had over 300 attendees! We simply could not do this without the support of those who attend, donate, sponsor, and volunteer. Thank you, Thank you, Thank you!

Special shout out to Ferris Bueller's Revenge for donating their time and talents to this year's event. Ferris Buellers is "The #1 80's Party Band" in Pittsburgh. They take you back to the greatest decade of all time...the BIG 80's! From Rick Springfield to Bon Jovi to George Michael to Poison- Ferris Bueler's covers all the greatest hits from the BIG 80's!" Check out their website at <http://www.ferrisbuelersrevenge.com> or their Facebook page for their schedule-they are a group you will want to follow.

Mark your calendar now for the 7th Annual JamFest tentatively scheduled for Sunday, March 29, 2020. We hope to see you there!





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girlfriends  
for good

5th Annual

# Purse Bash



**THANKS** to each and every one of you for taking time from your busy schedule to support – in a very enjoyable way – the mission of the SBAWP at our 5th Annual Girlfriends for Good Purse Bash. This year, the SOLD OUT event, brought 160 friends together for designer purses, laughter, and an amazing cause- what better way to spend a Saturday afternoon!

Attendees enjoyed a wonderful lunch by Aviva and amazing homemade desserts-a Pittsburgh cookie table delight! There were chances to win 25 designer purses, bottles of wine, auction baskets and mystery bags full of wonderful surprises. Local women-owned businesses were also on-site for shopping before and between drawings. Special thanks to Karen Brackett from Nextier Bank and Norma Liebenguth for lending their talent as Emcees again this year!

Words are inadequate to express the heartfelt appreciation to everyone that attended, volunteered, or supported our event! Together, we raised \$7,000 to support our programming and directly impact the lives of those with disabilities in the local area.

Our venue is changing...Mark your calendar for this year's event that will be held on November 9, 2019 at St. Ferdinand Church's Oldenski Hall in Cranberry Township.



Please Join us at our Upcoming Events...  
your support makes all the difference!

# WALK FOR A HEALTHY COMMUNITY



May 11 Stage AE on North Shore 9:00 am

To register or to donate visit [walkforahealthycommunity.org](http://walkforahealthycommunity.org)



## 4TH ANNUAL NOLL-SPRATT-GOLF SCRAMBLE JUNE 8, 2019 • BEAVER VALLEY GOLF CLUB

### Events of the Day:

11:30 a.m. Registration

12:00 p.m. Lunch

1:00 p.m. Shotgun Start

6:00 p.m. Dinner & Prizes

All proceeds from this event benefit

Spina Bifida Association of Western Pennsylvania (SBAWP).

For more information, please contact SBAWP at 724-934-9600

Rebecca Spratt at [r.spratt@me.com](mailto:r.spratt@me.com) • Jordin Noll at [jordinnoll@gmail.com](mailto:jordinnoll@gmail.com)



## 2019 SHOOT FOR SBAWP WEDNESDAY, SEPTEMBER 11

The Shoot for SBAWP will be held at Seven Springs

Registration & Snacks: 11 am Flight: 12—3 pm

Welcome & Safety: 11:45 am—Noon Dinner: 3—5 pm

Registration and Sponsorship Opportunities to follow.

Questions: Contact Archie Leonard at

(814) 244-7196 or [archie.leonard@gmail.com](mailto:archie.leonard@gmail.com)



# CAMPS & RETREATS



## Summer camp is approaching!

While we've been patiently waiting to all come together again at summer camp, we've had some good times at our fall and spring retreats. It's always a great time reuniting with our friends. At our retreats, we celebrated multiple holidays and birthdays, and had fun doing a wide range of activities. We worked out and kept in shape by playing laundry ball, baseball, and doing "hopscotch" activities. We also stayed festive by decorating gingerbread houses, St. Patrick's Shamrocks, flower boxes, and doing our annual Christmas Gift Exchange!



We are very excited to have everyone back for our Summer Camp this year, which is going to follow a "Challenge" theme! We experimented with this theme last year, competing in different challenges and trying to gain as many points as possible. Along with our regularly planned activities and routines, campers will participate in different challenges all week long. At the end of the week, the big prize will be revealed and campers will get to utilize the points they earned!



Join us for great memories as we enjoy our time with Firefly's and Camp Guyasuta's Staff! It's going to be a summer full of swimming, zip lining and rock wall climbing, sports, crafts, BB Gun and Archery shooting, boat rides, camp fires, s'mores, and much more!





## Camp Dates:

**Adults:**

**June 30-July 6, 2019**

**Youth and Teen:**

**July 7-July 12, 2019**

*2019-2020  
camp and  
retreat dates  
coming soon!*



## Thank You!

We are very thankful to NexTier Bank for their ongoing support of SBAWP participants and programs. The EITC contribution supports our camps and retreats programs. Thank you!



*L to R: Diana Priganc, Adele Duffy, Karen Brackett, Rebecca Crim, Sally Bayuk*

# Calendar of Events

## May 2019

- 10-12 Youth & Teen Retreat
- 12 Mother's Day Brunch  
(Camp Guyasuta)
- 11 Highmark Walk

## June 2019

- 8 Noll Spratt Golf Outing
- 25-28 Camp Counselor Training
- 27 Kennywood (Adults)

## July 2019

- June 30- 6 Adult Camp
- 7-12 Youth & Teen Camp
- 29 Boilermakers Golf Outing

## September 2019

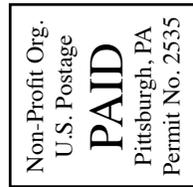
- TBD Wellness Conference
- 11 Clay Shoot Seven Springs
- 27-29 Adult Retreat

**SAVE THE DATE**  
**2019 Shoot for SBAWP**  
**Wednesday, September 11**



*(see page 13 for details)*

**Phone: 1-800-243-5787**  
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**The 4th Annual**  
**Noll-Spratt**  
**Golf Scramble**

**Saturday, June 8, 2019**  
**Beaver Valley Golf Club**  
**Beaver Falls, PA.**

*(see page 13 for details)*



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of Western Pennsylvania  
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