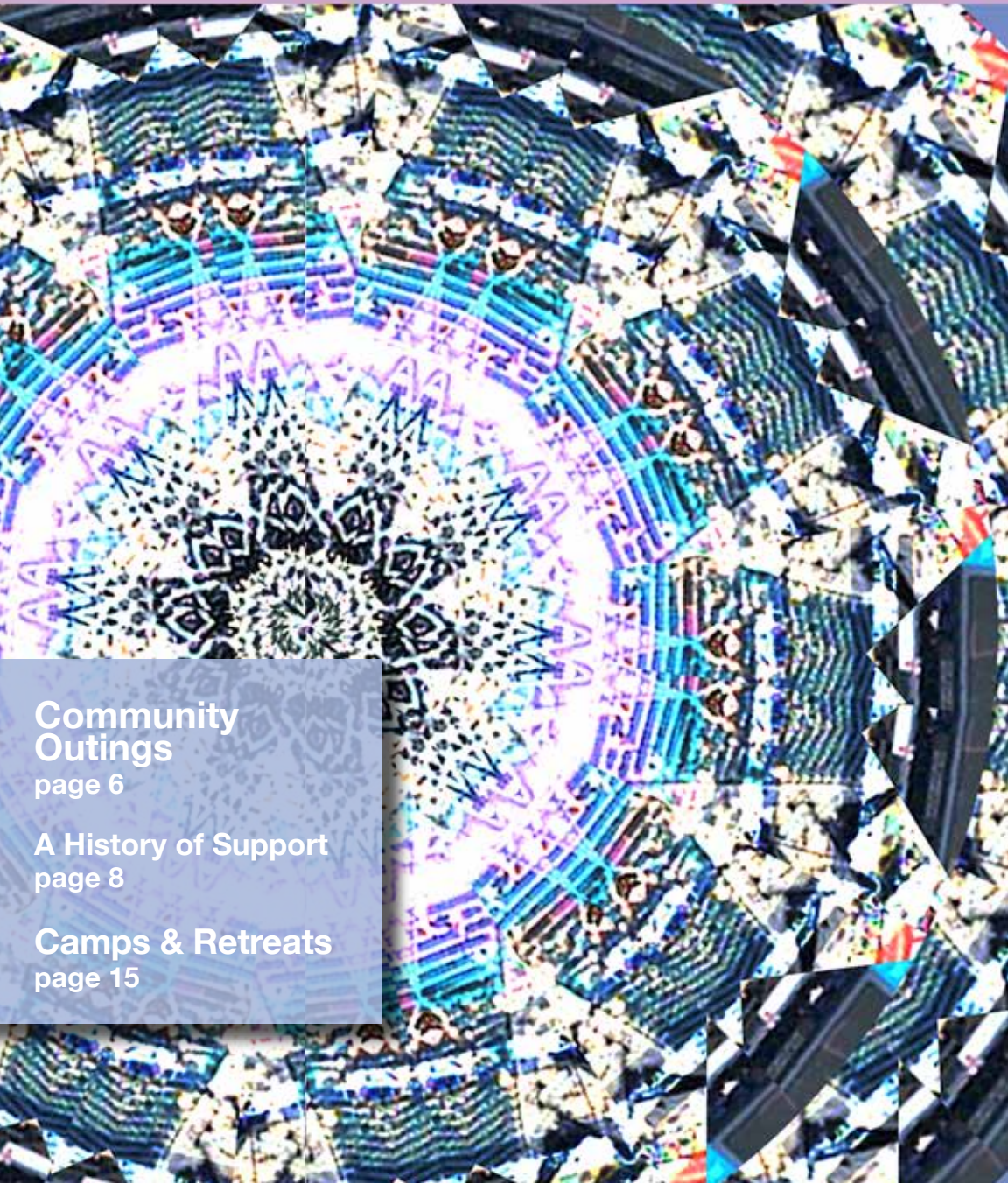


Kaleidoscope

changing ... adapting ... growing



Community Outings

page 6

A History of Support

page 8

Camps & Retreats

page 15

Kaleidoscope

changing... adapting... growing

Contents

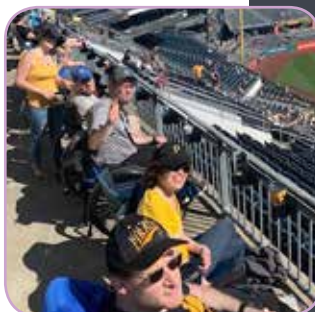
winter | 2020

In Our Community 3

Changes in SBAWP Leadership
A Letter From Rebecca
Health and Wellness
Community Outings

Special Events 8

A History of Support
4th Annual Noll Spratt Golf Scramble
2nd Annual Clay Shoot
Purse Bash Thank You
Mark your calendars – Highmark Walk & Purse Bash
Summer Camp & Retreats



Spina Bifida Association of Western Pennsylvania
3000 Stonewood Drive, Suite 100, Wexford, PA 15090
Phone: 1-800-243-5787 • Fax: 724-934-9610
www.sbawp.org • 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,
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

Chairperson | Joe McCormick
President | John Liebenguth
Vice President | Stephanie L. Schneck-Jacob, M.D.
Treasurer | Jeryl Rauluk
Secretary | Jeffrey B. Balicki, Esq.

Board of Directors

Joe H. Bucci, Esq.
Joe Cieply
Robert Davies
Kenneth Nickel
Archie Leonard III
Christine Shambach
Richard L. Smith

Emeritus Board of Directors

Peter Kochis
Susan Lanzel

Changes in SBAWP Leadership

SBAWP Says Farewell to Sally Bayuk as the Executive Director



In October 2019, SBAWP was saddened to accept the resignation of Sally Bayuk, Executive Director, to pursue her accounting career at Bates Barksdale Ickert & Co. Sally has been with SBAWP since April 13, 2010. In her first role

with SBAWP as part-time 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 years, Sally assumed increased responsibilities and a leadership role in working with SBAWP staff in the areas of budgeting and programming. It was only natural that Sally be appointed Executive Director in January 2017 when there was an opening for a new Executive Director. Her financial knowledge and skills were instrumental in growing the programs and services that SBAWP currently provides. Sally took on additional responsibilities as the state implemented Managed Care Organizations and related policies and procedures to better provide personal care services for SBAWP program participants.

In her nine years at SBAWP, Sally and her family have taken an active part in annual fundraising events by volunteering at the Summer Festival, Girlfriends for Good Purse Bash, Afternoon Jamfest at Jergel's, Noll-Spratt Golf Outing and the Clay Shoot events. Sally unselfishly gave her time, talents and treasures for SBAWP program participants and staff.

Sally stated, "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 on a daily basis to make a positive difference in the lives of the very special program participants and families we serve."

We are thankful for Sally's ongoing commitment and friendship as she will continue to be part of the SBAWP family as she plans to serve on the SBAWP Board of Directors. Although we will miss Sally's friendly smile and willingness to stop and listen no matter how busy she was, we know that Sally will still be just a text, email and/or phone call away because of her dedication to SBAWP. Sally, on behalf of "our" community, we wish you continued success!



A Message from Dana Schutte as the New Executive Director



I am happy to address you for the first time in my new role as Executive Director of the Spina Bifida Association of Western PA. I've spent my entire career working to improve the lives of people with disabilities and look

forward to continuing that work with SBAWP. I believe strongly that we have a responsibility to not only lift up those who are struggling, but to provide them with the tools they need to realize their full potential. My work experience spans the spectrum from direct care through senior leadership. In those years I've managed through endless funding and regulatory changes that continuously challenge nonprofit organizations. My educational background includes a Master of Science in Professional Leadership/Nonprofit Management from Carlow University and a Bachelor of Science in Psychology from Edinboro University.

It has been a pleasure to learn about SBAWP and I am beyond impressed with both the employees and individuals served by the organization. What strikes me as remarkable is how much this organization can do with so little. Many of the services and supports provided by SBAWP are not funded through

continued on page 4...

continued from page 3...

public dollars or medical insurance...but the work continues due to dedicated board members, staff, volunteers and an amazing community of donors who understand the value of supporting people with spina bifida and other related disabilities. I look forward to getting to know all of you soon!

My family is also excited to serve the mission of SBASP through the many events and fundraisers. My husband, Bill, and daughters, Lauren and Maddie, look forward to the Afternoon Jamfest at Jergel's in March. This will be the first of many charitable events attended by my granddaughter, Nora, who will have just turned one...we've already been warned to have ear protection handy!

In the near future, I will be exploring new sources of funding, encourage creative programming, and supporting self-advocacy among those receiving services. I look forward to building on the tremendous work that's helped create and sustain SBASP through its incredible 50 years! I'm inspired by the work that has been done and am honored to join you all in serving the mission.

A Letter from Rebecca



A little over 23 years ago I started a summer job. The first person I met while waiting for my interview with Shannon Jacobs was Henry Sheets and his mom.

That job changed my life. So many details so many lessons, so much laughter and so much heartbreak.

I met my husband, Randy, that summer. I learned to never judge a book by its cover- thank you Jonathan Dulemba for standing straight up out of your chair as that was an important lesson. I learned what real friendship looks like by watching those kids now adults come back month after month and year after year supporting each other through the good times and the bad and that no matter what, we had someone to lean on. I gained a family.

The Spina Bifida Association gave me more than I could have ever given. It has made me the person I am today. That person isn't always amazing, but it taught me that we accept each other as we are and how ever we are. It taught me that kindness matters and has given me some of the most amazing and hardest moments of my life. That job gave me everything and I am most thankful. It has prepared me to take this step and although I will no longer officially be an employee of the Spina Bifida Association any longer, I am thankful for all that I have learned in my time there. Writing this

makes me think of those amazing ending ceremonies and the songs we sang that made us all cry but those songs are so true about our experiences together and they ring so true:

And friends are friends forever
If the Lord's the Lord of them
And a friend will not say never
'Cause the welcome will not end
Though it's hard to let you go
In the Father's hands we know
That a lifetime's not too long
To live as friends

I attended a funeral for one of those friends a little while ago. The minister handed out puzzle pieces. She talked about how much this person enjoyed puzzles and how she would get mad if there was a piece missing because the puzzle was incomplete. The message is that we have become a part of the puzzle of each other's life- each piece fitting together to make the picture complete. Every piece no matter how small is as important as the others to complete the picture. Thank you for letting me be a small piece of your puzzle. I will carry you with me always!

You will still see me. The Spina Bifida Board has asked me to join them. I am honored and humbled to continue to be a part of the organization that helped make me who I am. So although I will not be an employee, you can't get rid of me that easily.

And as the days go by, I'll think of you and sigh, it was goodnight and not goodbye.

Health and Wellness

Healthy Cooking

In conjunction with the SBAWP Health and Wellness Program, Sara Izzo, UPMC Research Associate, held a Cooking Safety Class in the Fithian House Community Kitchen. Sara, with the help of resident, Kenia Hernandez, prepared crispy slow cooker Cornish hens for all class attendees while demonstrating cooking safety and techniques related to healthy eating. The result was good food, good information and good fun!



Healthy Lifestyle

We had a visit from Jon Kolb, #55 offensive left tackle for the Steelers during the "Glory Days". He played with the Steelers for 13 seasons and is a 4-time Super Bowl Champion. He went on for 10 more years as the defensive line coach. His passion now is working with people with disabilities to improve their function for everyday life. He does this through his non-profit organization, Adventures in Training with a Purpose. He spoke to our residents about the importance of values, motivation and the importance of exercise. He shared that it isn't always easy, but through challenge comes change. (Take the "lle" out of the word challenge and you get change.) Jon explained how no one can do it for them, they must want to do it for themselves. He gave the residents hope and encouragement to lead a healthier lifestyle.



Health and Wellness

Dan McCoy and Theresa Crytzer continue to facilitate the monthly Health and Wellness Program meetings. Residents of the Gatehouse and the Fithian House share healthy snacks, ideas for setting and achieving goals, and exercise techniques with latex-free stretch bands to strengthen their upper and lower body. Participants learn that health and wellness can be fun when done in a group or with a partner.

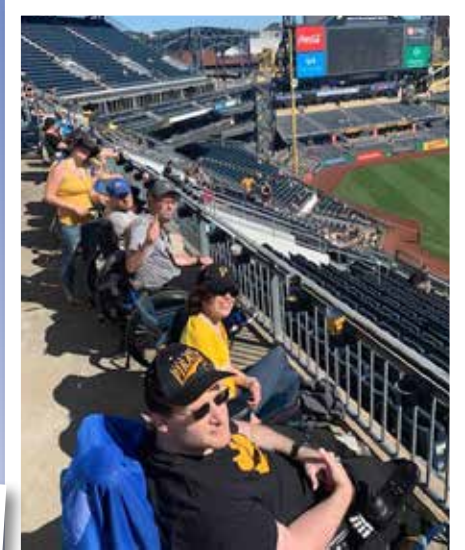


Community Outings and Activities sponsored by SBAWP

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.



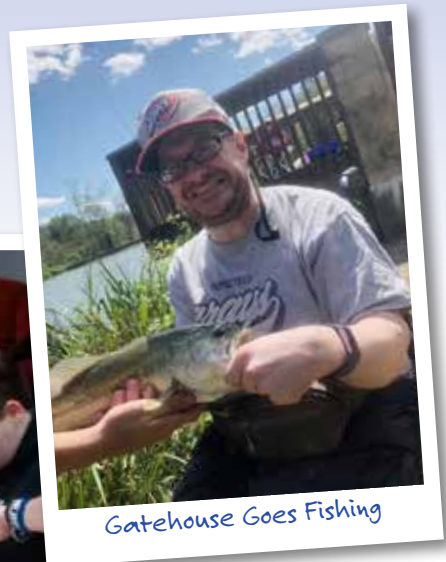
4th of July Celebration



Pirate Game



Lumaze



Gatehouse Goes Fishing



Gatehouse Fine Arts



Community Services
Halloween Party



Oktoberfest with
Community Services



Dave and Busters, October



Gatehouse tree trimming



Pittsburgh Penguins practice at
UPMC Lemieux Center



Dale Carnegie Workshop



Carnegie History Museum

A History of Support and Events Continues as
Longtime Friends of SBAWP Come Together for

Good Food, Good Fun and a Good Cause!

For 31 years, the Boilermakers Local 154, Ironworkers Local 3 and Steamfitters Local 449 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.

grilled sandwiches, a delicious steak dinner and dessert. Golfers had a chance to win \$1 million on a hole-in-one, a set of golf clubs, auto-graphed Phil Kessel jersey and other great door prizes. Once again, Dino Guarino generously donated a framed Sidney Crosby painting as a special raffle item. Skill prizes and awards were also presented. Kelly Timms, Jonathan Dulemba and Aaron Spang, (members of the SBAWP and local union community) assisted Dan Quinn with the drawings for the basket auction items and the 50/50 raffle. A good time was had by all!

As you read this article about the 31st annual John L. Moroney III Golf Classic, please know that plans have already begun for the 32nd Annual Golf Classic. Dan Quinn's enthusiasm in networking and fundraising for this event is contagious! He networks year-round. Anyone who meets Dan for the first time will most likely get an invitation to the event or request for a donation.

So why has Dan Quinn, retired Financial Secretary-Treasurer/Business Agent for the Boilermakers continued to spear-head the preparation and day of event activities for going on 32 years? Well, it goes back to first grade and Dan's friendship with John L. Moroney II, now a retired Boilermaker. Dan has known John's wife Patty Moroney since sixth grade. When Dan and John were Boilermaker/coworkers, John and Patty gave birth to John



Sam Depe, Dan Quinn, Aaron Spang, John L. Moroney II,
Johnathan Dulemba, Kelly Timms

The 31st John L. Moroney III Memorial Golf Classic was held on July 29, 2019 at Hickory Heights Golf Course in Bridgeville, PA. Dan Quinn, Honorary Chairman, once again lead the preparation for this very successful event. The outing had over 100 sponsors and donors! The weather was perfect, and the golfers enjoyed a delicious brunch, fresh



New Friends



L. Moroney III who was born with spina bifida. Dan saw firsthand the joys, struggles and uncertainties of raising a child with a disability as John III underwent numerous surgeries prior to age five.

Young John was about 2 years old when the Boilermakers started fundraising with raffles, T-shirt sales, pledges for running and eventually the annual golf outing to benefit SBAWP summer camp. Additionally, members of the Boilermaker and Ironworker community helped raise funds for "family members" Jonathan Dulemba, Aaron Spang and Kelly Timms who also had spina bifida.

The unions and their family members decided to fundraise collectively to send their children to the spina bifida summer camps. The unions reached out to other trade unions

Young John was about 2 years old when the Boilermakers started fundraising with raffles, T-shirt sales, pledges for running and eventually the annual golf outing...

through the Pittsburgh Building Trades. Soon, employers' union contractors, investment and money managers, local government officials, legal firms, professional sports teams/players (Pittsburgh Penguins, Steelers and Pirates) and local restaurant owners throughout the Western Pennsylvania area became sponsors and generous donors for the annual Golf Classic. Thus, began the local grassroots annual John L. Moroney III Memorial Golf Classic.

We would be remiss in not mentioning the many longtime volunteers who are employees

and friends, including Karen Demma, Premier Power Solutions Account Executive. She has a heart for fundraising and our community and sometimes rivals Dan in his networking efforts. And, we give a shout out of thanks to Sam Depe III, former golf pro at South Hills Country Club and owner of Hickory Heights Golf Course in Bridgeville, PA. For the past 9 years, Sam and his staff have done an outstanding job of hosting the Golf Classic. Sam and Dan coordinate every detail of the event from assigning the foursomes, tee signs, awards dinner and finally dessert!

Original organizers of the Golf Classic, along with many of the golfers still participate in contributing to the success and longevity of this local grassroots fundraiser. The relationship between the SBAWP and the Boilermakers, Ironworkers and the Steamfitters local unions has a rich history of members, families and friends who continue to give back to their community and the SBAWP community for going on 32 years!

If you happen to see Dan Quinn out in the community, and he asks you for a sponsorship or donation for the 32nd Annual Golf Classic, please take a minute and thank him for his year-round support of SBAWP, John and Patty Moroney, Jonathan, Aaron and Kelly. In the meantime, we at SBAWP say, "THANK YOU!" Looking forward to working with you on the 32nd John L. Moroney III Memorial Golf Classic, July 27th at Hickory Heights Golf Course, Bridgeville, PA!



Old Friends

The 4th Annual Noll-Spratt Golf Scramble



The 4th Annual Noll-Spratt Golf Scramble was, once again, a huge success raising money for the Firefly Summer Camp Program. Thank you to Rebecca Spratt and Jordin Noll and the Noll and Spratt families for continuing this event to support SBAWP.

In 2016, for their senior project, Brandon Noll and Tanner Spratt were inspired by the impact spina bifida had on individuals and their families. This year, their sisters, Jordin Noll and Rebecca Spratt, carried on the tradition by organizing the event at the Beaver Valley Country Club on June 8, 2019 for their senior project. With the support of their

family, friends and community, they marketed the event, solicited tee sponsors and donations for the food, beverages, skill prizes and auction baskets. SBAWP is thankful for their support and dedication to the event and the SBAWP Firefly Summer Camp Program.

The weather was perfect for golf and everyone who attended had a wonderful time!

Save the Date for the 5th Annual Noll-Spratt Golf Scramble: June 13, 2020



2nd Annual Shoot for SBAWP

The 2nd Annual Shoot for SBAWP was held on September 11, 2019 at Seven Springs Mountain Resort. Thank you to all of our sponsors and volunteers for helping make the clay shoot a successful event. We couldn't ask for better weather. Everyone had a great time.

What is sporting clays you ask? Patience. Precision. But mostly exhilaration! Often described as "golf with a shotgun." Unlike trap and skeet, shooting clays are thrown in a great variety of trajectories, angles, speeds, elevations and distances, which simulates hunting conditions. It's great for novices and competitive shooters of all ages. Clay shooting is taking off as a favorite hobby in Western PA.

Sound like fun? Look for information about the 3rd Annual Shoot for SBAWP on our Facebook Page and come join us!



THANK YOU to every one of you who sponsored, donated, and/or attended the 6th Annual Purse Bash on November 19, 2019. This year's event was the biggest yet, with 200 attendees and raising over \$10,000!

In addition to the opportunity to win a designer purse or accessory there were various vendors, fabulous food by Aviva Brick Oven, spectacular spirits, a bountiful basket auction, winning wine pull, and a marvelous mystery table, ensuring that LOTS of ladies left the event with BIG smiles.

As a friend of SBAWP, you are the 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!

Mark your calendars for next year's event on November 14, 2020. Hope to see you there!



Purse Bash

THANK YOU

to our Sponsors:

Gold Sponsor



Reverse Raffle Sponsor



Purse Sponsors

*Rebecca Crim
Beth Duch
Betty Lou Luketich
Sherrie Murrman
Kathy Yetsick
Christine Shambach*

Beverage Sponsor



SPINA BIFIDA ASSOCIATION OF WESTERN PENNSYLVANIA
PRESENTS THE 7TH ANNUAL

AFTERNOON JAMFEST

SUNDAY, MARCH 29, 2020 1:00-5:00PM
JERGEL'S RHYTHM GRILLE, WARRENDALE, PA

TICKETS ARE \$10 IN ADVANCE
AVAILABLE AT SBAWP.ORG
\$15 AT THE DOOR
(COST DOES NOT INCLUDE FOOD OR DRINK)
BASKET RAFFLE AND 50/50

FEATURING



WALK FOR A HEALTHY COMMUNITY



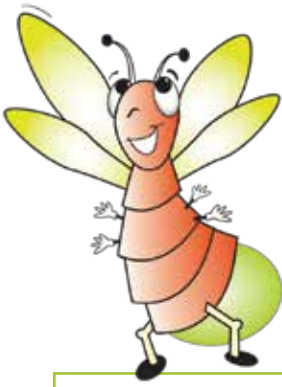
MAY 9

HEINZ FIELD

9:00 am

To register or to donate visit walkforahealthycommunity.org





Camps & Retreats

New Team Member

We are pleased to announce that Gracie Crim has officially joined our team as Manager of Youth Services. Gracie will work alongside Brennan McMahon in running the SBAWP Firefly Camps and Retreats programs.

Gracie is a very familiar face. She has been part of our team since she was very young as her parents, Randy and Rebecca Crim, first met as counselors at Spina Bifida Summer Camps. As she grew up, Gracie began volunteering her time when she could at SBAWP alongside her parents.

2020 will be Gracie's 5th summer camp. When she turned 18, she ranked up to Co-lead in our summer camps and was promoted to Assistant Manager the following year. Not only has Gracie worked for our camps and retreat programs, but she has also worked part-time as a direct care worker to the clients that we serve out in our community. Gracie has also volunteered at the annual SBAWP Jamfest at Jergel's for the last 4 years. In November 2019, Gracie did an outstanding job as Co-Master of Ceremonies for the Annual Girlfriends for Good Purse Bash. Because of her lifetime of commitment to the Association, in 2018 Gracie was awarded the Junior Chairman's Award for her dedication and services to SBAWP.

While Gracie dedicates so much time to the SBAWP, she is also a Division 3 student-athlete at La Roche University. Gracie is studying criminal justice, with the intent to graduate and enroll in a police academy. When she is not studying, Gracie plays collegiate women's lacrosse for her school.

Gracie never fails to make sure the campers are having the best time of their lives. One of Gracie's biggest goals in her position is to make sure everybody is smiling and having a great time always. Gracie's enthusiasm and energy are always sure to pick someone up!

We would say welcome Gracie, but she has been here for a while.



OUR FAVORITE TIME OF THE YEAR IS APPROACHING!

SUMMER CAMP DATES:

Youth & Teen:
June 28th-July 3rd, 2020
Adults:
July 5th-11th, 2020

In the meantime, our spring retreats will be scattered throughout the months before so we can still see our friends!

RETREAT DATES:

Youth & Teen:
March 13th-15th, 2020
May 8th-10th, 2020
Adults:
March 6th-8th, 2020
April 17th-19th, 2020

We are beyond excited for the new year and cannot wait to see what it holds!



Calendar of Events

March 2020

- 6-8 Adult Retreat
- 13-15 Youth & Teen Retreat
- 29 Afternoon Jamfest

April 2020

- 17-19 Adult Retreat

May 2020

- 8-10 Youth & Teen Retreat
- 10 Mother's Day Brunch
(Camp Guyasuta)
- 9 Highmark Walk

June 2020

- 13 Noll-Spratt Golf Outing
- 23-26 Camp Counselor Training

July 2020

- June 28-July 3 Youth & Teen Camp
- 5-11 Adult Camp
- 27 Boilermakers Golf Outing

September 2020

- TBD Clay Shoot Seven Springs

The 5th Annual **Noll-Spratt Golf Scramble**

Saturday, June 13, 2020



Beaver Valley
Golf Club
Beaver Falls, PA

(see page 10 for details)

Phone: 1-800-243-5787

Fax: 724-934-9610

www.sbawp.org • info@sbawp.org

Non-Profit Org.
U.S. Postage
PAID
Pittsburgh, PA
Permit No. 2535

SPINA BIFIDA ASSOCIATION OF WESTERN PENNSYLVANIA
PRESENTS THE 7TH ANNUAL
**AFTERNOON
JAMFEST**
SUNDAY, MARCH 29, 2020 1:00-5:00PM
JERGEN'S RHYTHM GRILLE, WARRENDALE, PA
TICKETS ARE \$10 IN ADVANCE
AVAILABLE AT SBAWP.ORG
\$15 AT THE DOOR
(MOST DOES NOT INCLUDE FOOD OR DRINK)
BASKET RAFFLE AND 50/50
FEATURING
FUNKY UNCLES
See page 13 for more details.



Spina Bifida Association
of Western Pennsylvania
3000 Stonewood Drive, Suite 100
Wexford, PA 15090