

# Kaleidoscope

*changing . . . adapting . . . growing*



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*changing... adapting... growing*

Fall 2012

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Donations may be made on line at:  
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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.

## { program updates

### ***Parents and Caregivers: Don't Miss Out! Join Us Monthly!***

**SBAWP and National Rehab have partnered together to sponsor monthly Spina Bifida Support Group Meetings on the second Tuesday of every month!**

Each month guest speakers join us to educate parents and caregivers about topics related to spina bifida. Every meeting is FREE and includes FREE childcare and light refreshments. Our meetings begin at 6:30 pm and last until approximately 8:30 pm. Please be sure to let us know if you need childcare so we can have enough care staff on hand for the evening.

The upcoming months are packed with good information you don't want to miss!

November 13th- TBD

December 11th - Dr. Brad Dicianno, Director of the Adult Spina Bifida Outpatient Clinic, Pittsburgh, Pa

January 8th - TBD

February 12th- PEAL Center-IEP Mini-Series: Part 1- Develo ping a Strong IEP

March 12th - TBD

April 9th - PEAL Center- IEP Mini-Series: Part 2- Working Effectively With Your School Team

May 14th - PEAL Center- IEP Mini-Series: Part 3-Parental Rights and IEP Clinic (includes information on Section 504 Plans)

Support Group will break for the summer months and will return in full swing September 2013!

Special Thanks to LaRoche College Students for helping with childcare, The PEAL Center, Dr. Dicianno, Melanie Dragovits, Achieva and all of our other speakers!

Please call (724) 934-9600 and speak with Barb Ruetschi and/or Rebecca Crim if you have any questions or would like to speak at our next support group meeting! Visit [www.sbawp.org](http://www.sbawp.org) for details on where the next support group meeting is! Find us on Facebook, too!

\*Meeting locations change on a monthly basis\*■



### **Steelers Raffle Benefits Firefly Camps and Retreats**

**2 tickets to  
Steelers vs. Bengals  
December 23, 2012  
1:00 p.m. at Heinz Field**  
**Autographed  
Roethlisberger Jersey  
\$200 CASH**

**Winning number from the  
Big4 PA Lotto held on:  
December 11, 2012 at 7:00 p.m.**

**\*If no winner it will go to the next  
night's lotto**

**ONLY \$1.00 a ticket!  
Contact the main office  
at 724-934-9600 to get  
your tickets today!**

**ARE YOU READY FOR  
SOME FOOTBALL?!**





**Kennywood!**

# BOOT CAMP



**Aye Aye Captain**



**Dance the night away**



**Sports maniac**



**Friends are friends forever**



**Swimming days are FUN**



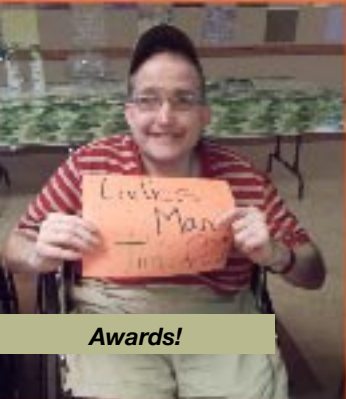
**Yummy fruit salad!**



**Friends**



**Fun in sports**



**Awards!**



**Catch of the day**



**Miracle League Baseball Fun**

## SEE YOU NEXT SUMMER!



Healthcare products you need.  
Service you deserve.

## Enroll in the Partners in Care Program

National Rehab (NR) is now offering Spina Bifida (SB) patients the opportunity to enroll in the Partners in Care Program. This program provides information and education about SB as well as support from two full-time WOCNs and Insurance and product specialists.

### REASONS TO ENROLL IN THE PARTNERS IN CARE PROGRAM

- Caregivers or families will benefit from having WOCNs address their overall supply needs.
- Product orders are then given to an Insurance specialist to determine what your Insurance plan will cover.
- Program addresses supply needs such catheters, incontinence (briefs & pull-ups), wound care and skin care items.
- Every patient that enrolls into the program will receive a welcome kit that includes a backpack, educational materials and Intermittent catheter samples provided by Hollister.

### HOLLISTER LATEX-FREE INTERMITTENT CATHETER

The Apogee Intermittent Catheter complements the growing Hollister Continence Care family. The ready-to-use packaging allows for clinical clean procedures. The Intermittent catheter gives patients the flexibility and control they need to manage their continence with confidence.

- Designed for comfort
- Ready-to-use
- Distinctive ultra-smooth eyelets
- Clean technique for Intermittent catheterization
- Full range of sizes available in two lengths, 6 inch (15cm) and 16 inch (40cm)
- Latex-free
- Straight or cove tapered tip available
- Curved packaging

For more information, please contact National Rehab (NR) at:

**T 1-800-451-6510**

When calling please reference Promo Code 101.

## { *partnerships & special events*



On May 19, 2012, 140 SBAWP supporters joined the more than 10,000 people gathered at Stage AE on Pittsburgh's North Shore to participate in the 2012 Highmark Walk for a Healthy Community. Walkers from more than 70 local non-profit organizations had a perfect day for the 5 K walk through the North Shore and downtown Pittsburgh that raised \$485,000 to benefit their organizations. Highmark Blue Cross Blue Shield underwrites 100% of the cost of the events and all the funds raised go directly to support the charities.

This year's event marked SBAWP's third year of participating, and we were pleased to have a record number of walkers registered in 2012. We already have our calendars marked for the 2013 Highmark Walk for a Healthy Community on Saturday, May 18, 2013!





# Entertainment Books and Enjoy Books

## Save Money and Help SBAWP:

The Entertainment and Enjoy Books are filled with money saving coupons for restaurants, movies, travel, theaters and much more. Two or three coupons will pay for the price of the book, which is good from the time you purchase it through



November 2013, more than a year's worth of savings. SBAWP will earn between 40% and 50% of the cost of each book, all of which will support the programs of the Spina Bifida Association.

## How You Can Help:

Buy the Entertainment and Enjoy Book(s) from SBAWP for yourself or as gifts. Call Diana at 724-934-9600 to place an order.

Share this information with your friends and family through e-mail and/or phone calls.

Family or friends who live in other parts of the country can also help. They can purchase an Entertainment Book that serves their area online [www.entertainmentbook.com](http://www.entertainmentbook.com). SBAWP can get credit for the sale if you use the purchase code 744196. Thank you for supporting SBAWP!



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# Fourth Annual Summer Festival

## Sponsored by Seubert & Associates

**An unseasonably cool and overcast day could not dampen the spirits of those in attendance at the Fourth Annual Summer Festival presented by Seubert and Associates on Saturday, August 11, 2011.** Between 500 and 600 people attended the event, SBAWP's largest annual fundraiser and a great day of fun in Blueberry Hill Park in Franklin Park.

There was something for everyone at the Festival. The kids enjoyed a Bounce House and inflatable slides provided by ELF Entertainment, and Spinning the Wheel for prizes. Kids got "artsy" with glitter tattoos, sand art, and candy art. Carol Vicini and Steel Dog read from "The Adventures of Steel Dog" for the little ones, and Steel Man, the Pirate Parrot, and Max and Erma mingled with the crowd.

People of all ages enjoyed playing and competing in horseshoes and archery and trying their hand at a corn hole toss. Bingo provided some indoor recreation and prizes for some of the bigger "kids" in attendance. Festival goers could win a number of auction baskets and prizes, including merchandise from the Steelers, the Penguins and the Pirates, day spa packages, Steeler tickets and much more!

Pets (and their owners) got to strut their stuff for fun and prizes in this year's Pet Parade. Congratulations to Golden Doo-

die Jude Smith and his owner Colby Smith for taking Best of Show.

Joe McCormick, SBAWP Board President and Dick Smith, Chairman of the SBAWP Board presented the Chairman's Award to Ann Hill, Gatehouse graduate and a long-time friend and supporter of SBAWP programs.



Live music entertained Festival goers throughout the day. The North Star Kids kicked off the performances, sparkling as they delighted the crowd with a selection of Broadway show tunes. Just Us and Southern Comfort thrilled with some cool

jazz, while Priest, Sage, Roots and Soul, The Humans and headliner Midlife Crisis jammed with some classic rock and roll. Festival goers had the opportunity to take their own turn behind the mike with some Karaoke in the Community Center.

We are especially appreciative of all who contributed so much to make this event such a success, all for the benefit of SBAWP programs, including: the Summer Festival Committee, our Corporate Sponsors and Donors, Auction and Prize Donors, the Fund Development Committee, SBAWP Board and Staff, and all our tireless volunteers. ■



## New Friends and Old Friends of SBAWP Come Together for Good Food, Good Fun and a Good Cause!

### Old Friends...

Once again, the Boilermakers Local 154, the Steamfitters Local 449 and the Ironworkers Local 3 hosted the Tony Yakemowicz Annual Golf Tournament for the Spina Bifida Association of Western Pennsylvania. The event was held July 30, 2012 at the Hickory Heights Golf Club in Bridgeville, Pennsylvania where 32 foursomes enjoyed a delicious brunch, mid-afternoon sandwiches and a great steak dinner.



Dan Quinn, Financial Secretary-Treasurer for the Boilermakers, has led the preparation for this very successful tournament for many years along with Raymond Ventrone, Business Manager. This year's outing had over 70 sponsors and donors! Golfers had a chance to win \$1 million on a hole-in-one, new cars on

dreds of children and teens with spina bifida and other related disabilities to summer camp. Together they have worked to give these deserving individuals a summer experience like no other! The theme for the 2012 Summer Program was "Boot Camp". At camp, youth who often are isolated by their disability receive the support and encouragement that enables them to embrace success by participating in the many activities and challenges in daily life.

SBAWP gives a special "Thank You!" to Dan Quinn and all the sponsors and dedicated individuals who have supported this event for the past 24 years!

### New Friends...

SBAWP partnered, for the first time, with the Men in Christ Pittsburgh Smoker Ministries for their 11th Annual Gentlemen's Night - The Pittsburgh Smoker dinner and charity event held at the IBEW Circuit Center in the South Side on May 24, 2012.

Special Guests included Bill Hillgrove, voice of the Pitt Panthers and Pittsburgh Steelers, as well as, Randy Grossman, member of the first four Pittsburgh Steeler Super Bowl championship teams. Local area businessmen and women united with Pittsburgh sports figures for dinner, talk, entertainment, prize drawings, and silent and live auction items, including sports memorabilia.

*During the 24 years that the Unions have been golfing together, they have helped to send hundreds of children and teens with spina bifida and other related disabilities to summer camp.*

holes-in-one, a set of golf clubs and numerous other prizes. Awards were given for other skill items in addition to a silent and live auction of sports memorabilia.

During the 24 years that the Unions have been golfing together, they have helped to send hun-

Proceeds from this event benefitted SBAWP, the Fellowship of Christian Athletes and several other local charities. SBAWP gives a special "Thank You!" to the Pittsburgh Smoker Ministries as we look forward to partnering with our new friends again next year! ■

## 20 Years



For Jody Ahern, SBAWP Gatehouse Manager who celebrated her 20th year with SBAWP this year, it all started with a tiny want ad in her college newspaper from SBAWP looking for camp counselors. She applied and was hired a few weeks later to work as a Camp Counselor for Camp Variety for Spina Bifida the following summer.

"It was kind of crazy," says Ahern, "I knew nothing about spina bifida and had never been around individuals with disabilities."

She learned quickly, and came back to work as a Unit Coordinator at the Camp for the next two summers. During the Fall and Spring of those years she also worked at the Weekend Retreats, a new program being offered by SBAWP.

Following her third summer working with the Camps and Retreats programs, Ahern was approached by Andrew Kiefer, then manager of the Gatehouse Program, to see if she would be interested in working in the residential program which helps young people with spina bifida to make the transition to adult life. She started out working a long weekend shift, and then assisted with community integration and vocational placement. As an Aftercare Coordinator, she followed up with past graduates of the Gatehouse.

Ahern was promoted to Assistant Gatehouse Manager, and eventually to Gatehouse Manager, a position she still holds today. "I really think it's just where I'm meant to be," says Ahern.

Ahern married her husband, also named Jody, in 1998 and they have three children – 11-year-old daughter Devynn, 7-year-old son Dylan, and their four-legged "baby" Rocky (their yellow lab). But Ahern also explains that "the families of the SBAWP have become my second family."

## Meet our Newest SBAWP Housing Board Members!



Theresa Marie Crytzer, DPT, ATP, is an Assistant Professor in the Rehabilitation Science and Technology Department at the University of Pittsburgh. Her clinical responsibilities as a physical therapist involve evaluating

individuals with multiple disabilities, including people with spina bifida, for wheelchairs at the UPMC Center for Assistive Technology. Her research is focused on spina bifida and exercise. Theresa was the recipient of the 2011 Spina Bifida Association/Ashley Rose Foundation Young Investigators grant to investigate whether there are cardiac or pulmonary limitations to maximal exercise in adolescents and adults with spina bifida. Theresa was also the recipient of the Spina Bifida Research Award, Honorable Mention, recognizing the presentation of original research that significantly contributes to the scientific and medical literature at the 2nd World Congress on Spina Bifida Research and Care in Las Vegas, Nevada, March 11 - 14, 2012 for a paper on Exercise Capacity of Adults with Spina Bifida. In June 2011, Theresa completed a T32 post-doctoral study involving individuals with spina bifida exercising on either a GameCycle or Saratoga arm ergometer who were randomized to receive text message reminders or no reminders to exercise. She completed this work with her mentor Dr. Brad Dicianno, a nationally and internationally regarded expert in the medical management of spina bifida and Ms. Andrea Fairman, a highly respected researcher and occupational therapist in the field of spina bifida research. Theresa co-authored a research study published in Pediatric Physical Therapy, related to a community-based fitness program for children with disabilities. Prior to her post-doctoral studies Theresa

provided full-time physical therapy services and assistive technology to children age 3 to 21 with visual impairment and multiple disabilities at the Western Pennsylvania School for Blind Children for several years. She graduated with a doctoral degree in physical therapy from Slippery Rock University in 2000 and has a Bachelor of Arts Degree in Psychology from Carlow University. Theresa was a previous HOPE network assistant volunteer coach for the Steel City Starz, Pittsburgh's womens wheelchair basketball team. Theresa currently volunteers her time and expertise to the Spina Bifida Association of Western Pennsylvania as a member of the SBAWP Housing Board of Directors. ■



Dr. Ashli Molinero is an Assistant Professor in the Department of Rehabilitation Science and Technology at the University of Pittsburgh, School of Health and Rehabilitation Sciences (SHRS).

Dr. Molinero earned her Doctor of Science degree in Information Systems and Communications from Robert Morris University in 2004 and her Master in Education degree in Instructional Design and Technology from the University of Pittsburgh in 2001. Her experience includes over 10 years in web development and accessibility for people with disabilities.

As an educator, she currently teaches on ethics and the health related professions and the individual and social experience of disability. Prior to joining the faculty at SHRS, she taught advanced information systems analysis and design and e-business strategies at both the undergraduate and the graduate levels in the Department of Computer and Information Systems at Robert Morris University and the School of Leadership and Professional Advancement at Duquesne University. ■





## First Pitch

As a child growing up in Washington County, Diana Schwab (an employee in the SBAWP Gatehouse Program) would lie in her bed during baseball season eagerly listening to Bob Prince announcing Pittsburgh Pirate games on the Pirate transistor radio that her grandfather gave her. She dreamed of one day throwing out the first pitch

*She dreamed of one day throwing out the first pitch out at a home game for her beloved Pirates.*

out at a home game for her beloved Pirates.

Schwab fulfilled that lifelong dream when she threw out the first pitch when the Pirates took on the Atlanta Braves on Monday, October 1, 2012 at PNC Park. However, the road from her childhood home to PNC Park was far from easy.

In July of 2010, Schwab was a busy wife, mother of two teenaged children and a staff RN for the Bariatric Center when she was diagnosed with Ovarian Cancer, Clear Cell, Stage III, at the age of 49.

Schwab started chemotherapy treatments in September of 2010, and finished that initial phase of chemo in January 2011. She was now in remission, but when she was asked to be a part of a study for a new cancer drug called Avastin she readily agreed, although it meant an additional 15 chemotherapy treatments.

“As a nurse I know how important these studies can be in finding new ways to treat diseases,” explains Schwab, “so I really felt as though I had no choice but to participate.” She finished her Avastin treatments in January 2012.

In May 2011, while still in treatment on Avastin, Schwab visited the Spina Bifida Association of Western Pennsylvania (SBAWP) Gatehouse Program where she worked as a Wellness Coordinator in a study funded by a grant from the Highmark Foundation from 2007 to 2009. She decided she would like to return to the program which helps young people with spina bifida and other disabilities as they make the transition into living in the community. She returned to the Gatehouse staff as a part-time Life Skills Instructor (LSI) in

June of 2011, and she uses her background as a nurse to work on nutrition and menu planning with the Gatehouse residents.

In July of 2012, two years after Schwab's diagnosis, Margaret Malanosky, her 76-year-old mother, sent a “prayerful request” to Pittsburgh Pirates president, Frank Coonelly. Malanosky explained that her daughter had “always been a true-blue, diehard PIRATE FAN” and asked him to help Schwab celebrate the “second year of the rest of her life” by fulfilling her fondest wish to throw out the first ball at a Pirate game to her hometown hero, Neil Walker. Coonelly obliged.

So, on October 1st, Diana Schwab lived out that life-long dream. Rooting her on from the stands was her husband Bob and several excited Gatehouse and Fithian House residents. Her mother (after a meeting with Frank Coonelly) and her two children, Sydney and Bo, accompanied her on the field. She was also wearing a pair of sneakers loaned to her by Gatehouse resident Anthony Martin as she finally threw that long-awaited pitch to Neil Walker. ■

# Calendar of Events

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## November, 2012

- 13 | **Spina Bifida Support Group** 6:30-8:30 pm
- 16-18 | **FireFly Adult Retreat** at Family Retreat Center
- 30-12/2 | **FireFly Adult Retreat** at Family Retreat Center

## December, 2012

- 11 | **Spina Bifida Support Group**

## January, 2013

- 8 | **Spina Bifida Support Group**

## February, 2013

- 12 | **Spina Bifida Support Group**
- 15-17 | **FireFly Adult Retreat** at Family Retreat Center

*\*For details please visit [www.sbawp.org](http://www.sbawp.org)\**





# Gone to the Dogs

**Theresa Chutz has gone to the dogs.....literally!  
She has been a volunteer at the Western PA  
Humane Society since April of 2005.**

"I worked for the North Hills YMCA for two years as a camp counselor and as an after school aide. When I was laid off due to budget cuts, I began looking for something else. I heard about a volunteer position at the Humane Society".

She went down to check it out and found that the position was for an assistant trainer in the Puppy Preschool. Being an avid dog lover, Theresa jumped at the opportunity. Eventually, she decided to check out other positions at the shelter. She did all sorts of things, such as grooming dogs, cat cuddling, and, with assistance, walking the dogs.

"After exploring the various things available, I discovered that I really liked the customer service position best. I became

a greeter at the Welcome Desk. My main responsibility was to be at the front of the shelter and make people feel welcome. I liked the people that I met and seeing all of the animals that came in.

Just recently, I was moved from there to the Adoption Center, which is a little further back in the building, closer to the kennel and two other rooms where the animals are housed. This was for my safety because sometimes animals are brought in that the owners cannot control. I love working in the Adoption Center because not only do I greet the customers as they come in, I also get to greet my fellow volunteers and the paid staff. Right beside the kennels is the door that the dog walkers use to enter and exit the shelter. We affectionately call it the "doggie door". When the dogs come in from their walks, the dog walkers sit down with me and allow me the chance to interact with the dogs. As I pet the dogs and spend time with them, I get lots of dog kisses. There are days when I wonder why I wash my face because the dogs have done it for me". Another reason Theresa likes being at the Adoption Center is "because I get to talk with people who are excited about getting an animal. It is bittersweet for me when one of my favorite dogs is finally adopted. While I am happy that they are being adopted, it is sad to see them go. However, I do not want to see them back unless it is for obedience classes. I love to talk with the new owners and my final word of advice to them is "do me a favor and spoil them rotten".

*She has compassion  
for the animals that  
have had a hard life  
or were returned.  
Her goal is to show  
them love and to  
help them to find a  
forever home.*



Theresa gets very close to the animals, and is concerned about their well-being. "I have learned that you can't be in the animal care industry without getting attached. If you do not find yourself getting attached, don't do it". Theresa knows the history of all of the animals. "They are my kids". She knows the name of every dog and cat in the shelter. She also knows every volunteer and staff person. She attends and/or helps out at every shelter event.

While Theresa loves the "happy" moments, there are some that are not so happy. The surrender of animals, the animals that were confiscated from cruelty cases, the times when an animal is humanely euthanized, when customers feel the surrender is taking too long and just leave, abandoning the animal. "When I hear about an animal being returned for any reason, I go back to the kennel or cat room and visit with and comfort that animal. I always feel bad when an animal is brought back. It is even harder when I am there and see it happening."

Theresa thinks about the animals 24/7. Not a day goes by that she does not talk about them. "It is like a family. We look out for each other. Everyone knows how much I care about the animals so I am kept as informed as possible about everything that goes on there. It makes me feel good. There is no place else I would rather be".

Part of Theresa's job is to visit with and socialize with the animals. She pets and plays with them, gives out treats and talks to them. She has compassion for the animals that have had a hard life or were returned. Her goal is to show them love and to help them to find a forever home. Theresa's face lights up like a lit Christmas tree when she talks about the animals and good times at the shelter. On the other hand, she gets very emotional when talking about the bad times. She is a definite animal advocate and it shows in everything she says and does.

Theresa owns a cat named Oreo, whom she adopted from the shelter. While Theresa would love to own a dog, she feels that her current living situation is more suited to having a cat. Around Thanksgiving of 2006, her dad told her to pick out a cat at the shelter. In the cat room, "it was mutual love at first sight between me and Oreo". Oreo is a black and white domestic short hair cat. He was a stray on the streets of Latrobe. He was brought to the shelter where it was determined that he had no owner, so he was put up for adoption. Living with Theresa, Oreo is a changed cat. He used to be very skittish and would not let people touch him. Not anymore. He is a happy cat in a happy home.

With Theresa's great love for animals, volunteering at the Western PA Humane Society is a perfect fit for her. ■



## **Show your support of the Firefly Camps and Retreats by purchasing a beach towel or tumbler!**

Beach towels are 100% mid weight cotton and are 60"X30" with the Firefly logo printed on them. Towels sell for \$15.

Tumblers are insulated double walled with screw on lid and straw. The Firefly logo is pressed between the walls of the tumbler. Tumblers sell for \$8.

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