

# Kaleidoscope

*changing . . . adapting . . . growing*



## **Any Dream Will Do**

Page 4

## **What's In a Name?**

Page 6

## **Disability Awareness Night 2009**

Page 22

# Kaleidoscope

changing... adapting... growing

Summer 2009

## Contents

**3** A note from Dick  
The Fourth of July *by Dick Lynch*

**4** In Your Interest  
Any Dream Will Do  
A Story of Survival

**8** Program Update  
What's In A Name?  
Camp

**12** In the Community  
Unions Tee Off for Spina Bifida Camps  
First Annual Spina Bifida Summer  
Festival Attracts Hundreds

**16** Get Involved  
Special Thanks for an Overwhelming  
Number of Volunteers  
Introducing the BluePrints Program  
2010 Entertainment Books Available

**22** Activities & Events  
Calendar of Events  
Disability Awareness Night 2009

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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.





## *The Fourth of July*

There is something about an outdoor concert and fireworks on the Fourth of July! There is something about sitting under an open sky and hearing songs like “And the Band Played On” and “Stars and Stripes Forever”. During my lifetime, I have had the privilege of hearing the Pittsburgh Symphony at the Point; the Boston Pops on the Esplanade along the Charles River; and this year, The River City Brass Band by the lake on the campus of Westminster College in New Wilmington, PA.

As I sat on the hillside at Westminster, I was reminded of the freedom that is ours and of the men who took that first faithful step in Philadelphia. They are people like John Hancock and Thomas Jefferson. It took courage to sign a document that could just as easily have brought death rather than freedom. And indeed, over the decades, many have given their lives in preservation of what those individuals started 233 years ago.

I was reminded of those who first formed SBAWP. They are people like Howard and Carolyn Burrell who incorporated the Association; then served the Association for many years; and who continue to serve the Association even to this day (Howard is Secretary of SBAWP Housing, Inc. - The Fithian House).

I was reminded of those who are helping to preserve what was started. They are people such as the late Ted Fithian who volunteered countless hours in service to SBAWP and Pete Kochis who has picked up where Ted left off. There are those who started with us as a camp counselor and have continued to serve the Association. They are people like Jody Ahern, Wayne Martin, and Rebecca Crim.

At each concert, when the music fades and darkness falls, the fireworks light up the sky! I was reminded that while there is celebration, we still have much more to be done. We still have camps and retreats that we want to offer but each season, indeed each passing month, the cost of operating a retreat or camp continues to increase. **As an Association, we will commit to you that we will stretch every dollar that is given to insure that we provide the service to the individuals who are in need. But those rising costs are putting our camps and retreats in jeopardy! Fall may see a scaled back schedule from the one shown on page 22 unless we can raise \$75,000 now.**

Let us redouble our efforts and commitment to continue to serve those with Spina Bifida and their families! Thank you for your generosity in helping in this cause! Thank you for your continued support of SBAWP! Now ... Let the fireworks begin!

A handwritten signature in black ink that reads "Dick Lynch". The signature is written in a cursive, flowing style.

{ *in your interest*



Any  
Dream  
will do

***Do you remember those times when you sat and looked at the clouds and imagined what you could see? Do you remember having a vision for something so great and all encompassing that your first reaction was, “I can never accomplish that!”***

Then as the years pass and small steps are made toward that goal, do you remember pausing to think, “We have a chance! We are close to making this happen!”

The SBAWP dream started forty years ago with a parent support group and along the way, bit by bit, the Association grew. In 1979, we successfully advocated for supplemental health insurance for Pennsylvanians with Spina Bifida. In 1981, we hired our first professional staff. In 1983, Camp Variety for Spina Bifida was created and our first summer camp program was held in 1984.

Our Family School Partnership program celebrates its 20th anniversary this year and our Gatehouse program has just “completed high school” – it is 18 years old! In 1998, SBAWP created the Woodlands Foundation to market, manage, and maintain the 32-acre camp facility. With that move, SBAWP became a tenant and a user of the facility. And since that time, we have seen innumerable changes in the facility itself.

The spinoff of the Woodlands was a strategic move to enable the Association to concentrate on our mission of providing

the continuum of services to individuals with Spina Bifida and to their families. The Woodlands Foundation is now a separate, standalone entity with its own mission statement and thrust as well as its own staff for fundraising and development. Contributions to the Woodlands are for the benefit of operating that facility while contributions given to SBAWP are directly used to benefit individuals with Spina Bifida and others with disabilities whom we serve.

Unencumbered by the burden of operating the camp facility, we have grown and developed new initiatives. Initiatives such as the expansion of the Gatehouse program through community living support and the newly opened 14-unit handicapped accessible apartment complex. Initiatives such as the STRIVE vocational program to help individuals seek and maintain competitive employment. Initiatives such as our BluePrints program to provide toddlers with Spina Bifida and other disabilities the opportunity to gain motor and sensory skills.

With that growth, we needed to expand beyond the campus that we called home for many years. We needed space within the community to operate these various programs. We needed to pull together our administrative, marketing, and development staff in order to be more effective in our support of the programs.

To do that, and to provide a home for our STRIVE program, the first step was to relocate our offices to the Cranberry area. In May, we made the move to the intersection of Dutilh and Freeport Roads. Our volunteers and staff

have been hard at work transforming the space into our new home.

When the parent group first met in 1969, they may not have had the dream of an Association with wide-ranging programs for every age – but that is what the Association is today. Your generous contributions to SBAWP are used for one main purpose – to assist those with Spina Bifida and their families.

*Your generous contributions to SBAWP are used for one main purpose – to assist those with Spina Bifida and their families.*

The musical, Joseph and the Amazing Technicolor Dream Coat, contains a song titled, “Any Dream Will Do”. In our case, it is not “any” dream; it is a “specific” dream – a dream to help those with Spina Bifida to live active, productive, independent lives. During our current economic climate, your contributions to SBAWP are more important than ever before! Please take a moment to send us a donation or contribute online at [www.sbawp.org](http://www.sbawp.org) so that this dream can continue!■



# A Story of Survival

*The story of June Lazier*



From Left to Right: Donna York, June Lazier, Shirley Camp, Georgia Ann Mahl, Debbie St. Clair, and Lori Baird

On April 19th, 1949, Lenore and George Lazier gave birth to their fourth daughter, June Lazier, at their home in Boswell, PA. Right after her birth, the Lazier's doctor diagnosed baby June with spina bifida and told Lenore and George that their newborn would not live past two days. The doctor recommended that the Laziers leave baby June at the hospital to live out what little life she had left. Lenore and George adamantly refused the recommendation and brought their daughter back home insisting that June was their baby and that they would not leave her.

Sixty years later, June's recollection of the story her mother told her many times about her birth, still moves her in a way that only a mother's love of her child can. Not so long ago, the average life span for an individual with spina bifida was 30 to 40 years, with renal failure as the most typical cause of death. Because of improved medical care, especially urologic management, people with spina bifida are living long lives.

The SBAWP was fortunate to hear about June's story of survival through her sister, Donna York, in a recent email to the association. We were not only inspired by June's age but also very curious as to how June had "made it" this far assuming that fifty years ago, individuals with disabilities surely had to struggle much harder to survive than those who are born with a disability today. When we shared June's story with six month Gatehouse Resident Lindsay Speak she had many questions for June and June was more than happy to answer them. June's responses were eye opening to say the least and a reminder that although we have come a long way in improving the quality of life for individuals with spina bifida and other disabilities, we still have a very long road ahead of us.

**Q: Were you teased as a child by other children who didn't have a disability?**

A: No, never. I think kids are different these days. They know more and are exposed to more adult things. No one ever even asked me why I wore braces or used crutches.

**Q: Were you ever treated differently by your family or family friends?**

A: No, never. My family and all of our family friends treated me well. They never made me feel bad or left out.

**Q: Did you ever have a moment in your life when you wished you didn't have a disability? If so, how did you get through it?**

A: Sure I have, but you have to go on with your life. It is what it is. A friend of mine got into a really bad automobile accident that left her paralyzed. She was so mad at the world for such a long time. But it's just no use to be that way. You are what you are, you were given what you were given and sometimes things get taken away from you, like with my friend, but you just have to accept it and face life with a smile each day and keep going. But, I have had my moments. My family and God helped me through all of those times and it always made me feel loved and blessed. That's how I got through it.

**Q: Have you ever had a job?**

A: Yes, I sold Avon once, it never amounted to much though. My parents took care of me and when they passed away they left me my house, the one I was born in. When I was 19 my Dad bought me a CB Radio Device. Back in the day before Mapquest and GPS systems, I would help delivery/truck drivers get directions from route

219 to the turnpike and so forth. I would be there for them during a really bad storm and sometimes I would be up at all hours of the night helping folks out. It was one of the best presents my dad ever gave me. I didn't get paid to do it, but I did it for fifteen years and it was so much fun. I made a lot of friends and used to go to a lot of "CB" parties with other people who were on the radio.

**Q: Was it ever hard for you to get a job?**

A: Oh yes, I never even knew where to start and it was intimidating. You need confidence and training to get a good job. I didn't think that people would have been okay with hiring me, so I never pursued it that much. Also, people just didn't understand (and sometimes still don't) how hard it is to get around when you have a disability. Getting out of a chair and into a car (if you can drive) and going to an office where nothing is accessible at all, not even the front door, didn't help matters. I know it has gotten much better but can you believe that there are still so many places that aren't accessible?

**Q: What kind of tools and technologies did you have as a young adult to help you live more independently?**

A: Well, when I was younger I didn't even have a wheelchair; I rolled around on the floor to get around my house. I used to roll up the steps to get to the bathroom to take a bath and downstairs there was a portable bathroom for me to use. Things were different back then, even the kitchen cabinets were higher, I could never reach anything. I depended on my parents and my sisters. I eventually got braces and crutches but it got harder as I got older to get around. I eventually got a wheelchair and when I got older I could drive.

**Q: Have you ever had a relationship?**

A: Zilch. I met a boy once on the CB, we talked a lot but it never amounted to much. He didn't have a disability. It's very hard and it's so unfair. The first thing anyone sees is your wheelchair. I wish folks could understand that there is a very real person with wants and needs sitting in it. If there is one thing in the world I could change that would be it.

**Q: What did you do for fun as a kid?**

A: I was home schooled when I was little but then I went to Gladehurst School for the Physically Handicapped. That's where a lot of my friends

were. We used to talk on the phone a lot and we did school plays together. I was Mary once and my friend was Joseph in a play, it was so fun. When I was a teen I also stayed at the Crippled Home for Children in Pittsburgh on the weekends, I had some good friends there to. Once I was done with school, friends from school sort of faded away but I had a lot of fun doing things with my family.

**Q: Have you done a lot of traveling?**

A: Yes, I have done some. My sister Donna took me on my first vacation ever to Niagara Falls. I have been to Arizona....that was a hard trip....., Rhode Island to visit my sister, and recently to Las Vegas to celebrate my 60th birthday with my sisters. We had a blast! I never went abroad. It was just too hard. There are a lot of obstacles when traveling. For instance, I need to have my clothes washed every day. If you can't stay somewhere that has an accessible laundry facility, what do you do? (Visit <http://www.disabledtravelers.com> for more info.)

**Q: If there was anyone you could meet, who would it be?**

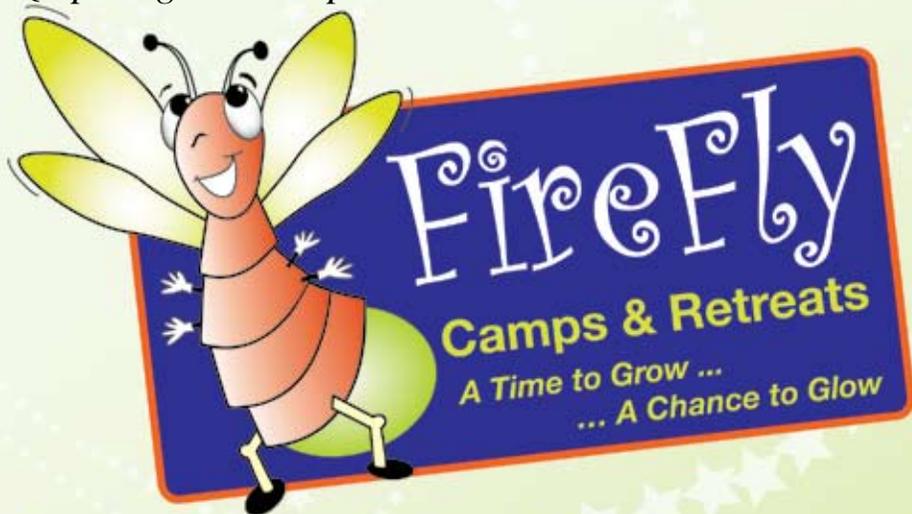
A: Joni Eareckson Tada, she is an inspiration. A diving accident left Joni a quadriplegic in a wheelchair when she was 17. After two years of rehabilitation, Joni came out with a determination to help others in similar situations. Joni has authored a bestseller, she has a radio program, a film called Joni and she has her own TV show, "Joni and Friends". (Visit <http://www.joniandfriends.org> for more info.)

**Q: Is there anything else you would like to share?**

A: I didn't have the bulge on my back repaired until I was eleven years old. It's not like it is now where it gets removed after you're born. My mom got a job at the hospital cleaning rooms just so she could be near me past visiting hours while I went through the long recovery. My parents are gone now. My dad died in 1979 and my mom in 1986. I just wanted to thank them and my sisters for always taking care of me and I wanted to give thanks to God for giving a little newborn who didn't have more than two days to live a lifetime. ■

*For more information on aging with spina bifida please visit us at [www.sbawp.org](http://www.sbawp.org), click on "What is Spina Bifida?"; and then on Stages of Life: Aging with Spina Bifida.*

{ *program update*



**What's in a name?** By definition a name is a word or combination of words by which a place is designated, called, or known. When naming something or someone we often attempt to give them a name that has meaning, either for us personally or is representative of something that we cherish or hold dear. In either case, we put a great deal of effort and thought when we place a name on something or someone.

For as many years as anyone reading this can remember the developmental camping programs offered by the Association have been mostly nameless. We have been defined simply by where the program was located. When the camp program began in the late 1980's the camp was called Camp Variety for Spina Bifida and then became The Woodlands in 1996. However, these are names of a facility and do not at all capture the identity or the essence of the programs that the Spina Bifida Association of Western PA conducts. The property at that time was being leased exclusively to the Association

and therefore it was acceptable that the name carried over into the program.

With the creation of the Woodlands Foundation, the Association became a user of the facility and the Association programs have been without a name. The programs were simply called Circle of Friends, Youth/Teen camp, etc.

**They are given the opportunity to shine and rise above their disabilities; to make friendships; and to experience success.**

Early this year, we decided that we wanted to name the programs both to attempt to capture the essence of our programs and to identify our programs as being those of the Association.

Firefly Camps and Retreats is the new name of the developmental camping programs of the Association. The motto of the program is, "A Time to Grow – A Chance to Glow." But why did we choose the Firefly?



First, fireflies are the Pennsylvania state bug. Since we are the Spina Bifida Association of Western Pennsylvania, we felt it an appropriate choice. Our camps have always been a place where an individual can “grow”. While attending programs, whether they be the summer or weekend retreats, individuals with spina bifida and related disabilities are empowered and, in essence, have the opportunity to “glow”. They are given the opportunity to shine and rise above their disabilities; to make friendships; and to experience success.

As children, and even as adults, when we look into the summer night and see it light up with the flashes of fireflies we want to capture that moment and remember it forever. That is our second reason for choosing the name – camp creates wonderful memories that we want to jar up and keep with us wherever we go! That way when life gets us down, we can simply look at our jar of fireflies and remember that we have strength.

As with any change we realize that there may be some questions, so we are going to attempt to answer some we anticipate. However, if you have any other questions, please do not hesitate to give us a call!

#### **Will there be changes to the program?**

The program will stay the same. Firefly Camps and Retreats is simply a name change. The program continues to be a program of the Association. We will continue to offer the weekend retreats and summer programs to individuals with spina bifida and related disabilities.

#### **Will the location of the camp change?**

One of the major benefits of creating

the Woodlands Foundation to manage the camp property is that the Association can run programs wherever they are needed. We will continue to run some programs at the Woodlands property but some may be held at other camp properties.

#### **Will this change anything else?**

No, nothing else will change. The philosophy of the programs will stay the same. The program will stay the same. The leadership will stay the same and most importantly the goal of enriching the lives of individuals with spina bifida will stay the same.

#### **When will this take place?**

We will begin using the name Firefly Camps and Retreats with our fall retreat season.

#### **Is this a permanent change?**

Yes, we have been considering giving our developmental camping programs an identity for some time now and believe that giving our program an identity is crucial to the future success of the program.

#### **Will the registration process change?**

You will still receive your mailings for the programs from the Association. You will have the ability to register online for retreats this fall (please check the website for details) or you can continue to register by mail by sending it to our new Association office address – 1158 Dutilh Road, Mars, PA 16046. You will continue to make your checks payable to SBAWP.

#### **I have other questions. Who can I talk to?**

Rebecca Crim will be happy to field your additional questions. Her number is 724-935-5433 or you can email her at [rcrim@sbawp.org](mailto:rcrim@sbawp.org). ■ 

# Camp

## Circle of Friends Camp Kicks Off Season

June 7th saw the return to the Woodlands campus of adults attending our Circle of Friends camp. The theme for all of our summer camps this year was “A Summer Round-Up”.

And what a round-up it was! One night saw a rodeo and a rodeo clown contest. Everyone thought it was funny! Josh Minnich’s choir came one night to provide a mini-concert and Jess Cogis’s Fashion Show with the campers has become an annual tradition.

Cooking around camp is always an exciting experience. This year, the campers made

smokey white pizza, bacon ‘n’ cheddar bubble bread, granola bars, and salsa! Plus, every night, the campers made the camp snack!

In art, they finally found a good use for all of those syringes that some are accustomed to seeing – they painted with them! The best art project ever was the “Wanted” signs that featured each camper and provided decorations for the big dance on the last night of camp.

Sports also played an important role during the week with everything from capture the flag, to baseball to basketball to archery! But the sport highlight of the week was watching the Penguins victory parade on the big screen TV!

## Mentor Weekend and Youth Camp Round Out the Summer

Mentor Weekend started off the July 4th weekend with a bang! Twenty-six campers poured into camp on July 3rd to be a part of the experience.



Then on Sunday, July 5th, another 23 campers arrived to fill the camp cabins at 49 for the week. Carrying on the Summer Round-Up theme, we watched as each individual posed for their personal “Wanted” poster. Then the counselors would painstakingly “burn” the edges and mounted them on paper so that it looked like the real thing!

The camp newsletter was a hit as each person had the opportunity to contribute to it. The pool party is always a hit at Youth Camp and this year was no exception.

Everyone agreed that everyone’s favorite memory of camp was the Tuesday trip to Kennywood! The folks at Kennywood Park had graciously donated all day tickets so that the campers and the counselors could enjoy the day and the rides!

We brought out the stars on Thursday with our first camp talent show. There were some singing routines, some acting, some art and the counselors brought down the house with their rendition of It’s Raining Men. A great time was had by all.

We of course ended our week at camp with a dance and ending ceremony. We danced into the night and then circled up to share our favorite memories of the week. It’s always so sad when our time together comes to an end, but we know that we will all be together soon at a retreat. ■





*Playing for SBAWP were (left to right) Mike Goldbaugh; Wayne Martin, Manager Adult Community Services; John Liebguth, SBAWP Director; and John Conwell.*

## UNIONS TEE OFF FOR SPINA BIFIDA CAMPS

For over 20 years, three local unions have joined hands to sponsor the Tony Yakemowicz Annual Golf Tournament for the Spina Bifida Association of Western Pennsylvania. The Boilermakers Local 154, the Steamfitters Local 449, and the Ironworkers Local 3 have raised over \$500,000 for Spina Bifida camps.

Each year on the last Monday in July, foursomes take to the links to help send dozens of children and teens with Spina Bifida to camp. This year's event was held on Monday, July 27th at the South Hills Country Club. In prior years, the field was limited to 36 foursomes but for the past two years, the number of foursomes was expanded to 50. This year, 15 foursomes teed off in the morning and 36 in the afternoon.

The day includes either breakfast or brunch,



*Dan Quinn of the Boilermakers organizes the annual outing for SBAWP*

depending on the tee time, and dinner that evening. Special awards for a hole in one and other skill items are given in addition to a silent and a live auction of sports memorabilia.

Dan Quinn, Financial Secretary-Treasurer / Business Agent for the Boilermakers, has led the preparation for the tournament for many years. Each year, he looks at the prior year and attempts to make things better so that they can raise more money to help defray the cost of camps. This year's outing had over 75 sponsors and donors!

Ray Ventrone, head of the Boilermakers Local, expressed his gratitude to those who played in this year's tournament. He said how thankful he was for the Boilermakers to continue to sponsor this event "... to raise money for Spina Bifida. I hope it will continue on long after all of us are gone."

Dick Lynch, Executive Director, commented, "Words cannot express the Association's gratitude for the work that the Boilermakers, Steamfitters, and Ironworkers pour into this golf outing every year. The monies raised by this group are vital to sustaining our camping programs in that it covers just over 20% of our summer camp costs." Lynch went on to say that "we appreciate these three unions uniting with SBAWP to meet the needs of individuals with Spina Bifida." ■



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# First Annual Spina Bifida Festival Attracts Hundreds

They came by car and public transportation (Access). They started arriving at 3:30 Saturday afternoon and some did not leave until after midnight. Nearly 400 people attended Spina Bifida Association of Western Pennsylvania's First Annual Summer Festival held at Greentree Farm in Cheswick, PA on June 20, 2009.

During the late afternoon and early evening, those in attendance played horse-shoes, volleyball, bocce, and corn hole. Many learned how to shoot a bow and arrow from accomplished marksmen! The children had the opportunity to make sun catchers and do other crafts in addition to enjoying an inflatable obstacle course that was never idle!

Continuous music was started at 4:15 with performances by the Southern Comfort Band; Blues Box Seven; square dancing with caller Barbara MacDonald; and special guest and an individual with Spina Bifida, Harry Prince. The headliner band,

Midlife Crisis, took the stage at 9 pm. After two numbers, a cloudburst moved through the venue with everyone taking shelter in the barn. After the rain passed, the bonfire was lit and the band returned to the stage rocking the house until after midnight!

Dick Lynch, Executive Director for the Spina Bifida Association of Western Pennsylvania (SBAWP) said that "the day surpassed all that we had envisioned. The SBAWP team of over 60 volunteers led by Sue Powers our Director of Development did an excellent job in planning and preparing for a great day! According to one SBAWP employee, "the mix of music and games coupled with hamburgers, hot dogs, and chicken grilled on site over a charcoal bed made the day feel like a southern bar-b-que".

Interviews with many of the SBAWP team were interspersed throughout the day. Emceeding the program and conducting the interviews was Andy Lynch from WTLW-TV in Lima, Ohio, where he is the Sports Director and anchor for the Sports Report which airs Tuesday through Saturday.

The SBAWP gratefully acknowledges all those who sponsored and/or donated their time, talent and effort to making the Summer Festival a success!

Seubert & Associates • Life Access • Comcast • Blackburn's Medical Supply  
Consolidated Communications • Midlife Crisis • The Southern Comfort Band  
Blues Box Seven • Pittsburgh Pirates • Interstate Communications and Electronics  
Intergroup Communications • Food for Thought-Caterer • Bountiful Foods and Gift Baskets  
Miss Elaineous Balloons • Independent Concepts, Inc. • WheelFlex Inc.  
Three Rivers Holdings, LLC • Ian Glaum • Jessica Bryant • Sumati Deustcher

All the Volunteers, SBAWP Staff and SBAWP Board Members

Special thanks to Mr. and Mrs. Brian Long for their tremendous generosity. Without their time, resources and effort this event would not have been possible.

In addition to the interviews that discussed the various programs offered by SBAWP, there were also demonstrations of equipment that can assist individuals in maintaining their health and wellness. These demonstrations included the GameCycle that promotes cardiovascular fitness through use of the upper body to “race” over an animated course using only the arms and hands.

A special guest appearance by the Pittsburgh Pirates’ Parrot afforded the opportunity to demonstrate both the Jogger (an electronic device designed to prompt individuals about certain events that need to take place during the day) and the Wheel Flex (a device that attaches to a wheel chair so that the individual can do exercises without the need of special equipment).

***For everyone there, it brought to light the challenges of this disability and the opportunities to become a part of helping the SBAWP help others.***

The keynote moment of the day was when Joe and Melissa McCormick took the stage along with their daughter Abby who has Spina Bifida. In the space of a few short minutes, the McCormick’s shared their journey with Abbi and the challenges that they have faced and continue to face as parents of a child with Spina Bifida. For everyone there, it brought to light the challenges of this disability and the opportunities to become a part of helping the SBAWP help others.

Sue Powers commented, “Words cannot express our gratitude to our key sponsor for the day – Brian Long, President of Seubert & Associates. Brian and the team that run Greentree Farm worked tirelessly in preparation for the event and during the event as well. And just like any major event, we begin planning for the 2010 festival with the formation of our festival team in early July!” ■



{ get involved



# Special Thanks for an Overwh



*Webster defines volunteer as: One who enters into or offers himself for a service of his own free will. That means he is not motivated by financial or material gain.*



With the conditions of the current economy as they are, people have cut back on their spending and giving. Fortunately for SBAWP, people continue to generously give their time as volunteers to serve others because they still want to give back to the community.

SBAWP has been privileged to have many volunteers offering their time and

room. The residents and staff were most appreciative of the spring-cleaning efforts and couldn't say enough about the church taking on such a project. The volunteers enjoyed the opportunity to chat with residents and Gatehouse staff over Subway sandwiches and snacks.

The

## Increasing Number of Volunteers

talents to assist in projects and events over the past few months.

On May 31, 2009 the New Community Church located in Wexford sponsored a Compassion Day whereby teams made up of families and individuals performed services for individuals and businesses in the community. Two such teams volunteered to do service projects for SBAWP.

The first team consisted of nine adults and two children. They arrived at 9 AM that Sunday morning to do some "serious spring cleaning" at the Gatehouse facility where young adults with Spina Bifida participate in a residential program to prepare for their future success by developing a personal goal plan and learning self-care skills necessary to live independently. Several team members cleaned floors, walls and three large refrigerators. Other team members washed windows, inside and out, picked up leaves, and painted the facility laundry

second team consisted of 10 adults and 2 children. They volunteered to help "beautify" the grounds at the new SBAWP office located at 1158 Dutilh Road in Mars. The building had been empty for several years and was definitely in need of some landscaping. Team members pulled waist high sticky weeds, the kind that go thru two pairs of gloves, and carried numerous bags to the dumpster. The team members then worked to load wheel barrows to spread 6 yards of mulch in the freshly weeded flower beds. It was hard work, but the weather was on their side and the grounds were beautifully transformed!



Volunteers have assisted SBAWP staff in building two wheelchair accessible ramps at the SBAWP office in compliance with the Americans with Disabilities Act requirements. The ramps will be used by participants of the Skills Training and Rehabilitation for Individual Vocational Enhancement (STRIVE) Program that provides the opportunity for individuals with disabilities to learn the skills necessary to secure and retain employment.

On June 20, 2009 SBAWP held its first annual Summer Festival. There were over 60 volunteers consisting of employees, families and friends in bright orange shirts assisting Festival attendees with admissions, parking, activity stations, and the first aid station. A good time was had by all as you can tell by the comments from the volunteers.

...“Volunteering at the Spina Bifida Summer Festival was a wonderful experience! It was so nice to see so many smiles and to hear so much laughter from everyone involved. You think of the young people with spina bifida in terms of their needs; but when you see them at play you realize how much they have overcome and how much they enjoy a fun-filled day at the Festival. Success is seeing everyone at play side-by-side, whether standing or in a wheelchair...just enjoying! I truly look forward to next summer’s Festival.”  
– Joan Peterson



...“It was a pleasure to serve as a volunteer at the Spina Bifida Festival this year. Sometimes just a small, kindly gesture is all that is needed to bring a smile to someone’s face. Thank you for allowing me to become a part of the Festival.”  
– Roy Peterson

...“The SBAWP is an amazing nonprofit association! I felt privileged to have the opportunity to volunteer at the Festival. I would gladly help out anytime!”  
– Tim Lyon



# The Conwell Family SBAWP Camp Tradition

Jeannine Conwell has been attending SBAWP weekend retreats and summer camps for almost 20 years. She is a regular attendee of the retreats scheduled for adults with spina bifida and a secondary diagnosis of mental retardation. Every year, the Conwells provide a meal for all camp attendees.

This year, Jeannine's parents, Jim and Jeannine Conwell arranged a pizza party for the adult weekend retreat in November 2008. The Conwells, with the help of their friends and neighbors, made pizzas and salads for all the adults that attended camp that weekend. They provided beverages and dessert, as well. All the adults loved it! The volunteers were a great help that evening, and they enjoyed socializing with the camp attendees. A special note of thanks to families like the Conwells that help make SBAWP camps a memorable experience for staff and attendees.



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# Introducing the BluePrints Program

Funded By PNC Charitable Trust and Allegheny County Medical Society

Parents of a child with a disability often spend many hours in hospitals and physician's offices. These experiences are often stressful and can contribute to a parent's decision to not let their child play freely for fear of them getting hurt. The SBAWP BluePrints Program offers a release from this fear in that it provides an opportunity not only for their child to play, but also provides them with a safe environment to play in.

BluePrints offers young children ages two through five with disabilities, especially those with spina bifida, the opportunity to develop social, motor, and sensory skills by interacting with their peers in a fun and stimulating environment. The aim of the program is to provide a place where parents and children can interact in a play/support group setting under the careful supervision of a seasoned SBAWP professional in combination with qualified activity specific instructors (i.e. music and art instructors located at participating community sites).

BluePrints also allows parents to have a shared experience and learn from watching a professional interact with their child. An additional feature of the program is that it offers parents/guardians the opportunity to collect information and resources from SBAWP staff that will support future planning for their child's develop-

mental needs. For example, BluePrints staff will share information on disability rights, schooling options, supportive governmental programming and help parents navigate through the healthcare system via quarterly e-newsletters, a resource toolkit and the availability of SBAWP staff to answers questions or concerns during working hours.

With funding generously granted from the PNC Charitable Trust and the Allegheny County Medical Society, the SBAWP has partnered with Sewickley's Sweetwater Center for the Arts, The Baiel Family YMCA in Sewickley, Fern Hollow Nature Center and Music Together to provide seasoned instruction and house weekly playgroup sessions at their respective locations. All locations are fully accessible and programming will begin in September 2009. Plans are also in place to expand BluePrints locations across the Allegheny County and to eventually provide integrated playgroups with those who do not have a disability.

Details about upcoming classes will be posted on the SBAWP website at [www.sbawp.org](http://www.sbawp.org) in mid August. For more information please contact Rebecca Crim, Youth Services and Family School Manager via phone at 724-935-5433 ext 302 or via email at [rcrim@sbawp.org](mailto:rcrim@sbawp.org). Please visit our website at [www.sbawp.org](http://www.sbawp.org) to donate to the BluePrints Program. ■



ATTENTION SPINA BIFIDA  
ASSOCIATION SUPPORTERS

# 2010 Entertainment Books

The SBAWP will be selling the 2010 Entertainment Books as a fundraising project. We can sure use your help!

As you know, the Entertainment Book is filled with money saving coupons for Dining, Movies, Travel and so much more. Many of the coupons are for places you would be patronizing anyway! Others may be for new places you would like to try. The cost is \$20 each – less than you'll save by using 2 or 3 of the coupons! Many people have saved \$20 in just the first month. And the rest of the years savings are a bonus! The potential savings on a year's worth of dry-cleaning alone are over 3 times the cost!

If we can sell 726 Entertainment Books, we would raise enough to cover what it costs the SBAWP to hold a Week-End Retreat. In these tough economic times, the SBAWP, like all organizations, is finding it harder to raise funds for our mission, purpose and programs. People need to get full value for every dollar. The Entertainment Books are a Win-Win! The person who buys it saves many times their cost and the SBA raises money as well to serve our clients!

You can help in 2 ways:

First, if you purchase the book each year anyway, please consider buying it from the SBAWP. We will appreciate your business.

Second, do you know other people who would like to buy one? Would you help the SBAWP by taking orders from those you know? Could you send an email to all of your LOCAL friends? Some people buy more than one for themselves or as gifts for family and friends.

The books will be delivered in August. People can start using them immediately and the coupons are good until November 1, 2010. OVER a year's worth of savings and value for just \$20.

Call Hope or Diana at the SBAWP office – (724) 934-9600 –to order your books or to get more details on how you can help us reach our goal of 726 Entertainment Books sold. We appreciate all you do to support the people we serve.

There are over 150 editions of Entertainment books in North America. If you have family or friends in other parts of the country they can go on line at [www.entertainment.com/support](http://www.entertainment.com/support) and order books. They can enter Spina Bifida's member ID #744196 and we will receive credit for the books ordered. ■





The Circle of Friends campers pause for a photo opportunity on their day at Kennywood Park.

## Calendar of Events

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### September

- 5 | SBAWP Night at PNC Park (see back cover for details)
- 18-21 | Firefly Youth Retreat/Woodlands
- 25-27 | Firefly Adult Retreat/Woodlands

### October

- 9-10 | Firefly Youth Retreat/Family Retreat Center
- 16-19 | Firefly Adult Retreat/Woodlands

### November

- 6-8 | Firefly Youth Retreat/Family Retreat Center
- 13-15 | Firefly Adult Retreat/Woodlands

### December

- 4-6 | Firefly Adult Retreat/Woodlands
- 13-15 | Firefly Youth Retreat/Woodlands

# Disability Awareness Night 2009 **Colorado Rockies vs. Pittsburgh Pirates**

By Anthony Martin

On May 16, 2009, residents from the Gatehouse, Fithian House and Villa Rivera were all invited to join the Pittsburgh Pirates in celebrating its 4th Annual Disability Awareness Night.

Many faces attended this celebration, including Pittsburgh's mayor, Luke Ravenstahl. SBASP's clients enjoyed networking on Federal Street with local vendors, agencies, and service providers all serving those with disabilities. Some of the agencies that attended were the Office of Vocational Rehabilitation, Hope Network, Achieva, Wheel Flex, United Cerebral Palsy and many others.

A lot of the stands had free items for people to learn more about their organization and how they help people with disabilities. This was a good idea because it teaches people that with a little bit of help those with disabilities can be independent too.

On to the exciting part of the evening, the game. The game was filled with thrills and chills. It felt like a roller coaster ride with my emotions going up and down. Every time the other team pitched the ball my heart would start racing hoping that they would hit the ball.



At the end of the third inning they had a little race with Mrs. T's Perogies. That was a funny and nice break from the game. Speaking of breaks the food at the game was excellent! My choice of food that evening was pizza. I strongly recommend it for all you pizza fans out there.

Then later in the game it started to rain. The game was delayed for about an hour. That was the only downer the whole night. Eventually the rain did stop and the game did resume. The final score was 7-4, the Pirates came out of the game with a victory. So, the day started good and ended with a BANG! ■

*Editor's note – Anthony is in our Gatehouse program and this was the first time he attended a Pirates baseball game!*

# **SBAWP night at pnc park Sept 5 at 7:05 pm**



## **Zambelli Fireworks & Irish Celebration**

**Authentic Irish food, festivities  
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to the game. Zambelli Fireworks  
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