

# Kaleidoscope

*changing . . . adapting . . . growing*



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# Kaleidoscope

changing... adapting... growing

Fall 2009

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Spina Bifida

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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.

{ a note from Dick



## *Thanks!*

In mid-October, my wife and I along with twenty other friends boarded the pontoon boat at Moraine State Park for a fall foliage-dinner cruise. As the sun shone on the beautiful hues of red and gold along the shore, we watched as two deer drank from the edge of the lake. And while we heard the naturalist tell about the history of the park, we saw a blue heron perched on a limb and three loons floating on the lake. When the boat pulled back into port, an osprey flew within yards of us.

That trip reminded me how thankful I am for relationships and for the beauty of the creation. In my first year on the job at SBAWP, I have had the privilege of discovering many new relationships. But more importantly, I have had the opportunity to view firsthand the relationships that those whom we serve have with others. Whether it is a group gathering in the lobby of the Fithian House or that first night on a weekend retreat, the relationships are real and genuine.

Those relationships would not have happened without your help. Whether you are a donor or a volunteer; if you stretch your budget so that your child can go to camp or on a weekend retreat, we who get to watch the relationships grow and flourish want to say “thank you!” Your gift to SBAWP – whether monetary or physical – is a gift to help us provide these most deserving individuals the opportunity to continue to expand their relationships!

At this time of year when all of us pause to give thanks for this great land and for our freedom; for family and friends; and for relationships that have endured throughout the years and in some cases across the miles – thank you for your support and commitment!

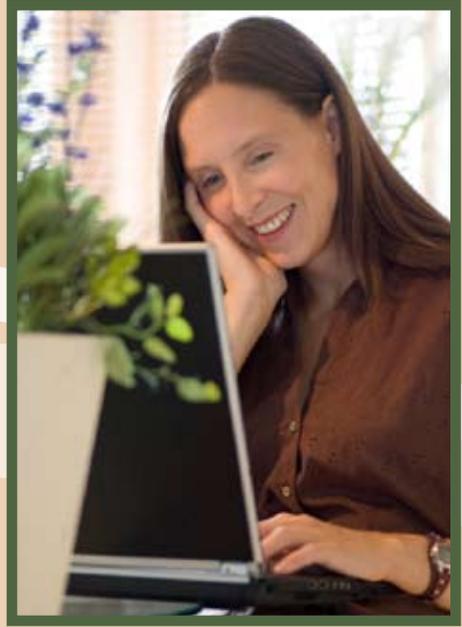
Have a Happy Thanksgiving and a blessed holiday season!

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



{ *in your interest*

# Save While You Shop & Support SBAWP



## **Good Shop.com**

What if the SBAWP earned a donation every time you searched the Internet? Or how about if a percentage of every purchase you made online during this holiday season and all year long went to support the SBAWP? Well, it can! Here is how it works:

GoodSearch.com is a new Yahoo-powered search engine that donates half its advertising revenue, about a penny per search, to the charities its users designate. Use it just as you would any search engine, get quality search results from Yahoo, and watch the donations add up!

GoodShop.com is a new online shopping mall which donates up to 37 percent of each purchase to your favorite cause! Hundreds of great stores including Amazon, Target, Gap, Best Buy, E-bay, Macy's and Barnes & Noble have teamed up with GoodShop and every time you place an order, you'll

be supporting the SBAWP!

Just go to [www.goodsearch.com](http://www.goodsearch.com) and be sure to enter, the "Spina Bifida Association of Western Pennsylvania" as the charity you want to support. Once you have confirmed us as your charity click on "Get the GoodSearch Toolbar" or add us onto your search box" then "Download the Toolbar", and be sure to spread the word!

Every time you go directly to a participating GoodShop store, the toolbar will highlight what percentage of your purchase will be donated to the SBAWP and if any coupons are available. So you can actually save money while donating to the SBAWP! Listen to what Pete Kochis, SBAWP Board President, had to say about using this great new tool.

"In a very short time I have earned almost \$10 for the Association using GoodShop, and it has saved me money! I have saved

about \$50 in freight and discounts during this time period. I installed the GoodShop tool bar. It sits along the top of my computer screen and offers two open search

## *You can actually save money while donating to the SBAWP!*

windows which more visibly remind you to use GoodSearch, but more importantly if you are online shopping and are on a site, like Barnes and Noble, which is a GoodShop affiliate, the toolbar automatically tells you about coupons and discounts and enables the SBAWP to receive a donation. So once you've gone through the initial step of selecting the Spina Bifida Association of Western Pennsylvania as your charity and installing the toolbar you never have to remember to use GoodShop!"

- Peter Kochis  
SBAWP President



The SBAWP encourages you to download the GoodShop toolbar before you begin all of your online holiday shopping!

## Entertainment Books

The SBAWP is selling the 2010 Entertainment Books to help pay for the FireFly Weekend Retreats! As you may know, Entertainment Books are 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 of each book is \$20 - 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 year's savings are a bonus! The potential savings on a year's worth of dry-cleaning alone is 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 Weekend 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 three ways:

**First**, if you purchase the book each year anyway, please consider buying it from the Spina Bifida Association of Western Pennsylvania. We will appreciate your business.

**Second**, do you know other people who would like to buy an Entertainment Book? Please tell your friends and direct them to our website.

**Third**, contact us if you would like to sell Entertainment Books on behalf of the SBAWP.

The books are available at the Association Office. You 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! To have your book mailed, a small shipping and handling fee of \$5 will be added.

Call 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 selling 726 Entertainment Books. ■

{ *program update*

# Our clients **STRIVE** to meet their goals

Since its inauguration on August 17th, the STRIVE program has delivered great results! The new prevocational program helps participants secure employment that accommodates each of their unique strengths, weaknesses, physical limitations and personal/professional goals. The program is cut up into three phases where participants are placed in one, two or all three phases depending on their abilities. Using this approach, STRIVE better prepares participants for job exploration, acquisition, sustainability and ultimately, greater independence.

Phase 1 of the program included five students: John Moroney, Nicole Bongiolatti, Kenia Hernandez, Casper Lawson, and Brittany Hewitt, who at the beginning of the program, were admittedly skeptical about the necessity of prevocational classes as a step towards finding, securing and maintaining employment. After a few weeks in class, attitudes drastically changed and participants started to open up to the experience. During this initial phase, they learned about time management, planning, motivation, attention, social awareness, hygiene, communication, problem solving and organization. This knowledge helped them set realistic employment goals which then graduated them to Phase II of the program.

Phase II welcomed three additional participants who after extensive interviewing were able to skip Phase I. When Ken Ebel, Libby Powers, and Jared McKinley joined Phase II they were tasked with completing a comprehensive vocational project. Based on their strengths, weaknesses and personal



career goals, each of these individuals performed extensive research on employment related to recreational therapy, the restaurant industry and special education. They interviewed and engaged in job shadows of successful people in their field and identified physical accommodations that would promote their success in the field. All three individuals are now currently employed and continue to interview in the hopes of securing their dream jobs! Phase III of the program will continue to support these individuals via job coaching.

The program has received positive feedback from participant parents and great attention from the Office of Vocational Rehabilitation (OVR). One father noted a change in his daughter's mood and motivation, "Before the program she was depressed and unmotivated and now I can see a huge change in her behavior, I am grateful for the STRIVE program!" OVR recently acknowledged the merit of the program for individuals with all disabilities living in the northern part of Allegheny County, where services are extremely limited. STRIVE is currently recruiting clients for Phase I of the third session beginning December 14th. Applications are available on the STRIVE section of [www.sbawp.org](http://www.sbawp.org). ■

**"Before the program she was depressed and unmotivated and now I can see a huge change in her behavior, I am grateful for the STRIVE program!"**

# A New View (Back on My Feet)

by Nicole Bongiolatti

“Holy cow what happened to the floor?!” That was my first thought when I looked down and saw that the floor was a lot further away than I remembered it to be. As I stood there staring at the floor I felt so many emotions, among them were dizziness, nausea, shock and the biggest one of all, pride. “I have never had so many emotions running through my head at one time.” I was very happy to have so many people there with me for support. The main person that I was thrilled to have there was my boyfriend Mike. I am not really sure who actually cried

even walking. When I was first confined to my chair I felt like my life, as I knew it, was somewhat over. Walking was all that I had ever known before that. I knew that being in my chair was probably going to be easier for me in the long run, but I was so used to being up and moving that it was a huge adjustment for me. The main thing that I remember was all of the eyes that I felt on me every day and how uncomfortable they made me feel.

This was not the first time that I had tried

***Now that I have tried and succeeded at standing, I absolutely love it and did not want to sit down that first day. I kept asking if I could do it again and again***

more, me or him. I have also received a lot of encouragement and support from Beth Marunczak, the Wellness Coordinator at the Villa. Having Beth present gave me the courage I needed to reach my goal. My motivation comes from family and friends, but my biggest motivation came from myself. I really want to get back into shape and get a different view of the world by getting out of my chair.

I couldn't believe that after 20 years here, I was standing up and actually staying up, despite the dizziness. The last time that I was even remotely vertical, was back in 5th grade before my first of two spine fusions. I always had the motivation to stand and walk but stopped due to surgery. The first thing that I thought when I sat in my chair for the first time was “Will I ever get out of this stupid thing?”

Over the last 20 years I have had so many things going through my head about whether or not I should even attempt standing or

to get up and stand. I had tried this at least a year ago with no results. I would have liked that to be the first and only time but there were quite a few mitigating circumstances that prevented this. The biggest factor standing in the way was the physical

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# Spina Bifida is a Family Affair

Melissa McCormick



We decided very early on (when being told that Abby had Spina Bifida) to treat the news as a family diagnosis. We educated ourselves as best as we could and looked to local resources for support and opportunities for Abby. We learned about the Spina Bifida Association of Western PA and attended our first summer picnic when Abby was 3 years old. The staff was nice and the campus was beautiful. Rebecca Crim, Director of Youth Services, was always available to answer our questions and even acted as a liaison on a few occasions at a couple of Abby's school IEP meetings. Especially when it was time to transfer to kindergarten, it was great to have an advocate who could help educate the educators on what they needed to do to create an adaptive environment for Abby. Between the resources of the Spina Bifida Association of Western PA and the Spina Bifida Clinic at Children's Hospital, we were always able to meet

Abby's needs. She enjoyed attending the summer picnic and was so anxious to attend Spina Bifida camp that she started a year earlier than the recommended age. SB Camp opened up a whole new world for her and gave her a whole new group of friends who shared the same issues and a place where she could just be herself. A place where no one cares if she has different bathroom habits, can't wear fancy shoes or doesn't get around very fast. She's been attending every summer (and some retreats throughout the year) since 2005. The campers and the camp counselors are family to Abby, and I can't imagine what her life would be like if we hadn't looked into what the Association had to offer.

That same year, thanks to a recommendation from the Association, Abby was blessed with a unique opportunity to be the "cover girl" for Pittsburgh Parent Magazine's special needs edition. She had a blast going to a real photo studio and posing for the camera. This will be a memory that we'll never forget and from that moment on, a star was born! This, along with countless other experiences afforded by the Association, helped to

boost Abby's self-esteem. She is now the first to volunteer for anything, a true social butterfly, and wants to try everything. The Association staff taught Abby the importance of independence, acceptance, inclusion, internal beauty, and true friendship.

Realizing the importance of the camp connection, Abby is always talking about raising money for kids who can't afford to attend. Through a Sunkist-sponsored lemonade stand campaign offered during the summer of 2008, Abby and I wrote about her desire to give back. She was sent an official Sunkist Lemonade Stand. We finally had an opportunity to use it during a Safety Fair at Abby's school last Spring. Abby (with help from a few of her friends) sold lemonade to the fair attendees and made approximately \$28.00. Although

he (along with the other board members) has dedicated countless hours to trying to improve the opportunities, programs and services of kids and young adults who have Spina Bifida. The most rewarding event to come full circle during Joe's involvement with the Association to date has been the completion of the Fithian House project. He looks forward to the fruition of other success stories for the Association's clients and leaving a legacy of a strong support resource for the younger generation (like Abby) and their families to rely on.

We are lucky to have such a great organization supporting the needs of our children (mental, physical, and spiritual), and we are personally fortunate to have them pretty much in our backyard. We appreciate the efforts of the Association staff, board members, and camp

The Association staff taught Abby the importance of independence, acceptance, inclusion, internal beauty, and true friendship.

it wasn't a huge amount, the girls were very excited and hope to take the Lemonade Stand to other events in the area. Abby was equally as thrilled when Mr. Priganc offered to match her donation at SBAWP's First Annual Summer Festival this past June. Even Abby's cousin Samantha caught the bug and held her own Lemonade Stand to raise money for SB. It's been great to see the kids embrace the idea of giving to other kids, and we hope the momentum will continue to grow.

In an effort to give back to the Association, learn more about Spina Bifida, and give a voice to the younger SB generation, my husband Joe became a member of the Board of Directors for the Association and the Housing Board in April 2006. He was elected Treasurer for both in 2007. During his term on the Board,

counselors. We also wish to thank the Spina Bifida families who travel from a far distance to come to the camps/re-treats. Without your willingness to do so, Abby wouldn't have had the opportunity to befriend your children and her life wouldn't be as full. Hopefully, with the new efforts of the Association, we may be coming to a campsite in your direction in the near future.

Times are recognizably hard right now for our individual households and for all non-profit organizations including the SBAWP. If we can support the Association's programs and fundraising efforts, the need for flexibility, and support each other as a family, the future will be as bright as the friendships that hold our fireflies together. ■

# The Xiao Procedure



For the past three years, healthcare professionals and health-related organizations have been watching progress in a nerve rerouting surgical intervention being researched and developed by a Chinese Urologist, Dr. Chuan-Guo Xiao. Dr. Xiao is a professor and Chairman of the Department of Urology at Union Hospital, Tongji Medical College in the People's Republic of China. From research beginning in the 1980s, Dr. Xiao has developed a nerve rerouting surgical procedure which has been reported to be effective for some children with spina bifida. This procedure involves surgical rerouting of lumbar to sacral nerves in the spine. Its goal is to provide

If successful, this procedure has the potential to reduce barriers to socialization, increase self-esteem and help improve family dynamics for children with spina bifida.

a new pathway for voluntary stimulation of the bladder.

The Xiao Procedure holds the promise that children with spina bifida will be able to self-initiate bladder and bowel functions - eliminating the life-long need for catheterization and the use of diapers to guard against accidents. If successful, this procedure has the potential to reduce barriers to socialization, increase self-esteem and help improve family dynamics for children with spina bifida.

In 2007, Dr. Xiao supervised urologists at Beaumont Hospital in Michigan to perform a surgical trial involving nine children with

spina bifida. In 2008, neurosurgeons and urologists from Atlanta traveled to China to train with Dr. Xiao. That surgical team is currently conducting a surgical trial of the Xiao Procedure in Atlanta.

In an interview by Tallahassee, Florida's WCTV Medical Minute, Dr. Gerald Tuite, a pediatric neurosurgeon at All Children's Hospital in St. Petersburg, Fla., explained that a three year study at All Children's Hospital is currently being conducted to "analyze the effectiveness of the procedure and that there are risks involved". When asked about risks by WCTV reporters, Dr. Tuite explained, "Yes, there are risks, because you are taking a part of the nerve that usually controls some motor function -- some muscle in your leg -- you're taking a portion of that and sewing it to a nerve that controls the bladder. For patients who have no leg function at all, of course they're not going to lose any more strength in their legs, but for say, kids with spina bifida who have some

leg function, there is some extra risk, we believe, to taking part of that nerve. Studies will show whether or not that risk will be long-term."

Professor Xiao has performed the procedure in close to two thousand patients in China, and he's reported very good results -- something in the order of 60 to 80 percent control of bowel and bladder function. To learn more about the Xiao Procedure visit <http://www.allkids.org> or <http://sophiesvoicefoundation.org>

*Content for this article was derived with permission from Sophie's Voice Foundation*

# GOLF TRAINING MARATHON BENEFITS SPINA BIFIDA

Rich Conwell, PGA Head Golf Professional at Uniontown Country Club, conducted a teaching marathon to benefit Spina Bifida. This event was held at Uniontown Country Club on Saturday, September 5th and 6th.

Conwell gave twenty-two golf lessons in two days time and was able to spend time with many different people, from youngsters just beginning to seasoned veterans. All players experienced improvement and there was plenty of fun had by all and a worthy cause was greatly supported.

The main reason for the selection of

this charity is that Conwell's sister, Jeannine Conwell, is afflicted with Spina Bifida. The research and prevention of this disease is of utmost importance to Rich Conwell and his family.

This event was held to benefit the Spina Bifida Association of Western Pennsylvania. The money was given in order to offset the costs associated with individuals with Spina Bifida attending weekend retreats or the always-popular summer camp. Conwell was pleased to announce that \$1,400.00 was raised through this event.



From Left to Right, David Hughes, Uniontown Country Club President, Rich Conwell, Head Golf Professional, C. H. (Dick) Lynch, Jr., Executive Director of the Spina Bifida Association of Western Pennsylvania, and Jim Ulmer, Golf Chairman, Uniontown Country Club.

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therapy place threw out my braces without telling me about it. Another factor standing in the way was finding a place that took my insurance. Many of the places I looked did not take my insurance, leaving me defeated and stressed.

Now that I have tried and succeeded at standing, I absolutely love it and did not want to sit down that first day. I kept asking if I could do it again and again. I would take that dizzy and nauseous feeling over being stuck in my chair. I am so unbelievably proud of myself and happy that I did this. Instead of saying that I was too scared and coming up with excuses, I met my goal. I remember the next thought that popped into my head after I sat down again was "Can I

do it again PLEASE?" I was so ecstatic that I didn't want to hear people tell me that I couldn't stand again.

My main motivation for wanting to get up and walk again was mostly that I wanted to get back into the great shape that I was when I was younger. I also want to be able to walk down the aisle at my wedding someday and look my man in the eye at his level. My long

term goal is to be a happier and healthier me. I think once I get over the initial unpleasant stuff, I will definitely be willing and able to reach my short term goal of standing, and my long term goal of walking.

I hope that anyone who sees this article and is feeling like these things are not possible will read it and think "Wow if she can do this after 20 years maybe I can do something just as great to have a happy and fulfilled life." ■



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The logo features a blue arc at the top with a red heart rate line in the center. The words "LIFE" and "ACCESS" are in a serif font, separated by the heart rate line. Below this, "SOLUTIONS FOR INDEPENDENT LIVING" is written in a smaller, sans-serif font. A small trademark symbol is to the right. The entire logo is enclosed in a red rectangular border.



# The Firefly Camp and Retreat Season is Off to a Fang-tastic Start!

The Firefly Camps and Retreats kicked off the season with a Youth and Teen Retreat at the Family Retreat Center. A ghoulishly good time was had by all! We painted ceramic pumpkins, made ghosts, carved pumpkins, and dressed up in our costumes for a Halloween dance with our volunteer DJ John Fitzgerald cranking out the tunes.

The participants were happy to be at a retreat. We were not without challenges this weekend, but we overcame them and realized that we can go anywhere and do anything as long as we are willing to work together. One camper who was happy to be at the retreat center said that camp is not where you are it's who you are with and all my friends are here and we had a good time together!

The adults celebrated the start of the retreat season at the Woodlands. They were happy to be together again. Dan the archery man made an appearance at the archery range for sports while others cooked up some dip with veggies and Frankenstein cupcakes. The dance is always the highlight of the weekend and we were happy to have two volunteer DJ's, Svetlana Mishna and John Fitzgerald.

We are looking forward to many more adventures together! See you at the next retreat!



{ *get involved*

# Light Up A Life Campaign



Funds raised from the Light Up a Life Campaign will provide individuals with disabilities, especially those with spina bifida, and their families with the support they need to succeed through all of life's developmental milestones.

The SBAWP is fortunate to have hundreds of supporters and volunteers constantly asking how they can help individuals like Nicole (pg.7) and others with disabilities, especially those with spina bifida, and their families. In response to these generous and kind requests we have launched an annual \$250,000 online fundraising campaign, otherwise known as the "Light Up a Life Campaign"! The campaign allows individuals and teams of individuals to easily create their own customized website that they can then share with family, friends and co-workers via email and other social networking sites in an effort to raise awareness and raise funds in real time to support a number of SBAWP programs and services.

The campaign is truly unique in that you could choose to make a donation via the site or more importantly get involved by acting as an awareness builder and campaigner on behalf of the SBAWP!

One hundred percent of your efforts as a campaigner and as a contribu-

tor will directly benefit one or all of the following SBAWP programs and services.

**BluePrints Program:** Provides social, motor and sensory playgroups for toddlers and networking opportunities and resources for parents new to the disability community

**Family School Partnership Program:** Works with parents and teachers to provide young children and teens with individualized educational plans to promote academic success

**Firefly Summer Camps and Year Round Weekend Retreat Programs:** Provides children, teens and adults with overnight summer camps and monthly retreats that build self-esteem, promote healthy social development and provide hard working, loving parents and guardians with respite

**The Gatehouse Program:** A transitional independent living facility that provides young adults with hands on life skills training that promotes health and wellness and fosters independence

**The STRIVE Program:** Provides adults with intensive vocational training and job placement/retention services.

Visit the website and follow the easy-to-use instructions on the homepage, <http://lightupalife.sbawp.org>.



- Set a personal or team fundraising goal amount
- Write a personal message as to why you are raising funds on behalf of the SBAWP
- Upload a personal picture of yourself or your team
- SHARE your site with your family, friends and co-workers via email, facebook, twitter and/ or other social networking sites featured on your page.
- Watch the donations pour in from your generous contributors and see your fundraising bar change in real-time

For questions about the campaign or for help with registration call 724-934-9600 or email [development@sbawp.org](mailto:development@sbawp.org)

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# Volunteers for

Winter, Spring, Summer and Fall, SBAWP continues to see new and familiar faces volunteering their time and talents to assist in the upkeep and beautification of the SBAWP properties and to spend quality time with the residents and staff. Volunteers who come to SBAWP have a genuine heart to serve, and they leave with a feeling of accomplishment and a better understanding of the residents' disabilities and strengths.

SBAWP has three different facilities to maintain. The Gatehouse and the Fithian House, located in Wexford, are residential housing facilities for young adults with Spina Bifida and other related disabilities. The SBAWP main office with eight staff members, located in Mars, also houses the STRIVE vocational program for young adults with Spina Bifida and other disabilities. Seasonal changes create a need for additional maintenance at these properties. Leaves need raked, flower beds need planted, weeded or cleaned out. Inside, windows need cleaned, and just like at your home, there are major cleaning projects that go above and beyond the daily dusting and sweeping. That is why volunteers, whether individuals, churches or businesses, are greatly appreciated.

## North Park Church Celebrates Compassion Day



October 10, 2009 was a dreary, wet fall day. However, it did not dampen the volunteer efforts of the North Park Church. Six adults and two youth volunteered to work with Pete Kochis (SBAWP Board officer and volunteer) to coordinate the construction of an emergency exit wheel chair ramp. The ramp had to be in compliance with specifications of

the Americans With Disabilities Act in order to meet the township occupancy requirements. The ramp will be used in conjunction with the Skills Training and Rehabilitation for Individual Vocational Enhancement STRIVE program currently running its second session.

Although the volunteers were experienced in working with domestic and international mission projects, circumstances did not allow the volunteers to complete the project in one day. One team member has returned several days to assist Pete Kochis in building the ramp. And, North Park Church has offered to send a team again if necessary. SBAWP is grateful for the dedication of these volunteers, and looking forward to future projects with this group.

# All Seasons and All Reasons

## North Park Youth Group

On August 10, 2009, the North Park Church high school youth group, grades 9-12, arrived at The Gatehouse to do some light cleaning and to spend some fun-time with the young adults with Spina Bifida who live at the Gatehouse. The group wiped down walls and assisted residents with other individual needs. Additionally, the group played basketball with some of the residents out on The Gatehouse parking lot. It was a win-win, fun day for everyone involved. At SBAWP, we welcome and appreciate volunteers of all ages.



## New Community Church Celebrates Compassion Day

Coinciding with the North Park Church Compassion Day celebration on October 10, 2009, thirteen adult volunteers from New Community Church arrived at The Gatehouse to do some serious grounds clean-up and maintenance. However, a change in the weather called for a change in plans. The five volunteers who came prepared in waterproof boots and warm clothing raked leaves, pulled weeds and picked-up sticks and rocks. The remaining volunteers chose to work inside The Gatehouse cleaning windows, scrubbing floors, dusting and sweeping. Some of the volunteers had assisted with the spring clean-up at The Gatehouse.

Melissa McCarrell, Staffing and Training Coordinator, took time to explain to the volunteers that the Gatehouse is a unique program in that it offers both

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housing for young adults with Spina Bifida and teaches them life skills necessary to live independently.

John Fitzgerald, resident of The Gatehouse, shared his passion to educate others on the importance and uniqueness of The Gatehouse program a presentation that he has often done in public.

Harry Prince, Fithian House resident and SBAWP employee, took time to speak to the group about what the SBAWP programs mean to him. Harry said, "The Spina Bifida Association and the Fithian House facility has allowed me to move from Philadelphia to Pittsburgh, where I am able to make my own choices ...good or bad." The volunteers enjoyed interacting with the residents and getting to know more about SBAWP programs. SBAWP welcomes the opportunity to share our mission with volunteers. We extend a special thanks to the new faces and familiar faces from New Community Church!



## MedRad 10th Annual Day of Caring

On September 11, 2009, employees of Medrad arrived at The Gatehouse and the Fithian House to participate in a fun-filled day starting out with breakfast and introductions. The Medrad volunteers talked about the organization and then went on to talk about "Interview Do's and Don'ts". Later in the morning, the volunteers held one-on-one mock interviews with the residents. Residents also had the opportunity to fix up their resumes. At noon, lunch was served and everyone enjoyed cookie cake to celebrate the 10th Anniversary for Day of Caring. The rest of the afternoon consisted of enjoying some guitar playing and singing by Dave Callen, Medrad Project Coordinator. Dave has been helping coordinate Day of Caring activities at the Gatehouse for the past six years. Everyone also enjoyed the rest of their afternoon at the Woodlands No Handicap Golf Course. Thanks Medrad! We can't wait until next year!

# Fed-Ex Day of Caring



September 14-18, 2009 was the official Fed-Ex Cares Week with a week of volunteer events. Here in the Pittsburgh area, Fed-Ex chose to support five organizations with six days of volunteering. On September 14th, 10 volunteers traveled to Wexford to serve as shopping assistants for the residents of the newly built Fithian House. The Fithian House is a 14-unit apartment building built for low-income people with disabilities, primarily Spina Bifida, who meet certain criteria. The young adults are thrilled to be living on their own for the first time in their lives. The Fed-Ex team wanted to provide support for these young adults by helping them purchase some everyday use items for their new apartments. Fed-Ex had taken eight other residents shopping this past spring.

As five of the new residents, all in wheelchairs, loaded on the bus, their smiles beamed with enthusiasm for their “day out with Fed-Ex”. The Fed-Ex employee volunteers teamed up with these young adults and spent the afternoon shopping at the local Wal-Mart purchasing everything from storage bins and towels to flashlights and cleaning supplies. The residents returned home with many items to make living on their own a better and more enjoyable experience.



*MedRad volunteers come to work and play!*

One veteran Fed-Ex volunteer commented that this was a nice change from traditional maintenance work. “Working one-on-one with the residents was an incredible experience.”

At the end of the shopping day, the employees and residents cooked and ate dinner together. When everyone was finished, resident Harry Prince wheeled out of the kitchen to return to his room and said, “Don’t be strangers now. Y’all are great friends to have.” A special SBASP thanks to Fed-Ex for your continued support.

## Sled Hockey

Have you ever picked up a hobby and knew immediately that you were going to love it? Recently, I've had that experience, and now I'd like to share it with you. Several people from the Gatehouse and Fithian house including RJ Bird, Kevin Smith, and myself, John Fitzgerald, have recently started going to Blade Runners in Harmarville, PA to play a game called sled hockey. Sled hockey is very similar to regular hockey, but it's modified for people with disabilities. It has the same rules but regular skates aren't used. Riders sit on sleds that have blades under them and we use a hockey stick. At the end of the hockey stick there is a pick that we push into the ice, you can use it to help maneuver around the ice. All around the United States sled hockey is used as an alternative to traditional hockey for people with varying disabilities. The game is great exercise and a lot of fun, too!

*Written by John Fitzgerald, a resident of the Gatehouse program*



## Pittsburgh Zoo

Lions and tigers and bears, oh my! Recently moving to the Pittsburgh area has given me many wonderful opportunities and fun adventures. One fun adventure was the Pittsburgh Zoo and PPG Aquarium. Never have I been to a zoo with not only tons of animals you're used to seeing at the zoo, but also an aquarium where you're able to see and touch wild life as you crawl through the sting rays attraction to seeing baby elephants in plain sight. If you're looking for a fun day out with the family the Pittsburgh Zoo is the place to go.

*Written by Karin Thum, a resident in the Gatehouse program*



## Our Trip Up North

On Wednesday, August 26th, 2009 a small group of us from the Villa Riviera Apartments went on an outing to the Crawford County Fair, in Meadville, PA. After entering the fair, we met up with my parents. The first activity we did, was to tour many buildings that housed a variety of farm animals for the week such as, (rabbits, horses, goats/sheep, pigs and cows). We also toured many buildings full of crafts and home-grown vegetables, such as squash, pumpkins, rhubarb, and zucchinis, from people all over the area. After we were finished touring the fairgrounds, we enjoyed some “yummy” fair food.



After a fun-filled day at the fair, we took a brief jaunt to my house. While there, we were anxiously greeted by my parents’ dogs. We also toured my house. Still our day was not complete.

We traveled further up the road to the Linesville Spillway. While we were there, we fed the ducks and the enormous amounts of large carp, lots of loaves of old bread, buns and doughnuts. There is believed to be a saying that states, “Ducks walk on the fish’s back.” We found out first hand that this is a true statement.

After about five hours of touring Crawford County, we started our journey back home. My friends and I, (Fred Steach and Alycia Lazar) would like to thank Rachel for an exciting and fun filled excursion to Crawford County!

*Written By Jennifer Speicher, resident of the Villa Riviera*



# Calendar of Events

## November, 2009

- 5 & 12 | BluePrints Start of Introductory Program at Sweetwater Center for the Arts
- 6-8 | FireFly Adult Retreat/Family Retreat Center
- 13-15 | FireFly Youth Retreat/Family Retreat Center
- 19 | BluePrints Introductory Program at Baierl Family YMCA
- 30 | STRIVE Session 3 – Application Deadline

## December, 2009

- 3, 10 & 17 | BluePrints Introductory Program at Baierl Family YMCA
- 4 | STRIVE Session 2 – End Date
- 14 | STRIVE Session 3 – Start Date
- 18-20 | FireFly Adult Retreat/Location to be Determined

## January, 2010

- 19 & 26 | BluePrints Program at Baierl Family YMCA
- 21 & 28 | BluePrints Program at Sweetwater Center for the Arts

## February, 2010

- 2 | STRIVE Session 4 – Application Deadline
- 2, 9, 16 & 23 | BluePrints Program at Baierl Family YMCA
- 4, 11, 18 & 25 | Blue Prints Program at Sweetwater Center for the Arts
- 5 | STRIVE Session 3 – End Date
- 5-7 | FireFly Youth Retreat/Location to be Determined
- 12-14 | FireFly Adult Retreat/Location to be Determined
- 15 | STRIVE Session 4 – Start Date

# Around Town Happenings

Eat, Drink and Be Merry!

Please join us at these and other upcoming lively events around town to build awareness around spina bifida and other related disabilities! Remember to check out our website regularly at [www.sbawp.org](http://www.sbawp.org) for updates on these and additional community events. For more information please call us at 724.934.9600 or email [development@sbawp.org](mailto:development@sbawp.org).

## Eating “For Good” In the Neighborhood

**Thursday December 3, 2009**

The SBAWP has teamed up with **Applebee’s** in Cranberry! Grab a bite to eat at this location on December 3rd and a percentage of your bill will be donated to the SBAWP. In order for the SBAWP to receive a donation you will need to present the Applebee’s/SBAWP event flyer, (downloadable from our website), to your server prior to your meal. We can also email or mail the flyer to you. You may have as many flyers as you want to spread the word and invite others to dine at Applebee’s Cranberry that day in support of the SBAWP! The address is, Applebee’s Cranberry, 1685 Route 228, Cranberry Twp, PA 16066



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## A Film for Philanthropy

**December 7, 2009**

Join us for a showing of “My Destiny” a film written by Deidre Howard, creator of the Inner City Film Project and a native of Clairton, PA. A percentage of ticket sales from the movie event will be donated the SBAWP! Filmed entirely in Pittsburgh, PA, the movie explores the life of a famous pop star from Clairton who is coping with the recent murder of her mother while battling with the choice of whether or not to leave behind her life of fame and fortune in LA to help the destitute in her hometown. The film is Directed by Blake Steigerwald son of Penguins announcer Paul Steigerwald; Produced by Daryl Price and George Milan Manolovich; and stars Roy Jones Jr., current NABO and IBC light heavyweight boxing champion along with Pittsburgh based actors Alan Lee, Haley Holloway and Margo B. The film is currently still in production so please check back on our website for exact show times and ticket prices.

Thank you for your continued support of the SBAWP. We’ll see you around town!



To our Volunteers and Contributors, Thank you for your physical and financial support in 2009!



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