

Kaleidoscope

changing . . . adapting . . . growing



Celebrating
40
Years

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Special Needs:
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Kaleidoscope

changing... adapting... growing

Winter 2009

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{ a note from Dick

Our Heritage



Welcome to our first issue of Kaleidoscope!
And to the start of our 40th year!

As I take the reins of the association, I am reminded of the great heritage that has made SBAWP what it is today. When I think of our heritage, I think of the vision of Dr. Donald Reigel and his wife Gay Simpson-Reigel when they set about to connect parents of children with Spina Bifida to one another. Parent support groups provide an opportunity to learn from the experiences of others so that the unknown can become the familiar.

When I think of our heritage, I think of the Reigel's vision as I walk the campus of the Woodlands and see a place where persons with Spina Bifida can come and partake of a camp experience; where life skills can be taught and enhanced; where friendships can be made and renewed. What an enormous heritage we have in the camps and weekend retreats that we hold each year at this very special place in Allegheny County.

When I think of our heritage, I think of the successes we have had with our vocational assistance program, our academic support program, and most recently, our wellness program. I think of the number of individuals who have gone on to college or who have jobs within our community because SBAWP was here to provide the help and the teaching that they needed.

When I think of our heritage, I think of the thousands of people who have contributed so faithfully over the years to insure that we as an association are here to meet the needs; to provide the life skills training; to provide help in the daily routine of life so that individuals can live independently within our communities. I am humbled by what you and others have sacrificed over the years to help us meet the needs of persons with Spina Bifida and their families.

When I think of our heritage, there is much to build upon. And there is still much more to be done! Changes such as the one you are holding in your hand and changes such as can be seen on our new website point toward the start of our next 40 years! With your partnership and financial help, we will continue to develop new programs to meet the needs of our changing population while continuing to strengthen our Gatehouse program and our community services.

In the pages of the Kaleidoscope, we will endeavor to keep you posted on progress being made not only at SBAWP but also in the medical community at large such as the work of Dr. Fauza as reported on page 7.

Twenty years from now when one of my successors looks at our heritage, I hope that he or she will be able to say, "Look at what the people did in the first two decades of 2000 – look at the heritage they have left for us!"

Dick Lynch

{ *program update*



Have you logged on lately?

The adage “new year, new you” takes on a whole new meaning for the Spina Bifida Association of Western PA with the recent launch of the organization’s redesigned web site. To better meet the needs of its participants and families, as

well as those of the general public and health care community,

SBAWP went back to the drawing board to build a site that is user friendly, informative and easy to navigate. The result is a site that we think you’ll like. New features include access to a DVD about SBAWP’s programs and services, expanded information for parents, participants and caregivers, an up-to-date calendar of events, and an FAQ section to answer some of your questions. To check out the new site, go to www.sbawp.org. ■

www.sbawp.org
www.sbawp.org
www.sbawp.org
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Staff to speak at ACA conference

Two members of the SBAWP staff will be speaking at the 2009 American Camp Association’s Tristate Camp Conference in Atlantic City in March. Rebecca Crim, Manager of Youth Services, and Rachel Bestwick, Community Integration Coordinator, will be presenting, along with members of the Woodlands Foundation, Inc. staff, on how to train camp staff to be sensitive to the special needs of their campers. Nearly 4000 camp professionals, seasonal staff, youth development professionals, and “out of school” experiential educators attend the event each year. ■



SBAWP HIRES DC FUNDRAISING POWERHOUSE FOR NEW DEVELOPMENT POSITION

Sue Powers has joined the staff of the Spina Bifida Association of Western Pennsylvania (SBAWP) in the newly created position of Development Director.

Ms. Powers recently relocated to the Pittsburgh area from Washington, D.C. where she served in the Director role for several national organizations including the American Heart Association and the American College Health Association. In these positions she was tasked with a yearly fundraising goal of \$1 million and was responsible for cultivating and maintaining relationships with over 3000 foundations. She brings a strong background in foundation, corporate, state and federal fund development and has also managed special events including auctions, walks, galas and outdoor festivals for a variety

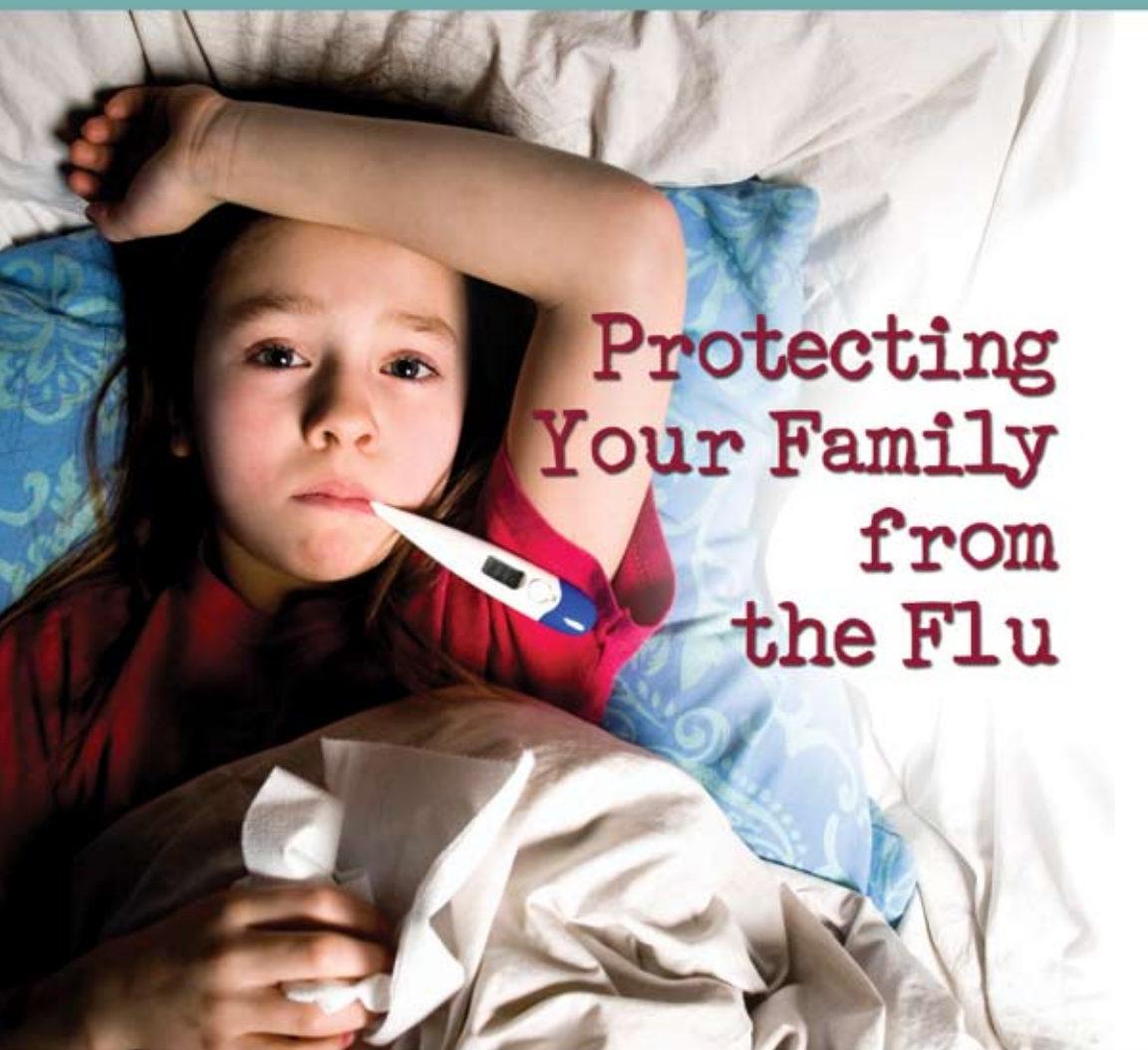
“I am delighted to have the opportunity to work on behalf of an organization committed to improving the quality of life for people with disabilities, especially those with spina bifida”

of non-profit organizations. Ms. Powers also brings significant experience in organizational advocacy and marketing to her new position with SBAWP.

“I am delighted to have the opportunity to work on behalf of an organization committed to improving the quality of life for people with disabilities, especially those with spina bifida,” said Powers. “I look forward to forging strong and meaningful relationships with charitable organizations and individuals in the region to enhance all of the critical programs and services provided by the Spina Bifida Association of Western Pennsylvania.”

Ms. Powers earned a Masters Degree in Public Policy and International Affairs from the University of Pittsburgh’s Graduate School of Public Policy and International Affairs and a Bachelor of Arts Degree in International Studies from Dickinson College. ■

{ *in your interest*



Protecting Your Family from the Flu

It's that time of year again. Noses start running and bodies, heads and throats start aching. Flu season has arrived.

According to the Centers for Disease Control (CDC), each year 5% to 20% of the population gets the flu and more than 20,000 people are hospitalized from flu complications. Below is some useful information from the CDC to help you and your family stay healthy this year.

Flu symptoms

Fever (usually high)

Headache

Extreme tiredness

Dry cough

Sore throat

Runny or stuffy nose

Muscle aches

Nausea, vomiting, and diarrhea
(more common in children)

What is the difference between a cold and flu?

Both the flu and the common cold are respiratory illnesses, but each is caused by different viruses. Because symptoms are similar it can be difficult to tell the difference between these two illnesses. In general, the flu is worse than the common cold and symptoms such as fever, body aches, extreme tiredness, and dry cough are more common and intense.

Protect yourself

The CDC recommends a yearly flu vaccine as the first and most important step in protecting against this serious disease. While there are many types of viruses, the flu vaccine protects against the three main flu strains that research indicates will cause the most illness during the flu season. If you do get the flu, prescription antiviral drugs are an important treatment option that can help keep the flu viruses from reproducing in your body and make your illness milder. They may also prevent serious flu complications.

In addition, practicing everyday preventive measures such as frequent hand washing decreases your chances of getting the flu. To keep from spreading the disease around if you are sick, reduce your contact with others and cover your mouth when you cough. Interestingly, experts now recommend using your sleeve to cover your cough, rather than your hand if no tissues are available, to reduce your risk of spreading germs since you are likely to touch common surfaces before you have the opportunity to wash your hands. And finally, try to avoid touching your eyes, nose or mouth as germs often spread this way. ■

Medicine on the Cutting Edge

A recent on-line article www.childrenshospital.org/cfapps/research/data_admin/Site292/mainpageS292P0.html detailed some promising research being led by Dr. Dario Fauza from Children's Hospital Boston (Boston, MA). According to the article, Dr. Fauza demonstrated that neural stem cells can partially repair damaged areas of the spinal cord in a large animal model of spina bifida. This could lead to improved outcomes in the treatment of this devastating disease. He is now perfecting the methods for isolation of neural stem cells and their delivery to the fetus or newborn, before human trials can be pursued. ■



The Other Child with Special Needs:

Understanding siblings of children with disabilities

The complex bond shared by siblings has been described as the most influential of all relationships. Enduring ties that join brothers and sisters outlive marriages, survive well past the years of their parents, and extend long before the birth of their own children.

When one child in a family has a disability, sibling relationships can become even more dynamic. In the past, even family-centered approaches to understanding the impact of disability have concentrated primarily on parents. The voices of siblings have been left unheard. These children have equally special needs, and more information is needed on their unique perspectives.

Disability by Association

Researchers have recently corrected the false belief that the impact of disability on a family is universally damaging. While chronic illness does introduce greater levels of stress for all members of the family, the result is not necessarily negative. Children with siblings who are disabled are offered unique opportunities to develop positive attributes, including loyalty, insight, and altruism. They embrace a greater tolerance for others and become more attuned to society's treatment of differences.

Unfortunately, children with disabled siblings are often not mere observers of discrimination. In the form of rejection and intolerance from peers, they are also the victims of social stigmas. Peter Burke, author of *Disability and Impairment: Working with Children and Families*, has termed this experience "disability by association." This knowledge heightens the need for parents and professionals to view disability as a source of adversity met by the entire family.

Reducing Guilt through Validation and Acceptance

Many parents of mixed-ability children agonize over the seemingly impossible task of dedicating equal time to all family members. Several recent studies should bring some relief. Even young children realize that fair treatment is more important than equal treatment. When parents join the child with a disability for a hospitalization or drastic differences in household chores are assigned, a child's understanding of differential needs can be exceeded.

To reduce rivalry and feelings of isolation, parents should be active listeners and validate the feelings of all family members. Parents can prevent the

internalization of resentment through communicating that siblings do not have to feel guilty. The consequences of long-standing guilt can have detrimental psychological effects, leading to shame and a feeling of worthlessness.

The Upside of Sibling Rivalry

Parents working tirelessly to avoid sibling rivalry may be denying their children a valuable opportunity to develop crucial social skills. Learning how to express wants and needs, testing limits, and feeling empowered to assert oneself are skills gained through the role modeling of some of our earliest teachers—our siblings. The essential factor that seems to determine whether rivalry is damaging or empowering is the level of warmth shared.

Brothers and sisters with the nurturance of occasional rivalry matched with affection, acceptance, and support are at a great advantage in the development of several important life skills. A strong bond with siblings forms a secure bridge to the outside social world.

While it is important to recognize the dangers of paying too little attention or overburdening siblings of disabled children, it is also essential to understand the research that provides hope to these children and their families.

The experience of having a sibling can offer positive opportunities for development that are nearly impossible to recreate. Embrace the challenge of disability as a family, and support your children in their growth! ■

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{ *get involved*



*“helping others is a great
way to simultaneously
improve yourself and make
a meaningful impact on
the lives of those in need”*

RESOLVE
TO GET
INVOLVED

New Year' Eve has traditionally been a time to reflect on the changes we want (or need) to make to improve the quality of our lives in the coming year. We often make resolutions pertaining to our health, loved ones, or learning something new. In 2009, the SBAWP encourages you to add to your resolutions list, "Helping Others".

Whether it's helping a neighbor, volunteering or getting involved in your community through an organization like the SBAWP, helping others is a great way to simultaneously improve yourself and make a meaningful impact on the lives of those in need.

While resolutions are made with the best of intentions they are often hard to keep. However, with the right planning, information, expectations and support, you can make a positive

difference in your life and the lives of others.

At the SBAWP we resolve each year to provide exceptional programs and services to children, teens and adults with spina bifida. We also offer a number of opportunities and tools for individuals, like you, to get involved in your community by helping those with spina bifida lead productive, happy and healthy lives. For example, you can volunteer your time or services to facilitate an SBAWP fundraiser, mentor a child, serve on our Board or help staff during one of our year-round weekend and summer camp retreats. You can also help individuals with spina bifida by supporting the SBAWP with in-kind donations or financial contributions to one or all of our many programs and services.

To learn more about ways to volunteer and/or donate visit our new website at www.sbawp.org or call us at 724-934-9600. We wish you success in keeping all of your New Year's resolutions and ask that you make 2009 the year where you resolve to get involved with the SBAWP!■



*With the right planning,
information, expectations and
support, you can make a
positive difference in your life
and the lives of others.*

TO VOLUNTEER - 724-934-9600

TO LEARN MORE - WWW.SBAWP.ORG

Gatehouse Residents Give Back To The Community



Gatehouse residents and staff greeted shoppers at Ross Park Mall with a smile as they collected money for the Salvation Army. Pictured above (L to R) are: Justin Savage, John Merolillo, R.J. Bird, John Fitzgerald, Harry Prince, and Ryan Woullard

Christmas is traditionally known as a time of giving and receiving gifts. One of the most meaningful gifts anyone can give is the gift of their time. And, that is just what the residents of the SBAWP Gatehouse Community decided to do this year. Barb Levandowski, Advanced Life Skills Instructor and Shannon Juengst, Vocational Coordinator for the SBAWP connected with the Salvation Army and arranged for our residents to volunteer as “bell ringers” at the Ross Park Mall on December 17th and 18th: Those who participated were R.J. Bird, John Fitzgerald, Tara Graver, Erik Grunst, Lynn Kiesel,

Anthony Martin, Lori Rodgers, Justin Savage, Ryan Woullard.

The Residents worked in shifts over a six-hour period each day. They were strategically located at the bottom of the escalator on the lower level of the mall and greeted busy shoppers with a smile as they descended from the second floor to the first. (Unfortunately, they were not permitted to really ring the traditional Salvation Army bell in the mall.) Many people took the time to search through their purses and pockets to find dollars to put in the Salvation Army Red Kettle.

“It is a good feeling to know that we helped someone even though we may never meet them.”

The Gatehouse Residents enjoyed getting out in the community and lending a helping hand during the busy Christmas season. According to John Fitzgerald and R. J. Bird, it is an accomplishment and privilege for the residents to give back to the community. “They give so much to us that we want to be a part of something even bigger like serving as bell ringers and collecting money for those less fortunate than us.”

Resident, Justin Savage shared that his parents used to work for the Salvation Army. He had the opportunity to serve as a bell ringer for a number of years. For Justin, “Being a bell ringer is giving back to God by being a servant in the community”.

Harry Prince, SBAWP Life Skills Instructor and former Gatehouse resident, said, “It is a good feeling to know that we helped someone even though we may never meet them.”

The Residents of the Gatehouse Community look forward to future opportunities to work together and continue to give back to the community at large.■

Smith elected Chairman of the Board

Richard Smith was elected Chairman in October, 2008, after the death of SBAWP's previous Chairman, Ted Fithian. Smith joined the board in 2006 and was elected President in 2007. "Ted's shoes cannot possibly be filled, but we, as a Board of Directors, can follow in his footsteps and continue to seek the positive results for SBAWP clients that he and many others have accomplished," said Mr. Smith. "SBAWP is an organization that has a proven track record of providing positive results for the clients we serve."

An accomplished businessman, Smith formed a public accounting firm that served small and mid-sized clients in diverse industries early in his career. As a financial advisor and business-planning consultant, he led the turnaround of multiple businesses while assisting clients in securing bank, private, and public financing. After his accounting firm was sold to employees in the late 1980's, Smith joined Omega Systems, a Pittsburgh high-tech company where he served as CFO, Secretary, and Board Member. After the sale of Omega Systems in 1998, Smith authored the "Manual for Business and Personal Success" that serves as an information source for a coaching process he produced and facilitates for entrepreneurial business owners who are committed to succeeding in their business and personal life.

Smith holds a Bachelor of Science degree from the University of Pittsburgh where he graduated Summa Cum Laude in 1973. In 1994, he completed the Entrepreneurial Management Program in the Graduate School of Industrial Administration at Carnegie Mellon University. ■

In Memorium



Theodore Fithian

The Spina Bifida Association of Western Pennsylvania grieves the loss of our dear friend and leader, Theodore (Ted) Fithian, who passed away in September, 2008. Ted was more than just the Chairperson of the Board of SBAWP, he was a passionate leader, devoted volunteer, determined advocate and enthusiastic cheerleader. Our words cannot adequately articulate the value of Ted's contributions to this organization and the community; nor can we count the number of lives on which he had a profound and meaningful impact. We extend our deepest condolences to Ted's wife, Martha, and their family, and thank them for sharing Ted with us over the last decade.



Calendar of Events

February

13-15 | adult retreat

20-22 | youth/teen retreat

April

17-19 | youth/teen retreat

24-26 | adult retreat

March

20-22 | youth/teen retreat

27-29 | adult retreat

May

8-10 | youth/teen retreat

The farmhouse pictured here is one of the original buildings on the property where the Spina Bifida Association of Western PA held its first summer camps for children. The property eventually became known as the Woodlands and SBAWP continues to hold summer camps, as well as weekend retreats, at this location.

Horsing Around

SBAWP's Adult Community Services program offers many opportunities such as this for participants to get out into the community, try new things and have some fun with friends. Other recent outings have included trips to the Grove City outlet mall, zoo, Hines Ward Show, Steelers' Training Camp, and a pumpkin patch.



Laurie Shaffer, a resident at the Villa apartments, takes a moment to get acquainted with her horse before going for a ride during a recent adult community outing to an adaptive horseback riding facility.



Spina Bifida

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The Powers Scholarship Fund

The Powers Scholarship Fund is set up in memory of long-time supporter and friend to the SBAWP, Dr. Gary James Powers. As a parent of a child with spina bifida, Gary knew all too well the importance of SBAWP's Year Round Weekend Retreat and Summer Camp Programs. Recognizing the strong need to keep these programs alive, the Powers Family committed start-up funds in his memory to a scholarship program that would afford individuals with spina bifida, in need, the opportunity to attend SBAWP weekend retreats and summer camps.

Both programs offer much needed social and recreational outlets for children, teens and adults with spina bifida. Individuals with disabilities can often feel isolated due to their physical and cognitive limitations. It is vital that they are offered a safe and engaging atmosphere among their peers that will support healthy social and emotional growth. The SBAWP's retreats and camps offer this environment and much more.

The SBAWP kindly asks that you donate to the Powers Scholarship Fund so that we may continue to offer these vital weekend retreat and summer camp programs to all those in need. Your contributions can be used as follows:

\$1500

will sponsor an adult summer camp experience or six year-round weekend retreats

\$1000

will sponsor a child or teen's summer camp experience or four year-round weekend retreats

\$500

will sponsor two year-round weekend retreats for two children, teens or adults

\$250

will sponsor one year-round weekend retreat for one child, teen or adult

\$150

will sponsor one day at summer camp for one child, teen or adult

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