

Kaleidoscope

changing . . . adapting . . . growing



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Kaleidoscope

changing... adapting... growing

Winter 2012

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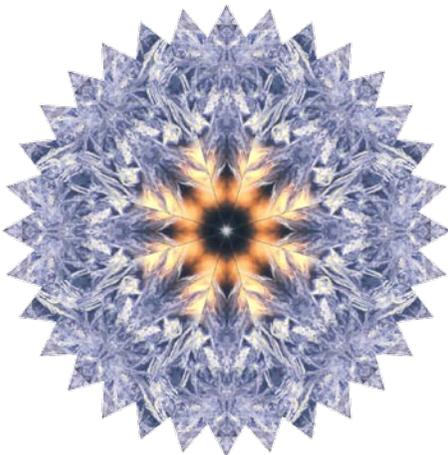
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Executive Committee

Chairperson | Richard Smith
President | Joseph F. McCormick
Vice President | Jeffrey B. Balicki, Esq.
Vice President | Stephanie L. Schneck-Jacob, M.D.
Treasurer | Karen Rath
Secretary | John Liebenguth

Board Members

Peter Kochis, Immediate Past President
Joseph H. Bucci Esq.
Susan Lanzel Sandstrom

Director of Operations | Adele Duffy

Graphic Design | Beth Beiter



Spina Bifida

Spina Bifida Association of
Western Pennsylvania
1158 Dutilh Road
Mars, PA 16046
Phone: 1-800-243-5787
Fax: 724-934-9610
www.sbawp.org
info@sbawp.org

Donations may be made on line at:
www.sbawp.org or by check made payable to
"Spina Bifida Association of Western PA"
and mailed to:

Spina Bifida Association of Western PA,
1158 Dutilh Road, Mars, PA 16046-9448

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.

SBAWP ELECTS NEW BOARD OFFICERS

On December 15, 2011, the Spina Bifida Association of Western Pennsylvania elected new officers to its Board of Directors. Joseph F. McCormick was elected Board President, and Karen Rath was elected Treasurer of the Board. Peter Kochis was named Immediate Past President.

McCormick, who previously acted as Treasurer of the SBAWP Board, is an Assistant Vice President of the Corporate Finance Department at Federated Investors, Inc. McCormick oversees the administering and reporting of the company's total revenue, lines of credit, investment portfolio, share-based compensation programs and cash activities. McCormick holds a bachelor's degree in accounting from Washington & Jefferson College. He is a Certified Public Accountant, a Certified Treasury Professional, a member of the Association for Financial Professionals and a volunteer for

the Miracle League of Southwestern Pennsylvania. McCormick and his wife Melissa have one daughter, Abby. They reside in Robinson Township, Pennsylvania.

Rath is a Not-for-Profit Specialist for The Huntington National Bank who joined the SBAWP Board of Directors in 2011. She has also worked in Treasury Management for the bank, focusing on corporate clients. She earned her Certified Treasury Professional certification in 2010. Previous appointments include positions as a Vice President at PNC (working as both a Product Manager in Treasury Management and with PNC Advisors) and as an AVP at Federated Investors, holding many different roles focusing on corporate projects with mergers and acquisitions. Ms. Rath obtained her NASD Series 7 and 63 in 1990 while working at Smith Barney. ■

BUCCI NAMED PRESIDENT OF SBAWP HOUSING, INC.

Joseph H. Bucci was elected to serve as President of the Board of Directors of SBAWP Housing, Inc. Bucci is a Partner in the firm of Leech Tishman Fuscaldo & Lampl, and is Chair of Leech Tishman's Construction Practice Group.

An active volunteer in the Pittsburgh community, Joe has served on the Board of Directors of both the SBAWP and SBAWP Housing, Inc. for several years. Joe's two-year term as President began in October 2011.

With over 35 years of ground-up experience in the construction, design and real estate development industries, Joe's extensive legal practice includes representation of clients who are contractors, subcontractors, suppliers, owners, developers, architects, engineers, sureties and property managers. ■

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CONGRATULATIONS

Pete Kochis

Congratulations to Pete Kochis, Immediate Past President of the SBAWP Board of Directors, for his selection by the Pittsburgh Post-Gazette as one of 50 local volunteers in 2011 to receive a Jefferson Award, known as the “Nobel Prize for volunteerism”. Pete received this award in recognition of his hours of service to SBAWP, both as a board member and a devoted hands-on volunteer.

Pete served as Board President of SBAWP until December of 2011, guiding SBAWP through a challenging transitional period in a distressed economic climate, which involved a change in leadership and relocation of the agency headquarters. Not only did SBAWP survive this transition, it has thrived – with stronger programs and administrative practices – largely due to Pete Kochis’ dedicated service and leadership.

As an advocate, Pete has attended legislative events to create awareness of the need for housing options for people with disabilities and devoted countless hours to researching and sharing current medical information about spina bifida. He is brave and persistent in asking for support from legislators, government agencies, corporate leaders, and other individuals.

Anyone involved with SBAWP in the past five years knows Pete Kochis on a more personal level because he has a real heart for both the SBAWP consumers and staff. He shares his time, talents and treasures with them. He carries both a notebook and a tool belt. He continues to assist in building handicap accessible ramps and maintaining three SBAWP facilities. He channels his complete dedication to them

into actions that enable SBAWP to continue its mission to improve the lives of individuals through education, advocacy and direct service programs.

In 1972, Jacqueline Kennedy Onassis, U.S. Senator Robert Taft Jr., and Sam Beard founded the Jefferson Awards program to honor the unsung heroes of our country. Named after founding father Thomas Jefferson, the Jefferson Awards are presented on the national and local level to honor individuals for their achievements and contributions through public and community service.

In 1976, former Pittsburgh Post-Gazette editor John Craig established a local program honoring Western Pennsylvania’s “Community Champions” -- everyday citizens who encountered problems in their neighborhood and created solutions to fix them. Today, the Post-Gazette continues to honor

outstanding volunteers each week through the Jefferson Awards program, which is now also supported by Highmark, The Pittsburgh Foundation and The Heinz Endowments.

Each of the local Jefferson Award recipients will be highlighted in a newspaper ad and honored at an elegant reception at which they will receive the bronze Jefferson Award medallion, commissioned by the Franklin Mint. Local leaders then choose six to eight of those honorees as finalists for our region’s Most Outstanding Volunteer award. One winner will be chosen and will represent Western Pennsylvania at the national Jefferson Awards ceremonies in Washington, D.C. For full information on the Jefferson Awards, check <http://www.post-gazette.com/pgcharities/jefferson/program.asp> ■



Rebecca Droke/Pittsburgh Post-Gazette

KNOCK - KNOCK

Door Decorating Contest!

The residents at the Fithian House, a 14 unit apartment building for adults with Spina Bifida, got into the Christmas spirit by decorating the doors to their apartments. Some doors displayed scenes from popular Christmas specials like “A Christmas Story” and “A Charlie Brown Christmas.” Other doors had crafted snowmen made out of cotton batting or were wrapped up like Christmas presents. No matter the design, the doors sure helped create Christmas spirit within the building.

To kick up the competition and spark creativity, a staff member announced that there would be prizes for first, second and third place winners and then donated gift cards as prizes. Pete Kovich, Immediate Past President of the SBAWP Board of Directors, as well as several Association staff and friends came to the Fithian House to judge the residents’ originality on their decorating.

Due to the amazing job everyone did, it was not an easy job to choose the winners, but after much contemplation, the winners were finally chosen. The first place winner of the door decorating contest

was RJ Bird, followed by Dan Benati in second place, and Carrie Irvine in third place. Congratulations to all the winners and their neighbors for a job well done!

The residents and staff had a great time getting together to “compete” against each other. With the door decorating contest being a hit, the staff at the Fithian House plan to organize activities each month such as “Guess Whose Baby Picture.” Look for that contest and others in our future newsletters! ■



CHRISTMAS CAROLERS

The weekend of December 2-4, 2011, Camp Firefly hosted its annual Christmas retreat for the adult campers at the Family Retreat Center. The Christmas retreat is a wonderfully cheerful time for our campers to enjoy the Christmas season with their friends. This year 16 campers attended the weekend retreat. During the weekend, they socialized with their friends, did arts and crafts, and decorated for Saturday evening's festivities.

This year was exceptionally festive with Santa Claus, Christmas carolers, and a DJ on hand to help create a festive mood during the Saturday night entertainment portion of the retreat. Common Ground Fellowship Church out of Hopewell brought 13 carolers along. As a group, they sang traditional Christmas favorites such "Silent Night", "Hark the Herald Angels Sing" and "Go Tell it on the Mountain and "Feliz Navidad". Sara McCarrell, the youngest caroler of the group sang a solo during the carolers' performance of "Jingle Bells".

The campers visited with Santa Claus. They sang along with the carolers and boogied on the dance floor as DJ Bill Leist spun tunes to keep the party going. Santa handed out boxes of treats to all the campers. A great time was had by all!



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We Are Looking For A Few Good Men and Women!

Spina Bifida Association of Western Pennsylvania is looking for people to fill several positions here at the Association. We are looking to fill both paid positions: Summer Camp Staff and Direct Care Staff, and unpaid positions: a Communications Intern to assist with planning the Annual Summer Festival, and volunteers for all programs.

Summer Camp Staff are needed from the end of June to the middle of July. Training and room and board are provided, as well as a great experience for those who are Education, Special Education, Occupational Therapy, Recreational Therapy, Nursing, and Psychology majors. Camp staff assists in all aspects of personal care, dressing, toileting and hygiene for our campers. Staff must be over 18 and eligible for Act 33/34 clearances.

Direct Care Staff are needed in all residential programs. The hours are flexible and weekend and evening staff are needed immediately. Full and part time positions are available. Come help our adults to live their lives to the fullest! You will be responsible for all areas of daily living to enable our adults to remain healthy and able to live in their own apartments. Staff

must be over 18 and eligible for Act 33/34 clearances.

2012 Summer Festival Intern or Volunteer - Assist the Director of Development with the planning of the 2012 SBAWP Annual Summer Festival sponsored by Seubert and Associates. Responsibilities would include preparing and distributing event promotional materials and soliciting donations from local companies to be used as prizes and auction items. Intern must be over 18 and eligible for Act 33/34 clearances. We would prefer a college student majoring in communications or marketing, or someone with experience in marketing or special events planning. Non-paid internship would begin in May or June 2012 and run through August 17, 2012.

Volunteers are needed in all areas. If you are willing to help us keep our buildings clean, mow grass, rake leaves, lead a study hall or two a week, we need you! Volunteers should be 18 or older and eligible Act 33/34.

If you think you've got what it takes to help SBAWP in any of these capacities, please contact Kelly Mayer at 724-934-9600 for more information!

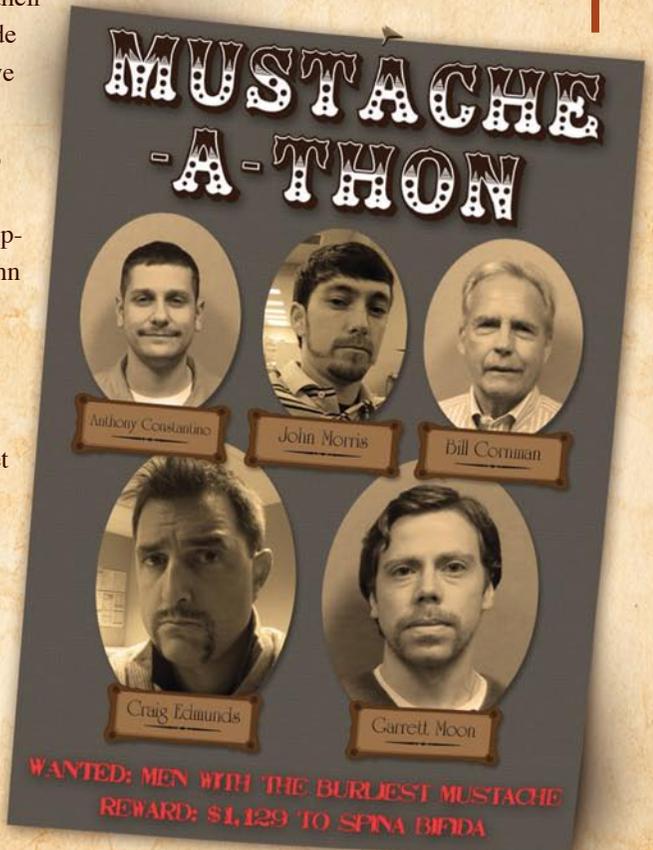
{ *continued supporters & partnerships*

National Rehab First ever Mustache-A-Thon

Every month the wonderful folks at National Rehab ask their employees to raise money for a non-profit. In December, they chose the Spina Bifida Association.

The men of NR were asked to take part in the first ever NR Mustache-A-Thon to raise money for Spina Bifida. The guys had two weeks to grow their burliest mustache and persuade the women in the office to give their sponsorship to them.

Thanks to the employees who participated and to National Rehab for being such great supporters of the Association: John Morris (\$35), Bill Cornman (\$100), Anthony Constantino (\$100), Garret Moon (\$105), Jonathon Martin (\$254) and Craig Edmunds (\$285). Garret Moon won the best mustache and Craig Edmunds raised the most money. Thanks to Heather for matching Craig's highest amount raised. The total amount raised for Spina Bifida was \$1,129!





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Enroll in the Partners in Care Program

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

REASONS TO ENROLL IN THE PARTNERS IN CARE PROGRAM

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

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- Distinctive ultra-smooth eyelets
- Clean technique for intermittent catheterization
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- Latex-free
- Straight or coude tapered tip available
- Curved packaging

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

T 1-800-451-6510

When calling please reference Promo Code 101.

NR Corporate Headquarters: Airside Business Park | 540 Lindbergh Drive | Moon Township, PA 15108
NR Southeast Division: 1667 Shug Jordan Parkway | Suite 403 | Auburn, AL 36830

www.nationalrehab.com

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Volunteers Make a Difference at SBAWP In 2011

Year after year, SBAWP relies on volunteers of all ages and abilities to assist in maintaining The Gatehouse, Fithian House and SBAWP Association offices. This year SBAWP welcomed back past volunteers, as well as, new volunteers to clean, paint, build, landscape and much more.

In addition to maintaining the SBAWP properties, SBAWP depends on volunteers to assist with special events and fundraisers. In 2011, SBAWP staff, families, friends, Board members and program participants played a large part in the success of the 2011 Annual Summer Festival, Cabaret musical review and hoagie and Sarris Candy sales. Funds raised from these activities were used to support the SBAWP programs such as Camps, Weekend Retreats, BluePrints and Family School Partnership.

In 2011, with the help of local schools, SBAWP successfully raised money for youth and teen and young adults with Spina Bifida and other disabilities to attend SBAWP Camps and Retreats. The local schools participated in "Quarter Wars" and "Pop Can Tabs" collection competitions. Students had fun competing and the opportunity to give back to the community.

Once again, the list of volunteers is too long to list in this Newsletter, and for that SBAWP is grateful. Our volunteer list includes representatives from local churches, local businesses, boy scouts, school children, a national fraternity, medical professionals, SBAWP Board of Directors and their families and friends who chose to give back to the community by utilizing their time, talents and treasures to serve SBAWP and their program participants. Please know that we appreciate each and every one of you and thank you for repeatedly helping to make a difference at SBAWP over this past year!

Please know that we appreciate each and every one of you and thank you for repeatedly helping to make a difference at SBAWP



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THEY REALLY HELPED – GOVERNMENT OFFICIALS AND ELECTED REPRESENTATIVES!

Pete Kochis, Immediate Past President

The Association is very grateful to three Federal Government officials who have with compassion and an earnest interest in serving our community, helped the Association succeed in its mission.

The Association, a few years ago, undertook to build and operate a 14 unit apartment complex for adults with spina bifida. This was a major undertaking and had many financial and operational challenges; it was a significant new and uncharted venture for the Association. We are grateful to, and acknowledge the help of:

Christopher Rosselot; Field Representative of Senator Robert Casey's office.

Brian Murray; Chief, Project Management US Department of Housing and Urban Development – Pittsburgh.

Scott Smith; Chief, Production Branch, Government Technical Representative, U.S. Department of Housing and Urban Development, Pittsburgh Multifamily Program Center.

We appreciate their ongoing support in assuring that the SBAWP housing project, referred to as the “Fithian House”, is an operational and financially secure venture. Their advice and assistance has been an oasis of support among a sea of tribulations. To these “friends” of the Association we say Thank You and we are truly grateful for you and your assistance.



Sign your child up today for SBAWP's 2nd Annual BluePrints "mini- day camp"!!!



Calling all children ages 2-5 with spina bifida and related disabilities to join us for three very exciting days in July! Day camp is scheduled for July 16, 18, and 19th this year at The Family Retreat Center, Mars, Pa from 11:00am-2:00pm each day. Parents/Guardians are required to stay with the children. Siblings are invited to attend as well! This opportunity allows parents and their children to get the "camping" experience together as a family, while

ing a spina bifida support group for parents, guardians and caregivers! Childcare is always offered by local college students, SBAWP staff, and National Rehab staff. The kids have a great time playing while the parents are offered a speaker. Thanks to Parent to Parent, EKidz Care, Hollister and all of the other agencies that have supported our group! Our meetings are monthly and usually the 2nd Tuesday of every month! Information regarding our support

Information regarding our support group can be found by going to www.sbawp.org. You can also find us on Facebook and Twitter! Please help to spread the word about this new and exciting group!

meeting other families in the area! Registration is currently open and the fee is \$60 per child (\$20 per day). Siblings are just an additional \$10. Some of the activities include swimming, crafts, and sensory play. Lunch is included. Please call 724-934-9600 to sign up your child today!!! Spots are limited.

group can be found by going to www.sbawp.org. You can also find us on Facebook and Twitter! Please help to spread the word about this new and exciting group! ■

Spina Bifida and National Rehab have teamed up AGAIN!!! Last September SBAWP and National Rehab began offer-



Penguins Raffle to Support Campers!

Throughout the last few years we have been actively searching for ways to help our campers raise the funds they need to attend the Firefly Camps and Retreats programs. Every year we offer opportunities for individuals and families to fundraise either for their own registration fees or to help others by supporting the Powers Scholarship Fund. The scholarship fund allows families to request monies to decrease or eliminate their registration fees so they may attend the retreats or camp. Times are tough for families and non-profits alike so these fundraising opportunities are a win/win for everyone involved. They allow the families to raise money that goes into an account they can draw on to pay registration fees and allow us to continue to provide scholarships to those that need it. Currently, thanks to a generous donation by Bob Mihalko, we are conducting a raffle for Penguins ticket.

Tickets are only \$1.00 a chance and include:

2 tickets to the March 27th game against the Islanders

(seats are accessible)

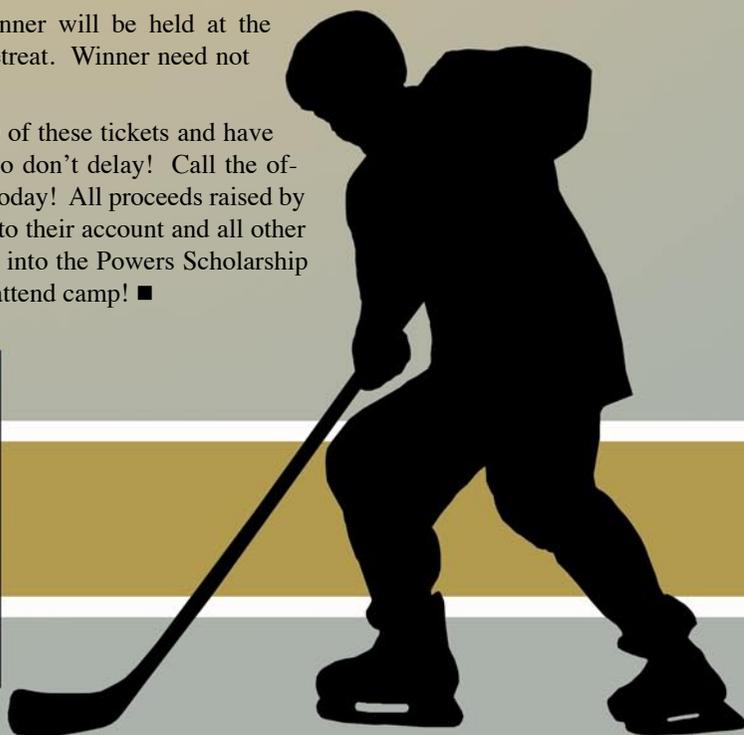
Signed Fleury Jersey

Parking pass for the garage

\$100 CASH

The drawing for the winner will be held at the March 9th Youth/Teen retreat. Winner need not be present to win!

We are only selling 3000 of these tickets and have already sold over 1700 so don't delay! Call the office and get your tickets today! All proceeds raised by families will be credited to their account and all other proceeds will go directly into the Powers Scholarship fund to help individuals attend camp! ■



Calendar of Events

February, 2012

17-19 | **FireFly** Adult Retreat at Family Retreat Center

March, 2012

9-11 | **FireFly** Adult Retreat at Family Retreat Center

23-25 | **FireFly** Youth Retreat at Family Retreat Center

April, 2012

20-22 | **FireFly** Adult Retreat at Family Retreat Center

May, 2012

11-13 | **FireFly** Youth Retreat at Family Retreat Center

19 | **Highmark Walk** for a Healthy Community

Wish List

SBAWP is always in need of new or gently-used furniture and equipment for our residential programs. Please consider a donation of the following to SBAWP:

4 Saucepans w/lids *
4 Fry pans 10**
2 Fry pans 8" *
2 Stockpots (dutchoven)*
2 Small frypans *
1 Coffee pot
1 Handmixer
8 Serving bowls
Serving plates
4 Anti-slide mixing bowls
2 Microwaves
3 Cooking utensils sets
3 Serving utensils sets
20 Plastic drinking cups
(not white, various sizes)
4 Sets casual dishes –
non breakable, not white
4 Full sets flatware
2 Knife blocks
4 Sets dishtowels
4 Sets hot pads/mitts
3 9X12 baking pans
3 8X8 baking pans
2 Muffin pans

2 Loaf pans
4 Cake pans
3 Casseroles w/ lids
Pie pans
3 Blenders
4 Cutting boards
2 Sets measuring cups
2 Sets measuring spoons
8 Sets broom/dustpan
4 Steak knives sets
4 Room dividers/privacy screens
1 Couch (vinyl or leather – not fabric)
9 Single (twin) beds with mat-
tress – drawers or storage below
2 Full beds with mattress
–Drawers or storage below
11 Night-stands w/drawers
2 Vacuums

*Restaurant Quality preferable, Non-rusting

Celebrating Ten Years

HIGHMARK WALK FOR A HEALTHY COMMUNITY



SAVE THE DATE!
SATURDAY, MAY 19, 2012
STAGE AE – PITTSBURGH, PA

We are one of 70 organizations participating in the 2012 Highmark Walk for a Healthy Community.

Highmark Blue Cross Blue Shield underwrites 100 percent of the cost of the event and funds raised directly benefits the participating organizations.

Mark your calendar, find those walking shoes, and look for more information to come soon.



WALKFORAHEALTHYCOMMUNITY.ORG



Spina Bifida Association of Western Pennsylvania

2012 SBAWP Annual Summer Festival presented by Seubert and Associates – Bigger and Better than Ever.

Mark your calendars now for SBAWP's Fourth Annual Summer Festival presented by Seubert and Associates, which is scheduled for **Saturday, August 11, 2012 from 2 p.m. to 8 p.m. at Blueberry Hill Park in Franklin Park.**

This year's event promises to be bigger and better than ever— more music, more food, more activities, and more fun with all proceeds benefitting SBAWP programs.

See you there!



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