

Kaleidoscope

changing . . . adapting . . . growing



Movin' In
page 4

Miracle League
Opens it's Doors in
Southwestern PA
page 6

Summer Festival
page 10

Kaleidoscope

changing... adapting... growing

Spring 2009

Contents

- 3** A note from Dick
Give Up? *by Dick Lynch*
- 4** Program Update
Movin' In
- 6** In Your Interest
Special Needs Toys
Miracle League Opens its Doors in
South Western PA
SBAWP Receives Grant Awards
- 10** Get Involved
SBWAP Summer Festival
- 12** In the Community
Peter J. Kochis, President of the Board
Gaming Our Way to Health
- 14** Activities & Events
Calendar of Events
On the Slopes at Hidden Valley

Executive Committee

Chairperson | Richard L. Smith
President | Peter Kochis
Vice President | Jeffrey B. Balicki, Esq.
Vice President | D.J. Hammerschmidt
Vice President | Suresh C. Ramanathan
Vice President | Stephanie L. Schneck-Jacob, M.D.
Treasurer | Joseph F. McCormick,
Secretary | Susan Powers

Board Members

Joseph H. Bucci
Peter W. Clakeley
Dr. Warren Reed Clark
John Liebenguth
Boyd Murray
Susan Lanzel Sandstrom
Rep. Mike Turzai

Executive Director | C. H. (Dick) Lynch, Jr
Director of Development | Sue Powers

Graphic Design | Beth Beiter



Spina Bifida Association of
Western Pennsylvania
134 Shenot Rd
Wexford, PA 15090
Phone: 1-800-243-5787
Fax: 724-934-9610
www.sbawp.org





Give Up?

Brad Cohen always makes his presence felt. Sometimes it's because of his involuntary verbal tics, or the puffs of air he blows, which can make a phone conversation sound like it's taking place in a wind storm.

Those are the result of Tourette's syndrome, which Cohen has called his "constant companion" since early childhood. But his relentlessly upbeat approach to life is what gets him noticed. His story is chronicled in a recent Hallmark Hall of Fame movie "Front of the Class," a movie that follows him from being a teased, misunderstood youngster to achieving his dream of becoming a teacher.

The movie aired in early December of 2008. As I watched, I was riveted to the story and the demonstration of the fact that an individual born with a disability can succeed. At one point, late in the film, the class is asked what Mr. Cohen had taught them. Their response did not center on the knowledge they had absorbed but rather on one inspiring thought. They said, "He taught us never to give up!"

As I think of Brad Cohen, my thoughts turn to the children and young adults that we see each and every day on our campus. They too have a constant companion that they were born with – Spina Bifida. Whether the disability is audible as in Tourette's or physical as in Spina Bifida, the challenges faced by the individual and the family are present every day.

The more I understand about the formation of a human life in the womb; the more I read about the amazing changes that take place during the development of a child; the more I understand that we who have been blessed with able bodies and no disabilities must carry the flag for those who cannot.

Our staff continues to say to those we serve, "Never give up". And neither can we! We will never give up in our efforts to serve those with Spina Bifida. We will never give up in our quest to help them live more independently or to help them go back to school or to help them secure that job. We will never give up in our support of parents and families of those with Spina Bifida.

We will never, never, never give up!

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

{ program update

MOVIN' IN!



Three years ago, the SBAWP envisioned the creation of a fully accessible apartment building that would afford young adults with Spina Bifida the opportunity to live independently in the community. Armed with a dream and generous support from the Department of Housing and Urban Development (HUD), Allegheny County and numerous community supporters, the SBAWP recently realized its vision.

On February 9th, 2009, the newly constructed Fithian House at The Groves welcomed its first resident, Harry Prince. Since Harry's arrival 13 additional young adults with spina bifida have had the opportunity to call the building home. Thanks to the SBAWP's devoted staff and spirited cooperation from resident families, the highly anticipated "move in" was a great success.



Kenia Hernandez, who moved in on Valentine's Day shared, "It's just a great place. I feel like I have more freedom and independence than I have ever had before, not to mention decorating my own place has been a blast!" Kenia's "place", in addition to every other unit in the building, was carefully designed to meet the resident's needs. Efforts were also made to make the building environmentally friendly with features like energy efficient lighting, windows and insulation. Each unit contains an accessible bathroom, bedroom, living room and kitchen including appliances. Furthermore, the two story building has an accessible elevator and laundry room in addition to a community kitchen and lounge to encourage socialization.

The lounge, like the building was lovingly named after former SBAWP Board Chairman, longtime friend and SBAWP advocate, Ted Fithian who passed away in September 2008. At the building's dedication ceremony that took place in December 2008, those who knew him best repeatedly expressed, "Ted would be really of proud of this place."

For questions about the Fithian House please contact the SBAWP at 724-934-9600 or via email at info@sbawp.org. ■



{ *in your interest*



The Miracle League Opens Its Doors in Southwestern PA

With over 90 locations and 100 more under construction, The Miracle League will officially open its doors in Southwestern PA! The Miracle League is an organized baseball league for special needs children. League participants develop socialization skills and have fun by playing baseball at a field especially designed for them. The Miracle League of Southwestern PA will be located at the baseball field complex of the Dick's Sporting Goods Sportplex at Graham Park in Cranberry Township. The field and park are currently under construction and will be totally handicap accessible. It will have a synthetic surface that allows for easy use of wheelchairs, walkers, and other adaptive devices. Opening Day for the Miracle League is scheduled for May 16, 2009. The inaugural season will be nine weeks with all league games taking place on weekends.

Every child, no matter his or her level of ability, can participate in the Miracle League of Southwestern Pennsylvania. For the first season (2009), players must be no younger than 5 years of age and no older than 18 years on or before August 30, 2009. Based on the level of interest after the first season, additional age categories may be added in

the future. Each
game typi-
cally

lasts about two hours. They are non-competitive in nature, with each player batting, running the bases and scoring each inning. Each team will have 12-13 players.

“The Miracle League of Southwestern PA is thrilled to invite eligible participants from the SBAWP to join our league.

- Mike Sherry, President

Volunteers called “Buddies” are assigned to each individual for assistance throughout the game. There are no losers in this game, only winners with the score tied at the end of each game. The focus is more on participation than on winning. The Miracle League of Southwestern PA will also need a variety of volunteers for the inaugural season. Volunteers will be needed to be managers, coaches, Buddies, umpires, team parents, and for general help like registration, equipment and field maintenance.

To register to be in the league as a participant or volunteer please contact Dan Pollock via email at dpollock1@zoominternet.net or visit: www.mlswpa.org for more information. The Miracle League of Southwestern PA is a registered 501(c)(3) charity founded in 2007. ■

SBAWP Receives Grant Awards

FISA Foundation

The SBAWP was recently awarded a generous grant from the FISA Foundation. The mission of the FISA foundation is to build a culture of respect and improve the quality of life for three populations in southwestern Pennsylvania: women, girls, and people with disabilities.

The grant award will be used to purchase adaptive and assistive equipment in support of the SBAWP's Skills Training and Rehabilitation for Individual Vocational Enhancement Program (S.T.R.I.V.E). Developed by the SBAWP in spring 2008, the S.T.R.I.V.E. program assists individuals with spina bifida and other related disabilities in developing the coping and problem solving skills that will allow them to acquire and maintain employment. Serving individuals in the northern region of Allegheny County, the program provides participants with the training needed to understand their physical and cognitive strengths and limitations. Furthermore, it teaches them to develop realistic and appropriate career goals and to have an understanding of how to develop compensatory strategies in employment and community-based settings.

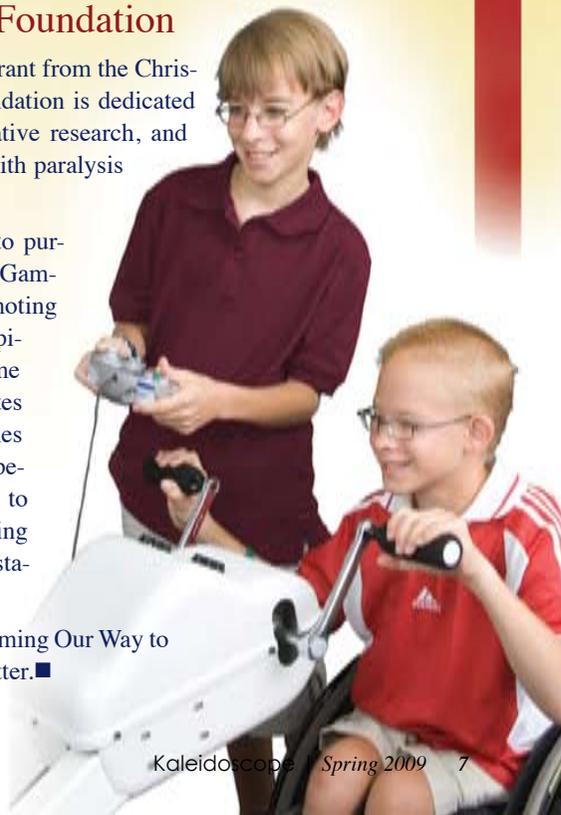
The skills learned through S.T.R.I.V.E. enable individuals to be more independent in career exploration, job seeking and maintaining competitive employment. Visit www.sbawp.org and click on Programs and Services to learn more about the S.T.R.I.V.E. Program.

Christopher and Dana Reeves Foundation

The SBAWP was recently awarded a generous grant from the Christopher and Dana Reeves Foundation. The foundation is dedicated to curing spinal cord injury by funding innovative research, and improving the quality of life for people living with paralysis through grants, information and advocacy.

The grant award will be used by the SBAWP to purchase a Game Cycle in support of the SBAWP's "Gaming Our Way to Health" initiative aimed at promoting healthy living through exercise for adults with spina bifida and other related disabilities. The Game Cycle is a unique exercise device that incorporates the use of Nintendo GameCube racing video games to promote upper body fitness. The device is especially beneficial for wheelchair users and leads to an array of therapeutic exercise benefits including improvements in strength, range of motion, core stability, endurance and cardiovascular fitness.

To learn more about the Game Cycle and the "Gaming Our Way to Health" initiative refer to page 12 of this newsletter. ■



Special Needs Toys: Find or Create the Best for Your Child

Parents are a child's first and most beloved play companions. They are entrusted with the important task of choosing the most nurturing toys and creating a welcoming environment that promotes learning. Special needs toys - toys for kids who have physical or developmental disabilities - can provide children many different opportunities to play, share, and learn. Providing toys that your child will love is one of the fun parts of special-needs parenting. It's also one of the most effective ways to nurture their growth, happiness, and the development of a strong sense of self. Access to a variety of stimulating toys allows children with special needs to reach their fullest potential.



Choosing a Toy – Focus on Fun

Choosing the right toy is often an unexpected challenge for any parent. The added complexity of finding toys for children with disabilities can leave parents unsure of where to even begin their search. For parents on the hunt for special needs toys, however, it's important to remember the real purpose of all toys—fun! It can be tempting to select toys based solely on their therapeutic or educational value. But if a learning tool doesn't bring your child joy, it's unlikely that it will be used frequently enough to reap the hoped-for benefits. Most parents are familiar with the frustration of purchasing the “perfect” toy only to see it hardly leave its box.

Switch Toys and Adaptations

There are a few specialty companies that design and build toys specifically for children with physical, cognitive, or developmental disabilities. Some parents find these toys expensive, but the growing ingenuity of companies when it comes to meeting diverse needs may provide your child a play opportunity that isn't available in the mainstream market. One company, Science Shareware, provides free DIY instructions for adapting electric cars (e.g., Power Wheels) to be powered from a light switch near the steering wheel. With these adapted switch toys, children who cannot hold their foot to the pedal or who cannot use their legs can practice the early skills of driving without sacrificing the element of fun. Another variation on switch toys familiar to those who've been special needs parenting for awhile is altering mainstream toys, one of the most diverse options for play. One of the most common adaptations includes the addition of large switches to operate electronic toys. Empowering children to turn toys on and off, experiencing the independence of activating their own toys, gives them confidence-inspiring con-

trol over their environment. Special Needs Toys and Beyond Play both offer these switches for use with a number of well-known toys.

Getting the Kids Involved

As children learn to communicate, most will gladly join you in the search for new toys. What if an item on their wish list isn't accessible? Independent play is important. Your child may lack the coordination necessary to press small buttons or dress dolls. What if their wheelchair doesn't fit through the door of their playhouse? Many parents prefer to tap their own creativity and ingenuity to adapt toys for their children. Choosing or building a playhouse with widened doorways and adequate area to turn a wheelchair or walker is one way to offer access – and demonstrate both love and support for your child.

One of the Most Important Lessons of Special-Needs Parenting

Don't forget to consider safety when purchasing toys for any child, whether or not special-needs toys. To prevent choking and injury, think about a child's special needs and unique capabilities rather than general age recommendations. No safety precautions can match the importance of parental supervision. A watchful eye on all aspects of your child's development will also foster awareness of the unique power of toys to influence the development of body image. But keep in mind this basic precept of special needs parenting: all children should enjoy toys that represent the diversity of people in a positive way. Careful selection and presentation of the best toys for your child will be rewarded by their growth into creative and confident adults. ■

First published by and reprinted with permission of, Disaboom.com.

{ *get involved*

SBAWP Annual Summer Festival

June 20, 2009

1st Annual SBAWP Summer Festival

As part of our year long 40th anniversary celebration, the SBAWP will hold its 1st Annual Summer Festival Fundraising Event! Open to all SBAWP members and families in addition to the general public, attendees will be given the opportunity to learn about and make charitable contributions to all of our programs and services at various booths while participating in a number of accessible adult and kid friendly activities.

Entertainment will include square dancing, volleyball, horseshoes, corn hole, jewelry making, Wii and GameCycle matches and much more! Original works of art and other items will also be sold at the event to further strengthen that SBAWP's ability to serve individuals with spina bifida and their families.

The event, graciously sponsored by Brian Long, President of Seubert & Associates, will take place on Saturday, June 20, 2009 beginning at 4:00 pm at Greentree Farm located at 8 Greentree Lane, Cheswick, PA 15024. Evening activities will include a live performance by "Midlife Crisis" and a bonfire. Food and non-alcoholic and alcoholic beverages will be provided at no-charge.

Registration for the event is required and should be done via our website

at www.sbawp.org by June 1, 2009. Admission to the event is \$30 per car and should be paid upon arrival at the event. All proceeds from the event will go towards strengthening all of SBAWP's programs and services. Please spread the word and feel free to invite family and friends. For questions related to the event please contact Sue Powers via phone at 724-934-9600 or via email at spowers@sbawp.org.

We hope to see all of you there!

Who is “Midlife Crisis?”

When the bones began to creak and the midsections expand, these baby boomers didn't scale Everest but turned to the passion of their youth, to Rock and Roll, re-inventing themselves as Midlife Crisis. And it's been a wild ride ever since. Midlife Crisis is comprised of five musicians that have played together for, well, not all that long. They have formed a musical bond that comes through in their music – offering fans their own special spin on every type of rock. Midlife Crisis plays music that ranges from The Cars to The Doors; from The Cure to The Dead.

The members of the band include Brian Long on harp, rhythm guitar, & vocals (whose day job is President, Seubert and Associates); Nick Nichols on keyboard & vocals (whose day job is President, Pittsburgh Regional Minority Purchasing Council); Doug Caye on lead vocals & guitar (Principal, Music Training Company and Realtor); Big Bob Connolly on bass guitar & vocals (President, Bevomatic); and Allen Long on drums (he doesn't sing but his day job is Principal, Heritage Seubert Financial).

To hear their sound, visit www.midlife-crisis-band.com or click on the link from the Summer Festival area at www.sbawp.org.

Then come, see and hear them live at our Summer Festival!



Peter J. Kochis, President of the Board

Peter J. Kochis was elected President of the Board of the SBAWP effective October 2008, replacing Mr. Smith who accepted the responsibilities of Chairman of the Board. Mr. Kochis has been associated with campus activities for almost nine years, and was elected to the board in 2007 on the recommendation of Mr. & Mrs. Fithian. He has been heavily involved in many critical issues of the association, chairs the audit committee, and was a member of the finance committee, and the search committee for a new Executive Director. He also serves on several other committees and the SBAWP Housing board.

In referring to the board, Mr. Kochis noted that “he has never been associated with a finer group of people dedicated to such a noble purpose.” People he notes that work very hard to stay on mission despite many of today’s challenges, people whose focus is those they serve.

Gaming Our Way to Health



“Gaming Our Way to Health” is an SBAWP initiative aimed at promoting healthy living through exercise for adults with spina bifida and other related disabilities. Residents at the Gatehouse will have fun and be motivated to exercise more thanks to a grant from the Christopher and Dana Reeves Foundation that SBAWP will use to purchase a GameCycle.

The GameCycle combines upper body exercise with visual feedback through Nintendo videogames resulting in a fun, challenging and functional workout for the Residents. The GameCycle can accommodate Residents who use a wheelchair, and the device features adjustable heights and different handgrip options for various hand functions. An electronic brake enables users to adjust the difficulty of a workout. To steer, Residents tilt the cranks left or right; to increase speed, they turn the arm cranks.

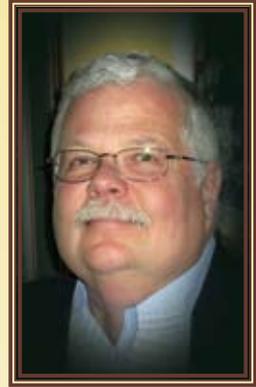
Through consistent “fun” exercise regimens, Residents will increase their strength and core stability, improve their range of motion and improve their cardiovascular fitness. SBAWP staff are working on plans for an in-house competition program to add to the fun and encourage regular use of the GameCycle.

Continuing in its efforts to promote healthy lifestyles and physical fitness, SBAWP hosted its first ever Wii Tournament on March 28th. Residents of the Gatehouse and Fithian House, as well as, individuals attending the March 27-29 Adult Weekend Retreat joined in the fun and the spirit of competition.

Wii is an interactive electronic gaming system that allows individuals to play a variety of video games wirelessly. Wii games include golf, tennis and bowling. The Tournament allowed Residents the opportunity to promote upper body fitness while providing the challenge to “game their way to health” as they played their favorite sport and competed in teams for prizes. Check our website, www.sbawp.org, for the results of the competition! ■

With four successful children, all of whom make him proud, and thirteen grandchildren, all of whom keep him young as they continue to challenge his stamina and memory, and who continue to quiz him on percentage calculations and the history of presidents, he has still found time to support the Association.

A diverse background in aspects of various industries including manufacturing, heavy industry, consumer products, government businesses, and broadcasting has developed a wealth of experiences which Mr. Kochis brings to the table. He succeeded as a Field Service Engineer for General Electric's Atomic Motor Business Division and worked for over twenty years as VP and Chief Financial Officer for various TV, radio and broadcasting network properties for companies including General Electric, Lorimar Telepictures, Meredith Corp. (Better Homes and Gardens) and Sheridan Broadcasting. Mr. Kochis began his career in Schenectady, NY, which led to assignments in Denver, Portland, and Nashville, before settling in Pittsburgh, PA, in 1985. He is published in the Broadcast Financial Management Journal and in Radioactive age on the subjects of cash management and data processing.



Kochis holds a Bachelors of Science degree in Business Administration from the State University of NY at Albany with a concentration in accounting; an Associate Engineering Degree from Dutchess Community College in Poughkeepsie, NY, with a concentration in electronics; post graduated studies in calculus at Union College in Schenectady, NY and is a graduate of the General Electric Financial Management Training Program. ■

We're proud to SUPPORT

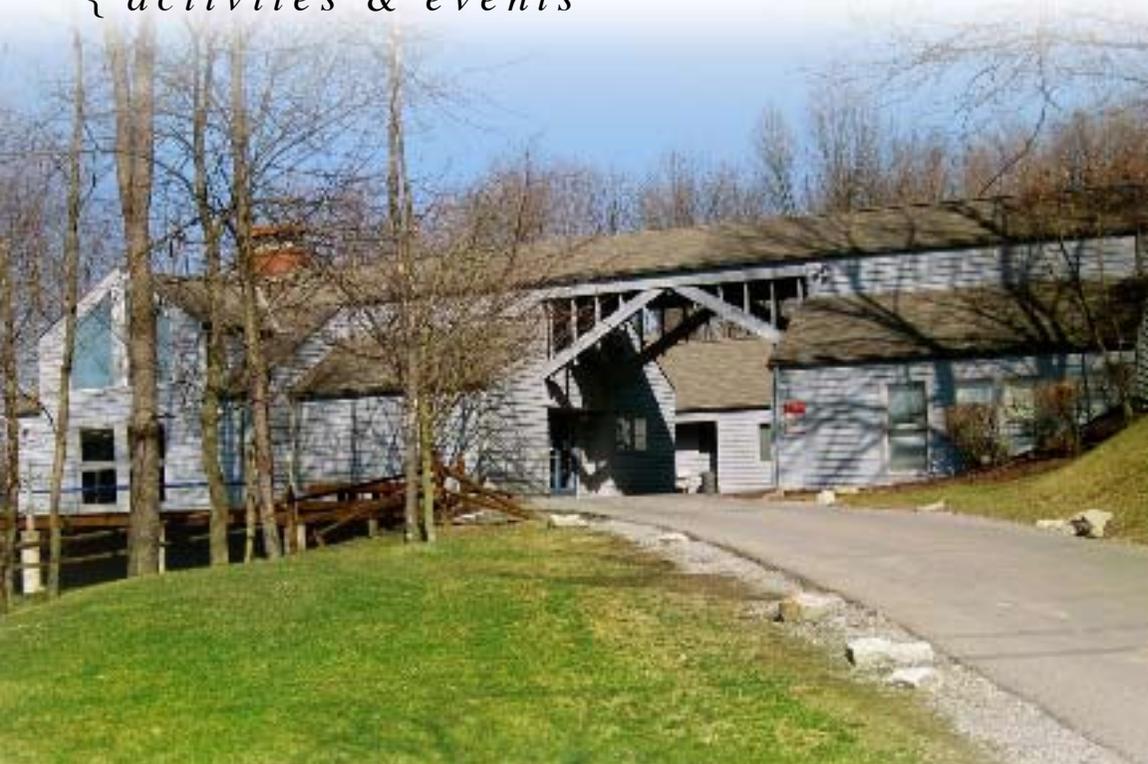
Spina Bifida Association of Western Pennsylvania



Your single source for insurance and investment services

1010 Ohio River Blvd. • Pittsburgh, PA 15202

Phone: 412/734-4900 • Fax: 412/741-1130



Calendar of Events

April

17-19 | Youth/Teen Retreat

24-26 | Adult Retreat

May

8-10 | Youth/Teen Retreat

16 | SBASP day at Miracle
League of Southwestern PA
(Pirates Charity Miracle League
Field, Cranberry Twp, PA)

June

2 | Kennywood Park

7-17 | Circle of Friends

20 | Summer Festival

July

3-5 | Beginner/Mentor Camp

5-11 | Beginner/Teen Camp

Constructed in 1991, “The Gatehouse” is home to our transitional learning program where young adults are taught life skills such as how to maintain their checking account, how to apply for a job, and how to follow their medication regimen. Many graduates of the Gatehouse program are living independently within the community. More information on this program and others can be found on our website – www.sbawp.org.

On the Slopes at Hidden Valley!

The Spina Bifida bus pulled out of the campus late afternoon on Sunday, January 25th. In it were twelve residents and three SBAWP staff members. Each year, the HOPE Network holds an annual Ski Classic at Hidden Valley for handicapped individuals. Our bus load of residents was headed to Donegal to spend the night before hitting the slopes the next day!

Rachael Adil, a resident at the Gatehouse and a first time skier, expressed that she “had fun and it was interesting and exciting seeing how they make it accessible for us to ski.”

Also there that day, was Luke Kelley, a student at Slippery Rock University. He was volunteering his time as a part of his Inclusive Leader Services course. He assisted several in getting into the adaptive ski units. After serving everyone for the day, Luke commented, “We (who are able bodied) take a lot of things for granted. It was really great to experience the enthusiasm and to see everyone enjoying themselves on the course!”

Lynn Kiesel summed up everyone’s feeling when she asked, “Can we stay the rest of the week?!”

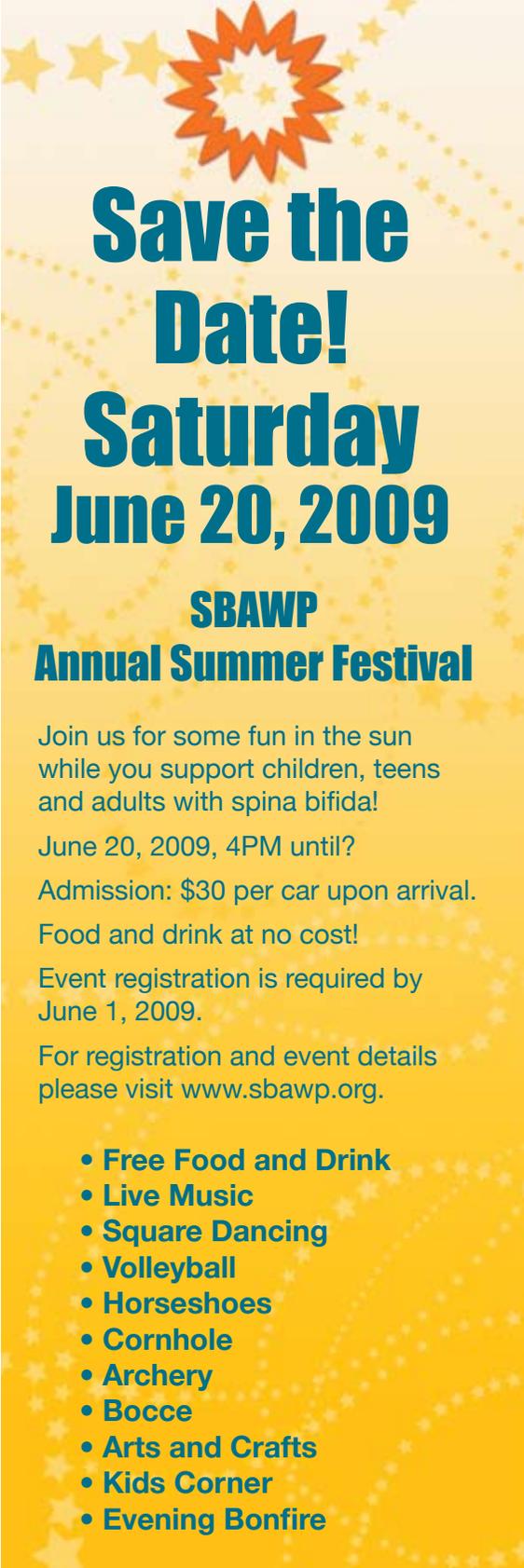
Attending from Spina Bifida were Jen Speicher, Fred Steach, Mike Lermineau, Laurie Schaffer, Lynn Kiesel, Rachael Adil, Tara Graver, Alycia Lazur, Erik Grunst, Ken Ebel, R. J. Bird, and Ryan Woullard. SBAWP staff members included Rachel Bestwick, Amanda Miller, and John Merolillo. ■





Spina Bifida

Spina Bifida Association
of Western Pennsylvania
134 Shenot Rd
Wexford, PA 15090
Phone: 1-800-243-5787
Fax: 724-934-9610
www.sbawp.org • info@sbawp.org



Save the Date!

Saturday June 20, 2009

SBAWP Annual Summer Festival

Join us for some fun in the sun while you support children, teens and adults with spina bifida!

June 20, 2009, 4PM until?

Admission: \$30 per car upon arrival.

Food and drink at no cost!

Event registration is required by June 1, 2009.

For registration and event details please visit www.sbawp.org.

- Free Food and Drink
- Live Music
- Square Dancing
- Volleyball
- Horseshoes
- Cornhole
- Archery
- Bocce
- Arts and Crafts
- Kids Corner
- Evening Bonfire

Non-Profit Org.
U.S. Postage
PAID
Pittsburgh, PA
Permit No. 2535