



Crossroads

FALL 2008

Fall Golf Outing

It was a picture-perfect day for the annual SBA of IL Fall Golf Outing held September 19 at the White Deer Run Golf Club in Vernon Hills. Some 120 golfers teed off at the challenging course following lunch. They enjoyed shrimp and mojitos on the 15th hole, provided by Pete Miller's Steakhouse who donated \$7 to SBA of IL for every golfer who signed up for the Clean Plate Dining Club. Following their rounds, the golfers gathered in the clubhouse for dinner, socializing and prizes. James Fuller, a 14-year-old with Spina Bifida, spoke to the crowd and shared some of his experiences with them.

SBA of IL president Scott Munkvold, who headed the winning team, said, "A big 'thank you' goes to all who participated, to Tom Hoffland and Don Cassier who again did a great job in organizing the day's events, and to all our sponsors and donors."

To see pictures from the event, turn to page 6.



Mark Your Calendar

Oct. 27 - Dec. 1 SBA of IL runs CTA ad campaign	Nov. 15 AAC Coffee Shop meeting, Chicago
Nov. 27 Thanksgiving	Dec. 6 Holiday Party, Rolling Meadows
Dec. 24 - Jan. 1 Office closed for holidays	Feb. 12 First Look for Charity, McCormick Place

Sweet Chic Kicks Off 40th Anniversary Celebration

The SBA of IL 40th anniversary celebration got off to a stylish start with "Sweet Chic," a benefit cocktail party and fashion show featuring designs inspired by the candies of Tootsie Roll: Tootsie Rolls, Charms, Dots, Sugar Daddy, Sugar Baby Junior Mints and other products of Tootsie Roll.

Held October 11 at the Museum of Contemporary Art in Chicago, the event drew some 300 partygoers who nibbled on gourmet appetizers and sipped their favorite beverages while viewing fashions created by 28 Chicago designers. Clothing designs incorporated candy wrapper materials and some even featured ornamentation made from the sweets.

Amy Maggio, Executive Director, said, "This unique event was a wonderful kick-off to our 40th anniversary year. We extend our sincere thanks to Tootsie Roll Industries for their tremendous generosity and unwavering support. I also want to thank the Apparel Industry Board, Inc., and the many sponsors and donors who made significant contributions to our very successful event."



Elizabeth Conroy, SBA of IL scholarship winner, who welcomed the partygoers, poses with one of the models. To see more pictures from the event, turn to page 4.

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AAC Update

Connecting Adults with Spina Bifida

By Carolee Laird

The second half of the year was just as eventful as the first part of the year. In July, the Adult Advisory Committee (AAC) enjoyed an outing to the zoo. The event seemed to be a huge success. The next scheduled outing will be Saturday, November 15, 2008, at 2PM. Adults with Spina Bifida will meet at Starbucks (1900 W Montrose Ave Chicago, IL 60613). This is a great opportunity for a relaxed social gathering. Please join us for great coffee and conversation. In December, the AAC will meet at the SBA of IL Holiday Party in Rolling Meadows. Details will be sent closer to the event. In January we will be sending out our annual surveys to assess the needs of adults with Spina Bifida. Also, please watch your mail for details regarding a February teleconference. For questions, comments, or to get involved, contact aac@sbail.org or call the SBA of IL office at: (773) 444-0305.

Online Survey for Parents and Teens

The University of Illinois at Chicago is currently conducting an online survey for parents and teens to better understand environmental and social factors related to childhood obesity and its potential consequences. To participate in this research your child must be between the ages of 12 and 18 and have a physical or cognitive disability. All information will be kept confidential.

To complete the survey go to:
www.healthforyouth.org
Enter access code:
SBAA

For information or if you have difficulty accessing the survey please contact:

Brienne Davis
bdavis7@uic.edu
(312) 355-4054

University of Illinois at Chicago
Department of Disability and Human Development

Calling adults with Spina Bifida! Are you interested in getting more involved?

We are looking for an assistant to the chair for the Adult Advisory Committee (AAC) – a great resume builder!

The assistant to the chairperson will help the chairperson with duties of running the Adult Advisory Committee. The duties include, but are not limited to:

- Taking notes during meetings
- Assisting with advertising and planning for upcoming events
- Writing articles for newsletter
- Data entry as needed

Qualifications should include:

- Excellent communication skills
- Proficiency with the Microsoft Office Suite
- Excellent note-taking skills

This is an unpaid position. Please send resumes to the SBA of IL office or email aac@sbail.org.

Crossroads- Amy Maggio

When I look back on 2008, and my first year at the Spina Bifida Association of Illinois, I am amazed at all the things we've accomplished and the enormous impact on me both personally and professionally.

By far, my most memorable moment was at our open house this spring for Camp Ability®. Many of our families and campers joined me and the staff at Camp Redleaf to tour our new home for the summer of 2008. It was still cold but the sun was bright that day and the enthusiasm was contagious..... In that single moment, I went from knowing to understanding how truly important our work is on behalf of kids, adults and families affected by Spina Bifida.

By all accounts, Camp Ability was a great success! Families and campers made the adjustment to our new home in Lake County and judging by the feedback and photos from camp, everyone had a great time! SBA of IL is committed to continue to provide the very best in specialized, residential camping for people with Spina Bifida. This coming year, we plan to work closely with Dr. David McLone and Camp Independence to collaborate on residential and camping programs and we will continue our partnership with Dr. Grayson Holmbeck and Loyola University through their family research study and independence skills program.

October is national Spinal Bifida Awareness Month and SBA of IL is rolling out its highly successful media outreach plan throughout the Chicago Metropolitan area.....Beginning on October 27th and running through mid-winter 2009, advertisements and public education messages that promote the use of folic acid to reduce the risk of neural tube defects (NTD) will be featured on bus and transit ads and distributed to library bulletin boards throughout the Chicago area. The campaign will be conducted in both English and Spanish with particular emphasis on outreach to Latino women of child-bearing years who experience the highest rates of pregnancies affected by NTD.

On the fundraising front.....2008 marks the beginning of our celebration efforts leading up to our 40th anniversary of SBA of IL. In early summer, we launched our 40th anniversary campaign and

many of you have given so generously to this new program. We also moved SBA of IL into the fashion and social arena with the very successful first event called Sweet Chic which was held at the Museum of Contemporary Art on October 11th. Our wonderful friends at Tootsie Roll helped to create this one-of-a-kind fashion event with over 28 fashion and accessory designers creating fashion art using the brands and candies of Tootsie Roll. Over 300 guests were treated to drinks and appetizers and sweet libations and treats as they viewed exhibits of dresses, necklaces, and extraordinary fashion! SBA of IL enjoyed the support of many corporations and businesses that helped to sponsor as well as provide raffle packages for our event. Mercedes Benz, BBJ Linen, J&L Catering, Event Creative, Sidetrack, Madame Tartine, Chicago Social, Jet Tools, Bloomingdales, W Hotel, Ritz Carlton, Pascal Pour Elle, 900 Shops and of course, Tootsie Roll.

And, our yearly golf outing was a huge success! Over 120 golfers, friends and supporters enjoyed a great day at White Deer Run in Vernon Hills and this year's event raised over \$50k for the programs and services of SBA of IL. This year also marked the 14th year of our Walk and Roll-a-thon and we celebrated the 14th year raising over \$13k for SBA of IL.....And celebrating its 11th year, the central Illinois Walk and Roll-a-thon raised over \$5k for SBA of IL. My heartfelt thanks to all of our generous supporters and our tireless volunteers who give so much year after year to make these Walk and Roll-a-Thons a huge success!

I recognize that these are challenging and difficult times for our families, our association and the country at large. My experience tells me that in the toughest of times we see the most resolve and the most hope. As we move into this special holiday season..... know that the board and the staff of the Spina Bifida Association of Illinois remains committed to providing much needed information, services and support to our families and friends. We ask each of you to consider making a special year-end gift to SBA of IL and its 40th anniversary campaign. Look for our letter in the next few weeks!

Have a wonderful fall and a very special holiday season!

Sweet Chic



One of the junior models enjoys her "accessory."



Joy and Barry Bowen, son Brad, and Rebecca Wylie enjoy the evening.



SBA of IL Board Members Elliott Quigley, center, and Tom Hoffland greet Christine Poward of SBA.



Board Member Matt Richmond with grandmother Elaine Benjamin and parents Michael and Marla.



SBA of IL president Scott Munkvold and fiancée Rachel Hinrichs admire one of the fabulous creations.



Chicago's leading apparel and accessory designers participated in the show.



Tootsie Roll candies were well-represented in the fashions!

Windy City Corvette Raffle Supports SBA of IL

The annual raffle of a Corvette sports car by the Windy City Corvettes club was held August 3 at Bill Kay Chevrolet in Lisle. Young adults with Spina Bifida were on hand to tell raffle participants how they were assisted by SBA of IL services.

Amy Maggio, SBA of IL Executive Director, said, "We are deeply grateful to Larry Pagliaro and all members of the Windy City Corvettes for their continued support of SBA of IL. The scholarships and other services we provide have an enormous impact on individuals with Spina Bifida and their families."

The lucky winner was an out-of state resident.



Helping with registration for the Corvette Raffle are (from top) SBA of IL members Mary Weiler, Brent Anderson, Patrick Juris and Sam Gustin. Windy City Corvettes member Fred Trombley is just visible between Brent and Patrick.



Windy City Corvettes members brought their pride-and-joy 'Vettes to display.



SBA of IL scholarship winner Bridget Evans selects prize-winning raffle tickets after giving a short talk about how the support of Windy City Corvettes has helped SBA and her. She is now a sophomore at the University of Illinois.



Posing after the raffle are (left to right) SBA of IL board member Don Cassier, SBA President Scott Munkvold, Executive Director Amy Maggio, Windy City Corvettes President Larry Pagliaro, and SBA of IL board member Tom Hoffland.

Fall Golf Outing



First Place Team Winners and friends are: left to right: Jon Hertz, Rob Mager of the Chicago Rush, Chris Casey, Rob Boss of the Chicago Rush, Scott Munkvold and Tim Pilipauskas.



Beat the Rush Raffle Winner Janice Munkvold is shown with Rob Mager, Chicago Rush Wide Receiver, left, and Rob Boss, Chicago Rush Tight End.



Amy Maggio, SBA of IL Executive Director is shown with James Fuller and his parents Joanne and Doug Fuller.

Thank You to Our Fall Golf Sponsors

Event sponsors Rocco & Roxanne Martino
Hole in One Sponsor – Gillespie Auto Group

CDW	Clean Plate Club Restaurant Group
Grayson Holmbeck	Tom & Sara Hoffland
Imbert International	Improv Comedy Club
Jamerson & Bauwens	Key Bank
Lisle Savings	MF Global
QTG Sales	Shelton Family
Kelly Schultz	Turner Construction
Yasakawa Electric America	

Fall Golf Donors

Joan Ackerman	Carl & Ruth Koenemann
Adler Planetarium	Hyatt Regency Chicago
Allied Heating & Plumbing, Inc.	Improv
Anita Dee Yacht Charters	Key Lime Cove Water
Apple Tree Theatre	Resort
ASICS	Lawry's The Prime Rib
Bakers Square	Lucky Strike
Bally Total Fitness	Lush Wine and Spirits
Brookfield Zoo	Amy Maggio
Brunswick Zone	Marriott Lincolnshire
Carlucci Rosemont	Metropolis Performing Arts
Casey's Market	Centre
Cassier Family	MF Global
CDW	Munkvold Family
Cheesecake Factory	Murphy's Rooftop
Chicago Bulls	Company
Chicago Children's Museum	Raymond & Lana Osmus
Chicago Cubs	P.F. Chang's
Chicago Fire Soccer	Paramount Theatre
Chicago Rush	Philly G's
Chicago Sky	Quartino Ristorante
Chicago Symphony Orchestra	Realmark Realty Group
Chicago White Sox	Rialto Square Theatre
Chicago Wolves	Rocco & Roxanne Martino
Clean Plate Club Restaurant Group	Rosebud Restaurants
College of DuPage	Rosewood Restaurant
Colonial Café	Safari Land
Cubby Bear North	Salt Creek Golf Club
Dave & Buster's	Shedd Aquarium
Days Inn Chicago	Susan Shelton
Dick's Sporting Goods	Six Flags
Eaglewood Golf Course	Southport Lanes & Billiards
Fairmont Chicago	Southwest Airlines
Francesca's on Taylor	Spare Time Corporation
Gino's East	Streelman Family
Hancock Observatory	Tony n' Tina's Wedding
Harangody Family	Uncle Julio's
Hawkeye's Bar & Grill	Bonnie Valiant
Hilton Lisle/Naperville	Villa Olivia
Hoffland Family	Waukegan Park District
Hooters	White Deer Run
Bill & Lyndsey Kindorf	

New Members

Lisa Berns
3550 W. Montrose #306
Chicago, IL 60618
Social Worker

Michelle Leal
3737 W. McLean
Chicago, IL 60647
Parent of Jeremiah Feliciano 2/7/07

Jennifer & Casey Bessette
414 Beach Ave. #2C
LaGrange Park, IL 60526
Parents of Josiah 1/28/08

Amber Gengenbach
1930 Pine St., Apt. B
Murphysboro, IL 62966
Associate member

Carla & Dewey Stewart
810 N. 13th St., Box 341
Pawnee, IL 62558
Parents of Joshua 11/7/86

Carol & Paul Zellner
1421 W. Lexington St.
Chicago, IL 60607
Grandparents



In Appreciation

SBA of IL gives thanks to the following organizations for their contributions received since the last newsletter, which help provide quality direct services to people with Spina Bifida and their families:

Family Resource Center on Disabilities	The Cuneo Foundation
Jay Johnson Trust	Spina Bifida Association
Amvets Post 66	Central DuPage Kiwanis Foundation
Wheaton Junior Women's Club	Mecum Auction Inc.
WalMart Foundation	Dodge County Human Services & Health Department

SBA of IL also thanks you, the individual, for the many public donations received during this time.

Central Illinois Walk

By Lynn Bradtke

The eleventh annual Central Illinois Walkathon, held September 28, provided participants a beautiful afternoon on which to walk, roll, picnic, and socialize. New families as well as familiar faces enjoyed the day together. The Walk was held in memory of Kaylin Rood and we also remembered Shannon Kolodzieski who passed away this year.

The Prize winners were:

12 and under: Cameron Pries

13-18: Bekka Rood,

19-35 Michael Kenny

Over 35 Mary Ann Graham

Team participation: Eganhouse family.

The Walk began and ended at the Tipton Trail North Shelter in Bloomington, where participants enjoyed a picnic lunch and received commemorative T-shirts. We would like to thank our sponsors who made the event a success: Central Illinois Corvette Club, Avanti's Italian Restaurant, Enterprise Leasing, Pepsi, Frito Lay, R&R Automotive and Rob Knight's SwimAmerica.

Look for our next big event Saturday, Feb.7, 2009: Candlelight Bowl in Bloomington.



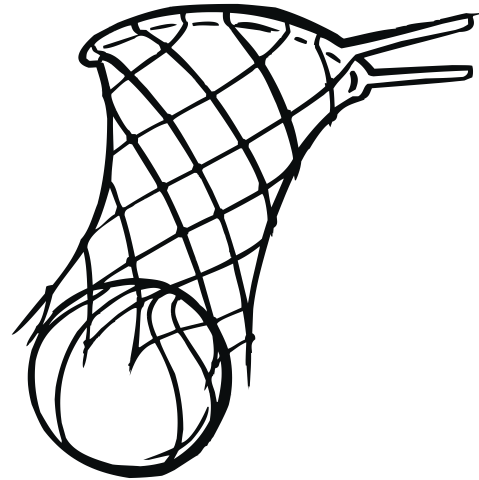
Participants head out for the Trail led by Michael Eganhouse, left foreground.



Registering walkers are Carol Grabher, seated left, Lynn Bradtke and Jennifer Bradtke.

Central IL Candlelight Bowl

Join us for the annual Central IL Candlelight Bowl on Sat. Feb 7, 2009 at Circle Lanes in Bloomington. Last year we almost filled the alley, so get your team or individuals together and come out for an evening of bowling for fun and fundraising. Cost is \$15/person and includes 2 1/2 hrs of bowling, shoes, pizza, and popcorn. Raffle prize tickets are also available at \$2/ticket or 6/\$10. Items range from manicures to shows to an autographed football. Come have an evening socializing with others with Spina Bifida and our friends, families, and supporters! Contact Lynn at (309)452-9937 or lynn.bradtke@comcast.net to make your reservations.



Shooting Hoops

Come out and watch a local wheelchair basketball team compete! Glenbard North High School will host the Windy City Warriors as they play against the Panthers Staff on Wednesday, December 17, at 7pm. This is a great way to watch some teacher vs. student basketball and cheer on one of your local teams. For details and for tickets (\$3/person), contact Western DuPage Special Recreation Association at 630-681-0962 x 114.

Northern Illinois Walk-and Roll-a-Thon

The Northern Illinois Walk took place on October 19, a beautiful autumn day. Walkers gathered at the Ty Warner Park in Westmont, and they, too, enjoyed a picnic and received T-shirts following the mile-long walk around the park.

Originally scheduled for September 14, the Walk was rescheduled when Chicago experienced severe storms on the September date. In spite of the date change, an enthusiastic crowd of nearly 100 people gathered for the Walk.

The Prize winners were:

12 and under: Ethan Hurtado & Arianna Pescetto

13-17: Brianna Fuentes

18-29: Erik Munkvold

30-55: Grayson Holmbeck

Over 55: Ed Gill

Top Team: Loyola University Research Group

Largest Team: Team Hannah

A Message From Karen Marnell

I would like to take this time to thank all those that came out for the rain date. We had a great turnout of nearly 100 people for our 14th Walk and Roll-a-thon. The walk went on without Anne's "get it in order now" disposition at the registration table, but I know she was there in spirit. We love seeing the return walkers as well as new faces each year. I would like to thank my family for all their support and for coming out and helping every year for such a worthwhile event – Virginia and Becky also, for answering all my numerous questions as the date got closer. A special thank you to my sister, Sue, for coming up with the idea 14 years ago to do something to raise awareness so that others would know about the issues that affected her nephew – a subject that many people knew very little about. Thank you to the new volunteers also. You were all such a big help, we couldn't have done it without you.

(This year's walk was held in memory of Anne Bergh, Karen's mother, who passed away recently. Anne was always in charge of the registration table and kept things running smoothly. She is missed by all.)



Team Hannah

New Camp Location A Big Hit

Nearly 90 campers enjoyed three 2008 Camp Ability® sessions, held for the first time at Camp Red Leaf in Ingleside, Illinois. The three week-long sessions ran from August 3 to August 23 and included a wide range of camping activities plus an intensive program of independence training. Campers reported that they greatly enjoyed the camping facilities and programs.

Amy Maggio, Executive Director, said, "I want to thank Board Members Matt Richmond and Lynn Bradtke for their hard work in developing this year's camping schedule and curriculum. And thanks also go to Board Member Grayson Holmbeck and his staff for their continuing efforts in preparing and presenting the independence program."



Santa Says: Plan to Attend the Holiday Party

Santa reports he and his elves are busy preparing for the SBA of IL Holiday Party, scheduled from 11 am to 3 pm on Saturday, December 6, at the Learning Academy in Rolling Meadows. Games and raffles will be open to all, and a lunch buffet will be served at noon. After lunch, Santa will arrive with gifts for the children.

New parents: This will be a fine opportunity to meet other SBA families. And youngsters, teen and adults will also have opportunities to socialize.

There is no charge for persons with Spina Bifida and their immediate families but reservations must be made in advance. To make your reservation, call the SBA of IL office at 773-444-0305.

Spina Bifida Resources

By Carolee Laird

One day while working on the computer, I did a search for the term "Spina Bifida." To my surprise, I had over 1500 results returned. Then I decided to go to yahoo.com and look up the same term. 115 e-mail groups! I was astounded. I found everything from personal pages of persons with Spina Bifida to associations relating to Spina Bifida located as far as Saudi Arabia. As a 10+ year veteran of the internet, I should not be amazed by this. The internet has grown tremendously in the past few years.

One of the sites that I like to frequent is the Spina Bifida Association website (www.sbaa.org). It boasts a wealth of information. It has a directory of clinics and local associations listed by state. Almost every state has at least one chapter or associate member organization related to the SBA. It also offers a great deal of information regarding Agent Orange and Latex Allergy.

When looking through the yahoo.com results I found a wide variety of interests and age groups. The interests ranged from groups dealing with specific geographical locations some of the more popular ones were: Bifida-chat, Bifida-l, sb-adults, and SBmoms-n-dads.

Bifida-chat is a general discussion group. They talk about things related and unrelated to living with Spina Bifida. Their membership comprises mostly of friends and family of persons with Spina Bifida.

Bifida-L is slightly more on-topic, meaning they only talk about things related to living with Spina Bifida. The membership is still very diverse, ranging again from friends and family of persons with Spina Bifida to those individuals with Spina Bifida.

SB-Adults offer a more restrictive membership. SB-Adults members are only those adults (18+) that have Spina Bifida. The members talk about anything relating to having Spina Bifida.

SB Moms-N-Dads is for "moms, dads & caretakers of children with Spina Bifida."

Even our very own SBA of IL has a website (www.sbail.org) full of resources from current events to a web forum (<http://www.sbail.org/forums/>) where people across the state and country can send messages to each other looking for information on a variety of subjects.

If you're looking for a way to connect with people with Spina Bifida, all you have to do is enter "Spina Bifida" into any search engine. Any of 100 sites will be of people somehow affected by Spina Bifida. Whether it's a caretaker of a person with Spina Bifida, an adult with Spina Bifida, or a parent of a child with Spina Bifida, you will find what you are looking for.

Why Not Me?

By James Fuller (age 14)

Something that drives me insane is when someone who's "different" from the average person is underestimated, or thought that they can't do something, simply because it's more difficult for them. I've had this happen to me on multiple occasions, but there's one in particular that stands out.

One day, I remember, I was at summer school, just last year. It was the end of the day, and I was headed off to my sports camp, as I did everyday after summer school. When I arrived, everything felt normal; all the people that were normally there were there. But as I would come to realize, there would be absolutely nothing normal about the rest of my day.

After I'd eaten my lunch, it was time to go outside, and implement the "sports" into sports camp. I was so excited, because we were playing one of my favorite sports, basketball. Two captains were picked, and one by one, so were the teams. We had an odd number of kids, so there was going to be someone extra. Sure enough, it just happened to be me. As if it wasn't bad enough not to be picked, one of the captains came up to me and started yelling, "You know why you weren't picked? It's because you can't do anything because of those things on your legs!" The moment after I heard this, I was devastated. It had rattled me so much, I almost started to agree with him. I was thinking, "He's right. I'm different, and can't do anything." It felt like I was losing my mind. Then I snapped out of it. I could feel my face turning tomato red, because now I was angry. I could do anything anyone else could, and I was going to prove it when we did our next sport.

Although it was at first hard for me to deal with what this person had said, I almost appreciate him saying it. It wasn't right, and still makes me mad that he said it, but it was good for me. I needed to hear that from someone eventually, so I could realize that it was completely false. Those that are considered "normal" shouldn't make fun of people that are "different." "Different" people just have to put more effort into something, technically meaning they do it better than normal people. I truly believe that I was given Spina Bifida for one reason and one reason only, and that is to prove everyone wrong, and do something with my life. My goal is to virtually beat Spina Bifida, meaning that it won't go away from my life, but I'll be so normal it'll seem like it.

People shouldn't judge those that are different from them by saying they can't do anything right, because they really can. People that are "different" just have to work harder, and I'll just say one thing..... I'm ready.

Awareness Ads Reach Chicago

In recognition of October being Spina Bifida Awareness Month, SBA of IL will roll out their yearly ad campaign on October 27 for the buses, trains and train platforms in Chicago. These ads focusing on, "What is Spina Bifida?" and mentioning prevention through folic acid are estimated to reach over 2,800,000 people. Along with your donations, part of the funding of this project was made possible through a grant from the national Spina Bifida Association, and services through Titan Worldwide, and we would like to thank everyone for the support.

The ad campaigns, running into December, will be followed with a campaign in Chicago Public Library bulletin boards. We welcome all of you to also contact your local library in Illinois to ask about posting materials in your bulletin board. Should you be interested in a packet of materials for posting in your library, please contact the SBA of IL office.



**SPINA BIFIDA ASSOCIATION
OF ILLINOIS**

The most common disabling birth defect in the United States.

WHAT IS SPINA BIFIDA?

Research has shown that the B-vitamin folic acid reduces the risk of birth defects like Spina Bifida up to 70%.

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