



# Crossroads

WINTER 2008

## Meet Amy Maggio -Our New CEO



Amy N. Maggio has joined SBA of IL as its new CEO. She comes to our organization with over 20 years of experience working in the healthcare arena. Her positions include several key management spots at the American Lung Association, the AIDS Foundation of Chicago and the National Stop AIDS Project. She brings considerable

fundraising, strategic planning and volunteer development skills to the association.

A native of New York, she graduated from Iona College and has completed graduate work at DePaul University. She lives in Chicago and is active in the political life of the city as well as serving on a number of boards and cultural committees for a variety of organizations.

## Camp Ability® 2008

We are excited to announce the new location for Camp Ability® in 2008! This year, camp will be held at Camp Red Leaf in Ingleside, IL (<http://www.jcys.org/redleaf/>). We are hoping to welcome a large group of both new and veteran campers to this exciting new camping experience. Camp programming, activities, counselor ratio and medical care will remain very similar to past years and will continue to include horseback riding, swimming, arts & crafts, campfires, the dance, our independence program, and more.

Camp is also still scheduled to run from Sunday afternoon thru Saturday mornings, although the dates of the three sessions will be moving to the three weeks between August 3 and August 23, 2008.

Please contact the office for a camp application if you have not received one in the mail by March 1. Applications are also available on our website ([www.sbail.org](http://www.sbail.org)). All applications are due in the SBA of IL office by June 5.

## Conference- "Advocating For Our Children" - Special Education Programs, Education Law And Policy For Children With Spina Bifida And Their Families

Where: Waubonsie Gold-School Campus - 1305 Long Grove Drive, Aurora, Illinois

When: Saturday, May 17th

Time: 9 - 12:30 PM (day care will be provided)

This important conference will feature leading attorneys, special education advocates, and transition specialists providing critical legal and education information for parents of children from Birth-age 21.

For more information or to register for our conference please call Virginia Munkvold at: 773-444-0305.



## Mark Your Calendar

February 29 Nutritionist at AAC Meeting 2pm Chicago	April 15th Scholarship Application deadline	April - TBD O'Malley fundraiser at Emerald Isle, Chicago	May 17th Mini-Conference 9:00 am - 12:30 pm Aurora, IL	
May 17th Spring Swing Golf Outing Palos Country Club Orland Park	May 30 - June 1 Pro/Am Bowling Tournament Joliet, IL	June 5th Camp Ability applications due	Aug 3 Windy City Corvettes Show- Bill Kay Chevrolet, Lisle, IL	

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## Calling All Book Worms!

Spread the word about Spina Bifida in 2008! Do you wish more people were familiar with Spina Bifida? Contact your local library to ask if they have a display case where you can post materials about Spina Bifida and/or folic acid. If you find your library has availability, contact the SBA of IL office. We will send you a packet with posters and brochures. Feel free to add your own designs, objects and photos to personalize the display.

## NEW MEMBERS

Janice Dugan  
2300 Oakmont Way #201  
Darien, IL 60561  
Adult with Spina Bifida

Allyson and Matt Murphy  
1005 Hastings Circle  
Birmingham, AL 35242

## 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:

Anonymous  
John W. Anderson Foundation  
Family Resource Center on  
Disabilities  
Gillespie Auto Group  
Max Goldenberg Foundation  
Jay Johnson Trust  
Kiwanis Foundation  
Bowman C. Lingle Foundation  
Palatine Presbyterian Women  
SBA St. Louis  
SBA Wisconsin  
The Ward Foundation  
Unilock Chicago

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

# President's Message



SCOTT J. MUNKVOLD

Happy New Year! As we build on the successes of 2007, I am confident this will be our most exciting and successful year in our history.

It is my pleasure to introduce to you our new CEO, Amy Maggio. Amy has an extensive background in the non-profit arena and I know she will be a great asset to SBA of Illinois.

Her experience includes working for the AIDS Foundation in Chicago and the American Lung Association. In fact, she is the one responsible for the Hustle up the Hancock Building benefiting the Lung Association. Be sure to check out the article in this newsletter telling a little more about her.

You may have heard some rumors about changes being made to Camp Ability®. In fact, we have been busy working to improve camp and are pleased to announce the camp is moving. The new location for camp is at Camp Red Leaf in Ingleside, Illinois. The reasons for moving camp were numerous, but first and foremost was the commitment of SBA of IL to provide the best possible experience for all of our campers. I realize that change is difficult and some of our long-time campers may be hesitant about trying something new, but we all truly believe that this will be a positive experience for everyone.

Those of you living in Chicago and riding the CTA blue line, red line, and Chicago buses may have seen our ads in the buses and trains. Thanks to the generosity of the Kiwanis Clubs and an anonymous donor, we were able to place ads on 30 bus tails and 150 train cars during the months of December, January and February. We estimate over 1,000,000 people saw these ads. As our mission states, we are dedicated to promoting the prevention of Spina Bifida and to enhance the lives of all affected – to reach so many people and educating them on the benefits of taking folic acid is certainly a step in the right direction.

We are currently looking for a new site for our Walk and Roll-a-thon in the western suburbs. While the location for 2007 was beautiful, it did not work out well for our needs. Anyone interested in helping with the planning for the 2008 Walk, please contact the office. The walk will once again be combined with the family picnic, as everyone seemed to enjoy it last year.

The Pro/Am Bowling Tournament will be held May 30-June 1 at Town & Country Lanes in Joliet. We hope to see you all there.

This year's golf outing will be held once again at White Deer Run in Vernon Hills. Last year we had a record number of golfers attend and this year we will be forced to limit the attendance to 144 golfers. We are adding a nine-hole, afternoon golf outing scheduled for May 17 at the Palos Country Club in Orland Park. So, watch the mail for details and get your reservation in early.

Our first annual Fashion Show held in October 2007 was such a tremendous hit that the committee began working on the 2008 show almost immediately. This year's show will be held on October 11th at Salvage One in Chicago. The committee and board of directors are very excited about this new event and I encourage everyone to attend. Thanks again to the Fashion Show Committee for all of their hard work.

Spina Bifida continues to affect all of our lives in many different ways. For me, giving generously and volunteering for SBA of IL has brought a profound meaning to my life. Please consider giving your support to help SBA of IL continue to grow and meet the needs of those affected by Spina Bifida. For those of you that have given so much, including the Board of Directors, staff, volunteers and those that have attended our past events, thank you for your support. Without each and every one of you, we could not provide the services we do. I wish you all the best in 2008.

## Chicago Buses and Trains Carry Folic Acid Messages

Some 150 Chicago CTA elevated trains and 30 buses are carrying messages about the importance of folic acid in preventing birth defects such as Spina Bifida. The Chicago Area Kiwanis Clubs joined SBA of IL in sponsoring the advertising program.

Launched in December, the program continues until the end of February.



A CTA Rapid Transit car carries the folic acid message ad developed by SBA of IL.

## New Adult Wheelchair Basketball Opportunity!

Western DuPage Special Recreation Association (WDSRA) has an opportunity for Recreational Wheelchair Basketball for any adults out of high school. This is a new program, so everyone is encouraged to come out and try it!

It's taking place at Johnson School, 2S700 Continental in Warrenville, IL. The program is planning to run from 1:00pm-2:00pm February 2 - March 8, and, after a three week break, resuming April 5 - May 10. The program runs a total of 12 weeks and the cost would be \$70 to cover staff & gym time. Currently, you do not need to have a sports wheelchair to be able to participate.

If you are interested, please visit [www.wdsra.com/adaptedsports.htm](http://www.wdsra.com/adaptedsports.htm) or contact Trent Thenhaus at [trentt@wdsra.com](mailto:trentt@wdsra.com) or (630) 681-0962.

## Smiles Abound at 2007 Holiday Party

Santa again found his way to the annual Holiday Party, held December 8 at the Learning Academy in Rolling Meadows, and he received a big welcome from youngsters who enjoyed games and craft activities while awaiting his arrival. Teens and their families met old friends, made new acquaintances and enjoyed lunch treats. Happy faces all around!



SBA of IL program director Becky May, left, greets Holiday Party chair Linda Faust. See pictures of the Holiday Party on pages 6 - 7.

### Educational Rights Training Seminars

Do you know that once a student accepts a diploma from a public school, he or she becomes ineligible for transition services, such as job training? A high school senior may walk through a graduation ceremony with classmates, but not accept a diploma, in order to qualify for on-going training and transition skills provided through the school system. A counselor, available through the Division of Rehabilitation Services (DRS), should be present at the student's last few Individualized Education Plan (IEP) meetings to help connect the student with appropriate services.

This is one of the topics being discussed at the Family Resource Center on Disability at the monthly Educational Rights Training sessions. The meetings explain the services students are entitled to through the school system and review Individualized Education Plans; how to prepare for IEP meetings with school officials, helpful tips about whom to include at the meetings, what steps to take if the correct services are not given, and how to follow through.

The Family Resource Center is located at 20 E. Jackson Blvd. in Chicago; the classes are presented at no cost to attendees. All sessions run from 10 am to 1 pm and are held on every Saturday and on the second Tuesday of every month in English, and on the third Wednesday of every month in Spanish. Although there is no fee for the sessions, prior registration is required. To register, please contact FRCD at (312) 939-3513.

### Central Illinois Plans Speaker Program

Looking ahead, the Central Illinois group plans special speaker programs on the second Wednesday of each month at 7pm at the Carle Clinic in Bloomington. However, on Wednesday, April 16 the program will begin at 6:30 pm featuring Jan Kliisa who will speak on understanding Individual Education Programs. Please contact Lynn Bradtke with any questions: (309) 452-9937 or [lynn.bradtke@insightbb.com](mailto:lynn.bradtke@insightbb.com).

### It's Time to Apply for SBA of IL Scholarships

SBA of IL awards scholarships to young adults with Spina Bifida for post-secondary education. Applications are being accepted from high school seniors as well as students already enrolled in a college or other post-secondary school.

Last year, four young women and five young men received scholarships totaling \$17,500.

Scholarship applications are available on our website ([www.sbail.org](http://www.sbail.org)). Please contact the SBA of IL office to receive an application via mail or for questions regarding the application guidelines.



**the official  
wheelchair  
basketball team of  
the Chicago Bulls**

together with

present



**The  
Jack DeLoss  
Taylor  
Charitable Trust**

## The 19th Annual Day For Kids!

**where kids with disabilities and their families  
spend an afternoon with the Wheelchair Bulls**

**February 23, 2008  
Centennial Park, Addison IL  
On Rohlwing Road, 1 block south of Rt 20**

*a great day!*

### *schedule of events*

- 10:00 Junior All Star Game
- 11:30 Kids and their families have lunch with Wheelchair Bulls
- 12:30 Children with disabilities and players take the court for an hour of fun
- 1:30 Kids take the sidelines while Wheelchair Bulls warm up for game
- 2:00 Chicago Wheelchair Bulls  
vs.  
Indiana Pacers  
Raffle at Halftime

- Spend time with the Wheelchair Bulls
- Face Painting
- Other Great Activities
- Great Raffle Prizes
- See Benny The Bull!
- Every child with a disability receives a gift bag from the Wheelchair Bulls



Space is limited so please e-mail to register [wheelchairbulls@comcast.net](mailto:wheelchairbulls@comcast.net) or call 847/593-5485. Please give your child's name and indicate how many children and adults will attend

*also sponsored by*

- Northeast DuPage Special Recreation Association
- Jelly Belly • Wilson Sporting Goods •  
Jewel Osco • The Chicago Bulls  
and  
Your Chicago Wheelchair Bulls

For information, call the Wheelchair Bulls at 847-593-5485

*Holiday Party*





## Physical Activity Guidelines for Individuals with Spina Bifida

By Shubhra Mukherjee, MD

Spina Bifida (SB) is a condition that is present at birth, and results from an abnormality in the development of the neural tube, which forms the spinal cord. Depending on the abnormality, there is weakness in the areas that the damaged nerves control, such as sensory areas and muscles to the abdomen, legs, and bowel and bladder. Most people with spina bifida also have a shunt, to help drain the cerebrospinal fluid out of the brain ventricles. Involvement may be cervical (at the neck), or thoracic (chest), lumbar (low back) or sacral (base of spine).

### Importance of Exercise

- Prevents deconditioning, and promotes function and endurance.
- Helps prevent obesity.
- May help improve constipation, resist infection, improve mood, reduce stress, prevent diabetes and atherosclerotic heart disease, and helps lower blood pressure.

### Important Considerations When Exercising

- Maintain proper posture at all times.
- Many people with spina bifida have latex allergy. If this is the case, always check beforehand to make sure that the exercise equipment is not made of latex. Equipment manufacturers such as Thera-band® offer latex-free versions of their products.
- Incontinence (flaccid or neurogenic bowel/bladder) - Individuals may experience a loss of control with their bowel or bladder. KEY: Monitor urinary cycle, be sure to empty your bowel and bladder before starting exercise.
- If you have a shunt or have had scoliosis surgery, you should discuss exercise activity with your doctor. Avoid excessive trauma to the shunt and tubing.
- Thermoregulation - Irregular body temperatures are often experienced by individuals with SB. KEY: Wear appropriate clothing, drink plenty of fluids and take precautions in certain environments; in warm environments, a fan and water spray will aid in cooling, and in cold environments, wear extra layers.
- Pressure sores (decubitus ulcers) - Damage to the skin or underlying tissue caused by prolonged

sitting, using old wheelchair cushions, sitting on hard surfaces, shear forces or as a result of a fall. KEY: Check skin regularly and perform regular wheelchair push-ups, or have the individual reposition him-/herself regularly especially when engaged in wheelchair sports. (See strength-training section for protocol.)

- Fractures - the bones of the weak limbs may not be as strong as normal (osteoporosis), and can be at risk of breaking with less force than normal. In areas of poor sensation, the only signs of fracture may be redness and swelling of the limb, without pain. If the individual has a concern, have him/her see a doctor.
- Transfers - When applicable, wheelchair users need to know how to transfer him-/herself safely from the wheelchair to an accessible exercise machine. People who provide assistance to wheelchair users should be trained to follow the appropriate guidelines for safe transfers.
- Balance - Use straps or other physical assistance to hold the trunk in position during upright exercise.
- If during exercise, foot and leg swelling occurs, resolve with leg elevation. If swelling is persistent, the individual should discuss this with his/her doctor. Compression stockings may also be helpful to keep swelling down. Monitor skin closely for breakdown in areas of swelling.
- Spasticity - This condition is characterized by high muscle tone and hyperactive stretch reflexes. It typically occurs in the muscles below the site of injury and is aggravated by exposure to cold air, urinary tract infections and physical exercise. KEY: You should stretch spastic muscle groups and avoid exercises that cause excessive spasticity. When you are at home you should extend your legs as often as possible. Discuss ways to reduce muscle spasticity that interferes with activity, with your doctor or physical therapist.

### Important Safety Considerations

- Inform your physician that you are starting a regular exercise program.
- Start slowly, beginning with only a few sets and/ or repetitions, or with lesser resistance/ weight. Then gradually build these elements up as you go.
- Warm-up for approximately 10 minutes before starting your exercises, and cool-down after your exercise session.
- Regularly monitor blood pressure, heart rate, and rate of perceived exertion (RPE). (See NCPAD's General Exercise Guidelines factsheet for more information.)

- Stop exercising if you feel pain or discomfort. Don't exercise if you are ill (i.e., cold, flu, bladder infection, pressure ulcer, unusual spasticity).
- Check medications and their effect on exercise tolerance.
- Extended periods of inactivity may cause osteoporosis.

### Cardiovascular Training Guidelines

- Aerobic exercise is important for everyone to maintain cardio-respiratory fitness and endurance.
- The American College of Sports Medicine (ACSM) recommends performing 20 to 60 minutes of continuous aerobic exercise or multiple sessions of short duration (approximately 10 minutes) for three to five sessions per week. For individuals just starting an exercise program, a circuit-training program is effective.
- Aerobic exercise can be monitored using an individual's maximal heart rate (MHR) or rating of perceived exertion (RPE). MHR for individuals with SB may be significantly lower than normal, while RPE should be moderate to somewhat strong. (See NCPAD's General Exercise Guidelines factsheet for more information.)
- Types of cardiovascular training that benefit individuals with spina bifida are upper-body calisthenics, using the rowing machine, hand cycles and arm ergometers, functional electrical stimulation-leg cycle ergometer (FES-LCE), and adapted sports such as, basketball, track, swimming.

### Strength Training Guidelines

- Individuals should strength train all active muscle groups. Start with low weights and gradually build up the program as you get stronger. A fitness trainer may be helpful in setting up a program for you.
- Training sessions should be held three days per week.
- Refrain from training the same muscle groups on consecutive days.
- In order to maintain proper body posture, balance, and equilibrium, wheelchair users need to strengthen the muscles of the shoulder and upper back.
- Upper-body pushing and pressing exercises (bench press, overhead press) will strengthen muscles used for transfers and wheeling, while pulling/rowing exercises will help prevent shoulder overuse injuries and improve sitting posture.
- Perform wheelchair push-ups every 10 to 30 minutes during the day, and hold for 30 to 60 seconds. When

doing wheelchair push-ups, be sure to bend the elbows slightly. Lock the wheels and keep anti-tip bars in position. One way to remember this is the "rule" 30 second push-up off the chair every 30 minutes. Some people find it helpful to get a digital watch that beeps every 15 minutes as a reminder.

- For individuals who have movement in their legs, leg exercises can include knee lifts from a sitting position (marching movement), and foot lifts from a sitting position (straightening the knee). Do up to 10 on each side once or twice a day, and add sets of 10 as you gain strength. You can also add ankle weights as your strength improves.
- Use straps or a trained partner for stabilization and balance.
- Vary the type of strengthening exercises to reduce over-use injuries.
- Types of strength training that benefit individuals with spina bifida are free weights, weight machines (Nautilus, for example), medicine ball, wall pulley, and Thera-band®.

### Flexibility Training Guidelines

- Flexibility training is important to maintain range of motion in joints, as well as to prevent shoulder injuries in persons who use wheelchairs or crutches.
- Flexibility training also helps to prevent contractures (permanently shortened muscles). Paralyzed muscles should be stretched by a physical therapist, exercise specialist, or by a trained assistant or family member. Muscles that need to be stretched include the hamstrings (the back of the thigh), adductors (inner thigh), muscles that flex the hip, muscles that flex the foot, and muscles that extend the back. Having the individual lie on his/her stomach for rest periods can also help stretch muscles of the hips and back of the thighs.
- Stretches for the muscles of the chest and front of the shoulder are recommended especially for wheelchair users, who tend to have a crouched posture.
- Stretch the shoulders by grasping the elbow with the arm overhead, and pulling back to stretch gently. You can also stretch the front of the shoulder by placing your hand on a wall, fingers pointed backwards with the arm outstretched, and lean forward towards the wall. Hold for one minute each side.
- Stretching the calf muscles helps to decrease swelling, especially if combined with leg massages.
- Types of flexibility training are passive resistance, Thera-band® elastic bands or tubings, standing in a standing frame (if not medically contraindicated), yoga and Pilates.

*Continued from page 9*

NCPAD Online References  
 NCPAD Factsheets:  
 NCPAD's Spinal Cord Injury and Exercise Factsheet  
 General Exercise Guidelines for Individuals with Disabilities  
 NCPAD Minute Videos  
 Seated Stretching Exercise Series  
 Seated Strengthening Exercise Series

#### Note

*The information provided here is offered as a service only. The National Center on Physical Activity and Disability, University of Illinois at Chicago, the National Center on Accessibility, and the Rehabilitation Institute of Chicago do not formally recommend or endorse the equipment listed. As with any products or services, consumers should investigate and determine on their own which equipment best fits their needs and budget. Consult a physician before beginning any physical activity.*

National Center on Physical Activity and Disability  
<http://www.ncpad.org>  
[ncpad@uic.edu](mailto:ncpad@uic.edu)

(800) 900-8086 (voice and TTY)  
 (312) 355-4058 (facsimile)

#### Organizations

**March of Dimes Birth Defects Foundation:**  
 White Plains, New York

#### **Easter Seals:**

Chicago, Illinois

#### **Spina Bifida Association of America:**

Washington, District of Columbia

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## Peer Mentor Program

Access Living and Rehabilitation Institute of Chicago have teamed up to provide peer support to patients and their families within the RIC system. This program has "positive role model" Peer Visitors who can share examples of the "lived experience" of disability and support the psycho-social development of patients and family members. The program puts people with disabilities in touch with one another for problem-solving and informal discussion about personal issues and concerns, and matters related to disability. This is done through 1 to 1 peer visits/matches, weekly on-site unit availability; and education therapy groups. The Peer Visitation Program is provided through RIC's LIFE Center.

#### Objectives

- Provide safe opportunities to express fears, anger, frustration, and concerns with a chance to be listened to from someone who's "been there."
- Provide real life examples to illustrate concepts of independent living and possibilities of the future beyond rehab.
- Re-enforce guidelines for healthy living and community integration.
- Support and facilitate access to community resources such as: housing options, personal assistance, transportation, and understanding of civil rights protections.

Peer support does not give medical advice and it does not replace professional therapy. It complements existing supports and services and can serve as model for quality of life and integration into the community.

Peer support is provided by persons who have been able to put their disabilities into perspective and achieve their individual maximum levels of independence, have a positive attitude towards life, exhibit a caring for their fellow human beings, and are able to share themselves and their experiences with others.

If you are interested in becoming a part of this program or utilizing this service, please contact:

Carrie Kaufman  
 Peer Counseling Coordinator  
 Access Living of Chicago  
 115 W Chicago Ave  
 Chicago, IL 60610  
 (312) 640-2103  
[ckaufman@accessliving.org](mailto:ckaufman@accessliving.org)

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4590 MacArthur Blvd., N.W., Suite 250

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**GLASA****SLED HOCKEY**

Sundays 4:10 - 5:10 pm

Ages 8 and up

Session 1: Jan. 27th thru March 9th

Session 2: April 1st thru May 18th

Fee: \$45.00 per session

Location: Hot Shot Ice Rink  
Rt 41

Lake Bluff, Illinois

To Register contact GLASA

847-283-0908

[www.glasa.org](http://www.glasa.org)

Save the Date

**Adaptive Sports Camp Trek**

June 16 thru June 20, 2008

Libertyville, Illinois

## Volunteers Needed for Walk/Picnic

Last summer, the Northern Illinois Walk-a-Thon and Family Picnic were combined into a fun-filled afternoon. This event offers wonderful opportunities for family fun and information-sharing while raising money to support the activities of SBA of IL.

Planning is getting underway for this summer's Walk-Picnic, with consideration of a new date and a new location. This is a volunteer-driven event, and your ideas and participation will be most welcome!

For more information, call the SBA of IL office and we will put you in touch with the walk planners.



## Golfers: Tee Up for a Spring Swing

The Fall SBA of IL Golf Outing has been so successful that a second outing is being arranged for Saturday, May 17, at the Palos Country Club in Orland Park, Illinois. The "Spring Swing" will be a nine-hole, afternoon outing followed by dinner. Cost will be \$95 per person including 9 holes of golf, cart, dinner and prizes. For more information call Don Cassier at 708-710-4258 or email him at [birdie@tournamentedgegolf.com](mailto:birdie@tournamentedgegolf.com).



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