



**SPINA BIFIDA ASSOCIATION  
OF NORTHEASTERN NEW YORK**

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# SBA of NENY News to Use

**Issue #48, August 2011**

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## MESSAGE FROM THE CHAPTER CHAIR

Seems like summer just started and I've already heard some "back to school" sale advertisements! Holiday decorations will be going up soon... Before that happens, though, we hope many of you will be able to attend the SBANENY Summer Family Picnic on August 28<sup>th</sup>. (If you need more information, you can find it in this newsletter).

With the economy being what it is, it came as no real surprise that federal funding for the few federal Spina Bifida programs has been cut. What this means to those of us with vested interests in those programs is that personal advocacy is more important than ever. If you're asking yourself, "but what can one person do?" the answer is "quite a lot."

- Contact your legislators! It just takes a few minutes to write a quick note to your members of the Assembly, State Senate, House, or US Senate. Tell him or her that you support Spina Bifida programs and would like them to as well.
- Join SPEAK! More information about the grassroots **Spina Bifida Policy, Education, Advocacy, and Knowledge** program appears on the SBA website ([www.sbaa.org](http://www.sbaa.org)) and elsewhere in this newsletter.
- Participate in organized research! Yes, more information on this is available in this newsletter as well!
- Join a SBANENY committee! We are always looking for help, even if only for a few hours here and there. If you have any new ideas for programs, let us know!
- Attend a SBANENY event! See the calendar which (you guessed it!) can be found within the newsletter.
- Be original! Do something that sounds like fun to you.

Enjoy what remains of your summer! And watch out for those holiday sales.

**Kevin Chamberlain**  
Chapter Chair

# SBANENY CHAPTER PROGRAMS & ACTIVITIES

## ADULTS!

### EMPLOYMENT SKILLS FOR ADULTS WITH SPINA BIFIDA

On May 21<sup>st</sup>, a group of adults from our chapter participated in a program about employment skills at the Independent Living Center of the Hudson Valley. The discussions covered a variety of topics including applications, interviews, first contacts with potential employers, benefits, and shared tips for success. Participants left with reference materials and knowledge of service resources in the community.

The next program for adults is being planned for the fall. Stay tuned for a flyer and emails announcing the details!

**Are you interested in participating in SBANENY programs offered for adults?**  
Contact our office at 399-9151 or [sbaneny@aol.com](mailto:sbaneny@aol.com).

## EVERYBODY! SBANENY SUMMER FAMILY PICNIC

**Who:** Individuals with SB & their families (parents, siblings, spouses, children, caregivers)

**What:** Getting to know you picnic  
Food, beverages, games, crafts, activities, fun!

**When:** Sunday, August 28<sup>th</sup>, Noon to 4 PM  
Rain or Shine!

**Where:** Elm Avenue Park, Delmar, NY 12054

**Fee:** \$5/adult, 14 & under free!

**RSVP Please!**

For your convenience there is a form enclosed with this newsletter.

**Please RSVP by August 22<sup>nd</sup>.**



## PARENTS!

### SPINA BIFIDA FAMILY RETREAT WEEKEND AT DOUBLE H RANCH

**Date:** October 21 – 23, 2011

**Time:** 6 PM Friday to Noon Sunday

**Place:** Double H Ranch, Lake Luzerne, NY

**Who:** Child with SB (must be aged 5 to 21) and their immediate family.

**All participants must submit the necessary Double H applications by October 7, 2011.**

Registration forms are available to download on the homepage of our website at [www.sbaalbany.org](http://www.sbaalbany.org). If you don't have access to the internet, please call our office and we would be happy to mail registration forms to you.

### ASK THE YOUNG ADULTS! PROGRAM

On June 3<sup>rd</sup>, three of our young adults with SB met with a group of our parents to share their experiences and thoughts about what has been helpful as they have grown up with this disability. Thank you to Heather, Lyndsi, & Bryan for your willingness to share and assist the parents of our younger children!

The next program available for families with children (don't forget the SBANENY picnic on August 28<sup>th</sup>!) will be the Spina Bifida Weekend at Double H Ranch, October 21<sup>st</sup> to 23<sup>rd</sup>. (*NOTE: Child with SB must be ages 5 – 21. Program includes immediate families.*) There are medical forms required for participation in this event. You may download information and forms from our website at [www.sbaalbany.org](http://www.sbaalbany.org).

### CONFERENCE COMMITTEE 2012 WELCOMES NEW MEMBERS!

The SBANENY Conference Committee will be coordinating our second local conference. Volunteers are needed assist in all areas. The conference will be held on Saturday, April 28, 2012. Please consider joining the committee.  
**Please call for more information!**

## MY EXPERIENCE AT SBA NATIONAL CONFERENCE

BY SHAMEKA ANDREWS

In June of this year I had my first opportunity to attend the SBA National Conference. The thought of going to the National Conference was both exciting and terrifying at the same time. This was my first experience flying without a group, which I hope to write about in future articles. I learned three things from my flying experience. 1) If I don't challenge myself I could miss out on some great opportunities. 2) Even though things don't always go as planned you can get through it. 3) I can do anything I put my mind to even if I am scared out of my mind while I am going through it!

The conference was full of great information for people with SB, parents, and professionals. Some of my favorite parts of the conference were the fitness and health workshop where we did chair yoga, learning from and asking the doctors and the other people that attended about how to take better care of myself and have fun too. I also enjoyed the workshops about the National SBA Board and what they do.

The biggest benefit for me of the conference was the networking opportunity. Being able to talk to parents, professionals and other people with SB and hear about their experiences and lessons learned was worth the challenges of getting there and back. If you have not had the opportunity to go to National Conference I would highly recommend it, especially for adults with SB. Hope to see you in Indiana for SBA National Conference 2012.

## SOUTHERN ADIRONDACK INDEPENDENT LIVING CENTER (SAIL)

### MEDICAL EQUIPMENT LOAN PROGRAM

SAIL provides free loans of assistive technology and durable medical equipment for 30 days. This time limit can be extended if needed and the equipment is not needed by another consumer. The program has recently expanded, purchasing new early intervention equipment to add to their loan closet.



SAIL loan closet serves people living in any of the following counties; Warren, Washington, Saratoga, Columbia, Greene, Rensselaer, Albany, Schoharie, and Schenectady Counties. This equipment is available through the Glens Falls or Saratoga offices or one of SAIL's drop off locations throughout the region.

SAIL's Equipment Loan Closet provides a cost effective way for consumers to try out equipment before buying it, to use a device that may only be needed for a short developmental period, or to donate old equipment that was purchased but no longer can be used. SAIL offers letters acknowledging all donations that can be used for tax receipts.

For more information, contact SAIL at (518)792-3537 or [Jblanchard@sail-center.org](mailto:Jblanchard@sail-center.org)

**Do you live in a county not covered by SAIL's program?** Contact the Independent Living Center for your area to learn about similar programs that they may have available for you. Go to [www.nls.org/ilc](http://www.nls.org/ilc) for a list of Independent Living Centers in New York State.

## RESEARCH PARTICIPATION OPPORTUNITIES

### Kennedy Independence Scales – Spina Bifida Version:

Dr. Andrew Zabel of the Kennedy Krieger Institute is the Principal Investigator conducting a research study to see how well a new electronic checklist measures the skills of adolescents and young adults with Spina Bifida. His research team is looking for people in three different age groups to consider participation in his current research:

- Parents of individuals with SB ages 10 to 17
- Parents of individuals with SB ages 18 to 29 and their adult child with SB
- Adults with SB ages 18 to 29

Recently, individuals and families in these age group categories on the SBANENY mailing list received a mailing that included tools that Dr. Zabel has developed for parents to use as they

work with school systems to plan educationally for their children. Dr. Zabel's goal is to develop additional tools that will provide information to educators to help maximize the educational experience for children with SB. These tools were developed using the results of previous research.

Dr. Zabel is working to create an executive functioning questionnaire specific to individuals with Spina Bifida. Participants in the research complete an online questionnaire. The checklist usually takes 20 minutes or less to complete. Participation is voluntary and anonymous.

For those interested in participating in the research go to <https://www.psychdata.com/s.asp?SID=128186>.

## **Neural Tube Defects Research – University of Miami Miller School of Medicine**

Researchers are trying to identify the genetic and environmental causes of Neural Tube Defects.

Who can participate?

- Individuals diagnosed with Neural tube Defect
- Parents or siblings of individual(s) with NTD
- Friends or caregivers who have not been diagnosed with NTD to serve as control group

For more information or to participate, please contact Maria Ciliberti, study coordinator toll free at 1-877-686-6444, email: [Mciliberti@med.miami.edu](mailto:Mciliberti@med.miami.edu) or log on to [www.hihg.org](http://www.hihg.org).

## **SPEAK FOR SPINA BIFIDA**

### **What is SPEAK for Spina Bifida?**

- SPEAK stands for: **Spina Bifida Policy, Education, Advocacy, and Knowledge.** **SPEAK** is an advocacy program, developed by the Spina Bifida Association (SBA), to help YOU share your story with your Members of Congress.

### **How does SPEAK work?**

- It's as simple as signing up. When you sign up for SPEAK, you will learn about issues and legislation important to individuals with Spina

Bifida and their loved ones – and how and when to contact your Members of Congress.

### **Why join SPEAK?**

- Congress **MUST** hear from you! The federal government invests in important programs, like the National Spina Bifida Program, that raise awareness, provide resources and education, as well as fund the Spina Bifida Clinics.
- These programs are in jeopardy! Congress is looking to make deep cuts in the coming years and entire programs could be eliminated! The only way to prevent the National Spina Bifida Program from being eliminated entirely is for you to get involved. You need to help spread the word on what it is, what it does and how it changes lives.
- No one can tell your unique story like you – you are your own best advocate. National SBA staff can, and does, go to Capitol Hill on a regular basis to share the important work of the National Spina Bifida Program. But there's only so much we can do. Members of Congress want to hear from YOU, their constituents, who are affected by this disability every day.

### **By signing up for SPEAK, you'll get information on how to:**

- Write, call and request a meeting with your Member of Congress;
- Follow your Representative and Senators on Twitter and Facebook and how to use those tools to share your story;
- Send an email directly to your members with customizable text;
- Find information about SBA's public policy priorities and the latest with the National Spina Bifida Program.

Now, more than ever, lawmakers in Washington, DC, need to hear from their constituents. It is critically important that those living with Spina Bifida – and their loved ones – reach out to their Members of Congress.

**Visit [www.spinabifidaadvocacy.org](http://www.spinabifidaadvocacy.org) to sign up for SPEAK!**



## QUESTIONS TO ASK YOUR DOCTOR

How would you describe your relationships with your doctors? Do you feel comfortable asking questions and making decisions together? Some people ask more questions when ordering a meal or when buying a cell phone than they do during medical appointments.

When you ask questions about your care, your diagnosis, your treatment, and any medications prescribed to you, you get answers that can help you make better decisions and receive better quality care. While your doctors should be your consistent guides and advocates in managing your health, health care quality and patient safety is a team effort.

You can improve your care and the care of your loved ones by taking an active role in your health care – and questions are the answer.

Are you visiting your health care clinician or pharmacist soon? It is important to be prepared. The Agency for Healthcare Research and Quality (AHRQ) has created a list of the top 10 questions that patients should ask their doctor.

### Do You Know the Right Questions to Ask?

1. What is the test for?
2. How many times have you done this procedure?
3. When will I get the results?
4. Why do I need this treatment?
5. Are there any alternatives?
6. What are the possible complications?
7. Which hospital is best for my needs?
8. How do you spell the name of that drug?
9. Are there any side effects?
10. Will this medicine interact with medicines that I'm already taking?

The AHRQ Web site ([www.ahrq.gov](http://www.ahrq.gov)) offers a great tool that allows you to create a personalized list of questions that you can take

with you to your appointment. For instance, if you answer "yes" to any of the following questions listed, the online tool helps you build questions around that specific topic.

- Did your clinician give you a prescription?
- Are you scheduled to have medical tests?
- Did you recently receive a diagnosis?
- Are you considering treatment for an illness or condition?
- Did your clinician recently recommend surgery?
- Are you choosing a health plan?
- Are you choosing a clinician?
- Are you choosing a hospital?
- Are you choosing long-term care?

### Tips for Young People

Going to the doctor can be a very different experience for teenagers or young adults as they transition into the role of managing their own health care.

An 18-minute video found on the Institute for Child Health Policy Web site teaches teens how to communicate effectively with health care providers so that they answer teens' questions and give the information and supports teens need to be more in charge of their own health. Teens will also learn how to prepare and give health care providers the information they need to give teens the best possible medical care.

In the video, several young people talk about their experiences and how they have learned to be good communicators. Also shared is a simple technique that can be used to help a young person feel more comfortable and confident when talking to his doctors.

The video can be found at [www.ichp.ufl.edu/videos/twyd](http://www.ichp.ufl.edu/videos/twyd).

*This article was reprinted from Insights Into Spina Bifida®, the Spina Bifida Association's national magazine. To order a subscription to Insights, please visit [www.spinabifidaassociation.org](http://www.spinabifidaassociation.org).*

➤ **DISCLAIMER:** SBA of NENY does not endorse or recommend products, services or manufacturers and assumes no liability whatsoever for the use or contents of any product or service mentioned herein. The information provided in this newsletter is for information, educational and entertainment purposes only. It is not intended as medical or professional advice.

# SBANENY DEVELOPMENT UPDATE

SBANENY 2011

MOHAWK HUDSON MARATHON UPDATE

**4 Runners to Raise Awareness  
for Spina Bifida!**

**Wouldn't you like to cheer for  
"Team SBANENY"?!**

SBANENY has a team of four runners who have committed to represent our chapter as runners in the October 9<sup>th</sup> marathon, raising awareness while raising funds to support chapter programs and services. Thank you to our runners!

**You Can Help to  
Raise Awareness About Spina Bifida!**

Our chapter will be hosting one of the water stations during the marathon. This is a great opportunity for our chapter to raise SB awareness, and of course to cheer on our runners! Please join us!

Any questions or to sign up, please contact Jim Gallagher through our office at 518-399-9151 or email [sbaneny@aol.com](mailto:sbaneny@aol.com).

## SBANENY WALK-N-ROLL FOR SPINA BIFIDA



The SBANENY Walk-N-Roll for Spina Bifida is being planned for spring of 2012. Committee planning meetings will begin in September. Are you interested in participating on this committee? Please call or email the SBANENY office as soon as possible. We look forward to the 2012 Walk-N-Roll for Spina Bifida and welcome your help to plan and organize it!

## LOVING HANDS IN ALL SEASONS QUILT GUILD STITCHING BLOCKS FOR SPINA BIFIDA

Loving Hands in All Seasons Quilt Guild was formed in 1994. Describing themselves as a small group, they have 44 adult members and 2 junior members, the size being limited due to the capacity of their meeting space. The quilt guild meets at the Florida Reformed Church in (Minaville) Amsterdam, NY. The group is comprised of beginners to experts all interested in sharing an interest and passion for quilting and a desire to further their skills!

Each year the Guild reaches out to charities/non-profits with an offer to assist in some fashion. This year the Guild made and donated a quilt to the Spina Bifida Association of Northeastern New York for SBANENY to raffle. The quilt measures 84" X 95" and is machine quilted.

Raffle tickets may be purchased:

\$1 for one ticket

\$5 for six tickets

**See the enclosed form to purchase your  
raffle tickets today!**



*The Guild hopes that the proceeds made from the quilt raffle will in some small way make a difference to someone living with SB.*

# SBANENY..... A TEAM EFFORT!

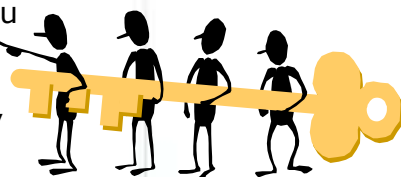
## TEAMWORK IS THE KEY

As you browse through this newsletter, you will notice the many skills, talents, and time that a large number of people put together to make the programs, services, and activities of SBANENY happen.

### There is room for and need for everyone!

Each time you do something to help out, no matter how big or how small, you fill in one piece of the puzzle that is necessary to accomplish all that SBANENY does to enhance the lives of those affected by Spina Bifida.

Please take a look at the list of volunteer opportunities listed below. Consider where you might be able to serve. Call our office if you have questions. Complete the form and pop it in the mail to our office. If you aren't already involved, we welcome your help! If you already are, thank you!!



## SBANENY

### VOLUNTEER OPPORTUNITIES

**Please Note:** Committee participation can usually occur through conference calls.

- ☐ Walk-N-Roll 2012 Committee
- ☐ SBANENY 2012 Conference Committee
- ☐ SBANENY Board of Directors
- ☐ SPEAK for Spina Bifida
- ☐ October 9<sup>th</sup> Marathon Water Station
- ☐ Program Planning Committee
- ☐ Capital Rep Fundraiser Committee
  - ☐ Ticket sales
  - ☐ Program Ads
  - ☐ Silent Auction
- ☐ Office Clerical Help
- ☐ IT expert project
- ☐ Other

Name \_\_\_\_\_  
Phone \_\_\_\_\_  
Email \_\_\_\_\_



## SBANENY THANKS...

### COHOES HIGH SCHOOL STUDENT

#### STEPHANIE CONCEPCION ORGANIZES A FUNDRAISER FOR CLASS PROJECT

On Friday, June 10, 2011, students, faculty, and staff of Cohoes High School participated in a fundraiser for the Spina Bifida Association of NENY. The event was organized by student, Stephanie Concepcion as part of her Participation In Government community service project. Money was raised through a pie toss event. Students could donate \$1.00 so they could try to throw a pie in their teachers' faces. It was a HUGE success, raising \$300. Many thanks to Stephanie for her commitment to a project that has benefited the Spina Bifida community.



## SBANENY THANKS

### AMERICORPS VOLUNTEERS!

Over the past several months, a team of AmeriCorps volunteers have provided over 100 hours of clerical office assistance. With their help, resource materials have been organized and catalogued, and two large bulk mail projects have been completed.





123 Saratoga Road  
Scotia, NY 12302

**RETURN SERVICE REQUESTED**

## SBANENY CHAPTER CALENDAR

### AUGUST

August 28

SBANENY Family Picnic

### SEPTEMBER

September 10

Board of Director's Meeting

### OCTOBER

October 2

New England SB Conference, Sturbridge, MA  
Go to [www.sbaMass.org](http://www.sbaMass.org) for details.

October 9

Hudson-Mohawk Marathon –  
SBANENY Runners!  
Spina Bifida Retreat Weekend

October 21 - 23

### NOVEMBER

November 12

Board of Director's Meeting

### DECEMBER

December 15

SBANENY Goes to the Theater!  
Man of La Mancha  
at Capital Repertory Theater

APRIL 28, 2012

Spina Bifida Conference, Albany



*Let Walk-N-Roll 2011 begin!*



*SBANENY Walk-N-Roll Participants offer up a big group cheer to celebrate the event!*



Please consider responding to the recent Mail Fundraising Campaign to support SBANENY programs & services, such as this newsletter, with a tax deductible donation.

Yes, I want to provide support to people living with Spina Bifida and their families.  
Enclosed is my tax deductible donation.

\_\_\_\_\_ \$25 \_\_\_\_\_ \$50 \_\_\_\_\_ \$100 \_\_\_\_\_ \$200 \_\_\_\_\_ \$250 \_\_\_\_\_ \$500 \_\_\_\_\_ Other  
(Please make checks out to SBA of NENY.)

Name \_\_\_\_\_  
Street \_\_\_\_\_  
City \_\_\_\_\_ State \_\_\_\_\_ Zip Code \_\_\_\_\_  
Email Address \_\_\_\_\_ Phone \_\_\_\_\_

Thank you!



Rain or Shine!



or



## SBANENY Summer Family Picnic Reservation

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Email: \_\_\_\_\_ Phone: \_\_\_\_\_

# of Adults \_\_\_\_\_ X \$5.00 Total Enclosed \$ \_\_\_\_\_

Ages of children \_\_\_\_\_

Please make checks out to Spina Bifida Association of NENY and  
mail to 123 Saratoga Road, Scotia, NY 12302



### Stitching Blocks for Spina Bifida Quilt Raffle

Ticket Price: \$1 for one ticket; \$5 for 6 tickets

Drawing to be held at SBANENY sponsored  
Spina Bifida Conference on April 28, 2012.

*Many thanks to Lovina Hands in All Seasons Quilt Guild!*

## Stitching Blocks for Spina Bifida Raffle Ticket Order Form

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_ Email \_\_\_\_\_

# of Raffle Tickets \_\_\_\_\_ \$ \_\_\_\_\_

Please make checks payable to SBA of NENY.

Mail raffle ticket order form along with check to:

Spina Bifida Association of NENY, 123 Saratoga Road, Scotia, NY 12302.

We will fill out & place your raffle tickets in the drawing!