



**SPINA BIFIDA ASSOCIATION
OF NORTHEASTERN NEW YORK**

123 Saratoga Road
Scotia, NY 12302
518-399-9151
sbaneny@aol.com
www.SBAAlbany.org

SBA of NENY News to Use

Issue #41, September 2009

TABLE OF CONTENTS

MESSAGE FROM THE CHAIR	Page 1
CDC ISSUES UPDATED VACCINATION RECOMMENDATIONS FOR H1N1 VIRUS	Page 2
FLU VACCINATION INSURANCE COVERAGE	Page 2
AAHD 2009 SCHOLARSHIP PROGRAM	Page 3
SCHENECTADY ACCESS TO HOME GRANTS	Page 3
RESEARCH STUDY ON USE OF ASSISTIVE DEVICES	Page 3
CDC E-CARDS	Page 3
PIZZA MAKING (& EATING!) PARTY	Page 4
TRANSPORTATION MENTORING	Page 4
YOUNG FAMILIES GROUP CRAFTS WITH HEATHER	Page 4
SB WEEKEND AT DOUBLE H	Page 5
WE'RE OFF TO THE RACES! A WINNER!	Page 6
2009 CREATIVE FUNDRAISING AWARD	Page 6
BULLYING & HARASSMENT & STUDENTS WITH SPECIAL NEEDS	Page 6
SEFA CAMPAIGN	Page 7
CHAPTER CALENDAR	Page 8

MESSAGE FROM THE CHAPTER CHAIR

This has been a very busy few months for the board. We held our annual "We're Off to the Races" at Saratoga, and thanks to our member families, we were able to raise funds to continue our programs. Special thanks go out to Jim and Jen Gallagher, who chaired this event. I'd also like to thank everyone who sold advertisements for the program and tickets to the event, who obtained business sponsorships so others could attend, and who came to the Day at the Races to have fun and to support our work.

We also are involved in grant writing activities. We just completed our first grant from the National Spina Bifida Association which allowed us to hire a bilingual educator to conduct prevention education in the community, with an emphasis on reaching young Hispanic women of childbearing age. It was so successful, we reapplied. We also applied to National to support using social media to enhance our outreach efforts. If awarded funding we will overhaul our website and create a Facebook page. Lastly, we have written several grants in the hopes of sponsoring our first local conference. If we are successful, the conference will take place next October in Albany.

Without fundraising, the SBA of Northeastern NY could not be a source of information and support, which brings me to the next important event for our chapter. It is Fall, so it must be Double H time. Elsewhere in this newsletter is information about the weekend and how to register. PLEASE consider joining us. If you have come in previous years you know what a wonderful time it is. If you haven't attended in the past, please give it a try. This year, our theme is advocacy. The Counsel to the Commission on Quality of Care for Persons with Disabilities, Robert Boehlert, Esq. will be talking to us about the most effective ways for persons with disabilities to advocate for themselves. He has over 30 years of experience addressing advocacy in the disability community; Mr. Boehlert believes that the best people to advocate for persons with disabilities is themselves. Please come and either learn new skills, or polish up what you already know.

**Barb Devore
Chair, SBANENY**

CDC ISSUES UPDATED

VACCINATION RECOMMENDATIONS FOR H1 N1 VIRUS (SWINE FLU)

There has been much in the news about influenza (swine flu), a respiratory disease of pigs caused by the type A/H1N1 influenza virus. Normally, people do not get swine flu, but human infections can happen. Like seasonal flu, swine flu may cause a worsening of some chronic medical conditions. People with Spina Bifida, including children, are at risk of complications of H1N1 Virus. **We recommend that you speak with your health care provider regarding immunizations for your family. He/she will know what to do, but you need to ask.**

H1 N1 PREVENTION

Swine flu can go from exposure to infection within one to four days, so prevention is the key to battling such a fast-acting virus. All individuals, including people living with Spina Bifida, can take the following simple steps to avoid germs, including swine flu:

- Wash your hands often with soap and water (or use sanitizing gels when hand washing is not available) to remove germs and prevent germs from spreading.
- Avoid touching your eyes, nose, and mouth.
- Cover your mouth or nose with a tissue when coughing or sneezing.
- Stay home if you are sick.
- Avoid close contact with people who are sick.
- Seek medical care if you experience fever, chills, cough, sore throat, body aches, headache and fatigue.
- Get the H1N1 influenza vaccine if you are in one of the recommended groups.

Among the groups that the CDC (Center for Disease Control and Prevention) is recommending flu shots are:

- All people from 6 months through 24 years of age
- Persons aged 25 through 64 years who have health conditions associated with higher risk of medical complications from influenza.

For details about recent findings and recommendations published by Center for Disease Control and Prevention go to www.cdc.gov/h1n1flu.

FLU VACCINATION INSURANCE COVERAGE: WHO PAYS?

Governor David A. Paterson has announced that insurers must cover seasonal flu and novel H1N1 vaccinations for children who are aged 19 and younger and enrolled in comprehensive health plans. The policy is **This year, ACIP has advised that children should receive both the seasonal flu and novel H1N1 vaccines. Therefore, under State law, they must be covered and not subject to co-payment, co-insurance or annual deductible.**

is consistent with New York's preventive and primary care provisions known as the Child Wellness Law, which require insurance coverage for vaccinations recommended by the Advisory Committee on Immunization Practices (ACIP) of the federal Centers for Disease Control and Prevention (CDC). This year, ACIP has advised that children should receive both the seasonal flu and novel H1N1 vaccines. Therefore, under State law, they must be covered and not subject to co-payment, co-insurance or annual deductible.

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 informational, educational and entertainment purposes only. It is not intended as medical or professional advice.

AMERICAN ASSOCIATION ON HEALTH & DISABILITY 2009 SCHOLARSHIP PROGRAM

The American Association on Health and Disability (AAHD) has announced the creation of the 2009 AAHD Scholarship Program.

The AAHD Scholarship Program will support students with disabilities who are pursuing higher education. Preference will be given to students who plan to pursue undergraduate/graduate studies in the field of public health, health promotion, or disability studies, to include disability policy and disability research.

Please visit www.aahd.us to read more about the Scholarship Program and to download the application.

SCHENECTADY ACCESS TO HOME GRANTS

Schenectady Access To Home is a State of New York program that will provide qualified occupants of homes in targeted areas of the city the opportunity to modify their existing home to provide access to persons with mobility limitations and/or disabling conditions, and to enable persons to remain living independently.

Qualifying modifications include ramps, kitchens and bathrooms, and changes for interior accessibility. For information contact Better Neighborhoods Inc. at 372-6469 or www.better-neighborhoods.org.

RESEARCH STUDY ON USE OF ASSISTIVE DEVICES BY CHILDREN WITH MYELOMENINGOCELE

Researchers from the University of Michigan's (UM) Developmental Neuromotor Control Laboratory are currently recruiting participants for a study: "The effect of assistive devices on gait, muscle activity, and oxygen uptake in children with myelomeningocele."

Your child may be able to take part if:

1. Your child is 5-12 years old.
2. Your child has a lumbar/sacral lesion.
3. Your child can walk 8-12 steps without walking aids.
4. Your child has had no surgeries over the past year and no current demonstration of neurological compromise or heart problems.
5. Your child can follow directions.

If your child is interested in participating in this research study, please contact the research staff for more information.

Phone: (734) 615-1494, Cheryl or Jennifer
Email: csdren@umich.edu or jksansom@umich.edu

CDC E-CARDS

The CDC has an E-card which you can send to family and friends. This contains important tips and information about programs relating to the health and wellness of people with disabilities. For more information go to: <http://www2a.cdc.gov/eCards/message/message.asp?cardid=262>

PIZZA MAKING (& EATING!) PARTY FOR ADULTS WITH SB

DATE: SUNDAY, OCTOBER 4, 2009

TIME: 12:30 TO 2:30 PM

PIZZA, SALAD, AND BEVERAGES INCLUDED

PLACE: HALL OF SPRINGS

108 AVENUE OF THE PINES

RSVP: BY FRIDAY, SEPTEMBER 25TH

QUESTIONS? EMAIL SBANENY@AOL.COM OR
CALL 399-9151

MARK DELOS HAS A CULINARY ARTS DEGREE FROM THE CULINARY INSTITUTE OF AMERICA. HE IS THE VICE-PRESIDENT OF OPERATIONS AND GENERAL MANAGER AT THE MAGNIFICENT HALL OF SPRINGS IN SARATOGA SPRINGS. MARK IS EXCITED ABOUT TEACHING THE ART OF PIZZA MAKING TO OUR ADULTS. HE IS PLANNING A VARIETY OF GOURMET PIZZAS (AND WILL INCLUDE A REGULAR NEW YORK STYLE PIZZA FOR THOSE WHO MIGHT BE LESS ADVENTUROUS!)



COME PREPARED TO MAKE AND SAMPLE PIZZAS. YOU WILL LEAVE WITH THE RECIPES SO THAT YOU CAN CONTINUE TO MAKE YOUR FAVORITES!

PLEASE NOTE:

- LET US KNOW IN ADVANCE IF YOU HAVE ANY FOOD ALLERGIES.
- **TRANSPORTATION A POTENTIAL PROBLEM?** LET US KNOW AND WE WILL DO OUR BEST TO HELP YOU FIND TRANSPORTATION SOLUTIONS.
- RSVP IS REQUIRED TO PARTICIPATE IN THIS ACTIVITY.

RSVP BY FRIDAY, SEPTEMBER 25TH. MAIL, CALL OR EMAIL THE FOLLOWING INFORMATION:

- NAME & AGE OF INDIVIDUAL WITH SB
- FOOD ALLERGIES
- LET US KNOW IF YOU NEED HELP WITH TRANSPORTATION IN ORDER TO BE ABLE TO ATTEND THIS EVENT.

TRANSPORTATION MENTORING

Shameka Andrews, who serves on our chapter board, is also a master with public transportation. She has offered her expertise to help others learn how to access transportation in our community. Are you interested in an activity in the newsletter? Pizza? Tennis? Double H? Is transportation the barrier? Call or email our office. Shameka will work with you to learn the ropes!

YOUNG FAMILIES GROUP TO ENJOY CRAFTS WITH HEATHER & COFFEE CHAT FOR PARENTS

Craft Activity for the Children – Painting with Heather!

Heather Horwedel is a young adult who creates with clay. She is attending Schenectady County Community College with a goal of pursuing a career in remedial reading. Heather will appreciate early RSVP's so that she knows the number and ages of children to prepare for in advance!

DATE: SATURDAY, SEPTEMBER 26, 2009

TIME: 9:30 – 12:30

PIZZA LUNCH INCLUDED

PLACE: COLONIE COMMUNITY CENTER
1653 CENTRAL AVE, ALBANY

RSVP: BY MONDAY, SEPTEMBER 21

QUESTIONS? EMAIL SBANENY@AOL.COM
CALL 399-9151



PLEASE NOTE:

- BRING AN OLD SHIRT THAT YOUR CHILD CAN WEAR FOR A PAINTING SMOCK.
- LUNCH OF PIZZA AND FRUIT WILL BE PROVIDED.
- CHILDCARE WILL BE PROVIDED FOR CHILDREN WITH SB AND THEIR SIBLINGS DURING THE COFFEE CHAT PORTION OF THE PROGRAM.
- EACH CHILD SHOULD BRING TWO TOYS OR GAMES TO SHARE WITH THE GROUP.
- RSVP IS REQUIRED TO ENSURE THAT WE HAVE APPROPRIATE CHILDCARE, MATERIALS, AND FOOD!

SBA OF NENY GETS READY FOR SPINA BIFIDA WEEKEND AT DOUBLE H

TENTATIVE WEEKEND SCHEDULE:

**Register Now:
Spina Bifida Weekend
Double H Ranch
October 23rd to 25th**

Arrival: Friday, Oct 23, 6:00 PM

Departure: Sunday, Noon

(If your arrival or departure varies from this, please let us know so that Double H can plan food and activities accordingly.)

Friday Evening: Light dinner, storytelling, games, campfire, ice cream social

Suggestion/Question Box: We will have a suggestion box available Friday evening and Saturday morning. This is an opportunity for you to communicate your ideas or ask questions of the chapter board or Executive Director. *(You may also suggest and ask questions during the annual meeting, but we are offering this as an alternative to everyone.)*



Saturday Daytime:

Guest Speaker: Mr. Robert Boehlert, Counsel, New York State Commission on Quality of Care & Advocacy for Persons with Disabilities. Mr. Boehlert will present about the importance of self & group advocacy.

SBA of NENY Annual Meeting: Get an update on what is happening with our local chapter, hear responses to everyone's questions & suggestions, and recognize outgoing board members.

Enjoy Double H facilities: swimming (indoor pool), art's & crafts, high ropes course, hiking, fishing & boating, discovery center, pumpkin carving

Saturday Evening: Halloween party, campfire, World Series Game 6

Sunday Morning: Breakfast, reflection, gift shop.

Our weekend is 5 short weeks away! Please don't wait. Some people will need to get a doctor's signature to complete their registration in which case you will need to act soon!

Several things that you should know:

1 - The deadline for registering -- getting all of your paperwork in and delivered to Double H is October 16th.

2 - Registration is on a first come first serve basis. (There are limited rooms available.)

3 - This program is for children, teens, and adults who have Spina Bifida and their families. Adults over the age of 21 may attend independently. The event is an excellent place to develop new friendships, renew old ones, network, learn, relax, breath the fresh air of the Adirondacks, exercise, play, and enjoy the atmosphere and staff of Double H Ranch. *(Please note there is not staffing to provide personal assistance. If you require this, please plan to bring someone with you who can provide for these needs.)*

Three more things to make a note of:

1 - This weekend is intended for individuals with SB and their immediate family (or a caregiver) of the individual with SB.

2 - In the rare necessity of making a substitute for someone who is registered, this must be pre-approved prior to arrival at Double H.

3 - *We will need to give preference to those who live in our chapter's region (northeastern NYS), but can usually*

SPINA BIFIDA WEEKEND AT DOUBLE H (CONTINUED)

accommodate some who live outside of that region, and so this notice is sent out to all on our mailing list.

REGISTRATION:

Call or email our office for the registration forms; 518-399-9151, sbaneny@aol.com.

Please mail completed forms to:

Double H Ranch
Kate Walsh, Program Director
97 Hidden Valley Road
Lake Luzerne, NY 12846

After you register, you will receive more detailed information about the weekend, including a schedule, packing list, and waiver forms with further instructions.

Questions? Call or email to SBA of NENY.

"WE'RE OFF TO THE RACES!" A WINNER!

On August 9th, our chapter had over 100 constituents, family members, and community supporters attend the 4th annual "We're Off To The Races!" at Saratoga Thoroughbred Race Track. Attendees enjoyed a buffet luncheon and were present for a presentation of appreciation for Senator Neil Breslin. Senator Breslin has been a vocal supporter of our chapter and services for those affected by Spina Bifida. Final numbers for the fundraiser are not in as donations are continuing to come in, but we expect that the fundraiser will have raised in excess of \$9,000.

2009

CREATIVE FUNDRAISING AWARD

Bob Thorpe was honored at "We're Off To The Races!" for creating and implementing a throw raffle to benefit SBA of NENY. Bob is a local photographer who specializes in pictures of nature. Using one of his images, he had a throw made for the chapter, and then proceeded to sell raffle tickets. Before Bob was finished, he had raised in excess of \$500! Many thanks go out to Bob for his dedication and support of SBA of NENY.



"Nature's Mother & Child" throw

BULLYING & HARASSMENT & STUDENTS WITH SPECIAL NEEDS WORKSHOP

Presented by
**Wildwood Programs Family &
Community Services**

Target Audience: Parents & Professionals

Date: Friday, October 2, 2009

Time: 9 to 11AM

Presenter: Julie M. Keegan,
Special Education Resource Specialist

Children with disabilities are especially vulnerable to bullying and harassment. This workshop will provide parents with an understanding of the "who, where and when" of bullying, how to use an IEP to protect your child, school-based prevention strategies, how to use anti-discrimination laws to protect children with disabilities, and what to do if your child is the bully.

Ms. Keegan has been an advocate for parents of children with disabilities for many years.

Please Note These Important Reminders....

SEFA

(STATE EMPLOYEES FEDERATED APPEAL)

Designate Spina Bifida Association Albany/Capital District Chapter for your employee giving program.

Our chapter is registered with SEFA for work place giving. These campaigns are occurring throughout the state over the next few weeks. Please keep us in mind during this campaign. Encourage family and friends to offer their support as well!

Karen Wentworth, chapter Executive Director, will be at the Empire State Plaza representing our chapter on October 7th. Please visit our chapter booth.

Note: *Our chapter has changed our name to SBA of Northeastern New York to better reflect the area that we serve. SBA of Albany/Capital District Chapter is the same organization under which we registered earlier this year.*

Your donations through employee giving program are crucial to supporting the programs and activities of the chapter.

INK CARTRIDGE REMINDERS...

Our chapter's ink cartridge fundraiser has been very successful with reducing expenses of office supplies. What can you do to help?

Just collect used ink cartridges (not toner). Ask you family and friends to collect theirs. See if you can put a collection box at your work, doctor's office, dentist's office, church, or a local business. Bring your collection of ink cartridges to the next chapter event. We turn these in and receive up to \$30/week in office supplies. That's \$1,560 per year!

LOOKING FOR A PLACE TO MAKE A TAX DEDUCTIBLE DONATION BEFORE THE END OF THE YEAR?

Consider a donation to Spina Bifida of Northeastern New York.

Checks can be made out to:

SBA of Northeastern New York
123 Saratoga Road
Scotia, NY 12302

THANK YOU!



It's Time To

GoodSearch!

GoodSearch is an internet search engine that makes donations to not-for-profit organizations when people register with them and use GoodSearch while surfing the net.

Please take two minutes right now and set up GoodSearch on your computer so that our chapter will benefit as you surf the net and shop! It's just a few simple steps!

Here are the step-by-step directions:

1. On your desktop: double click "MY COMPUTER"
2. Once opened: double click "CONTROL PANEL"
3. Once opened: double click "INTERNET OPTIONS"
In the General Tab where it has the homepage section, type www.goodsearch.com.
4. Click apply at the bottom and then click ok.
5. Go back to your desktop and click on your internet explorer icon, when it opens you should be at GOODSEARCH. You will need to choose a cause. ***This is where you type in "Spina Bifida Association of Northeastern New York."***
6. Done!

Now every time you search the internet you will be helping our organization receive funds.

2009 Calendar of Events

September 26 Young Family's Program
Coffee Chat/Crafts with Heather

October Spina Bifida Awareness Month

October 3 Chapter
Board of Director's Meeting

October 4 Pizza Making Party for Adults

October 23 – 25 Spina Bifida Weekend
at Double H Ranch

October 24 Chapter Annual Meeting

January 17, 2010 Willard Mountain Tubing Party

Ongoing *Call for Information:*

Weekly Accessible Tennis Lessons

Quarterly Teen & Young Adult Support Group
Young Family Support Group



123 Saratoga Road
Scotia, NY 12302