



TABLE OF CONTENTS

- * **SBANENY BASEBALL OUTING**
- * **EQUIPMENT EXCHANGE**
- * **SBANENY FAMILY RETREAT WEEKEND** Page 2
- * **LATEX ALLERGIES**
- * **ASSISTIVE TECHNOLOGY SURVEY**
- * **ACCESSIBLE VOTING INFORMATION** Page 3
- SBANENY DEVELOPMENT**
- * **GO TO THE THEATRE FOR SBANENY!**
- * **WALK-N-ROLL FOR SB 2013** Page 4
- * **SB GENETICS RESEARCH**
- * **OPTIMIZING HEALTH OVER 40** Page 5
- * **RIGHTS FOR TREATMENT IN HEALTH CARE SETTINGS**
- * **ASK THE EXPERT: BUILDING INDEPENDENCE** Page 6 - 7
- FOR YOUR CONVENIENCE!**
- **THEATER TICKET ORDER FORM** Insert

MESSAGE FROM THE CHAPTER CHAIR

It seems like summer just began and now September 1st is here. I love the summer time. It's a great time to go out and get to together with friends and family, have picnics, BBQs, go swimming and visit a local park. I spent a lot of time this summer going to the different parks in the Capital Region. It is always amazing to realize how many beautiful things we have to see in New York State that are just a short drive away. Hopefully you were able to get out and about with your family and friends.

SBANENY has been very busy planning activities for the fall and the upcoming year. We are working on increasing board membership. I would like to welcome our two newest board members, Kevin Bean and Dr. Matthew Adamo. I would also like to thank Jim Gallagher for all of his hard work. Jim has decided to step down from the board at this time. We are continuing programs that we know are very important to individuals and families. If there are programs and activities you would like to see us offer, please let us know. You can share your ideas with us by visiting our website www.sbaneny.org, or you can visit Spina Bifida Association Northeastern NY on facebook.com.

This past week several of our families met at the Tri-City ValleyCats stadium to see a baseball game and picnic together. In October we will be offering a retreat weekend for families with children with SB ages ages 4 to 21. We are also developing plans for adults to meet and share their expertise of advocacy skills. In November, we will be hosting our 7th annual fundraiser. This year's event will be a performance of "This Wonderful Life" at Capital Repertory Theatre in Albany. The evening will include a silent auction, wine pull, appetizers and desserts.

Thank you to everyone who helps to plan these events. I hope everyone has a great rest of the summer and I hope to see many of you at our events in the fall.

Shameka Andrews
Chapter Chair

SBANENY

Board of Directors

- Shameka Andrews, Chair
- Vacant, Vice-Chair
- Stephanie Mumford, Treasurer
- Dan O'Connell, Secretary
- Kevin Chamberlain, Past Chair
- Amy Clinton
- Barbara Devore
- Hali Holmes
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- Dr. Matthew Adamo
- Kevin Bean

Disclaimer: *Spina Bifida Association of Northeastern New York 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.*

SBANENY NEWS

SBANENY SUMMER OUTING AMERICA'S PASTIME



August 25th found a group of our families at the all American pastime of a baseball game with a picnic.

MEET & GREET SPONSORED BY SELF-ADVOCACY ASSOCIATION OF NEW YORK STATE, INC.

To: All Capital District Self-Advocates and Self-Advocacy groups. Recommended for teens age 16 through adults.

What: Meet self-advocates from around the Capital Region. This will be a time to learn and share with each other.

Where: Albany Public Library
161 Washington Ave, Albany

Date: Tuesday, September 18, 2012

Time: 5 to 8 PM

SBANENY EQUIPMENT EXCHANGE PROGRAM

One of our families has a hand powered tricycle that they would like to pass along to another child. Their son has outgrown it. The bike is for a preschool age child. If you are interested in this for your child, please contact our office.

SBANENY Email Address Change

Please note we have a new email address:

admin@sbaneny.org.

Please change this in your records. We no longer use our old email address, so messages sent there won't be answered. Thank you!



SBANENY FAMILY RETREAT WEEKEND

DATE: October 26 to 28, 2012

TIME: 6 PM Friday to Noon Sunday

PLACE: Frost Valley,
2000 Frost Valley Road, Claryville, NY

WHO: Child with SB (age 4 to 21) and their immediate family (siblings & parents/guardians)

COST: \$20/adult, \$10/child

Why Attend? This weekend provides parents, children with SB, and siblings an opportunity to meet and grow networks and connections with others facing similar experiences.

This weekend is open to families with children with Spina Bifida between the ages of 4 & 21 regardless of ability to pay. Scholarships are available to cover the cost of registration fees. Information regarding scholarships will be kept confidential. Please pay an amount that you feel you are able.

Registration Deadline: All participants must submit registrations by October 12, 2012. Registration forms are available to download on the homepage of our website at www.sbaneny.org. If you don't have access to the internet, please call our office at 518-399-9151 and we would be happy to mail registration forms to you. Forms should be mailed to Spina Bifida Association of NENY, 123 Saratoga Road, Scotia, NY 12302.

Weekend Activities:

Campfires	Apple Cidering
Arts & Crafts	Halloween Games
Climbing Wall	Fishing & Boating
Low Ropes Activities	Face Painting
Hayrides	Archery
Zip Line (Over age 12 only)	

Lodging: Participants will be assigned to accommodations as family units. Direct parent/guardian supervision of children under the age of 12 is required at all times.

Visit Our Website at
www.sbaneny.org
or see us on Facebook!

RESOURCE INFORMATION FOR LATEX ALLERGIES

American Latex Allergy Association has fact sheets available.

- Latex Allergy Information
- Allergy Fact Sheet
- Asthma & Occupational Asthma
- Anaphylaxis
- Latex Allergy Check List
- Latex Cross-reactive Foods

Go to www.latexallergyresources.org or call 1-888-972-5378 for more information.

WHEELCHAIR SEAT ELEVATOR MEETS MEDICAL NEED

Recently a Fair Hearing resulted in a decision that a Seat Elevator of a power wheelchair met the definition of medical need for a child. This decision opens the door for children with disabilities in New York State who could benefit from this durable medical equipment option. For further information, contact NYS Assistive Technology Advocate, Marge Gustas at mgustas@nls.org.

SURVEY ON ASSISTIVE TECHNOLOGY

Independent Living Research Utilization (ILRU) is conducting a survey to assess the assistive technology needs of people with disabilities. The goal of this survey is to determine both the current availability of such technologies and the potential for new, innovative devices. By identifying the assistive technology needs of people with disabilities, ILRU will be better able to work with policymakers and funders to address assistive technology needs.

To participate in the survey, go to the link at: <https://docs.google.com/spreadsheets/embeddedform?formkey=dF9mMzNzblJxOXVVM5qSm1EY0FWSWc6MQ>

TECHNOLOGY GIVES ACCESS TO VOTING FOR PEOPLE WITH DISABILITIES

Election Day is November 6, 2012

THE ACCESSIBLE VOTING SESSION

When requested, an inspector at your polling site can create an accessible voting session for you. Make sure to let the Inspector know what assistance, if any, you prefer. You will be asked which accessible device you would like to use. Your choices may include the Audio Tactile Interface, called an ATI, a Sip and Puff, or a paddle device. Once selected, the Inspector will connect the device to the Ballot Marking Device (BMD.)

We recommend that you plan ahead.



- ✓ Every voter has a right to privacy.
- ✓ Call ahead to learn about your polling site.
- ✓ For more information or to watch a video on accessible voting, go to <http://www.vote-ny.com/english/transcripts-sequoia/>. For information on your polling place, call the Voter Info Hotline at **1-800-367-8683**.

Question:

How do I register to vote?

Answer:

There are several options:

- You may register at your local board of elections or any state agency participating in the National Voter Registration Act, on any business day throughout the year.
- You can download a PDF version of the Voter Registration Form, complete it, and mail it to your county board of elections. Go to <http://www.elections.state.ny.us/Voting.html>.
- You can also call 1-800-FOR-VOTE to request that a voter registration form be mailed to you.

SBANENY DEVELOPMENT UPDATE

Go to the Theatre for SBANENY

Fundraising Event!

Capital Repertory Theatre & SBANENY Present:

**THIS
Wonderful
LIFE**

Special Engagement

Adapted by Steve Murray (and Mark Setlock)

*"All the pleasure of Frank Capra's classic movie -
in only 70 minutes!"*

November 29th at 6:30 PM

*** Appetizers & Desserts**

*** Silent Auction**

*** Cash Bar**

**Thank you to Silver Sponsor:
Socha Plaza**

**To purchase tickets
and for more information:**

www.sbaneny.org
admin@sbaneny.org
518-399-9151

General Admission Tickets:

Director's Level \$75
(name will be listed in program)
Actor's Level \$45
Stagehand (Under 18) \$15

Please stop in and say "Thank You!" to these businesses for their sponsorships of Go to the Theatre for SBANENY:

~ ~ Silver Sponsor ~ ~
Socha Plaza

~ ~ Copper Sponsors ~ ~
Albany Financial Group
InfoEd International
Price Chopper
Stuyvesant Plaza

Teal Becker & Chiaramonte, CPAs, P.C.

What can you do to help make this SBANENY Annual Fundraiser a success?

- o **Contribute in-kind donations** for the silent auction. Contact our office if you have ideas for this.
- o **Attend the event** if you are able.
- o **Help with publicity** for ticket sales! Forward emails about the fundraiser to family, friends, co-workers. Copy & post flyers on community bulletin boards.
- o **If you live a distance** from the greater Capital District, please encourage family and friends that you have in the Albany area to attend!



SBANENY Walk-N-Roll 2013 Committee Needs You!

This committee is beginning to work to make SBANENY Walk-N-Roll for Spina Bifida 2013 bigger and better. This is a great opportunity to raise awareness about SB while raising funds to support services and activities that SBANENY provides. Please consider how you might help with the planning committee. Contact our office today to sign up!

SPINA BIFIDA GENETICS RESEARCH

Spina Bifida Genetics Research Project is in the second phase of a study that will hopefully provide information toward **the goal of reducing the incidence of Spina Bifida affected pregnancies.**

Help make a difference.
Participate in our
Spina Bifida Study>

 SBgenetics.org

One of the things that we can do for future generations is to consider participating in research such as this project. Finding the answer for prevention of Spina Bifida is critical for the next generation.

To be successful, the researchers need 1700 mothers of children with Spina Bifida and 3,000 moms of children without a birth defect to participate. **To date, 45 moms from New York State have signed up and 23 of those moms have completed their participation.**

To encourage participation, the researchers have organized a competition to help raise money for Spina Bifida Association chapters. **If 5 more moms sign up for the study and then all of the moms signed up return their kits for the research, the Spina Bifida Genetics Project will donate \$2,000 to SBANENY.**

Participation takes about 15 minutes of your time in two steps. You start with a survey. Once this is completed, they mail you a test kit. In 5 more minutes, you provide a sample by spitting in a small test tube and placing this in the supplied postage paid envelope to mail.

Have you signed up & only need to return your test kit? Please complete your sample & mail it today.

Would you like to participate? Call 866-575-0110 or go to www.sbgenetics.org and select ENROLL today!

The deadline for this research participation promotion is October 1, 2012.

Thank you!

OPTIMIZING HEALTH FOR THOSE OVER 40

SBANENY sent Executive Director Karen Wentworth to the 39th SBA National Conference in June. The following are notes that Karen brought back from a session she attended. Presenter was Brad Dicianno, MD from the University of Pittsburgh Medical Center, Director, Adult Spina Bifida Clinic.

Because recommendations for screening can change frequently and can also vary for individuals, you should discuss any concerns you may have with your doctor.

Are you over 40?

Do you use a wheelchair or crutches?

Do you know that you are at higher risk for musculoskeletal problems?

Shoulder, hand, and wrist pain are common. It is important to treat these problems early to prevent bigger long term problems.

Proper fit of your wheelchair for your arm length is critical. Before problems arise, talk to a wheelchair expert. Ensure that your wheelchair is set up properly to allow you to propel in long, smooth strokes.

Lymphedema – is much more common in people who have Spina Bifida. It is important to seek medical treatment early. Ask your doctor to rule out blood clots.

Back Pain – might be caused by a variety of problems; tethered cord, arthritis, muscle strain, and shunt problems among them. Seek medical attention.

Obesity – puts you at risk for a number of health problems including diabetes, high blood pressure, stroke, sleep apnea, cancers, depression, and arthritis. What can you do?

- ❖ Watch your diet
- ❖ Exercise – The National Center on Physical Activity and Disability (NCPAD) has tips on exercising as well as a video for people with Spina Bifida.

Screenings to Consider:

- Osteoporosis – bone density
- Blood pressure & weight – at every doctor visit, at a minimum once a year
- Cholesterol should be checked
 - Men over age 34, every 5 years
 - Women over age 44, every 5 years
- Blood Sugar – annually
- Colon Cancer – Starting at age 45 for African Americans and at age 50 for everyone else
 - Yearly stool blood test
 - Colonoscopy every 10 years or a flexible sigmoidoscopy every five years
- Breast Cancer
 - Yearly mammogram and clinical breast exam for women starting at age 40 – 50
 - Earlier if family history of breast cancer
 - Monthly self breast exams
- Gynecological exams/Pap smear – regularly, talk to your doctor
- Prostate Cancer – Annual blood test and digital rectal exams for African American men at age 45 and all other men over age 50
- Testicular Cancer
 - Do self exam once a month
 - Annually at doctor visits
- Dental exam – yearly exam and cleaning
- Immunizations –
 - Consider yearly flu vaccine
 - Tetanus every 10 years
 - Consider one time pneumonia vaccine
- Vision – annual vision checkups
- Osteoporosis – talk to your doctor about screening

NEW INITIATIVE TO PROTECT THE RIGHTS OF PEOPLE WITH DISABILITIES IN HEALTH CARE SETTINGS

On July 26th, the Department of Justice announced an initiative designed to enforce laws that protect the rights of individuals with disabilities in health care settings. The Barrier-Free Health Care Initiative is designed to ensure that people who are disabled are not discriminated against in their access to health care.

Included in the concerns to be addressed are physical access to medical buildings and facilities to ensure that people with disabilities are able to receive critical medical testing and information.

For more information about the Barrier-Free Health Initiative, go to <http://www.ada.gov/usao-agreements.htm>.

Ask the Expert: Tips for Parents Building Independence: How to Develop Better Initiation and Attention

By Margaret Lohr Calvery, PhD

What are initiation and attention?

Initiation and attention are foundational executive functions. Initiation and attention are necessary to meet daily academic, vocational, and personal goals. Initiation is the ability to independently start an action or activity. Attention is the ability to sustain and/or divide focus on the information necessary for learning or completing a task. Research reveals that individuals with Spina Bifida are more likely to have diminished attention and initiation in comparison to the general population. To remediate initiation and attention weaknesses, skill building and accommodations in school and at home are essential.

Behavior symptoms associated with diminished initiation include:

- Tremendous discomfort and difficulty adjusting to new situations or changes in the routine
- Avoidance of typical peer activities
- Lack of common sense (“street smarts”)
- Social isolation

How does poor initiation affect independence and skill building?

Individuals with poor initiation appear “passive,” disinterested, or lacking in motivation. Individuals with poor initiation volunteer less often to participate and are content to let others complete tasks for them. Individuals with poor initiation do not “push” for independence, which results in less independence with self-help or self-care skills.

Behavior symptoms associated with diminished attention include:

- Ignores or “does not hear” directions, appears to have a “memory” problem
- Interrupts conversations
- Does not follow through with directions or tasks

- Has inconsistent performance in school, makes careless mistakes with schoolwork, and/or fails to give close attention to schoolwork
- Talks excessively
- Doesn't stay in seat
- Fidgets in seat
- Is forgetful
- Blurts out answers or questions
- Loses things
- Jumps from activity to activity without completion
- Is easily distracted
- Is overly active
- Is physically intrusive
- Has difficulty taking turns
- Has difficulty doing more than one thing at a time

How does poor attention affect skill building?

Individuals with poor attention do not “choose” to not pay attention. Attention is best understood across a spectrum. Individuals with poor attention are more often hyperactive, inattentive, or over-focused but they do have periods of time with well controlled attention. Poor attention results in missed information, frequent negative feedback, and poor task follow-through.

What are some ways to improve Initiation?

At Home:

- Use everyday events (such as dressing, eating, bowel and bladder management) to practice building initiation with significant hands-on supervision.
- With younger children, use “Simon Says” and “Red Light, Green Light” games that have a simple direction followed by an immediate action.
- Become involved in group activities with a specific focus and routine (such as art class or Boy Scouts).
- Physical prompts and modeling should be routinely used.
- Do not give directions for future activities; focus only on the immediate here and now.

At School:

- Teach the student to use cues such as picture checklists, watches, timers, or a written mini schedule to remind him to “get started” on an activity.
- Practice “say-do” routines in which you help the student to first state what she is going to do and then immediately follow through with the activity. Use modeling and physical prompts if needed.
- Don't wait for the student to initiate social behavior. Facilitate coordination with peers for

lunch and recess times. Assist in planning other group and social events.

What are some ways to improve attention?

At Home:

- When giving instructions or directions, use visual, verbal, and physical cues before and during your explanation.
- Use short directions without rationales.
- Reduce options and choices.
- Try not to become irritated by the need to repeat directions.
- Eliminate distractions for optimal focus. Set up a quiet homework or work environment with frequent and short “get up and move around” breaks.

At School:

- Develop a specific routine, such as keeping desks and supplies organized, turning assignments in at a certain time or in a certain way, and keeping work spaces cleaned and neat.
- Adjust seating assignments. Distractions are minimized when a student is seated close to the teacher, away from the door, and near peers without attention struggles.
- Restriction from physical activity or recess is not an effective consequence for incomplete work or inattention behavior. Instead, regular physical activity is necessary to provide mental and physical breaks.
- Your student is more likely to react first without stopping to check if he has his facts straight. Remind him to pause and check his facts. Then discuss “how to proceed.”
- Teach self-checking skills and good attention to detail. (For example, highlight the “sign” on math computation problems.)
- Assign specific responsibilities and jobs.
- Use visual and physical prompts routinely.
- Reward “on task” behavior more often than you reprimand “off task” behavior.
- When grading, focus on the quality of the work rather than the neatness of the paper or missed questions.

Margaret Calvery, PhD, is a pediatric psychologist for the University of Louisville, Department of Pediatrics, Weisskopf Child Evaluation Center.

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



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OF NORTHEASTERN NEW YORK**

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SBANENY CALENDAR OF EVENTS

SEPTEMBER

September 8
September 18

SBANENY Board of Director's
Teens & Adults attend
SANYS Meet & Greet

OCTOBER

October 26 - 28

SBANENY Fall Family Weekend Retreat

NOVEMBER

November 10
November TBA
November 29

SBANENY Board of Director's
Adult Meeting
SBANENY Goes to the Theater! Annual Fundraiser. See inside for details.

JANUARY 2013

January 12
January 20

SBANENY Board of Director's
SBANENY Tubing at Willard Mountain

MAY 2013

May 4

SBANENY Walk-N-Roll for Spina Bifida 2013