



SPINA BIFIDA ASSOCIATION OF NORTHEASTERN NEW YORK



SBANENY News to Use

CHAIR LETTER

Empowerment through Making Connections: Living with Spina Bifida

This was the theme of the 4th biennial SBANENY Education Day held on Saturday, April 2nd at the SUNY School of Public Health in Rensselaer, NY. We host this conference every other year as a way for families across New York State to come together and learn from professionals across multiple fields, such as medicine and law, and, perhaps most importantly, each other. For the first time, we decided to hold two socials in the evening after the conference, one for families of people with Spina Bifida and the other for adults with Spina Bifida. While I can only speak for the adult social as that is the one I attended, I know a good time was had by all and everyone benefited from meeting new people to relate to across the state.

In everything we do at SBANENY, our goal is to make connections. Whether we are connecting families to resources or each other, connecting to other agencies to strengthen services in the community, connecting to businesses to achieve financial goals and gain better visibility, or connecting consumers to information to strengthen themselves, we try to ensure that information regarding Spina Bifida is spread throughout the community. Our four main goals in the strategic plan for SBANENY are to advocate, educate, lead and grow. Through events like our conference, we make connections throughout the community that allow people with Spina Bifida to live the best life possible.

Mid-year at SBANENY is a busy time. Not only are we winding down from the conference, we are gearing up for a get together for families in the New York City area in April and our Walk-N-Roll fundraiser in May. More information can be found throughout this newsletter. Additionally we welcomed multiple new board members to SBANENY this year to expand our connections in the community and their connection to us. Please help us in welcoming them to SBANENY!

As we go into the middle of the year and prepare for programs, please keep in contact with us either by phone, email, Facebook or the SBANENY website. We would like to hear your feedback from events you attend as well as other things you might be interested in. The connections we have to all of you make us a stronger organization better able to serve and meet the needs of the Spina Bifida community. Happy Spring!

Lyndsi Holmes-Wickert, Board Chair

ISSUE #67 APRIL 2016

SBANENY Education Day 2016

SBANENY Pool Party

NYC Meet & Greet Event

SBANENY Walk-N-Roll

News & Information

Scholarships

SBANENY Internship Program

Toolkit for Educators

Journey Along the Erie Canal

Community Events

Calendar of Events

SBANENY BOARD

Chair: Lyndsi Holmes-Wickert

Vice Chair: Michelle Miller

Past Chair: James Dunham

Treasurer: Heather Green

Secretary: Margaret Smith

Directors:

James Alescio

Peggy Felt

Annmarie Fennicks

Margaret Huff

Executive Director

Karen Wentworth

SBANENY Events

Check out what's happened so far this year!

SBANENY Education Day, 2016 Empowerment through Making Connections: Living with Spina Bifida



Keynote Speaker: John Robinson

Managing Partner & CEO of Our Ability Inc.

Author of "Get off Your Knees"



KIDS CAMP

Creative Arts

Stephanie R. C. Harageones

Therapy Dogs

Patty Rekse, Schenectady
Therapy Dogs International



*Thank you to the individuals, families,
providers, and volunteers who made the
SBANENY Conference possible!*



Conference Sessions

Ticket to Work & Social Security Work Incentives, Neurological
Updates, Chair Yoga, Urological Updates, Special Needs Trust,
Mapping your Family's Strengths



Great conversations...

Thanks to our conference session presenters!

Geri Walsh, Suzy Sherer Arenos, Dr. Laura
Chang Kit, Ed Wilcenski, Julianne Magnano, &
Dr. Alexandra Paul



Family & Adult Socials



*Thank you to the Conference
Planning Committee members for
helping make Education Day 2016
successful!*



Vanessa Chamberlain, Chair
Shameka Andrews
Chris Darby-King
Barbara Devore
Jennifer Gallagher
Lyndsi Holmes-Wickert
Karen Wentworth

Special thanks to our sponsors, vendors, and not-for-profit displays!

Presenting Sponsor Cure Medical



Cure Medical donates 10% of net income to medical research in pursuit of a cure for spinal cord injuries and central nervous system disorders.

RESEARCH

Research is the key.

The Cure Medical Commitment to the sustained financial support of research for a cure for SCI and CNS/D is unsurpassed in the industry. As a result, simply by using the Cure Twist®, Cure Medical® Pocket Catheter, Cure Catheter®, or the Cure Catheter® Closed System you can experience all these premium quality benefits at an exceptional value:

- Always smooth polished eyelets for comfort
- Not made with DEHP*, BPA or natural rubber latex
- Always supporting research for a cure

For FREE SAMPLES of Cure Medical catheters, contact your local supplier of quality healthcare products or visit www.curemedical.com.

Visit SBANENY Presenting Sponsor: Cure Medical

* See CA EPA Office of Env. Health Hazard Assessment List of Chemicals Known to the State to Cause Cancer or Reproductive Toxicity, December 8, 2006.



Silver Sponsor: Mobility Works



Not-for-Profit Displays

Ainsley's Angels of America
Independent Living Center of the Hudson Valley
SBANENY Information Table/Lending Library

Bronze Sponsor: Hollister

Conference Booster Sponsors:

Monroe Wheelchair
Coloplast
Discovery Toys

Grant funding for this conference was received from

- ◇ New York State Developmental Disabilities Planning Council
- ◇ Cohoes Saving Foundation



Often times opportunities are disguised as challenges...

John Robinson

SBANENY Pool Party

Beating those winter blues....
Young Children & Families Program at
the Ciccotti Center!



We hope to see you next time!



Pool fun!



SBANENY Events: What's to come!

NEW YORK CITY MEET & GREET EVENT

What: Individuals and families affected by Spina Bifida living in the New York City area are asked to come and get to know each other, share support and resources, & make connections!

When: April 23, 2016 from 12:00pm-3:00pm

Where: Fordham University, 441 East Fordham Road, Bronx, NY

Please RSVP by April 22, 2016

To RSVP, for more information or questions, please contact Julia Duff

Phone: 518-399-9151

Email: casemanager@sbaneny.org

Staying Informed



DISABILITY BLOGS

You can stay up to date on what is happening in the disability community. Subscribe to receive blog updates through disability.gov by visiting <https://usodep.blogs.govdelivery.com/>

There are a variety of guest bloggers including individuals and providers and the blogs cover many important topics including benefits, voting, employment, and health!

Healthy Aging & Physical Disability The Rehabilitation Research and Training Center University of Washington

This website has factsheets for the questions you may be having as you age with a physical disability and provides tips on how to improve your health! Topics include:

- [How to Stay Physically Active](#)
- [How to Cope with Depression](#)
- [How to Get the Most Out of Your Health Care Visits](#)
- [How to Sleep Better](#)
- [How to Find Trustworthy Health Information from the Internet](#)
- [Tips for Improving Memory & Thinking](#)
- [Employment Concerns](#)
- [How to Prevent Falls](#)
- [How to do a Lot with a Little: Managing Your Energy](#)

Check out the website for more information: <http://agerrtc.washington.edu/info/factsheets>.

Ten Things to Know before Traveling from disability.gov

1. Learn about your rights as an air passenger with a disability.
2. ADA (American's with Disabilities Act) protects people with disabilities from discrimination in public transportation services and facilities. The ADA also requires public transit agencies to provide free paratransit services for people who cannot use regular services because of a disability.
3. When traveling by railway travel you may eligible for certain discounts. It is recommended you inform your rail carrier prior to travel to arrange necessary accommodations.
4. Winter weather: Prepare for emergencies, prepare your car, research driving tips, consider cancellations, dress warmly!
5. Find information about financial assistance, trainings, and fact sheets on adaptive driving and vehicle modifications through Disability.gov's Guide to Transportation and United Spinal Association's Adaptive Driving Guide.
6. Information is available through National Aging and Disability Transportation Center (NADTC) including technical assistance, referral to resources, and community grants.
7. Read "A Safety Guide for Pedestrians with Disabilities" and use mobile apps like AXS Map to find accessible routes in your area.
8. Visit disability.gov for a list of resources for financial assistance to purchase a vehicle or pay for car repairs. Help paying for transportation. Check with your local Independent Living Center or Aging and Disability Resource Center to learn more about programs near you.
9. International travel: Know how to manage health abroad! Several guidebooks are available to help you to better prepare for your trip.
10. Resources for rides to appointments include Medicaid (non-emergency medical) Visit Disability.gov's Finding a Ride and Paratransit Services for additional resource information.

SB Insights Spring Issue is here! *Subscribe to SB Insights to stay updated on the SBA year in review, community stories, and SBA events in 2016!*

The Spring SB Insights is available for you to read about people living with Spina Bifida who have experienced the power of personal transformation while refusing to be defined by their limitations.



SBANENY SCHOLARSHIPS AVAILABLE

FRANK BUCINO JR.

MEMORIAL SCHOLARSHIP

The purpose of this scholarship is to award financial assistance to individuals with Spina Bifida of any age living in New York State to support;



Conference Attendance: Individuals who have Spina Bifida and their immediate family's attendance at a national or regional Spina Bifida conference. The goal of the scholarship is to encourage individuals and families to attend an SBA Conference or Education Day, or an SBANENY sponsored conference. These events provide a great opportunity to meet others living with Spina Bifida; learn more about living with Spina Bifida, make friends and enjoy seeing old friends; share tips and tricks; learn the latest medical information from doctors and other experts; and have an amazing experience overall!

OR

Educational Scholarship: Individuals with Spina Bifida who are pursuing education or technical training.



**SPINA BIFIDA ASSOCIATION
OF NORTHEASTERN NEW YORK**

HELEN R. MERTENS

EDUCATIONAL SCHOLARSHIP

Sponsored by

Spina Bifida Association of Northeastern New York

Are you pursuing an educational or training goal?

The purpose of the Helen R. Mertens Scholarship is to award financial assistance to persons who have Spina Bifida living in Northeastern New York who are pursuing higher education, technical training, or driver's education.

The deadline for receiving scholarship applications and all supporting materials is April 15, 2016.

For further information, guidelines, & applications go to our chapter website at www.sbaneny.org or contact our office.

ADDITIONAL SCHOLARSHIPS TO EXPLORE

180 Medical

- Award amount: \$1,000
- Available to full time students registered in two-year, four-year, or graduate school programs. Applicants must be under a physician's care for a spinal cord injury, Spina Bifida, transverse myelitis, or neurogenic bladder

American Association on Health and Disability

- Award amount: under \$1,000
- Available to undergraduate and graduate students with a documented disability. Preference given to students majoring in public health, disability studies, health promotion or a field related to disability and health.

AmeriGlide Achiever Scholarship

- Award amount: \$1,000
- Available to college students who have finished at least one year of college and use a manual or electric wheelchair

ChairScholar Foundation

- Award amount: varies
- Available to high school seniors and college freshmen with a profound physical challenge and are under 21.

Gabriel's Foundation of HOPE

- Award amount: varies
- Available to students living with a diagnosed disability and to immediate family members related to a person living with a disability

For more information about these scholarship opportunities visit the SBA website:

<http://spinabifidaassociation.org/scholarships/>

SBANENY INTERNSHIP PROGRAM

SBANENY is excited to announce our new internship program for individuals with Spina Bifida! The SBANENY Internship Program, funded by the William Gundry Broughton Charitable Private Foundation, is designed to provide individuals the opportunity to gain meaningful work experience in a professional setting, expand upon professional skills and enhance awareness of personal values, skills, and needs.

Here is what our first intern has to say about her experience:

"My name is Alexa Wyszomirski and I've been an intern at the Spina Bifida Association since February 2016. I have enjoyed working here because I'm learning how to apply the skills I'm learning in an office setting with other people and budget my time to complete tasks by a deadline. I'm happy that my employers help explain projects when I request it. Throughout my time so far, I've learned different responsibilities that increase my knowledge of the organization and gaining valuable employment skills."

We plan to expand this opportunity and excited to see where this program will go! Keep an eye out for future information and address any inquiries to our office.

Journey along the Erie Canal



In January 2016, Our Ability Inc. launched the New York Business Leadership Network to bridge the gap between employment opportunities in New York and candidates with disabilities. John Robinson, CEO & Managing Partner of Our Ability Inc., encourages businesses to provide employment and internship opportunities and New Yorkers to find the ability within to find meaningful employment. At SBANENY's 2016 Education Day, John Robinson spoke of his experience hand cycling 350 miles across New York State

in hopes of raising awareness about this initiative. This summer, the journey continues. Individuals with disabilities, community organizers, political leaders and historians will join together to participate or support the hand cycle ride across NYS.

On July 7, 2016 this journey will be passing through Schenectady County from Amsterdam to Niskayuna, a 28 mile ride. The SBANENY Team is planning to join in this initiative and we ask you to join us! Readers are encouraged to participate by hand cycling or showing their support at by welcoming riders at Price Chopper Headquarters. If you are interested in joining our team, contact our office at 518-399-9151 or by email casemanager@sbaneny.org. For more information on the hand cycle ride and travel schedule visit <http://www.ourability.com/journey-erie-canal>.

If you live in Central or Western New York and want to participate in ride events local to you, visit Our Ability website at <http://www.ourability.com/journey-erie-canal/> to learn when the riders will be in your area.



Toolkit for Educators is complete!

During the 2014 SBANENY sponsored conference in Albany, a discussion

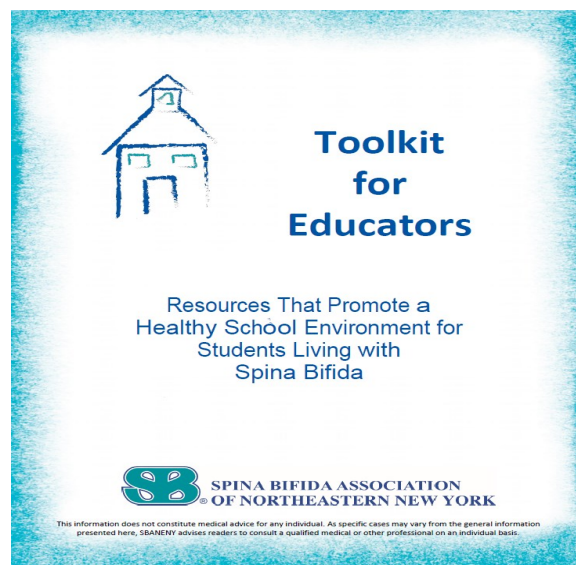
evolved over the course of the day about some of the unique educational needs that children with Spina Bifida might have. A group of people expressed interest in assisting with the development of a resource to offer to educators that would provide basic information about these needs and additional resources that might be helpful to them as they work with students with Spina Bifida.

In January a group convened to develop this resource that we have named "Toolkit for Educators." As of April 2016, this booklet is complete. We are planning to distribute this resource to school districts where we are aware of children with Spina Bifida.

If you have a school age child with Spina Bifida, please assist us by being prepared to providing us with your school's name, address, child's teacher, school nurse, and school social worker.

This resource is available for parents as well.

Thank you to the representatives of SBANENY who provided their expertise and experience to complete the project!





**SPINA BIFIDA ASSOCIATION
OF NORTHEASTERN NEW YORK**

123 Saratoga Road
Scotia, NY 12302

NONPROFIT ORG
US POSTAGE
PAID
Burnt Hills, NY
PERMIT NO. 6

RETURN SERVICE REQUESTED

***Estate Planning
Memorials
Honorariums***

Have you considered including SBANENY in your estate plans? You may also want to consider honoring or memorializing a friend or a loved one with a gift to SBANENY.



**Become a sponsor, walker,
or donate at sbaneny.org.**

ABOUT SBANENY

The mission of SBANENY is to promote the prevention of Spina Bifida and enhance the lives of all affected.

SBA of NENY serves the needs of the community of northeastern New York State.

UPCOMING EVENTS

NYC MEET & GREET EVENT

Saturday, April 23, 2016
12:00 PM- 3:00 PM
Fordham University

SBANENY

***WALK-N-ROLL FOR SPINA BIFIDA &
FAMILY & FRIENDS PICNIC***

Saturday May 21, 2016 — Mark your calendars!! Central Park, Schenectady

SBANENY MEETS OUR ABILITY

Thursday, July 7, 2016

FALL FAMILY RETREAT WEEKEND

October 21—23, 2016

***DARE TO DREAM WITH
SBANENY ANNUAL
FUNDRAISER***

Saturday, November 19, 2016

FOR MORE INFO CONTACT:

Karen Wentworth
admin@sbaneny.org
t (518)399-9151
f (518) 399-5639
sbaneny.org

***COMMITTEES TO JOIN
& Next Scheduled Meeting***

Walk-N-Roll (4/25, 7 PM)
Dare to Dream (5/10, 6:30 PM)
Board of Directors (5/14, 9 AM)
SBANENY Education Day (TBD)
Toolkits for Educators
Young Families (TBD)
Adult Group (TBD)
NYC Metro Planning Group (TBD)

SBANENY WALK-N-ROLL FOR SPINA BIFIDA 2016

Presented by The Daily Gazette



Saturday, May 21, 2016

Central Park Schenectady

Registration begins: 9:00 am

Walk begins: 10:00 am

Family & Friends Picnic 11:30 am

- Register to walk
- Start your own team
- Virtual walkers welcome

To register: Visit our website. Click on Walk-N-Roll and then on "Register Here."

To donate: Visit our website and click on general donation.

To become a sponsor: Visit our website. Click on Walk-N-Roll and then on "Become an Event Sponsor."

**Visit our website:
www.sbaneny.org**

We hope to see you there!

COMMUNITY EVENTS

Picnic & Accessible Gardening Workshop

When: Sunday May 15, 2016; 12:00pm-3:00pm

Where: Picnic pavilion at Thornden Park in Syracuse, NY

Including: Presenters on benefits of gardening, appearance from Mrs. New York Allison Trenk, and planting of accessible gardening starter kits for each family!

RSVP by April 22, 2016 to Kristen Davis

Phone: 315-464-2806

Email: daviskri@upstate.edu

*Indicate preference for a raised bed or hanging basket to be provided for your family.



Do you have what it takes
to be an Ainsley's Angel?

Ainsley's Angels of America was one of the not-for-profit vendors at our 2016 Education Day. Inspired by a young girl named Ainsley, this organization has created a race series that focuses on inclusion in endurance events. An Angel Team has one rider and one runner. Riders can use the carrier to be pushed by a rider, or push themselves in a chair.

"In addition to ensuring everyone can experience endurance events, Ainsley's Angels of America aims to build awareness about America's special needs community through inclusion in all aspects of life."

Upcoming races:

4/23 - Fox Trot 5K - South Glens Falls

5/8 - Kelly's Angels Mother Lovin' 5K - Saratoga

5/15 - SPAC Rock & Run - Saratoga

For more information contact the local Ambassador Jill Burwell

518-421-4909 / Albany@ainsleysangels.org

Ms. Wheelchair New York Night at Glennpeter Diamond Centre

- When: May 19, 2016; 5:30pm-7:30pm
- Hot and Cold hors d'oeuvres, cash bar, raffles and giveaways, games, music and more!
- Suggested donation: \$5.00
- Ms. Wheelchair NY is an advocacy and empowerment program for women who use wheelchairs. This volunteer run organization is one of 25 programs apart of Ms. Wheelchair America.
- For more information visit: <http://mswheelchairnewyork.com/>

Center for Research on Women with Disabilities (CROWD) Four-Part Webinar Series

Join the webinar series to hear from specialists in the field and ask your questions involving issues affecting women with mobility impairments. This four-part webinar series will include:

- Pelvic Health for Women with Mobility Impairments presented by Sophie Fletcher, M.D. and Margaret Nosek, PhD., April 6, 2016
- Pelvic Health Transitions for Girls with Mobility Impairments presented by Ellen Fremion, M.D., April 20, 2016
- Bladder and Bowel Issues that Affect Sexuality presented by Leanne Beers, PhD., May 4, 2016
- Access to Quality Pelvic Health Care for Women with Mobility Impairments presented by Wendy Wilkinson, J.D., May 18, 2016

For more information or registration: www.BCM.edu/crowd

