



SPINA BIFIDA ASSOCIATION OF NORTHEASTERN NEW YORK



SBANENY News to Use

CHAIR LETTER

Hello, I hope everyone is enjoying the warmer weather!

SBANENY has been very busy these last few months, especially in May. In the beginning of the month a group of five of us from SBANENY all traveled to Baltimore, Maryland to attend the Education Day sponsored by the national Spina Bifida Association. It was a jam-packed (rainy!) day with a lot of new information, innovative ideas and links to great resources.

In May SBANENY also held another successful Walk-n-Roll for Spina Bifida Presented by The Daily Gazette and led by our great Walk-N-Roll Planning Committee. We lucked out with great weather and we had more participants in the Walk-N-Roll than we ever have before. This year we also had some help with donation collection and Spina Bifida awareness from DeMarco's Restaurant. Thank you to Heather, Nicole and the entire Walk-N-Roll committee for a job very well done!

Lastly, Karen Wentworth, who has been our Executive Director and a driving force behind the growth of SBANENY has decided to retire at the end of the year. Karen has been an amazing leader; her enthusiasm and dedication to everything we do is infectious and has inspired many of us throughout the years. She will definitely be a tough act to follow for the next Executive Director!! The Board of Directors has started a committee to find and transition to the next Executive Director and we will keep everyone up to date as the process moves forward.

Best wishes for a warm, fun-filled summer!

Shelley Miller, Board Chair

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SBANENY BOARD

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MARK YOUR CALENDARS!

Upcoming SBANENY Events

Picnic & Tri-City ValleyCats Game



Enjoy a picnic and baseball game with SBANENY!

When: Wednesday, August 16, 2017

Picnic: 6:00-7:00 in the pavilion,
game at 7:00pm

Price: \$10 per person over 18, SBANENY consumers

FREE for children with Spina Bifida ages 18 and younger and their siblings thanks to the **Stewarts' Holiday Match Program!**

Contact the office for reservation and payment information!

Y-Knot Sailing at Camp Chingachgook

SBANENY is going sailing on Sunday, July 30

THIS PROGRAM THROUGH SBANENY IS CURRENTLY FULL

However, I encourage you to visit Y-Knot for free and accessible sailing! Check out the available sailing days by visiting the website: <https://yknotsailing.org/calendar/>



Fall Family Retreat at the Double H Ranch

This year, Double H is extending the Spina Bifida Family weekend to **3 days!**

Check in will be taking place on Thursday, October 26th at 5:00pm and departure will remain the same, Sunday October 29th after breakfast.

Registration forms will be available through email or our website in late summer.

Keep an eye out!



Dare to Dream with SBANENY

Live & Silent Auction

Appetizers, Desserts & Live Entertainment

November 18, 2017

6:00 to 10:00 PM

Wolferts Roost Country Club, Albany, NY

Honorary Chair Jason Gough of WNYT

There are many ways to

Dare to Dream with SBANENY!

- ◇ Become a sponsor
- ◇ Join the honorary committee
- ◇ Place an ad in the event program
- ◇ Donate an item for the silent auction
- ◇ Plan to attend Dare to Dream with SBANENY

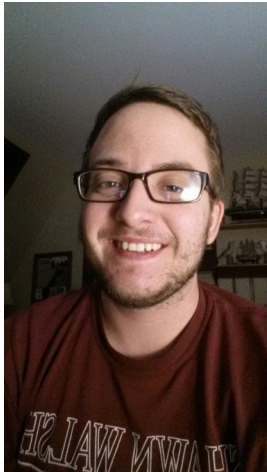
For more information, please visit our website or contact our office.

SBANENY UPDATES

Scholarship Recipients

Congratulations to the recipients of the SBANENY scholarships!

Aaron Petersen was awarded \$1,000 from the SBANENY Helen R. Mertens Educational Scholarship to assist with the cost of college tuition.



Heather Horwedel was awarded \$200 from the Frank Bucino Jr. Memorial Scholarship to assist with the cost of attending the Baltimore Education Day



Keep an eye out for the next SBANENY scholarship application period!

National SBA Education Day

On May 5, SBANENY staff, Heather Horwedel, Michelle Miller and Corrie Harting traveled to Baltimore, Maryland for a one day conference at the Kennedy Krieger Institute. The day consisted of eight informative sessions from some of the providers at the John Hopkins Spina Bifida Clinic. Topics included:

Bowel management, managing incontinence, bladder and kidney health, tethered cord and blocked shunts, aging impact on bones and joints, staying healthy, sexuality & fertility, apps & other aides helping in school and life.

Here is a highlight of just some of the healthcare information that we heard at the education day:

- It is common to find neurogenic bowel misdiagnosed as irritable bowel syndrome
- It is recommended that individuals receive periodic urodynamic and bloodwork testing to monitor kidney and bladder health
- Signs of shunt malfunction include fever, headaches, vomiting/nausea, irritability, decline in academic performance, loss of balance, and more. For more symptoms you can view the full list by visiting: <http://spinabifidaassociation.org/resource-directory/neurologic-needs-and-care/>
- Staying healthy- looking for healthy eating tips? Check out choosemyplate.gov for suggestions. Or, if you are looking to become more active, check out youtube.com for accessible and at-home work outs.



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ADAPT

ADAPT History

Reported by Julia Duff, Case Manager



On Monday June 26, I attended an ADAPT training to learn about this grassroots activist group that began in the 1970s. Historically, ADAPT is known for taking nonviolent direct action to raise public awareness about the lack of civil rights for individuals with disabilities. ADAPT is often recognized for their original protests around this time nearly 30 years ago. On July 5-6 1978, 19 people blocked three busses in Denver Colorado, immobilizing public transportation to draw attention to the lack of accessibility. Similar campaigns



continued into the 1980s and by the passage of the ADA in 1990, bus lifts were required by law. Originally, ADAPT's name was an acronym that stood for Americans Disabled for Accessible Public Transit, since the group's initial issue was to get wheelchair accessible lifts on buses. The group now stands for Americans Disabled Attendant Programs Today and continues to take action and advocate for disability rights. You may have seen the recent action that took place in Washington D.C. where nearly 60 individuals showed up to Senator Mitch McConnell's office to protest the healthcare bill that would take Medicaid away from millions. "No cuts to Medicaid! Save our Liberty!"

ADAPT Training

On Monday, Bruce Darling, CEO of Center for Disability Rights hosted an informational session at the Independent Living Center of the Hudson Valley (ILCHV) where I was joined by about 15 other advocates and members of the local Albany ADAPT chapter. The discussion focused on how to effectively plan and take action as a group. Major points included:

- The power of ADAPT comes from the collective
- The chosen issue to address should be specific, **shared** by the group, and personal
- Choose a target individual who can act on your cause—or the people who have influence on the individual
- When deciding on a course of action, start with what do

you want the outcome(s) to be, and then identify the means of achieving this.

- Select 3-5 demands that are written out to be shared
- Designate clear roles for group members during the action
- Plan an exit strategy— either one of the demands or, what are acceptable alternative outcomes?

Action Day

By the end of training Monday, we planned an action for the following day. The group decided to address the lack of an ADA Coordinator in the city of Troy and target Mayor Patrick Madden. The group drafted a press release with the demands stated, made signs to support the cause, mapped a route and entry strategy to City Hall, and designated individuals to talk to the press, police and target. That afternoon, we took to the streets chanting, "What do we need? Access! When do we need it? Now!" Upon entering City Hall, we made our way to the mayor's office where we were greeted by one of the office staff. The group began explaining the issue at hand: how inaccessibility and the lack of an ADA coordinator in Troy affects individuals with disabilities. Furthermore, how cities like Troy are legally responsible to designate a coordinator to address compliance with federal laws regarding access, including the ADA. We demanded to meet with the mayor or at least confirm a scheduled meeting. As a result, we were scheduled to meet with the mayor for Thursday, June 29th.

Meeting with the Mayor

On Thursday, we met with the mayor to discuss the accessibility issues people with disabilities experience in Troy and potential solutions. We spent one hour brainstorming with how to better meet the needs of Troy residents with disabilities. The group agreed that by including them in the city planning process and appointing someone to address ADA Coordinator duties, Troy was taking steps in the right direction. As a result of this meeting, Troy constituents and disability advocates will be meeting with the mayor and the intended person to assume the roles of an ADA coordinator on Wednesday, July 12 to continue the discussion.

Conclusion

My take away from this training was that actions speak louder than words—it is not always what you say but how you say it. Group advocacy can be very powerful and with the help of Bruce Darling, ADAPT and ILCHV I was able to learn strategies that are most effective for organizing and acting with a group. If you are interested in becoming more active as an advocate and have the opportunity to attend an ADAPT training, I would definitely recommend it!

STAYING ACTIVE

Accessible Hiking

John Dillon park is a fully accessible wilderness facility located in the beautiful Adirondacks of northern New York. The park has fully accessible trails, lean-tos and other services to accommodate people with all types of disabilities. Stop by the park and see how Paul Smith College and International Paper have made this idea a reality.

Questions?

Visit their website or call their office!

<http://www.paulsmiths.edu/johndillonpark/>

518-524-6226



Student Committee Encourages Inclusion, Tolerance

Lee Coleman published an article in the Daily Gazette in March about the Youth Activation Committee at Stillwater High School. The committee was created to encourage the student body to support an inclusive basketball team for **all students**. The unified team will practice, compete in games, playoffs and championships.

According to Special Olympics New York, the goal of the committee is “authentic social inclusion where learning happens through meaningful social, recreational, and extracurricular opportunities providing for respect and dignity for all.” Stillwater High School has created a committee that is facilitated by a school counselor, all of which have attended a conference on how to “educate, motivate, and activate youth to become agents of change in their communities through advocacy for respect, inclusion, and acceptance of all people.” The committee is now taking action at school by promoting the sporting events at school to energize students to attend games and demonstrate their support.

This new committee is part of a program created by the New York State Public High School Athletic Association and Special Olympics New York to encourage unified sports across the state. Coleman, L. (2017, March). Student committee encourages inclusion, tolerance. *Southern Saratoga Magazine*. 23-24.

Collar City Ramble

September 23, 2017 | 9:00 AM to 2:00 PM

Its time to RAMBLE! Tour Troy's urban trails by foot, bicycle, water, GPS, or whatever in this alternate transportation festival – discover places you have never seen! The Collar City Ramble covers Troy in ways that anyone can find to enjoy. Explore the historical, the undeveloped, the water, the hidden treasure, and the urban areas with a tour group or independently with materials from the booth. Event includes walking and biking group tours and self-guided tours, kayak rides, bike safety classes and even a geocaching expedition!

Events are FREE unless otherwise indicated.

Save the date and watch for a full schedule of events!



Still planning a summer vacation?

Morgan's Inspiration Island is opening in San Antonio, Texas. This is a first-of-its-kind splash park designed to accommodate people with various special needs. The water park features five play areas with pools, geysers, jets, water cannons and more! The new park is located adjacent to Morgan's Wonderland, a fully-accessible 25-acre theme park that opened in 2010.

Read the full article here: <https://www.disabilityscoop.com/2017/06/15/water-park-special-needs-open/23817/>



NEWS TO USE

The Songs of Love Foundation

The Songs of Love Foundation is a nonprofit 501(c)(3) organization dedicated to providing personalized uplifting songs, free of charge, for children and teens currently facing tough medical, physical or emotional challenges. Through their service, Songs of Love strives to improve the mental and emotional health of not only that child, but also his or her family. Often, families report that they see their child responding, smiling and laughing for the first time in months.

More than 27,000 songs of love have been created for as many children world-wide since the organization's inception in 1996. Every song is 100% original and tailor-made based on the child's interests and favorite music. Each song is professionally produced in approximately 4-6 weeks and recorded onto a CD with printed lyrics as a keepsake; mp3 files are also available.

Requesting a Song of Love is easy! Visit <https://www.songsoflove.org/request/> to request a song electronically or by printing a form that you can fax or send to us by mail. Check out two of the children who already received their song!



ADVOCACY

The June issue of **National Disability Institute's Washington Insider** gives an update on the fight to save Medicaid. Contents include:

- ◇ The Current Threat to Medicaid
- ◇ How to Find Your Senators
- ◇ How to Communicate with Your Senators
- ◇ Share Your Story
- ◇ My Medicaid Story: Testimony from

Chris Rodriguez

Find this important and informative article by visiting this website—http://www.realeconomicimpact.org/newsletters/wash_insider_june_2017.html#1

Are you trying to [stay informed about the latest healthcare developments](#) and how this will impact constituents in NYS? The **NYS Health Foundation's New York Health Reform Watch** offers current information and analyses of what is taking place on state and national levels. Visit their page for up-to-date developments and resources: <http://nyshealthfoundation.org/resources-and-reports/new-york-health-reform-watch-2017>

Share your voice!

On July 25-27, 2017 representatives from the United States Department of Health and Human Services, Substance Abuse and Mental Health Services Administration (SAMHSA), Center for Mental Health Services (CMHS), Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program will visit Disability Rights New York, the Protection and Advocacy system for the state of New York, in Albany.

[SAMHSA/CMHS invites you to send written comments about the PAIMI Program services and activities conducted by Disability Rights New York.](#)

Please email your comments to
PAIMI@samhsa.hhs.gov

Toolkit for Educators

Last summer we shared our *Toolkit for Educators* with school districts where we believed there was a student with Spina Bifida. The Toolkit was created as a resource for educators, providing basic information about the unique educational needs of children with Spina Bifida and provide resources that may be helpful as they work with these students. Toolkits were sent to Superintendents and Special Education Department Chairs.

Parents of children 1-18 were also sent the *Toolkit for Educators*. In addition, they were given a *Parent Supplement*. The supplement was created to offer support and information to parents throughout their child's school years. The packet provides a general overview of the special education experience and process for a parent of a child with Spina Bifida.

Did you receive yours Toolkit & Parent Supplement? Do you need additional copies? Contact the office!

SBANENY Peer Support Network

Peer support is a service we are able to facilitate because of the willingness of adults and families to support others. SBANENY has been able to connect parents and adults with each other to share information and experiences as a way to provide support. We are now taking steps to create a list of individuals who are interested in being peer support volunteers to improve the facilitation process.

Many of people have already confirmed their willingness to connect with other adults or parents via phone or email and this is greatly appreciated. If you are interested in being included on this list or have additional questions about peer support, please email casemanager@sbaneny.org or call the office—518-399-9151.

SBANENY will still continue to follow the same procedures by asking individual permission before facilitating any connections.

ILCHV PROGRAMS

Disability Empowered Women's Wellness Series Kickoff

When: July 26th at 5:30pm

Where: ILCHV, 15-17 3rd St Troy

Enhance your self-esteem and explore your sensual side with Affirmative Music & Movement for Women of all shapes, sizes, abilities, backgrounds, and ages 18+. You will learn mindfulness and body-positive techniques to incorporate into your daily life to increase confidence and vitality.

Stephanie Marie Fox, owner of Foxy Trot Dance, recognizes that most people are deficient in "Vitamin M": music, movement and meaningful connections. Stephanie empowers individuals to experience the joys of dance and drawing from her vast experience of 10 years as a dance instructor, storyteller and Iroquois Studies educator.

RSVP by July 24th to Shameka Andrews at sandrews@ilchv.org or 274-0701



I Am Able: What I Love About Me

A workshop using fiber collage, printmaking, painting, and stenciling to create works of art. Presented by Jeanne Thomma with Independent Living Center of the Hudson Valley, Inc.

Participate in a three week class to learn to use a variety of artistic materials. Participants will create two pieces of art; one for the assemblage at ILCHV and one to keep.

When: August 8, 15, & 22 from 5:30-7:30 with refreshments available from 5-5:30.

Where: Independent Living Center of the Hudson Valley: 15-17 3rd St., Troy, NY 12180

No formal experience required and all materials will be provided at no cost.

You must RSVP to participate. Contact Barbara Devore at 518-274-0701 or bdevore@ilchv.org no later than July 24, 2017 to ask questions and participate in this opportunity!

SBANENY Walk-N-Roll for Spina Bifida

Presented by The Daily Gazette



Thank you to the Walk-N-Roll committee, individuals, families, friends, providers, volunteers and legislators who helped make this year's event a success!

Enjoy more pictures on www.sbaneny.org or facebook.com/SBANENY



THANK YOU to this year's SBANENY Walk-N-Roll for Spina Bifida Sponsors



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"Brother" Lou Roberts



Bronze Sponsors

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***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.

Memorial forms are available. Please contact our office.



**Become a sponsor, plan to attend,
or donate at sbaneny.org.**

ABOUT SBANENY

Our purpose is

*Support
Health & Wellness
Awareness
Respect & Dignity
Empowerment*

UPCOMING EVENTS

TRI-CITY VALLEYCATS

Picnic and baseball game
August 16, 2017
Joe Bruno Stadium

FALL FAMILY RETREAT

October 26—October 29 2017
Double H Ranch

***DARE TO DREAM WITH
SBANENY***

Saturday, November 18, 2017
Wolferts Roost Country Club

COMMITTEE MEETINGS

Board Development— TBD
Fundraising & Marketing— 7/31
Walk-N-Roll— January 2018
Dare to Dream with SBANENY—
8/8/17
Board of Directors—9/9/17
Education Day 2018 —TBD

FOR MORE INFO:

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Call us toll free: 855-722-6369

COMMITTEES TO JOIN

Walk-N-Roll
Dare to Dream with SBANENY
SBANENY Education Day
Young Families
Adult Group
NYC Metro Planning Group
Fundraising & Marketing

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