



## SPINA BIFIDA ASSOCIATION OF NORTHEASTERN NEW YORK



### SBANENY News to Use

#### CHAIR LETTER

SBANENY is successful in so many ways! We had a very successful Walk-N-Roll at Schenectady's Central Park on May 2<sup>nd</sup>. There were a record number of participants, vendors and sponsors for the event. Perhaps most importantly the large number of participants allowed for an increased number of connections, conversations, and sharing between those at the event. It is always a relief when we can hear common concerns, solutions to common problems, and identify new available resources. The Walk-N-Roll Committee and the Board of Directors were very pleased and proud of the results of the event. Next year's Walk-N-Roll will be Saturday, May 21<sup>st</sup>, again at Schenectady's Central Park. Put it on your calendar and start forming your teams! Make sure that you join us to share in the FUN and watch for the New Logo.

I continue to be so very impressed with the dedicated SBANENY staff and volunteers. Our chapter is successful only due to their continuing efforts. On top of a successful Walk-N-Roll, we also have an active planning committee meeting to organize our Dare to Dream Fundraiser Auction Gala on November 21<sup>st</sup> at the Colonie Country Club in Voorheesville. Last year's event was a lot of fun and the committee is making it even better this year! Please mark your calendars, watch our website ([sbaneny.org](http://sbaneny.org)) for updates, and join us with your friends at the event.

Another Board Member and I are looking forward to attending a regional weekend leadership conference in Louisville Kentucky this month. We will be able to collect information on what other chapters are doing and perhaps bring back some new ideas. As was true with the Walk-N-Roll, it is great to make new connections, share solutions and resources. One of the ways that SBANENY supports those in our region is to offer scholarships, so that you can attend conferences also. Please contact our office at (855) 722-6369 or locally at (518) 399-9151 for further information.

*Jim Dunham*  
Chapter Chair

**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.

#### ISSUE #64 JULY 2015

Adult Summer Picnic  
Positively Playful Family Event  
Scholarship Awarded  
Spina Bifida Fall Family Weekend  
Supported Employment Services  
Kids Wish Network  
Accessibility Survey  
Adaptive Recreation  
Fit-In Conference  
Dare to Dream with SBANENY  
Walk-N-Roll for Spina Bifida 2015

#### SBANENY BOARD

**Chair:** James Dunham  
**Vice Chair:** Lyndsi Holmes-Wickert  
**Past Chair:** Kevin Chamberlain  
**Treasurer:** Heather Green  
**Secretary:** Michelle Miller  
**Directors:**  
Raymond Langelier  
Margaret Smith  
Peggy Felt

**Executive Director**  
Karen Wentworth

## ADULTS...



## PICNIC...



## & STRESS MANAGEMENT!

## ADULT GROUP SUMMER PICNIC

DATE: Saturday, August 15, 2015

TIME: 3:30 to 5:30 PM

WHERE: The Gathering Room at The Crossings

580 Albany Shaker Road, Loudonville, NY

WHO: Adults with Spina Bifida

WHAT: Picnic will be combined with a Stress Management Workshop.

Bring tips & tools to share with others! Picnic food will be provided.

FEE: SBANENY is covering the cost of the event. It is free to attend!

RSVP by August 12th to

Shameka at [mwny2006@yahoo.com](mailto:mwny2006@yahoo.com) or 518-432-3202

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*Would you like join the Adult Program Planning Group?  
Contact our office for information.*

## YOUNG FAMILIES....



## HIPPOTHERAPY & ADAPTIVE RIDING

GROOMING, FEEDING &  
EXPOSURE TO HORSES!

FOOD, FUN, & FRIENDS!

SAVE THE DATE!

## POSITIVELY PLAYFUL EVENT! FOR FAMILIES WITH CHILDREN (UNDER 18) WITH SPINA BIFIDA

DATE: Saturday, August 22, 2015 (Raindate August 29th)

TIME: 2 to 4 PM

WHERE: Positively Playful Occupational Therapy!

118 Hurst Road, Delmar, NY

WHO: Under 18 children with Spina Bifida, & their immediate family  
(Siblings are included!)

WHAT: Hippotherapy, adaptive riding, grooming & feeding horses.

Picnic food will be provided.

FEE: SBANENY is covering the cost of the event. It is free to attend!

RSVP by August 14th to [admin@sbaneny.org](mailto:admin@sbaneny.org) or 518-399-9151

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*Do you have ideas of programs you would like to see?  
Would you like to be involved with planning programs for  
families? Please contact our office?*

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# SCHOLARSHIPS AWARDED

## Frank Bucino Jr. Memorial Scholarship

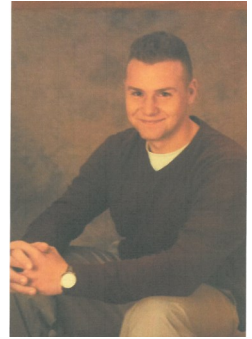


Samuel Rivers of Lowville has been awarded the 2015 scholarship of \$1,000. Sam will be attending Jefferson Community College for Computer Science in the fall.

**Frank Bucino Scholarship Fundraiser**  
Clarks Shurfine Food in Dryden, NY  
Wednesday, August 12th,  
11:30 AM to 6 PM  
Please stop in!

## Helen R. Mertens Educational Scholarship

Joseph Nuzzi of Burnt Hills has been awarded the 2015 scholarship of \$1,000. Joe will be attending Hudson Valley Community College for Human Services this fall.



*Congratulations and best wishes to both scholarship recipients in their new educational endeavors!*

*SBANENY sponsors two scholarship funds intended to support and encourage educational pursuits including higher education, technical training, driver education, and attendance at Spina Bifida conferences.*



## SPINA BIFIDA FALL FAMILY WEEKEND

DATE: Friday evening, October 23rd through Sunday October 25th at noon

WHERE: Double H Ranch, 97 Hidden Valley Road, Lake Luzerne, NY  
(about 1 hour north of Albany)

WHO: Children ages 5 to 21 who have Spina Bifida and their immediate families

WHAT: A weekend of Serious Fun! Campfires & songs, high ropes, arts & crafts, fishing, pumpkin carving, Halloween party, food and more food combined with conversation and laughter.

Bring tips & tools to share with others! Picnic food will be provided.

FEE: There is no fee to attend Double H Programming.

Advanced registration is required. We anticipate forms becoming available in late August. Please watch your email for details. Register early! This program usually reaches capacity and some families are wait listed.



## HOW WOULD YOU LIKE TO BE INVOLVED? HERE ARE SOME ADDITIONAL OPTIONS FOR YOU AND YOUR FAMILY...

- ⇒ **Metro NY Support Group Planning Committee** — Planning by conference call.
- ⇒ **Tool Kits for Educators & Families Project** — In person meetings with conference call available. Anticipate 3 more meetings bi-monthly for the first stage of the project.
- ⇒ **Fundraising & Marketing Committee** — Committee that looks at the overall chapter strategies for fundraising and marketing and reports their recommendations to the Board of Directors.

**Which activity is a good fit for you? Let us know!**



## OPWDD SUPPORTED EMPLOYMENT SERVICES

### Enhanced Supported Employment Pilot Project (ESEMP) –

ESEMP is designed to demonstrate that motivated individuals who may need high levels of support can successfully work in regular jobs in the community. Enhanced services may include person-centered vocational planning, customized job development, individualized job coaching, travel training and transportation assistance, behavioral interventions and supports, personal assistance and other supports customized to the individual's needs.

### Employment Training Program (ETP)

ETP offers individuals an opportunity to work in an internship that will lead to permanent employment in a community business. During the internship, wages will be paid through ETP while the individual learns the skills needed for the job. ETP participants also attend job readiness classes that present topics such as conflict resolution and how to dress for work. ETP services include increased job development and job coaching as well as assistance with other employability skills.

### Supported Employment (SEMP) –

SEMP provides the supports individuals need to obtain and maintain paid competitive jobs in the community. Individuals with developmental disabilities will typically transition to SEMP after they have received supported employment services funded by the NYS Adult Career and Continuing Education Services-Vocational Rehabilitation (ACCES-VR) and require limited job coaching to successfully maintain their employment. Individuals also come to supported employment from programs that offer intensive training such as ESEMP and ETP.

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*Have questions about Social Security disability benefits, how going back to work may affect your benefits, or how to appeal a decision? Check out Disability.gov's "Guide to Disability Benefits."*

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## KIDS WISH NETWORK

Kids Wish Network is a national charitable organization dedicated to infusing hope, creating happy memories, and improving the quality of life for children having experienced life-altering situations. Kids Wish Network assists children and their families through several key programs. Visit our website for more information [www.kidswishnetwork.org](http://www.kidswishnetwork.org).

Anyone can refer a wish kid. Here are a few guidelines in order for a child to begin the process of applying to Kids Wish program:

1. The child has to have a life-threatening condition
2. The child has to be between the ages of 3 to 18
3. The child has to communicate verbally or non-verbally via sign language, with pictures, electronic device, switch, etc.

More information as well as referral forms are available through the website at [kidswishnetwork.org](http://kidswishnetwork.org).



Office for People With  
Developmental Disabilities

## ACCESSIBILITY OF ACCOMMODATION FACILITIES

Dr. Lauren Lieberman and Ozkan Tutuncu from Department of Kinesiology, Sport Studies, and Physical Education at the College at Brockport, SUNY are conducting a study to determine the accessibility of accommodation facilities with the life experiences of people with disabilities. The study involves a questionnaire for people with disabilities, their families and traveling companions. It takes about 10 minutes to complete the questionnaire. Results are expected to help improve the accessibility of tourism facilities.

The link for the questionnaire is: <http://www.gumus.com/survey/>



## Second annual "Fit-In" Conference! ACTIVATING COMMUNITIES: Grassroots Inclusive Fitness in Central NY

**When:** 9-4, Friday October 9, 2014

**Where:** 415 W. Fayette Street, Syracuse

**To Register:** Contact Regina McConnell at 464-7561 or [Mcconner@upstate.edu](mailto:Mcconner@upstate.edu).

**Who:** This inter-disciplinary conference is for athletes (with and without disabilities), families, high school students, community leaders, professionals in sports media, adapted physical education, physical therapy, occupational therapy, dance, pediatrics, physical medicine and rehabilitation, public health, urban planning, and anyone who has an interest in adapted sports and inclusive fitness.

**Why:** Learn, network, advocate for inclusive fitness in Central New York.

*The Fit-In Conference is brought to you by SUNY Upstate Medical University Foundation/Golisano Children's Hospital; SUNY Upstate's Physical Therapy Program; SUNY Upstate's Department of Physical Medicine and Rehabilitation, SUNY Cortland Department of Adapted Physical Education; and Syracuse University's Burton Blatt Institute, David B. Falk College of Sport and Human Dynamics, the School of Education, the Lerner Center for Public Health Promotion at the Maxwell School, and LaCasita Cultural Center.*

## ADAPTIVE RECREATION EXPERIENCES

**Sponsored by**  
**Sunnyview Rehabilitation Hospital Therapeutic Recreation Department**

### Adaptive Recreation Exploration Day

Come see about all the great programs you could join.

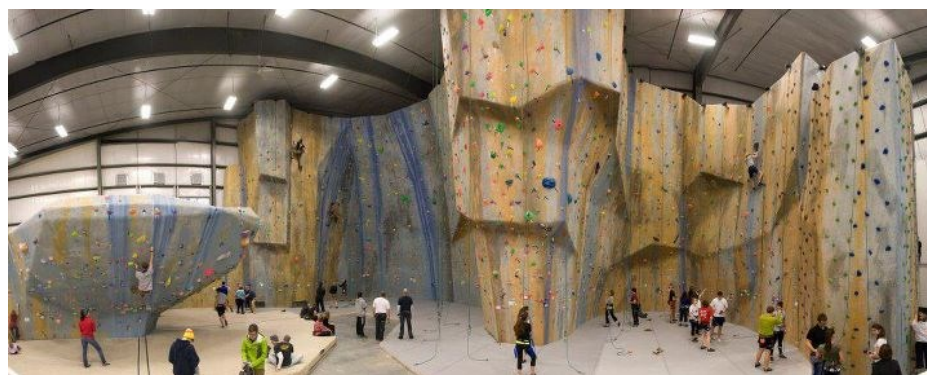
Saturday, August 15

10 AM to 2 PM

Southern Saratoga YMCA

1 Wall Street, Clifton Park, NY 12065

Join Sunnyview, Southern Saratoga YMCA, and other organizations/agencies from throughout the Capital District that offer adaptive programs and equipment for recreational pursuits. Information tables as well as some hands on demonstrations from a variety of programs will be available. No registration or fee is required to attend.



### Adaptive Rock Wall Climbing

*Ready to try something new and exciting?*

Saturday, November 14 or January 9, 2016

9 AM

The Edge of Half Moon

With the use of specialized harnesses, some adaptive equipment and a little assistance, you can climb even if you have limited arm or leg use. Instructed by Sunnyview therapists and experienced rock wall experts, most participants will be able to try to scale a wall.

For questions or registration, please contact the Therapeutic Recreation Department at (518) 382-4576 or by email at [Connie.Todt@sphp.com](mailto:Connie.Todt@sphp.com).

### LOVE SOMEONE WITH SPINA BIFIDA?



*"I love someone with Spina Bifida." long sleeve t-shirts are available in blue or black, adult and youth sizes, for \$10 each plus shipping. Check it out online or contact our office to place your order!*



# Gala Live & Silent Auction Fundraiser!

**Dare to Dream with SBANENY**

**Save the Date!**

Saturday, November 21, 2015  
6:00 to 10:00 PM  
Colonie Country Club  
141 Maple Road, Route 85A, Voorheesville, NY

Music by Fresh of Albany  
Magic by Matt Episcopo  
Live & Silent Auction

Appetizers by Ruggiero's Catering  
Desserts by local restaurants  
Cash Bar



## Honorary Chairs

**Tom Wilson & Kristin Koehler**

**Gold Sponsors Bill & Shelly Socha**

*Would you like to join the Dare to Dream planning committee? There are monthly meetings that you can attend in person or by conference call. The next meeting will be Tuesday, July 28th at 7 PM. We hope to see or hear from you then!*



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



Cure Twist™



Cure Medical®  
Pocket Catheter



Cure Catheter®  
regular & new  
hydrophilic



Cure Catheter®  
Closed System

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 nor 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](http://www.curemedical.com).

\* 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.





## SBANENY WALK-N-ROLL FOR SPINA BIFIDA 2015

*It was a picture perfect day!*



*Mark your calendars! SBANENY Walk-N-Roll for Spina Bifida is already scheduled for Saturday, May 21, 2016! Would you like to join the group of people who make this terrific event possible? Let us know!*







**SPINA BIFIDA ASSOCIATION  
OF NORTHEASTERN NEW YORK**

123 Saratoga Road  
Scotia, NY 12302

RETURN SERVICE REQUESTED

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US POSTAGE  
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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.*

**Gala  
Live & Silent Auction  
Fundraiser!  
Dare to Dream with  
SBANENY**

**Become a sponsor,  
purchase admission,  
or donate at [sbaneny.org](http://sbaneny.org).**

**ABOUT SBANENY**

*The mission of SBA of NENY 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**

***ADULT SUMMER PICNIC***

Saturday, August 15

***POSITIVELY PLAYFUL FAMILY  
EVENT***

Saturday, August 22

***FALL FAMILY RETREAT WEEKEND***

October 23rd—25th, Double H Ranch, Lake Luzerne, NY. Registrations will be available at the end of the summer.

***DARE TO DREAM WITH SBANENY***

Saturday, November 21st at Colonie Country Club. Gala fundraising event including live & silent auctions.

***SPINA BIFIDA CONFERENCE 2016***

Spring 2016 — Date to be announced.

***WALK-N-ROLL FOR SPINA BIFIDA***

***FAMILY & FRIENDS PICNIC***

May 21, 2016 — Mark your calendars!!

***PROGRAMS TO BE ANNOUNCED —  
WATCH FOR FLYERS!***

Metro NYC Program

***COMMITTEE MEETINGS***

**Walk-N-Roll:** Late fall

**Dare to Dream:** July 28, 7 PM

**Board of Directors:** 9/19, 9AM— 2PM

**SBANENY Conference—August TBD**

**Toolkits for Education — TBD**

**Young Families — TBD**

**Adult Group — TBD**

**FOR MORE INFO CONTACT:**

Karen Wentworth

[admin@sbaneny.org](mailto:admin@sbaneny.org)

t (518)399-9151

f (518) 399-5639

[sbaneny.org](http://sbaneny.org)