



## SBANENY News to Use

### CHAIR LETTER

Hello and happy New Year!

My name is Michelle (Shelley) Miller and I am proud to assume the role of Board Chair for 2017. I have been involved with SBANENY for the last few years, starting with participating in the Walk-N-Roll and then joining the Board of Directors as Secretary in 2013. Most recently, I was the vice-chair of the Board for 2016 as well as the Committee Chair for last year's Dare to Dream with SBANENY.

This past September the Board of Directors focused on developing a values statement for our organization. This values statement is in addition to the SBA mission of promoting the prevention of Spina Bifida and enhancing the lives of all affected. The values statement is what we as an organization feel is most important. I am happy to announce what we came up with: Our purpose is:

**Support**

**Health & Wellness**

**Awareness**

**Respect & Dignity**

**Empowerment**

You will start to see our value statement in future communications, SBANENY signs, t-shirts, on our website, and Facebook.

In November we held our annual fundraiser, Dare to Dream with SBANENY and it was a huge success! There was entertainment, food, a live auction and "Spin to Win" where individuals who do not typically use a wheelchair were given the chance to experience something new. There was a prize raffle for all who participated.

The Board of Directors continue to work toward building relationships within the surrounding communities to help further our ability to continue & improve programming and outreach. We are always looking for volunteers so if you see something in this newsletter that you would like to become involved in the planning of or increase your participation in, please feel free to contact Karen Wentworth or Julia Duff in the office.

Thank you for your ongoing support of SBANENY. I'll see you at our next event!

Shelley Miller, Board Chair

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### ISSUE #70 JANUARY 2017

Chair Letter

Upcoming Events

SBANENY News

Double H Ranch

Beyond All Limits Video Contest

Dare to Dream with SBANENY

Dare to Dream with SBANENY  
Sponsors

Scholarships

Events & Committees

### SBANENY BOARD

**Chair:** Michelle Miller

**Vice Chair:** Margaret Smith

**Past Chair:** Lyndsi Holmes-Wickert

**Treasurer:** James Alescio

**Secretary:** Peggy Felt

**Directors:**

Kevin Chamberlain

James Dunham

Peggy Felt

Annmarie Fennicks

Margaret Huff

**Executive Director**

Karen Wentworth

# KEEPING BUSY THIS WINTER



## ATTEND A CONFERENCE

### Recipe for Success Conference 2017

**Tuesday, March 14, 2017**

**8:00 am – 1:30 pm**

**University at Albany**

An interactive conference focused on preparing for the transition to college, designed for high school students with disabilities and their parents.

Lunch & parking available for free.

Contact the SUNY Albany DRC Office  
for more information: 518-442-5490

## TELL YOUR DOCTOR TO ATTEND!

Third World Congress on Spina Bifida Research and Care

Loews Coronado Bay Resort in Coronado, California

March 16-19, 2017

The Third World Congress on Spina Bifida Research and Care will feature research on the latest in treatment and prevention of Spina Bifida. Doctors, nurses, clinicians, and other healthcare professionals should attend.

*For more information:*

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

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## ADAPTIVE SPORTS PROGRAMS

**Double H Ranch**

- Adaptive Skiing
- 6-16 year olds
- January—March
- <http://www.doublehbranch.org/programs/winter/criteria/>

**Helen Hayes**

- Snow Skiing, Sled Hockey
- Individuals with disabilities
- Four season programming
- <http://helenhayeshospital.org/adapted-sports-recreation/>

**Adaptive Sports Foundation**

- Skiing & Snowboarding
- 5 years + with a disability
- Windham Mountain
- <http://www.adaptivesportsfoundation.org/programs/winter-programs/>

**STRIDE Adaptive Sports**

- Skiing, Sled Hockey, Swimming & Tennis
- 4 years + physical or cognitive disability
- <http://www.stride.org/sports/>

## JOIN A COMMITTEE

SBANENY is seeking new members to join us in planning and preparing for our programs and events. Here is a list of active committees where we could always use extra help!

- Regional Education Day Planning Committee  
(**FIRST MEETING IN FEBRUARY**)
- Walk-N-Roll Planning Committee  
(**NEXT MEETING Tuesday 2/7/17**)
- Dare to Dream with SBANENY Planning Committee  
(**NEXT MEETING TBA in February**)
- Program Planning Committee
- Young Family Activities & Programs Planning Committee

### **Who?**

**Adults, teens, family members, friends...** all are welcome!

**Planners & schemers**— idea people! Brainstorm and come up with creative ideas for the event.

**Worker bees**— complete needed tasks prior to the event

*Committee members meet once per month for 1.5 hours.  
Snacks and drinks are provided for the meetings.*

Join one of our friendly & energetic groups for the opportunity to meet other people in the community, become more actively involved, for a sense of accomplishment on the day of the event, and even to build your resume!

**Contact our office to join & for more information!!**

## NEWS TO USE

### [Using data to protect babies born with Spina Bifida](#)

#### **A new treatment plan has been designed for babies born with Spina Bifida to protect their kidneys!**

Complications associated with Spina Bifida can lead to severe kidney problems. CDC research suggests individuals with Spina Bifida develop kidney failure at a younger age than individuals without. This study aims to help identify how and when to intervene to protect the babies' kidneys. The data collected and analyzed will help to determine a new "best practice" standard of care for babies born with Spina Bifida.

Find more information on the research, what parents should know, and the urological protocol for healthcare professionals by visiting this link!

<https://www.cdc.gov/features/spina-bifida-data/index.html>

## TAX REFUND DELAYS

**If you are claiming the Earned Income Tax Credit or Additional Child Tax Credit, due to a new law, the IRS is required to hold refunds until February 15, 2017.** Therefore, individuals may not receive their actual refund until the week of February 27. The IRS Commissioner, John Koskinen states that, "For this tax season, it's more important than ever for taxpayers to plan ahead."

For tips on preparing for refund delays and filing taxes, visit [www.irs.gov](http://www.irs.gov).

## FREE TAX PREP

The Volunteer Income Tax Assistance (VITA) program offers free tax help to people with disabilities who need assistance in preparing their own tax returns. IRS-certified volunteers provide free basic income tax return preparation with electronic filing to qualified individuals.

Visit this link to find a VITA location near you:

<https://www.irs.gov/individuals/free-tax-return-preparation-for-you-by-volunteers>

## SOCIAL SECURITY

In December, Social Security launched a new service for my Social Security account holders where the public can check on the status of an application for benefits or an appeal filed.

This new addition to the my Social Security suite of services will provide detailed information about retirement, disability, survivors, Medicare, and SSI claims and appeals filed either online at [socialsecurity.gov](http://socialsecurity.gov) or with a Social Security employee.

Individuals can still check the status of their benefit applications by phone, by calling 1-800-772-1213, and providing the confirmation number they received when they filed their claim.

## MOBILITY WORKS



Are you thinking about purchasing a wheelchair accessible vehicle?

Mobility Works created a free guide with 7 ways to fund your accessible vehicle. Visit the link to download your free guide today.

<http://go.pardot.com/l/67872/2016-03-02/5wc3s8>

Also, visit [mobilityworks.com](http://mobilityworks.com) to see what grants and financial resources exist in your area!

## VISITABILITY TAX CREDIT

Is your home universally visitable? Or are you making modifications in order to do so?

You may be eligible for a tax credit up to \$2,750!

Universal visitability modifications require, among other things, at least one wheelchair-accessible entrance at ground level, at least one accessible bathroom on the same floor as the entrance, and doors and doorways with a minimum 32" clearance. For modifications of an existing residence, the tax credit will be 50% of the cost of modifications, to a maximum of \$2,750.

Read more about this legislation by visiting [www.nysenate.gov](http://www.nysenate.gov) and search for Senate Bill S2967A



**FALL  
FAMILY  
WEEKEND  
DOUBLE H  
RANCH  
2016**



**★ BEYOND ALL LIMITS VIDEO CONTEST ★**

During our trip to Double H Ranch, SBANENY videoed new clips and compiled old material to submit for the 2016 #BeyondAllLimits Video Contest hosted by the National SBA. The chapter with the most YouTube views would be awarded two scholarships to the 2018 National Conference and...



**SBANENY WON!!**



Check out the video here: [https://www.youtube.com/watch?v=urr\\_8GV43pg](https://www.youtube.com/watch?v=urr_8GV43pg)





Wheelchair experience



Spin to win

# DARE TO DREAM WITH SBANENY 2016



Thank you  
Honorary Chairs

Richard & Theresa Sleasman



Thank you

JD Fielding Photography!

## THANK YOU...

To the committee members, volunteers, donors, sponsors and guests of Dare to Dream with SBANENY! We look forward to celebrating with you all again next year.



You Make A  
Difference Award  
recipient  
Double H Ranch

Thank you  
Fresh!



Dare to Dream  
with SBANENY  
Committee



Silent Auction



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## 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.

OR

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

### 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.

*For further information, guidelines, & applications go to our chapter website at [www.sbaneny.org](http://www.sbaneny.org) or contact our office. The deadline for scholarship application submission and all supporting materials is March 1, 2017!*



**SPINA BIFIDA ASSOCIATION  
OF NORTHEASTERN NEW YORK**

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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.*



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

**UPCOMING EVENTS**

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

Saturday, May 20, 2017  
Central Park, Schenectady

***FALL FAMILY RETREAT***

October 26—October 29 2017  
Double H Ranch

***WATCH FOR FLYERS!***

***COMMITTEE MEETINGS***

**Walk-N-Roll—January 3, 2017  
Conference—February, 2017  
Dare to Dream with SBANENY  
February TBA**

***COMMITTEES TO JOIN***

**Walk-N-Roll  
Dare to Dream with SBANENY  
SBANENY Conference  
Young Families  
Adult Group  
NYC Metro Planning Group**

**ABOUT SBANENY**

*Our purpose is*

*Support*

*Health & Wellness*

*Awareness*

*Respect & Dignity*

*Empowerment*

**FOR MORE INFO CONTACT:**

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[facebook.com.sbaneny](https://facebook.com/sbaneny)



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to SBANENY as you  
Dare to Dream  
for the consumers  
that you serve!”*



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