



SBANENY News to Use

CHAIR LETTER

Happy Fall!

I hope everyone had a great summer! The chill is back in the air and that means fall is here. The next few months are extremely busy at the Spina Bifida Association of Northeastern New York (SBANENY) and we hope that you join us for many of the activities we have going on.

October is Spina Bifida awareness month and we hope that you use this as an opportunity to not only educate your family and friends on Spina Bifida, but you help us do so as well. At the end of the month is our Fall Family Weekend. From October 21st-23rd, families of children with Spina Bifida between the ages of 5 & 21 come together at Double H Ranch, a camp in the Adirondacks, for a weekend of fun, relaxation and building connections. Double H has graciously hosted this weekend for over 10 years free of charge. Every year proves to be a great time with fun had by all. If you have not registered for this year, we encourage you to do so soon. There are limited openings left. If not, make a note of it for the weekend in 2017.

Speaking of Double H, on Saturday, November 19th SBANENY will be hosting its annual Dare to Dream with SBANENY celebration fundraiser at Wolferts Roost Country Club from 6-10pm. We will be honoring Max Yurenda, CEO of the Double H Ranch and his team. This event is a great opportunity to not only come and support SBANENY and allow it to keep doing work in the community, but is also a chance to recognize the great work Max and his team have done for our community. Whether you are a former or present camper, counselor, volunteer or family member associated with Double H, or want to support SBANENY and the work it does, or both!, please consider joining us for this fun event! Your support is greatly appreciated.

As always, in this newsletter we have information about events going on in the community. If you are interested in attending, or helping to plan future events, we welcome everyone's assistance and input in order to put on the best events possible.

Lyndsi Holmes-Wickert, Board Chair

ISSUE #69 OCTOBER 2016

Chair letter

**Dare to Dream with SBANENY
Annual Fundraiser**

Spina Bifida Awareness Month

Upcoming Events

**Live & Silent Auction
Sneak Preview**

SBANENY Updates

Staying Informed

Disability Tips

Calendar of Events

SBANENY BOARD

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Treasurer: Heather Green

Secretary: Margaret Smith

Directors:

James Alescio

Peggy Felt

Annmarie Fennicks

Margaret Huff

Executive Director

Karen Wentworth



Dare to Dream

with SBANENY



Live & Silent Auction
Appetizers, Dessert & Entertainment

November 19, 2016

6:00 - 10:00 p.m.

Wolferts Roost Country Club
120 Van Rensselaer Blvd., Albany, NY 12204



Honorary Chairs Richard & Theresa Sleasman, CBRE-Albany



Honoree: Max Yurenda, Double H Ranch

All proceeds from *Dare to Dream with SBANENY*
support the programs and services of
Spina Bifida Association of Northeastern New York.

To purchase tickets, visit our website sbaneny.org

 **SPINA BIFIDA ASSOCIATION
OF NORTHEASTERN NEW YORK**

October is Spina Bifida Awareness Month!



How can you help raise awareness?

Share your story!



How have you or someone you know in the Spina Bifida community demonstrated you are living **#BeyondAllLimits**

What is beyond all limits? Beyond all limits is a campaign that embodies the spirit of the boundless *opportunity* for all in the Spina Bifida community.

It is *overcoming* adversity, *exceeding* expectations, *challenging* those who doubt **your abilities**.

It is the adults in the community, the parents educating themselves, the teen playing sports, and the baby taking first steps!

Connect with others in the community by sharing and using the hashtag **#beyondallimits.**

Find more ideas for how you can **join the celebration** by visiting spinabifidaassociation.org/am.



Wear your **I love someone with Spina Bifida** shirt to raise awareness



Don't have one?



Contact the SBANENY office to purchase yours.

518.399.9151 / casemanager@sbaneny.org

Options available:

- ◇ Youth: S, M, L
- ◇ Adults: S, M, 2XL
- ◇ Choose black or blue

Cost: \$10.00 + \$2.00 shipping



Upcoming events

FALL FAMILY RETREAT

At the Double H Ranch

97 Hidden Valley Rd.
Lake Luzerne, NY 12846



Friday, October 21 - Sunday, October 23

Applications are available at our website: sbaneny.org



Pictures from this year's trip to Double H will be available on our website, Facebook page: facebook.com/Sbaneny and in the January 2017 edition of the SBANENY newsletter!

WEBINARS

WEBINARS AVAILABLE

Recent webinar archives published by the Social Security Administration on Ticket to Work:

<https://www.chooseworkttw.net/webinars-tutorials/webinar-archives.html>

Upcoming webinar: Customizing Employment: Success through Partnerships <http://www.leadcenter.org/webinars/customizing-employment-success-through-partnerships>

Visit **WorkforceGPS** to find resources on the importance of saving and financial literacy for individuals with disabilities. <https://ion.workforcegps.org/resources/>

Independent Living Center of the Hudson Valley Wellness Center

Week of: 9/6



ILCHV Fitness Fun Days

2nd and 4th Tuesday of Every Month

5:30-6:30

15 Third St Troy NY

Exercises and Information to help you
improve or maintain your health

Healthy Snacks will be served

Interested in wellness activities?

Call/email Shameka at:

518-274-0701

sandrews@ilchv.org

Superfest International Disability Film Festival

The festival taking place in Berkeley and San Francisco, California on October 22-23 is celebrating its 30th anniversary as the longest-running disabilities film festival in the world!!

The festival is featuring 13 films about disability, with actors and characters with disabilities, and produced and directed by people with disabilities. This year, 140 submissions were made from 18 countries. The event aims to be fully accessible and promote intersectionality.

For more information on the festival, visit the link:
<http://facesofspinabifida.com/articles/superfest-international-disability-film-festival-celebrates-30-years>

DISABILITY
EMPOWERMENT
DAY
2016



SBANENY Updates

As of September, SBANENY has distributed the *Toolkit for Educators: Resources That Promote a Healthy School Environment for Students Living with Spina Bifida* to school districts where we believe there is a student with Spina Bifida and to parents of children with Spina Bifida (ages birth-18) as part of a pilot project.

In addition, parents received a second resource, the *Toolkit for Educators: Parent Supplement*. The idea to create this resource came from discussions regarding the distribution of the original *Toolkit* to schools and parents. The *Parent Supplement* provides general information on the federal laws in place to protect individuals and students with disabilities, the education system and special education services across developmental stages, and general tips and rights for parents to help prepare for the

services and personnel they will likely encounter during school years.

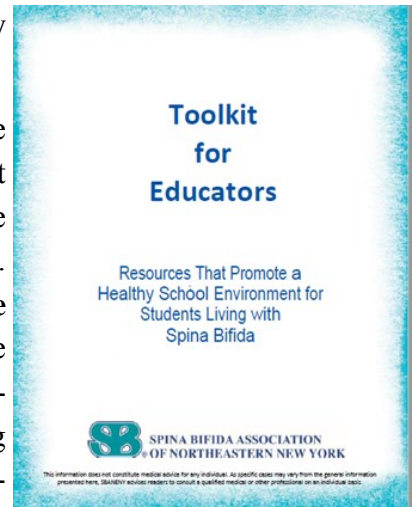
Please contact the office if you believe you or your child's school district should have and did **NOT** receive these resources or to request additional copies. In addition, we would **greatly appreciate your feedback** on the contents of these resources. Your comments and suggestions are important for understanding how we can continue to provide and improve this service. If you would like a copy of the survey(s), contact the office **OR** complete the surveys online!

School personnel: <https://www.surveymonkey.com/r/2BXXKX3>

Parents: Toolkit: <https://www.surveymonkey.com/r/S3M8LTT>

Parent Supplement: <https://www.surveymonkey.com/r/SHNGXRP>

Thank you!



THANK YOU to the Toolkit committee and additional contributors who helped with the drafting, editing, distribution, and completion of these projects!

Y-knot Sailing

Here are some of the photos from this years accessible sailing trip on Lake George!



Information on Y-knot Sailing

- ◇ Sailing and lunch are provided free by Y-knot!
- ◇ Sailing is accessible with available lifts and assistance entering the boat
- ◇ Sailors are accompanied by a knowledgeable skipper
- ◇ Visit the link: <http://yknotsailing.org/sailing/> for more information and to plan your trip!

Disability Tips

TIPS FROM SOCIAL SECURITY

How to Prepare for Your Disability Interview When Applying for Social Security Benefits

Be prepared to answer questions on:

- When your condition became disabling
- Doctor visits, last date of work, medications, marital information

When applying for SSI disability payments:

- Current income, current living arrangement, amount of your resources

Learn more at socialsecurity.gov.

Disaster Readiness Tips for People with Mobility Disabilities

Prepare: Assess community hazards, create a network of trusted individuals to take part in planning for emergencies

Evacuate: Don't wait until the height of an emergency to evacuate, plan the quickest way to evacuate, have a plan when in multi-story buildings, request your facility's manager purchase an evacuation device and educate leaders about the benefits of having one, and locate refuge areas in your building.

Shelter: Prepare to shelter in place, know where your public shelters are and determine if they are accessible beforehand.

Ready Kit and Go Bag: Fill with supply items. For a comprehensive checklist, visit the American Red Cross website: www.redcross.org

FACES Magazine
OF SPINA BIFIDA
a place to celebrate diversity

IT'S ELECTION SEASON!

Ten tips for voters with disabilities

1. Learn more about voting laws (Help America Vote Act, Americans with Disabilities Act), registration deadlines, accessible machines and locations, and alternative voting options by contacting your local or State election office.
2. Register to vote!
3. Choose the right voting method for you—at your local polling place or mail in your absentee ballot early.
4. Communicate your needs in advance. Contact your local elections office prior to voting to discuss options for voters with disabilities.
5. Check the location and accessibility of your polling place. Your State and local elections office can tell you the location and information on the accessibility of your polling place.
6. Know your rights! Research the laws and resources for voters with disabilities.
7. Follow up with the elections office after you vote—What was your experience voting like? Positive or in need of improvement?
8. Know who can help if voting is not accessible— In addition to your State or local elections office, contact the Department of Justice Voting Rights Division.
9. Stay informed— Stay connected with your local elections office and consider getting involved directly!
10. Get more information— Connect with local organizations that support people with disabilities and assist with voting rights and resources!

These tips are provided from the U.S. Election Assistance Commission. For more information: www.eac.gov

FALL SAFETY TIPS

- * Develop a disaster preparedness plan, family communication plan, emergency kit.
- * Prepare for Fall weather (flooding, hurricanes) and find recovery tips from American Red Cross.
- * Prevent falling outdoors and at home by assessing risk and using strategies like balance training.
- * Follow medication storage guidelines.
- * With the new school year beginning, don't forget to

brush up on school safety tips.

- * Secure your home— smoke detectors, escape plan, carbon monoxide detector.
- * Prevent personal crime by researching tips to protect yourself at home, in the community, and online.
- * If a disaster does occur, recover financially by visiting Red Cross, DisasterAssistance.gov, Disaster Unemployment Assistance and Disaster Assistance Emergency Relief Programs

* *Tips provided from disability.gov*



Easterseals 2016 Election Survey

Easterseals is asking you to take the time to tell those running for office what matters most to you by taking their brief disability issue survey. The responses will be included in an open letter to the presidential candidates and those running for public office. The survey can be found at the link below!

[http://www.easterseals.com/explore-resources/living-with-disability/2016-election-survey.html?](http://www.easterseals.com/explore-resources/living-with-disability/2016-election-survey.html?utm_source=eappeal&utm_medium=email&utm_campaign=ElectionSurveyFY16)

[utm_source=eappeal&utm_medium=email&utm_campaign=ElectionSurveyFY16](http://www.easterseals.com/explore-resources/living-with-disability/2016-election-survey.html?utm_source=eappeal&utm_medium=email&utm_campaign=ElectionSurveyFY16)

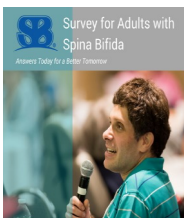
ADULTS WITH SPINA BIFIDA

NATIONAL SURVEY

If you are an adult with Spina Bifida, the national SBA is asking for your help!

This survey aims to understand more about life as an adult with Spina Bifida in order to create better options for treatment and build a better tomorrow!

https://www.research.net/r/sba_adult_survey



CENTER FOR FUTURE PLANNING

Future planning is necessary and possible!

In 2014, the ARC launched the Center for Future Planning to encourage, support and ease the process for adults with disabilities and their families.

Visit the website to find informational webinars and stories on person-centered planning, supported decision-making and guardianship, housing options, financial planning, employment and daily activities, social connections, and addressing urgent needs.
<https://futureplanning.thearc.org/>

In addition, check out the new tools available:

- * Build Your Plan— Create an account and begin to build your plans within the Center
- * Professional Services Directory— Find professionals in your community to help create and build a plan



National Disability Institute's Publications

Real Economic Impact: Network News

- Issue 30, Sept. 2016 includes articles on public benefits, work supports, saving, taxes and preparation, financial education, asset development, and public policy.

Washington Insider

- The September publication provides an ABLE legislation update, response to the income and poverty report, final report from the WIOA Advisory Committee, Social Security hearing summary, and August employment profile.

Visit realeconomicimpact.org/ to read and subscribe to these valuable resources for Americans with disabilities!

ABLE Accounts

[10 things you should know from ABLE National Resource Center](#)

What they are, why the need, eligibility, limits to the account, allowed expenses, **nationwide programs**, investment options, **how is ABLE different** than a special needs or pooled trust, how to know **which program is right for you**.

Find more information here: www.ablenrc.org/about/what-are-able-accounts



**SPINA BIFIDA ASSOCIATION
OF NORTHEASTERN NEW YORK**

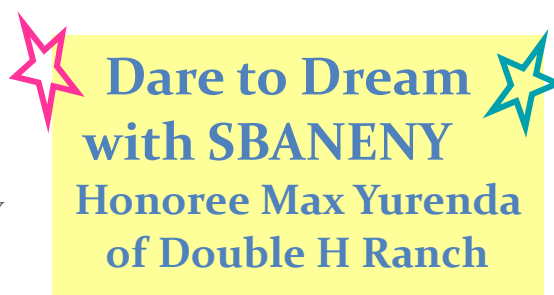
123 Saratoga Road
Scotia, NY 12302

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.



**Participate through our website 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

FALL FAMILY RETREAT WEEKEND

October 21–23, 2016

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

Saturday, November 19, 2016

**FOR MORE INFORMATION
CONTACT:**

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t (518)399-9151
f (518) 399-5639
sbaneny.org

COMMITTEES TO JOIN

**Walk-N-Roll
Dare to Dream
Board of Directors (11/12, 9 AM)
SBANENY Education Day
Toolkits for Educators
Young Families
Adult Group
NYC Metro Planning Group**



**SPINA BIFIDA ASSOCIATION
OF NORTHEASTERN NEW YORK**



Live & Silent Auction Sneak Preview!

Southwest[®]



Southwest Airline Tickets

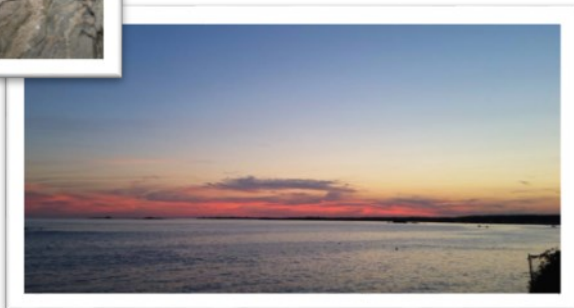
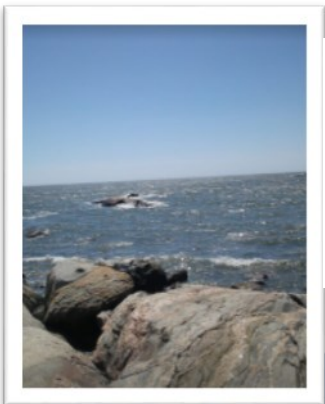
4 one-way travel domestic travel passes

Connecticut Get-Away

Shore House in West Brook, CT (Old Saybrook)

7 days/6 nights

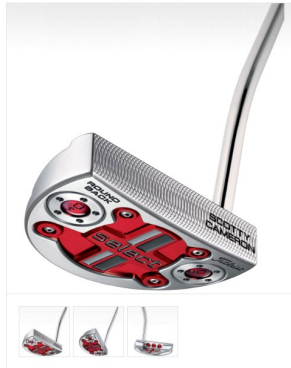
Newly constructed home with 4 king-size bedrooms



Beer Caddy by Halfmoon Works



Scotty Cameron Titleist Golf Putter



Kulak's Nursery & Landscaping \$100 gift certificate



American Girl Doll Isabelle



Restaurant Gift Certificates...

Texas Roadhouse
Bonefish Grill
Wolfs Inn
Outback Steakhouse
Teds Fish Fry
Red Lobster
Chilis
Ruggiero's
And more!!!!

Coach Pocketbooks



Sterling Silver Earrings



Stay tuned for more ...

Coach for a Day
Adirondack Get-Away
Backpack Survival Kit
Kimberley's Day Spa
SBANENY Board Wine
Basket
Romantic Evening with a
couple's massage

Children's books & stuffed animals

