



SPINA BIFIDA ASSOCIATION OF NORTHEASTERN NEW YORK

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SBA of NENY News to Use

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MESSAGE FROM THE CHAPTER CHAIR

The SBANENY's mission is to promote the prevention of Spina Bifida and to enhance the lives of all affected. Our chapter does this through providing workshops, seminars, social events, educational materials, information, support and services. We've also focused on expanding awareness of Spina Bifida. We believe that 2014 was a successful year for us, and we are enthusiastically looking ahead to the New Year.

I have the honor of becoming the new Chair of the Board of Directors. I am a retired elementary principal and have served on the Board for the last three years. Many years ago I had the pleasure of working with some of this chapter's founding members as parents, their children and their teachers. It is rewarding for me to now see and interact with these "children" whom have developed into impressive and remarkable adults. I think that it speaks to the value of our chapter and some of what it can accomplish.

This newsletter will update you as to the many things that we've been doing recently, and some of our upcoming plans. I also invite you to visit our website sbaneny.org and follow us on Facebook to stay informed about all of our programs, services and events. The reason for any of our success is our dedicated part time staff and our many passionate volunteers. I ask you to consider becoming involved in our organization in any way that you'd like. There are many ways that you can take an active part in our organization. Please contact us to discuss these possibilities by phone or email. We look forward to hearing from you.

Jim Dunham, Chair

SBANENY Board of Directors

James Dunham, Chair
Lyndsi Holmes, Vice Chair
Heather Green, Treasurer
Michelle Miller, Secretary
Kevin Chamberlain, Past Chair
Raymond Langelier
Margaret Smith

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.*

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ADULT PROGRAM



Tips to Maximize Your Travel Pleasure – Destinations Near & Far!

Do you have a disability and are thinking about taking a vacation? Join SBANENY and ILCHV to explore the accessibility of vacationing with a disability, including cruises, national and state parks, and other popular destinations.

All people with disabilities and their families are welcome. Free information will be provided and light refreshments will be served.

DATE: Saturday, February 21st

TIME: 1 to 3 PM

LOCATION: Independent Living Center of the Hudson Valley, 15 3rd Street, Troy, NY

RSVP: to Shameka Andrews at 274-0701.

This program is a collaborative effort of SBANENY & ILC of the Hudson Valley.



SPINA BIFIDA ASSOCIATION
OF NORTHEASTERN NEW YORK



ADULT PROGRAM PLANNING COMMITTEE

Our Adult Program Planning Committee welcomes adults with Spina Bifida! Would you like to have input in planning future programs? Contact Shameka Andrews, Barbara Devore, or our office for information.

**LIKE SBANENY PAGE &
FOLLOW US ON FACEBOOK!**

SHARE OUR PAGE WITH YOUR FRIENDS!

FAMILIES WITH CHILDREN...

CURE YOUR CABIN FEVER JOIN US FOR A POOL PARTY!



Join SBANENY and our young families group for a pool party, complete with pizza and drinks for dinner! The pool is completely accessible for everyone.

Where: Ciccotti Center,
30 Aviation Road, Albany, NY

When: Saturday, February 21st, 2015

Time: 3:30 pm – 6:30 pm

Who: Families with minor children with Spina Bifida up to age 21. Immediate family members including siblings are welcome!

RSVP: By February 13th to 518-399-9151 or rachael.strohl@sbaneny.org.

This program is free of charge to families of children with Spina Bifida.

DOUBLE H RANCH SUMMER RESIDENTIAL CAMP

ATTN: Children ages 6 to 16: From June until the end of August, the Double H Ranch offers children, age 6-16 during regular session and ages 17-21 during the alumni session, dealing with critical or life-threatening illnesses (including Spina Bifida) the chance to experience the magic of the Adirondacks. The Double H Ranch provides camp experiences that are medically sound, memorable, exciting, fun and empowering.

Each session lasts 6 days with a camper to staff ratio of 2:1. The fully equipped medical

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facility allows Double H to provide a physically safe camp experience for all children.

Campers get to participate in the typical summer camp activities including arts and crafts, swimming, fishing and boating, horseback riding and small animal care, hands on science activities, nature based activities and camping, sports and recreation, archery, and a high ropes course. All activities are adapted to fit the needs of each child that attends Double H. Our program staff and counselors work to ensure all activities and events are inclusive for all children. Each session Double H campers enjoy an offsite visit to our local amusement park Six Flags (Great Escape) and our older campers are able to experience the thrill of whitewater rafting.

DOUBLE H RANCH SIBLING PROGRAM

Double H Ranch is offering two sessions for siblings, June 24- June 29 and July 2- July 7. Siblings of qualifying campers enrolled in any of the summer sessions are eligible to participate. For more information or the summer application, go to <http://www.doublehbranch.org/summer-camp/criteria/> or contact Caroline Kenney, Admissions Coordinator, at ckenney@doublehbranch.org or 518-696-5676 ext. 263.

FALL FAMILY WEEKEND 2015

DOUBLE H RANCH

It's time to mark your calendars! Fall family weekend at Double H Ranch is scheduled for October 23rd - 25th. This retreat weekend is for children ages 5 through 21 who have Spina Bifida and their families. It is filled with activities including high ropes, art & crafts, indoor swimming, campfire songs, and much more! It is a great opportunity for



making connections with other families. Thanks to Double H Ranch, there is no cost to families for participation.

Mark your calendars. We anticipate that registration forms will be available in late summer. Plan to register early. This event fills up quickly!

SPINA BIFIDA CONFERENCE 2016 EMPOWERMENT THROUGH MAKING CONNECTIONS: LIVING WITH SPINA BIFIDA

The SBANENY conference committee is busy planning for the next conference day event. Their target is spring of 2016. This will be the 4th conference sponsored by SBANENY and promises to be bigger and better than ever!

The planning committee welcomes new members. Please contact our office to learn about how you can be involved.

Watch for "Save the Date" announcements coming soon!

WELLNESS WEDNESDAYS SPONSORED BY ILC OF THE HUDSON VALLEY

- **Honest Weight Food Co-op**, January 28th 5:30 PM (Note the time change.) Co-op will discuss the workshops and activities that they offer. Program will include a food demonstration and giveaways.
- **Chair Yoga** February 18th 5:00 PM. Presented by Chris Darby-King.
- **Tai Chi** February 18th, 5 PM.

All workshops are open to everyone and are free. Healthy snacks and giveaways will be included. Please RSVP to programs with Shameka at 274-0701.

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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;



1. **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

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

Information, guidelines, and applications are available on our website at www.sbaneny.org or by contacting our office.

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 & applications go to our chapter website at www.sbaneny.org or contact our office.

The deadline for receiving scholarship applications and all supporting materials is May 1, 2015.

EQUIPMENT EXCHANGE PROGRAM

2005 Chrysler Town and Country Van

55,000 Miles. For sale for \$8,700.

2 Wheelchair lifts: one goes inside the van, the other is an exterior drive on. For more information or to view the van call Ed Tucker (315) 343-4507 or e/mail etucker@twcny.rr.com.



Do you have equipment or supplies that you no longer need? Let us know and we will list them in the next newsletter to help pass them along to someone who could benefit!

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TIPS TO SHARE.... From Heather...

Do you or does your child need to wear a medical ID bracelet but resist it because of style? I found a resource online that might help. Creative Medical ID offers a variety of bracelet styles for males and females of all ages. I found one that fit my style and almost never take it off, even in water. Now with my bracelet, I know that my needs can be met in a medical emergency, but I can also enjoy wearing my bracelet! For information, go to <http://www.creativemedicalid.com/>.



Do you have a tip to share? Please submit your tips to our office for future newsletters!

NEW YORK CITY AREA

Plans are in the works for the next Greater Metro New York program. Do you live in that region of New York State? Please be sure that you are on our mailing list so that you will be notified of future events!

Lyndsi & Christina welcome others to join this planning committee. (Meetings are done through conference calls.) *Please contact our office if you would like to help with this project.*

IN THE MEANTIME....

SIBSHOP WORKSHOP

Sibling Support Group Workshop is geared toward children who have a brother or sister with a neuromuscular disease. Leaders from the medical and educational fields will provide children with a variety of opportunities to share the challenges and joys of living with a sibling with a neuromuscular disorder.

WHO: Siblings of children with neuromuscular disorders including Spina Bifida

WHERE: Columbia-Presbyterian Medical Center in NYC

DATE: Spring 2015 to be determined based upon interest

PLEASE CONTACT Rachel Mirkin, 339-234-0295 and request to have your name placed on an information list to be notified when the next workshop is being held. The more interest expressed from consumers, the sooner the workshop will be scheduled.

TIDBITS ON ASSORTED TOPICS RESOURCE INFORMATION

SPECIAL NEEDS TRUSTS

One of the common worries of parents/guardians of a child with special needs is how the future needs of their child will be met.

Are you the parent of a child (minor or adult) with special needs? Do you have important legal documents in place such as a Power of Attorney? Special Needs Trust? These documents help to address families' concerns about how their child's money will be managed when they are no longer around to oversee it.

Experts recommend that families create a "special needs" or "supplemental needs" trust. A properly designed trust fund can provide for expenses ranging from residential programs to haircuts, while not cutting off access to government benefits, such as Medicaid or Supplemental Security Income (SSI). Rules governing special-needs trusts are complex. They vary by state and by the source of the funds.

Experts recommend that parents/guardians have these documents in place as early as possible and review them periodically to keep them current. Special-needs planners are professionals who guide families through the process. They help to set up trusts, insurance policies, retirement plans, and estate-planning documents.

How do you find a professional who specializes in Special Needs Planning? At least two professional groups -- the Academy of Special Needs Planners and the Special Needs Alliance -- provide referrals to lawyers familiar with special-needs planning expertise and other resources. Some financial services firms also have divisions devoted to special-needs planning.

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BUILDING INCLUSION

In her blog, Kathy Martinez, Assistant Secretary of Labor for Disability Employment Policy, US Department of Labor asserts that “true progress on disability employment requires a broader view than we as a society have afforded it in the past. That’s not to say individual policies and programs aren’t important, because they are. But they alone are not enough. Rather, they’re the individual building blocks that support a larger structure, one we all play an important role in shaping, whether we have a disability or not.... [Expect. Employ. Empower.](#) Those three brief but powerful words provide a framework for a more holistic approach to increased workforce inclusion of those of us with disabilities.”

To read more go to <http://social.dol.gov/blog/building-inclusion/>.

JUSTICE CENTER LAUNCHES STATEWIDE TRAINING FOR LAW ENFORCEMENT OFFICERS

The NYS Justice Center for the Protection of People with Special Needs will be providing training for law enforcement officers. Among the topics that will be covered are an overview of disabilities, disability awareness training, victimization of persons with disabilities, and the responsibilities of mandated reporters. The goal of the training is to ensure that people with disabilities are ensured the same protections as the general population.

For more information go to: http://www.justicecenter.ny.gov/sites/default/files/documents/TAPressRelease_dswtlp.pdf

WORKING SMOKE ALARMS SAVE LIVES: TEST YOURS EVERY MONTH

Did you know that...

- a working smoke alarm cuts the risk of dying in a home fire in half?
- your family has about three minutes to get out of your home if there is fire before the air is too toxic to survive?

Something to consider:

- Does anyone in your home need assistance getting out of the home quickly?
- If so, who will be in charge of helping that person?

The [United States Fire Administration](#) recommends everyone should have a comprehensive home fire protection plan that includes smoke alarms, fire sprinklers and practicing a fire escape plan. For more information about [smoke alarms](#), [escape plans](#), [home fire sprinklers](#) and a [home safety checklist](#), as well as other fire safety topics at www.usfa.fema.gov.

IT’S NOT A LAUGHING MATTER

Guest Blogger Wayne Connell, Founder and President, [Invisible Disabilities Association \(IDA\)](#) talks about how humor and laughter are frequently overlooked tools for health. He quotes Invisible Disabilities Association Advisory Board Member and Neurohumorist expert Karyn Buxman, RN, MSN that “laughter is good medicine.” To learn more, go to <http://usodep.blogs.govdelivery.com/2014/10/17/its-not-a-laughing-matter/>

For more interesting reading on a variety of topics related to people with disabilities, go to Disability.Blog.

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GALA LIVE & SILENT AUCTION FUNDRAISER FALL 2015 DARE TO DREAM WITH SBANENY

Seeking Sponsors: Would you like to be a Corporate or Individual Sponsor of our annual event? Do you know an individual or business who would like to be a sponsor of this event? Please contact our office as soon as possible! Sponsor information is available through our website at www.sbaneny.org or through our office.

Dare to Dream will be held in the fall. The committee is working to confirm details and will announce the date & location as soon as everything has been determined.

This committee is a great way to get involved. New committee members are welcome! Let us know how you would like to help.

**Welcome this year's Honorary Chairs
Thomas Wilson & Kristin Koehler**



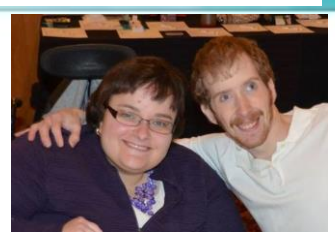
DARE TO DREAM WITH SBANENY 2014 INGREDIENTS TO SUCCESS...



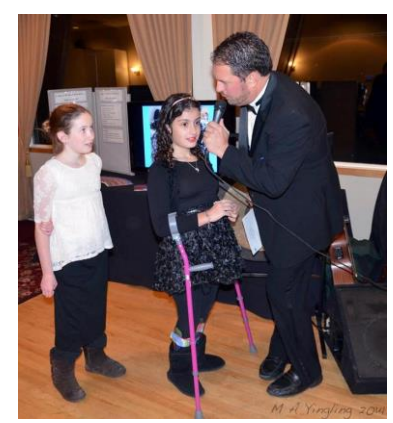
*Honorary Chairs
Bill & Shelly Socha....
Great auction prizes...*



*Old SBANENY friends
& new!*



*Live auctioneer Jim Gallagher
& his assistants...
Food – plentiful & fabulous!*



*Serious bidders....
Happy volunteers!*





**SBANENY Walk-N-Roll for Spina Bifida
presented by The Daily Gazette**

&

SBANENY Family & Friends Picnic

DATE: Saturday AM, May 2, 2015

WHERE: Central Park, Schenectady, NY

Benefiting programs & services of



**SPINA BIFIDA ASSOCIATION
OF NORTHEASTERN NEW YORK**

(SBANENY)

TO REGISTER:

go to www.sbaneny.org and click on



SOCHA PLAZA



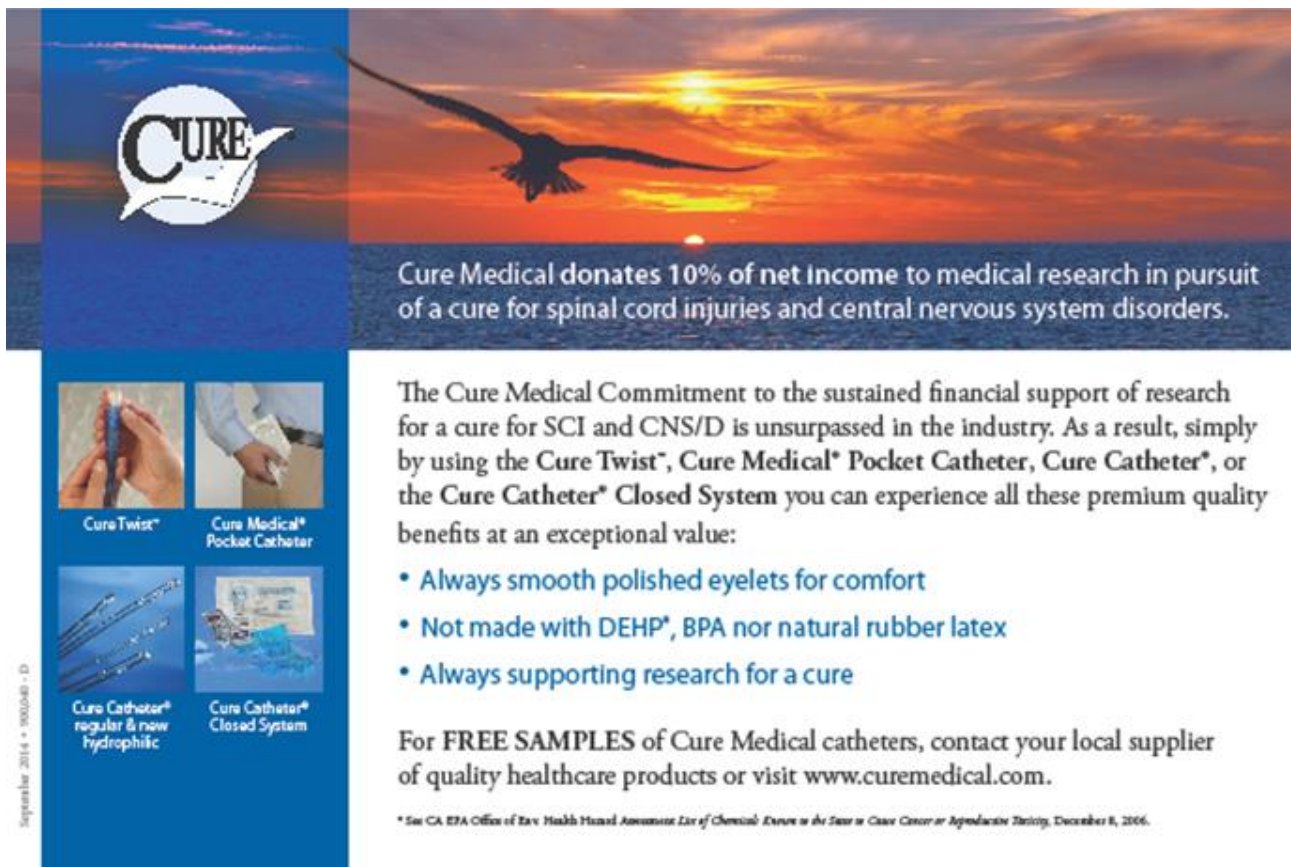
MODERN ELEGANCE

Retail: Just 1,000 square feet of prime retail space is left on the first floor of our gorgeous new building.

Office: Over 8,200 square feet of commercial office space is available on the second floor, offering beautiful views, 24/7 security, and convenient access for employees and clients.

Apartments: Those looking for a true luxury apartment will find it at Shady Lane Apartments at Socha Plaza. Our luxury apartments offer soaring glass windows, hardwood floors, and fireplaces. They are a must-see.

CALL SOCHA MANAGEMENT
518-399-0990



CURE

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

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.

* 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.

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SBANENY CALENDAR OF EVENTS

- FEBRUARY 21** Adults – Travel Tips
Families with Children – Cabin Fever Pool Party
- MAY 2** SBANENY Walk-N-Roll for Spina Bifida
- OCTOBER 23 – 25** Fall Family Retreat Weekend, Double H Ranch
- FALL 2015, TBA** SBANENY Gala: Dare to Dream with SBANENY
- TBA** Greater Metro NYC Program

NEXT SBANENY BOARD MEETING March 14, 2015

Want to learn more about upcoming SBANENY programs and services?

- **Follow us on Facebook**
- **Visit our Website at www.sbaneny.org**
- **Watch for emails & flyers**
- **Check your phone messages**

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.*

*For more information, contact Karen at 518-399-9151 or
admin@sbaneny.org.*