



SPINA BIFIDA ASSOCIATION OF NORTHEASTERN NEW YORK



SBANENY News to Use

CHAIR LETTER

Who, What, Why and What Next?

Who: The Board of Directors of the SBANENY is a diverse group of individuals who have been touched by Spina Bifida in a variety of ways. There are three parents of children and adults with Spina Bifida, an aunt of a child with Spina Bifida, two Directors with Spina Bifida, and two Directors who are special educators. We are educators, a CPA, a retired business finance manager, a technology wizard, a bank executive, a provider & a manager of services for people with disabilities. We are in our 20's, 30's, 40's, 50's and 60's. We all strive to make a difference for those needing support services. In future newsletters we will introduce you to our Directors individually. In this issue we seek to recognize the two Directors who will be stepping away from our Board, as prescribed by our Bylaws.

What: The programming that we provide is in response to the needs of the community of individuals that we serve with Spina Bifida. As you browse this newsletter and our website (www.sbaneny.org) you can see the variety of ways we work to meet our community's needs.

Why: Our Mission is to promote the prevention of Spina Bifida and to enhance the lives of all affected. Our Vision: We envision a world in which no pregnancies are affected by Spina Bifida. People living with Spina Bifida thrive in a barrier-free world that offers ready access to an array of effective treatment options and uniformly excellent medical care. Their individual life choices are not impeded by Spina Bifida and all experience rich and personally fulfilling lives.

What Next: The Board of Directors are in the midst of developing our next three year Strategic Plan. We spent most of a day in September, using our current Strategic Plan, deciding on how we want to challenge our organization for the next three years in meeting the needs of our community. We will be adding measures to our goals and objectives, so that we can gauge our progress. Our Plan will be finalized in November.

YOU! How do you fit in? How would YOU like to help? There are a variety of ways. All of our events and programs need volunteers to make them successful. Would you like to join us? We would love your help. Please contact our office at 518-399-9151 and talk with us about your interests. We promise to help you feel successful and valued.

Jim Dunham, Chapter Chair

ISSUE #65 OCTOBER 2015

Adult Programs & Activities
Spina Bifida Fall Family Weekend
Equipment Available
Toolkits for Educators
SBANENY Sponsored Scholarships
Board Service Thank yous
SBANENY Conference April 2, 2016
October Spina Bifida Awareness Month
Adaptive Skiing & Tennis
Dare to Dream with SBANENY
Silent & Live Auction Sneak Preview!

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

EQUIPMENT AVAILABLE

Two wheelchairs, 1 power & 1 manual, available for small adult (100 lbs.). The current owner is interested in giving them to someone who could use them. If you are interested in either chair and would like to learn more, please contact our office.



Do you have equipment that you have outgrown or are no longer using that you would like to pass along to someone who could use it? With a picture and description, we can help you to connect to a potential owner!

ADULTS ENJOY A PICNIC & SHARE TIPS ON STRESS MANAGEMENT

On August 15th, a group of adults met at The Crossings in Colonie for a picnic and conversations about stress management.

Have you tried...

- ♦ Listening to music?
- ♦ Working out?
- ♦ Coloring/scribbling?
- ♦ Spending alone time in a quiet place?



Activities & Programs for Adults....

Sneak Preview.... In the planning stages....

Visit to the Planetarium... Movie Night! Stay tuned....

FALL FAMILY WEEKEND RETREAT AT DOUBLE H RANCH

DATE: Friday, October 23—Sunday October 25

As of this writing, there are 17 families with over 70 people all set to go to the Spina Bifida Fall Family Retreat Weekend at Double H Ranch in Lake Luzerne. Designed for families with a child with Spina Bifida between the ages of 5 & 21, it is a wonderful opportunity to meet others who are facing similar challenges while enjoying the beautiful Adirondacks.

Lots of fun activities are being planned, the Double H staff and volunteers are gearing up, and we are getting ready to pack up the supplies, and yes, the pumpkins for carving, and head north! It is always a great weekend for all involved to reconnect. We look forward to sharing stories and pictures upon our return!

There are a few openings available on a first come/first serve basis. Please call as soon as possible if you are interested.



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!

TOOLKITS FOR EDUCATORS

During the 2014 SBANENY sponsored conference in Albany, a discussion evolved over the course of the day about some of the unique educational needs that children with Spina Bifida might have. A group of people expressed interest in assisting with the development of a resource to offer to educators that would provide basic information about these needs and additional resources that might be helpful to them as they work with students with Spina Bifida.

In January a group convened to develop what is now being called Toolkit for Educators. The project is nearing completion. We anticipate that copies will be available in January. Initially, we will provide these toolkits to school districts where we know there are children with Spina Bifida. Eventually, we hope to have funding that will support a broader distribution of the resource.

If you have a school age child with Spina Bifida, please assist us by being prepared to providing us with your school's name, address, child's teacher, school nurse, and school social worker.

Parents are welcome to copies of this resource as well.



SCHOLARSHIPS AVAILABLE:

- ♦ **FRANK BUCINO, JR. MEMORIAL**
- ♦ **HELEN MERTENS EDUCATIONAL**

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. Consider these as you & your family explore the possibility of attending the 2016 SBANENY conference in East Greenbush (near Albany) or the 2016 national SBA conference in Minnesota, June 25—28. Information about the scholarships is available on our website at www.sbaneny.org.



SBANENY Board of Directors spent a Saturday working together deciding on how we want to challenge our organization for the next three years in meeting the needs of our community.

SBANENY HAS A VARIETY OF COMMITTEE & BOARD SERVICE NEEDS.

HOW WOULD YOU LIKE TO BE INVOLVED?



Kevin Chamberlain has served on the SBANENY board in a variety of positions; Chair, Past Chair, Secretary & Director. In addition, Kevin has served on many board and chapter committees. Kevin is the person behind our website and the one who responds to our IT SOS calls for help, "Kevin, we can't figure out how to....."

Ray Langelier has been involved with SBANENY as a volunteer since the chapter was first incorporated in 1993, many of those years serving as a Director & a Treasurer on the board. Ray is always willing to pitch in with an extra set of hands!



Kevin & Ray, thank you both for your years of board service!

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.

EMPOWERMENT THROUGH MAKING CONNECTIONS: LIVING WITH SPINA BIFIDA

CONFERENCE SPONSORED BY  SPINA BIFIDA ASSOCIATION
OF NORTHEASTERN NEW YORK

DATE: Saturday, April 2, 2016

PLACE: SUNY School of Public Health, 1 University Place, Rensselaer

We anticipate that scholarships will be available to assist with registration, lodging, and travel expenses related to individuals and families attending the conference.

More information coming soon.

Please mark your calendars!

Spina Bifida Health & Information Resources

We have a variety of resources that we provide free of charge.

Picture Books For Children:

- Another Way to Go (Using catheters)
- Detour Ahead (Surgeries & hospitalizations)

For Parents:

- Health Guide for Parents of Children with Spina Bifida
- Encouraging Social Development of the Young Person with Spina Bifida

For Adults & Parents:

- Health Guide for Adults with Spina Bifida
- Bowel Management and Spina Bifida
- Sexuality and Spina Bifida

If you haven't received these publications through our periodic mailings and are interested in copies, please contact our office.

OCTOBER IS SPINA BIFIDA AWARENESS MONTH

This October we need your help to raise awareness and join in the celebration of our community. National Spina Bifida Association is inviting everyone to share your stories. How you are living beyond all limits.

What is living #beyondlimits? Overcoming adversity? Exceeding all expectations? Challenging those who doubt your abilities? Being an everyday hero? Living beyond all limits is all that and so much more.

Help us celebrate by sharing your story and learning about how others are living #beyondlimits.

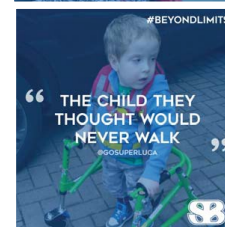
Sharing your story is as easy as the 3Cs:

1. Choose –
2. Create –     your story
3. Connect – share using #beyondlimits

Not sure where to start? Visit spinabifidaassociation.org/am

Join the movement today!

Together we can reach #BEYONDLIMITS



DO YOU HAVE HIGH BLOOD PRESSURE?

If you have been diagnosed with High Blood Pressure or have been told by a health professional that you are at risk, you are invited to attend a Living Healthy With High Blood Pressure Workshop.

This is a one session workshop. Registration is required.

DATE: Tuesday, November 3rd
TIME: 9:30 AM to Noon
LOCATION: Independent Living Center of the Hudson Valley
15-17 Thirds St Troy NY
TO REGISTER: Call 518-442-5530



LOVE SOMEONE WITH SPINA BIFIDA? HOW ABOUT ONE OF OUR T-SHIRTS FOR A HOLIDAY GIFT?



"I love someone with Spina Bifida." long sleeve t-shirts are available in blue or black, adult and youth sizes, for \$10 each \$2 plus shipping. Check it out online or contact our office to place your order!

CLAIMING OUR POWER, SHARING OUR STORIES

Opening Reception for an Exhibit of Stories & Collages by People with Disabilities

DATE: Friday, October 23, 2015 from 5 to 7 PM

LOCATION: Independent Living Center of the Hudson Valley
15—17 Third Street, Troy, NY 12180

Light refreshments will be served.

RSVP to Barbara Devore (518) 274-0701

This project is made possible in part through a Community Arts Grant, a program funded by The Arts Center of the Capital Region through the New York State Council on the Arts.

WINTER IS AROUND THE CORNER....

WOULD YOU LIKE TO TRY ADAPTIVE SKIING? CHECK OUT THE AVAILABLE OPTIONS!

Double H Ranch Adaptive Winter Sports Program Lake Luzerne, NY

The Double H Ranch Adaptive Winter Sports Program offers children ages 6-16 dealing with chronic and life-threatening illnesses the opportunity to participate in various winter sports FREE of charge with necessary equipment provided. Activities include instruction in Alpine skiing, snowboarding, and snowshoeing. Programs are designed for enjoyment by the entire family. Participation is based on approval by the Medical or Nursing Director. Register in advance. Program space is available on a first-come, first-serve basis.

Windham Adaptive Sports, Windham, NY

Windham offers adaptive ski lessons for children and adults with physical disabilities. For information, call 518-734-5070. Advanced reservations required.

STRIDE Adaptive Sports

STRIDE offers adaptive skiing and snowboarding lessons for people with physical disabilities.

Jiminy Peak Mountain Resort in Hancock, MA

For information, contact mmoran@stride.org or (518) 598-1279.

Catamount Mountain in Hillsdale, NY

For information, contact Gail Tagan at (860) 482-2931.

Advanced reservations are required.

DO YOU PREFER AN INDOOR EXERCISE OPTION?

STRIDE ADAPTIVE TENNIS LESSONS

STARTING: Sunday, November 1st

WHERE: Sportime, Schenectady

FOR INFORMATION: Melissa Lachanski

mlachanski@stride.org 518-598-1279





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

Admission

Diamond Level \$75 (names listed in program)
Emerald Level \$30 before 11/1; \$35 after
Topaz Level (under 18) \$20 before 11/1; \$25 after

To purchase tickets:

Online: Go to www.sbaneny.org

USPS Mail: Send check made out to Spina Bifida Association of NENY to
Spina Bifida Association of NENY
123 Saratoga Road
Scotia, NY 12302

By Phone: Call the SBANENY office at 518-399-9151.



Honorary Chairs

Tom Wilson & Kristin Koehler

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Socha Plaza, Bill & Shelly Socha

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Bronze Sponsor

Kevin & Vanessa Chamberlain

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Ray & Margie Langelier



Our Online Pre-event Silent Auction will go live on November 1. Our sneak preview in this newsletter offers a small sampling of the items that will be available through our Dare to Dream with SBANENY fundraiser gala. Plan to attend on November 21st so that you can bid on the many other great things that will be available!

VISION TO LEAD. EXPERIENCE TO BUILD.

*"Bringing TW&A Construction Management on board
was the best decision I made."*

– William J. Socha



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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.**

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

FALL FAMILY RETREAT WEEKEND

October 23rd—25th, Double H Ranch, Lake Luzerne, NY.

Pre-registration required.

DARE TO DREAM WITH SBANENY

Saturday, November 21st, 6 to 10 PM at Colonie Country Club. Gala fundraising event including live & silent auctions.

Pre-Event Online Auction 11/1 to 11/19

SPINA BIFIDA CONFERENCE 2016

Saturday, April 2, 2016

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

May 21, 2016 — Mark your calendars!!

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

Adult Programs —

Movie Night, Planetarium

Metro NYC Program

COMMITTEE MEETINGS

Walk-N-Roll: Late fall

Dare to Dream: 10/27, 7 PM

Board of Directors: 11/7, 9—11 AM

SBANENY Conference: 11/10 5 PM

Toolkits for Education — TBD

Young Families — TBD

Adult Group — TBD

NYC Metro Planning Group — TBD

FOR MORE INFO CONTACT:

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t (518)399-9151

f (518) 399-5639

sbaneny.org

DARE TO DREAM WITH SPINA BIFIDA LIVE & SILENT AUCTION SNEAK PREVIEW!

A Room with a View!

10 day stay
3 bedroom—2 bath condo
Punto Gorda, Florida
View from the condo of
Charlotte Harbor!



Lake George

Fort William Henry Hotel

One night Bed & Breakfast Package for up to 4 people
Includes admission to the Fort.



And of course Vera, Bling, & More!



Round Trip Airline Tickets
Any City to Any Nonstop City



Police Chief for a Day

Heart & Soul!!

Queen Size
Wrought Iron
Head &/or Foot boards

