



**SPINA BIFIDA ASSOCIATION
OF NORTHEASTERN NEW YORK**



SBANENY News to Use

CHAIR LETTER

Happy New Year! I hope everyone had a happy, healthy holiday season!

With a new year comes new changes and new adventures at SBANENY. Every year the board appoints a new chair. It is my great pleasure to assume this role. My name is Lyndsi Holmes-Wickert and I have been involved in SBANENY since its inception. Shortly after being born with Spina Bifida, my parents, along with other parents and medical professionals, began SBANENY as a way for families to get support and network with each other to learn about community resources and programs. What started in 1993 has grown significantly in programming and geographic coverage. I look forward to continuing the mission and vision of SBANENY as we strive to improve the quality of life for people living with Spina Bifida and their families.

As chair, I hope to assist the board in networking with other organizations and companies that can assist us in reaching our goals, in programming and financially. Throughout my life I have personally felt the power of connecting families to resources and with each other. I believe that these goals are the core of everything we do.

As you look through the newsletter, please take advantage of all the programming that SBANENY does and other community events we have made connections with. Get involved with what makes sense for you and your family. Is there something missing that you would like to see? Please feel free to contact our office at any time with your thoughts and ideas. Karen Wentworth, our Executive Director, would be happy to hear your ideas. She, along with our new energetic Case Coordinator, Julia Duff, are always open to new ideas on how to serve our consumers and knowing where your interests and needs are. Additionally if you have a particular skill or interest, we are always looking for people to assist us in projects and programs if interested!

I look forward to meeting and corresponding with many of you over the next year and in the many years to come. Thank you for being a part of SBANENY and for your continued support!

Lyndsi Holmes-Wickert, Board Chair

ISSUE #66 JANUARY 2016

Fall Family Retreat at Double H Ranch

Children and Family Pool Party

NYC Meet and Greet

Focus Groups

SBANENY Walk-N-Roll for Spina Bifida

SBANENY Conference

SB Insights

Washington Insider

Social Security News Release

Dare to Dream with SBANENY

Thanks to Our Sponsors

Upcoming Events

SBANENY BOARD

Chair: Lyndsi Holmes-Wickert

Vice Chair: Michelle Miller

Past Chair: James Dunham

Treasurer: Heather Green

Secretary: Margaret Smith

Directors:

Peggy Felt

Annmarie Fennicks

Margaret Huff

Executive Director

Karen Wentworth

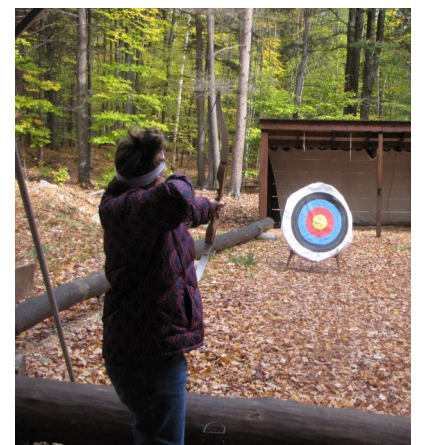
FALL FAMILY WEEKEND RETREAT AT
DOUBLE H RANCH...
SEE THE FUN FROM THIS YEAR!



Ropes Course & Halloween Party!



Fishing, Pumpkin
Carving & Archery



*We hope to see you at the next Fall Family Retreat at Double H Ranch
Save the date... **October 21-23, 2016!**
Keep an eye out for more information.*

MISSING SUMMER? SBANENY IS HOSTING A CHILDREN & FAMILIES POOL PARTY!

- ◆ Who: Children with Spina Bifida 18 and younger, siblings and parent/sguardians.
- ◆ Where: Ciccotti Center
30 Aviation Road, Albany NY
- ◆ When: February 13, 2016 @
2:00—5:30 PM

SBANENY will be providing pizza and drinks for all guests.

This program is free of charge.



Rudy A. Ciccotti Family
Recreation Center



NEW YORK CITY MEET AND GREET EVENT

GET TO KNOW US, GET TO KNOW YOU AT BRONX INDEPENDENT LIVING SERVICES

ADDRESS: 4419 3RD AVE #2C, BRONX, NY 10457

DATE: APRIL 30, 2016 from 12:00—3:00pm

In line with the theme of our SBANENY April 2nd Conference, "Empowerment through Making Connections: Living with Spina Bifida," SBANENY is hosting a meet and greet event at the Bronx ILS. On April 30th, individuals and families affected by Spina Bifida living in the New York City area are asked to come and get to know each other, share support and resources, and make connections!

*If you have any questions about this event, please contact
Julia Duff at 518-399-9151 or at casemanager@sbaneny.org*

ATTENTION: Women with disabilities between 40-75....

Due to recent awareness of the many existing barriers for women with disabilities to receive routine mammograms, the Independent Living Center of the Hudson Valley (ILCHV) is conducting focus groups for women to share their experiences. Consider participating in this important research opportunity to improve service accessibility and receive a \$10 gift card to Target!

When: Tuesday February 9th from 3:30-5:00 or Thursday February 11th from 5:00-6:30 @ ILCHV, 15-17 3rd St Troy, NY

Registration is required. Please call Tina McQuiston, Project Coordinator, at (518) 274-0701 ext. 136 or email tmcquiston@ilchv.org by February 2nd 2016

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!

EMPOWERMENT THROUGH MAKING CONNECTIONS: LIVING WITH SPINA BIFIDA

CONFERENCE SPONSORED BY  SPINA BIFIDA ASSOCIATION
OF NORTHEASTERN NEW YORK

Date: Saturday, April 2, 2016

9:00 AM to 5:00 PM

Place: University at Albany
School of Public Health

1 University Place, Rensselaer, NY

This conference is for individuals with Spina Bifida of all ages, their families, and the professionals who work with them.

Keynote Speaker:

John Robinson,

**Managing Partner & CEO of
Our Ability**

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

SB Insights Last Issue of the Year

Ready, Spirited and Strong

The December SB Insights is available for you to read about people living with Spina Bifida who have experienced the power of personal transformation while refusing to be defined by their limitations.



Subscribe to SB Insights to stay updated on the SBA year in review, community stories, and SBA events in 2016!

National Disability Institute's Washington Insider

December 2015 | Vol. 7 Issue 10

This monthly newsletter addresses federal policy and legislation affecting the financial and economic development of all individuals with disabilities. Check out this month's newsletter to learn more about the National Disability Institute's efforts to improve the poverty rate for people with disabilities, employment opportunities, and celebrating the one year anniversary of the Achieving Better Life Experience Act.

<http://www.realeconomicimpact.org/resources/washington-insider-newsletter>

SOCIAL SECURITY NEWS RELEASE: LAW DOES NOT PROVIDE FOR A SOCIAL SECURITY COST-OF-LIVING ADJUSTMENT FOR 2016

With consumer prices down over the past year, monthly Social Security and Supplemental Security Income (SSI) benefits for nearly 65 million Americans will not automatically increase in 2016. As determined by the Bureau of Labor Statistics, there was no increase in the Consumer Price Index for Urban Wage Earners and Clerical Workers from the third quarter of the 2014 to the third quarter of 2015. Therefore, under existing law, there can be no cost-of-living adjustment (COLA) in 2016. Since there is no COLA, the statute also prohibits a change in the maximum amount of earnings subject to the Social Security tax, along with the retirement earnings test exempt amounts. For additional information on Medicare premium changes go to www.medicare.gov and for information on Social Security, go to www.socialsecurity.gov/cola.

Dare to Dream with SBANENY 2015

Thank you for your commitment, expertise and enthusiasm...

Honorary Chairs Tom Wilson & Kristin Koehler



Fine food & company!



Magic by Matt Episcopo



The Wheelchair Experience



Silent & Live Auction



Music by Fresh of Albany



Heads or Tails!



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.

Special Thanks to Our Sponsors



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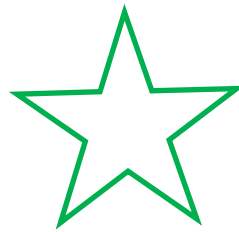


Thank you for Daring to Dream with SBANENY!

Many thanks to those who generously gave in-kind donations.

Gold Star In-Kind Donors

CBRE-Albany
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Schenectady YMCA
Bill & Shelly Socha



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Kimberley's Day Spa
New York Jets
Peggy O'Neill
Pinehaven Country Club
Tattoo Blues
The Rose and Kettle Restaurant

Bronze Star In-Kind Donors

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Gold Sponsor



SOCHA PLAZA



MODERN ELEGANCE

Retail: Only 1,000 square feet of prime retail space remain on the first floor of this state-of-the-art building with entry/exit to both the beautiful lobby and to the main parking lot.

Office: Approximately 4,000 square feet of commercial space remain available on the second floor, which offers beautiful views, spacious community bathrooms, and convenient access for employees and clients.

Apartments: The entire third floor houses Shady Lane at Socha Plaza. While the standard and luxury apartments are fully rented, there are beautiful, fully furnished corporate apartments available for short-term living (3-month minimum preferred) at prices significantly lower than extended-stay hotels.

CALL SOCHA MANAGEMENT
518-399-0990



**SPINA BIFIDA ASSOCIATION
OF NORTHEASTERN NEW YORK**

123 Saratoga Road
Scotia, NY 12302

RETURN SERVICE REQUESTED

NONPROFIT ORG
US POSTAGE
PAID
Burnt Hills, NY
PERMIT NO. 6

***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.**

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

SPINA BIFIDA CONFERENCE 2016

Saturday, April 2, 2016

9:00 AM– 5:00 PM

University at Albany
School of Public Health

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

Saturday May 21, 2016 — Mark your
calendars!! Central Park, Schenectady

SBANENY POOL PARTY

Young Children & Families

Saturday, February 13, 2016

2:00 PM - 5:30 PM

Rudy A. Ciccotti Center

NYC MEET & GREET EVENT

Saturday, April 30, 2016

12:00 PM- 3:00 PM

Bronx Independent Living Services

WATCH FOR FLYERS!

FALL FAMILY RETREAT

DOUBLE H RANCH

OCTOBER 21-23 2016

DARE TO DREAM WITH SBANENY
ANNUAL FUNDRAISER,
NOVEMBER 2016

COMMITTEE MEETINGS

Board of Directors: March 12, 2016

COMMITTEES TO JOIN

Walk-N-Roll

Dare to Dream with SBANENY

SBANENY Conference

Toolkits for Educators

Young Families

Adult Group

NYC Metro Planning Group

FOR MORE INFO CONTACT:

Karen Wentworth

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t (518)399-9151

f (518) 399-5639

sbaneny.org

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. 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

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



SPINA BIFIDA ASSOCIATION
OF NORTHEASTERN NEW YORK

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.

The deadline for receiving scholarship applications and all supporting materials is April 15, 2016.

For further information, guidelines, & applications go to our chapter website at www.sbaneny.org or contact our office.

ADDITIONAL SCHOLARSHIPS TO EXPLORE

180 Medical

- Award amount: \$1,000
- Available to two-year, four-year, or graduate school program full time in the fall are eligible to apply. Applicants must be under a physician's care for a spina cord injury, Spina Bifida, transverse myelitis, or neurogenic bladder

American Association on Health and Disability

- Award amount: under \$1,000
- Available to undergraduate and graduate students with a documented disability. Preference given to students majoring in public health, disability studies, health promotion or a field related to disability and health.

AmeriGlide Achiever Scholarship

- Award amount: \$1,000
- Available to college students who have finished at least one year of college and use a manual or electric wheelchair

ChairScholar Foundation

- Award amount: varies
- Available to high school seniors and college freshmen with a profound physical challenge (chair-confined) and are under 21

Gabriel's Foundation of HOPE

- Award amount: varies
- Available to students living with a diagnosed disability and to immediate family members related to a person living with a disability

For more information about these scholarship opportunities visit the SBA website:

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

WALK-N-ROLL FOR SB®

REGISTRATION BEGINS

FEBRUARY 1, 2016!

Please visit our website to register to participate in the **SBANENY Walk-N-Roll for Spina Bifida** on May 21, 2016.

www.sbaneny.org

Promoting the prevention of Spina Bifida and enhancing the lives of all affected.



SBANENY wishes a Happy New Year to all of our families, friends, and donors!



Thanks for making it a great year!