



SBANENY News to Use

CHAIR LETTER

Greetings and happy New Year! As we say goodbye to another year, I feel it's always worthwhile to take some time to reflect on the years successes. The year 2017 was a very successful year for SBANENY for many reasons. Most importantly, we were able to continue our mission of supporting our consumers and their families in the areas of support, health and wellness, awareness, respect and dignity, and empowerment. In the area of support, over 17,000 targeted outreach contacts were made to consumers with information pertinent to living with Spina Bifida. The organization also served as a resource for other service and health care providers in the community. Programs such as the Y-Knot sailing program and a family retreat weekend hosted by Double H Ranch are examples of programs that develop health and wellness. In the area of awareness, SBANENY staff and volunteers visited with community leaders and elected state and federal officials to raise awareness about Spina Bifida. They also attended disability awareness and empowerment days to educate the general public about Spina Bifida. Finally, the organization always strives to show respect and dignity to all those that we serve and empower them in any way that we can.

It's a new year now and 2018 is going to be a year of change for the organization. First, we will be saying goodbye to our wonderful executive director Karen, who will be retiring in January. I think I speak for all of you when I say that words can't express the gratitude that we feel for all of the years of dedicated service that Karen has shared with us. It is because of her and countless others that SBANENY is the wonderful organization that it is today. Karen, we wish you all the best in your retirement, and we hope that you will enjoy this time doing the things that mean the most to you.

I am happy to report to you that the search and transition committee has selected our new executive director, Barb Diesem-Zimmons. She comes to us with experience in many areas including fiscal management, knowledge of Spina Bifida, grant writing, leadership as an executive director/training specialist for NYSADSA, project coordinator for the Research Foundation/Office of Mental Hygiene, chair of the public service commission of the Capital District Consumer Utility Advisory Council, and a member on a variety of boards. Barb is enthusiastic about her new role and shares our passion of helping those with Spina Bifida.

Finally, I am going to be the Chair of the Board this year. I previously served as Vice Chair and Secretary and I'm looking forward to my new role. I'm a special education teacher in a preschool classroom at the Cloverpatch site for the Center of Disability Services. I look forward to meeting you this coming year. I would like to invite you to get involved in the organization by attending programs and events, volunteering for one of our fundraising events such as Walk N' Roll and Dare to Dream or perhaps if you have more time, serve on one of our committees such as Fundraising and Marketing, Board Development, Policy and Procedures, and the Conference Committee to name a few. Together I know that we can achieve great things this year!

Thank you.
Peggy Smith, Board Chair

ISSUE #74 JANUARY 2018

Chair Letter
SBANENY updates
Education Day
Walk-n-Roll for Spina Bifida
Dare to Dream
Adaptive Dance
Sponsors

SBANENY BOARD

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Kevin Chamberlain
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Executive Director
Barbara Diesem-Zimmons

SBANENY UPDATES

WELCOME OUR NEW EXECUTIVE DIRECTOR

BARBARA DIESEM-ZIMMONS

As most know, Karen Wentworth retired after 16 years of dedicated leadership. We are excited to welcome Barbara as our new Executive Director.

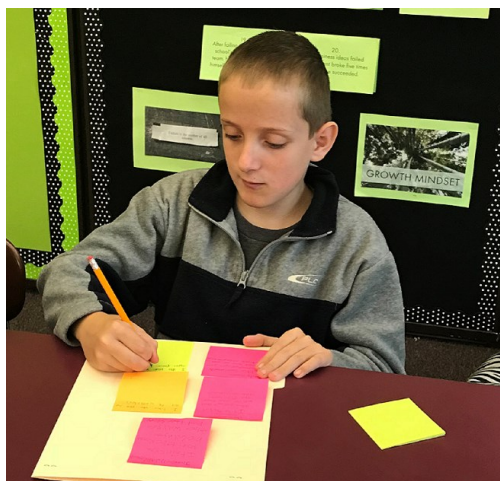
Barbara comes to us with a variety of experience and expertise that will continue to lead SBANENY forward in our mission and goals to have quality support services and programs available for people living with Spina Bifida in northeastern New York and NYS.

CONGRATULATIONS NICHOLAS HENDERSON

Nick was recently awarded with Student of the Month in his English Language Arts class at school!

"Nick was chosen because of the exemplary character that he demonstrates and his continued effort in writing. Nick is extraordinarily kind. Nick constantly volunteers to help get the class set up or pass out work.

He gets along with all students and he is willing to work with everyone."



PROGRAM SURVEYS

Thanks to Albany Rotary Foundation, SBANENY was able to create 300 surveys for adults, parents of adults, and parents of children living with Spina Bifida to identify program wants and needs. The surveys are intended to provide program feedback and input that will guide program design and outreach.

Surveys are available in print and online through our website: www.sbaneny.org

We welcome and encourage consumer input at all times. This feedback is significantly important as we plan our 2018 activities. **Submit your survey by February 1, 2018 and you will be entered in a raffle to win a \$50 gift card!**

Email casemanager@sbaneny.org for questions, additional copies, or to submit your survey!

PARENTS IN OR NEAR NYC

Based on conversations with families, there was a recognized need to facilitate local connections between families living downstate or in NYC. SBANENY created a closed Facebook group to create a forum for sharing information and resources.

If you are a parent of a child or adult living with Spina Bifida and live in the following counties, you are welcome to join:

Bronx	Putnam
Dutchess	Queens
Kings	Richmond
Manhattan	Rockland
Nassau	Suffolk
New York	Westchester
Orange	

This is a closed group- meaning anyone on Facebook can see the group exists but only approved members can see the posts. This group is being managed by the Spina Bifida Association of New York. **If you would like to join, email casemanager@sbaneny.org in order to receive the group invite!**

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.

Dare to Dream

with SBANENY



Honorary Chair, Jason Gough of WNYT



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SOCHA PLAZA

115 Saratoga Road | Glenville, NY | 518-399-0990 | Sochamanagement.com

UPCOMING EDUCATION DAY

Empowerment Through Planning for the Future

Saturday, April 14, 2018

8:30-4:30

University at Albany School of Public Health
1 University Place, Rensselaer, NY 12144

Keynote Speaker: Matt Davis, Assistant Director of Student Services at Western Kentucky University

Matt is a 51 years old adult with Spina Bifida. He is from Bowling Green, KY and currently reside there as well. He has been with the Student Accessibility Resource Center (SARC) at Western Kentucky University since August, 2001 and have been recently been appointed Assistant Director of the SARC. He graduated with both a Bachelor's and Master's Degrees in Social work from WKU.

Nationally Renowned Presenters!

Dr. Andrew Zabel, Clinical Director of the Department of Neuropsychology at Kennedy Krieger Institute

Dr. Eric Levey, Chief Medical Officer of Health Services for Children with Special Needs Washington, D.C.

What YOU can expect

- Medical updates in the fields of neurology, urology, bowel management, and executive functioning
- Information supporting planning for the future including benefits advisement, emergency preparedness, intimacy, and self-direction
 - Sessions regarding adaptive recreation and self-care
 - Kids Camp: Activities for teens and tweens including therapy dogs and adaptive fashion

Evening Socials: Adult and Young Family Socials; dinner provided as attendees reflect on the day and build on connections.

Sunday Workshop: Activity to be determined

Keep an eye out for...

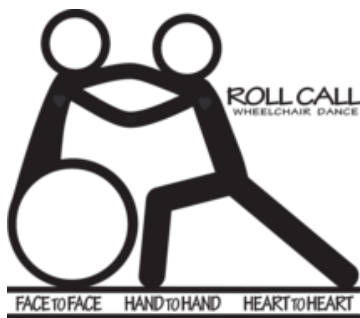
- Final schedule and registration forms.
- Scholarships through SBANENY– financial support for the cost of travel, lodge, and registration to attend a local conference!
- Childcare registration for families with young children.

SAVE THE DATE

WALK-N-ROLL FOR SPINA BIFIDA

MAY 19, 2018—CENTRAL PARK—SCHENECTADY, NY

Roll Call Wheelchair Dance



Dare to
Dream,
11/18/17



Partner Dance Workshop - 11/19/17



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ASSOCIATION
of Northeastern New York**

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TAKE ACTION WITH SBANENY

In the upcoming months, consumers will be receiving draft letters encouraging contact be made with their representatives supporting SBANENY. We are seeking your support in our ongoing advocacy efforts to be recognized by New York State.

Why are we advocating for NYS recognition?

- SBANENY does not charge for services with the exception of occasional small fees to commit attendance
- There has been more than a 50% increase in request for services in 2016 and an additional 30% increase in 2017
- Over 50% of the services we provide are for individuals and families who live outside of northeastern New York, our service area.

What are we asking of you? - Submit a letter or phone call testimony to your representative.

- How have our services impacted you and/or your family?
- Feel free to include a personal story about life with Spina Bifida, or a picture to help raise awareness!
- Research your representative
 - **Find my Senator:** <https://www.nysenate.gov/find-my-senator>
 - Create an account on nysenate.gov so you can share your thoughts and feedback with your senator.
 - **Find my Assemblyperson:** <http://nyassembly.gov/mem/search/>
 - Visit your assemblyperson's page, select contact to find contact information to share your thoughts and feedback

Thank you for your time and energy in supporting SBANENY. We appreciate your advocacy as we pursue NYS recognition and our mission to enhance the lives of all affected.



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



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OF NORTHEASTERN NEW YORK**

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Scotia, NY 12302

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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.

Memorial forms are available. Please contact our office.



**Become a sponsor, plan to attend,
or donate at sbaneny.org.**

ABOUT SBANENY

Our purpose is

*Support
Health & Wellness
Awareness
Respect & Dignity
Empowerment*

UPCOMING EVENTS

***EDUCATION DAY: EMPOWER-
MENT THROUGH PLANNING
FOR THE FUTURE***

APRIL 14, 2018

SUNY School of Public Health

***WALK-N-ROLL FOR SPINA BIFI-
DA***

Saturday, May 19, 2018

Central Park, Schenectady NY

COMMITTEE MEETINGS

Walk-N-Roll— January 2018

**Education Day 2018 —February
2018**

Board of Directors— 3/10/18

Board Development —TBD

Fundraising & Marketing—TBD

COMMITTEES TO JOIN

Walk-N-Roll

Dare to Dream with SBANENY

SBANENY Education Day

Fundraising & Marketing

Board Development

Policy & Procedures

Audit & Finance

FOR MORE INFO:

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**VISIT OUR WEBSITE —
FIND US ON FACEBOOK!**

Website: sbaneny.org

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