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MESSAGE FROM THE CHAPTER CHAIR

Summer is in full swing. The adult group is planning a picnic in Colonie at the Crossings in August. There are also plans in the works for an activity for parents with minor children. So stayed tuned! More information will be coming soon about that.

Back in May we had a great turn out for our annual Walk-N-Roll for Spina Bifida and Family & Friends Picnic in Schenectady's Central Park Pavilion. This year, in addition to this Schenectady walk, several families and individuals organized events in their home towns to raise awareness and funds for Spina Bifida. Thank you to the Henderson Family, Aly McDonald, and Adam Magee for organizing great events. If you would like to organize an event your area for Spina Bifida, please call the office for more information. We are always looking for more support and new ideas.

We are also getting ready for our biannual regional conference in September in Albany. This year's theme is "Empowerment through Advocacy: Living with Spina Bifida." We have many great speakers planned. Be sure to save the date! Registration forms and detailed information will be available soon.

SBANENY is always looking for people that would like to be a part of our committees and our board. If you are interested in helping to plan any of our events like the Walk-N-Roll, the conference, programs, or the annual fundraiser gala, please let us know. Would you like to be a part of our board? Please call our office to find out how you can participate. It is always great to see new faces on our board and committees. I always enjoy talking with individuals and families at our events. It is very helpful to hear what people like and don't like. We have many more great things planned the rest of this year. Plan to be a part of it!

Stay cool, drink plenty of water, and enjoy the rest of your summer.

Shameka Andrews
Chapter Chair

SBANENY Board of Directors

- Shameka Andrews, Chair
- James Dunham, Vice Chair
- Stephanie Mumford, Treasurer
- Michelle Miller, Secretary
- Kevin Chamberlain, Past Chair
- Amy Clinton
- Raymond Langelier
- Lyndsi Holmes

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SBANENY NEWS

ADULTS SHARE EXERCISE TIPS

Adults joined in Albany on Saturday May 10th to share resources and ideas about how to keep fit. We passed around guides, viewed and tried out exercises we found on websites for chair Zumba and chair yoga, and brainstormed ways we can incorporate exercise into our everyday lives.

The next adult meeting is being planned with the young adult group. As a group we will host a picnic at the Crossings in Colonie on Saturday, August 16th. We will include chair zumba, as well as other activities to get us moving before and after our meal. Stay tuned for more information.



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.

**HELP STRENGTHEN THE
SPINA BIFIDA COMMUNITY!
LIKE OUR PAGE &
FOLLOW US ON FACEBOOK!**

FAMILIES WITH CHILDREN

SBANENY CONFERENCE SEPTEMBER 6th

The SBANENY sponsored conference will have a variety of topics of interest for parents. Childcare will be provided on site. See page 4 for more information. PLEASE NOTE: Pre-registration is required for childcare.

FALL FAMILY RETREAT WEEKEND

DATE: October 24th - 26th, Friday evening - Sunday noon

WHERE: Double H Ranch, Lake Luzerne, NY

WHO: Children with Spina Bifida ages 5 to 21, their parents/guardians & siblings

WHAT: Meet other families while participating in a variety of activities including high ropes, swimming, arts & crafts, campfires, and more!

HOW: Be prepared - Make an appointment for a physical for your child with SB. (If your child is attending Double H this summer, you are all set.) **Registration in advance is required.** Registration forms will be available shortly.

REFLECTIONS ON

ATTENDING A CONFERENCE

Executive Director, Karen Wentworth, attended the national SBA conference in Anaheim, CA from 6/29 - 7/2/14.

As I sit and wait for the shuttle that will take me to the airport for my trip back home, I find myself thinking of the journey that I have taken over the past few days. It is Wednesday. I arrived in Anaheim, California late Saturday night to attend the national Spina Bifida Association conference. As I leave I find myself thinking about what I have gained, learned, experienced, and shared with others in the national Spina Bifida community over the past few days and what I am bringing home to our SBANENY community in New York State.



SBANENY NEWS

Sunday morning as I got off the elevator to join the group for breakfast, my conference experience began with a greeting by a smiling Disney cast member saying, "Have a magical day!" That was definitely foreshadowing for what was about to come. Having attended annual conferences over the past six years, I was immediately exchanging "Hello!" and "How ARE you?" with people that I have met at previous conferences. It is always good to renew these friendships and continue to learn and grow together. What struck me, however, is that each year I attend, this list grows. In my first session, I had the opportunity to meet several people. Little did I know Sunday morning that by Tuesday evening I would be riding a roller coaster with a mom/nurse, an Executive Director of another chapter, and a researcher from the national Center for Disease Control. (Don't get too excited – It was an "introductory" roller coaster, and plenty of excitement for my liking!).

So... Why do I attend? It's not for the rides at theme parks, although sharing a fun experience is part of developing and strengthening these relationships. There are many benefits that I believe I bring back to our community in New York State to better lead SBANENY.

- **Current information** – During the conferences, I attend sessions that offer the most current information about Spina Bifida. A wide variety of topics are covered; medical (neurology, urology, orthopedics), education, social, transitions, health and well-being are just a few examples.
- **Connecting with others in the Spina Bifida community** – Through these conference days, I interact with many people; parents, adults with Spina Bifida, representatives from our national affiliate, as well as from chapters around the country. We all learn from each other.
- **Vendors** – There are always an assortment of vendors present with samples and

information. My goal is to have a conversation with each one to learn about what their companies and organizations have to offer.

- **Leadership** – During the conference, there are typically meetings of national and chapter leaders. With the goal of building a stronger Spina Bifida community, we meet to consider how we can better work together to achieve the mission and vision of our organizations.

What are your options for conference attendance? On Saturday, September 6th, our chapter is sponsoring a regional conference in Albany. You will find more information about this elsewhere in this newsletter. I strongly urge you to review this information, reserve the day on your calendar, and make travel plans today if you are attending from a distance. There will be something for everyone. There will be sessions to learn current information, there will be others from the Spina Bifida community to learn from and share with, and there will be vendors. Gatherings such as our conference and Walk-N-Roll also help to build a stronger Spina Bifida community in New York State.

SBANENY Scholarships – We recognize that there will be travel and lodging expenses for people who are coming in from out of town to attend the conference. There is scholarship money available to help cover these costs. If travel expenses are a concern for your family, please contact me.

Registrations for our conference will be available in the next couple of weeks. The committee has been meeting over the past year to plan this event. Please help them by registering early! (There is an early bird special for those who do!)

I look forward to seeing you at our conference on September 6th. In the meantime, read on for more information...

Karen Wentworth
Executive Director, SBANENY

SBANENY NEWS

SBANENY SPONSORS ITS THIRD SPINA BIFIDA CONFERENCE EMPOWERMENT THROUGH ADVOCACY: LIVING WITH SPINA BIFIDA”

Who: Individuals with Spina Bifida and their families, caregivers, & service providers

When: Saturday, September 6th, 2014

Time: 9:00 AM to 5 PM

Where: Bryant & Stratton College, Albany, NY

Keynote Speaker:

Barbara Devore *has been involved in the SBANENY for a number of years, as a board director and chair. A retired Deputy Director of the NYS Department of Health, Barbara works at the Independent Living Center of the Hudson Valley, helping to secure funds for expansion. In her leisure time, Barbara loves working out at the local YMCA, participating in 5K races, and Kayaking.*



People secure their rights in many ways. Sometimes they vote, or they may advocate and yes, sometimes they participate in civil disobedience. Equal rights for people with disabilities were achieved using all of these methods, and were carried out by people with disabilities and those that care for and about them. Barbara will share her own experiences with pushing for her rights, and the audience will share their successes and on-going challenges that require advocacy in their own life.

Other Conference Highlights Include:

- **Workshops addressing:**
 - ❖ Employment and Advocacy
 - ❖ Work Incentives
 - ❖ Advocacy for Quality Health Care
 - ❖ Advocacy for your Student's Education
 - ❖ New Information from the OPWDD (like Front Door and Self Direction)
 - ❖ Transitioning Out of High School

- ❖ Medical updates in the areas of neurology, urology, and bowel management.
- **Opportunities to connect with old and new friends** throughout the day, including time at the included breakfast, lunch, and reception (held immediately after the last session of the day).
- Dedicated time to talk to **Vendors and Service Providers** from the community

We welcome people from throughout New York State and neighboring areas.

Scholarships will be available to help with the cost of registration, travel, and lodging. There will be information about this in the registration materials.

Lodging: A limited number of rooms (both accessible and non-accessible) with deeply discounted rates for Friday (9/5) and/or Saturday (9/6) are available at the Springhill Suites by Marriott, 8 California Avenue, Albany, only a few blocks from the Conference site. The rate is \$109.00 plus tax (currently 14%). To reserve a room, call the hotel (518-724-7999) and request a room held under the name of "Chamberlain." Supply the hotel with your name, credit card information, and phone number. *Reservations are on a first come, first served basis and must be made by **Friday, August 15, 2014 to ensure the discounted rate.***

What should you do about the conference today?

- ✓ Save the date – mark "SB Conference" on September 6th on your calendar today!
- ✓ Watch your mail, email, Facebook & www.sbaneny.org for more information and registration forms.
- ✓ Reserve your room ASAP (discounted rooms are limited in number) but not later than Friday, August 15th to get the discounted rate.

SBANENY NEWS

NEW YORK CITY AREA PROGRAMS KICKOFF EVENT

As planned, a group of consumers met in Manhattan on May 10th. In addition to hearing a presentation about accessibility and recreation in the City, they also met each other. Participants responded with enthusiasm to the opportunity to get together.

Plans are in the works for the next Greater Metro New York program this fall. 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 have been done through conference calls.) *Please contact our office if you would like to help.*

SPINA BIFIDA AWARENESS PARTY! IN MONTOCHELLO

Adam Magee has been busy raising awareness of Spina Bifida in his community. Co-hosting with good friend Justin Bass, Adam held a "Spina Bifida Awareness Party!" in a park in Monticello. People



celebrated in support of the cause with catered food, raffles, a 50/50, and a live band.

Would you like to raise awareness of Spina Bifida in your community? Are you looking for ideas about how to do that?

We can put you in touch with Adam & Justin as well as others who have been very successful.

Funds raised from their party were donated to SBANENY. Thank you Adam & Justin!!

AREA RESIDENTS "WALK FOR NICK" IN COPAKE

Stephanie Henderson, mother of seven-year-old Nick, organized a Walk/Roll for Spina Bifida "Team Nick" at the Copake town park. The third annual event was a great success, and is aimed at raising awareness as well as funds for Spina Bifida.

Players and coaches from the Taconic Hills Little League in which Nick competes also took part in the event. Little league coach Bill Mulrein of Ghent was among those on hand.



"He's the heart of our league, so we'd do anything to help out," Mulrein said. "We have approximately 200 kids in our league and there isn't one of them that has more heart than that little boy."

Local Girl Scouts had a crafts table to raise money, and there were also raffles with prizes donated by local stores and a lunch.

SBANENY NEWS



for Spina Bifida

SBANENY Walk-N-Roll

For Spina Bifida 2014

Presented by The Daily Gazette

Raised over \$26,000 to

Support Programs & Services!

Congratulations to the 2014 prize winners!

Aly McDonald, team leader of Aly's Aim for Awareness, was recognized for Individual Raising the Most Money. Her team won for Team Raising the Most Money. Great job Aly!



Paul Lukasiewicz is Team Leader of Team Too Inspired To Be Tired, winning the prize for Best Team Name. Paul took his inspiration beyond the event, joining the committee for 2015!

Say "Thank you!" to our sponsors!

Titanium Sponsor

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Event Photographer: Kaelco

Event Emcee: Lou Roberts

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Event Beverages: Pepsico

Event Bagels: Manhattan Bagel

Corporate Friends

1st National Bank of Scotia

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Stewarts



Team NyAshia won the prize for Best Team Spirit. They led the day with smiles and a wave for everyone!



SBANENY NEWS

ANNUAL GALA SILENT AUCTION FUNDRAISER!

DARE TO DREAM WITH SBANENY: CELEBRATING OUR SUCCESSES!

DATE: November 15, 2014

TIME: 6 to 9 PM

PLACE: Pinehaven Country Club, Guilderland

ENTERTAINMENT:

Music by Shadowland

Live & Silent Auction



**Please SAVE THE DATE....
Mark your calendar...**

**ASK FRIENDS & FAMILY
TO SAVE THE DATE TOO!**



Join the Dare to Dream with SBANENY Annual Fundraiser Planning Committee!

WHERE: SBANENY office, 123 Saratoga Road, Scotia or call in by conference call.

WHAT:

- Plan silent auction "basket" displays
- Create display signage for "baskets"
- Create bid sheets for "baskets"
- Plan evening's events
- Create evening program
- Create invitation
- Assist with mailing preparation
- Assist with publicity
- Coordinate dessert donations
- Assist with soliciting silent auction donations
- Assist with thank you letters to donors
- Audio/Visual display preparations



Day of/ Evening of the Event Volunteers:

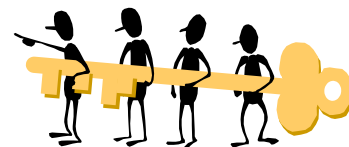
- Set-Up and Break Down
- Welcome Table
- Greeters
- Auction Assistance



- Coat Check
- Audio/Visual & Backstage Assistance
- Photography

Questions? There are many tasks to be done. *This is where you can make a difference.* This committee welcomes new members with fresh energy & enthusiasm! Please contact our office as soon as possible to find out where you can help out. Thank you!

MANY HANDS: THE KEY TO OUR SUCCESS!



How would you like to be involved?

- ✓ Program committees?
- ✓ Party planning for our Annual Gala & Silent Auction?
- ✓ Graphic Design?
- ✓ Database expertise/Microsoft Access?
- ✓ Clerical tasks? Mailing?
- ✓ Worker bee?
- ✓ Other?

Please give us a call and we will work with you to find a role that works for you and SBANENY!

Your time and talents can make a difference!



Members of the Walk-N-Roll 2014 Committee & Day of Event Volunteers take a moment to gather for a group picture. Great job! Thank you to everyone!



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SBANENY CALENDAR OF EVENTS

- AUGUST 16** Picnic for Adults
- SEPTEMBER 6** SBANENY sponsored regional conference
- OCTOBER 24 – 26** Fall Family Weekend, Double H Ranch
- NOVEMBER TBA** Greater Metro NYC Program
- NOVEMBER 15** SBANENY Gala: Dare to Dream with SBANENY – Celebrating Our Successes

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**

SBANENY BOARD MEETINGS July 12, September TBD, and November 8

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.