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MESSAGE FROM THE CHAPTER CHAIR

Those of you who are paying close attention may be wondering "what happened to Shameka's letter?" and/or "who is this Kevin person?" Fear not! Shameka has stepped down from the SBANENY board but remains involved as a volunteer, including being on the regional conference (I hope those of you who attended that great session last month found it rewarding!) and auction fundraiser committees.

Speaking of Shameka volunteering, the Chapter is always looking for help. Even if you only have a couple of hours to spare, we can find a way to use them! Just let Karen know (her email address and phone number are here in the newsletter, and you can always check the website: sbaneny.org). The number of individuals and families that we have been able to reach has increased and that's a good thing -- to know that we are making a difference in so many lives is the reason we do what we do every day – but we can always use another hand!

Getting back to who I am, I was board chair immediately before Shameka took up the reins. I will be filling in as acting chair until January, when Jim Dunham takes over. If you have any thoughts or issues to bring to my attention, please feel free to do so at kevin.chamberlain@sbaneny.org .

We have a busy autumn planned. The Family Weekend at Double H – always a lot of fun – is happening at this printing, the exciting Gala Auction event is on Saturday, November 15th, and a NYC and Young Family events are being planned as well.

Kevin Chamberlain,
Acting Chair

SBANENY Board of Directors

Kevin Chamberlain, Acting Chair
James Dunham, Vice Chair
Stephanie Mumford, Treasurer
Michelle Miller, Secretary
Raymond Langelier
Lyndsi Holmes

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.*

SBANENY NEWS

ADULTS SHARE LUNCH & ZUMBA

On Saturday, August 16th, a group of adults met at the Crossings in Colonie. They enjoyed lunch together and then were led in a class of chair Zumba. Of course, there was lots of conversation as well!



The next activity for the Adult Group will be held Saturday, October 18th. They plan an afternoon of fun with a visit to the Henry Hudson Planetarium and lunch at a nearby restaurant.



Are you interested in attending Adult Group programs? For more information, contact our office.

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!

SHARE OUR PAGE WITH YOUR FRIENDS!

FALL FAMILY RETREAT WEEKEND AT DOUBLE H RANCH

This past weekend, we filled Double H Ranch housing with a group of 70 people from 19 families! We gathered Friday evening, October 24th and enjoyed a full schedule of activities through Sunday morning. While our time was filled with lots of activities like high ropes, archery, and arts & crafts, the retreat weekend served as a great opportunity for parents to talk with other parents, children with Spina Bifida to meet and develop friendships, and siblings to join in and be included. It is always a great event. Thank you to the staff and volunteers of Double H Ranch that make this retreat weekend possible! Enjoy the pictures later in this newsletter!

NEW YORK CITY AREA PROGRAMS KICKOFF EVENT

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 have been done through conference calls.) *Please contact our office if you are able to help.*

WELCOME TO SBANENY'S PART-TIME ADMINISTRATIVE ASSISTANT

Please join us in welcoming Heather Horwedel to our SBANENY staff. Heather has been involved in programs and activities as a volunteer for over 10 years. As such, she not only brings her office skills, but also an in-depth knowledge of the workings of our organization.



SBANENY NEWS

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

September 6th, people from around New York State attended the SBANENY sponsored Spina Bifida conference in Albany.



Participants shared information and experiences, learning from each other.



Speakers presented on a variety of topics, sharing their expertise and responded to questions from the audience.



Old friends reconnected. New connections were established.



Vendors were available with samples and information about a variety of products.



Staff & an administrator from Warrensburg Central School District attended to bring back information to benefit their students.



The younger crowd enjoyed a day of activities in Kid's Camp including a session of line dancing with local celebrity, Kevin Richards and friends.

SBANENY NEWS

EQUIPMENT EXCHANGE PROGRAM

2009 HONDA ODYSSEY WHEELCHAIR

VAN WITH 20,200 MILES for sale for \$25,000.

To view the van or to ask questions, call Paul Wing (518-439-5096) or e-mail (pwing3@verizon.net).



Child's Wheelchair – Sized for pre-school age. Please contact our office if you would like more information.



ALSO AVAILABLE

- WonderPants – training pants for boys & girls, Size L (32 to 40 Lbs.)
- DynaLube – 2 boxes of 144 packets each
- Catheters
 - Cure 12 Fr.
 - Mentor 8 Fr.

If you can use any of these items, please contact our office by December 1st. We will ship supplies to you at no cost to you.

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!

RESOURCE INFORMATION

New York State Birth Defects Registry has launched a website with sections for parents, families, researchers and health professionals. There is birth defects information and contacts

for national, state and local services. To check out the website, go to www.health.ny.gov/birthdefects.

Offer your feedback at the "We'd Like Your Feedback" link in the left column of their webpage.

J-ROB FOUNDATION PROVIDES ADAPTIVE SPORTING EQUIPMENT TO 18 & UNDER

The J-Rob Foundation, Inc. is a not-for-profit organization that provides adaptive sporting equipment to youths with medically documented physical disabilities/challenges. The foundation wants to provide access to the equipment that children need to maintain a healthy and active lifestyle and enjoy sports and athletics.

The goal of the foundation is to offer these children the opportunity to participate in sporting and athletic activities by providing them with the equipment that they need. Potential equipment includes, but is not limited to hand cycles, racing wheelchairs, and adaptive ski equipment.

Funding is available for youth age 18 and under. For more information and to apply, go to www.jrobfoundation.com.

2015 ADAPTIVE WINTER SPORTS PROGRAM AT DOUBLE H RANCH

Applications are now available for the **2015 Adaptive Winter Sports Program** at Double H Ranch. Medically qualifying children (ages 6-16 years old) have the opportunity to learn to ski or snowboard. There are day programs for local participants and five Family Sleepover Weekends for participants travelling from a distance (2+ hours away from camp). This program is *FREE* of charge however, the family must provide their own transportation to and from camp.

The online winter application is now available on the Double H website at www.doublehranch.org. The deadline for applications is December 1st. Slots fill up quickly so apply soon!

SBANENY NEWS

SPECIAL EDUCATION ADVISORY – COMMON CORE STANDARDS AND STUDENTS WITH DISABILITIES RESOURCES FOR PARENTS

The New York State Education Department has resources designed to assist parents of children with disabilities to have a better understanding of the Common Core Learning Standards, IEP's and the inclusion of recommendations to support your child's progress toward those standards. The information includes resources to:

- understand the Common Core Learning Standards, definitions of terms that may be new;
- questions to bring to CSE meetings that will help to facilitate consideration of goals and supports for your child; and
- questions that you may want to ask your child's teacher.

To view the complete memo go to [HTTP://WWW.P12.NYSED.GOV/SPECIALIZED/COMMONCORE/PARENT-CCLS-JUNE2014.PDF](http://www.p12.nysed.gov/specialized/commoncore/parent-ccls-june2014.pdf).

If you do not have access to the internet and would like a copy of this memo, please contact our office.

JUSTICE CENTER ANNOUNCES NEW ASSISTIVE TECHNOLOGY EXCHANGE PROGRAM

Adapted from: disabilitynews.ny.gov

The New York State Justice Center for the Protection of People with Special Needs, TR Aid Program, is pleased to announce a new Equipment Exchange Program to improve access to devices for Individuals with Disabilities!

TR Aid recently partnered with the New England Exchange Program, to create getATstuff, an Assistive Technology Exchange in New England and New York. GetATstuff is an electronic matching program that helps connect individuals who need assistive technology devices with persons who are selling or donating devices they no longer need.

Participation in the getATstuff will improve the quality and functionality of the equipment exchange system and increase the likelihood of matches. The site enables users to search for items within a 7 state area, including New York. As of September 8th, users can log on to <http://www.getatstuff.com/> and create an account to request equipment or list equipment for sale or donation.

If you need additional information, please call the Justice Center's Information and Referral line at 1-800-624-4143.

CAPITAL REGION UNITED FAMILY ADVOCATES IS LOOKING FOR MEMBERS...

- Do you have a family member with disabilities?
- Do you have a family member in need of services?
- Are you willing to lend your voice to others, to bring the plight of our loved ones with developmental disabilities to the forefront?

If you answered yes to any of these questions then you might want to contact the Capital Region United Family Advocates. They are a small group of concerned family members trying to organize a family advocate group to address the serious lack of funding for services for people with developmental and intellectual disabilities. They are not a political group but a group of concerned families that have already felt the sting of budget cuts. The group's immediate goals are to bring awareness to the general public and legislators regarding the serious lack of funding for housing (did you know that there are over 11,000 individuals currently waiting for housing?) and the critical need to develop new day habilitation programs for individuals aging out of the school systems.

If you are interested in joining with other family members to bring about this goal, please contact Linda Karins at lkarins53@gmail.com.

SBANENY NEWS

“SEE THROUGH OUR EYES. HEAR OUR HEARTS”

PHOTOJOURNALISM EXHIBIT
BY PEOPLE WITH DISABILITIES

The Independent Living Center of the Hudson Valley (ILCHV) is hosting “See Through Our Eyes. Hear Our Hearts,” a photojournalism exhibit featuring the work of eight artists with disabilities. Two of the artists were born with Spina Bifida and have been involved in our organization for many years.

Funded in part by a Community Arts Grant, a program of The Arts Center of the Capital Region through the New York State Council on the Arts, the exhibition includes essays and photographs produced by the artists describing their own disability journey. Their work is the result of a six-week workshop guided by Lee Anne Morgan, a nationally recognized fine arts photographer and writer. The pictures and essays will be available for viewing until early December. If you are interested, please call Barbara Devore at 274-0701 to arrange a time to view the exhibit. ILCHV is located at 15-17 Third Street, Troy NY. The building is on a bus line and is wheelchair accessible.

NEW AAHD FREDERICK J. KRAUSE SCHOLARSHIP

AAHD is accepting applications for the AAHD Scholarship Program (2014-2015) which supports students with disabilities pursuing higher education in a field related to disability and health. Scholarships are limited to under \$1,000. Scholarships are competitive each year. Please visit the AAHD website at www.aahd.us/scholarship to download an application.

Deadline for submission is November 15, 2014. For information, please contact Maria Manolatos, AAHD Scholarship Coordinator, at mmanolatos@aahd.us.

FALL FAMILY RETREAT WEEKEND AT DOUBLE H RANCH A WEEKEND OF SMILES.....



SBANENY NEWS

ANNUAL GALA LIVE & 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

Food: Appetizers, Desserts, Cash Bar

LIVE & SILENT AUCTIONS!

Please Purchase Your Tickets Today!
Invite family & friends to attend – The more the merrier!

LIVE & SILENT AUCTION SNEAK PREVIEW!

**Silent Auction Sneak Preview &
Pre-Event Bidding**

November 1st through November 13th.



Go to www.sbaneny.org to check the auction out and place your bids!

PLEASE

PASS THE LINK TO FRIENDS AND FAMILY!

Ask them to attend and shop to benefit the SBANENY cause...



Cure Twist™



Cure Medical®
Pocket Catheter



Cure Catheter®
regular & now
hydrophilic



Cure Catheter®
Closed System

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 Exempt to the State or Class Category of Agricultural Toxicity, December 8, 2006.



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SBANENY CALENDAR OF EVENTS

- | | |
|---------------------|---|
| TBA | Greater Metro NYC Program |
| NOVEMBER 15 | SBANENY Gala: Dare to Dream with SBANENY
Celebrating Our Successes |
| JANUARY 2015 | Young Family Program – Ciccotti Center
Albany, NY. Details to be announced |

*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 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.*