



**SPINA BIFIDA ASSOCIATION
OF NORTHEASTERN NEW YORK**

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SBA of NENY News to Use

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MESSAGE FROM THE CHAPTER CHAIR

I don't know about you but I am ready for summer. The weather has been full of so many ups and downs but I guess that's what you have to expect when you live in upstate New York. But ups and downs don't only apply to the weather; they also apply to life in general. Life is full of ups and downs, successes and failures. I'm not sure who said it but there is a saying that goes, "If you never fail you never truly succeed."

This past month the chapter experienced two great successes; our second regional conference and Walk-N-Roll. It was a full weekend of great activities.

Our conference was held Saturday April 28, 2012 at Bryant and Stratton College in Albany. This year's conference theme was "Expanding Your Horizons through Healthy Living." We had lots of workshops on healthy living tips and activities with 66 people attending. Thank you to everyone that helped make this year's conference a success.

On Sunday April 29, over 100 people came together for SBANENY Walk and Roll for Spina Bifida 2012. This year's Walk-N-Roll was held in Schenectady's Central Park. Country 107.7 WGNA's Lou Roberts joined us for the second year in a row as our emcee and DJ for the day. This year's Walk-N-Roll raised \$13,000.

I want to thank the Conference and Walk-N-Roll committees and all the volunteers who came out that weekend to help make this a success. Events like these would not happen if we didn't have volunteers serving on committees, on the board, and helping out the day of the events with set up, registration, childcare and more.

On November 29, 2012 we will hold our 3rd Annual *SBANENY Goes to the Theatre* event at Capital Repertory Theater in Albany, NY. This year's play is *This Wonderful Life*. For tickets or event information please contact our office or visit our website www.sbaneny.org. It's sure to be a good time. Hope to see you there.

Shameka Andrews
Chapter Chair

SBANENY **Board of Directors**

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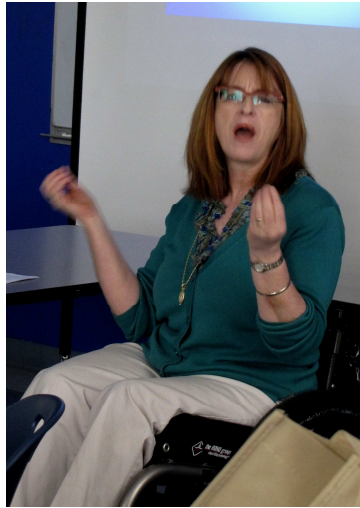
SBANENY SPONSORS

SPINA BIFIDA CONFERENCE

“EXPAND YOUR HORIZONS THROUGH HEALTHY LIVING”

Message from Our Keynote: 56 Years Living with Spina Bifida and Still Learning!

Dorothy (Dot) Nary, Ph.D. received her doctoral degree from the Department of Applied Behavioral Science (ABS) at the University of Kansas and is currently a research associate at the Research and Training Center on Independent Living. She received a Switzer Fellowship in 2011.



Advice: What I've Learned from Life:

1. Know your disability history.

- Who was the person who started to make changes to create opportunities for you? Know who paved the way for you.
- What can we do in the future to make changes for the next generation?
- Read the book No Pity. This book will tell you our history.

2. Educate others.

- We will all have to educate others throughout our lives.
- People don't know what it's like to have a disability. Accept that you are the educators. You are the people who know what it's like to have a disability and you need to share this with other people.
- It does get tiring but it's really important that we all educate others for each other.

3. Advocate, advocate, advocate.

- We are the change agents. We will always have

to be advocates.

- Tools for change:

a) Laws (i.e. ADA)

b) Surgeon General's call to action to improve the health and wellness of people with disabilities:

Goal #1 - People nationwide understand that persons with disabilities can lead long, healthy, productive lives.

Goal #2 - Healthcare providers have the knowledge and tools to screen, diagnose, and treat the whole person with a disability with dignity.

Goal #3 - Persons with disabilities can promote their own good health by developing and maintaining healthy lifestyles.

Goal #4 - Accessible health care and support services promote independence for persons with disabilities.

4. Find a mentor and be a mentor.

- If you have a disability, you are going to have to break the rules because the rules don't always work for us.
- Get a mentor - Find somebody who is doing something that you would like to do that you can learn from. After you do that, mentor the next generation. We need to take and then we need to give back.

5. Remember - your health is not just physical. Mental health is very important.

Dealing with Depression:

1. Create routines and follow them. Set and maintain healthy routines.

a) You may not want to get out of bed in the morning, but make sure you get up everyday.

b) Get out and wheel around the block. Fresh air and being outside is very important.

c) Pay attention to your diet. Make sure you get 5 fruits and vegetables everyday.

d) Stay in touch - Call someone every day, even if you don't have anything important to say, just to keep in touch. Join a faith community if you are interested. Get support.

2. Contribute.

a) Everyone can contribute something to the community (volunteer at the library, serve on a

board, visit someone in a nursing home, etc.). You get a lot back when you contribute.

b) Reach out your hand to those who are not involved in the community. Bring someone new with you to an event to get them involved too.

***"Promise me you'll always remember:
You're braver than you believe, and
stronger than you seem, and smarter than
you think."***

- Christopher Robin to Winnie the Pooh



Attendees enjoyed hearing Dr. Nary's ideas and philosophies.



A variety of vendors spent time talking with attendees, providing information and samples of their products.



Attendees had the opportunity to learn from a variety of presenters who made themselves available long after sessions were over, informally responding to questions.



Many thanks to our Conference Committee of volunteers....

Many thanks to Vanessa Chamberlain, Conference Committee Chair, and the group of committee members. Your time and dedication over the past year plus resulted in a great day for all those who were able to participate.

Attendees had opportunities to talk with peers, and parents found opportunities to talk with and learn from adults with Spina Bifida.



Several sessions encouraged active participation, interaction among participants, and in "Yoga Fun for Kids", between parents and children.



In concert with the theme of the conference, attendees had options for healthy foods throughout the day.



Children were included, making friends in childcare while parents attended sessions.

Many thanks to.....

- **Bryant & Stratton College for providing the venue for the conference.**
- **Our conference grantors, sponsors, and vendors:**

NYS Developmental Disabilities Planning Council
 Christopher & Dana Reeve Foundation
 Vitapath Genetics
 180 Medical
 Mobility Works
 Monroe Wheelchair
 MV-1 of Upstate New York
 Sampson's Prosthetics & Orthotics Lab
 CR Bard

Colonie-Guilderland Rotarians Pitch In To Help

It's the story of the knight & lady in shining armor riding in on the horse to save the day... As conference day drew near, the planning committee was approached by this generous group of Rotarians. Did we need any help with

set up or clean up for the event? Would a donation be helpful to support the cause?

As promised, a group of four Colonie-Guilderland Rotarians arrived on Friday afternoon with energy and enthusiasm. Moving furniture, boxes, setting up equipment, arranging food tables, cleaning – no task was too daunting. On Saturday, to the extreme relief of the then tired Conference Committee, the Rotarians were back! They made quick work of getting everything back in order. We are very grateful to our new friends!

HELEN R. MERTENS EDUCATIONAL

SCHOLARSHIP 2012 RECIPIENTS ANNOUNCED

Congratulations to this year's recipients of the Helen R. Mertens Scholarship with awards of \$500 each.

Alexa Wyszomirski is pursuing an Associates Degree in Graphic Design at Mildred Elley in Albany. Her career goals include creating her own graphics business and developing a young adult clothing line.

Bryan Darby will be attending Mohawk Valley Community College this fall, pursuing a degree in Media Marketing and Management.

Roy Forster plans to attend Mount Saint Mary College to study the sciences. His long term goal is to pursue a career in medicine.

Grady Picinich is a student at SUNY Albany, enrolled as a Chemistry major, Math minor. After graduation, Grady plans to attend a missionary trip out of the country and to teach Chemistry or Math on the high school level.

We are grateful to Helen R. Mertens and her estate, as well as private donor, for making this scholarship program possible for constituents of SBANENY.

SBANENY

EQUIPMENT EXCHANGE PROGRAM

Spring cleaning? Do you have equipment that your child has grown out of but it is still in useable condition? Or maybe you are an adult, and you haven't outgrown it, but you know that you won't use it anymore? Give us a call or send us an email with a description of the equipment. We will get the information to people who might be able to benefit and help your families to connect.

Cabin Fever Party



Families enjoyed good food, good company, and entertainment with juggler Miles Garfinkel at the SBANENY Cabin Fever Party on March 3rd.



SBANENY's New Look

Visit Our Website at

www.sbaneny.org!

Thanks to the contributions of time and talent from Jeff Urell, and upkeep and maintenance from Kevin Chamberlain, our website has an entirely new look. We believe that visitors will find it to be user friendly with information that is current. Please check it out and mark it as a "favorite."

SBANENY

Email Address Change

Please note we have a new email address:
admin@sbaneny.org.

Please change this in your records. We no longer regularly check the sbaalbany102@aol.com address and at some point soon will be discontinuing it.

SBANENY DEVELOPMENT UPDATE



for Spina Bifida

SBANENY Walk-N-Roll for Spina Bifida 2012 was a great success. With over 100 people participating, and donations from over 300 individuals and organizations, the community pulled together to raise \$13,000. Congratulations to the committee who worked to make this a successful event for our community! Special thanks to our sponsors.



*Most Creative Team Tee
Team Zayne Rebb*



*Team Raising the Most Money
CNY Superstars!*



*Most Creative Team Name
Maddie's High Rollers!*



*Lou Roberts of WGNA,
event DJ and Emcee
with Heather
Horwedel, event chair.*

Thank you to Platinum Sponsor



In Print. Online. All the Time.

The Times Union, as the region's leading media organization, is deeply embedded in this community. Our commitment to reporting the news fairly and independently, sponsoring local events and supporting local businesses helps to strengthen our area and make it a better place for all to work and live.

Each year, we sponsor hundreds of non-profit organizations throughout the Capital District area. This helps the fund-raising and awareness efforts of local organizations engaged in arts and culture, health and human services, youth, environment, economic development and education.

The Times Union is part of Hearst Corporation, one of the world's leading media companies. In the Capital Region, our suite of products extends beyond the daily newspaper, to include seven magazines, the region's leading Web site, a mobile site and a tablet platform. Our digital media platforms; Search Engine Optimization and Search Engine Marketing help local businesses get found on the web. All this makes the Times Union a valuable resource for the growing and diverse needs of the Capital Region's business community.

Please stop in and say "Hi!" to these businesses for their support of SBANENY Walk-N-Roll 2012:

**Manhattan Bagel, Socha Plaza, Scotia
Price Chopper
Stewarts Shops
MV-1 of Upstate New York**

**Thank you to Gold Sponsor
Vitapath Genetics**

Help make a
difference.
Participate in our
Spina Bifida Study>

Please see the enclosed brochure with information about Vitapath's research for Spina Bifida prevention.

 **SBgenetics.org**

Loving Hands in All Seasons Quilt Guild STITCHING BLOCKS FOR SPINA BIFIDA

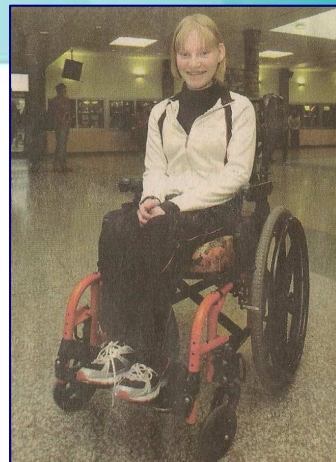
Congratulations to Ms. Sue Pickett! Sue's name was pulled for the quilt raffle during the reception at the April 28, 2012 conference. Special thanks go to Joyce Neznec who led this fundraising effort to benefit programs and services provided by SBANENY. Her efforts, combined with the talents of her quilt guild, raised \$900 for SBANENY.



Joyce Neznec, right, is a member of the Loving Hands in All Seasons Quilt Guild and led this fundraising project. She was present for the raffle drawing.

TEEN ORGANIZES SPINA BIFIDA FUNDRAISER

Corning teen, Britany Troutt, organized a one-mile walk fundraiser for SBANENY. Together with her mother and sister, Britany received great support from her community for her cause. As a bonus for Britany, the fundraiser walk counted as a sophomore class project. In addition to raising awareness in her community about Spina Bifida and services available to individuals and families, Britany's project also successfully raised donations of \$1,700. Thank you to Britany and her family!



Go to the Theater for SBANENY!

NOVEMBER 29, 2012

SEE PAGE 11 FOR DETAILS

**THIS
Wonderful
LIFE**

**ORDER TICKETS TODAY WITH
NEWSLETTER INSERT**

GRANTS FOR MEDICAL CARE

United Healthcare Children's Foundation is a 501(c)(3) non-profit charity dedicated to facilitating access to medical-related services that have the potential to significantly enhance either the clinical condition or the quality of life of the child and that are not fully covered by the available commercial health benefit plan. This "support" is in the form of a medical grant to be used for medical services not covered or not completely covered by commercial health benefit plans. For more information, go to www.uhccf.org or call (952) 992-4459.

WHEELCHAIR ACCESSIBLE TAXIS FOR ALL OF NEW YORK STATE

Cliff Perez, Systems Advocate of Independent Living Center of the Hudson Valley, is working on a project to promote statewide legislation for wheelchair accessible taxis. A Legislative Proposal has been written calling for a percentage of all taxis to be energy efficient and universally designed/wheelchair accessible. This proposal has been presented to the NYS Assembly's Task Force on Disability.

Do you believe that legislation is required in order to ensure or maximize the opportunities and availability of wheelchair accessible taxis? Here are suggestions from Cliff about what you can do to help:

➤ **Write a letter to:**

Ms. Kimberly T. Hill, Director
New York State Assembly
Task Force on People with Disabilities
Agency Building 4, 12th Floor
Albany, NY 12248
hillk@assembly.state.ny.us
518-455-4592 – phone

Points to consider for your letter:

- Wheelchair accessible taxis are just as important in your part of the State as they are in New York City.
- Include reasons why your area could benefit from wheelchair accessible taxis.
- Wheelchair accessible taxis could supplement the local Transit Authority's Paratransit program. This will save money for the Transit Authority.
- It will save the State money by providing an alternative for medical non-emergency rides that are now costing the State's Medicaid program much more than it would otherwise spend if people had access to wheelchair accessible taxis.
- Does your area have virtually no public transportation? One wheelchair accessible taxi will provide a greater community living option for many wheelchair users such as; Americans with disabilities, Older Americans and wounded Veterans.

If you have questions regarding this, please call Cliff Perez at (518) 274-0701 Ext. 128

Ask the Expert: Tips for Parents Whose Visit is it? Managing the Clinic Visit and Care

By Michele Roland, MD

Why is it important that youth achieve independence in self care?

Being independent in self care produces better health outcomes. It also helps build confidence and self-esteem, traits that will benefit all aspects of a young person's life, not just their medical care. These traits also improve their social interactions and life skills. Compared to their medically healthy peers, youth with Spina Bifida tend to be more socially immature and have more difficulty in initiating and establishing peer relationships. This is why it's so important to give them opportunities to practice self care.

How can parenting styles affect the transition to autonomy?

Parents of children with Spina Bifida tend to exhibit higher levels of intrusiveness (overprotectiveness), according to research conducted by Grayson Holmbeck, PhD. This tends to be associated with lower levels of decision-making autonomy which are, in turn, related to higher levels of externalizing symptoms (such as anxiety and withdrawal). These behaviors tend to be linked with less desirable child outcomes.

I would encourage parents to involve youth early and work to strengthen core life skills and knowledge in the areas of transportation, finance, communication, and relationships/social skills. Let them pay the bills, order when you go out to eat, and assist with meal planning. Allow them to handle a pharmacy refill and the reordering of supplies. They should keep a laminated copy of their insurance card with them. Encourage them to negotiate transportation in their community by taking the subway or bus, or by giving friends and others directions.

I also believe that there are times when it is helpful for the parent to leave the room during a doctor visit. A teen is better able to take ownership of his or her doctor visit when a parent leaves the room. It's not that there's some big secretive thing going on, but the teen tends to be more engaged. They are empowered and learn how to be a health care consumer.

What are some tools that can increase youth participation during health care visits?

The unofficial clinic binder is a must. You can make it with your child. A good starting point is SBA's *Health Guide for Adults Living with Spina Bifida*, and then you can continue to add to it. The teen should bring it to all visits, and it should contain sections for: short- and long-term goals; list of problems the patient wants to address with his or her doctor; equipment; provider contact information; health care team (doctors, nurses, orthotics, etc.); suppliers of equipment and medication; summary of visits or to-do list; resources (such as community resources or Web sites); school contact/information about the child's IEP or 504; nutrition; and insurance information. You may also want to include a section for journaling or for the teen to write down questions as he or she thinks of them.

Smartphones can be great tools also. A teen can use apps to help with task organization and medication reminders, and they can use the phone to record appointments and/or to snap a photo of a doctor report or problem list while at clinic. I also advise my young patients to keep a list of all of their medications, their medical problems with proper medical terminology, and emergency contact information in their phones.

What is some advice for young people preparing for a doctor or clinic visit?

They should bring their binder to clinic. Also encourage the teen to outline questions ahead of time and bring them to the visit. At the start of the visit, they should share any forms or updates on tests or care they have had since the last visit by any other providers.

It would be helpful for the parent to review with the teen the important parts of a comprehensive health evaluation so they know what to expect and can prepare accordingly. These parts typically include:

- Introduction, during which time the health care provider does a "check-in" and interval history review (what has happened since the last time that provider saw you)
- Review of systems (questions about the person's body to determine if there are potential or current problems)
- Physical examination
- Laboratory and radiographic examinations
- Assessment and plan to-do list
- Team conferencing

What can the parent and doctor do to help a teenager move toward autonomy?

To achieve independence in self care, teenagers need to understand their diagnosis in lay and medical terms and how it impacts their life now and in the future. Parents and doctors over time should help teenagers understand the various types of Spina Bifida and their specific type. Teenagers also need to understand how the urinary system and bladder work so that they can understand their treatment and why their goals for urinary tract management are so important.

Visual support helps. For example, sometimes I will show X-rays to a young patient to help him understand the difference between a neurogenic bladder and a healthy urinary collection system. A clear understanding of pressure ulcers and the Malone/Mitrofanoff procedures is also important.

Education about sexual activity and the importance of folic acid should be covered as well. One research study of youth with Spina Bifida age 13-21 showed that 28 percent reported previous sexual activity, the average age of sexual activity was 17 /2 years, and 16 percent used contraception, compared to 60 percent contraception use in a control group of able-bodied teens. The best information is getting it before you need it! That's a discussion we have with parents and young people together with the assumption that no one is having sex yet but let's make sure they have this information.

Michele Roland, MD, is a faculty member of the department of Adolescent Medicine at Children's Hospital Los Angeles. She has board certification in Adolescent Medicine and Pediatrics and has expertise in adolescent health and transition. She is an integral member of the comprehensive Spina Bifida Program led jointly by the Keck School of Medicine at USC and Children's Hospital Los Angeles that provides medical care and transition support to teens and their families.

This article was reprinted from *Insights Into Spina Bifida®*, the Spina Bifida Association's national magazine. To order a subscription to *Insights*, please visit www.spinabifidaassociation.org

SAY AH! Tips for Talking with Your Doctor



Check out the website <http://www.justsayah.org>. Click on "Tips For You" to help you make the most out of your health and health care, and improve your health literacy.

FREE NATIONAL PARKS PASS FOR PEOPLE WITH DISABILITIES

Summer's almost here, so get out and enjoy the great outdoors! And now, people with disabilities can enjoy federal recreation sites for free.

When you visit a federal recreation site, just present some documentation of disability status and ask for the free Access Pass. Documentation includes a physician's statement, or a document issued by a State or Federal agency like the Veteran's Administration, Social Security Disability Income, Supplemental Security Income, or a vocational rehabilitation agency. This pass gives you and three adults free admission to federal recreation sites around the country, and it's good for life!

For more details, or to find a recreation site, visit the National Park Service's Web site: http://www.nps.gov/fees_passes.htm and <http://www.nps.gov/findapark/index.htm>

SUNNYVIEW REHAB HOSPITAL 2012 ADAPTIVE SPORTS CLINIC SCHEDULE

Fishing Clinic, Friday June 8 or Friday June 22
Tennis Clinic, Friday, July 13

For more information please call the Therapeutic Recreation Dept at 382-4576 or email todtc@nehealth.com

Kids Wish Network

Kids Wish Network is a national charitable organization that grants wishes to children living with life-threatening illnesses. The organization brings smiles to many deserving children who just need a break from their illness.

Kids Wish Network grants wishes to children between the ages of 3 and 18 who have not had a previous wish granted by any organization. The child must have a doctor verified life-threatening condition and be able to somehow communicate his or her wish.

Kids Wish Network contacted SBANENY as an organization that would serve children who might qualify for their programs. For more information, contact (727) 937-3600 x237 or Julie@kidswishnetwork.org

The Bus Stop Club

The Bus Stop Club, a not-for-profit organization, provides opportunities for siblings of children with chronic illness or special needs to go under the care and supervision of healthcare workers and get the support they need to help overcome the everyday battles they are faced with.

Many times, siblings face problems at home and at school that go unnoticed because their brother or sister has been diagnosed with a physical or mental disability requiring much of the parents' attention. By providing a safe and fun environment, The Bus Stop Club allows each member to express themselves, and more importantly, to just be kids!

Bus Stop Clubs are currently available at the following YMCA's; Bethlehem, Guilderland, Greenbush, Southern Saratoga, and Troy.

For more information or a registration form, go to www.busstopclub.org or write to:

The Bus Stop Club, Inc.
PO Box 771
Guilderland, NY 12084-0771

Capital Region Friendship Circle

The Capital Region Friendship Circle is a program designed to bring together two groups; children with special needs and their families, and teens in middle and high school. The program provides children with special needs with positive and meaningful interactions with peers who are teens. Through the program, children and teens have opportunities to learn interaction and friendship skills. Families receive support, acceptance of their child, and respite opportunities. The middle and high school teens are able to experience a meaningful volunteer opportunity during after school and weekend time.

For more information, go to www.capitalfriends.org or call 518-438-4220.



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SBANENY CALENDAR OF EVENTS

JUNE

June 28 – July 1 SBA National Conference,
"Gearing Up for the Future"
Go to www.spinabifidaconference.org for information

JULY

July 14 SBANENY Board of Director's

SEPTEMBER

September 8 SBANENY Board of Director's

NOVEMBER

November 10 SBANENY Board of Director's
November 29 SBANENY Goes to the Theater! Chapter Annual Fundraiser. See inside for details.



Programs for Families with children and adults are in the planning stages. Watch for information on our website, through emails, and flyers in the mail!



You Can Help Reduce the Risk of Birth Defects

with just a few minutes of your time



Research has shown that genetics play a role in the birth defect, spina bifida.

This study is the second phase of our research to determine genetic factors that contribute to the incidence of spina bifida. We are focusing on the genes involved in how our bodies utilize the vitamin folic acid. Through this research, we hope to help decrease the incidence of spina bifida.

We need mothers to participate that:

- Have a child with spina bifida, and did not participate in our first study (*cases*)
- Have children with no birth defects (*controls*)

What is a case and what is a control in a research project?

Individuals who have the disease or condition are designated *cases* and individuals without the disease or condition are designated *controls*. For this study, mothers who have a child with spina bifida are *cases*, and mothers who do not have a child affected by a birth defect are *controls*. Our research project will compare the genetic profiles of the *cases* to the genetic profiles of the *controls*.

It only takes a few minutes to help.

Participants will be asked to complete a short online survey and then to provide a DNA sample using a simple at-home saliva collection kit.

For more information and to enroll in the Spina Bifida Genetics Research Project as a case or control mother, please go to **www.sbgenetics.org** and select ENROLL. The website and survey are available in English and Spanish.

Participants receive a \$10 gift card or we'll donate \$10 to a spina bifida organization of their choice.

The Spina Bifida Research Project includes scientists from UC Berkeley, Stanford University, UC San Francisco, Children's Hospital Oakland Research Institute and VitaPath Genetics.

Special Engagement

THIS Wonderful LIFE

Adapted by Steve Murray (and Mark Setlock)

*"All the pleasure of Frank Capra's classic movie - in
only 70 minutes!"*

November 29th at 6:30 PM

Light Fare * Silent Auction * Cash Bar

_____Yes, I will attend, and enclosed is
my check for the November 29th event.

_____No, I am unable to attend, but
enclosed is my donation of \$ _____

Director's
Level \$75

Actor's
Level \$45

Stage Hand
(Under18)\$15

Name: _____

Address: _____

City, State, Zip: _____

Phone: _____

E-mail: _____

Please Make Checks payable to:
Spina Bifida Association NENY
SBANENY
123 Saratoga Rd.
Scotia, NY 12302