



## SPINA BIFIDA ASSOCIATION OF NORTHEASTERN NEW YORK



### SBANENY News to Use

#### CHAIR LETTER

Feeling GOOD! Our Chapter has so many things to feel GOOD about. Join us and share the GOOD feelings also! As you read through this newsletter, decide which events or programs match your skills and what you like to do. If you have any questions, go to our website ([www.sbaneny.org](http://www.sbaneny.org)) or contact us at (518) 399-9151.

On Saturday, May 2<sup>nd</sup> we are having our annual Walk-N-Roll event at Schenectady's Central Park. Check-in begins at 9:00 am with our Walk-N-Roll beginning at 10:00 am. We are also planning a fun Family & Friends Picnic afterwards, with delicious food and many friendly people. Music will again be by "Brother" Lou Roberts. This is one of our three fundraising events throughout the year.

A planning committee has been working since the end of 2014 to plan this fun event. Thanks to their efforts, time and talent we are expecting a lot of fun and warm weather. They've done a wonderful job!

You might have seen one or more of our ads in the Schenectady Daily Gazette, who has been a very valuable repeat sponsor of this event. We are also very pleased that we have many new community businesses joining us this year as new sponsors. Please Join Us!

Our Chapter is actively supporting families, children and adults with Spina Bifida with a variety of programs, services, and activities, thanks to community support and successful fundraising events. We feel GOOD about all of the businesses and individuals that sponsor and plan these activities. We embody the phrase: Many hands make light work." Wouldn't you like to join us and share the GOOD feelings we have?

*Jim Dunham*  
Chapter Chair

**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.

#### ISSUE #63 April 2015

Vacationing with a Disability: Exploring Accessibility & Sharing Travel Tips

Family Programs —

Cabin Fever Pool Party

Health Benefits of Regular Physical Activity

Tidbits — Resources & Information

"Fit In" Conference

Police Chief for a Day

SBANENY Walk-N-Roll for Spina Bifida 2015 presented by The Daily Gazette

#### SBANENY BOARD

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## AIR TRAVEL TIPS BY BARBARA

- \* When you make a reservation tell the agent you will be using a wheelchair.
- \* Make sure you get the seat that will make travel easier. In some cases that is the bulkhead. In my case, because I can ambulate a few steps on long trips, I get the seat closest to the bathroom.
- \* When I check in, I explain what I need again to the agent; my experience is they try to be as accommodating as possible.
- \* People who need extra time can pre-board which keeps the crowds away and helps you to get settled. Be near the boarding area at least 10 minutes before boarding so you can go on first.
- \* Never put your medications or any medical supplies that are critical in your checked baggage; luggage does get lost on occasion. Always carry it on.
- \* I pack a backpack with my book, all my medications, a change of clothes, and my medical supplies.
- \* When I leave the plane I put the backpack on the back of my wheelchair and have free hands to push.
- \* Bring twice the amount of medicine and supplies you usually need, just in case being somewhere different affects your routine.

## VACATIONING WITH A DISABILITY: EXPLORING ACCESSIBILITY

On February 21st the Adult Group of SBANENY met at the Independent Living Center of the Hudson Valley in Troy to discuss traveling with Spina Bifida. The guest speaker was Carol Fraser, Access Coordinator for the New York State Department of Environmental Conservation. In her position she advocates for accessibility of New York State parks for people with disabilities. Ms. Fraser showed a power point presentation with pictures of accessible parks around New York State. Some were in the Capital region or were a short trip away. Many parks have accessible trails, bathrooms, and campsites.

The Adult Group discussed coordinating a day trip to one of the parks, to include walking on the trails and a picnic lunch. We will work on scheduling the event for the summer. For more information about NYS parks and their access features go to <http://www.dec.ny.gov/outdoor/34035.html>.

There was a lot of interest on the part of the group about how to ne-

gotiate air travel. We talked about preparations necessary prior to going and how to be more comfortable on the flight. Barbara Devore has taken many airplane trips in her life. The shortest was to Washington D.C. (one hour) and the longest to Israel (11 1/2 hours).

"I enjoy traveling but airplane travel for someone with Spina Bifida who uses a wheelchair can be complicated. My experience is to plan ahead.

There were other aspects of air travel left unanswered at the meeting. Participants wanted to know what to do on long flights when you self cath, and when you travel with a respirator. Resources were provided after the meeting.

Based upon the high degree of interest shown, the Adult Group will continue to discuss this issue, to include speakers to address airline screening/pat downs, hints for bowel and bladder management on long trips, and accessible places to visit.

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*"I enjoy traveling but airplane travel for someone with Spina Bifida who uses a wheelchair can be complicated. My experience is to plan ahead."*

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## HOTEL TRAVEL TIPS BY HEATHER

- \* When making hotel reservations, be specific about your needs; shower chair, wheel-in shower, refrigerator, wheelchair accessible room, number of beds, are several examples.
- \* One week before you leave on your trip, call ahead to confirm your reservation, including verifying specific room needs.
- \* When you arrive in your room, make sure that the room is set up to meet your needs; you can reach the shower head, clearance around furniture, you can access the refrigerator, sufficient towels.

## STATE & NATIONAL PARK ACCESS TIPS

- \* Apply for the NYS Access Pass ([nysparks.com/admission/documents/AccessPassApplication.pdf](http://nysparks.com/admission/documents/AccessPassApplication.pdf)). This pass enables free or discounted access to state parks, historic sites, and recreational facilities operated by NYS Office of Parks, Recreation and Historic Preservation and the NYS Department of Environmental Conservation for the person with disabilities and their family.
- \* National Park Service: Website for their America the Beautiful Access Pass is [store.usgs.gov/pass/access.htm](http://store.usgs.gov/pass/access.htm). This similarly allows free entry for people with disabilities and their families.
- \* Find general accessibility information about national parks at [www.nps.gov/accessibility.htm](http://www.nps.gov/accessibility.htm).
- \* Go to the websites of the individual national parks to find out about access.
- \* One group participant has traveled to several national parks and found surprisingly good wheelchair access including Yosemite and the Grand Canyon.

## OTHER CHAPTER ACTIVITIES & COMMITTEE PROJECTS

- ⇒ **Young Family Program Planning Committee** — Anticipate quarterly meetings. In person or by conference call.
- ⇒ **Adult Program Planning Committee** — Planning occurs by conference call, email, or occasional in-person meetings.
- ⇒ **Metro NY Support Group Planning Committee** — Planning by conference call.
- ⇒ **Tool Kits for Educators & Families Task Force** — In person meetings with conference call available. Anticipate 3 more meetings bi-monthly for the first stage of the project.
- ⇒ **Walk-N-Roll Planning Committee** — Anticipate wrap up meeting after the Walk-N-Roll on May 2nd. This meeting is a good time to join the group. Planning meetings for 2016 will begin in late fall.
- ⇒ **Family & Friends Picnic Planning Committee** — This has not been a separate committee to date but it would be very beneficial if 2 to 3 people could volunteer to coordinate this. Time frame to anticipate activity is January, February, and the 3 weeks prior to next year's Walk-N-Roll in May.
- ⇒ **Dare to Dream Annual Fundraiser Planning Committee** — Monthly planning meetings. The next meeting will be in early June.
- ⇒ **Fundraising & Marketing Committee** — Committee that looks at the overall chapter strategies for fundraising and marketing and reports their recommendations to the Board of Directors.

**Which committee is a good fit for you?**

**Let us know how you would like to get involved!**





## FAMILIES TAKE A BREAK FROM WINTER

On February 21st a group of families met at the Ciccotti Center in Colonie for a Pool Party. Despite another winter storm, everyone had a fun afternoon enjoying swimming, lunch, board games, and conversation.

Our family programs are designed for families with children who have Spina Bifida under the age of 18. Siblings are always included.

The next event will be our Walk-N-Roll for Spina Bifida and Family &

Friends Picnic on May 2nd.



*Families cured cabin fever at a pool party on February 21st — despite another winter storm!*



## WANTED — YOUR FEEDBACK AND INPUT

Over the next few months, we will be reaching out to families for input and feedback about SBANENY programs and services. Please begin to think about your answers to questions such as:

- ◇ How are we doing?
- ◇ What would you find helpful?
- ◇ What programs are you most interested in?
- ◇ If you didn't attend a program, please tell us why.

We will be reaching out to you with the survey through a mailed form, email, Facebook, and as much as possible through phone calls. You don't have to wait to hear from us — Please feel free to contact us with your input at any time.

## EQUIPMENT EXCHANGE

**Bruno Chair Lift.** Designed to be installed into a mini-van to lift a power wheelchair up and into the van. (It is not designed to lift a chair with a person in it. The lift raises the chair up and in a separate operation swings it into the back of the van. This lift is being offered by the current owner to someone who needs it at no charge. Please contact our office if you are interested.



## LATEX ALLERGIES SPANDEX ALLERGIES & SENSITIVITIES

The following websites provide some potential resources and information for those who need to avoid latex and spandex in their clothing.

<http://www.cottonique.com/>

<http://www.naturalclothingcompany.com/clothes-without-spandex>

<http://www.rawganique.com/index.htm>



## REGULAR PHYSICAL ACTIVITY PROVIDES IMPORTANT HEALTH BENEFITS FOR EVERYONE, INCLUDING PEOPLE WITH DISABILITIES.

### Stay Active with a Disability: Quick Tips!

Adapted from [healthfinder.gov](http://healthfinder.gov)

Regular physical activity is good for everyone's health, including people with disabilities. Getting active can help you:

- ◆ Strengthen your heart
- ◆ Build strong muscles and bones
- ◆ Improve coordination
- ◆ Relieve stress, improve your mood, and feel better about yourself

### Before you start...

- ◆ Talk to your doctor about the types and amounts of physical activity that are right for you. If you are taking medicine, be sure to find out how it will affect your physical activity.
- ◆ It's also a good idea to talk to a trained exercise professional. Find a fitness center near you that is comfortable and accessible. Ask if they have experience working with people with similar disabilities.

### Aim for 2 hours and 30 minutes a week of moderate aerobic activities.

Choose aerobic activities – activities that make your heart beat faster – like walking fast or pushing yourself in a wheelchair, swimming, or raking leaves.

Start slowly. Be active for at least 10 minutes at a time and gradually build up to doing 30 minutes at a time.

Aim for 30 minutes of aerobic activity on most days of the week.

### Do strengthening activities 2 days a week.

These include activities like crunches (sit-ups), push-ups, or lifting weights.

Try working on the muscles that you use less often because of your disability.



### Find support and stick with it.

Take along a friend, especially if you are trying out a new activity. If you don't meet your physical activity goal, don't give up. Start again tomorrow.

Be active according to your abilities. Remember, some physical activity is better than none!



## TIDBITS: RESOURCES & INFORMATION

**Public Input Wanted on Employment Regulations - Deadline April 20** The U.S. Equal Employment Opportunity Commission (EEOC) is asking for public comments on which equal employment regulations should be changed, expanded or eliminated. EEOC's review includes regulations related to employment of people with disabilities. Please email comments to [Public.Comments.RegulatoryReview@eeoc.gov](mailto:Public.Comments.RegulatoryReview@eeoc.gov) by April 20, 2015.

*For information about other disability-related laws and regulations read Disability.gov's Guide to Disability Rights Laws.*

### **Different Types of Discrimination Highlighted During April's Fair Housing Month**

The U.S. Department of Housing and Urban Development kicked off this year's Fair Housing Month by launching a national media campaign. The campaign will help Americans learn about housing discrimination and what to do if they believe their housing rights are being violated. It also addresses housing discrimination experienced by Veterans and some of the challenges people often face when trying to buy a home.

*For more information about the Fair Housing Act and other housing resources read Disability.gov's Housing Guide.*

### **Paying for Assistive Technology (AT)**

Do you know of some AT or durable medical equipment that would help to improve the quality of your life but the cost is prohibitive? Disability.gov suggests several sites that have helpful information and resources.

- ⇒ Disability.gov's Guide to Assistive And Accessible Technology. Visit the section on finding and paying for AT.
- ⇒ NYS Assistive Technology Program (TRAIL) TRAIL's mission is to coordinate statewide activities to increase access to and acquisition of assistive technology in the areas of education, employment, community living and information technology/telecommunications. <http://www.justicecenter.ny.gov/services-supports/assistive-technology-trail>
- ⇒ Visit the guest blog by [Thom Gressman on Disability.Gov](#).
- ⇒ Check out AbleData's guide, [What Are Your Options to Pay for Assistive Devices?](#)

**Need help with your job search? Here are some programs that you might want to explore:**

American Job Centers: Your local Job Center has lists of recent job openings, computers you can use to search for jobs, and career counselors who can help you with your job search, locate training for a new career, and get help writing your resume. <http://jobcenter.usa.gov/>

ACCES-VR: Counselors work with job seekers to find, train for, and keep a job. <http://www.acces.nysed.gov/vr/>

Independent Living Centers: Your local ILC may provide job coaching, training and other services. ILCs can also help you develop skills to live independently. They often have information about employers in your area who are interested in hiring people with disabilities.



## POLICE CHIEF FOR A DAY

Joe O'Connor, winner of our "Police Chief for a Day" silent auction item last November at Dare to Dream with SBANENY, spent a day in March enjoying a variety of activities as a guest of Albany Police Department. Congratulations Joe!

Thank you to Police Chief Steven Krokoff & Officer Steve Smith for planning and orchestrating a great experience for Joe.

Save the Date! This year's SBANENY Live & Silent Auction will be Saturday, November 21st at Colonie Country Club from 6 to 10 PM. Watch for details!



*Joe was presented with a Police Chief for the Day resolution from Albany Mayor Kathy Sheehan by Police Chief Krokoff, attended a meeting of local leaders, experience practice on the firing range, and visited the canine unit.*



*Joe O'Connor enjoyed his silent auction winning of "Police Chief for a Day."*

## Second annual "Fit-In" Conference! ACTIVATING COMMUNITIES: Grassroots Inclusive Fitness in Central NY

**When:** 9-4, Friday October 9, 2014

**Where:** 415 W. Fayette Street, Syracuse

**To Register:** Contact Regina McConnell at 464-7561 or [Mcconner@upstate.edu](mailto:Mcconner@upstate.edu).



**Who:** This inter-disciplinary conference is for athletes (with and without disabilities), families, high school students, community leaders, professionals in sports media, adapted physical education, physical therapy, occupational therapy, dance, pediatrics, physical medicine and rehabilitation, public health, urban planning, and anyone who has an interest in adapted sports and inclusive fitness.

**Why:** Learn, network, advocate for inclusive fitness in Central New York

*The Fit-In Conference is brought to you by SUNY Upstate Medical University Foundation/Golisano Children's Hospital; SUNY Upstate's Physical Therapy Program; SUNY Upstate's Department of Physical Medicine and Rehabilitation, SUNY Cortland Department of Adapted Physical Education; and Syracuse University's Burton Blatt Institute, David B. Falk College of Sport and Human Dynamics, the School of Education, the Lerner Center for Public Health Promotion at the Maxwell School, and LaCasita Cultural Center.*



**SPINA BIFIDA ASSOCIATION  
OF NORTHEASTERN NEW YORK**

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***Estate Planning  
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*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 Spina Bifida  
Register or donate at  
[sbaneny.org](http://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 by northeastern New York State.

**UPCOMING EVENTS**

***WALK-N-ROLL FOR SPINA BIFIDA***

Saturday, May 2. Registration begins at 9 AM. Walk-N-Roll will be followed by the SBANENY Family & Friends Picnic through 1 PM.

***FALL FAMILY RETREAT WEEKEND***

October 23rd—25th, Double H Ranch, Lake Luzerne, NY. Registrations will be available at the end of the summer.

***DARE TO DREAM WITH SBANENY***

Saturday, November 21st at Colonie Country Club. Gala fundraising event including live & silent auctions.

***SPINA BIFIDA CONFERENCE 2016***

Spring 2016 — Date to be announced.

***COMMITTEE MEETINGS***

**Walk-N-Roll:** 4/28 6 PM; 5/1 5 PM

**Dare to Dream:** Early June

**Board of Directors:** 5/16, 10 to noon

**Toolkits for Education — TBD**

**Young Families — TBD**

**Adult Group — TBD**

***PROGRAMS TO BE ANNOUNCED —  
WATCH FOR FLYERS!***

◇ ***YOUNG FAMILY PROGRAM***

◇ ***ADULT PROGRAM***

(June date TBD)

◇ ***METRO NYC PROGRAM***

**FOR MORE INFO CONTACT:**

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## SBANENY Walk-N-Roll for Spina Bifida

Saturday, May 2, 2015

Central Park Pavilion, Schenectady, NY

Check-In Begins at 9 AM

FOOD PRIZES MUSIC VENDORS

### Family & Friends Picnic

immediately following the Walk from 11:30 to 1:00 PM

Visit our website [sbaneny.org](http://sbaneny.org) to:

\* Register to walk \* Start a team! \* Virtual walkers welcome!

\* Make your tax deductible donation

THANK YOU TO OUR SPONSORS!

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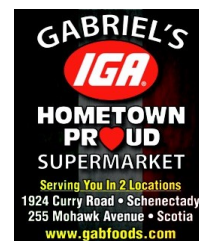
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#### Bronze Sponsors



#### Silver Sponsors

"Brother" Lou Roberts





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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](http://www.curemedical.com).

\* See CA EPA Office of Env. Health Hazard Assessment *List of Chemicals Known to the State to Cause Cancer or Reproductive Toxicity*, December 8, 2006.



Dare to Dream



# Gala Live & Silent Auction Fundraiser!

Save the Date!

Saturday, November 21, 2015  
6:00 to 10:00 PM



Honorary Chairs

Tom Wilson & Kristin Koehler



Saturday, November 21, 2015  
Colonie Country Club  
Voorheesville, NY

Gold Sponsors Bill & Shelly Socha



**Our Ability Connect** © is making the complex simple by offering a platform where candidates with disabilities can enter their skills and experience, and then receive endorsements and references that reinforce their value to future employers.

**Our Ability** is a certified disability-owned business that creates game-changing strategies for enabling full inclusion of individuals with disabilities. They invite both active and passive job seekers, whether or not they are currently employed, to enter their information. There is no charge to participate in the system as a candidate.

**Our Ability Connect** will continue to grow their candidate database, which will include new graduates to skilled executives across all disciplines, with apparent and non-apparent disabilities, those individuals who are interested in positions across all industries and sectors. Our 2015 goal is to enroll 10,000 candidates with disabilities.

Sign up here:

<http://connect.ourability.com> – a connection for Individuals and Employers to employment.