

Spina Bifida

February 2007

NEWS

To Use

**Spina Bifida Association
Albany/Capital District Chapter
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EDUCATION * SUPPORT * AWARENESS

Dear Friends,

As I send this newsletter out to everyone, I want to be sure that you all take the time to check out the information inside. There are many things that I believe will be important to our readers.

- Please note that our board has been working hard over the past months to offer a new grant for families and individuals for the Spina Bifida Association national conference in June which will be in Louisville, Kentucky.
- There are many chapter activities coming up including programs for families of preschoolers, a day trip to Mohonk, fundraising committee meeting, tennis, teen group, Freihofer's Community Walk, and Saratoga Day at the Races. Please mark your calendars and watch for more information.
- Please make note of the many ways that everyone can contribute to help make the chapter's programs and services available to our families.

Finally, I want to remind you that last week, you should have received a mailing for annual membership. I know that many people have already responded – thank you! If you haven't, please take the time now to fill out the membership form. If you don't have the form, you will find the information that I asked for inside this newsletter. Any piece of paper will do, but it would be very helpful to me to have updated information on everyone! If you are able to be a paid member, we appreciate the show of support. If you are unable to pay at this time, your current information is still important to us. Please take the time to respond. It will save us time and money to have current addresses and emails for everyone.

I look forward to meeting more people at upcoming events!

Karen Wentworth

Executive Director

Time to Mark Your Calendar!



Accessible Tennis

Jim Neal continues to provide lessons on an almost weekly basis at the Schenectady Racquet Club. Are you interested in joining? Newcomers are welcome. We recommend that you call ahead before you attend the 1st time to be sure that lessons are happening that week. Be sure that we put your name, phone and email on our call list so that we can notify you if there is a change in the schedule.

Freihofer's Community Walk

Saturday, June 3, 2007

8:15 AM

Empire State Plaza, Albany

Regional Educational Conference

sponsored by

Spina Bifida Association of Connecticut, Inc.

Saturday, March 24, 2007

8:15 a.m. to 4:00 p.m.

Hartford, Connecticut.

Go to SBAC.org

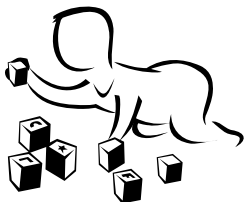
Preschool Program

Saturday, March 3rd

9:30 AM – 12:30 PM

Colonie Community Center

1653 Central Ave, Albany



Membership Registration

Reminder: Please complete your membership information now.

Name

Address

Phone

Email

Newsletter by email _____ US mail _____

Name of individual with SB

Date of Birth

Male/Female

in family

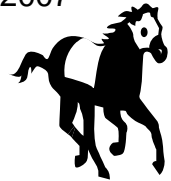
Interested in board meetings _____

Interested in fundraising or program committee meetings _____

Saratoga Day at the Races

Sunday, August 12, 2007

12:30 PM



Mohonk Day Trip

Tentatively planned for

Saturday, May 5th

10 AM – 3 PM

Teen Support Group

1 Saturday each month

10 – 11:30 AM

Contact us for schedule.

Saratoga Fundraising Committee Meeting

Saturday, 3/10/07

10 – 11:30 AM

Colonie Community Center

1653 Central Avenue

Albany, NY



Come work with the Gallaghers. It will be fun!

Scholarships & Grants

SBA National Conference Grant Information

In realizing the importance and benefits of attending the annual national Spina Bifida Association conference, SBA Albany/Capital District Chapter Board of Directors has agreed to provide a grant to a chapter individual with SB, and a parent(s) or companion wishing to attend. Reimbursement is for specified expenses up to \$1750.

This year's National SBA Conference will be held in Louisville, Kentucky from June 25 - 27, 2007. June 24th is the Adult day and provides a full day for adults with SB to network prior to the start of the conference. The full conference sessions begin on Monday, June 25 and continue for 3 full days until Wednesday, June 27. Generally there are 20 – 30 different conference sessions offered per day, from 9:00 am to 5:00 pm. These sessions are extremely informative and cover a wide range of topics including: psychosocial concerns, medical, research, latex allergy, adult issues, technology, sports, etc. There is also a Kids Camp that is offered to children birth – 19 years of age. This is available during the entire conference sessions June 25 – 27.

****For families wishing to apply, please see the attached application. The application deadline is March 15, 2007. More information on this year's conference can be obtained at the national SBA website at: www.sbaa.org or by contacting us directly at the Chapter phone: (518) 399-9151 Opening reception is June 24. Travel days of June 24 and late the 27th or the 28th.**

Helen R. Mertens' Educational Scholarship Fund

Sponsored by the

Spina Bifida Association Albany/Capital District Chapter

The purpose of the scholarship is to award financial assistance to persons who have Spina Bifida and are pursuing higher education, technical training, or driver's education. The amount of the grant is a maximum of \$1000 per fiscal year. It is intended to be used toward the cost of tuition, fees, and books. The exact amount to be disbursed will be at the discretion of the Scholarship Committee. The number of scholarship applicants will be a factor in this decision.

Eligibility Requirements:

1. Applicants must have Spina Bifida or a spinal cord disability resulting in similar challenges and/or needs.
2. There is no age limit.
3. Applicants must demonstrate acceptance by a school or higher education, technical training, certificate program, or driver education training program.
4. No financial statement shall be required.

If you are interested in receiving further information, or would like to obtain a copy of the application, please contact the chapter.

We are very grateful to Helen R. Merten and her estate for making this scholarship program possible for our chapter.

Saratoga Fundraising Committee

Last year, Jim & Jennifer Gallagher worked together with family and friends to plan and execute a very successful fundraiser at Saratoga Race Track to benefit our chapter. We are extremely grateful that they have offered to head up this effort again. **They are asking for a few good people to come forward and help them.** They have scheduled a meeting at the Colonie Community Center on Saturday, March 10th from 10 – 11:30 AM. Coffee will be served. If you haven't had the pleasure of meeting the Gallaghers, *they are a blast, with a ton of energy and ideas!* They welcome whatever you might be able to offer ---- from help in coordinating to being a worker bee. Please join them and find your niche! We are sure that everyone will be very glad that they joined this committee!

**Use GoodSearch.com for a search engine....
pick Spina Bifida Association Albany/Capital.....
and they will donate to us!**

One of our members recently sent us information about a search engine that we can all use to browse the internet. When you do this, the search engine will donate a few cents to your choice of charities, and our chapter is registered there!



Please give it a try and support our chapter!

The site is powered by Yahoo!, so you'll get the same quality search results that you're used to. What's unique is that they have developed a way to direct money to your charity or school with every click.

The more people who use this site, and choose our chapter as their charity, the more benefit we should see from this over time. Our member, Michelle, reports that her parents are involved in a charity that is benefiting from this. She says, "I realize it's just a few pennies, but it does add up after a while...."

Michelle, thanks for the tip!

United Way Donations... Did you know that you can donate to the United Way and designate SBA Albany/Capital District Chapter as the recipient of the donation? Please consider choosing this chapter for future donations. For those of you who are already doing so, thank you!

SEFA (State Employees Federated Appeal).... Our chapter is also registered with SEFA for work place giving. Please keep us in mind later this year during the campaign!

Your donations through these programs helps us to put more focus on chapter programs and provision of services.

Thank you!



Hand-Powered Tricycle

The Schenectady area Marine Corps League has contacted us again with an interest in purchasing a hand-powered tricycle for a Preschooler in our chapter. If you have a child who is preschool age and would benefit from a hand-powered tricycle, please call or email the chapter as soon as possible. The representatives from the Marine Corps League are hoping to order the tricycles in the near future so that they might be in the hands of the children to enjoy by early summer.



Nonverbal Learning Disorder Website

NLDLine has a website designed to educate the caregivers and associates of individuals with Nonverbal Learning Disorders, and to build NLD databases in order to network parents, NLD adults, and professionals. The primary goal stated for the website is to educate about NLD. In addition, the website seeks to help those interested in networking with each other. www.nldline.com



Helpful Tips from Parents

The Flying Turtle

We received a tip from a parent whose son had a problem with skin breakdown from scooting on his bottom when he was younger. They purchased the "flying turtle" for him and it worked really well for getting around when he didn't want to use his wheelchair, and his bottom needed a break from the pressure. Here is the website

http://cgi.ebay.com/Flying-Turtle-Scooter-New-Mason-Corp-PURPLE_W0QQitemZ280066356377QQcmdZViewItem



Break Dancer – Young man with Forearm Crutches

It is well established that we need to encourage our children to be more active. You might want to check this video out. Perhaps it will help your teen to try something new!

<http://www.youtube.com/watch?v=DqeVXbTQ8NA>

Riddle for the month....

What do chocolate and folic acid have in common?

You might want to try CocoaVia dark chocolate bars from the Dove Company. We heard recently that each bar has about 15% DV folic acid per serving, and has B6, B12, calcium, and vitamins C & E as well. Do we have any chocolate critics out there? We would love to hear your reports on this product!



PARTNERSHIP FOR PRESCRIPTION ASSISTANCE

- The Partnership for Prescription Assistance (PPA) brings together America's pharmaceutical companies, doctors, other health care providers, patient advocacy organizations and community groups to help qualifying patients who lack prescription coverage get the medicines they need through the public or private program that's right for them. Many will get them free or nearly free.



- SBA is a member of PPA and attended the PPA Health Care Summit this year. Every state has a PPA initiative working to help people with their medications. Know the names of the medicines that you take and speak with a trained specialist available to answer your questions and help you apply.

- For more information on PPA or to find out who qualifies, visit www.pparx.org or call 888-4PPA-NOW

Folic Acid Campaign

In early January, a study was published in the Centers for Disease Control and Prevention (CDC) Morbidity and Mortality weekly report that noted from 1999 through 2004 there was an 8% to 16% decline in the level of the vitamin folate in the blood of U.S. women of childbearing age. SBA, our national organization, initially responded to this alarming statistic with a release to the press that was distributed in conjunction with Folic Acid Awareness week.

Also in response, SBA developed a Hispanic awareness outreach campaign that aired in conjunction with Valentine's Day. The Love Yourself campaign appeared both in print and on the radio in large Hispanic markets across the country. It was designed to remind women of childbearing age of the importance of folic acid for their health.

In this chapter's last newsletter, folic acid brochures were distributed. *Please take a few minutes and send an email to those women you are close to between the ages of 18 and 45, giving them the important information they need to know about the vitamin folate in their diet. Ask them to forward the message to their list and keep passing the information along!*

Folic Acid Reminder:

Taking folic acid before and during early pregnancy reduces the risk of Spina Bifida and other serious birth defects up to 70%. All women who could become pregnant should take a vitamin with 400 micrograms (mcg) of folic acid every day.

SBA Albany/Capital District Chapter 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.

Chapter Territory



Often I am asked questions that I realize might be information that I should share with our readers. This months question is what geographic region does Albany/Capital District Chapter serve?

The closest chapters are in Rochester to the west and Long Island to the south. New York City falls within the SBA of Tri-State Region. We respond to calls and emails from as far south as Westchester & Rockland Counties, north to the Canadian border, and west to the Utica area. We assist people with contacting a closer chapter if they are not within this region.

We attempt to better serve those who live at a greater distance from Albany by holding our spring and fall programs south and north respectively.

If you would like additional clarification, please contact us!

Right Under My Nose

A Book for Children with Spina Bifida

by Claire Austin, MPhil and Stacey Mizokawa, PhD

Illustrated by Matthew Bates



Right Under My Nose is available online. The “book” provides fun activities for your child with Spina Bifida. It offers tips for parents and caregivers. Free copies are available at www.myspinabifidabook.org. You can print a copy, listen to the story online, and play interactive games.



Kids on Wheels

Kids on Wheels is a magazine. There is a section written for young children and one for their parents. If you want to find out more information about Kids on Wheels, check out their website at www.kidsonwheels.cc.

Special Needs Estate Planner

This months topic provided by Jones & Wilcenski PLLC is entitled: Income Tax Considerations for Parents of Children with Special Needs.

Let us know if you are interested in receiving a copy. We can send it out my email or snail mail.

Attention Parents!

Our national organization, SBA, has a Listserv available for parents of children with Spina Bifida. Chris reports that lots of good information is shared here. You can check it out at SBParents-on@lists.sbaa-communities.org

The SBA website has other listserv information as well. Go to:

<http://www.sbaa.org/site/c.gplLKXOEJqG/b.2017627/k.8186/eCommunities.htm>

From SBA National Conference June 2006....

Chris Darby-King and Vanessa Chamberlain attended the national SBA conference in 2006 as delegates for our chapter. They provide the following information from their experience there. Both recommend attending conference as a valuable experience. Read on.....

One of the presenters we had an opportunity to hear was a representative of BlazeSport America. She told us about her organization which provides sports training, competitions, summer camps, and other sports and recreational opportunities for youth and adults with various disabilities (including spina bifida) who use wheelchairs. Participant ages, depending on the program, range from 6 years through adulthood, which may make it a viable option for some of our members as they age out of other local opportunities such as Double H. There are several ways individuals might find this useful. One way we might participate is through the formation of a local club. Though BlazeSports is centered in Georgia, there are community programs in operation in 25 states and the District of Columbia (at the time of the conference, the nearest to the Capital District was Buffalo). Clubs are the "bedrock of BlazeSports America" and provide community-based, year round programs delivered through local recreation providers. These grassroots programs offer instruction for youth and adults with physical disabilities in a variety of adaptive sports, based on local interests and facilities.

Should someone be interested in developing a local presence, clubs can be started by a nonprofit organization, city, state or government agency, rehabilitation hospital, school, or recreation and leisure service provider that offers sport and physical activity programs for youth and/or adults with physical disabilities. The representative indicated that BlazeSport would provide significant support to that start-up group with training for community instructors and coaches, sports training manuals, operations standards, and other direct benefits.

Although a local club would be a wonderful idea (if you build it we will come!) the other possibility which might be an option is the BlazeSports' sports instruction training camps. These are specifically focused on seasonal sports (e.g., wheelchair basketball, wheelchair tennis, rugby, swimming, and track and field). For adults, there are weekend sports instruction camps (which offer an even broader array of sports such as golf and kayaking) throughout the year. BlazeSports uses Para-olympic and nationally and internationally recognized athletes and coaches to guarantee the highest level of instruction performed at the highest level of the sport. Many are open to individuals who could travel to that location to attend.

For further information, see BlazeSports' website www.blazesports.com or contact me at 518/393-4834 or NessTrey@aol.com.



Chapter Activities

Preschool Family Program
March 3rd, 9:30 Am – 12:30 PM

Saratoga Fundraising Committee Meeting
March 10th, 10 – 11:30 AM

Regional Educational Conference
March 24, 8:15 AM – 4:00 PM

sponsored by SBA of Connecticut, Inc.
Mohonk Day Trip, tentative
May 5th, 10 AM – 3 PM

Freihofers Community Walk
June 3rd, 8:15 AM

SBA national conference, Louisville, KY
June 24th – 27th

Saratoga Day at the Races
Sunday, August 12, 12:30 PM

Accessible Tennis
Saturdays, weekly, call ahead

Teen Support Group
Saturdays, monthly, call ahead

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