

Spina Bifida

October 2006

NEWS To Use

Albany/Capital District Chapter
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Dear Families,

The purpose of Spina Bifida Association of America (SBAA), and therefore our purpose as a group member, is to promote the prevention of spina bifida and to enhance the lives of all affected. October is Spina Bifida Awareness Month. Therefore, I am taking this opportunity to pass along to you a brochure about spina bifida. I am hopeful that this will be helpful to you as you hear the question, "What is spina bifida?" You will find up-to-date information about the incidence of spina bifida, the different kinds of spina bifida, the effects of spina bifida, and prevention. I am sure that you already know much if not all of this information, but I believe that having the information available in this form might be helpful to you as we all work to raise awareness of this disability and the impact that it has on individuals who have it, their families, loved ones, and caregivers.

I am always looking for opportunities to raise awareness and so I ask you to consider the following:

- Is there a place at your job or church where you could display a poster related to spina bifida?
- Is there an opportunity to display or hand out literature such as the enclosed brochure about spina bifida at your job or church?

If you believe that you could do either of these things, please call or email me. I have brochures and posters that have been provided by our national organization and can supply you with copies to distribute or post.

SBAA continually provides its chapters with resources and ideas to help promote the purpose of the organization. This is an opportunity for all of us to work together to promote prevention and to enhance the lives of those affected by raising awareness. Thank you for considering partnering with us!

Karen Wentworth
Executive Director

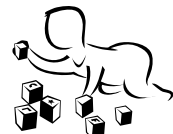
WHAT'S NEW? Attention parents of preschool children!!

You have asked for an opportunity to meet, talk, and share while your children get to play together. Please let this date aside! We have a special education teacher who has volunteered to provide activities for the children while the parents meet with each other in the next room.

Date: December 2 **Time:** 10—11:30 AM

Place: Colonie Community Center, 1653 Central Ave, Albany

RSVP: Please call or email number of adults, & children & their ages, indicating which is the child with spina bifida.



Your Donations Count....

Employee giving campaigns.....

Payroll deduction programs.....

Our chapter, Spina Bifida Association Albany/Capital District Chapter is a member of Community Health Charities of New York and is registered with United Way. Both CHC and United Way assist not-for-profits with funding through employee workplace giving campaigns.

Do you have a workplace giving campaign at your employment sponsored by Community Health Charities or United Way? Please consider designating our chapter for your charity of choice. Donations from work place giving help to support the programs and services provided for individuals who have spina bifida, their families and caregivers, in eastern upstate New York State.

Does your place of business have a workplace giving campaign? If not, would they consider it? If you are interested in more information about employee giving campaigns and payroll deduction programs, please call/email our chapter and we will assist you.

We thank you for any contribution or assistance you are able to offer!

Chicken Soup for the Special Needs Community



Do you have heart-warming, insightful and powerfully moving stories about what life has taught you and how to live life to its fullest? The authors of the New York Times Best-selling book series Chicken Soup for the Soul are currently seeking stories to be included in a new book tentatively titled Chicken Soup for the Special Needs Community: 101 heartwarming, helpful, healing stories that offer inspiration and promise surrounding the lives of special needs individuals. Through these stories, the readers learn how others facing similar challenges can learn to overcome the many obstacles they have. They do this by connecting with emotions in the real life experience by learning they can choose peace and happiness in each situation regardless of how challenging it appears from the outside.

Now you have an opportunity to contribute to this new series by sharing your strength, insights, knowledge and wisdom. Topics of interest for submission are: attitude, family dynamics, early learning, the teen years, friendships and relationships, celebrating differences, humor is healing, adulthood, transitions, empowering everyone. If you have a story you would like to submit, please email your stories to hmcnamara@verizon.net.

Kids On Wheels



2 volumes packaged together

Volume 1: A Young Person's Guide to Wheelchair Lifestyle

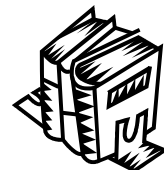
Written for grade school children to help plant the seeds of independent living and disability pride.

Volume 2: A Guide to Wheelchair Lifestyle for Parents, Teachers and Professionals..

Learn how to empower kids to live a full, independent life.

To order a copy call
1-888-850-0344, ext 209
or go to www.kidsonwheels.cc

* Copies of these books are available through our chapter's lending library. If you would like to borrow one, call or email the chapter.



**Emergency Preparedness for
People with Disabilities
and Their Families**

“The Take and Go Emergency Book”

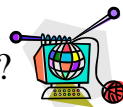


Emergency

In the aftermath of Hurricane Katrina, much was realized about how important key information can be in an emergency situation, even more so for a person who is disabled. In response to this, a small booklet was developed by individuals with disabilities and their families in collaboration with the Office of Citizens with Developmental Disabilities. It is designed to outline all pertinent information that a person might need in order to get medical care in either a personal or regional emergency situation.

These booklets will be available for families who are attending Double “H” weekend at the end of this month. This will help us to save on postage! Copies will be mailed after that for families who are interested.

Are you looking for local or national government resources?



Go To

http://www.govbenefits.gov/govbenefits_en.portal

This website is designed for those looking for financial assistance, support, and/or resources both locally and nationally. You can search topics such as employment, disability, and medical information. Questionnaires will help you to determine if you are eligible for any of the programs.

**Special Needs Estate Planning
by**

Edward V. Wilcenski, Esq.

Edward Wilcenski, Esq. provides us with newsletters on topics related to special needs estate planning. The two most current editions are:

* Medicaid Reform & Estate Tax Repeal,
July 2006

* One-Two Punch
— Limiting the Medicaid Lien in
Litigation Recoveries,
August/September, 2006

If you are interested in copies of these, or of previous topics, please call or email us and we will send them out to you.

MedicAlert Bracelets

MedicAlert bracelets allow your medical information to be available to emergency medical personnel. MedicAlert and the Spina Bifida Association of America are working together to offer a special saving of \$5 off new MedicAlert membership. To take advantage of this special offer, call MedicAlert toll-free at 888-904-7629 and mention code 5558, or visit www.medicalert.org/sbaa.

Latex Allergy Update

1. The Spina Bifida Association website (www.sbaa.org) contains a comprehensive list of latex products found in the home and the hospital.
2. Ask our chapter for a copy of Latex in Home and Community, 2004 Fact Sheet.
3. The American Latex Allergy Association (www.latexallergyresources.org) has a good website that can help connect you with educational materials, support groups, publications and product information.

SBA Albany/Capital District Chapter does not endorse or recommend products, services or manufacturers and assumes no liability whatsoever for the use or content 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.

[Taking Charge of Your Future:](#)

[A Financial Guide for People with Spina Bifida and Their Families](#)

Printer Friendly Now Available!

The new online publication, [Taking Charge of Your Future: A Financial Guide for People with Spina Bifida and Their Families](#), is now available in a printer friendly format. This is the first financial guide prepared specifically for the Spina Bifida Community. This online publication helps to take some of the mystery out of your financial planning with two sections:

1. [Financial Planning Guide for Parents/Caregivers of Children with Spina Bifida](#)
2. [Financial Planning Guide for People with Spina Bifida](#)

Check out this guide at <http://www.sba-resource.org/NEFE/>.

A reminder about how you can help...

Our chapter is always very appreciative of gifts given in honor of someone on a special occasion, or in memory of a loved one. These honorariums and memorials help to support all of the chapter's activities. Please consider supporting SBA Albany/Capital District



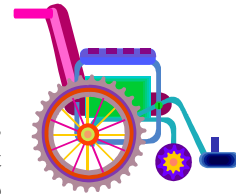
- when you are celebrating a birthday, anniversary, retirement for that loved one who “doesn’t need anything”.
- when considering a gift in memory of a loved one who has passed away.

Living memorials or honorariums are thoughtful gifts. Donations such as these provide the material means for our chapter to provide ongoing support services to children & adults who have spina bifida and their families.

Each gift to our chapter is acknowledged with a letter to the donor and is deductible for tax purposes. A letter of acknowledgement is sent to the honored person or family of the deceased, with the name(s) of the donor(s).

Equipment Available

One of our member families has recently moved and has a variety of equipment that they would like to pass on to someone who could use it.



Sizes are listed by age to give you an idea of when this child used it. If there is something listed that you could use, please call or email the chapter and we will put you in touch with the family.

- Quickie Kidz Wheelchair—in nearly perfect condition, has all of the extra pieces and tray. Used by 2—4 yr old.
- Tricycle — adapted with hand controls and bike seat (infant seat for adult bikes) for support. Red, like new. Red, ages 3—6.
- Scooter — the style used in gym class, but adapted with seat with back support and extra bars for shorter legs to be placed on. Like new, ages 4—8.
- ETAC Sting Wheelchair — the frame and seating are in good condition, would need new wheels. Also has tray and all extra parts. It’s the size up from the little Quickie Kidz.

Holiday Planning Time ***Order Flowers & Support Spina Bifida***

As the holidays approach we thought it would be a good time to remind everyone about the partnership that our national organization has with USA Florist. Simply click on the USA Florist link that appears on the homepage of the SBA website (www.sbaa.org), make your purchase, and 20% of that purchase is donated to SBA. So think of SBA when you have floral needs and feel good about giving twice in one purchase.



The following letter was submitted by Vanessa Chamberlain and Chris Darby-King, chapter delegates for this years national Spina Bifida Association of America conference, held in June. They will be presenting at our chapter's annual meeting at Double "H" Hole in the Woods on October 27th.

Dear Membership,

First of all, we would like to thank the board of directors and Spina Bifida Association Albany/Capital District for allowing us the privilege of representing our chapter at the National Spina Bifida Association conference in Atlanta, Georgia from June 23—26 this past summer. It was a wonderful experience for both of us as well as for our families. We were able to network with several professionals, parents, other chapters, and vendors, and to meet the staff of the National SBAA. There were approximately 660 conference attendees and 162 children who participated in the conference organized "children's program." The children's program was for children, birth to age 19 years and was extremely well organized. It was a wonderful time for children with spina bifida and their siblings. What a joy it was to see over 100 children in wheelchairs getting to know with each other, sharing experiences, and truly feeling like they were not alone. There was also a greater effort this year to involve adults with spina bifida both with social activities, and in addressing issues which directly affect them (e.g. obtaining optimal health care). As many of the children and young people in our local as well as national association become adults, this will become increasingly important.

The day before the official conference started, we were able to participate in a Group Member Day, which was designed for delegate and/or chapter representatives. Over 100 chapter representatives were able to be part of this day and we worked with National on detailing the Strategic Plan for SBAA to fulfill our mission statement. We were also allowed a forum to discuss our chapter concerns and learn how National can support us. We shared our concerns about the closing of the spina bifida clinic at Albany Medical Center Hospital, lack of adult clinic settings and the need for increasing adult services. We witnessed a good organizational support system from National and were impressed with Doug Sorocco, the current chair of SBAA. Doug is an adult with SB, and also a caring competent professional who listened to topics of importance to others and helped coordinate everyone's input into a vision for SBAA's overall plan.

The conference sessions were three very packed days of up-to-date medical (urology, neurosurgery, orthopedic, wound care, sexuality) information from the medical professionals top in the field on SB. There were also many sessions on advocacy, educational issues, equipment, opportunities in sports, accessible living, financial issues, sibling matters and current research. The information gathered was invaluable and provided a terrific learning experience. There were also several medical and equipment vendors with much to share and samples to use. The new "hydrophilic" catheters and "state of the art" shunts were very interesting to see. Rest assured, there is much research continuing and new products available.

Day 5 of the conference was the Delegate meeting, which is the Annual Meeting for SBAA National. The importance of sending delegates to represent our local issues was illustrated by us having a voice which stresses the need to expand National's research on clinics to include our particular circumstance (an area with a previously active clinic which now has none). Delegates elected three Board members at this time. The current SBAA Board of Directors appears to be a very competent and organized group of medical professionals, parents and volunteers committed to the organization. The current focus of SBAA is "Research, Information and Education, Advocacy, Public Awareness, Organizational Capacity and Funding." It was heartening to see how diligently National has worked to bring issues related to spina bifida to the attention of our elected officials, and how this will impact on spending of increasingly limited public funds. They have also been busy networking with other nonprofit organizations to accomplish tasks which affect all concerned.

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There is so much to report, briefly this is an overview of the 5 days of information gathered. We are looking forward to sharing all of this with you at our annual chapter meeting in October at the Double "H" weekend. We purchased conference tapes for the chapter to share with anyone interested in more details of individual sessions. We also have additional literature we will make available there. One particularly noteworthy publication from National is a Health Guide for Adults Living with Spina Bi-fida. It is a large binder (which may be copied) designed as a workbook which provides factual information on all areas of health care and forms which are useful recordkeeping tools.

It was truly a wonderful opportunity for our whole family and we strongly urge more families to participate. Next year's conference will be held June 24—27, 2007 in Louisville, Kentucky. With our new contacts with other chapters from New York, we hope to be able to provide more programs and educational conference days in this area. Stay tuned.

Vanessa Chamberlain

Chris Darby-King

Chapter Delegates

Looking Ahead...

Time to mark your calendars!

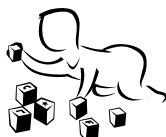


Teen Support Group

Continues to meet each month at Colonie Community Center, 1653 Central Ave, Albany. Is your teen interested in participating? Call or email for information and the schedule.

Families of Preschoolers!

Saturday, 12/2 from 10—11:30 AM
Colonie Community Center, 1653 Central Ave, Albany
RSVP: # of adults and children,
399-9151 or SBAAAlbany102@aol.com
Childcare provided
by Special Education Teacher



Double "H" Hole in the Woods Weekend Retreat

Friday, October 27—Sunday, October 29
Schedule includes ranch activities, yoga, chapter annual meeting, Halloween costume party, World Series Game #6? and lots more!



Adapted Tennis Lessons

Lessons will begin in November for the next season. Details to follow. If you are interested in participating, please call or email our office and we will be sure to get you the information.

Union College Women's Hockey Game & Post game skate with the team!

January, 2007

Details in future editions of News to Use



Cheesecake Tasting Fundraiser at Cooperstown Bed & Breakfast to benefit

Double "H" Hole in the Woods
Sunday
February 11, 2007
2—5 PM



Regional Conference Planned

The Connecticut chapter will be running our 3rd Annual Educational Conference on Saturday, March 24, 2007. Mark your calendars and watch for details in future newsletters or emails.