

Spina Bifida NEWS

Fall, 2002

Albany/Capital District Chapter
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FALL MEETING

October 19, 2002, 10 AM to 11:30 PM
Colonie Community Center
1653 Central Ave, Albany
Come share ideas, develop friendships,
and enjoy activities for the children!

**UPCOMING
EVENTS!!!**

HOLIDAY PARTY

December 14, 2002 3 PM to 5 PM
River Front Center, Amsterdam, NY
Come enjoy refreshments, children's activities,
music, and good company!

Dear Members,

It seems odd to be writing a letter as co-presidents, rather than reading the latest from Chris and Helen. In fact, it seems very intimidating following them and trying to fill their shoes. The first thing, then, we need to do is thank them for all the years they served as co-presidents. The time and hard work they expended helped lead our organization and set its course. It was and is greatly appreciated and we'll try our best to continue their legacy.

A second acknowledgement also must be made to Bobbi Nigro and the committee that sponsored the Dominic Melita Charity Golf Tournament this summer. A check for \$5372.00 was given to our chapter from monies they raised. A second check was given to a child who has Spina Bifida and multiple other health concerns who lives in our chapter. The child's family was in desperate need of a van. We sincerely appreciate all the hard work and support from the golf tournament committee in Dom's memory.

Thirdly, we would like to report back on the annual national conference, which was held in Florida this June. We heard some excellent speakers and caught up on the current standings in the medical, educational, and legislative arenas. We brought back a number of tapes, which Karen has just cataloged, for members to borrow from the chapter's Lending Library. We also will be ordering books on nonverbal learning disabilities and how to address them (aimed at both families and educators) and will let you know when they arrive. Though the number of vendors seemed less than in the past, we did get some brochures and information, too, which we look forward to sharing at our next meeting. Hope to see you all then!

Vanessa & Kevin Chamberlain
Co-Presidents

FALL TENNIS PROGRAM—

Lessons are being sponsored by our chapter.
Lessons provided by SAFE
(Sports Are For Everyone)

Where: Schenectady Racquet Club

When: 10/19, 10/26, 11/2, 11/9,
11/16, 11/23

Time: Exact time TBA (Late afternoon)

RSVP: You **must** pre-register to participate in this program. There are limited class spaces available. Call the chapter at 399-9151 or email at SBAA1bany102@aol.com.

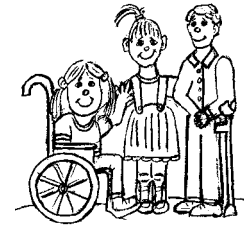
Spina Bifida Research Resource

Last spring we attached a request for participants for a research study from The Spina Bifida Research Resource of the University of Pennsylvania Medical Center. The initial report that we received from them is that we had nearly 50% participation from the people on the mailing list who receive this newsletter. Thank you to everyone who is helping by participating in their research. We have requested information from them regarding the results of the research, and will be sure to pass information along as we are informed.

PRESCHOOL PLAYGROUP

Are you a parent of a child who is preschool age and has Spina Bifida? Would you be interested in meeting other parents of children in this age group? We would like to offer to set up a playgroup for you! If this is of interest to you, please call or email us. Do you know of someone who might be interested in a play group but might not be on our mailing list? Please pass this information along to them!

“Challenges” Update



In our spring newsletter we told you about a program that is being sponsored by our chapter called “Challenges: Understanding People Who Are Differently-Abled”. It is a disability awareness training program designed for students in grades 4 through 6 to help them develop a better understanding of the challenges that are faced by people who are disabled. We are pleased to tell you that at the June conference for the national SBAA, our chapter was given third place for “Most Innovative Program Award”, in honor of our efforts with this program.

This year we plan to expand the availability of the program to all school districts in Schenectady County. We have applied for BOCES aid funding. This means that school districts can be reimbursed a percentage of the cost of the program, thus making it more affordable.

EQUIPMENT NEEDED

We are currently looking for a wheelchair and a pair of crutches that would fit the size of an average 5th grade student. Please call or email us if you might have either piece of equipment that we would be able to use for the program.

STAFF PEOPLE NEEDED

We are also looking for people who might be able to help staff the program. The hours are generally during the day, and are set up in advance with each of the staff and the interested school. If you think that you might be interested in applying, please call or email the chapter and we will get back to you with more information.



LENDING LIBRARY NEWS

We have made some new additions to our lending library including tapes that were purchased at the SBAA national conference in June as well as a few books. If you are interested in finding out what we have, this page will be updated on our web site shortly. You will be able to "check it out" at www.SBAAlbany.org!

WELCOME BABY PROGRAM

Our chapter has developed a program to help welcome new babies who have Spina Bifida. New families will receive the book Children With Spina Bifida: A Parent's Guide by Lutkenhoff, as a gift from our chapter, as well as a complimentary one-year membership to national SBAA and this chapter. If you are a family of a new baby with whom we have not yet had contact, please call us so that we might get you your gift! You can find more information about this program on www.SBAAlbany.org.



MEETING LOCATIONS

In response to requests from our membership, we are going to try varying the locations of our meetings. Please make note of the meeting locations in the newsletters and announcements. We will include directions as well. We hope that this will better meet the needs of everyone.

www.SBAAlbany.org

That is our new address on the web! Thanks to a group of students at Bryant and Stratton College in Albany, we now have a web site for our chapter. We hope that the information that we have provided will be helpful and informative. You will find information about Spina Bifida, secondary conditions related to SB, links to other web sites that we thought might be helpful, programs that our chapter sponsors, as well as information about how to become members of this chapter and how to make donations. Many thanks to Denise Montgomery, Jason Moreland, and most especially to John Kutey. While all three students developed the site for a class project required for graduation, John has been continuing to work on the completion of the site and has volunteered to maintain the site for our chapter. We hope that you will visit the site and will find it a helpful way to access the chapter and important information.



UNITED WAY

Did you know that our chapter of the SBA receives funds through United Way? You may designate any portion of your United Way gift to a specific non-profit organization. United Way simply processes your gift and passes it on to the selected agency. If you give to the United Way, you may designate your donations to be directed toward SBA: Albany/Capital District Chapter. If you would like to do this and have questions, please call our chapter at 399-9151 or the United Way at 372-4761.

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.

Dream With Me Tonight Fundraiser

The attached pages "Dream With Me Tonight" provide information regarding a fund raiser for the Spina Bifida Association of America. To find out more about how to order, go to either one of these web sites:

www.sbaa.org
or
www.dreamwithmetonight.com



This might be a good baby gift idea!

EQUIPMENT LOAN PROGRAM

Our chapter has historically had an informal Equipment Loan Program. We would like to expand upon this to make a wider variety of equipment available to a greater number of people. If you have equipment such as a wheelchair, crutches, etc. that your child has outgrown and you would be willing to give them to someone else for their use, we would ask that you register that equipment with us. We will keep track of what we have in our "closet" and will do our best to match someone's request for a particular piece of equipment with the items registered with our chapter. We are hopeful that you will be able to store the equipment, as we have no office or storage space that belongs to our chapter. We also assure you that we will keep track of your personal information in a confidential manner.

You may register equipment that you have available for the EQUIPMENT LOAN PROGRAM by visiting our web site, www.SBAAlbany.org completing the tear-off below and mailing it to our chapter, by emailing or calling the chapter at 399-9151, SBAAlbany102@aol.com.

Thank you for your support of this valuable program!

NAME _____ PHONE _____
STREET _____ EMAIL _____
CITY/STATE _____

EQUIPMENT **APPROXIMATE SIZE**
1. _____
2. _____
3. _____

Please mail this form to: 109 Spring Road, Scotia, NY 12302
or

You may register your equipment
by calling 399-9151 or emailing SBAAlbany102@aol.com.

Thank you for supporting this worthwhile program!