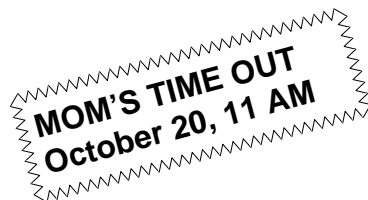


# Spina Bifida

## NEWS To Use

Albany/Capital District Chapter  
109 Spring Road, Scotia, NY 12302  
(518) 399-9151  
SBAAlbany102@AOL.com



Dear Friends,

As we head back into the school year, and what for many of us is an increase in the intensity of our schedules, I am hopeful that we were all able to take some time during the summer to enjoy family and friends and to relax. As I put the newsletter together, I was amazed and grateful to all of the people who have helped to make things happen for this chapter. There are many. I hope that I don't miss anyone, but wanted to extend a public "thank you" for the time, energy, and financial support that we are so blessed to have.

- We have been very lucky to have a golf tournament committee who have worked over the past five years to raise funds that have been crucial to the support of the chapter.
- Kerri Saunders has been working as a facilitator for our Teen Support Group for over a year.
- Jim Fitzgerald of SAFE (Sports Are For Everyone) has been working with us for over two years to provide wheelchair tennis lessons for our children.
- We have a team of 12 people who work with our disability awareness training program "Challenges: Understanding People Who Are Differently-Abled".
- The Board of Directors for our chapter consists of a group of six parents and two community members who have worked together for as many as ten years to provide guidance and lead the organization.
- We have members who periodically call and offer time, ideas, and equipment that have helped the chapter to better serve people who have Spina Bifida and live in upstate eastern New York.

If you see or talk to any of these generous people, please extend another thank you!

*Karen Wentworth*

Administrative Director



# “DOUBLE H” HOLE IN THE WOODS WEEKEND CAMPING TRIP

- DATE: October 24 –26
- TIME: Friday night dinner through Sunday afternoon lunch
- Place: Double H Hole in the Woods  
97 Hidden Valley Road  
Lake Luzerne, NY
- \* Double H is approximately 1 hour north of Albany
- WHO: Families who have members who have Spina Bifida
- ACTIVITIES: indoor swimming, high ropes course, hiking, fishing, boating, arts & crafts
- ACCOMMODATIONS: Cabins equipped to hold 2 to 4 people. Cabin assignments will be by family.
- FEE: Double H does not charge a fee for use of their facilities. They depend upon private and corporate donations to cover their expenses. They are a not-for-profit organization.
- Questions? Call 399-9151 or email us at [SBAAlbany102@aol.com](mailto:SBAAlbany102@aol.com)
- RSVP: by Thursday, October 16

*We are looking forward to having a great weekend together,  
to enjoy the beautiful Adirondacks in the fall, with terrific company!*



## TEEN SUPPORT GROUP

I hope everyone had a great summer! The following is a meeting schedule for the Teen Support Group. We will continue to meet at the Colonie Community Center, except for field trips. We will plan our field trips and adjust our schedule accordingly during future groups.

Groups will take place one Saturday per month.

DATES: 9/27, 10/25, 11/15, 12/13

TIME: 10:00—11:30 AM

PLACE: Colonie Community Center  
1653 Central Ave, Albany

If you have not participated in the group before, and are interested in joining, please call our chapter at 399-9151 or email us at [SBAAlbany102@aol.com](mailto:SBAAlbany102@aol.com).

## TENNIS ANYONE?

Our chapter will be continuing to sponsor the wheelchair tennis lesson program with SAFE (Sports Are For Everyone) for our children will be continuing this fall.

DATES: Saturdays, 10/11, 10/18, 11/1, 11/8, 11/15, & 11/22

TIME: 3—4 PM

PLACE: Schenectady Racquet Club  
2699 Curry Road  
Schenectady

The tennis program is indoors and will be held RAIN or SHINE.

*There are limited spaces available.  
Pre-registration is required.*

To register please call 399-9151 or email [SBAAlbany102@aol.com](mailto:SBAAlbany102@aol.com)

# WHAT CAN YOU DO TO

## Dream With Me Tonight CHAPTER FUNDRAISER

Our chapter has CD's that we are offering as a fundraiser. The "Dream" CD's put out by Sandman Records and has a selection of award-winning, parent-friendly lullabies. It is the winner of the Parent's Choice Award, Oppenheim Platinum Award, Nappa Gold Award. It will make a great baby shower or welcome baby gift! If you would like to order a CD from us, please send us a check made out to SBA: Albany/Capital for \$12.00. Be sure to include your mailing address, and we will ship it out to you! (See more about the songwriter on page 5.)



## Membership Drive

We had a really great response to our membership drive this spring. We now have 26 paid members plus two new families who have joined us through our "Welcome Baby" program. We have 71 families on our mailing list who receive our newsletter for our chapter. While membership is not required, it is of course appreciated!

Would you still like to join? There are several easy ways to do that.

- Call our chapter at 399-9151 and request a membership form.
- Email us at SBAAlbany102@aol.com & request a membership form.
- You can visit our website at [www.SBAAlbany.org](http://www.SBAAlbany.org), click on membership, and download a

## THE GIVING PROCESS

Gifts that our chapter receives helps us to focus on offering opportunities and support for people who have Spina Bifida and their families. In addition to helping our chapter, giving to a charity such as this one that is not-for-profit may help you, the donor, as well. Because we are a tax-exempt organization, gifts to Spina Bifida Association: Albany/Capital District Chapter are tax deductible to the full extent allowed by law. If you itemize your deductions, a gift to our chapter may help to reduce your tax liability.

There are many ways that people can give to this SBA chapter.

- Monetary donations
- Gifts & bequests that individuals have designated in their wills
- When making a gift, donors might want to consider using stock as opposed to cash, especially if the stock has a capital gain and the stock has been held longer than 12 months. The reason is that the net cost of the gift, after considering tax issues, may be less when gifting stock.

Do you have questions about gifting? You might wish to speak with your accountant, financial planner, or lawyer for advice. We cannot provide advice regarding this process, but please call us if we can assist you!

## United Way

Just a reminder.....If you give to the United Way, you may designate your donations to be directed toward this chapter, 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. To those who have chosen to designate your United Way donation to our chapter, we would like to say, "Thank you so much for your sup-





## MOM'S TIME OUT

Recently, one of our moms brought up a suggestion. She has requested a "Mom's Time Out". I can't say it better than she did, so I will share her explanation: "I was thinking that once school is started, a bunch of us could have lunch or something, kind of like book clubs. I find that talking to other people about the stress and anxiety of complications with SB can benefit all of us. I swear that I am going absolutely crazy sometimes.... I find support from my family but....We (moms) need to have time alone to have appetizers and a sangria. I am putting all of us in TIME OUT!! LOL."

**Therefore, we are happy to announce that we will be having our 1st Mom's Time Out!**

**Date:** Monday, October 20, 2003

**Time:** 11 AM to 1 PM

**Place:** Olive Garden  
178 Wolf Road, Colonie

**RSVP:** Please call or email by *Friday, October 17th* so that we can make appropriate reservations.

Please email SBAAlbany102@aol.com or call 399-9151 if you have any questions.

Have fun moms ~ You deserve it!



## Vital Card™

Designed by the parents of a child with Spina Bifida, Hydrocephalus, Chiari Malformation and Syringomyelia. The Vital Card™ is a handy new resource for people of all ages from children to seniors, with these or other serious conditions. By compiling medical information, insurance numbers and emergency contacts all in one, the Vital Card™ aims to eliminate stress and miscommunication during the time of an accident or health emergency.

The cards cost \$49.95, which includes three laminated copies of your Vital Card™ containing your medical information, specifically formatted for quick and easy viewing.

Information included, but not limited to: insurance/Medicaid numbers; emergency contacts; surgical history; allergies; CT and/or MRIs, medications and much more.

For more information check out the website ([www.vitalcard.net](http://www.vitalcard.net)). You can also contact Vital Card™ by phone (518-569-8595) or email (Karen@vitalcard.net)

## IEP & Transition Planning (July 2003) (NCSET Web Topic)

This NCSET Web topic provides information on strategies to support students, families, and professionals to participate in developing a student's Individual Education Plan (IEP) and transition plan. Includes an introduction, frequently asked questions, related research, emerging practices, Web sites, and additional resources.

<http://www.ncset.org/topics/ieptransition/default.asp?topic=28>



## CHIARI MALFORMATION

We received an email recently from a member asking that we let our members know that the North Shore Jewish Memorial Hospital in Long Island has a new neurosurgery center and Chiari Institute. For information, you can visit their website at [www.northshorelij.com](http://www.northshorelij.com) and search under Chiari Institute.

*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.*

## **CHALLENGES:**

### **UNDERSTANDING PEOPLE WHO ARE DIFFERENTLY-ABLED**

is a disability awareness training program sponsored by our chapter. Groups of staff people provide the program in a classroom-size setting with the goal of raising awareness about the needs of people who have challenges. While the program addresses a variety of types of disabilities, we would really like to offer this program to classrooms with one of our children who has Spina Bifida.

The reverse side of this page has a flyer with additional information about the program. We also have a brochure that provides more details. What we need is for you to help us to connect with your child's classroom teacher. Would you be interested in this program being presented in your child's classroom? If your answer is yes, call us at 399-9151 or email us at [SBAAlbany102@aol.com](mailto:SBAAlbany102@aol.com). It would be great to have some of our children benefit from their friends and fellow classmates having a better understanding of what it is like to face their challenges every day.

**Dream With Me Tonight CD Fundraiser ~ More about the songwriter....**

# CHALLENGES:

## UNDERSTANDING PEOPLE WHO ARE DIFFERENTLY-ABLED

### A Disability Awareness Training Program

#### *Sponsored by*

**Spina Bifida Association: Albany/Capital District Chapter**  
109 Spring Road  
Scotia, NY 12302

(518)399-9151

SBAAlbany102@aol.com

Available to Albany,  
Schenectady, Saratoga,  
& Schoharie Counties

### NATURE OF PRESENTATION:

- ~ Presented by four instructors to classroom-sized groups of 16 to 28 students ~
- ~ Hands-on exhibits offer simulations of a variety of disabilities ~
- ~ Instructors lead discussions and answer questions ~

### STUDENTS EXPERIENCE:

- ~ What it might be like to be a person who is disabled ~
- ~ Methods a person who is differently-abled might use to address his or her challenges ~
- ~ Responses that students might offer to someone who is differently-abled ~
- ~ Examples are given of disabilities that are visible and those that are not. ~

### CURRICULUM AREAS:

character education  
tolerance  
respect for others  
Courtesy  
dignity



### TARGET AUDIENCE:

**Grades 4 – 6**

Clubs and organizations  
in middle school, high school,  
& community groups

### PROGRAM COST:

\$150.00 for a 1¾-hour session

- Price is subject to change.

### NATIONALLY RECOGNIZED PROGRAM

Most Innovative Programming Award  
3rd place, 2002  
Spina Bifida Association of America

### INFORMATION & SCHEDULING?

(518) 399-9151  
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