

# Spina Bifida NEWS

Winter, 2002

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



## **ADULT SOCIAL**

Over the past year, we have noticed an increase in the number of adults with Spina Bifida who are wanting to connect with others facing similar challenges. In response to this, we have arranged to have an opportunity for the adults to meet, enjoy a casual dinner together, and decide what they as a group would like to do together in the future.

**DATE:** Friday, January 24, 2003

**TIME:** 6:30 to 10:00 PM

**PLACE:** First Reformed Church  
224 North Ballston Ave  
Scotia, NY 12302

**WHO:** Adults who have Spina Bifida  
& their guest.

**Please join us for dinner!**

**RSVP:** by Monday, 1/20/03 399-9151  
or email at SBAAlbany102@aol.com

### **DIRECTIONS:**

Take NYS Thruway to Exit 26. Follow signs on exit ramp to Scotia. At stoplight cross Rte 5 onto Vley Road. Go approximately 3 miles to the end at Rte 50. Take a sharp left onto Rte 50. The church is almost immediately on your right-hand side. (You will see the sign for the First Reformed Church. The church is set back from the road and has a cemetery in front.) Park in front of the building toward the school end of the building. We will be eating in Brink Hall ~ go in the building and turn to your right.

- **Call 399-9151 if weather conditions are questionable**

## **HOLIDAY PARTY**

Due to the many activities that occur in December, the holiday party has been postponed. We hope that the new date we have picked in January will allow more people to attend!

**DATE:** Saturday, January 11, 2003

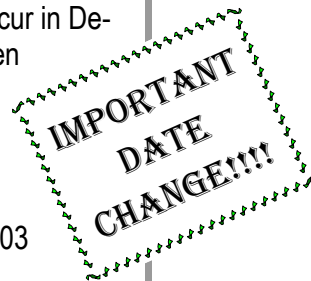
**TIME:** 1—3 PM

**PLACE:** RiverFront Center, Amsterdam  
Make your own subs.

Activities for the children.

**DIRECTIONS:** Take Rte 5 West to Amsterdam. Bear right onto CR-157 (Lower East Main St.—Rte 5). Continue on E Main St. (Rte 5) until you are at a STOP sign and facing Riverfront Center. Take a left to park in the rear/parking garage.

- **Call 399-9151 if weather conditions are questionable**



## **TEEN SUPPORT GROUP**

Did you know:

- There is a teen support group sponsored by our chapter that meets once/month
- The group is open to teens ages 11 to 16 who have Spina Bifida
- The group is open to new members at any time

Are you interested in more information about this group? Call our chapter for details.

## FALL TENNIS

Our teens just concluded another six week session of tennis sponsored by our chapter. Eight participated in a six week program held at the Schenectady Racquet Club. The players continue to get stronger and develop more skills. They are looking forward to tennis in the spring beginning May 3rd. Registration is limited, but there are more openings for those who are interested in becoming involved! Stay tuned for further information in early spring. Feel free to call with questions.

## WELCOME BABY PROGRAM

Are you the parent of a new baby who has Spina Bifida with whom we have not yet had contact? Do you know of a family with a new baby with Spina Bifida? Please call us so that we might deliver our Welcome Baby gifts! You can find more information about this program on [www.SBAAlbany.org](http://www.SBAAlbany.org).



## PRESCHOOL PLAYGROUP

We would like to help get a play group started for children with Spina Bifida who have not yet started Kindergarten. A play group would offer the children interaction and friendships with peers facing similar challenges. In addition, families of these children would gain support and networking possibilities.

If you are interested in joining a play group, or would like to help plan activities for this age group, please call or email us. We are open to suggestions about how to best meet the needs of our youngest children and their families.

## YOUNG ADULT

### SUPPORT GROUP BEGINS!

We are pleased to announce that this chapter is sponsoring a group for young adults with Spina Bifida. The group had its first meeting December 4th. The group facilitator, Ms. Tammy Komp, will be working with the group to determine discussion topics, as well as dates, times, and locations of the group's future meetings.

*It's not too late to join!* The support group is open to people between the ages of 17 & 24 who have Spina Bifida. The group is open to new members at all times. If you are interested in more information, or in joining the group, please call or email the chapter.

## THE VERMONT CONNECTION

Over recent months, we have received a number of inquiries from people in the Vermont and Plattsburgh area. Due to the distance involved from the core of our chapter, we decided that it might make sense to assist these families in connecting with each other. With their permission, we have helped the families that are known to us from this area to exchange information. If there are additional families living in this northern area who would like to join this "connection", please send us written permission allowing us to share your name, address, phone, and email. We will help to get you in contact with the other families. We hope that this leads to a successful "Vermont Connection" for these families.

## 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.



## LENDING LIBRARY NEWS

There are several new highlights in our lending library:

### BOOKS

- All Kinds of Friends, Even Green, by Ellen Senisi. Bethesda, MD: Woodbine House, 2002.

### TAPES

- ***Future and Special Needs Planning for Persons with a Disability.*** Bart Stevens, SBAA Conference, 2002.
- ***Chronic Sorrow: Managing the Emotions of Parenting a Child with Spina Bifida.*** Timothy Onkka, SBAA Conference, 2002.
- ***Independence.*** Dana Gass & Josyln Kressman, SBAA Conference, 2002.
- ***Latex Allergy.*** Jacki Frost, SBAA Conference, 2002.
- ***Depression and Anxiety in Individuals with Spina Bifida.*** Gregory Liptak, SBAA Conference, 2002.
- ***Transitioning Urologic Care from the Parent to the Teenager.*** David Joseph, Mark Rich & Michael Keating, SBAA Conference, 2002.
- ***What's New in Spina Bifida? An Update of Health Related Issues.*** Gregory Liptak, SBAA Conference 2002.
- ***Spina Bifida Outcome: A 25-year Perspective.*** Robin Bowman, SBAA Conference, 2002.
- ***Neurological Causes of Scoliosis in Myelomeningocele.*** Mark Dias, SBAA Conference, 2002.
- ***Chiari Malformation Update.*** Mark Dias, SBAA Conference, 2002.
- ***Tethered Cord Update.*** Carolyn Carey, SBAA Conference, 2002.
- ***An In-service Model on Nonverbal Learning Disabilities for the IEP Team.*** Carol, Fletch & Tally Russell, SBAA Conference, 2002.

If you would like to view a complete list of the materials available through our lending library, visit our web site at [www.SBAAlbany.org](http://www.SBAAlbany.org)!

## BOOK REVIEW

All Kinds of Friends, Even Green, written and photographed by Ellen Senisi, is a picture book written for children ages 4 to 8 about a boy named Moses who has Spina Bifida. Moses has an assignment to write about a friend. As he contemplates which friend to write about, he explores a variety of different kinds of friendships that he has in his life.

Through these thoughts about friendship, Moses also explores ideas about facing the challenges of being disabled. It might be a helpful tool to use to open discussions about these topics with your child.



## [www.SBAAlbany.org](http://www.SBAAlbany.org)

Have you had the opportunity to look at our new web site? We are pleased to tell you that many people have been visiting us there. We hope that it continues to be helpful to you. Please let us know if you have any suggestions for further additions to the site!



## ABLEDATA

“ABLEDATA is a federally funded project whose primary mission is to provide information on assistive technology and rehabilitation equipment available from domestic and international sources to consumers, organizations, professionals, and caregivers within the United States.” The website is sponsored by the National Institute on Disability and Rehabilitation Research (NIDRR). The database contains information on more than 29,000 assistive technology products, including price and company information. Visit the website at [www.abledata.com](http://www.abledata.com).

*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” Update

### EQUIPMENT NEEDED

We received a donation of a wheel chair for the “Challenges” program that is a good size for intermediate-age students. Thank you to the Burdette family for their generous contribution!



We are now looking for a pair of forearm crutches that would be the right size for 10-year-old students. If you have a pair that you think might be the right size that you could donate, please call and we will make arrangements to meet with you at your convenience.

### PROGRAM PRESENTATIONS

In October, a mailing was sent to all of the elementary schools in Schenectady County with brochures announcing our new disability awareness program. Since that mailing, we have given the program to four groups of students; three elementary school classrooms and a group of high school students in a service learning class. As we expected based upon the results of the pilot program, it has been very well received. We currently have two additional programs scheduled, and two more to be scheduled. WE NEED YOUR HELP! We would like to be scheduling more “Challenges” programs in the Albany/Capital district area. We would be especially interested in offering the program in schools where there is a child or children with Spina Bifida. We believe that offering this experience to school-age children will help others to better understand and be better friends with people who are differently-abled. If you might be able to help us be invited into your school district, please call or email our chapter.

### EQUIPMENT LOAN PROGRAM

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.

You may register equipment that you have available for the EQUIPMENT LOAN PROGRAM by visiting our web site, [www.SBAAlbany.org](http://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

You may also register your equipment  
by calling 399-9151 or emailing [SBAAlbany102@aol.com](mailto:SBAAlbany102@aol.com).

*Thank you for supporting this worthwhile program!*