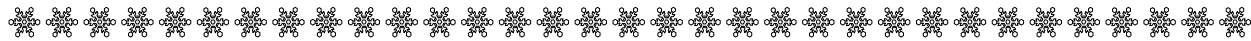


# Spina Bifida

## NEWS To Use

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



Happy Thanksgiving!

As we head into the holiday season, and the weather is beginning to feel more and more like winter is around the corner, this is often a time of the year when people look for opportunities to offer thanks. I think back to the end of October, and the wonderful weekend that a large number of our families spent together at Double "H" Hole in the Woods and am grateful for the opportunities such as this when our chapter is able to come together and connect with each other. I look forward to future events where these friendships can continue to grow, and new ones can be developed.

At our annual meeting at Double "H", our treasurer, Margie Langelier, reviewed the financial status of our chapter. As part of this, she indicated that one of the key income sources are donations that people make to our chapter. These gifts are typically given either in memory of a loved one or friend, or in honor of a loved one who is celebrating a special occasion in their life. When these gifts are received, our chapter sends an acknowledgment of the donation either to the family, in the case of a memorial gift, or to the person being honored.

As you take time to give thanks, and to begin making your purchases for holiday gifts, please consider whether a donation to the Spina Bifida Association: Albany/Capital District Chapter might be just the right way of honoring someone in your life. Forms for donations are included in this newsletter. Thank you for your generosity!

Wishing you all happiness and health in this holiday season!

*Karen Wentworth*  
Administrative Director



## Spina Bifida Connection

The following information was sent to our chapter email. You may be interested in exploring this for your family.

“Discussions have been underway at <http://spinabifidaconnection.com> for a few months now. There is no cost involved in becoming a member. The forum is fun, informational and very easy to use. Please join us today and spread the word in your newsletters. We all have such unique experiences with spina bifida and it is important that we connect as a community, even if we are spread all over the world.

See you on the board!”

From: [barb@spinabifidaconnection.com](mailto:barb@spinabifidaconnection.com)  
(Barb)

## Volunteers Needed for a Research Study

This research is being conducted by Keith Williams, Ph.D., Feeding Program, Penn State Hershey Medical Center and Kimberly Schreck, Ph.D., Psychology Program, Penn State Harrisburg.

They are conducting a research study on relations between eating habits, obesity, and bowel habits among children with spina bifida. Children with spina bifida aged 3-18 years and their parents are eligible to participate. The study involves having parents or caregivers complete a questionnaire that will take no more than 15 minutes.

The study does not gather any identifying information such as names or addresses. All participation is completely voluntary. You may contact the researchers by email [feedingprogram@hmc.psu.edu](mailto:feedingprogram@hmc.psu.edu) or by calling at (717) 531-7117.

This research has been approved by the Institutional Review Board, under Federal regulations,

## Teen Group Schedule

**When:** Our next group will be Saturday, December 17, 2005

**Time:** 10:00-11:30 AM

**Where:** Colonie Community Center

**Who:** People ages 11 or 12 and up to 19 who have spina bifida.

**Questions?** If you would like more information about teen group and whether or not it might be something for you or your teen, please call our chapter line at 399-9151 or email [SBAAlbany102@aol.com](mailto:SBAAlbany102@aol.com).



## Latex Free Dentistry

We received this information from a retired (due to latex allergy) dental hygienist who spotted this announcement in her professional journal, the October issue of RDH magazine. There was a full page ad for \*latex free\* anesthesia. The company is called Septodont (no financial interest) and they have a website

[www.septodontusa.com](http://www.septodontusa.com). It reads, in part,

"now available to US dentists and hygienists from your local dental dealer. Septodont is pleased to introduce the first full line of dental local anesthetic products in 100% LATEX FREE DENTAL CARTRIDGES. Septocaine, Lignospan Standard and Forte, Scandonest Plain and Scandonest 2% L are currently being sold with 100% latex free enclosures."

You may wish to pass this information along to your dentists.

Karen Wentworth  
Spina Bifida Association:  
Albany/Capital District Chapter

*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.*

## **Intersection: Navigating the Road to Work**

V. 2 No. 10 November 2, 2005

Intersection: Navigating the Road to Work, is an electronic newsletter of the National Collaborative on Workforce and Disability for Youth (NCWD/Youth). The newsletter and the NCWD/Youth website offer information to improve services to youth and especially youth with disabilities.

*IMPORTANT: If you would like the delivery of this publication to your inbox, please add the email address [intersection@ncwd-youth.info](mailto:intersection@ncwd-youth.info) to your address book.*

### **Research for Guideposts to Success on NCWD/Youth website**

The research supporting the NCWD/Youth's Guideposts for Success has been posted on the website (download supporting research in Microsoft Word format or supporting research in Adobe PDF format).

The research review was conducted jointly with the National Alliance for Secondary Education and Transition's National Standards and Quality Indicators. The research summary and citations are available in Adobe PDF and Microsoft Word format.

The document identifies and presents research, federal government documents, commissioned reports, and other sources that serve as the foundation upon which the Guideposts for Success are based. The Guideposts include five categories that can help families, institutions and youth themselves through the transition processes. The five categories that all youth need are:

- School-Based Preparatory Experiences
- Career Preparation & Work-Based Learning Experiences
- Youth Development & Leadership
- Connecting Activities
- Family Involvement & Supports

More information about the guideposts is available at [http://www.ncwd-youth.info/resources\\_&\\_Publications/guideposts/index.html](http://www.ncwd-youth.info/resources_&_Publications/guideposts/index.html).

### **New Publications available from ODEP**

The Office of Disability Employment Policy (ODEP) has added several new or updated fact sheets on the following subjects: mentoring, disability data and research resources, interviewing tips for job candidates with disabilities, recruiting employees with disabilities, emergency preparedness, and an overview of the Job Accommodation Network.

These fact sheets as well as previous ODEP publications are available in PDF and html formats at <http://www.dol.gov/odep/pubs/publicat.htm>

### **Important Information**

All comments and inquiries should be sent to [newsletter@ncwd-youth.info](mailto:newsletter@ncwd-youth.info).

Funded under a grant supported by the Office of Disability Employment Policy of the U. S. Department of Labor, grant # E-9-4-1-0070. The opinions contained in this publication are those of the grantee/contractor and do not necessarily reflect those of the U. S. Department of Labor.

Note: There are no copyright restrictions on this document. However, please credit the source and support of federal funds when copying all or part of this.

From the National Collaborative on Workforce & Disability for Youth: Navigating the Road to Work: Making the Connection between Youth with Disabilities and Work.

## **COMING SOON: Visit the SBAA website for a new online publication:**

### **Taking Charge of Your Future:**

#### **A Financial Guide for People with Spina Bifida & Their Families**

Includes a financial guide for parents and caregivers, covering these topics:

- How can you assess the present situation?
- How can you teach money management to your child?
- How can you support your child's educational goals?
- How can you support your child's employment goals?
- Where can you turn for help?
- How can you plan for the future?

There is a planning guide for people with spina bifida covering these topics:

- What do you want to do in life?
- What else should you know about money?
- What if you want to go to college?
- What if you want to get a job?
- What if you want to live on your own?

### **Job Openings:**

#### **Spina Bifida Association National Office**

The Spina Bifida Association National Office is recruiting for two positions:

\* Field Services Manager

\*Director of Development

The jobs are based in Washington, DC. No relocation costs will be covered.

Interested persons should send a cover letter and resume to [hr@sbaa.org](mailto:hr@sbaa.org).

For job descriptions or further information email [hr@sbaa.org](mailto:hr@sbaa.org).

*Christine A. Poward, COO*

*Spina Bifida Association of America*

*4590 Mac Arthur Boulevard, NW*

*Washington, DC 20007*

*202.944.3285 x12*

### **SB Parents ListServ**

The SB Parents ListServ is for any parent of a child with spina bifida. Use the SB Parents listserv to exchange ideas, resources, debate & have some great discussions.

For more information, or to add yourself to the ListServ

\* go to: [SBAA.org](http://SBAA.org)

click on eCommunities

click on SB Parents ListServ

This web page explains how to sign up for ListServ, as well as providing some guidance with general ListServ etiquette.

### **Spina Bifida Association Youth Adult Alliance**

The YAA is a link for adults with spina bifida, young and old, to communicate with each other about a wide range of issues of common interest.

- Go to [www.sbaa.org](http://www.sbaa.org)
- Click on eCommunities
- Click on YAA ListServ

You might also want to check out YAA BLOG!

Link into the spina bifida community. You'll meet fascinating people, learn about the latest treatments and research, & find out about the most recent events that affect adults of all ages living & thriving with spina bifida. The YAA BLOG is updated regularly so visit often.

## **Sensitivity Training**

The following are some helpful tips for being sensitive to the feelings of someone who is disabled that were passed along to our chapter. It might be a useful document to share with staff at school or others at work.

1. Always try to remember to use people first language - in other words instead of saying something like "a spina bifida patient" say "a patient with spina bifida", it may seem simple but many with disabilities are offended when they are referred to by the disability label they carry rather than a person.
2. Be careful of words like "suffer" "victim" "patient" - they label a person in ways that are not correct. I have spina bifida - I am not a victim of it. The term patient is fine in a medical setting but not in most public settings. Likewise, avoid emotional qualifiers such as "unfortunate" "pitiful" "poor" etc.
3. Never refer to people with a disability as "cripples" or even "handicapped". Try to use more up to date terms like "disabled" or "person with a physical impairment".
4. Avoid referring to healthy people as "normal". I am quite "normal" even though I have spina bifida.
5. Do not use terms like "wheelchair bound" or "confined to a wheelchair" try to use the term "wheelchair user".
6. Beware of the "hero story". Not only is the hero approach a cliché, most people with a disability do not wish to be portrayed as either heroes or victims.
7. When speaking to a person with a disability - speak to them as you would any other person, do not speak with their attendant, interpreter or companion unless they are the ones you need to address.
8. Always ask before you help. I have often had people grab my arm without asking when I am struggling with balance and had them be more in my way than a help. Not to mention this is an invasion of my private space.
9. Don't make assumptions - People with disabilities are the best judge of what they can or cannot do. Try not to make decisions for them about participating in any activity. Also, If you have questions about their needs and how you can accommodate them like what specifically you can do for them, how to do it, what language or terms to use - ask the person with the disability.
10. If a person who is blind needs to be guided - offer your arm - do not grab his or hers.
11. If you are speaking with a person with a speech impairment and are having trouble understanding them - ask them to repeat. It will show that you are really wanting to understand their message. Likewise, do not finish their sentences for them. If you are unsure of what they said, repeat it back to them and ask if you got the message correctly.
12. Do not pet or otherwise distract dog guides or any service animal - they are working and must not be distracted.
13. Treat adults - as adults.
14. When talking to a person in a wheelchair or who is considerably shorter than yourself - attempt to place yourself at eye level and in front of the person to facilitate the conversation.

## Double "H" Hole in the Woods Ranch Parent Group

Double "H" Hole in the Woods Ranch provides much support and programming to many of our children and families, some of which is connected with our chapter, but much of which is independent of us. I know that many parents are interested in being able to give back to the ranch. In light of that, I would like to pass along Cheryl Woll's email address to our members. If you would like to be a part of the Double "H" parent group, you may contact Cheryl for more information. Recent activities have included volunteering at a thank you dinner given for the ski instructors and a family work day.

Anyone who wants to be a part of the Double H parent group can get on Cheryl's e-mail list. Contact her at [cherylwoll@aol.com](mailto:cherylwoll@aol.com) or if you would rather, the phone number of the ranch is 518-696-5676.

## Spina Bifida Research Resource

Many families from our chapter are participating in a research study through the Spina Bifida Research Resource. If you are interested in learning current information about these studies, visit their website at [www.sbrr.info](http://www.sbrr.info) or write:

SBRR

Texas A&M Health Sciences Center—IBT

2121 W. Holcombe Blvd.

Houston, Texas 77030.



## STRIDE

(Sports & Therapeutic Recreation Instruction/Developmental Education)

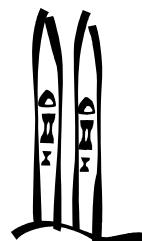
### Adaptive Skiing Lessons

Stride will offer adaptive skiing lessons in 2.5 hour time blocks on Tuesday through Thursday evenings 6:00 to 9:30 PM and Saturday & Sunday from 9 to 11:30 AM and 1:00 to 3:30 PM.

The price of a lesson is \$45 at Jiminy Peak and \$40 at Cata-mount.

For information, call 598-1279 or email [stride@capital.net](mailto:stride@capital.net).

The STRIDE website is [www.stride.org](http://www.stride.org).



## ACCESSIBLE TENNIS SCHEDULE

**Dates:** Saturday, 12/3, 12/10, 12/17

(2006 dates to be announced)

**Time:** 2—3 PM

**Place:** Schenectady Racquet Club

**Who:** Children to young adults who have spina bifida

**Cost:** SBA: Albany/Capital District is sponsoring the lessons, with instructions being provided by 15 Love. There is no cost to the participants.

**Equipment:** 15 love will provide racquets for those who do not have one.

**\*\*\* Please plan to arrive for lessons by 1:45 so that students are on the court and ready to play by 2:00.\*\*\***

### Directions to Schenectady Racquet Club:

Take 87 South to the NYS Thruway.

Take the Thruway west toward Buffalo.

Take Exit 25 onto I-890 West.

Take Exit #9 for Route 7 W.

Turn right at the end of the exit onto Curry Road.

You will see signs for the Racquet Club very soon on your right-hand side.



Enclosed is a gift in the amount of \$ \_\_\_\_\_ given  
in honor of (Name) \_\_\_\_\_  
to celebrate (Occasion) \_\_\_\_\_.

**Gift Given By:**

Name \_\_\_\_\_  
Address \_\_\_\_\_  
City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

**Please send an acknowledgement of this gift to:**

Name \_\_\_\_\_  
Address \_\_\_\_\_  
City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

**Your monetary gift to the Spina Bifida Association: Albany/  
Capital District Chapter is greatly appreciated.**

\* A donation in honor of someone or celebrating an occasion is a thoughtful gift. 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.

\* An acknowledgement of the donation is sent to the person being honored, with the name and address of the donor(s). The amount of the gift *is not* indicated in this letter.

Checks should be made out to SBA: Albany/Capital District Chapter. The chapter address is 109 Spring Road, Scotia, NY 12302

Enclosed is a memorial gift in the amount of \$ \_\_\_\_\_  
in memory of (Name) \_\_\_\_\_

**Memorial Given By:**

Name \_\_\_\_\_  
Address \_\_\_\_\_  
City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

**Please send an acknowledgement of this memorial to:**

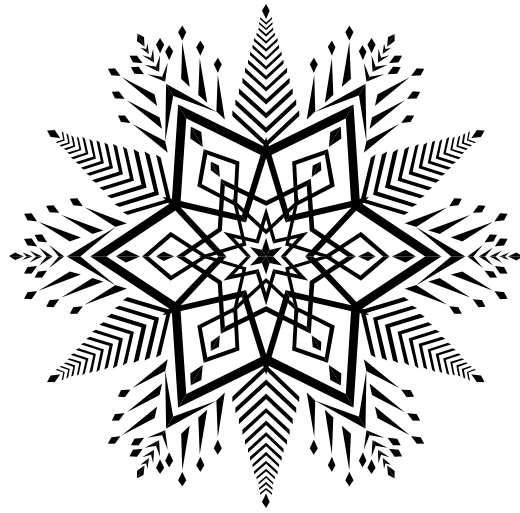
Name \_\_\_\_\_  
Address \_\_\_\_\_  
City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

**Your memorial gift to the Spina Bifida Association: Albany/  
Capital District Chapter is greatly appreciated.**

\* A living memorial is a thoughtful gift. 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 memorial acknowledgement is sent to the family of the deceased, with the name of the person honored and the name or names of the donor(s). The amount of the gift *is not* indicated in this letter.



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