

# 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 shovel out from the many snowfalls of this winter, our chapter has been planning activities and events in an attempt to respond to the concerns that we hear from people through emails, phone calls and personal contacts. I ask that you take some time now to look through this newsletter, paying added attention to these activities, marking your calendars, and letting me know in which events you will be participating.

- **We hear concerns from parents of teens and young adults about their children's futures. We hear from the young adults & adults about some of the difficulties that they are experiencing in living in the community.**

*We have asked the Center for Independence, Inc. to present to our adults who have spina bifida and parents, discussing the options that this organization has available. We would like this to be the beginning of future meetings, presentations and activities that will be helpful to address the needs of this group.*

- **Parents of preschool age children are looking for ways in which they can meet, support and network with each other.**

*We are planning a get-together for families with children who have spina bifida under the age of 10. In addition to the parents getting to know each other, the added benefit of this will be that the children will start early to develop friendships that will be helpful to them as they grow. Parents of our teens feel strongly that these early relationships and friendships have been important for their children.*

- **Parents of preteens & teens who have spina bifida indicate a need for their children to have friends who are facing similar concerns.**

*We have a support group for this age range where children can talk about these concerns with their peers. In addition, this group can develop friendships by participating in tennis lessons which are designed to be accessible. These are scheduled for spring, summer, and fall. Joining in the chapter activities such as hiking, camping at Double "H" Hole in the Woods, and whitewater rafting are other ways in which this group can connect with each other.*

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- We hear from young adults & adults that they would like opportunities to get to know each other.

*Again, the presentation by the Center for Independence would be an opportunity to meet and discuss ideas and make plans for future activities. In addition, chapter activities such as hiking, whitewater rafting, & camping are great opportunities for our adults to get together and have fun!*

- Parents of elementary school age children ask for opportunities for their children to get together and develop friendships.

*Some of these children may be old enough to enjoy our tennis program. Watch for information about the Under 10 family gathering. They can all join in with the chapter activities of hiking, white water rafting and camping to begin to develop these friendships.*

Inside this newsletter you will find a schedule with dates and times of upcoming events. Please review this and see which of them will work for you and your family. Call or email if you have questions or concerns. If you have suggestions of activities that might be fun for our chapter in your area, please let me know. I would be happy to work with you to plan future events. New ideas are always welcome!



*Karen Wentworth*  
Administrative Director

## MEMBERSHIP REMINDER!

Please send in your membership to the chapter as soon as possible.

Checks should be made out to:

SBA: Albany/Capital District

109 Spring Road

Scotia, NY 12302



Please take a moment to pencil these dates in on your calendar.



- Teen Support Group—3/19, 4/9

- Independent Living Center presentation—Saturday, 4/9  
Colonie Community Center  
1653 Central Ave, Albany

*For adults who have SB, & parents of teens and adults. Please RSVP by phone or email if you will be attending.*

- Spring Tennis— Call to register  
Saturdays 4/2 to 5/21



- White Water Rafting—  
Saturday, 8/27

- Double “H”  
Camping Weekend—  
10/28 to 10/30



The following are tentative dates. Watch our chapter newsletter and emails for updates.

- Under 10 gathering—  
To be scheduled



- Spring Hiking Day Trip  
Saturday, 6/4

- Summer Tennis—  
Mondays, 7/11 to 8/15



## Resource Booklets available from the United Spinal Association



- Access State & Local Government: Your rights and responsibilities under Title II of the Americans with Disabilities Act
- Understanding the Fair Housing Amendments Act: A Publication of United Spinal Association
- Understanding the Americans with Disabilities Act (ADA)
- Taking Action: A Step by Step, Self-Help Guide to Becoming a Self-Advocate & Making A Difference
- Fire Safety for Wheelchair Users at Work & at Home
- Accessible Air Travel: A guide for People With Disabilities
- Disability Etiquette: Tips On Interacting with People with Disabilities
- Parking Reminders for handicapped parking areas

*HELEN R. MERTENS'*  
*EDUCATIONAL SCHOLARSHIP FUND*  
SPONSORED BY THE

**Spina Bifida Association: Albany/Capital District Chapter**

109 Spring Road  
Scotia, NY 12302

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SBAAAlbany102@aol.com

The purpose of the scholarship is to award financial assistance to persons who have Spina Bifida and are pursuing higher education, technical training, or driver's education. *The scholarship fund is available to paying members of the Spina Bifida Association: Albany/Capital District Chapter only.* The amount of the grant is a maximum of \$1000 per fiscal year. It is intended to be used toward the cost of tuition, fees, and books. The exact amount to be disbursed will be at the discretion of the Scholarship Committee. The number of scholarship applicants will be a factor in this decision.

**Eligibility Requirements:**

1. Applicants must have Spina Bifida or a spinal cord disability resulting in similar challenges and/or needs **AND** be a paid member of the Spina Bifida Association: Albany/Capital District Chapter for a minimum period of one year.
2. There is no age limit.
3. Applicants must demonstrate acceptance by a school of higher education, technical training, certificate program, or driver education training program.
4. No financial statement shall be required.

If you are interested in receiving further information, or would like to obtain a copy of the application, please call or email our chapter.

*We are very grateful to Helen R. Mertens and her estate for making this scholarship program possible for our chapter.*



## REASONS TO ATTEND...

### THE SPINA BIFIDA ASSOCIATION OF AMERICA ANNUAL CONFERENCE

- This year SBAA has joined forces with the International Federation for Spina Bifida & Hydrocephalus for the conference.
- Medical Sessions: Discover up-to-the-minute information about urology, orthopedics, neurology & neurosurgery treatment.
- Workshops: Join others who live with spina bifida or those who care for people who have spina bifida as you enhance your own perspective.
- Presenters: Learn from those who are most informed — physicians, nurses & other clinicians, educators, researchers and people who have spina bifida.
- Exhibits: Experience the latest products and services to help you or those you care for stay healthy and live life to its fullest.
- Social Events: Enjoy many opportunities to socialize — An Opening Reception and other special events designed for every attendee.

#### Programs are designed for:

- **Adults who have spina bifida:** Gain vital information about making the most of your life and your health.
- **Parents of children who have spina bifida:** Learn innovative ways of helping your children grow into independent and active adults.
- **Doctors, Nurses & other Clinicians:** Sharpen your clinical skills and learn about new therapies.
- **Children who have spina bifida:** Experience Kids Camp just for the fun of it! You'll have the time of your life and learn just how much you can accomplish.

***See attached information sheet for details about the national conference.***

## LENDING LIBRARY NEWS

We have a new picture book added to our collection; My Pal, Victor by Diane Gonzales Bertrand. It is bilingual in English & Spanish, & recommended for ages 4 to 8. In the story, Victor tells heart-booming ghost stories, claps the loudest at Dominic's baseball games, and performs a fabulous floating frog stroke. Two boys experience carefree camaraderie, despite one boy's disability. This book might be helpful to recommend to primary level teachers needing to address social situations related to children who have disabilities in school settings.

Books are available on loan through the mail by calling or emailing the chapter. For a list of other books and resources that are available, please see our website at [SBAAlbany.org](http://SBAAlbany.org).



*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.*

# DOUBLE "H" HOLE IN THE WOODS RANCH



Founded in 1992 by Charles R. Wood and Paul Newman, the Double "H" Hole in the Woods Ranch is located in upstate New York's beautiful Adirondack Mountains. It provides hope and adventure to over 1000 children with critical illnesses each summer in addition to the participants in the Winter Adaptive Sports Program. Family based programs also serve hundreds of children throughout the Fall and Spring months. During summer camp, children participate in activities such as swimming, arts & crafts, horseback riding, the ropes course and a day at the amusement park. Summer camp sessions are 6 or 7 day sessions that run from June-August. Aside from transportation, there is *NO* cost for a child to attend the Double "H" Hole in the Woods Ranch.

## Summer eligibility criteria are as follows:

- 1.) Ages 6-16 years old.
- 2.) A diagnosis of malignancy, serious blood disorders such as leukemia, sickle cell anemia, hemophilia, HIV/AIDS, congenital heart disease and selected neuromuscular impairments (such as cerebral palsy, spina bifida, muscular dystrophy, etc.).
- 3.) Completed application- parent/medical forms.

## DOUBLE "H" HOLE IN THE WOODS

*a testimonial by  
Lyndsi Holmes, age 15*

"I started going to the Double "H" Hole in the Woods camp four years ago, and every year I tell myself that I wish I had started earlier. Double "H" Hole in the Woods Ranch is one of the best things that has ever happened to me, and I mean that with all my heart."

"Everyone who goes to camp stays for about a week. However, for many, the experience also includes skiing in the winter and many parties at the ranch as well. When a camper and his/her family arrive at the ranch the first day, volunteers waiting to help the camper move in immediately surround them. The family goes to the main office and meets some of the counselors the camper will have during the week. After registration, the camper moves into his/her cabin, accompanied by a counselor. At this point, they meet the rest of the counselors and the campers in the cabin. When the camper is settled in, which usually only takes a few minutes, and the family is ready, which can take a while for first times, the family leaves. This is when the fun really begins."

"Every cabin's week is a little different, but everyone does everything at some point."  
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chapter as soon as possible. Checks  
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Thank you to everyone who has already  
joined for this year!

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