

# Spina Bifida

## NEWS To Use

**Albany/Capital District Chapter**  
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Dear Families,

This fall has been a busy one with many activities for our chapter . We started with the dance troupe, Dancing Wheels, coming to town. Throughout the fall, we have also had wheelchair tennis and our teen support group occurring on Saturdays. "Challenges", our disability awareness training program, provided two programs for Scotia-Glenville High School GIVE , a service learning program, with 45 students attending. We have added two new resources to our lending library, and have tapes on order from this year's national conference which will give up-to-date information on a variety of topics that our families address.

For our biggest event, many of our families spent a refreshing weekend at "Double H" Hole in the Woods Ranch. You will find more details of our trip later in this newsletter, but I would like to note here that "Double H" does not charge families and campers for the activities that they provide. As a result, our families were able to attend free of charge. As a token of our gratitude, our chapter gave two gifts to the ranch; a selection of books for the library as our official "thank you" for our day of horseback riding last spring, and a summer camper sponsorship for our camping weekend this fall. We truly are grateful for all that "Double H" does for our children and families throughout the year!

As always, we are open to new ideas and assistance. Please feel free to contact us either by phone or email with your suggestions or offers to help!

On behalf of the board of directors of our chapter, I would like to wish everyone a wonderful holiday season filled with the blessings of family, friends, health, and happiness.

*Karen Wentworth*  
Administrative Director





## “DOUBLE H” HOLE IN THE WOODS FALL FAMILY WEEKEND

The weekend of October 24—26, 17 families gathered at the ranch in Lake Luzerne for time together relaxing and playing. We were very lucky to have beautiful crisp fall weather. All of the children had the opportunity to try out the high ropes swing and play low ropes games together. The indoor swimming pool gave everyone the opportunity to warm up from the chill of the day. Later that evening, we had very creative pumpkin carving with some terrific costumes. It was great to end the evening relaxing and enjoying the final game of the world series together. After a sound night's sleep, families spent time at the lake fishing and going out on the lake in the ranch's row boats & paddle boats. As if all of this wasn't enough, there was plenty of good food! This was our chapter's first attempt at such an event and all participants seemed to agree that it was a great success!



### LENDING LIBRARY New Resources

We have two new additions to our lending library. The first is a picture book for young children, written by a local author. The main character is a boy who has Spina Bifida.

Senisi, Ellen. All Kinds of Friends, Even Green. Woodbine House: Hong Kong, 2002.

The second is a chapter book for parents, especially moms.

Marsh, D.B. Marsh. From the Heart: On Being the Mother of a Child with Special Needs, 1995.

If you would like to check out either of these books, or any others in our lending library, just send us an email or call indicating the book or topic in which you are interested!



### Lending Library Circulation

We have two books that have been borrowed from the lending library, but we do not know where they are. They are:

“You Will Dream New Dreams: Inspiring Stories by Parents of Children With Disabilities” by Klein & Schive.

Taking Charge: Teenagers Talk About Life & Physical Disabilities, by Kriegsmann & Zaslow.

If you have borrowed either one of these books, would you please let me know either by calling or by email. Also, if you have any other materials out and are finished with them, it would be great if you could return them so that they will be available to others. Thank you!

*Do you have any books that you would recommend we add to our lending library? Please send us an email or call and let us know!*



### **The Care Notebook (2003) (Guidebook)**



The Care Notebook and Care Organizer are tools for families who have children with special health care needs. Families use Care Notebooks to keep track of important information about their child's health and care. This makes it easier to find and share key information with their child's care team. It was created by The Center for Children with Special Needs. For more information, visit their website at:  
<http://www.cshcn.org/resources/CareNtbk.htm>.

### **Family Caregiver Alliance**

Family Caregiver Alliance was the first community-based nonprofit organization in the country to address the needs of families and friends providing long-term care at home. FCA offers programs at national, state and local levels to support and sustain caregivers.



<http://www.caregiver.org/caregiver/jsp/home.jsp>

### **WEBSITE RESOURCES FOR CAREGIVERS**

The following websites were passed on to us by one of our parents with the note that they might be helpful to explore if you are a caregiver. Thanks for sharing the information!

<http://www.nfcacares.org/>

<http://www.aoa.gov/prof/aoaprogram/caregiver/caregiver.asp>

<http://www.caregiving.org/>

<http://www.caregiver.com>

<http://www.cyfernet.org/hottopic/famcaregivers.html>

Janice Fitzgerald, Executive Director, Parent to Parent of NYS  
[www.parenttoparentnys.org](http://www.parenttoparentnys.org)

### **WEB SEMINAR**

#### **~ INVOLVING FAMILIES IN SECONDARY TRANSITION ~**

January 26, 2004

Involving Families in Secondary Transition

2:00-3:30 p.m. Eastern Time

(Web-based Event)



Effective relationships between schools, families, and communities can result in increased student achievement, enhanced post-school outcomes, and greater independence for youth with disabilities. This seminar will present practical strategies for creating expanded partnerships with parents during the secondary transition years. Participants will develop a plan to enhance their own parent involvement program based on a presentation of the five roles that parents can play during the secondary transition years and learn how educators can empower parents to become partners. This Web seminar is sponsored by the Council for Exceptional Children (CEC) and is available nationwide by Internet and telephone.

[http://www.cec.sped.org/pd/webseminar/jan26\\_04if.htm](http://www.cec.sped.org/pd/webseminar/jan26_04if.htm)

## Thank you! Thank you! Thank you!

~ We recently received a check from *Singles Outreach Service* of Albany, donating money to our chapter. Thank you to them for their generosity!

~ Many thanks to all who make donations to our chapter during the course of the year. We receive funds through United Way that people designate to our chapter through United Way deductions in their paychecks. If you are interested in doing this, you may specify our chapter as SBA: Albany/Capital District Chapter. We receive periodic payments from United Way for these funds.

~ A donation to our chapter can also be a special way to acknowledge a person's birthday or special occasion. Along with your donation, send us the name and address of the person that you are honoring, and we will send an acknowledgement to them of the donation made in their name.

~ We also occasionally receive private donations from people demonstrating support of our activities.

Donations such as these are crucial to the continuing operation of our chapter and the support and assistance that we are able to offer to people in our area. Again, thank you for your generosity.

## ARE YOU HOLIDAY SHOPPING FOR AN INFANT, TODDLER, OR EXPECTANT PARENTS?

How about buying an award winning CD of lullabies that will be enjoyed by parents and children while supporting a fund raising effort from our chapter?



### Dream With Me Tonight CHAPTER FUNDRAISER

Our chapter has CD's that we are offering as a fundraiser. The "Dream" CD is 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!

***There are still a few days to get your order in time for Christmas!***

## Safe Play

For  
Children  
Who Have



## Spina Bifida

During the holiday season or any gift-giving occasion, it is important to navigate the array of toys on the market very carefully and ask for assistance in selecting latex-free toys for children with Spina Bifida.

More than 70,000 Americans have Spina Bifida, and an additional 1400 children are born with the condition each year. Children with Spina Bifida often develop serious latex allergies. This is due to frequent exposure to medical devices during ongoing surgeries—and reactions to the natural rubber can sometimes be deadly.

Finding latex-free toys for little ones with Spina Bifida can be a challenge; a variety of playthings, including silly string, water toys, balloons, bicycle handgrips and many items of clothing contain latex.

Women can reduce their risk of having a child with Spina Bifida by taking the B vitamin folic acid every day. To learn more, call the Spina Bifida Association of America at 1-800-721-3141 or visit [www.sbaa.org](http://www.sbaa.org), or by contacting your local chapter at 518-399-9151 or email at [SBAAlbany102@aol.com](mailto:SBAAlbany102@aol.com).

The following is a list of information brochures on a variety of topics that we have received from NICHCY (National Information Center for Children and Youth with Disabilities).

- **Spina Bifida** ~ in English and Spanish
- **Transition Planning: A Team Effort** by Sharon H. deFur, Ed.D. Discusses the transition from high school to adult life.
- **Resources for Adults with Disabilities.** Lists agencies and organizations that might be helpful to contact regarding employment, education, recreation, independent living, & assistive technology.
- **Learning Disabilities.** Offers general information about learning disabilities, tips for parents and teachers, related resources and organizations.
- **Parenting a Child with Special Needs.** Talks about issues parents have with coping with having a child who has a disability.
- **Disability Awareness.** Lists a variety of resources ~ books, children's books, videos ~ that can be used to help raise people's awareness of the needs of a person who has a disability.

Please call or email if you would like to receive a copy of any of the topics. We will get it out to you in the mail.



Please support our  
Dream With Me Tonight  
CD fundraiser!

It's not too late to order for Christmas!

Send a check for \$12.00

Payable to SBA:Albany/capital district chapter  
To 109 spring road, Scotia, ny 12302

Today!

We will mail your cd to you!

Thank you for supporting this fundraiser!

(See page 2 for more information about this CD.)



