

# Spina Bifida

## NEWS To Use

**Albany/Capital District Chapter**  
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Holiday Greetings to Everyone!

This newsletter contains a variety of information and resources that have been coming across my desk that I wanted to share. I hope that this will help to expand your networks.

We had a great response to our weekend at Double "H" Hole in the Woods at the end of October. Twenty-five families came together for the weekend that was full of fun activities for everyone including the high ropes course, arts & crafts, swimming, and a Halloween party. While people relaxed and played with their families, old friendships were renewed and new friendships were developed. To those people who were able to be there, it was great to see you! We are planning another weekend next fall and hope that even more families will be able to join us.

In addition to the teen support group and wheelchair tennis lessons that are already going on, there are several activities in the works. We are in the process of arranging for a presentation from the Independent Living Center. They offer many services that may be very helpful to many people in our chapter. On the fun side for 2005, we are looking forward to another ice skating outing, a hiking trip, and, back by popular demand, white water rafting. You will want to watch for information in future newsletters!

On behalf of our board of directors, I would like to wish everyone a very happy holiday season and all of the best for the new year!

*Karen Wentworth*

Administrative Director

**Conway Circle of Performing Arts Studio** offers wheelchair line dancing.

1293 Rugby Road, Schenectady, NY

Currently, classes are Monday evenings from 7:30 to 8:30.

We have a number of teens from our chapter who participate in this dance class, and the studio has openings for more students. The late hour makes it a little difficult for bedtime but the teens have been doing it for several years. They enjoy the social experience and the opportunity to move to music. They perform in the studio's yearly recital in June. If you are interested, call the studio at 377-3929.



## 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 U.S. <http://www.abledata.com/>

This article was excerpted from the National Center on Secondary Education and Transition E-News, an e-mail newsletter which can be found at <http://www.ncset.org/enews/>.<sup>2</sup>

### SPINAbilities

Available Only from SBAA

SPINAbilities, the popular book about growing up with spina bifida, is no longer being published. You can only get it from SBAA. SPINAbilities offers teens and young adults suggestions for becoming independent and managing their own health care. It's also recommended for parents, siblings, friends and teachers.

Tell your members who want to purchase this important publication to go to [www.sbaa.org/site/PageServer?pagename=sbaa\\_publications](http://www.sbaa.org/site/PageServer?pagename=sbaa_publications).



## The Healthy Student A Parent's Guide to Preparing Teens for the College Years

(2004) (Brochure)

While this brochure is not explicitly designed for teens with disabilities or chronic health conditions, it identifies and briefly addresses many of the issues that concern youth with special health care needs who plan to attend college, including insurance, medical records, prescriptions, confidentiality, and student health services. Published by the Adolescent Medicine Web site. Available in PDF format (8 pages). [http://www.adolescenthealth.org/html/The\\_Healthy\\_Student.pdf](http://www.adolescenthealth.org/html/The_Healthy_Student.pdf)

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### Lending Library News

Featherless by Juan Felipe Herrera is the story of a young boy who has spina bifida. He learns that being differently-abled doesn't mean that he is unable to do what he wants to do. Instead, he needs to learn how to do some things his own way. Featherless is a picture book written in both English & Spanish.

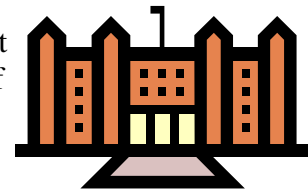


Call or email our chapter if you would like to check it out!

## Moving on to High School: A Tip Sheet for Parents of Children on Individualized Education Plans (March 2004)

(Fact Sheet)

Even though families don't have much influence over how schools structure courses, there are things they can do to make the most of what their schools have to offer. This tip sheet is based on the experiences of students with disabilities in public schools age 14-17, and their families. All the students had Individualized Education Plans, and all were moving on from the middle school grades to high school (9th grade). <http://www.communityinclusion.org/publications/pub.php?page=to19>



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## **Solving the Employment Puzzle**

The Strategies for Workforce Inclusion and Family Training (SWIFT) Project at PACER Center, with support from the U.S. Department of Labor, Office of Disability Employment Policy, presents a new family training curriculum. It is designed to help parent centers and other organizations introduce parents and youth to practical career development strategies. The site is also designed to promote awareness of community and government resources that can help youth with disabilities prepare for work, find a job, and stay employed. It includes a self-determination component, as well as information designed to prepare youth who have disabilities for postsecondary education, employment, or employment-related adult services. Available online in PDF/PPT and html formats. <http://www.pacer.org/swift/index.htm>

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## **New Staff Member at the White House**

Tracy R. Justesen recently joined the White House staff as Associate Director for the Domestic Policy Council. He will handle the President's New Freedom Initiative and issues important to individuals with disabilities. He comes to the White House after serving as an attorney in the Civil Rights Division of the Department of Justice, a technical advisor to the President's Commission on Excellence in Special Education, and President and Chief Executive Officer of one of the nation's premier centers for independent living. He may be reached by e-mail at [TJustesen@opd.eop.gov](mailto:TJustesen@opd.eop.gov)

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## **Preparing for Postsecondary Education**

This revised NCSET Web Topic, directed at students, teachers, and parents, provides an overview of self-advocacy, rights, responsibilities, and other issues students with disabilities need to think about when considering a postsecondary education. Like all NCSET Web topics, it includes an introduction, frequently asked questions, related research, emerging practices, Web sites, and additional resources. <http://www.ncset.org/topics/preparing/default.asp?topic=6>

## **Spina Bifida Association of America's 32nd Annual Conference —**

**Save-the-Date**

### **Building Bridges to Advance Understanding**

Minneapolis, Minnesota

June 26 – 29, 2005



Please be sure to review the attached sheet regarding the conference. The back side of the page includes a list of organizations that may offer support to people wishing to attend conferences.

## **National Dropout Prevention Center**

This site, produced by the National Dropout Prevention Center/ Network and the National Dropout Prevention Center for Students with Disabilities, with funding from the U.S. Department of Education Office of Special Education Programs, provides knowledge and promotes networking for researchers, practitioners, policy-makers, and families to increase opportunities for youth in at-risk situations to receive the quality education and services necessary to successfully graduate from high school.

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

## **Medicaid Coverage for Children with Disabilities Expanded**

Hundreds of thousands of middle-income families with children with disabilities are eligible for Medicaid under legislation that passed the Senate in early May. The bill is designed to address the dilemma faced by parents who have to turn down jobs or raises and, in some cases, give up custody of their disabled children to continue receiving government-paid health care. Parents would be able to buy into Medicaid while continuing to work and earn an annual income of up to 250 percent of the federal poverty level, roughly \$47,000 for a family of four.

<http://cme.kff.org/Key=2868.CtR.C.D.Gf7JF7>

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## **Career Guidance and Exploration (November 2004)**

(Web Topic)

This revised NCSET Web Topic explores how families and professionals can help youth with disabilities to gain an understanding of their interests, skills, abilities, and aptitudes as they relate to employment. Like all NCSET Web topics, it includes an introduction, frequently asked questions, related research, emerging practices, Web sites, and additional resources. Revised in November 2004 (originally posted in August 2002).

<http://www.ncset.org/topics/career/default.asp?topic=1>

Students.gov  
(Web site)

Students.gov, student gateway to the U.S. Government,<sup>2</sup> is a Web site with a comprehensive information portal providing answers to questions on education, financing education, career development, government, military service, travel, community service, and more.

<http://www.students.gov/STUGOVWebApp/index.jsp>

This information was received from the National Center on Secondary Education and Transition E-News, an e-mail newsletter which can be found at <http://www.ncset.org/enews/><sup>2</sup>

## **The Spina Bifida Research Resource Research Update**

SBRR currently has over 500 families, including over 2,800 individuals enrolled in a research study to explore the causes of spina bifida. They are seeking additional families to participate. All of the study activities required to be included can be done entirely by phone or email.

If you are interested in becoming a participant in this study, please contact Katy Hoess at 1-866-275-SBRR or Barbara Weyland at 1-866-521-SBTX.

## **Accessible Attractions Greater Capital Region & the Adirondacks**

A new website is now available that may help to plan outings that are accessible. The site covers a variety of venues such as sports & fitness facilities, outdoor parks, trains, restaurants, theaters, museums, conference center, hotels & motels. In addition, information will be available regarding campsites, boat launches & fishing piers. For more information, check out the website at [www.upstateaccess.org](http://www.upstateaccess.org).

To contact Upstate Access Network, email [info@upstateaccess.org](mailto:info@upstateaccess.org).

**Capital District Center for Independence (CDCI)** offers a variety of support groups; Advocacy Group; I Can: Self Advocacy Group; and Women's Group. For information, call CDCI at 518-459-6422 or visit their website at [www.cdciweb.com](http://www.cdciweb.com).



## Double "H" Hole in the Woods Adaptive Sports Program



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

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

109 Spring Road  
Scotia, NY 12302

(518)399-9151  
SBAAlbany102@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.*



**CHAPTER ACTIVITIES FOR 2005**

- Teen Support Group, one Saturday each month
- Wheelchair tennis lessons — Spring schedule, starting April 2, 2005
- Ice Skating outing—March, date to be announced
- Hike in the Catskills—May, date to be announced
- White Water Rafting—August, date to be announced
- Double “H” Hole in the Woods camping weekend—October, date to be announced

*Please call 399-9151 or email SBAAAlbany102@aol.com with questions or concerns.*

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