

Spina Bifida NEWS TO USE

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



HORSEBACK RIDING OUTING

DATE: Saturday, June 21, 2003

TIME: 12—3 PM

PLACE: The Double "H" Hole in the Woods Ranch
97 Hidden Valley Road
Lake Luzerne, NY



We have been invited to go to the Double "H" Ranch to enjoy lunch together, and then work with their counselors on horseback riding. The ranch and their activities are accessible to people in wheelchairs. If you are not familiar with their facilities, you may want to visit their web site at www.doublehranch.org.

RSVP is required. We need to know how many children, siblings, and parents will be attending. We will design activities based upon these numbers to ensure that everyone has a great time.

Please call our chapter at 399-9151, or email at SBAAlbany102@aol.com to RSVP or get questions answered. Deadline for RSVP is Monday, 6/2/03.

Directions: Take I-87 North to Exit 21 (Lake George/Lake Luzerne). Take a left onto Route 9N South and go 4 1/2 miles. Turn right onto Hidden Valley Road (just after Ciro's) and follow the signs for Double "H". It is approximately 1 hour north of Albany.

Happy Spring Everyone!

As we finalize this newsletter, we again hope that you can take the time to check out all of the activities that we have going. Please check out the information about horseback riding, tennis, and support groups. We try to plan activities and services based upon the needs and interests that we are hearing about from people. If you have an idea or need that you would like to propose, please call or email and share your thoughts with us.

We periodically email people with information in between newsletters with information that would not be timely waiting to be printed here. If you have not heard from us in the last month and would like to be on our email list, send us an email at SBAAlbany102@aol.com, indicating email address update in the subject line. We will add you to our list!

I would like to say a special thank you to Crystal for finding the opportunity for us to go horseback riding next month. Her enthusiasm has been terrific!

Karen Wentworth
Administrative Director

EDUCATION & TRANSITION

National Center on Secondary Education and Transition has a web site with a variety of articles of interest to parents and their teens who are in high school and preparing to transition post high school education or employment.



If you are unable to access this through the internet, call and we will send copies of the materials that are of interest to you.

Parent Briefs

- ~ Supplemental Security Income: A Bridge to Work, So You Have Decided to Apply
- ~ Age of Majority: Preparing Your Child for Making Good Choices
- ~ IDEA 1997 Transition Issues
- ~ Parenting Post-Secondary Students with Disabilities: Becoming the Mentor, Advocate, and Guide Your Young Adult Needs

Www.ncset.org and click on publications

TENNIS PROGRAM

WHO: Children—Young Adults who have Spina Bifida

What: Tennis lessons

WHEN: Saturdays, 5/3, 5/10, 5/17, 5/31, 6/7, 6/14

TIME: 3—4 PM

PLACE: Schenectady Racket Club

Tennis rackets are provided.

Registration is required. Please call 399-9151 or email SBAAAlbany102@aol.com.

This program is being sponsored by Albany/Capital District Chapter of the Spina Bifida Association, with a generous contribution from Stewarts to partially offset the cost.

Instruction is being given by SAFE (Sports Are For Everyone).

CHALLENGES FOR SIBLINGS

The following is a list of books that might be helpful in to families who are addressing issues that siblings of a child with special needs might experience. The first, Views From Our Shoes, is available from our lending library.

Meyer, Donald, Editor. Views From Our Shoes: Growing Up With a Brother or Sister with Special Needs. Bethesda, MD: Woodbine House, 1997.

Meyer, Donald J., Vadasy, Patricia F., and Rebecca R. Feurell. Living with a Brother or Sister with Special Needs: A Book for Sibs. Recommended for Jr. High.

Peterkin, Allan. What About Me? Recommended for Elementary.

Ratto, Linda Lee. Coping with a Physically Challenged Brother or Sister. Late Elementary— Jr. High.

Rosenbert, Marine B. Finding a Way. Living with Exceptional Brothers and Sisters. Late Elementary.

Thompson, Mary. My Brother, Matthew. Elementary.



AIRLINE NEWS

The Department of Transportation recently established an Aviation Consumer Disability Toll-Free Hotline to assist individuals who experience disability-related air service problems. You can reach the hotline at: 1-866-754-4368 (TTY).



Traveling via airplane is never an easy thing but it can be further complicated when you are a wheelchair user. To help eliminate uncomfortable and often embarrassing situations for wheelchair passengers, Delta Express has created the Delta Air Chair. It features a patent-pending hydraulic lift system to transfer passengers from the gate area onto the airplane. It works by lifting the passenger to the height of the handrail so the airline personnel can easily pass the individual over the armrest and into their seat.

** Taken from SBA of Connecticut newsletter.

Web Site Gathers Recommendations on Disability Research Needs

A new web site has been developed by the federal government's Interagency Committee on Disability Research (ICDR) to gather comments and recommendations on research needs for Americans with disabilities. The committee, chaired by Steven James Tingus, director of the Education Department's National Institute on Disability and Rehabilitation Research, produced the site to help ensure that federal research efforts meet the needs of the disability community.

The site can be found at www.icdr.us.

Clicking the link "Send your comments to the ICDR" takes the reader to a comment form where individuals may offer their ideas about access to technology, education, employment, community life, health care and other needs.

Other links on the page cover topics such as:

- President Bush's New Freedom Initiative to help people with disabilities;
- The ICDR statutory authority and mission;
- Membership of the committee; and
- Links to other disability sites.

The ICDR web site will serve as a catalyst for information sharing and be a source for recommendations to the president and congress on policy and priorities related to disability and rehabilitation research. The site will also increase awareness of federal disability research activities and make new research outcomes more available to the public.

TICKET TO WORK PROGRAM

The Ticket to Work Program is designed by the Social Security Administration to help those with disabilities who receive SSI or Social Security to go to work while retaining medical benefits. This program is part of the Ticket to Work and Work Incentives Improvement Act that was signed into federal law in 1999.

Provisions of the law include fund benefits planners, protection and advocacy assistance, assistance back into the SSA rolls if you become unable to work again, and employment network services, vocational rehabilitative services, and an individual employment plan. There are no charges for these services. You can find out details about the Ticket to Work Program by visiting the following websites:

[Www.yourtickettowork.com](http://www.yourtickettowork.com) or
http://www.ssa.gov/work/Ticket/ticket_info.htm.
Or call toll-free 1 866-968-7842

NATIONAL THEATRE WORKSHOP OF THE HANDICAPPED

Are you interested in workshops, programs, or courses in the arts? You may want to visit their website at www.ntwh.org.



**RESNA Rehabilitation Engineering
& Assistive Technology Society
of North America**
International Conference
On
Technology & Disability
Research, Design, Practice, & Policy
Atlanta, GA June 19-23, 2003
Early bird registration discount through 5/26/03.
<http://www.resna.org/conferences/>

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FASHION NEWS



ABOVE THE CHALLENGE offers T-shirts for the disabled. Grant Marx is owner of the company. In his flyer, he states, "I am a "wheeler" due to the #1 birth defect in the U.S., Spina Bifida. I mention this because it is what led me to begin a business. In the past, when I would go to purchase a t-shirt, the design was often printed on the back of the t-shirt. As a person in a chair, that is just the right place to hide the message or image for which I bought the shirt! Let's face it, those of us with disabilities and in wheelchairs can always use a bit of encouragement and inspiration in our lives. We face special challenges that we must rise above. So, I designed a line of t-shirts with the following goal in mind: To serve the practical and inspirational needs of those with physical challenges... Visit my website at www.abovethechallenge.com!"

STEWART'S HOLIDAY MATCH

Stewart's recently awarded our chapter a \$500 grant from their Holiday Match program. The funds are being used to help offset the cost of the youth tennis program scheduled for the year.

To those children who have Spina Bifida who might enjoy tennis, we are currently in the spring season of lessons. There will be a third series of lessons scheduled this summer. Please call or email if you are interested.

Come and join us!

Thank you to all who support Stewart's Holiday Match during the holidays. **Thank you to Stewart's for their support of this program!**

HELP IS HERE FOR HARD TO FIT FEET

The following retailers will accommodate individuals who require two different shoe sizes. They charge no additional fee for this service!

Nordstrom's department stores at 1-800-285-5800 allows you to buy attractive, comfortable, mis-mate shoes at no additional charge. This policy was established because the original Mrs. Nordstrom had polio and needed mis-mated shoes.

Birkenstock also has a policy of selling split-size shoes for one price. You can get more information by visiting www.birkenstockexpress.com and clicking on the "Specials Orders" tab.

** Taken from SBA of Connecticut newsletter.

CLOTHING FOR PEOPLE WITH MOBILITY ISSUES

www.silverts.com. Silverts offers clothing for men and women and for particular needs including Alzheimer's, mobility, arthritis, foot problems, incontinence and scoliosis. 1-800-387-7088

www.speciallyforyou.net. Carolyn and Mellisa Weinert Design sew and sell adaptive clothing for people with special needs. Catalogs for people with special needs are available.

1-605-765-9396 Toll charges may apply.

www.fordes.com/index.html. Fordes Functional Fashions offers woman's and men's apparel, accessories and outerwear.

** Taken from SBA of Jacksonville newsletter.

SOCK EM!

If you've ever had trouble finding socks that fit comfortably under your AFO's, Sock Em's are a knit knee sock made from 75% cotton, 20% nylon and 5% lycra, featuring a small foot and an extra long calf length. This blend ensures durability and conformity to the original shape and size of the sock. Because of the close fit of lycra, the sock can be stretched over the AFO while providing a good fit at the heel. Socks are available in a variety of colors and fabrics in toddler to adult sizes. For more information, or to order these socks, please visit www.sock-em.on.ca

** Taken from SBA of Jacksonville newsletter.