

Spina Bifida

NEWS To Use

Albany/Capital District Chapter
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UPCOMING EVENTS:

MEMBERSHIP DRIVE DEADLINE ~ March 15, 2004

- Teen Support Group ~ Saturday, March 20 from 10 to 11:30 AM
- Wheelchair Tennis ~ Scheduled to begin Saturday, April 24. Reservations required.
- Scholarship recipients to be determined by May 15, 2004.
- Spring Skating Party ~ dates to be announced.
- Double "H" Hole in the Woods weekend retreat Friday, October 29th— Sunday, October 31st.

*The **Freihofer's Run For Women** is scheduled for Saturday, June 5, 2004. This is a very exciting event to participate in, either as a runner, a walker in the community walk, a student in the kids fun run, or as an observer. I am wondering if this is something that we might attend as a group. I believe that we have some walkers, wheelers, and runners among us! If you would be interested, please let me know with a quick phone call or email. I will put together a plan for the event if there is interest.*

Dear Friends,

As this newsletter reaches you, I hope that you are all finding relief from the cold and enjoying some of the beautiful sunny days that have been coming our way and will surely become more frequent over the months ahead.

We are pleased to announce the beginning of the Helen R. Mertens' Educational Scholarship Fund. Several years ago, Mrs. Mertens bequeathed money to our chapter that has been instrumental in helping to develop and support the programs that we are able to offer. This scholarship has been developed in her honor, and as a demonstration of our appreciation. Our board of directors has been busy developing guidelines and an application process for this scholarship which will be offered to members of our chapter. You will find details about the scholarship fund inside.

This is very exciting for our chapter. We believe that the scholarship is in concert with the stated mission of the chapter of "helping people who have Spina Bifida develop to their fullest potential."

This newsletter also marks the beginning of our annual membership drive. A membership application is included for your convenience. We hope that the services that we provide throughout the year have proven helpful to you and your family, and appreciate the support that you show by continuing or becoming a paid member of the chapter. We are looking forward to hearing from you and as always, please call or email if we can be of assistance!

Karen Wentworth

Administrative Director

We are pleased to announce the establishment of the

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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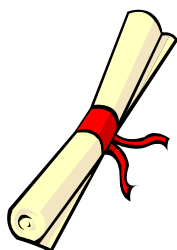
The purpose of the scholarship is to award financial assistance to persons who have Spina Bifida and are pursuing higher education, technical training, or driver's education. *The scholarship fund is available to paying members of the Spina Bifida Association: Albany/Capital District Chapter only.* The 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.



Transition Link: Supporting Transition-Age Youth with Disabilities

Transition Link is an online community for sharing ideas, strategies, resources, and information concerning the transition to life after high school for adolescents with disabilities.
<http://www.transitionlink.com/>

Project T.E.A.M.S.

The purpose of this website is to act as a central location for resources addressing Transition, Employment, Advocacy, Mentoring, and Self-Determination for assisting Special Education students, their families, and professionals in the field.
<http://www.projectteams.org/>

SearchDisabilities.com

SearchDisabilities.com is a resource for anything related to disabilities, from independent living to assistive technology. It was launched to provide timely breakthrough research and health news to people interested in disability research and assisted living programs. Part of the Wisdomatics Health Information Network, the Web site is compiled by experienced editors and includes content from a wide range of reliable news sources including press services, government, private agencies, universities and the thousands of small companies that work towards increased opportunity for people with disabilities.
<http://>



IEP & Transition Planning (July 2003) (NCSET Web Topic)

This NCSET Web topic provides information on strategies to support students, families, and professionals to participate in developing a student's Individual Education Plan (IEP) and transition plan. Includes an introduction, frequently asked questions, related research, emerging practices, Web sites, and additional resources.



<http://www.ncset.org/topics/ieptransition/default.asp?topic=28>

Healthy & Ready to Work

The Healthy and Ready to Work initiative promotes a comprehensive system of family-centered, culturally competent, community-based care for children with special health care needs who are approaching adulthood and may need assistance in making the transition from pediatric to adult health care and to postsecondary education and/or employment.
<http://www.mchbhrtw.org/>

New Disability Policy Website

A new disability policy website went online on September 1, 2003 containing training materials, policy papers and policy briefs prepared by Robert "Bobby" Silverstein, Director of the Center for the Study and Advancement of Disability Policy (CSADP) in Washington, DC and former staff director and chief counsel to the US Senate Subcommittee on Disability Policy, chaired by Senator Tom Harkin. The address for the website is: [Http://www.disabilitypolicycenter.org](http://www.disabilitypolicycenter.org). The website is organized by relevant topic areas, including Advocacy Training Materials, Americans with Disabilities Act (ADA), Disability Policy, Individuals with Disabilities Education Act (IDEA), State Medicaid Buy-In Programs and State Work Incentive Initiatives, Workforce Investment Act (WIA) and more. The website includes hot links to other disability policy-related web sites.

Taken from SBADV News, Spina Bifida Association of the Delaware Valley newsletter.

THE SIBLING SUPPORT PROJECT

The Sibling Support Project of the Arc of the United States is now scheduling workshops for 2004. The Sibling Support Project is dedicated to the concerns of brothers and sisters of people with special health, developmental and mental health concerns. They specialize in providing lively, family-friendly and highly rated workshops on sibling (and father and grandparent!) issues to audiences of parents, service providers, university staff and students and siblings of all ages.

If you would like to learn more about their workshops, seminars and keynotes please contact Don Meyer, Director, Sibling Support Project of the Arc of the United States at 206-297-6368 or donmeyer@siblingsupport.org. Information may be accessed online at www.thearc.org/siblingsupport/ or www.calsnet.net/sibshop.

Taken from SBAA Direct Link, September 5, 2003.

OUTDOOR ACTIVITIES FOR PEOPLE WHO HAVE DISABILITIES

The New York State Department of Environmental Conservation publishes a booklet called "Opening the Outdoors to People with Disabilities" for New York State. The information includes a listing by county of accessible fishing sites and a chart of recreation areas and the facilities included in each. Finally, there is a listing of regional offices that could be called for further information. Contact phone numbers for regional offices covered by this chapter of SBA are listed below.

Region 4	1150 North Wescott Road Schenectady, NY 12306-2014 (Albany, Columbia, Rensselaer, Schenectady)	(518) 357-2234
Region 4	Jefferson Road, Route 10 Stamford, NY 12167-9503 (Delaware, Greene, Montgomery, Otsego, Schoharie)	(607) 652-7364
Region 5	Hudson Street, Box 220 Warrensburg, NY 12885 (Saratoga, Warren, Washington)	(518) 623-3671
Region 5	701 South Main Street, PO Box 458 Northville, NY 12134 (Fulton, Hamilton)	(518) 863-4545

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.

LENDING LIBRARY UPDATE

Our chapter has recently purchased a variety of materials, including many tapes from the 2003 SBAA conference, that are available to you through our lending library. If you are interested in borrowing one, call or send us an email indicating your name, address, phone number, email address. We will send it out to you in the mail and ask that you return it in one month.



TAPES – SBAA CONFERENCE, 2003.

Health Care Issues for Adults with Spina Bifida. Timothy Brei & Mark Merkens, SBAA Conference, 2003.

Challenges of Depression & Anxiety. James Loomis, Conference, 2003.

Facilitating Social Skills Development. James Loomis, Conference, 2003.

Sexual Issues. Steve Sloan, Conference, 2003.

Coaching: Redefining the Parenting Role. Richard Horowitz, Conference, 2003.

Urinary Continence: Medical & Surgical Options. Bowel Continence: Surgical Options. Earl Cheng & Tom Bartholomew, Conference, 2003.

Living Successfully as Young Adults with Spina Bifida. Conference, 2003.

The Spine in Spina Bifida. Andrew King, Conference, 2003.

Chiari Malformation: Surgical Approach, Controversies & Best Available Evidence. Jeff Blount, Conference, 2003.

Orthopedic Considerations in the Child with Spina Bifida. Karl Rathjen, Conference, 2003.

Nonverbal Learning Disabilities & Independence in the Teen & Adult. Jo Ann Evans & Melanie Fralick, Conference, 2003.

Update on Tethered Cord. Arthur Marlin, Conference, 2003.

Articles & Brochures

“Disability Awareness.” NICHCY, March, 2003.

“Employment Outcomes.” Focus Technical Brief, 2003.

“Spina Bifida.” NICHCY, January 2003.

“Learning Disabilities.” NICHCY, August 2002.

“Parenting a Child with Special Needs.” NICHCY, 2003.

“Rehabilitation Research and Training Centers and Employment Outcomes Research.” Focus Technical Brief, 2003.

“Resources for Adults with Disabilities.” NICHCY, January 2000.

“Spina Bifida.” NICHCY, January 2003.

“Transition Planning: A Team Effort.” NICHCY, January 1999.

Resource Books

Liptak, Gregory S. MD. Evidence-Based Practice in Spina Bifida. Washington, DC: May 9 – 10, 2003.

Are you looking for information on topics not listed above?

Please let us know. We have many other materials available to you. If we don't have your particular topic, it might be something that we should consider purchasing to make it available to people in our chapter!



PLEASE NOTE:

* IMPORTANT MEMBERSHIP INFORMATION INSIDE!
MEMBERSHIP REGISTRATION NEEDS TO BE RETURNED
BY MARCH 15, 2004.
THANK YOU FOR YOUR SUPPORT!

* REGISTER NOW FOR
SPINA BIFIDA ASSOCIATION OF AMERICA 31ST
ANNUAL CONFERENCE ~ June 20th—23rd, 2004

ALSO NOTE THIS ANNOUNCEMENT:

* HELEN R. MERTENS EDUCATIONAL SCHOLARSHIP FUND