

Spina Bifida NEWS

Fall 2001

To Use

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

EDUCATION * SUPPORT * AWARENESS

YOU ARE INVITED TO THE HOLIDAY PARTY!!!

Featuring

Mr. Philip Singer, Caricature Artist
who will complete drawings
of the children

DATE: Saturday, December 8, 2001

TIME: 3—5 PM

PLACE: Colonie Community Center

Also: Craft Activities and Refreshments

1653 Central Ave, Albany

PRESIDENTS MESSAGE

Greetings to all! We are hoping everyone is now well immersed into the school year and gearing up for the holiday season around the corner. On Saturday, December 8 from 3 to 5 pm we will be having our *annual holiday party* at the Colonie Community Center. It's a great family event with entertainment and refreshments. We hope to see many of you there! We are in the process of planning for upcoming meetings and events and would like to know how we can serve you better. Do you have speakers you'd be interested in hearing or topics you would like to know more about? Please drop us a line, call the chapter phone, or e-mail us with any suggestions.

This past August, the 3rd Annual Dominic Melita Golf Tournament was held in Johnstown, NY. It has become a yearly event organized and run by friends and community members of the Melita family. This has been a wonderfully successful event and we send out our thanks to this terrific group for all their efforts.

This fall we organized a *Tennis Camp* with the S.A.F.E. program. It ran for 6 weeks at Central Park in Schenectady for children from our program and was a huge success. We will run an additional session in the Spring. Watch for details in the next newsletter.

Food for thought: After having a sudden hospital experience, we were reminded again how important it is to keep certain supplies on hand at all times. You might want to carry an emergency kit with items specific to you/ your child's needs (i.e. Non-latex gloves, catheters, g-tube supplies, epipen, non-latex tourniquet). It is also very important to carry a card with a list of medications and dosages in your wallet. It can be difficult to accurately recall this critical information in a stressful situation!

We are continually looking at new programs to offer. We would love to hear any input you have regarding programs that would be beneficial.

Happy Holidays!

Chris Darby-King & Helen Eggenberger
Co-Presidents

**The CDC announced on June 19, 2001 that NTD's including Spina Bifida have decreased 19% following folic acid fortification of the U.S. food supply and related educational efforts!
~U.S. Dept. of Health and Human Services~**

How Can I Ensure Enough Folic Acid in My Diet?

By now, we have all heard that folic acid reduces neural tube defects (NTD's) including Spina Bifida. The March of Dimes as well as The Centers for Disease Control and Prevention recommends women of child-bearing age should consume 400 micrograms of folic acid each day. Sometimes, you may see that amount written as 0.4 milligrams of folic acid. It's the same amount, just written differently (like a half a pound verses 8 ounces). That's a handy piece of medical info. **But, what is folic acid anyway? What does it do? Where does folic acid come from? How can we be sure we are getting enough each day? Which foods contain folic acid?**

Folic acid is a common water soluble **B vitamin**. It is essential for the functioning of all human bodies. During periods of rapid growth, such as pregnancy and fetal development, the body's requirement for this vitamin increases.

There are four ways for women to receive sufficient amounts of folic acid in their diet:

- 1—multivitamin supplements
- 2—breakfast cereals fortified with folic acid
- 3—cereal-grain products, ex. Breads, pasta, rice
- 4—foods naturally rich in folic acid called folate.

That's great but give me some specifics. Some foods that contain natural folate are **dark green leafy vegetables such as broccoli, spinach, and asparagus. Others are dried beans, egg yolks, beef and chicken liver, oranges and orange juice, peanuts, as well as other nuts and seeds.** Read the nutrition labels on hot and cold cereals, oatmeal, grits, whole grain food products, pastas and rice products. Many have been fortified with varying percentages synthetic folic acid. None of them contain 100% of the daily recommended requirement. The natural folate must be broken down by the body into a usable form. It is not known whether the consuming 400 micrograms of natural folate from foods everyday provides the same level of protection as a supplement.

Multivitamins, fortified breakfast cereals, and enriched cereal grain products contain a synthetic form of folic which is more easily absorbed by the body than natural folate. The body can absorb almost 100% synthetic folic acid. **That's why you should consume a folic acid supplement in addition to a well-balanced diet.** Check your multivitamin label or ask your pharmacist or doctor to see if it contains 400 micrograms of folic acid.

No matter what age you are now, taking a folic acid supplement along with a well planned diet is good for you. The younger the better. Take it at the same time everyday to develop and establish the habit as a daily routine. Take it when you brush your teeth, feed your fish, or have your morning coffee. No one plans an unexpected pregnancy! If you are taking the recommended folic acid supplement daily, you significantly reduce the risks of an NTD.

Women who are at a higher risk of an NTD are those who themselves have an NTD, have a child with an NTD or have lost a pregnancy due to an NTD. Those women need to see their doctor for a prescription dosage of folic acid (4000 micrograms) to be consumed at least three months prior to pregnancy.

IMPLEMENTATION OF THE BENEFIT ELIGIBILITY SCREENING TOOL (BEST)

In April of this year, SSA will implement a new public service on its internet web site. This service, known as the Benefit Eligibility Screening Tool (BEST) will enable users to screen for themselves (or friends, relatives or clients) potential eligibility for:

- Social Security retirement, survivors and disability insurance benefits
- SSI benefits (including Federally-administered Optional State Supplements)
- Special benefits for World War II veterans (Title VII)
- Medicare (including ESRD, QMB,SLMB, QI-1 and QI-2)

The user will answer a series of questions related to the eligibility factors for the various programs. The screening tool will compare the answers with the eligibility requirements for each benefit program and determine if individuals are potentially eligible for any of the programs. If the user appears to be eligible for one or more categories of benefits, he or she will be advised to contact SSA to file an application in order to get a formal determination. This service is being provided to SSA's customers as an informational tool and any actions resulting are at the discretion of the user. At least initially, SSA will not retain user input after the user exits the program. The screening tool will not ask for personal identifiers (i.e. name and SSN and there is no use or disclosure of existing SSA data. The screening tool will include a disclaimer that the results do not constitute an official determination of eligibility/ineligibility and that the individual must file an application to obtain such a determination. The user will also be advised that, if he or she is interested in filing an application, he/she should contact SSA as soon as possible to avoid possible loss of benefits. Since SSA will not capture the user's name or SSN, use of the tool will not serve as a protective filing.

Reprinted from SBAA Direct Link.

ADAPTIVE EQUIPMENT

Have you always wanted to water ski, fish, horseback ride, or do other fun activities, but felt limited because of your wheelchair? Now there are several companies making adaptive equipment to help the disabled.

Here are some resources for adaptive equipment:

Access to Recreation, Inc.
AccessTR.com
800-634-4351

Makes items including gun mounts for wheelchairs, lifts for water access, fishing equipment and water floatation devices.

Blackberry Technologies
Blackberrytech.com
800-413-4824 Manufacture wheelchair mounts to hold guns, fishing poles, and cameras.

Freedom Rider
Freedomrider.com
888-253-8811

(Taken from "Adaptive Equipment—"A Huge Boost for the Disabled" Newsday 3/25/01

SCHWAB FOUNDATION NEWSLETTER: LD MATTERS

If you have a child with learning disabilities, LD Matters is a new newsletter for you. LD Matters from the Schwab Foundation for Learning, gives parents information about general issues about learning disabilities, research results regarding learning disabilities, where you can find more information about learning disabilities and things you can do now to help your child succeed at school and at home. The newsletter contents come from experts, teachers, parents of kids with LD and children with LD themselves. You can download the publication at <http://www.schwablearning.org/main.asp?page=3.6>. Free print subscriptions are available from the Schwab Foundation for Learning, 1650 South Amphlett Boulevard, Suite 300, San Mateo, CA 94402. Voice 650-655-2410, Fax 650-655-2411, www.schwablearning.org.info@schwablearni

CHECK OUT OUR LENDING LIBRARY!

Christal: Coping with Spina Bifida. *Karen Snyder Travis.* Branden Books, 2001.

Uncommon Fathers: Reflections on Raising a Child with a Disability. *Edited by Donald J. Meyer.* Woodbine House, 1995.

Motherhood Magnified: Inspiring Stories of Insight and Lessons Learned from Raising a Child with Special Needs. *Jill Rose Ford.* Writers Club Press, 2000.

Living with Spina Bifida: A Guide for Families and Professionals. *Adrian Sandler, M.D.* University of North Carolina Press, 1997.

Children with Spina Bifida: A Parents' Guide. *Edited by Marlene Lutkenhoff, R.N., M.S.N.*

Delicate Threads: Friendships Between Children With and Without Special Needs in Inclusive Settings. *Debbie Staub, Ph.D.*

Spinabilities: A Young Person's Guide to Spina Bifida. *Edited by Marlene Lutkenhoff, R.N., M.S.N., and Sonya G. Openheimer, M.D.* Woodbine House, 1997.

Taking Charge: Teenagers Talk about Life & Physical Disabilities. *Kay H. Kriegsman, PhD., Elinor L. Zaslow, M.A., Jennifer D'Zmura-Rechsteiner, M.A.* Woodbine House, 1992.

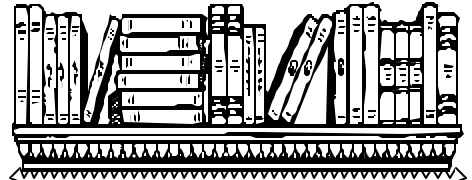
You Will Dream New Dreams: Inspiring Personal Stories by Parents of Children With Disabilities. *Edited by Stanley D. Klein, Ph.D. and Kim Schive.* Kensington Books, 2001.

Views From Our Shoes: Growing Up with a Brother or Sister with Special Needs. *Edited by Donald Meyer.* Woodbine House, 1997.

Enabling Romance: A Guide to Love, Sex, and Relationships for the Disabled (And the People Who Care About Them). *Ken Kroll & Erica Levy Klein.* Woodbine House, 1995.

Reproductive Issues for Persons with Physical Disabilities. *Edited by Florence P. Haseltine, Sandra S. Cole, & David B. Gray.* Paul H. Brookes Publishing Co., 1993.

Preventing Secondary Conditions Associated with Spina Bifida or Cerebral Palsy: Proceedings and Recommendations of a Symposium. *Edited by Donald J. Lollar, Ed.D.* SBAA, 1994.



Our local chapter has recently purchased a number of new books and tapes to add to our collection. We thought that this would be a good time to provide you with a list of what is available to borrow. We are making these resources available to our current members at no charge. If you would be interested in borrowing any of the resources listed here, please call 399-9151 or e-mail us at SBAAbany102@aol.com. We will send the book/tape to you with a return label enclosed. We would ask that you return the material in one month. (We will enclose a reminder of the return date with the item. If you need an extension, please call or e-mail us for permission. If we have not received any other requests, we would be happy to do that. We will be tracking the whereabouts of the materials so that we can keep them available for the benefit of all.

Would you like to preview the materials first? We will have them available at our local meetings for you to browse through. You may check them out at that time as well.

Do you have suggestions of other materials that you would recommend we make available? Please let us know so that we can continue to expand on these resources for everyone!

Still looking? Here are more books...

Children With Spina Bifida: Early Intervention and Pre-school Programming. *Edited by G. Gordon Williamson, Ph.D., OTR.* Paul H. Brookes Publishing Co., 1987.

An Introduction to Spina Bifida. *David G. McLone, M.D., Ph.D. & Joy Ito, R.N.* Children's Memorial Spina Bifida Team, 1998.

Preventing Neural Tube Birth Defects: A Prevention Model and Resource Guide. *Beth Burke.* Centers for Disease Control and Prevention, 1998.

Social Development and the Person With Spina Bifida. *Donald J. Lollar, Ed.D.* Spina Bifida Association of America, 1994.

A House for ALL Children: Planning a Supportive Home Environment for Children with Disabilities. *Richard V. Olsen, Ph.D., B. Lynn Hutchings, M. Arch., & Ezra Ehrenkrantz, F.A.I.A.* Center for Architecture and Building Science Research, 2000.

Bowel Continence and Spina Bifida. *Susan Liebold, MS, RN, Pat Braun, RNC, MA, MSN, Jeane Cole, RN, ARNP, Paula Peterson, MS, PNP.* Spina Bifida Association of America, 1995.

DETERMINED TO WIN

BY: Jean Driscoll

What do all these things have in common? Eight-time winner of the Boston Marathon, two-time Olympic Silver Medallist, voted one of the top 25 female athletes of the century by Sports Illustrated for Women, spoke and sang at the SBAA 2000 Conference, Author of the newly released book: *Determined to Win.*

If you want an honest, personal account of what it is like growing up with Spina Bifida, this is the book to read. *Determined to Win* is written for all age levels. It is truly a remarkable account of an inspirational woman. It is a must read book for people whose lives have been touched by Spina Bifida. *Determined to Win* is published by SHAW. *Reprinted from SBADV News, the newsletter of the SBA of the Delaware Valley, P.A.*



CASSETTE TAPES

These tapes were purchased by our chapter at the 2001 Spina Bifida Association of America conference for use by members of our chapter.

“Pioneer—survivors: Insights on childhood resilience by the first generation of adults with Spina Bifida.” *Dr. Nienke Dosa, JoAnn Armstrong & Dr. Gregory Liptak.*

“If we knew then what we know now: The over 40 crowd speaks out.” *Tom Baroch, Jane Reise & Ben Skillman*

“From puberty to menopause: Women with Spina Bifida.” *Dr. Joseph Bellina.*

“Bowel management for adults with Spina Bifida.”

“Tethering.” *Dr. Michael Partington.*

“Bowel management: A systematic approach for continence.” *Susan Liebold.*



SKI PROGRAMS

Double "H" Hole in the Woods Ranch will be offering weekend ski & snowboard activities January 5 through March 23, 2002.
For information call (518) 696-5676.

Adaptive Sports Foundation in Windham is offering skiing and snowboard lessons beginning December 1, 2001 through March 23, 2002.
For information call (518) 734-5070.



SWIM PROGRAM STRIDE

Sports & Therapeutic Recreation Instruction/ Developmental Education

will be sponsoring an 8 week swimming program beginning on Wednesday, October 17 at the Public Bath Number Two in downtown Albany.
For information, call Winn Huntley at (518) 272-5715.

~FUTURE EVENTS~

Local chapter meetings including parent meetings/support, guest speakers (to be announced), pre-teen/teen group meetings.

Saturday, February 9th, 2002
3—5 PM

Saturday, April 6th, 2002
3—5 PM

Meetings are held at the
Colonie Community Center
1653 Central Ave
Albany.

SAFE



(Sports Are For Everyone)

Over the winter months, SAFE will be sponsoring tennis and soccer programs. For information contact Jim Fitzgerald at (518) 383-8076 or e-mail at coachjimfitz1@yahoo.com.



COLLEGE SCHOLARSHIPS AVAILABLE
The Spina Bifida Association of America offers two scholarships for post-high school education:

1. Four-year scholarships are awarded to high school juniors and seniors.
2. Annual scholarships are awarded to high school graduates pursuing higher education.

For information: 1-800-621-3141 or log on at www.sbaa.org

The Hydrocephalus Association offers the Gerald S. Fudge Scholarship for individuals ages 17 to 30 for educational purposes.

For information: 1-415-732-7040 or log on at www.hydorassoc.org.

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