

Spina Bifida NEWS To Use

Albany/Capital District Chapter
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Local SBA Chapter Meeting

February 9, 2002 3—5 PM

Guest Speaker:

Mr. Ken Hamdin, CSE Chairperson,

Scotia-Glenville Central School District

Mr. Hamdin is a school psychologist & professional mediator/
facilitator with 28 years experience in Special Education.

*Meetings are held at the Colonie Community Center
1653 Central Ave, Albany, NY*

You need not be a member to attend!

Looking Ahead!

Chapter Meeting

April 6, 2002 3—5 PM

"WELLNESS FOR CARETAKERS"

Spring Tennis Program:

Dates to be announced

PRESIDENT'S MESSAGE

Happy New Year to all and here's wishing you a healthy and happy year ahead. We start the New Year by sending out get well wishes to Eric Crow who has been hospitalized for the past few weeks both here in Schenectady and in Michigan. Hope you're feeling well soon!

This year as an organization we continue our progression of moving forward and also enlisting support from our membership. We are now seeking volunteers for our slate of officers (elections at the April meeting) and also for our Board of Director's. It is truly a positive and rewarding experience to serve in either capacity and it is not a time consuming or demanding role(s). Board members are asked to attend quarterly board meetings and offer input regarding the affairs and finances of the organization in the community. If you are interested in becoming more involved, we welcome your input and energy. Please contact the chapter phone with any questions or to become more involved.

Our upcoming meetings will offer information concerning parent advocacy and questions regarding your child's annual IEP meetings. We also will focus on "Wellness" and how to better take care of ourselves as caretakers, etc. If you're interested in a massage, stay tuned!

As always, we are here for your support, questions and ideas.

Chris Darby-King & Helen Eggenberger

Co-Presidents

Membership Information

We will soon be receiving membership packets from Spina Bifida Association of America, our national affiliate. We will be sending this along to you and will appreciate your prompt response. Membership dues of \$20 entitle each member to receive Insights, as well as discounts on publications and the conference registration rate. While it is not necessary to be a member to attend local meetings and participate in most activities of this chapter, the support of active membership and your time and efforts makes a difference for all of our children.

Spina Bifida Association of America Annual Conference

June 24—26, 2002 workshops
(Monday—Wednesday)

*June 26 evening & June 27 morning—
delegate meeting
Orlando, Florida

If members are interested in attending the national conference, you may apply for financial assistance with our chapter to be sent as a delegate. Call, write or e-mail us if you think that you might be interested in attending.

*The following is a message from the Spina Bifida Association of Dallas,
sponsors of the meeting described below.*

Joanne Cafiero, RN, Member
Board of Directors, Spina Bifida Association of Dallas

Invitation

You are invited to the Texas Birth Defects Conference 2002, March 7-1, 2002 in Fort Worth, TX. This biennial event brings together an audience focused on epidemiology, research, diagnosis, treatment, and prevention of birth defects among children born in Texas. Speakers will include both internationally known and Texas specific experts on topics such as Down Syndrome, Neural Tube Defects, Services for Children with Disabilities, Alcohol and Brain Development, and Folic Acid.

For more information or to register online, please visit
[Http://www.tdh.state.tx.us/tbdmd/conf_page.html](http://www.tdh.state.tx.us/tbdmd/conf_page.html), or contact Amy Case at (512)458-7232, amy.case@tdh.state.tx.us

TECHNOLOGY OPENS DOORS

New York State Governor's Expo
June 20, 2002
Empire State Plaza, Albany, NY

Discover the
POWER & POTENTIAL
of Assistive Technology (AT)
for People with Disabilities
Exhibits of AT Devices and Services
1-800-522-4369
(Voice/TTY/Spanish-in NYS Only)
(518)474-2825
(Voice) (518) 473-4231 (TTY)

[Www.advoc4disabled.state.ny.us](http://www.advoc4disabled.state.ny.us)

“DISABILITY LAW DAY”

Saturday, April 13
9 AM to 4 PM

Seminars are on a variety of subjects:

*educational services— early intervention, school age, transitional, vocational rehabilitation, assessments, & inclusion, higher education.

*discrimination, employment, housing, accommodation, public benefits, future care planning.

For information call 458-2328
Sponsored by Albany Law Clinic.
Seminars are free to the public.



REMEMBER OUR LENDING LIBRARY!

We have a wide variety of books and tapes covering many subjects including education, medical, social, support, and advocacy. Call or e-mail us today if you are interested in borrowing any materials.

ADRIAN'S CLOSET

We received an e-mail advertising a web site gift registry for “adaptive clothing to make dressing and bathrooming easier and more dignified”. While we have no personal experience with this organization, and therefore can offer no recommendations, we thought you may want to check this out as a potential resource. If you are interested in learning more about this, you may to call 800-831-2577.

RECURRENCE PREVENTION PROGRAM MAKING PROGRESS

The Recurrence Prevention Program at SBAA strives to educate women with a history of neural tube defects (NTDs) and health care providers about the relationship between folic acid and NTDs, specifically spina bifida. We recently completed a follow up survey to assess current awareness and knowledge levels among women who have a history of spina bifida since the baseline survey we conducted last year. Women at increased risk for having a pregnancy affected by an NTD, like spina bifida, women who have a child with spina bifida, have had an affected pregnancy, or have spina bifida participated in this survey. Over 490 completed surveys were received.

Here are the key findings:

- About 44% of women at high risk know that they need this amount of folic acid. This represents an increase of 13% over the initial baseline survey.
- Overall, more health care providers are mentioning folic acid. Women report that a health care provider has counseled them about folic acid about 58% of the time. This is a 9% increase from the initial folic acid awareness survey.
- Approximately 35% of women report taking folic acid as compared with 33% observed in the baseline survey.
- About 51% of women reported that folic acid is actually effective in reducing the risk of NTDs.

This information was obtained from the Direct Link electronic publication for group members of the SBAA.

Employment Tips for Those Who Are Differently-Abled Check out this website!

Are you in need of employment information and need to understanding the supports available to those who are differently-abled? The US Social Security has a web site designed to offer a variety of resources and information: [Http://www.ssa.gov/work](http://www.ssa.gov/work), including “Project ABLE”, “Ticket to Work”, SSI and SSDI, Medicare and Medicaid, Trial Work Periods, and PASS (Plans for Achieving Self-Support). The 2001 Red Book on Employment Support offers a summary guide to employment support available to people with disabilities under the social security disability insurance and supplemental security income programs. The book can be viewed on this web site or by writing to Social Security Administration Public Information Distribution Center, P.O. Box 17743, Baltimore, MD 21235, or by calling 1-410-965-0696.

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.

Suggested Questions For Parents to Ask at Individual Education Plan (IEP) Meetings

1. Where will my child be throughout the day including recess and special services? Is all of that area physically accessible to my child?
2. Has the teacher who will implement the IEP ever worked with a child like mine? If not, who will educate him/her about the peculiarities of students with Spina Bifida in general and mine in particular?
3. Will an aide be available to increase individual attention and/or assist with toileting, etc.?
4. Does the proposed program for placement actually exist? Can the program actually be implemented or will additional staff need to be acquired?
5. How many students will be in my child's class at any one time?
6. What is the range of ages and disabilities of those students?
7. How does the proposed program differ from the one my child has been in before?
8. Is the academic program being offered comparable with the school's regular academic program? What makes it different?
9. How is the instruction designed to meet my child's unique needs?
10. What related services will be offered? Describe their frequency and duration and whether they will be offered in a group or individually.
11. Will provisions be made for material that is missed while my child is receiving a related service? Is there somehow for those services to be implemented at times so that class time will not be missed?
12. What existing program opportunities were considered but not chosen for my child?
13. Is the program to be carried out in my home? Is there a provision for consistency between the school and my home?
14. What opportunities exist for my child to interact with students who are not disabled?
15. How will teacher and therapist absences be handled?
16. Do summer services need to be planned?
17. What disciplinary sanctions are appropriate or inappropriate?
18. Is the school counting on us (parents) to perform certain services in order to reach planned goals?
19. When and how often can I expect to receive a report of my child's progress? What form will that report take?
20. Are there other parents of disabled students in the school who would be willing to speak with me about the school's programs?

Questions are courtesy of Sunny Stephens, PhD., Director of Special Education, 2415 W Southcross, San Antonio, TX 78211

Reprinted from PERCEPTIONS, the Newsletter of the Spina Bifida Association of Nebraska, Inc.

WOULD YOU LIKE TO BE ON OUR MAILING LIST?

You have received this newsletter through the kindness of Dr. Malone. Due to the rules of confidentiality, we are unable to access this mailing list. Therefore, in order that we might develop a mailing list for the Albany/Capital District Chapter of the Spina Bifida Association, we ask that you fill out the information below and return in the enclosed self-addressed envelope. With your assistance in this matter, we will be able to continue to serve you. Thank you.

NAME _____

STREET ADDRESS _____

CITY/STATE _____

ZIP CODE _____ **E-MAIL** _____

*** Thank you to those of you who responded to our last request for this information.
You do not need to complete the form again.**