

Spina Bifida

NEWS To Use

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



From the presidents....

As we read all that Karen has included in the newsletter, we are so excited to see all the wonderful programs with which our chapter is involved. After meeting last June with people at the National Conference who do not have such active (if any) local chapters, we feel very fortunate to be living in this SBAA area. The support -- both formal and informal -- we've received since our son Greg was a baby has been invaluable. The activities in which he's participated and the friends with Spina Bifida whom he's met have been equally important to him. I leave every board meeting inspired to continued involvement with present activities and hoping to begin new ones. Unfortunately, like everyone already involved with SBAA, our busy schedules leave time in short supply.

There are so many ways in which families can become involved with our organization: we can always use help with existing endeavors and we are trying to launch several new support groups as well as a scholarship program. We would welcome any and all's participation in whatever way possible. We would like to encourage you all to become involved in our -- your - chapter. The rewards for us and the children would be enormous.

Vanessa and Kevin
Co-Presidents



Membership Drive

You will find forms enclosed for this year's membership drive. We would ask that you complete and return the forms even if you are unable to join as a paid member at this time. This is helpful to us to know who it is that we are serving. Please note that you will only receive the national SBAA newsletter, Insights, if you are a paid member. We send our chapter newsletter to everyone on our mailing list.

Many people receive our newsletter through Dr. Malone's office, and are not included on our chapter mailing list. If you want to be sure to receive all of our mailings, as well as emails if you are online, you will need to complete the forms and return them. We will be sure to include you on our SBA mailing list for the chapter newsletter and other information that we periodically send out to people.

SKATING PARTY

DATE: Saturday, March 22

TIME: 12:30 ~ 2:00 PM

PLACE:

Schenectady County
Recreational Facility
15 Airport Road, Scotia

The party is a family event. The facility will accommodate for varying needs.

Would you like further information?
Call 399-9151 or
SBAAlbany102@AOL.com

PLEASE RSVP BY
3/19/03.



WEBSITE FOR YOUNG CHILDREN

www.geocities.com/sbmice/ is a cute website designed for young children to read and learn about children with Spina Bifida. It is a website version of a picture book for elementary school age children.

NONVERBAL LEARNING DISORDERS

We received an paper addressing Nonverbal Learning Disorders from SBACI. It is written by Patti White RN, MSN, Clinical Nurse Specialist Spina Bifida Program, Riley Children's Hospital, Indianapolis, IN. The article addresses the following headings:

- What is a Learning Disability?
- What is a Nonverbal Learning Disability?
- Tactile (touch) Perception
- Psychomotor Coordination (physical awkwardness)
- Adaptability
- Spatial Orientation
- Mental Flexibility
- Executive Function and Organization
- Pragmatics of Language
- Generalizing Information
- Social Skills
- Emotional Stability
- What Causes NLD?
- Diagnosis of NLD
- What Happens After NLD is Diagnosed?
- Recommended Resources related to NLD

The article is 4 pages long, and therefore difficult to include with our newsletter. If however you would be interested in having a copy of it, please call or email, and we will be happy to send it to you.

STEP



SARATOGA THERAPEUTIC EQUESTRIAN PROGRAM

Located in Scotia, STEP is a program designed to use horses to improve the quality of life of children who have disabilities. Children work with volunteers and staff to experience the rewards of horseback riding. Pre-screening and medical evaluation are required prior to participation. The program runs from May to October. If you are interested in more information, call the barn at (518) 374-5116 on weekends.

SPINA BIFIDA ASSOCIATION OF AMERICA 30TH ANNUAL CONFERENCE

SUNDAY, JUNE 22, 2003 ~
WEDNESDAY, June 25, 2003

San Antonio, Texas

Reservations: (800) 233-1234
Email: conference@SBAA.org
Website: www.sbaa.org

Highlights include Kids!Camp is available for infants through 19 year olds.
Keynote Speaker: Jackie Pflug, inspirational speaker.

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.

NICHCY

National Information Center for Children and Youth with Disabilities

P.O.Box 1492, Washington, DC 20013-1492

800-695-0285 Voice/TTY

Email: nichcy@aed.org

www.nichcy.org

NICHCY is an information and referral center that provides information on disabilities and disability-related issues. Children and youth with disabilities (birth to age 22) are our special focus.

Anyone may contact NICHCY for information. They offer a number of services:

~ A Web site of all of their publications, and many other resources, are available free online;

~ Personal responses to questions on disability issues, including specific disabilities, early intervention, Individualized Education Programs (IEPs), special education and related services, mediation, family issues, positive behavioral supports, transition to adult life, multicultural issues, education rights, and much more;

!Publication, including state resource sheets, fact sheets on specific disabilities, issue and briefing papers, parent guides, student guides, resource lists, and materials in Spanish and alternative formats;

~ Referrals to other organizations and agencies, including national and state disability groups, regional and state organizations, professional associations, information centers, parent groups, and advocacy groups;

~ Information searches of NICHCY's databases and library; and

~ Technical assistance to parent and professional groups.

- • • • •
- **Spring Tennis Program**
- DATES: 5/3, 5/10, 5/17, 5/31, 6/7, 6/14
- TIMES: To Be Announced
- PLACE: Schenectady Racquet Club
- RAIN or SHINE!
- Lessons are taught by SAFE (Sports Are For Everyone). Lessons are being sponsored by Spina Bifida Association: Albany/Capital District Chapter.
- **REGISTRATION IS REQUIRED:**
- *There is limited space in the program, so please call and register in advance!*
- • • • •

SERVICE DOGS

Service Dogs are specially selected, bred, raised, and trained to assist people who have physical disabilities. They can open doors, pick up dropped items, carry belongings in a backpack, retrieve objects, operate light switches, and perform many more physical tasks. These dogs increase their partner's independence, security and offer them loving companionship.

There are a number of service dog resources in New York State. The closest to the Capital District area is:

Canine Working Companions, Inc.
Pat McNamara, Director
RD #2, Box 170
Gorton Lake Road
Waterville, NY 13480
(315)861-7770

