

Spina Bifida Association of Connecticut, Inc.

December 2002

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THE SPINA BIFIDA ASSOCIATION OF CONNECTICUT, INC.

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SBAC ELECTION RESULTS

The SBAC held its elections for the Officers and Board of Directors at the Fall Weekend at Harkness Memorial State Park. The results of those elections are:

President and Treasurer: Kiley Carlson Secretary: Fred Liguori

Board of Directors: Jerry Beck Anthony Lanzetti
Marybeth Petersen Michelle Tardiff

Thank you to our departing officers and board members on your dedicated service.

Please join us as we welcome aboard our newly elected officials.

MARGARITA'S RESTAURANTS SUPPORT THE SBAC By, FRED LIGUORI

For 2002 Margaritas Mexican Restaurants have continued to support the SBAC by sponsoring our organization during their Full Moon Madness Nights. Full Moon Madness occurs monthly at each of the restaurants. There is an emcee for the evening that organizes contests and raffles off prizes donated by local merchants. As the organization being sponsored for the evening, we have the opportunity to explain to the patrons about spina bifida and the SBAC. Not only do we have a chance to improve public awareness but Margaritas also donates 5% of the evening's lounge sales of food and beverage to the organization being sponsored.



The Margaritas Restaurants in Branford, Mystic and Mansfield sponsored the SBAC for the 3rd quarter 2002 which included July, August and September. For the three Full Moon Madness Nights at those locations, Margaritas wrote SBAC a check for **\$2,235.13**. The restaurant in Canton is privately owned and they sponsor a different organization each month. SBAC was sponsored in October for a single night and we received a check for **\$570.00**. Not bad!!

I am very thankful for the support Margaritas Restaurants have shown us. They provide us with a public awareness platform and much needed revenue. Margaritas began to sponsor the SBAC in 2000 and since that time has donated over \$4,500 to our organization. If you stop into any of the Connecticut Margaritas Mexican Restaurants, please ask to see the manager and thank him, or her, for their support of the SBAC. And while you're there, be sure to order a Gold Margarita on the rocks with salt, I highly recommend them!

A LETTER FROM THE PRESIDENT

Dear Members,

Seasons Greetings!

I would like to start by thanking you for the honor and privilege of serving as the President of the SBAC for a third time. I thoroughly enjoy working for this great organization and look forward to the next two years in this position. I hope I can count on you, our members, individuals and families affected by spina bifida, to help the SBAC not only achieve the goals we have set for ourselves, but to help us create new ones to reach.

This organization needs your input. The board can come up with its own ideas of where the SBAC should be going and what we should be doing, but we would like to hear your thoughts about the SBAC's direction. Please drop us a line and let us know your thoughts.

I would also like to thank my predecessor, Dennis Maloney for his 3 plus years of service as President. Dennis was the driving force behind the long-range plan that is my guide to leading this organization. Thanks, Dennis for all your hard work!

Another thank you to Jerry Beck for stepping up and filling in when Dennis had to leave us, and to the rest of the board for going with the flow during the transition. It is people like you that energize me to continue to work for the Association. Cheers!

Finally, to all SBAC members I wish a Happy and Healthy Holiday Season, and I hope to hear from you in the New Year.

Yours truly,

Kiley J. Carlson

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We welcome comments and suggestions regarding the content or appearance of the Newsletter, as well as commentary on issues related to Spina Bifida. We reserve the right to edit all submissions. Letters must include your name, address and phone number. Mail all correspondence in care of the association. Or, call us anytime with suggestions, questions, impressions, or contributions at: 1-800-574-6274 or visit us on the web at : <http://sbac.org>.



SUMMER CAMP = FUN & INDEPENDENCE!

BY, JIM HEUS

Last winter my wife and I decided we should consider a residential camp program for our daughter, Kiki, age 12. There are few summer opportunities in our area for Kiki and we were of the opinion that she needed to become more independent and self-sufficient. Kiki was not yet self-cathing which is why it was difficult to find programs that would provide for her needs.

I spent hours researching summer camps on the internet. I also attended a Special Camp Fair in NYC for children with special needs where I picked up a copy of Camps 2002: A Directory of Camps and Summer Programs for Children and Youth with Disabilities and Special Needs in the Metro New York Area (February 2002) www.resourcesnyc.org. I identified two programs: **Pine Tree Camp** in Rome, Maine and **Camp Spifida** in Millville, Pennsylvania.

Camp Pine Tree is sponsored by the Pine Tree Society (149 Front Street, P.O. Box 518, Bath, Maine www.pinetreesociety.org). They sponsor a ten day program which is designed for children with physical disabilities. (They have other programs for children/youth with developmental needs.) Kiki was one of 60 boys and girls and the age range was from 7-15. Kiki loved it and made very good social connections with other children, some with Spina Bifida. Some were confined to motorized wheelchair and needs extensive assistance, others were highly mobile. The staff was quite large and the ratio seemed to be about one counselor to every 2 campers. Everyday they swan in the lake adjacent to their cabins, attended arts and crafts sessions, joined in drama class and limited sports. They even had an overnight adventure camping in the woods. While Kiki was both excited and anxious about attending, she came back very confident and proud of herself. We observed a real change in her attitude towards her self-confidence and willingness to take care of herself. The nurses tried to help her self-catch, but it just didn't happen.



The second camp, Camp Spifida, was a five-day residential program designed expressly for children ages 8-15 with Spina Bifida. (The director is Sasha Hovak, telephone [570] 437-3924) Again, this camp was well staffed, and the program was thematic (this year's theme was the Middle Ages: Camp Cathalot) and highly creative. Kiki, as a first time camper, was allowed to bring either a sibling or a friend. Her best friend joined her and had a good time as well. The best part was that the head of the nursing facility, Dr. P. Bellino, worked with Kiki and taught her to cath herself. How our lives have changed!

Camp Pine Tree cost \$1300, though they did offer 'camperships' for deserving families. Camp Spifida cost \$160 and, much to my surprise, this fee was reduced to only \$50 since they had received a generous grant from the Hershey Foundation.

Kiki wants to return next year and I will be on the outlook for other opportunities as well (perhaps I can find something closer to home).

THE NEAT MARKETPLACE

BY, REBECCA EARL & LEE LEARSON

A brand new, state-of-the-art building set up just for the display and use of assistive technology, amazing! A place where consumers and others with an interest in them can “shop” to find the AT that meets their needs, it’s about time! You’d have to agree that it’s all quite NEAT, at least, you’d have to if you knew what NEAT is...

Start with the basic premise that the inability to access the equipment and devices that mitigate the effects of disabilities is, in fact, a disability in and of itself. People with disabilities need to know about the wide range of options that exist for them in equipment that helps with walking, talking, seeing, hearing, and other essential life functions. They also need to have the opportunity to see and try out that equipment before taking the, often very expensive, plunge of purchasing it. The New England Assistive Technology (NEAT) Marketplace was established three years ago to help to provide that access. During those three years, the need for the services of the NEAT Marketplace has been underlined many, many times.



The Demonstration Center component of the program is designed to provide people with disabilities, their families, and the professionals who work with them access through information about essential products. *Regular presentations by vendors* of the newest of their products, like Play Attention, give people a chance to learn all the features and applications of programs, to try them out and to spend as much time as needed with the vendor, finding answers to all the hard questions. *Expos* bring several vendors of similar products together under one roof to enable consumers to compare similar products. *Training and workshops* such as the presentation by Dr. Dave Edyburn on curriculum access or the regular Saturday sessions of Intellitools training make the NEAT Marketplace a resource for everyone. The *Information and Resource Service* helps people to take the first step in researching equipment by providing catalog, website and other pertinent information. *The Computer Lab* is designed with playing in mind. Eighteen computers are set up with all kinds of adapted hardware and software for people to play with. Switches abound. It is the perfect environment for teachers and therapists to bring students, or for rehab specialists to meet with adult clients getting ready to go back to work.

The Equipment Restoration Center completes the access picture by giving people an opportunity to buy gently-used, donated durable medical equipment at savings of up to 80% of the same item new. We work through vendor members who buy the restored items from the NEAT Marketplace, add their specialized seating or other personalized adaptations to the piece, and sell it to the consumer at huge savings. This connection with a vendor gives consumers a resource for future purchases, and a source for on-going maintenance and support of the equipment. The inventory of equipment is posted on our website. Don Hoerman, Equipment Manager, is available to answer any of your questions about donations and purchases from ERC.

Our new 25,000 square foot building on the corner of Coventry and Holcomb Streets in Hartford is an amazing place to visit, again and again. It even includes a small store where you can buy switches, specialized software, and other really NEAT things. You can reach us toll-free in CT at 866/526-4492 or by checking our website, www.neatmarketplace.org. It will keep you up to date on all our doings and give you a contact link with us. We are a resource you should know about.

Rebecca Earl is President of the NEAT Marketplace. Lee Learson is its Director.

THE FAMILY CENTER IN BRISTOL, CT

BY, MARYBETH PETERSEN

Recently my family joined the Family Center in Bristol and has been very pleased with the programs they have to offer. We wanted to share a bit about the center with others who might be as happy with it as we are.

The center offers many recreational and educational programs including day care services but we were primarily interested in getting our children (Andrew who is almost 4 and Katherine who is 2 ½ and has spina bifida) in the swimming programs. The big draw for us, with small children, is the center's new "toddler pool" that is only 1 foot deep and has water at "spa" temperatures – perfect for little ones! We enrolled Katherine in a swimming class and are also taking advantage of the week-end "open swim" times as a family. So far we have been delighted with the pool and the facility overall.

Additionally, the Family Center offers play groups for socializing toddlers. One of the play groups is an hour long and takes place in the center's gymnasium that is set up with climbing equipment, toddler toys, a ball pit and more. They also offer a second play group for children with special needs. Although that play group is new and relatively small, it is growing!

Parents are encouraged to bring their typical children along to the special needs play group and vice versa.

One thing we have been most impressed with is the caring staff at the Family Center – they have been quick to meet our requests for special accommodations and have encouraged us to speak up whenever we need anything to make our visits easier and more enjoyable. The center employs a Special Services Director named Barbara Campbell. She's a very kind person and has cheerfully met our every need and request.

If you live within a reasonable distance from Bristol, it's worth checking out the Family Center!

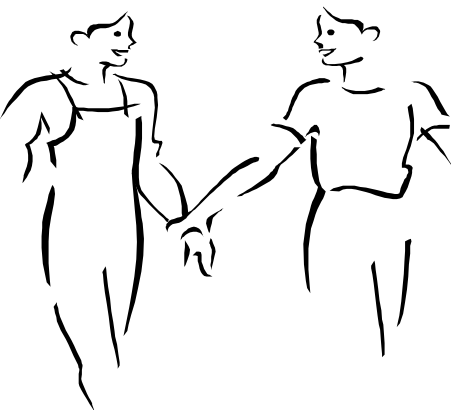
The Family Center
47 Upton Street – Bristol, CT 06010
(860) 583-1679

e-mail: kids@familycenter.org
homepage: <http://familycenter.org>

OUTREACH COMMITTEE UPDATE

One of the missions of the Spina Bifida Association of Connecticut is to provide support, educational information, and referrals to other families who have a loved one with Spina Bifida. To help meet those goals, an Outreach Committee was recently formed. Thus far, the committee has made contacts with some other organizations throughout the state in order to receive referrals of families in need of this important connection to others that truly understand.

Several successful "matches" have been made between families who are currently members of the SBAC and others who needed to talk with someone able to relate to their concerns. It is the committee's goal to open up the lines of communication among many families in Connecticut in a responsible and timely manner.



Additionally, members of the Outreach Committee recently attended a "Listener Training" program and hope to continue with more training in the future.

If you have questions or concerns and would like to talk with another parent or adult with spina bifida or are interested in doing outreach yourself, we would like to hear from you. Call Marybeth Petersen @ (860) 673-4310 or Michelle Engel @ (860) 648-0624.

COULD YOU USE A “MINI-VACATION”?

Caring for a child with special physical needs can be both demanding and extremely rewarding. But from time to time, everyone needs a little break from their routine and the demands of being a caregiver. When you are caring for a child that has special medical concerns, however, there never seems to be enough money left over to take a mini-vacation.

Well, the Respitality Program that’s part of the United Cerebral Palsy of Greater Hartford can help! The UCP has teamed up with some Connecticut’s finest hotels to provide mini-vacations to families of children with special physical needs. The hotel rates are deeply discounted off normal rates and are charged on a sliding-scale according to your income. Eligible families are welcome to “take a break” 3 weekends a year! The UCP deals directly with the hotel to make the accommodations on your behalf – what could be easier?

Here are just some of the hotels that are participating in the Respitality program:

Four hotels in the Windsor Locks area – close to the New England Air Museum, Bradley Teletheater, Six Flags New England, Mt. Tom Waterslide, and The Basketball Hall of Fame!

The Farmington Marriott Hotel featuring indoor and outdoor pools and a health club. True luxury!

Two hotels in Downtown Hartford. Why not catch a show at the Civic Center or the Hartford Stage? How about a leisurely dinner and a stroll downtown?

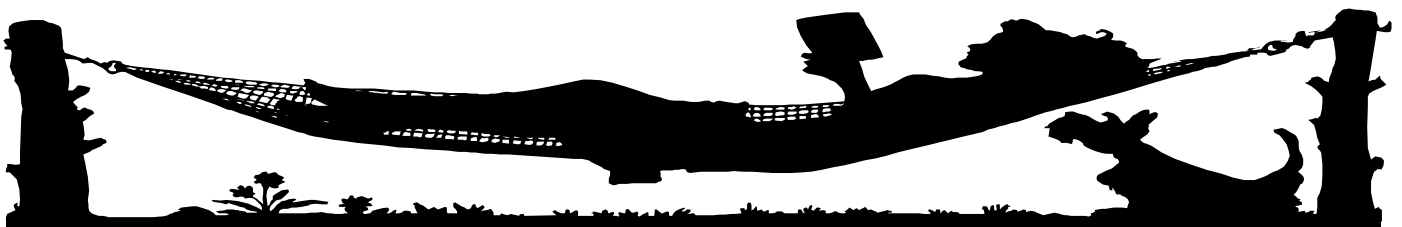
What about the Old Mystic Motor Lodge in Mystic? It’s within walking distance to Old Mistick Village, The Mystic Aquarium & Seaport!

The Sheraton Four Points Hotel in Norwalk features a lounge and healthclub, complimentary morning coffee and is close to the Maritime Center and Historic South Norwalk.

The Simsbury Inn in Simsbury is a first-class hotel in the heart of Simsbury’s quaint center. It’s close to antique shopping, local farms and fabulous dining.

Interested? Who wouldn’t be?! For more information or to obtain the forms to sign up for the program, contact:

Meg McDermott
Respitality Coordinator
United Cerebral Palsy of Greater Hartford, Inc.
80 Whitney Street
Hartford, CT 06108
(860) 236-6201 Ext. 340



ADDING FIBER FOR YOUR GOOD HEALTH

BY, BETH CHATFIELD M.S. R.D AND KATE VANCE R.D
CONNECTICUT CHILDREN'S MEDICAL CENTER

Issues related to constipation are a concern for families with children with myelomeningocele. Neurogenic bowel, decreased activity, low fiber food choices and inadequate fluids may all contribute to constipation. Adding appropriate high fiber foods and adequate fluids will aid in regulating normal bowel movements.

A well balanced diet including liberal amounts of whole grains, fruits and vegetables on a daily basis, will help promote good health and is considered a high fiber diet. Fiber acts like a sponge by absorbing water in the bowel and helps to make bowel movements softer and easier to pass. Different foods provide different types of fiber. The fiber from grains and cereals (insoluble fiber) is helpful for treatment of constipation.

A high fiber is recommended for the good health of all family members. Your child's specific fiber goals can be calculate by this equation:

Goal: Child's age + 5= grams of fiber needed per day.

Gradually increase fiber intake over one to two weeks to avoid a potential problem of abdominal discomfort, gas, and diarrhea. Good choices of high fiber foods include dietary fiber content of 2-3 grams per servings.

See suggestions below:

<u>Usual Food</u>	<u>Fiber Grams/Serving</u>	<u>Use This Instead</u>	<u>Fiber Grams/Serving</u>
Bagels	0 gm / half cup	Thomas' Honey Wheat English Muffins	3 gm / muffin
Rice Krispies or Captain Crunch	0 gm / half cup	Multi Grain Cheerios Honey Nut or Frosted Mini Wheats	3 gm / cup 4-5 gm / cup
Corn Flakes	0 gm / half cup	Raisin Bran	7-8 gm / cup
White Bread	0 gm / slice	100% Whole Wheat Bread	2 gm / slice
Ritz or Saltines	0 gm / 1 cracker	Triscuits or Wheat Thins	3 gm / 6 crackers
Spaghetti	0 gm / half cup cooked	Whole Wheat Spaghetti	6 gm / half cup cooked
White Rice	0 gm / half cup cooked	Brown Rice	3 gm / half cup cooked
Eggo Waffle	0 gm / waffle	Eggo Multi Grain or Whole Wheat Waffles	2 gm / waffle
Snack Mixes	1 gm / 2/3 cup	Multi-Grain Chex Cereal	2 gm / 2/3 cup
Nutri-Grain Bar	0 gm / bar	Nature's Valley Crunchy	1 gm / bar
Fruit Snacks	0 gm / serving	Dried Fruit	2-6 gm / tablespoon
Chips & Dip	0 gm / serving	Veggies & Dip	2 gm / half cup raw

FLU VACCINE ALERT!

With flu season upon us and so much information in the news concerning flu shots, those who have latex allergies should be informed about latex in the packaging for the vaccine product.

The National Immunization Program at the Centers for Disease Control and Prevention has checked with all three influenza vaccine manufacturers and confirmed that the packaging (vials and syringes) for vaccine produced by Evans (Fluviron), contains only synthetic rubber, and does not contain latex-containing rubber. (However, Fluviron is not approved for children under 4.) Packaging for influenza vaccine produced by both Wyeth and Aventis Pasteur both contain dry natural rubber, which contains the impurities believed to be associated with latex allergy.




If someone in your family is sensitive to latex you should discuss this information with your doctor before obtaining a flu shot.

MEMBER NEEDS INFORMATION ON SPINAL FUSION SURGERY

Have you or your loved one with spina bifida undergone spinal fusion surgery? If so, one of our members would like to speak with you about their 11 year old son's spinal fusion surgery that is scheduled for January 2003.

Perhaps you could help by sharing your personal experience with Mark or Dana? It would be a big help to prepare the family for the surgery! Please can call Mark or Dana at (860) 653-9856 or send an e-mail to them at: Wichmann@erols.com.

 <p>Fun Fiber!</p> <p>Did you know that popcorn contains a great deal of fiber?</p> <p><i>For example:</i></p> <p>Pop Secret Light Microwave Popcorn contains <u>4 grams</u> of fiber per serving!</p> <p>Newman's Own brands contain <u>3 grams</u> per serving!</p> <p>Check the label on your favorite brand – a yummy way to get your fiber!</p>	<h3>Homemade Kettle Corn</h3> <p>One half cup un-popped popcorn kernels One Quarter cup white sugar Four tablespoons vegetable oil</p> <p>Place the popcorn and sugar in a large pot with the vegetable oil. Over medium-low heat begin to pop the popcorn. Constantly shake the pot to keep the kernels from burning...be patient, it will burn if the heat is too high! Once the popping has slowed, remove the pot from the heat. Add salt to taste. Enjoy!</p> <p><i>Note: Using brown sugar in place of the white will make the popcorn taste more like caramel corn.</i></p> <p>Makes 5 servings. <u>3 grams of fiber</u>, 209 calories, 2/4 grams protein, 11.8 grams of fat per serving.</p>
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IT'S ALMOST BRIDAL SHOW TIME!

The 18th Annual Connecticut Bridal Show is fast approaching! This year's event will be held on January 25 and 26, 2003 at the Connecticut Expo Center in Hartford. Once again this year, the SBAC will have an informational booth at the show to provide information on spina bifida and the use of folic acid to reduce the incidence of birth defects. The bridal show forum is very important in our outreach efforts as young brides will be the next generation of mothers.

Would you consider volunteering some of your time to help out at the booth? We'll be there on Saturday from 11 am to 6 pm and Sunday from 11 am to 5 pm; any time you can lend would be appreciated. If you're interested, please call Kiley Carlson at (860) 345-8768 or e-mail him at Kiley.C@sbac.org.

We hope to see you there!

THANKS TO THE PINE GROVE ELEMENTARY SCHOOL

Many thanks to the Pine Grove Elementary School in Avon, Connecticut for their support of the SBAC! The school recently conducted a "Dress Down Day" to benefit the SBAC. In exchange for a financial donation, faculty and staff members could wear casual clothes for the day. The fundraiser netted \$54.00 and raised awareness of our organization.

What a fun and creative way to raise funds. Thank you Pine Grove!!

WHAT'S A NON VERBAL LEARNING DISORDER? REPRINTED FROM THE SPINA BIFIDA ASSOCIATION OF GREATER NEW ORLEANS (SBAGNO) NEWSLETTER

Nonverbal Learning Disability (NLD) is a developmental disability, which has been associated with Spina Bifida, Hydrocephalus and other syndromes, such as Asperger's, Turner's and Autism. The term Nonverbal Learning Disability is actually misleading. These children are clearly quite verbal with their areas of deficit being in the nonverbal domains. In addition, it is not a learning disability in the classic sense. We understand a learning disability such as dyslexia to be academically based. NLD on the other hand, is a life learning disability. The children or adults require instruction in all areas from academic to social to problem solving to independent living.

NLD is a learning disability that all too often goes undiagnosed. These individuals are often bright, sometimes incredibly so. As young children they may actually be targeted as gifted, due to their mature vocabulary, rote memory skills, and apparent reading ability. However, parents likely realize early on that something is amiss. As preschoolers, these youngsters probably have difficulty interacting with other children, with acquiring self help skills, are not physically adept, are not adaptable, and present with a host of other troublesome problems that are of concern but not alarming. In all likelihood, the children bump along (literally and figuratively) through their early elementary years, handling the academic demands fairly well, except when their fine motor difficulties get in the way or they fail to attend to a math symbol or some other subtle symptom of their disorder derails them. As these children enter the upper elementary grades they are left to handle more tasks on their own. Things rapidly begin to deteriorate. They get lost, forget to do homework, seem unprepared for class, have difficulty following directions, struggle with math, can't read their social studies textbook, can't write an essay, continually misunderstand both their teachers and peers, and are often anxious in public and angry at home. They are accused of being lazy, rude, uncooperative, and worse. Nothing could be farther from the truth! They have NLD! (P.B. Tanguay and D. Mooney)



Looking for a gift for the person
who "has everything"?

Want to give a more meaningful
gift this holiday season?

Consider making a donation to the SBAC
in someone's honor or in memory of a loved one.

It's a truly thoughtful and memorable gift!

And, all the work will be done for you;
A gift card acknowledging your contribution
will be mailed on your behalf.

Better yet, all donations are tax-deductible!



Thank you for thinking of the SBAC for your gift giving needs. This completed form and a check payable to the SBAC, Inc. should be mailed to:

The Spina Bifida Association of Connecticut, Inc.
P.O. Box 2545 – Hartford, CT 06146

[HTTP://SBAC.ORG](http://sbac.org)

GIFT DONATION FORM

Your Name: _____

Address: _____

Gift to be made (choose one):

In Honor of: _____

In Memory of: _____

Amount of Donation: \$ _____

Mail Acknowledgement to:

Name: _____

Address: _____

Optional: Please accept this donation in support of the following program:

- Allocations Fund - Assists members with unpaid medical bills.
- Campership Fund - Funds to help cover the cost of summer camps for individuals with spina bifida.
- Scholarship Fund - A scholarship fund for individuals with spina bifida.
- Angel Program - The SBAC distributes gift certificates to families during the holidays.



The Spina Bifida Association of Connecticut, Inc.
 P.O. Box 2545
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For more information on any of these events or any of the HSC Sports Teams please contact:
 Ann Thompson, Sports Program Manager
 Hospital for Special Care Community Health & Fitness
 2150 Corbin Avenue, New Britain, CT 06053
 Phone: 860-832-6220 - - fax: 860-832-6236
 email: athompson@hftsc.org

Supreme Sports Saturdays
 December 21, 2002 - Sled Hockey
 January 18, 2003 - Football & Soccer
 February 15, 2003 - Cross-Country Skiing
 March 22, 2003 - Challenge Course

HSC Sports Teams:
 Cruisers Wheelchair Track & Field
 Spokebenders Wheelchair Basketball
 Chargers Wheelchair Soccer
 Wave Swim Team

Ski Trips - Vermont Adaptive Ski & Sports
 January 11, 2003 - - and - - February 1, 2003

3rd Annual Wheelchair Basketball Clinic
 February 8, 2003

Hospital for Special Care
 Sports, Training & Leadership
 Winter 2002-2003 Programs

