

Spina Bifida Association of Connecticut, Inc.

March 2003

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THE SPINA BIFIDA ASSOCIATION OF CONNECTICUT, INC.

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SPRING WEEKEND GET-TOGETHER

Due to the budget problems facing the State of Connecticut, we regret that Camp Harkness is not accepting any applications for the campground area. Unfortunately, that means the Spring Weekend we've enjoyed for so many years is not possible this year. It's disappointing because we only get together as a group a few times a year and we all look forward to those outings. While the Board of Directors is currently examining other options for a location to hold the function, there are no firm plans as we go to press with this newsletter.

If the organization is able to secure a convenient, accessible, affordable location to host an event, we'll need lots of help from our membership to pull it off. If you can help with any of the following, please contact Kiley Carlson or Marybeth Petersen to express your interest.* Together we can make it a party to remember!

Party games and/or activities for young children

Games and/or activities for teenagers/young adults

Putting together "Goody Bags" for the kids to take home

Purchasing and setting up party decorations and paper goods

Coordinating purchase and pick-up of food from a local restaurant

Clean up crew after the event

* Expenses incurred will be reimbursed by the SBAC.

CONNECTICUT ADULTS WITH SPINA BIFIDA GROUP NOW FORMING!

Are you an adult with spina bifida who is interested in meeting other adults with spina bifida in Connecticut? Would you like to join others for social get-togethers and outings? Now's your chance to get involved in this adults-only group that's part of the SBAC.

For more information and to get involved, call Helena Afonso at (860) 233-5959 or e-mail her at fonzie615@aol.com.

A LETTER FROM THE PRESIDENT

Hello Everyone,

WOW! What a winter we've had! After all the snow and cold temperatures have started to move on, the SBAC is usually in the final stages of planning for the bowl-a-thon and getting ready for the Spring Camp Harkness weekend. Well, if you've noticed you haven't heard much, if anything, about either. But that will soon change.

The bowl-a-thon has been scheduled to take place in the fall of this year, so you have a few months to sharpen your game and to build a couple of teams to join in the fun. The Camp Harkness weekend is a different story. Due to state budget cuts, the camp is not taking reservations. We are looking into a new venue to hold this very popular event, although it may only be a day trip instead of an overnight adventure.

Some of you have been asking about the scholarship fund for this year. Applications will be sent out in a few weeks with all the details. Also, look for an expansion of the allocation fund categories. We hope all of you that are eligible will take advantage of these programs.

Hope you all have a wonderful Spring, and please drop us a line if you have any questions or comments.

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.

Call us anytime with suggestions, questions, impressions, or contributions at: 1-800-574-6274 or visit us on the web at : <http://sbac.org>.

SBAC & SBC/SNET "Community Connections"

The SBAC recently received \$64.10 from SBC/SNET's Community Connections program – to date, we've collected \$790.89! However, we could do better!

Not yet signed up for the program? It's easy!! For more information or to sign up over the telephone, call SNET at 1-800-635-7638.

The SBAC's Organization Code is: C2302.



DID YOU KNOW? RESPITE CARE IS AVAILABLE!

By, MARYBETH PETERSEN

It's hard to pick up the newspaper or to turn on the television or radio in Connecticut without hearing of the state's serious fiscal crisis. There have been cutbacks to human services leaving many of our members without their in-home respite care from the DMR or other agencies. Personally, our family's respite care provider was laid off with no one left in the department to cover her case load. Fortunately, we have a great deal of family support and never a lack of concerned babysitters, however, not everyone is so lucky.

What can a parent with a medically complicated child do to get a well-deserved break? Never fear...there is still help available through the DMR and their Respite Centers located in Hamden and Meriden. These state-of-the-art facilities, staffed with caring and loving personnel, are equipped to handle any medical challenges a child may have. For more information about eligibility or to arrange a tour call: the Hamden center at (203) 248-6087 – or Meriden at (203) 514-3250. You may also contact Greg Damato of the DMR at (860) 679-7047.

FREE PAMPHLET FOR PARENTS

Yale New Haven Hospital is offering a free pamphlet entitled "Pediatric Patient Safety: Keeping Children Safe in the Hospital." The information is invaluable for any parent with a child facing an upcoming surgery or hospitalization. The pamphlet may be obtained by calling (203) 688-2000 or toll-free at 1-888-700-6543.

HYDROCEPHALUS AND SURGICAL SHUNT CARD

Bel-Med is a company that offers a "shunt card" that contains the patient information, type of shunt, proper pressure setting and 6 views of the MRI or CTscan film that shows usual ventricle size when the shunt is working properly. This is an excellent way to protect yourself or your child in case of a shunt malfunction when traveling or away from your neurosurgeon. In an emergency situation, the examining physician would be able to know exactly which type of shunt is present and be able to compare ventricle size with the views on the card. The cost for the card is \$30.00. For more information call Bel-Med at: 1-800-531-9614.

SAVE ON YOUR SNET TELEPHONE BILL

If you are a SNET customer you may be eligible to receive a credit of up to \$7.00 a month on your phone bill if you meet certain criteria including Title 19 Medicaid and SSI. For More information or to receive an application, call "Lifeline" at SNET at 1-800-540-7638.

THE SIBLING SUPPORT PROJECT

Announcing two webring for siblings of people with special needs. SibKids is for younger brothers and sisters and SibNet is for older siblings. Both lists have members from the United States, Canada, Australia, England, Japan, and beyond. For more information or a free subscription to the service, contact the Sibling Support Project's Web Page at <http://www.thearc.org/siblingsupport> or contact the project's director, Don Meyer at (206) 297-6368.

CECOSTOMY

AN OPTION FOR SOCIAL BOWEL CONTINENCE

By, Wendy Garizio

"Although research is done by Wendy in good faith using reliable sources, this is not intended to replace advice given by your own MD or NP"

Because spina bifida usually causes neurogenic bowel, that is, abnormal bowel function due to decreased enervation to the area, some kind of bowel routine or intervention is usually necessary. Furthermore, as the person with spina bifida gets older and desires to blend in with the rest of society, some additional adaptation may be necessary to achieve social continence. Continence is the normal functioning of the bowel, whereby the person can hold and expel stool at will. Social continence means the person will be continent throughout the day while they are interacting with society, and will have the control over his bowel in order to expel stool at a time when it is convenient for him. This can be achieved through various means, some of which are often combined. A person uses diet to control the consistency of stool, making it easier for the body to push the stool along. Oral laxatives as well as suppositories may be used. Timing can be important, as the body can get used to a routine of expelling the stool at the same time each day, and the benefit of the "gastrocolic reflex" (reflexive bowel function which occurs shortly after a meal) can be used. Often many of these remedies are used for awhile and then they may cease to efficiently empty the colon. At this point a person may begin to use enemas on a regular basis.

The traditional fashion for administering an enema is via the rectum; this is called a retrograde enema. There are two basic types of cecostomy. One type, usually just called a percutaneous cecostomy, uses an artificial conduit, attached to the end of the cecum and extending out of the person's body. The outer opening is located at the belly button or low in the abdomen and has an opening with a cap often called a "button." A catheter can be easily inserted into the button and the enema flushes the bowel from above and empties out of the anus, this is called an antegrade enema. The other type of cecostomy is called a MACE. The M stands for either Mitrofanoff or Malone (more common), after those who pioneered the procedures. A is for antegrade. C stands for either colonic or continence and E is for enema. The MACE uses part of the person's appendix to form the conduit from the bowel to the outside of the abdomen. A stoma is then created which is an artificially created opening, which has the ability to be catheterized. The enema is then administered with a similar technique as for the percutaneous cecostomy.

The advantages of having a cecostomy are that the entire bowel is emptied, instead of just the tail end (pardon my pun.) Social continence is more readily achieved if the entire large bowel is evacuated. Also, the person can administer his own enema, since the stoma or button is more easily accessible to him than his own rectum (especially if he uses a wheelchair.)

The disadvantages include general surgical complications and possible infection of the stoma. One final note: a Mitrofanoff is more often used to refer to a bladder ostomy, whereby a conduit is created from the bladder to a stoma at the belly button which is catheterized regularly. This procedure usually uses the appendix, but often only part of the appendix can be used, preserving the other part for a cecostomy, or a button cecostomy can be used. With a combination of these procedures, a person can achieve both social bowel and social bladder continence.

ABILITIES EXPO

The Abilities Expo will be held at the New Jersey Convention & Expo Center on April 11-13, 2003. For more information and a listing of exhibitors and workshop descriptions, visit: www.abilitiesexpo.com. The SBAC has **free VIP Passes** available to anyone who would like to attend the show. If you are interested, please call Marybeth Petersen at (860) 673-4310.

UROMED AD

SOCKS MADE TO FIT OVER AFO'S

Have you had trouble finding socks to fit comfortably over AFO's? A company called Sock 'Em sells socks designed specifically to fit over AFO's. They're made for children and adults. A friend tells me that her 2 year old has been wearing them with great comfort. You can reach Sock 'Em by telephone at (519) 268-3293 or on their website at: <http://www.sock-em.on.ca/index.html>.



BIRTH DEFECTS PREVENTION MONTH EVENTS HELD

January is Birth Defects Prevention Month, and to do our share, the SBAC took part in two events. The first was Mohegan Sun Employee Health Day. Each month the Mohegan Tribal Health Department sets up shop in the Uncas Grill, the employee cafeteria at the casino, to hand out information on different health issues. Information about the SBAC and folic acid was distributed. Mohegan Sun has been a sponsor of the SBAC bowl-a-thon for many years and the SBAC is glad to be able to lend a hand to educating some of their 11,000 employees.

The second event is the annual CT Bridal Expo held, for the second year, at the CT Expo Center in Hartford. This event gives us the opportunity to pass on information about folic acid to brides-to-be, as they prepare to start their new families. Thanks to Francine Hebert, Jill and Fred Liguori, for helping out at this year's show.

UPDATE: THE OUTREACH COMMITTEE

The outreach committee of the SBAC is happy to report that we've continued to make contact with and provide support for new families affected by spina bifida. In the past 6 months we've made several successful matches between parents of children with spina bifida and adults as well. As you might imagine, the matches have been rewarding for the mentor and extremely helpful for the new families.

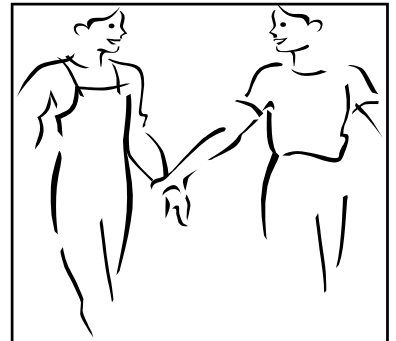
While we've been successful at finding parents of young children to act as mentors for the program, we still need more teenage and adult volunteers. Occasionally we hear from a new parent who would like to speak with an adult who has spina bifida or we meet an teenager or adult with spina bifida who would like to meet others with similar challenges. The time commitment on the part of the mentor can range from minimal to as much time as you are interested in spending with the new member.

If you're a teen or adult with spina bifida and would like to get involved with the mentoring process, please call Marybeth Petersen at (860) 673-4310 or Michelle Engel at (860) 648-0624.

We would love to have you on our team!

Listed below are the stories of some families that requested assistance from the Outreach Committee.

Please take a moment to consider if you can help one of these families with their needs. Your small commitment of time will pay off big!!



*The better part of one's life
consists of his friendships.*
- Abraham Lincoln

FIVE YEAR OLD BOY IN THE LEDYARD AREA

A family with a five year old boy who has spina bifida are interested in speaking with other families and children of similar ages concerning issues concerning continence and cathing routines. If you can help, please contact the boy's mother, Lisa, at (860) 886-2991 or e-mail her at allynce@netzero.net.

FAMILY MOVED TO CONNECTICUT FROM CALIFORNIA

What a shock it must have been for this family to move to Connecticut from sunny Southern California this January – Brrrr! The family recently moved to Trumbull with their 21 year old daughter who has spina bifida; their 24 year old son stayed out West. As you might imagine, they're in need of specialists, an orthopedic shop, and other medical professionals in the area. They're also interested in any information or assistance concerning driving schools and/or specific requirements for handicapped driving requirements in the State of CT. If you can help, please call Maureen at (203) 375-1765.

SEARCHING FOR A SPANISH SPEAKING FAMILY

The Association was recently contacted by an advocate for a Spanish speaking family of a 4-year-old girl with spina bifida who are new to Connecticut. The family requires assistance locating doctors, housing, transportation, etc. They are also interested in meeting Spanish speaking families affected by spina bifida. If you would be able to offer help to this family while they get settled in our state, please contact Marybeth Petersen of the SBAC Outreach Committee at (860) 673-4310 or:

Rosa Guzman, Family Advocate
Manchester Head Start
57 Hollister Street – Manchester, CT 06040
(860) 647-5045

EN BUSCA DE UNA FAMILIA QUE HABLE ESPAÑOL

La asociación recientemente fue contactada por la persona que esta intercediendo por una familia de habla hispana que tiene una niña de 4 años con espina bifida que son nuevas en el estado de Connecticut. Esta familia necesita ayuda en localizar doctores, vivienda, también necesitan ayuda con transportación, y etc. Ellos también les gustaría reunirse con las familias de habla Hispana que tengan niños afectado con esta condición de la espalda (espina bifida). Si usted o ustedes le podrían ofrecer ayuda a esta familia en lo que ellos se acomodan en nuestro estado, por favor de hablar con La Sra. Marybeth Petersen del comité SBAC que ayuda a estas familia en nuestra comunidad al (860) 673 – 4310 o a;

Rosa Guzman, Intersectora de la familia
Manchester Head Start
57 Hollister Street – Manchester, CT 06040
(860) 647 - 5045

TWO YEAR OLD GIRL IN NEW BRITAIN

A New Britain family of a two year old girl with spina bifida are interested in meeting other families of young children with spina bifida. If you're interested in getting acquainted, please call Lisa at (860) 225-9947.

EMPLOYMENT ASSISTANCE NEEDED

The SBAC has an adult member with spina bifida living in Windsor that is looking for employment in the receptionist/clerical field. Due to transportation issues, she needs to confine her search to the Hartford, Bloomfield, Windsor area.

If you have information that might be helpful, please call Barbara at (860) 688-7055.



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Calling All Adults with Spina Bifida!

An "adults-only" group is now being formed under the SBAC. This group will provide support, mentoring, information-sharing, friendship, social opportunities, outings and much, much more. Be among the first to come together and get involved on the ground floor of this unique and exciting opportunity. See page #1 of the newsletter for contact information.