



Spina Bifida  
Association  
of Connecticut, Inc.

## The *Interactive*

A Quarterly Publication Exclusively For  
Members & Friends of the SBAC

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### Northeast Passage: Recreational Opportunities for the Physically Challenged.

Who says there's "nothing to do"? Do you think your opportunities for physical activity are limited because you're a wheelchair user? The folks at Northeast Passage (NEP) in New Hampshire would say: **Non-sense!** Read this excerpt from their mission statement and you'll agree:

*NORTHEAST PASSAGE works to create an environment where individuals with disabilities can recreate with the same freedom of choice and independence as their able-bodied peers. All individuals, disabled or able-bodied, should have the freedom of recreational choices and opportunities to connect with themselves, their families, friends, community and nature.*

**Try Cycling!** NEP's Cycling program gives individuals the opportunity to ride with others that have similar interests and allows for a social contact.

**What about Water skiing?!** With trained staff and volunteers people of all abilities can experience the freedom of water skiing on our adaptive skis.

**How about Sled Hockey?** The competitive Sled Hockey program gives disabled athletes the opportunity to enjoy the great sport of hockey with other athletes across the United States.

Wheelchair sports including

**rugby, lacrosse, basketball, football, and racquetball** are all played throughout the year. Sport specific equipment is available and allows friends and family to join in as well.

**Always wanted to try SCUBA diving? Now is your chance!** Underwater diving is not only intriguing but accessible. NEP runs yearly SCUBA trainings, certification courses and trips to explore the sport.

**Golf anyone?** The NEP Golf program offers individuals the opportunity to get back out on the links with use of adaptive clubs and carts.

**Take a Hike!** The opportunity to get out into the woods, a national park, or a backyard is a right everyone has. NEP makes this possible for people with physical disabilities with the use of adaptive equipment.

**Cross Country Skiing** allows participants the peace, tranquility, and excitement able-bodied skiers have with the use of adaptive skis. NEP provides the equipment to get out with friends and family and exercise in the New England country.

Whether it's for you or your child with spina bifida, the op-

portunities for recreation and friendship through NEP's programs is boundless. Contact them today to find out more about their programs and schedule. Here is the contact information:

Northeast Passage  
Hewitt Hall, 4 Library Way  
Durham, NH 03824  
Email: [Northeast.Passage@unh.edu](mailto:Northeast.Passage@unh.edu)  
Telephone: (603) 862-0070

Inside  
This Issue:

## A Letter From The President – Kiley Carlson

Greetings,

I would like to thank all of the members who attended our annual meeting on February 8<sup>th</sup>. We elected two new board members, Jerry Carriera from Wallingford and Rob Nevers from Unionville. These gentlemen, both of whom are living with spina bifida, will bring a much needed element to our board, and we enthusiastically welcome them.

Members also accepted proposed changes to our bylaws, the guidelines by which the board manages the organization. Eighteen, much needed, changes were made to this document. This was the first time, in the

eleven years since they were first accepted, that the bylaws were changed. Many were simple changes, but some were very important to keep in line with the way the organization has changed since 1992.

The board thanks you for accepting these changes and allowing us to fulfill our duties to the SBAC and its members.

- Kiley

## WANTED: Used Rabbit

Check your basement, look in the attic – do you have a “rabbit” hiding in your house? If so, we have a 20-month-old girl with spina bifida that is looking for a “**Snug Seat Rabbit**” mobile stander for her physical therapy and, sadly, her insurance company will not pay for one. Using the mobile stander she currently has on loan, she’s made tremendous strides in her

mobility and determination, however it needs to be returned to its owner shortly.

If you have something like this that you are willing to donate or loan, please contact Mary Ann Delaney Tuttle, PT, MS, PCS at (860) 870-7701 or via email at: [madtpt@comcast.net](mailto:madtpt@comcast.net).



Best wishes to  
Ryan Pelletier on  
his recovery from  
a recent surgery.

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We welcome comments and suggestions regarding the content or appearance of this 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>.

# Caring For The Caregiver

By, Marybeth Petersen

With record numbers of people acting as caregivers for their chronically ill loved ones, the problem of *Caregiver Burden* is reaching epidemic proportions. Most of the research on Caregiver Burden focuses on people who are caring for their elderly parents or relatives, however, unlike someone who is caring for the elderly in the final stage of their life, being a caregiver to someone with a chronic condition can be more stressful because the person often needs care for their entire lifetime.

While caring for your child or loved one with spina bifida is often your number one priority, as it should be, it is equally as important to care for yourself. I know what you're thinking: "*Why focus on myself when there is so much I need to do for my family?*" Here's some statistics that might surprise you:

- 61% of caregivers suffer from clinical depression – that's 6 times the national average!
- There is a 63% increased mortality rate in caregivers than their peers in the general population.
- About 12% of caregivers become ill or injured *as a result of caregiving*.

The message is painfully clear – **caregivers don't take care of themselves.**

We've all been on an airplane and heard the Flight Attendant's safety speech that includes this directive: "*In the event of a sudden change in cabin pressure, oxygen masks will drop from the overhead compartments. Please put on your own oxygen mask before attempting to assist a child or loved one*". This advice illustrates the importance of taking care of

yourself first, then helping others who need it.

Understanding the importance of caring for you **first** is easier said than done, however! How can you schedule time for yourself with the ever-increasing demands on your time? While it isn't easy, it's crucial; here are some strategies you can try to help reduce the burden on yourself:

## Maintain a life of your own.

Create a list of 10 activities you love doing. Now write down the last time you actually did these things. *Are you surprised?*

Now, schedule time in your day for one of those activities that will take ½ hour or less, like going for a walk or reading a paperback book. Now that the event is on your calendar, treat it as like a doctor's appointment and don't break it!

Once you get a little better at scheduling time for yourself, you might want to schedule a weekly break for a couple of hours. Seek help from family, friends, and community organizations if you need coverage for your responsibilities at home.

## Recognize and care for your emotional needs.

Watch out for signs of emotional distress and stress (losing your temper, crying, sadness, anger, anxiety). Seek professional help or support from your close friends and family when you recognize these changes in your mood. Catch it early! Don't allow yourself to get too "blue" before you seek help.

## Pay attention to your own physi-

## cal health.

- Make time to eat 3 healthy, well-balanced meals a day.
- Get at least 8 hours of sleep a night.
- Exercise as often as possible, ideally 20 minutes per day. Try parking further away from the hospital or doctor's office and enjoying a short walk.
- See your own doctor and dentist according to schedule.

## Examine and attend to your spiritual needs.

Even if you are not affiliated with a formal religion, examining your own personal beliefs can give you inner peace and strength to deal with life's stress. Additionally, speaking with a priest, chaplain or religious figure might allow you to work through your feelings with someone outside your circle of friends and family.

- Accept help when it's offered and suggest specific things friends can do.
- Be open to ideas that promote your loved one's independence.
- Grieve for your losses, then dream new dreams.

The information contained in this article is taken from a recent seminar at the Wolfson Palliative Care Program at New Britain General Hospital, entitled "*Caring for the Caregiver*". If you would like more information on mental health services, you can obtain a referral from InfoLine by dialing "211", by contacting the Counseling Center at your local hospital or New Britain General Hospital at (860) 224-5267, or by speaking with your family physician.

## Hospital For Special Care WAVE Swim Team

Hospital for Special Care WAVE Swim Team members, Mary-Christine Beck, Chelsea Bilodeau, Jaclyn Lanzetti and Lauren Roseman, along with coach Joan Karpuk, attended the Paralympic Academy Catch the Spirit Swim Clinic and Competition in Birmingham, Alabama during the weekend of January 16th - 18th.

The instructors of the swim camp were paralympian athletes who offered campers first hand instruction on swim techniques. The final day of camp consisted of a USA Swim Meet during which all swim members excelled.

Congratulations to the WAVE for their continued success!

to welcome Stephanie Hebert as the newest member! Additionally, the WAVE thanks Hospital for Special Care for their continued support and encouragement.



The WAVE would also like

## The Spina Bifida Research Resource: Researchers Explore the Causes of Spina Bifida

*Just a reminder - In our September 2003 newsletter, we provided information about a research study. The study is actively seeking participants and would love to hear from interested individuals and families.*

Laura Mitchell, Ph.D. with the Center for Environmental and Genetic Medicine, Institute of Biosciences and Technology, Texas A&M University System Health Science Center in Houston, and Steven Whitehead, D. Phil., with the University of Pennsylvania School of Medicine in Philadelphia have joined forces to **identify the causes of spina bifida**. However, they cannot achieve this goal alone – in-

dividuals and families must become involved to accomplish this important objective.

Those who participate in the Spina Bifida Research Resource (SBRR) will be asked to complete an interview and some family members will be asked to provide a sample of their DNA. DNA can be provided from a blood or cheek cell sample. Samples of cheek cells can be painlessly obtained by rubbing the inside of the cheek with a small brush. The DNA will be used to study genes that may be related to spina bifida.

There are no costs associated

with joining the SBRR and no travel is required. Participants will receive a newsletter at least once a year that provides information about the research being done by the SBRR and other organizations.

You may learn more about the SBRR at their website (<http://www.sbrr.info>) or contacting the SBRR Project Coordinator:

**Barbara Weyland, MPH**  
(713) 677-7573  
**1-866-521-SBTX (toll free)**  
bweyland@ibt.tamu.edu

## Annual Meeting Re-Cap

The SBAC held its Annual Meeting on Sunday, February 8<sup>th</sup> at New Horizons Village in Unionville. A dozen members and their families attended the event. Everyone enjoyed the camaraderie while munching on yummy pizza and homemade desserts.

After lunch, the children were treated to a visit by “Robo the Clown” whose antics kept them in stitches! While the children were being entertained by Robo, the adults conducted a meeting to discuss the business end of our organization.

Kiley Carlson, President & Treasure, discussed the events of the prior year and gave the membership a glimpse of what the SBAC

has planned for 2004. A vote was taken and the proposed changes to our bylaws were passed unanimously. There were four open positions on the Board; two current members, Anthony Lanzetti and Marybeth Petersen, were eligible to serve another term and were elected to serve for another two years. The remaining two vacancies were filled by when Rob Nevers and Jerry Carriera were each elected to serve a two-year term (see the “Spotlight” on Rob and Jerry on page \_\_\_\_).

Before the meeting was adjourned, Kiley presented a very special award to Darlene Bilodeau who has long served as the Coordinator of the SBAC’s Bowl-a-Thon. Darlene was awarded the “Golden Bowling Pin”

award as special recognition for her years of tireless dedication, hard work and devotion to the Bowl-a-Thon. Darlene has displayed unwavering support of our organization and has been planning the Bowl-a-Thon for the past 5 years! An incredible amount of work goes on behind the scenes to plan this event and Darlene’s attention to detail and devotion what has made the event so successful for us! Her careful planning and meticulous record keeping will ensure the success of future Bowl-a-Thons for years to come!

Thank you, Darlene!

**See photos from the Annual Meeting on page \_\_\_\_.**

## How To Compare & Choose A Nursing Home

Until now, finding one source for unbiased information and data to make an informed decision about choosing a short or long term care nursing home was nearly impossible, but now there is help.

You can use the internet to access detailed information about the past performance of every Medicare and Medicaid certified nursing home in the country. You’ll be able to search by *Geography* (all nursing homes in a particular state),

by *Proximity* (within a certain number of miles) or by *Name* of the facility.

Some of the information you will find is number of nursing staff hours per resident, per day, you’ll find out if there is an on-site hospital facility, important contact numbers, and much more. You can also view recent inspection reports of the facility and the findings including a grading system comparing the facility against the average for the state.

To access this information, go

to: [www.Medicare.gov](http://www.Medicare.gov) and follow the links to “Nursing Home Compare”.



## Swimwear For The Incontinent Person

Summer is coming (*yes, it really is!*) and for many, our minds turn to warm, sunny days lounging by the pool or beach. Lack of affordable or suitable swim diapers shouldn't keep you and your family from enjoying these activities this summer! Here are a few resources to help you find the appropriate incontinent swimwear:

**Disposable swim diapers** are available at most grocery and drug stores and have several pro's and con's. Disposables offer throw-away convenience but are expensive – a package of 10 diapers sells for between \$7 and \$9. They are only available in the pull-up style, which can be difficult to put on someone who has difficulty standing up. This is a good solution for traveling or the occasional trip to the beach.

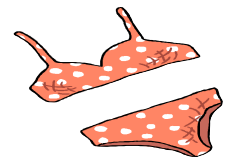
**Reusable, washable swim diapers** are sold at some specialty children's clothing stores and in mail order catalogs or on-line retailers. This type of swim diaper is available in the traditional pull-up style and in a style that is fastened around the body with Velcro (similar to how diapers are wrapped around) which is much easier to put on people with mobility issues. These diapers can be machine-washed and line dried and come in many colors and prints. They are re-useable, and offer an affordable option.

Here are two resources for reusable swim pants. There are many more available on line by searching for "Incontinent Swim Products":

One Step Ahead Catalog online: [ONESTEPAHEAD.COM](http://ONESTEPAHEAD.COM) or toll-free: 1-800-274-8440

"Potty Training Stuff" online: [POTTYTRAININGSTUFF.COM](http://POTTYTRAININGSTUFF.COM) or call: (706) 855-7059

**Incontinent adults** may have more difficulty finding appropriate swimwear, however, [SWIM-DIAPERS.COM](http://SWIM-DIAPERS.COM) is one site that sells swimwear for adults. Although you may not find this style particularly fashionable, it can be discreetly worn underneath traditional swimsuits. Their products are available ranging between 24" and 41" waist size. If you don't have internet access, call them at: 1-888-4GABBYS.



## Easter Seals Camp Hemlocks

From campfire sing-a-longs and late night ghost stories, to boating, nature walks, swimming, and arts and crafts, **Easter Seals Camp Hemlocks** provides the same excitement and activity available at other camp programs.

*The difference?* Easter Seals campers experience the joys and challenges of camp in an inclusive fully-accessible setting.

Independence, creativity, and learning in a setting without barriers. These are just some of the goals of Easter Seals Camp Hemlocks. Camp Hemlocks is the place where people of all ages with various disabilities conquer their fears, realize their dreams and strive to reach their highest potential in an environment that encourages independence and self-reliance. Easter Seals Camp Hemlocks, located on 160 acres of unspoiled woodland surrounding Jones Pond in Hebron,

Connecticut, is a modern, barrier-free facility combining the use of cedar/pine and glass to help blend the outdoors and indoors in an accessible environment.

Originally established in 1950 in Trumbull, Connecticut, Camp Hemlocks relocated to its present site in 1974 to facilitate greater numbers of campers from Greater Hartford and other areas of the state. Camp Hemlocks serves the entire state of Connecticut and the greater northeast region, currently welcoming more than 600 campers throughout the summer months to a variety of programs. Camp Hemlocks fills the recreational gap for citizens of all ages with disabilities and gives them a place where they can experience the outdoors without physical barriers.

Campers choose from a wide variety of social, recreational and educational activities during their stay. Favorite activities include

talent shows, arts and crafts, outdoor living skills, boating and fishing, a new challenge education course, and computer instruction using adaptive equipment. Swimming also plays an integral part of camp. Campers are allowed, sometimes for the first time in their lives, to move without restriction in our fully accessible heated indoor pool. It is here that through simply having fun, campers find the supportive atmosphere in which to stretch their limits and reach new personal bests.

*To obtain more information about the programs offered by Easter Seals Camp Hemlocks, contact: Sunny Ku, Director of Camping and Respite Services by calling (860) 228-9496 Ext. 101 or via e-mail at: [sku@eastersealsoftct.org](mailto:sku@eastersealsoftct.org).*

# Spina Bifida & Tethered Cord

By, Wendy Garizio

One concern of parents who have a child with spina bifida is that the child will develop tethered cord. This can be a concern to adults with spina bifida also, but it is much less likely that an adult will develop tethered cord. Myelomeningocele remains the main cause of spinal cord tethering. Other causes include the related spina bifida occulta, lipoma (fatty tumor - called a lipomyelomeningocele if the tumor extends into the spinal cord), intrathecal dermoid, (a cyst containing skin or hair that extends into the spinal column), or haemangioma (a tangle of abnormally formed blood vessels.)

The spinal cord should float freely in its bath of cerebrospinal fluid within the spinal column. Normally, the spinal cord ends at approximately level L2. Tethered cord occurs when scar tissue forms on the spinal cord, adhering it to another structure and stretching it as the person grows. Since all people form scar tissue to one extent or another and since all children with myelomeningocele have surgery to close their lesion, all children with myelomeningocele (MMC) have tethered cord. Additionally, although many have tried preventing tethering by altering MMC repair techniques, none have been successful thus far. Attempts to minimize scarring include using "slippery" biologic materials or grafts such as Silastic, Gore-Tex™, AlloDerm®, and artificial dura, among others. Also, the abnormal bunch of nerve fibers (called the neural placode) present at the end of the spinal cord of a baby with MMC can be repaired in a way to make tethering less severe, or even make untethering surgery less difficult later on. The big question is, then, when is intervention necessary. On MRI and

other diagnostic scans, tethered cord is noted whether the person is having symptoms or not.

Symptoms of tethered cord include a change in orthopedic status such as new difficulty walking, a leg dragging which previously was not, a foot or leg turning out or in, sudden tightness in muscles of the legs, numbness, tingling or pain, or worsening scoliosis. Gastrointestinal/Urologic symptoms include leaking urine between catheterizations, urinary retention, frequent or more frequent urinary tract infections, changes in urologic tests (such as urodynamics) or a change in bowel control or worsening constipation. A person can also experience pain over his lesion site, back pain or even changes in the strength of the arms. Spina bifida is not a degenerative disease, therefore any deterioration in function should be evaluated for the cause. Even if the reason for deterioration is not tethered cord, often it is something treatable, and not treating can unnecessarily cause permanent loss of function. Tethering usually occurs at or just after a time of growth spurt, so it is unusual for very young children to need untethering surgery. There is concern in the medical community that fetal surgery may cause earlier tethering, as the surgery is done on a fetus before a major physical growth period (the last few weeks of pregnancy and into the first year of life.) At this point it is also important to note that shunt malfunction can also initiate symptoms which mimic tethered cord symptoms. A thorough neurosurgical evaluation must be done before the decision to have the surgery is made.

Prior to surgery, the person will usually have an MRI, in order to determine if there are any other

problems which also need to be addressed, such as a syrinx (fluid filled pocket in the spinal cord), dermal sinus tract (opening to the surface), or a dermoid tumor. The untethering surgery takes several hours. It is a delicate procedure due to possibility of further nerve damage. The back is opened, usually in the lumbar-sacral area since that is where most tethering occurs. The spinal cord is exposed by opening the dura (covering over the cord), the scar tissue is removed, and the cord and nerves are detached from the surrounding tissues (untethered.) During the surgery, the neurosurgeon may use electrical nerve stimulation to identify the different nerves in order to protect them. There is also some use of intraoperative urologic testing to ensure a successful untethering. At this time any other problems such as syrinx, cysts or tumors are removed, shunted or otherwise appropriately treated.

Complications include nerve damage, re-tethering due to new scar tissue formation, recurrence of cysts or tumors and leakage of cerebrospinal fluid (CSF.) To help prevent CSF leakage, sometimes a patch is used on the dura and the person usually has to spend from 24 to 72 hours on bedrest. Other postoperative complications include the usual ones that accompany major surgery. There may be a restriction of activity for several weeks and intensive physical therapy may be needed. The person is monitored for changes in neurologic function.

*Continued on Page 8...*

Once again it must be noted that MRI and other scans will show re-tethering, but the key is to decide if there are symptoms associated with

## Yummy, High-Fiber Recipe

What food is often thought of as a fruit but is really a vegetable? Here's a hint: it also contains zero calories, no fat, no cholesterol, no sodium and provides 2 grams of fiber, 8% RDA of calcium and 10% RDA of vitamin C per 2/3 cup serving? *Give up yet?* It's rhubarb!

Adding fiber to the diet of a person with spina bifida is an important part of overall good health. However, did you ever try to get a child to eat stewed rhubarb? **Good luck!**

However, here's a recipe from Kraft-Foods.com™ that's simple to prepare and provides fiber and counts as a serving of vegetables.

It's guaranteed to be enjoyed by everyone in your family – just don't tell them that it's rhubarb!

### Strawberry Rhubarb Cup Dessert

#### Ingredients:

1 lb. Fresh rhubarb, cleaned, cut into 1/2" thick slices.

1/2 cup sugar

1 package (4 serving size) Jello-O Brand Strawberry Flavor Gelatin

#### Directions:

Combine rhubarb and sugar in a large saucepan. Stir in 1 cup of water. Cook and stir on medium heat until mixture comes to a boil, then continue to boil for 2 minutes. Remove from heat. Stir in gelatin until completely dissolved. Pour evenly into 7 dessert cups. Refrigerate for 3 hours or until firm. Garnish with Cool Whip and a fresh strawberry if desired.

*Continued from Page 7...*

Once again it must be noted that MRI and other scans will show re-tethering, but the key is to decide if there are symptoms associated with the re-tethering.

The overall incidence of tethering requiring surgery for people with MMC is about 25%. I pray that if you are among that 25%, your surgery is a successful one.

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

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Tethered Cord *Your Child and Neurosurgery* by Fred Epstein, M.D. Edited by Rick Abbott, M.D.

Tethered Cord Syndrome: Questions and Answers by Joseph R. Madsen, MD. Copyright © 1999-2000 Boston Neurosurgical Foundation, All Rights Reserved.

Neurosurgery4kids.com

<http://www.neurosurgery.org/health/patient/answers.asp?DisorderID=75>

A new look at meningocele. (Letter to the Editor) *Pediatrics*, June, 2003, by Gordon Worley.

## Spotlight On: Two New Board Members: Jerry Carriera & Rob Nevers



The SBAC recently elected two new members to its Board of Directors and we would like to take this opportunity to introduce them to you.

**Jerry Carriera** is an adult living with spina bifida. He grew up in Darien, Connecticut and was the first child who used a wheelchair to attend the public school system there. He reports that he was always treated kindly by the other children and was fully integrated into the school curriculum.

Jerry continued his education and earned his BS in Accounting from Sacred Heart University. He has worked as an Accountant for the Connecticut Housing Finance Authority (CHFA) where he assists first-time home buyers. Jerry has wanted to become involved with the SBAC for some time and saw the opportunity to become a board

member as his chance to increase the involvement of our adult members. He hopes to work on projects that will “promote friendship and support”. A worthwhile goal indeed! Welcome aboard, Jerry!

Many of you already know **Rob Nevers** who is an adult with spina bifida who has been a member of the SBAC for several years. He has previously served a term on the Board of Directors and has decided to return to the Board for another 2-year term.

Rob lives at New Horizons Village in Unionville and is a regular at most SBAC events.

The addition of Rob and

Jerry to the Board is a very important step and comes at a time when the SBAC is working hard to get more participation from the adult members of our group.

There is a tremendous need for a support network among adult members to exchange information and ideas as well as provide friendship and camaraderie – but we cannot do it alone!

Won't you help us welcome Jerry and Rob to the Board and share your ideas and enthusiasm with them?

Remember, you don't need to be a Board Member to volunteer your time to the SBAC. **We need you!**

# The *Interactive*

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**THE SPINA BIFIDA ASSOCIATION  
OF CONNECTICUT, INC.**

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