



Spina Bifida
Association
of Connecticut, Inc.

The *Interactive*

A Quarterly Publication Exclusively For
Members & Friends of the SBAC

September 2004

Bowl-a-Thon 2004 is Almost Here!

By, Fred Liguori

WHEN: Sunday, October 24th - from 1:00pm-4:00pm

WHERE: AMF Silver Lanes, 748 Silver Lane, East Hartford, CT

WHY: To have some fun, see some friends and hopefully raise lots of money!

The Bowl-A-Thon is SBAC's one, and only, fundraising event of the year. The SBAC helps keep you informed through mailings of quarterly newsletters and website updates. We provide financial support through medical allocations and camperships to those who apply, and scholarships to those who apply and are selected. We work hard to promote public awareness of spina bifida and we are putting increased emphasis on organizing social events for our members. These are things we feel are essential to the organization and **they all require money!** So please set the date aside, blow the dust off your bowling shoes, get your team sponsored and come out to Silver Lanes in East Hartford on Sunday, October 24th to support the SBAC.

If you haven't already received it, you will receive a Bowl-A-Thon packet in the mail shortly. The format for this year is slightly different. This year we are pre-signing teams of 4 bowlers. Teams can register through Tuesday, October 19th. You can sign up your team by mail, by email or by phone. The bowling start times are 1:00pm and 2:30pm and will be awarded on a first come first served basis. The minimum amount for sponsorship is \$100 per team, although we hope teams will exceed the minimum. Please remember to sign up your team not-later-than Tuesday, October 19th.

We look forward to seeing you on Sunday, October 24th for BOWL-A-THON 2004!

Should you have any questions, please contact me at (860) 653-1976.

Inside
This Issue:

A Letter From The President – Kiley Carlson

Hello Everyone. Well, it's September already. The end of summer, the kids are back in school and time to change the calendar on the SBAC's business year.

As October approaches we are working on our annual bowl-a-thon fundraiser. I encourage all of you to participate in this fun day of bowling while helping to support the SBAC's programs. We have some changes in store for you to make for a great day.

As our new fiscal year begins we also have some business to take care of. We will be holding our annual membership meeting with elections to the Board of Directors. Come out to hear what we have done this past year, what we have planned for the future and cast your vote and weigh in on the issues. Make your voices heard. If you or someone you know is interested in running for a directors seat, please contact us for more information.

It is also time for our annual membership drive. Your membership is important to the SBAC. As a voice of the spina bifida community, being able to say we represent a certain number individuals and families can really make a difference when doing advocacy or applying for funding for our programs. Check your mail for information on both of these important events.

As always, if you have any questions or comments, I encourage you to contact the SBAC. You can also get updates by logging on to our award winning website, SBAC.ORG.

I hope all of you will be able to attend our upcoming events. I look forward to seeing you.

Kiley

If you use "Normal Saline" for bowel irrigation and have been buying the solution pre-mixed you will know it can be very expensive. You may be able to make your own normal saline using the following recipe, the chemical composition is the same as the solution you purchase. *However, always check with your physician before you make any change to your bowel management program, including using this formula.*

Normal Saline – Homemade Recipe

Measure exactly 2 teaspoons of salt and add to 1,000 cc's of water and mix well.

(Note: 1,000 cc = 32 ounces = 1 quart = 1 liter)

Store the solution in a clean container, tightly capped and out of direct light. Use solution within 3 days.

Use a metal measuring spoon only – plastic can warp in the dishwasher which distorts the measurements. You may use tap water but do not use well water. If you wish, you can purchase distilled water. "Level off" the salt measurement to get an exact teaspoon.

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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>.

Full-Moon Madness Returns At Margarita's Restaurant in Branford



Margarita's Restaurants (with locations in Branford, East Hartford, Mansfield, Mystic, and Canton) have been very generous supporters of the Spina Bifida Association of Connecticut. To date, the restaurant group has donated over \$4,500 in support of our programs and generously hosted our group for a fun social outing in July (*see page _____ for photos and details*).

Once again, Margarita's Restaurant & Watering Hole on East Main Street in Branford will be holding it's Full Moon Margarita Madness party to benefit the SBAC. If you've never been to a Full Moon Margarita Madness Party, you've been missing out on a great time! The party has giveaways of items from T-shirts and gift certificates to DVD players, snowboards and everything in-between. There are food and drink specials throughout the evening and best of all: 5% of the entire evening's gross lounge sales are donated to the SBAC.

Make a point to attend at least one of the following Full Moon Madness events at the Margarita's located at 377 East Main Street in Branford and be sure to thank the friendly staff for making the event possible:

Tuesday, September 28
Wednesday, October 27 and
Friday, November 26th

Halloween Costumes

By, Marybeth Petersen



Anyone who knows me knows Halloween is one of my favorite holidays. I often joke that the reason I had children was so I could make Halloween costumes for them! (Which is, of course, only *partially true*!)

When our daughter, Katherine, was born with spina bifida we were forced to become more creative with her costumes to accommodate her bulky braces and ever-present walker; obviously the average magazines and books didn't have any ideas for us. In doing some on-line research I found a website that has photos for over a dozen costumes for children with walkers, crutches or in wheelchairs. The site also has a resource area complete with downloadable instructions for making each costume. Perhaps you will find an idea for your child's costume as well. Here is the web address:

http://www.bridgeschool.org/about/about_halloween.html

We would love to receive photos of your child's creative Halloween costume to share with the membership via publication on our website and future newsletters. Please send your ideas and photos to the SBAC at P.O. Box 2545, Hartford, CT 06146 or e-mail to: Marybeth@SBAC.org.

If The Shoe Fits . . . Selecting Proper Footwear



Shopping for back-to-school attire is often challenging: from the cost of outfitting growing children to the perennial arguments between parent and child over what is an “appropriate” style of dress! However, when your child has spina bifida and wears braces it can be even more difficult to find fashionable, affordable shoes that will fit properly without causing skin breakdown issues.

Here are a few common-sense tips on selecting proper footwear that should make your shopping experience a bit easier:

- Feet swell during the day. Plan to shop for shoes late in the day to accommodate any normal swelling.
- Make sure your child wears a clean pair of socks that are the normal thickness he or she wears – no thinner or thicker than usual.
- Try on both the left and right shoe (see below for information on mis-match shoe sizes).
- If your child can stand up, have him do so when trying on the shoe. Place your thumb at the tip of the child’s big toe and ensure that there is at least ½” of space between the toe and the tip of the shoe.
- Allow for some wiggle-room on width. Shoes should fit securely but not tightly.

Once you have selected your footwear consult your child’s Orthotist with any questions on proper fit. Most Orthotists will schedule time to see you and examine your child’s new shoes for proper fit over bracing.

If your child has a discrepancy between shoe sizes on either foot, you might consider contacting Nordstrom’s Catalog Division to take advantage of their “Split Shoe Service”. According to a representative at Nordstrom they “offer a split shoe service for individuals who have a 1 1/2 size difference in their shoes. Split shoe orders cannot be placed on the website, so you will need to call your order into our catalog division at 1.888.282.6060.”

Sources: Kansas State Research & Extension; ARA Content.

Backpack Safety

Much has been reported in the news lately about children carrying too much weight in their backpacks and suffering health problems as a result. For children with spina bifida, in particular, the added weight from a backpack can exacerbate some of their symptoms and lead to fatigue.



A new style of school bag on the market in recent years is one that can be worn like a traditional backpack but also has wheels and a handle so the bag can be pulled (similar to airport luggage). However, many of our children cannot use this type of bag because it requires you have a free hand to pull the bag and their hands are busy with crutches or a walker. If your young child can walk without crutches or a walker this type of bag is a good solution.

According to Dr. Jeffrey D. Thomson of Connecticut Children's Medical Center in Hartford, "*Common sense is the best advice to follow*" in selecting a backpack for your child. Here are a few of Dr. Thomson's suggestions to keep in mind regarding use of backpacks:

- Limit the backpack to no more than 15% of the kid's weight.
- Wear it properly. Make sure both shoulders straps are used and that they keep the backpack at the correct position relative to the back. Use the waist belt if provided.
- Don't carry unnecessary stuff. Those extra items the kids carry, such as key chains, can add on significant weight.
- Buy a lightweight backpack.
- Pick up the backpack using your knees and hips. Also, don't stand at the bus stop wearing the backpack while waiting for the bus. Take it off if you will be stationary for more than a few minutes.

A common misconception, according to Dr. Thomson, is that backpacks cause scoliosis. He says, "*Backpacks do not cause scoliosis. Heavy backpacks can be associated with back strain but one of the most common injuries from backpacks is that the child actually trips over the backpack when it is on the ground.*"

To read more on backpack safety and spine health Dr. Thomson suggests: "*There are many websites that have good and bad information. One of the better websites is www.spine-health.com but even this one suggests that backpacks cause scoliosis. Overall it has good suggestions and it is easy to read.*"

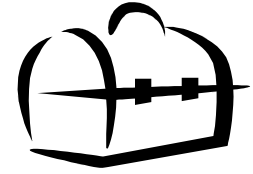
BACK-TO-SCHOOL

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BACK-TO-SCHOOL

Packing Healthy Lunches



BACK-TO-SCHOOL

In response to the alarming rate of childhood obesity and juvenile diabetes in this country, there has been a huge movement to make school lunches healthier. In addition to changing the school lunch menus, many schools have completely banned soda and snack machines. It seems that schools are just catching up with what Moms and Dads have always known: *you are what you eat!*

BACK-TO-SCHOOL

For individuals with spina bifida, healthy eating is important for other reasons: reducing obesity due to being sedentary or less active than peers and increasing fiber intake for a healthy digestive system. While it may be difficult to find healthy alternatives to kid's favorite snacks and lunchbox choices, it isn't impossible if you make small changes. Here are some suggestions to add nutrients and fiber while lowering fat and sodium content:

BACK-TO-SCHOOL

Instead of:

Canned fruit cup

Cookies

"Fruit" snacks

White bread

Plain tuna salad

Plain chicken salad

Potato chips

Try This:

Fresh grapes for increased fiber, or freshly cut fruit with skins on. (*No time to cut up fruit?* Look in your supermarket's salad bar for pre-cut fresh fruit).

Trail mix or granola bars (homemade or store bought)

Real fruit "leather" roll-ups contain natural sugars, vitamins and fiber.

Whole wheat pita pockets or whole wheat bread.

Add cut up celery for increased fiber.

Add grapes cut in half & chopped nuts for added fiber, flavor and protein.

Flavored rice cakes or whole wheat pretzels for a high fiber, low fat treat with crunch!

BACK-TO-SCHOOL

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BACK-TO-SCHOOL

Packing Healthy Lunches (*continued*)

Kids love Lunchables (the pre-packaged meals with lunch ingredients in small compartments) but the fat and sodium content are astronomical. On average, these packaged meals derive about 67 percent of calories from fat (about 35 grams of fat, including 17 grams of saturated fat) and 1,670 mg of sodium! Instead of choosing these pre-packaged meals, try packing inexpensive food storage containers with compartments and make your own Lunchable (or “Mom-able”) using some of these suggestions:

- Whole wheat crackers, cheese cubes and fresh fruit.
- Cut up veggies with blue cheese or ranch dressing for dip.
- Strawberries with chocolate dipping sauce.
- Whole wheat pita bread cut in squares with hummus spread.
- Pretzels with mustard or cheese dip.
- Fruit with a dip made of 1 part Cool Whip and 1 part fruit flavored yogurt mixed together.

If your child craves the candy bar that is typically added to Lunchables for dessert, buy the small snack-size candy bars and include them for a small treat to be eaten after a healthy lunch.

Nutritionists agree that changing unhealthy eating habits takes time. Don’t rush the process and risk having it fail. By introducing new foods slowly; for instance, mix whole-wheat pasta with enriched-pasta or slowly changing from whole milk down to 2% and ending with 1% or skim. If the changes are made over a period of time, it is less likely your children will reject the new foods and accept the healthy changes.

By getting the entire family involved in selecting healthy foods at the store and preparing meals at home, you will learn more about their likes and dislikes and discover together how you can make better choices. Good Luck!

Aging & Spina Bifida

By, Wendy Garizio

From gerontologists to Geritol, from wrinkle cream to hair coloring, from ginkgo to Viagra, from, well, you get the picture. Aging is big business. It's also a complicated business, and even more so if you have an underlying diagnosis such as spina bifida. One of the biggest problems is that adults with spina bifida used to be children with spina bifida that were treated for the most part at clinics where the care of many specialists was coordinated. There are few adult SB clinics, and there are few doctors who are knowledgeable about SB as it was considered a pediatric condition. We all know that the invention of the shunt and other medical advances, along with greater societal acceptance of people with disabilities has ensured that the adult SB population is growing.

People with spina bifida deal with many of the issues of aging long before they get old. Urinary incontinence and constipation, immobility and independence issues are old hat for those with SB, as compared to peers who are dealing with these things for the first time. On the other hand, having spina bifida gives a person an increased risk of developing problems that might not have occurred otherwise. Michael Marge, Ed. D calls these "secondary conditions" and defines these as "an additional health complication that results from the increased risk created by a primary disabling condition (like spina bifida or hydrocephalus). It is associated with a primary disabling condition and occurs after the primary condition." For example, fractures can occur with greater frequency in people with SB because of bone and muscle weakness and immobility.

Immobility is also the underlying cause of pressure sores, contractures (tightening of the tendons and ligaments) obesity, and osteoporosis. Arthritis can occur prematurely in people with SB especially those with an altered gait who might use their trunk and shoulders to assist with balance and momentum. Muscle loss is a well-known effect of aging. For someone with SB who relies on upper body strength for mobility and transfers, this loss of muscle can be devastating. Worsening scoliosis and bone infections from untreated or slowly healing pressure sores are also areas of concern.

Those with neurogenic bowel and bladder can expect to continue managing those issues as they get older. They have the advantage of knowing their routine and being familiar with which products work for them. As people get older they may be less able to do these things for themselves and face the issue of having to rely on a caregiver, and to familiarize that person with the correct routines. Several bowel and bladder surgeries have come onto the scene within the last few years and the long-term effects of these procedures are not known. These include bladder augmentation surgery and the MACE for bowel flushing. It is also not known what the long-term effects of chronic urinary catheterization or chronic enema use is.

Tethering, shunt failure, chiari brain stem compression and latex allergy are chronic issues of SB and continue to be a concern in the elderly. In particular, shunt failure and chiari compression might be overlooked in an elderly person, if the symptoms included progressive confusion. Careful assessment of any mental status change is warranted. If a detethering, shunt replacement or chiari decompression surgery were necessary, an older person's mere age would make them a higher surgical risk.

Older people with SB are also at risk for heart disease, hypertension, diabetes, stroke and all of the other conditions that everyone else is at risk for. The difference is that people with SB will have higher risk due to their low muscle tone, lack of cardiovascular fitness, obesity and the other problems mentioned above.

Continued on next page . . .

Aging & Spina Bifida (Continued...)

Recommendations include continuation of exercise especially any weight bearing exercise that someone is able to do. The pool is excellent for cardiovascular workouts without the accompanying muscle and joint strain. Adults of all ages are encouraged to do weight training, something attainable for those with SB no matter what their mobility status. All are encouraged to maintain their ideal body weight to avoid the stress and strain of obesity, diabetes, an increased risk of heart disease, stroke and cancer. If someone is using urinary catheterization, they must continue in order to maintain the health of their kidneys. All are strongly urged to remain under the care of a physician, especially one who can work together with any specialists you might have. Physicians and patients need to address the issue of people taking multiple medications and possible interactions between them.

It is important that those who are aging maintain contact with their family and friends. Isolation is a problem for the elderly and those with disabilities may need more frequent checking in on. As with children, illness can come on suddenly in the elderly so people should have a support system in place. I leave you with some quotes on aging.

Inside every older person is a younger person -- wondering what in the world happened.
-Cora Harvey Armstrong-

The hardest years in life are those between ten and seventy.
-Helen Hayes (at 73)-

Things are going to get a lot worse before they get worse.
-Lily Tomlin-

Old age ain't no place for sissies.
-Bette Davis-

Thirty-five is when you finally get your head together and your body starts falling apart.
-Caryn Leschen-

I try to take one day at a time -- but sometimes several days attack me at once.
-Jennifer Unlimited-

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