

# Spina Bifida Association of Connecticut, Inc.

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### ~~THE SPINA BIFIDA~~ ASSOCIATION OF CONNECTICUT, INC.

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## Transition By, Joanne Field

Change is what makes life new and interesting. In this issue of our newsletter you will see that a change has taken place. The newsletter has a new look and we have welcomed a new Editor, Marybeth Petersen. When Marybeth joined our organization and expressed an interest in working on the newsletter, I realized that it was the right time for a transition.

My life has been changing in the time that I have been working within this organization, and on this newsletter. At first it was a shared effort. For the first few years Alysoun Reichardt and I served together as co-editors until she and her family moved to Ohio. In those early years of our organization my husband, Frank, and I were the parents of an elementary school student. We shared many challenges and experiences with other families of children with Spina Bifida in our membership. This newsletter was a wonderful way to communicate information and friendship, which helped us immeasurably. I could not have done it without the technical and personal support of my husband Frank, who gave up many hours of sleep over the years helping me to get the newsletter ready for print.

Now many years and milestones later we are the proud parents of a confident college student. Our SBAC family has also been changing and growing. We have an increasing population of families with young children joining us. I feel that this change in editorship will more effectively serve the needs of our membership.

Frank and I will continue to be involved in the SBAC and to be willing to share our experiences as veteran parents. It is exciting that we have new people, like Marybeth, with talent and energy getting involved in our organization. We look forward, with gratitude and confidence, to seeing the newsletter continue and evolve.

# LETTER FROM THE "NEW" EDITOR

BY, MARYBETH PETERSEN

Hello! I would like to take this opportunity to introduce myself as a new member of the Spina Bifida Association of Connecticut and editor of the Newsletter. I had the pleasure of meeting many of you at the Holiday Soiree and look forward to seeing many more of you at upcoming SBAC events.

My husband, Scott, and I have two children – a two-year old boy named Andrew and a six-month-old daughter named Katherine, who has spina bifida. Katherine's lesion was repaired in-utero at Children's Hospital of Philadelphia in April of 2000 and she was born in July. She's a bright, beautiful child and, together with her brother, fills our lives with joy.

Scott and I feel fortunate to be involved with the SBAC. We've found it to be a community of people from whom we can learn how to manage the challenges of raising a child with spina bifida. Everyone has been quick to share their experiences, lend us an ear, and offer support to us. It has been a tremendous comfort for us to feel so welcome in the organization.

If at any time you have suggestions, comments, or information you would like to have included in the newsletter, or if you just want to say "hello", please feel free to contact me!

## FOOD FOR THOUGHT

A philosophy professor stood before his class and had some items in front of him. When class began, wordlessly he picked up a large empty mayonnaise jar and proceeded to fill it with rocks, rocks about 2" in diameter. He then asked the students if the jar was full? They agreed that it was. So the professor then picked up a box of pebbles and poured them into the jar. He shook the jar lightly. The pebbles, of course, rolled into the open areas between the rocks. The students laughed. The professor then picked up a box of sand and poured it into the jar. Of course, the

sand filled up everything else. "Now," said the professor, "I want you to recognize that this is your Life. The rocks are the important things - your family, your partner, your health, and your children - anything that is so important to you that if it were lost, you would be nearly destroyed. The pebbles are the other things that matter like your job, your house, and your car. The sand is everything else. The small stuff. If you put the sand into the jar first, there is no room for the pebbles, and the rocks. The same goes for your life. If you spend all your energy

and time on the small stuff, you will never have room for the things that are important to you. Pay attention to the things that are critical to your happiness. Play with your children. Take time to get medical checkups. Take your wife out dancing. There will always be time to go to work, clean the house, give a dinner party and fix the disposal." "Take care of the rocks first - the things that really matter. Set your priorities. The rest is just sand."

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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 on the web at : <http://sbac.org>.

## LEGAL VICTORY

The state of Connecticut recently agreed to pay \$100,000 to programs for the disabled and \$2,500 to attorney Michelle Duprey to settle a lawsuit over handicapped parking stickers. Ms. Duprey filed a federal suit in 1996 under the *Americans With Disabilities Act* arguing that the \$5 fee levied by the Department of Motor Vehicles for a handicapped parking tag was discriminatory.



# FETAL SURGERY FOR SPINA BIFIDA

Fetal surgery is a relatively new procedure with only a few hundred attempts worldwide. Because of the risk of inducing pre-term labor and delivering too early in the pregnancy, fetal surgery traditionally was reserved for life threatening circumstances. However, because of the potential benefits of an early repair of the myelomeningocele, doctors feel fetal surgery for spina bifida is worth the risk.

Fetal surgery for spina bifida is intended to decrease the handicaps associated with spina bifida by protecting the fetuses previously exposed spinal tissue from additional damage by the amniotic fluid and intrauterine movement. Doctors are careful to say this procedure is not a cure and will not restore neurological function which has already been lost, but it may prevent additional loss from occurring due to the intrauterine environment. As an added and unexpected benefit, it was discovered that the procedure apparently affects the way the brain develops in utero, allowing the Arnold Chiari Malformation, typically associated with spina bifida, to correct itself.

"It's extraordinary that the malformation goes away," Dr. Scott Adzick told the Philadelphia Inquirer. Dr. Adzick continued "Research appears to indicate that children whom have had fetal surgery for

spina bifida, are less likely to require a shunt. Perhaps a 33% to 50% reduction in the need for shunts.

"No shunts or fewer shunts is a significant benefit to patients, hospitals and insurance companies," says Dr. Joseph P. Bruner, director of fetal diagnosis and therapy at Vanderbilt. "It will decrease the overall rate of hospitalization and care these children receive."

## ***"FETAL SURGERY FOR SPINA BIFIDA IS INTENDED TO DECREASE THE HANDICAPS ASSOCIATED WITH SPINA BIFIDA"***

Certain risks must be considered with any surgery. In fetal surgery, there are separate risks for the mother, and for the fetus. Risks to the mother may include, infection, blood-loss leading to transfusion, gestational diabetes, weight gain due to bed rest. The mother can assume that all future pregnancies will need to be delivered via c-section.

Of all the risks to the fetus, the risk of complications due to premature delivery tops the list. Depending on the gestational age at delivery, premature babies are at risk for lung immaturity, blood transfusion, brain hemorrhage, organ

immaturity, and the risk of death. Because fetal surgery for spina bifida is so new, unforeseen, unimaginable, and numerous unanticipated other problems could arise.

Simply put, fetal surgery for spina bifida requires the mother to undergo surgery to expose the fetus. Then a neurosurgeon carefully closes the lesion on the baby's back. The procedure of the closure is very similar to the one performed after birth. The fetus is then closed back inside the womb, the mother is sewn up, and the pregnancy continues.

Fetal surgery for spina bifida is currently being performed in only three institutions in the world: The Children's Hospital of Philadelphia in Pennsylvania and Vanderbilt University in Nashville, Tennessee, and University of California in San Francisco.

*Information in this article is reprinted from Todd Gardner's website: [www.Fetal-Surgery.com](http://www.Fetal-Surgery.com). Visit his website for the most requested photos on the web, photos of the fetal surgery, links to the doctors performing the surgery, and much more!*

# EMERGENCY INFORMATION FORM

The American College of Emergency Physicians recently released a significant document for parents of children with special health care needs: **The Emergency Information Form (EIF)**. The form is designed to give emergency room physicians immediate access to a child's medical history, diagnoses, past procedures, and physicians and specialists. The EIF will ensure that a child's complicated medical history will be available when it is needed the most – in an emergency. The form can be downloaded, filled in by the parent and child's doctor, and will then be kept on file by the Medic Alert Foundation (*annual membership in the Medic Alert Foundation is required.*) Once the document is on file with Medic Alert, it can be faxed anywhere in the world, 24 hours a day. To obtain a copy of the form for your child or for more information, visit the following website: [www.medicalert.org/eif.html](http://www.medicalert.org/eif.html) or telephone the Medic Alert Foundation toll-free at: 1-888-633-4298.

# PEN PAL PROGRAM FOR KIDS WITH DISABILITIES

The *Children's Hopes & Dreams Foundation* is sponsoring a pen pal program for children with disabilities. If you are interested in pairing your child with another child of the same sex, age, and illness category, send a letter containing the following information: child's first and last name, address, city, state and zip to: Children's Hopes and Dreams Foundation, 280 Route 46, Dover, New Jersey, 07801. The child's legal guardian must sign the letter. You can also join by calling (973) 361-7366 or logging on to their website at: [http://spinabifida.intranets.com/register\\_member.asp](http://spinabifida.intranets.com/register_member.asp).

## FREE SAMPLES

Receive two free *Pull-Ups* brand of disposable absorbent underpants and a money saving coupon!

Visit their website at: [www.goodnites.com/offer](http://www.goodnites.com/offer) and fill out a brief survey to receive your free samples by mail.

Receive a catalog and free samples of Youth Briefs from Woodbury Product, Inc. of New York. Call them 24-hours-a-day at: 1-800-777-1111.

## STAY ORGANIZED

Every parent of a child with special medical needs has some sort of filing system for phone numbers and important medical information – just how organized it is, however, is another story! If you are not so happy with your filing system, perhaps you could get some help in creating a Care Notebook from the following web site: <http://mchneighborhood.ichp.edu/CARENotebook/care-notebook.htm>.

You'll find 39 forms you can fill in to help keep track of your child's health care information. Families may use these pages to keep track of appointments and health care, to create a list of their care team and resources, and to create a summary of their child's abilities and care needs.

## PARENTAL SUPPORT GROUPS

One area in which our membership is growing is parents of newborns with spina bifida. Having a new baby, especially one with special health care needs, can be overwhelming. It is of great support, however, to form friendships with people who are in similar situations. One of the best ways to gather together to share information and experiences is through support groups.

If you are interested in joining together with other parents of similar age children, **no matter how old your child is**, please contact Marybeth Petersen at (860) 673-4310, or e-mail: [MBandScott@home.com](mailto:MBandScott@home.com). Groups will be composed of parents whose children are approximately the same age and will meet at member's homes on a rotating schedule to be determined by the group.

*Friendships formed when our children are young are the ones that last a lifetime!*

## HERE COMES THE BRIDE.....

The SBAC has gone to the chapel, twice in one month. As a part of our ongoing public awareness and prevention program, the SBAC set up shop at two bridal fairs, to encourage women to take folic acid to reduce the chance of having a child with spina bifida.

On January 27<sup>th</sup> and 28<sup>th</sup> we were in Hartford at the Connecticut Bridal Expo. This show is one of the biggest and most attended show in the state. Osborne-Jenks Productions has been our host for the six years we have been doing this show. They have given us a reduced price for the space each year. This years show was the best one yet, having handed out over two hundred information packets to brides-to-be and their friends and family.

On February 25<sup>th</sup>, we headed south to New Haven to participate in the KC101 Bridal Fair at the New Haven Coliseum. Clear Channel Broadcasting which operates 3 area radio stations was our host this time, as we shared space at the WELI booth with the Make A Wish Foundation. Radio personality Jerry Kristafer spent some time at the booth with us, greeting the attendants. About seventy-five packets were distributed at this show.

Each year, more and more people that stop by our booth have some knowledge of either spina bifida or folic acid, which is very encouraging.

The SBAC would like to thank Joanne Field, Marybeth Petersen and Ingrid Arrojo and her Mom for helping out at the Hartford show.

## MARK YOUR CALENDAR

### UPCOMING SBAC EVENTS:\*

**April 20th, 21st, & 22nd –**  
Spring Camp-Out at Camp Harkness, Waterford, CT  
See pages 9 & 10 of this newsletter for more details!

**May 30th –**  
SBAC's Board of Directors Meeting  
Holiday Inn, Cromwell - 7:30 to 9:00 PM

**June 25th-27th –**  
National Conference  
Hyatt Regency New Orleans  
*For more information visit: [http://sbaa.org/html/sbaa\\_conference.html](http://sbaa.org/html/sbaa_conference.html)*

**July 9th –**  
SBAC's Board of Directors Meeting  
Holiday Inn, Cromwell - 7:30 to 9:00 PM

**September 15th –**  
SBAC's Board of Directors Meeting and Strategic Planning Day  
at the home of Darlene Bilodeau.  
*Time to be determined.*

**October 12th, 13th, & 14th –**  
Fall Camp-Out at Camp Harkness, Waterford, CT.  
**October 14th –**  
SBAC's Board of Directors Meeting at the Camp-Out.  
Time to be determined.

\* **Note:** All dates and times are subject to change.  
Consult our website: <http://sbac.org> or call Dennis Maloney for the latest dates and times.

## VIETNAM VETERANS

The Department of Veteran's Affairs is again focusing on outreach efforts to identify birth children of Vietnam veterans who have been diagnosed with spina bifida. Currently, only about 800 persons are taking advantage of the VA Spina Bifida Healthcare Benefit. If you know of members in your area who are veterans and who may benefit from this information, please feel free to contact Marsha B. Thomas, Interim Resource Center Coordinator, National Resource Center, SBAA National Office (SBTsbac@aol.com)

## NEED A RAMP?

The Ramp Guy at <http://www.wheelchairramp.org> offers plans for wooden ramps to eliminate barriers at home. The best part of the plan is that ten people, including one with basic carpentry skills, can put one of them up in a day! Log on or write to: Metropolitan Center for Independent Living, 1500 University Avenue W, Suite 16, St. Paul, MN 55104.

## WEB RESOURCES

Ideas & strategies for including youth with disabilities in school-to-work programs:  
[www.sna.com/switp/aed.htm](http://www.sna.com/switp/aed.htm)

Improving student outcomes: promising programs & practices:  
[www.ed.uiuc.edu/sped/tri/aed.pdf](http://www.ed.uiuc.edu/sped/tri/aed.pdf)

Resources & information on engaging employers in school-to-career.  
Features several resources for serving youth with disabilities:  
[www.nelc.org](http://www.nelc.org)

Pass\*IT\*On Program – a national effort to engage youth with disabilities in IT careers:  
[www.ita.org/workforce/programs/passiton.htm](http://www.ita.org/workforce/programs/passiton.htm)

## PAIN-FREE FUNDRAISING WITH SNET!

### Gab on the phone and help your favorite charity!

SNET Community Connections is the easiest way for you to help The Spina Bifida Association of Connecticut raise money! SNET Community Connections<sup>SM</sup> helps the SBAC raise money and gives you a great deal on your own long distance bill at the same time.

If you sign up for the Community Connections plan, The Spina Bifida Association of Connecticut gets 5% of every dollar you spend on SNET long distance calling including in-state toll calls, out-of-state and international long distance calls, even calling card calls.

Already a SNET All Distance customer? No problem. Sign up for SNET Community Connections and keep your existing calling plan or check with SNET to see if there's a better plan for your calling needs.

**There's no extra charge to help your favorite cause.**

*Already signed up?*

Cut out this information  
and pass it along  
to a friend!

## IN MY HUMBLE OPINION

BY, KILEY CARLSON

### To Folic Acid or not to Folic Acid

Whenever you mention folic acid to someone in the spina bifida community, you get a reaction. Some are all for it, some aren't so sure. Even here within the SBAC there is a difference of opinion about how much effect folic acid has in reducing the chance of a pregnancy being affected by a neural tube defect. Prevention is a part of the SBAC's mission, which can cause some conflict with some of the members' beliefs or opinions. So, I am going to try and explain, in the first installment of **IN MY HUMBLE OPINION**, why the SBAC promotes the use of folic acid and how this benefits the association.

In 1992, the Centers for Disease Control (CDC) issued its first recommendations in regards to using folic acid in reducing the incidence of neural tube defects (NTDs). Shortly after, the SBAA issued their own position statement supporting folic acid. Since then, folic acid has become a major campaign. A national task force and campaign has been set up. State task forces have been organized (SBAC is a member of CT's). The March of Dimes has made it one of their largest projects. Some studies say it is also good for your heart and other parts of the body. So, why should the SBAC promote folic acid? One reason: **Folic acid is good for you.** But it isn't as simple as that.

When the SBAC started promoting folic acid it was for two main reasons:

- 1) To reduce the incidence of spina bifida. Plain and simple. I would not wish spina bifida upon anyone and if taking folic acid can help keep a child from being born with, then I am all for it. Now, I know it is not the "CURE ALL" and the SBAC does not present it as such, but in some cases it might help. In order for it to work women have to take it, and it is the SBAC's goal, to inform them of that fact.
- 2) To increase public awareness of spina bifida and the SBAC. If someone does not know what spina bifida is, it is likely that they will NOT want to help the SBAC in any way. Many people still have not heard of spina bifida or if they have, do not know what it is. In order for the SBAC to serve its members it needs resources like money, volunteers, and supporters. Most of these resources are coming from our membership, which is really defeating the purpose. These are the reasons that we must increase awareness of spina bifida and where folic acid comes in to play. By promoting the use of folic acid we increase awareness of spina bifida in general, which in the long run is good for the SBAC.

Now, some may not agree with the whole folic acid thing, and that's OK. But, I hope you will agree that the SBAC has, and will continue to promote folic acid for what it is, an aid to reducing risk, not a cure all and as a way to reach the general public and educate them about spina bifida. **IN MY HUMBLE OPINION.**

## HELP WANTED

This newsletter is *your* newsletter – a forum for you to exchange ideas and share information with fellow members of the SBAC. Have a yummy, high-fiber recipe to share? What about an item you've found to be helpful and want to let others know about? You could even share some of your favorite web sites with us. If you don't have the time to write an article yourself, how about sharing ideas for topics you would like to see covered in the newsletter? We are always open to suggestions and comments!

Please send your tips, ideas, suggestions, etc. to the association's address and mark it "Newsletter" or send it via e-mail to SBAC-NL@home.com.

We look forward to hearing from you!

# **Spina Bifida Association of Connecticut's Annual Pins-For-Grins Bowl-A-Thon**

**Saturday, March 24, 2001**

**12:30 PM – 5:00 PM**

**AMF Silver Lanes**

**748 Silver Lane, East Hartford, CT (860) 569-2990**

**We need people to bowl on teams for pledges  
as well as sponsors and volunteers.**

**The more people that are involved,  
the more money we can raise together for  
important programs that benefit individuals  
with Spina Bifida and their families.**

**This promises to be a fun afternoon for all!  
Even if you don't bowl, find family and friends that do  
and come on down! (The facilities are handicap accessible.)**

**This is our largest and main fundraiser of the year!  
If you've never participated in the past, make this your first year –  
come on down!**

**Back by popular demand, we will be holding a raffle  
with tons of great prizes!**

**There will be a bake sale again this year.**  
Anyone wishing to contribute baked goods or donate some of their time to the bake sale,  
please contact Janet Lanzetti at (203) 481-9669.

**For more information, please contact:  
Darlene Bilodeau at 860-429-0783, Kiley Carlson at 860-429-0783,  
Dennis Maloney at 860-464-2512, or the SBAC at 1-800-574-6274.**



## SBAC Camp Harkness Spring Weekend

**Friday, April 20 (after 6 PM) – Sunday morning, April 22, 2001**

**Camp Harkness For The Handicapped**

301 Great Neck Road - Waterford, CT - Phone: (860) 443-7818

Our Spring Outing is coming! Save the date and plan on bringing the whole family! There's lots of fun to be had and memories to be made. Here's a brief outline of the festivities and a preview of the yummy food we'll have. We'll see you there!

**Friday:**     **Dinner** (after 6:00 PM): Sandwiches and cold salads.

**Saturday:**   **Breakfast:** Marco's popular hot breakfast from the grill including pancakes, eggs, bacon, toast, muffins etc.

**Lunch:** Cold or grilled sandwiches and cold salads.

**Afternoon Festivities:**\* (2:00 to 5:00 PM): Kid's party including a Candy Egg Hunt and fun crafts.

**Dinner:** Kentucky Fried Chicken, mashed potatoes & salad. Plus your delicious desserts!

**Sunday:**     Continental breakfast and clean-up before we say goodbye.

If you are on a special diet or prefer different foods, feel free to bring whatever you need from home. Refrigerator and cabinet space is available and all food brought from home must be clearly labeled with your name.

**PLEASE RSVP BY PHONE BY APRIL 6<sup>th</sup>**

to Joanne Field at (860) 528-1510.

In order to plan our events, we will need to know what events you will be attending, how many people are staying overnight and for which nights so we can reserve beds.

*\* For information about Saturday afternoon's festivities you can call Marybeth Petersen at (860) 673-4310.*



## SBAC Camp Harkness Spring Weekend More Important Information You'll Need:

### **What To Bring:** *(Think of this as a camping trip.)*

- ▶ A dessert to share with the group.
- ▶ A flashlight - it's very dark at night going around the camp.
- ▶ Plenty of linens/bedding, or a sleeping bag and a pillow. (No linens will be provided.)
- ▶ Clothing for any possible weather condition (warm coat, hat, gloves, etc.)
- ▶ Medical/personal supplies, medications etc., for the entire weekend.
- ▶ Towels and toiletries.
- ▶ Paperback books, deck of cards, etc. for idle time.
- ▶ Bikes are allowed – but NO roller blades or skates will be permitted!

### **Remember:**

- ▶ You will be sharing cabins with other members of the group.
- ▶ We are near the water and have a campfire at night.
- ▶ **CHILDREN MUST BE SUPERVISED AT ALL TIMES AND ARE THE SOLE RESPONSIBILITY OF THEIR PARENTS. CHILDREN SHOULD NOT WANDER ALONE AS WE ARE NEAR HIGH ROCKS AND THE OCEAN.**

### **Directions:**

From the west: Take 84 East to Route 9 South to 95 North.

From the east: Take 91 South to Route 9 South to 95 North.

From either direction: From 95 North, take Exit 75 and go straight for several miles. Take a right onto Avery Lane (you will see Silva's Package Store as a landmark). Follow signs to Camp Harkness. **DO NOT TURN INTO HARKNESS MEMORIAL PARK.** At the stop sign right after the sign for the park you will take a right for the camp. Then you will take an almost immediate right onto a small road. (There is a blue and yellow sign for the camp but if you come at night it's easy to miss.) Follow the road up and around until you see the brown cabins. Park in the parking lot near the cabins. Leave your gear in the car. Go to the mess hall a short distance up the road from the parking lot and cabins. Go to the large mess hall building. (You will see a blue car parked outside.) Someone will arrive by 6:00 to unlock everything, set up dinner and help you to get situated. Dinner will still be available for late arrivals. There will be lots of food - help yourself rule for the refrigerator all weekend!

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