

# Spina Bifida Association of Connecticut, Inc.

Volume 2 / 2001

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

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## A Letter From The President By, Dennis Maloney

Greetings All,

This year is off to a fast start. Kiley Carlson put together two well-received awareness events in January and February. Well-done Kiley! In March, we had another successful Bowl-A-Thon, which has grown for the second straight year. Nice job to Darlene Bilodeau for leading and organizing this event! In future newsletters, we plan to interview the three top money donators at this year's event to share their techniques with our membership.

In April, we held our annual Spring Fling campout at Harkness Park. Thanks to Joanne Field for her continued support organizing this campout and to Jill Liguori and Marybeth Petersen for the Arts-and-Crafts and egg hunt.

I'd like to welcome Marybeth Petersen as our new newsletter Editor and say, "Thanks" to Joanne Field for her many years of work with the newsletter. In June, we are sending Fred Liguori and Kiley Carlson as our delegates to the National Conference in New Orleans.

Hope to see many of you at the Margarita's night out in June. For other events this year, check out our website "Schedule of Events" at <http://sbac.org>. Have a happy and safe summer!

Warm Regards,  
Dennis

## The Bowl-A-Thon By, Darlene Bilodeau

Hi everyone! Well, Bowl-A-Thon 2001 is now behind us. If you haven't heard, it was a huge success. We grossed over \$16,000.00 with pledges still coming in. That's over \$5,000 more than last year!

Our thoughts now look to next year's event. As a SBAC Board Member, we have discussed on many occasions how to get more of our membership involved. Bowl-A-Thon 2002 will be your perfect opportunity. Believe it or not, planning should begin in early fall. If every member could bring in at least one sponsor – yes, only one – our annual fundraising event will explode with possibilities. Please give this some thought and we will keep you posted in the coming months.

At this time, most important to me are the many thanks to all of those who helped out behind the scenes and the day of the event. Without you, this event wouldn't have been possible.

I look forward to seeing and talking with you soon.

# SCHOLARSHIP PROGRAM

If you have a child that will be going on to further his or her education in the fall, it's time to start thinking about tuition bills – AURGH! Luckily, the SBAC is here to help with its Scholarship Program!

Included in this edition of the newsletter is a scholarship application form that can be submitted to the Board of Directors for consideration of scholarship monies. It sure can help with those mounting college expenses. Have your college-bound student take this opportunity to apply for these funds today!



**The deadline for application of July 31, 2001.**

# SUMMER CAMP APPLICATIONS

It's that time of year again – the weather has warmed up and the days are getting longer. This can only mean one thing: time for summer camp!

Is your child signed up for summer camp? If so, the SBAC can help you pay for camp fees! This edition of the newsletter contains an application for Campership funds from the Association. Send your completed application, a copy of the camp brochure and a letter of recommendation to the Association mailbox today!

**Deadline for application is July 31, 2001.** Happy Summer!

# MEDICAL ALLOCATION FORMS DUE JULY 31, 2001

Included in this edition of the Newsletter is a form for reimbursement of medical expenses incurred from February 1, 2001 to July 31st, 2001.

This is one of the most important services the Association offers to its members and, in today's economy, can make a big difference in many families' budgets.

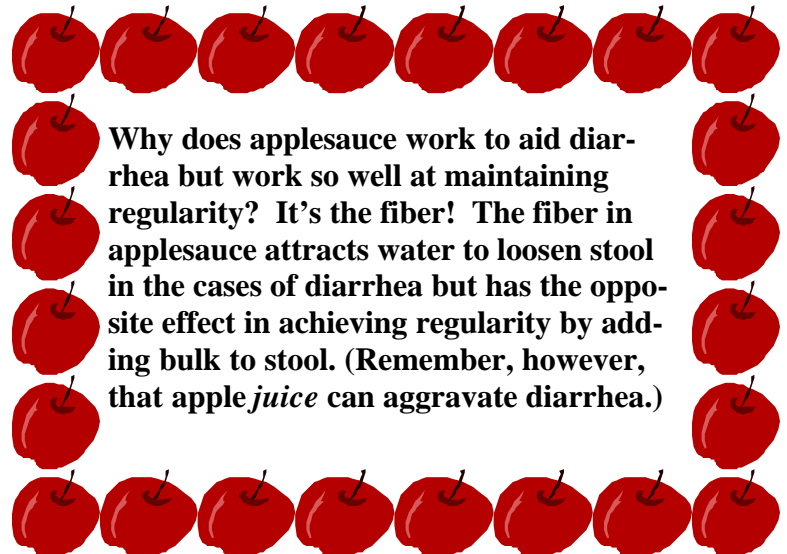
The process of application and reimbursement is confidential and open SBAC members only. Completed applications must be postmarked no later than **July 31, 2001**. Questions on the allocation process or eligibility should be directed to Janet Lanzetti at (203) 481-9669.

The Newsletter is published quarterly by the Spina Bifida Association of Connecticut, Inc. P.O. Box 2545, Hartford, CT 06146-2545. Subscription rate is \$15.00 per year. The Spina Bifida Association of Connecticut, Inc. is a non-profit corporation. Board meetings are held quarterly at the Holiday Inn in Cromwell, CT.

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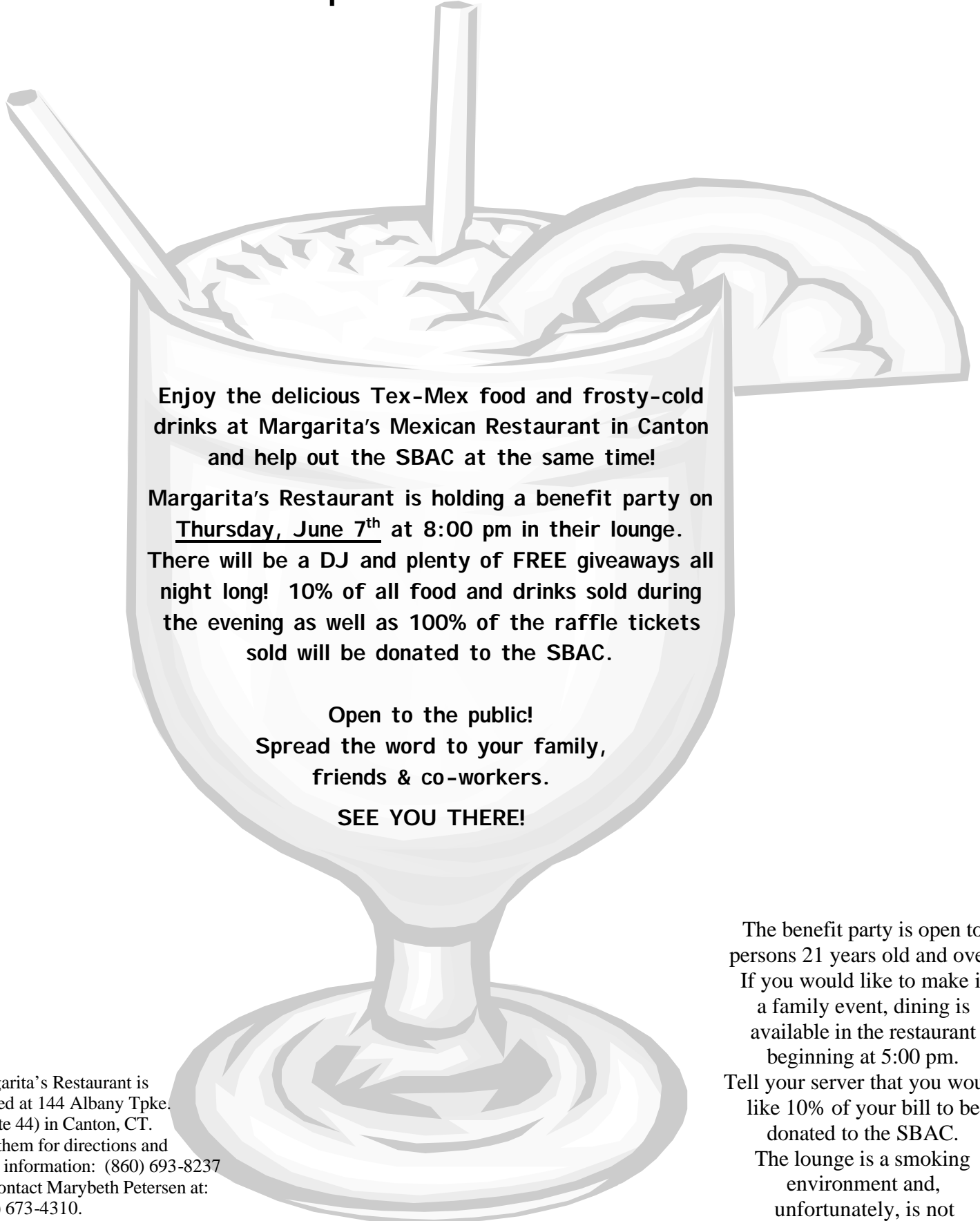
We welcome comments and suggestions regarding the content or appearance of the Newsletter, as well as commentary on issues related to Spina Bifida. We reserve the right to edit all submissions. Letters must include your name, address and phone number. Mail all correspondence in care of the association.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



**Why does applesauce work to aid diarrhea but work so well at maintaining regularity? It's the fiber! The fiber in applesauce attracts water to loosen stool in the cases of diarrhea but has the opposite effect in achieving regularity by adding bulk to stool. (Remember, however, that apple juice can aggravate diarrhea.)**

# **It's A Margarita Party**

**To Benefit The Spina Bifida Association of Connecticut!**



**Enjoy the delicious Tex-Mex food and frosty-cold drinks at Margarita's Mexican Restaurant in Canton and help out the SBAC at the same time!**

**Margarita's Restaurant is holding a benefit party on Thursday, June 7<sup>th</sup> at 8:00 pm in their lounge.**

**There will be a DJ and plenty of FREE giveaways all night long! 10% of all food and drinks sold during the evening as well as 100% of the raffle tickets sold will be donated to the SBAC.**

**Open to the public!  
Spread the word to your family,  
friends & co-workers.**

**SEE YOU THERE!**

Margarita's Restaurant is located at 144 Albany Tpke. (Route 44) in Canton, CT. Call them for directions and more information: (860) 693-8237 -or-contact Marybeth Petersen at: (860) 673-4310.

The benefit party is open to persons 21 years old and over. If you would like to make it a family event, dining is available in the restaurant beginning at 5:00 pm. Tell your server that you would like 10% of your bill to be donated to the SBAC. The lounge is a smoking environment and, unfortunately, is not accessible to wheelchairs.

# **SPINA BIFIDA GENETIC RESEARCH PROJECT**

## **INFORMATION SUBMITTED BY, FRED LIGUORI**

This is an ongoing research project at Northwestern University Medical School. The project director is Dr. Jeffrey S. Nye. Dr. Nye is currently Assistant Professor in the Molecular Pharmacology and Biological Chemistry and Pediatrics Departments at Northwestern University and an attending physician in the Neurology Department of Children's Memorial Hospital. Supporting his groups efforts are Dr. David McLone, Chairman of the Division of Pediatric Neurosurgery, Children's Memorial Hospital (CMH), Editor in Chief of *Pediatric Neurosurgery* and on the Editorial Review Board of *Spina Bifida Therapy*.

The goal of the project is to determine what genetic factors may be causes or risk factors for spina bifida or neural tube defects (NTDs). The success of the Project rests heavily on how many families are willing to participate. The more families they study, the more likely they are to find something and the more likely they are to have confidence in those findings. Some of the families have participated in a survey. The survey helps to identify environmental and physical factors that may possibly play a role or be correlated with NTDs. The other aspect of the study is the DNA analysis.

First, the genetics lab analyzes the chromosomes to see if there are any large abnormalities. If such an abnormality is found, the family is notified. The DNA is then isolated from the remaining blood sample. There are roughly a hundred genes they have reason to believe are candidates for playing a role in NTDs based on their function, reported abnormalities in some patients or their role in NTDs in mice. They need to examine each of these genes in great detail. Dr. Nye says, "this is by no means a quick process, it will take years to do these analyses and even then we can't know for certain we'll be successful. So why bother? Because one thing we do know for certain – we can't be successful if we don't try."

Ideally they would like to have DNA samples from 1,000 families but presently have just over 300. Surveys and/or blood sample kits can be sent to you. The paperwork can be filled out and you can then wait to have blood drawn in conjunction with any other medically necessary blood draw. Only one blood draw is required for the study.

Much research has already been done in mice and other animals, which has given the Project a good foundation of knowledge regarding neural tube defects but in the end, a mouse is not a man and a man is not a mouse. There is no substitute for families like ours that can provide the information needed to find answers to the questions we all have.

If you are willing to participate in the study you can contact the Spina Bifida Genetic Research Project at (312) 503-1761 or e-mail [spinabifida@nwu.edu](mailto:spinabifida@nwu.edu).

***“Unless someone like you cares a whole awful lot, nothing is going to get better. It's not.” -Dr. Suess.***

## **COMMITTEES WITHIN THE SBAC**

### **BY, FRED LIGUORI**

My wife Jill and I joined the Spina Bifida Association of Connecticut in January 1999 after the birth of our son Nicholas. Nicholas was diagnosed with spina bifida when Jill was 18 weeks pregnant. We elected to undergo fetal surgery at Children's Hospital of Philadelphia to repair the opening of the spine in utero. The surgery was performed when Jill was 25 weeks pregnant and Nicholas was born almost 3 months later. The decisions we needed to make, the uncertainty of the future and the time prior to his birth was by far the most stressful time in our lives. Today he is the joy in our lives.

The experience of having a child with spina bifida changed a part of me forever. It does not consume me but it has given me another focus in my life. My goal is to do what I can to help individuals with spina bifida, to increase the public's awareness of the birth defect and to help researchers find a cause and a cure for neural tube defects.

As a relatively new member of the SBAC and a new member of the Board of Directors (BOD) I have various ideas about the organization, where I think we are and where I would like to see us go. To achieve all, or any, of these goals requires two things; some time on behalf of a few individuals and money. The Catch-22 here is that it takes the public's understanding of spina bifida to enable us to raise money and it takes money to improve the public's understanding. So where do we begin? We begin with the SBAC Bylaws which call for 4 standing committees, 2 of which are 'Fundraising/Speakers & Activities' and 'Newsletter/Membership/Publicity'.

*Continued on next page.....*

## COMMITTEES WITHIN THE SBAC, CONTINUED.....

Next we look for individuals who have the same type of focus I mentioned above. Maybe they had the experience of having a child born with spina bifida, maybe they are directly affected by spina bifida, or maybe they just want to help. We need 2 or 3 people per committee plus the chairperson that would be willing to donate a few hours a month.

These two committees really have overlapping goals. Back to the Catch-22, increase the publicity and we increase our fundraising ability but where do we get the money to increase publicity. None of this will come to fruition overnight. I'll use an analogy of building a house. You can't build a house in a day and you can't build it all at once. You do it little by little, a section at a time. Some parts aren't very easy and you are bound to hit some snags along the way. But if you persist you will achieve your goal and the house will get built, although it is never completely finished. You are always looking for ways to improve it and it always requires updating. That is how I see our organization. The foundation is there. The house is built. We need some new ideas from motivated individuals to improve and update our house.

I am very much interested in working the 'Fundraising/Speakers & Activities' committee. I would like to have 3 additional people, preferably from various parts of the state, with at least one from the southwestern part of Connecticut to work with me. If you are interested in participating in either of these committees or would like some additional information please contact Kiley Carlson at (860) 345-8768 or me at (860) 653-1976.

Even if you don't have the time for a committee we should all be working the publicity side of the organization. I prefer to call it public awareness. The end result of improving the public's awareness is increased opportunity to raise money but more importantly reduce the incidence of neural tube defects through the use of folic acid. I don't push myself on anyone but I never miss the opportunity, should it arise, to explain about spina bifida. For those of you who participated in the Bowl-A-Thon in March, how many of the sponsors you contacted knew about spina bifida? How many times did you get that 'deer in the headlights look' when you told people the Bowl-A-Thon was for spina bifida? I explained about spina bifida so many times I sounded like a recording. How many times do you think Jerry Lewis has to explain about muscular dystrophy? And how common is that? But over the years, rather decades, they have concentrated on the public's awareness of muscular dystrophy. How much trouble do they have raising money? We need to focus on the 'section at a time' house analogy. We can achieve these goals but it will take some work and it's not going to happen overnight. We all have busy schedules but we always manage to make time for the important things in our lives. What you need to ask yourself is, is it a worthwhile goal? You bet it is! Do you have a focus? I do, and the Board does, but we need help. **Please give us a call and a couple of hours a month.**

## IN MY HUMBLE OPINION BY, KILEY CARLSON

When I am not spending time with my kids, or working to pay the bills, I do a bunch of volunteer activities. Besides being involved with the SBAC, I have been twice appointed to sit on the Connecticut Council on Developmental Disabilities. The council is a federally funded organization that works to "promote full inclusion of people with disabilities in community life". As a parent I saw things a certain way, as it pertained to my son and my family. Through the work of the council I have learned a great deal about individuals with a wide range of disabilities and their desire to be included, as equals, in their communities. One of the tools that have helped them to reach this goal has been the Americans with Disabilities Act.

The Americans with Disabilities Act (ADA) is the most comprehensive federal civil-rights statute protecting the rights of people with disabilities. It affects access to employment; state and local government programs and services; access to places of public accommodation such as businesses, transportation, and non-profit service providers; and telecommunications.

Signed into law in 1990, the ADA has since undergone numerous changes and is under constant interpretation by the court system. Recent court decisions have ruled against the ADA and have weakened its ability to protect the rights of the disabled.

The ADA Coalition of Connecticut is set to start a campaign to make the ADA a part of Connecticut State Law. This would make the state government open to lawsuits under the ADA, just like every other employer. The hope is that this campaign will also spark the revival of the disability rights movement here in Connecticut.

Although this project is just getting underway, I thought it was important to let you know what was going on, and I will keep you posted as the campaign progresses. If you would like more info on the ADA, you can check out the ADA home page at <http://www.usdoj.gov/crt/ada/adahom1.htm> or contact us here at the SBAC.

The ADA affects us all and it must not be lost. In My Humble Opinion.

# IVAN LENDL JUNIOR WHEELCHAIR SPORTS CAMP

**It's time once again for the Ivan Lendl Junior Wheelchair Sports Camp!** The camp is offered free of charge to children ages 7 to 18 with physical disabilities. It provides an opportunity to receive instruction in sports such as tennis, swimming, basketball and track & field.

The camp provides instruction by world-class disabled athletes, sports equipment, lunch and camaraderie. Campers must provide their own wheelchair.

This year's camp will take place the week of August 13 to 17, 2001 at St. Joseph's College in West Hartford. The registration deadline is August 1, 2001.

For additional information or to receive a brochure and registration form, contact the camp director, Marguerite DeCrescente, at (860) 267-2457.



## NEWSLETTER NAME CONTEST

The Spina Bifida Association of Connecticut's Newsletter needs a name! The Board of Directors has decided to issue a challenge to the Association's youth to give the newsletter a name and felt that a contest would be the perfect way to go about it!

*Can you think of a clever name for the publication?* Some of the other chapters in the United States have catchy names like "Spinabilities", "The Enabler" or "The Spinal Column" for their newsletters. If you are an Association member under the age of 18 and think you have a good idea for a name, we would love to hear from you! Our new newsletter name will be chosen from all entries submitted and the winner will receive a \$25.00 gift certificate to the store of their choice!

So, get those creative juices flowing and send in your suggestion along with your name, address and telephone number. Entries can be mailed to the Association's mailbox and labeled "Name Contest" or sent via e-mail to SBAC-NL@home.com. Entries must be e-mailed or postmarked no later than **July 31, 2001**.

The winner and the new name will be announced in an upcoming edition of the "newsletter."

## PAIN-FREE FUNDRAISING WITH SNET!

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.**

It's easy – you can even sign up over the internet! Visit: <http://www.snet.com/About/0,1847,22,00.html> for more information or to use their simple on-line order form. For more information or to sign up on the telephone, call SNET at 1-800-635-SNET (7638). The Spina Bifida Association of Connecticut's Organization Code is: C2302.

## UPCOMING SBAC EVENTS:\*

### June 7th –

Full Moon Madness Margarita Party  
at Margarita's Restaurant – Route 44 in Canton at 8:00 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

### July 31 – DEADLINES:

Campership Applications Due

Scholarship Applications Due

Medical Allocation Requests Due

Newsletter Name Contest Submissions Due

### 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 13th –

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 web site: <http://sbac.org> or call Dennis Maloney for the latest dates and times.

# HOSPITAL FOR SPECIAL CARE SUMMER 2001 EVENTS

- **Connecticut Rehab and Medical, Inc. Expo - Wheelchair Basketball Demonstration**

June 9, 2001: 10am -3pm

Enjoy a day of learning more about wheelchair basketball as well as seeing all the newest advancements in the field of wheelchairs for all occasions.

Call Connecticut Rehab an Medical, Inc, for more information; 860-666-888

- **Celebrate New Britain 150: Wheelchair Basketball Demonstration**

June 9, 2001: 4pm-6pm

Help to Celebrate New Britains 150 years by learning all about everything that happens in town, including Hospital for Special Care's sports programs featuring a hands-on wheelchair basketball demonstration for everyone to participate in.

Call Gerry Berthiaume, HSC sports director for more information: 860-827-1958 x5088

- **Cruisers Night at the Ball Park (Rock Cats) with Ralston Purina**

June 22: 5:30pm

Watch as the Cruisers wheelchair sports team throws out the first pitch and help the team to celebrate another successful season with the support of Ralston Purina.

Call Gerry Berthiaume, HSC sports director for more information: 860-827-1958 x5088

- **Junior National Wheelchair Championships: Cruisers and WAVE teams competing**

July 22- July 29

Rutgers New Jersey

The top junior wheelchair athletes in the country, as well as several invited international junior athletes, come together to compete in track, field, swimming, weightlifting and table tennis.

Call Ann Thompson, HSC sports program manager for more information: 860-832-6220

- **One up one down Doubles tennis tournament**

June 30, 2001: CCSU: 10am - 6pm

A unique doubles tennis tournament with one wheelchair tennis player competing along side an able-bodied tennis player. We are expecting 15 teams for the inaugural event.

Call Gerry Berthiaume, HSC sports director for more information: 860-827-1958 x5088

- **Sail Access Connecticut Sailing Clinic**

July 11, 2001: 9am-5pm, Westbrook, CT

The Sail Access Connecticut Program has invited HSC to participate in a day long adapted sailing clinic, which will include dry-land training and actual sailing on Long Island Sound.

Call Ann Thompson, HSC sports program manager for more information: 860-832-6220

- **Adapted Golf Clinic: 3pm - 5pm**

July 15, 2001

Join the HSC sports staff and The Physically Challenged Golf Association for an adapted golf clinic at Blue Fox Run in Avon. The clinic will be taught by PGA golf professionals. This is a chance to try golf for the first time or tune up your existing skills with the help of professionals and the latest in adapted equipment.

“The probability that we may fail in the struggle  
ought not to deter us from the support of a cause we believe to be just.”

- Abraham Lincoln

## NEWS FROM NATIONAL

The Spina Bifida Association of America (SBAA) congratulates and welcomes the news of the establishment of the National Center on Birth Defects and Developmental Disabilities (NCBDDD). Created by the Children's Health Act of 2000, the National Center on Birth Defects and Developmental Disabilities (NCBDDD) was recently established at the Centers for Disease Control and Prevention (CDC). NCBDDD will work to improve the health of children and adults by preventing birth defects and developmental disabilities, promoting optimal child development, and promoting health and wellness among children and adults living with disabilities including spina bifida.

"The Spina Bifida Association of America is excited about the creation of the new Center, and looks forward to working in partnership with the Center on the many issues of critical importance to people with spina bifida. We were very pleased to learn that a focus for the new Center is a nationwide educational campaign to promote the use of the vitamin folic acid to prevent spina bifida," said SBAA Chief Executive Officer Cindy Brownstein.

Ms. Brownstein further commented, "We offer our congratulations to both Dr. Cordero and Ms. Holloway and are eager to work with them to further the Center's initiatives and to help the over 70,000 people in the United States living with spina bifida."

The spina bifida community was a very active supporter of the establishment of the new Center. The Spina Bifida Association of America and its members played an integral role in advocating for the Center, educating their Congressional representatives on the need for a separate Center at CDC to focus on Birth Defects, Developmental Disabilities and addressing health and wellness issues for persons with spina bifida and other disabilities.

## THE MESSAGE ABOUT FOLIC ACID

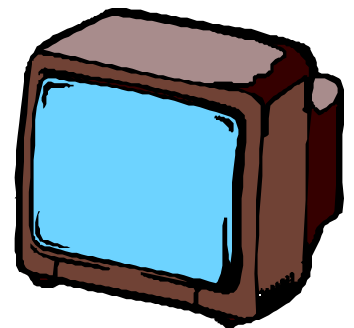
The New York County Medical Society web site currently features an article on SBAA's Recurrence Prevention Program which educates about the use of folic acid to prevent birth defects.

The Manhattan medical society is one of the largest in the United States! To read the article, go to [www.nycms.org](http://www.nycms.org) under the "News Flash" section.

## NICKELODEON NETWORK AIRS CARTOON SERIES FEATURING A 13-YEAR-OLD IN A WHEELCHAIR

Kudos to the Nickelodeon Television Network on their groundbreaking animated series featuring a 13-year-old boy named Pelswick who is in a wheelchair. Pelswick, a quadriplegic, demands to be treated like his peers and pokes fun at the odd predicaments he is faced with daily. The show's creator and author, John Callahan, uses a wheelchair himself as a result of a spinal cord injury.

Pelswick can be seen on Nickelodeon on Saturdays at 5:00 pm and Sundays at 6:30 am.



# WHY SHOULD IT BE DIFFERENT?

## AN ESSAY BY COURTNEY BURNS

The first time I, Courtney Burns, saw Mary-Christine Beck was at the sixth grade orientation at Chipens Hill Middle School. This orientation was to show the new sixth graders where their teams were. While we were going down the stairs to see our teams, I was stuck behind a girl with crutches. Later that week I met this girl and we became immediate friends. Mary-Christine and I have been friends ever since.

Mary-Christine, (M-C) and I have been friends for three years and I have never seen anything that she couldn't do. Every summer she and I go swimming and rollerblading. In the winter M-C goes skiing. Any weekend that M-C and I are bored, we either have a sleep over or we go to the movies. After school Mary-Christine and I will go to basketball games where she sits and watches the game, while I cheer with my squad. At Chippens Hill I am a Blue Team cheerleader. Mary-Christine and I are also in the school band. I play the flute and she plays the clarinet. M-C and I go to the school dances that are held at Bristol Eastern High School. Mary-Christine is a very nice person to have as a friend.

Some people think that it would be different to have a friend with a disability and that is why they won't be their friends, but really it isn't any different. Mary-Christine is as normal as any person. All people have a disability whether it is their sight, hearing, or they can't talk. Just because Mary-Christine has spina bifida doesn't mean that she can't do things another person does. Sure she'll need help getting something off a high shelf, but don't we all? People who aren't tall enough will need help with this too.

Mary-Christine's weeks are as complicated as an adult's. An adult has to get up in the morning, go to work, and then come home and make dinner for their family every day of the week. Mary-Christine has to get up, go to school for 6 hours, come home, eat, and go to her practices. On Monday she goes swimming at Giamatti, Tuesday she goes swimming at the Hospital for Special Care (where my mom works) with a different swim team, Wednesday she goes to Giamatti, Thursday she goes to Giamatti and then to Cruisers (wheel chair racing practice), and on Fridays she goes skiing during some of school and then goes to Giamatti for another swim practice. Every other Saturday Mary-Christine goes to swim meets with the Bristol Splash Swim Team. I hope that people with disabilities will soon be treated like normal people which they are.

## PEOPLE NEWS

**Get well** wishes to Haidee Kupecz who is recovering from recent surgery and hospitalization. Here's to a speedy recovery, Haidee!

**Congratulations** to Janice, Hervie & "big brother" Nathan Lamb on the birth of their baby, Hannah, on April 16!

**Condolences** are being sent to Julie Handfield and her family on the death of her mother, Florence Weber. The Association also gratefully acknowledges the generous memorial donations made to the Campership Program on behalf of the family.

## WEB RESOURCES

Find state and federal forms, government information as well as contact information necessary to transact with government agencies at:  
<http://www.hicitizen.com/>

On-line resource for parents of kids with spina bifida:  
<http://www.waisman.wisc.edu/~rowley/sb-kids/index.htmlx>

## BOOK REVIEW & EXCERPT

Motherhood Magnified is a new book written by Jill Rose Ford who is a mother of a child with special health care needs. The book offers inspiring parenting stories from a fresh affirming perspective that captures the unique challenges of raising a child with special needs. These stories describe ordinary everyday experiences where difficulties are confronted and sorted out to create a stronger, healthier perspective on life. Issues that are especially concerning to moms are written about in a warm, straight-forward way with splashes of humor that are certain to grab the attention of virtually any mom.

Jill says she wrote this book with the intention of helping other moms who have children with special needs by validating their struggles and efforts. Here she shares with us an excerpt about giving her daughter medicine.

*...One particular day I had Jackie pinned down on the floor as was typical for us at this point. Her lips were pressed especially tight together and when I squeezed her cheeks together to get her lips to open ever so slightly, she had her teeth locked so tightly that there was no opening to squirt in the greenish-yellow stuff. Using force and overpowering her like that, I felt more like a child abuser than her mom. That was the last straw! What a dilemma! I felt like a horrible mother no matter what I did. The only way I could get her to take her medication was to use force or trickery but by doing this I had lost my daughter's trust and was damaging our relationship. Yet, I would certainly be a terrible mother if I didn't give her the medication that she needed. Determined to find a better way, I called the doctor's office and spoke to his nurse about our situation. I asked if we could try a pill. At the suggestion of one of my friends, I put the tiny pill in a spoonful of ice cream. The idea being that Jackie would simply swallow the spoonful of ice cream that had the pill in it. Jackie, almost three years old at the time, willingly took the spoonful of ice cream in her mouth. Within seconds her face scrunched up in a puzzled look and she took the pill out of her mouth. She held it up to me and asked, "What's this mommy?" When I explained that it was a pill and that I wanted her to swallow it, she simply said, "Okay." Jackie popped the pill back in her mouth and swallowed it with no water, no ice cream and no bribery. You could've knocked me over with a feather...*

Motherhood Magnified is available from most internet booksellers such as Amazon.com, BN.com and Borders.com.

## ACCESSIBLE PLAYGROUND PROJECTS CHALLENGE

Boundless Playgrounds is a non-profit organization dedicated to helping communities across America develop fully integrated and universally accessible playgrounds where children of all abilities can play together. Twenty-four Boundless Playgrounds projects are now complete around the world with more than 80 others currently in development and more than 200 requests for help and information being received by their offices each month! Here is a list of playgrounds currently under construction in Connecticut:

Annie Fisher School – Hartford

Mikey's Place – Wethersfield

Friendship Place – Berlin

St. Joseph's School for Young Children – West Hartford

Our Children's Place – Newington

Devon's Place – Norwalk

Easter Seals Camp Hemlocks – Hebron

For more information or to find out how you can help Boundless Playgrounds in their efforts, call (860) 243-8315 or visit their web site at [www.boundlessplaygrounds.org](http://www.boundlessplaygrounds.org).

# HIPPOTHERAPY

By, WENDY GARIZIO

I'd like to start off by saying -- thank goodness it doesn't really involve a hippo. Literally translated, hippotherapy means "treatment with the help of a horse," and has been around since the 1960's. It is used as an adjunctive therapy by people with many types of disabilities including cerebral palsy, traumatic brain injuries, autism, and spina bifida as well as a host of others.

There are myriad benefits to hippotherapy. From a physical or gross motor standpoint, hippotherapy can strengthen the muscles of the back, abdomen, legs and hips as well as improve trunk and head control. Just sitting on the horse provides stretching and flexibility for the rider. Riding a horse mimics the motions of human walking, using the same muscle groups. The horse's gait feels as close to walking as you can get, say adults who have lost the ability to walk through disease or injury. Hippotherapy has been shown to enhance attention, boost social skills, and improve coordination and motor planning. Therapy sessions can include the use of different types of saddles with various belts or braces or no saddle at all. Different riding postures are used such as sidesaddle, backward riding or others. Riders may use balls or rings and toss or catch while riding, "race" other riders or ride with varied rhythms. Usually, three people control each horse during therapy, a leader and two "sidewalkers." This will vary with each riding center and the particular needs of the rider; some adults and older children can take more control of the horse.

It may surprise you, as it did me, that hippotherapy can be tremendously helpful in speech therapy.

Human language is complex, consisting of speech, graphics, sign language and written words.

Communication and the development of language depend on coordination of many body systems; normal speech requires normal motor function, posture, timing, normal sensory feedback and coordination of breathing and speaking. Input during hippotherapy includes vestibular, visual, tactile and proprioceptive (awareness of one's body and its positioning.) Additionally, riding can enhance attention and aid in cortical organization. The movement of the horse stimulates the muscles of the mouth, respiratory tract and enhances trunk and head control. Careful manipulation of the gait and position of the horse as well as the position of the patient is used by the therapist in addition to traditional speech therapy methods.

The most docile of horses are used in hippotherapy, for riders are of varied physical disabilities and are often very young. Horses go through special training to prevent them from being "spooked" by sudden noises or commotion, or from shying away from the various types of equipment (such as wheelchairs) which invariably accompany some participants. Therapists should be specially trained as well, there are places around the United States and the world where physical, occupational, speech, and psychiatric therapists can be trained in hippotherapy.

As for the riders, medical clearance is required for participation and detailed history is usually requested in order that the best precautions can be taken for each individual's safety. Each diagnosis can offer its own set of risks or challenges, but most centers are up to the challenge. Usually the minimum age is 2 but can be higher depending on the center and what kind of staff and equipment they have available. Many centers run with the help of volunteers.

For children with developmental delays, or children and adults who need to preserve function they already have, hippotherapy can be a great addition to the therapy they are already receiving. It is often described as something so fun that it does not feel like therapy at all. Practitioners report that children are often unaware that they are working their muscles hard, or that they are getting such a wonderful stretch of the legs and hips, something they might be acutely aware of during traditional therapy.

For more information contact NARHA, the North American Riding for the Handicapped Association, a Denver-based group that is dedicated to promoting therapeutic riding for disabled people. [www.narha.org](http://www.narha.org)



# HIPPOTHERAPY IN CONNECTICUT

In CT, you can contact:

High Hopes Therapeutic Riding, Inc.  
36 Town Woods Rd  
P.O. Box 254  
Old Lyme, CT 06371-0254  
(860) 434-1974

High Hopes is one of the oldest and largest of over 600 NARHA-member centers. There, training is provided for therapists and many programs are provided for riders. They provided the equestrian venue for the 1995 Special Olympics World Games.

Also:

Pegasus Therapeutic Riding Programs  
their website: [www.pegasustr.org](http://www.pegasustr.org)  
Or call: (203) 356-9504  
Or write: 45 Church Street, Suite 205  
Stamford, CT 06906

Participating Pegasus centers are in:

Darien  
Ox Ridge Hunt Club  
512 Middlesex Road, Darien, CT 06820

Greenwich  
Kelsey Farm  
1016 Lake Avenue, Greenwich, CT 06831

New Canaan  
New Canaan Mounted Troup  
22 Carter Street, New Canaan, CT 06480

Newtown  
Corgi Hollow Farm  
68 Boggs Hill Road, Newtown, CT 06470

Roxbury  
Laurel Ridge Farm  
45 Goldmine Road, Roxbury, CT 06783

Weston/Westport  
Lion Hill Farm  
1020 Sport Hill Road, Easton, CT 06612

Other NARHA Therapeutic Riding Centers

Equistrides Therapeutic Riding Center, Inc.

160 Grandville Rd.  
North Granby, CT 06060  
(860) 844-0342  
[etrci@PortOne.com](mailto:etrci@PortOne.com)

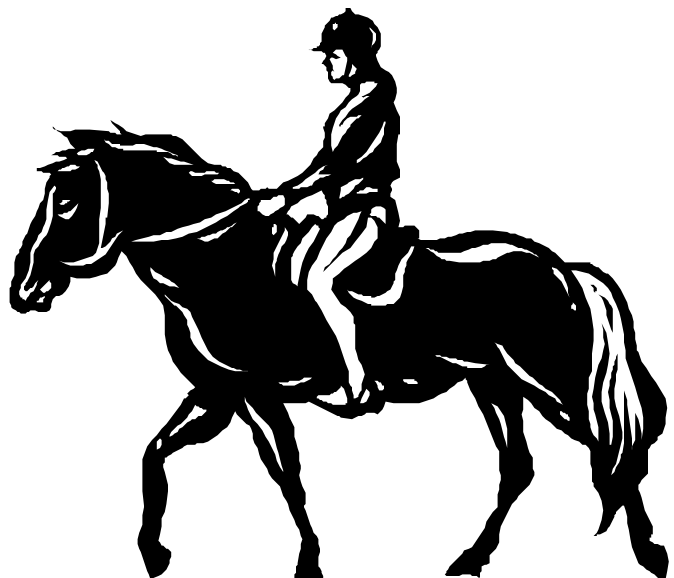
Lake Grove School  
459R Wallingford Rd.  
Durham, CT 06422-0659  
(860) 349-3467

The Learning Clinic Inc.  
Route 169 Box 324  
Brooklyn, CT 06234  
(203) 928-5274

Litchfield Little Britches  
56 Westwoods Rd.  
Sharon, CT 06069  
(860) 364-5671

Manes & Motions  
900 High Road  
Kensington, CT 06037  
(860) 827-9788  
[Jmassi@aol.com](mailto:Jmassi@aol.com)

Rising Stars Therapeutic Riding Center  
P.O. Box 531  
Unionville, CT 06085-0531



## NEW SECTIONS TO THE NEWSLETTER

The following two sections will soon be appearing regularly in the newsletter:

### *Tips of the Trade*

### *Favorite Family Recipes*

*Tips of the Trade* will include any of those little things you've found to make living with spina bifida easier. These ideas might include how you pack cathing supplies for travelling or ideas on how to avoid or work around common barriers to mobility.

*Favorite Family Recipes* may include, but are not limited to, high fiber recipes to aid in constipation. Of course, any yummy family recipe that you would like to share would be welcome!

***However, In order for these two sections to be a success, we need your submissions!***

Send your ideas for Tips of the Trade or Favorite Family Recipes to the association mailbox or via e-mail to: SBAC-NL@home.com. Please provide your full name so proper credit can be given!

## TIPS OF THE TRADE

This first "Tip of the Trade" was submitted by Francine Hebert who learned it from the school nurse when her daughter was in kindergarten. It has helped to greatly reduce the incidence of urinary tract infections caused by urine left in the bladder.

When cathing, sit on the toilet. When the flow of urine has stopped, stand up before removing the catheter. This will use gravity to drain the remaining urine from the bladder thus making the catheterization more successful.

You might want to discuss this technique with your urologist if you have any questions about how it might help you. You might also discuss how to adapt the technique if you cannot stand, by elevating the body by pushing up with the arms.

## CAN YOU HELP?

Has anyone found a disposable absorbent underpant that would be helpful for my 12 year old daughter who, although she stays dry between cathings, has an occasional wetting accident due to laughing or coughing?

We've tried the Good Nights but have found them too much like a diaper. The Depends and Poise products are simply too large for a pre-teen and pantliners and pads are not absorbent enough.

I would be grateful to learn what others have found to be helpful as maintaining dryness while offering discretion. If you have a suggestion that might be helpful, please call me.

Thank you,  
Francine  
(860) 282-0522

# "THE TEENAGE PAGE"

## Newsletter Columnist Needed!

The Spina Bifida Association of Connecticut is looking for a few of its teenage members who are interested in becoming regular contributors of articles for the "Teenage Page" of the Newsletter. This is your chance to be a voice for the teenagers in our group.

The articles should be related to living with spina bifida but can be of any topic the writer chooses. All articles must be typewritten and submitted according to the Newsletter's quarterly publishing schedule.

This is the perfect opportunity for someone interested in the field of journalism.

Interested parties should contact Marybeth Petersen at (860) 673-4310 or via e-mail at: SBAC-NL@home.com.

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## On-Line Support Group:

If you are interested in becoming a member of an on-line chat group for teenagers with spina bifida, join the SB-Teens e-mail list today! Membership is over 180 worldwide and new members are always welcome! To sign up, get your parent's permission and then log on to: [http://www.homestead.com/\\_sb\\_teens/index.html](http://www.homestead.com/_sb_teens/index.html).

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## College Bound?

Going to college in the fall? Be sure to apply for the Spina Bifida Association of Connecticut's scholarship. All the forms and information you need to apply are in this edition of the Newsletter. You might also want to consider visiting the following web site (your parents will be glad you did!):

*[http://www.ed.gov/prog\\_info/SFA/StudentGuide/2001-2/index.html](http://www.ed.gov/prog_info/SFA/StudentGuide/2001-2/index.html)*

The site provides resources on student financial aid from the U.S. Department of Education. It covers the Department's major aid programs, including Pell Grants, Stafford Loans, and PLUS Loans.

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## Birthday Freebies

Here are a couple of great freebies offered by local businesses to be taken advantage of on your next birthday!

**Baskin Robbins Ice Cream & Yogurt** on South Main Street in West Hartford offers a free ice cream cone for kids under 13.

**Hollywood Video** locations offer a free video rental to birthday folks with a membership card.

*Call ahead to confirm details of these offers and enjoy!*

**BOWL-A-THON 2001 AT  
SILVER LANES IN EAST HARTFORD**

**SPRING FLING WEEKEND AT  
HARKNESS PARK IN WATERFORD**

Spina Bifida Association of Connecticut, Inc.  
P.O. Box 2545  
Hartford, CT 06146  
*HTTP://SBAC.ORG*

**You're Invited To A  
Margarita Party!**

See page 3  
for details.

