

Spina Bifida Association of Connecticut, Inc.

June 2002

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THE SPINA BIFIDA ASSOCIATION OF CONNECTICUT, INC.

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A Letter From The Acting President By, Jerry Beck

Dear Members:

I'd like to first update you on some highlights of the Board of Director's Meeting held June 10th. Our organization is sending two delegates to the upcoming National Conference at the end of June and we look forward to their feedback of information that we can pass along to the membership.

Also coming up at the end of June is the National Sports Festival which is being held at Connecticut College in New London. The SBAC is proud to sponsor an ad in the Program Book. We will be setting up an awareness booth with literature at this sports festival. Volunteers manning the booth will be selling items such as SBAC Beanie Babies and snack items. Come on down and support our athletes who are competing. You'll find amazing talented individuals competing in swimming, track, field events, etc.

Featured in this newsletter issue are topics such as Mom's Hearts Speak Out - a survey completed by moms, our spring Camp Harkness weekend, folic acid survey, Awareness Committee updates and much more interesting reading.

I want to remind everyone of the July 31st deadline for applications to be submitted for our scholarship, campership, and allocation programs.

Coming in October, 2003, we will be holding our annual bowl-a-thon. Please stay tuned for updates on this event in future newsletters.

I continue to encourage you to become involved in the SBAC. With the help of your continued support, we will make our organization more successful.

Have a great summer!

Jerry Beck

CHILD CARE FOR CHILDREN WITH COMPLEX MEDICAL NEEDS: LINKING THE MEDICAL HOME

The University of Connecticut's A.J. Pappanikou Center for Developmental Disabilities is funded by the U.S. Department of Health and Human Services, Administration for Children and Families, to demonstrate the successful inclusion and accommodation of infants and toddlers with complex medical needs and disabilities into community-based child care centers. Our goal is to include childcare providers within the medical home, so they serve as partners with parents, medical providers, and early intervention specialists. If you or a family you know has an infant or toddler with complex medical needs and would like help finding a childcare and an opportunity to promote socialization, please contact:

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-or-

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NEW BABY CONGRATULATIONS!

Congratulations to the Garizio family on the birth of their son, Christian (they're calling him "CJ") on June 17th. He weighed in at 6 pounds, 10.5 ounces and was 21.5 inches long. Initial reports are that he has his mom's red hair!

CJ and his mom, Wendy, are due to go home and join his Daddy, Paul and siblings, Jamey, Katie and Allie soon. We wish them the best of luck with their new bundle of joy!

IT'LL BE A *SCARY* GOOD FUNDRAISER!

The SBAC is planning a fundraiser during the month of October to coincide with Spina Bifida Awareness Month. We plan to sell paper "Ghosts" similar to the ones sold for fundraising events at supermarkets and larger stores. In order for the fundraiser to be a success, however, **we need your support!** We are looking for outlets to sell the ghosts. There is minimal effort involved on your part and the payoff is great for the SBAC!

Think about the places you do business (drug store, coffee shop), your church or synagogue, day care center, or your employer? Perhaps the purchase of a ghost would allow a "dress down day" at the office? For more information or to sign up, please contact one of the SBAC officers listed on page 1 of the newsletter.

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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>.

Congratulations to:
Michelle & Marco Tardiff.
Who were married in March.

Michelle is very active in the SBAC and is currently serving on the Board as Secretary as well as her position as the nurse for the HSC's Cruisers team. Most of you know Marco from the outings at Harkness and his help each year at the bowl-a-thon as well as his volunteer activities with the Cruisers.

*Good luck to
Michelle & Marco!*

BOOK RECOMMENDATION NONVERBAL LEARNING DISORDERS

The Source For Nonverbal Learning Disorders by, Sue Thompson (Linguistics; ISBN: 0760601631; October 1997, 182 pages) has been identified by one of our members as an excellent resource for parents concerned about their children's education can be affected by a nonverbal learning disorder. The book can be obtained by calling 1-800-PRO-IDEA.

WANTED: HAND-POWERED TRICYCLE

If you have a hand-powered tricycle or similar hand-powered toy (appropriate for a 2 year old child) that you would like to sell, please call: Marybeth or Scott Petersen at (860) 673-4310.

HIGH-FIBER SUMMER PICNIC FAVORITE!

I get raves about these at every picnic or pot-luck! My family loves them, too. Don't let the raisins and apple scare you off! No one ever guesses the 'secret' ingredients! The longer they cook, the thicker they get!

Barbecue Baked Beans

32 ounce can of pork and beans
3/4 cup barbecue sauce
1/2 cup light brown sugar
1 tart apple, *chopped (Granny Smith)*

1 small onion, *chopped*
1 tablespoon *minced* garlic
1/3 cup golden raisins
3 strips bacon (*if desired*)



Preheat oven to 350-degrees. Drain beans and remove the fat pieces. Combine beans with remaining ingredients except for bacon. Pour into a greased 1 1/2 quart casserole dish. Arrange bacon on top. Bake uncovered for 50-60 minutes. Makes 6-8 servings – **9 grams of fiber per serving!**

5-MILE BRANFORD ROAD RACE

Congratulations to all our members who participated in the 5-mile Branford Road race on June 16th. It was the first time the Branford race had wheelchair athletes participating and was great public awareness. Our own Jaclyn Lanzetti beat out some of her teachers that were running!

If you missed the event this year, mark it on your calendar for next June!

HOW MUCH FAT OR FIBER?

If you ever wondered how your diet compares with the government standards for healthful eating but didn't want to do the math of adding up calories, carbohydrates, protein, and fat, then check out the Interactive Healthy Eating Index on-line at: www.usda.gov/cnpp. All you do is type in what you ate and how much!

AWARENESS COMMITTEE OPENINGS

By, FRED LIGUORI

Although the response to my request for volunteers for the Awareness Committee was overwhelming, there are still several openings. OK...that was a slight exaggeration, actually one person called, so we really do have several openings remaining.

Public awareness of spina bifida is vitally important to our organization's ability to move forward. We have several goals we hope to achieve over the next five years and each one requires funding in one way or another. We need to raise more money through public and corporate donations and that is very difficult to do when the majority of the public either has never heard of spina bifida or they have heard the words but do not know what it is.

Once again I am asking for your assistance. Working on this committee does not require attending monthly board meetings. What I need is assistance at various events throughout the year providing information on spina bifida, a subject I am sure you are all well versed on. For the remainder of this year we are committed to the Milford Oyster Festival on Aug. 17th, the Norwalk Oyster Festival on Sept 6, 7 and 8th, Margarita's Full Moon Madness Parties during July, August and September at the Branford location and possibly at the Mansfield and Mystic locations as well.

At this time we really need help with the Norwalk Oyster Festival. It is 3 full days and we need 2 people at the booth at all times. I am hoping for enough people to volunteer so I do not need anyone for more than one 4- hour period. Even if you are not interested in committee work but would volunteer 4 hours on either Sept 6, 7 or 8th, please give me a call.

Helping to educate the public will help SBAC to achieve our goals. If you can volunteer any of your time please call me at (860) 653-1976 or Jerry Beck at (860) 583-9426.

FOLIC ACID SURVEY

MORE WOMEN AWARE OF THE BENEFITS, BUT STILL DON'T TAKE FOLIC.

Almost 70 percent of American women of childbearing age fail to take the B vitamin folic acid every day even though many of them are aware it helps prevent birth defects, according to the latest survey released in June by the March of Dimes.

The survey found that only 31 percent of women between the ages of 18 and 45 who are not currently pregnant take a daily multivitamin containing folic acid. The figure has increased only slightly since 1995, the first year the March of Dimes surveyed women. This is despite the fact that 80 percent of all women of childbearing age now say they are aware of folic acid, up from 52 percent in 1995.

A comparison of seven annual surveys conducted nationally by The Gallup Organization for the March of Dimes also shows that the number of women who know that folic acid must be consumed before pregnancy has increased to 10 percent in 2002, up from only 2 percent in 1995. Those who know that folic acid prevents birth defects has increased to 20 percent in 2002, up from only 4 percent in 1995.

A separate study conducted by The Gallup Organization for the March of Dimes focusing on folic acid awareness in individual states, showed that in Connecticut, 28 percent of respondents reported taking a vitamin with folic acid daily. Seventy-four percent of women 18-44 report being aware of folic acid, and 14 percent of respondents reported being aware of the role of folic acid in preventing birth defects. Daily consumption of the vitamin beginning before pregnancy is crucial because serious birth defects of the brain and spine known as neural tube defects (NTDs) occur in the early weeks following conception, often before a woman knows she is pregnant.

The March of Dimes is in the fifth year of its national folic acid education campaign aimed at reducing NTDs, which are among the most serious birth defects in the United States. Each year, an estimated 2,500 babies are born with these defects, and many additional affected pregnancies result in miscarriage or stillbirth. The most common NTD is spina bifida, a leading cause of childhood paralysis. Another NTD is anencephaly, a fatal condition in which a baby is born with a severely underdeveloped brain and skull.

To help prevent NTDs, all women capable of having a baby should consume a multivitamin containing 400 micrograms of folic acid every day beginning before pregnancy, as part of a healthy diet containing foods with folic acid, such as leafy green vegetables, orange juice, peanuts, beans, and fortified grains.

The survey was conducted for the March of Dimes by The Gallup Organization under a grant from the U.S. Centers for Disease Control and Prevention.

MOM'S HEART SPEAKS OUT

BY, WENDY GARIZIO

Happy summer everyone! This article is the follow up to "Love, Dad," which gave us insight into the hearts and minds of dads who have children with spina bifida. Now it's time to hear from mom.

How did you learn of your child's spina bifida?

- Upon birth
- Via a routine ultrasound at 21 weeks.
- At birth. Years ago some of the current tests were not out. However, I am very intuitive. I had strong feelings that there was something wrong with my baby. I read many magazine articles and books about raising a child with a disability although my OB assured me that all seemed well with the baby. I even called my insurance company to make sure the baby would be covered from the moment of birth. We knew a couple who had insurance that didn't cover the first 24 hours and they were left with a huge bill. I really didn't even know if my baby would live. I could not feel what was wrong. It was tough on me that everyone, including my husband, all disregarded my premonition. I am glad I had those feelings, so I had time to prepare emotionally.
- Through afp test and ultrasound; I got the message over the phone.

What was your reaction, your first thoughts?

- My reaction was complete sadness. My first thought was "Will my baby die?"
- I was totally scared with, of course a million questions. I was pretty out of it after the c-section but I remember my husband praying "just let me be able to talk with my child." Our prayers were answered.
- I was very worried that my baby would die, especially before we knew all about her condition, and while she underwent surgeries. After that, I felt much grief thinking about how other children would treat her, and as a result what her quality of life would be, but at the same time determined that she would be showered with love and attention from her parents.
- I did not know what spina bifida was. My first thought was to find out what it is.

Was this different from the child's father's reaction?

- My husband and I were both in shock and had a lot of questions.
- Yes, All I could think about was the future for her and our family.
- My husband has an amazingly positive attitude, and is fortunate to feel almost at all times that everything will be okay. I am glad, as I am always very anxious and we balance each other. It was hard at times because faith can sometimes come across as detachment. I have felt alone with anxious feelings, as he can't seem to relate to that at all, though he tries to be sympathetic. My husband concentrated his efforts on what he could do something about, being with us as much as he could and being an excellent provider.

How did other family members react?

- Our family members all reacted with sadness and a lot of questions. No one knew much about SB.
- Our families were beyond kind and compassionate. They helped to keep the home fires burning, gathered SB info, and were just "there." After awhile my mom's pity upset me, I needed a positive attitude; after all, my child with SB was "just my baby girl." Supportive, sympathetic, loving. One family member did tell me I was lucky that my husband didn't leave me, or reject the baby. I thought this was quite insensitive but it helped me to realize early on how certain people cannot handle imperfection. It makes me feel glad that I was never one of those people.
- Most said we could have other children and asked if we were sure we wanted to make that commitment. Others said it was our decision that we would have to live with.

How has your perception of spina bifida changed over time?

- I now realize that it is devastating and complex but manageable in most cases.
- Absolutely! The older my child has gotten, the more I see she's just a kid and wants to be treated like every other kid. Using a wheelchair which at first seemed like a sentence, is now looked at by us as a mode of transport and a way for her to participate in sports.
- In the early years it seems that most of our concern would be about physical needs, mobility and educational focus. These were the physically demanding, exhausting years. Learned a lot about advocacy was empowering. I am finding adult issues are more painful. We are out of the pediatric health system and pretty much on our own, which is scary. Adult successes are much harder to achieve. There are issues of motivation, depression, how cognitive difficulties affect education and training for a career, and whether driving will be possible as well as safe for our child and others around. What is hard on me is lack of control. In the early years a parent has control over many aspects of a child's life. Attitudes out in the world about people with disabilities need to evolve. I am hearing from families that it is tough for young adults with SB to get hired. I think a lot of employers see a person in a wheelchair and freak out about the ADA and what they will have to provide as an employer.
- I don't think I will ever be totally prepared. Things are always changing for those with SB and so is the technology.

What concerns do/did you have about your (other) typically developing children?

- I'm concerned that my "Non-SB" child will resent the extra attention that my SB child receives. I'm also hopeful that he will be more understanding of others and their differences because he's being raised with a non-typical sibling.
- Feelings that are typical for any mother with more than one child: Is one getting more attention than the other? Are the

chores equal? Etc. I only hope that my other child grows up to be a person of kindness, understanding and acceptance of all people.

Will they understand? Will they accept her? Can they handle that she will need me more?

- Will they feel like they have to protect her?
- I feel that my other children are richer for having a sibling with disabilities. I believe it is their responsibility to help her, and I tell them that this is the family God put them in, He expects them to be part of the family and do their part. I also believe it is their responsibility and privilege to help her when they all become adults. It is how I feel about my own siblings and parents. I think our society puts too much emphasis on fun and superficial happiness. Nothing wrong with fun, but commitment and duty are probably more important in life.

How has being the mother of a child with spina bifida changed your life? What kind of changes have you made personally in order to accommodate the changes in family life?

- My life has changed 100%! I am now more appreciative of everyday things, things I used to take for granted. I've learned that there is a certain color of green that the trees turn in the spring just before leaves come out. The trees are never that color but one day. It's beautiful! I notice something like that every day now.
- How could your life not be changed? My child with SB has taught me a lot about inner strength. Boy, you get pushed right to the hairy edge! People will still say to me that God wouldn't give you more than you could handle. Even though I wonder if there isn't some sort of truth to that, I got tired of hearing that a long time ago. I do wonder very briefly once in a while how my life would have been different without my child.
- I feel that since the day my daughter was born she has been my #1 focus. With everything I do, I consider if I will still be available enough to get our daughter what she needs. It is stressful. I have been very limited in what I could do as far as work, trying to fit in medical appointments, hospitalizations, and activities. I am grateful beyond measure that my husband is such a good provider, in spite of living nearly his whole life with a chronic disease. Even now that our daughter is an adult, I am trying to figure out what I can do with my own schedule so that she can get a summer job and go to class next semester as I still provide transportation. My husband's employment does not make him available for transportation and all other family members work. We feel hopeful that driving training she is going through right now will work out. A license for her will open a door of great freedom for both her and myself.
- It has been like a reality check. I took a lot for granted but I appreciate now the things God gave me. One of the changes we have made is that I work at night, so I can take my child to appointments and work a little less than I used to. We are also trying to make the house more adaptable for her.

How has it changed your view of your work?

- In the intensive care nursery we decided that I would be the primary caregiver at home. For many years I worked very

little outside the home. Now I look for work that will fill my spirit so that I have the energy I need. Sometimes I have held very simple jobs, which have offered me this. I find myself being a caregiver no matter what job I take. I like people. I try to learn from their stories how to keep the faith and go on in spite of life's difficulties. What I like about my current job as a dental assistant is that the dental chair is like the Freudian couch. I love the stories people tell me, which are healing and inspiring.

- I like to work I only work part time but it gives me a chance to take a break.

Has it changed your philosophy of life?

- I'm more understanding of others - friends, family or strangers in the supermarket. You just never know what's going on in someone's life. Maybe that person who cut you off in traffic just got really bad news at the doctor? I'm much more forgiving and accepting.
- I was brought up with the philosophy of not relying on others and of having inner strength and self-sufficiency. What I have learned that it is not a failing to rely on others, that it adds to life. None of us can get by without others helping us, and there is no shame in that. I have realized that connections with others are invaluable and add immeasurably to our quality of life. We have especially benefited from our SBAC and Cruisers Wheelchair Sports Team (made up mostly of SB kids) communities. We have found support, encouragement, vital information, and friendship. I have also learned how important it is to give back to the extent that is possible so that the caring flows in a circle, which benefits many.
- I think the biggest change is how I relate to other people. I suppose you could say my spirit is hardened. I used to go out of my way to be nice to adults so they would like my child. Now, I prefer to spend my time with people who share common struggles and don't mind talking about bowel stuff through dinner.
- Yes - you can't take anything for granted !!

Has it changed how you relate to your family?

- I have less of myself to give to extended family members and friends. As for our own family, we try to make our time together fun and meaningful. I tend to be a solitary person, introspective, so I need to guard against being too lost in my own little world. At the same time getting time alone is energizing, and I get crabby without it.
- Things certainly have been difficult at times between my husband and me. We have shared so much together in bringing up a child with challenges. I don't know if I would ever open my heart to anyone else that way.
- Some parts of my family yes. I have to say that it's been very hard to accept and not feel a bit of anger toward the babies that came after my SB child, ones that are healthy and doing typical stuff. Some people have been very supportive and others just are there.

When you think about your child's future, what do you see?

- I have accepted my child's condition and foresee her future just as my typical child's. I recognize her strengths and weaknesses and hope I am doing my job to prepare her for

coping with these things.

- I pray that she can live independently and support her self. I try to be realistic about her future. Her goals seem high to me, which freaks me out because of course although you want your kids to aim high, I don't know if she would make it with such demanding training. I'd love to see her be a teacher, she can do this job whether sitting or standing.
- I feel that she will have a job, get married and probably have a family. She would like to travel also. These are goals she has shared with us. It remains to be seen what type of work she will do. The transportation issue is also in the process of unfolding. She is a very determined young lady and that will help her to create the life that she is looking for.
- I see her being strong and trying to do what everybody else is doing, but at the same time being disappointed because some things she can't.

Along the way, what has helped? Is there any special coping mechanism/routine/person who has come to your rescue?

- Having friends from the SBAC and in an on-line support/chat group. It's the SB Families and SB adults who have made ALL THE DIFFERENCE.
- On a daily basis I find some activity or experience which fills the spirit; my favorite ritual is an early morning cup of coffee along with an inspirational reading, which starts me off on the right track. Journal writing, and other writing I do has been very rewarding. We have greatly benefited from people we met early on at the former Newington Children's Hospital, especially the families making up the support group of the families of children with SB, which evolved to our current SBAC.
- I think whether you realize it or not you create your own support network. Probably nothing can beat other parents. Trying to find the positive has helped although it has sometimes been a struggle.
- Talking with other people who have children with the same issues. Some of them have helped to educate me a little better. It helps knowing they're always there to lend a helping hand if I need one. Their emotional support and understanding help; I know they are going through the same things as our family.

What didn't help?

- Worrying about things I couldn't change. I've stopped doing that.
- Pity doesn't help.
- It would have been better for our daughter if we had expected more from her. I once went to a conference session where they said that future success is determined by how involved a child is in doing chores at home. It is very easy to do too much. Later, it does not add to their confidence or motivation. A child can really benefit from a good balance of love and expectation that they contribute to the best of his ability.
- Trying to just use my family and friends for support. I also didn't have much luck with counseling.

As the primary caregiver/keeper of records/go-between for your child, what particular difficulties have you had? Do you feel that medical, educational and other professionals have treated you differently because you are female? How, and

what have you done about it?

- I come on very strong at the doctor's office - I'm all business. (One time a nurse at the urologist's office asked me what my medical training was!) I do this so the doctors don't dismiss me as a worried or overbearing mom. I treat the encounters like I would treat a business meeting and find that I get the best results that way!
- I felt respected because I came across as knowledgeable, prepared, and persistent. It was clear that we were involved and prepared to do our part in partnership with the school so that our daughter's needs would be met. It was also clear that we knew what our rights were. In the school system we interacted with, there were mostly females in leadership roles. We were also fortunate to be in a town we could work with.
- I don't think I've been treated differently as a female. It's all what you choose to put into it.
- One of the difficulties is that you can't pick and choose your own doctors. It is also difficult when you have the same type of doctors suggesting different things for the same issue. Who do you follow?

What advice would you have for a mother who has just learned that her child has spina bifida?

- Find other families in your area - hook up with your local chapter of the SBA - read anything you can. I wish I had met with other families and adults with SB before my baby was born but I didn't - all I did was read books and materials from the doctor's office. By the time my daughter was born, I was imagining the worst! If I had met some other families I would have seen happy, productive people with SB.
- Get the best insurance you can get so that your child will have the availability of the best medical care possible. Become knowledgeable about every aspect of SB. Look beyond what is available in the immediate area. If possible attend national conferences where professionals around the country share info. Get support from wherever you need it. Everyone's needs and resources are different. Have as much fun as possible. If your child is in the hospital, have someone stay with them, especially at night. Take care of yourself so that you have the strength and positive attitude you need in the years ahead. Follow your gut instincts (most important point); you know your child better than any professional. Become an advocate for your child, and then teach them to advocate for themselves to the best of their ability. Be careful about your attitudes since your expressions and attitude are a mirror to your child. If you tell them enthusiastically that their new purple Velcro strapped braces are beautiful and their silver wheelchair is really fast and so cool they will integrate those kinds of positive feelings.
- Become a stronger person, a stronger couple with your spouse. You will need to rely on each other for support.
- Only talk to people that are educated about this subject and talk to other people that live with it.

If your child/family attracts attention in public, what do you think about and/or what reaction do you have?

- I hate when people really stare. I mean, people look at people, we all do, but there's a difference.

I figure they're just curious. I know that I would steal a glance if I were in their shoes. I try to be polite and pity them for they'll never know my child's true beauty.

- I realize that people do not mean to be unkind, it is mostly ignorance. A sense of humor is important. In the early years kids get a lot of attention because they look adorable in their tiny little wheelchairs and leg braces. Most of our kids are extremely cute. I think children look at how their parents are reacting. Just keep smiling. Work out how you feel so that the reactions of other people don't rattle you. Building up a child's self esteem and confidence will get them through every situation. It doesn't hurt to talk with your child about how people will look at them because they are curious because no one in their family has leg braces or a wheelchair and simply because when you are beautiful people love to look at you.
- If it's children I try and explain the best I can. Depending on how I'm asked or approached will determine how I might react. Most of the time I'm brief and just say she has spina bifida.

What particular benefits/joys has having a special needs child brought to your life?

- Patience, amazing experiences, love. I feel that in spite of the challenges, our life has been an amazingly rich experience. I would do it all over again. I have learned what is meaningful and what is possible. I have no patience for pettiness and shallowness anymore. Every life is precious and we are all here for a reason. Children with disabilities are great teachers to everyone around them.
- The biggest is that when she does accomplish something it's 10 times more exciting and it was something I know she had to work twice as hard to accomplish. Also I have met some really great people, some of whom I have built a great relationship with.

Comments and other advice:

- I know for now that my kids are my top priority. If I can manage to squeeze a little time in there for myself, yeah!
- Educate yourself the best you can about whatever your challenges might be and then, pray a little bit!
We learned to become educated about SB as it was our job to educate the school about our child's needs. In order to do this you need to prove what you need with medical reports, articles, etc. I would advise young families to start a file. Any meeting you have, go prepared. It is best to try to establish a good relationship. You can be firm but it is counter-productive to become adversarial or nasty. Showing gratitude helps. People react well when you point out that you have noticed and appreciated their efforts and it helps when the time comes for requests.

Many thanks to the SBAC moms who bared their hearts and souls for this article. An excellent book for those who want to read more of how moms think and feel is From the Heart: On Being the Mother of a Child with Special Needs Edited by Jayne D.B. Marsh, published by Woodbine House, 1995.

SPRING WEEKEND RECAP

The SBAC Annual Spring Outing at Harkness State Park was held April 26-28.

We were blessed with gorgeous weather and had a great turnout. The kids painted flower pots that were then planted with beautiful marigolds. Each one was so pretty and unique. Everyone had a fantastic time finding candy eggs hidden outside! The food was plentiful and delicious (many thanks to Joanne Field who once again planned the menu and did all the shopping!)

If you didn't make it to this outing or haven't taken a trip down to one of our weekends yet, why not join us in the Fall? There's always lots of food, fun and friendship. The Fall Weekend is planned for October 25-27. Watch upcoming newsletters for all the details!

There are only two ways to live your life

One is as though nothing is a miracle.

The other is as if everything is.

- Albert Einstein

HELP WANTED

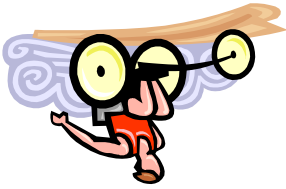
The SBAC is looking for a **Certified Public Accountant** to assist in auditing the organization's financial records in preparation of attracting corporate sponsorships for fundraising purposes.

Benefits are many and include a pleasant working environment, good friendship, the occasional coffee and cookies, feelings of personal fulfillment and many thanks from the entire organization!

If you or someone you know would be willing to help in this way, please contact Jerry Beck at (860) 583-9426.

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

The NEAT Marketplace (New England Assistive Technology) invites you to attend a **Grand Opening Celebration** at their new, expanded location. The event will be held Thursday, July 18 from 10 am to 4 pm. at the new location at 120 Holcomb Street in Hartford. There will be over 35 vendors, the latest assistive technology products and fun prizes! For more information, directions and a list of gently used adaptive equipment for sale, contact the NEAT Marketplace at: (860) 243-2863 or visit their website: www.neatmarketplace.org.



<i>Austin Wheaton</i>	<i>Abe Vaughn</i>
<i>Millie Suggs</i>	<i>April Sportbert</i>
<i>Sam Sage</i>	<i>Lauren Roseman</i>
<i>Carlos Quiles</i>	<i>Ryan Pelletier</i>
<i>J.T. Marcil</i>	<i>Jaclyn Lanzetti</i>
<i>Bobby Jenner</i>	<i>Mandy Hinkel</i>
<i>Sam Cohen</i>	<i>Shaun Bucchere</i>
<i>Chelsea Bilodeau</i>	<i>Mary-Christine Beck</i>

Good luck to all the athletes, especially these members of the SBAC who are competing in this year's event:

The National Sports Festival for the Disabled will be held June 24-30th at Connecticut College in New London. The festival, affiliated with the National Disability Sports Alliance (NDSA), is recognized as a premier host of athletic competitions for athletes with a disability. Events focus on showcasing talent as well as providing an opportunity for competing against others of similar ability. For more information, please call (860) 267-6757 or visit: www.nationalsportsfestival.org.