

Spina Bifida Association of Connecticut, Inc.

March 2002

INSIDE THIS ISSUE:

- Bowl-a-Thon Recap,
Page 2
- Committee News,
Page 3
- Spring Weekend,
Page 4
- "Super Saturday",
Page 5
- A Look Into Our
Dad's Hearts & Minds,
Page 6
- Marine Marathon,
Page 10
- Medicaid News,
Page 11

THE SPINA BIFIDA ASSOCIATION OF CONNECTICUT, INC.

P.O. Box 2545
Hartford, CT 06146-2545
1-800-574-6274
<http://sbac.org>

ACTING PRESIDENT:

Jerry Beck
JerryB@sbac.org
(860) 583-9426

SECRETARY:

Michele Duclos
MicheleD@sbac.org
(860) 292-8794

TREASURER:

Janet Lanzetti
JanetL@sbac.org
(203) 481-9669

NEWSLETTER:

Marybeth Petersen
Newsletter@sbac.org
(860) 673-4310

A Letter From The Acting President By, Jerry Beck

Dear Members:

I have recently assumed the responsibilities as President of the SBAC. For personal reasons, Dennis Maloney has decided to withdraw from his role as president. I have been involved with the SBAC from its inception and will continue to give it my dedication in this position.

As a parent of a teenager with spina bifida, I feel a strong desire to be a part of an organization that has provided my family with insight, direction, and friendship. I would just like to touch slightly on what belonging to the SBAC has meant to my daughter. Coming to the SBAC events since she was a small child has enabled her to make friendships with others that will last a lifetime. In her day-to-day life many friends surround her, but the friends she has made through the SBAC are a treasure to her. They are kids that are experiencing physical challenges much the same way as she is. They get together and have good times and share a very special bond, which has a positive impact on all of them. In addition to the kids, adults have bonded and learned from one another. We wish these opportunities for all the members of the SBAC. Please join us at any of our upcoming functions.

I wish to take this opportunity to thank former President Dennis Maloney for his hard work, diligence, and guidance. His involvement over the years with the SBAC has been invaluable and deeply appreciated. Best wishes to Dennis and his family.

Additionally, I would like to thank the members of the Board of Directors and all those involved in "making things happen". We have a wonderful group of individuals who work extremely hard at making this organization a success. We are striving to reach higher goals and dreams and we hope to bring on board other individuals that will assist in achieving this. The SBAC already has so much to offer and we all have great ideas for the future, but we need you to help. We hope that you will consider how you can become more involved in the SBAC.

Sincerely,

Jerry R. Beck
Acting President, SBAC

BOWL-A-THON 2002 RECAP

BY, DARLENE BILODEAU

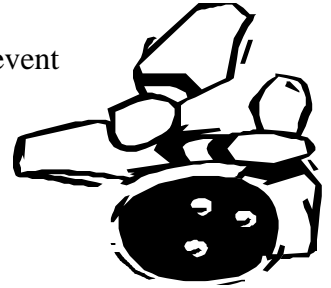
Hello Everyone-

Spring is almost here and that means another bowl-a-thon has come and gone. First and foremost I'd like to thank Fred Liguori for his countless hours of work in getting the Norwalk bowl-a-thon up and running. A huge undertaking to say the least! We raised approximately **\$14,000.00** this year. Not quite as much as last year's event, but nothing to shake a stick at.

We had a great day and it's always good to spend time with friends and family. As always, we want to see more of you. Have you ever attended a SBAC event? Maybe 2002 is your year to get involved! Hopefully we will be able to post some pictures of the event on our website (sbac.org).

Last but not least, I'd like to thank everyone who volunteered their time on the day of the event and also in preparation for the bowl-a-thon. This event wouldn't be possible without **you!**

Have a great day and I/we hope to meet some new members in 2002.



ADULTS WITH SB NEEDED FOR RESEARCH STUDY

Doctors at the Kirch Center at Strong Memorial Hospital in Rochester, New York are looking for adults, aged 40 or older, with spina bifida to participate in a research study. The study aims to improve care for children with spina bifida by studying the experiences these adults had with childhood experiences at home, in school and in their neighborhoods as well as in the medical system and how these experiences helped them form resilience to foster productive adult lives.

If interested in participating in the study, please contact Dr. Nienke Dosa at (315) 445-8872 or send an e-mail to: dosan@upstate.edu.

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.

Materials in this newsletter may be reproduced without permission, provided proper credit is given.

No endorsement of any product or procedure which appears in this publication is given or implied by the Association.

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>.

Thanks go out to our very special angels,
Alice & Rick Lombardi.

Through their generosity and kindness, 31 families of children with spina bifida in Connecticut received a toy or clothing gift certificate this past December through the SBAC Angel Program.

The Lombardi family has funded and assisted the growth of this program for many years through their extremely generous annual donation.

Thanks also go out to
Mr. and Mrs. Clinton Harvey

for their annual donation
which is also deeply appreciated.

AWARENESS COMMITTEE NEWS

BY, FRED LIGUORI

In past newsletters you have read about the formation of committees within the SBAC to help the Board of Directors achieve the primary goals of the organization. One of the goals from the Strategic Planning meeting held last September, was to increase public awareness of spina bifida. With that goal in mind the **Public Awareness Committee** was formed. I have been selected by the Board of Directors to build and Chair that committee.

During the next six months we intend to have informational booths and displays at town fairs throughout the state. Last year my wife Jill and I had such a booth at the Milford Oyster Festival and we felt it was very successful. We spoke to numerous people throughout the day that wanted to learn about spina bifida. We also met a number of families, in one way or another affected by spina bifida, which did not know about our organization. We intend to provide the same informational service this year at the Milford Oyster Fest, the Norwalk Oyster Fest and the Mystic Chowder Fest at a minimum.

I am looking for individuals willing to assist on this committee. If you have an interest in improving the public's awareness of spina bifida and reaching more individuals and families within the state affected by spina bifida, I need your assistance. I realize most of us do not have much spare time these days and we will work around that as well. I will not ask you for more time than you are willing to give. If your city or town has a local fair and you would like to help provide information at that event only, let me know. I will help you the day of the event and provide all the necessary supplies.

One person does not make a committee and our goal of increasing public awareness cannot be accomplished without your help. If you are willing to help, please contact me at (860) 653-1976 or Jerry Beck at (860) 583-9426.

ASSESSMENT COMMITTEE NEWS

Congratulations to **Jim Heus** of Ridgefield! Jim was the \$200.00 winner of the needs assessment drawing who most graciously contributed his winnings back to the Association at the Norwalk Bowl-a-thon.

We'd like to thank all those who participated in the completion of the assessment. You have given us beneficial information on the services sought from our organization.

If you haven't already sent us your completed assessment, it's not too late. Please take a moment, fill it out, and send it in! We need YOUR feedback!

Thanks!
The SBAC Needs Assessment Committee

VOLUNTEER GRANT MONEY FROM SAFECO

The SBAC thanks SAFECO Insurance Company for their \$250.00 grant to the organization. SAFECO supports their employees' volunteer efforts and annually awards a grant to employees who contribute a specific amount of time volunteering for a particular organization.

Once again this year, SAFECO presented their employee, **Stephanie Beck**, with the \$250.00 volunteer grant to be presented to the SBAC.

If you work for a company that recognizes volunteer efforts in such a way, look into it. Volunteer some time to the SBAC - we need you!



SPRING WEEKEND AT HARKNESS PARK

Friday, April 26 (after 6 PM) – Sunday morning, April 28, 2002

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! Whether you stay for the day or plan on bunking down for the weekend, there's fun to be had for everyone. 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: 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.

**PLEASE RSVP BY PHONE BY APRIL 20th
to Joanne Field at (860) 528-1510.**

In order to plan our events, it is imperative that you RSVP so we'll have enough food and overnight accommodations for everyone. Thank you for your consideration, see you there!

- ▶ Please bring a dessert to share with the group.
- ▶ If you plan to stay for the weekend, pack like you're going on a camping trip. You should bring all your own personal items, toiletries, bed linens and medications. Cabins will be shared among members of our group. If you are unsure of what to pack or what will be provided, please ask Joanne Field when you RSVP.
- ▶ *For information about Saturday afternoon's festivities or to **volunteer to help with the party portion of the weekend**, please call Marybeth Petersen at (860) 673-4310. Your help would be greatly appreciated!
- ▶ For directions to Harkness Park, visit the SBAC web site at: [HTTP://sbac.org](http://sbac.org)

P.S. Save the date for our Fall Outing at Harkness which will be held on October 25-27.

SUPER SATURDAY

BY, FRED LIGUORI

Today is Saturday, March 16th, the deadline for articles to be submitted for the April newsletter. It also happens to be the day Connecticut Children's Medical Center held "SUPER SATURDAY" for children with spina bifida and their families. Shortly after the day began at 9:00 this morning I knew I would have to return home and immediately write something for this newsletter regarding Super Saturday. The day consisted of divided programs for parents and their children and was absolutely fantastic!

The parents program began at 9:00 with a seminar by Jim Loomis, PhD titled "Teaching Independence with Self Care." Dr. Loomis is an extraordinary speaker and the information he presented was extremely informative for parents of children of all ages with spina bifida. Elli Meeropol, MSN, RN, from Shriners' Hospital, followed with a seminar titled "Bowel & Bladder Management." Elli is one of the most informative individuals in the area regarding bowel management, something we can never seem to get enough information about. Matt Luginbuhl, PT, followed with a seminar titled "Motivating Kids to Move" about the benefits of a more active lifestyle and how to make it happen. And finally "Having Fun with Fiber" was presented to the children and families together by Certified Dietician, Pam Roscow. The seminars ended around 1:00 followed by lunch.

I have attended the last two SBAA National Conferences in Milwaukee and New Orleans. The information provided at CCMC today was as good, if not better, than the seminars at National. The day was informative, convenient and free of charge. It doesn't get any better than that. I spoke to Stacey Richer from CCMC, who together with Michelle Engel organized the day, and asked if this is something they could do again. She seemed to think they could. If at all possible, I highly recommend that you attend. You will not be disappointed.

I would like to express my sincere thanks and gratitude to Michelle Engel, from the SBAC Board of Directors, and Stacey Reicher from CCMC for coming up with the idea of Super Saturday and organizing the day. A very special thanks to Dr. Jim Loomis, Elli Meeropol, Matt Luginbuhl and Pam Roscow, who sacrificed their Saturday and gave exceptional presentations. And not to be forgotten, a special thanks to the volunteers who babysat the young children while their parents attended the seminars. I know there is a special place in heaven for the two ladies that put up with my 4 month-old son, Matthew.

ADAPTIVE EQUIPMENT DONORS & BUYERS WANTED

Are you looking to buy gently used adaptive equipment like a stander, walker, etc.? Do you have any such items taking up space in your garage or attic? If so, here's good news for you! The NEAT (New England Assistive Technology) Equipment Restoration Center is now open in Hartford!

Have equipment to donate? The "Neat Marketplace" accepts donations of equipment, in good condition, for resale (at fantastic prices) and will furnish you with a certificate for a tax deduction!

Need to buy a piece of specialized equipment? At the Neat Marketplace, you can try before you buy and take the equipment home the same day! You can even view an on-line inventory at: www.neatmarketplace.org before you head down to the store.

The NEAT Marketplace
120 Holcomb Street - Hartford, CT 06112

Open Monday-Friday
8:30 a.m. – 4:30 p.m.

Telephone (860) 242-2274 or toll-free in CT 1-866-526-4492

LOVE, DAD.

A LOOK INTO THE HEARTS & MINDS OF SOME FATHERS OF CHILDREN WITH SPINA BIFIDA

BY, WENDY GARIZIO

Recently I purchased a book for my husband called UNCOMMON FATHERS: Reflections on Raising a Child with a Disability. Although he hasn't read it yet, I did and found it to be a wonderful insight into some of the things that he might be thinking and feeling about our daughter. I adapted some questions from the book into a survey for fathers of children with spina bifida, and the results of that survey follows in this article. Here's what some of our dads think:

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

- About four weeks before birth a sonogram picked up the spinal deformity. Due to the position in the womb, it was not apparent to our doctor until late in the term.
- Three weeks prior to my daughter's birth my wife was experiencing low back pain and was admitted to the hospital. During an ultrasound, it was then diagnosed.
- Following delivery, during the "cleaning of the baby", I noticed a quarter-sized clear patch at the base of the spine.

What was your reaction, your first thoughts?

- Fear. Anger. Adoption.
- What is SB? Is it a birth defect?
- Surprised. Scared. Thought we were going to lose the baby.
- At first it was uncertainty due to ignorance of SB, but prompted an internet search for info. At confirmation, it was gut wrenching fear and borderline nausea, and sadness.
- Overwhelmed with the initial diagnosis. It took some time to get over the initial shock, then acceptance.
- First thoughts were to get her to a neurosurgeon at another hospital for an evaluation, we delivered at a community hospital with no intensive care nursery. I was concerned that we get whatever was needed. It wasn't until later that I found out all that was involved.
- Sadness for my wife, and child.

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

- My wife wanted no part of the baby. She had been in the hospital for several months waiting for the birth. She wanted the baby to be adopted because she did not feel she could care for her and the other children. I did not want to give the baby up and persuaded my wife that we would somehow manage.
- My wife's heritage precludes her having a reaction. She manifested very little emotion one way or another.
- Mother: at different location than the intensive care nursery, much more emotional. Father: Back and forth between hospitals, very focused on the facts, and no "gut" feeling of any serious danger, I somehow knew that it would be ok in the long term.

How did other family members react?

- Everyone suggested abortion.
- Their initial reaction was that it wasn't going to be as bad as WE thought it was. They were sad but comforted us.
- Some were shocked, terrified & terribly sad, others were encouraging & spoke of how fortunate the child would be to be born to us.
- There were a variety of reactions, but, as a whole, everyone jumped in with support and care.
- Apathy, nobody really knew much about it.

How has your perception of spina bifida changed over time?

- I began with complete ignorance & now am well informed of the condition. Nonetheless, the public at large has little understanding.
- I know what it is now. I've come to think of it as an adjective in the description of my son, no different than cute, smart, big or small.
- I think initially that I believed that our lives would be chronically adversely affected. At this point we have grown so accustomed to everything that I rarely think of my daughter in terms of having SB. She is who she is and how she is.
- To see a person with spina bifida and to see what they can accomplish is so uplifting.
- Our perception changed as we experienced pleasant surprises watching our daughter learn to do things the doctors originally said she might not be able to. Since we were unaware of spina bifida until our daughter's birth, we had no early perceptions.

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

- Worry that my other children have "less" of me. They probably don't for they understand their sister's needs are extraordinary, but I worry about this.
- I don't really have any concerns with our other child, but because of our first child's SB I know I'll pay a lot more attention to him than I normally would have. SB challenged me to become a more interactive parent, and our other child will benefit as a result.
- That he won't be supportive of his sister's needs. Won't respect her or give her the understanding she needs. That he'll make fun of her.
- I feared that my other daughter would be denied attention, material items and a degree of her own childhood as she was forced to assume responsibilities in the care of her sister.
- My daughter at times may need additional attention due to her condition and I wanted to be sure that my other children did not feel that I was taking any time away from their lives. Also, I don't want them to feel that they have a responsibility for their sister's care as they grow older and it's a nice feeling when I see them helping her in any way possible.

- We do not have any other children, so one of our biggest challenges was determining whether certain behaviors were, in fact, normal vs. a side effect of the condition. Since the doctors could only tell us generalizations and we had no other children, it was sometimes difficult to detect a problem. Also, the fact that children with spina bifida can vary widely with regard to their challenges made it difficult to anticipate.
- Our daughter was mainstreamed in school right from the start, and was able to do quite well with only a small amount assistance as she worked to overcome the organizational challenges most of these children face.

How has being the father 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?

- I have devoted a disproportionate amount of time to our daughter's care and worry that my other children have "less" of me. They probably don't, for they understand their sister's needs are extraordinary, but I worry about this.
- I'm more involved being a father and caregiver than I ever expected to be.
- I've had to become more patient and accommodating towards my family. No matter how well things are going medically, SB still raises the level of stress in the household and I've realized that it's too easy to lash out at those closest to me. So, I've had to become more accommodating, understanding and patient a person than I ever was before.
- I'm more understanding of my children and family. Try to be around home more often.
- I think being a father of a SB child has increased the value to the time I spend with my family. We are building a home that is designed to improve her quality of life. Every consideration put into the design of the home was factored around her needs and abilities. Given the potential for her to spend a disproportionate amount time indoors relative to other children, her interests were paramount to all other design and decorating considerations.
- During the first few years of my daughter's life it was difficult to adjust to the needs of her medical care. When my daughter was first born all I wanted was that she be independent. She has already exceeded my expectations. As a parent I will always be concerned of her health and I have become stronger to deal with obstacles that I am confronted with when it comes to my daughter and the dealing of spina bifida. We have to make modifications to our home to make it accessible for my daughter's mobility and in the future her driving a vehicle will become another challenge to deal with.
- Our biggest challenge was adapting to the difficult schedule requirements for doctor visits, hospital stays, & sudden need to respond to changes (shunt failure, for example) in our daughter. These children do not become independent as quickly as others do.
- Yes, dealing with physical, & mental issues takes a lot of time. Having a kid with SB is like having 2 kids.

How has it changed your view of your work?

- I work in a school and educators are not always as well informed as they need to be.
- I'm self-employed and my business is different now than before SB. The big difference is time; I cannot waste time at work because it will cost me time at home. As a result my productivity increased.
- Made work take a back seat. Lower priority.
- Work is means by which I can provide and care for my girls, nothing more. The paradigm shift that occurs so effectively marginalizes the importance of work that effort needs to be exercised just to convince me that it matters at all.
- In my professional life nothing is different. I am very involved in the Spina Bifida Association of Connecticut and I hope that the time I volunteer can have an impact on one person's life.
- I was fortunate to have an employer who values the family and so it did not have a dramatic impact on my view of work. It did reinforce the importance of family over career however. I come from a strong close family & so had this background at the start.
- At first work was not as important, after adjustment to life with SB work (life) seems to be back to normal.

Has it changed your philosophy of life?

- Yes and no. I see every life infused with challenge, and our daughter's is more obvious than most. Philosophically, I remain positive and hopeful and don't dwell on the "what ifs".
- Abilities can overcome any disabilities. When I see someone with a disability, I know in some way, he is a very special person and can offer a lot to society.
- I have learned that life is to be lived, and that it is an adventure!
- Things happen all the time and we should work with the changes and not waste time worrying about what the next change will be, but, rather, experience and enjoy what is happening right now
- Yes, more tolerant of people with disabilities.

Has it changed how you relate to your family?

- I have assumed the bulk of our daughter's care and frankly, the fact she is not self-cathing and taking better care of herself is wearing me down and I am less tolerant of others as a result.
- I am very positive and encouraging about my feelings when it comes to my daughter as it relates to spina bifida and I always make the attempt to express those feelings to my immediate family.
- Not really, I come from a strong and close family. We have always had a strong support network within.

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

- A lot of unknowns. I see a fairly normal educational life but beyond that it is hard to imagine her as an independent adult.

- I see success. I'm not sure what he'll do for work, and I don't really care. I expect he'll enjoy what he's doing as much as I enjoy what I'm doing. That's success, and that's what I see in his future.
- I see a woman in a wheelchair with a smile on her face. I see a loving and caring person.
- I have a great deal of hope for my daughter's future, given society's growing acceptance of handicapped people. We always have hope that the vast sums of money directed towards research will yield some breakthrough. I am still concerned about the painful and frustrating times she will go through socially, emotionally and physically, as she grows up.
- I am a very lucky person when it comes to my daughter. To see how she has developed into a bright independent person, her accomplishments and abilities. I foresee no obstacles in her way to set out to achieve her desires.
- I see a young lady who can and will choose her path, and who has the will to achieve whatever interests her. I also have learned over the years that challenges can be met and so do not see barriers for her.
- Hopefully, independence, and if not - a strong support system.

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

- Yes. I always enjoy being with other parents of Spina Bifida children. Seeing others cope and struggle helps to reassure me that I am not alone.
- Literally thousands of people have helped us with our son. Doctors, nurses, therapists, counselors, teachers, family members, volunteers, the list stretches on and on.
- Knowledge about SB helps. A lot of knowledge.
- My daughter's personality is so wonderful - she's so sweet and happy and that's what gets me through. Nothing phases her. She's always happy and makes me forget about SB!
- My wife's ability to care for our daughter's needs and handle the mountain of medical paperwork has eased my mind's burden while I am working, because I know my daughter is well cared for I can do my job better and tolerate the day to day. Her efforts to track the medical bills and deal with the providers and insurance has probably saved us more money than I earn.
- My wife has been my support and has always been encouraging and uplifting.
- My involvement with the Spina Bifida Association has opened the doors of support from other parents and I am able to offer my support to others when it's needed.
- Our strong family has helped tremendously. The next groups in line, the SBAC along with the Cruisers, were the best things to happen to us. Through our work with them, we learned about spina bifida and how to cope with issues very specific to that. The group itself has been wonderful for sharing information and for sharing concern.
- Inner strength, time with my child.

What didn't help?

- Guessing doesn't help. SB requires us as parents to be decision-makers concerning our son's medical treatment. In order for us to cope the best with making important decisions concerning his care we don't guess on anything. We try to know all we can about SB and its associated problems.
- We question doctors & treatments constantly. It is up to us to decide a course of action concerning his treatment, & for us to be comfortable with our decisions we cannot guess that because we like a doctor his recommendations will be best for our son. Knowledge helps; guessing doesn't help our son.
- Seeing how some of the other children with SB haven't done so well.
- When seeing the same person always expressing sorrow for her condition.
- The doctors and hospitals are very challenged with having information regarding raising a child with spina bifida. They understand the medical challenges, but do not have the experience and knowledge for dealing with schools, etc. This is where an organization like SBAC does it best work.
- Incompetent therapist.

If you are NOT the primary caregiver/keeper of records/go-between for your child, what advice would you have for schools and other agencies to assure that the other parent (usually the father) is brought into the loop?

- Neither my wife nor I will let the other out of the loop.
- If I could see a copy of the visit reports (similar to what early intervention leaves) that would be helpful for my wife and me!
- I think it is the responsibility of the 'other' parent to see to it they are involved, informed and in the loop. The primary is often overwhelmed with day to day maintenance of the household and childcare. The other parent needs to ask questions, attend appointments and otherwise inform himself of what's involved in their child's life.
- Only to advocate it, we always prepared and attended together on every significant meeting. Keep the father informed.

If you ARE 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/male? How and what have you done about it?

- We had petition the school for a classroom aide. (It worked). Haven't had any difficulties with medical services. I do wish that there was a way to better coordinate all the doctor's we see and that there was one 'point guard' physician who would help to oversee the many medical matters. Yes, in theory, the pediatrician should do this, but it doesn't always work this way.
- My wife and I play 'good cop, bad cop' with just about everyone who deals with our son. This allows us to get the tough questions asked and still not be too abrasive. Basically, most doctors respect what we have to say because we're informed and educated about SB and our son in particular. Any doctor who doesn't listen to us is discarded. We deal with professionals who take us and our son's

SB treatment seriously.

- I've been very fortunate in dealing with medical and educational professionals involving my daughter's life. If you ask a lot of questions and be proactive in what you want and need for the benefits of your child any obstacle can be overcome.

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

- Be patient. Stay connected with other Spina Bifida parents on a regular basis.

- Learn what SB is and what you'll be dealing with. Decide with your spouse what you need to do as a family. Don't let anyone else dictate to you what you should do. Look for advice, seek advice and answers, but do not put yourself into a position that one day you'll look back on and regret someone else making decisions for you. When you learn your kid has SB, there are no easy decisions. But be sure that you and your spouse make the hard decisions for your family and your child. There will be a lot of people offering a lot of advice, but none of them will live with the results of their advice.

- Do as much research on it as you can so you understand what it is and how it's managed, ways of prevention in the future.

- I would tell them they are in the darkest point of the journey and that though there are certainly difficult times ahead, the spina bifida is not omnipresent or all consuming. The difficulties you and your child will face will be secondary to the love and joy that you and your child will share as a family. Also, educate yourself; seek the best medical care you can, even if it means travel. Not all medical care is equal and there is no substitute for good doctors you can trust, for both your child's health and your peace of mind. Fight for and protect your child in all instances, if you, especially Moms, have a 'feeling' regarding your child, trust it and pursue its resolution.

- Learn as much as you can about spina bifida and most importantly stress to your child the ability to be independent and you will be amazed of their accomplishments and this alone will make you a very happy person.

- Get in touch with the local support group and/or other parents ASAP!

- There is much to know which is not in print or available at the hospitals.

- Contact the SBA for the latest publications and for chapter information.

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

- She doesn't attract too much attention. She is used to the stares and doesn't say too much. She really hates it when people try to speak with her in a manner they wouldn't use with her brother and sisters.

- We realize that most of the people staring at us are much uglier than we are.

- I get embarrassed. I try to straighten her legs out so she will fit in better.

- My daughter is 2.5 and has a wheelchair that she is quite skilled at using which draws a lot of attention. It is almost always polite; people smile and subtly point her out. I by and large don't mind nor does she but sometimes there is the problem of people getting way too close to her and she can't easily move away.

- If someone asks I simply explain that she has spina bifida and needs assistance in her abilities to walk.

- People who cannot see beyond don't really count. Self-esteem is everything.

- Protective, but willing to talk as long as the questions are not too stupid, or insulting.

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

- In many ways it has given me focus and stopped me from allowing my job to consume me.

- My son is the best thing that has ever entered my life.

- Every time I think of my daughter, I smile. No matter what life brings kids they cope with it and make the best of it and they're just happy. It amazes me!

- Reinforces the fact that we only know what we are.

- I have no other joy than I have from my other child, there are no benefits or joys beyond her being her.

- It makes you realize the importance of a person's goals and accomplishments and the amazement of seeing these experiences first hand and can be so proud of your child's life.

- Each time he overcame an obstacle or performed something we did not expect, it was a special surprise, a wonderful occurrence.

- The same joys as my non special-needs child does.

Comments?

- As a father it is your duty to be strong for both your child and your family. If you are upset about your child's condition don't let them see you cry. They need you for strength. I know it sounds macho, or tuff but it is a reality.

YUMMY, HIGH-FIBER RECIPE

Even picky kids will like this one and it's great for spring and summer picnics!

Wild Rice Fruit Salad

2 c Cooked, chilled wild rice	1/4 c Chopped Italian parsley
1/2 c Golden raisins	2 T. Lemon juice
1/2 c Green pepper, chopped	1 t. Curry powder
1 c Seedless grapes	1/2 c No-fat mayo, <i>or enough to moisten the grains.</i>
1 Bunch green onions, sliced	

Combine all ingredients and allow to sit for at least one hour.

Servings: 4, **Fiber: 4 grams**, Calories: 204, Total Fat: 1 gram.

MARINE MARATHON NETS \$2,800 FOR THE SBAC

A great big salute and special thanks go out to **Bill Leahy, Trish Hagar, Phil Grey** and **Bob Pagoni** who recently ran in the United States Marine Marathon and raised \$2,800 in donations for the Spina Bifida Association of Connecticut.

The group is active in Fred Liguori's National Guard Unit and are friends of Fred, Jill, Nicholas and Matthew.

Fred said that the idea to use the marathon as a way to raise funds for the SBAC was entirely thanks to Bill . Unfortunately, Bill was injured while training shortly before the marathon and wasn't able to run. However, the funds raised wouldn't have been possible without Bill's unselfish idea.

The marathon was Trish's first ever **and** she completed the race! What a tremendous feat! Trish was responsible for raising over \$2,000 of the total amount.

Many thanks to Bob, Phil, Trish, and Bill on behalf of the entire membership of the SBAC!



INSTEAD — BY, HUYGEN HILLING SUBMITTED BY, WENDY GARIZIO

Instead of walking with you

I will crawl with you,

Instead of talking with you

I will find ways to communicate with you,

Instead for focusing on what you cannot do

I will reward you with love for what you can do,

Instead of feeling sorry for you

I will respect you.

WHAT IS THE MARCH OF DIMES?

The March of Dimes was founded in 1938 by President Franklin D. Roosevelt and Basil O'Connor, to find a cure for polio. Roosevelt himself was afflicted with the disease and his personal struggles with polio inspired his efforts to help others. By 1955, after years of March of Dimes funded research, the war against polio was won. The March of Dimes achieved its goal and became the only voluntary health organization ever to defeat its targeted disease. In 1958, the March of Dimes turned its attention to the nation's single largest child health care problem, birth defects. One out of every 14 infants born in the United States is stricken by one of over 3,000 distinct maladies, including spina bifida and other defects of the brain and spine. The March of Dimes continues working to improve the health of these precious babies, by preventing birth defects and infant mortality through programs of research, community services, education and advocacy.

Everyone IS someone who has been touched by the March of Dimes. The March of Dimes has funded research which has assisted in the development of polio vaccinations; newborn screening tests, particularly for PKU, for which every baby is tested at birth; neonatal intensive care units; surfactant therapy to help babies with underdeveloped lungs breathe; and the list goes on. In 1996, following three years of advocacy efforts by the March of Dimes, the FDA approved the fortification of enriched grain products with folic acid, a B-vitamin found to help reduce the risk of birth defects of the brain and spinal cord. Since the March of Dimes began its folic acid education efforts three years ago, neural tube defects have dropped 19% nationwide. That means 500 babies in the U.S. have been saved from possible life-threatening birth defects. Women contemplating pregnancy should begin taking folic acid at least three months prior to conception. Folic acid can be found in most multivitamins or in leafy green vegetables, peanuts, orange juice and whole grains.

Anyone who wants free information about folic acid and healthy pregnancies can call the March of Dimes toll free at 1-888-MODIMES. Multilingual health information specialists are available from 9 a.m. to 8 p.m. EST to provide general information or answer specific questions. Questions may also be directed to the March of Dimes Connecticut Chapter by calling toll-free at 1-800-446-9255.

MEDICAID NEWS FOR EMPLOYED DISABLED PER-

A new state program is eliminating a 'Catch-22' situation that forced people with disabilities to choose between going to work and keeping their health insurance. The 'Medicaid for the Employed Disabled' program, administered by the Department of Social Services, allows individuals to earn up to \$75,000 and still keep the medical and personal care services they need to live and work in the community.

"No one should have to choose between a job and health care," said Social Services Commissioner Patricia A. Wilson-Coker. "For too long, people with disabilities have been discouraged from pursuing their goals in the workplace because of restrictive Medicaid rules. With this initiative, Governor Rowland and the legislature are saying that special needs for health coverage won't hold you back from your right to enjoy a career and bring your talents to the job market."

To get information and an application for the new Medicaid for the Employed Disabled Program, call a local office of the Department of Social Services. For the location of the nearest DSS office, check the blue government pages of your phone book or call Infoline at 211. Information is available on-line at www.dss.state.ct.us/divs/medemp.htm.

People with disabilities interested in applying for vocational rehabilitation services can call 1-800-537-2549.

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

A rectangular box with a decorative border of small floral icons. The text inside is centered and reads: "Spring Weekend at Harkness Park April 26 - 28 Details Inside! Hurry - RSVP By April 20th!"

A large rectangular box with a decorative border of a repeating zig-zag pattern. The text inside is centered and reads: "Gab on the phone and help your favorite charity! To date, the SBAC has received over \$500 from SNET! 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."