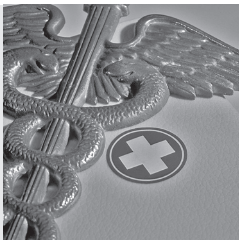
sbaMass news

Spring 2011 The Newsletter of the Spina Bifida Association of Massachusetts



sbaMass

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YEARS

1971-2011

Letter from the President

by Cara Packard

Spring is FINALLY here and change is in the air. It is so nice to see some green grass and even a few crocuses instead of all that snow. Baseball and sunshine are always a welcome change. As we start this new season, SbaMass will be welcoming many changes to our organization as well. You will be finding the majority of these changes as we head into the summer months.

As you will find in the beautiful pictures inside this newsletter, SbaMass kicked off Spring with a blast, or more accurately a wonderful new program called BLING (Better Living `N Girls). On March 4-5, ten young women with Spina Bifida and their mothers gathered at the Omni Parker Hotel in Boston for a weekend of learning, bonding, and healthy pampering. As you can see from the articles and photos, everyone involved had a wonderful time and learned a lot about themselves and healthy living. You can learn more about this event by clicking on the BLING link on our website. SbaMass is grateful to Children's Hospital and the Metro Women's Alliance for their collaboration and grant which allowed this event to happen. We are especially grateful to Rebecca Sherlock, MSN PNP, the coordinator of the Myelodysplasia Clinic at Children's Hospital and SbaMass board member, who conceived this idea and brought it to outstanding success. SbaMass is already looking forward to BLING 2012!

In other new developments, I am very excited to report that our plan to expand our service area to include our neighboring New England states has almost reached completion. We are awaiting final approvals. While SbaMass has always welcomed anyone from the neighboring states to participate in our events and access our services, our official chapter status has been focused on Massachusetts. As we move forward with our expansion plans, we will be able to offer services and events in some of our neighboring New England states, such as the event we helped sponsor in Augusta, ME last November. We expect the approval process to be completed by June. At that time, we will have a big announcement of our new service area and name change. That's right - starting sometime this summer, we will be moving forward with a new name that reflects the larger population that we will be serving. None of our current programs, staff, and services will go away, but we will be operating under a new name. So keep your eyes peeled for our exciting new beginning.

You will be able to see many of these changes on our new website that will launch in July. Since early 2011, SbaMass has been working to revamp our website to make it more user-friendly. We hope that you, our constituents, will be able to find our events and services more easily. Again, although our look may be changing, the website will reflect the same mission and energy that we have committed to you in all of our previous years.

While you are on our new website, please take the time to find our Walk N' Roll information and sign up yourself, or a whole team of your supporters, to participate in our 2nd annual Walk N' Roll, scheduled for September 25th at The Endicott Estate in Dedham, MA. We already have a number of teams signed up to Walk N' Roll and hope to have you join us as well. Last year was a tremendously successful day, in raising awareness and community spirit, as well as much needed funds for our organization. We have many volunteer opportunities in our Walk N' Roll committees. You can find information about these on our current website, in this newsletter or on our Facebook page. We hope that you will be able to join us once again in this fun and adventurous day.

Hopefully some of you will be making the trip to CA in June to attend the SBA National Conference at the Disneyland Hotel. As in previous years, SbaMass will award conference scholarship money to assist some of our constituents with the cost of attendance. The conference is a wonderful opportunity for networking with individuals and families living with Spina Bifida. If the trip to CA is too far for you, hopefully you will be able to attend our regional conference in October. For the first time, SbaMass will be joining forces with SBA of Connecticut in sponsoring a regional conference on October 1, 2011 in Sturbridge, MA. The conference planning committee is working hard to ensure that you have a fun and educational experience there. We hope you will be attending!

Among all of the changes, SbaMass will still be offering our traditional events this spring and summer. We are especially looking forward to celebrating our 40th birthday with all of you at our annual summer picnic, date and time TBD. As always, please check our website, our Facebook page, or simply call the office to receive information on when and how you can join us.

I wish you all a very happy and healthy spring!

BLIN'G Weekend a Success!

On March 4th and 5th 10 girls, ages 11-16, and their parents arrived at the Omni Parker House, Boston for the Inaugural **BLING (Better Living n' Girls) Weekend**, a weekend of fun, social and learning activities. Upon arriving at their rooms each girl received a welcome balloon and goody bag. **Ms. Wheelchair Massachusetts 2010, Santara Sen**, joined us Friday evening to share her experiences. There was also a game of BLINGO, winners were **Julia Gouveia**, **Karina Nordhal** and **Antonetta Bowen**. Log onto **www.sbaMass.org** for a photo gallery!

Saturday was jam packed with happenings. The girls all had the opportunity to have a makeover, received a Reiki therapeutic massage, and learned about exercise, healthy eating and body image. The parents also had the opportunity for a massage and attended a presentation entitled "School Days to Pay Days" presented by **Amelia Robbins-Cureau**, Work without Limits. Late afternoon Saturday the group walked a block up Beacon St. to MOOO Restaurant for a late lunch in a private dining room. Following lunch, everyone in the group was exhausted, but energized and ready for BLING 2012. Planning is underway for next year, more girls and hopefully two nights.

Many thanks to **Metro West Women's Alliance**. The MetroWest Women's Alliance, is a collaboration of the United Way of Tri-County and the MetroWest Chamber of Commerce. The MetroWest Women's Alliance provided financial support for the BLING Weekend. The mission of the MetroWest Women's Alliance is to educate, engage and empower women and girls.

Sincere appreciation to **Rebecca Sherlock**, MSN, PNP, Myelodysplasia Clinic (CHB). Rebecca coordinated the speakers, goody bags, balloons, massages and makeovers and lunch. Rebecca's energy and enthusiasm, made BLING the terrific weekend it was. THANK YOU Rebecca!

Thanks and Appreciation

- Children's Hospital-Boston (CHB)
- Maria Carvalho (CHB) - Human BLINGO
- Julia O'Connell Hunter (CHB) - Commit 2 B Fit
- Suzanne Anzalone & Alyssa Chiaradonna - De Anza Salon & Spa , Andover, MA
- Maggie Dylewski - (CHB) Eating Right with Color
- Dawn Hown (CHB) The Balanced Plate
- Cindy Graziano & Marilyn Moonan-(CHB) Reiki Massage Therapy
- Rosemary Grant (CHB) - Goody Bag Donations
- Annette Bradley - Gift Bags with Baked Goods
- Tocci Dental Associates - Goody Bag Donations
- Herminai Shermont (CHB) - her participation and support
- Karen Sites sbaMass Board of Directors - BLINGO Logo Design
- CHB Child Life - Balloons
- Anonymous Benefactor - Lunch at MOOO

Ms. Wheelchair Massachusetts 2011 Megan Mamaty

I was born in Boston on April 26th, 1981. When I was two my sister was born and my family moved to Quincy, Mass where I spent most of my childhood. I attended public school until about fourth grade. When my baby brother was about a year old I started at the Massachusetts Hospital School in Canton, Mass. I went to MHS until 2000. After graduation I returned home for about a year and went to beauty school to become a nail tech.

After finishing beauty school I moved into my own apartment and I am proud to say that I have had the same place place for about ten years now. For the past ten years I have held various volunteer jobs. These jobs have included, a video project through Children's Hospital Boston, my local animal shelter, a nursing home and speaking at UMass Boston and mentoring for Partners for Youth with Disabilities.

In my spare time, I love hanging out with friends, listening to music, almost any outdoor activity and playing with my four cats.

Welcome to our new Board Members

Karen Sites

I live in Bangor, ME where I was born and raised, with my 2 children David, 7 and Emma Grace 2 and my husband, Joe. I found out David was going to be born with Spina Bifida when I was about 16 weeks pregnant.

I had never even heard of Spina Bifida before that day. Since then we have been through many surgeries and countless hours of therapy. But David is doing excellent and is an inspiration to me everday. We have also met many wonderful people including everyone at sbaMass that we are grateful to have a part of our life. I am excited to be working with sbaMass as a board member to continue the great work they are doing in Massachusetts throughout New England. In addition to being a mom and board member, I work from home as a graphic designer and homeschool David. Our days are busy and blessed.

Brandon Casten

Brandon Casten joined sbaMass as a board member in September of 2010. Brandon had been living in Pittsburgh for the prior 5 years and working with a non-profit called the HOPE Network, which focuses on athletic programs for people with disabilities. His brother, Ryan, has Spina Bifida and was an active participant in the athletic programs in Pittsburgh.

Brandon moved back to his native New England in the summer of 2010 with Ryan and his fiancé, Carolyn. They reside in Brookline, MA. Brandon has been in the insurance industry since his graduation from Bowdoin College in 2004.

SAVE THE DATE

Saturday, October 1, 2011

8:30 AM - 4:30 PM

New England Spina Bifida Conference-
Spina Bifida and Families:
Understanding the Issues,
Celebrating the Strengths

Sturbridge Host Hotel and Conference Center
Sturbridge, MA

Medical Research Corner

Medications Taken During Pregnancy Linked to Spina Bifida

by Virginia Briggs

I don't usually write about the prevention of Spina Bifida (SB), because I think most of our members are more interested in living with Spina Bifida, but this recent research report seemed worth mentioning. The research results were recently reported as the result of a large, well-designed study about birth defects. The study had some interesting findings, and one of them involved the potential effects of taking certain types of medications before or during pregnancy.

Supplementation with folic acid during pregnancy has been well documented as a safe and effective way of reducing the risk of giving birth to a child with SB. In families where SB already exists, taking folic acid before and during pregnancy is even more important. However, there has been limited research on other exposures linked to the prevention of or cause of SB. A recent report published through the National Birth Defects Prevention Study found a higher rate of SB cases in children of women who had taken certain kinds of pain killer (analgesic) medications during pregnancy.

The National Birth Defects Prevention Study is a multi-site study that gathered information about mothers and their infants who were born between 1997 and 2005 in 10 states (including Massachusetts). The study focused on 30 different major birth defects as well as various exposures before and during pregnancy. Women were asked about many types of exposures, including medications taken that contained any type of opioid analgesic. The opiates that were considered were medications that contained any of the following: codeine, hydrocodone, meperidine, oxycodone, propoxyphene, morphine, tramadol, methadone, hydromorphone, fentanyl, or pentazocine. Any dosage of these medications was counted and the time of interest was 1 month before conception to 3 months after conception. Out of 17,449 women, 454 reported taking at least one of these medications during this period.

It was found that women who took any of these medications were twice as likely to give birth to infants with Spina Bifida. The chance of other types of birth defects was also increased, including several types of heart problems and gastroschisis (a defect of the intestines).

Though this study provides just one piece of evidence about what may be linked to Spina Bifida and other birth defects, it is important information and medications taken just before or during pregnancy (even over-the-counter) should be discussed with your physician.

REFERENCE: Broussard CS, Rasmussen SA, et al.; National Birth Defects Prevention Study. Maternal treatment with opioid analgesics and risk for birth defects. American Journal of Obstetrics and Gynecology. 2011 Feb 21.

Save the Date for the 2nd Annual Walk-N-Roll for Spina Bifida!

September 25th, 2011

Endicott Estate in Dedham, MA.

WALK-N-ROLL for Spina Bifida

The Walk-N-Roll for Spina Bifida is a family-friendly, 1.5 mile walk event being held to raise awareness about Spina Bifida and celebrate the accomplishments of the over 180,000 Americans living with SB. All proceeds are used for programs and services for people living with Spina Bifida.

To volunteer, contact Wendy Potts at wpotts@sbamass.org.

Start recruiting your team members now!
www.walknrollsbamass.org

Special Needs Planning: Why We Need to Act Today

This article is the first in a series of pieces that New York Life has created to help foster awareness of the vital need for financial and estate planning for families with special needs.

If something were to happen to you today, who would be there to protect your loved ones – particularly those with special needs? Think of all your current and future special needs-related expenses, such as special residential homes, employment assistance and other costs. While it may be difficult to meet these obligations now, imagine the implications after you're gone.

As you probably know, the government provides several programs offering financial assistance, primarily Supplemental Security Income (SSI) and Medicaid, but not without conditions. SSI provides monthly cash benefits used for food, shelter and clothing; Medicaid provides comprehensive coverage, including medical care and equipment as well as rehabilitative and custodial services. However, if a disabled individual receives funding for any of these purposes from an alternate source, the government cuts back support. For example, eligibility for SSI payments can be jeopardized if a disabled individual has more than $2,000 in his or her name. Moreover, if you are a caregiver who needs to ensure government funding for a loved one whom you are not legally obligated to support (e.g., an adult child), you may be limited in what you can spend on that person, and more importantly, what you can leave to that individual as part of your estate. Funds used to place a loved one in the residence of your choice, for example, can be deemed income and jeopardize eligibility for government benefits. Even gifted funds, inherited assets and unstructured beneficiary designations on such assets as life insurance, IRAs and pension plans can affect eligibility as well.

A Special Needs Trust is a planning tool that offers an affordable way to meet the ongoing needs of a loved one, while at the same time helping to financially secure their continued care should something happen to you – without affecting eligibility for government funding. Specifically designed to provide funds to supplement the basic expenses, a Special Needs Trust may also help pay for additional items not covered by SSI or Medicaid, including education, recreation, travel, travel guardians, transportation, vacations, cable television, computers and more.

Imagine that something happens to you today. Are you certain that your disabled loved ones will receive the care that you want for them? Do you have a plan in place that will ensure continued support without jeopardizing government benefits? Are you concerned that your other children may miss out on opportunities due to special needs-related expenses? Many individuals delay planning, often creating disastrous consequences for their families and disabled loved ones.

As the parent or guardian of a special needs child, New York Life agents Daniel Manea and Mark P. Raupp have personal experience with the sensitive issues and worries unique to families with disabled loved ones. They are dedicated to helping other families design, fund and implement comprehensive financial and estate plans to ensure that the care they give now will last a lifetime, not only for their loved ones with special needs, but other family members as well. This educational third-party article is being provided as a courtesy by Daniel Manea and Mark P. Raupp. For additional information on the topics discussed, please contact them at 508-616-4902 or 508-616-4910.

new balance
FALMOUTH
ROAD RACE

Team sbaMass will once again participate in the 39th running of the
New Balance Falmouth Road Race
on Sunday, August 14, 2011.
The race's Numbers for Non-Profits program has given sbaMass 25 charity numbers.

In 2010, our dedicated Team raised over $35,000 for sbaMass!
We hope to reach $40,000 in 2011.

Interested in running for Team sbaMass?
Contact Wendy Potts at wpotts@sbamass.org

Embracing Freedom

The Emotional Journey of Mobility

"I'm multi-mobile!" laughs Marianne DiBlasi of Winchester, Mass. Her gray titanium crutches, stowed neatly behind her, extend above her wheelchair like a flag on a bike. Embracing her mobility devices and appreciating them for their value have been a life-long process for Marianne. A process that has brought increasing freedom.

Marianne describes her relationships with braces, crutches, and wheelchair as though they were with people. The relationships have changed throughout the years as Marianne has changed her way of thinking about mobility and her disability. She has grown to respect these devices for the doors they open for her.

Coming Full Circle

Born with Spina Bifida, Marianne learned to walk with full-length braces—treatment for drop foot. When she was 7, she was able to use half length ones—what today would be called AFOs (ankle-foot orthotics). But Marianne's braces were not the custom-fitted molded plastic AFOs of today. They were steel, with brown leather orthopedic shoes—the kind Forrest Gump wore. "I longed for pretty shoes," she remembers. "My braces were ugly and they kept me from wearing the shoes I wanted to wear. They were something to be gotten rid of."

When she was in high school, Marianne had a surgery that allowed her to leave her braces behind. She celebrated with a new pair of shoes in blue suede, and didn't wear braces again for 35 years. But at the 2009 Spina Bifida Association (SBA) National Conference, Marianne began to notice how many people were wearing AFOs. She became curious, and questioned an orthopedic doctor who recognized the signs of drop foot, and suggested that she might find AFOs helpful.

"It was emotional—going back to wearing a brace," Marianne recalls. "I thought my surgery had let me leave them behind forever." When she first got her AFO, it lay in the bag for three days before Marianne could muster the courage to try it on. "It was extraordinary how much easier it was for me to walk with the AFO," she says. "I hadn't realized how much effort it took to pick up that foot, and how I had to contort my body to do it. I couldn't believe I had been walking that way for 35 years!"

Mobility in Public

Having used crutches all her life, Marianne's relationship with them had a different character—a more public one. "Crutches are the first thing people see when they look at me," she observes. "Kids stare at them, and strangers ask, 'What happened to you?' That question puts the burden of responsibility onto me to figure out what they're referring to—my crutches? Is there a stain on my shirt? Is my hair green?"

Marianne has given her answer to that question much thought. In the early years she would try to explain her Spina Bifida. But it didn't take long to discover that an honest answer made people uncomfortable. Thinking her condition was a temporary injury, they were embarrassed they had asked. They pulled away.

So Marianne experimented with different answers. "It was a sky-diving accident," or "I broke my leg on the ski slopes." These answers maintained connection with people, but as Marianne matured, she settled on an approach that raises awareness. "Are you referring to my crutches?" she will now say. "Asking them to qualify what they're referring to - my crutches - is my way of saying it's okay to talk about disability openly and directly."

Marianne stubbornly used wooden crutches for many years, thinking they looked more 'temporary' than aluminum ones. When she finally tried aluminum crutches, they were lighter, but squeaky. She knew she'd fully accepted her crutches when she bought her new sleek, gray titanium ones. "They're cool looking," she says. "And when you're investing up to $1,000, you know you've accepted their permanence in your life."

Strolling Toward Freedom

After 51 years of walking with crutches, Marianne bought her first wheelchair. "I'd always thought of a wheelchair as the dreaded thing to be avoided at all costs," she explains. "I thought it would limit my mobility. And it sent the message of permanence I was trying to avoid." She would sometimes use a wheelchair at an airport, museum, or theme park, but she hated the lack of control she felt when people pushed her.

Again, it was her experience at an SBA conference that opened her eyes. Marianne saw many people who used a wheelchair as a choice, and she found that they could go faster and farther than she could walking with her crutches. "I used to plan my time at the conference by the location of the sessions and how far I would have to walk. Now I go to the sessions I want to attend without worrying about getting tired," she says.

Marianne did her homework before ordering her custom-made wheelchair. She consulted with expert fitter Joe Thieme at the conference, and chose a chair outfitted with a holder for her crutches, and no handles on the back so that no one is tempted to push her. "It's fabulous!" she boasts. "It's lightweight and fits in my trunk. When I travel, I'm not exhausted by a trip through an airport."

Her new-found freedom has allowed Marianne to experience places she could not have enjoyed before. She frequently takes public transportation now, and once accompanied a friend on a 4 ½ hour "strolling" tour of the neighborhoods of Boston. "There's a bike path near my home that circles a lake," she says. "I take long strolls there now. The trees, the birds, the sound of leaves rustling under my wheels. These are things I couldn't revel in when all my energy and attention was absorbed just by walking."

Article title was reprinted from Insights Into Spina Bifida, SBA's national magazine, with permission from the Spina Bifida Association.

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Note: The information in this newsletter is provided solely for informational purposes. It is not intended to be, nor is it, medical advice on the management or care of a person with Spina Bifida. Although every effort is made to assure that information is accurate and current, knowledge in the field of Spina Bifida is growing rapidly and all data are subject to change without notice. Neither the SBA of Massachusetts nor any parties who supply content to this publication make any warranty concerning the accuracy of any information found herein. The sbaMass does not endorse any specific medical regimen. You should not change your medical schedule or activities based on the information provided in this publication. Always consult with a doctor, health care provider, or other medical professional before making any medical decisions. The sbaMass does not employ medical personnel in its organization.

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