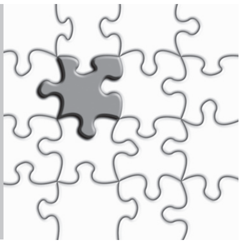
sbaMass news

Summer 2010 The Newsletter of the Spina Bifida Association of Massachusetts



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Letter from the President

Cara Packard

Happy summer everyone! Hopefully all of you are already enjoying your warm weather activities. SbaMass has been busy planning our events and activities as well.

We kicked off our summer season with the First Annual Walk-n-Roll on May 23 at the Endicott Estates in Dedham, MA. As you can read in further detail inside this newsletter, the event was an outstanding success on many levels. While the fundraising was fantastic, the energy and wonderful sense of community generated by our group on this day was even more appreciated by all who attended. On behalf of our Board of Directors, I thank all of you who worked so hard to make this event such a success. In particular, we appreciate the many hours dedicated by our Operations Team, Ellen Heffernan-Dugan and Wendy Potts, as well as the many hours given by Joe and Denise Mearn, the backbone of our fun raffle. We hope that many more of you will be inspired to join us in this wonderful event next year.

This year the SBA National Conference took place in Cincinnati, OH with the theme of Leading the Way to the Future. SbaMass was proud to be able to send 7 individuals and families to conference this year through our scholarship program, a number of them first time attendees. A special congratulations goes to the Cardenas family, chosen for the first MaryJo Dunleavy scholarship. We hope that their experience will reflect the wonderful learning and social experience that MaryJo always recommended through conference.

Please mark your calendars for July 24, the date of our annual summer picnic. This year we are trying a new venue, Hale Reservation in Westwood, MA. We will still have the same food , games, and fun conversation. The reservation also has a sand beach for swimmers of all ages to enjoy. Details and directions are enclosed inside the newsletter. Let's hope for good weather!

For those who really like to plan ahead, we will be hosting a fall gathering in Western MA at Stanley Park in Westfield on October 3rd. Stanley Park has an ADA playscape that comes highly recommended by some of our families. We plan to invite SBA chapters from Connecticut and Albany to participate as well. Sounds like a fun way to spend a beautiful New England fall weekend.

For those of you in or near Maine, you will be pleased to know that SbaMass is collaborating with interested parents to become a bigger presence there. We know that some of our most competitive Walk-n-Roll teams hailed from Maine, so we look forward to being there with you.

On behalf of the Board, I invite any of you who might be interested in joining our committees or Board to reach out to us. We are always appreciative of new ideas, faces and energy. Early this fall we will be hosting an informational event for those of you who may want to help.

I hope to see many of you at our events over the summer months. I wish all of you a very happy, healthy Summer!

On Sunday, May 23, the Spina Bifida Association of Massachusetts held its first annual Walk-n-Roll for Spina Bifida at the Endicott Estates in Dedham, MA. Over 200 people from all over New England came out for this family-friendly event. Walkers and Rollers took on a 1.5 mile course and helped build awareness about Spina Bifida. Following the walk, Walkers and Rollers were able to connect with members of the community. This was not only a fundraising event, but a celebration!

The Walk-n-Roll for Spina Bifida is being held in various locations across the country to raise awareness about Spina Bifida and celebrate the accomplishments of the over 180,000 Americans living with it. All proceeds are used for programs and services for people living with Spina Bifida.

The name "Walk-n-Roll" was selected because it embodies a sense of inclusiveness and invokes the sense of empowerment which the Spina Bifida Community embraces in all that it does. A belief in a better tomorrow is our vision and the steps taken in this walk represent steps on a path to realizing that dream.

Over $30,000 has been raised for the Spina Bifida Association of Massachusetts through the Walk-n-Roll for Spina Bifida. This is a remarkable amount for the first year! Donations are still being accepted at www.walknrollsbamass.org. Thank you to all who participated and volunteered! You made the Walk-n-Roll a success!

Plans for the 2011 Walk-n-Roll for Spina Bifida are already underway. If you would like to be a member of the Walk-n-Roll Committee or would like to volunteer, contact Ellen Heffernan-Dugan at edugan@sbamass.org.

Congratulations!

TOP 5 FUNDRAISERS

Marianne DiBlasi
Amy Michalowski
Denise Mearn
Yvette Anger
John Regan

TOP 5 TEAMS

Olivia's Smile
Amazing Grace
Marianne's Movers and Shakers
Tiny But Tough
Dino's Dynamos

Turn the page for more photos! ☞ ☞ ☞ ☞ ☞ ☞ ☞

Walk-n-Roll Brings Hope

by Veronica Demer

I am a 41 year old woman born with Spina Bifida. Growing up I never got involved in any type of support organization. Recently I have been suffering a major battle with depression and anxiety. It was recommended that I find others like me, that are going through similar challenges. I decided to look at the Spina Bifida Association website. My children were sitting beside me and noticed the first sbaMass Walk-N-Roll being held at the Endicott Estates in Dedham MA on Sunday May 23, 2010. They were quick to say “Mom we can do this”. They told me they would help me. They knew deep in my heart I always wanted to get involved and help others like me.

My husband (Bob) our children (Drue and Grace) and myself, with about two months left, recruited our team which Grace named Veronica’s Angels. In this short period of time my team existing of family and close friends were able to raise over $1000. Bob, the children and I started Walking-N-Rolling around our local high school track to prepare for this mile and half challenge. My niece Nicole with her artistic abilities helped us design t-shirts.

On Sunday May 23, 2010 Veronica’s Angels arrived at the First sbaMass Walk-N-Roll. I was so blessed seeing children and adults like myself. This strength inside me that I forgot was there started to awaken. At 10:30 when the walk began Veronica’s Angels where in the back of the crowd. A little voice inside of me said let’s do it. I started pushing myself and before I knew it I could hear my team members shouting there she goes. Bob, Drue and Grace and her friend Mikayla quickly caught up to me and cheered me on. A few pushes on the hills from Bob, and cheers from the kids. I was able to cross the sbaMass Walk-N-Roll finish line first.

Talking to others after the walk helped me realize that I am not alone in this world! There are others like me going through these same types of challenges. This has left me with a overwhelming feeling of encouragement and strength. I just wanted to say thank you sbaMass for one of the most enjoyable days of my life. I look forward to getting involved in helping others both young and old like myself. We can overcome any obstacle in our way! One last note, get ready Angels for next year. I am greatly thankful and love all of you!

Walk-n-Roll Memories

by Yvette Anger

When I first found out that sbaMass was hosting the Walk-n-Roll, I immediately signed up our family as **Team Olivia's Smile**. Since the birth of our youngest daughter, learning everything about Spina Bifida and educating others became a mission of mine. Our team grew very fast. I was really amazed to see how many people we chose to call friends and family wanted to come out and support us.

Every time we met our fundraising goal I would then log in and raise it. I figured that if we could raise $1000 then we could raise $3000. Then when we raised $3000 I figured that we could definitely raise $5000. I knew that we also needed T-Shirts showing our pride and joy, Olivia on them. We have to thank our cousin **Meg Sartini** and the generosity of **Diman Vocational High School** for them.

I was really nervous showing up for the walk at first. Not really knowing what to expect. I had talked with some families up at Children's Hospital on Clinic days, but really hadn't met many families with Spina Bifida. To my surprise we met our first family in the parking lot, **the Sites Family from Maine**. I also managed to find a family that I had met at Clinic the previous month, **the Wilson Family**. This helped me a bunch. It is a great thing to know that there are people out there that I can always turn to for advice and support for no other reason that we share this bond.

My team was also very excited. Excited for my family, for our daughter Olivia and mainly just happy to be able to support us in something that really meant a lot to us. We all really can't wait for next year's walk. Our goal for fundraising will be a lot higher. I guess this is where my obsessive compulsive personality pays off. I am hoping to bring as much awareness about Spina Bifida as I possibly can. My other 3 children had so much fun with the DJ, games and the raffle that they also cannot wait for next year as well.

Save the Date!

Annual Summer Picnic

New Date and Location!

July 24th
Hale Reservation
Westwood, MA

See insert in this newsletter!

Thank You!

The following companies have recently matched employee's gifts to sbaMass:

Bank of America
Verizon
Arbella

If you are uncertain if your employer has a Matching Gift program, log onto www.sbaMass.org and link to Matching Gifts.

Insights Subscriptions

SBA's quarterly magazine, serves to educate and enlighten with articles about medical conditions, employment, family issues, advocacy, research, and SBA activities. 1 Year subscriptions are available for $25; 3 Years for $66 and 5 Years for $90. Log onto the SBA website www.sbaa.org and click on Marketplace.

SBA Announces 2010 Award Recipients

The Spina Bifida Association recently announced 2010 Award Recipients. Awards were presented during the 37th Annual SBA Conference, Celebration Luncheon held on June 30th in Cincinnati, Ohio. Both sbaMass nominations were chosen as winners in their categories. They are the **sbaMass Chapter for Community Outreach Award** and **SBA Young Adult Leadership Development (Santara Sen)**.

The Spina Bifida Association of Massachusetts (sbaMass) annually participates in several outreach activities related to prevention of Spina Bifida and Folic Acid awareness. These include, bridal fairs, women's expos, health fairs and other community events. Typically attendees move quickly through an exhibit hall and there is just a brief opportunity to grab their attention. The sbaMass developed a business size card with "Fast Facts about Folic Acid" derived from SBA materials. The card reads:

Fast Facts about Folic Acid

- All women who could possibly become pregnant need 400 micrograms per day
- Most women don't plan a pregnancy, so it is important to get in the habit of taking folic acid every day so your body has it when you need it.
- Folic Acid is most important when building new cells, like before and during pregnancy.
- Folic Acid helps reduce the risk of neural tube birth defects by 70%.
- Folic Acid can be found in: vitamins, Folic Acid pills; Food Sources: Cereals, grains pasta ½ cup chickpeas, 1 cup cooked frozen peas, 1 cup of strawberries, 1 medium orange, Dark green leafy vegetables, ½ cup steamed broccoli, and whole wheat bread.

For more information log onto www.sbaMass.org

This card is attached to an item i.e.: key chain, pill box. These items are easy to distribute and are welcomed by most all attendees, men and women. Frequently an individual will request a second or third for their daughter, daughter in law, niece or neighbor.

The sbaMass has accomplished three goals with each interaction: outreach to women and their partners about the benefits of folic acid, awareness of the Spina Bifida Association and a positive contact with sbaMass. For individuals who request, additional information is available at the booth.

YOUNG ADULT LEADERSHIP AWARD: The Spina Bifida Association of Massachusetts (sbaMass) nominated **Santara Sen** for the Young Adult Leadership Development Award.

Santara Sen received a Bachelor's degree in Psychology with a concentration in Child Psychology in May of 2009 from Bridgewater State College. Since graduation, she has continued to work on behalf of children with disabilities at Challenger Camp in Norwood and also the Massachusetts Hospital School in Canton. She hopes to go back to school for a degree in Early Childhood Education and become a kindergarten teacher in a public school system in Massachusetts. Santara took course on disability issues while in college and signed up to be a part of the ADA New England's Student Advisory Group. This group assists people with disabilities share their stories through video. Her video is available on You Tube, type in " Sanatara's Spina Bifida Disability" .

These factors and her own confidence and perseverance helped her secure the title of Ms.Wheelchair Massachusetts 2010. (www.mswheelchairmass.org). In November 2009, Santara was crowned Ms. Wheelchair Massachusetts 2010. It was important for Santara to have this role because when her parents first found out that she was going to be born with a disability (Spina Bifida), they were overwhelmed with the news. At the time they did not know who to turn to for help or advice and felt very much alone. She does not want other families to go through that. Instead she wants families to know that there are resources and people who can help them.

Santara has participated in events related to disability awareness at the Massachusetts State House. In addition, Santara was the Honorary Chairperson for the Inaugural sbaMass Walk-n-Roll held in May. Her platform during her reign is to raise disability awareness. This year she hopes to not only advocate for the rights of individuals with disabilities and their families, but to convey the message that people with disabilities are just like everyone else. Santara wants to work towards eliminating stigma associated with disability about what we "should do" and replacing it with the things that we "can do".

As Santara has moved into her post college years, she has begun to expand her leadership and advocacy skills. Santara has exhibited skills as a teacher and coach working with young children, a leader in advocating for disability rights at the state level and as a mentor in her role as Ms. Wheelchair Massachusetts.

The Spina Bifida Association of Massachusetts is pleased to have the opportunity to work with Santara.

2010 sbaMass Conference Awards

Seven individuals or families received Conference Awards to attend the 37th Annual National Conference, held this year in Cincinnati, Ohio. Children and adults with Spina Bifida, their families, physicians, nurses, and other clinicians had the unique opportunity to gain information on the latest medical care and network on various issues which affect their lives and professions. Attendees have the chance to learn up-to-the-minute information about urology, orthopedics, neurology, neurosurgery treatment: Attend workshops and special programming that address specific interest areas; Network with various interest groups - from others living with Spina Bifida to health professionals and product manufacturers; Find out how researchers are paving the way for more knowledge about Spina Bifida and Hear from leading Spina Bifida partners about the important role advocacy plays in our Community's success.

If you were unable to attend this year, watch the sbaMass Quarterly News and the website www.sbaMass.org for 2011 Conference and Award information.

Congratulations to the 2010 recipients!

The Batty Family
Marianne DiBlasi
Robyn Hand
The Hartwell Family
Genevieve Medeiros
Steven Niedzwiecki

Thanks!

Hannah Farrell and the Farrell Family

As in years past, Hannah and her family have raised funds donated sbaMass.

Hannah hosted a home party with Jenny Boston www.jennyboston.com.

THANK YOU to Hannah and her family for their ongoing support of sbaMass.

Mary Jo Dunleavy Conference Award

The sbaMass is proud to announce the recipient of this year's award:

The Cardenas Family

Congratulations!

Bits & Pieces

Ellen Dugan, Executive Director

- Check out the Family Support Center on Disabilities: Knowledge and Involvement Network at www.familysupportclearinghouse.org. Subscribe to their newsletter. This month they have focused on transition from high school, planning for college etc.
- Dave Carl, author, is an individual with Spina Bifida living in Washington State. He recently had a children's adventure book published called "Super Cyclist". The book is about a person who has used a wheelchair his whole life. He always wanted to fight crime but he was told by his peers that he couldn't because he's in a wheelchair. He doesn't let that stop him. He decides to become a superhero using a special handcycle to protect people. Dave is a social worker by education and would like to use this book as a tool to teach children (with and without disabilities) to believe in themselves. The book will be available on Amazon.com shortly.
- A new 55-page guide from the Family Center on Technology and Disability (FCTD) helps families learn how assistive technology can help them with transition planning for their youth with disabilities. It includes contributions from PACER Center. A free copy is available at fctd.info/resources/newsletters/upload/FCTD-AT-&-Transition-Guide.pdf. An accessible online version also will be available. Individuals may order one free print copy of the guide. Additional copies are available for $10.
- SUMMER ACTIVITIES: 1) New England Wheelchair Athletic Association (NEWAA). Volunteer organization that helps individuals with physical disabilities participate in recreational and sports activities. The NEWAA provides opportunities for athletic competition by sponsoring regional and local meets. 2) Piers Park Adaptive Sailing Program provides programs for disabled youth and adults aboard 23-foot sonar sailboats on a no charge basis. Serves those with amputations, paralysis, cerebral palsy, muscular dystrophy, autism, hearing impaired, sight impaired and other disabilities. Successfully integrates youth with disabilities into summer youth sailing programs. Scholarships are available for all adaptive sailing programs. Contact Maureen, Adaptive Sailing coordinator, maureen@piersparksailing.org, (617) 561-6677.
- Tips for Using Assistive Technology with Young Children Assistive technology (AT) is anything that helps people do what they couldn't otherwise do. For young children, it can make daily activities, family outings, and playtime more fun and educational. AT can be as simple as a foam grip on a crayon. Find many helpful tips in the March issue of the Tot'n'Tech newsletter from Thomas Jefferson University and Arizona State University. www.tnt.asu.edu/files/march2010
- Assistive Technology Guide to assist in transition Planning: A new 55-page guide from the Family Center on Technology and Disability (FCTD) helps families learn how assistive technology can help them with transition planning for their youth with disabilities. It includes contributions from PACER Center. A free copy is available at fctd.info/resources/newsletters/upload/FCTD-AT-&-Transition-Guide.pdf. An accessible online version also will be available. Individuals may order one free print copy of the guide. Additional copies are available for $10.
- SBA has a new publication "Bowel Management and Spina Bifida" It is available thru SBA. Log onto www.sbaa.org and click on Marketplace.
- Two great websites: For young girls/teens/women. The Center for Young Women's Health of Children's Hospital. They have a companion site for young men as well. Visit: www.youngwomenshealth.org

Who put the “A” in ASSUMING?

Tracey Craven, sbaMass Parent

What is it our parents or grandparent always said: “You know what they say about assuming it makes you look like an a**.”

The same goes when Advocating for a child or young adult with special needs.

Do not assume whatever you are being told by an Agency or Medical Practitioner is all there is to hear. You have a degree in your child. As a guardian, parent and loved one of your child, you know them better than anyone else in the world.

Just because you don’t have a degree in Medicine, Psychiatry … whatever we do not know, we can find, what we can’t find, we can ask that professional or an Agency. In some instance some agencies still have the “Don’t ask don’t tell.” That can be even more true, especially in dealing with State and Federal Agencies.

Now a days, thanks to the world wide web we have unlimited access to knowledge and resources. Frankly, in dealing with the professionals, it can really tick them off having an educated parent/guardians. A majority of the Agencies, healthcare professionals only see inside the box. That person or agency in the position of *Assuming* you and/or your partner don’t know anything! Most of the time, they are the ones, mostly through no fault of their own, who are not vested enough in the patient care or it’s not in their job description. That is unfortunately what many are taught now a days.

We as Advocates, can use that to our advantage. We don’t know everything for sure, but sometimes we need to ever so gently remind the people who are taking care of our child, stating they have “their best interest at heart”, that they don’t know everything either. Believe me, like in the wild , some people smell fear, and if you speak English as a second language or do not have a lot of experience in dealing with Agencies or in Healthcare or Medicine…some will try to take full advantage of this.

Never Assume all that is said is so and never assume we know everything. Communication, and clarity, and having resources like the sbaMass and SBA is always “A” in my book. Like they say in the newspaper biz, double check, triple check your facts!

Then we all don’t look like A****.

THE MASSACHUSETTS
CONFERENCE
FOR WOMEN

Your Time Is Now!

December 9
BOSTON

6th Annual Massachusetts Conference for Women

December 9, 2010

Boston Convention and Exhibition Center
Registration is open!

sbaMass is a Supporting Organization for 2010
Two of keynote speakers have been announced:

- Judge Glenda Hatchett
- author Elizabeth Lesser

Log onto www.maconferenceforwomen.org for more information

Get Ready for Team sbaMass' Running in the Falmouth Road Race!

Team sbaMass has once again been invited to run in the 38th CIGNA Falmouth Road Race on Sunday, August 15. In 2009, our dedicated runners raised $35,000 for the Spina Bifida Association of Massachusetts. This year, we have been given 25 charity entries and we hope to surpass that amount as we continue to build awareness about Spina Bifida. The money raised will be used to pay for our benefits programs, our social programs, and our scholarship programs.

The beautiful 7 mile course runs from Woods Hole to Falmouth Heights. If you are on the Cape, please come cheer the team on as they work hard for you!

Interested in becoming a member of Team sbaMass? Please contact Wendy Potts at wpotts@sbamass.org.

Visit us on Facebook!

http://www.facebook.com/pages/Spina-Bifida-Association-of-Massachusetts/171955252933

Help sbaMass "GO GREEN" and cut our costs by receiving the sbaMass Quarterly News via email in pdf format. Contact wpotts@sbaMass.org and let her know that you would like to receive the newsletter via email beginning this Fall.

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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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