sbaMass news

Fall 2010 The Newsletter of the Spina Bifida Association of Massachusetts

sbaMass

3 9

YEARS

1971-2010

Letter from the President

by Cara Packard

School has started and the leaves are changing, signs that Fall has arrived here in Massachusetts. Just like the kids heading back to school, sbaMass has some exciting new events planned, as well as some familiar news.

On October 5, sbaMass is hosting a volunteer recognition event at the sbaMass office, located at 25 Birch Street, Building B in Milford, MA. As our organization and activities have expanded over the last year, so has our group of volunteers. In addition to thanking our volunteers, we hope to encourage any of you thinking about joining as a volunteer to jump in. Opportunities abound at sbaMass ranging from serving on our Board to assisting at specific events. We would love to have you join us. If you cannot attend the meeting, but are interested in helping, please contact Ellen Heffernan-Dugan, our Executive Director, at 888-479-1900 or edugan@sbaMass.org. She will be happy to talk with you!

sbaMass would especially like to recognize the Cadete /Cadette families, and in particular, Olivia Cadette, for organizing and hosting the 2010 Golf Tournament on September 20 at Cyprian Keyes. The day was filled with beautiful sunny skies, lots of golfing, plenty of fun, and many donations to sbaMass. We deeply appreciate the generosity and hours of work that the Cadete/Cadette families provided to sbaMass. The success of this tournament will go far in assisting our programs and services.

Our other volunteer fundraising force, Team sbaMass, had another very successful year running the Falmouth Road Race. The runners and cheering fans enjoyed a beautiful sunny day and a really fun celebration afterwards. Please make sure that you check out the photos and details inside this newsletter. As always, our thanks go to the Potts family for hosting and to all the runners who trained hard, ran hard and fundraised for us.

I hope that all who attended the summer picnic enjoyed the day. I understand that the weather wasn't perfect, but I hear that many of you really enjoyed the beach and each other's company. Thanks to all of you who attended and made this such a fun event.

Please keep your eyes on our calendar for this fall, as there are a number of fun events planned. On Sunday, October 17, sbaMass is heading westward, to Westfield, MA. We will be hosting a fall gathering at Stanley Park, a park with an accessible playscape for all to enjoy. The day will include lunch, pumpkin painting, and, of course, lots of fun conversation. For further information, please check the website. Additionally, sbaMass will be co-hosting an event in Augusta, ME on November 6, for our neighbors to the north who are looking to create some opportunities for folks to get together. Please contact Ellen Heffernan-Dugan for more information if you are interested.

sbaMass will also be hosting lunch-and-learn gatherings as well as opportunities for the Young Adult Group to meet. Dates and locations will be posted on our website or you can get information by calling our office at 888-479-1900. While you are checking those locations, don't forget to mark your calendar for the annual Holiday Party on December 5. Sadly, winter will be here before we know it.

In the meantime, I hope you are all enjoying successful transitions out of summer and back to school. We hope to see you at some of our fall events. Enjoy this beautiful New England time of year!

Team sbaMass runs for Spina Bifida

On Sunday, August 15, 2010, Team sbaMass once again participated in the 37th Annual CIGNA Falmouth Road Race. A mostly cloudy morning, ideal for mid-August running, the team set out on the 7.2 mile course with inspiration in their hearts and the common goal to "run for those who cannot."

This year, sbaMass received 25 charity numbers, but we had 2 additional team members, John Jamison of Scarborough, Maine and JT Schakel of Cotuit, Massachusetts, both whom have Spina Bifida. Our 27 member team was as committed as ever to raising awareness about Spina Bifida and funds for sbaMass. On average, each of our team members raised over $900 each!

In total, our team raised an amazing $35,000! Thank you Team sbaMass!

The 38th CIGNA Falmouth Road Race will take place on Sunday, August 14, 2011.

Running for sbaMass

Thank you Runners and Sponsors!

8th Annual Summer Picnic by the lake

On Saturday July 24th members of the sbaMass community came together at Hale Reservation, Westwood for the annual summer picnic. Although the new location presented some bumps in the road, the pavilion and pond were enjoyed by many, and the rain held off until the end of the day!

Thank you to Hannaford's Markets and Whole Foods for supporting this event.






Medical Research Corner:
Research Shows Avoiding Latex Has Paid Off

by Virgina Briggs, PhD

Most parents of children with Spina Bifida (SB) under the age of about 15 years, have been told to keep their kids away from latex. With so many other health issues going on during those first few years, it may have been difficult to think about something that seemed so small compared to leaking spinal fluid and shunt surgery. However, recent research has shown that keeping a latex-free environment for kids with Spina Bifida not only reduces the risk of developing latex allergies but also reduces the development of other types of allergies.

RESEARCH STUDY DETAILS

German researchers recently completed a study where they compared the outcomes of SB children who were kept latex free beginning at birth, to SB children who were exposed to latex. They evaluated 120 children (ages 6 months to 12.5 years) who had never been exposed to latex (to their knowledge) and compared them with 87 children (ages 3 months to 11.5 years) who had been exposed to latex, beginning at birth. The groups were compared in three ways:

1) Blood test (measuring the amount of latex allergy antibodies).
2) Skin prick test (where a small amount of latex was placed under the skin and watched for allergic reactions).
3) Glove test (wear latex glove on one hand and compare skin reactions to the other hand with non-latex glove.
4) Parent questionnaire about allergy symptoms.

RESULTS

The results showed a large difference between the two groups. In the latex-free group, only 5% of the children had blood test results that showed a significant number of latex antibodies, compared to 55% of the children who had been exposed to latex starting at birth. In other words, the children who had been exposed to latex showed a sensitization to latex 10 times higher than the latex-free children. Another significant difference was found concerning airborne allergens such as various plants, dust mites, cats and dogs. Of the children who had been exposed to latex, 44% showed a sensitization to these things, compared to only 23% of the latex-free children. When they further tested these allergens separately (using blood tests), the latex-exposed group consistently had about twice the problems that the latex-free group had. It should be noted that when they studied food allergies, however, the two groups were not different. Another interesting comparison was made using results from a questionnaire completed by the parents of children in both groups. When the parents were asked about symptoms of wheezing, skin irritations and other allergic reactions, 15% of the latex-free children had shown these symptoms at some point compared to 35% of the latex-exposed children.

MESSAGE TO PARENTS

This study supports the recommendations of health professionals to avoid contact with latex through life. It is important to introduce a latex-free environment beginning at birth and continuing throughout adulthood. Avoiding contact with latex can reduce the number of complications while receiving medical treatment in the future, and may very likely reduce the number of other allergies children can develop as they grow.

REFERENCE:

Blumchen K, Bayer P, et al. Effects of latex avoidance on latex sensitization, atopy and allergic diseases in patients with Spina Bifida. Allergy. 2010 Jul 23.

REMINDER

Applications for the **2010 ANNUAL FINANCIAL BENEFIT**
Must be faxed, emailed or postmarked by midnight December 31, 2010
Applications received after that date will not be accepted
Please contact Ellen Heffernan-Dugan with any questions

ADA Celebrates 20th Anniversary

by Linda M. Long-Belli, Ph.D., J.D.

For many years, I was a mentor to a teenage girl with Spina Bifida. One day about a dozen years ago, we were talking and it suddenly dawned on me that she did not remember the days before the existence of handicapped parking. I asked her if that was so and, indeed, she was surprised to learn that handicapped parking spaces were a fairly recent invention. Being born in 1962, I certainly remember the days before handicapped parking (and my mother REALLY remembers them). I attribute this difference in our perspectives to the passage of the Americans with Disabilities Act (ADA) in 1990.

The ADA has done a lot to raise the expectations of people with disabilities and our families. But, as we know all too well, the existence of rights does not guarantee the ability to exercise them. How many times have we arrived somewhere only to find the last HP spot occupied by someone without an HP plate or placard? We have benefitted a great deal from the ADA because it has given us rights that make many things possible, but there is still a long way to go. Raising the awareness of individuals without disabilities is an ongoing task, and not only when it comes to handicapped parking.

The ADA was passed 20 years ago, but still only about 22% of people with disabilities are working as compared to 70% of people without disabilities. Clearly there is much to be done. Employers need to be educated about the skills that people with disabilities can bring to the workplace and, in turn, youth and adults with disabilities need to do more build our skills so that we can compete in an increasingly competitive marketplace. Only with individuals with disabilities, parents, educators, employers and society at large working together will we ever be able to achieve the integration and equality that the ADA was intended to create.

Research Study Participants Needed

Kennedy Krieger Institute

Do you have a child (ages 10 – 29) with Spina Bifida? Or, are you an adult under the age of 30 with Spina Bifida? If so, researchers from Kennedy Krieger Institute invite you to participate in an online research study! We are interested in learning more about how and when children with Spina Bifida learn to manage their medical self-care and home responsibilities. The study does not require a clinic visit and can be completed using a computer in your home or elsewhere. The online survey usually takes about 15-20 minutes to complete and is anonymous, so no personal information such as names, social security numbers, or IP (computer) addresses will be collected. Please be aware that if your child is over the age of 18, we will ask you to obtain your child's consent. If you have questions about this study, Dr. Zabel can be reached at zabela@kennedykrieger.org.

If you are interested in participating in this study, we invite you to go to www.psychdata.com. If you are a parent of a child between ages 10 -29, please enter survey # 128186. Adults with Spina Bifida (ages 18-29) are also encouraged to participate and will be asked to give their consent for parent ratings; please enter survey # 128187. We thank you very much for being willing to help us and other individuals with Spina Bifida by participating in this study!

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.

2010 Jean Driscoll Award Recipient

Aime Pantano is the 2010 recipient of the Jean Driscoll Award. This annual award is given to a sbaMass constituent, age 14 and up, with Spina Bifida who best demonstrates the character and determination of the scholarship's namesake. Aime is currently attending Keene State College, working towards a degree in Elementary Special Education and Psychology. After graduating college, Aime's goal is to be hired as a full-time teacher's assistant or as a special education tutor for elementary-age students. When this goal is reached, she will then be able to live independently and begin life as a working adult. Ultimately her "dream big" goal is to travel the world. Aime has begun to research programs through which she will someday be hired to teach in Europe for at least a couple of years. Living and working in Europe will allow Aime the opportunity to travel and to experience a way of life that is different from the one she has known.

Aime exemplifies the character and determination of Jean Driscoll and is "dreaming big" for her future.

Congratulations Aime!

Board Notes And Updates

- The 2010 sbaMass Strategic Plan is finalized and available for download on the sbaMass website. If you would like a copy mailed, contact the sbaMass office at 888-479-1900 or edugan@sbaMass.org.
- The sbaMass Board continues to meet on a quarterly basis. The Annual Meeting of the sbaMass Board will be held on November 2nd at the sbaMass Office, Milford, Ma All constituents are welcome to attend. To confirm date, location and time or if you have items you would like placed on the agenda, please contact Ellen Heffernan-Dugan at edugan@sbaMass.org or 888-479-1900.
- The sbaMass continues to work toward meeting the expectations of the Affiliation Agreement with SBA by June 2011. If you are interested in being part of this process, assistance is needed on the Finance or Development Committees, contact the sbaMass office for more information..
- A group of families from Maine has begun to work with sbaMass in an effort to support families and individuals living in Maine, NH and Vermont. The first event will be held on Nov 6th in Augusta, ME. If you would like more information, or are interested in attending, please contact Ellen edugan@sbaMass.org. If you know of families in the northern NE area, please let them know.

Folic acid, a water-soluble B vitamin, helps your body to build healthy cells. Studies have shown that for women of childbearing age, taking 400 micrograms of folic acid every day can reduce the risk of having a birth affected by a Neural Tube Defect, such as Spina Bifida, by up to 70%.

Red and Green Fruit Salad

Ingredients

- 6 oz. raspberries
- 2 kiwi, peeled and cut in 1/2 inch pieces
- 1 cup green grapes,
- cut in half lengthwise
- 6 oz vanilla yogurt

Directions

Combine ingredients, being careful not to over mix, although some breaking apart of the raspberries will improve the flavor. Chill if desired. This will keep in the refrigerator for a day or two.

Other fruits you can use include blueberries, blackberries, plums, or red grapes.

(Makes 4 servings, inspiration for the idea was from Kaye)

Recipe reprinted permission of Kalyn's Kitchen http://kalynskitchen.blogspot.com

National Conference Report

by Geni Medeiros

I am very glad I was able to attend the conference. As a first-timer, I can say that I learned a lot and it was well worth the trip. Other than belonging to the local and national listserves I was never very involved with the SBA, so I was unsure of what to expect from the conference. But I have, and continue to, learn a lot from those groups so I was sure that the conference would be a good experience.

When I found out I received an sbaMass scholarship to attend the conference I was very excited! Of course I was a bit nervous as well; this was my first time traveling by myself. But I asked a couple of the other ladies that have attended the conference in the past for advice on how to pack, etc. and they were very gracious about giving me tips & tricks. The airline and hotel staffs were wonderful and more than willing to offer assistance. I was even lucky enough to meet a few of the conference attendees on the flight out to Cincinnati.

I initially had some concerns that the information would not pertain to my situation. However, I was gathering information that will help me personally and professionally from the moment I entered the reception until the final seminar. The exhibitors on the expo floor had some really innovative products and I was impressed at how knowledgeable they were about Spina Bifida and related issues. The seminars were very informative and offered many opportunities to ask questions.

I would be remiss if I did not mention the social aspect of the conference. The socializing is a huge part of the event. It was great to meet, face-to-face, many of the people from the listserves as well as other people. I even got to see some old friends that I grew up with who now live in Cincinnati!

I will certainly be planning to go again next year, this time with my son in tow as I think the kids camp would be an excellent experience for him. Thank you so much to the speakers, exhibitors, members of the National SBA, but mostly to the sbaMass for helping me get there!!

ASK the DOCTOR

from SBA

Are there specific precautions to having a VP shunt such as avoid rolling or hanging upside down or putting pressure on the location of the shunt?

For a specific answer to this question, it would be important to know more information about your hydrocephalus, type of shunt, and your neurosurgeon's preferences. Thus, the best answer to this question should occur between a patient and his/her neurosurgeon.

In general terms, over 90% of neurosurgeons who were recently surveyed about sports participation and ventricular shunts felt non-contact physical activity was safe. A review of the literature found that less than 1% of all shunt problems were attributed to sport-related incidents. The Medical Advisory Board and the Board of Directors of the Hydrocephalus Association have issued a consensus statement encouraging participation in "regular activities including school and after school physical education programs and recreational sporting activities." This would include usual amounts of tumbling, rolling, and hanging upside down. This would also include non-sustained pressure over the shunt and tubing.

There is a difference of opinion about participation in contact sports, with equal thirds of neurosurgeons recommending 1) no participation in any contact sports, 2) participation in some contact sports, or 3) full participation in any contact sport. This is another specific question for your own neurosurgeon.

References:

Sports And Pediatric Cerebrospinal Fluid Shunts: Who Can Play? Blount, Jeffrey P. M.D.; Severson, Meryl M.D.; Atkins, Vickie J.D.; Tubbs, R. Shane Ph.D., P.A.-C.; Smyth, Matthew D. M.D.; Wellons, John C. M.D.; Grabb, Paul A. M.D.; Oakes, W. Jerry M.D. Neurosurgery: May 2004 - Volume 54 - Issue 5 - pp 1190-1198

Sports and Pediatric Cerebrospinal Fluid Shunts: Who Can Play? http://www.spinabifidasupport.com/whocanplay.htm

WorkWithoutLimits

Putting abilities to work in Massachusetts.

Have you started thinking about what your son or daughter will be doing after s/he leaves high school? Does a job right out of high school look like the way to go?

If so, there are resources available to help your family think about, plan for and do the "groundwork" that will help get your son/daughter to where s/he wants to be. These resources provide guidance about how to work with your son/daughter's school towards employment goals, information about the state agencies in Massachusetts, and other players, who might be involved, and facts about Social Security benefits that need to be considered.

Work Without Limits: Putting Abilities to Work in Massachusetts, (WWL) is a Massachusetts disability employment initiative and a partnership of the Massachusetts Executive Office of Health and Human Services, UMass Medical School and the Institute for Community Inclusion at UMass Boston funded by the Centers for Medicare and Medicaid Services. A lot is happening behind the scenes in this initiative, all aimed at maximizing work opportunities for youth and adults with disabilities, addressing the needs of employers and strengthening the Massachusetts workforce.

What does this mean for families? In the short term, families can now take advantage of a website with lots of information about employment topics, everything from how to get started when still in school, to conducting a job search, to benefits and transportation considerations. There is lots of resource information and links to publications to help families learn and plan.

This website will be growing and improving over the coming months as WWL builds in more information and topics. In the meantime, check it out at www.workwithoutlimits.org where you can click on the tab "Individuals and Families" to learn more, think about employment strategies and link to resources. There is also a place to sign up to receive updates and notices on employment-related events and topics. Finally, you can also stay connected by Facebook and Twitter.

"SCHOOL DAYS TO PAY DAYS"

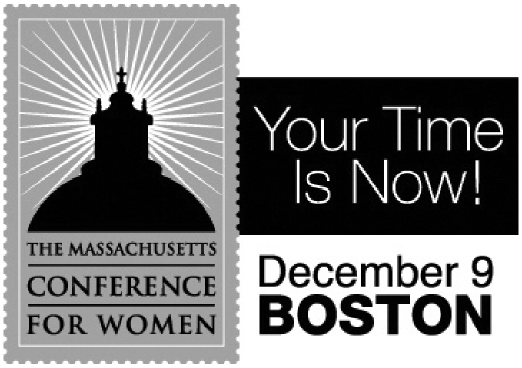
Saturday October 16th - 12:00 – 4:00 PM
A light lunch will be served
Parents and caregivers are invited as well as Individuals living with Spina Bifida, age 15 -22
sbaMass Office 25 Birch St Bldg. B; Milford, Ma
(Accessible entrance and parking in the rear of building)

Presented by WORK WITHOUT LIMITS: www.workwithoutlimits.org

Part I: Laying the Foundation: Led by Maria Paiewonsky
Maria will cover the basics for infusing employment-related planning into the high school program. She will address the importance of, reasons for, and ways to include employment topics in the IEP and school program.

Part II: What Comes After High School?: Led by Amelia Robbins-Cureau
Amelia will help families understand the service system available to families once high school ends, highlighting employment supports.

RSVP to edugan@sbaMass.org or 508-482-5300



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

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.

Contacts

sbaMass Tel. (toll-free)	**(888) 479-1900**
sbaMass Tel (toll)	**(508) 482-5300**
sbaMass Fax	**(508) 482-5301**

Board of Directors

President
Cara Packard
Email: cpackard@sbaMass.org

Vice Chair and Treasurer
Matt Neal
Email: mneal@sbaMass.org

Clerk
Barbara Lee
Email: blee@sbaMass.org

Dr. Stuart Bauer
Email: sbauer@sbaMass.org

Jen Fitz-Roy
Email: jfitzroy@sbaMass.org

Joyce Hillis
Email: jhillis@sbaMass.org

Linda Long-Bellil
Email: llongbellil@sbaMass.org

Kathleen Pease
Email: kpease@sbaMass.org

Operations

Ellen Heffernan-Dugan (888) 479-1900
Executive Director
Email: edugan@sbaMass.org

Wendy Potts (888) 479-1900
Operations Associate
Email: wpotts@sbaMass.org

sbaMass Regional Representatives

Southeastern Massachusetts
Aimee & Brandon Shanks (508) 587-6788
Email: orchid502@yahoo.com

Central Massachusetts
Jean Cusick (508) 756-3918

Cape Cod and the Islands
Judy Morgan (508) 896-5085
Email: judjon1@comcast.net

Western Massachusetts
Betty Niedzwiecki (413) 774-3489
Email: bniedzwiecki@hotmail.com

North Shore / Merrimack Valley
Cindy Ward (978) 682-9330
Email: muna000@aol.com

SBA Tel. (toll-free)	**(800) 621-3141**

Committee Chairpersons

Arnold Chiari Information
Kevin & Maureen Walsh (781) 337-2368
Also try World Arnold Chiari Malformation Association at http://www.pressenter.com/~wacma/

Benefits Program
Ellen Heffernan-Dugan, Executive Director
Email: edugan@sbaMass.org

Canister Collections
Ellen Heffernan-Dugan, Executive Director
Email: edugan@sbaMass.org

Falmouth Road Race
Wendy Potts, Operations Associate
Email: wpotts@sbaMass.org

Fundraising
Ellen Heffernan-Dugan, Executive Director
Email: edugan@sbaMass.org

Literature and Lending Library
Danielle Everett (781) 826-4485

Medical Issues
Ginny Briggs
Email: gbriggs@sbaMass.org

Membership
Ellen Heffernan-Dugan, Executive Director
Email: edugan@sbaMass.org

Memorial Donations
321 Fortune Blvd (888) 479-1900
Suite 5
Milford, MA 01757

Parents Helping Parents
Cara Packard, President
Email: cpackard@sbaMass.org

Public Awareness / Publicity
Ly Weintraub
E-mail: ly@limetartan.com

Youth & Adults Group
Ellen Heffernan-Dugan, Executive Director
Email: edugan@sbaMass.org

Walk-n-Roll
Wendy Potts, Operations Associate
Email: wpotts@sbaMass.org

Wheelchair Sports
Dick Crisafulli, Mass Hospital School (781) 828-2440

Editor: Peter Jablonski
Asst. to the Editor: Amy Blanchard

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.

Spina Bifida Association of Massachusetts
25 Birch St
Building B
Milford, MA 01757

Toll Free Phone: (888) 479-1900
Web site: **www.sbaMass.org**

CHANGE SERVICE REQUESTED