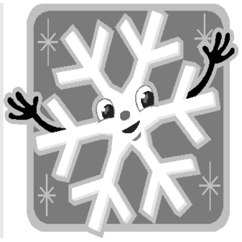
SBAGNE news

Fall 2011 The Newsletter of the Spina Bifida Association of Greater New England



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YEARS

1971-2011

Letter from the President

by Cara Packard

As the leaves turn colors and the temperature drops, we all become very aware of the fall changes around us here in New England. Like the weather, SBA of Greater New England's changes are now fully visible and being felt around the region. We hope that all of you have been able to participate in all of our exciting events and programs.

Since our last publication, we have officially become the **Spina Bifida Association of Greater New England (SBAGNE)**. As we have previously mentioned, our organization has remained dedicated to the same service and mission. We now just have a longer name! We will be serving families and individuals living with Spina Bifida in Maine, New Hampshire, Vermont, and Massachusetts. With the adoption of our new name, we also acquired a brand new website, which will hopefully be easier for everyone to navigate. A few of our updates are still in progress, but should be fully implemented by the end of the month.

Our traditional summer events were well attended and enjoyed as usual. This year our **Summer Picnic** took place at the Mass Hospital School grounds in Canton, MA. Our attendees were able to enjoy the beautiful lake and pontoon boats as well as the wheelchair accessible pool. The ice cream sundae bar was another big hit. The gorgeous day only added to the fun and friendly atmosphere. Please check out our pictures on the new website as well as within this newsletter.

The picnic was quickly followed by our annual **Falmouth Road Race** event. As you can see from the photos and article inside this newsletter, we once again owe many thanks to our running Team, now known as Team SBAGNE. Through their hard efforts on the fundraising front and while hitting the pavement in Falmouth, MA, the team members raised $40,000 for SBAGNE. The team's dedication and generosity is truly inspiring in this difficult economy.

The Falmouth runners were not the only ones working hard to raise funds and awareness. This year we had over 300 participants in our second annual **Walk-n-Roll**, held at the Endicott Estate in Dedham, MA on September 25th. As you can see inside this newsletter, the participants raised nearly $55,000 while also promoting awareness about Spina Bifida. Like last year, the day was a beautiful celebration of the lives and accomplishments of all of our families living with Spina Bifida. We hope to carry the success of that day forward to all of our future events.

Speaking of success, our first joint conference, hosted in conjunction with SBA of Connecticut, was a rousing success. We had over 200 attendees of all ages at the conference in Sturbridge, MA on October 1st. The very informative lectures ranged from the topics of executive function to nutrition. The children were entertained as well, with a variety of craft projects and games. Everyone enjoyed the delicious food and opportunities to connect with other families and individuals living with Spina Bifida. The reviews we have received have been overwhelmingly positive. We hope to be able to offer this great educational experience next year as well.

If you were not able to join us at any of the previously mentioned events, hopefully you will be able to attend one of our **Holiday Parties**. There will be a party in **Augusta, Maine on December 3rd**, followed **the next day with a party in Waltham, MA**. Our hope is that both events will provide an opportunity for our community to connect while enjoying seasonal fun. We hope to see many of you there!

As a final note, I would like to thank all of you for contributing to the success of SBAGNE over the years. As our organization is heading off in new directions, my term as Board Chair has come to an end. In looking back, I am so thankful and proud to see the incredible growth that our organization has achieved over the years. I know that the community and camaraderie my family has experienced while participating in the SBA events has been enormously important to us. Hopefully that sense has been returned to you and your families as well. I look forward to seeing the great heights this organization will reach under the new leadership of **Matt Neal, our next Board Chair**. Matt has served this organization in many capacities over the years and I wish him the very best as he takes on his newest role. I also wish the very best to all of you and thank you for the honor and pleasure of serving you. May you all have a very happy and healthy future!

Team SBAGNE Runs the Falmouth Road Race

Runners raise nearly $40,000!

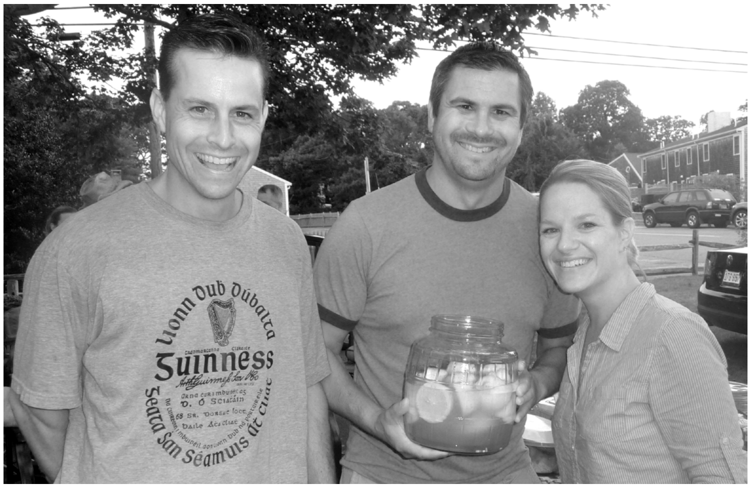
SBAGNE owes a giant thank you to Team SBAGNE for the achievements of its members this year. Once again, the team's outstanding efforts raised nearly $40,000 for SBAGNE. On August 15, the team joined thousands of runners in the Falmouth Road Race making the trek from Woods Hole to Falmouth, MA. Under cloudy skies, our team stood out in their flashy Team SBAGNE singlets. As they raced to the finish, the team brought awareness to our organization while they raised funds for us.

As always, the team gathered for a post race party hosted by the Potts family. There the runners got to kick their tired feet up and celebrate each other's finish times and fundraising totals. Our top 5 runners each raised over $2,000 this year, an accomplishment for which our organization is extremely appreciative. As a whole, it looked like the team was very close to reaching its goal of $40,000 at press time. Given the tough economy, it appears that Team SBAGNE was able to work wonders!

SBAGNE is immensely grateful for all of the generous individuals who have made the Falmouth Road Race a success for our organization. We thank The Potts family for graciously opening their home for the post-race celebration. Wendy Potts, as always, did an excellent job as Team Captain. We appreciate all of the donors, who make serving our mission possible. And most importantly, we send huge thanks to all of our wonderful, dedicated runners, who make this event happen. Through their efforts, we will be able to continue providing programs and services to our members. We are hopeful that all of our runners will return next year for another SBAGNE success!

Thanks Team SBAGNE!

Team SBAGNE 2011



Brian Packard, Brian Rusciano and Wendy Potts relax after the race

Fans cheering on the Team

Annie Hitchcock and Jeff Hitchcock (back) greeting the fans

Katie Packard and runner Matt Lombardi

Thank you!

SBAGNE has received a Reward Your Passion Grant from BLACKBAUD Inc to honor their employee **Dave Balardini**.

Each year Dave has continued to raise funds for SBAGNE through Falmouth Road Race. Dave has also graciously assisted in the office as well as in the recent move of our office.

THANK YOU to Dave and Blackbaud Inc!

2nd Annual Walk-n-Roll a Great Success!

On September 25, the Spina Bifida Association of Greater New England held our 2nd Annual Walk-n-Roll for Spina Bifida at the Endicott Estate in Dedham, MA. Over 300 participants 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 $55,000 has been raised for the Spina Bifida Association of Greater New England through the Walk-n-Roll for Spina Bifida. This is a remarkable amount!

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 2012 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 Wendy Potts at **wpotts@sbaGreaterNE.org**.

Thank you to our Walk-n-Roll Sponsors!

Platinum

Dunkin' Donuts/ Couto Management

Gold

Children's Hospital Boston

Mix 104.1

Silver

Stop and Shop

Exhibitor:

RideAway

UroMed

Thank you for your generous donations!

Hannaford Supermarkets

Whole Foods

Polar Beverages

BJ's Wholesale Club

ATent for Rent

United Site Services

Summer Picnic and 40th Anniversary Celebration

On Saturday July 9th SBAGNE held its Annual Summer Picnic at Massachusetts Hospital School (MHS), Canton MA. Attendees enjoyed the luncheon prepared by MHS food services department, the accessible pool and accessible pontoon boats. Several past Board Members were welcomed to honor their contributions to our growth. SBAGNE would not be the robust organization it is today without the collaboration and backing of some many through the years. Now onto the next 40 years! Thank you to Hannaford Market for their continued support of the Summer Picnic.

Thank you!

to the following corporations for their recent support of the SBAGNE Summer Picnic

Build a Bear
Hannaford Market
Seekonk Speedway
Southwick Zoo

Congratulations!

To the individuals who won Door Prizes at the Annual Summer Picnic

Brittany Batchleder
Chrissy Bernhard
Caitlin Brown
Marianne DiBlasi
Faherty Family

SBAGNE has a new look!

As part of our expansion to include Maine, New Hampshire and Vermont, the SBAGNE website has been updated with a fresh new look. We hope the site is easier to navigate. Our goal is to insure the site is the go-to resource for the Spina Bifida community in Greater New England. **www.sbaGreaterNE.org** will include additional information and resources, state-specific information (coming soon) and up-to-date information relevant to the Spina Bifida community.

If you have an event, a resource, or news of interest, please forward to Wendy Potts at **wpotts@sbaGreaterNE.org**.

All submissions will be reviewed to insure they are suitable for posting.

Bookmark Now: **www.sbaGreaterNE.org**

Spina Bifida University (SBU)

SBU is a self-paced educational experience which covers a wide variety of topics of importance to the Spina Bifida community. From seminars featuring leading health care providers from across the country to presentations on educational and vocational opportunities, SBU has something for everyone!

The best part is that all of the SBU sessions are FREE! You simply need to **register** to receive a username and password to access the seminars. Log onto **www.sbaa.org** and click on SB University on the right side of the home page.

Massachusetts Conference for Women

December 8, 2011 at the Boston Convention & Exhibition Center

The Spina Bifida Association of Greater New England is a supporting organization at the Massachusetts Conference for Women!

The conference is **December 8, 2011** at the Boston Convention & Exhibition Center, 415 Summer Street, Boston, Massachusetts 02210

With motivational keynote speakers, the Career Pavilion, hundreds of exhibits, and unparalleled networking, the conference promises to give attendees the information and motivation to help imagine their own path to purpose and boldly transform, to live fearlessly!

Some important news for our members:

- Registration is open! Please use this promotional code to receive our supporting organization registration discount: MACP24
- View the latest newsletter: **http://0808project.com/women/email/mas/071911/indexx1.html**

SPEAK for Spina Bifida (Spina Bifida Policy, Education, Advocacy, and Knowledge)

Grassroots advocacy is at the heart of our advocacy efforts . Through grassroots efforts, our Community is empowered to take real action that can make a tangible difference for everyone who lives with the challenges of Spina Bifida.

To help grow these efforts, SBA has established the SPEAK for Spina Bifida program. SPEAK stands for Spina Bifida Policy, Education, Advocacy, and Knowledge. Participants in this program help to shape public policy and programs around Spina Bifida by interacting with their federal and state representatives in a variety of ways. For more information on how you can become a part of this groundbreaking program, Log onto **www.sbaa.org** to sign.

SB Tween2Teen

A new place for Tweens and Teens living with Spina Bifida. Blogs, videos, Ask the Expert, real stories and Fact Sheets. Visit **www.sbaa.org** and click on the SB Tweens2Teens Logo.

Education Fact Sheets Available Online

SBA has recently published three new Education Fact Sheets on reading, math, and a quick reference sheet for educators of individuals with Spina Bifida. They are now available on the SBA website. Visit the link below, and then click on the Education sheets.

www.spinabifidaassociation.org/site/c.liKWL7PLLrF/b.2642343/k.8D2D/Fact_Sheets.htm

Perspectives from a first-time SBA Conference attendee

by **Amanda McEvoy, RN, BSN, CPN**
Coordinator, Spina Bifida Program
Maine Medical Partners

Who, one may wonder, would ever be excited to go back to work after spending four days at Disneyland, the happiest place on earth? After my experience at the 38th annual SBA Conference, I can honestly say that I was.

One month after being hired as the new Spina Bifida Program Coordinator in Portland, Maine, I boarded a plane to California in anticipation of getting a few of my Spina Bifida-related questions answered. My background in working with inpatient pediatric patients provided me with basic knowledge about Spina Bifida, so I felt that this conference would reinforce this knowledge and hopefully teach me more. Little did I know the extensive education I would get from experts around the country in topics ranging from learning disabilities to latex allergy to the complex world of bowel management. Additionally, I had the amazing opportunity to chat with several persons with Spina Bifida who not only shared their inspirational stories with me, but also helped me to gain more perspective on what it is like to live with Spina Bifida.

Four days, twenty lectures, and roughly fifteen pounds of brochures and medical equipment samples later, I said good-bye to the palm trees and my new network of Spina Bifida Clinic coordinators from various states. I headed back into work confidently with new knowledge and a great number of wonderful resources at my fingertips. I am grateful that the SBA organizes this conference each year and highly recommend to other healthcare professionals working with the Spina Bifida population.

New England Spina Bifida Conference

On Saturday, October 1st, 200 individuals living with Spina Bifida, their families and caregivers from across New England attended the 1st Annual New England Spina Bifida Conference at the Sturbridge Host Hotel, Sturbridge MA. The conference included sessions on Executive Function, Urology, Bone Growth, Employment, Neurology, Financial Planning and Transition amongst others. The keynote was given by **Carmen Head**, SBA Director of Education and Support Services. Carmen provided an update on activities at SBA and the variety of online programs and services available though SBA. Once again the Spina Bifida community came together to Understand the Issues: and Celebrate the Strengths. Based on feedback, SBAGNE and SBA of Connecticut hope to have this become a regular event.

Dances with Wood Project

Surgery of Fetus Reduces Spina Bifida Complications

The Management of Myelomeningocele Study (MOMS) is a study funded by the National Institutes of Health that was started in 2003 to compare prenatal surgery (surgery before birth) with postnatal surgery (surgery after birth) in children who had myelomeningocele (MMC), a form of Spina Bifida. Experimental studies had suggested that closing the opening on the back before a baby with MMC is born is associated with better neurological outcomes. Recently, some findings from the study were published in the New England Journal of Medicine.

Members of SBA's Professional Advisory Council (PAC) have reviewed these outcomes for both historical and future perspective for the Spina Bifida community. A summary of the outcomes from the study is provided below and a fuller commentary can be found at **www.sbaa.org**.

Origins of the Study

MOMS was a scientific study designed to compare surgery before birth (also called prenatal, maternal-fetal and in-utero surgery) and surgery after birth (also called postnatal surgery) in children with Spina Bifida. It came about because doctors had noticed that nerve function in babies with Spina Bifida seemed to worsen as a pregnancy progresses. This observation suggested that the damage to the nerves of those with Spina Bifida may be a two-part process: some damage occurring when the spinal cord and associated nerves do not develop fully in the first month of the pregnancy with additional damage occurring throughout the pregnancy.

Early studies done in animals seemed to confirm that the amount of nerve damage could be lessened if the open spine was closed early in a pregnancy. This led researchers to want to compare the safety and effectiveness of prenatal and postnatal surgery.

It was determined that the study would seek to enroll 200 women who were carrying a baby affected by myelomeningocele (MMC), the most severe form of Spina Bifida. The affected pregnancies would all be diagnosed with Spina Bifida by ultrasound between the 19th and 25th weeks. In 100 cases the opening in the spine would be closed between the beginning of the 19th and the end of the 25th week of pregnancy. In the other 100 cases, the baby would have surgery to close the opening in the spine after they are born. Participating women were not "selected" for one type of surgery or the other, but rather were to be randomly assigned to one of the groups.

Over 1,085 women were screened for participation and 299 were referred to one of the three study centers for further screening. Women could be excluded from the study for maternal, obstetric, or fetal reasons; the most common of which were maternal obesity, a prior history or risk factor indicators for pre-term birth, or severe spine curvature or other anomalies not associated with Spina Bifida in the fetus. Enrollment concluded at the end of 2010 with 183 women participating in the study.

Findings

On February 9, 2011, the New England Journal of Medicine published the results of the MOMS trial. Below is a breakdown of the outcomes.

Positive Outcomes

Hydrocephalus Ventricular shunts were placed less often (40%) in those treated surgically in the prenatal period than in those who had not received prenatal surgery (82%). Since the presence of hydrocephalus is associated with many negative outcomes in individuals with MMC such as learning problems and more dependence, this outcome may have significant positive implications for the future of these children.

Chiari Malformation

The children who had prenatal surgery had less evidence of hindbrain herniation (downward displacement of the back of the brain) (64%) than those who had surgery after birth (96%). This suggests that closing the opening on the back before the baby is born equalizes the pressure between the brain and the lower spinal column, which allows the brain to develop in a more normal location. This may be linked with better learning in the future, but it is too early to tell.

Mobility

The children who had prenatal surgery were more likely to be walking independently (42%) than those who had surgery after birth (21%). Also, children who had prenatal surgery had better motor function than what would be expected based on the level of the opening of the back. This suggests that closing the back early may prevent some secondary damage (e.g., from the spine being exposed during the entire pregnancy), which preserves nerves that are important for movement.

Intelligence

No difference was found between the two groups. The follow-up was short, so this may change in the future.

Urological function

These results have not yet been reported. Stay tuned!

The Study in Perspective

This study is a major milestone in the treatment of children with MMC, and used methods that maximize our trust in the findings (being both valid and reliable). However, the follow-up of the babies at this point is short–many of the results were noted for children at their first birthday. Time is necessary to see how well the positive differences hold up, and to see if side effects might occur. The surgery that was performed requires a tremendous amount of training on the part of the surgeons, as well as a large support team to provide care for the unborn baby and mother after surgery. This type of surgery cannot be performed in any community hospital. The costs of the intervention when compared to the benefits have not yet been discussed. This may be important when trying to decide what type of care should be funded. Finally, the mothers who were chosen for this study were chosen to ensure the best outcomes. The findings cannot be applied to those mothers who did not meet the criteria of the study (e.g., those who are obese).

Reference

Adzick NS, et al.; the MOMS Investigators. A Randomized Trial of Prenatal versus Postnatal Repair of Myelomeningocele. N Engl J Med. 2011 Feb 9. [Epub ahead of print]

Letter to the Editor of the New England Journal of Medicine

To the Editor of the New England Journal of Medicine:

In the report on the results of the Management of Myelomeningocele Study (MOMS) (March 17 issue), a randomized trial comparing the efficacy of prenatal repair of myelomeningocele with that of postnatal repair, *Adzick et al.* state that prenatal closure reduced the need for ventriculoperitoneal shunting and improved gait function postnatally. However, lower urinary tract function was not addressed.

We cared for 5 children who participated in MOMS but who received postnatal care at Children's Hospital Boston because of its proximity to their domiciles. They ranged in age from 1.5 to 36 months; all showed complete external urethral sphincter denervation on needle electromyography and detrusor overactivity on urodynamic studies. This denervation causes intractable wetting that will require surgery when the patients are older. These findings were compared with those in 88 children of similar age in whom the neurologic level of the myelomeningocele was similar and whose defect was closed postnatally at Children's Hospital Boston. We found significantly less denervation of the external urethral sphincter and near-normal detrusor activity in the children who underwent postnatal surgery as compared with those who received prenatal surgery.

Given our experience, we are concerned that any enthusiastic adoption of prenatal closure that MOMS may generate will not be advantageous in the long term because of the urologic problems that may ensue. We believe that further study of the effects of prenatal repair on the urologic and other organ systems should be conducted in children who participated in MOMS before this approach to myelomeningocele repair is wholeheartedly endorsed.

Stuart B. Bauer, M.D.
Children's Hospital Boston, Boston, MA
stuart.bauer@childrens.harvard.edu

From the Myelodysplaisa Program – Children's Hospital Boston

In addition to the 'Letter to the Editor' that appeared in the New England Journal of Medicine, we are preparing an update regarding an additional 6 patients who had prenatal closure of their meningocele at either Children's Hospital of Philadelphia or Vanderbilt Children's Hospital. Thus far, 11 children have been followed in our Myelodysplasia program since their birth and we have compared their progress with a similar group of children who had their myelomeningocele repaired AFTER they were born. At an average age of 7.2 years we found no difference in the capacity of the bladder, the presence of premature contractions, elasticity of the bladder, nerve function in the urethral sphincter muscle, nor pressure at which they leaked urine from their bladder when filled to its capacity. Of the children who were on clean intermittent catheterization (9 of the 11 with prenatal closure and 14 in the postnatal closure group), 66% (6 of 9) versus 83% (12/14) in the postnatal closure were wet between catheterizations. Three of 11 prenatal closure patients had vesicoureteral reflux whereas 7 of the 22 postnatal closures had reflux.

Thus, there was no difference, nor advantage, in the urologic outcome in those children closed prenatally versus those closed after birth. In addition, we did not find a difference in the need for ventriculoperitoneal shunting in these 2 separate groups, even though the authors in the New England Journal of Medicine article reported there was a markedly reduced incidence in the need for this surgery in children whose back was closed prenatally.

Our findings suggest that prenatal closure of myelomeningocele needs further study before it is routinely recommended. We are contemplating a program to manage and evaluate children identified prenatally at this time.

Board Meeting Notes

- SBAGNE has a new address: **219 East Main St, Suite 100B, Milford MA**. Our phone and fax numbers remain the same.

- The SBAGNE continues to meet on a quarterly basis. **The Annual Meeting is scheduled for Tuesday November 1, 2011 at 7 PM.** 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@sbaGreaterNE.org** or 888-479-1900. Agendas will be posted on the SBAGNE website

- Volunteers are needed for various committees. If you have questions about committee responsibilities or you are interested visit **www.sbaGreaterNE.org** or contact Ellen Heffernan-Dugan.

- Are you interested in hosting a fundraiser for SBAGNE? Many area restaurants provide nonprofits the opportunity to have a fundraising day with a percentage of sales being donated to the sponsoring organization. If you are available to assist SBAGNE by hosting an event at a restaurant near you, contact Wendy Potts (**wpotts@sbagreaterne.org**). SBAGNE can assist with promotion of the event and paperwork. Watch **www.sbaGreaterNE.org** for a list of restaurants.

Support SBAGNE
Triathalon, Run, Walk, Swim

Do you, a family member or friend want to support SBAGNE? For almost 10 years SBAGNE has had a team participate in the Boston Marathon or the Falmouth Road Race to raise funds and awareness for Spina Bifida. In addition individuals have participated in the Chicago and San Diego Marathons to raise funds and awareness in support of SBAGNE. If you, a family member or friend are participating in an upcoming event and wish to support SBAGNE, contact **wpotts@sbaGreaterNE.org** for information on how SBAGNE can support and spread the word about your efforts on our behalf and how you can support SBAGNE!

Thank you to the Original Wedding Expo for their continued support of SBAGNE!

Are you planning a wedding or supporting a friend through the planning process? **The Original Wedding Expo (www.originalweddingexpo.com)** continues to provides exhibit space to SBAGNE to support our outreach to women of childbearing years regarding the benefits of folic acid. SBAGNE will be exhibiting on **November 20th, in Newton, MA; January 29th, in Burlington, MA and February 19th in Marlborough, MA**. If you would like to assist in staffing the booth , please contact **edugan@sbaGreaterNE.org**. If you are visiting one of the above expos, stop by and say HI!

Mark Your Calendars for the 2011 sbaMass Holiday Parties!

Saturday, December 3, 2011 from 12:30 PM - 4:30 PM
Senator Inn, Augusta, Maine

Sunday, December 4, 2011 from 12:30 PM - 4:30 PM
Hilton Garden Inn, Waltham, MA (new location)

Parties will include:

- Lunch!
- Fun and Games for all ages!
- Special Holiday Guest (with a gift for all children attending
- Holiday Sing-a-Long
- Yankee Swap for Adults*
  (Bring a wrapped gift worth no more that $10)
  *Adults with S.B. do not need to bring a Yankee Swap item

SBAGNE is requesting that gently used books, DVDs, or simple small toys be brought to the holiday parties. These items will be packaged by SBAGNE volunteers who will make gift packages for children staying overnight at Children's Hospital or Maine Medical Center.

Come up with a name for the packages and email to **edugan@sbaGreaterNE.org** or bring it to the Holiday Party. The individual whose name is chosen will receive a gift from SBAGNE. Be creative!

****Please RSVP by Friday, November 25, 2011****

By Email: **edugan@sbaGreaterNE.org**
By phone: **(888) 479-1900**
Online at: **www.sbaGreaterNE.org**

Include the following information in your reply:

- Party you will be attending (Massachusetts or Maine)
- Your first and last name
- Your phone number
- How many people are in your group
- Names and ages of everyone in your group
- Please specify the name of the person with Spina Bifida

Directions to the Party are on web at sbaGreaterNE.org!

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% .

Vegetarian Black Bean Soup

Ingredients:

2	tablespoons olive oil
1	medium red onion finely chopped
1–2	jalapeños, depending on how spicy you prefer
3	cloves of garlic, minced
1	tablespoon ground cumin
2	cups dried black beans
2	cups vegetable stock
1/4	cup finely chopped cilantro
1/2	teaspoon kosher salt

Directions:

Clean and rinse the beans. Cover the beans with water and soak refrigerated overnight. When ready to prepare the soup, put the beans in a stockpot and cover with cold water and cook until tender. Do not salt the beans until they are almost finished cooking. After the beans are fully cooked add the beans and the bean broth to the sautéed mixture. Add vegetable stock if you want a thinner soup. While the beans are cooking, heat the oil in a heavy, large stockpot over medium-high heat. Add onions, jalapenos, garlic, salt and cumin. Sauté the onions until tender. Remove from the burner. When the beans are cooked, add the beans and bean stock to the sauté mix. Stir well to mix the flavors. Reduce the heat to medium-low, cover and simmer until the flavors blend, approximately 15 minutes. Mix in the cilantro. Season with salt and pepper. This can be served with a spoonful of plain yogurt or sour cream and tortilla chips. Brown rice also makes a good addition to the soup.

Makes 4 eight-ounce servings. Reprinted permission of www.azcentral.com

Spina Bifida Association of Greater New England - 888-479-1900

Research Participants Sought

Kennedy Krieger Institute is looking for parents of individuals with Spina Bifida between the ages of 10 to 29 to fill out an online questionnaire. We could really use all of your help, as we are trying to create an executive functioning questionnaire specific to individuals with Spina Bifida. It's hard to develop these kinds of instruments, and the more people that participate the better. Participation is entirely voluntary and anonymous.

To participate as a parent of someone with Spina Bifida between the ages of 10 and 29, visit: **https://www.psychdata.com/s.asp?SID=128186**. If your child is between the ages of 10 and 17, you will be able to proceed directly to the survey. If your child is 18 to 29, you will asked to invite your adult child with Spina Bifida to participate/consent first, and then to generate a password that you can use to participate.

If you are an adult with Spina Bifida between the ages of 18 and 29 and would like to participate, please visit link: **https://www.psychdata.com/s.asp?SID=128187**.

The official announcement of the online survey if you would like to review is below.

Research Announcement

Research Study Name: Validation of the Kennedy Independence Scales – Spina Bifida Version (Johns Hopkins University School of Medicine IRB # NA_00039136)

Who? We are looking for the parents of individuals (ages 10 to 29) with Spina Bifida.

What? Dr. T. Andrew Zabel of the Kennedy Krieger Institute is the Principal Investigator conducting a research study to see how well a new electronic checklist measures the skills of adolescents and young adults with Spina Bifida. Individuals with Spina Bifida often learn important medical skills during their teenage and young adult years. The goal of this research is to determine at what age most individuals with Spina Bifida learn medical self-care skills and other skills of independence. This study focuses upon adolescents and young adults who have a clinical diagnosis of Spina Bifida and are between 10 and 29 years of age.

Where? This study can be completed over the computer, and does not require any clinic visits.

How long? The study will require the parents of individuals with Spina Bifida to complete one computer-based checklist made up of multiple-choice questions. The checklist usually takes 20 minutes or less to finish.

This survey is anonymous, and no personal information such as names, social security numbers, IP addresses, or telephone numbers will be collected. If you would like to participate or learn more about it, please click on the following link:

For Parents of individual with Spina Bifida: **https://www.psychdata.com/s.asp?SID=128186**.
If your child is between the ages of 18 and 29, the survey will guide you to obtain your child's permission before proceeding.

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If you are an adult with Spina Bifida between the ages of 18 and 29, we invite you to participate in this research as well. Completion of your portion of the checklist usually takes 5-10 minutes. Please click the following link for more information:

For Adults (ages 18 to 29) with Spina Bifida: **https://www.psychdata.com/s.asp?SID=128187**

This research project has been approved the institutional review board of the Johns Hopkins University School of Medicine. If you have questions about this study, **Dr. Zabel** can be reached at **zabela@kennedykrieger.org** for more information!

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