SBAGNE news

October 2014 The Newsletter of the Spina Bifida Association of Greater New England

Notes from the Chair

Barbara Lee

Happy fall! Hope you are doing well!

SBAGNE had a very successful Conference located at the Radisson Hotel in Nashua, NH. We are always excited to see many new families attend from Maine, New Hampshire, and Massachusetts, Rhode Island and Connecticut. We received great feedback regarding the breakout sessions. Everyone attending enjoyed our informal Friday night reception which allowed people to socialize and have some relaxing fun! We will be shooting for another Conference next year as long as we have the funds to support it. Thank you to all who volunteered and participated!

SBAGNE offers many programs and services to our constituents. They include: **The Annual New England Spina Bifida Conference**, **Constituent Reimbursement**, and **Reimbursement for Parking for Hospital**, the **Summer Picnics**, and **Holiday Parties** that take place throughout the SBAGNE Region, **Jean Driscoll Award**, **Get Active**, **Illuminations**, **SBAGreaterNe.org website**, **SBAGNE newsletter** and **Information and Referral**. Without your donations and sponsorships we would not be able to provide these programs and services. What we hear from you is the SBAGNE community is important to you and the time you have to be with one another is priceless.

SBAGNE Board and staff will be calling you in October to hear from you directly as to what you would like us to continue and recommendations for new programs. We truly appreciate your feedback. SBAGNE is here for YOU and we want to provide programs and services that you want!

Unfortunately, we currently experiencing a budget short fall which will impact what we can offer to for the remainder of 2014. Our goal is to not eliminate any services or programs but in reality we may need to. If you see something on the list above that you attended, participated in or were able to benefit from then PLEASE donate online at www.SBAGreaterNE.org or when you receive the Annual Appeal.

Wishing you all a very happy and safe Thanksgiving Holiday!
Thank you,

Sincerely,

Barbara Lee

Chair SBAGNE

OCTOBER IS SPINA BIFIDA AWARENSS MONTH

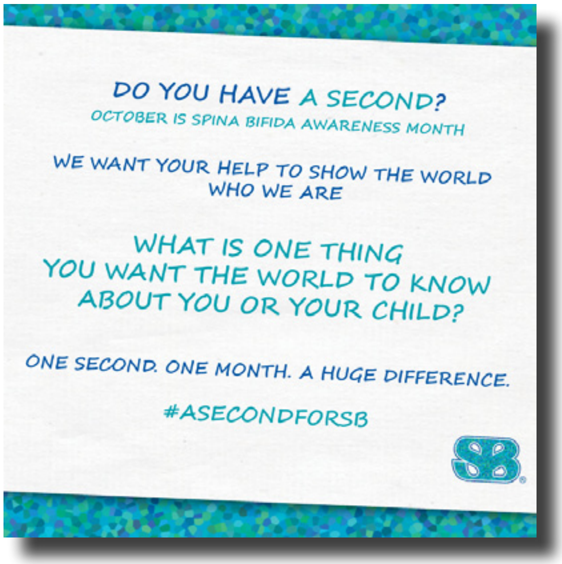
Each year Spina Bifida Awareness Month helps us educate the public and further understanding of what it's like to live with spina bifida. Spina Bifida Awareness Month was created to help us celebrate the challenges, successes and accomplishments of those living with spina bifida.

Spina bifida is not one condition; it is a multitude of problems that affect the mind, the body and the spirit. Advancements in treatment and prevention, however, have opened new doors for those living with spina bifida. While challenging at times, those affected are able to attend school, work, raise a family, and spend time with friends just like everyone else.

Top 5 Ideas to Spread Awareness

- Call the offices of elected officials at the local, state, or federal level is one of the easiest and most effective ways for patient advocates to communicate with policymakers on issues of interest and priority
- Post on Facebook or Twitter daily a fact or question about spina bifida
- Write a "Letter to the Editor" including information about SBAGNE, and your personal story.
- Read a story or do a presentation in your child's classroom about spina bifida and living with a disability.
- Like the SBA of Greater New England Facebook Page and share our posts and challenges for the month.

SBAGNE Staff are available to assist with any information or questions you may have to raise awareness!



DO YOU HAVE A SECOND?
OCTOBER IS SPINA BIFIDA AWARENESS MONTH

WE WANT YOUR HELP TO SHOW THE WORLD WHO WE ARE

WHAT IS ONE THING YOU WANT THE WORLD TO KNOW ABOUT YOU OR YOUR CHILD?

ONE SECOND. ONE MONTH. A HUGE DIFFERENCE.

#ASECONDFORSB

Thank you to the following for supporting the recent Walk N Rolls for Spina Bifida and the New England Spina Bifida Conference

American Installations

Hollister

MAC

SYMBIUS MEDICAL

WMS WILMINGTON MEDICAL SUPPLY, INC.
ACHC ACCREDITED

Hope for Improved Care: Spina Bifida Collaborative Care Network

Many in the Spina Bifida communityhave recognized a need for improved medical care for those with Spina Bifida.

To improve access and quality care, Spina Bifida Association and the U.S. Centers for Disease Control and Prevention (CDC) have partnered with other advocates to create the Spina Bifida Collaborative Care Network (SBCCN).

A grant from the Disability Research & Dissemination Center (DRDC) funded the development of a strategic plan to standardize and improve patient care in clinics. SBA and CDC statff, medical professionals, SBA Charter representatives, adults with SB, and parents of children with SB were represented on the initial planning committee.

Dr. Tim Brei, the SBA Medical Director and member of the SBCCN leadership committee, noted that while much of the focus will be on clinical care, that's only one component.

"It's also how we disseminate information for families, advocate at national, state, and local levels for the health needs of those with Spina Bifida, and how we communicate with everyone so that care - and the lives of people with Spina Bifida - can be improved," Brei said.

The strategic plan outlines the need for standardized guidelines for care. What those guidelines should be, and how to assess the performance of clinics, wll be determined and implements over the next five years as part of another grant from CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) and the Division of Human Development and Disability (DHDD).

Input from nearly 1,000 electronic and social media survey responses, as well as focus group data collected at the SBA Conference in June, will help establish uniform practices for improved care.

Lisa Azzou, a member of the planning group whose daughter has Spina Bifida, led focus groupss at Conference with Chapter representatives, adults with Spina Bifida and health care professionals.

"We need to determine what the best practices are, what the clinics need, how to reach the adults, and how to facilitate and effective system, and they're pointing us in the right direction to answer these questions," Azzou said.

Several themes emerged from the focus groups responses, many regarding adult care.

"The basic goal of the adults was to get access to adult medical care. They'd like to have adult specialists who understand their background and can treat them," Azzou said.

Many also want more control over their own healthcare decisions.

"They feel that doctors often explain things to their parents rather than the adult patient, and the health care providers loved hearing that the adults want to be more involved," Azzou recounted.

Hope *continued from page 2*

The steering committee will consider the focus group reports and survey data in order to identify the SBCCN's next steps and begin transforming care for people with Spina Bifida.

"Health care providers have advocated for change for a long time, but in today's environment, they can sometimes do relatively little to change what happens at their own institutions," Dr. Brei explained.

Whle majore changes will take time, the SBCCN will create an infrastructure with the long-term potential to improve not only health care, but also overall quality of life, for people with Spina Bifida.

The SBCCN will:

- Monitor, track, and evaluate SB clinic care
- Provide input into research priorities for NSBPR
- Advocate for the adoption of best practices

"SBCCN is all of us working together and using the power of various consituencies - patients, health care providers, and the SBA - to effect change that one group alone couldn not," he said.

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SBAGNE Constituent Survey

An SBAGNE Board Member or Staff person will be contacting you in the upcoming weeks. Our hope is to update contact information and to gather your thoughts on SBAGNE programs and services. Please take the time to take our call.

Holiday Parties

are just around the corner!

SBAGNE is once again hosting Holiday Parties
in
Wellesley, Massachusets
Augusta, Maine
and
Holyoke, Massachusetts

Please visit SBAGreaterNE.org for details

The 2014 Falmouth Road Race Team

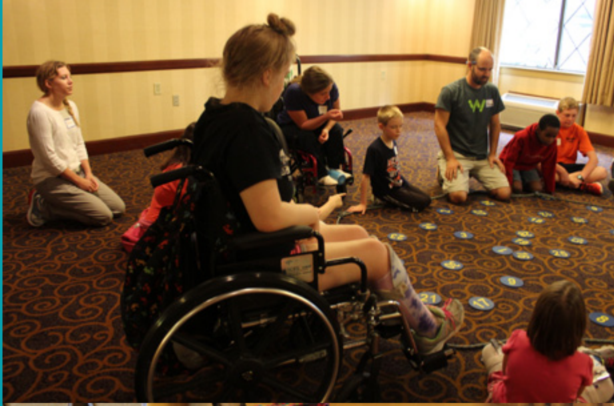
Once again, the SBAGNE Falmouth Road Race Team rose to the occassion and raced for spina bifida raising more than $30,000! Thank you to all the participants.

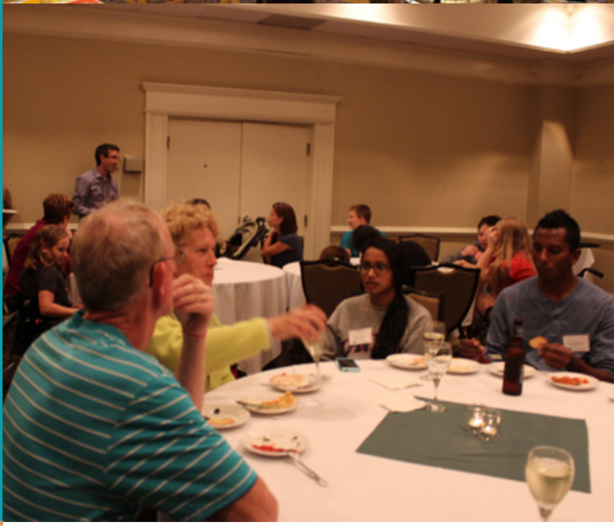
On September 13th, 140 individuals living with spina bifida, their families and caregivers came together for the **4th Annual New England Spina Bifida Conference**. This year the conference changed location and was held at the Radisson Hotel, Nashua, NH. The conference began on Friday evening with an informal social. Those gathered enjoyed light refreshments and the opportunity to make new friends and catch up with old acquaintances.

Bright and early Saturday morning attendees began joining together for breakfast and the Keynote Panel "Lessons for a Lifetime." Many thanks to **Brendan Sullivan**, **Abigail Boudreaux** and **Andy Wise** who were willing to share their stories, success and challenges. The remainder of the day included breakout sessions on various topics including accessible housing, nutrition and obesity, adaptive driving, sexuality, transition tips, bullying, adaptive recreation and hydrocephalus.

Kid's Camp included team building activities with **Waypoint Adventures**, a presentation by **Empower Spinal Cord Injury**, a discussion on bullying, games, arts and crafts.

Special thanks to conference sponsors: **Coloplast**, **NuMotion**, **Symbius Medical** and **Ride Away**.





Contacts
Spina Bifida Association of Greater New England
219 East Main St, Ste 100B
Milford, MA 01757
888-479-1900 - SBAGreaterNE.org

Ellen Heffernan, Executive Director
edugan@SBAGreaterNE.org

Thushy Muruges, Operations Associate
tmuruges@SBAGreaterNE.org