

SBAGNE

news

Fall 2013

The Newsletter of the Spina Bifida Association of Greater New England

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Notes from the Chair

by Matt Neal

Welcome readers, to the latest issue of your SBAGNE newsletter! This is the final issue of 2013 and so it is also the last note from this chair. My two years are up in December, at which time the Chair-ship will be assumed by the very capable Barbara Lee. No doubt this change will be met with much relief from those noble persons (Ellen, Pete, once Wendy and now Thushy) who work so hard to get this really excellent newsletter out the door on time only to have the whole thing screech to a halt waiting for me. My sense is that Barbara's notes will be more timely.

I have seen a lot of change, a lot of growth, in our organization since my wife Ginny and I joined the board way back in 2003. I will try not to bore you all with too many details of all the happenings of the intervening years. But believe me, we are a very different organization. When we signed on, it was good thing to have a husband and wife team on the board, then (about 5 years later) it wasn't. So Ginny resigned (but has remained extremely active) and I stayed on. Now I am resigning and Ginny is set to return. Grace was 3, now she's 13, and man didn't that go fast! Through it all it has always been true that we have gotten far more out of the organization than we ever put in. The people we've met and built relationships with, the things we've learned, the places we've been. It's been awesome and will continue to be so.

It has been an honor to take on the chair role and to follow the lead and build on the progress of all the previous boards and chairs. We have added so many services and service area in recent years, and I think gotten a pretty good handle on the whole fund raising thing. This is the thing of which I am most pleased, this combination of growth and stability. It has been a struggle but I believe we have reached sustainability, and reached it through growth.

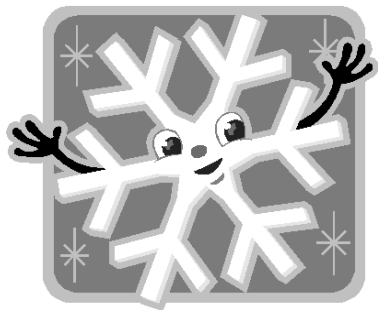
Anyway, thank you all for this unique opportunity!

SBAGNE

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YEARS

1971-2013



Holiday parties

Yes, it's hard to believe, but Winter is just around the corner. SBAGNE is once again preparing for the snowfall and also the Holiday Parties. This year there will be three parties. The locations and dates are as follows:

Eastern Massachusetts – Sunday, December 1, 2013 - Marriott/Newton (NEW LOCATION) 12 PM - 4:30 PM

Maine – Saturday, December 7, 2013 - Senator Inn, Augusta, ME 11:30A-3:30P

Western Massachusetts – Sunday, December 8, 2013 - Summit View, Holyoke, MA 10:30A – 2:30P

Visit www.SBAGreaterNE.org for more information and directions.

Team SBAGNE Runs the FRR for Spina Bifida!

On Sunday, August 11th, Team SBAGNE hit the pavement again in the 41st running of the New Balance Falmouth Road Race. Our 20 member team ran the 7.1 miles from Woods Hole to Falmouth Heights wearing their signature “Running for Spina Bifida” shirts, showing support for the Spina Bifida Association of Greater New England.

The Falmouth Road Race has been a mainstay in the SBAGNE fundraising calendar and this year the Team came through once again raising close to \$35,000!

We thank all of our Team members for their commitment to our cause and for going above and beyond in their fundraising efforts!

The 2014 New Balance Falmouth Road Race will take place on Sunday, August 17th.

If you are interested in joining the team, contact Thushy at:
tmuruges@SBAGreaterNE.org.





SBAGNE is collaborating with the national Spina Bifida Association for Team Spina Bifida. Team Spina Bifida is the Spina Bifida Association's athletic program for spina bifida supporters across the country. Friends of SBA train for and complete a marathon, half-marathon or other endurance event (triathlon, cycling, mountain biking, etc.) or participate in a team sporting event. Team Spina Bifida seeks to RAISE FUNDS and AWARENESS for spina bifida.

Join Team Spina Bifida and commit to run a marathon or half-marathon, while raising vital funds for the Spina Bifida Association and SBAGNE.

Travel to Los Angeles and participate in the March 9th LA Marathon. Rock it with the stars for SBA and SBAGNE!

How does it work?

After you sign up with Team Spina Bifida, you will raise money for SBA while training for your event. SBA will cover the entry fee and depending on the amount you raise, the costs for you to participate in the event, including travel to/from event and lodging. In exchange, you agree to raise a minimum amount for SBA. SBA will provide you with fundraising tips, ideas, forms, online webpage, and constant support along the way! Your participation will make a HUGE difference for those affected with spina bifida.

Why should I join Team Spina Bifida?

If you or someone you know are passionate about spina bifida and assisting those affected, this is a great way to get into the game to help. Pledge to make a difference by pushing your own boundaries and sign up today! Contact Ellen at edugan@SBAGreaterNE.org.

Welcome Thushy!

Hello SBAGNE Family! My name is **Thushyanthi (Thushy) Muruges**. I am your new Operations Associate. I started this August and I have enjoyed every moment working with SBAGNE. I earned my B.A. in French at Berry College in Georgia. As a Bonner Scholar in undergrad, I became interested in community service and non-profit work. I served at various non-profits in Rome, Georgia.

Upon graduating, I served one year as a City Year Corps Member in Little Rock, Arkansas. I am currently a second year graduate student at Clark University where I am pursuing a M.A. in International Development and Social Change.

I am looking forward to meeting you at the various SBAGNE events. Please feel free to contact me with any questions, comments or suggestions. I welcome your input in SBAGNE operations.



3rd New England Spina Bifida Conference

On September 21st, SBAGNE collaborated with SBA of Connecticut for the 3rd New England Spina Bifida Conference. Approximately 200 participants heard **Gina Gallagher** and sister **Patty Kojoian** speak on the *Movement of Imperfection*. Attendees laughed out loud and as some said following the presentation, shed a few tears. Additional topics included: *Helping your Child Cope with Hospital Visits*, *Understanding and Designing a Medical Home*, *Making the Most of your Clinic Visit*, *Sleep Disorders* and *Panel of Adults living with Spina Bifida*. Kids Camp included a visit from a group of therapeutic dogs, wheelchair ballroom dancing with DANCE Arts CT and lessons on self-defense from IMPACT Ability. SBAGNE and SBACT would like to thank all who made the day possible, volunteers, speakers, supporters and attendees. Once again a fantastic day for connecting with others in the spina bifida Community! Watch your calendars for 2014.



Conference Sponsors

Yale New Haven Hospital

Symbius Medical

180 Medical

Christopher and Dana Reeve Foundation



Farewell to a True Friend

SBAGNE lost a true friend and fervent supporter on October 23, 2013. **Judy Potts** passed away following a courageous battle with cancer. With her help and generosity, Team SBAGNE raised several hundred thousand dollars for SBAGNE over the years.

As members of Team SBAGNE will fondly recall, Judy hosted the post-race party for the team following the Falmouth Road Race each August. In fact, Judy and her family inspired past SBAGNE president, **Brian Packard**, to seek out charity numbers from the Falmouth Road Race and create the team. Since its creation, the team has grown successfully each year. In each of the past few years, the team has raised funds in the neighborhood of \$40,000. Until this year, Judy tirelessly cheered the runners on the last hill before welcoming them to the congratulatory feast and kazoo party. Her generosity and passion will long live in the memories of those who knew her.



Those of you who did not attend the road race may recall her as one of the cheerleaders at the end of the walk-n-rolls, or may have seen her setting up the big tents for the events. Judy was always willing and happy to help. SBAGNE will surely miss her, but her passion and efforts will remain with us. Just as the memories of her kazooing and cheering will live on in the memories of our Falmouth Running team, so will her legacy in those of the SBAGNE community who benefit from the programs funded with dollars that Team SBAGNE has raised over the years. Farewell, and thank you, Judy.

Dance Art!

by Deanna Cardenas



My daughter, Elaina, and I have been huge fans of *Dancing With The Stars* for a number of years, and searched for a way that Elaina could experience what she loves so much. We finally found the “pot of gold at the end of the rainbow”, according to Elaina, by the name of Dance Art Wheels. The fabulous instructors of Dance Art Wheels have brought Elaina into a whole new exciting world of Wheelchair Ballroom and Latin Dance. It’s not only a great way to exercise, increase strength and core stability, according to Elaina, it’s also “a lot of fun”. The instructors are highly-trained and skilled professional dancers, certified through the American DanceWheels Foundation, and are “really, super-nice”, according to Elaina. I would have to agree 100%!! Elaina is looking forward to an upcoming show, and maybe even a little competition in

the future. As a mom, I love to see her try something new and enjoy it so much. We have been very happy with the experience. My husband and I are looking forward to a lesson in the near future.

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studio@danceartct.com
www.DANCEARTCT.com
www.DANCEARTWHEELS.com

WE COULDN'T DO IT WITHOUT YOU!

***Thank you to all who made the
New England Spina Bifida Conference a Success!***

**Rolando Barros, John Debassio and Nicole DelVecchio, Abigail Bordeaux
Sharlette and Lila LaPorte
Brian Pariser and Family/Therapy Dogs
Marlboro YMCA and Cynthia Arroway
DANCE Arts CT**

Thank You to the Farrell Family

On October 6th **Kim and Hannah Farrell** hosted the annual fundraiser in support of SBAGNE. Held at **Jenny Boston Boutique**, 25% of sales were donated to SBAGNE and attendees left with some great accessories! **Arbella Charitable Foundation** continues to support this event in honor of Sean Farrell. Thank you to **Kim, Hannah, Jenny Boston and Arbella**.

During the last six years the Farrell Family has raised approximately \$35,000 for SBAGNE. Over \$20,000 has been raised at the **Jenny Boston** Event and **Ryan Farrell's** 2 years of the **Falmouth Road Race** raised \$14,000.

Annual Appeal Support SBAGNE

The 2013 Annual Appeal is currently underway. You may have received an e-mail or letter describing what your ongoing support means to SBAGNE, our programs and services. Visit **www.SBAGreaterNE.org** if you wish to donate online. A check can also be mailed to:

**SBAGNE
219 E. Main St.
Suite 100 B
Milford, MA 01757**

Does your employer have a Matching Gift Program? If so, SBAGNE could accomplish twice the work with a matching gift from your company. Your company could double, even triple your gift. Many companies also match gifts from retirees and spouses, so please check all possibilities.

Annual Benefit Program

Deadline : Midnight November 30, 2013 - Via mail, fax or e-mail
Additional information and application at **www.SBAGreaterNE.org**
or contact Ellen at **edugan@SBAGreaterNE.org**

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Youth & Adults Group

Ellen Heffernan-Dugan, Executive Director

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Walk-n-Roll

Wendy Potts, Operations Associate

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Wheelchair Sports

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

Editor: Peter Jablonski

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 Greater New England nor any parties who supply content to this publication make any warranty concerning the accuracy of any information found herein. The SBAGNE 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 SBAGNE does not employ medical personnel in its organization.



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CHANGE SERVICE REQUESTED

SBAGNE is going green in 2014!

Beginning in the Winter 2014 the SBAGNE Quarterly News will become a bi-monthly e-newsletter. The primary intent is to keep SBAGNE constituents informed on programs, events and news related to the SB community in a more timely way. And of course we will be saving a few trees along the way!

Please contact Ellen at **888-479-1900** or [**edugan@SBAGreaterNE.org**](mailto:edugan@SBAGreaterNE.org) if you wish to continue receiving a paper version of the SBAGNE News. Also if your e-mail address has changed since first contacting SBAGNE, please forward an updated e-mail address.

The initial issue will be in your Inbox the first week in February 2014!