SBAGNE news

Winter 2012 The Newsletter of the Spina Bifida Association of Greater New England

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YEARS

1971-2012

Letter from the President

by Matt Neal

Matt Neal!? Who's Matt Neal?

I am. **Cara Packard** has just finished two years of noble service as President of our organization, and now it's my turn. I'll say more about me in a bit (I know, you can't wait) but first, on behalf of everyone who has had anything to do with SBAGNE over the last several years, a heartfelt Thank You to Cara for everything she has done for us. Cara, your creativity, vision, patience, and perseverance have been invaluable as SBAGNE has expanded services and service area in spite of this little global economic firestorm of the last four years. No small feat. Thank you.

If you've been to a SBAGNE event recently, you've probably seen me wandering around. Tall, thin, not a whole lot of hair – that guy. I'd attach a picture, but I look better without one. I've been on the Board in one capacity or another since 2003, just about the time Cara's husband Brian started his tenure as President. I've been the treasurer since 2007 and Vice-Chair (you'd have to ask the national organization why we've had to start calling ourselves 'chairs' instead of presidents and such) since 2009. Thankfully, a Chair can't be a Vice-Chair too, or a Treasurer for that matter. I am pleased to say those duties are now handled by our new Vice-Chair **Barbara Lee** and our new Treasurer **Brandon Casten**. Congratulations and Thank You to the both of you! I am really excited about this opportunity to serve the local Spina Bifida community and I'm looking forward to continued growth and innovation in service ahead!

What's Coming up This Year

One great new program from last year is getting bigger and multiplying into two great new programs! I'm talking about BLING (Better Living 'n Girls) and her brand new sibling BEST (Boys, Esteem, Success & Training). The driving force behind these events, produced by SBAGNE in partnership with the Myelo Clinic at Children's Hospital Boston, is our own board member **Rebecca Sherlock**, Clerk (not only our own, Rebecca is also the Nurse Coordinator at the Myelo Clinic at CHB). This program was a brilliant idea and has really taken off under her inspired leadership!

The program is for kids with spina bifida between the ages of 11 and 17 and one of their parents. Last year was such a success for **BLING** that **BEST** was created, so now boys have a program too. My daughter Grace and my wife Ginny attended last year's BLING at the Omni Parker House in Boston and the reports I got back were glowing! The only downer was that it all ended too soon, so this year it's an entire weekend (March 2-4). It's all about makeovers, educational seminars, and socializing with the theme of managing the not-so-trivial transitions of that age as a person living with Spina Bifida. The cost is only $25 for each mother/daughter couple and I ask you - how else could you spend a fun weekend in a fancy Boston hotel with a whole bunch of new-found friends so affordably? You can't – and you couldn't here either without the generous support of the **Metrowest Women's Alliance** and **Children's Hospital League**. BEST is the same idea, but for boys and one of their parents. No makeovers for the boys in case you wondered. The focus shifts a bit to athletics and active lifestyle. BEST starts out as a one night affair (April 27-28) just the way BLING did last year. The activities will be at the Mass Hospital School with accommodations at a nearby hotel.

All you have to do is clear out your schedule for the relevant days and sign up! There are only a few spaces for each event, but not all of them are spoken for yet, so don't wait! The info on page 5 of this newsletter tells you how to sign up.

Wasn't that Walk 'n Roll we did together last September fun? I think so, just an electric family atmosphere. Not only that, we raised 60% more than our first Walk 'n Roll last year. We just love the depth of community response to these events and are so grateful to everyone who has participated! We can't spend it unless we raise it first, so it's great to have annual events like this with so much potential for growth.

This year we are moving the Walk 'n Roll to late spring/early summer. That will make the time between annual Walk 'n Rolls a fair bit less than a year this time, but it will only be this once. From now on the Walk 'n Roll will be in May or June, bank on it. We're making the change to create a more balanced schedule of events throughout the year - and because of the weather. We'll make the time & place announcement soon, but I wanted to take this opportunity to let you know about this change. It's still only once a year, so please don't sit this one out!

OK, this is a good place to sign off. Enjoy the rest of the newsletter!

Holiday parties in Massachusetts and Maine!

Massachusetts Holiday Party

On December 4th, SBAGNE held its Annual Holiday Party at the Hilton Garden Inn in Waltham, MA. More than 100 people of all ages gathered for the yearly event that included food, fun, games and of course a visit from a special guest!

All of the children enjoyed receiving a gift from Santa Claus and having the chance to tell him their own holiday wishes. Adults got gifts of their own during the Yankee Swap!

Not only was this a special way to celebrate the holiday season, but families got to meet new friends and catch up with old!

If you missed the Holiday Party this year, we hope that you will try to fit it in to your busy holiday schedule in 2012! It is always a great time for all!

Thank you to our Elves: Patricia, Jessica, Ian, Erica and Emily.

Special Thanks to Amelia Cordischi, photographer – "On The Slide"

Maine Holiday Party

On Saturday December 3rd, SBAGNE held its inaugural Holiday Party at the Senator Inn, Augusta ME. Many Maine families attended, enjoyed lunch, cookie decorating, crafts, music and the afternoon's activities.

The day's activities were made a success with the assistance of **Ed Podgurski** (Santa), **Cindy Pooler** (cookie decorating), **Mike Burd** (ukulele music), **Kerri Podgurski-Gordon** (Santa's helper and helped assemble the gift bags) and the **Glatzer Family**. Watch the SBAGNE Quarterly News and visit **www.SBAGreaterNE.org** for upcoming events.

Special Thanks

Mark Palmer of
Granite Telecommunications
Jeans Day $1700

Bob Day of Maine Swim
$1000

Walk-N-Roll 2011
Congratulations to Top 10 Teams for Walk N Roll for Spina Bifida
Special Thanks to the Teams from SBAGNE – You Rock!

1. Team Little Warriors (SBA of North Texas)
2. Team Hannah (SBA of Colorado)
3. Olivia's Smile (SBA of Greater New England)
4. Team Wishbone (SBA of Washington State)
5. Team Vreize (SBA of Connecticut)
6. Amazing Grace (SBA of Greater New England)
7. Colton's Crusaders (SBA of Greater New England)
8. Team Hot Rollers (SBA of Colorado)
9. Tyler's Troops (SBA of Greater New England)
10. Race for Riley (SBA of Colorado)

Watch the website and newsletter for the 2012 WNR date and information.

BEST

JOIN

Children's Hospital Boston, Myelo Clinic and SBAGreaterNE for the Inaugural BEST Weekend

BEST (Boys, Esteem, Success and Training) Weekend will include one night stay at a hotel, educational seminars about healthy living, nutrition and athletics.

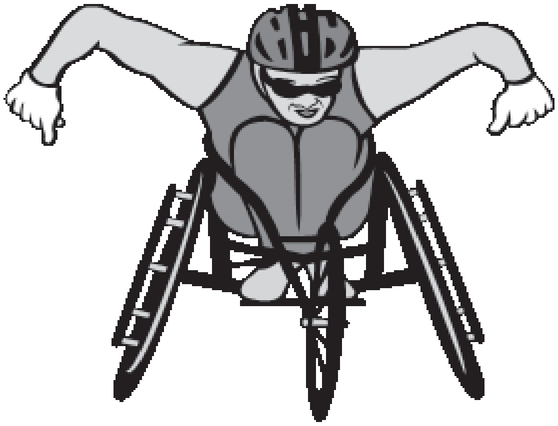
When: April 27th-April 28th

Where: Hotel to Be Determined; Saturday Activities will be held at Mass Hospital School, Canton

Who: 10 Boys (ages 11-17) living with Spina Bifida and one parent
(Space is limited to 10 boys and a parent. A waiting list will be available)

Cost: $25.00 per parent/son

RSVP: By March 15, 2012 to Ellen at
edugan@SBAGreaterNE.org or 888-479-1900



BLING

Better Living N' Girls

JOIN

Children's Hospital Boston, Myelo Clinic and SBAGreaterNE for the 2nd Annual **BLIN'G** camp

BLIN'G Camp will include two night stay at the Omni Parker House, Boston, dinner, educational seminars about healthy living, and makeovers.

When: March 2th -March 4th, 2012

Where: Omni Parker House, Boston

Who: 15 Girls (ages 11-17) living with Spina Bifida and one parent
(Space is limited to 15 girls and their parent. A waiting list will be available)

Cost: $25.00 per parent/daughter

RSVP: By February 17, 2012 to Ellen at
edugan@SBAGreaterNE.org or 888-479-1900

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the children's hospital league
bringing laughter and smiles

MetroWest Women's Alliance
engage. educate. empower.

Medical Research Corner

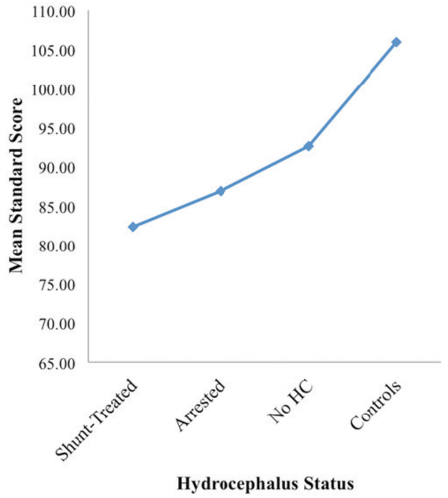
by Virginia Briggs, Ph.D.

Hydrocephalus and shunts in people with spina bifida have been associated with poor motor, spatial and executive functions, I.Q. scores, math skills, reading skills and more. However, this has not been covered very well in research yet. A study published in late 2011 examined neuropsychological outcomes in children with spina bifida, and compared those with and without shunts. Results showed that there were small differences between children with and without shunts, but there were significant differences between those with and without spina bifida.

The study included 208 children with spina bifida (average age, 11 years) and 61 children without spina bifida (as controls). The spina bifida children were divided into three groups; hydrocephalus with shunt, hydrocephalus without shunt and children with no hydrocephalus. In general, the children with hydrocephalus with or without shunts, had similar scores on the neuropsychological tests. However, all three groups of children with spina bifida had lower scores than the children without spina bifida.

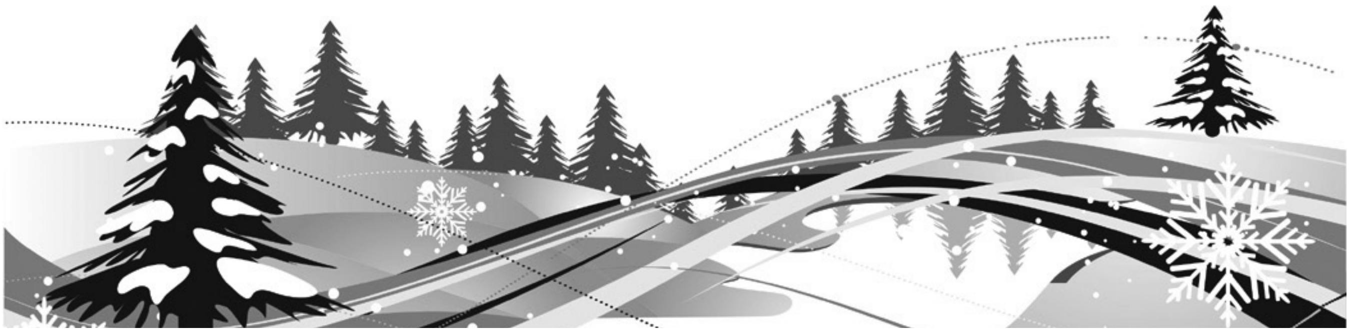
Overall, children with shunted hydrocephalus performed at the lowest level, followed by those without shunts, those without hydrocephalus and those without spina bifida. The graph below shows the overall results of the neuropsychological tests. Though this study does not provide us with overwhelming information, it does contribute to the knowledge base necessary to learn more about the effects of shunting in children with spina bifida. It may also help to mold education programs to better fit the needs of spina bifida children.

Average Neuropsychological Test Scores in Children With and Without spina bifida



(“Arrested” hydrocephalus = hydrocephalus with no shunt)

REFERENCE: Hampton LE, Fletcher JM, Cirino PT, Blaser S, Kramer LA, Drake J, Dennis M.; Journal of Neurosurgery: Pediatrics. 2011 Sep;8(3):289-98. “Hydrocephalus status in spina bifida: an evaluation of variations in neuropsychological outcomes”. (Department of Psychology, University of Houston, Texas).



Nine Time Boston Marathon Champion Inspires Area Groups

by Tim Sullivan

Ernst van Dyk, wheelchair racing legend made several area appearances prior to racing in the 115th Boston Marathon. Ernst shared his inspiring message of overcoming adversity, stressing to the crowds throughout the day that true victory can mean many things and is often borne from how you get back up when you get knocked down. Ernst finished third in a photo finish at the Boston Marathon. However, with his 9 titles, he holds the record for most wins for anyone in any division in the storied race's 115 year history.

"Sports have given me the opportunity to help others in realizing that life does not end with disability but that it's merely a beginning to a new way of life," said Ernst Van Dyk. "My hope is that through my story people are inspired to try new challenges and enjoy their lives in ways they thought might never be possible."

Ernst was born in apartheid South Africa with congenital limb differences. Doctors told his parents he would only face a lifetime of hardship. Rather than listen to what people told him he could not do, Ernst was raised to believe that anything was possible. Today, Ernst is a world-renowned athlete, advocate, and champion who is an inspiration to thousands across the globe.

On behalf of Spaulding Rehabilitation Network and in partnership with Massachusetts Rehab Commission (MRC), a few days before the Marathon, Ernst addressed a crowd of hundreds at the Riverview School for youth with complex language, learning and cognitive disabilities in Sandwich. He also visited with patients and staff at Spaulding Hospital Cape Cod and ended his day by being honored by MRC at the Massachusetts State House addressing legislators, youth groups and community organizations. Beginning in 2003, the Spaulding Rehabilitation Network has been one of van Dyk's major sponsors.

"To be able to bring to our community such a decorated athlete and remarkable person like Ernst who is such a symbol of perseverance is something MRC is very proud of. I know our constituents and the many attendees found his message both uplifting and inspiring," said Commissioner Charles Carr, Mass Rehab Commission.

"Spaulding is so proud to have this longstanding sponsorship with Ernst to support him as he continually rewrites the record books and challenges perceptions of what is possible," said David Storto, President, Spaulding Rehabilitation Network. "Ernst embodies the very best qualities of strength and dedication that our caregivers and courageous patients display each day at Spaulding."

In addition to marathon victories all over the world, Ernst has won multiple medals at the Paralympics, including gold at the 2008 games in Beijing. Ernst was also honored in 2006 as the Sports Star of the Year by the international Laureus Sport Foundation, joining figures such as Lance Armstrong, Serena Williams and Roger Federer.

Ernst is now looking ahead to how he can continue to expand his impact for the community with disabilities worldwide. He launched a new sports equipment brand, Enabled Sport, based in Africa that offers a range of sports and recreational products for persons with a disability. In just two years, Enabled Sport is already one of the largest equipment dealers in Africa. Beyond the business ventures and racing victories, it was obvious throughout the day that his greatest impact is the example he gives to all who meet him that anything truly is possible if you believe in yourself.

Tim Sullivan is Director of Communications, Partners Continuing Care & The Spaulding Rehabilitation Network

Reprinted with permission from Disability Issues(Vol.31, No.2, Summer 2011)

Ernst van Dyk inspiring others.

SUPPORT SBAGNE and Have Fun!

A Game Day is a fun and exciting way for kids and adults of all ages to make a difference. While they play their favorite games they are raising money for the Spina Bifida Association of Greater New England. There are many ways to host a Game Day. A typical Game Day is about two to three hours long.

SBAGNE will be hosting a Game Day soon. Watch the website for date and location.

If you are interested in hosting a Game Day Please contact Ellen by e-mail at **edugan@SBAGreaterNE.org** or by phone at **888-479-1900**.

SBAGreaterNE wants YOU to go to the SBA Conference this June!

The SBA Conference is the biggest event of the year and YOU can be a part of it!

Apply Now if you want to…

- Meet other people living with Spina Bifida
- Learn more about living with Spina Bifida
- Make friends and enjoy seeing old friends
- Get away to a new city
- Share tips and tricks
- Learn the latest medical info from doctors and other experts
- Have an amazing experience

Funds Available:
Scholarships of $1500 each are awarded.

Spina Bifida Association
2012 Annual Conference
June 28-July 1, 2012
Indianapolis Indiana

Application Submission Deadline
March 25, 2012

Notification Deadline to Scholarship Awardees
April 15, 2012

Applications are available online at **www.SBAGreaterNE.org** or email or call Ellen Heffernan-Dugan at **edugan@SBAGreaterNE.org** and leave a message at **888-479-1900**

Spina Bifida Doesn't Slow Her Down!

My name is **Elizabeth Brodeur**. I'm an 18-year old with Spina Bifida. I recently just finished an Administrative Office training program at Family Resources Community Action in Woonsocket, RI. I'm currently doing an internship at SBAGNE. As part of my internship I've been helping plan a Game Day fund raiser. Also as part of this internship I've been stuffing envelopes with fliers and addressing them to be mailed out. I've also been looking up different websites that people can go on for mobility, equipment, travel and other resources.

I'm hoping that after this internship that I'll be able to get a job somewhere. The type of job that I want is to be a receptionist in a doctor's office or a dentist office. I'm a very sociable young women and like to be with other people. That is why I think that is the right job for me.

There's No Place Like Home

"There's no place like home," chants Dorothy in the Wizard of Oz, tapping her heels three times. Dorothy is right. There is no place like home, and for people faced with a new or progressive disability or limitation, living at home independently shouldn't feel like a dream at the end of a rainbow.

No and Low-interest loans for Home Modifications are available for Massachusetts Homeowners and Small Landlords.

While many Commonwealth programs are facing budget cuts, long waiting lists and lack of resources, the Home Modification Loan Program is well funded and seeking applicants. The program serves elders, as well as adults and families with children with disabilities. Since 1999 these loans have helped hundreds of Massachusetts residents finance; the addition of ramps and lifts to improve their ability to get in and out of the home, kitchen and bathroom modifications to improve their ability to live independently within the home, and the widening of doorways and floor renovations to improve mobility within the home.

The Massachusetts Rehabilitation Commission (MRC), in partnership with the Community Economic Development Assistance Fund (CEDAC), funds these no and low-interest loans of up to $30,000 for eligible homeowners. Landlords with buildings with fewer than 10 units can also apply for a 3% loan to improve accessibility for a tenant. Program income guidelines are quite generous, for example a family of two with an income of $77,100 or less would qualify for a 0% loan. Additionally, applicants eligible for 0% loans make no monthly payments, no interest accrues and they do not have to repay the loan until the property is sold or transferred. Regional nonprofit agencies around the Commonwealth handle the application process and determine the eligibility of the modification and the applicant. For regional agency contact information, or for more information about the program, visit **www.mass.gov/mrc/hmlp**, or contact **Susan Gillam** at **617-204-3739** or **susan.gillam@state.ma.us**.

Verizon's Center for customer with disabilities

Were you aware that Verizon Communications, Inc. has a center devoted entirely to serving customers with disabilities? The Verizon Center for Customers with Disabilities (VCCD) was first opened in 1992 in Marlboro, Mass. and has since grown, resulting in Verizon adding more representatives as well as a second office in California. "The Verizon Center for Customers with Disabilities provides our customers with equal access by offering the ability to talk to representatives who understand the challenges we face in our everyday lives when it comes to using the phone, TV and internet," said **Tom Boudrow**, a deaf outreach manager at the center. Whether the customers call through traditional phone means, a TTY, or even a Videophone, VCCD is ready to take their call. When the center first opened in 1992, the focus was only on telephone services. Today it has expanded to include telephone, data and television through its award winning FIOS network. The center currently handles in excess of 1500 calls per day which go directly to representatives, with no menus or recorded prompts between the customer and the customer service representative. "I always tell people the definition of a disability is when the person and the environment do not match, so our job at the center is to make it match. Because of our knowledge on disability access we are able to best match our packages with the person's individual needs, depending on their disability, said Boudrow. "We have many new products come out throughout the year. For example, most recent is our home monoriting and control service. This is a wonderful added feature for our customers who can, through their cell phone or computer, turn on their home lights, turn on the heat before they arrive home or even receive input from a security camera located inside or outside their home. We welcome the opportunity to talk with customers who have any kind of disability. Call us and see how the VCCD can offer you outstanding value, meet your telecommunications and entertainment needs, and exceed your customer service expectations."

The center is open Monday to Friday from 8:30 AM to 5 PM. **800-974-6006** voice or tty.

SBgenetics.org

Help us make a difference today.
Participate in our **Spina Bifida Study** >

The Spina Bifida Genetics Research Project is starting the second phase of a study to determine if genetic variations in folic acid metabolism account for an increased risk of having a child affected by Spina Bifida. From the results of the study, it may be possible to develop a test that can identify women who may not be adequately protected by standard prenatal vitamins, but who might benefit from high dose folic acid therapy prior to conception.

We are seeking mothers who have had children with Spina Bifida, and who did not participate in the first phase of this study, which was conducted in 2009-2010. We are also enrolling mothers of children who have not had children affected by Spina Bifida to serve as controls for the analysis.

Participants in the study are asked to complete a brief online survey and provide a DNA sample using a simple, at-home saliva collection kit that is delivered and returned by mail. For more information and to enroll in the Spina Bifida Genetics Research Project, please go to the website at **www.sbgenetics.org** and select ENROLL. The website and survey are available in both English and Spanish.

Upon completion, participants may choose to receive a $10 gift card or we will donate $10 to a Spina Bifida organization of your choice.

The Spina Bifida Genetics Research Project includes scientists from UC Berkeley, Stanford University, UC San Francisco, Children's Hospital Oakland Research Institute and VitaPath Genetics.

Contacts

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

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

Board of Directors

President
Matt Neal
Email: mneal@SBAGreaterNE.org

Vice Chair and Treasurer
Barbara Lee
Email: blee@SBAGreaterNE.org

Treasurer
Branden Casten
Email: bcasten@SBAGreaterNE.org

Clerk
Rebecca Sherlock, PNP
Email: rsherlock@SBAGreaterNE.org

Dr. Stuart Bauer
Email: sbauer@SBAGreaterNE.org

Jen Fitz-Roy
Email: jfitzroy@SBAGreaterNE.org

Linda Long-Bellil
Email: llongbellil@SBAGreaterNE.org

Karen Sites
Email: ksites@SBAGreaterNE.org

Operations

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

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

Contacts

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

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

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

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

Medical Issues
Ginny Briggs

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

Memorial Donations
219 Main St (888) 479-1900
Ste 100B
Milford, MA 01757

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

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

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

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.

Spina Bifida Association of Greater New England
219 East Main St
Ste 100B
Milford, MA 01757

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

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would like to receive the
newsletter via email.