Summer 2015

SBAGNE
news

Aime Patano (center)
2015 Jean Driscoll
"Dream Big" Awardee

SBAGNE
news

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Save the Dates!

Summer is here and 2016 is on it's way!

Join SBAGNE for a series of events through the Spring and Summer. For more information, visit **SBAGreaterNE.org**.

October 17th
Rock Climbing
Location: Quincy Quarries, Quincy, MA

2016

SBA National Conference, Minneapolis, MN

June 25 - Adult Day and Opening Reception

June 26-28 - Conference and Kid's Camp

Events

WALK-N-ROLL 2015

The Walks are underway. The Massachusetts Hospital School and Rock Church walks are complete but we still have Northampton and Nashua walks on the schedule. The Walk-N-Roll is our largest fundraiser of the year. We need your support to reach out goals so we can continue programs and services.

Northampton, MA, Look Park - **September 12th**
Nashua, NH - **October 3rd** (virtual walk)

Visit **SBAGreaterNE.org** for links to each site.

Abilities Expo

September 18th - 19th

This event features three days of products and services, compelling workshops, fun-for-the-whole-family activities and has become the leading event for the community of people with disabilities.

Abilities Expo reaches out to all ages and all sectors of the Community including wounded veterans, persons recovering from immobilizing accidents, seniors with age-related health concerns, children with disabilities, individuals with mobility and spinal issues, people who have vision and hearing impairments, people with developmental disabilities and many more. Whether your challenges are mild or severe, this is your event.

Admission is free.

Regional Education Days

SBAGNE will be hosting 3 Education Days, across the service area, in Fall 2015. It is hoped that the 3 Education Days will give increased numbers of individuals and families the opportunity to participate. Watch your mail and visit **SBAGreaterNE.org** for more information.

Saturday, October 24th – Shriners Hospital Springfield Mass

Saturday, November 7th – Boston Children's Hospital, Waltham Mass

Maine – Date and location to be determined

BEST Re-scheduled

October 16th - 18th

BEST is for young men, living with Spina Bifida, ages 12 -17

Register at **SBAGreaterNE.org**

Questions? Contact Ellen Dugan at **edugan@SBAGreaterNE.org**

Hello All!

Hello Everyone,

We hope that all of you are having a wonderful summer! This happens to be my favorite time of year when we can enjoy the outdoors and don't have to shovel snow!

As we are quickly approaching the end of the summer we want to remind you of the upcoming activities and events that are scheduled and hope you may be able to take part. I would like to thank all of you who are participating and have donated to the **Falmouth Road Race** that took place on August 16th. Some of us were able to enjoy fundraiser **Lena Williamson's** cupcake baking fundraiser which wasn't only yummy but very productive. Thank you!

Walk-N-Rolls are scheduled in the fall; Northampton, MA on September 12th and Nashua, NH on October 3rd. Please go to the SBAGNE website to register and plan on supporting SBAGNE. As always we want to thank everyone who is participating and have donated.

BEST (Boys, Success, Esteem and Training) Weekend is re-scheduled for October 16th - October 18th! On October 17th we have coordinated a **Get Active Event - Rock Climbing**! Those that participated last year loved it and couldn't believe how much fun it was. Again we need you to register from the SBAGNE website.

As you can see from the many events and activities the SBAGNE community is keeping very busy. Enjoy the rest of your summer and hope to see you at some upcoming events.

Sincerely,

Barbara

Barbara Lee, Chair SBAGNE

SBAGNE kicked off the Walks for 2015 with great success and a new logo! We're so excited to share the new Walk-N-Roll for Spina Bifida logo with you representing the active and engaged living we support within our SB community!

On June 6th the Canton, Massachusetts walk was held and on June 20th the Scarborough, Maine walk. The feeling of community was amazing, the weather was perfect for both events and the SBAGNE community did a tremendous job of fundraising to support programs and services. Nearly 300 individuals participated in the combined events. **Slyde**, the New England Revolution mascot, joined us in Canton and **Crusher**, the Maine Red Claws mascot in Scarborough.

Walking and rolling, bubbles, snacks, connecting with old friends, making new friends – both events were a tremendous success. Photos from both events may be found on the SBAGNE website (**SBAGreaterNE.org**).

The Board and staff of SBAGNE are very grateful for the continued support of the greater New England Spina Bifida community, your family and friends.

We could not accomplish all that we do without your assistance!

In the News

Piers Park Sailing!

SBAGNE collaborated with **Piers Park Adaptive Sailing Program** on May 30th for a day of sailing. The Adaptive Sailing Program at Piers Park Sailing Center (PPSC) is a nationally recognized non-profit sailing program which has served over one thousand people with disabilities since the program's inception in 2007. PPSC's program objective is to empower our sailors living with disabilities to realize their recreational goals using adapted teaching methods and a full array of adapted equipment. A small but enthusiastic group participated. It was a picture perfect day for sailing on Boston Harbor, sunny and just enough wind.

Don't wait for summer 2016, visit piersparksailing.org for information on 2015 events.

Annual Reports

Each year SBAGNE publishes it's Annual Report. You may download the latest and past reports by visiting: SBAGreaterNE.org/about/annual-reports/

Annual Benefits Program Renamed

In July 2015 SBAGNE renamed the Annual Benefit Program; it is now the **Annual Empowerment Benefit**.

The name change was brought about to more aptly signify SBAGNE efforts to support individuals living with SB, to live active and enriching lives.

The application process and items eligible for reimbursement remain the same. Applications can be downloaded from SBAGreaterNE.org.

Jean Driscoll "Dream Big" Awardee Aime Patano

Amie Pantano was born in 1989 with spina bifida myelomeningocele. At the age of 2, after a couple of corrective surgeries, she began walking with the help of AFOs. As a kid, Amie enjoyed swimming, playing town youth soccer, and even water skied for the first time at age 13. Over the years, she has had nine surgeries related to spina bifida and struggled with self-confidence. However, Amie made lifelong friends, graduated from both high school and college with honors, received her teaching certificates in elementary and special education, began graduate school, and worked for the past four years as a teaching assistant. Amie's dream big goals are to become a lead teacher of Special Education and/or Reading, to finish graduate school with honors, and to receive teaching certifications in both Reading Specialty and English as a Second Language. In her young adulthood, Amie began to feel a need to be more connected with the SB community. She would love to have the opportunity to volunteer and mentor young adults, teens, or children affected by spina bifida. Receiving this award is a huge honor and Amie feels so grateful to SBAGNE for this opportunity.

Handling 'Help'

by Ned Fielden

One cannot live without it. I am not a rock, not an island. My life is interconnected with dozens of others closely — and the rest of the world's sentient beings — whenever I am out and about. Life without help is isolating, and helping hands grease the human experience, smoothing pathways, enabling, making all sorts of things possible that would not be otherwise.

Disabled people know this well, and gratitude is on our minds often when someone does the odd favor, gets us out of a jam, reaches that book on a high shelf. Help is handy, help is sublime, help is necessary.

Unless it is not desired.

And when it puts the grand spotlight of life squarely on your disability.

So this is the dicey part. I want to encourage altruism. I want it to flourish. It is an essential component of being human. Without it we descend into chaos and a brutal, self-centered way of life. But I am fond of my own sanity too, and the abbreviated but precious independence I have fiercely and relentlessly wrested from my post-accident life.

I am a male T8 paraplegic from a hit-and-run bicycle accident 25 years ago. I grew up in backwoods New England, where independence is as stoutly defended as anywhere in the world. In my town you dug your own post-holes, repaired your own roof, stayed frugal. Self-reliance was a religion, a way of life.

My, oh my — becoming disabled was a jolt.

I couldn't even get into my own house any more. Could barely pull on my trousers. Couldn't mow my lawn or fix my gutters. I managed to lose most of everything I had worked 35 years for — house, marriage, job, almost my children.

In those early years, avoiding unsolicited help was relatively easy. I could dash around in my ultra-light, my big newly muscled arms like tree trunks, while the wild, defiant air on my face kept people at bay. I was going to do things my way, thank you very much, and I gritted my teeth at the grocery when I had to ask someone to reach the pickles on the top shelf.

I have mellowed a bit, but it is a rare day when I leave the house and don't have at least one unsolicited, unwanted, highly intrusive offer of help.

I suspect most of us recognize the usuals. Holding the door open (but standing in the way). Elevators. And now that my beard is gray, I am an old gray codger-in-a-wheelchair. I must need help all the time!

People can't stop themselves.

I cannot pause on the street to blow my nose without someone coming over. Never mind dropping my keys, reaching in my backpack for a book, going up a hill!

It is a wonder I can do anything on my own, and there are days that Satan appears, sitting on my shoulder, ready to offer educational elbows to the ribs of the well-intentioned but clueless.

The wheelchair, as we all know, is a powerful, highly visible symbol. Evidence suggests it alters the consciousness of others. First, in nondisabled eyes, your IQ drops 20 points. Your age goes up 20 years. Your help quotient hits the ceiling. How could you possibly be in a wheelchair and not be grateful for any and every offer? And if you decline mine, you really can't mean it — I will just step in and do the obvious anyway. Why you are snarling at me? These ungrateful cripples are so aggravating.

I work at a university with a hilly campus. Several times a week someone offers to push me up a hill on the way to the bus stop. I always politely decline, which works about 60 percent of the time, but the interaction often escalates.

"You sure?" they ask, worried that maybe I will clutch my throat and have a heart attack if I go another 10 feet. I cannot possibly be telling the truth.

"Fine, thanks," I respond, accent on the second word.

And more times than I care to contemplate, the good Samaritan can't stop himself and starts pushing me anyway.

"No!" I bellow. "Get your hands off me!" I have perfected a sudden wheeling move that gets them darting their shins out of harm's way. "Don't you ever touch a wheelchair user without asking first!"

They hold their hands up, as in "only trying to help. …" Drives me nuts.

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Summer Picnic Fun

The Annual SBAGNE summer picnic was held on Saturday July 18th, 2015 at the Massachusetts Hospital School in Canton. Despite the cloudy skies and a few raindrops we had a great time! There was swimming in the indoor heated saline pool, followed by a tasty BBQ lunch of hot dogs, hamburgers, chicken and all the fixings under the outdoor pavilion. Always a favorite at a picnic, there was a make your own sundae for dessert. During the gathering, there were raffles and **Amie Pantano** was awarded the Jean Driscoll "DREAM BIG" Award 2015.

The picnic was a great opportunity for families to connect. Several of the BLING girls were there, and they were definitely trying to recruit some new additions. Smiles and fun were had by all. Looking forward to another great gathering next year!

Handling Help, continued from pg 4

In 2012 the San Francisco Giants baseball team won the World Series. At the victory parade, their top relief pitcher, Sergio Romo, a Mexican-American, wore a T-shirt that proclaimed "I only look illegal!" —highlighting the immigration debate. Maybe I need a shirt that says "I only look pathetic!" Or maybe if I fasten some gleaming scythe-like blades to my wheelchair wheels, a la Ben Hur in the chariot race scene, people will leave me alone.

Another aspect of unsolicited help is the attention brought on you. If you were going along, minding your own business, blending in with everyone else, acting as a regular human, your cover is now blown. The patronizing look down at you. Everyone else notices the interaction. Your wheelchair, previously invisible, or at least a secondary part of your human existence, is now Front Stage.

A couple of offers I have had over time stand out as exemplary, one just the other day. A 20-something female student said, "Looks like you have everything under control, but if you would like a push, I am happy to help you up the hill."

Perfect. Polite. The request makes it clear that it would be my choice. It is respectful and lets me know the person will actually listen to me.

I am sure that there are lots of folks out there who do a lot better than I do with this help business. Like most disabled people, I have a lot of patience. Like a lot of disabled people, it is not an infinite store. My issue is staying civil, holding to my own ethical and moral code, without letting the idiots of the world ruin my sanity.
I would love to hear more about everyone's coping strategies in the face of unwanted, unsolicited help. In the meantime, the following rules, designed mostly for wheelchair users but likely adaptable to those with other types of disabilities, might be handy to pass on to your loved ones or the large herd of yet-to-be-educated nondisabled types who witness your disabled traverse through life. Print it out. Put it on your refrigerator. Sing it!

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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

Chair
Barbara Lee
Email: **blee@SBAGreaterNE.org**

Vice Chair
Rebecca Sherlock
Email: **rsherlock@SBAGreaterNE.org**

Treasurer
Linda Long-Bellil
Email: **llongbellil@SBAGreaterNE.org**

Clerk
Ginny Briggs
Email: **gbriggs@SBAGreaterNE.org**

Dr. Stuart Bauer
Email: **sbauer@SBAGreaterNE.org**

Abigail Bordeaux
Email: **abordeaux@SBAGreaterNE.org**

Emily Cooke
Email: **ecooke@SBAGreaterNE.org**

Shannon Cutter
Email: **scutter@SBAGreaterNE.org**

Stefan Gagnon
Email: **sgagnon@SBAGreaterNE.org**

Jason Paynich
Email: **jpaynich@SBAGreaterNE.org**

Ashley Robinson
Email: **arobinson@SBAGreaterNE.org**

Aimee Williamson
Email: **awilliamson@SBAGreaterNE.org**

Operations

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

Jeff Vendetti (888) 479-1900
Operations Associate
Email: **jvendetti@SBAGreaterNE.org**

Contacts

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

Falmouth Road Race
Ellen Heffernan-Dugan, Executive Director
Email: **edugan@SBAGreaterNE.org**

Fund raising
Ellen Heffernan-Dugan, Executive Director
Email: **edugan@SBAGreaterNE.org**

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

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

Parents Helping Parents
Cara Packard
Email: **cpackard@SBAGreaterNE.org**

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

Walk-n-Roll
Ellen Heffernan-Dugan, Executive Director
Email: **edugan@SBAGreaterNE.org**

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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