



SBAGNE

news

Summer 2013

The Newsletter of the Spina Bifida Association of Greater New England

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Walk-N-Roll
Report and
Photos!



Notes from the Chair

by Matt Neal

Welcome readers, to the latest issue of your SBAGNE newsletter! This time around Notes from the Chair will include bullets! Plus I will not start off with the beautiful summer weather – or will I?

Get Active!

Thanks to the hard work of our intrepid grant-writing team (Ellen Heffernan and Ruth Tarbox) SBAGNE has secured a wonderful \$20,000 grant from the Constance O. Putnam Foundation. We received this grant to help expand our 'BLIN'G' and 'Best!' programs in 2014 and to begin a new program in 2013 that we are calling 'Get Active!'. We believe that an active lifestyle is a key component of addressing the mobility challenges that are a part of everyday life for nearly everyone living with Spina Bifida. The Get Active! program will be all about teaming with partner organizations to provide venues for fun activity and to help deal with those thoroughly vexing transportation problems that often get in the way. You'll find more details on what is coming up this fall/winter in an article a little further into this newsletter. Part of the fun and one of the keys to success for this program is going to be doing this together! We need each other for encouragement to get going when we don't really feel like it, to get out the door when it is easier to just stay home – even though we know staying home is part of a cycle of staying home and feeling bad about it. So 'Get Active!' will be built to promote and enable getting a group together, to do things together, to make small changes in lifestyle, that build a foundation for a healthier, more fulfilling, engaged, energetic, and successful life. So come on, join us, Get Active!

Wendy

With a touch of sadness and a great deal of gratitude we must say farewell to Wendy Potts, SBAGNE operations associate for the last four years. The title 'Operations Associate' doesn't even begin to hint at the value Wendy has brought to SBAGNE. She has been the backbone of our event planning and implementation. Producing that first Walk 'n Roll on short notice with no idea what to expect or what to avoid was – well, let's just say it was a bonding experience for Wendy and Ellen. This is only one of the many, many important things Wendy has done for SBAGNE over the last four years, but I'm not writing a book here. Wendy began her association with the organization by volunteering to manage Team SBAGNE at the Falmouth Road Race a long time ago. After a while, she agreed to take on the OA role working part time out of her house (which happens to be shouting distance from Ellen's place). This worked for her because her three small children keep her pretty busy around the house and it worked for us because she is great. Now Wendy is ready to go back to school to study nutrition or something very similar. And so her time as SBAGNE OA will come to an end this month. Please join me in thanking Wendy for all she has done for SBAGNE and wishing only the best in her studies, her family life, and her future career.

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Jean Driscoll
Recipient



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Holiday
Party
Announcement



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SBAGNE &
Waypoint
Adventure
Team Up!



SBAGNE

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YEARS

1971-2013



for Spina Bifida

Presented By



On June 15, the Spina Bifida Association of Greater New England held our 4th Annual Walk-N-Roll for Spina Bifida. This year, the Walk took place at 3 separate locations simultaneously: Mass Hospital School in Canton, MA, Stanley Park in Western, MA and at Rock Church in Scarborough, ME.

Over 370 participants from all over New England came out for this family-friendly event. Holding the event in 3 locations enabled more participants from Greater New England to participate and for SBAGNE to expand its reach further into the community.

In each location, Walkers and Rollers took on a 1.5 mile course and helped build awareness about Spina Bifida. Following the walk, they were able to connect with members of the community. This was not only a fundraising event, but a celebration!

Over \$100,000 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 and far exceeded our fundraising goal!

Donations are still being accepted at www.walknrollsbagreaterne.org.

Thank you to all who participated and volunteered, especially to those in Western, MA and in Maine for making the Walks in those locations happen. You made the expansion of the SBAGNE Walk-N-Roll a success!

Plans for the 2014 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 Ellen Dugan at edugan@SBAGreaterNE.org.



Big Y representatives, Jim Wilson and Lisa Gaudette, present SBAGNE check for \$5000 as presenting sponsor the 2013 Walk N Roll for Spina Bifida. Thank you to Big Y for their support of SBAGNE!

Check out all the photos on
www.SBAGreaterNE.org!







***Thanks to all who
participated and
donated to the
Walk-N-Roll!***



SAVE THE DATE

Saturday,

September 21, 2013

8:30 AM - 4:30 PM

New England Spina Bifida Conference
Sturbridge Host Hotel and Conference Center
Sturbridge, MA

Educational Sessions & A Full Day of Activities for the Kids!!!

Don't miss Keynote Speakers, Gina Gallagher and Patricia Konjoian, authors of

***"Shut Up About Your Perfect Kid! A Survival Guide
for Ordinary Parents of Special Children"***

Learn about our "Bring a Volunteer" discount and our Conference Stipend.

For more information and to register go to:

www.sbac.org or www.SBAGreaterNE.org

REGISTRATION OPENS AUGUST 1



Join SBAGNE

PORTLAND
SEADOGS VS
Trenton Thunder
Saturday August 31,
2013 - Game 5PM
\$5.00 per ticket
(limited tickets)

Meals will be served from
one hour prior to the game
until one hour after the
first pitch and includes
Hamburgers, Hot Dogs,
BBQ Pulled Chicken, Cole
Slaw, Beans, Assorted
Coca-Cola products and
Sea Dogs Ice Cream
Biscuits

RSVP by August 15th to
edugan@SBAGreaterNE.org



Jean Driscoll Recipient 2013 - Shakayna Bowen

Shakayna is truly the definition of the Jean Driscoll "Dream Big" Award. She is currently attending Boston Arts Academy, focusing on becoming a gospel singer and of course her academics. In the future Shakayna would like to sing on stage, in shows, clubs and weddings, as well for residents in nursing homes and children in homeless shelters. Quoting Shakayna – "Spina Bifida does not define me as a person. I am a girl who can do the same things as other people."

Congratulations Shakayna!

Thank you
**BEST/BLING
Volunteers**

Marilyn Noonan

Michael Mercier

Dr. Emilie Johnson

Dr. Duong Tu

Megan Geno

EPIC Team Leaders

WE COULDN'T DO IT WITHOUT YOU

Thank you to all who made the 4th Annual Walk-N-Roll a Success!

| | |
|--|---|
| Emily Cook | Emily, Cambry and Caleb Cutter |
| Shannon Cutter | Panera of West Springfield and Chicopee |
| Western Mass Band - TIME | Westfield Fire Department |
| Emerson Family | Kate O'Donnell |
| Sarah Haywood & Ryan | Rod, Laura & Emma Dowland |
| Ashley Robinson | Stephanie Martin |
| Lisa Gaudette | Isacc Martin |
| Kristen Gagnon | Kayla Martin |
| Tammy Lynch | Jessica & Megan Lynch |
| Kathy Hardy | Connie Maloney |
| Gretchen and Eliza Bellegarde | Susan and Eme Bowie |
| Paul Cutter | Rock Church Community & Pastor Steve |
| Alex Cutter | Scarborough Police Dept. |
| Eric Cutter | Glatzer Family |
| Derek Cutter | Karen and Joe Sites |
| Rebecca Sherlock | Linda Long Bellil |
| Nicole Tarzia | Donut Dip |
| Cassandra Boutet & Tambria Hebert | Cassandra Boutet & Tambria Hebert |
| <u>PHOTOGRAPHERS</u> | |
| Jennifer Cherry & Blue Glass Photography | |
| Katelin Hardy Photography | |
| Kathy Hardy | |



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

Check back in late Fall and visit www.SBAGreaterNE.org for more information and directions as they become available.

SBAGNE and Waypoint Adventure are partnering for our new GET ACTIVE! program



- The cost of the GET ACTIVE! Events are covered by a grant.
- SBAGNE will cover and/or help arrange transportation if needed.
- Events are for adults 18+ and LIMITED openings are available.
- RSVP to Ellen: edugan@sbagreaterne.org or 888-479-1900

Both programs are fully accessible to people with disabilities

Outdoor Kayaking

The **Waypoint Outdoor Kayaking program** will give you and your group access to some of New England's most beautiful lakes, rivers and coastline all while enjoying the support of your friends or family. This program will provide you with equipment that can be adapted to fit your needs, and our highly trained staff will instruct, support and encourage you as you learn new skills or further develop your existing ones.

Date: Saturday, August 24, 2013

Time: 10:00 AM - 2:00 PM

Site: Boat Launch, Woerd Ave Waltham, MA (across from office park at 48 Woerd Ave)

Conditions: Parts of the terrain will be uneven and sandy. Paddling will be in a fresh water lake. Maximum paddling distance is 2 miles.

Hiking

Waypoint Hiking will open your eyes to the exciting and accessible world of the New England woods. On this program you will be encouraged to reach your individual and group goals all while learning skills to travel safely and effectively through the wilderness environment. Some of the lessons may include layering, packing the 10 essentials, map and compass land navigation, teamwork, communication, and perseverance.

Date: Saturday, October 19, 2013

Time: 10:00 AM - 1:00 PM

Site: Assabet River Wildlife Refuge, 680 Hudson Rd. (Rt. 27), Sudbury, MA

Conditions: The terrain is rough with some roots and rocks. The weather may be very wet which will make the ground muddy. Please dress appropriately.



Donated Item

A 5 year-old Quantum 600 Power Wheelchair is available. It has a new battery and joy stick. It needs a new cushion. Please note, that the picture at right is representative of the Quantum 600 and may not reflect the actual item. If you're interested in this beauty, please contact Ellen Heffernan-Dugan at edugan@SBAGreaterNE.org.

Boston University Research Study: Advocacy, goal setting, and transition to adulthood

Do things in your environment sometimes make it hard for you to do activities? Get a “Game Plan” to deal with environmental barriers. **This study is looking for teens and young adults ages 14- 21 with developmental disabilities such as Spina Bifida, autism, or intellectual disability to participate in a training called “Project TEAM”.** Project TEAM (Teens making Environment and Activity Modifications) teaches teens and young adults how to change social and physical barriers in the environment. Project TEAM is taught by adults with and without disabilities and includes mentorship from young adults with disabilities. Trainees meet as a group to complete 8 training modules and 2 community trips. Training activities are designed to be fun and enjoyable. Trainees will receive gift certificates for completing the study. Groups run each semester until 2015.

You may also choose to participate in an alternative study. Teens and young adults will set a goal and receive a \$50 gift certificate to try a new activity, like going to the movies or going to a restaurant. They will complete questionnaires three times over 4 months, and receive gift certificates each time they and their parents complete the questionnaires.

If you (your teen) are interested, contact **Jessica Kramer**. She is in charge of this study at Boston University. She can answer questions and help you decide if you (your teen) want to become a trainee. You can reach her at **kramerbulab@gmail.com**, 617-353-7522 or 617-353-2702.

Why consider community college?

by Mary Mazzoni

Life After IEPS (lifeafterieps.com)

When teens plan for college – there’s a lot to consider.

For starters, what is your child’s career goal? After all, college isn’t an end in itself. What education or training is needed for your child’s career of choice?

For many students, community college is an ideal path toward career goals.

Even if your child is working toward a four year degree, there can be real benefits to starting at a community college.

Skeptical? Take two minutes to watch this recent CNN video. I’ll wait.

Intrigued? Let’s dig deeper!

Earning power of associate degrees

Were you surprised that 28% of employees with an associate degree earn more than those with bachelor degrees? It’s true! And the trend is likely to continue in that direction as companies look for employees with targeted skill sets.

Check out this chart from the Bureau of Labor Statistics Occupational Outlook Handbook. Compare the median salary of Athletic Trainers to Cardiovascular Technologists, for example. A quick glance at the chart shows many other associate degree careers in healthcare that pay more than jobs requiring a bachelor degree.

Salary is not the sole factor in choosing a career. Still – let’s bust the myth that a four year degree always commands a higher salary than an associate degree.

Career guidance and networking opportunities

Most high school graduates lack an in-depth knowledge of career options. They may be unaware of the diversity of careers within their field of interest, or lack insight into labor market needs in their area.

Community colleges generally have a close working relationship with local businesses. Their mission is to prepare students for career opportunities. Often, local professionals serve as adjunct faculty.

Students who seek out opportunities for career counseling and internships, and those who seek career guidance from faculty, will gain insight and connections that can lead to informed career choices and potential job opportunities.

Career pathways

In many fields, there are pathways from careers that require an associate degree to those requiring a bachelor degree. Sometimes, it’s even possible to get started in a field with a non-credit certificate.

There are real advantages to this step-by-step career approach. Students who attain a credential and a job in their field while continuing their education are honing key skills and building their resume. They’re also developing relationships that can lead to career opportunities not accessible to those who go directly through a bachelor degree program.

In today's job market, career networking and relevant work experience can make all the difference between two applicants with the same level of education.

What's more? Some companies provide tuition assistance for relevant courses.

Less debt

Even if your child won't begin a career until after attaining a bachelor degree, starting at a community college can dramatically reduce costs.

By working closely with community college counselors, your child can choose courses that can transfer to his or her four-year college of choice.

Tuition at the four year school will likely be at least three times more than community college. Not to mention the savings in room and board costs.

More gradual transition

The differences between high school and college are profound. Most first year students struggle to make the adjustment.

Starting postsecondary education at community college can help your child ease into increased responsibilities.

For example, 3 hours of out-of-class work is recommended for every hour of college class time. That requires self discipline and time management. A lot to expect from a teen adjusting to dorm life!

Class sizes at community colleges are typically smaller than those in freshman classes at four year schools. Generally, there is more opportunity for extra help and relationship with instructors.

If your child is living at home for the first year of college, you can monitor how s/he is coping with new demands. You'll want to be sure to offer more independence than in high school, but you'll also be able to suggest resources and strategies when your child needs support.

Avoiding SATs and ACTs

Not all four year schools require SATs and ACTs. But, most still do. And those hurdles can be difficult to clear.

The accommodations allowed by SAT and ACT may not align with those to which your child has become accustomed in high school. And the tests themselves may not be the best measure of your child's ability to succeed in college.

SAT and ACT tests are not required for community college admission. And, after several successful semesters at community college, four year colleges will not require transfer applicants to take these tests.

HOWEVER – be advised that community colleges DO require placement tests before allowing students to enter certain credit courses required by degree programs. Most community colleges use either the Accuplacer or the Compass.

While still in high school, your child should ask the disability support office which test is used and how to prepare. Also – s/he should ask how to apply for placement test accommodations.

Look before leaping

There is great variance in the quality of community colleges. This article from CNN Money includes tips and research sites for evaluating the quality of community colleges.

And it's critically important to thoroughly research the supports available at a particular two or four year school before making a final decision to accept admission. Here are some questions to get you started as you speak with disability support professionals at various colleges.

Expect community colleges to provide "reasonable accommodations" in accordance with the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act. And community colleges often have tutorial support for students with and without disabilities. However, it's important to understand that the individualized education provided in K-12 schools under IDEA is not required under ADA or Section 504, and will not be available at most colleges.

In future posts we'll look at specialized college programs designed for students with disabilities that exceed legal requirements. These programs tend to be expensive, and this type of support is not available at community colleges.

Your turn

Once again, we've covered a lot of ground in one post. In the end, you and your child will need to decide what school is the best fit.

Note: This article was reprinted with the kind permission of the author. It may accessed online at: <http://lifeafterriepps.com/why-consider-community-college/> where you may access all the links.

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

Board Chair

Matt Neal

Email: mneal@SBAGreaterNE.org

Vice Chair

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

Emily Cooke

Email: ecooke@SBAGreaterNE.org

Jessica Guest

Email: jguest@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

Fund raising

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 East 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

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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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