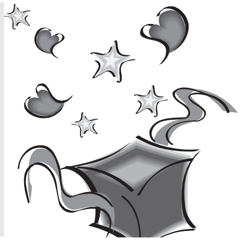
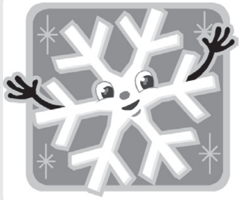
SBAGNE news

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





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YEARS

1971-2012

Notes from the Chair

by Matt Neal

Hurricane Enough for Ya?

That's right; I'm leading with the weather. It's okay though because: hurricane. It's the day after Sandy as I write this and several days after as you read it. A very exciting non-event up here in Marlborough, lots of preparation and some fairly high winds but no real damage. Governor Patrick says Massachusetts as a whole is in the same fortunate boat, as is the whole of SBAGNE territory. Lots of power outages and a much more impressive display of Mother Nature's might along the coast, but we surely got off lucky this time. So we kick off our New England winter a little early for the second year in a row. We also kick off the winter as SBAGNE for the second year in a row. Look at that, I wasn't sure how I was going to segue to SBAGNE relevance but then it happened.

Coming Up and Just Happened

The 2nd Annual New England Spina Bifida Conference took place on September 22nd in Sturbridge, MA and once again it was very successful. We are already thinking about how we can make it even better for next year. Send us your comments and stay tuned! It is also almost the end of Spina Bifida Awareness Month (October) so we've been busy trying to make the general population aware that 1) we are here and 2) all women of child-bearing age should take a multivitamin that contains folic acid (they pretty much all do). Anything any of us can do on a personal level to raise awareness is all good too.

Holiday party season is coming up now too! We are doing one in Waltham, MA and one in Augusta, ME. We are definitely open to putting on more of these because all we really want to do with this type of thing is get as many people as possible together for a fun social event. If these are both a little too far away for you to get to and you wish they weren't, consider contacting us ('us' means Ellen at 1-888-479-1900 or edugan@SBAGreaterNE.org) to volunteer to help us set up something that serves your area better. We can start of modestly and build on it if we know there's interest.

We are also trying another something new in a few weeks. On November 28 we will have Guest Bartender Night at McCreevy's Irish Pub on Boyleston Street in Boston. We are working on getting a couple of really fun bartenders to step in and serve from 6-9 that night and all of their tips will go to SBAGNE! So stop by, do a good deed, have a pint, and share a few laughs. We sent out 'Evites' a little while ago, if you didn't get one or you want another just contact Ellen!

Annual Appeal

By now you should have received our Annual Appeal letter in the mail, and we are working on getting an email follow up out shortly. This is our last major fundraiser of the calendar year, and then we lay low till the Walk 'n Roll next spring. You may be thinking 'I can really only make a smallish donation right now, what's the point. I mean, here's an organization that sends me $400 or so to help with Spina Bifida related expenses, how's my $xx gonna help? Wouldn't it be better to just submit a smaller benefit request?' Well, my fellow SBAGNE constituent let me tell you now that yes it matters, and it matters a lot. As a grass-roots local organization, our life's blood is not so much money as it is participation! We are here to serve our people. The more the people we serve show that they value our presence by making some contribution – no matter the size – the better the case we can make to other donors, sponsors, grant-giving institutions, etc., that we matter and we are worth helping. One of the things these organizations ask us is 'how many of your constituents contribute back to your organization?'. So please consider responding to our appeal with whatever works for you.

Thanks for reading, and I hope you enjoy the rest of our newsletter!

new balance FALMOUTH ROAD RACE

Team SBAGNE did it again! This year marked the 40th Falmouth Road Race and our amazing 25 person team crushed their fundraising goal and raised over $42,000 for the Spina Bifida Association of Greater New England!

The weather on Sunday, August 12 started out glum. The rain was coming down, but it didn't dampen the spirits of Team SBAGNE. As has become the tradition of Team SBAGNE, the team members joined together to ride the bus to Woods Hole and to shout "SPINA BIFIDA" in solidarity before beginning the race. Wearing jerseys adorned with "Racing for Spina Bifida," our runners build awareness for our cause and for SBAGNE. And at gun time, the rain had cleared.

SBAGNE is immensely grateful for all of the generous individuals who have made the Falmouth Road Race a success for our organization. We thank The Potts Family for graciously opening their home for the post-race celebration. We appreciate all of the donors, who make serving our mission possible. Most importantly, we send huge thanks to all of our wonderful, dedicated runners, who make this event happen. This year, all of our runners raised over $1000 each! Through their efforts, we will be able to continue providing programs and services to our members.

Falmouth Top Five

Brian Packard: $5856

Matt Lombardi: $2615

Mary Honan: $2510

Bob Bertolino: $2308

Kathleen Brannigan: $2151

Annual New England Spina Bifida Conference

On September 22, SBAGNE in collaboration with the Spina Bifida Association of Connecticut, held the 2nd **Annual New England Spina Bifida Conference**. The full-day conference was held at the Sturbridge Host Hotel in Sturbridge, MA. With approximately 170 people from the Greater New England and Connecticut areas in attendance, the conference served as both a day of education and for networking and socializing with the Spina Bifida community.

Several physicians and experts from the area led sessions on topics such Spina Bifida and Spinal Deformity, How to Manage Social Security Benefits and Employment and many other topics related to Spina Bifida. Between sessions attendees were given the opportunity to visit several exhibit tables. While parents and caregivers were in sessions, children were treated to a full day of activities Kids Camp. Kids Camp included arts & crafts, a visit from Therapy Dogs and a storyteller.

Many thanks to **Ginny Briggs** and the **volunteers from Regis College and Nichols College** for the outstanding job running Kids Camp!

Thank you to our sponsors!

Coloplast

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Wilmington Medical

Thank you to our exhibitors

Ride A Way

Rochester Medical

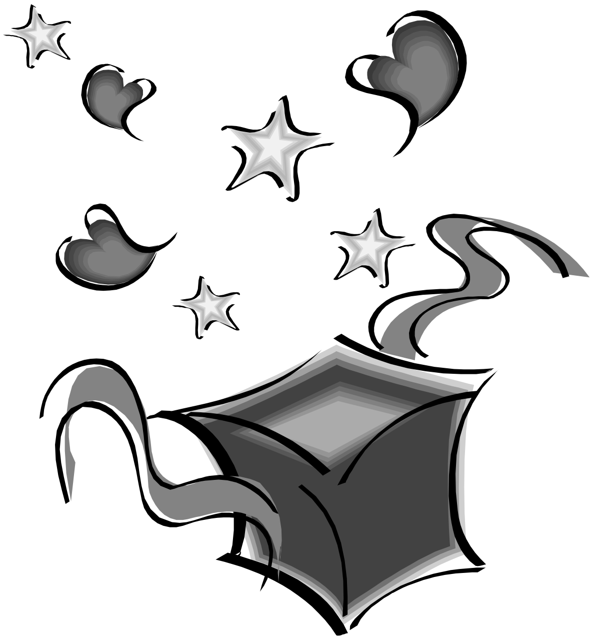
Vital Cards

Meaningful Gift-Giving

Revolutionary Common Sense by Kathie Snow

www.disabilityisnatural.com

Ahhh, the joy of sharing during wonderful gift-giving times: holidays, birthdays, and more! What's on your shopping list? Toys, clothes, electronics, books, DVDs, or…? Your friends and loved ones will be happy with the gifts you give. Did you know you can give even more without spending a penny? Check out the following avenues for meaningful gift-giving:



Parents: Give your child's teacher Permission to Fail. Most educators try diligently to do their best. But teachers in inclusive classrooms may be unsure of themselves as they learn new strategies to include and support children with disabilities. In addition, they may often feel an extreme amount of pressure to do things perfectly. As the parent of a child with a disability, I learned many years ago that what worked with my son at one time, or in a particular environment, didn't always work the way I thought it would at other times or in other environments. My husband and I frequently need to try new things at home, *knowing we'll make mistakes.* We need to give educators (and anyone else who works with our children) the same Permission to Fail that we give ourselves. When parents let educators (and others) know it's okay to make mistakes, so long as they're willing to keep trying new things and do whatever it takes to be successful, educators can relax and do a better job. So with kind eyes, a warm smile, and a gentle touch on the hand or shoulder, say something like, "I'm not a perfect parent, and I don't expect you to be a perfect teacher. It's okay if you make mistakes, and I support your efforts as you try new things. Let's keep working together and help each other figure out the best ways to ensure both you and my child are successful and feel good about everything!"

Educators: Give mothers and fathers the gift of Respect for Parental Expertise. Parents of children with disabilities have years of experience—*they are experts!* Recognize that combining your professional expertise with parents' intimate knowledge of their child will result in success for you and the student.

Parents and Educators: Give children with disabilities the gift of Responsibility. When we expect children to be responsible, they know we trust them and believe in them. Being responsible can take many forms, such as: doing chores at home, making their own decisions (small and large), actively participating in their IEP meetings (including writing goals), finding their own jobs, and…the list is endless! When we *expect* a child to be more responsible, we send the message that we believe she's competent and able, and then *she* will believe she's competent and able. This is a gift that can change a child's life, now and in the future!

Parents: Give your child a Vacation to Kidland. The daily routines of too many children with disabilities are governed by disability-related services. *Many don't have time to be kids!* So give your precious son or daughter a two-week break (or more) from home visits, speech/physical/occupational therapies, and other special services. Let him choose what to do with the hours in Kidland: sleep, watch a DVD, play with friends, do nothing, sit for hours playing a computer game, or spend dynamite time with mom and dad. Grown-ups take two week vacations from work. Why shouldn't kids get a vacation from the *work* of therapies and special services? Think how you and other family members will enjoy this vacation, too! (And, who knows, you might just decide to extend the vacation indefinitely!)

Children and Adults with Disabilities: Give someone the gift of Friendship. Too many people with disabilities are seen primarily as *recipients* of help and assistance, and they're surrounded by professionals and paid staff. But people with disabilities—just like people without disabilities—need friends and companions, *and* they need to be "givers," not just "recipients." Someone in your community needs your friendship and support! And the best way to "get a friend" is to "be a friend." So make connections through church, community groups, or volunteer organizations, and find that person who needs you for a friend. When you give the gift of friendship, you give yourself a gift at the same time!

The only gift is a portion of thyself.
Ralph Waldo Emerson

Moms and Dads of Children with Disabilities: Give yourself the gift of Serenity. Many parents are on the never-ending merry-go-round of services, IEPs, therapy goals, interventions, and more. When all this "disability business" is combined with being a wife/husband, having a job, and parenting *all* your children, disaster is in the making. Perpetual stress, exhaustion, and burn-out can create chaos in our lives, as well as in the lives of our loved ones. Everyone loses! Resolve to live a more peaceful, calm, serene life—be good to yourself and those you love. You don't have to "do it all!" What can you stop doing? What can you let go of?

Parents around the country are discovering that cutting back on "disability business" has enabled them to rediscover a "normal" life. On a regular basis, ask yourself, "Will this [therapy, services, or whatever] really matter six months, one year, or five years from now?" We're often so caught up in the daily grind that we fail to look at the long-term outcomes. Do whatever it takes to simplify your life so you can enjoy time for yourself, and with your precious children and sweetheart.

Make Simplicity part of your daily life, in all areas—not just disability issues. Clear out the clutter in your house, your car, your life. Say "no" more often, so you don't overextend yourself or your children. Turn off the TV. Play a game with your family one night each week. Play some music and dance together. Cook together, then clean up together. Read a book together. Let everyone pile in one bed and cuddle together!

Give the gifts that truly matter—meaningful gifts from your heart and soul.

Comedy Night with Jimmy Keys

On Friday, August 24 the **Cadette family and friends** hosted "Comedy Night with Jimmy Keys" at Cyprian Keyes Country Club in Boylston, MA. Over 200 people attended this entertaining evening in support of the Spina Bifida Association of Greater New England.

After a delicious dinner, **Jimmy Keys** entertained the crowd with his musical and comedy act, including hysterical impressions. The night concluded with the silent auction.

Thank you to **Olivia Cadette**, **Erin O'Hara**, and **Marty McDonald** for organizing this fantastic event and raising over $15,000 to support SBAGNE programs and services.

Jeff Hammond : Inspiration for Us All

***Jeff Hammond** is a good family friend of the Robinson's who have a young son, **Colton**, living with Spina Bifida. **Ashley Robinson**, Colton's Mom tells us about Jeff.*

Jeff has really a huge heart and is a really good person. He recently helped spread the word about Spina Bifida and is a great advocate as well. Not many people know about Spina Bifida, so this was awesome. I had numerous people come up to me because an article was placed in the local paper about what Jeff was doing. Everyone has told me it was very inspirational!

Jeff really understands the pathophysiology of Spina Bifida as he will be graduating as an RN next May. After learning about managing and treating so many disorders he was motivated to get out there in the public and get people to donate and become aware about Spina Bifida. He feels that people love athletic challenges and it is was a great way to generate more interest. He also felt that running for a cause gave him that extra push to succeed because he did not want to let Colton down. His hobbies and interests are running, competing in MMA, and he is passionate about becoming a nurse! He recently ran in the Hartford Ing Marathon and finished in 3.17 hrs and placed 199 out of over 2000 runners.

Come to our
Guest Bartender Event at McGreevy's
on Boylston Street on
November 29 from 6 - 9 PM.

The guest bartender's tips will benefit SBAGNE!

Contact Wendy Potts at
888-479-1900
for more information

Mark Your Calendars for the 2012 SBAGNE Holiday Parties!

Sunday, December 2, 2012 from 12:30 PM - 4:30 PM
Hilton Garden Inn, Waltham, MA (new location)**

Saturday, December 15, 2012 from 11:30 PM - 3:30 PM
Senator Inn, Augusta, Maine

Parties will include:

- Lunch!
- Fun and Games for all ages!
- Special Holiday Guest (with a gift for all children attending
- Holiday Sing-a-Long
- **Yankee Swap for Adults (Massachusetts Party Only)
  (Bring a wrapped gift worth no more that $10)
  *Adults with S.B. do not need to bring a Yankee Swap item

****Please RSVP by Friday, November 25, 2011****

By Email: **edugan@SBAGreaterNE.org**
By phone: **(888) 479-1900**
Online at: **www.SBAGreaterNE.org**

Include the following information in your reply:

- Party you will be attending (Massachusetts or Maine)
- Your first and last name
- Your phone number
- How many people are in your group
- Names and ages of everyone in your group
- Please specify the name of the person with Spina Bifida

Directions to the Party will be on web at SBAGreaterNE.org!

WAYPOINT
ADVENTURE

Waypoint Adventure was founded in 2010 by a seasoned team of experiential education professionals. Experiential Education transforms individuals and communities through challenge adventure. Waypoint provides these transformational programs to people with and without disabilities.

The Need

- Persons with disabilities make up 11% of the population of MA.
- About 15% of children between the ages of 6 and 17 are receiving special education in school in Massachusetts (2nd Highest percent in the US).
- Additionally, there are over 300,000 children living with a disability alone and over 36% of these families are in financial need.
- 26.8% of those aged 18-65 living in poverty in MA were persons with disabilities.

The challenges faced and the support discovered on Waypoint programs transform people's views of themselves and their abilities. Individuals walk away from our programs with their heads held high and a new realization of their strengths and abilities thus becoming more self-determined, contributing members of the community.

Key Accomplishments

In less than two years, Waypoint's unique adaptive techniques and custom tailored program curriculum established it as a leader in the Greater Boston community. During 2011, Waypoint implemented 100 fee-for-service programs serving over 1,500 participants. Waypoint provides ongoing programming with many influential community and educational organizations including Perkins School for the Blind, The May Institute, Boston Public schools and Spaulding Rehab Hospital.

Waypoint Adventure Inc. is a 501(c)(3) non- profit organization located in Waltham, Massachusetts.

66 Arlington St. Newton, MA 02458
781-454-5297 OR 978-417-0315

www.waypointadventure.org

www.facebook.com/waypointadventure

MASS
CONFERENCE
FOR WOMEN
DEC 6
Boston

The 8th annual Massachusetts Conference for Women will be Thursday, December 6, 2012, at The Boston Convention and Exhibition Center. The Conference will feature nationally recognized speakers like Arianna Huffington, one of TIME magazine's 100 most influential people in 2011 and president of the Pulitzer Prize winning Huffington Post Media Group, Vera Bradley co-founder Barbara Bradley Baekgaard, and 'Good Morning America' workplace contributor and CEO of Women For Hire and Spark & Hustle Tory Johnson.

This year's theme, Imagine!, dares women to find their purpose and make a difference in our own lives and in the communities and world we live in. The Conference features motivational keynote speeches, engaging workshops and panel discussions that cover a vast range of topics specifically designed for women, including healthcare, leadership, managing change, finding work life balance and personal finance.

To register, please visit **www.maconferenceforwomen.org**.

Registration includes access to all keynote and breakout sessions, the Career Pavilion, the Health & Wellness Pavilion and the exhibit hall.

Scholarships are available for high school juniors and seniors through the Conference's Young Women's Program and student tickets are also available at a reduced rate.

Ask the Expert

Q: I am 18 years old and need to find a doctor. What do I do?

A: You are now legally an adult and will be able to make your own decisions about your health care. In searching for adult-oriented doctors, there are some things to consider: Everyone should have a primary care physician to go to with common illnesses that anyone can get, as well as health maintenance care like immunizations, cholesterol screening, and blood pressure checks. For you, the best type of primary care adult medicine doctor is most likely a family medicine physician because they are familiar with Spina Bifida. You need a urologist who treats neurogenic bladders and, if you have a shunt, a neurosurgeon. As an adult, since you have stopped growing, you are less likely to need frequent care by an orthopedic surgeon or to have new bone issues requiring surgery. However, you would benefit from a physical medicine and rehabilitation specialist (also known as a physiatrist) who can help with musculoskeletal issues, as well as with bracing, wheelchair, and other equipment assessments. A physiatrist can also help with physical therapy and occupational therapy referrals, if needed. They can also help you find an orthopedist if a surgical issue arises. If you are a woman and are contemplating having children, it is best to discuss all of the issues of a potential pregnancy with an obstetrician who specializes in high-risk deliveries. You should meet with this sub-specialty obstetrician before you become pregnant.

Q: Are people with Spina Bifida at higher risk of developing type 2 diabetes?

A: People with Spina Bifida who have any of the following risk factors are at higher risk for developing type 2 diabetes:

- Obesity: People who are overweight, especially those whose fat settles in the abdomen rather than the legs and hips, are at high risk for insulin resistance and diabetes. At least 50% of children and adults with Spina Bifida are obese, putting them at very high risk for diabetes in their life.
- Inactivity/immobility: Increased exercise helps to maintain a healthy weight. Furthermore, exercise burns glucose for energy, increasing the cells' ability to use the insulin. There are many options for exercise for people with Spina Bifida, both those who can walk and for those who have difficulty with walking or use a wheelchair.
- Family history: Hispanics, American Indians, Asian Americans, and African Americans are the highest risk groups for type 2 diabetes. However, any family history of diabetes should be shared with your physician.
- Personal history of pre-diabetes or gestational diabetes (diabetes during pregnancy).
- Age: Risk increases with age. People over the age of 45 are considered high risk. However, insulin resistance and type 2 diabetes is increasing among children and adolescents. This increase is attributed to obesity, poor nutrition and lack of exercise. To decrease your risk, eat nutritious meals and maintain a healthy weight.

Q: Do you have any exercise or safety tips for adults with Spina Bifida who want to become active?

A: You will want to first make sure you are healthy enough to exercise. Inform your physician that you are starting an exercise program. As you choose the right program for you, make sure the activities you choose are varied, fun, and rewarding. Exercise as often as you can, ideally performing strengthening exercises three to four days a week. The National Center on Physical Activity for People with Disabilities (NCPAD) advises that you be active throughout the day - just keep moving.

The Health Guide for Adults Living with Spina Bifida includes a section on physical activity and weight control that is helpful for adults concerned about their general health. This publication is available from SBAGNE or at SBA's Marketplace.

*Adopted from Ask the Expert, Spina Bifida Association (**spinabifidaassociation.org**)*

SPAULDING™
ADAPTIVE SPORTS CENTERS

Spaulding Adaptive Sports Centers support individuals of all abilities in leading active, healthy lives through participation in adaptive sports and recreational activities. Spaulding opened its first Adaptive Sports programs in Boston and Cape Cod in 2001, and since that time has expanded to include the North Shore. These three sites offer a wide range of land and water based adaptive sporting activities that focus on the value of sports and fitness.

At these 3 Centers, participants living with disabilities play wheelchair tennis, hand cycle, kayak, windsurf or row using adaptive equipment in the summer, and engage in other activities through which they learn new life skills, make new friends and enjoy themselves as they rebuild their strength, independence and self-confidence. This fall we began therapeutic horseback riding, and we will soon transition into our winter sports of nordic and alpine skiing, wheelchair court sports and indoor rock climbing.

The programs are delivered by Spaulding clinicians and adaptive sports professionals, and are open to children and adults. Staff members help each participant find the most appropriate activities to meet their capabilities and Find Their Strength. Please visit **www.spauldingrehab.org** or call **877-976-7272** for more information on our seasonal and regional programs. We look forward to helping you find activities you love doing to stay active this year!

WE COULDN'T DO IT WITHOUT YOU!

On August 24th **Olivia and George Cadette, Erin O'Hara and Marty MacDonald** hosted a Comedy Night on behalf of SBAGNE, at Cyprian Keyes Golf Club, Boylston, Mass. Jimmy Keys was the headliner and attendees enjoyed a great night of humor in support of SBAGNE.

Thank you to the 25 runners who participated in the Falmouth Road Race and raised funds and awareness on behalf of SBAGNE. Thanks to **Judy and Joe Potts** for hosting the FRR After Party at their home.

On Saturday October 13th **Jeffrey Hammond** ran the Hartford Marathon in honor of **Colton Robinson**, a young boy living Spina Bifida. Thank you to Jeffrey who, while running in honor of Colton, raised funds for SBAGNE!

The New England Spina Bifida Conference, held on September 22nd included many topics of interest as well as a tremendous Kid's Camp. Many thanks to **Ginny Briggs** who over saw the planning and day of event management of Kid's Camp. Kid's Camp is central to insuring a successful conference, allowing families to attend presentations, knowing their children are enjoying the day and actively engaged in entertaining activities.

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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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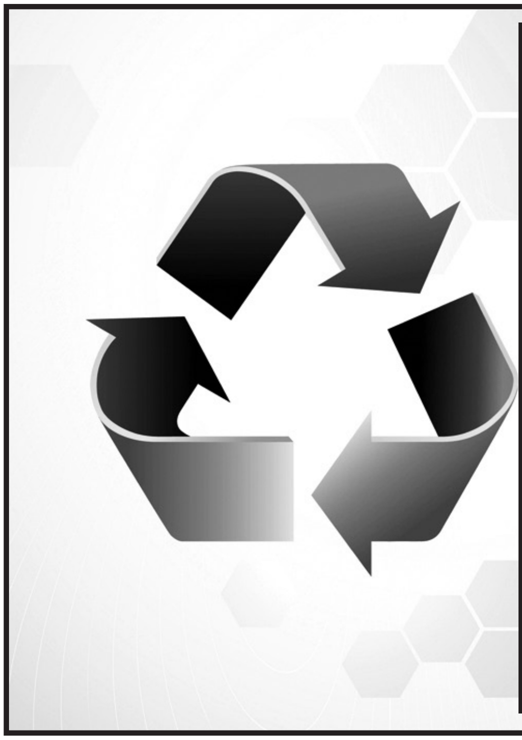

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