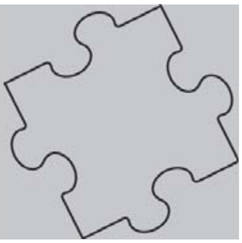
sbaMass news

Winter 2010 The Newsletter of the Spina Bifida Association of Massachusetts

Blin’g



sbaMass

3 9

YEARS

1971-2010

Letter from the President

by Cara Packard

I hope that this time of year finds you all enjoying the holidays with family and friends. It is hard to believe that 2010 is soon coming to a close. Though the year passed quickly, sbaMass has accomplished many exciting things. As we look back, we have much to be proud of as an organization.

We rolled out a revised Benefits Program in January that has continued to assist our members in need. We hope that you have found the revised program easier to manage. Additionally, we were able to award seven Conference Scholarships of $1500 in June. sbaMass had quite a showing at the National Conference in Cincinnati this year. We look forward to sending next year’s applicants to Disneyland!

Our Walk-n-Roll was, by far, the most exciting new addition to our calendar. The walk successfully raised money for sbaMass, but more importantly grew our organizational pride and spirit. The smiles and sense of accomplishment from that day have carried us on through the year. We hope that next year’s walk, already scheduled for September 2011, will be even greater.

As always, our social events were well attended and fun. I heard that Santa made many new friends at this year’s Holiday Party. For the first time in many years the day did not feature a snow storm! Hopefully the travel was easier for some of you as a result. Year after year, it is wonderful to see so many families connecting while enjoying the holiday cheer.

In addition to our regular events this year, sbaMass was also able to reach out to new locations. We held an event in Western Mass and also had a well attended event in Augusta, Maine. We look forward to growing our presence in Maine and hosting additional events in 2011. Maine will not be our only growth point. We also have some exciting new programs planned for 2011. BLING (Better Living ‘N Girls) will thrill some of our teens with the opportunity for makeovers and tips on healthy living. We’re also hoping to implement a parking assistance program through the Myelo Clinic at Children’s Hospital.

We always welcome any thoughts and ideas from you, our members, on ways that sbaMass can improve or assist you. 2011 is full of exciting possibilities for sbaMass, and hopefully for you and your families as well. I wish you a very happy and healthy New Year!

Golf Tournament

On September 20, sbaMass and the Cadete/Cadette Family held the 2nd Annual Cadete/Cadette Family Golf Tournament at Cyprian Keys Golf Club in Boylston, MA. All proceeds benefited the Spina Bifida Association of Massachusetts.

Over 90 golfers attended the tournament on this beautiful Fall day. The shotgun style tournament included several contests along the course to keep the game exciting. Following the tournament, there was a fantastic dinner, a live auction and a comedy show.

The enthusiasm and generosity of the golfers was amazing. In total, over $45,000 was raised for sbaMass! A special thank you to the tournament hosts, the Cadete/Cadette Family, for their continued kindness and support of sbaMass and to all of the generous sponsors!

The 3rd Annual Cadete/Cadette Family Golf Tournament is scheduled for June 13, 2011.

Thank you to the Gold and Silver Sponsors of the 2010 Cadete/Cadette Family Golf Tournament!

DUNKIN' DONUTS®

AMERICA RUNS ON DUNKIN'℠

Dunkin' Donuts and the Batista family, franchise owners in Worcester since 1976, proudly support the work of the Spina Bifida Association of Massachusetts.

Workers' Credit Union

Doing what's right...for you.℠

Workers' Credit Union, founded in 1914, is headquartered in Fitchburg, MA. With assets over $780 million, the Credit Union serves over 66 thousand members with personal and business services from fourteen offices in Acton, Chelmsford, Fitchburg, Gardner, Groton, Lancaster, Leominster, Lunenburg, Orange, Townsend and Workers' Online at wcu.com.

RBT Rollstone Bank & Trust®

Rock Solid Banking Since 1846

Rollstone Bank & Trust is a mutual savings bank, headquartered in Fitchburg and serving the people, businesses, and organizations of Central Massachusetts. It has 7 branches, plus full-service Commercial Lending and Financial Services Division, and continually earns 5-star ratings for safety and soundness. We are pleased to be an ongoing sponsor of sbaMass' great work.

- **Cape Management Team, LLC**
- **Montuori Oil Delivery, Inc.**
- **Clementi Family Charitable Trust**
- **Lisa & Sousa Ltd-Atty at Law**
- **Karyn Polito for State Treasurer**
- **PGR Construction, Inc.**
- **Carlos Andrade**
- **Homeland Builders**
- **Burlington Donuts**
- **L & K Donuts**
- **Midstates Packaging**
- **Wayne J. Golab**

sbaMass Annual Holiday Party

On December 5th the sbaMass community came together for the Annual Holiday Party at the Hampton Inn, Natick. Great food, friends, Santa, crafts, music and a Yankee Swap. And once again, the weather cooperated!

To view additional pictures visit http://www.sbaMass.org

THANK YOU!
Vitapath Genetics for their support of this event.

To the girls from **So Buttons**, website http://www.wix.com/sobuttons/so-buttons-2

Amelia, Jessica, Patricia and Erica for their assistance with crafts, games and as elves.

Erin Fallon, DJ, for her music

Amelia, for her photography. Her website is http://www.wix.com/ontheslide/ots

Bits & Pieces

ONLINE RESOURCES available through sbaMass and SBA

sbaMass eCommunities

YAG Listserv (ages 17+) An online community for Youth and Adults in New England who have Spina bifida. This group is meant to be a community where individuals can connect, plan activities, and generally provide support to each other. Web site address: **groups.yahoo.com/group/sbaMassYAG**. This group is ONLY for folks who actually have s.b. As much as we love our parents, they are not allowed to sign up for this group. We want to make sure sbaMass YAG members feel they can talk about their issues without having to edit what they say. **WHO RUNS THE LIST?** sbaMass staff manages the list. **HOW TO SIGN UP!** There are several ways to do this: 1) Send a blank email message to this address: **sbaMassYAG-subscribe@yahoogroups.com** or 2) go to the Youth and Adults sbaMass web page, click on the "Subscribe to sbaMass YAG Yahoo!Groups link, and fill out the form.

sbaMass Parents Listserv

A discussion group for families in New England who have children with Spina bifida. The group is here to help each other out by sharing thoughts, questions, ideas and support. Web site: **groups.yahoo.com/group/MSBAParents/**.

WHO RUNS THE LIST? sbaMass staff manages the list. **HOW TO SIGN UP!** There are several ways to do this. Send a blank email message to this address: **MSBAParents-subscribe@yahoogroups.com**. Go to the Programs area of the sbaMass web site, click on the "Subscribe to sbaMass Parents Yahoo!Groups" link, and fill in the form.

Maine Parents Listserv

An online community for individuals living with Spina Bifida and their families in Maine and Northern New England. This group is meant to be a community where folks can connect, plan activities and generally provide support to each other.

WHO RUNS THE LIST? sbaMass staff manages the list. **HOW TO SIGN UP!** Send an email message to this address: **maineparents-subscribe@yahoo.com**

Spina Bifida University

Spina Bifida University (SBU) is a new online educational tool offering both live and archived seminars on topics related to Spina Bifida. Session topics vary, from health-related seminars presented by medical professionals to employment or education discussions from subject matter experts. Individuals can log on to **www.sbuniversity.org** to register and become a part of this new online learning experience. Sessions are available 24 hours a day, seven days a week.

SB Tween2Teen

SB Tween2Teen is a Web site for tweens and teens with Spina Bifida to discuss issues important to them. Complete with blogs, videos, real stories, fact sheets, and an Ask the Expert feature, the interactive site helps tweens and teens navigate the difficult road to adulthood which can be complicated further by this challenging birth defect. Youth with Spina Bifida can log onto **www.sbtween2teen.org** and become part of a new community.

SB Preparations

SB Preparations, a new transition-focused Web site launching in November, will provide parents, caregivers, and clinicians information and tips on helping a person with Spina Bifida achieve key developmental milestones that lead to greater success in adulthood. The tips are generated based on a questionnaire completed by the user and take into consideration the age of the person with Spina Bifida (pre-school, school-age, adolescent, or young adult). This tool can even be used by young adults themselves to help remedy some transitional challenges they may be experiencing. **www.sbpreparations.org**

SBA eCommunities

Log onto **www.sbaa.org**, click Programs and Services/ Quality of Life. Options are:

- **SBProfessionals ListServ**: Provides an online discussion resource for nurses, nursing students, physical therapists, occupational therapists, and other health care personnel who are routinely involved in the treatment and care of individuals with Spina Bifida.
- **SB Parents ListServ**: For any parent of a child who has Spina Bifida. Use the SB Parents ListServ to exchange ideas, resources, debate, and have some great discussions.
- **SBA Occulta Listerv**: A networking opportunity for the Spina Bifida occulta community.
- **Youth and Adult Alliance (YAA) ListServ**: A way for adults with Spina Bifida, young and old, to communicate with each other about a wide range of issues of common interest.

BLIN'G

Better Living in Girls

Children's Hospital, Myelodyspalsia Clinic and sbaMass are in the process of planning a BLING (Better Living N' Girls) Camp for tween and teen girls living with Spina Bifida. We are working collaboratively to hold the inaugural camp in Boston during February or early March 2011 and are planning for 10 attendees. The BLING Camp will include overnight stay at a hotel in Boston, dinner, educational seminars about healthy living, and makeovers. Those already committed and volunteering their time include a hairdresser, esthetician, nutritionist, physical therapist, social worker, reiki practitioner, and Ms. Wheelchair Massachusetts 2010. This is not a fundraising event, but a weekend designed to meet the needs of young girls living with Spina Bifida. Watch your mail and log onto www.sbaMass.org for details as they are available.

Thank you for your kindness

To customers of T-Stop Superette of Lynn for their ongoing commitment of sbaMass.

As in years past, the customers of T-Stop have generously donated supporting sbaMass programs and services.

Save the Date for the
2nd Annual Walk-n-Roll for
Spina Bifida!
September 25th, 2011
at the
Endicott Estate in Dedham, MA.

The Walk-N-Roll for Spina Bifida is a family-friendly, 1.5 mile walk event being held to raise awareness about Spina Bifida and celebrate the accomplishments of the over 180,000 Americans living with it . All proceeds are used for programs and services for people living with Spina Bifida.

Start recruiting your team members now!
www.walknrollsbamass.org

sbaMass Goes West

by Nicolle Tenters

On Sunday, October 17th, the sbaMass went westward to Stanley Park in Westfield, MA, where attendees were treated to a light lunch, a fantastic handicapped accessible playground, and great conversation. Although there were not many families who came, those who did had a great time getting to know each other. It was small and cozy and the perfect weather for spending the afternoon outside. This park comes highly recommended for families with young children of all abilities. What a treasure!

Aside from the playground, there was pumpkin painting, which the kids really enjoyed, and one of the older sibs pulled out the face paint and gave all the younger kids some pretty fantastic designs. When this small group of kids went back to the playground, with their cool-looking faces, they attracted the attention of other kids who were not with the sbaMass group. More than one group came over to our pavilion to see about getting their faces painted. Great job, Makayla!

sbaMass Partners with Maine!

by Karen Sites

In early November, sbaMass helped put on the first gathering for SB families and adults in Maine in many years. It was a great success with over 50 people in attendance. The group included everyone from the very little ones to veteran SB adults. After some much needed conversation and sharing we enjoyed playing a game and a delicious lunch together. The kids spent some time together doing crafts while the adults discussed some business. Everyone shared ideas of what they would like to see our group in Maine accomplish. Everything from reaching new SB parents to startng an email list that would enable us to stay in touch easier in such a large geographic state. We are excited to work with sbaMass as well on the great projects they are already working on. We are very grateful to sbaMass and all its members for supporting this new group in Maine. Without your generous support this group would not be possible.

Board Notes And Updates

- The sbaMass Board held its Annual Meeting on November 2, 2010. Two new members were elected to the Board. Welcome to Brandon Casten and Karen Sites. Also a very grateful Thank You to Kathleen Pease and Joyce McKenna Hillis, who have served on the sbaMass Board for several years. It is with the commitment of the sbaMass Board Members that we are able to continue services and expand programs.
- The Annual Benefit Policy, SBA Conference Policy and Jean Driscoll Award were reviewed and approved for 2011. These programs will continue and updated information will be available in January 2011.
- The 2nd Annual Walk N Roll is planned for September 25, 2011. Watch for updates here and on the website **www.sbaMass.org**. This was a successful fundraising and community event in 2010. We look forward to an even bigger and better Walk-N-Roll for 2011!
- The sbaMass is in the process of planning a New England Area Spina Bifida Conference for October 2011. The sbaMass is collaborating with SBA of Connecticut for this event. The conference will be a daylong event covering a variety of topics including medical, social, education and employment related topics.
- Volunteers are needed The Program/Conference Committee and Development Committee. If questions about committee responsibilities or you are interested please contact Ellen at **edugan@sbaMass.org**.

Insights Subscriptions

SBA's quarterly magazine, serves to educate and enlighten with articles about medical conditions, employment, family issues, advocacy, research, and SBA activities. 1 Year subscriptions are available for $25; 3 Years for $66 and 5 Years for $90. Log onto the SBA website **www.sbaa.org** and click on Marketplace.

Visit us on Facebook!

http://www.facebook.com/pages/Spina-Bifida-Association-of-Massachusetts/171955252933

Top Ten Internet Resources

by Jen Fitz-Roy
sbaMass Board Member
Boston College/National Youth Leadership Network Resource Consultant

1. SB-TEENS listserv (communicate with other teens with Spina Bifida)
   http://health.groups.yahoo.com/group/SB-TEENS/

2. Kids As Self-Advocates (leadership and advocacy activities for youth with disabilities)
   http://www.fvkasa.org/

3. National Youth Leadership Network (leadership and advocacy activities for youth with disabilities)
   http://www.nyln.org

4. Disabled And Proud website (learn about disability history and disability culture)
   http://www.disabledandproud.com/

5. American Association of People with Disabilities (internship and leadership opportunities)
   http://www.aapd-dc.org/

6. Mobility International USA (international travel programs, scholarships, and resources)
   http://www.miusa.org

7. Adolescent Health Transition Project (information and resources about taking charge of your healthcare)
   http://depts.washington.edu/healthtr/

8. Medic Alert Foundation (health records and emergency notification services)
   http://www.medicalert.org

9. Northeast Passage (recreation and sports for people with disabilities)
   http://www.nepassage.org/resources.html

10. WebMD (information about medications, procedures, and conditions. Do not use as medical advice!)
    http://www.webmd.com

SPED Child and Teen Helps Parents with Hard-to-Find Disablility Events

by Sharon Lipsi Riddle

There are lots of free and low cost special-needs events and services around Massachusetts. It’s just that no one ever tells you about them. Not the doctors. Not the teachers. Not the therapists.

But now Massachusetts has a disability website and newsletter SPED Child and Teen www.spedchildmass.com, that lists many of the upcoming family events, parent workshops, important conferences and renowned speaker series that happen every day in our area.

From sensory friendly theaters showing Harry Potter movies, to **Dr. Ross Greene** discussing his book “The Explosive Child”, to assertive technology and camp fairs throughout the state, SPED Child and Teen publishes what parents need and are looking for to help their special child.

SPED Child and Teen also ensures that a variety of disability programs are published. That’s because the owner of the website, **Sharon Riddle**, is herself the parent of a child with a disability, and knows that there are multiple and cross over issues that face our unique children.

So whether your child is very young, in elementary school, or transitioning to adult services, SPED Child and Teen wants you to know that there are conferences, services and events that will help your family. And their newsletter and website are the one telling you about them.

Top Ten Tips for Living Like a Champion

by Jen Fitz-Roy
sbaMass Board Member
Boston College/National Youth Leadership Network Resource Consultant

1. Get involved in both disability-related activities (like adaptive sports or advocacy) and mainstream activities (like music, writing for your school paper, or volunteering at the local hospital). Doing something beyond school and friends lets you meet new people, discover new skills and build self-esteem and self-confidence.
2. Set your sights on traveling internationally one day. Going out of the country broadens your horizons like no other experience. There are many scholarships and resources available for people with disabilities to study, work, or volunteer abroad.
3. Take charge of your healthcare. Learn as much as you can about spina bifida and how it affects you, know your surgical and medical history (request your medical records and talk to your parents) and ask questions of your doctors.
4. Be evaluated to see if driving is a possibility for you. Being able to get around as a young adult is important to independence. If you've been evaluated and it's been determined by an occupational therapist that driving is unsafe for you, become the local expert on paratransit and public transportation in your area.
5. Don't rule out the possibility of attending a four-year university. Dealing with learning disabilities, mobility issues, and medical problems can be tough, but having a college experience will be well worth it in the long run. Not only is it empowering, but your education will help you in finding meaningful employment down the road. There are thousands and thousands of scholarships and other funding sources for students with disabilities.
6. Be proud to have Spina Bifida. Your disability makes you unique and contributes to many of the qualities that make you who you are. Don't let your disability define you, but realize that you wouldn't be yourself if you didn't have spina bifida. Learn to recognize your strengths and use them!
7. Take risks. No one is perfect, and you might fail or look silly as you're trying out new skills and learning to be independent. Try new skills anyway. If you never take risks (with friends, with your education, with travel, with new activities, with taking charge of your healthcare, etc.) you'll never learn how much you're capable of.
8. Develop and maintain relationships with as many people as possible. As you begin to become independent and move away from your parents, relationships with friends and adult mentors become more and more important. Create strong relationships with teachers, pastors, doctors, social workers, peers, and other people who can support you, guide you, and love you. Use other people as resources.
9. Do physical activity every day. Exercise is fun, it makes you feel good, it's great for your body, and it's great for your emotional health. No matter what, make an effort to be active, and make an effort to have fun, no matter what type of recreation you choose.
10. Give back. Volunteering, mentoring, and other forms of community service are the best ways to feel good about yourself and truly be a champion. Use your unique skills and background to help others in whatever way possible.

Contacts

sbaMass Tel. (toll-free)	**(888) 479-1900**
sbaMass Tel (toll)	**(508) 482-5300**
sbaMass Fax	**(508) 482-5301**
SBA Tel. (toll-free)	**(800) 621-3141**

Board of Directors

President
Cara Packard
Email: cpackard@sbaMass.org

Vice Chair and Treasurer
Matt Neal
Email: mneal@sbaMass.org

Clerk
Barbara Lee
Email: blee@sbaMass.org

Dr. Stuart Bauer
Email: sbauer@sbaMass.org

Brian Casten
Email: bcasten@sbaMass.org

Jen Fitz-Roy
Email: jfitzroy@sbaMass.org

Linda Long-Bellil
Email: llongbellil@sbaMass.org

Rebecca Sherlock
Email: rsherlock@sbaMass.org

Karen Sites
Email: ksites@sbaMass.org

Operations

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

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

sbaMass Regional Representatives

Southeastern Massachusetts
Aimee & Brandon Shanks (508) 587-6788
Email: orchid502@yahoo.com

Central Massachusetts
Jean Cusick (508) 756-3918

Cape Cod and the Islands
Judy Morgan (508) 896-5085
Email: judjon1@comcast.net

Western Massachusetts
Betty Niedzwiecki (413) 774-3489
Email: bniedzwiecki@hotmail.com

North Shore / Merrimack Valley
Cindy Ward (978) 682-9330
Email: muna000@aol.com

Committee Chairpersons

Arnold Chiari Information
Kevin & Maureen Walsh (781) 337-2368
Also try World Arnold Chiari Malformation Association at
http://www.pressenter.com/~wacma/

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

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

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

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

Medical Issues
Ginny Briggs
Email: gbriggs@sbaMass.org

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

Memorial Donations
25 Birch St. (888) 479-1900
Bldg. B
Milford, MA 01757

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

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

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

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

Editor: Peter Jablonski
Asst. to the Editor: Amy Blanchard

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

Spina Bifida Association of Massachusetts
25 Birch St
Building B
Milford, MA 01757

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

NONPROFIT ORG
US POSTAGE PAID
DUNSTABLE MA
PERMIT NO. 20

CHANGE SERVICE REQUESTED

Help sbaMass
“GO GREEN” and cut
our costs by receiving
the sbaMass Quarterly
News via email in
PDF format. Contact
wpotts@sbaMass.org
and let her know that
you would like to
receive the newsletter
via email.