sbaMass news

Summer 2009 The Newsletter of the Spina Bifida Association of Massachusetts

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Letter from the Vice President

by Cara Packard

Happy summer to all of you. I think that anyone living in our service area would agree that this spring and summer period has been one of the rainiest in memory! However, we all know that with each rainy period comes growth. As we head into a hopefully sunny and bright summer, growth is one of the central focuses of sbaMass.

As always, our programming for members has continued to gain popularity. On June 16th sbaMass hosted a very informative session on adaptive driving for the Teen Group and their parents. Mark Whitehouse of Adaptive Driving Inc. an adaptive driving instructor, advised our group about the many benefits and concerns to consider with adaptive driving. Additionally, the tween group participated in a fun board game day on June 13th. Our Programming Committee has done a wonderful job of increasing the variety of offerings this year. We hope that attendance at these events will continue to grow as well.

Judging by the number of applicants for this year's Conference Scholarships, quite a few of us are looking forward to the SBA's National Conference in Orlando, Florida, from June 30 - July 3. This year's theme is "Imagine the Possibilities" and takes place at the Swan & Dolphin Hotel in the Walt Disney World Resort. This year sbaMass was able to provide scholarships to seven attendees so that they can learn about realizing their possibilities and experience the fun and excitement of conference (we were happy to see the number of applicants grow this year).

Hopefully we will all have some good summer experiences to share by July 18, the date of the annual summer picnic. As in past years, the picnic will take place in Dannehy Park in Cambridge. We hope to have you join us for some fun in the spray park, some good food, wonderful conversation, and, of course, the exciting presentation to this year's winner of the Jean Driscoll Award. By then we surely will be deserving some real sunny weather! Watch your mailboxes and e-mail for further details.

For those of you looking for an exciting way to support sbaMass, you may want to consider cheering on Team sbaMass as they run the Falmouth Road Race on August 9th. Each year our dedicated runners raise nearly $35,000 for SbaMass, money that is used to pay for our benefits programs, our social programs, and our scholarship programs. The course is beautiful, between Woods Hole and Falmouth Heights on the Cape. The runners would greatly appreciate your cheers for them as they work hard for you!

Lastly, the Executive Board is happy to report that we met with Sara Struwe, the Chief Operating Officer of SBA's National Office regarding the potential for SbaMass to grow into an even larger, more successful organization. We will be counting on your participation to make it happen. We look forward to growing with you in the future.

Congratulations to Alex Danahy of Hopkinton Mass.

Jean Driscoll Award Recipient

Alex is the 2009 Jean Driscoll Award recipient. Alex has been accepted to Curry College, Milton Ma and plans to major in Communications. He hopes one day to be an on air sports analyst, favoring New England Sports teams where he has grown up, where he knows the teams, their history and the players.

Alex wrote in his application that his teachers never gave up on him and stood by him though his high school years. When he was sick and unable to attend school, teachers made sure he had the work and helped him complete assignments. The efforts of the teachers helped him achieve what he has today and he is able to do succeed because of their persistence. The school also arranged for his friends to maintain contact with him, visiting him at home. Teachers often came to hang out as well.

Alex's recommendation reads in part "Alexander's greatest strength is his ability to seek help for himself when necessary. Alex at times struggled with certain aspects of the curriculum, but he did not allow this to be a discouragement. Alexander frequently sought help and guidance from a variety of resources thus becoming a vocal self advocate. Alexander is one of those students who will leave a lasting impression and will always be held in the highest regard for his strength of mind and working toward his goals."

The sbaMass is pleased to be able to honor Alex as this year's recipient of the Jean Driscoll Award.

HAPPY 100TH BIRTHDAY!

Lillian LaRosa, of Wellesley, celebrated her 100th birthday in March with family and friends. Lillian has been a constant supporter of sbaMass since her great granddaughter was born with Spina Bifida five years ago. In honor of her 100th birthday Lillian requested donations be made in her name to sbaMass. The sbaMass would like to thank Lillian, her family and friends for their tremendous generosity.

Happy 100th birthday from the sbaMass Board of Directors and staff. We wish you many more healthy and happy years!

Wheelchair Needs a Good Home!

Adult size wheelchair Storm Trac available for pick up in Medford. Approximately 4 years old, in good condition but needs new battery.

Contact Michelle 781-248-2183

Adopt-a-Ghost

October is Spina Bifida Awareness Month. Each year sbaMass participates in the Adopt-a–Ghost program to raise awareness of Spina Bifida. The Adopt-a–Ghost program consists of offering small paper ghosts for sale in your community. It relies on building a relationship with stores, restaurants, and businesses in your local area. Local stores and businesses offer the ghosts for "resale" during Spina Bifida Awareness Month in October. Each ghost is "sold" for a $1.00 donation to the Chapter.

The basic program is very straight forward, simply looking to your local businesses to put ghosts up for adoption. It can also be included at larger fundraising events at schools, girls and boys groups, churches or synagogues, and other venues. This program raises awareness of Spina Bifida as well as funds to continue and expand programs and services provided by sbaMass. If you are interested in volunteering to contact businesses and other organizations in your community contact Ellen Heffernan-Dugan at 888-479-1900 or ***edugan@sbaMass.org***.

Partners for Youth with Disabilities: Mentor Match Program

More than 1,100,000 residents of Massachusetts have disabilities, and 70,000 of those individuals are youth ages 15 and under – individuals that will soon face major transitions with respect to continuing their education, obtaining employment, and integrating into the community.

Partner for Youth with Disabilities (PYD) has had a tremendous impact on youth with disabilities for over twenty years by connecting youth to adult role models (with and without disabilities) in one-to-one mentoring programs, peer and group mentoring programs. PYD is seeking to expand the number of mentees and mentors participating in their programs.

For more information: Visit PYD's website: ***www.pyd.org*** or Contact **Alex Freeman**, Match Specialist; ***afreeman@pyd.org*** Phone: 617.556.4075 x 18; TTY: 617.314.2989.

sbaMass Online Discussion Groups

Did you know that the sbaMass offers online discussion groups for our constituents? The sbaMass offers a Youth and Adults Yahoo Group, (YAG), ages 17 + and Parent's Group. Both are online communities and are meant to be a community where individuals and families can connect, and provide support to each other. Although many sbaMass constituents already participate, the more members, the more active the information sharing will be. In addition sbaMass regularly posts information regarding opportunities and events of interest outside of sbaMass activities. Join us today and add your information and expertise!

HOW TO SIGN UP For YAG- Send a blank email message to this address: ***sbaMassYAG-subscribe@yahoogroups.com***.

HOW TO SIGN UP For Parent's Group - Send a blank email message to this address: ***MSBAParents-subscribe@yahoogroups.com***

New England News Corner

by Ellen Dugan

1. The **Rhode Island Parent Information Network (RIPIN)** provides information, support, and training to empower parents, families, individuals, and family-serving professionals to become effective advocates for themselves and the children with disabilities and special health care needs in their care. RIPIN hosts a number of workshops and support groups and the schedule is available at ***www.ripin.org***. Check regularly to learn more about the latest information.

2. **CEDARR Family Center – RI Department of Human Services.** About Families CEDARR Center was certified in April 2001 by the Rhode Island Department of Human Services as the State's first CEDARR Family Center. About Families is committed to providing access to coordinated services for children with special needs and their families.

   A family can seek services at the CEDARR Family Center to help them (a) understand their child's needs, (b) plan services and treatment, (c) link to identified supports, (d) monitor their child's progress, and (e) advocate for their child.

   About Families CEDARR Center was created through a partnership of the Groden Center, Meeting Street Center, and The Providence Center. The three organizations bring their collective experience in providing care, education, and support services for children with special health care needs and their families. Together, the three organizations serve children across all the disability categories. About Families has the capacity to work with children regardless of their presenting need or disabling condition, assuring that there are multiple doors to appropriate services. Log onto ***www.aboutfamilies.org.***

3. The mission of the **Vermont Assistive Technology Program** is to increase awareness and knowledge, and to change policies and practices to ensure assistive technology is available through all services to Vermonters with disabilities.: The mission of the Vermont Assistive Technology Program is to increase awareness and knowledge, and to change policies and practices to ensure assistive technology is available through all services to Vermonters with disabilities. Log onto Vermont Assistive technology Program at ***www.dad.state.vt.us/atp/.***

4. The **Vermont Parent Information Center (VPIC)** is a statewide network of support and information for families who have a child with special needs or disabilities, and the professionals who work with them. Founded in 1992, VPIC serves families of children with special needs from birth to 26 years of age. Our goal is to offer programs to families that are helpful, relevant and easy to access. Most of the programs are free of charge. Log on to ***www.vtpic.org*** for more information.

5. The department's special education consultants provide technical assistance to schools and other organizations to help ensure that schools understand and comply with federal and state laws and regulations related to providing special education services. In addition, the special education division offers a due process procedure to parents who have concerns about the services offered to their

   Under the federal Individuals with Disabilities Education Act, or IDEA, Vermont is required to identify and evaluate students who have disabilities and to offer them individualized education programs (IEP) for special education and related services. Decisions regarding the services that are included in an IEP are made by a team using a process specified in the law. An IEP team includes a student's classroom teacher, special educator, parent(s) and a representative of the school district who is empowered to commit resources such as staff time or funding. By law, schools are required to carry out provisions outlined in a student's IEP. Log onto ***www.education.vermont.gov/new/html/pgm.*** Find information about the following: Laws & Regulations, Policy & Administration (e.g, monitoring; dispute resolution process; secondary transition), Data Reports & Publications, Special Education Forms, General Resources and Parental Resources.

Advocacy

by Ellen Heffernan-Dugan

Take Action!

Are you interested in staying up to date on local and national legislation impacting the disability community? There are a number of websites available to do so. Below is a small sampling.

Spina Bifida Association: ***www.sbaa.org***
Click onto "How to Help" and follow the links to review national legislative priorities and sign up for action alerts.

American Association of Persons with Disabilities: ***www.aapd.com***
Click onto Advocacy. AAPD maintains an activists blog and distributes a weekly newsletter "Justice for All"

Easter Seals: ***www.eastersealsma.com***
Sign up for their Legislative Action Network and receive emails regarding legistive issues of interest to the disability community.

United Spinal: ***www.unitedspinal.org***
Click on link for advocacy and you can sign up for email action alerts for issues of interest.

Massachusetts State Legislature: ***www.mass.gov/legis/***
Locate information regarding bills that have been proposed in the state legislature. Track the progress of bills and how your representative has voted.

Federal Legislative Information: ***www.thomas.gov/***
The Library of Congress THOMAS site is the source for federal legislative information. THOMAS provides several options for finding bills, resolutions, and identifying your representative.

Research Articles Online

Online Resource Now Updated

SBA National Office has just updated the results of a quarterly scientific publication search on Spina Bifida and related topics on the web in Research Articles Online. This Resource Center section features highlights of research articles on topics that are most frequently requested by National Resource Center patrons. This section can be found on the SBA Web site at ***www.spinabifidaassociation.org/site/c.liKWL7PLLrF/b.2643271/k.A5E9/Research_Articles.htm***.

Thank you to Dr. Gregory Liptak for his continuing work on this project!

Thank You

The following companies have recently matched employees gifts to sbaMass
Verizon / Goldman Sachs / Nike / Bank of America

Special thanks to Arbella for their continuing support of sbaMass and the Farrell Family fundraising efforts.

If you are uncertain if your employer has a Matching Gift program, log onto ***www.sbaMass.org*** and link to Matching Gifts.

111th Congress 1st Session

The Spina Bifida Association (SBA) exists to enhance the lives of all individuals and families affected by Spina Bifida. To that end, the SBA respectfully calls upon Congress and the Administration to support increased funding and legislative, regulatory, and programmatic efforts to prevent Spina Bifida, reduce its myriad adverse complications, and improve quality-of-life for all individuals and families affected by this complex condition.

Prevent Spina Bifida and Reduce its Adverse Complications
More than 65 million American women of child-bearing age are at risk of a Spina Bifida pregnancy; however, adequate daily consumption of folic acid helps reduce the risk of Spina Bifida and other neural tube defects, by up to 70 percent. Despite the positive impact of folic acid consumption, the nation has a population of more than 70,000 individuals with Spina Bifida, who need and deserve access to quality, comprehensive care and programs that help reduce and prevent the secondary effects of Spina Bifida and enhance quality-of-life. Therefore, SBA calls upon Congress to provide the following allocations in FY 2010:

- $7 million for the National Spina Bifida Program at the National Center on Birth Defects and Developmental Disabilities, within the Centers for Disease Control and Prevention (CDC) to expand program activities to fulfill unmet needs. This level of investment will allow the program to continue its current scope of work, increase its folic acid awareness/Spina Bifida prevention efforts, further develop the National Spina Bifida Patient Registry, and sustain the National Spina Bifida Resource Center – all efforts to support daily living activities for individuals affected by Spina Bifida.
- Increase funding for the CDC's national folic acid education and promotion efforts for the prevention of Spina Bifida and other neural tube defects. The CDC partners with SBA, the National Council on Folic Acid, and other national organizations to educate all women about the importance of consuming adequate daily levels of folic acid, so they can minimize their risk of a Spina Bifida pregnancy.
- Increase funding to strengthen the CDC's National Birth Defects Prevention Network, so that our nation can answer critical questions regarding the causes of birth defects and how they can be prevented or reduce.
- Increase funding for the CDC's National Center on Birth Defects and Developmental Disabilities to increase the nation's efforts to prevent and address birth defects and developmental disabilities.
- Increase funding for the Agency for Healthcare Research and Quality (AHRQ) to enable this important public health agency to engage in activities that improve health care quality. Additional funding is needed to support AHRQ's efforts to validate quality treatment data measures for the National Spina Bifida Patient Registry, so that information can be gleaned to improve the provision of care given to individuals with Spina Bifida, helping them to live the healthiest and most productive lives possible.
- Increase funding for the National Institutes of Health (NIH) to support biomedical research. NIH should expand applied and basic research efforts focused on improving the understanding of the etiology, prevention, cure, and treatment of Spina Bifida and its related conditions, including hydrocephalus, the neurogenic bladder, latex allergies, paralysis, and developmental delay.

Enhance and Ensure Quality-of-Life for All Individuals Affected by Spina Bifida
Care of persons with Spina Bifida is complex, involving different organ systems and, correspondingly, different clinical specialists. Thanks to advances in diagnostic equipment and testing, and other medical breakthroughs, people with Spina Bifida are living much longer than previous generations. With this extended lifespan, individuals with Spina Bifida are facing new challenges – including unprecedented medical complications associated with aging.

To address the myriad challenges that people with Spina Bifida face, SBA urges Congress to ensure that all children and adults with Spina Bifida have access to:

- Appropriate, affordable, quality, comprehensive public and private health insurance coverage. To that end, SBA encourages Congress to reform the nation's health care system, sustain and expand the services and benefits provided under the Medicaid and the State Children's Health Insurance programs, and eliminate all pre-existing condition limitations under both group and individual health insurance.

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- Durable/non-durable medical equipment and pharmaceutical drugs through all public and private health plans.
- Comprehensive information to prevent and reduce secondary effects and complications of Spina Bifida and improve quality-of-life.
- Federal employment, training programs, and related services.
- Health insurance that addresses the special/unique needs of individuals living with birth defects, mobility limitations, and other developmental and physical disabilities; no individuals with Spina Bifida should face pre-existing condition limitation exclusions.

SBA has also called upon the Food and Drug Administration to increase folic acid fortification levels of corn and wheat products grown and consumed, both domestically and internationally, to ensure that women of child-bearing age benefit from the advantages of folic acid contained in enriched foods.

Congressional Spina Bifida Caucus
Caucuses are formally organized and recognized entities formed by Members to direct focus and attention to specific issues. Separate and distinct from congressional committees, caucuses are neither restricted in membership nor tied to the political makeup in the Congress so any member can join.

Support SBA's advocacy efforts
Please take a few moments and urge your Representative to join the Congressional Spina Bifida Caucus. Log onto www.sbaa.org and click on How to Help/ Advocacy and Public Policy Priorities.

To contact your senator and representative log onto ***http://www.house.gov/*** and ***http://www.senate.gov/*** to let them know how you feel about these important issues.

Spina Bifida Association Holds Groundbreaking First World Congress

The Spina Bifida Association (SBA) recently concluded the First World Congress on Spina Bifida Research and Care in Orlando, Florida. This international event brought together over 350 clinicians, medical professionals, and researchers in the area of Spina Bifida to discuss the future of care for this challenging and complex birth defect.

Anchored by keynote sessions delivered in each of the eight major disciplines involved in Spina Bifida, the Congress was highlighted by breakout sessions in which the work of over 150 scientists was presented.

"To date, very little research has been conducted on the many components of this complex birth defect. Recognizing this, SBA established this event so that work that is being conducted could be furthered and glaring necessities in the Spina Bifida research landscape could be recognized and addressed," stated Joseph Giffels, SBA's Research Director.

One of the most potentially impactful findings presented during the three-day Congress was a revised figure on the number of Americans living with one of the various forms of Spina Bifida. Preliminary findings from a study conducted at the Centers for Disease Control and Prevention (CDC) indicated that instead of the 70,000 figure which has been widely used, the actual number is closer to 185,000 living in this country with this challenging birth defect.

"While further quantitative evaluation needs to be done to support this finding, this research clearly demonstrates the prevailing need for more work to be done in understanding and managing Spina Bifida and its related conditions," stated Giffels.

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Sponsored in part by the CDC, the National Institutes of Health (NIH), and the Agency for Healthcare Research and Quality (AHRQ), the First World Congress also featured famed journalist Judy Woodruff delivering the Hal Pote Memorial Lecture, named for the founding President of the Spina Bifida Foundation who passed away in 2007. Woodruff, the mother of a son living with Spina Bifida, addressed the need for further funding to support research efforts as well as offered insight into the impact public policy development could make on these challenges.

Information about the First World Congress on Spina Bifida Research and Care, including abstracts for the majority of work presented, can be found on the event Web site at http://medicalconference.spinabifidaassociation.org.

sbaMass Awards

by Ellen Heffernan-Dugan

The Spina Bifida Association of Massachusetts (sbaMass) is pleased to report that the Spina Bifida Association has recently announced 2009 Award Recipients. Awards will be presented during the 36th Annual SBA Conference, Celebration Luncheon to be held on July 3rd in Orlando Florida. Massachusetts is the proud home of two recipients.

Children's' Hospital, Boston - Myelodysplasia Clinic is the 2009 recipient of the Outstanding Service Provider Award. This award recognizes the Spina Bifida Clinic providing outstanding medical service to people with Spina Bifida. The nominee must provide "multi-disciplinary" services (e.g., orthopedic, neurological and urological) on a regular schedule and also must offer a balance of services and disciplines, so that social, psychological, and medical needs are met.

The Spina Bifida Clinic is available to and often begins providing services prenatally. Interdisciplinary staff are available to meet with and counseling pregnant women and their partners who are carrying a fetus with Spina Bifida. Individuals are then seen from birth on through young adult years. At present the clinic provides services to 300+ patients per year.

Children's Hospital – Myelodysplasia (Spina Bifida) Clinic time and again provides exceptional medical and ancillary service to individuals, across the age continuum, with Spina Bifida. The clinic is staffed by able professionals who truly care about the individuals in their care and their families.

Jen Fitz-Roy is the recipient of the 2009 SBA Young Adult Leadership Development Award. This award is given to the individual or Chapter who best exemplifies the involvement of young adults in local activities – as board members, activity leaders, Support Group leaders, newsletter editors, advocacy speakers, etc. Jen's nomination reads in part: Jen currently is a member of the sbaMass Program Committee and involved in events across all age groups. In the past year Jen has been instrumental in assisting sbaMass in developing programs and events to better serve the needs of our constituents. She attends these events, leading discussion in areas of Transition to Adulthood, Self Advocacy, and Understanding Spina Bifida. Jen consistently demonstrates the qualities of a dynamic leader. Jen is dedicated to the mission of the Spina Bifida Association as evidenced by her availability to connect with other individuals with Spina Bifida and their families. She conveys an openness to discuss her achievements as well as her challenges.

Join the Spina Bifida Association of Massachusetts for an event in support of **Parents of Children, Tweens, Teens and Adults** who are living with Spina Bifida

Saturday August 15, 2009, Noon - 5:00PM (a light lunch will be served)
Children's Hospital Boston, 300 Longwood Ave
Room: Byers A & B

"Loving Your Child … Managing Systems: Unveiling and exploring the Unique Stresses of Parenting a Child living with Spina Bifida"

- As a parent of a child born with Spina Bifida, do you often find yourself stuck in the middle between tending to the precious heart and spirit of your child, while needing to manage all the medical, education, and social service systems required to care for your child's health needs?
- Do you experience stress from being responsible for making life-altering decisions for the child you love, based on having a huge amount of information and no guarantee of outcomes?
- Parents will be offered ways to see themselves, their situations and their child from a wider viewpoint. With new insights, new possibilities may emerge for parents so that they may stand more solidly on behalf of their child and themselves, while navigating through a myriad of systems.
- **Space is Limited** – RSVP no later than Tuesday August 11, 2009 to ***edugan@sbamass.org*** or **888-479-1900**.

This program is offered as a gift to the Spina Bifida community by Alaya Chadwick on behalf of Marianne DiBlasi - in honor of Marianne's courage to embrace her feelings and experiences related to living with Spina Bifida, and in doing so awakening to her wholeness.

Presenters:
Alaya Chadwick, M.Div., M.S.W., L.I.C.S.W., B.C.D., CMTR*, Licensed Psychotherapist and Teacher, Certified Imago Relationship Therapist, Teaching Reiki Master, published Author, National Speaker, and Master Storyteller.

Marianne DiBlasi, Adult living with Spina Bifida, Certified Integral Life Coach, Certified Master Teacher of the Wisdom WAY™ Level 1, Reiki Master, and Graduate of the Awakening Divinity program.

In the Dance of Relationships, Who’s Leading - Who’s Following?

by Kathie Snow

This year, my husband and I proudly celebrate our 28th wedding anniversary, and we’re looking forward to the next 28! But it wasn’t always so. After about ten years of marriage, I was frustrated and decided to seek the help of a family counselor. What was the problem? Something most wives can probably relate to: my hubby didn’t always put the toilet seat down or hang his wet towels up, and so on and so forth—all minor irritants that (in my mind) generated major stress!

Off to the counselor I went. She first asked if these were new behaviors of my husband—had he just started doing these things? No, and that was part of the problem; I’d had ten years of this! She chuckled and noted that my husband’s actions must have been acceptable at one time, for I didn’t complain before. Darn—I had to admit she was right! She empathized with me, and then explained that when two people are in any type of relationship, it’s like they’re dancing a slow dance. She asked, “Do you want to keep ‘dancing’ with your husband or are you ready to end the marriage?” No, I didn’t want a divorce—I just wanted him to change! She replied, “OK, so it’s like the slow dance. When you’re slow dancing, one person has to follow the other’s lead. If you want to keep dancing with your husband, you need to change your dance steps, and he’ll change his.” So, if I changed my behavior, I’d see changes in my husband? Yes, and she was right. My hubby got better at putting the toilet seat down and I got better at putting things in perspective. We both changed, and the slow-dance philosophy has been helpful to me ever since.

In so many situations, two people—husband/wife, parent/child, teacher/student, teacher/child’s parent, service provider/person with a disability—get locked into patterns of behavior. One person may attempt to exert power and control, the other resists. In the process, a battle of wills ensues, and neither person is aware of the pattern that repeats itself, which may escalate into all-out war!

Every person is born with the innate need to control one’s own life. Unfortunately, personal power is often stripped from children and adults with disabilities—by parents, teachers, service providers, and others in positions of authority. Similarly, many parents of children with disabilities justifiably feel they have no power as members of their children’s IEP teams, and/or in other situations where “someone in authority” (physician, service provider, teacher, etc.) is exerting powerful influence. But when a person feels she has little or no control, she’ll take every opportunity to exert control, whenever and wherever possible—in subtle or not-so-subtle ways.

For example, when a person with a disability doesn’t robotically follow the demands of a parent, teacher, therapist, service provider, or other “authority,” and actively or passively resists, we may say the person is “non-compliant” or “manipulative.” We may then slap a “behavior problem” label on him. At that point, we may exert even more control, which causes him to resist harder, and the vicious cycle escalates (to the grave detriment of the person with a disability). This situation may be especially common if the goal, activity, or demand is not relevant and meaningful and/or doesn’t make sense to the person.

When my son, Benjamin, was six, the physical therapist recommended water therapy. It seemed like a good idea, since he loved playing in the water. The therapist had a set of weighted rings that she would drop to the bottom of the hot tub, one at a time. Benjamin was to retrieve these by “swimming” to the bottom of the tub, and this was supposed to help his gross motor, fine motor, and deep-breathing skills.

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She dropped the first ring, and in his desire to “help,” Benjamin retrieved it for her. But when she dropped the second one, he looked at her like she was a big dummy—he was more than willing to pick up the first ring she “dropped,” but if she was dumb enough (in his mind) to drop a second one, she could get it herself! Thus, he refused to go underwater a second time, and after cajoling, nagging, and near-scolding by the therapist, she labeled him as “non-compliant.” But when Benjamin and his dad played similar “games” in our hot tub—activities which were relevant and meaningful and made sense to him—he enthusiastically participated. Thus, we probably should examine our hypothesis about the genesis of someone’s “behavior problem.” Is it the result of a person’s diagnosis? Is it a situational or environmental issue? Or could it be the direct result of our behavior? Whose “behavior problem” is it, really?

But what could happen if we apply the slow-dance philosophy? Whether one is a parent, teacher, therapist, service provider, etc., what if we changed our dance steps?

- What if we communicate differently—in our facial expression, tone of voice, body language, words, and more?
- What if we ask, instead of tell?
- What if we listen better, and really hear the person, and even try to dance in his shoes?
- What if we recognize that what’s important to the person with a disability—not what we might think is important—is the more critical factor?
- What if we wonder if our difficulties are the result of the other person’s long-term habits, actions, personality, etc., or our intolerance of same, as in my personal story described earlier?

Might any of these actions on our part result in a positive change in the other person’s behavior, reaction, or response? In turn, could that generate a more positive reaction from us, which again cycles into a more positive response from the person, and so on? Imagine how different IEP/ISP meetings and/or other personal interchanges might be different—and better—under these circumstances.

Let’s go further and think about the so-called inappropriate behaviors of children or adults with disabilities, like when we say a person is “non-compliant” or “manipulative.” Is it possible the person’s behavior is, in fact, a compelling means (to him) of exerting some control over his life? And since so many people with disabilities are considered incompetent or unable, shouldn’t this effort be viewed as a positive, instead of a negative? Similarly, and using the example of my son and the water therapy rings, is the person’s behavior a reaction to a nonsensical, irrelevant, and meaningless request? Again, shouldn’t we celebrate and respect—instead of demean—the person’s awareness and perspective? If the therapist had changed her dance steps and seen things from my son’s perspective, her actions, as well as her opinion of his behavior, would have been quite different.

In too many cases, maintaining heavy-handed power and control—not common sense, not respect and dignity, and not what’s important to the person with a disability—may be the core of our actions. But in the slow dance of relationships, a delicate balance is required. Changing our dance steps can result in a whole new dance (and a whole new relationship). Being light on our feet, remaining responsive, and gently and patiently helping our dance partner learn new steps when necessary are also essential.

On the other hand, if you and your dance partner are continually stepping on each other’s toes or worse, it might be time to gracefully bow out and let someone else dance in your place—temporarily or permanently. And when our dance partner is a person with a disability, shouldn’t she take the lead and shouldn’t we follow? Whose life is it anyway?

Get Ready to Run for sbaMass!

Year 3 promises to be better then ever!

If you happen to be in or near **Falmouth, MA on August 9**, please come cheer on Team sbaMass as they run the Falmouth Road Race. For the past three years sbaMass has been fortunate enough to gain charity entries to the Falmouth Road Race, a beautiful 7 mile course along the shores of the Cape in Falmouth, MA. Our team is easy to find in their bright blue singlets with orange racing flames on the sides. They give us a boost, not only financially, but also by bringing attention to our organization. We hope that this year's Road Race will be another successful day for Team sbaMass.

Over the past three years, our dedicated members of Team sbaMass have raised more than $75,000 for our organization. The runners ask for donations to support their run, and have succeeded in greater numbers each year. We hope that 2009 will follow the trend. The day brings much more than financial success. Our Team members have found the entire experience to be very rewarding in so many ways: from the satisfaction of finishing a 7 mile race, hearing the cheers along the way, being part of a fun-loving team with a great post-race party, raising money for so many who need help and knowing they have done a job well. We are so thankful for all their hard work. We would love to have any supporters out there join is in cheering the runners on the course.

If anyone you know might like to be a part of the team, please e-mail Cara Packard at ***cpackard@sbamass.org***. We hope we'll see you on race day along the course!

For a complete list of upcoming events, please see page 14 of this newsletter.

Update

The sbaMass Annual Golf Tournament

The 5th Annual Golf Tournament is being downsized, like much else in our world!

The sbaMass has decided to put the Golf Tournament held at Sky Meadow each year on hold until 2010.

Instead, the **sbaMass will hold a Mini Golf Tournament on October 17th from 2-5 pm at Trombetta's Farm (which is a handicap accessible indoor course so no weather worries!) located in Marlborough MA.**

This will be a family-friendly event to raise funds for the sbaMass and awareness of Spina Bifida during October, Spina Bifida Awareness Month. Look for more information on www.sbaMass.org.

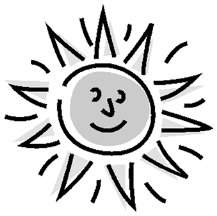
Mark Your Calendars for the

Seventh Annual sbaMass Summer Picnic

Saturday, July 18, 2009

12:30 pm - 4:30 pm

Cambridge, MA



Parking Lot and Picnic Area
near the office & restrooms

More Information Can Be Found At
www.sbamass.org

2009 Calendar

(All dates subject to change)

July

Tuesday 7/7 - Board Meeting - 7PM
Saturday 7/18 - Summer Picnic
Monday 7/20 - Golf Tournament - ***Cancelled***

August

Sunday 8/9 - Falmouth Road Race
Saturday 8/15 - For Parents of Children with SB - Unveiling and Exploring the Unique Stresses of Parenting a child with Spina Bifida
Monday 8/24 - Red Sox Community Home Stand
Saturday 8/29 - YAG Lunch

September

Saturday 9/12 - Teens Meeting (ages 7-12)
Sunday 9/20 - Bridal Fair Sturbridge

October

Saturday 10/3 - Tween Meeting (ages 7-12)
Saturday 10/3 - Red Sox Community Home Stand
Tuesday 10/6 - Board Meeting 7PM
Monday 10/12 - Let's Jump In – Old Orchard Beach
Saturday 10/17 - Mini Golf Tournament – Trombetta's Farm, Marlborough
Saturday 10/24 - 5th Annual YAG Lunch and Learn

November

Saturday 11/14 - Parents of Young children (newborn-age 6)
Sunday 11/15 - Bridal Fair - Braintree

December

Sunday 12/6 - Holiday Party

* An IEP for my Child and Creating a Vision, presented by the Federation for Children with Special Needs are being scheduled for the fall. Dates to be announced

Check the web site (**www.sbaMass.org**) for updates and changes

**sbaMass
constituents should review
all benefits requirements, before submitting
applications, as some requirements have been changed
for 2009. Please contact Ellen Heffernan-Dugan at
edugan@sbaMass.org or (888) 479-1900 with
any questions.**

Contacts

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http://www.pressenter.com/~wacma/

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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.

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