SB® sbaGNE news

Summer 2011 The Newsletter of the Spina Bifida Association of Greater New England

COMMUNITY
OUTREACH AWARD

PRESENTED TO
SBA OF MASSACHUSETTS
AND CHILDREN'S HOSPITAL
OF BOSTON FOR THE BLIN'G
(BETTER LIVING N'
GIRLS) WEEKEND

SPINA BIFIDA
ASSOCIATION

JUNE 2011

sbaMass

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YEARS

1971-2011

Letter from the President

by Cara Packard

Happy summer to all of you! Summer is the time for celebrating. Many of you are celebrating the end of the school year, maybe some family vacation time or just plain old fun and barbecues. SbaMass has a lot to celebrate this summer as well.

We are thrilled to announce that moving forward, our organization will be officially known as **SBA of Greater New England**. The SBA National Board approved our application to expand our service area to include the individuals and families in Maine, New Hampshire and Vermont. As we mentioned in our last newsletter, although our name will change and our boundaries will grow, we will remain the same strong organization at heart. We will be providing the same services and maintaining the same staff to assist you. We remain dedicated to improving the lives of individuals and families affected by Spina Bifida.

One of the places you may first see our name change is on our brand new website, which will be launching this month. We hope that the changes incorporated into the new site will make it easier for you to locate helpful information and assistance from us. We were very fortunate to receive a grant from **Blue Cross /Blue Shield Catalyst Foundation** to assist us in bringing these changes to you.

Our name and service area change is happening just as our organization celebrates its 40th year of serving you. In 1971, a group of dedicated parents came together to create the Spina Bifida Association of Massachusetts. Over the years we have grown into the strong organization we are today. We could not possibly have reached this milestone without the leadership and dedication of the many volunteers who gave so much to sbaMass over the years. We are truly grateful to them and hope that as we celebrate the 40th year of our organization, that they, too, rejoice in the fruits of their hard work. We held special celebration of our 40th Anniversary at the annual summer picnic, which took place on July 9th at the Massachusetts Hospital School in Canton. We celebrated with pontoon boat rides, an accessible swimming pool, and, of course, ice cream! While there, we also celebrated our recent award from SBA National, for the BLIN'G program. At the National Conference, **sbaMass and Children's Hospital were awarded the Community Outreach Award for the success of BLIN'G**. We are thrilled that this wonderful program received attention across the nation and hope that its success will be duplicated here and around the country for years to come.

Following the picnic, on **August 14th, our 25-member Team sbaMass running team will once again head to the starting line of the Falmouth Road on Cape Cod** for their annual fundraising run. We wish them the best of luck as they aim to raise $40,000 this year. Tell your friends and family to visit **falmouthroadrace2011.kintera.org** to support one of our runners!

We also hope that many of you will be joining us for our **Regional Conference jointly sponsored by SBA of Connecticut on October 1 in Sturbridge, MA**. Having just returned from National Conference, I can think of no better way to connect with other families and individuals living with Spina Bifida. The conference planning committee has already lined up many impressive speakers who will provide a wonderful learning experience for all of those who attend. Among other topics, the conference will provide valuable information for you to share with your school or workplace to help others understand some of the complicated issues that surround Spina Bifida. Please plan on joining us there!

Finally, I hope that you are all signing up to take part in our **2nd Walk-n-Roll, scheduled for September 25th at the Endicott Estate in Dedham, MA**. Last year's event was a wonderful celebration of the lives of those living with Spina Bifida. There is plenty of information inside this newsletter about how you can participate and be a part of this wonderful day. Please come join us and bring your friends!

I hope to see many of you soon at our various events. If not, enjoy the summer and all of the happiness and celebrations it brings!

Congratulations to Dr. Benjamin Warf, Children's Hospital - Boston

2011 recipient of the SBA Health Care Achievement Award

The Health Care Achievement Award encourages and rewards innovation in the development of surgical techniques, medical technologies, or health care practices that substantially improve the quality of life for persons with Spina Bifida. The recipient may be a person, corporation, or institution, but one who/that most clearly exemplifies the goals of SBA.

Benjamin Warf, MD, a board-certified pediatric neurosurgeon, currently the director of Neonatal and Congenital Anomalies Neurosurgery in the Department of Neurosurgery at Children's Hospital Boston, has spent many years researching an alternative to the standard shunt treatment for hydrocephalus. He has developed an innovative minimally invasive surgical technique for treating hydrocephalus in infants which may result in decreased shunt dependence in hydrocephalus.

Even with constant monitoring, most shunts will fail at some point, requiring immediate to treatment to avoid death. Originally developed to help those underserved in developing countries, his innovative procedure combines endoscopic third ventriculostomy with bilateral choroid plexus cauterization (ETV/CPC). During the procedure, an opening is created inside the brain that allows the trapped fluid to escape, and then part of the tissue that produces the fluid is cauterized. This safely reduces the problematic buildup and negates the need for the sometimes unreliable shunts.

Dr. Warf helped establish a pediatric neurosurgery hospital in conjunction with Cure International, an organization that helps provide medical treatment in developing nations. In 2005 the results of Dr Warf's research were published in the prestigious Journal of Neurosurgery and he was the 2005 recipient of the IF Award for "thrusting back the frontiers of knowledge for the treatment of Hydrocephalus in Africa".

Since returning to the United States, Dr. Warf has investigated the role of ETV/CPC in North American infants, and also continues to work in international neurosurgery development. He rejoined the team at Children's Boston in 2009, and was appointed Director of Neonatal and Congenital Anomaly Neurosurgery.

sbaMass and supporter receive awards at the 38th SBA Conference and Celebration luncheon

SBA Chair - 2011 Extended Service Award

Through the years, the recipients of this award have been some of SBA's most steadfast champions.They are people who have dedicated their time and their efforts to our cause, and without them; quite frankly, our work could not be done.

This year **Brian Packard**, former sbaMass Board Member and President was honored. Brian joined the Spina Bifida Association Board of Directors in late 2008. He has served four years on the SBA Business and Finance Committee and currently serves as SBA's Secretary/Treasurer.

He was previously named the Outstanding Spina Bifida Champion by SBA in 2008 for his work with SBA of Massachusetts. He served on the Chapter's Board of Directors from 2000 through 2007 where he held the office of Chapter President among others. While there, he created Team sbaMass, a running team that has raised roughly $300,000 in its three appearances in the Boston Marathon and other road races.

In his "real life" Brian is the CEO of Packard Innovations, a marketing and commercialization firm focused on launching new consumer medical technologies. As the father of four children including Katie his teenage daughter with Spina Bifida, Brian devotes his service with to enhance the lives of all affected by Spina Bifida.

SB Tween2Teen

A new place for Tweens and Teens living with Spina Bifida. Blogs, videos, Ask the Expert, real stories and Fact Sheets. Visit **www.sbaa.org** and click on the SB Tweens2Teens Logo.

Spina Bifida University

SBU is a self-paced educational experience which covers a wide variety of topics of importance to the Spina Bifida Community. From seminars featuring leading health care providers from across the country to presentations on educational and vocational opportunities, SBU has something for everyone!

The best part is that all of the SBU sessions are FREE! You simply need to **register** to receive a username and password to access the seminars. Log onto **www.sbaa.org** and click on SB University on the right side of the home page.

sbaMass and Children’s Hospital - Boston receive 2011 SBA Community Outreach Award

A collaboration of Spina Bifida Association of Massachusetts and Children’s Hospital Boston

SBA Celebration Luncheon - Community Outreach Award Presentation for BLING 2010. Rebecca Sherlock PNP, Children's Hospital Boston; George Strum, SBA Board Chair, Cara Packard, sbaMass Board Chair.

During the SBA Annual Conference in June 2010 sbaMass and Children’s Hospital Boston began discussions regarding possible ways to collaborate in meeting the needs of young girls, ages 11-16, living with Spina Bifida. From those discussions **BLIN’G (Better Living N’ Girls)** was born.

BLIN’G Weekend consisted of an overnight at the Omni Parker House Hotel - Boston for 10 girls and a parent. Cost to participants was $25 for the weekend. Attendees arrived Friday evening, and had time to meet and socialize with other attendees and hear a presentation by Ms. Wheelchair Massachusetts 2010, **Santara Sen**. Saturday activities included a healthy breakfast and snack and speakers on nutrition, positive living and healthy choices. In addition each girl received a therapeutic Reiki massage and a makeover (including hair, nails, and makeup). Parents were educated by the Center for Community Inclusion and also had the opportunity for a therapeutic massage and networking. The day ended with the girls and parents having a late lunch at MOOO Restaurant with a chance to show off their new selves! The girls were energized by sharing their experiences, learning from others, meeting with and discussing opportunities from women living with disabilities and receiving some healthy pampering. Everyone left planning for a bigger and better BLIN’G 2012.

No matter how much a person accepts and embraces their disability, most people with a disability struggle to fit in with and assimilate to the rest of society. It is often the ease and confidence with which a person goes through life that determines their ability to do so. A person with a disability often spends a significant amount of time learning to be as self-sufficient as possible to overcome the stereotypes of disability. BLIN’G Weekend was initiated to help adolescent girls learn to confidently embrace their abilities, individuality, and femininity.

BLING Weekend was supported in part by a grant from the MetroWest Women’s Alliance. The Children’s Hospital League has awarded a grant for 2012. Many of the activities were provided by volunteers and they are eagerly anticipating their participation in 2012. Both sbaMass and CHB are committed to ongoing support for this effort. SbaMass and Children’s Hospital – Boston have begun discussions regarding providing a similar event for boys.

Education Fact Sheets Available Online

SBA has recently published three new Education Fact Sheets on reading, math, and a quick reference sheet for educators of individuals with Spina Bifida. They are now available on the SBA website. Visit the link below, and then click on the Education sheets.

http://www.spinabifidaassociation.org/site/c.liKWL7PLLrF/b.2642343/k.8D2D/Fact_Sheets.htm

Inclusion: The Natural State

By Kathie Snow

In the United States and many other democracies, every person is born included! This is not a time or place of European serfs, American slaves, or a caste system where your position in the social hierarchy—including whether you're included or segregated—is preordained. In our society, inclusion is not a right that must be earned; it is the natural state.

That's the ideal we operate from. But it's not the reality for many children and adults with disabilities who are subjected to an archaic paradigm: at the moment a disability condition is diagnosed, they're consigned to segregation and second-class citizenship! Like serfs, slaves, or "untouchables" in other times or cultures, they're placed at the bottom of the social hierarchy, controlled by others, and segregated in "special" places with their "own kind." Opportunities for an ordinary life, education, and employment are limited (a substandard education automatically limits employment). It can be nearly impossible to climb out of the gutter of special, segregated programs.

Unlike other times or cultures where segregation was automatic, in our society we have to do an extraordinary amount of work to ensure segregation and second-class citizenship. And our efforts take place at both systemic and individual levels.

Systemically, we've created special programs/services which are often located in special places, and staffed by specialized experts: early intervention, special education, special sports, special church programs, special college programs, special habilitation services, special vocational assistance, and more. In the process, we inadvertently created a duplication of services. For example, our communities already have schools, sports activities, employment services, and so much more!

Historically, however, these ordinary services and activities were not thought to be appropriate for people with disabilities. For the last 200 years or so, we've operated from the paradigm that people who happen to have conditions we call disabilities needed to be cured/treated and protected from a cruel society, while simultaneously protecting society from the "menace" of the "defectives," so institutions (the ultimate in special, segregated places) were created.

Fast-forward to the deinstitutionalization efforts begun in the 1960s: if the "inmates" of institutions were to be released, "community-based" services must be created to meet their "special needs." The special services mindset was entrenched (along with a burgeoning new industry which employs millions). But think about it: at the time—and even today—which is easier, better, and more cost-effective: to modify the existing services in a community to meet the needs of all, or to create a new and separate set of services (which result in segregation)?

Beyond the moral and ethical issues involved, how can we continue to fund segregated programs with government funds (tax dollars), when federal and state laws (ADA, IDEA, Rehab Act, and more) mandate nondiscrimination, least restrictive environment, and other basic tenets which promote inclusion, equal access, and more? (There is a huge disconnect between what our laws say and how government funds are spent, which needs further examination in another article.) So, systemically, we've worked very hard and spent billions of dollars on programs and services that (intentionally or unintentionally) promote segregation and erase the natural state of inclusion.

At the level of the individual, we also expend great amounts of energy. We diagnose, assess, observe, and test, often using multi-disciplinary teams of experts. Then we study, quantify, and qualify the data; write reports; share those reports; and assess some more, to determine the prognosis, treatment, intervention, etc. Then we have meetings (IFSPs, IEPs, IPPs, I-cetera) to formalize, sanction, and justify our decision to segregate, such as placing a child in a life-skills class or an adult in a group home or day program. Then we treat, intervene, therapize, supervise, manage, and more. Oh, how much work it all takes! And everyone—teachers, providers, parents, and others—complains: too much work, too much time, too much stress, and too many rules and regulations to follow.

Of course, throughout all these systemic and individual processes, no one ever utters the words: "Let's figure out how to segregate this person and consign him to a second-class citizenship." Instead, we talk in terms of "helping." Regardless of our words or our intent, the outcome is the same: the loss of the natural state of inclusion, and with it, the loss of opportunities: to live a real life; to grow up like your brothers and sisters; to be a friend, neighbor, lover, spouse, softball player, bookworm, exuberant child, determined student, enthusiastic employee, selfless volunteer, or whatever you want to be. The loss of inclusion is like a living death: the devastating loss of ordinary, but precious, hopes and dreams.

But what can happen when we embrace, internalize, and base our actions on the fact that every person is born included, and that no one has the right to impose segregation and second-class citizenship on another? No one has the right to deliver the unspoken and soul-crushing message of today's conventional wisdom: "Because you have a disability, you are not-okay the way you are. But we will try to make you 'better' with treatments and interventions and services. And if you work hard enough, you may—one day—earn your way out of segregation." Substitute "Because you have been found guilty of a crime..." and it's easy to see that many people with disabilities are treated as if they're convicted criminals.

No parent, therapist, or service provider has the right to replace the joyous freedom of childhood with a regimen of treatments; no teacher has the right to exclude a child with a disability and rob him of the opportunities to learn and grow from ordinary classroom and social experiences; no human services system has the right to incarcerate an adult with a disability in a congregate setting.

Inclusion is the natural state; anything else is an artificial environment. What could happen if our highest guiding principle was to ensure the natural state of inclusion continues throughout a person's life? This would require us to hold inclusion as a higher value than services and interventions geared to "help" the person. In many quarters today, inclusion isn't even on the radar screen; we focus on services—and segregation continues.

Yes, many people with disabilities may need more or different assistance, than those without disabilities, but as previously mentioned, our communities are rich with generic (and inclusive) services. So why can't a person with a disability be helped to access the "regular" employment services offered in his state? Why can't an adult with a disability be helped to live in the place of her choice, with roommates of her choice, and with the supports she needs (natural and/or system supports)? Why can't a child with a disability be in general ed classrooms? Why can't a child take a ballet or karate class or do other fun activities (with consultation from a therapist, if necessary), instead of receiving therapy for years? Why don't we ensure people with disabilities have the accommodations, supports, and assistive technology they may need to be successful in inclusive environments?

Those who have chosen to stay on the path of inclusion have learned that it can be done—this is not pie-in-the-sky thinking! And, yes, it can sometimes take a little more work or time or negotiation, but the effort is worth it, and it's much less effort, in total, than the extraordinary amount of work to segregate!

We may think our actions are driven by, and can be justified by, the type or level of disability. But it's never about a person's disability; it's always about our attitudes, perceptions, and beliefs—our values. And where does inclusion fit in our hierarchy of values?

Look into the face of a person with a disability and acknowledge that he or she was born included, then question how the segregation and second-class citizenship of that person—along with the unmitigated and tragic loss of inclusion, opportunities, and hopes and dreams—can be justified. Keep looking, and imagine the awesome possibilities when inclusion is your highest operating principle.

new balance
FALMOUTH
ROAD RACE

Team sbaMass will once again participate in the 39th running of the
New Balance Falmouth Road Race
on Sunday, August 14, 2011.

The race's Numbers for Non-Profits program has given sbaMass 25 charity numbers.

In 2010, our dedicated Team raised over $35,000 for sbaMass!
We hope to reach $40,000 in 2011.

Interested in running for Team sbaMass?
Contact Wendy Potts at wpotts@sbamass.org

Bits and Pieces

By Ellen Dugan

- **Marianne DiBlasi**, an adult living with Spina Bifida in MA has recently been hired as the editor of Disability Issues quarterly newsletter. This publication is devoted to providing education and resources for individuals and families living with disability, and their advocates. If you'd like to receive a copy of this newsletter, please e-mail Marianne at marianne.diblasi@gmail.com with your mailing address (to receive a hard copy at home) or e-mail address (to receive a PDF by e-mail). Past issues of Disability Issues are available to view online and download at **www.workwithoutlimits.org/DisabilityIssues**.

- **"Possibilities: A Financial Resource for Parents of Children with Disabilities"**, a booklet first published in 2004 by the National Endowment for Financial Education (NEFE) and PACER, has been revamped and expanded in an online format. This guide offers tips and information on organizing financial records, managing money, dealing with debt, preparing income taxes,understanding insurance and more. Each section includes links to additional resources. **www.pacer.org**.

- In a new 15-minute podcast produced in collaboration with PACER Center, **Cate Weir**, project coordinator for Think College, introduces families to postsecondary education opportunities and answers some of the basic questions that families have on postsecondary education options for their sons and daughters with intellectual disabilities. The podcast and related transcript,including links to additional resources, are available here. Think College, an initiative of the Institute for Community Inclusion, conducts research and provides technical assistance related to postsecondary education for individuals with intellectual and other developmental disabilities. **www.pacer.org**.

- **Inclusion Revolution with host Tova Sherman**. Inclusion Revolution is a television show dedicated to the inclusion of persons with all types of disabilities. Inclusion Revolution is entertaining and gives information about important issues that affect us all.

Each show is about an interesting new issue that experts and self-advocates talk about. The host, Tova Sherman, is always sure to explore topics inside and out. Inclusion Revolution is designed to change the way we view disabilities in our community, workplace, and beyond. All three seasons are online for free! Go to **www.inclusionrevolution.com** and click "Watch Online." You will be directed to the YouTube channel where all episodes are listed. Episodes are about building self-confidence, living independently, challenges faced by self-advocates and many more topics.

Massachusetts PCA directory makes finding workers easier

Thanks to the Massachusetts PCA Directory the task of finding and hiring a Personal Care Assistant (PCA) has become easier for people with disabilities. The web-based, self-directed registry, available at **www.mass.gov/findpca**, connects people with disabilities, elders, and their families to the caregivers they need. The Directory is free to individuals who receive PCA services through MassHealth. The Directory has an active, searchable database of more than 7,000 personal care assistants in Massachusetts. A service of the Massachusetts PCA Workforce Council, the Directory is managed by Rewarding Work Resources, Inc, a non profit organization located in Brookline, Mass.

The website, which also is available in Spanish, is completely accessible for people using any kind of assistive technology. Another feature of the Directory is the ability for PCA users to search for workers by zip code and specific criteria – allowing them to find a PCA from as close as 1-mile up to 100 miles from where they live. The Directory also allows PCA users to save their search criteria and receive an email notification when new workers who match their criteria apply. An optional feature allows PCA users for a small fee to post job listings describing their specific needs.

PCA consumers with general questions can call toll-free 1-866-212-9675. Elders and people with disabilities who participate in the MassHealth PCA program and do not have access to a computer or who have questions about using the Directory, should contact their Personal Care Management (PCM) agency for assistance.

Individuals looking for work as PCAs can register free-of-charge 24 hours a day on the website at www.mass.gov/findpca or by calling the applicant call center toll-free at 1-866-211-WORK (9675).

People who do not qualify for the MassHealth PCA program may still access the Directory of PCA workers through the Rewarding Work website (www.rewardingwork.org). This service is a subscription-based service starting at a low fee of $10 for one month.

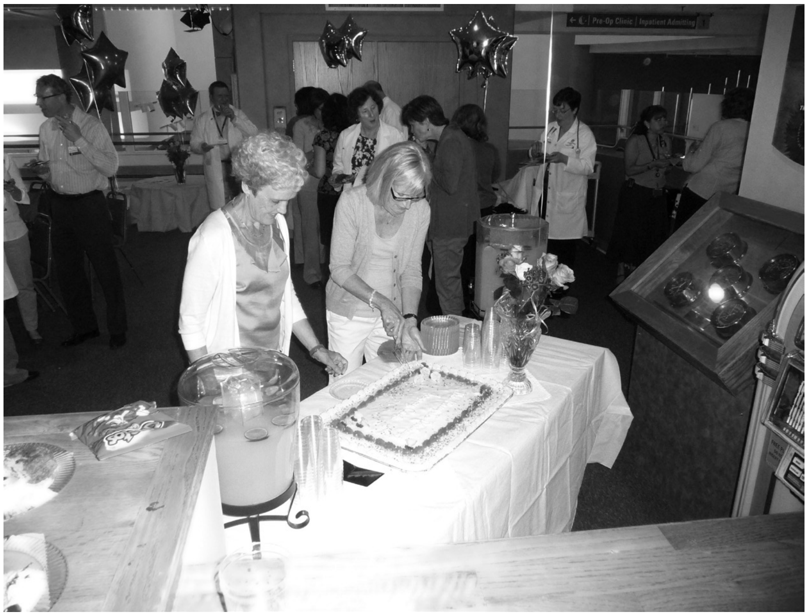
Mary Jo's legacy lives at Children's

By Cara Packard

The next time you head to the Myelo Clinic at Children's Hospital, you may find yourself in a Wii battle or playing a DS game. If arts and crafts are more your style, then you will be happy too. Thanks to the newly dedicated Mary Jo Dunleavy Entertainment Cart, patients of the clinic will be entertained for years to come.

On June 8, members of the Myelo Clinic and Surgery Department honored Mary Jo's long lasting wish to have a mobile entertainment cart for patients waiting at the clinic. They hosted a wonderful ceremony with reflections on Mary Jo's lasting impact on the lives of the patients and caregivers at Children's. Mary Jo cared very deeply for the patients and families of the clinic and always wanted to make their experiences at Children's better. The mobile cart, with its games and fun activities, will surely keep the patients happy while waiting at clinic. Like the many smiles that Mary Jo brought to clinic, this cart will do the same.

Mary Jo was a wonderful friend and advocate of SbaMass. She was one of our main sources of community connections for many years. More importantly, she provided so much comfort and hope to many of our members. SbaMass is proud to help sponsor the cart and the replenishment of the activities it will provide. So please give it a try the next time that you are there!



The cutting of the cake. Mary Jo's sister and Ellen O'Donnell PNP, Children's Hospital-Boston.

Back Row, Mary Jo's sisters and nieces, Ellen O'Donnell PNP, Children's Hospital-Boston

Front Row: Katie & Cara Packard, sbaMass Board Chair; Rebecca Sherlock PNP Childrens's Hospital-Boston

Items Available

Several items are available. First a comode. It has a soft seat and is brand new. Next, a bathtub seat which is a couple months old and it can either be used high up or take off the lower part and it can be lower in the tub.

A multi-function bed fully loaded and with an air mattress (which should go with the bed). The mattress is for someone with bed sores and is valued around $4000. It is desired that all items go together. If you have any questions, please call Ellen Heffernen-Dugan (888) 479-1900 or email her at **edugan@sbamass.org**.

THANK YOU!

On Sunday May 15th Hannah and Kim Farrell held a fundraiser in support of sbaMass at Jenny Boston Boutique, Hingham, Mass. The combined efforts of the Farrell Family and Jenny Boston raised more than $2000 for sbaMass.

In her own words: Advocacy at the local level

Massachusetts Mom Advocates for $2M to Upgrade Neighborhood Train Station

When Jean Batty and her husband relocated their three children to Winchester, Mass., in 2007, they chose a beautiful home in part because of the ease of public transportation and the excellent local school system. Nestled about 20 minutes outside of Boston, Winchester offered just want they wanted with one unknown exception—their nearby commuter rail stations did not offer accessibility for their then 2 ½ -year-old son, Theo, who has Spina Bifida and uses a wheelchair. The stay-at-home mom, and then future Chair of the local Disability Access Commission, decided to take action for change at the Wedgemere Train Station by working with local, state, and national leaders to make the platform accessible.

Jean reflects on her efforts to bring accessible transportation to her neighborhood.

What was it about this issue that fueled your efforts to have your local rail station made accessible?

Fundamentally, I wanted my son to have access to all the educational and employment opportunities that Boston has to offer. But it was more than that. Here we are, celebrating the 20th anniversary of the Americans with Disabilities Act (ADA), and many rail stations across the country are still completely inaccessible. I was shocked when I discovered this loophole in ADA, and I kept thinking, “How can this be? Why is this okay?” The “key stations” which are accessible are generally located in more expensive neighborhoods—not ones in which people with disabilities can usually afford to live.

What was the cost of your advocacy to your family?

Of course the time I invested in this project was part of the cost, but more significant was the loss of privacy. Our family needed to share our story, to share our hopes and dreams for our son, and to put ourselves in the public eye. But the payoff has been much greater than the cost. In addition to accessibility for our son, we have made it possible for others with disabilities to make the commute to Boston. Someday, as we age, my husband and I may even benefit. Others invested of themselves to pass ADA 20 years ago, but I see this as a relay race. Our family has made a small contribution to the solution—it has a ripple effect.

What was your most powerful tool in effecting this change?

I founded and chair the Disability Access Commission for our community, but my position on that board was not my most effective tool. It was the power of a mom speaking for her child. I was not just the head of yet another commission at a hearing—I was the mother of a child who was unable to travel to Fenway to see a Red Sox game. We sent Theo’s video to government officials and used it to encourage people to write to their Representatives. Stories move people more effectively than facts or statistics.

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Thank you!

sbaMass would like to acknowledge Erin Murphy who organized a fundraiser in support of sbaMass at California Pizza Kitchen, Prudential Center.

SAVE THE DATE

Saturday, October 1, 2011

8:30 AM - 4:30 PM

New England Spina Bifida Conference- Spina Bifida and Families: Understanding the Issues, Celebrating the Strengths

Sturbridge Host Hotel and Conference Center
Sturbridge, MA

Thank you!

to the following corporations for their support recent of sbaMass

Arbella
Bank of America
Blackbaud
Federal Home Loan Bank of Boston
Johnson and Johnson
Verizon

My Back Surgery Journal

By Katie Moynihan

Throughout my life I had many back and leg surgeries which all made a difference in my life. In May of 2010, I had the most major spine surgery so far tht really changed my perspective on life. Most importantly this experience made me a stronger person. It taught me how to be patient and laos made me realize how fortunate I am to be alive. I was able to reach my goals at the end of this surgery by making a full recovery after a long journey.

I had my surgery at the Boston Children's Hospital and I stayed there for about two weeks. The morning of my surgery, I was nervous, yet also confident at the same time eager to get the operation over with. In my mind I know I could handle the process of this surgery because I managed others in the past. I was asleep during my surgery so I couldn't hear or feel anything.

After my surgery, I was drugged with differetn medicines to take away the pain which made me sleepy so I could only hear some voices. At first it was hard to make them out because I was slow to open my eyes and realize my surroundings, but eventually I could recognize my mother's voice talking to the staff. When I woke up I felt sluggish, lazy and scared because all my body wanted to do was move but could not. I could feel that my face was swollen, so much that my eyes were barely open as if I had a bad allergic reaction to something. It was difficult to move, especially since I had to stay on my stomach for a week in order to keep the pressure off of my back and incision. All of this made me disappointed and aggravated at the time.

I continuously got pain medications and felt pain at times when the medicines wore off. If felt like little needles were poking at me over and over again. If felt annoyed and uncomfortable and also frustrated that I wasn't able to do anything or even listen to anyone. I didn't want to be bothered in any way or else I'd probaby cry or scream. During this time, things I can still remember are the smells of rubbing alcohol or any sterile things they gave to me. I remember the taste of the cold, refreshing popsicles in my mouth, the disgusting taste of the liquid medicine and the bland taste of food or drinks they gave me. I could also feel the touch of people around me such as people, friends, doctors and nurses that came in to evaluate me.

When I was at Children's, the nurses and staff made me feel comfortable and had plenty of things for me to do. There were activities and arts and crafts I coud do such as a bracelet making to pass the time. They also had a garden outside where I could go to eat or site around to get some fresh air. Not only was the staff good at trying to keep my busy, but if I was feeling depressed, I could talk to a councilor and tell them what was bothering me or talk to them about my day.

After two weeks at Children's, I had to transfer to Spaulding Rehab hospital to recover and get all the help I could to help me get back to where I was before. I stayed overnight with my mom there for 3 weeks. It felt longer than 3 weeks though! It was very hard to wake up because I was stiff and sore sometimes. I often cried because I was in pain. However, I started to recover more and more each day, but still needed a lot of therapy and pain pills. I got physical therapy everyday because I needed to learn how to re-walk again so I could get as much strength back as I had before. The healing process was very slow and patient. I had to wear a back brace for three months to keep the rods in my back in place so it could heal right away. In addition to physical therapy, I also had speech therapy and tutoring EVERY day. The tutoring helped me catch up on schoolwork. It exercised my brain because my tutor made me read at least a chapter of my summer book out loud to him everytime. It was very hard to get me in the habit in the beginning because I was tired and all I wanted to do was sleep.

The second week in Spaulding, I started to feel much better and was more up to doing things. I could walk longer and I could hold myself up. The back brace helped a lot and gave me the support I needed. I also was in a better mood and became more socialable. I met a couple of friends while I was there, and realized they were going through a difficult time like me, some of them who were even worse off. I got really close to them and when I had to leave, it was heartbreaking.

My mom, dad and sister were a great support for me. They took turns staying the night with me while in the hospital, and I always had someone by my side. If it wasn't for my family, I wouldn't be where I am today. They had to put up with everything, whether it was talking to the nurses, to help me out of bed or putting up with my bad days. If I was in pain or needed food, they would tell someone right away. They basically helped me with everything I needed. I am more appreciative toward them because they were always there for me during this difficult time.

When I was doing better and was stronger, I got to go home and get outpatient services. When I was home and settled, it was the end of June and I was worried about school starting in September. My goal was to back to school and only use my crutches and I was able to have an aide and not use a wheelchair. My goals did come true because when the time came I was all ready and set to go. I didn't have to use a wheelchair and I only came with my crutches and my aide. I am glad I succeeded my goals this year.

I think what has happened to me throughout my life, this surgery in particular has made me a stronger person mentally and physically. Each surgery is tough but I always managed to surprise people including my family, friends, myself and even the doctors! I appreciate life and am more mature after all this. It shows that hard work pays off. My family is very proud of what I've accomplished. I'm most proud of my recovery through this surgery because it took so long to heal. I may have been very impatient but I still made it through it all. I am very glad I've come this far!

Spina Bifida Advocacy (SPEAK)

SBA actively engages in advocacy efforts to raise awareness about Spina Bifida with our nation's lawmakers. Through a process of education, SBA, its partners, and its volunteers work together to lay the groundwork for a better tomorrow for the 166,000 Americans who live with the challenges of Spina Bifida each day.

SBA's Grassroots Advocacy Program

Members of the Spina Bifida Community can help our grassroots efforts by becoming a part of the SPEAK for Spina Bifida program. **SPEAK** stands for **S**pina Bifida **P**olicy, **E**ducation, **A**dvocacy, and **K**nowledge. Participants in the program seek to educate and help shape public policy related to Spina Bifida through grassroots efforts such as writing a letter to their Member of Congress, attending a town hall meeting in their home town, signing up to receive SBA's online Action Alerts, or visiting with their representatives at home or in Washington, DC. Sign up today to find out more about SPEAK!

For more information on Spina Bifida grassroots advocacy program and tools that you can use at home to help, visit the SBA Grassroots Advocacy Web site at **www.spinabifidaadvocacy.org**. And don't forget to visit the Legislative Action Center to sign up to receive online Advocacy Alerts!

Annual Report 2010

The 2010 sbMass Annual Report is available online at www.sbaMass.org

If you wish to have a copy mailed, contact Ellen Heffernan-Dugan at 888-479-1900

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CHANGE SERVICE REQUESTED

Save the Date for the 2nd Annual Walk-N-Roll for Spina Bifida!

September 25th, 2011
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 SB. All proceeds are used for programs and services for people living with Spina Bifida.
To volunteer, contact Wendy Potts at wpotts@sbamass.org.

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