news
sbaMass

Fall 2008 The Newsletter of the Spina Bifida Association of Massachusetts

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Letter from the President

by Brian Sullivan

Change.

Change can be a unique word. There can be change for the good, and change for the bad. Interpretation of change depends on the benefits or complications that one perceives to accompany change. Personally, in less than two weeks, I will welcome one of life's greatest changes – marriage. But, as I undergo this exciting but life-altering change sbaMass is also encountering an important, challenging change in its history.

At the annual SBAA conference this past June, local Spina Bifida chapters and associations were asked to sign a formal affiliation agreement with National SBA. These affiliation agreements bind the local organizations as legal chapters of the National organization – as opposed to loosely affiliated organizations. The purpose and belief is that as one unified organization we could affect greater change for our members then as individual units advocating admirably but not having the ability and power of a unified national organization. I am happy to report that sbaMass formally signed an affiliation agreement at Conference and has accepted its status as an affiliated chapter of National SBA.

What will change? Well, similar to my impending nuptials – much will change and at the same time nothing will change. From a service perspective, you will still have a local resource to advocate for your needs and assist in any way we can. As a National organization, SBA will continue to advocate for our community on Capital Hill and throughout the country – including funding research through the Spina Bifida Foundation. The change you will witness is that as a unified National organization we hope to better promote our community, we will advocate for more support on the local and national level throughout government and healthcare, and we will do a greater job informing our country of prevention methods.

Like a new marriage, there will be period of transition with our new affiliation. Certain responsibilities, roles, and expectations have yet to be finalized and will be a work in progress as both organizations become accustomed to our new relationship. Most important, however, is that the level of service we provide our local members will not decline. In fact, with support, ideas, and resources from National we will look to enhance our capabilities in the local community.

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As we enter this new period in our organization's history, I look forward to our organization continuing to thrive – as a local support organization and now as an affiliated representative of a national advocacy organization. As our new union grows, it will be like any marriage – growing only as far as those within it wish it to grow. Our future is unwritten, and possibilities remain endless. As a partner with us in this organization, I envision growing with you until our future is written and new possibilities abound.

Join sbaMass at UNO's Chicago Grill, Braintree Plaza, for a Dough Raiser!

This is a great opportunity to get out, catch up with old friends, meet new people and enjoy some delicious food! In addition **UNO's will donate up to 20 % of your check to sbaMass** for food (dine in or take out) or bar purchases on **Thursday October 9th, 2008**. sbaMass volunteers will on hand from 4:30 to 7:30 that evening. A 50/50 raffle will be held, with the winner being drawn at the end of the evening. **Look for your donation ticket in this newsletter.** Additional tickets can be obtained for friends and family by contacting Ellen Dugan at **edugan@sbaMass.org**, 888-479-1900, or download from the sbaMass website, **www.sbaMass.org**

Hope to see you there!

Let's Swim for Spina Bifida!

A Fund Raiser is being established at Old Orchard Beach Maine on **October 13, 2008**. Come and join in on the fun and help a great charity. **Robert E. Day** of Allentown New Hampshire has been taking his last swim on Columbus Day for 44 years and is creating an event to remember his son Bobby Jr. along with his father William E. Day Sr. Bobby was born with Spina Bifida and through his life endured many surgeries. In 2004, at the age of 26, Bobby died ending his battle. His Grandfather died a mere 15 months later but at the age of 96. Although they had two quite different lives they both enjoyed the Ocean.

Bob Day decided that this being his 45th year it would be fitting to establish this event to honor his Son and Dad by raising money for Spina Bifida. Bobby Jr. suffered with it and William enjoyed swimming on that date every year until the age of 88. If you are one of those people that love to jump into the cold water for a great cause then this is just the event for you. Robert Day is not expecting the world on the first year but it certainly would be wonderful to raise a few thousand dollars

This event is at **Old Orchard Beach Maine on October 13th at 1:00 pm** and all are welcome and any donation will be accepted. If you are interested in participating contact Ellen Dugan, Operations Associate at 888-479-1900 or **edugan@sbaMass.org** and request the Pledge and Waiver forms for the Columbus Day swim.

Winners of the raffle items at the Summer Picnic

Congratulations to All!

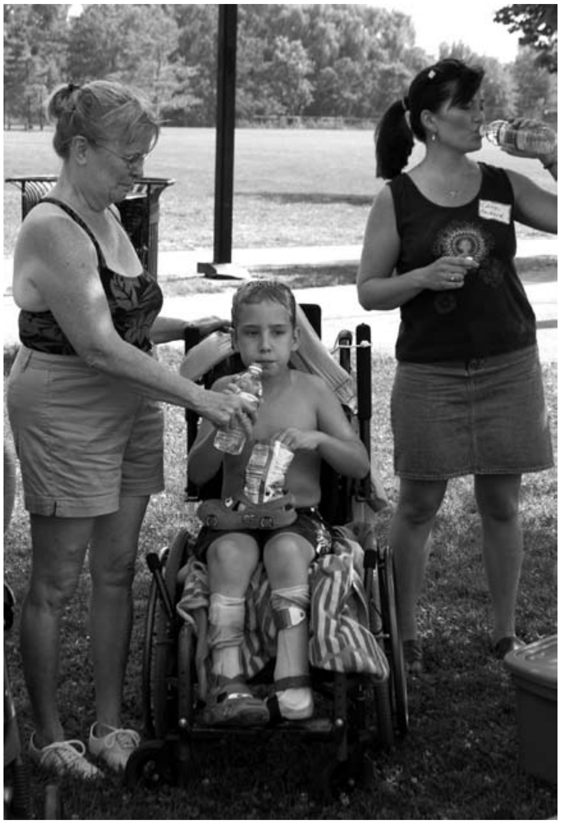
Joseph Sites
Leslie Campbell
Andrew Bemis
Batty Family
Matt Neal
Marianne DiBlasi
Mary Faherty
Katie Packard

Thank You to the following companies for their donations to the sbaMass Summer Picnic

Hannaford's Markets
Polar Beverages
iParty

And to the following for donations to the Picnic door prize drawing

Fisher Cats
Southwick Zoo
Seekonk Speedway
Roger Williams Park and Zoo
Davis Farmland or Mega Maze
Story Land, NH



Thank You Team sbaMass!

Team sbaMass

Standing (l to r): Anne Hitchcock; Derek Happas; Mary Honan; Dave Balardini; Brian Packard; Lisa Mokaba; Matt Lombardi; Don Martin; Evan Fay; Christian Potts; and Team Captain, Wendy Potts

Sitting (l to r): Jeff Hitchcock; Kelly Palumbo; Renee Fay; Kathleen Brannigan; Bob Bertolino; Becky Swissler; Leanne Martin

Front Row: Katie Packard & Jon Paul Potts

Runners Janelle Tribble & Brian Packard

Team Captain and organizer, Wendy Potts, celebrates a job well-done with Katie Packard

by Cara Packard

The beautiful sunny skies on August 10th provided the perfect setting for the rousing success of Team sbaMass' return to the **Falmouth Road Race**. Once again, our wonderful runners dedicated themselves to raising funds and creating and public awareness for our organization. Through the efforts of the 24 member team, **we expect to raise over $30,000 for the sbaMass community**.

Though the day was hot and the hills seemed long, our team members finished the race smiling. The new running singlets made Team sbaMass easy to spot as they passed by our cheering sections. Cheers for sbaMass mixed with the sounds of kazoos, a banjo and "Sweet Caroline" while our runners flew past us.

The fun continued at the post-race party where all 24 members of the team were able to celebrate their great achievement with more kazoos, delicious food and very fun company. At the party the Team was also able to thank Wendy Potts, our "Team Captain" this year. Wendy kept the team rolling this year with her expert organization of everything from submitting the team applications to clean-up of the post-race party. We are very grateful for her work on behalf of the team and for the continued generosity of the Potts family in hosting the post-race party.

We are thrilled that most of Team sbaMass plans to return next year. We thank all of the team members from the bottom of our hearts. By running for sbaMass they contribute in large part to keeping our important programs running. Thank you!

Bits & Pieces

by Hyacinth Bellerose

SPINA BIFIDA REFERENCED AT THE OLYMPICS:
Did you hear? Olympic heavy weight boxer, **Deontay Wilder**, has a little girl named Naieya and she has Spina Bifida. Deontay Wilder said that his daughter is his inspiration. Deontay is also an inspiration for many people as he just started boxing in 2005 and won a Bronze metal this year. If Naieya has the motivation of most of the people that we know with Spina Bifida and the motivation of her dad, watch out world!

CELEBRITIES:
As for celebrities… did you know that there are quite a few celebrities that have Spina Bifida or have children with Spina Bifida? From **Hank Williams, Sr.** to **Rene Kirby** and more….. For details and a website with a lot of cool information, see the **Children and Adults with Spina Bifida** website at **www.waisman.wisc.edu/~Rowley/sb-kids/index.html**.

EDUCATIONAL CONFERENCES:
This is not meant as an exhaustive list or an endorsement of the conferences; I'm just passing along information that I've noticed recently. Back to school….

17th Annual World Conference for Learning Disabilities (**www.socialskills.org**) - There are sessions on NVLD, social skills, math difficulties and much, much more. You can attend all or part of the program **November 6, 7, & 8, 2008, Boston Marriot Hotel, Burlington, Massachusetts**.

Home and School Interventions for NLD and Asperger's Syndrome in **Hyannis on September 29, 2008 and Westborough on October 17, 2008**. Contact the Maple Leaf Center for more information at **www.mapleleafcenter.com** or call 802-446-3601.

The Federation for Children with Special Needs has programs at least weekly throughout the year and throughout the state on many topics from IEPs to Sports to Basic Rights. If you have a particular interest, concern or need, the FCSN is a great place to start. Check out **www.fcsn.org** or call 800-331-0688. Programs also offered in languages other than English.

The Special Needs Advocacy Network, Inc. also has ongoing programs on specific and general education issues. For information, see **www.spanmass.org** or call 508-655-7999.

The New England ADA Center The Center provides standard and custom training, on-site workshops and day-long seminars on all aspects of the ADA and accessible IT information technology. Spanish available. See **adaptiveenvironments.org/neada/site/home**.

ACCESSIBLE NASCAR RACING:
No, I'm not referencing the stadium seating; I'm talking about driving the cars! Check out this new event in which real NASCAR race cars are modified to meet the needs of drivers that have disabilities! **www.accessibleracing.com**.

Thank you to the followning who have recently donated passes to sbaMass for the benefit of our members

ECOTARIUM
Roger Williams Park & Zoo
Museum of Science
Story Land
Basketball Hall of Fame
Plimouth Plantation
NH Fisher Cats
NE Aquarium
Franklin Park Zoo
Children's Museum, RI

Youth and Adults Group Update
Tips to Getting the Most Out of Your Health Care Visits

With the new school year underway, here are some tips for coping with the challenges of Nonverbal Learning Disabilities, often found in individuals with Spina Bifida. For a listing of resources in your area, please contact the Spina Bifida Association of Massachusetts.

Learning
Everybody learns differently. Some people learn by listening, while others learn by seeing or doing. Most people with spina bifida have strong verbal skills but may have difficulty in other areas. As an adult with Spina Bifida you may experience some or all of the following learning challenges. These may have been labeled as Nonverbal Learning Disabilities (NLDs). Each challenge listed has practical tips that will help you cope.

Memory
Although you may understand information at the time it is presented, remembering it later without reminders is tough. If you have difficulty recalling what is seen or heard:

- Use a calendar, Palm Pilot, computer, or tape recorder to remember daily routines.
- Make lists of tasks to be done.
- Use a calculator to do math.
- Use a watch with an alarm to remind youwhen to take medications, catheterize, or exercise.
- Make a mental image of new information.

Understanding
You may be able to communicate your thoughts well but might have difficulty understanding what others are saying or asking you. To increase understanding:

- Ask speakers to repeat themselves if their statements are confusing.
- Restate what the other person has said, and ask them if you have “got the main idea” of what he or she is saying.
- Ask for extra time or instruction to ensure that you are learning the information.

Attention
Trouble paying attention is a common problem for individuals with Spina Bifida. To help you improve attention:

- Sit near the person speaking so you can hear and see what is being presented.
- Try to reduce distractions. Clear your work area of everything. Keep out only the things you need. If you have a great deal of trouble paying attention or if you act before you think, talk with your health care provider. Medication may help you focus.

Organization
You may have some organization issues if you are unable to keep things organized or have a tendency to lose things. Clutter is your enemy. To improve your organization skills:

- Use tools to organize materials by topic or function (folders, notebooks, containers).
- Use a wall calendar, computer planner, or a programmable watch to keep track of your appointments.
- Develop lists of things that need to be done.
- Break down hard activities into small steps.
- Seek assistance in ways to organize.

Sequencing
People with Spina Bifida may have difficulty keeping things in the correct order, which can cause problems with math, the ability to do several tasks, make change, and tell time. Sequencing problems can also decrease your ability to complete self-care tasks, such as catheterization. The following suggestions can help with sequencing problems:

- Identify the order of the steps to do an activity.
- Use pictures to remind you of the order of the steps.
- Practice a daily routine. Learn that each activity is to be done at a specific time and in a specific order.
- Seek assistance if you need it to help you learn the order of steps to do activities.

Decision Making and Problem Solving
Often, individuals who have problems with memory, attention, organization, and sequencing will also have problems making decisions and solving problems. Making a decision involves choosing from different

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Youth and Adults Group Update continued from ***page 6***

options. Solving a problem involves applying previously learned information or experiences to a new situation to come up with a solution. Every day there are opportunities to make decisions. Learning to make good choices takes practice. The following suggestions may help you make decisions and solve problems:

- Practice making choices.
- List the good and bad things about each possible choice.
- It's okay to talk about these choices with a friend.
- It's okay to ask a trusted friend or family member for help in making decisions.

Perceptual-Motor Skills

People with shunted hydrocephalus often have poor coordination between their eyes and hands that causes them to have trouble "seeing" or "picturing" things in their head, moving around in a space, and being coordinated. Reading, writing, and math skills are all affected. The following suggestions may help improve visual and motor skill issues:

- Practice activities that require using your hands and eyes together.
- Use a tape recorder rather than taking notes when learning information.
- Ask for written copies of materials.
- Use a keyboarding device.
- Use the Personal Health Care Record* to help with your learning challenges so that you can manage your own health care. You can use the Personal Health Care Record to keep track of your medical care, appointments, and medications.

TAKE HOME MESSAGE: People can find ways to deal with their learning issues and be successful. Many state vocational agencies or other resources in your area, such as an independent living center or your local SBA, can provide help.

*A copy of Personal Health Care Record can be found in the Heath Guide for Adults Living with Spina Bifida, published by the Spina Bifida Association or by contacting the Spina Bifida Association of Massachusetts. You may prefer to use your own healthcare tracking mechanism to maintain your medical history

REFERENCE LIST

Spina Bifida Association of America. Learning Among Children with Spina Bifida. Washington, DC: 2001 Fact Sheet.
Spina Bifida Association of America. Insights into Spina Bifida, Vol. IV, No. 4: 2A. July/August 2003. Nonverbal Learning Disabilities and Spina Bifida: Understanding the Challenges in School, at Home and in the Community

Reprinted from Heath Guide for Adults Living with Spina Bifida, published by Spina Bifida Association, 2005.

Upcoming sbaMass YAG Events

Saturday, October 25, 2008 – 4th Annual Lunch and Learn. Morse Institute Library, Natick, MA 11:30AM – 4:30PM. RSVP deadline October 13, 2008. RSVP to **jkuhar@sbamass.org** or 888-479-1900. Scheduled topics include skin care and a discussion on using your voice to ask for what you need and want. Adults with Spina Bifida, teens (13 and older) with Spina Bifida, along with their PCA, and parents of children with Spina Bifida are welcome to attend.

Saturday, November 1, 2008 – Parent and Teen Get Together. Children's Hospital Boston, Byers A&B Rooms, 12:30 – 4:00PM. RSVP deadline October 24, 2008. RSVP to **edugan@sbamass.org** or 888-479-1900. Topics of discussion will focus on transition, independence and social issues. Teens (ages 13-17) with Spina Bifida and parents of children with Spina Bifida are welcome to attend.

Sunday, December 7, 2008 – Holiday Party, Hampton Inn- Natick, MA. You will not want to miss this annual tradition! Contact Ellen Dugan if you would like to help out. There are many volunteer opportunities available!

For more details on all events, please watch your mailbox, visit our website, **www.sbamass.org**, or call 888-479-1900.

Telling the teacher: What I want my child's classroom teacher to know

by Patricia Bill

Most children with disabilities are included in the "regular" classroom for part of their day. Yet many general classroom teachers say that sometimes they feel unprepared and uncertain about how to work with students who have special needs. Many add that they'd welcome ideas. "We parents do understand that teachers are incredibly busy with large numbers of students, lack of resources, and other challenges," said Beth Davis, the New Brighton mother of two teenagers with disabilities."I've always encouraged both of my children's teachers—yes, even all the ones in high school—to contact me if I can help them understand anything at all about either one of my children," she continued. children with disabilities are willing to help teachers and others at school to work with their child. Some families, however, don't offer help or suggestions because 1) they believe that the teacher must know best, or 2) they don't want to appear critical of the teacher. Past issues of PACESETTER have printed articles on what teachers suggest to parents as they send their children with disabilities to school. Parents now offer their suggestions for classroom teachers. In the spirit of parent-school partnerships, you may wish to share the following ideas at your child's school.

My child is a person

- Greeting my child by name when he comes to class can make a huge difference in his day. Developing a relationship with him establishes his existence. You set the stage for how others at school treat him.
- Like any child, mine is unique. She has passions, dislikes, things she is good at, things she is not. Your efforts to learn about her interests and strengths validate her.
- My son's identity is more than a diagnosis or a label on an Individualized Education Program (IEP). The disability is only part of who he is. Please look beyond it to see more of him.
- Understanding the disability may affect how you perceive my daughter. I'm happy to give or help you find information.
- Please be discreet. What you say about my son—good or bad, in the teachers' lounge or elsewhere—affects his reputation, as well as your own.

We can talk

- I gladly will share ideas and thoughts, as well as concerns, about my child. If you contact me, I can probably offer insight to her behavior and share strategies that work at home.
- My son may look like a typical 12-year-old, but his disability is real. Our family worked with professionals through a long and sometimes painful process to reach a diagnosis for him. If you acknowledge that my son has a disability, we can communicate openly about how to address it.
- The only way my daughter can succeed at school is through our partnership. I know that you are a professional, but I am an expert when it comes to my child, and I will be part of her life forever.

My child can learn

- You can relax. I don't expect miracles, but I hope you will have high expectations for my son. I assume he can do a certain task until he proves otherwise. If we work together, our expectations for him likely will be realistic.
- Arranging groups and teams to include everyone will help my daughter feel that she belongs to the class and the school community. She learns from peers.
- My child's experiences in your classroom are the foundation of his future success at school or in employment. Encouragement is crucial for him to keep trying.
- My son may not be able to express himself in customary ways, but he benefits from being in your class. He gains knowledge, even if he is slow at a task, scores low on tests, or does not respond at all. His IEP, which you have received, tells what accommodations he needs to progress.

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- My child probably can develop her abilities—if we encourage her. It may be easy to coddle her, but together we need to help her "fly" on her own.
- Try using code words or discreet signals to guide my daughter. Calling out her name in class for what her disability will not allow her to do ("Mary, sit down," "Mary, be quiet," or "Mary, hurry up") brings negative attention and affects her self esteem.

My child has gifts

- Children with all types of disabilities can offer much to others. If you look for it, my son can contribute something valuable to the classroom that no one else can.
- Above all, I hope you can find something to genuinely like about my child. I know you will.

Reprinted from Pacesetter, Fall 2006, vol. 26, issue 3.

Karaoke for Katie A Success

by Cara Packard

If you happened to be passing by the **Quincy Lodge of Elks** on July 19th and heard some unusual sounding tunes, then you were probably treated to a smile by the Karaoke for Katie night held there that evening. **Jack Raymer and his wife, Cathy**, organized a very fun event to promote awareness and raise money for sbaMass.

Jack, a talented singer himself, invited family and friends to make donations to the sbaMass in order to hear those attending sing. In some cases, people paid to hear the singing stop! All in all, the evening was a wonderful success, with lots of laughter and over **$1300 raised on behalf of sbaMass**.

The sbaMass Board is extremely grateful for the generosity of Jack & Cathy Raymer for organizing the event and for the generosity of the Quincy Lodge of Elks. **The Quincy Elks not only hosted the event, but they also made a donation of $500 to the sbaMass.** We also are thankful to all the wonderful and not so wonderful singers who helped raise the money. Thanks to everyone for a great evening.

Inclusive Schools Week

December 1-5, 2008

The **Inclusive Schools Network** (ISN) is a web-based resource for families, schools and communities that promotes inclusive educational practices. This resource has grown out of Inclusive Schools Week™, an internationally-recognized annual event sponsored by Education Development Center, Inc. (EDC). ISN's mission is "to encourage, embolden and empower people to design and implement effective inclusive schools, by sharing insights and best practices and by providing opportunities for connection."

You care about the dignity of all children—those with disabilities and those from diverse backgrounds—and you know that your school and community can do a better job of meeting their needs through the use of inclusive educational practices. ISN encourages you to take the lead in coordinating Inclusive Schools Week in your school, school district, or community. Thousands of individuals—teachers, family members, and schools administrators—local, state, and national organizations and advocacy groups, and entire school districts have enthusiastically stepped up to this task—and have found this experience to be extremely rewarding in terms of its impact on children and youth.

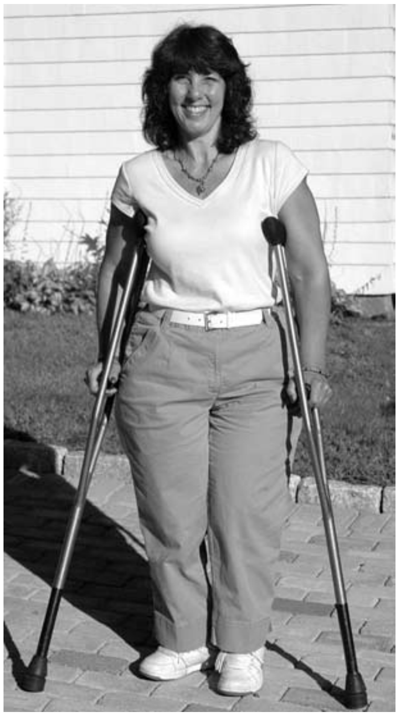
Get Involved: Log onto **www.inclusiveschools.org** for information on how to plan activities for your local schools.

Brian and Katie Packard give Jack Raymer a kazoo in thanks for his efforts in creating and running Karaoke for Katie, a fun-filled karaoke fundraiser.

Coming Home at 50:

Reflections of Being a First Time Attendee at the June 2008 National Conference

by Marianne DiBlasi



I was born with Spina Bifida on August 14, 1958. For much of my first 50 years, I have been running away from the Spina Bifida part of myself. During the summer of my 50th birthday, I gave myself the gift of attending my first national conference and coming home to more of myself and to the Spina Bifida community. Being able to receive the gift of attending the conference has been a life long journey.

I was 14 years old when the sbaMass chapter was created. When I was born, my parents didn't have the support of a community to help them sort through all their emotions and the overwhelming medical issues of having a baby with Spina Bifida. Together, my parents and I struggled through my younger years not knowing any individuals who were born with Spina Bifida. I survived my childhood by being as "normal" as possible to fit in and belong. When I was a teenager I attended a couple of sbaMass meetings because there was a place inside of me that wanted to be with others like me, who were born with Spina Bifida. Back then, the meetings were for parents and they talked about all sorts of potential medical issues and surgeries. As a teenager, I couldn't bear to see and hear all those "awful" things about myself or about what might happen in the future so I ran away in an attempt to not feel the painful truth of being born with Spina Bifida.

As a young adult, I certainly knew about the national conferences. I had been encouraged to attend by the medical staff at Children's Hospital but by this time, I had no interest in going to any conference. I didn't want to know or hear more about Spina Bifida than I absolutely had to. I didn't want to be with other people with Spina Bifida and I didn't want to be part of the Spina Bifida community.

As far as I was concerned, my life was going just fine. I lived on my own, had a professional career, great friends, a fun social life and boyfriends. I was living the "normal" life of my dreams. It wasn't until my late 30's that I began to realize that behind my happy, smiling face I was not doing just fine. I felt broken, alone and there was an empty hole in my heart that nothing seemed able to fill. I figured there was nothing I could do about my broken Spina Bifida body, so I began a quest to fix myself on the inside. I spent many years going to therapists, attending self-discovery workshops and reading countless personal development books – all in an attempt to feel whole and complete.

I didn't know that my quest to heal my inner self would lead me to the very thing I had been so desperately running away from – the Spina Bifida part of myself. This quest transformed itself into a spiritual journey of embracing my wholeness. To be whole means accepting and welcoming my deformed outer body and all my inner suppressed feelings related to being born with Spina Bifida. On this journey, I became certified as an Integral Life Coach, a Reiki Master and a Teacher of the Wisdom WAY™ model of healing and transformation. Becoming certified and embodying the wisdom of these healing models has deepened my own healing, and enables me to guide and support others who are longing to embrace their wholeness.

Up until this point, I had been doing all of this inner transformation without any connection to others born with Spina Bifida. I had gone as far as I could go on my own. To go deeper on my journey of wholeness, I needed to re-connect with the Spina Bifida community. I began by attending the SBA Mass Youth and Adults group gathering in September 2007. This was my first Spina Bifida event since I was a teenager, 33 years ago.

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I was terrified walking through the door and the voices inside my head were saying, “What if they reject me the way I had rejected them so many years ago?” and “What if, even after all I’ve done to embrace my disability, I discover I still reject the Spina Bifida part of myself?” Instead, what I experienced when I walked through the door was a warm and generous spirit of welcome that put me at ease right away. And, much to my surprise, I felt comforted to be with people who had a Spina Bifida body type like me, who walked like me, and who easily talked about Spina Bifida-related topics. I felt great relief that my first experience of coming home to the Spina Bifida community went so well. I kept attending more Youth and Adult group gatherings and I looked forward to the camaraderie and conversations.

Then came time to decide about going to the June 2008 National Conference in Tucson AZ. Four days of being with hundreds of people with Spina Bifida of all ages and their parents. YIKES!! Taking a deep breath, I bravely completed the SBA Mass scholarship application. Part of me was thrilled to receive the generous scholarship and part of me was dreading going. Nevertheless, the time came to get on the plane and fly to Tucson AZ.

Walking into the hotel was a moment I’ll never forget. I saw groups of people with Spina Bifida who came in all shapes and sizes and who used manual wheelchairs, power wheelchairs, crutches, canes and no assisted devices at all. I felt like I was seeing every color of the rainbow expressed as people with Spina Bifida. The energy was like a grand reunion of friends and comrades with enthusiastic greetings and excited conversations. I remember feeling a stab of sadness and longing that I had missed out on being part of this community all these years. With the close-knit reunion atmosphere, I was afraid it would be difficult to connect with people. Instead, I found it easy to be a social butterfly and walk up to people saying “Hi! I’m Marianne. Can I join you?” The response was always “Sure!” I was delighted at how easy it was to fit in and be welcomed.

On Sunday, I attended the Adult Day sessions. The topics and speakers were educational and inspiring. However, as the day went on, my comfortable, easy experience began to shift. The challenging part for me was - they were actually talking about what it was really like for them to have and live with Spina Bifida. Because the speakers dared to be real about their experiences, it brought to the surface many emotions I hadn’t expected to feel and that I wanted to push away. I also began hearing stories from the attendees about medical issues and surgeries they were experiencing as adults, which sometimes impacted their ability to work or live independently. I haven’t had any surgeries since I was in High School and the realization that surgeries are a very real possibility hit me hard. All the pain, horror and terror of being hospitalized and having surgeries came flooding back. The past was no longer tucked away as a distant memory. I was reliving all my painful feelings again in the present moment. As I continued going to sessions, I heard, saw and felt more and more of what I had spent so much energy running away from for so many years. My Spina Bifida was in my face and there was nowhere to run, nowhere to hide - Spina Bifida was everywhere.

During the last session of the second day, I finally heard one story too many. The emotions I’d been suppressing came rushing to the surface and poured out. I left the session in tears and my heart breaking open with a flood of painful feelings rising up from deep inside of me. I went back to my room and called friends who know my heart. Sobbing into the phone, I cried “I want to come home!” Even as I said this, I knew in my heart, I already was home, being at the conference with others who were born with Spina Bifida. There was just a part of me that was also crying out, “But I don’t want this to be home!”

My friends helped me to sort through my feelings and accept the truth of what is – I have Spina Bifida and I may or may not have some of the medical issues and surgeries that I was hearing about. They helped me to let go of my need to know the future and embrace this moment of being Marianne, who is having my particular experience of Spina Bifida. I was comforted and supported as I felt the truth of this wisdom settle into my heart.

After my conversation with my friends, I went downstairs to the community dinner. I looked for Carol, a first time attendee from MA who had been in the last session of the day with me. I shared my experience with her and was supported again by

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her understanding of having gone through a similar experience earlier in her life. We joined a group of people at a table and I was supported even further by the camaraderie, conversation and laughter.

During the last two days of the conference, I found myself gradually feeling lighter. My heart was expanding and I felt more and more at ease being with Spina Bifida. As I continued talking with people and sharing stories, I experienced a sense of Oneness. I no longer wanted to push away the Spina Bifida in myself or in them. By the last night of the conference, my heart was wide open with love for the little kids with Spina Bifida, for the people I had talked and listened to, the ones I only knew by seeing them walking up and down the halls, and last but not least, for myself!

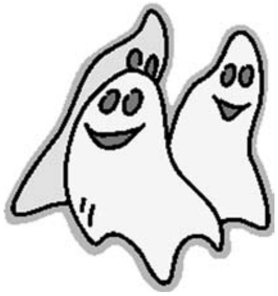
In summary, my experience of being a first time attendee at the national conference was two days of my heart breaking open in agony and two days of my heart opening with love. Going to the conference turned out to be a greater birthday gift than I could ever have imagined - the gift of coming home to more of myself and to the Spina Bifida community.

You may be wondering what the transition back into my post-conference life has been like. I was in a loving, openhearted place for a couple of weeks where I felt deeply loving to myself and connected with the Oneness of life. Slowly, the intense feelings softened as I digested the experience. I wish I could tell you that since the conference, I now miraculously love every bit of my Spina Bifida self. It hasn't been that like for me. The spiritual journey of embracing my wholeness continues. I have experienced more moments of feeling the painful truth of being born with Spina Bifida and it hurts all over again. Sometimes I'm able to open my heart to accept, welcome home more of the Spina Bifida parts of myself, and sometimes I'm not ready yet, so I don't. The difference is, since attending the conference I'm not as alone with my Spina Bifida. I've connected with others like me and I have a deeper sense of unity and camaraderie that makes my heart feel all soft and warm. I am part of a group of funny, creative, smart, talented, brave, thoughtful, bold, tender, adventurous, caring, generous, beautiful kindred spirits who were born with Spina Bifida. The Spina Bifida community is part of me and I am part of the community.

Attending the conference offered me one final unexpected surprise. While I was there I met a man, Steven who lives in FL. Over the summer we've been developing a long distance relationship. It's been both wonderful and challenging for me to be engaged in an increasingly intimate relationship with a man who has Spina Bifida. Our relationship is inviting me to go to an even deeper level of embracing Spina Bifida – mine and his. As I write this article, Steven is coming to Boston in three days for a visit over Labor Day weekend. It's the first time we will be together in person since the conference and we're both excited and a little nervous – just as any "normal" long distance couple would be. This is where my story ends, and the journey continues….

If you would like to contact Marianne, you can email her at **marianne.diblasi@gmail.com**

Are you available to help?



Adopt a Ghost is a national fundraising program of the SBA. The Adopt a Ghost Program consists of offering small paper ghosts for sale in your community. Are there local business which you frequent 2-3 times per week, upcoming school or church fairs, who do you have a relationship with in your community. The program will not cost the business anything but will assist sbaMass in fundraising efforts and in raising awareness of Spina Bifida during Spina Bifida Awareness Month (October) For more information please contact Ellen Dugan at **edugan@sbaMass.org** or 888-479-1900.

Spina Bifida In The Workplace: How Do We Get In?

by Ginny Briggs

While serving on the sbaMass board these last few years, I have had the pleasure of meeting a variety of people with Spina Bifida (SB). I have been impressed by the accomplishments of so many and concerned for the future of those who were not able or old enough to go out in the world on their own. “Independence” is one of the keywords that frequently comes up in conversations within our community. So many elements come into determining if and how a person with a physical disability can lead a satisfying, fulfilling and independent life. One of the key ingredients in reaching that point is to be able to work. A recent study was published that looked at how SB people are doing in the workplace and what may have contributed to their success. The information is not all that surprising, but there are some things to think about for both parents of SB kids as well as SB adults.

In the Netherlands, they have done a very good job of keeping up with their SB population and a fair amount of decent information has come out of their research studies. In this recent study, they collected employment information from 136 SB people (59 men, 77 women) from 21 to 32 years old. Only 14 people did not work at all, and the rest either volunteered, worked part-time or worked full time.

Here is a breakdown of who did what:

14	No work at all
37	Volunteer
26	Less than 24 hours per week
33	24-35 hours per week
36	More than 36 hours per week

Though about half of these people reported problems getting a job because of their disability, the majority said they enjoyed their work (82%)! Therefore, it is important to think about what can be done to maximize an SB person’s chances of landing a job, whether or not it’s volunteer, part-time or full-time.

So, what can we do? Not surprisingly, the factor that had the most affect on finding a job of any kind was education (the more the better!). Education also improved the odds of finding a job that paid and that was full-time. Other things that helped were being male, being able to walk and being independent in terms of self-care. Well, there are some things that can’t be changed, but there are some things that can be improved on, like education. Parents of SB kids may want to consider this important piece of information when helping their child plan their future. For SB adults interested in working, it may be beneficial to consider returning to school.

Another important point raised in the study was that people who received help finding a job after they finished school were more likely to find employment. It’s possible that receiving public assistance benefits may affect some people’s motivation for finding work after graduation, so it was recommended that families reach out to each other.

There are many benefits available for people with disabilities who would like to get a higher education (in the form of scholarships and grants). Kids in high school should check with their guidance counselors and adults should contact the schools they are interested in attending. Some colleges are better than others in terms of accessibility, so that should also be considered. Another great option is to consider taking classes online or over the internet. The extra effort could very well be worth it and could provide a satisfying and independent lifestyle!

Reference: Work participation among young adults with Spina Bifida in the Netherlands; van Mechelen MC, Verhoef M, van Asbeck FW, Post MW; Dev Med Child Neurol. 2008 Aug 11.

Mark Your Calendars for the 2008 sbaMass Holiday Party!

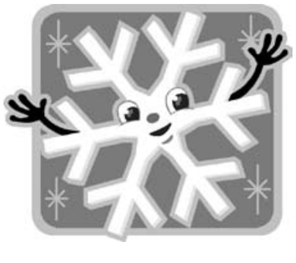
Sunday, December 7, 2008 from 12:30 PM - 5:00 PM
at the Hampton Inn, Natick

Party will include:

- Lunch!
- Fun and Games for all ages!
- Special Holiday Guests!
- Coloring contest for the kids!
- Yankee Swap for Adults*
  (Bring a wrapped gift worth no more that $10)

  *Adults with S.B. do not need to bring a Yankee Swap item

****Please RSVP by Monday, November 22, 2008****



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

Include the following information in your reply:

- Your first and last name
- Your phone number
- How many people are in your group
- Names and ages of everyone in your group
- Please specify the name of the person with s.b.

See Directions to the Party on the insert!

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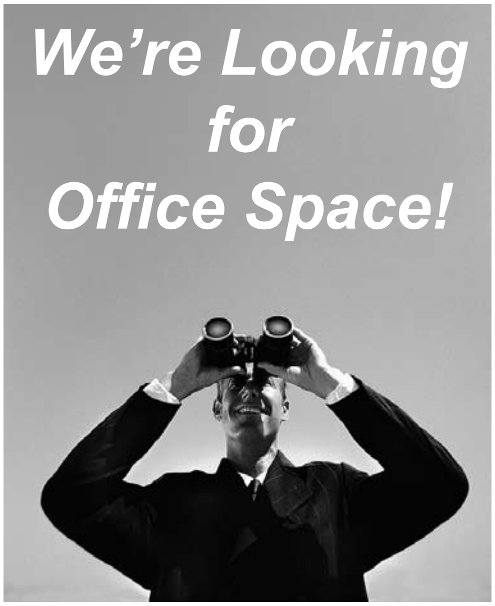
Note: The information in this newsletter is provided solely for informational purposes. It is not intended to be, nor is it, medical advice on the management or care of a person with Spina Bifida. Although every effort is made to assure that information is accurate and current, knowledge in the field 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.

We're Looking for Office Space!



The SBA of Massachusetts is continuing to seek free or low cost office space. The ideal space would be located on or near Route 128, (accessible to The RIDE), and include space for 3 desks, meeting space to accommodate up to 20, wheelchair accessible, 24/7 access and accessible restrooms. Shared space with another non-profit or business will be considered.

Please contact Ellen Dugan, Operations Associate,
if you or someone you know can help!
(888) 479-1900 or edugan@sbaMass.org

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