sbaMass news

Fall 2007

The Newsletter of the Spina Bifida Association of Massachusetts

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Letter from the President

By Brendan Sullivan

How do you fill the shoes of a leader who helped transform the SBA of Massachusetts (“sbaMass”) into a thriving community of support through his dedication and visionary leadership? The answer is simple, you don’t. What you do is set those shoes aside because they can’t be filled. What is possible is to try to emulate the leadership your predecessor exhibited so that the organization may sustain its momentum. Of course, the “he” I speak of is Brian Packard, who recently ended his term as President of sbaMass.

On behalf of the Board of Directors and the entire membership, I would like to thank Brian for his contributions over the past seven years. In his last President’s Letter, Brian spoke of his work with spina bifida as his “other job”. However, I know this work was not a job for Brian. It was a rewarding passion that allowed him to help others and affect their lives in a positive manner. Though he has left the Board, I know Brian will not be far from the sbaMass in the future, and for that we are very grateful. He is a talented professional, a cherished friend, and most importantly, a loving father. Thank you, Brian, for all you have done in the past seven years.

As an individual with spina bifida, I am honored to assume the role of President of sbaMass. Since 2002, I have been a member of the Board of Directors of sbaMass, holding the role of Treasurer during that time as well. This experience has been more rewarding than I could have imagined. In addition to the personal accomplishments of running two Boston Marathons and one Falmouth Road Race on behalf of sbaMass, I have realized that a thriving community of individuals and families, bound together by the most common debilitating birth defect, exists in Massachusetts. In five years, I have seen the unity of this community improve advocacy for those with spina bifida in Massachusetts, and my hope is for that advocacy to lead to even greater achievements in the next few years.

At the recent Annual Meeting of the Board of Directors, the remaining officer positions were also filled. After most recently serving as Secretary of the Board, Jen Kuhar was appointed to the position of Vice-President. In addition, Matt Neal accepted a nomination to the position of Treasurer and Joyce Hillis accepted the position of Secretary. These individuals will join the rest of the Board of Directors as well as Ellen Dugan, Operations

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Letter from the President

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Associate, in leading the organization to new heights in the years ahead.

In this issue, you will find many interesting articles about upcoming events and recent happenings in the sbaMass community. Primary amongst those happenings is the upcoming annual sbaMass Holiday Party, which will take place on Sunday, December 2nd. Please save-the-date and join sbaMass in celebrating the holiday season. As always, we are expecting a visit from a very special guest!

Finally, October is Spina Bifida awareness month. I'm happy to report that sbaMass was fortunate enough to receive an advertising grant from SBA. This grant will allow sbaMass to place awareness advertising in a number of newspapers throughout the state during the month of October. Our hope in this endeavor is to make more people aware of spina bifida and inform them of the resources available for those with spina bifida in Massachusetts.

Again, it is a pleasure and an honor to serve sbaMass as President. It is a leadership title only in name because the leadership that moves the association forward comes from its active membership, and not from one officer position. While I hold this position for the next two years, I cherish the opportunity to be the steward of that leadership so that we may together come to achieve more great things for the spina bifida community in Massachusetts.

Safe health and we will see you in December at the Holiday Party!

Santa's Helpers Wanted!

The SBA of Massachusetts **Holiday Party** is fast approaching. Although if felt like summer recently, we are no longer in the warm days of summer! If you are interested and available to help Santa shop for gifts, wrap, plan games or craft activities, please get in touch with Ellen Dugan, Operations Associate at edugan@sbaMass.org or (888) 479-1900.

Music Therapy

by Ginny Briggs

Does music help you heal faster? Can people learn faster, move more easily and feel happier with the help of music? Some research says it can. In fact, so many studies have found an association between better health and exposure to music that "music therapy" has been born and is used to help people with a wide range of health problems. People with physical disabilities may particularly benefit by being involved in music. Not only has it been shown to reduce stress, but to improve balance and movement, strengthen relationships and improve health.

Movement

Physical therapy (PT) can sometimes be a difficult and uncomfortable experience. However, some research has shown that combining music with the exercises can help the process. For example, in a study of Parkinson's Disease patients who got music during PT, they reported that they felt better and were more active at home. They also said that PT without music seemed to have no emotion, and they didn't feel motivated to do their exercises. Once the music was added, they felt more interested in completing their physical therapy. Another study showed that older adults who participated in a movement and music program for 5 weeks could walk better and had improved balance.

Play

Play is recognized as an important part of emotional and physical development in children. Children with physical disabilities may have a harder time playing with other kids because of their physical limitations. Studies have shown that kids with physical disabilities spend more time playing by themselves and tend to watch other kids who are playing rather than try and participate. This can be a difficult thing for a parent to watch, but there are creative ways to get them involved. One way, is a computer program called "Movement-to-Music". The program uses a camera, so the person can see an image of himself on the computer screen. When he moves, music is played. He can decide what music he wants to hear by moving different parts of his body (even just facial expressions can make music). In a study where kids used this program, parents reported that they became more sociable and more interested in music.

Stress and Health

Most of us have probably found that listening to our favorite music after a long, hard day has had a relaxing effect. This simple experience has also been shown to help children cope with pain, anxiety and fears while in the hospital. For example, listening to a favorite song can calm a child both before and after surgery. Another study showed that adults who listened to music before and after day surgery had lower stress. Stress has also been shown to be related to decreased immunity, or more of a tendency to get sick. This is particularly a problem for people who already have health problems, such as urinary tract infections or shunt problems in people with spina bifida. So, if there is a way to encourage relaxation in a stressful situation (like getting a shunt revision!), it may be a good idea to try it.

Music is an inexpensive, widely available source of therapy. It's easy to add it to our daily routines, and may help us live longer, healthier and happier lives.

References:

Avers L. Music therapy in pediatrics. Clin Pediatr (Phila). 2007 Sep;46(7):575-9.

Tam C. Movement-to-music computer technology: a developmental play experience for children with severe physical disabilities. Occup Ther Int. 2007;14(2):99-112.

Pacchetti C. Active music therapy in Parkinson's disease: an integrative method for motor and emotional rehabilitation. Psychosom Med. 2000 May-Jun;62(3):386-93.

More News from the 2007 SBA National Conference

by Jen Fitz-Roy

Although my family was active in our local SBA chapter while I was growing up in New Jersey, I didn't attend my first national conference until 1999, at the age of fourteen. My father and I drove out to Hershey, Pennsylvania, and I attended the Kids!Camp Teen Program. It was a life-changing week; I had fun, learned about self-advocacy and independence, and got to know countless other people living with spina bifida. After my first conference, my parents and I made it a priority to attend the SBA conference each June. With the exception of 2004, when I couldn't turn down a full scholarship to spend the summer studying in Norway, I've been to conference every year since.

After graduating high school and leaving the Kids!Camp Teen Program in 2002, the Kids!Camp director asked me if I'd be willing to give a presentation to the teens on my college transition. I hesitated at first, not sure that I'd have anything to offer, but in 2003 in San Antonio, I found myself with a group of thirteen to nineteen year olds with spina bifida. I spoke about what it was like applying to college, making friends, and succeeding academically during my freshman year, and to my surprise, the teens were bursting with questions. How do you find a university that's wheelchair accessible? What scholarship opportunities are out there for people with disabilities? What was it like moving four hours away from home to go to college? We talked about everything from parties to dating to bowel programs while living in a dorm. In 2005 in Minneapolis and 2006 in Atlanta, we expanded our topics to discuss driving, extracurricular activities, independence, and healthcare, and I developed year-round relationships with the teens, exchanging many emails and phone calls.

As early preparations for the 2007 conference in Louisville began, I received a phone call from the Kids!Camp director, and he asked me if I would be willing to work with the Youth Program this year. They wanted to add to the program's educational component by incorporating "What is Spina Bifida?" sessions for the seven to twelve year olds. Although spina bifida affected all of their lives, they found that many of the children couldn't explain what spina bifida was. I loved the idea, and immediately agreed to work as conference faculty in Louisville.

My talk and discussion was a "station" that each of the twelve groups rotated to. Each group contained both children with spina bifida and children who had a sibling with spina bifida, but all were very eager to learn about spina bifida. We talked about the moment we had realized that we were "different" and the types of questions we were asked by other people like, "Why are you in a wheelchair?" or "Why do you walk funny?"

Spina bifida is a complicated disability and explaining it to other people is a major challenge for most adults, let alone a seven year old. By breaking things down into simple language, drawing, showing pictures, and using teddy bears, we talked about how the spinal cord sends messages from our brain to the rest of our body, and how the spinal cord might work differently in someone who has spina bifida. Because those messages sometimes didn't get through all the way, many people with spina bifida use the bathroom differently and walk differently.

We discussed what a shunt was, learned how to pronounce "hydrocephalus", and talked about the reasons behind all of that "boring" medical stuff, like orthopaedic procedures, skin breakdown, braces, and physical therapy. The kids were chattering nonstop about their different surgeries and all of their experiences at spina bifida clinic, at therapy, and at the hospital. Having the space to talk about those things and having the support of other kids was really helpful and fun. However, we made a priority to stress how everyone, with or without spina bifida, is different and that no two people with spina bifida are alike.

At the very end of our session, I posed what I thought would be a challenge –to name all of the good things about having spina bifida or having a sibling with spina

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Youth and Adults Group Update

Brighten Up Your Winter Days: Head for the Slopes - You CAN Do It!

by Jen Kuhar

Adaptive skiing – we have all seen it on TV, read about it, or know someone who participates. Some of us have even tried it. But for many of us, when encouraged to participate, fear sets in and the answer is "No way!", or "Are you kidding me – I can't do THAT!". **Tim Race, an AbilityPLUS volunteer from Waterville Valley**, joined us on September 15th at Cary Memorial Library in Lexington and calmed our fears and changed our attitudes when it comes to adaptive winter sports. He gave an overview of the Adaptive Skiing and Snowboarding Programs offered by AbilityPLUS, a non-profit organization that offers a wide variety of adaptive sports ranging from snow skiing to waterskiing. Headquartered in Waterville Valley, AbilityPLUS has several Affiliates all over New England, with two Affiliates located at Mt. Wachusett and Nashoba Valley. Thanks to the kind donations of many corporations and individuals, along with more than 250 dedicated volunteers like Tim Race, AbilityPLUS gives individuals of all ages and abilities the opportunity to participate in various sports and recreational activities. Volunteers come from all walks of life, ranging for the medical community to folks like Tim, someone who loves to ski and just wants to help put a smile on someone's face as they zoom down that mountain. Equipment used can range from duct tape to the latest in adaptive ski equipment (which Tim tells us they often adapt!). The equipment available is truly amazing, as well as the dedication of the staff and volunteers. Tim is full of energy and it was obvious to us all that he is very passionate about helping his ski students hit the slopes. We left the day actually wishing for winter so we could hit the slopes. For more information, log onto www.abilityplus.org, or contact Kathy Chandler, Director, at (603) 236-8311, ext. 3175. Be sure to tell her Tim Race sent you! You want to ski? As Tim emphasized, folks at AbilityPLUS CAN help you make it happen!

Note: Before participating in any physical activity, always consult a medical professional.

A day enjoyed on the slopes!
Back row (l to r): Trainers Phil Mitchel and Peter Fellman
Front row (l to r): Jackie McMullen (Aimee's sister), Aimee Shanks and Brandon Shanks

Donation Item!

Six cases of Dignity incontinence pads for women (sealed and unopened). The family that has them to donate lives in Barton, VT. A meeting place can be arranged. Please contact edugan@sbaMass.org or call the sbaMass office at (888) 479-1900 if you are interested.

Thanks! Thanks!

Thank you
Outdoor Explorations
for your kind donation to the
YAG Let's Talk and Lunch
and Learn Days!

Mark Your Calendars for the 2007 sbaMass Holiday Party!

Sunday, December 2, 2007 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 19, 2007****

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!

Bits & Pieces

By Hyacinth Bellerose

- **Christopher and Dana Reeve Paralysis Center** provides great tools for people with various types of paralysis, including spina bifida. From wheelchair seating issues to bowel care, check out the Resource Guide (Free copy, available in England and Spanish, at **www.paralysis.org** or by calling (800) 539-7309. Information Specialists are available every day from 9-5 EST. They can respond in English or Spanish on a variety of issues.

- Based at the University of New Hampshire's Durham campus, **Northeast Passage** runs six core programs for people with disabilities, their families and friends. For adaptive cycling, hiking events, skiing and more, check out Northeast Passage. The office is located in New Hampshire (Durham, NH, Tel: (603)862-0070, northeast.passage@unh.edu) but events are throughout MA and NH. Get out there! Check out **www.nepassage.org**.

- **The Allen Institute** (**www.thealleninstitute.org**; Tel: (866) 666-6919 offers a specialized collegiate experience for students with special needs while helping them build independence and develop skills for the work force, social relationships and daily living. This program assists in transition to independent academic or work environments within a college experience.

- Taking time to check out this website may save you time and aggravation this winter. **www.adaptationsbyadrian.com** supplies standard and custom adaptive clothing featuring back-openings with hook and loop closures, side zippers and wide band elastic waists for easy dressing, fashion and comfort. The clothing is customized for wheelchairs and other motor skills issues. How about boots easy to slip on while in a wheelchair? The thought put into the items is clearly from the perspective of a parent of a child with physical disabilities!

- **A Craigslist for Assistive Technology** – from bath chairs to beds and strollers to power chairs, this website is a great resource for used equipment for sale in New England. Check out **www.getatstuff.com**!

- A Springfield-based agency, **Child & Family Service**, has been strengthening families since 1877. They counsel, educate and support adults and children to help them develop their strengths and successfully face life's challenges. Part of their program involves a disability center. Interested in wheelchair soccer? Check out Wild Wheels!!! For more information on available programs, contact Nancy J. Bazanchuk, Program Director of Child & Family's Disability Resource Program, 367 Pine St., Springfield, MA 01105, Tel: (413) 788-9695; Email: nbazanchuk@cfs.org.

- For ALL GIRLS AGES 10-16: **The Office on Women's Health in the Department of Health and Human Services** developed **www.girlshealth.gov** to promote healthy positive behaviors in girls between the ages of 10 and 16. The site gives girls reliable useful information on the health issues girls will face as they become young women, and tips on handling relationships with family and friends, at school and at home.

Thanks to
The Children's Hospital-Boston Orthopaedic Surgery Foundation for their
ongoing support of sbaMass!
We appreciate it!

Powerlifter’s athleticism shines through despite paralysis

by Steven Ryan

Needham - Don’t let the wheelchair fool you; Oakland Avenue’s Anderson Wise is one powerful guy.

For those keeping count, Wise, 24, who is paralyzed from the waist down, can bench press 374 pounds, without the use of his legs for added power and stability — a demonstration of his natural athletic ability.

“From the very time I saw him, I knew there was something special about Andy,” said Dale Wise, Anderson Wise’s father.

Anderson Wise was 4 years old when he was officially adopted by his parents, Dale and Sally Wise, who actually took him home from the hospital when he was an infant. And although he was born with spina bifida, a birth defect that causes the spine to fuse incorrectly, Anderson Wise never let it stop him from excelling in sports, becoming an excellent skier and having played sports such as wheelchair basketball and sled hockey since he was 6 years old.

“I have closed my eyes and wondered if he didn’t have these challenges, where he would’ve been [athletically],” said Sally Wise. “I look at the size of him and look at all the different surgeries and think, ‘Oh my goodness! Who would’ve thought?’”

But powerlifting is now Anderson Wise’s main focus.

“Powerlifting is an in-depth sport,” Anderson Wise said. “You have to be careful about which activities you’ve got going.”

Anderson Wise first became serious about weightlifting during his first year in college.

“I was in the fitness center, messing around,” Anderson Wise said. “One day, I got on the bench press and thought it was fun.”

He is now a member of the U.S. Paralympic powerlifting team and will be traveling to Rio de Janeiro, Brazil, in August to compete in the ParaPan-Am Games. He broke the junior disabled powerlifting record in 2003 and won adult national championships in 2004 and 2006. He recently finished sixth in the 145-pound weight class out of about 30 competitors at the World Powerlifting Championships in South Korea.

“I still consider myself a rookie until I compete in the Paralympic Games, which is a whole new level of competition,” Anderson Wise said.

Anderson Wise has his sights set on the 2008 Paralympics in Beijing, China, and hopes to improve his chances for making the team by trying to finish fifth at the ParaPan-Am Games. He trains at the Gold’s Gym on A Street and is coached by Jim Kempf, a former Paralympic powerlifter living in Rhode Island. Kempf learned about Anderson Wise through the young man’s father.

“His dad told me how much he was lifting, and I was impressed,” Kempf said about first hearing of Anderson Wise’s abilities.

Kempf said Anderson Wise trains three days a week for two hours a session. An able-bodied person would have to lift both legs onto the bench to simulate how Anderson Wise’s disability affects how he bench presses, Kempf said. His protégé’s goal is to break the 400-pound mark.

“All his balance and strength comes from the waist up,” Kempf said. “Andy’s an exceptional athlete. He loves the sport, loves the challenge.”

Dale Wise said his son is also very focused on his education. A Needham High School graduate, Anderson Wise graduated from Massachusetts Bay Community College in December and now attends Bridgewater State College, where he’s studying to become a strength and conditioning coach.

“His goal was to get a college education,” Dale Wise said. “He turned down opportunities to join the 2000 Paralympic track team while in high school and the 2002 Paralympic ski team in college. He would’ve had to take time from school to train.”

Anderson Wise’s father is also heavily involved with sports for the disabled. Dale Wise is the president of the New England Wheelchair Athletic Association, runs the Northeast Sled Hockey League and helps out with the New England Bruins sled hockey team, which is run by former Boston Bruin Rick Middleton.

He also used to play sled hockey. A veteran Dover Police officer, Dale Wise lost his left leg in 1993 from a bone infection caused by cancer. He said his son's ability to excel despite the paralysis lifted his spirits when he had to have the leg amputated.

“Andy was a big inspiration,” Dale Wise said. “Just thinking about what Andy goes through everyday helped me get through my amputation and move on with my life.”

Steven Ryan can be reached at sryan@cnc.com.

Reprinted with permission from the Needham Times

Oakland Avenue resident Anderson Wise, a member of the U.S. Paralympic powerlifting team, trains at Gold's Gym on A Street. Wise, who has been paralyzed from the waist down since birth, will travel to Brazil this summer for the competition.

Photo by Mark Thomson

More News from the 2007 SBA National Conference

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bifida. For these kids, it was a piece of cake, and they were effortlessly shouting out all of the positives of having spina bifida and naming all of the experiences they'd had where it was a good thing to be in a wheelchair or have a disability. Nearly all of my groups came up with giant lists, most of which my imagination-deprived adult brain had never even thought of! Their positive energy and creativity taught me more than I ever could have taught them. The sessions got great reviews from the parents and staff, and I'm already looking forward to seeing the kids in Arizona.

Proceedings of the 2007 conference are now available for purchase at:

http://www.actsonline.biz/sb0107_75_ctg.htm

See you in Arizona!

Board Meeting Notes & Updates

By Ellen Dugan

Below is a summary of the SBA of Massachusetts activities in the last few months. Board Meetings are now held once a quarter. All members are welcome to attend. If you are interested in attending a meeting or have any issues or concerns to be brought up at a meeting, please contact edugan@sbaMass.org.

- The sbaMass Board held a Strategic Plan Review Day on September 16th. The Board reviewed the current Strategic Plan and priorities, including, programs and services, fundraising and development, and development of an adult clinic. The updated Strategic Plan will be posted on the sbaMass website shortly. If you wish to receive a copy via mail, contact Ellen Dugan at edugan@sbaMass.org.
- The sbaMass Annual Meeting was held on October 1st. A new slate of officers was elected. Congratulations to Brendan Sullivan, President; Jen Kuhar, Vice President; Matt Neal, Treasurer; and Joyce Hillis, Secretary.
- The sbaMass Board has voted to change to a quarterly meeting schedule. Meetings will be held on the first Tuesday of January, April, July and October at 7:00 PM at Panera Bread, Burlington, MA. Log on to www.sbaMass.org to confirm meeting dates, time and location or call (888) 479-1900.
- As sbaMass moves forward in meeting the needs of its constituents, several new volunteer and committee opportunities will be developing. Log on to www.sbaMass.org to discover what opportunities are available or call (888) 479-1900.

Thanks to the following companies for their Matching Gifts

Arbella Charitable Foundation
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$500 for 2007

$$$$$$$$

MEMBERSHIP INFO: Update Annually for a FREE GIFT

For the official Posting or Application for BENEFITS or MEMBERSHIP

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Also try World Arnold Chiari Malformation Association at
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.

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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