MSBA NEWS

A PUBLICATION OF THE
MASSACHUSETTS SPINA BIFIDA ASSOCIATION

MEMBER, SPINA BIFIDA ASSOCIATION OF AMERICA

- SPRING 2004 -

LETTER FROM THE PRESIDENT

BY BRIAN PACKARD

Spring has sprung... perhaps a bit early for the 24 hearty runners of Team MSBA, who endured high-eighty-degree temperatures April 19th, on their journey from Hopkinton to Boston. But with the 2004 Boston Marathon® behind us, we welcome the warmth as we get ready for another wonderful season of MSBA activities and the National Conference in Washington D.C.

This year's Boston Marathon fundraising effort was our biggest and best ever. Despite the second-hottest temperature in the history of the race, nearly all of the Team MSBA runners completed the 26.2 miles, cheered on by loyal MSBA members along the way. The official MSBA cheering section in West Natick provided a huge boost to our runners, who stood out from the pack in their blazing orange running singlets. Weekend events, including a fundraising party at Boston Beer Works, a runners' dinner at Legal Seafoods and a post-race party at the Westin, Copley Place, drew over 300 attendees. As of this printing, we have raised nearly $90,000, and with donations still coming in, we may well reach our lofty goal of $100,000.

On marathon weekend we were pleased to announce this year's winner

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NEW LOGO!

BY DOMINIQUE SAVINELLI

The Massachusetts Spina Bifida Association was founded in 1971, and since that time, has used the logo created for the Spina Bifida Association of America whenever it needed a graphic for printed materials like newsletters or posters. Over the past few years, the Board of Directors has periodically discussed the idea of creating a new logo, designed specifically for the MSBA. About 8 or 10 months ago, I was present when the discussion turned to this topic, and I

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INSIDE THIS ISSUE

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THE DATE FOR... THE MSBA PICNIC!!
JULY 17, 2004 LOCATION & DETAILS TBA

YOU WILL RECEIVE A FLYER IN THE MAIL ONCE DETAILS HAVE BEEN CONFIRMED.

PRESIDENT'S LETTER

CONTINUED FROM PAGE 1

of the Jean Driscoll Scholarship – Jen Fitz-Roy. Jen was presented with a check for $1,000 during the runner's dinner on April 17th in recognition of her dedication and perseverance. You can learn more about Jen's amazing accomplishments on pages 6 and 7.

We have much to look forward to in the next few months. The Spina Bifida Association of America's Annual Conference will be taking place in our nation's capitol from June 20 – 23rd with the theme: "Take Action: Advocate, Educate and Advance." So far, we know of at least 18 MSBA members who will be attending – a great showing! For those still considering attending, it's not too late to register! And don't forget the additional $500 support you can receive this year, over and above the normal $500 Benefits Program funding available each year to MSBA members. For details, see page 12 in this newsletter or contact our Treasurer, Brendan Sullivan.

Also, mark you calendars for this year's annual Summer Picnic, set to take place on July 17th at a location to be determined.

Organizationally, we continue to make significant progress at creating a more efficient chapter to serve your needs. We will finalize our committee structure this summer at our strategy session, but it is already clear that we are in need of volunteers to help support our initiatives. We now have the financial capability to expand and enhance our programs... we just need dedicated people to help staff our efforts. Do not hesitate to contact any of us if you'd like to get involved.

Lastly, please note that, beginning in June, we will be starting a Parents Chat Group. See page 14 for more details and please plan on attending. This informal network will function much like our MSBAYA group and we hope it will be as successful.

Best to each of you for a healthy and happy Spring.

TEAM MSBA 2004

BELOW IS A LIST OF THE 24 FANTASTIC INDIVIDUALS WHO RAN ON BEHALF OF THE MSBA IN THE 108TH BOSTON MARATHON® ON APRIL 19, 2004. TO DATE, THEY HAVE RAISED ALMOST $90,000!

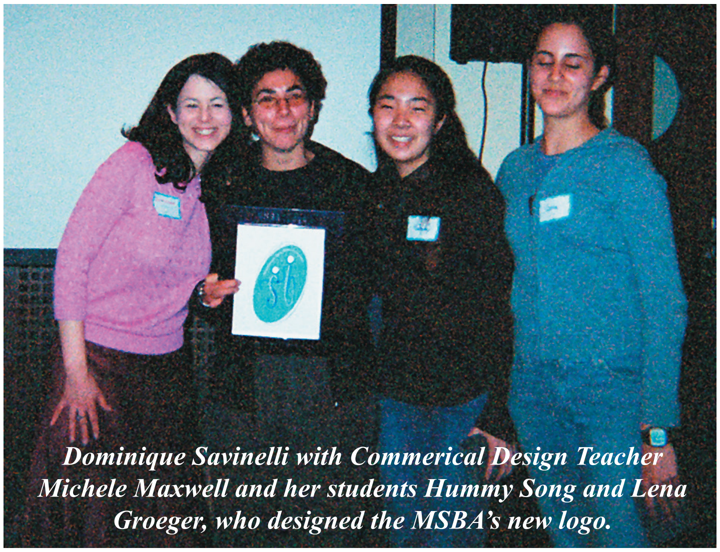
- Chris Alexander of Malden, MA
- Melissa J. Conroy of Brighton, MA
- Paul Goughan of Dedham, MA
- Melissa A. Hackel of Brookline, MA
- Jeffrey M. Hitchcock of Somerville, MA
- David J. Hoffman of Houston, TX
- Joel K. Kamm of Brighton, MA
- John B. Kane of Roslindale, MA
- Marita C. Keane of Chicago, IL
- Cliff Kemp of Lake Mary, FL
- Karen Liu of Brookline, MA
- Alisa M. Mantoni of Brooklyn, NY
- John P. McNeill of San Diego, CA
- Bob Moquin of Simpsonville, SC
- Tarah L. Nisbet of Melrose, MA
- Brian K. Packard of North Andover, MA
- Katherine M. Pinzino of Marlboro, MA
- Brian Rhodes of Jamaica Plain, MA
- Brendan J. Sullivan of Charlestown, MA
- Michael B. Sullivan of Charlestown, MA
- Ruth A. Tarbox of North Andover, MA
- Deborah L. Trapp of Westboro, MA
- Janelle M. Tribble of Newton, MA
- Belinda Zola of Santa Barbara, CA

NEW LOGO
CONTINUED FROM PAGE 1

immediately thought of my friend Max.

I first met Michele "Max" Maxwell over two years ago. She was a new teacher at the Cambridge Rindge & Latin High School, in their Commercial Design program. She had come with the practical expertise of managing her own design business and was eager to impart the excitement of creative design to a new group of interested students.

Today, I see what she has accomplished. Entering her classroom, visitors immediately sense a dynamic, inspiring environment. Student work is hung around the room, splashing reds, greens, yellows and blues in attractive forms. Inspirational words – "Sensitivity", "Tenacity", "Courage", "Flexibility", "Originality" – ornament the walls. When the idea of designing a new logo for the MSBA was discussed, I immediately thought of Max and her work.


Dominique Savinelli with Commerical Design Teacher Michele Maxwell and her students Hummy Song and Lena Groeger, who designed the MSBA's new logo.

When I approached Max with the idea of outsourcing the new logo design for the MSBA as a class project, she loved it. Her kids would receive "real world" experience working with a "client". It was exciting for them to think that one of their classroom projects might leave a lasting impression. For the MSBA, it was a great way to connect to and educate a classroom of high school seniors about spina bifida. The project also allowed us to harness volunteer talent within our own community.

Robyn Hand, Jen Kuhar and Michele Scaramozza with the new MSBA Banner at our official Marathon Cheering Section in West Natick.

Hummy Song and Lena Groeger are seniors at the high school. They are also two of Max's star students. She assigned them the task of designing a logo for the MSBA. Neither Max, nor Hummy nor Lena knew much about spina bifida, so I launched the effort with information from our MSBA website and from the SBAA's. I urged the girls to research spina bifida and try to imagine the network of affected individuals, family, and friends affected by it. As the "client", I asked that the logo have color, be dynamic, and convey a sense of community. I wanted something subtle yet bold, sensitive yet provocative. How they would put my words into a picture - that was beyond my imagination.

I waited. Max kept me updated on the creative process, as she guided her students through the preliminary stages of their work.

When they were ready, I was shown the first draft designs that sprung from a couple of different ideas. One design immediately drew my attention. Two curvy stick figures appeared to be holding hands. They were fluid & seemed to be moving - together. To me, this simple picture expressed much about the MSBA. The two figures emphasize that the MSBA is a network of people. I liked that they were physically connected and that mobility was suggested, but in a subtle way. The simplicity of it was very attractive. Also, the curvy bodies spelled out "sb", a clever way to incorporate our name.

The MSBA Board also liked the work the students had done very much. We tweaked a few colors, tried a few different border choices, then enthusiastically approved the final version of the logo. Hummy and Lena finished the final design in time for our Spring Party, where we were able to unveil the new MSBA logo - to the delight of all the families present. By Marathon Monday, the new design was printed on tee-shirts and buttons. Friends, family and MSBA members all along the race route wore them proudly, revealing our "new look" to the public.

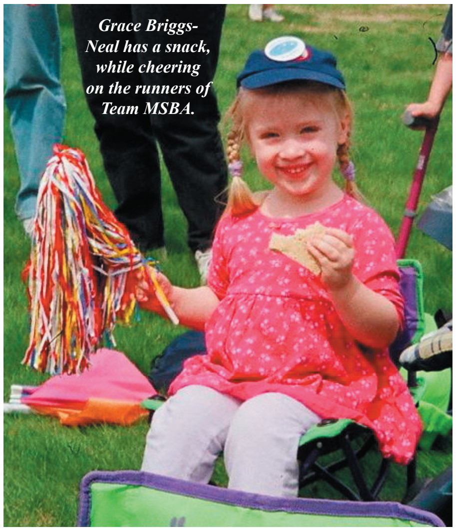
Few high school students are afforded the opportunity to make such a lasting impression on their community. Through their originality and generosity, Hummy and Lena did just that. The MSBA will be using their design long after they graduate and move on to college (Hummy to Harvard and Lena to Brown). Their talent has been a great gift to the MSBA, and a tribute to their teacher.

Max, meanwhile, will be welcoming a new group of students next year. For her, students like Hummy and Lena are the best part of her job.

MSBA BOARD MEETING NOTES

BY JEN KUHAR

Below is a summary of what the MSBA Board has discussed over the past few months. Board meetings are held on the first Monday of each month (exceptions noted in the newsletter Calendar of Events) from 7:00 to 9:30PM. 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 any one of us.


Grace Briggs-Neal has a snack, while cheering on the runners of Team MSBA.

- As you can see with this newsletter, the new logo is here! Five variations of the logo were submitted to the Board for voting. We are very pleased with the final project. Special thanks to the commercial design students at the Cambridge Rindge and Latin School for all their hard work. The Board voted to unveil the new logo at a ceremony during our Spring Party, held April 4, 2004 at Boston College. We hope you like the new logo as much as we do!
- The Board is working on devising an advertising policy for the newsletter.
- It was decided that the pre-marathon dinner for runners, their families, Board members and the Jean Driscoll Scholarship recipient would be held at Legal Seafoods in Kendall Square on April 17, 2004, two days before the race itself.
- The Board voted to present Team MSBA members with marathon jackets in appreciation of their unbelievable efforts on our behalf.
- The Board voted to allow Team MSBA member Janelle Tribble to earmark some of the money she raised through the Marathon for a special purpose. After over an hour of deliberation, we agreed that seventy-five percent of the funds Janelle raised - above the $2,500 minimum required of all Team MSBA members – could go towards the renovation of the Mason Rice School playground in Newton, to make it accessible to children with disabilities. MSBA member Marianne Mahoney is a student at this school. The MSBA will keep you all posted on the progress of this project.
- The MSBA recently completed its yearly accreditation procedures. This involves compiling a comprehensive list of MSBA members for the Spina Bifida Association of America. The process ensures that we have appropriate representation of Delegates at the SBAA Annual Meeting and that every MSBA member or member family receives the SBAA's Quarterly newsletter *Insights,* free of charge.
- The MSBA recently received several large donations, prompting the Board to discuss the need for a consistent policy on how to handle such donations. We will work on developing a policy and report back to you in the near future.
- Due to Marathon activities, the Board decided to put our committee structuring project temporarily on hold. We have scheduled a strategic planning meeting for later this summer, which will be completely devoted to this project. We will keep you posted as to the outcome of that meeting.
- Since this was the last year the MSBA was able to participate in the Boston Marathon as an official charity - for at least a couple years - the MSBA is looking into the possibility of creating a travelling team of runners, who could participate in road races throughout the state, the country, or even beyond.


At the Spring Party Egg Hunt, Sophia Bellerose, Britney Poindexter, Katie Packard, Andrew Briggs-Neal and Daniel Packard dig through bags of goodies.

- Hyacinth Bellerose and Cara Packard will be hosting the very first, official Parents Chat Group in the near future. Please see page 14 for details.
- We are very pleased that several MSBA members have taken advantage of the special funding available for attending this year's SBAA conference in Washington, D.C. Don't forget, it's not too late to register!!!
- The Board is looking into a central location for the MSBA's Summer Picnic, being held on July 17th, 2004. Please let us know if you have any suggestions.
- We are also looking for a new location for our monthly Board meetings. Please let us know if you have suggestions for this as well.

THE 2004 JEAN DRISCOLL SCHOLARSHIP

BY CORI COUTURE

In 2002, when the MSBA was applying to become an official charity of the Boston Marathon, one of our greatest promoters and sources of support was Jean Driscoll. An adult with spina bifida, Jean holds the record for winning the Boston Marathon more times than any other individual. She reached the finish line ahead of her competitors a total of eight times, in the wheelchair division of the race. During the lead up to Team MSBA's first year in the Marathon, Jean came to Boston to tell the story of her efforts. A wonderful motivational speaker and a genuinely kind person, she made everyone in the room feel like they could do anything. In thanks for the help and encouragement she offered both to our Marathon Team and to the members of the MSBA, the Board established an annual scholarship in her name. The Certificate given to the person who wins the award each year reads

> "In appreciation for her support, inspiration and dedication to the spina bifida community in Massachusetts, the Board of Directors and members of the Massachusetts Spina Bifida Association created the Jean Driscoll Scholarship. Presented annually, this $1000 award is to be used by the recipient for educational, athletic, developmental or assistive programs." Through this award, we honor "the individual with spina bifida in Massachusetts who best demonstrates the character and determination of the scholarship's namesake."

THIS YEAR'S RECIPIENT: JEN FITZ-ROY

Jen Fitz-Roy is a sophomore in the Lynch School of Education at Boston College. A Human Development and Philosophy double major, she participates in the Honors Program and is on the Dean's List. Jen grew up in Glen Ridge, N.J., was born with spina bifida (lipomyelomeningocele L1-2) and uses a wheelchair as her primary means of mobility.

As soon as she knew she was going to be a student at Boston College, Jen contacted the MSBA. She began attending our Youth and Adults Group gatherings during her senior year of high school, and has become a highly valued member of our community. As you will see from the items below, excerpted from her Jean Driscoll Scholarship Application, Jen is involved with an impressive array of activities, both school-related and beyond.

- **National Youth Leadership Network**: *a federally sponsored organization for young adults with disabilities*
  - o One of 50 students nationwide selected to attend the NYLN's 2002 *annual conference*.
  - o Now a Member of the *Governing Board*, which coordinates year-round activities, including the annual leadership conference held in Washington, D.C.
  - o Coordinated a youth-directed research project, worked on the development of the 2003 *Policy Agenda*, instrumental in organizing the 2003 Advanced Youth Leadership Institute.
  - o As *Public Information Chair*: maintains website content, publishes the quarterly NYLN newsletter, and coordinates the development and distribution of all network materials for the organization.
  - o Currently overseeing the *selection process* for the 2004 conference, on leadership training and disability rights education.
- **Guest on the *Oprah Winfrey Show***, in November, 2000, discussing experiences of growing up with spina bifida and how a positive attitude helped her to overcome physical limitations and cope with multiple surgeries and hospitalizations.
- **Spina Bifida Association of America**
  - o *Annual Conferences* (New Orleans 2001, Orlando 2002, and San Antonio 2003): presented on topics including self-advocacy, independence, and leadership development.
  - o ***Insights into Spina Bifida*** newsletter: has written a number of articles directed towards teens and young adults with s.b.
- **Summer exchange program to the United Kingdom**, for college students with disabilities: one of twelve US delegates. Traveled around the UK to learn about disability culture and to share experiences of living with a disability in the United States.
- **Office of Special Education Programs**: Gave a presentation in December 2003.
- **International Children's Congress in Norway, June 2004**: will be delivering a presentation on secondary transitions.
- **Spina Bifida Association of the Tri-State Region:** Gave conference presentations on several occasions.

In High School, Jen was Editor-in-chief of her school newspaper, a member of the National Honor Society and of the National French Honor Society, Secretary of the French Club and Vice-president of her school Chorus. As a sophomore, junior and senior, she was a participant in Regional Choir. In her junior year, she made it all the way to the New Jersey All-State Chorus. Jen was a member of the Chancel and Handbell Choirs at her church and Section Leader in the New Jersey Children's Choir (through which she performed in Carnegie Hall twice and at the New Jersey Center for the Performing Arts eight times).

At Boston College, she is an alto in the University Chorale and a member of the Jenks Leadership Program. She completed BC's selective Emerging Leaders Program during her freshman year. She volunteers at the Boston College Campus School for children with severe multiple disabilities and works part-time as a research assistant for the Early Intervention Collaborative Study. This school year, she co-founded the Boston College Disability Council with a visually impaired friend, and that organization has coordinated a number of disability awareness programming initiatives on campus. The council has also worked with Disability Services towards improving campus accessibility for the visually impaired and for those with mobility disabilities.

2004 Jean Driscoll Scholarship Recipient Jen Fitz-Roy with MSBA President Brian Packard

Here's how Jen sees herself now:

I learned to drive with hand controls at the age of seventeen, have traveled alone by plane well over a dozen times, and despite others' predictions, have lived successfully in a college dorm five hours away from home for almost two years. I maintain my own medical records, coordinate my own medical care, and manage all aspects of my self-care. My independence is something that I value very highly, as it enables me to be a "typical" college student, living with friends, going to parties, and being active. As I have grown older, both my independence and self-advocacy skills have increased dramatically; I am never slow to speak up for myself. I can be willful and stubborn at times, but I am determined to participate in all aspects of society.

Jen Fitz-Roy (right) and her Mom chat with MSBA President Brian Packard after dinner at Legal Seafoods in Cambridge

Next year, I plan on entering an accelerated program in the Boston College Graduate School of Social Work, where I will work towards obtaining my masters degree in clinical social work, while simultaneously finishing my B.A. I will also serve as a Resident Assistant at the St. Ignatius Gate Residence Hall and take the position of Director of Disabled Student Services in the undergraduate government. I am and always have been a very busy individual, but with this long list of achievements and recognitions also comes a list of rejections and times when I was discouraged. I believe myself to be an extremely dedicated and persevering individual who always tries to remain optimistic. Those who know me for even a short while will be quick to remark that I always have a smile on my face, and I often remark that life is simply too short to worry about that over which we have no control. If I spend my life grieving over the fact that I cannot walk normally, I will never be able to realize my abilities or appreciate the positive things in life. My faith and my spirit have sustained me through a great deal of adversity in my life, including my disability, my mother's serious illness and my father's death.

My disability-related extracurricular pursuits are motivated by a genuine passion to create access and equality for people with disabilities, and I hope to work either in disability policy or in a disability-related social work position. Although I had a very difficult time accepting my disability as a preadolescent, I couldn't imagine myself not having spina bifida. It hasn't been an easy road to get to where I am today, but the journey has been well worth the knowledge, insight, and strength I've gained along the way. Spina bifida does not define me, but it has influenced me in many positive ways, and I cannot deny the ways in which it has shaped my character, my views, and my passions. I would be an entirely different person had I not been born with spina bifida, and I have grown to love the woman I have become.

WHO'S OUT THERE?

(MSBA MEMBER SPOTLIGHT)

THIS MONTH'S FEATURED MEMBER: ALLEN JOHNSON

BY GINNY BRIGGS

Our little community is full of success stories. Our members have overcome both physical and emotional hurdles to succeed in a world designed for people without these difficulties. If anybody could serve as inspiration for any of us, able-bodied or not, it is 59 year old Allen Johnson. I had the pleasure of meeting Allen at his home in Worcester, where he also runs a small, private psychotherapy practice. Having spent much of his life as a social worker with the Salvation Army, as well as a brief period with the Massachusetts Department of Public Health, he opened his own practice in 1977, and has been helping patients there ever since. Dr. Johnson seems quite content in his environment. His office is attached to his home in a quiet residential neighborhood. Patients park in front of his home and can enter using a private entrance to a waiting area. I visited him on a cold, February day and found his office to be warm and inviting. Settling back in his comfortable recliner and surrounded by books, he began telling me about his childhood.

Allen was born with spina bifida in Bridgeport, Connecticut in 1944, to two dedicated social workers for the Salvation Army. He was born with a "waistline" defect, hydrocephalus, clubfeet and crossed eyes. Having been told their son would probably die of hydrocephalus, his parents decided they should be closer to better medical care and moved to Brooklyn, New York. Though there was no surgery available at the time for the treatment of his clubfeet, the hydrocephalus "corrected" itself at 4 months old, to everyone's surprise. Allen moved on to public schools, lots of friends, academically accelerated programs and was president of the Honor Society in both high school and college. At age 16 he was fitted for orthopedic shoes to help him walk. After moving several times for his parents' work, he graduated from Worcester High School, Worcester Junior College and Queens College in New York, where he earned a Bachelors Degree in Sociology. After earning a Masters Degree in Social Work from New York University, he followed in his parent's footsteps and spent the next three years as a caseworker for the Salvation Army. Always moving forward, he then spent a year as Director for Big Brothers and Big Sisters in Queens, NY. After that, he was on to Smith College for three years, to earn a Ph.D. in Social Work. He opened a private psychotherapy practice following the completion of his doctorate.

During his life he has spent a significant amount of time in wheelchairs, usually due to surgery on his feet for ulcerations. He remembers using a wheelchair for a year and a half during one episode and actually crawled up two flights of stairs to attend services in a church that was not designed for people with physical limitations.

I ask Allen if he is married. "Yes" he smiles, "I married late in life - I've been married twelve years". "Where did you meet her?" I ask. Allen smiles again, " at my mother's funeral". It turns out his mother was good friends with Lori's grandmother. They had never met before, and well, things just worked out. At the time, Lori was a nurse living in Waltham. Now, she works as a Nurse Leader with the Northridge public schools. Soon after marriage, the couple decided to adopt a child. They specifically wanted a child with a disability and three years after their marriage, they found Misha, a two-year-old boy from Russia. Misha was born with *hemi-facial microsomia*, a condition where half the face does not grow normally. Now 11, he is a happy, active child and involved with a group through their church similar to the Boy Scouts. He attends Whitingsville Christian School, has been studying piano for 5 years and is the very proud owner of a Russian Tortoise.

For fun, Allen and his family are very active in their church and both he and his wife enjoy singing in the church choir. As often as they can, they take weekend trips up to Old Orchard, Maine, a seaside town situated on the coastline of southern Maine. They just bought a house there and hope to retire in Old Orchard someday.

Born at a time when very little was known about spina bifida, the future looked bleak for Allen, but his rocky start and physical limitations did not deter him from building a rich and rewarding life. Together with a supportive and loving family, life is good for this member of our community.

MEDICAL RESEARCH CORNER

BY GINNY BRIGGS

NEW DEVICE MAY REDUCE SHUNT PROBLEMS

A new device designed to minimize infections and complications with VP* shunts is now being researched. A study recently conducted in the United Kingdom reports that the device is "useful in the long-term management of patients with shunted hydrocephalus". The idea behind the device is relatively simple. In the event that there is shunt blockage or an infection, the device or "reservoir" provides separate access to the cerebral spinal fluid (CSF). This access allows faster identification of infections and measurement of pressure changes, so treatment can be administered more quickly.

The study, published in 2003, looked at the long-term effects of the device in 52 children, beginning in the early 1970's. Thirty-five patients had spina bifida with hydrocephalus and 17 were born with just hydrocephalus. The age of the participants when the device was inserted ranged from 3 days to 15 years old. The study compared the results between the "pre-reservoir" period (before the new device or reservoir was inserted) and the "post-reservoir" period (after the new device or reservoir was inserted).

The researchers found that the number of shunt revisions was significantly lower after the reservoir was inserted. Overall, there were fewer shunt mechanical failures and fewer infections. They also monitored seizures and vision, but did not find any changes associated with the device. Based on limited information available, it appeared they were not able to make an accurate assessment of intelligence and cognitive abilities.

An advantage of the device shown in this study was that it was used frequently in all but 2 patients, and an average of almost 4 occasions per patient to diagnose shunt problems. More than half of the time, the device was used to measure and control pressure. This allowed quick diagnosis and treatment. However, the device did not always work correctly. On several occasions, it failed to provide access to the fluid due to blockage, infection or overgrowth of bone. The failures occurred at different times, but the average device lasted 30 years without problems.

This study was relatively small, but it is rare to see research of long-term effects of spina bifida treatments. As with any new technology, there are always risks. More research is needed to determine if the benefits outweigh the risks of this new device. Shunt malfunctions and infections continue to be of concern to most people with spina bifida, and advances in medicine like this are encouraging.

REFERENCE: *Long term risks and benefits of a separate CSF access device with *ventriculoperitoneal shunting in childhood hydrocephalus*. Developmental Medicine and Child Neurology 2003;45: 28-33

MSBA MEMBERSHIP INFORMATION

The Massachusetts Spina Bifida Association is a nonprofit corporation founded in 1971 by a group of concerned parents of children with spina bifida. A member of the Spina Bifida Association of America, the MSBA is dedicated to enhancing the lives of people in Massachusetts affected by spina bifida by providing a community of support, advocacy and education.

- A few of the benefits members enjoy include meetings, a strong Youth and Adults Group, fundraising, a benefits program, social events, a developing Parents Helping Parents program, a Parents Chat Group, and a lending library.
- The MSBA Board is open to suggestions from members as to how we can better serve our community. Please watch this newsletter and our website at www.msbaweb.org for ongoing events and programs.
- In order to receive the MSBA's newsletter, the SBAA's quarterly newsletter *Insights*, and to receive other MSBA benefits, it is necessary to be a member of the Association.
- There is no membership fee, but tax deductible donations are appreciated. ***To become a member, simply fill out the application on the next page***, and return it to:

MSBA Membership, 733 Turnpike Street, #282, North Andover, MA 01845

- Please note that MSBA financial benefits are available only to members who (1) have spina bifida, and (2) live in Massachusetts or in a New England state that does not have its own spina bifida association.
- Please send us an update whenever there are any changes to your information.
- Members can also update their information by sending an email to mattneal@alum.mit.edu.

MSBA EMAIL REQUEST

THE MSBA IS WORKING ON GETTING INFORMATION TO YOU MORE EFFICIENTLY. IF YOU ARE INTERESTED IN BEING ON AN EMAIL LIST FOR REMINDERS ABOUT UPCOMING EVENTS, PLEASE SEND YOUR EMAIL ADDRESS TO HYACINTH BELLEROSE AT BELLEROSE33@CHARTER.NET. AN UPCOMING EXAMPLE OF THE USE OF THIS SYSTEM WOULD BE NOTIFICATION OF THE SPECIFIC TIME AND LOCATION FOR THE MSBA SUMMER PICNIC ON JULY 17TH.

WE WILL DEFINITELY BE SENDING OUT A MAILING ABOUT THAT TIME AND LOCATION, BUT, IN THE FUTURE, WE WOULD LIKE TO SAVE ON EXPENSES AND SEND INFORMATION TO OUR MEMBERS VIA EMAIL AS OFTEN AS POSSIBLE.

MSBA MEMBERSHIP APPLICATION/UPDATE FORM

Please fill out the following information as applicable to your situation:

Type of Membership:

___ Teen or Adult with spina bifida
___ Parents of Child with spina bifida (Family Membership)
___ Interested Friend or Family Member
___ Medical Professional

Name of person with spina bifida: ______________________
Date of Birth ♦ (Important. This information helps us provide appropriate support to members of different ages): ________ __
Spouse/Partner Name : ____________________

Member Name (if different from person with s.b.): ____________________________
Organization and Title (if appropriate): _______________________________________
Street Address: ____
City, State, Zip: ____
Telephone: ____________________ **Email**: _________________________________

Please contact me about becoming a volunteer ___

Optional tax deductible donation$____________

Other information you would like us to know (siblings, level of sb lesion, suggestions, etc...):
____
____
____
____

MSBA Membership
733 Turnpike Street #282
North Andover, MA 01845

** MSBA Benefits Programs **

By Hyacinth Bellerose

Are you aware of the MSBA Benefits Program? Did you know that if you are a Qualified Member of our association you may be eligible for $500 each year? Or that you may be eligible for an additional $500 toward attending the National SBAA conference in Washington, D.C. this summer? See the policy below to find out more.

What constitutes a Qualified Member? A person with spina bifida or the parent/guardian of a person with spina bifida, who resides in Massachusetts or a state bordering Massachusetts that does not have its own Spina Bifida association, and whose information is up to date in the MSBA database. Benefits are available to only one person per membership, unless there is more than one person with spina bifida covered under that membership.

Annual Benefits Program: A Qualified Member is entitled to $500 per year to be used to improve his/her life as it is affected by spina bifida. These Annual Benefit funds may be used for braces, diapers, summer camp, assistive technology, education or similar purposes. An application must be submitted to the MSBA via postal mail or by email and will be reviewed by the Board of Directors at the following month's Board meeting. Once the application has been approved, there are two ways for a Qualified Member to receive Benefit funds.

1. The Qualified Member may present a receipt showing payment of an eligible expense already incurred. Once this receipt is received, the MSBA will write a check to be paid to the Qualified Member as reimbursement. OR
2. Alternatively, a bill or invoice for the eligible expense *to be* incurred may be presented to the Board in advance. In this case, the MSBA will write a check directly to the benefit provider or vendor for the expense in question.

The MSBA reserves the right to revise this policy in accordance with the changing financial position of the MSBA.

2004 Special Provision: This year, Qualified Members are entitled to *an additional $500*, to be used expressly for expenses related to attending the SBAA Annual Convention in Washington, D.C., June 20-23, 2004.

The terms for approval and payment are the same as for the regular Annual Benefits Program.

Please note, however, that the MSBA must receive the application for the 2004 Special Benefit in advance - even if the amount is only an estimate of expenses to be finalized later.

MSBA BENEFITS FORM

Name: ______________________

Street Address: ____

City, State, Zip: ____

Telephone: ____________________ **Email**: _________________________________

Check as Applicable:

___ Request for Annual Benefit of $500
    ___ Receipt Attached
    ___ Make check payable to enclosed provider

___ Request for 2004 Special Benefit of $500 (estimate)
___ Request for 2004 Special Benefit of $500 (final)
    ___ Receipt Attached
    ___ Make check payable to enclosed provider

Please attach an explanation of the benefit you are requesting and what it will be used for.

No particular format is required.

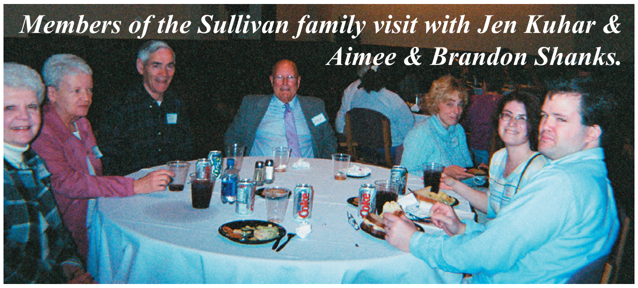
Please tear out this application form and return it to:

MSBA Membership
733 Turnpike Street #282
North Andover, MA 01845

MSBA Spring Party Recap

By Dominique Savinelli

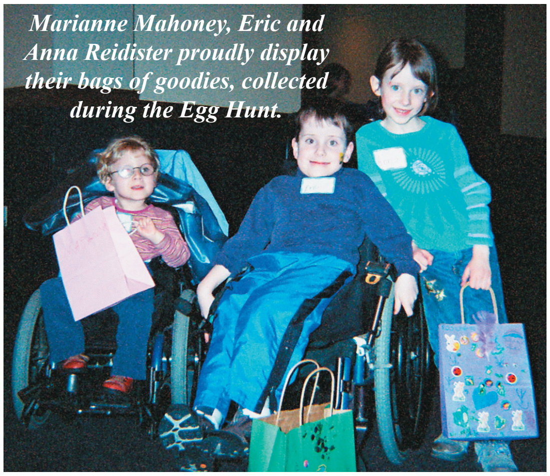
Runner Janelle Tribble and Marianne Mahoney work on an art project at the Spring Party.



Members of the Sullivan family visit with Jen Kuhar & Aimee & Brandon Shanks.

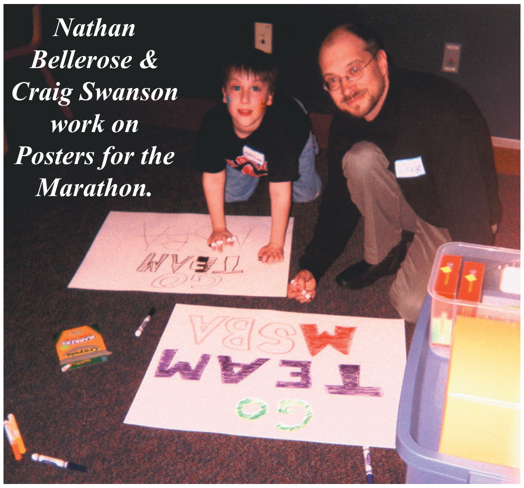
The MSBA's Spring Party, held on April 4th, was an event that brought many people together. Hosted through the generosity of Boston College and the coordination of Jen Fitz-Roy, attendance reached nearly 100 people! Jen is one of our young adults with spina bifida, and is a student at B.C. The facility B.C. provided for us was lovely - one large function room, with a smaller one on either side. In one room, B.C. staff set up a lunch buffet, in the other, B.C. student volunteers set up tables with arts and crafts activities for the kids. We can't thank them all enough for their efforts.

The success of the occasion highlighted the wide range of people included in the MSBA community. First, I could not miss the kids. They were everywhere! There were tiny babies, pre-schoolers, and older children. Some had spina bifida; others were siblings or friends. They all swarmed around the kids' craft table, where the B.C. student volunteers helped out all afternoon. When the time came, the children eagerly explored every inch of the space during our egg hunt.



Marianne Mahoney, Eric and Anna Reidister proudly display their bags of goodies, collected during the Egg Hunt.

A number of our Boston Marathon runners made it to the event as well, and were impressed by our supportive, enthusiastic party-goers. Some had already experienced the MSBA in full swing. For others, the party offered a sense of the wonderful group for which they were fundraising and running.



Nathan Bellerose & Craig Swanson work on Posters for the Marathon.

The Cambridge Rindge and Latin School students who designed our new logo, along with their teacher, came to help us celebrate as well, and to unveil their creation to our community. Loud cheers and clapping erupted when they held up an MSBA banner featuring the new logo.

Other attendees included parents, spouses, and caring friends, all of whose lives are affected by spina bifida. It was also great to see many of the older teens and independent adults from our MSBA Youth and Adults Group socializing with each other and with other members of the community.

The last attendee I must mention was the attention-getter of the day: Brant, who is the service dog for MSBAYA adult Michele Scaramozza. He was so well behaved and sweet that adults and children alike were drawn to him like a magnet. Michele was generous enough to allow folks to pat, scratch and cuddle with him all afternoon. Everyone wanted to take him, or a dog just like him, home.

As part of the MSBA Board of Directorrs, I hope that the Spring Party allowed people to make new friends, mix with new groups, and renew old ties. See you all next year!

Members of the Pinzino family and Marc Bellerose socialize over lunch.

NEW****NEW****NEW****NEW****NEW****NEW****NEW****NEW****NEW****

PARENT CHAT GROUPS

SAVE THE DATES

July 14, 2004 and
September 14, 2004 at 7:00 p.m.

LOCATION

Barnes & Noble Cafe
98 Middlesex Parkway
Burlington, MA
(across from the Burlington Mall
at the intersection of Route 128 and Route 3)

Beginning on June 13th, 2004 and then on the second Tuesday of every other month, the MSBA will be hosting a chat group for parents of children with Spina Bifda. The first two meetings will be at the times and locations indicated above. New locations and dates will be added as needed. You do not need to come to every meeting but are welcome to as many as you wish to attend.

Parents will meet to discuss topics true and dear to our hearts such as timing and techniques for cath'ing, eating issues, IEPs, attitudes, sports programs, frustration, bowel issues, socialization, etc. The discussion will flow depending on the people involved and concerns raised by parents at each meeting. Hopefully one person's experience will be a help to another.

We look forward to providing a forum for sharing information and ideas, both positive and negative. From swim diaper sources to accomplishments in sports programs, the topics for our parents are endless. We hope to have as many Moms and Dads as possible. An RSVP is not necessary, but would be appreciated, so that we will know if we need to reserve space.

See you soon!!

CHILDREN'S HOSPITAL BOSTON CHAT GROUPS

PROPOSED SCHEDULE

Third Wednesday of each month
during Myelo Clinic

As a means of reaching out and trying to be more accessible to more families, the MSBA will be hosting a chat group for parents at the Spina Bifida Clinic at Children's Hospital. We plan to begin this program on the third Wednesday in July (the 21st), and on successive third Wednesdays thereafter, in the waiting room at the Myelo Clinic. Childcare and light refreshments will be provided to allow parents the opportunity to speak freely with each other, while waiting for their appointments, or for a chat afterward. Both Children's Hospital and the MSBA hope to foster communication between parents in order to strengthen the support system we all need and can provide for each other.

If you have a question about these programs or want to confirm the date and time prior to attending, please call or email one of the parents listed below.

Cara Packard
978-683-6644 (days)
packard44@comcast.net

Hyacinth Bellerose
978-649-8724 (days)
bellerose33@charter.net

If we have a positive response to these programs, they will be extended to additional times and locations. If you would like to volunteer to assist in hosting a parent chat, please let us know. Come one and all; we look forward to sharing our experiences and hearing about yours!

PLEASE NOTE: These programs are not meant to be professional counseling. These forums just provide an opportunity for people in similar circumstances to meet and discuss issues and daily life in an informal yet established setting. All participants will be provided with a disclosure to be signed acknowledging that neither Children's Hospital nor the MSBA will be responsible for the topics discussed nor for the content of the discussions. If anyone needs professional assistance, they will be directed to their doctor.

NEW****NEW****NEW****NEW****NEW****NEW****NEW****NEW****NEW****

MSBA YOUTH AND ADULTS GROUP (MSBAYA) UPDATE

BY BRENDAN SULLIVAN

On Sunday, February 15th, the MSBA's Youth and Adults Group held its second set of "**Roundtable Discussions**" at Children's Hospital Boston. With 17-20 people in attendance, the turnout was very good. The idea for these discussions came from similar Roundtables held at the SBAA's annual conference in San Antonio last June. Topics included issues faced every day by older teens and adults with spina bifida.

At our first Roundtable Day, last October, we had a carefully planned schedule for our discussion topics. This was a fine way to approach our first attempt, as we weren't sure how attendees would respond. We found, however, that some topics garnered much more interest than others, and subsequently needed more time to work through.

At this second day of Roundtables, the MSBAYA Committee decided to run the afternoon with less structure. We came up with general topic ideas and let the afternoon's discussions flow without any time parameters. This seemed to work well.

Topics discussed included dating, friendships, independence and transportation. Dating/romance was was included during the previous roundtable day, but the time allotted for it was not sufficient. Leaving the schedule flexible for this second session allowed us more time to explore such topics in depth.

From the discussion of dating and relationships flowed a conversation about meeting new people in general. Many people talked about their struggles around how to find new people with whom to socialize. The number one inhibitor seemed to be lack of opportunities for meeting new people. So, we focused on areas where more opportunities might arise, such as hobbies, social clubs, friendships developed at work, etc…

MSBA YOUTH AND ADULTS GROUP CONTACT INFO

Cori Couture
Phone: 781-321-4920
Email: coricouture@yahoo.com
Jen Kuhar
Phone: 508-620-3963
Email: jenkuhar@msn.com

Dominique Savinelli
Email: dominiqueSavinelli@hotmail.com

Brendan Sullivan
Phone: 617-241-8561
Email: ndsully01@yahoo.com

Finally, the discussion turned to the Internet as a means of meeting individuals for both friendship and dating. Fears around this idea seemed to arise based on previous negative experiences, as well as from the public stigma many people perceive to be associated with meeting people online. There was some agreement in the end, however, that *in a safe environment*, computer communication can be both healthy and helpful to fostering new relationships.

Eventually, the discussion turned to transportation and independence. Transportation seems to be a consistent problem for many individuals in this community. (Though it must be noted that all the attendees managed to get to our February event independently. This was potentially due the location (Children's Hospital), which is a familiar and easily accessible venue.) Transportation and scheduling issues around the RIDE were discussed at length, and will, it seems, be a hot topic at future gatherings.

Overall, the second Roundtable Day was highly successful and we look forward to more in the future. For now, we are taking a break from formal gatherings. After a busy season of attending the Spring Party and several Marathon Events, the MSBAYA will be getting together this summer for an afternoon of **Board Games**.

We will meet on Saturday, **June 12th**, from **11 am to 3 pm** at **Children's Hospital**

MSBAYA Members and families at the Spring Party: Jodi & Kathy Leach, Beth Miller, Michele Scaramozza, Robyn Hand, Lindsay Meuse, Sarah Pinzino, Brian & Cheryl Smith

AN INTERVIEW WITH ORTHOTIST JOHN WALL

BY CARA PACKARD

Every six months, or so, our daughter, Katie, makes a trip to Salem, MA to see her orthotist, John Wall, PT, CPO. Katie has been fortunate to be under John Wall's care for her bracing needs for the past five years. While she always enjoys his expansive Disney music and video collection, we both find his expertise in pediatric orthotics and his kindness to be invaluable. I recently interviewed John Wall in the hope that I could share his wealth of knowledge and care on the subject of orthotics with our Spina Bifida community.

How would you describe your practice?

Approximately 80% of my patients are pediatric cases. Between 40 and 50% of the children I see are very involved, with multiple disabilities. I also attend a pediatric rehabilitation clinic at the North Shore Children's Hospital and provide clinic services for multiply involved children in a long-term care facility each week. Part of my clientele is composed of sports bracing, some prosthetics cases and scoliosis orthotics. The primary focus of my work, though, is on pediatric patients. Pediatric orthotics is the majority of what I do, and what I feel I do best.

How did your training as a physical therapist impact your job as an orthotist?

I worked for six years as a physical therapist before being trained as an orthotist. My work at institutions such as the Shriner's Burn Hospital allowed me to discover that working with children was a lot more fun than the sports medicine program I had planned to follow. My background as a physical therapist has given me knowledge and skills that other orthotists may not have. I find that instead of simply looking at the patient from the view of someone making the braces, I do a PT evaluation on each patient I see. My PT skills make me a better clinician and as a result, I am able to provide better care to my patients. There isn't another job that I would rather have.

When treating your patients who have spina bifida, what do you see as the goal of bracing?

As you know, spina bifida is one diagnosis, but it is rare to find two children who are exactly the same. While they may look alike in some ways, each is often trying to control different issues. With that in mind, the general goal is to try to correct the anomaly as much as possible. With young children, that means preventing common problems by designing braces based on their individual needs. For example, I often see a crouched gait and posture in children with Spina Bifida, due to weakness in the calf muscles. I generally use a floor reaction design to correct this type of posture. If this issue is not controlled at a young age, the patient can develop even more of a crouch. As a rule, it is far easier to prevent than to correct.

How often do you recommend that your pediatric patients see you?

I believe that follow-up care is so important. So much can happen in a year, so I generally see my patients more frequently. With pediatric cases, I like to see the patient one month after the initial brace fitting. Then I have the patient return at three months for follow-up. Once I have a sense of how the patient does with the braces, follow-up appointments can be scheduled at 6 month intervals. Six months is the maximum I would recommend between appointments because it is so critical to stay on top of bracing problems.

What are the biggest mistakes that you see patients make with their braces?

The biggest problem occurs when a person notices a problem with his or her braces and does not call me soon enough! I tell my clients to keep a close eye on their braces, checking them for nicks and cracks. Routine maintenance can prevent critical problems, which is why I like to see my patients every six months. With my spina bifida clients, the biggest preventative measure I stress is to check their skin every day when the braces come off and every morning before they go on. **Spina bbbifida patients need to make a skin check a part of every day's routine because of the lack of sensation.** Without a visual check, skin breakdown could go unnoticed and cause infection. For younger patients, parents must help with this routine. They need to check for reddened areas and/or skin breakdown so that the risk of infection can be avoided.

What should people look for in a good orthotist?

There are several qualities:

1) A good orthotist should be able to design a bracing system that fits the needs of an individual child. Kids with different diagnoses don't all look the same and should not all be treated the same. If all of the braces from an orthotist look exactly the same, there is concern that the individual needs aren't being met.
2) Just like a good physician, a good orthotist needs to listen to the concerns of the parent. If we are good listeners we can provide better care.
3) Most importantly, the orthotist needs to care about your child as an individual. I follow the Golden Rule; I would want my child treated the same as I treat your child. A good orthotist needs to be willing to go the extra mile for your child, such as providing hours beyond the 9-5 schedule. They should never be satisfied with "that's good enough."

We know that John Wall goes the extra mile. Last summer, Katie's AFO broke just as we were leaving for a vacation. Since Katie's Grandma was unfamiliar with the directions to Salem, he met Katie and her grandma at Richardson's Ice Cream to deliver the repaired AFO. Now that's a good orthotist! To find out more about his practice, you can contact him directly at Wall Prosthetics & Orthotics, 978-745-3500.

BITS AND PIECES

….from websites to single events to quick tips…

Please submit Bits and Pieces to Hyacinth Bellerose (contact info on page 1)

BY HYACINTH BELLEROSE

- www.kid-power.com Kid Power is a support and informational web site for families living with cerebral palsy and other disabilities. They have done an excellent job at centralizing useful information. Some of the links are outdated, but, in general, the site is very helpful. The Home Page has many references, but the most significant resource is "Special Needs Links", which has pages and pages of categorized links on everything from Adaptive Clothing to Aging with a Disability to Feeding Issues to Education and Inspiration. So, if you are trying to research a specific topic or just want to do some exploring into the issues we all face, check out this site.
- www.state.ma.us/dem/rec-act.htm This web site is part of the Commonwealth of Massachusetts' web site and lists accessible parks, pools, campgrounds, swimming, boating, etc... Please note that this listing is for Massachusetts state properties and does not include city, community or county parks. My favorite find was "Beach Wheelchairs" that are available free of charge at about a dozen state parks. These wheelchairs allow access to the usually impossible sand at beaches. Many of the beaches also have ramps built for wheeling right into the water! It's about time….
- www.kidsindisabilitysports.com K.I.D.S. was organized in April of 1999 to provide a sports program for children with disabilities. Athletes from all areas are welcome, but the events take place in the Lowell area so it is most practical for people in the Merrimack Valley. From baseball to golfing to dances to attending professional athletic events, the K.I.D.S. program provides a community for helping children to achieve their athletic dreams and enjoy a sense of physical accomplishment. The organization has plans for a recreation center and is currently looking for a location.
- www.braintalk.org Mass General Hospital's Neurology Department web site. You will need to go to the Spina Bifida section. There are notes, comments and resources as well as a chat room. There is also an archive of previous comments and questions.
- Help Wanted - in the *search for a location for our 2004 Summer Picnic in July*. We can use Nathan's Nana's house again but it would be fun to find a different location. If anyone knows of a really great accessible playground or a "spray park" (zero depth water playground), please let us know as soon as possible. If more that one perfect spot is found, we may have to have a second summer event in August!

Great buddies Olivia Goughan and Katie Packard had several chances to play together at events before and after the Boston Marathon.

SPECIAL CONTRIBUTIONS

In Honor of ***Joanna Piantes:***

- Christine & Anthony DiFilippo, Brighton, MA
- Leona Makredes, Arlington, MA

In memory of ***Carmella Rancatore:***

- Lynda DiMarzio, Billerica, MA
- Paul Nardella, Wakefield, MA

FAMILY FOCUS

BY ALLEN F. JOHNSON, PH.D.

THIS ISSUE: THE MENTAL HEALTH OF PERSONS WITH SPINA BIFIDA (LIKE ME)

As a mental health counselor for children, adolescents and adults with disabilities, I am often asked "What is mental health for the disabled?" It has always been easier to define mental illnesses than to define mental health. In the United States, the American Psychiatric Association has traditionally been the organization to define mental disorders. In fact, the area where I live has been a mecca for such discussions, since the first in-patient psychiatric facility, Worcester State Hospital, is in our backyard.

Nonetheless, more recently, many have recognized that mental health is more than the absence of mental illness. Even though many of us with disabilities don't suffer from a diagnosable mental disorder, it is clear that some of us are mentally healthier than others. The study of the characteristics that make up mental health has been called "positive psychology." Here are some of the ideas that have been put forward as characteristics of good mental health:

- **The ability to enjoy life** - The ability to enjoy life is essential to good mental health. James Taylor wrote that "The secret of life is enjoying the passage of time. Any fool can do it. There ain't nothing to it." For example, the practices of mindfulness and meditation, which have been around for thousands of years, are a couple of ways to cultivate the ability to enjoy the present. We, of course, need to plan for the future at times. We also need to learn from the past. Too often we make ourselves miserable in the present by worrying about the past and future.
- **Resilience** - The ability to bounce back from adversity — which those of us with disabilities know a lot about — has been referred to as resilience. It has been long known that some people handle stress better than others. Why are some Viet Nam combat veterans emotionally disabled for life, while others become United States senators? Why do some adults raised in alcoholic families do well, while others have repeated problems in life? The characteristic of resilience is shared by those who cope well with stress.
- **Balance** - Balance in life seems to result in greater mental health. We all need to balance time spent socially with time spent alone. On the one hand, those who spend all of their time alone may be labeled as "loners", and they may lose many of their social skills. Extreme social isolation may even result in a split with reality. On the other hand, those who ignore the need for some solitary time also risk such a split. Balancing these two needs seems to be the key - although we all balance these needs differently. Other areas where balance seems to be important include the balance between work and play, the balance between sleep and wakefulness, the balance between rest and exercise, and even the balance between time spent indoors and time spent outdoors.
- **Flexibility** - We all know people who hold very rigid opinions. No amount of discussion can change their views. Such people often set themselves up for added stress by the rigid expectations that they hold. Working on making our expectations more flexible can improve our mental health. Emotional flexibility may be just as important as cognitive flexibility. Mentally healthy people experience a range of emotions and allow themselves to express these feelings. Some people shut off certain feelings, finding them to be unacceptable. This emotional rigidity may result in other mental health problems.
- **Self-actualization** - What have we made of the gifts that we have been given? We all know people who have surpassed their potential and others who seem to have squandered their gifts. We first need to recognize our gifts, of course, and the process of recognition is part of the path toward self-actualization. Mentally healthy persons are persons who are in the process of actualizing — or living up to their potential.
- **Spirituality** - I believe that to be mentally healthy one must be spiritually healthy as well. Many research studies show that a person with a positive spiritual faith can be healthier in numerous ways, including emotionally. A spiritual life has certainly brought me a sense of value, understanding and meaning in what, at times, may seem like a most difficult existence.

Spring is a wonderful time to improve one's mental health outlook. After the recent long and cold winter, may each of us strive for all of these aspects of mental health in life.

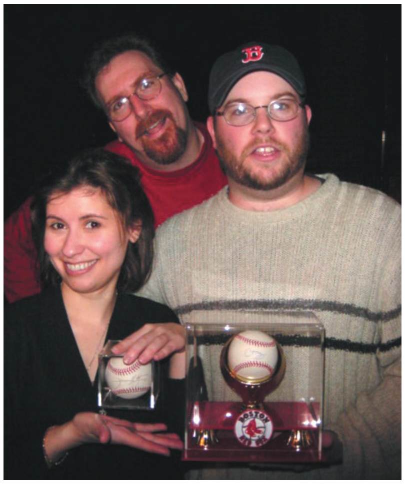
Allen F. Johnson, Ph.D., a Licensed Family Therapist, is an adult born with spina bifida. Dr. Johnson welcomes comments and queries. You can contact him at (508) 832-4297 or at drallenfrank@aol.com.

MSBA CALENDAR OF EVENTS

Date	Event	Location
June 12, 2004	MSBA **Youth & AdultsEvent — Board Games** 11am-3pm in the Pavillion Conference Dining Room	Children's Hospital
June 20-23, 2004	**Spina Bifida Association of America Conference**	Washington, DC
July 12, 2004	Board of Directors Meeting	Waltham, MA
July 14, 2004	**Parent Chat Group** 7:00 pm (see page 14 for details)	Barnes & Noble, Burlington, MA
July 17, 2004	**Summer Picnic**	TBA
July 21, 2004	**Parent Chat Group** at Myelo Clinic (see page 14 for details)	Children's Hospital
July 31, 2004	**Summer Newsletter Deadline**	To Cori Couture
August 9, 2004	Board of Directors Meeting	TBA
September 15, 2004	**Parent Chat Group** 7:00 pm (see page 14 for details)	Barnes & Noble, Burlington, MA
September 19, 2004	**Youth and Adults Group Gathering**	TBA

BOSTON BEERWORKS FUNDRAISER

On Friday, April 16th, thre days before the Boston Marathon, Brendan and Michael Sullivan hosted and event at Boston Beerworks as part of their fundraising efforts. Both brothers ran in this year's Marathon and finished. During the Beerworks event, they raised $4000, through admissions, as well as through an auction of some terrific sports memorabilia.



Massachusetts Spina Bifida Association

733 Turnpike Street, #282
North Andover, MA 01845

Phone: 888-479-1900

Web Site: www.msbaweb.org

Newsletter Deadline

July 31, 2004

PLEASE SUBMIT ARTICLES AND INFORMATION FOR PUBLICATION TO:

Cori Couture
c/o MSBA
733 Turnpike Street #282
North Andover, MA 01845
E-Mail: coricouture@yahoo.com

UPDATE YOUR MEMBERSHIP TODAY!

MEMBER FEE IS OPTIONAL TO INDIVIDUALS WITH OR FAMILIES OF INDIVIDUALS WITH SPINA BIFIDA

(SEE PAGES 10-11 FOR DETAILS)

Newsletter Editor: Cori Couture

You can view this and previous newsletter issues in full color on our web site:
www.msbaweb.org

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