MASSACHUSETTS SPINA BIFIDA NEWS

Winter 2004

A PUBLICATION OF THE MASSACHUSETTS SPINA BIFIDA ASSOCIATION
MEMBER OF THE SPINA BIFIDA ASSOCIATION OF AMERICA

LETTER FROM THE PRESIDENT

I hope each of you and your families had a wonderful holiday season. It would have been nice for us to say that in person at the Holiday Party, but Mother Nature got the best of us. Who would have thought that an early December gathering would need to be cancelled because of 30 INCHES OF SNOW?

We are presently working on rescheduling this party - tentatively to Sunday, March 21, 2004 at Boston College. Once we know for sure, flyers will be sent to the entire MSBA membership with details and directions. I hope to see you all there.

As we settle into 2004, the MSBA Board is busy planning the details for Team MSBA's running of the *108th Boston Marathon*® on Monday, April 19, 2004. This year, we have 22 runners on the team, and are hoping to raise $100,000 in donations, while increasing awareness of spina bifida in Massachusetts and beyond (a few of our runners are from out of state).

See page 16 for details about our official cheering section and other gatherings that will happen before and after the race.

Also, I urge you to familiarize yourself with the VERY BOLD running singlets the team will be wearing. This year we've made them outrageously bright so you will be able to easily spot our runners and cheer them on. You'll find the .pdf image on the web at this address: www.sugoi.ca/team/53002/90479.pdf.

Please, don't forget to submit your entries for the $1,000 *Jean Driscoll Scholarship* by March 15, 2004. (See application details on page 3) The winner will be chosen in late March and the award presented at a pre-Marathon event on April 17th.

The Board continues to review the MSBA's by-laws, committee structure and governance policies, in order to streamline the way we do business. We intend to have a full committee matrix completed in the 1st Quarter and will publish it in the next newsletter as a means to solicit volunteers for specific areas of need.

Finally, in our January meeting, we voted on an *important policy change* that could positively affect MSBA members considering attending the SBAA's annual Conference this summer in Washington D.C. I think we all agree that Conference is one of the most effective educational and social services available to the spina bifida community.

In an effort to defray the ever-increasing costs of Conference and to encourage attendance by MSBA members, **we are offering to reimburse up to $500 of each member's conference expenses for 2004.** This money is **in addition to the normal $500** available to each member who has spina bifida **through our Annual Benefits Program**. Funds from the Annual Benefit Program can also be used toward conference. (See page 12 for more information.)

To receive this extra funding, please follow the instructions on page 12. We are pleased to be in the financial position this year to make these funds available and we will evaluate the program's success to determine if we can continue it going forward.

Best wishes to each of you for a healthy and happy 2004.

Brian Packard
MSBA President

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Dick Crisafulli, Mass Hospital School 781-828-2440

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 from 7:00PM 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.

Web Site

MSBA member Brandon Shanks is hard at work redesigning the MSBA website. He presented his ideas at the December board meeting and the Board was very impressed with his design and ideas. He is looking for someone with graphics experience to assist him. If you are interested, please contact any of the Board members listed inside the front cover of this newsletter. Thanks, Brandon for your help!

New MSBA Logo

Graphic design students at Cambridge Rindge and Latin High School are working on a new logo for the MSBA and have come up with several ideas that they will be presenting to the Board of Directors in the near future. We would like to thank them for all of their hard work!

MSBA Database and Membership Analysis

- Matt Neal has begun an in-depth process of redesigning the MSBA's database. He has come up with a clear set of principles, and is working to make the database an efficient a tool assiting the MSBA to meet its organizational goals and mission.
- Matt has also created a map of Massachusetts, which shows where MSBA members are located. This map will be an important tool for us going forward. It has already helped us that there is a high concentration of members in Norfolk and Middlesex counties, but a very low concentration in the western part of the state. We hope to use this information to improve our efforts to serve people affected by spina bifida in *all* parts of the state.

Boston Marathon

Team MSBA 2004 has been formed. The team consists of 22 runners from all over the country (20 charity runners plus 2 who qualified on their own).

- Cori Couture has been coordinating the design of the singlets (runners' shirts). This year they will be brighter than ever, including flames of bright orange, yellow and teal. So, if you are watching the Marathon (hopefully you will join us at the MSBA cheering section) you will not be able to miss them! For details about our cheering section location, see page 16.
- The post-marathon party will once again be held at the Westin Hotel, Copley Square. See more details on page 16. We hope to see you there!
- Don't forget to submit your Jean Driscoll Scholarship application by **March 15, 2004**. The second annual award will be presented at an event during Marathon weekend.

SBAA Conference, June, 2004

- In order to assist MSBA members who wish to attend the 2004 National Spina Bifida Conference in Washington, D.C., the Board of Directors has unanimously approved a ***special funding policy for 2004***. In

CONTINUED ON PAGE 19

SCHOLARSHIP APPLICATION DEADLINE APPROACHING

The MSBA Board of Directors is now taking applications for the

2ND ANNUAL
JEAN DRISCOLL SCHOLARSHIP.

The MSBA began this program in 2001 as a tribute to eight-time Boston Marathon Champion and adult with spina bifida, Jean Driscoll. This scholarship will be awarded to an individual with spina bifida in Massachusetts who demonstrates the character and determination of the scholarship's namesake.

This $1,000 award may be used for educational, developmental or assistive programs or needs.*

To be considered, please send a one-page letter describing why the individual should be considered for this award to the MSBA Board at:

Massachusetts Spina Bifida Association
733 Turnpike Street, #282
North Andover, MA 01845

The winner will be named in late March and the scholarship will be awarded at an event during Marathon weekend.

** During the year of this special scholarship award, the recipient will not be eligible to participate in the $500 benefit program which the MSBA regularly distributes.*

APPLICATION DEADLINE: MARCH 15, 2004

WHY AM I RUNNING THE BOSTON MARATHON?

BY BRENDAN SULLIVAN

Fear and excitement. Those are the two emotions that I waver between since I first decided to run the 2004 Boston Marathon in support of the MSBA. The sense of fear comes from the thought of having to place one foot in front of the other for 26.2 miles. In my short twenty-five years on this planet, I don't think I have run 26.2 miles total. However, when the fear begins to overwhelm me I think of the excitement that will come that early spring day in Hopkinton and later in Boston as the course winds down Beacon Street and onto Boylston Street. In my mind, I've already crossed that finish line a thousand times and every time a chill runs down my spine. I can't wait for April 19th to get here so I can run my first Boston Marathon. Those are words I thought would never come from my mouth.

On January 12th, 1979 I was born into this world with the most common permanently disabling birth defect, spina bifida. Like all parents faced with this reality, my parents were scared and frightened. But they were also curious about my ailment. No one in my family had ever been afflicted by spina bifida before, so they were unprepared for this surprise.

Thankfully with the help of family, friends, and the people at the New England Medical Center/ Floating Hospital my parents were able to help me grow into the person I am today. Whether it was shunt revisions, brace fittings, X-Rays, foot surgeries, or regular checkups, my parents were always there to comfort, answer questions, and most importantly, to help me. Without them, I would not be in the position I am today medically, socially, and professionally. One lesson they have ingrained into my mind is to never accept limitations. That lesson is what will bring me to the starting line in Hopkinton in April.

I speak highly of my parents as a source of motivation with good reason. Though they may not see it this way (because they are concerned for my health) my running the Marathon is a thank you to them for helping me reach my current physical shape that allows me to run. However, they are not the only source of motivation I draw from when training for this challenge. Another source of motivation is my brother, Michael.

Mike ran the Marathon last year for the MSBA and I've never been prouder to be called his brother. Seeing him run down Boylston Street pumping his fist is what made me want to join him. Thankfully, Mike is running the race again this year, because I could not consider taking one step in this race without my best friend.

> BRENDAN SULLIVAN SAYS HE IS RUNNING HIS FIRST BOSTON MARATHON TO SUPPORT THE MSBA, AND ALSO “BECAUSE I CAN”

I am also running for a young man named Nathan Bellerose. I call Nathan a man even though he is only 8 years old, because of the character he has shown me every time I've met him. Nathan is the son of another MSBA Board Member and also has spina bifida. He walks with the assistance of crutches, but still finds the energy and will power to compete in many athletic events.

Last spring, Nathan decided to run a kid's road race in Groton and he asked me to run with him. The race was only 2 miles, but for him I know it was a Marathon. Seeing him compete and finish that race is one reason why I committed to running the Boston Marathon. If he can put his heart and soul into his own Marathon, then I know I can put one foot in front of the other for 26.2 miles.

Finally, my last source of motivation is the MSBA's Board of Directors and the rest of the people within the organization. Having served the past two years on the Board, I have seen first hand the hard work that these Directors give the organization. To fight your own struggles with spina bifida is admirable, but to undertake your own fight *and* help others with theirs makes me hold each Board member in the highest regard. In addition, the people within the organization have been a source of motivation because of their wonderful personalities, prestigious accomplishments, and unheralded resiliency. All of which are done in the face of constant struggle and pain. Seeing the work that is being done by the organization and the community it helps, makes me want to raise as much money as I can because I know it will go a long way in helping someone.

Simply stated, I am running the Boston Marathon in support of the MSBA. But in my mind I am also running for my parents, my brother, my extended family, Nathan, Katie, Grace, Cori, Jen, Dominique, and the rest of the MSBA community. No one source of inspiration is more important than the others. I am thankful to all of them for showing me how to live with spina bifida.

26.2 miles. 8 hours to complete. One step at a time. Please come support TEAM MSBA on April 19th, 2004 and make those steps from Hopkinton to Boston a little easier to take.

MSBA YOUTH AND ADULTS GROUP CONTACT INFO

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Second Annual Marathon Fundraiser at Boston Beer Works

Supporting the MSBA!

Hosted by:

Brendan and Michael Sullivan
Team MSBA Runners

Date

Friday April 16th
7:00-10:00 P.M.

Location

Boston Beer Works
Canal Street
Boston

Cost: $20 per person

Please join us, Brendan and Michael Sullivan, on the evening of Friday April 16th at Boston Beer Works on Canal Street (near North Station and the Fleet Center) in Boston as we gather to support our run as members of TEAM MSBA in the Boston Marathon.

The night will be filled with **free pool** (bring your cues not your bathing suits), hot and cold appetizers and **auction** items including sports memorabilia and tickets.

Take this opportunity to help **support the MSBA** and also to **meet** some **TEAM MSBA runners**, just days before they take to the streets and run for the MSBA.

A $20 donation is requested at the door and gives each attendant access to **free appetizers** and free use of the pool tables during the evening. The bar will be open and has a full assortment of micro-brewed beer and wine. All proceeds go towards the MSBA and will be credited towards the fundraising totals of both Brendan and Michael Sullivan.

Hope to see you on the 16th!! If you have any questions please feel free to contact Brendan at (617)-686-0696.

KATE PHILBIN WINS EASTER SEALS "INDEPENDENCE AWARD"

When 12-year-old Kate Philbin returned from her first summer as an Easter Seals camper, she surprised her mother by asking if she could go back. And she did – to the very next camp session.

"I loved it from the very beginning," Kate said.

A Lancaster resident, Kate never lost her love for camp.

She has gone back every summer, eventually becoming a counselor in training and a junior counselor.

Now 20, she recently completed her third year as a counselor at Agassiz Village in Maine.

Kate, who has spina bifida, has learned from the campers, but she also believes that the campers have learned something from her.

"I've shown these kids that they can overcome challenges in their lives," Kate said. "I've shown them that despite being in a wheelchair, I can still do anything I want if I put my mind to it. I've proven to the Easter Seals campers that being disabled means you can be your own person and do your own thing. They can be independent just like anyone else can."

A junior at the University of Massachusetts Amherst, Kate has designed her own major, combining psychology, sociology, business and education.

She also is taking part in a Big Sister program on campus.

Kate just received Easter Seals Independence Award for her work at Easter Seals Camp.

"She's an outstanding role model for kids with and without disabilities," said Easter Seals president Kirk Joslin.

"They're amazing kids," she said. "They can make even the worst day worthwhile."

WHO'S OUT THERE?

(MSBA MEMBER SPOTLIGHT)

THIS MONTH'S FEATURED MEMBER: DIANE RAMSEY

BY GINNY BRIGGS

Diane Ramsey 35, lives independently in Natick with her pet parakeet, "Blueberry". Born and raised in Natick, she attended Natick public schools until the third grade, when her parents moved her to the Boston Cotting School. Her parents believed she would receive better education there with her special needs, including an apparent learning disability. Diane's experience was not a good one at Boston Cotting, so when she complained of problems with both students and teachers at the school, her parents moved her back to Natick. She then attended Natick High School until graduation in 1987.

In high school, her educational experiences improved. She made friends and joined the Speech Team, competing regularly with her classmates and placing third in an individual competition for prose reading.

After completing high school, she took several classes in various areas including sign language, manicuring and computer skills. Diane still attends computer classes weekly at the Independent Living Center in Framingham. She has a home computer and access to assistance. She has been living in her apartment complex since 1990 and, in general, is satisfied with her living arrangements. The building is large, with wide hallways and elevators. In addition, the complex conducts regular events for its residents including parties and entertainment.

Medical Research Corner

By Ginny Briggs

In this issue, we welcome the return of another feature to the MSBA newsletter – Medical Research Corner. Board Member Ginny Briggs is an Epidemiologist in training and mother of Grace, a three-year-old with spina bifida. In each issue, Ginny will highlight some of the latest medical research affecting people who have spina bifida. We hope this information will prove enlightening, and will encourage all of us to keep asking questions and trying to learn all we can about spina bifida.

Do Young Adults With Spina Bifida Have Slower Intellectual Development?

A Dutch study recently published examined this very question, by testing 168 young adults with spina bifida. The participants of the study were aged 16 to 25 years old. Many studies have been conducted addressing this issue, but rarely on people older than 16 years of age.

The project collected information and test scores on spina bifida patients with and without hydrocephalus.

The participants were all part of the Adolescents With Spina Bifida in the Netherlands project. They were given tests measuring general intelligence, memory, verbal learning, language and reaction time.

The study also collected information on lesion level, number of shunt revisions, continence, living arrangements, wheelchair use and employment.

The results showed test scores for individuals with hydrocephalus (111 people) and without hydrocephalus (20 people).

The remaining 37 people had spina bifida occulta, a milder form of s.b. that involves a small amount of missing bone in the spine.

Though test scores were lower in the group with hydrocephalus, half of these participants had a normal intellect.

When the hydrocephalus group was broken down into categories, the test scores were lower in those who had epilepsy or more than 5 shunt revisions.

The IQ scores for those with 0 to 1 shunt revisions averaged 86, 2 to 4 shunt revisions averaged 86 and

Continued on Page 18

Public Awareness Update

By Dominique Savinelli

This issue: **Latex & Shopping**

Holiday activities were undoubtedly filled with family and friends this year, but at one moment or another, most of us found ourselves at the mall or on amazon.com. Many of us with spina bifida experience latex allergies, with symptoms ranging from mild to life threatening.

Latex is found in many products, which makes it difficult for us and our families and friends to buy the things we want. Retail workers are often only marginally aware when asked latex product safety questions. I am also surprised when I find that the general public is still so uneducated on this issue.

With this in mind, the MSBA sent out latex allergy and product information packets, targeting toy stores in the state. The packet included general information about the allergy and specific guidelines concerning new latex-free products.

Here is a list of the stores in Massachusetts to which we sent this latex information:

- The Right Start
- Zoinks!
- Toys R Us
- Stellabella Toys
- No Kidding!
- Toys etc
- Learning Express
- KB Toys

Do you ever go shopping and wish you had this kind of information? Please feel free to email me (dominiquesavinelli@hotmail.com) and I will send you a packet. Or you can go to the Spina Bifida Association of America's web site (www.sbaa.org) for comparable content.

Next time you go shopping, take a moment to mention to a store clerk that you are specifically interested in buying latex free products. If they are successful retailers, they want your business and they will listen.

As for traveling, Diane fully enjoyed a trip to the Bahamas several years ago with her sister and hopes to attend this year's conference in Washington DC.

Diane would love to have a dog or cat someday, something that is allowed in her apartment complex, but joked that a cat would probably not mix well with her parakeet. Since "Blueberry" is nearly 8 years old and parakeets live long lives, Diane is not in a rush to find another pet just yet.

HELPFUL AGENCIES AND ORGANIZATIONS

In each issueof the MSBA Newsletter, we will offer news and information about Agencies and Organizations around the state and around the country, which provide services and assistance that may help you or your family member who has spina bifida. To offer suggestions of agencies or organizations we should include, please contact Cori Couture at 781-321-4920 or coricouture@yahoo.com, so we can get the word out to our membership.

PARTNERS FOR YOUTH WITH DISABILITIES

Now Recruiting youth, young adults and mentors with disabilities to participate in our one-to-one, group, and online mentoring programs. Mentors really can make a difference.

Visit our website at www.pyd.org or call (617) 556-4075 x18 to learn more about how you can get involved.

EASTER SEALS SCHOOL-RELATED SERVICES

Easter Seals School Services can be a partner in helping your child bridge the gap between his or her disability and educational goals.

School-To-Work Transition

Young people with disabilities face many obstacles as they transition from school to work. Early planning is crucial.

Researchers have identified lack of preparedness as a key factor influencing low employment outcomes for individuals with disabilities.

Vocational planning should begin at approximately age 14, so schools can productively utilize the high school years to prepare students for their chosen career path.

A fundamental step is a vocational evaluation that determines areas of interest and ability. Preparation for the job market may include job shadowing - visiting a variety of work sites to observe specific jobs being performed, job searching, resume writing and interviewing.

Job placement and support provides practical, ongoing help in getting and keeping a good job.

Computer skills training is strongly recommended if adaptive equipment can help make the student more employable.

Assistive Technology

Easter Seals Assistive Technology Specialists come to your child's school to do training, assessments and consultations.

Assistive technology is a powerful tool in allowing students with disabilities to demonstrate not only what they know but also provides a process that allows your child to stay in his or own community school.

Physical, occupational and speech therapy are also a component of Easter Seals School Services.

For additional information regarding Easter Seals School Services, contact Rosalind Fisher at 800 244-2756 ext. 851, or via e-mail at rozf@eastersealsma.org or visit our website at www.EasterSealsMa.org.

EASTER SEALS SUMMER PROGRAMS

Easter Seals of Massachusetts is now accepting referrals for Residential summer camps in Maine and Connecticut (Accredited by the American Camping Association) as well as for Summer Computer Programs in Worcester and Boston.

Summer Camp

Massachusetts residents aged 7 to 30, who have physical disabilities, are eligible to attend.

Activities for campers include Swimming, Arts & Crafts, Music & Drama, Nature Study, Archery, and much more!

There are two camps. Agassiz Village in Poland, Maine offers youngsters with mild/moderate physical disabilities ages 7-12 the chance to enjoy typical summer camp activities side-by-side with able-bodied campers. Camp Hemlocks in Hebron, Connecticut is specially set up for children and young adults with moderate/severe physical disabilities. It has adapted docks for boating, fishing and easy wheelchair access. Camp sessions last from 6 to 13 days, depending on the camp.

While actual costs can range from $1,600 to $3,000, families are expected to make only an appropriate contribution toward the full tuition. Scholarships make up the difference. Easter Seals provides a guideline based on family income. Campers are accepted, regardless of the family's ability to meet the fee.

To apply, download a PDF camper referral form at the Easter Seals web site http://ma.easterseals.com, call 1-800-922-8290 or send email to camp@eastersealsma.org.

Have the form filled out by a teacher, therapist other professional who works directly with the prospective camper.

Once the completed referral is returned to Easter Seals, eligible applicants receive application packets.

Complete the forms in the application packet and send them to Easter Seals.

An initial assessment will be arranged for first-time campers.

Summer Computer Program

Easter Seals Summer Computer Program is designed for students age 14-22 with special needs and those for whom standard computer access is challenging.

Participation in this program helps to reinforce students' skills, routines and structure, and to develop new computer skills in a fun manner.

Students use educational and fun software that addresses money skills, pre-reading skills and pre-vocational skills. Specific computer skills include the basics of Microsoft Office, Microsoft Picture It (Digital Imagery), using the Internet and email as well as playing games.

This wide variety of activities offers many benefits.

- The social setting prepares students for interactions in work settings and post-secondary educational environments.
- The program can be integrated into a student's existing IEP.
- Special equipment such as IntelliKeys is available through Easter Seals Assistive Technology department.

Classes held in Boston (89 South St.) and Worcester (484 Main St.).

For more information, email: jte@eastersealsma.org.

MSBA MEMBERSHIP INFORMATION

The MSBA is a nonprofit corporation founded in 1971 by a group of concerned parents of children with spina bifida. The MSBA is 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 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.

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6 WAYS TO REDUCE URINARY TRACT INFECTIONS

BY DENNIS M. KAY, M.D.

1. The Solution to Pollution is Dilution

Bladder urine is a warm, comfortable medium for growing bacteria. To interrupt this growth, drink three to four quarts of water per day. Keep the tide flowing out. If you intermittent cath, you will need to cath 4 to 6 times per day. Ask your urologist how much your bladder holds so that you know how often you should be emptying your bladder. An overfull bladder will weaken and put stress on your kidneys. Develop a wide range of healthy drinks to enjoy: fruit-flavored waters, sugar-free, caffeine-free teas, sport drinks and fruit smoothies. Avoid coffee, tea, alcoholic beverages and drinks high in sugar and salt, as they tend to dehydrate the body. Take lemons and, well, make lemonade!

2. Make them Uncomfortable — Lower your pH

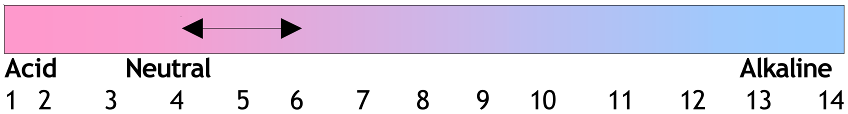
Bacteria multiply in an alkaline environment. Normal urine has a pH of 6 to 7, which is approximately neutral. Keeping your urine slightly acidic is helpful in discouraging bacterial growth. A pH of 4 to 6 is ideal. Urine test strips are available on-line or in drug stores to test the pH of your urine. (Be sure to get the ones that test for pH – for example, Labstix® on www.drugstore.com) Your first waking urine specimen is usually highly acidic so choose another time to get a more accurate reading.

What you eat and drink affects the pH of your urine. A diet rich in citrus fruits, most vegetables, and legumes will keep the urine alkaline, while a diet high in meat will keep the urine acidic. To lower the pH of your urine, some doctors recommend up to 3,000 milligrams of vitamin C tablets every 8 hours or a prescription of Mandelamine®. People with kidney problems or a history of kidney stones should ***not*** take these mega doses of Vitamin C without first consulting their physician, since it can aggravate the problem. (The USDA recommends 845 milligrams of Vitamin C each day for good health.) With a protein-rich diet and Vitamin C supplements, you can make a urine environment that's tough for bacterial growth.

3. Cranberry PACs a Punch

Cranberry juice may help you avoid urinary tract infections. Contrary to popular opinion, cranberry juice does ***not*** work by lowering the pH of your urine. Cranberries contain proanthocyanidins or PACs that prevent the bacteria from adhering to the wall of the bladder. An 8-ounce glass provides this benefit for up to 10 hours, so two or three

CONTINUED ON PAGE 16



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 above): ____________________________
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...):
____
____
____

Please tear out this application form and return it to:

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? 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 (no later than May 1, 2004) - even if the amount is only an estimate to be finalized in June.

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

IN THIS LEAGUE, PLAYING IS WHAT COUNTS

CHALLENGER DIVISION GIVES KIDS WITH DISABILITIES A PLACE ON THE BALL FIELD

BY CAROLINE LOUISE COLE

ANDOVER - In this Little League baseball game, no one counts the runs, the umpires never call anyone out, and when the batter gets a hit, both sides cheer wildly.

With its all-inclusive mission to give any child a chance to play baseball regardless of physical limitations, Andover's Little League Challenger Baseball Division is attracting players from town and across the region, most in wheelchairs and walkers.

"For Emmy, just getting the chance to wear her own Red Sox uniform and get out on the field with the other kids makes this experience hugely rewarding," said Mary Jurek, mother of the 8-year-old with Leigh's syndrome, following the season opener two weeks ago. "She was always asking when she'd get to play baseball like her older sisters. Now she can."

Labor attorney Matt Haymer started the league five years ago after moving to Andover from California, where similar programs are well established, he said.

"I had gotten involved through a friend whose child had Tourette's [syndrome] and just got hooked," he said. "When I moved here and discovered Andover didn't have a team for kids with disabilities, I figured I'd start one. This was a good way for me to get involved with the community."

This year the Challenger Division is fielding two teams, the Red Sox and Giants, with players ranging in age from 3 1/2 to 18.

They play a schedule that includes three games against each other and three against Chelmsford's Challenger team, and will participate in the regular Little League awards banquet in June.

Sports has given 6-year-old Sam Paster of Swampscott a whole new outlook on the world, said his dad, Glenn Paster, as he helped his son maneuver his walker onto the ball field at Merrimack College last Saturday for a contest against the Chelmsford Red Sox.

"Cerebral palsy slows his body down, but his cognition is unaffected," Paster said. "That means he is right in the middle of his kindergarten class as far as learning to read and do arithmetic. It also means he has the same desire as any child his age has to play sports, to be part of a team."

Labor Attorney Matt Haymer, founder of Andover's Challenger Division, gives Michael Farrah, 13, of North Andover some bunting tips.
Photo copyright by Christina Caturano

This past winter Sam tried downhill skiing as part of the adaptive ski program at New Hampshire's Loon Mountain.

"That was so successful we were pleased to find a spring sports program for him," Paster said.

"It is also good bonding time for us, father and son."

Because each child may need the help of two buddies while on the field, Haymer invited members of the regular Andover Little League program to help out at each game.

"When they arrive, I stress right off that this is not baseball as they know it, that the most important thing they can do is just be ncouraging," Haymer said.

As the Challenger Division has grown, so has its impact on the regular Little League program, according to Andover Little League president Peter Malaguti.

"As you watch the buddies interact with the Challenger players, you see just how important it is for them as people to work closely with a child who has to deal with severe handicaps every day," Malaguti said.

Playing shortstop Saturday, Sam Paster listened with interest to running commentary on game pointers offered by his buddy, Matt Washburn, 11, as Glenn Paster kept his son's walker upright.

Then when Chelmsford's Peter Stanszler hit a solid line drive in his direction, Washburn fielded the ball and tossed it to Sam, who threw it back to the pitcher, all smiles.

"No it isn't how we play the game, but this is still fun," said Washburn, as another player was helped into the batter's box and Sam turned his attention to the next play.

"It's great to see how much fun everyone is having and to be part of it."

This article first appeared in The Boston Globe on Thursday, May 15, 2003, and is being reprinted with the permission of the author and the photographer.

BLACK BELT DEFIES ODDS SINCE BIRTH

BY JAYDA EVANS

SEATTLE TIMES STAFF REPORTER

Anyone can purchase a black belt. Plop down about $7 at any martial-arts supply store and the cotton/polyester blended belt of honor made in China is yours.

So, the significance behind the prestigious accessory didn't lie in the 2-inch-wide belt with chain stitching for Jeremy Gregory. The meaning is only understood by peering into a window at the Firdale Village in Edmonds, WA.

Inside a wooden-floored studio with a red-brick back wall and room-length mirror, Gregory demonstrates a karate sequence while imagining sparring with an invisible partner. Wearing a crisp white uniform that accentuates his sky-blue eyes and his newly engraved black belt tied around his waist, Gregory, 23, is like any other "sempai" (senior student).

Except for the wheelchair.

Born with spina bifida, a birth defect in which the spinal cord and nerves fail to develop correctly, Gregory has fought to prevent anything from ending his dreams.

He was a multimedal winner at the USA National Karate-Do Federation's National Championships in San Jose, Calif., in July. He is the only known wheelchair black belt on the West Coast. And he's the only manual chair sempai (others use power chairs, and the highest ranking in that group is a green belt — three notches below Gregory).

Gregory's path to a black belt began with his love of Jackie Chan and the "Teenage Mutant Ninja Turtles" cartoon.

Now he'd like to become the "sensei" (teacher) of his own class of wheelchair and other disabled karate students.

"I've watched Jeremy accomplish a lot in his life," said his grandmother, Millie, who has raised Jeremy since he was a newborn. "I don't think any one thing meant more to him than earning his black belt. He never listened when doctors told him he couldn't do this or that. And now, they're all amazed at what he's doing. They never thought this was possible. "Most people don't — until they see it."

No gimmes

Gregory, a 1996 graduate of Shorecrest High School, didn't roll into Satori Martial Arts studio and earn a black belt simply for being in a wheelchair.

"No, they beat the crap out of him for two hours and he passed the test like everyone else," said Cheryl Wieser, **Gregory's sensei.**

But it didn't start on that cool September evening when Gregory faced combat from seven senseis with various martial-arts backgrounds.

It took Gregory the average six years to complete the lower grade lessons in preparation for the black belt.

Step number one was how?

How does a person in a $6,000 manual chair that weighs 40 pounds study karate when it's a full-body, contact sport? And where do you go to find out?

"I started with the phone book," said Millie, who pulled out the Yellow Pages and started with the first listing under "Martial Arts."

"I called and described Jeremy's situation and what he could do and that this was something he really wanted to try, so could they help?"

Dead silence.

Then the voice on the other end, whether male or female, would stutter through a polite way to say it's not possible. Probably instructors at the dozen schools Millie called had never seen a person in a wheelchair compete in martial arts.

And karate-chop hand movements are a cheap imitation of a sport with serious philosophical roots.

"No one knew what to do with him," Millie said with an exasperated sigh.

Until Wieser.

Not that Wieser, a 46-year-old black belt in weapons, had done this before. When told Gregory would be added to her class of able-bodied students, Wieser started with a solo meet-and-greet that looked like a duel at high noon.

Wieser stood, faced Gregory in his wheelchair and stared.

And stared. And stared.

"Both of us were sizing each other up and I'm thinking, 'How am I going to do this?' " Wieser said.

Finally an icebreaker — surgeries.

Wieser, a former softball player, has had eight surgeries ranging from her hips to shoulders and she can't put much sustained pressure on her left knee.

Well, Gregory topped that easily with his 30 surgeries, ranging from inserting a torso-length rod in his back to a tube extending from behind his ear to his chest to help drain the fluid that builds up in his brain.

Wieser figured if martial arts could be adjusted for her bum knee, she could tweak it for Gregory.

Plus, her emphasis is self-defense — doing enough to escape danger.

"He's disabled," Wieser said. "If he stands around and tries to talk like you see in the movies, of course he's going to get killed. I'm about self-defense and believing in yourself.

Jeremy doesn't need to prove anything to anybody. In competition, you do enough to get out of danger or win and that's it. Martial arts isn't about showing off."

The way Wieser saw it, Gregory did have legs in a sense.

They're his wheels.

As he demonstrates moves, a crescent moon kick is replaced with Gregory kicking up his right or left wheel and sharply swinging it around.

Double-front kicks are both wheels charging at you twice. And the arm movements are the same, except that Gregory is lower and needs to aim at an opponent's waist or hips.

"And his chair is a weapon," Wieser said. "I always tell him to use it and just roll people over."

In other words, Gregory is not treated like a Faberge egg.

His grandmother cringes as Wieser and Gregory demonstrate he's not weak by tossing Gregory to the ground so he has to quickly get back in his wheelchair and defend himself. It's almost too easy a challenge for Gregory.

Still, that didn't mean others wanted to spar with the budding student. Other sempais were afraid of the chair, so their fake punches were an extra foot away from Gregory. Padding was added to the lower bars where Gregory's legs are normally held together with Velcro because the left is stronger than the right.

At first Gregory was only sparring with younger kids because they are the same height.

As they more became comfortable with the idea, adults twice the size of Gregory became his competitors.

During his testing for the black belt, Gregory ran through his forms and had to verbalize what the foot movements would be for an able-bodied student.

He broke a 1-by-1-inch piece of pine with his elbow on the third try, and sparred with several sensei, including one in judo, who lifted Gregory by his feet.

"I stopped it right there, though," Wieser said, explaining that the tube that runs from Gregory's head to his chest can be easily snapped, which would be fatal. "Yeah, my eyes got big and I decided that was enough."

Afterward, Gregory was asked what it means to be presented with a black belt engraved with his name in gold Japanese characters. He couldn't find the words.

"(Karate) has made me more confident in myself," said Gregory, who also notes that it has awakened the muscles in his pelvis so he no longer has to keep track of when to use the restroom. Now, he can feel when it's time.

"It's given me more self-esteem. But originally I got into this because I wanted to teach others and let them know there's nothing you can't do."

Michelangelo

It's amazing Millie's hair isn't gray.

"My hairdresser says the same thing all the time," said Millie, 65, as she fluffs her sandy-brown hair.

When Gregory was born June 1, 1980, Millie was given the full list of things the newborn would not be able to do, including walk or live beyond 20.

Gregory was running with crutches at 2½.

His mother, Millie's daughter, decided she couldn't handle Jeremy, and left him with Millie as a newborn.

"It's always been me and Jeremy," said Millie, who divorced her husband long ago.

And boy, did he give his grandmother a workout.

Whether it was the fight to be in tumbling school (yes, he did a somersault once), watching the boy shimmy up ropes, or ski down slopes without a guide, Gregory has always been a daredevil.

"We'd fight all the time about what he shouldn't do," she said.

"I'd do them anyway," he interrupts.

"Finally, I told him to ask his doctors and if they said it was OK, then fine," Millie finished.

The love of martial arts began with a cartoon character named Michelangelo.

Outfitted with an orange bandana-like eye patch and nunchaku, Michelangelo would fight evil with the other "Teenage Mutant Ninja Turtles" on Saturday mornings.

Gregory would replicate this with empty toilet rolls and string as his nunchaku and he would make his way around his Shoreline home battling invisible bad guys.

At the USA National Karate-Do Federation's National Championships in July, he won a silver medal in short weapons — nunchaku.

"He's amazing," Wieser said. "We hate to treat him like a circus show, but unless you see him do it you never believe that he is like any other student. He's just in a chair."

Knowing the benefits, Gregory wants to give back.

Wieser worked with the YMCA to set up a program called Ability Unlimited of Washington, which is a class tailored for students with disabilities, although all are welcome. Currently there are four students, including Gregory.

While he works as a clerk in the federal building in Seattle, he hopes to also teach martial arts someday.

"Something is coming from up there that's helping me through this, it's not all me," Wieser said as she pointed to the heavens. "I'm just along for the ride and it's been real fun."

With Gregory at the helm, why wouldn't it be?

LET'S GET TOGETHER ON MARATHON MONDAY TO SUPPORT TEAM MSBA!!

BY JEN KUHAR

Just think, in less than two months, it will be spring, and Marathon Monday (April 19, 2004) will be upon us. Team MSBA is already hard at work training for the run of their lives, the Boston Marathon. Just think of all of the sacrifices they will have made to run this 26.2 mile race for people with spina bifida. Their hard work and generosity has raised over $160,000 over the past two years for the MSBA. When I stop and think about the fact that there are these amazing people running on behalf of our spina bifida community, it is an overwhelming feeling that I cannot put into words. Watching them run by while standing on the sidelines the past two years has been unbelievable. It has been an experience I know I will never forget.

This will be the last year the MSBA will be able participate in the Boston Marathon Charity Program for at least two years, so let's get as many people together as possible to cheer on Team MSBA, to show our support, and to say thanks for their unbelievable efforts to raise awareness and money for the MSBA. Grab your friends, family, and coworkers, and join us to cheer on Team MSBA!!!!

As last year, the ***MSBA Cheering Section*** will be located at the West Natick Commuter Rail station located on Route 135 in West Natick. Look for us on the westbound side of the street (the same side as the train station and strip of shops).

If you are standing on the sidewalk facing the train station, we try to set up post on the sidewalk near the entrance to the train station parking lot, which is to the right of the shops. A few board members will arrive around 9:00 AM to secure a prime spot.

This location has accessible bathrooms as well as food shops, and the commuter rail station is wheelchair accessible.

Keep in mind that if you are driving to West Natick, the road closes fairly early, so check the newspaper for details, and plan accordingly.

Once the runners have passed, we will hop on the commuter rail to Back Bay (also an accessible station) to watch Team MSBA cross the finish line, and then attend the MSBA Post-Marathon party at the Westin Hotel located right near the finish line.

Together, we can make the MSBA cheering section the loudest and most visible group in West Natick!

Please contact me at jenkuhar@msn.com for more information. We hope to see you on race day!

SUMMER CAMP INFORMATION NEEDED

BY HYACINTH BELLEROSE

We are preparing a listing of summer camp contact information for the spring issue of the MSBA newsletter.

If you know of any camps we could include, please contact me by email at bellerose33@charter.net or call me at my office:1-978-649-8724.

If you have had experience with a particular camp, we would very much appreciate your input.

A short paragraph describing your experience, whether it be positive or negative would be extremely helpful to us.

Also, please remember that we are always looking for newsletter contributors, and will happily accept a full article on your experience at camp or on any other topic! Thank you.

UTIs

CONTINUED FROM PAGE 10

servings a day provide around-the-clock protection. Be sure that you start with 100 percent pure cranberry juice. You may need to sweeten it with grape juice or artificial sweetener. The nicest thing about cranberries is that they can spice up your diet as juice, fresh berries, dried berries or sauce. The minimum quantities to achieve beneficial results are shown in the box on the next page.

4. Border Patrol – Keep Bugs Out!

Bacteria thrive in a warm damp environment, which is why you must keep your skin AND clothes dry. Wash your personal areas with soap and water every day to remove bacteria. Bacteria like moisture, so after bathing dry your skin thoroughly. Stool bacteria can be transferred to the urinary opening via underwear. Fresh underwear daily can help, especially for women because their urethras are shorter. Wash immediately after you have any urine leakage or bowel activity and change clothes and/or pads. Bacteria can survive nicely in damp clothes or pads and contaminate your skin again.

Any tube entering your body is a highway for bacteria. Bacteria grow inside your collection bag and travel up your leg bag and drain tube to your bladder. To keep your bag fresh, have two bags on hand. Wear the fresh bag, tube and connector, while the other set is soaked in a 10% bleach solution (3 cups of water to 1/3 cup bleach), then air dried. Then switch. This way you have a fresh bag each day. Replace the bags, tubes and connectors each month.

Steps for Cleaning a Leg Bag or Bed Bag

Assemble the following items:

- Clear Jar or Bottle for Disinfecting Solution
- Disinfecting Solution (1 part bleach to 9 parts water)

- Hanger
- Clamp
- Plastic Pan
- Small Funnel or Syringe

1. Disconnect the used bag, tubing and connector from the catheter.
2. Attach a clean bag, tubing and connector to the catheter.
3. Empty urine out of the bag.
4. Close the drainage valve.
5. Using a small funnel, pour water through the connector and tubing into the bag, 1 pint for a 1000 cc bag or 1 quart for a 2000 cc bag.
6. Clamp the top of the tube.
7. Slosh the water around and empty the bag.
8. Close the valve, fill with bleach solution and clamp the tube.
9. Slosh and empty.
10. Wash off outside of bag with antiseptic soap.
11. Close the valve, fill both the bag and tube with bleach solution and clamp the tube.
12. Shake the bag to distribute the solution and lay it and the tube in the plastic pan.
13. Let it lay for 2 hours.
14. Open the clamp and drainage valve and drain out bleach solution.
15. Hang the tube and bag open to the air. It is important that the bag is thoroughly dry. Bacteria cannot survive well without moisture.

If you see mineral build up, soak the tubing and connector for 6-8 hours in disinfectant solution.

5. Handle with Care

INTERMITTENT CATHETERIZATION

If you perform intermittent catheterization, you can introduce bacteria directly into the bladder if you are not careful. Even though your equipment is sterile, your skin is the next potential source of bacteria. Washing with soap and water will kill bacteria.

To prepare for intermittent catheterization, lay out all of your materials on a clean surface, wash your hands and then do not touch anything except your catheter – especially not the wheels of your chair! This is very important, especially in public restrooms where the floors may not be clean. Paper towels are not sterile but they are relatively free of bacteria and can give you a clean surface for working. Clean the urinary opening before inserting the catheter.

If you retain urine and perform intermittent catheterization and have repeated infections, try a closed system catheter, which will provide a sterile environment. This type of catheter protects against the spread of bacteria because your hands do not touch the catheter. It is more expensive initially but less expensive in the long run if you are having infections. Besides being expensive themselves, repeated infections can lead to serious complications.

EXTERNAL CATHETERS

External catheters are less likely to transmit bacteria to the bladder than internal or intermittent catheters.

External catheters include condom catheters and the ECD. Men who are uncircumcised cannot use a condom catheter but may use the BioDerm ECD. The BioDerm ECD secures only to the tip of the penis with a skin-friendly hydrocolloid material. The skin is not exposed to urine and the urinary opening is sealed off from any access to stool bacteria, reducing the potential for infection. Men with frequent infections who intermittent cath sometimes elect to have a sphincterotomy, so they can switch to an external product with less chance of infection. A sphincterotomy is a medical procedure that opens the valve at the bottom of the bladder.

Urine outflow can then be managed with a condom catheter or the ECD.

6. Showdown at the OK Corral

The best alternative is to prevent the infections in the first place. Once an infection starts, however, you simply must bring out the guns. Any doctor you see should be familiar with the unique infection issues of individuals with spina bifida. Frequent infections can lead to long-term problems such as bladder or kidney stones. At the same time, people who are treated frequently with antibiotics can develop bacteria resistant to antibiotics. To reduce that chance, do not take antibiotics until a urine sample has been taken and the specific bacterium is identified, allowing the doctor to prescribe the ***correct*** medication.

Equivalents Provided by the Cape Cod Cranberry Growers' Association

Once you start on an antibiotic, take all of it as instructed. You must totally kill the bacteria to prevent the infection from becoming resistant.

The first rule of combat is to know the enemy. With this game plan, you will be less likely to have an infection, your diet will be healthier, and your skin will benefit from the hydration. You may even influence your friends and family to live a healthier lifestyle!

Dennis M. Kay, M.D. is the CEO of BioDerm, Inc.

Please Note:The contents of this column are for informational purposes only and are not intended to replace medical diagnosis and treatment. The MSBA does not diagnose medical conditions, offer medical advice or endorse specific products, services, procedures or companies. If you would like to know if the information in the article is appropriate for you, please consult your medical doctor.*

SBAA OFFERS SUGGESTIONS FOR SOURCES OF FUNDING FOR 2004 CONFERENCE IN WASHINGTON D.C.

One mother of a son with spina bifida reported her fund-raising success story for SBAA's 2003 Annual Conference. She wrote letters to several of the vendors she buys from, describing the conference, the benefits of attending for her and her son, and asking for a moderate donation towards conference costs, such as $200-$300. She sent the same letter to several potential donors. And the good news: Several offered to help!

Her experience makes a couple of important points. First, it's probably easier to find several donors willing to donate small amounts than it is to find one donor willing to donate a large amount. Second, asking several potential donors doesn't require much more effort than asking one. Third, it maximizes the chances of success. If you submit your request to eight organizations, it's not likely that all eight of them will say no, and that at least *some* will say yes.

So don't wait! Don't miss the valuable information, the friendship, and fun that's waiting for you at SBAA's 2004 Annual Conference in Washington, DC, June 20-23, 2004!

The following organizations offer support for people wishing to attend conferences. Some organizations may offer support only to people who live in a certain geographic are and some may offer only partial support. But it's always worth a try!

Kiwanis International
Website: www.kiwanis.org

Lions Clubs International
Website: www.lionsclub.org

National Dissemination Center For Children With Disabilities (NICHCY)
Website: www.nichcy.org

Rotary International
Website: www.rotary.org

State Councils on Developmental Disabilities
Website: www.acf.dhhs.gov/programs/add/states/ddcouncils.htm

University Centers on Developmental Disabilities
Website: www.acf.dhhs.gov/programs/add/states/uap.htm

MEDICAL RESEARCH CORNER

CONTINUED FROM PAGE 7

those with 5 or more revisions averaged 77.

Those in the spina bifida occulta group had normal scores and are considered to have intellectual abilities similar to the general population, a fact supported by previous research.

As with any study, these results could have been affected by many things. In this study, there were only 20 people in the "without hydrocephalus" group. This is much smaller than the 111 people in the "with hydrocephalus" group.

The scores may have been more similar if the group sizes had been closer (the larger the study group, the more reliable the results).

Another issue that could have affected the accuracy of the results in this study is that some participants did not finish all the tests.

Again, a smaller number of participants and their test scores could have had an impact on the final, averaged scores.

Do young adults with spina bifida have slower intellectual development? The answer is, maybe. This study suggests that having hydrocephalus and multiple shunt revisions causes lower IQ test scores.

It is certainly encouraging that there is research being conducted looking at this and it could be useful information in determining the educational needs of people with spina bifida.

However, since there hasn't been much research on this subject yet and this study was a relatively small one, it would be prudent to wait for more evidence before we respond.

Reference: Barf HA, Verhoef M, et al. Cognitive status of young adults with spina bifida. Developmental Medicine and Child Neurology 2003 December; 45(12):813-20

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SPECIAL CONTRIBUTIONS

In memory of ***Christopher Dunne:***
- Kirk and Sheila Joslin of Holliston, MA

In memory of ***David Everbeck, Grandfather of Marianne Mahoney:***
- Roy & Virginia Everbeck of Bernard, ME
- The Hanrahans of Randolph, MA
- Louise & Philip Cash of Ashland, MA
- Peg & John Fallon of Nashua, NH
- The Dory Family of Quincy, MA.

In memory of ***John Andrews, Great Uncle of Kerry Mello:***
- Thomas & Mary Ambrose of Jackson, MN
- Michael & Patricia Mellow of Stoughton, MA

In Recognition of ***Emily Barron:***
- Rose Salter of West Palm Beach, FL

MSBA CALENDAR OF EVENTS

Date	Event	Location
March 1, 2004	Board of Directors Meeting	Newton
March 15, 2004	**Deadline for Jean Driscoll Scholarship Applications**	See page 3
March 21, 2004	*(Tentative!)* **Annual Party & Meet the Runners!** *This is the rescheduled and redesigned Holiday Party!*	Boston College Chestnut Hill
April 1, 2004	**Summer Camp Articles Due**	See page 16
April 16, 2004	**Spring Newsletter Deadline**	To Cori Couture
April 16, 2004	**Marathon Fundraiser** *hosted by Brendan & Michael Sullivan*	Boston Beer Works, North Station
April 19, 2004	**Team MSBA — Boston Marathon** *MSBA Official Cheering Section*	West Natick Train Station
April 19, 2004	**Boston Marathon Post Race Event (4:00 pm)**	Westin Hotel, Boston
May 3, 2004	Board of Directors Meeting	Newton
June ?, 2004	**Youth and Adults Group Activity** *(Board Games Party)*	TBD
June 7, 2004	Board of Directors Meeting	Newton
June 20-23, 2004	**Spina Bifida Association of America Conference**	Washington, DC
July 17, 2004	**Summer Picnic**	TBD
September, 2004	**Golf Tournament**	TBD

MSBA BOARD NOTES

CONTINUED FROM PAGE 3

addition to the $500 available to each member with SB through our regular Benefits Program, the MSBA has allocated ***an additional $500*** to each member with SB to be used toward the cost of attending conference. (Receipts will be required in order to receive funding.) For more information on conference funding, please contact the MSBA. We hope that you will take advantage of these funds available to attend conference.

- The MSBA Board is also in the process of reviewing the conference reimbursement policy for Board members attending conference to ensure that it is in line with other SB chapters and is in accordance with other rules and regulations.

By-Laws and Committee Structure

The Board is still busy updating MSBA by-laws and committee structures, as well as planning for the future. Stay tuned for more details. Once committees have been finalized, you will be the first to know. We hope to get as many MSBA members involved in the organization as possible and are looking forward to your ideas and feedback!

MASSACHUSETTS

SPINA BIFIDA ASSOCIATION

MEMBER-SPINA BIFIDA ASSOC. OF AMERICA
733 TURNPIKE STREET, #282
NORTH ANDOVER, MA 01845

NEWSLETTER DEADLINE

APRIL 1, 2004

PLEASE SUBMIT ARTICLES AND INFORMATION FOR PUBLICATION TO:

CORI COUTURE
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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 PARENTS OF INDIVIDUALS WITH SPINA BIFIDA

(SEE PAGES 10-11 FOR DETAILS)

NEWSLETTER EDITORS: MIKE HIGGINS AND CORI COUTURE

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