MSBA NEWS

A PUBLICATION OF THE
MASSACHUSETTS SPINA BIFIDA ASSOCIATION

MEMBER, SPINA BIFIDA ASSOCIATION OF AMERICA

- SPRING 2005 -

INSIDE THIS ISSUE

PLUS A SPECIAL COLOR INSERT INCLUDING:

New Web Site Sneak Peak
Golf Tournament Flyer

NEW WEB SITE LAUNCHED!

BY GINNY BRIGGS

We are very excited to announce the debut of our brand new web site! The new design features easy access to programs, events, web links, newsletters and more. With the help and dedication of our new Web Master, Peter Jablonski, we now have an active web site that will be updated with new information and announcements monthly. We hope this improved site will provide MSBA members with quick, up-to-date information and easier access to the wide array of useful information available on the Internet.

Among the features you will see are:

- A list of upcoming events, immediately visible on the home page. Detailed information for each event will also be posted, including time, location and directions.
- Current and past issues of the MSBA newsletter.
- Discussion groups.
- Board meeting notes.
- Benefits programs.
- Quick Links to useful web sites, such as summer camp programs, medical contacts, information on adaptive and assistive technologies, and the Spina Bifida Association of America.

SEE COLOR INSERT FOR A SNEAK PEAK!!

If you haven't seen the new web site yet, please take the time to have a look. It's at the same address as before (www.msbaweb.org). Please let us know if you have any suggestions. We'd love to hear them!

LETTER FROM THE PRESIDENT

BY BRIAN PACKARD

Finally! We have emerged from one of the worst winters on record in New England to see that there really were some flowers and grass living under all that snow (and sand, and salt...) I hope each of you is enjoying this beautiful spring and looking forward to warm weather with friends and family.

We have lots of great MSBA activities and events coming up, including our first Golf Tournament, our Annual Summer Picnic and many fun MSBAYA gatherings.

Final preparations are underway for the **First Annual MSBA Golf Tournament** to be held on June 2nd at the exclusive Sky Meadow Country Club in Nashua, NH. Our Vice President, Hyacinth Bellerose, has done an outstanding job working to make sure that the tournament will be a successful fundraiser and awareness event. But, we still need your help! We are looking for volunteers for the day of the event; corporate sponsor contacts; and general help with creating some "buzz" about the tournament in the community. Please contact Hyacinth (her contact information is on page 2) to help us make this the first of many awesome Annual MSBA Golf Tournaments.

Continued on Page 3

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67 Spring Street, Weymouth, MA 02188
Also try World Arnold Chiari Malformation Association at
http://www.pressenter.com/~wacma/

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EDUCATION / SCHOLARSHIPS
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35 Harbor Lane, Norwell, MA 02061

FUNDRAISING
Hyacinth Bellerose 978-649-8724
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LITERATURE & LENDING LIBRARY
Danielle Everett 781-826-4485
21 Elm Street, Pembroke, MA 02359

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Email: ginnybriggs@yahoo.com

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YOUTH & ADULTS GROUP
Michele Scaramozza 339-927-7227
Email: mozzas@comcast.net

WHEELCHAIR SPORTS
Dick Crisafulli, Mass Hospital School 781-828-2440

President's Letter — Continued from page 1

We're also looking forward to our **Annual Summer Picnic**, to be held this year on Saturday, July 23rd from 1:00 – 5:00 PM at the beautiful (and accessible) Danehy Park in Cambridge. Every year this event draws a big, fun crowd of our MSBA friends and family, and this year will be no exception. We want to do everything we can to get members from near and far to attend, so please start thinking about transportation now. You may want to call your Regional Representative to get a car pool going. (Contact info for all Regional Reps is also on page 2.)

The **MSBA Youth and Adults Group**, as usual, has a busy schedule ahead. On June 11th, the group will gather at Children's Hospital Boston at 12:30 for a **Board Game Day**, and then in late September for a sports clinic. Further details on these events will be provided to MSBAYA members as they develop. Also, thanks to everyone who attended the **MSBAYA's Lunch and Learn** event in Sturbridge in April. Nearly 30 members attended and had a wonderful time at this educational and social program. Thanks to all the MSBA Youth and Adults Committee members for their great work making this day happen.

I'd also like to thank **Janelle Tribble and Michael Sullivan**, two Team MSBA runners who were able to obtain numbers to run the **Boston Marathon** this year. Both finished with respectable times and glad hearts, happy to know they were carrying on a grand tradition of fundraising and awareness for the MSBA. **Mike and Brendan Sullivan** hosted their annual **Boston Beer Works fundraising event** on marathon weekend and raised $4600 for the cause! Great work, guys.

Separately, I am happy to report that we have successfully launched a new online discussion group for the parents in our organization **MSBAParents@yahoogroups.com**. This forum has been very active over the last few months, providing a great community for our parents to share their thoughts and ideas on raising a child with s.b. To learn more, visit our web site and follow the link to "Discussion Groups".

Speaking of the web site...**THE MSBA HAS A BRAND NEW WEB PRESENCE!** Please take a moment to visit the completely redesigned MSBA web site at www.MSBAweb.org . Also, see Ginny Briggs' article on page 1 and the color insert included in this newsletter for details and a sneak peek.

Finally, don't forget to make your plans for the **SBAA Annual Conference** in Minneapolis June 26-29. The **Early Bird registration deadline** has been extended from May 14th to **May 22nd**. Don't forget that the MSBA can help fund your trip through our Benefits Programs (pages 12-13). Also, check out Hyacinth's article on pages 4 and 5, and our web site for links and more information.

The MSBA has lots of great things going on right now and it's shaping up to be a great summer season. We hope to see many of you at our upcoming events. Until then, best happiness and health to each of you.

— Brian Packard —

Jean Driscoll Scholarship Application Deadline Extended to May 31, 2005

The MSBA Board of Directors is now accepting nominations and applications for the 3rd Annual Jean Driscoll Scholarship. The MSBA offers this program as a tribute to eight-time Boston Marathon Champion and adult with spina bifida, Jean Driscoll. The scholarship will be awarded to an MSBA member with spina bifida who best 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, or to nominate someone, please send a one-page letter, describing why the individual should be considered for this award to:

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

SBAA CONFERENCE 2005

A REVIEW OF THE BASICS

Visit the SBAA's web site for complete information: (www.sbaa.org)

DATES: Sunday, June 26 - Wednesday, June 29, 2005

The Spina Bifida Association of America is joining with the International Federation for Spina Bifida and Hydrocephalus (IF) to present a Conference that is multi-cultural and multi-national.

CONFERENCE THEME: "Building Bridges to Advance Understanding." The Conference will offer the most current information about advances in orthopedics, urology, neurosurgery and neuropsychology, as well as adult health, psychosocial and family issues, employment, sex, depression, latex allergy, self-determination and learning disabilities.

ADULTS DAY: For the first time ever, there will be a whole day devoted to issues faced by adults with spina bifida on on Sunday, June 26. Don't miss this great opportunity!

LOCATION: Hyatt Regency, Minneapolis, MN (Overflow hotel: The Millenium Hotel, which is attached to the Hyatt by a walkway) (NOTE: If you haven't booked a room yet, call immediately, as they are in short supply!)

****EARLY REGISTRATION DEADLINE**** ~~May 14, 2005~~ **Extended! to Sunday, May 22, 2005.** (To register online or download a copy of the registration form for printing, visit the SBAA web site (www.sbaa.org) and click on the link for "SBAA's 32nd Annual Conference". There are also links to the forms on the MSBA web site.

AIRLINES: Northwest Airlines is the only carrier that flies non-stop from Boston to Minneapolis.

FUNDING: Remember that the MSBA is offering special, extra funding for members who attend Conference. You can apply for up to $750.00 above and beyond our normal $500.00 Member Benefits Program. See pages 12-13 for all the details!

CONFERENCE IS HERE AT LAST!

PART 3 IN A SERIES OF ARTICLES ON THE NATIONAL CONFERENCE

BY HYACINTH BELLEROSE

When I first started encouraging people through the newsletter to attend, the SBAA's Annual Conference seemed very far away. But this is the last newsletter before the event! Conference articles in prior newsletters (available at www.msbaweb.org) have focused on information about this year's conference city, Minneapolis, on conference hotels and the surrounding area, and on questions of accessibility. This article offers a list of events happening in and around Minneapolis during the week of conference. I hope it will help you make plans for evenings during conference week or for an extended stay.

WHAT'S ON DURING CONFERENCE WEEK?

- **The Local** — 931 Nicollet Mall. Think karaoke - but instead of songs, you do scenes from your favorite movies! Sunday nights, 9 pm – Midnight. For more information, contact John Cosgrove at 612-252-1615.
- **Donna Summer** — Live Music, 6/26/2005 at Mystic Lake Casino & Hotel. For more information and tickets, visit www.ticketmaster.com or call 651-989-5151.
- **Santana** — Live Music, 6/29/2005 at Xcel Energy Center, with Los Lonely Boys. Phone 612-265-4800.
- **Minnesota Twins Baseball** — 7:00 games on June 28th and 29th and a noon game on June 30th. Check out the competition! Betty Niedzwicki is organizing a group to go one of these games. Contact her if you'd like to attend. 413-774-3489 or bniedzwiecki@hotmail.com. Thanks Betty!
- **Basketball** — Minnesota Lynx vs. Seattle Storm, 6/26 at 5pm. Vs. San Antonio Silver Stars 6/28 at 7pm. Games held at Target Center. Tickets are $10.00 - $100.00. For more details and tickets, visit www.targetcenter.com or www.ticketmaster.com or call 651-989-5151.
- **Tales of the Territory** at the Minnesota History Center features over 150 artifacts documenting Minnesota's early years. For details, visit www.mnhs.org .

- **Plastics and the Cool Factor**. An exhibit at Aamodt's Apple Farm, Wells Fargo Center, 7th and Marquette in Minneapolis. Visit www.artsmia.org/exhibitions .
- **Happily Ever After** – An exhibit of wedding dresses, historical photos, cake toppers and wedding gifts at the Minnesota History Center. Visit www.mnhs.org .
- **Charles Beck: Woodcuts**. An exhibit at the Mill City Museum. Visit www.millcitymuseum.org for details.
- **Upstream: Fly Fishing in the American West** and **Tricking Fish: How and Why Lures Work** — Exhibits at the Bell Museum of Natural History. Examine the tradition of angling through a series of dramatic black and white photos of fly fishing. Unravel the mystery of what makes fish bite - or not bite. Photographs and hands-on objects provide observant anglers with insights into the fish's point of view. Details at www.bellmuseum.org . For tickets, call 612-624-7083.
- **Illuminating the Word: The Saint John's Bible** — An Exhibit running from 4/17/2005 to 7/3/2005 at the Minneapolis Institute of Arts. The Saint John's Bible exhibition consists of 60 of the more than 200 Bible pages that are being created for the first handwritten, illuminated Bible from the modern era. Scribes in a Wales scriptorium, under the artistic direction of Donald Jackson, one of the world's foremost calligraphers and Scribe to Queen Elizabeth, are creating the Bible. View this exhibit at the Target Gallery: www.artsmia.org .
- **25th National Veterans Wheelchair Games**, MCC Public Events, Minneapolis Convention Center. Over 600 veterans in wheelchairs will compete for gold, silver and bronze medals at the Minneapolis Convention Center and throughout the Twin Cities area in events such as Track and Field, Swimming, Basketball, Weightlifting, Softball, Air Guns, Quad Rugby, Bowling, 10K Hand Cycling, Archery, 9-Ball, Table Tennis, Slalom, and more. For details, contact Sharon Skoblik at 612-467-5273. THIS IS IN THE BUILDING CONNECTED TO OUR HOTELS.
- **Lettice and Lovage** — A play at the Theatre de la Jeune Lune. A dizzy conspiracy erupts between two women, one a wayward tour guide with a complete disregard for anything ordinary, the other a formidable guardian of Truth with an undiscovered penchant for flights of fancy. More information, visit www.jeunelune.org .
- **Walker Art Center** – With a new expansion and renovation completed in April of 2005, the Walker Art Center is dedicated to presenting the finest contemporary, visual, performance, film and media artists. Its new expansion doubles the size of the facility and includes impressive new galleries, a 385-seat theater, the largest regional library of contemporary art and interactive educational lounges. It also includes a Sculpture Garden, web art, and much more. For more information, visit www.walkerart.org .

BEFORE YOU LEAVE FOR CONFERENCE, BE SURE TO OBTAIN AN INFORMATION PACKET, A VISITOR'S GUIDE AND A MAP FOR MINNEAPOLIS AND SURROUNDING AREAS, THROUGH ONE OF THE FOLLOWING SOURCES:

- The Minneapolis Tourism Office – Call 1-888-676-MPLS (6757).
- The Greater Minneapolis Convention and Visitors Association
  - By Mail at:

    250 Marquette Avenue South, Suite 1300
    Minneapolis, MN 55401
  - OR on the web at

    www.minneapolis.org . (The web site includes lots of information, as well as opportunities to subscribe to an e-newsletter and to request printed materials.

FOR AIRPLANE READING, BE SURE TO BRING:

- General Information packet, which you will be calling to order or requesting online,
- Articles about Conference from this year's MSBA newsletters, and
- Your conference registration package (to work on choosing which conference sessions you want to attend each day). A pdf version of the Conference Schedule is available in the Conference area of the SBAA's web site www.sbaa.org .

The SBAA's Annual Conference is always an incredible experience in and of itself, but I hope you will also make time to enjoy some of what the city has to offer. After all, who knows when you will be able to visit Minneapolis again! See you there. — Hyacinth

MSBA YOUTH & ADULTS GROUP (MSBAYA) FOCUS

BY JEN KUHAR

There has been quite a buzz within the MSBA Youth and Adults Group! The past few months have been quite busy. For one, online membership has jumped from approximately 60 members to over 90 members since our last newsletter! We are so excited that more folks ages 17 and up are taking advantage of what the MSBAYA has to offer and look forward to seeing participation in the group continue to grow!

There have been a few administrative changes within the MSBAYA Planning Committee. Cori Couture has stepped down from her post on the MSBAYA Planning Committee. As you all know, she is the Editor of our award-winning newsletter and is leaving this committee to give herself more time to focus on the newsletter. We want to thank Cori for all of her hard work over the past few years. She was the original Moderator of the MSBAYA Youth and Adults Group and we want to thank her for all of her efforts in helping the MSBAYA Group become what it is today. She has assured us that we will still see her at most MSBAYA events!

Additionally, we would like to welcome Robyn Hand to the MSBAYA Planning Committee. Many of you have probably met Robyn or at least spoken to her on the phone recently when she called to remind you about the Lunch and Learn Day. Robyn is a long time MSBAYA member and we are thrilled to have her joining us on the Planning Committee. Welcome Robyn!

We would also like to thank everyone on the Planning Committee who has worked so hard in putting together recent and upcoming events, as well as keeping the online Yahoo! Group up and running. We could not do this without all of your help!

The MSBAYA Group met on February 19th at Children's Hospital from 12-3PM for lunch and an informal group discussion. Nearly fifteen members participated in this event. Discussions focused on the SBAA Conference, coming up in June in Minneapolis, Minnesota and on ideas for upcoming local events. Some possible activities that were discussed were bowling, board games and a computer clinic day. Thank you to all who worked very hard coordinating the day and to Boston Children's Hospital for their hospitality!

Since that event in February, the MSBAYA Planning Committee has been working out the details of events for the remainder of the year. See the box at the bottom of page 7 for a schedule. Watch the MSBAYA Yahoo! Group, the MSBA web site (www.msbaweb.org) and your mailboxes for more information. We hope to see you soon!

MSBA YOUTH & ADULTS GROUP COMMITTEE

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LUNCH & LEARN RECAP

On April 10th, nearly 30 MSBAYA members gathered at the Sturbridge Host Hotel in Sturbridge, MA for our very first **Lunch and Learn Day** from 10:30AM to 5:00PM. Basically a mini conference, the day was filled with three very informative presentations and a wonderful buffet lunch prepared by the Sturbridge Host Hotel.

The presenters for the day were Susan Nicastro, the Making Healthy Connections Program Coordinator (Springfield, Western MA) with Partner's for Youth with Disabilities (PYD); Nicole Knee, a Clinical Dietician at the Shriners Hospital for Children in Springfield, MA; and Tom Carr, a Certified Therapeutic Recreation Specialist and Program Director from Northeast Passage at the University of New Hampshire.

Many new faces from the MSBAYA attended this event. It was great to see members rekindle old friendships with people they had not seen in years as well as make new friends. Folks walked away with a wealth of information that they plan to put to practical use! The MSBAYA Planning Committee hopes to make this event an annual tradition.

Special thanks go out to Ride-Away Vans of Londonderry, NH for donating the use of a wheelchair accessible van for the day, so that folks who would not normally be able to attend our events were able to get to this one. We also want to thank Brendan Sullivan, our volunteer van chauffeur for the day. And of course, a big thanks goes out to all of the speakers for giving up their Sunday to come speak to us all!

Although it was a long day, it is safe to say that all participants had a wonderful time and are already looking forward to next year. For those of you who were unable to attend, below is a summary of the presentations for the day.

Susan Nicastro spoke about the **Mentoring Program** offered by **Partners for Youth with Disabilities** and provided us with some mentoring statistics. Statistics show that mentored youth have a better chance of going on to higher education and have better attitudes towards school. Participating in a mentoring program increases social skills and promotes healthy social attitudes and relationships. The types of mentoring programs offered by PYD include Face to Face (ages 6-24), Group (ages 14-22), and Online (14-24). They are always looking for new mentors and mentees. Another interesting program offered by PYD is the **Access to Theatre program**, which takes place in Boston! Offered during the summer, this program involves participants creating theatre productions and then performing them for a live audience. For more information on all of PYD's programs, you can call 413-534-4479 (Western MA office) or 617-556-4075 (Boston office). You can also send email to Susan: snicastro@pyd.org, or to Maureen Gallagher at mgallagher@pyd.org. And, of

ESTIMATED CALORIE NEEDS FOR PEOPLE WITH SPINA BIFIDA

The lower range is for less active people based on 7 cm/kg body weight.

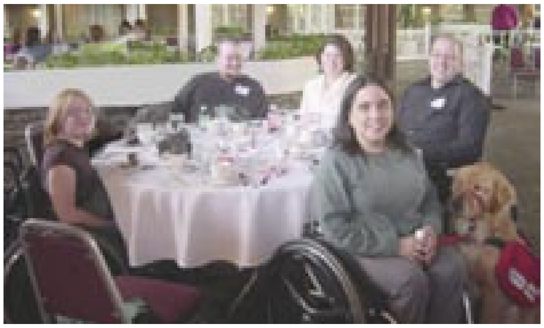
The higher range is for more active people based on 10 cm/kg body weight.

Ht in feet & inches	Calorie range
4’ 5”	942 - 1346
4’ 6”	960 - 1372
4’ 7”	978 - 1397
4’ 8”	996 - 1422
4’ 9”	1013 - 1448
4’ 10”	1031 - 1473
4’ 11”	1049 - 1499
5’	1067 - 1524
5’ 1”	1085 - 1549
5’ 2”	1102 - 1575
5’ 3”	1120 - 1600
5’ 4”	1138 - 1626
5’ 5”	1156 - 1651
5’ 6”	1173 - 1676
5’ 7”	1191 - 1702
5’ 8”	1209 - 1727
5’ 9”	1227 - 1753
5’ 10”	1245 - 1778

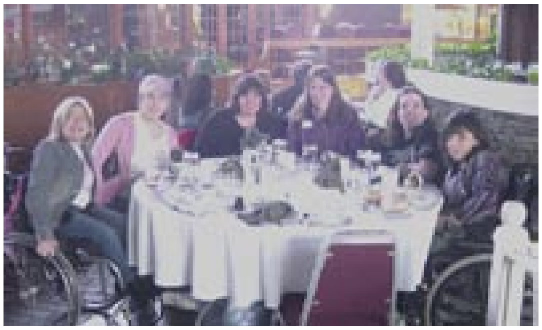
course, info is always available at the PYD web site: www.pyd.org.

Nicole Knee, the Clinical Dietician from Shriners in Springfield, talked about the importance of good nutrition and how serving sizes have grown significantly in recent years. She emphasized the importance of portion control and eating a balanced diet. Folks with mobility issues only need about 70% of the daily calories of people without mobility issues! (See the box on this page, which breaks down calorie needs as determined by weight and height.) Nicole stressed, among other things, that a healthy diet promotes healthy skin, which is very important for the healing and/or prevention of pressure sores. One of her suggestions for portion control while dining out was to ask for a “To Go” container when your meal arrives, and immediately put half of your meal into it so that you do not overeat. Everyone left this presentation with better awareness of how to eat healthy and thinking next time they eat out they might forgo those French fries!!

Tom Carr discussed recreational programs offered by the organization he works for, **Northeast Passage**. Activities include hiking, cycling, white water rafting, and water skiing. He emphasized that NEP can adapt equipment for all situations so that anyone can participate in their programs (although for safety reasons, some programs do require folks to be able to do certain activities on their own before they can participate). Even though Northeast Passage is located at the University of New Hampshire in Durham, NH, they do offer programs in many New England states, including Massachusetts. For example, on May 21, 2005, they will be holding a Cycling clinic at Whittier Rehabilitation Hospital in Westborough, MA. This will give folks the opportunity to work with specialists and try out different styles of adapted cycles. For more information on programs offered by Northeast Passage, please contact Tom Car by phone at 603-862-0070 by email at tcarr@maple.unh.edu, or check out the Northeast Passage web site at www.nepassage.org .



MSBA Youth and Adults Group



MSBAYA Members and speakers enjoy a pleasant lunch break during our Lunch & Learn at the Sturbridge Host Hotel on April 10.

UPCOMING MSBAYA EVENTS

• Saturday, June 11, 2005	Board Game Day (12:30 - 4:00 PM)	Pavilion Conference Dining Room Boston Children’s Hospital
• Saturday, August 13, 2005	Bowling (Time TBD)	Lanes & Games, Cambridge, MA
• Sunday, September 25, 2005	Activity, TBD	Location, TBD
• Sunday November 6, 2005	Activity, TBD	Location, TBD

MEDICAL RESEARCH CORNER

BY GINNY BRIGGS

DOES HOW WELL YOU FUNCTION AS A PARENT IMPACT YOUR CHILD WITH SPINA BIFIDA?

The results of a study conducted at Loyola University in Chicago were recently published, looking at the influence of parental behavior on the development of kids with spina bifida. The study examined 68 families that had a child aged 8-9 with spina bifida and compared them to similar families with able-bodied children. It was determined that how a parent functions has greater impact on the development of a child with s.b. than on an able-bodied child.

ABOUT HOW THE STUDY WAS DONE:

The parents in the study were evaluated in 3 ways; parenting stress, parent psychosocial functioning and marital satisfaction. Parenting stress was determined by answering questions about self-perceived parental competence, feelings of restriction due to parenting and satisfaction with socializing or seeing friends. Parent psychosocial functioning was determined by completing a checklist of 90 psychosocial symptoms (not described any further in the article). Marital satisfaction was determined by answering 32 questions about how strong the marriage was (content of these questions was not described in the article).

The children in the study were evaluated in three ways as well; internalizing and externalizing symptoms, depression and observed adaptive behavior. Internalizing and externalizing symptoms was determined by asking the children (and their teachers) about their activities, social life and school. Depression was evaluated by asking the children questions about symptoms of depressive feelings and behavior. Observed adaptive behavior was rated by researchers who visited the home of the family and observed how they responded to various situations.

The families were interviewed twice; the first time was when the child was between 8 and 9 years-old, and the second was 2 years later. The study examined how the children and parents rated at the first interview vs. the second interview and if there were any changes.

RESULTS:

The results showed that kids with s.b. had more problems with activities, social life and school when their parents felt stressed or had lower marital satisfaction. The amount of stress experienced by the father alone at the first interview was also associated with the same types of problems in kids with s.b. In addition, when there was an increase of symptoms of stress in either or both parents between the first and second interviews, there was also an increase in the child's depression during that same period. Overall, functioning of the father had more impact on how well the child adjusted than did the functioning of the mother. This finding has been reported in other studies as well, showing how important the role of the father is to the development of socialization of their children.

DISCUSSION:

This study suggested that - since it has been shown that kids with s.b. tend to be particularly dependent on their parents, those children would be particularly sensitive to their parents' feelings, and would be more easily affected by those feelings than children without s.b. It was also suggested that the children studied were relatively young and that the study, therefore, may not have captured behaviors typically seen in adolescence. Depression, for example, is more widely seen during puberty, so the results for depressive symptoms may have been different had the study included older kids.

Most of the significant findings in this study showed that parental function predicts child adjustment levels that are similar between families of kids who have s.b. and families with able-bodied children. However, it has been shown that parents of kids with s.b. experience higher stress in general, which put those kids at a greater risk for adjustment problems than other kids.

Reference: Deborah Friedman, Grayson N. Holmbeck, et al. (2004) Parent functioning in families of preadolescents with spina bifida: Longitudinal implications for child adjustment. Journal of Family Psychology, 18, 609-619.

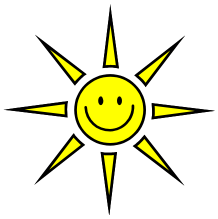
***RESEARCH DISCLAIMER**: The contents of this article are for informational purposes only and are not intended to replace medical diagnosis and treatment. The research provided is for educational and information purposes only. The reference to these research studies does not present an endorsement or recommendation of such studies. There are many other studies, which for various nondiscriminatory reasons, are not presented in this publication. The MSBA does not diagnose medical conditions, offer medical advice or endorse specific products, services, procedures or companies. The MSBA makes no representations or warranties with respect to quality, efficacy, safety, reliability, qualifications, or desirability of the studies or researchers, and specifically disclaims any other warranties, express or implied. If you would like to know if the information in the article is appropriate for you, consult your medical doctor.*

Mark Your Calendars for the

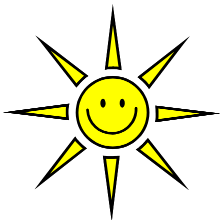
Third Annual

MSBA Summer Picnic

Saturday, July 23, 2005



(Rain Date Sunday, July 24th)



1:00 pm - 5:00 pm

at Danehy Park

(** Entrance at 99 Sherman Street, not main entrance **)

Cambridge, MA

Parking Lot and Picnic Area
near the office & restrooms

Flyer, Map, and Directions available soon at www.msbaweb.org

- ***Food and Beverages***: Lunch will be provided.
- ***Please bring***: Sunscreen and a lawn chair (if you prefer a chair to the grass!).
- ***Picnic Fun***: Sand Art, Scavenger Hunt, and Surprises.
- ***Other activities*** at Danehy Park include a water spray park, playground & sports fields.

**** Please RSVP ****

If you know ahead of time that you will be attending, please let us know how many people you expect to bring with you, for planning purposes. Please RSVP to Cara Packard at packard44@comcast.net or to the MSBA number which is 1-888-479-1900. Feel free to join us if your plans change last minute and you did not RSVP. If you need to confirm that we are using the Rain Date, call 978-549-4848 on the morning of the picnic.

by Phone **(888-479-1900)** or online at www.msbaweb.org.

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, an extensive 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 web site at www.msbaweb.org for ongoing events and programs.
- In order to receive the MSBA's quarterly newsletter, the SBAA's newsletter *Insights*, and to receive other MSBA benefits, it is necessary to be a "Qualified 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 .

- **Who is a "Qualified Member"?** A person with Spina Bifida who (1) resides in Massachusetts or a New England state that does not have its own SBAA affiliated entity, and (2) who is actively registered with the MSBA. Benefits are available to only one person per Membership, unless there is more than one person with spina bifida covered under that Membership. (See information on page 12 for more details on our Benefits programs.)
- Please send us an update whenever there are any changes to your information, including your email address!
- Members can also update their information by sending an email to mattneal@alum.mit.edu.

Special Contributions

In Memory of ***Mary Reilly:***

- Ms. Lois Barry, Reading, MA
- Mr. & Mrs. Richard Tyrell, Winthrop, MA
- Ms. Mary Osborne, Winthrop, MA
- Ms. June Doherty, Winthrop, MA
- Mr. & Mrs. Anthony Della Piana, Saugus, MA
- Mr. & Mrs. Nes H. Nelson, Peabody, MA
- Mr. & Mrs. James Nowlan, Stoneham, MA
- Stoneham Public School Administrators
- Mr. Robert Finn, Winthrop, MA
- Mr. Joseph Rebello, Bridgewater, MA
- Ms. Pamela Kosinski, Winthrop, MA
- Ms. Blanche Kearney, Ipswich, MA
- North Suffolk Mental Health, Chelsea, MA
- Ms. Judith Ditmars, Saugus, MA
- Mr. Lee Fich, Winthrop, MA
- Ms. Maureen Ward, Dorchester, MA
- Ms. Lorraine Grever, Hingham, MA
- Mr. Edward A. Bond, Jr., South Hamilton, MA
- Mr. & Mrs. Julie Key, Louisville, KY
- Mr. & Mrs. John Vanbruskirk, Lake Suzy, FL
- Mr. & Mrs. N.P. Boniface, North Reading, MA
- Mr. & Mrs. John Heneghan, Marshfield, MA
- Mr. & Mrs. Glen Ellegood, Billerica, MA
- Ms. Maureen McQuinn, Stoneham, MA
- Mr. & Mrs. Timothy Corcoran, North Reading, MA
- Falbo, Solari and Goldberg, P.A., Winthrop, MA
- Saltmarsh Insurance Agency, Winchester, MA
- Ms. Mary Skinner, South Boston, MA
- Ms. Elizabeth La Camera, Winthrop, MA
- Ms. Mary Louise Strain, Melrose, MA
- Mr. & Mrs. Ernest Duval, Winthrop, MA
- Mr. & Mrs. Richard Heneghan, Newbury, MA
- Mr. & Mrs. Walter Guertin, Belmont, MA
- Mr. & Mrs. Jon Van Dalinda, Winthrop, MA
- Mr. & Mrs. Joseph Fisher, Randolph, MA
- Mr. & Mrs. Timothy McCusker, Jr., Stoneham, MA
- Ms. Barbara Talanian, Malden, MA

In Memory of ***Beatrice Gately:***

- Mary E. Dunne, Watertown, MA
- John & Madeline Barry, E. Dennis, MA
- Robert & Elizabeth Mullen, E. Dennis, MA
- Nancy & Paul Stankus, E. Dennis, MA

MSBA MEMBERSHIP APPLICATION/UPDATE FORM

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

Type of Membership:

___ Qualified Member (Teen or Adult with spina bifida)
___ Family Membership (Parent(s) of Child with spina bifida)
___ Associate Member (Interested Friend or Family Member)
___ Medical Professional

Name of person with spina bifida: ______________________
Date of Birth (*Important. This info helps us provide appropriate support to members of different ages): ____________
Spouse / Partner / Other Family Members : ____

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...):

____
____
____
____
____
____

Please tear out this application form and return it to:

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

** MSBA Benefits Programs **

Qualified Members
of the MSBA are now eligible for up to $1,250 a year through our Benefits Program and the 2005 Special Conference Benefits Program!

What is a "Qualified Member"?

A person with Spina Bifida who 1) resides in Massachusetts or a New England state that does not have its own SBAA affiliated entity, and 2) who is actively registered with the MSBA. 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 enhance independence, increase mobility or otherwise improve his/her life as it is affected by spina bifida. The funds may be used for braces, crutches, canes, catheters and continence supplies, summer camp, assistive technology, educational items or other similar expenses.

A Benefits application must be submitted to the MSBA by the Qualified Member or their parent or guardian via postal mail, fax or email, and will be reviewed for approval at the following month's Board of Directors meeting. Once the application has been approved, there are two ways for a Qualified Member to receive Benefits funds:

1. Reimbursement: The Qualified Member may present a receipt showing payment of an eligible expense already incurred. Once this receipt is received and reviewed, the MSBA will write a check to be paid to the Qualified Member or their parent or guardian, as reimbursement.

   OR

2. Direct Pay: A bill or invoice for the eligible expense *to be incurred* may be presented to the Board of Directors in advance. In this case, the MSBA will write a check directly to the benefit provider or vendor for the expense in question.

2005 Special Conference Provisions

This year, Qualified Members are entitled to a **Conference Benefit of $500** (in addition to the Regular Annual Benefits Program), to be used expressly **for expenses related to attending the SBAA Annual Conference** in Minneapolis, MN., June 26-29, 2005. A further **Bonus Benefit of $250** will be granted if the member agrees to perform a service for the MSBA, such as serving on a committee, writing an article for the newsletter about Conference experiences or helping to organize an MSBA event.

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 2005 Special Conference and Bonus Benefits *in advance* - even if the amount is only an estimate of expenses to be finalized later.

Requests outside of this scope will be reviewed on an individual basis.
Benefits Program payments can take up to 30 days to process.
The MSBA reserves the right to revise this policy in accordance with the changing financial position of the MSBA.

MSBA BENEFITS FORM

Name: ______________________

Street Address: ____

City, State, Zip: ____

Telephone: ____________________ **Email**: _________________________________

I AM APPLYING FOR:

___ **MSBA Annual Benefit of $500**
  ___ Receipt Attached
  ___ Make check payable to enclosed provider

___ **2005 Special Conference Benefit of $500**
  ___ (estimate) OR ___ (final)
  ___ Receipt Attached OR
  ___ Make check payable to enclosed provider

___ **2005 Bonus Conference Benefit of $250**
  ___ (estimate) OR ___ (final)
  ___ Receipt Attached OR
  ___ Make check payable to enclosed provider

____
\+ ____________
\+ ____________
= ____________ GRAND TOTAL REQUESTED

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

BEQUEST

Last summer, the MSBA received an unexpected donation. In her will, a Reading woman named Elizabeth M. Aldrich left $10,000 to the Massachusetts Spina Bifida Association. Mrs. Aldrich died last year, and her family sent the money as requested in her will.

According to her step-daughter, Mrs. Aldrich had surgery for spina bifida 84 years ago in Germany. “With much success, Elizabeth lead a full and healthy life with only a slight turned in foot... Hopefully this donation will help in some small way to finding a cure for Spina Bifida.”

The MSBA is most grateful to Mrs. Aldrich for her thoughtfulness and generosity. The Board is considering how best to spend the money, so that it may be used to advance research into the causes and prevention of spina bifida, thus satisfying her wishes.

MSBA PARENTS GROUP CLOTHING AND EQUIPMENT PROGRAM

BY HYACINTH BELLEROSE

The MSBAParents Group is a new online discussion list solely for member parents within the MSBA. To join the group, go to the MSBA's new web site (www.msbaweb.org) or send me an email at bellerose33@charter.net .

Recently, the group has begun implementing a clothing and equipment sharing program. It is a vehicle to allow parents to give clothing, shoes, equipment, etc. to other parents within the group. Items that might be passed on include: shorter than usual pants, shoes without the innersoles, walkers that no longer fit a child, etc... All of these items are unlikely to be used by other children, even when donated to a worthy cause. We hate to see them cluttering up one house when they could be getting used in another!

The rules for this program are simple but must be followed to maintain privacy for all involved:

(1) Post an email on the MSBAParents Group offering free clothing, shoes or equipment to other MSBA parents, include as much information as possible;
(2) Include your direct email address at the bottom of your offer;
(3) Indicate if your offer is "all or nothing" as we do not want to make this a hassle;
(4) Conduct all transactions within private emails;
(5) Once the clothes are given away, do a quick email to the group indicating that the items are taken but do not mention the name of the person to whom they were given.

Please note that all members are still welcome to provide equipment listings for the MSBA newsletter or web site and do not need to be a part of the MSBAParents Group to participate in any similar newsletter or web site offers. If you have any further questions, please call Hyacinth at 978-649-8724. Thank you.

Disclaimer: The MSBAParents Group clothing program is not a part of the MSBA, nor has its content been validated, approved, supported, or in any other way endorsed by the MSBA. The MSBA bears absolutely no liability or responsibility for the use or accuracy of the information or items provided. All liability is held solely between the individual or individuals choosing to participate in this program.

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 7:00 to 9:30 PM. All members are welcome to attend. If you are interested in becoming more involved or have any issues or concerns to be brought up at a meeting, please contact any one of us.

- Delegates representing the MSBA during official procedings at the 2005 SBAA Annual Conference will be Brian Packard, Matt Neal or Ginny Briggs (TBD), Jen Kuhar and Jen Fitz-Roy.
- MSBA 2004 Credential Reporting has been completed.
- During our March meeting, Thomas Sileo of Morgan Stanley was invited and spoke to Board members on the topic of developing an investment strategy for the MSBA's assets. Subsequently, he developed a rough draft of a strategy, which the Board is currently reviewing.
- The Board continues to solidify the MSBA committee structure and strategic plan.
- Ride-Away Vans of Nashua, New Hampshire has donated the use of a wheelchair accessible van for the MSBA to use for transporting folks to and from our events. The MSBA plans to use this service for its larger events as we go forward.
- The new MSBAParents Yahoo!Group is up and running. Visit http://www.msbaweb.org/programs.shtml to learn more and sign up.
- Peter Jablonski is the MSBA's new WebMaster. He has redesigned and built us a brand new site, which launched the weekend of April 16, 2005 (www.msbaweb.org). Be sure to check it out.
- The MSBA has been granted a permit to hold its annual Summer Picnic at Danehy Park in Cambridge on Saturday, July 23, 2005 from 1-5PM. Rain date will be July 24, 2005.
- In the upcoming months, the MSBA will be working with the Myelodysplasia (spina bifida) Clinic at Children's Hospital Boston. They are looking for feedback on how they can improve their clinic.
- Cori Couture has resigned from the MSBAYA Committee. She will continue to serve on the Board and to edit the newsletter.

BOSTON BEER WORKS FUNDRAISER

BY BRENDAN SULLIVAN

On Friday, April 15th, over 50 people gathered at Boston Beer Works near North Station for the 3rd Annual Sullivan Brothers Fundraiser in support of the MSBA. This fundraiser was created as part of the MSBA's Marathon fundraising effort, and is hosted on Marathon weekend when one, if not both, Sullivan brothers is running the Marathon for the benefit of the MSBA. Brendan, a Board member with the MSBA, and his older brother Michael hosted the evening, which was filled with good friends, good sports memorabilia for auction, and good beer!

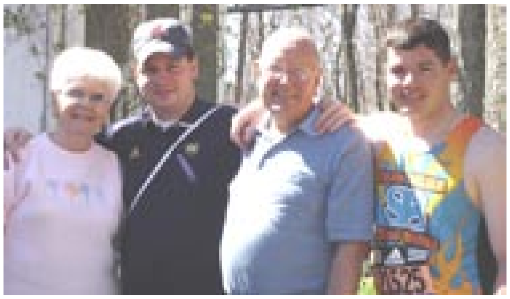
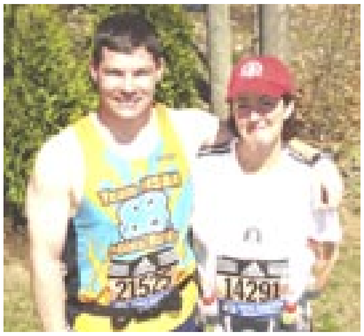
When all was said and done the event raised over $4,500 for the MSBA, which brings the three-year total for this event to over $15,000. Please mark the Friday of 2006 Marathon Weekend in your calendar so that you can attend next year's event when both Sullivan Brothers plan on running the 2006 Boston Marathon!










STANDING OVATION

BY LAUREN NORDAHL

Clinical studies have indicated that there are numerous benefits to be derived from weight-bearing and standing therapy for people with spina bifida. Surprisingly this information is not always passed on effectively to parents or individuals who have s.b. themselves. While we strive to learn all we can at each doctor's appointment or clinic visit, it is impossible to touch on every subject related to life with spina bifida in such a short amount of time. Often we are focused on immediate health needs or problems, and long term goals or non-urgent issues are left for future visits. Perhaps that is why parents of young children with s.b. frequently hear about standing programs from other parents, rather than from medical professionals. With that said, the value of a weight-bearing program should not be overlooked, considering the many positive results it can offer.

So, exactly what is a stander? Simply put, it is a piece of equipment designed to support a person, who is not normally able to stand, in an up-right position. Standers are available for children *and* adults of all sizes and abilities, so it is never too late to try one. People who were never informed about weight bearing benefits as a child have been known to start stander programs well into adulthood. With proper guidance and safety measures (and of course the physician's approval) there is no age restriction for beginning this therapy.

Now, for all of us dealing with s.b., schedules are tight. For many of us, they already include physical therapy, speech therapy, occupational therapy and school or work. Add in bladder and bowel management and *some* time for activities with family or friends, and most of us have little time left. Is implementing a standing/weight-bearing program really important? Is it worth finding the time in our schedules to fit it in? "Absolutely," according to all of the therapists I interviewed.

The physical benefits of weight bearing include improved circulation and digestion, decreased spasticity, reduction of pressure sores, decreased pain and *increased* range of motion. Some studies suggest that weight bearing can iniate bone development, or at least can *lessen* the *loss* of bone mineral density. However, conflicting studies make this an arguable point.

The psychological and social rewards of standing are noteworthy. For all humans, engaging in conversation at eye level offers a drastically different interpersonal dynamic than a standing person speaking to a seated person. A stander allows small children to play at peer level. In the process, being able to see things from their playmates' perspectives and to see the facial expressions of those other children *as* they interact, enhances social development. Also, objects previously out of a child's reach become accessible to explore, and broaden the child's overall scope of experience.

Standers address the same physical, psychological and emotional issues for older children and adults as they do for small children. Being able to look people in the eye and reach for things without having to ask for help increases self-confidence. As we all know, there are many environments, like stores and offices where reaching items from a wheelchair is problematic, and a stander can offer a better option.

Older infants and toddlers often need only: the appropriate bracing, non-skid shoes, and their parents' support to start reaping the benefits of weight bearing. A few minutes several times a day can mean huge rewards for your child.

Of course, a weight-bearing program should only be initiated after consulting your doctor and physical therapist. While most patients are great candidates for such a program, there *are* exceptions. People with hip subluxations, skeletal development issues or any of several other conditions might not be good candidates for a stander. This speaks to the fact that every patient should be carefully assessed by a doctor before being given the go ahead to try such a program.

Once you ***do*** make the decision to dive in however, a standing program need not be time consuming or overwhelming. What *is* vital, is consistency.

The initial duration of standing sessions should be guided by the individual's tolerance and a therapist's recommendations, with re-evaluations as necessary. Many people see significant improvement in several areas of their health after only a week or two of consistent weight bearing.

However, tolerance for standing time should be built up gradually. Pressure points such as feet and ankles should be checked regularly for any signs of irritation. Any changes you notice should be reported to your physical therapist or doctor.

Proper equipment, alignment, and support are essential for both the safety and effectiveness of a standing program. Improper alignment can place added stress on weak joints, muscles, and bones. Your physical therapist can be an invaluable resource when choosing from different kinds of standing equipment. To ensure balanced load bearing and patient comfort, they can also teach proper supporting techniques and ensure that bracing requirements are met.

One major distinction between different types of standers is between mobile and stationary models. Mobile standers are quite versatile and offer endless variations to your standing program. You can see the world from a whole new perspective — upright — and can move around at will. For an active child or adult, a mobile stander is preferable, as it allows you to go anywhere that is wheelchair accessible. In addition, many people find the height they reach in a mobile stander is advantageous while shopping and at events where there are many people gathered. Many of us who use or have used a wheelchair find being surrounded by a large standing crowd particularly confining. Using a mobile stander allows some relief from this feeling, not to mention a much better view of the events.

Models such as the Standing Dani have large wheels that are easy to maneuver and customized support systems to fit a variety of needs. The Dani also offers a prone position and tilting to make reaching for things more convenient. The Easy Stand is an example of a "sit to stand" model, whose range of positions makes transfers easier to accomplish. The Easy Stand has a special seating system that allows individuals to enter the unit seated, rise to a standing position, then return to sitting.

In general, both mobile and stationary standers offer numerous options for support and function, such as seating and harness systems, motor attachments and removable trays. Tara Souve, a physical therapist at the Rehabilitation Hospital of the Cape and Islands, feels a tray is essential for children. The available large trays offer a surface to play and eat on. They also function wonderfully in school settings.

The Standing Dani offers a large, removable, clear tray that allows the user to see through to the floor and does not impede movement while attached. Tara Souve also recommends ensuring that children use their standers during the school day for continuity with home use, and for maximum positive results.

The cost for a stander varies and can be substantial. However, many funding sources are available. Some insurance companies will cover your stander themselves, but, don't be surprised if they deny you at first. If this happens, enlist the help of your physical therapist and doctor to educate the insurance company about the long-term benefits of weight-bearing. It is vital to list not only the effectiveness and results obtained from standing, but to document the risks and negative effects of *not* standing. This kind of logic can improve your chances of getting coverage for the equipment.

For outside funding, be sure to check with your local Spina Bifida Association for available benefits (the MSBA offers $500 per year for expenses related to living with s.b.). Also consider local organizations such as the Lions Club and Knights of Columbus, which often have programs to subsidize the cost of medical equipment. In addition, your local department of public health, physical therapy center, and early intervention program often have lists of helpful programs you might want to consult.

MORE INFORMATION: Many web sites offer helpful information pertaining to all aspects of weight bearing and standers. A web search for "standers" and "weight bearing" will yield a long list of results. As a starting point, the sites below outline the benefits of a standing program, along with information on medical studies and clinical findings on the subject.

www.standingdani.com

www.easystand.com

www.rifton.com

www.fsma.org/standing1.shtml

EASTER SEALS OFFERS THREE OPTIONS FOR CAMPERS WITH SPECIAL NEEDS

Easter Seals is now accepting referrals for two **residential summer camps** and a **summer computer camp** for youngsters with physical disabilities. Trained counseling and nursing staffs and specially adapted facilities provide campers with a program appropriate for their needs.

At Agassiz Village in Poland, Maine, campers aged 8 to 13 with disabilities participate in activities with campers their own age. Camp activities include swimming, archery, arts and crafts, overnight camp-outs, wheelchair sports and field games. A high counselor-to-camper ratio allows each camper to participate to the fullest extent of his or her ability.

Easter Seals also offers a program for campers aged 7 to 18 at Camp Hemlocks in Hebron, Connecticut. Camp Hemlocks is designed to accommodate campers with more complex needs. Special adaptations include an easily accessible pool and a dock fitted out for fishing from wheelchairs. Financial assistance to Agassiz Village and Camp Hemlocks is available for qualifying youngsters.

Easter Seals **Summer Computer Camp** is designed for students with learning, social and physical disabilities and their siblings aged 12 to 22. The program combines educational instruction and recreational activities. Interactive software is utilized to strengthen functional skills in a social setting. This camp starts June 28 and runs weekly through August 26 at the Easter Seals computer lab in Worcester. Families can choose from a 2- to 8-week session.

For more information, call Easter Seals at 800 922-8290 ext. 851 or visit the Easter Seals Web site at:

www.eastersealsma.org .

FOR MORE INFO, CONTACT

Ann Hall
978-475-9187
ahall@eastersealsma.org

BITS AND PIECES

…from web sites to single events to quick tips…

Please submit Bits and Pieces to Hyacinth Bellerose: bellerose33@charter.net .

BY HYACINTH BELLEROSE

- **MOTHERS UNITED FOR MORAL SUPPORT, INC.** (MUMS) is a Parent-to-Parent Network organization for parents or care providers of a child with any disability or health condition. MUMS' mission is to provide support to parents in the form of a networking system that matches them with other parents whose children have the same or a similar condition. MUMS has a dynamite newsletter with lots of stories, bios of children, and contact phone numbers from almost every state. If parents cannot afford the subscription fee, the newsletters and the matching service are provided for free. You can contact MUMS toll-free at 877-336-5333 or at 920-336-5333. Their address is 150 Custer Court, Green Bay, WI 54301-1243. You can also write to them via email at mums@netnet.net or visit their web site at http://www.netnet.net/mums/ .
- For **INFORMATION ON SUMMER CAMPS**, check out http://www.campchannel.com/camps/. Also check out "Summer Camps" in the Links section of the new, improved MSBA web site (www.msbaweb.org)!
- Some parents within the MSBA and from other chapters have developed **PERSONAL WEB SITES**. Updated regularly by parents, friends and grandparents, these inspirational sites include a variety of material from family information to details about the child with s.b. to links to other sites. Reviewing them reminds me that each person with s.b. faces both very similar and very different issues. To see a sampling, check out the "Personal Web Sites" Link on the MSBA's site. We plan to keep a running list as we find more, so be sure to come back and visit regularly.
- **ANDOVER/NORTH ANDOVER YMCA** runs a **SPECIAL OLYMPICS SWIM TEAM** that meets every Sunday from 2-3pm. The swimmers are assigned lanes and beginners are assigned a one-on-one "buddy." Local high school swim team members provide assistance and motivation for the team. One mom offers this review: "Julia absolutely loves this program and the volunteers are fantastic!!" There are several meets throughout the course of the season and swimmers of all abilities are welcome.
- **NEW ENGLAND INDEX** stands for Information on Disabilities Exchange. Basically, it is a database of organizations that provide various kinds of support to people with disabilities. To do a search, you can enter criteria like "Type of Program", "Type of Service", "Type of Disability or Condition", and the "Region" within which you want it to search. You can look up specialists and agencies, and follow links to learn more about disability issues in general.
- **MSBAPARENTS YAHOO!GROUP** — Our new online parent chat group is up and running and is already going strong. We have 29 active members, most of whom have introduced themselves online. Please consider joining. To those parents who have already joined, please remember to put your questions or concerns out there. You never know if another parent has already faced your issue and will be able to offer you some valuable wisdom. The next step in our group's evolution will be to begin working towards having face-to-face meetings. Keep watching. To join the online group, send email to me at: bellerose33@charter.net or go to the link on our web site under "Programs".
- If you live anywhere near Westminster, MA (and even if you don't), check out **WHEELING WONDERS** - a play group designed especially for kids with physical challenges. The group was started by Mary Varteresian and Chris Haley in late 2003 with the intention of gathering kids with differing abilities, their brothers, sisters, friends and families. Their hope was to introduce our kids to others with similar challenges that, so they wouldn't feel as alone as they sometimes can, and it is working! Their goal is to live it up! So click onto their web site at www.wheelingwonders.com.

Disclaimer:
The resources, events, requests for participation in studies, entertainment options, and other information provided in this newsletter are provided solely for informational purposes. The MSBA does not endorse any of this information or these resources unless it is specifically funded by the MSBA. You are encouraged to review all information available by the sponsor of the resource or activity prior to providing any information about yourself or attending an event.

MSBA CALENDAR OF EVENTS

DATE	EVENT	LOCATION
** May 22, 2005 **	**Early Bird Registration Deadline for SBAA Annual Conference**	See page 4 for details or www.sbaa.org and click on "Annual Conference"
• May 31, 2005	**Jean Driscoll Scholarship Application Deadline**	(see page 13 for details)
• June 2, 2005	**First Annual MSBA Golf Tournament**	Sky Meadow Country Club Nashua, NH
• June 6, 2005	Board of Directors Meeting	The Centres at Burlington
• June 8, 2005	**RSVP Deadline for MSBAYA Board Game Day**	888-479-1900 or msbaweb.org
• June 6, 2005	**MSBAYA Board Game Day** (12:30 PM - 4 PM)	Pavillion Conference Dining Rm., Boston Children's Hospital
• June 26-29, 2005	**SBAA Annual Conference**	Minneapolis, MN
• July 11, 2005	MSBA Board Meeting	The Centres at Burlington
• July 23, 2005	MSBA Summer Picnic 1-5PM	Danehy Park, Cambridge, MA
• July 24, 2005	Raindate for MSBA Summer Picnic	Danehy Park, Cambridge, MA
• August 1, 2005	MSBA Board Meeting	Centres at Burlington
• August 13, 2005	MSBAYA Bowling Event (Time TBD)	Lanes & Games, Cambridge, MA
• Sept 12, 2005	MSBA Board Meeting	Centres at Burlington
• Sept 25, 2005	MSBAYA Event	Details TBA

For the most up-to-date info on MSBA events and info, visit our web site (www.msbaweb.org) and sign up for ou online discussion groups: msbaya@yahoogroups.com and msbaparents@yahoogroups.com .

APPLICATIONS ARE NOW BEING ACCEPTED TO JOIN THE MSBAYA PLANNING COMMITTEE

The MSBAYA Planning Committee needs your help! With the recent growth in MSBAYA membership and participation, the MSBAYA Planning Committee is looking for volunteers to assist with activities including coordinating events, transportation, flyer preparation and moderating its online Yahoo!Group. Planning Committee meetings are held every other month at the Burlington Mall in the Food Court. If you are interested in participating (you do not have to have spina bifida to volunteer your time), please email a paragraph or two about yourself and why you would like to volunteer to Jen Kuhar at jenkuhar@msn.com, or via postal mail to the MSBA at:

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

Massachusetts Spina Bifida Association

733 Turnpike Street, #282
North Andover, MA 01845

Phone: 888-479-1900

Web Site: www.msbaweb.org

Newsletter Deadline

July 8, 2005

Please submit articles and information for publication to:

Cori Couture
c/o MSBA
733 Turnpike Street #282
North Andover, MA 01845
Email: coricouture@gmail.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.