



SBSTL NEWSLETTER



Spina Bifida of Greater St. Louis

8050 Watson Rd
Suite 115
St. Louis, MO 63119

www.sbstl.com

314-843-2244
1-800-784-0983

Board of Directors:

Chair:
Mark Abbott

Co-Vice Chairs:
Laura Baer
Victoria Portell

Treasurer:
Pam Abbott

Secretary:
Norma Asher

Members at large:
Kelly Abbott
Jeanne MacAinsh
Sandy Grassi
Bruce Sterling

We have a website: www.sbstl.com Check it out!

We have also started a **Facebook** group as another way to stay connected. Look for Spina Bifida of Greater St. Louis and join!

Suggestions for items to add to the website or newsletter are certainly welcome; please email Bob and Laura Baer at fivebaers@charter.net.

!!! IMPORTANT !!!

IMPORTANT- Starting in 2010, the newsletter will only be published electronically. Hard copies can be made available for a small fee to cover printing and mailing costs. Please call or e-mail the office to update your e-mail information.

Board Meetings:

All are welcome at Board meetings! It is a great way to get involved and/or find out what's going on! The Board meets at 7 pm on the third Monday of every month, except December. Meetings are held at the SBSTL office. Meeting dates are:

11-16-09 1-25-10 2-22-10 3-15-10
Hope to see you sometime!

DISCLAIMER: The information and other materials contained in this newsletter are provided for educational and informational purposes only and are not a substitute for legal, medical advice or treatment. Neither recommendations nor endorsements are implied.

Letter from the Chair

An old saying goes: "Time flies when you are having fun". Well, we have been having a real blast, and the days and weeks have just been flying by. The last warm days of summer are gone, and the kids are well into the new school year. Halloween just flashed by into the past and Thanksgiving is on the horizon. Of course that means that Christmas cannot be far behind!

The SBSTL has enjoyed several activities since the last newsletter including the Fall Campout and Halloween Party where everyone had a great time at Babler State Park, with fellowship, games and costumes - we saw many old friends and families and also made some new friends.

The SBSTL Christmas Holiday Party is coming in December, with lots of food and fun for young and old. The Young Adults will be gathering together for another fun time at Dave & Busters. Last, but certainly not least; the New Parents Group (birth to age 5) and the K-to-10 Group (Kindergarten through grade 5) have meetings and other events planned. There will be activities that fit your age and interests - check out the calendar! If there is something you would like to do - then contact us and let us know what kind of event you would like to attend!

Regardless of how busy our calendars get at this time of the year with all the holiday events and scheduled obligations, we need to remember to take time to celebrate with our friends and our families. Taking time to enjoy our families and personal relationships is one of the best ways to enjoy the true meaning of all the holiday timeframes.

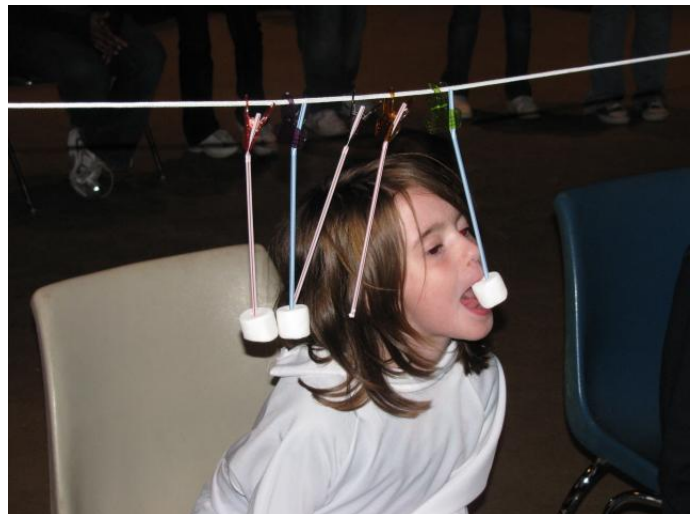
The SBSTL is excited to be making the final transition of the Newsletter to an electronic format. Due to rapidly increasing costs of paper, printing and postage, this is the last large hardcopy printing of the Newsletter. In 2010 we will complete our conversion to an electronic format for the Newsletter, where we will deliver the newsletter via email or you can get it through the website. If you cannot access the Newsletter electronically please let us know in advance; hardcopies of the Newsletter can be made available for a small cost.

A follow-up on some "business" news - the SBSTL has completed the process of officially changing our legal name from "Spina Bifida Association of Greater St. Louis (SBASTL)" to "Spina Bifida of Greater St. Louis (SBSTL)". Along with the name change, we have completed our first full year as an independent organization with no national affiliation. There have been and will continue to be challenges, including developing and executing fund-raising activities in this changing and difficult economy. However, with your help the Board of Directors will continue to do our best to help the SBSTL provide interesting, fun and informational activities to the SB community. Keep your eyes on the growing website (WWW.SBSTL.COM) for new features and more information to meet your needs, including the electronic newsletters.

As always, if you would like to help work on an event or activity, please let us know - we need your participation to be successful. Perhaps you are willing to bring your skills and talents to support the SBSTL by joining the Board of Directors? We elect new Board members at the annual Christmas party - are you interested? If you have any ideas, questions or concerns, please feel free to contact us via email at SBSTL@charter.net, or call the SBSTL office at 314-843-2244 or toll-free at 800-784-0983. Hope everyone has a great and joyous holidays season.

Mark Abbott
Chair, SBSTL Board of Directors

Fall Camp-out



The 2009 Fall camp-out was a ton of fun for all who came. Thirteen people camped in the accessible cabins and enjoyed new and old friendships. Thank you to Brad Spinner and Al & Norma Asher for preparing all the meals. The party held on Saturday was a huge success thanks to the crazy games created by Norma Asher. Kids of all ages enjoyed painting pumpkins, catching dangling marshmallows and racing under parachutes!

Group News

New Parents (birth-5) Group

This is our group for families with children ages birth-5. The group was revived in July 2008 and membership is growing! We meet every other month or so for playdates, seasonal activities, and other outings. The format and location varies each month. We are scheduling activities for 2010 so if you have any ideas, please contact Victoria Portell at 314-495-0285 or vger48335@yahoo.com.

If you want to join this group, please contact Victoria Portell (phone number and email address above) or send an email to SBASTL_New_Parents-subscribe@yahoogroups.com

Youth & Adult Alliance

Calling all young adults & adults!!

We will be getting together at Dave and Buster's on December 5th and would love to see you there!

Come join us for various activities we do throughout the year. We have recently gained a few new faces but would like to see more. If anyone has any suggestions of things (specific topics) they would like to see here please feel to pass those along as well.

Contact-Kelly Abbott
618-980-3377
kjabbott@charter.net

Fun on Wheels!

Families from the New Parents and K-10 groups enjoyed a "play-date" at Good Shepherd School for Children on Nov. 10th. The large play room has enough space for the children to ride bikes, tractors, and inchworms! It also was a great place to show off wheelchair skills! The relaxed atmosphere was great for parents to chat and compare notes on latest equipment, shoes and therapies. We'd love to see you at our next outing!!



Group News (cont.)

K-10 Group

This is a new group we are trying to start, to bring together families with children between the ages of 5 (kindergarten) and 10 who have sb. We did have one recent outing at Eckert's Orchard in Belleville, IL. Three families met and enjoyed a tractor ride out to the apple trees to choose the sweetest apples of the harvest (we had to taste a few to be sure, of course!) We then enjoyed rides, a petting zoo and apple cider samples! It was a lot of fun for all the girls. We look forward to more get-togethers to build the friendships started. If your child with spina bifida is between kindergarten-age and 10, we are looking for you!! There are about four of us, so far, that would like to get together, become friends, provide support and have fun! Please call Laura at 618-632-3140 or Sabine at 636-244-0217. We would love to hear from you and plan a get-together soon!



Share Info & Win a Prize!

Do you have trouble keeping your (or your child's) feet warm because of low circulation? How about a fun contest: **"How Do You Keep Your Feet Warm in Cold Weather?"**

E-mail or snail mail your experience and advice, which we'll publish at the Holiday Party and on the website. And we'll randomly draw a winner from all submissions. The winner will get a \$25 gift card from Wal-Mart.



It's fun and informative for all!

Submissions due: November 30th for regular post and December 2nd for e-mail.

Mail your ideas to: **Spina Bifida of Greater St. Louis**
8050 Watson Road Suite 115
St. Louis, MO 63119

Or e-mail: fivebaers@charter.net

Holiday Party- December 6th
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This is a great time to meet old friends
and make new ones!

Come see **The Amazing Keith** as he dazzles the crowd with his magic and comedy! Also, enjoy a delicious catered lunch and a visit from Santa! If you would like Santa to give your child a gift, please bring a wrapped gift with your child's name on it.

When: Sunday, December 6th, 12:30- ?

Where: Kirkwood Community Center

RSVP: Norma Asher at (314) 283-8350

SBSTL 2009-2010 Calendar of Events

December

- 12-5-09 YAA Dave & Buster get-together
- 12-6-09 Holiday Party at Kirkwood Community Center

February

- 2-19-10 Longaberger Basket Game Night
At the Bethalto Senior Citizen Center

May

- 5-16-10 Spring Camp-Out –**Save the Date!**

Related Activities (not sponsored by SB StL)

November

- 11-14-09 Variety Club- 2009 Bikes for kids (check out their website varietystl.org)
- 11-17-09 What About the Siblings? Class-6:30-8 pm. (www.solutionwhere.com/ssd)
- 11-20-09 -
11-22-09 DASA- Midwest Sled Hockey League Competition (dasasports.org)

December

- 12-5-09 Character Breakfast at Good Shepherd
Call Laurie at 314-469-0606

June

- 6-17-10 -
6-20-10 THE 11TH NATIONAL CONFERENCE ON HYDROCEPHALUS (hydroassoc.org)

Member News



In mid-October, David Grassi competed in his first marathon. David is a freshman in college in Chicago. His mom is SB StL Board member Sandi Grassi. She is very proud of his success in school and in athletics.

David's Marathon Stats:

Time: 2:07:37.

Overall placement: 15th

Team placement: 9th

Bright Ideas

I am an adult with SB. One thing I have learned over the years when I am going in for a procedure that requires an IV is to prepare my arm/s for the onslaught by using a product like Nair. It makes the removal of the tape far less painful. I am pretty fair and have never had a problem with it coming back in darker or heavier, and trust me I'd notice if it did!

Submitted by: Dawn Onanian



In Loving Memory

Paul Romero, son of Marco and Linda Romero, passed away Saturday, October 31st at 1 a.m. of respiratory failure. Paul was 29 years old. He was very active in Boy Scouts and other service organizations. Our condolences to his family and friends.



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We're on the web!

See us at:

www.sbstl.com