

# The Spinal Column



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## Calendar of Events

### **September**

9/19/11 Board Meeting 7:00pm at SB office

### **October**

10/9/11 Bowling at Brunswick Zone Lakeside Lanes 1-3 (ALL)

10/17/11 Board Meeting 7:00pm at SB office

10/28/11 Longaberger Game Night (ALL)

### **November**

11/5/11 Edwardsville Children's Museum 10:00am (0-5, K-10)

11/21/11 Board Meeting 7:00pm at SB office

### **December**

12/3/11 Dave & Buster's (YAA)

12/4/11 SBSTL Family Christmas Party at the Kirkwood Community Center

12/9/11 Quarter Auction

**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 - Spina Bifida of Greater St. Louis (SBSTL) - 8/1/ 2011

Hello everyone - It has been a busy (and HOT!) Summer; but with fundraisers (Golf Scramble & Longaberger Basket Bingo) and social activities (Summer Campout, Bowling Party, Pizza Party and New Parents meetings) the time just seems to fly past. Fall is just around the corner, and school will soon be starting, so make sure to contact your local school district if you have not completed an IEP (Individual Education Plan) for your child.

We have two more SBSTL fundraisers scheduled for this Fall, a Longaberger Basket Bingo night where two dozen beautiful crafted baskets will be up for prizes, and a new event called a Quarter Auction where you get to bid on all kinds of great prizes, but it only costs you one quarter (\$0.25) for a bid per \$25 of prize value. Both events are a lot of fun and you can take home some great prizes. If you would like more information on either of these events, check the calendar section of the website ([www.SBSTL.com](http://www.SBSTL.com)) or contact Pam Abbott at 618-972-3388.

New information continues to develop regarding Spina Bifida treatment and causes. The medical community has stated that Fetal (pre-natal) surgery is the new "gold standard" (e.g. the best) option for treatment of babies with spina bifida. There is also growing information about drug interactions increasing the risk of spina bifida. The medications that pose the most potential increase in risk of spina bifida for infants are anti-seizure or antiepileptic medications that contain valproic acid (a common epilepsy medication). Results are pending from a study by the Centers for Disease Control and Prevention (CDC) evaluating other prescription medications and their potential for increasing the risk for spina bifida.

Reminder - The new **SBSTL Trading Post** is available on the [sbstl.com](http://sbstl.com) website. This website feature allows you to list items you no longer need (wheelchairs, crutches, catheters, and other supplies) which you can donate FREE to other members of the SB community. Members of our SB community can then contact each other to make arrangements to donate/receive the items. This is a great way to get rid of items which you no longer use while not throwing them away in a landfill. Please note that this share site is for items to be donated for FREE; if you want to sell items please use other web sites like Craigslist. Items can be picked up or shipped - if items are shipped it is expected that the receiving party will pay the shipping costs.

Details about all the upcoming SBSTL social and fundraising activities are available elsewhere in this newsletter, and are published on the SBSTL website ([www.sbstl.com](http://www.sbstl.com)). Remember, your support and participation is what makes SBSTL successful. If you have any questions or concerns, contact us via email at [SBSTL@charter.net](mailto:SBSTL@charter.net), or call the SBSTL office at 314-968-2244 or toll-free at 800-784-0983. I hope to see you at the next fundraiser and at the Christmas Party!

Mark Abbott

Chairman, SBSTL Board of Directors

## Grants are Available

This is a reminder that we have several grants available through the SBSTL organization. The SBSTL Grant Programs are now available upon request and online at the website <http://www.sbstl.com/grants.htm> . Applications for each grant program are different, so please make sure that you use the correct application for the grant program which you are requesting. There are three different SBSTL grant programs currently available to the Spina Bifida community:

**SBSTL Activity Program** The Activity Program was established to enhance opportunities for persons born with Spina Bifida to achieve their full potential through life-skill or therapeutic activities. Activity Program funding from SBSTL make it possible for the student to choose life-skill activity pursuits that may otherwise be outside of financial reach. Examples of acceptable programs include (but are not limited to) fees to attend a specialized camp, special swimming lessons, therapeutic horsemanship or other life-skill programs.

**Parsons Oil Company Support Program** The intent of the Parsons Program is to help children with Spina Bifida enhance their quality of life and to help those individuals achieve their full potential. The Parsons Support Program supports activities and equipment that impacts the overall quality of life for the individual born with Spina Bifida, and for their family, that may otherwise be outside of financial reach. Examples of acceptable requests include (but are not limited to) construction of a ramp, specialized equipment (braces/walkers), therapy, travel for special medical treatment or other unique requirements.

**SBSTL Scholarship Program** The Scholarship Program was established to enhance opportunities for persons born with Spina Bifida to achieve their full potential through higher education. SBSTL Scholarships can make it possible for the student to choose educational pursuits that may otherwise be outside of financial reach. Scholarship grants are for post-secondary education, at 2-year or 4-year colleges or certified vocational schools.

The SBSTL Board of Directors (SBSTL BOD) evaluates each application on its merits based on the criteria set for the requested grant program. The SBSTL BOD will then award the funding after carefully weighing the factors for selection. Grant program funds are awarded at the discretion of the SBSTL BOD under the SBSTL Bylaws. We truly wish we had a bottomless bank account and could fill every request we receive, but in the current economy this is simply not possible. However, we do not want to discourage anyone from applying - after all, you just might have your request approved and thus provide the opportunity to improve a loved one's life!

# Transportation Issue Resolved

I am writing this article as a follow up to the one I wrote on the prices of accessible vans.

We wanted to find an accessible van for Michelle and Trey without signing on for a big debt as we are now both retired.

I decided to check web sites. I went to all the familiar sites like eBay, craigslist, auto trader.com, car soup.com. You want to make sure that on eBay you only go to classified ads where you can put in your zip code and get vehicles fairly close to your home so you can personally go look at them.

We found some cars that Michelle would be able to transfer to; however, there was no response from any of the ads. They could have put sold by their ad, or something. I even left phone numbers etc.

Well low and behold I tried CarSoup.com. This was the best decision I ever made. We found a 1999 Grand Dodge Caravan IMS already accessible van with only 50,000 miles on it. The owner's husband had passed away so she was selling the van. We made the trip to look at it and drove it. Everything worked great and Michelle was able to roll up the ramp. There are tie down straps for behind the driver. The front bucket seat is removable and on WHEELS. We wheeled it out and put the chair in the basement. Michelle is able to sit in the passenger area that also has tie down straps.

We went in together with Trey's parents and were able to purchase the van for a little over \$10,000. Of course we wished the circumstances would have been different but we were blessed to find this van. The owner was very happy to see that the van was going to be used by a person who really deserved it.

I would HIGHLY RECOMMEND CAR SOUP.COM. It only took about 10 minutes to be contacted by the seller. It may be because the owner and her family were just wonderful caring people, but I would start there.

I hope this helps somebody out there looking for transportation, but not looking to break the bank!!!!!!!!!!!!!!

Norma Asher

Secretary

## Independence Day Air Show Celebration as viewed from Malcolm W. Martin Memorial Park

Kelly, Pam and Mark Abbott attended the July 3<sup>rd</sup> Independence Day Air Show Celebration at Malcolm W. Martin Memorial Park located directly across from the Gateway Arch in Illinois. Our association was invited by the Metro East Park and Recreation District (MEPRD) to the air show viewing for people with disabilities. Information was sent out to our members about this opportunity via e-mail and was posted on our website. Close up parking was very good. Golf cart shuttles were available if needed as were accessible bus shuttles from parking lots located further away. Cooling buses were available at all times. Participants were advised to bring lawn chairs and umbrellas for sunshade. It was permissible to bring a cooler but NO glass bottles were allowed. A limited amount of shade under a pavilion was available. Accessible air conditioned restrooms were close by. Driving directions were provided in the e-mail message and the site was near the Casino Queen in Illinois.

The park offered great views of the air show without fighting all of the crowds at the arch. Participants could arrive any time after 10:00 AM and had to depart by 3:30 PM. Gateway Center of Metropolitan St. Louis, Illinois American Water and the Bank of Edwardsville joined with MEPRD to provide this opportunity. Individuals with special needs and an aide/personal assistant, who registered prior to the June 17<sup>th</sup> deadline, received a free food voucher that provided a choice for sandwich, chips and a drink. Sandwiches included hamburgers, hot dogs or brats. Drinks included soda or water. Additional food items or snow cones were available for purchase.

Besides the air show, the event also featured interpreters for the hearing impaired, live music from an on-site DJ, audio casts of the air show via speakers on site, a juggler, magician, stilt-walking Uncle Sam, free caricature art and the Gateway Geyser that shoots water 600 feet into the air. Participants could view the air show from the three level Mississippi River Overlook (viewing tower) if they chose to. It was a great day and I hope more people will plan to attend in 2012! If an individual in your group is sensitive to loud sounds, such as when the Marine Corps Harrier flew by, be sure they have ear protection so they can enjoy the full show. There were about 150 participants there but the site will accommodate many more. Make sure we have a current e-mail address on file at [sbstl@charter.net](mailto:sbstl@charter.net) for your family so you receive important announcements about future opportunities such as this Independence Day Celebration!



## **Cardinal Power Kids Classes and Field Trips**

### **For children who are developmentally delayed or physically challenged**

Team Central offers a “modified” gymnastics and movement program endorsed by medical professionals and physical therapists called “Cardinal Power Kids” for children who are developmentally delayed or physically challenged. Team Central Gymnastics also offers one-hour group Cardinal Power Kids field trips for organizations and schools. (Giant Steps participates at our facility twice daily.) Physical therapists have assisted with the selection of modified equipment to enhance the physical and emotional progress of each child. Our professional staff create a fun, safe and educational environment.

Our program develops flexibility, coordination, strength, and self-confidence. Equipment provided includes: special modified equipment, in ground trampoline, balance beams, climbing nets and ropes, bars, incline mats, parachute games and more. Financial-needs scholarships are available. The Cardinal Power Kids program offers special discounted weekly class tuition rates, and 50% off yearly registration fee. Classes are available for children ages 3 and up (parent participation). Call 314-291-0101 for more information about group field trips or weekly classes or to **receive a FREE first time trial class visit.**

**Cost:** \$5.00 per day for the Saturday 8:00 am-8:50 am Supervised Open Gym Weekly Event

**First time free visit to 8:00-8:50 am Supervised Open Gym Event**

**Children may attend weekly or on occasion on Saturdays 8:00-8:50 am**

9:00-9:50 am weekly class available for advanced student (discounted tuition and half off yearly registration fee)

\$6.00 per child for group field trips with a minimum of 7 children signed up

**\*An adult must participate with each child during all of the Cardinal Power Kids programs**

**\*Pre-registration is required for all programs and events**

Contact Person: Lynn Watson

Phone: 314-291-0101

E-Mail: [Lwatson@teamcentral.org](mailto:Lwatson@teamcentral.org)

Team Central Gymnastic Academy

2675 Metro Blvd

Maryland Heights, MO 63043

[www.teamcentral.org](http://www.teamcentral.org)

## SBSTL activities are fun!

Campouts, bowling parties, baseball games, group play dates for our younger members or social activities for our adults, Christmas party, newsletters, whatever the group decides to do! We had a great turnout on 7/17/11 for our family bowling party at Lakeside Brunswick Zone Lanes. We have another family bowling party scheduled for October 9<sup>th</sup> and a bowling outing scheduled for August 7<sup>th</sup> for YAA, our group for SB adults age 17 and older. Both from 1 – 3 PM at Brunswick Zone Lanes.

Financial resources to pay for these activities comes from individual donations, designated government employee donations through the local Combined Federal Campaign and from fundraisers sponsored by your SBSTL board members. These fundraisers include a golf scramble in the spring, two Longaberger Games Nights (bingo type games) and a new activity – a Quarter Auction to be held this December. Help ensure we have funds for activities by participating in our fundraisers or make a donation on-line at [www.sbstl.com](http://www.sbstl.com) !

Our two remaining activities for 2011: Friday, October 28<sup>th</sup>, there will be the Longaberger Games Night held in Bethalto, IL – only about 10 minutes from Alton, IL! This is a fun activity where individuals play bingo type games. There are 20 games played during the evening with all winners receiving Longaberger products as prizes. In addition, there is a specialty basket raffle and a 50/50 raffle.

Friday, December 9<sup>th</sup> A new opportunity for SBSTL, the Quarter Auction will be held at the Alton-Wood River Sportsmen's Club, 3109 Godfrey Road, Godfrey, IL 62035. This facility is easy to access from MO by coming across the Alton Bridge and following Rt 67 north. The "Original" Quarter Auction by Andrea Abbott & Megan Moore is sponsoring our event. <http://www.quarterauctionmania.com/>

A Quarter Auction is a cross between an Auction, a Raffle & a Home Party all wrapped into one!! New & Discontinued items from local Direct Sales Vendors will be auctioned off for 1 to 4 Quarters per item! Each item up for bid will be displayed for all guests to see. The auctioneer then gives a brief description, retail value and how many quarters you will need to bid. Guest will give their bid (in quarters) and hold up their numbered paddle. If you have more than one paddle, you must place a bid for each one. When all bids are collected by your table monitor, the auctioneer will draw a numbered chip from the container. If the number on the paddle matches the number on the chip drawn, the guest wins that item. If a matching numbered paddle is not held up, the auctioneer will draw again, until we have a winner. Once we have a winner all chips will be placed back in the container and go to the next item to be auctioned. Retail values range from \$5 up to \$100 with bid increments as follows: 1 quarter (\$5-\$25 item value), 2 quarters (\$26-\$50), 3 quarters (\$51-\$75), & 4 quarters (\$76-\$100). Bring friends and have a great social time together while supporting your SBSTL!



# Trout Fishing on Wheels

by Kelly and Mark Abbott

You may not know that Missouri has some of the best trout fishing in the entire Midwest. The Missouri Department of Natural Resources (DNR) operates four trout hatcheries in four different state parks (that each offer trout fishing), and also stocks trout in many other streams within the state of Missouri. Missouri also has naturally breeding populations of trout in other streams. So with much experience to guide you, this brief article will introduce you to the world of trout fishing in Missouri's largest Trout Park - Bennett Spring State Park near Lebanon, MO.

Bennett Spring is one of the largest springs in the state of Missouri. During an average day more than 100 million gallons of fresh, cold spring water gushes forth from the ground. The spring stream runs approximately 1.3 miles through the park before it flows into the Niangua River. The park is split into three different zones: zone #1 is for flies and single-hook spinners that must have hair/fur/feathers attached, zone #2 is for flies, hard plastic lures and spinners with treble-hooks, and zone #3 is for treble-hook lures and bait fishing. Bennett Spring has both Rainbow Trout (most colorful) and German Brown Trout (which can get really BIG). The Missouri DNR has developed multiple sites within the park to accommodate the need for accessible fishing.

Within zone #1 there are three wheelchair accessible piers that extend out into the river, one pier above the Holland dam and two piers downstream of the Holland dam. Each accessible pier is paved and is reached by paved paths that lead from the parking areas. The accessible piers also have concrete parking logs around the edge of the piers to protect a wheelchair from rolling off into the water. There are also other areas in zone #1 where you can simply wheel up to the edge of the stream and fish, including directly into the Spring Hole where the water emerges.

In zone #2, there is an area called the "Long Hole" where anyone can wheel up to the edge of the stream; or people can fish from the "Whistle Bridge". The Whistle Bridge is the dividing line between zone#2 and zone #3, and you can fish off the bridge in either direction. Fishing into zone #2 the stream is flowing toward you, so you usually have to cast and reel pretty quickly.

In zone #3 there are two accessible areas, the Whistle Bridge and the "Suzy Hole" (don't ask me how it got named). When you fish off the Whistle Bridge in zone #3, the stream is flowing away from you, so you can usually just cast your lure or bait out and let the current do the work to move it around and attract the fish. The water flow can be pretty strong so the usual problem is getting enough weight on the line to get the lure/bait down to the fish. However, you better believe there are fish there! The last time we went down to Bennett Spring a man caught a brown trout while fishing off the Whistle Bridge that weighed more than 8 pounds! At the second wheelchair accessible location in zone #3, the Suzy Hole, you wheel down a concrete path to a stream bend where fish swimming upstream from the Niangua River stop and rest.

Fishing can cost as much or as little as you desire. There have been some monster trout caught on \$10 Wal-Mart spincast rod/reels, or the sky is the limit if you want to go crazy with fly fishing. If you have a Light or Ultra-Light fishing rod/reel, then you probably already have the gear to get started. The only regular cost is the price of a fishing license (price depends on state residency) and the daily Trout Tag which always costs \$3. Missouri residents over the age of 65 and "disabled" Missouri residents are exempt from paying the MO state license, but still have to buy a Trout Tag. Contact Missouri DNR for the official definition of who qualifies as disabled. Missouri Non-Residents must purchase a state fishing license regardless of any disability.

The state park has a limited number of accessible cabins with various amounts of bedrooms and sleeping facilities - you have to contact the Park office to reserve an accessible cabin. There are many other hotels and motels outside the general area of the park, and these also have limited numbers of accessible rooms/cabins. Early reservations for sleeping accommodations are frequently required due to the popularity of the State Park and the Trout fishing.

Last, but certainly not least, trout are Delicious! The daily limit in the Park is four fish for each person purchasing a trout tag. This means over a weekend your family can all go fishing and bring back enough fresh trout to have a great fish fry in the evening, and take some back for more meals at home. The Park Lodge has a full service restaurant, and if you are not sure how to cook your trout, you can take the trout you caught that day to the Lodge and they will cook it for you, any way you want it - fried, broiled, poached.....YUM!

Final comment - when a child, youth or young adult hooks and lands that first fish, the smiles tell the whole story. You may want to try trout fishing once, but you might get hooked for a lifetime.



## Tips & Tools for Working with Your Child's Educators

As you prepare your children for the upcoming school year, understanding how to get the most from the educational system can require a lot of work. Whether you choose an Individualized Education Plan (IEP) or a 504 plan, successfully accommodating the educational needs of a child with a disability has to be a team effort. Nonverbal learning disorder (NLD) is a common problem in individuals with Spina Bifida, and parents need to educate school personnel, not only about the disability, but about the specific ways in which the disability affects their individual child.

A 504 plan, available under Section 504 of the Americans with Disabilities Act Amendments Act of 2008 (ADAAA), is a general education initiative that can be implemented in the regular classroom. Its purpose is to prevent discrimination against a person with a disability, and to assure that every child has free access to learning. Section 504 is enforced by the U.S. Office of Civil Rights.

An Individual Education Plan is mandated by the Individuals with Disabilities Education Act (IDEA) and allows more specific interventions, going beyond what a regular classroom teacher can provide. Compliance is enforced by the U.S. Office of Special Education, but each state has its own compliance procedures. Contact your state's Department of Education for information. Curriculum cannot be changed under either plan, but with an IEP it is possible to change the tools with which the curriculum is accessed. The use of a calculator and digital clock are good examples. A student with a disability will learn the same material as another student, but he may not go to the depth another student would without the necessary tools.

Generally, implementing an IEP involves a more formal, written process, and is more rigidly controlled than a 504 plan. For example, IDEA mandates re-evaluation at least every three years. A 504 plan requires documentation that a disability exists and how it interferes with a normal life activity, but does not require re-evaluation. Federal law provides schools with additional funding for students on an IEP. No such funding is available for students on a 504 plan.

The laws that provide for both a 504 plan and an IEP place responsibility on the school to provide a "free and appropriate public education" (FAPE) for every child.

### **Recommendations for parents with children in elementary school**

- Reinforce the individuality of your child by bringing a photograph to each intervention team meeting.
- Be open to insights contributions, and new ideas that educators will bring to the table.
- Parents can bring to the table a list of accommodations they feel are needed, but should be prepared to be flexible. Choose which accommodations you need to insist on, and which can be optional.
- As a student grows, his needs or abilities may change, making necessary changes to his intervention plan. The district is responsible for re-evaluating the plan as needed, at a minimum of every three years for an IEP.

### **Recommendations for parents with children in junior high school**

- As your child progresses to higher grade levels, more teachers become involved. Choose one person who can serve as your main contact person. Usually that is a counselor or assistant principal. Your communication with individual teachers for specific issues is still important, but general communications should be made through the contact person.
- Have your child tour the new building before school ends for the summer, allowing him or her to see students at work and to meet some of the teachers. Have her meet the main contact person, be it a counselor or assistant principal, so that she can begin to build a strong relationship with him.
- The lack of recess in junior high may make it necessary to build sensory breaks or a study hall into a student's schedule.
- Work with the teachers to create an IEP for home use which implements many of the strategies that are helpful at school. If you are not reinforcing the positive things that are happening at school, "everyone is just wasting the teacher's time."

For more information on NLD and Education Implications view [SB University's education and employment session](#) titled **Nonverbal Learning Disability and Education Implications** presented by Jannel Phillips, PhD and Kimberly Rotundo, MEd.

**Other resources:**

[IEP – The Complete IEP Guide: How to Advocate for Your Special Ed Child](#), by Lawrence M. Siegel is available through the SBA Marketplace at [www.spinabifidaassociation.org](http://www.spinabifidaassociation.org).

**504 Plan** – Visit the U.S. Department of Education at <http://www2.ed.gov/about/offices/list/ocr/504faq.html> for a list of Frequently Asked Questions.