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## GREETINGS!

Webster's Dictionary defines change as "an event that occurs when something passes from one state or phase to another." Winter changes to spring, time changes forward or backward, and our minds are changed all the time. It is time for a change with SBKC.

After serving on the Board of Directors since 2004 & 2005, Jennifer and I have decided it is time for others to take the lead in the operation of SBKC and will step away from the Board when our terms end on June 30, 2010. We have thoroughly enjoyed working with, and getting to know, all of you as SBKC has grown. Over the years, membership has grown from a few families to currently over 100 on our roster! That is great! This growth is due to your desire to help not only

your own family, but to help all SB families in the Kansas City area. I encourage you to keep this momentum going and get involved in leading SBKC. Elections will be held in June and I hope you realize this is your opportunity to use your skills and talents to have a positive impact on the Spina Bifida community.

Jennifer and I would like to thank each of you for supporting SBKC and we look forward to seeing you at the upcoming events.

Sincerely,

Scott Von Behren  
Chairman

## BIRTHDAYS

### APRIL

Joe Ironwing 4/3

Taylor Smith 4/3

Emily Hallet 4/5

Tony Orr 4/9

Seth Cooper 4/13

Kelly Abrahamian 4/27

Seth Cooper 4/27

### MAY

Brooks Ferguson 5/13

Louise Christianson 5/17

Ryan Glover 5/20

### JUNE

Jasmyn Sloan 6/1

Daniel Fuchs 6/11

Colton Ferguson 6/14

Baylee Ropp 6/21

Taylor Jade McWilliams  
6/21

Andrew Hodges 6/24

If you are having a birthday (April, May or June) and are not listed in this issue, we don't have you on our list. Please fill out the membership application in this newsletter and mail it to us. We would like to acknowledge everyone.



# HORSING AROUND

## An introduction to Hippotherapy

by **Christina Benson** SBKC Secretary

We just started our journey into Hippotherapy. Mia (2.5) loves to be on the horses and we have high hopes that the sessions will help to improve her balance, core strength and hips. It may also help her speech. It is amazing to watch such a little girl on a big horse. We are going to Helping Hands Therapeutic Riding Center ([www.hhtrc.org](http://www.hhtrc.org)). There are several other centers in the metro that may be available for therapy.

The following information is from

[www.adventurous-kids.com/hippotherapy1.htm](http://www.adventurous-kids.com/hippotherapy1.htm)

### WHAT IS HIPPO THERAPY?

Hippotherapy is a term used to describe the movement of a horse as part of a treatment strategy when used by physical, occupational, and speech therapists. The word hippotherapy comes from the Greek word "hippos" meaning horse. Hippotherapy requires a prescription from a physician.

### HOW DOES HIPPO THERAPY WORK?

The natural movement of the horse is used to help individuals increase their functional abilities. The horse's movement translates through the person, causing many parts of the body to do work. This response is sometimes achieved without the person's awareness of their effort. The therapist can modify the horse's movement to promote specific responses within the person. This approach to treatment uses meaningful activities and specific goals, while providing the individual with a joyful experience, in a natural setting.

### WHY A HORSE?

The horse's pelvis moves in the same three ways as a human pelvis does. This creates a movement pattern similar to human walking. The horse also provides

sensory input which impacts the person's vestibular, tactile, and proprioceptive systems. A foundation for the development of sensorimotor abilities is established. Therefore, motor planning abilities are promoted.

### WHAT IS THE DIFFERENCE IN HIPPO THERAPY AND THERAPEUTIC RIDING?

Many people question the difference between therapeutic riding and hippotherapy. The term therapeutic riding is used to describe the recreational aspect of riding. As a recreational activity, riding skills are instructed. Hippotherapy is a medical treatment. During a hippotherapy session, therapeutic goals are addressed to increase neuromuscular function.

### WHAT ARE THE BENEFITS OF HIPPO THERAPY?

Hippotherapy improves:

- JOINT MOBILITY
- BALANCE
- MUSCLE TONE
- HEAD & TRUNK CONTROL
- STRENGTH
- MOTOR SKILLS & COORDINATION
- CARDIOVASCULAR CONDITIONING
- POSTURAL CONTROL
- SYMMETRY
- SENSORY INTEGRATION
- COMMUNICATION SKILLS
- PSYCHOLOGICAL, COGNITIVE, & BEHAVIORAL FUNCTIONING

### WHO CAN BENEFIT FROM HIPPO THERAPY?

Individuals approximately 2 years of age and older can benefit from hippotherapy. They can have a variety of diagnoses including spina bifida and many, many more.

# Doctors Operate on Gorilla with Spina Bifida



In early 2008 veterinarians and doctors from a children's hospital in Seattle operated on a young gorilla born with cyst from near the spine and Spina Bifida. It is believed to be the first procedure of its kind performed on a gorilla.

The baby gorilla was born with the cyst at the base of her back. Because of the way gorillas hold their babies, the mass wasn't noticeable at first, but it continued to grow. Tests showed that it had become infected. Before the surgery, zookeepers trained the mother to carry her baby to them so they could give her antibiotics to help fight the infection.

Doctors confirmed during surgery that the baby also suffers from mild spinal bifida, which is not expected to be a concern as she grows older, they said.

Because gorillas pick at each other to remove dirt or insects, surgeons buried the baby's sutures under the skin and covered them with surgical tissue glue. Zookeepers also painted Amanda's nails red, so she would be distracted and pick at her nails instead of her baby's incision.

Everyone involved was very optimistic about the young gorillas chances at a long healthy active life.

Article taken from: [www.seattlepi.com/local/346922\\_gorilla11.html?source=myspi](http://www.seattlepi.com/local/346922_gorilla11.html?source=myspi)

## SBKC IN CYBERSPACE



You can now become a fan of SBKC on Facebook and follow us on Twitter.

On Facebook search for Spina Bifida Kansas City and become a fan.

On Twitter search for SpinaBifidaKC and follow us.

## CALLING ALL BLOGGERS

Do you have something to say to the SBKC community? Are you familiar with blogging? SBKC is looking for contributors for our blog. If you are interested please email Christina Benson for details: [secretary@sbkc.org](mailto:secretary@sbkc.org)

## ADVERTISEMENT

SPONSORED BY VITAPATH GENETICS

# We're almost there.

Along with our collaborators at UC Berkeley, Stanford University, UC San Francisco and Children's Hospital Oakland Research Institute, we are still seeking 100 more mothers of children with Spina Bifida to enroll in a study.

### Research has shown that genetics play a role in Spina Bifida.

We are developing a groundbreaking genetic test that will enable doctors to identify women at high risk for Spina Bifida. With this advanced knowledge, doctors will be able to safely treat these women with high-dose folic acid.

### Join 900 other mothers who have already enrolled.

Participants will be asked to provide a saliva sample with a simple at-home kit and answer a few brief questions. For more information or to enroll, go to [www.sbgenetics.org](http://www.sbgenetics.org) or e-mail [info@sbgenetics.org](mailto:info@sbgenetics.org).

 SBgenetics.org



# SPRING INTO FITNESS

## What are some enjoyable exercise routines that would fit into life with Spina Bifida?

If you already have an exercise plan, that's a great start. Bear in mind that the purpose of an exercise plan is more than just losing weight. There are many things that exercise provides that are more important in terms of assuring quality of life, such as cardiovascular health, muscular strength, mobility, balance, kinesthesia (physical awareness), and metabolic benefits (for example, improving insulin sensitivity). This doesn't mean that you shouldn't care about maintaining healthy levels of body fat, especially since excess weight can limit mobility and have various negative effects, but it does mean that there are many things to consider when judging whether an exercise plan "works." The benefits of regular activity may not always be immediately obvious.

## What should you look for in your exercise plan?

There are two main things to consider when looking for exercise that you'll stick with:

What your own abilities are (i.e. What

movements can you do easily? do with some tolerable discomfort or difficulty? not do at all? What fits best into your lifestyle and schedule?)

What kinds of things do you personally enjoy? (e.g. Do you like things that are social? Challenging? Sport-based? Etc.)

## Exercise plan considerations for people with spina bifida

People with spina bifida tend to have lower levels of muscle mass compared to the general population, which means they require fewer calories overall. It also means that they are likely to benefit from a well-designed resistance training program.

If you need to be seated for much of the exercise, there are plenty of variations on good basic weight training exercises that you can do with free weights (which can be as light as you need). Check out this bodybuilding website ([bodybuilding.com/exercises](http://bodybuilding.com/exercises)) and Exercise Rx ([exrx.net](http://exrx.net))—there are plenty of seated versions shown in the exercise directories. In addition, check out The National Center on Physical Activity and Disability's website ([ncpad.org](http://ncpad.org)). They have plenty of ideas for training with spina bifida and mobility disorders.

Also, be creative! I've worked with clients who were in wheelchairs because of mobility disorders, and come up with lots of outside-the-box ideas for fun, interesting workouts. For example, we removed the seat from a regular stationary bicycle, pushed the wheelchair up behind it, and voila! instant cheapo recumbent bike! We did shadow boxing, practicing hitting and kicking targets from seated positions. If clients could stand and walk without too much effort, we'd swing a sledgehammer around, squat by getting in and out of a chair for reps, or have walking races uphill. Sometimes they could do quite a lot as long as they had something to hang on to for balance.

Bottom line: Think of the movements you can do, and then think of ways to make them fun and challenging. And add resistance, if possible.

Just a reminder: A good nutrition program is essential for losing body fat. You may wish to consult with a dietitian who can help you work towards your goals.

Krista Scott-Dixon, PhD

Article taken from: [thedietchannel.com/Spina-Bifida-Exercise-Suggestions.htm](http://thedietchannel.com/Spina-Bifida-Exercise-Suggestions.htm)  
[seattlepi.com/local/346922\\_gorilla11.html?source=mypi](http://seattlepi.com/local/346922_gorilla11.html?source=mypi)



A new fully accessible theme park is set to open on April 10 in San Antonio Texas. Morgan's Wonderland is the World's First Ultra Accessible Family Fun Park designed specifically for children and adults with special needs,

their family members, caregivers, friends and the entire community. This 25-acre park is a unique oasis, that through the spirit of inclusion, allows people of all abilities to play, learn and share life changing experiences together, in a fun and safe environment. Reservations are required for all quest to ensure proper accommodations. For more information and to make reservations contact

[www.morganswonderland.com](http://www.morganswonderland.com) or call 877.495.5888



*Spina Bifida*

*Kansas City*

sbkc.org

**MEMBERSHIP APPLICATION**

**IMPORTANT NOTICE: This form must be filled out and returned with dues to remain on our membership roster. Please complete this form and return it to:**

**SBKC — Membership, Post Office Box 1041, Belton, MO 64012**

\_\_\_\_\_ \$15 Individual Adult with Spina Bifida (over 18 living independently) OR \_\_\_\_\_ \$35 Family

Name: \_\_\_\_\_ E-Mail: \_\_\_\_\_

Relationship to individual with Spina Bifida: \_\_\_\_\_

Telephone- Home: \_\_\_\_\_ Cell: \_\_\_\_\_ Other: \_\_\_\_\_

Person w/Spina Bifida: \_\_\_\_\_ Email: \_\_\_\_\_ DOB: \_\_/\_\_/\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_ I am including an additional \$5 so I may continue to receive the newsletter and other correspondence via standard mail rather than electronically.

**Enclosed please find a check for \$ \_\_\_\_\_**

**Please check below if you are interested in:**

Phone calls – Connect with Individuals & Families

Serve on Special Event Planning Committees

Assist in Fundraising

Hospital Visits

Communications – Newsletter & Publicity

Other: \_\_\_\_\_

\_\_\_\_\_



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FINANCIAL ASSISTANCE APPLICATION

Patient's Name: \_\_\_\_\_ Parent or Guardian: \_\_\_\_\_

Address: \_\_\_\_\_ Home Phone: \_\_\_\_\_

\_\_\_\_\_ Cell Phone: \_\_\_\_\_

Patient's Date of Birth: \_\_\_\_\_ E-Mail Address: \_\_\_\_\_

Diagnosis: \_\_\_\_\_

EQUIPMENT (include prescription(s)):

Item(s) Prescribed: \_\_\_ Wheelchair \_\_\_ Braces \_\_\_ Crutches

Other: \_\_\_\_\_

EQUIPMENT COST (approximate):

\$ \_\_\_\_\_ Wheelchair

\$ \_\_\_\_\_ Braces

\$ \_\_\_\_\_ Crutches

\$ \_\_\_\_\_ Other

EQUIPMENT PROVIDER:

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

PRESCRIBING AUTHORITY:

Doctor: \_\_\_\_\_

Facility: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

Phone: \_\_\_\_\_

Other Other Relevant Information: \_\_\_\_\_

\_\_\_\_\_

INSURANCE:

Insurance Coverage? \_\_\_Y \_\_\_N

Covered Amount: \_\_\_\_\_

I, \_\_\_\_\_, give permission to the SB-KC to contact the prescribing authority and equipment provider above for specific information on the patient's case and necessary equipment.

Signature: \_\_\_\_\_

Relationship to Patient: \_\_\_\_\_

Date: \_\_\_\_\_

SBKC USE ONLY
Date Approved: \_\_\_\_\_
Amount: \_\_\_\_\_
Check #: \_\_\_\_\_
SBAKC Representative
\_\_\_\_\_



# SBKC FISHING DAY

**May 22, 2010  
2 - 5 pm  
Prarie Hollow  
at James A. Reed Lake**



Please  
RSVP by  
May 15 to

816.277.9087  
or

[info@sbkc.org](mailto:info@sbkc.org)

## CONTACT US

Many of our events require an RSVP in order to adequately prepare for each event. There are two ways to contact SBKC. You may call (816) 277-9087 any time or you may visit our web site. You may also e-mail us direct at [info@sbkc.org](mailto:info@sbkc.org).

### FREE TO SBKC MEMBERS AND THEIR FAMILIES.

Fishing equipment will be provided but you may bring your own if you desire. Lunch will be provided. One mile east of Lee's Summit on Ranson Road and 1 1/2 miles south of Highway 50.



*Spina Bifida  
Kansas City*

Post Office Box 1041  
BELTON, MO 64012