



Board of Directors

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GREETINGS!

SBKC has had a busy year! We started out with the Skating Party in February with over 50 of you enjoying the music, games and just plain fun at Skate City. Fishing Day in May was another great success with almost 60 of you trying to catch "the big one"! Thanks to Brett and Sheila Hedrick for coordinating this event and to the many sponsors that helped make this an enjoyable day for all. Also in May was our first Applebee's Pancake Breakfast Fundraiser. We raised over \$800 and got to enjoy some great breakfast and fellowship. Thanks to Marianne Sherman for coordinating this event and to Applebee's in Lee's Summit for hosting us! In July and September, several of us enjoyed a Royals game, Buck night and fireworks. Thanks to the Royals for donating the tickets for this game and 2 others this season!

Education Day 2009 was held on September 19 at the Rehab Institute. Sponsored by Hanger, United Seating and Mobility and S.A.V.E., over 125 members, vendors and guests attended and got lots of good information on several topics. Several families attended the discussion on ADHD/

Non-Verbal Learning Disorders by Dr. Carol Russell. Her presentation created several "Ah Ha!" moments as many of the symptoms were right on target for what a lot of our kids deal with daily. Speaking of Education Day, mark your calendars now for next year's event. **Our 3rd Annual SBKC Education Day will take place on Saturday, September 18, 2010.** Once again, the Rehabilitation Institute will provide the location for this fabulous event.

We are currently in our Second Annual Fall Fundraising Campaign. **Please be sure to have your 10 fliers returned to the SBKC office no later than October 31, 2009.** The funds raised from this campaign, our fundraising breakfast and other donations are vital in SBKC's ability to continue offering programs and services to our member families living with the daily challenges of Spina Bifida. Please continue to ask your family, friends and co-workers for their support of our worthy cause!

Your SBKC is operated completely by volunteer families and these families are the ones that put in the time and effort to provide these

programs and events for you. We need more volunteers to step up and help us out. Don't freak out! We're not asking you to help with every event, but we do need you to help with something throughout the year. Can you be available to do hospital visits for our members that are having procedures? Can you help serve and clean up at our next Applebee's Fundraiser? Can you help with Education Day? Can you help with the Christmas Party? Surely there is something you can do to help. No amount of help is too small! Please watch the website and e-mail for how you can help SBKC be as effective as possible!

Lastly, it's Christmas Party time again!! **Mark your calendar for Saturday, December 5, 2009.** We will party from 5pm – 8 pm. Several fun activities are planned for your enjoyment and we will announce the winners of the Fall Fundraising Campaign here as well. The party will be held at the same location as last year, South Haven Baptist Church, in Belton. Watch the website and e-mail for more information!

Thanks for being a part of SBKC!

BIRTHDAYS

OCTOBER

Johannes Ziemann 10/2
Lindsey Collier 10/4
Emberlyn Kala Brown 10/9
Keith Womack 10/13
Declan Beshears 10/27

NOVEMBER

Josh Ruoff 11/1
Samantha Smith 11/9
Chaz Murphy 11/24
Christopher Etchells 11/29

DECEMBER

Jessica Hurst 12/5
Austin Fitzgerald 12/09
Savannah Armendariz 12/10
DeAngello Vincent 12/19
Alexis Brumfield 12/20
Joseph Johnson 12/28
America Grubb 12/30

If you are having a birthday (October, November or December) 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.

CAROL'S CORNER

As I was mulling over a topic for this newsletter, several different ideas surfaced. I definitely want to do an article on dental care but honestly couldn't find the handout on my desk! So probably organization could be the topic but then I am not good at that so we don't do it this time! What kept coming up was colder weather and skin issues. Even though I have discussed it in the past, skin is our biggest organ and does deserve a lot of attention as it protects us from the outside elements which include bacteria. The very basic care of our skin is to keep it clean and dry but moisturized. On my rounds at the hospital, I see so much really dry skin especially on legs and feet. So my first recommendation is to make sure that you apply a good lotion or cream after bathing each and every day. This is even more important as the weather gets colder. Cold air tends to be drier and it makes our skin more dry as well. When skin is dry, it cracks and this leads to the opportunity for sores to develop. Of course, it allows bacteria to enter our body as well. Putting cream on your skin also allows you or your child to check the feet, legs and buttocks area regularly. That is the second recommendation, skin checks are important to do every day. With younger children, mom and dad need to do this check but this is a great job to turn over to the older school age child or teen. However, you do have to make sure they follow through. If you note reddened areas from pressure of the brace, shoes, etc, you can take action right away. If the skin is reddened when the brace is removed, watch closely and see if that redness fades after 15-20 minutes. It should be totally faded by 30 minutes. If it isn't, that is the beginning of a pressure sore and will only get worse if you continue to put pressure on it. That is the time to take action and remove all pressure from the site. Once that skin returns to normal, gradually introduce the shoes or brace again and see if you have a problem.

Better yet, get the brace checked out so that it can be fixed while your child is not wearing it. My third recommendation is to make sure with any new braces and/or shoes, that you put them on for 30 minutes and then check for red spots and keep stretching out the wear time with rechecks. Again, prevention is so much easier and takes far less time than dealing with a wound. When you do find a wound, it is a big deal. Because of poor circulation of blood in the legs, feet and buttocks area, children with spina bifida do not heal quickly. They are very much like the person with diabetes. It is called neuropathic foot for the diabetic

and this is very much the same issue for the child with spina bifida. Seek help from your doctor or nurse early so that

SKIN IS OUR BIGGEST ORGAN AND DOES DESERVE A LOT OF ATTENTION.

you can treat aggressively. Heels and bottoms are the more vulnerable areas for skin breakdown. Sometimes, parents don't think about a change in the child's mobility. This is especially true after surgery when your child may have to be in a wheelchair more than usual. It could also be that they are casted with one leg or both and there is increased pressure on their heels when in bed. My last recommendation is make sure that heels are off the bed if they are casted or the child is not able to change positions by themselves. Support the entire lower leg with a pillow and allow the heels to hang over this. In the wheelchair, set the watch for every 30 minutes to beep and do weight shifts. This means lifting up so that your bottom is off the cushion. Work up to holding for a count of 10 and then gently going back down. It is great if the child can work up to 3 of these in a row but at least doing one is a help. Moving weight from one buttock to the other is also a help. So as we move into this cold season, think prevention and use that wonderful skin lotion, cream to keep skin healthy and intact.





RECIPES FOR HEALTHY BOWELS

We would like to thank Linda Rowley for allowing us to publish her list of bowel friendly recipes. Visit her site at <http://www.waisman.wisc.edu/~rowley/sb-kids/>

POWER PUDDING RECIPE

yield 7 servings (1/2 cup each)

- 1/4 cup applesauce
- 1/2 cup bran
- 3 cups diet liquid red gelatin*
- 1/4 cup prune juice

Mix all 4 ingredients and chill until almost set. Stir and portion into seven 1/2 cup servings.

*made with 1 large box gelatin, 1 1/2 cups hot water, 1 1/2 cups cold water. Mix in a blender.

SENNA BARS*

In a food processor mix the following ingredients:

- 12 oz. raisins
- 12 oz. dates
- 12 oz. prunes
- 8 oz. figs
- 2 oz. senna leaves or ground senna (in health food stores).

Spread in a greased 8"x12" pan and press to 1" deep. Top with graham cracker crumbs. Cut into 1 inch by 1 inch bars and they can be frozen. Try 1 bar a day to start. May be able to reduce to 1/2 bar later on.

SENNA AND PRUNES*

Boil one ounce of senna leaves gently in one quart of water. Strain off leaves and simmer liquid with one pound of prunes until all or most of liquid has been absorbed. Eat one to three prunes every two to three nights.

SPECIAL JELLO

- 1/4 cup apple juice (or other juice)
- 1/4 cup applesauce (or other pureed fruit)
- 2 Tablespoons Psyllium Powder or Citrucel Powder
- 1 small box flavored gelatin
- 3/4 to 1 and 1/4 cup water

FRUIT-LAX

- 1 cup prunes, pitted
- 1 cup dates, pitted
- 1 cup raisins, seedless
- 1/2 cup orange juice
- 2/3 cup prune juice

Steam dried fruit over boiling water to soften. Blend thoroughly in food processor until of spreading consistency. Refrigerate. Can be eaten alone or served on toast, crackers, hot cereal or other food items.

FRUIT PASTE RECIPE*

- 1 pound prunes
- 1 pound raisins-pitted
- 1 pound figs
- 4 oz senna tea
- 1 cup brown sugar
- 1 cup lemon juice

Prepare tea using about 2 1/2 cups boiled water. Steep 5 minutes.

Strain tea to remove tea leaves and add only 1 pint tea to a large pot, then add fruit. Boil fruit and tea for 5 minutes.

Remove from heat and add sugar & lemon juice. Allow to cool.

Use mixer or food processor to blend fruit mixture into smooth paste.

Place in plastic container and place in freezer.

Remove what you need each day, paste doesn't freeze solid.

Dose: 1-2 tablespoons per day

Spread it on toast, eat off a spoon or add hot water and make a drink.

*Senna, a natural laxative, can be very helpful in treating constipation. However, due to the very serious possible senna side effects you should take caution, and speak with you doctor, before using this powerful supplement. Notice: The information provided here is for informational, educational and entertainment purposes only. It is not intended to replace, and should not be interpreted or relied upon as, medical or professional advice.

SPINA BIFIDA RESEARCH STUDY

The Spina Bifida Genetics Research Project is enrolling participants in a study to determine if genetic variations in folic acid metabolism account for an increased risk of having a child with Spina Bifida.

Our objective is to validate a test that can identify at-risk women prior to conception. They could then be treated by their physicians the same way as women who have had a child with Spina Bifida – with high dose folic acid supplementation. Participants in the study are asked to complete an on-line questionnaire and then provide a saliva sample. More information about the study is available at www.sbgenetics.org

NEW SITE

We have updated our website. Feel free to email your comments and suggestions to: webmaster@sbkc.org. Come check it out! sbkc.org



2009 ABILITY DAY - Recreation & Education Fair

Sunday, October 18, 1 - 4 pm THE VIEW- 13500 Byars Road - Grandview, Mo 64030

Individuals and families of all ages are invited to come join in the fun and learn, free of charge, what Kansas City agencies, organizations, and providers can do for them and their loved ones living with disabilities.

Many fun and interesting activities are planned including: · Meet David DeJesus of the Kansas City Royals!, Face Painting, free giveaways, food/refreshments and other great activities! Sports offered at Ability Day: Track and Field * Cycling * Soccer * Bowling *Yoga / Gymnastics *Cheerleading * Golf * Extreme Sports * Basketball * Baseball *Swimming * AND MORE!

REGISTER NOW: 816.316.4888 or www.nscd.org

PEOPLE OF NOTE BORN WITH SPINA BIFIDA:

JADE CALEGORY, actor, main character in Mac and Me.

LUCY COLEMAN, from the children's TV show Signing Time!

JAMES CONNELLY, Paralympian, 2006 Bronze Medal Winner; Sledge hockey

JEAN DRISCOLL, Olympian and eight-time Boston Marathon winner

AARON FOTHERINGHAM, US wheelchair skateboarder

TANNI GREY-THOMPSON, Welsh Paralympian

LAWRENCE GWOZDZ, US saxophonist

BLAINE HARRISON, of the British band Mystery Jets

ROBERT HENSEL, Guinness record holder

RENE KIRBY, Actor in films like: Shallow Hal and Stuck on You

JOHN MELLENCAMP, US rock and roll musician

DR. KARIN MURASZKO, chair of Department of Neurosurgery at University of Michigan, first female appointed to position in the country

DAVID PROUD, British actor

GEORGE SCHAPPELL, conjoined twin and country music musician

BOBBY STEELE, US punk rock guitarist and songwriter

JEFFREY TATE, British conductor

DALE TRYON, Australian socialite and friend of Prince Charles

HANK WILLIAMS, Country Singer

LUCINDA WILLIAMS, Country music singer/songwriter

MILLER WILLIAMS, US poet

JUSTIN YODER, US soap box racer

SB AWARENESS MONTH. WHAT CAN I DO?

by **Christina Benson** - Secretary SBKC



We have had a chance to meet some of you and we look forward to meeting you all. Our daughter Mia was born two years ago with Spina Bifida. She is an absolute blessing. We have learned a lot about SB in these 2.5 years since her diagnosis and we are eager to share this information and spread the word.

National Spina Bifida Awareness Month is a great opportunity to spread the word about SB advocacy and prevention. You might consider providing information to your co-workers, congregation, other parents at daycare or school or even just sharing new knowledge with friends or family. I know that Tim & I had no information about what Spina Bifida was until we found out about Mia. Knowledge is power!

Tim, Mia & I just were recently able to take this to heart. We had an opportunity to meet with a family that had a new little boy with Spina Bifida. They did not know about it until he arrived so they were full of questions and concerns. You could see a little weight lift off of their shoulders when they met Mia and saw her commando crawling around and being her cute little self (mother's bias here). To see a child doing so well and being so normal can make a big difference. We were so happy to be able to provide support to this family that was in the place we were just two short years ago.

We can all do our part to help others prevent Spina Bifida by spreading the word about folic acid. The CDC urges women to take 400 mcg of folic acid every day, starting at least three months before getting pregnant, to help prevent major birth defects of the baby's brain and spine, including spina bifida. Women who had one pregnancy affected by spina bifida are at an increased risk to have another. Women can talk to their doctors about taking 4,000 micrograms (4.0 milligrams) of folic acid each day at least 3 month before getting pregnant and during the first few months of being pregnant. This is ten times the amount most people take. As you brag about the great things your child is doing, or explaining Spina Bifida do not forget to pass this important information along. You'd be surprised how many women are not informed.

Often as we go about our day to day lives people may seem curious about our, or our children's, differences in ability. What are great opportunity we have to educate others! Often these people may have the best intentions and truly would like to be informed but may feel embraced or rude about asking. This is an opportunity to open up a dialog about SB. So get out there and spread the word.



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: _____



Spina Bifida

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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



UPCOMING EVENTS

OCTOBER

2nd Annual Fall Fundraising Campaign

NOVEMBER

12-15 Ararat Shrine Circus (Municipal Auditorium)

DECEMBER

5 Christmas Party - South Haven Baptist Church, in Belton.

For more information & updates visit us at 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.

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