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this issue

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GREETINGS!

As I pondered what I wanted to bring to you in this issue of the newsletter, the voice in my head said "I don't have time for this". As I grappled with that feeling, I recalled a short story I recently heard that I believe we all can learn something from.

A man received a letter from his bank with some outstanding news. Each and every morning at 8:00, the bank will deposit \$86,400 in his bank account. That's right, \$86,400 every day will be his to do whatever he pleases. The ONLY stipulation is that he has to spend every bit of it in that 24 hour period. He can invest it, spend it or even give it away, but he has to use all \$86,400 every day. If he fails to use it, even just one time, he will lose the opportunity to get that \$86,400 every morning. Zip. Nada. Zero is what he'll receive if he does not take full advantage of this wonderful opportunity. What would we do if we had that opportunity? What if, instead of \$86,400 every morning, we got 86,400 of something else?

Well, amazingly enough, each of us gets exactly 86,400 of something every morning. Every single, solitary day you and I each get 86,400 seconds. And, unlike the man in the story, we get another shot at the 86,400 seconds every day no matter what we did with our previous stash of time.

Living with the daily challenges of Spina Bifida is not easy for anyone. Some families struggle more than others. SBKC is here to help but is only as effective as it's membership wants to be. Please do not misunderstand. I know we are all very busy. But is it possible for you to use part of your 86,400 seconds to help other families that are in the same situation you are in or have been in the past? The first thing I'll ask you to do is get your membership application/information update forms turned in with your annual dues (\$15 for individual with SB or \$35 for a family). For those of you that attended the Christmas Party, the application was in the info packets you got when you

checked in. If you participated in the Fall Fundraising Letter Campaign, your dues have been waived. The second thing I'll ask of you is to consider giving a little of your time to help with some of our events and activities. Can you help coordinate the skating party? Can you help get sponsors and donations for Education Day? Can you make hospital visits? Can you be a support line for new SB families? Can you help prepare for the next Christmas Party? Anything else you can think of?

In closing, I'd also ask some of you to consider helping guide SBKC by becoming a member of the Board. While all current Board members continue to be dedicated to keeping SBKC in strong shape for the future, several have made this commitment for upwards of 5 years or more and are ready for others to step up and take the lead. Please contact any Board member if you have questions about how you can help lead the way!

Scott Von Behren

BIRTHDAYS

JANUARY

Alyson Walker 1/3

Matt Sherman 1/14

Annabelle Walston 1/26

Ava Hawn 1/27

FEBRUARY

Ashley Cardin 2/9

Delaney Murphy 2/15

Dakota Brown 2/27

MARCH

Jeremy Turner 3/2

Michael Schaeffer 3/3

Brett Hedrick 3/20

Joseph Stoermann 3/22

Lauren Cox 3/26

Zaylee Zahabi 3/27

Zaylee Bell 3/31

If you are having a birthday (January, February or March) 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

by Carol Hafeman

Professional Advisor to SBKC

FEBRUARY IS KNOWN AS HEART HEALTH MONTH so I thought it was appropriate to ponder a few minutes on heart health. I decided to focus on heart health of the moms and dads out there for this column.

If we have healthy moms and dads, we will definitely have healthier children so it does all fit! But where do you find the time? There is no easy answer to this question as you know but recent studies have pointed out that finding 15 minutes a couple times a day is beneficial.

Taking a walk at lunch, walking the steps instead of the elevator or doing some yoga stretches can be invigorating as well as good for you. Using cans of food in the pantry to do some upper body strengthening is also readily available and doesn't have to take a lot of time.

Many employers are now offering health fitness classes as they know it makes business sense to have a healthier workforce. A yoga or pilates class gives you the opportunity to focus for a short time on you and can be very relaxing. More important, starting a program will spill over into other parts of your life. You may notice that you make healthier choices at the grocery store or when picking up that quick meal for dinner for the family. Most of all you will begin to notice how much better you feel about yourself.

A wonderful benefit may be that your children will want to join in. So begin to look for those short periods during the day to have some "me time" and know that you are making your heart healthier. Find a way to care for your heart and it will help you care for those you love.

Happy healthy heart month!



Quotes

"Every accomplishment starts with the decision to try."

Author Unknown

"More than anything else, I believe it's our decisions, not the conditions of our lives, that determine our destiny."

Anthony Robbins

"Be who you are and say what you feel because those who mind don't matter and those who matter don't mind."

Dr. Seuss

Folic Acid Awareness

Sponsored by the National Council on Folic Acid (NCFA), Folic Acid Awareness Week (Jan. 4-10, 2010) is intended to educate all women about folic acid, which can help prevent birth defects of the brain and spine.

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 have had a 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 1 month before getting pregnant and during the first few months of being pregnant. This is ten times the amount most people take.

For more info about Folic Acid Awareness Week, go to <http://www.folicacidinfo.org>

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

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Help make a difference

You can make a difference in the future with a few minutes of your time.

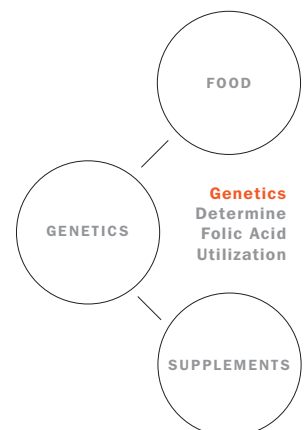
Research has shown that genetics play a role in Spina Bifida. We are trying to identify genes associated with an increased risk for Spina Bifida. Our hope is that this study results in a better understanding of Spina Bifida so that some day it may be prevented.

It's easy to help. We are seeking mothers of children with Spina Bifida to enroll in this important study. Participants will be asked to complete a brief online survey and provide a DNA sample using a simple at-home saliva collection kit. Once the project is complete, participants will receive a complimentary test for a personalized genetic report.

For more information and to enroll in the SB Genetics Research Project, please go to www.sbgenetics.org and select ENROLL. Our website and survey are available in both English and Spanish. If you would prefer to take the survey by phone, call 1-866-561-3538.

PARTICIPANTS MAY CHOOSE TO RECEIVE A US\$10 GIFT CARD OR TO HAVE US DONATE US\$10 TO SPINA BIFIDA.

The SB Genetics Research Project includes scientists from UC Berkeley, Stanford University, UC San Francisco, Children's Hospital Oakland Research Institute and VitaPath Genetics.



BARRIER-FREE LIVING

A LOOK AT UNIVERSAL DESIGN



Universal design is a way of designing all products and environments in a way that makes them usable by everyone, to the greatest extent possible, regardless of age, ability, or situation. It serves people who are young or old, with excellent or limited abilities, in ideal or difficult circumstances. Universal design benefits everyone by accommodating limitations.

A new movement has arose to encourage more Universal Design in everyday objects and places. It is nice to know that as we make adjustments to our homes or plan for new ones to accommodate our, or our children's, evolving needs that these resources are available.

There are seven main principles of Universal Design:

1. Equitable Use:

The design is useful and marketable to any group of users.

2. Flexibility in Use:

The design accommodates a wide range of individual preferences and abilities.

3. Simple and Intuitive Use:

Use of the design is easy to understand.

4. Perceptible Information:

The design communicates necessary information effectively to the user.

5. Tolerance for Error:

The design minimizes hazards and the adverse consequences of accidental or unintentional actions.

6. Low Physical Effort:

The design can be used efficiently and comfortably.

7. Size and Space for Approach and Use:

Appropriate size and space is provided for approach and use.

Here are some of the common Universal Design features used in homes:

No-step entry.

No one needs to use stairs to get into a universal home or into the home's main rooms.

One-story living.

Places to eat, use the bathroom and sleep are all located on one level, which is barrier-free.

Wide doorways.

Doorways that are 32-36 inches wide let wheelchairs pass through. They also make it easy to move big things in and out of the house.

Wide hallways.

Hallways should be 36-42 inches wide. That way, everyone and everything moves more easily from room to room.

Extra floor space.

Everyone feel less cramped. And people in wheelchairs have more space to turn.

In the Kansas City area the Coalition for Independence is available to help individuals and families adapt or plan changes to living spaces allow for a more Universal Design.

Living independently and comfortably in one's own home can be achieved at virtually every level of physical ability or stature. CFI's Universal Design Housing Network can help design new or modify existing structures for barrier-free living. Through a partnership with the Home Builders of Greater Kansas City and LifeStyle Properties, the EasyLiving Home® Idea Center demonstration model, housed at CFI's Missouri office, features concepts and resources to create easy access, more mobility, increased safety, and greater comfort in a home. Visitors to the Easy Living Home® Idea Center may experience a universal design home complete with living room, kitchen/dining area, bedroom, laundry room, and two bathrooms.

For more information about the Coalition for Independence contact them at 913-321-5140 or www.cfi-kc.com.



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

Kansas City

sbkc.org

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: _____

INSURANCE:

Insurance Coverage? ___Y___N

Covered Amount: _____

Other Relevant Information: _____

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



EVENTS

Here is our schedule of events for 2010. Some dates are tentative. We will post updates to sbkc.org as new information becomes available.

Skating Party - 4/3

Fishing Day - 5/22

Royals Game - July or August TBD

Education Day - 9/18

Christmas Party - December TBD

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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Spina Bifida
Kansas City

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