



The Evergreen

November 2009

Spina Bifida Association of Washington State
A chapter of the national Spina Bifida Association

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WHAT IS SPINA BIFIDA?

Spina Bifida is the most common permanently disabling birth defect in the United States. An average of eight babies every day are born with Spina Bifida or a similar birth defect of the brain and spine. There are over 60 million women in the US who could become pregnant and each one is at risk of having a baby born with Spina Bifida.



WHAT IS SBAWS?

SBAWS is the Washington chapter of the national Spina Bifida Association (SBA), which serves over 180,000 adults and children who live with Spina Bifida. Since 1973, SBA has acted as the nation's only voluntary health agency dedicated to enhancing the lives of those with Spina Bifida and the more than 250,000 people whose lives they touch. Through SBA and its network of chapters, parents of children with Spina Bifida are empowered with information and support services, teens transition into newfound independence, and adults lead productive and fulfilling lives.

Newsletter Editor
 Celeste McCormick
 celtutt@yahoo.com

Have you moved recently? Is the postal service forwarding this newsletter to your new address? We do not want you to miss an issue or any other important mailing from SBAWS, so please send us your updated contact information!

GETTING TO KNOW YOU: THE SBAWS OFFICE

The regular “getting to know you” piece usually features the story of an individual friend, member or constituent of SBAWS so that we can get to know each other better and show the rest of the world who we are one person at a time. In this issue, though, we will have the chance to get acquainted with a feature of our chapter that is just as important as *who* we are because provides tangible sense of *where* we are: our permanent office. Maintaining a permanent office is an SBA-affiliation requirement. A new computer and accessible bookshelf were recently installed in our Spokane office, located at 2128 N. Pines Road Suite 17-3. The costs of this equipment were subsidized by donations. Please visit the office in person whenever you are next in Spokane!



NEED A COMPUTER? SBAWS HAS ONE FOR YOU FOR FREE!

by Patti Logan, Chair of the Board
In the June 2009 issue of *The Evergreen* we first introduced you to the partnership between SBAWS and Oly-Geek in Olympia to refurbish computers and provide them free of charge to friends in need. The computers include Windows XP, Microsoft Office 2007 Pro Plus and various anti-virus and email programs.

As of October 31, the first two computers have been matched with new homes. Eight more will be made available, so now is the time for those of you WITHOUT computers or who have NEVER had a computer to speak up. We can provide one for you for FREE. Just two requirements: 1) We need to know who you are and 2) You need to identify someone in your area that can give you technical support as you use the computer. Each individual user is responsible for securing internet service. If you live within 100 miles of

Olympia, we will help you set it up in your workspace.

This first computer was nicknamed Pilot since it took 440 hours of tech time to prepare for us. SBAWS has paid for all the licenses and set up. Would you or someone you know benefit from this gift? This is a true resource for someone who might want the medical information, resources and networking opportunities available through the internet. Are you isolated from cyberspace? Would you like to browse the internet and email friends but don't have the money for a new computer? These are not just basic computers—they come loaded with full versions of all the primary programs. If you or someone you know can benefit from a personal computer, please contact SBAWS: email sbaws@yahoo.com or call 253-589-3700/toll free 1-888-289-3702 or Patti Logan 360-491-3171.

President
Ed Kennedy, ejk@cordwa.info
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az@w-link.net
Secretary
vacant
Treasurer
Jon Tutt, jon_tutt@msn.com

Board Members
Patti Logan (Chair)
Mariah Bates
Linda Bailey
Michele Hopkins
Brian Knowles
Jason Lane
Gloria Olson
Meg Paulsen
Nicole Williamson

Our popular feature “the President’s message” will return in our next issue.

OPEN CALL FOR OFFICER & DIRECTOR NOMINATIONS



Jon Tutt

Dear Association Members:

At the December 2009 SBAWS Board of Directors meeting, new officers and directors will be nominated and elected. The Board would certainly appreciate your input on this very important matter as we move forward into the new year.

We believe we have an exciting year ahead with lots of changes and exciting activities and would like our board to reflect a wide area of knowledge and expertise.

If you would like to volunteer to serve on the board and/or would like to nominate someone for one of the open positions please let us know by calling or sending us an email before the end of November.

Questions? Comments? Let us know!

Jonathan A. Tutt, Secretary/Treasurer/Webmaster

Why aren't we "members" anymore? Get the scoop here... According to our new bylaws which were recommended by SBA, approved by the Board in October and take effect on January 1, 2009, we are no longer a "membership-based" organization. Basically, this means that paying dues is not a necessary requirement for belonging to our chapter. Furthermore, our constituency base is the entire population of the state of Washington. Therefore, after a lengthy discussion at the Board of Directors meeting in October, it was agreed that, when referring to persons with whom our chapter interacts, we will call them "members, donors and constituents" (terms which are also being used by other SBA chapters) . Members are those with whom we are in regular contact; donors are those who contribute financially; constituents are everyone else. To see the full text of the new bylaws, visit the SBAWS website or contact SBAWS to receive a copy.

October 2009 was National Disability Employment Awareness Month.

Read others' stories of success at <http://www.ed.gov/about/offices/list/osers/deam-2009/index.html>.

TechSoup.org offers nonprofits a one-stop resource for technology needs by providing free info, resources, and support. In addition to online information and resources, it offers a product philanthropy service called TechSoup Stock. Here, nonprofits can access donated and discounted technology products, generously provided by corporate and non-profit technology partners. Visit www.techsoup.org for info.

GROUP DISCOUNTS AVAILABLE ON NEW BOWEL MANAGEMENT PUBLICATION

Through your affiliation with SBAWS, a chapter of the national SBA, you are eligible for a group discount on a new guide called "Bowel Management and Spina Bifida." Contact SBAWS if you wish to make a purchase. With the group discount, the cost is \$9.00 plus shipping and handling. Shipping & handling costs are cheaper if more people order at once. For a description of the guide, visit

<http://www.spinabifidaassociation.org/site/apps/ka/ec/product.asp?c=liKWL7PLlrF&b=2705387&en=ojPKXOMJeIPKdNLJ8IUJeMWJIIQJ3POKiJOIaOYJxG&ProductID=454740>. Other publications are available from SBA's online marketplace, but the discounted rate is only available through SBAWS and Leaders Online.

SBAWS celebrates SB Awareness Month with fundraising efforts



Michael charms another shopper

October was Spina Bifida Awareness month and SBAWS conducted several important fundraising campaigns: SBA's Adopt-A-Ghost, Macy's Shop for a Cause, and a special in-store event at Cursty Bella in Seattle. The final numbers have not yet been crunched, but they should be available by the next Board meeting in December. THANK YOU to everyone who worked so hard at these events to raise money for our programs. We are especially grateful to Michele Williamson who organized the Adopt-A-Ghost program again this year and to Jon Tutt who coordinated Shop for a Cause. Jon and his grandson, Michael, spent all afternoon at Northtown Mall in Spokane and Michael sold passes like hotcakes—even to people done with their shopping and on their way out the store! Was it because of Michael's natural charm or those signs that Jon made us wear around our necks? Only the shoppers know.

**we need
your help**

My name is Heather Logan. I was born with Spina Bifida 23 years ago. I am a volunteer Facilitator for SBAWS. We would like to organize a 1 mile/5 mile Walk & Roll for Spina Bifida awareness in the Olympia/Lacey area March 20, 2010, along a portion of the Chehalis Western Trail. If you are interested in the details on the Chehalis Western Trail, its website is <http://www.co.thurston.wa.us/parks/Trails/cw-trail.htm> (The SBAWS walk would begin at Pacific Highway in Lacey, WA by Taco Bell/Pizza.)

We need a lot of help to make this a successful and safe event. Would you like to be part of our planning team? Would you like to walk or roll with us on March 20? What skills do you have to help us? Have you participated in a similar event, and if so, what was your experience? We'd like to hear from you! Thanks in advance for your help. We are all equal!

Here's what we know we need help with so far:

- **Researching online donation companies to generate contact info for donors**
- **Creating a brochure for the event**
- **Contacting other SBA chapters that have successfully completed a walk**
- **Finding a T-shirt company at low cost**
- **Updating and expanding the SBAWS Partners & Donors database**
- **Recruiting day-of-race volunteers**
- **Recruiting corporate sponsorships**
- **Procuring food & beverages**
- **Researching insurance needs and companies**
- **Marshalling crafters to make Spina Bifida bunnies**
- **Requesting the attendance of legislators and the governor**
- **Arranging for awards, prizes, and items to be sold**
- **Scheduling media coverage**
- **Teaching us how to use Facebook, Twitter and/or My Space for donations**



SBAWS Board of Directors approves new fundraising plan

In October, the Board of Directors approved a new fundraising plan for our chapter (see the full text of the plan at www.sbaws.org/development.html). The SBAWS Development Committee is responsible for carrying out the plan and needs more members! Do you have an idea for a fundraiser? Are you interested in contributing your time and talent to our upcoming fundraising programs? If so, please send your name and ideas to sbaws@yahoo.com.

Third Quarter 2009 Comparative Financial Statements

	2009	2008	\$ Change	% Change		
Income						
Membership Dues	\$ 90.00	\$ 765.00	\$ (675.00)	-88.2%		
General Donations	\$ 476.40	\$ 232.61	\$ 243.79	104.8%		
Fundraising Activities	\$ 471.15	\$ 2,232.71	\$ (1,761.56)	-78.9%		
Special Donations	\$ 370.00	\$ 1,247.60	\$ (877.60)	-70.3%		
Summit Registrations	<u>\$ -</u>	<u>\$ 520.00</u>	<u>\$ (520.00)</u>	-100.0%		
Total Donations	\$ 1,407.55	\$ 4,997.92	\$ (3,590.37)	-71.8%		
Other (Interest)	<u>\$ 511.51</u>	<u>\$ 1,119.53</u>	<u>\$ (608.02)</u>	-54.3%		
Total Income	<u>\$ 1,919.06</u>	<u>\$ 6,117.45</u>	<u>\$ (4,198.39)</u>	-68.6%		
Expenses						
		% of \$ Spent		% of \$ Spent		
Mission/Program	\$ 10,612.17	82.7%	\$10,496.00	84.9%	\$ 116.17	1.1%
Depreciation	<u>\$ 708.82</u>	5.5%	<u>\$ 432.72</u>	3.5%	<u>\$ 276.10</u>	63.8%
Total Mission/Program	\$ 11,320.99	88.3%	\$10,928.72	88.4%	\$ 392.27	3.6%
Administration	\$ 1,043.50	8.1%	\$ 1,154.31	9.3%	\$ (110.81)	-9.6%
Fundraising	<u>\$ 462.52</u>	3.6%	<u>\$ 278.82</u>	2.3%	<u>\$ 183.70</u>	65.9%
Total Expense	\$ 12,827.01	100.0%	\$12,361.85	100.0%	\$ 465.16	3.8%
Net Income (Loss)						
			\$ (6,244.40)		\$ (4,663.55)	74.7%
Total Assets						
	\$ 32,422.34		\$41,440.47		\$ (9,018.13)	-21.8%
Total Liabilities						
	<u>\$ -</u>		<u>\$ -</u>		\$ -	
Total Equity						
	\$ 32,422.34		\$41,440.47		\$ (9,018.13)	-21.8%

Financial statements are of most value in comparison to something, a budget or previous year's performance; that's why I present them this way.

Income: Our total income was almost **70% LESS** during the first three quarters as compared to last year. Membership donations have almost all but vanished, fundraising only consisted of Don Stevenson's walk as we sold no Domino's cards and the Macy's event wasn't until October. We didn't have a silent auction this year and we didn't have a Summit. The only bright spot is that general donations doubled, but that only amounted to \$232.

Expenses: Although it was spent in different ways, our Mission/Program expenses were virtually a mirror image as last year. The difference in Administrative and Fundraising expenses was statistically insignificant..

Net Income (Loss): Our net loss this year is 75% greater this year as compared to last, not because of increased expenses, but due to significantly reduced income.

Expenditure by Category: are still at an acceptable level as the standard in the non-profit world is no more than 25% for Administration/Fund Raising.

Net Worth: Our fund balance (cash in the bank) decreased by \$9,018.13 or 21.8% between September 30th, 2008 and September 30th, 2009

Trend Analysis: Spending more than you take in is a trend that cannot go on indefinitely or we'll go broke. As I've said many, many times before, decreasing our spending is not the answer, but increasing our income is, and it needs to be done very soon!

Jonathan A. Tutt, Treasurer

National Walk-N-Roll Web Site Launches

This year SBA is testing its new Walk-N-Roll event in three locations (Washington, DC, Phoenix, AZ, and Madison, CT). To support these efforts, and future Walk-N-Roll events, SBA has created a National Walk-N-Roll Web site linked to the National SBA Web site. It can also be found at www.walknrollforsb.org. If you are interested in participating in this pilot, please contact Sara Struwe at sstruwe@sbaa.org or 800-621-3141 ext. 12



Laura Tellado

Hello Friends in the Spina Bifida Community!

My name is Laura Tellado, and I am a 22-year-old University of Central Florida student with spina bifida. Recently, I began a blog (<http://willyoubemyhero.wordpress.com/>) that will in part chronicle my life with SB, as well as educate people and promote awareness of SB. My goal is to keep the blog for at least a year, during which time I will write to one celebrity or public figure per day, in the hope of finding a person willing to become the national spokesperson for people with spina bifida. I have been working toward this goal since I was ten years old by writing letters, but my attempts proved futile, and many times I grew discouraged. I sincerely hope you will all forward it to anyone and everyone that you know. I figure if I can now count on the support of all those in the SB community, I have a better chance of fulfilling my dream. It's about time that spina bifida receives the level of recognition it deserves, given the high level of incidence. As many prevention initiatives prove fruitful, I fear that public interest in those of us already living with it is rapidly decreasing.

Please do not allow us to be forgotten.

You can also join Laura's social networking site promoting awareness and providing support for people with Spina Bifida : <http://willyoubemyhero.ning.com/>:

The Kitsap Cluster hosted an Autumn Party on October 24. The event, sponsored by SBAWS, featured fun fall events like pumpkin painting. To get involved with the Kitsap peninsula cluster or find out about upcoming events, contact cluster leaders **Dave Lewallan 360-871-5139** or **Rebekah Uhtoff 360-782-0467**

MAKE-A-WISH SENDS SPOKANE FAMILY TO DISNEY WORLD

A wish recently came true for Michael Hoyt, 11, living with Spina Bifida: thanks to the Make a Wish Foundation, he and his family (sister Chandra, 9, and parents Colette and Chris) traveled to Florida in October to visit Disney World, the Magic Kingdom and Universal Studios. Michael says that on his birthday he was surprised with the trip "out of nowhere!" Both kids had a blast on the park rides: Chandra's favorite ride took her to the top of a high mountain and then sent her back down backwards! Michael loved the 3D Spiderman roller coaster: it was "so cool" and felt like Spiderman was really on the roller coaster with him. Chandra, who loves animals, had her picture taken holding a huge snake. She said "it was so heavy I could hardly stand up!" For Michael, "the best part ever" was another surprise. One day during the trip, he and his sister were told they would get ice cream if they were good. "Well, we didn't get ice cream—instead we went to a real live wrestling match!" It was a taping of Total Nonstop Action (TNA) Wrestling and Michael got to meet one of favorite wrestlers, Bobby Lashley. Michael says "my autograph book is totally filled." The kids certainly appreciate the gift they received. Chandra wants everyone to know that the "Make A Wish people were so generous and nice to send us there."



Michael & Chandra
At Disney World



Michael was granted a wish because his parents filled out an application and his eligibility was confirmed by a treating physician. Eligibility is determined by a life-threatening (not necessarily terminal) condition. To learn more about the process, visit www.wish.org



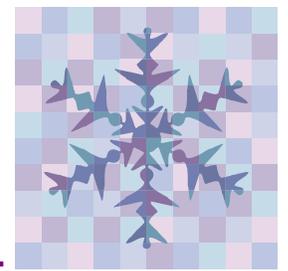
Elizabeth Scriven
with KC the kitten

Growing up with a disability is not always easy.

Especially in those teenage years, I remember! A new group is forming within SBAWS with the goal of connecting teens with SB ages 13 and over with adults who have SB in an informal mentoring group. We would do group activities on a quarterly basis and would hopefully be able to link teens and adults who live in the same area together to make getting together on a regular basis easy. Adults would be responsible for sharing their experiences, answering questions from the teen, and being a positive, healthy role model. Teens would be able to ask questions about life, have fun with someone else in a chair, and hopefully learn that they are not the only ones with SB and that they are whole, complete, and valued individuals just the way they are! **If you have questions, comments or would like to get involved please contact me, Elizabeth Scriven, by phone or email: 425.280.3168, liz-biz@iname.com.** The group will hopefully start coming together soon with our first activity in the new year.

The Seattle Cluster's annual holiday party is Saturday December 12!

This fun event is regularly attended by over 100 people, so mark your calendars! Details (like when & where) will be forthcoming from the cluster or you may contact the Seattle cluster leaders by phone or email seattlespinabifidagroup@hotmail.com.



SBA'S SOCIAL NETWORKS

facebook

YouTube

myspace[®]
a place for friends

twitter

Would you like your story featured in *The Evergreen* and on the SBAWS website? We want the world to know that we are more than just SB—we are real people. It's okay if you're not sure how to get started —just contact the newsletter editor for help!

To get involved with a cluster group or to find out about upcoming events, please contact the cluster leader in your area.

GET INVOLVED WITH YOUR CLUSTER TODAY!

City/State	Leader Name	Contact Phone
CLUSTER DEVELOPER	Michele Hopkins	425-844-1262
Everett & Eastside Seattle	Brenda Stroud	425-385-2487
	Michele Hopkins	425-844-1262
Spokane WA	Ed Kennedy	509-465-0676
South King County WA	Brian Knowles	253-887-0888
Seattle WA	Nicole Williamson	303-877-5083
	Jason Lane	206-363-3726
Kitsap WA	Dave Lewallan	360-871-5139
	Rebekah Uhtoff	360-782-0467
South Puget Sound WA	Heather Logan	360-888-0782
	Patti Logan	360-888-7701
Leavenworth WA	Ed Baroch	509-548-5697
Spanish	Anthony Williams	253-588-4411

SPINA BIFIDA IS NOT A DIAGNOSIS.

by Dr. David Shurtleff, Medical Advisor to SBAWS, with Celeste McCormick

The term “Spina Bifida” (SB) is used broadly to refer to a wide range of neural tube birth defects, but in itself is insufficient to describe the nature of a true medical condition. It is important to understand the distinctions between the various forms not only so that we as representatives of SBAWS can speak with authority and understanding but, more importantly, so that those affected by the various forms can be well-informed about the unique causes, consequences and treatment of each type. Dr. David Shurtleff, Medical Advisor to SBAWS, provided the following clarifications.

Spina Bifida Aperta (Myelomeningocele) is the most common form and is generally what people mean they say “Spina Bifida.” This form invariably affects the entire neural tube, causing varying degrees of mental impairment from mental retardation to learning disorders. This type of disorder can be reduced by at least 50% in siblings, off-spring of the af-

The Folic Acid approach to prevention does not take into account an emerging differential diagnosis of inheritance.

affected person and first degree relatives by intake of large doses of Folic Acid (4 milligrams per day by mouth) starting three months prior to conception. This blanket approach to prevention of the Aperta form of SB does not take into consideration an emerging differential diagnosis of inheritance: namely, that the Aperta form can be inherited (i.e., of either genetic or chromo-

somal origin). Within the last six months, Dr. Shurtleff has made the chromosomal diagnosis in two Aperta patients using new micro-chromosomal analysis. The patients’ families are now getting workups at a genetics clinic because of the possibility that first degree female relatives may be carrying the chromosomal abnormality.

Another form of Spina Bifida Aperta called Meningocele has a skin-covered protrusion of membranes only. This form is not associated with other nervous system abnormalities nor has it been identified as being caused by abnormalities of genes or chromosomes and is not known to reoccur in families nor be decreased in recurrence by folic acid. Babies are born without paralysis but unfortunately may develop loss of function of nerves to the sphincters or legs later in life due to spinal cord tethering.

Spina Bifida Occulta comes in many forms that are not easily classified. However, they are distinguished from the Aperta forms (which have an area that is not skin covered) because the Occulta lesions are skin-covered. All Occulta forms share the common association of leaving the brain normal unless there is another existing condition. In addition there is a much reduced recurrence in offspring and first degree relatives. These forms are also not affected by the woman at risk by taking large doses of Folic Acid.

The most common Occulta form is characterized by a split in L5 that sometimes is fused with the sacrum (S1). This type, as detected by x-ray, occurs in approximately 7% of persons. This abnormality has no neurologic consequences. It is more common in families with multiple cases of Spina Bifida Aperta than in families with none. However, Spina Bifida Occulta at L4 or higher is much more frequent in families where an Aperta form is already present.

Lipomeningocele and Lipomyelomeningocele are the most common Occulta forms, characterized by fat (lipo), membranes covering the nervous system (meningo) a sac (cele) and sometimes nerves (myelo).

According to Dr. Shurtleff, these two forms should more accurately be divided into three types.

1. Lipomyelomeningocele is the most common of the

Definitions:
 cele = sac
 lipo (or lipoma) = fat
 myelo = nerves
 meningo = membranes covering the nervous system

So, exactly how many people in Washington have Spina Bifida?

There is no official count of the number of persons with Spina Bifida (SB) in the state of Washington. However, the Washington Department of Health recently issued new estimates on the prevalence of Spina Bifida in the state. Based on these statistics, the SBAWS approximates that about 1500 people in Washington have SB. However, Dr. David Shurtleff, Medical Advisor to SBAWS, points out that assessments like the one done by the health department are still just educated guesses because there are no standards regarding which types of Spina Bifida are counted nor are all new SB births reported accurately. To read the full report from the Washington Dept. of Health, go to http://www.nbdpn.org/current/2009pdf/StateProfiles/WA_2009.pdf

SPINA BIFIDA: many forms, causes, treatments

(Continued from page 8)

lipo Occulta forms. It may present at birth with or without paralysis and with or without external signs. Obvious signs at birth include: a bulge that is skin covered over the lower spine or sacrum; vascular lesions over the same area; a dimple above the gluteal cleft (usually not in the midline but off to one side); a hairy patch over the same area. A person with true Lipomyelomeningocele has a high risk of developing irreversible paralysis if no paralysis is present at birth. Therefore, Dr. Shurtleff and his colleagues at the University of Washington recommend early preventive surgery with de-bulking. This type of Lipomyelomeningocele usually cannot be completely resected because the fat tissue is in the central portion of the spinal cord and to attempt to remove it would cause further paralysis. This type has a high risk of progressing to cause paralysis and, therefore, requires close follow up and de-bulking soon after paralysis develops. Follow up at a knowledgeable center is as important as the original surgery.

2. Lipoma (fat) in the filum terminale (the elastic cord that attaches to the end of the spinal cord) is the second type of lipo Occulta. This type rarely causes symptoms until later in life and is usually associated with a thick, non-elastic filum terminale that pulls on the spinal cord producing "tethered" cord. This syndrome is associated with progressive loss of nerve functions and can be surgically corrected. Tethering of the spinal cord is less likely than with the Lipomyelomeningocele form but can occur and, therefore, requires follow up by knowledgeable physicians.

Spina Bifida is a multi-faceted group of disorders about which we need to learn more.

3. Lipoma of the spinal cord that does not penetrate the Filum Terminale and the spinal cord is the third form of lipo Occulta. It can be completely removed and has a lower risk for spinal cord tethering. Other Occulta forms of Spina Bifida could fill a text book. Some of these forms of Spina Bifida Occulta include: Myelocystocele, characterized by a sac that usually has multiple compartments and causes paralysis and, in some cases, a skin-covered bulge in the lumbosacral area (small of the back and rear side of pelvis between the hips); tumors of the lumbosacral, tumors of the lower spinal canal, anterior myelomeningoceles, anterior meningoceles, Diastematomyelia and other rare types. The distinctions among the variable forms of Spina Bifida are essential for the individuals and families involved since there is a great deal of difference between them. Each family and person affected by Spina Bifida requires the pathologic diagnosis of the original surgical repair not just for management of the medical condition but also for genetic counseling. "In my opinion," stated Dr. Shurtleff, "Spina Bifida is a multi-[cause], multi-faceted group of disorders about which we need to learn more."

Read about the CDC's updated vaccination recommendations for Swine Flu and the CDC's New Text Messaging Pilot Button

http://www.spinabifidaassociation.org/site/c.liKWL7PLLrF/b.5384875/k.52B%200/August_18_2009_CDC_Issues_Updated_Vaccination_Recommendations.htm

To enroll or get more information, visit sbgenetics.org



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

From the results of the study, it may be possible to develop 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.



Help us make a difference today.
Participate in our **Spina Bifida Study**>

Participants in the study are asked to complete a brief online survey and provide a DNA sample using a simple at-home saliva collection kit. For more information and to

enroll in the SB Genetics Research Project, please go to the website and select ENROLL. The 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.

Upon completion, participants may choose to receive a \$10 Target gift card or to have SB Genetics donate \$10 to their designated Spina Bifida organization. If the study results are positive, SB Genetics will provide complimentary versions of the test to participants.

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

HowStuffWorks.com Campaign Proves Determination and Curiosity More Powerful than Gravity

ATLANTA - July 22, 2009 - HowStuffWorks.com teamed up with Aaron "Wheelz" Fotheringham, the first person to perform a back flip in a wheelchair and also the inventor of hardcore sitting, for the return of the highly acclaimed "Keep Asking" campaign. This year's campaign [was] designed to demonstrate the power of determination and curiosity, while encouraging people to get smarter. Fotheringham, who was born with spina bifida, mastered the back flip on July 13, 2006, in his hometown of Las Vegas. While looking for compelling footage for this year's campaign, the HowStuffWorks.com team found Fotheringham's footage, felt it embodied the spirit of the site and was compelled to help tell Aaron's story.

In addition to the commercial, Aaron also tells the world how the wheelchair back flip came to be on the site. For the summer campaign, HowStuffWorks.com also partnered with the Spina Bifida Association to drive awareness and donations to the organization.

"Aaron's achievements are an example of overcoming life's challenges and soaring to amazing heights -- literally," said Cindy Brownstein, president and chief executive officer of SBA. "He is one of the over 180,000 individuals living with spina bifida in this country for whom the SBA actively provides programs and support services in hopes of a better tomorrow. We're thrilled that the HowStuffWorks.com campaign captures Aaron's tremendous spirit while bringing greater understanding to spina bifida."

Watch Aaron's back flip at

<http://adventure.howstuffworks.com/outdoor-activities/urban-sports/wheelchair-backflip.htm>.

FIRST NATIONAL STUDY ON CRIME AGAINST PERSONS WITH DISABILITIES

Press Release from the Dept. of Justice, 10/1/09, Washington, DC – The first national study on crime against persons with disabilities was released today by the Justice Department's Bureau of Justice Statistics (BJS), Office of Justice Programs. In 2007 persons age 12 or older with disabilities experienced about 716,000 nonfatal violent crimes, including rape or sexual assault (47,000), robbery (79,000), aggravated assaults (114,000) and simple assaults (476,000). They also experienced about 2.3 million property crimes during the year.

Based on interviews for the National Crime Victimization Survey (NCVS), the study identified six types of disabilities among persons who experienced criminal victimization: sensory, physical, cognitive functioning, self-care, go-outside-the-home and employment. A disability was defined as a long-standing (six months or more) sensory, physical, mental or emotional condition that makes it difficult for a person to perform daily living activities.... Examining specific age groups, the risk of violence was higher for young and middle-age persons with a disability than those of similar age groups without disabilities. Persons age 12-19 and those age 35-49 with a disability experienced violence at nearly twice the rate as persons of the same age groups without a disability. The rate of violence did not differ by disability status for persons age 50 or older. Persons age 65 or older, with or without a disability, had the lowest rates of violent crime. The age-adjusted rate of violent crime against females with a disability (35 per 1000 persons age

12 or older) was almost twice the rate for females without a disability (19 per 1000 persons age 12 or older). Males with a disability also experienced higher age-adjusted rates of violence than males without a disability (30 per 1,000 compared to 24 per 1000).

16% of violent crimes against females with a disability were committed by an intimate partner, defined as a current or former spouse, boyfriend or girlfriend. 5% of violence against males with a disability was committed by an intimate partner. Among persons without disabilities, intimate partners were responsible for 27% of nonfatal violence against females and 3% of nonfatal violence against males....

Nearly one in five violent crime victims with a disability believed that they became a victim because of their disability. Victims with disabilities perceived offenders to be under the influence of either alcohol or drugs in about a third of all violent crimes against them. Violent crime victims with or without a disability were equally as likely to face an armed offender, report the crime to the police or suffer an injury during the crime....

Data in this report represent the first estimates of victimization of people with disabilities produced in response to the Crime Victims with Disabilities Awareness Act. Disability was measured in the NCVS using procedures developed for the U.S. Census Bureau's American Community Survey. The report, *Crime Against People with Disabilities, 2007* (NCJ 227814) can be found at <http://www.ojp.usdoj.gov/bjs/abstract/capd07.htm>.

ONLINE RESEARCH OPPORTUNITY FOR PARENTS

Do you have a child (ages 10 – 29) with Spina Bifida? If so, researchers from Kennedy Krieger Institute invite you to participate in an online research study! We are interested in learning more about how and when children with Spina Bifida learn to manage their medical self-care and home responsibilities. The study does not require a clinic visit and can be completed using a computer in your home or elsewhere. The online survey usually takes about 15-20 minutes to complete and is anonymous, so no personal information such as names, social security numbers, or IP (computer) addresses will be collected. Please be aware that if your child is over the age of 18, we will ask you to obtain your child's consent. If you have questions about this study, Dr. Zabel can be reached at zabela@kennedykrieger.org. If you are interested in participating in this study, we invite you to go to www.psychdata.com and enter survey # 128186. We thank you very much for being willing to help us and other individuals with Spina Bifida by participating in this study!

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The Paralympic Sport and Accessibility team at Chicago 2016 was proud to launch a public service announcement promoting Paralympic sports during Chicago's bid for the 2016 Olympic and Paralympic Games!

Watch Paralympian Matt Scott and Olympian and Chicago Bull Luol Dengand show us how the Paralympics and Olympics may be two games but one in spirit.

<http://www.chicago2016.org/chicago-2016-videos.aspx>



The Campaign for Disability Employment and Best Buy Honor Blake Watson, Winner of the What Can YOU Do? Video Contest

The Campaign for Disability Employment and Best Buy honored the winner of the What Can YOU Do? Video Contest during a Best Buy in-store event in Flowood, MS. The national video competition, which attracted more than 130 videos promoting the talent and skills that people with disabilities bring to America's workplaces, was won by Mississippi native Blake Watson. During the event, Mr. Watson was honored with a \$1500 gift card from Best Buy. Mr. Watson's innovative video, "Meet Sue" demonstrates what it would be like to have your many characteristics noticed before your disability and is showcased on the Campaign for Disability Employment's Web site. View the video now at www.whatcanyoudocampaign.org.