



The Evergreen

October 2010

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

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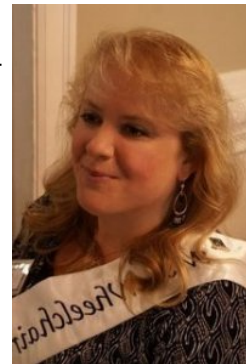
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New Executive Director Paulsen plans enhancements

Greetings Membership,

I am proud to introduce myself as the newly appointed, intern-
ing Executive Director of the Spina Bifida Association of
Washington State – what an exciting time for all of us!

I was born 45 years ago with Spina Bifida and have spent half
of those years as an advocate for our community. I was a mil-
itary brat and moved around quite a bit as a youth and even
spent a few years living in Australia which turned out to be a
real eye opening experience – especially for my parents. I
was in the fourth grade when on November 29, 1975 Presi-
dent Ford signed into law the Education for All Handicapped
Children Act– up until that time, any child with a physical
disability was deemed unable to attend school with his or her peers. My parents
had fought for years to get me into the school that was three houses down from
our home – instead, I was bussed 20 miles away to a special school where I re-
ceived more physical therapy than education – the expectations of my intellectu-
al abilities were nil so I was not given the right to even prove myself. The Act



Meg Paulsen

(Continued on page 2)

CDC studies prevalence of SB among children

SBA has worked with Centers for Disease Control and Prevention (CDC) on releasing
information about the first-ever estimate on Spina Bifida among children and adoles-
cents in the United States. In 2002, there were almost 25,000 children between 0
and 19 years of age living with Spina Bifida, according to a study by the CDC re-
leased ... in Pediatrics, the Journal of the American Academy of Pediatrics. The
study, "Prevalence of Children and Adolescents with Spina Bifida in 10 Regions of the
United States," found that among the group of children included in the study, the
prevalence of children living with Spina Bifida was 30% lower among non-Hispanic
black children than among non-Hispanic white children.

About this study:

This is the first study to provide population-based estimates of the prevalence of
Spina Bifida among children and adolescents in 10 diverse regions in the
United States. These estimates could be useful for determining the need for
local and regional resources to address the long-term care needs of individu-
als born with Spina Bifida.

This CDC study used population-based, birth defect surveillance data from 10
U.S. regions to estimate the prevalence of Spina Bifida among children and
adolescents in 2002. The term, population-based, means that the surveil-

(Continued on page 3)

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!

Chair
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Chair Elect
Linda Bailey,
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megpaulsen@hotmail.com
Ryan Callaway
Jason Lane
Nicole Williamson
Tracy Wright
Annette Zweig-Donham

RECENT ACTIONS BY BOARD OF DIRECTORS

MAY

- All Walk-N-Roll registrants, donors and volunteers added to SBAWS constituent database
- Motion passed to continue providing SBA’s *Insights* to constituents
- 2011 Walk-N-Roll confirmed for March in Lacey

JULY

- SBAWS contributed a donation to help with memorial expenses for late Board member Gloria Olson
- Motion approved to dedicate 2011 Walk-N-Roll to Gloria
- Meg Paulsen instated as Executive Director

SEPTEMBER

- Income through August = \$32,483, i.e. 65% of annual fundraising goal of \$50,000
- Spending through August = 28% of \$50,000 goal and needs to be increased
- Motion approved to purchase 8,000 ghosts, total of \$320, for annual fundraiser
- Next in-person meeting and elections on Dec 4 in Seattle at the annual holiday party

Paulsen’s experiences inspire her in new role

(Continued from page 1)

passed and I finally found myself in school with my brother and friends from the neighborhood - going from reading at a first grade level to a seventh grade level within a short time. Six months later we moved to Australia where there had NEVER been educational segregation – for the first time in my life I was not considered an outsider at school. I returned to the United States an educated and socially well rounded adolescent – what a gift! Since that time, I have been able to develop into my potential and look back at my early educational experiences with amazement. These experiences drive me to be an agent of change within my community and accepting the Executive Director role

with SBAWS is the perfect opportunity to do just that! We have lots of upcoming plans for events and other activities that will not only enhance the lives of those of us who are affected by Spina Bifida, but these enhancements also serve as a catalyst of change to improve society’s view of people with disabilities as a whole. Along with providing education about preventing the most widely occurring and very preventable birth defect, we as an organization strive to offer resources, support and, maybe most importantly, realization that we as a community do not stand alone – we are in this together and “together we make the difference.” Looking forward to serving you and our community as a whole,
Meg Paulsen

Join SBAWS & win tickets to the Outdoors for All Gala Auction!

SBAWS has purchased a Table of Ten at the Outdoors for All “Heroes for All” 2010 Gala Auction. SBAWS will hold a drawing to give away five seats at the table. SBAWS hopes the seats will go to recreational enthusiasts who want to learn more about Outdoors for All.

To enter the drawing, simply submit your membership application to SBAWS! The membership application is available online at www.sbaws.org/Join%20Us.html or call 425-351-3252 to get a paper application. Each ticket is valued at \$150. Winners must provide their own transportation to the event.

The Gala is Saturday, November 6, from 5:30pm—12:00am at the Seattle Design Center, 5701 6th Ave South in Seattle WA. To learn more, visit http://www.outdoorsforall.org/Auction_BoxOffice.html.

Outdoors for All (OFA) is a national non-profit that provides year-round instruction in outdoor recreation for people with physical, developmental and sensory disabilities. The annual Gala is the most important fundraiser of the year for OFA, and is always a fun and inspiring event. This year SBAWS has purchased a table at the Gala and is raffling off five tickets at the table.

Other SBAWS members attending the Gala include: Krystal Monteros, Miss Wheelchair Washington 2010; Meg Paulsen, Executive Director; Heather Logan, Walk-N-Roll leader; Nicole Williamson, Seattle Cluster co-leader; Mikey Williamson, OFA participant.



JOB OPENINGS FOR NEWSLETTER EDITOR & REPORTERS!

Do you like to write? Do you always have ideas for articles and stories that should be covered in the newsletter? Then we need you! *The Evergreen* newsletter has openings for both Newsletter Editor and Reporters.

REPORTERS: The time commitment is about 2 hours per month. You will receive assignments from the Editor and write an article on a designated topic. *Start date: November 2010*

EDITOR: The time commitment would be about 15-20 hours every two months, with most of the time spent within the last two weeks before deadline. *Start date: January 2011*

Please volunteer! This is a fun opportunity to educate readers about life with and prevention of Spina Bifida while providing resources and connections to our members. Your contribution is important!

CDC releases first estimate of children, adolescents living with SB

(Continued from page 1)

lance systems look at all children and adolescents with Spina Bifida who live in the regions. The study also examined variations in prevalence of Spina Bifida among children, according to age group, race/ethnicity, and gender.

Important findings from this study include:

The overall prevalence of Spina Bifida among children and adolescents 0 to 19 years of age was 3.1 cases per 10,000, which represents about 24,860 children and adolescents living with Spina Bifida in the United States in 2002.

The prevalence of Spina Bifida among non-Hispanic white children was higher than among non-Hispanic black children.

The overall prevalence of Spina Bifida among children was highest among children aged 4-7 years and was 14% higher among females than among males.

More studies are needed to find out why the prevalence of Spina Bifida among children and adolescents varied between different groups. Further study is also needed to estimate the prevalence of Spina Bifida among adults in the United States.

For more information about the study, please visit the CDC's Spina Bifida webpage <http://www.cdc.gov/ncbddd/spinabifida/>.



SBAWS Summit 2010 was held August 7 & 8 in Seattle. The schedule was packed with speakers, presentations, discussions and socializing.

Summit Speakers:

- Beth Ellen Davis, MD -
Medical Transitions
Tacoma Community College -
Educational Transitions
- WA Vocational Services -
Vocational Transitions

- Saturday, August 7th:
- 11am to 2pm: Summer Picnic
 - 4pm - Welcome Reception
 - 5pm - Dinner
 - 6pm - "Right to Risk" Movie
 - 7pm - Discussion & Day 2 Preview

- Sunday, August 8th:
- 8am - Breakfast Reception
 - 8:30 - 10am - Speaker Topics
 - 10 - 10:30am - Break
 - 10:30am - 12pm - Speaker Topics

ALL DAY: MODES OF MOBILITY & INCLUSION- Durable Medical & Recreational Equipment Demos

Tacoma Community College's Access Services presented the topic "Educational Transitions" at the 2010 summit. For more resources in this area, please contact one of the staff members or visit the website at <http://www.tacomacc.edu/resourcesforstudents/counselingandadvisingcenter/accessservices/>

Kathryn Held, Accommodations Coordinator
253.566.5328 / kheld@tacomacc.edu

Dr. Dave Howard, Counselor
253.566.5339 / dhoward@tacomacc.edu / [Homepage](#)

Troy Peterson, Accommodations/Assess Technology Specialist, tpeterson@tacomacc.edu

"Right to Risk" producers present film at Summit



Kathleen Jo & John Ryan with Keaton Brown

Kathleen Jo Ryan and her brother John presented their documentary "Right to Risk." It was filmed in 2005 by KJR Productions and accompanies eight individuals with significant physical disabilities on a 15-day whitewater raft trip down 225 miles of Colorado River through the most inaccessible and awe inspiring environment of Arizona's Grand Canyon. One of the participants gives her perspective as a person with Spina Bifida. This film is a true testament to the power of people with disabilities to be active participants and in our society and independent in their own lives. Summit attendees had the opportunity to discuss with the Ryans both their film and their efforts in the state of Washington for community inclusion and promoting inclusion by the state government.

Dr. Beth Ellen Davis, MD, MPH, presented Summit topic “Rolling in the Right Direction: Medical Transitions.”

Achieving a successful medical transition depends on many factors, and in her presentation Dr. Davis provides advice to successfully navigate them. The goal is a seamless transition through the following areas: growth & nutrition; neurological & musculoskeletal issues; urological & bowel issues; skin & latex issues; sexuality issues. For a copy of her Power-Point presentation, which includes recommendations for further reading, contact SBAWS.

Finding your voice: One step at a time!

- Toddler (encourage self soothing, allow play and peers, find temperament)
- School age (self care, find strengths, find your “village”)
- Tweener (find structured activities, camps, bowel and bladder programs, get involved in band, find passions)
- Teen (maintain social connections, camps, bowel and bladder programs, band, find skills)
- Young adult (allow for a different timeline, transportation, find personal care support, find autonomy)

Excerpted from Dr. Davis' presentation

SB Genetics Research Project achieves goal of 1000 samples

VitaPath Genetics and everyone involved in the Spina Bifida Genetics Research Project thanks those SBAWS members who participated in this very important study. Because of their support, VitaPath has reached its ambitious goal – the enrollment of more than 1,000 mothers of children affected by Spina Bifida and the collection of saliva samples. This is truly an extraordinary achievement, and one that would not have been possible without the support of this incredibly caring community.

VitaPath is currently analyzing the DNA from the study participants (mothers and children). Once the analysis is complete, the results will be submitted for publication in a peer-reviewed journal, so that the findings can be shared with the medical and scientific community. This process can take some time, and during the review period, it is not possible for VitaPath to provide any information about the research. If the results are positive, they could appear in a journal as early as the end of the year.

To receive updates on the study, visit the blog at <http://www.sbgenetics.org/Spina-Bifida-Genetics-Research>.

OCTOBER is Spina Bifida Awareness Month



All proceeds go to
SBAWS and its
members

A fun, easy
way to
promote
awareness
of Spina
Bifida and
raise funds
for your
local cluster and
the SBAWS

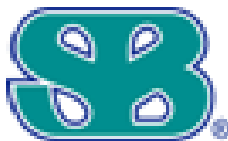
The SBAWS provides
family support,
education,
information,
community outreach
programs, advocacy
and social events for
individuals with
spina bifida and their
friends & families.

**Adopt-A-Ghost
program**

Attention SBAWS Members: The Adopt-A-Ghost Program will begin October 1st and will continue through October 31st. The program will give you the opportunity to raise funding for programs supported by the Spina Bifida Association of Washington State. Each family would begin by getting businesses in their community or family members or friends to participate in the program during the month of October. Simply hand out ghost flyers with your name and number along with a supply of ghosts and collect the "ghost money" and return to the SBAWS: c/o Jonathan Tutt 2128 N. Pines Rd., Suite 17-2, Spokane, Washington 99205.

Look for details in your Adopt-A-Ghost information packet.
For additional information, please contact Nicole Williamson at (206) 877-2568 or
seattlespinabifidagroup@hotmail.com.

**Thank you for supporting the
Spina Bifida Association of WA State**



WORKING TOGETHER TO MAKE A DIFFERENCE

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

SBA launches new Web site for tweens and teens with Spina Bifida

Interactive site SBTween2Teen (www.sbtween2teen.org), complete with blogs, videos, real stories, fact sheets, and an Ask the Expert feature, helps tweens and teens navigate the difficult road to adulthood which can be complicated further by this challenging birth defect.

SBA recognizes that being a teenager means a lot of change - it can mean new schools, harder classes, more social issues - all while trying to become more independent. No one ever said the journey towards becoming an adult was easy. The information on this brand new site has been provided by other teens, tweens, young adults with Spina Bifida and professionals - all intended to make the teen years as rewarding and awesome as possible.

Funded by American Legion Child Welfare, SBTween2Teen is a hybrid site with a static content portion open to all tweens and teens with SB and a members-only section for Facebook subscribers. Both sides of the site offer information and opportunities for interaction between peers.

Through our more than 5,000 friends and fans following SBA on Facebook, the organization learned that many of its young constituents wanted more information to which they could relate. "The Spina Bifida community has a dynamic group of young, amazing individuals who are doing great things. This Web site opens a communications stream that allows them to contribute to each others' lives that we hope will ease some of the anxieties that they have about growing up," says Cindy Brownstein, SBA's President and Chief Executive Officer.



GET INVOLVED WITH YOUR CLUSTER TODAY!

| City/State | Leader Name | Email | Contact Phone |
|----------------------------|------------------------|------------------------------|---------------------|
| CLUSTER DEVELOPER | Michele Hopkins | michele@thehopkins.us | 425-844-1262 |
| Everett & Eastside Seattle | Brenda Stroud | | 425-385-2487 |
| | Michele Hopkins | michele@thehopkins.us | 425-844-1262 |
| Spokane WA | Ed Kennedy | ejkcordwa@live.com | 509-465-0676 |
| South King County WA | Brian Knowles | crazy5720003@yahoo.com | 253-887-0888 |
| Seattle WA | Nicole Williamson | bathingsunbeauty@hotmail.com | 303-877-5083 |
| | Jason Lane | jlane101@comcast.net | 206-363-3726 |
| Kitsap WA | Dave Lewallan | | 360-871-5139 |
| | Rebekah Uhtoff | | 360-782-0467 |
| South Puget Sound WA | Heather Logan | heather_logan@juno.com | 360-888-0782 |
| | Patti Logan | patti_logan04@yahoo.com | 360-888-7701 |
| Leavenworth WA | Ed Baroch | debaroch@charter.net | 509-548-5697 |
| Spanish | Anthony Williams | | 253-588-4411 |
| Cowlitz County (new) | Tressa Croft | tressacroft@yahoo.com | 360-261-1767 |

Right Under My Nose

A Book for Children with Spina Bifida



Claire Austin, MPhil and Stacey Mizokawa, PhD

Illustrated by Matthew Bates

www.myspinabifidabook.org

Right Under My Nose was created to help children with spina bifida understand their condition, discover new ways to enrich their lives and help their parents and caregivers answer many of the tough questions that arise.

With a fully interactive story, activities, tips, and a printable version of the whole book, this site is intended to be educational and fun. Enjoy!

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!

SBA PUBLIC SERVICE ANNOUNCEMENTS AVAILABLE ON YOUTUBE

This summer SBA launched a series of PSAs to run on the CBS "Super Screen" in Times Square Plaza in New York City. Each PSA ran estimated 18-20 times a day and was viewed by over 1.5 million people per day. Two more PSAs will be released this fall. View the first two PSAs, which have already aired, on YouTube:

- Give Your Baby a Healthy Start/¿Quiere darle a su bebe un comienzo saludable? (bilingual) <<http://www.youtube.com/watch?v=q1e3nJVLbng>>
- Give Your Children a Gift Today PSA <<http://www.youtube.com/SBAOrg>>

**NEED A COMPUTER? DOES A FRIEND?
SBAWS HAS ONE FOR YOU FOR FREE!**

Please visit us at

www.sbaws.org

For specific information
on how to get yours!

SBAWS FINANCIAL STATEMENT: Jan—Sept 2010

| | <u>Jan - Sep 10</u> | | <u>Jan - Sep 09</u> | | <u>\$ Change</u> | <u>% Change</u> |
|---|-------------------------|---------------------|--------------------------|--------------|-------------------------|------------------------|
| Ordinary Income/Expense | | | | | | |
| Income | | | | | | |
| Donations Received | <u>40,093.79</u> | | <u>1,407.55</u> | | <u>38,686.24</u> | <u>2,748.48%</u> |
| Total Income | 40,093.79 | | 1,407.55 | | 38,686.24 | 2,748.48% |
| Expense | | % Spent by Category | | | | |
| Mission Program Ex- penses | 17,564.35 | 74.70% | 10,727.17 | 87.69% | 6,837.18 | 63.74% |
| Administrative Expenses | 2,023.21 | 8.60% | 1,043.50 | 8.53% | 979.71 | 93.89% |
| Fund Raising Expenses | <u>3,925.07</u> | <u>16.69%</u> | <u>462.52</u> | <u>3.78%</u> | <u>3,462.55</u> | <u>748.63%</u> |
| Total Expense | <u>23,512.63</u> | 100.00% | <u>12,233.19</u> | 100.00% | <u>11,279.44</u> | <u>92.2%</u> |
| Net Ordinary Income | 16,581.16 | | -10,825.64 | | 27,406.80 | -253.17% |
| Other Income/Expense | | | | | | |
| Other Income | | | | | | |
| Interest Income | <u>311.38</u> | | <u>511.51</u> | | <u>-200.13</u> | <u>-39.13%</u> |
| Total Other Income | 311.38 | | 511.51 | | -200.13 | -39.13% |
| Other Expense | | | | | | |
| Depreciation Expense | <u>0.00</u> | | <u>708.82</u> | | <u>-708.82</u> | <u>-100.0%</u> |
| Total Other Expense | <u>0.00</u> | | <u>708.82</u> | | <u>-708.82</u> | <u>-100.0%</u> |
| Net Other Income | <u>311.38</u> | | <u>-197.31</u> | | <u>508.69</u> | <u>-257.81%</u> |
| Net Income | <u>16,892.54</u> | | <u>-11,022.95</u> | | <u>27,915.49</u> | <u>-253.25%</u> |
| | | | | | | |
| Total Assets | <u>53,809.07</u> | | <u>32,307.34</u> | | <u>21,501.73</u> | <u>66.60%</u> |

Income: What a difference a year can make. Due to the Walk-N-Roll in Lacey in March and the significant In-Kind Donation made by Meg Paulsen volunteering to be our Executive Director without compensation our income during the first quarter was over \$40,000, 2750% greater this year than last. With 75% of the year gone we are at 80% of our \$50,000 annual fundraising goal and budget.

Expenses: Total Expense increased by over \$11,000 or 92%, but at \$23,500 we have only spent 47% of our \$50,000 spending goal. This is the first year since I've been Treasurer where we need to spend more!

Net Income (Loss): For the first time since I've been Treasurer, 2010 will show a true net income as opposed to a loss. \$16,892 this year as opposed to (-\$11,022) last year.

Expenditure by Category: These are now at acceptable percentages.

Net Worth: Our total assets, fund balance (cash in the bank) **INCREASED** by \$21,501.73 or 66.6% during the first three quarters of 2010 as opposed to a loss of (\$9,133) for the same time period in 2009.

Trend Analysis: I really hope this mean we've turned the corner on making more, or at least as much as, we spend each year.

Submitted by Jonathan A. Tutt, Treasurer

RIGHT TO RISK

EMBRACING DIFFERENCE SUMMITS – 2010

ISLAND COUNTY – SKAGIT COUNTY – WHATCOM COUNTY
NOVEMBER 9 NOVEMBER 10 NOVEMBER 17

CONCEPT

Community-wide summits that challenge local leaders to work together in creating the policies, partnerships, and programs that will empower all citizens to thrive and participate fully in the richness of their community.

Each summit will provide:

- A forum through which the complexity of disability can be explored and understood in terms of wider socio-economic conditions and relations;
- An alternative and positive view of disability, and a framework through which discrimination, exclusion and inequality can be challenged and addressed;
- Inspiration to local leaders through highlighting successful local programs and replicable “best practices,” from effective initiatives in other communities.

GOAL

Maximize independence, assure safety and security, promote inclusiveness and provide choices by removing barriers that prevent individuals with disabilities from participating fully in all aspects of community life.

OBJECTIVES

The Summits will focus on developing common understanding and a unified approach to addressing issues of disability in order to:

- Educate community leadership on the nature and type of barriers that prevent individuals with disabilities from participating fully;
- Shift the focus - move from viewing challenges as those of an individual or family, to recognizing and removing barriers as the responsibility of the community;
- Localize Issues - identify barriers, set priorities, define solutions appropriate to the community's needs;
- Involve all community institutions where citizens are already interacting; engaging faith-based organizations, service clubs, schools, businesses and government agencies;
- Implement practical and actionable projects within the community structure, systems and resources.

COMMUNITY BENEFITS

- Consensus on issues and priorities;
- Commitment to work together and mobilize resources;
- Improved communication across agencies, organizations and institutions;
- Reduced fragmentation of services and supports;
- New collaborations that leverage ideas and resources.

KJR Media, LLC. PO Box 670, Coupeville, WA 98239 360-678-2222 360-632-0181 www.righttorisk.org

NEW BOOK! APPLE-BITES: Commonsense Disability Strategies for Everyone

It's a little book with BIG, life-changing ideas, and it's priced just right at \$10.00. *APPLE-BITES: Commonsense Disability Strategies for Everyone* is divided into three sections: ATTITUDES (new ways of thinking and talking), VOICES (what people with disabilities want us to know), and ACTIONS (how we can do things differently). Each page features one main idea or strategy, illustrated by a graphic and detailed in text. It's a valuable tool for people with disabilities, families, educators, service providers, therapists, physicians, and anyone else who is involved in the lives of children or adults with disabilities. This powerful little book can help us all regain our common sense and generate positive, long-lasting change! To learn more, visit http://www.disabilityisnatural.com/shop?page=shop.browse&category_id=1.

Spina Bifida Association launches SB University

SBA Press Release, October 4, 2010

This month the Spina Bifida Association (SBA) launches a new online educational platform called SB University (SBU). SBU offers both live and archived seminars on topics related to Spina Bifida. These can vary from health related seminars with medical professionals to employment or education tips from subject matter experts. The goal is to increase education about topics that are important to our Community.

Initially, the site features taped sessions from the 2010 SBA National Conference. As time goes on, live sessions will begin. All live sessions will be recorded and archived on the site. The idea is that educational opportunities are available 24 hours a day, 7 days a week with computer access.

"SBU represents a new frontier for SBA," says SBA Chief Operating Officer Sara Struwe. "The range of application is tremendous. We are very excited to provide a forum which puts the most up-to-date information into the most hands as quickly as possible."

SBU sessions are offered at no cost. All the user needs is a computer with Internet access. Users will need to register to receive a user name and password to access the site.

Log onto to www.sbuniversity.org to register and become a part of a new online learning experience.

SBU's October Schedule

Oct 4: Education and Employment

Building Independence
College Survival Skills 101
Non-Verbal Learning Disability and Education
Implications
Educational and Vocational Guidance (age 16+)
...and more!

Oct 11: Urology

Medical Management of the Neurogenic Bladder:
Late Childhood to Adult
Evaluation and Management of the
Neurogenic Bowel in Spina Bifida

Oct 18: Aging with Spina Bifida

Aging and Adulthood Issues with Spina Bifida
Managing Changes in Later Adulthood

Oct 25: General Health & Preventative Medicine

Proper Wheelchair Seating
Latex Allergy: 2010 Update
SOS: Save Our Skin!
The Role of Gait Analysis in Persons with
Myelomeningocele



SBA, VitaPath Genetics launch new iPhone App

VitaPath Genetics, the Spina Bifida Association and the National Council on Folic Acid recently launched a free iPhone application, the VitaTrack Folate Tracker, which allows women to track their daily intake of folate and folic acid. The VitaTrack Folate Tracker is available through the iPhone App Store and through iTunes. For more information, including download links, a tutorial and an FAQ on folic acid, please visit www.vitatrack.org

SPINA BIFIDA ASSOCIATION OF WASHINGTON STATE

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Phone: 253-589-3700/Fax: 775-766-1654

Toll free: 888-289-3702

Email: sbaws@yahoo.com

*For more resources,
visit us online!
www.sbaws.org*

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.



Spina Bifida Association
of Washington State

