



The Evergreen

December 2010

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

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Exciting recent & upcoming events promote mission

by Meg Paulsen, Executive Director

Greetings Membership,

I have been very busy this last month connecting and networking with other organizations that the SBAWS can partner with in our mission to educate the public about Spina Bifida (SB) and its prevention, as well as improving the lives of those living with SB! We received a grant from VitaPath (a Folic Acid distributor) to have a booth at the Northwest Women's Show in March – we will be demonstrating the company's



Meg Paulsen

application that allows you to check your Folic Acid (FA) levels any time you want. I am also currently working with Seattle Super Supplements to create a Folic Acid campaign that will highlight the importance of FA (and our organization) in over twenty of their retail locations throughout the Northwest.

In our efforts at educating the public about Spina Bifida, Nicole Williamson (Co-Leader of our Seattle Cluster) and I womaned a booth at the Auburn Social Security's annual health fair and handed out about a hundred SBAWS flyers as well as Spina Bifida awareness buttons. Last month we made our presence known at the

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A VOLUNTEER'S PAYCHECK

by Katie Euphrat, reprinted with permission from SBA's Insights Fall 2010

People hustled up and down the hallways, frantically looking for which hospital room held their husbands, wives, parents, friends. Christine Nickle was just a teenager, but she knew how to help.

The scene was familiar. She'd been frequenting the hospital for as long as she could remember because of her Spina Bifida. From her spot behind the hospital's information desk, Christine helped restore calm, directing people to where they could find their loved ones.

Christine began volunteering at Abington Memorial Hospital during high school because she wanted to a job she could do despite walking with crutches and braces. "The jobs that were available back then were McDonald's-types of jobs, and something that I could not physically do," she explains. "I wouldn't be able to carry

the tray."

So she asked to be a candy striper in the hospital located just outside of Philadelphia. "It was just something to do to get myself out there in the community,"

Christine says. "I was showing people that, yeah, a person with a disability can do the same thing as a typically-abled person." She went on to volunteer at the Children's Hospital of Philadelphia where she had been treated since infancy, and then moved to Budapest, Hungary, to do volunteer work as a missionary for 10 years.

Now 39 years old, Christine hasn't stopped giving to her community. In January she got something back. She accepted a part-time job after less than a year of volunteer work at a hospice in Forest City, NC, where she now lives. "I was delighted," Christine says. "I had heard

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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!

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HIGHLIGHTS FROM BOARD OF DIRECTORS' MEETING ON DECEMBER 4, 2010

- Officers update
 - Ed Kennedy's term as Chair ends Dec 31, 2010; he will assume the role of Immediate Past Chair
 - Linda Bailey will assume the role of Chair on Jan 1, 2011
 - Jason Lane will assume the role of Chair Elect on Jan 1, 2011
 - Patti Logan requested that she not be re-elected to the Board; she was thanked for her many years of service
 - All other Board members remain in place
- Budget update
 - We met our fundraising goal for the year—over \$50,000 raised to date! Largest revenue sources were Walk-N-Roll (over \$30,000) and Director Meg Paulsen's in-kind donation (\$12,5000)
 - Expenditures of \$37,500 are only at 75% of our goal but the division of expenses is in line with non-profit standards (80% = mission, 6% = administrative, 14% = fundraising)
 - Motion made and approved to start a \$3000 account for the Director to use as needed
- Other SBAWS initiatives
 - Ed Kennedy was elected Chair of the Governance Committee; Jason Lane will serve on the committee with him
 - Director Paulsen is working on several initiatives, including: partnering with the son of late Board member Gloria Olson on future fundraisers; hosting a VitaPath-sponsored booth at the Northwest Women's Show in Seattle in March; forming a Folic Acid campaign with Seattle Supplements
 - When requested, SBAWS donates funds toward burial costs for people with Spina Bifida who pass away; the Board's standards in these cases are as follows:
 - \$500 will be awarded for non-members
 - \$1000 will be awarded for members
 - Death certificate plus clarification of Spina Bifida diagnosis must be provided
- Next meeting: Thursday February 17 at 7pm by teleconference



Board members at the Dec meeting,
L-R: Jason, Krystal, Linda, Meg,
Ed, Jon, Nicole

A true story: SBAWS brings together faraway friends

by Michele Hopkins, Cluster Developer

Today's technology makes it easy to connect and reconnect with our friends and meet new friends. Most of us know friends do come and go as with the members of the SBAWS. At one point, our unpretentious group decided to branch out and reach new friends and their family members in the outer areas of the Pacific Northwest. One such area was Idaho. It was amazing how many new members I connected with in such a short time while we were expanding. One person stood out in my mind: Roxanna Trautman. We realized in a short time that we had some things in common to start a lasting friendship (Spina Bifida wasn't the only thing we could talk about!). For the most part, we just chatted though email, sharing stories, supporting each other during some difficult times and talking about our past and present health issues. The SBAWS decided to once again return to assisting only people in Washington State. My newfound friend was

without a support group. I tried to keep in touch as much as possible while she moved out of Idaho. Within the first few years of knowing her, I could match a face to the name since we mailed holiday cards with pictures, but we still had not met face to face. She decided to move back to Idaho in the summer of 2010 and we both wanted to make the effort to see each other. We decided the Tri Cities was a good half way point. When we finally saw in each other in person, we spent the evening talking as if we had not talked in years. When it was time to say goodbye it was a sad moment, but I was excited to know my friend really wasn't that far away. Today, we continue to give each other support and hope to meet up again in the near future. We both put comfort in knowing we are not alone. Roxanna hopes to come to the Seattle area someday, but for now she lives in Boise, Idaho with her cute, little dog, Oscar. She has recently gone through a surgery and is recovering at a hospital in Boise, Idaho.

JOB OPENINGS FOR NEWSLETTER 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 unlimited openings for 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: 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!

Michael Hoyt competes at national championship

by Diana Tutt, Reporter for *The Evergreen*

SBAWS' own Michael Hoyt made the cut this past July to participate in the 2010 National Junior Disabilities Championship in Deerfield, Illinois. Michael, longtime member of SBAWS and son of Colette and Chris Hoyt, was 11 years old when he traveled with his teammates from Team St. Luke's to the Championship. The team, whose athletes are generally drawn from Eastern Washington, flew out of Spokane International Airport and stayed at a hotel without their parents. This independence enabled them to broaden their life experiences and mature into more independent individuals. They were accompanied by coaches and some college students interested in pursuing careers in therapeutic fields. The athletes shared rooms and had a lot of fun when they were not focused on their events. Michael participated in track and field events, but prefers the field events, especially javelin and discus. When asked what was the best part of the whole trip, he said, "the food, and I laughed so hard my face turned blue." Michael was happy to meet up with old friends from previous meets, which is another benefit of belonging to Team St. Luke's. Participants not only strengthen their bodies and push themselves to the limit, but also make friends from all over the United States. I am sure we will be hearing more of Michael's travels and accomplishments.

For more about the 2010 National Junior Disabilities Championship, see www.njdc2010.org.



Michael at a previous meet

DO-IT program proves you CAN go to college

by Diana Tutt, Reporter for The Evergreen



An article in the August 26, 2010 edition of the Spokesman-Review caught my eye and intrigued me. I decided to delve further into the story and phoned Benji Migliuri and talk to him personally. Benji, a seventeen-year old Mead High School student, had returned from a ten-day stay at the University of Washington. Benji has been a quadriplegic since birth, and his stay at the University was made possible by the DO-IT (Disabilities, Opportunities, Internetworking, and Technology) Scholars Summer Study program. The program is funded by the State of Washington, the National Science Foundation, and the US Department of Education. Its purpose is to allow students with disabilities to explore and experience college life. Benji shared a dorm room with another student with a disability.

Benji was reluctant at first to apply for admittance to the program, but his therapist helped encourage him. Now he says, "I'm so glad I did." He said that one of the hardest parts of the experience was realizing that it is okay to ask for help. He hired a cousin to accompany him as his personal attendant. Benji has made new friends and now communicates year-round via the Internet. He and his friends mentor each other and he has even offered to mentor a local boy personally. Benji's positive attitude and ability to know that it is okay to ask for help show real maturity and kindness in offering to mentor others.

All parents and teens can consider this program as they plan for post-high school education. From Benji's point of view, the sky is the limit! Benji, we wish you all the success in the world and thank you for sharing your story. To all of our children and grandchildren living with Spina Bifida, we also say you too can "DO-IT!"

For more information on DO-IT:

www.washington.edu/doit } doit@u.washington.edu | 206-685-3648

Save the date!



APRIL 30, 2011
OLYMPIA, WA

Executive Director looks forward to a new year of growth, learning for SBAWS

(Continued from page 1)

Outdoors For All Gala Auction. We had a table of ten, all of us in our SBAWS costumes – the theme was Super Heroes so we had masks and capes on – we were able to distribute quite a few flyers and buttons at that event. It was a fun event and gave us inspiration to see just how far a nonprofit organization that serves the same community can go – we can do the same with persistence and determination!!

We are also in the midst of planning our next fundraising event – a Five-Course Folic Acid Feast that will include a menu made up entirely of five delicious dishes that are high in FA. I am attempting to book a local chef to cater the event and we will have an auction to raise funds for SBAWS. We will keep you posted!

This weekend is our Holiday Celebration – Nicole Williamson and Jason Lane (the other Co-Leader of the Seattle Cluster group) have both worked hard to create an event that will bring holiday cheer to our membership families! Thanks so much to our sponsors – especially the StarLight Children's Foundation who donated gifts for over seventy of our kids!

In closing, I am so excited to be starting a new year – it will certainly prove to be one of learning and growth for our organization and I appreciate the efforts of each of you who attend our events, sit on our board and volunteer time to ensure that SBAWS is meeting its goals and mission – we could not do this without YOU!

Looking forward and working together to make the difference, Meg Paulsen

A volunteer's paycheck: the rewards of serving others

(Continued from page 1)

that if you are looking for employment—and I was—volunteering is the best way to get your foot in the door.”

Paid employment was a well-deserved reward for Christine's 20 years of volunteering, and a goal she hopes other volunteers with Spina Bifida can work toward. Even if you're not looking for employment, however, volunteering is deeply beneficial for the mind, body and soul.

What will you gain?

For Kemi Williams, a 59-year-old who has Spina Bifida, it's all about the people. She's been serving the community on-and-off for 30 years. After retiring four years ago, she decided to volunteer full time as a way to keep active and social. She now helps plan events for the Spina Bifida Association of Greater San Diego Support Group and mentors young women with Spina Bifida through a program called What's Next. Kemi has found that she's meeting an entirely new, culturally diverse community in San Diego, where she lives with her husband.

“The people I've met accept me unconditionally,” Kemi says. “They always give me a hug when I come in, and they hug me goodbye. They're there to help each other. It's taught me a lot of respect and caring for a part of the community that I just never knew.” When she walked in the door to volunteer on her birthday earlier this year, all of the children ran over and sang “Happy Birthday” to her. Tearing up, Kemi recalls, “It was so sweet. I just feel so accepted, appreciated, and loved.”

Friendships formed through volunteering

are meaningful for both the volunteer and recipient. One of Kemi's mentees, 25-year-old Jenny, was shy and isolated before meeting Kemi. They have now become good friends. Jenny told her that one of the mentor activities was “the best time of her life,” and she called the mentors her “angels.” There's no better boost to your self-esteem and confidence than knowing you've improved the quality of another person's life, while making a new friend.

Helping others also gives you networking opportunities and an improved skill set that can help you find a job. Christine's employer was impressed with her hard work volunteering. Kemi also was offered several employment opportunities, but found the skills she gained from volunteering to be more useful in everyday life. “It taught me a lot of good techniques that I use as a lawyer, as a teacher, as a parent, as just a person,” Kemi says. “I hadn't expected that. I'd expected that I'd give whatever I could, but I got a lot out of it as well.”

Volunteering has even been shown to improve your health. According to a study by the Corporation for National and Community Service, volunteering can lengthen your life and reduce your risk for depression and heart disease. Because of all of the benefits you gain from giving, it's no surprise that more than 63 million Americans volunteer. And it's been estimated that for each of these Americans, every volunteer hour provides about \$20.25 in value to the organization he is helping.



HOW TO GET STARTED

All you need to get started is a little courage. Even if you're isolated at home, volunteering is a way to get out of the house and develop friendships. “It may be uncomfortable for a while if you're shy,” Christine says. “I think it's brought me out of my shell.”

Spina Bifida Association of WA State | www.sbaws.org | 888-289-3702

Your local chapter of the Spina Bifida Association is always in need of volunteers and has opportunities to suit a wide range of skill sets and commitment levels.

VolunteerMatch | www.volunteermatch.org

United We Serve | www.serve.gov

At either of these web sites, enter your Zip code and key words to find organizations in your area that are looking for volunteers.



SBAWS Seattle Annual Holiday Party December 4, 2010



A fun time was had by all at this year's party, which featured cookie decorating, presents for the kids, and a production of "A Christmas Special" performed by Taproot Improv Comedy of Seattle.



SBAWS would like to thank the sponsors of this year's holiday party: Astratech, the ABC Guild, Sue & John Calhoun, Church of Jesus Christ of Latter-Day Saints (Lake Forest Park Ward), the Lougheed family, Starlight Children's Foundation WA and the Taproot Theatre Company



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



Follow SBAWS
on Facebook



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	seattlespinabifidagroup	303-877-5083
	Jason Lane	@hotmail.com	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

Resource Spotlight



Washington Access Fund

Independence is priceless. We make it affordable.

About Washington Access Fund

What is the Washington Access Fund?

The Washington Access Fund is a 501(c)(3) nonprofit, Community Development Financial Institution (CDFI) established by and for people with disabilities in Washington state. Washington Access Fund provides low-interest loans and other financing services to help individuals with disabilities obtain the technologies and business equipment needed to live independently and to succeed at school, at work, at play and in the community.

Our Mission

Washington Access Fund's mission is to promote access to technology and economic opportunity for individuals with disabilities in Washington State.

What does Washington Access Fund do?

Washington Access Fund provides:

- Low interest loans for assistive technology and home and vehicle access modifications ("Assistive Technology Loans")
- Low interest loans for business equipment needed by employees and entrepreneurs with disabilities who choose to work from home or start/expand their own business locations on a full or part-time basis ("Business Equipment Loans").
- Long term, low cost rentals of Closed Circuit TV Magnifiers to individuals with significant vision loss to support independent living, education and employment and
- Individual Development or Matched Savings Accounts to help Washington residents with disabilities purchase assistive technologies and/or business equipment needed for employment or education and training intended to lead to employment.

How can I learn more?

Location: 100 South King Street, Suite 280, Seattle WA 98104

Voice: 206-328-5116 | 877-428-5116 | TTY 888-494-4775 | Fax 206-328-5126

Email: info@washingtonaccessfund.org

Online: <http://www.washingtonaccessfund.org>

**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 Services and Programs



- Emotional support for everyone affected by Spina Bifida, including meetings at numerous local cluster support groups throughout the state
- Newsletter "*The Evergreen*" detailing local SBAWS activities and providing news on medical, therapeutic, rehabilitative advances, recreational and legislative issues
- Website www.sbaws.org and toll free contact number to connect you directly to SBAWS
- A lending library containing information on Spina Bifida, secondary conditions and pertinent information on the rights of people with disabilities
- Social events for children, teens and adults to gather, have fun and share their life experiences
- "New Parents" packets to help parents learn about Spina Bifida and to help manage their children's health care needs
- Scholarships awarded for educational needs
- Subscriptions to the national Spina Bifida Association's "*Insights*" magazine and access to other current information on Spina Bifida
- A limited Equipment Fund to assist people with purchasing mobility devices, medical supplies and other necessary items not covered by insurance
- Refurbished computers, new software and personalized training to help our constituents connect online with us and the rest of the world
- Delegates sent every year to SBA's annual convention



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!



Justice Dept reaches agreement with Hilton Worldwide Inc. over ADA violations at Hilton Hotels and major hotel chains owned by Hilton

Press Release from the US Dept of Justice, Office of Public Affairs, Tuesday, Nov 9, 2010

WASHINGTON – The Justice Department and Hilton Worldwide Inc. today announced a comprehensive, precedent-setting agreement under the Americans with Disabilities Act (ADA) that will make state-of-the-art accessibility changes to approximately 900 hotels nationwide. The agreement is in the form of a proposed consent decree filed today in federal court to resolve a simultaneously filed lawsuit under the ADA.

The department's complaint alleges that Hilton's hotels designed and constructed after Jan. 26, 1993, fail to comply with the ADA and Department of Justice regulations.

"The ADA protects the rights of people with disabilities to stay in accessible hotel rooms."

Hilton operates a system of hotels throughout the United States under the trade and service names of "Hilton," "Conrad Hotels & Resorts," "Doubletree," "Embassy Suites," "Hampton Inn," "Hilton Garden Inn," "Hilton Grand Vacations," "Homewood Suites," "the Waldorf Astoria" and "Home2Suites." Hilton Worldwide Inc. (HWI), owns, operates, or has entered into and maintains franchise license agreements for each hotel in the HWI system.

"The ADA protects the right of people with disabilities to stay in accessible hotel rooms, and to reserve those hotel rooms through the same convenient systems as everyone else," said Thomas E. Perez, Assistant Attorney General of the Civil Rights Division. "Persons with disabilities who travel for pleasure or business must be able to count on getting the accessible room they reserved, and the hotel must provide the choice of amenities that everyone comes to expect from a major national hotel chain like Hilton."

The agreement is the result of a lengthy investigation and negotiation. Hilton officials cooperated with the department throughout the process. Allegations in the department's complaint include failure to provide the required number of accessible rooms, failure to disperse accessible rooms among the various categories of available accommodations, failure to provide individuals with disabilities the ability to reserve accessible rooms through Hilton's central reservations system on-line or by telephone, and failure to provide individuals with disabilities with the accessible sleeping accommodations that they reserved.

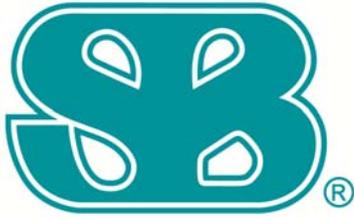
Today's settlement represents the first time the Department of Justice has required a franchisor to require all franchised or managed hotels that enter into a new franchise or management agreement, experience a change in ownership, or renew or extend a franchise agreement, to conduct a survey of its facilities and to certify that the hotel complies with the ADA. It is also the first time that an agreement under the ADA has specifically detailed how a hotel reservations system should be made accessible. The agreement also represents the first time that a hotel chain has been required to make its online reservations system accessible and to provide on its website current data about accessible features in guest rooms throughout the chain.

"The agreement is the result of a lengthy investigation and negotiation."

Under the agreement:

All owned and joint venture hotels built after Jan. 26, 1993 will be surveyed and brought into compliance with Department of Justice ADA title III regulations, including dispersing accessible rooms among the various classes of available accommodations, providing accessible rooms with roll-in showers and tub seats, and providing accessible rooms for guests with hearing impairments;

For franchised and managed hotels built after Jan. 26, 1993, where Hilton enters into a new franchise or management agreement, renews or extends an agreement for more than six months, or agrees to a change of ownership, Hilton will require the owners to survey their hotels for compliance with specified provisions of the ADA, and where necessary, bring their hotels into compliance;



SBA is excited to announce the launch of a new online educational Web site called "SB Preparations."

This site employs an assessment technique that allows parents, caregivers, and clinicians to gauge the development of a child with Spina Bifida at different stages of life and learn potential interventions they can use to help the child develop into a successful and happy adult. It also has information for young adults seeking ways to become more independent and lead a fuller, richer life.

Log onto www.sbpreparations.org to learn more.

The Hydrocephalus Association is proud to announce a new online Hydrocephalus Resource Library.

For decades now, the Association's hydrocephalus support professionals have been providing education, information, and support to those living with hydrocephalus, their families and loved ones, and professionals working in the field. They know well how many burning, unanswered questions there are regarding the complicating factors associated with hydrocephalus. To provide further support, the Association has created an online library filled with expert advice, research findings and plain old good thinking. The Hydrocephalus Resource Library allows you to search as deeply as you wish for answers or advice for the many complex questions you may have — at anytime!

Visit the online library today at:

<http://www.hydroassoc.org/education-support/hydrocephalus-resource-library-6/>



Hilton hotels must be brought into compliance with ADA, according to agreement

(Continued from page 10)

Hotels constructed in the future will be required to comply with the ADA;

Specific ADA training will be provided for staff;

Hilton's reservations system will be improved so individuals with disabilities can reserve accessible rooms with specific available options and amenities, and have the same opportunity to guarantee a reservation for an accessible room as that offered for any other reservation;

Hilton will improve the accessibility of its websites;

Hilton will appoint a national ADA compliance officer responsible for Hilton's compliance with the ADA and the consent decree;

Hilton will appoint ADA on-site contact persons at each hotel responsible for resolving ADA-related complaints at the local level; and

Hilton will pay a civil penalty of \$50,000 to the United States.

People interested in finding out more about the ADA or this consent decree can call the toll-free ADA Information Line at 800-514-0301 or 800-514-0383 (TDD), or access the ADA website at www.ada.gov.

SPINA BIFIDA ASSOCIATION OF WASHINGTON STATE

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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**

