



The Evergreen

July 2009

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

SBAWS President seeks membership help with outreach

by Ed Kennedy, President

Hi Everyone. As President of the Spina Bifida Association of Washington State (SBAWS) I want to thank all our members for your standing with us to reach out to others in the State of Washington who have in some way been affected by Spina Bifida. I truly feel honored to be your President and hope that "together" we can meet some very high goals as set out for us by our own Board of Directors and by the National SB office. I want to say a special "Welcome Back" to Celeste McCormick, our newsletter editor, who has finished her Master's Thesis on the Spina Bifida Association of Washington State. She will be making a presentation of her findings to the Board of Directors at our "in-person" board meeting tentatively scheduled for August. A big part of my job as President, I feel, is to inform and encourage each of you to consider a few things in respect to the needs, goals, and hopes of the SBAWS. As for

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Free computers foster awareness and connections

by Heather and Patti Logan

Our partnership with OlyGeek in Olympia is finally paying off. The first recycled computer destined for SBAWS members has just been delivered to Patti Logan ready for shipment to one of our own. Building the image on this computer took over 400 hours of technical work. Now that the image has been built, subsequent computers for SBAWS will take only about 5 hours of tech time. These computers will have Windows XP, Microsoft Office 2007 Pro Plus and various anti-virus and email programs included. Each individual user is responsible for securing internet service.

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. Heather and Patti are heading for Orlando and the Spina Bifida Conference! Several others will be joining us there. We will have news to spread in preparation for our Awareness Walk (set sometime in October). We will be starting some e-chat sessions in conjunction with our SBAWS web site. The chat room will hold up to 10 of us (that is, our computers) at once. Multiple times

and days of the week are possible. This will be a pilot program to see how much need and interest in the chat room format we can develop before spending any money on upgrades and expanded service.

Do YOU know others whose lives have been changed because of Spina Bifida? Would you like to see and talk with someone with similar experiences? Are you an adult, teenager, young adult living with Spina Bifida? Are you a parent or grandparent of someone with Spina Bifida? Or are you a professional in the medical field? Each of these categories can have its own time for an e-chat. Are YOU interested in reaching out to others affected by Spina Bifida? Moreover, this can be your chance to help reduce the births of babies with Spina Bifida. Would YOU like to help plan events for Awareness & Prevention of Spina Bifida throughout the State of Washington? This is a beginning....watch for your invitation in your email inbox. If you do not have an email address, see above for requesting a computer that is internet-ready.

We will send out invitations and a short email survey to members who have computer access. Would you like to join our expanded e-groups? What is your availability? What would YOU like to talk about with other SBAWS members?

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Newsletter Editor
 Celeste McCormick
 celtutt@yahoo.com

SBAWS mourns the loss of Janet Davis, our purple princess

This May, the Spina Bifida Association of Washington State lost one of its most beloved and active members, Janet Davis. She was 37 years old. Janet was born with Spina Bifida and spent much of her life assisting others with disabilities. She advocated for the independent living movement with a strong passion. She worked in social services for over ten years, including positions at independent living centers in the Seattle area. She most recently worked as a Disability Navigator Specialist with the Snohomish County Worksource. She served as a member of the Board of Directors for SBAWS and organized the 2008 chapter summit.



Janet Davis

Janet is survived by her husband, James, and her dog that she loved as her own child. She is remembered for her positive, upbeat outlook on life and her in-laws said she was a true gem to their son. Fellow Board member Brian Knowles, who worked with her on last year's summit, described her as "a really good person" who was "personable and easy to get along with" and who cared a great deal about people with Spina Bifida. Friend and SBAWS member Wendy Richeson described Janet as insightful, resourceful, kind, non-judgmental and ready to help anyone. "She had a great laugh. She may not have driven, but that woman could get around and knew all the bus schedules. Her husband said she referred to herself as a drama queen. She liked having fun and to go shopping." Janet will be remembered for her sense of humor, helpful nature, and love of the color purple. Her charm and warm spirit will be greatly missed.

SBA'S SOCIAL NETWORKS

facebook

YouTube

myspace®
a place for friends

twitter

President

Ed Kennedy, ejk@cordwa.info

Vice President

Annette Zweig-Donham,
az@w-link.net

Secretary

vacant

Treasurer

Jon Tutt, jon_tutt@msn.com

Board Members

Patti Logan (Chair)

Nicole Anderson

Mariah Bates

Linda Bailey

Michele Hopkins

Brian Knowles

Gloria Olson

Meg Paulsen

SBAWS President seeks membership help with outreach, awareness of SB

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needs, our organization could always use people who are interested in investing a bit of their time each month to serve on a committee or on our Board of Directors, writing articles for our newsletter, helping at outreach events, etc. We have over 125 members and when you include the families of each of these we are an organization of over 400! We understand the time commitments and health issues of our constituents and want to work with each person to help you become as involved as you wish and yet have the time you need to deal with your personal life issues. But the fact remains; we cannot do this without more of you stepping up to help us in this effort. I have seen the same people serve on the board and on committees for some time now and are very thankful to them, but it gets a bit "routine" without new voices being heard. As for our goals, one of our goals is to be able to

do a better job of reaching out to women of child bearing age to prevent Spina Bifida and other related birth defects. Our Board of Directors is committed to this and need your help to be where women meet to get them vital information about the need for higher intake of folic acid during their child-bearing years. Our hopes are endless, a world where no more babies are born with Spina Bifida and where those already affected by it have not just the "minimum" care they need, but excellent care and knowledgeable practitioners who are aware of Spina Bifida and how to care for those with it. Finally, if you have any ideas about how the SBAWS can better serve our communities, and you are members, please feel free to contact me and give me your input.

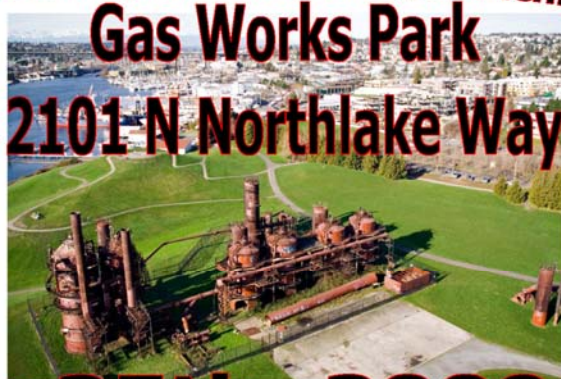
(509) 326-6355 or ejk@cordwa.info

SBAWS, Seattle, Annual Summer Picnic



In partnership with

Demo handcycles,
track/field chairs, &
basketball chairs!



July 25th, 2009 11 a.m. to 3 p.m.

Please bring the following item to share:

If your last name begins with A-I: salad/fruits/veggies

J-R: side dish/snacks

S-Z: dessert

Main dish, drinks, activities, and paper products provided.



Directions from I-5:

- Take 45th St. Exit.
- Go West on NE 45th St.
- Turn LEFT on Meridian Ave. N.
- Meridian Ave. N ends at Gas Works Park.
- Turn RIGHT on N Northlake Way to turn into parking lot (on LEFT).

Bring a Kite!!



Please RSVP by July 18th to seattlespinabifidagroup@hotmail.com

or Jason Russo in Neurodevelopmental clinic at Children's Hospital #206-987-2204.

Thanks to Outdoors for All, Seattle Adaptive Sports, AstraTech, Seattle Children's Hospital, and SBAWS.

ADVOCACY UPDATE

In June President Ed Kennedy met with Cathy McMorris Rogers, Republican Congresswoman from Eastern Washington, about the joining the Congressional Spina Bifida Caucus. The Caucus comprises Representatives from across the country but currently has no members from Washington state. According to SBA, the Caucus "advances policies and programs to reduce and prevent suffering from Spina Bifida and to promote quality-of-life programs that support people with Spina Bifida so they can live fulfilling and productive lives." Rep. McMorris Rogers, who has a son with Down's Syndrome, informed President Kennedy that she wished all disability-advocacy organizations would hold one caucus which would be more convenient for Representatives to attend rather than trying to attend all of the specific caucuses to which they are invited.

Kennedy intends to follow up their conversation with a letter formally requesting her to join the Spina Bifida caucus. To learn more about the Caucus and invite your Representative to join, visit this link on the SBA website:

http://www.spinabifidaassociation.org/site/c.liKWL7PLLrF/b.2663641/k.443F/Advocacy_Public_Policy_Priorities.htm

CHAPTER NEWS

Summit cancelled...

At its June meeting, the SBAWS Board of Directors voted to cancel the 2009 Summit in favor of holding at least one (and possibly two) in-person Board meetings late in the summer. The first meeting is tentatively scheduled for August and will be held in the Seattle area; exact date and location will be announced at a later date. The decision to switch from the annual summit to an in-person Board meeting was made for two primary reasons. First, SBA requires regular in-person Board meetings for all affiliated chapters. Second, interest in the Spokane summit was depressingly low. What do YOU want to get out of next year's summit? Send your ideas to SBAWS now and start thinking about the personal contribution that you can make to the event.

Board member changes...

Gloria Olson, with regrets resigned as Chair in June 2009 citing health issues. She will stay on as a Board member. *Patti Logan* was duly elected Chair. ~ The Board voted to remove *Pam Hoppman* as a member due to lack of attendance but would welcome her back anytime if she can attend meetings regularly. ~ *Meg Paulsen*, past Ms. Wheelchair Washington, was appointed as a new Board member by President Ed Kennedy. ~ Seattle cluster co-leader *Jason Lane* will most likely be appointed as a Board member within a few weeks.

VOLUNTEER NEEDED:

Do you have good computer skills and a few hours a month to contribute to SBAWS? Then please consider volunteering to be chapter Secretary. Jon Tutt, Treasurer, is currently filling in for this vacancy and is finding it hard to keep up with both roles. Free training is offered. Call 888-289-3702 or email sbaws@yahoo.com.

Meet Jannette Saxton, Ms. Wheelchair Washington 2009

Press release from Tammy Wilber, Ms. Wheelchair Washington pageant coordinator Jannette Saxton, of Lakewood, WA, who has had Cerebral Palsy since birth, was crowned the 2009 Ms. Wheelchair Washington on February 21st. The Northwest Chapter of the Paralyzed Veterans of America kindly hosted this year's pageant in Burien, WA.

As the new 2009 Ms. Wheelchair Washington, Jannette encourages people with disabilities to pursue a higher education. She believes her education has been an investment and lead to her independence. She is very proud of her Bachelor's degree in Journalism and Public Relations from Arizona State University and her Master's degree in Counseling from the University of San Diego. In 2006, she graduated with a 3.98 grade point average.

Currently, she works as a Specialist for the Mobilization and Deployment Program of Fort Lewis, WA. She works with dual-military and single parent soldiers as they prepare guardianship for their children during a deployment under Operation Iraqi Freedom, Operation Enduring Freedom, and other military operations of the Armed Forces. This year she wants to work with the Paralyzed Veterans of America and follow up with soldiers when they return from their deployment and visit soldiers who have been injured.

Jannette also has a strong passion to motivate young people with disabilities to strive to accomplish their dreams and feel inspired to achieve their life goals. She knows first-hand that children with disabilities can often feel isolated, but with a positive self-image they can find an optimistic spirit through nurturing, inspiring, confidence and enrichment. That is why as Ms. Wheelchair Washington Jannette's platform is titled "Taking A.C.T.I.O.N: Achieving Confidence Through Inspiration, Optimism, and Nurturing."

Jannette believes that the greatest gift a person can give others is not just words of encouragement, but the strength and consistency of one's example. An inspirational life does more than ponder its significance, but ultimately "takes A.C.T.I.O.N" and change!

"I am grateful for the ability to directly impact soldiers and listen as they prepare for a life altering and potentially harmful mission, far from America's shores."

Jannette Saxton



Jannette Saxton

To contact Jannette for speaking engagements or events, please contact Tammy Wilber, Ms Wheelchair Washington State Coordinator, by email at mwheelchairwashington@yahoo.com or by phone at 206-714-1253.

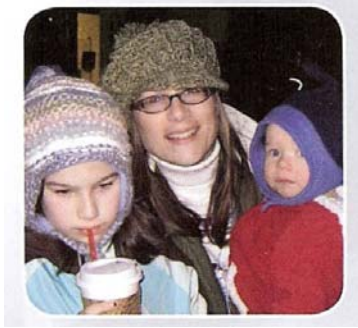
SBAWS member shares pageant experience, dreams

by Heather and Patti Logan

Do you know about the Ms. Wheelchair Washington Pageant? Heather Logan, SBAWS member, would like to be Ms. Wheelchair Washington 2010. Heather and her mother, Patti, had a wonderful time in Burien on February 22 at this year's pageant. They got to meet each Ms. Wheelchair Washington from 2006, 2007 and 2008. They are all awesome women.

Heather was inspired watching Meg Paulsen, fellow SBAWS members, give up her crown to Jeanette Saxon, Ms. Wheelchair Washington 2009. Everyone there was so supportive and enthusiastic about advocating for those who use wheelchairs instead of walking. Lots of rolling jokes predominated, bring smiles to the listeners. Heather is busy working on her platform for next year's pageant, where she will talk about how she wants to help others with disabilities. Watch for next year's competition—Heather will likely invite you all to come! Bring your own chair.

Visit Jannette's website at: <http://www.mwheelchairwashington.blogspot.com>



Michele Hopkins, SBAWS Cluster Developer, was featured in the Winter 2009 issue of SBA's Insights magazine. Read the article online at:

<http://www.sbaws.org/Michele%20Hopkins%20Winter%2008%20Insights.pdf>

ADOPT-A-GHOST SEASON IS COMING SOON...

Please consider contributing your time this September and October to the annual Adopt-A-Ghost fundraising program. Last year we raised over \$4000! Your time and energy commitment will be very minor thanks to the excellent management of Nicole Anderson, Coordinator of the Adopt-A-Ghost program. Contact SBAWS today to sign up and stay tuned for more information! Remember, all funds raised are funneled back into the chapter and help support our programs and events.



Nicole Anderson and one of the cute little ghosts



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 Anderson	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

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

Guidelines for the use of person-centered language

The use of certain words or phrases can express gender, ethnic, or racial bias, either intentionally or unintentionally. The same is true of language referring to persons with disabilities, which in many instances can express negative and disparaging attitudes.

It is recommended that the word disability be used to refer to an attribute of a person, and handicap to the source of limitations. Sometimes a disability itself may handicap a person, as when a person with one arm is handicapped in playing the violin. However, when the limitation is environmental, as in the case of attitudinal, legal, and architectural barriers, the disability is not handicapping—the environmental factor is. This distinction is important because the environment is frequently overlooked as a major source of limitation, even when it is far more limiting than the disability.

The guiding principle for non handicapping language is to maintain the integrity of individuals as whole human beings by avoiding language that: implies that a person as a whole is disabled (e.g., disabled person); equates persons with their condition (e.g., epileptics); has superfluous, negative overtones (e.g., stroke victim); or is regarded as a slur (e.g., cripple).

Put people first, not their disability. Preferred expressions avoid the implication that the person as a whole is disabled or defective.

PROBLEMATIC

disabled person
defective child
mentally ill person

PREFERRED

person with (who has) a disability
child with a congenital disability
person with mental illness

Use emotionally neutral expressions. Objectionable expressions have excessive, negative overtones and suggest continued helplessness.

PROBLEMATIC

stroke victim
afflicted with cerebral palsy
suffering from multiple sclerosis
confined to a wheelchair

PREFERRED

Individual who had a stroke
person with cerebral palsy
people who have multiple sclerosis
uses a wheelchair

Do you want to chat with SBAWS friends across the state?

SBAWS will soon begin unveiling online communication groups. Here is how you can participate:

- **E-Chat Room Group Sunday at 4 pm.** Is another time better? We can do more of these....
- **Suggest another time for an e-chat.** Let us know who you want to share with and when. There will be a chance to do that when you receive your invitation.
- **Webcam Match-ups.** Would you like to have a Spina Bifida Buddy? Do you have a Webcam? Most new computers have them built-in. (If you aren't so lucky as to have a newer version, you can purchase a simple webcam for around \$17.) We will gladly match you up with another member who shares an interest (age, hobby, love-life, whatever).
- **Email bulletins—do you want more email or less?** Respond to any of these questions/ideas by writing to patti_logan04@yahoo.com or sbaws@yahoo.com or calling Patti at 360-491-3171.

Excerpted from the American Psychological Association online style guide. Read more at <http://www.apastyle.org/disabilities.html>



MEDICAL NEWS!

HARBORVIEW
MEDICAL
CENTER
UW Medicine

Surgery restores penile nerves for males with Spina Bifida

by Dr. David Shurtleff with Celeste McCormick

Dr. David Shurtleff, Professor of Pediatrics at the University of Washington and both friend and Medical Advisor to SBAWS, announces a major medical advance for men with spinal cord impairment: the first and (and also the first successful) case in the United States of thigh nerve to dorsal penile nerve to produce sensation in a previously insensitive penis. Known as the "TOMAX" procedure, it entails transferring a branch of the nerve supplying sensation from the thigh skin to the dorsal nerve of the penis.

Dr. Max Overgoor of The Netherlands already experienced success with 18 successful operations; those operations included two patients who had experienced spinal cord trauma resulting in lost sensation or development and 16 patients with Spina Bifida. Dr. Shurtleff invited Dr. Overgoor to Seattle to assist with the procedure. Dr. Thomas Lendvay, Urologist and Dr. Anthony Avellino, Neurosurgeon, both with Seattle Children's Hospital, performed the operation under Dr. Overgoor's direction. This first US patient to have the procedure, a 20 year old with Myelomeningocele, had the TOMAX procedure performed at Seattle Children's in March 2009. He recently notified Dr. Shurtleff that he is experiencing tingling at the site of the operation in the head of his penis. Dr. Overgoor explained that his 18 successful patients reported this pattern as a precursor to the return of full sensation in the area of the transplanted nerve. It is hoped that this medical advancement will add tremendously to the medical community's ability to treat boys and young men and will greatly enhance their psychological development.

Eligible patients must have sensation over the anterior and medial skin of the thigh. Any male with trauma to the spine or any form of Spina Bifida would qualify if he has this combination of nerve function and loss. Dr. Shurtleff advises patients to be informed of the operation's potential and undergo the procedure only when the boy (or man) is old enough to understand its significance. The only barrier to wider-spread use of the TOMAX procedure in the United States is a cost of \$15,000 - \$20,000 for the hospitalization and whether Medicaid, Medicare or insurance companies will reimburse for the procedure. Seattle Children's Hospital's Medical Director convinced the hospital to waive the hospital cost for the first patient and the surgeons charged no operative fee. Use of the procedure may become more common if men start applying to their insurance companies and/or the government for coverage of the operation. In the meantime, Dr. Shurtleff urgently wants to form an advocacy group of interested males and/or their parents to help lobby the government and insurance companies. Dr. Shurtleff has permission to assess one adult per month at Seattle Children's Hospital. Please contact him if you are interested in learning more about this procedure and securing financing or reimbursement.

Contact Dr. Shurtleff: Department of Pediatrics, MS: A-7938, Univ. of Washington, Seattle WA 98195, david.shurtleff@seattlechildrens.org

Additional regional medical news...

In the Seattle area, superb care is already provided for adults with Hydrocephalus and/or Myelomeningocele and other forms of Spina Bifida through the office of Dr. Richard Ellenbogen, Chairman of the Department of Neurological surgery at UW.

However, in July of this year Dr. Avellino will assume Directorship of the New Neurosciences Institute at the University of Washington (UW) and one of his goals is to establish an inpatient and outpatient program at Harborview Medical Center for adults who have graduated from pediatric care. A main objective of the program is to provide specialty care for adults with conditions such as Spina Bifida. Dr. Avellino will be in charge of Psychiatry, Psychology, Rehabilitation Medicine, Neurology and Neurosurgery and plans to enlist urologic, gastrointestinal and orthopedic care as well. He hopes to develop a coordinated clinic like the one at Seattle Children's Hospital for these patients with multiple system disorders. Dr. Shurtleff founded the program at UW Medical Center in 1960 and for the first 17 years cared for adults and children in the Birth Defects Clinic sponsored by the March of Dimes.



SPINA BIFIDA ASSOCIATION OF WASHINGTON STATE

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**Outdoor and other
enrichment programs
around this summer
throughout Washington state**



Sports: Outdoors For All offers activities for the whole family from water activities, hiking, kayaking, cycling and camping. There are day activities, as well as overnight trips. Looking for a cycling trip....Join the Seattle to Portland team. For more information visit <http://www.outdoorsforall.org>.

Children's Camps: Seattle Children's Hospital Resource Directory offers a list of many Washington camps for youth; visit

<http://cshcn.org/resources-contacts/summer-camp-directory>

Career & Employment Services: DO-IT Program serves to increase the participation of individuals with disabilities in challenging academic programs and careers. It promotes the use of computer and networking technologies to increase independence, productivity, and participation in education and employment. This program prepares young people with disabilities for college, careers, independent living, and leadership roles in society. Training is offered in July and August each summer. Sign up to be a DO-IT Pal and meet some great individuals. <http://www.washington.edu/doit/>.


**Spina Bifida Association
of Washington State**

