



# The Evergreen

September 2009

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

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## SBAWS takes action to promote prevention, increase outreach

by Ed Kennedy, President

The SBAWS is on the move! Your Board of Directors took great steps at our in-person Board of Directors meeting in August to provide for a bright future for people in Washington State who live with Spina Bifida or are at risk of having a child with Spina Bifida.

First, we discussed and decided that the SBAWS needs to, and will be taking a more active role in, reaching out to those who are at risk of having a child with a neural tube defect such as Spina Bifida. Our efforts in the past, although well meaning and good, have been almost entirely to reach out to those already affected by Spina Bifida. This message of "Prevention" is something that SBA encourages and we have always mentioned when doing various presentations, but have not specifically sought out audiences to take the message to as we plan to do in the years to come. Just recently the SBAWS wrote a grant proposal to SBA to help fund our "Prevention" program. However, the Board also decided that this message must be a part of our outreach regardless of whether or not we get this additional funding. If you would like to be a part of this Prevention Outreach or know of venues that would be good for this message of prevention (such as Bridal fairs, health and wellness expos, etc.) to be presented, please contact any member of the Board of Directors so we can plan to

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## CDC Issues Updated Vaccination Recommendations for Swine Flu

Washington, D.C. - Influenza (swine flu) is a respiratory disease of pigs caused by the type A / H1N1 influenza virus. Normally, people do not get swine flu, but human infections can happen. Like seasonal flu, swine flu may cause a worsening of some chronic medical conditions. According to the Spina Bifida Association Professional Advisory Council, unless one has a weakened respiratory or immune system, people with Spina Bifida run no greater risk contracting the virus. Swine flu can go from exposure to infection within one to four days, so prevention is the key to battling such a fast-acting virus. All individuals, including people living with Spina Bifida, can take the following simple steps to avoid germs, including swine flu:

- Wash your hands often with soap and water or use sanitizing gels when hand washing is not available-to remove germs and prevent germs from spreading.
- Avoid touching your eyes, nose, and mouth.
- Cover your mouth or nose with a tissue

when coughing or sneezing.

- Stay home if you're sick.
- Avoid close contact with sick people.
- Seek medical care if you experience fever, chills, cough, sore throat, body aches, headache and fatigue.
- Get the H1N1 influenza vaccine if you are in one of the recommended groups:  
 Pregnant women because they are at higher risk of complications and can potentially provide protection to infants who cannot be vaccinated  
 Household contacts and caregivers for children younger than 6 months of age because younger infants are at higher risk of influenza-related complications and cannot be vaccinated  
 Healthcare and emergency medical services personnel because infections among healthcare workers have been reported and this can be a potential source of

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**WE NEED A SECRETARY!**

This is a volunteer position. Can you contribute to SBAWS in this leadership role? See page 3 for details.

Newsletter Editor  
 Celeste McCormick  
 celltutt@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!*

President  
Ed Kennedy, [ejk@cordwa.info](mailto:ejk@cordwa.info)  
Vice President  
Annette Zweig-Donham,  
[az@w-link.net](mailto:az@w-link.net)  
Secretary  
vacant  
Treasurer  
Jon Tutt, [jon\\_tutt@msn.com](mailto:jon_tutt@msn.com)

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

# What a difference a day makes!

Saturday, October 17, 2009



Since 2006, **Macy's** "Shop For A Cause" Event Has partnered with the **SBAWS** and other non-profit organizations nationwide to raise more than \$28 million for their ongoing charitable efforts. This is your chance to be part of this monumental event and help the SBAWS.

In exchange for each **\$5 Donation** to the SBAWS we will give each donor a nationwide Macy's "Shopping Pass" that entitles the holder to a 10-20% discount on most items in the store, a 25% discount on any one item, a chance to win a \$500 gift card and, this year, the passes can be used online on Saturday, October 17, 2009.

If **every constituent** were to buy and then resell or give away **only 10 shopping passes each**, we could increase our previous largest total raised by 50% and become our largest fundraiser to date. Join in the fun and benefit our association as well by ordering your passes today. Write or call our treasurer at 509-868-1485 or order online by sending an email to [sbaws@yahoo.com](mailto:sbaws@yahoo.com) **TODAY!!**

## SBAWS is on the move

*(Continued from page 1)*

have a presence at such times and places.

Another very exciting decision that came out of our meeting was that the Board made a goal of hiring a part-time Executive Director for the SBAWS. I personally feel that this step alone will help our organization become more financially and organizationally stable for many years to come. This person will be responsible for, at first, primarily to search for new additional fundraising opportunities for the SBAWS. Initially this, along with Prevention, will be the main job duties for this person and the current officers and Board of Directors will still be overseeing the overall activities of the organization. More information about the search for an Executive Director will be forthcoming in weeks and months to come.

And if that were not enough, the Board adopted new SBAWS Bylaws that were a suggestion from SBA to help all the various chapters across the country resem-

ble each other more and operate in a like manner. We will be asking for everyone's participation in the near future to either ratify or deny the Board's decision regarding this issue. You can see both our old and proposed new bylaws on our website at [www.sbaws.org](http://www.sbaws.org). As you can tell - our board did a great job in making difficult decisions for the future of the SBAWS. If you have any concerns or questions about any of these issues please feel free to contact me at [ejkcordwa@live.com](mailto:ejkcordwa@live.com). Lastly, on behalf of the Board, we'd appreciate if you'd give serious consideration of giving your time, talent and treasure to the association. We want your ideas and input on what we can do to better fulfill our mission. If you have a few spare hours a week or month we'd appreciate you donating it to the Association and of course, we can always use financial support. Please seriously consider making regular monetary donations and thank you for being a part of the SBAWS.

## Letter to members from the Interim Secretary

**Please  
vote!**

*Board member  
Nicole Anderson  
got married in May  
and now goes by  
Nicole Williamson.  
Congratulations  
Nicole!*

New Association Bylaws were approved by the Board of Directors at their meeting on August 15, 2009. These new bylaws were the result of many hours of work by the association bylaws committee and were based on a model provided by the national Spina Bifida Association. It is national's desire that all credentialed chapters have bylaws based on their model so that all chapters across the country resemble each other and operate in a like manner. This recommendation is based on consultation with various profit and non-profit agencies across the country such as the Internal Revenue Service, Board Source and the Better Business Bureau. It is national's opinion that the model bylaws most clearly represent current "best business practices" in today's non-profit world.

In some ways the new bylaws don't change a thing, but in others represent drastic changes. The most apparent aspect is that the traditional office structure of President, Vice-president, Secretary and Treasurer are replaced with Chair, Chair-Elect, Secretary, Treasurer and Immediate Past Chair. In spite of the new titles, the job descriptions and duties of the new officer positions are pretty close to the old. Another major change is that we will no longer be a membership based organization and in the future will refer to our "members" as "constituents". Under these new bylaws "members" will be those elected to the Board of Directors and they will be the only ones that vote on anything.

Under our current bylaws however, any amendments, restatements or replacements of the bylaws must be by affirmation of a two-thirds majority of the members (current definition not the board) that vote, after a 30 day voting period.

Copies of the new and old bylaws are posted on our website [www.sbaws.org](http://www.sbaws.org). The voting period will be the month of September, 2009 and all votes cast will be counted on October 1, 2009. Please cast your ballot and let your voice be heard. Ballots may be cast in any manner that, in the opinion of the Secretary, clearly indicates the voter's choice.

	I Vote Yes and Affirm the new bylaws approved by the Board of Directors on August
	I Vote No and do not affirm the new bylaws approved by the Board of Directors.
	Signed:

Please indicate your vote above by placing and "X" or check mark in the box preceding your choice, sign the form and return it to the Secretary by any of the methods listed above. Feel free to make any inquiries you desire.

Sincerely, Jonathan A. Tutt, Interim Secretary

**Do you read your free copy of Insights or is it lining your cat box?**  
Are you getting two copies? If you want to STOP receiving your free copy of Insights or if you have been receiving an extra copy, we want to know. SBAWS pays for all each subscription and only wants to order one for people who really want it.

**VOLUNTEER NEEDED:**  
Do you have good computer skills & 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 finds it hard to keep up with both roles. Free training is offered. Call 888-289-3702 or email [sbaws@yahoo.com](mailto:sbaws@yahoo.com).



# OCTOBER is Spina Bifida Awareness Month

Please  
participate  
in the  
Adopt-A-Ghost  
program  
\$1.00 per ghost



This is a fun, easy  
way to promote  
Awareness of Spina  
Bifida and raise funds  
for your local cluster  
and  
the SBAWS

All proceeds go to SBAWS  
and its members

The Adopt-A-Ghost Program will begin October 1<sup>st</sup> and will continue through October 31<sup>st</sup>. 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, WA 99206. For details about how the program works, visit <http://www.sbaws.org>.

Look for details in the Adopt-A-Ghost information packet, available online at [www.sbaws.org](http://www.sbaws.org). For additional information, please contact Nicole Williamson at (206) 877-2568 or [seattlespinabifidagroup@hotmail.com](mailto:seattlespinabifidagroup@hotmail.com).

## save the date

The first annual SBAWS Walk & Roll Fundraiser is slated for March 20, 2010. This event will occur in Olympia, with the one-mile course leading participants to the steps of the capitol. Raising money and promoting awareness are the two main goals for the day—and we also hope to have fun! **SIGN UP TODAY** by contacting SBAWS! We want to see you there!

## Mid Year 2009 Comparative Profit and Loss Statements

	2009	2008	\$ Change	% Change		
<b>Income</b>						
Membership Dues	\$ 90.00	\$ 625.00	\$ (535.00)	-85.60%		
General Donations	\$ 774.55	\$ 210.00	\$ 564.55	268.83%		
Special Donations	\$ 370.00	\$1,121.00	\$ (751.00)	-66.99%		
<b>Total Donations</b>	\$ 1,234.55	\$1,956.00	\$ (721.45)	-36.88%		
Other (Interest)	\$ 393.50	\$ 796.82	\$ (403.32)	-50.62%		
<b>Total Income</b>	<b>\$ 1,628.05</b>	<b>\$2,752.82</b>	<b>\$ (1,124.77)</b>	<b>-40.86%</b>		
<b>Expenses</b>						
		<b>% of \$ Spent</b>	<b>% of \$ Spent</b>			
Mission/ Program Cash	\$ 6,569.70	83.28%	\$2,349.06	62.71%	\$ 4,220.64	179.67%
Computer Depreciation	\$ 141.90	1.80%	\$ 288.48	7.70%	\$ (146.58)	-50.81%
Total Mission/Program	\$ 6,711.60	85.08%	\$2,637.54	70.41%	\$ 4,074.06	154.46%
Administration	\$ 935.99	11.87%	\$1,057.61	28.23%	\$ (121.62)	-11.50%
Fundraising	\$ 240.93	3.05%	\$ 50.92	1.36%	\$ 190.01	373.15%
<b>Total Expense</b>	<b>\$ 7,888.52</b>	100.00%	<b>\$3,746.07</b>	100.00%	<b>\$ 4,142.45</b>	<b>110.58%</b>
<b>Net Income (Loss)</b>			<b>\$ (993.25)</b>		<b>\$ (5,267.22)</b>	<b>530.30%</b>

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:** Due to the money raised by Don Stevenson through his walk for the SBAWS, general donations increased significantly, but all other incomes categories decreased: membership, special donations, total donations and interest. Total income was 41% or \$1125 less in the first half of 2009 compared to 2008.

**Expenses:** Mission/Program expenses were up significantly due to the office rent (which we did not have last year) and because we paid the *Insights* subscriptions later last year, but even so with our increased membership, we paid over \$1000 more this year than last. The difference in Administrative and Fundraising expenses was statistically insignificant.. Total expenses more than doubled from last year to this.

**Net Income (Loss):** Our net loss this year was more than 5 times greater than last years, but should not be that way at year end because of the *Insights* being paid earlier in the year.

**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 \$9,622 or 20.6% between June 30<sup>th</sup> 2008 and June 30<sup>th</sup> 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 times, decreasing our spending is not the answer, but increasing our income is!

### SBA's 4b4the4th Fundraising campaign exceeds expectations

Designed to strengthen SBA's presence on various social media sites as well as to raise visibility, awareness, and funds for Spina Bifida, the results show that social media is a powerful and essential tool for our work.

- In just over 8 weeks, SBA saw its "friends," "fans" and "followers" on Facebook & Twitter increase by 144%
- A newly designed Spina Bifida Facebook cause page garnered over 1,350 fans and supporters – all simply through word of mouth and the power of social media.

- Donations in support of the 4b4the4th campaign exceeded the \$25,000 goal.

Information about new informational booklets, research studies, SBA Chapters, and Spina Bifida news has been shared with thousands – instantly – and we receive instantaneous feedback which helps us evaluate programs and efforts.

# Please join us for the SBAWS Seattle Cluster October field trip!



Everyone is invited to join us. Date to follow.

Prices for field trips are currently \$8.00 per child (no charge for adult chaperones). Please contact Nicole at [seattlespinabifidagroup@hotmail.com](mailto:seattlespinabifidagroup@hotmail.com) or #206.877.2568 for more information.

### The Pumpkin Patch (preschool-grade school)

Hooray! It time to come and pick out a great Pumpkin, join us in a harvest time celebration, pet the animals, go on a hay wagon ride, play in our historic barn with its three story hay maze and slide, check out the antics of Peter Rabbit in Mr. McGregor's garden!

The Farm is owned and operated by [Ben and Carol Krause](#) at 7301 Rivershore Road in Snohomish, WA. Phone number: 425.334.4124

From I-5 take Exit 194 to Highway 2 (onto the trestle). Take the Ebey Island/Homeacres Rd. exit off the trestle then follow the signs to "The Farm."

From Highway 9 (North or South) take the Snohomish Exit and turn west onto Riverview road follow signs approx. 3,5 miles to The Farm. (Riverview Rd. becomes Rivershore Rd.)



## LET'S DO LUNCH!

### with the Everett/Eastside Cluster

The Everett/Eastside Cluster Group is now meeting every other month starting on September 19th, 12 noon. Lunch will be provided for our fall kick-off meeting. We will meet in the food court at Alderwood mall. Look for the sign that should read "Eastside Cluster Group". Or, please contact Michele Hopkins @ 206 909 4186 if you wish to attend. We look forward to seeing as many of you as possible!

### Everyone had fun at the Seattle Cluster summer picnic!

*by Nicole Williamson, Seattle Cluster Co-Leader*

We had 90 guests join us at Gasworks Park this past July, including the staff from Outdoors for All & Seattle Adaptive Sports!! ... and I believe no one melted in the heat:)

Thank you, Outdoors for All and Seattle Adaptive Sports, for providing a demo day with various pieces of equipment. Thank you to Astratech, Husky Deli, Tom McLaughlin, Jason Lane and all the families for supporting our group with food & drink donations. Thank you to the SBAWS for supporting our group with the ability to reserve the picnic location & crafts.

Thank you to former Ms, Wheelchair WA, Tammy & Meg, for speaking about the pageant, as well.

The link below features the pictures from the SBAWS Seattle Summer Picnic 2009.

Photos are also available from [www.sbaws.org](http://www.sbaws.org).

[http://picasaweb.google.com/SeattleSpinaBifida/SBAWSSeattleSummerPicnic2009?authkey=Gv1sRgCNPXza2W-a\\_6UQ&feat=directlink](http://picasaweb.google.com/SeattleSpinaBifida/SBAWSSeattleSummerPicnic2009?authkey=Gv1sRgCNPXza2W-a_6UQ&feat=directlink)



Ms Wheelchair WA named 1st runner up at national pageant

Jannette Saxton, 2009 Ms. Wheelchair Washington, was named the 1st runner up at the 2010 Ms. Wheelchair America pageant, held August 29th in Rapid City, South Dakota. Jannette, who resides in Lakewood, WA, has had Cerebral Palsy since birth. She works as a Deployment Specialist at Fort Lewis, WA and sets up services for the families of soldiers before they deploy far from America's shores. As Ms. Wheelchair Washington, Jannette has been giving back to veterans and thanking them for their service to our country. She had the honor of attending the National Paralyzed Veterans games, held in Spokane, WA in July. In fact, Jannette's own call to service has been to share her message of Taking A.C.T.I.O.N: "Achieving Confidence Through Inspiration, Optimism, and Nurturing." Jannette says, "I am so honored and thrilled to become the 1st runner up this year at the 2010 Ms. Wheelchair America pageant, and am so proud to represent the great state of Washington!"

## Researcher seeks mothers of children with SB:

Patti Logan was contacted at the national convention by Vitapath Genetics, Inc. about research being done on absorption rates of vitamins due to genetic makeup. They are looking for women who have had a child with Spina Bifida to participate in their research project. A representative from Vitapath will be in attendance at the next in-person Board of Directors meeting in Seattle on October 3. Contact SBAWS to participate.

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

## Children's Hydrocephalus Support Group

*Please come to our next Children's Hydrocephalus Support Group meeting with our very special guest speaker, Dr. Samuel Browd*

**Date:** Thursday, September 24th, 2009, 6:30pm - 8pm

**Location:** Seattle Children's Wright Auditorium and G-1027

**Address:** 4800 Sand Point Way NE, Seattle, WA 98105

For more information and to RSVP please visit <http://event.pingg.com/HydroSupport>

## FREE CDC MATERIALS FOR PREVENTION & AWARENESS

Courtesy of the Centers for Disease Control, SBAWS has a wealth of materials, including brochures and posters, to educate the public about Spina Bifida and how to prevent it.

If you or your cluster could benefit from these materials, please contact SBAWS today so that they can be shipped to you free of charge.

## GET INVOLVED WITH YOUR CLUSTER TODAY!

City/State	Leader Name	Contact Phone
<b>CLUSTER DEVELOPER</b>	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

## Kitsap Support Group's

# PICNIC

For people with Spina Bifida and/or Hydrocephalus  
and their families and friends!

**Saturday, Sept 12, 1:00-4:00pm**

Evergreen Park in Bremerton at picnic shelter #3 near the kids' playground

Please bring your favorite picnic foods to share:

Salads, Side Dishes or Desserts.

Hamburgers, Hot Dogs, Drinks and Serviceware will be provided.

**Please RSVP by Sept 10 to Group Leaders:**

Dave Lewallen, 360-871-5139 or Rebekah Uhtoff, 360-782-0467



### Disability Unemployment & Employment Participation Stats Released

According to the U.S. Department of Labor's Bureau of Labor Statistics (BLS) the July 2009 disability unemployment rate was 15.1 percent compared to 9.5 percent for people with no disability. The percent of people with disabilities in the labor force was 23.0 percent compared to 71.8 percent for people with no disability.

Note: Data are not seasonally adjusted. Seasonally adjusted numbers are not yet available for disability specific statistics from BLS because the statistics are still too new.

Information courtesy of the National Collaborative on Workforce and Disability for Youth; visit <http://www.ncwd-youth.info/> for more info

Also visit the Office of Disability Employment Policy:

<http://ent.groundspring.org/EmailNow/pub.php?module=URLTracker&cmd=track&j=287973014&u=3172571>

### Back2Sports.net designs new snow-ready wheelchairs

by Tom Hemon, President, [Back2sports.net](http://Back2sports.net)

Over the past few years we have been working on perfecting a wheelchair that will give you unlimited mobility in any amount of snow. Our snow chair is an outdoor wheelchair with removable wheels and attachable skis to use when you are faced with non-shoveled sidewalks and parking lots. The small skis and collapsing poles fit under the seat. When the skis are in use the wheels plug into the back rest for easy storage and transport.

We are offering a limited number at a special price of \$1950, which includes a light weight aluminum frame, 130cm to 180cm skis with quick release bindings, collapsing ski poles, 6 inch off-road front

wheels, 26-inch Velocity Wheels with mountain bike tires and 20-inch outdoor push rings to keep snow off your hands.

I now love winter; I use it to walk my dog, go for winter walks with my girlfriend, get to the luge track, use the cross country trails and play sled hockey (ice blades are extra).

Call 616-451-4716 or visit our web site at [www.back2sports.net](http://www.back2sports.net) for more information and videos. Pricing is for a limited time only and expires Nov 1 2009.





## AAPD launches new segments in its disability/advocacy email newsletter

by Sarah Peterson, Moderator, Justice for All

Sunday, July 26 was the 19th Anniversary of the ADA. Across the country political leaders, disability advocates and community members alike, used this special moment to recommit themselves to the work of the ADA. I too am using this day to reflect on my work as JFA Moderator and how it contributes to the promise, to the challenge, of the ADA: equality of opportunity, full participation, independent living and economic self-sufficiency.

To those ends, I am launching two new segments in Justice for All: [first], "AAPD: Focus on..." and [second], "Ask the Expert." "AAPD: Focus on..." will be original content produced by AAPD staff and our allies in the movement which clarifies, explains or describes the work we are doing in pursuit of those goals. Not seeing what you want or need? "Ask the Expert" will be a chance for any reader to pose their question to a trained professional in disability rights. Questions can be submitted by emailing [jfa@aapd.com](mailto:jfa@aapd.com) and listing "Ask the Expert" as the subject. Questions should be no more than 200 words in length. One question will be answered each week. See the segment below for a short bio on our first expert: Day al-Mohamed.

Both of these changes came from feedback I've received from JFA Readers. Please continue to let me know what I can do to better serve you and our movement. *Justice for All is a free email service from the American Association of People with Disabilities. To sign up, visit [www.aapd.com](http://www.aapd.com).*

## Disability.gov Launches New Website: [www.disability.gov](http://www.disability.gov)

The U.S. Department of Labor launched [Disability.gov](http://www.disability.gov), a redesigned federal Web site that connects the more than 50 million Americans with disabilities to thousands of trusted resources on disability-related issues, programs and services. Formerly known as [DisabilityInfo.gov](http://www.disabilityinfo.gov), the site has been completely redesigned and updated with new social media tools, such as a blog and a Twitter feed, to encourage feedback and interaction among visitors. Disability.gov is not just for Americans with disabilities, but also for parents of children with disabilities, employers, workforce and human resource professionals, veterans, educators, caregivers and many others. *Information courtesy of the National Collaborative on Workforce and Disability for Youth; visit <http://www.ncwd-youth.info/> for more info*



## Outdoors for All staff would like to say THANK YOU

to all our 2009 Outdoors for All Seattle to Portland Team members. What an amazing ride. Over 200 miles of camaraderie and fun! About \$8,000 was raised to support Outdoors for All. THANK YOU 2009 team for your participation in this years team. We hope to see you next year! If interested in being part of the 2010 Outdoors for All STP Team, please contact Missy Gresen to get on next years contact list at:

[outreach@outdoorsforall.org](mailto:outreach@outdoorsforall.org). Upcoming events (visit [www.outdoorsforall.com](http://www.outdoorsforall.com) or call 206-838-6030 for more info):

**September 18-20: Weekend Excursion**

**September 19: Cycling**

**September 26-27: Weekend Excursion**





## YOU CAN INFLUENCE CONGRESSIONAL FUNDING FOR SB!

People from all over the country are taking action to support people with Spina Bifida. Everyone in attendance at the Spina Bifida Association (SBA) National Conference in Orlando, FL sent postcards to their Members of Congress asking them to support increased funding for the National Spina Bifida Program at the Centers for Disease Control and Prevention (CDC). Now we need advocates from across the country to take action and send the same message to Congress via email!

**Background:** The National Spina Bifida Program housed at the Centers for Disease Control and Prevention (CDC) supports critical programs, research, and services for those who live with Spina Bifida. In the more than five years since it was created, it has done great work to improve the quality of life for those living with Spina Bifida.

**The Problem:** Members of Congress are most responsive to their constituents. Your elected officials in the House and Senate need to be asked directly by you to allocate \$7 million in Fiscal Year 2010 for the National Spina Bifida Program. The more people who contact Congress about this important program – the more likely it is to happen.

**Send an Email Today:** Taking action will take less than 5 minutes and it will have a significant impact. With thousands of people all contacting Congress today about Spina Bifida funding our voices will be loud and clear: increase funding to improve quality of life for people with Spina Bifida! **Make a Phone Call:** Just call 202-224-3121 and ask to be connected to your elected officials’ offices – let them know you support increased funding for the National Spina Bifida Program!

Your help can improve the quality of health care provided to Americans with Spina Bifida. Make your voice heard! Your voice does make a difference.

**Act Now** by going to the site below:

<http://www.kintera.org/TR.asp?a=bgLFITNELiQKaJ&s=8qIKLOOBJaLNJ3MzGkH&m=jeLRJUMpH9LSE&af=y>

### National Conference Handouts & Sessions available online

Conference session handouts are now available online at <http://conference.spinabifidaassociation.org>.

Click on *Educational Sessions* on the left hand side of the page.

Leadership Institute Sessions are available online at <http://leadersonline.spinabifidaassociation.org>.

### National Teen Bullying Prevention

**Website:** [www.teensagainstbullying.org](http://www.teensagainstbullying.org)  
 PACER Center’s National Center for Bullying Prevention launched an innovative bullying prevention resource. Teens themselves participated in the creative process of developing the site. Through videos, blogs, and social networking, the site’s resounding message is the end of bullying begins with you. Information courtesy of the National Collaborative on Workforce and Disability for Youth; visit <http://www.ncwd-youth.info/> for more information.

## Swine flu vaccinations recommended for persons in high risk categories

(Continued from page 1)

infection for vulnerable patients

Children from 6 months through 18 years of age because we have seen many cases of novel H1N1 influenza in children and they are in close contact with each other in school and day care settings, which increases the likelihood of disease spread

Young adults 19 through 24 years of age because we have seen many cases of novel H1N1 influenza in these healthy young adults and they often live, work, and study in close proximity, and they are a frequently mobile population

Persons aged 25 through 64 years who have health conditions associated with higher risk of medical complications from influenza.

CDC does not expect that there will be a shortage of novel H1N1 vaccine, but flu vaccine availability and demand can be unpredictable and there is some possibility that initially the vaccine will be available in limited quantities. For more information visit [www.cdc.gov/h1n1flu](http://www.cdc.gov/h1n1flu).



# National Institutes of Health

The Nation's Medical Research Agency

Participate in a National Study Sponsored by the NIH

**Gene Talk: What Do We Expect From Families and their Doctors?** is a US national study sponsored and funded by the National Institute of Health. The purpose of this study is to collect thoughts, opinions, and beliefs from patients and providers about who has responsibility for sharing genetic risk information within families, and when it is morally acceptable not to share information. The investigators believe that the opinions of people like you, who actually live with these situations, are key to their research. In addition to information gathered from patients and their families, information has been collected from experienced health care professionals, medical doctors, and health care consumers inexperienced in genetic illnesses.

The data will be collected through an IRB-approved mailed survey. The survey will present 12 short stories about different ways providers and patients might react to situations that might involve sharing genetic information with family members. Each brief story is followed by 2 questions. The entire survey takes about 15 minutes to complete

The first step is to provide your contact information at this website ([http://cts.vresp.com/c/?MoonwareDesign/fcfad58af4/31c4bcd171/61888a3e4a/sm=C\\_2fGj736r\\_2fLAHxJnp1YMBRQ\\_3d\\_3d](http://cts.vresp.com/c/?MoonwareDesign/fcfad58af4/31c4bcd171/61888a3e4a/sm=C_2fGj736r_2fLAHxJnp1YMBRQ_3d_3d)) so the survey can be mailed to you at the address you provide. *All information that you do provide will remain confidential and your survey answers will not be connected to your name.* Thanks for helping with this very important survey. This research is an important initiative to improve the health of so many!

## Expressing Rates of Spina Bifida

Statistics on Spina Bifida have recently been reevaluated. To properly express the rates of Spina Bifida, access this fact sheet:

<http://leadersonline.spinabifidaassociation.org/site/c.mk1VLAMRJR/b.3348055/k.EE4E/Resources.htm>. This valuable resource provides rates of NTD-pregnancies, newborns with Spina Bifida as well background on the new number of the Spina Bifida population (from 70,000 to 180,000 plus).

**Senator Murray Shares More Washington State Stories, Senate Speech Outlines What Health Care Reform will Mean for Those with Rising Insurance Premiums** (Press Release, July 22, 2009)  
Today, U.S. Senator Patty Murray (D-WA) delivered a speech on the floor of the Senate calling attention to the rapidly rising costs that health care consumers are facing and urging Congress to move quickly on health care reform.

Excerpts from Senator Murray's speech:

"I understand that many Americans are satisfied with the level of care their insurance provides. These are the Americans who want to know what's in it for them. What will they get out of reform?"

"It's not just the uninsured who are impacted by not being able to access preven-

tative medicine or having to seek costly care in our E.R.s. These costs get passed on to those with insurance in the form of higher insurance premiums. It's estimated that a family of four is paying an added one-thousand dollars in premiums a year to help pay for those with no coverage. Essentially, it's a 'hidden tax.' This tax is hurting families who are insured and it's hurting our businesses. And it needs to end."

"For those of our colleagues who ask how we can afford to pay for this, I'd like to tell them to ask Patricia Jackson – or any of their constituents. Because the real question is how can we afford not to."

For the full text of her speech and to learn more about where Senator Murray stands on health care, visit her new website [murray.senate.gov/healthcarereform](http://murray.senate.gov/healthcarereform).

Tom Smith  
Outreach and Media  
Liaison  
[Hydrocephalus  
Association](#)  
870 Market St., Suite  
705 San Francisco, CA  
94102  
(415) 732-7043



## SPINA BIFIDA ASSOCIATION OF WASHINGTON STATE

2128 N Pines Rd Ste 17-2 Spokane WA 99206  
Phone: 253-589-3700/Fax: 775-766-1654  
Toll free: 888-289-3702  
Email: sbaws@yahoo.com

*Please send us your  
email address!  
We don't want to  
miss important  
updates and info  
from SBAWS!*

***We're online!  
www.sbaws.org***

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### At 12:01 am on January 1, 2010, history will be made...

...\$100,000 will be raised to support people with Spina Bifida and their families. All across the country on New Year's Eve, 100 fundraising parties will be in full swing, each with a goal of raising \$1,000 for the Spina Bifida Association (SBA). We'd like you to host one too! Many friends of SBA have already begun planning their parties.

They include:

- A wine and chocolate party
  - A tour of a local winery
  - An office pizza party
  - Sending a donation to SBA in lieu of holiday gifts
- Some folks can't participate on New Year's Eve, so they are holding events on different dates. Some examples include:

- A Labor Day BBQ
- Asking the local Rotary or Elks Club to make a donation directly to SBA.
- A "sweet 16" birthday party
- A "ghost" party where people pay not to attend.
- An "auction" where a local theater donated 2 tickets and a restaurant provided 2 complimentary meals.
- A mailing to all their friends asking them to make a donation (note, the letter is already written...we'll help you mail it!)
- Having their company match their personal donation.

Have fun! Be creative! There are many clever and inexpensive ways to have a great time. Make it clear, however, that this is a fundraiser for a very important cause. For more information, please feel free to contact Christopher Vance, Director of Development, at [cvance@sbaa.org](mailto:cvance@sbaa.org).



**Spina Bifida Association  
of Washington State**

