



# The Evergreen

January 2013

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

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## SBAWS plans many fun, informative events for 2013

by Meg Paulsen, Executive Director, [megpaulsen@sbaws.org](mailto:megpaulsen@sbaws.org)

I hope everyone had joy filled holidays with family and friends! The New Year is always an exciting time for me – thinking about all of the new opportunities that will present themselves and imagining new efforts and endeavors coming into fruition! After spending lots of time and energy creating our three year strategic plan and settling into our new office space – we are now ready to face the challenges of successfully meeting our goals and make the SBAWS a stronger, more sustainable organization.



Meg Paulsen

Here are some of the projects and programs we will be working on and towards our goals this year:

Java January – Give Uppa Cuppa this month for the SBAWS!

Here is where YOU can help make the difference – go to [www.sbaws.org](http://www.sbaws.org) and donate the cost of a cup of coffee (or a week's worth of your morning coffee). It doesn't take much for a donation to make a difference—if we all donate just \$5 or \$10 our contributions add up to something significant and translate into stronger SBAWS programs for all of us!

(Continued on page 6)

## New procedure restores genital sensation in men with SB

by Celeste McCormick, Editor

A new surgical procedure restores genital sensation and improves sexual function in men with Spina Bifida or spinal cord injuries. The procedure has long been known and championed by Dr. David B. Shurtleff, friend of SBAWS and physician at Seattle Children's Hospital.

The procedure was pioneered and piloted by Dr. Max L. E. Overgoor from Isala Clinic, Zwolle, The Netherlands. Dr. Overgoor and Dr. Shurtleff are colleagues and friends who have been communicating about the procedure for the past several years. In fact, Dr. Shurtleff helped review and edit an article on the procedure that was published in October 2012 in the online Journal of Urology. The print version

will be released this February.

Details of the results of Dr. Overgoor's pilot are described in detail in a Reuter's Health article, which can be read at this link: [http://](http://www.thedoctorschannel.com/view/procedure-restores-genital-sensation-in-men-with-spina-bifida-spinal-cord-injury/)

[www.thedoctorschannel.com/view/procedure-restores-genital-sensation-in-men-with-spina-bifida-spinal-cord-injury/](http://www.thedoctorschannel.com/view/procedure-restores-genital-sensation-in-men-with-spina-bifida-spinal-cord-injury/). In general, most participants reported improved measures of sexuality, including increased satisfaction with their sex lives and better sexual functioning.

Dr. Overgoor told Reuters Health his expectations for future results of the surgery: "In about 90% of the patients this will lead to restored sensation which is firstly felt in the groin, but in most patients this will be trans-

(Continued on page 10)



Newsletter Editor  
Celeste McCormick  
[celtutt@yahoo.com](mailto:celtutt@yahoo.com)

## HIGHLIGHTS FROM BOARD OF DIRECTORS MEETING December 12, 2012

*For full content of the minutes, visit [www.sbaws.org/Minutes.html](http://www.sbaws.org/Minutes.html)*

*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!*

- In attendance: Jason Lane, Krystal Monteros, Nicole Williamson, Dave Carl, Elizabeth Lovelace, Ryan Callaway, Linda Bailey, Ashley St. Clair, Jon Tutt (absent: Jamie Heckinger, Amy Miller)
- Guests: Meg Paulsen
- Treasurer's report:
  - Total income YTD \$48,256 (90% of goal); more donation receipts yet to be turned in; end of year fundraising push planned
  - Discussion regarding in-kind donations as source of revenue stream; Jon and Jason recommend counting in-kind donations unless SBA says in writing that it is not allowed; more research before next meeting
- Secretary's report: Annual holiday party a success; 100 attended
- President's report: Affiliation
  - Affiliation paperwork submitted on time; will hear back soon
  - Investigating cost, benefit of joining Chamber of Commerce in Seattle, Tacoma, Bellevue, Issaquah
- Chair-Elect: Development Committee report
  - Strategic Plan, Fundraising Plan, calendar adopted
  - Upcoming programs: Java January, Kids on the Block puppets, Safe-way Corporate Grant
- Executive Director's report: Snohomish office should be fully functional by end of the month; pursuing networking opportunities in Snohomish area and rest of state
- Actions taken by the Board since the last meeting
  - Approved three-year Strategic Plan (through 2015); sent to SBA
  - Approved \$250 grant for Michael Hoyt
- Old Business: SBA claims it is sending out publications but our chapter has not received any; Meg will follow up
- New Business:
  - Renewed FirstGiving contract (\$300/year)
  - Meg's Executive Director contract renewed; positive feedback for her work; due to medical issues she did not accomplish as much as intended last year but she has much planned for the coming year including a grant-writing class, better communication with the Board, improved fiscal & HR management, outreach in school districts and at community events targeting women age 12-40
  - 2013 Board of Directors election will occur in Dec 2013; slate approved by Board; current officers approved

NEXT MEETING:

**Wednesday February 27, 2013 by teleconference**

### The Evergreen reporting staff:

Michele Hopkins, [michele@thehopkins.us](mailto:michele@thehopkins.us)  
Elizabeth Lovelace, [chairelect@sbaws.org](mailto:chairelect@sbaws.org)  
Elizabeth Scriven, [liz-biz@iname.com](mailto:liz-biz@iname.com)  
Diana Tutt, [nanatutt@msn.com](mailto:nanatutt@msn.com)

#### Chair

Jason Lane

[chair@sbaws.org](mailto:chair@sbaws.org)

#### Chair -Elect

Elizabeth Lovelace,

[chairelect@sbaws.org](mailto:chairelect@sbaws.org)

#### Secretary

Ashley St. Clair

#### Past Chair

Linda Bailey,

[gingersnap8160@yahoo.com](mailto:gingersnap8160@yahoo.com)

#### Treasurer

Jon Tutt, [jon\\_tutt@msn.com](mailto:jon_tutt@msn.com)

#### Directors

Meg Paulsen, Exec. Director,

[megpaulsen@sbaws.org](mailto:megpaulsen@sbaws.org)

Ryan Callaway

Dave Carl

Jamie Heckinger

Amy Miller

Krystal Monteros

Elizabeth Scriven

Amy Shiel

Nicole Williamson

**Spina Bifida Association of Washington State**  
**Financial Statement Summaries**  
**As of December 31, 2012**

	2012		2011		\$ Change
Profit & Loss Comparison					
Income					
Donations					
Fundraising					
Walk N Roll	\$ 19,123.61		\$ 17,887.20		\$ 1,236.41
Adopt-a-Ghost	\$ 1,973.00		\$ 1,647.00		\$ 326.00
Shop for a Cause	\$ -		\$ -		\$ -
Other	<u>\$ 932.73</u>		<u>\$ 1,979.90</u>		<u>\$ (1,047.17)</u>
Total Fundraising	\$ 22,029.34		\$ 21,514.10		\$ 515.24
In Kind Donations					
ED Meg Paulsen	\$ 21,360.00		\$ 25,000.00		\$ (3,640.00)
Other	<u>\$ 6,609.57</u>		<u>\$ 6,065.75</u>		<u>\$ 543.82</u>
Total In-Kind Donations	\$ 27,969.57		\$ 31,065.75		\$ (3,096.18)
Restricted Donations	\$ 300.00		\$ 5,175.00		\$ (4,875.00)
Other Donations	<u>\$ 4,730.09</u>		<u>\$ 5,378.30</u>		<u>\$ (648.21)</u>
Total Donations	\$ 55,029.00		\$ 63,133.15		\$ (8,104.15)
Interest					
	<u>\$ 231.94</u>		<u>\$ 320.27</u>		<u>\$ (88.33)</u>
Total Income	<u>\$ 55,260.94</u>		<u>\$ 63,453.42</u>		<u>\$ (8,192.48)</u>
Expenses					
		% by Category		% by Category	
Mission/Program	\$ 50,493.52	78.50%	\$ 56,608.15	84.86%	\$ (6,114.63)
Administration	\$ 3,687.99	5.73%	\$ 3,275.61	4.91%	\$ 412.38
Fundraising	<u>\$ 10,142.63</u>	<u>15.77%</u>	<u>\$ 6,820.97</u>	<u>10.23%</u>	<u>\$ 3,321.66</u>
Total Expenses	\$ 64,324.14	100.00%	\$ 66,704.73	100.00%	\$ (2,380.59)
Net Income (Loss)	<u>\$ (9,063.20)</u>		<u>\$ (3,251.31)</u>		<u>\$ 5,811.89</u>
Balance Sheet Comparison					
Assets (cash in the bank)	\$ 39,131.06		\$ 48,194.26		\$ (9,063.20)
Liabilities	<u>\$ -</u>		<u>\$ -</u>		<u>\$ -</u>
Total Equity (Fund Balance)	<u>\$ 39,131.06</u>		<u>\$ 48,194.26</u>		<u>\$ (9,063.20)</u>

**Income:** Total Income was 110% of our \$50,000 goal. In-Kind and cash donations were evenly split at 50% each of the total.

**Expenses:** We exceeded our \$50,000 goal by \$14,324.14 or 28% so our total spent was 128% of our goal.

**Net Income (Loss):** Is in the negative since we spent more than we took in and the loss was three time greater than last year, which is an indication that we need to hold the line or cut back on our spending unless we can significantly increase our income.

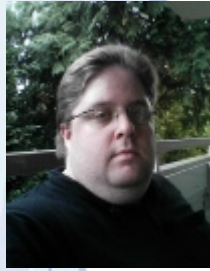
**Expenditure by Category:** These percentages are acceptable but not as good as last year. The biggest jump was the amount spent on fundraising.

**Net Worth:** Our total assets, fund balance, cash in the bank decreased by \$9,063.20, almost 19%, as compared to a year ago which is not a good trend. This is obviously because we spent more than we took in. We have no liabilities (unpaid bills).

**Trend Analysis:** It's time to once again increase our income and hold the line on spending.

**Jonathan A. Tutt, Treasurer**





Jason Lane

## Fundraising efforts fall short of annual goal

by Jason Lane, Chair of the Board of Directors of SBAWS

Happy New Year! I hope you all had a happy and joyous holiday season in the final months of 2012. Now that 2012 has left us behind, I would like to take a moment to outline some accomplishments from last year, and give a brief outline of what is to come in 2013.

Many exciting things occurred last year. As our Executive Director, Meg Paulsen mentions in her article, we moved our business office from Spokane, WA to Snohomish, WA this past November. This will allow us to conduct business meetings and other functions from the office, giving SBAWS a more professional business look when trying to attract donors, sponsors, volunteers, etc.

The Board of Directors approved a Three Year Strategic plan to help guide SBAWS for the next three years. We also formed our Development Committee which is charged with overseeing our fundraising and various programs for SBAWS. Our fundraising plan for 2013 is vast, as we are trying many new things not attempted before. Please take a moment to look at it online and let us know how YOU will be able to assist in implementing or participating in these new programs. I would like to thank Chair-Elect and Chair of our Development Committee, Elizabeth Lovelace, and Meg Paulsen for their assistance in these projects.

We also began a formal volunteer program that Meg Paulsen will be overseeing. We hope by having a formal program in place we will be able to better identify our needs, and attract the BEST people to help fulfill those needs. While we made many great strides in 2012, there are storm clouds ahead in 2013. The New Year will usher in the new three year affiliation agreement with the national SBA office in Washington, DC. While we managed to raise \$27,291.37, it was not enough to meet

the affiliation requirement of \$50,000 raised per year, leaving us \$22,708.63 short of the required goal. Since we have not been averaging the \$50,000 for the past three years, we were given Provisional Status for 2013. What this means is, by the end of 2013 we must raise at least \$50,000 in revenue, or SBAWS could be forced to dis-affiliate from national and give up our 501(c)(3) status with the IRS. This would be tragic given all the hard work the Board of Directors and others have put into SBAWS over the past many years to get us to where we are today.

In order to avoid such an ending to SBAWS, the Board of Directors and Development committee have implemented an aggressive fundraising plan for 2013 as previously stated. In order for that plan to be successful, we *NEED YOUR HELP* by spreading the word about our fundraisers to other family members, friends, coworkers, church members, other people you know in the community, etc. We also need YOU to volunteer time and resources to our fundraisers and to SBAWS in general so we can pull off our events as smoothly as possible.

We will also begin applying for any grants that SBAWS may qualify for to help offset some of the fundraising goal, but most of our funds will need to come from fundraising and the community at large. As we progress into the future, we will need to raise even more on a yearly basis. By the end of 2015 SBAWS will need to bring in a minimum of \$75,000 per year in order to remain in operation.

While SBAWS has its work cut out for it in 2013 (and beyond), I am confident that we will meet the challenges ahead with the support of YOU, our Constituency, and our community throughout the great state of Washington.

I look forward to seeing you at our fundraisers and events throughout the year!

While we appreciate all in-kind donations as well as financial donations, SBA currently recognizes only financial donations or grants as revenue toward each chapter's annual fundraising goal.

## **SBAWS needs volunteers, donations to continue quality programs**

The motto of SBAWS is “Making the Difference Together” which means that all of us need to participate as we launch another year of providing the highest quality events and programs. If the SBAWS will continue to make the difference in OUR community then we need YOU! Please visit our website at

[www.sbaws.org](http://www.sbaws.org) to make your donation directly – you may give a general donation or designate it toward any of our mission-based endeavors:

- Social events for children, teens and adults affected by Spina Bifida
- New Parents Packets
- Educational/camp scholarships
- General Purpose fund to assist families with medical expenses
- Computer/tablet purchase assistance
- Annual Conference Scholarships
- Educational Outreach
- Folic Acid Prevention Campaign



If you prefer to mail in your donation by check – please send to:

**SBAWS**

2128 North Pines Road, Suite 17-B

Spokane, WA 99206

If you cannot afford to make a financial donation we understand BUT ask you to please take action – we still need YOU! We need volunteers to help us grow – there are dozens of ways you can help make the difference with us – just ask! Together we can keep the SBAWS growing and offering more and more resources to our community. Without the assistance of those who believe in our mission we cannot promise that this organization will remain sustainable – together is the only way we can ensure our future commitment to YOU!

Folic acid, a water-soluble B vitamin, helps your body build healthy cells. Studies have shown that for women of childbearing age, taking 400 micrograms of folic acid every day can reduce the risk of having a birth affected by a Neural Tube Defect, such as Spina Bifida, by up to 70%.



Courtesy of the Spina Bifida Association, enjoy try the many delicious recipes rich in folate, the natural form of folic acid. Visit the link below for a smorgasbord of scrumptious recipes including broccoli soup, lentil chili, nutty noodles, hummus, and peanut butter cookies.

[http://www.spinabifidaassociation.org/site/c.evKRI70XloJ8H/b.8029681/k.9EDD/B\\_Healthy\\_Recipes.htm](http://www.spinabifidaassociation.org/site/c.evKRI70XloJ8H/b.8029681/k.9EDD/B_Healthy_Recipes.htm).



Elizabeth Lovelace

## Great things will be seen in 2013!

by Elizabeth Lovelace, SBAWS Chair-Elect

Welcome to a new year of focused fundraising, friendship building, and fine tuning of the Folic Acid Awareness Campaign. February is the month the SBAWS sets in motion collaboration with local culinary experts, CSA (Community Supported Agriculture) farms and bakeries to implement the 5 Course Folic Acid Feasts: Spring Fresh Fare (April) & Autumn Harvest Fare (October). Folic acid awareness efforts continue in March with our presentations at the NW Women's Show and Duncan Seminar. The Board of Directors approved efforts to raise funds to support the adoption of Valerie Perkins and Joanne Spinoza, members of the Kids On the Block (KOB) Master Puppetry Program. Valerie and Joanne will serve as a vehicle to broaden our base of presentation venues to include schools, nursing colleges and medical clinics, to name a few. The KOB Spina Bifida program in a nutshell: "Script material covers specific issues such as a description of Spina Bifida, Valerie's use of braces and crutches, "person-first" language and the importance of choosing words sensitively. Self esteem and going after opportunities in life (particularly in social situations), is also discussed. The complete curriculum consists of large hand-crafted puppets, four scripts, props, follow-up activities and resources to teach children about Spina Bifida." As with Java January, we will post the adoption on the SBAWS website, Facebook and create a Firstgiving page where donations can be made. This fundraiser will continue until the total amount of the adoption for the puppetry program is reached (\$2,060) and can be ordered from Kids On the Block, Inc.

We would like to encourage everyone to help us spread the word about this program and other monthly fundraising efforts. How can you do this? Simply by forwarding our emails to all of the contacts in your personal and professional address books. One key to successful fundraising is successful advertising. Just think if you tell two friends, and they tell two friends, and so on and so on....

Aid us in our efforts to continue providing resources, programs, and education to the residents of Washington State. Pass it on—Together We Make the Difference. Great things to be seen in 2013!

## Volunteers needed for upcoming SBAWS events

On Saturday, March 30th we will hold a fundraiser at the Glassybaby factory in Seattle - the evening will include snacking on appetizers with accompanying wine, watching beautiful Glassybabies (glass tea-light holders) being hand-blown by master glass artists and coming away with your very own Glassybaby (worth \$44). We will have 50 tickets available at \$100 per person. If you are interested in volunteering at this exciting event please let us know! Go to the website at [www.glassybaby.com](http://www.glassybaby.com) to learn more about this amazing organization that donates so much to important causes. See the photo on the left for a sampling of Glassybaby products.

In the spring we will hold an open house for our new Snohomish office to showcase the extensive resource center and place of support we offer our SB community. The office will also serve as a place to expand our volunteer program - we will offer specialized training for those who wish to make a difference by donating much needed time, energy and talent to the events and programs we offer our community. Of course we will be hosting our usual events of the year - the annual summer picnic, Walk-n-Roll for SB and autumn educational summit. In addition to these events we are implementing our new awareness and fundraising event, the Five Course Folic Acid Feast that focuses on the benefits and preventative measures that folic acid offers women of childbearing age.

With all of these plans and goals, the only thing really missing is YOU - how can YOU help make the dreams and ambitions of YOUR SBAWS come true?? We look forward to hearing from YOU and working together to make the difference in our new year.



## HOW CAN I MAKE A DIFFERENCE IN MY COMMUNITY?

Do you ever ask yourself this??? If you want to find out please keep reading – the SBAWS needs YOU!!! The SBAWS is growing in leaps and bounds and we are now ready to fully implement our volunteer program! This is your chance to go through practical volunteer training with our staff and start reaping the benefits of serving our community.

The program will log your hours spent with us making a difference in our community and then give you credit towards awareness items – cool shirts, book bags, water bottles and other bling. Our supplier is CafePress ([www.cafepress.com](http://www.cafepress.com)) – if you search Spina Bifida you will see all types of advocacy styles – everything from puppies and kittens to tribal tattoos.

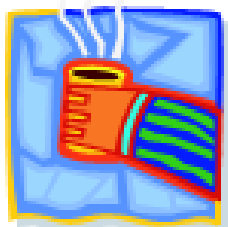
You will also be provided with SB Awareness Kits that will include our flyer along with buttons and other bling you can hand out to those who may ask you about your situation – this will allow us as an organization to have as many positive role models providing education regarding Spina Bifida as possible!

We have many, many ways you can contribute to the SBAWS –right now we're seeking help with ensuring our message is getting out there in the social media. Krystal

Monteros has been doing a great job with our FaceBook page but we need help with establishing a presence on Twitter – we would like more than one person posting to each page at a few times a day. We also need others with website design, video, YouTube interest and experience. Hours spent can be logged from home so you can make the difference when it's convenient for you.

If you're looking to make the difference in person we not only need volunteers to help with our fun family friendly events but also those who may want to help out at our newly established resource center in Snohomish. Our Board of Directors and Development Committee both need to add members – your experience and perspectives are priceless to us – we have two in-person board meetings and four conference call meetings a year – only 12 hours a year to really make a HUGE difference!

If the SBAWS is to continue to be sustainable we need as many people as possible helping us towards our mission so please truly consider how you can help us keep making the difference in our community – we would be thrilled to work with you! Please join our efforts by responding to this email so that we can start making the difference together!  
*Meg Paulsen, Executive Director*



### Make the Difference TODAY! Give Uppa Cuppa in Java January

Benefiting the Spina Bifida Association  
of Washington State

1. Go to [www.sbaws.org](http://www.sbaws.org)
2. Locate Make the Difference Today arrow and press DONATE button.
3. Choose the Cuppa you want to give Uppa.

**Together We Make the Difference!**

#### Cuppa Levels:

Short = \$5

Tall = \$10

Grande = \$15

Venti = \$20



# SBAWS, Seattle, Annual Holiday Party



On December 1, 2012, a wonderful time was had by all at the annual SBAWS Seattle holiday party. Everyone enjoyed delicious food, fun crafts, and a production of "Jingle Bell Rock" performed by Clay Martin's Puppet Theater. Plus the children received gifts! Special thanks to Nicole Williamson and Jason Lane, co-chairs of the SBAWS Seattle cluster, for coordinating this special event.





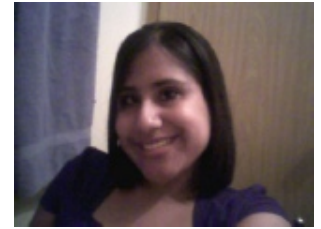
*Special thanks to the ABC Guild, Sue & John Calhoun, the Shoreline Cash&Carry, the Lake Forest Park Ward Church of Jesus Christ of Latter-Day Saints, the women of the Fellowship Church of Christ, friends of SBAWS, the Lougheed family, Seattle Children's Hospital, Spina Bifida Association of WA State, the Starlight Children's Foundation of WA, Wellspect and Whole Foods Market Interbay.*



## Modeling experience was fun and eye-opening

by Krystal Monteros, SBAWS Board of Directors

In 2010, a friend of mine brought it to my attention that Varilite Seating and Mobility was looking for “more diverse” models. I was hesitant at first due to an insecurity that I had about my appearance. Despite my insecurity, I decided there was no harm in at least trying it. Once I did my first photo shoot, I loved it! It was such a fun and eye opening experience for me. I gained a confidence within myself that I never would have thought I could have. I was excited about the experience, but still thought it was just a one-time thing. To my surprise, they called me six months later with the opportunity to be in a video for them. I enjoy modeling so much now! I look forward to doing more in the future. I have plans for another photo shoot with Varilite soon and hope to get more opportunities to be a model in the future. If there is one message I could leave you with today, it would be to not place limits on yourself just because you think that something “just isn’t for you.” Get out there and at least try it! It may do something for you that you could have never imagined!



Krystal Monteros



**Please consider contributing to the fundraising efforts of SBAWS that support SBAWS programs and services, such as this newsletter, with a tax deductible donation. Go to [www.sbaws.org](http://www.sbaws.org) and click on the “Donate” button in the top right corner.**

## Procedure not yet widely performed in the USA

*(Continued from page 1)*

ferred to the glans penis through plasticity of the brain.”

Unfortunately, the TOMAX procedure has not yet been performed widely in the United States because insurance companies do not readily cover it. The operation has been performed previously in the United States, first at Seattle Children’s Hospital in 2009 by Dr. Overgoor (with waived surgeon and hospital fees) which, according to Dr. Shurtleff, “resulted in full sensation in half of the patient’s penis and greatly enhanced his sexuality.” Two more procedures were performed on a patient at Harborview Medical Center in Seattle.

Patients interested in the procedure

will have to petition their insurance providers, but would likely find support and advocates in their physicians. Publication of the procedure in the prestigious Journal of Urology will also aid in raising the profile of the procedure and hopefully help shift it to the mainstream.

Anyone interested in learning more about the procedure may contact SBAWS and ask to be put in touch with Dr. Shurtleff, or alternatively may contact Harborview and ask for Dr. Claire Yang, a neurophysiological specialist with urologist training who would perform the preoperative evaluation, including a complete neurological examination of the male urinary and reproductive functions.

# Resource Spotlight



## Summer 2013 at Camp Korey!!!

Each Summer our Camp continues to grow in new and exciting ways. We are thrilled to share our 2013 Program schedule and great growth plans!

### Summer 2013 Camp Schedule:

**Session 1.....** June 24-28

*"Camp Reflection"*

**Session 2.....** July 1-5

*Friends of the Craniofacial Center*

**Session 3.....** July 8-12

*Solid Organ Transplants*

**Session 4.....** July 15-19

*Metabolic Bone Conditions/Mitochondrial Disease/"General"*

**Session 5.....** July 22-26

*Skeletal Dysplasia*

**Session 6.....** July 29- Aug 2

*Mitochondrial Disease/"General"*

**Session 7.....** Aug 5-9

*Friends of the Craniofacial Center/Mitochondrial Disease/"General"*

### Exciting camp changes!

- We are growing our camp size and serving more campers than ever!
- Families have more options in choosing a week for their camper to attend Camp Korey.
- Campers will be able to request attending the same week as a friend that they met previously at Camp.
- **"General" group:** Campers who have graduated from Stamm Camp, or are living with a condition that we have not previously served .

### Applications available: January 1st, 2013

To learn more, and apply: [www.campkorey.org](http://www.campkorey.org)

**Questions? Please contact:**

Cora Weed, Camp Director: [cweed@campkorey.org](mailto:cweed@campkorey.org)

Dr. Ron Dick, Medical Director: [rdick@campkorey.org](mailto:rdick@campkorey.org)

Camp Korey hosted several SBAWS families for a Spina Bifida Family Weekend this past November, and has invited the SB community to all of its "General" sessions in summer 2013 (see schedule above). According to Seattle cluster co-chair Nicole Williamson, "Camp Korey is awesome!" Some of the camp's features include:

- Golf carts & vans to carry campers safely from building to building
- As much independence as possible for campers
- A "pal" near each camper throughout the entire session
- Medical staff available 24 hours a day
- Cabins that are similar to hotels in that each has the capacity for four people on bunk and twin beds, plus a bathroom and common area with fireplace
- Food choices to accommodate special needs (e.g. gluten-free, vegan, and Nicole said "All the food was wonderful!")
- A wheelchair-accessible rope course plus fishing, swimming, tennis, etc.

Space is limited, so submit your application as soon as possible! Campers will only be accepted if the camp can truly meet all of their needs. The camp is dedicated to serving those needs but must have adequate time to prepare for them. Campers can request to be with other kids with Spina Bifida and/or specific people they know might be going. Families within 1000 miles can look into Angel Flights for airfare.

We hope to see you at camp this summer!

## SPINA BIFIDA ASSOCIATION OF WASHINGTON STATE

611 2nd Ave Suite A, Snohomish WA 98290  
Phone: 253-589-3700/Fax: 775-766-1654  
Toll free: 888-289-3702  
Email: sbaws@yahoo.com

*For more resources,  
visit us online!  
[www.sbaws.org](http://www.sbaws.org)*

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## WHAT IS SPINA BIFIDA?

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

## WHAT IS SBAWS?

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

  
Spina Bifida Association  
of Washington State

