

Spina Bifida Association of Washington State

2013 Annual Report

The Spina Bifida Association of Washington State

MISSION

The mission of the Spina Bifida Association of Washington State is to promote the prevention of Spina Bifida and to enhance the lives of all affected.

ABOUT SPINA BIFIDA

Spina Bifida occurs when the spine of the baby fails to close during the first month of pregnancy, leaving a permanent opening in the spinal column. Those who are born with Spina Bifida often must learn to live with conditions such as hydrocephalus (fluid on the brain), full or partial paralysis, bladder and/or bowel complications, learning disabilities, depression, and deadly latex allergy, as well as social development issues.

Affecting the lives of tens of thousands of men, women, adolescents and children in the United States alone, Spina Bifida is the most commonly occurring, permanently disabling birth defect. All women of childbearing age are at risk of experiencing a Spina Bifida pregnancy. However, it is estimated that up to 70 percent of birth defects like Spina Bifida could be prevented with folic acid supplementation.

ACCOMPLISHMENTS

In 2013 the SBA of Washington State made strides in efforts to support individuals with Spina Bifida along with their family constituents, friends and the professionals who work with them. In addition, high priority was given to educating the public about Spina Bifida. During 2013 the Spina Bifida Association of Washington State has:

- Collaborated with like-minded partners to service the needs of our community;
- Educated the public, physicians and other health professionals about Spina Bifida;
- Operated support services to assist individuals with Spina Bifida, their families and caregivers;
- Educated women of childbearing age about the prevention of Spina Bifida and the benefits of folic acid supplementation;
- Maintained and developed the two SBAWS' offices – resource & training rooms;
- Held open house to introduce SBAWS offices, resources, events & programs;
- Planned and maintained an active 2013 Calendar of Events;
- Created a comprehensive SBAWS orientation presentation to be shown to new volunteers, social service organizations who could offer funding, potential donors and anyone else interested in seeking more info regarding the organization.
- Developed and created the SBAWS' Volunteer Program;
- Secured loan of Kids on the Block Master Puppetry Program to fuel Volunteer Program and create a revenue stream.

ACTIVIITES

Educational, Preventative & Training Efforts

NW Women's Show

March 1st-3rd @ Qwest Field Event Center attended by over 23,000 women from 25 to 65 years old. We displayed bilingual displays regarding folic acid prevention and general SB education. Again, we distributed close to a thousand flyers and met over 50 individuals who either worked with or were affected by Spina Bifida. We had our Spin for Spina Bifida donation wheel – which, again, brought many people to our booth so that we could inform, educate and connect. There, we met Kathy Buck with JuicePlus (fruit and vegetable capsules that have 100% of the RDA for Folic Acid) and have met with her several times developing a connection with her and are in the process of figuring out how we can partner together.

Duncan Seminar

March 22nd was the Duncan Seminar at Seattle Children's Hospital where we were invited to set up our presentation – we were one of two booths – the other was ARC of Washington so we connected with their Director who gave us some great ideas and offered her support. We also connected with many of the PTs, OTs and other medical professionals who were provided with SB related educational packets and other info as requested. Dr. Walker came by the booth to visit and confirmed his involvement with the Walk-n-Roll.

Volunteer Management Training

In April I started my Volunteer Management Training through the United Way of King County. This helped me to develop the current Volunteer Program we are now offering – it also assisted me in seeing where the SBAWS' weaknesses around recruiting volunteers. Because of our continued challenge in fostering the constituency support that needs to be in place to support any organization, I realized we needed a whole different way to recruit volunteers.

The Kids on the Block Master Puppetry Program will serve as the corner stone of our Volunteer Program as it not only a fun and very different way to not only involve people but to also provide a message of advocacy and support to our constituents.

Paralympic Leadership Training

At the end of April I attended the four day Paralympic Leadership Conference in Colorado Springs, Colorado compliments of Seattle Adaptive Sports. I attended educational workshops around organizational growth best practices and made many of the connections

there that I utilized for creating and implementing our Annual Educational Summit with an adaptive recreational theme.

Washington Non-Profit Conference

May 17th was the Washington Non-Profit Conference held in Bellevue. Elizabeth and I attended where we took as many classes between the two of us as possible and networked with many other leaders of non-profit organizations. We were able to visit various vendors who were offering services and resources. Please see Elizabeth's detailed report that was presented at the following board meeting.

Annual Educational Summit – “Come Play with Us”

Our educational Summit was held October 5th at Magnuson Park. The theme was round adaptive recreation and we had several vendors share their wares – OutdoorsForAll, Footloose Sailing, Tacoma Parks Adaptive Recreation Program, Seattle Adaptive Sports, Camp Korey and Shadow Seals Swim Team. Along with the vendors, we provided a raffle and refreshments. In addition to the recreational opportunities presented, we kicked off October's Adopt-A-Ghost fundraiser. Attendance was limited but we did meet a family new to the area that has a young son with SB.

Outreach Efforts

Orientation Presentations Focus and efforts are being made to start taking our orientation on the road. On December 12th we will make our first presentation at the Snohomish County Rotary Club in Monroe. We hope to continue this effort with any and all social service organizations. We have also scheduled an orientation with Mark Twain Elementary school in the Tri-Cities in the spring that will include school nurses, counselors, teachers and staff.

Kids on the Block Master Puppetry Program With access to a KOB Master Puppetry Program's comprehensive program, we can not only fuel our Volunteer Program and a solid Advocacy effort, but to also provide a revenue stream for the SBAWS. This is a COMPLETE program includes not only the puppets but also the scripts and all of the forms needed to run this program. The program will allow us access into schools and serve as a direct service program focused on our constituents' school districts first and expanding out as needed.

Preventative Display Our bilingual folate/folic acid prevention display was presented at local health and wellness fairs and a farmer's market throughout the year.

Snohomish Community Coordinating Committee Member Meetings We have been attending these monthly meetings to highlight what we are doing locally and bring attention to our organization to gain support and create partnerships with local for-profit businesses.

Fundraising Efforts

Java January

The month of January was devoted to our first annual Give Uppa Cuppa Java January fundraising program. Due to a holiday delay with the poster printer, we started a week later than planned. We ended up covering the cost of the materials (along with enough post it pads for another year or two) and created a First Giving page connected to the website.

Glassybaby Evening

May 4th was the Glassybaby Evening fundraiser – it was a lovely evening but we ended up having to purchase more votives to meet their minimum which ate into any profits we had.

Jamba Juice

On June 15th Elizabeth and I were at Jamba Juice all day collecting donations outside the store. It was a fun day of collecting donations and offering customers info on the SBAWS.

Walk-n-Roll for Spina Bifida

July 20th was the Walk & Roll for Spina Bifida at Bradley Lake Park in Puyallup. TiLite and Bellevue Healthcare were the main sponsors of the event and local celebrity, Pat Cashman, again lent his humor and charm to our event. We had 16 teams (including Dr. Walker's SCH Team) Please see financials regarding the amount raised.

Adopt-A-Ghost

A local effort was made by Elizabeth and me in Snohomish where we distributed over 1000 Ghosts and secured eight (8) free tickets to Downtown Seattle's Ghost Tour to add to an incentive basket with ghost candies to the retailer who collectss the most donations. We collected close to \$700 and now most merchants know about the SBAWS and are interested in supporting other fundraisers we will have in the future.

Supporting Services

Additionally, the SBAWS offered:

- Emotional support for families and individuals affected by Spina Bifida.
- Our digital newsletter “**The Evergreen**” details local SBAWS activities, provides news on medical, therapeutic, rehabilitative advances, recreational and legislative issues.
- Sponsorship of the Ms. Wheelchair Washington Program.
- Social events (Summer Picnic and Holiday Party) for children, teens and adults to gather, have fun and share their life experiences.
- New Parents Packets to help parents learn about Spina Bifida and to help manage their child’s health care needs.
- Health guides and other Washington based resources for all age groups affected by Spina Bifida.
- Educational scholarships awarded for educational purposes. Proof of SB required.
- A limited “General Fund” to assist people with mobility devices, medical supplies and other necessary items not covered by insurance. Proof of SB required.
- Contribution to the Molly Salazar Memorial Fund.
- A limited “Technology Fund” to assist people with acquiring laptops/tablets. Proof of SB required.

Washington State Counties Served:

- Asotin
- Benton
- Chelan
- Clark
- Cowlitz
- Douglas
- Ferry
- Grant
- Grays Harbor
- Island
- King
- Kitsap
- Klickitat
- Lewis
- Lincoln
- Mason
- Okanogan
- Pacific
- Pend Oreille
- Pierce
- Skagit
- Snohomish
- Spokane
- Stevens
- Thurston
- Whatcom
- Whitman
- Yakima

Spina Bifida Association of Washington State
Financial Statement Summaries
As of December 31, 2013

	2013	2012	\$ Change
Profit & Loss Comparison			
Income			
Donations			
Fundraising			
Walk N Roll	\$ 18,054.10	\$19,123.61	\$ (1,069.51)
Adopt-a-Ghost	\$ 717.00	\$ 1,973.00	\$ (1,256.00)
Shop for a Cause	\$ 65.00	\$ 80.00	\$ (15.00)
Glassybaby Evening	\$ 3,780.72	\$ -	\$ 3,780.72
Other	<u>\$ 1,265.37</u>	<u>\$ 852.73</u>	<u>\$ 412.64</u>
Total Fundraising	\$ 23,882.19	\$22,029.34	\$ 1,852.85
In Kind Donations			
ED Salary	\$ 18,000.00	\$21,360.00	\$ (3,360.00)
Other	<u>\$ 3,383.99</u>	<u>\$ 6,609.57</u>	<u>\$ (3,225.58)</u>
Total In-Kind Donations	\$ 21,383.99	\$27,969.57	\$ (6,585.58)
Restricted Donations			
Other Donations	\$ 100.00	\$ 300.00	\$ (200.00)
Total Donations	<u>\$ 47,334.78</u>	<u>\$55,029.00</u>	<u>\$ (7,694.22)</u>
Interest	\$ 70.09	\$ 231.94	\$ (161.85)
Other Income	<u>\$ 300.00</u>	<u>\$ -</u>	<u>\$ 300.00</u>
Total Income	<u>\$ 47,704.87</u>	<u>\$55,260.94</u>	<u>\$ (7,556.07)</u>
Expenses			
		% by Category	
Mission/Program	\$ 46,391.45	77.39%	\$50,493.52
Administration	\$ 4,161.38	6.94%	\$ 3,687.99
Fundraising	<u>\$ 9,395.92</u>	<u>15.67%</u>	<u>\$10,142.63</u>
Total Expenses	\$ 59,948.75	100.00%	\$64,324.14
Net Income (Loss)	<u>\$(12,243.88)</u>		<u>\$(9,063.20)</u>
Balance Sheet Comparison			
Assets (cash in the bank)	\$ 26,887.18	\$39,131.06	\$ (12,243.88)
Liabilities	<u>\$ -</u>	<u>\$ -</u>	<u>\$ -</u>
Total Equity (Fund Balance)	<u>\$ 26,887.18</u>	<u>\$39,131.06</u>	<u>\$(12,243.88)</u>

Income: Total Income was only 95% of our \$50,000 annual goal and 14% less than last year.

Expenses: We exceeded our \$50,000 goal by 20% in spite of decreasing it from last year by almost 7%

Net Income (Loss): Is in the negative since we spent more than we took in and the loss was 35% 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 just about the same as last year.

Net Worth: Our total assets, fund balance, cash in the bank decreased by \$12,244, over 30% as compared to a year ago which is not a good trend. This is obviously due because we spent more than we took in. We have no liabilities (unpaid bills).

Trend Analysis: As it has been for a while it's time to once again increase our income and/or dramatically decrease our spending.

Jonathan A. Tutt

Treasurer

Administrative Staff and Board Listings

Board of Directors

Officers

Chair: Jason Lane 12534 15th Ave NE # 14 Seattle, WA 98125

Chair-Elect: Elizabeth Lovelace PO Box 985, Monroe, WA 98272

Secretary: Ashley St. Clair 11555 SE Blakeney St., Beaverton, OR 97008

Treasurer: Jonathan A. Tutt, 2128 N. Pines Rd., Suite 17-B, Spokane WA 99206

Board of Directors (includes Officers above)

Ryan Callaway 227 N. 73rd Ave., Yakima, WA 98908

Nicole Williamson PO Box 75014, Seattle, WA 98175

Jamie Heckinger 31009 149th Ave SE, Kent, WA 98042

Dave Carl 250 Gage Blvd., Richland, WA 99352

Amy Miller 17708 106th St. E., Bonney Lake, WA 98391

Full details are on our website at: <http://www.sbaws.org/board.html>

No Longer on the Board of Directors

Krystal Monteros 2305 S 96th St Tacoma, WA 98444 (reassigned to Social Media)

Elizabeth Scriven 5421 85th Place NE, Marysville, WA 98270

Immediate Past Chair: Linda Bailey 1539 22nd NE Auburn, WA 98002

Administrative Staff

Meg Paulsen, Executive Director: 700 Ford Ave., Unit 3, Snohomish, WA 98290

Respectfully Submitted,

Meg Paulsen
Executive Director