



The Evergreen

March 2012

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

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Message from Meg: Spinning for Spina Bifida

This year's Northwest Women's Show SBAWS booth was a huge success! We had an SBAWS awareness roulette wheel where people could donate a dollar for a spin – every spin was a win!

We met hundreds of generous women and girls who absolutely loved the bracelets, lapel pins and charms they “won” by supporting our organization – proceeds paid for the items and we have lots of



Meg Paulsen

leftovers so we will be doing the same at upcoming events. Along with our spinning for Spina Bifida activities we had our folic acid preventative information available in both English and Spanish. We also had examples of our



The SB roulette wheel

(Continued on page 6)

SBA announces strategic plan, new mission statement

From the February 2012 Field Update distributed by SBA headquarters

On October 22, 2011, the SBA Board of Directors adopted a new strategic plan that shapes the organization's direction into the future. The adoption of the 2012-2014 Strategic Plan is the culmination of work that the Board of Directors began at its retreat in the spring of 2011 and from input received by Chapter leaders during the Leadership Institute later in that year.

During the process, six goals were identified:

PREVENTION

By December 31, 2014 provide life changing information about the importance of taking folic acid to 25% more people.

SERVICE

By December 31, 2014 increase by 25% participation in SBA programs and services that address improved quality of life.

RESEARCH

By December 31, 2014 double the amount of research funds available through Spina Bifida Association grants, particularly in basic science, clinical, education and psychosocial areas.

ADVOCACY

By December 31, 2014 expand and emphasize grassroots network to every state through federal and local advocacy to preserve and grow the SBA mission.

REVENUE GENERATION

(Continued on page 7)



Newsletter Editor
 Celeste McCormick
 celtutt@yahoo.com

HIGHLIGHTS FROM BOARD OF DIRECTORS MEETING February 23, 2012

For full content of the minutes, visit 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, Jon Tutt, Nicole Williamson, Dave Carl, Elizabeth Lovelace, Ryan Callaway, Linda Bailey
- Absent: Jamie Heckinger
- Secretary’s report: Motion made and passed to assist Debbie Rodger and her niece to attend the SBA conference; two new members gained since the last Board meeting
- Chair’s report: Jason is reviewing SBA’s chapter policies and procedures in order to assist with our chapter’s
- Actions taken by the Board since the last meeting
 - Motion made and approved to reduce Meg’s monthly compensation from \$1000 to \$720 per Meg’s request
- Old Business
 - Elizabeth submitted her 2011 conference report; no one else has submitted one yet
 - Jason will complete Meg’s performance review by June
- New Business:
 - \$350 laptops for the public are available through Tech Soup; this is a better use of the \$3500 technology grant than giving out 8-year-old computers; however a policy needs to be setup on computer requests; Jason will follow up with the family currently requesting a computer
 - Board comprises only nine members (which is the minimum required; more Board members are needed as well as a Chair-Elect; Nicole is considering the Chair-Elect position
 - Meg and Jason are updating the database as requested by the January 2012 Field Update from SBA
 - Motion made and approved to send Dave Carl to the SBA conference; motion made and approved to allow \$1800 to reimburse conference expenses; Jon suggested sending the Chair and Executive Director
 - Walk-N-Roll 2012: at Bradley Park in Puyallup; motion made and approved to allow a \$6500 budget for the planning committee to spend for 200 people
 - Affiliation with SBA was extended for another year
 - New “Chair’s Message” will be on the SBAWS website
 - SBAWS Board meetings will now alternate Thursday and Sunday evenings
- **NEXT MEETING: Sunday, April 22, 7pm**

Chair
Jason Lane
jlane101@comcast.net

Secretary
Krystal Monteros,
babykeitho@aol.com

Past Chair
Linda Bailey,
gingersnap8160@yahoo.com

Treasurer
Jon Tutt, jon_tutt@msn.com

Directors
Meg Paulsen, Exec. Director,
megpaulsen@sbaws.org
Ryan Callaway
Dave Carl
Jamie Heckinger
Elizabeth Lovelace
Nicole Williamson



Jason Lane,
SBAWS Chair
2012

Jason grew up in Federal Way, WA and graduated from Federal Way High School in 1991, then attended both Green River Community College and Highline Community College. Now an employee of Seattle Children’s Hospital, he has worked over 10 years as an Administrative Program Assistant in the Department of Surgery. Since 1993, Jason has sat on the board for the Stanley Stamm Children’s Hospital Summer camp. The Stanley Stamm Camp is an overnight camp for disabled youths between the ages of 6-14. Residing in North Seattle his interests include computers and music.

Spina Bifida Association of Washington State Financial Statement Summaries As of December 31, 2011

	2011	2010	\$ Change
Profit & Loss Comparison			
Income			
Donations			
Fundraising			
Walk N Roll	\$ 17,887.20	\$ 29,782.16	\$ (11,894.96)
Adopt-a-Ghost	\$ 1,647.00	\$ 2,652.37	\$ (1,005.37)
Shop for a Cause	\$ -	\$ 730.00	\$ (730.00)
Other	<u>\$ 1,979.90</u>	<u>\$ 503.43</u>	<u>\$ 1,476.47</u>
Total Fundraising	\$ 21,514.10	\$ 33,667.96	\$ (12,153.86)
In Kind Donations			
ED Meg Paulsen	\$ 25,000.00	\$ 15,000.00	\$ 10,000.00
Other	<u>\$ 6,065.75</u>	<u>\$ 2,983.86</u>	<u>\$ 3,081.89</u>
Total In-Kind Donations	\$ 31,065.75	\$ 17,983.86	\$ 13,081.89
Restricted Donations	\$ 5,175.00	\$ 1,250.00	\$ 3,925.00
Other Donations	<u>\$ 5,378.30</u>	<u>\$ 5,407.74</u>	<u>\$ (29.44)</u>
Total Donations	\$ 63,133.15	\$ 58,309.56	\$ 4,823.59
Interest	<u>\$ 320.27</u>	<u>412.32</u>	<u>\$ (92.05)</u>
Total Income	<u>\$ 63,453.42</u>	<u>\$ 58,721.88</u>	<u>\$ 4,731.54</u>
Expenses			
		% by Category	% by Category
Mission/Program	\$ 56,608.15	84.86%	\$ 35,877.67
Administration	\$ 3,275.61	4.91%	\$ 2,491.95
Fundraising	<u>\$ 6,820.97</u>	<u>10.23%</u>	<u>\$ 5,823.22</u>
Total Expenses	\$ 66,704.73	100.00%	\$ 44,192.84
Net Income (Loss)	<u>\$ (3,251.31)</u>		<u>\$ 14,529.04</u>
Balance Sheet Comparison			
Assets (cash in the bank)	\$ 48,194.26		\$ 51,445.57
Liabilities	<u>\$ -</u>		<u>\$ -</u>
Total Equity (Fund Balance)	<u>\$ 48,194.26</u>		<u>\$ 51,445.57</u>

Income: Although our Walk-N-Roll and other fundraising income was significantly less this year, our total income increased by over 8% mainly due to Meg Paulsen's In-Kind donation in being our Executive Director. Total income was 127% of our \$50,000 goal, and 8.3% greater than last year.

Expenses: Total Expense increased by over \$22,000 (over 50%) and we spent 134% of our \$50,000 spending goal. This year we spent \$3,251.31 (approximately 5%) more than we took in, which isn't good. Our goal is to receive and spend the same amount.

Net Income (Loss): Is in the negative for the year because we spent more than we took in and 122% less than last year.

Expenditure by Category: These are acceptable percentages. Mission spending increased while Administration and fundraising decreased, which is a good trend.

Net Worth: Our total assets, fund balance, cash in the bank decreased by 6.3% during the year. We have no liabilities (unpaid bills).

Trend Analysis: It's time to once again increase our income and hold the line on spending but we are a lot closer to where we should be than at any other time in recent history.

Jonathan A. Tutt, Treasurer



SBA Communication Initiatives for 2012

2012 promises to be a busy year for SBA, both at the Chapter and the National level. The following list outlines the communications campaigns SBA will conduct.



- **January: New Year, New You**

- This social media initiative (*Facebook* and *Twitter*) identifies potential health problems associated with Spina Bifida and provides preventative advice and resources. Daily postings include topics like kidney health, osteoporosis prevention, weight control, increased exercise, and lowering the risk of type 2 diabetes.

- **January 8 – 14: Folic Acid Awareness Week**

- In addition to the activities of the National Council on Folic Acid, SBA will be doing outreach on social media highlighting our various folic acid related PSAs and online videos.

- **Late February/early March: SB Clinic List Update**

- SBA will promote the release of our latest Spina Bifida clinic directory.

- **March 12 – 14: Second World Congress on Spina Bifida Research and Care**

- SBA will conduct this meeting of international medical professionals and researchers in the Spina Bifida field in Las Vegas. Promotion efforts for the Congress will occur until the event. Abstracts and further summaries of the event will be available on the Web site prior to and after the event.

- **April: National Walk-N-Roll for SB Promotion**

- With most 2012 Walk-N-Roll dates confirmed, SBA will conduct a drive to get people to register for an event in their area or to be a virtual walker for an event.

- **June 28 – July 1: SBA 39th National Conference**

- Findings from the Second World Congress on Spina Bifida Research and Care as well as other health and quality of life information related to Spina Bifida will be translated and presented to the lay audience. The Conference will be held in Indianapolis, Indiana.

- **Late June/ July: New Web Site Launch**

- SBA will launch its new Web site with up-to-date Fact Sheets and Information Sheets and new information portals for various audiences (individuals with SB, parents, caregivers, health care professionals, etc.). Through our social media networks, SBA will offer a “tour” of the new site highlighting a different resource or area of the site each day in the month of July.

- **September: The Hispanic Community and SB**

- For Hispanic Heritage Month, SBA will share important folic acid messages in Spanish.

- **October: SB Awareness Month**

To help enhance our joint awareness efforts, we encourage you to share the information from these campaigns with your constituents using outreach methods like the Chapter’s Web sites, eNewsletters, *Facebook*, and *Twitter*. For info please contact Amanda Darnley, Director of Communications and Marketing, at adarnley@sbaa.org.

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Diana Tutt, nanatutt@msn.com

Sadly we report the loss of one of our young members, Molly Salazar.

Molly was eight years old and passed away February 25th due to complications from Spina Bifida. Molly was a member of Team St. Luke's basketball and loved to ride her bike and play in the snow.

She will be dearly missed by friends and family. Donations can be made to "The Molly Salazar Memorial Fund" at Bank of America. You may also participate in the "Molly's Miracle" fundraiser at the Liberty



Lake Pizza Hut on Wednesday March 14 from 3-9pm. 20% of all proceeds will be provided to Molly's family to help offset Molly's funeral expenses. *The SBAWS Board of Directors recently voted to donate \$300.00 to the fund.*



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 and click on the "Donate" button in the top right corner.

Are YOU interested in volunteering for SBAWS?

SBAWS is currently seeking volunteers for the following positions:

- **Treasurer:** this position sits on the Board, reconciles the bank account, prepares financial statements and more. Term begins January 2013.
- **Historian:** the SBAWS history page (www.sbaws.org/History..html) needs rewritten with more accurate and up-to-date information.

Contact SBAWS today to learn more about these opportunities.



Walk-N-Roll 2012: Tips for Team Building

by Elizabeth Lovelace

It is time to start forming teams of walkers and rollers for the Walk-N-Roll, July 7th, 2012 at Bradley Park in Puyallup. If you are a returning Team Captain, or building a new team this year, we want to help get you off to a fantastic start. Team Captains help make a meaningful impact on the lives of those with Spina Bifida by helping to raise much needed funds. Aside from raising funds for an important cause, there are many benefits to forming a team. Teams provide an opportunity for people to come together to meet a common goal; a Team activity may serve as a wellness activity for groups of people; a Team event can be used as a marketing tool for businesses; and being on a Team serves as a morale booster by encouraging team spirit and cooperation among groups of people.

Here are some Tips for Team Building:

- Invite friends, family members and business associates to participate as members of your Walk-N-Roll for Spina Bifida team.

- Encourage team members to set fundraising goals.
- Plan a team-building kick-off and invite attendees.
- Share enthusiasm and excitement with your team as you strive together to reach your fundraising goal.
- Share Walk-N-Roll for Spina Bifida fundraising advice, team progress, and walk day information with your team members.
- Have fun and build team spirit. Create a team T-shirt, banner or hat to help identify and encourage your team.
- Ask for help!

Let's get walkin' and rollin' to form our teams! SBAWS is here to help you in any way we can along your journey as a Walk-N-Roll for Spina Bifida Team Captain. **Together Everyone Achieves More**



Elizabeth Lovelace

NW Women's show raises funds, awareness of Spina Bifida

(Continued from page 1)

membership materials, educational professionals' materials and personal invitations for those who may want to become partners with us. We met several nutritional organizations that are looking forward to sponsoring a Folic Acid sample roulette wheel at next year's event!

As we continue our mission of educating the public about the importance of folates (and other preventative measures) and support of those affected by Spina Bifida, our hearts are full with appreciation for the efforts of each of you who attend our events, sit on our board and



Elizabeth n the SBAWS booth

volunteer time to ensure that SBAWS is meeting its goals and mission – we could not do this without YOU! Looking forward and working together to make the difference, Meg Paulsen



SB materials at the NW Women's Show

39th SBA National Conference
GEARING UP
 FOR THE FUTURE

June 28 - July 1, 2012
 Indianapolis, Indiana

SBA's National Conference has earned its place as the world's premier conference serving the Spina Bifida Community. Join us **June 28 – July 1 in Indianapolis, Indiana for the 39th National Conference!** From exceptional medical sessions to practical workshops and memorable social events, the SBA National Conference has something for everyone.

Log onto www.spinabifidaconference.org to find out more or register today!

NEED HELP PAYING YOUR CONFERENCE EXPENSES? SBAWS will sponsor attendees by paying registration and attendee fees. In return, sponsored individuals must agree to a post-conference obligation such as writing an article or giving a presentation on the conference experience. To apply for your sponsorship, visit www.sbaws.org and click on "Conference Scholarship." Applications are due 90 days before the conference.

Who should attend?

- Adults with Spina Bifida
- Parents of children with Spina Bifida
- Children with Spina Bifida
- Medical professionals

Why should you attend?

- To gain vital information about making the most of your life and health.
- To learn innovative ways to help your children grow into independent and active adults.
- To experience the fun of Kids! Camp. Learn from other kids how much you can accomplish while having the time of your life!
- To sharpen your clinical skills and gain insight into cutting edge therapies



New vision statement based on feedback from members with Spina Bifida

(Continued from page 1)

By December 31, 2014 increase total income by 5% per annum through diverse revenue sources, ensuring that no single source exceeds 40% of total annual revenue.

CAPACITY BUILDING

By December 31, 2014 increase the quality, consistency and scope of the SBA presence nationally.

Chapters can use this plan to create a strategic plan that mirrors these goals but encompasses local needs. The Strategic Plan can be found on the SBA Web site at: http://www.spinabifidaassociation.org/site/c.liKWL7PLLrF/b.2642991/k.DE3F/About_SBA.htm.

Revised Vision Statement

On October 22, 2011, the SBA Board of Directors amended the SBA Vision Statement based on feedback received from adults with Spina Bifida and Chapter leaders during the 2011 National Conference. The new SBA Vision Statement reads:

We envision a world in which no pregnancies are affected by Spina Bifida. People living with Spina Bifida thrive in a barrier-free world that offers ready access to an array of effective treatment options and uniformly excellent medical care. Their individual life choices are not impeded by Spina Bifida and all experience rich and personally fulfilling lives.

Medical News

A reminder from Kersey Mobility:

Do You Need Financial Assistance? Washington Access Fund Might Be Able To Help!

Sometimes getting the necessary financial assistance to acquire the equipment and services needed to be completely independent is extremely difficult. Fortunately, there are organizations out there that can help. One such organization is the Washington Access Fund.

The Washington Access Fund is a 501(c)(3) nonprofit, Community Development Financial Institution (CDFI) established by and for people with disabilities in Washington state. To learn more about how the Washington Access Fund can help, visit the Kersey Mobility blog page at <http://www.kerseymobility.com/blog.php>!

[Kersey Mobility Sumner](#)

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Sumner, WA 98390
866-626-VANS (8267)

[Kersey Mobility Spokane](#)

5805 W Thorpe Rd
Spokane, WA 99224
866-626-VANS (8267)



If you were unable to join the February 22, 2012 ONLINE LIVE Q & A: SOLUTIONS FOR FECAL INCONTINENCE with Dr. Marc Levitt, the presentation is available online. Simply click on the link below and wait for the video to load.

http://www.livestream.com/partnershub/video?clipId=pla_cdaa1fdc-8bee-493c-8591-94f8b4bb23a1

The Spina Bifida Genetics Research Project is starting the second phase of a study to determine if genetic variations in folic acid metabolism account for an increased risk of having a child with Spina Bifida. We are seeking mothers who have had children with Spina Bifida, and who did not participate in the first phase of this study, conducted 2009-2010. Participants in the study are asked to complete a brief online survey and provide a DNA sample using a simple, at-home saliva collection kit that is delivered and returned by mail. To enroll or find out more information please visit <http://sbgenetics.org><<http://sbgenetics.org/>>. The study will only be open until July so it is important to participate today!

SBAWS Services and Programs



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



Would you like your story featured in *The Evergreen* and on the SBAWS website? We want the world to know that we are more than just SB—we are real people. It's okay if you're not sure how to get started —just contact the newsletter editor for help!



Resource Spotlight



Today, a silent war is being waged against Americans with disabilities. States like Rhode Island, Pennsylvania, California, and Texas have all cut funding to vital programs around healthcare, employment, transportation, and education for people with disabilities. These cuts represent a dismantling of America's commitment to our community.

POWER UP!

There is hope. With your renewed financial support of AAPD, we will take a strong position against these troubling trends. **Please take a moment to renew your commitment to equality for Americans with Disabilities today.**

This year we're pleased to offer new AAPD products along with your membership. We hope you'll wear and display these items to show your pride in our community.

- \$20 Membership - includes AAPD sticker mailed with your acknowledgment letter
- \$35 Membership - includes AAPD sticker AND new AAPD lapel pin
- \$100 Membership - includes 4 AAPD stickers and 4 lapel pins

Your membership supports core programming including -

- Disability Mentoring Day, which brings together over 16,000 people with disabilities and potential employers;
- Anti-Bullying Initiatives, which reaches students and parents nationwide;
- The AAPD Internships, which cultivates tomorrow's leaders;
- The Higher Education Project, which enables us to work with colleges and universities to make education more accessible for every student;
- Interfaith Initiatives, which brings our work to congregations across this country; and
- Disability Vote Project, which educates and turns out the disability community on Election Day.

In 2012, we will reinforce that our community is more powerful and influential than ever before, and we will do it together.

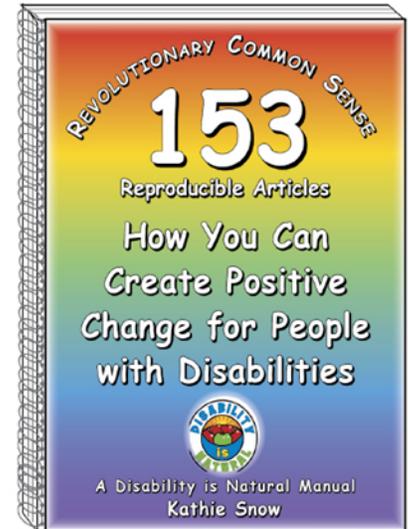
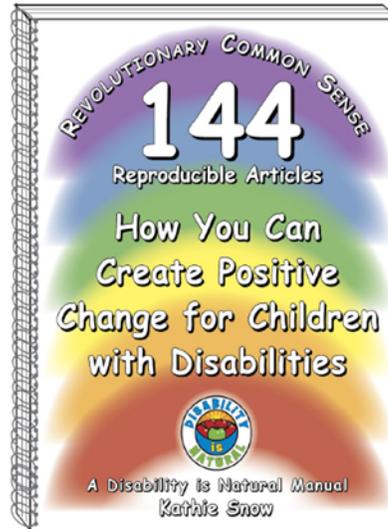
On behalf of everyone at AAPD, thank you for the strength and determination you put into our fight for equality day in and day out. We couldn't do this without you. **Thank you for renewing your membership and for being part of the AAPD family.**

VISIT DISABILITY IS NATURAL

at

www.disabilityisnatural.com

New Books! We're "retiring" our *101 Reproducible Articles* book, replacing it with two new books of articles--both are bigger and better:



TIDBITS

A new website for parents and teachers, [Educational Learning and Training](http://www.educationalllearningandtraining.com/), was recently launched by Vaughn Lauer, an educator for over 30 years. Visit <http://www.educationalllearningandtraining.com/> to learn more and take advantage of the many resources available there.

A class action lawsuit has been filed in Oregon, seeking an end to segregated sheltered workshops. [Learn more at Oregonlive.com](http://www.oregonlive.com).

Check out a new YouTube video by 14-year-old Reuben called "We Speak Different Languages" about the different ways people can communicate and challenges they have being understood. Watch the video at <http://www.youtube.com/watch?v=PaRvBj6p5V0>.



Refurbished Windows 7 Desktops and Laptops



TechSoup's new stock of refurbished desktops and laptops has Windows 7, Norton AntiVirus 2012, and Microsoft Office 2007 already installed. Plus: these computers come with restoration disks, so you can restore your systems in the event of

a crash or virus.

- [HP C2D Desktop or Minitower](#) (admin fee: \$272) featuring a 1.8–2.13-GHz Core 2 Duo processor, 80-GB hard drive, and 2-GB RAM.
- [Dell C2D Notebook](#) (admin fee: \$349) featuring a 1.8–2.2-GHz Core 2 Duo processor, 160-GB [Seagate](#) hard drive, and 2-GB RAM.
- [Dell P4 Desktop](#) (admin fee: \$140) featuring a 2.4–2.8-GHz Pentium 4 processor, 40-GB hard drive, and 1-GB RAM.
- [HP or Dell P4 Desktop](#) (admin fee: \$204) featuring a 3-GHz Pentium 4 processor, 80-GB hard drive, and 1-GB RAM.
- [HP C2D Desktop or Minitower](#) (admin fee: \$320) featuring a 1.8–2.13-GHz Core 2 Duo processor, 80-GB hard drive, 2-GB RAM, and 17-inch LCD monitor.

Desktops and minitowers come equipped with new keyboards and mice. All refurbished hardware is protected by a 90-day warranty. [See our entire catalog of refurbished hardware.](#)

SPINA BIFIDA ASSOCIATION OF WASHINGTON STATE

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*For more resources,
visit us online!
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

