



The Evergreen

September 2011

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

SBAWS spreads prevention message across the state

by Meg Paulsen, Executive Director

Thanks so much to all of you who helped make our "Come Grow with Us!" themed annual summer Picnic/Summit held at Seattle Children's PlayGarden such a great event! The adults enjoyed the educational summit presented by Leslie Gilchrist with Compass Personal Development coaching and mini-makeovers provided by Beauty Control. The kids had a blast with garden

themed crafts, water fountain fun, hanging out with very friendly chickens and ducks, wheelchair basketball and antics on the mini-mountain. Our ladybug theme was celebrated throughout the day and ended with a family raffle, ladybug cookies and a lucky ladybug launch where we let a thousand live ladybugs loose to become new residents of the garden.

In June five of our Board members and I attended the annual National SBA Conference held in Anaheim, CA. We learned a lot and made our presentation available at the picnic. If you are interested in attending next year's conference please note



Meg Paulsen

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 Celeste McCormick
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ASK THE EXPERT, TIPS FOR PARENTS: 20 TIPS TO PROMOTE SELF-ESTEEM

by Richard D. Lavoie, MA, MEd

The following article appeared in the Summer 2011 Edition of the SBA magazine Insights and is printed with permission. While the article intends to arm parents with tools for promoting their children's self-esteem, the lessons are applicable for all of us who are in a position to positively influence others.

A dynamic relationship exists between self-esteem and skill development. As a child improves in self-esteem, his academic competence increases. And as the competence increases, his self-esteem improves. The caring and concerned caregiver must come to realize that positive self-esteem is both a prerequisite and a consequence of academic success. Here are 20 tips to help foster a child's self-esteem.

- Value each child as an individual with unique strengths, needs, interests

and skills.

- Focus on the child's strengths. Emphasize and celebrate his "islands of competence."
- Reject the child's behavior, but never reject the child. Use affectionate terms and nicknames when scolding. ("Your room is a mess, honey. Now turn off the TV and make your bed.")
- Remember that sincere interest can be more effective and meaningful than praise. Demonstrate a genuine interest in her activities, hobbies, etc.
- Establish realistic, achievable goals for your child. Anticipate success.
- Avoid using sarcasm with kids – children with language problems often misinterpret it.
- When discussing an issue or a problem, avoid bringing up past difficulties.

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HIGHLIGHTS FROM BOARD OF DIRECTORS' MEETINGS in June and August 2011

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!

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Elizabeth Lovelace
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- Executive Director's Report
 - Eastern Washington Outreach created some new partnerships with Sacred Heart and multiple Planned Parenthood locations in Eastern Washington. A similar trip outreach is going to be planned to service Western Washington.
 - The 800 phone number has been moved
- Secretary's Report
 - Database is now updated with all 2011 walk registrants and donors. Volunteers will be added as soon as Dave provides that information
 - We have had two new constituents since the 2011 Walk N' Roll
- Treasurer's Report
 - So far [June minutes], the WNR donations are just under \$18,000, a far cry from the \$50,000 goal. WNR expenses so far are \$4,751.36, which is 63% of the \$7,450 budget that was approved. In total, from a financial aspect, the WNR was not nearly the success that it was last year. These figures may be affected by future accounting on the In-Kind donations/expenses.
 - Financial report submitted and SBAWS is on track if not ahead of schedule to meet financial goals and expectations for both fund raising and spending
 - Jon Tutt reminded the board that his term ends Dec. 2011 and [and he will serve one more one-year term through Dec 2012].
 - A call for 'Treasurer' interest is going out to board members
- Old Business
 - We need a formal contract for Meg, as Executive Director
 - Motion to start paying Executive director @ \$1000 per month starting Aug 1st, 2011; approved
 - Post 2011 Walk N' Roll-A-Thon Report-
 - We should move the walk further north next year
 - Bowling event with new members for next year's walk
 - California Pizza Kitchen: 20% of bill can be donated to our organization. We can hold an event then go there for lunch so people can automatically donate
 - Summit Wrap-up: there seemed to be good feed back for a joint event of Picnic/Summit combination. Attendance seemed lower than RSVP.
- New Business:
 - Web Site Improvements: Jon Tutt reviewed some literature/guidelines provided by Linda Bailey. It appears that SBAWS meet the majority of the guidelines. Jon is open to specific suggestions for website improvement; suggestions presented at meeting: larger fonts; less crowding or clearer segregation of information [Note: the website has since been updated]
 - Elizabeth Lovelace is taking classes for Library Certificate with a focus towards an SBAWS library; she is open for suggestion or feedback for any current books or recourse for Spina Bifida or Special Needs
- NEXT MEETING: **October 27, 2011 (to be held telephonically)**



Please consider supporting 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.

WELCOME NEW & CONTINUING REPORTERS FOR THE EVERGREEN!

These volunteers have generously offered their time and talent to make regular contributions to the SBAWS newsletter. If you have a story idea, feel free to contact one of them or the Newsletter editor. Thank you reporters!

Michele Hopkins, michele@thehopkins.us

Elizabeth Lovelace, emeraldsweety2002@yahoo.com

Elizabeth Scriven, liz-biz@iname.com

Brenda Stroud, frizzle3@verizon.net

Diana Tutt, nanatutt@msn.com

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.

How Krystal “got” Jesse... and then got a new wheelchair!

by Krystal Monteros, SBAWS Secretary



In 2003, I got a new wheelchair while living in Colorado. I moved to Washington state in 2005. In 2007, I was due for a new wheelchair. The one I was using was slowly breaking down on me. After taking the request to my insurance for a new wheelchair, I was told that because I received my current wheelchair in Colorado, I could not get a new one in Washington state. I had already gotten wheelchairs in California and Colorado so I was not going to accept this information. The only thing my insurance said they could do for me was repair the broken parts of my wheelchair. That did not help because the wheelchair itself just did not work anymore. Aside from that, the wheelchair I had was 18 inches wide and the size I needed was 15 inches. Because of this I had an increased amount of back and shoulder pain. My request for a new wheelchair was denied three times by my insurance. Then I decided to "Get Jesse." After a four year battle with my insurance, in stepped Jesse Jones—consumer advocate with King 5 News in Seattle. A mere six months later I got my new wheelchair! Watch my story at <http://www.king5.com/video?id=126339093&sec=549122>.

SBAWS Summit 2011



by Michele Hopkins

The Summit is a great way for people to get to know each other, learn from each other and hear dynamic speakers. This year we were able to hear Leslie Gilchrist speak about her experiences raising a child with Spina Bifida. Linda Bailey, Chair of the Board of Directors, took time to answer some questions about the Summit and hopefully this will help families understand why the Summit is valuable to the SBAWS and encourage more to sign up next year!

MH: Did you feel the guest speaker met the audience's needs?

LB: Yes. She had a very engaging speaking style and provided valuable insight.

MH: What made the Summit so successful?

LB: Executive Director Meg Paulsen and Board member Nicole Williamson did a superb job of co-ordinating this event. The venue, food, and speaker were of high quality.

MH: What were some of the things you would like to have seen go differently?

LB: Half of the families who registered for the Summit failed to attend. This was disappointing. The quantity of food ordered, seating arrangements, gift items, etc. are based on the number of people who register. When families fail to show up for an event, food and other resources are wasted, and the funds used to purchase the wasted items could have gone to meet other SBAWS expenses.





COME GROW
with US!!



**Leslie
Gilchrist**

Mother of Merrill, a nurse at Children's Hospital living with SB, Compass Coach Leslie will provide us with tools useful in reaping our rich and abundant gardens of potential.



SBA CONFERENCE INSPIRES FRIENDSHIP BUILDING

by Elizabeth Lovelace, Board member
 With a new academic year upon us, I thought it a good time to share what I learned at this year's annual conference. First and foremost I would like to say that the experience was not only educational, but facilitated "building friendships," the topic of this article.

For me, the most profound words spoken were those of Dr. Zabel during his session

titled "Children and Young Adults with Spina Bifida: How to Develop Social Skills that Build Friendships."

Dr. Zabel stated, "Create natural opportunities to build relationships." This rang in my ears for a moment but, I had to stop and question what he meant by "natural."

Zabel emphasizes one way to engage children and young adults in friendship building activities, is with group sports. It is a "natural" means for building friendships. A shared commitment, shared interest, shared goal. A group of people working together for a common outcome lends itself to building trust, confidence and respect.

Through training and my experience in the field of education, I have learned the importance of "friendship building" and the part it plays in student success. Social skills are acquired through interactions with others. We learn proper social etiquette from the modeling and guidance offered by our parents and teachers, and through interactions with our peers. People learn and grow together

when they have a common goal, interest, or desire.

As a teacher I would dedicate the first two weeks of every school year to friendship building-



Elizabeth Lovelace

and like Zabel suggests, engaged children in a variety of "group" activities. There was a common goal, commitment, and outcome. The camaraderie was impressive and the friendly tone was set for the year.

Friendship building is a process that takes time and nurturing. Giving children and young adults the opportunity to participate in a group, team, or partner activity, is essential for developing the skills needed to foster meaningful, lifelong friendships.

One doesn't have to play sports to be on a team. There are many other avenues for team/partner building. It is important to follow the personal interests of each individual and to think outside the box. A new academic year is a great time to connect with others who have common interests, ideas, and goals. Get ready to partner or team up, and have some fun with friends!

Fantastic

Real

Inspiring

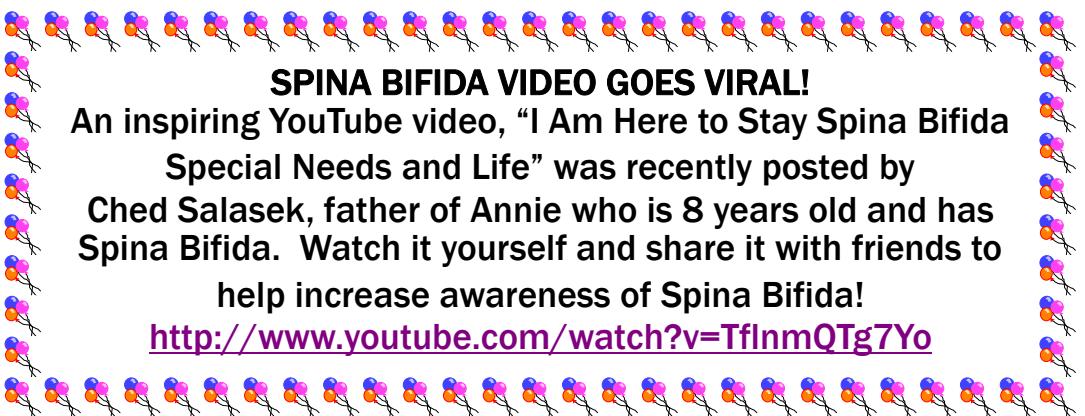
Encouraging

Nurturing

Dependable

Special

Share your ideas for partner/team activities with Elizabeth Lovelace emeraldsweety2002@yahoo.com



SPINA BIFIDA VIDEO GOES VIRAL!

An inspiring YouTube video, "I Am Here to Stay Spina Bifida Special Needs and Life" was recently posted by Ched Salasek, father of Annie who is 8 years old and has Spina Bifida. Watch it yourself and share it with friends to help increase awareness of Spina Bifida!

<http://www.youtube.com/watch?v=TfInmQTg7Yo>

Spina Bifida Association of Washington State
Financial Statement Summaries
As of June 30, 2011

	2011	2010	\$ Change		
Yearly Profit & Loss Comparison					
Income					
Donations					
Fundraising					
Walk N Roll	\$ 17,887.20	\$ 29,769.15	\$ (11,881.95)		
Adopt-a-Ghost	\$ 67.00	\$ 51.00	\$ 16.00		
Shop for a	\$ -	\$ -	\$ -		
Other	<u>\$ 472.00</u>	<u>\$ 403.00</u>	<u>\$ 69.00</u>		
Total Fundraising	<u>\$ 18,426.20</u>	<u>\$ 30,223.15</u>	<u>\$ (11,796.95)</u>		
In Kind Donations					
ED Meg	\$ 15,000.00	\$ -	\$ 15,000.00		
Other	<u>\$ 20.00</u>	<u>\$ 490.71</u>	<u>\$ (470.71)</u>		
Total In-Kind Dona-	<u>\$ 15,020.00</u>	<u>\$ 490.71</u>	<u>\$ 14,529.29</u>		
Restricted (Directed)	\$ 675.00	\$ 75.00	\$ 600.00		
Other Donations	<u>\$ 1,869.07</u>	<u>\$ 1,206.61</u>	<u>\$ 662.46</u>		
Total Donations	<u>\$ 35,990.27</u>	<u>\$ 31,995.47</u>	<u>\$ 3,994.80</u>		
Interest	<u>173.14</u>	<u>207.22</u>	<u>\$ (34.08)</u>		
Total Income	<u><u>\$ 36,163.41</u></u>	<u><u>\$ 32,202.69</u></u>	<u><u>\$ 3,960.72</u></u>		
Expenses		% by Category	% by Category		
Mission/Program	\$ 23,637.16	77.42%	\$ 4,714.41	49.96%	\$ 18,922.75
Administration	\$ 2,474.65	8.10%	\$ 1,664.43	17.64%	\$ 810.22
Fundraising	<u>\$ 4,420.59</u>	<u>14.48%</u>	<u>\$ 3,057.96</u>	<u>32.40%</u>	<u>\$ 1,362.63</u>
Total Expenses	<u>\$ 30,532.40</u>	100.00%	\$ 9,436.80	100.00%	\$ 21,095.60
Net Income (Loss)	<u><u>\$ 5,631.01</u></u>	<u><u>\$ 22,765.89</u></u>	<u><u>\$ (17,134.88)</u></u>		
Yearly Balance Sheet Comparison					
Assets (cash in the bank)	\$ 57,076.58	\$ 59,682.42	\$ (2,605.84)		
Liabilities	<u>\$ -</u>	<u>\$ -</u>	<u>\$ -</u>		
Total Equity (Fund Balance)	<u>\$ 57,076.58</u>	<u>\$ 59,682.42</u>	<u>\$ 2,605.84</u>		

Income: Although our Walk-N-Roll income was significantly less this year, our year-to-date income is greater than last mainly due to Meg Paulsen's In-Kind donation in being our Executive Director. YTD income is 72.3% of our \$50,000 goal after 50% of the year is gone. Last year it was 64.4% at the same time.

Expenses: Total Expense increased by over \$21,000 and we've spent 61.1% of our \$50,000 spending goal. This is in line. So far this year we've taken in more than we've spent, which is good, but our goal is to receive and spend the same amount.

Net Income (Loss): Significantly less than last year, but still on the positive side and more in line with our goals.

Expenditure by Category: These are acceptable percentages.

Net Worth: Our total assets, fund balance, decrease slightly over the last year in spite of spending significantly more.

Trend Analysis: It appears we've turned the corner on making more, or at least as much as, we spend each year.

Jonathan A. Tutt, Treasurer

Resource Spotlight

NON-PROFIT PROVIDES HOME IMPROVEMENT ASSISTANCE

by Diana Tutt, Evergreen Reporter



Rebuilding Together is a wonderful nonprofit organization that I learned about through David Tutt, Michael Hoyt's uncle. This nationwide organization began in 1988 and since then volunteers have donated 37 million hours of time. David Tutt is the president of the Spokane branch of Rebuilding Together, and I interviewed him and conducted online research to provide our readership with information that could be very helpful in keeping them in their own homes. This is for homeowners only.

Rebuilding Together Spokane began 11 years ago as a proud affiliate of the nation's largest non-profit organization dedicated to preserving homeownership and revitalizing communities. David Tutt explained that the organization's projects focus on around warmth, safety, independence and security to homeowners who may be disabled, elderly or low income or in some particular need. A home may need grab bars, extra insulation, shower repair, gutters, etc. Repairs can also be done for non-profit buildings. Rebuilding Together tries to "go green" if possible and offers advice and information to the homeowners on saving energy.

Gonzaga University is one of the major contributors to the program. The students live by the motto "live together, rebuild together." The Roman Catholic University is dedicated not only to formal education, but donating time and treasure. Albertsons/Savon Pharmacy is another major corporate sponsor. David Tutt is a store director at the Indian Trail Albertsons in Spokane; he became involved through his company and was elected president of the Spokane affiliate. He enjoys helping people stay in their homes safely, warmly and independently. Joe Albertson began his business with the creed of "give the customer what they want at a price they can afford, complete with tender loving care." The Albertson family must be very proud that this goal is still being carried out through their many good deeds.

To find out more and read actual stories with photos, go to www.rebuildingtogetherspokane.org for Spokane accomplishments. To see the headquarters of Rebuilding Together go to www.rebuildingtogether.org. My mission in telling this story is not just to reach those of us living with Spina Bifida, but to help anyone who might have an elderly parent or neighbor needing help. Just pass this information along. We especially thank David Tutt and all the volunteers who worked so hard to make a house a home for those in need.

Disaster preparedness links for people with disabilities are always good to have on hand...

<http://www.abilitycenter.org/resources-and-tools/disaster-prep-checklist>

<http://frontlinemobility.blogspot.com/2011/08/online-training-for-fire-safety-for.html?spref=tw>

<http://www.ready.gov/>

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!



Medical News

According to a recent article in *Justice For All*, electronic newsletter for the American Association of People with Disabilities, more than one in six Americans who work a full- or part-time job also report assisting with care for a relative, family member or friend who is elderly or has a disability. To read more about the statistics discovered as a result of this Gallup poll, visit <http://www.gallup.com/poll/148640/one-six-american-workers-act-caregivers.aspx>.

The National Center for Learning Disabilities has released the State of Learning Disabilities: Facts, Trends and Indicators, which provides a national and state -by-state snapshot of learning disabilities in the United States, and their impact on the ability of students and adults to achieve educational success and employment.

To learn more, visit <http://www.ncld.org/stateofld>

Self-esteem issues particularly significant for students with disabilities

(Continued from page 1)

- Never compare one child to another.
- Help the child develop decision-making and problem-solving skills.
- Understand that mistakes are an inevitable (and valuable!) part of any learning experience. Use these as an opportunity to teach and assist.
- Divide large tasks into smaller, more manageable ones. This will ensure success, mastery and retention.
- Maintain a file of his academic work. Use this to demonstrate his progress and development when he is feeling down.
- Encourage her to maintain “collections” (e.g. stamps, rocks, etc.). This allows her to be the resident expert on a topic.
- If he does not participate in team sports, promote individual sports (e.g. skiing, golf, swimming). This will provide opportunities for success, exercise and peer interaction.
- Communicate your confidence in the child and his future.
- Permit and encourage the child to follow the normal fads of her peer group (e.g. clothing, music). This will enhance her acceptance at school and in the community.
- Emphasize the positive aspects of his behavior or performance, even if the task was not completely successful. Reward direction, not perfection.
- Anticipate that the child will have plateaus, failures, backslides, setbacks and regressions. Support and encourage her at these times. Kids need love most when they deserve it least!
- Look for opportunities to offer him choices to allow him to practice decision-making skills.
- Never, ever communicate disappointment to your child. The disappointment of an adult may be too great a burden for a child to carry.

Remember: your child's self-esteem will be determined by the conditional acceptance that she receives from others – and the unconditional acceptance that she receives from you. And your child's self-esteem will be determined by success and progress in four areas:

- Social (acceptance, friendships)
- Competence (in a skill area)
- Physical (clothing, attractiveness)
- Character (effort, generosity, etc.)

Emphasize, recognize and reinforce all four areas!



LET'S GET READY FOR WALK-N-ROLL 2012!

Planning has begun for the next Walk-N-Roll! It is not as far away as you might think. SBAWS Walk-N-Roll 2011 was modestly successful and the goal for 2012 is to surpass those accomplishments in many areas. The only way we can make this happen is with your help! SBAWS needs more people involved and that means YOU! Involvement does not take a lot of time – but your voice, opinions and ideas will help guide and mold the event into one that you and others will greatly enjoy.

2012 Walk-N-Roll Chair:
Jamie Heckinger
Member of the SBAWS
Board of Directors
Co-Captain, Team Wishbone
Father of a son with SB



The first planning meeting was held by conference call on August 25 and jumpstarted an already growing grassroots determination to make Walk-N-Roll 2012 a fruitful event. Initial preparation will focus on outlining the planning processes, discussing suggestions for event locations, considering corporate donors like Children's Therapy Center, evaluating fund-raising websites, and starting the fundraising effort as early as possible.

If you are interested in participating in the planning process, please email Jamie Heckinger at jheckjr@aol.com for details about future meetings and how to contribute to this critical fundraiser.

SBAWS outreach efforts successful, says Paulsen

(Continued from page 1)



that we now have an official application for sponsorship of airfare, accommodations and food expenses – let us know if you're interested as space will be limited. Next year's conference will be held in Indianapolis, Indiana. Please see Elizabeth Lovelace's article about the conference in this issue!

Our Eastern Washington outreach was a huge success – we dropped off folic acid prevention information (in both English and Spanish) to ten Planned Parenthood offices. We also distributed SB specific books and materials to several agencies including EasterSeals Child Development Centers, Children's Village in Yakima and ARC of Tri-Cities. At the end of our journey we met with fellow board members from Spokane for a March of Dimes event. We now have partners in Yakima, Tri-Cities and Spokane to help further our mission outside of the Puget Sound area. We set our sights now on doing the same type of outreach here in Western Washington.

We will head back to Spokane next month to be part of the Combined Fund Charity Fair where we will have a booth to present our information, resources and services available to Washington State employees so that they have the chance to choose SBAWS to receive their contributions. If you are interested in donating to SBAWS please visit our website at www.sbaws.org.

As we enjoy our dog days of summer and start to gear up for heading back to school, we appreciate the efforts of each of you who attend our events, sit on our Board and 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!

SPINA BIFIDA ASSOCIATION OF WASHINGTON STATE

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***For more resources,
visit us online!
www.sbaws.org***

SBA'S SOCIAL NETWORKS



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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**

