



The Evergreen

February 2011

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

by Meg Paulsen, Executive Director
 Happy New Year, Membership!

As usual, I have been investing my time connecting and creating partnerships with other organizations so that SBAWS can make as big an impact as possible in our mission to educate the public about Spina Bifida and its prevention, as well as improving the lives of those living with SB!

A few weekends ago the 2011 Ms. Wheelchair Washington Pageant was held in Seattle! Five contestants vied for the title, including our own Heather Logan whose platform "Stop Bullying," which deals with children learning equality despite differences, was well received. Ms. Wheelchair Washington 2010 Krystal Monteros, who is also SBAWS Secretary on our Board of Directors, gave her farewell speech and well wishes to new titleholder Kendra Schraml whose platform is E-Mobility. Congratulations to all of the contestants – it was a challenge for the judges as all women contending were such tremendous advocates with impressive levels of achievement in our community.



Meg Paulsen

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US Dept of Health and Human Services Launches Healthy People 2020

Reprinted from SBA's *elnsights*, January 2011
 In December 2010, the US Department of Health and Human Services (HHS) launched Healthy People 2020 (<http://www.healthypeople.gov/2020>). Over 300 public health and medical professionals, as well as students, were in attendance at the event hosted by the George Washington University School of Public Health and Health Services. Some 10,000 additional viewers registered online to participate in the launch from across the country. The launch featured speakers and panelists who discussed how Healthy People 2020 was developed as well as suggestions and strategies for implementing it. A major focus at the launch was on the use of technology and social media to implement and measure state and local agency success in achieving Healthy People 2020 objectives.

Health agencies nationwide use the objectives in Healthy People2020 to justify their work to funders, develop relevant programs, and

measure organizational success. It provides science-based, 10-year national objectives for improving the health of all Americans. For the past 30 years, Healthy People has established benchmarks and monitored progress to: encourage collaborations and partnerships; guide public and individual decision making; and measure the impact of prevention activities. Organized by section, Healthy People 2020 contains hundreds of objectives, all seeking to reduce the burden of illness and prevent death through individual, community-based, or institutional actions. The objectives cover major health issues including chronic and infectious diseases, cancer, reproductive health, environmental health, injury and violence prevention, maternal health, racial and ethnic health inequities and, health and disability.

The Healthy People 2020 section on health and disability aims to improve quality of life and access to care. It is categorized into four

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Newsletter Editor
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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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SBAWS member Dave Carl interviewed for national magazine

Dave Carl, SBAWS member best known for the children's book he wrote called *Super Cyclist*, was recently interviewed for an article in "Advocate," the magazine for the National Alliance on Mental Illness (NAMI). The article, titled "Identity and Mental Illness: Constructing a Strong Recovery Narrative" examines how a sense of identity is essential to psychiatry and "any discussion of improving the quality of life for people living with mental illness."

Carl was interviewed to discuss how people with "visible" disabilities maintain a health sense of self, so that perhaps people living with serious mental illness – and struggling with their self-image – can learn

those lessons too. Carl was born with Spina Bifida, and in the article explains that "his family always treated him as if he came first, and the wheelchair and the condition came afterward. This gave him the strong sense of self necessary to withstand teasing at school as well as learning disabilities ... 'When people think I can't do things, I have to prove them wrong,' he says."

To read the full article and learn more about Dave Carl, visit [http://www.nami.org/ADVTemplate.cfm?Section=Advocate_Magazine&Template=/ContentManagement/ContentDis-
play.cfm&ContentID=114083&Istid=274](http://www.nami.org/ADVTemplate.cfm?Section=Advocate_Magazine&Template=/ContentManagement/ContentDisplay.cfm&ContentID=114083&Istid=274).

New books recommended by Disability is Natural:

I Am Justice; Hear Me Roar by Cara Coleman is a wonderful children's book about her daughter, Justice, and has a discussion guide about being friends with children with disabilities:

www.seesaycreate.com/book.php?book=IAMJustice.

Beaux, the Blue Crawfish by Wendy Cartozzo is another great new children's book about differences: www.createspace.com/3489499.

Walk-N-Roll 2011 will be dedicated to Gloria Olson, says Paulsen

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This month I spent time at Swedish Hospital reestablishing connections to implement a prenatal prevention educational program as well as working with various social workers to set up services and resources for their patients and families who are affected by Spina Bifida. While there I had the privilege to meet our newest (literally) member of SBAWS – Melinda Lacy who was born in December! Melinda is a beautiful baby girl whose proud parents, Savannah & Paul, are becoming active members and have even registered their team Melinda's Movers for our annual Walk-N-Roll event!

Speaking of the Walk & Roll, we are busy working on making this year's event a fun-filled fundraising event. We are dedicating this event to Gloria Olson who passed away this past year. Gloria was a valued board member and contributor for many years – her presence is missed but she still inspires us with her

remembered passion and dedication to SBAWS. Many thanks to our Committee Members who are making this event possible – please see the other articles in this issue of the newsletter to learn more about the kick-off event and how to become involved either as a team of walkers and rollers or as a volunteer or sponsor for this exciting event!

In closing, I am so excited to start a new year – it is already proving to be one of learning and growth for our organization and I appreciate the efforts of each of you who attends our events, sits on our board and volunteers time to ensure that SBAWS is meeting its goals and mission – we could not do this without YOU!



Gloria Olson

SBA Revenue Sharing Task Force Convened

On November 13, 2010, the Revenue Sharing Task Force of the Field Relations Committee held its first meeting in Washington, DC, to begin planning for the development of SBA revenue sharing policy recommendations. You may recall that the current Affiliation Agreement, which went into effect in 2008, was amended to defer revenue sharing implementation until the next affiliation period. The current Affiliation Agreement will end in 2011, and work must begin now in order to produce final recommendations in a timely way.

The Task Force began its work by focusing on team processes, creating a shared vision for the optimum policy, reviewing relevant information/data, and organizing the revenue sharing project. Consistent with the Task Force's commitment to transparency and stakeholder participation, a plan for communicating with and involving Chapter Board members and Executive Directors at key points throughout the project was drafted. The Task Force met a second time by webinar on December 3, 2010 to continue its work.

Members of the Task Force are:

Douglas Sorocco, Chair, SBA Board of Directors
 Barbara Devore, SBA of Northeast New York Board Member
 Patty Dissell, SBA of Kentucky Executive Director
 Ellen Heffernan-Dugan, SBA of Massachusetts Executive Director
 Yvonne Horner, SBA of Houston Gulf Coast Board Member
 Joyce Jones, SBA Board of Directors
 Amy Maggio, SBA of Illinois Executive Director
 Elizabeth Starrs, SBA of Colorado Board Member
 Cindy Brownstein, SBA President and CEO
 Sara Struwe, SBA Chief Operating Officer
 Christopher Vance, SBA Director of Development

In early January 2011, SBA Chapter Board Chairpersons and Executive Directors will receive a letter which details revenue sharing project particulars including opportunities for Chapter involvement. Please be alert to the arrival of this letter. If you have any questions in the interim, the Task Force asks that you direct your inquiries to Sara Struwe at 800-621-3141, extension 12 or email her at sstruwe@sbaa.org.

NEW SBAWS PROPOSED POLICIES READY FOR VOTE

SBA requires that each of its chapters has a Fundraising Policy and a Privacy Policy. Draft versions of these policies have been developed by SBAWS and will be reviewed and voted on at the Board of Directors meeting on February 17, 2011. To see a copy of these proposed policies and share your feedback with the Board, please contact SBAWS.

JOB OPENINGS FOR NEWSLETTER REPORTERS!

Do you like to write? Do you always have ideas for articles and stories that should be covered in the newsletter? Then we need you! *The Evergreen* newsletter has unlimited openings for Reporters to start right away!

REPORTERS: The time commitment is about 2 hours per month. You will receive assignments from the Editor and write an article on a designated topic.

Please volunteer! This is a fun opportunity to educate readers about life with and prevention of Spina Bifida while providing resources and connections to our members. Your contribution is important!



APRIL 30, 2011

Heritage Park on the eastside of
Capitol Lake in Olympia, WA

In memory of Gloria Olson

On SATURDAY, APRIL 30, 2011 SBAWS will hold its second annual Walk-N-Roll event to benefit those in the State of Washington who are affected by Spina Bifida. The event is being held at Heritage Park on the Eastside of Capitol Lake in Olympia. It will be dedicated to the memory of Gloria Olson who was a major contributor to the organization for many years.

“This is our chance to work together to make a difference in the lives of those who live with Spina Bifida!” states Heather Logan, one of the coordinators of the event. Funds raised will go toward the mission of the organization, which is the education and prevention of the birth defect and service to the Washington State membership of families and individuals who are affected by Spina Bifida.

A kick-off event will be held on Sunday, March 20th at Heritage Park on Capitol Lake where the 2011 Walk N Roll will launch six weeks later. From 3-6pm volunteers will be distributing flyers announcing the event to walkers and rollers along the Capitol Lake paths. At 6pm, all Volunteers, Team Captains, Committee members, Board Members, and interested persons are invited to a complimentary buffet and rousing kick-off presentation at Traditions Restaurant located at 300 5th Avenue SW, Olympia, WA, just north of the lake.

For more information on how to create and register your team of walkers and rollers, please see our website at www.sbaws.org/walknroll2011.html.

REGISTER TODAY & HELP US REACH OUR \$50,000 GOAL!

The Walk-N-Roll for Spina Bifida is April 30, 2011 at Heritage Park on Capitol Lake in Olympia! Will you help us reach our fundraising goal of \$50,000? Visit www.firstgiving.com/sbaws to register and for tips on fundraising.

Have You Registered Yet??? It's Simple!!!

Step 1 - Log On - Go to www.firstgiving.com/sbaws

Step 2 - Register - Click on the “Get Started” button in the center of page and then select your event: Walk-N-Roll for Spina Bifida 2011

Step 3 - Decide How You'll be Walking - Choose one of three registration options: Start a Team, Join a Team, or Join as an Individual

Step 4 - Make Your Commitment - What is your fundraising goal? Challenge yourself and remember your reason for committing to the Walk-N-Roll for Spina Bifida. **If you raise \$100 or more, your team wins free Walk-N-Roll t-shirts!**

Step 5 - Personal Fundraising Pages—You can raise more money with less effort by setting up a personal webpage and sending it to your friends and family. We've made the "setting-up" process simple for you; all you have to do is follow the simple instructions that pop-up during the Registration Form process—it will take you less than 10 minutes! You can personalize your webpage with your story, photos and why you support the Spina Bifida Association. From here, you can send fundraising emails to everyone in your email address book, track donations and send thank you notes. Team Captains can manage their own fundraising campaigns, as well

SBAWS Financial Statement Summaries as of Dec 31, 2010

	2010	2009	\$ Change		
Profit & Loss Comparison					
Income					
Donations					
Fundraising					
Walk N Roll	\$ 29,782.16	\$ 534.01	\$ 29,248.15		
Adopt-a-	\$ 2,652.37	\$ 2,323.25	\$ 329.12		
Shop for a	\$ 730.00	\$ 1,100.89	\$ (370.89)		
Other	<u>\$ 503.43</u>	<u>\$ 680.26</u>	<u>\$ (176.83)</u>		
Total Fundraising	<u>\$ 33,667.96</u>	<u>\$ 4,638.41</u>	<u>\$ 29,029.55</u>		
In Kind Donations			\$ -		
ED Meg	\$ 15,000.00	\$ -	\$ 15,000.00		
Other	<u>\$ 2,983.86</u>	\$ -	<u>\$ 2,983.86</u>		
Total In-Kind Dona-	<u>\$ 17,983.86</u>	<u>\$ -</u>	<u>\$ 17,983.86</u>		
Restricted (Directed)	\$ 1,250.00	\$ 1,511.00	\$ (261.00)		
Other Donations	<u>\$ 5,407.74</u>	<u>\$ 2,202.72</u>	<u>\$ 3,205.02</u>		
Total Donations	<u>\$ 58,309.56</u>	<u>\$ 8,352.13</u>	<u>\$ 49,957.43</u>		
Interest	<u>412.32</u>	<u>\$ 622.64</u>	\$ (210.32)		
			\$ -		
Total Income	<u>\$ 58,721.88</u>	<u>\$ 8,974.77</u>	<u>\$ 49,747.11</u>		
Expenses		% by Category	% by Category	\$ -	
Mission/Program	\$ 35,877.67	81.18%	\$ 13,568.88	88.18%	\$ 22,308.79
Administration	\$ 2,491.95	5.64%	\$ 1,106.76	7.19%	\$ 1,385.19
Fundraising	<u>\$ 5,823.22</u>	<u>13.18%</u>	<u>\$ 712.89</u>	<u>4.63%</u>	<u>\$ 5,110.33</u>
Total Expenses	<u>\$ 44,192.84</u>	100.00%	<u>\$ 15,388.53</u>	100.00%	<u>\$ 28,804.31</u>
Net Income (Loss)	<u>\$ 14,529.04</u>		<u>\$ (6,413.76)</u>		<u>\$ 20,942.80</u>
Balance Sheet Comparison					
Assets (cash in the bank)	\$ 51,445.57		\$ 36,916.53		\$ 14,529.04
Liabilities	<u>\$ -</u>		<u>\$ -</u>		<u>\$ -</u>
Total Equity (Fund Balance)	<u>\$ 51,445.57</u>		<u>\$ 36,916.53</u>		<u>\$ 14,529.04</u>

Income: for the year was 117% of our \$50,000 goal. Our biggest income sources were the Walk-N-Roll and Meg's in-kind donation in volunteering her services as our Executive Director.

Expenses: Total Expense increased by over \$28,000 but we only spent 88% of our \$50,000 spending goal. This is the first year since I've been Treasurer where we need to spend more!

Net Income (Loss): For the first time since I've been Treasurer, 2010 showed a true net income as opposed to a loss. \$14,529 this year as opposed to (-\$6,413) last year.

Expenditure by Category: These are now at acceptable percentages.

Net Worth: Our total assets, fund balance (cash in the bank) **INCREASED** by \$14,529 (the amount of our net income) during the year.

Trend Analysis: I really hope this mean we've turned the corner on making more, or at least as much as, we spend each year.

Jonathan A. Tutt, Treasurer



Please join the Spina Bifida Association (SBA) for the **38th National Conference to be held at the Disneyland Hotel (Anaheim, CA) from June 26 - June 29, 2011**. Children and adults with Spina Bifida, their families, physicians, nurses, and other clinicians have the unique opportunity to gain information on the latest medical care and network on various issues which affect their lives and professions.

- Learn up-to-the-minute information about urology, orthopedics, neurology, neurosurgery treatment, and much more!
- Attend practical workshops and special programming that address your own interest areas.
- Network with various interest groups - from others living with Spina Bifida to health professionals and product manufacturers.
- Find out how researchers are paving the way for more knowledge about Spina Bifida.
- Hear from leading Spina Bifida partners about the important role advocacy plays in our Community's success.

[Register today](#) and find out why the SBA National Conference has earned its place as the world's premier educational event for the Spina Bifida Community.

Visit <http://www.spinabifidaconference.org/> for all conference details, including registration deadlines, FAQs and specially-priced tickets to Disneyland!

Events

Kids!Camp

SBA's Conference has a place for children of all ages with and without Spina Bifida at Kids!Camp. This is the only national camp specifically designed for children with this birth defect. It offers programming for kids with Spina Bifida and their siblings.

Adult Day

Focus on the issues that concern adults with Spina Bifida - from health challenges associated with aging to employment, relationships, advocacy, and more.

SB Health Care Professionals Day

Nursing and Health care professionals can sharpen their skills in this one-day event.

Did you know that in July 2010 the Christopher Reeve Foundation named Seattle the top most livable city for people with paralysis?

Click here to read more about the [Top 20 Most Livable U.S. Cities for Wheelchair Users](#)

Or go to <http://www.christopherreeve.org/site/c.mtKZKgMWKwG/b.6150343/k.F282/>

[Top 20 Most Livable US Cities for Wheelchair Users.htm](#)

ROOMMATES NEEDED: Several SBAWS members are already planning to attend the national conference and would like to share hotel costs with roommates. If you are interested, contact SBAWS today to be put in touch with these folks!

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



[Follow SBAWS on Facebook](#)



GET INVOLVED WITH YOUR CLUSTER TODAY!

City/State	Leader Name	Email	Contact Phone
CLUSTER DEVELOPER	Michele Hopkins	michele@thehopkins.us	425-844-1262
Everett & Eastside Seattle	Brenda Stroud		425-385-2487
	Michele Hopkins	michele@thehopkins.us	425-844-1262
Spokane WA	Ed Kennedy	ejkcordwa@live.com	509-465-0676
South King County WA	Brian Knowles	crazy5720003@yahoo.com	253-887-0888
Seattle WA	Nicole Williamson	seattlespinabifidagroup	303-877-5083
	Jason Lane	@hotmail.com	206-363-3726
Kitsap WA	Dave Lewallan		360-871-5139
	Rebekah Uhtoff		360-782-0467
South Puget Sound WA	Heather Logan	heather_logan@juno.com	360-888-0782
	Patti Logan	patti_logan04@yahoo.com	360-888-7701
Leavenworth WA	Ed Baroch	debaroch@charter.net	509-548-5697
Spanish	Anthony Williams		253-588-4411
Cowlitz County (new)	Tressa Croft	tressacroft@yahoo.com	360-261-1767

Resource Spotlight



**United Spinal
Association**

Adapt Achieve Inspire

Spinal Cord Injury - Multiple Sclerosis - Polio
Amyotrophic Lateral Sclerosis - Spina Bifida

Free publications are available from the United Spinal Association at <http://www.unitedspinal.org/disability-publications-resources/disability-publications/>. Topics include: Disability Etiquette, Accessible Air Travel, Fire Safety for Wheelchair Users, the Americans with Disabilities Act, Accessing Local Government, and many more! You can even print off “Parking Pads” which are notices to leave on the windshield of someone illegally parked in a handicapped space.

ALL KIDS COUNT: CHILD CARE AND THE ADA

How does the Americans with Disabilities Act impact child care centers? What do child care providers and parents need to know?

Visit www.adainformation.org/ChildCare.aspx for a variety of helpful information on related topics.

**NEED A COMPUTER? DOES A FRIEND?
SBAWS HAS ONE FOR YOU FOR FREE!**

Please visit us at

www.sbaws.org

For specific information
on how to get yours!

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
- Refurbished computers, new software and personalized training to help our constituents connect online with us and the rest of the world
- 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

Antegrade Contenance Enemas (ACE) and Bowel Management Programs: A Successful Pairing

(reprinted from SBA's *Enlighten* eNewsletter)

A study was recently conducted to examine the effectiveness of antegrade continence enemas (ACEs). Study findings suggest that when a successful ACE has been performed, patients should continue to have a bowel management program in place. The study (Bischoff A, Levitt MA, Bauer C, Jackson L, Holder M, Pena A. Treatment of fecal incontinence with a comprehensive bowel management program. *J Pediatr Surg* 2009 June;44(6):1278-83.) determined that valuable lessons could be garnered from the implementation of bowel management programs in nearly 500 fecally incontinent patients. For the study, the patients were divided on the basis of a contrast enema and symptoms. Specifically, 220 patients were identified as having constipation problems while 74 experienced problems with diarrhea. Colonic stool was monitored with abdominal radiographs, and bowel management plans were modified according to the patient's response and radiologic findings. For constipated patients, the emphasis was on the use of large enemas. For patients with tendency toward diarrhea, small enemas, a constipating diet, loperamide, and pectin were used. Diagnoses included anorectal malformation (223), Hirschsprung's (36), Spina Bifida (12), and miscellaneous (23). The management was successful in 279 patients (95%) - higher in constipated patients (98%) and less successful in patients with tendency toward diarrhea (84%). The study concluded that the key to a successful bowel management program rests in tailoring the type of enema, medication, and diet to the specific type of colon. Further, the study found that the best way to determine the effect of an enema is with an abdominal film and that ACE procedures should be recommended only after successful bowel management.

CUSTOMIZED EMPLOYMENT TRAINING

Griffin-Hammis Associates presents "Linking **Discovery and Self-Employment**," a 3-day intensive training session in Missoula, Montana, March 29-31, 2011. The training is appropriate for employment staff serving adults and transition age youth, and family members. For additional details contact Meg Hammis at mhammis@griffinhammis.com or Cary Griffin at cgriffin@griffinhammis.com.



Researchers Examine Root Causes of Depression and Anxiety in Young Adults with SB

(reprinted from SBA's *Enlighten* eNewsletter)

Researchers recently examined depression and anxiety rates in young adults with Spina Bifida in order to determine the root cause of these symptoms. The study (Bellin MH, Zabel TA, Dicianno BE, Levey E, Garver K, Linroth R, Braun P. Correlates of Depressive and Anxiety Symptoms in Young Adults with Spina Bifida. *J Pediatr Psychol* 2009 October 30.) examined several factors such as relationship with family and attitudes about Spina Bifida to determine their relationship to depression and anxiety.

Sixty-one individuals with Spina Bifida, ages 18 – 25, were surveyed to determine their attitude towards their Spina Bifida, their satisfaction with their family relationships, and their feelings about Chronic Care Model (CCM) services. Study participations were also asked questions about symptoms of depression and anxiety.

Researchers found a strong association with high rates of depression and negative feelings on living with Spina Bifida and dissatisfaction with family functioning. These factors ranked higher than any of the health care related triggers. The only health factor associated with anxiety symptoms in the study results was self-reported pain.

The results of the survey pointed to a need for multi-factor screening of young adults with Spina Bifida who are at risk for either depression or anxiety. Specifically, they believe that those reporting pain are more likely to demonstrate symptoms of anxiety. They concluded that encouraging a positive attitude about one's Spina Bifida or increasing satisfaction with family functioning may decrease the occurrence of depression in young adults in our community.

Healthy People 2020 addresses expanded areas of neural tube defects

(Continued from page 1)

areas: Systems and Policies, Barriers to Health Care, Environment, and Activities and Participation. Objectives contained in the Systems and Policies category include: increasing the number of state health departments that have at least one health promotion program aimed at improving the health and well-being of people with disabilities. The Barriers to Health Care section covers issues on access to appropriate and timely care such as: increasing the proportion of youth with special health care needs prepared to transition from pediatric to adult health care. Other areas of the Disabilities section in-

cludes objectives on increased accessible housing facilities and reduced barriers to participation in home, employment, school and community activities.

Areas in Healthy People 2020 that address neural tube defects have been expanded from those in Healthy People 2010 to include objectives on folic acid intake, red blood cell folate concentration levels, and a reduction in the number of infants born with anencephaly. A complete list of neural tube related objectives are listed in the box below. According to HHS's DATA2010, persons with disabilities are less likely to receive preventive health screenings and more likely to be overweight

Reduce by 10% the proportion of women of childbearing potential who have low red blood cell folate concentrations.

Increase by 10% the proportion of women delivering a live birth who received preconception care services and practiced key recommended preconception health behaviors, such as taking multivitamins/folic acid prior to pregnancy.

Reduce the occurrence of Spina Bifida to 30.0 per 100,000 births. The current birth rate is 34.2 per 100,000 births.

Reduce occurrence of anencephaly to 22.1 per 100,000 births. The current birth rate is 24.6 per 100,000 births.

To view all the objectives of Healthy People 2020 visit:

<http://www.healthypeople.gov/2020/topicsobjectives2020/pdfs/HP2020objectives.pdf>

and have high blood pressure. These trends make a strong case for increased preventive services, care, and support to persons living with disabilities. As outlined in our own mission, the Spina Bifida Association is engaged in efforts to prevent neural tube defects as well as to support the lives of those living with Spina Bifida so the importance of Healthy People 2020 cannot be minimized.



SPINA BIFIDA ASSOCIATION OF WASHINGTON STATE

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Email: sbaws@yahoo.com

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

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**

