



The Evergreen

April 2011

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

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LIKE SPRING, SBAWS IS EXPERIENCING NEW GROWTH

by Meg Paulsen, Executive Director

Spring has sprung and, like the season, SBAWS is blooming!

We kicked off the month by presenting our bilingual, preventative and educational booth at the NW Women's Show and met over 50 individuals who either worked with or were affected by Spina Bifida. I met the editor of Seattle Metro Woman Magazine - the upcoming issue will include an article I wrote highlighting SB and SBAWS. I will also be on KKNW's Chat with Women Network on April 6th at 8am promoting SBAWS and our upcoming Walk-N-Roll event.



Meg Paulsen

The Walk-N-Roll Kick-off Event was hosted in Olympia - we distributed our postcards and posters - directly to stores/individuals and also to attendees who will be distributing going forward. Thanks to our sponsors John (CCS Medical) and Melissa (Rocky Mtn. Medical) for their support! We invite you to get involved - let us know if you would like to assist in distributing info or volunteering for the main event being held

(Continued on page 6)

New law would mandate accessible health care

by Ilisa Halpern and Jeremy Scott, Drinker Biddle and Reath LLP; reprinted with permission from SBA's Insights magazine, Winter 2011

As Congress is set to reconvene for a new session, it is important to take stock of the legislative accomplishments Spina Bifida Association (SBA) had over the past year in helping to bring attention to the needs of the more than 166,000 Americans living with all forms of Spina Bifida. The upcoming session of Congress provides us with an opportunity to educate the many new Representatives and Senators and their staffs about Spina Bifida and the challenges faced by affected individuals and their families.

Throughout 2010, SBA worked with our champions in the Congressional Spina Bifida Caucus to develop legislation addressing the many barriers that exist for individuals with Spina Bifida and other disabilities in accessing quality primary—and preventive—health care. We are extremely proud to announce that these efforts resulted in

ills being introduced in both the Senate and the House of Representatives.

The "Debbie Blanchard Access to Health Care for Individuals with Disabilities Act of 2010" (S. 3907) was introduced on September 29 by Congressional Spina Bifida Caucus Senate co-chair Senator Chris Dodd (D-CT) and co-sponsored by Senator Sherrod Brown (D-OH). The legislation was named in memory of Debbie Blanchard, a woman who lived with Spina Bifida for nearly 56 years and passed away in August 2008 from cervical cancer. Due to the significant challenges she faced in finding a health care provider whose office and examination tables were accessible for individuals with disabilities, Debbie was not able to seek regular well-woman examinations, including cervical cancer screenings. The barriers Debbie faced in physically accessing the regular preventive care she needed unfortunately delayed the detection of her cancer until it was too late. The lack of access to health

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Newsletter Editor
Celeste McCormick
celtutt@yahoo.com

HIGHLIGHTS FROM BOARD OF DIRECTORS' MEETING ON FEBRUARY 17, 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!

- Chair's Report
 - Motion was made and approved to move our regular scheduled board meetings from the 2nd to the 4th Thursday of every other month
- Executive Director's Report
 - Motion made and approved to accept the proposed Walk-N-Roll budget
 - CS Medical sponsored the Walk-N-Roll at the \$500 level
 - VitaPath gave SBAWS a \$1000 grant for the Northwest Women's Show; motion made and approved to use \$1260 for the Show (I-Pad will be purchased and raffled off)
- Secretary's Report
 - Since December 2010, six new members have been added to the SBAWS database
- Treasurer's Report
 - Motion made and approved to accept Year-End Financial Report Statements
 - Motion made and approved to accept the proposed fundraising and privacy policies as prepared by the Treasurer
- New Business
 - Election of SBA Convention Delegates- Motion made and approved to send Linda Bailey and Krystal Monteros to the SBA Convention as delegates and Meg Paulsen, Jason Lane and Jamie Heckinger as attendees, on a reimbursement basis. Five total at a cost of \$1200 each (\$6000) plus the registration for the five at about \$300 each for a total cost of \$7500
 - Motion made and approved to get rid of the SBAWS fax number; the 253 and 800 numbers will be kept
 - Motion made and approved to accept Jamie Heckinger as a new Board member
- NEXT MEETING: Thursday April 30, 2011 (in-person meeting after the Walk-N-Roll in Olympia)

Chair

Linda Bailey,
gingersnap8160@yahoo.com

Chair Elect

Jason Lane
jlane101@comcast.net

Secretary

Krystal Monteros,
babykeitho@aol.com

Treasurer

Jon Tutt, jon_tutt@msn.com

Immediate Past Chair

Ed Kennedy
ejkcordwa@live.com

Directors

Meg Paulsen, Exec. Director,
megpaulsen@sbaws.org

Ryan Callaway

Jamie Heckinger

Nicole Williamson

Tracy Wright

Annette Zweig-Donham

Did you know about ... SBA's National Resource Center?

The National Resource Center (NRC) annually fields thousands of calls and emails related to Spina Bifida. Some of the questions are straightforward and related to basic information about Spina Bifida. However, according to the new Chair of the SBA Board of Directors, George Sturm, many more questions come from "people in crisis: people who are facing new challenges or uphill battles and desperately need information." SBA tries to respond to these inquiries as soon as possible with effective solutions. Sturm says that SBA also uses what it learns from these conversations to create various programs and resources that can provide help and information to people in need.

*Adapted from "Letter from the Chair,"
SBA's Insights magazine, Winter 2011*

SBA CONTINUES TO DISCUSS REVENUE SHARING WITH CHAPTERS

The first two weeks of February were filled with conversations between SBA Chapter and National leaders about an important topic—revenue sharing—when the Revenue Sharing Task Force hosted a series of four webinars which took place between February 1st and February 9th. In total, over 60 people representing 16 Chapters and the National Board of Directors engaged in our first conversation on the topic. Leaders from our own Washington State chapter participated.

The Power Point presentation, all of the talking points, and relevant handouts can be accessed here:

[SBA Divisibility Worksheet \(PDF\)](http://leadersonline.spinabifidaassociation.org/atf/cf/%7bdaf83018-7b57-4330-a4f3-47767dc907a8%7d/SBA%20DIVISIBILITY%20WORKSHEET%2012.19.2010.PDF) <http://leadersonline.spinabifidaassociation.org/atf/cf/%7bdaf83018-7b57-4330-a4f3-47767dc907a8%7d/SBA%20DIVISIBILITY%20WORKSHEET%2012.19.2010.PDF>

[SBA Revenue Sharing Presentation with Notes \(PPT\)](http://leadersonline.spinabifidaassociation.org/atf/cf/%7bdaf83018-7b57-4330-a4f3-47767dc907a8%7d/SBA%20REVENUE%20SHARING%20PRESENTATION%20WITH%20NOTES%20FINAL.PPTX) <http://leadersonline.spinabifidaassociation.org/atf/cf/%7bdaf83018-7b57-4330-a4f3-47767dc907a8%7d/SBA%20REVENUE%20SHARING%20PRESENTATION%20WITH%20NOTES%20FINAL.PPTX>

What was covered in the first series of Webinars? The first set of webinars introduced the SBA Revenue Sharing Project, including background on the project, the Task Force charge, members of the Task Force, and the Operating Principles that govern how the Task Force works. In addition, the Task Force shared its vision for the SBA revenue sharing policy, the important terms and concepts, revenue streams, and a proposed divisibility plan. The webinars concluded with an overview of the timeline for the project and a question and answer session.

Will there be other opportunities my Chapter to participate in the development of the revenue sharing policy? Yes! This was the first in a series of conversations on revenue sharing that will take place over the next several months. This series was an opportunity to introduce the concepts and the approach we are taking in our work. The next set of webinars is scheduled for April. For a complete look at the proposed timeline, go here:

http://leadersonline.spinabifidaassociation.org/site/c.mkIVLaMRJrE/b.6571689/k.8A68/Revenue_Sharing.htm

Additional SBU Sessions Now Available

New sessions have been added to SB University, SBA's new online education platform. The new sessions cover some important health topics, Medical Management of the Neurogenic Bladder (Birth to Age 10), Sexual Function in Men with Spina Bifida, and the importance of Folic Acid intake (in Spanish). A total of sixteen educational sessions are now available to view free of charge 24/7. Sessions cover a number of Spina Bifida related issues including aging, bowel and bladder management, general health and preventive medicine, and education and employment. Click [here](#) to view sessions.

AN ONLINE LEARNING EXPERIENCE

Medical Management: Neurogenic Bladder (Birth to Age 10)

Presenter: Elizabeth Yerkes, MD

This session provides detailed information on bladder function and management in children living with Spina Bifida.

Sexual Function and Health in Men with Spina Bifida

Presenter: John Wiener, MD

This session addresses sexual function and health of men with Spina Bifida.

Ácido Fólico ;Todos Mujer los Dias!

The importance of Folic Acid intake (in Spanish)

Presenter: Alina Flores MPH

Esta sesión explica la importancia de tomar el ácido fólico para prevenir defectos de nacimiento que ocurren en el tubo neural.

Check out www.sbuniversity.org today to access these and other great educational sessions!



APRIL 30, 2011

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

In memory of Gloria Olson

The Walk-N-Roll for Spina Bifida is April 30, 2011 at Heritage Park on the east side of 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

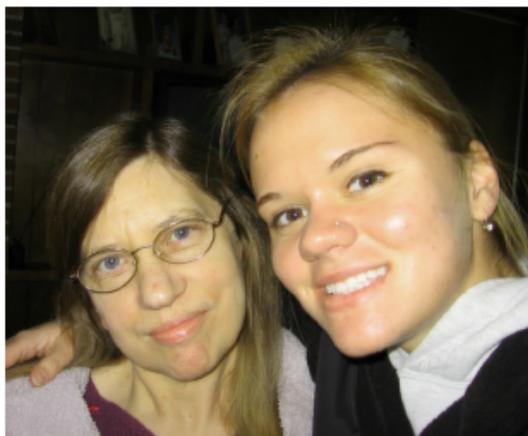
Step 4 - Make Your Commitment - What is your fundraising goal? Challenge yourself and remember your reason for committing to the Walk-N-Roll for Spina Bifida. **If you raise \$100 or more, your team wins free Walk-N-Roll t-shirts!**

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 as educate, recruit and motivate their team members.

To register for the walk or donate, visit:

www.firstgiving.com/sbaws

Together we make the difference.



The 2011 SBAWS Walk-N-Roll is dedicated to the memory of Gloria Jean Olsen, a long-time friend and supporter that we lost in 2010.

This event is sponsored in part by



Join the Spina Bifida Association of Washington State for its annual Walk-N-Roll.

Date: Saturday, April 30, 2011

Location: Heritage Park at Capitol Lake
301 5th Ave. SW
(5th Ave. SW & Water Street)
Olympia, Washington 98501

To register for the
walk or donate, visit:

www.firstgiving.com/sbaws

Together we make the difference.

Time: Registration opens at Noon
Walk begins at 1:00 PM
Special program at 2:00 PM

This is a great family-friendly, walk event to raise awareness about Spina Bifida and celebrate the accomplishments of the over 180,000 Americans living with it.

What is Spina Bifida?

Spina Bifida is the most commonly occurring complex birth defect in this country. There is no known cause and each of the 65 million women of childbearing age in this country is at risk for an affect pregnancy.

Come and support the thousands of individuals in our area who live with Spina Bifida!

All proceeds are used for programs and services for people living with Spina Bifida or to promote the prevention of this birth defect. For more information visit www.sbaws.org or contact

Meg Paulsen 425-351-3252 or sbaws@yahoo.com. The Spina Bifida Association of Washington State

www.sbaws.org



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 was held on Sunday, March 20th at Heritage Park on the east side of Capitol Lake where the 2011 Walk N Roll will launch on April 30. Volunteers distributed event flyers to walkers and rollers along the lake paths. Afterward, all volunteers, Team Captains, Committee members, Board Members, and interested persons enjoyed a complimentary buffet and rousing kick-off presentation at Traditions Restaurant.

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.



Over 180,000 Americans live with Spina Bifida—the most commonly occurring permanently disabling birth defect. Help us help them.

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!

SBAWS continues to forge partnerships, thanks to Paulsen’s efforts

(Continued from page 1)

Saturday, April 30th at noon in Olympia. For more information regarding registration for both teams and individuals, please go to www.firstgiving.com/sbaws - we would love to see you!!

We are now officially partners with EasterSeals of Washington! This organization will be distributing our information from its six child development locations throughout WA – Auburn, Renton, Seattle, SeaTac, Yakima and Spokane. Their services include: Camp Stand by Me (year-round child and ADULT camps), Computers for Kids, Assistive Technology Services and Workforce Development. We have agreed to mutually sponsor events – I will be helping with and then attending its upcoming 30-year Birthday Celebration of Camp Stand By Me in May and EasterSeals will be sponsoring and assisting at the Walk-N-Roll.

Upcoming April in-services with the Family Support Services Dept. at Swedish Hospital will be held to present our family support materials and plan for providing formal resource services and educational programs for patients. Once these programs are in place we will move forward and offer programs to other Washington state hospitals and medical services programs.

So, as the sun starts to coax Spring into bloom, we are grateful our organization is also starting its own growing season and we 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!

Looking forward and working together to make the difference!

Chair Bailey, Executive Director Paulsen, and other volunteers promoted SBAWS at the Northwest Women’s Show in Seattle last month. According to Paulsen it was a great success: hundreds of people visited the booth, including over 50 people who either have SB, have a loved one with SB or work with our community. One of them even signed up as a new volunteer! Nearly 1000 VitaTrack magnets were distributed, further advertising this app from VitaPath. The I-Pad also attracted people to the booth and the cost of the prize was recovered by the raffle.

Overall, SBAWS received thanks from the numerous visitors to the booth and also ed-



Paulsen in the SBAWS booth at the Show

ucated many more who had no prior knowledge about Spina Bifida.



REGISTER TODAY AT www.spinabifidaconference.org/

ROOMMATES NEEDED: Several SBAWS conference attendees would like to share hotel costs with roommates. If you are interested, contact SBAWS.

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

Visit www.sbaws.org to get yours!

CLUSTER NEWS: The Eastside/Everett cluster recently merged with the Seattle Cluster. For cluster activities in the Seattle area, please contact the Seattle Cluster.



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
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



Ask the Expert Feature on SBA's Website Takes Off

In November 2010, SBA converted its previous Ask the Doctor feature on the national website to an Ask the Expert feature. This move, intended to recognize the need for a broader scope of information related to Spina Bifida, has already had an immense response.

From questions ranging from higher education concerns to specific new surgeries, SBA's Ask the Expert feature links members of our community with subject matter experts from around the country. Popular questions and answers are featured regularly on SBA's Facebook page (www.facebook.com/spina.bifida.learn).

To submit a question, just visit SBA's home page at www.spinabifidaassociation.org, go to Programs/Services, select National Resource Center, and click on the Ask the Expert button link.



Do you have a desire to improve communication with others,

particularly in a work setting? If so, you may want to read the following article written by SBAWS member [Dave Carl](#). Carl is a social worker and [writer](#) who helps people living with disabilities learn job skills and enter the workforce for what is often the first time. For the full article on the website for the National Alliance on Mental Illness, click:

http://www.nami.org/ADVTemplate.cfm?Section=Advocate_Magazine&template=/ContentManagement/ContentDisplay.cfm&ContentID=116271&Istid=274



Pierce County Coalition
for Developmental Disabilities

NOT JUST FOR PIERCE COUNTY RESIDENTS: Visit <http://pc2online.org> for a variety of resources and services to assist Washington state residents with development disabilities. Features include: breaking news, a resource guide, legislative advocacy, age-specific issues, meetings, training and events.

www.abilitytrip.com

has accessibility info for your next trip!

If you are traveling to a place you have never been before, would you not find it helpful to simply get online and quickly find the best transportation and accommodation options, accessible sight-seeing tours, and contacts for medical equipment suppliers?

The website www.abilitytrip.com provides this information and much more. Founded in 2008 by husband and wife Darren and Faith Brehm, this site is a centralized resource for accessibility travel information—a travel guide—for the community of travelers who have disabilities and desire to travel more.

Log on 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
- 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



MOMS study shows that Fetal surgery can reduce complications from SB

The Management of Myelomeningocele Study (MOMS), an NIH-funded study, shows that surgery reduces the rate of disability yet increases preterm birth risk in pregnant women carrying a child with myelomeningocele. SBA is encouraged by the study's findings, and hopes that it can serve as the basis for many more studies on this complex birth defect. For information on the complete study go to: http://www.spinabifidaassociation.org/atf/cf/%7Beed435c8-f1a0-4a16-b4d8-a713bbcd9ce4%7D/MOMS_FINDINGS_9FEB2011.PDF

As an organization, we truly believe that research is the key to unlocking the mysteries surrounding this complex birth defect. We are encouraged by the recent information released by the Management of Myelomeningocele Study (MOMS) and hope that it can serve as the basis for many more studies on Spina Bifida. Any questions regarding the specifics of the study, should be directed to the National Institute of Child Health and Human Development (NICHD): Robert Bock or Marianne Glass Miller, 301-496-5133, bockr@mail.nih.gov

Additional Press Links:

- NYTimes, Success of Spina Bifida Study Opens Fetal Surgery Door: <http://www.nytimes.com/2011/02/10/health/10fetal.html?emc=eta1>
- CNN, Study: Major benefits for Spina Bifida surgery in the womb: <http://www.emailthis.clickability.com/et/emailThis?clickMap=viewThis&etMailToID=1716506037>
- MSNBC, Surgery in womb spares babies worst effects of spine defect: http://www.msnbc.msn.com/id/41498028/ns/health-kids_and_parenting/from/toolbar
- Voice of America, Delicate Surgery Reduces Complications of Devastating Birth Defect: <http://www.emailthis.clickability.com/et/emailThis?clickMap=viewThis&etMailToID=1905773484>
- NBC Nightly News Report (video): <http://www.msnbc.msn.com/id/3032619/vp/41499228#41499228>

FDA solicits public feedback about risks of powdered gloves

The Food and Drug Administration (FDA) is announcing the establishment of a public docket to receive comments related to surgeon's gloves and patient examination gloves (medical gloves) that contain or use donning or dusting powder. FDA is interested in the potential health effects from the use of powder on medical gloves and is soliciting comments regarding risks and benefits of powdered gloves. FDA is interested in any potential benefits of powdered gloves so that the Agency can consider how best to address the risks in light of any benefits. Elsewhere in this issue of the **Federal Register**, FDA is publishing a notice of availability for a draft guidance document entitled "Recommended Warning for Surgeon's Gloves and Patient Examination Gloves That Use Powder." The draft guidance document provides a recommended warning statement for powdered glove labeling that will inform health care providers and consumers of the risks associated with glove powder.

Publication Date:

Monday, February 07, 2011

Action:

Notice; Request For Comments.

Dates:

The Agency encourages interested parties to submit information and comments by April 25, 2011.

Comments Close:

04/25/2011

POST YOUR COMMENTS BY APRIL 25:
<http://www.federalregister.gov/articles/2011/02/07/2011-2542/information-related-to-risks-and-benefits-of-powdered-gloves-request-for-comments>



USDA and HHS Announce New 2010 Dietary Guidelines

The USDA and Department of Health and Human Services (HHS) recently released the 2010 Dietary Guidelines for Americans. These nutritional guidelines promote health, reduce the risk of chronic diseases, and reduce the prevalence of overweight and obesity through improved nutrition and physical activity. They are a good way to either get back on track or start a healthy regimen.

To learn more, visit:

http://www.spinabifidaassociation.org/site/c.liKWL7PLLrF/b.6583655/k.4CE4/February_2011_USDA_and_HHS_Announce_New_Dietary_Guidelines.htm



The Guidelines include 23 key recommendations for the general population and six additional key recommendations for specific population groups, such as women of childbearing age. These recommendations are the most important messages within the Guidelines for improving health. A few examples include:

- Enjoy your food, but eat less
- Avoid oversized portions
- Make half your plate fruits and vegetables
- Switch to fat-free or low-fat (1%) milk
- Compare sodium in foods like soup, bread, and frozen meals; choose the foods with lower numbers
- Drink water instead of sugary drinks

More consumer-friendly advice and tools, including a next generation Food Pyramid, will be released by USDA and HHS in the coming months. MyPyramid offers personalized eating plans and interactive tools to help you plan/assess your food choices.

To view the full recommendations, go to <http://www.spinabifidaassociation.org/atf/cf/%7beed435c8-f1a0-4a16-b4d8-a713bbcd9ce4%7d/KEY%20RECOMMENDATIONS.PDF>.

Two recent pieces of legislation highlight and honor Debbie Blanchard

(Continued from page 1)

care she faced clearly contributed to her untimely death. The “Debbie Blanchard” Act would help facilitate access to health care for individuals with disabilities, including—but not limited to—those with Spina Bifida and help them to identify providers whose offices and examination rooms are accessible for individuals with disabilities. The bill also helps increase awareness among health professionals of the need to provide an accessible environment and empowers individuals with disabilities with information and tools that can help them to identify accessible providers.

In the House, Representatives Chris Smith (R-NJ) and co-sponsors Bart Stupak (D-MI), Dan Burns (R-IN), and Raul Grijalva (D-AZ) introduced the “Spina Bifida Awareness Month Resolution” (H. Res. 1664). This bipartisan resolution raises awareness of the ongoing, life-long medical and psychosocial needs of individuals with Spina Bifida. This measure also recognizes the importance of increasing access to health care through facilities and examination rooms easily accessible and usable for individuals living with Spina Bifida and other disabilities.

These bills mark a significant step forward in the recognition of the challenges faced by individuals with Spina Bifida and the need for policies and programs to improve access to care and quality of life. SBA extends many thanks to Senators Dodd and Brown and Representatives Smith, Stupak, Burton and Grijalva for their efforts. Unfortunately, the session adjourned before Congress could take action on these proposals; however, SBA remains steadfast in its commitment to ensure policymakers understand the need to take action to improve and ensure access to care for people with Spina Bifida.

We encourage you to contact your Representatives and Senators—particularly the new members of the House and Senate—and urge them to show their support for the Spina Bifida Community by joining the Congressional Spina Bifida Caucus (if they have not already done so), and to support funding for the National Spina Bifida Program at the National Birth Defects and Developmental Disabilities Center at the Centers for Disease Control and Prevention (CDC). For more information on SBA’s advocacy efforts, please visit www.spinabifidaadvocacy.org.

SPINA BIFIDA ASSOCIATION OF WASHINGTON STATE

2128 N Pines Rd Ste 17-2 Spokane WA 99206

Phone: 253-589-3700/Fax: 775-766-1654

Toll free: 888-289-3702

Email: sbaws@yahoo.com

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

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**

