



The Evergreen

Summer 2008

Spina Bifida Association of Washington State

A chapter of the Spina Bifida Association of America

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OUTGOING PRESIDENT WISHES LUCK TO MEMBERSHIP

by Joe Nugent, outgoing President

As your outgoing President I would like to thank all of you for your support over the last year. I would like to congratulate you on becoming Spina Bifida Association of Washington State in June 2008. Wish you and your new Board all good luck and hope for the future.

As you all know Evergreen Spina Bifida Association now does business as Spina Bifida Association of Washington State with its service area being Washington State. Oregon has become Spina Bifida Association of Oregon (support group) under the national Spina Bifida Association. Montana has become Spina Bifida Association of Montana (support group) under the national Spina Bifida Association.

Over the next three years, there is a lot of hard work ahead for Spina Bifida Association of Washington State, but with your new leadership and board in place you will make it through the hard times. Spina Bifida Association of Washington State is planning to hold a Summit in September 2008.

Next year's National Conference will be 30 June 2009 to 3 July 2009 in Orlando FL. If you want to attend, start working on it now so you will be ready for it. The ground work for the Spina Bifida Association of Washington State has been laid, all you need to do as a chapter along with your members is to work hard to keep moving forward.

Our chapter and newsletter have new names! We are now the Spina Bifida Association of Washington State (find more details about this in the following pages). Also, for the first time our newsletter has a title—*THE EVERGREEN!* The name is a bridge to our established reputation under our former name of Evergreen Spina Bifida Association and also illustrates a constant renewal of our commitment to the never-ending demands of our mission.

IN MEMORIAM: KALI MARIE REXROTH

by *Beth Ellen Davis, MD*

As a pediatrician, I have known Kali for ten of the twenty years she has received care at Madigan. First let me share with you the Kali I knew for the first 5 of those years, and then I will share with you the Kali I got to know as part of a Spina Bifida Support group—including Amanda, Kathy, Antonio, Heather, Patti, Jennifer, Anthony—a group of fabulous young adults who meet every month and get free pizza. The medical part of Kali's life is more than all of our medical experiences combined! I am reminded about Kali's inner **strength and endurance even from the beginning**: She was born about 5 weeks early in on Feb 19, 1985. Weighing only 5lbs 7 oz, her dad mentioned that he held her all night long that first night because the nurses were short staffed and they did not want any pressure on her spinal cord. The next day, she endured an 11 hour neurosurgery! She spent her first 69 days of life in the neonatal intensive care unit and had multiple surgeries. Since then she's had 30 surgeries. One of her visits when she was 6 years old, and starting 1st grade noted that Kali is very agile in her wheelchair making her own bed and cleaning her own room! The doctor seeing her mentioned that she was VERY talkative and was a little girl who knew what she wanted. She didn't ask for a new back pack—she told the doctor what she really needed was a new pink wheelchair! At 10 years of age, she mentioned that her favorite activities did NOT include school, rather bowling, basketball and most fun was getting to take her wheelchair on the roller rink and roller(chair)

with the other kids!

She was a teacher to most of the developmental pediatricians in the Army! Today her legacy reaches around the world through the many doctors she taught about the complex and complicated condition called Spina Bifida. I specifically remember a visit during 2001, when Kali had again endured a difficult year full of medical surgeries, including loss of a kidney, and she came in dressed up with nails done and began reeling off her 11th grade classes at Steilacoom HS, and that her progress report had all A/B/Cs. She was studying 1-3 hours a night to achieve her goal! She was wholeheartedly dedicated to doing well in school that year and took in stride the extra medications, blood draws, hospital visits, and making up missed school work! But it has been the last five years that I have gotten to know and love the Kali of our Group. We meet to share experiences, offer advice and be each others' friends. During these Friday evenings I found out that Kali loves country music, loves to have her nails done, loves lipstick with a statement, wears a leopard skin coat and hat better than anyone! Always poised, always smiling. She has a great sense of humor, too. There is a ton of drama in our group, especially when a few of the members were trying to fly around the country to see live concerts of Clay Aiken, even at State Fairs in Iowa. Kali and I laughed so hard we couldn't breathe! Despite the obstacles in life that most of us will never have to face, Kali embraced her days with courage, poise, and a smile, always a smile! I will miss her very much.

President

Ed Kennedy, ejk@cordwa.info

Vice President

Annette Zweig-Donham,
az@w-link.net

Secretary

Patti Logan,
patti_logan04@yahoo.com

Treasurer

Jon Tutt, jon_tutt@msn.com

Past President

Gloria Olson,
ole5068@comcast.net

Board Members

Brian Knowles (Chair),
crazy572003@yahoo.com

Nicole Anderson

Linda Bailey

Mariah Bates

Janet Davis

Michele Hopkins

Pamela Hoppman

LaDonna Kirkaldie

Have you renewed your membership for 2008?

The form is new so if you have not filled one out please do so as soon as possible! Getting new forms from all members is very important to us, first to verify our contact information and second because national will not allow us to include you in our membership count without it. If you have not done so already, please request a copy of the form by calling 888-289-3702 or emailing Evergreensba@yahoo.com. You do not have to send any money with the application. We do not require "dues" or "membership fees." Donations are graciously accepted and greatly appreciated, but not required. The important thing is to PLEASE take time to do it RIGHT NOW so we can get you on our list!

Fundraising news

Read more about Kayla's senior project in an online article from the News Tribune in Tacoma:

<http://www.thenewstribune.com/news/local/>



STUDENT RAISES FUNDS FOR UNPAID MEDICAL BILLS

Kayla Huggins, a recent graduate of Sumner High School, coordinated a silent auction this past April to raise funds for the Spina Bifida Association of Washington State (at the time known as ESBA). The auction was Kayla's senior project and she was inspired with the idea while babysitting Kelahna Miller, a member of SBAWS who has Spina Bifida. According to Kelahna's mother, Amy, the auction was "great" and received donations from individuals and businesses in the Bonney Lake/Sumner community.

In total Kayla raised over \$1100 for SBAWS. Kayla's first wish for the money is that it be given to members in need of "uncompensated care" in this order: unpaid medical expenses, necessary medical supplies, and special equipment needs such as braces, wheelchairs, shoes, etc. Any remaining funds will be funneled to our scholarship program which targets the educational needs of people affected by Spina Bifida.

Unfortunately, the auction saw sparse attendance from SBAWS members. Greater participation from the membership was both hoped for and expected. Kayla, all of us here at SBAWS extend our deepest thanks to you for all of your efforts. Your project perfectly embodied our two-fold mission: the auction increased awareness of Spina Bifida and the funds raised will enhance the lives of those affected by it.

To inquire about becoming a recipient of these funds, call SBAWS at 888-289-3702 or send an email to evergreensba@yahoo.com.

Thanks to the efforts of our Chair Brian Knowles, SBAWS will now participate in the following state fundraising campaigns:

Combined Federal Campaigns:

- Olympic Peninsula
- King County
- North Puget Sound
- Walla Walla Area
- Yakima-Kittitas
- South Puget Sound
- Pacific Northwest
- Island County
- Mid-Columbia
- Inland Northwest
- Kitsap-Mason

Other Washington state campaigns:

- State of Washington's Combined Fund Drive
- King County Employee Giving Program
- Snohomish County Employees Charitable Campaign
- Snohomish County PUD Employees Charitable Giving Program

Thank you!

SAVE THE DATE: MACY'S SHOP FOR A CAUSE, SATURDAY SEPTEMBER 20 2008
SBAWS is starting to make arrangements to participate again in Macy's Shop For a Cause fundraising program. The event date is Saturday September 20. Stay tuned for details as they get confirmed.

How the program works: Macy's provides us with passes that we sell for \$5. Each pass gives the shopper 20% off most items in the store for one day only.

PLEASE PARTICIPATE!

Last year we raised nearly \$5000!

To get passes, contact Jon Tutt at jon_tutt@msn.com or 888-289-3702.



Treasurer's Report

Profit and Loss Previous Year Comparison For the six-month periods ending June 30th, 2007 and 2008

		Jan-Jun 08	Jan-Jun 07	\$ Change	% Change
Income					
	Donations \$	835.00	\$ 813.00	\$ 22.00	2.71%
	Interest \$	<u>796.82</u>	<u>\$ 1,087.78</u>	<u>\$ (290.96)</u>	-26.75%
Total Income		\$ 1,631.82	\$ 1,900.78	\$ (268.96)	-14.15%
Expenses					
		<u>% Spent</u>			
Mission		68.83% \$ 2,447.39	\$ 4,049.60	\$ (1,602.21)	-39.56%
Admin		29.74% \$ 1,057.61	\$ 1,195.44	\$ (137.83)	-11.53%
Fundraising		1.43% \$ 50.92	\$ -	\$ 50.92	100.00%
Total Expenses		100.00% \$ 3,555.92	\$ 5,245.04	\$ (1,689.12)	-32.20%
Net Income		<u>\$ (1,924.10)</u>	<u>\$ (3,344.26)</u>	<u>\$ 1,420.16</u>	42.47%

Prepared by Jon Tutt, Treasurer

Income: Even though the donations we received this year increased slightly, our total income decreased by over 14% because the interest we received decreased significantly. I had said in the past that our interest income had peaked and would be declining as our savings balance decreased. Lower interest rates contributed to this as well.

Expenses: Mission/Program expenses were down dramatically, basically because this year we haven't had to pay any "dues" to national, but the board has agreed that the association should pay to national member subscriptions to their magazine *In-sights* at \$20.00 per member, so that expense is still coming. Administrative expenses decreased slightly and Fundraising expenses increased slightly, but neither variance is significant. The percentage of the total spent for Administrative expense is higher than desirable because during April we paid our annual insurance bill, which is usually our biggest item in that category. The year-end percentage should be more acceptable.

Net Loss: The good news is that our loss year-to-date was almost 43% less than last year. The bad news is that we continue to spend more than we take in. This can only go on so long, so if we are committed to fulfilling our mission, and meeting national's new "minimum requirements" for chapter affiliation, we must increase our income and fundraising efforts.

Assets and Liabilities: As of mid year 2008, we had \$44,923.75 cash in the bank, \$274.03 in cluster advances that had not been expensed, and the depreciated value of the four-laptop computers that the association bought a while back was \$562.99. Total assets were \$45,760.77. The association has no liabilities, no unpaid bills, so our net worth is the same as our assets.

**ALL MEMBERS
ARE WELCOME
TO ATTEND
BOARD MEETINGS**

View photos from the Seattle Cluster's July 19
summer picnic by going to this link:

http://www.kodakgallery.com/l.jsp?c=trrghi9.v9o2hdh&x=1&y=l4fgri&localeid=en_US

The Washington Health Care Caucuses: Speak up for quality, affordable health care

Lend your voice to the effort to achieve quality, affordable health care for all Washingtonians.

Learn what steps we have taken and what the next steps will be.

You are invited to participate and help shape the principles and values we want in Washington's health care system.

Be part of the community that is committed to changing the health care system in Washington state.

You are invited to attend a caucus hosted by the Healthy Washington Coalition:

SPOKANE—JULY 29 6:30-8:30pm
1st Presbyterian Church
318 S Cedar St
Spokane WA 99201

BELLEVUE—AUGUST 12 6:30-8:30pm
Temple B'nai Torah
15727 NE 4th St
Bellevue WA 98008

EVERETT—SEPT 9 6:30-8:30pm
Everett Station
Weyerhauser Room
3201 Smith Ave
Everett WA 98201

VANCOUVER—SEPT 13 6:30-8:30pm
Clark Public Utilities
Vancouver Service Ctr, Community Room
1200 Fort Vancouver Way
Vancouver WA 98663

For more information about the Town Hall Meetings and the Healthy Washington Coalition, please go to www.healthywacoalition.org.

GET INVOLVED WITH YOUR LOCAL CLUSTER TODAY!

City/State	Leader Name	Contact Phone
Everett & Eastside Seattle WA (combined)	Brenda Stroud	425-385-2487
	Janet Davis	425-514-3448
	Michele Hopkins	425-844-1262
Madigan Army Medical Ctr.	Dr. Ellen Davis	253-968-0253
	Heather Logan	360-888-0782
Spokane WA	Ed Kennedy	509-465-0676
South King County WA	Brian Knowles	253-887-0888
	Nicole Anderson	303-877-5083
	Alex Bugni	206-706-5665
Seattle WA	Jason Lane	206-363-3726
	Dave Lewallan	360-871-5139
Kitsap WA	Rebekah Uhtoff	360-782-0467
	Heather Logan	360-888-0782
Olympia WA	Patti Logan	360-888-7701
	Ed Baroch	509-548-5697
Leavenworth WA	Anthony Williams	253-588-4411
Spanish		

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

The Spina Bifida
Association has joined
myspace.com! Join us!

myspace.com
a place for friends

2008 Summit Conference

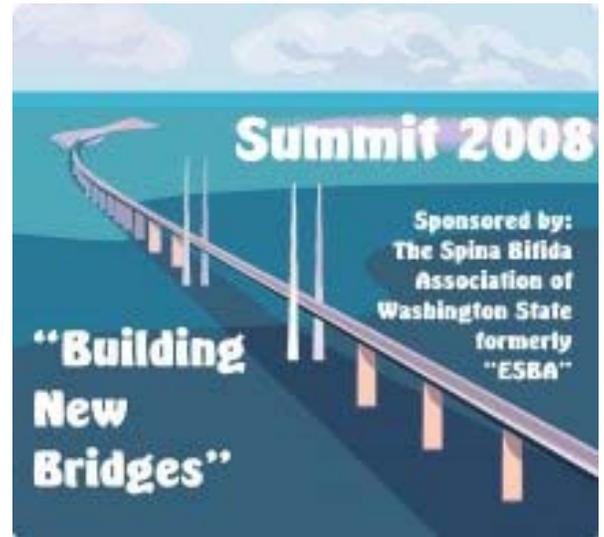
The Spina Bifida Association of Washington state invites you to its 2008 Summit Conference!

WHEN: September 5-6 2008 (Fri & Sat)

WHERE: Comfort Inn

31622 Pacific Hwy South

Federal Way WA (same hotel as last year)



PROGRAM HIGHLIGHTS

Keynote speaker (tentative), *Meg Paulsen, Ms Wheelchair WA 2008*

Friday night board meeting, *open to everyone*

Assistive Technology: Devices and Funding Sources,
Washington Assistive Technology Foundation

Service Dogs and ADA Laws, *Dr Don Martin and Sue Martin of Paws Abilities Dog Training Center*

Issues Facing Adults and Young Adults with Spina Bifida: Transition, Anxiety, Depression, *Dr Beth Ellen Davis*

Building New Bridges: SBA 2008 Convention Report and Transitioning from ESBA to SBAWS, *Patti Logan*

Special kids programs and childcare will be provided. The summit schedule will promote a relaxed atmosphere with long and frequent breaks. We will have plenty of time to visit and get to know each other better and we will not have to choose between simultaneous sessions.

~ Meg Paulsen crowned Ms. Wheelchair Washington 2008 ~
"My lifelong ambition has been to make the world a better place for members of my community."

Meg Paulsen feels that her disability serves as a "gift" and has always made the choice to lead her life by example. She is an active, energetic person who loves outdoor activities like hand-cycling, cross-country skiing, boating/sailing, and traveling.

Meg's Platform Title: **Employment of Wheelchair Users of ALL Abilities**

Meg's Platform Focus: **"I will utilize my resources and networking opportunities to enhance the recruitment, hiring and employment practices used by companies in regards to potential and current employees with disabilities. It is my hope that these efforts will in turn change the behaviors and environments of those corporations and that these changes will lead to the creation of sustainable career opportunities and win/win situations for both employees and employers."**

Visit her blog at <http://mswheelchairwashington.blogspot.com> or send her an email at megpaulsen@hotmail.com.

Lunch & dinner on Saturday will be provided & the hotel hosts a continental breakfast.

Directions to the summit:Get on I-5 & head North or South depending on your location relative to Federal Way. Take Exit 143 (S 320th St) & head West to the Pacific Hwy South/US 99 and turn North (right) toward Seattle to the Comfort Inn. For more information call the hotel toll-free at 877-821-8618.

Our Goal: Bring together as many SBAWS (ESBA) members and interested individuals for an Annual Meeting and sharing of ideas, to help us understand and highlight our awareness of each others abilities and disabilities and to promote the growth of our association.



REGISTRATION FORM

Please complete and send this form no later than August 20th, 2008, to the Spina Bifida Association of Washington State, 2128 North Pines Rd. Suite 17-2, Spokane, WA 99208. We need attendee counts for meals, childcare, etc.

Registration cost for the Summit is \$40 for the first member of an immediate family and \$20 for all other members of that family. This fee includes a catered lunch and dinner for Saturday. No one will be excluded because of an inability to pay. Travel and hotel stipends will be available for long distance travelers. If you need a stipend or to have the registration fee waived in order to attend, please email your request to Jon_Tutt@msn.com.

Date: _____

Individual or Family Name: _____

Address _____

Contact person/phone: _____

Email: _____

Number of people attending _____

Names of people attending (please include the ages of any children):

Will you need a hotel room? YES ___ NO ___

If yes, for what night (s) ? _____

Please call the Federal Way Comfort Inn toll-free at 1-877-821-8618 for room reservations. Reference Account Number 2719 and ask for the SBAWS (ESBA) Group Rate of \$84 + tax.

Special Accommodations required (including dietary needs): YES ___ NO ___

If yes, please explain accommodation requested.



Patti Logan

NATIONAL CONVENTION DELEGATE SHARES EXPERIENCES

by Patti Logan, Secretary

Thank you, Evergreen Spina Bifida Association dba SBA of Washington State for sending me to the 2008 SBA Convention. It was a highlight of my years of working with you.

How do I tell you about the changes occurring at the national level? How do I start? For one thing, from now on we need to think of the Spina Bifida Association as similar to the American Heart Association or the American Cancer Society or the March of Dimes. And we need to think of partners in envisioning a world without Spina Bifida. We are a national organization, and we are a state chapter of that organization.

We have officially changed our name. That does not mean we cease to exist. In fact, we will grow stronger and do much more with our partners.

These partners are not only those others with Spina Bifida—they can also be found everywhere in goodhearted men and women who care for our cause. They can be found in Washington DC at the national office, but also in your next door neighbor. They will be found in volunteer organizations, sewing circles, and churches.

As one big example, I point to the one piece of business I did as your representative. We delegates voted by acclamation a young woman

Donna Marie Jones to serve on the na-

Purchase conference photos at www.lambesisphoto.com

tional SBA Board. She is an advocate for us in Washington DC, and I hope you all will get the chance to see her or hear her talk about the future for the first generation of children with Spina Bifida to reach adulthood. She is one of that generation, and working for all the future babies born with and without Spina Bifida who will be helped by our efforts to educate about folic acid and support those affected by Spina Bifida.

Conference session handouts are now available online at <http://conference.spinabifidaassociation.org>

Dr. William Walker was the moderator of the main presentation Monday morning of the Convention. Many of you will know Dr. Walker; he was Heather's doctor at Madigan for several years before moving to the University of Washington Medical Team. I got to talk with him, and know he will be a good partner as we reach out to serve the people of Washington.

I will be sharing more about the link between ESBA/SBAWS and the national office as time goes on. There is a place for all of us in this expansion. We will all need to work together, have a transparent, sharing relationship with many folks, and do a lot of connecting. I believe it can be done with help. Now I see that we will be getting the help. I look forward to all that comes

The National Spina Bifida Program housed at the Centers for Disease Control and Prevention (CDC) supports critical programs, research, and services for those who live with Spina Bifida. In the more than five years since it was created, it has done great work to improve the quality of life for those living with Spina Bifida.

The Problem: Members of Congress are most responsive to their constituents. Your elected officials in the House and Senate need to be asked directly by you to allocate \$7 million in Fiscal Year 2009 for the National Spina Bifida Program. The more people who contact Congress about this important program – the more likely it is that elected officials will provide increased funding.

Take Action Today: Taking action will take less than 5 minutes and it will have a significant impact. With thousands of people all contacting Congress about Spina Bifida funding our voices will be loud and clear: increase funding to improve quality of life for people with Spina Bifida! Take action today by visiting this site:

<<http://www.spinabifidaassociation.org/site/c.liKWL7PLlrF/b.4196675/>>

Make a Phone Call: Learn how to make an effective phone call

<http://www.spinabifidaassociation.org/site/c.liKWL7PLlrF/b.2664009/k.726B/Top_Ten_Tips_For_Calling.htm> to your Members of Congress. Just call 202-224-3121 and ask to be connected to your elected officials' offices – let them know you support increased funding for SB!

**ADVOCACY
ALERT: You
can help**

INCOMING PRESIDENT LOOKS FORWARD TO THE FUTURE



Ed Kennedy

Hi Everybody! So much is happening with the Evergreen Spina Bifida Association (ESBA). I want to take just a moment to update you on some of these happenings. First, as of July 1, 2008, the leadership of our organization will once again change. Yours truly, Ed Kennedy is in the President's saddle. Thanks for your confidence in me.

I'm excited about this as I will be serving with a GREAT Executive Committee: Annette Zweig-Donham – Vice President, Jon Tutt – Treasurer, Patti Logan – Secretary, Brian Knowles – Board Chair, and Gloria Olson - Past President. Our newly elected Board members are Nicole Anderson, Linda Bailey, Mariah Bates, Janet Davis, Michele Hopkins, Pamela Hoppmann, and LaDonna Kirkaldie. Each one is highly committed to the ESBA, and I hope you will take some time to get to know them personally. (You'll get the chance this September in Federal Way at Summit II.) We will do our best to serve you. I want to let you know that it is my intention, first and foremost, to be there for our member-constituents in Washington. I want you to feel heard and cared for. Whenever possible, we will assist with #1 our friendship, #2 our knowledge and personal experiences, #3 possible resources and #4 whatever else is possible for an organization such as ours to provide its "constituents." (At the summit let's have a discussion about who is our constituency!)

Also, as you have probably heard we will no longer be an organization serving five states (Washington, Idaho, Montana, Oregon, and Alaska). Instead, we will be serving Washington State alone. The other states will become groups of their own under the direction of the National organization. I'm looking forward to this change because we can do a better job with a smaller service area. I would really like to hear from everyone your ideas of how we might reach the entire state of Washington.

With the change of our "service area" comes a change of our name (to some degree). You will still be able to refer to us as Evergreen Spina Bifida Association since we will be dba (doing business as) SBA of Washington State. Now, I bet you are asking yourself why is this happening if the end result is the name will still be Evergreen Spina Bifida Association. Good question, and the best answer I can give is that the national Spina Bifida Association is hoping that if we all follow the same template in our name (that being "Spina Bifida Association of [our service area] we will all then be better recognized as part of a larger organization, similar to the names of such organizations like the American Cancer Society, Multiple Sclerosis Society, or the Muscular Dystrophy Association. Having one name in every location just makes it more possible for people to associate the name of the disability and then if anyone needs to find us having this common name should make that easier as well. It is also hoped that donors will also be able to better recognize us and be more willing to give.

Most of you have sent in your renewal forms and we thank you very much for your standing beside others with Spina Bifida. However, if you haven't sent your renewal form in as of yet – please do so right now. It truly is a concern to me when we don't hear from someone who for one reason or another decides not to renew. If you can't give to ESBA right now that's ok – just please let us know that you want to stay a part of our group and keep receiving our ESBA Newsletter along with the National Insights Magazine. (ESBA is paying the subscription price for all who renew.)

In closing, we are continuing in our efforts to do our best to make this organization one that you can be proud to be a part of. You can help. You may want to take part by sharing your story with someone you meet who has Spina Bifida, taking brochures to your doctor's office, being a part of (or starting) a local Cluster group, joining a committee, entering articles for our newsletter, or by participating in events that bring us together during the year. With each one doing our part, we can make it happen!

I thank you for this opportunity to serve you and look forward to talking with many of you in the coming months.

We owe thanks to our Board of Directors which just voted to pay for each member's subscription to SBA's quarterly newsletter *Insights*. You may also sign up for the electronic version at www.spinabifidaassociation.org.



Matt Scott, a wheelchair basketball athlete with Spina Bifida, was nominated for ESPN's ESPY awards and will also be a member of the Beijing paralympic basketball team. He was also featured in a recent issue of SBA's INSIGHTS magazine. The ESPY awards show is July 20. Go to this link to see a Nike commercial he starred in earlier this year. According to his fans, "IT IS AWESOME!"
<http://www.youtube.com/watch?v=obdd31Q9PqA>

UN pact for rights of disabled comes into force

Ecuador - By Patrick Worsnip, UNITED NATIONS (Reuters) , May 3 2008

A UN convention aimed at ensuring equal rights for the world's 650 million disabled people in work, education and social life went into force Saturday.

The pact, the first of its kind and billed by the United Nations as the first new human rights treaty of the 21st Century, took effect 30 days after being ratified by 20 countries that have signed it. That figure has since risen to 25, but does not include the United States and Russia. In a statement last month, UN Secretary-General Ban Ki-moon called the implementation of the pact less than two years after its adoption by the General Assembly -- a short time by U.N. standards -- a "historic moment."

Ban said it showed the world was committed to combating "the egregious neglect and dehumanizing practices that violate the human rights of persons with disabilities."

The 32-page U.N. Convention on the Rights of Persons with Disabilities outlaws all forms of discrimination at work on the basis of disability, including in hiring, promotion and working conditions. It requires equal pay for work of equal value. It also calls on signatory states to promote the employment of disabled people, including through "affirmative action" programs that favor them.

The pact stipulates that the disabled may not be excluded from mainstream education systems. It demands that governments provide them with physical access to transportation, schools, housing, medical facilities and workplaces.

So far, 127 of the 192 U.N. member states have signed the convention. But only just over half of those have signed an annex allowing individuals and groups to complain to the United Nations that their governments are not implementing the convention. In such cases, a UN committee would refer the complaint to the government concerned, which must provide a written explanation within six months.

U.S. officials said the document was weaker than the U.S. Americans with Disabilities Act of 1991 and therefore could complicate enforcement of that law. UN officials said the new convention did not create new rights but aimed to ensure that benefits of existing rights were guaranteed. "Persons with disabilities have routinely suffered discrimination in the job market, in schools and in receiving public services," said Akiko Ito, a UN official specializing in the issue. "This convention will make sure that these people will no longer be ignored." (Editing by Jackie Frank)

Youth and Disability Disclosure: The Role of Families and Advocates

This InfoBrief highlights NCWD/Youth's *The 411 on Disability Disclosure* and explores the role families and advocates play in helping youth understand the importance of appropriate disability disclosure.

Vocational Assessment and Its Role in Career Planning

This InfoBrief discusses career planning and vocational assessment for transition-age youth.

All publications can be downloaded at <http://www.ncwd-youth.info/> or single copies can be requested and multiple copies purchased from NCWD/Youth by calling (202) 822-8405.

HEALTH CORNER

More professionals know about ABCs of Folic Acid Counseling, SBA's free online Continuing Education tutorial developed in collaboration with CDC. This is a significant increase of awareness of this program, up 21% from the last national survey. Encourage health professionals in your area to take the ABCs of Folic Acid Counseling online at: <http://sba-resource.org/sbaacd/>

SPINA BIFIDA COOK BOOK FOR SALE

A cookbook has been written specifically for people living with Spina Bifida. *Eat Food and Other Advice for a Healthy Diet* features recipes rich in Folate, addresses ways to improve bowel and bladder health through diet and gives lots of tips for healthy living. It was written by Jennifer Shore, Family Support Coordinator for the Spina Bifida Association of the Tri-State Region (SBATSR: New Jersey, metro New York and Southern Connecticut). The recipes in no way replace medical care, but give tools to follow sound nutritional wisdom. High fiber, protein and low fat recipes give tasty choices.

The cookbook made its debut at SBATSR's latest Regional Conference where recipes were sampled in the Healthy Habits workshop and received rave reviews by the participants. For more information go to www.sbatsr.org and order your copy today.

Do you know families who could use some extra food during the summer?

If so, please refer them to the Summer Meals Program. Summer Meal sites can offer breakfast, lunch, snacks and dinner (options vary by site). Free Summer Meals are available to all children from infants to age 18. No paperwork is required. To find a Summer Meals site near you, visit www.parenthelp123.org or call the Within Reach Family Food Hotline at 888-4-Food-WA (888-436-6392) M-F 8:00am-5:30pm.



The International Federation for Spina Bifida and Hydrocephalus reports that a recent study published in the international journal [Birth Defects Research](#) shows the South African government's food fortification program has led to a 40% decline in Spina Bifida. In Oct 2003 South Africa started a program of Folic Acid fortification of staple foods. The study shows a substantial decline in the prevalence of Neural Tube Defects following Folic Acid fortification in the country. Before the food fortification program began, an estimated 970 babies were born each year with Spina Bifida, and the addition of Folic Acid to staple foods saw that figure drop closer 570. Mandatory fortification of maize and wheat flour has been the largest contributor to the decline in Spina Bifida.

MEDICAL UPDATES FROM DR SHURTLEFF, MEDICAL ADVISOR TO SBAWS

We have scheduled the first male for re-ervation of his penis by transfer of the ileo-femoral anterior medial branch to the penis. We are negotiating to have an urologist from Utrecht, The Netherlands visit us and participate in the surgery. This operation was pioneered at the University of Utrecht.

Our review of patients with cerebrospinal fluid shunts performed by our team over the last 50 years has revealed a very high frequency of *Hemophilus influenzae* and *Streptococcus pneumoniae* infection of the nervous system. Although there have been sporadic reports of these infections amongst patients with cerebrospinal fluid shunts, none were large enough studies to allow calculation of prevalence. Our computerized data management system has kept track of our patients and allowed us to do the calculations. These observations are important for two reasons: there are immunizations to protect against some of the subtypes of these organisms; and these infections can be successively treated with appropriate antibiotics without having to remove the shunt. This presentation was recently given to the International Society for Research into Hydrocephalus and Spina Bifida and the manuscript sent to a scientific medical journal to consider publication.



WANT TO ENJOY SOME FUN IN THE SUN?

Summer programs are underway and fall programs are lining up at OUTDOORS FOR ALL!

Visit www.outdoorsforall.com to get involved. Participants, volunteers and donations are welcome.

**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: evergreensba@yahoo.com

Members of the Spina Bifida Association of Washington State are adults or children with Spina Bifida and parents, friends, relatives, and professionals with an interest in this spinal tube birth defect.

We're on the web!
***[www.evergreen
spinabifida.org](http://www.evergreen
spinabifida.org)***


**Spina Bifida Association
of Washington State**

**Disabilityphoto.com
Online stock photo library
seeks photographers and illustrators**

A new stock photo agency, Disabilityphoto.com, is aggressively seeking photos and illustrations of, by, and for the disability community.

The site's goal is to offer a unique place for royalty-free and rights-managed photography and illustrations.

Art from prominent photographers in the disability community has already been lined up. For instance, buyers on the site will be able to obtain the works of Christopher Voelker, Chris Hamilton, Eric Stampfli and and many others. However, Creative Director Jennifer Ruf wants to get the word out that there's no limit to DisabilityPhoto's quest for talent.

"We're creating something that's never been done before...a place where a huge amount of disability artwork will be available at a buyer's fingertips. We're calling on all artists, from amateurs to professionals, to contact us.

It's a great opportunity."

Disabilityphoto.com will be a well-organized site so that finding the right works for any project will be a snap. "This site is intended to offer high end photography and illustrations in an easy-to-use format," says Ruf, "The site has a great layout to make it easy to find exactly what you're looking for. "With the goal of stocking the site with thousands of photos and art, Disabilityphoto.com promises to be the premier source for anyone seeking disability-related images.

To submit artwork or learn more about the site, please go to
www.disabilityphoto.com