



Evergreen Spina Bifida Association Newsletter

ESBA votes to divide into state chapters and groups

by Joe Nugent, President

Hello everyone. I do need to make a correction to my last message which was in the January newsletter. I left out one step in the process and that was after getting the information from the membership in every state it goes to the ESBA board for approval then is sent to national. And this information was sent to national SBA by the 1 March 2008 deadline.

Here are the results of what the whole membership and board said.

ESBA (known as the five states Washington, Montana, Oregon, Alaska, and Idaho) intends to do the following by 1 July 2008 when agreements are signed with SBA's National Board as it pertains to each state.

Washington state will be a chapter and will be SBA of ? (there is a need to come up with a name for the Washington State service area) and will be led by a new board that Washington state mem-

bers elect in June.

Montana will be a support group under national SBA, with its name as SBA of Montana (support group) led by Joseph Nugent.

Oregon will be a support group under national SBA, with its name as SBA of Oregon (support group) led by Bill Pfankuch.

Alaska members will stay with members of Washington, and the Alaska service area will go to national SBA to be handled. Idaho members will stay with the members of Washington, and the Idaho service area will go to national SBA to be handled. The Alaska and Idaho members could also just be members of the national SBA.

At the March 2008 ESBA Board meeting our delegates were chosen for the SBA National Conference in June 2008 in Tucson AZ. The delegates are Joseph Nugent and Patti Logan, and the alternate is Jill Pfankuch.

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OREGON, IDAHO,
MONTANA & ALASKA**

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Is PEMCO Guilty of Discrimination?

by Skip Dreps, Government Relations Director,
Paralyzed Veterans of America (NW Chapter)

Recently one of our members informed me his vehicle insurance rate had doubled since last year. I asked him several questions to get to the bottom of the unreasonable increase:

Where you involved in an accident within the last 12 months? **No.**

Have you disclosed the actual value of the vehicle and its adaptive equipment? **Yes.**

Do you drive the vehicle? **No.**

How long have you been insured by the company? **25 years.**

Have you made any claims against your insurer for policy coverage in the last year? **Never.**

The more I asked the more the picture became clear.

How much was your insurance last year? **Under**

\$400.00.

How much is the rate increase? Here is where the answer became outrageous! The actual insurance for the vehicle had not increased. The PEMCO insurance agent informed our member that they would no longer insure the conversion part of his van unless he paid an additional \$740.00 a year! That figure is twice as much as he paid for the premium on the van which is worth twice as much as the conversion. Furthermore, the PEMCO agent informed him that their company was raising their premium for all of their wheelchair conversion clients.

The member claimed that the company was unfair in its practices and the new practice was discriminatory. Based on the information our

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Celeste and nephew Michael
Photo courtesy of Colette Hoyt

GETTING TO KNOW YOU: Newsletter Editor Celeste McCormick

by *Diana M Tutt*

When our editor reminded me to submit my article for this issue, I knew it was time to introduce our community to the editor. Celeste McCormick came to ESBA by way of her nephew, nine-year-old Michael Hoyt who has Spina Bifida. Celeste is a "hands on" aunt to Michael and his sister Chandra. This December their mom, Colette, was out of town for a week for work and Celeste and her husband came in from Lewiston Idaho to care for them. We all know how important family support is. The Spokane Cluster enjoys Celeste's company when she can attend, like our summer park gatherings. Last year she came to the swimming party at the lake

and brought another niece, Sophia, to add to the fun.

When Celeste was in high school in Spokane she was the co-editor of the school newspaper. She went on to graduate from the University of Montana in Missoula, then to Seattle to work at Seattle University, and is presently an IT supervisor at Lewis-Clark State College in Lewiston. She is continuing her graduate degree at the University of Idaho in Public Administration. Celeste lives in Lewiston with her husband Emmett, a pilot, and their cat Betty. I would like to take this space to thank her for producing such a superior newsletter, keeping us informed in a great format. Thanks Celeste!

HOPKINS FAMILY WELCOMES A NEW ADDITION

by *Michele Hopkins*

Mark, Michele and Skylar are proud to announce their new baby! Xander Paul was born on February 11, 2008. Weighing in at 9 lbs. 12 oz., delivered via c-section. I'm doing well, but trying to deal with the lack of sleep. Skylar is very proud to be the "big" sister and helps me out a lot at home. Xander is in good health. The Dr. saw a small dimple on his lower back at his first visit. After a close examination, it was determined it was nothing. The Dr. was impressed at how much knowledge I had about spina bifida (she didn't realize I have a form of it). I'm a stay at home mom now and I'm trying to adjust to that. It has been a rocky road, but we are strong! Thanks to all who sent us their love and blessings.



Baby Xander, Photo courtesy of Michele Hopkins

PEMCO guilty?

(Continued from page 1)

member provided and a review of the Revised Code of Washington (RCW) I concluded that the practice was discriminatory and referred him to the Office of the Insurance Commissioner, former 9th District Congressman Mike Kriedler, and encouraged him to file a complaint.

If PEMCO is raising its rates and separating the van from the conversion for insurance purposes, then what are the other insurance companies in Washington State doing? I need you to call me if you have a conversion van and tell me if your rates increased. I share the concerns our member has expressed: "If PEMCO can do it, the oth-

ers are not far behind especially if PEMCO prevails."

Moreover, will we see insurance companies separating the lift and other adaptive equipment from the vehicle even if the adaptation is built into the vehicle at the point of manufacture? Stay tuned to this subject in [Paralyzed Veterans of America's] newsletter and find out if the Office of the Insurance Commissioner agrees that PEMCO's practice is discriminatory or legal. Either answer still remains an issue of dramatic concern for our members.

Contact info for Mr Dreps:
616 SW 152nd Street
Burien, WA 98166

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



WHAT'S HAPPENING WITH ESBA?

Important highlights from March 2008 Board meeting

The Board of Directors unanimously authorized and directed President Joseph Nugent to complete the "Letter of Intent" to national SBA, indicating that it is the intent of ESBA to sign a Chapter Affiliation Agreement with SBA with the understanding that its future "service area" will only be Washington state and allowing two of its states (Montana and possibly Oregon) to become Support Groups under SBA with two of its states' members (Alaska and Idaho) staying with ESBA and handing over their service areas to SBA for administration.

The By-Laws may need to be revised, but the exact details of the revision are still unknown. Therefore any revisions are on hold until SBA issues the new Operations Manual. A discussion about changing the name of ESBA was tabled until the May Board meeting.

The 2nd annual ESBA summit is in the very early planning stages. So far the dates of August 8, 9 and 10 are under consideration.

Community Health Charities of Washington (CHCWA), which is tied with the Combined Federal Campaign, promotes workplace giving by employees to charitable organizations. ESBA completed an application to be included in these programs which could turn out to be a very significant source of future designated funds. The application is still pending approval. ESBA also registered with the State of Washington as a Charitable Organization.

In this and the next four newsletters, we will provide contact information for Independent Living Centers (ILCs) in our five state region. Each issue will focus on one state. For ILCs in Montana, turn to the last page of this newsletter!

Have you signed up for the electronic version of SBA's quarterly newsletter Insights? Visit www.spinabifidaassociation.org today to get your address on the email list!

Six ESBA members will attend national conference

SBA's national conference will take place June 22-25 in Tucson Arizona. Six members of ESBA plan to attend: Heather Logan, Patti Logan, Joe Nugent, Nancy Nugent, Naomi Nugent and Jill Pfankuch. These representatives will take advantage of the educational and networking opportunities available at the conference and return to us with plenty of information to share!

Proposed Sessions and Invited Speakers were recently announced (but remain subject to change):

- Spinal Deformities in Myelomeningocele with Lee Segal, MD
- Family, Friends, and Adjustments in Adolescents with Spina Bifida with Grayson Holmbeck, PhD
- Assistive Technology Tools for Adolescents and Adults with Nonverbal Learning Disorders with Sue Lin, MS
- Shopping for a Medical Home – It's More than Just Location, Location, Location with William Walker Jr., MD
- Tethered Cord with Robin Bowman, MD

Many more sessions are yet to be announced!

Visit www.sbaa.org for conference updates.

**ESBA membership renewals are due this month!
Please do not let your membership lapse.
Renew today by submitting this form.**

EVERGREEN SPINA BIFIDA ASSOCIATION

2008 MEMBERSHIP/CONSTITUENT APPLICATION FORM

Name: _____ Spouse's Name: _____

Street Address: _____

City: _____ State: _____ Zip: _____

Home Phone: _____

Email Address: _____

Person with Spina Bifida: _____ Date of Birth: _____

Total number in immediate family _____ State of affiliation: _____

Please send a donation of any size to help us reach out to those affected by Spina Bifida. Evergreen Spina Bifida Association will pay for membership in the Spina Bifida Association for its members.

How would you prefer to receive your newsletter?

A. Email only, B. Mail Only, or C. Both

Please complete this form and return it to:

Evergreen Spina Bifida Association (ESBA)

c/o Jonathan Tutt

2128 N. Pines Rd., Suite 17-2

Spokane, WA 99208

OR email to evergreensba@yahoo.com

No one will be denied membership for inability pay. If this form is completed and returned, you will be a full member of the Evergreen Spina Bifida Association.

If you have any comments or suggestions about the newsletter OR PREFER TO RECEIVE IT BY EMAIL please email Evergreensba@yahoo.com.

ELECTIONS SCHEDULED FOR WASHINGTON BOARD MEMBERS

There are still positions open for nominations to the Board of Directors for the soon-to-be-formed Washington state chapter. Vice-President, Secretary, and other membership slots are available. Please contact Brian Knowles, Board Chair, by emailing crazy5720003@yahoo.com. Now is the time to stand up and be counted for the future of Evergreen SBA.

**Thank you,
Your Board of Directors**



TREASURER'S REPORT: FUNDRAISING TIES TO MISSION GOALS

Evergreen Spina Bifida Association				
Income and Expense Report 1st Two Months 2007 and 2008				
		Jan-Feb 07	Jan-Feb 08	
Income				
Donations		\$ 387.00	\$ 5.00	
Interest		<u>\$ 322.17</u>	<u>\$ 295.73</u>	
Total Income		\$ 709.17	\$ 300.73	
Expenses				
Mission		\$ 620.55	\$ 911.04	90.74%
Admin		\$ 86.45	\$ 45.36	4.52%
Fund Raising		<u>\$ -</u>	<u>\$ 47.56</u>	4.74%
Total Expenses		\$ 707.00	\$ 1,003.96	100.00%
Net Income (Loss)		\$ 2.17	\$ (703.23)	

*by Jonathan A Tutt,
Treasurer*

We continually spend more than we receive, but the answer is not to decrease our spending, lest we risk not meeting our mission goals, but to increase our income by increasing our fundraising efforts. We make good use of the money we receive by spending over 90% of our expenses on our mission.

	Jan - Feb 08	Jan - Feb 07	% Change
Ordinary Income/Expense			
Income			
Donations Received	5.00	387.00	-98.71%
Total Income	<u>5.00</u>	<u>387.00</u>	<u>-98.71%</u>
Expense			
Mission Program Expenses	814.88	507.17	60.67%
Administrative Expenses	45.36	86.45	-47.53%
Fund Raising Expenses	47.56	0.00	100.0%
Total Expense	<u>907.80</u>	<u>593.62</u>	<u>52.93%</u>
Net Ordinary Income	<u>-902.80</u>	<u>-206.62</u>	<u>336.94%</u>
Other Income/Expense			
Other Income			
Interest Income	295.73	322.17	-8.21%
Total Other Income	<u>295.73</u>	<u>322.17</u>	<u>-8.21%</u>
Other Expense			
Depreciation Expense	96.16	113.38	-15.19%
Total Other Expense	<u>96.16</u>	<u>113.38</u>	<u>-15.19%</u>
Net Other Income	<u>199.57</u>	<u>208.79</u>	<u>-4.42%</u>
Net Income	<u>-703.23</u>	<u>2.17</u>	<u>-32,506.91%</u>

NOTES ABOUT THE BUDGET: The budget committee did meet and came up with a recommended budget for 2008. The two largest items in the 2008 budget were the \$27,950 income listed as "Revenue Sharing from National" and the \$25,000 expense item "Minimum Requirements Institution." However the work has proven to be futile, due to subsequent developments: the fact that ESBA will not need to go through the credentialing process until July; and national's new stance on revenue sharing.

MOTHER ADVOCATES FOR DAUGHTER'S DAYCARE

by Heather Logan



My mother told me the Day Care story and showed me our pictures in the newspaper. When I was in kindergarten, I went to a school across town because that was the best school for kids with special needs like mine. In order to go to that school, we had a daycare close to it and I took the Dial-a-Lift bus every day. I liked my Daycare and the person who ran it, Nancy Vincent. One day Nancy decided to get insurance for her Daycare. When she filled out the paperwork, she proudly said "yes" when they asked if she had any children there with special needs and told about me.

Nancy was denied the insurance if I was there! My mom had to get another Daycare. (We found one next door so I could still go to that school.) Then my mom became my advocate and started calling everyone she could to find help with this situation as she knew it wasn't fair.

Finally, my mom called our local paper, The Olympian. She wrote a letter to the insurance company, too, telling it that this was not fair. The Olympian reporter came out to our house and took pictures of my mom and me and ran an article about it. Then the insurance company changed its mind and let me go back to Nancy Vincent's Day Care.

Retrieved March 29, 2008 from www.irs.gov

Starting in May, the Treasury will begin sending economic stimulus payments to more than 130 million households. To receive a payment, taxpayers must have a valid Social Security number, \$3,000 of income and file a 2007 federal tax return. IRS will take care of the rest. Eligible people will receive up to \$600 (\$1,200 for married couples), and parents will receive an additional \$300 for each eligible child younger than 17. Millions of retirees, disabled veterans and low-wage workers who usually are exempt from filing a tax return must do so this year in order to receive a stimulus payment. But there are more details to know about!

Visit the Economic Stimulus Payments Information Center at <http://www.irs.gov/newsroom/article/0,,id=177937,00.html> or call toll-free 800-829-1040/ 800-829-4059 (TDD).



SPRING ATHLETIC PROGRAMS GEARING UP

Northwest Adaptive Sports provides athletic opportunities for people with disabilities in western Washington and northern Oregon. Sport seasons run year round. Call 206-726-3984 or visit www.northwestadaptivesports.org/.

Outdoors for All provides outdoor recreation for people with disabilities. Activities occur throughout the greater Puget Sound area and in a few other parts of the state. Spring brochures are now available. Call 206-838-6030 x200 or visit www.outdoorsforall.org.

The Evolution of AT (Assistive Technology): A Long Night's Journey into Day

Reprinted from the March 2008 newsletter of The Family Center on Technology and Disability

In the beginning the technology had no defining name. Its pioneers included earnest engineers aiming to help their own kids with disabilities or their friends' children, or a neighbor or a school. Then, in 1982, a writer specializing in this emerging technology, while researching an article he was preparing for the Washington Post, tried to conjure an evocative name for what he was describing. "The story was about a blind user of a talking terminal. I began to jot down possible names for the technology, but I couldn't pronounce them," recalls the writer, John M. Williams a lifelong stutterer. "All the words were associated with 'aids' or 'helps.' Then I arrived at the word 'assists.' I looked at that word on my writing pad and said to myself, 'Yes, that's what the technology does, it assists. But I couldn't pronounce the various forms of 'assists' - until I came to assistive technology. That was a term I could pronounce. I used the term in the story and the editor let it go by.'" Soon, he remembers, friends and colleagues began telling him how much they liked the name assistive technology. "They said it was unique, accurate and memorable."

Powered by federal and state disabilities legislation, the concept of "assistive technology" has evolved with the technology revolution driving the information age. Today, in its high-tech iteration, it is as sophisticated and effective as any technology in any category. In its no- or low-tech version it is simple yet effective. This month, we are pleased to welcome John M. Williams, a seasoned AT writer and user of assistive technology. Those, like John Williams, who have witnessed AT's evolution and experienced AT's benefits and growing acceptance continue to marvel at the road traveled from darkness into light. This issue takes a look back at AT's evolution and offers a glimpse of what is to come.

To read the full story go to <http://www.fctd.info/resources/newsletters/index.php>.

Read the rest of the article for an interview with John M Williams, veteran AT commentator and longtime AT user

TELL CONGRESS TO SUPPORT INCREASED FUNDING FOR THE NAT'L SPINA BIFIDA PROGRAM

from Cindy Brownstein, SBA,
sbaa@sbaa.org

The Spina Bifida Congressional Caucus Co-Chairs, Representatives Bart Stupak (D-MI) and Chris Smith (R-NJ), have joined together again this year to lead the charge to boost funding for the National Spina Bifida Program. Representatives Stupak and Smith currently are circulating a "Dear Colleague" letter urging their fellow Representatives to join them in sending correspondence to their colleagues who determine federal funding, asking that they provide \$7 million to the National Spina Bifida Program in FY 2009. The more signatories on the letter the greater the impact it will have.

BACKGROUND: The National Spina Bifida Program supports critical programs, research, and services for those who live with Spina Bifida. Since it was created, the Program has done great work to improve the quality of life for those living with Spina Bifida.

THE PROBLEM: In order for the National

Spina Bifida Program to continue its vital work, funding must be increased to \$7 million in FY 2009.

We need your help to secure as many signatories on the Stupak-Smith "Dear Colleague" letter as possible. Although signatures were collected only until March 14th, your Representative still needs to hear from you today about the importance of increased funding for the National Spina Bifida Program. **Act Now! SEND AN E-MAIL TODAY:** Please take a few minutes to send an email to your Representative asking if he/she signed to the Stupak-Smith letter and show support for the Spina Bifida Community. Your emails to elected officials do make a difference!! Send your email today!

MAKE A PHONE CALL: Learn how to make an effective phone call to your Members of Congress. Your help can improve the quality of health care provided to Americans with Spina Bifida. Make your voice heard! Your voice can make a difference. **Act Now!**



HELP REPRESENT ESBA AT A COMMUNITY EVENT

We have an opportunity to participate in the Auburn Fourth of July Event at Les Gove Park from 11:00 AM-4:00 PM. This would be a perfect opportunity for us to put ourselves out in the community and tell folks what Spina Bifida is and what we do. I would like see all Cluster Leaders to participate as I will need the help from anyone who can. I feel like we have this opportunity and we cannot pass it up! The cost of the booth is \$10.

Brian Knowles, ESBA Board Chair



Would you be willing to share your experiences with others?

Northwest Adaptive Sports received a request for some conversation about the Mitrofanoff surgery. There is a young teenager girl thinking about having this surgery. If you have had experience with this procedure, please share your pros and cons., including any Ace experiences as well.

This is a good way to start hearing each other's stories. To join the conversation, email info@northwestadaptivesports.org, the ESBA Seattle cluster at seattlespinabifidagroup@hotmail.com, or the ESBA Washington listserv at ESBA_WA@yahoogroups.com



Chapter and Board Members Contact Information

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Janet Davis-Board Member

purpleprincessjanet@yahoo.com

425-514-3448(H)



ESBA's brochure has undergone a makeover! A large number of the new brochures has been printed. Help us distribute the brochures far and wide to increase awareness about ESBA and its mission. Contact ESBA to get your bundle today!

SOUTH KING COUNTY CLUSTER MEETING
APRIL 8 2008 7:00-8:30 pm
ZION LUTHERAN CHURCH 1350 17TH ST SE AUBURN WA



The ESBA South King County Cluster will hold its monthly meetings every second Tuesday at Zion Lutheran Church 7:00-8:30pm.

Those with Spina Bifida and their families, any professionals or others interested in learning about Spina Bifida are invited to attend.

FOR MORE INFO PLEASE CONTACT Brian Clayton Knowles
 253-887-0888 CRAZY5720003@YAHOO.COM



GET INVOLVED WITH YOUR CLUSTER TODAY!

City/State	Leader Name	Contact Phone
Portland OR	Gina Schuermyer	503-761-8193
	James Haxby	503-414-9220
Helena MT	Joe Nugent	406-458-9549
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
Salem OR	Bill & Jill Pfankuch	503-362-8062
Spokane WA	Ed Kennedy	509-465-0676
South King County WA	Brian Knowles	253-887-0888
Seattle WA	Nicole Anderson	303-877-5083
	Alex Bugni	206-706-5665
	Jason Lane	206-363-3726
Kitsap WA	Dave Lewallan	360-871-5139
	Rebekah Uhtoff	360-782-0467
Olympia WA	Heather Logan	360-888-0782
	Patti Logan	360-888-7701
Leavenworth WA	Ed Baroch	509-548-5697
Idaho	TBA	TBA
Alaska	Brynn Ploetz	907-490-6919
	Honnen McLeod	907-688-8456
Center for Independence	Leslie Carey	253-582-1253
Spanish	Anthony Williams	253-588-4411

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

EVERGREEN SPINA BIFIDA ASSOCIATION
SERVING WASHINGTON, OREGON, IDAHO, MONTANA
& ALASKA

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 Evergreen Spina Bifida Association 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

For a variety of Independent Living resources, visit Independent Living Research Utilization at <http://ilru.org>


Evergreen Spina Bifida
Association



CONTACT INFO FOR MONTANA INDEPENDENT LIVING CENTERS

Mike Hermanson, SILC Liaison

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Helena MT 59604
406-444-4175/877-296-1197
MHermanson@mt.gov

MT Independent Living Project

Amy Caliendo, acaliendo@milp.us
626 Ferguson Ave Ste 1 Office C
Bozeman MT 59718
406-522-7300

North Central IL Services Inc

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1120 25th Ave NE
Black Eagle MT 59414
800-823-6245 (TTY too)

North Central IL Services (branch)

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406-228-2075 (TTY too)

Carol Lambert, SILC Chair

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