



June 1 2007

Evergreen Spina Bifida Association Newsletter

NEW PRESIDENT REMINDS US OF CHANGE, MISSION

by Joe Nugent, ESBA President

I am going to start off with a few announcements:

1. SBA 35th Annual Conference will be June 22-25, 2008 at Tucson Arizona. We should start planning and saving now if you want to attend.
2. "Help Wanted." Due to new Federal Rules about all family members serving on Boards or as Officers together, our Secretary, Nancy Nugent, will be stepping down by June 30, 2008. We need to find a replacement and have him or her train with Nancy before she has to leave her position.

I will let you know now that change is coming. The changes will be happening over the next year to three years with realignments, recommendations, re-

structuring, and reorganization from the National Board and staff all the way down to the Chapters, the smallest Support Group, and Individual members in SBA.

What all this means is that the National Board, National staff, Chapters, Support groups, and individual members who are going to be part of SBA will be doing the realigning of Service areas for Chapters and Support groups. The restructuring of Chapters and Support groups is to do the work of SBA and be uniform in doing this, reaching all people with Spina Bifida and those who are affected by Spina Bifida as well as women of child-bearing age.

No matter what changes happen, we

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Brownback, Kennedy Reintroduce Pre-natally and Post-natally Diagnosed Conditions Awareness Act

7/18/2007 press release from Senator Sam Brownback

WASHINGTON - U.S. Senators Sam Brownback (R-KS) and Edward Kennedy (D-MA) today reintroduced the Pre-natally and Post-natally Diagnosed Conditions Awareness Act, legislation which would require that families who receive a diagnosis of Down syndrome or any other condition, pre-natally or up until a year after birth, will be given up-to-date information about the nature of the condition and connection with support services and networks that could offer assistance.

"We as a society must offer as much

protection as we can to 'the least of these,'" said Brownback. "When a mother receives the news that her unborn child may be born with a disability, she should be supplied with current and reliable information about the many options available for caring for children with disabilities."

The Pre-natally and Post-natally Diagnosed Conditions Awareness Act would provide for the expansion and further development of a national clearinghouse on information for parents of children with disabilities, so that the clearinghouse would be better equipped to

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

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Newsletter Editor
Celeste McCormick

STILL TRUE TODAY:

Spina Bifida birth rates are not reported by the US Census bureau in Alaska, Idaho, Montana, Oregon and Washington. Source: <http://www.census.gov>, 2/2007

GETTING TO KNOW YOU: THE PFANKUCH FAMILY

by Diana M Tutt

Please meet the Pfankuch Family, members of ESBA. I recently spoke with Bill and Jill so we could all get to know them a little through this column. Bill and Jill are from Fullerton, CA, now residing in Salem, OR. They have a daughter, Emily who is 18 months old. Rounding out the family is Ashley, their niece who is 14. The Pfankuch family has belonged to ESBA for about a year now. Emily was born with Spina Bifida. Bill and Jill are very involved parents, always seeking the best treatments and opportunities for Emily. They get a lot of questions and comments about the "Star Car" Emily uses, which Jill describes as a miniature wheelchair. This gives them the opening to inform and educate others on Spina Bifida. Emily is an active child, motoring around the house, getting into cupboards and exploring. She enjoys coloring with markers. Watermelon is one of her favorite foods. Bill and Jill both expressed Emily is a very sensitive child. They can see her having a future in a nurturing profession. In talking with Bill, he expressed a concern regarding families with special needs children. Unfortunately, some fathers face difficulties in maintaining a family connection. Bill has a special calling to minister to young fathers, encouraging their full participation in the family knowing that a father's place is so important to the well-being of the family. ESBA is blessed to have the Pfankuch Family in our association.

If you have any comments or suggestions about the newsletter, please send them to Evergreensba@yahoo.com.

Harold "Hal" W. Pote , Founder, Spina Bifida Foundation , passes away

by Tanya M. Coogan, CTRS, Director of Chapter Development, SBA

Harold "Hal" W. Pote, the founder of the Spina Bifida Foundation and president and CEO of American Financial Realty Trust passed away suddenly on June 26 2007 while vacationing with his wife in Turkey. "We are very saddened by the sudden loss of Hal Pote," says Cindy Brownstein, CEO,

Spina Bifida Foundation. "Hal was a man of great vision and extraordinary compassion who was deeply committed to moving Spina Bifida research, awareness, and financial support forward. Inspired by the challenges of his nephew Gregory who has Spina Bifida, Hal was exemplary in his leadership of the Spina Bifida community. Our thoughts and prayers go out to his family. "

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!

HELP ESBA UPGRADE THE WEBSITE—IT IS YOUR RESOURCE TOO!

ESBA's website not only presents the organization to the rest of the world but can link you to other members, important projects and news about ESBA! The website needs a serious overhaul and now is the time to get your suggestions on the list! Send any ideas to Annette Zweig-Donham at az@w-link.net or call ESBA at 253-589-3700 or 888-289-3702.

TWO VOLUNTEER POSITIONS ARE NOW AVAILABLE IN ESBA LEADERSHIP: SECRETARY & LIBRARIAN

WOULD YOU RATHER RECEIVE THE ESBA NEWSLETTER BY EMAIL?

NOT ONLY WILL YOU GET THE NEWSLETTER FASTER AND IN FULL COLOR BUT YOU WILL HELP ESBA SAVE VALUABLE TIME AND MONEY!

To get the newsletter in PDF format via email, email to evergreensba@yahoo.com .

ESBA BUDGET IN CRISIS

The ESBA budget has been negatively affected by the following:

- **Net income has decreased by one-third**
- **Program costs and administrative expenses continue to rise**

At the current rate of spending, ESBA will not be viable long term. However, successful fundraising can save ESBA!

Please join these esteemed members in forming the ESBA Fundraising Committee. A chairperson has not yet been elected. If you possess marketing, fundraising or networking skills (or even if you just think you would be a good fit) please join the committee!

Current members include Brian Knowles, Patti Logan, Nancy Nugent and Bill Pfankuch. The committee seeks a representative from each state.

SHARE YOUR TALENTS WITH ESBA TODAY—WE NEED YOU!

PRESIDENT'S MESSAGE, continued from page 1

must be positive and proactive about the changes. We must adopt the SBA mission and the two visions listed below:

SBA Mission: "To promote the prevention of Spina Bifida and to enhance the lives of all affected."

SBA Internal Vision: "SBA is a diverse, inclusive, amply resourced, voluntary health agency that is a model of expertise, and efficiency reaching 100% of its constituency with the highest quality programs. We speak with a single, global voice on behalf of the Spina Bifida Community and all women of child-bearing age."

SBA External Vision: "We envision a world in which no babies are born with Spina Bifida. People living with Spina Bifida thrive in a barrier-free world that offers ready access to an array of effective treatment options and uniformly excellent medical care. Their individual life choices are not influenced by Spina Bifida and all experience rich and personally fulfilling lives."

AWARENESS ACT, continued from page 1

assist parents whose children have recently been pre- or post-natally diagnosed. The bill also provides for the expansion and further development of national and local peer-support programs. The bill also calls for the creation of a national registry of families willing to adopt children with pre- or post-natally diagnosed conditions.

"One of the hardest moments in the life of an expectant mother is when she receives news that she is going to have a child with special needs," said Kennedy. "Access to the best support and information about the condition, and the quality of life for a child born with that condition, can make all the difference to a woman trying to make an informed and difficult decision. I believe this kind of support is a vital element to strengthening a true culture of life in America."

Currently, 90 percent of children pre-natally diagnosed with Down syndrome are aborted. That percentage is similar for children pre-natally diagnosed with other conditions such as spina bifida, cystic fibrosis, and dwarfism.

Brownback is a member of the Senate Judiciary and Appropriations Committees.

SEXUALITY ISSUES FOR PEOPLE WITH SPINA BIFIDA

SEXUALITY TRAINING FOR AND LEARNING BY THE CHILD WITHOUT A DISABILITY

An important, but frequently overlooked, aspect of transition and a necessary precursor for independent toilet training is the child's ability to undress and dress. These two skills are learned gradually during late infancy and early childhood. The removal of clothing also encourages autonomy. However, unless undressing occurs in the proper social circumstances, it leads to condemnation rather than approval. Parents teach their young children not to expose their perineum – frequently called their "private parts" – in public, particularly in the presence of the opposite sex. During this developmental period, infants and children fondle their genitalia and parents tell them that this should not be done; at least, the child soon learns not to do so in the presence of others. Masturbation is a normal aspect of development. The social disapproval of masturbation should be explained in terms appropriate for the child's age but should not include threats of bodily harm. Young children of three to four years of age may also ask questions about where babies come from: their interest is usually brief and superficial. Simple explanations will both correctly inform the children and end their questioning. They observe that mother develops a large abdomen, comes home from the hospital or comes out of a home birthing room with a great reduction in her abdominal girth and a baby. Stories such as a stork delivering the baby are not appropriate.

Children at this age also notice differences between boys and girls, men and women. Some will satisfy this natural curiosity by comparing their "private parts" to other children of both sexes. Children with disabilities are no different in their curiosity or methods of exploration.

For younger children, the explanations should be accurate but superficial. Explanations for older children should also inform the children about their future sexual potential

This is the last of several articles excerpted from the soon-to-be published work of David B. Shurtleff, MD, Carole Sobkowiak, FCSP, SRP, Society for Research into Hydrocephalus and Spina Bifida, and William Walker, MD, University of Washington. A complete bibliography is available upon request.

SEXUALITY TRAINING FOR THE INFANT OR EARLY TODDLER WITH SPINA BIFIDA

When normal early childhood genital exploration amongst peers is postponed to later childhood, there can be severe social consequences. We have knowledge of 3 late childhood and early teenage boys convicted of and incarcerated for sexual molestation after engaging in curiosity driven comparison of their genitalia with younger children, despite our testimony. A fourth was successfully exonerated after embarrassing social criminal investigations. A female with spina

bifida was reportedly accused of indecent exposure for demonstrating her clean intermittent catheterization technique to some boys. Playing nude in front of a mirror is also effective in teaching the difference between boys and girls. Infants and young children enjoy learning about themselves from a mirror and exploring their body parts. We recommend that caretakers of the child with spina bifida consider directing the child's attention to the genitalia seen in the mirror, explaining the difference between girls and boys.

SEXUALITY TRAINING FOR PRESCHOOL AND EARLY SCHOOL YEARS FOR THE CHILD WITH SPINA BIFIDA

The suggestions in the sexuality training section for infants and early toddler with spina bifida also apply to children in their preschool and early school years. At these ages, parents and caregivers can more easily explain sex differences and appropriate behaviors with language that the child can understand. Children at these ages are

more likely to ask questions about sex and child-birth. For younger children, the explanations should be accurate but superficial. Explanations for older children should also inform the children about their future sexual potential, particularly the recurrence risk for their birth defect in their own children. The aspects of privacy and protection of their genitals have been covered in the previous section on toileting.

SEXUALITY ISSUES FOR PEOPLE WITH SPINDA BIFIDA

SEXUALITY FOR THE LATE CHILDHOOD AND PRE-ADOLESCENT CHILD WITH SPINA BIFIDA

Several independent activities are acquired by children in the myelomeningocele group prior to 12 years of age. The most notable of these skills are personal toileting, hygiene for teeth, hair and nails; personal choices when shopping; being on time for activities outside the home; knowing their own telephone number; understanding time as measured by a clock; monitoring their spending and remembering special dates such as birthdays. Data for more intimate situations such as first date of sexual intercourse, on the other hand, are not well known.

Children born with spina bifida, like their same age peers without disabilities, develop an interest in their ability to develop intimate relationships and procreate. Their lack of mobility and socially appropriate stool and urine hygiene potentially interfere with achieving these goals. We, therefore, recommend that teachers and medical staff bring these issues surrounding normal development and sexuality to the attention of parents of children with disabilities. When the child shows evidence of entering into puberty, we rec-

ommend discussing with them all the aspects of sexuality pertinent to any teenager. Open communication between parent and child is a psychosocial independent variable that predicts better adjustment at this age. These discussions should include the medical reasons for not participating in indiscriminate sexual intercourse to avoid pregnancy for the girl, responsibility for a child born out of wedlock for the boy and venereal diseases for both. For girls we also discuss the complications of pregnancy, the increased frequency of urinary tract problems and the possibility of developing herniated vertebral discs and need for cesarean section birth. In addition, we discuss recurrence risk of their disability in the affected child's children, prevention, prenatal diagnosis, and prognosis for various types and degrees of neural tube defects, particularly anencephaly and different levels of myelomeningocele, as discussed above.

They should also be taught to report to their like-sexed parent any touching of their genitals by others than their like-sexed caretakers. Girls with spina bifida are at risk for seduction or rape if they lack understanding about sexuality.

VISIT FREEDOM SHORES FULLY ACCESSIBLE MEXICAN RESORT!

If you were ever disappointed on vacation because the hotel/resort staff just did not have time to bother with you, then you come to Freedom Shores! Our staff knows that the only reason they are here is to care for you & make you happy!



Photo courtesy of
www.isla-aguada.com

Freedom Shores is a newly constructed, universally designed resort complex on the Laguna de Terminos on the Gulf of Mexico. This beachfront luxurious island getaway was built by a quadriplegic who knows what the word accessibility really means! Bill & Thelma Bussear always dreamed of opening a place for wheelchair veterans in beautiful Mexico. In December of 2005, their dream came true! They renovated 2 1/2 acres of beachfront property, and created a wheelchair accessible resort in Isla Aguada, Campeche, Mexico with 300 feet of gorgeous beach on the Laguna de Terminos.

Freedom Shores is located 25 miles from the Ciudad Del Carmen, Campeche airport & is only a two-hour flight from Houston. Handicapped transportation is available to and from the airport for \$50. The resort has a gorgeous, state-of-the-art restaurant featuring Jesus Damas, an amazing chef who offers a wide variety of American, Mexican, Italian, Chinese and other epicurian delights.

RESERVATIONS OR INQUIRIES: Contact William & Thelma Bussear
FROM THE USA - Tel: 951-801-2716 - Cell: 951-218-2716 - Fax: 951-742-8326
Email: Bill@Freedom-Shores.com Website: www.isla-aguada.com

Reach The Summit

Evergreen Spina Bifida Association
Awareness Summit Conference
August 17-19, 2007
The Comfort Inn, Federal Way, Washington
31622 Pacific Highway South



Registration cost for the Summit is \$30 per person. We have a family rate available of \$60 for members of an immediate family (parents and dependent children under 18). Children under 10 participate for free. This fee includes a catered lunch and dinner for August 18 and should be paid with your registration. No one will be excluded because of an inability to pay!

Hi Folks, Reach for THE SUMMIT!!! Bring your friends.

This is Patti Logan, your Past President, Cluster Developer, and....most importantly at this time, Event Organizer for the 2007 Awareness Summit.

I know many of you are already planning to come. We have passed our early registration date of July 18 and enough people have signed up to make it a success.

This Summit has been designed for you, our members. We will have lots of info about ESBA that you will want to know. A brief look at the program will show you though that ANYONE with an interest in spina bifida will learn a lot by attending.

Have I convinced you yet?

I can imagine some of your questions: What does the Summit have to offer a Cluster Leader? What if your group hasn't started up yet--should you come? What if you don't have the money to pay for registration (\$30) and a hotel room (\$79)? What benefits can I get from attending?

If \$\$\$ is a problem, we have thought of that. ESBA will pay for the \$30 registration fee for anyone who is willing to work for us. If you need that \$30 paid by ESBA, just let me know. I'll help you get it. Besides that, the Board voted \$50 for members to help with transportation to the Summit. Again, that money is for you if you need it. So, don't let finances stand in the way of your participation.

I want to see you all at the Summit. Most of you are dear friends of mine as well as co-workers and volunteers for ESBA. This will be a reunion for us. Also, please invite and bring ANYONE affected by spina bifida who wants to come. This is for non-members, potential Cluster members, ANYONE who wants to come.

Questions, anyone? Just ask your friendly Cluster Leader (me), and I'll see if I have the answer. Just reply to this message or call me at 360-481-3171 anytime.

SUMMIT HIGHLIGHTS:

Meet the new ESBA President Joe Nugent from Montana

Meet the new Vice President Bill Pfankuch from Oregon

Hear a rep from SBA in Washington DC talk about the future

Speak with pediatricians Dr Shurtleff and Dr Beth Ellen Davis

Take FREE lessons about using computers for meetings from home

Get a computer for anyone needing one

Attend the Annual Meeting and see what happens in those Board Meetings

Watch a good Cluster Meeting in action

Meet others from our five states who are affected by Spina Bifida

Network with your peers in other clusters

Talk with experts in service dogs, affordable housing and social security

**RESERVATIONS
ACCEPTED UNTIL
AUGUST 17
EVERYONE IS
INVITED!**



GET TO KNOW A COUPLE OF THE SUMMIT SPEAKERS

Donald C Martin Ph.D.

My academic career displays a fine sense of indecision. My initial majors were electrical, mechanical and industrial engineering. ... When financial problems forced me to drop out of college, I took a low level job with RCA Service Co. at Cape Canaveral in Missile Range Data reduction. I worked up to the job title of mathematician at RCA [and] went back to college. By the time I was forced to graduate I happened to be in mathematics. ... A chance remark caused me to start graduate studies in statistics ... My initial academic appointments were in Biomathematics and Engineering Research at North Carolina State University. Remember: I dropped out of engineering. To avoid burnout from 60+ hour weeks of research and technology my wife and I started breeding and showing Old English Sheepdogs. I then moved to the University of Washington in Biostatistics with an Adjoint appointment in Psychiatry and Behavioral Sciences. Remember: I dropped out of psychology. I have approximately 100 scientific publications and hands on experimental experience. I retired from UW in 1996 suffering from academic burn out and worked part time in Health Services Research at the Veterans Administration.

I have bred or finished 23 AKC champions ... My Old English sheepdog kennel is listed in the top 100 champion producing kennels in the history of the breed. Of course I use an Old English sheepdog as my service dog. ... My wife and I spend 10 days a year visiting schools and explaining about service dogs

Ed Kennedy

50 years old, married to Theresa, 2 step sons (Patrick and T.J.).

Career: I have been working for the Coalition of Responsible Disabled (CORD) an Independent Living Center in Spokane, Washington for the past 4 years, where I assist people with various disabilities by helping them in reaching their personal, professional, and social goals through advocacy, independent living skills training, peer support or information and referral.

Past President of Evergreen Spina Bifida Association – a 5 state organization whose mission is to promote the well being, education, and socialization of all people affected by Spina Bifida and foster public awareness of this birth defect.

Personal Interests: I enjoy fishing (although I don't do it enough), photography, and playing cards.

Call ESBA at 253-589-3700 or 888-289-3702 for a registration form and mail it to Evergreen Spina Bifida Association, C/O Jon Tutt, 2128 North Pines Rd Suite 17-2, Spokane WA 99208. If you need assistance meeting the financial obligations, send an email to Jon_Tutt@msn.com.

ABOUT THE SUMMIT LOCATION— FEDERAL WAY COMFORT INN

Located at 31622 Pacific Highway South ,Federal Way WA 98003, this hotel is neat, clean, comfortable and friendly. Amenities include free in-room coffee, free Continental breakfasts, free high speed internet, non-smoking rooms, guest laundry, whirlpool baths, fridges and microwaves, as well as a heated indoor pool, spa & fitness rooms. You will find it accessible, affordable and close to Top Foods, Sea Tac shopping, King County Aquatic Center, Wild Waves/Enchanted Village & Celebration Park .

DIRECTIONS:

- Get on Interstate 5 and head North or South (as appropriate from your location) toward Federal Way midway between Seattle and Tacoma
- Exit the freeway at Exit 143 (South 320th Street) and head West to the Pacific Highway South/US 99
- Turn North (right) toward Seattle to the Comfort Inn
- Website with hotel info & map:

<http://calhotels.us/map.php/137943-comfort-inn-federal-way-washington/>

ESBA CLUSTERS SPEND FUN IN THE SUN



Last month the Kitsap Cluster held its Annual Picnic and enjoyed 24 attendees—its biggest event yet! The cluster is FINALLY beginning to grow after 2 and a half years.



In July the Spokane Cluster met at Jump Off Joe Lake for its annual summer picnic. A cool swim helped fend off the 90+ degree heat but left many with swimmer's itch!

Calling
all
Olympians!

Hi Folks,

Olympia ESBA members, are we interested in having a table at the Combined Fund Drive Fair? Would anyone like to join me in September at a table at the Capital Campus Fair and tell people about ESBA and spina bifida? I can get funds and brochures. I'd like to have at least one mate at the table.

I'm asking the members of our Evergreen Spina Bifida Association Olympia Cluster with this message, but I'm well aware that this is my advertising list for the Olympia area. That means some of the rest of you work for other non-profits that might want a table for their own group. Please feel free to use the attached application for your own group. Together we make the difference, Patti

Coffee Talk with a Cluster Group Leader

Would you like to have a one on one chat with someone in a cluster group? I will host intimate gatherings & meetings throughout the year when able. If I cannot answer your question(s) I am sure I can find someone who can! I hope to leave no questions unanswered. Keep in contact with me or others within the group. If you would like to join me for coffee email at michele.hopkins@comast.net or 206-909-4186.



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 253-566-0944
Salem OR	Bill & Jill Pfankuch	503-362-8062
Spokane WA	Ed Kennedy	509-465-0676
	Susan Curalli	509-892-6757
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	Patti Logan	360-888-7701
Leavenworth WA	Ed Baroch	509-548-5697
Idaho	Pam Hoppmann	208-522-6206
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


Evergreen Spina Bifida
Association



PATRONIZE THESE RECOMMENDED WHEELCHAIR FITTERS

Jennifer Hastings, Pt, Phd, NCS at Maximum Mobility
Downtown Seattle, free parking
206-499-9704 maxmobility@comcast.net

Called "the most amazing person at both finding new chairs/seating systems and adapting what people have to work better for them."

Care Medical Equipment

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"... An excellent provider. They have a large well-trained staff and I have only heard good things about them."

A & H Medical

Renton, WA * 425-255-7083

www.ahstores.com/medical.html

Recommended for adults with Spina Bifida

"We were always very pleased with their service and they gave us a more personal touch than we found from some of the larger medical equipment providers. They are a much smaller service and it is very easy to get them out to make changes or address any problems."

Recommendations were shared on the ESBA_WA Yahoo Community.

**START PLANNING NOW FOR THE
2008 NATIONAL CONVENTION!**

The next National Convention is in Tucson AZ
June 22-25 2008 at the JW Marriott Starr Pass