



Evergreen Spina Bifida Association Newsletter

TOGETHER WE MAKE THE DIFFERENCE

by Ed Kennedy, ESBA President

Hi Everyone. I have a lot I want to share with you all so get ready and here we go. First, I want to thank everyone for being a part of ESBA. I just this past month was reminded again by a new Spokane cluster member why I, and we, are members of ESBA. People whose lives have been affected by spina bifida need and want to be associated with others who have walked down the path of this disability. That's the bottom line and I think we are doing a reasonably good job of reaching out to others affected by SB – But there is more work to be done.

And, that work is getting done! We are still pressing forward on putting together a

“summit” meeting to be held (we hope) sometime this coming fall. The summit will allow all our members to come together for a few days to hear speakers and mainly just get to talk to one another face to face and share our experiences. The summit has a ways to go to become a reality so if you are interested in being a part of this please contact myself, Brian Knowles or Patti Logan as soon as possible. We want and need you to help us make this happen! Lastly, I want to take this opportunity to say goodbye to you as President. It's been an honor being president of ESBA these past 2 years and I can honestly say that I truly wish I had more time (and energy) to com-

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MEET THE NEW MS WHEELCHAIR WASHINGTON 2007

Press Release

Sigrid Laegreid's life changed forever on December 26th, 1991, when she was run over by a drunk driver. She sustained a permanent spinal cord injury, which left her paralyzed from the mid-chest down for the rest of her life. Despite her paralysis, Sigrid has not let it slow her down, in fact she describes herself as adventurous, generous and goal oriented. Sigrid simply states, “In life, I always strive to do my best and not complain. I try to focus on my blessings and not worry about my limitations.” Sigrid has worked for Nordstrom's

since 1987 and received the “All Star” award in 1998 and again in 2004. She was also honored by Antioch University with a humanitarian award for her years of service at Teen Hope, as a founding Board Member and Fundraiser. Sigrid's community achievements



Sigrid Laegreid (photo credit unknown)

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EVERGREEN SPINA BIFIDA ASSOCIATION
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Celeste McCormick

STILL TRUE TODAY:

15 million Americans live in poverty despite living in homes headed by a fulltime worker.
Source: www.mattmilleronline.com

IN MEMORIAM: EDIE GILBERT, BELOVED FRIEND

by Diana M Tutt

It is with sadness we report the passing of Edie Gilbert, a member of ESBA from Kent, WA. Edie passed away at the age of 57 from multiple complications of diabetes.

Edie was a special friend of Amanda Henry, a member of ESBA. Although Edie did not have Spina Bifida, she joined ESBA in solidarity with our community and as a support for Amanda. They met at Pierce College in Puyallup, Washington where they were fellow students. Edie had plans to complete her education at the University of Washington with an eye towards being a college advisor.

Amanda fondly recalls Edie's great sense of humor and her ability to take a joke. They enjoyed sleepovers and hours of visiting. Edie provided the transportation for both she and Amanda to attend the Young Adults with Spina Bifida group in Lakewood WA. Edie will certainly be missed but remains in the hearts of those who knew her. We are grateful for her contribution to ESBA. Our condolences to Amanda and Edie's family.

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



ESBA VOLUNTEER OPPORTUNITIES

Desperately seeking Fundraising Committee Chairperson and members: This committee is critical for the viability of our organization and for meeting the new minimum requirements for chapter affiliation with the national SBA. To date, members of this committee include Patti Logan, Nancy Nugent, Brian Knowles and Bill Pfankuch. If you think that your time and talent would be an asset to this committee, please contact ESBA today to join. Any volunteer is welcome!

Person needed to help with expos, disability seminars and the like: ESBA needs the help of our members in various Washington areas such as Tacoma, Olympia and Sumner to help man a table at various seminars and expos. The Everett/Eastside cluster is helping with any expos and seminars in Seattle, the Eastside and surrounding areas. With your help, we can cover more events! If you are interested please let Michele Hopkins know - call 206-909-4186 or email michele.hopkins@comcast.net. Your help is greatly appreciated!

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mit to this great organization. We've come along way and I look forward to more good things to come. Upon my vacating the President's position, Joe Nugent will become the new ESBA President (this is because I am leaving with one year left of my term). I know

Joe has the commitment and enthusiasm to bring about good things for ESBA in the future.

Lastly, I'd like to say that what Patti Logan has said for so many years is still true today - "Together - we make the difference." How true that is Patti!

HOT OFF THE PRESS

ESBA's brochure has undergone a makeover! A large number of the new brochures has been printed. We hope to distribute the brochures far and wide to increase awareness about ESBA and its mission. If you have ideas about events or locations where our brochures would be welcome, please contact ESBA to receive a bundle!

Elections scheduled for June

Ballots will be sent by US mail to members who do not have email addresses and via email to those who do.

Board of Directors candidates (four open seats):

Gloria Olson James Haxby Patti Logan Janet Davis

Officer candidate for Vice President:

Bill Pfankuch

Note: Ed Kennedy will step down as President effective 7/1/07. Joe Nugent will move up from Vice President to finish the balance of Ed's term (one year to the end of June 2008) until the next election.

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.

ADOPT-A-GHOST™



The Adopt-A-Ghost™ program is a new major source of funding for the programs and services offered through ESBA. By participating, you can help ESBA at no cost to you!

PROGRAM HIGHLIGHTS:

- Paper Ghosts are “adopted” for \$1.00.
- The Ghosts may be used to decorate an area or kept by the “adopter.”
- There is NO COST to participate.
- Program typically runs from October 1 – October 31; however Ghosts may be adopted prior to October 1.
- The money from the Ghost Adoptions is sent to ESBA at the end of October.
- Program materials, instructions, paper ghosts and posters are shipped to all establishments and individuals from ESBA prior to October 1st or earlier upon request.
- Incentives are put into place for employees, group challenges or individuals.
- The Adopt-a-Ghost program helps raise awareness throughout our community about spina bifida, how to possibly prevent this birth defect and the challenges these children and individuals face.

The proceeds from Adopt-a-Ghost support the programs and services provided by the ESBA. To learn more details about the program and find out how you can help, contact ESBA today!



Need a computer? ESBA is finalizing plans to place rebuilt computers in members' homes. An organization in Olympia would donate the computers and ESBA would ship them anywhere in our five states. The goal is to reduce the isolation of any members who currently cannot afford a computer.

Watch for details in the next newsletter.

SEXUALITY ISSUES FOR PEOPLE WITH SPINDA BIFIDA

INTRODUCTION

Forty years ago, one of us learned an important lesson in the development of a child with a disability: 6 to 9 year old patients with myelomeningocele did not know whether they were boys or girls. A subsequent study demonstrated that parents were embarrassed to ask whether their infant or young child could become a competent reproductive human being! This lack of information is in stark contrast to what is actually known. Adult patients with myelomeningocele are able to reproduce. A patient's potential sexuality can be discussed in a straightforward manner. For parents of children initially treated elsewhere, their understanding should be clarified and discussion. If their understanding of the issue will not be clarified unless their knowledge is improved. Therefore, we discuss the issue regardless of age, of their fetus' or child's reproductive potential.

Parents were embarrassed to ask whether their infant or young child could become a competent reproductive human being.

of a particular concept prior to any further discussion. If the understanding is correct, require further discussion. If the understanding is out of date, discuss with new families, the parents' knowledge of their child's sexuality and re-

This is the fifth 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.

Females with the various forms of Spina Bifida and normal reproductive organs will usually experience "orgasm" and are usually fertile and are capable of bearing children. Exceptions to this general statement are children with Exstrophy of the Cloaca and the rare patient with additional malformations of the reproductive organs. Males have a much more complex genitourinary system which depends on an intact autonomic nervous system. Males can have erections that are due to urinary bladder base stimulation, erotic thoughts or noxious stimulation of the thigh, perineum, pubic area or penis. They can be fertile if their prostate, epididymus and at least one testicle are not malformed and have not been destroyed by infection. Ejaculation may be retrograde, forward or non-existent; ejaculation is not necessary for fertility. Some males will ooze prostatic fluid containing sperm during the sex act, successfully impregnating their partner without ejacu-

lation. Retrograde ejaculation can be reversed either by adding an artificial sphincter proximal to the prostate or by closing the urinary bladder neck and adding a catheterizable stoma. For the 75 to 80% of males with infertility, there is a 75 to 80% probability that needle aspiration of the testes can recover sperm or the DNA of its precursor cells. These cells or DNA can be used to fertilize his partner's egg via intracytoplasmic sperm injection. The fourth and last portion of the male sex act is potency. This term is used to include the ability to satisfy a sex partner, not just satisfactorily performing sexual intercourse. There are many ways to

Guilt-ridden parents have greater difficulty in helping their child develop an intact personality.

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SEXUALITY ISSUES FOR PEOPLE WITH SPINA BIFIDA

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achieve orgasm. Parents are unlikely to either understand or divulge such information, and peers cannot be relied upon! The male and female with

any type of Spina Bifida need to learn from movies, television, a sexual counselor or sexually explicit literature how to perform these techniques to satisfy their sexual partners.

**In the next
Issue:
Sexuality
Training for
and Learning
by Children
with &
without a
Disability**

The last aspect of reproduction discussed with both sexes is their ability to lower the recurrence of spina bifida in relatives, their parents and the affected child's children. The only studies known to us about the recurrence rate in first-degree family members (mother's and dad's brothers and sisters and the affected child's siblings) suggest that the recurrence rate of first-degree relatives is approximately 1 in 30. For second-degree relatives (mother's sister's or brother's children) is approximately 1 in 220. Others report a recurrence risk among mothers or an affected child's first degree relatives as high as 1 in 70 to 140 in first degree relatives of mother. Studies show recurrence rates in second and third degree relatives of 1 in 90 and 1 in 40 for sisters of the mother of an affected child and for the offspring of those sisters. She reported mother's brothers and father's sisters and brothers to have lower recurrence risks of 1 in 140-190. Affected mothers appear to have only a 0.5 to 1 % chance of having a child with a neural tube defect.

The Medical Research Council first conclusively proved that when women with a prior child with a neural tube defect took 4 mg of folic acid daily beginning three months prior to conception, there was a 70% reduction in recurrence in subsequent offspring. Wald et al have recommended 5 mg daily. Because of the higher occurrence in first and second degree relatives, we recommend 4 mg daily beginning three months prior to a planned conception. We suggest the effect in the United States may be nearer to a 40-50% reduction for two reasons. First, Berry et al (1999) demonstrated a 79% reduction in occurrence in high incidence in north China but only 40% in south China when the women took 0.4 mg of folic acid periconceptually. The incidence of neural tube defects in the

United States is closer to southern than northern China. Secondly, recent data from Canada and Mexico are the first to indicate that lower incidence communities on the North American continent can achieve a 45 – 55% reduction in occurrence with a regimen of 5 mg of folic acid per week and supplementation added to dietary fortification.

A discussion of etiology, genetics and prevention is also important to help parents learn about causation and to decrease any remaining guilt associated with the diagnosis of a fetus or infant with a congenital anomaly. Guilt-ridden parents have greater difficulty in helping their child develop an intact personality. Frequently, parents' imagined causes for their child's neural tube defect occurred long after the closure of the neural tube at 27 days gestation; the parents can be firmly reassured their guilt is misplaced.

Females with various forms of Spina Bifida are usually fertile and are capable of bearing children.

Join university study on pain, tiredness in children with disabilities

Many kids with physical disabilities experience pain, tiredness and other symptoms. These symptoms can make it hard for them to take part in important activities such as school and recreation. Health-care professionals do not have good ways to evaluate and treat pain and tiredness.

The University of Washington (UW), Children's Hospital and Regional Medical Center, Madigan Army Medical Center, Oregon Health and Science University and Washington State University Vancouver are doing a study to develop more effective ways to evaluate and treat recurrent pain and tiredness in children with disabilities. The study is funded by The National Institutes of Health.

Your child may be able to take part in our study if he or she:

- Has a chronic condition associated with experiences of pain or fatigue such as cerebral palsy, spina bifida, spinal cord injury, limb deficiency, neuromuscular disease or muscular dystrophy;
- Speaks English;
- Is 8 to 20 years old.

You will be interviewed one time and your child will be interviewed six times over two years. If your child takes part in the study and you live within 50 miles of the UW, we will ask you and your child to come to the UW or Children's to be interviewed by a researcher. If you live more than 50 miles from the UW, a researcher can interview you and your child over the phone instead. We will ask about your child's experiences with pain and tiredness. We will also ask questions about his or her daily activities, mood and general outlook. Each interview may take up to 120 minutes. Your child does not have to have pain or tiredness to be in the study.

Your child will be given \$25.00 for each interview plus a bonus for all six interviews. If you had to travel to the UW or Children's for the interview, we will pay you back for parking costs as well.

Principal Investigator: Dagmar Amtmann, University of Washington, Rehabilitation Medicine

Ms Wheelchair Washington will promote fitness, responsible drinking

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include her involvement with a National Injury Prevention program called Think First. She has given presentations to students of all ages about the importance of making "good choices, so they don't get hurt," with an emphasis on the importance of reducing underage drinking.

As Ms. Wheelchair Washington 2007, Sigrid will focus on promoting healthy lifestyles for people with disabilities through education within the commu-

nity. She titles her platform, "Wheels 2 Fitness—Access for better health through exercise." She also hopes to increase awareness to exercise facilities throughout Washington State to provide equal access to wheelchair users.

Sigrid will travel to Baltimore, Maryland in July to compete in the National Ms. Wheelchair America Program.

The Ms. Wheelchair Washington 2007 Pageant was sponsored by NEXTSTEPS NW and VARILITE®.

Sigrid Laegreid, Ms. Wheelchair Washington 2007

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Tammy Wilber, State Pageant Coordinator \Ms. Wheelchair Washington 2006

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Email: Tammywheels@yahoo.com or Tammy.Wilber@Varilite.com

For more info, please contact UWCORR
University of Washington Center for Outcomes Research Rehabilitation
(206) 221-2414 or 1-800-504-0564
Email: uwcrr@u.washington.edu (confidentiality of e-mail is not guaranteed.)
Web: <http://uwcrr.washington.edu/>

Contact info for speaking engagements:

Kids!Camp 2007 Details Now Available!

Instilling self-reliance, inspiring confidence, building socialization skills, and encouraging independence, this life changing experience is a can't miss for the kids! It is the only national camp specifically designed for children with Spina Bifida and their siblings.

Register Now! Activities at this year's camp include:

Horseback riding	Alternative nutrition lessons	Board games
Arts and crafts	Tour of Muhammad Ali Museum	Fishing lessons
Bowling	Hand Cycling	Rock wall climbing
Theater	Tour of Louisville Slugger Museum	

Register online at www.sbaa.org or call 800-621-3141 to have a registration packet sent to you.

VOLUNTEER NEEDED! ESBA SEEKS A LIBRARIAN.
CONTACT ESBA IF YOU ARE INTERESTED IN
CONTRIBUTING YOUR TALENTS TO
SUCH AN IMPORTANT ORGANIZATION.

ARTICLE SPOTLIGHTS FORMER NEW ORLEANS SBA PRESIDENT—SBA Director of Communications and Marketing, Amanda Darnley, recommends reading At this “wonderful article” that “not only tells Jan's story but also highlights Spina Bifida, Jan's work with SBA and the plight of the victims of Hurricane Katrina.” To read the article online, visit

http://www.journalnow.com/servlet/Satellite?pagename=WSJ/MGArticle/WSJ_BasicArticle&c=MGArticle&cid=1173350836131. To reach Amanda Darnley email adarnley@sbaa.org or call 800.621.3141 x15.

UNIVERSITY OF FLORIDA DEVELOPS GENETIC FORTIFICATION PROCESS FOR TOMATO— This article is being lauded by Patricia Fulvio, Executive Director of the Greater Pennsylvania SBA. “Wow -there's lots of good news out there! Scientists at the departments of Horticultural Sciences and Food Science and Human Nutrition, at the University of Florida, Gainesville, FL have developed a process to genetically engineer tomatoes to contain the entire recommended dietary allowance of folic acid for a young child and almost half of that for an adult. The study, published in the National Academy of Sciences, found that genetic manipulation of a tomato's genes, specifically two molecular pathways which produce pteridine and p-aminobenzoate, would result in 25 times the amount of folate naturally occurring in tomatoes. The scientists discuss that this study, considered a "proof of concept study," suggests that it is possible to substantially increase the folate levels in fruits. Genetic fortification of cereal crops, rice, fruits and vegetables could lead to fortification benefits in less developed countries where folate deficiencies are widespread.” The full article was written for a scientific audience but the press release can be read online at

<http://emailer.privatelabelmail.com/go.shtml?20070330142547211347&m57815&http://news.ufl.edu/2007/03/06/folate-tomato/>

NEWS

Oregon cluster makes its voice heard at the capitol

by Bill Pfankuch

Wednesday's rally was a tremendous success! More than 500 people with disabilities and their caregivers came to the Capitol to make their voices heard! We filled the Capitol steps and then some, and providentially the rain for the most part held off until our speeches and chants were done. Signs, buttons, and enthusiasm abounded. Our message was communicated loudly, succinctly, and with passion.

We also heard messages of solidarity from legislators. Senate Majority Leader Kate Brown, Senator Bill Morrisette, Speaker of the House Jeff Merkley, House Majority Leader Dave Hunt, and Representatives Sara Gelsler, Chris Edwards, Chip Shields, and Deborah Boone all rallied the crowd!

And the media was there, too. I've attached a story from Today's Statesman Journal about the rally. Also, KVAL, a Eugene TV station, took the time to ride up to Salem with the Eugene folks. The footage aired last night. The story and video can be accessed here:

Video: <http://www.kval.com/news/6981347.html?video=pop&t=a>

Text: <http://www.kval.com/news/6981347.html>

A tremendous thank you is due to everyone who helped make this event not just possible but the huge success that it was. While we want to leave no one out, the efforts of Shangri-La, PCL, Kerr, and everyone from Eugene who came up on the bus stand out.

Next step: Ways and Means at the end of the month!



Olympia Cluster picnicked May 12 at Yauger Park in West Olympia. The group shared a potluck, nice weather & good company.

MADIGAN YOUNG ADULT CLUSTER EXPERIENCES RECORD ATTENDANCE

by Patti Logan

The Madigan Cluster met Friday, April 13. It was a lucky day for us! We had a record attendance of 11 people. All of our regulars who have Spina Bifida showed up at once, except for Antonio who was represented by his mother. In addition, we were visited by a pediatrician from Japan who is working with Dr. Davis for several weeks. There was much sharing of life stories and signing of a card for Edie Gilbert, who is in the hospital. Anthony Williams was back from a trip to California and showed us the keys to his OWN apartment. We celebrated Amanda Henry's birthday and Heather Logan's record bowling score.



From SBAA Leaders Online:
"The first two sessions were fabulous!"

Eclectic Women with Spina Bifida Telegroup

This telegroup is a peer support group for women with spina bifida who are mothers, married, working, interested in holistic health approaches, and/or were diagnosed with spina bifida later in life.

A telegroup is a professionally facilitated interactive support group which meets once monthly for one hour via telephone conference call. No special equipment is required, simply dial in from your home phone. **Registration is free but required.** SBATSR participants may dial in toll-free. For non-SBATSR participants the only cost is your long distance carrier's charges for your call or low-cost phone cards may be used. Dial-in information is sent to you prior to the telegroup session.

For further information, contact Betty McLaughlin at bmclaughlin@sbatsr.org or 856.825.0838

Spina Bifida Association Tri-State Region (SBATSR)
84 Park Avenue, Suite G-106 * Flemington, NJ 08822
Fax (908)782-6102 email info@sbatsr.org

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.



CLUSTER CONTACT INFO HAS BEEN UPDATED!

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

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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



SBA ANNUAL CONFERENCE SESSION DETAILS

The 2007 SBA Annual Conference is just around the corner. Being held June 24 - 27 in historic Louisville, Kentucky, this year's conference will be a can't miss event for anyone in the Spina Bifida community.



Just announced: This year's conference offers an incredible general session exploring Spina Bifida clinics and the care of people with Spina Bifida. Leaders in the medical and research fields will examine the challenges of care in the next 20 years, including transitioning children to adult clinics and developing Spina Bifida clinics through a system-wide approach that would include credentialing. Also on the agenda for discussion are the goals of reducing variability in care and creating a patient registry to foster research and improve medical approaches.

Also now available: valuable airline discount information you don't want to miss out on! And don't forget about the Registration Raffle Contest being held for Group Members... It is your chance to win a free 2008 Conference Registration to share with your Group!

Visit the SBA Web site (www.sbaa.org) for more recently announced session topics and speakers. There's truly a session for everyone!

Amanda Darnley, Director of Communications & Marketing, SBA
800-621-3141 x15 - adarnley@sbaa.org