



Evergreen Spina Bifida Association Newsletter

ESBA FACES TRANSITIONS AND DECISIONS

by Joe Nugent, President ESBA

Just like the United States, ESBA and other Chapters and Support Groups and SBA (national) itself are in a transition to become a better organization. The transition started back in June of 2005, and has been progressing forward every year since.

ESBA's transition got on track in June of 2007 at the SBA National Conference 2007 and has continued into August 2007 at ESBA's summit. From there it went to ESBA Board Meeting in September of 2007, where the ESBA Board was asked to vote on adopting the SBA mission statement and be organized solely for the purpose of supporting that mission. (Mission statement: to promote the prevention of Spina Bifida and to enhance the lives of all affected). ESBA's Board vote was as follows: eight voted to adopt, two voted not to

adopt, and three did not vote. In this transition the membership will notice little change in the operation of ESBA. In December 2007 and January 2008, ESBA as a chapter was broken down by states. This way the membership in each state will be making the decision on what the state will be doing. Each state has been asked to make some choices on what to do. These choices by each state will determine their future with SBA (National). The choices that each state makes will be checked with their state laws for organizations, and then forwarded on to SBA (national). Now, only the President of Evergreen or a Board member that lives in your state will be contacting you if there are any more questions and/or decisions to be made by the membership of that state until July 1, 2008.

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Spokane mourns the loss of founding member Susan Curalli

by Ed Kennedy, Past President ESBA

It is with deep sorrow that I write about the sudden and unexpected death of my (our) friend - Susan Curalli.

I met Susan at a church that we both attended back in 1982. Susan was a "kindred spirit" in that we both have Spina Bifida and had dreams to live and goals to meet. For me during those early years Susan was my "fire" to get up on Mt. Spokane and learn to ski. Susan had already been a part of the Spokane Parks and Recreation Department Specialized Ski Program and wasn't about to let me not partake in this thrilling sport. Over the years we talked each other through many hard and trying times and shared in many great and fun activities. You see we didn't know about ESBA back then and so our sharing with

each other was our "cluster group."

When the time came for me to step up to the plate to begin a local Spokane Cluster group - I could think of no better person to have with me on the ride than Susan - as many of you know it was she who did a lot of the work to keep our group moving forward with numerous phone calls, getting the word out to various doctors and agencies, being a person for others to speak to at our Sacred Heart Hospital Spina Bifida Clinic, and arranging for speakers to come to our cluster meetings. We won't be able to replace Susan and I can only hope that I will let her memory push us forward to help others. Susan leaves behind a daughter, Alex, who is pregnant and I ask you to please keep her in your thoughts and prayers.

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

2128 N Pines Rd Ste 17-2
Spokane WA 99206
Phone: 253-589-3700
Toll free: 888-289-3702
Fax: 775-766-1654
Email:
evergreensba@yahoo.com

Newsletter Editor
Celeste McCormick
celtutt@yahoo.com

IN MEMORIAM: SUSAN CURALLI

by *Diana Tutt*

Our family and the Spokane area are missing a wonderful human being. Susan Curalli died in January. Jon and I were blessed to know Susan for about four and a half years, meeting at our first Spokane Cluster gathering. From the start, Susan was a joy to know. Her upbeat attitude toward life and in facing many challenges was an inspiration. Susan had a great laugh and could "make lemons into lemonade". Jon and I got to know Susan even more when we drove to Camp Prime together. Jon likes to say he got more hugs that weekend than ever since he lifted and assisted her as she needed. One or two members of our cluster group usually attend the Spina Bifida Clinic monthly at Sacred Heart Medical Center. Susan was a regular, despite having to travel some distance taking many hours out of her day. There is no telling how many people

have benefited from just knowing her. Personally, I could call Susan and just talk to her about life, and though I am several years older than Susan was, she was full of wisdom. She educated me about being disabled (although she didn't like that word!) and encouraged me as a grandmother to Michael, who has Spina Bifida. But lest I define Susan by Spina Bifida, that is not my intention. She was a daughter, sister, mother, friend and Christian. Susan was so looking forward to the birth of her first grandchild. The last time I saw her, she talked about getting well so she could be there for Alex, her beautiful daughter. I choose to think of Susan now as the Guardian Angel for our cluster group and her family. Our last phone conversation Susan ended wishing me a Merry Christmas, and a God Bless You. For that I am very thankful.



Susan Curalli
Photo courtesy of
Ed Kennedy

Chapter and Board Members Contact Information Chapter ph: 253-589-3700/ 888-289-3702 Chapter email: evergreensba@yahoo.com

Brian Knowles-Board Chair
crazy5720003@yahoo.com
253-887-0888

Pamela Hoppmann-Board Member
barrysmisspam@aol.com
208-522-6206(H)

Joe Nugent-President
MTGPPbear@yahoo.com
406-458-9549 (H)
406-410-1083 (C)

Patti Logan-Board Member
patti_logan04@yahoo.com
360-491-3171(H)

Bill Pfankuch-Vice President
Pfankuch_bill@yahoo.com

Gloria Olson-Board Member
ole5068@comcast.net
253-927-2188(H)

Nancy Nugent-Secretary
MTgrandmabear@yahoo.com
406-458-9549 (H)

Michael Schuermyer-Board Member
michael@josiahsjourney.com
503-761-8193(H)

Jon Tutt-Treasurer
jon_tutt@msn.com
509-467-8745(H)

Annette Zweig-Donham-Board Member
az@w-link.net
253-588-3366(H)

Ed Kennedy-Past President
ejk@cordwa.info
509-326-6355(W)

James Haxby-Board Member
JHaxby40@msn.com
503-414-9220(H)

Janet Davis-Board Member
purpleprincessjanet@yahoo.com
425-514-3448(H)



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 Idaho, turn to the last page of this newsletter!

MODEST FINANCIAL PROGRESS SHOWS WE HAVE FAR TO GO

by Jonathan A Tutt, Treasurer ESBA

The ESBA has two major **Income** types: **Interest and Donations**. Interest Income has been rising, but has probably peaked since our savings is declining. Donations have been rising, basically due to our fundraising efforts. Over the last three years our average annual total income was \$6595, but rising; 2005:\$3794, 2006:\$5,547 and 2007:\$10,446, almost a 100% increase from 2006 to 2007.

Expenses (expenditures) have been fairly consistent, averaging \$15,781 per year. Of the money spent, 88% or \$41,763 went to **Program Mission Expense**, 12% or \$5,517 was spent on **Administration**, and 0% or \$63 was spent on **Fund Raising**.

We have consistently spent more than we've taken in, a situation that cannot go on forever. One positive trend in this area is that with our increased income, our annual deficit has been lessening. Each of the last three years' loss has been less than the previous years.

Because we've spent more than we've earned our **Assets** have been declining at a steady rate. Since the association has no **Liabilities**, no long or short term debt (loan and credit cards) our **Equity** has been declining at the same rate as our assets.

Spending more than we make is a prescription for disaster in the long run.

Conclusion: If we are to maintain or increase our level of support to the Spina Bifida community we will have to continue the positive trend and until our income is equal to or greater than our expenses by **increasing our Fund Raising efforts and results!** We made a start in 2007, but need to do even more.

Update on "Shop 4 a Cause" results: On October 13, ESBA received the following notice from Macy's: "As your organization was the winner of the Shop 4 a Cause Best Attendance prize, I am pleased to enclose Macy's check in the amount of \$1895, which represents the total raised through tickets sold in-store at your local Macy's." Since ESBA had a presence at several stores, we do not know which local store resulted in the success. However, what really matters is that we got it and it raised our total to \$4222!

PRESIDENT'S MESSAGE (Continued from page 1)

By July 1, 2008 SBA (national) and all Chapters and all Support Groups will have started on their new look and how things will be done across the United States. (This will be a "work-in-progress" for a few years.)

In conclusion, when this process is done, SBA (National) and its Chapters and Support Groups will form a better organization with a united look and a united operation crossing the United States. Also the entire membership of ESBA will be notified of each state's decision about what to do.

Chapter, Support Group, ???

by Jonathan A Tutt, Treasurer ESBA

The national SBA has asked that by March 1st, 2008, each Group Member (the ESBA is currently a Group Member of national) complete and sign a "Letter of Intent." The form letter that was designed by national has three choices. It states that by July 1st, 2008 the Group Member, at the Annual Meeting (the convention in Arizona this June) will either: 1) Sign a **Chapter Affiliation Agreement**, or 2) Sign a **Support Group Agreement**, or 3) Will not sign any type of Affiliation Agreement. To me, the main difference between a chapter and support group, as defined by national standards, is that a support group has a basic mission of enhancing the lives of people affected by Spina Bifida, while a chapter has an additional obligation of also promoting the prevention of the birth defect. Of course

there are other factors involved. To me, the big one about reverting to a support group status is that national would want us to surrender our non-profit tax exempt status with the IRS, which would greatly affect our ability to raise funds and carry on as we have been. On the other hand, it might be easier than meeting all of national's new "Minimum Requirements" for chapters, one of which (among a host of others) is that we would have to raise and spend at least \$50,000 every year. Our President has decided that each of our five states is going to sign a different intent letter, rather than just one for the ESBA. If you would like additional information on any of this, or if you have not yet voiced your opinion, now is the time to do it. We need to make a decision in February. Contact any board member and to share your opinion.

Reminder of the SBA national conference:

**June 22-25 2008,
Tucson Arizona,
JW Marriott
Starpas hotel**

WHAT CAN AN INDEPENDENT LIVING CENTER DO FOR YOU?

Adapted from a presentation by Janet Davis and Ed Kennedy at the August 2007 ESBA summit that utilized information from the Independent Living Resource and Utilization website at <http://llru.org>

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

HISTORY BEHIND THE INDEPENDENT LIVING PHILOSOPHY

The Self-Help Movement that began in the 1950s really took root in the 1970s. Self-help and “peer support” groups were recognized as key points in independent living philosophy. People with similar disabilities were believed to be more likely to assist and understand each other than individuals who did not share that experience.

In the “demedicalization” movement, people with disabilities began to look at a more holistic approach to their healthcare, including a shift away from the authoritarian medical model to individual empowerment and responsibility for defining and meeting ones own needs.

HOW THE NATIONWIDE SYSTEM WORKS

- Independent Living Centers (ILCs) are funded primarily from a grant through the Department of Education.
- All Independent Living Centers are governed by a Board of Directors with at least 51% membership comprising people with disabilities.
- Independent Living Centers are scattered throughout our country and in every state that ESBA currently serves.
- Listings of these centers are available (see page 10 of this newsletter; a different state is featured in each issue).

CORE SERVICES OF ILCs

- Individual and systems advocacy
- Grievance support
- Community barrier removal, mediation with benefits programs
- Information and referrals
- Peer Support – finding services, assessing options
- Independent Living skills training – budgeting, meal preparation, shopping, organizing.
- Institutional transitions
- Additional services – attendant care, ADA evaluations, support groups etc



ARE YOU PREPARED FOR A DISASTER?



The city of Auburn Washington and the American Red Cross have compiled disaster preparedness tips for people with disabilities. See the full text of the tips, including worksheets and checklists for making the recommended preparations, advice for specific disabilities, at http://www.auburnwa.gov/_media/docs/Emergency-AMC_Disability.pdf.

Here are some of the most useful tips!

- **UNDERSTAND DISASTERS.** After a disaster, the environment may be very different: normal exits and routes may be impassable. Learn about what kinds of disasters could affect your area, how your community is notified of their possibilities, and what the potential effects could be. Get all of this information from your local Red Cross office. Confirm that your insurance covers these potential disasters; regular insurance often does not cover floods.
- **CREATE A PERSONAL SUPPORT NETWORK.** Organize one at home, work, or any other place where you spend a lot of time. Recruit people you trust. Write down your needs and capabilities and how your network could best assist you. Provide your network with your emergency information, especially any necessary medicine, special equipment or supplies, and service animal instructions.
- **IDENTIFY SAFE PLACES TO GO.** Locate safe places in your home and in your community. Learn where and how to disconnect the main utility valves in your home. Map escape routes based on a floor plan of your home. Practice evacuating.
- **KEEP PERSONAL INSTRUCTIONS WITH YOU.** Write a script to repeat or share with emergency service personnel or volunteers about how to best assist you. For example, “I am deaf—please write things down for me” or “I am diabetic—please get my insulin from the refrigerator.”
- **GATHER A DISASTER SUPPLIES KIT.** Include basic disaster supplies plus any disability-related equipment. Stock at least three days’ worth. Consider dietary and service animal needs. Restock your kit regularly to prevent getting trapped in a disaster with expired items!

Vote!

WHERE DO THE CANDIDATES STAND ON HEALTHCARE?

Want to know more about the presidential candidates' healthcare platforms? Visit www.Health08.org, a website hosted by the Kaiser Family Foundation, for primers on the candidates' positions plus news about the election.

National Survey of the Spina Bifida Community

Fill out the National Survey of the Spina Bifida Community and enter to win a \$50 gift certificate to the store of your choice! It takes just five minutes to help the Spina Bifida Association by giving your important input.

You must be 18 years old to participate.

Link to the online survey at <http://66.34.124.214/>.

The survey is available in both English and Spanish.

Stay tuned for the results of the survey!

YOU CAN CONTRIBUTE TO SPINA BIFIDA RESEARCH AND STATS

We all decry the dearth of Spina Bifida statistics, not only nationally and internationally but in our home states. Now you have the opportunity to contribute to the collection and analysis of data regarding Spina Bifida. Visit the National Birth Defects Prevention Network survey website at <http://www.nbdpn.org/FolicAcidSurveys/> to find national and state surveys that need your input!

HOW DOES OCCUPATIONAL THERAPY IMPACT CHILDREN WITH DISABILITIES?

from the Family Center on Technology and Disability (FCTD)

The name of [our] profession has been made archaic by the evolution of language and the passing of time, but occupational therapy's impact on children with disabilities, especially those requiring assistive technology, remains timeless. Today, according to the American Occupational Therapy Association, occupational therapy is "a health and rehabilitation profession that helps people regain, develop and build skills that are important for independent functioning, health, well-being, security, and happiness." OTs in the 21st century, supported by assistive technology, strive toward a single goal: enhancing the opportunities for individuals with disabilities, including children and young adults, to achieve independence. [The October] issue examines the role of the occupational therapist in employing AT to support children and young adults with disabilities. [It] features an interview with Miriam Struck, OTR/L, ATP, Occupational Therapist, Certified AT Practitioner with Montgomery County (MD) Schools. Supporting our interview with Ms. Struck are resources aimed at describing the relationship between occupational therapists and AT. We also feature members of our Knowledge Network. The members spotlighted this month focus on occupational therapy and assistive technology. We invite you to contact these members for further information.

Please share this newsletter with other organizations, families and professionals who may benefit from it. We invite you to visit us at <http://www.fctd.info>. We welcome feedback, new members and all who contribute to our growing knowledge base. Email us at fctd@aed.org or read the full story at <http://www.fctd.info/resources/newsletters/index.php>.



Independence, well-being and happiness are the goals.

Folic Acid News

Folic acid may help prevent depression

Researchers at the University of York in England found that women who skimped on folate-rich foods were more prone to depression. Folate triggers the release of serotonin, a neurotransmitter that is believed to influence mood. - *Self magazine*



Green tea can block absorption of folic acid

A new report found that pregnant women who drink one to two cups per day of green tea during the first trimester may double their risk of having a baby with Spina Bifida. Green tea's antioxidants may block the absorption of folate. - *First magazine*

Folate-dense foods cut risk of pancreatic cancer

A recent study in *Cancer Research* reports that eating folate-rich foods like spinach can cut the risk of pancreatic cancer by as much as 60% in normal-weight women. The benefit was not realized by those who took folic acid supplements; instead they experienced an increased risk. - *Self magazine*



GET MORE FOLIC ACID TODAY BY EATING SPINACH, ORANGES AND BEANS!

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.

ICE Campaign - "In Case of Emergency"

We all carry our mobile phones with names and numbers stored in the memory but nobody, other than ourselves, knows which of these numbers belong to our closest family or friends.

If we were to be involved in an accident or taken ill, the people attending us would have our mobile phone but would not know which number to call as an emergency contact.

In response, the ICE "In Case of Emergency" campaign has been taking root as a method to help medical personnel identify your emergency contact. To join, simply store the number of your emergency contact person or persons under the name of ICE (or ICE1, ICE2, etc for multiple listings).

According to urban legend the idea was invented by a paramedic who found that when he went to the scenes of accidents, most patients had mobile phones but he did not know which number to call. He therefore thought that it would be a good idea if there was a nationally recognized name for this purpose. If this story is not true and if medical personnel never actually look in your phone for ICE, you will only have lost a few minutes of your time and one entry in your address book. But if it turns out to be true then you will have helped yourself, your family and those attending to your urgent medical needs.

CLUSTER DEVELOPMENT HELP IS HERE!

by Michele Hopkins, Cluster Developer

Some of you know that I am pretty close to my due date (February 17th or sooner!). I will have my hands full, but I will try my best to keep up with emails and help as much as I can with each cluster group.

I would like to share with the cluster groups some ideas and look forward to hearing your ideas too to share with the next newsletter. Also, please email me regarding your activities with your cluster groups. I like to pass on to other groups how you have entertained each other. Try having a theme meeting! Ask folks what some of their main concerns are or what some of their favorite activities (try to do some of those!).

Some of you are struggling to keep your groups going or growing. Keep in mind some of the best places are right in your neighborhood to leave flyers, pamphlets, etc. If a store has a bulletin board, type/write up a little information about your group and post it. I like to leave information at libraries, public health clinics and even restaurants! Keep your meetings as much as you can in the same location and same time. Take attendance and if you cannot make it, ask someone on the list to take your place so you do not need to cancel the meeting. Also, having the attendance list with names and numbers can allow you to get feedback as to what date and times works best.

I am stocked with folic acid pamphlets and posters and need them to be distributed! Please contact me and I will mail you out some.

Looking forward to hearing from you!

Please feel free to contact me at michele@thehopkins.us.



SEEKING ESBA REPS TO ATTEND OREGON CONFERENCE

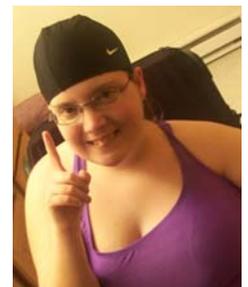
Oregon Health & Science University (OHSU) holds an annual conference on spina bifida each year in Portland. The audience is intended to be individuals and families, school providers, medical providers. It is scheduled for Sat March 15 in 2008. ESBA is invited to present briefly on activities at the local and national level. Perhaps some members could host a small information table in the lobby. According to Cluster Developer Michele Hopkins, she can provide more than enough information and materials to use at the conference. Please contact Michele or Barb Dworschak, LCSW at OHSU. Michele's contact information can be found elsewhere on this page in the newsletter and Barb can be reached at dworschak@ohsu.edu or 503-494-0574.

READY TO SWIM AGAIN

by Patti Logan, January 9

Heather [is swimming again]. Her coach put her back using the floatation device, which didn't please her, but after 22 months of being away from the water, she is back. She is BACK! See that smile!!!! Heather start[ed] Bowling, is Boxing every Monday and Thursday (plus working out several times a week on her own punching bag), and swimming on Thursdays. Whew! She and her transportation (me) are getting lots of exercise.

Heather Logan
Photo courtesy of
Patti Logan



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
MARCH 11 2008 7:00-8:30 pm
ZION LUTHERAN CHURCH 1350 17TH ST SE AUBURNWA



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

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



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
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	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


Evergreen Spina Bifida
Association



CONTACT INFORMATION FOR IDAHO INDEPENDENT LIVING CENTERS

Idaho Independent Living Council
Kelly Buckland, Executive Director
Kelly.Buckland@silc.idaho.gov
350 N 9th St/PO Box 9601
Boise ID 83720-9601
208-334-3800/TTY 208-334-3803

Living Independence Network Corp
Roger Howard
2500 Kootenai
Boise ID 83705
info@lincidaho.org
208-336-3335 (TTY okay)

Disability Action Center NW
Amy Dreps
1323 Sherman Ave Ste 7
Coeur d'Alene ID 83814
cda@dacnw.org
208-666-1362 (no TTY)

Disability Action Center NW
Lewiston: 307 19th St Ste A-1
Lewiston@dacnw.org
208-746-9033 (TTY okay)
Moscow: 124 E 3rd St
Moscow@dacnw.org
800-475-0070/TTY 208-883-0523

LIFE * satellites
Diane Nielsen
2110 Rollandet Ave
Idaho Falls ID 83402
eici@ida.net
208-529-8610 (TTY okay)

Sandra Dressel, sandrad@idlife.org
2311 Park Ave Ste 7
Burley ID 83318
208-678-7705 (TTY okay)

Wendy Parker, wparker@if.rmci.net
PO Box 4185
Fort Hall ID 83202
208-748-3952 (no TTY)

Lucy Navo, lucyn@idlife.org
PO Box 86
Blackfoot ID 83221
208-785-9648 (TTY okay)

Dean Nielson, dean@idacomm.net
640 Pershing Ave Ste 7
Pocatello ID 83205
208-232-2747/TTY 208-232-2753

**** Living Independently for Life***