



# Evergreen Spina Bifida Association Newsletter

## ESBA—WHO ARE WE?

*by Ed Kennedy, ESBA President*

As the current President of ESBA I try to keep sight of what it is that we are trying to accomplish and how are we at doing just that? The answer to this might be answered in a few words. One of the words is “relationship.” I realize that a lot has changed over the years with ESBA but one of the primary things that I hope we have provided throughout the years and still provide as an organization is relationships of varying kinds to people who have had Spina Bifida affect their lives in many different ways. For me, as I have stated in previous articles, I didn’t meet another person with Spina Bifida until I was in my early 20s and can only imagine what an impact it would have made on my life to have someone who I could have spoken with especially during my young pre-teen and teenage years who, I felt, could relate to my feelings and questions. It has been my hope that this type of situation would not happen for others. As a “support” group and affiliated with the National Spina Bifida Association it has been requested that we live in a world of HIPPA (Health Information Privacy Protection Act) and therefore, what we can and cannot share with others is sometimes rather problematic even as a “support group.” We are still trying to work through all the HIPPA regulations but one thing that I

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## Spokane County is of “100 Best Communities for Young People”

*In Partnership with Capital One, Competition Recognizes Outstanding, Innovative Efforts That Benefit Children and Youth*

(Spokane, Wash.) - The Spokane Area Economic Development Council/Spokane Regional Chamber of Commerce announced today that Spokane County is a winner of a national competition to identify the 100 Best Communities for Young People. In partnership with Capital One, the 100 Best competition honors communities – ranging from small towns to urban neighborhoods across America – for their commitment to provide healthy, safe, and caring environments for young people. Hundreds of

communities in all 50 states, the District of Columbia, Puerto Rico and the U.S. Virgin Islands took part in the competition.

According to America’s Promise, Spokane County is one of the 100 Best, for the following key reasons:  
 The low high school dropout rate in Spokane and services for kids in need;  
 The community’s dedication to mentoring underserved populations;  
 Spokane’s strong focus on school successes for all students; and  
 The community’s enduring commitment to youth service and leadership opportunities

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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:

43 million Americans are uninsured—  
 80% are in families with a full-time worker.  
 Source: [www.mattmilleronline.com](http://www.mattmilleronline.com)

## GETTING TO KNOW YOU: HEATHER LOGAN



*by Heather Logan*

**Meet Heather Logan, a 20-year-old woman. Heather lives in Lacey, Washington. She keeps herself busy by volunteering at a Children's Center twice a week. In her spare time, she does swimming with the Special Olympics Thunderfish Swim Team and crafts making people dolls. She is also writing a book about her life. The working title is *Dealing with Disability*.**

*Do you have a story to share about an ESBA member? You can write it yourself or give the idea to the newsletter editor.*

### Spokane County wins national award for its community environment

*(Continued from page 1)*

"Nothing is more important than seeing that our children and youth have the resources and support systems they need to thrive and succeed," said America's Promise Founding Chairman General Colin L. Powell, USA (Ret.). "When a community provides all that its young people need to be healthy and secure, they deserve to be honored and showcased as an outstanding example of what it takes to successfully nurture this nation's young people."

100 Best Communities for Young People was first launched in 2005 by General Powell in partnership with Capital One Financial Corporation. ...

The 2007 100 Best Communities for Young People competition opened in September 2006. Spokane County and the

other winners applied for the honor and were chosen by a distinguished selection panel of civic, business and nonprofit leaders, including United Way of America President Brian Gallagher, U.S. Chamber of Commerce President Tom Donohue, NBC News Washington Bureau Chief and Moderator of Meet the Press Tim Russert, CEOs for Cities' President and CEO Carol Coleta, and former Denver mayor, Wellington Webb.

The selection panel evaluated 100 Best entries that required detailed information about each community's efforts to fulfill the Five Promises – the fundamental resources our children and youth need to succeed: caring adults who are actively involved in their lives; safe places in which to learn and grow; a healthy start toward adulthood; an effective education that

***For more details about the 100 Best competition and winners, please visit [www.americaspromise.org](http://www.americaspromise.org).***

**Did you see the January 18 Associated Press article about studies tallying the cost of birth defects? One study conducted by the University of Arkansas and the US Centers for Disease Control, used 2003 data from 36 states and examined what hospitals charge patients. Another by the US Agency for Healthcare Research and Quality used 2004 data from 37 states and measured the cost for hospitals of these birth defects. Both studies published the average prices for various birth defects—e.g. \$3800 for babies born with anencephaly who usually die within two days of birth. What do you think of this article and the studies? Tell us your opinion and read the article at <http://www.msnbc.msn.com/id/16693006/wid/11915773/?GT1=8921>.**

## **THE EVERGREEN SPINA BIFIDA ASSOCIATION 2007-2008 MEMBERSHIP/RENEWAL APPLICATION FORM**

Name: \_\_\_\_\_ Spouse's Name: \_\_\_\_\_  
Street Address: \_\_\_\_\_  
City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_  
Home Phone: \_\_\_\_\_  
Email Address: \_\_\_\_\_

Person with Spina Bifida: \_\_\_\_\_  
Date of Birth: \_\_\_\_\_

Rather than a set dues amount, membership in Evergreen Spina Bifida Association for 2007-2008 is on a donation basis. 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 all our members.

Would you like to be in the Member Directory? Please mark yes or no.  
Yes \_\_\_ No \_\_\_

And if yes, which information would you like in it?

Name: Yes \_\_\_ No \_\_\_  
Address: Yes \_\_\_ No \_\_\_  
Email: Yes \_\_\_ No \_\_\_  
Phone number: Yes \_\_\_ No \_\_\_  
Other: \_\_\_\_\_

Please complete this form and return to:  
**The 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 to pay. If this form is completed and returned, you will be a full member of the Evergreen Spina Bifida Association

### **ESBA: we are still dedicated to support and relationships**

*(Continued from page 1)*

know is we can do this. If you feel that you want to be in contact with others who you hope will be able to relate to your situation, please contact me and what I will do is get permission from other members, so you can then contact them or vice versa. We used to provide our members with a membership contact list but the National Spina Bifida Association is suggesting that none of their affiliated Associations do this any longer in accordance with HIPPA. I want to ask you all

to please, if you have an idea about how we can better connect people to one another and stay within HIPPA laws, let us know. We would gladly consider ideas about how we can do a better job at this. Speaking about relationships I want to let you know about a new relationship that is currently taking place within ESBA and that is with Brynn Ploetz of North Pole, Alaska who has already started a cluster group and is working hard to further the work of ESBA in Alaska. Thanks Brynn!!

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

**VOLUNTEER  
NEEDED! ESBA  
SEEKS A LIBRARIAN.  
Contact ESBA if  
you are interested  
in contributing your  
talents to this  
important  
organization.**

## TOILET TRAINING ISSUES FOR THE CHILD WITH SPINA BIFIDA

*This is the third 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.*

*Children without a disability and their parents usually learn toilet training before developing sufficient vocabulary or understanding to remember how it was learned. They learn on their own, by trial and error, and from caretaker cues.*

### INFANCY & TODDLERHOOD

While the issues of urine and stool toilet training and sexuality ... are critically important to the proper development of a child's psyche, they are also topics that are either avoided in social discourse or not fully understood. It is important for those who care for child with spina bifida to understand this and work with the child to develop good hygiene habits.

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 young children not to expose their perineum – frequently called their "private parts" - in public,

particularly in the presence of the opposite sex. Children at this age also notice differences between [the sexes and may] 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. One mother related the following story about 3 children four and five years of age. The children came in from playing outdoors [and] entered the bathroom together. The first, a boy, stated, "This is how I pee." A prolonged tinkle ensued. The second, a girl, said the same. Her shorter but louder stream of urine could then be heard splashing in the toilet bowl. The third, her son, stated, "I don't have to take my pants down and I pee quicker." He then flipped his urostomy bag over the top of his pants and pulled the plug. The subsequent swoosh was, indeed, quicker. Then two awed little voices exclaimed together, "Wow, are you lucky!"

### TOILET TRAINING FOR CHILD WITHOUT A DISABILITY

The timing of toileting skill acquisition in children with myelomeningocele should approximate the age of other children in the family and the individual child's development. The typical method used to teach toilet training to a child without a disability involves a positive reward system .... This process should not cause guilt in the child; it may last until 6 to 8 years of age for both day and night control. This recommended process does not imply stool or urine is "bad." However, in most societies, a negative attitude toward excreta is introduced by discouraging children from having toileting accidents. A second critical skill that evolves during this same developmental period is the acquisition of language. The young child learns socially acceptable words for urine and stool and to not repeat vulgar or obscene words for these same entities. ...

Each culture has its own childhood teaching methods for the child to conform to attainable goals, including toilet training. Toddlers without disabilities begin developing their toilet training skills when they are in a stage of denial. A two or

three year old frequently uses the word "No" as one of her first experiments in learning autonomy and testing limits. Therefore, we need to review how each of us learned or was taught socially appropriate toileting hygiene and how to discontinue about it.

Dependence on the sense of smell as a backup warning for stool or urine leakage is not completely reliable in either the child or adult with or without a disability. "A man who smells bad is the last to smell himself" (an old Yankee saying based on a well known phenomenon, habituation). Toileting accidents for the child with Spina Bifida of any degree with perineal nerve involvement usually occur with small leaks, initially generating little odor. The odor gradually increases, becoming more pungent as the child is involved in other activities and does not recognize the slowly increasing malodor. The initial odor also dulls later recognition of the noxious odor [and after] a relatively brief time, the bad odor is no longer detectable (habituation). Children, therefore, frequently and truthfully deny they have a bad odor because their noses have lost their ability to sense their own malodor.

### TOILET TRAINING FOR CHILD WITH SPINA BIFIDA

There are many publications describing special methods to assist children with Spina Bifida learn independent toilet training. The reader is referred to these references for specific tech-

niques and their rationale. This chapter will concentrate on toilet training as it relates to emotional and behavioral development. Brazelton recommends toilet training for the

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## TOILET TRAINING ISSUES FOR THE CHILD WITH SPINA BIFIDA

*Toileting that depends on the immediate presence of mother or another caretaker impairs the child's development of autonomy and delays the transition/separation process.*

child with out disabilities after the age of 2 years or when the child: 1) Has developed sufficient language to understand the parents' chosen words to describe urine and stool; 2) Is able to sit for at least 5 minutes independently with or without a distracting activity; 3) Is able to undress and dress his/her lower body, and 4) has expressed an interest.

How different it is for children born with Spina Bifida, with their delayed motor development, some with an inability to sit independently, and their sphincter motor impairment, lacking sensation in the anal canal and urethra! This is further compounded by complex toileting procedures while encased in cumbersome braces and protective garments to guard against toilet accidents.

Toileting that depends on the immediate presence of mother or another caretaker impairs the

child's development of autonomy and delays the transition/separation process. For parents to effectively teach toileting skills to their children with sphincter impairment, they need to understand toilet training for the child without disability, the impact of their child's specific impairment and how their child best learns. The child with fourth and fifth sacral nerve impairment lacks the ability to distinguish between stool, gas and diarrheal fluid. Neither can he or she contract the voluntary anal sphincters. The child with no function in the fourth and fifth sacral dermatomes has no sensation in either the anal canal or the skin of the perineal area but many can identify a predefecation urge when peristalsis pushes bulky stool into the rectum. Learning disabilities are a common accompanying problem for these infants and children with Spina Bifida both with and without hydrocephalus.

### MORE INFORMATION ABOUT TOILET TRAINING FOR CHILD WITH SPINA BIFIDA

Infants and toddlers without sensation in their legs and perineum and swaddled in stool and urine collecting clothing do not have the opportunities to become appropriately aware of their lower body and lower extremities. We believe teaching infants or toddlers with any form of Spina Bifida to recognize that the lower parts of their bodies and legs are part of them is an important objective at this age. Playing before a mirror with the children nude can help them understand that the lower portion of their bodies and legs are indeed a part of them. These paralyzed and senseless parts of their bodies should be incorporated into their concept of self. Modifying their clothing can improve their physical ability to don and doff their clothes and braces. Velcro fasteners are important facilitators. These two concepts may lead to the older child becoming interested in his bodily functions and learning how to control them. We recommend a cool and disinterested attitude toward the older child when the diaper is soiled. Even infants and tod-

dlers understand their caretaker's communications through attitude and facial expression. Toddlerhood is the time to begin using non-verbal interactions to communicate that stool and urine are not pleasant. Whenever the diaper is found to be clean and dry, the caretaker should consider spending a short, pleasant time with the child. Continuing diaper clean up as a pleasant experience into childhood conveys the wrong message to the child. At our suggestion, one of our students followed this approach with his 10-year-old daughter with developmental delay and incontinence but intact fourth and fifth sacral nerves. Impressed with the achievement of his non-verbal child, he applied the same positive attitude for clean diapers and a cool attitude toward soiled diapers to a population of profoundly mentally retarded, non-verbal adults in an institution. When the attendants found clean diapers they spent a few minutes providing a pleasant interaction. When soiled diapers were found, they changed the patients with no interaction. Within a few months the number of soiled diapers markedly decreased.

*We recommend explaining to the child with sphincter impairment that while they cannot prevent accidents, they should strive to keep themselves odor free.*

Some normal children are not fully toilet trained for 24 hours until 6 to 8 years of age; they do well unless they are made to feel guilty. Hence, we believe the actual techniques and timing of toilet training of children with sphincter impairment can be delayed until they understand and are

physically able to perform the necessary and complex procedures without impairing their emotional adjustment. We recommend explaining to the child with sphincter impairment that while she cannot prevent accidents, she should strive to keep herself odor free.

## REPORTER BLOGS ABOUT RIGHT TO LIFE QUESTIONS WHILE PROFILING TEENAGER WITH SPINA BIFIDA

by Celeste McCormick, Editor

Learn about the story behind the story as Crocker Stephenson, a reporter for the Milwaukee Journal Sentinel, keeps a blog while profiling a young man with Spina Bifida. Stephenson started the blog (an online journal) in October 2006 when he first began exploring the story of Tim Krahlung, a 19-year-old whose birth and subsequent medical treatment (or lack thereof) sparked much debate. According to Rita Flores from SBA of Wisconsin, "Much controversy and legal battles surrounded the decisions made about how he would be medically treated when he was a new born. His prognosis for survival was grim. Nineteen years later, Tim is still alive, and his story still brings about lively and passionate discussions."

The reporter expresses his awe at the

power of the story and its affect on his life: "I have been a journalist for 21 years, and a story has never so engaged me. I wish you could feel the thrill I feel as I write Tim's story. I have never experienced, ever, any thing like it."

At its essence the blog invites discussion and new ways of thinking about controversial questions while at the same time delivering a very personal and human perspective to these same questions that can otherwise seem too philosophical and far away.

Reader contributions are welcome to the blog. You can access it at

<http://www.jsonline.com/blog/?id=204>. The article series began running January 28 2007 and its first part can be found at

<http://www.jsonline.com/story/index.aspx?id=557625>.

2007 DISABILITY  
POLICY SEMINAR  
March 4 - 6, 2007  
The Hyatt Regency  
Hotel  
400 New Jersey  
Avenue NW  
Washington, DC  
20001

## Washington's economy is doing better and the state budget has a surplus. Tell Olympia it's time to expand affordable health care.

by the Save Health Care in Washington Team

The 2007 state legislative session is just getting started, but the debate over the future of affordable health care is already heating up. We need your voice right now. [Tell your legislators and the Governor](#) to curb rising costs and reduce the number of uninsured people in our state. They already have the tools to make a huge difference. The number of uninsured in our state has increased 31% since 2000. Yet simply investing in the cost-effective programs we already have in place would provide the majority of Washington's uninsured people with coverage – without the need for a big new government program. [Make sure affordable health care gets the attention it deserves in the Legislature.](#)

Here are the three most responsible and effective ways to get immediate results:

- Provide all Washington children with health coverage and access to care.
- Expand the Basic Health Plan for lower-income workers who contribute to the cost of their care.
- Give small employers and their lower-income employees assistance to purchase affordable health coverage and give larger employers a choice to provide employee health insurance coverage or contribute to the cost of covering employees through public programs in order to save taxpayers money.

[Please send your elected officials a message now](#) through Save Health Care in Washington's new and improved Action Central Web site: [www.SaveHealthCareInWA.org](http://www.SaveHealthCareInWA.org). We'll need your voice again throughout the 2007 state legislative session. Beginning with this e-mail, we will contact you at key points during the 2007 state legislative session. Each time we will ask you to urge your state legislators and the Governor to "get health coverage up!" [Each message you send will create more pressure on your elected officials to take action.](#)



## EXPERIMENTAL SURGERY MAY RELIEVE BLADDER CONTROL PROBLEMS

According to a December 19 article by Fox News, doctors at William Beaumont Hospital in Royal Oak Michigan began a unique experiment to see if rerouting the nerves of paralyzed patients can ease their bladder control problems. According to the article, “surgeons cut open a spot on the spine and sew two normally unrelated nerves together - one from the bladder to one from the thigh - with a single hair-thin stitch. It will take months for this new nerve bridge to heal...” The technique was pioneered in China and will be reproduced in the US through this experiment. The doctors will perform the surgery on six to eight patients and then delay conducting any others unless and until the first set of patients show success. According to Dr. Kenneth Peters, Beaumont’s urology research chief, the surgery carries risks “including general anesthesia and wound infections. For children with spina bifida who can walk, rerouting the thigh nerve causes a small risk of some foot weakness” The cost is \$30-40K per person but is being funded through a private donor. ESBA member Michele Hopkins contacted the Beaumont urology department and learned firsthand about the program. “They are looking for folks with Spina Bifida to use for their newest study. Sometime around April they are going to start a study with folks who have Spina Bifida. The success rate on this surgery is about 88%. They are not asking any money for the surgery. The catch!?? Well, yes, you have to travel with expenses not paid. From what I can remember off the top of my head (I’ll receive information in the mail soon) you need to travel about 6 – 7 times a year to the hospital to be monitored. The surgery will keep you around the hospital for about 2 weeks, so plan on a hotel stay too!! ... The study does last about 3 years. The doctor in China has performed this surgery quite a bit and has a huge waiting list. I hear this doctor from China will be there assisting. If the surgery doesn’t work, you go back to the way things were.”

Look in the next newsletter for more information about this program. To read the Fox article, go to <http://www.foxnews.com/story/0,2933,237479,00.html>.

## SBA encourages partnerships with direct support professionals

*by Julia Washenberger, Vice President, Spina Bifida Association of Minnesota*

This past weekend I attended a conference sponsored by the National Alliance for Direct Support Professionals. I learned that each state is developing an organization to recognize the work of direct support professionals as a profession/career. I thought it would be a great idea for our local SBAs to make a contact with your local DSP organization to support their efforts for those that provide such great services (PCA and other) to our families and individuals. Here is the organization information for your reference:

<http://www.nadsp.org/about/> and a bit about what DSPs do. If DSPs had a living wage we would as individuals have better services in the community. Please consider partnering with your DSP organizations for a mutually beneficial partnership.

The NADSP is a coalition of organizations and individuals committed to strengthening the quality of human service support by strengthening the direct support workforce. The group has representatives from the fields of mental health, developmental disabilities, child welfare, education, and many others in the human services community.

The Alliance has developed a national agenda to address conditions chronicled for 25 years that are harmful to people who rely on human services. These conditions include high staff turnover, low social status, insufficient training, limited educational and career opportunities, and poor wages. These undermine the commitment of the Direct Support Professionals, and have made it very difficult to recruit and train qualified and committed individuals in direct support roles in every area of human services.

The NADSP believes that service participants and direct support professionals are partners in the move towards a self-determined life, and in complimenting and facilitating growth of natural supports. We recognize that people needing support are more likely to fulfill their life dreams if they have well-trained, experienced, and motivated people at their side in long-term, stable, compatible support relationships. We also recognize that well-planned workforce development strategies are needed to strengthen our workforce.



## Petition for high school wheelchair athletes succeeds

*By Mary Turcotte*

**Hello ESBA Friends!**

**My daughter Rachel has been involved with recreational and school sports for quite some time. Her involvement on her school teams does nothing to help her team. The Washington Interscholastic Athletic Association has maintained swimming and track for kids with physical disabilities "demonstration sports" for 10 years! Too long! We are advocating for wheelchair using kids to "count for points" so that their efforts are recognized (they can help win meets!) and coaches will be encouraged to want these kids on their teams.**

**Now, thanks to everyone who signed the petition at**

**<http://www.thepetitionsite.com/takeaction/698554792>, WIAA did accept the proposal (it is provisional- it will be in place for 2 years and will be looked at again after that time) for high school disabled athletes to participate and "count" when they place in events at the state track meet! Districts (regional meets where school districts compete to see who will qualify for the state meet) will have the option of including these athletes or not, but as you can see in the attached document, there will be 2 state trophies: one category for teams competing with able-bodied athletes and another for able-bodied and disabled athletes with combined points. Now Washington and Louisiana are the only states with similar language with regard to track participation. I hope swimming is next, followed quickly by wheelchair basketball!**

Petition content:

"Able-bodied track athletes currently receive points for their team when they compete in a track meet. We are requesting that wheelchair track athletes also receive points when they compete at those same track meets." *Sponsored by Teresa Skinner of Team St Luke's and Riverside School District*

**Sponsored by the Spina Bifida Association of Cincinnati; funding provided by Ohio Settlement Funds Cincinnati Bell & Business Technology Solutions**

### 2007 Setting Your Sight For the Future: Strategies to Get What You Need and Most of What You Want!

**Participate in a unique tele-program from the convenience of home!**

**Would you like to connect with other individuals with Spina Bifida and share tips?**

**Can you talk about what your strengths are?**

**What are the resources to help you be independent?**

**What do you need to start today to create the life you want?**

**Join our telephone community for 1 hour a week for 9 weeks and discuss topics and learn strategies that will propel you *into the future!***

**What you will gain by participating:**

Confidence and self-assurance

Skills for managing healthcare

How to identify your strengths and extend opportunities

Information and resources

How to make good decisions

Leadership skills

**Ideal participant:**

Teens and young adults with spina bifida

Out-going and articulate

Looking forward to the future

Email access preferred but not mandatory

Contact: Sharon Sellet, Program Director

513- 467- 9292 or [sharon@perceptioncheck.com](mailto:sharon@perceptioncheck.com)

Winter session start date: February 5 2007

If you are Cluster leader or point of contact, PLEASE notify Secretary Nancy Nugent at MTgrandmabear@yahoo.com to get you a Conflict of Interest Statement (which HAS to be signed if you are to remain a cluster leader), and then Nancy will forward your name to Treasurer Jon Tutt for the financial information needed by the IRS.



**EVERETT CLUSTER MONTHLY MEETINGS**  
 Join the Everett cluster every first Tuesday of the month  
 from 12:30 to 4PM at the  
 Everett Transit Center on Smith Ave and 33rd  
 For more information contact  
 Brenda Stroud at 425-385-2487 or frizzle3@verizon.net

### Connect with a cluster group

Region	Leader Name	Contact Phone
Portland OR	Gina Schuermyer	503-761-8193
Helena MT	Joe Nugent	406-458-9549
Madigan Army Med. Ctr.	Dr. Ellen Davis	253-589-3700
Vancouver WA	James Haxby	(503) 414-9220
Spokane WA	Ed Kennedy	509-465-0676
South King CO WA	Brian Knowles	253-887-0888
Eastside Seattle	Michele Hopkins	425-844-1262
Kitsap WA	Dave Lewellan Rebekah Uhtoff	360-871-5139 360-782-0467
Olympia WA	Patti Logan	360-888-7701
Walla Walla WA	Garrison Redd	509-301-0243
Eugene OR	Anne Moon-Glen	541-689-2125
Butte MT	Paula Christenson	406-683-4793
Alaska	Honnen McLeod	907-688-8456
Center for Independence	Cliff Schulman	253-582-1253
Spanish	Anthony Williams	253-588-4411
Bend OR	Diane Cole	541-318-7075
Idaho Falls ID	Pam Hoppmann	208-522-6206
Leavenworth WA	Ed Baroch	509-548-5697
Seattle	Nicole Anderson	seattlespinabifida-group@hotmail.com
Everett	Brenda Stroud	425-385-2487 frizzle3@verizon.net

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](mailto: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](http://www.evergreen-spinabifida.org)***

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.

SBA's survey is online at: <http://66.34.124.214>

Please pass this announcement along and let your voices be heard!

We appreciate your time and look forward to sharing the results.

## REGISTER ONLINE FOR SBA ANNUAL CONFERENCE

  
Evergreen Spina Bifida  
Association



SBA's Annual Conference has earned its place as the world's premier conference serving the Spina Bifida Community. Our presence in Louisville - site of SBA's largest conference a decade ago - will add to the excitement of the experience for all who attend.

Home to the Kentucky Derby and featuring over 980 miles of the Ohio River, Louisville is within a day's drive of half of the nation's population and easily accessible by air. Register now at [www.sbaa.org](http://www.sbaa.org)!

**Who Should Attend?**

**Adults with Spina Bifida:** Gain vital information about making the most of your life and health.  
**Parents of Children with Spina Bifida:** Learn innovative ways to help your children grow into independent and active adults.

**Children with Spina Bifida:** Experience the fun of Kids!Camp. Learn how much you can accomplish from other kids while having the time of your life!

**Medical Professionals:** Sharpen your clinical skills and gain insight into cutting edge therapies.

**Group Member Leadership:** Network with other leaders while attending helpful workshops designed to increase rewards and ease challenges.

Register online today at [www.sbaa.org](http://www.sbaa.org)! Or call 1-800-621-3141 to have a packet sent to you.

EXPANDING OUR  
**HORIZONS**  
  
**SBA 34TH ANNUAL CONFERENCE**  
June 24-27, 2007 | Kentucky Convention Center | Louisville, KY