



# Evergreen Spina Bifida Association Newsletter

## PRESIDENT'S MESSAGE

by Ed Kennedy

Hi there everyone, I certainly hope that everyone's bones are beginning to warm up to spring and a little more sunlight each day. I know that I myself sometimes find it quite difficult to deal with the short daylight hours of winter, so, I'm excited to see the seasons change. Now onto ESBA stuff! I put out an e-mail a couple of weeks ago asking about any interest in having an ESBA "summit" sometime this late summer or early fall. Wow!!! The interest is certainly there! From the feedback I received I could definitely see that there is greater interest in having this in the Seattle area (by Seattle area I mean the Puget Sound area in Western Washington.) Brian Knowles and Janet Davis have both be-

gun the footwork to research the costs of such an event in the area and would very much appreciate your help and input as to what you would need, want and/or expect at this. The slate is quite open right now and so please speak up (as many of you have) and let's try to see how this might all work out. As for calling it a "summit" - that's just kind of what I called it because I was looking at bringing our members together from wherever reasonably possible they might want to come from. I also hope that for those who cannot be there in person we might be able to have phone conferencing for something like our annual business meeting. So it's steady as she goes and we will be sharing more about this as the summer progresses.

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## GEORGIA HOUSE OF REPS PASSES MEDICAL INCLUSION BILL

HB 279, introduced by [Georgia]state Representative Doug Collins of Gainesville, was approved by a vote of 163-0 in the Georgia House of Representatives and has been sent to the Georgia Senate. HB 279 mandates on-going medical assistance for children with myelomeningocele spina bifida in Georgia, amending criteria for the inclusion of children with spina bifida for eligibility in Georgia's Tax Equity and Fiscal Responsibility Act of 1992, known as the Katie Beckett Waiver.

Under the proposed legislation, a child would qualify for coverage if: Born with myelomeningocele, the most severe form of spina bifida, "as these children

for one year after birth will require surgical correction of the spine, most will require shunting and complications from shunting will usually occur in the first year"; OR After the first year of birth has a least three of the following: (1) Shunted hydrocephalus; (2) Neurogenic bladder/bowel; (3) Severe physical mobility impairment including, but not limited to, wheelchair bound individuals; (4) Mental issues or learning disabilities which shall be evidenced by documentation that may include, but shall not be limited to, a formal individualized education program (IEP) or its equivalent; or (5) Rehabilitation needs or therapeutic

(Continued on page 3)

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

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[evergreensba@yahoo.com](mailto:evergreensba@yahoo.com)

Newsletter Editor  
Celeste McCormick

## STILL TRUE TODAY:

The least prepared teachers are systematically sent to teach America's neediest children.

Source: [www.mattmilleronline.com](http://www.mattmilleronline.com)

The regular "Getting to Know You" feature, which spotlights individual ESBA members, will return next issue.

## WOULD YOU ATTEND AN ESBA SUMMIT?

Dear ESBA members,

I am in the early stages of looking into planning an ESBA "summit." I need to find out an approximate number of people who might be interested in a "get-together" or "summit" in late summer or early fall 2007. I envision it to be a time where we can have time to get to know each other and hear from area professionals regarding spina bifida issues. There would be a cost involved and so I need to know a few things first.

1) Would you be interested if we had this event in the Spokane area? What if it was held in the Seattle area?

2) How much time would you be willing to spend on such an event - I envision it being a Friday afternoon, all day Saturday, and Sunday morning type of thing. We could also have our annual Business meeting.

Please let me know of your interest or disinterest and any other input you might have about such an event. I need your input within the next week to know how to proceed. Thanks!

Ed Kennedy - ESBA President

Write, phone or email your responses to Evergreen Spina Bifida Association c/o Jonathan Tutt 2128 N. Pines Rd., Suite 17-2 Spokane, WA 99208  
Toll-free: 888-289-3702 - WA: 253-589-3700 - Fax: 775-766-1654  
Email: [evergreensba@yahoo.com](mailto:evergreensba@yahoo.com)

# NEWS

**Changes expected in "No Child Left Behind" law - An AP article printed in February describes changes expected for the federal law that will make it more flexible for children with learning disabilities (who often include children with Spina Bifida) and children who are not native speakers of English. Under the current federal statute, accommodations like skipping the exam or having questions read to them are not available to these children; however, the law is scheduled to be rewritten next year. According to the article, "The dilemma is how to fix the problem without abandoning kids with special needs." The article highlights both sides of the issue, representing both those who want to redesign the law with more flexibility and those who caution against making it too lax. Read the full text of the article at**

[http://seattletimes.nwsourc.com/html/education/2003566743\\_nochild11.html](http://seattletimes.nwsourc.com/html/education/2003566743_nochild11.html).

**Scientists growing organs - Scientists grew a bladder for a 17-year-old girl with Spina Bifida using cells from her own body. She is one of seven people to receive a custom made bladder and without it she faced a lifetime of dialysis. The article shares details about this emerging science and its prospect for the future. Read the full text of the article at**

<http://abclocal.go.com/wls/story?section=health&id=5165588>.

## WALK ACROSS AMERICA THIS MONTH!

March of Dimes annual walk across America events are scheduled throughout our five-state region in April and May. To find an event in your area, visit <http://walkamerica.org/>



## HIGHLIGHTS FROM FEBRUARY BOARD OF DIRECTORS MEETING

- ESBA will provide \$500 to each delegate attending the national SBA convention; delegates are Joe Nugent and Ed Kennedy
- ESBA will not fund delegates to the Infant & Early Childhood conference
- The Spina Bifida Clinic in Billings Montana has received new funding
- Three-to-five year strategic plan is in development
- The recent set of Dr. Shurtleff’s newsletter articles have been sent to interested parties in Germany to increase knowledge about Spina Bifida

## ADOPTED BOARD POLICIES & SUGGESTED BYLAW AMENDMENTS

At the March board meeting, the following three policies were adopted. The proposed bylaw amendment was approved and will be submitted to the general membership for voting; this amendment is part of national SBA's new "minimum requirements" to maintain chapter status in the future.

### **Policy Statement: Conflict of Interest Statement**

In order to insure the ESBA's compliance of its tax-exempt status with the Internal Revenue Service's Section 501 [3] {c} regulations, it shall be the policy of the Association that all officers, directors and cluster leaders, as well as any members having any influence on the financial matters of the Association, shall sign and agree to adhere to and comply with the Conflict of Interest Statement that has been approved by the Board of Directors. Failure to sign the statement and adhere to its implementation shall make that person ineligible to hold their position in the association, whether elected, appointed or acting as a volunteer.

### **Policy Statement: Cluster Income &/or Finances**

To continue the mission of the Association, it is important that we protect our tax-exempt 501(3){C} status with the Internal Revenue Service. One way that this can be done is by adhering to accepted accounting principles, one of which is "Report all income". This should include all income generated by cluster leaders, even if the leaders maintain possession of those funds for their own cluster group activities. This will include any money given or received at any event sponsored by, involved in, or under the color of authority of the Association.

### **Policy Statement: Congenial Communications**

Recognizing that disagreements will occur, while acknowledging that there is a "right way" and a "wrong way" to handle them and agreeing that all discussion on disagreements should be handled in a statesman-like, diplomatic and democratic manner, in order to promote open, friendly and honest communications between officers, directors, members, interested potential members, the public at large and the national Spina Bifida Association, it shall be the policy of the ESBA that all communication between the above parties, whether written or oral, shall be courteous, respectful, mature and professional. Furthermore, any communication that does not comply with that, or that is berating, belittling, demeaning, or involves yelling or the use of profanity, shall not be tolerated, and will be sufficient grounds for removal from office by the Board of Directors.

Also, written communications by any officer as a representative of the ESBA, except when acting as a board or committee member of the national SBA, to said national Spina Bifida Association, to members or to the public at large, shall be cc'd to all members of the Executive Committee; all correspondence by other board members acting as a representative of the ESBA shall be cc'd to all board members.

### **Bylaw Amendment: Term Limits**

No officer or director of the ESBA shall be allowed to serve more than four consecutive two-year terms in the same office or position.

*(Continued from page 1)*

activities or exercises which shall be furnished directly by or under the supervision of technical or professional personnel no less than twice per month; OR After the first year of birth, has three or more hospitalizations for spina bifida related problems including, but not limited to, shunt malfunction, urosepsis, orthopedic surger-

ies or urological surgeries. ...

SBAG is working with Rep. Collins for Georgia Senate approval of HB 279 before it adjourns this session. Rep. Collins is the father of a 14 year-old daughter with spina bifida. Collins has never filed for the Katie Beckett Waiver, nor does his family have any future intention of filing for the coverage.



**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.**

## TOILET TRAINING ISSUES FOR THE CHILD WITH SPINA BIFIDA

### Toilet Training for the Preschool and Early School Years for the Child with Spina Bifida

No single process will work for all children; no single process will be effective across the lifetime of a child. Therefore, ongoing consultation with specialists in toilet training a child with impaired sphincters is often needed. We suggest the interested persons contact a nurse coordinator of their local, multiple disciplinary, spina bifida clinic for advice, references and ongoing consultations appropriate for the child in question. We will discuss the needs for participation by the child in whatever procedure is being used to help establish and support their autonomy and self worth.

Incontinence hampers participation in peer interactions and social activities. Medical and surgical management techniques are very good at

preserving health. However, in our experience, they successfully establish continence in less than half of the children with spina bifida at this age. Attitudes toward soiled and clean diapers described above for the infant and toddler should continue. Caretakers should consider explaining to their children that while they cannot prevent accidents because of their paralysis, odor free cleanliness is achievable and necessary for social acceptance. This objective and others can be explained without embarrassing or humiliating the child. There are four additional objectives for this age child: 1) Learn to dress and undress, 2) Assist in preparing for toileting procedures, 3) Learn that their noses may not detect the odor of urine or stool (habituation), and 4) Cooperate with caregivers during toileting procedures until completely independent.

*This is the fourth 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.*

Learning to dress can be taught in the morning, at naptime on awakening, before and after toileting and while undressing at nighttime for bed. In a similar manner, learning to assist with toileting procedures should begin and be advanced in small increments as the child incorporates each step into the daily regime. Learning may initially be slow and take extra time because of learning difficulties .... It is essential to teach these skills to the child or learned helplessness will result. Creating a detailed list of the steps required for successful toileting and posting them in the child's toileting area will help teach the entire process. That their child's nose does not detect foul odors needs to be acknowledged by parents and primary caretakers. If the children do not understand this process of habituation, they will deny that they smell bad. To teach them that their soiled clothing has a bad odor, the children can clean themselves with as little help as necessary. The soiled clothes should then be placed in an open container in a small room or closet. After a half hour or so the children should be led to the space with the soiled clothing and asked if they now detect the odor. This exercise, repeated if necessary, can teach the children that their noses are unreliable and defuse their tendency to argue with caretakers who state they have a bad odor and suggest the need to clean themselves.

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### NEW ALTERNATIVES TO BLADDER MEDICATIONS REDUCE SIDE EFFECTS

*by James Haxby*

In the past I've always had trouble taking bladder meds because of harsh side-effects. But I have come across a couple of good options for getting around these problems. One is a new medicated patch that you wear right on your skin. If you wear it very low on your abdomen it works great with minimal side effects. The only caution is that if you wear it too high up on your stomach, it gives you bowel problems. The other option that a Urologist recently showed me is putting ditropan directly into your bladder by dissolving it in a small amount of water and using a catheter to put it in, which minimizes side-effects. I am not saying that any of these advances keep you totally dry - just that they keep you somewhat dryer; you feel fewer cramps and spasms. And you don't get so many of the side-effects, like sleepiness and dry mouth, that you get with pills.



## TOILET TRAINING ISSUES FOR THE CHILD WITH SPINA BIFIDA

*continued from page 4*

Learning to cooperate with parents and caretakers in the toileting process requires teaching the child the following five concepts. 1) At this age, children are interested in their bodies' anatomy and function and how they differ or are similar to others. The anecdote related [in the last newsletter issue] about the 4 and 5 years olds, two boys, one with a urostomy bag, and a girl, passing urine illustrate this phenomenon. 2) They are old enough to begin understanding how their sphincter mechanisms should, but do not, work. 3) They can be assured that their particular manner of toileting can be private and neither revealed nor discussed with others. Federal Law in the United States and the United Kingdom require that schools offer private toileting places for children with impaired sphincters (Individuals with Disabilities Education Act, USA, Blackburn, 2002). Children at this age begin to understand the need for privacy for their genitals. They should have same-sex caretakers perform

and teach them about clean intermittent catheterization and various anally introduced medications for stool elimination. 4) Many persons with spina bifida can feel urinary bladder fullness and the predefecation urge. Some believe that children at this age can be taught these sensations during urodynamic studies and biofeedback sessions. There is a need for odor free cleanliness. Children with uncontrolled incontinence should be taught to examine themselves on a routine basis, both before and after physical activities that involve the Valsalva maneuver. They also need to learn to inspect and clean themselves when parents, friends, teachers and others who are aware of their sphincter impairment suggest they have a foul odor. Obviously, this goal can only be achieved if the primary caretakers share the knowledge of the impaired sphincters with those individuals who come in close contact with the sphincter-impaired child. Subtle, non-verbal communications should be used to prevent embarrassing the child.

Frequently, the odor increases slowly or develops when the children are concentrating on play.

### Toilet Training for the Late Childhood and Preadolescent Child with Spina Bifida

Unfortunately, our data indicate that the acquisition of independent toileting skills has changed only slightly over the past 15 years. Only half of our patients acquired socially acceptable independent toileting skill by 8 to 9 years of age, despite advances in urinary and bowel management. The antegrade continence enema may contribute to easier bowel management, but is not a solution for the non-compliant child or family. Urologic advances have improved renal health but have not solved the problems of continence. Placing the CIC catheter in the lying position, then sitting up allows better drainage of urine over the edge of the bed and reduces residual urine. We have observed significant complications, including an increase in urinary tract infections, following placement of

a Mitrofanoff stoma. Having the child change from a sitting position to a side lying position with a 45-degree turn toward the abdomen during drainage of the urinary bladder allows urine to drain downhill via the Mitrofanoff catheter, reducing residual urine. Reducing the residual volume has decreased the frequency of urinary tract infections. Children this age must acquire cleanliness and independent toileting; otherwise, they will enter middle or late adolescence with persistent and unacceptable stool and urine incontinence and odor. [We are sure that cleanliness] is a prerequisite to sexiness. Failure to develop independence in toileting can lead to disruption of the development of the typical relationship patterns. Without independence in stool and urine toileting, these two developmental processes are severely handicapped.

***In the next  
issue:  
Sexuality***

## Driver Mobility Resources in ESBA regions

*If you can recommend other resources, please share them with ESBA!*

**The Disabled Dealer of the Northwest  
(WA, OR, ID, AK)**

Online and In Print:

<http://www.disableddealer.com/>

21104 70th Ave W Edmonds WA 98026

800-854-4176 - Fax 425 -771-3946

Email [ddm@accessams.com](mailto:ddm@accessams.com)

**Silver Star Mobility**

578 Mason Way Medford OR 97501

[www.silverstarmobility.com](http://www.silverstarmobility.com)

**Silver Star NW**

Tacoma WA - 253-223-4034

877-848-9270

### Mobility Systems

Host of the Mobility Expo where ESBA has often had a table

Called "good idea people" by Patti Logan  
Sumner/Pierce County - 253-863-4744

### Mobility Concepts Inc

1017 54th Ave E Fife WA 98424

253-896-0970 - (888) 227-6375

Fax 253-896-0971

[www.mobilityconceptsinc.com](http://www.mobilityconceptsinc.com)

**Driving Rehabilitation Program Coordinator, Department of Rehabilitation Medicine, Division of Occupational Therapy, University of Washington Medical Center**

Recommended to Patti Logan by Julia

Hulsey: ask for Mary Lewis

PO Box 356490 Seattle WA 98195-6490

206-598-5857

<http://depts.washington.edu/rehab/care/driving.html>

Disabled Driving Clinic - 206-598-4830

*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  
SUCH AN IMPORTANT ORGANIZATION.**

## PARTICIPATE IN SPOKANE COMMUNITY PROGRAMMING

Greater Spokane's Cable Channel 14 is developing a new format called "Community-Minded TV." The goal is to include a diversity of community interests and points of view by providing residents of all ages with the opportunity to produce and distribute digital video programming. Your input to any of the questions below will help guide the development of this new local resource.

- Channel 14 will highlight positive things that are happening in our area. What does the phrase "positive things" mean to you? What kinds of shows would make a positive difference in our community and in your life?
- When you think about watching shows that focus on your communities, what comes to mind? What would "Real Spokane Life" TV look like?
- What's happening locally that you think is important, and that you'd like to see more about on TV? What groups or issues should be represented that might be hidden or neglected?
- Do you have an aspect of community life to celebrate or a community solution to share?
- What kinds of new local shows would you find enriching? What information or advice would you find meaningful if it was offered on Channel 14 programming?
- Do you have a particular idea or passion for any of these categories?
 

* Recreation & Environmental	* Health and Wellness	* Arts & Culture
* Business/Economy	* Family/Kids	* Adolescents/Youth
* Spirituality	* Social Equity	* Community Serving Agencies
- Are you involved in a community group that might be interested in watching or producing programs for CMTV? Could we lead a discussion with that group (8 - 12 people is ideal) and allow the meeting to be videotaped?
- Would you like to volunteer at CMTV? In what capacity? What would you need in order to feel comfortable producing your own community access TV show?

Please respond by sending an e-mail to [cmtv@community-minded.org](mailto:cmtv@community-minded.org), or leaving a message at 509-444-3088 ext 207. Thank you for your interest and participation.

## WATF Spring Workshop Series: For People with Disabilities & Seniors

### Find & buy the right assistive technology

Do you use assistive technology like ramps, hearing aids, wheelchairs or specialized computers? If so you know that selecting the right assistive technology for your needs can be difficult and costly. This workshop will walk you through the steps to successfully find the right assistive technology for your needs and introduce you to all of the funding sources available to purchase your assistive technology.

Seattle: April 3rd 1:00pm-3:00pm @ Center Park

### Do you want to own a business?

Have you always dreamed of opening up your own business? Learn more about the world of business ownership and the steps needed to be prepared to turn your dream into a reality.

Seattle: April 10th 1:00pm-3:00pm @ Center Park

Tacoma/Lakewood: April 9th 4:30pm-6:30pm @ Center for Independence

### Where to find startup business funding

Do you have a small business idea that needs money to get started? Are you running a small business that needs funding to bring it to the next level? This workshop will discuss what business funding options are available to people with disabilities in Washington State.

Seattle: April 17th 1:00pm-3:00pm @ Center Park

Tacoma/Lakewood: April 16th 4:30pm-6:30pm @ Center for Independence

### Better Budgeting

Do you want to fine tune your spending, reduce your debt or save more money? This seminar teaches principles, practices and skills of good money management that will make your financial life easier and help you reach your goals. Come and learn how to create your personalized spending plan.

Seattle: April 24th 1:00pm-3:00pm @ Center Park

### Understand & improve your credit score

Learn about credit, how to obtain free credit reports and how to manage your reports. You will get the information and skills to read your credit report, correct information, expand your knowledge of the FICO score, plus fraud and identity theft prevention. Tips on re-establishing credit also included.

Seattle: May 1st 1:00pm-3:00pm @ Center Park

### Home ownership resources for people with disabilities

If you would like to own your own home in the future, this workshop is a must. Representatives from Washington State Housing Finance Commission and HomeStreet Bank will share with you all of the resources available to first time homeowners, people with low incomes and people with disabilities.

Tacoma/Lakewood: April 26th 4:30pm-6:30pm @ Center for Independence

*Please let us know at least two weeks before the workshop if you will need an interpreter or any other accommodation.*

### REGISTER NOW!

Space is limited so call or email NOW to reserve your place.

206-328-5116

877-428-5116

800.214.8731

TTY: 866.866.0162

Fax: 206.328.5126100

South King St Ste 280

Seattle, WA 98104

Web: [info@watf.org](mailto:info@watf.org)

Email: [www.watf.org](http://www.watf.org)

## Summer Camp Directory Available Now

Looking for summer camps and programs for children with special needs? The 2007 Washington State Summer Camps & Programs for Children with Special Health Care Needs directory lists over 70 camps and programs in Washington State for children with special health care needs or disabilities. To get a free copy:

- Call the Children's Hospital Resource Line at 206-987-2500 option 4 or toll free at 866-987-2500 option 4. Leave a message requesting the Summer Camp Directory
- Visit the Center for Children with Special Needs website at

<http://www.cshcn.org/resources/campcalendar.cfm?intro=yes>



**An Idaho cluster is in the formation stage! Contact new Idaho cluster leader Pam Hoppman at 208-522-6206 or [barrysmispam@aol.com](mailto:barrysmispam@aol.com) for more information.**

### **OREGON CLUSTER IS OFF THE GROUND WITH ITS FIRST MEETINGS**

The Oregon cluster had its first meeting Saturday March 24 in Salem OR. It was more of a getting to know one another gathering for sharing ideas, struggles, and concerns about Spina Bifida in Oregon. Topics included current legislature activity and how effective the new cluster can become in the future for the state of Oregon. All are welcome—whether affiliated with ESBA or not—to attend upcoming meetings.

**Contact cluster leader Bill Pfankuch for more information: [pfankuch\\_bill@yahoo.com](mailto:pfankuch_bill@yahoo.com) or 503-362-8062. The next meeting is on May 19 at 4pm at 2344 Banyonwood Ave NW Salem Oregon 97304**

### **EVERETT & EASTSIDE SEATTLE CLUSTERS MERGE**

**The Eastside cluster has joined with the Everett Cluster! It does not yet have a new name, but for now will be called the Everett-Eastside cluster. The Eastside cluster met for the first time with the Everett cluster in March and learned the exciting news that Michele Hopkins and Janet Davis had met before. The group talked about how it can grow and what new things Michele could bring. The group will meet every first Tuesday of the month at the Everett Transit Station (be wary of Mapquest's directions which are not quite accurate). Meetings usually run from 12:30 – 2:30pm (end time varies with attendance). Snack & beverages will be provided. On the day of the meetings Michele Hopkins can be reached at 206-909-4186 so call her if you get lost! The cluster looks forward to seeing you!**

***For more information contact Brenda Stroud at 425-385-2487 or [frizzle3@verizon.net](mailto:frizzle3@verizon.net)***



**E-clec-tic:** to be made up of or gathered from a variety of sources

### **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](mailto: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](mailto: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](mailto: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

**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)***



## 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](http://www.sbaa.org)) for more recently announced session topics and speakers. There's truly a session for everyone!

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