



April 1, 2006

# Evergreen Spina Bifida Association Newsletter

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

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Newsletter Editor  
Celeste M McCormick

## US House votes to nullify 200 state food laws

*By Eric Keldeman, Stateline.org, 3-9-2006*

At least 200 state laws on food safety and labeling would be undermined by a bill predicted to pass the U.S. House of Representatives this week, says a broad coalition of state officials, environmentalists and consumer protection groups.

Everything from Alabama's nutritional standards for grits to the way Wisconsin labels cheese and smoked meats would be invalidated if the legislation were enacted, a bipartisan group of attorneys general argued at a news conference Tuesday [March 7].

But food industry representatives and the bill's sponsor argue that the legislation is meant to unify a patchwork of state laws that are costly to business and confusing to consumers.

US Rep. Mike Rogers, a Michigan Republican, is the main sponsor of the bill, titled the National Uniformity for Food Act, which will standardize food labeling and require states to petition the federal Food and Drug Administration (FDA) for safety regulations that are more stringent than the national

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## I THINK I'M FEELING SEASICK! Things are changing in ESBA

*By Ed Kennedy, President of ESBA*

I don't think Evergreen Spina Bifida (ESBA) has been the place to be lately if you are at all prone to getting any kind of motion sickness. Things have been happening and changes are definitely in the works for all of us in ESBA.

One thing still being "thrown around" by the National Spina Bifida Association (SBA) and ESBA is whether or not ESBA will have to change its name to conform with new "branding" requirements by SBA. SBA is asking that all chapters affiliated with National follow a basic template in their name, that template being, "Spina Bifida Association of \_location\_". In other words we would need to change our name to something like, "Spina Bifida Association of the Pacific Northwest." We have dialoged with national regard-

ing this change and are very concerned because we have been known as Evergreen Spina Bifida Association for so long that we will very possibly lose some recognition in our service area not to mention the costs involved for us to make this change. Stay tuned for more on this issue in upcoming months.

Another big change in the works for ESBA is that our bylaws have been rewritten and will soon be made available to everyone for ratification. These new bylaws lead to another big change because we will possibly be moving from our current "Advisory" board type of governing body to a new "Board of Directors." Our officers will still be taking responsibility for the day-to-day operations of the organization but the Board of Directors will state to the

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## Current changes in ESBA can cause motion sickness

*(Continued from page 1)*

officers the direction that they want the organization to go and the board will be responsible for the budget and overall actions of the organization. If that was not enough, our "Bylaws" committee has now become the "Policies" committee and will be addressing policies for our organization

to ensure that we deal with different issues in a consistent manner. So rest assured we are moving forward and I believe accomplishing our mission to the best of our ability. Can we do things better? Of course, and I believe that these changes will be just another step in the right direction. Thank you all for being part of ESBA!!!

## House approves bill to eliminate state food safety laws

*(Continued from page 1)*

standards.

Rogers' bill, which passed the House Committee on Energy and Commerce without hearings, has 226 cosponsors, including 59 Democrats, said his spokeswoman, Sylvia Warner. The 435-member House could vote on the bill as soon as this week. A companion bill has not yet been introduced in the U.S. Senate.

Backlash to the bill has been equally broad-based and includes 39 state attorneys general who have signed a letter urging Congress to reject the measure. The Association of Food and Drug Officials and the National Association of State Departments of Agriculture also oppose the bill, as does the non-profit Consumers Union, the Natural Resources Defense Council (NRDC) and the National Environmental Trust.

### ■ **SHARE YOUR LIFE EXPERIENCE AND HAVE IT PUBLISHED**

#### ■ **New book coming: Your life experiences wanted!**

■ ***By Kathie Snow, Disability is Natural Free Press***

■ **If you're familiar with my presentations, books, or articles, you're aware that my greatest teachers have been people with disabilities---they're the true experts. Specifically, adults with developmental disabilities have shared personal experiences of their lives---experiences from their childhoods and their lives today--- and they've helped me become a better parent and a wiser human**



**being. In turn, I've tried to share this wisdom with others. But I know there's much more wisdom out there, and I'm collecting the personal stories of adults with developmental disabilities in a new book---a book that can help parents, educators, service providers, and others learn what's really important to children and adults with developmental disabilities! You can retrieve the Request for Stories from the home page at**

■ **[www.disabilityisnatural.com](http://www.disabilityisnatural.com) or write to me at [kathie@disabilityisnatural.com](mailto:kathie@disabilityisnatural.com) and request the appropriate version of the Request for Stories---and please share this request with the adults with developmental disabilities in your life!**

## Getting to know you: ESBA spotlights member Michael Hoyt

*By Diana Tutt*

Meet Michael Hoyt, age 7½, through the eyes and heart of his Nana. He is a very loving, affectionate big-blue-eyed, red-haired dynamo. Our grandson is a charter member of the Spokane Spina Bifida Support Group. He loves to attend the meetings and recently enjoyed a pizza party with the group. He was joined by his greatest supporter and advocate, his mom, Colette. Younger sister Chandra along with his Nana and Papa and our regular group all enjoyed the get-together. Our president Ed Kennedy is a great role model for Michael. The Spina Bifida support group is a blessing. While Michael has faced many medical issues and surgeries, he is always up to the challenge with a smile and a loving hug. He is my hero. Due to his mother's determination that he be all he can be and live a full and happy life, he plays on St Luke's wheelchair basketball and track teams. He is quite a good athlete. Michael recently attended a basketball tournament in Vancouver, Washington. As required to be on the team, he rode the team bus and stayed in a hotel without his mother and bonded with the team.



*Michael Hoyt, photo courtesy of Jon Tutt*

This is quite an accomplishment for any 7 year old! His mom was able to attend the tournament and video the event. Michael loves to ride his quad motorcycle in our backyard along with Chandra on her jeep and Papa supervising. Nothing stops him from having a happy fun childhood, even though he often tells me, "Nana, don't be so worried." Michael loves Power Rangers and can do the moves. He wants to be a police officer when he grows up. School can be a challenge, but his mom is making sure he gets all the services and help he needs to be successful. We are so fortunate that Michael and family live only a few blocks from us so we can see them all the time. When I learned Michael would be born with Spina Bifida, I was devastated for my daughter and the baby. This has turned into knowing Michael is exactly as God intended and a blessing of the deepest kind to our family and community. Michael always says, "you're the best!" Well, I send it back to you Michael, you're the best!

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

***He often tells me, "Nana, don't be so worried!"***

### New website launched for youth with disabilities

The National Consortium on Leadership and Disability for Youth (NCLD-Youth) has launched its website at <http://www.nclid-youth.info>. NCLD-Youth is a youth-led resource, information, and training center for youth and emerging leaders with developmental disabilities, housed at the Institute for Educational Leadership and funded by the Administration on Developmental Disabilities.

The project is led by the next generation of young leaders with disabilities for the next generation of young leaders with disabilities-- taking a positive development approach to working with the next generation of disability community leaders, and developing materials to better prepare them for the transition to adulthood, and leadership. The website can be found at <http://www.nclid-youth.info>.



## Attend the Seventh Annual Washington State Youth Leadership Forum for High School Students with Disabilities

**About the forum:** The forum is a five-night, six-day innovative and exciting career awareness program that bring together young people with disabilities to help them develop leadership skills, improve academic success, become more involved in extra-curricular activities (such as sports, arts, music or community involvement), and learn to interact effectively with other people. Presenters who will meet with the students include disability community leaders, legislators and other professionals.

**Events at the forum:** The Forum includes small group discussions with fellow students, large group presentations by successful community leaders, a dance, a talent show, a formal luncheon with community leaders and a meeting with the Governor or her representative.

**When it will occur:** The Forum will take place **August 6-11, 2006**, at Evergreen State College in **Olympia Washington**.

**Cost:** The project is completely funded by private donors and requires **no cost** for attendance.

**Sponsorship:** The Youth Leadership Forum is a cooperative project with the state Employment Security Department, the Developmental Disabilities Council, Department of Personnel, Bates Technical College and many other disability organizations.

**Eligibility:** The Forum is for high school juniors and seniors (as of December 31 2005) with disabilities who want to be or are leaders in their communities and schools. (Some age exceptions may be made.) Students **do not have to be receiving services** to apply for this Forum.

**How to apply:** Application packets are available from Debbie Himes at 360-438-3246 (voice), 360-438-3167 (TTY), or [dhimes2@esd.wa.gov](mailto:dhimes2@esd.wa.gov) (email). Completed application packets must be postmarked **by May 15, 2006**. 35-45 students with disabilities will be selected to attend.



June 9 - 10, 2006  
 Hilton Washington  
 Washington, D.C.  
**REGISTRATION  
 DEADLINE:**  
 Wednesday, May  
 3, 2006  
[www.vsarts.org](http://www.vsarts.org)

### ***VSA ARTS INTERNATIONAL CONFERENCE*** **Exploring Accessibility, Inclusion, and Arts Education**

The *VSA arts* International Conference is a gathering of professionals in the arts, education, and disability fields committed to growing inclusive communities and taking bold steps to expand opportunities for all people to learn through, participate in, and enjoy the arts.

#### ***JOIN US IN TAKING Bold Steps in Breaking through Barriers***

***Bold steps*** to create unquestioned access to inclusive arts learning programs in schools and communities that develop artistic, academic, and social skills for everyone. ***Bold steps*** to establish an inclusive arts community where everyone is welcome and can fully experience and delight in the offerings. ***Bold steps*** to empower people with disabilities to become accomplished professionals in their field of choice within the arts.

#### **Keynote Speakers and Book Signing**

**Elliot Eisner, Ph.D.**, author and leading theorist on arts education and curriculum studies.

**Temple Grandin, Ph.D.**, best-selling author and noted speaker on autism.

Dr. Eisner and Dr. Grandin will be available to sign books following their keynote presentations. *The Arts and the Creation of Mind* and *Animals in Translation* can be purchased in the signing area courtesy of Politics and Prose Bookstore and Coffeehouse.



## Confused by the new Medicare Prescription Drug Program?



Need help sorting through all the plans to find the right plan for you? Then come meet with a representative from Statewide Health Insurance Benefit Advisors (SHIBA) who will sit with you at a computer and help you find a plan that meets your specific needs.

Bring your list of medications and dosages to  
**Aging and Long Term Care of Eastern Washington**  
**1222 N Post Spokane WA 99201**  
**Every Tuesday March 7 through May 9, 9am–5pm**

*You will be helped on a first-come first-served basis*  
*For more information call SHIBA and ask for*  
**Kathy or Leslie**  
**509-458-2509**

## 2006 SUMMER CAMP DIRECTORY FOR CHILDREN WITH SPECIAL NEEDS NOW AVAILABLE

This free directory lists 70 camps and programs in Washington and Idaho serving children with special health care needs or disabilities. The camps and programs are hosted by a variety of organizations and serve children with physical disabilities, learning and developmental disabilities, behavior disorders, general medical conditions and many specific medical conditions including asthma, diabetes, sickle cell disease, muscular dystrophy, cancer, Down's syndrome, hearing loss, epilepsy, autism, hemophilia and HIV/AIDS.

**Browse the directory online** at the Center for Children with Special Needs Website [www.cshcn.org](http://www.cshcn.org)

**Get camp info over the phone** from the Children's Resource Line at 206-987-2500 option 4 OR 866-987-2500 option 4

### Access additional resources related to special needs camps

- *Sending your child with special needs to camp*, provided by KidsHealth for Parents, [www.kidshealth.org/parent/system/ill/sending\\_child\\_camp.html](http://www.kidshealth.org/parent/system/ill/sending_child_camp.html)
- *Finding a Camp for Your Child with Special Needs*, provided by KidsHealth for Parents, [www.kidshealth.org/parent/system/ill/find\\_camp\\_special\\_needs.html](http://www.kidshealth.org/parent/system/ill/find_camp_special_needs.html)
- *Discover Camp: A Booklet on Camps for Children with Disabilities*, provided by National Center on Physical Activity and Disability, [www.ncpad.org/get/discover/index.html](http://www.ncpad.org/get/discover/index.html)



## ***THE EVERGREEN SPINA BIFIDA ASSOCIATION*** **2006-2007 MEMBERSHIP/RENEWAL APPLICATION FORM**

**Membership in the Evergreen Spina Bifida Association for 2006-2007 is on a donation basis. Please send a donation of any size to help us reach out to those affected by spina bifida. The Evergreen Spina Bifida Association will pay for membership in the national Spina Bifida Association for all of our members as well. For donations over \$40, membership will be for two years beginning July 1, 2006.**

**Please complete this form with your donation and return it to the following address before March 20, 2006.**

**The Evergreen Spina Bifida Association (ESBA)  
P.O. Box 642  
Sumner, WA 98390**

***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.***

NAME

SPOUSE NAME

STREET ADDRESS

CITY

STATE

ZIP

HOME PHONE

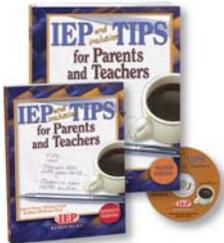
EMAIL ADDRESS

PERSON WITH SPINA BIFIDA

DATE OF BIRTH

### **HAVE BETTER IEP MEETINGS**

Check out the newly published *IEP and Inclusion Tips for Parents and Teachers*, a great resource and written from a parent perspective by Anne Eason, an inclusion attorney, and Kathleen Whitbread, an associate professor. Anne and Kathleen present 127 helpful tips which can enable parents and educators to work together more effectively and ensure the success of their students. Learn more by visiting [www.attainmentcompany.com](http://www.attainmentcompany.com), then type "IEP and Inclusion Tips" in the search box.



### **ODEP REDESIGNS WEBSITE**

The Office of Disability Employment Policy (ODEP) in the US Department of Labor has redesigned its website to better reflect the policy nature of its mission. The website can be found at <http://www.dol.gov/odep>. ODEP provides national leadership by developing and influencing disability-related employment policy and practice affecting the employment of people with disabilities.

## Coretta Scott King called us to build the Beloved Community

*Building the Beloved Community*  
By Coretta Scott King

In the "I Have A Dream" speech, delivered by my husband, **Martin Luther King, Jr. in 1963, he challenged the nation to eliminate racial injustice, and he filled the hearts and souls of freedom-loving Americans with his clarion call to unify America in "a beautiful symphony of brotherhood."**

It has been a long time since we heard our political leaders talk about brotherhood and sisterhood hasn't it? Yet, I believe that the full rainbow of humanity has not been tossed on these shores by mere coincidence, but to provide an irresistible demonstration of community for the rest of the world. Our strivings to meet this challenge is the great work of democracy. When this vision of unity is finally fulfilled throughout the nation, then the America of our noblest ideals will become a reality.

And a daunting challenge it is.

... The struggle against racial injustice must continue. **But justice requires that we be equally vigilant in protesting against all forms of bigotry, prejudice and discrimination based on religion, gender, nationality, sexual orientation, age, physical or mental disability and other kinds of injustice** that degrade the quality of life for millions of citizens.

Brotherhood and sisterhood is not only about group identity, but also respect for diverse political beliefs. This is also a cornerstone of our democracy and a great source of strength for our nation. In this election year, our challenge is to conduct the dialogue of democracy on a high plane of civility, to respect the dignity and personhood of our political adversaries, even as we disagree on

issues and matters of policy.

**We have learned that no single group can fulfill the Dream by itself.** Yet, together we can co-create a society rooted in multicultural brotherhood and sisterhood, in which all citizens can have a fulfilling, productive life.

During the Civil Rights Movement... We learned that inclusiveness was not just a political goal, but also the way to bring greater justice and unity to America. My husband once said, "We have to be together, before we can learn to live together."

We have also learned that legislative reforms can reduce discrimination, but no laws can change attitudes. **To make the great ideals of brotherhood and sisterhood a reality, we have to create a revolution in the heart.**

My husband frequently used the term "the beloved community" to describe the kind of society, in which every person was valued and where all conflicts could be reconciled in a spirit of goodwill and mutual benefit. **We are still struggling to make America a beloved community, where all of us can live together in a climate of understanding, cooperation and unity.**

We have to do a lot more consciousness-raising to build the great coalition of all races and cultures needed to make his dream a reality. We must work together with an energetic determination to build new bridges of understanding and trust, cooperation and goodwill between our communities. Everyone can make this important contribution to fulfilling the dream.

**... May we, the people of all races, religions and nations, have the vision and courage to create the global community of caring and compassion, where all people can live together in peace and justice?**



*Coretta Scott King*  
(1927-2006)

*These words are excerpted from an article written by Coretta Scott King and provided by the Justice For All Email List at [www.jfanow.org](http://www.jfanow.org). Photo courtesy of [free-stock-photos.com](http://free-stock-photos.com).*

# Kitsap Cluster Potluck PICNIC

**Saturday, June 17 12-4pm, Evergreen Park in Bremerton**

at picnic shelter #3 near the kids' playground

*In case of rain, we will meet at the ARC of Kitsap County 3243 N. Perry Ave. Bremerton*

**Please bring your favorite picnic foods to share: salads, side dishes or deserts.**

**Hamburgers, hot dogs, drinks and service ware will be provided.**

**Please RSVP by June 10 to one of the Kitsap Peninsula Cluster Co-Chairs:**

**Dave Lewallen, 360-871-5139, Daviddlbg@aol.com**

**Rebekah Uhtoff, 360-782-0467, ruhtoff@att.net**

### **About the Kitsap Peninsula Cluster**

The Kitsap Peninsula Cluster has three main goals.

1. Provide opportunities for people with Spina Bifida, their friends and families, and support professionals (i.e. in the medical and educational fields) on the Kitsap Peninsula to meet on a regular basis.
2. Establish networks to provide support, experience, and information valuable to people with SB and their families in an effort to improve quality of life.
3. Attend community activities, such as health or resource fairs and diversity activities, in an effort to educate everyone about the benefits of daily folic acid supplements in the prevention of SB and other neural tube birth defects and to increase awareness of SB and compassion for those people whose lives are effected by birth defects.

### **Cluster events planned for 2006**

September 30 - Autumn Fest with caramel apples

December 2 - Holiday party with gift exchange

# Livable Communities Fair

**Saturday April 8 at the Puyallup Fairgrounds**

A Pierce county-wide effort aiming to raise awareness about projects and programs that make communities more livable

\*

An opportunity for individuals, companies, developers, nonprofits and government agencies to share ideas for improving the community

\*

**For more information contact**

Fair manager Diane Braaten at 253-798-7477

Or visit the fair website [www.livablepiercecounty.org](http://www.livablepiercecounty.org)

## Meet some of the oldest people in the world living with Spina Bifida

The International Federation for Spina Bifida and Hydrocephalus (IF) sought to identify the oldest person living with Spina Bifida. That title has been given to Albert De Greve who is 82 years old. During its search, IF met other interesting older persons living with Spina Bifida. Read below for their stories.

*All stories and photos are courtesy of IF.*



**Albert De Greve**

**Albert De Greve** lives in a retirement home in Sint-Niklaas, and says he is very happy there. He has a low lesion Spina Bifida and no hydrocephalus. "Not having hydrocephalus saved my life, because back in those days, there was no treatment for it. Children with hydrocephalus were left to die," he says. He suffered 45 years with a chronic infection on his foot. Doctors could not do much more than make an incision and prescribe foot baths.

Disabilities to him are restrictions by society. In the past ... poverty, World War II and hunger were ... more prominent [issues] than his disability. He says, "what is disability? Limping, like me, or totally relying on others like this 60-year old woman down the corridor [with] Multiple Sclerosis?" He is still very lucid and mobile, despite the paralyzed feet and calves. Albert never got married and did not have children. ... He was not lonely: he had many friends, likes to play cards and dance. "Not a quick waltz, of course, but a nice tango."



**Françoise Chabot-Quigley**

*The story of **Françoise Chabot-Quigley** is shared by Ginette Bélisle, director of the Association de Spina Bifida et d'hydrocéphalie du Québec:*

"Françoise was born ... in 1926 ... [making] her almost 80 years old. She was [diagnosed] with a spina bifida right after her birth. She was operated for her spina bifida in July 1927 .... After that she wasn't operated ... [on] anymore.

"She grew up physically and mentally normal. One of her legs is a little shorter than the other one ... [so] she wore prosthesis in her shoes. She studied at Couvent des Soeurs Ste-Chrétinne near Québec, she recalled notto (sic) like math and grammar but enjoyed history and geography. She is quite handy. When her feet were cold, she was slightly incontinent. The worst is climbing stairs or doing tasks with her arms up in the air.

"She married in 1949 ... and had no children. In 1954, the couple bought a house and moved to Laval Quebec where she has lived since. Shortly after her husband's death, she took courses and received her driver license at 68 years of age...I find her a woman of high spirit and very pleasant to talk to."



**Krista Raynor**

***Krista Raynor** of Virginia USA is introduced by her mother Susan Belongia.*

"Krista was born in 1969... She had her first surgery at 1 hour of age and has had 9 surgeries since then. ... Five of those surgeries were for shunts. She went to regular public school. Krista was the first in our city to force the schools to do this. As she rose through the school system, they built ramps in the schools for her. She then attended and graduated from college."

"Near the end of college, Krista married. She was able to give birth to three boys. They are a handful, but she is able to care for them almost entirely on her own. Krista is married, but her husband is gone most of the time. She copes with her situation in a small rental house, where she can not reach the sinks or the washer and dryer. Krista does not ask for help though. She has taught herself to cook well and care for her children. ... I think Krista is very special."

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

**PO Box 642 Sumner WA 98390**  
**Phone: 253-589-3700**  
**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)***

**Connect with a cluster group**

City/State	Leader Name	Contact Phone
Portland OR	Gina Schuermyer	503-761-8193
Helena MT	Joe Nugent	406-458-9549
Madigan	Dr. Ellen Davis	253-589-3700
Vancouver WA	James Haxby	360-258-4148
Spokane WA	Ed Kennedy Susan Curalli	509-465-0676 509-892-6757
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

