



Evergreen Spina Bifida Association Newsletter

ESBA EXPERIENCES CHANGING OF THE GUARDS

by Ed Kennedy, ESBA President

Hi to everyone, I hope all of you are having an enjoyable and safe summer! As most of you already know we have had a “changing of the guard” in that we now have a new “Board of Directors” and new officers for ESBA.

I want to take this opportunity to thank each person who has served as an officer or on our advisory board for the past year or two (or in some cases longer). As past officers there is Brian Knowles, Co-Chair and Annette Zweig-Donham, Treasurer. Both of these people have served the ESBA over the long haul and have been instrumental in helping ESBA in becoming a better organization. Brian and Annette have both been elected to serve positions on our new Board of Directors.

All of our past Advisory Board Members were invited to and will serve in positions on the new Board of Directors (BOD); however, we did have a couple of people who have decided to step aside for the time being. First, Ed Baroch of Leavenworth, WA has been an active and dedi-

cated member of ESBA. Ed has been a real catalyst for change in the organization and an unofficial “liaison” between the ESBA and a couple of organizations that he is heavily involved with. I personally am thankful for Ed and Dorothy’s continued support of ESBA as early in my tenure as Co-Chair of the organization I found Ed to be supportive and a straight-shooter when it came to issues he felt strongly about and in the best interest of ESBA. Next, Susan Curalli of Spokane WA has been a personal friend of mine for over 20 years now and it has been a pleasure to work with her on ESBA issues. It is with Susan’s support and encouragement that I began my journey with ESBA and we together started the Spokane Cluster. Susan will remain active in leadership of the Spokane Cluster of ESBA.

Lastly, I want to welcome a few new people who have stepped up to serving on our Board of Directors who have not served in a leadership capacity in the past. They are James

(Continued on page 5)

Inside this issue:

Getting to know you	2
ESBA may change its name	2
Eugenic abortion opinion piece	3
Spina Bifida opinion piece	4-5
National convention highlights	6-7
Cluster news	8-9

SBA strives to increase Folic Acid consumption in Latino communities

by Christine Poward, Chief Operating Officer, SBA

As we alluded to at the Annual Meeting last month, SBA took a leadership position in our ongoing efforts to reduce the incidence of Spina Bifida in the Latino community. Yesterday at the Annual Meeting of the National Council of La Raza (NCLR) it was announced that GRUMA, one of the world’s largest producers of corn flour and tortillas, has begun researching and conducting product testing with the goal of enriching its corn products with folic acid in the U.S. by the end of 2006.

SBA Chair Doug Sorocco and Jesus Arroyo, a member of Colorado SBA were among the featured speakers at this historic announcement. Doug spoke eloquently about the ramifications for 60 million [at-risk] women ... of a Spina Bifida Community and of SBA’s dedication to the special needs of the Hispanic Community. Jesus shared his personal experience as he spoke about the food his family loves as a representative of Latino families in the U.S. We are proud of these two outstanding representatives of SBA and the Spina Bifida Community.

Please visit SBA’s Web site to learn more about this important development in the history of SBA and the Spina Bifida Community. We urge you to share this news with your members. Please keep watching www.sbaa.org for ongoing updates as this story continues to unfold.

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

PO Box 642
Sumner WA 98390
Phone: 253-589-3700
Email:
evergreensba@yahoo.com

Newsletter Editor
Celeste McCormick

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!

GETTING TO KNOW YOU: JUANITA HALLAM

by Ed Kennedy, ESBA President

Meet Juanita Hallam, a 45-year-old woman who lives in Spokane WA at Mary Glen, a parent co-op group home. Juanita



Juanita Hallam (photo by Jon Tutt)

keeps her day busy with various activities like ceramics on Tuesdays, bowling on Wednesdays, stitchery on Thursdays and volunteering at Coalition of Responsible Disabled on Fridays. Juanita has lived at Mary Glen since she was 18 years old and likes the home-style atmosphere. Juanita often spends weekends with her parents in Kettle Falls where she enjoys visiting with her various family members. Juanita has been a joy to have at our monthly Spokane Cluster meetings with her continuous and never ending smile that brightens every room. Thanks Juanita for being a great part of ESBA!

ESBA considers changing its name to fit national standards

by Celeste McCormick, Newsletter Editor

Recent policy changes at the national level of the Spina Bifida Association (SBA) have resulted in a requirement that ESBA change its name if it wants to remain a credentialed chapter. According to ESBA Vice President Joe Nugent these policy changes began at the 2005 national conference. "SBA put out something they called Branding...; all things printed using the SBA logo must meet SBA standards," he explained, because the SBA logo is a registered trademark. At the 2006 national conference a draft of the new policies was issued; one new policy mandates that chapter names must identify the chapter and its service area. "ESBA has a service area of five states... so we need a name that IDs our service area," said Joe.

ESBA President Ed Kennedy explains that without the credentials from SBA "we would still be able to do our cluster activities [but] it would make it harder for us to do any kind of fundraising. I personally feel that being credentialed by national gives us the ability to say to potential funders that we are serious about our need and about what we do as an organization and are a part of a nationwide entity and this gives us some 'clout' ..." In mid-July the ESBA Board of Directors agreed to explore removing Evergreen from the name and adding "Northwest" or "Northwestern" instead.

To circulate this news and get members' input

Joe emailed a survey on July 19 asking anyone to submit suggestions for names that identify the service area and follow the format "Spina Bifida Association of [chapter name]." Other names already suggested are "Spina Bifida Association of the Northwest United States" and "Spina Bifida Association of the Northwestern United States." The email also asked for opinions about these candidates. ESBA Treasurer Jon Tutt explained his preference for the former: "[It] accurately describes our five state region. To me even though Washington is the 'Evergreen State' that really only refers to western Washington."

The name change could have practical consequences for ESBA—several of which were raised by member Patti Logan. "...We will likely have to change our email address and web site domain name... with [post office box] change and phone number change that will mean EVERY AVENUE OF COMMUNICATION with our group will have changed. My biggest fear is that folks out there won't be able to find us at all!" To prevent this possibility Patti recommends involving the members in the name change process and then using the new name as much as possible to make it familiar. She also thinks that "It would be helpful if it is a name we can say easily."

For now the name change is still in progress and this newsletter will continue to report developments. Any members who have opinions about the new name are encouraged to contact ESBA.

ESBA BOARD MEETING MINUTES are available upon request from Secretary Nancy Nugent at MTgrandma-bear@yahoo.com.

A disabled person's perspective on eugenic abortion

by Celeste McCormick, Newsletter Editor

Several ESBA members recently discovered a 2003 abortion editorial on the website of Society for the Protection of Unborn Children (SPUC) written by Allison Davis, Coordinator of SPUC group No Less Human, who has Spina Bifida. She offers research supporting her opinion that the medical field exerts undue pressure for prenatal screening and, when screening discovers an abnormality, for eugenic abortions. Here are a few of Davis' supporting points.

- She cites many sources to indicate that most pregnant women, especially those who have a disability, are pressured to have prenatal screening. One report stated that if an abnormality is found "counseling about an abortion should be given as a matter of course...."
- She also cites sources that report parents are not always given accurate information about the baby's condition nor directed to support groups that could provide information
- She sees a disconnect between the perceived "tragic" potential that screening could eliminate a "healthy" child when compared to the "justified" elimination of disabled babies
- She questions why health services' discrimination against disabled persons is considered unacceptable but aborting disabled babies is considered acceptable
- She takes issue with the term "at-risk" pregnancy: "Risk implies a bad outcome. Does anyone ever speak of the 'risk' of something good happening?"
- She relates several anecdotes from parents who withstood pressure to terminate their pregnancies; one mother said of her daughter, "I wouldn't want to change her in any way."

After reading the article ESBA members Patti Logan and Jon Tutt offered their reactions.

- From Jon: "To think that doctors, who take the Hippocratic Oath of "Do No Harm," could encourage pregnant women to abort their babies because they will have disabilities smacks of Nazi Germany and Hitler's endeavor to create a 'perfect race.' I find it appalling."
- From Patti: "I am glad I refused genetic testing early in my pregnancy with Heather and also glad I knew she had Spina Bifida before she was born, but abortion for that reason is not something I would choose. I was angered that these 'counselors' are not giving support to families who choose to keep their babies. That's where our organization comes in, and hopefully good counselors will refer them to us and other groups like us."

Do you have a reaction to this article? We want to hear it! Please send any comments to the newsletter editor at Evergreensba@yahoo.com. To read the article online please go to

<http://www.spuc.org.uk/documents/papers/e-0079b.pdf>

***Eugenic:
Pertaining to or
causing
Improvement in the
type of offspring
produced.***

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

LETTERS TO THE EDITOR

Dear Editor,

It has been brought to my attention that when you interviewed me and when I acted as your only proofreader for the article in the June issue of the ESBA newsletter regarding the new bylaws, that I overlooked mentioning one very important name in the process that we as a committee went through: Ed Baroch.

Ed was one of two members that attended the "Legal Compliance Issues" session at the 2005 national conference. From that session he left with the knowledge that our bylaws needed to be reworked and was the driving force before and at Camp Prime Time that actually got

the process started. Although Ed was unable to actively participate in our committee meetings because he was out of the country, Ed's initial encouragement and suggestions, including emails, meetings and phone calls, went a long way in moving the bylaws to the point where the committee took over.

I firmly believe that the efforts of all ESBA volunteers should be recognized and acknowledged. It was my fault alone that Ed's name was not mentioned in the article and I apologize to Ed and his family and request their forgiveness.

Jon Tutt, Chairman, ESBA Bylaw Review Committee

OPINION: WHAT IS SPINA BIFIDA?

by David B Shurtleff, MD, Medical Advisor to ESBA

I have been asked as to why I object to the term “**Spina Bifida.**” I will attempt to explain. The term was introduced by Nicolas Tulpius in 1463 as a result of the autopsy examinations of babies that died with an open form of Spina Bifida Aperta. In this form, the process of folding and fusion in the mid line fails, there remains an area of bone in two parts (Spina Bifida) and a failure of skin to cover the intervening space [Aperta]). Today this type lesion is called Myelomeningocele (Myelo {nerves} menigo {membranes that cover the spinal cord and brain}cele{sac}) or Meningomyelocele. Since the time of Tulpius, a number of scientific advances have demonstrated that the term “Spina Bifida” is insufficient to describe the many normal and other types of “Spina Bifida.”

The most benign ... involves the separation of the bony portions of the usually closed spinal vertebral arch not being closed and, hence “spine in two parts” = spina bifida. One in every 7 persons **without a family history** of an open spinal vertebral defect – “Spina Bifida Aperta” – have x-ray evidence of posterior vertebral spine failure to close. Nicholas Tulpius, of course, did not know this since we did not learn of this frequency of the isolate bony abnormality without symptoms until 500 years after his death. Why is “without a family history” in bold? Simply because **some** families have more than one relative with Spina Bifida Aperta and their immediate relatives will have an increased frequency of the failure of the posterior vertebral spinous processes to fuse.

Is there a way to determine this? Yes! Ordinarily the spine is comprised of 8 cervical (neck) vertebrae, 12 or 13 thoracic vertebrae (vertebrae with ribs), 4 or 5 lumbar vertebrae (without ribs and just above the pelvis) and the 5 or 4 sacral vertebrae that are fused into one bone, the sacrum, that is part of the pelvis separated by the sacroiliac joints. Families with multiple cases of Myelomeningocele will have relatives with posterior vertebral arches open at above the lumbar 4 and below the 1st sacral vertebra more frequently than ... families without a family member with a Myelomeningocele. How long has this phenomenon been known? Not until the discovery of x-ray. However, Paleolithic finds have demonstrated bony evidence of these abnormal “spina bifida” amongst Northern European skeletons dating to 300-400 years BC, Spanish skeletons dating to 10,000 BC, Egyptians dating to 3000 BC, North American native Modoc Indians and Eskimos dating to 2000 BC. Were these Paleolithic finds representative of Myelomeningocele, (Spina Bifida Aperta)? The only evidence I know is the Egyptian hieroglyphics that portray babies with anencephaly or encephalocele (brain anomalies) amongst holy objects along with hibiscus and monkeys.

What is the connection between these last two brain abnormalities and “Spina Bifida?” A number of family and epidemiologic studies have identified these two abnormalities of the central nervous system (brain) and Myelomeningocele. These lesions are more common in the families of patients with Myelomeningocele and are the brain equivalents of Myelomeningocele with brain protruding into the sac ... or absent with no sac ... They are collectively called “neural tube defects.”

Why is such a relationship of importance? These two severe brain abnormalities are fatal shortly after birth and are reduced in family recurrence and the general population occurrence by administration of large (100x the daily recommended dose) of Folic Acid to the mother beginning three months prior to conception.

So what about the other types of “Spina Bifida” that are neither Myelomeningocele nor “normal?” They are the so called “**Spina Bifida Occulta**” lesions. The most important reason is that they do not, in general, involve the same embryologic process of development. They do not include abnormalities of the brain. They arise as an abnormality of the second process whereby the lower spine and lower body nerves develop. The Myelomeningocele (Spina Bifida Aperta) lesions cause not only abnormalities of the function of lower body nerves but, more importantly, cause malformations of the brain that range from fatal in infancy as described in the three previous paragraphs to interference with mental function as children and adults.

(Continued on page 5)

The term Spina Bifida is insufficient to describe the many normal and other types of Spina Bifida.

Severe brain abnormalities called “neural tube defects” are reduced by administration of 100x the daily recommended dose of Folic Acid to the mother three months before conception.

OPINION: WHAT IS SPINA BIFIDA?

(Continued from page 4)

These **Spina Bifida Occulta** lesions are usually skin covered and not associated with hydrocephalus. Eighty to ninety percent have the ability to ambulate without aids and have normal intellect. Their medical diagnoses are: **Meningocele** (skin covered fluid filled sac of spinal cord coverings and spinal fluid but no nerves), **Myelocystocele** (the same as Meningocele but with several fluid filled sacs that are not connected to one another or the central nervous system), **Caudal Regression Syndrome** (absence of the development of the nerves, muscle, bones and tissues of the lumbar spine and/or sacrum, with or without fat tissue in the spinal canal surrounding the nerves), and the most common **Lipomyelomeningocele** (lesions that are both the most difficult to diagnose in some cases and the cause of recurrent episodes of loss of lower body nerve function loss that can be prevented by medical intervention). ... Other Lipomyelomeningoceles can present at birth as a huge protruding, skin covered lesion. Between the barely perceptible ... and the grossly obvious is a continuum of gradations of presentation starting from a dimple above the gluteal cleft but off to one side of the midline or abnormal skin pigment.

These **Spina Bifida Occulta** lesions are not known to be prevented by excessive doses of Folic Acid, rarely are associated with hydrocephalus, are associated with lesser degrees of paralysis, obesity and intellectual impairments such as learning disorders, are much less frequently familial in occurrence and carry a much better prognosis for future adjustment .

These are the reasons, as your medical advisor, I state you should know your diagnosis. It is not sufficient to state that you have "Spina Bifida." The only way you can be sure of your diagnosis is to obtain a report of your own or your child's original operative report and pathologic findings. This information is important for you, your child and the entire family. Medical recommendations are directly related to the original diagnosis as to the type of "Spina Bifida."

You should know your diagnosis. It is not sufficient to state that you have "Spina Bifida."

WATF Summer Workshop Series For People with Disabilities & Seniors

IS SELF-EMPLOYMENT RIGHT FOR YOU?

This workshop teaches about the world of business ownership and the steps you need to be prepared to take to turn your dream into a reality.

Seattle: August 5, 2-4pm at CenterPark

Bremerton: August 30, 6:30-8:30pm at Positive Solutions

Everett: September 7, 4-6pm at Disability Resource Connection

HOME OWNERSHIP RESOURCES FOR PEOPLE WITH DISABILITIES

Emily Nolan of the Washington Home Ownership Center will share with you all of the resources available to first time home owners and people with disabilities.

Seattle: August 23, 3-5pm at Hearing Speech & Deafness Center

UNDERSTANDING CREDIT

This seminar will provide you with information and skills so you can read your credit report, cor-

rect information, expand your knowledge of the FICO score, plus fraud and identity theft prevention. Tips on re-establishing credit also included.

Seattle: July 26, 10-12pm at Hearing Speech & Deafness Center

BETTER BUDGETING

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: August 2, 4:30-6:30pm at CenterPark

Everett: August 29, 3-5pm at Disability Resource Connection

WHERE TO FIND START UP BUSINESS FUNDING

This workshop will discuss what business funding options are available to people with disabilities in Washington State.

Seattle: August 21, 4:30pm-6:30pm at CenterPark

REGISTER NOW!
Space is limited so call or email NOW to reserve your place.
206-328-5116
info@watf.org

(Continued from page 1)

Haxby, Pamela Hoppman, and Michael Schuermyer. I look forward to serving with all of our newly elected Board Members and hope that we will be able to look back 5 or 10 years from now and be able to say, once again, that much good came from our efforts during the time that we have served the ESBA. HAVE A GREAT REST OF YOUR SUMMER!!!

ESBA member James Haxby shares his experiences at SBA's national convention

by James Haxby

I am a 40 year old man with Spina Bifida from Vancouver WA and a Board member of [ESBA]. I recently had the pleasure of attending the Spina Bifida Association's (SBA) national conference, which was held the last week of June in Atlanta.

It was **attended by well over 1000 people** with Spina Bifida (SB), their families, medical professionals, and researchers from around the country. ... **there were more members from the west coast than in the past.** The conference began with a full-day presentation by adults with SB on healthy living. The highlights of what was discussed are available in the Guide to Healthy Living published by SBA. They talked about the importance of secondary prevention to avoid physical and psychological problems that can become worse in people with SB as they age.

...I also attended a session on medical updates ... **about efforts to re-grow nerve and bladder tissues using stem cells.** Contrary reports in the news media, efforts to grow bladder tissue so far have failed to be an adequate solution for enlarging the bladder. Research continues ... but is still in the early stages. Two pediatricians Dr. Pope and Dr. Cheng gave the keynote presentation on SBA goals and progress. ... Congress approve[d] 6 million dollars for SB research but there still needs to be uniform care nationwide for adults with SB like there is for other disabilities. Also, the rate of SB in Hispanic children continues to rise sharply. Afterward a panel discussion included SBA board member Doug Scirocco, who is an attorney with SB, as well as a doctor from Puerto Rico who works with patients with SB in Latin America. Dr. Mark Merkens from Portland spoke on care and

transition for adolescents with SB. He touched on non-verbal learning disabilities, which are common in youth with SB, and the need [to evaluate] their learning styles. He said that if a child's test scores in the non-verbal areas are 25% below their verbal scores this is an indication of non-verbal learning disability. He spoke about the importance of self care to avoid worsening function in teens. He also emphasized the need for young adults to acquire work-related training and work skills which may come from college, vocational, technical, or professional trade schools. ... I also went to sessions on medical insurance issues, where they emphasized efforts to show insurers that disability is not the same as ill-health, and that people with disabilities do benefit from secondary preventive care, to limit the severity of our impairments. Someone made the point that by paying for treatments that we need sooner, insurers could avoid paying for more expensive complications later on. I also attended a session on research into genetics and risk factors involved with SB. Even though they do still encourage women who are of child-bearing age to take folic acid, they cautioned against taking large doses of multi-vitamins, because getting too much Vitamin A can increase the risk of having a child with SB. They also are looking into a possible risk with mothers eating imported corn or home-grown corn because of a fungus that is suspected of causing SB. The fungus isn't present in commercially grown corn. In addition to all of the great information that I learned at the conference, it is just a great opportunity to talk to other people with SB and their families. We shared our experiences with living with SB and had a wonderful time.

I also attended an adult night where they had fake poker for prizes to raise money for the SBA. They also had several dinners hosted by the SBA and medical suppliers.

Eight major areas will be considered while striving to meet the new requirements:

- 1. Affiliation prerequisites**
- 2. Accountability**
- 3. Mission delivery**
- 4. Governance**
- 5. Business operations**
- 6. Marketing**
- 7. Advocacy Programs**
- 8. What support group rules would be if there are any support groups**

New chapter requirements unveiled at National SBA convention

by Joe Nugent, ESBA Vice President

Here are some facts: **There are 3800 SBA members. There are over 70,000 people who have Spina Bifida. There are over 250,000 people affected by Spina Bifida and 60 million women of child-bearing age. There are 57 Chapters/Groups in only 30-34 states.**

Basically, the numbers are saying SBA National and all SBA Chapters/Groups are not meeting the mission of SBA by getting the word out and getting known across the country. This is where branding from the 2005 Conference came about or Phase 1.

Now, Phase 2: Re-structuring of SBA and its Chapters. Shaping the future comes down to SBA's Mission Statement: **"The mission of SBA is to promote the prevention of Spina Bifida and to enhance the lives of all affected."** This means we need to get the word out on Folic Acid and helping to enhance the lives of those affected by Spina Bifida and to

get each Chapter [and] National [well] known. Under the current re-structuring of SBA, the 3 tier system will be gone and everyone will be a Chapter.

Everything is in draft form ... [and] we will then have 3 years to meet the SBA minimum requirements for all credentialed chapters. ... Some requirements will apply to us and some will not. It will all depend on Chapter size, location, and income. National will try to help us when possible. If we do not meet some of the requirements after 3 years, with National Board's approval, we would be grandfathered [if we] show forward progress to the goals.

As this is still in draft, there is room for change and the information will be passed along as it is received from National. The big item that was stressed to us is **be proactive in this and start working on the requirements even though it is still in draft form;** [so] the transition will be easier when it happens.

Nursing & Healthcare Professional Council targets many issues at SBA convention

by Nancy Nugent, ESBA Secretary

The Nursing and Healthcare Professional Council Education information presented at National Convention is evidenced-based practice in the areas of skin care, bowel issues, and asymptomatic bacteriuria as well as an overview of what evidenced-based practice is. The other subjects covered included Hydrocephalus and Chiari malformations, updates of health-related issues in Spina Bifida, assets and deficits in attention skills in individuals with Spina Bifida, how our genes and the environment may affect Spina Bifida and other neural tube defects.

SKIN CARE: The evidenced-based practice portion spoke of skin care ... to us as healthcare providers, to the caregivers, and to the individual with Spina Bifida himself ... the importance of taking care of the skin as the first line of defense against infection. To encourage independence, the person needs to be mobile, but yet the wheelchair or bracing can also be a source of pressure on bony prominences such as hips and knees to name just two areas. Another is the bowel and bladder issue of continence as a cause for skin breakdown. Many of these issues are preventable on some level. Various treatments were also discussed depending upon the severity of the skin breakdown from a pressure area to a stage IV decubiti and treatments from lotion to surgery as determined again by the severity of the problem.

TO TREAT OR NOT TO TREAT, THAT IS OUR QUESTION: Bacteriuria was a topic, especially of the asymptomatic variety. Various situations were presented as to what constituted bacteriuria, and presentation of the patient. Evidenced-based practice has suggested that in the presence of asymptomatic bacteriuria, with no reflux, most providers do not treat, dependent upon the prior

history of the patient. There is to be more research done on this subject.

SPINA BIFIDA CLINICS: I learned that there were 172 Spina Bifida Clinics throughout the US, of which only 73 returned the forms with 68 completed and five clinics indicating that they were no longer in operation. These stats are not good for getting care in Spina Bifida clinic for a child, much less an adult. Most adults end up in the rehabilitation system along with the spinal cord injuries as there are effects of both in medical issues that are shared. This to me was a little overwhelming and might make more sense to our other professionals.

THE SANDI PROJECT: SANDI is an acronym for Spina Bifida Assessment Neurobehavioral Development International ... a five-year multimillion-dollar collaborative project on child behavioral development to early adulthood on a national as well as international level. The presenter gave me her information about transitioning children through pre-school to school-age, teen, and beyond into adulthood with life's independence issues, getting a job, going to college, and the like. These reports are also available along with the various websites' information and stats and SANDI has its own website.

BREAKOUT: MENTORING-TYPE PROGRAMS: Our breakout session was a teen and young adult mentoring project that had been done [and funded] by SBA of Cincinnati utilizing a "bridge-line" for internet-type communications. The title was "Setting your Sight Beyond High School: Strategies to Get What You Need and Most of What you Want." The speaker Sharon Sellet from SBA Cincinnati noted that she had more mentors than mentees. Sharon is willing to talk to anyone who might want to set up this type of program.

I tried to attend sessions with the newest information about statistics, the various issues that face people with Spina Bifida and the more overlooked areas of skin care and the Spina Bifida Clinics.

I brought back many handouts and these are all available on request.

ESBA members Juanita Hallam, Colette & Michael Hoyt, Ed Kennedy and Jon Tutt were guests on Spokane's cable access program "Spokane Cares" that aired July 5 & 19. They shared educational information about Spina Bifida, lauded the goals and accomplishments of the Association, and raised critical disability issues like respect and disability etiquette.

THANK YOU TO THIS GROUP FOR LIVING THE MISSION OF ESBA!
DVD & VHS copies of the program are available for \$10 donations to ESBA

Spokane Cluster fosters sharing between members

by Ed Kennedy, Spokane Cluster Co-Leader

The Spokane Cluster of the Evergreen Spina Bifida Association has been busy these past few months with a number of events. On the evening of June 15 2006 we met at St. Josephs Care center to partake in our drug of choice – “FOOD” – OK, it was really cookies and punch provided by the wonderful people at St. Joseph’s. As we talked and shared with each other about what being a member of Evergreen Spina Bifida Association meant to us, we decided we wanted to share these things with everyone.

Juanita Hallam, who joined ESBA last year, says with a smile that she, as a result of being a member of ESBA, has learned how to share with others about living with Spina Bifida. Further, Juanita states that the books given to her by ESBA – “Living with Spina Bifida” and “Adults with Spina Bifida” – have been great resources that she has given to new employees of the group home she resides in to read so they can in turn be of better assistance to her.

Robert Gomes states that he appreciates the things he has learned as a person with Spina Bifida, and that he has been able to share what he has learned with the staff and other residents at St. Joseph’s.

Susan Curalli says she has appreciated the educational opportunities she has had to share her personal experiences and she is thankful for what she has learned from other group members as a person with Spina Bifida.

Over the past year, our cluster has had a great time during our pizza parties, picnics, movie nights and especially our regular monthly meetings when we can just sit down and share our lives with each other and be able to relate to one another on a basic level that is hard to match with those who have yet to begin to understand what it is to live with Spina Bifida.

**VOLUNTEER
NEEDED!**

**ESBA SEEKS A
LIBRARIAN.**

**Contact ESBA if
you are interested
in contributing your
talents to this
important
organization.**

SEATTLE CLUSTER

**of ESBA is now being created to serve Seattle and
the Central Puget Sound region!**

Join us for a spaghetti dinner

SATURDAY SEPTEMBER 23 5-7pm

North Seattle Family Center

3200 NE 125th St, Suite #2 Seattle WA 98125

The group leaders will provide spaghetti and drinks

Last name A-H: bring salad

Last name I-P: bring dessert

Last name R-Z: bring a side dish

**At this event we hope to establish leadership of the group,
future activities, and other issues in which to get the Seattle
Cluster off to a prosperous start.**

We ask that you RSVP via e-mail to

seattlespinabifidagroup@hotmail.com or contact

Children’s Hospital

Attn: Spina Bifida

4800 Sand Point Way NE, M/S M2-8

Seattle, WA 98105

Spokane Cluster Picnic
SATURDAY AUGUST 12
3pm Audubon Park
2800 w Courtland, Spokane
Chicken, drinks, plates & cutlery
will be provided
Bring a side dish, salad or dessert
OR just bring yourself and your family!
TO RSVP OR GET INFO CONTACT
Ed Kennedy 509-326-6355
or Susan Curalli 509-892-6756

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 Army Med. Ctr.	Dr. Ellen Davis	253-589-3700
Vancouver WA	James Haxby	360-258-4148
Spokane WA	Ed Kennedy Susan Curalli	509-465-0676 509-892-6756
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
NEW Seattle	TBA	TBA

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

PO Box 642 Sumner WA 98390
Phone: 253-589-3700
Email: evergreensba@yahoo.com

Members of the Evergreen Spina Bifida Association are adults or children with Spina Bifida and parents, friends, relatives, and professionals with an interest in this spinal tube birth defect.

We're on the web!
www.evergreen-spinabifida.org


**Evergreen Spina Bifida
Association**



NEWS CORNER

WOMEN NEED THEIR FOLIC ACID

This June 18 USA Today article looks at measures taken over the past 15 years to increase folic acid consumption and concludes that no significant changes have resulted.

http://www.usatoday.com/news/health/yourhealth/2006-06-18-folic-acid_x.htm

JUDGE HELPED PUT CONTROVERSY ON FAST TRACK

This May 29 Baltimore Sun column offers an opinion regarding the controversy surrounding wheelchair athlete Tatyana McFadden (who was featured in the last issue of the ESBA newsletter) and her high school track team. In April a US District Court judge issued a judgment that McFadden could race alongside other runners; in May McFadden and another teammate were disqualified under the ruling that McFadden acted as a pacer for her teammate.

<http://www.baltimoresun.com/sports/highschool/bal-sp.kent29may29,1,2205511.column>

PHYSICIANS DISAGREE OVER CONFLICTING VITAMIN STUDIES

This July 9 LA Daily News article describes conflicting information passed onto consumers from several recent vitamin studies that concluded supplements provide no benefits and may even harm those who take them. The author presents perspectives from a wide range of experts including scientific researchers, medical directors, professors, doctors and registered dieticians.

http://www.dailynews.com/travel/ci_4025203