



Evergreen Spina Bifida Association Newsletter

We are still EVERGREEN SPINA BIFIDA ASSOCIATION

by Ed Kennedy, ESBA President

We are still the Evergreen Spina Bifida Association – at least for a little while longer. So, for the present we will probably be printing up minimal amounts of our brochures and other printed materials with the Evergreen Spina Bifida Association name on them to get us through. This may be a year or even longer. In recent conversations with the national Spina Bifida Association regarding our name change they suggested we “hold off” for the time being until national has the opportunity to meet, discuss and approve or dis-approve our new name. This is a small step I should have taken once we had the name change narrowed down a bit, and I apologize for this omission.

By the way, have you heard what our membership voted to be our new name? The name chosen by the membership is “Spina Bifida Association of the Northwest.” I know many of you devoted a lot of your time to giving us your input and voting on this issue and I want to thank you. We know we will be changing our name but we need to jump through all the hoops to ensure our name will be one that we can stick with for a very long time to come. Keep reading your ESBA newsletter to stay up on what is happening with this and other issues.

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New toll free number!

**EVERGREEN SPINA BIFIDA ASSOCIATION
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Newsletter Editor
Celeste McCormick

Disability is a civil rights issue

by Toby Olson, executive secretary of the Governor's Committee on Disability Issues and Employment; reprinted with author's permission from the October 23 Seattle Post-Intelligencer article at http://seattlepi.nwsourc.com/opinion/289810_disability25.html

Each October we celebrate National Disability Employment Awareness Month, yet we have made little or no progress toward initiating the open, mature public dialogue essential to improving public awareness on disability. As a result, we continue to endure the human and economic costs inflicted by attitudes and policies shaped by widely held, but false assumptions and myths.

As things stand now, the general public is consistently, spectacularly wrong in nearly every truth it holds dear about the experience of life with a disability.

When I say that to someone, that person usually will look sad and thoughtful and nod in agreement, and I'll know that person is thinking, "He's right; I couldn't possibly imagine how horrible it must be."

Let me tell you, every one of us has much more than enough experience imagining how horrible it must be, and if our imaginations were ever to fail us in this regard, we could always count on Hollywood to shovel out yet another overblown, melodramatic, cliché-riddled treatment to help us along. What the general public is unprepared to imagine is just how wonderful, rewarding and full of accomplishment life with a severe disability usually is.

There have been dozens of studies that have shown not just a disconnect but

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GETTING TO KNOW YOU: ROBERT GOMES

by Ed Kennedy, ESBA President
Meet Bob Gomes, a 37-year-old gentleman with SB and who resides in Spokane at St. Josephs Care Center. Originally from Santa Rosa, CA, Bob

enjoys reading (mostly mysteries), working on his computer, visiting with people and harassing the staff at St. Josephs. Since joining the ESBA Bob has been a real advocate regarding his own needs and others with Spina Bifida as he has shared materials about Spina Bifida with staff and other residents. Bob used to live independently until the effects of an auto accident that happened in 1980 caught up with him and he required further assistance with his personal care needs. Bob has been a faithful attendee of the Spokane Cluster whenever his health has permitted. Thanks Bob for being a great part of ESBA!



Robert Gomes (photo by Jon Tutt)

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!

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

ESBA INVITES MEMBERS TO JOIN ITS COMMITTEES

Advocacy Committee: based on the concepts of advocacy (the act of pleading or arguing in favor of something, such as a cause, active support) and being an advocate (one that argues for a cause, a supporter or defender and one that pleads in another's behalf).

Awareness/Outreach/Chapter Development Committee: This committee will create a plan on how to get the word out on Spina Bifida and our

chapter, how to better network, and how to better cover our service area.

Fundraising/Grant Writing: This committee's purpose will be to find ways of bringing money into the chapter to run the chapter, fund chapter projects, and set fundraising/grant writing policies.

For more information about these committees contact Joe Nugent, ESBA Vice President, at mtgrandpabear@yahoo.com



NEWSLETTER CORRECTIONS: The article "Getting to Know You: Susan Curalli" in the last issue of the newsletter was written by President Ed Kennedy. The photograph of Susan was taken by Treasurer Jon Tutt.

Disability is a civil rights issue

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rather an immense chasm -- we're talking the Grand Canyon here -- between the popular assumptions and the actual experiences of people with disabilities. One of the earlier studies compared overall satisfaction and happiness rates for people with paraplegia and people who had won the lottery, and found not much difference. I buy lottery tickets, and I see this as very good news. Since my odds of having a spinal cord injury are much better than they are for picking those winning numbers, it's good to know that either way, once I make it through the disruptive process of adjustment to the dramatic changes in my life, I'll probably end up being about as happy as I am right now.

The kinds of things that the popular perception of the experience of significant disability consistently and spectacularly underestimates include: what we can do; how happy we are; our level of self-esteem and virtually every other measure of competence, productivity and quality of life. All of this plays well for telethons, personal injury suits and other efforts to tug at heartstrings to loosen purse strings, but it's a real disadvantage in any endeavor that requires being accepted as a competent, functioning adult. Some examples include applying for a job, trying to get a date, rent an apartment, preserve parental rights or help someone else understand that disability is first and foremost a civil rights issue. We must develop a public dialogue that actively challenges the preconceptions and stereotypes about people who have disabilities, forces an examination of those beliefs and replaces them with beliefs informed by the actual experiences of people with disabilities. In other words,

we need to talk.

We need to talk about the backlash currently directed against the Americans with Disabilities Act. We need to talk about why the only right of a person who has a disability that seems to be capable of commanding the public's attention and inspiring the media is the right to die.

We need to be talking about why there remains so much distance and misunderstanding between the disability rights movement and its progenitors, those earlier civil rights movements that by their example taught people with disabilities

how to understand the nature of our predicament and provided us with the model for redressing it. Because of the failure to develop this discourse, myths about disability are so uncritically accepted as common knowledge that they nearly crowd all serious discussion

of the reality of the experience of disability from the mainstream marketplace of ideas.

Most of us know people with disabilities who are going about their lives, working, supporting themselves and their families and actively contributing to the diversity and vitality of our communities. But these examples can be before us on a daily basis and have surprisingly little impact on our preconceptions. We accommodate our stereotypes by perceiving such people to be something extraordinary. We need to challenge that. We should not see people with significant disabilities who have achieved some measure of satisfaction and success as brave, heroic or inspirational. Such people should be the norm. Such people should be exactly what we expect.

Instead, we should be looking at the lives of people with disabilities who have been denied those experiences and asking what went wrong.

"Folks have been sending this [article] around within the disability community and it has been getting a good response, but it wasn't really intended for us. We all already know this. So I encourage your readers to share their experiences and try to get a discussion going in their own mainstream media." - Toby Olson

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

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

TRANSITION/SEPARATION ISSUES FOR THE PERSON WITH SPINA BIFIDA

This is the second 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.

Absences by children from their parents to be with same-age peers and to develop autonomy should be encouraged.

Brazelton states that a sense of discipline is a parent's second most important gift to a child next to love. He also notes that setting limits in a consistent, effective manner is one of the most difficult tasks for parents. Limit setting is essential. It enables the child to learn self-control before interacting with peers.

PRESCHOOL & EARLY SCHOOL YEARS FOR THE CHILD WITHOUT A DISABILITY

The toddler progresses to the next stage of development having learned trust and mistrust from mother or primary caretakers. Shame, part of Erikson's first stage of development of man, is replaced by autonomy. Autonomy, Erikson's second stage of development, is practiced through interaction with parents, caretakers and family members. The young child may first identify with one parent and then the other, excluding the opposite parent during each time period. Close contacts experience the young child's frustration, anger, hostility and aggression. ... [Young children benefit] from social interaction with peers in five major ways (Brazelton, 1992; Erikson, 1950). During these interactions, they learn: 1) The need for self toileting as they tease

one another about wearing diapers; 2) The difference between boys and girls; 3) The limits on exposing their perineum; 4) The limits on their anger and aggression toward others; 5) To accomplish joint tasks or develop industry as opposed to inferiority. The young child begins to accomplish these developmental tasks by separating from family through attendance at church school, play school, day care and... preschool. Initially, these activities are closely supervised and attended by parents or their caregiver. The time away from parents and caregiver gradually lengthens, becoming more frequent and less supervised. The child's absences from their parents and caregiver provide opportunities to learn about themselves. They become more mobile and "liberated," learning to use their wheeled vehicles - first the tricycle and then the bicycle.

PRESCHOOL & EARLY SCHOOL YEARS FOR THE CHILD WITH SPINA BIFIDA

Too often, the young child with Spina Bifida is separated from parents by hospitalization [which is] an emotionally and physically traumatic experience for any child. At this age, children attribute the creation of all objects and order in their lives to ... their parents (Piaget, 1929). Hospitalizations, therefore, require explanation and support from the parents or primary caregiver. Preparation for the hospital admission should include clear reasons and objectives and [explanations] of events. The parent or primary care giver should be with the child during admission, bloodletting and other painful procedures, preoperatively and during recovery Separation for social reasons such as daycare, parents' absences, etc should be associated with clear limits, the exact time of return and assur-

ances that the parent will return, helping the child overcome any anxiety about abandonment. ... Parents of children with Spina Bifida tend to avoid, rather than encourage, such separation because of the child's limited mobility, incontinence and previous traumatic hospital separations. What children with Spina Bifida learn during separation from their parents are the same five noted above for children without a disability. Erikson describes child play as an opportunity to learn self-control with other children, new mastery skills over fantasy, and the give-and-take with peers ... Parents should ... involve their children with Spina Bifida in social activities with family, friends, in group activities ... [and in] childhood social groups such as Boy & Girl Scouts... to place the child in situations to interact with other children both similarly disabled and able-bodied in order to learn autonomy.

AMBULATION IN PRESCHOOL & EARLY SCHOOL YEARS FOR THE CHILD WITH SPINA BIFIDA

The mobility needs discussed [in the last newsletter] for infants and toddlers become more important for the preschool and early school age child. Opportunities for floor level play unencumbered by heavy bracing should be considered to provide opportunities to explore and learn autonomy. Caretakers should consider restricting brace and crutch-assisted ambulation to exercise periods, teaching the child without producing frustration and intolerance or interfering with the child's opportunity to explore and be with age peers. We believe that mobility devices

for the more severely motor-impaired and wheelchairs should be provided to brace and crutch-assisted walkers in order to learn how to compete in wheelchair activities and experience extended trips. ... A number of authors describe many biped ambulatory children with Spina Bifida prefer wheelchair use as adults at least part time. Many of the activities suggested for increasing a child's social interactions such as basketball, ... fishing, etc noted above can be performed more easily with the assistance of a wheelchair. They cannot be performed when the child's arms are holding crutches. At this age

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TRANSITION/SEPARATION ISSUES FOR THE PERSON WITH SPINA BIFIDA

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parents and caretakers should encourage multiple methods of alternative mobility and partici-

pation in, rather than observation of, other children's games and activities.

Erikson describes teenage as a normal phase of crisis with increased conflict characterized by fluctuations in ego strength and a high growth potential. The preadolescent and adolescent are learning independence and are often in as much turmoil over these changes as their parents (Brazelton, 1992).

LATE CHILDHOOD & PREADOLESCENCE FOR THE CHILD WITHOUT A DISABILITY

This period of growth and development includes the second phase of conflict between the child and authority figures [when children] are entering into the last of the four stages of the development of man described by Erikson: 1) Learning limits on self identity ... [and] to distinguish between self-centered existence and participation in the world of peers; 2) Learning intimacy ... [and] the difference between close, friendly and intimate relationships with a personal partner; 3) Learning generativity ... deciding if they will become productive, contributing members of society or withdraw into themselves; 4) Establishing ego integrity ... being able to keep one's self-identity while interrelating to others rather than collapsing into [an] isolated state. ... Offer

(1969) describes adolescence as a transitional period ... with special burdens, challenges and opportunities. The children develop personalities independent from their families, increase their self confidence, establish a sense of ...strength in their own abilities, and make important decisions for their future ... Elkind (1976) describes adolescents as being in a state of extreme egocentricity: everyone is watching them. ...

... The study by Davis et al (2001) demonstrates several independent activities are acquired by children in the myelomeningocele group prior to 12 years of age ... [most notable are] personal toileting; hygiene for teeth, hair and nails; personal choices when shopping; being on time for activities; knowing their own telephone number; understanding ... monitoring their spending and remembering special dates such as birthdays.

LATE CHILDHOOD & PREADOLESCENCE FOR THE CHILD WITH SPINA BIFIDA

Rutter (1980) has demonstrated that severely deprived children can overcome early childhood deprivation if provided the opportunity in later childhood. This stage of childhood development is the last opportunity to prepare the child for transition in adolescence. Davis et al, (2002) have described patients with myelomeningocele being 2 to 5 years behind same age peers in acquiring daily living skills. Children with myelomeningocele younger than 12 years of age had accomplished 11 of 31 skills for independent living. In her study, the acquisition of independence skills correlated best with cognition and

was not related to level of lesion or gender. The greatest discrepancies between children without disability described by Sparrow et al ... involved stool and urine hygiene (Davis et al, 2002). The average age for attainment by 75% of the former was 4 years of age compared to 14 years for the latter. Participation in organized extracurricular activities declined to only 30-40% among older teenagers. Of teenagers 18 years of age, 21% did their own laundry, 37% fixed their own meals, 49% cleaned dishes [and] 39% managed their own money. Hopefully, teaching the developmental stages and using some of this article's suggestions will properly prepare children with myelomeningocele for the period of transition.

Adolescents learn responsibility, independence & heterosexual relationships. Data for more intimate situations such as first date of sexual intercourse, on the other hand, are not well known.

We suggest that during this period of development, children also become oriented to independent mobility within the community using public transportation. They should also be assessed for hand-control automobile driving.

CHILDHOOD/PREADOLESCENCE SEPARATION/TRANSITION WITH SPINA BIFIDA

During this stage of development, children's increase in body size and acquisition of autonomy skills often lead those brought up in a biped ambulatory program to "retreat" to a wheelchair, despite the early childhood goal ... to acquire and maintain biped ambulation. They often gain sufficient weight to become obese, preventing efficient ambulation. Do those children, brought up to equate walking with success, become depressed when they fail to continue walking and withdraw into themselves and overeat? Have these expectations placed them in a position

where they are bound to fail? Like the Oglala Sioux described by Erikson, they may have been presented with an unattainable goal, suppressing their initiative and becoming apathetic and depressed. A sense of despair and hopelessness will only compound underlying developmental problems. If the marginal crutch and brace walker is also taught wheelchair use as a younger child, this assumption of wheelchair mobility may limit the conflict between their self concept and their physique (Anderson and Clarke, 1982; Friedrich and Shaffer, 1986; Piaget, 1929). Wheelchair use should be seen as a normal method of achieving mobility, not a "retreat."

YOUNG IDAHO MAN WITH SPINA BIFIDA SEEKS PEN PAL



Cory Potter's senior portrait

20-year-old Cory Potter from Blackfoot Idaho would like to correspond with others who have Spina Bifida. Potter is a graduate of Blackfoot High School and has taken classes at Idaho State University. He swam the relay on the Blackfoot Swim Team, earned the Eagle Scout rank in Boy Scouts, and skis with the Pocatello Adaptive Ski School. Potter has been active in disabilities rights issues: in 2005 he attended the Conference on Independent Living in Boise during which he marched on the capitol and talked to his senator about the proposed "Idahoans with Disabilities Act." To contact Potter please send an email to wpotter@onewest.net. To read more about Potter and see photos of all his activities go to

<http://www.onewest.net/~wpotter/cory.htm>



Potter on one of his outdoor adventures

Athletes with disabilities excel in their sports

by Celeste McCormick, newsletter editor

Many able-bodied individuals may think sports are unrealistic for those with disabilities. Contradicting this perception are many competitive disabled athletes. For them, minor adaptations may be all that stand between them and their dreams of athletic prowess.

21-year old Colt Wynn, profiled in the November 2006 issue of *Muscle & Fitness* magazine, is the Mr. Olympia of wheelchair bodybuilding. He became paralyzed from the waist down at 14 years of age during a hunting accident. At first he asked himself, "Why me?" but then started asking, "Why can't I lift weights?" Weightlifting was already a hobby in his family and it has now given Colt both goals and purpose. In 2003 he won the overall title at the NPC Wheelchair Bodybuilding National Championships and he plans to compete for the title again in 2007. Colt is grateful for his experiences since the accident. "If something like this was going to happen to someone, it should happen to someone like me who has the determination and drive to overcome it."

ESBA member Heather Logan recently overcame obstacles to her own athletic pursuits. In October the Special Olympics would not let her swim with the team because its pool

did not have accommodations for getting her in and out of it. Additionally, her local bowling alley Aztec Bowling denied her use of its special bowling ramp. Heather has since learned that Special Olympics' bowling team had transferred from Aztec Bowling to Westside Lanes where its membership received a warmer welcome. And after pursuing options at other pools and writing a letter to the Program Director of Thurston County Parks, the lift at the Special Olympics pool was fixed and Heather is now able to swim with her team. Swimming brings great joy into Heather's life – according to her mother Patti, "she is so happy it's hard to keep her in the chair!!!"

Heather is not the only young ESBA member who competes in sports. Eight-year-old Michael Hoyt plays basketball and competes in track – all from a wheelchair. In June Michael qualified to compete with Spokane's St Luke's track team at nationals in Florida but he was too young to make the trip. For now he plays sports for the sheer fun of it – like going fast in his wheelchair – but is beginning to understand the rules of the game and what it means to win.

All of these athletes prove that their disabilities have only encouraged them to achieve their athletic dreams.



Heather Logan
(photo courtesy of ESBA)



Michael Hoyt
(photo by Celeste McCormick)

To read more inspiring stories about athletes with disabilities, visit www.lat34.com/hard_core_sitting

ATTEND SBA & DISABILITY EVENTS ACROSS THE COUNTRY

The 34th SBAA National Conference in Louisville Kentucky June 24-28

Regular conference: Sunday June 24 to Wednesday June 27

Officers & Board members conference: Saturday June 23 to Sunday June 24

Chapter business regular conference Sunday June 24 to Wednesday June 27

National annual board meeting: Thursday June 28

Based on these dates, any delegates to the annual conference need to plan on being there from June 24 TO June 28 & are advised to start planning & saving for conference now.

2007 DISABILITY POLICY SEMINAR

March 4 - 6, 2007

The Hyatt Regency Hotel

400 New Jersey Avenue, NW Washington, DC 20001

From Irene Ballart, President, Spina Bifida Association of Southeast Florida, P.O.Box 559046, Miami, FL 33255-9046, 305-220-2559, SBAOFSEFL@bellsouth.net:

Just want to let you know that Spina Bifida Association of Southeast Florida would be having a Universal conference in May 2007. We call it Universal because we have many families that come from out of the country and we have been doing this conference bilingual from the beginning. Many years ago we were the only one putting together a conference in English and Spanish. So if you would like I will email everyone the information and yes all are welcome to come. We have almost everything done. The location is the only thing missing and we have a few very good leads. Hope to see you in the sunshine state of Florida.

From Marybeth Petersen, Connecticut, <http://www.sbac.org/>: The Connecticut chapter will be running our 3rd Annual Educational Conference on Saturday, March 24, 2007. Our conference is open to anyone interested in attending (parents, adults, family members, professionals, etc.) We also ask chapters in our neighboring states to advertise the conference in their newsletters. Last year we had participants from as far away as Pennsylvania! I'm interested in hearing from other chapters who are planning local conferences. Maybe we could start a Yahoo Group to share ideas and ask questions. Anyone interested?

From Gaye Morrison, SBA of North Texas at sbnorthtexas@aol.com:

We are having a 5 State Regional Conference (Texas, New Mexico, Oklahoma, Louisiana and Arkansas) February 17-18, 2007 at the Holiday Inn Express Hotel & Suites in Plano, Texas. Topics: neurosurgical issues, urological issues, wound prevention & care, bowel continence. Adult track with adult issue programming. Educational issues, including common learning challenges and working with your child's school. Will have simultaneous Spanish translation(earphones). On site child care children 6 & younger. A "kids program" for children ages 7 to 14. Fee: \$35 per family and discounted hotel rooms will be available. Online registration should be available from our website (www.sbdallas.org) in November. Anyone is welcome to attend.

Community Minded Enterprises in Spokane WA

is hosting an early evening celebration with

Latin music, South American wine, tapas and tango

December 5th at CenterStage, 1017 W First in downtown Spokane.

For more information contact

Luke at lukey@communityminded.org or 509-444-3088 ext 209.

EVERETT CLUSTER MONTHLY MEETINGS

Join the Everett cluster every first Tuesday of the month
from 12:30 to 4PM at the

Everett Transit Center on Smith Ave and 33rd

For more information contact

Brenda Stroud at 425-385-2487 or frizzle3@verizon.net



Have a blast at the Spina Bifida holiday party

Saturday, December 9th 1-4pm

at the Church of Jesus Christ of Latter Day Saints

14901 30th NE Shoreline WA 98155

Please come and join us for lots of holiday cheer! Do not miss this great chance to connect with other families and friends!

The party will feature delicious Italian food, fun craft projects and entertainment from the Junior Sonics Basketball Team from Northwest Adaptive Sports.

Please R.S.V.P. to (206)987-2184 or Julia.hulsey@seattlechildrens.org

Sponsored by the ESBA Seattle Cluster, ABC Guild and the Children's Hospital Neurodevelopmental Program. Many thanks to the Church of Jesus Christ of Latter Day Saints, Pam Newman of Astra Tech and the Lougheed Family for making this event possible! ESBA is not affiliated with the Mormon Church.

We had a great time at The Farm

by Nicole Anderson, Seattle Cluster co-leader

Hooray! *The Farm* invited the ESBA Seattle cluster on October 21st to pick out a great pumpkin, join in a harvest time celebration, pet the animals, go on a hay wagon ride, play in a historic barn with its three story hay maze and slide, & watch the Pig Show featuring the 4 little pigs & the great big wolf.

If you would like to be included in our monthly playgroup activities or join the Seattle cluster, please provide your contact information to us via e-mail at seattlespinabifidagroup@hotmail.com.

We always have something fun going on somewhere in the Seattle area!

- October: The Farm Pumpkin Patch in Snohomish
- November: Ballard Library & Cupcake Royale
- January (TBA): Hosting parents' neighborhood/activity

The Farm is owned & operated by [Ben and Carol Krause](#) at 7301 Rivershore Road in Snohomish WA. Contact the farm: 425.334.4124 or www.washingtoncornmaze.com



MADIGAN YOUNG ADULT CLUSTER TACKLES ACCESSIBILITY ISSUES

by Heather Logan

The Spina Bifida Young Adult Group from Madigan went bowling at Westside Lanes in Tumwater. They had a lot of fun and laughs while playing. The group did really well and got good scores. One particular person got a score of 128. Dr. Davis said that person was lucky, so much that everyone was using the lucky ball. Afterwards, they went to Apollos for something to eat and to celebrate a job well done. The food was great but the bathrooms are not really wheelchair accessible. There is no stall for the wheelchair to fit, counters too high and soap and towels unreachable. I did something about that; I talked to the manager and they suggested I write a letter to the person in charge of fixing the bathrooms so I did.

The Olympia Cluster hosted a parent group on November 4 with Therese Vafaezadeh, MSN, ARNP and her daughter Soba. Therese gave practical information on the reality of transition and is available to help ESBA members and families with resources and information.

Connect with a cluster group

Region	Leader Name	Contact Phone
Portland OR	Gina Schuermyer	503-761-8193
Helena MT	Joe Nugent	406-458-9549
Madigan Army Med. Ctr.	Dr. Ellen Davis	253-589-3700
Vancouver WA	James Haxby	(503) 414-9220
Spokane WA	Ed Kennedy 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
Seattle	Nicole Anderson	seattlespinabifida-group@hotmail.com
Everett	Brenda Stroud	425-385-2487 frizzle3@verizon.net

To get involved with a cluster group or to find out about any upcoming events, please contact the cluster leader in your area.

EVERGREEN SPINA BIFIDA ASSOCIATION
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& ALASKA

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Toll free: 888-289-3702

Email: evergreensba@yahoo.com

New toll free number!

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

NEWS CORNER

CANADIAN TEENAGER WITH SB LOCKED IN BURNING SHED BY BULLIES

This article on Canadian news site www.cbc.ca tells the story of 14-year-old Brian McKay who was locked in a shed by local bullies who then set the shed on fire. McKay was pulled from the shed by other local children and by Joseph Bird, the 39-year old boyfriend of McKay's neighbor. Bird said "It's a good thing we were here when we were here. Otherwise a little child would have passed away." McKay, who was new in the neighborhood and lives there with his grandmother, said he knows why he was targeted. "Because they know I was weak ... because I was born different." McKay was treated for smoke inhalation and says of his recovery, "It was just amazing... someone was, like, protecting me." Winnipeg Police Arson Strike Force is investigating the incidence and issuing warnings to the bullies who are too young to be formally charged with a crime.

<http://origin.www.cbc.ca/canada/manitoba/story/2006/10/16/shed-fire.html#skip300x250>

DISABLED WOMEN FACE HIGHER RISK OF DOMESTIC VIOLENCE

This article in the online magazine www.360usainc.com describes results from a University of Manitoba study published in *Violence Against Women*. The study analyzed statistics from over 7000 women and reports that male partners of women with disabilities are 2.5 times more likely to "behave in a dominating manner" and 1.5 times more likely to "be unreasonably jealous towards their disabled partners."

http://www.360usainc.com/article_detail.cfm?article_story_id=253

CEREBRAL PALSY VOCATIONAL PROGRAM EMPLOYS MAN WITH SB

This article in the November 2006 issue of the United Cerebral Palsy's (UCP) newsletter *Life Without Limits* describes the life of John McCormick, 47, a New York state resident with Spina Bifida who works in the UCP of Suffolk Vocational Workarea. From his wheelchair John also serves on the Executive Director's Consumer Advisory Committee as a representative for his Vocational Workarea coworkers. The Executive Director describes his pride in John by saying, "John is one of many active people with disabilities that I have the privilege of spending time with everyday." UCP hosts a variety of programs that advance independence and promote the potential of people with disabilities.

http://ga4.org/publicpolicy/notice-description.tcl?newsletter_id=3759996


Evergreen Spina Bifida
Association

