



Evergreen Spina Bifida Association Newsletter

Inside this issue:

A mother's reflections	2
WA state law changes regarding newborn screening	2
Assistance with obtaining wheelchairs	2
Volunteers sought for various studies	3
Folic acid awareness quiz (en Español, 5)	4
More info about Medicare prescription drug coverage	6
Highlights from other association newsletters	7
Contact information for all ESBA cluster groups	8

United Nations report addresses abuse of disabled children

In July 2005 the United Nations (UN) Secretary General summary report "Violence Against Disabled Children" was released. Outlined below are a number of the report's findings and recommendations.

Findings

In-home abuse of disabled children can occur for numerous reasons. Infants are often harmed or killed due to perceptions that they bring shame to the family or are better off dead. Both neglect and stress of caring for a disabled child are precursors of violence. A disability can compound abuse, e.g. a disabled child is less able to defend himself or flee.

Schools and care facilities are also

sites of violent encounters. Disabled children can be targeted by bus drivers, bullies and predators. Teachers and support staff in the classroom who do not understand a disabled child's limitations can be abusive; other children in the classroom usually model the teacher.

Disabled children are at risk from community-based violence as well. Due to perceived stigmas of disability, perpetrators see no worth in the children and bystanders are less likely to intervene. Disabled children may desire so strongly to be included socially that they will accept peer abuse in order to belong. Consequences for abusers are usually mild. Many families of disabled children

cannot afford legal services. Legal facilities can be physically inaccessible to disabled people. Additionally, the legal system lacks knowledge about disabilities.

Recommendations

- Both general and disability-specific violence prevention programs should include disabled children
- Within UN organizations initiate greater awareness of abuse against disabled children.
- Federal legislation and government agencies at all levels should lead progress toward prevention of violence

Continued on page 7; see violence report

ESBA President offers thanks, reflections

By Ed Kennedy, ESBA President

Happy Holidays everyone!!! I guess because I find myself at almost 50 years of age I tend to be a little reflective regarding the "old days" and what the holidays mean to me. I do try to be thankful for many things and remember that even though life with Spina Bifida has not always been easy - I do believe it has been worth it.

I was recently speaking to someone with a disability who told me that he is thankful for his disability because he felt it made him a stronger and more sensitive individual. I will not even try and tell you that I am always "thankful" for having Spina Bifida but I will say I think, as the old saying goes, "that which does not kill me makes me stronger." Some of the ways it has made me stronger are not that great either, like when someone says I

am not permitted to do a particular thing because of my Spina Bifida - I will do my best to do that particular thing - just to prove the person wrong. It sometimes will not even dawn on me that the thing that I am doing is of no big concern for me - I am doing it just to prove to someone I can. So that is not a great "positive" attitude. On the other hand I do enjoy working on behalf of someone who is having a particular issue or problem because I do not easily give up. For that I am thankful. Another thing that I am thankful for is the children in our groups who give us much cause to, hopefully, make their lives with Spina Bifida a little bit better than what we ourselves may have experienced. For the older people affected by Spina Bifida in one way or another I am thankful that they continue to share their insight and experience with the rest of us to en-

courage and direct us. I also want to say I am thankful to one particular individual in our organization, Patti Logan, without whose consistent concern and care I am not sure where we would be. As most of you know Patti has stepped back a bit from the everyday work of ESBA to take care of some other business and just relax a little. Patti is still in contact on a regular basis and I hope she knows how many lives she has touched by her dedication to ESBA. Lastly, as I look back on this past year I want to say I am thankful for each of you and your continued participation and support of ESBA. I truly believe we are living up to our mission statement "to promote the well being, education, and socialization of all people with Spina Bifida and foster public awareness of this birth defect." Thank you all for what you do!!

All are invited...

The Evergreen Spina Bifida Support Group Olympia Cluster invites you to a discussion surrounding issues that affect persons with Spina Bifida and their families and friends. Our mission is to enhance the lives of people touched by Spina Bifida and to educate others about this birth defect.

SPECIAL TOPIC THIS MONTH:
Letter to new parents

Please come and enjoy a pizza/salad bar/dessert bar dinner compliments of the Evergreen Spina Bifida Association.

When: 1:00 pm
Saturday December 3
Where: Izzy's Pizza,
Pacific Ave & Lilly Rd, Olympia WA

Share your story with others

If you and your family are still waiting for community services, the Arc of Washington State and the Developmental Disabilities (DD) Council wants to share your story with legislators and media. For the 2006 legislative session the two organizations are preparing a booklet and DVD to provide personal stories and photos of families in need. To date almost 40 families have volunteered; a total of 200 families is sought.

Cynara Lilly, from the DD Council's public relations firm Harris and Smith Public Affairs, states that "We will be very respectful of people's needs and wishes for privacy and will seek approval of anything created for publication."

If you or someone you know is waiting for services, please consider getting involved in this project. A representative from Harris and Smith would like to contact family members directly, conduct an interview and explain how the project works.

If you or someone you know is waiting for services, please consider getting involved in this project. For more information contact Cynara at 206-343-0250 or via email at cynara@harrisandsmith.com

"The paper is more than just a paper for me. It is also a way to see what types of situations my brother may face in the future."

UPS student asks to include personal stories in her Spina Bifida paper

"Hello. My name is Tracy. I am a student at the University of Puget Sound in Tacoma, Washington. I also live near Tacoma. I am taking a class called Disability Identity and Power. I am focusing a paper for this class on Spina Bifida. I chose Spina Bifida because my youngest brother has it. ...The paper is more than just a paper for me. It is also a way to see what types of situations my brother, Kyle, may face in the future that we

have not thought of. He is soon to be 14 years old (we are going through those tough teenage years) and is an integral part of the paper. In particular my paper will focus on what types of social, economic and political issues that adults who have Spina Bifida face and how they deal with them. So my sincerest hope is that some or any of you will be interested in passing information on to me. Real names will not be used

in the paper to insure confidentiality. However, if any of you would like to be a part of this I would like to pass the information on to my brother. I would be most grateful to anyone who would like to participate."

Please contact Tracy by

DECEMBER 7 at
trhodes@ups.edu or
ditabo80@yahoo.com

Researchers seek volunteers for study of children's eating habits

A research study will be conducted on relations between eating habits, obesity and bowel habits among children with Spina Bifida. Children with Spina Bifida aged 3-18 years and their parents are eligible to participate. The study involves having parents or caregivers complete a questionnaire that will take no more than 15 minutes. We are not gathering any identifying information such as names or addresses. All participation is completely voluntary.

Research is being conducted by

Keith Williams, PhD

Feeding Program, Penn State Hershey Medical Center

&

Kimberly Schreck, PhD

Psychology Program, Penn State Harrisburg

~

Obtain a questionnaire by mail, fax or email

Email: feedingprogram@hmc.psu.edu

Phone: 717-531-7117

~

This research has been approved by the Institutional Review Board, under Federal regulations, at the Penn State Milton S. Hershey Medical Center and Penn State University.

HOW MUCH DO YOU KNOW ABOUT FOLIC ACID?

1. Folic Acid is
 - a. B vitamin
 - b. C vitamin
 - c. mineral
2. Folic Acid reduces the risk for
 - a. spina bifida only
 - b. anencephaly only
 - c. both spina bifida and anencephaly
3. All women of childbearing age should consume ____ of folic acid everyday
 - a. 400 micrograms (mcg)
 - b. 200 micrograms (mcg)
 - c. 4 milligrams
4. You would need to eat ____ cups of broccoli to get the recommended daily amount of folic acid
 - a. 1
 - b. 2
 - c. 5
5. Spina Bifida and Anencephaly
 - a. are the most common preventable birth defects
 - b. in 95% of cases occur in women who have no history of spina bifida in their families
 - c. result in varying degrees of damage to the spinal cord and nervous system
 - d. all of the above
6. About ____ pregnancies are affected by spina bifida and anencephaly each year in the US
 - a. 500
 - b. 2,000
 - c. 4,000
7. In order to help prevent neural tube defects, folic acid must be taken
 - a. after a woman becomes pregnant and has her first prenatal appointment
 - b. before conception and during her first trimester
 - c. during the third trimester
8. While it is important to eat a healthy diet, the EASIEST way to get the right amount of folic acid everyday is to
 - a. eat 2 cups of whole grains
 - b. eat 5 servings of fruits and vegetables
 - c. drink a quart of milk
 - d. take a multivitamin containing 400mcg of folic acid
9. Women between the ages of ____ and ____ should take folic acid every day
 - a. 20-30
 - b. 15-44
 - c. 35-45
 - d. 18-30
10. A woman should be taking folic acid if she is
 - a. planning a pregnancy
 - b. capable of becoming pregnant even if not planning it
 - c. thinking she might become pregnant sometime in the future
 - d. all of the above

ANSWERS:
 1. a
 2. c
 3. a
 4. c
 5. d
 6. c
 7. b
 8. d
 9. b
 10. d

The folic acid awareness quiz was provided by Nora A. Oyler, Executive Director of The Spina Bifida Association of Texas, Inc. 10615 Perrin Beitel Ste. 701 San Antonio TX 78217 Ph/fax 210-653-1800

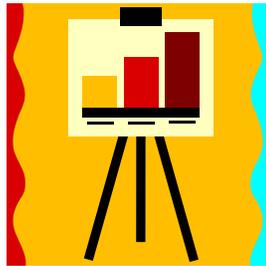
¿CUÁNTO SABE USTED ACERCA DEL ÁCIDO FÓLICO?

1. El ácido fólico es una forma de:
 - a. vitamina B
 - b. vitamina C
 - c. un mineral
2. El ácido fólico reduce el riesgo de:
 - a. solamente la espina bífida
 - b. solo la anencefalia
 - c. la espina bífida y la anencefalia
3. Todas las mujeres en edad de tener hijos deben ingerir
 - a. de ácido fólico a diario
 - b. 400 microgramos (mcg)
 - c. 200 microgramos (mcg)
 - d. 4 miligramos (mg)
4. Usted necesitaría comer ____ tazas de brócoli para obtener la cantidad diaria recomendada de ácido fólico.
 - a. 1
 - b. 2
 - c. 5
5. La espina bífida y la anencefalia:
 - a. son los defectos de nacimiento evitables más comunes
 - b. ocurren en mujeres sin antecedentes personales o de familias en 95% de los casos
 - c. resultan en daño a la médula espinal y del sistema nervioso
 - d. todos
6. Cerca de __ embarazos en los Estados Unidos son afectados por la espina bífida y la anencefalia cada año
 - a. 500
 - b. 2,000
 - c. 4,000
7. Para prevenir un defecto del tubo neural, una mujer debe tomar ácido fólico:
 - a. después que ella llega a estar encinta y tiene su primera consulta médica prenatal
 - b. antes de la concepción y durante su primer trimestre
 - c. durante el tercer trimestre
8. Aunque es importante seguir una dieta sana, la manera más fácil de obtener la cantidad correcta de ácido fólico es
 - a. comer 2 tazas de granos integrales todos los días
 - b. comer 5 porciones de fruta y verduras todos los días
 - c. beber un cuarto de galón de leche todos los días
 - d. tomar una multivitamina que contiene 400 mcg de ácido fólico todos los días
9. Las mujeres entre las edades de ____ y ____ deben ingerir ácido fólico todos los días
 - a. 20-30
 - b. 15-44
 - c. 35-45
 - d. 18-30
10. Una mujer debe ingerir ácido fólico:
 - a. si esta planificando un embarazo
 - b. si puede llegar a estar encinta
 - c. si ella piensa que querrá estar en cinta en el futuro
 - d. todos

Resposta
correctas:
1. a
2. c
3. a
4. c
5. d
6. c
7. b
8. d
9. b
10. d

Updates from International Federation for Spina Bifida and Hydrocephalus

Inter-American Development Bank: The Disability Team spent three years collecting and analyzing disability data from 26 countries in Latin America and the Caribbean. The region can now provide disability reports and statistics. To see the data go to www.iadb.org/sds/soc and click on Disability.



Attention older people with Spina bifida:

International Federation (IF) met Albert De Greve, 82, who has Spina Bifida and lives a happy life in Sint-Niklaas. IF seeks the oldest living person with Spina Bifida in order to show that someone with Spina Bifida can live a long fulfilling life. Unique issues, which have not yet been widely addressed, confront older people with Spina Bifida. If you or someone you know could be the oldest person with Spina Bifida, please email Lieven Bauwens at info@ifglobal.org.

Spina Bifida Association of America:

A new online manual *Health Guide for Adults Living with Spina Bifida* is available from the SBAA website at www.sbaa.org/programsqol.



The comprehensive and easy-to-read manual includes topics dedicated to managing your own health at any age. This website also provides resources for teens and youth.

Sign up for the 2006 Disabilities Community Legislative Reception

Parkview Services, the Washington state Developmental Disabilities Council, and the Governor's Committee on Disability Issues and Employment are coordinating the 26th Annual Legislative Reception as forum for communicating disability issues and concerns with legislators.

WHEN:
Wednesday January 18th 2006

WHERE:
Capitol Campus, Legislative Building, 3rd Floor, Olympia WA

ACCOMODATIONS:
Contact Debbie Himes
360-438-3246
by **December 12, 2005**

Traveling? The Spokane Parent Coalition and the Coalition of Responsible Disabled are making arrangements for travel from eastern to western Washington.

Cannot attend? Contribute to the stipend fund!
Suggested contributions:
Agency sponsorship = \$50-100
Individual Sponsorship = \$10

Contact Kristina Fyfe of Parkview Services, 206-335-5675, for more information about utilizing or contributing to the stipend fund.

Learn more about Medicare's new prescription drug coverage

Medicare will offer new prescription drug coverage on January 1, 2006. Your costs and coverage may change. To learn how these changes may affect you, contact Medicare 24 hours per day 7 days per week.

Phone: 1-800-MEDICARE
(1-800-633-4227)

TTY: 1-877-486-2048

www.medicare.gov/pdphome.asp

Get help with:

- **Basic information**
- **Cost estimates**
- **State plan information**
- **Drug plan finders**
- **Enrollment**
- **Other publications**

413,236
wheelchairs
in
143
countries and
geographical
areas

The Wheelchair Foundation donates around the globe

In its Winter 2005 newsletter the Wheelchair Foundation reports encouraging statistics: 413,236 wheelchairs have been committed or delivered in 143 countries and geographical areas around the world.

Relieving Gulf Coast hurricane victims

The foundation has already sent 280 wheelchairs to the Houston Center for Independent Living and intends to send 3200 more to those affected by hurricanes Katrina and Rita. The foundation's president Ken Behring stated, "We are shipping every available wheelchair in our inventory to Louisiana, Mississippi and other states to help our fellow Americans in this time of crisis." A \$150 donation ships a brand new wheelchair to organizations assisting these victims. Donations can be made with a check to "Wheelchair Foundation Katrina Relief."

Eastern European countries need wheelchairs

Wheelchair needs in eastern European countries, including Bosnia & Herzegovina, Lithuania, Romania, Poland, Ukraine and Russia, have been profiled by the foundation. Research from the past five years shows that "...approximately three percent of the population of most developing countries fall into the category of 'in need of a wheelchair but cannot afford one.'"

www.wheelchairfoundation.org

Hydrocephalus Association Fall 2005 newsletter highlights

- Recap of the first-ever National Institutes of Health-sponsored hydrocephalus workshop
- First story in a new series called "My Hydrocephalus Story" designed to show Congress the personal side of hydrocephalus
- A form to submit your own hydrocephalus story
- Tips and support resources to assist those caring for older adults with hydrocephalus or other chronic health conditions
- Suggestions and resources for preparing a personal safety plan for disasters, including advice assisting disabled persons in emergencies
- Updates from Association TEAM fundraising events throughout the country

To read the HA newsletter go to

http://216.82.69.211/pdf/Fall05_news.pdf

A teenager distributes wheelchairs in China
Crystal Walters, 18, joined her parents on a trip to China and made special friends with recipients of the wheelchairs. In her own words, Crystal tells of meeting an elderly woman who sobbed with gratitude for the precious gift of a wheelchair. A young boy thanked her for his wheelchair because he could now play with his friends. Pictures from Crystal's story are available on the foundation website.

Emotional memories from Vietnam

Armon Helvig helped the Wheelchair Foundation supply 740 wheelchairs in Vietnam and shared personal reflections about his trip.

"...What really got to me were the tiny wheelchairs. I had never seen [wheelchairs] that small before... a little boy next to me ...was having such a good time rolling back and forth. And I thought, he is such a joy."

"[A] man had been in bed for more than six months due to a heart attack or stroke. When he was seated in his wheelchair... [he] spoke.... The wife said that this was the first time her husband had spoken in four months."

"When you give a recipient a wheelchair, you liberate the family as well because no one has to carry around the person as much. Many recipients say that ...the best gift is that people are no longer a burden to their siblings and folks."

Violence report; continued from page 1

- The community at large, especially people who work with children, should strive to change social consciousness about disabled children's issues
- Transparent mechanisms for accountability and reporting by institutional and educational staff and administrators must be implemented
- Expertise of disability and parent advocacy groups must be utilized
- Disabled children and their families must be empowered to advocate for themselves
- Disabled children and their families should be included in outreach and research efforts

To read the entire summary report, go to www.unicef.org/videoaudio/PDFs/UNICEF_Violence_Against_Disabled_Children_Report_Distributed_Version.pdf

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

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

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)**


Evergreen Spina Bifida
Association



Connect with a cluster group

CLUSTER	CITY/STATE	LEADER NAME	CONTACT PHONE
POR	Portland OR	Gina Schuermyer	503-761-8193
EVT	Everett WA	Brenda Stroud	425-385-2487
MAD	Madigan	Dr. Ellen Davis	253-589-3700
VAN	Vancouver WA	James Haxby	360-258-4148
SPO	Spokane WA	Ed Kennedy Suan Curalli	509-465-0676
SSE	South Seattle WA	Brian Knowles	253-887-0888
CHS	Children's Seattle WA	Phil Terry	360-491-3171
ES	Eastside Seattle WA	Michele Hopkins	425-844-1262
KIT	Kitsap WA	Dave Lewellan Rebekah Uhtoff	360-871-5139
OLY	Olympia WA	Marcus McInnes	360-402-9418
WWW	Walla Walla WA	Garrison Redd	509-301-0243
OR	Eugene OR	Anne Moon-Glen	541-689-2125
MT	Butte MT	Paula Christenson	253-589-3700
ID	Idaho	Shirley Russell	208-884-3261
AK	Alaska	Hoonen McLeod	907-688-8456
CFI	Center for Independence	Cliff Schulman	253-582-1253
SPA	Spanish	Enia Warren	253-912-4437
OR2	Bend OR	Diane Cole	541-318-7075
ID2	Idaho Falls ID	Pam Hoppmann	208-522-6206
LEA	Leavenworth WA	Ed Baroch	509-548-5697