



Evergreen Spina Bifida Association Newsletter

'Baby Noor,' discovered during US raid, has Spina Bifida

By Mike Stobbe, AP

ATLANTA (Dec. 31) - An Iraqi infant with severe birth defects arrived in Atlanta for at least a month of medical treatment that was offered after U.S. soldiers discovered the child during a raid on a home.

Noor al-Zahra or, "Baby Noor," was accompanied Saturday by her grandmother and father. The smiling baby, wearing an orange outfit, was carried by the grandmother through the airport and to a waiting ambulance.

"She said they're happy to be here," an airport worker said, translating the grandmother's comments from Arabic.

U.S. troops discovered the baby three weeks ago during a raid

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

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

*Newsletter Editor
Celeste M McCormick*

President recaps accomplishments, looks toward future

By Ed Kennedy, ESBA President

Hello and Happy New Year to Everyone! ESBA has been very active in the past year and it is exciting to see where we are headed. I personally believe that our summer camp at Camp Prime Time was a highlight of the past year and an event that we hope to continue in the future. The committees that came out of that have been busy trying to make ESBA a better organization for everyone. We will have a new set of bylaws to vote on shortly that we hope will better represent our organization as it is today as well as guide us into the future. The new "cluster developer" concept that we are trying in Western Washington will, I hope, be a model to follow in other areas where we serve. And, as most of you know, a few "changing of the guards" have taken place. Patti Logan has stepped down (a little) from leadership and is the new Cluster Developer that I spoke about earlier. Brian

Knowles and myself are trying to fill Patti's shoes (they are awfully big shoes) as Co-Chairs. Gloria Olson who was our "greetings" chairperson has stepped down and we have that opening still available. Then we also have a new newsletter editor, Celeste McCormick, who filled this position when Linda Bailey had to step down due to time constraints. This is also the first full year that ESBA has had an advisory board in place to help in making ESBA an even better association.

It is my desire that this new year will only make us stronger and better as we continue to make needed changes to help serve people affected by spina bifida in Idaho, Montana, Oregon, Alaska, and Washington. I hope that all of you will feel free to contact myself, an ESBA officer or board member if you have any questions, ideas, opinions, etc. about where ESBA is headed in the future. Thank you for being a part of ESBA!

Iraqi infant arrives in Atlanta for health care

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of a house in Abu Ghraib, a poverty-stricken district west of Baghdad. The soldiers noticed paralysis in the baby's legs and what appeared to be a tumor on her back. They later learned the 3-month-old child had spina bifida.

It isn't clear how much physicians would be able to do to help the child, said Dr. Roger Hudgins, a pediatric neurosurgeon who agreed to take the case.

U.S. doctors were sent e-mail photos of the baby and received some medical information, but on Saturday evening they will begin a thorough evaluation to plan their next step, he said.

Doctors will proceed with surgery if a critical problem is diagnosed, such as an infection-inviting leak in the sac. Otherwise,

the initial surgery won't be done for about a week, Hudgins said. Baby Noor's health care is to be provided for free, he said. Hudgins praised the soldiers for their role in getting Baby Noor to the United States, saying that he believes "the chances of her survival are good." Without more medical care, "she would have died," he added. The baby will probably need one or two months in the United States to complete the surgery and recovery. Her grandmother and father are to stay with a host family arranged by Childspring International, a faith-based children's medical charity. The trio are to return to Iraq after the care is completed. Childspring International will arrange follow-up medical care for the infant there, said Rose Emily Bermudez, the organization's executive director.

Keep in touch with ESBA through your local Cluster

By Patti Logan

If you have been around Evergreen Spina Bifida Association (ESBA) very long you have heard the word "Cluster." A Cluster is a group of our members and friends that keeps in contact regularly. It is one of those inside buzz words that expresses an idea of a group, and this is the one we chose to convey the impression of a coming-together of ESBA members and friends within a specific geographic area. We also have dreams of some electronic and/or special interest Clusters like the Yahoo Chat group and a Spanish-speaking group.

What does a Cluster look like?

It is led by one of our ESBA members who has indicated his or her willingness to be the central figure in reaching out to his/her community and outlying areas (in some cases, hundreds of miles) to find others interested in sharing knowledge and everyday experiences of living with Spina Bifida. These people come together on a regular basis, usually every few months, and provide local contact for the necessary in-between questions and need for a sympathetic ear.

Could I start a Cluster in my area?

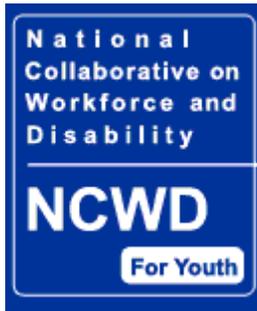
We would love for you to start a Cluster! Any member of ESBA can be a Cluster Leader. ESBA will pay all expenses for starting a local Cluster, help you get started, and give you assistance in finding contacts and filling out the necessary forms.

How do I get started?

Patti Logan retired in December and would like to work with Cluster Leaders to build their clusters. She will keep you going with occasional phone calls and share ideas from other group leaders. Contact her at patti_logan04@yahoo.com or 360-888-7701 to find out more information about finding or starting a Cluster in your area.



The last page of the newsletter lists contact information for all current Cluster leaders.

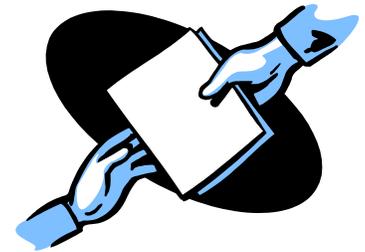


Organization helps youths with disabilities transition to adulthood

“Navigating the road to work for youth transitioning to adulthood can be challenging, so it is useful to have guidance,” states the National Collaborative on Workforce and Disability for Youth. Therefore, the collaborative provides many services and resources to assist in the endeavor. The collaborative is funded under a grant supported by the Office of Disability Employment Policy of the US Department of Labor.

NCWD can connect you to:

- A database of links to websites for other youth organizations and programs, including state and locally operated programs providing youth with opportunities to explore jobs and education leading to careers in technology
- Resources and publications, including a new brochure called “Guideposts for Success” designed to steer youth and their families through the transition to adulthood
- Inspirational success stories
- An “Ask the Experts” utility where you can pose questions about topics like employment/business, policy making, youth and family, and youth service administration
- Events such as conferences, forums and webinars; many are currently scheduled for February



You can find more information and assistance at their website

www.ncwd-youth.info or by phone 1-877-871-0744/ 877-871-0665 (TTY).

Remember to sign up for their free electronic newsletter, *INTERSECTION: Navigating the Road to Work*.

SKIFORALL seeks participants, volunteers, donors

SKIFORALL Foundation, a national nonprofit organization, endeavors to “improve the quality of life for people with disabilities by providing opportunities to participate in year-round outdoor recreational activities through education and training,” according to its mission.



SKIFORALL Foundation
1621 114th Ave SE, Suite 132
Bellevue, WA 98004-6905
Telephone: 425/462-0978 TTY: 425/462-0979
Fax: 425/462-0980
Email: info@skiforall.org
Web: skiforall.org

“We couldn’t believe it! Our granddaughter (Nicole, who has cerebral palsy) may not be able to walk (yet) but she sure can ride a bike—thanks to SKIFORALL!”

~Grandfather of Nicole Heikell, SKIFORALL participant.

PARTICIPATE: Winter activities are still in progress. Spring and summer activities are just around the corner! Contact SKIFORALL to register.

VOLUNTEER: Training programs for volunteers in March have been scheduled. Please contact John Stevenson at johnstevenson@skiforall.org or 425-462-0978 for more information.

DONATE: Funds and services are acceptable donations! You can even donate online. To learn more about the many ways to contribute, visit SKIFORALL’s website.



Non-profit offers services that improve communities

Community-Minded Enterprises, located in Spokane Washington, is a non-profit organization that “facilitates and enhances community well-being” according to its website. The organization tackles major social issues through initiatives that encompass healthcare and disability access, child care, workforce development and community safety.

Services are provided to a wide range of agencies in many areas, including

- Grant writing and proposal development
- Custom training programs
- Technical assistance
- Event planning
- Budget management

Community-Minded Enterprises welcomes volunteers and new members for their various advisory groups. Donations are also accepted.

For more information:
Phone: 509-444-3088
Email: info@community-minded.org
Web: www.community-minded.org

OLYMPIA SPINA BIFIDA CLUSTER INVITES YOU

Join us for a discussion surrounding issues that affect persons with Spina Bifida and their families and friends. Everyone is invited! Our mission is to enhance the lives of people touched by Spina Bifida and to educate others about this birth defect.

Enjoy a pizza/salad bar/dessert bar dinner compliments of ESBA

WHEN: Saturday February 4 1:00pm

WHERE: Izzy’s Pizza, Pacific Ave & Lilly Rd, Olympia WA

For more information contact Patti Logan at 360-888-7701 or patti_logan04@yahoo.com



SPINA BIFIDA: AN EDUCATIONAL UPDATE

*A Conference for Health Care
Professionals and Families*

Sponsored by
Child Development and Rehabilitation Center
Department of Pediatrics,
Oregon Health & Science University
The Elizabeth Foundation
Shriner’s Hospital

WHEN:

Saturday, March 18, 9am – 4pm

WHERE:

Shriners Hospital, Portland, Oregon

COST :

\$35.00

KEYNOTE SPEAKER:

David G. McLone, M.D., Ph.D.
 Medical Director
 Spina Bifida Program
 Children’s Memorial Hospital
 Professor of Pediatric Neurosurgery
 Northwestern University's
 Feinberg School of Medicine

Scholarships will be available to cover the costs for those in need. Brochures containing the registration form will be sent in January.

**PLEASE MARK YOUR
CALENDAR NOW!**

Health, wellness research project needs volunteer families

Parents of children with disabilities aged 6 to 18:

Are you looking for ideas about:

- ♥ How to get your child to eat his veggies?
- ♥ How to promote physical activity for your child?
- ♥ How other families are able to encourage healthier behaviors for their children with disabilities?



Raising kids with special health care needs to be healthy and fit is a challenge for families. The **Family Matters** project, funded by the **Centers for Disease Control and Prevention**, is developing ideas and materials to make your job easier. Your ideas and involvement will help us learn crucial information about how families are facing and meeting these challenges.

Would you like to receive, all at no cost to you:

- ♥ Information?
- ♥ Family materials for children with special health care needs?
- ♥ A chance to work with a mentor parent to share ideas?
- ♥ Regular support by phone or email at convenient times for you?

Families and professionals will benefit from what we discover about the ways families use available information about kids' health and how they may adjust it for their children and youth with special health care needs.

Family Voices and **Tufts School of Medicine** invite you to participate by contacting Amy Lightbody by phone at 509-879-5569 or by email at amylightbody@msn.com.

Raising kids, especially those with special health care needs, to be fit and healthy is a challenge for families.

VISIT DHHS SITES FOR HEALTHCARE RESEARCH

LINKS PROVIDED BY THE AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ), AN AGENCY OF THE US DEPT OF HEALTH AND HUMAN SERVICES

(AHRQ) main web page <http://www.ahrq.gov/>

AHRQ 2005 National Healthcare Quality and Disparities reports
<http://www.ahrq.gov/news/press/pr2006/nhqdrpr.htm>

AHRQ video on *Tips for Taking Medicines Safely*
<http://www.ahrq.gov/consumer/chkmedvid.htm>

AHRQ-SUPPORTED CLINICAL PRACTICE GUIDELINES

National Guideline Clearinghouse (NGC), a public resource for evidence-based clinical practice guidelines and an initiative of AHRQ <http://www.guideline.gov/>

National Center for Biotechnology Information (NCBI) clinical practice guidelines (main) <http://www.ncbi.nlm.nih.gov/books/bv.fcgi?rid=hstat2.part.4408>

NCBI Pressure Ulcers in Adults: Prediction and Prevention
<http://www.ncbi.nlm.nih.gov/books/bv.fcgi?rid=hstat2.chapter.4409>

NCBI Treatment of Pressure Ulcers
<http://www.ncbi.nlm.nih.gov/books/bv.fcgi?rid=hstat2.chapter.5124>



HHS Secretary Mike Leavitt with Ms. Wheelchair America 2005 Juliette Rizzo. HHS photo by Chris Smith May 2005

Connect with ESBA through live Yahoo chats

Follow these helpful instructions to get started

By Patti Logan

Do you feel isolated or cut off from the group? Do you not know what is going on or do you want to know about the latest Spina Bifida research? Do you have a challenge you are looking for some friendly advice about? Come to our ESBA Chat Room and meet the folks...

Maybe you have tried to join our chat. If so, and you did not make it into chat, do not give up - there is a learning curve. It takes patience and time to get on the list and start using it. Once you learn how, it is a good way for several people to relay information and make decisions in real time. Meetings can be conducted in the chat room and, most importantly, you get to ask your questions and get responses immediately. Getting started is the hardest part, but hopefully these step-by-step directions will help.

To Join Chat:

Get to the Chat Room one of two ways:

- If you like, we can send you a personal invitation to chat. Just ask by email or phone (see sidebar above). With the invitation, you just click on the button, and you are asked to sign up. When you get the invitation, follow the steps below carefully, remembering to bookmark the site in some way. Our group is not one of the general chats, and so you need a shortcut to find it again.
- Copy/Paste or Type http://health.groups.yahoo.com/group/ESBA_WA/ into your Internet browser or address line. Again, please bookmark the site or add it to "My Favorites" so you can return easily later.

Once there, you need to join:

- Fill out the profile information and give your email address preferences so you can communicate with the group and get our messages periodically.
- If you do not already have a Yahoo account, you will be asked to create one. This is free. You will need a login ID and password to access your account. Just make one up, but remember it for the future.
- **BEFORE you are ready to chat:** go to the bookmarked site and click on CHAT. You will be asked permission to download some free software. You need to do this step before you can participate in a chat session.

Ask a friend to meet you in Chat:

- Contact someone else from the group (you can use the member list in the ESBA Yahoo group) to meet you at a convenient time and check it out. Practice helps allay the fear.
- Remember to log out. You will be asked your Yahoo member ID and password to re-enter Chat each time to log on.

After signing up, just go to the web site (now bookmarked) each appointed time. Please come into the room as close to the hour as possible; the moderator will leave the room after 15 minutes if no one else comes. **Chat times for the month of February are Saturdays at 6 pm PST and Mondays at 4 pm PST.**

For personal help getting signed up, contact Patti Logan by email patti_logan04@yahoo.com or phone 360-888-7701. She will walk you through the steps herself!

http://health.groups.yahoo.com/group/ESBA_WA/

If you have scheduled a chat or would like to set one up, please email the ESBA secretary at evergreenesba@yahoo.com. We will try to find at least one buddy to meet you there!

ESBA welcomes new parents of children with Spina Bifida

The following letter has been prepared by ESBA for distribution inside informational packets for new parents of children with Spina Bifida.

Dear Friend:

Thanks for contacting us. We know that learning that your child has Spina Bifida can be overwhelming. The day-to-day living can tax the most resourceful individual. We have been there and want to be here to help you in the challenges that are ahead. The goal of the Evergreen Spina Bifida Association (ESBA) is to assist and enhance the lives of all affected by Spina Bifida. We have included in this packet some general information and some resources to contact for more help.

We have been working in Washington State for over 20 years. Just recently, we have expanded our influence in other states—Montana, Oregon, Idaho, and Alaska. By helping each other we seek to improve the quality of life of people with Spina Bifida, exchange ideas with parents and others touched by Spina Bifida, improve treatment, and research into causes and prevention through our organization. We encourage you, your friends, family, and others affected by Spina Bifida to join our association.

We have a Chat Room in Yahoo Groups called ESBA_WA. The link to find our room is http://health.groups.yahoo.com/group/ESBA_WA/. Join us with your queries and experiences. It is just a group of people getting together and talking about their mutual concerns. Use any of the contact information to ask us for the upcoming chat times.

Log on to our web site for more information about ESBA and share our site with others - <http://www.evergreenSpinaBifida.org>. Also, please check out the Spina Bifida Association's web site at <http://www.sbaa.org>.

To share your questions, concerns, or plans for activities, please write us an email at evergreensba@yahoo.com or POB 642, Sumner WA 98390, or call 253-589-3700. If you would like to talk with me personally, please call me at 1-877-606-2680.

Let's work together to make a difference. Thank you.

Sincerely,
Ed Kennedy
President
Evergreen Spina Bifida Association

Do you need more information about Spina Bifida?

In Washington state:

Spina Bifida Association: 1-800-641-3161

Hydrocephalus Association: 1-888-598-3789

Evergreen Spina Bifida Association: 253-589-3700

Answers for Special Kids (Healthy Mothers, Healthy Babies): 1-800-322-2588

Web site for ASK Resource Line: www.hmhbwa.org

**Children's Hospital Center for Children with Special Needs Resources Line:
1-866-987-2500**

Web site for Center for Children with Special Needs:

www.doh.wa.gov/cfh/mch/CSHCNhome2.htm

Travel safely with these six disability travel tips

By James Haxby

As a person with Spina Bifida one of my favorite things to do to enhance my sense of independence and have fun is to travel. I often go on trips with my best friend Julie, who also has Spina Bifida. We have traveled together to places like Quebec, Washington DC, and on a cruise to Mexico. Separately, the two of us have traveled to places like Cuba, Eastern Europe, and Costa Rica. However, during my travels, I have been in some situations where I had unexpected problems related to my Spina Bifida and I had to find unique ways of dealing with these challenges. So in an effort to help others with Spina Bifida who would like to travel more, I have put together a list of helpful hints for dealing with traveling and the situations you may find yourself in when traveling with Spina Bifida.



A good resource for young adults with disabilities who want to travel abroad at reduced cost is Mobility International USA, which is affiliated with the University of Oregon in Eugene:

www.miusa.org

1. Ask your doctor for a prescription of antibiotics to take with you. I became ill with an infection just as I arrived in a remote jungle area in Costa Rica and had it not been for another group member who brought antibiotics I would have been in real trouble.
2. Keep a 24-hour supply of all medications and medical supplies with you on your person at all times. I was on a plane that got diverted due to weather, and I found myself stranded overnight in Salt Lake City without my luggage and with barely enough medical supplies to get through the night. Travel early in the day so that if your plane gets delayed or diverted you will be less likely to get stranded overnight.
3. Ask your hotel if you can mail your luggage to it. I often call the hotel ahead of time and pack my luggage in duffel bags inside boxes and mail it to the hotel so it is there waiting for me and I do not have to wrestle with it in the airport. When my trip is about over I box most of my stuff back up and have it shipped to my house.
4. At the airport, the security people will probably ask you to remove your shoes and will pat the full length of your legs, so wearing a leg bag to the airport would not be a good idea. Ask if you can board early, even if you are not in first class. I have often boarded first, with the first-class passengers, and just told the gate attendant that I have walking problems, and that I need a little extra time. Also, you can ask them to phone ahead and have a wheelchair meet you at the gate when you arrive at your destination.
5. Always make sure you have a printed copy of your ticket. We were stranded in Minneapolis for several hours because of a problem processing a paperless ticket and finally arrived in Washington DC at 2 o'clock in the morning.
6. Phone ahead to inquire about special accommodations you might need. After arriving at a Spina Bifida conference the people who needed wheelchair-accessible vans found out that the local cab companies had vans available during very limited time slots. Also ask for a room on a lower floor. At another disability conference, the elevators in the hotel broke down stranding hundreds of people with wheelchairs and other walking difficulties.

APPLY FOR A FREE RAMP FROM RAMPATHON 2006

The Master Builders Care Foundation seeks applications from homeowners needing free access ramps in King and Snohomish WA counties. Homeowners must be approved and will have no costs. Contact the Master Builders Care Foundation at 425-451-7920 for an application or more information. Applications are due February 20 2006. Rampathon is Saturday May 20 2006.



Eastside Spina Bifida Cluster meeting

Share your questions, concerns and successes about Spina Bifida with this support group for people with various forms of Spina Bifida and their families. Adults and children welcome. Light refreshments will be served.

TOPIC: Come talk about your New Year's resolutions!
Have you broken them yet? Do you believe in them?

WHEN: Saturday, February 25th 2006, 2–4pm

WHERE: Bothell Library, 18215 98th Ave NE, 425-486-7811

Directions

North Seattle: Take Lake City Way (it becomes Bothell Way at NE 145th St), follow Bothell Way into city limits, turn left at NE 180th St (first traffic light at Brooks-Biddle Chevrolet dealer), go one block, turn right onto 96th Ave NE, go another block, turn right onto Dawson St (NE 182nd St), library is two blocks ahead at 98th and Dawson.

From I-405 North or South: Take Exit 23 (Highway 522) and drive west into Bothell through two traffic lights, go one block past the second light, turn right onto 98th Ave NE, entrance to the parking lot is 1/2 block on the left.

Metro Transit: The Bothell Regional Library is served by King County Metro Transit bus routes 236, 238, 251, 312, 342, & 372; Community Transit bus routes 105, 106, 120, 121 & 435; and Sound Transit bus routes 522, 530 & 535.

Hosted by Michele Hopkins

Please RSVP at 206-909-4186 or michele.hopkins@comcast.net

Are you a carrot, an egg or a coffee bean?

A daughter lamented how difficult life was. Tired, uncertain, and frustrated, she wanted to give up.

Her father took her into the kitchen. He filled three pots with water and placed each on a high fire until they came to a boil. In one pot, he placed carrots, in the second eggs, and in the last ground coffee beans. He let them sit and boil, without saying a word. The man fished out the carrots and placed them in a bowl. He pulled out the eggs and placed them in a bowl. Then he ladled out the coffee and placed it in a cup.

“What do you see?” he asked. “Carrots, eggs, and coffee,” she replied.

“Feel the carrots,” he suggested.

The young woman noted they were soft. Her father then asked her to take an egg and break it. After pulling off the shell, she noticed the egg was hard-boiled. Finally, he asked her to sip the coffee. “But what does this mean?” she asked.

Each item, the man explained, had reacted differently to the same adversity. The carrot went in strong, hard and unrelenting; in the boiling water, it softened. The egg had been fragile, but after boiling, it became hardened. The coffee beans, the father pointed out, were unique. They changed the water. “How do you respond to adversity?” he asked then. “Are you a carrot, an egg, or a coffee bean?”

- *Catholic Digest, January 2006*

The coffee beans were unique.

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

Connect with a cluster group

City/State	Leader Name	Contact Phone
Portland OR	Gina Schuermyer	503-761-8193
Helena MT	Joe Nugent	406-458-9549
Madigan	Dr. Ellen Davis	253-589-3700
Vancouver WA	James Haxby	360-258-4148
Spokane WA	Ed Kennedy Susan Curalli	509-465-0676 509-892-6757
South King CO WA	Brian Knowles	253-887-0888
Eastside Seattle	Michele Hopkins	425-844-1262
Kitsap WA	Dave Lewellan Rebekah Uhtoff	360-871-5139 360-782-0467
Olympia WA	Patti Logan	360-888-7701
Walla Walla WA	Garrison Redd	509-301-0243
Eugene OR	Anne Moon-Glen	541-689-2125
Butte MT	Paula Christenson	406-683-4793
Alaska	Honnen McLeod	907-688-8456
Center for Independence	Cliff Schulman	253-582-1253
Spanish	Anthony Williams	253-588-4411
Bend OR	Diane Cole	541-318-7075
Idaho Falls ID	Pam Hoppmann	208-522-6206
Leavenworth WA	Ed Baroch	509-548-5697


Evergreen Spina Bifida
Association

