



# The Evergreen

November 2011

Spina Bifida Association of Washington State  
A chapter of the national Spina Bifida Association

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## SB Awareness Month kicks off fundraising season

by Meg Paulsen, Executive Director

Fall is finally upon us and kicked off October's Spina Bifida Awareness month. Our Adopt-A-Ghost campaign is nearly over and we appreciate those businesses that are always supportive – a big thank you to a variety of University Village retailers and Top Foods of Auburn! If you've never been involved with this campaign, please consider getting involved with this fun and festive fundraiser –



Meg Paulsen

it's an easy way to help us stay in the business of serving you and your families!

We have been busy at work presenting the SBAWS mission at various Combined Fund Charity Fairs here in the Puget Sound area. We set up our SBAWS booth to present our information, resources and services available to federal employees so that they have the chance to choose SBAWS to contribute to. If you're interested in donating to SBAWS please visit our website at [www.sbaws.org](http://www.sbaws.org).

In September I attended a Directors of Disability Organiza-

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## Study finds prospective memory worse in adults with SB

Reprinted with permission from the Sept. 2011 issue of *Enlighten*, SBA's research and medical information eNewsletter.

Individuals with neurodevelopmental disorders have been observed to show accelerated cognitive aging or even dementia as early as 30 and 40 years of age. Memory deficits are an important component of age-related cognitive loss. A recent study (Dennis M, Nelson R, Jewell D, Fletcher JM. Prospective memory in adults with spina bifida. *Childs Nerv Syst* 2010 December;26(12):1749-55) investigated prospective memory - remembering intentions to be activated in the future, such as taking your medication at a particular time, or remembering to deliver a message to a certain person.- which is often impaired in aging. The study assessed a group of 32 adults with Spina Bifida Meningocele (SBM), including members of the oldest living cohort successfully treated with

shunts to divert excess cerebrospinal fluid to treat hydrocephalus, who are now around 50 years of age.

A comparison group of 17 typically developing adults was utilized for analysis. The researchers concluded that the SBM and comparison groups differed in the prospective memory total score as well as in time-based and event-based sub-scores. In addition, the researchers found that prospective memory was impaired in older and younger individuals with SBM. However, the percentage of individuals with impaired or poor prospective memory was three times higher in the older SBM group than in the younger SBM group. The results are considered in relation to specific features of the complex brain reorganization in SBM. Previous studies have shown that adults with Spina Bifida have problems with working memory (activating and manipu-

(Continued on page 10)



Newsletter Editor  
Celeste McCormick  
[celtutt@yahoo.com](mailto:celtutt@yahoo.com)

## HIGHLIGHTS FROM BOARD OF DIRECTORS' MEETING October 27, 2011

*For full content of the minutes, visit [www.sbaws.org/Minutes.html](http://www.sbaws.org/Minutes.html)*

*Have you moved recently? Is the postal service forwarding this newsletter to your new address? We do not want you to miss an issue or any other important mailing from SBAWS, so please send us your updated contact information!*

- In attendance: Jason Lane, Jon Tut, Krystal Monteros, Elizabeth Lovelace, Ryan Callaway, Linda Bailey (by proxy to Jason), guest Meg Paulsen
- Absent: Tracy Wright, Annette Zweig-Donham, Nicole Williamson, Jamie Heckinger, Dave Carl, Ed Kennedy
- Executive Director's Report
  - Signed up for membership with the Directors of Disabilities Association
  - Getting involved with Charity Sears events to spread information about SBAWS at their events
  - TOP Foods signed up for the Adopt-A-Ghost Program
  - Although the Walk N' Roll conference call was canceled, Meg and Jason have looked at three possible park locations for the next walk, and they are still looking for more park options
  - Meg and Elizabeth completed the Eastern Washington Outreach distributing approximately 1,000 SBAWS flyers
  - In the next two months, Meg and Elizabeth will be the western and southern parts of Washington, including the Spina Bifida Clinic in Portland and Vancouver
  - Motion made and approved to provide reimbursement for travel, hotel and mileage for Meg's outreach trips
- Chair-Elect's Report: Chair Elect: Will be attending the United Way of King County Board Chair class on December 1, 2011
- Treasurer's Report
  - We have reached our goal to raise and spend \$50,000 for 2011
- Old Business
  - Jamie was not present for a Walk N' Roll Committee Report
  - Nicole was not present for an Adopt-A-Ghost review
- New Business:
  - Potential Board members: Vote on the potential new board members will occur at the December Board meeting
  - Direct aid requests:
    - Direct Aid Request form has been made;
    - Add something for Personal Aid Request"
    - Jason, Ryan & Linda will form a committee to update the Direct Aid Request on the website
  - Holiday party plans: will likely be first or second Saturday of December; Starlight Foundation will donate gifts
  - Unsolicited donations: The Vogelpohl family and friends sent checks totaling \$1,100 in honor of Jackson Vogelpohl
  - Insight subscriptions: Motion made and approved to buy Insights subscriptions for those who opt-in from an email
- **NEXT MEETING: At the annual holiday party (date/location TBA)**

Chair  
Linda Bailey,  
gingersnap8160@yahoo.com  
Chair Elect  
Jason Lane  
jlane101@comcast.net  
Secretary  
Krystal Monteros,  
babykeitho@aol.com  
Treasurer  
Jon Tutt, jon\_tutti@msn.com  
Immediate Past Chair  
Ed Kennedy  
ejkcordwa@live.com

Directors  
Meg Paulsen, Exec. Director,  
megpaulsen@sbaws.org  
Ryan Callaway  
Dave Carl  
Jamie Heckinger  
Elizabeth Lovelace  
Nicole Williamson  
Tracy Wright  
Annette Zweig-Donham

**OCTOBER WAS SPINA BIFIDA AWARENESS MONTH**

*How did you spread the word?*

# SBAWS, Seattle, Annual Holiday Party



**December 3rd, 2011  
11 a.m. to 2 p.m.**

Bring the whole family! Please join us for Food, Crafts, and the  
Book-It Repertory Theatre's production,

"Where the Mountain Meets the Moon." around 12:30 pm.

Gifts\* will also be presented to all children.

*Special thanks to Astratech, the ABC Guild, Book-It Repertory Theatre,  
Church of Jesus Christ of Latter-Day Saints (Lake Forest Park Ward),  
the Lougheed Family, Spina Bifida Association of WA State, and the  
Starlight Children's Foundation WA.*

Directions from I-5:

- Exit NE 145th St/ WA-523 east towards Lake City Way/WA-522
- turn N on 30th Ave NE (dead ends into church parking lot) entrance on SE corner of building  
accessible bathroom entrance on NW corner of building

Please **RSVP by Nov 28th** to [seattlespinabifidagroup@hotmail.com](mailto:seattlespinabifidagroup@hotmail.com)  
or text/call Nicole Williamson, SBAWS Seattle Co-leader, at 206-877-2568.

**\*Please provide us with the number of attendees AND name and age of all children attending.**

## SBAWS continues outreach efforts across state

*(Continued from page 1)*

tions (DDO) networking event consisting of Directors of various organizations that serve people with disabilities. We are now annual members of this organization that is bringing leaders together to educate, advocate, and collaborate. I have joined their Coordinating Committee to ensure that SBAWS is represented at all future events.

Our Eastern Washington outreach was a huge success – we now embark on part two of our efforts. November and December are being dedicated to doing the same for Northern, Western and Southern Washington. We will be visiting 25 Planned Parenthoods, four EasterSeals Child Development Centers and other similar organizations who work with our community to prevent birth defects and serve families affected by Spina Bifida. Next year we be will be attending the Kick Off event held at the Seattle Convention Center where there will be thousands of potential donors.

We are now starting to plan our 2012 Walk & Roll awareness raising and fundraising event. We have been scoping out possible locations in our attempts to find one that meets our ADA and parking needs. If you have any suggestions for, or want to become involved with, this exciting, family fun event please contact us!

As the chill of the season comes upon us, our hearts are warm with appreciation for the efforts of each of you who attend our events, sit on our Board and volunteer time to ensure that SBAWS is meeting its goals and mission – we could not do this without YOU!

Looking forward and working together to make the difference!



**Please consider contributing to the fundraising efforts of SBAWS that support SBAWS programs and services, such as this newsletter, with a tax deductible donation. Go to [www.sbaws.org](http://www.sbaws.org) and click on the “Donate” button in the top right corner.**

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**The Evergreen reporting staff:**

Michele Hopkins, [michele@thehopkins.us](mailto:michele@thehopkins.us)  
Elizabeth Lovelace, [emeraldsweet2002@yahoo.com](mailto:emeraldsweet2002@yahoo.com)  
Elizabeth Scriven, [liz-biz@iname.com](mailto:liz-biz@iname.com)  
Brenda Stroud, [frizzle3@verizon.net](mailto:frizzle3@verizon.net)  
Diana Tutt, [nanatutt@msn.com](mailto:nanatutt@msn.com)

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## SBAWS receives \$3500 technology grant from SBAWS

by Celeste McCormick, Newsletter Editor

In September, SBAWS was among several chapters awarded a \$3500 technology grant from the Spina Bifida Association. After submitting the application, Executive Director Meg Paulsen was notified by Sara Struwe, Chief Operating Officer at SBA, of the award. The grant stipulates that SBAWS "spend the funds on technological improvements which will result in greater outreach and education to people affected by Spina Bifida." Although there is no deadline by which the money must be spent, all expenditures must be documented. As the funds are used, the grant requires that SBAWS provide a "report which includes the purchases or payments made with the funds, the impact the funds will have on people with Spina Bifida, and planned activities to be impacted by the purchases."



The grant was a topic at the recent meeting of the Board of Directors of SBAWS. Those present reached a consensus that the chapter should use



the funds to revamp its commitment to provide "refurbished computers, new software and personalized training to assist people in need to be in contact with the world and us." There is interest in expanding the program to include laptops and tablets, which are increasingly in demand and would be easier to ship and distribute to constituents around the State. A suggestion was made to research the potential of using TechSoup, which has computers for around \$30.

If you have ideas for how these funds can be best put to use, please contact either Meg Paulsen or anyone on the Board of Directors to discuss your ideas.

### Are YOU interested in volunteering for SBAWS?

SBAWS is currently seeking volunteers for the following positions:

- **Treasurer:** this position sits on the Board, reconciles the bank account, prepares financial statements and more. Term begins January 2013.
- **Historian:** the SBAWS history page ([www.sbaws.org/History..html](http://www.sbaws.org/History..html)) needs rewritten with more accurate and up-to-date information.

Contact SBAWS today to learn more about these opportunities.



## Family support runs far and wide

by Elizabeth Lovelace



Elizabeth Lovelace

On October 7-8, 2011, Down the Hatch, a 12-person team made up of family and friends, gathered together for the 200-mile re-

lay on Kentucky's scenic Bourbon Trail. The focus of the team's efforts was 2-year old Jackson Vogel-

pohl of Enumclaw, Washington. The Vogelpohl family understands the importance of team efforts and the impact they have on reaching goals. In 2010 team Super Jack was formed for the Seattle Walk-n-Roll, raising money for Spina Bifida education and prevention research. Not able to participate in the Walk-n-Roll this year, Jackson's grandparents, Ken and Susan, took it



Jackson

upon themselves to form a fundraising team for the Kentucky Bourbon Run. This 2-day, 250 team re- lay is de- signed to sup- port 3 specific

non-profit charity groups; however, team Down the Hatch chose to run for the Spina Bifida Association of Washington State.

Jackson was born in Germany with Spina Bifida & Hydrocephalus, in need of surgery and experienced medical care. After



Team Down the Hatch

researching their options, his parents decid- ed to move to Washington to seek the spe- cialist care offered by Children's Hospital in Seattle. Today Jack, his twin Sammy, sister Brea and their parents, Heidi and Scott, live in Enumclaw, WA close to family, friends, and an expert neurosurgical team.

The Vogelpohl family's dedication to and advocacy for education, prevention and research on Spina Bifida is felt and greatly appreciated. Thank you - together we make the difference!

*"Real generosity toward the future lies in giving all to the present." Albert Camus*

Association for Spina Bifida and Hydrocephalus (ASBAH) in the UK is now known as SHINE, with a new website: [www.shinecharity.org.uk](http://www.shinecharity.org.uk). Log on today!



# Shine

Spina bifida • Hydrocephalus  
Information • Networking • Equality  
[www.shinecharity.org.uk](http://www.shinecharity.org.uk)

## Spina Bifida Association of Washington State Financial Statement Summaries As of September 30, 2011

|                                     | 2011                 | 2010                | \$ Change             |
|-------------------------------------|----------------------|---------------------|-----------------------|
| <b>Profit &amp; Loss Comparison</b> |                      |                     |                       |
| <b>Income</b>                       |                      |                     |                       |
| Donations                           |                      |                     |                       |
| Fundraising                         |                      |                     |                       |
| Walk N Roll                         | \$ 17,887.20         | \$ 29,782.16        | \$ (11,894.96)        |
| Adopt-a-Ghost                       | \$ 67.00             | \$ 51.00            | \$ 16.00              |
| Shop for a Cause                    | \$ -                 | \$ -                | \$ -                  |
| Other                               | <u>\$ 472.00</u>     | <u>\$ 403.00</u>    | <u>\$ 69.00</u>       |
| Total Fundraising                   | \$ 18,426.20         | \$ 30,236.16        | \$ (11,809.96)        |
| In Kind Donations                   |                      |                     |                       |
| ED Meg Paulsen                      | \$ 20,500.00         | \$ 7,500.00         | \$ 13,000.00          |
| Other                               | <u>\$ 2,939.78</u>   | <u>\$ 459.68</u>    | <u>\$ 2,480.10</u>    |
| Total In-Kind Donations             | \$ 23,439.78         | \$ 7,959.68         | \$ 15,480.10          |
| Restricted (Directed)               |                      |                     |                       |
| Donations                           | \$ 675.00            | \$ 75.00            | \$ 600.00             |
| Other Donations                     | <u>\$ 2,506.01</u>   | <u>\$ 2,113.66</u>  | <u>\$ 392.35</u>      |
| Total Donations                     | \$ 45,046.99         | \$ 40,384.50        | \$ 4,662.49           |
| Interest                            | <u>250.69</u>        | <u>311.36</u>       | \$ (60.67)            |
|                                     |                      |                     | \$ -                  |
| Total Income                        | <u>\$ 45,297.68</u>  | <u>\$ 40,695.86</u> | <u>\$ 4,601.82</u>    |
| <b>Expenses</b>                     |                      |                     |                       |
|                                     |                      | % by Category       | % by Category         |
| Mission/Program                     | \$ 41,991.01         | 83.28%              | \$ 17,796.92          |
| Administration                      | \$ 2,857.73          | 5.67%               | \$ 2,052.28           |
| Fundraising                         | <u>\$ 5,574.42</u>   | <u>11.06%</u>       | <u>\$ 3,954.14</u>    |
| Total Expenses                      | \$ 50,423.16         | 100.00%             | \$ 23,803.34          |
|                                     |                      |                     | 100.00%               |
|                                     |                      |                     | \$ 26,619.82          |
| Net Income (Loss)                   | <u>\$ (5,125.48)</u> |                     | <u>\$ 16,892.52</u>   |
|                                     |                      |                     | <u>\$ (22,018.00)</u> |
| <b>Balance Sheet Comparison</b>     |                      |                     |                       |
| Assets (cash in the bank)           | \$ 46,320.09         | \$ 53,809.07        | \$ (7,488.98)         |
| Liabilities                         | <u>\$ -</u>          | <u>\$ -</u>         | <u>\$ -</u>           |
| Total Equity (Fund Balance)         | \$ 46,320.09         | \$ 53,809.07        | \$ (7,488.98)         |

**Income:** Although our Walk-N-Roll income was significantly less this year, our year-to-date income is greater than last mainly due to Meg Paulsen's In-Kind donation in being our Executive Director. YTD income is 91% of our \$50,000 goal after 75% of the year is gone; last year it was 81% at the same time.

**Expenses:** Total Expense increased by over \$26,000 and we've spent 100.8% of our \$50,000 spending goal. It is time to slow down on our spending. So far this year we've spent over \$5000 more than we've taken in, which isn't good. Our goal is to receive and spend the same amount.

**Net Income (Loss):** In the negative for the first time this year.

**Expenditure by Category:** These are acceptable percentages.

**Net Worth:** Our total assets, fund balance, decreased by 14% over the last twelve months.

**Trend Analysis:** It's time to once again increase our income and hold the line on spending

Jonathan A. Tutt, Treasurer

# Resource Spotlight

## Update on SB University

One year ago SBA launched SB University (SBU), [www.sbuniversity.org](http://www.sbuniversity.org), an online educational tool offering both live and archived seminars on topics related to Spina Bifida.

Recently, SBU has been updated to feature our newest sessions and improve the user experience. To use the new and improved SBU, users will need to create a unique login one time only. This must be done even if you have previously accessed SBU sessions. But it's simple!

Log on to [www.sbuniversity.org](http://www.sbuniversity.org) and click on the link create a login.

Once you are taken to the new SBU interface, click the Login/Register button in the top right hand corner.

Complete the New Customer form to generate your new login and password. The next time you visit, you can use your login and password to sign in as a recurring customer. Select the sessions you'd like to view by searching the subject areas on the SBU homepage

Complete the Buy and Checkout process for the selected session(s) and then access the "My Account" tab to view sessions you have selected. (Note all SBU sessions are free of charge for viewing)

Start viewing all the wonderful SBU sessions available to you!

A wide variety of sessions covering a number of topics are available, including health-related seminars presented by medical professionals and employment and education discussions from subject matter experts. Sessions can be accessed 24 hours a day, seven days a week.

SBA announces its new SPEAK advocacy program for Spina Bifida. At the SPEAK website, you can:

- View SBA's 2011 advocacy priorities
- See if your senator or representative has joined the SB Caucus
- Learn about various ways you can personally advocate for SB issues

Visit

[http://www.spinabifidaassociation.org/site/c.knKLINNKiG/b.5631237/k.5EB3/Spina\\_Bifida\\_Association.htm](http://www.spinabifidaassociation.org/site/c.knKLINNKiG/b.5631237/k.5EB3/Spina_Bifida_Association.htm) to get started! Together across the county we make the difference!



## Spina Bifida Grassroots Advocacy

"All politics is local!"  
- Former U.S. Speaker of the House  
Thomas P. ("Tip") O' Neill

Grassroots advocacy is at the heart of the work the SBA does. It empowers our Community to take real action which can make a difference in the lives of the over 166,000 Americans who live each day with the challenges of Spina Bifida

This site is intended to be a resource to you – a vital member of SBA's grassroots advocacy team – to support your efforts in this cause.

## SBAWS Services and Programs



- Emotional support for everyone affected by Spina Bifida, including meetings at numerous local cluster support groups throughout the state
- Newsletter *"The Evergreen"* detailing local SBAWS activities and providing news on medical, therapeutic, rehabilitative advances, recreational and legislative issues
- Website [www.sbaws.org](http://www.sbaws.org) and toll free contact number to connect you directly to SBAWS
- A lending library containing information on Spina Bifida, secondary conditions and pertinent information on the rights of people with disabilities
- Social events for children, teens and adults to gather, have fun and share their life experiences
- "New Parents" packets to help parents learn about Spina Bifida and to help manage their children's health care needs
- Scholarships awarded for educational needs
- Subscriptions to the national Spina Bifida Association's *"Insights"* magazine and access to other current information on Spina Bifida
- A limited Equipment Fund to assist people with purchasing mobility devices, medical supplies and other necessary items not covered by insurance
- Delegates sent every year to SBA's annual convention



Would you like your story featured in *The Evergreen* and on the SBAWS website? We want the world to know that we are more than just SB—we are real people. It's okay if you're not sure how to get started —just contact the newsletter editor for help!



# Medical News

## SBA Partners with Grain Foods Foundation



The Spina Bifida Association (SBA) is pleased to announce a new partnership with the Grain Foods Foundation, a nonprofit organization dedicated to advancing the public's understanding of the important role grain-based foods play in a healthful diet. The scope of the project will include SBA's participation in an ongoing broadcast PSA campaign beginning in 2012 during January's National Birth Defects Prevention Month. The campaign encourages individuals to incorporate folic-acid-fortified grain foods into their diets. The campaign originally began four years ago and, since then, it has aired 37,428 times, reaching 811.5 million viewers. Airings have increased year to year since its inception. The campaign reminds all women of childbearing age of the important role folic acid plays in preventing birth defects like Spina Bifida. Daily consumption of the B vitamin folic acid, beginning before pregnancy, is crucial as neural tube defects like Spina Bifida can occur in the early weeks following conception, often before a woman knows she is pregnant.

### *What foods are important for prevention and why?*

Bread, crackers, bagels, pasta, pretzels and tortillas made from fortified, enriched white flour are important sources of folic acid. Enriched grains are the primary source of folic acid in the diet of Americans.

### *Is there a target group?*

Daily consumption of folic acid is important for all women of childbearing age particularly the Hispanic community, as Hispanic women are twice as likely as the rest of the population to have a baby born with a neural tube defect.

Because Hispanic women are more likely to have a child born with a neural tube defect, it is critical that they boost their folic acid intake before they get pregnant. Eating enriched grains – like white bread and tortillas – are an easy way to meet folic acid requirements.

"We are always looking for ways to get out our message of prevention, and this offers a perfect opportunity on a broad scale," said Cindy Brownstein, CEO and President of the Spina Bifida Association.

"We are thrilled about the partnership with the Spina Bifida Association, and are confident the PSA will prove to be just one of many successful joint ventures," said Judi Adams, president of the Grain Foods Foundation.

### *About the Grain Foods Foundation*

The Grain Foods Foundation, a joint venture of members of the milling, baking, and allied industries formed in 2004, is dedicated to advancing the public's understanding of the beneficial role grain-based foods play in the human diet. For more information about the Grain Foods Foundation, visit [gowiththegrain.org](http://gowiththegrain.org).

## SBA's Resource Directory has tips for memory loss

*(Continued from page 1)*

lating information in the short term) and episodic memory (recalling and recognizing context-specific events). This study found that prospective memory is worse than expected in adults with Spina Bifida and was more impaired in older adults. Adults with Spina Bifida should consider using memory aids like calendars or note pads, digital planners, and reminder systems (like alarms) as well as memory training to ensure that they can function adequately.

Here are some learning and education tips from SBA's [Resource Directory](http://www.spinabifidaassociation.org/site/c.liKWL7PLLrF/b.4861737/k.3AA1/Learning_and_Education_Adults.htm): [http://www.spinabifidaassociation.org/site/c.liKWL7PLLrF/b.4861737/k.3AA1/Learning\\_and\\_Education\\_Adults.htm](http://www.spinabifidaassociation.org/site/c.liKWL7PLLrF/b.4861737/k.3AA1/Learning_and_Education_Adults.htm).

## New online fitness class for people with disabilities

Dear SBAWS,

My name is Kristin McNealus, and I am a physical therapist in Southern California. I started a group exercise class for people with physical disabilities, and had so much positive feedback, that I have now made the class available for online access! People who have trouble getting to a gym can get a great workout at home.

I believe that health promotion to decrease secondary complications is important, and I am excited to give people an opportunity to exercise even if transportation or time is usually an issue. I also offer nutritional guidance and individual workouts virtually.

My website is [scitotalfitness.com](http://scitotalfitness.com) and the class is \$25/month. I put up new workouts every Wednesday and Saturday, and it is a seated workout that can be as challenging as each participant wants it to be.

Thank you!

Kristin McNealus, PT  
562-645-6348

[kristin@scitotalfitness.com](mailto:kristin@scitotalfitness.com)

[scitotalfitness.com](http://scitotalfitness.com)



**Kristin McNealus, PT, ATP** received her Masters in Physical Therapy from Boston University and went on to earn her Doctorate in Physical Therapy from MGH Institute of Health Professions. Work experience includes being a staff physical therapist on inpatient rehabilitation for people with spinal cord injuries at a number of hospitals in Southern California, as well as Director of a community adaptive gym for people with neurological injuries. She currently works as a physical therapist at Rancho Los Amigos National Rehabilitation Center, providing inpatient rehabilitation to people with new spinal cord injuries and people who have undergone myocutaneous flap surgeries for pressure sores. She has her ATP certification, and performs frequent seating evaluations for people with various diagnoses.

## New book tells emotional journey of mother with child with Spina Bifida

Have you ever received the worst news possible—news that would change your life forever? Have you ever been in a dark place, trying hard to search for light and peace and hope? *Gabby's Gift – Hope in the Heart of a Child* is an inspiring book written by the mother of a child born with Spina Bifida. This mother's journey is a touching one taken directly from the emotional pages of her daily journal entries.

In an account that reads almost like a novel, Sharon Ennis tells the true-life story of her daughter's physical disabilities and needs and of her own battles and triumphs experienced in dealing with the situation as a mother. Sharon shares with her readers how she learned to accept what she cannot control and to focus instead on the gift given to her from the start of that incredible journey. It is a hope that will help you gain victory over whatever pains and doubts might populate your own personal narrative and challenge your capacity to dream, persist and finally overcome.

Ennis is the mother of 4 children and she lives in Toronto, ON. This is her first book and she will soon start a book tour called "Beautiful Feet" which she hopes will bring awareness about this birth defect and support for her daughter, Gabrielle. Portions of the proceeds will go toward raising funds for the Spina Bifida & Hydrocephalus Association of Ontario.

Learn more at these links:

- Gabby's Gift Spirit Wheel Walk Run 2011: <http://www.sbhao.on.ca/stories/spirit-wheel-walk-run-stories/gabbys-gift>
- Daytime Toronto talk show with Sharon Ennis: <http://youtu.be/Xs27lzS0-mg>
- Gabby's Gift Trailer: <http://youtu.be/nNH1mx5YJ48>

## SPINA BIFIDA ASSOCIATION OF WASHINGTON STATE

2128 N Pines Rd Ste 17B Spokane WA 99206  
Phone: 253-589-3700/Fax: 775-766-1654  
Toll free: 888-289-3702  
Email: sbaws@yahoo.com

*For more resources,  
visit us online!  
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## WHAT IS SPINA BIFIDA?

Spina Bifida is the most common permanently disabling birth defect in the United States. An average of eight babies every day are born with Spina Bifida or a similar birth defect of the brain and spine. There are over 60 million women in the US who could become pregnant and each one is at risk of having a baby born with Spina Bifida.

## WHAT IS SBAWS?

SBAWS is the Washington chapter of the national Spina Bifida Association (SBA), which serves over 180,000 adults and children who live with Spina Bifida. Since 1973, SBA has acted as the nation's only voluntary health agency dedicated to enhancing the lives of those with Spina Bifida and the more than 250,000 people whose lives they touch. Through SBA and its network of chapters, parents of children with Spina Bifida are empowered with information and support services, teens transition into newfound independence, and adults lead productive and fulfilling lives.

  
Spina Bifida Association  
of Washington State

