



The Evergreen

April 2013

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

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SBAWS announces new volunteer program and roster

by Meg Paulsen, Executive Director

Happy Spring Everyone! I just love seeing all of the signs that we're leaving the wintery days behind even when Mother Nature has been throwing curve balls (and snow balls for some of us) here in Washington!

Rebirth and growth abound around us and with the SBAWS as well! One of the most growth-oriented plans coming into fruition is our Volunteer Program. I am hard at work creating a program that includes an orientation that not only educates others about the



Meg Paulsen

resources and services we offer as a specialized organization but also WHY spending your time, energy and talent working with us makes such a difference in the lives of countless people here in Washington and can be as fulfilling as possible to you personally. Please keep an eye out for the Volunteer Roster and Incentive Program we will be posting on the website and social media sites. I encourage you to really consider the positions and incentives we list and to think about how you, your family, your friends and peers may benefit from serving such a busy and up-and-coming organization! On Memorial Day weekend we will be holding an open house at our

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Vitamin D deficiency common in children with Spina Bifida

Reprinted with permission from SBA's electronic newsletter *Enlighten*.

Vitamin D deficiency is common in children. However, children with Spina Bifida (SB) may have unique predisposing factors to Vitamin D deficiency such as immobility leading to decreased sun exposure, dietary limitations, and chronic kidney disease. Children with SB have higher rates of fractures than other children, with risk factors including higher level of neurologic defect, decreased sensation, osteopenia, and non-ambulatory status. Researchers at Children's Hospital, Harvard Medical School conducted a retrospective chart review of patients in the Children's Hospital Boston Myelodysplasia Program from 1999 to October 2011, age 1 month to 19 years old to determine the prevalence of Vitamin D deficiency among children and adolescents with SB and to determine the relation between Vitamin D status and fracture risk. Data

on the first 250 subjects was presented (108 male, 142 female). Of those 250, data was available for 166.

Seventy-five percent of subjects had suboptimal Vitamin D levels, 40% with Vitamin D deficiency and 35% who were insufficient. No difference in Vitamin D status was noted between genders or race. 52 (22%) had a documented fracture. Fractures were more common in non-weight bearing than in those who were ambulatory ($p < 0.001$) and in children with a thoracic lesion compared to those with a lumbar or sacral lesion ($p < 0.007$). Fractures were not associated with Vitamin D status ($p = 0.5$). The researchers concluded that Vitamin D deficiency and insufficiency are highly prevalent in children with SB, and more prevalent than in the general population. Both thoracic level lesions and non-weight bearing status play a key role in

(Continued on page 4)



Newsletter Editor
Celeste McCormick
celtutt@yahoo.com

SBAWS Annual Summer Picnic

Now that summer is on its way, please save the date for the annual SBAWS summer picnic on Saturday, June 1st, 2013. The summer picnic is early this year because the Walk-N-Roll will occur mid-summer on July 20th at Bradley Lake Park in Puyallup!

The summer picnic will be at The Seattle Children's Playgarden in south Seattle. We had such a wonderful time previously at the Seattle Children's Playgarden and look forward to another great day!

The picnic is from 11:00am to 2:00pm. The exact agenda is subject to change, but for now the schedule is:

- 11:00am-12:00pm: Scavenger hunt, wheelchair basketball & crafts
- 12:00pm-12:30pm: Lunch/open crafts
- 12:30pm-1:30pm: Entertainment
- 1:30pm-2:00pm: Water feature, bunnies and chicks, lady bug launch

SBAWS is very excited to host this event and hopes you will come!

The picnic is potluck style: SBAWS provides the main dish with help from our sponsors, and the picnickers bring a side dish.

If your last name starts with:

A-H: Fruit/veggie tray

I-P: Dessert

Q-Z: Side dish or salad

We are looking forward to seeing everyone this summer!

A formal invitation with a map and directions will be distributed soon. Please RSVP as soon as possible. Include your family name and number of guests, including the number of children. Please mention any food allergies in your RSVP so that we can take those conditions into catering considerations!

RSVP deadline is Friday, May 17th.

For more information, contact Nicole Williamson of SBAWS Seattle at seattlespinabifidagroup@hotmail.com or 206.877.2568 (txt ok).

Chair

Jason Lane

chair@sbaws.org

Chair -Elect

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Secretary

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Past Chair

Linda Bailey,

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megpaulsen@sbaws.org

Ryan Callaway

Dave Carl

Jamie Heckinger

Amy Miller

Krystal Monteros

Elizabeth Scriven

Amy Shiel

Nicole Williamson

Seattle Children's Playgarden

1745 24th Ave South

Seattle, WA 98144

(206) 227-5458

Directions from I-5 N/S

Exit onto I-90.

Take exit 3; turn right onto Rainier Ave; get in left lane.

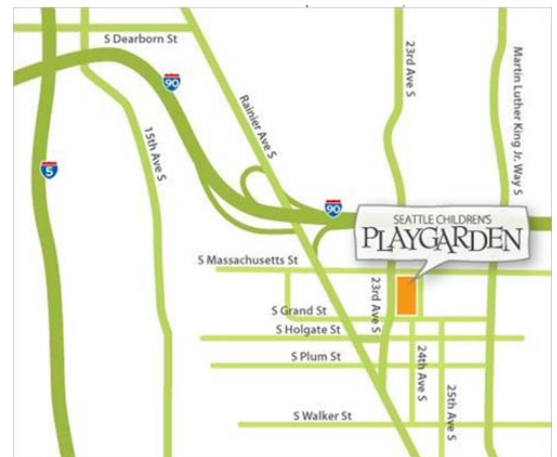
Turn left at first light onto S Massachusetts.

Turn right at 24th Ave S.

The Playgarden is on the right, south the Colman Playfield.

Metro directions:

Rainier Ave S and S Plum St



NEWS FROM THE BOARD OF DIRECTORS

The Board of Directors of SBAWS held regular meetings in both February and April 2013. For details of decisions made and motions passed, please see the minutes which are available online at

www.sbaws.org/Minutes.html.

Spina Bifida Association of Washington State
Financial Statement Summaries
As of March 31, 2013

| | 2013 | | 2012 | | \$ Change |
|-----------------------------|-----------------------|------------|----------------------|------------|----------------|
| Profit & Loss Comparison | | | | | |
| Income | | | | | |
| Donations | | | | | |
| Fundraising | | | | | |
| Walk N Roll | \$ - | | \$ 1,475.00 | | \$ (1,475.00) |
| Adopt-a-Ghost | \$ - | | \$ 52.00 | | \$ (52.00) |
| Shop for a Cause | \$ - | | \$ - | | \$ - |
| Other | <u>\$ 730.28</u> | | <u>\$ 598.00</u> | | \$ 132.28 |
| Total Fundraising | \$ 730.28 | | \$ 2,125.00 | | \$ (1,394.72) |
| | | | | | \$ - |
| In Kind Donations | | | | | |
| ED Meg Paulsen | \$ 4,500.00 | | \$ 5,340.00 | | \$ (840.00) |
| Other | <u>\$ -</u> | | <u>\$ 590.08</u> | | \$ (590.08) |
| Total In-Kind Donations | \$ 4,500.00 | | \$ 5,930.08 | | \$ (1,430.08) |
| | | | | | \$ - |
| Restricted Donations | | | | | |
| Other Donations | \$ - | | \$ 100.00 | | \$ (100.00) |
| Other Donations | <u>\$ 702.45</u> | | <u>\$ 745.42</u> | | \$ (42.97) |
| Total Donations | \$ 5,932.73 | | \$ 8,900.50 | | \$ (2,967.77) |
| | | | | | \$ - |
| Interest | | | | | |
| | <u>27.75</u> | | <u>60.19</u> | | \$ (32.44) |
| Total Income | <u>\$ 5,960.48</u> | | <u>\$ 8,960.69</u> | | \$ (3,000.21) |
| Expenses | | | | | |
| | | % by Cate- | | % by Cate- | \$ - |
| Mission/Program | \$ 12,959.09 | gory | \$ 9,843.69 | gory | \$ 3,115.40 |
| Administration | \$ 2,191.50 | 76.71% | \$ 2,044.71 | 75.41% | \$ 146.79 |
| Fundraising | <u>\$ 1,742.43</u> | 12.97% | <u>\$ 1,165.10</u> | 15.66% | \$ 577.33 |
| Total Expenses | \$ 16,893.02 | 10.31% | \$ 13,053.50 | 8.93% | \$ 3,839.52 |
| | | 100.00% | | 100.00% | |
| Net Income (Loss) | <u>\$ (10,932.54)</u> | | <u>\$ (4,092.81)</u> | | \$ (6,839.73) |
| Balance Sheet Comparison | | | | | |
| Assets (cash in the bank) | \$ 28,198.52 | | \$ 44,101.45 | | \$ (15,902.93) |
| Liabilities | <u>\$ -</u> | | <u>\$ -</u> | | \$ - |
| Total Equity (Fund Balance) | \$ 28,198.52 | | <u>\$ 44,101.45</u> | | \$ (15,902.93) |

Income: This years YTD income is 33% less than it was last year and only 12 % of our annual \$50K goal.
Expenses: We spent 30% more (\$3,913.46) this year so far which is already 34% of our annual \$50K goal
Net Income (Loss): Our YTD Loss is over \$10K which is 167% greater than last years' first quarter because we took in significantly less and spent significantly more. This has to stop or we'll go broke.
Expenditure by Category: These percentages are acceptable at this time of the year but not as good as last year. These should improve as the year goes along.
Net Worth: Our total assets, fund balance, cash in the bank decreased by \$15, 902.93, 31%, in the first quarter of 2013 and almost \$20,000 over the last 12 months, obviously because we spent more than we took in.
Liabilities: We have no liabilities (unpaid bills).
Trend Analysis: We need to quit spending until our income improves.
Jonathan A. Tutt, Treasurer

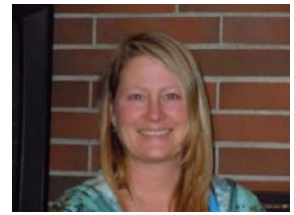


Development committee keeps the wheels turning

by Elizabeth Lovelace, Chair-Elect

The months past have shown continual forward motion in planning and preparing for the SBAWS events ahead. I would like to take this opportunity to remind you of upcoming Spring/Summer events:

- May 4th Glassybaby Glassblowing Evening 6-9pm - Seattle
- May 27th SBAWS OPEN HOUSE for newly opened Resource Office - Snohomish
- June 1st Summer Picnic Seattle Children's Play Garden - Seattle
- July 20th 4th Annual Walk and Roll for Spina Bifida - Bradley Lake Park, Puyallup



Elizabeth Lovelace

There are many other irons in the fire as we hope to have a fundraiser on June 15th with a local retailer, and a Car Wash and/or Wheelchair Wash in August. Please visit <http://www.sbaws.org/Development.html> to read the Development Committee Meeting Minutes. There you can learn more about the work we are doing.

SBAWS 4th Annual Walk-n-Roll 2013

The season is upon us and it is Time to Team-up!
 Show your support for the Spina Bifida Association of Washington State and become the LEADER of the pack.
 If you are interested in a rewarding role as Walk-n-Roll Committee Chair and would like to help with Team Building and Team Fundraising, this is your opportunity!
 You can become the next SBAWS WNR Team Leader!
 Please contact Elizabeth if you would like to learn more.
 Email chairelect@sbaws.org.



Vitamin D study finds children with SB have higher fracture rate

(Continued from page 1)

fracture risk. Although Vitamin D status did not correlate with fractures in this analysis, Vitamin D status should be optimized in this patient population and further evaluation of bone health considered.

[Click here to read the Full Abstract.](#)

- Michelle Baum, MD
- Deborah Stein
- Henry Feldman
- Nedda Hobbs
- Catherine Gordon





May 4th 2013
6pm – 9pm
Benefiting the SBAWS

glassybaby

3406 East Union Street
Seattle, WA 98122

The date has changed!

Join us for a festive evening benefiting the Spina Bifida Association of Washington State. Enjoy appetizers, wine and sweets while watching glass blowing experts create beautiful glassybaby candle holders and votives.

Take home a glassybaby gift of gratitude for your gracious support. Gift has a \$44 value. Donations go directly towards fulfilling SBAWS' mission of promoting the prevention of Spina Bifida, and enhancing the lives of all affected in Washington State.

Tickets

\$100 per person includes 1 glassybaby gift
\$150 per couple includes 1 glassybaby gift

Email us at fundraising@sbaws.org to RSVP and purchase your tickets.
Due date for RSVP & ticket payment is April 19th

We hope you are able to spend the evening with us!

Due date to sign up is April 19. We need at least 30 attendees or the event will be cancelled. Please sign up now to support SBAWS. Your participation will help all of our programs and services to continue serving the SB community in Washington state!

Annual conference focuses on transition, independence

by Jason Lane, Chair, SBAWS Board of Directors
On Saturday March 16th, Board of Directors' Secretary Ashley St. Clair and I attended the 13th Annual Elizabeth Conference on Spina Bifida at Shriner's Hospital on the Oregon Health and Science University (OHSU) campus in Portland, OR.

The Elizabeth Conference is a yearly conference that focuses on Spina Bifida, with the primary audience being parents of children with Spina Bifida who receive their healthcare from OHSU in Portland.

There were speakers whose topics ranged from discussing a self-management study and independence preparedness, to an orthopedic presentation and separate orthotics presentation. My article will focus on two presentations by Dr. Kathleen Sawin, while Ashley will report on the other topics in a separate article.

The first speaker was Dr. Kathleen Sawin, who is a nurse researcher, clinician and professor at the College of Nursing from the University of Wisconsin-Milwaukee and Children's Hospital of Wisconsin. She has been the advanced practice nurse in the Spina Bifida program for two decades, with a focus on self-management and transition to independence in adolescents living with Spina Bifida.

Young people with Spina Bifida have been found to lag behind their peers.

Dr. Sawin focused on two presentations "Adolescents Managing Their own Condition: Expectations and Reality" and "How to Optimize Independence and Employment Skills." The focus of her first presentation centered on adolescence and young adults developing self-reliance in becoming independent. This was a data heavy presentation of a self-management study involving parents with children with Spina Bifida and expectations on skills needed for a smooth transition in to adulthood. I have chosen a few areas of the presentation to highlight here. The reason behind looking into self-reliance and independence of young people with Spina Bifida is that even those with typical intelligence have been found to lag behind their peers in autonomy skills, face challenges with employment and have been reported to have lower levels of independent living. Dr. Sawin and her group feel that if these circumstances limit full participation in

life, then understanding the strengths and challenges youth with Spina Bifida face in self-management and independence become important.

It was pointed out that in study of transition-age youth across the

country, improvements in self-management were associated with decreased incidences of depression. The more a person is self-reliant and independent, the lesser the chances of depression may occur. If an adolescent or young adult is involved in their own self-management by increasing responsibility, this helps to develop skills needed for transitioning into adulthood and independent living.

Areas that Dr. Sawin's study looked at as part of their study on self-reliance and independence were things such as managing money, making health care appointments, ordering medications/medical supplies, and community living skills such as meal planning, shopping, etc. Chores and responsibilities are key skills that can greatly affect how adolescents and young adults can develop self-reliance and independence needed for transitioning to adulthood. Parents should, however, build the expectations for responsibilities based on the development of the child and unique components of his/her Spina Bifida.

If your child has learning problems, one should understand that not everyone learns by "observation" (such as watching you or a sibling complete a task) and they may wait for others to initiate activities. It may be helpful to establish goals around chores/responsibilities, or have actions broken down into steps and practice. In most adolescents and young adults with Spina Bifida, most parents' expectations were that their child's independence skills would "just happen" but often they did not. Overall the final messages about developing self-reliance and independence in the adolescent and young adult with Spina Bifida come down to these points:

- The transition into adulthood begins in infancy.
- The learning issues for children with Spina Bifida mean that independence skills need to be addressed intentionally, introduced



Jason Lane

Preparations online tool helps parents, kids with transition

(Continued from page 6)

early, and practiced often to be internalized.

- Parents should plan and health care providers can assist in knowing how. The second presentation by Dr. Sawin had to do with Optimizing Independence and Employment skills. A majority of her time was spent discussing the Preparations Website located on the Spina Bifida Association of America website. As stated on the website, the website is an interactive online tool created to give parents and clinicians tips and tools to help children with Spina Bifida develop into successful and happy adults. The site can also help young adults to find ways to become more independent and lead a fuller, richer life. There is an entire section of the site specifically devoted to young adults. These questions can be answered by the young adults themselves.

Developed in partnership with the Centers for Disease Control and Prevention (CDC), the site utilizes actual answers inputted by users to generate a report specific to your child's (or your) developmental needs. The report will offer suggested tips and interventions for areas in which your child, or you, may need additional focus.

Visit the site today at www.sbpreparations.org to generate your own report!

Overall I am glad I had the opportunity to attend this conference. I was able to connect with a mother of a child with SB who lives in Southwest Washington who was not aware our organization existed. It was also interesting to get a small perspective on the OHSU Spina Bifida program. Hopefully someday a similar conference can be started here in Washington State between the University of Washington Medical Center and Seattle Children's Hospital.



Preparations:

Becoming an Adult Living Successfully with Spina Bifida

Generate your own report of transition recommendations at www.sbpreparations.org

... Upcoming Events ...

Glassybaby Evening
5/4/13

2013 Education Days
5/11/13 Los Angeles

Development Committee Meeting Sunday
May 19, 2013 7 PM
1st Annual Open House
Monday May 27, 2013

Annual Picnic 6/1/13
Seattle Children's Playgarden

Summer 2013 at Camp Korey

Next Board Meeting
July 20, 2013

Walk & Roll 7/20/13
Bradley Lake Park

Go to www.sbaws.org for full details!

SBA is Celebrating 40 years and We Want YOUR Help!

In honor of the Spina Bifida Association's 40th Anniversary, the [4b4the4th campaign](#) is changing its look!



We are super excited to offer [NEW prizes for fundraisers](#) like tickets to the 2014 National Conference, an iPad, and gift certificates, but more importantly, we are thrilled to provide an opportunity for those with Spina Bifida to show how SBA has helped your family! **Anyone who raises \$40 or more will be featured on our 40forthe40th Wall of Fame, where you can share your story!**

Last year's top fundraiser, Erica Hoke, has a special message for you about this campaign:

"As many of you know, living with Spina Bifida is an unpredictable, emotional roller-coaster. Even though I can't change the fact that my son, Roman, has Spina Bifida, I can advocate. I can educate. I can spread awareness. And I can raise money for an organization that has been providing FREE services for families like ours for the past 40 years. **AND YOU CAN, TOO!**

We want SBA to be around for the next 40 years, so sign up as a fundraiser and invite 40 friends to make donations and help us spread the word! Visit www.40forthe40th.org to sign up today!

Let's do this together! Sign up today in honor of your loved one with Spina Bifida or in honor of yourself at www.40forthe40th.org."

[Help us celebrate 40 Years of SBA service by participating in 40forthe40th!](#)

Dreams do come true, thanks to the generosity of SBAWS

by *Diana Tutt, Evergreen reporter*

This article is an example of what can be accomplished with perseverance, love of one another and willingness to share funds for those in need. Michael Hoyt, one of our members, is now 14 and in eighth grade and must use a wheelchair to navigate his school. Books, lunch trays, crowded halls, time constraints all contribute to the need of the wheelchair. It has also caused physical problems due to sitting so long. Michael recently underwent surgery to mitigate some of these problems.

However, a daily struggle he has is he lives on a hill, struggling up to the front door, backpack hanging on the back of the chair increasing the burden. Due to the diligence of his mother and of other family members, Michael now has a ramp to wheel up to the door! This is especially crucial living in Spokane with snow and ice in the winter months.

We are familiar with The Arc, an organization to make life easier for people with disabilities and provide gatherings of a social nature. Michael's mother Colette contacted The Arc and they agreed to generously contribute \$250 to construction of the ramp. Our own SBAWS decided to also contribute \$250, all of which was greatly appreciated. Jon Tutt, my husband and one of the backbones of SBAWS, and I, are Michael's grandparents and we completed the cost, as was our pleasure. We have seven grandchildren, each special and loved dearly. However, we all know the high price of everyday living.

The ramp was custom designed by Simon Way, an experienced contractor whom we know personally. The driveway and stairs are curved and uphill requiring a specially designed metal angled piece to join the rest of the ramp. Provisions were made for proper drainage. Gripping strips were applied for traction.



Michael Hoyt

Michael is very pleased with the ramp and said it "sure makes it easier to get into the house." We want our children to accomplish all they can, and this was an important matter of safety for him.

Track has now started at school; last year Michael was the first wheelchair athlete at Mountainside Middle School and he lettered. He also qualified for Team St Luke's basketball team and has been asked to participate in a national wheelchair basketball competition in Louisville, KY this summer. All may not have been possible without a safe ramp for Michael. God bless The Arc and SBAWS.



**SPINA BIFIDA ASSOCIATION
OF THE INTERMOUNTAIN REGION**

The Spina Bifida Association of the Intermountain Region (SBA of IR) officially opened in January 2013 to promote the prevention of Spina Bifida and to enhance the lives of all affected. We have identified a dynamic group of individuals willing to serve the Spina Bifida Community in Idaho, Nevada, and Utah (the Intermountain Region) by providing resources, education, advocacy, and networking opportunities. To learn more about this new regional chapter of the Spina Bifida Association, visit

www.sbaofir.org

SBA is pleased to announce that [registration for our 2013 Education Days is now open!](#) Five locations will be delivering vital Spina Bifida education and support through this new program. Designed to offer more educational opportunities to more people than ever before, at an affordable price - a cost of \$35/adult. Free childcare for children aged 10 and under is available at most places. Lunch is included. We hope you can join us at one!

2013
EDUCATION 
Setting the Course
for Tomorrow
DAYS

- Los Angeles, California (May 11, 2013)*
- Baltimore, Maryland (TBD)*
- Charlotte, North Carolina (July 13, 2013)
- Salt Lake City, Utah (October 5, 2013)*
- San Jose, California (November 2, 2013)*

To learn more about any of these great locations – or to register – just visit us at www.sbeducationdays.org! Space is limited at some locations, so early registration is recommended! *Can't make it to one of these locations? Don't forget [SB University](#) is available online 24 hours a day/7 days a week to deliver educational sessions on a wide variety of topics related to Spina Bifida – and it is all FREE to registered users. And mark your calendars for the 2014 return of our biennial National Conference. Dates and location information to be announced summer 2013.*



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 and click on the “Donate” button in the top right corner.

SBAWS Resource Office in Snohomish to offer Memorial Day open house

(Continued from page 1)

new Snohomish office to showcase the extensive resource center and place of support we offer our SB community. The office will also serve as a place where we expand our volunteer program by offering specialized training for those who wish to make a difference by donating much needed time, energy and talent to the events and programs we, in turn, can then offer our community. Our annual events (picnic, Walk-n-Roll and holiday party) don't just happen on their own - we have a dedicated handful of people who manage to do well despite little assistance from others. In addition to these events we are implementing our new fund and awareness raising event, the Five Course Folic Acid Feast, that focuses on

the benefits and preventative measures that folic acid offers women of childbearing age. As you can see, there is much work to be done and in order to continue and sustain a healthy organization we need to delegate. Imagine what we COULD be creating with the addition of new ideas, energy and talent – as our Chair Elect says “Great things to be seen in 2013!” – I couldn't agree more!

As I stated in the last newsletter, with all of these plans and goals, the only thing we are really missing is YOU – how can YOU help make the dreams and ambitions of YOUR SBAWS come true in a way that is truly meaningful to YOU?? Looking forward to working together to make the difference TOGETHER!

**ABC Medical and Faces of Spina Bifida
Join the Same Team**



ABC Medical and Faces of Spina Bifida online magazine have teamed up to benefit ABC Medical customers and readers of Faces of Spina Bifida. The collaboration between ABC Medical and Faces of Spina Bifida includes supporting Faces of Spina Bifida readers with free, 24/7 access to an ABC Medical nurse for health questions and information. In addition, FSB readers have access to ABC Medical monthly newsletters, original news content, adaptive sports events in the United States, scholarships and sponsorship opportunities.

ABC Medical customers benefit greatly from this new relationship by being connected to a community of people with Spina Bifida who support each other, receive daily updates in Spina Bifida research, organizations and support groups around the world.

Sign Up for Your Free Newsletter from Faces of Spina Bifida

As a member of the greater-ABC Medical family, we are extending this offer to members of the NWBA. We encourage you to sign up for your FREE Faces of Spina Bifida monthly e-Newsletter at:

**[http://facesofspinabifida.us4.list-manage.com/subscribe?
u=5ef5518658d1cf701342bdd32&id=e23d672940](http://facesofspinabifida.us4.list-manage.com/subscribe?u=5ef5518658d1cf701342bdd32&id=e23d672940)**

And engage ABC Medical and Faces of Spina Bifida through Facebook:

<https://www.facebook.com/faces.of.spina.bifida>

<http://www.facebook.com/myabcmedical>

And Twitter:

@FacesofSB

@MyABCMedical

The Evergreen is moving to a quarterly schedule!

Issues will be published the first day of the month in March, June, September and December. Submissions are due one week prior.

The schedule for the remainder of 2013 is:

- June 1 issue: submissions due May 25
- Sept 1 issue: submissions due Aug 25
- Dec 1 issue: submissions due Nov 24

The Evergreen reporting staff:

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Elizabeth Scriven, liz-biz@iname.com

Diana Tutt, nanatutt@msn.com

Resource Spotlight



Kiwanis

Camp Casey

Camp Casey is a week long summer camp for children ages 6-17 who have physical disabilities. It is provided by the North Central Seattle Kiwanis Club and all staffing, nurses and counselors volunteer to help create "the best week of the year" for our campers.

Camp is located next to Fort Casey State Park on Whidbey Island in the old WWII army barracks (now owned by SPU). Transportation to and from Camp is provided from the North Seattle area.

For over seventy-five years the Seattle North Central Kiwanis Club has fully funded the camp, so it is free of charge!!



Lighthouse at For Casey State Park

Camp Casey is known as the BEST camp for youth with physical disabilities.

And it's free!

The camp has openings for girls ages six to 13 and boys six to 17 years old.

Visit the website at

www.campcasey.org

Camp Casey Quick Facts

- Camp Casey started in 1931 with about 12 boys one week and about 12 girls the next week.
- These two weeks were later combined and there are now usually 90-100 campers and about 50 counselors.
- There are counselors on duty in each barracks 24 hours a day.
- Everyone gets to go swimming in Camp Casey's heated pool.
- Each camper and counselor receives their own T-shirt at the end of the week.
- Camp costs about \$45,000 to run, all of which is raised by Kiwanis through fundraisers and donations.
- Camp is walking distance from both Fort Casey and the beach, both popular places to go during free time.
- All of the buildings have been equipped with wheelchair ramps and have accessible bathrooms.

SPINA BIFIDA ASSOCIATION OF WASHINGTON STATE

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Toll free: 888-289-3702
Email: info@sbaws.com

*For more resources,
visit us online!
www.sbaws.org*

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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

