



The Evergreen

June 2013

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

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Important volunteer opportunities abound at SBAWS

by Meg Paulsen, Executive Director

Sunny days are ahead!!! I just returned from our first annual Memorial Day Open House to introduce our resource office and orientation/volunteer training room to the public. We offered ice cream floats – the ice cream was compliments of Snoqualmie Ice Cream – thanks to Elizabeth for her fantastic float fixing! We also offered Memorial Day mementos for both kids and adults. We personally took people on tours of the facilities and provided awareness about the SBAWS and our programs and events.



Meg Paulsen

Speaking again of volunteers - we have been laying the foundation for our new Volunteer Program – I've spent the past few months researching successful Volunteer Programs and taking United Ways' Volunteer Management workshops and learned not only of new resources for recruitment, but also how this generation of volunteers is much different from past generations of volunteers. It is our goal that we create a compelling and crea-

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Spina Bifida presents unique health challenges with age

Reprinted with permission from the May 2013 issue of *e-Insights*

The majority of people born with Spina Bifida are now living long, full lives, but they often encounter unique health challenges as they age. Some issues are directly related to Spina Bifida, while others are part of the normal aging process. What problems are unique to adults over age 40 living with Spina Bifida, and what can be done to prevent and treat them? In addition to normal issues associated with aging, older adults with Spina Bifida may face problems associated with wheelchair use, shunts, and tethered cord syndrome. Musculoskeletal problems, particularly shoulder, hand, and wrist pain are common among wheelchair and crutch users. If you use a wheelchair, talk to an expert to make sure your chair is set up properly. Using long, smooth strokes to propel yourself and avoiding repetitive move-

ments can also prevent problems associated with overuse.

Lymphedema, the swelling of one or both of the legs, is another condition seen in older adults living with Spina Bifida. It may be related to wounds, wheelchair use, infections, injury, or obesity. If you experience tense, "non-pitting" swelling in your legs, seek treatment and make sure your doctors rule out the possibility of blood clots.

Back pain, which can be caused by tethered cord syndrome, arthritis, muscle strain, and shunt related problems, is also very common. Because back pain can be the result of many factors, it is important to see a doctor to identify the cause. If no serious medical issues are revealed, physical therapy is usually the first line of treatment. Injections may be an option for some types of pain. Obesity can contribute to back pain.

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Newsletter Editor
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SBAWS Annual Summer Picnic

The annual SBAWS summer picnic has been rescheduled for Saturday, August 10th, 2013.

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!

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

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megpaulsen@sbaws.org

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Amy Miller

Krystal Monteros

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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.

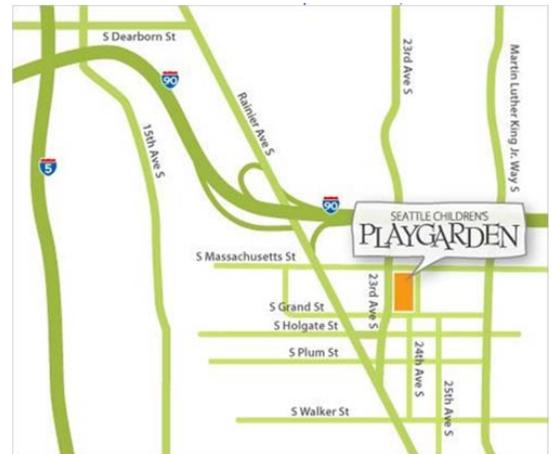
Turn left at first light onto S Massachusetts.

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



The Evergreen reporting staff:
 Elizabeth Lovelace, chairelect@sbaws.org
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SBAWS 1st Annual Open House

On Monday May 27 SBAWS hosted its first annual open house at its newly developed resource and volunteer center located at 611 2nd Street in the heart of historic downtown Snohomish. The event was hosted by Meg Paulsen and Elizabeth Lovelace of SBAWS and boasted ice cream donated by Snoqualmie Ice Cream plus Memorial Day prizes the kids. The event was a great way for the community to learn more about how SBAWS is working to improve the lives of those affected by Spina Bifida. If you missed the open house, you can still stop by and see what the center has to offer or learn more about how you can volunteer your time to help this great organization do even more!



Go to www.sbaws.org
for more details!

Volunteers needed to help SBAWS reach its maximum potential

tive volunteer program so that we can grow stronger, serve more people, create an environment of abundant sustainability and meet our highest potential as an exceptional social service organization.

Here are some of the positions available – please note that several of these positions (*) can be done from the comfort of your home to fit your schedule:

- *Online Fundraisers – Java January, Giving Tuesday and End of Year Fund Drive
- *Social Media Coordinators (SMC)
- *Newsletter Editors
- *Webmasters
- Office Assistants
- Folate/Folic Acid Awareness Campaign/
- Face2Face February Awareness Raisers
- Event Assistants – For our Annual Picnic, Walk & Roll for SB and Holiday Party
- Northwest Women’s Show Booth Displayers

Adopt-A-Ghost Program Adoption Coordinators

To further enhance our knowledge and effectiveness, we attended the Washington State Non Profit Conference. Elizabeth concentrated on the sessions dedicated to fundraising and development while I attended ones dedicated to educating and leading Executive Directors in positive directions. It was very inspiring to meet so many dedicated leaders in the social service industry and we feel very supported by those we met and connected with during the conference. It is our sincere hope that you consider joining us in working together to make the difference – please send me an email directly at megpaulsen@sbaws.org so that we can start working together in our mission is to promote the prevention of Spina Bifida and enhance the lives of all affected.

New Resources Gathered - 2013 WA Nonprofit Conference

by Elizabeth Lovelace, Chair Elect

May 17th proved to be a day of valuable resource gathering and relationship building with other nonprofit leaders. The Washington State Nonprofit Conference held at Meydenbauer Center in Bellevue has given me a new enthusiasm and zest for learning more about what is happening in our state with regard to nonprofit organizations and the important role they play in the economic status of our state. Governor Jay Inslee helped to bring that understanding to light when he shared that the economic stability of our state is largely due to nonprofit groups and their efforts to get resources to the people.



Elizabeth Lovelace

Here I want to make mention of a few of the resources I learned about at the conference:

501 Commons – provides nonprofits with management and technology assistance, including consulting, leadership coaching, etc.

WAACO (WA Attorneys Assisting Community Organizations) – Offer nonprofit legal assistance at a set rate of \$100 per project (to cover application fee).

Nonprofit Guidelines: Secretary of State – www.sos.wa.gov/charities

Nonprofit & Philanthropy Resource Center housed within select libraries around the state – maintained to assist nonprofits with acquiring the resources they need to carry out their missions such as grant research, proposal writing, fundraising plans, volunteer management, and more.

Puget Sound Peers – Project Managers teaching nonprofits how to organize and manage Volunteer Programs.

AFP (Association of Fundraising Professionals) – A professional association of individuals responsible for generating philanthropic support for a wide variety of nonprofit, charitable organizations.

The Nonprofit Assistance Center (NAC) – NAC's mission is to empower communities by building strong nonprofits and community leaders who shape institutions and policies to achieve social justice and equity.

This is a short list of the countless resources presented at the conference. As Development Committee Chair, I am enthusiastic about accessing and utilizing many of these incredible resources to help the SBAWS meet the needs of the SB community! Together We Make the Difference!

"I've learned that you shouldn't go through life with a catcher's mitt on both hands. You need to be able to throw something back." - Maya Angelou



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.

On your mark, get set, GO!
It is time to gather your teams for
the 4th Annual Walk-N-Roll
for Spina Bifida.
Our Firstgiving fundraising site will
be up and running June 1st



[http://www.firstgiving.com/sbaws/
2013-walk-roll-for-spina-bifida](http://www.firstgiving.com/sbaws/2013-walk-roll-for-spina-bifida)

We can't wait to see you at
this year's Walk-N-Roll on
July 20 at Bradley Lake Park
in Puyallup, WA.



The 2013 Walk-N-Roll
is sponsored in part by:



The SBAWS will 'Take Over the Store'



**Alderwood Mall Location
June 15th
11am-3pm**

**Mention you want to support
the SBAWS and 20% of your
purchase before taxes will go
to support our mission.
Come jamba with us!**

Nutrition, exercise and regular screenings are cornerstones of good health while aging

(Continued from page 1)

Keeping your weight under control helps alleviate problems caused by wheelchair use as well as other conditions, such as lymphedema, diabetes, high blood pressure, stroke, sleep apnea, some cancers, depression, and arthritis.

People with Spina Bifida are also at a greater risk of low bone density, which can cause osteoporosis. Vitamin D and calcium help improve bone density, but high levels of intake can cause problems with kidney stones in some people. Check with your doctor about adding these vitamins to your daily regimen.

What health screenings are important for older adults living with Spina Bifida?

Blood pressure and weight should be checked at every doctor's visit, or at least once each year. Some people may need to monitor their own blood pressure more frequently. Dental and vision exams should also take place annually.

Cholesterol should be checked every five years in men over 34 and women over 44, and blood sugar should be monitored every three years in those over 45 more often for people with pre-diabetes.

Men should be screened for colon, prostate, and testicular cancers, while women should be checked for breast

and endometrial (uterine) cancers and osteoporosis, and should continue regular gynecological exams and pap smears.

Screenings are currently in development to test Vitamin D levels, Vitamin B12 and folate deficiency/anemia, and testosterone levels.

What can people do to develop and maintain healthy lives as they age?

You are what you eat! Consuming the recommended amount of fruits, vegetables, and whole grains daily and avoiding high-fat dairy products, red and processed meat, fried foods, high-calorie baked goods, and alcoholic beverages are the keys to a healthy diet.

It is also recommended to get 30 minutes of physical activity on five or more days of the week.

Getting the proper immunizations also promotes health and wellness. Vaccines are recommended to protect against influenza, tetanus, pneumonia, varicella, shingles, measles/mumps/rubella, and hepatitis A and B.

The preceding Q&A was with Brad Dicianno, MD and is from the Winter 2013 issue of Insights Into Spina Bifida.

Related Links:
[Health Information Sheets for Adults](#)

Recommended Screenings

- **Blood pressure:** Every doctor visit or annually
- **Weight:** Every doctor visit or annually
- **Cholesterol:** Establish baseline at age 20; Every five years for men over 34 and women over 44
- **Blood Sugar:** Every three years for all 45+; Every 1-2 years if pre-diabetic
- **Dental:** Annually; Cleaning every six months
- **Vision:** Establish baseline at age 40; Comprehensive exam at 65; Annually in adult diabetics
- **Skin exam:** Annually
- **Colon Cancer (men):** Fecal occult stool blood test annually after age 50; Colonoscopy every ten years
- **Prostate Cancer (men):** Screening based on family history; Consult your doctor
- **Testicular Cancer (men):** Annually, with monthly self-exams
- **Breast Cancer (women):** Annual mammogram beginning at age 40
- **Pap Smear (women):** Every three years from 30-70, after three consecutive normal tests
- **Endometrial (Uterine) Cancer (women):** At age 50
- **Osteoporosis (women):** Annually in women over 65, or over 60 if certain risk factors are present

ALL	WOMEN	MEN
Blood pressure annually/every visit	Cholesterol annually (44+)	Cholesterol annually (34+)
Weight annually/every visit	Breast Cancer annual mammogram	Colon Cancer annual test; colonoscopy every 10 years
Blood Sugar every three years	Pap Smear every 3 years from 30-70	Testicular Cancer annual
Dental annually	Endometrial (Uterine) Cancer at age 50	
Vision annually	Osteoporosis annually over age 65	



My friend!

I'm off to a great start, but I still need your help.

You may or may not have already heard from me. If you have, thank you very much for your willingness to listen to my story. If you haven't, my name is Jon Harmatz, and I'm trying my best to raise \$10,000 to fund AAPD's anti-bullying campaign.

I'm about half way there; can I count on you to help me reach my goal?

Please rise up to the challenge and contribute \$15, \$50, \$100, \$250 or whatever you can to help make a difference in the lives of the 65% of people with disabilities who are bullied on a daily basis.

AAPD's anti-bullying campaign is powered by the realities of everyday Americans.

Last week, I answered a phone call from a young woman who was bullied in the work place for not having any fingers on her left hand.

Last year, George Hodgins, an autistic adult was murdered by his caregiver and public discussion focused on expressing sympathy for his killer.

A mother of four is diagnosed with bipolarity and her friends never look at her the same way ever again.

An accomplished professional is denied a promotion and relegated to the back of the office because her prosthetic arm broke the company's desired aesthetic.

A 14-year old special needs student in Ohio is bullied by her teachers to such an extent that she starts harming herself in order to stay away from school. We live in troubled times, and we must make a difference today.

Donate today! And, I will make sure that someone from our team personally reaches out to you, and keeps you posted about the progress of our work!

Thank you for your incredible support of AAPD!

Warmly, Jon

Donate today at:

http://power.aapd.com/site/Donation2?df_id=1353&1353.donation=form1



American Association of People with Disabilities
2013 H Street NW, 5th Floor | Washington, DC 20006

Resource Spotlight

Direct Aid Reimbursement Service offered by SBAWS

What is Direct Aid Reimbursement?

Direct Aid Reimbursement is a payment from SBAWS, up to an annual maximum of \$250, for goods or services directly related to the care of a person affected by Spina Bifida. Covered costs include but are not limited to: partial education and camp scholarships; medical equipment; uncovered medical expenses. The request must be due to financial need and the funds must be used for the intended purpose.

How do I know if I qualify?

A qualified applicant is a person with Spina Bifida or that person's parent or guardian who resides within the SBA of Washington State's service area. Physician documentation confirming the Spina Bifida diagnosis is helpful but not required.

How do I apply?

Complete the online application at <http://www.sbaws.org/Direct%20Aid%20Reimbursement%20Application%202013.pdf> and mail it to SBAWS, 611 2nd Ave Ste A, Snohomish WA 98290. In addition to the application, you will need to provide information about the person with Spina Bifida, copies of receipts or invoices for the covered costs, and a description of the purpose for the items or services for which aid reimbursement is being sought.

How does the process work?

Once your application is received by SBAWS, you will be contacted by Executive Director Meg Paulsen to confirm receipt and assess the situation. A final determination will be made at the next scheduled Board of Directors meeting (held every other month). You will be notified of the Board's decision within seven days following the meeting.

What are my obligations?

If you are the recipient of direct aid, you will be added to the mailing list for *The Evergreen* newsletter and asked to volunteer your time and talent with SBAWS. There are many ways to volunteer, both out in the field and from the comfort of your own home: join event committees, participate in events, write articles for the newsletter or website, coordinate cluster events, and more.

What if I have further questions?

Email Meg Paulsen, Executive Director of SBAWS, at megpaulsen@sbaws.org for more information.



**Spina Bifida Association
of Washington State**

"Together We Make The Difference"

www.sbaws.org

SPINA BIFIDA ASSOCIATION OF WASHINGTON STATE

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

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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

