



The Evergreen

August 2012

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

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MEG INVITES YOU TO “COME LEARN WITH US”

by Meg Paulsen, Executive Director, SBAWS

Wow – July was super busy and definitely exciting for the SBAWS – our 3rd annual Walk-N-Roll for Spina Bifida was a smashing success! We had a great day of family, fun, food and fellowship – see SBAWS Chair Jason Lane’s detailed article dedicated to bringing you the exciting details on page 4.

Now – on to continuing our efforts to bring the SBAWS’ missions to life. We have now begun the planning for our next event – our annual Summit. As you may re-



Meg Paulsen

member, last year we combined our Summit with our picnic and had a fantastic time at Seattle Children’s Garden – the theme was “Come Grow with Us.” This year’s theme is “Come Learn with Us” and will be based around medical issues for those of us affected by Spina Bifida. The half day event will be held Saturday, October 6th from 10am to 2pm at Northcut Landing down the street from Seattle Children’s Hospital. Two physicians are scheduled to speak. First is Dr. David Shurtleff who has been working with Seattle Children’s Hospital for many, many years – he was MY doctor when I was a kid!

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SBA Releases Statement on Supreme Court Decision Upholding Affordable Care Act

On June 28, 2012, the U.S. Supreme Court announced its decision to uphold the Affordable Care Act and its provisions. The Spina Bifida Association (SBA) commends the Court on its decision that will help ensure that Americans living with Spina Bifida have access to the health care they need to live healthy, productive lives. SBA issued the following statement on the ruling. Spina Bifida – the most common, permanently disabling birth defect – affects an estimated 166,000 people in the United States. Spina Bifida occurs when a baby is in the womb and the spinal column does not close all of the way; depending on the location of the hole in the spinal column, a person may have minor or significant disability.

People with Spina Bifida can have physical, mental, and social problems. Physical and health problems associated with Spina Bifida include difficulty with walking and getting around or going to the bathroom, latex allergy, obesity, skin breakdown, gastrointestinal disorders, learning disabilities, depression, tendonitis and sexual issues. While some people with Spina Bifida qualify for Medicaid and/or coverage under federal or state disability programs, many require health insurance coverage and access through the commercial market. As such, through its expansion of access to health insurance coverage, the Affordable Care Act should result in more people with Spina Bifida

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Newsletter Editor
 Celeste McCormick
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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!

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HIGHLIGHTS FROM BOARD OF DIRECTORS MEETING July 7, 2012

For full content of the minutes, visit www.sbaws.org/Minutes.html

- In attendance: Jason Lane, Krystal Monteros, Jon Tutt, Nicole Williamson, Dave Carl (by proxy to Jon), Elizabeth Lovelace, Ryan Callaway, Jamie Heckinger, Linda Bailey, Leslie Gilchrist (by proxy to Jason)
- Guests: Meg Paulsen, Amy Miller
- Treasurer's Report:
 - \$11,500 raised year-to-date through FirstGiving
 - Meg will follow up with SBA regarding the fact that no SBAWS members received their Insights subscriptions
 - Since Annette and Ed left the Board in December, Meg will present them with a plaque and \$100 gift certificate as thanks
- President's report:
 - Field Relations want to meet with SBAWS officers to discuss minimum affiliation requirements for chapters
 - Motion made and passed to install Elizabeth as chair of the Development Committee
- Executive Director's report:
 - Meg is searching for more office space and storage space; she is also investigating purchasing tents for events
 - Motion made and passed to let Meg purchase computer for up to \$500 and be reimbursed 45%
- Actions taken by the Board since the last meeting
 - Voted unanimously not to support the 2012 Hydrocephalus walk
 - Voted to add \$2000 to Walk-N-Roll budget, now totaling \$8500
- Old Business
 - Walk-N-Roll raised nearly \$11,000 through FirstGiving (compared to \$17,887 last year)
 - Meg will distribute survey to participants for feedback; Jon recommended separating future events so that constituents have more opportunities to get together
 - Jamie is stepping down from Development Committee
- New Business:
 - Motion made and passed to install Elizabeth as Chair Elect
 - Motion made and passed to accept Krystal's resignation as Secretary and install Nicole in her place for the remainder of 2012
 - 2012 Summit ideas discussed: Meg may try to get local doctors to present; vendors and other disability-advocacy non-profit organizations should be invited to host booths
 - Motion made, passed to install Amy Miller as a new Board member
- **NEXT MEETING: either Thursday September 27 by teleconference or Saturday September 29th in person after the Summit**



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Spina Bifida Association of Washington State
Financial Statement Summaries
As of June 30, 2012

	2012		2011		\$ Change
Profit & Loss Comparison					
Income					
Donations					
Fundraising					
Walk N Roll	\$ 6,959.32		\$ 17,887.20		\$ (10,927.88)
Adopt-a-Ghost	\$ 52.00		\$ 67.00		\$ (15.00)
Shop for a Cause	\$ -		\$ -		\$ -
Other	<u>\$ 598.00</u>		<u>\$ 472.00</u>		<u>\$ 126.00</u>
Total Fundraising	\$ 7,609.32		\$ 18,426.20		\$ (10,816.88)
In Kind Donations					
ED Meg Paulsen	\$ 10,680.00		\$ 15,000.00		\$ (4,320.00)
Other	<u>\$ 629.78</u>		<u>\$ 20.00</u>		<u>\$ 609.78</u>
Total In-Kind Donations	\$ 11,309.78		\$ 15,020.00		\$ (3,710.22)
Restricted Donations	\$ 100.00		\$ 675.00		\$ (575.00)
Other Donations	<u>\$ 1,106.40</u>		<u>\$ 1,869.07</u>		<u>\$ (762.67)</u>
Total Donations	\$ 20,125.50		\$ 35,990.27		\$ (15,864.77)
Interest					
	<u>\$ 116.92</u>		<u>173.14</u>		<u>\$ (56.22)</u>
Total Income	<u>\$ 20,242.42</u>		<u>\$ 36,163.41</u>		<u>\$ (15,920.99)</u>
Expenses					
		% by Category		% by Category	
Mission/Program	\$ 20,392.26	78.85%	\$ 23,637.16	77.42%	\$ (3,244.90)
Administration	\$ 2,500.36	9.67%	\$ 2,474.65	8.10%	\$ 25.71
Fundraising	<u>\$ 2,970.48</u>	<u>11.49%</u>	<u>\$ 4,420.59</u>	<u>14.48%</u>	<u>\$ (1,450.11)</u>
Total Expenses	\$ 25,863.10	100.00%	\$ 30,532.40	100.00%	\$ (4,669.30)
Net Income (Loss)	<u>\$ (5,620.68)</u>		<u>\$ 5,631.01</u>		<u>\$ 11,251.69</u>
Balance Sheet Comparison					
Assets (cash in the bank)	\$ 42,573.60		\$ 57,076.58		\$ (14,502.98)
Liabilities	<u>\$ -</u>		<u>\$ -</u>		<u>\$ -</u>
Total Equity (Fund Balance)	<u>\$ 42,573.60</u>		<u>\$ 57,076.58</u>		<u>\$ (14,502.98)</u>

Income: With 50% of the year passed our YTD income is only 140% of our annual goal of \$50,000 and 44% less than last year at the same time. This is basically due to the fact that the Walk-n-Roll is much later this year, resulting in donations coming in slower and because we've started paying Meg so her in-kind donation has decreased. Hopefully the Walk-n-Roll will make our income numbers look better but I am concerned that it will not.

Expenses: Total expense is pretty close to being right on target at 52% of our \$50,000 annual goal, and this years total expense was over 16% less that last years. Our goal is to receive and spend the same amount.

Net Income (Loss): Is in the negative since we spent more than we took in and the loss was significantly more that last year. Last years positive income at this point is almost exactly the same as the years negative loss. Hopefully this will turn around with the Walk-n-Roll.

Expenditure by Category: These are acceptable percentages given this time of the year, especially with our insurance cost being an annual expense and paid in the first quarter. We have probably spent about 65% of our administrative cost for the year. These percentages will more than likely improve as the year goes along.

Net Worth: Our total assets, fund balance, cash in the bank decreased by over 25% as compared to a year ago.. We have no liabilities (unpaid bills).

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

Jonathan A. Tutt, Treasurer



2012 3rd annual Walk-N-Roll raises over \$18,000 for SBAWS

by Jason Lane, Chair, SBAWS Board of Directors
On a bright sunny July 7th, many supporters and volunteers of the Spina Bifida Association of Washington State converged on Bradley Lake Park in Puyallup, for the 3rd Annual Walk n Roll for Spina Bifida. This year's walk was sponsored by several businesses with special thanks going out to Coloplast and Ti-Lite.



The day started out at 8:30am when our volunteers from Kolh's, Susan Baron and some Boy Scouts arrived to begin set-up so registration could be opened by 9:30am. As people began to arrive, with music playing in the background, coffee donated by Starbucks, and food donated by Pam Newman with Astratech, were made available so folks had enough energy in preparation for the walk soon to begin. Our 2012 emcee, Pat

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Cashman, made sure as people arrived that they checked in with registration and got their 2012 Walk N Roll t-shirts provided by Sales Makers Inc., as well as adding some witty banter throughout the day.

As 11:15am neared, the time of the walk, teams started gathering at the starting point. Finally it was time, at 11:15am the walk began. Those in attendance in support of SBAWS walked around paved path around Bradley Lake. It took about 20 minutes for most to walk around the 1.5 mile path. Along the route were signs with Team names and our promotional poster provided by 4ZDesign. As people passed the finish line, they began to gather and cheer, along with Wendy Ogden who offered her clown services to SBAWS for the day, as others finished the walk. The cheering section kept growing until everyone had crossed the line. After everyone completed the walk, it was time for lunch. This year we had sandwiches, salad, and fresh baked cookies provided by the local Honey Baked Ham Company, who graciously delivered and helped serve the lunch as well. They also provided items for the various raffles we had at the walk. As the temperature began to rise during the day, we also had water provided by the local Top Foods, and other beverages to refresh those coming off of the walk.

While everyone was chatting with one another, and enjoying lunch, we began our awards presentation. Each team received a certificate of participation and mini trophy as well as a team photo taken by Justin Olsen. Again, our emcee Pat Cashman assisted in the presentation making folks smile along the way.

At 1pm, we had our entertainment for the day, provided by The Bubble Guy. The Bubble Guy put on an amazing show of...you guessed it, Bubbles! The kids seemed to be impressed with what you can do with Bubbles. By 2pm the day was winding down.

We would like to acknowledge our volunteers from Kohl's, Susan Baron and the Boy Scouts, and our many other donors such as Costco, Walmart, and OfficeMax who all provided gift certificates, or made other in-kind donations to the walk.

A BIG "thank you" to all those that participated on the 2012 Walk n Roll Planning Committee, without their support, and the support of the community, we would not have been able to pull off such a huge event. I also would like to "thank" the Board of Directors for SBAWS for their support.

All in all, the 2012 Walk n Roll for Spina Bifida was a great success raising over \$18,500, beating last year's total of \$17,887. We are now looking to form our 2013 Walk n Roll Planning Committee. The SBAWS Board of Directors hopes to get more of our constituents involved, as all the funds raised at the walk stay in the state of Washington to help you, our constituency. If you would like to assist on the walk planning committee, or any other committees, please contact us at SBAWS@yahoo.com and let us know.



Elizabeth Lovelace

CONTINUING MY COMMITMENT

by Elizabeth Lovelace

Now that the Walk-N-Roll has been implemented with success, I asked myself:

“What’s next? How do I continue my service to the SBAWS? How can I impact the growth of the organization and what it offers its constituency?” I received my answer at the last Board Meeting when the question was raised, “Who is interested and available to take the position of Development Committee Chair?”

You guessed it! I, Elizabeth E. Lovelace, am interested and available to serve as the Development Committee Chair for the SBAWS and will work to build a committee of people to carry out the mission and meet the goals of the organization over the course of my term in this position.

As Committee Chair, I will need to build a team of people who are knowledgeable about the Chapter, the community and fundraising strategies. I will need people with the right temperament, and interests to carry out our strategic plan. The responsibilities of the committee are, but not limited to: scanning the environment for partnerships and event venues; ensuring a strong case for support; developing

and monitoring a year-round fundraising plan, i.e. Individual Gifts (special, major, BOD), Corporate/Foundation Gifts, Special Events, Annual Appeal, Planned Gifts; involving, motivating, and engaging the Board of Directors and others; and ensuring compliance with the organization’s standards.

Here is the question that still remains: Are YOU one of these people? Are you available to share your time, ideas, and expertise as a Development Committee Member? Please ask yourself, not what your organization can do for you, but “What can you do for your organization?” I heard it said, “There is no I in TEAM, but there is a U in volunteer.”

It is my goal to have the committee formalized by September 1st. If you are interested in becoming an integral part of the SBAWS Development Committee, please email me chairelect@sbaws.org or give a call 206.234.2699 to learn more about how you can make the difference! Never doubt that a small group of committed people can change the world. Indeed, it is the only thing that ever has. – Margaret Mead–

2012 Summit will focus on SB medical issues

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He will speak about adjustment in school and the learning problems of children with the various forms of Spina Bifida, a topic which many SBAWS constituents expressed an interest in learning more about. The second speaker is Dr. Jeffrey Ojemann from neurosurgery, and his topic is yet to be determined. There may be other medical professionals joining us so networking should be at a premium. We have invited several vendors to exhibit their wares at the event – providers of medical equipment and supplies, recreational organizations and other non-profits will have tables where participants can gather helpful information. Look for the flyer to hit your email inboxes soon with the specifics!

The Summit will be provided free of charge in celebration of the fact that October is not only Disability Awareness Month, but also specifically Spina Bifida Awareness Month! October is also our Adopt-A-Ghost campaign so at the Summit we will have stacks of ghosts who are ready to be adopted. Participants can either pre-donate in \$20 increments (and reimburse themselves by collecting donations) or take ghosts that can be distributed during the month of October and then send the donations to SBAWS. We are offering free lunch to the first twenty people who register in person the day of the event!

As we bask in the summer warmth, we appreciate the warmth in the generous hearts of those 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!

KITSAP CLUSTER GOES BEYOND ACCESSIBLE PLAY

by Jay Johnson, member of the Kitsap Cluster and father of Matthew

It all started with a question during a SBAWS Kitsap Cluster meeting, "Why don't we have a place where our special needs children can play together with able-bodied kids?" That was how Bremerton Beyond Accessible Play got started a little over a year ago. Since then, a dedicated group of parents, educators and community members have been working together to create accessible and inclusive play areas for children of all abilities and ages. Chances are your local community and school



*For more information about Bremerton Beyond Accessible Play or the Kitsap Cluster, contact **Rebekah Uhtoff**, SBAWS Kitsap Cluster Co-Chair and Vice President and Design Chair of Bremerton Beyond Accessible Play
360-620-9804 or uhtoff@msn.com*

parks aren't adequate to handle the mobility challenges of those with Spina Bifida. Even if they happened to be ADA compliant, they still provide significant obstacles to allowing special needs kids to do what kids love best - have fun! Parents in Kitsap County, WA faced a 45 minute drive to the nearest playground that could accommodate their children's needs. But now BBAP is working with the City of Bremerton to open a new accessible playground, hopefully by the summer of next year. Find out more about us at our Facebook page www.facebook.com/BeyondAccessiblePlay. You can also contribute to our project here: www.hollyridge.org/playgrnd.html (donations are tax-deductible).

Are YOU interested in volunteering for SBAWS?

SBAWS is currently seeking volunteers for the following positions:

- **Secretary:** this position sits on the Board, takes minutes at Board meetings, and answers the SBAWS email.
- **Historian:** the SBAWS history page (www.sbaws.org/History.html) needs rewritten with more accurate and up-to-date information.

Contact SBAWS today to learn more about these opportunities.



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.

SBA national conference both educational and fun

by Mackenzie Miller and Debbie Rodger

Wow! What a wonderful experience! The National Spina Bifida Conference was held June 28 - July 1 in Indianapolis, Indiana. Along with great speakers and a fantastic exhibit hall there was also time to meet and greet new friends and explore this beautiful city.

The classes were well thought-out and the speakers were exceptional. There were classes about wheelchair fitting, maintaining friendships, being empowered, transitioning to adult healthcare, new medical developments and developing personal wellness plans. We found the classes to be educational and we learned something new in each one.

The exhibit hall featured many companies and outreach organizations that were informative and helpful. It took two afternoons to see all that is new and available to make our lives a little easier. One of the favorite booths for adults and youth alike was the Canine Companion for Independence. Four of the most beautiful dogs and their trainers were available to answer questions and show how a dog can enhance the life of a person who is wheelchair bound. A stop by the Colours Wheelchair booth was fun as well as educational. Many of the new designs are much more streamlined and the new colors are awesome. Who is ready for a new chair? And it was a highlight to meet and get a photo with Michael Johnson, formula racing's first paralyzed driver. Michael is redefining the sport and erasing boundaries, proving any obstacle can be overcome.

Along with great classes there were several opportunities to get together. Many attended the minor league baseball game and watched the Indianapolis Indians beat Toledo 4 to 2. After the game we were treated to a spectacular fireworks show. The other evenings were spent in the splendid lobby of the hotel; filled with camaraderie, conversation, laughs, catching up with old friends and meeting new.

The finale for the conference was a luncheon with guest speaker Jean Driscoll. What an inspiring and empowering speaker! Not only is she the first eight time winner of the Boston Marathon but she also set 5 new course records as well as 5 world best times and has held Boston's fastest time in the women's wheelchair division since 1990. After hearing Jean speak we felt motivated to change the world or at least our little part of it. It was a great way to end the conference.



Mackenzie & Debbie at the game



Mackenzie (center) and friends

SBA releases statement supporting Affordable Care Act

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da having access to treatment and adequate medical care to manage their condition. In particular, the Spina Bifida Association is pleased with the provisions that: ensure guaranteed issue of insurance, provide for community rating, preclude pre-existing condition limitations, eliminate annual and life-time caps on insurance benefits, and allow children to stay on their parents insurance through age 26.

On behalf of the 166,000 individuals Americans with Spina Bifida, we remain steadfast in our efforts to advance and ensure access to comprehensive, affordable care for people with Spina Bifida. We will work with others in the disability and chronic disease communities to monitor and help implement the Affordable Care Act to ensure that its provisions will have a positive impact on the lives of the individuals and families we represent.

Just 10 minutes of your time could win up to \$20,000 for SBAWS !

By participating in the Spina Bifida Genetics Research Project, you are bringing your Spina Bifida organization a step closer to **winning a sponsorship!**

- Sponsorships range from \$2000 to \$10,000, depending on the number of participants.
- There is a chance to win an additional \$10,000 grand prize for the organization in North America that has the most participants!
- Plus, every mother who participates will receive a \$10 gift card or can have the funds donated to the Spina Bifida organization of her choice.

About the Study

Mothers of children with spina bifida have important genetic clues in their saliva that are critical to helping scientists better understand this rare condition. World-class scientists are on the cusp of developing a way for doctors to identify women who may be at high risk for birth defects, so they can receive customized care before they get pregnant.

An additional 1400 participants are needed by August 31, 2012.

It takes just 10 minutes

To participate, **mothers of children with Spina Bifida** simply complete a short online survey and provide a saliva sample using an at-home collection kit by August 31, 2012. (Mothers who participated in the first phase of our study are not eligible to participate in this second and final phase.)

Please visit SBgenetics.org for more information, or contact SBAWS today.

Kids Wish Network is a national 501(c)(3) organization that grants wishes to children living with life-threatening illnesses. Our organization brings smiles to many deserving children who just need a break from their illness.

Kids Wish Network grants wishes to children between the ages of 3 and 18 who have not had a previous wish granted by any organization. The child must have a doctor verified life-threatening condition and be able to somehow communicate his or her wish, either verbally, with the assistance of communication devices, by pointing at pictures, shaking his or her head yes or no, by signing or any other way that we can indicate what the child's wish is.

There are several differences between Kids Wish Network and other wish granting organizations. Kids Wish Network grants wishes to children with life threatening illnesses, which means that the condition does not have to be terminal; we want for our wish children to get better. We also understand that not all of our wish children will recover, that is why we also offer funeral assistance to families whose child received a wish through our organization.

To apply, please contact:

Julie Rys
Kids Wish Network
4060 Louis Avenue
Holiday, FL 34691
(727) 937-3600 x237



Kids Wish Network®

...where dreams really do come true!

Resource Spotlight



Cirrus Concept Design Launches New Medical Device, RetroLift™ Improves Quality of Life For Wheelchair Users -Reduces Risk of Injury to Health Care Workers

The idea first occurred to the inventor- Dale Bell in the mid-1990s while working as a registered nurse in the home of a large man who had suffered a stroke. Simple tasks like moving him from a chair to a bed were daunting. The RetroLift™ is a battery powered seat that attaches to a conventional wheelchair. The wheelchair user sits on the RetroLift™ and with a touch of a button can gain over 17 inches of vertical lift making everyday tasks easier and safer- getting a coffee cup from a cabinet, reaching for produce at the grocery, getting into bed, conducting banking business, getting a gallon of milk out of the refrigerator. The RetroLift™ improves the quality of life, independence, and dignity for wheelchair users.

The RetroLift™ reduces the risk of injury to health care professionals that transfer or lift patients. Nurses, Certified Nursing Assistants, Radiologists, X-Ray Technicians, Physical and Occupational Therapists all perform physically demanding lifts every shift. The RetroLift™ transforms a basic wheelchair into a viable vertical lifting device by raising the patient to the level of the examination table or bed. The health care provider can laterally transfer the patient instead of lifting or lowering them. In certain situations the RetroLift™ eliminates the need for costly and cumbersome lifting devices.

The RetroLift™ aids with getting an individual that has fallen back on their feet. The patient is transferred onto the RetroLift™ and then raised enabling them to get their feet squarely on the ground to help regain the standing position. This application may be used in medical facilities as well as the home by care providers and fire departments that are called to assist fallen individuals.

Watch a demo at

<http://www.retrolift.com>

For more info contact Jeff Wise, VP

(Jeff@RetroLift.com)

1-877-IT-LIFTS!, RetroLift™ by Cirrus Concept Design, Dayton OH



RetroLift in the "up" position



RetroLift in the "down" position

care providers and fire departments that are called to assist fallen individuals.

Doctors make breakthrough for sexual health of patients with SB

by *Diana Tutt, Evergreen Reporter*

Dr. David B. Shurtleff, MD, has passed on information regarding surgeries done in the Netherlands and Seattle. This is an issue that is of importance to both men and women with Myelomeningocele (MM) as it has to do with quality of life.

A procedure named TOMAX(R) requires a transplant of a branch of the ileofemoral nerve to the dorsal nerve of the penis to provide sensation to the glans penis. This procedure has been performed in the Netherlands to at least 30 patients by Dr. Max Overgoor. He sent the description of the procedure and results of these first 30 patients to *The Lancet*, a well-respected English language medical journal. Two successful surgeries have been performed in Seattle by Drs. Thomas Lendvay and Anthony Avelino. The doctors made a presentation accepted by the USA Society for Urology of America. More surgeries have been performed since I received this information as a

wealthy man from California came to Seattle to have the other nerve repaired. What a testimonial to the success of this surgery. At the University of Washington a female doctor is studying the enervation of the female clitoris to determine if the same surgery could be successful for females. If you are a female with MM or know of someone who is, please contact the University of Washington Urology program. If there are not many interested, the study will not continue.

The only other significant news about MM is the well-known hype about intrauterine repair. Dr. Shurtleff and his colleagues are of the opinion that is still to be proven worth the risk for mother and infant because of the risk for uterine damage and prematurity. Appropriate patients (based on strict selection criteria) are being referred to the University of California San Francisco, where results have been much better than other experiences.

The City of Coconut Creek, Florida, recently produced an uplifting video featuring a young man with Spina Bifida and his great spirit. See it on YouTube at <http://www.youtube.com/watch?v=YJlkyRvcU-o>

FACES Magazine

OF SPINA BIFIDA a place to celebrate diversity

Faces of Spina Bifida is an online magazine that aims to “celebrate diversity among people living with Spina Bifida.” The site aggregates news and events from other sources on the internet to make them available in one central location. Videos, health news, human interest stories and blogs are just some of the features available through the online magazine. The website also hosts an online community where people can share their experiences and connect with each other. Visit *Faces of Spina Bifida* today to experience it for yourself!

<http://facesofspinabifida.com>

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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

