



The mission of the Spina Bifida Association of Arizona is to promote the awareness of Spina Bifida and enhance the lives of those affected.

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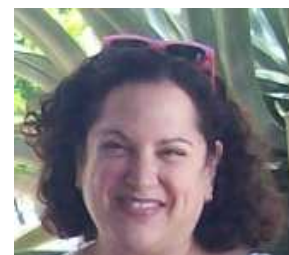
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Summer 2009 Newsletter

Summer 2009

June 15, 2009

Meet your new Executive Director Judi Goldfader



Through a serendipitous meeting with the Executive Board; Judi Goldfader has joined SBAAZ as its new Executive Director.

With a background in management, PR and fundraising, Judi has contributed her heart and soul to the expansion of several nonprofits including the Santa Monica Museum of Art, the Peace Alliance, Insight Seminars and the Good Works Foundation. She is an active advocate for children in foster care and is looking forward to getting to know the children and families who are served through SBAAZ's programs. She envisions the Phoenix headquarters as a safe haven for all and a place of joyful laughter and upliftment for those who visit and volunteer. "We can't do it alone" she says. "Thanks to the many who have brought the organization to where it is today and continue to seed its growth. With our new national affiliation, the sky is the limit to what we can create and achieve together."

A frequent visitor to the Valley beginning in the mid 60's, Judi has recently returned home to central Phoenix with her 22 month old daughter, Ella Rose. In her spare time, Judi is a passionate collector of contemporary art and lover of all chocolate. She invites you to contribute your gifts and talents to SBAAZ and welcomes your ideas and feedback. "We hope you will think of us as your friends and partner in education, health and community."

To reach Judi, please call the office or send an e-mail to jgoldfader@sbaaz.org

Meet your new Office Manager Sharri Muscarella



Sharri has been a Phoenix transplant since 1999 coming from Orlando, Florida with her husband, Jeff, and two sons, Seth & Jordan. Now enjoying the phase of 'empty nester', Sharri spends her free time involved with her North Phoenix community and the neighborhood children.

As our new Office Manager, Sharri brings to SBAAZ comprehensive experience in business administration and the non profit arena.

"My first weeks have been excellent," says Sharri, "the people that make up our membership and board are the greatest. I am very much looking forward to serving those with Spina Bifida and their families, and helping to make SBAAZ a foundational support resource in Maricopa County and beyond.

To reach Sharri, please call the office or send an e-mail to office@sbaaz.org

Thank you & Farewell



Dear Spina Bifida Families and Friends,

The time has come for me to say goodbye. I have truly enjoyed working with all of you. I will miss you. I enjoyed every aspect of the job, including clinic on Friday, talking with those of you who called, or came in to pick up urinary care supplies, and meeting you at the holiday parties, etc. I also enjoyed the office aspect of the job; bookkeeping, urinary care supplies and everything that goes with the job. But the time has come for me to return to Oregon to spend time with my family.

I will miss all of you.

Arlene

We also wanted to express our thanks to Dolores Herrera who also has served on the board for three years. Thank you for all of your hard work.

New Board Members Elected

Lisa Purdy

Lisa is 28 years old and was born with Spina Bifida. She has been together with her husband Adrian to whom she married in 2007. Lisa graduated from ASU with a BA degree in Fine Arts and Photography. She also recently became the mother of a beautiful girl, and currently works for ABIL (Arizona Bridge to Independent Living). She will bring a unique prospective to our board and we are excited to have her.



Alan Potter

Alan served on the Arizona Epilepsy Foundation Board of Directors for 15 years. He became acquainted with Spina Bifida when his daughter became pregnant while on anti-seizure medicine and the doctor warned them of the danger of birth defects. This was the first time that Alan had heard of Spina Bifida despite his interest in medical science. He is well educated and currently has one year left to achieve his Ph.D. in International Business Relations. He will be a great addition to our board.



Genetic Testing for Spina Bifida.

VitaPath Genetics is developing a simple check-swab assay to identify women at high risk for Spina Bifida. Along with their collaborators at UC Berkeley, Stanford University, and Children's Hospital Oakland Research Institute (CHORI), we are recruiting mothers of children with Spina Bifida to provide a saliva sample for validation of our genetic test. We are very excited about the results from our research program and are now in need of 1,000 mothers to participate in the Validation Study of the clinical effectiveness of our test.

They are in the final stages of a research program aimed at developing a genetic test to identify women at-risk for Spina Bifida. This test will use a simple cheek-swab as a source for DNA, and analyze for genetic factors that influence how your body utilizes the vitamin folic acid. Once developed, this genetic test will identify women who are at high risk based on their genetic profile. These women, identified as high-risk based on their genetic profile, will be counseled under the care of a physician to take a 4mg/day dose of folic acid – the same recommendation given to women at high-risk based on history (prior affected pregnancy or Spina Bifida).



This is strictly an informational article. **The Spina Bifida Association of Arizona will not be providing Vitapath with any information of our members.** If you are interested in participating in the study it will be at your own will. Please check out the website to gain all the information possible to make an educated decision at www.vpgenetics.com, or contact the SBAAZ offices for more information.

General Information

- SBAAZ continues to have apartments for rent at very reasonable prices. Please contact the office if you are interested or know of someone who might be.
- Volunteers and assistance is always needed for all events & programs. Please join us at any of our board meetings to let us know how you can help.

[Next Board meeting is: July 21, 2009](#)

- Tell your friends and family about us online as well as on Facebook.
www.sbaaz.org <http://apps.facebook.com/causes/>
- Pass the word along to all those you know with Spina Bifida that membership is free for those with Spina Bifida. We want to make sure we are getting information out to all.
- We are looking for pictures of persons with Spina Bifida. If you would like to send a short story about yourself or child that would be great as well. We will keep those in a binder for all to take a look at as well as publish them on our website as well as other publications to inform people about those with Spina Bifida.

Annual Events

Bike Event 2009

The 11th Annual Bike Event was held on March 7, 2009. Thanks to the efforts of The Chandler Regional Hospital Volunteers, Barb Farmer, and CVS, it was a great success. 28 cycles were given away, each one customized for the recipient.



Para-Olympian Erik Hightower stopped by to tell of his experience in Beijing and encourage all to exercise and stay fit. It was a great day to meet new people and reconnect with old friends.

If you or anyone you know has Spina Bifida and would like to receive a bike please go to www.sbaaz.org to fill out an application or call the SBAAZ office at 602-274-3323.



10th Annual Golf Tournament

The 10th Annual Golf Tournament was held on May 15, 2009 at Superstition Mountain Country Club. This year's fundraiser was a great success!

With prizes to win for longest drive, closest to the pin, longest putt and best all around score, everyone brought their best game, especially the General Dynamics group who took home first place. But the true winners in the end are the families and friends in Arizona that will benefit from the money raised.

We would like to thank everyone that came out to support our cause. We would like to give special thanks to Manuels who has sponsored and participated for 10 years straight. Hanger P.O. has been another great continuous sponsor as well. We would also like to thank two of our newest sponsors; General Dynamics and The Arizona Cardinals Charities.



We would also like to thank Bruce Reeser who has been the chairman of the golf tournament for 10 years. This fundraiser has been a great success because of his tireless efforts and selfless service for these past 10 years. Thank you Bruce, we hope to continue the legacy you have created in this tournament.

SAFSB Walk-A-Thon

Southern Arizona Firefighters for Spina Bifida 1st Annual Walk/Roll-a-Thon

On May 9th the first walk/roll-a-thon was held for Southern Arizona Firefighters for Spina Bifida (SAFSB). The event was a great success and all of our goals were reached this year. This was due to our many wonderful sponsors and the participants who showed up to walk/roll in the event.



The walk was held at the Glad-den Farms Community Park in Marana Arizona. There was lots of food and drinks for the participants as they registered. We began the 5K walk at about 8:30. The path taken was around the park (about 1.25 miles each lap) on well maintained paved trail. The University of Arizona Wheelchair Athletics Department came and supported our event as well, which was a treat for every-

one at the event! All the participants expressed what a great time they had. After the walk was done, we had a raffle for many great prizes including a propane BBQ Grill from The Home Depot, and many other prizes/services. We also still have t-shirts available if anyone is interested in them.

We would like to especially thank a few of our sponsors, because without their support this event would have not been successful. The Scanlan Family and Northwest Firefighters were our silver sponsors. Our distance sponsors were CPR Restoration and Pizza Hut. Also, our finish line sponsors were Edward Jones and Green Valley Firefighters.

Next year's event will be held at the same location on **March 27, 2010** so put it on your calendars now! We hope to see everyone there next year to support our firefighter families. If anyone would like to sponsor next year's event, please contact Greg Chmara at (520) 404-7918 or at Greg.Chmara@hotmail.com.





**Spina Bifida Association
of Arizona**

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JUNE-JULY 2009

June 30-July 3

National Spina Bifida Conference



36TH NATIONAL CONFERENCE

June 30 - July 3, 2009 • Orlando, Florida

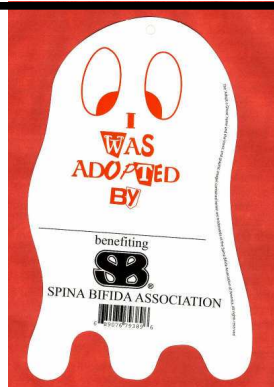
October 2009

All month long

National Spina Bifida

Awareness Month

Ghost Giving



DECEMBER 2009

December 12

Annual Christmas Party

**NEW OFFICE HOURS FOR
SBAAZ OFFICES**

Mon	9-12 1-3	Thurs	9-12 1-3
Tues	9-12 1-3	Fri	9-11
	Wed	CLOSED	

DON'T FORGET THE 3RD WEDNESDAY OF EVERY MONTH THERE IS A SUPPORT GROUP MEETING AT 7:00 P.M. AT THE TLC. NEXT DOOR TO THE SPINA BIFIDA OFFICE: 1001 E. FAIRMOUNT AVE. PHOENIX, AZ 85014

VISIT US ON THE WEB FOR UPDATED EVENTS AND PROGRAMS

WWW.SBAAZ.ORG

JOIN US ON FACEBOOK UNDER THE SPINA BIFIDA ASSOCIATION OF ARIZONA