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# Arizona Hemophilia eNewsletter



**Fall-Winter 2009**

<http://www.hemophiliaz.org>

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## **A New Face at the Association**

Ashley Gilliam is the new Volunteer Coordinator at the Arizona Hemophilia Association as of the beginning of September through the philanthropic organization, Public Allies.

Under the umbrella of AmeriCorps, Public Allies works to prepare the nonprofit leaders of the future by placing highly qualified, selected adults, ages 18-30, at a nonprofit for ten months of service. Once the competitive selection process is complete, individuals and organizations are paired based on a criteria of needs and skills. During the ten months of servitude, each individual will go through immense training and volunteer work, as well as gain useful information and tools in order to more effectively benefit their nonprofit.

Ashley earned her degree in public relations at Arizona State University in May 2009 from the esteemed journalism and communications schools. Ashley's first-class education and experience in public relations coupled with her compassionate nature and determined drive make Ashley an invaluable asset to the Arizona Hemophilia Association.

As volunteer coordinator she is thrilled to begin meeting and working with the community. If you are interested in volunteering with AHA or want to talk with Ashley about some of her experiences you can contact her at [volunteercoordinator@hemophiliaz.org](mailto:volunteercoordinator@hemophiliaz.org) or 602-955-3947.

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### **Desert Classic Golf Tournament By Katie Stringham**

The Arizona Desert Classic took place on Friday, October 2nd at the beautiful Legend Trail Golf Club in North Scottsdale. Over 100 golfers enjoyed a picture-perfect day on the greens including a wonderful lunch hosted by Macayo's. There were fun and games on the course including the Cazadores Margarita Hole, a hole in one opportunity sponsored by Volvo, a chance to use the pro's tee shot and everyone's favorite – the "ladies" hole! Great golf, raffle and silent auction prizes capped off the day. Congratulations to the winning team from Macayo's! Thanks so much to the sponsors of the day including PCH HOPE, Novo Nordisk, Wyeth, Corona/Coors Light, United Financial Services, Accredo, Baxter, Talecris, CSL Behring, Sarto Pools and Burdette Cabinet Co.

Thanks also to all of the incredible volunteers who helped make the event a tremendous success! Thanks to Arizona Hemophilias Association Board Members Steve Helm, Cindy Komar, Jessica Steed and Lennox Punch Jr. for volunteering for this event. Also special thanks to Guy Boss, Amber Cenzano, Micael Garcia, Ursula Dinkins, Phil Hardt, Pronto Parenteau, Elizabeth Pulley, Ken Pulley and Storm Understiller.

We hope to see everyone there again next year!

<http://www.hemophilia.org/az-desert-classic.aspx>

### National Hemophilia Walk 2009

The Arizona Hemophilia Association's second national Hemophilia Walk was really fantastic. This year we raised \$59,502.00. Some of these funds will help us continue to provide services and programs, while creating awareness about hemophilia throughout Arizona.



Special thanks to our many sponsors, volunteers and walk participants. We certainly look forward to seeing you next year.

<http://www.hemophilia.org/walk/>





### **Women's Retreat By Laurel Pennick**

The Third Annual Women's Bleeding Disorders retreat was held at Westward Look Resort in Tucson, AZ, Sept. 19th and 20th.

It involved two tracks: one for Women with vWD and Bleeding Disorders and another track for mothers, sisters and wives of males with hemophilia. The topics presented at the retreat were Personal Motivation and Development, Genetics of Hemophilia, History of vWD, a vWD consumer's story, and Healthy Eating, Healthy Life Style.

After a day full of scrumptious food, the attendees got to work it all off with an hour of Belly Dancing. Chair massages were available to those who wanted them. The day ended with dinner at a local Tucson Italian Restaurant. A Saturday night stay at Westward Look Resort was provided to those who attended.

The Women's Retreat has become a yearly event. We encourage our female patients and family members to attend.

<http://www.cascadefoundationaz.org>

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**CAMP H.U.G. (Hemophilia Uniting Generations) By Laurel Pennick**

Camp H.U.G. was held Columbus Day Weekend, Oct 9th-11th 2009, at the Triangle Ranch YMCA in Oracle, AZ.

The Camp began Friday night with registration, dinner, ice breakers, the making of family banners, s'mores and astronomy (for those who were still awake).

On Saturday the families had a choice of activities ranging from: horseback riding, zip line, high ropes and climbing wall, hiking, caving, arts and crafts and sports/field games. The infirmery staff provided individual infusion teaching H.U.G. KIDS! Day care was provided for the younger children. Saturday night there was a Piñata for the kids and a Talent Show, put on by the families and Hemophilia camp staff.

Sunday morning was more of the above activities. After lunch, the "Family Tournaments" began. Families competed in balloon races, egg tosses, obstacle courses and ping pong ball shoots. The weekend wrapped up with an outdoor picnic of hamburgers and hot dogs.

The winners of the family tournament are as follows: The Heinrich family - first place, The Ibarra/Rios family - second place and The Yee-Trujillo Family - third place winners.

Camp H.U.G. is jointly sponsored by the Cascade Foundation and the AZ Hemophilia Association.

Photos are courtesy of Jessica Casper. To view more Camp H.U.G. photos, log onto [http://web.me.com/jessicacasper/joy/Home\\_Page.html](http://web.me.com/jessicacasper/joy/Home_Page.html).  
[http://web.me.com/jessicacasper/joy/Home\\_Page.html](http://web.me.com/jessicacasper/joy/Home_Page.html)

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**Share Your Thoughts on Hemophilia By Andy Blackledge**

Have you ever written a letter to someone but never sent it? Perhaps you had emotions that you just couldn't put a finger on, or your feelings were so strong that you felt like you would explode?

Putting words on paper can be a cathartic experience. Just reading what you wrote can have a therapeutic effect.

Having a bleeding disorder adds a dimension to life that few people fully understand. The helplessness and even guilt you feel when you get a bleed, describing your pain that frequently falls outside of the traditional 1-10 pain scale, the mind games some people play with their painful joints just to take those first steps out of bed in the morning, and hurtful comments made by people who don't understand the complexity of bleeding disorders all come to mind. Bottling up the emotions that have accumulated throughout your life can lead to self-destructive patterns and actions that can hurt you and your relationships.

Guy Boss is a member of the Arizona hemophilia community. He was born before clotting factor was developed, and before many in the medical community and general population had a complete understanding of bleeding disorders. Guy spent countless months in the hospital as a young man, just to get control of bleeding episodes. He endured the therapies and procedures that today's generation would think of as perhaps medieval torture. He suffered the painful words uttered by protectionist half-brains of that generation. A scoutmaster forbade him from joining the cub scouts because his hemophilia made him a drain on society. A father thought it would be a sin to let him date his daughter because hemophilia was God's affliction.

If you met Guy, you would never know how much he has had to put up with in his life – he is funny and compassionate, and has an easy smile. Guy has started a blog at <http://guysmissingfactor.blogspot.com/>. For those unfamiliar with the "blogosphere," a blog is simply a Website where a person can share thoughts. People can subscribe to blogs, and they are accessible by all users of the Internet. Guy writes about all sorts of things, including an aversion to chocolate chip cookies. He has set aside a portion of his blog for his thoughts and experiences with his bleeding disorder. Reading his posts may be an "a-ha!" moment for you – his experiences are probably not that different from your own. Parents of young children may view the posts perhaps as an account from a "trailblazer" in the early days of hemophilia care. They can gain a better appreciation for the medical and societal advances that have been made, and translate them into positive messages for their affected children.

Guy has generously offered to use his blog as a place where other people can also post their own experiences with hemophilia. Sure, today's generation has access to great medications to treat the disorder, but we all endure our own challenges and obstacles related to bleeding issues every day. Please visit Guy's blog for more details (see the left side bar). If you're interested in sharing your story and having it posted to his blog, you can e-mail him at [missing9@cox.net](mailto:missing9@cox.net). Happy writing!

Andy Blackledge is a volunteer with the Arizona Hemophilia Association, and currently serves on the Camp Committee. He works for Accredo's Hemophilia Health Services as a Customer Account Manager

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## **NHF's 61st Annual Meeting - San Francisco, California**

This year's conference was October 29 - 31, 2009 at the Marriott Hotel in beautiful San Francisco, CA. The Hemophilia Foundation of Northern California hosted the three-day conference. The Arizona Hemophilia Association staff, as well as other nationwide Hemophilia Organizations participated in educational workshops, clinical and advocacy updates, and many social events.

The Arizona Hemophilia Association awarded Joshua (Josh) Shear a scholarship to the national conference, which included air-fare,

hotel accommodations and conference registration. You may log onto Josh's Website and learn more about his wonderful experience.

<http://www.joshed.info/2009/11/nhf-2009-meeting-building-bridges.html>

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### **Arizona Hemophilia Association's Board of Directors**

Steve Helm, President

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Joseph McKenzie Treasurer

Sarah Fey, Secretary

Cindy Komar, Member at Large

Lennox Punch Jr., Member at Large

Victor Alonzo, Member at Large

Jerame Pearson, Member at Large

Aaron Gordon, Member at Large

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