



818 East Osborn Road. Suite 105. Phoenix, Arizona 85014. 602-955-3947.
www.hemophiliaz.org We strive to enhance the quality of life for people with inherited bleeding disorders through education, awareness and social service.

A MESSAGE FROM OUR EXECUTIVE DIRECTOR, ALEXIS CHRISTENSEN

Dear Arizona Hemophilia Association Community,

This is our first e-newsletter and we are all on cloud 9 at the office. We hope you enjoy and find it filled with great information. It seems like we have been on a constant roller coaster - we have had so much happening. Hemophilia Awareness Month is winding down, and we celebrated in a variety of ways.

First, Arizona Hemophilia Association night was sponsored at Cold Stone Creamery. Arizona Hemophilia Association volunteers served ice cream, and 20% of the proceeds came back to the chapter. The next night was Arizona Hemophilia Association night at NYPD Pizza, and again the chapter benefited from some of the proceeds.

The month concluded with "Lunch on the Lawn" on Monday, March 30th. Several Legislators joined us for lunch while we educated them on hemophilia. Several families were able to connect with the Legislators to share their stories. It was a huge success and we are completely thrilled with the event.

The Association is getting ready to kick-off our YMCA program in Tucson. We were able to receive some funding to provide 15 families with one year memberships to the YMCA in Southern Arizona as a part of the Physical Activity Initiative from the National Hemophilia Foundation. We are looking forward to the success of the program and hope to expand it to Maricopa County.

Please mark your calendars for the Salsa Challenge on April 25th from 11:00 a.m. – 6:00 p.m. at Tempe Beach Park.

There are several upcoming events planned, so please stay tuned and we look forward to seeing you!

Sincerely,
Alexis

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ADVOCACY...BY KEN AND ELIZABETH PULLEY

ADVOCACY - we do this for ourselves and our kids everyday. If we don't advocate for ourselves, WHO WILL? The trick I have always had is that people tell me to advocate, but I've never been given the details on how to do it on a city or state level. That is precisely what we learned at " Nuts and Bolts" – a plan-o-gram on how to make our opinion heard by our elected officials in a productive way.

On Saturday, January 31st, 2009, The Arizona Hemophilia Association held an Advocacy Event. There were three speakers presenting at the event:

Derek Naten, Director of Government Affairs from Bayer, spoke about national events. In these tough economic times all States are looking for ways to cut costs. Cutting costs means finding ways to limit access. In Nevada cutting costs means a "Preferred Drug List" and in California it means "Supplemental Rebates." In order to avoid these outcomes in Arizona, we have to act.

Know who your legislators are.... Go to AZLeg.gov to find them.

Make sure they know who you are.... Send them a letter/e-mail introducing you to them.

Need letter formats? – go to the National Hemophilia Foundation's website at www.hemophilia.org. and click on "Advocay Center."

Since the last election, many of the legislators have changed and many new people are now in office, or they are on new committees. Committees of interest are the House, Health, and Human Services Committee; the Senate Health Committee; and the Senate Appropriations Committee.

Keys to communicating with your legislators is to personalize the letter, be passionate but courteous, be brief and concise, and stick to the facts.

Bert Coleman, PhRMA/Public Affairs/Political Consultant in the state of Arizona, spoke about knowing the legislators starting with an e-mail, getting close with the secretary, and having an elevator speech to quickly get your point across to them. An elevator speech is a 30-second, "Who you are, what you want, and how it effects you personally," speech.

Chris Healey, VP of Government and Public Affairs from Grifols, spoke about what we should ask the legislators for once they have gotten to know who we are. These should be coordinated efforts with the Arizona Hemophilia Association. The legislators are in office to serve us. It is our job to give them something they can do for us. These things could be as simple as a Hemophilia Awareness Day in Statute or as complex as setting up a High-Risk Insurance Pool for individuals who do not qualify for private insurance due to their health status.

Chris suggests a hook, line, and sinker approach.

1. The hook - contact your representatives

2. The Line – tell your story

Talk about your / your child's diagnosis

Set yourself apart – hemophilia is different from other diseases

3. The sinker – ask for help

Now.....How do we get there? Advocacy Days, follow-up meetings, letters, phone calls, and public speaking opportunities are some of the ways that we can accomplish our goals.

Please contact any member of the Advocacy Committee to learn the first step of what you can do to ensure our voices are heard.

Ken and Elizabeth Pulley

LUNCH ON THE LAWN WITH OUR STATE LEGISLATORS

On Monday, March 30, 2009, The Arizona Hemophilia Association, thirty families, along with the members of the Board of Directors, met with our state legislators for "Lunch on the Lawn" at the State Capitol.

Our families seized the opportunity to meet with our State of Arizona Legislators to discuss the needs of the Hemophilia Community. Needless to say, the event was an overwhelming success. Our legislators sat with our families and enjoyed delicious bar-b-que, cole slaw, potato salad, baked beans and brownies while engaging in one-on-one conversations about hemophilia and its impact within the families of the bleeding disorder community. One our our families also brought a vile of factor to demonstrate the process of what a person with hemophilia has to go through. Medical treatment as well as medical insurance were some of the vital subjects that were discussed. Tyler and Ken Pulley had the privilege of meeting with Senator Ken Chevront of District 15 (see photo).



A very special thank you to all of our legislators who attended our lunch. And a very special thank you to Judy Connell and Paul Layeus of Colmen Dahn and Associates for their expertise in helping us navigate through the proper protocol and legislative procedures.

What a great way to end Hemophilia Awareness Month activities with such a wonderful occasion.

MY NANA'S BEST TASTING SALSA CHALLENGE 2009

The 25th Annual My Nana's Best Tasting Salsa Challenge & Cazadores Margarita Mix-Off is Saturday, April 25, 2009 at Tempe Beach Park, Tempe, AZ

Taste more than 70 salsas prepared by valley chefs and vote for your favorite!

Admission: Tickets \$10, kids under 12, free

Discount tickets are available at www.salsachallenge.com

Proceeds benefit the Arizona Hemophilia Association.

Visit www.salsachallenge.com for contestant registration, vendor, volunteer and ticket information. Or contact the Arizona Hemophilia Association at 602-955-3947.

<http://cts.vresp.com/c/?ArizonaHemophiliaAss/10ca5a190e/a7ea6987c2/3048da3749>



IT'S TIME FOR CAMP HONOR

When: Monday, June 1, 2009 through Saturday, June 6, 2009

Where: YMCA Chauncy Ranch in Mayer, Arizona

This year's theme is "Hemophilia Around the World."

The deadline for all camper registration is Friday, May 15, 2009 at 5:00 PM. We will not accept applications after this date.

On Wednesday, May 13, 2009 from 1:00 PM until 5:00 PM, the Arizona Hemophilia will provide physicals for our campers who do not have medical insurance. Please call Yleana Hughes or Melinda Cadena at 602-955-3947 to schedule an appointment.

We still need volunteer camp counselors. For more information call Yleana Hughes or Melinda Cadena at 602-955-3947. You may also log onto www/hemophiliaz.org and click on the Camp HONOR logo.

More information will be forthcoming about our Camp HONOR "Super Seven" visitor's day. This day is set aside so that our seven year old community members, who will be eligible for camp next year, may spend a day at Chauncy Ranch. Be looking for an email or an invitation in the mail.

We still need the following donations:

Towels
Soap
Shampoo

Sunscreen
Socks
Flip Flops
Feminine Hygiene Products
Pajamas (boys and girls sizes 8 to 18)
Bathing Suits (boys and girls sizes 8 to 18)
Tennis Shoes (Kids' Sizes 12 - 4)
Tennis Shoes (Adult Sizes 5 - 11)
Target, Wal-Mart, Kohl's Gift Cards

Thank you for continuing to support of our families.
<http://www.hemophiliaz.org>

NEWS FROM TUCSON...

Summer Kick-off and Camp HONOR sign-up, sponsored by the Tucson HTC is Friday, April 17, 2009 from 3:00 PM - 6:00 PM at Brandi Fenton Park in Tucson. Please call Laurel Pennick at 520-626-7494 for more details.

The Annual Women's Retreat has been moved from July to Sept. 19 - 20, 2009. This year two educational tracks will be incorporated; one that will address the issues of von Willerbrand Disease (vWD) patients and one that addresses the need of mother, wives, daughters and sisters of bleeding disorder patients.

If you would like additional information, please call Laurel Pennick at 520-626-7494 or e-mail her at lpennick@azcc.arizona.edu.

ARIZONA HEMOPHILIA ASSOCIATION'S UPCOMING EVENTS...

April 8, 2009 - Educational Program - Managing the Costs of Hemophilia

April 25, 2009 - My Nana's Best Tasting Salsa Challenge

May 6, 2009 - "Planning Your Future," A practical guide to personal finances

May 15, 2009 - Deadline for Camp HONOR Applications

June 1, - June 6, 2009 - Camp HONOR

August 1, 2009 - Annual Meeting

Sept. 19 - 20, 2009 Women's Retreat

For information on any of these events, please call 602-955-3947 or toll free at 1-888-754-7017.

ARIZONA HEMOPHILIA ASSOCIATION'S BOARD OF DIRECTORS

Cindy Komar, President

Jessica Steed, Vice President

Joseph McKenzie, Treasurer

Sarah Fey, Secretary

Rob Silver, Member at Large

Steve Helm, Member at Large

Dana Christine Newell, Member at Large

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