

GET INFUSED

OFFICIAL NEWSLETTER OF ARIZONA HEMOPHILIA ASSOCIATION

JANUARY & FEBRUARY 2018



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A Note from our Executive Director, Cristina Barnes

Hello Friends!

This year has already been very busy for us! We have had FAME nights, both in Phoenix and Tucson, Parents Night Out, our very first Young Adults Group Meeting and College Prep Academy. We kicked March off with our Bleeding Disorders Awareness Month BBQ. In the next few months, we hope to see you at Legislative Day and let's not forget the Salsa Challenge! Camp Honor is celebrating its 25th year and we are so excited to be at a new location. We cannot wait to see the children's faces when they see Lost Canyon! It's an amazing facility with lots of fun activities. The week will be filled with lots of fun, a few surprises, and a big 25th celebration. Registration is open so don't forget to sign up!

Continued on page 3...

thank you

to all of our donors, sponsors, and volunteers!

We are grateful for your continued support!



We would not be able to accomplish all that we do without the help of so many wonderful contributors! The Arizona Hemophilia Association depends on the generous support of individual donors and volunteers as well as corporate sponsors to provide essential programs and services. If you or someone you know is interested in making a difference, please contact us today!

contact us

(602) 955-3947
ArizonaHemophilia.org
826 N. 5th Ave
Phoenix, AZ 85003

Continued from page 1...

Team AHA works very hard to offer meaningful programs, events, and education for our members. Your participation and volunteer hours are crucial to our success. On behalf of Team AHA we thank you for your dedication, support and time. If you would like to provide feedback, ideas for future events, volunteer your time, or just stop by to say hello we would appreciate it. Nothing makes our day better than to visit with our members. Looking forward to seeing you all at the next event!

With Gratitude,

Cristina Barnes



Advocacy- We Make a Difference!

Arizona Hemophilia Association advocacy committee is off to an exciting start this year!

We've teamed up with local fashion brand State Forty Eight to sell t-shirts that raise money for our advocacy efforts. These shirts say Existing Not Preexisting and with them, we are sending a message and creating awareness for bleeding disorders and other diseases.. Our hope is to reshape the way the public and lawmakers view preexisting conditions—they are existing people with a story and not a term used to categorize risk.

If you're interested in supporting our advocacy efforts and telling your story you can visit our website arizonahemophilia.org or you can also stop by the office to grab your shirt.

We're excited to send the Future Leaders to Washington D.C. with their Existing Not Preexisting shirts to explain our message to the legislators they meet. If you don't know, our Future Leaders program is for teens and young adults in our community who are interested in learning about advocacy. These Future Leaders learn about the history of bleeding disorders, the importance of having a voice in their community, about access to quality and affordable healthcare and how to speak with public officials. Every March we take a group of these young adults to Washington D.C. to help spread awareness about bleeding disorders because March is declared Bleeding Disorders Awareness Month.

On March 29, we hold a day similar to Washington Days on a state level called Legislative Day. Legislative Day is a day at the Arizona State Capitol where we set up legislative appointments for our members to meet with the legislators in their district. We also provide lunch on the Capitol lawn for our community and the legislative staff, this provides another opportunity for us to speak to decision-makers about key issues facing our community. We would love it if all of our members joined us, please visit our website or call the office if you would like to sign-up for Legislative Day.

If you're interested in being involved in the Advocacy Committee, please email tori@arizonahemophilia.org.

Member SPOTLIGHT

Imagine... you are whisked away in a limousine only to find yourself dropped off at the world renowned Bruce Wayne Research and Development Lab. This was a reality for our community member Aaden Ayres and his closet friends and family.

Aaden was treated to the ultimate crime fighting experience while exploring the lab and even got to drive the Bat Mobile! But being a Super Hero isn't just about cool cars and a cool lab - it's also about helping those in need. At the conclusion of the evening, Aaden received a check to present to the charity of his choice and he chose the Arizona Hemophilia Association!!!

We can't say thank you enough to Aaden and his family for their generosity and to the Colten Cowell Foundation that works with Bruce Wayne to put this together.



thank you

FOR YOUR FACEBOOK BIRTHDAY DONATION

Facebook has a tool that you allows you to donate your birthday to a non-profit of your choice. We want to thank everyone who donated their birthday to fundraise for the Arizona Hemophilia Association.

JULIE PYNE
BUTCH BROWN
CYN M.
DIANE LEE
SALLY GARRISON
BRITTANY PETTINGER
CASSIDY HOLLINGSWORTH
HARMONY CHIRSCO
ABEL FRANCO MORENO
ALEXIS NICOLE HIAVECK
SHERRY MINKS

ALL THE SALSA YOU CAN EAT AND MORE

Taste over 100 salsas prepared by Valley chefs and vote for your favorite.

Live Music, KidZone, Margaritas and More!



SLOAN PARK

2330 W. Rio Salado Pkwy., Mesa, AZ 85201

April 14, 2018

10:00am - 6:00pm

April 15, 2018

10:00am - 4:00pm

Admission

General: \$15

VIP Ticket: \$55

Kids under 12 are free

Discount tickets

Available at:

SalsaChallenge.com

Margarita Mix-Off

12:30 - 3:30pm

Main Stage

Live music all day



Watch some of the Valley's best bartenders shake it up in our Margarita Mix-Off Competition.

For more info: 602.955.3947 or SalsaChallenge.com

Funds raised will benefit the Arizona Hemophilia Association.

Across the STATE



Last year the Arizona Hemophilia Association made it a priority to reach our members across the entire state. We focused on hosting new events in Tucson, Yuma, and Northern Arizona. We had our Annual Meeting in Tucson last year, along with FAME nights and a Hispanic Heritage Day. This year our Annual Meeting will be in Flagstaff and our Women's Retreat will take place in Sedona. Another big accomplishment was hosting our own holiday party in Tucson and our first ever holiday party in Yuma!



While we work to make exciting programs and events happen close to everyone in Arizona, it's up to you to tell us your needs. We look to our community to provide feedback about what education would help you and how we can better serve your family.



If you want to make a difference, we've also started community committees in Tucson and Yuma. The focus of these committees is to strategize ways to improve our reach and plan new events throughout Arizona. We're always looking for fresh ideas and generous people who want to give back. Please call our office if that's you!



YOUNG ADULTS GROUP

We are so excited to announce that the AHA hosted our very first Young Adults meeting! The Young Adult Group is a peer-led social support group that consists of members from the Bleeding Disorders Community and their siblings ages 18 through 28. The purpose of this group is to create a support network for our young adults. It is a space where our young adults can honestly discuss their life challenges in a safe environment where their peers truly understand what they are going through.

On February 1st, our young adults were given the opportunity to share their own experiences on how they are affected by a bleeding disorder. The night included dinner and lots of discussion on topics that are affecting our young adults. Tony Hernandez was invited to be the evening's special guest. He kindly shared his personal experience of transitioning from a young person to an adult. Everyone had a great time and is looking forward to the next meeting.

Future meetings will include special guests, advocacy, fun outings and more. Living with or being affected by a bleeding disorder can sometimes be isolating and confusing. Speaking with peers can help gain new insights and support to make good changes and decisions in life. More importantly, it can lead to creating lasting friendships.

The group is a place to empower our young adults to work towards their goals. All young adults are always welcome to participate or just listen. If you or someone you know is interested in joining or has questions about our Young Adult group please contact us.

Save the Date

GRAND OPENING



Thursday April 19th
2pm - 8pm

Join us as the the Arizona Hemophilia Association and Biotek reMEDys celebrate the opening of AvasaRX

About AvasaRX

AvasaRX was created to assist in the dispensing of factor and other home infusion therapies

Why a Pharmacy?

The AHA creates a revenue stream where the profits made from factor and other home infusion therapies are reinvested back into the local bleeding disorder community.

AvasaRX | 480-900-7450 | info@avasarx.com | www.avasarx.com



25th Anniversary

By: Andy Blackledge Camp Co-Director

Camp HONOR started 25 years ago by the leadership of the Arizona Hemophilia Association, in partnership with the Hemophilia Treatment Centers in Phoenix and Tucson.

Mike Rosenthal was the Association's director at the time, and he started a camp committee to plan Arizona's first bleeding disorder camp. They first needed a name, so a contest was held. Andrew Heinze was the winner of the contest for coming up with the name and acronym for Camp HONOR (Hemophiliacs Overcoming New Obstacles Resourcefully), and was one of Camp HONOR's first campers!

Looking at the photo from the first year, I can see that Marilyn August, Lori Wagner, Barb Eady, Rachel Blackledge, Mary Lou Damiano, Isaac Provencio, Rick and Penny Murphy, Laurie Lamb, Karen Keogh, Yleana Hughes, and I were part of the original crew who made camp happen.

1994's inaugural Camp HONOR was held at Camp Charles Pearlstein in Prescott, Arizona. There were just over 50 campers – boys and girls with bleeding disorders and their siblings. Given our community's connection with the HIV community at the time, campers from the local HIV clinic were welcomed at Camp HONOR as well. That partnership continues today, and Camp HONOR has grown to over 125 campers!



Camp HONOR's early traditions included a camp-wide slime fight and a memorial tree planting, a talent show, camp songs, and fun final night dinner with a dance party.

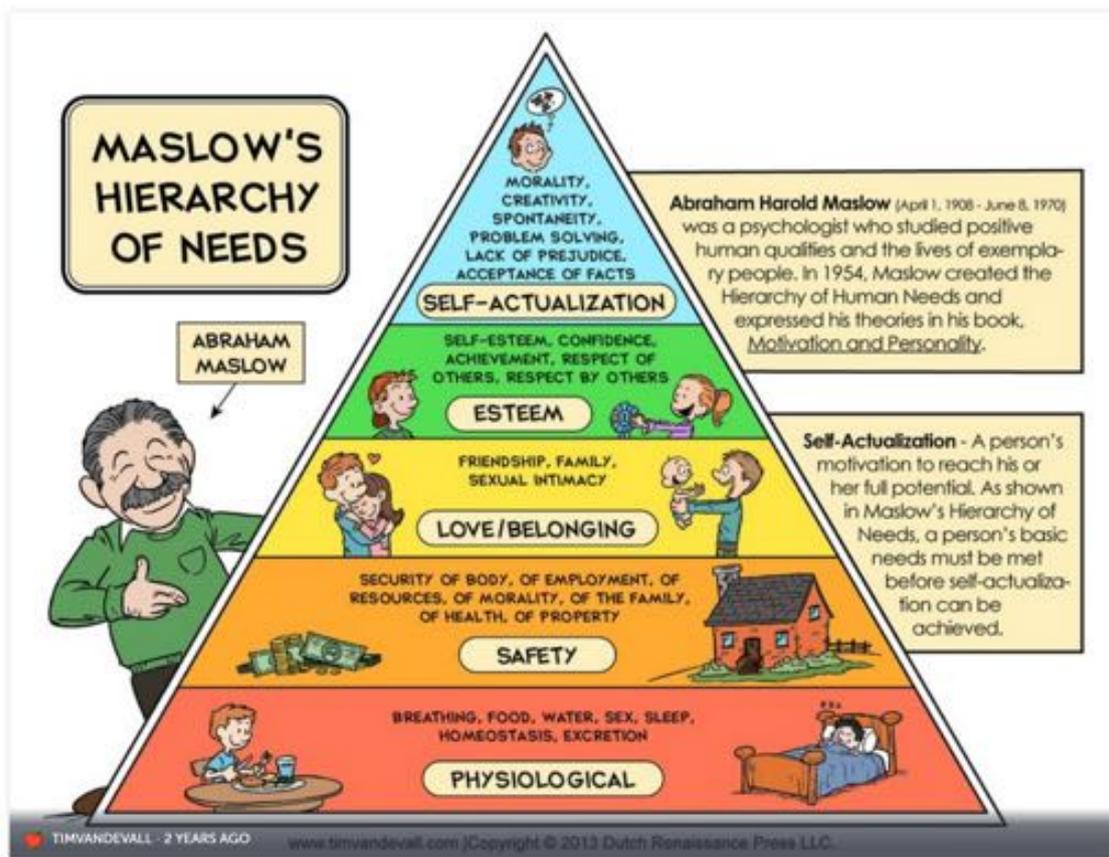
Independence with self-infusion has always been promoted and taught at camp by the medical team and continues today. Campers who can complete the infusion process independently are given the Big Stick award!



Camp HONOR is one of the biggest programs for the Arizona Hemophilia Association. We have over 80 volunteers attend to help the 125 campers have the best week of their life!

For our 25th year we will be at a new location, Lost Canyon Camp, in Williams, Arizona. The camp has used 5 different facilities over the years due to growth! But a camper's statement from years ago sums it up: "Camp HONOR isn't about where it is, but what it is."

At the Arizona Bleeding Disorders Health and Wellness Center, we strive to help you achieve your health goals. The “security of the body” is one of the most basic human needs. We know that with care we can reduce the burden of the bleeding disorder or health condition, to allow a person to grow and fulfill their desired potential. We pledge to partner with you and help you understand how your health affects the rest of your life and offer skills to improve your health. Health and “security of the body” is a key part of a happy, fulfilled human. If you have any questions, please give us a call at (602) 680-7722.



Simple things you can do to improve the health and security of your body:

- Meditate for 1-4 minutes every day
- Exercise for 30 minutes 4 to 5 days every week (yoga, walking, biking, swimming, gardening), anything that is fun for you
- Journaling for 5 minutes a day
- Drink 3 Liters of water every day (4 normal water bottles)
- Take a probiotic, purchase ones that are refrigerated
- Eat a small meal every three hours
- Avoid processed foods
- Eat 3 servings of fruits and vegetables every day

MAKE A NOTE

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CHANGING YOUR LIFE: SETTING GOALS

L.A. Aguayo and Chad White

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Motivational guru Tony Robbins says, “If you talk about it, it’s a dream. If you envision it, it’s possible. But if you schedule it, it’s real!”

How do you make a dream become reality? When we set a goal, no matter what it is, we focus on achieving it 100%. Creating Hemolife, bodybuilding, a competition, whatever the goal may be. We start by setting the target. Next, we want to document it: tell people our plans. This creates accountability. We would feel terrible, and would lose credibility and self-respect, if we told everyone we were doing something and then quit. Documenting our goal makes us work that much harder at it, even on days when we don’t feel up to it. We can reach our goal only by making ourselves vulnerable and accountable. So we show our journey toward our goal in the raw—on Facebook, Instagram, Snapchat—as it unfolds. We want to let people know that we are no different than they are, and that they, too, can reach their goals. This also can help inspire others. Goals take work, long and hard work, 24/7! We must do whatever needs to be done.

A great way to get started on a goal is to ask the most influential people you know for help. Get a team together if you can, and work together on your goal.

One important aspect of goal setting is to constantly reset your goals. When you achieve one goal, make another!

Don’t be afraid to fail; if you do fail, then adjust your goal as you go along. Maybe aim a little lower to create some small wins, or change up your schedule. Remember, if you do the same thing you’ve always done, you’ll get the same thing you’ve always gotten. If you’re experiencing difficulties repeatedly, then stop, evaluate, and make big changes. Failure isn’t an option with this mentality. It’s like climbing a hill or mountain that you thought was too high. Goals are a nonstop journey. If the goal is big enough, there will always be adversity and setbacks. That’s part of growing. Goals are not meant to be easy. Most people don’t even take the first step because it seems too hard and the results aren’t guaranteed.

If you’re experiencing success, great! Now double up on whatever it is you are doing.

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L.A. and Chad's Formula for Success!

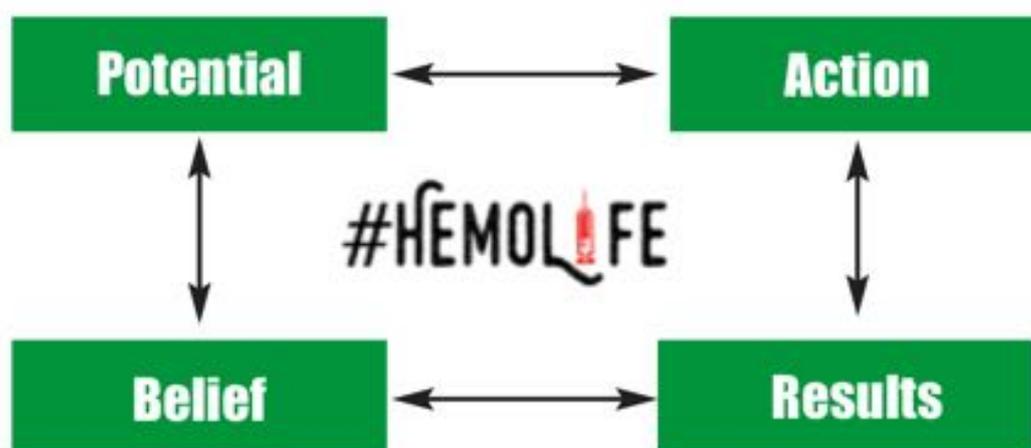
1. Choose a goal (no matter how big).
2. Define why you want it (your purpose).
3. Define what your desired outcome will be.
4. Decide on a timetable, and schedule it.
5. Find influential people who have achieved what you want and ask for advice.
6. Make a detailed plan to reach your goal and write it down.
7. Tell people your goals and document your journey.
8. Take massive action!
9. Don't be afraid of failure and be ready to adjust along the way.

CHANGING YOUR LIFE: SETTING GOALS

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Hemophilia is an obstacle, but not one that has the power to stop us. Our minds are stronger than that! Remember, the body can do anything the mind can convince it to do. If you have hemophilia, factor up regularly! Reaching a goal is worth it, and once you do, you'll be addicted to success. Nothing is more gratifying than setting a tough goal and achieving it. Make a solid plan on how to go through each step to the finish, and then knock off each step, one by one. Adversity along the way will create opportunity at the end.

Here's a mental framework we use to achieve our bodybuilding goals.



We all start off with some type of potential. Each person will be on a different level, but the potential is there; you just need to tap into it. When you realize you have that potential, you can take an action toward achieving your goal. And with that action, you'll get results. When the results are positive, you'll create new belief in yourself about the possibilities of achieving your goal. This new belief in yourself will increase your level of potential in return, giving you the ability to take a bigger action next time. The bigger action you take will get you bigger results, and the bigger results will create even more belief in yourself!

What if the results are negative? Go back to the action you took, reevaluate it, and take a new action. Keep the cycle going! If you keep repeating this process, you'll discover you're capable of accomplishing incredible things, because once your belief increases, you begin to develop new vision, which will create new goals.

Being with Hemolife is a dream come true. Not by magic, but by setting goals, and by hard work. Our next big goal is to speak at the World Federation of Hemophilia Congress! We believe it. So we know it's within our reach.

VOLUNTEERING

NEVER TASTED SO GOOD.

Come help make the Arizona Hemophilia Association's biggest event of the year a success. All volunteers will receive a volunteer shirt and free lunch.



SLOAN PARK

2330 W. Rio Salado Pkwy., Mesa, AZ 85201

April 14, 2018

10:00am - 6:00pm

April 15, 2018

10:00am - 4:00pm

We need volunteers to cover

- Ticket sales
- Event logistics
- Food and beverage sales
- and a whole lot more!

To register for a shift

Go to SalsaChallenge.com and click on "Volunteers"

For more info: 602.955.3947 or SalsaChallenge.com

Funds raised will benefit the Arizona Hemophilia Association.

MANAGING MILD HEMOPHILIA: BE PREPARED FOR THE UNEXPECTED

CAREFUL MONITORING AND PROMPT TREATMENT ARE ESSENTIAL

AUTHOR: NANCY MANN JACKSON

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When Sarah Watson was a toddler just learning how to walk, she stood up in her crib and accidentally bit her tongue. When her parents came to check on her, they were in for a shock: Both child and crib were a bloody mess. Because hemophilia runs in her family, Watson was tested and diagnosed as a symptomatic carrier of hemophilia A. Later, she was diagnosed with mild hemophilia, which can cause serious—and often unexpected—bleeds among both male and female patients.

“People with mild hemophilia are often surprised because they can go for such a long time and not have any problems, and then all of a sudden they have a bleed,” says Sue Geraghty, RN, who served for 25 years as nurse coordinator at the University of Colorado Denver Hemophilia and Thrombosis Center until her retirement in 2013. “Because they are not dealing with bleeds or infusions on a regular basis, sometimes it is hard for them to wrap their minds around the fact that they have a chronic illness.”

While the bleeds may be infrequent, there’s a concern that people with mild hemophilia may take their symptoms less seriously when they do have a bleed. Injuries or bleeds must be treated promptly, or they can lead to dangerous complications.

What is mild hemophilia?



Historically hemophilia has been thought of as a “man’s disease,” but some women who carry the hemophilia gene, like Watson, have low enough levels of factors VIII or IX (FVIII or FIX) that they also have hemophilia. These women often experience similar symptoms and complications as men with hemophilia.

Many people with mild hemophilia are not diagnosed until an injury, surgery or tooth extraction results in prolonged bleeding. Jeff Reichert, of Cincinnati, learned he had mild hemophilia when he was 14 and playing football. “When I was hit in the thighs, I had bleeds into my quadriceps,” he says. “We knew there was some hemophilia in my family, but I started learning how to live with it when I was 14.”

MANAGING MILD HEMOPHILIA: BE PREPARED FOR THE UNEXPECTED

CAREFUL MONITORING AND PROMPT TREATMENT ARE ESSENTIAL

Continued from page

Challenges of mild hemophilia

Mild hemophilia is not typically associated with the type of frequent bleeds and chronic pain often seen in severe hemophilia, but men and women with mild hemophilia face their own set of challenges. And those challenges do include bleeding and pain, as well as developing inhibitors and difficulty getting care.

As a child, Watson regularly had severe bloody noses and missed a lot of school. As she grew older, she struggled with joint pain. Recently, the 35-year-old from Detroit had complications while giving birth to her daughter.

Watson has not developed inhibitors—antibodies that neutralize infused factor—however, some 5% to 8% of people with mild or moderate hemophilia A do develop inhibitors, which creates additional complications to managing the condition.

Another challenge for people with mild hemophilia is the struggle to obtain proper insurance coverage. Reichert has always maintained health coverage through his employer, but he felt relieved when the Affordable Care Act removed lifetime caps and stopped insurers from denying coverage for pre-existing conditions. Although his bleeds are infrequent, he keeps treatment product on hand—and because it's considered a specialty drug and is regularly reclassified, he says he never knows how much he'll have to pay for it when he needs a refill.

Preparation

Because mild hemophilia is unpredictable, it's important to remain vigilant about monitoring and treating the condition. “One bleed can set someone up for issues later in life,” Geraghty says. “I think the biggest challenge is that they forget they have hemophilia, so when they have an injury, they think ‘injury,’ not ‘bleed!’”

Even if bleeds occur very rarely, a person with mild hemophilia should take time to find providers they trust and determine the best plan for managing complications when they arise.

To confidently tackle whatever may come next with mild hemophilia, “the key thing to know is the location of your closest treatment center,” Geraghty says. Always know which hospital in your area carries factor in its pharmacy, especially if you do not keep a treatment product in your home, to ensure that you can obtain prompt treatment, Geraghty says. “You should collaborate with your HTC to develop a treatment plan that you can implement if you have a problem. And remember your HTC is only a phone call away. So if you think you may have a bleed starting or are feeling some unusual pain, call the HTC and run it by them. Prompt treatment is important for all people with hemophilia. 16

congratulations & thank you

to the 9 young adults and Advocacy Committee members that joined us in Washington D.C for the Future Leaders Washington Days Trip.

Paul Heinrich
Cassidy Hollingsworth
Tyler Lipinski
Juan Pablo Lopez
Faith Mackenzie
Jessica Steed
Jessica Klass
Krissy Miller

Kierra Maher
Dillon Parsons
Nicole Perkins
Jeremiah Wolfer



Mark Your Calendars for Our
2018 Events!



Legislative Day - March 29th

Salsa Challenge - April 14th - 15th

Camp HONOR - May 25th - May 30th*

**Annual Meeting - Flagstaff
Sept. 7th - 9th***

Camp HUG - Oct. 5th - 7th*

Zombie Walk - Oct. 21st

Golf Tournament - Nov. 30th



Check Our Website for the
Full Calendar.

*Community events are open to all registered AHA members and
their affected immediate family residing in their household.

WWW.ARIZONAHEMOPHILIA.ORG

time, treasures, talents... we need your help

time

The Arizona Hemophilia Association relies on volunteers who want to make a difference for the bleeding disorders community. We have 4 fundraising events that we need help with – the Salsa Challenge, Golf Tournament, Zombie Walk, and Zoo Walk

treasures

Do you have old clothes that you want to donate? Donate them to the AHA! Do you have a car that you think isn't worth anything? Donate it to the AHA and we can get cash for your donation. If there is anything you're not sure about give us a call and we'll find a family that might need your old treasures.

talents

If you have a hidden talent we don't know about, let us know!



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Frank Schaffer- Secretary
Mark Boesen
Butch Brown
Tony Doan
Jim Durr
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Lindsay Bogard- Salsa Challenge Event Planner

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