

# Arizona Hemophilia Association Annual Report 2013



**Serving the bleeding disorder  
community in Arizona  
for over 45 years**



*The Arizona Hemophilia Association is dedicated to enhancing the quality of life for people with inherited bleeding disorders, while advocating for a cure.*

**Special Thanks to all of our sponsors, donors, volunteers and contributors throughout the year. We are grateful for your continued support!**



We would not be able to accomplish all that we do each year 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!

*The Arizona Hemophilia Association is a 501(c)(3) non profit organization as well as a Qualifying Charitable Organization in the state of Arizona. Tax ID 86-0209257.*

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## **Contact Us Today!**

**(602) 955-3947**

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# Message From our Board President

Welcome to our Annual Report!

On behalf of the Board of Directors of the Arizona Hemophilia Association (AHA) and our staff I want to thank all of the volunteers and community members for their support in 2013. Without you everything that AHA accomplished in 2013 would not have been possible.

In 2008 I first became active in this organization. Working with you has been both fun and rewarding. On my own behalf I want to thank all of the volunteers and community members that I have met for their support, humor, and understanding of the impact of a bleeding disorder on a person.

One of my favorite things to do is visit the AHA office at 826 N. 5th Ave., in downtown Phoenix. It is served by the Phoenix bus system, close to the Light Rail and 4 blocks off the I-10; so easy to get to. Cindy, our Executive Director, has accurately dubbed it to be the 'Community Home' and I think that it is.

In addition to the many programs, events and conferences which the AHA has been putting on over the years, in 2013 it expanded its activities as follows. AHA worked with the Governor's office and other non profits to persuade the State to reinstate AHCCCS coverage for single adult males. We continued our Twinning project with the country of Macedonia and continued to learn how poor the care is in some areas of the world. We also participated for the first time in the AZ Beer Fest and, in addition to raising money, educated the general population of the issues surrounding the bleeding disorder community.

In closing I want to extend an invitation to each of you to call or email any of the board members with your questions or concerns.

Best,

*Steve Helm*

President, AHA Board of Directors



# PROGRAMS

*The Arizona Hemophilia Association provides several programs throughout the year for all age levels and interests. We strive to best meet the needs of the bleeding disorder community.*

## Social Groups

**B**leedHERs is an adult social and educational group for women with bleeding disorders, as well as carriers, mothers, wives, daughters and sisters of individuals with inherited bleeding disorders. We had quarterly meetings this past year and had an average of 30 women attend each event. The women enjoyed time at Brush Party, Dream Dinners, and Cibo while learning about balancing work and life as well as shopping and cooking on a budget. They also built support baskets for parents who have a child in the hospital.

**B**lood Brotherhood is in conjunction with the Hemophilia Federation of America. This program is designed for adult men with hemophilia and von Willebrand Disease. It is a multi-avenue outreach program that provides education, social support and a sense of community through online forums, face-to-face local meetings and National Blood Brotherhood Webinars. We held several programs this year with an average of 25 men attending each event. The men learned about physical therapy and healthy aging while biking from Phoenix to Tempe and enjoying an Arizona Cardinals game.

**N**ew Family Mentoring is for families recently diagnosed with a bleeding disorder or new to our community. It matches the new family up with another family who has a bleeding disorder to help them learn to navigate the ins and outs of having a bleeding disorder. We are working in partnership with the Hemophilia Treatment Center in Phoenix.

**H**APY (Hemophilia Program for Youth) is an educational and recreational program for youth ages 8 to 17. HAPY builds a caring community, along with self-esteem, while increasing our youth's knowledge of bleeding disorders. This past year we went to Make Meaning, Dave & Busters, and the Arizona Science Center.

**S**panish Speaking Support Group is a social opportunity for our Spanish speaking families. Education and sharing is provided in Spanish. We provide programs in Spanish twice a year in addition to the Annual Statewide Meeting. We had over 100 attendees for our event in September called Hispanic Heritage Day.

**E**PIC provides an opportunity for the developing teens in our community to start their own epic journey and discover their inner hero. The purpose of the program is to create outlets for getting involved in the bleeding disorder community as well as analyze better ways to get involved in their immediate communities, and take a proactive approach to their young-adult lives. This past year the youth learned about paying for college and speaking up for themselves while exploring downtown and rock climbing.

## Educational Retreats

**Women's Retreat** is an educational and social event focusing on issues faced by those who have a bleeding disorder as well as carriers, mothers, wives, daughters and sisters of individuals with inherited bleeding disorders. It provides support and education to women in a relaxing environment. There were 28 women who attended.

## Camp Programs

**Camp HONOR** is a week-long summer camp for children in the inherited bleeding disorder community, ages 8 – 17 years. This program integrates patients and their siblings in a program of fun, caring, education, guidance, and self-empowerment. There were 125 children who attended and over 80 staff at Camp Sky Y in Prescott. We celebrated our 20th anniversary year of camp with a Homecoming theme. Campers honored those who came before them and we invited former campers, staff and their families to attend the final evening celebration.

**Camp HUG** is a family camp for families affected by inherited bleeding disorders. It provides education and fun for the entire family and gives parents the opportunity to see what camp is all about. It introduces young children to camp life and brings Camp HONOR kids back together. We had over 25 families attend at the YMCA Camp Chauncey Ranch in Mayer, AZ.

**CIT (Counselors in Training)** program is our leadership program focusing on Camp HONOR campers ages 16 and 17. The program focuses on preparing our campers to become leaders in camp and in life. This past year we had 14 teens participate.

## All-Community Programs

**Annual Statewide Meeting** is an education event that provides opportunities for individuals and families affected by inherited bleeding disorders to learn about their bleeding disorder and how to better manage it as well as meet and share with other community members. We had over 250 folks attend from across the state. It was held at the Pointe Hilton Squaw Peak.

**Holiday Party** is a social get together to celebrate the holiday season and get a chance to see old friends, meet new friends and ring in the new year. Fun for the whole family. We had over 300 attend in Phoenix and over 100 attend in Tucson.

**Camp Picnic** is an event for everyone to learn more about Camp HONOR and Camp HUG, with fun activities for the kids and adults. It is held in the spring every year and is attended by approximately 100 families who want to learn more about going to camp.

**Educational Series** are learning events offered throughout the year in partnership with pharmaceutical companies and home health care organizations to bring relevant and meaningful education to the bleeding disorder community.

# SERVICES

*The Arizona Hemophilia Association provides several services throughout the year to best meet the needs of the bleeding disorder community.*

**Hemophilia Treatment Center Collaboration and Support** where staff at AHA attends comprehensive visits and has a strong partnership with the HTC's both in Phoenix and Tucson.

**Client Services** include assistance to medical visits, English/Spanish interpretation, and support for physical, medical, and social services assistance.

**Education Services** includes assistance with school visits to educate teachers, administrators and medical staff about bleeding disorders. We can help identify the need for Individual Education Plans (IEP) and 504 Plans. We can help educate daycare workers and pre-schools about how to manage a child with a bleeding disorder.

**Scholarship** identification, application and submission assistance is available for Colleges, Universities and Trade Schools.

**Lifeline** provides financial assistance with insurance premiums, gaps in coverage, COBRA premiums, and medical, dental and vision bills.

**Insurance Annual Review** provides assistance in reviewing and interpreting insurance 'language' to help you make the most appropriate choices on coverage for you and your family. AHA works in partnership with Phoenix Children's Hospital in providing this service to you.

**Emergency Financial Assistance** is available to families or individuals who find themselves in a crisis situation. The assistance is limited and is not intended to be on going.

**DNA Testing** is available on a limited basis to find out where the genetic mutation is on the DNA strand to assist in family planning. This service is provided in partnership with Hemophilia Treatment Centers.

**Transition Mentorship Program** provides assistance to teens and young adults affected with a bleeding disorder in transitioning from youth to adulthood. Its purpose is to develop essential real-world life skills that empower them to become successful independent adults. Its focus is on working together to develop an individual plan with goals and steps for achievement. Assistance in career planning, life planning, daily living skills, school, tutoring, and personal growth are among the services offered.

**Resource Center** is where community members can get connected to other resources for education, career, life skills, parenting skills, and insurance.

**M**edic-Alert bracelets are provided for first time enrollees who have a financial need. It is very important to have a bracelet in the case of an emergency.

**S**cholarships to National Hemophilia Foundation and Hemophilia Federation of America annual meetings are provided by AHA. This year a family was selected for each conference with all expenses paid by AHA.

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## ADVOCACY

*The Arizona Hemophilia Association advocates to promote access to healthcare, to create greater awareness about those living with bleeding disorders, and to build relationships with policy makers. The Arizona Hemophilia Association empowers our members to advocate for themselves.*

**M**edicaid Expansion: AHA was instrumental in championing the Medicaid expansion in Arizona. One of our community members, Brent Davila, spoke at the Governor's rally last May and was also featured on television news. AHA partnered with other non-profit agencies and the governor's office to help get the expansion passed. Fortunately, it passed in June restoring coverage to many childless adults with bleeding disorders and providing access to health care to many Arizonans living with a chronic bleeding disorder.

**L**egislative Day is a day at the state capitol where we set up legislative appointments for our members to meet with their legislators. We also have a lunch on the capitol lawn with our legislators and have an opportunity to make them aware of the needs of our bleeding disorder community. Last year our focus was to advocate for the Medicaid Expansion. We had over 50 legislative appointments.

**A**mbassador Program is an opportunity to become an ambassador for those affected by a bleeding disorder to our state legislators and public policy makers. We match participants with their legislator to build relationships and create greater awareness of the needs and concerns of those with a bleeding disorder.

**V**olunteer Speakers Bureau consists of members from our inherited bleeding disorder community who have been trained to speak to groups about bleeding disorders and on behalf of the AHA. Its purpose is to build a greater awareness with the general public.

**A**dvocacy Training is provided to empower our community to take action and let their voice be heard. Experts come in and provide education on what issues could affect us, learn how the legislature operates, and how we can make an impact. It explains the key talking points that we want to address with our legislators when we meet with them.

**A**dvocacy Summit: AHA hosted a meeting with all key stakeholders in Arizona to discuss the healthcare reform issues and its impact on those with bleeding disorders in Arizona. We explored ways to collaborate together in ensuring our community has access to healthcare.

# CONFERENCES

*The Arizona Hemophilia Association hosts national conferences that benefit the bleeding disorder community both nationally and locally.*

**NACCHO:** AHA hosts NACCHO (North American Camping Conference for Hemophilia Organizations) held in Tempe, Arizona in January each year. The conference has over 200 attendees from all around the world. We celebrated the 11th year of NACCHO. The conference is funded through a grant from Pfizer.

**NOW:** The 2nd Annual NOW (National Outreach for von Willebrands) conference was held at the Pointe Hilton Squaw Peak with over 190 attendees, including families from around the country. The conference is funded through a grant from CSL Behring.

**Fundfusion:** Now in its 7th year, Fundfusion was held in August at the Pointe Tapatio Cliffs. It is a fundraising workshop bringing together chapters from around the country to learn how to better fundraise, share ideas and collaborate with one another. The workshop is funded through a grant from Baxter.

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# FUNDRAISING EVENTS

*The Arizona Hemophilia Association organizes several fundraising events throughout the year to raise awareness and support our programs and services.*

**Salsa Challenge:** The Salsa Challenge is a culinary festival with over 100 salsas prepared by individuals and professional chefs competing to become the Grand Champion. It was held at Tempe Beach Park and hosted over 20,000 attendees. AHA organizes and runs this large event with over 300 volunteers and wonderful partners. It is held in the spring each year.

**Salsa Challenge 5K – Too Hot To Trot!:** Last year we held our second 5K run in conjunction with the Salsa Challenge. We had over 600 participants! They received free entry into the Salsa Challenge, a T-shirt and a margarita after the race.

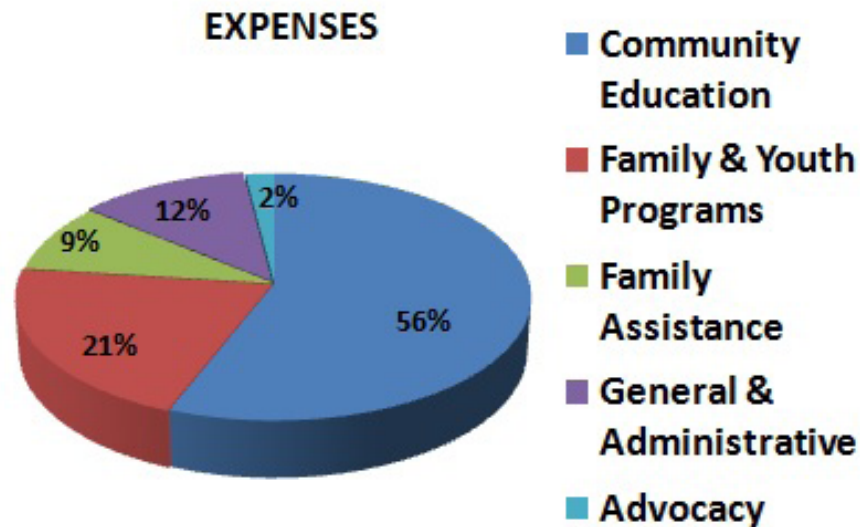
**Arizona Hemophilia Walk:** We held our 6th Walk at the Phoenix Zoo in November with over 1,200 walkers. All participants got free entry into the zoo for the day!

**AHA Charity Golf Tournament:** We held our 13th annual golf tournament in November. It was held at the Arizona Grand Resort with over 120 golfers.

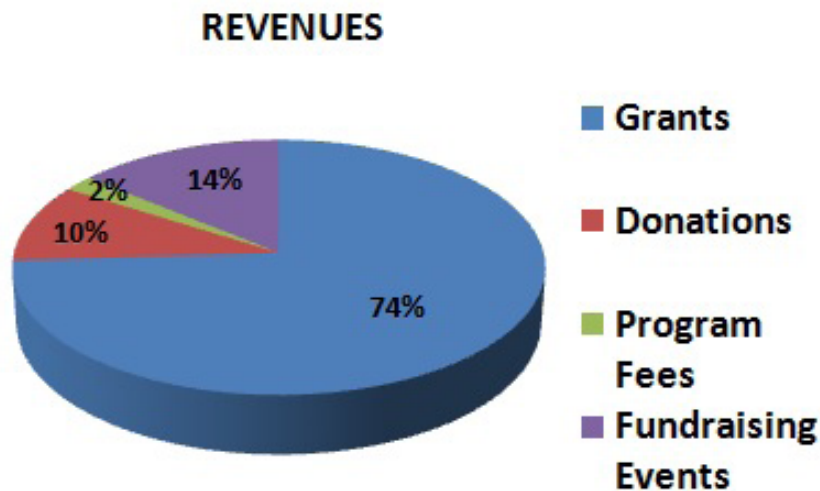


# How Your Gifts Help

*Each year the Arizona Hemophilia Association makes decisions and sets goals for how our resources are used to provide a range of services to persons with bleeding disorders and their families. The Board of Directors establishes long range plans and annually approves the budget and programming to achieve those goals.*



# Where Does Funding Come From?



## Affiliations/Memberships

*The Arizona Hemophilia Association is affiliated with the National Hemophilia Foundation and is a member of the Hemophilia Federation of America.*



**NATIONAL HEMOPHILIA FOUNDATION**

[www.hemophilia.org](http://www.hemophilia.org)



Hemophilia Federation of America™

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## Communications

**“Get Infused” monthly e-newsletter:** Our electronic newsletter includes current activities, upcoming events, news articles of significance, stories from our community members, updates on advocacy issues and other resources available in and around Arizona.

**Mailed Newsletter:** In an effort to save costs and become more environmentally friendly, we are mailing a newsletter twice a year which will provide a summary of the e-newsletters.

**Social Media:** You can find us at [www.arizonahemophilia.org](http://www.arizonahemophilia.org), Facebook and Twitter.

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## Ways to Get Involved

**T**ime: We are always looking for Volunteers to help with various events and office work. We appreciate your time in working with us. We have over 300 volunteers that help AHA annually. If you are interested, please complete the volunteer form on our website. We have opportunities to serve on our board of directors, fundraising, advocacy, or communications committees. We also have committees for our largest activities, including Camp HONOR, Salsa Challenge, Charity Golf Tournament and the Arizona Hemophilia Walk. Please let us know if you would like to get more involved!!!! There is something for everyone!

**T**alent: We partner with many people and organizations that have a service that can help us. Your experience and expertise is much appreciated! With all of our activities, we need speakers, building repair services, computer assistance, financial planning, healthcare, etc. Please just reach out if you think you might be able to help!

**T**reasures: We are a non-profit organization that relies on the generosity of individuals and corporations to support our mission. Any assistance you can provide in helping us raise those needed funds is appreciated! Whether it is by making a donation, putting us in touch with your employer or someone you know who could become a sponsor or donor, or helping us fundraise, every effort helps!

*Thank you again for supporting the Arizona Hemophilia Association!!*



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# 2013



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**Arizona Hemophilia Association**  
**826 N 5th Ave**  
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***Special Thanks***  
**to all of our sponsors, donors, volunteers and**  
**contributors throughout the year!**  
**We are grateful for your continued support!**