Hello Families,

I can’t believe that we are in December already! This has been a very busy and exciting year for the AHA. We are proud that we were able to provide many events and programs for our families this past year. Some mentions include our educational FAME nights which were presented all around the state. We sent 8 future leaders to Washington DC, hosted 30 families at Camp Hug and sent 120 children to Camp HONOR. We also held our Annual Meeting in Flagstaff for the very first time.

It must be said that without the support of our sponsors and our community this would not be possible. We would like to thank all of you who have volunteered in many different ways to the AHA. We appreciate your time and all of your efforts to ensure that our events and programs are successful. As we gear up for an exciting 2019 we encourage you to share your ideas with us and get involved. It is important that we hear from you so that we continue to meet the needs of our community.

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...

We are here for you and it is our wish that we are able to connect with each and every one of our members in the upcoming new year.

We are kicking off 2019 with very important advocacy educational programs. Our Advocacy Committee works hard to monitor issues on both the state and federal level that impact our bleeding disorders community. It is our hope that we see more of our members getting involved with our advocacy efforts. We ask that you join our committee and participate at our Legislative Day which is scheduled for April 1, 2019.

On February 24th we will be holding our annual Arizona Hemophilia Zoo Walk and we hope to see all of you there. Please keep an eye out for more information on these two upcoming events. We will also be sending you lots of information on fun, interesting and exciting programs and events for the upcoming new year.

On behalf of Team AHA we want to wish you all a happy holiday season and a Happy New Year!

With Gratitude,
Cristina Barnes

*thank you FOR YOUR DONATION*

This section includes general donations, monthly donations, annual tax campaign donations, and Giving Tuesday donations.

Marilyn August
Elizabeth Blackledge
Mark Bosen
Tonya Branaghan
Robin Forrester Brown
David Cabrera
Guilermo Campillo
Annette Copeland
Nathaniel Curtis
Angel Diaz

Tony Doan (Honoring former board member Butch Brown)
Stephanie Doughty
Kathleen Esguerra
Tj Evans
Margaret Goggins Filo (In Memory of Alexander Pond)
Sara Gale
Steve Helm
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Amy Kahler
Mark Kaplan

Keith Katz
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Melinda McGuire
Alexas Mckinney
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Julie Pyne
Jason Richards
Robert Schoenbachler
Mandy Short
Michele Steed
Jessica Steed
Patrick Sullivan
Gary Sutherland
Bonnie Swain
John Thorson
Koha Tran
Soyla Valenciano

Facebook has a tool that allows users to raise funds on their birthday by requesting donations to their charity of choice. The following people donated their birthday to our Association and raised funds to help support our community programs and events. From the team at AHA with sincerely thank your for your support and hope you had an amazing birthday!

Chetan Bafna
Chiane Bond
Felicia Carrasco
Mike Caruth
Nikki Cole
Vanessa Freemore
Alifonazo W Garcia

Lupita Garcia
Petra Garcia
Chelsea Guffy
Michael Guffy
Blanca Herndon
Katie Nevarez-Daigneault

Carolina Neely
Gloria Perry
Natalie Ratliff
Cosette Reimann
Alicia Lee Scott
Lara Seitz
Camp HUG, held at Prescott Pines Camp, hosted 35 families this year! HUG stands for Hemophilia Uniting Generations, which is exactly what we aim to do at camp. We encourage families to bond as a community through education and programming. This year’s camp, our families participated in canoeing, zipline, gaga ball, human foosball and many other outdoor activities. Our theme this year was Families Towards Tomorrow which we celebrated with some futuristic science experiments such as crystal growing, glow in the dark slime and lava lamps. One Sunday, everyone was surprised to wake up to snow! We always love our time in the pines with our families and enjoy coming together as a community. We are already looking forward to next year! See photos on next page!
What type of performances do you do?
"Musicals"

How did you get into performing?
"I've always loved singing and music. When I found out you could mix the two I was excited. Musicals also interested me because there are so many different genres of music in them. I got into performing musicals in the 4th grade at a local performing arts studio."

What kinds of obstacles have you had to overcome?
"I just got done with a major surgery and there was a lady who said “Don’t put her in a major role because you don’t know how her health is going to be”. It was hard to hear with everything I had going on because I never missed a rehearsal. I still showed up everyday and gave it my all."

What advice do you have for people wanting to start performing?
"Make sure you love what you’re doing! If you don’t get a lead role, keep trying."

Do you have any big goals in life?
"To make it to Julliard and Broadway."
Dana is a Kansas City, MO native, but Arizona is her home now. She is so grateful for this amazing, beautiful community. Her goal is to help every patient leave with the confidence and education to take control of their health and make it a team effort to be on track to living a healthy life.

Dana has been a Registered Nurse for over 23 years and a Family Nurse Practitioner since 2015. In 1995 she graduated from the University of Central Missouri with a Bachelor of Science in Nursing (BSN). After working as a Post-op nurse for many years, she then went on to receive a Master’s of Science in Nursing (MSN) as a Nurse Educator at the University of Central Missouri in 2009. She was a Nurse Educator for LPNs in Missouri, and then moved to Arizona in 2011 to teach for the University of Phoenix LPN to BSN nursing program. In 2015 she received her Master’s Degree as a Family Nurse Practitioner.

She has worked in Family Practice, Urgent Care, and she currently owns her own business in Dermal Aesthetics in Gold Canyon. She is committed to helping out the communities around her and has a passion for treating her patients as a whole. Her philosophy is to treat patients with dignity, understanding and empowerment. Patients need to be on top of their own health—but know that she will be there to organize and facilitate anything needed to diagnose, treat and cure most ailments. Education is the key and she will help teach, facilitate, and refer to those who can assist with the total care of the patient.

Dana has 2 children—ages 28 and 30—and a very active 4 year old grandson! Her family is very important to her and she is grateful to have her family close while enjoying a career that she loves. She is happy to be a part of this great community and would love to be your primary care provider!
Arizona Hemophilia Zoo Walk

Come out to the 10th Annual Zoo Walk fundraiser!

Sunday, February 24th, 2019
8am - 10am
At the Phoenix Zoo

Create a team and spread the word! Our fundraising goal this year is $75,000!

Register at walk.arizonahemophilia.org

Arizona Hemophilia Association

Register by January 20th to be eligible for a 2019 Walk shirt!
Giving Tuesday is a global day of giving fueled by the power of social media and collaboration. Celebrated on the Tuesday following Thanksgiving (in the U.S.) and the widely recognized shopping events Black Friday and Cyber Monday, #GivingTuesday kicks off the charitable season, when many focus on their holiday and end-of-year giving.

We want to express our gratitude for showing up on #GivingTuesday! This small-but-mighty non-profit is blown away by your support and generosity! While we didn’t make our goal of $1,500, we ended very close with $1,270 raised in ONE DAY. Because of your help we can provide more services and programs to the bleeding disorders community. Thank you from the bottom of our hearts!
The 13th Annual Statewide Meeting was held at the Little America Hotel in Flagstaff. We were happy to be able to move this meeting up North where our members were able to enjoy a beautiful venue and a chance to get away from the summers heat. The meeting kicked off on Friday night with a nice buffet dinner. After dinner, members attended sessions with pharmaceutical companies to hear the latest news about their products. Saturday began with an appreciation ceremony. We were pleased to acknowledge members of our bleeding disorders family whose passion and dedication to our community were honored with a special award. Monse Sotelo received the Volunteer of the Year award, Jessica Steed received the Advocate of the Year award, Yleana Hughes received a 25 Years of Service award, and Cindy Komar was given an award of Appreciation for her passion, unconditional commitment, and enduring dedicated service to the AHA. After the awards ceremony members attended a keynote titled “The Science of Stress and how we can manage it” which was presented by Dr. Ronesh Sinha. Educational sessions included information on stress, vonWillebrand Disease, nutrition, gene therapy and much more. We ended the day with a BBQ outdoors surrounded by beautiful pine trees and perfect weather. Sunday morning started with breakfast and members attending more educational sessions followed by a keynote on “Rebuilding a Solid Foundation in Life” that was presented by Jerry Ervin. The weekend wrapped up with a closing ceremony which included our raffle. Families won many fun items including staycations, tablets and much more. This Annual Meeting was a great success and we look forward to the next one. We want to thank all of our sponsors who helped make this meeting possible, there support means so much. We would also like to thank the families who attended, we hope that you enjoyed your weekend as much as we enjoyed seeing you. We look forward to our next Annual Meeting which will be held in Phoenix. Be on the lookout for more information in the coming months.
UNLOCKING YOUR SELF-POTENTIAL

ONLY ADVATE® HAS 15 YEARS OF EXPERIENCE IN THE REAL WORLD AS A RECOMBINANT FACTOR VIII

- Proven in a pivotal clinical trial to reduce the number of bleeding episodes in children and adults when used prophylactically.
- Third-generation full-length molecule, similar to the factor VIII that occurs naturally in the body.
- Multicenter, open-label, prospective, randomized, 2-arm controlled trial of 52 previously treated patients with severe to moderately severe hemophilia A. Two different ADVATE prophylaxis regimens (standard, 20-40 IU/kg every 48 hours, or pharmacokinetic-driven, 20-80 IU/kg every 72 hours) were compared with on-demand treatment. Patients underwent 6 months of on-demand treatment before 12 months of prophylaxis.

The market leader in hemophilia A treatment (Based on 2016 data published July 2017)

Learn more at ADVATE.com

ADVATE Important Information

What is ADVATE?
- ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called “classic” hemophilia).
- ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A. Your healthcare provider (HCP) may give you ADVATE when you have surgery.
- ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).
- ADVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADVATE?
Do not use ADVATE if you:
- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.
Tell your HCP if you are pregnant or breastfeeding because ADVATE may not be right for you.

What should I tell my HCP before using ADVATE?
Tell your HCP if you:
- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADVATE passes into your milk and if it can harm your baby.
- Are or become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What important information do I need to know about ADVATE?
- You can have an allergic reaction to ADVATE. Call your HCP right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, light-headedness, dizziness, nausea or fainting.
- Do not attempt to infuse yourself with ADVATE unless you have been taught by your HCP or hemophilia center.

What else should I know about ADVATE and Hemophilia A?
- Your body may form inhibitors to factor VIII. An inhibitor is part of the body’s normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

What are possible side effects of ADVATE?
- Side effects that have been reported with ADVATE include: cough, headache, joint swelling/aching, sore throat, fever, itching, unusual taste, dizziness, hematuria, abdominal pain, hot flashes, swelling of legs, diarrhea, chills, runny nose/congestion, nausea/vomiting, sweating, and rash. Tell your HCP about any side effects that bother you or do not go away or if your bleeding does not stop after taking ADVATE.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.
For additional safety information, please see important facts about ADVATE on the following page and discuss with your HCP.

For Full Prescribing Information, visit www.ADVATE.com.


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S40727 07/18

Shire

[Antihemophilic Factor (Recombinant)]
**Important facts about ADVATE [Antihemophilic Factor (Recombinant)]**

This leaflet summarizes important information about ADVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADVATE. If you have any questions after reading this, ask your healthcare provider.

**What is ADVATE?**
ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called “classic” hemophilia). The product does not contain plasma or albumin. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A.

Your healthcare provider may give you ADVATE when you have surgery. ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

**Who should not use ADVATE?**
You should not use ADVATE if you:
- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

Tell your healthcare provider if you are pregnant or breastfeeding because ADVATE may not be right for you.

**How should I use ADVATE?**
ADVATE is given directly into the bloodstream.

You may infuse ADVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADVATE to use based on your weight, the severity of your hemophilia A, and where you are bleeding.

You may have to have blood tests done after getting ADVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

Call your healthcare provider right away if your bleeding does not stop after taking ADVATE.

**What should I tell my healthcare provider before I use ADVATE?**
You should tell your healthcare provider if you:
- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

**What are the possible side effects of ADVATE?**
You can have an allergic reaction to ADVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Side effects that have been reported with ADVATE include:
- cough
- headache
- joint swelling/aching
- sore throat
- unusual taste
- diziness
- hematomas
- abdominal pain
- hot flashes
- swelling of legs
- diarrhea
- chills
- runny nose/congestion
- nausea/vomiting
- sweetening
- rash

Tell your healthcare provider about any side effects that bother you or do not go away.

These are not all the possible side effects with ADVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

**What else should I know about ADVATE and Hemophilia A?**
Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

Medicines are sometimes prescribed for purposes other than those listed here. Do not use ADVATE for a condition for which it is not prescribed. Do not share ADVATE with other people, even if they have the same symptoms that you have.

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADVATE. The FDA approved product labeling can be found at www.advate.com or 1-888-4-ADVATE.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

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Shire
The AHA hosted another successful NOW conference this past November at the beautiful Pointe Hilton Squaw Peak Resort. The NOW conference is in its 7th year, with 2 conferences a year for the last 4 years. 180 attendees from across the country attended. The weekend was jammed pack with information, speakers included a keynote presentation from Dr Montgomery on What is VWD and Why Do I Bleed?, sessions by Dr. Sinha on The Science of Stress and How to Manage It, and Pamela Crim spoke on The wild ride of life. Bella Viner preformed a session on Sunday to get everyone up and Dancing. The attendees enjoyed beautiful weather, great food, and phenomenal presentations. The children were entertain by Jungle Jill, a Magician, Art Workshop, even the Phoenix Zoo brought some critters for the children to see. It is such an honor to be able to host the NOW conference and to hear the stories of the attendees that appreciate the information presented to them and how “life changing” this conference is. We are looking forward to the May conference. Thank you to CSL Behring for sponsoring this amazing conference!

Congratulations,
Yleana Hughes!

Our very own, Yleana Hughes, was recognized by Camelback Ford and Lincoln for her dedication to the Hispanic community. We are grateful for her service to the Arizona Hemophilia Association and congratulate her on this wonderful achievement!
Be a Part of Making Tough Decisions Now

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Written by Steve Place

I have lived for 64 years with mild hemophilia and have voluminous experience, from which I came to my own rock-solid conclusions about how someone with a bleeding disorder can participate in sports and other potentially life-changing activities.

One experience was a significant life change at age 10. When I sustained a serious head injury, I felt able to ride my bike with no hands. Sand and a quick moment of unbalance tossed me off my bike, and my head hit the pavement hard.

I got myself up and walked back home with my bike. My sister saw me and screamed. That’s when I felt a huge lump on my forehead and knew I was in trouble. Our doctor, who made house calls, wrapped my head with a pressure bandage and told my parents to give me two aspirin every four hours and added that if I made it through the night, I probably would be all right. Aspirin and all. I survived.

All of a sudden, I was prohibited from participating in contact sports. This is tough for a 10-year-old boy. Although I was always the smallest kid in my class and the last to be chosen at sports, it still hurt. Fortunately, my mom and dad and sister were very supportive, and we got through it together. They steered me to other avenues that led me to a happy, healthy, and productive life. I thank God every day for my hemophilia.

I look back and wish I could have accepted at age 10 what I strongly believe about my bleeding disorder today. I went from “Boo-hoc, I can’t do certain things!” to “Drop back, punt, and come up with a new plan.”

Now that may sound a bit harsh, but the sooner we accept our limitations in life and pursue the best and safest path, the better off our lives and our families’ lives will be. Yes, we must think about our families, too; it’s not all about the person with hemophilia. Every person with a bleeding disorder has affected and will continue to affect the lives of those we love most. Our bleeds seem to come at the most inconvenient times, for us and for them!

It was traumatic when at age 10. I had to stop doing the things my buddies were doing. But here I am today, happy, married for 40 years with two daughters, successful, and in excellent health. I am physically active in my daily pursuits.

I am a professional handyman and sole proprietor, and I work daily with all types of sharp tools, both power and manual. Safety and thinking through a job are paramount. Knee pads and elbow/forearm protection are vitally important. The most dangerous tool in my toolbox is a dull blade.

I treat on demand and prior to some potential bleeding situations. I have 95% mobility in all of my joints. The only time I infuse, apart from surgery, is when I make a mistake.

We all want to be the best parents we can be for our kids. Good, tough parenting and steering today can result in a wonderful life later on for them. I made a very strong, positive personal decision that has guided my life for the last 50-plus years. I decided that I will respect my disorder, but I will not be afraid of it. I will determine what I will do, and what I will not do. I basically took charge of my life.

Steve is 64 and has been married for 40 years. He has two adult daughters, and works 50 hours a week. He is active in his church, both teaching and leading. He believes that life is great, especially when “I respect my disease, but am not afraid of it.” sclplace122@comcast.net
Hispanic Heritage Day in Phoenix on September 23, 2018 was one for the books! We began the event with a talk on resilience. Other presentations throughout the day included financial planning, dental health and pain management. The children had an amazing time with activities that included arts and crafts, a balloon workshop and a game truck. The children ended their day with Denise “Bella”, a local dance instructor who helps at-risk children in Arizona. For our closing, the children showed off what they learned to the adults. It was a great day to celebrate our Hispanic Heritage. A big thank you to Shire for sponsoring this educational day!
No-Show Policy

As our community continues to expand, the Arizona Hemophilia Association (AHA) is implementing new policies to accommodate our growth. On September 7th, 2018, a no-show policy was applied to better serve our community. The AHA lost over $28,000 in no-show costs in the last year and $47,000 the year before.

Please be aware of the new no-show policy. It will be strictly enforced.

If you do not show up to an AHA event that you registered for without notifying an AHA staff member via phone call or email within 72 hours of the event, you will then be placed on a wait list for the next scheduled AHA event that you have registered for and the following like-event that you missed. For example: If you registered and do not show up to Annual Meeting without notifying AHA within 72 hours of the first day of Annual Meeting, you will be wait-listed for the next event that you have registered for and be wait-listed for the next Annual Meeting.

If you have any questions, please feel free to contact the Member Services Department. We value your support and participation. We look forward to seeing you at our future events!
Mark Your Calendars for Our 2019 Events!

FAME- Tucson: February 1st

FAME- Phoenix: February 5th

Zoo Walk: February 24th

Bleeding Disorders Awareness Month Kickoff BBQ: March 8th

FAME-Phoenix: March 12th

FAME-Tucson: March 15th

NHF Washington Days: March 26-30th

Legislative Day: April 1st
time, treasures, talents... we need your help

The Arizona Hemophilia Association relies on volunteers who want to make a difference for the bleeding disorders community. We have 3 fundraising events that we need help with – the Salsa Challenge, Golf Tournament, and Zoo Walk. If you are interesting in helping the AHA please give us a call!

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.

If you have a hidden talent we don't know about, let us know! We are always looking for talent to assist us with our events and programs.

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