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

Thank you to all of our donors, sponsors, volunteers and contributors. We are grateful for your continued support!

Do you want to Make a Difference?

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.

Contact Us Today!

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

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Message From our Executive Director

Hello Friends!

We have been very busy at the start of 2014! We are excited to announce the opening of the Arizona Bleeding Disorders Health and Wellness Center to provide primary care to our adult members with bleeding disorders and their adult family members as well as care for their bleeding disorder. The best part is that the center is across the street from the Arizona Hemophilia Association, to make it convenient and community focused. Stop by and check it out!

In the newsletter you will see several ways to get involved in the Arizona Hemophilia Association. You can attend our many programs, volunteer at our events, or give back through donations or help get your employer involved. We have social groups that provide opportunities to make friendships and share with others who are coping with a chronic bleeding disorder. We also have committees you can join including the following:

Advocacy – this committee keeps abreast of legislative and policy decisions and looks for opportunities to create greater awareness with the general public, including outreach to school nurses and other medical professionals. Ensuring access to healthcare is paramount to the quality of life for anyone affected by a bleeding disorder.

Fundraising – this committee spearheads our fundraising efforts. Without fundraising our organization would not exist. This committee is critical in continuing to build relationships with individuals and companies who provide donations to our organization.

Specials Events – these committees organize our events throughout the year, including the Salsa Challenge, Walk and Golf Tournament. It is a great opportunity to learn the ‘behind the scenes’ of these large events as well as meet others in our bleeding disorder community.

Camp Committee – We organize, staff and manage Camp HONOR, a week-long summer camp for children with bleeding disorders and their siblings. All of our staff are volunteers who make the camp fun, meaningful and memorable for the kids!

Don’t have much time but want to help? You can ask your company to contribute to us through jeans days, 50/50 raffles, or becoming a sponsor for one of our events. You can ask your company for matching funds (many will match whatever you donate). You can donate items for camp, clothes, or even a car!

In whatever way you can or want to get involved, we hope to see more of you! We are here to create a community of sharing, whether it is providing you help when you need it, or having you help others in need. We are here to serve you and to build a strong bond among all of us coping with living with a bleeding disorder.

We hope to see you at the Annual Statewide Meeting! Make sure to register today.

With gratitude and appreciation,

Cindy Komar
The 30th annual My Nana’s Best Tasting Salsa Challenge was held March 8th at Steele Indian School Park. The event is the largest fundraiser for the Arizona Hemophilia Association, raising over $100,000 to help fund programs and services provided to those living with chronic bleeding disorders. This is a culinary festival where contestants compete for the best tasting salsa! Each year we have over 100 salsas entered to be judged for the honor of becoming the Grand Champion salsa. The winner receives $1,000 cash, a retail opportunity through El Sol Foods to manufacture, distribute and retail their salsa for one year and the title as the best tasting salsa!

This year the event achieved many ‘firsts’! The event was held for the first year at Steele Indian School Park to be more centrally located for those attending. We raised more money in the Patron Margarita Mix-off (over $17,000) than ever before. We partnered with El Sol Foods and attempted to break the Guinness Book of World Records for the largest serving of Salsa! The record was just under 7,000 lbs of salsa. We made 7,308 lbs of salsa! Now that’s a lot of Salsa!!! We are eagerly awaiting final confirmation that we are the new record holder! Special thanks to El Sol Foods, Fry’s Foods, Fastsigns Chandler, Southwest Scale and State Industrial.
This is all possible because of the wonderful volunteers and sponsors that we have! Special thanks to My Nana’s Best Tasting Tortilla Chips, Title Sponsor, for donating over 3,000 lbs of chips for the event! Thanks also to El Sol Foods, Cazadores, Casino Arizona, Fry’s Foods, Patron, CopperPoint, SRP, Macayo’s, Mexican Moonshine, USBG Phoenix, New Belguim, Dos Equis, Strongbow, Tecate, Tecate Light, Pepsi, Sun Orchard, Ironwood, MRK Sound Solutions and Chicks with Picks.

We had over 300 volunteers that are critical to the success of the event! Special thanks to General Dynamics, Phoenix Philanthropists, HomeNet Automotive, Grifols, GoDaddy, Kohls, and Wells Fargo!

We look forward to seeing you at next year’s event on March 7, 2015!!

Salsa Challenge 2014 Winners!

Grand Champion for Salsa Competition: Sommer Greene- Individual Hot

Grand Champion for Margarita Mix-Off: Luke Lambert- Virtu’ Honest Craft Sweet Sweet Living

INDIVIDUAL HOT
1st Sommer Greene
2nd Jeff Smith
3rd Bea Salas

INDIVIDUAL MILD
1st Sommer Greene
2nd Eric Gherna
3rd Keith Blair

INDIVIDUAL ANYTHING GOES
1st Bea Salas
2nd Joe La Spina
3rd Terry Letterly

BUSINESS HOT
1st Pfizer
(Rebecca Carillo)
2nd Pod-rico Shilia Salsa
(Camarena Chili Sauce Co.)
3rd Biogen Idec
(Martha Bojorges)

BUSINESS MILD
1st Walgreens

BUSINESS ANYTHING GOES
1st Edwards Sweet N’ Heat
2nd Casino Arizona
3rd Edwards Sweet N’ Heat

RESTAURANT HOT
1st Macayo’s
2nd El Palacio
3rd Victoria’s Catering

RESTAURANT MILD
1st Scottsdale Plaza Resort
2nd Macayo’s
3rd El Palacio

RESTAURANT ANYTHING GOES
1st El Palacio
2nd El Palacio

Best of Show 2014 Winner: Mouth of the South Salsa
Best Booth 2014 Winner: Mamas Chelo’s
People’s Choice Award Winner: Walgreens

Congratulations to all of this year’s winners!!
support that may help you change the possibilities in hemophilia

When you or your child has a bleeding disorder, the costs can add up quickly. SevenSECURE® is a valuable tool that may help you with health insurance, educational grants and scholarships, health and fitness memberships, and reimbursement assistance for medical and dental expenses. And it’s now available online, so support is always a click away.

Discover support with SevenSECURE®. Visit ChangingPossibilities-US.com to learn more about the program and enroll today.
Arizona Hemophilia Walk
October 26, 2014

Mark your calendars for this year’s Hemophilia Walk!

Whether you wish to walk or simply register to be a fundraiser, collecting donations from family, friends and co-workers, your efforts will help improve the quality of life of those individuals and families affected by bleeding disorders!

Sunday, October 26, 2014
@ the Phoenix Zoo

Registration at 7am/Walk at 8am

Online Registration opens
August 1, 2014!!

Charity Golf Tournament
November 14, 2014

The 15th Annual Arizona Desert Classic Golf Tournament is a competitive golf tournament that benefits the Arizona Hemophilia Association. Registration includes 18 holes of Golf, breakfast, lunch, drink tickets, tee gift, silent auction, raffle prizes and more! Spend a beautiful day on the Arizona Grand Golf Course and help support a great cause!

Friday, November 14, 2014
@ the Arizona Grand Golf Course

Shotgun Start at 8am

Online Registration opens
August 15, 2014!!
Camp HONOR

Camp HONOR (Hemophiliacs Overcoming New Obstacles Resourcefully) is a week long summer camp in Prescott, Arizona that is open to children ages 8-17 from the bleeding disorder community. This includes those who have a bleeding disorder, as well as their siblings, as we believe that a bleeding disorder affects the entire family. The mission of Camp HONOR is to enrich the lives of children affected by an inherited bleeding disorder by providing life-changing camp experiences that are exciting, empowering, and educational, in a physically safe and medically sound environment. Our camp is designed to allow children with medical needs the opportunity to experience the camp activities such as archery, camping, sports, team building games, arts and crafts, and swimming, in a loving environment that can meet the special needs of each child.

At Camp HONOR we strive to:
* Develop medical independence.
* Foster memorable friendships.
* Teach life skills.
* Enhance self-worth and self-confidence.
* Create a community of peers facing similar situations.
* Provide mentoring and leadership opportunities.
* Empower campers to gain acceptance of their medical condition.
* Educate campers to become self-advocates for medical care.
* Provide the highest quality medical care that is non-intrusive to camp life.

The theme for our 21st year of Camp HONOR was Peace, Blood, Rock ‘n’ Roll. The week was full of dress up days coinciding with top musical and cultural themes of each decade! Campers participated in programs designed to help them discover their inner rock stars and be comfortable with who they are. We discussed what it takes to become a rock star and how we can learn from the good things that rock stars have done and the things they have overcome in their lives. We highlighted this idea by ending the week with the Camp HONOR Music Awards. Camp HONOR 2014 was a huge success and one for the Rock ‘n’ Roll Hall of Fame.

This year we served over 115 campers with the help of more than 100 volunteers and staff. All of our camp staff are volunteers who have given up their week to make a difference in the life of a child. The experiences the camper has at camp create memories for a lifetime. Thank you to all of our camp staff for taking the time out from your busy day-to-day to be with our community and make a huge impact on our campers! At Camp HONOR our vision is that our campers will embrace our camp values and one day take personal responsibility for their own lives and become strong advocates for their own care.
Each year Camp HONOR medical staff teach campers with bleeding disorders how to self infuse. For the patient with a bleeding disorder, learning the practice of self-infusion is of the utmost importance in their transition to independence and adulthood. At Camp HONOR, we are committed to assisting our campers who are infusion dependent in mastering the skill of self-infusion through daily infusion workshops, one-on-one instruction with a hemophilia nurse, and encouragement from other campers and staff members. They end up really wanting to learn and to help others learn which is what Camp HONOR is all about.

The ‘Big Stick’ award is given to campers who successfully infuse on their own for the first time. This is a big deal at camp and is celebrated by everyone. This year we had 11 kids who received the award!!

The Jeremy Storms’ STRAIGHT ARROW AWARD

Jeremy Storms loved Camp HONOR. As a hemophiliac, he attended from its very beginning until the year he passed away in 1996. He loved the fun, fellowship and challenges. He always demonstrated respect for the camp staff. He was diligent in his efforts in the events and in the encouragement of others. One of the things Jeremy loved at camp was archery. The arrows on the award are a symbol of that love. His family is happy to present this special award in Jeremy’s honor to the camper who best displays the courage, integrity and honor at Camp HONOR that Jeremy demonstrated in his life. Jeremy’s life verse from the Bible is Jeremiah 29:11 “For I know the plans that I have for you” declares the Lord, “plans to prosper you and not to harm you, plans to give you a hope and a future.” (New International Version)

This year’s recipient of the STRAIGHT ARROW AWARD was Dylan Brabon. It was only his second year of camp, but he quickly embraced the camp spirit and the true meaning of being a camper at Camp HONOR. In between having fun and developing lasting friendships, Dylan worked hard to be able to self infuse his medications in order to become more independent and help manage his own medical care. He was one of the youngest campers to ever receive the award, and we are all very proud of him. Congratulations Dylan!!
Eco-Trek is a one-player, multi-level game package that tests your outdoor survival skills

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(602) 741-7275
patrick_wagner@baxter.com

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CITs (Counselors in Training)

We had a record number of 24 CIT candidates for Camp HONOR attend the CIT orientation this year! This group is very cohesive and are great future leaders! The teens had the opportunity to participate in a full day team building program that included a high ropes course and zip line. They also got to cook all of their own meals and even do all the grocery shopping. In the evenings, the CITs participated in counselor skill building workshops rounded out with some relaxation by the camp fire before bed each night.

For the first time this year, the Counselors in Training were divided into two groups while at Camp HONOR. The first year CITs spent time each day in workshops designed to build their counselor skills, followed by some observation time in the afternoon, while our returning CITs were fully immersed in the cabins as live-in staff. All the Counselors in Training successfully assisted in the evening activities and daily life at camp. We are very excited to welcome many of the second year CITs back as counselors next year for Camp HONOR 2015. We encourage anyone who is interested in the CIT Program to contact Josh at our office!

New Family Picnic & Camp Picnic

Each year in the spring we host a New Family Picnic and a Camp Picnic for members of the bleeding disorder community in Arizona. The New Family Picnic was in March for families of children who have never been to camp. It provided them with an opportunity to meet some of the camp staff and have questions answered. It helped parents and kids decide if camp is right for them! The Camp Picnic was in April and we had over 70 in attendance. The picnic gave both new and returning campers and their parents an opportunity to mingle and discuss camp with both camp staff and experienced campers. Campers enjoyed playing games while parents spoke with other parents and heard presentations from senior camp staff members.
**BleedHERs**

BleedHERs is a program designed to give women affected in some way by a bleeding disorder an opportunity to get together and unwind while having a good time. In February, the “Treat Others, Treat Yourself” evening began with a presentation from a Certified Nurse Educator from Pfizer on overcoming challenges in living with or caring for someone with a bleeding disorder. The ladies treated others by creating Emergency Food Baskets for families in need in our community. They then treated themselves with a special spa treatment from Spa Fly while enjoying a delicious dinner from Zoe’s Kitchen!

In May, several women joined together for an afternoon of bonding and friendly competition while they enjoyed a catered meal and state of the art bowling lanes at Main Event in Tempe.

Have questions about the BleedHERs program? Call our office at (602) 955-3947 today!

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**Blood Brotherhood**

The Blood Brotherhood program which serves men 18 and older with a bleeding disorder is a partnership between the Arizona Hemophilia Association, The Center for Disease Control, and the Hemophilia Federation of America. It is designed to be a multi-avenue outreach, to provide education and support, promote good health, and establish a sense of community for adult men.

The first Blood Brotherhood event of the year was held at K1 Speed Indoor Kart Racing. The men enjoyed pizza and refreshments while learning about Advocacy and how to play an active role in the community. On the racetrack, several of the participants set new record track times and earned a position on the podium. Alex Parra took first place with a lap time that was quite faster than anyone else in the group and earned a spot in the “Fastest times of the Month”. Everyone really enjoyed the opportunity to get together, network, learn about advocacy, and do some racing. In April and June, the men got together for educational sessions and to attend both Phoenix Suns and Arizona Rattlers games.

If you would like more information about our men’s group, please contact Josh at our office.
HAPY & Epic

HAPY, the Hemophilia Association Program for Youth, is for children 8 years old to 8th grade. Epic is our teen program that focuses on pairing education with entertainment in preparing them for college and adulthood. We had a great time in January at Gameworks in Tempe. The kids who came out enjoyed an afternoon full of games, food and fun.

Many of the kids remarked that their favorite part was getting to do group races in the race simulator.

The kids at HAPY had a great time in May bowling and enjoying the video arcade at Main Event in Tempe. They also had an opportunity to participate in a round of laser tag in between catching up with old friends and getting ready for Camp HONOR. Many of our Epic teens attended the CIT training this year and had the opportunity to participate in a full day team building program that included a high ropes course and zip line.

Epic is now in Tucson!!

A Celebration of Community

A Celebration of Community, sponsored by Biogen Idec, was a day of learning, connection, and celebration for the Spanish speaking bleeding disorder community. It was held in late June at the ASU Mercado location in downtown Phoenix. Over fifty people attended the informative and practical workshops, designed to help build life skills. While parents networked and attended sessions, children aged 5-17 enjoyed a day at the Arizona Science Center, including the viewing of “Mummies in 3D” and “Arizona Skies” in the Planetarium.

The morning began with registration and breakfast from Einstein Bros Bagels and then a welcome from Arizona Hemophilia Association and Biogen Idec. Part one of the Motivated, Vibrant, Powerful! Life-Skills Workshop covered the topic of Managing Chaos. Attendees enjoyed a delicious luncheon catered by Cafe Rio. Individuals then participated in one of two CoRe Conversations Programs - Setting Educational Expectations or Understanding the Value of Genotyping. The afternoon concluded with part two of the Motivated, Vibrant, Powerful! Life-Skills Workshop with a session on Positive Assertiveness.

Families enjoyed the fun, engaging workshops, and informative discussions, as well as the opportunity to network with others in the bleeding disorder community!
Help your local hemophilia chapter raise sponsorship funds by participating in the 4th annual Bayer Virtual Walk for Hemophilia.

Spread the word to your friends and family. Every virtual walker brings your chapter one step closer to making a difference in the community!

Back to School and Community Picnic
August 2, 2014

Saturday, August 2, 2014
10am-2pm

Arizona Hemophilia Association
826 N 5th Ave
Phoenix, AZ 85003

Join us for a great time as we enjoy water slides, great food and celebrate the
back to school season with the bleeding disorder community!

Food and drinks will be provided - please bring a towel.
Children between 5 and 18 years old will receive
a back to school care package.

Please RSVP to Josh by July 31st!

Annual Statewide Meeting
August 22-24, 2014

The Annual Statewide Meeting is an education event that provides opportunities for
individuals and families affected by inherited bleeding disorders to
learn about their disorder and how to better manage it as well as meet and
share with other community members.

This year’s theme is Change Happens...Are You Ready? The 9th
Annual Statewide Meeting will be held at the Sheraton Wild Horse
Pass Resort. The weekend will be filled with fun and educational activities
including information on Exercise, Healthy Living, Advocacy, Nutrition,
Insurance, Joint Disease, Arthritis and more! Childcare with age appro-
priate activities will be provided for children aged 17 years and younger.
Participation is strictly reserved for members of the bleeding disorder
community and their immediate family members only.

Register on our website by Friday, August 1, 2014!
BAYER HEALTHCARE & COMUNIDAD HEMOFÍLICA:

Compromiso, liderazgo e innovación
Mark your calendars for a fun weekend of family camp! Camp H.U.G. (Hemophilia Uniting Generations) is the only family camp in Arizona for people with inherited bleeding disorders. This is an opportunity for you and your family to live a weekend of the true summer camp lifestyle with hiking, arts & crafts, and much more!

Camp H.U.G. will be held this year October 10-12, 2014 in Mayer, Arizona. Transportation will be provided.

*Online Registration will open August 25, 2014!*

### UPONING PROGRAMS

**Women’s Retreat**
**September 6-7, 2014**

The Women’s Retreat is an educational and social event focusing on issues faced by those who have a bleeding disorder, as well as mothers, wives, daughters and sisters of inherited bleeding disorder patients. It provides support and education to women while enjoying a relaxing environment.

This year’s event will be held September 6-7, 2014 at White Stallion Ranch in Tucson, Arizona.

*Online applications will be available July 21, 2014!*

**Hispanic Heritage Day**
**September 28, 2014**

Mark your calendars for our annual Hispanic Heritage Day on Sunday, September 28, 2014!

Hispanic Heritage Day is an educational day sponsored by Baxter to not only bring Spanish speaking families together that are diagnosed with a bleeding disorder but to also encourage these families to be active participants in their community.
Advocacy Update

As most of you probably are aware, the Affordable Care Act (aka ‘Healthcare reform’, aka ‘Obama-care’) was implemented in January 2014. While we are not sure of its impact yet, many Americans signed up for the Insurance Marketplace. As you may know, Arizona had the option to run its own Marketplace or to opt into the federally run Insurance Marketplace. Arizona chose the federally run option.

The Arizona Hemophilia Association is a Certified Application Counselor to help our members understand the Insurance Marketplace offerings and to assist them in signing up. There are still many questions on out of pocket costs, what policies are best for our members (there were over 100 policy offerings in just Maricopa County alone), out of network doctors and facilities, and formularies. We should have a better understanding of its impact on our community members in the next 6 months to a year. AHA is a member of Cover AZ, a coalition of organizations in Arizona that work with Health and Human Services to identify and resolve issues with the Insurance Marketplace.

Please let us know if you have signed up with the Insurance Marketplace and what your experience is so far. If you are having any issues, please reach out for help.

We are also working to expand our Speaker’s Bureau, where community members are trained to represent the Arizona Hemophilia Association in speaking engagements throughout Arizona, to build awareness about bleeding disorders and its impact.

Help contribute your voice to the cause! Reach out to Brent at the AHA office today and get involved. Our goal is to educate the general public about hemophilia and von Willebrand Disease, among other bleeding disorders.

Access to healthcare remains our focus. Get involved in advocating for yourself, your family, our bleeding disorder community and our cause!!!

Please help us continue to make a difference! We are confident that together we can improve the quality of life of those living with a bleeding disorder.
ALPROLIX provides protection* from bleeds starting with at least a week between prophylaxis infusions.

Dosing regimen can be adjusted based on individual response.

*Protection is the prevention of bleeding episodes using a prophylaxis regimen.

To learn more, contact CoRe Manager Jessica Klass
E: jessica.klass@biogenidec.com T: 623.238.0244

Indications and Important Safety Information

Indications
ALPROLIX, Coagulation Factor IX (Recombinant), Fc Fusion Protein, is a recombinant DNA derived, coagulation factor IX concentrate indicated in adults and children with hemophilia B for:
- Control and prevention of bleeding episodes
- Perioperative management
- Routine prophylaxis to prevent or reduce the frequency of bleeding episodes

ALPROLIX is not indicated for induction of immune tolerance in patients with hemophilia B.

Important Safety Information
Do not use ALPROLIX if you are allergic to ALPROLIX or any of the other ingredients in ALPROLIX.

Tell your healthcare provider if you have or have had any medical problems, take any medicines, including prescription and non-prescription medicines, supplements, or herbal medicines, have any allergies and all your medical conditions, including if you are pregnant or planning to become pregnant, are breastfeeding, or have been told you have inhibitors (antibodies) to factor IX.

Allergic reactions may occur with ALPROLIX. Call your healthcare provider or get emergency treatment right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

Your body can also make antibodies called “Inhibitors” against ALPROLIX, which may stop ALPROLIX from working properly.

ALPROLIX may increase the risk of formation of abnormal blood clots in your body, especially if you have risk factors for developing clots.

Common side effects of ALPROLIX include headache and abnormal sensation of the mouth. These are not all the possible side effects of ALPROLIX. Talk to your healthcare provider right away about any side effect that bothers you or does not go away, and if bleeding is not controlled using ALPROLIX.

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.

Please see Brief Summary of full Prescribing Information on the next page. This information is not intended to replace discussions with your healthcare provider.
ALPROLIX™ /əlˈprɔlɪks/  
[Coagulation Factor IX (Recombinant), Fc Fusion Protein]

Please read this Patient Information carefully before using ALPROLIX™ and each time you get a refill, as there may be new information. This Patient Information does not take the place of talking with your healthcare provider about your medical condition or your treatment.

What is ALPROLIX™?
ALPROLIX™ is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital Factor IX deficiency.

Your healthcare provider may give you ALPROLIX™ when you have surgery.

Who should not use ALPROLIX™?
You should not use ALPROLIX™ if you are allergic to ALPROLIX™ or any of the other ingredients in ALPROLIX™. Tell your healthcare provider if you have had an allergic reaction to any Factor IX product prior to using ALPROLIX™.

What should I tell my healthcare provider before using ALPROLIX™?
Tell your healthcare provider about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal medicines.

Tell your doctor about all of your medical conditions, including if you:
- are pregnant or planning to become pregnant. It is not known if ALPROLIX™ may harm your unborn baby.
- are breastfeeding. It is not known if ALPROLIX™ passes into breast milk or if it can harm your baby.
- have been told that you have inhibitors to Factor IX (because ALPROLIX™ may not work for you).

How should I use ALPROLIX™?
ALPROLIX™ should be administered as ordered by your healthcare provider. You should be trained on how to do infusions by your healthcare provider. Many people with hemophilia B learn to infuse their ALPROLIX™ by themselves or with the help of a family member.

See the Instructions for Use for directions on infusing ALPROLIX™. The steps in the Instructions for Use are general guidelines for using ALPROLIX™. Always follow any specific instructions from your healthcare provider. If you are unsure of the procedure, please ask your healthcare provider. Do not use ALPROLIX™ as a continuous intravenous infusion.

Contact your healthcare provider immediately if bleeding is not controlled after using ALPROLIX™.

What are the possible side effects of ALPROLIX™?
Common side effects of ALPROLIX™ include headache and abnormal sensation in the mouth.

Allergic reactions may occur. Call your healthcare provider or get emergency treatment right away if you have any of the following symptoms: hives, chest tightness, wheezing, difficulty breathing, or swelling of the face.

ALPROLIX™ may increase the risk of forming abnormal blood clots in your body, especially if you have risk factors for developing blood clots.

Your body can also make antibodies called, "inhibitors," against ALPROLIX™, which may stop ALPROLIX™ from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

These are not all the possible side effects of ALPROLIX™. Talk to your healthcare provider about any side effect that bothers you or that does not go away.

How should I store ALPROLIX™?
Store ALPROLIX™ vials at 2°C to 8°C (36°F to 46°F). Do not freeze.

ALPROLIX™ vials may also be stored at room temperature up to 30°C (86°F) for a single 6 month period.

If you choose to store ALPROLIX™ at room temperature:
- Note on the carton the date on which the product was removed from refrigeration.
- Use the product before the end of this 6 month period or discard it.
- Do not return the product to the refrigerator.

Do not use product or diluent after the expiration date printed on the carton, vial or syringe.

After Reconstitution:
- Use the reconstituted product as soon as possible; however, you may store the reconstituted product at room temperature up to 30°C (86°F) for up to 3 hours. Protect the reconstituted product from direct sunlight. Discard any product not used within 3 hours after reconstitution.
- Do not use ALPROLIX™ if the reconstituted solution is cloudy, contains particles or is not colorless.

What else should I know about ALPROLIX™?
Medicines are sometimes prescribed for purposes other than those listed here. Do not use ALPROLIX™ for a condition for which it was not prescribed. Do not share ALPROLIX™ with other people, even if they have the same symptoms that you have.

Manufactured by
Biogen Idec Inc.
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U.S. License #1697
Legislative Day

In March, the AHA once again held our annual Legislative Day and Lunch on the Lawn event! Individuals and families affected by bleeding disorders from across the state joined us at the Arizona State Capitol to raise awareness and to make their voices heard! Our community members attended over fifty scheduled meetings with Arizona’s congressional leaders where they shared some of the challenges that families within our community face and encouraged them to keep our families in mind while they make policy decisions. Congratulations to Mary Sands - she won a DVD copy of *Hunger Games, Catching Fire* for attending Legislative Day and representing her district! We also had a couple hundred legislators and legislative staff members join us on the House Lawn for lunch where they had a chance to meet our community and learn about bleeding disorders.

Legislative Day and other advocacy efforts present opportunities for community members to impact the lives of people with bleeding disorders throughout Arizona. Simply sharing your experiences goes a long way to informing lawmakers about the challenges our community faces, making them much more likely to consider the implications their decisions could have for people with bleeding disorders. Thank you again to everyone that made Legislative Day a great success this year; if you were unable to participate, we really hope you can join us for Legislative Day 2015! If you are interested in helping to further our advocacy efforts, please contact the AHA to find out what you can do to get involved!

NHF Washington Days

This year, five representatives from the bleeding disorder community in Arizona spent three days at the National Hemophilia Foundation’s Washington Days event in Washington D.C. We joined over 300 people from 43 different states in meeting with our respective representatives in the US Senate and House of Representatives. The Arizona constituents had scheduled meetings with the offices of Senator John McCain, Senator Jeff Flake, Representative Kyrsten Sinema, and Representative David Schweikert. We explained many of the challenges facing families with bleeding disorders and urged lawmakers to support continued federal funding for programs that work to address some of them, such as funding for Hemophilia Treatment Centers. We also discussed the cost of treatment and the difficulties that many people with bleeding disorders will have covering the co-insurance costs of “specialty tier” medications.

We asked that our legislators support HR 460, the Patient’s Access to Treatment Act, in order to address this issue. This is a bi-partisan bill meant to help prevent greater cost-sharing requirements for specialty tier medications, like those used to treat bleeding disorders and many other chronic conditions.

If you would like help contacting your legislators, please contact the Arizona Hemophilia Association!
Arizona Bleeding Disorders Health and Wellness Center

Come Meet our Team!
Your First Appointment is on Us!

The Arizona Bleeding Disorders Health and Wellness Center:
- Provides treatment for bleeding disorders
- Focuses on treating the whole person
- Provides primary care to All Adult family members
- Combines HTC model with Patient Centered Home
- Partners with YOU to provide comprehensive integrated care

Why We Started: Historically, those with hemophilia and other bleeding disorders did not live to adulthood. Today the treatment of bleeding disorders has advanced that those affected are expected to live a normal life expectancy! One of the biggest challenges today, however, is that adults with bleeding disorders experience greater medical concerns from co-morbidities associated with aging. Complications from age related health conditions such as cardiovascular disease, high blood pressure, diabetes remain a significant area of concern.

The Arizona Hemophilia Association established the Arizona Bleeding Disorders Health and Wellness Center to provide quality, integrated care for adults living with bleeding disorders and their adult family members. It is critical that adults receive comprehensive and integrated care so that the medical team understands the complicating factors with other procedures and/or diagnoses.

We Can Be Your Primary Care Provider: The Arizona Bleeding Disorders Health and Wellness Center is changing the paradigm of bleeding disorder care. Our combination of a traditional hemophilia treatment center model and primary care given under the patient centered medical home model offer the best of both worlds. Our care team can be your primary care specialist, with an internist trained in the treatment of bleeding disorders. This unique approach allows us to address all of the patient’s medical issues, help with the challenges patients face as they transition from youth to adulthood, and also manage co-morbidities.

We believe that bleeding disorders affects the entire family and having one primary care physician for all adults in the family creates a collaborative approach to care. The unique advantage of this approach is that we will be able to address all of the patient’s medical issues and coordinate your care with other specialists to provide a seamless, integrated approach to your care.

Our Mission: Our mission is to provide high quality, integrated comprehensive care to treat the whole person that leads to lifestyle optimization.

Call today to schedule your appointment!
(602) 680-7722
Upcoming Events & Programs

September
- (6-7) Women’s Retreat
- (18-20) NHF Annual Meeting
- (20) Epic
- (28) Hispanic Heritage Day

October
- (10-12) Camp H.U.G.
- (26) Walk @ Phoenix Zoo

November
- (8) BleedHERs
- (9) Men’s Group
- (14) Charity Golf Tournament

December
- (7) Holiday Party
- (14) Epic

Contact Information Update
Have you moved recently?
Have you changed email addresses?

We are constantly updating our database so if you receive any mail/email with incorrect information please let us know so we can fix it! Please call our office at (602) 955-3947 or email millie@arizonahemophilia.org with any updates.

For more information visit our website
ArizonaHemophilia.org
Everybody Bleeds...Not Every BODY Stops
Help Stop the Bleeding!

*Thank you for making a difference!*

The Arizona Hemophilia Association is a Qualifying Charitable Organization. When you donate to us, your gift qualifies for an Arizona Tax Credit. You can receive a dollar-for-dollar tax credit on your Arizona state income tax return while helping us make a difference for those living with a bleeding disorder - at no additional cost to you!

You do not need to itemize deductions in order to claim the tax credit. (Taxpayers filing as “single” and “head of household” status may claim a maximum credit of $200. Taxpayers filing as “married filing separate” may claim a maximum credit of $200. Taxpayers that file as “married filing joint” may claim a maximum credit of $400.)

Make a Gift Today!

It’s easy! Just visit www.ArizonaHemophilia.org, click on Donate Now at the top of the page, fill out your information and we’ll send you a letter for your taxes!