Semi-Annual Newsletter Get Infused!

Winter 2015

ARIZONA HEMOPHILIA ASSOCIATION

Serving those living with inherited bleeding disorders

Serving the bleeding disorders community in Arizona for over 45 years

ARIZONA HEMOPHILIA ASSOCIATION

Serving those living with inherited bleeding disorders

EVERYBODY BLEEDS... NOT EVERY BODY STOPS

In this Issue

Executive Director News	3-4
AHA Events	5-8
AHA Programs	11-15
Advocacy & Healthcare	16
AHA Updates	19

ARIZONA HEMOPHILIA ASSOCIATION
Serving those living with inherited bleeding disorders

HELP STOP THE BLEEDING TODAY!
ArizonaHemophilia.org

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 and sponsors who contributed throughout 2015. 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!

Contact Us Today!

(602) 955-3947

826 N 5th Ave

info@arizonahemophilia.org

Phoenix, AZ 85003

Board of Directors

Steven Helm	President
Jim Durr	Vice President
Victor Alonzo	Treasurer
Mark Boesen	
Butch Brown	
Greg Brown	
Robert Kerrigan	
Jennifer Maggiore	
Steven Miller	
Frank Schaffer	
Al Schmeiser	

AHA Staff

Cindy Komar	Chief Executive Officer
Chastity Fermoile	Executive Director
Yleana Hughes	Director of Client Services
Lindsey Bogard	Director of Operations
Josh Traulsen	Program Director
Millie Dillman	Resource & Technology Coordinator
Gretchen Pacheco	Program & Services Coordinator
Steve Pond	TEAM Outreach Coordinator
J. David Cabrera	Administrative Assistant
Joan Gustin	Conference Coordinator
Chelsea Bolyard	Development Coordinator

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.

New Year's Resolution – Get More Involved!!!!

WE NEED YOUR HELP!

The Arizona Hemophilia Association relies on volunteers who want to make a difference for the bleeding disorders community. It operates on funds raised through our 3 events – the Salsa Challenge, Golf Tournament and Walkathon. Additionally, we write many grants to help fund several programs. In order to offer all of the programs, services, camps and conferences, we rely on help from many volunteers like you!

We currently have the following important opportunities to get more involved. You can live anywhere in the state to get involved!!!

Arizona Hemophilia Association Board of Directors: We have openings for board members on our Board of Directors. The Board of Directors sets strategic direction and provides fiscal oversight for the organization.

Arizona Bleeding Disorders Health and Wellness Center Board of Directors: The health center is starting its own board of directors to help govern the health center. The board will help determine the vision and strategic direction for the health center in best serving the bleeding disorders community.

Consumer Advisory Board for Health Center: We are starting an advisory board of community members whose input will be used for strategic planning purposes and consumer feedback on an on-going basis. The primary mission of the Board is to facilitate open communication among consumers, the AHA Board of Directors, and the Health Center Board of Directors. Members have the opportunity to influence decision-making and to represent all of the bleeding disorders members in helping to ensure your needs are being met.

Newly Diagnosed Steering Committee: We want to provide more tailored programs and services to help those newly diagnosed through resources, mentoring and support networks. If you are interested in becoming involved in helping new families with the challenges they are facing, this is a great opportunity for you!

Statewide Outreach Team: We are making a huge effort to offer more programs and services statewide. We are looking for volunteers that are willing to help with providing outreach across the state. We would like to have some members who live in Phoenix to cover certain areas of Maricopa County. We are also looking for members who live in other counties across the state to reach other cities and rural areas.

Please contact Cindy Komar at cindy@arizonahemophilia.org to find out more!

Exciting Changes at the AHA!

We want to let you know of some exciting changes at the Arizona Hemophilia Association (AHA). Cindy Komar, who has been the Executive Director at AHA for the past seven years, has been promoted to the Chief Executive Officer (CEO) of AHA. Cindy will focus on setting the organization's vision and strategic direction in collaboration with the Board of Directors. She will be responsible for government relations, key stakeholder outreach, and business development. She will continue to report to the Board of Directors.

Chastity Fermoile, who has been the Vice President of Fundraising for AHA, has been promoted to Executive Director, responsible for the operations, fundraising and management of AHA, reporting to the Board and to the CEO. Chastity has significant nonprofit leadership experience working at the Valley of the Sun YMCA for over 17 years.

Please join us in congratulating Chastity and Cindy as they transition into their new roles. As always, our focus is to serve those living in Arizona with chronic bleeding disorders to improve their quality of life.

Sincerely,
Arizona Hemophilia Association Board of Directors

Queremos hacerle saber de algunos cambios muy interesantes en la Asociación de Hemofilia de Arizona (AHA). Cindy Komar, que ha sido el Director Ejecutivo en AHA durante los últimos siete años, ha sido ascendido al Consejero Delegado (CEO) de la AHA. Cindy se centrará en el establecimiento de la visión de la organización y la dirección estratégica en colaboración con el Consejo de Administración. Ella será responsable de las relaciones del gobierno, el alcance de actores clave, y el desarrollo de negocios. Ella seguirá informando al Consejo de Administración.

Chastity Fermoile, que ha sido el vicepresidente de recaudación de fondos para la AHA, ha sido ascendido a Director Ejecutivo, responsable de las operaciones, recaudación de fondos y la gestión de la AHA, la presentación de informes a la Junta y al CEO. Chastity tiene experiencia en el liderazgo sin fines de lucro que trabaja significativa en el Valle del Sol YMCA durante más de 17 años.

Por favor, únase a nosotros para felicitar Chastity y Cindy en su transición a sus nuevas funciones. Como siempre, nuestro objetivo es servir a los que viven en Arizona con disordenes de sangre crónicos para mejorar su calidad de vida.

Sinceramente,
Junta Directiva de la Asociación de Hemofilia de Arizona

Charity Golf Tournament

The 2015 Arizona Hemophilia Association Charity Golf Tournament was one to brag about! We were able to fill every foursome again for this year's tournament and welcomed 144 golfers to a new course. For the first time, we hosted this year's tournament at the beautiful but challenging Ocotillo Golf Resort in Chandler, Arizona.

We brought back all the favorites, including the Ladies Hole, Salsa Holes, our Pro Hole, and our popular auction. Donations for the auction came in from generous organizations all over the country, including trips to locations all over the nation, staycations, autographed sports memorabilia, tickets to shows, plays and various Arizona sporting events, golf, dinners, spa treatments and more! With such a great turn out and some extremely generous sponsorships, this year's Charity Golf Tournament brought in a record amount of over $70,000!

All of the money raised at the event helps enable us to provide many programs to the bleeding disorders community, including Camp HONOR. We are very thankful to be able to continue offering our programs and services and we thank the support of our sponsors, golfers and volunteers!

The players experienced many festivities on the greens this year, including a Patron Hole, Tecate Light Hole, and a New Belgium Hole. This year's tournament took place on December 3, which was later in the year than our tournaments in the past, so the day started out chilly but quickly warmed up. Lunch was served and awards were given, including our popular "your height in beer" award.

At our tournament, the golfers get the chance to really let loose, enjoy a fun day, play a sport they love, all while taking in the beautiful greens and laughing with friends. Our golfers took home some great deals on auction items, and helped us raise money for members of Arizona's bleeding disorders community, some of whom were in attendance this year, testing their skills on the greens!

This year's winners were Ted Brown, Tim Nedin, Desmond Cooley and Seth Bryant! Questions about Golf? Call Chelsea at (602) 955-3947!

Arizona Hemophilia Walk

On October 18, 2015, the Arizona Hemophilia Walk was once again held at the beautiful Phoenix Zoo. We were excited to see so many familiar faces as well as many new AHA friends and family at the event!

Together, we raised over $80,000 that will help support our 2016 programs and services for the Arizona bleeding disorders community. Thanks to the fundraising events we organize and the support of the community, we are able to continue providing services and programs to our bleeding disorders community throughout the year. We are thankful for everyone who so graciously gives back through these fundraising events each year.

Over 1,000 walkers came out this year and left their "footprint" on the association by raising funds and walking with us!

We would also like to thank our generous sponsors who helped make this event such a huge success; without you it would not be possible to assist as many families as we do.

This year we were able to introduce a new online fundraising site, bring in several new sponsors, and continue the ability for walkers to "sponsor a participant", which allowed over forty walkers to attend who may not have otherwise been able to fund their own registration fee.

We also had several fun competitions at the event including fundraising level raffles, largest team winners, most spirited team winners, most funds raised by a team, and most funds raised by an individual.

These competitions presented winners with some great prizes, including an iPad, a Phoenix staycation, Salsa Challenge VIP Tickets, and more! If you didn't get a chance to win one of these amazing prizes this year, have no fear, we will have more great prizes ready and waiting for you to snag next year as well!!!

We got into the Halloween spirit with the face painters and became honorary zoo dwellers for the day; lions, tigers and bears (oh my!). A world renowned yo-yo artist dazzled us with a show and

some amazing tricks. The energetic DJ pumped up the crowd for a session of Zumba and many fun engaging dances.

Thank you again for your continued support of the Arizona Hemophilia Walk. The Arizona Hemophilia Association Zoo Walk is a super fun day shared with our families and the community while raising funds! We look forward to seeing you all again next year!

Questions about the Walk? Call Chelsea at (602) 955-3947!

BAYER

COMING SOON

KOVALTRY™

Antihemophilic factor (recombinant)

Register for updates at **www.KOVALTRY.com**

Bayer and the Bayer Cross are registered trademarks of Bayer.
KOVALTRY is a trademark of Bayer.
© 2015 Bayer HealthCare Pharmaceuticals Inc.
All rights reserved. Printed in USA 08/15 PP-675-US-0006

Will you be there? 2016 My Nana's Best Tasting Salsa Challenge!

The Salsa Challenge is a culinary event that hosts over 20,000 attendees, attracting individuals and families who want to enjoy the day filled with live music, a kids zone, salsa tasting and fun activities. The event features over 90 contestants, featuring salsa categories of Hot, Mild and Anything Goes! It is the largest annual fundraiser for the Arizona Hemophilia Association!

We need volunteers!!! Email Chelsea@ ArizonaHemophilia.org if you're interested!

Buy your discount tickets now at SalsaChallenge.com or Fry's!

Back to School Picnic

Our second annual Back to School Picnic was another success! We had over 200 people in attendance from across the state. This event, which was held on August 1st, was a great opportunity for families with bleeding disorders to get together, relax and have a great time. Kids had the opportunity to go down inflatables, play water games, enjoy popcorn and snow cones. Each school-age child received a backpack full of brand new school supplies, and 150 backpacks were handed out in total. Invitations for 2016's Back to School Picnic will be in the mail this summer. Questions? Call Josh at (602) 955-3947 or email him at Josh@arizonahemophilia.org!

An injectable medicine used to control and prevent bleeding in people with hemophilia A

David, 22 years old, *lives with hemophilia A.*

Novoeight® is ready when you are

UP TO **86°F** **FOR 12 MONTHS**

Highest storage temperature for the longest time[a]

Because you seek out new experiences, you need a treatment that is ready when you are. Designed to fit into your world, Novoeight® can be stored at up to 86°F for 12 months and up to 4 hours after being mixed.

Visit **Novoeight.com** to learn about additional features and see how Novoeight® can fit into your world.

Please see Prescribing Information for complete storage instructions.

[a]Compared with other recombinant factor VIII products.

Indications and Usage

Novoeight® (Antihemophilic Factor [Recombinant]) is an injectable medicine used to control and prevent bleeding in people with hemophilia A. Your healthcare provider may give you Novoeight® when you have surgery.

Novoeight® is not used to treat von Willebrand Disease.

SATISFACTION GUARANTEED

Terms and conditions apply.

Important Safety Information

You should not use Novoeight® if you are allergic to factor VIII or any of the other ingredients of Novoeight® or if you are allergic to hamster proteins.

Call your healthcare provider right away and stop treatment if you get any of the following signs of an allergic reaction: rashes or hives, difficulty breathing or swallowing, tightness of the chest, swelling of the lips and tongue, light-headedness, dizziness or loss of consciousness, pale and cold skin, fast heartbeat, or red or swollen face or hands.

Before taking Novoeight®, you should tell your healthcare provider if you have or have had any medical conditions, take any medicines (including non-prescription medicines and dietary supplements), are nursing, pregnant or planning to become pregnant, or have been told that you have inhibitors to factor VIII.

Your body can make antibodies called "inhibitors" against Novoeight®, which may stop Novoeight® from working properly. Call your healthcare provider right away if your bleeding does not stop after taking Novoeight®.

Common side effects of Novoeight® include swelling or itching at the location of injection, changes in liver tests, and fever.

Please see brief summary of Prescribing Information on following page.

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.

Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.

Novoeight® is a registered trademark of Novo Nordisk Health Care AG.
© 2015 Novo Nordisk All rights reserved. 1114-00024065-4 April 2015

novo nordisk®

novoeight®
Antihemophilic Factor (Recombinant)

novoeight®

Antihemophilic Factor (Recombinant)

Patient Product Information
Novoeight® (NŌ-vō-eyt)
Antihemophilic Factor (Recombinant)
Rx Only
This is a BRIEF SUMMARY of important information about Novoeight®.

Read the Patient Product Information and the Instructions For Use that come with Novoeight® before you start taking this medicine and each time you get a refill. There may be new information.

This Patient Product Information does not take the place of talking with your healthcare provider about your medical condition or treatment. If you have questions about Novoeight® after reading this information, ask your healthcare provider.

What is the most important information I need to know about Novoeight®?

Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing Novoeight® so that your treatment will work best for you.

What is Novoeight®?

Novoeight® is an injectable medicine used to replace clotting factor VIII that is missing in patients with hemophilia A. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

Novoeight® is used to control and prevent bleeding in people with hemophilia A.

Your healthcare provider may give you Novoeight® when you have surgery.

Novoeight® is not used to treat von Willebrand Disease.

Who should not use Novoeight®?

You should not use Novoeight® if you

- are allergic to factor VIII or any of the other ingredients of Novoeight
- if you are allergic to hamster proteins

Tell your healthcare provider if you are pregnant or nursing because Novoeight® might not be right for you.

What should I tell my healthcare provider before I use Novoeight®?

You should tell your healthcare provider if you

- Have or have had any medical conditions.
- Take any medicines, including non-prescription medicines and dietary supplements.
- Are nursing.
- Are pregnant or planning to become pregnant.
- Have been told that you have inhibitors to factor VIII.

How should I use Novoeight®?

Treatment with Novoeight® should be started by a healthcare provider who is experienced in the care of patients with hemophilia A.

Novoeight® is given as an injection into the vein.

You may infuse Novoeight® 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 hemophilia treatment center or healthcare provider. Many people with hemophilia A learn to infuse the medicine by themselves or with the help of a family member.

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

You may need to have blood tests done after getting Novoeight® to be sure that your blood level of factor VIII is high enough to clot your blood. This is particularly important if you are having major surgery.

Your healthcare provider will calculate your dose of Novoeight® (in international units, IU) depending on your condition and body weight.

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

Development of factor VIII inhibitors

Your body can also make antibodies called "inhibitors" against Novoeight®, which may stop Novoeight® from working properly.

If your bleeding is not adequately controlled, it could be due to the development of factor VIII inhibitors. This should be checked by your healthcare provider. You might need a higher dose of Novoeight® or even a different product to control bleeding. Do not increase the total dose of Novoeight® to control your bleeding without consulting your healthcare provider.

Use in children

Novoeight® can be used in children. Your healthcare provider will decide the dose of Novoeight® you will receive.

If you forget to use Novoeight®

Do not inject a double dose to make up for a forgotten dose. Proceed with the next injections as scheduled and continue as advised by your healthcare provider.

If you stop using Novoeight®

If you stop using Novoeight® you are not protected against bleeding. Do not stop using Novoeight® without consulting your healthcare provider.

If you have any further questions on the use of this product, ask your healthcare provider.

What if I take too much Novoeight®?

Always take Novoeight® exactly as your healthcare provider has told you. You should check with your healthcare provider if you are not sure. If you inject more Novoeight® than recommended, tell your healthcare provider as soon as possible.

What are the possible side effects of Novoeight®?

Common Side Effects Include:

- swelling or itching at the location of injection
- changes in liver tests
- fever

Other Possible Side Effects:

You could have an allergic reaction to coagulation factor VIII products. **Call your healthcare provider right away and stop treatment if you get any of the following signs of an allergic reaction:**

- rashes including hives
- difficulty breathing, shortness of breath or wheezing
- tightness of the chest or throat, difficulty swallowing
- swelling of the lips and tongue
- light-headedness, dizziness or loss of consciousness
- pale and cold skin, fast heart beat which may be signs of low blood pressure
- red or swollen face or hands

These are not all of the possible side effects from Novoeight®. Ask your healthcare provider for more information. You are encouraged to report side effects to FDA at 1-800-FDA-1088.

Tell your healthcare provider about any side effect that bothers you or that does not go away.

How should I store Novoeight®?

Prior to Reconstitution:

Store in original package in order to protect from light. Do not freeze Novoeight®.

Novoeight® vials can be stored in the refrigerator (36–46°F [2°C–8°C]) for up to 30 months or up to the expiration date, or at room temperature (up to 86°F [30°C]) for a single period not exceeding 12 months.

If you choose to store Novoeight® at room temperature:

- Note the date that the product is removed from refrigeration on the box.
- The total time of storage at room temperature should not exceed 12 months. Do not return the product to the refrigerator.
- Do not use after 12 months from this date or the expiration date listed on the vial, whichever is earlier.

Do not use this medicine after the expiration date which is on the outer carton and the vial.

The expiration date refers to the last day of that month.

After Reconstitution (mixing the dry powder in the vial with the diluent):

The reconstituted Novoeight® should appear clear to slightly unclear without particles.

The reconstituted Novoeight® should be used immediately.

If you cannot use the Novoeight® immediately after it is mixed, it should be used within 4 hours when stored at ≤ 86°F (30°C). Store the reconstituted product in the vial.

Keep this medicine out of the sight and out of reach of children.

What else should I know about Novoeight® and hemophilia A?

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

For more information about Novoeight®, please call Novo Nordisk at 1-844-30-EIGHT.

More detailed information is available upon request.
Available by prescription only.

Revised: 09/2014

Novoeight® is a trademark of Novo Nordisk A/S.

For information about Novoeight® contact:
Novo Nordisk Inc.
800 Scudders Mill Road
Plainsboro, NJ 08536, USA

Manufactured by:
Novo Nordisk A/S
DK-2880 Bagsvaerd, Denmark

© 2014 Novo Nordisk
1214-00024657-1 12/14

novo nordisk®

Annual Statewide Meeting

Our 10th Annual Statewide Meeting was held at Hilton Phoenix/ Mesa for the first time this year. This conference is one of the best ways for us to reach out to the entire Arizona bleeding disorder community and provide them with a weekend of education, entertainment, and making connections. Educational sessions were provided throughout the weekend and included speakers providing information on bleeding disorders, health insurance, parenting, joint health, dental health and much more! Children in attendance were able to spend time at the hotel's pool, listen to stories, watch a magic show, get up close and personal to awesome and exotic animals, and learn some impressive yo-yo tricks! There was also a game room set up for the kids of all ages to choose their own activities.

We honored Jeff Rhodes, Director of Restaurant Operations for Macayo's Restaurants, as our 2015 Volunteer of the Year. Jeff and Macayo's creative ideas are endless, many of which we have incorporated into our events. His commitment and passion have helped us raise significant funds and allowed us to provide programs and services.

On Saturday evening we had dinner and a ton of fun at Sun Splash! Watch for registration for this year's Statewide Meeting to open in the summer!

Camp H.U.G.

Camp H.U.G. (Hemophilia Uniting Generations) is our weekend family camp held in October each year. This program affords families an opportunity to get a glimpse into life at Camp HONOR. For the first time this year, Camp H.U.G. was held at Prescott Pines Camp. We provided activities and educational sessions but allowed a lot of time for families to relax, reconnect and enjoy the camp experience.

We had about forty families in attendance and families were given the opportunity to choose from yoga, canoing, arts and crafts, human foosball, and much more. We look forward to the next chance to gather again around a campfire at this year's Camp H.U.G., which will be held October 23-25, 2015.

Registration for this year's family camp will become available at the end of the next Annual Statewide Meeting in August. Call us at (602) 955-3947 or email Josh@arizonahemophilia.org if you have any questions about our family camp!

BleedHERs

BleedHERs is our 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. The women have been busy since this summer. In July, the ladies got together for food and a session testing their artistic skills while also building upon relationships and making new ones (see the photo below). In August, the group gathered again for a women's only lunch at the Annual Statewide Meeting. The women in our bleeding disorders community then met in October for the Women's Retreat in Tucson for a fun filled evening (read more below). In December, everyone worked together to create cookie jars to donate to the bleeding disorders community (see the photo to the right), then they shared a delicious lunch and participated in a cookie recipe exchange. We look forward to hosting more events through the rest of Winter and into Spring! Call us if you're interested in participating at (602) 955-3947!

Women's Retreat

The 9th Annual Women's Retreat was held again this year at the White Stallion Ranch in Tucson, AZ. This retreat was open to women 17 years and older who are affected by a bleeding disorder, including women who have a bleeding disorder and mothers, sisters, and children of those who have a bleeding disorder.

The group created a weekend long project that represented commonalities among the women, both culturally and personally. They also participated in several other educational, entertaining and relaxing activities while enjoying time together and some well earned "me" time. The weekend provided the perfect ambiance for rekindling existing friendships and creating new ones. Special thanks to Laurel Pennick for her help with organizing the event!

If you're interested in participating, give us a call at (602) 955-3947!

Men's Group

The Men's group is for men 18 years old and older to get together and hang out while learning and having fun. It is designed to have an impact on many aspects of the men's lives through providing education and support, promoting good health, and establishing a sense of community. The group attended the Cardinals home opener on Sunday, September 13th! The men met at the Arizona Hemophilia Association office for lunch, networking and an educational seminar. They were then transported as a group to the University of Phoenix Stadium for the 1:15 PM kickoff of the Cardinals against the New Orleans Saints!

Then, On Saturday, January 23rd the Men's Group attended a Suns game against the Atlanta Hawks. They got together to enjoy camaraderie and a chance to network with each other at the home of a local community member, then they all headed over to the evening game!

If you have any questions about the Men's Group, give Steve a call at (602) 955-3947!

Epic

Epic is our teen program focusing on transitional education and networking. At our Annual Statewide Meeting in August, the teens gathered together with Steve, our TEAM Outreach Coordinator for introductions and to discuss Epic goals for the year. In October, the teens kicked off the cooler weather with a hike through the Phoenix Mountain Preserve Conservation Park in North Phoenix. They learned the importance of fitness and keeping active and then rewarded their physical activities of the day with some frozen yogurt. In December, the teens met to get the latest info on scholarships, ACT/SAT test prep, and to get a start on the real-world job hunt. For more information about the program, email Steve at steve@arizonahemophilia.org.

Hispanic Heritage Day

For the first time this year, we were able to offer two Hispanic Heritage Day celebrations, one in Phoenix and one in Tucson, both sponsored by Baxalta. This statewide program allows families who may have never met with the community or are newly diagnosed share cultural and educational programming in their primary language. This educational event focuses on bleeding disorder education in the Spanish speaking community. The first event occurred on Sunday, September 27th and was located in Phoenix. The second Hispanic Heritage Day event was located in Tucson on November 22, 2015 and included entertainment and educational programming for our Southern Arizona families. Questions about Hispanic Heritage Day? Call (602) 955-3947!

Holiday Party

Both the Phoenix and Tucson Holiday Parties were big hits this year! Tucson's holiday party was held on Sunday, December 13th at the Omni Resort in Tucson from 2pm-5pm. Attendees enjoyed gifts for the families, a visit from Santa Claus, a delicious buffet meal and a station for attendees to make their own s'mores!. Special thanks to the Cascade Foundation for co-sponsoring the holiday party in Tucson!

The Phoenix holiday party was held again at McCormick Stillman Railroad Park. We had fun inflatables, food trucks, popcorn, candy canes, a special visit from Santa Claus, and gifts for all the kids! The party was held from 4 until dark, just in time for the Railroad Park's unique train ride to see holiday lights around the park! Check out photos of this year's Phoenix Holiday Party on our Facebook page! Facebook.com/AZHemo

Legislative Day/Lunch on the Lawn –Can I Make A Difference?

Annually the Arizona Hemophilia Association members come together to educate our elected officials about the challenges we face in living with a bleeding disorder. We host a lunch on the state capitol lawn for legislators to sit down with our members to learn about the impact of living with a bleeding disorder not just medically but also emotionally and financially.

Some ask does it really make a difference? It absolutely does. Each year we gain greater awareness about our cause, we build relationships with our legislators and educate about what it is like to live with this condition. Now in our 10th year, we have garnered a strong reputation for being professional, involved and highly organized at our Arizona State Capitol. We have become strong voice in representing those with chronic medical conditions.

It is more important than ever that we all come to the Capitol this one day to have one voice together. There are many changes in healthcare that could impact your access to the medication you want, from the provider you want, at the time you want it. We have to have a voice at the table when decisions are being made by our legislators that impact our lives. It is your responsibility and mine to stand up and be heard so that we can protect the care provided today and have access to all of the new advancements in treatment in the future.

Join us on March 23rd at the Capitol for this very important day for the bleeding disorders community. Call us at 602-955-3947 to sign up today.

Advocating for Product Choice

Since longer lasting products emerged on the scene two years ago, we have been working with AHCCCS to have them added to the formulary so that patients can have access to these new products that can improve our quality of life, increase compliance with treatment, and reduce the number of infusions per year. We are still trying to get these new products approved by AHCCCS. We anticipate that they will be added in the next 6 months but are concerned that the state may require a patient to try less expensive options before trying the newer products. We are trying to educate the state officials on the importance of having product choice for everyone. Similarly, with over 30 new products in the pipeline for hemophilia and von Willebrands over the next 5 years, we may see more scrutiny on allowing all of the products on the formularies for the private insurers.

AHCCCS
Arizona Health Care Cost Containment System

It will be critical that we focus on continuing to advocate for access to care and product choice. We need your help to make it happen! Please get involved in Advocacy at the AHA. Please contact Cindy@arizonahemophilia.org to lend your voice!!!

Arizona Bleeding Disorders Health and Wellness Center

ARIZONA BLEEDING DISORDERS HEALTH & WELLNESS CENTER

Family Focused Primary Care For All
Children 10 years and up • All Adults

The Arizona Bleeding Disorders Health and Wellness Center is a non-profit health clinic focused on patient centered, comprehensive and integrated treatment. We provide chronic disease management, preventative care, and ancillary services to promote a health lifestyle in partnership with the patient and family. We believe that the chronic care conditions affected the entire family so we take a family focused approach to care. **All profits are reinvested into offering education, outreach and other free services to benefit the bleeding disorders community.**

Chronic Care Management:
- Von Willebrands Disease
- Hemophilia
- Diabetes
- Asthma & Allergies
- Thyroid Disease
- Pain Management
- Behavioral Health
- Sickle Cell Anemia

The clinic was established by the Arizona Hemophilia Association to provide primary care integrated with bleeding disorders care. We have since expanded to include all chronic care management. We are focused on treating the whole person under a patient centered medical home model. We take the time to listen to you and partner with you to create a plan that works for you. We provide continuity of care by working with specialists to close the loop on ensuring you are getting your medical and emotional needs met. Our care team includes the medical provider, social worker, physical therapist, nutritionist, dentist and case manager to treat the whole person. The unique advantage of this approach is that we are able to address all of the patient's medical and emotional needs, ensure continuity of care, and manage co-morbidities.

Preventative Care:
- Dental Assessments
- Physical Therapy Evaluations
- Men's , Women's and Children's Health
- Counseling
- Naturopathic medicine
- Pain Management

Healthy Lifestyle Education:
- Nutrition
- Physical Fitness
- Lifestyle Management
- Wellness Education Series

Call to schedule your appointment today!!!
821 N. 5th Avenue, Phoenix AZ 85003 • 602-680-7722 • www.azbleed.org
We accept private and public insurance plans and uninsured patients.

ELOCTATE®
[Antihemophilic Factor (Recombinant), Fc Fusion Protein]

THE FIRST FACTOR VIII WITH A PROLONGED HALF-LIFE

Learn how a prolonged half-life may affect your infusion schedule

Meet your CoRe Manager Jessica Klass
E: jessica.klass@biogen.com T: 623-238-0244

Indications

ELOCTATE, [Antihemophilic Factor (Recombinant), Fc Fusion Protein], is a recombinant DNA derived, antihemophilic factor indicated in adults and children with Hemophilia A (congenital Factor VIII deficiency) for: on-demand treatment and control of bleeding episodes, perioperative management of bleeding, and routine prophylaxis to reduce the frequency of bleeding episodes. ELOCTATE is not indicated for the treatment of von Willebrand disease.

Important Safety Information

Do not use ELOCTATE if you have had an allergic reaction to it in the past.

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, are breastfeeding, are pregnant or planning to become pregnant, or have been told you have inhibitors (antibodies) to Factor VIII.

Allergic reactions may occur with ELOCTATE. 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 ELOCTATE, which may stop ELOCTATE from working properly.

The most frequently occurring side effects of ELOCTATE are headache, rash, joint pain, muscle pain and general discomfort. These are not all the possible side effects of ELOCTATE. Talk to your healthcare provider right away about any side effect that bothers you or that does not go away, and if bleeding is not controlled after using ELOCTATE.

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.

Biogen

© 2016 Biogen. All rights reserved. Printed in U.S.A. ELO-US-0492 02/16

FDA-Approved Patient Labeling
Patient Information
ELOCTATE® /el' ok' tate /
[Antihemophilic Factor (Recombinant), Fc Fusion Protein]

Please read this Patient Information carefully before using ELOCTATE 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 ELOCTATE?
ELOCTATE is an injectable medicine that is used to help control and prevent bleeding in people with Hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ELOCTATE when you have surgery.

Who should not use ELOCTATE?
You should not use ELOCTATE if you had an allergic reaction to it in the past.

What should I tell my healthcare provider before using ELOCTATE?
Talk to your healthcare provider about:

- Any medical problems that you have or had.
- All prescription and non-prescription medicines that you take, including over-the-counter medicines, supplements or herbal medicines.
- Pregnancy or if you are planning to become pregnant. It is not known if ELOCTATE may harm your unborn baby.
- Breastfeeding. It is not known if ELOCTATE passes into the milk and if it can harm your baby.

How should I use ELOCTATE?
You get ELOCTATE as an infusion into your vein. Your healthcare provider will instruct you on how to do infusions on your own, and may watch you give yourself the first dose of ELOCTATE.

Contact your healthcare provider right away if bleeding is not controlled after using ELOCTATE.

What are the possible side effects of ELOCTATE?
You can have an allergic reaction to ELOCTATE. Call your healthcare provider or emergency department 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 ELOCTATE. This can stop ELOCTATE from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

Common side effects of ELOCTATE are headache, rash, joint pain, muscle pain and general discomfort.

These are not the only possible side effects of ELOCTATE. Tell your healthcare provider about any side effect that bothers you or does not go away.

How should I store ELOCTATE?

- Keep ELOCTATE in its original package.
- Protect it from light.
- Do not freeze.
- Store refrigerated (2°C to 8°C or 36°F to 46°F) or at room temperature [not to exceed 30°C (86°F)], for up to six months.
- When storing at room temperature:
- Note on the carton the date on which the product is 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 ELOCTATE after the expiration date printed on the vial or, if you removed it from the refrigerator, after the date that was noted on the carton, whichever is earlier.

After reconstitution (mixing with the diluent):

- Do not use ELOCTATE if the reconstituted solution is not clear to slightly opalescent and colorless.
- Use reconstituted product as soon as possible.
- You may store reconstituted solution at room temperature, not to exceed 30°C (86°F), for up to three hours. Protect the reconstituted product from direct sunlight. Discard any product not used within three hours.

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

44279-02

Manufactured by:
Biogen Inc.
Cambridge, MA 02142 USA
U.S. License # 1697
ELOCTATE® is a registered trademark of Biogen.

Meet Chelsea, Our New Development Coordinator!

Chelsea Bolyard was the former program director at Camp Sky-Y and worked with AHA's Camp HONOR 2 years in a row back in 2013 and 2014. After leaving the camp she worked for a couple local marketing companies and realized she couldn't stay away from the AHA. We have brought her to our team as the new Development Coordinator where she will be working on all of our fundraising events, marketing, and anything else she can get her hands on!

Upcoming Events & Programs

February

23-28 - Future Leaders Washington Trip (Advocacy)

24-26 - NHF Washington Days

March

5 & 6 - My Nana's Best Tasting Salsa Challenge
19 - Camp HONOR Picnic
21-23 - Future Leader's Program
22 - Advocacy Training
23 - Lunch on the Lawn

April

1-3 - Men's Retreat
17 - Community Education Day (Phoenix)
22-24 - NOW Conference
30 - Community Education Day (Tucson)

May

6-8 - Counselors in Training (CIT) Trip
7 - BleedHERs
14 - Community Education Day (Yuma)
May 30-June 4 - Camp HONOR

June

May 30-June 4 - Camp HONOR
25 - Men's Group

For more information, visit our website:

www.ArizonaHemophilia.org

ARIZONA HEMOPHILIA ASSOCIATION
Serving those living with inherited bleeding disorders

Contact Information Update

Have you moved recently? Changed your email address?

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.

ARIZONA HEMOPHILIA ASSOCIATION
Serving those living with inherited bleeding disorders

826 N 5th Ave
Phoenix, AZ 85003

32nd Annual My Nana's Best Tasting Salsa Challenge

ALL THE SALSA YOU CAN EAT AND MORE!

March 5 & 6

Get your Tickets Today!

$12 Early Bird
Available Now Online!

$15 Gate
Kids under 12 are free!

$55 VIP
Available Now Online!

My Nana's Best Tasting Salsa Challenge March 5-6, 2016 Presented by Arizona Hemophilia Association

Steele Indian School Park
300 E Indian School Rd, Phoenix, AZ 85012

Saturday AND Sunday

Do you have a great SALSA recipe?
Winner each day receives $1000 cash!

Retail opportunity for the Grand Champion with El Sol Foods*
*Some restrictions apply, details at www.SalsaChallenge.com

www.SalsaChallenge.com