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OFFICIAL NEWSLETTER OF ARIZONA HEMOPHILIA ASSOCIATION

1967 ARIZONA HEMOPHILIA ASSOCIATION 2017

50th ANNIVERSARY

IN THIS ISSUE...

A Note from our CEO, Cindy Komar

Hello Friends!

It was great to see so many of you at the Annual Statewide Meeting in September in Tucson. With over 420 in attendance, we are excited to see it continue to grow! It all started eleven years ago with 100 in attendance.

We have several exciting changes that I want to share with you:

*Cristina Barnes has been promoted to Executive Director of the AHA! I am still going to be involved - working on special projects, building relationships with public policy officials, focusing on access to healthcare and growing AHA. Cristina has been the Office Manager at AHA for the past year and a proven leader. As Executive Director she will be managing the operations of the AHA. She has been a huge asset to our organization, and is a great team builder! She is passionate about AHA and making a difference in our community. Please join me in congratulating Cristina! **Continued on page 3...**

ARIZONA HEMOPHILIA ASSOCIATION
Serving those living with inherited bleeding disorders

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...

*With the celebration of our 50th Anniversary, AHA is continuing to expand its programs and services to better serve the entire state. The Annual Statewide Meeting was held in Tucson for the first time and we are planning on moving it around the state in future years. We are starting FAME (Family and Member Education) programs throughout the state to get local bleeding disorder communities together. We are starting with Tucson, Yuma and Flagstaff. You can get involved by reaching out to Cristina.

*AHA has revitalized the Advocacy Committee. With over 40 members and going strong, we are addressing the access to healthcare issues arising both federally and locally. This is a great way to get involved and let your voice be heard!

*The Zombie Walk is coming up October 28th. It is the second year that the AHA has taken over this event. Come help volunteer at this unique and fun Halloween event.

*The location of the Salsa Challenge is changing to Sloan Park, the Chicago Cubs spring training facility. The event used to be held at a stadium so we are bringing it back to its roots. The dates are April 14 & 15th. More information to come.

*We are excited to announce that the Arizona Bleeding Disorders Health and Wellness Center (ABDC), established by AHA, has added Jeff Kallberg to the team! He has joined ABDC as the physical therapist and program coordinator for the bleeding disorder program. Jeff brings unique experience to ABDC having over 23 years of clinical experience as a physical therapist and having severe hemophilia as well.

*ABDC has also opened an infusion suite to provide medical and wellness infusions for all. Just reach out to the clinic at 602-680-7722 to find out more.

*The best part is that ALL profit from the clinic and infusion suite go back to support the clinic and our bleeding disorder community. So tell your friends, neighbors and family to use our clinic and help us support you! The clinic is across the street from the Arizona Hemophilia Association, to make it convenient and community focused. Stop by and check it out! Call 602-680-7722 today to schedule an appointment.

In order to make this all work, we need your help. As we announced at the Annual Meeting in Tucson, we have noticed a trend of ‘no shows’ at several of our events so we started tracking them. Over the past year we have estimated a cost to the AHA of almost $50,000 due to members just not showing up after they have RSVP’d that they will attend. These are not members who had an emergency or called us beforehand to cancel – they simply did not show up. This is a huge cost to our organization and not fair to our other members, our sponsors, and our staff. For every event/program we do, we have to commit to a number of attendees by a certain date – for food, the location etc. So if you just don’t show up, we still have to pay for the food, use of the room, daycare etc. Moving forward, we will establish an attendance policy for our members to set expectations and consequences.

The AHA team is here to provide community for those living with a bleeding disorder in Arizona. To best serve you, we need to hear from you! We need your input and assistance! You can volunteer by giving of your time at a particular event, in the office or as a speaker in our volunteer speaker’s bureau. You can get together a walk team for our Walk, or simply let others know about our events so they can also come. We are always looking for members who want to help organize our programs, come up with new ideas and help us make sure we are meeting the needs of our community. **Continued on page 3...**

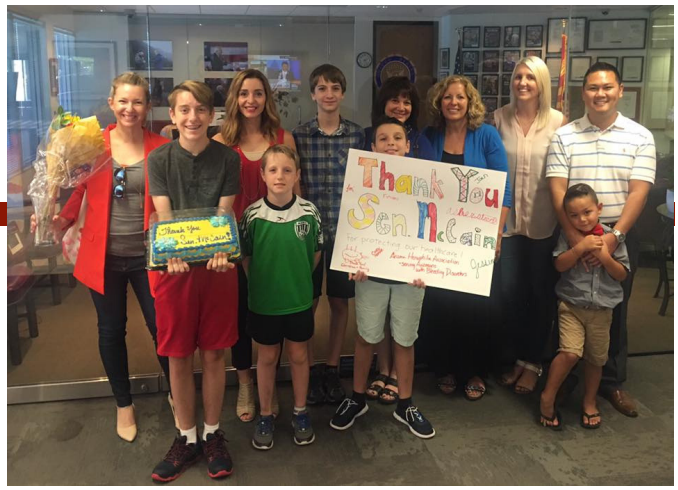
Continued from page 2...

Don't have much time but want to help? You can get your company to contribute to us through jean's day, 50/50 raffles, or becoming a sponsor for one of our events. You can help us get silent auction items donated at our golf tournament or the Salsa Challenge. 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.

With gratitude,

Cindy Komar
CEO



Advocacy-
We Make a Difference!

Jessica Steed

Arizona Hemophilia Association advocacy committee has been busy this year. We've held not one, but two special events called Hour of Power where we contacted our Senators via social media to encourage them to vote against healthcare cuts. Each time, we had community members at AHA (or home/work) coordinate for one hour to post photos, video, and send messages to amplify our voices. Thanks to all who participated! We were thrilled to see Senator McCain cast a deciding vote to protect healthcare and we thanked him with flowers and a cake!

Despite this big win, the battle against healthcare continues, including 2018 formulary changes to AZ ACA plans. Our committee is working with AHA to advocate for product choice to the Ambetter plan of Healthnet.

Fortunately, increased participation in the Advocacy committee has allowed us to focus our efforts in subcommittees where we work to answer these questions-

1. Communication
How do we notify members of action items, for example: creating and utilizing a regional phone tree?
What education and support to members need to take action?

2. Personal Advocacy and Ambassadors
What examples do we have of personal advocacy and how do we develop these skills in our members?
How do we increase connection with the AHA, with other members?
How do we create awareness of the resources offered at AHA and available to the community?

3. Federal and State
What changes are happening at the federal and state level that affect our community?
How are we maintaining connection with our state and fedarl legislators?
What bills will we introduce in next year's state legislative session?

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

Indications for RIXUBIS [Coagulation Factor IX (Recombinant)]

RIXUBIS is an injectable medicine used to replace clotting factor IX that is missing in adults and children with hemophilia B (also called congenital factor IX deficiency or Christmas disease).

RIXUBIS is used to control and prevent bleeding in people with hemophilia B. Your healthcare provider may give you RIXUBIS when you have surgery. RIXUBIS can reduce the number of bleeding episodes when used regularly (prophylaxis).

Detailed Important Risk Information

You should not use RIXUBIS if you are allergic to hamsters or any ingredients in RIXUBIS.

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 hamsters, are nursing, are pregnant or planning to become pregnant, or have been told that you have inhibitors to factor IX.

Allergic reactions have been reported with RIXUBIS. Call your healthcare provider or get emergency treatment right away if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea, or fainting.

Your body may form inhibitors to factor IX. An inhibitor is part of the body's defense system. If you form inhibitors, it may stop RIXUBIS from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for development of inhibitors to factor IX.

If you have risk factors for developing blood clots, the use of factor IX products may increase the risk of abnormal blood clots.

Common side effects that have been reported with RIXUBIS include: unusual taste in the mouth, limb pain, and atypical blood test results.

Call your healthcare provider right away about any side effects that bother you or if your bleeding does not stop after taking RIXUBIS.

Please see following page for RIXUBIS Important Facts.

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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RIXUBIS
[COAGULATION FACTOR IX (RECOMBINANT)]
MOVING FORWARD

RIXUBIS
[COAGULATION FACTOR IX (RECOMBINANT)]

Important facts about

RIXUBIS [Coagulation Factor IX (Recombinant)]

This leaflet summarizes important information about RIXUBIS. 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 RIXUBIS. If you have any questions after reading this, ask your healthcare provider.

What is RIXUBIS?

RIXUBIS is a medicine used to replace clotting factor (Factor IX) that is missing in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Hemophilia B is an inherited bleeding disorder that prevents blood from clotting normally. RIXUBIS is used to prevent and control bleeding in people with hemophilia B. Your healthcare provider may give you RIXUBIS when you have surgery. RIXUBIS can reduce the number of bleeding episodes when used regularly (prophylaxis).

Who should not use RIXUBIS?

You should not use RIXUBIS if you

- are allergic to hamsters
- are allergic to any ingredients in RIXUBIS.

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

What should I tell my healthcare provider before using RIXUBIS?

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 hamsters
- are breastfeeding. It is not known if RIXUBIS passes into your milk and if it can harm your baby
- are pregnant or planning to become pregnant. It is not known if RIXUBIS may harm your unborn baby
- have been told that you have inhibitors to factor IX (because RIXUBIS may not work for you).

How should I infuse RIXUBIS?

RIXUBIS is given directly into the bloodstream. RIXUBIS should be administered as ordered by your healthcare provider. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia B learn to infuse their RIXUBIS by themselves or with the help of a family member.

Your healthcare provider will tell you how much RIXUBIS to use based on your weight, the severity of your hemophilia B, and where you are bleeding. You may have to have blood tests done after getting RIXUBIS to be sure that your blood level of factor IX is high enough to clot your blood. Call your healthcare provider right away if your bleeding does not stop after taking RIXUBIS.

What are the possible side effects of RIXUBIS?

Allergic reactions may occur with RIXUBIS. Call your healthcare provider or get emergency treatment right away if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting. Some common side effects of RIXUBIS were unusual taste in the mouth and limb pain. Tell your healthcare provider about any side effects that bother you or do not go away. These are not all the side effects possible with RIXUBIS. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about RIXUBIS?

Your body may form inhibitors to factor IX. An inhibitor is part of the body's defense system. If you form inhibitors, it may stop RIXUBIS 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 IX.

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

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.

The risk information provided here is not comprehensive. To learn more, talk about RIXUBIS with your healthcare provider or pharmacist. The FDA-approved product labeling can be found at http://www.shirecontent.com/PI/PDFs/RIXUBIS_USA_ENG.pdf or by calling 1-800-FDA-1088.

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Empower the Girl, Empower the Woman

Wendy E. Owens

Let's talk about your daughter and whether she might be a carrier for a genetic mutation that causes hemophilia. According to National Hemophilia Foundation's (NHF) Steps for Living, there's a chance that a woman is a carrier ifshe is the mom, grandmother, or sister of a biological son,grandson, or brother with hemophilia; or the aunt, cousin, or niece of a male with hemophilia related through her mother. If your daughter fits any of these scenarios, NHF's Medical and Scientific Advisory Council (MASAC) recommends that she undergo genetic testing to determine her carrier status.

What Is Genetic Testing?

Though once in the realm of sci-fi novels, genetic testing is now mainstream. Genetic testing identifies changes in the normal structures of proteins, genes, and chromosomes. An integral part of genetic testing is the counseling that goes with it. Meg Bradbury, senior genetic counselor at GeneDx, Inc., describes genetic counseling as "the process of helping patients understand and adapt to medical, psychological, and familial implications of genetics contributing to disease."1

Bradbury explains that genetic counseling breaks down into three parts: "interpretation of medical histories to assess the chance of disease occurrence or recurrence; education about inheritance, testing, management, prevention, resources, and research; and counseling from a genetic counselor to promote informed choices and adapt to the risk or condition."

Does Insurance Cover Testing?

Many large health insurance plans cover genetic testing when it's recommended by a doctor. In fact, $5 billion annually is spent on genetic testing. Within the next ten years, this number could reach $15 billion to $25 billion.2 ""Often, genetic testing for hemophilia is a covered benefit because learning hemophilia carrier status can impact medical care," says Sumedha Ghate, genetic counselor at Hemophilia Outreach Center in Wisconsin."When you are making decisions about whether or not to pursue gene testing for carrier status and you have questions about insurance coverage, first talk to a genetic counselor. They have up-to-date information and can answer your questions."

Many insurance companies consider genetic testing medically necessary if a person is at risk for inheriting a disease or disorder. Aetna Inc., for example, offers policies that cover genetic testing for hemophilia A and B. Aetna considers genetic testing medically necessary if a patient "is at direct risk of inheriting the mutation in question and the result of the test will directly impact the treatment," among other reasons.3 The trouble is, insurance coverage for genetic testing is inconsistent among health insurance companies, and even within a single company's plans. For instance, Medica Health Plans covers single-gene testing for carrier status of heritable disorders when (1) testing is ordered by board-certified medical geneticist or genetic counselor; or (2) the patient has symptoms of or a family history of a genetic disorder.4 But while Medica covers genetic testing for hemophilia A, it doesn't cover the same testing for hemophilia B.

The Practical Impact of Testing

Your daughter has a right under the US and state constitutions to make certain reproductive choices, including having genetic testing.5 But there are pros and cons to genetic testing. It's essential to talk to your daughter about the risks of not being tested,

1. Hemophilia Federation of America, https://www.youtube.com/user/VoicesHFA (accessed May 17, 2017). 2. Christina Farr, "If You Want Life Insurance, Think Twice Before Getting a Genetic Test," https://www.fastcompany.com/3055710/if-you-want-life-insurance-think-twice-before-getting-genetic-testing (April 6, 2016, accessed May 3, 2017). 3. "Genetic Testing," Aetna, http://www.aetna.com/cpb/medical/data/100_199/0140.html (accessed May 3, 2017). 4. Medica Coverage Policy, Genetic and Pharmacogenetic Testing (policy name), https://www.medica.com /-/media/documents/provider/coverage-policies/genetic_and_pharmacogenetic_testing_cp.pdf?la=en (accessed May 31, 2017). 5. Institute of Medicine (US) Committee on Assessing Genetic Risks, Lori B. Andrews et al., eds., "Social, Legal, and Ethical Implications of Genetic Testing" (Washington, DC: National Academies Press, 1994),https://www.ncbi.nlm.nih.gov/ books/NBK236044/ (accessed May 31, 2017).

given her chances of being a carrier, as well as the risks of being tested.

Michelle Alabek, genetic counselor at the Institute for Transfusion Medicine, advises parents and relatives of potential carriers, “Talk to your daughter or female relative about genetic testing for carrier status, share information with her, and help her understand why this could be so important.” For example, knowing carrier status before a medical procedure can help prevent bleeding complications. Equally important is testing factor levels of girls with a family history of hemophilia at as early an age as possible. “If we know someone is a carrier and at risk for bleeding with a procedure, I can develop a proactive plan with a carrier to minimize bleeding risk,” says Alabek. “Without this management plan, a female may have avoidable bleeding with or after the procedure, which can lead to negative health outcomes.”

According to MASAC, 50% of women and girls who are carriers for hemophilia also have factor levels below 50%, putting them at risk for excessive bleeding during delivery of a baby as well as during a surgery, accident, or menstruation.6 Carriers who plan to become pregnant need to know their factor level and create a bleed management plan for delivery. Having a plan is critical in avoiding complications for both mother and baby.

According to Bradbury, “If the genetic variant that causes bleeding is known, then you can make choices about options for genetic testing pre-conception and post-conception. An informed mom-to-be can work with her ob/gyn to create a delivery plan using MASAC guidelines. A plan may include having factor on hard, avoiding the use of assistive delivery devices, and planning for procedures, like circumcision, after a baby is born.”

It’s also important that your daughter understands the risks of being tested. These range from emotional impact to potential genetic discrimination. When a woman learns she’s a carrier, she may feel anxious, depressed, angry, or guilty. “Genetic testing can elicit a variety of emotions,” explains Alabek. “Individuals within the same family may respond differently to the same results, so having genetic counseling ahead of time can help a woman with the psychosocial aspects of testing, promote informed decision making, and anticipate reactions to the different possible test results.”

What about the risk of genetic discrimination? After 13 years of trying, in 2009 Congress barred health insurance companies from denying coverage to people with a genetic mutation and prohibited genetic discrimination in employment by passing the Genetic Information Nondiscrimination Act (GINA).7 But this hard-fought win doesn’t mean that your daughter is free from genetic discrimination. GINA does not apply to employers with fewer than 15 employees who provide health insurance to their employees. GINA also does not apply to other types of insurance, such as life, disability, or long-term care insurance.8

The Price of Privacy

For privacy reasons, some people choose to pay out-of-pocket for genetic testing so that the testing and results do not appear in their medical record. Those costs range from $200 to $3,000 plus.9 Ghate recommends asking a genetic counselor about the actual cost of testing. “If the specific causative mutation has been identified in the affected family member, carrier testing cost is quite reasonable, with the cost varying by lab and specific mutation.” She explains, “In 2017, eligible potential carriers can seek carrier testing at no cost through the My Life Our Future program at qualified hemophilia treatment centers.” If you do not receive care at a hemophilia treatment center (HTC), Bradbury recommends that you visit the National Society for Genetic Counselors website (www.nsgc.org) to find a genetic counselor. For more on My Life Our Future, visit www.mylifeourfuture.org.

6. “MASAC Recommendations Regarding Girls and Women with Inherited Bleeding Disorders,” https://www.hemophilia.org/Researchers-Healthcare-Providers/Medical-and-Scientific-Advisory-Council-MASAC/MASACRecommendations/MASAC-Recommendations-Regarding-Girls-and-Women-with-Inherited-Bleeding-Disorders (Nov. 16, 2016, accessed May 3, 2017). 7. Farr, “If You Want Life Insurance, Think Twice Before Getting a Genetic Test.” 8. “What Is Genetic Discrimination?” Genetics Home Reference, US National Library of Medicine, National Institutes of Health, https://ghr.nlm.nih.gov/primer/testing/discrimination (accessed May 3, 2017). 9. “Frequently Asked Questions About Genetic Testing.”

2017

VOLUNTEER OF THE YEAR- ALEX PARRA
BETSY BLACKLEDGE ADVOCATE OF THE YEAR- BRENT DAVILA

Our 2017 Volunteer of the Year award was given to Alex Parra. Alex has been a part of the bleeding disorder community for many years. He has shown true passion for the community by volunteering his time as a Field Maintenance lead for the Salsa Challenge, a Unit Head at Camp HONOR, and has spent many weekends helping with childcare and AV at our various conferences. Alex also sits on the Zombie Walk, Camp HONOR and Salsa Challenge committees. We would like to recognize Alex for his commitment to the Association. Thank you for all your hard work!

In Honor of Betsy Blackledge, an advocate for the bleeding disorder community and for education, who helped start Camp HONOR and many of the AHA programs, last year we established this award. Betsy was a mother of two sons with hemophilia and gave so much in order to all of us to have the many programs and services AHA provides today. The award is given to a community members who exhibits her enthusiasm in making a difference, her persistence to have our voices heard, and her passion for the bleeding disorder community. This year the Betsy Blackledge Advocacy Award was given to Brent Davila. In the past few years Brent has shown his true advocacy efforts by attending all of our State Legislative Days and helped facilitate our Washington Trip for our Future Leaders. Recently, Brent gave a testimonial to the ACCHSS Committee which helped lead the way to provide more product options for our community. We commend Brent for all his hard work and dedication to advocate for the bleeding disorder community. Congratulations, Brent!

Hundreds Gather at National AIDS Memorial to Dedicate Newly Built Hemophilia Memorial Circle to Honor Lives Lost in Early Days of AIDS Epidemic

From Prnewswire.com

Hundreds of hemophilia advocates and survivors came together at the National AIDS Memorial to dedicate the Hemophilia Memorial Circle, a beautifully designed permanent feature built to forever honor all the lives lost in the hemophilia community to AIDS.

During a touching dedication ceremony, the names of the first loved ones whose names will appear in the Hemophilia Memorial Circle were read aloud and red roses were placed in the memorial in their honor. The names include family members, friends, supporters and loved ones in the Hemophilia community who lost their lives to AIDS. Each name will be inscribed in the memorial over the next month and included as part of World AIDS Day ceremonies on December 1st.

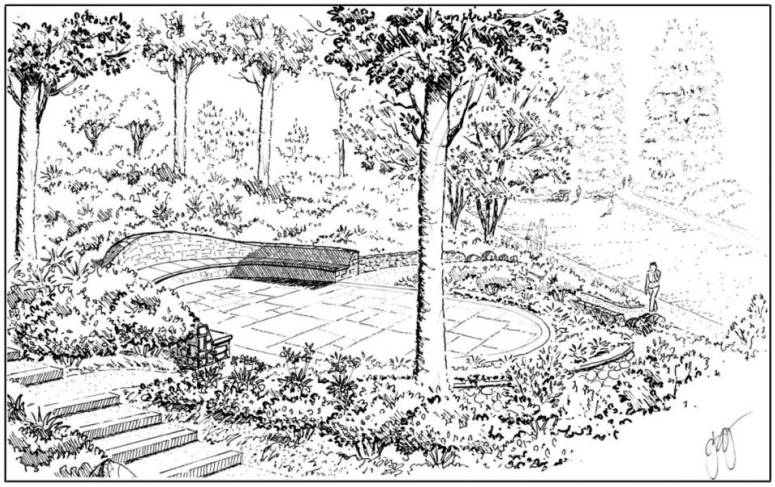
The Hemophilia Memorial Circle consists of a new stone circle and surrounding landscape with benches inscribed with the names of those in the hemophilia community who have died from AIDS. It also pays tribute to the courage and activism of those who worked tirelessly on behalf of the hemophilia community to ensure America's blood supply is safe and that the tragedy they lived through never happens again.

"The story of AIDS is a story of darkness, and a story of light -- of hope, healing, and gratitude. One of these stories is that of the hemophilia community, which nearly thirty years ago suffered through the loss of thousands of lives," said John Cunningham, Executive Director of the National AIDS Memorial. "Each name inscribed here will tell a story of a person who was loved, and who was gone too soon. Telling their stories we help future generations understand the past and use those lessons to shape a better tomorrow."

Hemophilia is a genetic condition that prevents a person's blood from clotting. Common sites of bleeding are muscles and internal joints and organs, including the brain, which can cause injury and death.

In the 1980s, the hemophilia community's lifeline was a medicine – clotting factor – derived from a large and diverse blood supply. It was only after people with hemophilia began to be diagnosed with HIV that they realized the blood supply was tainted. Eventually, 90% of people with severe hemophilia were infected with HIV from contaminated factor.

Cries for help were met with silence from drug corporations and the federal government. People with the disease were left to fight this fight on their own, and they have served as the guardians of the nation's blood supply ever since.



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"Were it not for the strength of so many in both the hemophilia and HIV/AIDS communities who stood up during the worst of times, the breakthroughs we see today in HIV research, prevention, and treatment would not have happened," said Kimberly Haugstad, President and CEO of the Hemophilia Federation of America. "This memorial will serve as a permanent reminder of the lives that were lost and will pay tribute to the bravery and activism of a community that has suffered so dearly."

This year marks nearly thirty years since the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was signed into law, creating the most extensive federal program that provides services exclusively to people living with HIV. Ryan White, a person with hemophilia whose story captivated our nation and the world, never lived to see passage of the new law, but his bravery, courage and heart will never be forgotten. His mother, Jeanne White-Ginder, a prominent activist and supporter of both the Hemophilia and HIV/AIDS Communities, was a strong advocate for the new memorial.

"For decades, I have worked side-by-side with brave and dedicated people to tell Ryan's story and stories of those like him," White-Ginder said. "The construction of this memorial – inside the National AIDS Memorial, which has already brought hope to so many for decades – is a long overdue acknowledgment of those in the Hemophilia community who lost their lives so tragically."
The completion of the Hemophilia Memorial Circle at the National AIDS Memorial forever brings the hemophilia and gay communities together, bound by their common stories of fear, prejudice, loss and hope.

"The tragedy that struck this community is one that cannot be forgotten," said Val Bias, CEO of the National Hemophilia Foundation. "It is our duty to find a way to provide a place for people to remember those who lost their lives, and this memorial does just that. We are honored to be able to partner with organizations that share this mission."

The National AIDS Memorial partnered with the Hemophilia Federation of America and the National Hemophilia Foundation to build the Hemophilia Memorial Circle, which serves as a place where the community can grieve and remember those lost during the early days of the AIDS epidemic. For more information on the Hemophilia Memorial Circle at the National AIDS Memorial and how to have a name inscribed, visit www.aidsmemorial.org/hemophilia.

Introducing Jeffrey Kallberg, PT, DPT.

ARIZONA BLEEDING DISORDERS HEALTH & WELLNESS CENTER

Jeff brings unique experience to the Arizona Bleeding Disorders Health and Wellness Center having over 23 years of clinical experience as a physical therapist and having severe hemophilia as well. This combination provides Jeff has an unparalleled understanding of the physical and social challenges faced by our community members.

Jeff has been featured in HemAware Magazine for his accomplishments with unique treatment strategies for both recovery from injuries, chronic pain, arthritis and in improving athletic or physical performance. Jeff earned a black belt in Tae Kwon Do at the age of 38 despite his joint problems crediting that success to careful conservative management and adaptation. Personally, Jeff focuses his time on his wife and 3 kids, and enjoys motorsports. Jeff earned his physical therapy degree from the University of Minnesota and his Doctorate from the University of South Dakota.

IXINITY®
coagulation factor IX (recombinant)

Factoring in your world™

Just B Determined

"The IXINITY reps really make you feel like, 'that's the kind of person I can trust'.

—Felix has hemophilia B and uses IXINITY

See why Felix switched to IXINITY at **JustBIXperiences.com**

This information is based on Felix's experience. Different patients may have different results. Talk to your doctor about whether IXINITY® may be right for you.

INDICATIONS AND IMPORTANT SAFETY INFORMATION

What is IXINITY®?

IXINITY [coagulation factor IX (recombinant)] is a medicine used to replace clotting factor (factor IX) that is missing in adults and children at least 12 years of age with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Hemophilia B is an inherited bleeding disorder that prevents clotting. Your healthcare provider may give you IXINITY to control and prevent bleeding episodes or when you have surgery.

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

IMPORTANT SAFETY INFORMATION for IXINITY®

- You should not use IXINITY if you are allergic to hamsters or any ingredients in IXINITY.
- You should tell your healthcare provider if you have or have had 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 hamsters, are nursing, are pregnant or planning to become pregnant, or have been told that you have inhibitors to factor IX.
- You can experience an allergic reaction to IXINITY. Contact your healthcare provider or get emergency treatment right away if you develop a rash or hives, itching, tightness of the throat, chest pain, or tightness, difficulty breathing, lightheadedness, dizziness, nausea, or fainting.
- Your body may form inhibitors to IXINITY. An inhibitor is part of the body's defense system. If you develop inhibitors, it may prevent IXINITY from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for development of inhibitors to IXINITY.
- If you have risk factors for developing blood clots, the use of IXINITY may increase the risk of abnormal blood clots.
- Call your healthcare provider right away about any side effects that bother you or do not go away, or if your bleeding does not stop after taking IXINITY.
- The most common side effect that was reported with IXINITY during clinical trials was headache.
- These are not all the side effects possible with IXINITY. You can ask your healthcare provider for information that is written for healthcare professionals.

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

Please see accompanying brief summary of Prescribing Information on next page.

Aptevo™ Therapeutics

Aptevo BioTherapeutics LLC, Berwyn, PA 19312

IXINITY®
coagulation factor IX
(recombinant)

Factoring in your world™

IXINITY® [coagulation factor IX (recombinant)]

Brief Summary for the Patient

See package insert for full Prescribing Information. This product's label may have been updated. For further product information and current package insert, please visit www.IXINITY.com.

Please read this Patient Information carefully before using IXINITY. This brief summary does not take the place of talking with your healthcare provider, and it does not include all of the important information about IXINITY.

What is IXINITY?

IXINITY is a medicine used to replace clotting factor (factor IX) that is missing in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Hemophilia B is an inherited bleeding disorder that prevents clotting. Your healthcare provider may give you IXINITY when you have surgery.

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

Who should not use IXINITY?

You should not use IXINITY if you:

- Are allergic to hamsters
- Are allergic to any ingredients in IXINITY

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

What should I tell my healthcare provider before using IXINITY?

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 hamsters
- Are breastfeeding. It is not known if IXINITY passes into your milk and if it can harm your baby
- Are pregnant or planning to become pregnant. It is not known if IXINITY may harm your baby
- Have been told that you have inhibitors to factor IX (because IXINITY may not work for you)

How should I infuse IXINITY?

IXINITY is given directly into the bloodstream. IXINITY should be administered as ordered by your healthcare provider. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia B learn to infuse their IXINITY by themselves or with the help of a family member.

See the step-by-step instructions for infusing in the complete patient labeling.

Your healthcare provider will tell you how much IXINITY to use based on your weight, the severity of your hemophilia B, and where you are bleeding. You may have to have blood tests done after getting IXINITY to be sure that your blood level of factor IX is high enough to stop the bleeding. Call your healthcare provider right away if your bleeding does not stop after taking IXINITY.

What are the possible side effects of IXINITY?

Allergic reactions may occur with IXINITY. Call your healthcare provider or get emergency treatment right away if you have any of the following symptoms:

- Rash
- Hives
- Itching
- Tightness of the throat
- Chest pain or tightness
- Difficulty breathing
- Lightheadedness
- Dizziness
- Nausea
- Fainting

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

The most common side effect of IXINITY in clinical trials was headache.

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

Call your healthcare provider for medical advice about side effects. You may report side effects to the FDA at 1-800-FDA-1088.

How should I store IXINITY?

250 IU strength only; store at 2 to 8°C (36 to 46°F). Do not freeze.

500, 1000, 1500, 2000 and 3000 IU strengths; store at 2 to 25°C (36 to 77°F). Do not freeze.

Do not use IXINITY after the expiration date printed on the label. Throw away any unused IXINITY and diluents after it reaches this date.

Reconstituted product (after mixing dry product with Sterile Water for Injection) must be used within 3 hours and cannot be stored or refrigerated. Discard any IXINITY left in the vial at the end of your infusion.

After reconstitution of the lyophilized powder, all dosage strengths should yield a clear, colorless solution without visible particles. Discard if visible particulate matter or discoloration is observed.

What else should I know about IXINITY?

Your body may form inhibitors to factor IX. An inhibitor is part of the body's immune system. If you form inhibitors, it may stop IXINITY from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests to check for the development of inhibitors to factor IX. Consult your doctor promptly if bleeding is not controlled with IXINITY as expected.

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

Always check the actual dosage strength printed on the label to make sure you are using the strength prescribed by your healthcare provider.

Aptevo™ Therapeutics

Manufactured by:
Aptevo BioTherapeutics LLC
Berwyn PA, 19312
U.S. License No. 2054

Part No: 1000973_1
CM-FIX-0078

ARIZONA BLEEDING DISORDERS HEALTH & WELLNESS CENTER

Interview with Dr. Danielle Nance: Hemophilia doctor, patient and mom!

From Mircohealth.com

Five quick questions for a hemophilia expert: Danielle Nance, M.D.

1. Why did you become a hematologist?

I first thought of a career as a doctor during the 5th grade. My own experience in hospitals and with hemophilia as a child made me curious about blood and bleeding. It was a natural fit for me to want to learn more about it. After my son Isaac was born with severe hemophilia, my resolve was renewed. I wanted to be able to “pay it forward” and help create a health care system that would be strong for him when he grew up.

2. What have you learned by approaching hemophilia from multiple dimensions (as a doctor, as a patient and as a mom)?

Sometimes I wonder what it would be like to separate hemophilia from the rest of my life, but there aren’t any vacations from a bleeding disorder! As a young child, my family and I didn’t talk much about hemophilia, and we didn’t share the diagnosis with anyone except our closest friends and family. As a young woman in college, I was introduced to the National Hemophilia Foundation, and the weight of being alone with hemophilia was suddenly lifted off of me and shouldered by a national community of wonderful and caring people. Since then, hemophilia has become my strength and opened so many doors for me and my family to learn and grow and become whole. My experience as a patient first helped me to anticipate the worries and discomforts of my own patients when I am the one who is providing care. The privilege of being a doctor for me is like a major body hack – I get to learn about all the ways hemophilia and bleeding disorders affect a person, and that helps destroy the fear of hemophilia. I hope that I can help others know hemophilia from many angles and learn how to work with their bodies.

3. What are the things that you do to keep yourself and your patients healthy?

For those of us with a bleeding disorder, getting all of our planned doses of factor is the first priority to maintain our health. The very next thing, is to stay active and find a fun way to exercise. A person should exercise every day that he or she eats. We all need 30 minutes of activity every day to keep our brains and bodies happy. Finally, finding ways to be kind to ourselves and each other deepens our sense of well being and helps us get through health challenges.

4. At MicroHealth we use a new concept called “Total Prophylaxis” [which means adding “Prophylactic Monitoring” to “Prophylactic Prescribing"]. Do you think real-time treatment monitoring is important?

Continued from page 14...

Yes, I do. I read your publication showing that using MicroHealth with your treatment center for monitoring is linked to a 57% reduction in bleeds. This resonates with my own experience using the app as doctor and person with hemophilia. Over the past year, I have been lucky to have a large number of my patients using the MicroHealth app. I have a secure way to connect with my patients, and I enjoy seeing the alerts when patients reach their prophylaxis goals. It's also very helpful to get notified early when a patient has a bleed, especially when it's unexpected or it isn't resolving on time. I don't have to wait until the next clinic visit to learn about problems they might be having. Instead, I can help out right away. I like the convenience of the MicroHealth layout – logging in is simple, and running the reports takes very little effort. The MicroHealth app has strengthened my relationships with my patients and helps me feel connected to their care in real time. I also think the app has great potential to conduct research. I encourage your team to keep publishing science that helps our community.

5. How do you see the future of hemophilia?

Hemophilia for my son is so much different than it was for me growing up. He gets bruises sometimes, but he doesn't miss activities, he isn't "leaky" and rarely bleeds or oozes from cuts. Other than needing infusions, he basically lives a normal life. As we learn how to use the new treatments for hemophilia, the new extended half-life factors, gene therapy, and the new proteins that change the clotting cascade, I am hopeful that bleeding disorders will simply be a part of life, rather than a daily worry that changes how we approach life. I hope that we will see these treatments spread across the globe, where refrigeration is difficult, or for those who have trouble getting infusions. Then truly, we can say that we have conquered bleeding disorders!

Dr. Nance with her Son and Daughter

A look back at our
EVENTS...

Arizona Women's Bleeding Disorder Retreat

The Arizona Women's Bleeding Disorder Retreat was held on July 29th & 30th at the Sheraton Grand at Wild Horse Pass in Chandler. We welcomed new community members, reconnected with those we had not seen in a while, and enjoyed each other's company! During the weekend, the women participated in sessions such as Taking Control of Your Money and Healthy Lifestyles to Manage Stress. Sunday morning started with an energizing yoga class! Cindy Komar ended our weekend with a message about the importance of Advocacy in our community and how we can all get involved at the local and national level. This Retreat was a fun and educational weekend that was enjoyed by all.

Camp HONOR & CIT Trip

This year our campers took a journey into the world of Harry Potter. They learned how to play quidditch, mix potions and were sorted into their very own Harry Potter house. Along with the normal camp activities such as swimming, archery and rock climbing, the campers enjoyed the themes integration throughout the week.

Our hope with Camp HONOR every year is that we educate and provide support to children affected by an inherited bleeding disorder. This year we did this for over 120 campers! We had 80 staff dedicate their time and effort into making Camp HONOR 2017 a magical week for everyone.

The Counselor in Training (CIT) program produced 15 amazing teens this year. These kids learned how to work a long side our experienced counselors to become more well-rounded when worker with campers. For their hard work they were rewarded with a end of the summer trip to Catalina Island!

A look back at our
EVENTS...

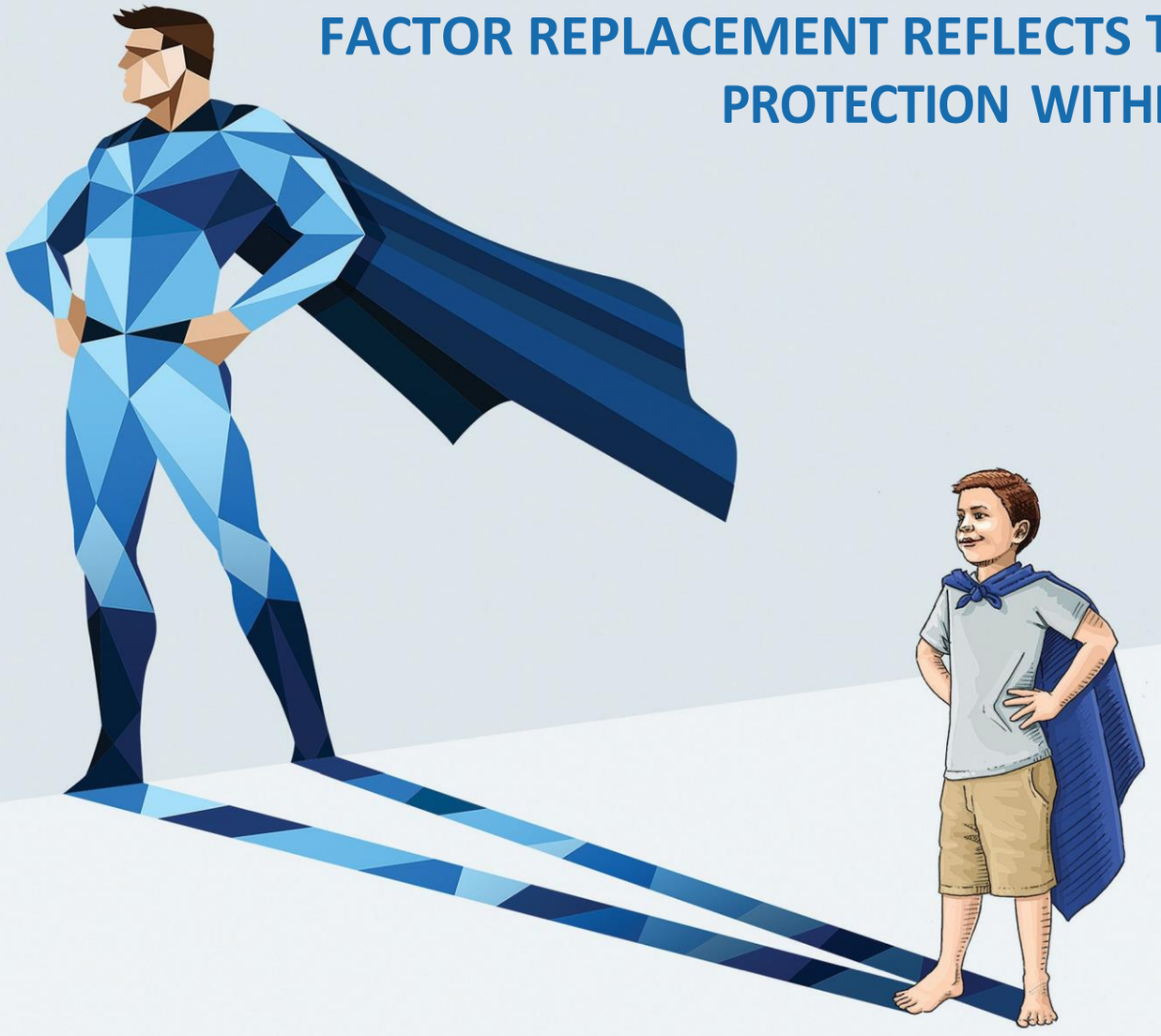
Thank you, Men, for your dedication! With your help, we accomplished many things so far. We saw the Diamondbacks get an awesome win on opening day event at Chase field (fireworks post game was a bonus). We went camping up to Sedona at the peaceful Manzanita campground (no rain on our parade). Thank you, Pfizer, for sponsoring this wonderful event! We also watched one of the most anticipated fights of the year at our fight night. All while growing our relationships with each other. We can't wait for what is next to come.

Men's Group

Hispanic Heritage Days

We celebrated culture and community at our Hispanic Heritage Days in Tucson on August 19 and Phoenix on October 7. Families came together in individual breakout sessions to learn about health and wellness for those with hemophilia. Both events were a great time for our community members to bond and meet new people. The day ended with a group Zumba session, it was an energetic finish to a great Hispanic Heritage Day. Thank you, Shire, for sponsoring this cultural event!

FACTOR REPLACEMENT REFLECTS THE PROTECTION WITHIN



For people with hemophilia, Factor treatment temporarily replaces what's missing.[1] *With a long track record of proven results, Factor treatment works with your body's natural blood clotting process to form a proper clot.*[2,3]

Brought to you by Shire, dedicated to pursuing advancements in hemophilia for more than 60 years.

Stay empowered by the possibilities.

References: 1. Peyvandi F, Garagiola I, Young G. The past and future of haemophilia: diagnosis, treatments, and its complications. *Lancet.* 2016;388:187-197. **2.** Wolberg AS. Plasma and cellular contributions to fibrin network formation, structure and stability. *Haemophilia*. 2010;16(suppl 3):7-12. **3.** King MW. Introduction to blood coagulation. http://themedicalbiochemistrypage.org/blood-coagulation.php. Last modified January 2, 2017. Accessed January 2, 2017.

Shire

congratulations

to the 4 kids from Arizona that won Shire Teen Impact Awards last week at the National Hemophilia Foundation's Annual Meeting! These awards bring attention to teens affected by bleeding disorders who make an impact on their communities through their actions and the positive examples they set.

Tyler Lipinski
Juan Pablo Lopez
Dillon Parsons
Tyler Pulley

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

time

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

treasures

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

talents

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

Board of Directors

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