Nevada Chapter
National Hemophilia Foundation
www.hfnv.org

Hemophilia News and Views

Summer Edition 2017

Inside this issue:

Chapter News

A Message from Kelli Walters:

I wanted to take a moment to reach out to all of you to say farewell. My last day with NHF Nevada is June 20th, 2017.

As Winnie the Pooh once said, "*How lucky am I to have something that makes saying goodbye so hard*."

For the last 5 years, I've been working with NHF and the extraordinary Nevada bleeding disorder community. It's been such an incredible journey on both a personal and professional level. I will miss the smiles, personalities, and talents of those I have worked closely with over the years. Keep up the good work and good luck to you all, I know you will do great things for this important cause.

I will also greatly miss all of the families that NHF Nevada serves. Getting to know all of you has been a great pleasure for me. All of you are so passionate about the issues that you and your family face on a daily basis. Please keep on being the best advocate that you can for you and your family. I just spent my last week with the chapter at camp with all of our campers…. can think of nothing better to end with!

Lastly, I need to thank two fabulous ladies, Anne and Maureen. I was lucky to work with them and will miss them very much! They will continue serving the Nevada bleeding disorder community. NHF is currently in the final interview process for my replacement. Thank you for a wonderful 5 years.

We would all like to thank Kelli for her years of dedication to the bleeding disorders community in Nevada. She will be missed very much. Please rest assured that the National Hemophilia Foundation and the Advisory Board of the Nevada Chapter are working diligently to find a new Executive Director that can build upon the foundation that Keli built and continue to grow and improve the programs & services offered here in Nevada. We look forward to introducing you to the Executive Director soon. Sincerely, Brandi Dawkins, Advisory Board President

Annual Picnic & Back to School Event

Saturday, August 5 at 5:30 pm

YMCA Outdoor Waterpark Pool

4141 Meadows Lane

Las Vegas, NV 89107

Dinner and fun are included!

Backpacks will be provided for all school aged kids!

RSVP online at hfnv.org - Go to News & Events/Events Calendar

Or call or email Maureen at 702-564-4368 or mmagana@hemophilia.org

RSVP by July 19, 2017

BAYER
access solutions

Don't let insurance or financial challenges get between you and your treatment

Free Trial Program*

- Enroll today for up to 6 free doses†
- KOVALTRY®, Antihemophilic Factor (Recombinant), or KOGENATE® FS, Antihemophilic Factor (Recombinant), is delivered to your home free of charge
- Any patient who has not taken KOVALTRY® or KOGENATE® FS is able to participate, regardless of type of insurance or if you have insurance

Access to Therapy

Concerned about maintaining access to treatment?

We might be able to provide KOVALTRY® or KOGENATE® FS at no cost if you are‡:

- Experiencing challenges getting insurance coverage for KOVALTRY® or KOGENATE® FS
- Uninsured or underinsured
- Between jobs and experiencing a gap between insurance coverage

$0 Co-pay Program§

If you have private insurance, you may be eligible for the $0 Co-pay Program.

- You may be able to receive **up to $12,000 in assistance** per year, regardless of income
- **Assistance is awarded per patient.** Multiple members of the same household can apply
- Enrollment can be started and completed in **one short phone call**

Live Helpline Support

- Consult with an expert in insurance
- Spanish-speaking Case Specialists are also available

Call **1-800-288-8374** 8:00 AM–8:00 PM (ET) Monday–Friday

*The Free Trial Program is available to newly diagnosed patients and patients who are currently using other therapy. Patients currently using KOVALTRY® or KOGENATE® FS are not eligible for the respective Free Trial programs. Participation in the Free Trial Program is limited to 1 time only per treatment. The medication provided through this program is complimentary and is not an obligation to purchase or use KOVALTRY® or KOGENATE® FS in the future. Reselling or billing any third party for the free product is prohibited by law.

†The Free Trial Program includes up to 6 free doses to a maximum of 5,000 IU for new patients and 40,000 IU for previously treated patients.

‡The program does not guarantee that patients will be successful in obtaining reimbursement. Support medication provided through Bayer's assistance programs is complimentary and is not contingent on future KOVALTRY® or KOGENATE® FS purchases. Reselling or billing any third party for free product provided by Bayer's patient assistance programs is prohibited by law. Bayer reserves the right to determine eligibility, monitor participation, determine equitable distribution of product, and modify or discontinue the program at any time.

§People with private, commercial health insurance may receive KOVALTRY® or KOGENATE® FS co-pay or co-insurance assistance based on eligibility requirements. The program is on a first-come, first-served basis. Financial support is available for up to 12 months. Eligible patients can re-enroll for additional 12-month courses. The program is not for patients receiving prescription reimbursement under any federal-, state-, or government-funded insurance programs, or where prohibited by law. All people who meet these criteria are encouraged to apply. Bayer reserves the right to discontinue the program at any time.

Kogenate FS antihemophilic factor (recombinant)

Kovaltry Antihemophilic Factor (Recombinant)

Nevada Chapter of the National Hemophilia Foundation
2017 Program and Events Calendar

You can register for all events on our website:
www.hfnv.org Go to News & Events/Events Calendar

July 12, 2017
Spanish Education Dinner
Maggiano's Fashion Show Mall

July 15, 2017
Couples Retreat
Henderson, NV

July 19, 2017
Spanish Support Group
Firefly Tapas Kitchen

July 21-23, 2017
Northern Nevada Family Weekend
Elko, NV

August 5, 2017
Back to School Picnic
YMCA Pool

August 9, 2017
Education Dinner
Claim Jumper Town Square

August 24-26, 2017
NHF Annual Meeting
Chicago, IL

September 16, 2017
Reno Walk & 5K
Bartley Ranch Park

September 23, 2017
Las Vegas Walk & 5K
Floyd Lamb Park

November 3-5, 2017
Gettin' in the Game
Phoenix, AZ

Indications for FEIBA [Anti-Inhibitor Coagulant Complex]

FEIBA is an Anti-Inhibitor Coagulant Complex indicated for use in hemophilia A and B patients with inhibitors for:

- Control and prevention of bleeding episodes
- Use around the time of surgery
- Routine prophylaxis to prevent or reduce the frequency of bleeding episodes.

FEIBA is not indicated for the treatment of bleeding episodes resulting from coagulation factor deficiencies in the absence of inhibitors to coagulation factor VIII or coagulation factor IX.

Detailed Important Risk Information for FEIBA

WARNING: EVENTS INVOLVING CLOTS THAT BLOCK BLOOD VESSELS

- **Blood clots that block blood vessels and their effects have been reported during postmarketing surveillance following infusion of FEIBA, particularly following the administration of high doses and/or in patients with a risk of forming blood clots.**
- **If you experience any of these side effects, call your doctor right away.**

You should not use FEIBA if:

- You had a previous severe allergic reaction to the product (reactions causing discomforts that are damaging and life threatening)
- You have signs of development of small blood vessel clots throughout the body
- You have sudden blood vessel clots or blocked blood vessels, (e.g., heart attack or stroke)

Events involving blood clots blocking blood vessels can occur with FEIBA, particularly after receiving high doses and/or in patients with risk factors for clotting.

Infusion of FEIBA should not exceed a dose of 100 units per kg body weight every 6 hours and daily doses of 200 units per kg of body weight. Maximum injection or infusion rate must not exceed 2 units per kg of body weight per minute.

At first sign or symptom of a sudden blood vessel clot or blocked blood vessel (e.g., chest pain or pressure, shortness of breath, altered consciousness, vision, or speech, limb or abdomen swelling and/or pain), stop FEIBA administration promptly and seek emergency medical treatment.

Allergic-type hypersensitivity reactions, including severe, sometimes fatal allergic reactions that can involve the whole body, can occur following the infusion of FEIBA. Call your doctor or get emergency treatment right away if you get a rash, hives or welts, experience itching, tightness of the throat, vomiting, abdominal pain, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Because FEIBA is made from human plasma it may carry a risk of transmitting infectious agents, e.g., viruses, the variant Creutzfeldt-Jakob disease (vCJD) agent and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent.

The most frequent side effects observed during the prophylaxis trial were anemia, diarrhea, bleeding into a joint, signs of hepatitis B surface antibodies, nausea, and vomiting.

The serious side effects seen with FEIBA are allergic reactions and clotting events involving blockage of blood vessels, which include stroke, blockage of the main blood vessel to the lung, and deep vein blood clots.

Call your doctor right away about any side effects that bother you during or after you stop taking FEIBA.

Please see next page for Important Facts about FEIBA.
To see the Full Prescribing Information, including BOXED WARNING on blood clots, go to www.FEIBA.com.

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.

References: 1. Pergantou H, Matsinos G, Papadopoulos A, Platokouki H, Aronis S. Comparative study of validity of clinical, X-ray and magnetic resonance imaging scores in evaluation and management of haemophilic arthropathy in children. Haemophilia. May 2006;12(3):241-247. **2.** Gringeri A, Ewenstein B, Reininger A. The burden of bleeding in haemophilia: is one bleed too many? Haemophilia. Jul 2014;20(4):459-463. **3.** FEIBA Prescribing Information. **4.** Antunes SV, Tangada S, Stasyshyn O, et al. Randomized comparison of prophylaxis and on-demand regimens with FEIBA NF in the treatment of haemophilia A and B with inhibitors. Haemophilia. 2014;20(1):65-72.

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Important Facts about FEIBA (Anti-Inhibitor Coagulant Complex)

What is FEIBA used for?

FEIBA (Anti-Inhibitor Coagulant Complex) is used for people with Hemophilia A or B with Inhibitors to control and prevent bleeding episodes, before surgery, or routinely to prevent or reduce the number of bleeding episodes. It is NOT used to treat bleeding conditions without inhibitors to Factor VIII or Factor IX.

When should I not take FEIBA?

You should not take FEIBA if you have had hypersensitivity or an allergic reaction to FEIBA or any of its components, including factors of the kinin generating system, if you have a condition called Disseminated Intravascular Coagulation, which is small blood clots in various organs throughout the body, or currently have blood clots or are having a heart attack. Make sure to talk to your healthcare provider about your medical history.

What Warnings should I know about FEIBA?

FEIBA can cause blood clots, including clots in the lungs, heart attack, or stroke, particularly after high doses of FEIBA or in people with a high risk of blood clots. Patients that have a risk of developing blood clots should discuss the risks and benefits of FEIBA with their healthcare provider since FEIBA may cause blood clots. FEIBA can cause hypersensitivity or allergic reactions and infusions site reactions, and these reactions can be serious. Because FEIBA is made from human plasma, it may carry the risk of transmitting infectious agents, for example, viruses, including Creutzfeldt-Jakob disease (CJD) agent, and the variant CJD agent. Although steps have been taken to minimize the risk of virus transmission, there is still a potential risk of virus transmission.

What should I tell my healthcare provider?

Make sure to discuss all health conditions and medications with your healthcare provider. If you are pregnant or are planning to become pregnant, or are a nursing mother, make sure to talk with your healthcare provider for advice on using FEIBA.

What are the side effects of FEIBA?

The most frequent side effects of FEIBA are: low red blood cell count, diarrhea, joint pain, hepatitis B surface antibody positivity, nausea, and vomiting. The most serious side effects of FEIBA include: hypersensitivity reactions, including anaphylaxis, stroke, blood clots in the lungs, and blood clots in the veins. Always immediately talk with your healthcare provider if you think you are experiencing a side effect.

What other medications might interact with FEIBA?

The use of other clotting agents with FEIBA is not recommended, for example, tranexamic acid and aminocaproic acid. Be sure to talk with your healthcare provider and pharmacist about all medications and supplements you are taking.

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 FEIBA with your healthcare provider or pharmacist. The FDA-approved product labeling can be found at http://www.feiba.com/us/forms/feiba_pi.pdf or by calling 1-800-423-2090 and selecting option 5.

Gettin' in the Game

Do you like baseball, golf or swimming*? Are you between the ages of 7–18 and have a bleeding disorder? Would you like to travel to Phoenix, AZ for a weekend of baseball, golf or swim clinics for FREE? If you have answered yes to the questions above, "Gettin' in the Game" Junior National Championship presented by CSL Behring may be for you!

Date: Friday, November 3-Sunday, November 5, 2017
Phoenix, Arizona

NHF Nevada can nominate two youth, for either baseball, golf, or swimming* for this program. CSL Behring will pay all travel costs and meals for the patient and one caregiver. A caregiver must accompany child.

NHF Nevada will hold an essay contest for all who qualify and would like to participate.

If you interested in attending the "Gettin' in the Game" program submit an essay on one of these topics: what lessons have you learned through your experience of having a bleeding disorder **or** how have you given back to the bleeding disorder community? Please indicate if you are interested in the **baseball, golf or swimming*** program. Include your name, age, diagnosis, address, phone number, email address, and your parent or guardian's name.

*Swimming participants must be able to swim 25 yards without assistance (no stopping or holding onto walls etc.)

Mail to
NHF-NV, Gettin' in the Game Essay Contest
7473 W. Lake Mead Blvd., Suite 100
Las Vegas, NV 89128

All entries must be received by September 1, 2017 and the two winners will be notified by October 1, 2017.

Biotherapies for Life® CSL Behring

IDELVION®, Coagulation Factor IX (Recombinant), Albumin Fusion Protein
Initial U.S. Approval: 2016

BRIEF SUMMARY OF PRESCRIBING INFORMATION

These highlights do not include all the information needed to use IDELVION safely and effectively. Please see full prescribing information for IDELVION, which has a section with information directed specifically to patients.

What is IDELVION?

IDELVION is an injectable medicine used to replace clotting Factor IX that is absent or insufficient in people with hemophilia B. Hemophilia B, also called congenital Factor IX deficiency or Christmas disease, is an inherited bleeding disorder that prevents blood from clotting normally.

IDELVION is used to control and prevent bleeding episodes. Your healthcare provider may give you IDELVION when you have surgery. IDELVION can reduce the number of bleeding episodes when used regularly (prophylaxis).

Who should not use IDELVION?

You should not use IDELVION if you have had life-threatening hypersensitivity reactions to IDELVION or are allergic to:

- hamster proteins
- any ingredients in IDELVION

Tell your healthcare provider if you have had an allergic reaction to any Factor IX product prior to using IDELVION.

What should I tell my healthcare provider before using IDELVION?

Discuss the following with your healthcare provider:

- Your general health, including any medical condition you have or have had, including pregnancy, and any medical problems you may be having
- Any medicines you are taking, both prescription and non-prescription, and including any vitamins, supplements, or herbal remedies
- Allergies you might have, including allergies to hamster proteins
- Known inhibitors to Factor IX that you've experienced or been told you have (because IDELVION might not work for you)

What must I know about administering IDELVION?

- IDELVION is administered intravenously, directly into the bloodstream.
- IDELVION can be self-administered or administered by a caregiver with training and approval from your healthcare provider or hemophilia treatment center. **(For directions on reconstituting and administering IDELVION, see the Instructions for Use in the FDA-Approved Patient Labeling section of the full prescribing information.)**
- Your healthcare provider will tell you how much IDELVION to use based on your weight, the severity of your hemophilia B, your age, and other factors. Call your healthcare provider right away if your bleeding does not stop after taking IDELVION.
- Blood tests may be needed after you start IDELVION to ensure that your blood level of Factor IX is high enough to properly clot your blood.

What are the possible side effects of IDELVION?

Allergic reactions can occur with IDELVION. Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the chest or throat, difficulty breathing, light-headedness, dizziness, nausea, or decrease in blood pressure.

Your body can make antibodies, called inhibitors, against Factor IX, which could stop IDELVION from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

IDELVION might increase the risk of abnormal blood clots forming in your body, especially if you have risk factors for such clots. Call your healthcare provider if you experience chest pain, difficulty breathing, or leg tenderness or swelling while being treated with IDELVION.

A common side effect of IDELVION is headache. This is not the only side effect possible. Tell your healthcare provider about any side effect that bothers you or does not go away.

Please see full prescribing information, including FDA-approved patient labeling.

Based on November 2016 PI revision.

References: 1. Data on file. Available from CSL Behring as DOF IDL-002.

IDELVION®
Coagulation Factor IX (Recombinant), Albumin Fusion Protein

WALKING DOESN'T MAKE BETTER TREATMENTS FOR BLEEDING DISORDERS, BUT FUNDRAISING DOES! WILL YOU STEP UP?

Saturday, September 17th in Reno
Saturday, September 24th in Las Vegas
Registration is Now Open!

The first 10 people to register and raise or donate $50 will receive your choice of Hemophilia Walk branded headphones or picnic blanket.
To Register go to www.hfnv.org

The Nevada Chapter of the National Hemophilia Foundation is dedicated to improving the quality of care and life for people with hemophilia, von Willebrand disease, and other inherited bleeding disorders through education, peer support, and advocacy.

Hemophilia News and Views is published 4 times a year by the Nevada Chapter of the National Hemophilia Foundation (NHF-NV). We welcome advertisers. Please contact the office at 702.564.4368 for advertising rates.

Physical Activity and Exercise for Hemophilia by Carolina Henriques

About hemophilia

Hemophilia is an inherited X-linked recessive bleeding disorder, caused by a deficiency in coagulation factor VIII (hemophilia A), factor IX (hemophilia B), or factor XI (hemophilia C), that results from mutations in the clotting factor genes; it mainly affects males (hemophilia A and B, the two most common forms of this disease) and can be mild, moderate, or severe.

Physical Activity and Exercise for Hemophilia

Until the mid-1970s, hemophilia patients were advised to refrain from exercising due to a perceived risk of bleeding. But the consequences of physical inactivity, like obesity and bone density loss, were found to be more harmful than exercise. Today, physical activity is recognized as being essential for good health and health maintenance in people with hemophilia.

In its Guidelines for the Management of Hemophilia, the World Federation of Hemophilia recommends that physical activity be encouraged to promote fitness and neuromuscular health, with special attention paid to muscle strengthening, coordination, general fitness, body weight, and self-esteem.

For patients with significant muscle and bone weakness or problems, weight-bearing exercises that promote the development and maintenance of healthy bone density are encouraged (to the extent their joint health permits). Choice of activities should reflect an individual's interests, ability, and resources. Non-contact sports, like swimming, are recommended, while high-contact and collision sports, like rugby or football, are to be avoided. The guidelines also stress that patients should consult with a muscle and bone specialist before engaging in physical activities, discussing whether a particular planned exercise or activity is appropriate, protective gear that might need to be used, needed prophylaxis (treatment factor and other measures), potential target joints (joints susceptible to bleeds), and required physical skills. After a bleed, it is best to return to any physical activity in a gradual manner, building up to a full pre-bleed level, so as to minimize the chance of a re-bleed.

A number of studies also report that physical activity can improve the effectiveness of treatments and prevent bleeding episodes in hemophilia patients. In older patients, a lack of physical can further increase the risk of diabetes, high blood pressure, high levels of fat in the blood, obesity, and osteoporosis and related fractures, in addition to hemophilia-related complications.

According to the World Health Organization (WHO), physical inactivity is the fourth leading risk factor for mortality, accounting for 6 percent of deaths worldwide. Health problems associated with physical inactivity are more severe for patients with hemophilia than for the general population. Obesity, for instance, is linked to an increased risk of cardiovascular disease and chronic joint inflammation, which promotes bleeding in the joints and the risk of fractures. In addition, muscle and bone disorders caused by hemophilic joint inflammation and aging are risk factors for falling injuries.

Generally, the point is that a strong body helps protect a person from bleeding. Besides, the benefits of physical activity are not just physical – they're also emotional and spiritual.

Main physical benefits

Strong and flexible muscles support the joints, which help prevent bleeds and joint damage. Feeling fit and having energy helps reduce fatigue. Being of a healthy weight reduces the stress placed on the joints, which is particularly important in aging bodies. Improved balance and coordination helps joints and muscles work better together, which again helps protect against bleeds.

Main psycho-social benefits

- Sweating is a great outlet to help relieve stress, and relax the mind
- Being active boosts self-esteem, confidence, and is fun for children and adults, as long as you do something you like
- Regular exercise can promote social acceptance and provide a peer group for social interaction.

Top 10 recommended activities: Swimming; Table Tennis; Walking;; Fishing; Dancing; Badminton; Sailing; Golf; Bowling; Cycling;

Top 10 activities to avoid: Boxing; Rugby; Soccer/Football; Karate; Wrestling; Motorcycling; Judo; Hang-gliding; Hockey; Skateboarding

Activities for older adults with hemophilia

As we age, our risk of joint damage increases. As a result, older adults may experience chronic pain and reduced mobility. However, it is still essential to remain active to help strengthen joints and muscles, maintain a healthy weight, and provide an outlet for stress or tension.

Older adults are advised to choose activities that "go easy" on the joints, such as walking, swimming, yoga, Pilates, cycling, strength exercises (weight-bearing), dancing, or bowling. Activities like jogging, basketball, or soccer/football are not recommended.

Preparing for physical activity

Prophylaxis (or treatments to prevent bleeding episodes) is advised before engaging in any activity with a higher risk of injury. Preliminary replacement therapy and prophylaxis are sometimes used together, depending on the bleeding risk.

Before a physical activity, prophylactic treatment is recommended, depending on coagulation factor activity levels. Adequate levels of clotting factors are always required (above 5 percent is standard for a normal level of daily activity, and greater than 15 percent is recommended before sports). The study cited above recommends physiotherapy on the day that prophylaxis is performed. A clotting factor level of 20 to 40 percent is advised prior to physiotherapy, it notes, although it goes on to note that a recommended pre-activity/physiotherapy dose has not been reported for patients with inhibitors.

People with hemophilia are strongly recommended to consult and work closely with pediatricians and physicians regarding physical activity and to check on coagulation system test values.

Meet **Jessica**, your CoRe Manager

Hello! I'm Jessica Klass, and my brother has hemophilia A. I'm also a CoRe Manager for Bioverativ. It is my job to connect you with others in the community, share insights taken from my personal experience, introduce our educational programs, and to support you on your journey. I am here so we can take action together!

Contact me!

[Jessica.Klass@bioverativ.com] | [623.238.0244]

Bioverativ

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Golf 4 The Kids Raises A Whopping $85,000 for Two Local Nonprofits

Annual Tournament Has Raised Almost $300,000 for Nevada Children

A lot of golfers swung into action at the 5th annual **Golf 4 The Kids Tournament**, raising almost $85,000, which will be split equally between two Nevada nonprofit organizations: **Cure 4 The Kids Foundation** and the **Nevada Chapter of the National Hemophilia Foundation**.

This event, which started in 2013, was held at the Red Rock Country Club on Monday, May 1, 2017, where golfers played the club's private Mountain Course.

Cure 4 The Kids Foundation will use the proceeds raised in the tournament to fund the **Charity Care Program**, which helps ensure patients who don't have medical insurance or the ability to pay for treatment, receive the medical attention they need.

"This is an important fundraiser for us as it helps us to provide the unduplicated services that are at the very core of our mission," said **Annette Logan**, Cure 4 The Kids Foundation CEO and co-founder. "We are so thankful for the sponsors and the participants in the tournament who each help towards ensuring our goal that patients who are unable to pay for treatment get the medical attention that they need."

The **Nevada Chapter of the National Hemophilia Foundation** will use the funds to send children to **Camp Independent Firefly**, which is a medically supervised summer camp, where youth can test their limits, gain new skills for living independently with their disorder, and meet others similarly affected with bleeding disorders.

At the tournament's award ceremony, organizers encouraged participants to make individual pledges to send additional children to Camp Independent Firefly. Golfers donated hundreds of dollars. In fact, during one heart-stopping moment, one attendee, **Stephen Chiang**, made a donation of more than $20,000!

"That was an absolutely amazing moment that I will remember for the rest of my life," said **Kelli Walters**, Executive Director of the Nevada Chapter of the National Hemophilia Foundation. "If it weren't for the amazing and generous residents in our community, we would not be able to send such a large number of our youth to Camp Independent Firefly at no cost to them."

CSL Behring was the Presenting Sponsor at this year's event.

Professional PGA golfer Perry Parker hosted and participated in the Golf 4 The Kids Tournament held May 1, 2017 at the Red Rock Country Club. The annual event raised $85,000 which will be split equally between two nonprofit organizations: Cure 4 The Kids Foundation and the Nevada Chapter of the National Hemophilia Foundation. Parker, who was diagnosed with hemophilia as a child, spoke during the awards ceremony and strongly encourages those with bleeding disorders to remain active throughout their lives.

During the Golf 4 The Kids awards ceremony, Stephen Chiang, donated $20,000 to send dozens of children to Camp Independent Firefly, a special medically supervised summer camp available to attendees at no cost. The camp allows a child with a bleeding disorder, and their siblings, to safely enjoy the outdoors while also learning to increase independence as it relates to their disorder. (L to R: Stephen Chiang, Marco Magana and son, Andres.)

NUWIQ®

Antihemophilic Factor
(Recombinant)

For more information, contact your
Octapharma Representative:

LYNN BARKER
PHONE | 801-209-9368
EMAIL | Lynn.Barker@Octapharma.com

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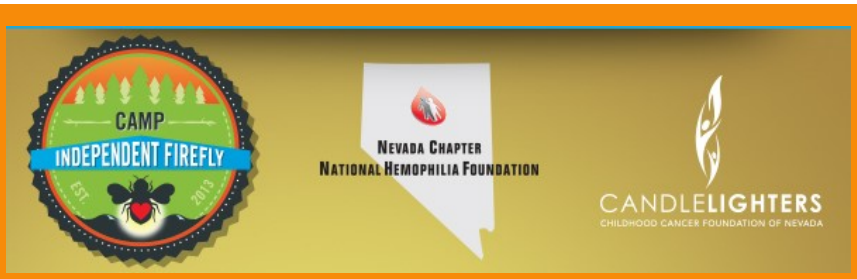
For the safe and optimal use of human proteins



Camp Independent Firefly 2018

Save the Date!

Camp Independent Firefly 2018 will be taking place
June 12 – 16, 2018!

Online camper applications will be available
February 1, 2018

This information is based on Marcus' 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

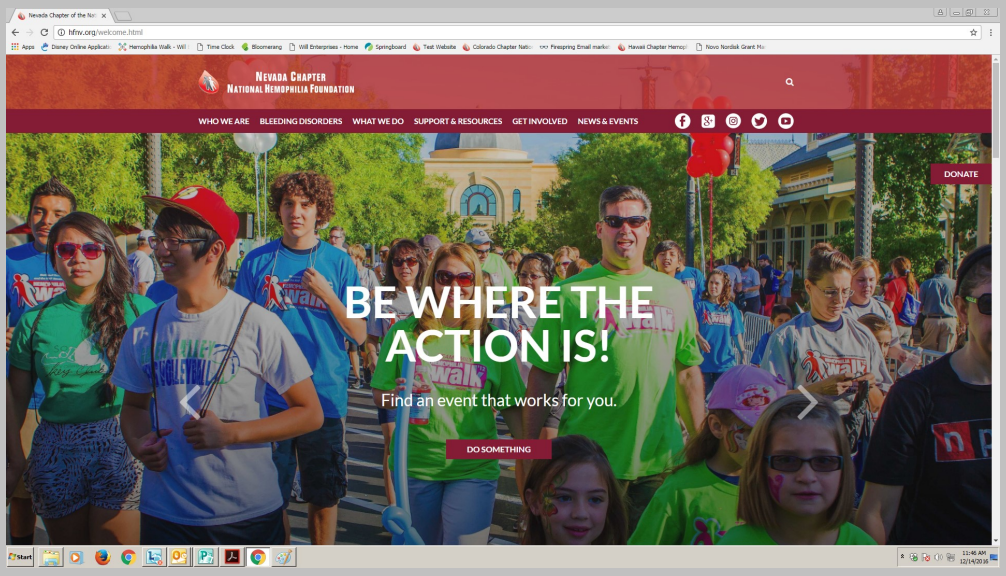
Manufactured by:
Aptevo BioTherapeutics LLC
Berwyn PA, 19312
U.S. License No. 2054

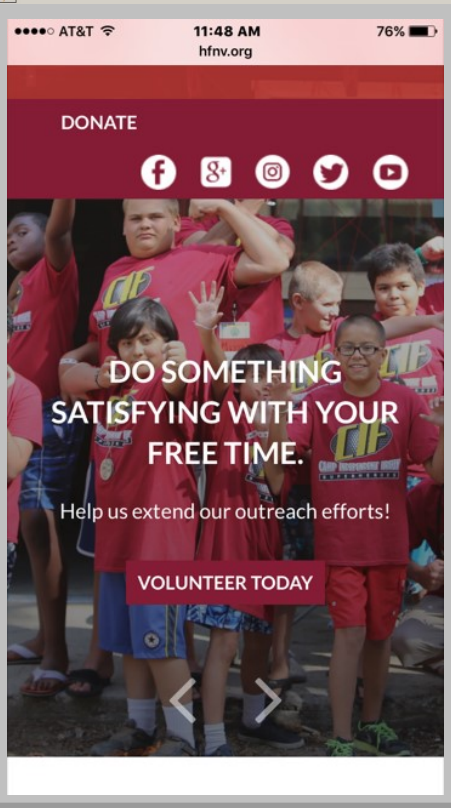
Part No: 1000973_1
CM-FIX-0078

Register for Events on NHF Nevada's new Website!

We are excited to announce that NHF Nevada has a new and improved website! The website is updated daily and gives you the ability to register for programs and events! It is mobile friendly too! Check it out at **www.hfnv.org**. It also includes links to national resources!

To register for one of our upcoming programs and events on our event calendar. Go to www.hfnv.org, click on **News & Events** and then go to the **Event Calendar**.





AFSTYLA®, Antihemophilic Factor (Recombinant), Single Chain
For Intravenous Injection, Powder and Solvent for Injection
Initial U.S. Approval: 2016

BRIEF SUMMARY OF PRESCRIBING INFORMATION
These highlights do not include all the information needed to use AFSTYLA safely and effectively. Please see full prescribing information for AFSTYLA, which has a section with information directed specifically to patients.

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

- Your healthcare provider or hemophilia treatment center will instruct you on how to do an infusion on your own.
- Carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing this medicine.

What is AFSTYLA?

- AFSTYLA is a 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.
- Does not contain human plasma derived proteins or albumin.
- Your healthcare provider may give you this medicine when you have surgery.
- Is used to treat and control bleeding in all patients with hemophilia A.
- Can reduce the number of bleeding episodes when used regularly (prophylaxis) and reduce the risk of joint damage due to bleeding.
- Is not used to treat von Willebrand disease.

Who should not use AFSTYLA?

You should not use AFSTYLA if you:

- Have had a life-threatening allergic reaction to it in the past.
- Are allergic to its ingredients or to hamster proteins.

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

What should I tell my healthcare provider before using AFSTYLA?

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 hamster proteins.
- Have been told you have inhibitors to Factor VIII (because this medicine may not work for you).

How should I use AFSTYLA?

- Administer directly into the bloodstream.
- Use as ordered by your healthcare provider.
- You should be trained on how to do intravenous injections by your healthcare provider or hemophilia treatment center. Once trained, many patients with hemophilia A are able to inject this medicine by themselves or with the help of a family member.
- Your healthcare provider will tell you how much 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 to be sure that your blood level of Factor VIII is high enough to clot your blood.
- Call your healthcare provider right away if your bleeding does not stop after taking this medicine.

What are the possible side effects of AFSTYLA?

- Allergic reactions may occur. Immediately stop treatment and call your healthcare provider right away if you get a rash or hives, itching, tightness of the chest or throat, difficulty breathing, light-headedness, dizziness, nausea, or decrease in blood pressure.
- Your body may form inhibitors to Factor VIII. An inhibitor is a part of the body's defense system. If you form inhibitors, it may stop this medicine from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.
- Common side effects are dizziness and allergic reactions.
- These are not the only side effects possible. Tell your healthcare provider about any side effect that bothers you or does not go away.

What else should I know about AFSTYLA?

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

Please see full prescribing information, including full FDA-approved patient labeling. For more information, visit www. AFSTYLA.com

Manufactured by:
CSL Behring GmbH
35041 Marburg, Germany

for:
CSL Behring Recombinant Facility AG
Bern 22, Switzerland 3000
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Distributed by:
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Kankakee, IL 60901 USA

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7473 W. Lake Mead Blvd. Suite 100
Las Vegas, NV 89128

Phone: 702-564-4368
website: www.hfnv.org

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ACT—Access to Care Today
Achieve a CURE Tomorrow

Save the Date

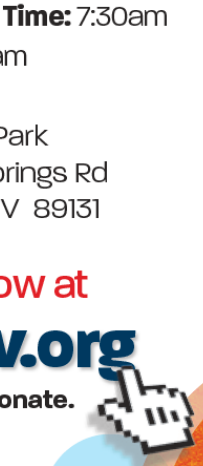
National Hemophilia Foundation and Nevada Chapter of NHF Present
HEMOPHILIA walk
Every step makes a difference
National Presenting Sponsor
Shire

SATURDAY, SEPTEMBER 23, 2017

Join us to support the Hemophilia Walk! We will walk to raise critical FUNDS and AWARENESS for the bleeding disorders community. Your support is greatly appreciated!

For more information, please contact: Anne McGuire, at 702.564.4368 or amcguire@hemophilia.org, or visit www.hfnv.org.

Registration Check-In Time: 7:30am
Walk Start Time: 8:30am
Distance: 1 mile and 5K
Location: Floyd Lamb Park
9200 Tule Springs Rd
Las Vegas, NV 89131



Register online now at
www.hfnv.org
Participate. Volunteer. Donate.