



Factor Nine News

The Coalition for Hemophilia B

Fall 2016



Topics in Hemophilia

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Meetings on the Road!



On the Road!

Minneapolis, Minnesota

Our first 2016 Coalition B **On the Road** meeting was held in Minneapolis, Minnesota on September 17th. Very informative speakers, Kim Isenberg and Angela McCoy, presented *Sharing Your Story: Advocacy in the Bleeding Conditions Community*, followed by Pfizer's Nurse Educator Specialist, Gladis Murillo who spoke on *Exploring Emotional Well-Being in the Hemophilia Community*. It was so nice to see our Coalition B family members in person! 🇺🇸



St. Louis, Missouri

On the Road!

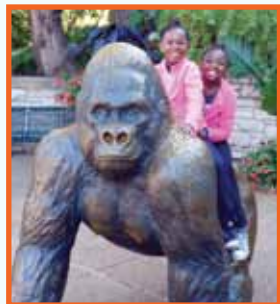


Our second **On the Road** meeting took place in St. Louis, Missouri on October 22nd. While tweens and teens enjoyed a fun-filled trip to the St. Louis Zoo, Angela McCoy and Gladis Murillo presented their educational sessions to the adults, *Sharing Your Story: Advocacy in the Bleeding Conditions Community* and *Exploring Emotional Well-Being in the Hemophilia Community*, respectively.

After lunch, Rick Starks held his famous Taji Fit Class for the whole group! Later in the afternoon, we gathered for a session on *Product Updates* by Dr. David Clark, and to discuss the current hot topics in the community. A special celebration was in store for Coalition's little member, Miss Elianna Shelton's 2nd birthday. To Elianna's surprise, her birthday announcement was made by Elsa the Princess! The children gathered for stories and goody bags as everyone wished Elianna a very happy birthday!

It was wonderful having the chance to catch up with our Coalition B family members! We had a wonderful time and look forward to seeing everyone again soon! 🎉

Special thanks to our generous sponsor, Pfizer!





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Dosing schedule that fits into your lifestyle



High and sustained Factor IX levels



A median annualized spontaneous bleeding rate of zero in 7- and 14-day prophylaxis

*In appropriate people 12 years and older. Talk with your doctor.

Important Safety Information

IDELVION is used to control and prevent bleeding episodes in people with hemophilia B. Your doctor might also give you IDELVION before surgical procedures. Used regularly as prophylaxis, IDELVION can reduce number of bleeding episodes.

IDELVION is administered by intravenous injection into the bloodstream, and can be self-administered or administered by a caregiver. Do not inject IDELVION without training and approval from your healthcare provider or hemophilia treatment center.

Tell your healthcare provider of any medical condition you might have, including allergies and pregnancy, as well as all medications you are taking. Do not use IDELVION if you know you are allergic to any of its ingredients, including hamster proteins. Tell your doctor if you previously had an allergic reaction to any FIX product.

Stop treatment and immediately contact your healthcare provider if you see signs of an allergic reaction, including a rash or hives, itching, tightness of chest or throat, difficulty breathing,

lightheadedness, dizziness, nausea, or a decrease in blood pressure.

Your body can make antibodies, called inhibitors, against Factor IX, which could stop IDELVION from working properly. You might need to be tested for inhibitors from time to time. IDELVION might also increase the risk of abnormal blood clots in your body, especially if you have risk factors. Call your healthcare provider if you have chest pain, difficulty breathing, or leg tenderness or swelling.

In clinical trials for IDELVION, headache was the only side effect occurring in more than 1% of patients (1.8%), but is not the only side effect possible. Tell your healthcare provider about any side effect that bothers you or does not go away, or if bleeding is not controlled with IDELVION.

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

Please see brief summary of prescribing information for IDELVION on next page.

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.

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3rd Annual Women's Retreat



By: Christian Villarreal

Our **3rd Annual Women's Retreat** was held Friday, October 6th to Sunday, October 8th at the Carefree Resort and Conference Center in Carefree, Arizona. The women arrived at the resort and were instantly greeted by our team with hugs and welcome bags filled with snacks and important educational materials.

On Friday upon arrival, our volunteer Deena Lipinski escorted the ladies on group tours and showed them around the resort, pointing out key locations for our daily sessions. After the tours, the ladies went for 15 minute chair massages to comfort them after their long travel. They then sat down for lunch and began networking among each other.

Shortly thereafter the ladies joined together to hear Donnie Akers Esq. speak on the

transition from childhood to adulthood, the importance of medical powers of attorney, medical directives and access to medical information. Donnie, a graduate of the Louisiana State University Law School (LSU) and the University of Louisiana-Lafayette (ULL), helped the ladies learn about financial planning tools known as "special needs trusts" and the "ABLE account" to shelter resources and remain eligible for public benefits such as Medicaid. Afterwards the ladies freshened up and rejoined the group for The Coalition's Welcome and Introductions and the ladies then introduced themselves and shared their experiences. Spouses, caregivers and women with hemophilia B alike all shared their stories and learned from each other. Later they engaged in a laughter therapy program designed to remind the ladies to take a moment out of their day to just laugh. Characters came in costumes, played a video and





challenged the women to split into groups and make each other laugh. And laugh they did! As the room filled with joy, the ladies all agreed to take a moment out of their hectic day to practice their laughter therapy!

After a break, Andrea Piraino came in to talk about Nutrition. The ladies heard the latest information on the importance of choosing the right foods and getting the right nutrients to maintain a healthy lifestyle. As some were taking pictures of Andrea's slides on nutrition, others were writing notes down to take home with them. Both sessions with Donnie and Andrea had lots of Q&A. Following the session, the women took a break and continued networking. In the evening, the women came together to enjoy a "Taste of Tuscany" dinner and a champagne toast in honor of the ladies coming to the retreat to better their lives, learn new things, take time to practice some self-care and enhance their support of sisterhood!

Saturday morning began with fresh fruit and muffins as the ladies were given a few options of what to do next. We arranged for them to choose beginner yoga class with Colleen Meehan, take a nature walk with our excellent and very entertaining volunteer Deena Lipinski, or do exercise water aerobics with our very own Pamela Williams. The ladies marveled at the choices and each split up into one of their three groups exercise sessions.

After morning exercise, the women gathered on the resort's beautiful sunset terrace to enjoy their breakfast. After breakfast, Luanne Stevenson part of Biogen's AMA speaking program talked about different ways of "Managing Chaos". Informational pamphlets and useful tips were given to each attendee. The women learned how to learn to cope with unforeseen circumstances and a multitude of many other coping skills.

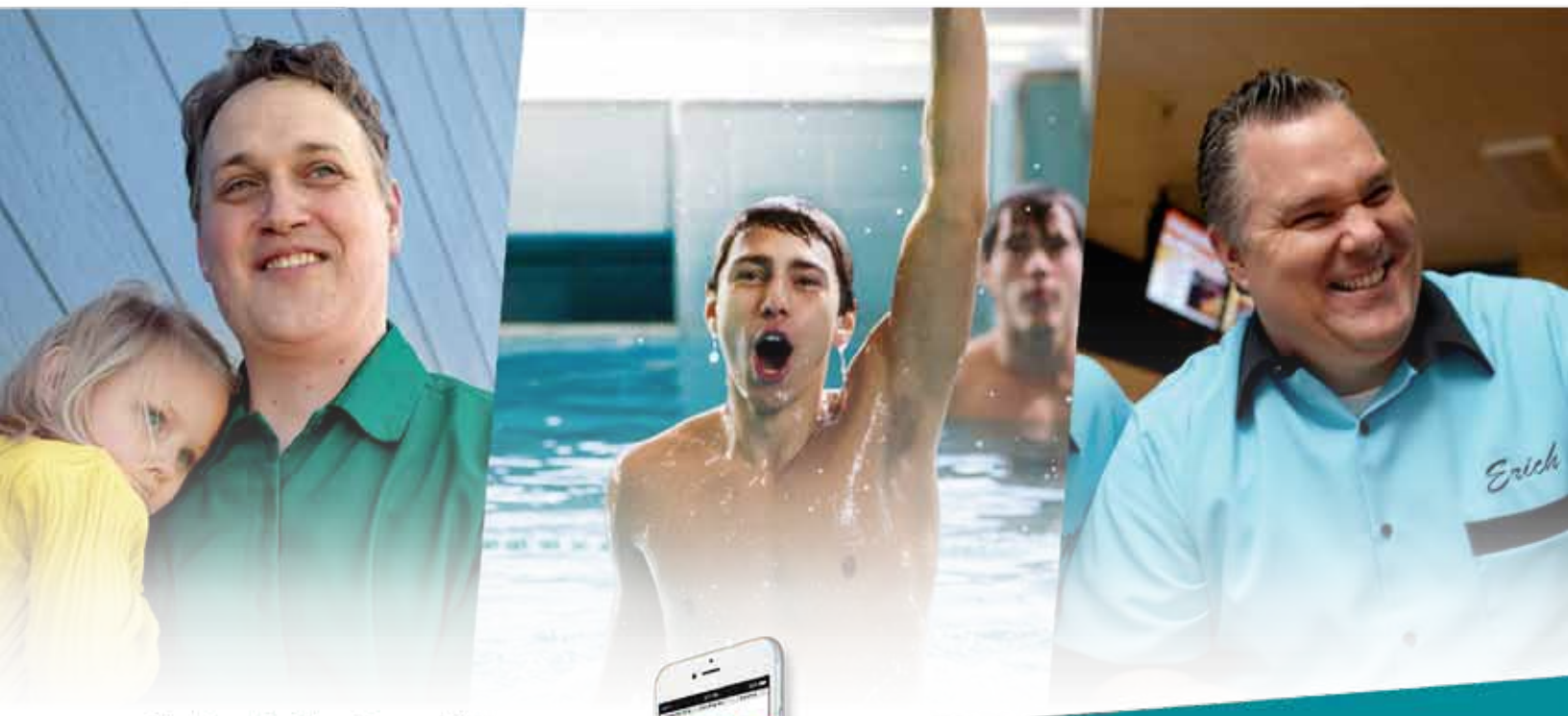
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BeneFix + YOU = GIVE FORWARD

19
YEARS
YOUR
EXPERIENCE
MATTERS

BeneFix
Coagulation Factor IX (Recombinant)
Room Temperature Storage



The BeneFix Give Forward™ Program allows patients and caregivers to

- Learn about hemophilia and things that can impact your health
- Have fun and earn points
- Make charitable donations



Visit BeneFixGiveForward.com
and get started right now!

What Is BeneFix?

BeneFix, Coagulation Factor IX (Recombinant), is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease.

BeneFix is **NOT** used to treat hemophilia A.

Important Safety Information

- BeneFix is contraindicated in patients who have manifested life-threatening, immediate hypersensitivity reactions, including anaphylaxis, to the product or its components, including hamster protein.
- Call your health care provider right away if your bleeding is not controlled after using BeneFix.
- Allergic reactions may occur with BeneFix. Call your health care provider or get emergency treatment right away if you have any of the following symptoms: wheezing, difficulty breathing, chest tightness, your lips and gums turning blue, fast heartbeat, facial swelling, faintness, rash or hives.
- Your body can make antibodies, called "inhibitors," which may stop BeneFix from working properly.
- If you have risk factors for developing blood clots, such as a venous catheter through which BeneFix is given by continuous infusion, BeneFix may increase the risk of abnormal blood clots. The safety and efficacy of BeneFix administration by continuous infusion have not been established.
- Some common side effects of BeneFix are nausea, injection site reaction, injection site pain, headache, dizziness and rash.

Please see the Brief Summary for BeneFix on the next page. You are encouraged to report negative side effects of prescription drugs to the FDA.

Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

*BeneFix was approved February 11, 1997.

R_x only

Brief Summary

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.Pfizer.com or call our medical communications department toll-free at 1-800-934-5556.

Please read this Patient Information carefully before using BeneFix and each time you get a refill. There may be new information. This brief summary does not take the place of talking with your doctor about your medical problems or your treatment.

What is BeneFix?

BeneFix is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease.

BeneFix is **NOT** used to treat hemophilia A.

What should I tell my doctor before using BeneFix?

Tell your doctor and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies.

Tell your doctor about all of your medical conditions, including if you:

- are pregnant or planning to become pregnant. It is not known if BeneFix may harm your unborn baby.
- are breastfeeding. It is not known if BeneFix passes into the milk and if it can harm your baby.

How should I infuse BeneFix?

The initial administrations of BeneFix should be administered under proper medical supervision, where proper medical care for severe allergic reactions could be provided.

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

You should always follow the specific instructions given by your doctor. If you are unsure of the procedures, please call your doctor or pharmacist before using.

Call your doctor right away if bleeding is not controlled after using BeneFix.

Your doctor will prescribe the dose that you should take.

Your doctor may need to test your blood from time to time.

BeneFix should not be administered by continuous infusion.

What if I take too much BeneFix?

Call your doctor if you take too much BeneFix.

What are the possible side effects of BeneFix?

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

wheezing	fast heartbeat
difficulty breathing	swelling of the face
chest tightness	faintness
turning blue (look at lips and gums)	rash
	hives

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

Some common side effects of BeneFix are nausea, injection site reaction, injection site pain, headache, dizziness and rash.

BeneFix may increase the risk of thromboembolism (abnormal blood clots) in your body if you have risk factors for developing blood clots, including an indwelling venous catheter through which BeneFix is given by continuous infusion. There have been reports of severe blood clotting events, including life-threatening blood clots in critically ill neonates, while receiving continuous-infusion BeneFix through a central venous catheter. The safety and efficacy of BeneFix administration by continuous infusion have not been established.

These are not all the possible side effects of BeneFix.

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

How should I store BeneFix?

DO NOT FREEZE BeneFix. BeneFix kit can be stored at room temperature (below 86°F) or under refrigeration. Throw away any unused BeneFix and diluent after the expiration date indicated on the label.

Freezing should be avoided to prevent damage to the pre-filled diluent syringe.

BeneFix does not contain a preservative. After reconstituting BeneFix, you can store it at room temperature for up to 3 hours. If you have not used it in 3 hours, throw it away.

Do not use BeneFix if the reconstituted solution is not clear and colorless.

What else should I know about BeneFix?

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

If you would like more information, talk to your doctor. You can ask your doctor for information about BeneFix that was written for healthcare professionals.

This brief summary is based on BeneFix® [Coagulation Factor IX (Recombinant)] Prescribing Information LAB-0464-9.0, revised August 2015.

Following this program, we had our *Core Balancing* session in the Mesquite room of the resort. Upon entrance you could hear the sound of Moroccan music, belly dancing veils and coin belts were given to the women and they had one hour of belly dance lessons by Mahin. It was loads of fun and laughter but it is also a very low impact exercise that is good for all ages and tones the body. After the unique experience, the women met again on the sunset terrace to enjoy their lunch and then outside for a group picture. Next session was with Dr. Karen Petersen Licensed psychologist who spoke on *Coping with the Effects of Chronic Illness on Mood, Temperament, and Well-being*. Attendees learned to recognize when the effects of chronic illness have gone beyond the "normal" range of frustration, anger, and helplessness – and tools to learn how to cope.

A lovely afternoon tea was held at the English Tea Room and then networking continued throughout the afternoon until dinner time and the ladies walked over to a western themed BBQ dinner for fun and excitement! With lights, hay stacks, cowboy hats and wheelbarrows decorating the Kuchina Courtyard of the resort, the women each received a cowboy hat and a private line dancing workshop to show off their moves. Along with dinner the ladies received the treat of having an old style dress up picture theme, where they wore old fashioned saloon gear and took fun photos! The retreat finished up on Sunday morning after breakfast and as the women said their goodbyes they all reflected on the new friends they made, the important life lessons they learned and the memories they will never forget. 🍷



My Life, Our Future Adds Carrier Testing

By Dr. David Clark

My Life, Our Future (MLOF) is the free genotyping program offered through many of the hemophilia treatment centers (HTCs). MLOF has now tested almost 5000 people with hemophilia A or B, and 84% of those participants have agreed to have their blood samples stored in the research repository for future study. This is a wonderful start on a program that will potentially provide significant new knowledge about the genetics of hemophilia.

After a successful pilot study last year at a few HTCs, genotyping of carriers is now being offered. Known or potential carriers can have their factor VIII or IX gene genotyped at no charge. If you are a female

blood relative of a person with hemophilia A or B, you are at least a potential carrier and may be eligible to participate. In addition to learning your own carrier status, factor level and mutation, if any, your information will be added to the growing hemophilia gene database. An advantage of having the carrier information is that genetic family trees can be constructed to follow the mutations across generations. All information is totally de-identified, so every subject remains completely anonymous.

If you are interested, contact your local HTC. More information on the program and a list of participating HTCs is available at www.mylifeourfuture.org.



Generation IX Project: Next Generation

On September 29, 2016, a group of individuals came together in the wilderness outside Traverse City, Michigan for a weekend of development, fellowship and community building – Generation IX Project: Next Generation. Camp Hayo-Went-Ha was the backdrop for the weekend event where emerging young leaders joined with individuals who have been advocates in the community for a number of years – a sort of Mentoring of the Mentors. Bringing together men and women with Hemophilia B from the “younger” and “older” generations created a unique opportunity to learn and teach each other. This was the fifth Generation IX Project, but the first that connected such a diverse range of ages and experiences to talk about advocacy, mentorship and leadership specifically for the Hemophilia B community. Like all Generation IX Projects, the team from GutMonkey delivered this program with their unique experienced-based educational approach, blending together group discussions, team building events, ropes courses and a very challenging canoeing program – water runs fast and high after days of heaving rain!

I'm tired and sore, but I had a blast and learned so much. ~ Program Participant

The weekend event opened on Thursday evening as everyone arrived and spent a casual night getting acquainted. The Friday program began with several activities to introduce one another, talk about challenges faced both individually and as a community and really start the dialogue about advocacy. And of course, no better way to build relationships than to be paired with someone new on a ropes course! Check out the photos of our participants in action!

On Saturday it was off to the river for a challenging, sometimes nerve-wracking, but always safe, canoeing activity involving a

Continued on page 14



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MAY BE RIGHT FOR YOU

Visit RIXUBIS.com to find your
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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)]

FDA-approved Patient Labeling

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 are the RIXUBIS dosage strengths?

RIXUBIS comes in five different dosage strengths: 250, 500, 1000, 2000 and 3000 international units. The actual strength will be imprinted on the label and on the box. The five different strengths are color coded, as follows:

Light Blue	Dosage strength of approximately 250 international units per vial
Pink	Dosage strength of approximately 500 international units per vial
Green	Dosage strength of approximately 1000 international units per vial
Orange	Dosage strength of approximately 2000 international units per vial
Silver	Dosage strength of approximately 3000 international units per vial

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

How should I store RIXUBIS?

- Store at refrigerated temperature 2° to 8°C (36° to 46°F) for up to 24 months. Do not freeze.
- May store at room temperature not to exceed 30°C (86°F) for up to 12 months within the 24 month time period. Write on the carton the date RIXUBIS is removed from refrigeration. After storage at room temperature, do not return the product to the refrigerator.
- Do not use after the expiration date printed on the carton or vial.
- Reconstituted product (after mixing dry product with wet diluent) must be used within 3 hours and cannot be stored or refrigerated. Discard any RIXUBIS left in the vial at the end of your infusion.

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.

Resources at Baxalta available to patients

For information on patient assistance programs that are available to you, including the Baxalta CARE Program, please contact the Baxalta Insurance Assistance Helpline at 1-888-229-8379.

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Generation IX Project *Continued from page 11*

puzzle-making challenge to encourage folks to build new relationships. Overturning one's canoe was not originally part of the challenge, but some folks enjoyed that adventure, as well!

Most intense four days of my life. Truly a brilliant event. ~ Program Participant

The program ended on Saturday evening with discussions around men and women with Hemophilia B, the various roles community members play and a closed-group discussion with program nurse, Jim Munn. A veteran of the Generation IX Project, Jim always ensures that they participant learn something new during his sessions.

While the weekend was not without its heated discussions, the strength of the community shone through as folks came together to form new friendships, rekindled old friendships and generate ideas to help continue to and strengthen the hemophilia B community. Check out more pictures on our Facebook page.

I had an incredible time last weekend at the Generation IX: Next Generation Program. It was wonderful to see old friends and make new ones. The program was spot on and one of the best I've been to. Hemophilia isn't something any of us would have chosen, but the bond we all have is mind blowing. ~ Program Participant

About the Generation IX Project

The Generation IX Project is a Coalition for Hemophilia B program that provides mentorship, leadership and community building programs exclusively for individuals with Hemophilia B. The Generation IX Project is made possible through funding from Aptevo Therapeutics.

Applications are now open for the upcoming Generation IX: Leadership program January 3rd through 8th for individuals with hemophilia B, ages 18 to 35. Go to www.ApplyGenerationIXProject.com to apply, or follow the Facebook page for more details on this and future Generation IX Projects.

Aptevo Therapeutics is very proud to sponsor the Coalition for Hemophilia B's Generation IX Project. After every event, I am so amazed at the feedback we hear, the friendships and bonds that are created and the skills the participants learn that they can apply to strengthening the hemophilia B community and furthering the work of the Coalition. 🏆

~ Grant Belsham, Aptevo Therapeutics



Our Journey Ahead

My name is Milinda DiGiovanni. I am a mother and caregiver for my son, Andrew, who is 13 and has severe hemophilia B. My daughter, Gabriella, is 12 and in the 7th grade. I am divorced, alone and faced with many difficult challenges with having a son with hemophilia. When I learned about my son's condition, he was 9 months old. Going back to that day, it was a nightmare come true. I had no idea what I would be facing, so many questions popping in my head. No one in my family had this condition. I was doing all this all by myself. I felt alone and shed many tears, and didn't know where to turn. I kept everything inside and had built up frustration. I am a vibrant, positive, cheerful, loving, caring being. How could this happen? Why me? Why my son? I turned to my faith and, keeping one foot in front of the other, decided this is what I was given, and this is my fight.

They say everything happens for a reason; well then, I had to be strong for my son and my daughter. I was and still am! Nothing will take me down! I pushed to learn as much as I can. Since Andrew was just a year old, I have taught him about hemophilia. I made sure to put some of the supplies out on the floor so he can play with them. When they were young, I taught my children the names of the supplies, and how important it is to care for our bodies. I understood how critical it was for Andrew to know how to infuse himself in case of an emergency if I wasn't there. I taught Andrew and 'Nurse' Gabriella (best



nurse/sister) the importance of self-infusion. At age 5, Andrew was able to infuse on his own - what an incredible accomplishment! I am so proud of my Andrew!

Today, Andrew has grown to face many challenges, but nothing will stop him and nothing will get in his way. He's just like his mother - he's energetic, loving, caring, protective, creative, fun, and most of all, he is a leader and has an amazing future ahead of him. As for my sweet, darling Gabriella, she has had to sit back and watch her brother through many hard times. She consistently encourages her brother and is always there for him in times of need.

Literally, catering to him! So sweet. I'm such a proud mom!

One day, my friend told me about the Coalition for Hemophilia B. Let me tell you, my heart filled with joy and happiness to learn there was a community of Bs. I have never in my life felt so loved, understood and welcomed! We had somewhere we can turn to and we were not alone! I am not alone! I can share with my family, because WE ARE family in this community. I found my B-sisters - other moms with the same issues I have, and Andrew and Gabriella have friends here that understand them. I am so grateful to the Coalition for Hemophilia B for their immense support. I know I can count on my Coalition B family. I don't have to fight by myself. We are B. We are strong. We are family! They will be with us through our lifes' journey, and I am not alone anymore! 🍷

In Memory

Dr. Jeanne M. Lusher, a pioneer in the treatment of hemophilia B, passed away on September 13 at age 81. Dr. Lusher retired in 2013 as Distinguished Professor Emeritus of Pediatrics and Co-Director of Hematology and Oncology at Wayne State University School of Medicine in Detroit, Michigan after a career of more than 45 years. Dr. Lusher received her medical degree from the University of Cincinnati College of Medicine. Her interest in blood disorders was sparked one night during her residency at Charity Hospital in New Orleans. A young girl was brought into the emergency room bleeding profusely from hemophilia, which is rare in females. Dr. Lusher helped treat the girl and began a lifetime of work helping those with blood disorders. She recognized early on the thrombogenicity problems with the factor IX products of the day and pushed for safer concentrates. She and her colleagues were among the first to recognize the risk for AIDS among hemophilia patients. She also started the first comprehensive hemophilia program at Children's Hospital of Michigan. She will be greatly missed by the hemophilia community.



*Jeanne M. Lusher, M.D.
1935-2016*



NATHAN'S IXperience™



Nathan and his doctor discussed the
98% RECOVERY†
of IXINITY



**HE'S INFUSING
4,000 IU***

with IXINITY—less
than in the past



He thinks
the IXINITY
reconstitution
device is
EASY TO USE

“When I heard the recovery rate was 98%, I thought,
'Wow, that's pretty close to the recovery of a plasma-derived product.'”

Watch Nathan's videos at PatientIXperiences.com

Nathan's experience with IXINITY may not be typical. Speak with your doctor to see if IXINITY may be a good option for you.

*Nathan uses 4000 IU per infusion. IXINITY recovery is an average based on lab tests of patients in the clinical study.†Your actual recovery and dose may be different. Speak with your healthcare professional about the right dose 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.

Reference: 1. IXINITY [coagulation factor IX (recombinant)] prescribing information. Winnipeg, MB, Canada; Emergent BioSolutions Inc.; April 2015.

Manufactured by Cangene Corporation, a subsidiary of Emergent BioSolutions Inc. and distributed by Cangene bioPharma, Inc., a subsidiary of Emergent BioSolutions Inc.

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emergent
biosolutions®



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?

Store IXINITY 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.

Do not use IXINITY if the reconstituted solution is not clear and colorless.

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.

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.

Manufactured by Cangene Corporation, a subsidiary of Emergent BioSolutions Inc. and distributed by Cangene bioPharma, Inc., a subsidiary of Emergent BioSolutions Inc.

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15th Annual Gettin' In The Game Junior National Championship

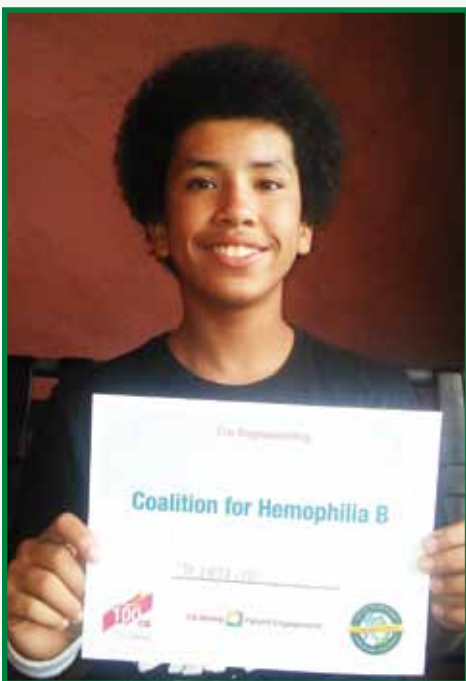


CSL Behring's **Getting in the Game** held in Arizona September 30th - October 2nd, had 111 participants from all across the country representing 62 bleeding disorder chapters and organizations in attendance. To celebrate the program's 15th anniversary, CSL Behring made a big splash and introduced swimming into the Gettin' in the Game Junior National Championship.

Developed by CSL Behring, the Gettin' in the Game Junior National Championship (JNC) was the first and is currently the only national golf, baseball, and swimming competition designed specifically for the bleeding disorders community. The JNC features accomplished Gettin' in the Game athletes, who themselves have

been diagnosed with bleeding disorders such as hemophilia and von Willebrand disease. During the program participants have the opportunity to take part in golf, baseball, or swimming activities to learn the fundamentals and enhance their skills in that sport. Learn about the importance of physical fitness in managing a bleeding disorder and receive instructions on proper stretching techniques and good athletic form. Show off their golf, baseball, or swimming abilities in a national competition with fellow participants from around the country. Connect and build relationships with fellow members of the bleeding disorders community by sharing their personal experiences with one another.

We were pleased to have Jermaine Davis and William McCarthy represent the Coalition for Hemophilia B this year!



"I was lucky enough to be chosen to attend the JNC tournament in Phoenix, Arizona this year! I had played 2 years ago and won the Golf tournament! I was pretty excited to go back and really wanted to win again and be able to give that scholarship to the Coalition for Hemophilia B. We got out to Phoenix, had some time by the pool, got to have a golf lesson with Perry on the driving range and also practiced our chipping and putting. I also had a lot of fun hanging in the game room with friends!

Unfortunately, no win this year but the experience was amazing and I learned a lot. This year I had Mr. Paul Perreault, the CEO of CSL Behring as my caddie! Not too many people get to say that. I got to spend many hours with him on the golf course talking to him and learning from him. I learned that he is really smart, down to earth and that our community is very important to him. It was a once in a lifetime experience. Perry Parker helped me work out some kinks in my golf swing that had been troubling me and gave me some tips to practice over the winter. Hopefully, next year I will be able to go back again! Even a bad day on the golf course is better than a day at school! I would eventually love to volunteer at the JNC event, helping to mentor and work with the younger kids. It is an awesome program that has given me unforgettable life experiences. Thank you to CSL Behring, The Coalition for Hemophilia B, Perry Parker and of course Paul Perreault for your caddie services!" ~ Will McCarthy

"I had such a wonderful experience at the Getting in the game event. I love swimming and was excited that it was included this year. I made friendships that will hopefully last a lifetime. Thank you, Coalition for Hemophilia B for letting me have these awesome memories!" ~Jermaine Davis



"AFTER WORKING
WITH MY DOCTOR
AND BASED ON MY RESPONSE,
I NOW INFUSE PROPHYLACTICALLY
EVERY 14 DAYS!"

Casey, on ALPROLIX

Casey, a MyALPROLIX Peer,[™] started on a once-every-10-day prophylaxis infusion schedule and adjusted to once every 14 days.

Learn more at www.alprolix.com/findyourfit

Extended protection* from bleeds

ALPROLIX is the first factor IX offering prophylaxis infusion schedules starting every 7 or 10 days with the potential to extend based on your response.

*ALPROLIX has been proven to help patients prevent bleeding episodes using a prophylaxis regimen.

The recommended starting prophylaxis regimens are either 50 IU/kg once weekly, or 100 IU/kg once every 10 days. Dosing regimen can be adjusted based on individual response.

Children under 12 years of age may have higher Factor IX body weight-adjusted clearance, shorter half-life, and lower recovery. Higher dose per kilogram body weight or more frequent dosing may be needed in these children.

Indications and Important Safety Information

Indications

ALPROLIX [Coagulation Factor IX (Recombinant), Fc Fusion Protein] is a recombinant DNA derived, coagulation factor IX concentrate indicated in adults and children with hemophilia B for:

- On-demand treatment and control of bleeding episodes
- Perioperative management of bleeding
- Routine prophylaxis to reduce the frequency of bleeding episodes

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

Important Safety Information

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

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

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

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

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

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

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

Please see Brief Summary of full Prescribing Information on the next page. This information is not intended to replace discussions with your healthcare provider.

ALPROLIX [Coagulation Factor IX (Recombinant), Fc Fusion Protein], Lyophilized Powder for Solution For Intravenous Injection.

FDA Approved Patient Information

ALPROLIX® /all' pro liks / [Coagulation Factor IX (Recombinant), Fc Fusion Protein]

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

What is ALPROLIX?

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

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

Who should not use ALPROLIX?

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

What should I tell my healthcare provider before using ALPROLIX?

Tell your healthcare provider about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal medicines.

Tell your doctor about all of your medical conditions, including if you:

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

How should I use ALPROLIX?

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

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

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

What are the possible side effects of ALPROLIX?

Common side effects of ALPROLIX include headache and abnormal sensation in the mouth.

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

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

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

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

How should I store ALPROLIX?

Store ALPROLIX vials at 2°C to 8°C (36°F to 46°F). Do not freeze.

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

If you choose to store ALPROLIX at room temperature:

- Note on the carton the date on which the product was removed from refrigeration.
- Use the product before the end of this 6 month period or discard it.
- Do not return the product to the refrigerator.

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

After Reconstitution:

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

What else should I know about ALPROLIX?

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

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FDA Warns about the Risk of Hepatitis B Reactivation When Taking Hepatitis C Drugs

By Dr. David Clark

The FDA has released a warning about hepatitis B virus (HBV) becoming reactivated in patients receiving direct-acting antiviral (DAA) drugs for treatment of hepatitis C virus (HCV) infection. From November 2013 until July 2016, FDA has received reports of 24 cases of HBV reactivation in patients co-infected with both HBV and HCV. This included two deaths and one patient who required a liver transplant. These were only the cases that were reported to FDA, so there are probably additional cases out there. It is not known why HBV reactivation occurs, but it has only happened in patients taking DAAs without interferon. HBV reactivation usually occurred within 4 - 8 weeks, 52 days on average, of starting HCV treatment.



should be monitored with blood tests to see if HBV infection becomes active while they are taking DAAs and for several months after their HCV treatment is completed.

Patients already taking DAAs should not stop taking their medication before talking to their healthcare professionals about any HBV history. Stopping mid-stream could make their HCV infection more resistant to future treatment. Patients should contact their healthcare professional immediately if they develop fatigue, weakness, loss of appetite, nausea and vomiting, yellow eyes or skin, or light-colored stools, as these may be signs of serious liver problems.

FDA is requiring a Boxed Warning, their highest level warning, about the risk, directing healthcare professionals to screen and monitor for HBV infection in all patients receiving DAAs. The DAAs involved include Daklinza, Epclusa, Harvoni, Olysio, Sovaldi, Technivie, Viekira Pak and Zepatier. Patients should inform their healthcare professional if they have a history of HBV infection (even if previously "cured") or other liver problems before being treated for HCV infection. Patients who have had HBV

HBV reactivation was not observed in the clinical studies for these drugs because patients with HBV co-infection were excluded from the trials. FDA urges all healthcare professionals and patients to report side effects involving DAAs and other medicines to the FDA MedWatch program, which can be accessed on the main FDA web page (www.fda.gov) under "Report a Problem" or by calling 1-888-INFO-FDA. The FDA warning is online at <http://www.fda.gov/Drugs/DrugSafety/ucm522932.htm>.



CONGRATULATIONS NEWLYWEDS!

Rocky Williams and Brittany Petersen (two of our best volunteers who have been very helpful in making our events a success!) tied the knot on Saturday, September 24, 2016, in the historic DANK Haus German-American cultural center in Chicago.

Rocky and Brittany met on Match.com in November 2012. Rocky sent Brittany a simple message: "Hi. How was your day?" In typical fashion, Brittany responded with three paragraphs of just how her day went. Intrigued, Rocky wrote back five paragraphs, and something began to blossom. The pair met for coffee and the conversation never ended! We wish them a lifetime of good health and happiness!



SHE SHARES HIS SYMPTOMS, but not his solutions.

- ✓ Below-normal factor IX levels
- ✓ Chronic pain
- ✓ Prolonged bleeding after dental work or surgery
- ✓ Easy bruising
- ✓ Joint damage from bleeding

“

I knew I was a carrier, and I was having symptoms for years, but I wasn't diagnosed until the age of 36.

— 46-year-old woman with hemophilia B

Women and girls can—and do—have hemophilia B.

Traditionally classified as carriers, women can have the same bleeding symptoms as men with hemophilia B.

They also face challenges all their own, like abnormally heavy and long menstrual cycles with large blood clots, excessive bleeding after giving birth, and anemia.¹⁻³

Don't let the wrong diagnosis be one of those challenges.

Early diagnosis and the right treatment can help or even prevent bleeding problems and improve quality of life.²

That's why Aptevo Therapeutics worked with women who have hemophilia B to create a quick guide that focuses on how this condition affects women, girls, and their families.

With help from this guide, you can feel confident talking about your symptoms with your doctor or nurse.

Download a women's guide to hemophilia B at WomenWithHemophiliaB.com

References: 1. Clark D. Women with hemophilia. Coalition for Hemophilia B. Available at <http://static1.squarespace.com/static/566b210340667a1cc1623840/t/56792e35a2bab8836bd402dc/1450782261872/Women-with-Hemophilia.pdf> Accessed June 28, 2016. 2. Rhynders PA, Sayers CA, Presley RJ, Thierry JM. Providing young women with credible health information about bleeding disorders. *Am J Prev Med.* 2014;47(5):674-680. 3. Hemophilia Federation of America. Are women affected by bleeding disorders? Available at: <http://www.hemophiliafed.org/bleeding-disorders/can-women-have-bleeding-disorders>. Accessed August 5, 2016.

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Therapeutics

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is now brought to you by

Aptevo Therapeutics— a company that's anything but ordinary

Aptevo Therapeutics is a new biotech company focused on improving the lives of people with bleeding disorders and cancer by advancing the science of what's next.

When it comes to the hemophilia B community, the same people from Emergent who pride themselves on working for a different kind of company are now part of Aptevo. IXINITY is still the same, and you'll still connect with the same people you've come to trust.

[Learn more at IXINITY.com](http://IXINITY.com)

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 BioTherapeutics LLC, Berwyn, PA 19312

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CHALLENGES
SOLUTIONS
GRATEFUL
ALTERNATIVES

Jay lives with severe hemophilia B with inhibitors.

Change the way you picture living with a rare bleeding disorder

Novo Nordisk is helping people like Jay write his story.

That's why we are continuously seeking new ways to help support and educate the bleeding disorders community. Because at Novo Nordisk, we're always committed to helping you make your potential possible.

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In Memory of Joe Feagins

By: Jenifer Feagins

On September 20th, 2016, I said goodbye to my best friend, my husband, the father of our three young boys. Joe was only 43 when he lost his battle with renal cell carcinoma, commonly called kidney cancer. He was diagnosed 18 months ago, and although his chance of survival was slim from the onset, he fought. He spent the last 18 months of his life on many different treatments, natural remedies, chemotherapy drugs, and experimental trials. Nothing stopped the progression of the disease in his body, and the progression of the disease in his body didn't stop his love for his family.

Our boys are 6, 8, and 12 years old. The oldest two have Hemophilia B. We attended our first Coalition for Hemophilia B event two weeks after Joe was diagnosed. He didn't complain of pain as we walked through and marveled over our first visit to the Big Apple. He watched with delight as his boys enjoyed all the city had to offer. I remember on the way home he told me his leg was hurting a little bit. Days later, scans revealed that "little bit" of pain was a 7cm metastatic tumor to his femur that was on the verge of fracture. Within a month he had his kidney removed and a rod put in his femur. These surgeries didn't stop Joe from trying to enjoy each day.

He returned to work. He said that the best lesson in life we could teach our boys is not to quit. He was tired, sick from chemotherapy, and in tremendous pain from the growths that were appearing throughout his body, particularly in his bones. He went to work, played with his boys, and curled up beside me every night. It didn't stop him from wanting to set an example for his boys.

When the tumors rapidly spread and the treatments were increased, Joe had to quit working. He woke up every morning and helped with breakfast for our three young boys, put on the littlest one's shoes every day, and found my keys and phone so I could get out the door. When we got home, he was always ready to hear about our adventures at school; no matter how sick he felt. He played chess, watched the kids play online, watched one million kid shows on Netflix, and often helped me make dinner and clean up afterwards. The cancer didn't stop him from being involved in our lives.

We had the opportunity to return to the Coalition's



symposium one year later, and he was so tired that he had to spend most of the time in the room. He would save his energy to attend the evening events with his boys. He wanted the pictures, he wanted them to have the memories, and he wanted to spend every minute he could with us. The pain didn't stop him from traveling with us.

It became too much. Too many metastasis, too many medicines, too many trips to the doctor, and he was overwhelmed. We knew the end was coming and he began preparing for the future. He contacted friends he knew and recruited volunteers to establish a trust account so people could donate to help our family after he was gone. He called friends and put plans in place for people to help take care of us emotionally after he was gone. He had friends draft all his end of life plans, made sure I knew everything I needed to know about his accounts and how to take care of things at the house. Even in his desperation, he didn't stop treatment. He said if any of those

treatments gave him one more moment with us, it was worth it. Fear of death didn't stop him from living.

Just days before his death, he woke up and made my coffee. He rode with me to drop the boys off at school, and he told me he was really feeling poorly. His health rapidly declined. Forty cancerous tumors in more than 13 organs was more than his body could handle. His body had failed him, and it was time for him to go. Each of the boys visited, and through indescribable pain he said goodbye. He gave his last energy to making each of us feel loved. The last words he ever spoke were, "I love you too" in response to me the day before he left his broken body. Even death didn't stop his love for us.

He was so worried about leaving us behind. It was one of his last acts to establish the trust to help support his boys. Even death couldn't stop him trying to provide for his family. I would like to also thank our extended Hemophilia B family for all their support. 🍷

If you would like to make a donation to help support the Feagins family, please send to:

The Feagins Family Trust, c/o The Trust Company
Attn: Virginia Couch, Esq.,
4823 Old Kingston Pike, Ste. 100
Knoxville, TN 37919

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Industry News



Catalyst Biosciences Announces Focus on Hemophilia Treatment

Catalyst Biosciences, a small biotech company based in the San Francisco area, has announced a restructuring and a new focus on products for hemophilia treatment. The company will concentrate its efforts on a next-generation factor IX concentrate for hemophilia B and an activated factor VII (VIIa) product for hemophilia patients with inhibitors. Both products are longer-acting higher-activity molecules that were identified from libraries of genetic variants. The factor VIIa product has completed a Phase I clinical study with positive results and is expected to start an efficacy trial in 2017. The factor IX product is in preclinical development and is also expected to begin clinical studies in 2017.



Sangamo Announces Orphan Drug Designation for its Gene Therapy Treatment

Sangamo BioSciences announced that it has received Orphan Drug Designation from FDA for its hemophilia B gene therapy treatment. Orphan Drug Designation is intended for products to treat rare diseases that affect fewer than 200,000 people in the U.S. It gives the manufacturer various incentives including tax credits and seven years of market exclusivity. Sangamo expects to start a Phase I/II clinical study later this year. Information on participation in the trial can be found at www.fixtendztrial.com.



SAVE THE DATES 2017!

New York

Thursday, March 2, 2017
10th Annual Fundraising Dinner
New York City

Florida

Thursday, March 30, 2017
1st Annual Golf Fundraising
Tournament
Vedra Beach, Florida

Florida

Friday, March 31, 2017
11th Annual Symposium
Sawgrass Marriott
Vedra Beach, Florida



The Coalition for Hemophilia B understands there are families within our bleeding disorder community who feel the effects of the current economic situation. We thought it would be a nice idea to ask our more fortunate Factor Nine Families to make a financial donation to the Factor Nine **“Holiday Fund”** to help buy gifts for children with hemophilia this holiday season. The Coalition for Hemophilia B will also contribute to this fund.

**If you wish to make a donation, please send a check payable to:
The Coalition for Hemophilia B “Holiday Fund”
825 Third Avenue, Suite 226; New York, New York 10022**

Please respond by **December 10, 2016**, so the Factor Nine Santa can load his sleigh with holiday gifts for all good girls and boys!

For those families in our community in need of a little Holiday Cheer, we would like to help put something under the tree for your children! Just fill out this form and send it to Santa’s special elf, Kim at the “East” Pole. Since the Factor Nine Santa has such a busy schedule, please send it to us no later than **December 10, 2016**. Your name and information will be kept strictly confidential. Send this form to:

**The Coalition for Hemophilia B Holiday Cheer
Attention: Special Elf Kim
825 Third Avenue, 2nd Floor; New York, New York 10022**

We wish you all a beautiful holiday season filled with love, happiness and good health!



Name: _____ Phone: _____

Address: _____

City, State Zipcode: _____

Please give us an **exact description** of the item your child is wishing for
If we have any questions, we will contact you directly.
Holiday gifts will be purchased by The Coalition and sent to your home.

Child’s Name and Age:

Child’s Name and Age:

Child’s Name and Age:

Wish List:

Wish List:

Wish List:

KIDZ KORNER!

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PEAR APPLE BROWN SCARECROW





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For the latest **B Scene** video sharing real life stories of members in our community, please visit our social media sites:

Website: www.hemob.org

Facebook: www.facebook.com/HemophiliaB/

Twitter: <https://twitter.com/coalitionhemob>

For more information, please contact Kim Phelan:

kimp@hemob.org or call 917-582-9077



Wishing You Safe and Happy Holidays!