Factor Nine News

The Coalition for Hemophilia B Winter 2014

Topics in Hemophilia

- Factor Nine Family Meeting at NHF
- Meetings on the Road: Texas, Tennessee & Indiana October – November
- First Annual Ladies Brunch
- Meet Kevin Harris
- Consumer Advisory Board
- Industry News by Dr. David Clark
- Hepatitis C Treatment Update
- B2B Educational Pamphlets Now Available ONLINE!
- Kidz Corner
- Save The Dates

The Coalition for Hemophilia B Factor Nine Family Meeting in conjunction with The National Hemophilia Foundation Meeting September 20th 2014

Booth Coverage at the National Hemophilia Foundation Conference in Washington DC September 18-20, 2014.

2014 MEETINGS ON THE ROAD

We held our first *2014 Meetings on the Road* in Ohio in July. Three others were held in Houston, Texas Saturday, October 25th at the Houston Marriot West Loop; Nashville, Tennessee, Saturday, November 8th at the Four Points Sheraton Nashville-Brentwood; and Indianapolis, Indiana at the Indianapolis Marriott, Saturday, November 15th.

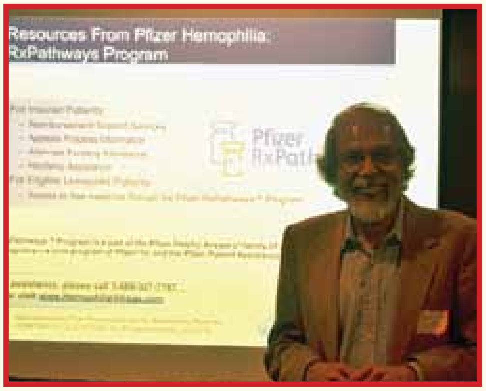
Topics included *Constructive Communication*, *Imagining Your Future*, *Making a Great Impression*, *Win-Win Conversations* and so much more! We want to thank our delightful speakers, exhibiters and also special presentation by Rick Starks teaching us all Taiji Fit which was so much fun!

We thank our wonderful chaperones who took the kids to great places such as the Houston Zoo and the Children's Museum of Indianapolis where the children were able to see the Ryan White exhibit. *The Power of Children: Making a Difference*, a permanent exhibit opened in November 2007. It began with an inquiry from Jeanne White-Ginder, the mother of Ryan White, an Indiana teenager with hemophilia who became internationally known in the 1980s when he contracted HIV-AIDS. His is a story of an extraordinary young person in history who can inspire children today to fight discrimination and intolerance and make a positive difference in the world.

Meetings on the Road

Texas, Tennessee and Indiana

October – November

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RIXUBIS
[COAGULATION FACTOR IX (RECOMBINANT)]

For more information, contact your Baxter representative today:

Laini Vogel

Phone: (201) 312-7533

E-mail: laini_vogel@baxter.com

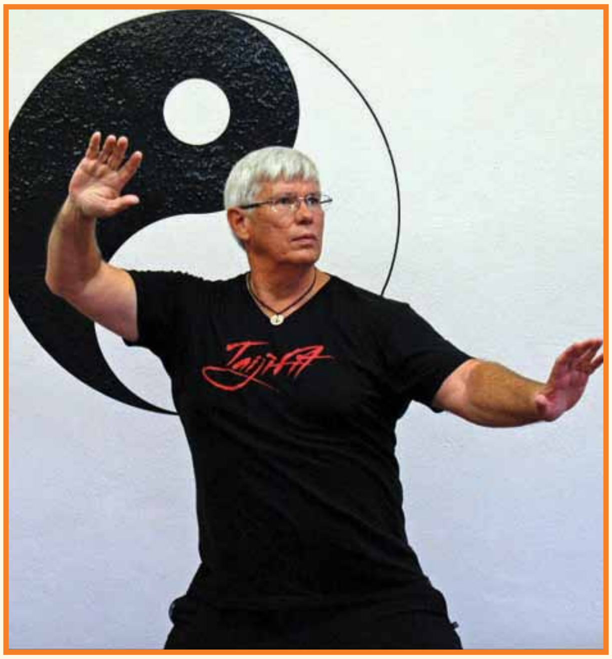
To learn more, visit www.RIXUBIS.com.

Baxter

Thank you to Pfizer for sponsoring our four meetings on the Road!

It was so wonderful to travel and see our hemophilia B families!

See you again in 2015!


TaijiFit


TaijiFit










BERIT OLSEN KROGH
Denmark
Principal Scientist, Mammalian Cell Technology

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

First Annual Ladies Brunch
Sunday, October 26, 2014

Our first ladies brunch was held at the famous Palm Restaurant in Houston. The ladies - moms, spouses and woman with bleeding disorders were treated to a lovely brunch in which they were able to gather and share information, create a bond and support each other.
It was priceless to see such wonderful bonding!

We would like to thank our sponsor Pfizer for their support of such a wonderful event!

Palm

"The Coalition for Hemophilia B"

Sunday, October 26, 2014

Farmers Market Fresh Fruit and Berry Display

Chef's Bakery Basket

Assorted Yogurt Cups

Crispy Smoked Bacon, Grilled Sausage Links

Beverages

Tea, coffee, cranberry juice, tomato juice, orange juice

Bloody Mary and Mimosa Bar

Sponsored by


THE COALITION FOR HEMOPHILIA B, INC.
WELCOME

HEMOPHILIA B:

MY OPPORTUNITY TO OVERCOME

By Kevin Harris

At a young age, how much did I truly know about hemophilia? Although I was diagnosed with moderate hemophilia B (3% factor IX) at 7 years old, I was already incredibly active playing countless sports and living a childhood like any other kid out there. Then came the bleeds. As a kid with only the sole intent to have fun and continue playing sports, the "inevitability" of bleeds started playing a huge role in my life. This had to stop.

Moving through high school and then on to college, I was exposed to an extreme sense of responsibility. I had to set my own alarm for the morning, decide to eat breakfast or not, choose whether or not to go to class, or to even leave the apartment at all; in other words the ultimate freedom to decide. The biggest change was the fact that my organized sports days were done and my activity level was up to me. I no longer had scheduled practice or games, but only my own time to set aside or not. I was also responsible for what went into my fridge, no longer waiting for my mother to return from Costco with a minivan full of groceries. This is when I realized it is 100% my choice of how my body felt. I began exercising 5-7 days a week, and paid close attention to my diet. I began to stay away from fast food and to appreciate the therapeutic effect that cooking had on me. I ran, lifted weights and stretched outside when the weather was nice. As time went by, I started having less bleeds. Why? I had to find out.

As I got deeper and deeper into my nutrition and exercise studies, I realized the direct correlation between hemophilia and fitness. My body mass had started changing, my joints started becoming stronger, I was more flexible. Taking a step back, everything seemed to make sense. Two critical places that hemophilia affects, joints and muscles, could be strengthened with hard work, dedication, and a large appetite for knowledge of the subject. Unknowingly, I had just figured out a way to decrease my risk of injury. All of a sudden, this intense passion came over me to change my life for the better, but now I knew how and more importantly why.

As advanced as our bodies may be, in a way they are quite simple. Be good to your body, it will be good to you. Enjoy the process of becoming healthy, as it doesn't happen overnight. I believe that things achieved gradually are most likely more genuine. One can never forget it is a constant learning experience. Personally, some things are just too good to give up, like bacon and the occasional pepperoni pizza. Part of being healthy is being happy, and understanding the idea of balance, not perfection.

Exercise is incredibly good for not only the body, but the mind and spirit. And what better way to reward yourself afterwards than with a colorful nourishing meal you've taken the time to prepare yourself. It is not easy, I'll tell you that. It takes hard work and heart, but nothing can compare to the satisfaction you will earn by feeling great, looking great, and learning to better manage your hemophilia. You may not have the ability to change everything, so change what you can. In the year 2014 I had one bleed, and I am ever so grateful for those who have helped me on my path to becoming healthy.

Consumer Advisory Board

Working Together for a Stronger Hemophilia B Community

By Wayne Cook

Generously Sponsored by Pfizer

Brief History

It was 18 years ago that a little-known company called Genetics Institute held a meeting of individuals who had factor IX hemophilia. The purpose of the meeting was to discuss its new and first recombinant factor IX product, BeneFix®. During this meeting, it became apparent that support was needed for people who had factor IX hemophilia, so a patient and consumer advisory board was created. It was the first of its kind in the hemophilia B community, and since then, it has developed into an important way of helping patients and caregivers.

In the years to come, Genetics Institute sold its product, BeneFix, to Wyeth Pharmaceuticals. Fortunately, Wyeth continued to support the advisory board meetings, as the company saw them as a great way to find out what the hemophilia B community needed. The meetings also could be used as a significant marketing tool. In 2006, I saw the need for a change in the advisory board if it was going to meet the growing needs of our hemophilia B community. I met with the upper echelon at Wyeth and presented a plan that I thought could work for both the hemophilia B community and the company. Out of that meeting developed a working board of individuals who became the advisory board—patients and caregivers, along with employees of Wyeth, working together to help the hemophilia B community by presenting programs and reaching out to the community through its publications. This group has come to be known as the B2B Consumer Advisory Board.

What We Do

Since 2006, a lot of good things have come from the B2B Consumer Advisory Board due to the hard work of its members. Meeting twice a year and holding periodic phone conferences with the executive board, the advisory board has made great progress toward helping people in the factor IX community. As an advisory group, we have an exchange of ideas not only with company employees but also with their research and scientific teams.

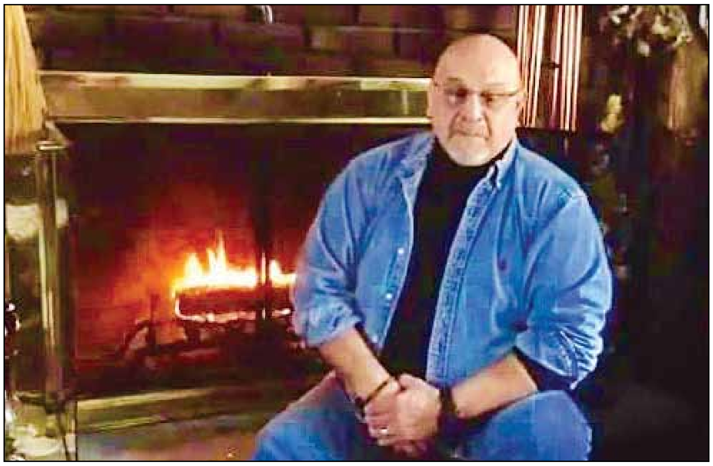
A few years back, Wyeth Pharmaceuticals was sold to Pfizer Inc., and with this sale came concern that the advisory board would be disbanded, but Pfizer saw what great work the board was doing and decided to continue to support it.

Patient for Patient

Over the past 18 years, the board has overseen the B2B program. This is a program where hemophilia B patients can help other hemophilia B patients live with their blood disorder. An important development from this program was a series of books that were written not only to discuss the lives of individuals who appear in the books, but they also try to answer frequently asked questions from individuals in the bleeding disorder community.

Other important contributions have come out of the advisory board. Feedback from the members helped Pfizer develop the BeneFIX rapid reconstitution (R2) kit, a fast and easy preparation process for infusions. Because the voices on the board let Pfizer know what they were hearing from the community, larger vial sizes were made, which were preferable to the smaller vials.

Pfizer has developed a strong working relationship with The Coalition for Hemophilia B. It has helped the coalition with programs that reach the factor IX community. In the past few years, the advisory board saw a growing need to reach out to the younger generation of consumers, so we started to add some new members from this age group in order to get their input. A few of these young men had one of their parents on the board, and the parents thought that it was time to have their sons replace them. In this way their sons could help mentor the younger generation.



Wayne Cook

The advisory board discusses everything from ever-present insurance issues to how to meet the needs of everyone affected by hemophilia B. One thing that has been discussed by the board over the years is having a men's retreat to get the older and younger generations together. This could give them a chance to bond and obtain some great information that would help them in their lives. The board has also held a meeting in which caregiver spouses were invited to discuss their needs and issues. We even have an individual on the board who developed a mobile app, with the help of Pfizer, to track bleeds on a smartphone.

Looking Forward

As we move into the future, we are putting everything online that we have produced in the past, so that it is available for everyone to see. You will be able to log on and see what we have worked on and read each of the B2B books in the series, as well as other publications that have come from the hard work of the advisory board. **Please visit www.B2Byourvoice.com.**

The B2B Consumer Advisory Board will continue to work with Pfizer to help meet the needs of everyone affected by hemophilia B, from patients and caregivers to spouses, siblings, and even grandparents and friends.

If you are interested in learning more about the B2B Consumer Advisory Board, please contact Wayne Cook at cookwa61@gmail.com.

BeneFIX®

Coagulation Factor IX (Recombinant)

Room Temperature Storage

Rx 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
difficulty breathing
chest tightness
turning blue (look at lips and gums)
fast heartbeat
swelling of the face
faintness
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. Store the diluent syringe at 36° to 86°F (2° to 30°C). 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.

Different storage conditions are described below.

Product labeled for Room Temperature Storage
Store at 2° to 30°C (36° to 86°F).
If you have the product kit labeled for room temperature storage, it can be stored at room temperature (below 30°C or 86°F) or in the refrigerator (2° to 8°C or 36° to 46°F).

Product labeled for Refrigerator Storage
Continuous refrigeration
[2° to 8°C (36° to 46°F)]
If you have the product labeled for storage in the refrigerator (2° to 8°C or 36° to 46°F) and you have not taken the kit out of the refrigerator, then the expiration date printed on the package still applies. You can store the product at room temperature (below 30°C or 86°F) for up to 6 months or until it has reached its expiration date, whichever comes first.

If you have taken the product kit labeled for storage in the refrigerator out of the refrigerator and stored it at room temperature (below 30°C or 86°), then use the product within 6 months from the time you took the product out of the refrigerator or until it has reached its expiration date, whichever comes first. If you cannot remember when you took it out of the refrigerator, then subtract one year (12 months) from the date that is printed on the end flap of the carton package. The date you get is your new expiration date. Throw away any product that has gone over the new expiration date.

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-0464-8.0, revised November 2011.

Wyeth®

Manufactured by Wyeth Pharmaceuticals Inc.
BUS420219-01

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July 2012

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BeneFIX®
Coagulation Factor IX (Recombinant)
Room Temperature Storage

IMPORTANT SAFETY INFORMATION FOR BeneFIX®

- 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 interfere with the effectiveness of BeneFIX.
- 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.

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.

Please see brief summary of Prescribing Information on 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.
[1]IMS National Prescription data October 2013.

Download your free HemMobile™ app.
HemMobile helps you keep track of your infusions and any bleeds you might have.

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Manufactured by Wyeth Pharmaceuticals Inc.
Marketed by Pfizer Inc.

INDUSTRY NEWS

by Dr. David Clark

Alnylam Pharma Announces Positive Results in their Phase I Study for Hemophilia Treatment

Alnylam Pharma has announced positive results in their Phase I study of ALN-AT3, an RNA interference treatment to reduce production of antithrombin and thus increase the clotting ability of the blood in patients with hemophilia and other bleeding disorders. Antithrombin, an anticoagulant, is produced by the body to help control the clotting process. Alnylam's idea is that by reducing the amount of antithrombin in circulation, the blood will be able to clot more easily, potentially without requiring factor VIII or factor IX. The study showed that weekly subcutaneous doses of ALN-AT3 were able to significantly reduce the body's production of antithrombin in both normal subjects and subjects with hemophilia. The treatment was well tolerated with no serious adverse events. The effect on clotting has not yet been evaluated.

Baxter Announces FDA Approval of RIXUBIS for Treatment of Children with Hemophilia B

Baxter Healthcare's Rixubis has received FDA approval for routine prophylactic treatment, control and prevention of bleeding episodes, and perioperative management in children with hemophilia B. The approval is based on the results of a clinical study investigating the efficacy and safety of Rixubis in 23 previously-treated male patients under 12 years of age.

Baxter Opens New Recombinant Processing Facility in Singapore

Baxter Healthcare recently opened a new recombinant processing facility in Singapore. When fully operational and approved by FDA, the new facility will be the primary worldwide production facility for Rixubis.

CSL Behring files BLA for Longer-Acting FIX Concentrate

CSL Behring has submitted a Biologics License Application (BLA) to the FDA for its new longer-acting factor IX concentrate, rIX-FP. rIX-FP is a fusion protein incorporating recombinant factor IX linked to recombinant human albumin. Albumin, the most abundant protein in plasma, has a relatively long half life, which also keeps the linked factor IX molecules in circulation longer. The clinical studies supporting the license application showed efficacy with dosing intervals of up to 14 days.

Novo Nordisk's Longer-Acting Factor IX is Effective and Well-Tolerated in Clinical Studies

Positive results were published from the clinical study of Novo Nordisk's longer-acting glycoPEGylated factor IX product N9-GP. The study looked at 74 hemophilia B patients divided into three groups. One group received weekly infusions of 10 IU/kg, one group received weekly infusions of 40 IU/kg, and one group was treated on demand. In the 40 IU/kg weekly infusion group, more than half of the patients did not experience bleeding episodes. The product was well-tolerated, and none of the patients developed inhibitors.

AlphaNine® SD
Coagulation Factor IX (Human)
Solvent Detergent Treated/Virus Filtered

INTRODUCING

The AlphaNine® SD Savings Card Program

Designed specifically for the needs of patients with hemophilia B

You could save up to **$500 per month** on the costs of your prescription for AlphaNine® SD (coagulation factor IX [human]).

Restrictions apply—see inside to determine if you qualify.

Please see Important Safety Information about AlphaNine® SD on back and refer to accompanying package insert for complete prescribing details.

GRIFOLS

Pfizer to Collaborate with Spark Therapeutics on Gene Therapy

Pfizer and Spark Therapeutics have agreed to work together to produce gene therapy treatments for hemophilia B. Spark Therapeutics is a gene therapy startup that was spun off from Children's Hospital of Philadelphia (CHOP) in late 2013. CHOP has been a pioneer in gene therapy research for hemophilia and other diseases. The collaboration will use adeno-associated virus vectors to introduce high-activity factor IX genes into liver cells. They expect to begin early-stage clinical studies in the first half of 2015.

Sangamo Plans Submission of an IND for Hemophilia B Gene Therapy in 2015

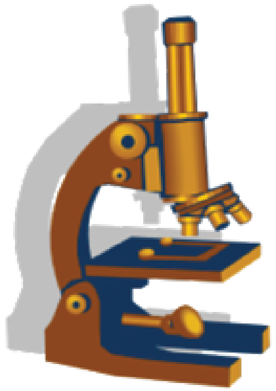
Sangamo Biosciences and their partner Shire have announced plans to file an IND for a clinical study of their zinc finger nuclease (ZFN) gene therapy treatment for hemophilia B. ZFN technology uses specialized enzymes to actually repair defective factor IX genes.

A Heartfelt Thank you!

Thank you to all our donors of the Factor Nine Holiday Fund
With your help we were able to help 53 children have a wonderful holiday!
We supplied gifts, coats, boots, clothes and food baskets.

THANK YOU! THANK YOU! THANK YOU!

Two New Treatments Approved for Hepatitis C



In the wake of the approval of Gilead's new hepatitis C drug, Harvoni, two additional treatments have been approved by FDA. Johnson & Johnson's Olysio has now been approved for use with Gilead's Sovaldi. AbbVie's Viekira Pak, which is a combination of four anti-viral drugs has also been approved.

All three products now provide all-oral treatments that do not require co-administration of interferon and ribavirin. Interferon and ribavirin were responsible for most of the difficult side effects of previous treatment regimens. The three new products provide over 90% cure rates for patients with Genotype 1 hepatitis C with minimal side effects. All are 12-week regimens, although in some cases, patients are cured in just eight weeks.

New Resourcee Now Available Online B2B Educational Pamphlets

The B2B Consumer Advisory Board
Members and PFIZER
are happy to announce the
B2B Educational Pamphlets
now available online!

Visit:
www.benefit.com/hemophilia-b-and-you

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

FDA Approved Patient Information

ALPROLIX™ /all′ prō 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.

Manufactured by
Biogen Idec Inc.
14 Cambridge Center
Cambridge, MA 02142
U.S. License #1697

NOW FOR HEMOPHILIA B...

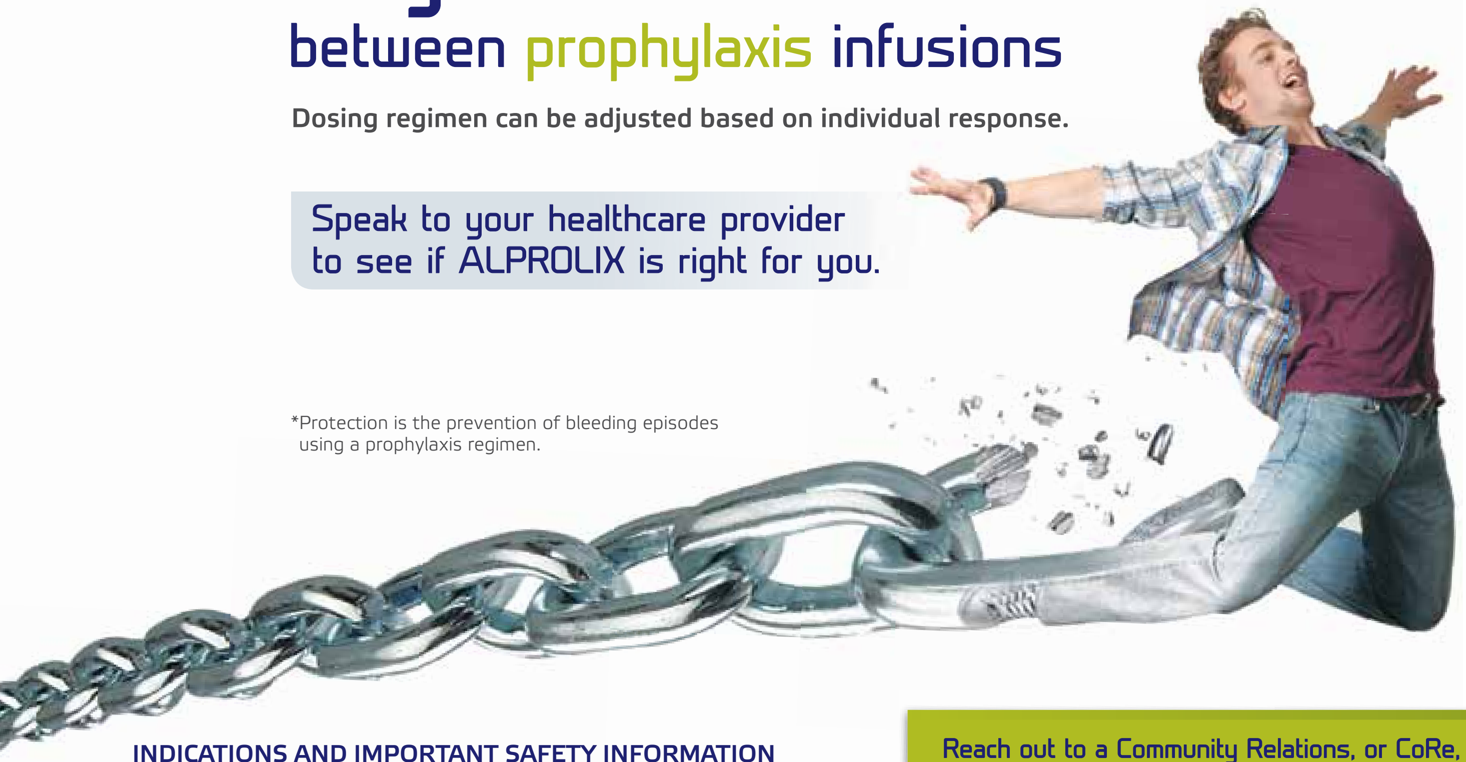
ALPROLIX™
[Coagulation Factor IX (Recombinant), Fc Fusion Protein]

Protection* from bleeds

Starting with at least a week between prophylaxis infusions

Dosing regimen can be adjusted based on individual response.

Speak to your healthcare provider to see if ALPROLIX is right for you.



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

Reach out to a Community Relations, or CoRe, Manager for support, product information, and to learn about events in your area.

Visit ALPROLIX.com/CoReManager

INDICATIONS AND IMPORTANT SAFETY INFORMATION

Indications

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

- Control and prevention of bleeding episodes
- Perioperative management
- Routine prophylaxis to prevent or reduce the frequency of bleeding episodes

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

Important Safety Information

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

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

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

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

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

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

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

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

biogen idec.

KIDZ CORNER

My name is Cole Croston, I'm 14 years old and live in Conroe, Texas. I was born with a serious liver condition called Biliary Atresia. I had my first surgery at 4 weeks old, which was a temporary fix. It ultimately resulted in a liver transplant, which I had when I was 18 months old.

At 3 years old I was diagnosed with factor IX deficiency also known as hemophilia B (mild). After all kinds of tests the doctors figured out that I acquired this from my transplant. Hemophilia was new to everyone in our family because nobody we knew had this.

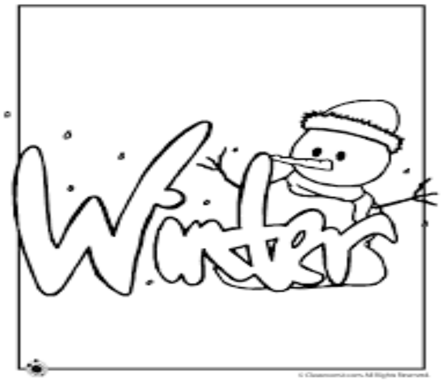
I've always liked to do anything and everything outdoors like riding dirt bikes, fishing, hunting, playing basketball but my passion is baseball. I'm a catcher and pitcher. I am a freshman in high school and hope to play in college.

Up until this summer I had never met anyone who had hemophilia. My mom, my sisters and I went to Austin, Texas to our first hemophilia convention with the Lone Star Chapter. Like I mentioned, I had never been around anyone else with this condition so I didn't know what to expect. We had a lot of fun and I learned a lot about myself.

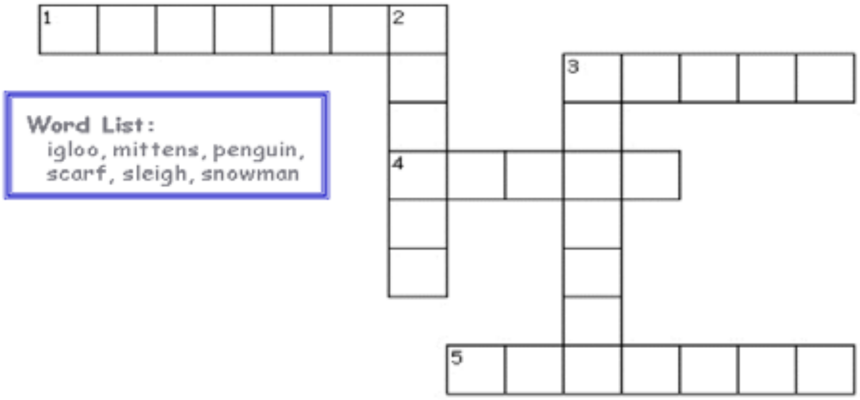
I met a man at a booth from the Coalition for Hemophilia B. He told me about a camp in Oregon that I should try to go to. We applied and later found out that I was getting to go! This camp was awesome. I met a lot of cool people and got to experience things I've never done before. I can't wait to go back next year.

This opportunity has given me a different outlook on hemophilia. I'm interested in getting more involved in the hemophilia community and hope to attend more conventions and camps in the future and hopefully become a mentor myself one day.

Winter Jumble



Winter Crossword



Word List:
igloo, mittens, penguin,
scarf, sleigh, snowman

Across

1.

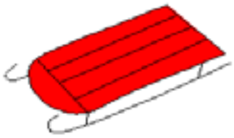
3.

4.

5.

Down

2.



3.

Coloring Time!

SAVE THE DATES

The Coalition for Hemophilia B 8th Annual Fundraising Dinner

Honoring “Eternal Spirit” Award Receipients: Chad Stevens and Joan McCarthy
Friday, March 6, 2015

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The Coalition for Hemophilia B 9th Annual New York Symposium

Grant Hyatt Hotel
Registration and exhibit forms available on our website
Saturday, March 7, 2015
Registration open www.coalitionforhemophiliab.org
Sponsored by Pfizer

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The Coalition for Hemophilia B 3rd Annual Men’s Retreat

March 20-22, 2015
Carefree, Arizona
Sponsored by Pfizer

◆

The Coalition for Hemophilia B 1st Annual Woman’s Retreat

April 10-12, 2015
Carefree, Arizona
Sponsored by Pfizer

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Generation IX Project

Mentor and Teen applications now available on our website
Mentors - June 11-14, 2015
Teens - June 9-14, 2015
Camp Collins; Portland, Oregon
Application forms on our website www.coalitionforhemophiliab.org
Application Deadline May 15, 2015
Sponsored by Emergent

◆

The Coalition for Hemophilia B First 2015 Meeting on the Road

Saturday, June 6, 2015
Albuquerque, New Mexico
Sponsored by Pfizer

For more information email Kim at hemob@ix.netcom.com or call 212-520-8272