



# Factor Nine News

The Coalition for Hemophilia B Spring 2014



## Topics in Hemophilia

- 7<sup>th</sup> Annual Fundraising Dinner
- 8<sup>th</sup> Annual Symposium
- CSL Behring Gettin' in the Game Essay Contest – Deadline August 1, 2014
- Family Meeting at HFA
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- Kidz Corner
- Save the Date

## *Seventh Annual Fundraising Dinner*

The Coalition for Hemophilia B held its Sixth Annual Fundraising Dinner on Friday, March 7, 2014 aboard the Atlantica Bateaux Yacht in New York Chelsea Pier. Approximately 200 people were in attendance, including the lotto families we flew in for the symposium, industry people and private donors. Monies raised will benefit the Coalition's Educational Programs and the William N. Drohan Scholarship Fund. Cocktail hour included entertainment by the wonderfully talented pianist and saxophonists, William Gati & Ensemble with special appearance by singer Antoinette Montique!



Dinner began with a warm welcome to our guests by Wayne Cook, President of The Coalition for Hemophilia B, followed by John Taylor who announced the William N. Drohan Scholarship

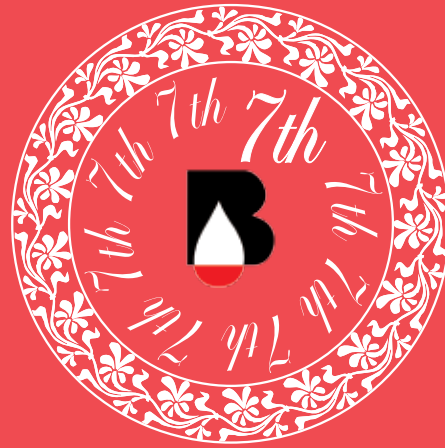
Winners. As of 2014 Scholarships awarded in the last seven years is \$190,000. Congratulations to this year's winners, Daniel Vetter, Sam Lathrop and Becky VanSant!

After dinner and dessert our super helpers announced the raffle prize winners. We continued the wonderful evening dancing, enjoying the great company, beautiful views and taking fun custom photos where a variety of cool background images could be selected. It was so much fun! Everyone had a good time indeed. We were delighted to see you all!

The Coalition for Hemophilia B sends a sincere thank you to all of our generous contributors. We hope you will join us next year at our Eighth Annual Fundraising Dinner at the Water's Edge Restaurant on Friday, March 6, 2015! 🍷



# Seventh Annual Fundraising Dinner













## The Coalition for Hemophilia B 8<sup>th</sup> Annual Symposium

Generously Sponsored by 

**T**he Coalition for Hemophilia B's Eighth Annual Symposium was held on Saturday, March 8, 2014 at the New York Grand Hyatt Hotel in New York City. The Symposium began with a warm welcome and opening comment by Wayne Cook, President of The Coalition for Hemophilia B

Our first speaker was Dr. Christopher Walsh, Hematologist at Mt. Sinai School of Medicine in New York City. Dr. Walsh spoke about *What's New in Hemophilia*, a review of important happenings in the hemophilia world! Topics covered were how hemophilia is steadily heading toward a cure. Dr. Walsh also stressed the importance of managing hepatitis C and how the new drugs will be able to treat almost all patients. Some will be oral pills so

if you have hepatitis now is the time to get treated! Dr. Walsh stated bleeds are preventable if you get enough factor. Even mild patients have to check their factor levels. Prophylaxis is key.

Dr. Walsh spoke on several companies coming out with news products. His talk was very passionate and eye opening for many. Symposium participants asked a multitude of questions for Dr. Walsh when he finished his presentation.

Next on the agenda was Karla White, Senior Manager, State Government Affairs from CSL Behring. Karla's talk was on *Insurance Updates*. Karla mentioned that National Hemophilia Foundation (NHF) has a *Personal Health Experience*

# 8<sup>th</sup> Annual Symposium



*Education...  
Advocacy...  
Friendship...  
Support...*





Stat Sheet available on their website and it's a great tool to help you figure out your needs. She also mentioned there is a shift to consumer focus in the market place, which is ultimately going to put more responsibility on the patient. The talk was very informative and well received.

Following we had a interactive session on *Positive Assertiveness* with Wendy Kaufman, a national executive trainer and life coach who brings work-life balance programs to corporations, non profits, employee assistance programs and educational institution. Wendy is part of Biogen's Life Skills Series. Wendy spoke about the *AEIOU Steps for Being Assertive*:

- A – Acknowledge the other person's positive intention
- E – Express your thoughts and feelings
- I – Identify your proposal plan
- O – Outlines the outcome you anticipate and its benefits
- U – Understand each other

After a wonderful lunch and time to visit the exhibit booths, Val Bias CEO of the NHF spoke on genotyping. NHF offers free genotyping, which increases our understanding and will lead to scientific breakthroughs. This is now happening for hemophilia A and B carriers, and they are talking about including vWD patients soon. No one will own the data - the four partners doing this will not own your data.

Next up was Linda Pollhammer, RN, a clinical nurse hemophilia educator with a background in infusion, home health care and supportive





education. Linda represents PFIZER's *Living with Hemophilia: A Community Education Series*. Linda's topic was *Overcoming Challenges*. She stated the important of logging infusions, communicating with your hemophilia medical team about all the medications you take, call your treatment center for any head injury, even if minor. One patient had what seemed to be a minor event where a branch hit his head while he was mowing his lawn, and he actually past away the next day from a head bleed. Linda stressed the importance of exercise to improve and protect your joints.



Pete Dyson, a middle school teacher and coach with hemophilia B shared his story about his grandfather who also had hemophilia B. His grandfather had recently passed away at the ripe of age of 90. He spoke about what his grandfather went through in the days before factor was available. Pete was very lucky to have his grandfather's wise advice and we all enjoyed hearing his story.



Following an afternoon snack break, Hope Woodcock, RN started the second half of the day with an *Infusion Session*. Hope has been in the hemophilia community for a number of years and is one of the co-founders of Camp Little Oak for girls with bleeding disorders, carriers and siblings. Many gathered around as Becky VanSant and Wayne Cook Self infused with Hope explaining the process to curious onlookers! I cannot express the importance of sessions like this to help children overcome their fear of infusion.



Babysitting was provided for the children. Children 4 and over took a chaperoned trip to Discovery Times Square and later were treated to special fun games with CSL Behring "Gettin in the Game" crew. They also had a wonderful session for ages 9 -25 called *Designing your Future* with Wendy Kaufman. This session was very interactive and



very helpful to all age groups as they were gently guided to get out of their comfort zone and in a fun way learned more about their interests.

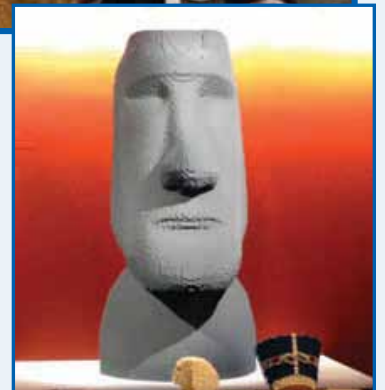
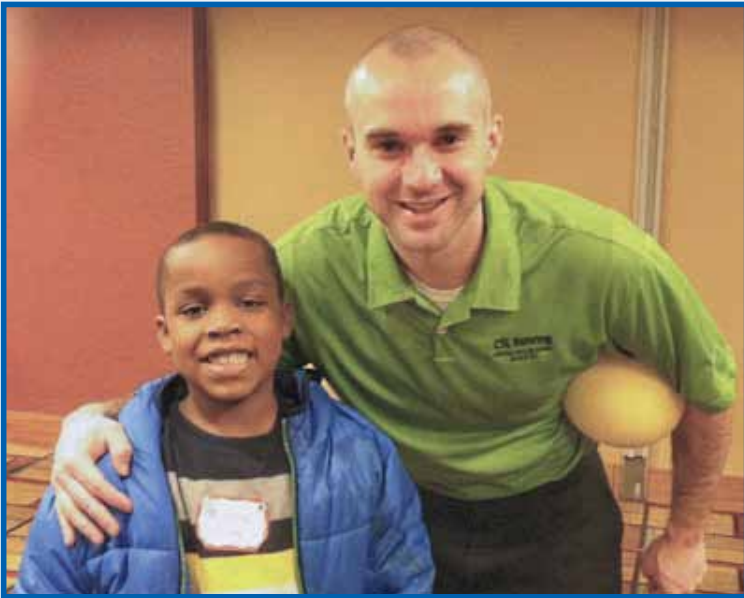
Later Chris Monda a Pro Bowler with hemophilia B spoke to the children about his passion for bowling. Chris is 18 and has been bowling since he was 6 years old. He is a turbo Grips Pro Staffer and bowler on the PBA Regional Tour. Chris uses his talent to raise awareness for hemophilia, mental health and breast cancer! The kids visited the exhibits booths and overall they had a blast! To end the day, we had breakout sessions and our Factor Nine Family meeting.

A big thank you to our sponsors, exhibitors and speakers for making our Annual Symposium a huge success! 🎉





**8<sup>th</sup> Annual  
Symposium**  
*Kids had fun!*



## Symposium Comments

**O**ur family enjoyed the Hemophilia B experience from the greeter with the bagpipes at the Fundraising Dinner to the educational experience on Hemophilia B and updated information on meds. Meeting new hemophilia B families was great and we are still in contact with several of them on a weekly basis! Hearing about hemophilia B and specific information on just hemophilia B, which was specific to our wants and needs! The yacht ride, dinner, and music was exceptional to say the least! It made Joseph feel more normal in a hemophilia B world and know that he is not alone. Kim goes out of her way to provide the kids as well as the adults interesting things to learn. I greatly appreciate the time in New York and the time spent with others! If I can help you in any way, please say so and I shall!  
DG - Chicago

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**B**oth my wife and I thoroughly enjoyed the Symposium as well as the Dinner Cruise. Thanks to the Coalition's great lottery program, we were very fortunate to be awarded financial support to attend our first national education program for both hemophiliacs and their families. It also offered us a wonderful opportunity to meet Coalition members from around the country.

As for the Symposium, the agenda was current and extremely informative. The hemophiliac community is living during exciting times where we are seeing dramatic scientific advances all the way from long-acting clotting products to successful gene therapy. We were pleased to see the agenda addressed the exciting new advances in Hepatitis C therapy. As an aside, I am now one of those Hep C-positive (30 + years) hemophiliacs who has been given the newly-FDA approved Hep C anti-viral medications, and I can now announce that I am free of the Hep C virus! The remaining symposium agenda was just as rewarding.

My wife, Linda, found that the group breakout sessions provided the best forum for hemophilia B family members to exchange ideas and experiences. Too often, due to low incidence of hemophilia B, their families live isolated from other

hemophiliac families. Thus, having the opportunity for the wives of hemophilia B individuals as well as some rare hemophilia B females to share their life experiences and knowledge was extremely gratifying. We would recommend that similar sessions be added to other Coalition meetings whenever the spouses are in attendance.

We look forward to future Coalition meetings and symposia! Again, I have to underscore that the staff and volunteers' organizational skills, professionalism and social expertise are the foremost reasons these complex events are executed flawlessly. We are living through some very interesting times in the hemophilia community, and we are indeed fortunate to have organizations like the Coalition for Hemophilia B to keep us educated, coordinated and always ready to serve as our advocate at all levels of government. On a personal note, we cannot thank the Coalition and its supporters enough for offering financial assistance to attend these critical meetings and workshops.  
RL - California

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**W**e were first time attendees and I can't say enough about how excited we were to meet other Factor 9 families! The experience was worth a million bucks to my family! We learned from the speakers and had plenty of fun too! Thank you so much for hosting an event that connects us Hemophilia B folks!  
KD - Virginia

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**T**his was the first time my husband attended a hemophilia event. He has been hiding in the shadows with his hemophilia and we are so grateful for this experience. I cannot tell you how this event has changed our lives and my husband now has a lot of support as do we all. We loved all the speakers - in particular Dr. Walsh is amazing! The education, the support... everything was just wonderful! Thankyou! Thank you! Thank you!  
CS - Chicago

R<sub>x</sub>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](http://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°F), 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.

**17+**  
YEARS  
YOUR  
EXPERIENCE  
MATTERS



**BeneFix**<sup>®</sup>  
Coagulation Factor IX (Recombinant)  
Room Temperature Storage

**I LIKE TO STAY ACTIVE.  
I HAVE NO PLANS TO  
CHANGE THAT.**

**BeneFix is the most prescribed recombinant factor IX treatment FDA approved for hemophilia B.<sup>†</sup>**

- Demonstrated bleed control in patients with moderate and severe hemophilia B
- Established safety record
- BeneFix Rapid Reconstitution (R2) Kit—designed for patients, by patients—offers a full range of dosing options

#### **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<sup>®</sup> 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 full Prescribing Information on next page.**

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

\*BeneFix was approved February 11, 1997.

<sup>†</sup>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.**



**Join Our Hemophilia Community**



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At CSL Behring

# Innovation leads the way

**Committed to making a difference in patients' lives**

As the industry leader in coagulation therapies, CSL Behring offers the most extensive portfolio of coagulation products for patients with factor deficiencies, including F1, FVIII, FIX, FXIII, and von Willebrand factor. And we continue to broaden our efforts with a number of recombinant factor therapies in development, including rFVIII, rFVIIa, rFIX, and rVWF.

For more information about our factor products for hemophilia, von Willebrand disease, and other rare bleeding disorders, or to learn about our innovative patient programs, please visit [www.cslbehring.com](http://www.cslbehring.com) or call consumer affairs at 1-888-508-6978.

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Biotherapies for Life™



# Gettin' in the Game



**CSL Behring** has invited us once again this year, to pick two winners to attend the **2014 Gettin' in the Game Junior National Championship**. Please send us an essay on one of the following topics:

- 1) Why I love baseball
- 2) Why I love golf

This contest is for kids with a bleeding disorder between the ages of 7 to 18. **The deadline is August 1, 2014!**

*Please email your essay to [coalitionforhemophiliab@gmail.com](mailto:coalitionforhemophiliab@gmail.com) or mail to: The Coalition for Hemophilia B, 825 Third Avenue, suite 226, New York, NY 10022 by August 1, 2014. Good luck!!!*

As you roll ahead in life with hemophilia B

## Imagine a different experience

Emergent BioSolutions is a specialty pharmaceutical company focused on improving the lives of people with rare conditions. We have been providing specialized products for people with rare conditions and blood disorders for over 45 years. Our long-standing history and focus on improving the lives of small patient populations have led us to develop the kind of experience necessary to make a positive impact on the hemophilia B community.

Our mission is simple—to protect and enhance life.

Emergent BioSolutions is a different type of company, and we are determined to make a difference for people with hemophilia B and those who care for them.

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**Sign up for updates at:**

**[EmergentBioSolutions.com/hemophiliaB](http://EmergentBioSolutions.com/hemophiliaB)**

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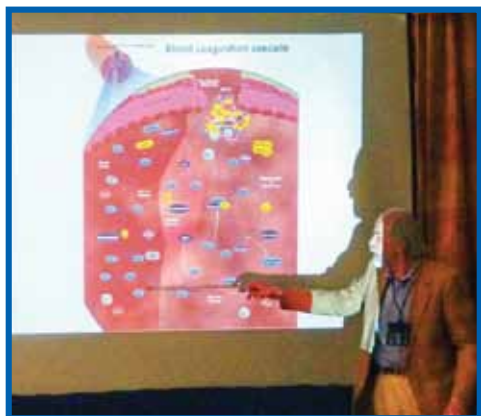




## The Coalition for Hemophilia B Family Meeting at HFA

The Coalition for Hemophilia B Factor Nine Family Meeting was held in conjunction with the Hemophilia Federation of America Symposium on Sunday March 30, 2014. We had a lovely breakfast meeting where Dr. Dave Clark spoke on current treatments for hemophilia B and we had our round table factor nine family group session

Thanks to HFA for giving us the meeting space and time! 🇺🇸



**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.

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Biogen Idec Inc.  
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Cambridge, MA 02142  
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NOW FOR HEMOPHILIA B...



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.



### 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](http://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.**

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](http://ALPROLIX.com/CoReManager)

Excellence in  
Home Infusion for  
More Than 30 Years



Coram is proud to be part of CVS Caremark, and this is now reflected in our brand. Together, we offer unparalleled support for the home infusion patient, and share a common purpose of helping people on their path to better health.

**A shared  
purpose of  
helping people  
on their path to  
better health.**

*"From a capabilities perspective, no other organization brings the range of specialty assets, the depth of experience and the integration of care that the combination of CVS Caremark and Coram can deliver."*

**- Jon Roberts, President,  
CVS Caremark Pharmacy Services**

1-800-423-1411 | [www.coramhc.com](http://www.coramhc.com)



**SUBMISSION DEADLINE EXTENDED TO SEPTEMBER 2, 2014**

Roundtrip travel from anywhere in the USA, meals and lodging expenses are paid for by sponsor.

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## Treatment News



### Biogen Idec's Alprolix is licensed by FDA

By Dr. David Clark

Biogen Idec's Alprolix, the first longer acting factor IX concentrate, was licensed by FDA on March 28, 2014. Alprolix, Coagulation Factor IX (Recombinant), Fc Fusion Protein,



is approved to help control and prevent bleeding episodes, manage bleeding during surgical procedures, and prevent or reduce the frequency

of bleeding episodes (prophylaxis) in adults and children with Hemophilia B. Alprolix consists of a recombinant factor IX molecule linked to the Fc fragment of an antibody molecule, which causes the product to last longer in the bloodstream requiring less frequent infusions. For prophylaxis, Alprolix is infused once every one or two weeks depending on the dose and the patient's pharmacokinetic response. The cost of Alprolix on a yearly basis is approximately equal to that of the other recombinant factor IX concentrates.







## The Coalition for Hemophilia B Second Annual Men's Retreat

Generously Sponsored by



Our First Annual Men's Retreat we put on last year was geared toward men 35 and older. The concept began with a simple question: "What happens to us older guys, the baby boomers who have always been cared for by someone else, when we become our own caregivers and even the caregivers for others later in life. Wayne Cook, President of The Coalition wanted to help older men like him expand beyond their comfort zone. "We want to take them beyond hemophilia and infusion...that's second nature...but what about high blood pressure, diabetes, joint problems, depression and other co-morbidities... how do we manage. How do we manage going into retirement dealing with our own health care and the prospect of caring for our loved ones." Wayne was hopeful that the success of the retreat would continue to help this special community into the future.

Happily and with the generous support from Pfizer, we held our Second Annual Men's Retreat for men ages 21 and over. The focus this year was to bring the younger

men and older men together to mentor and support. Our retreat was held on , March 14 to Sunday March 16 at the Carefree Resort and Conference Center in Carefree Arizona. Arrivals went smoothly this time (no hail storms ☺) and the weather was indeed our friend!

Attendees were welcomed upon arrival and given their agenda materials and backpacks. They enjoyed a nice lunch and our event kicked off at 4 pm on Friday with welcome and introductions by Wayne Cook followed by a session on *Depression* with speaker Maria Iannone, MS, LAC Counselor from the Hemophilia and Thrombosis Treatment Center in Arizona. Following Maria's talk a lovely outdoor dinner was served. Later, attendees gathered around a campfire to relax, get to know each other and talk.

Early Saturday morning attendees had an early *Rise and Shine* for outdoor TaijiFit with Rick Starks (who has hemophilia B himself). Rick started doing TaijiFit after having a heart attack in 2000, he gained a lot of



# Men's Retreat 2014



weight and had to wear a leg brace to relieve his ankle pain. He knew he must find something to relieve his arthritic pain, increase his flexibility and just get off the couch. He began doing Taijifit and became a certified instructor. He has not worn his braces since, and has had remarkable decrease in pain and increased flexibility and strength. It was a first for many of our attendees but they truly enjoyed it and said they would continue to do it at home as it really does help their joints!

A wonderful Black Mountain breakfast buffet was had by all and they continued on with the sessions of the day which included *Managing Chaos* with speaker Ben Shuldiner (who has hemophilia B) from the AMA, a life coach who brings work and life into balance. Ben challenged the men on so many levels, one in particular was how to get moving and do what you need to do, even when you do not feel like doing it. He stressed the importance of accountability and how you can help others but you must also take care of yourself too! One of Ben's handouts included a chart to follow to help create priorities.

Following session was *Pain Management* with Linda Chollar, NCR AAEd. Linda has over 20 years experience in the healing arts field. She is known nationally for her training programs. She specializes in therapeutic touch and mind-body modalities for pain and stress management. Linda taught the group about acupressure points in the feet that can relieve pain. The men were eager to get on the massage table and see how it works and it did relieve their pain. She taught the importance of meditation and aromatherapy such as lavender oil, as well as several other tools to help as alternative therapies to medication. Both sessions were very eye awakening and very helpful in giving the men the tools they need to take home and apply to



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The men enjoyed a nice lunch on the Terrace and the next session *Exercise: A Link to Healthy Joints* continued with Kevin Dusek, a physical therapist from the Southern Arizona Hemophilia Association. Following was *Insurance* with Kim Isenberg, Senior Manager for Reimbursement and Advocacy with Baxter Healthcare Corporation. The sessions were very well received and the men learned a lot! An "OI' Ballgame"

pm snack followed. After the men gathered to do some team building which consisted of a very cool scavenger hunt, created by Greg Price and Anthony Vetter! They really had the men searching all over the resort for clues. The men broke up into groups of three or four. It was very challenging. The winners, Wayne Cook, Dan Bond and Rocky Williams, each received a resort hat as a prize.

The men were treated to a Good Ol' Fashioned Western Cookout at the Stagecoach Pass which included a beer burro. Later there were fun-filled activities playing pool, card games, gathering around the campfire and a group sing-a-long to wish Chad Steven's a happy birthday!

We would like to thank Pfizer for supporting this extremely valuable program. The men bonded, learned a lot and went home knowing they have support and tools to help improve their quality of life, not to mention wonderful memories! 🍷



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## Retreat Attendee Comments:



"I heard about how great this event was going to be and was concerned that it wouldn't live up to the hype. After the first meal I realized I had nothing to be worried about. I instantly felt connected to everyone in the room and was amazed at how open and welcoming everyone was. I feel like I got a lot out of the sessions because I felt much more comfortable to ask questions that I otherwise would have."

"The Coalition for Hemophilia B does a fantastic job putting together their men's retreat. The event is well planned, and the education provided during the event is interactive and interesting. I had so much fun at the retreat. It was great to see everyone there. I even made a couple of new friends. Can't wait to see them at the next bleeding disorder event. This retreat is definitely worthwhile, and I highly recommend doing what it takes to be there. You will love it!"

"Thank you so much for organizing this event. It was nice to meet others and compare stories of our daily battles. I was able to relax and ate too much good food! I loved meeting my blood brothers and the education was priceless! Thank you!"

"This was truly one of the best conferences I have ever attended! I was welcomed upon arrival and felt like I was a Rock Star! I have some trouble walking due to knee pain and my bags were taken to my room for me, and I had a wonderful lady escort to my room so I did not get lost. I was given a tour so I would know where the first gathering would take place. It was wonderful to meet my blood brothers and to make new friends. I have not been to many meetings and this made me realize the importance of socializing. The education spectrum was amazing. It touched on so many topics I needed to learn about as well as some I needed to hear but had my head in the sand about. Thank you for getting my head out of the sand. I am going to incorporate some much needed changes in my life when I get home. Thank you to The Coalition and thank you to sponsor of this event. It was just wonderful! 🍷"





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For more information on the program or which products will be available for donation, contact Hannah Bildahi at AmeriCares: [productoffer@americares.org](mailto:productoffer@americares.org).

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Denmark  
Principal Scientist, Maximal Cell Technology



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# Inhibitor Family Camp

**Fall Session: Oct. 24-27, 2014**

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Location: Victory Junction located in Randleman, NC  
 Scheduled: Friday, Oct. 24th thru Monday, the 27th, 2014  
 Registration: OPENS Tuesday, July 1st (9 am, EST)

Space is limited, and attendance is on a first-come, first-served basis for those who qualify. To register, applicants must have an active inhibitor, or have had an active inhibitor within the past 12 months and fall between the ages of 6-19. This program invites the entire (immediate) family of the child with inhibitors and covers all expenses!



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**Answer to  
 KID'S CORNER  
 game on page 39.**

beach	sprinkler	swimming
sunshine	camping	popside
family	outside	swimsuit
volleyball	vacation	summer

# KIDZ TALK:

## TAKING YOUR MEDICATION TO TREAT YOUR HEMOPHILIA

**H**i, my name is Steven Sclafani, I'm 11-years-old and going into the 7th grade. I have hemophilia B (Factor 9 deficiency). I have been taking my home infusions since I was 4-years-old. Since I was 7 years-old, I have been mixing my own medicine. My father infused me up until 2013, when I took the final jump and began infusing myself.

Just because you have hemophilia, it doesn't mean you should be ashamed or afraid of it and not do things you enjoy. You just have to take your factor properly. If you take your medication properly then yes, you can play sports, play with your friends, play gym at school and much more.

Our clotting factor is very important because if you have severe hemophilia like me, without our medicine we have less than 1% of the protein we need for our blood to clot correctly, which is why taking the medication is so huge. When that factor is in our bodies we are protected just as any other kid without hemophilia would be, but without our medication we are more prone to get hurt.

For me personally, taking my factor allows me to play travel baseball for the Farmingdale Greendogs, basketball on St. Killian's C.Y.O. Team and flag football. My favorite sport is baseball - I bat leadoff and play second base. I am a very aggressive player and I really love the sport with all my heart. I enjoy every second while playing it so I don't want to get hurt and miss playing with my team. I take my factor as I should during the week and an extra shot on the weekend before my travel baseball games so I'm protected. As you might know, second base is a very important position in the game of baseball. I make many acrobatic plays and I might get bleeds or other injuries from if I didn't treat on a regular basis.

A quick story that proves that infusing appropriately is important. When I was stealing third base on a turf field in one of my travel baseball games last summer, the field was wet, I over slid third base and the third baseman missed the tag, so I jerked my hand back into the base. I was safe, but my thumb started to feel a



little sore and I was like, "Oh, it's just probably just jammed, I'm fine." After I scored, I told my dad and we iced it and kept an eye on it. The next morning my thumb was still irritating me a little bit, so we went to my treatment center and it turned out I had a minor sprain of my thumb, which stunk. I had to take a week off from baseball and then go back to see the doctor and physical therapist again. They allowed me back for the championship

game. They said, "You'll be able to play, but you have to make sure you continue to infuse and let your dad know if it starts to bother you again."



I was so grateful for my father and my treatment center staff for taking care of me. I was happy to be able to play in my championship game, but my point is that my factor saved me from a worse injury and it helped me get back on the baseball field sooner. I directly remember infusing before that game because if I didn't infuse that day, I wouldn't have been playing in that championship game.

Now that my story is over, I hope you realize how important it is to infuse on a regularly basis and for those extra times you feel you may need the protection. I hope I have influenced you to deeply care about infusing correctly 🙏

Steven Sclafani (A.K.A - One of Your Many Blood Brothers!)

We were there to hold her hand,  
as she let go of his...



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## **Terry Stone**

Regional Care Coordinator  
703-795-6269

[terry.stone@matrixhealthgroup.com](mailto:terry.stone@matrixhealthgroup.com)

## **Rania Salem**

Regional Care Coordinator  
613-570-5500

[rania.salem@matrixhealthgroup.com](mailto:rania.salem@matrixhealthgroup.com)

[www.matrixhealthgroup.com](http://www.matrixhealthgroup.com)

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# Kid's Corner



## Unscramble These Summer Time Words!

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ahebc

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sleipnrrk

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shnniue

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## Time to Color!



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## Save the Dates!

The Coalition for Hemophilia B Meetings

### **Dublin, Ohio**

*Columbus Marriott Northwest*  
Saturday, July 26, 2014

### **Houston, Texas**

*Ladies Lunch*  
Saturday, October 19, 2014

### **Houston, Texas**

Saturday, October 25, 2014

### **Nashville, Tennessee**

Saturday, November 8, 2014

### **Indianapolis, Indiana**

Saturday, November 15, 2014

These educational meetings are made possible through the generous support of:



For more information or to register, visit [www.coalitionforhemophiliab.org](http://www.coalitionforhemophiliab.org)



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