



Factor Nine News

The Coalition for Hemophilia B

Spring 2015



Topics in Hemophilia

- 8th Annual Fundraising Dinner
- 9th Annual New York Symposium
- Women with Hemophilia
- Is There a Higher Incidence of ADHD in Boys with Hemophilia?
- 3rd Annual Men's Retreat
- 1st Annual Women's Retreat
- Industry News
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- Save the Date

*The Coalition for
Hemophilia B*



Eighth Annual Fundraising Dinner



The Coalition for Hemophilia B held its 8th Annual Fundraising

Dinner on Friday March 6, 2015 at the Water's Edge Restaurant in New York. Approximately 300 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 Cassandra Hawkins!

Dinner began with a warm welcome to our guests by Dr. David Clark, Chairman of The Coalition for Hemophilia B. This year, we awarded Chad Stevens and Joan McCarthy, RN with the *Eternal Spirit Award* for their service and dedication to the hemophilia community. Joan is retiring from Mt. Sinai Hematology and Oncology this year and we wish her the best of luck! John Taylor announced the William N. Drohan Scholarship winners. In the past 7 years, \$205,000 in scholarships have been awarded.

Eighth Annual Fundraising Dinner

Congratulations to the 2015 recipients - Adara Gray, Evan Poole, Becky VanSant and Daniel Vetter! Thankfully Evan and his girlfriend arrived safely at the hotel after their plane slid into the gate at LaGuardia Airport

during our Thursday snowstorm. We are happy to say we were able to get everyone in except one couple. We will make it up to you next year.

After dinner and dessert our super helpers announced the raffle prize winners. We continued the wonderful evening dancing, enjoying the great company, taking in the beautiful views and having fun custom photos taken where a variety of cool background images could be selected. It was so much fun! Everyone had a good time indeed. A special thank you to the families who donated raffle prizes - it was so very generous of you! 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 9th Annual Fundraising Dinner on Friday, March 11, 2016!







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The Coalition for Hemophilia B 9th Annual Symposium

Generously Sponsored by 

The Coalition for Hemophilia B's 9th Annual Symposium was held on Saturday, March 7th, 2015 at the New York Grand Hyatt Hotel in New York City. On Friday before the actual Symposium, we held a meet-and-greet for families so they would have time to get to know each other before the meeting.



time to get treated! Dr. Walsh spoke on several companies coming out with news products. His talk was very passionate and eye-opening for many. A multitude of questions from the symposium participants followed.

The Symposium began with a warm welcome and opening comment by Wayne Cook, President of The Coalition for Hemophilia B. Our keynote 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! It was also discussed how hemophilia is steadily heading toward a cure. Dr. Walsh also stressed the importance of managing hepatitis C and if you have hepatitis, now is the



Next on the agenda was Mike Bradley from Baxter. Mike's talk was on *Insurance Updates*. The talk was very timely, informative and well received. Following we had a lively interactive session on *Motivational Interviewing* with

Linda Pollhammer, RN from Pfizer, who raised awareness of how we speak to each other and how we can obtain better results if we learn to phrase things in a different way from fear-based to empowered.

After a wonderful lunch, visiting the exhibit booths and posing for a Factor Nine Family Photo, we were



introduced to Pat Torrey of *GutMonkey* for a presentation on *Gaming the System*. In his fun and engaging workshop, Pat explored the impacts of working within a system and thinking outside the box to meet your goals and desires.

Up next was Kevin Harris with *My Story*. Kevin has hemophilia B and as a member of Emergent's speaking program, shared his own personal story of how he handles his hemophilia and the benefits of taking care of your body by eating properly and exercising.

We then took a break and resumed with some fun *Taiji Fit* with Rick Starks. Rick Starks was featured in our summer issue of *Factor Nine News* and is a 59-year-old with severe hemophilia. He has been practicing Taiji Fit for many years and is now teaching the benefits of it throughout the hemophilia community. We have had Rick teach Taiji Fit at our 2014 *Meetings On The Road* and his session is always well received. Rick is also part of Biogen's Peer speaking program.

After some fun exercise, Wendy Wollner, a popular speaker in our community (her dad also had hemophilia), presented *Express Yourself*. Wendy is part of Biogen's speaking program and her presentation focused on tips for effectively recognizing and managing emotions to confidently manage everyday interaction and help navigate challenging situations. After Wendy's presentation we had our *Infusion Session* with the wonderful Hope Woodcock, RN overseeing things. We thank Wayne Cook, Nate Lathrop and Steven Sclafani for volunteering to infuse! An ever-popular event and so educational! Everyone enjoyed their time with the exhibitors, especially the special exhibit booth offering chair massages!

The young children were treated to an exciting *Treasure Hunt Adventure* in the childcare room with *The Great Charlini*, a magic show, balloon treats and loads of fun-filled activities. The older children and teens went on a trip to *Ripley's Believe it or Not* in Times Square and lunch at John's Pizzeria. All sponsored by Pfizer. Later in the afternoon the children attended a *Camp Academy* program sponsored by Biogen where they learned to do circus tricks with real performers from the Big Apple Circus.

A big thank you to our sponsors, exhibitors and speakers for making our Annual Symposium a huge success! We look forward to seeing you next year in 2016 for our 25th Anniversary and 10th Annual Symposium! 🍷



Symposium Comments

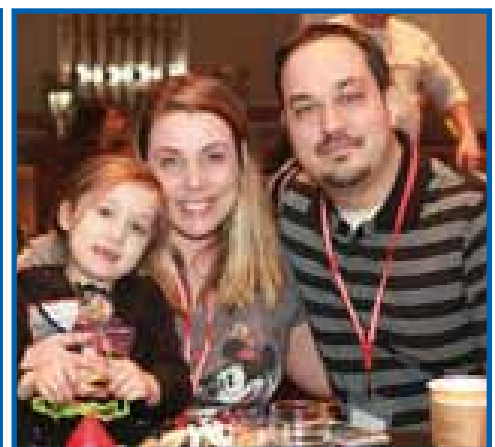
This was an amazing event! We really enjoyed hearing Dr. Walsh speak about the advances in hematology research. It was our first year attending the symposium, and because hemophilia B is so rare, it was great for our children to meet other kids like them. The dinner Friday night was out of this world! The childcare room was perfect and my 4-year-old had a great time. The big boys loved the circus trainers and enjoyed showing off their skills. Overall, I would say this was a HUGE success and we left knowing more about the bleeding disorder that affects us all!



First and foremost two thumbs up for overall experience! Second, hospitality of team was super. Meet-and-Greet was excellent way to start to connect with families. Third: The speakers were EXCELLENT! Great topics and very informative. Patrick Torrey and Dr Walsh were outstanding! Wendy was great as well! Fourth: The food at Meet-and-Greet, breakfast, lunch and afternoon break time was VERY MUCH appreciated, especially for a family. There is no quick or easy place to get an affordable snack.



Personally I really enjoyed the technical clinical information that Dr. Walsh present. This allowed the opportunity for all of us to understand what may be coming in the future and ask very general questions to what can be very dense information. Also, I think the addition of Pat "Big Dog" Torrey was exactly what we all needed to get out of our comfort zone and engage with one another. He is such a great face for our community and for him to represent for the Coalition like he did is truly inspirational! I also enjoyed the insurance talk, which can be a dry subject, it allowed me to better understand the health exchange and options we all have



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*The pharmacokinetics of IXINITY have been evaluated in 32 previously treated patients ≥12 years of age with severe to moderately severe hemophilia B.¹

†Third-generation product is defined by the National Hemophilia Foundation Medical and Scientific Advisory Council as recombinant factor IX (rFIX) produced in Chinese hamster ovary cells; no human or animal plasma-derived proteins are used in the manufacturing process.²

¹The efficacy (n=68) and safety (n=77) of IXINITY has been evaluated in a prospective, open-label, uncontrolled, multicenter trial in which previously treated patients (PTPs) between 7 and 64 years of age received IXINITY in either a routine or on-demand regimen.¹

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 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. **2.** National Hemophilia Foundation Medical and Scientific Advisory Council (MASAC). MASAC recommendations concerning products licensed for the treatment of hemophilia and other bleeding disorders. MASAC Document #230. September 2014.

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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.

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but may not be aware of. It was nice to see everyone. The accommodations were remarkable and the food was amazing. We had so much fun at the fundraising dinner. It will be a memory for a lifetime! I can't thank you enough for what you and the Coalition do for our small community and how it helps each of us come back to our areas and share such great stories and advice.



Honestly I have only great things to say. It was a wonderful informative event. The Coalition employs such compassionate folks. My family and I got so much out of everything. I can't think of one thing to say other than positive and I recommend other families to attend this event! It is life changing! THANK YOU!



We loved Motivational Interviewing and Taiji Fit! WOW! It was encouraging hearing Kevin's testimony. I think it's cool to hear from someone who actually lives day to day with hemophilia. Everything he discussed is something we are working on with my son. I think my son is actually getting it now. I also think it's really great you take the kids to do something fun like Ripley's Believe it or Not. They really had fun and it gave them the opportunity to bond and make friends with the other kids there.

We made a lot of memories. The massages were a nice treat and the organization and putting everything together was wonderful. I think y'all did a great job accommodating to such a diverse group!









GAME ON!

GETTIN' IN THE GAMESM JUNIOR NATIONAL CHAMPIONSHIP

October 23-25, 2015 | Phoenix, Arizona

CSL Behring is honored to host the 2015 Gettin' in the Game Junior National Championship, our 14th annual national baseball and golf competition for children with bleeding disorders. We will be inviting bleeding disorder chapters throughout the United States to each nominate two children, one for baseball and one for golf, to represent them during this national competition.

Attendees will have the opportunity to learn the fundamentals of their respective sports, participate in a friendly competition and have a chance to connect with fellow members of the bleeding disorder community from across the country. In addition, educational seminars focusing on the importance of physical fitness and other related topics will be provided on site.

Please contact your local bleeding disorder chapter for additional details on how to register to become your **CHAPTER NOMINEE!**

CHAPTER NAME: _____

CONTACT/ TITLE: _____

PHONE NUMBER(S): _____

For more information regarding the Gettin' in the Game Junior National Championship and other programs offered by CSL Behring, visit www.mysource.com or call 1.800.676.4266 to speak with a My SourceSM Care Coordinator.



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Women with Hemophilia

By Dr. David Clark

Many physicians would say that this title doesn't make any sense – women don't get hemophilia. Today we know that women can have hemophilia, and in fact, the number of women with hemophilia is significant. Unfortunately, this "news" hasn't reached many physicians, especially those who do not specialize in hemophilia treatment. This is in spite of the fact that the medical literature has contained reports of hemophilia carriers with factor VIII or IX deficiency and bleeding problems since the 1950s. Because the idea that women don't get hemophilia has been so ingrained, early researchers tried to imagine all kinds of other explanations for these reports. The genetics seemed so simple that there had to be an alternate reason. Now we know that the genetics are actually much more complex, and it is obvious that women can and do have hemophilia. The rest of this article will focus on hemophilia B, but the situation is very similar for hemophilia A.

The lack of recognition of an obvious condition can make it difficult for women with hemophilia to be taken seriously about their disease. This is not a small issue. Women with hemophilia are usually carriers, and it is estimated that there are up to five times as many carriers as there are men with hemophilia. Another estimate is that at least one-third of carriers have factor levels below the normal range. Although not all of them have bleeding problems, a significant number of them do. Today, more and more hemophilia treatment centers (HTCs) are treating carriers. However, there is still a general lack of information on bleeding tendencies and treatment options for women.

Carriers have a defective factor IX gene on one of their X chromosomes, which they can pass on to their offspring. All of the daughters of a man with hemophilia are carriers, sometimes called obligate carriers. On average, half of the daughters of a female carrier will also be carriers and half of her sons will have hemophilia. The carrier daughters might or might not have hemophilia. It depends on other things, most of which are not yet understood.

Chromosomes are structures in the nucleus of a cell that hold the genes. Except for a few specialized types of cells, every cell in the human body has 46 chromosomes which together hold a copy of all of the body's genes. Two of the chromosomes are the X and Y chromosomes, which determine the sex of a person. The X chromosome is called that because it is shaped like an X and the Y like a Y. Men have an X and a Y chromosome, and women have two X chromosomes. Men inherit their X chromosome from their mother and their Y chromosome

from their father. Women inherit one X from each. The factor IX gene is located on the lower leg of the X that is missing on the Y chromosome. Therefore, men have only one factor IX gene, but women have two, one on each X chromosome.

Because women have two X chromosomes, carriers usually have a second X chromosome that contains a normal factor IX gene. It is only the rare carrier who has defective factor IX genes on both X chromosomes. She would be the child of a carrier mother and a father with hemophilia B; on average, half of their female offspring will have two defective factor IX genes. These women unquestionably have hemophilia, even by old-school standards. This situation may not actually be as rare as the medical establishment has assumed. They look at the overall population and figure the chance a man with hemophilia will meet and marry a carrier is very small. This overlooks the fact that the hemophilia community has bonded together so that many hemophilia families know each other. In the rest of this article, we'll focus on the more common situation of carriers with one normal and one defective factor IX gene.

The idea that women do not get hemophilia comes from the fact that most carriers still have one normal factor IX gene. Reasoning that males with one normal factor IX gene do not have hemophilia, it was thought that most carriers should also not have hemophilia. However, this reasoning is faulty because it doesn't take into account a phenomenon that has only more recently become appreciated. It turns out that even though every cell in a carrier's body contains a normal factor IX gene, those genes are not all active. Because having two copies of every gene on the X chromosome could cause problems,





the body has a mechanism to inactivate one of the two X chromosomes in women. Therefore, a carrier's cells will only contain one active factor IX gene; the other one on the inactivated X chromosome will not produce any factor IX. This process is called "X chromosome inactivation" or "lyonization" after Mary Lyon, the researcher who discovered it.

Lyonization is normally a random process, so each cell has a 50-50 chance of having the active factor IX gene be the normal one. Therefore, in the liver, where factor IX is made, about half the cells will make normal factor IX and half will make defective or no factor IX, depending on the gene mutation. Thus, a carrier will usually have approximately half of the amount of normal factor IX that a non-carrier woman has. Several studies have found that the factor IX level in hemophilia B carriers can range from less than 1% to as high as 150% of normal (<0.01 to 1.50 units/ml of plasma). That encompasses the whole range from severe hemophilia (<1%) through moderate (1 - 5%) and mild hemophilia (5 - 40%) and the complete normal range of 50 - 150%. Thus, just based on factor levels, carriers can have anything from severe hemophilia to no bleeding problems at all.

No one knows why one carrier might have a factor level of 25%, for instance, and another might have a level of 150%. For persons without hemophilia, the actual level appears to depend on parameters such as blood type and body mass index, but those parameters do not

seem to affect levels for men or women with hemophilia. One thing that does appear to cause the extremely low factor levels seen in some carriers is a phenomenon called skewed X chromosome inactivation (sometimes called extreme lyonization). Again, for reasons that are not well understood, the lyonization process may preferentially inactivate one of the X chromosomes. If the X chromosome that is inactivated in more cells is the one with the normal factor IX gene, the carrier will primarily produce defective or no factor IX. She will thus have a much lower level of normal factor IX in her blood than would be the case if the inactivation were 50-50.

Carriers with low factor IX levels bleed the same way and have the same kinds of problems as males who have hemophilia and similar factor levels. They are susceptible to easy bruising, joint damage and bleeding problems after dental and surgical procedures among other things. They can also develop inhibitors and target joints. In addition, as women some of them have excessive menstrual bleeding, a tendency toward miscarriages and excessive bleeding after giving birth. These are all issues that can be managed once it is accepted that they have a bleeding problem.

Bleeding in carriers can also be due to other bleeding disorders. Just because a woman is a hemophilia carrier does not keep her from having other bleeding problems. Some carriers, for instance, might have von Willebrand Disease (vWD), which is much more prevalent

in the general population than hemophilia. Many of the symptoms are similar between some types of vWD and hemophilia, so proper testing is important to establish the actual cause.

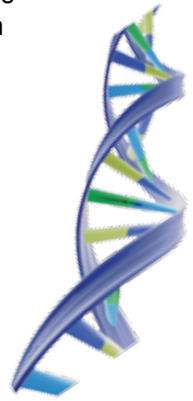
The nomenclature is also an issue. In the past, carriers who exhibit bleeding problems have often been called “symptomatic” carriers, as though they have bleeding symptoms but are somehow different from males with actual hemophilia. It is becoming more obvious that these women are not different. They have hemophilia as shown not only by their bleeding symptoms, but also by their genetics and factor levels.

One recent study has shown that carriers tend to develop reduced range of motion (ROM) in their joints, just like males with hemophilia. This indicates that they have suffered joint damage, presumably from bleeding into the joints. The reduced ROM gets worse with age and in general is worse in proportion to the carrier’s factor level - the lower her factor level, the greater the reduction in ROM.

According to the usual criterion, people with factor levels above 40% aren’t considered to have hemophilia and don’t suffer joint damage. However, a couple of the carrier studies have noted that women with factor levels in the 40 - 60% range sometimes do have bleeding problems and joint damage. The reason for this is unknown. Note that a similar occurrence can happen in men with hemophilia – the factor IX level does not always predict the severity of bleeding symptoms. For example, some men classified as severe because their factor level is below 1% bleed more like moderates, and some with mild or moderate levels bleed more severely.

With the recognition that carriers can have significant bleeding problems and suffer joint damage, it becomes

more important to identify them, assess their bleeding tendency and offer them treatment, if needed. Several studies have shown that women with bleeding problems are usually identified later in life than men. Men with hemophilia are often identified after circumcision, soon after birth, while many women with hemophilia are not identified until later, depending on the severity of their condition. Also, because of the incorrect perception that their bleeding is not as serious, only 27% of females with severe hemophilia B are on prophylaxis, according to the UDC database.



Many HTC’s offer carrier testing, but often not until a woman has reached adolescence. Since it is now known that joint damage can start to develop undetected at an early age, it would be beneficial to identify affected women early enough to help prevent those issues. Other reasons that it is beneficial for carriers to know their status include decisions about participation in sports, taking certain medications like aspirin, getting tattoos or piercings and most of the other things that a male with hemophilia needs to consider. Iron deficiency anemia also appears to occur more frequently in carriers.

The situation for women with hemophilia is slowly getting better, but there is still a lot of misinformation in the medical community. In addition to the Coalition for Hemophilia B, the Hemophilia Federation of America and the National Hemophilia Foundation, as well as a number of concerned medical professionals, have all recognized that there are significant unmet needs among the women of the hemophilia community. Hopefully, with their continued advocacy and leadership women will be able to receive the care they need. 🇺🇸

It’s Here!

The Coalition for Hemophilia B is happy to introduce the first BScene episode sponsored by Biogen. The BScene Series will post monthly and depicts real life experiences shared by members of the Hemophilia B Community and their families. We hope they will inspire you!

www.youtube.com/watch?v=CH4Sh-puMol



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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 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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Is There a Higher Incidence of ADHD in Boys with Hemophilia?

By Dr. David Clark



Attention deficit disorder with hyperactivity (ADHD), also known as attention deficit disorder (ADD), is the most common childhood psychiatric disorder. It features inappropriate inattention, impulsiveness and hyperactivity. Most individuals have symptoms of both inattention and hyperactivity-impulsivity, but one or the other pattern may be predominant. Hemophilia treaters have often observed that there seems to be

a disproportionately large number of boys with ADHD under their care. Several studies have shown a higher-than-normal incidence of ADHD in boys with hemophilia, but the studies have been small, and the question is not totally resolved.


Correctly diagnosing ADHD is important because it can affect education, interpersonal relationships, family stress and general quality of life. ADHD is also associated with higher rates of physical injury and a propensity for accidents. The cause of ADHD is unknown, but it is treatable. It appears to have a genetic component but also be affected by psychological factors such as stress. Why it might be more prevalent in hemophilia patients is a mystery.

Several studies have shown that boys with hemophilia have normal scores on measures of personality,



mood and behavior, and interestingly, studies have also shown that boys with hemophilia tend to have higher-than-average IQs. One study showed that over twice as many boys with hemophilia, compared with boys without hemophilia, are enrolled in classes for gifted learners, but others have found a significant number who exhibit learning difficulties and/or are in special education classes. Research has also shown that they demonstrate higher than average levels of educational and psychological problems. Affected boys also tend to be less physically coordinated. Overall, the issues may extend beyond the realm of ADHD.

School absenteeism, which is higher for boys with hemophilia, does not appear to be the cause of the educational problems, according to several studies. Studies have also ruled out neurological causes for the increased ADHD such as damage from intracranial hemorrhage (ICH). ICH, which is bleeding in the brain, occurs in about 4% of babies with hemophilia, usually around the time of birth. It can result in mental retardation, learning problems, seizures and other disabilities. One other possible cause for increased ADHD, which has not been ruled out, is the general stress involved in living with a chronic disorder.

While much remains to be learned about the association of hemophilia with ADHD and other psychological disorders, it is important for parents to be vigilant for behavioral symptoms. ADHD is highly treatable, and care is available through many hemophilia treatment centers. 



Third Annual Men's Retreat

Generously Sponsored by 

Our **Third Annual Men's Retreat** was held Friday March 20th to Sunday March 22nd at the Carefree Resort and Conference Center in Carefree, Arizona. And indeed, it was a sunny beautiful weekend in Carefree to host 27 men ranging in age from 21 to 75 years young!



Sunset Terrace. Rap sessions were held around the fire pit later that evening.

Early Saturday morning the men had an early rise-and-shine doing Taiji Fit with Rick Starks. Rick got everyone up, moving and ready

to start their day. After they all had a wonderful Black Mountain Breakfast Buffet and continued on with the sessions of the day, which included *Positive Assertiveness* with speaker Wendy Wollner of the AMA, a life coach who brings work and life into balance. She challenged the men on so many levels, one in particular was how to get in touch with your feelings and assert yourself in a positive manner. Next on the agenda was *Insurance Updates* with Elizabeth Stoltz. Elizabeth and the group held a lively and engaging conversation. It was one of the most enjoyable talks on insurance and the men got a lot out of it!





In the afternoon, the men enjoyed a nice lunch and the next session *Exercise: A Link to Healthy Joints* continued with Jeff Kallberg a physical therapist and also a person with hemophilia. The session was very well received! This year the weather was so cooperative they were treated to actual physical therapy in the pool with Jeff. Following Jeff we had Andrea Piraino, a certified health coach who spoke on *Nutrition and Healing the Body*. All sessions were very eye awakening, informative and helpful in giving the men the tools they need to take home and apply to everyday life.

After a break with an Ol' Ballgame snack, the team-building exercise named *The Bleeder Olympics* was held on the Sonoran lawn. The first annual Bleeder Olympics were a fantastic bonding experience for all involved. About two dozen men with hemophilia were split into pairs. Each pair came up with a team name and faced off at the outdoor games, including cornhole, hillbilly golf, kan jam, beersbee, mölkky and bocce ball. The festivities were a hit! A cookie face off required the men to use only their face to move cookies from their forehead to their mouth. And a game we called "a bit dicey" involved balancing dice on a Popsicle stick held in the mouth as you tried to place dice on top of each other and keep your balance. Several men took ideas home with them; one attendee has plans to build a mölkky set, and Chad is a real whiz with the Frisbee. The Bleeder Olympics was a true success--fun, memorable and a great time for all!

That evening they had a good *Old Fashioned Western Cookout* followed by a rap session and a relaxing time playing cards, enjoying the pool and sitting around the campfire. The next morning the men enjoyed Taiji Fit and a wonderful breakfast, final goodbyes and departures! 🍷





We want to thank all the men for being such good sports as we videotaped the whole weekend so those who have not attended will have a peek into the weekend activities.

Our First Annual Men's Retreat was geared toward men 35 and older. The concept began with a simple question: "What happens to us older guys, the baby boomers who've 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 infusions...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 is hopeful the success of the retreat will continue to help this special community into the future. As we embarked on third retreat, men 21 and older are able to attend. The younger men are mentored by the more mature men and while most of the programs are of interest to all, our goal next year is to have a few breakout sessions specifically geared toward certain age groups. We thank Pfizer for listening to the needs of our community! The retreats are so valuable and life changing. 🇺🇸



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PROGRESS
MAKING
A
DIFFERENCE

BeneFix
Coagulation Factor IX (Recombinant)
Room Temperature Storage

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BeneFix is the most prescribed recombinant factor IX treatment FDA approved for hemophilia B.*

- 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® 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, or call 1-800-FDA-1088.

*BeneFix was approved February 11, 1997.

†IMS National Prescription data October 2013.



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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
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.

Men's Retreat Comments

I am not an astronaut. I was not a prisoner of war. Yet, I am a member of a very small group of people who share a common problem, and a member of an even smaller, and ever-decreasing, group of people whose experiences resulting from this common problem mark us as unique and separate from the main population.

I've attended two of the three yearly Hemophilia-B retreats for older men, and only at these retreats do I find folks who have shared and suffered my same or similar challenges and hardships. When I attend these retreats, I learn life skills for the years ahead and better ways to manage my health that have immediate benefits. Yet the most valuable part of the retreat, from my perspective, is being able to look a blood brother in the eye and say, "I too missed several trick-or-treating adventures. I too endured the years before factor products, and the challenges that followed after their arrival. I too felt alternately left out and like a circus freak when carrying massive hematomas on the face."

I meet mostly families with young children with bleeding disorders at other meetings, and I see that these young folks will miss many of the hurdles I endured. There is not a lot of time dedicated to the older guys. If I want to feel validated and understood, and if I want to extend recognition and solace to others whose experiences I understand well, then the best place to do this is at one of these Coalition for Hemophilia B retreats. I am grateful to Kim and Chris for planning these events, and to the sponsor of these events, and I feel that my life is enriched by the topics covered and the people met there.



This was my second time attending the Men's Retreat and I found this experience more rewarding than the first time. The time to connect with older members of the community, fellowship, learn and laugh. A time to truly connect on a deeper level and learn value added information that is both timely and relevant. The representation from all walks of life of those adult men with hemophilia b makes this a truly awesome and worthwhile meeting for building and maintaining strong bonds and support. I look forward to attending again.



I have been fortunate to be able to attend two of the men's retreats and I want to thank you and all your team as well as the sponsors for making this event possible for us. I think all of you did a great job of putting this event together in a way that offered us scheduled informative and educational events as well as more unstructured time to just talk with and get to know all men who were there. Thank you.



I really enjoyed the retreat and appreciate the opportunity to attend by being chosen in the lottery. As a first time attendee, I liked the speakers, particularly the nutritionist and physical therapist. I really enjoyed Rick Stark's Taijifit - even though I was skeptical going in, I was very surprised and it was a fantastic workout! The food and service from all of the Carefree staff was exceptional! Every meal was great with choices for every taste. I certainly did not leave hungry.





First Annual Women's Retreat

Generously Sponsored by 

Our **First Annual Woman's Retreat** was held Friday April 10th to Sunday April 12th at the Carefree Resort and Conference Center in Carefree Arizona. The women were welcomed upon arrival and given their agenda materials and welcome bags. Inside their agenda folder was a welcoming letter that partly read the following:

We are so happy to have you join us for an exciting weekend of support and education! The concept of a women's retreat stemmed from a conversation among caregivers, spouses and women with bleeding disorders. After much discussion, the need became exceedingly

apparent for a retreat where women had the opportunity to learn tools they can use in their daily lives. We thank Pfizer for listening as well as their generosity in supporting our new program. When approved and plans were put in motion, we consulted with three women, a caregiver, a spouse and a woman with hemophilia, and asked what they envisioned for this program. With their insightful input, our agenda was created.

Women are most often tasked with taking care of everyone in the family - add a child with a bleeding disorder and she may be left with little time to even remember what her own needs are. As the wife of a man with a bleeding disorder, a woman may encounter feelings of concern and wanting to 'mother' her husband. Often, women with a bleeding disorder





are disregarded and not taken seriously, leaving them to suffer with issues that could very well be treated if diagnosed properly. Joined by the common denominator of a bleeding disorder, all of you here come from diverse backgrounds and have had different experiences. We believe it will be very interesting and thought provoking to have you all together - caregivers, spouses and woman with a bleeding disorder - sharing, learning and connecting. Our goal is for each of you is to be inspired, to find your voice, to learn self-care and to bond with your sisters in the community.

Kendrick. There were many questions and with such a large group, Noah suggested next year he come back with a lawyer and additional materials so the women will have further resources to assist them with decision making.

After Noah's talk, Kim Phelan welcomed the



Once the women were settled, they enjoyed a nice lunch and chair massages. Our event kicked off Friday afternoon with a session on *Financial Health* with Noah





women and each was given a necklace with three keys on it to represent caregiver, patient and spouse. They were also given a tiara because this weekend the women were going to be treated like "Queens" and a heart-shaped box to hold their wishes and visions. We tossed a question ball around the room and everyone introduced themselves and answered one question from the ball so they could get to know each other. We then met outside on the Sunset Terrace for a champagne toast. Kim Phelan toasted "To the Queen in all of you!" After our toast, we gathered to enjoy a *Taste of Tuscany* dinner. It was a beautiful evening.

Saturday morning began with something a bit different for most attendees - *Chakra Dance* with Emma Porter and then the ladies did Mandala drawings before enjoying a scrumptious breakfast on the terrace.

The morning speakers included Wendy Wollner who spoke on *Express Yourself* and Maria Iaconne spoke about *Anxiety and Depression*. Lunch followed on the terrace and we continued the afternoon with *Nutritional Healing* presented by Andrea Piraino. The women were quite excited about the information they learned and agreed to form a group when they returned home to continue working together to meet their nutritional goals.

Later in the afternoon we departed the resort for a special *Ladies Afternoon Tea* at the English Tea Room. Everyone was able to choose from a wide selection of beautiful hats to wear and all had a wonderful time enjoying a *Duchess of Bedford's Formal Afternoon Tea*, which included a pot of tea, three tiers of tea sandwiches, scones and a selection of petit fours.

In the evening we held a *Western Cookout*. The ladies gathered around the fire. We had a hula hoop contest and team building exercise in which each team was given 20 sticks of spaghetti, one yard of masking tape, one yard of twine and a marshmallow. They had 20 minutes to build the tallest free standing structure with the marshmallow on top. It was loads of fun and we applaud each team! The next morning we participated in a yoga class with Colleen Meehan, had breakfast and began our departures.

We thank all the ladies for their wonderful feedback. You all play such an important role in shaping future programs - we are listening and working on it! We look forward to putting on more women's retreats next year. Lotto forms will be coming in the mail soon for the next retreat. We also want to extend a great big thank you to all the attendees for agreeing to be videotaped throughout the weekend so we can share with all a small video clip on the experience. We also extend our sincere thank you to Chad Stevens for ensuring the safe arrival and departures of all the women! 🍷



Women's Retreat Comments

It was more than a retreat - it was a priceless bonding session where lifelong friends were made as well as reconnections with dear soul mates found through a previous Coalition event in 2008. It was invaluable to spend quality time and share personal stories with my blood sisters. We were spoiled by the Coalition with chair massages, a champagne toast including tiaras to make us feel like queens, an old fashioned barbeque as well as a traditional ladies tea, formal hats included. In addition, we attended several pertinent and valuable workshops and seminars from which we all took away a new awareness and knowledge of empowerment and strength.



All of the women who attended share the same life and challenges that outsiders just don't "get." It warmed my heart, soothed my soul and gave me peace on a level that occurs rarely. It doesn't get any better than that. Thanks to Kim Phelan and the team for all of their hard work preparing and attending to our every need and want on a weekend we will never forget!



A lovely weekend from start to finish! As a mom with a son with severe hemophilia it was so nice to have time to bond with other women in our community. It was nice to have the chance to focus and reconnect to what our needs are.

During the weekend, we had the opportunity to enrich our knowledge with sessions on *Financial Health* by Noah Kendrick; *Express Yourself* presented by Wendy Wollner; *Managing Depression and Anxiety* presented by Maria Iacone; and *Nutritional Healing* by Andrea Piraino. We learned so much about each other as we worked through the sessions. We enjoyed chair massages, Chakra dancing, yoga and time at the pool. One of my favorite highlights was a ladies tea, where everyone donned wonderful hats and enjoyed finger sandwiches and, of course, tea. *Our Taste of Tuscany Dinner* on Friday night was unbelievable and I didn't think it could get better until Saturday night when we had a cookout for dinner. With conversation around a warm fire pit, it gave us a true "Western" feel.

The Coalition for Hemophilia B gave moms, wives, sisters, girlfriends and





women with hemophilia a weekend that will not soon be forgotten. The Coalition truly out did itself with an amazing weekend and we are very thankful for it.



Since returning from our trip, things have gone back to our usual running around doing everything for the kids so they're happy, but also making more time for myself and enjoying a little more of an adult lifestyle. I was completely overwhelmed and overjoyed with how pleased I was to meet all my Beautiful Sisters! This trip really helped me to connect with all these women with the same issues and concerns that I'm going through. I can't even thank you enough from the bottom of my heart for introducing me to this fabulous group of women. Because of the Coalition of Hemophilia B, I was able to make these connections that I never had before.



Simply a LIFE-CHANGING EXPERIENCE! I had a blast, got away from the madness of everyday adventures in life and got to enjoy time with sisters...I learned so much about life, finances, new ways of thinking, letting go, dance, new experiences, being a Queen! Enjoying great company, friends, socializing more (especially on Facebook). Enjoying life and being thankful for everyday given. I learned so much! I was completely satisfied and enjoyed my time!! Thanks so much for the Beautiful Time! I WILL NEVER FORGET HOW SPECIAL I SPENT MY 40th BIRTHDAY! It meant so much to me! I really needed it! Thank you all! You did a GREAT JOB!



I absolutely loved it! For the first time, I felt truly valued as a woman with hemophilia. Kim and the team made us feel so special and





cared for. The venue was perfect. The programming was fantastic. (I learned so much!) and the company, of course, was wonderful. I got to spend time with old friends and I made a lot of new friends. I am so grateful that this event took place. I hope we get to do it again!

I thoroughly enjoyed the ladies retreat and feel so blessed to be a part of it. I think you did a great job of planning and organizing. The food was excellent especially the final night! I thought all of the speakers were interesting. Some more than others - I think that all depends on the person and their interests, but overall I feel like there was something for everyone. I thought the Chakra dance was going to be weird, but went anyway and was really surprised at how relaxing and fun it was. The tea was a fun addition as well. My most favorite part was friendships made with some really cool ladies from all over the country. I'm looking forward to seeing everyone again.



The woman's retreat in Arizona was one of the best weekends of my life I was excited to go and my expectations were superseded all weekend. I've made friends that will last a lifetime I learned a great deal about life, love and am reminded of the importance of listening, sharing, gathering, laughing trusting and creating. Presentations on finance, chakra dance and nutrition left me empowered excited and educated. The gifts I left with are physical and spiritual, and I will treasure both for a lifetime thank you! Thank you!



I absolutely loved it! For the first time, I felt truly valued as a woman with hemophilia. Kim and the team made us feel so special and cared for. The venue was perfect, the programming was fantastic (I learned so much!) and the company, of course, was wonderful. I got to spend time with old friends and made a lot of new ones. I am so grateful that this event took place. I hope we get to do it again!



I had an absolutely wonderful time. I met hemo moms I had never met. I laughed and shared with them. When I arrived, I knew Kim and one other person. I quickly met everyone else and had a great time. The massage was awesome, classes informative and relaxed. Food outstanding. Accommodations perfect. I attended everything and enjoyed it all. I had to leave early Sunday morning so I missed that day. Transportation to and from airport was top notch. Great food and drinks every day! I am grateful for the retreat and hope I can do it again. I would be more than happy to help in any way.



I really enjoyed myself. It was nice to get away and not have to worry about day to day life. I was blessed to have met such wonderful women that I could talk with that have the same issues I do. Coming from a very small town and not having anyone but our family with hemophilia, it is hard to have that special connection with anyone outside the family. I absolutely loved the massage and yoga. So relaxing! Overall, I learned new things that I couldn't wait to come home to share with my mom, sister and aunts. I hope you continue to host these retreats and maybe next year some of my family members will have the opportunity to experience what I did.



B for giving me an opportunity to be with so many extraordinary women!

I think the weekend was very nice, above what I could've ever expected. The location was beautiful, the activities were well planned and food was great. I

am grateful that I got the opportunity to meet women in various roles that had the common bond and hear their stories.

I loved the entire weekend. You can tell a lot of thought, planning and care went into this event and I am extremely thankful I got the opportunity to attend. As a mother, I often find it hard to take the time out for me. The massage, tea, gratitude journal, classes, tiara and wish box were just a few of the things that showed me how nice and important it is to take care of me. Thank you!

The women's retreat was magical. All women with same yet different stories. All having a place to share and compare and learn together. Also a wonderful break for moms who are 24/7 in demand to unplug and laugh, learn and recharge. Thank you Coalition for Hemophilia

Matrix Health Group

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Industry News



Alnylam Pharma Announces Phase I Results

Alnylam Pharma has announced interim results from their ongoing Phase I clinical study on ALN-AT3, a subcutaneous RNA interference drug that inhibits the body's production of antithrombin. Antithrombin is an anticoagulant that is a natural regulator of the coagulation cascade and inhibits clotting. Alnylam's idea is that reducing the concentration of antithrombin in the bloodstream will promote clotting in hemophilia A and B and other bleeding disorders. The initial results in three hemophilia patients showed a 70% reduction in circulating antithrombin with a marked improvement in clotting. ALN-AT3 was well tolerated. The first patient, who has hemophilia A, has remained bleed-free for 47 days with no replacement factor. Additional results are expected later this year.



Biogen Idec Changes Name to Biogen

On March 23, 2015, Biogen Idec changed its corporate name back to Biogen. The original Biogen was an early pioneer in genetic engineering. It became Biogen Idec when it merged with Idec Pharmaceuticals in 2003.



Biogen/TIGET Announce Results in Preclinical Gene Therapy Study

Biogen and the San Raffaele Telethon Institute for Gene Therapy (TIGET) in Italy are collaborating on development of gene therapy treatments for hemophilia B. TIGET recently announced results from a preclinical study in hemophilia B dogs using lentiviral vectors to deliver factor IX genes to the liver. The advantage of lentiviral vectors is that the majority of patients are not expected to develop antibodies to the vector, thus avoiding an immune response that would complicate treatment. The vectors are also larger than the AAV vectors used by several other gene therapy researchers, so they can potentially deliver a higher concentration of factor IX genes to the subject. By boosting the dogs' factor IX levels into the 1 to 3% range, the treatment was able to reduce the number of spontaneous bleeds from approximately five per year down to zero to 1 episode per year. Factor IX production in the dogs has been sustained for up to three years.



Emergent BioSolutions' IXINITY Recombinant Factor IX is Licensed

Emergent BioSolutions' IXINITY Coagulation Factor IX (Recombinant) was licensed by FDA at the end of April, 2015. IXINITY is indicated for the control and prevention of bleeding episodes, and for perioperative management in adults and children 12 years of age or older with hemophilia B. IXINITY is a third-generation factor IX concentrate with no human- or animal-derived proteins in the formulation or the manufacturing process. IXINITY was approved based on a global clinical trial in 77 subjects with severe or moderately severe hemophilia B, including one female carrier. The trial included both prophylactic and on-demand treatment regimens, as well as coverage during 19 major surgeries. IXINITY was well-tolerated, and no inhibitor development was observed during the trial. In terms of efficacy and pharmacokinetics, IXINITY performed similarly to the other recombinant factor IX products on the market.

IXINITY was originally developed by Inspiration Biopharmaceuticals, which was co-founded by John Taylor, the founder of the Coalition for Hemophilia B. Inspiration's goal was to develop a factor IX concentrate that would improve access to care for a wider group of hemophilia B patients. Inspiration ran into some technical difficulties with the product during their clinical studies and later sold the product to Cangene Corporation of Winnipeg, Canada. Cangene was able to modify the production process and resolve the issues. Cangene was later sold to Emergent BioSolutions of Baltimore, MD.



The Coalition for Hemophilia B in Action!



We have been busy on the road this spring attending NHF Washington Days on February 26th and HFA's Symposium March 26-28 in St. Louis, Missouri with Dr. David Clark, Kim Phelan, Christian Villarreal and Rocky Williams. We had such fun at the Final Night event with the 50's theme! Next stop - the Bleeding Disorder Association of Illinois (BDIA) where Rocky Williams exhibited; Southern California Chapter of the NHF May 2nd with Valinda Linarez; the Northern California Chapter of the NHF May 2nd with Christian Villarreal; Nebraska Chapter of the NHF Conference May 30th with Rocky Williams; NHF's Spring Soiree at the Lighthouse on May 21st with Kim Phelan and Christian Villarreal; and the National Hemophilia Foundation's 10th Annual Walk in Riverside Park on May 31st with Kim Phelan and Christian Villarreal. 🇺🇸



Spring



egg



snail



bee



frog



caterpillar



lamb



ladybug



butterfly



owl



sun

C	A	T	E	R	P	I	L	L	A	R	E
R	F	B	T	Y	V	I	L	Q	B	S	B
U	R	Y	W	S	D	F	V	N	U	N	C
F	O	E	A	V	M	L	Y	L	C	A	B
R	G	U	B	E	G	G	O	A	W	I	K
N	H	T	R	C	R	F	Y	D	B	L	I
O	W	L	G	H	V	T	A	Y	I	B	Q
M	N	P	O	T	G	L	E	B	S	Q	C
H	N	J	I	O	P	A	Q	U	V	G	H
F	C	N	L	F	I	M	B	G	F	Y	U
B	E	E	C	Y	Z	B	T	H	W	P	B
Y	B	U	T	T	E	R	F	L	Y	S	M





SAVE THE DATES

The Coalition for Hemophilia B Meeting on the Road

September 19, 2015 - Western Pennsylvania

October 3, 2015 - Southern California

October 24, 2015 - Northern California



Details coming soon!

Please note - we will be rebuilding our website over the summer months. We will do our best to keep information up; however, we may experience brief times when the site will be down. Video clips will be up on our facebook site shortly. Special thanks to the very talented Aaron Craig for doing an exceptional job!

For more information, please email:

hemob@ix.netcom.com

or call Kim Phelan at 917-582-9077

*We wish you all a
very happy summer!*