



Factor Nine News

The Coalition for Hemophilia B Spring 2013



Topics in Hemophilia

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The Coalition for Hemophilia B First Annual Men's Retreat
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The Coalition for Hemophilia B First Annual Men's Retreat



Our FIRST Annual Men's Retreat was held Friday, March 8 to Sunday, March 10 at the Carefree Resort and Conference Center in Carefree Arizona. Arrivals the first day were a bit of a challenge due to heavy rain and hailstorms, but we are happy to say everyone made it to the resort safely!

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 with a welcome and introductions by Wayne Cook, and followed by a session on *Securing Your Future: Caring for your Financial Well Being*. Speakers Charles Willoughby and Lynn Marble did a

wonderful job presenting the topic. Afterward, attendees were then treated to a backyard cookout.

To start the day early Saturday morning, attendees had a "Rise and Shine" for Yoga with Colleen Meehan from Yoga Breeze. It was a first for many, but they truly enjoyed it and said they would continue to do it at home as it really does help their joints!

After yoga everyone had a wonderful Black Mountain Breakfast buffet and continued on with the sessions of the day, which included *Express Yourself* with speaker Wendy Kaufman 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. The following session was *Dealing with Depression and Hemophilia* with Maria Iannone, a counselor with the Hemophilia and Thrombosis Treatment Center in Arizona.

Both sessions were very eye opening and emotional, but very helpful in giving the men the tools they need to take home and apply to everyday life.

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 and the men learned a lot! An *OI' Ballgame* afternoon snack followed.

After the men gathered to do some team building consisting of several jeeps, Johnny Ringo and his guides heading to the great Sonoran desert to the top of Humboldt Mountain. The men would learn Native American survival secrets about the many plants animals that fill the desert. When they arrived back they had a good *OI Fashioned Western Cookout*.

Our last session began early Sunday morning with Dr. Diane Dimon speaking on *Meditation for Chronic Pain and Stress Management*. Dr. Dimon also taught the men how to meditate. The session was wonderful and another tool they can take home and apply to their daily lives. Following was a wonderful breakfast and departures.

Our First Annual Men's Retreat was geared toward men ages 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 himself, 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 is hopeful that the success of the retreat will continue to help this special community into the future.

We plan to follow up with all the attendees with a webinar to see how they are managing since the retreat and we thank Pfizer for funding the First Annual Men's Retreat for men with Hemophilia B which was very successful. Since the news of this first retreat came out, we have received many requests to put on programs such as this for younger adults and woman with bleeding disorders. Please be patient; it will be coming down the road! 🇺🇸



Men's Retreat Attendee Comments

I would like to express my sincere gratitude for the opportunity to bond with my "B" brothers, to exchange viewpoints, make new friends, and learn something too, at the recent Coalition for Hemophilia B "Men 35 and over" Retreat. This would not have been possible without your generosity and kindness. There was a time as a youth, I didn't think I would live to see the age of 30, but with your dedication to hemophilia, I've reached the ripe age of 58! My wish is in the near future that the number of hemophiliacs over the age of 35 will increase substantially, and I know, with your support, we will! From the bottom of my heart, I am eternally grateful.

I want to thank you, Wayne and the Retreat's Organizing Committee for putting on the best hemophiliac conference I've ever had the privilege to attend. While each participant may have arrived at the retreat with different expectations, in my opinion within a couple of hours we had already bonded like only "brothers" can. Never have I felt so welcome and at ease during a symposium, which permitted me to take full advantage of the educational sessions as well as the timely advice offered by the speakers. Further, please pass along my deepest appreciation to the sponsors for providing the Coalition with the financial resources and expert personnel that made the retreat a resounding success. As a result, I came away from the meeting mentally uplifted and better educated! If you or Wayne ever need help organizing future meetings for us "old-timers," please feel free to give me a call! In the meantime, I'm really looking forward to staying in touch with my comrades-in-arms.

First and foremost I want to thank you for all that you did for the retreat. For the first time in a long time I can say that this was the best conference/retreat that I have attended in some time. Every detail was well planned and executed very well. The array of speakers with relevant and timely information was superb. For the first time I was at a meeting where I was not the odd ball out because of being hemo B. It was great to be in a room with fellow bleeders in my age bracket. Normally at chapter functions I am the odd man out or in the "mature" "OG" group and it was wonderful to learn more valued information from the older guys. This was a timely meeting in that our group has bridged many of the positive and negative things in community. I was able to disclose things to this group that I have not disclosed in other hemophilia sponsored events. I felt at home and a strong blood brother hood. I believe meetings of this nature need to continue and I would like to participate more if possible in the planning or whatever is needed. This was truly a community event with a wealth of knowledge, information sharing, great programming and an opportunity to meet others in my similar situation which I value greatly. Thank you so much for taking the lead in making this happen. Thanks from the bottom of my heart. Be well.

Again, I cannot express how truly grateful I am for the opportunity that you created for us!!! You are amazing!!! I cannot recall a time when I have felt closer to a group of men that I had never met before. It was inspiring!! You did an outstanding job of putting together this conference and words cannot express how much it meant to me....just know that I will always be thankful for the opportunity and the honor of meeting this bunch of brothers, and you as well....Eternally grateful.





NHF WASHINGTON DAYS

February 27 to March
1, 2013

It was a wonderful turn-out for NHF's Washington Days to "Walk the Hill" end February! Focus this year was to maintain the federal hemophilia programs at the Maternal and Child Health Bureau (MCHB) and Centers for Disease Control and Prevention (CDC) to ensure access to hemophilia treatment centers (HTCs) and other critical education, research and surveillance activities. Federal hemophilia programs must be adequately funded to ensure that patients with bleeding disorders continue receiving high-quality care! 🇺🇸



DC Days (left to right)

Kim Phelan, Jon Davis, Staff Member of New York Congresswoman
Caroline Maloney (D-12), Hope Woodcock and Jeri Krassner



(Left to right) Ryan Seeley, Val Bias, Aaron Craig, EJ Villegas,
Clyde Brawner and Lee Hall



biogen idec

HEMOPHILIA

It's your life. It's our passion.

We are Biogen Idec Hemophilia and we're dedicated to you—today and looking toward the future. Through our Community Connections program, we're pleased to bring you an inspiring selection of empowering opportunities, programs, resources, and support to help make that future the best it can be. Here are just a few of the programs and resources offered through Community Connections:



> Our passionate CoRe Team.

To build a powerful community, we look to the people most dedicated to it—and that includes patients, parents, and outspoken community advocates. Because they've been involved for decades, this CoRe Team believes in bringing you inspiring programs, including their spirited new Webinar series, CoRe Conversations.

> Our Motivated, Vibrant, Powerful LIFE-SKILLS SERIES.

We're committed to helping you live life to the fullest. That's why we've created a wide range of educational opportunities to help you make the most of it.

Sign up for Biogen Idec Hemophilia's Community Connections program now. It's our way of staying connected to the community—and helping you stay connected too.



Join today.

[www.BiogenidecHemophilia.com/
CommunityConnections](http://www.BiogenidecHemophilia.com/CommunityConnections)



Receive a cooler bag and more information when you register now.



Sixth Annual Fundraising Dinner



The Coalition for Hemophilia B held its Sixth Annual Fundraising Dinner at the Water's Edge Restaurant with beautiful views of the Manhattan Skyline on Friday, March 22nd, 2013. Approximately 240 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.

The cocktail hour included entertainment by the wonderfully talented pianist and saxophonists, William Gati & Ensemble, and dazzling Magician Erman!

Dinner began with a warm welcome to our guests by Dr. David Clark, Chairman of The Coalition for Hemophilia B, followed by Wayne Cook, President of The Coalition for Hemophilia B who had the special honor of presenting Carl Weixler with the "Eternal Spirit Award" for his many years of dedication and devotion to improving the health and quality of life for many people with hemophilia and their families. John Taylor announced the William N. Drohan Scholarship winners.

We were then treated to two solo pianist performances by John Taylor III and Elizabeth VanSant, who both have hemophilia B. A special performance by a group of young talented musicians all with hemophilia B that we referred to at the "B Flats" then followed. The B Flats include Nat Lathrop on drums, Sam Lathrop on guitar, William McCarthy on cello and Ryan Lee on drums.

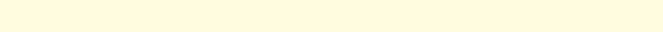
After a delicious dinner and dessert, Dr. David Clark and his super helpers announced the raffle prize winners. We continued the wonderful evening enjoying the beautiful views, the great company, dancing and taking fun custom photos where a variety of cool background images could be selected. It was 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 Seventh Annual Fundraising Dinner! 🍷

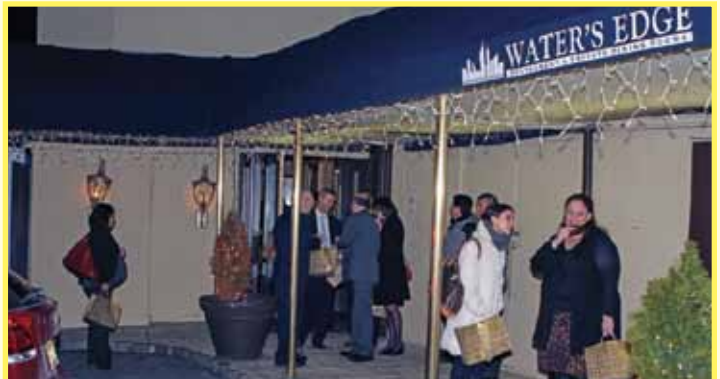












R_x only

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°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.

Wyeth

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Marketed by Pfizer Inc.
July 2012



15 YEARS
EXPERIENCE
MATTERS

BeneFix
Coagulation Factor IX (Recombinant)
Room Temperature Storage

You asked for 3000 IU in a single vial with the same 5-mL diluent. You got it.

BeneFix 3000 IU

The first 3000-IU dose for hemophilia B patients.



The individual depicted is not a hemophilia patient.
For illustrative purposes only.

What Is BeneFix?

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

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

Important Safety Information 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.

Should your doctor decide that BeneFix is right for you, you may be eligible to get a one-time 1-month supply

Up to 20,000 IU at no cost to you

Download the Trial Program Application today, then talk to your doctor to see if you are eligible.*



FreeTrialBeneFix.com

*One-time offer. Terms and conditions apply. Visit www.FreeTrialBeneFix.com for complete terms and conditions. You must be currently covered by a private [commercial] insurance plan. If you are not eligible for the trial prescription program, you may find help accessing Pfizer medicines by contacting Pfizer's RSVP program. For questions about the BeneFix Trial Prescription Program, please call 1.800.710.1379 or write us at BeneFix Trial Prescription Program Administrator, MedVantx, PO Box 5736, Sioux Falls, SD 57117-5736.

[†]BeneFix was approved February 11, 1997.

- 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.

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 for BeneFix on next page.

Wyeth

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December 2012



The Coalition for Hemophilia B



7th Annual Symposium

The Coalition for Hemophilia B's Seventh Annual Symposium was held on Saturday, March 23rd, 2013 at the New York Grand Hyatt Hotel. Pfizer Inc generously funded the educational symposium.

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 where we are and where we are headed with bleeding disorder products. Dr. Walsh also stressed the importance of managing Hepatitis C. His presentation was very passionate and eye awakening for many. A multitude of questions followed from symposium participants.

Next on the agenda was Michael Bradley, Vice President of Healthcare Economics and Reimbursement at Baxter BioScience. Mike spoke about *Insurance Updates* - and we all know the importance of keeping up with this right now! His talk was very informative and well received.

Following was *Meditation for Chronic Pain and Stress Management* with Dr. Diane Dimon, Founder of Matters of the Mind in California. Dr. Dimon taught us all the importance of meditation and the benefits it has to our health. Dr. Dimon's presentation is part of CSL Behring's Common Factors Program.

Next was *Winning with Hemophilia; Top Do's and Don'ts for Raising Happy, Healthier Kids* presented by Lisa Greene, a mom of two children with cystic fibrosis. Lisa's talk was motivational in helping parents to inspire their children to make wise choices about medication and self-care, to promote responsibility without nagging and put an end to power struggles amongst many other topics that mom's have to deal with on a daily basis with their children. It was a wonderful and much needed topic to empower parents.

Afterward everyone enjoyed a great lunch and

visited the industry exhibit booths, which were open during lunch, break times and during break-out sessions. We continued our afternoon with a session on *Healthy Lifestyle Choices: The Role of Medication Adherence* with Nayan Heath, BSN, RN. Ms. Heath is a nurse educator specialist with more than 17 years of nursing experience and has cared for many hematology and oncology patients. As part of Pfizer's speakers Bureau, she did an awesome job explaining the importance of adherence.

Following Ms. Heath was *Social Connection: The GPS to Meeting our Needs* presented by Patrick Torrey. Patrick has been designing and delivering innovative experiential educational program and trainings for the past 15 years, and once again he did not disappoint his audience! His fun, engaging and interactive talk was just wonderful for children and adults alike!

Break-out sessions followed with *Children's Rap Session, Teen Scene, Adult Men's Group, Moms Session* (held on Friday later afternoon) and *Dad's Session*. We also had Hope Woodcock lead a session for all attendees where she had three volunteers, Sam Lathrop, Elizabeth VanSant and Nat Lathrop all infuse in front of the audience. It was very educational for parents and children, and empowering. A special thanks to Sam, Elizabeth and Nat for stepping up!

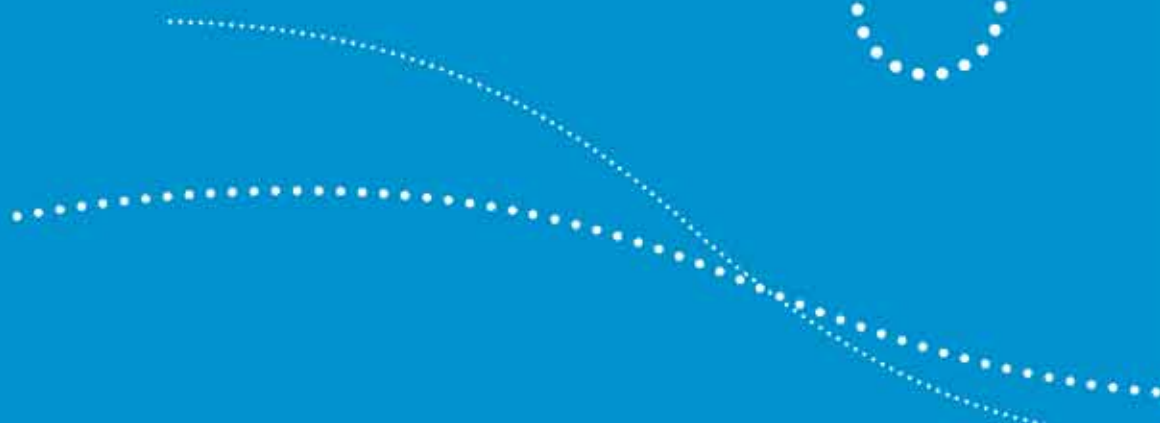
We ended the day with a motivational talk from Perry Parker who is part of CSL Behring's Getting in the Game. He is a golf professional and has played in many US Opens; he also has hemophilia. Perry took the kids out to Chelsea Piers and taught them to play golf during our Symposium. CSL Sponsored the outing as part of their Getting in the Game Program. The kids had a blast!

A big thank you to our sponsors, exhibitors and speakers for making our 7th Annual Symposium a huge success! 🎉



**Pfizer Hemophilia
congratulates Carl Weixler
on receiving the
Eternal Spirit Award.**

**Thank you for your years of
dedicated service to the
hemophilia community.**



Symposium Comments



We would like to extend our gratitude for the Wonderful symposium for those with Hemophilia B. It was exciting to hear and learn about the new developments and medicines happening for our “B” Families. It was also great to meet many new people from around the country. We talked to all the vendors. Having only “nine” info was interesting and less confusing than all the materials for all types and problems. The programs and speakers you put together were outstanding. We appreciated the scholarship for the trip - air fare, hotel, and symposium fees. Being that one parent is currently looking for a new job and on unemployment and the other parent only employed for six months after being out of work for 1 ½ years, this trip would never have been possible without your generosity.



It was great meeting new friends, connecting with old ones. I really enjoyed the Ladies-Only gathering. Patrick Torrey’s session at the end of the day was a great way to get us up and moving. And the kids infusing was amazing... I don’t think I could have done that in front of so many people. Dr. Walsh’s talk was very informative and I learned so much!



The speakers were fantastic and topics were right on with the times! I have heard about meditation, but never really paid much attention to it until I hear Dr. Diane Dimon speak. She taught me a lot and I am going to apply it to my daily life as pain management is something I desperately need! Thank you.



I have never been to a big city and our trip was great. It was fun meeting new people that live just like us. The people were great as well as the food and education. You made our stay GREAT! I don’t think you could have done anything else. If it was not for you we would never have been able to go. Thank you for everything.



We enjoyed talking with the other families at our table and hearing about their experiences. We liked the various speakers and the variety of topics. One of our sons thought it was cool to meet Perry Parker and also to be around so many other kids who had “the same thing he has.” My son finally got out of his shell! He also was impressed with how the kids were able to infuse themselves. We learned many things and also the speakers reinforced some ideas/topics that I had previously been introduced to. We made so many new friends! Our children enjoyed the golf outing. The conference was great and you did a fantastic job pulling that all together! I can’t imagine all the work that went into organizing something of that scale. Well done and everyone in my family will remember this for the rest of our lives! This was my family’s first year attending a Coalition of Hemophilia B event, but hope to attend many more in the years to come. Thank you again for everything.



My family and I would like to thank the Coalition for Hemophilia B for a wonderful time at the fundraising dinner and the annual symposium. It was our first time to the symposium and to be in New York. We met lots of new people and made a few great friends. The fundraising dinner was beautiful, the food was awesome and my boys really enjoyed themselves. The symposium was very informative. The speakers were very helpful and kept our interest. The boys had an awesome time at the outing with Perry Parker. Again we want to thank Kim, Wayne, Dr. Clark and everyone who helped put this together for all of their hard work that they put into planning this wonderful symposium for our families. Hope to be able to attend another one in the near future. Thanks so much!



The New York Symposium was an amazing experience! All the speakers did a great job. The whole programming was perfect for us and what we needed. We feel so blessed to have had this experience and will stay in touch with all our new friends! We hope to attend many more meetings and look forward to having The Coalition come to our state and do a factor nine family meeting!! Thank you!!

whole situation. I also made appointments with my cardiologist to make sure my heart and blood pressure were fine. This way I could make sure I was staying healthy enough to help take care of my dad.

When parents, spouses or significant others are the caregivers, we, as children, spouses or friends, sometimes take for granted their job of taking care of us. They do things not only to take care of us, but they manage our households when we are unable to work due to our own issues, whether it be a bleeding episode or any other health issue. There are a few steps to take when the tables are turned and you become the caregiver.

- Stay on top of your own health. Being unhealthy is not helping the person you are caring for. Don't be afraid to ask for help, whether it be from other family members or someone from an agency or home health care company.
- Make sure you get your rest and that you try to eat healthy and take some time for yourself. Try to do things that will help you with your stress, like meditation, reading a book or just going for a walk.
- Don't be afraid to talk to someone, whether it's a family member, a friend or even a professional to help you cope with the stress.



These are just a few things that I have learned to do to help me cope with taking care of my loved ones. I never thought I would be in situations as this, but being in them has made me understand

more about life, about myself and the issues I have endured over the years, and about the people who have taken care of me. To quote Ralph Waldo Emerson, "It is one of the most beautiful compensations of this life that no man can sincerely try to

help another without helping himself."

Here are a few of my other favorite quotes I have embraced over the past few years.

"Blood's thicker than water, and when one's in trouble, Best to seek out a relative's open arms."
~ Unknown

"Our most basic instinct is not for survival but for family. Most of us would give our own life for the survival of a family member, yet we lead our daily life too often as if we take our family for granted."
~ Paul Pearshall

"The happiest moments of my life have been the few which I have passed at home in the bosom of my family." ~Thomas Jefferson

"No matter what you've done for yourself or for humanity, if you can't look back on having given love and attention to your own family, what have you really accomplished?" ~ Elbert Hubbard 🇺🇸

Message From Kim...

We have received many requests for assistance from families in our community. We believe it takes a village, even \$5.00 will make a tremendous difference in the quality of life for people with hemophilia in need. We thank you for all your love, kindness and generosity to help families in need! We now have a PayPal account to make it easier to make donations! Just visit our website coalitionforhemophiliab.org and click on **donate**, which will bring you directly to our PayPal site, or go to PayPal and use our email (hemob@ix.netcom.com) address to donate.

Thank you! Thank you! **Thank you!!!**



RIXUBIS [Coagulation Factor IX (Recombinant)]**For Intravenous Injection****Brief Summary of Prescribing Information: Please see package insert for full Prescribing Information.****INDICATIONS AND USAGE****Control and Prevention of Bleeding Episodes**

RIXUBIS [Coagulation Factor IX (Recombinant)] is an antihemophilic factor indicated for control and prevention of bleeding episodes in adults with hemophilia B.

Perioperative Management

RIXUBIS is indicated for perioperative management in adults with hemophilia B.

Routine Prophylaxis

RIXUBIS is indicated for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults with hemophilia B.

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

CONTRAINDICATIONS

RIXUBIS is contraindicated in patients with:

- Known hypersensitivity to RIXUBIS or its excipients including hamster protein
- Disseminated intravascular coagulation (DIC) [see *Warnings and Precautions*]
- Signs of fibrinolysis [see *Warnings and Precautions*]

WARNINGS AND PRECAUTIONS**Hypersensitivity Reactions**

Hypersensitivity reactions, including anaphylaxis, have been reported with factor IX-containing products. The risk is highest during the early phases of initial exposure to factor IX concentrates in previously untreated patients (PUPs), in particular in patients with high-risk gene mutations. Early signs of allergic reactions, which can progress to anaphylaxis, include angioedema, chest tightness, hypotension, lethargy, nausea, vomiting, paresthesia, restlessness, wheezing, and dyspnea. Immediately discontinue administration and initiate appropriate treatment if allergic- or anaphylactic-type reactions occur. In case of severe allergic reactions, alternative hemostatic measures should be considered.

There have been reports in the literature showing an association between the occurrence of a factor IX inhibitor and allergic reactions. Evaluate patients experiencing allergic reactions for the presence of an inhibitor.

RIXUBIS contains trace amounts of Chinese hamster ovary (CHO) proteins. Patients treated with this product may develop hypersensitivity to these non-human mammalian proteins.

Inhibitors

Evaluate patients regularly for the development of factor IX inhibitors by appropriate clinical observations and laboratory tests. Perform an assay that measures factor IX inhibitor concentration if expected factor IX activity plasma levels are not attained, or if bleeding is not controlled with an expected dose. Contact a specialized hemophilia treatment center if a patient develops an inhibitor.

Patients with factor IX inhibitors are at an increased risk of severe hypersensitivity reactions or anaphylaxis if re-exposed to RIXUBIS. RIXUBIS may not be effective in patients with high titer factor IX inhibitors and other therapeutic options should be considered.

Nephrotic Syndrome

Nephrotic syndrome has been reported following attempted immune tolerance induction in hemophilia B patients with factor IX inhibitors. The safety and efficacy of using RIXUBIS for immune tolerance induction have not been established.

Thromboembolic Complications

The use of factor IX containing products has been associated with the development of thromboembolic complications (e.g., pulmonary embolism, venous thrombosis, and arterial thrombosis). Due to the potential risk for thromboembolic complications, monitor patients for early signs of thrombotic and consumptive coagulopathy, when administering RIXUBIS to patients with liver disease, with signs of fibrinolysis, peri- and post-operatively, or at risk for thrombotic events or DIC. The benefit of treatment with RIXUBIS should be weighed against the risk of these complications in patients with DIC or those at risk for DIC or thromboembolic events.

Monitoring Laboratory Tests• Monitor factor IX activity plasma levels by the one-stage clotting assay to confirm that adequate factor IX levels have been achieved and maintained [see *Dosage and Administration in Full Prescribing Information*].

• Monitor for the development of inhibitors if expected factor IX activity plasma levels are not attained, or if bleeding is not controlled with the recommended dose of RIXUBIS. Assays used to determine if factor IX inhibitor is present should be titrated in Bethesda Units (BUs).

ADVERSE REACTIONS

The most common adverse reactions observed in >1% of subjects in clinical studies were dysgeusia, pain in extremity, and positive furin antibody test.

Clinical Trials Experience

Because clinical trials are conducted under widely varying conditions, adverse reaction rates observed in the clinical trials of a drug cannot be directly compared to rates in the clinical trials of another drug and may not reflect the rates observed in clinical practice.

During clinical development, in a combined study, 91 male previously treated patients (PTPs; exposed to a factor IX-containing product for ≥ 150 days) received at least one infusion of RIXUBIS as part of either on-demand treatment of bleeding episodes, perioperative management of major and minor surgical, dental, or other invasive procedures, routine prophylaxis, or pharmacokinetic evaluation of RIXUBIS. Six subjects (6.6%) were <6 years of age, 10 (11%) were 6 to <12 years of age, 3 (3.3%) were adolescents (12 to <16 years of age), and 72 (79%) were adults (16 years of age and older). The subjects received a total of 7,353 infusions with a median of 85 infusions of RIXUBIS (range 3 to 212 infusions), for a median of 83 exposure days (range 83 to 209 days).

A total of 161 adverse events were reported in 48 (52.7%) of the 91 subjects. Adverse reactions that occurred in >1% of subjects are shown in Table 3.

Table 3: Summary of Adverse Reactions

System Organ Class	Adverse Reactions (AR)	Number of ARs (N)	Number of Subjects (N=91) n (%)	Percent per Infusion (N=7353)
Nervous System Disorders	Dysgeusia	2	1 (1.1%)	0.03%
Musculoskeletal and Connective Tissue Disorders	Pain in extremity	1	1 (1.1%)	0.01%
Investigations	Positive furin antibody test*	1	1 (1.1%)	0.01%
	Factor IX or furin antibodies of indeterminate specificity*	9	7 (7.7%)	0.12%

*See Immunogenicity.

Immunogenicity

All 91 subjects were monitored for inhibitory and binding antibodies to factor IX, and binding antibodies to CHO protein and furin, at the following time points: at screening, at 72 hours following the first infusion of RIXUBIS and the commercial recombinant factor IX product in the cross-over portion of the pharmacokinetic study, after 5 and 13 weeks following first exposure to RIXUBIS, and thereafter every 3 months. Antibodies against furin were tested by an in-house enzyme-linked immunosorbent assay (ELISA). A titer of 1:20 or 1:40 was considered to be indeterminate for the above validated assay, as these titers were too low to be verified by the confirmatory assay.

No subjects developed neutralizing antibodies to factor IX. Thirteen subjects (14.3%) developed low-titer, non-neutralizing antibodies against factor IX at one or more time points. Two of these 13 subjects were found to have these antibodies at screening, prior to receiving RIXUBIS. No clinical adverse findings were observed in any of these 13 patients.

Thirteen subjects (14.3%) had signals for antibodies against furin (indeterminate specificity). Four of these 13 subjects expressed signals for antibodies at screening, prior to RIXUBIS treatment. An additional subject had an antibody signal after treatment with the comparator product and prior to RIXUBIS treatment. Another additional subject had a positive titer of 1:80 that was not present when checked at a later time point and therefore considered transient. A second subject had a positive antibody signal after the data cutoff date that was also transient. No clinical adverse findings were observed in any of these 15 patients.

In a study of 500 normal volunteers, using the same assay as in the clinical trial, 7% had titers of 1:20 or 1:40 and 1.2% had higher titers ranging from 1:80 to 1:320. These antibodies are thought to be part of a natural immune system response. To date, these antibodies have not been associated with any clinical adverse findings.

The detection of antibody formation is highly dependent on the sensitivity and specificity of the assay. Additionally, the observed incidence of antibody (including neutralizing antibody) positivity in an assay may be influenced by several factors, including assay methodology, sample handling, timing of sample collection, concomitant medications, and underlying disease.

Thrombogenicity

There was no clinical evidence of thromboembolic complications in any of the subjects. Out-of-range values for thrombogenicity markers (thrombin-antithrombin III, prothrombin fragment 1.2, and D-dimer), determined during the pharmacokinetic portion of the combined study, did not reveal any pattern indicative of clinically relevant thrombogenicity with either RIXUBIS or a comparator factor IX-containing product.

Post-marketing Experience

Because the following reactions are reported voluntarily from a population of uncertain size, it is not always possible to reliably estimate their frequency or establish a causal relationship to drug exposure.

No post-marketing adverse reactions have been reported with RIXUBIS.

The following class adverse reactions have been seen with another recombinant factor IX: inadequate factor IX recovery, inhibitor development, anaphylaxis, angioedema, dyspnea, hypotension, and thrombosis.

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NEW RIXUBIS

[COAGULATION FACTOR IX (RECOMBINANT)]

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Available FALL 2013

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Danielle Kiesel

Phone: (862) 881-9889

E-mail: danielle_kiesel@baxter.com

To learn more, visit www.RIXUBIS.com

Indications for RIXUBIS [Coagulation Factor IX (Recombinant)]

RIXUBIS is an injectable medicine used to replace clotting factor IX that is missing in people with hemophilia B (also called congenital factor IX deficiency or Christmas disease).

RIXUBIS is used to prevent and control bleeding in adults with hemophilia B. Your healthcare provider may give you RIXUBIS when you have surgery. RIXUBIS can reduce the number of bleeding episodes in adults when used regularly (prophylaxis).

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

Detailed Important Risk Information for RIXUBIS [Coagulation Factor IX (Recombinant)]

You should not use RIXUBIS if you are allergic to hamsters or any ingredients in RIXUBIS.

You should tell your healthcare provider if you have or have had any medical problems, take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies, have any allergies, including allergies to hamsters, are nursing, are pregnant or planning to become pregnant, or have been told that you have inhibitors to factor IX.

You can have an allergic reaction to RIXUBIS. Call your healthcare provider or get emergency treatment right away if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea, or fainting.

Your body may form inhibitors to factor IX. An inhibitor is part of the body's defense system. If you form inhibitors, it may stop RIXUBIS from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to factor IX.

If you have risk factors for developing blood clots, the use of factor IX products may increase the risk of abnormal blood clots.

Some common side effects that have been reported with RIXUBIS include: unusual taste in the mouth and limb pain. Call your healthcare provider right away about any side effects that bother you or if your bleeding does not stop after taking RIXUBIS.

Please see Brief Summary of RIXUBIS Prescribing Information on following 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.

Reference: 1. RIXUBIS [Prescribing Information]. Westlake Village, CA: Baxter Healthcare Corporation; June 2013.

Sharing the Symposium with My Dad

By Pam Williams

Dads and daughters - they just go together... sort of like Oreo cookies and milk. It's always been said that a daughter is "daddy's little girl", and I truly believe that. I'll admit it...I'm daddy's little girl (even at age 53!), and I'm spoiled. I'm the only girl sandwiched between two brothers, and of course, my dad and I share something unique between us that the boys can't share. Dad has Hemophilia B and I'm a carrier. We didn't know any of that, however, until almost 16 years ago when my oldest son was diagnosed. But even before that, my dad and I have always had a special bond.

I encouraged dad to attend his first NHF annual meeting in 2006 in Philadelphia. He applied for and was awarded a first-time attendee grant, and we met in Philadelphia to experience the weekend meeting together. I had attended my first NHF meeting the year before, so I knew what to expect, but dad had no idea. He enjoyed himself, he learned some valuable information during the educational sessions, and as coincidence would have it, he caught up with his own HTC Nurse at the conference, as well. Because dad lives in Vermont, and the only NHF Chapter Association for him is housed in Boston, getting together for "local" hemophilia functions isn't always easy for him.

When the Lotto forms for the Coalition's annual symposium arrived in my email in November, I encouraged dad to apply. My sons and I, along with my eldest's fiancée, had attended the Symposium several years ago and found it amazing and very educational. We met up with

old friends, met some new ones, spent time exploring New York City, and learning all kinds of new things related to hemophilia B. I knew dad would enjoy it, so I sent him the form and said "fill it out, you never know". I filled mine out as well, and encouraged my cousin Ben and his family to do the same. "That way, if you are selected, and so is Ben, you'll have someone to travel with". As luck would have it, Dad and Ben were both selected to attend, so I knew he'd be okay traveling.



The month of December had not gone well for me. On December 14, I fell down approximately 10 stairs in my apartment building, breaking my neck and back. Dad immediately got on a plane on the 16th and flew out to Cincinnati to be with me and my boys, arriving at the hospital just before I returned from the operating

room. He stayed through Christmas, and because of weather issues, stayed even longer. He arrived back in Vermont in time to get the call from Kim that he was going to Symposium, and because of everything I'd been through, she wanted me to be there with him. I had no idea if I would be ready to travel, much less sit and walk all day, in three months, but we plunged forward. Then dad injured his shoulder. He went to physical therapy several times a week trying to improve, and while not perfect, he was in shape to travel by the end of March. He & Ben planned their flights together, and Ben helped dad with his bags as they walked through the airport. I arrived several hours later, and dad and I proceeded to Times Square for lunch at Bubba Gump's.

Courage of the Heart

A poem by
Christopher Maddix (aka Webster)



Reaching, reaching, reaching
for those stars
for those stars
for those stars

And its timeless meaning as we
Try to rise up against this heartache

As we stand alone in this struggle
for our independence
it gives us
courage to fight on
courage to fight on
courage to fight on

Making things much more
enduring towards us with
every fiber within our being
to overcome obstacles
that are around our hearts.

Shaping and sharing
those minds of contemporary aspects within
these teachings

For that's the only way
we can justify the flow of energy
to making us conceive
our boundaries
within ourselves
as human beings
to survive...

The fundraising dinner on Friday night was enjoyed by all. I introduced dad to all my "B buddies", and he engaged in deep conversation with the gentleman seated next to him from Indiana. I encouraged dad to have his photo taken with "Marilyn Monroe"...his significant other's name is Marilyn, so I thought that would be appropriate! The photo was a hoot and even Marilyn got a kick out of it when he returned to Vermont to show her. The rest of the weekend was busy with educational sessions and dinner at a cozy Italian restaurant. My flight was leaving early Sunday morning...Ben and dad wouldn't be leaving until late that afternoon...but we were both tired so we called it a night after returning to the hotel.

I was glad that I was able to attend the Symposium with my dad, and so very thankful to the Coalition for making that happen. Who knows if we'll ever make it to another hemophilia conference together again...we're 1000 miles apart, both have busy lives, and dad doesn't like traveling by himself too much anymore, especially when the flights require a layover and changing of planes. But, in 17 years, I've managed to get him to join me on two occasions, so I'd say I'm doing pretty well. He lived 62 years without a diagnosis, even served in an Army unit in the Korean War, so he missed out on all the early treatments of the disorder. Lucky for him, by the time he was diagnosed, safer alternatives in treatment had arrived.

Every daughter shares something different with her dad. I'm glad I share the hemophilia bond... it gives me a connection to my dad that my brothers cannot possibly understand. Boys have cars and hunting to share with their dads, girls just become "daddy's little girl" and I'm okay with that. My dad will always be the one I can count on for sending me flowers "just to feel better", or that box of chocolates on Valentine's Day, or that special Mother's Day card that says "thank you for giving me such wonderful grandsons". Even before we knew we had the hemophilia connection, we were connected...hemophilia just deepens that connection. And the funny part: my maiden name was *Blood*...yep, Blood with a bleeding disorder -LOL! 🍷



HEALTH CARE REFORM

**and the Five Things
You Need to Know
Moving Forward**

Signed into law in March 2010, the Affordable Care Act (ACA) makes health insurance more accessible for many people. This happens through a combination of measures, which include expanding Medicaid eligibility, tax credits for employers, new rules for insurance companies, requiring individuals to buy health insurance and more.

1. Most Of Us Don't Understand Health Care Reform

- At this point most people think they know whether they like or dislike the ACA. But when it comes to knowing what's actually contained within this mammoth retooling of our health insurance system, most of us haven't got a clue what it does.
- Recent polls by the Kaiser Family Foundation found that more than two-thirds (67%) of uninsured Americans age 65 and younger and 57% of the overall population say they do not understand how the Affordable Care Act will affect their lives. And, 42% of us are still unaware that health care reform has been the law of the land since 2010.

2. You Ain't Seen Nothing Yet

- January 1st 2014 seemed far away when Barack Obama signed the ACA into law back in 2010 but it is the date when the main parts of the ACA must go into effect. Parts to take effect include the mandate to buy insurance and the expansion of Medicaid. However, implementing all the changes in 2014 will not be easy.

- Beginning in 2014, insurers can no longer refuse coverage to the sick. The cost of insuring them will be paid out of insurance fees from cheap, healthy consumers—the law requires everyone to buy insurance or pay a penalty. The law also sought to extend Medicaid to all those earning up to 138% of the federal poverty level (\$15,415 for one adult in 2012). From 2014, those with incomes of 100-400% of the poverty level will qualify for subsidies on new state health exchanges, where individuals can shop for insurance.
- Other parts to go into effect in 2014:
 - ❖ Eliminating Annual Limits on Insurance Coverage
 - ❖ Ensuring Coverage for Individuals Participating in Clinical Trials
 - ❖ Increasing the Small Business Tax Credit

3. Premiums Will Increase For The Young and Likely Decrease For Older Patients

- Older patients typically utilize more, and higher cost health care services than younger patients. One way states can ensure that coverage remains affordable for everyone is to use age rating bands that spread premium costs over a range of age groups.
- Starting January 1, 2014, the law limits the age rating band to 3:1, causing an overnight increase in premiums for younger individuals (ages 18-49) that live in states that currently have higher age bands.





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- For example:
 - ❖ Now:
 - A 24-year-old's annual health insurance premium is currently \$1,200
 - A 60-year-old's annual health insurance premium is currently \$6,000
 - ❖ January 1st, 2014
 - Overnight, the younger individual's premium increases to \$1,800 annually. (Pays 50% more)
 - The older individual pays an annual premium of \$5,400. (Pays 10% less)



4. Physicians Will Be Focused On Value versus Volume

- The ACA will tie physician payments to the quality of care they provide. Physicians will see their payments modified so that those who provide higher value care will receive higher payments than those who provide lower quality care.

5. Not Everyone Is Covered

- One of the ACA's goals is to reduce the uninsured population, yet 31 million individuals will remain without health coverage in 2016. This is mostly a result of individuals declining to purchase insurance and illegal immigrants being ineligible for expanded coverage. By 2020, 30 million will remain uninsured.

In closing, the above are just a few of the key points regarding the ACA that we ALL need to learn more about in the coming days and years. There are many websites available to learn more about healthcare reform. (e.g. The White House website: <http://www.whitehouse.gov/healthreform#> or the U.S. Department of Health & Human Services: <http://www.hhs.gov/healthcare/facts/timeline/index.html>.)

Additionally, don't be afraid to call your local government official to help provide better clarity on how the law is being developed and how it impacts you, your family and your neighbors. 🇺🇸

References

1. 8 Biggest Mix-ups About Health Care Reform; By Jay MacDonald, 2013
2. Age Rating, America's Health Insurance Plans, 2013
3. CBO May 2013 Estimates of Effects of ACA on Insurance Coverage

Share a Moment in Your Spectacular Life!

Time is running out! Be sure to have your favorite photo included in our **2014 "A Moment in Your Spectacular Life" calendar!**

Our calendar will highlight just how amazing life can be, even with a bleeding disorder! It will be available this fall at the National Hemophilia Foundation's Annual Meeting in Anaheim, California, so be sure to send us your wonderful, happy photos (and photo release form) by September 1, 2013.

For more information or to obtain a calendar, visit our website www.matrixhealthgroup.com, contact a Matrix Health Group Regional Care Coordinator near you, or email Maria Santucci Vetter at maria.vetter@matrixhealthgroup.com.



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Factor Nine Holiday Fund 2013!

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

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

Please respond by *December 1, 2013* so that the Factor Nine Santa can load his sleigh with holiday gifts for all good boys and girls! 100% of your donation will be used to put a smile on a child's face.

We wish everyone a wonderful holiday season filled with love, happiness and good health!



For those families in our community in need of a little *Holiday Cheer*, we would like to help put something under the tree for your children! Just fill out this form and send it to Santa's special elf, Kim at the "East" Pole. Since the Factor Nine Santa has such a busy schedule, please send it to us **no later than December 1, 2013.**
(Your name and information will be kept *strictly* confidential.)

Send this form to: The Coalition for Hemophilia B Holiday Cheer
Attention: Special Elf Kim
825 Third Avenue, Suite 226
New York, New York 10022

Name: _____ Phone: _____
Address: _____

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

Child's Name and Age:	Child's Name and Age:	Child's Name and Age:
_____	_____	_____
Wish List:	Wish List:	Wish List:
_____	_____	_____
_____	_____	_____
_____	_____	_____

Never doubt that a small group of thoughtful, committed citizens can change the world; Indeed, it is the only thing that ever has.

~ Margaret Mead

Save the Date!

for The Coalition for Hemophilia B Meetings

Spend time with your peers and get the latest information on happenings in the World of Hemophilia B!

Join us and participate in our new "The B Scene"
"B in the Know" focusing on new Insurance changes coming in October.

Chicago Illinois – Saturday September 28, 2013 9:00 – 4:00 Pm
Austin Texas – Saturday November 9, 2013 9:00 am – 4:00 pm
Cleveland Ohio – Saturday November 23, 2013 9:00 am – 4:00 pm

Gas and tolls to the meetings is reimbursable. Please keep your receipts.

We will have a hotel group room rate and advise hotel shortly

Includes: Babysitting, Breakfast, Lunch, Afternoon Snack and Dinner, Parking, Industry Exhibits, and Raffles.

** Attendees of the meetings will be automatically entered into our drawing to attend the World Federation of Hemophilia and National Hemophilia Foundation joint Conference in 2016! It will be an amazing experience! **

We will also be exhibiting and holding Factor Nine Family Meetings at the following events:

October 3 - 5, 2013 – NHF in Anaheim CA

Factor Nine Family Breakfast Meeting - Saturday October 5, 2013, 7:00 - 8:30 am

October 10 - 11, 2013 – Northern Ohio Meeting

For more information, stop by our booth, visit our Facebook page or our website at www.coalitionforhemophiliab.org. Information will also be listed in our upcoming Summer Newsletter!

We look forward to seeing you!

Questions? Please contact Kim at hemob@ix.netcom.com or call 212-520-8272

We are now on Facebook!
Visit us under The Coalition for Hemophilia B



The *Factor Nine Group* moderated by Jill Lathrop is located on Facebook - search Hemophilia B Group

For back issues of **Factor Nine Newsletter** or for more information on research, please call or write to:
Kim Phelan; 825 Third Avenue, Suite 226; New York, New York 10022; Telephone (212) 520-8272
Telefax (212) 520-8501; E-mail: hemob@ix.netcom.com Website: www.coalitionforhemophiliab.org