



# Factor Nine News


The Coalition for Hemophilia B Summer 2012



## Topics in Hemophilia

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The Coalition for Hemophilia B held its first **Factor Nine Family Meeting on the Road**. The mini version of our New York Symposium was held at the Renaissance Hotel in Columbus Ohio on Saturday, September 22nd from 9:30 am – 4:30 pm. Shannon Pennica gave a wonderful talk on *Improving Compliance During Infusion*. Kimberly Jones spoke on *Charting Health Insurance Coverage*. Nayan Health's topic was *Healthy Lifestyle Choices* and we heard *A Mom's Perspective* by Gina Perez-Wiberg, mother of two boys with hemophilia B. After lunch we had some fun with a great crossword puzzle game to test your knowledge on healthcare and our game *Are you Smarter than your Hemophilia*. Following was a talk by Dave Clark on current events for Hemophilia B and our Factor Nine Group meeting. We had a nice turn out and enjoyed spending time with our B families in Ohio!

We are so grateful to our sponsors and look forward to holding more of these events in 2013! 





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*Walgreens*



# Summer Highlights!

## NHF Walk, New York City, Sunday, June 3rd Riverside Park

What a wonderful turnout for the NHF walk! Bill and I were so happy we could attend with our two dogs Bradley (with the NHF t-shirt on) and Shadow. A week prior Bradley had undergone surgery. We got a kick out of the fact that he wanted to walk with Bayer Pharmaceutical because that is where his medication came from! ~ Kim



## The Coalition for Hemophilia B exhibits in San Antonio, Texas

My 13 year old nephew Nicholas joined me in Texas this summer to help exhibit at the Texas Bleeding Disorder Conference held at the Westin La Cantera on August 10-11. This was a fantastic meeting with a wonderful attendance. Perry Parker was on hand to teach the kids how to play golf. Perry has hemophilia and has played in many US Opens! What a treat! Special thanks to Nick. Nick has been volunteering his time over the past several years to assist with the setup of our New York Symposiums.



Nicholas



Perry Parker



## William M. is on the Swim Team!

This summer I joined the Lakeshore Swim Team. I learned a lot of new strokes, butterfly, backstroke, breaststroke and freestyle. I got to practice every day with my friends and compete against other teams. In my first race I finished in second place!

I can't wait to swim again next summer and will be practicing over the winter (indoors of course).

# More Summer Highlights!

## Camp Little Oak



Our theme this year was nature.



The girls checked out the aquatic life at the lake.

2012 was the seventh year for Camp Little Oak, a summer camp for girls affected by bleeding disorders in New York State. Held at Camp Aldersgate in the scenic Adirondack Park in late August, we welcomed nineteen girls who have a bleeding disorder, are a carrier, or are the sibling of someone with a bleeding disorder. The girls were joined by ten staff members - nine counselors and a nurse - of whom four have bleeding disorders.

The campers and staff came from as far away as New Hampshire, Connecticut and Missouri. Camp was a week long and in that time we managed to pack in biking, hiking, Cup Cake Wars, swimming, campfires, volleyball, painting, learning about nature, our Girls Night and a day at the Camp Oswegatchie High Ropes Course. During our last night of camp we also discovered that someone had “gift wrapped” several of the cabins and duct taped bikes to trees. We asked everyone we could, but the explanation for

these events remains a mystery (wink-wink).

Camp was free to attend for the campers with funding provided by several generous donations from the bleeding disorders community and the Bleeding Disorders Association of the Southern Tier. All of the camp counselors and nurse were volunteers.

We believe from humble beginnings can grow great things. Camp Little Oak was founded to meet a need in the community for a camp dedicated especially to girls affected by bleeding disorders. The girls who came to camp all had a wonderful experience and helped to show us this need is real and can be met with a little faith and a lot of hard work.

~ Hope Woodcock, RN, BSN, Health Director

## Barry Haarde on the Road!

August 2012, 46 year old Barry Haarde became the first person living with HIV and Hemophilia to ride across the United States by bicycle. Barry’s “Wheels for the World” also helped raise money for Save One Life, a non profit founded by Laurie Kelley to help children in developing countries!

Congratulations Barry!



Barry Haarde and Laurie Kelley Celebrate!

## Musical Talent!

Siblings Michael and Meredith O'Connor performing in a local club in New York this summer.



## Spring Break Fun!

We went to Costa Rica on Spring Break and went ziplining!

Just last week we found out our son made the travelling AA baseball team, which as a 3rd grader is unusual, most are 4th graders. We want to find some type of face protection so he can pitch. If you know of anything let me know! (You can respond to Kim at [hemob@ix.netcom.com](mailto:hemob@ix.netcom.com))

~ Judith and Family



## Steve and Judy... A Summer to Remember

This has been a summer of wonder and adventure for us. A special time that I will never forget. A summer of travel starting with a chance to get back in touch with the outdoors after the long winter: a wagon trip through an amazing park full of animals followed a cabin trip shared by our hemophilia chapter; a chance to make connections, meet old friends and learn; along the way we made a slight detour for a day at the water park; letting our little one spend time with his best friend and soak away memories of school; getting our share of soaking on the twists and turns of breathtaking slides.



Later our summer journeys would take us to West Virginia to share a special anniversary - two old friends celebrating sixty-two years together and still very much in love. And then there was New England... the trip of a lifetime. The sights of Boston, the ocean, the whales, the food, the history and most of all, the company. From the light houses of Cape Cod to a romantic table in Main. The table I proposed at...the table where she said yes. A summer to remember.

Congratulations to the Happy Couple! We wish them many, many happy and healthy years together! ~ Kim





## Meet Inspiration Biopharmaceuticals

### We understand hemophilia

At Inspiration, we have made it our personal mission to make a difference in future treatment options available for people with hemophilia. The founding families of our company have been intimately impacted by hemophilia, as both families have sons who have hemophilia.

Our lead product candidate, currently in clinical trials, is a recombinant factor IX that is being developed for the treatment and prevention of bleeding in people with hemophilia B.

For more information, visit our website at [www.inspirationbio.com](http://www.inspirationbio.com)

### We are committed to:

- Broadening access to hemophilia care worldwide
- Improving treatment options for people with inhibitor complications

**Inspiration**  
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# Brook Kaser



**M**y name is Brooke Kaser, I am 16 and horses are my passion. I am a carrier of Hemophilia B and my two brothers have Hemophilia B. I compete with the International Barrel Racing Association and qualified for the National Finals to be held in Louisville, Kentucky. It is a great honor to represent the state of Indiana at this event.

I am currently ranked 16th in the First (fastest) Division out of 253 and continue to move up at each show. I am also ranked 3rd in the Third Division out of 253. I took first place in barrels at the Kosciusko County Fair this year.

I feel very fortunate to be able to compete with the IBRA but competitions are very expensive. If you would like to make a donation please send a check to The Coalition for Hemophilia B and write on the memo line *Donation for Brooke Kaser* or donate via paypal to the Coalition. I thank you in advance for any assistance and if I win, I will definitely make a donation back to The Coalition for Hemophilia B!

Wish me luck! Brooke

## *A Message From Kim...*

Hello All!

Over the past several months 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! And to make things easier, we have exciting news! We now have a PayPal account to make it easier to make donations! Just visit our website [coalitionforhemophiliab.org](http://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](mailto:hemob@ix.netcom.com)) address to donate.

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







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➤ **Biogen Idec Hemophilia Community Connections**

New members are signing up every day to stay informed on the most recent developments from Biogen Idec Hemophilia, and the issues that affect you most

Biogen Idec Hemophilia  
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**Join our community today!**

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



## *New Gene Therapy Study for Hemophilia B*


Gene therapy seems finally poised for success as a potential cure for hemophilia B. We reported on the promising results from the St. Jude/University College London (SJ/UCL) study at the end of 2011. Now, another gene therapy study for hemophilia B is getting started. Asklepios Biopharmaceutical (AskBio) in collaboration with Dr. Christopher Walsh at Mt. Sinai Medical Center in New York has developed a gene therapy treatment using adeno-associated virus, type 8 (AAV8) to deliver factor IX genes to the liver.

AskBio is using a method similar method to that used in the SJ/UCL study. One difference is that AskBio has a more highly purified AAV8 vector. That means that there are more active vector particles in a given dose, so a dose can potentially transform a larger number of cells to produce factor IX, hopefully with fewer side effects. AskBio is also using a modified factor IX gene to produce a protein that has a significantly higher clotting activity than normal factor IX. AskBio believes they can eventually increase patient's blood levels of factor IX to 40 - 50% of normal. That's enough to essentially provide a cure for hemophilia B if the factor IX production lasts. Previous methods have only attempted to increase factor IX levels into the 1 - 5% range, enough

to change severe hemophilia into moderate or mild hemophilia.

One important question will be whether the modified factor IX molecule will increase inhibitor development in patients. That occurred in Novo Nordisk's trial of a modified more-active factor VIIa product reported elsewhere in this issue. However, Novo's factor VIIa gene was produced in the laboratory and has three modified amino acids, while the AskBio factor IX gene contains only a single change. The modified gene came from an Italian family whose factor IX is naturally more active. The family has no history of inhibitors, but that doesn't necessarily mean that their factor IX couldn't produce inhibitors in other people whose immune systems had never encountered the modified protein. That remains to be seen.

This is a Phase I/II study looking at increasing doses in up to 16 patients. The primary goal of the study is to assess the safety of the proposed treatment. Other objectives are to investigate the pharmacokinetics of factor IX activity and its relationship to the amount of vector infused, to determine the dose of vector needed to elevate factor activity to 10 - 40% of normal, to look at the immune responses to both the vector and the modified factor IX protein and to determine how long the vector genes remain in the body.

AskBio is currently recruiting patients for the study. The initial follow-up requires weekly visits for the first twelve weeks, then less frequently after that. The initial study sites are Mt. Sinai in New York and the University of California at Davis, with more sites expected to open in the future. The sponsors will pay patients' expenses for travel to the study sites. More information can be obtained at [www.clinicaltrials.gov](http://www.clinicaltrials.gov). Search for study NCT01687608. 



**Article Title:**

Pfizer's Hemophilia Franchise Delivers New Dosage Strength for Patients with Hemophilia B

**Article Text:**

Pfizer Hemophilia is pleased to announce that the 3000 IU dose of BeneFIX® is now available for hemophilia B patients. BeneFIX is a recombinant coagulation factor IX product indicated for the control, prevention and perioperative management of bleeding episodes in adult and pediatric patients with hemophilia B.

Pfizer Hemophilia is the first to offer this new dosage strength for hemophilia B patients, providing reconstitution convenience for those taking 3000 IU or higher doses:

- Comes with the same 5-mL diluent
- May reduce the number of vials needed per infusion
- May save space at a patient's home or on the go
- May have less waste for disposal

Like all other BeneFIX vial sizes, 3000 IU can be stored at room temperature or under refrigeration (2°C to 30°C/36°F to 86°F) for up to two years until expiration.

The 3000 IU dose is a new addition to the range of doses available for hemophilia B patients from Pfizer Hemophilia.

To learn more about BeneFIX, visit [www.benefix.com](http://www.benefix.com).

**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.

**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,

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#### What Is BeneFix?

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

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

#### 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.

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

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

\*BeneFix was approved February 11, 1997.



Please see brief summary of full Prescribing Information for BeneFix on reverse side.

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# Camp Perspectives

## A Mom's Perspective

The Symposium held by the Coalition for Hemophilia B in March was a wonderful experience for our family. We enjoyed learning about new advances, meeting new families and reconnecting with families we've known for years. I had no idea, though, how much this trip would impact our summer and our daughter's journey toward self-infusion. While at the Symposium, all of our children were intrigued by the fake arm Hope Woodcock brought to help kids learn to infuse. While Hope and I chatted about the struggles my daughter had with infusing, Hope talked to me about an all female bleeding disorders camp in New York. She told me, "Send her to me. I can help her!" I thought that sounded like a great idea, except for the fact that we live in Missouri.

As the school year came to a close, Elizabeth tried everything to convince us that she didn't need to go to camp, but infusions still weren't easy. We began trying to figure out how to make it work to send her to a camp that was eighteen hours from home. Finally we decided to drive her to camp and then let her fly home. As plans came together, we learned of another teenage girl in our area that was interested in going to Camp Little Oak as well. Although we'd never met, her parents bravely allowed her to ride with us across country. We were able to secure plane tickets home but couldn't get the girls on a flight together. Hope was a calming force for all of us and continued to reassure us that everything was going to be fine.

When we arrived at Camp Little Oak, after a beautiful drive, I was a bit worried about my girlie-girl in these cabins that were a bit on the rustic side. After we checked her in with medications and plane tickets, we made our way to the cabins. The moment she entered the cabin, I knew it was worth the long trip to get Elizabeth to THIS camp! Other girls welcomed our Missouri girls readily and there was lots of chatter among all of them immediately. As the week progressed, Hope sent updates about Elizabeth's progress with infusions and assured us that she was having a great time. We were so excited to hear from Elizabeth

all about her week at camp, especially since we knew infusions had been successful.

The flights home for our Missouri girls were quite an experience! They ended up on the same flights and traveled through several airports. When they finally came out of the terminal, they were not only exhausted, but they were definitely stronger and more confident than they were when we dropped them off. At camp, Elizabeth made HUGE progress toward self-infusion and has successfully been infusing herself ever since. She made great friends and enjoyed the camp experience more than I ever dreamed she would. It was the kind of camp experience I often hear about from other families. I am so thankful that we were connected with Hope through the



Coalition. I am amazed by the difference this one week made in my daughter's life. She is more confident and independent because of camp and she made some great friends that understand where she is coming from as a girl with severe Hemophilia. Elizabeth can't wait to go back to camp next summer!

## A Daughter's Perspective

Camp this year for me was an experience that I will never forget! As usual for myself, I was rather skeptical on going someplace new where I knew no one. From the moment that I got to Camp Little Oak, though, I had a feeling that it would be a truly amazing experience. From doing the typical campy things like arts and crafts, pulling pranks on the other cabins, and having a movie night, I made some milestones when it came to self-infusing! Trying new veins, and talking to other girls who have to infuse was a great way for me to branch out and be more confident in my own infusions. I made so many great friends that week and I can't wait to go back next year! 🍓

Eric Lowe  
with his father



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Eric Lowe had the support of his family when he went through double knee replacement surgery.

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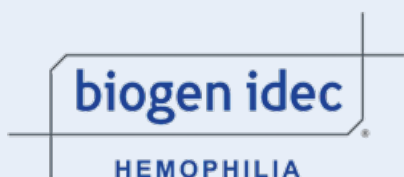
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## *Industry News*



### **Biogen Idec Reports Positive Results in the Phase III Study of their Longer-Lasting Factor IX Product**

Biogen Idec and their partner Swedish Orphan Biovitrum have announced positive results in a Phase III clinical study of their longer-lasting recombinant factor IX product, which is under development. The product, currently termed rFIXFc, is a recombinant factor IX molecule linked to the Fc portion of an immunoglobulin (antibody) molecule. The Fc portion of the new molecule gives the product a much longer lifetime in the blood stream. Use of rFIXFc is expected to allow hemophilia B patients on prophylaxis to significantly increase the length of time between infusions. Biogen expects to submit their U.S. license application for rFIXFc during the first half of 2013.

The study, called B-Long, included 123 male hemophilia B patients and looked at prophylaxis with infusions either once a week or individualized for each specific patient. It also looked at treatment of bleeding episodes and for use in surgery. rFIXFc was effective at preventing or reducing bleeding in all parts of the study. The median time between infusions for individualized dosing at the end of the study was 14 days. This suggests that many patients may be able to achieve effective prophylaxis with doses only once every two weeks.



### **Novo Nordisk Discontinues Development of a New Modified Factor VIIa Product for Treatment of Hemophilia Patients with Inhibitors**

Novo Nordisk, manufacturer of NovoSeven®, a recombinant activated factor VII (FVIIa) product for treatment of hemophilia A and B patients with inhibitors, has been developing a modified FVIIa product with the generic name vatreptacog alfa. Using genetic engineering, Novo had made some small changes in the molecular structure of the normal factor VII molecule that appeared to increase its activity. However, during a Phase III clinical study, some patients were observed to produce antibodies against the modified molecule. The antibodies have the potential to reduce the effectiveness of the new product and could also potentially cross-react with NovoSeven®. Patients have not previously been observed to produce antibodies against NovoSeven®. Because of the potentially serious consequences of this finding, Novo has decided to discontinue development of vatreptacog alfa.

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## New Publication from the World Federation of Hemophilia

The World Federation of Hemophilia has recently published an updated revision of their guidelines on hemophilia treatment in the journal *Haemophilia*. The guidelines are intended for healthcare providers, but also contain valuable information for patients with hemophilia. Patients may also want to give a copy to their physicians who are less familiar with hemophilia. A free copy can be obtained on the WFH web site at [www.wfh.org](http://www.wfh.org). Scroll down to the box labeled Recent Publications and click on Guidelines for the Management of Hemophilia, 2nd edition. The document can be printed or downloaded as a pdf file.

Note that the same box on the WFH web page also lists a new WFH publication on Carriers and Women with Hemophilia. Recognition that there are a significant number of females with hemophilia appears to be increasing.



## Inspiration Biopharmaceuticals' Factor IX Product Placed on Clinical Hold

Inspiration Biopharmaceuticals is developing a new recombinant factor IX concentrate for treatment of hemophilia B. The product, called IB1001 while it is still in development, would be a direct competitor of BeneFIX, currently the only recombinant factor IX product available in the U.S. market. Inspiration has already applied for licensure both the U.S. and Europe while continuing its Phase III clinical studies. IB1001 has so far showed good safety and efficacy in prevention and treatment of bleeding episodes.

However, more detailed analysis of the clinical data has shown that some patients treated with IB1001 have developed antibodies against proteins derived from the Chinese hamster ovary (CHO) cells used to manufacture the product. Because of this, the FDA and Inspiration have placed a hold on the clinical studies suspending further treatment until the issue can be resolved. Inspiration has also informed all of the non-U.S. regulatory bodies overseeing IB1001 clinical studies.

Fortunately, the antibodies do not appear to have produced any adverse reactions in the study patients or led to development of inhibitors against factor IX. Inspiration is currently investigating the issue and closely following the study subjects to make sure they do not experience any untoward reactions from the antibodies.

Many recombinant products, including BeneFIX, are produced in CHO cells and all face the challenge of removing any extraneous proteins produced by the cells. Usually, the process used to purify a product after it is made by the cells removes any contaminating proteins to low enough levels to prevent significant antibody formation in patients.

No additional information on the issue is currently available from Inspiration, but the solution could be as simple as tweaking the purification process to further reduce the amounts of CHO proteins in the product. The solution could also be more complex, but in either case it will take time to resolve. Additional pre-clinical testing will probably be needed before Inspiration and FDA feel confident enough to resume the study in humans. As in any clinical study, the safety of the study participants is always the foremost concern.

The Alliance looks forward to sponsoring the CSO luncheon at the upcoming annual meeting. The luncheon is one of the ways the now 90 hemophilia treatment centers who make up the Alliance membership are devoted to supporting your efforts. The Alliance Foundation, which receives 100% of its funding from the Alliance, is entering its fifth year of providing funding to help you build the critical infrastructure you need to sustain your organization. The dates for submitting grants will be mid-February to April 15th. If you are unsure about whether you are on the email list please drop me a note. We look forward to seeing you at the luncheon.



# THE HEMOPHILIA ALLIANCE FOUNDATION

June 28, 2012

Press Release

For Immediate Release

## Committee Members

Joyce Strazzabosco, Chair

The Hemophilia Alliance Foundation, building on a grant program started in 2009, has completed its 2012 grant cycle. Jeff Blake, chair of the Hemophilia Alliance, is pleased with the tremendous response to the 2012 grant cycle. “The Hemophilia Alliance has a vision to reinvest monies into the hemophilia community earned through the purchasing power of the HTCs. The result of this vision has been a unique series of partnerships with the hemophilia community. The success of the Foundation has been remarkable.”

Geoffrey Allen, M.D.

The vision is funded through administrative fees — dollars paid to the Hemophilia Alliance and their collaborative partner Apexus, the HRSA prime vendor, from the manufacturers who have contracted with the Alliance and Apexus.

Susan Karp, RN

The Hemophilia Alliance promised the hemophilia community in 2006 that it would reinvest these dollars into the community. Joe Pugliese, president of the Hemophilia Alliance, notes, “Our goal has always been to maintain a foundation made up of representatives from all parts of the hemophilia community. The foundation has focused its efforts on helping recipients build the capacity of their organizations. It is clear that this is an unmet need throughout the community. We have, through the end of the 2012 grant cycle, given back more than \$1.4 million to the hemophilia community.”

Michelle Rice

Mary Anne Schall

Joyce Strazzabosco is chair of the Foundation committee. Joyce notes that interest in the grant program continues to grow. “We are pleased with the interest shown from all parts of the community, and the thoughtfulness of the requests. We are also acutely aware of the tremendous need for ongoing support in the community. It is particularly satisfying to support chapters, HTCs and all of the federally funded regions.”

Chad Stevens

Crystal Sallens, MSW

*The Alliance will announce the 2013 grant cycle in January of 2013.*

\*The Alliance is a not-for-profit organization that currently is comprised of 91 hemophilia treatment centers. The purpose of the Alliance is to assist its members in providing outstanding care for their patients. Its mission is to provide member hemophilia treatment centers with resources and services to sustain the comprehensive care model for individuals with bleeding and clotting disorders. For more information about the Alliance and how you can help further our mission, visit it at [www.hemoalliance.org](http://www.hemoalliance.org) or email [info@hemoalliance.org](mailto:info@hemoalliance.org)



# Factor Nine Holiday Fund 2012!

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 3, 2012* 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 3, 2012.**

(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:

\_\_\_\_\_  
\_\_\_\_\_  
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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!***

We are delighted to present  
**The Coalition for Hemophilia B Factor Nine  
Family Breakfast Meeting!**  
**Saturday, November 10th, 2012 8:00 – 10:00 am**



In conjunction with the National Hemophilia Foundation Conference  
Washington Room; Orlando World Center Marriott Resort  
8701 World Center Drive, Orlando, Florida  
Agenda Details will follow shortly!

### **Hemophilia B Forum to**

**Discuss Current Topics • Share and Support • Meet New Families • Special Raffle Drawing!**

### **WE LOOK FORWARD TO SEEING YOU!**

Pre-registration is appreciated on our website [www.coalitionforhemophiliab.org](http://www.coalitionforhemophiliab.org)  
For more information please contact Kim 917-582-9077

**The 2013 William N. Drohan Scholarship application is now available on our website.  
Please visit [www.thecoalitionforhemophiliab.org](http://www.thecoalitionforhemophiliab.org) to apply. The deadline is March 5, 2013.**

## ***More Dates to Save!***



**6th Annual Fundraising Dinner**  
**Friday, March 22, 2013**  
Waters Edge Restaurant  
401 44th Drive  
Long Island City, New York

### **The Coalition for Hemophilia B**

**7th Annual New York Symposium**  
**Saturday, March 23, 2013**  
Grand Hyatt New York Hotel  
109 East 42nd Street; Park Avenue  
New York, New York 10017

**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](mailto:hemob@ix.netcom.com) Website: [www.coalitionforhemophiliab.org](http://www.coalitionforhemophiliab.org)