

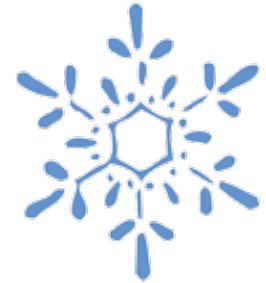


Factor Nine News

The Coalition for Hemophilia B Winter 2013

Topics in Hemophilia

- WFH 50th Anniversary
- Genotyping
- Our Community's Musical Talent
- Advocating for School-Aged Children
- 6 Ways to Beat Bleeds
- Industry News
- Scholarship News
- First Annual Men's Retreat
- Save the Date!



The Coalition for Hemophilia B
Applauds our Community's

MUSICAL TALENT



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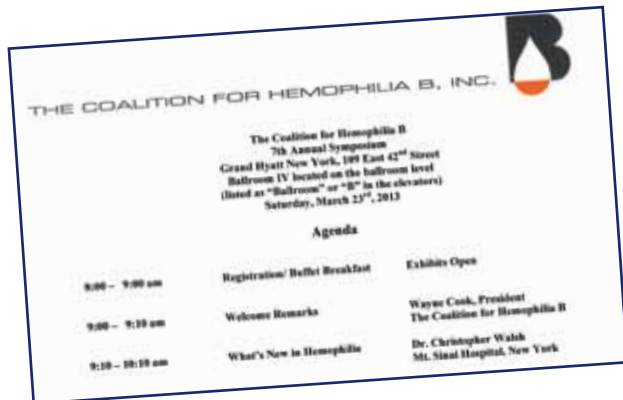
The Coalition for Hemophilia B



6th Annual Fundraising Dinner

Friday, March 22, 2013

Waters Edge Restaurant
401 44th Drive
Long Island City, New York



7th Annual New York Symposium Saturday, March 23, 2013

Grand Hyatt New York Hotel
109 East 42nd Street
New York, New York

For more information, please call or email:

Kim Phelan
Telephone (212) 520-8272
E-mail: hemob@ix.netcom.com

Register online at www.coalitionforhemophiliab.org



WFH launches 50th Anniversary

For 50 years, the WFH has been working globally to close the gap in care and to achieve treatment for all people, both men and women, with hemophilia and other inherited bleeding disorders, regardless of where they might live. As the WFH marks its 50th anniversary, we are reflecting on our many accomplishments, milestones, and lessons learned. Activities are planned through 2013 – our anniversary year – and on until the WFH 2014 World Congress in Melbourne, Australia.

Sign up at www.wfh.org/en/sslpage.aspx?pid=460&tab=1 to receive information about our 50th anniversary activities and Close the Gap campaign. In spite of the tremendous progress made over the last 50 years, the vast majority of people with bleeding disorders living in developing countries do not have access to proper care. The WFH continues to work to close the gap in care so proper treatment will be available for all around the world. As part of our 50th anniversary, we have launched the *Close the Gap* campaign.



The details can be viewed at www.wfh.org/en/page.aspx?pid=1391.

WFH 50th Anniversary Videos

Videos in this series will be released every six weeks through 2013. The Close the Gap videos series highlights key moments, programs, and people in the World Federation of Hemophilia's (WFH) 50-year history. These videos are available with Spanish or French subtitles. To view the videos, please visit: www.wfh.org.

Volunteering Brings Change

The video Volunteering Brings Change is dedicated to the remarkable people who donate generously their time, expertise, and energy to the WFH and its national member organizations.

Progressing Care Globally

Watch Progressing Care Globally and learn how China experienced rapid improvements in care after participating in the WFH's GAP Program.

Changing Lives Through Twinning

The sharing of knowledge and expertise is the greatest gift of twinning. In the video Changing Lives Through Twinning, Yuri Zhulyov and Paula Bolton-Maggs, MD, reflect on their involvement with the WFH Twinning Program.

The Winning Coalition

Dr. Assad Haffar narrates The Winning Coalition, a 20-minute film highlighting the establishment of a national care system for people with bleeding disorders in Senegal, through the work of local doctors, patients, governments, and international volunteers.

Close the Gap

This short video highlights the differences between children who have received care for their bleeding disorder and those who suffer without care.

Genotyping

At the November Annual Meeting, the National Hemophilia Foundation (NHF) announced a new program to offer free genetic testing or genotyping to people with hemophilia and their families. The program is jointly sponsored by NHF, the American Thrombosis and Hemostasis Network (ATHN), the Puget Sound Blood Center (PSBC) and Biogen Idec. The service will be provided through local hemophilia treatment centers (HTCs) with the actual testing performed by PSBC. ATHN will collect and maintain the data.

Hemophilia is caused by a mutation or mistake in a gene that encodes one of the proteins involved in clotting, a mutation in the factor VIII gene for hemophilia A or in the factor IX gene for hemophilia B. The mutation causes the body to make defective clotting proteins, or in some cases no protein at all. Not all people with hemophilia have the same mutation. Genetic testing identifies the mutation, by determining the sequence of the gene.

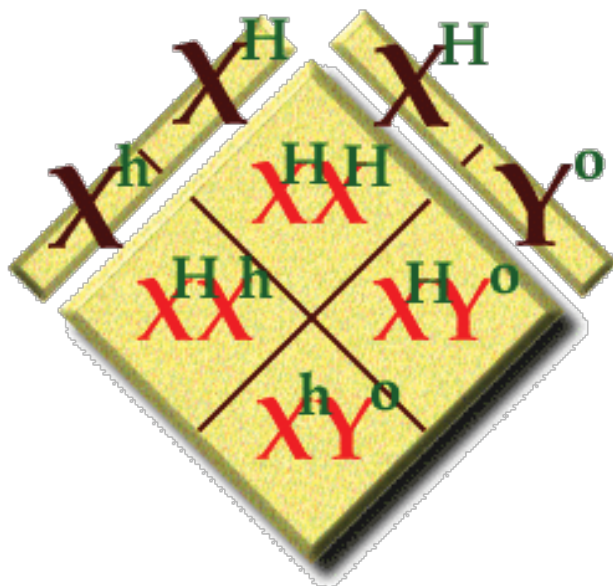
A gene is made up of a long string of chemical units, which are like letters in a word. The sequence

of the units spells out a recipe that tells a cell how to make a specific protein. Genetic testing reads the sequence to see what recipe it spells out. The sequence is called a genotype. Hemophilia genotypes have mutations or misspellings, so they make factor VIII or factor IX proteins that are defective. In cases of large misspellings or mutations they may not make any protein at all. Medical science is now at the point where we might be able to learn something from the misspellings.

Today, we categorize hemophilia as mild, moderate or severe, but within those categories there may be hundreds of different mutations. People with the same mutation don't always have the same severity of disease. In most cases, we don't know why. Except for a few specific mutations, little is known about the connection between the mutation and the characteristics of the disease. This is especially true for hemophilia B, which hasn't been studied as thoroughly because of its relatively small number of patients compared to hemophilia A.

Genetic testing is not new, although its use in the past has been limited by cost and inefficient testing methods. Most people with hemophilia in Europe and other developed countries have been genotyped with the cost covered by their national health plans. However, in the U.S. where most people have to depend on insurance coverage only about 20% of hemophilia patients have been genotyped. Newer testing methods are more efficient and less expensive, which has made this program feasible.

There are two primary goals for the program. One is to benefit the individual by helping their physician better tailor their treatment. In hemophilia B, for instance, it is known that people with major gene defects who produce no factor IX are at a higher risk for inhibitor formation. Other potential uses are to predict bleeding severity and for carrier detection and prenatal diagnosis. Carrier detection is much



simpler if you already know what mutation runs in the family.

The other goal is to provide data that researchers can use to better understand the disease and potentially devise improved treatments. ATHN already has a large database of clinical and demographic information on hemophilia patients. Coupling that with information on specific gene defects may produce new insights into the characteristics of the disease. Samples of each person's blood will also be stored for use in future research.

One recent study, for instance, used some of the European data to see if there are connections between certain mutations and the severity of bleeding. They found the connections, but, they also uncovered something unexpected. They discovered that some mutations lead to instability in the RNA molecules that the cell uses to manufacture factor IX. Those instabilities potentially reduce the amount of factor IX made by the cell, so not only is the cell making defective factor IX, but it's making less of it. That's a relatively new idea. Many defective factor IX molecules still have clotting activity, but if there aren't enough of them, the blood still won't clot.

So what's the catch? You mean I can help myself and the hemophilia community and someone else will pay for it? What about privacy? Can't they use my genetic information to discriminate against me? What does Biogen get out of this?

Actually, there doesn't appear to be a catch, but we should all be cautious and make up our own minds about whether to participate. Medically, there is little risk. It only takes a small blood sample. In terms of privacy, this is considered a clinical test and is covered by the privacy provisions of HIPPA, just like much of your other medical information. You own your information and can control who has access to it. Also, each HTC has an Institutional Review Board (IRB) that exists solely to protect patients. The IRB has to approve the program

before the HTC can participate.

Your data is only identified by a code number with nothing to identify the individual patient. Only you and your HTC will know your individual code. Insurance companies will not have access to your information. In fact, you can also decline to participate in the research part of the program and still get tested for your own benefit.

Discrimination is a real issue that we could all face as more and more of our genetic information becomes available. In this program they are only sequencing your factor IX gene. They already know you have hemophilia, so there doesn't seem to be any additional risk there. They do have your stored blood sample that could be tested further for future research, but they won't know it's yours.

Biogen, like all of the manufacturers, spends a lot to help their patients. They believe that creating good will is good business. Fortunately, they have chosen to support this program. Biogen will have no special access to the information, and anyone who wants to use the data for research has to present a proposal to a project review committee for approval first.

In the beginning, the program will only be available to people with hemophilia A or B. Later on, it will probably be extended to their family members (for instance for carrier detection) and possibly to patients with other bleeding disorders. The first stage is a pilot project starting in the first quarter of 2013 in seven HTCs. It will be expanded nationwide to all HTCs beginning in the second quarter of 2013.

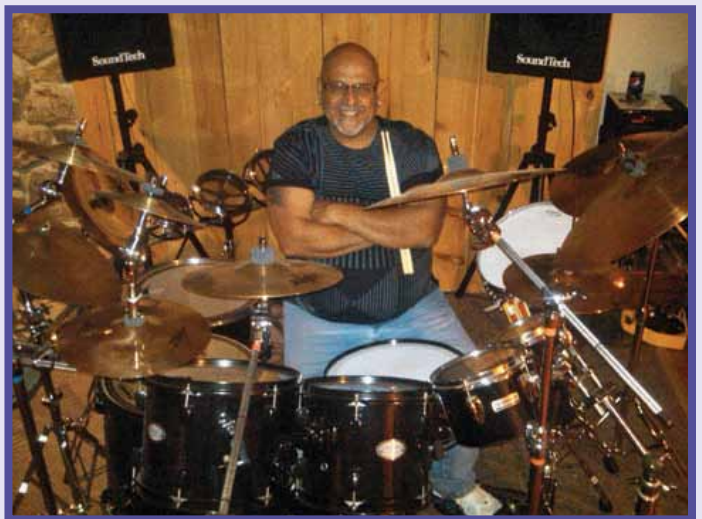
Science has made huge advances in the last few decades using genetic technology. The hemophilia community has benefitted from improvements in treatment such as recombinant clotting factors and the potential for gene therapy. This new program will add the possibility of better understanding the disease itself. 🐾

The Coalition for Hemophilia B Applauds our Community's

MUSICAL TALENT

Wayne Cook - Drums

I started playing drums when I was quite young. When I got into my teens and early twenty's, I started playing in various bands in upstate New York and also in Florida. I gave up playing to raise my family, but I always tried to practice when I could. About two years ago, I started playing seriously again. Recently, I have done some recording work at some local recording studios with a couple of different artists, and have also started playing again with a few different groups. I love to play as it is so good for all of my joints as it keeps me limber and strong in my joints. As I have gotten older though I have lost a little, but each time I play a little more comes back to me.



Spencer Duggan - Guitar

My passion for music began when I was 16; in fact, it happened at my birthday party. I never fit into the sports scene, so when my friends encouraged me to play my hand-me-down bass guitar, my fervor began. As I grew, my passion grew and my experiences widened, I began playing guitar, mandolin, and refined my singing before eventually going to college as a music education major emphasizing voice. After graduating, I formed a band playing guitar and singing with my girlfriend, Iliana, playing viola and singing. We call ourselves Iliandi.

We won an opportunity to open for the Chicago-based band Company of Thieves. They are going on an intimate, acoustic tour that stopped at Jammin' Java in Vienna. Iliandi beat out fifteen other contestants in a bracket tournament to take the stage as the opening act for this open-mic style concert.



Phil Hardt - Piano



When I was taken out of sports in 5th grade because of “bleeding” too much, my mom and older sisters began taking me to choirs and other musical events that featured someone playing the piano. They wanted me to see how popular the man at the piano was! I soon began taking piano lessons and excelled. Little did I know that playing the piano would become a solace to me during long bleeding episodes when I could not sleep at night. I would wake up in the middle of the night and play for hours on end. It brought me happiness and an outlet to express myself and recoup when I needed to. Unlike the sports I had to give up, I am still enjoying playing the piano and singing every day! It was really a blessing in my life.

Nat and Sam Lathrop

Nat Lathrop is a 14 year-old freshman in high school and has severe hemophilia B. He started taking private guitar lessons when he was 8 years old and continues to improve. He played saxophone and euphonium in his elementary school band because they didn’t have room for a rock and roll guitar player! He’s also played in his school’s jazz ensemble is always looking for friends to jam with. His musical taste is quite eclectic...he plays everything from punk rock to jazz.

Sam Lathrop also has severe hemophilia B and is 16 and a junior in high school. He’s been a drumming since he was in second grade. Sam has been active in his school’s band program for more than 8 years. He’s participated in concert band and jazz band as well as jamming with fellow musicians and friends. Sam’s also very active in his high school’s drumline and looking forward to his senior year and being Center Snare for the Marching Raiders.

Music has played a vital role in both Sam and Nat’s lives; they practice daily and think that music has been an important part of staying healthy. As a family, Sam and Nat play together when their parents force them to... which isn’t often enough!





Eric Lee - Drums

From a very young age, I have been involved in choirs, plays and musicals. In high school, I was involved in both choirs, ranked twice at all-region choral competitions, performed in several school musicals where I played significant male roles. During my junior year, I discovered a talent for playing drums and walking on our high school drumline as a tenor drum player the following year. I continued my vocal career as a member of the Arkansas State University choir which I was a part of for two years until scheduling conflicted with other classes for my major. I still continue learning to play the drums with the faculty here on campus and play in a local band with friends. I still have a lot to learn, but I make it a point to play at my best whenever asked.



Michael O'Connor - Composer, Writer

In addition to being a competitive swimmer during his four years at Amherst College, as his senior thesis, Michael Connor wrote an opera called "Royal Blood" about the Romanov empire. (He majored in both music and geology). Mike wrote both the music and the script, and staged the production at Amherst in March 2012. He hopes to get the chance to work on the opera again. Until then, he continues to compose music and enjoys living in the live music capital of the world - Austin, Texas - while he completes his masters in Hydrogeology at the University of Texas. Mike has Severe Hemophilia B.

When he is back home in New York, Mike occasionally plays back-up keyboards for his sister, Meredith O'Connor. Songwriting runs in the family, as Meredith is releasing her first EP of original country-pop music. Check out her EP, Meredith O'Connor, soon to be available on iTunes, and look for her on youTube (Meredithter). She is particularly proud of her song "The Game," which is an anti-bullying ballad. She performs live at various venues in New York City.





Will McCarthy - Cello

My name is Will McCarthy, I am eleven years-old. When I was nine, my mom's friend (the director of the Young Artists Debut Orchestra) asked us to come see the concert. Her friend Jessie asked if I would be interested in learning a classical instrument and thought it would be pretty cool.

I have performed in concerts, baseball games and also at my school. I like the cello because its challenging and I like playing with the group in the orchestra... everyone playing a different part to make it one song!

Elizabeth VanSant - Piano

Elizabeth has been playing the piano since she was barely able to reach the keys. As a baby, plunking out a "tune" always brought a smile to her face - even a shiner caused by the piano bench didn't diminish her love for the instrument.

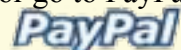
She started taking lessons early in elementary school and has been filling our home with beautiful music ever since.

Elizabeth plays piano for church and school, but mainly for herself. Playing helps soothe any nerves or anxiety she may be feeling and it is a great way to pump up her veins prior to an infusion! Elizabeth's love for music has inspired her to consider a career in music therapy and music education.



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!!!**

Advocating for Your School-Aged Children

By Ruthlyn Noel, MPA
Senior Manager of Public Policy at
the National Hemophilia Foundation

On the National Hemophilia Foundation's (NHF) Steps for Living Web site, there are resources to help families navigate the process of protecting children with bleeding disorders in the school setting. Examples include information on setting up IEPs and 504 Plans, as well as suitable sports and after-school activities for youngsters.



Setting up IEPs and 504 Plans are just the beginning. We often encourage families to get involved by sharing their stories with elected officials. Another way for parents and guardians to get involved and make a difference is through school-based advocacy. Below are some tools to help you effectively engage school officials:

- **Educate yourself about bleeding disorders so you can educate others.** The more you know about your child’s bleeding disorder and current treatment options, the better. Remember that when dealing with the staff at your child’s school, most may never have heard of hemophilia or von Willebrand disease. If you (the parent/guardian) can’t explain your child’s medical condition and needs clearly, your child may not receive the accommodations he or she needs to succeed educationally and socially.
- **Know how decisions are made in your local school district.** Each school district has its own way of doing business. You need to know how decisions are made in your district and by whom. You can often get this information by attending a PTA or school board meeting, or calling the district office. Once you know the decision-makers, offer to help coordinate meetings for the child’s medical team to talk with school officials. That can help speed up the time it takes to get a resolution on IEPs and 504 Plans.
- **Know your rights and responsibilities under the law.** You need to know the law and how it affects your child. The Individualized Education Program, or IEP, is federal authority granted under Part B of the Individuals with Disabilities Education Act (IDEA), which ensures a “free, appropriate, public education” (FAPE) for all children. When it comes to IEPs, educators, medical professional and parents should work together to assess a child’s needs and develop an “individualized” plan outlining what special education support and services that child will receive. Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA), both federal civil rights laws, prohibit discrimination against people with disabilities. The 504 Plan ensures certain reasonable accommodations are made for disabled students, but does not require that an “individualized” education program be set up for qualified students.
- **Be realistic.** What you may consider “appropriate” may not be deemed so under the law. And, budget cuts (federal, state and local) could affect the range of programs and services a school district makes available to your child. Understanding the laws mentioned above can help ensure that agreements reached when developing IEPs and 504 Plans are satisfactory for everyone involved.
- **Help your child succeed.** Studies have shown that children do better in school when parents are actively involved in their education. To ensure your child is getting the best education, learn how to interpret and use test scores to monitor your child’s progress. Blaming educators for your child’s failure won’t improve performance. Instead, propose appropriate solutions that you, your child and his or her educators could work on to help promote long-term progress. You can also help your child by attending parent-teacher conferences or volunteering at school events.
- **Get smart about keeping records.** Keep detailed written records of all encounters with school and district officials. Memories can fail you. Write things down when they happen and be specific.
- **Lend your voice to the cause.** You are your child’s #1 advocate. Speak up where it matters – your child’s education and well-being are too important for you to remain silent. Become a member of the PTA or school board. Join other parents in educating elected officials and their staff at events organized by national and state education and disability advocates. 🗣️

Additional Resources:

- Building the Legacy: IDEA 2004: <http://idea.ed.gov/>
- U.S. Dept of Education, Office for Civil Rights – Protecting Students with Disabilities: <http://www2.ed.gov/about/offices/list/ocr/504faq.html>
- Parent Technical Assistance Center Network: <http://www.parentcenternetwork.org/>
- National Parent Teacher Association: <http://www.pta.org/>
- National Hemophilia Foundation Steps for Living program: <http://www.stepsforliving.hemophilia.org/>

Six Ways to

BEAT BLEEDS

What's your first reaction when you experience a bleed? Some people with hemophilia B have little or no reaction – they've become so accustomed to pain, swelling and stiffness that bleeding is now “just part of life.” But by working with your hemophilia clinician on a comprehensive treatment plan, and by using today's therapies, you can beat bleeds.

Whether your reactions to a bleed and your long-term goals are to address pain associated with bleeds, stay active, or be there with your family, it's never too late to start taking charge of your health.

There are a number of options available for managing and reducing bleeds. You should partner with your Hemophilia Treatment Center (HTC) to find the treatment plan, including a personalized dosing schedule, that works for you.

Here are some tips that you can think about and discuss with your hemophilia clinician:

BEAT BLEEDS TIP #1: KNOW YOUR ABR

The first thing you can do to reduce or prevent bleeds is to know your annual bleed rate (ABR), which is the number of times you bleed in a year. It's an important number – like knowing your weight, blood pressure, cholesterol or blood sugar levels. Work with your HTC team to determine your goal.

BEAT BLEEDS TIP #2: TRACK YOUR BLEEDS

Know how often you are bleeding. Begin by tracking your bleeds for a month, capturing the date, location and type (joint, muscle, other) of each bleed you experience. Keep in mind the common signs of a joint bleed: tingling, pain, stiffness, heat, and swelling. Be aware of common signs of a muscle bleed: pain, stiffness, warmth, swelling, tightness of skin, redness, and numbness (this is a late sign).

Notice if your pain from bleeds has become worse

over time, and if so, how. Record how often in a month you have had to miss school, work, or other activities because of bleeds.

BEAT BLEEDS TIP #3: SET YOUR GOALS

Many people want zero bleeds. How many fewer bleeds do you want to have? What motivators might help you achieve your goals? What obstacles might get in the way of achieving your goals? Talk with your hemophilia clinician to set appropriate and realistic goals for you.

BEAT BLEEDS TIP #4: MAKE YOUR PLAN

To beat bleeds, you need a plan. Work with your HTC to create a treatment regimen that will help you accomplish your goals. Your plan will also focus on overall health. Keeping your joints and muscles strong now and in the future can be critical to help prevent bleeds. Exercise and eating well are key to staying strong and reducing stress on joints by maintaining a healthy weight.

A good plan helps you take charge, reduce bleeds, and minimize pain associated with bleeding. A great plan will help you do it in a way that works with your life. The key is to create a routine you can stick with over the long term. That way, it's easier for you to realize the

benefits of reducing bleeds. Be sure to talk with your HTC about your overall health needs and goals.

BEAT BLEEDS TIP #5: TRACK YOUR PROGRESS

On paper, a computer or smartphone, create a simple tracking system that works for you. Record things like infusions, weight, bleeds (remember the info in Tip #2), and successes. While you're tracking your progress, also note your patterns. What do you need to do to achieve your goals? What barriers are in the way? Every month, take a look at your data and take pride in your progress!

BEAT BLEEDS TIP #6: START TODAY!

Don't wait – put these tips into practice now to better manage your hemophilia, your health, or other areas of your life. By knowing the facts, setting goals, working with your HTC and making good choices, you can minimize the impact of bleeds on your life.

Go to thereforyou.com and sign up to receive a tool to track your annual bleed rate. Prefer to go paperless? Get the Beat Bleeds smartphone app to track your bleeds, and monitor your progress toward reaching your ABR goal.





Quality



Innovation



Safety



Life



Therapies



Patients



At CSL Behring

Innovation leads the way

Committed to making a difference in patients' lives

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

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

CSL Behring

Biotherapies for Life™

Industry News



Baxter recently announced positive results in their Phase 3 clinical study of a new recombinant factor IX product. The new product, code named BAX 326, was well tolerated with no evidence of inhibitor formation or anaphylaxis. They will probably submit a Biologics License Application (BLA) to FDA in the near future.



Biogen Idec submitted a BLA in January for their new recombinant factor IX-Fc fusion product (FIX-Fc). If approved, this will be the first longer-acting factor IX product to reach the market. FIX-Fc lasts significantly longer in the blood stream, which decreases the frequency of infusions for prophylactic treatment. The Phase 3 clinical study supporting their license application showed that infusions every one to two weeks provide good protection from bleeding. The product was well tolerated in the study with no evidence of inhibitor formation.



CSL Behring has announced that the first patient has been enrolled in their pediatric Phase 3 study of a recombinant factor IX-albumin fusion product FIX-FP. This is another longer-acting product that will potentially decrease the frequency of prophylactic infusions. In a related Phase 1 study, FIX-FP showed a 5.3 times longer lifetime in circulation than the conventional recombinant factor IX product used for comparison.



Grifols recently performed a study showing that the Alphanine® manufacturing process is effective in removing prions from the product. Prions are small proteins that are the apparent cause of a group of fatal diseases called transmissible spongiform encephalopathies (TSEs) including variant CJD (vCJD). The study shows that the purification process for Alphanine® product can remove significant amounts of prion infectivity, much more than would ever be found in the plasma pools used to produce the product.



Inspiration Biopharmaceuticals has announced the sale of OBI-1, its recombinant porcine factor VIII product for treatment of hemophilia A patients with inhibitors, which is currently under development. The development program was purchased by Baxter International who will have worldwide rights to the product. Inspiration is also in the final bidding stages for sale of their IB1001 recombinant factor IX development program. This is part of the settlement involved in Inspiration's Chapter 11 bankruptcy filing last fall.



Cangene Corporation of Winnipeg, Canada has agreed to acquire IB1001, Inspiration Pharmaceutical's recombinant factor IX product that is currently under development. Inspiration filed for bankruptcy late last year and is divesting its assets. Clinical studies for IB1001 are currently on hold in the U.S. because some patients developed antibodies against proteins from the CHO cells used to produce the product. Cangene will address that problem, continuing development of IB1001, which has license applications pending in both the U.S. and Europe. Cangene is one of Canada's oldest and largest biopharmaceutical companies and has several plasma-derived immune globulin products licensed in the U.S.

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.

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

Manufactured by Wyeth Pharmaceuticals Inc.
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Marketed by Pfizer Inc.
December 2012



Distinctly you



You share similarities, yet you're all very different from one another

At Baxter, we're focused on responding to your individual needs and those of the hemophilia B community. We continue to invest in research and development for the promise of tomorrow's breakthroughs.

- **We're committed** to advancing education and resources available to you
- **We're dedicated** to helping provide you with a higher level of support
- **We're devoted** to helping you build a strong hemophilia B community

Recognizing the differences

Connect with a world of hemophilia B resources at **DistinctlyB.com**

Scholarship News

Biogen Idec Hemophilia Scholarship Program



Amount of Awards – In our first year (2012), we awarded a total of \$50,000 divided among 11 deserving people with hemophilia, ranging from 17 to 51 years of age with diverse educational goals. We are honored to continue our support of the community’s dreams in 2013 as we plan once again to donate a total of \$50,000 to multiple winners, with individual awards ranging from \$2,500 - \$7,000.

Who can apply – Individuals with hemophilia A or B who are pursuing a vocational or technical certificate, a 2 or 4 year degree program or graduate degree are encouraged to apply.

How to apply? Starting February 14, a “2013 Scholarship Program” button will appear on our Biogen Idec Hemophilia scholarship page. This button will bring you to the scholarship application. We look forward to seeing your application!

Deadline – Our scholarship program opens on February 14, 2013 and all applications are due by midnight on June 15, 2013.

Website: www.biogenidechemophilia.com/scholarships

Current 2012 winners’ profiles are featured on our website! We encourage you to check out our 11 winners by clicking on the “2012 Winners” button to see these incredible stories and their accomplishments.

Contact Larissa Busby, 781-464-4266 or larissa.busby@biogenidec.com for more details.

Pfizer Soozie Courter Hemophilia Scholarship Program

The Soozie Courter Scholarship Program is part of Pfizer’s ongoing commitment to support patients, parents and advocates while providing care for people diagnosed with hemophilia. This program awards scholarships to students with hemophilia A or hemophilia B who are US residents attending school in the United States. Scholarship winners are selected based on a combination of academic achievement, letters of recommendation and personal essay. The program is open to high school seniors, students who have completed high school or an equivalent program (eg, general equivalency diploma [GED]), and students enrolled in an accredited college or university at the undergraduate or graduate level.



Applications can be downloaded from:

<http://www.hemophiliavillage.com/resources-support/scholarship-assistance.aspx>
or by calling our hotline at 1-888-999-2349 between 9 AM and 5 PM ET.

The application must be postmarked or received through e-mail to the program administrator, QD Healthcare Group, no later than May 24, 2013. Winners will be announced in July 2013.

Packaged with Mix2Vial® Filter Transfer Set



Available in the following potencies and color coded assay ranges

Potency	Diluent Size
500 IU FIX Range	10 mL
1000 IU FIX Range	10 mL
1500 IU FIX Range	10 mL



For more information: Grifols Inc.
Customer Service: 888 325 6579 Fax: 323 441 7968

A003-0911

1st Annual Men's Retreat!

For Men with Hemophilia B

Age 35 and over

March 8-10 2013

Carefree Resort & Conference Center

Carefree, Arizona



Tucked in the scenic foothills of the Sonoran Desert for 50 years in Arizona is Carefree Resort Conference Center! One of the Valley's most venerated and charming resorts. Playing hosts to some of Hollywood's brightest! The Carefree Inn – as it was known then – was a favorite retreat for the likes of Dick Van Dyke, Lucille Ball and Bob Hope.

Today this legendary resort retains much of the small-town hospitality and unique frontier heritage that guests have come to cherish. With beautiful panoramic views of the mountains and adobe-style fireplaces this is the perfect retreat for men to get together, connect and learn. This is a desert destination that has been hosting successful meetings for over 50 years with flawless execution, relaxed style and uncompromising attention to details.

We have been carefully planning the weekend and I am sure you will be pleased with the agenda which includes talks by experts in the fields of pain management, depression, finance, physical therapy and so much more! We have wonderful meals planned and time to enjoy some rest and relaxation with your peers around an open fire or swimming in the pool.

For a chance to win an all-expense paid trip to the retreat, please fill out the form below and return it to us no later than February 12th, 2013. Lotto winners will be announced February 16, 2013.

1st Annual Men's Retreat - LOTTO DRAWING

Name: _____ Age: _____

Address: _____ Phone: _____

City/State: _____ Cell: _____

Zip: _____

Email: _____

Please mail, fax or email by **February 16, 2013** to:

Kim Phelan, The Coalition for Hemophilia B

825 Third Avenue, 2nd Floor

New York, NY 10022

Fax: (212) 520-8501

hemob@ix.netcom.com

Lotto Winners will be contacted on February 16, 2013!



**Created
BY
Men with Hemophilia B
FOR
Men with Hemophilia B**



biogen idec

HEMOPHILIA

WE'RE LAYING THE FOUNDATION FOR Deeper Connections

**We are Biogen Idec Hemophilia,
and we're developing long-lasting factors**

But that's only the beginning...

› **From the community. For the community**

Our CoRe Managers, hand-selected for their passion and dedication, are currently out in the community working to improve the lives of people with hemophilia

› **BiogenidecHemophilia.com**

Our latest resource for everything you need to know about us and our involvement in the community. Connect with our CoRe team, watch videos about Biogen Idec Hemophilia, and more!

› **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
Community Connections

Join our community today!

www.BiogenidecHemophilia.com/CommunityConnections

Save the Date!

an Innovative CHES Program

Because everyone deserves a camp to call their own.



Inhibitor Family Camp was specially designed to meet the needs and limitations of children with hemophilia and inhibitors. Immediate family members are also invited because we understand the value of having a tight-knit support unit behind these children. We'll play, learn, and grow while we build a stronger community.

To register, applicants must have an active inhibitor and fall between the ages of 6-18. If you're interested, please act now. Space is limited, and slots are filled on a first-come, first-served basis for those who qualify.

Date: Friday, April 19th thru Monday, the 22nd, 2013
Location: The Painted Turtle in Lake Hughes, California
Registration Deadline: Thursday, February 15th

Learn More at:
www.InhibitorFamilyCamp.org

Presented by



Supported by an educational grant from



"Thank you
for making
an amazing
memory that
will last for a lifetime."
-anonymous



Psst... Can't make this one? Check out our fall program online in October.

Hemophilia Federation of America Annual Symposium



April 25-27, 2013 Dallas, Texas

The Coalition for Hemophilia B Family Breakfast Meeting

In conjunction with the HFA Annual Symposium
The Coalition for Hemophilia B will host a Breakfast Meeting

Sunday - April 28, 2013, 7:30 - 9:00 am

We look forward to seeing you!

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



STAY TUNED!

Factor Nine Family Meetings On The Road
Beginning May through October, 2013

Details coming soon!



We want to give special thanks to our
Generous Factor Nine Santa Holiday Donors!



With your help we were able to provide gifts
for seventy-two children and also eleven coats,
eight pair of boots and six food baskets!



Thank You! Thank You! **THANK YOU!**



The 2013 William N. Drohan Scholarship application is now available on our website.
Please visit www.thecoalitionforhemophiliab.org to apply. The deadline is March 5, 2013.

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