



Factor Nine News

The Coalition for Hemophilia B Winter 2014



Topics in Hemophilia

- Jordie Scheiner (Hemophilia B) Signs Minor League Baseball Contract
- Survey Results
- Should Ice be Used to Treat a Joint Bleed?
- The Affordable Care Act
- Treatment News
- IBleed (created by Dan Bond)
- Save the Date!

Wooster School Alumnus Jordie Scheiner '09 Signs Minor League Baseball Contract with Lancaster Barnstormers

Jordie Scheiner '09 is among the most decorated baseball players to ever put on a Wooster School uniform. He earned All-League honors during all four years, he won the team's *Most Valuable Player* award in both his junior and senior years, and he was the recipient of the Alvah Jessup Outstanding Athlete Award at graduation.

Jordie was recruited to play baseball at Division III Colby-Sawyer College and it wasn't until his sophomore year that Jordie began his pitching career. He quickly became a fixture in Colby-Sawyer's rotation, which was ranked #1 in the nation for fewest walks allowed. While developing a variety of pitches, his area of focus was the knuckleball.



biogen idec

HEMOPHILIA

A life well lived is a life well championed

At Biogen Idec Hemophilia, we salute our champions:

Our nurses, who keep us strong.

Our family members, who stand behind us.

Our scientists, who research new therapies.

Our chapters, who bring us together.

Our advocates, who tirelessly serve.

Our community, who give our work purpose.

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 [/BiogenIdecHemophiliaCoRes](https://www.facebook.com/BiogenIdecHemophiliaCoRes)



During the summers of his sophomore and junior years, Jordie played for the Torrington Titans in the very competitive Future Collegiate Baseball League - a league comprised of mainly Division I and Division II players who were recruited from across the nation. Jordie's pitching garnered interest from several professional organizations, including the Los Angeles Dodgers and Cincinnati Reds, and he was invited to several training camps. In this same time period, Jordie met and worked out with some of the best major league pitchers in the game today, such as Tim Wakefield and R. A. Dickey.

Jordie returned to the Torrington Titans after graduating college, but this time as a coach. In mid-August, a few weeks after his coaching career began, Jordie was contacted by Butch Hobson, former third baseman and manager of the Boston Red Sox, who was coaching the minor league Lancaster Barnstormers. Coach Hobson invited Jordie to a bullpen session and inked him to a contract on the spot. To date, Jordie has pitched in one inning - he picked up his first strike out and his first broken bat

We are proud of Jordie's accomplishments and wish him continued success.

Former Colby-Sawyer Baseball Player Signs with Lancaster Barnstormers



Sawyer baseball pitcher Jordie Scheiner '13 (Redding, Conn.) has signed his first pro contract with the Lancaster Barnstormers of the Atlantic League.

Scheiner, who specializes in the knuckleball, will be coached by former Boston Red Sox player and Coach Butch Hobson.

"Jordie worked extremely hard to develop his knuckleball during his time here at CSC, said Colby-Sawyer baseball Head Coach Jim Broughton. "I am happy to see all his hard work has paid off.

Scheiner had a good career on the mound for Colby-Sawyer. In 2012, he was one of five Chargers to have a sub 4.00 ERA at 3.86. He surrendered just one walk in 25.2 innings, helping the pitching staff lead the nation in fewest walks per nine innings at 2.14. In his senior season, he tossed a career-high four complete games, which included a four-hit shutout.

Scheiner is the latest Charger to sign a deal with a club since former standout Chris Hartery '10 signed with the Las Cruces Vaqueros of the Pecos League in spring of 2012.

NEW LONDON, N.H. – September 4, 2014

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 address to donate hemob@ix.netcom.com.

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



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



The Coalition for Hemophilia B

2012-2013 Survey Results

Product

BeneFIX – 82%
Mononine – 10%
Alphanine – 7%
Other – 1%

Age of Patient

1-12 – 40%
13-19 – 30%
25-49 – 25%
50+ – 5%

Gender (with hemophilia)

Boys – 98% Girls – 2%

Family History

With family history – 70%
No Family History – 30%

Severe Level

Severe – 75%
Moderate – 15%
Mild – 10%

Where Factor is Obtained

Home Healthcare – 62%
Hemophilia Treatment Center – 34%
Retail/Specialty Pharmacy – 3%
Other – 1%

Treatment Regimen

On Demand – 50%
Routine Prophy – 48% (2 +times a week)
Prevention Prophy – 2% (eg: before sports)

Who Infuses the Factor IX Product

Individual with Hemophilia B – 54% (self)
Parent or caregiver – 42%
(includes spouse, son, daughter)
HTC, nurse or home health provider – 4%
(majority were mild to moderate)

How old were you when you learned to infuse?

5-12 years old – 48%
13-19 years old – 46%
20-40 years old – 5%
40 plus – 1%

How did you learn to infuse?

Nurse – 38% At camp – 38%
HTC – 18% Parent – 6%

Any problems with current product?

No – 99.9 % Yes – <1 %

- Some wish it were easier
- Some have slight allergy and take Benadryl, hydrocortisone, prednisone
- Sometimes little “hat” does not go on vial correctly causing problem drawing up factor
- Sometimes plastic from cap breaks off before it punctures bottle, could use more caps

Would you change product during an operation?

No – 90% Yes – 10%

- Reasons for changing - If doctor recommends it; if another product might work better; regular product not available

Recovery/Half-Life

The *majority* do not know and/or have never been tested

Reasons for switching product?

Product Purity – 83%
Doctor Recommendation – 13%
Works better for me – 3%
Allergy/Inhibitor/Availability/Costs – 1%

Interest in future products

Longer acting Recombinant

Type of information helpful to you and/or your child: (Rated by most popular response)

1. Current Research in Hemophilia
2. Gene Therapy
3. Hemophilia Information Sources
4. Support Groups
5. Manufacturing Process
6. Product Information
7. Prophylaxis
8. Inhibitors (small percentage of IX's have inhibitors)

Other topics of interest and concerns

- Co-pay, Access and Choice, Changing Insurance Issues (Top concerns)
- Going to college with hemophilia, orthopedic Information
- Leaving college and beginning a career (how not to get turned away due to pre-existing condition)
- career opportunities
- How to deal with blood clots
- Being mild causes many problems as doctors don't listen. We really do get in many dangerous positions. We never know when to or not to treat
- I can't get properly diagnosed (female with history in family)

Female members in your family having bleeding problems

No – 75% Yes – 25% (Bleed or vWD)

Are you having any problems getting factor?

No – 99.9% Other being taken care of

Has your insurance company made you switch where you get your product?

No – 92% Yes – 7%

Are you happy with the service you are receiving once you were made to switch?

- Most were not happy with the change
- Some were able to switch back, but comment they do not provide homecare RN if needed
- My older provider was more attuned to my needs

If you take an antidepressant do you notice an increase in bleeds?

No – 99% Yes – 1%

Do you feel you get proper support from your HTC?

Yes – 99.9%

- As an adult, out-of-network costs for day clinic is \$1,000
- Insurance changed, now on Medicare, I can go back
- Some are just too far away

Those who do not go to a HTC

2% of those surveyed

Have you attended any national meetings?

Yes – 75% No – 25%

- Not many reasons why some did not go
- Few comments stated money or time issues

Do you attend local chapter meetings?

Yes – 70% No – 30%

- Not many reasons as to reasons why
- Some said no local chapter nearby

Emergency Room Experience

- Our ER is very helpful and receptive. Our HTC calls ahead and provides instruction
- Very Stressful
- Luckily he was treated by his ER RN brother!
- Had to wait for hours for ER to contact HTC or google hemophilia
- Awful – Will never go back
- Non-existent – Not good our hospital refuses to treat hemophilia and the other says to
- wait and see” after driving 30 miles
- ER Doctor brought his textbook into room
- HELP! No one knew what hemophilia was!
- Takes 10-13 hours to get factor
- You can't do it, eventually they will send you away
- I've got them trained and have a standing order when need one

What information would be beneficial to physicians, nurses and ER staff?

- Hemophilia 101 training, staff at ERs are constantly changing – Follow HTC protocol
- Have as much information about hemophilia and different types, also severity
- Advise them what is happening in the body and how painful it is
- Pamphlets -ASK about allergic reactions, have factor on hand ASAP
- Believe that females can have hemophilia
- Allow people with hemophilia to use the factor they carry with them
- LISTEN to the parent or patient, know bleeds need to be treated IMMEDIATELY - Then examine, LET parent or patient mix factor if you do not know how
- TRUST parent or patients knowledge
- Know each case is different based on type, severity, inhibitors, etc.
- Teach them how to reconstitute factor
- Know that a hemophilia patient may look normal but their internal bleeding is life-threatening
- Have fast reference charts, have immediate ice and pressure beneficial
- Posters on wall - TREAT FIRST - DO NOT MAKE A PERSON WITH HEMOPHILIA WAIT!

ER Patients should:

- Have PROOF with hemophilia card and hematologist phone number
- Call ahead if possible - Factor Log
- Have a Medic Alert or card with info on hemophilia type
- Know severity, factor product used, allergies, medications, doctor information
- Have contact numbers; Have your hematologists call the ER before you arrive
- Make an appointment for an in-service with the ER before you need them, but
- may need to be done frequently due to high turnover in the ER

Note: We have seen some improvement in Emergency Room experiences as about 17% have had good or adequate services now.

Activity Participation

Archery, Art, Baseball, Boating, Ballet, Bicycle Riding, Basketball, Boating, Boogie-boarding, Boy Scouts, Bowling, Building Street Rods, Camping, Canoeing, Choir, Croquet, Cub Scouts, Dodge ball, Dancing, Drums, Football, Fishing, Fencing, Golf, Guitar, Gymnastics, Gardening, Hiking, Horseback Riding, Hunting, Jogging, Jump Rope, King Fu, Kickball, Karate, Kayaking, Life Guard, Marching Band, Mountain Climbing, Piano, Photography, Push-ups, Racquetball, Rafting, Rock Climbing, Rollerblading, Running, Sailing, Soccer, Skateboarding, Snow Skiing, Softball, Singing, Soccer, Skiing, Ski Surfing, Racing, T-Ball, Tae Kwon Do, Tennis, Track and Field, Track Cross Country, Ultimate Frisbee, Volleyball, Walking, Water Polo, Water Skiing, Weight Lifting, Wii Fit, Wiffle Ball, Yoga.

Recommendations for the Factor Nine Newsletter

No Changes – 99%

- Great Job
- Interesting Articles
- Keep up the good work!

Improve – 1%

- Psychological Issues
- Success stories
- Fun kids articles
- Send sooner!
- Camp

People interested in having seminars in their area

Yes – 99% No – 1%



Thank you all for your time and valuable input!

Should Ice be Used to Treat a Joint Bleed?

by Dr. David Clark

There's a new controversy in hemophilia treatment.

For years physicians have recommended R.I.C.E. (Rest, Ice, Compression, Elevation) in addition to factor infusion to treat a joint bleed. Now Angela Forsyth and her coworkers at Rush Medical Center in Chicago have pointed out that using ice on a bleeding joint might not be a good idea after all.

The damage to bleeding joints is caused by the presence of blood in the space around the joint. The blood causes a series of reactions that eventually leads to degradation of the joint. The major goal in treating a joint bleed is to minimize the amount of blood that enters the joint space. Cold slows down clotting. Therefore, using ice could prolong the bleeding into a joint, leading to more blood in the joint space and potentially more damage.

The problem is that no one knows for sure - it hasn't been studied. Ice has a long history of medical use to reduce pain, swelling and bleeding. Hippocrates in ancient Greece recommended cold to treat bleeding, and today much of the literature on sports medicine and first aid still recommends ice to reduce swelling and pain. This may be one of those things that has been used so long that no one stops to question it. However, when you look for evidence that ice works, there really isn't much.

Ice does work to temporarily relieve pain, but studies of its effects on swelling and bleeding have not been able to conclusively show that

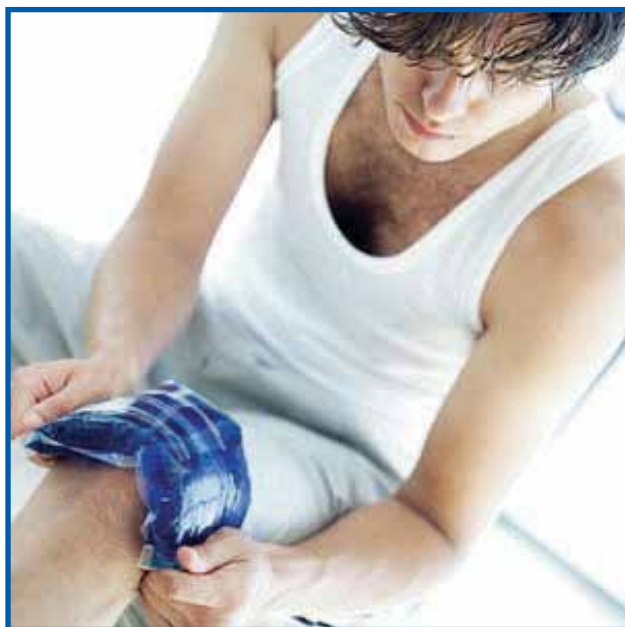


it is effective for either. On the other hand studies have shown that ice can significantly reduce the temperature within a joint and that clotting is significantly slower at the kinds of temperatures in an ice-treated joint.

The space around the joints is enclosed by the synovial membrane, which is rich in blood vessels. When you have a bleed, blood from those vessels enters the joint space causing the synovial membrane to fill up like a balloon. That's the swelling you see. The membrane is also rich in nerves, and the pain of a joint bleed is thought to arise from stretching of the membrane as it fills with blood. Although ice can temporarily ease the pain, if it also prolongs the bleeding, you could get more swelling and thus more pain in the long run.

The compression and elevation parts of R.I.C.E. help to reduce the swelling. Blood will stop flowing into the joint space when the pressure in the space is as high as the blood pressure. By wrapping the joint with a bandage, you prevent the synovial membrane from stretching as much, so the pressure builds up faster and bleeding is reduced. By elevating the joint above the heart, you also take advantage of gravity to reduce the blood pressure around the joint. Rest also helps, since when you are calm, your blood pressure is lower.

At this point all of this is just logical supposition, there's no proof one way or the other. So what should you do? Since the



only proven effect of ice is to temporarily reduce pain, if you can stand the pain or find another way to relieve it, you might want to try treating your next bleed without ice. Just use rest, compression and elevation.

There are a number of researchers talking about this in the literature, so we hope someone will do a study to try to find out the real story. That could take awhile, though. Since the damage happens gradually over time, a study would have to follow two groups for several years, one using ice and one not using ice. At the end, they would look at the changes in joint scores for each group to see

whether there was a difference.

The best advice until then is to get on or stay on prophylaxis and be sure to keep up with your infusions. It also helps to exercise regularly to strengthen the muscles around your joints. That that will all help to minimize joint bleeds. When you do have a bleed, make sure to get a factor IX infusion as soon as possible and emphasize rest, compression and elevation. Even if you need to use ice to relieve pain, the fewer bleeds you have, potentially the less long-term damage to your joints. 🇺🇸

New Study of Prophylaxis Compared with On-Demand Treatment

Investigators at Rush Hemophilia and Thrombophilia Center in Chicago have published a study comparing prophylactic and on-demand treatment of hemophilia B. The study included 47 males aged 6 to 65 with moderate to severe hemophilia B treated with BeneFIX. All subjects rotated between on demand treatment and two different prophylactic dosing schemes, so that

everyone received all three regimens. The mean annualized bleeding rates were 35.1 for the on-demand regimen, 4.6 when treated with 100 IU/kg once a week, and 2.6 when treated with 50 IU/kg twice a week. The difference between the two prophylactic regimens was not statistically significant. This is more evidence of the benefit of prophylactic treatment for hemophilia B.

The Affordable Care Act:

On March 23, 2010, the Affordable Care Act (ACA) was signed into law, representing the most significant overhaul of the U.S. healthcare system since Medicare and Medicaid were enacted in 1965.

The main goals of health reform are to expand health insurance coverage to an additional 32 million Americans, increase insurance protections, and improve healthcare delivery and quality. Some components of the patient protections and expanded insurance coverage went into effect when the law passed including the elimination of pre-existing condition exclusion for children, the phase-out of annual insurance spending limits, and allowing young adults to stay on their parents' insurance coverage until age 26.

However, 2014 is the year for most of the coverage expansions such as the health insurance marketplaces, expanding Medicaid, and the requirement that all individuals obtain insurance coverage or face a fine take effect. Additionally, 2014 will bring the elimination of lifetime and annual limits on insurance spending and eliminate pre-existing condition exclusions for adults.

The health insurance marketplaces, also known as exchanges, have been the hot topic of discussion in recent months. These marketplaces are online portals where individuals and small businesses can purchase private health insurance plans – similar to shopping around for car insurance or hotel bookings online. The law required that each marketplace be set up on a state-by-state basis, and state governments were

STATE COMMITMENT TO EXPAND MEDICAID ELIGIBILITY IN 2014



Source: Avalere State Reform Insights, Updated September 30, 2013

*Denotes states pursuing premium assistance models using exchange plans for part of their expansion populations; AR has received waiver approval, IA has submitted a waiver request, PA proposed a plan using premium assistance that would likely not take effect until mid/late 2014 (state has not yet submitted a waiver request), and TN's governor has voiced support for a premium assistance approach

**MI's expansion will likely begin in March/April 2014 and will require waiver approval from CMS for a number of provisions, including use of HSAs

What to Know in 2014

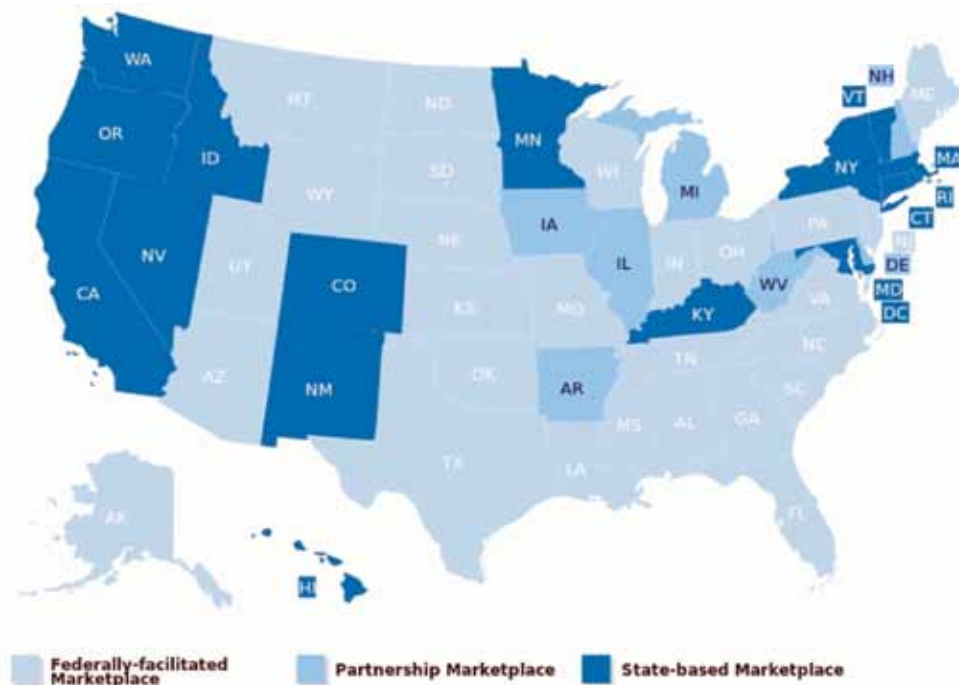
given the option to establish an exchange, partner with the federal government, or allow the federal government to take control over development of this enrollment portal.

To date, 17 states opted to build their own infrastructure, 7 are partnering with the federal government, and 27 have left the whole responsibility up to the federal government. All versions were supposed to “open for business” and begin enrolling individuals on October 1, 2013 through March 31, 2014. Insurers intending to sell plans in the marketplaces had to submit them for review by state and federal authorities, information is slowly being released about these plan option offerings and costs in the states.

Another key element of the ACA was a

required expansion of the Medicaid program – traditionally limited to low-income children and pregnant women – to all individuals up to 133% of the Federal Poverty Level (FPL). The Supreme Court determined the expansion should be optional on a state-by-state basis. At this time, 26 states are set to move forward with Medicaid expansion and 25 are not moving forward at this time. Individuals below 100% of FPL are not eligible to receive coverage through the exchange, meaning that states not expanding Medicaid could leave some of the most vulnerable individuals in this “coverage gap”.

Beyond the expansion of coverage through the state marketplaces and Medicaid in certain states, the ACA also seeks to provide a certain threshold of coverage, something known as the Essential Health





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™

The Affordable Care Act:

continued...

Benefits. Private insurance plans offered inside and outside the marketplaces must offer a comprehensive package of items and services, known as Essential Health Benefits, including: ambulatory patient services, emergency services, hospitalization, maternity and newborn care, mental health and substance use disorder services, prescription drugs, rehabilitative and habilitative services and devices, laboratory services, preventive and wellness services, pediatric services (including oral and vision care). Notably, although prescription drug coverage is required, plans could still use formularies or other restrictive measures limiting the range of available therapies.

Further, the federal government is providing premium credits and cost sharing subsidies for individuals with income levels from 100-400% FPL to assist with the purchase of coverage through the marketplaces. Those who receive coverage from their employer are not eligible for financial assistance unless their premium costs equal more than 9.5% of their income. Additionally, plans sold in the market places have limitations on the total maximum deductible (\$2,000 for an individual; \$4,000 for a family) and maximum

out-of-pocket costs (\$6,350 for an individual; \$12,700 for a family).

The health insurance marketplace plans are intended to provide coverage for currently uninsured individuals and small businesses, and so most individuals will continue to receive coverage through their current means – employer, Medicare, Medicaid.

It is important to be aware of any changes to your plan, the costs associated with your coverage (premiums, deductibles, out-of-pocket), and access to specialty providers and treatment options are covered in exchange plan options.



To learn more about how the Affordable Care Act impacts you and your coverage, visit the federal healthcare reform website at healthcare.gov. To learn more about state decisions for establishment of health insurance exchanges and Medicaid coverage expansions visit kff.org/health-reform/. To assist you in evaluating health insurance plan options, the National Hemophilia Foundation has created a Health Insurance Tool kit available at hemophilia.org under the Advocacy tab. 🇺🇸

AlphaNine® SD
Coagulation Factor IX (Human)
Solvent Detergent Treated/Virus Filtered

INTRODUCING

The AlphaNine® SD Savings Card Program

Designed specifically for the needs of
patients with hemophilia B



You could save up to **\$500 per month** on the costs of your prescription for AlphaNine® SD (coagulation factor IX [human]).

Restrictions apply—see inside to determine if you qualify.

Please see Important Safety Information about AlphaNine® SD on back and refer to accompanying package insert for complete prescribing details.

GRIFOLS

Treatment News

Baxter Baxter Healthcare

FEIBA, Baxter's plasma-derived treatment for hemophilia A and B patients with inhibitors has been approved by FDA for prophylactic use.

Baxter Healthcare

The first patients have been treated in Baxter's Phase I/II clinical study of BAX 335, a gene therapy treatment for hemophilia B. No results have been announced to date.



Biogen Idec

The results from Biogen Idec's B-Long Phase III study of their Alprolix longer-acting factor IX product were published in the December 12 issue of The New England Journal of Medicine. This is the primary clinical study that FDA is using to determine whether to license Alprolix. The study included 123 previously-treated severe hemophilia B patients divided into prophylactic and on-demand treatment regimens, plus eight surgical patients.

Group 1 of prophylactic subjects received weekly infusions with the dose adjusted to maintain a 1 – 3% trough level, while Group 2 received doses of 100 IU/kg with the dosing interval adjusted to maintain the same trough level. Group 1 had a median adjusted dose of 45 IU/kg and an annualized bleeding rate (ABR) of 3.1. Group 2 had a median adjusted dosing interval of 12.5 days and an ABR of 2.4. Over half of Group 2 had dosing intervals of 14 days or longer. Group 3, the on-demand group had an ABR of 18.7, higher as expected compared with prophylaxis.

Biogen also announced interim results from their study in 23 previously-treated children under age 12. Alprolix was well tolerated in both studies with no evidence of inhibitor formation in any of the subjects.



Spark Therapeutics

A spinoff from Children's Hospital of Philadelphia, Spark Therapeutics has an ongoing study of gene therapy for hemophilia B. One patient has now been able to go six months without factor.

Package Insert Information

Package Insert Information for advertise products can be found online.

If you do not have access to a computer, please contact Kim Phelan at 212-520-8272 to have the product insert mailed to you.

Pfizer BeneFix

<http://labeling.pfizer.com/showlabeling.aspx?id=492>

Grifols Alphanine

http://www.grifols.com/documents/10192/63643/ft_alphanine_eeuu_EN/e00e8dfa-7987-4064-9c3b-da9af3204541

CSL Behring - Mononine

<http://labeling.cslbehring.com/PI/US/Mononine/EN/Mononine-Prescribing-Information.pdf>

Baxter - Rixubis

http://www.baxter.com/downloads/healthcare_professionals/products/RIXUBIS_PI.pdf



The only FDA-approved recombinant factor IX indicated for routine prophylaxis to treat adults with hemophilia B¹

For more information, contact your Baxter representative today:

Danielle Kiesel

Phone: (862) 881-9889

E-mail: danielle_kiesel@baxter.com

To learn more, visit www.RIXUBIS.com.

RIXUBIS
[COAGULATION FACTOR IX
(RECOMBINANT)]

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).

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, limb pain, and atypical blood test results.

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.

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Baxter

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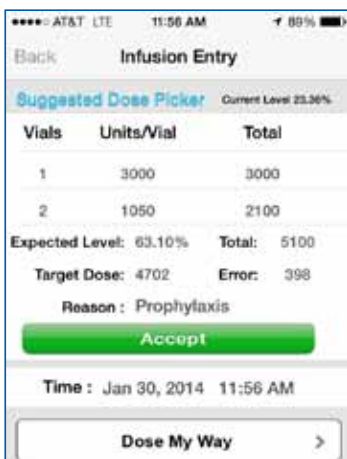
Created by Dan Bond
who has hemophilia B

iBleed is a patient-oriented factor tracking application for the iPhone and iPod Touch specifically designed for people living with Hemophilia. It offers users a simple and convenient method for tracking factor infusions and calculating the resulting levels. It graphically displays your current and predicted factor levels, calculate optimum dose size and timing based on your current inventory and user data. This tool will provide you with useful information to help in making informed decisions about treatment.

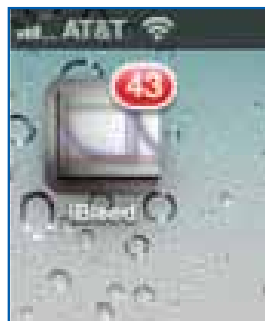
Development of iBleed was sponsored by Pfizer Hemophilia as part of a research study at the Gulf States Hemophilia Treatment Center.

Like all other logs, iBleed records your infusion time, date, number of units, number of vials and product type. It's what it does after with that information that sets it apart. With your log information, and the half life and recovery of the product you use, it calculates your current and future levels. Your inventory level is updated

automatically after each infusion. When you reach your minimum level an alarm will sound.



iBleed infusion entry screen shows your current level, suggested vial sizes, expected level from the infusion, reason for and date of infusion.



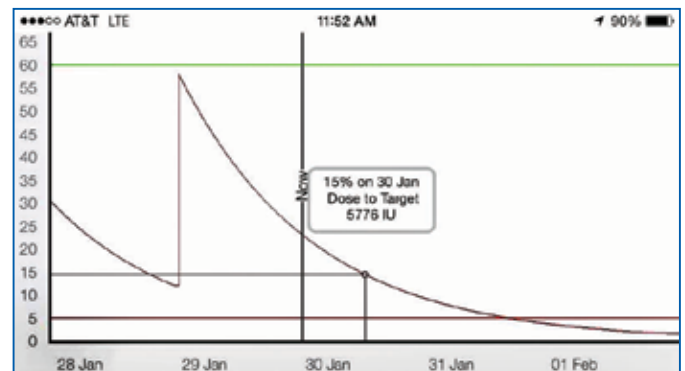
iBleed's icon badge shows your current level

iBleed helps optimize factor usage by calculating the exact combination of vials available from your inventory that will raise the factor level to your target level at any point in time. This means you can always use the minimum amount of factor to maintain the level you need. No other system on the market offers you this kind of decision support.

iBleed will ask if each infusion is for a bleed, prevention or prophylactic. If it's for a bleed, it will display a mannequin where you can point to the bleed location. The severity of the bleed can be color coded using whatever criteria you decide.

iBleed is not a reminder system, but one that encourages awareness and informed decision making. It encourages independence by providing information. Every feature is designed to increase your awareness of your factor level and how that relates to your quality of life. iBleed puts the control of the disease in your hand.

Enrollment in the iBleed study is currently limited to patients of the Gulf States Hemophilia Treatment Center. For more information, please contact Dan Bond at (409) 771-4164 or dan@iBleed.info.



iBleed graph shows your past, present and future level, as well as the number of units needed to get to your target level.

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



with you every step of the way


Matrix Health Group

Dedicated to Making a Difference
in the lives of people living with hemophilia and other bleeding disorders.

Terry Stone

Regional Care Coordinator

703-795-6269 terry.stone@matrixhealthgroup.com

www.matrixhealthgroup.com

Matrix Health 
MEDEX BIO-CARE

TRICARE APPROVED!



We are happy to announce our first monthly video of **THE B SCENE** video series is now available on our Facebook site. Each month we will feature a new person or their family member in the community with hemophilia B. If you would like to participate in our series please email Kim Phelan at hemob@ix.netcom.com.



KIDS B BLOCK



Our next issue of Factor Nine News will showcase kid friendly articles and games in a new feature called **KIDS B BLOCK**. We would also like to add in this section FUN stories, life lessons of a child, or comments you would like to share. We also encourage you to ask your child to write something and submit it as well. We welcome pictures too! It going to be fun! Something we can all create together! So please submit what you like and please note we will keep your names confidential unless you specify otherwise.

Please be advised we will hold several **Factor Nine Family Meetings on the Road** this year. A form will be coming to you to see which dates work best for you in your area. We appreciate your responses so we can begin planning exciting meetings in 2014!



2014

Factor Nine Family Meetings On The Road

Thank You!

Factor Nine Santa would like to give a heartfelt THANK YOU! to all of the of the wonderful people that so generously gave to the Holiday Fund this past season. The Coalition for Hemophilia B was very happy and proud to be able to make the holidays a little brighter for 47 children by providing gifts, coats, boots and food baskets!

Save the Dates!

Washington Days

Wednesday, February 26 to Friday, February 28, 2014



NHF's annual Washington Days empowers individuals in the bleeding disorders community to impact the legislative process. For information, please visit the NHF website at <http://www.hemophilia.org/>.

CHB New York Fundraiser

Friday, March 7, 2014

Atlantica, New York, New York

CHB New York Symposium

Saturday, March 8, 2014

Grand Hyatt Hotel New York, New York

CHB 2nd Annual Mens Retreat

Friday, March 14 to Sunday, March 16, 2014

Phoenix Arizona

CHB Factor Nine Family Breakfast Meeting

Sunday, March 30, 2014 7:30 am

in conjunction with the Hemophilia Federation of America
Meeting Room 4; Tampa Marriott Waterside Hotel and Marina

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

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:
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