Factor Nine News

The Coalition for Hemophilia B

SPRING 2018

Topics in Hemophilia B

ANNUAL SYMPOSIUM

THE COALITION FOR HEMOPHILIA B 2018 ANNUAL SYMPOSIUM

It was an exciting time for The Coalition for Hemophilia B as we held our 12th Annual Symposium in sunny Florida at the beautiful Sawgrass Marriott Resort and Spa in Ponte Vedra Beach, Florida March 23-25, 2018!

This year, we had an amazing turnout with over 450 attendees! Families began arriving Thursday through Friday mid-afternoon. Buses were provided throughout the weekend to pick up families and take them back to the airport on Sunday.

Our event officially began Friday morning with Tai Chi on the Spa Lawn (for all ages) with Rick Starks (Rick held Tai Chi each morning of the symposium), and a family breakfast sponsored by Aptevo. In the afternoon, a *Meet and Greet Luncheon* for families was hosted to connect and bond, also sponsored by Apetvo.

Following lunch, Wayne Cook and Bill Patsakos led the *Men's Meet-Up* at the Gator Lodge while Celeste Schimmels and Pam Williams headed the *Women's Social* with guest speaker Cassandra Starks, who spoke on the *Wisdom of Emotional Fluidity*. Late afternoon sessions included *Art Therapy* sponsored by Bioverativ, which was very enjoyable. Afterward, the art therapy projects were put on display for the duration of the symposium. Additionally, *Getting Hip to Hep C* with Dr. Shelby Smoak sponsored by BioMatrix and a *Nutrition & Wellness* program with Dr. William Patsakos sponsored by CVS Health were both presented to a wonderful turnout!

Friday evening began with a rockin' start as families enjoyed a nice dinner and were entertained by talented members of the hemophilia community. A band of blood brothers and sisters called the "Bleeders" made their debut. Groupies gathered around to take selfies and dance to the B-eat! We know this band is going to be a big hit! Exhibit booths were open after dinner for 3 hours and then it was time for the *Friday Night Hangout,* sponsored by Aptevo with fun games for all ages, including giant versions of popular games, snacks and animated selfies! Super fun!

Childcare services were provided during the symposium for infants to 4 years old from 7am to 11pm with professional nannies and our team members watching the children in a





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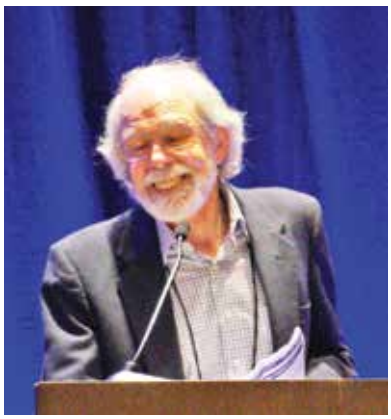
INSURANCE TRENDS
THE COALITION FOR HEMOPHILIA B
ANNUAL SYMPOSIUM
PONTE VERDA, FLORIDA
March 24, 2015

POWERING THROUGH



POWERING THROUGH

BLEEDING DISORDER
EMERGENCY ROOM / MEDICAL CARE











HEMC







POWERING
THROUGH


room filled with fun toys, play mats, stuffed animals, movies, snacks, and cribs for naptime.

Children ages 5-12 were entertained in their own room filled with movies, Xbox (raffled off at the end of the event), snacks, games, arts & crafts, and entertainment by magician Julius Magic. Fun filled activities such as *Wacky Olympics* and a *Perfect Pirate Party* programs were provided by Kids Camp Company and sponsored by Sangamo.

Sponsored by Accredo, *My Amazing Blood* was so much fun as children learned about blood by making cookies! The *Teen Track* on Friday began with a cool program called *Stop the Bleeding* with Patrick James Lynch sponsored by Shire, and an afternoon session, *Brought to You by Gutmonkey* with Jacose Bell, which was sponsored by CSL Behring. Saturday's Teen Track was sponsored by Bioverativ with interactive sessions *Chasing Summer*, *Cracking the Code,* and a *Drumming Session* with Robert Friedman. Rap sessions were held both days. The meeting room for the teens was filled with bean bag chairs, Play Station 4, movies and games. The PS4 was raffled off at the end of the event and the chairs were donated to a local charity.

Saturday morning, we had a industry sponsored *"B" Yourself Breakfast* sponsored by Novo Nordisk with presenters Paul Brayshaw and Dr. Chrisentery-Singleton discussing pharmacokinetic concepts, including recovery, half-life, and areas under the curve and how they relate to everyday life.




BloodStream Media

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HANGOUT

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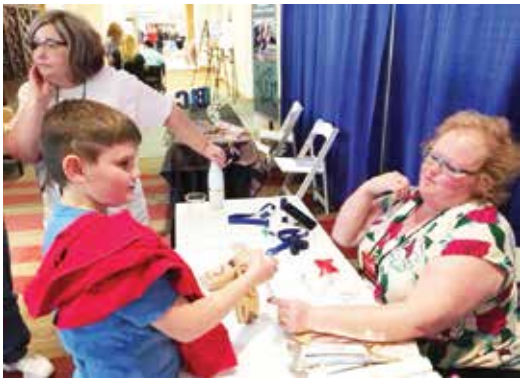


Our symposium sessions began with keynote speaker Dr. Christopher Walsh covering updates on hemophilia B products and what's in the pipeline. He emphasized the importance of controlling your bleeds and treating hepatitis C. Dr. Kim Mauer spoke on *Pain Management: Where Are We Going?,* the opioid crisis, alternative and new therapies, procedures and medications gaining popularity. Megan King followed with her topic on *New Diagnosis, New Normal: Mom's Perspective*. John Vieke shared his personal story accompanied by a video presentation. Later, attendees were able to sit outside for a while and enjoy lunch sponsored by CSL Behring.

The afternoon began with a panel discussion with Patrick James Lynch sponsored by NCHS & Believe Ltd. The panel included Charity Meadows, a mom of three boys with hemophilia B, Cyronn Herrington with hemophilia B, and a guest panelist Nicole Dalton who lives with Systematic Onset Juvenile Rheumatoid Arthritis. This is a nationwide conversational panel series on obstacles-challenges and what it takes to overcome. There was not a dry eye in the room. We thank each of them for speaking their truth, sharing their vulnerabilities and in turn allowing others to open up and share as well.

Later, we participated in a drumming session called the *Healing Power of the Drum* with Robert Freidman, a unique interactive program that explored the new science of drumming and wellness. Recent research demonstrates that hand drumming can improve the immune system and reduce stress. Robert Lawrence Friedman, a recognized expert in this field and published author of *The Healing Power of the Drum,* books 1 and 2, taught participants how to use rhythm-based exercises to demonstrate how the hand drum can help to release stress, experience joy, feel energized, and release negative emotions.

Donnie Akers spoke on *A Standard of Care in the ER & Insurance Trends* with focus on the use of *MASAC Guidelines #252, Guidelines for ER Management of Hemophilia & Bleeding Disorders*, and secondly on trends in insurance, including type of plan basics. The last session of the day was threefold - it included our infusion session with Hope Woodcock titled *Infuse with Hope*, *Music Therapy* with Elizabeth VanSant, and *Kinesiology* with Dr. Michael Zolotnitsky.

The afternoon ended with *Sunset Tai Chi* with Rick Starks on the Spa Lawn. The exhibit room was open all day for attendees along with a wellness area for chair massages. Saturday evening dinner was held poolside with entertainment by the *Bleeders*, along with open mic where attendees could come up and sing, play an instrument, or tell a joke! BLEEDERS GOT TALENT! It was a blast! Thank you to sponsors Novo Nordisk and Aptevo.

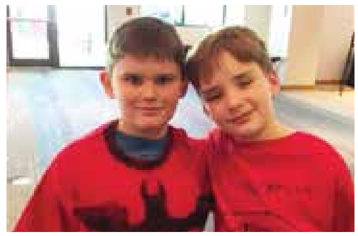
Sunday morning Natalie Lynch held a *Gentle Vinyasa-Style Yoga* class on the Cascade lawn, which was suitable for all ages. CSL Behring held an *Industry Sponsored Breakfast* with speaker Tori Tiger who shared a video presentation on the ever popular *Gettin in the Game* This is a wonderful program that allows children ages 5-17 to attend a weekend of learning and friendly competition in Arizona in the areas of swimming, golf and baseball. If you do not know about it please contact your local chapter or contact us.

Exhibits and the Wellness Area (chair massages) were open throughout the day and 3 minute video clips were shown to raise awareness of the wonderful programs available to the B community.

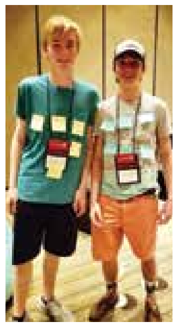








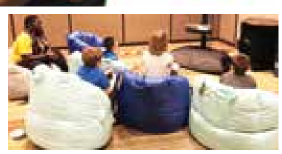




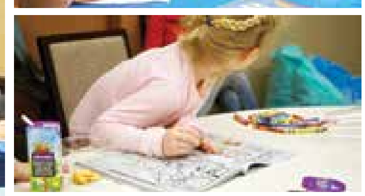
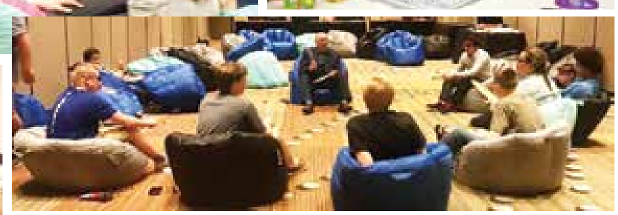









TEAM
LAC



Special thanks to our sponsors for their gracious and generous support! Thank you to our speakers, our team, and our volunteers along with the continued participation and engagement of hemophilia B patients and their families.We have been able to make great strides in accomplishing our goals for a quarter of a century! We look forward to seeing you again in 2019 at the Renaissance Orlando at SeaWorld March 14-17. We are adding one extra day to our programming to fit in additional programs from the survey requests!

DIAMOND

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GOLD

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FRIENDS

Accredo **BioMatrix** **Cottrill's** **CVS Specialty** **Diplomat**
Evolutionary Healthcare **Optioncare** **Paragon** **Rare Patient Voice**

Much appreciation to **ALNYLAM** for providing Wi-Fi for our attendees and to **BIOVERATIV** for sponsoring the water stations and for sponsoring 20 families to attend the event.

A TREMENDOUS THANK YOU TO:

novo nordisk® **(DIAMOND) AND** Aptevo Therapeutics **(GOLD)**

FOR SPONSORING OUR FINAL NIGHT EVENT!











John feels more confident with high factor levels. Do you?

"It's the peace of mind I get having higher factor levels. I can just do my job. I can play with my kid. I can do what I've always loved, but with more confidence."

21% FIX LEVELS WITH PROPHYLACTIC USE

**IDELVION offers high and sustained Factor IX (FIX) levels at steady state, giving John the protection he needs to do his job.[1]*

IDELVION is the first FIX FDA approved for 7- and 14-day dosing.†

Learn about the benefits that make a difference for John at IDELVION.com

Important Safety Information

IDELVION®, Coagulation Factor IX (Recombinant), Albumin Fusion Protein (rFIX-FP), is used to control and prevent bleeding episodes in people with hemophilia B. Your doctor might also give you IDELVION before surgical procedures. Used regularly as prophylaxis, IDELVION can reduce number of bleeding episodes.

IDELVION is administered by intravenous injection into the bloodstream, and can be self-administered or administered by a caregiver. Do not inject IDELVION without training and approval from your healthcare provider or hemophilia treatment center.

Tell your healthcare provider of any medical condition you might have, including allergies and pregnancy, as well as all medications you are taking. Do not use IDELVION if you know you are allergic to any of its ingredients, including hamster proteins. Tell your doctor if you previously had an allergic reaction to any FIX product.

Stop treatment and immediately contact your healthcare provider if you see signs of an allergic reaction, including a rash or hives, itching, tightness of chest or throat, difficulty breathing, lightheadedness, dizziness, nausea, or a decrease in blood pressure.

Your body can make antibodies, called inhibitors, against Factor IX, which could stop IDELVION from working properly. You might need to be tested for inhibitors from time to time. IDELVION might also increase the risk of abnormal blood clots in your body, especially if you have risk factors. Call your healthcare provider if you have chest pain, difficulty breathing, or leg tenderness or swelling.

In clinical trials for IDELVION, headache was the only side effect occurring in more than 1% of patients (1.8%), but is not the only side effect possible. Tell your healthcare provider about any side effect that bothers you or does not go away, or if bleeding is not controlled with IDELVION.

Please see brief summary of prescribing information on next page and full prescribing information, including patient product information, at IDELVION.com.

You are also encouraged to report negative side effects of prescription drugs to the FDA. Visit **www.fda.gov/medwatch**, or call **1-800-FDA-1088**.

*Steady state is a consistent and uniform amount of factor in the body with continued use. Steady-state levels measured FIX at trough levels before each infusion every four weeks until week 92 at 7-day prophylaxis.

†Appropriate people 12 years and older may be eligible for 14-day dosing. Talk with your doctor.

Reference: 1. Data on file. Available from CSL Behring as DOF IDL-002.

IDELVION® Coagulation Factor IX (Recombinant), Albumin Fusion Protein

IDELVION®, Coagulation Factor IX (Recombinant), Albumin Fusion Protein
Initial U.S. Approval: 2016

BRIEF SUMMARY OF PRESCRIBING INFORMATION

These highlights do not include all the information needed to use IDELVION safely and effectively. Please see full prescribing information for IDELVION, which has a section with information directed specifically to patients.

What is IDELVION?

IDELVION is an injectable medicine used to replace clotting Factor IX that is absent or insufficient in people with hemophilia B. Hemophilia B, also called congenital Factor IX deficiency or Christmas disease, is an inherited bleeding disorder that prevents blood from clotting normally.

IDELVION is used to control and prevent bleeding episodes. Your healthcare provider may give you IDELVION when you have surgery. IDELVION can reduce the number of bleeding episodes when used regularly (prophylaxis).

Who should not use IDELVION?

You should not use IDELVION if you have had life-threatening hypersensitivity reactions to IDELVION or are allergic to:

- hamster proteins
- any ingredients in IDELVION

Tell your healthcare provider if you have had an allergic reaction to any Factor IX product prior to using IDELVION.

What should I tell my healthcare provider before using IDELVION?

Discuss the following with your healthcare provider:

- Your general health, including any medical condition you have or have had, including pregnancy, and any medical problems you may be having
- Any medicines you are taking, both prescription and non-prescription, and including any vitamins, supplements, or herbal remedies
- Allergies you might have, including allergies to hamster proteins
- Known inhibitors to Factor IX that you've experienced or been told you have (because IDELVION might not work for you)

What must I know about administering IDELVION?

- IDELVION is administered intravenously, directly into the bloodstream.
- IDELVION can be self-administered or administered by a caregiver with training and approval from your healthcare provider or hemophilia treatment center. **(For directions on reconstituting and administering IDELVION, see the Instructions for Use in the FDA-Approved Patient Labeling section of the full prescribing information.)**
- Your healthcare provider will tell you how much IDELVION to use based on your weight, the severity of your hemophilia B, your age, and other factors. Call your healthcare provider right away if your bleeding does not stop after taking IDELVION.
- Blood tests may be needed after you start IDELVION to ensure that your blood level of Factor IX is high enough to properly clot your blood.

What are the possible side effects of IDELVION?

Allergic reactions can occur with IDELVION. Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the chest or throat, difficulty breathing, light-headedness, dizziness, nausea, or decrease in blood pressure.

Your body can make antibodies, called inhibitors, against Factor IX, which could stop IDELVION from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

IDELVION might increase the risk of abnormal blood clots forming in your body, especially if you have risk factors for such clots. Call your healthcare provider if you experience chest pain, difficulty breathing, or leg tenderness or swelling while being treated with IDELVION.

A common side effect of IDELVION is headache. This is not the only side effect possible. Tell your healthcare provider about any side effect that bothers you or does not go away.

Please see full prescribing information, including FDA-approved patient labeling.

Based on February 2017 PI revision.

IDELVION®
Coagulation Factor IX (Recombinant), Albumin Fusion Protein

11th ANNUAL ETERNAL SPIRIT AWARD DINNER

Community Gathers to Celebrate our Accomplishments and Ensure our Future at the 11th Annual Eternal Spirit Award Fundraising Dinner - March 1, 2018

The Coalition for Hemophilia B held its ***11th Annual Eternal Spirit Award Fundraising Dinner*** at Terrace on the Park in Flushing Meadow, New York. The festive celebration was held in the venue's spectacular penthouse with breathtaking views of the Manhattan skyline. Approximately 200 supporters attended, including families, community members and other donors. The evening had a 1940's theme with featured dancing and entertainment including music by Bill Gati and Fleur Seule, and comedy by John Pizzi of America's Got Talent.

The Eternal Spirit Award Dinner is a time to celebrate the community's many accomplishments over the past year, including a record number of events around the country and more families and individuals served than ever before. It is also when we recognize individuals in the community who have given their heart and soul to the community. This year's honorees were ***Laurie Kelley***, mother of a son with hemophilia, founder of LA Kelley Communications Project Share, Save One Life and author of ten books on hemophilia. Laurie is also founder and editor of the quarterly Parent Empowerment Newsletter. And ***Dr. William Patsakos***, father of 4 sons - 3 with hemophilia. He is a pharmacist and a Fire Department of New York Lieutenant. He also works with FEMA and is a staunch advocate and volunteer for the bleeding disorders community. We are very proud to honor them for their years of service and dedication to people with bleeding disorders.

A major portion of the funds raised during this special evening benefit the William N. Drohan Scholarship fund. The Scholarship was formed in memory of Dr. William N. Drohan who passed away from cancer in February of 2007. Dr. Drohan was a well-known microbiologist and educator who will long be remembered for his many contributions to science. He was a pioneer in using molecular biology to produce recombinant proteins and a visionary scientist who dedicated his life to improving the safety of blood and blood products. The fund was created to recognize deserving children who have hemophilia. In the last ten years, The Coalition for Hemophilia B has awarded $245,000 in scholarships.















Dinner proceeds also support other crucial programs including the BCares emergency assistance program. BCares provides urgent help to individuals or families affected by hemophilia B when faced with specific critical needs. These crisis situations may include housing, transportation, and utility bills, and others. With the help of dinner participants and other donors, last year we were able to distribute nearly $70,000 in emergency assistance.

The use of dinner proceeds to support these vital programs transforms the event from just a celebration to a sacred task that helps ensure that people with hemophilia B will have a brighter tomorrow. We are grateful to the many supporters who contributed through this special event. Please join them – and all of us - in making this dream a reality for the entire community. A very special thank you to our sponsors for allowing us to continue our good work!

A HUGE THANK YOU TO OUR GENEROUS SPONSORS!

Thank you for allowing us to continue our good work!

DIAMOND LEVEL

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GOLD

CVS specialty · novo nordisk

SILVER

Hemophilia Alliance · The Alliance Pharmacy (A non-profit pharmacy) · ENA Healthcare Communications

BENEFACTORS

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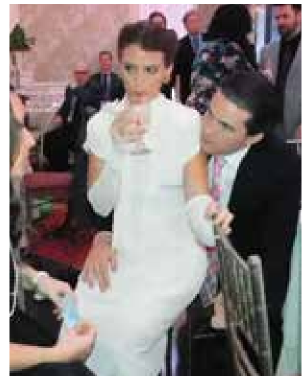
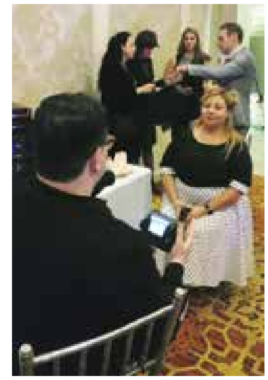
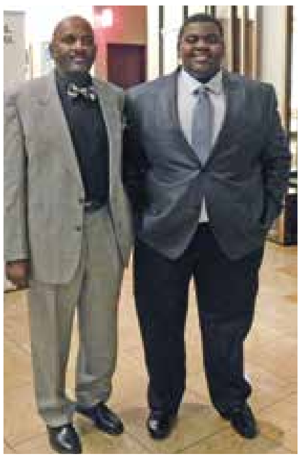












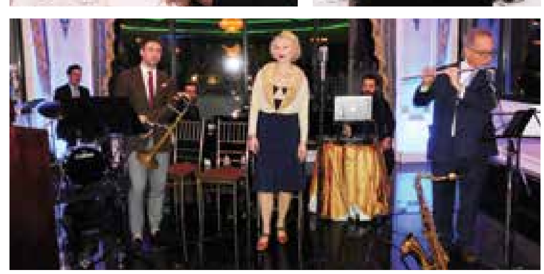

"HE'S MY CHILD WHAT I GIVE HIM MATTERS"

VISIT BENEFIX.COM TO LEARN MORE

19 years* of experience in previously untreated patients (PUPs) and children

BeneFix Coagulation Factor IX (Recombinant) is FDA approved to prevent and control bleeds in both newly diagnosed and pediatric patients with hemophilia B. It's been shown to be effective across a range of ages.

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

- 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 stop BeneFix from working properly.
- 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.

Consolidated support with Pfizer Hemophilia Connect

Pfizer Hemophilia Connect

- One number with access to all of Pfizer Hemophilia's financial resources and support programs
- Get matched with the financial support programs that best fit your needs
- Learn about community support resources and materials like HemMobile™, Patient Affairs Liaisons, and the CNE series†

Contact Pfizer Hemophilia Connect at 1.844.989.HEMO (4366)

Please see the Brief Summary for BeneFix on the next page.

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

*BeneFix was approved February 11, 1997.
†Eligibility may be required to participate.

19+ YEARS* YOUR EXPERIENCE MATTERS

BeneFix®
Coagulation Factor IX (Recombinant)
Room Temperature Storage

BeneFix®

Coagulation Factor IX (Recombinant)

Room Temperature Storage

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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	fast heartbeat
difficulty breathing	swelling of the face
chest tightness	faintness
turning blue (look at lips and gums)	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. 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.

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-0464-9.0, revised August 2015.

BUS780502-01

Printed in USA/October 2015

Pfizer

When Coalition for Hemophilia B President Wayne Cook was offered the possibility of holding a golf event during the ***12th Annual Symposium*** in Jacksonville, Florida, his eyes lit up. Yes, the idea of getting to play golf at this spectacular course overlooking the ocean was exciting. However, Wayne had a vision that went well beyond a day of golf. He understood how beneficial involvement in a sport like golf could be for members of the community and especially young people. Golf is a fun, relatively safe sport that engages participants in ways that promote lifelong joint health, self-esteem, camaraderie, agility, strength and endurance. Furthermore, golf is popular and a wonderful way to attract support for the Coalition and crucial programs it makes available to affected families. Wayne immediately accepted the offer of the venue and what would become the Coalition for Hemophilia B's "Let's Play Nine" program was born.

Wayne knew this was a big undertaking and he couldn't go it alone. He reached out to Jim VanSant who lives in St. Louis, MO with his wife, Becky, and their children. The VanSant's oldest child, Elizabeth, is now 22 and has severe hemophilia B with no family history. Furthermore, Jim was by profession a golf course superintendent for 25 years and ran countless tournaments during that time. Jim introduced Elizabeth to golf at an early age. Watching Elizabeth, who played competitively all through high school, Jim witnessed first-hand how golf could make such an enormous difference in a young person's life. It should come as no surprise that when he got the call from Wayne, his answer was "just tell me what you need me to do." Jim may not have realized it immediately, but he had just signed on as co-chair of "Let's Play Nine" with Wayne Cook.

In March, the Coalition for Hemophilia B hosted its 2nd annual "Let's Play Nine" golf outing at TPC Sawgrass in Point Vedra Beach, Forida. Participation is growing from year to year, with a large, enthusiastic group of players who come from the community as well as supporters from industry. The program featured a clinic with professional golfer Perry Parker, who has mild hemophilia A. Parker, who has played in no less than three U.S. Opens, is an active member of the hemophilia community. He has helped run golf clinics for thousands of community members all over the country, carrying the message of sports and exercise as a key to strong joints and good health. As importantly, Perry is a living example that it is possible for someone with hemophilia to live their dreams. Working with Perry was PGA Golfer Jared Schimmels, who has hemophilia B. Jared first met Perry when he was a youth participant in a clinic Parker ran as part of CSL Behring's Getting' in the Game. Today Jared is a pro golfer and teacher.

According to the Let's Play Nine co-chairs, education is a central part of the program. One of their goals is to continue to expand the teaching components, giving more members from throughout the community opportunities to learn and grow.

The program also featured the presentation of special golf packages to two deserving youth. Will McCarthy (16) received a golf lesson with Perry Parker, an upgrade to his

golf clubs and access to a club in his hometown.

Nicholas Marlatt (12) received a custom fitting and his first set of clubs, golf shoes, apparel, a beginner's lesson and everything he needs to learn how to play the game of golf.

The success of the program at getting community members involved with something as healthy and beneficial as golf is very gratifying to the organizers – but that doesn't tell the whole story of how golf is fulfilling their vision. Wayne and Jim understood from the beginning that golf was also a terrific way to engage supporters and raise funds for some of the crucial programs the Coalition for Hemophilia B maintains for the entire community. In addition to making the golf programs possible for the many who participate directly, funds raised through "Let's Play Nine" are used to support BCares and other crucial services. BCares provides direct assistance to families affected by hemophilia B who are facing a sudden emergency or monetary crisis. Last year, BCares was able to provide nearly $70,000 in direct support to families with desperate needs. Through this added dimension of the program, "Let's Play Nine" helps not only those who step out on the course, but also hundreds of families who may never touch a club. It's a true win-win situation.

The Coalition for Hemophilia B wishes to thank the many participants who joined us for the first two events, as well as the companies whose financial support made it all possible. These include CSL Behring (Diamond), Aptevo Therapeutics (Platinum), Bioverativ, Novo Nordisk and Pfizer (Gold), CVS Specialty and UniQure (Bronze). Thank you for your generosity!

WITH AGE COMES IMPROVEMENT

Sixteen-year-old golfer Will McCarthy, a young golfer with hemophilia B, has come a long way in the time he's been playing. "For many years I played with hand-me-down clubs, and my game wasn't very good," said Will. "It wasn't until I won my first JNC (CSL's Junior National Championship) that I was able to get a good set of irons."

"My game was better, but not the best it could be. With the new putter and wedge I have shaved almost seven strokes off my game and I am very thankful for everyone who made it happen. I'm starting college this year in hopes I can get onto the golf team and make a difference," he said.

Twelve year old Nicholas Marlatt was completely overjoyed when Jim presented him with a brand new set of golf clubs along with all the apparel and accessories to start learning the game. Nicholas could not be more excited to get out on the course this summer and start his lessons. Without this generosity, he would not be given the chance to experience all the benefits that golf can give an individual with hemophilia.


















B CONNECTED

THE COALITION FOR HEMOPHILIA B

FREE for people and families with HEMOPHILIA B. To join B Connected, set up your profile and download the mobile and desktop app, contact administrators, Rick Starks and Shad Tulledge at bconnected@hemob.org

THERE'S A NEW WAY

TO STAY CONNECTED TO

PEERS-FAMILIES-EXPERTS

Prior programs have included:
Kim Mauer, MD: Pain Management
Donnie Akers Esq: Legal Tools on the Road to Life While Keeping Public Benefits

contact: bconnected@hemob.org

Why B Connected?

New therapies are flooding the market. It's more important than ever that everyone in the Hemophilia B community has a way to:

» Get critical information in a timely manner.
» Dispel false rumors immediately and receive correct information from expert sources.
» Stay engaged with the community virtually, even if your hemophilia limits your mobility.
» Ask questions and share experiences with other patients and caretakers.
» Customize and control the content for which you want to receive notifications.

PEER SUPPORT & ASK THE EXPERT GUESTS

Through B Connected you can also digitally join online *Ask the Expert* sessions—hour-long discussions on topics such as advocacy, depression, pain management, unaffected siblings, physical therapy, how to cut down on joint bleeds, nutrition and exercise, inhibitors, new family support, aging with hemophilia, and much, much more!

JOIN TODAY!

Hemophilia B Connected online discussion board is hosted on Slack and is 100% HIPAA compliant.

The Coalition for Hemophilia B, Inc. 757 Third Ave., 20th Fl, New York, NY 10017
Tel: 212.520.8272 Email: contact@hemob.org

SPRING WOMEN'S RETREAT

By Christian Villarreal

The spring Women's Retreat was held in sunny Florida at the Hilton Grand Vacations at Tuscany Village. Women from across the U.S. gathered to spend a weekend connecting and learning tools to empower them. The focus was on overall wellness and self care.

We introduced a 3-part *Wellness* series with Cassandra Starks. The survey results came back with a very positive outcome. The weekend began with soothing chair massages and a poolside lunch after their long flights. The first session was with therapist Amy Brock, who spoke for two hours on self care and shared tools on how to better connect with your feeling and address needs that may often be put aside or forgotten due to a busy life. In addition, with the participant's permission, Amy delved deeper, sharing insight on many topics such as medical concerns, love, career and relationships. Her session ran overtime by 2 hours. The day ended with dinner and the first part of the wellness journey, Movie Night, where the ladies were hosted by Cassandra Starks while they enjoyed popcorn and a movie inspiring women toward self acceptance.

Friday and Saturday mornings, the women chose from one of three morning rejuvenation exercises; outdoor tai chi; a nature walk on the resort trail; or water aerobics. Afterwards, they had breakfast on the patio.

To begin the day, we played games for icebreakers and the women were introduced to each other and given a synopsis of the exciting events to follow. Cassandra Starks then took the











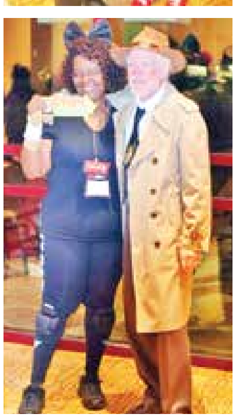



The Coalition went above and beyond this year to give us a relaxing, fun-filled, and educational weekend. I'm grateful for all they did to provide a wonderful weekend full of friendship and love for all of us!

C. S. - Florida






mic with the Part II of the women's wellness journey; *Following your Heart & Mind*. Cassandra led an interactive discussion about the connection of the heart and mind and how to tap into the inner knowing within. Stories were shared and bonds formed after an emotion filled first day. The last talk for Friday was entitled *Nutrition to Fit Your Lifestyle*, led by Ariana Hakman. She gave a nice balance of information and tools to help focus on maintaining a healthy life balance. In the evening, the women enjoyed a poolside dinner followed by a paint and sip event led by artist Terri. Creativity was abound as each canvas reflected their unique selves.

Saturday began with *Wellness Journey, Part III*. The talk was an interactive discussion on feelings and emotions, filled with activities to strengthen the participants connection to themselves and to each other. In the afternoon, belly dancer Melanie LaJoie showed the women how belly dancing can be fun way to work their cores in this low impact exercise enjoyed by many!

I am so thankful to have attended the Spring Women's Retreat. As a first-time attendee I was unsure as to what to expect but I am happy to have learned so much and I was able to leave there with friendships that will last a lifetime. The sessions were very informative and helped us learn about ourselves and each other. I will always be grateful to have support from The Coalition for Hemophilia B and their sponsors for the wonderful programs that help our Hemophilia B community grow and prosper.

B.C. - Indiana

Chit Chat and Chocolate was the final talk of the day, where attendees Tina McMullen, a caregiver; Danielle Phelps, a spouse of someone with hemophilia; and Pam Williams, a woman diagnosed with hemophilia B, all shared their life stories and then everyone in the room was able to touch on their own experiences to further create a strong bond of sharing and connection. Our final night dinner was a 1980's *Mystery Murder.* The women came dressed up in their best rocking 80's look! Many women were asked to be a part of the show and each truly played the part perfectly! A truly fun time was had by all! We held a Sunday morning yoga session and early departure farewells followed. Old connections renewed and new friendships made. We know they all walked away with something new to bring to their lives. We thank our generous sponsor, Pfizer, who made this retreat possible!

Stay Tuned for Summer 2019 B-Members Will Drop the B-EAT!

Nashville musicians should get ready for the incredible talent coming to their city next summer! Musically accomplished members of our community are creating an amazing program and are reaching out to musicians within the Hemophilia B Community to come join us!

The program will include Classical, Jazz, Rock, Hip Hop, Country, Instrumental and Voice performing groups and songwriters — and recording sessions! Our Hemophilia B community members will have the opportunity to work with some of the greatest in the music industry who will help them refine their skills and make lifelong friends through their shared love of music! A final night performance is also being planned.

Tell us more about your music interests and experience by taking our music camp survey. This information will help us plan our program!

MUSIC CAMP SURVEY

www.surveymonkey.com/r/musiccamp2

Your input is greatly appreciated!

SPRING MEN'S RETREAT

BY SHAD TULLEDGE

Our ***Spring Men's Retreat*** was held May 3-6, 2018 in Orlando, Florida at the spectacular Hilton Grand Vacations at Tuscany Village.

As the guys from near and far started to arrive, the excitement filled the air. Old friends reunited and new friends gathered. Lunch was served by the pool and everyone received complimentary 15-minute chair massages which was just what was needed to unwind after traveling. We kicked off the retreat with Ariana Hackman, a nutritionist who discussed the benefits of healthy eating and empowered us with a greater understanding of how to read food labels and how to choose good options when eating out. Afterward we held our Rap session (always a favorite) giving the guys time to get acquainted and allowing time for each to share "their" story.

Friday morning began with Rick Starks Tai Chi a light impact exercise that helps balance mind and body. Rocky Williams led the Trail Walk which was tranquil and scenic. We enjoyed a wonderful breakfast afterward. After breakfast Wayne Cook, the President of

the Coalition opened the session and welcomed everyone. Our first session was on Navigating Healthcare, presented by Donnie Akers Esq. Donnie educated us and shared useful tips on topics like understanding the Affordable Care Act and the direction it is going, what to do if you lose your insurance, or if you have to start a new job. Many men participated in the discussion by sharing their input and experiences with health insurance. Being a younger guy with hemophilia, listening in on this talk truly made an impression on preparing myself for the future.

During lunch I heard some of the guys discussing what they had learned; many had questions they wished they would have thought about to ask. Luckily our speakers joined us at lunch and additional questions were happily answered. Our last session on Friday was with Dr. Ruth Mulvany, a Physical Therapist who presented on “A Focus on Health and Fitness; Sharing Options on How to Enhance an Active and Healthy Lifestyle.” One of the things we learned was how to check our pulse before and after a light exercise like squats to show that you don’t have to go to the gym to exercise. After a short break the men gathered on the patio to enjoy wonderful weather and dinner. Later the group was “ALL IN” for Casino Night! We had 3 professional casino tables brought in, each with experienced dealers. The men enjoyed playing Roulette, Poker and Black Jack.


































It was a very beneficial event for a very fortunate group of males that have a very special bond around hemophilia B. These men were fathers and grandfathers of males and females with hemophilia B, persons with hemophilia B as well as a few spouses of persons with hemophilia B. The speakers were experts in their field and the content these speakers presented was top-notch and very rewarding to those in attendance. Fellowship and entertainment was had by all in attendance and time can't speed around soon enough to allow those in attendance to once again gather at another educational event sponsored by The Coalition For Hemophilia B.

– C.T., Pennsylvania

The spring men's retreat in Florida was a great experience with The Coalition for hemophilia B, I learned a lot from the guys and the speakers in the sessions, as a father of a son with the condition I feel fortunate knowing he will be in great company in the blood brotherhood, these are some excellent people, and what a great setting at this retreat for us all to unwind and get to know and learn from one another, I am extremely grateful for for the opportunity to attend.

– James D., Michigan

Saturday Morning Refresher offered the men with the choice of *Tai Chi* with Rick Starks or *The Trail Walk* with Rocky Williams. It was great that all of the guys could decide which one would jump start their day. After breakfast we gathered for our group photo. Wayne Cook started the day with his opening talks and then Dr. Mosi William, a psychologist, began his talk on how to live with a chronic illness and coping with depression. Following lunch, Robert Friedman discussed the spiritual healing power of the drum and we all sat in a circle and were given instruments for a great interactive session. This exercise was so cool and helped me personally express feelings and stress relief through music

Before dinner everyone gathered on the lawn for the traditional *Bleeder Olympics*. The Bleeder Olympics is an extremely competitive set of outdoor backyard games. Don't let the name fool you, the men played games like *Put-Put*, *Cornhole* and *Hillbilly Golf.* The winners were entitled to bragging rights all weekend! The final night gathering was just what the doctor ordered, we enjoyed pizza and hot wings with a side of great conversations. The guys enjoyed themselves so much they decided to go for an evening swim and partake in a game of catch in the pool.

On Sunday, we had departures throughout the day, but as many who have experienced events with The Coalition for Hemophilia B know, the Coalition is just like one large family, it's never *goodbye*, just *see you next time*. We would like to thank our sponsor Pfizer for generously sponsoring this event.

MEETINGS ON THE ROAD 2018
MAINE AND ALABAMA

ALABAMA MEETING ON THE ROAD - MAY 2018

We kicked off our first ***Hemophilia B Family Meeting*** on Saturday, April 14th in beautiful Portland, Maine! Our attendees learned that one size does not fit all when it comes to hemophilia and its struggles. And while we are as different as snowflakes, we are similar in many ways.

In addition to attendees visiting exhibitors throughout the day, many great sessions were available:

Megan King, mother of two children with hemophilia B, shared her tips on taking baby steps and staying calm while on information-overload or feeling overwhelmed.

Rick Starks led a *Tai Chi* session for all ages. The health benefits of Tai Chi have long been studied. Rick is a true example of those benefits. He also has hemophilia B. Read about his story in our issue of Factor Nine News Summer 2014 in the archive section of our newsletter on hemob.org. He was recently cited in HemAware online magazine for teaching Tai Chi as a mind-body pain management technique

Ben Shuldiner presented on *Advocating For Your Child - 504 Plans and IEPs*. The session explored ways for students and parents with bleeding disorder concerns to receive additional support as they navigate the educational system.

After lunch the kids came back from their day trip and joined the families for an interactive program covering *Kinesiology and Joint Support*. Dr. Michael Zolotnitsky, a licensed orthopedic and neurological physical therapist, spoke to the families about the benefits of Kinesiology taping for pain relief, reduced swelling, inflammation and a multitude of additional benefits. Michael demonstrated on a few attendees who had pain. They were quite grateful! Michael plans to release several videos in upcoming months - please contact us at contact@hemob.org for links to his videos.

Shelby Smoak shared upcoming hemophilia B treatments and we played our game *Are You Smarter than Your Hemophilia*, a fun game that sparks further conversation.

MAINE MEETING ON THE ROAD
APRIL 2018


















Special thanks to Rich Pezzillo, Jill Packard, Heather Case and Cheryl Ashmore for working with us to make this such a success!

In May, we headed to Birmingham, Alabama. Dr. David Clark, Chairman of The Coalition for Hemophilia B, welcomed everyone and Donnie Akers Esq. began his session on “Legal Tools for the Road of Life: Avoiding Poverty while Keeping Public Benefits.” The session focused on transition when a child becomes an adult, information on special needs trusts, the ABLE Act and tools to shelter assets and maintain Medicaid and other public benefits without having to live in poverty.

Steve Creel taught us the art of Tai Chi and how to apply the practice to our daily lives along with some Chinese martial arts self defense.

Dawn Hezel, RN presented on the B-HERO study, which focuses on psychosocial issues surveyed by 290 people with hemophilia B and 150 caregivers of children with hemophilia B. Their experiences and responses were documented to help us better understand how to address unmet needs in the hemophilia B community related to education, employment, and quality of life.

Attendees shared some personal stories during our family meeting in the afternoon and Dr. David Clark spoke on current products in hemophilia and what’s coming down the pipeline.

A big shout out to Vicki Jackson from the HBDA for working with us!

During each of our 12 Meetings on the Road this year, we will hold a special early raffle drawing to attend our 2019 Symposium at the Renaissance Orlando at SeaWorld March 14th-17th, 2018. Congratulations to our first winners - Tricia Hawk and Tristan Martin!

Thank you to our exhibitors and volunteers! You’re awesome! Special thank you to our sponsor, CSL Behring. We are grateful for your support!

CSL Behring

GAME ON!

CSL Behring

Biotherapies for Life™

The Coalition for Hemophilia B is delighted to nominate and send two members of our community to attend the ***2018 Gettin' in the Game Junior National Championship*** (JNC) presented by CSL Behring. The championship will take place September 28-29, 2018 in Phoenix, Arizona.

This contest is for kids between the ages of 7-18 with hemophilia B. To enter, you must write and submit an essay on **Why I Love** (choose one) **Baseball, Swimming or Golf**.

- Essay length should be age-appropriate.
- Include your name, age, diagnosis, address, phone, and your parent's name.
- All essays must be received by July 21, 2018, 5:00 pm.
- To submit your essays:
  - ◊ Email to karenb@hemob.org.
  - ◊ Or mail your submission to The Coalition for Hemophilia B, 757 Third Avenue, 20th Floor; New York, NY 10017
  - ◊ It can also be faxed to 212-520-8501
- The Coalition will announce its nominees on July 23, 2018
- Parents - encourage your kids, but don't write the essay for them. It's not about perfection. It's about letting them express their passion for a sport.
- Submit your essays early - by July 21, 2018 at the latest!

GOOD LUCK!

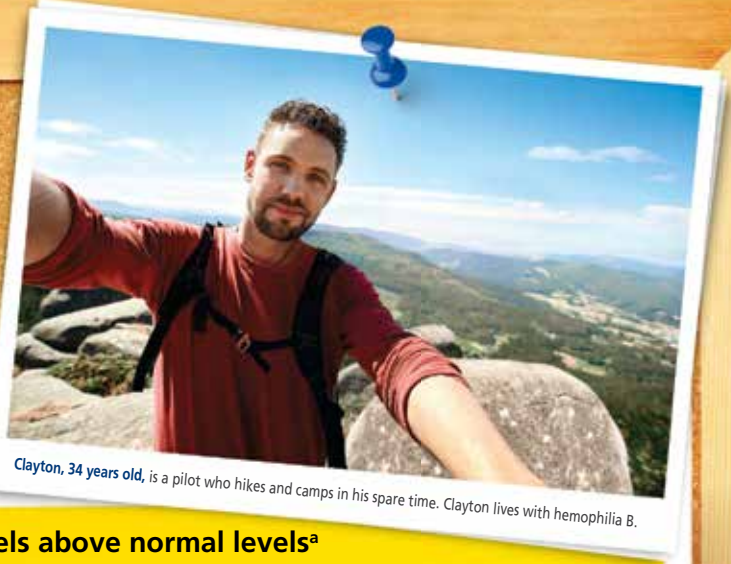
About JNC

- **The JNC program gives nominees the opportunity to participate in baseball, golf and swimming activities, enhance their skills, and learn the importance of physical fitness in managing a bleeding disorder— while engaging in a national competition with their peers.**
- **CSL Behring will sponsor each nominee and one accompanying adult to participate in the program. This sponsorship will include the coordination and cost of airfare, ground transportation in the program city, and hotel arrangements (attendees will be responsible for transportation to and from their hometown airport).**

In hemophilia B

TAKE CONTROL TO A HIGH LEVEL WITH REBINYN®

NOW AVAILABLE



Clayton, 34 years old, is a pilot who hikes and camps in his spare time. Clayton lives with hemophilia B.

Rebinyn® elevates factor levels above normal levels[a]

+94% Factor IX (FIX) levels achieved immediately after an infusion[b]

17% FIX levels sustained after 7 days[a]

With a single dose of Rebinyn® 40 IU/kg in adults with ≤2% FIX levels[a]

[a]In two phase 3 studies, factor levels were evaluated for 1 week after the first dose of Rebinyn® 40 IU/kg. The average levels after 7 days were 16.8% in 6 adults, 14.6% in 3 adolescents, 10.9% in 13 children ages 7 to 12 years, and 8.4% in 12 children up to age 6 years.

[b]Based upon a 2.34% increase in factor levels per IU/kg infused in adults.

Image of hemophilia B patient shown is for illustrative purposes only.

INDICATIONS AND USAGE

What is Rebinyn® Coagulation Factor IX (Recombinant), GlycoPEGylated?

Rebinyn® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Rebinyn® is used to treat and control bleeding in people with hemophilia B. Your healthcare provider may give you Rebinyn® when you have surgery. Rebinyn® is not used for routine prophylaxis or for immune tolerance therapy.

IMPORTANT SAFETY INFORMATION

What is the most important information I need to know about Rebinyn®?

- **Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center.** Carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing Rebinyn®.

Who should not use Rebinyn®?

Do not use Rebinyn® if you:

- are allergic to Factor IX or any of the other ingredients of Rebinyn®.
- are allergic to hamster proteins.

What should I tell my health care provider before using Rebinyn®?

Tell your health care provider if you:

- have or have had any medical conditions.
- take any medicines, including non-prescription medicines and dietary supplements.
- are nursing, pregnant, or plan to become pregnant.
- have been told you have inhibitors to Factor IX.

How should I use Rebinyn®?

- Rebinyn® is given as an infusion into the vein.
- **Call your healthcare provider right away if your bleeding does not stop after taking Rebinyn®.**
- Do not stop using Rebinyn® without consulting your healthcare provider.

What are the possible side effects of Rebinyn®?

- **Common side effects include** swelling, pain, rash or redness at the location of the infusion, and itching.
- **Call your healthcare provider right away or get emergency treatment right away if you get any of the following signs of an allergic reaction:** hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.
- **Tell your healthcare provider about any side effect that bothers you or that does not go away.**
- Animals given repeat doses of Rebinyn® showed Polyethylene Glycol (PEG) inside cells lining blood vessels in the choroid plexus, which makes the fluid that cushions the brain. The potential human implications of these animal tests are unknown.

Please see Brief Summary of Prescribing Information on the following page.

Rebinyn® is a prescription medication.

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.

Learn more at rebinyn.com

novo nordisk®

Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.

rebinyn®
Coagulation Factor IX (Recombinant), GlycoPEGylated

rebinyn®

Coagulation Factor IX (Recombinant), GlycoPEGylated

Brief Summary Information about:

REBINYN® Coagulation Factor IX (Recombinant), GlycoPEGylated

Rx Only

This information is not comprehensive.

- Talk to your healthcare provider or pharmacist
- Visit www.novo-pi.com/REBINYN.pdf to obtain FDA-approved product labeling
- Call 1-844-REB-INYN

Read the Patient Product Information and the Instructions For Use that come with REBINYN® before you start taking this medicine and each time you get a refill. There may be new information.

This Patient Product Information does not take the place of talking with your healthcare provider about your medical condition or treatment. If you have questions about REBINYN® after reading this information, ask your healthcare provider.

What is the most important information I need to know about REBINYN®?

Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing REBINYN® so that your treatment will work best for you.

What is REBINYN®?

REBINYN® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Hemophilia B is an inherited bleeding disorder in all age groups that prevents blood from clotting normally.

REBINYN® is used to treat and control bleeding in people with hemophilia B.

Your healthcare provider may give you REBINYN® when you have surgery.

REBINYN® is not used for routine prophylaxis or for immune tolerance therapy.

Who should not use REBINYN®?

You should not use REBINYN® if you

- are allergic to Factor IX or any of the other ingredients of REBINYN®
- if you are allergic to hamster proteins

If you are not sure, talk to your healthcare provider before using this medicine.

Tell your healthcare provider if you are pregnant or nursing because REBINYN® might not be right for you.

What should I tell my healthcare provider before I use REBINYN®?

You should tell your healthcare provider if you

- Have or have had any medical conditions.
- Take any medicines, including non-prescription medicines and dietary supplements.
- Are nursing.
- Are pregnant or planning to become pregnant.
- Have been told that you have inhibitors to Factor IX.

How should I use REBINYN®?

Treatment with REBINYN® should be started by a healthcare provider who is experienced in the care of patients with hemophilia B.

REBINYN® is given as an infusion into the vein.

You may infuse REBINYN® at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your hemophilia treatment center or healthcare provider. Many people with hemophilia B learn to infuse the medicine by themselves or with the help of a family member.

Your healthcare provider will tell you how much REBINYN® to use based on your weight, the severity of your hemophilia B, and where you are bleeding. Your dose will be calculated in international units, IU.

Call your healthcare provider right away if your bleeding does not stop after taking REBINYN®.

If your bleeding is not adequately controlled, it could be due to the development of Factor IX inhibitors. This should be checked by your healthcare provider. You might need a higher dose of REBINYN® or even a different product to control bleeding. Do not increase the total dose of REBINYN® to control your bleeding without consulting your healthcare provider.

Use in children

REBINYN® can be used in children. Your healthcare provider will decide the dose of REBINYN® you will receive.

If you forget to use REBINYN®

If you forget a dose, infuse the missed dose when you discover the mistake. Do not infuse a double dose to make up for a forgotten dose. Proceed with the next infusions as scheduled and continue as advised by your healthcare provider.

If you stop using REBINYN®

Do not stop using REBINYN® without consulting your healthcare provider.

If you have any further questions on the use of this product, ask your healthcare provider.

What if I take too much REBINYN®?

Always take REBINYN® exactly as your healthcare provider has told you. You should check with your healthcare provider if you are not sure. If you infuse more REBINYN® than recommended, tell your healthcare provider as soon as possible.

What are the possible side effects of REBINYN®?

Common Side Effects Include:

- swelling, pain, rash or redness at the location of infusion
- itching

Other Possible Side Effects:

You could have an allergic reaction to coagulation Factor IX products. **Call your healthcare provider right away or get emergency treatment right away if you get any of the following signs of an allergic reaction:** hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.

Your body can also make antibodies called "inhibitors" against REBINYN®, which may stop REBINYN® from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

You may be at an increased risk of forming blood clots in your body, especially if you have risk factors for developing blood clots. Call your healthcare provider if you have chest pain, difficulty breathing, leg tenderness or swelling.

Animals given repeat doses of REBINYN® showed Polyethylene Glycol (PEG) inside cells lining blood vessels in the choroid plexus, which makes the fluid that cushions the brain. The potential human implications of these animal tests are unknown.

These are not all of the possible side effects from REBINYN®. Ask your healthcare provider for more information. You are encouraged to report side effects to FDA at 1-800-FDA-1088.

Tell your healthcare provider about any side effect that bothers you or that does not go away.

What are the REBINYN® dosage strengths?

REBINYN® comes in three different dosage strengths. The actual number of international units (IU) of Factor IX in the vial will be imprinted on the label and on the box. The three different strengths are as follows:

Cap Color Indicator	Nominal Strength
Red	500 IU per vial
Green	1000 IU per vial
Yellow	2000 IU per vial

Always check the actual dosage strength printed on the label to make sure you are using the strength prescribed by your healthcare provider.

How should I store REBINYN®?

Prior to Reconstitution (mixing the dry powder in the vial with the diluent):

Store in original package in order to protect from light. Do not freeze REBINYN®.

REBINYN® vials can be stored in the refrigerator (36-46°F [2°C-8°C]) for up to 24 months until the expiration date, or at room temperature (up to 86°F [30°C]) for a single period not more than 6 months.

If you choose to store REBINYN® at room temperature:

- Note the date that the product is removed from refrigeration on the box.
- The total time of storage at room temperature should not be more than 6 months. Do not return the product to the refrigerator.
- Do not use after 6 months from this date or the expiration date listed on the vial, whichever is earlier.

Do not use this medicine after the expiration date which is on the outer carton and the vial. The expiration date refers to the last day of that month.

After Reconstitution:

The reconstituted (the final product once the powder is mixed with the diluent) REBINYN® should appear clear without visible particles.

The reconstituted REBINYN® should be used immediately.

If you cannot use the reconstituted REBINYN® immediately, it should be used within 4 hours when stored at or below 86°F (30°C). Store the reconstituted product in the vial.

Keep this medicine out of the sight and out of reach of children.

What else should I know about REBINYN® and hemophilia B?

Medicines are sometimes prescribed for purposes other than those listed here. Do not use REBINYN® for a condition for which it is not prescribed. Do not share REBINYN® with other people, even if they have the same symptoms that you have.

More detailed information is available upon request.

Available by prescription only.

For more information about REBINYN®, please call Novo Nordisk at 1-844-REB-INYN.

Revised: 11/2017

REBINYN® is a trademark of Novo Nordisk A/S.

For Patent Information, refer to: http://novonordisk-us.com/patients/products/product-patents.html

Manufactured by:
Novo Nordisk A/S
Novo Allé, DK-2880 Bagsværd, Denmark

For information about REBINYN® contact:
Novo Nordisk Inc.
800 Scudders Mill Road
Plainsboro, NJ 08536, USA

USA17BIO03951 12/2017

novo nordisk®

INDUSTRY NEWS

BY DR. DAVID CLARK

Much of the following news comes from the annual meeting of the American Society of Gene & Cell Therapy (ASGCT) in Chicago May 16 - 19, 2018, and the 2018 Congress of the World Federation of Hemophilia (WFH), May 20-24 in Glasgow, Scotland.

Alnylam/Sanofi on the Use of Bypassing Agents with Fitusiran

Alnylam/Sanofi presented results at WFH on the use of bypassing agents with their antithrombin inhibitor fitusiran in patients with and without inhibitors. They found that lower doses of bypassing agents, NovoSeven or FEIBA, can be used to treat breakthrough bleeds in patients on fitusiran.

ApcinteX Presents Data on SerpinPC in Mice

ApcinteX Ltd. is developing SerpinPC, an inhibitor of the anticoagulant activated protein C, to try to restore the clottability of the blood in hemophilia patients. Preclinical studies in mice show that SerpinPC can increase thrombin generation and restore hemostasis in hemophilic mice.

Catalyst Biosciences Halts Clinical Study

Catalyst Biosciences announced on June 18 that they are halting the clinical study of their subcutaneous CB 2679d factor IX variant. The company recently started the sixth higher-dose cohort of patients. The first two patients in the cohort both developed inhibitors to CB 2679d. Both patients had also participated in Cohort 5 during which neither had shown any evidence of inhibitor formation. The patients both reached trough levels in the low-30% range before the inhibitors were discovered. Fortunately, the inhibitors appear to be directed against CB 2679d and not normal factor IX, so the patients can continue treatment with conventional factor IX products. The study will be delayed indefinitely while Catalyst tries to figure out the problem.

CHOP Researchers Developing Skeletal Muscle Gene Therapy for Hemophilia B

Researchers at Children's Hospital of Philadelphia (CHOP) and their collaborators are developing a gene therapy treatment for hemophilia B in which the new factor IX gene is introduced into skeletal muscle cells rather than liver cells. They believe this will be a safer method without the threat of an immune response to the vector. They have gotten promising results in Hemophilia B dogs.

coreHEM Study presents results

The coreHEM project is jointly led by the National Hemophilia Foundation, the Green Park Collaborative and McMaster University to determine a core set of outcomes for clinical studies of gene therapy for hemophilia. This is to help patients, providers and payers compare various gene therapies along with the current standard of care. So far, there is consensus on three outcomes: bleed frequency, factor level and duration of factor expression. Additional outcomes will include pain, physical functioning, emotional functioning and others.

CSL Announces 3500 IU Vial for Idelvion

On May 31st, CSL Behring announced that they have received FDA approval for a 3500 IU vial size for Idelvion, their extended half-life factor IX product. Idelvion is now available in five vial sizes ranging from 250 to 3500 IU. The new size will increase convenience for patients who require larger doses.

FDA Plans to Speed Approval for Hemophilia Gene Therapies

FDA Commissioner Scott Gottlieb has announced that certain gene therapies may qualify for a less arduous review by the agency. The first therapeutic area to be addressed will be hemophilia. For instance, gene therapies for hemophilia may be licensed based on increased factor levels in the blood regardless of whether patients bleed less. However, companies may then be required to perform additional clinical studies after licensure to ensure that therapies actually do reduce bleeding and to explore the length of time that the benefit lasts.

LogicBio Presents Data on Hemophilia B Gene Therapy in Mice

LogicBio Therapeutics presented results at the ASGCT meeting showing that their GeneRide technology can successfully introduce a hyperactive factor IX gene into the albumin gene locus in hemophilia B mice. The treated mice had clotting times comparable to wild-type mice.

Medscape Launches Hemophilia Gene Therapy Education Program

Medscape in collaboration with the National Hemophilia Foundation, the European Hemophilia Consortion and the World Federation of Hemophilia, supported by a grant from BioMarin, recently launched a hemophilia gene therapy education program on the internet. It is mainly intended for healthcare professionals who treat hemophilia patients, but it is accessible to anyone. The first module is a quiz to test your knowledge of gene therapy. The site, which is at https://www.medscape.org/sites/advances/gene-therapy-hemophilia?src=acdmpart_nhf_gene-therapy-hemophilia will be updated periodically.

Novo Presents Data on Rebinyn

Novo Nordisk presented data at WFH from a pharmacokinetic study comparing their Rebinyn factor IX product with Alprolix. The recovery of Rebinyn after infusion was about twice that of Alprolix, and its half-life was 103 hours compared to 85 hours for Alprolix. The higher recovery of Rebinyn suggests that the PEG-coupled product may not migrate into the extravascular space (outside the bloodstream) in the same way that conventional factor IX products do. The role of extravascular factor IX distribution in the control of bleeding and joint damage is currently not well understood.

Novo Announces Results for Concizumab Study

Novo Nordisk is developing concizumab to inhibit Tissue Factor Pathway Inhibitor (TFPI), an anticoagulant in the clotting system, and potentially restore the clotability of the blood in hemophilia patients. One important question is whether tweaking the clotting system like that could lead to a dangerous situation in which the blood clots too easily. Novo looked at combinations of concizumab and either NovoSeven or FEIBA, which are both pro-coagulants used to treat hemophilia patients with inhibitors to see whether the treatments might promote too much clotting. They found no apparent problems.

Pfizer and Spark Present Gene Therapy Data

Pfizer and Spark Therapeutics announced results from their ongoing gene therapy clinical studies at the WFH meeting. All 15 patients treated to date have been able to discontinue prophylaxis with factor IX, with the first patients having been observed for as long as 121 weeks. There have been no serious adverse events and no evidence of inhibitor formation. The annualized bleeding rate was reduced from 8.9 before treatment to 0.2. Only one participant has experienced a bleeding episode.

Salk Institute Researchers Developing Liver Stem Cell Gene Therapy

Researchers at the Salk Institute are developing a gene therapy treatment for hemophilia B in which they use the CRISPR/Cas9 gene editing method to repair or replace mutated factor IX genes in liver stem cells. In experiments with mice, they harvested peripheral stem cells from the bloodstream and modified them to generate liver stem cells. They then used CRISPR/Cas9 to correct the mutated factor IX gene in the cells. The modified liver stem cells were then transplanted back into the mice where they generated human factor IX for at least ten months.

Shire Being Purchased by Takeda

Shire PLC, an Irish company that manufactures a number of products for treatment of hemophilia and other bleeding disorders, is being taken over by Takeda Pharmaceutical, a Japanese company for $62 billion. Shire had previously purchased Baxalta, the former hemophilia business of Baxter in 2016.

Sigilon Developing Cell-Based Gene Therapy for Hemophilia B

Sigilon Therapeutics is developing a hemophilia B gene therapy treatment that consists of genetically-modified cells that express factor IX. The cells are encapsulated in a polymer material called Afibromer that prevents the immune system from seeing them as a foreign body. The plan is to place the encapsulated cells in the lesser sac (omental bursa), which is a small cavity between the stomach and liver where they will generate factor IX.

UCLA Researchers Develop Nanospears for Gene Therapy

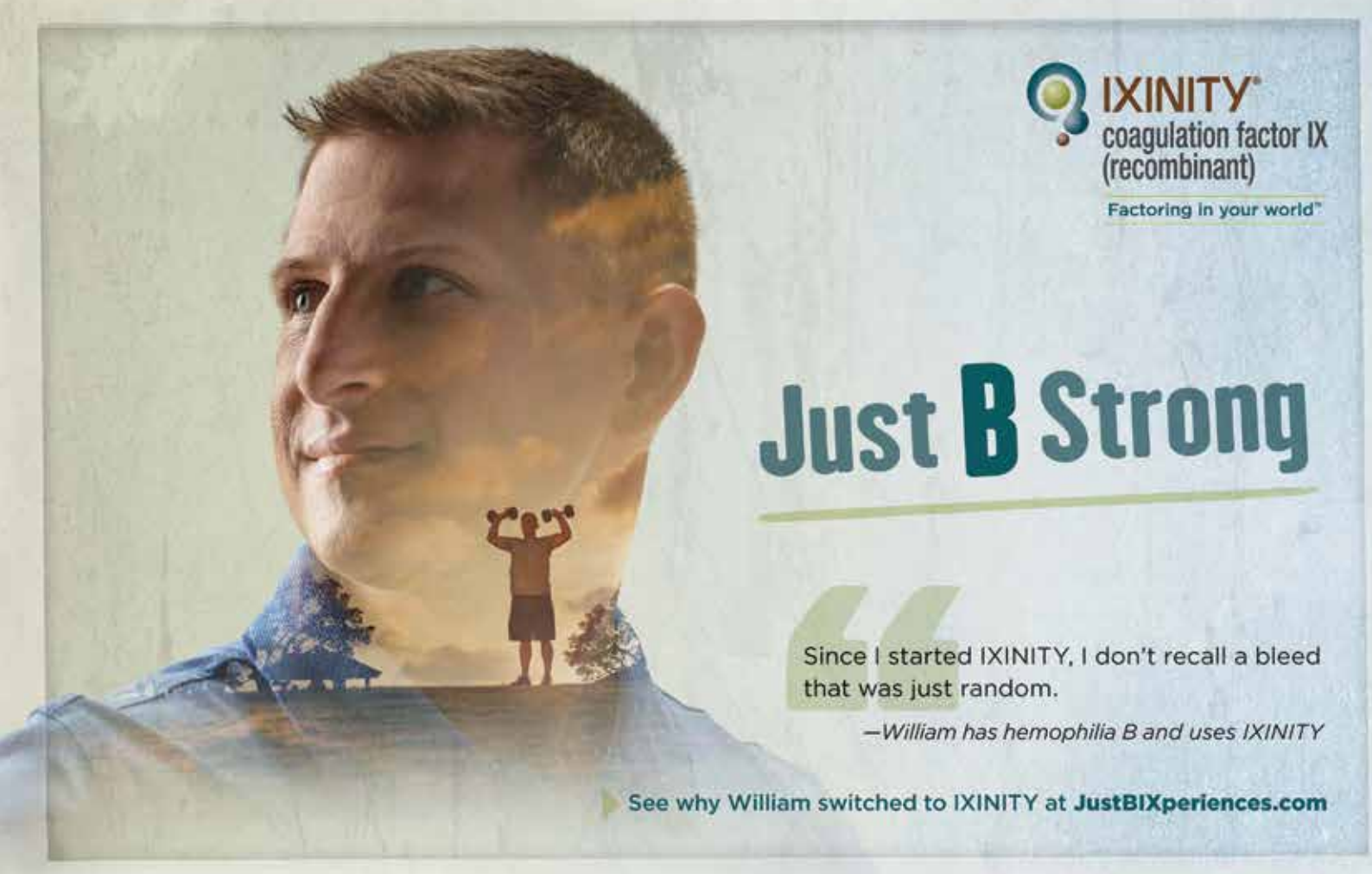
A group of researchers at the University of California, Los Angeles (UCLA) is developing needle-like nanospears that can transfer genetic material into cells for gene therapy. Inserting genetic material into cells is a challenge. Many of the early gene therapy treatments use modified viruses to deliver new genes to cells, but those can trigger immune system responses. The UCLA researchers have developed nanospears that are 1/1000th the diameter of a human hair and can penetrate cells without damaging them to deliver new genetic material. Cells would be harvested from the patient, then transformed in the lab with the new genetic material, and re-implanted back in the patient's body.

uniQure Reports on Gene Therapy Studies for Hemophilia B

At the ASGCT meeting, uniQure, a Netherlands-based gene therapy company, reported on a re-analysis of patient pre-treatment data that suggests that even patients with pre-existing antibodies to their AAV5 vector showed beneficial outcomes in the study. uniQure believes that they can increase the factor IX levels in patients by using the highly-active Padua variant, which is about eight times more active than normal factor IX. They plan to begin a dose-confirmation study in three patients by the end of the second quarter of 2018 and then initiate enrollment for a pivotal trial.

Washington University Developing CRISPR Gene Therapy for Hemophilia B

Researchers at Washington University School of Medicine in St. Louis are using the CRISPR gene editing technique to insert new genetic material into cells using adenoviruses. CRISPR can place a new gene into a desired location in the genome of a cell, providing much better control of the treatment. So far, they have obtained good results in mice with their technique.



IXINITY®
coagulation factor IX (recombinant)
Factoring in your world™

Just B Strong

"Since I started IXINITY, I don't recall a bleed that was just random.

—William has hemophilia B and uses IXINITY

See why William switched to IXINITY at JustBIXperiences.com

This information is based on William's experience. Different patients may have different results. Talk to your doctor about whether IXINITY® may be right for you.

INDICATIONS AND IMPORTANT SAFETY INFORMATION

What is IXINITY®?

IXINITY [coagulation factor IX (recombinant)] is a medicine used to replace clotting factor (factor IX) that is missing in adults and children at least 12 years of age with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Hemophilia B is an inherited bleeding disorder that prevents clotting. Your healthcare provider may give you IXINITY to control and prevent bleeding episodes or when you have surgery.

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

IMPORTANT SAFETY INFORMATION for IXINITY®

- You should not use IXINITY if you are allergic to hamsters or any ingredients in IXINITY.
- You should tell your healthcare provider if you have or have had medical problems, take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies, have any allergies, including allergies to hamsters, are nursing, are pregnant or planning to become pregnant, or have been told that you have inhibitors to factor IX.
- You can experience an allergic reaction to IXINITY. Contact your healthcare provider or get emergency treatment right away if you develop a rash or hives, itching, tightness of the throat, chest pain, or tightness, difficulty breathing, lightheadedness, dizziness, nausea, or fainting.
- Your body may form inhibitors to IXINITY. An inhibitor is part of the body's defense system. If you develop inhibitors, it may prevent IXINITY from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for development of inhibitors to IXINITY.
- If you have risk factors for developing blood clots, the use of IXINITY may increase the risk of abnormal blood clots.
- Call your healthcare provider right away about any side effects that bother you or do not go away, or if your bleeding does not stop after taking IXINITY.
- The most common side effect that was reported with IXINITY during clinical trials was headache.
- These are not all the side effects possible with IXINITY. You can ask your healthcare provider for information that is written for healthcare professionals.

You are encouraged to report side effects of prescription drugs to the Food and Drug Administration. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see accompanying brief summary of Prescribing Information on next page.

Aptevo™ Therapeutics

Aptevo BioTherapeutics LLC, Berwyn, PA 19312

IXINITY®
coagulation factor IX
(recombinant)
Factoring in your world™

IXINITY® [coagulation factor IX (recombinant)]

Brief Summary for the Patient

See package insert for full Prescribing Information. This product's label may have been updated. For further product information and current package insert, please visit www.IXINITY.com.

Please read this Patient Information carefully before using IXINITY. This brief summary does not take the place of talking with your healthcare provider, and it does not include all of the important information about IXINITY.

What is IXINITY?

IXINITY is a medicine used to replace clotting factor (factor IX) that is missing in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Hemophilia B is an inherited bleeding disorder that prevents clotting. Your healthcare provider may give you IXINITY when you have surgery.

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

Who should not use IXINITY?

You should not use IXINITY if you:

- Are allergic to hamsters
- Are allergic to any ingredients in IXINITY

Tell your healthcare provider if you are pregnant or breastfeeding because IXINITY may not be right for you.

What should I tell my healthcare provider before using IXINITY?

You should tell your healthcare provider if you:

- Have or have had any medical problems
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies
- Have any allergies, including allergies to hamsters
- Are breastfeeding. It is not known if IXINITY passes into your milk and if it can harm your baby
- Are pregnant or planning to become pregnant. It is not known if IXINITY may harm your baby
- Have been told that you have inhibitors to factor IX (because IXINITY may not work for you)

How should I infuse IXINITY?

IXINITY is given directly into the bloodstream. IXINITY should be administered as ordered by your healthcare provider. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia B learn to infuse their IXINITY by themselves or with the help of a family member.

See the step-by-step instructions for infusing in the complete patient labeling.

Your healthcare provider will tell you how much IXINITY to use based on your weight, the severity of your hemophilia B, and where you are bleeding. You may have to have blood tests done after getting IXINITY to be sure that your blood level of factor IX is high enough to stop the bleeding. Call your healthcare provider right away if your bleeding does not stop after taking IXINITY.

What are the possible side effects of IXINITY?

Allergic reactions may occur with IXINITY. Call your healthcare provider or get emergency treatment right away if you have any of the following symptoms:

- Rash
- Hives
- Itching
- Tightness of the throat
- Chest pain or tightness
- Difficulty breathing
- Lightheadedness
- Dizziness
- Nausea
- Fainting

Tell your healthcare provider about any side effect that bothers you or does not go away.

The most common side effect of IXINITY in clinical trials was headache.

These are not all of the possible side effects of IXINITY. You can ask your healthcare provider for information that is written for healthcare professionals.

Call your healthcare provider for medical advice about side effects. You may report side effects to the FDA at 1-800-FDA-1088.

How should I store IXINITY?

250 IU strength only; store at 2 to 8°C (36 to 46°F). Do not freeze.

500, 1000, 1500, 2000 and 3000 IU strengths; store at 2 to 25°C (36 to 77°F). Do not freeze.

Do not use IXINITY after the expiration date printed on the label. Throw away any unused IXINITY and diluents after it reaches this date.

Reconstituted product (after mixing dry product with Sterile Water for Injection) must be used within 3 hours and cannot be stored or refrigerated. Discard any IXINITY left in the vial at the end of your infusion.

After reconstitution of the lyophilized powder, all dosage strengths should yield a clear, colorless solution without visible particles. Discard if visible particulate matter or discoloration is observed.

What else should I know about IXINITY?

Your body may form inhibitors to factor IX. An inhibitor is part of the body's immune system. If you form inhibitors, it may stop IXINITY from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests to check for the development of inhibitors to factor IX. Consult your doctor promptly if bleeding is not controlled with IXINITY as expected.

Medicines are sometimes prescribed for purposes other than those listed here. Do not use IXINITY for a condition for which it is not prescribed. Do not share IXINITY with other people, even if they have the same symptoms as you.

Always check the actual dosage strength printed on the label to make sure you are using the strength prescribed by your healthcare provider.

Aptevo™ Therapeutics

Manufactured by:
Aptevo BioTherapeutics LLC
Berwyn PA, 19312
U.S. License No. 2054

Part No: 1000973_1
CM-FIX-0078

THE B VOICE AT NHF'S WASHINGTON DAYS

By Glenn Mones

From March 7-9, 2018, representatives from The Coalition for Hemophilia B were among the hundreds of community members gathering from across the country for ***NHF's Washington Days***, the bleeding disorders community's annual visit to our nation's capital. The event is an opportunity for people affected by bleeding disorders to communicate their needs and concerns to our elected officials.

During hundreds of meetings with legislators and staff members, patient, families, hemophilia organizations, chapters, and medical professionals throughout the USA brought attention to the importance of maintaining the gains of the Affordable Care Act (ACA), sometimes known as Obamacare. We also called for continued funding for programs that benefit our community, including the nationwide system of federally funded hemophilia treatment centers (HTCs).

Next year, we will raise our voices higher as we strengthen our presence and provide grants to some of our members to attend, and help ensure that the unique "B Voice" will always be included in the exchange of views and information. That's why we now call our ongoing advocacy program ***The B Voice.*** Through The B Voice program, we will create opportunities for community members to make their voices heard. These will include additional contacts with legislators, email campaigns, and advocacy discussions during The Coalition for Hemophilia B programs. We need everyone in the community to get involved. All of our health depends on it.

To sign up for advocacy notifications or to learn more, please visit http://www.hemob.org/advocacy/.

WHERE ARE THEY NOW?

Our scholarship recipients have reached for the stars and are achieving their dreams!

A diagnosis of hemophilia B can often place additional challenges on a family. The William N. Drohan Memorial Scholarship has helped ease the burden of the cost of education for our deserving students. We applaud their bright futures and wish them continued success! Please consider contributing to our scholarship fund designated to assist students with hemophilia B and their siblings.

Let's help them be the best they can be!

WHERE ARE THEY NOW?

DANIEL J.S. VETTER

Current: Ph.D. Student PsychoNeuroImmunology
Where: University of Illinois, Champaign/Urbana
Graduated: 2017 Illinois State Univ. Bloomington/Normal
Degree: BS in Biology

WILLIAM N. DROHAN MEMORIAL SCHOLARSHIP RECIPIENT

WHERE ARE THEY NOW?

ELIZABETH VANSANT

Current: Senior Student
Where: University of Kansas, Lawrence
Major: Music Therapy
Goal: Music Therapy Board Certification

WILLIAM N. DROHAN MEMORIAL SCHOLARSHIP RECIPIENT

WHERE ARE THEY NOW?

ALECIA SCLAFANI

Current: Freshman Student
Where: St. John's University, Queens, New York
Major: Speech PathologyEnglish
Minor: English
Goal: MA in Speech Pathology

WILLIAM N. DROHAN MEMORIAL SCHOLARSHIP RECIPIENT

WHERE ARE THEY NOW?

EVAN POOLE

Current: Mechanical Engineer
Where: Bloomington, Indiana
Graduated: 2017 Trine University Angola, Indiana
Degree: BS in Mechanical Engineering

WILLIAM N. DROHAN MEMORIAL SCHOLARSHIP RECIPIENT

WHERE ARE THEY NOW?

ANNA R. VETTER

Current: Deputy Chief of Staff
Where: House of Representatives Washington DC
Graduated: 2011 University of Illinois Champaign/Urbana
Degree: BA in Advertising/ Political Science

WILLIAM N. DROHAN MEMORIAL SCHOLARSHIP RECIPIENT

HEMOPHILIA & ANTICOAGULANTS IN CARDIOVASCULAR DISEASE

BY DR. DAVID CLARK

Medical science is now learning more about an increasingly common type of patient, the older hemophiliac. Until the development of clotting factor concentrates in the 1960s, most hemophilia patients did not live to old age. Then the AIDS crisis in the 1980s wiped out a large portion of the hemophilia community. It is only now in the early 21st century that we are encountering numbers of hemophilia patients needing treatment for the diseases of old age, including cardiovascular disease.

As people age, their cardiovascular risk factors such as hypertension (high blood pressure), obesity and diabetes generally increase. In fact, hemophilia patients are known to be at higher risk for hypertension. Smoking is another important risk factor, as it is for the general population. However, a hemophilia patient's risk of death from myocardial infarction (heart attack) and stroke is lower for unknown reasons. Their risk of atherosclerosis (hardening of the arteries, which can lead to a heart attack) is the same, but does not lead to death as often. This has raised the question whether there is a protective effect of having hemophilia, especially for severe patients. However, raising factor levels with prophylaxis may eliminate that effect.

Two additional cardiovascular issues being seen more frequently as hemophilia patients age are atrial fibrillation and acute coronary syndrome/angina. All of these are normally managed using long-term anticoagulants and antiplatelet medications, but are these appropriate for patients with hemophilia?

Hemophilia patients are typically warned to avoid medications like aspirin (an antiplatelet agent) because they could exacerbate their bleeding problems. Warfarin (Coumadin, an anticoagulant), which is often used as an anticoagulant for stroke prevention and treatment of atrial fibrillation and mechanical heart valves, is associated with an increased risk of intracranial hemorrhage, also an issue for hemophilia patients.

Because of the small number of patients, there is a real lack of data on treating hemophilia patients with cardiovascular diseases. The first approach is to reduce risk factors, wherever possible. Then, there are a number of reports in the medical literature of patients being treated successfully with anticoagulants and antiplatelet agents. Treating hemophilia patients is a complex matter. Each patient must be considered individually and monitored carefully, preferably with close cooperation between a cardiologist who has a thorough understanding of the cardiovascular properties of the drugs and a hematologist who has a good understanding of the clotting system.

Severe (FIX < 1%) and moderate (FIX 1-5%) hemophilia patients being treated with anticoagulants or antiplatelet agents are often placed on prophylaxis with trough levels in the 20-30% range. Mild patients (FIX 5-50%) can sometimes be treated while not on prophylaxis, but they should be monitored closely for any increased bleeding tendencies. Extended half-life factor products now make it easier to maintain higher trough levels, but the cost of treatment may be an issue. There is also a concern that increasing factor levels in elderly patients could trigger inhibitor development. Antiplatelet agents may be preferred in some cases because they are less dependent on maintaining higher trough levels.

Anticoagulants and antiplatelet agents that can be easily reversed are preferred, so that if bleeding occurs, it can be treated more quickly. Anticoagulants/antiplatelet agents should be used for the minimum time necessary, although with conditions like atrial fibrillation, therapy must be long term.

This is a new era in hemophilia treatment. There are no standard guidelines for treating many of the diseases of old age in patients with hemophilia. Physicians are generally proceeding carefully and are having success with many older patients. As they gain experience, treatment regimens should become better defined and more commonplace.

UPCOMING EVENTS 2018!

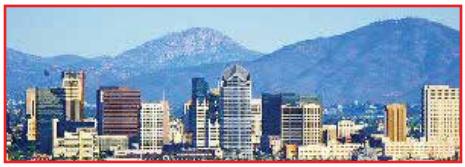
MEN'S RETREAT
PHOENIX, AZ
THURSDAY to SUNDAY
SEPTEMBER 13-16, 2018
Arizona Grand Resort
8000 Arizona Grand Parkway
Phoenix, AZ 85044

MEETING ON THE ROAD
CHARLOTTE, NC
SATURDAY
OCTOBER 6, 2018
Embassy Suites-Concord/ Charlotte
5400 John Q. Hammons Dr NW,
Concord, NC 28027

MEETING ON THE ROAD
SAN FRANCISCO, CA
SATURDAY
NOVEMBER 17, 2018
San Francisco Airport Marriott Waterfront
1800 Old Bayshore Highway
Burlingame, CA 94010

MEETING ON THE ROAD
PITTSBURGH, PA
SATURDAY
SEPTEMBER 22, 2018
Pittsburgh City Center Marriott
110 Washington Place
Pittsburgh, PA 15219

MEETING ON THE ROAD
PRINCETON, NJ
SATURDAY
NOVEMBER 3, 2018
Westin Princeton at Forrestal Village
201 Village Blvd
Princeton, NJ 08540



MEETING ON THE ROAD
ANAHEIM, CA
SATURDAY
NOVEMBER 17, 2018
Anaheim Marriott Suites
12015 S. Harbor Blvd.
Garden Grove, CA 92840

WOMEN'S RETREAT
PHOENIX, AZ
THURSDAY to SUNDAY
SEPTEMBER 27-30, 2018
Arizona Grand Resort
8000 Arizona Grand Parkway
Phoenix, AZ 85044

MEETING ON THE ROAD
RICHMOND, VA
SATURDAY
NOVEMBER 10, 2018
The Westin Richmond
6631 W Broad Street
Richmond, VA 23230

MEETING ON THE ROAD
SAN ANTONIO, TX
SATURDAY
DECEMBER 1, 2018
San Antonio Marriott Rivercenter
101 Bowie Street
San Antonio, TX 78205

MEETING ON THE ROAD
ALBUQUERQUE, NM
SATURDAY
OCTOBER 6, 2018
Albuquerque Marriott
2101 Louisiana Blvd NE
Albuquerque, NM 87110

MEETING ON THE ROAD
DENVER, CO
SATURDAY
NOVEMBER 10, 2018
Denver Marriott S. at Park Meadows
10345 Park Meadows Drive
Lone Tree, CO 80124

MEETING ON THE ROAD
CORTLAND, NY
SATURDAY
DECEMBER 1, 2018
Hope Lake Lodge & Indoor Waterpark
2000 NYS Route 392
Cortland, NY 13045

DON'T STAND ON THE SIDELINES

LEARN IF **RIXUBIS®** MAY BE RIGHT FOR YOU

Visit **RIXUBIS.com** to find your local Shire sales representative

Indications for RIXUBIS [Coagulation Factor IX (Recombinant)]

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

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

Detailed Important Risk Information

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.

Allergic reactions have been reported with 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 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.

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 following page for RIXUBIS Important Facts.

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.

Shire

RIXUBIS
[COAGULATION FACTOR IX (RECOMBINANT)]

MOVING FORWARD

RIXUBIS
[COAGULATION FACTOR IX (RECOMBINANT)]

Important facts about

RIXUBIS [Coagulation Factor IX (Recombinant)]

This leaflet summarizes important information about RIXUBIS. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about RIXUBIS. If you have any questions after reading this, ask your healthcare provider.

What is RIXUBIS?

RIXUBIS is a medicine used to replace clotting factor (Factor IX) that is missing in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Hemophilia B is an inherited bleeding disorder that prevents blood from clotting normally. RIXUBIS is used to prevent and control bleeding in people with hemophilia B. Your healthcare provider may give you RIXUBIS when you have surgery. RIXUBIS can reduce the number of bleeding episodes when used regularly (prophylaxis).

Who should not use RIXUBIS?

You should not use RIXUBIS if you

- are allergic to hamsters
- are allergic to any ingredients in RIXUBIS.

Tell your healthcare provider if you are pregnant or breastfeeding because RIXUBIS may not be right for you.

What should I tell my healthcare provider before using 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 breastfeeding. It is not known if RIXUBIS passes into your milk and if it can harm your baby
- are pregnant or planning to become pregnant. It is not known if RIXUBIS may harm your unborn baby
- have been told that you have inhibitors to factor IX (because RIXUBIS may not work for you).

How should I infuse RIXUBIS?

RIXUBIS is given directly into the bloodstream. RIXUBIS should be administered as ordered by your healthcare provider. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia B learn to infuse their RIXUBIS by themselves or with the help of a family member.

Your healthcare provider will tell you how much RIXUBIS to use based on your weight, the severity of your hemophilia B, and where you are bleeding. You may have to have blood tests done after getting RIXUBIS to be sure that your blood level of factor IX is high enough to clot your blood. Call your healthcare provider right away if your bleeding does not stop after taking RIXUBIS.

What are the possible side effects of RIXUBIS?

Allergic reactions may occur with 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. Some common side effects of RIXUBIS were unusual taste in the mouth and limb pain. Tell your healthcare provider about any side effects that bother you or do not go away. These are not all the side effects possible with RIXUBIS. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about RIXUBIS?

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.

Medicines are sometimes prescribed for purposes other than those listed here. Do not use RIXUBIS for a condition for which it is not prescribed. Do not share RIXUBIS with other people, even if they have the same symptoms that you have.

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.

The risk information provided here is not comprehensive. To learn more, talk about RIXUBIS with your healthcare provider or pharmacist. The FDA-approved product labeling can be found at http://www.shirecontent.com/PI/PDFs/RIXUBIS_USA_ENG.pdf or by calling 1-800-FDA-1088.

Issued 03/2016

Baxalta US Inc.

Westlake Village, CA 91362 USA
U.S. License No. 2020
S27967 02/17

Shire

Your Chance for a Travel Grant to Join Us in Orlando – March 14-17, 2019!

The Coalition for Hemophilia B's Annual Symposium will take place from Thursday, March 14 until Sunday, March 17, 2019 at the Renaissance Orlando at SeaWorld – that's an extra day over past symposium! This is your chance to be awarded a travel grant for airfare and three nights hotel in Florida.

The Coalition for Hemophilia B's Annual Symposium is the largest regular gathering geared exclusively for families and individuals affected by hemophilia B. It features educational meetings and multiple opportunities to share knowledge, strength and experience. A number of full travel scholarships are available to select eligible community members. To have your name placed into consideration, please complete the form on the second page and return as directed.

All forms must be received by September 15, 2018.

Please note that those who receive family grants will be asked to pay a fee of $150 to cover a portion of additional room costs. Other than this fee, just about everything is covered by the grant including:

- **3 hotel nights at the beautiful Renaissance at Sea World**
- **Roundtrip airfare**
- **Transportation to and from airport**
- **Gas and tolls reimbursed, parking is free**
- **Registration (includes access to all sessions)**
- **Most meals included**
- **Access to final night event**
- **Childcare provided throughout event weekend**
- **In-room Bottled Water (Refreshed once per day)**
- **Wireless In-Room Internet**
- **Free Disney World / Universal Studios / Premium Outlets Transportation (must not conflict with Symposium programming)**
- **10% Discount in Tradewinds for dinner**
- **Free Breakfast for Children 12 & Under (2 kids per 1 adult purchase, Tradewinds Restaurant only)**

THE COALITION FOR HEMOPHILIA B

Coalition for Hemophilia B Symposium
Registration for Travel Grant Chance

To have your name placed into consideration, please complete this form and return it to the Coalition for Hemophilia B, 757 Third Avenue, 20th Floor, New York, NY 10017, or scan and email to farrahm@hemob.org.

All forms must be received by September 15, 2018.

NAME _____ **TEL** _____ **CELL** _____

Address _____ **CITY** _____

STATE _____ **ZIP** _____ **EMAIL** _____

Please list the names of all family members who would be attending, including yourself. along with age and relationship to you. Place a check next to the names of individuals with hemophilia B. Please understand that if a grant is awarded, we cannot guarantee that all family members will be covered.

NAME	HEMOPHILIA B?	AGE	RELATIONSHIP TO YOU
	☐		
	☐		
	☐		
	☐		
	☐		
	☐		

THE COALITION FOR HEMOPHILIA

"One of the most important things you can do on this earth is to let people know they are not alone."

— Shannon L. Alder

BCares

THE COALITION FOR HEMOPHILIA B PATIENT ASSISTANCE PROGRAM

The high cost of medical care is often a challenge for people with hemophilia B. Fortunately, insurance coverage, government programs and other forms of patient assistance cover much of that cost. Unfortunately, these programs do not cover the cost of non-medical emergencies, which may interfere with a family or individual's ability to deal with day-to-day life with a bleeding disorder. These emergencies may involve struggling to having enough resources for housing, food, transportation, or a range of other necessary and critical needs.

When these needs are not met, the health and well being of the patient, as well as the entire family can be negatively affected. Often, assisting a person in an immediate circumstance is all that's needed to keep the situation from spiraling out of control.

The Coalition for Hemophilia B deeply cares about families and individuals, and the urgent needs they may face. Several years ago, because of this and in order to live true to our mission statement, we established a patient assistance program for hemophilia B patients and families. We reintroduce our program as ***BCares.***

BCares operates with funding generously donated by pharmaceutical manufacturers, homecare companies, business partners, and other interested supporters.

Those donating share our belief - in the case of an urgent situation, we can all do more to help. It is our obligation as a community to lend a hand and assist those in short term, dire straits.

The Coalition for Hemophilia B is able to offer a limited amount of financial aid to our factor 9 community members who face a financial emergency. Those requesting assistance can submit a simple, confidential application. Each application will be reviewed thoroughly by a committee, who will determine and prioritize grants based on the request and level of urgency.

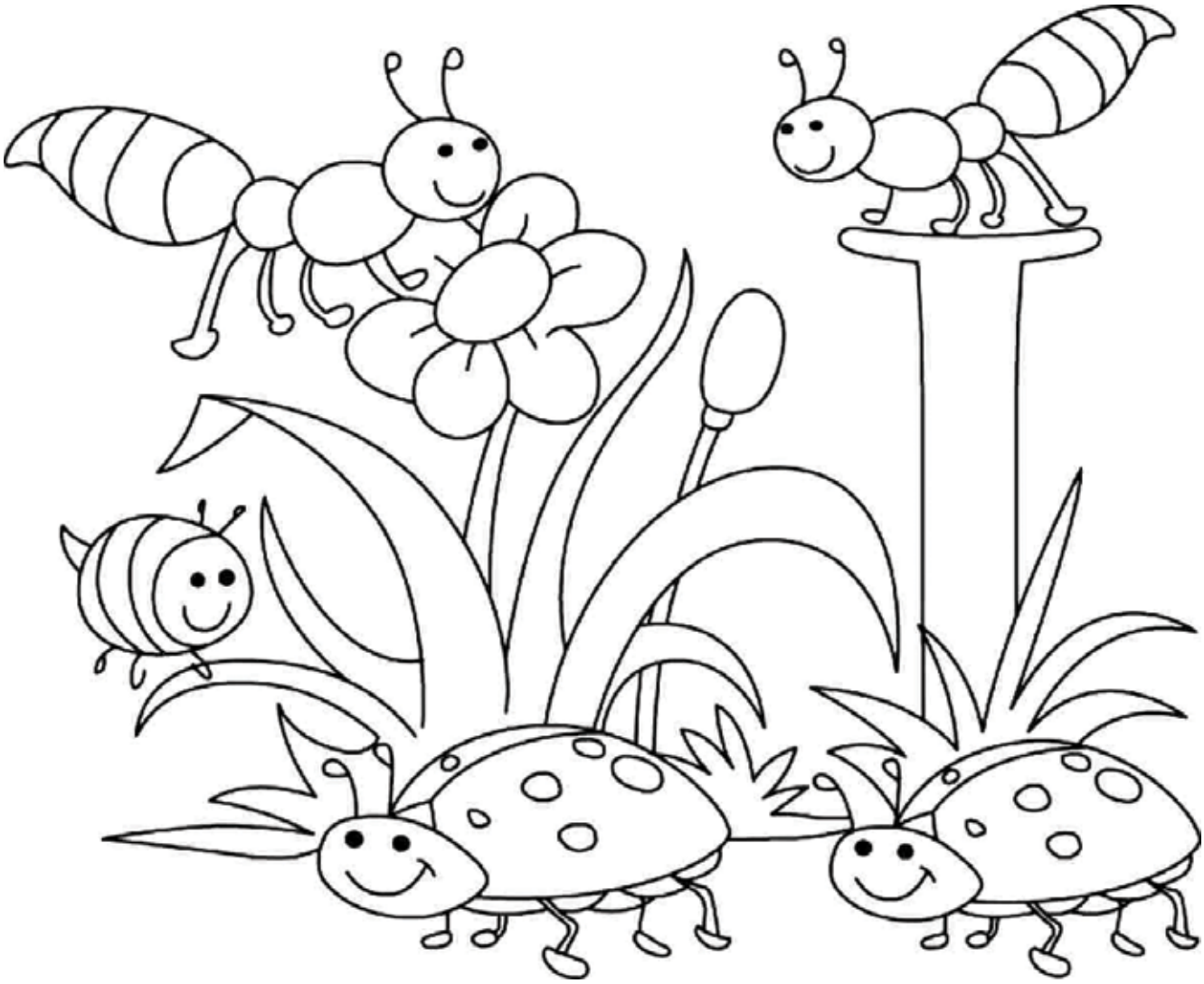
How you can help: We are exceedingly grateful to the donors whose charity and compassion have made this critical program possible. Please consider becoming involved by offering additional funds so we may help more hemophilia B patients through challenging times.

For more information, please contact:

Farrah Muratovic
farrahm@hemob.org
The Coalition for Hemophilia B

Tel: 212•520•8272
hemob.org

Kidz Korner!



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SPRING WORD SEARCH

BIRD
BUD
EGG
FLOWER
LAMB
NET
RAIN
SPRING

The Coalition For Hemophilia B

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Phone: 212-520-8272 Fax: 212-520-8501 contact@hemob.org

Visit our social media sites:

Website: www.hemob.org
Facebook: www.facebook.com/HemophiliaB/
Twitter: https://twitter.com/coalitionhemob

For information, contact Kim Phelan
kimp@hemob.org or call 917-582-9077