Factor Nine News

The Coalition for Hemophilia B

Winter 2018

Topics in Hemophilia B

Meeting on the Road: San Antonio, Texas (Page 17)

LIGHTING THE WAY
PHYSICAL THERAPIST MICHAEL ZOLOTNITSKY

By Michael Perlman

"I am grateful to live life with severe hemophilia without associated joint damage, and now I am thankful that I can travel nationwide and share my knowledge so others can live pain-free," says Dr. Michael Zolotnitsky, a 29-year-old highly skilled physical therapist who is a member of NJ Spine and Wellness in Old Bridge, New Jersey. For the past four years as a physical therapist, and even before that, he has exhibited much generosity of spirit. "I have a great job, where I can help others every day," he says. Additionally, he expresses much gratitude toward his very supportive family that has played a pivotal role in his life.

Dr. Zolotnitsky is a native of Rome, Italy, and was raised in Brooklyn before relocating to New Jersey. In 2014, he was the recipient of a Doctorate in Physical Therapy from Chatham University in Pittsburgh, Pennsylvania. He is a familiar face to his patients and to many hemophiliacs and their families, particularly at The Coalition for Hemophilia B symposiums. In 2015, he presented for the Hemophilia Federation of America, which is where he met Wayne Cook, President of The Coalition for Hemophilia B and a lifetime mentor to the community. He was extended an invitation to be a presenter at the Coalition's men's retreat. "From that point on," Zolotnitsky says, "I have proudly been giving presentations for The Coalition for Hemophilia B."

Dr. Zolotnitsky's role is to inform attendees of Coalition meetings how exercise can alleviate joint pain and improve mobility. He explains: "I love to give advice on how others can live life to reach full health and wellness. Last year, I began attending the men's retreats, where I met many great individuals and performed aquatic physical therapy. Then I attended the 2018 symposium in March in Ponte Vedra Beach, Florida, with over 300 attendees and performed kinesiology taping, which was a great success. Since that time, I have been traveling to the Coalition meetings in various states. My goal is to travel to every state and teach as many people as I can."

In 1989, Dr. Zolotnitsky was diagnosed with hemophilia A and would eventually view it as a beacon of strength and independence. After developing an interest in exercise and joint health, he continued to pursue his goal to become a physical therapist. He recalls, "Hemophilia taught me how to manage a chronic condition that includes pain and limits overall joint mobility, and I did not allow this to reduce my physical activity level. I taught myself how to modify activities and be safe, and from this I developed a passion for exercise and fitness. I did not want a bleeding disorder to hold me back and I persevered. My goal now is to teach others how to manage their condition and to continue to stay active to reduce the risk of joint bleeding."

Dr. Zolotnitsky's meetings and retreats emphasize the benefits behind kinesiology taping, aquatic therapy, alternatives to pain medication, and general exercise. "I educate families, so people with bleeding disorders should be able to live a normal life," he says. Furthermore, his expertise has contributed to his achievements not only nationally as a hemophilia community speaker, but internationally. "Most recently, I traveled to the World Federation of Hemophilia conference in Scotland," he says.




THE GOAL OF PAIN FREE MOVEMENT

"Swimming alone has been shown to burn more calories than jogging," says Dr. Zolotnitsky, whose personalized aquatic therapy program offers various benefits, with a goal of enabling pain-free exercise. As he explains, "Aquatic therapy is safe for everyone. It can allow people to reduce swelling using hydrostatic pressure. It has been shown to relax muscles to allow an improved stretch. Most importantly, it can allow an individual to exercise their upper and lower body to improve overall strength and muscle tone. Swimming is how I began to exercise when I was in pain and that assisted me to transition to land-based exercises."

Dr. Zolotnitsky works with multiple sclerosis, stroke, and Parkinson's patients, and also addresses dizziness and balance disorders. "I have witnessed top-notch results," he says. His therapeutic techniques continue to prove successful, as in the case of neurological treatments and the Mulligan Concept. "If done correctly, neurological treatments can help people regain strength and balance, and the Mulligan Concept allows pain-free motion that people may not know exists." He also performs high-level balance activities such as walking with one's eyes shut, walking on uneven surfaces, and incorporating boxing to offer additional challenges.

Dr. Zolotnisky's inspirations are part of his driving force, which includes "anyone who can motivate others," he says. "My father showed me how hard work is necessary to succeed, in addition to my brother," he recalls. Staying true to what is in his heart has been a catalyst for rewarding experiences. He explains, "A 13-year-old with severe hemophilia began coming to me, and after two months he said that his body felt normal again. Another gentleman in my clinic with a stroke sent me a video of himself walking on the beach for the first time without a cane."

With perseverance, he completed three half marathons,

Pittsburgh in 2012, followed by Pittsburgh and Philadelphia in 2013, and his goal is to continue to stay fit. Outside of Dr. Zolotnitsky's professional pursuits, his interests include exercising, spending quality time with his two nephews, learning languages, watching football, traveling, and dancing. Even then his humanitarian approach is very much in full swing.

Looking ahead, Dr. Zolotnitsky's professional pursuits are to continue educating the bleeding disorders community, establishing a recognized exercise program that is safe for individuals, and building on his YouTube channel *HemoDoc*, to further serve as an educational and beneficial resource. He can be reached at (732) 757-5430 or by email (Attention: Dr. Zolotnitsky) at info@spineandwellness.com.

B CONNECTED

THE COALITION FOR HEMOPHILIA B

FREE for individuals and families with HEMOPHILIA B.
To get instructions on how to join B Connected, 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**

WHY BE CONNECTED?

New therapies are flooded 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.

CONTACT: bconnected@hemob.org

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, inhibitor, new family support, aging with hemophilia, and much, much more!

JOIN TODAY!

B Connected online discussion board is hosted on **SLACK** and is 100% HIPAA compliant.

THE COALITION FOR HEMOPHILIA B, INC.
757 Third Ave., 20th Floor; New York, New York 10017 Tel: 212-520-8272 Email: contact@hemob.org

Meeting on the Road

Anaheim, California

By Christian Villarreal

The Coalition for Hemophilia B hosted a *Meeting on the Road* Saturday, November 17th in California at the Anaheim Marriott Suites. Families and individuals came together to attend powerful learning sessions beginning with Edgar Vega's *The Power of Empowerment*. Edgar discussed cultivating self-assurance and how it can be a challenge to feel empowered when experiencing new or difficult situations. Everyone discussed ways of becoming more empowered by acknowledging strengths, celebrating individuality, creating safe environments, enhancing confidence, and establishing supportive partnerships.

The group was joined by Cathy Tiggs who presented the results of the *B-HERO-S* survey. Taken by 290 people with hemophilia B and 150 caregivers of children with hemophilia B, the survey addresses psychosocial issues within the community. As Cathy explained, the survey gathered experiences and responses that help identify the needs in the hemophilia B community as they relate to education, employment, and quality of life.

Rick Starks led the group in a *Tai Chi Movements and Meditation* workshop. Rick helps participants find their inner chi through a system of coordinated body postures and subtle movements,

"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

breathing and meditation to promote health and wellness.

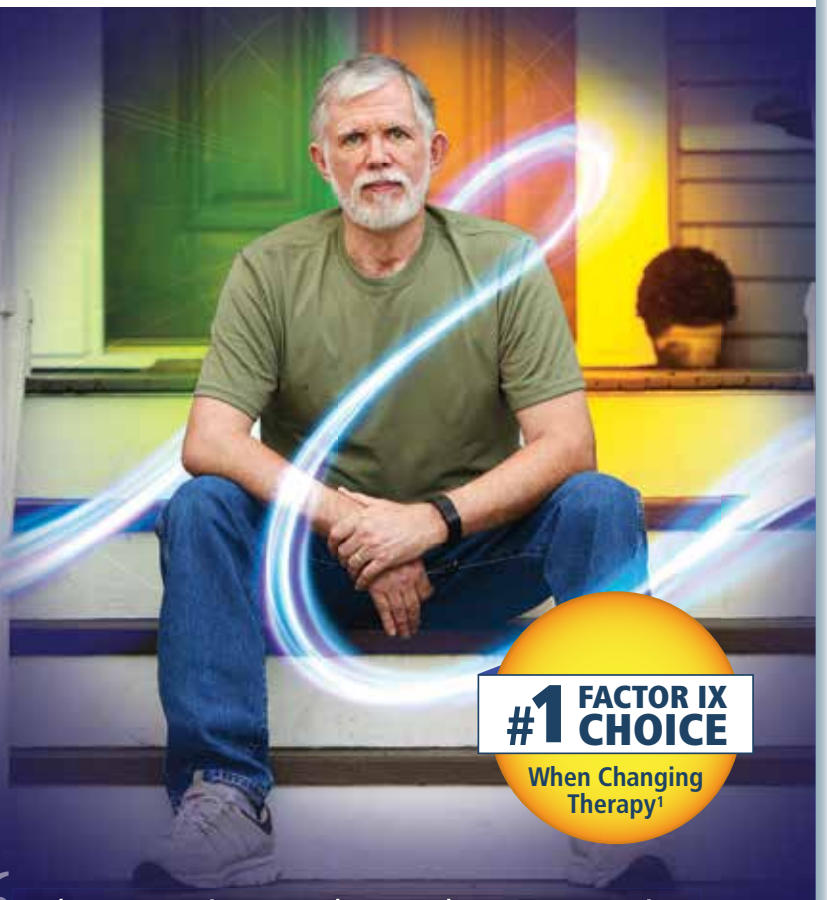
Robert Friedman took the spotlight and spoke about managing stress. Takeaways from this interactive presentation offered specific solutions for managing stressful challenges unique to those living with a bleeding disorder.

Our community kids had an exciting day of their own as they headed to Dave & Buster's for interactive arcade games! They returned in time to join their parents for a group photo in the meeting space, where raffle prizes were drawn and everyone put on their thinking caps to the test their hemophilia B knowledge by playing our game, *Are You Smarter Than Your Hemophilia?*

We are thankful to our sponsor, CSL Behring, for helping us put on this program.

CSL Behring

With 14-day dosing, Ray made the switch from on-demand to prophylaxis



SWITCHING FROM ON-DEMAND TO IDELVION PROPHYLAXIS 14-DAY DOSING* HELPED RAY **TO BETTER CONTROL HIS HEMOPHILIA B**

Now that Ray is on IDELVION, he infuses the same number of times he did while treating on demand, but has not had any bleeds. This protection helps him live everyday life with less worry about pain and joint damage from bleeds.

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

Learn about the benefits of switching to up to 14-day dosing at IDELVION.com

"When treating on demand, I was treating twice a month for an active bleed. With IDELVION—treating prophylactically every 14 days—I'm no longer having any bleeds."

—**Ray,** on IDELVION since March 2017

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.

Please see additional Important Safety Information and brief summary of prescribing information on adjacent page and full prescribing information including patient product information at IDELVION.com.

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

Reference: 1. Hemophilia FIX Market Assessment, Third-Party Market Research.

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

Important Safety Information (cont'd)

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.

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.

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

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

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

B2B: Your voice. Your life.

Interested in stories and personal experiences *from* the hemophilia B community *for* the hemophilia B community? Turn to B2B.

Download or view books
filled with patient stories that can inspire, empower, and educate

Listen to podcasts
that capture the voices of the hemophilia B community

View videos
that feature members of the community sharing their personal experiences

And there's much more, too!

More topics include . . .

- Educating your child's school about hemophilia B
- HEMO 101 for caregivers
- Managing relationships with hemophilia B
- Life for girls and women with hemophilia B

VISIT WWW.HEMOPHILIAVILLAGE.COM

to explore all B2B materials

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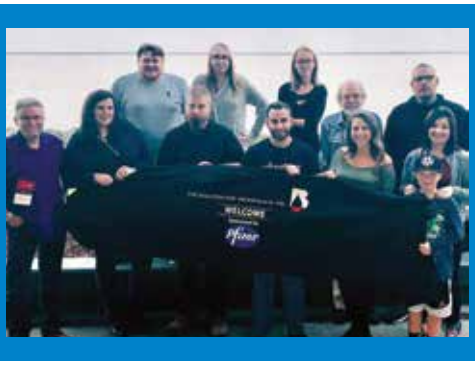
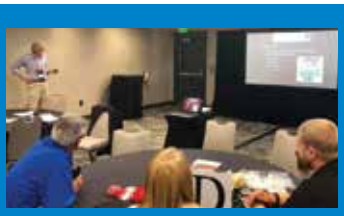




Meeting on the Road

San Francisco, California

By Shad Tulledge

The Coalition for Hemophilia B rolled into the fabled city of cable cars and Victorian houses—San Francisco, California—for another family *Meeting on the Road*. The program was held Saturday, November 17th at the San Francisco Airport Marriott Waterfront overlooking the bay.

A large group of enthusiastic families and individuals started the day with a delicious breakfast and an opportunity to visit with industry representatives at their exhibit booths. A warm welcome from Coalition Chair Dr. David Clark followed.

Educational programs began with a discussion led by Angelica Flores, RN. She spoke about tools for self-advocacy and the unique challenges hemophilia B patients and families deal with.

The next presentation was given by Patricia Amerson, RN, regarding the results of the *B-HERO-S* survey on psychosocial issues faced by people with hemophilia B and caregivers of children with hemophilia B. The responses to this survey are helping the community identify and address unmet needs related to education, employment, and quality of life.

During the last part of the morning program, participants learned about the practice of *Tai Chi* from local instructor Blair Sandler. This ancient art, which requires no special athletic ability, helps the practitioner develop mental and physical energy while achieving a feeling of peace and inner harmony.

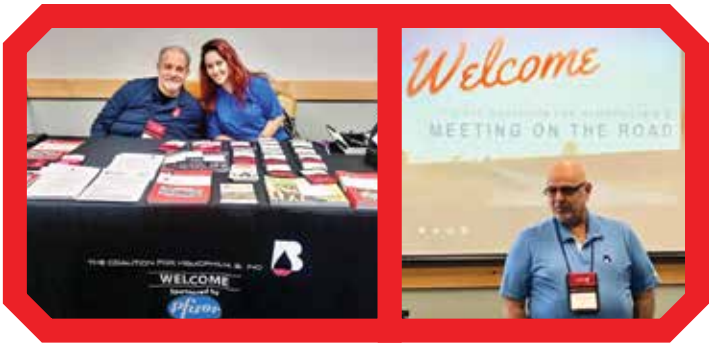
After enjoying a delicious lunch buffet, the attendees gathered for an afternoon session with physical therapist Dr. Michael Zolotnitsky, who instructed the group on how to use kinesio tape strips to reduce joint swelling and pain. Participants volunteered for live demonstrations and had an opportunity to try applying the tape to their own joints.

Dr. Clark wrapped up the meeting with a presentation on *What's New in Hemophilia B*, covering new therapies and much more, followed by a game of *Are You Smarter Than Your Hemophilia?*

The Coalition for Hemophilia B would like to thank Pfizer for sponsoring this terrific family event!

Meeting on the Road

Cortland, New York



By Glenn Mones

On December 1st, The Coalition for Hemophilia came to Cortland, in the center of New York State, for another terrific family *Meeting on the Road*. This Saturday meeting was the last of 12 local gatherings we hosted across the country this year for families and individuals affected by hemophilia B. The Cortland event was held at the lovely Hope Lake Lodge, in a beautiful natural setting surrounded by snow-covered hills. The property features an indoor water park and many other attractions.

After a warm greeting and introduction by Coalition President Wayne Cook, the educational program opened with a talk by pediatric hematologist Dr. Claudio Sandoval. He spoke about the results of the *B-HERO-S* survey and the understandings we gained from it regarding psychosocial issues in people affected by hemophilia B. These findings will help all of us better address the needs of people in our community.

The meeting also featured a session with Cassandra Starks on movement and other techniques for achieving a healthier mind and body. Through gentle, meditative movements we can become better equipped for dealing with mental and physical issues presented by living with hemophilia B.

Presenters at additional well-attended sessions were Gail McCarthy speaking about overcoming physical, financial and other challenges that come with a chronic illness, and Douglas Stringham demonstrating kinesio taping as a method of reducing joint pain and swelling.

The educational program wrapped up with an in-depth presentation by Dr. Shelby Smoak on current issues in hemophilia B, including new and developing treatments and reimbursement issues. One of the important takeaways was that the hemophilia world is changing rapidly and that we must stay informed to keep up with all of these changes.

Perhaps the most important part of our local meetings is the chance they offer for community members to come together and share their strengths and experiences. By creating these opportunities and making them available to families who can't always make it to national meetings, we make sure everyone has access to the support, information, and education they need to achieve the best possible outcomes.

We want to thank Pfizer for sponsoring the Cortland meeting, and we look forward to presenting a new series of *Meetings on the Road* in 2019. Stay tuned!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Rare Disease

CSL Beh
Biotherapies for Life

Aptevo













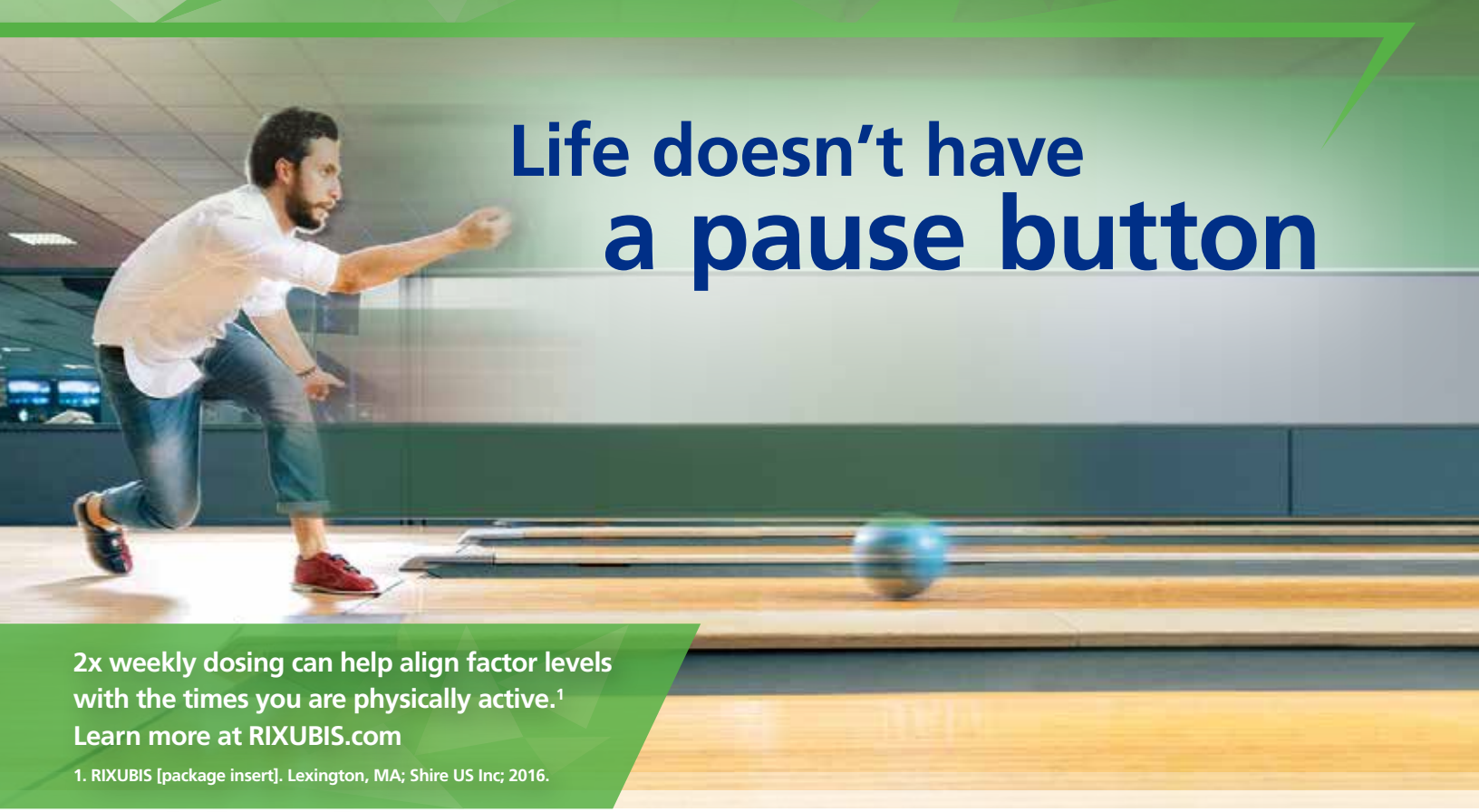

Life doesn't have a pause button

2x weekly dosing can help align factor levels with the times you are physically active.[1]
Learn more at RIXUBIS.com

1. RIXUBIS [package insert]. Lexington, MA; Shire US Inc; 2016.

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 for RIXUBIS®

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

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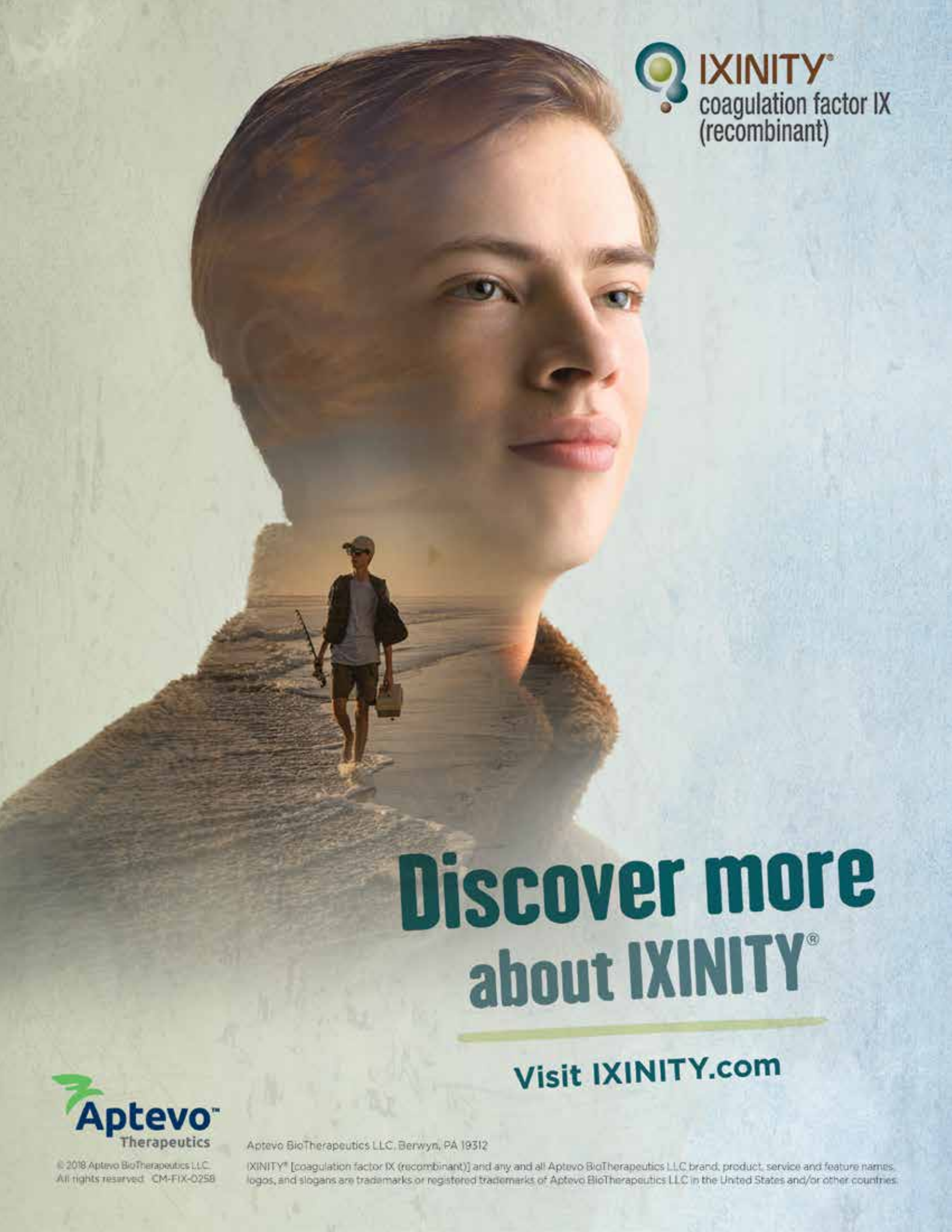


Aptevo BioTherapeutics LLC, Berwyn, PA 19312

Meeting on the Road

San Antonio, Texas

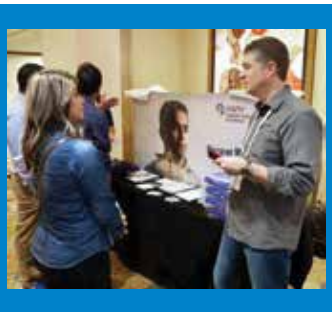
By Christian Villarreal

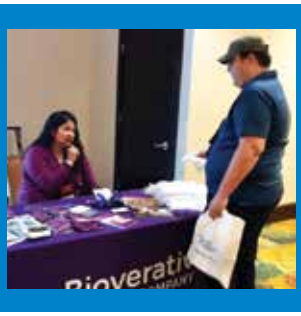
Right in the heart of San Antonio and its famous River Walk district, The Coalition for Hemophilia B hosted a *Meeting on the Road* Saturday, December 1st at the San Antonio Marriott Rivercenter. Our attendees started off with a hearty and healthy breakfast as they mingled and visited with industry representatives at exhibit booths. Dr. David Clark welcomed everyone and led a moment of silence to show respect for World AIDS Day.

Starting the day strong, the educational programs began with a session on *Overcoming Challenges*. Rachel Cooper-Leal delivered an overview of coping with chronic illness, learning to effectively communicate with healthcare teams and others regarding hemophilia, the financial considerations of managing healthcare through life stages, and the importance of staying physically active with appropriate activities.

The next session highlighted the results of the *B-HERO-S* survey. Patricia Amerson and hemophilia B mom Emili Lee led the discussion regarding the survey, which was taken by 290 people with hemophilia B and 150 caregivers of children with hemophilia B and focused on psychosocial issues. Emili Lee spoke about her experiences with hemophilia B as a patient and as a mom, as well as her first time attending the Coalition's Annual Symposium and the impact it had on her life.

After a short break, Rick Starks led everyone in a *Tai Chi* workshop. With slow and steady movements, the attendees learned how to focus on their core and strengthen muscles they've forgotten!





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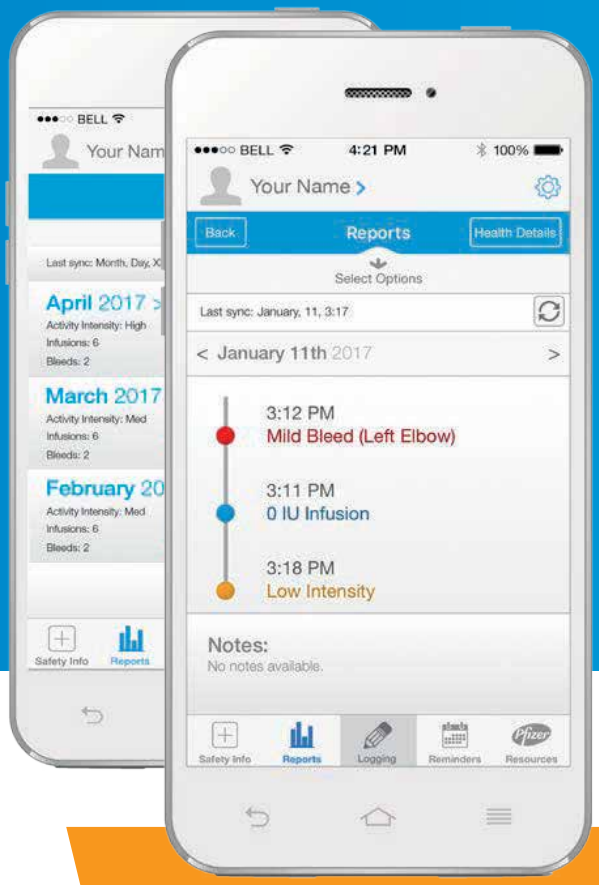
with *enhanced* activity tracking

The little app is getting bigger.

Talk to your doctor about HemMobile™—and which activities may be right for you.

- Log daily activities, infusions, and bleeds
- Share single consolidated reports with your treatment team
- Set reminders for resupply, appointments, etc
- Sync with fitness apps and wearable devices



Hemophilia can be difficult. Tracking it shouldn't be.

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For more information, contact Pfizer Hemophilia Connect, one number with access to all of Pfizer Hemophilia's resources and support programs.

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Pfizer

Following time for lunch, *Stress Management* with Robert Friedman was up next on the agenda. During this interactive presentation, participants were given the latest information on how to manage stress and learned specific solutions for their own challenges when dealing with hemophilia B and other stressors.

The last presenter of the day, Dr. Michael Zolotnitsky, demonstrated the art of kinseio taping and how to properly apply the tape to reduce swelling and provide joint support to improve walking ability. He explained taping's positive effects as compared to bracing and how kinseio has been shown safe in those with bleeding disorders. Samples were given to attendees so they may continue learning the methodology behind kinseio taping.

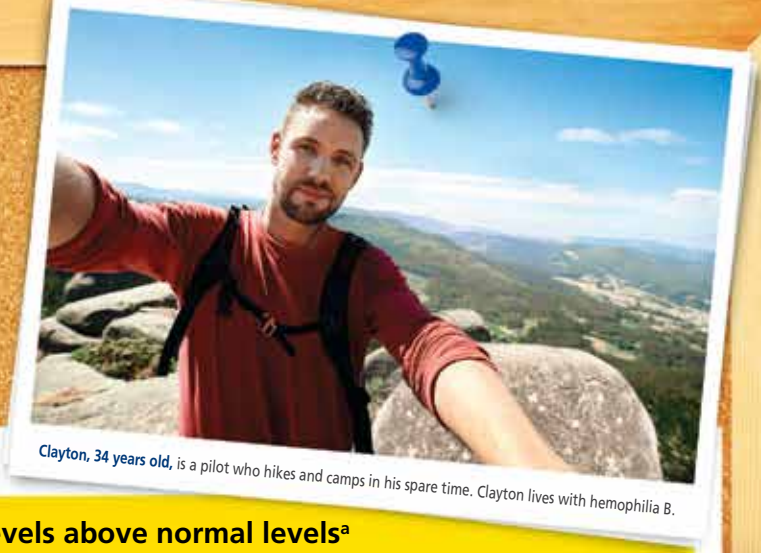
While the adults were absorbing education, our expert volunteers took the kids on an entertaining excursion to see the newest *Wreck-It Ralph* movie and to take an exciting boat ride along San Antonio's historic River Walk.

When the children returned from their fun-filled day, they reunited with their parents for a group photo. It was then time for a rousing round of our question and answer game, *Are You Smarter Than Your Hemophilia?* and to learn the winners of the raffle prizes.

We would like to thank Pfizer for sponsoring this wonderful event!

In hemophilia B

TAKE CONTROL TO A HIGH LEVEL WITH REBINYN®



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®

ASK THE EXPERT

Q&A on the B Connected Online Forum

The Coalition for Hemophilia B | bconnected@hemob.org

TOPIC: PRODUCTS IN DEVELOPMENT AND GENE THERAPY

JANUARY 24, 2019

B Connected on your phone or desktop
9-10pm EST (8pm CST, 6pm PST)

ASK THE EXPERT DR. DAVID CLARK

Chairman of the Coalition for Hemophilia B

With new treatments for Hemophilia B under development, including Gene Therapy, we know you have many questions: How long will treatment last? What about inhibitor development? What non-gene-therapy treatments are in the pipeline? Dr. David Clark will be happy to answer your questions in this one-hour online session to keep you informed and empowered!

<u>Current B Connected Members:</u>
Log in and post your questions in the Ask the Expert channel <u>before Jan. 24th</u>. Questions will also be taken during the live session.

First Time Joining B CONNECTED?

Our online discussion platform is hosted on Slack and is 100% HIPAA. For instructions on how to sign up and create a nickname for yourself for posting, email our admins at bconnected@hemob.org.

TREATMENT NEWS

The following items were presented at the American Society of Hematology Annual Meeting, December 1–4, 2018, in San Diego, CA.

By Dr. David Clark

Bioverativ Announces Final Results of Long-Term Alprolix Study

Bioverativ, a Sanofi company, has announced final results from the B-YOND study of the company's extended half-life factor IX product Alprolix. In 93 adult and adolescent patients, the median annualized bleeding rates (ABRs) for joint and spontaneous joint bleeds were less than 1.58 and 0.38, respectively. In 27 children 12 years and under in the Kids B-YOND study, the respective ABRs were less than 0.85 and zero. No study patients developed inhibitors, although inhibitors have been seen in other patients outside the studies. The study represents flexible dosing, as the study participants had variable infusion frequencies.

Catalyst Announces New Results for Inhibitor Treatment Under Development

Catalyst Biosciences has announced updated results for its variant activated factor VII product, MarzAA, under development for treatment of hemophilia A and B patients with inhibitors. MarzAA is a subcutaneous preparation for prophylactic use. The five patients who have completed treatment in the Phase II/III study had pre-treatment ABRs of 15.2–26.7. Three subjects had ABRs of zero after treatment, and the other two had significant reductions. There were no serious adverse reactions and no development of inhibitors to MarzAA.

Freeline Shows High FIX Levels in Gene Therapy Studies

Freeline Therapeutics presented results from its Phase I/II gene therapy study. The company is continuing the work done by University College London (UCL), as described below. The FLT180a treatment uses an improved AAV (adeno-associated virus) viral capsid that has a higher rate of gene incorporation in liver cells. Freeline also uses the higher activity Padua factor IX gene. The two patients treated to date have reached an average factor IX level of 45% in the Phase I/II study, sustained for six and nine months, respectively. The treatment was well tolerated with no signs of liver inflammation or inhibitor development.

UCL/St. Jude Announces Long-Term Follow-Up for Gene Therapy Studies

Researchers from University College London and St. Jude Children's Research Hospital have announced an eight-year follow-up for the gene therapy patients reported in the *New England Journal of Medicine* in 2014. In the 10 patients who have been treated for up to eight years, factor IX levels have remained steady at 1.9%, 2.3%, and 5.1% for the low-, middle-, and high-dose cohorts. The ABRs decreased by 82%.

The researchers also investigated whether the large number of empty capsids (viral vectors that do not contain genes) in many gene therapy preparations were the cause of the immune reactions seen in some patients. In a new study with a slightly higher dose and with a preparation depleted of empty capsids, patients still developed immune reactions, so that wasn't the answer. However, the new batch of patients reached an average factor IX level of 17%.

uniQure Announces Continuing Results from Gene Therapy Trials

The results are from uniQure's Phase I/II clinical study of AMT-060, its original gene therapy for hemophilia B, plus its current study of AMT-061, which is identical to AMT-060 but contains a more active factor IX variant. For AMT-060, which contains the wild-type (normal) factor IX gene, 10 patients have been followed for up to two and a half years. The treatment has been safe and well tolerated. All of the patients have been able to discontinue prophylaxis and significantly reduced their factor IX usage. The patients' average factor IX activity has increased over the study period from 7.1% in the first year to 8.9% currently.

For AMT-061, uniQure's improved therapy containing the higher-activity factor IX Padua variant, the mean factor IX level for the three patients in the Phase II dose verification study was 31% after six weeks and appears to be increasing. None of the patients required factor infusions, had bleeding events, or required immunosuppression. uniQure begins its Phase III study of AMT-061 in early 2019. Based on the good long-term results for AMT-060 and the higher factor levels from the improved AMT-061, uniQure believes AMT-061 will succeed in the studies.

THE WILLIAM N. DROHAN SCHOLARSHIP

c/o The Coalition for Hemophilia B
757 Third Avenue, 20th Floor,
New York, NY 10017

Dear Scholarship Applicant,

Please find enclosed an application for the William N. Drohan Scholarship. **The deadline for this application is February 15th, 2019.**

The William N. Drohan Scholarship was formed in memory of Dr. William N. Drohan who passed away in February 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. Other important contributions include investigating prion diseases in the blood supply, and his development of novel ways to treat traumatic injuries including fibrin-sealant bandages to stem hemorrhage.

Dr. Drohan was equally dedicated to scientific research and to mentoring students and young scientists. His career included important positions with the National Cancer Institute, the American Red Cross, and private companies dedicated to treating blood borne disorders, most recently as Chief Scientific Officer of STB, Ltd., as well as Chief Scientific Officer at Inspiration Biopharmaceuticals, Inc., and previously Chief Scientific Officer of Clearant, Inc. He was also a very involved Board Member of The Coalition for Hemophilia B. His passion, drive, and vision were instrumental in the formation of the Coalition when it began in the early 1990s. He also served as Professor in the Graduate Program of the Department of Genetics of George Washington University and formerly as Adjunct Professor in the Department of Chemical and Biochemical Engineering of the University of Maryland. Dr. Drohan published more than 145 scientific papers and held 30 U.S. patents. He served on the editorial boards of several scientific journals. In addition, was a member of the Scientific Steering Committee for Blood Products at the Walter Reed Army Institute of Research and the Chairman for the Panel on Biotechnology of the National Research Council.

Bill's professional and personal enthusiasm was always a great motivation for many people who were fortunate to have had the opportunity to work with him. Many young scientists will remember him for his altruistic mentoring role. In addition to his passion for science and business, he leaves to all of us a legacy of scientific achievement and inspirational leadership that was accompanied by an extraordinary level of kindness and generosity.

This fund was created for children of scientists, doctors, nurses, pharmacists, healthcare professionals who are part of the comprehensive care team, who have a need for funds, especially those who have lost their father or mother and for children with hemophilia B and their siblings.

If you have any questions regarding this application, please call Kim Phelan at 212-520-8272.

Regards,

Dr. David B. Clark

Join us at
Florida's Famed
COPPERHEAD COURSE
All-time Favorite PGA Tour Stop

The Coalition for Hemophilia B, Inc.

Let's Play Nine for Factor Nine

The wonderful and popular game of golf is one of the few sporting activities those living with hemophilia can safely enjoy. Through our golfing outing—and your generous donations—we are able to provide golf education and access to children within our hemophilia community so they can experience this fun, social activity and its many healthy benefits. Funds raised also benefit the BCares patient assistance program.

Join us and enjoy highlights:

- **Golf clinic with Perry Parker**
- **Assigned caddy for each foursome**
- **18 Hole Scramble!**
- **Awards Dinner!**
- **Silent Auction and Raffle Prizes!**
- **Optional tours of facilities...and more!**

THE COALITION FOR HEMOPHILIA B

Let's PLAY NINE

3RD ANNUAL GOLF OUTING

WEDNESDAY, MARCH 13, 2019

Copperhead Course
Innisbrook Resort,Tampa, FL

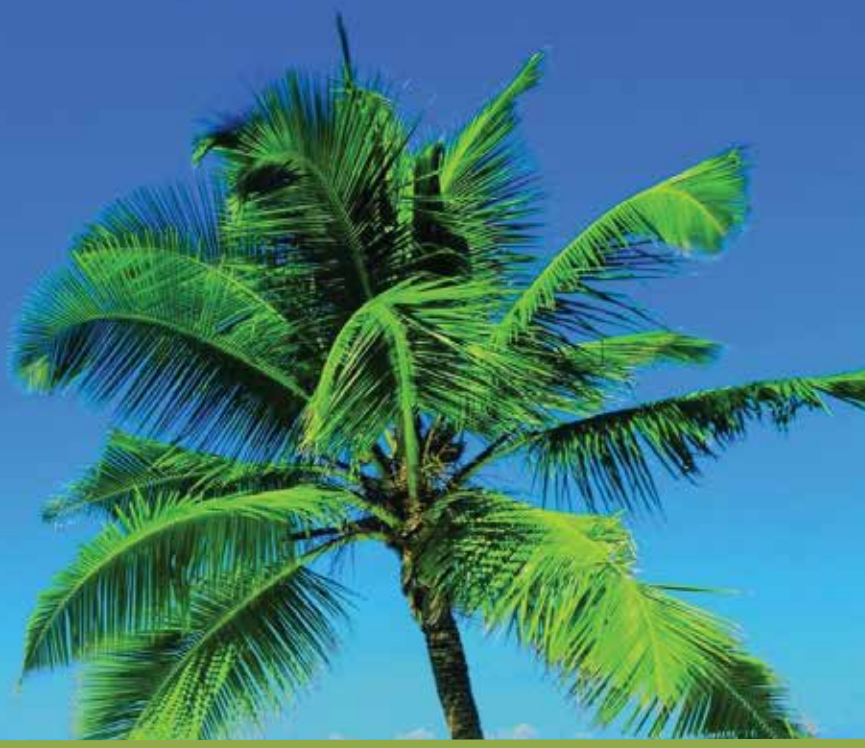
Rated "the best course on the PGA Tour"
Must-play course for anyone traveling to Tampa

Join the fun and support a great cause!

Contact Kim Phelan
kimp@hemob.org • 212-520-8272

Let's Play Nine Committee:
Jim VanSant, Wayne Cook, Jared Schimmels

SAVE the DATE



Thursday, March 14
to Sunday, March 17

The Coalition for
Hemophilia B
Annual Symposium

2019

RENAISSANCE ORLANDO at SeaWorld!

Register at
www.hemob.org/symposium2019

THE COALITION FOR HEMOPHILIA B

THE COALITION FOR HEMOPHILIA B
UPCOMING EVENTS 2019!

ETERNAL SPIRIT AWARD GALA

Thursday, February 28, 2019
Terrace on the Park
52-11 111th Street
Flushing Meadows Park, NY 11368
Honorees: Glenn Pierce, MD, PhD and Hope Woodcock-Ross, RN

To purchase tickets to the gala, please contact Kim Phelan at kimp@hemob.org or call 212-520-8272

ANNUAL SYMPOSIUM

Thursday, March 14 to Sunday, March 17, 2019
Renaissance Orlando at SeaWorld
6677 Sea Harbor Drive
Orlando, FL 32821
Tel: 407-351-5555

The 2019 gathering is extended by one full day! Registration is free and includes access to all sessions, meals and admission to our Saturday night final event. Register online at: www.hemob.org/symposium2019

THE BEATS MUSIC PROGRAM

Wednesday, July 31 to Sunday, August 4, 2019
Gaylord Opryland Hotel
Nashville, TN 37214

Apply online at:
www.hemob.org/thebeatsmusic2019
Deadline January 30, 2019

KENDALL FITZPATRICK: A MOM BEHIND "HELPFUL HEMO RNs"

By Michael Perlman

"Helping others is what helped me" are the simple yet meaningful words of Kendall Fitzpatrick, a 46-year-old humanitarian and infusion RN who exhibits a warm heart and much motivation for her family, friends, and her community. She is a trooper who has hemophilia B and von Willebrand disease, a quite rare combination on the basis of two distinct bleeding disorders.

Fitzpatrick was raised near Richmond, Virginia, and now lives on the outskirts of Williamsburg, where she is happily married and grateful for her close-knit family: her loving husband Brad, a 24-year-old son Trey, who has hemophilia, another son named Jared who is 18 and has autism, and two newer additions, stepsons Gabriel who is 10 and Elijah, 8.

Finding Purpose in Nursing

She pursued nursing in college as a single mom in 2006, graduating in the top of her class three years later. She explains, "I am very proud, since I had a lot on my plate, but I achieved outstanding grades that I never thought were possible. I discovered nursing was my passion, and it was hard—comparable to boot camp, but the most rewarding pursuit I ever experienced. As a result of my two boys having hemophilia and autism, I found my life's direction."

In 2015, Fitzpatrick launched a Facebook group called "Helpful Hemo RNs" along with another hemophilia mom, Jane Cotter Forbes, who shares a career as an infusion RN. Their complementary vision and dedication as nurses proved successful, despite living on opposite sides of the country. Fitzpatrick explains, "I hope my actions speak volumes of where my heart is, but if that isn't enough, I wanted to reach a larger audience and share resources with people who may not be able to attend meetings that I am privileged to attend. It has been three years and we grew [the Facebook group] to over 1,000 members." Their mission is "to provide education and health information that benefits the bleeding disorders community." Group administrators strive to educate and promote "best practices and [the] highest standard of care at the home

Pictured left page: Kendall Fitzpatrick with (left to right) stepsons Gabriel (age 10) and Elijah (8), Jared (18) who has autism, and her husband Brad

Kendall Fitzpatrick's son Trey, 24, living in Stafford, VA with hemophilia

infusion pharmacy level." The group is also "a source for original and timely health information, as well as other unique materials that benefit the community."

"No One Should Ever Be Alone with Hemophilia"
Fitzpatrick particularly draws inspiration from her father, her sons, other mothers she encounters, and nurses who devote their lives to the community. "I feel as if my life came full circle," she says, since her father took his life when she was 13. Reminiscing, she says, "I knew he was depressed and was declining over the years. I visited him in a halfway house, and on his last day I did not kiss him because I felt angry. That was the night that he took his life."

Fitzpatrick's son Trey was diagnosed with hemophilia B at age 2. As she recalls, "Visiting my mom one Easter, my son bled through six Band-Aids from a scratch on his nose, and she said that I should have him checked by a hematologist. Since she remembered that my father's knees would swell, she thought he had rheumatoid arthritis. The next day, blood work was taken and labs were positive. It occurred to me how much my father experienced all alone," she says, "and I felt conviction that no one should ever be alone with hemophilia. I also felt traumatized, seeing my son held down and stuck, [after] every fall, to get factor infused in him."

She began working at a specialty pharmacy to acquire an understanding of hemophilia, envisioned becoming an infusion nurse, and returned to school at age 36. "Now, I work full-time managing families with hemophilia, and since I have earned a nursing license, I am able to help them learn to infuse and provide education," she says. "I speak to my nursing class each year about hemophilia, and coming up, I will present hemophilia to my local ED [emergency department]. I do everything for the love for my son, but more so for my father, who I wasn't old enough to value before he was gone."

Fitzpatrick will always remember her first encounter with The Coalition for Hemophilia B Vice President Kim Phelan, and how generous the Coalition was to her and her children during lean times. "We had no extra money while I was in school," she says, "and I happened to see the form for Christmas to help families in need. We missed the deadline, but the Coalition sent me many gifts. My sons were surprised and saw their mom receiving Christmas gifts at a time when we had so little."

Challenges, Strength, and Growth
Although life has tossed her curveballs, it became a vehicle for strength and growth. She explains, "I felt lost at times, being a single mother to a child with hemophilia and my next son with autism. Autism was a greater challenge than hemophilia. Medicine is available for hemophilia, and you know at some point your child will direct their own care, if you teach them the skills. On the other hand, with autism, the future is unknown on good days and bleak when you think too long about what is unpredictable. My sons own my heart, so it was a lot of heartache for many years."

Reflecting on her past while having much hope for the future, she says, "I am grateful that the uncertain years raising the children and not knowing if we would all be 'okay' are over. We are all okay, and now I am remarried with a wonderful husband and two new sons."

Fitzpatrick's personal interests include traveling and helping her son with autism find a path in life. When she meets other mothers, who are sometimes overwhelmed with anxiety, she shares her story as a beacon of hope and guidance. "I know how impossible the challenges felt when they landed in my lap," she says, "but those challenges make us appreciate the little joys in life, and that is living in its best form. You should never forget how precious the days are, and that there is someone else that could use your help or friendship."

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