



Factor Nine News

The Coalition for Hemophilia B

Summer 2018



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GENERATION IX: PORTLAND, OREGON



GENERATION IX: PORTLAND, OREGON

BY CHRISTIAN VILLARREAL AND SHAD TULLEDGE



The Generation IX Teen/Mentor Program was held at the beautiful campgrounds of Camp Collins in Troutdale, Oregon, June 4th to June 6th, 2018. Participants included 22 mentors and 21 teens. The mentors arrived on Tuesday for their pre-training. They engaged in many team-building exercises, including *Escape Rooms*, *Initiative Training*, *High Elements Ropes Courses*, *Risk Management and Assessment Training*, and *Team Effort Training Hunger Games* and *Icebreakers*.

“The *Escape Room* was a really cool way start to the week. Being put in a room with people you have just met did seem a bit intimidating, but it also was a fast way to get to know each other and bond with the mutual goal of getting out of the room - we happily joined forces. With the timer counting down, it was a race to find clues to help us escape the room. With 2 minutes left on the clock, we all made it out in one piece! This activity taught me that sometimes, it is good to take a step back and see where I am most needed in order for the whole team to accomplish its objective. It also showed me that working as a team is much better than trying to do it all alone.” -S.T. Indiana

The next evening, the mentors participated in *The Team Training Hunger Games*. In teams of two, this activity gave them an opportunity to use their skills, with limitations given, to achieve a goal of finding their team’s token item. The teams soon realized they could not

complete their task on their own but had to communicate with the other teams to make sure everyone was able to find their token items. This training helped the mentors enhance their communication skills and their ability to work cohesively in small teams as well as in a large group.

On Thursday, the mentors went to the airport to welcome the teens as they arrived and gathered to have lunch together. Upon returning to the camp, the teens settled in their cabins and soon gathered for dinner and a fun-filled *Lip Sync Battle*.



Mentors and teens were split up in groups and were informed they had to assign team tasks to one another. The tasks ranged from costume designer, lighting director and performers. Each team had to decide what song they were going to perform in front of a panel of judges (Coalition and GutMonkey staff) and the audience. It did not take long for participants to jump into action to create the best shows to try to take the win. The night ensued with performances such as *Barbie Girl*, Eminem’s *Lose Yourself*, Disney’s *Frozen Let it Go*, Carlie Rae Johnson’s *Call*





Me Maybe, and many others! The teams laughed and cheered each other on, which enabled all of the participants to grow closer and bond.

On Friday, the mentors paired up with teens and formed 3 groups. The groups went their own way to engage in one of three different activities; high circuits ropes course, initiatives course or tomahawk throwing. For the high circuit ropes course, pairs of 2 worked together to maneuver different obstacles while over 30 feet off the ground! Each person participated at their own comfort level as the program is designed to let everyone choose their own challenge with no judgment. The tomahawk-throwing participants practiced their aim as they threw them at wooden bullseyes. The mentors put some of their training to work by running a few ice breaking activities with the teens such as helium stick and the bullring maze, where they had to work together to accomplish goals through patience, perseverance and teamwork! The mentors had to explain, manage and support the groups as they completed the tasks. After all the daytime practice, everyone geared up for a fan favorite, *The Nighttime Rappel*. Teens and mentors got in harnesses then paired up to scaled down a 50 foot wall at dusk while the

other teens and mentors support them by holding ropes and giving words of encouragement.

On the final day, everyone traveled to the beautiful city of Portland to engage in more fun-filled team building activities. The first stop was the *DIY Soda Shop*, which gave the group bonding time while they enjoyed a soda and worked on a craft project. They had the option to pick a project such as making luggage tags, passport holders, wallets, concrete succulent plant pots or nail art. They sat at tables in groups of 6 to 8 people and enjoyed some soda's as they worked on their projects.

The activity sparked conversations between mentors and teens about making leather passport holders for future trips, and how another wanted a new wallet since they he was starting a new job and would be making money. It was a great way to bond through creativity. Next, the GutMonkey team set up a Geocaching Scavenger Hunt where groups of mentors and teens toured the city of Portland finding clues to their next destinations. After a long day in the city, the participants returned to camp, rested, had dinner, then gathered for a final night bonfire where they debriefed and shared about the fun

things they experienced that day. On Sunday, mentors and teens enjoyed breakfast and said their goodbyes as they left to return home. We are thankful of our generous sponsor Aptevo for their support, and GutMonkey for putting on a wonderful program for our hemophilia B community.

“This was my first time with GenIX at Portland. I spent a fun-filled, packed week with my hemo B family. I was not really sure what to expect, but I loved it and had a great time! I especially liked the different rope courses. It was a great opportunity for me to come out of my comfort zone, bond with my community brothers and sisters, and experience some life-changing lessons. The Rappel activity was so much fun, I have never done anything like that before - it was truly a unique experience for me! It was empowering, fun, exhilarating and scary (but not too scary). Lastly, it was definitely an experience I will never forget!” – A. I. Missouri

A special THANK YOU to our generous sponsor!



BAKING SMILES DANIELA'S "LITTLE WISH"

BY MICHAEL PERLMAN

Meet 11-year-old Daniela Delgado, a humanitarian who has exhibited much passion and dedication since age 4, which was when she founded "Daniela's Little Wish." With the mission "Baking smiles for kids with severe illnesses or disabilities," she continues to achieve success, helping children and their families locally and gradually across America.



Daniela is an only child who lives with her parents in Sandy Hook, Connecticut, and attends the sixth grade. She is very spiritual and grateful for her close-knit family, which extends beyond her hometown and includes her maternal grandmother, Tita. She also loves her two miniature schnauzers, Toby and Luna, and a yorkie named Nina.

At age 4, Daniela observed her parents who were baking a cake, and drew inspiration from their talents as cake artists. Ever since then, she made a promise. She reminisced, "I raised my magic wand – 'the spatula,' and I wished I could bake cakes for kids with life-threatening conditions or severe disabilities. I asked my parents if they would help me, and they supported my dream ever since that day."

Most of all, Daniela's inspiration originated from a boy she attended daycare with. She explained, "He had cerebral palsy, and every day I helped him and enjoyed being with him. I didn't like it when other kids laughed about how he walked or when I saw him alone in a corner. That made me realize every kid, no matter what condition or how they look, they are kids like me and everyone's kids, and deserve to be treated right."

Every cake is custom-made and "made with love" for a multitude of causes over the years, according to Daniela. She recalled offering 15 to 20 guests birthday cakes at no cost for sick children. "I ask children or their parents for their favorite character or theme, flavor, and filling. My

cakes are covered with fondant or butter cream depending upon the request or design." In addition, cupcakes or cakes are available for large fundraisers, special need schools, and non-profits.

Daniela's Little Wish began as a local program in Stamford, where she was raised, and then as she had the opportunity to meet more children from nearby towns, she began delivering cakes to various areas of Connecticut, followed by New York, Rhode Island, and New Hampshire.

Most recently, she expanded her outreach and began traveling to Chicago and Arizona, and Ohio is in the works. "I don't like to miss an opportunity to bring a cake with me for a birthday kid with a severe bleeding disorder, which is my community," said Daniela.

Daniela has been diagnosed with von Willebrand Type 1c, a severe bleeding disorder, which she inherited from her mother. She said, "I am having a very hard time where I bleed for 3 months straight. My medications are not working properly, and I'm missing a lot of school. Some days I am in such pain I'm unable to walk or

do any activity, but I never lose hope that someday we will find the cure." In addition, she has been diagnosed with Joint Hypermobility Syndrome, also known as Ehlers-Danlos Syndrome, which has affected her knees and ankles.

Nevertheless, Daniela is a beacon of hope and perseverance. She said, "My illnesses will never define who I am. I am strong, independent, motivated, and a normal girl who has a long life ahead. While I am living





on this earth, I will do everything in my power to help anybody, anywhere, anytime.”

Reflecting on her experiences, she considers each one an inspiration in a different way. Daniela said, “They not only open their door for me, but also their hearts, and share their sadness, worries, hopes, and happiness. Every delivery is unique.” There are stories where children who she inspired emotionally have passed away and even though she finds it “hard to swallow,” she remains motivated by knowing she helped generate their smiles.

In order to fulfill her dream, her initiative is underway to become a non-profit. She has established a GoFundMe page to help pay the associated fees. “I want to organize events to raise funds, have workshops where we bake and decorate cakes, and I want to travel nationwide and bring cakes for many more kids.” In addition, Daniela foresees traveling abroad. “Kids with severe illnesses or disabilities have fewer opportunities than kids in our country. They need to know someone like them cares, and also need a lot of smiles and hope, even if the hope comes from a birthday cake.”

Daniela’s Little Wish maintains a presence on Facebook, Instagram, LinkedIn, and YouTube. The initiative is mostly funded by Daniela’s parents, while some donations are collected from individuals and organizations such as The Coalition for Hemophilia B and CT Block Party. Although her parents are not wealthy, they join her in sacrificing as much as they can towards making a difference. She explained, “My parents are very hard workers and are actually immigrants from Colombia and Mexico. I am the first generation. Even if they don’t say anything, they sometimes cancel their jobs in order to help me make the cakes and travel. They offer me money to buy baking supplies and ingredients.”

Daniela’s long-term goal is for her organization to be www.hemob.org

recognized worldwide, but first she has a vision for the next decade. “I assume I will be in college studying medicine, since I want to be a scientist and help cure illnesses, but also fight for human and animal rights.”

Daniela owes much gratitude to everyone around her who has been a positive influence in some way. She shares, “I am so grateful for my parents. How they are raising me, and their high values, morals and care for others is what inspires me. They are teaching me respect, equality and love for everybody, and for animals and nature. Through Daniela’s Little Wish, I have the honor to meet people who care for others, love with intensity, and are now our dear friends. They are people with such beautiful hearts.”

When she is not in school or fulfilling her mission statement, her humanitarian pursuits continue as an advocate for her bleeding disorder community. “I attend events to learn more about my condition, help raise funds, and speak in public about my condition,” she said. This month, she will travel nationwide and give presentations about her disorder while teaching others how to decorate cupcakes.

There are several ways others can become humanitarians. “People can donate funds needed to deliver a cake for a child and become a birthday cake fairy,” she expressed with a chuckle. Other accepted donations include baking tools and ingredients. The community can keep track by “liking” her Facebook page www.facebook.com/DanielasLittleWish, sharing her cause and referring a sick child.

With the help of her parents, she created another page, www.facebook.com/freeservicesforchildrenwithillnessesordisabilities, which has become a valuable source for advertising non-profits and individuals that offer complimentary services and gifts for children and families with illnesses or disabilities.

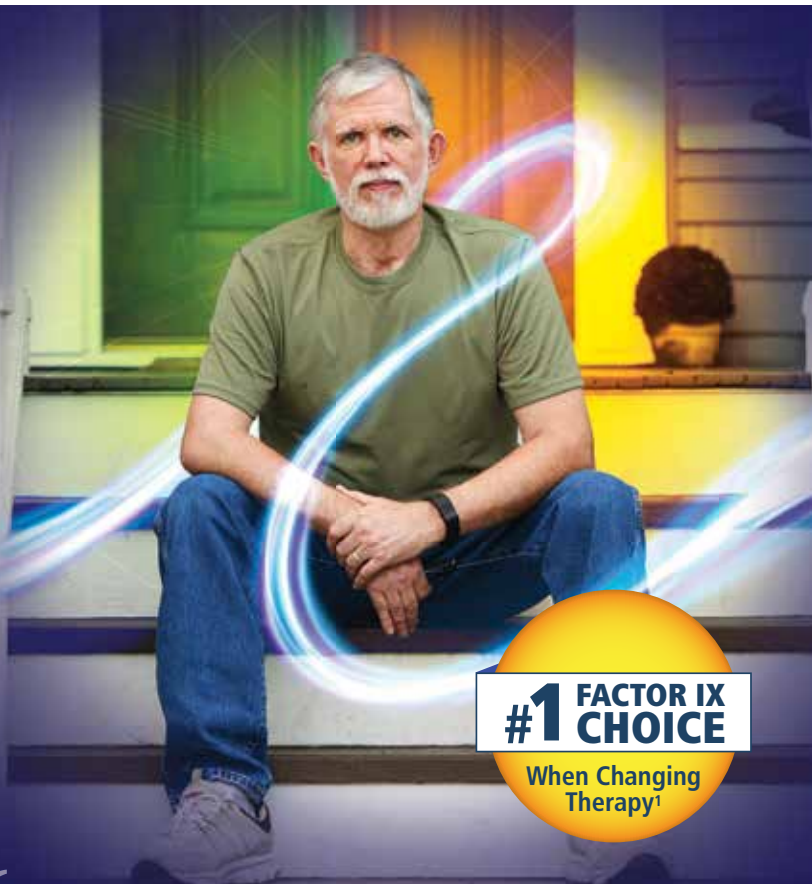
With 14-day dosing, Ray made the switch from on-demand to prophylaxis

**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



**#1 FACTOR IX
CHOICE**
When Changing
Therapy¹

“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.

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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.

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)

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.

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.

THE BEAT OF HUMANITARIAN ROBERT LAWRENCE FRIEDMAN

A STRESS SOLUTION!

BY MICHAEL PERLMAN



One is bound to acquire a greater meaning for the drum after coming face to face with Robert Lawrence Friedman, who calls Forest Hills, New York home. He is the founder and president of *Stress Solutions, Inc.* and *Drumming Events*, and his multiple hats are corporate trainer, keynote speaker, author, and psychotherapist. “Through offering my programs to over 10,000 individuals in seven countries, my participants have taught me that everyone can benefit from drumming,” he said.

Friedman launched the *Healing Power of the Drum* workshop, a positive, interactive, and community-based program responsible for physical, emotional and psychological benefits ranging from stress relief to anger release. He ensures that no experience is necessary, and explained, “Despite race, religion, color, background, or ideology, all are joined together through this ancient instrument’s calling. The drum becomes a vehicle for transporting all who utilize it across all boundaries, to an experience of wholeness and community.”

The Coalition for Hemophilia B and the community has greatly benefited from Friedman’s expertise and guidance.

He provided programming for the Coalition’s 2018 symposium in Florida and his success continued by participating in the men’s and women’s retreats in Arizona.

Kim Phelan, Vice President of The Coalition for Hemophilia B, said, “I am delighted at the success of the drumming sessions for people with Hemophilia. This is truly another tool for them to de-stress, while being invigorated.”

Friedman has published three books, *The Healing Power of the Drum—A Psychotherapist Explores the Healing Power of Rhythm* (2001), *The Healing Power of the Drum II—A Journal of Rhythm and Stories* (2010), and *How to Relax in 60 Seconds or Less* (2011).

As versatile as he proves the drum to be, the demographics are also widespread. He offers a drumming session that ranges from children to young adults between the ages of 3 to 19, adults from 20 to 80, and senior citizens ages 75 to 104. He said, “Currently, I am providing programming in Barcelona to 300 individuals in a five-day workshop. This varies from what I offer 25 adults who would like to have an interactive family reunion.”

“I am grateful for today and for the many opportunities to work with so many extraordinary individuals,” said Friedman, who has become an inspiration to Alzheimer’s patients, cancer patients, Parkinson’s patients, stroke patients, as well as children with autism. His diverse pursuits also serve those who have bullied classmates in schools, prisoners, young adults who are detainees, war veterans, abandoned children, and at-risk children who have been incarcerated. He also assists “normal functioning individuals” by definition, which may include corporate executives, young adults, adults, and seniors.

From age 7 to 18, Friedman was raised in Rochdale Village in South Jamaica, New York. Despite negative memories of being bullied in his early teens, he reoriented his energy. “I would take my anger, frustration, and sadness, and come home and hit my drums. I later received a Master’s Degree in Counseling Education





from Hunter College, and post-graduate Certificate in Psychosynthesis. I purchased 100 drums to see if non-drummers could gain the same benefits. In 1986, the New Age Health Spa decided to try a radical idea of placing drums in front of non-drummers, and since it was so successful, I ran my program *Drumming Away Stress* for 17 years. My passion for drumming was something I always had, but my passion for helping others originated due to the drums which helped me work through my pain." Friedman enjoys playing hand drums, a drum set, the conga which originated in Cuba, and the djembe, descending from West Africa. His talents continue as a Remo artist.

Friedman owes much gratitude to role models such as his mother Sylvia, who passed away this year. "I called her 'the world's diplomat,' as she would talk to anyone she met, and develop an instant friendship through her warmth and love. Her words I will remember forever; 'be yourself, and they are lucky to have you.'" Other inspirations are Martin Luther King, Jr. and Mahatma Gandhi, who aimed to improve the world through their belief and actions.

A session's sequence and program changes based on attendees, but one program began with listening to a drum using entrainment, which is the tendency to follow a dominant rhythm. It is analogous to tapping one's foot to a song's rhythm. Friedman explained, "I had participants simply listen to a drum while they breathed in to a slow and steady beat for nearly five minutes. By slowing the rhythm of their breath, they slow their heart rate, begin normalizing their blood pressure, increase circulation, and change the brain rhythm to an alpha state for inner peace and tranquility." Through the *Take One Pass One* exercise introduced by music therapist Barry Bernstein, participants pass around a shaker egg and increase the pace until all eggs lands on the floor. This is followed by participants creatively expressing themselves on drums, potentially through a solo, matching a beat, building a rhythm, or learning African rhythms. Friedman continued, "We may end with a meditation or an imagery exercise. As the drum consciously and unconsciously releases stress, participants are usually experiencing a combination of euphoria, peace, or energy at the end."

As author Layne Redmond stated in *When the Drummers Were Women*, when individuals drum together, the hemispheres of their brain typically operate in 20-minute cycles of dominance, as well as in synch, which is known as hemispheric synchronization. Friedman explained, "Scientists believe that hemispheric synchronization only occurs in deep meditation and when people drum together, and it is the scientific basis of transcendent states of consciousness. What occurs at the end of a drumming program is quite extraordinary, as people leave feeling energized yet relaxed; two polar opposite emotions. I believe these emotions occur due to hemispheric synchronization."

After the Sandy Hook massacre, an invite was extended to Friedman, who coordinated a drumming session for children, parents, and teachers. He reminisced, "These experiences were particularly moving, as drumming was providing a therapeutic benefit of emotional release. I remember one woman who said that she felt the drum enabled her to release some of her pain and remember happiness, even for a brief moment that we were drumming together."

He also recalled his encounter with a 97-year-old resident of Cliffside Nursing Home. "As she drummed, she thanked me for helping her remember her youthful, playful, and joyful self."

In a Dominican Republic hospice unit, he met a boy with cancer. He explained, "When I asked him if he would like to drum with me, he shared that he would, but could only play with one hand due to chemotherapy. Then I watched this precious child slowly move from lying down to sitting up and smiling. As I taught him rhythms, I saw a sweet child of 12 years old for a moment forget his illness and move into a place of happiness. His mother walked in beaming, as she saw him focused on drumming, and she shared that before his illness, he loved the drums. I decided to give him the drum and drum sticks. He looked up and asked, 'When are you coming back?'" Friedman learned that he was released from hospice and is currently home.

When the International Burn Congress, an organization

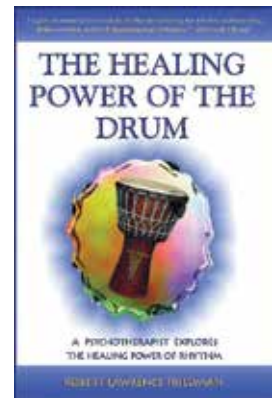
that provides support for burn survivors, extended an invite to Friedman to offer a drumming program at their annual conference, he was humbled by the individuals that he encountered. Some firemen experienced burns to 75 percent of their body during 9/11. He recalled an interactive and moving experience. "Being burned to that extent creates enormous scars physically, emotionally, and psychologically."

Another encounter was with a woman who is a meditator. He explained, "One day, she was home in a long dress, preparing to meditate. There was a small tea light on the floor, and as she stood up, her dress went up into flames. She told herself that she could walk into the bathroom with her dress ablaze, but by that time, her dress was completely in flames. She stepped into the shower, but that day she happened to change the faucets, forgetting which one was which. She turned on the hot water. She was able to call her husband who went pale when he saw her. She was admitted into the hospital with burns to 75% of her body, and lost her leg, her arm, and had scars throughout. She was placed in a medical coma for three months."

Friedman pointed out that this experience awakened her appreciation of a life that she did not have before. He continued, "When I ran my workshop, she was jumping up and down as she drummed, with a smile that was beaming. To watch someone with that level of challenge finding joy so ebulliently, deeply touched me."

In New York, Friedman's sessions have been held in nursing homes such as Parker Jewish Institute and Fairview Rehab & Nursing Home, libraries such as Great Neck Library and Lynbrook Library, higher education facilities including Queens College, Nassau Community College, and in schools including Francis Lewis High School, PS 130, PS 200, PS 5, PS 8, and PS 9. He has also worked with camps such as Mohawk Day Camp and corporations such as Standard & Poor's, HBO, and Hyatt Hotels. He can also be spotted in hospitals including

Cornell and Monmouth Medical Centers, working with teachers for the NYC Board of Education, and benefiting organizations including Big Brothers and the Girl Scouts. "Internationally, I have provided leadership and team-building drumming programs for 12 years for the YPO and Village Camps in Leysin, Switzerland, a music therapy conference in Singapore, and leadership training programs in Malaysia, Spain, England, and Ireland," he said.



Through Friedman's organization, Stress Solutions, Inc, he is a consultant for RWJ Barnabas Health, and is a corporate trainer offering beneficial programs to nurses, doctors, and staff members with titles including *Managing Stress, Conflicts in Relationships, and Staying Motivated*. To date, his success is evident through the development and facilitation of approximately 30 seminars. Other corporations that he provided non-drumming programs for include Pitney Bowes, Accenture, and S&P Global. Many of his courses are available at www.stress-solutions.com.

Friedman served as Chairman of the Health and Wellness Committee for the Percussive Arts Society for 14 years and presently sits on the Advisory Board of the Drum Circle Facilitators Guild. In 2014, he was the recipient of the Hearst Scholar Award by the University of Northern Iowa for drumming and wellness. As a stress expert, he appeared on "Class of '75," a year-long documentary on Discovery Health Channel. Other appearances were on The Today Show on NBC, Fox News, CNBC, and numerous television shows throughout Japan. Printed media appearances include The Wall Street Journal, The Washington Times, U.S. News & World Report, and a three-page feature in Newsday.

On June 15 from 6 PM to 7 PM, Friedman offered "Healing Power of the Drum" the first public workshop of its kind in Forest Hills at the Genesis Tree of Life Yoga & Wellness Center at 102-06 Metropolitan Avenue. "My short-term goal is to have more public workshops locally and launch a regular series at Genesis Tree of Life."

Friedman maintains an active web presence at www.stress-solutions.com, www.drumming-event.com, and www.mypersonaloasis.com, where his books are available, in addition to Amazon. He is proud to interact with the public via email at rff@stress-solutions.com



TREATMENT NEWS

Development of Treatments for Hemophilia B - Patients Needed

Compared to a few decades ago when nothing was happening, there is a tremendous number of new treatments for hemophilia B under development. This is good news, but it is also exhausting the supply of patients willing to volunteer to participate in the required clinical trials. All new treatments have to be tested in human subjects before they can be approved by FDA and put on the market. There are only about 4000 hemophilia B patients in the U.S., and many of those can't participate because of various factors (every study has different entry requirements). Others may be wary of the risks or don't have the time, but some patients might just not have thought about participating or didn't know there was a need.

Many older patients have been participating in various trials over the years. They feel they want to give back to the community that has helped them through thick and thin and want to contribute to the welfare of the younger generations. We owe them a lot of gratitude.

If you are interested in possibly participating in a study, or if you are on the fence and just want to know more, talk to your hematologist or HTC. Many of them are already treating patients in various trials or have colleagues who are. Clinical studies are usually run by outside physicians to eliminate the bias that could occur if the studies were run directly by the companies developing the products. Because our community is relatively small, many hemophilia treaters are involved in multiple trials.

Another source of information is www.clinicaltrials.gov, a list of all of the studies approved by FDA. Search under "hemophilia B". However, the descriptions don't really tell you all you'll want to know, so if you are interested in a specific trial, it's best to contact the person listed or ask your hematologist or HTC for more information.

Catalyst Announces Positive Results for Factor VIIa Variant

Catalyst Biosciences has reported positive interim results for the Phase II/III study of its subcutaneous factor VIIa variant for treatment of hemophilia A and B inhibitors. The variant, called marzeptacog alfa (activated) or MarzAA has a higher activity and longer half-life than normal factor VIIa. Three patients have been treated. The first patient, who had an annualized bleed rate (ABR) of 26.7 prior to treatment with MarzAA, had no bleeds for 50 days on a dose of 60 µg/kg and one bleed at day 46 at a lower dose of 30 µg/kg.



The second and third patients who had pre-study ABRs of 16.6 and 15.9 also had no bleeds for 50 and 44 days, respectively with a 30 µg/kg dose. No inhibitors to MarzAA have been observed. Catalyst also found that MarzAA has a half-life of 3.5 hours when dosed intravenously but 9.5 hours subcutaneously.

Catalyst has also had some problems with its subcutaneous factor IX product in development (see last issue). Because of this and other issues, a group of investors is conducting an investigation into possible violations of securities laws. The investors believe that a series of statements by Catalyst concerning its business, prospects and operations, might have been false and misleading.

That may or may not be true, but it shows some of the difficulties that small companies face when they are dependent on outside funding. R&D is a tricky business. You're always dealing with the unknown and your next big problem may be just around the corner. Most of those problems eventually get solved, but investors don't like the uncertainty. Stock prices for these small companies take huge jumps up or down depending on the latest news, and that can impact the amount of money they have available for research.

City of Hope Developing New Gene Editing Technology

Researchers at the City of Hope Medical Center in California are developing a new gene editing method for hemophilia A that, if successful, could also be adapted to treat hemophilia B. Many gene therapy companies are using adeno-associated virus (AAV) vectors to deliver normal genes to patients with genetic diseases. Most of these genes are just added to the nucleus of the affected cells and do not replace the mutated genes in the patient's genome. The City of Hope researchers have isolated a subtype of AAV from human blood stem cells (cells that reside in the bone marrow and continuously produce new blood cells) called AAVHSC. AAVHSCs can deliver gene sequences to targeted cells that will actually correct the mutations in a patient's genes, which should lead to a lifelong effect. City of Hope has licensed their technology to Homology Medicines, Inc., which continues to fund the research.



CRISPR Controversy

CRISPR/Cas9 is a gene editing method that has been touted as the future of gene therapy. None of the



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gene therapies currently being developed for hemophilia use CRISPR/Cas9, but several companies are using it to develop gene therapies for other diseases and could target hemophilia in the future. However, some recent studies have suggested that CRISPR/Cas9 could cause cancer in some cell types or other undesirable effects elsewhere in the body. Both CRISPR/Cas9's potential benefits and now its possible dangers have been over-hyped by the press. Scientists appear to have a more balanced view of both the benefits and dangers and seem to be proceeding cautiously. No company wants to spend large amounts of money developing a gene therapy treatment, only to find it causes problems.

EXPRESS SCRIPTS® **Express Scripts Limits Products Available for Hemophilia A**

Express Scripts is one of the largest Pharmacy Benefit Managers (PBMs) in the U.S. PBMs work with insurance companies and Medicare to administer the pharmacy portion of a healthcare insurance policy. Express Scripts recently released their formulary for 2019, and it excludes several recombinant factor VIII products for hemophilia A patients. That means those products will not be covered and patients will either have to switch to “comparable” products or pay full price. “Comparable” is in quotes because it is well known in the hemophilia community that not all products work equally well for all patients.

So far, no factor IX products and no plasma-derived products have been excluded. However, some other drugs used by hemophilia B patients have been, such as some HIV and hepatitis C treatments, some of the newer anticoagulants (blood thinners) used by heart patients, some epilepsy treatments and some pain drugs. The factor VIII products that are being excluded are Eloctate from Sanofi/Bioverativ, Recombinate from Shire/Baxalta and Xyntha from Pfizer. Note that Eloctate is a longer-acting factor VIII analogous to Alprolix, the longer-acting factor IX also from Sanofi/Bioverativ. Is this a portent of things to come for the longer-acting factor IX products? Note the report below from Prime Therapeutics that the cost of treatment for patients switching to the longer-acting products has approximately doubled.

Patients under Express Scripts can apply for an exception if they cannot use one of the preferred drugs. However, that can be a lengthy process, and the patient might need to try and fail on the other drugs first.

Express Scripts blames the drug companies for raising their prices and delaying generic/biosimilar competition. Express Scripts claims their changes will provide “better patient outcomes.” They think they will be better than the patient’s hematologist at choosing the right drug for that patient. If other PBMs and payers adopt this approach, this may be the beginning of a major change in hemophilia treatment.

Express Scripts in Talks to Distribute Gene Therapies Exclusively

Express Scripts is also in talks with BioMarin Pharmaceuticals (Hemophilia A) and Spark Therapeutics (A and B) to be the exclusive distributor of their gene therapy products through its specialty pharmacy. Express Scripts already has an agreement with Spark to exclusively distribute its recently-licensed Luxturna gene therapy for a rare eye disease in children. By using its own specialty pharmacy, it is able to hold onto more of the profits in the drug distribution chain.

FDA Wants to Accelerate Gene Therapy Development

FDA Commissioner Scott Gottlieb says he is determined to clear the pathway for development of gene therapies. He said the FDA will focus on hemophilia first because it’s already an area seeing a lot of development activity. They are compiling a series of guidance documents for industry, including one specifically for hemophilia. The draft document *Human Gene Therapy for Hemophilia* is available on the FDA website and is open for comment from the public.

All licensed products are approved on the basis of both safety and efficacy. The draft guidance document suggests evidence of efficacy may be based solely on ABR or factor activity. Information on long term effectiveness, for instance, would come from postmarketing studies (collection of data from regular patients after the product is on the market). Developers would also be eligible for *Regenerative Medicine Advanced Therapy* designation to further speed their path to licensure. This would be a boon for industry, because they could potentially get their products on the market more quickly with less testing.

However, would this be good for patients? FDA thinks it is a benefit because quicker licensure would lead to more products, more competition and thus increased patient benefit. They think this could also help lower costs, but that has never happened in the hemophilia world. FDA is also pushing innovative manufacturing methods to lower costs, but manufacturing costs are not the main driver of the cost of drugs.

FDA and the National Institutes of Health (NIH) are also proposing NIH discontinue its role in overseeing the safety of gene therapy treatments in development. NIH will continue to watch over development of recombinant products.

So what happens to a patient who signs up for a new gene therapy that has been approved through this pathway but not fully tested? He becomes a guinea pig who never volunteered for a clinical study. Hopefully the product will work fine. Most of the leading gene therapy companies are being very diligent in their development efforts. They



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know the success or failure of their product depends on its acceptance in the marketplace, not just whether FDA approves it. The hemophilia community is very tight-knit and word travels fast about new products. Because of the past harm to the hemophilia community, we are a skeptical bunch.

There are a lot of questions about gene therapy for hemophilia: how long will the treatment last; can a patient be treated a second time if the first fails; what about inhibitor development and can inhibitor patients be treated; what about cost and who pays, etc.? Gene therapy has been touted as a potential cure since the 1990s. There have been a lot of good results in the recent studies, and gene therapy will probably be a success in the long run. Unfortunately, the patient and his/her physician may be on their own in choosing whether to try early forms of gene therapy, without complete information from FDA.

French Researchers Explore Inhibitor Development

The mechanism for development of inhibitors in hemophilia is still only poorly understood. Inhibitors are antibodies that a patient develops against infused factor that keeps the factor from working. Both hemophilia A and B patients can develop inhibitors, although they are much more common in hemophilia A. French researchers studying hemophilia A and factor VIII have determined that oxidation (reaction with oxygen) of factor VIII plays a significant role in inhibitor development.

After an injury, the cells at the injury site (including a bleeding joint) release pro-inflammatory molecules as part of the healing process. Some of the pro-inflammatory molecules are reactive oxygen species (ROS) - molecules that contain oxygen and can easily oxidize other molecules. To stop the bleeding associated with the injury, clotting factors also congregate at the injury site where they are susceptible to oxidation by the ROS. The French study showed in mice that oxidation of factor VIII increases its immunogenicity (makes it more easily recognized by the immune system as a potentially undesirable molecule) and makes the risk for development of anti-factor VIII inhibitors more likely. Further research will be needed to determine whether a similar process occurs with factor IX.

Medscape Launches New Gene Therapy Programs

Medscape, the medical website at www.medscape.com, has just launched several new gene therapy modules in its Clinical Advances for Gene Therapy in Hemophilia series. These are continuing medical education (CME) courses intended for medical professionals, but they are free and available to the general public. The series is presented through a collaboration among the National Hemophilia Foundation, the European Hemophilia Consortium and the World Federation of Hemophilia and sponsored by BioMarin,



a company developing a gene therapy treatment for hemophilia A. The programs are fairly technical but may be interesting to the layperson with some basic understanding of gene therapy.

My Life, Our Future Update

My Life, Our Future (MLOF), is a program to genotype (analyze the genes of) individuals with hemophilia and carriers of hemophilia. It is being conducted through most of the Hemophilia Treatment Centers (HTCs) in the U.S. The initial phase of the program concluded in December 2017 with 11,356 patients and carriers included. Genotyping has been completed for 9,453 participants. The study has so far found 687 previously unknown genetic variants in 1,111 subjects. 81% of participants elected to have their blood samples stored in the research repository for future studies.



New research is already being conducted with these samples. In collaboration with the National Heart, Lung and Blood Institute (NHLBI, part of NIH), 5141 samples are receiving whole-genome sequencing, that is, they are sequencing all of the genes in each patient's sample, not just the factor genes. This is to try to better understand the fundamental biological processes that underlie heart, lung, blood and sleep disorders. For instance, analysis of the whole genome might show why patients with the same factor level can bleed very differently. The answer may lie in other genes than the factor genes. The studies are part of the National Institute of Health's (NIH's) Precision Medicine Initiative to provide disease treatments tailored to a person's "unique genes and environment."

My Life, Our Future Female Telegenetics Study

Female MLOF participants are invited to take part in a study to explore the use of telemedicine (a private video chat with a medical specialist over the internet) in providing genetic counseling for genotyping results. The study is sponsored by the National Hemophilia Foundation. Participants will be split into two groups. One group will receive genetic counseling by telemedicine, and the other will receive the counseling the way they normally would through their Hemophilia Treatment Center. The telemedicine sessions will be conducted on a smartphone or computer over a HIPPA-compliant secure link. The session will be private, and nothing will go to the participant's physicians, insurance carriers or anyone else without the subject's approval. The session will be followed by secure online surveys over a period of six months to assess whether the participant's health behaviors have been influenced compared to the control group (the group that did not use telemedicine). Women interested in participating in the study should contact Maria Santaella at (347) 918-6608 or msantaella@hemophilia.org.



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Pfizer and Spark Initiate Phase III Gene Therapy Trial

Pfizer, which has taken over continued development of the hemophilia B gene therapy treatment developed by Spark Therapeutics, is initiating their Phase III clinical study. The first



part will be a six-month lead-in study to collect information on each patient's experience with their current factor IX product and prophylactic regimen. This will provide a baseline against which to compare the patient's results after gene therapy. Spark/Pfizer's treatment has been given the generic name fidanacogene elaparvec and consists of an AAV vector carrying the gene for a high-activity factor IX.

It may be a good thing Pfizer has taken this project over from Spark. They are more immune to the fickleness of the stock market. Spark recently had some poor results in its studies of a gene therapy for hemophilia A, and its stock fell almost 30% in one day. Wall Street doesn't have the patience needed for the ups and downs of R&D, which makes it difficult for small companies that don't have the resources of a company like Pfizer.

In another area, Pfizer has announced that it is reorganizing into three new business units, all under the Pfizer name. They will be Innovative Medicines, Established Medicines and Consumer Healthcare. They are also moving their New York corporate headquarters from their well-known location on 42nd Street to The Spiral, a new office skyscraper in Manhattan's Hudson Yards development.

Prime Therapeutics Finds Costs Double for Extended Half-Life Products



Prime Therapeutics, a pharmacy benefit manager (PBM) owned by Blue Cross/Blue Shield announced the results of a cost study for hemophilia patients switching to extended half-life (EHL) products. They found that the actual costs approximately double. Using pharmacy and medical claims data from their patients, they identified 20 hemophilia B patients who had switched. They found that the average six-month cost for standard half-life products was \$116,909. After the switch, the average six-month cost was \$230,210, 1.97 times higher, for the EHL products. For hemophilia A, the comparable six-month numbers are an increase of 2.36 times from \$127,168 to \$300,429.

Prime stated that the increased costs "need to be justified clinically." This and similar studies by other PBMs could lead to restrictions on who can switch, what products they will use and potentially how many units they can have. This is already happening for hemophilia A patients - see the Express Scripts report above.

TREATMENT NEWS

TAF Announces Program to Help Hemophilia Patients with Medical Costs



The Assistance Fund (TAF), an independent charitable foundation aimed at helping patients afford high out-of-pocket medical costs, recently started the Hemophilia Financial Assistance Program. Information can be found on their website www.tafcares.org.

uniQure Enrolling Patients in Phase III Gene Therapy Study



uniQure announced that it is enrolling patients for the Phase III clinical study of its AMT-061 gene therapy treatment. Meanwhile, they are conducting a small Phase IIb dose-confirmation study with three patients. uniQure got good results with their original factor IX treatment, AMT-060, but their factor IX levels were lower than those of the competition. To remedy that, they switched to AMT-061, which uses the gene for Padua factor IX, a higher-activity variant. After comparability studies to show that the previous results with AMT-060 also support the safety and efficacy of AMT-061, both FDA and the European Union approved uniQure's continuing their studies with the new variant. Before they start the full-blown Phase III study to acquire the data needed for licensure, uniQure is performing the small Phase IIb study to make sure they know the optimum dose for AMT-061.

University College London Developing Fetal Gene Therapy



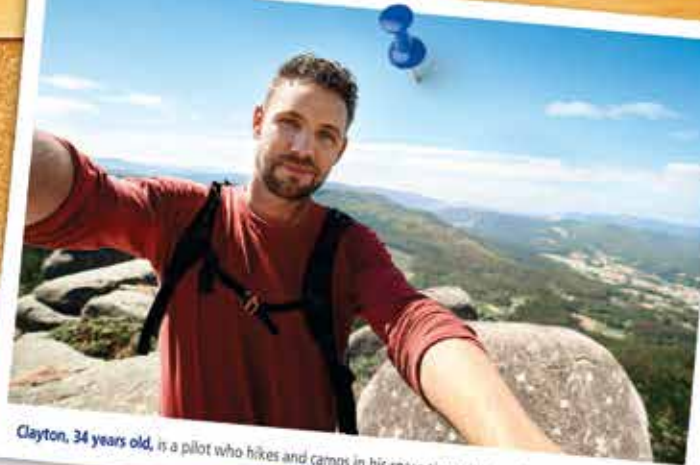
Researchers at University College London (UCL) are developing a gene therapy method to treat fetuses before birth. They are currently focusing on Gaucher Disease, but if the method is successful, it probably could be adapted to treat hemophilia. The method uses AAV-9 vectors containing the corrective genes injected directly into the fetus in the womb. So far, they have gotten good results in mice and monkeys.

XaTek Developing ClotChip, a Portable Clotting Analyzer



XaTek, a new company in Cleveland, OH, is developing technology invented at Case Western Reserve University to produce ClotChip, a portable clotting analyzer that only uses a drop of blood. ClotChip uses dielectric spectroscopy to see changes like clotting and can also monitor the quality and firmness of the clot. The small portable devices could be used in real time in a physician's office, avoiding the need to send samples to an outside lab. XaTek is targeting hemophilia treatment as well as monitoring anticoagulants in patients with heart disease. They plan to begin a Phase I (safety) study in September in Cleveland.

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 $\leq 2\%$ FIX levels^a

^aIn 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.

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.

^bBased upon a 2.34% increase in factor levels per IU/kg infused in adults.

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

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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

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Keep track of your bleeds, infusions, and activity.

HemMobile™

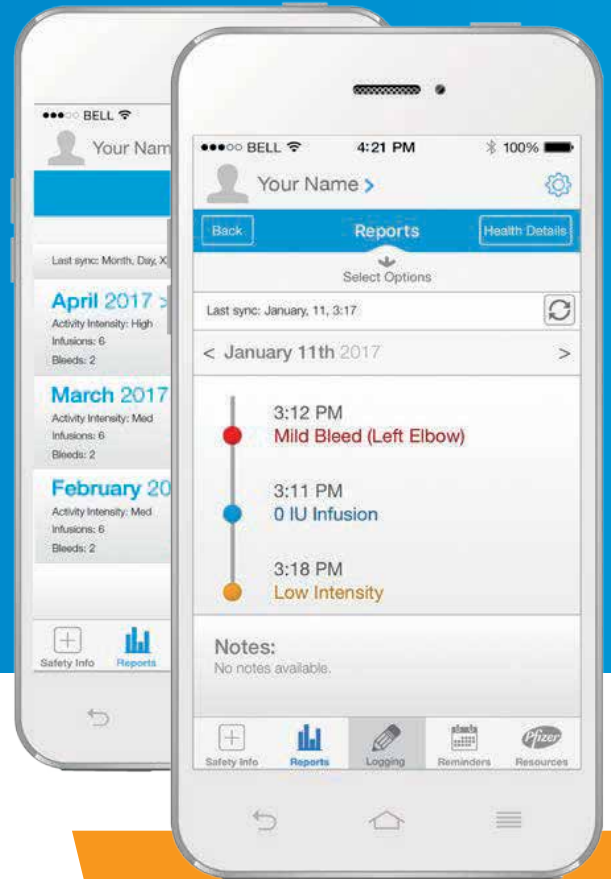
with *enhanced* activity tracking

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.

HemMobile™ was designed to help you keep track of your bleeds, infusions, and factor supply.*

Now it can also help you keep track of your daily activities and, when paired with our custom wearable device, track your heart rate, steps, distance, and activity duration. You can have an even more informed discussion with your treatment team about your activity level as well as your dosing regimen.

Download the app,
pair your device,
and start tracking



For iPhone® and Android™



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

Call **1.844.989.HEMO (4366)** Monday through Friday from 8:00 AM to 8:00 PM Eastern Time.

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A PERSPECTIVE ON ANKLE REPLACEMENT SURGERY

BY RICK STARKS

Spring 2018 was a time of anticipation, yet trepidation. I was scheduled to have ankle replacement surgery May 23, 2018, at 5:30 am. I had spoken with my physical therapist a few months earlier and with the increase in pain, I had decided it was time. Both ankles were in bad shape. Due to numerous bleeds dating back to my childhood years, CT scans and X-rays showed massive deterioration of both ankles. As a child, I was always twisting and spraining my ankles. Each time, I'd be admitted to the hospital for at least a week with my arm strapped to an IV board, receiving infusions of fresh frozen plasma. I would be in a cast for 4-6 weeks, or as long as they'd last. It was a toss up as to which ankle would be replaced first. So Wednesday morning at 5:30 am, I checked in at the Anschutz Center in Denver, Colorado and reported to pre-surgery.



The normal pre-surgery procedures ensued – stripping down and modeling the fashionable hospital gown, vitals checking and rechecking, and removing all jewelry and replacing with the lovely hospital bracelet. The anesthesiologist arrived to check my throat, IVs put in place, blood draws taken, and a pre-surgery visit with my surgeon, Dr. Kenneth Hunt. The hemophilia treatment center nurse arrived and dosed me to a 100% factor level. Anesthesia professionals came in and started the nerve block. This was my choice for the procedure as I would be able to avoid pain meds throughout my stay. Guided by ultrasound to ensure proper placement, a catheter needle was inserted on the inside of my knee. The nerve block was administered on a drip to numb my leg from the knee down. It worked great!

'Happy juice' was given to me through my IV as I was wheeled into surgery. The next thing I knew I was in recovery waking up with a splint on my leg, from knee to toe. Dr. Hunt arrived and said he was very happy with how the surgery went. Using *Prophecy Total Ankle System* hardware from Wright Medical Group N.V., the surgery took 2 hours to complete. Due to the lack of mobility for so many years, my Achilles tendon had shrunk and had to be lengthened. Additionally, the tendon on the top of my foot that connects to the big toe, had also shrunk. Every time I tried to extend my ankle, my big toe would stick straight up! In addition to the ankle joint being replaced, 3 additional incisions were made to fix these issues. The rest of the day was uneventful as I was transferred to a

hospital room for the remainder of my stay.

The next day, I began physical therapy and walked with a walker. Hopping with a walker caused increased pain in the other ankle and supporting my weight with arthritic elbows was difficult too. However, I felt I could handle the pain and wanted to reduce the drip of the nerve block. I was mistaken – in just 20 minutes as the nerve block wore off, the pain became excruciating. The nurse immediately increased the dosage to provide pain relief. Clotting factor was again infused to reach 100%. I was discharged from the hospital the next day.

For the most part over the next week, I stayed in bed and kept my foot elevated. A painful throbbing began every time I let my foot hang down, so the pillow kept under it was soon my best friend. Two weeks later, I returned for a follow up visit and the splint and sutures were removed. Though my ankle was still swollen, there was already more range of motion than before surgery! There was some loss of sensation, but that improves daily. At approximately 5 weeks post op, bruising and discomfort has been minimal and I'm able to fully bear weight and walk unassisted.

Although it's only been a few weeks, I have no pain in my ankle. All the discomfort I have is in the ankle that hasn't yet been replaced. Therapy continues twice a week and I'm feeling stronger and very relieved I finally had the procedure done. Would I do it again? Absolutely! In fact, I'm going to have the other one done this December!

CAN I BE AN ATHLETE IF I HAVE HEMOPHILIA?

BY PARENT, ANGELA FORD BARDEN

When I was initially contacted to share our story, it was because I had posted on my social media page a photo of my 16-year-old son, Austin, preparing for the annual Illinois Marathon 5-k Run. I was honored to be asked to share our story so that others can see the true joy they can experience by being an athlete and the pride a parent of an athlete can have, even with a diagnosis of hemophilia. So here we go...

In 2004, a month prior to my son's 2nd birthday, my 5-month-old nephew, Zachary, had a medical episode that caused him to be transferred to Dallas Children's Hospital for immediate surgery. Because of the severity of Zachary's condition and having the possibility that we would lose him, we had immediately flown down to Dallas to support my family through this time. I remember sitting in the conference room with my crying sister, my parents, the doctors, and the social worker questioning if we had a history of bleeding disorders in our family. Our answer was no. We were then told Zachary had severe hemophilia B.

The staff began explaining to us what hemophilia was, what we would need to watch for and what life would mean for Zachary through the years. I looked at my son playing with his toys on the floor in the corner of the room and I immediately knew he had this too. The medical professionals proceeding with the meeting as though Zachary was a first generation mutation; however, the more I listened, the more I was convinced that Austin had hemophilia too. We had him screened and were struck with the same news, my son was officially diagnosis with severe hemophilia B. This led us to the realization my sister, my mother and I were all carriers.

While all of this was extremely emotional in the moment, we look back and realize how truly blessed we were that God watched over us those first two years. While Zachary's situation was life threatening, I believe it was meant to be that way so that I would find myself present in the conference room. I believe God had Zachary in good hands at Dallas Children's Hospital. Being in a much larger city, the doctors were more familiar with bleeding disorders and recognized my nephew's symptoms, knew to test for it, and knew how to treat it.

Living in central Illinois, hemophilia was not something our local hospital saw often or had on their radar. For the first two years of my son's life, I brought my concerns of multiple unexplainable bruises and swollen ankles to his pediatrician. His symptoms were always chalked up to boys being boys and we were sent home with instructions



to wrap his joints with ace bandages. So on that day in April 2004 in Texas, our hemophilia journey began...

As many of the parents reading this know, you feel all different emotions when facing a disorder like hemophilia and you want to protect your child. It's easy to say wrap them in bubble wrap and don't let them get hurt, but it's my belief it is more important to raise a child that isn't defined by hemophilia, but a child who is defined by his own story. That brings me to Austin's story of who he is today. He is a determined, compassionate, disciplined, and competitive athlete with a high tolerance for pain who writes his own story in which hemophilia is nothing more than a chapter in his book.

Austin's journey has included playing competitive soccer, baseball, basketball, and running in 5k marathons. All of course with his doctor's approval, even though sometimes it has taken some serious negotiations between him and his doctor, but we have always raised him with explaining the risks and consequences if he gets injured, then have allowed him to make his own decision whether it's worth it. While I want to protect him, I know that only he knows what he feels inside, only he knows what he has the strength to do, so the goal has always been to educate him, support him and encourage him in what he wants to achieve. We have a strong rule of NO football, but outside of that, we've allowed him to try a variety of sports and



the last. Yes, there have been injuries along the way, some pretty severe that have landed him in the hospital and some that are just the usual injuries that every athlete experiences. Yes, it's extremely hard to be the parent in the stand knowing that one hit could land him in the hospital for a long period of time or something worse, but the joy of seeing him smiling and enjoying the game/run is what makes it all worth it. So you educate your child about their disorder, you educate yourself, you ensure treatments are being done on schedule and you immediately treat with additional factor if you suspect an injury. Today, Austin and I always say treatment is nothing more to his routine than brushing his teeth.

activities. He is an overall good athlete. On his own, he eventually gave up soccer and baseball. But he continues today playing basketball and running in the 5ks. Basketball is his love, as he plays on his school's basketball team and in the off season is on a traveling league. He dreams of playing basketball in college in a couple of years. Running is a personal goal for him; he runs to challenge himself to achieve a better time than

So what has Austin learned from being an athlete? He's learned that hard work now makes it easier later; he's learned performance is based on his inside perseverance and not outside forces; he's learned only he can set his limitations; he's learned that setbacks happen, but life goes on; he's learned time management; he's learned how to self-reflect; he's

learned that you will not always win; he's learned that you have to work hard to reach your goals; he's learned what it means to be part of a team... and so much more.

These lessons will take him far. In a couple years, he will leave our home to attend college. I anticipate it will be an extremely emotionally day for me, but I'm confident he will be ready to take on the world and will grow into a successful adult. As parents, that's what we want for our children. It makes those days of sitting on the bleachers fearfully watching each hit and bump with clenched teeth and racing heart all worth it.

While my primary reason for this article was to share Austin's story, it began with the unusual way we came to learn his diagnosis. That was my nephew Zachary. Zachary is an athlete too. He plays baseball and golf. He is a fantastic pitcher and plays for the love of the game. So in closing, to answer the question of the title of this article, "Can I be an athlete if I have hemophilia?" The answer is YES! Live life to the fullest!

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!

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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.



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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.

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B Connected, contact administrators,
Rick Starks and Shad Tullidge at:
bconnected@hemob.org

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- » 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

RARE BLEEDING DISORDERS

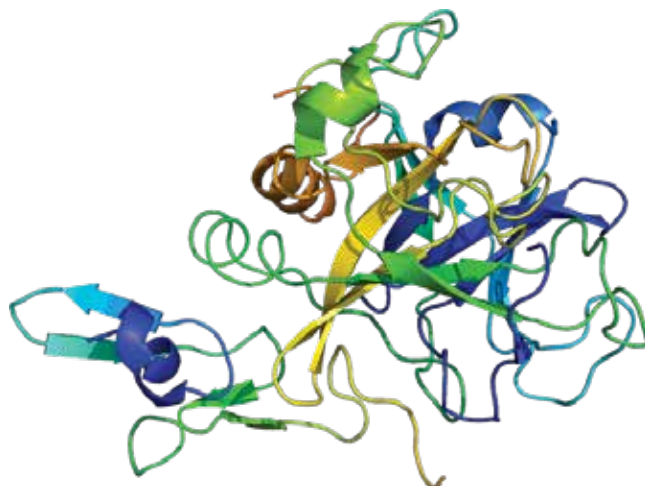
FACTOR X DEFICIENCY

BY DR. DAVID CLARK

Hemophilia B, factor IX deficiency, is a relatively rare bleeding disorder with a prevalence of about one in 25,000 to 30,000. There are estimated to be about 4000 hemophilia B patients in the U.S. However, there are a number of even rarer bleeding disorders, including factor X deficiency. Factor X deficiency has an estimated incidence of one in one million for the severe form. That means there are only about 325 severe factor X deficient patients in the U.S.

In the clotting cascade, factors VIII and IX work together to activate factor X. Factor X goes on to activate factor II, which converts fibrinogen to fibrin to form a clot. Therefore, if there is a deficiency in any of the three factors, VIII, IX or X, the clotting process tends to slow down or stop at that step and insufficient amounts of fibrin are formed. Thus, the symptoms of factor X deficiency are similar to those of hemophilia A and B, but not identical.

Before the development of purified factor IX products, hemophilia B patients were often treated with Factor IX Complex, and before that with plasma. Until 2015, that was also the state of the art for factor X deficient patients. These are effective, but problematic, treatments. Plasma has a large volume compared to the amount of factor X it contains, so patients can only be given limited amounts at a time. This often results in hospital stays for patients with severe bleeds. Factor IX Complex is a mixture of clotting factors including factors II, IX and X, and in some products factor VII. It was used for years to treat hemophilia B, but it has the problem of being thrombogenic when used in large amounts or for extended time periods. That is, it can cause too much clotting, which can be dangerous or even fatal. Hemophilia B patients could be treated with Factor IX Complex for routine bleeds, but prophylaxis or surgery were very risky.



The development of purified factor IX products, first from plasma and later recombinant, revolutionized the treatment of hemophilia B. The same thing is now happening for factor X deficiency. Coagadex, a purified plasma-derived factor X concentrate was licensed in the U.S. in 2015 for treatment of factor X deficient patients. Coagadex is produced by Bio Products Laboratory (BPL), a British company. BPL is a relatively new company, but its heritage goes back to the Lister Institute and the Elstree plasma fractionation facility, British labs that were pioneers in developing blood products and vaccines.

The Coalition for Hemophilia B was originally founded to assist patients with the relatively rare bleeding disorder hemophilia B. Over the past 27 years, much more attention has been paid to hemophilia B and factor IX products, and now hopefully that is being extended to patients with other rare bleeding disorders. The Coalition for Hemophilia B as well as other organizations across the country are taking more active roles in supporting patients with rare bleeding disorders. We are in this together to make life better for individuals and families affected by a bleeding disorder.



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ONE HUNDRED YEARS AGO, THE LAST RUSSIAN ROYAL WITH HEMOPHILIA DIES

BY DR. DAVID CLARK



Infante
Gonzalo
of Spain

Hemophilia is sometimes called the “Royal Disease” because Queen Victoria (1819-1901) of Great Britain was a carrier whose children spread the disease by intermarriage with other royal families of Europe, including Spain, Germany and Russia. The disease was only recently determined to be hemophilia B after the remains of Victoria’s great grandson, Russian Prince Alexei, were analyzed. Prince Alexei, along with the entire Russian royal family, was assassinated by the Bolsheviks during the Russian Revolution on July 17, 1918, one hundred years ago. Alexei’s health was one factor contributing to the fall of Imperial Russia, since he was heir to the throne.



Queen Victoria

Queen Victoria was apparently a spontaneous carrier as there is no evidence of hemophilia in her or her husband Prince Albert’s families. Spontaneous mutations occur more often with older fathers, and Victoria’s father was 51 when she was born. Victoria had nine children. Only three have

been confirmed as being affected: daughters Alice and Beatrice were carriers and son Leopold had hemophilia B. The status of three other daughters is unknown. None of Victoria’s children married back into the British royal family, and therefore hemophilia was removed from that lineage. Her oldest son was unaffected and became King Edward VII.

Rulers often cemented political alliances by marrying their sons and daughters into their allies’ royal families. Victoria was no exception; three of her children married into other European royal families. The offspring of those marriages helped spread hemophilia even farther. Tsar Nicholas II of Russia married Victoria’s granddaughter Alix. They had four daughters and one son, Alexei, who we now know had hemophilia B. Modern genetic analysis shows that one daughter appears to have been a carrier, but the identity of which daughter is in dispute. It may have been either Maria or Anastasia. Maria reportedly hemorrhaged severely during a tonsillectomy and might have had hemophilia. Anastasia was popularly rumored to have escaped the assassination attempt and to have survived into the late

20th century, but has never been proven.

In desperation, Alix, by then Empress Alexandra of Russia, sought out the best doctors in Europe to try to cure her son Alexei. When they failed, she turned to less orthodox healers, including Rasputin, a mystic and self-proclaimed holy man. Rasputin purportedly healed Alexei, although later sources attributed the “cure” to hypnosis, which made Alexei feel better temporarily. With this success, Rasputin inserted himself more deeply into the royal family and became an advisor to the tsar. However, many in Russia considered him a charlatan, which contributed to both his and the royal family’s unpopularity. Rasputin was assassinated in December 1916 by a group of nobles who considered him a threat to the empire. The Russian Revolution of 1917 led to the fall of the tsar.

Today, none of the survivors of the various European royal dynasties is known to have or carry hemophilia. The last known descendent of Victoria to have hemophilia was grandson Infante Gonzolo of Spain who bled to death after a car accident in 1934 at age 19. There is a small chance that hemophilia B could show up again in one of the female lineages of Victoria’s descendents, but as time goes on, that is less and less likely.



The Coalition for Hemophilia B understands there are families within our bleeding disorder community who feel the effects of the current economic situation. While the Coalition will also contribute to this fund, we ask our more fortunate Factor Nine Families to help us by making a financial donation to the Factor Nine “**Holiday Fund**” to help buy gifts for children with hemophilia.



To make a donation,
please send a check payable to:

The Coalition for Hemophilia B Holiday Fund
757 Third Avenue, 20th Floor
New York, New York 10017

Please respond by **November 19, 2018**,
so the Factor Nine Santa can load his sleigh
with holiday gifts for all good girls and boys!

For families in our community in need of a little holiday cheer, we would like to help put something under the tree for your children! Fill out this form and send it to Santa’s special elf, Kim, at the “East” Pole. Factor Nine Santa has a busy schedule, so please send this form no later than **November 19, 2018**. Your name and information will be kept strictly confidential. Send mail this form to:

The Coalition for Hemophilia B Holiday Cheer
757 Third Avenue, 20th Floor; New York, New York 10017

Name: _____

Street Address: _____

City, State, Zipcode: _____

Phone: _____

Please give an **exact description** of your child’s wish item.
Gifts will be purchased and sent to your home.

Child’s Name and Age:

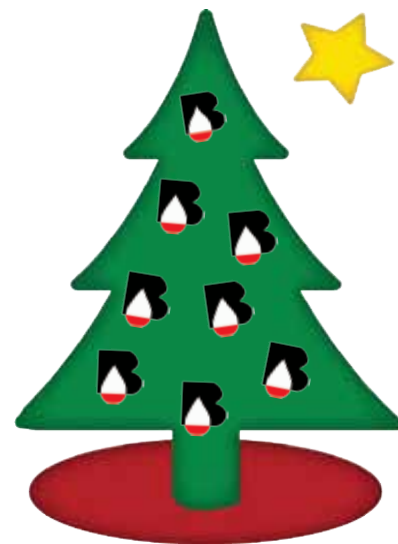
Child’s Name and Age:

Child’s Name and Age:

Wish List:

Wish List:

Wish List:



**We wish you all a
beautiful holiday
season filled with
love, happiness
and good health!**

NHF WALK NEW YORK



Sunday, June 3, 2018 the New York City Hemophilia Chapter held its 13th annual New York City Hemophilia Walk in Riverside Park. Now part of the National Hemophilia Foundation's *Unite for Bleeding Disorders Walk*, the NYC Walk is the oldest and largest event of its kind in the country. This year, over \$320,000 was raised, with thousands of community members participating.



WE CELEBRATE A WEDDING!

Saturday July 21st, Shannon Cook married Michael Degenero in a romantic, sunflower field setting in Lakeside Farms in Ballston Lake, New York. Shannon is the daughter of Wayne Cook, President of The Coalition for Hemophilia B. An intimate reception followed with family and close friends celebrating the newlyweds! We wish them a lifetime of happiness!

"I had the opportunity to cross another milestone off my bucket list – walking my beautiful daughter Shannon down the aisle on her wedding day. The sun was shining, the sky was blue, and as we danced the father–daughter dance to the song *Butterfly Kisses* playing in the background, we both cried as I shared the memory of the day she was born, when she took her first step, and other precious moments in her life. Michael danced the traditional mother–son dance with his sister in memory of his mom who sadly passed away last year. Shannon will always be my little girl and as the saying goes, we're really not losing a daughter, but gaining a son. We welcome Michael into our family with open arms and look forward to the happy memories they will make for years to come." ~ Wayne Cook



SAVE *the* DATE



**Thursday March 14
to Sunday March 17**

The Coalition for
Hemophilia B
Annual Symposium

2019

RENAISSANCE ORLANDO at SeaWorld!

Event and registration details will be
announced soon at HemoB.org and on
social:



THE COALITION FOR
HEMOPHILIA



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



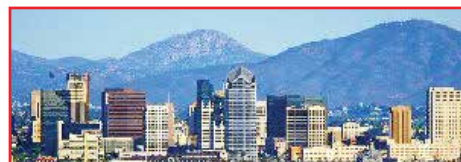
MEETING ON THE ROAD
PITTSBURGH, PA
SATURDAY
SEPTEMBER 22, 2018

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

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

— Shannon L. Alder



**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:

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The Coalition for Hemophilia B

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hemob.org



KIDZ KORNER!

SUMMER FUN!



SUMMER FUN WORD SEARCH

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CHALK	SUNGLASSES
FAMILY	SUNSHINE
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FIREWORKS	TOWEL
FRIENDS	VACATION
FUN	VOLLEYBALL
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Provided By Chicken Scratch NY



The Coalition for Hemophilia B

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Website: www.hemob.org

Facebook: www.facebook.com/HemophiliaB/

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For information, contact Kim Phelan
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