



Factor Nine News

The Coalition for Hemophilia B

FALL 2018



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CO-PAY ACCUMULATORS: THE NEWEST CHALLENGE TO ACCESSING AFFORDABLE CARE

By Glenn Mones

Life with hemophilia has sometimes resembled a roller-coaster ride. In the early days, there were no truly effective treatments and a diagnosis of hemophilia meant uncontrolled bleeding, horrific joint damage, and far too often, an early death. The development of treatments like cryoprecipitate and, later, clotting factor replacement therapies were revolutionary. While not a cure, these products for the first time made it possible for people with hemophilia to lead longer, healthier lives. Tragically, it wasn't long before the roller coaster plummeted again. It turned out that the clotting factor products were tainted with blood-borne pathogens from the plasma used in the manufacturing process. More than half of all people with hemophilia were infected and most lost their lives. Today, while there is still not a cure, products are very safe and effective, with new and improved products coming out on a regular basis. The challenge: How does it get paid for? If you can't get your product, it might as well not exist, and down goes the roller coaster again.

Accumulator programs have the potential to make hemophilia treatments unaffordable for many patients. It is of utmost importance everyone potentially affected understand what they are, what kind of impact they may have on access to care, and what we all can do about them.

Hemophilia drugs are expensive. This is partially a function of the amount of research and development involved and partly a function of the small size of the hemophilia population. There are no generics, and without adequate reimbursement, there would be no incentive for manufacturers to develop new and better products. This issue resonates particularly with patients in the hemophilia B community, who for the first time in history have a range of life-saving products intended for their factor IX deficiency. Unfortunately, insurance companies don't like paying for them, and have often done everything in their power to avoid having to do so. The Affordable Care Act (ACA), also known as Obamacare, went a long way toward requiring payers to "do the right thing," but the current political climate has taken the teeth out of the ACA, leaving insurance companies to go back to their old tricks while introducing some new tricks.

The latest strategy that insurance companies and the

pharmacy benefit managers they employ have started to introduce is something called co-pay accumulators or accumulator adjustors. These accumulator programs have the potential to make hemophilia treatments unaffordable for many patients. Therefore, it is of utmost importance that everyone potentially affected understand what they are, what kind of impact they may have on access to care, and what we all can do about them. The following Q&A explains the most important things about accumulators we all need to know.

Q: What is a co-pay accumulator?

A: Many health insurance policies require covered patients to pay a portion of the cost of their medicines until an out-of-pocket maximum for the year has been reached. With expensive therapies like those for hemophilia, this maximum will almost always be reached, costing the patient many thousands of dollars. For a lot of families

and individuals, this amount is simply more than they can afford, threatening them with financial ruin and lack of access to treatment. This problem has been addressed through the introduction of co-pay assistance programs in which

drug companies and/or third-party nonprofits cover all or part of the co-payment costs. It's a practical solution to a real problem. Enter the accumulator adjustor. Under these programs, any payment made on behalf of a patient by a third party is NOT counted toward the out-of-pocket maximum, leaving the patient with the same problem the co-pay assistance programs were intended to solve. For

Strategies going forward will include our educating payers, so they understand why hemophilia is different, as well as alerting state insurance commissioners to the severity and possible outcomes of this vexing problem.

example, let's say someone has a policy with a \$5,000 out-of-pocket maximum, and that a drug manufacturer or other third-party organization pays that \$5,000. In the past, that patient was considered to have met their out-of-pocket maximum, leaving the insurer to pay all covered costs for

the remainder of the year. Now let's say that the insurer introduces an accumulator adjustor program. Suddenly, the \$5,000 in co-pay assistance paid by the third party is no longer counted against the out-of-pocket maximum because the funds did not literally come out of the patient's pocket! The patient is held responsible for the \$5,000 and may have difficulty accessing treatment until the amount is paid.

Q: Why are insurance companies doing this?

A: Well, that partly depends on who you ask. Insurers claim that co-pay assistance programs are just a way for pharmaceutical companies to sell their products at high prices. They also claim that without shifting more of the financial burden to the end-consumer, patients will have no incentive to use cheaper generic drugs or avoid trying drugs they may not really need. However, these programs allow insurance companies to increase their already substantial profits by essentially “double dipping” — collecting the co-payment once from the third party and again from the patient.

While this strategy may have limited validity for some disease states, it is NOT appropriate for many chronic, rare disorders like hemophilia. There are no generic treatments for hemophilia, so no “lower-cost alternatives” are available. Furthermore, hemophilia treatments have been proven over and over to be highly effective when dosed adequately as determined by an appropriate



are using an accumulator adjustor. Don't be afraid to ask questions!

Q: What can I do about this problem? I'm just one person.

A: First, you are not just one person. You are part of a small but vocal and highly effective community of advocates who don't take no for an answer when it comes to access to healthcare. The Coalition for Hemophilia B has a program called the B Voice, designed to give our members ways to influence policies that affect our health and our lives. You can learn more and get involved by visiting www.hemob.org/advocacy.

Other national organizations are actively involved in this issue. They include the National Hemophilia Foundation (www.hemophilia.org/Advocacy-Healthcare-Coverage), the Hemophilia Federation of America (www.hemophiliamed.org/advocacy), and the National Organization for Rare Disorders (rarediseases.org/advocate). Each of these organizations offers additional information on this issue, resources, and ways to take action.

You might also want to contact your local chapter or association, or the social worker at your treatment center. They may have particular experience dealing with the payers in your area.

One of the most important things you can do to help national and local organizations fight on your behalf is to share your story. If you think your insurance company is either already using or thinking about using an accumulator adjustor, don't keep it a secret! Let The Coalition for Hemophilia B as well as the other aforementioned organizations know what's happening. That way, we know exactly where this problem is rearing its head and we are better equipped to do something about it. Our strategies going forward will include educating the payers, so they understand why hemophilia is different, as well as alerting state insurance commissioners to the severity and possible outcomes of this vexing problem.

Together, there is no problem we cannot solve. Together, we can truly make a difference.

Co-pay assistance programs are a practical solution to a real problem. Enter the accumulator adjustor. Under these programs, any payment made on behalf of a patient by a third party is NOT counted toward the out-of-pocket maximum, leaving the patient with the same problem the co-pay assistance programs were intended to solve.

clinician in consultation with the patient. No one would ever use a hemophilia treatment if they didn't need it. Finally, even a significant reduction of the cost of treatment would not alter the impact of a large co-payment on patients.

Q: How do I know if my insurance company has introduced, or is contemplating the introduction of, an accumulator adjustor?

A: Often, an insurance company will inform patients by letter of the introduction of an accumulator adjustor, so make sure to read your mail. You can also call your insurer and ask. Insurers should be able to tell you and asking is not going to make them suddenly introduce one of these programs. During open enrollment, be sure to review all plan documents to determine whether your insurance plan has implemented an accumulator adjustor program.

Finally, if you know your co-payment was paid by a third party but the insurer tells you that you still owe your full out-of-pocket maximum, there's a pretty good chance they



2018 FALL MEN'S RETREAT

By Wayne Cook



The Coalition for Hemophilia B held its second men's retreat of the year September, 13th–16th, at the beautiful Arizona Grand Resort in Phoenix, Arizona. This meeting was particular special because it included guys with hemophilia B and had more dads of children with hemophilia B participating than ever before.

Day one began on Thursday - our attendees arrived and were greeted and welcomed by our committee members. After lunch, massages, and time to relax, we kicked off our meeting with two programs: one for the dads presented by Dr. William Patsakos on the topic of being the dad caregiver, and then I presented the men's program on the "aha" moments we have as we age.



When the programs were completed, we enjoyed a relaxed dinner buffet along with great conversations and good laughter. Following dinner, the men gathered for what is one of the best parts of our meetings—the ice breaker rap session. The guys all have the opportunity to share something about themselves and their family and speak openly about whatever they would like. This session was very emotional for some of our new dads who have never been a part of a group that welcomes, accepts, and understands their situation.



Both Friday and Sunday began with a relaxing session of Tai Chi with Rick Starks or a brisk walk around the hotel complex and golf course, led by Rocky Williams. The activities were followed by a buffet breakfast before the day's activities began.

Addressing Physical and Mental Health

Friday began with Jacob Tullos, a fitness and nutrition trainer, presenting on how to *Get Rid of the Diet and Eat for Life*. He discussed fad diets and gave advice on how to navigate a nutrition path and how to identify the good and the bad in certain foods, including fruits and vegetables. After a short break, Debbie De La Riva, who has been part of the hemophilia community for more than 20 years, led





our second session. She is a professional counselor, mental health instructor and a former executive director of the Lone Star Chapter of the National Hemophilia Foundation in Texas. Debbie presented information on how mental health can impact someone with a bleeding disorder and how to train your mind to work in your favor. This session was very well received with the men asking lots of questions.

Fun and Games at the Bleeder Olympics

The afternoon gave way to lunch and taking a group photo at the beautiful waterfalls on the first hole of the golf course. After that, we attended our last presentation of the day with Dr. David Clark, who shared an update on clinical trials and what's new in the pipeline for factor IX treatments.

Then it was time for our famous *Bleeder Olympics*, a much-loved tradition at our retreats where we play typical backyard summertime games: Hillbilly Golf, Corn Hole, Molkky, and even Water Bucket Pong with giant red solo cups. Each game was played with teams of two, one person with hemophilia and one father of an affected child. Adding to the fun were ice breaker games put together by Rocky Williams. The games included *Poetry in Action* where each team recites and acts out the poem, and the ever-favorite *Chubby Bunny*. This game is so funny with the winner being the person who can stuff the most marshmallows in his mouth and still be able to say, "Chubby Bunny." Friday ended with everyone enjoying loads of laughs.

Discovering Ways to Live a Positive Life

Saturday morning had an option of Tai Chi or a walk as morning exercise. With a very busy day ahead, we began our first session with Dr. Mosi Williams. A severe hemophiliac, Dr. Williams holds a doctoral degree in clinical psychology and is also part of the international *AFFIRM* hemophilia leadership program. The guys responded enthusiastically to his session which covered how to work toward being your best self a little bit at a time.



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Our second session was led by Robert Freidman, a psychotherapist, author and musician who delivers interactive rhythm-based programs all around the world. He has become somewhat of a staple at our Coalition events and is best known for his talks on drumming to relieve stress. For our retreat, he introduced two programs - *What's So Funny?*, focusing on how humor affects us physically, mentally and emotionally, and how we can benefit from it in our daily lives, and *Living an Empowered Life*, which gave us tools for living a more positive and powerful life. Dr. Freidman's sessions are highly interactive, making the presentations even more powerful.

The Wrap-Up

On the final night, we always try to plan something extra special. In the past, we have gone to a professional baseball game, a car show, went cart racing and earlier this year, hosted a casino night. The tradition continued as we held a 1920s gangster-themed gathering with all the guys donning fedoras and chomping on cigars! Some of the men really got into dressing for the occasion. We also participated in an *Escape Room* where we divided into teams to gather clues and work our way to the escape. It was a lot of fun to see the guys inclusively problem solve and bond. New friendships were made and old ones renewed. Needless to say, the night was a huge success!





I wish to thank my committee members, Rick Starks, Rocky Williams, Felix Garcia, Carl Weixler and Fel Enchandi for their efforts in organizing this great event. I especially want to thank Shad Tulledge for his hard work and dedication to this program. He handled the difficult task of logistics, making sure that everyone arrived seamlessly and accommodations were in order. Thank you for coordinating the scooters for those who needed one, lining up the escape room, coordinating the meals, your trips to Costco and working with the hotel staff to make sure everything ran well. Thank you to Kim Phelan, Christian Villarreal and Farrah Muratovic for the behind-the-scenes organization.

We thank our sponsor Pfizer for making this another successful retreat. Last, but not least, thanks to all the guys who attended and walked away knowing they are not alone. We are all in this together!



COMMENTS

As a stepdad who is relatively new to hemophilia B, being invited to attend the men's retreat was hugely beneficial to me. It gave me many new insights into what my boys' lives are like, and I felt embraced into the hemophilia B family in a way that I had never experienced before. The men's retreat focused more on what's going on inside the heads and hearts of the men and we got to be incredibly candid about our individual struggles. Because of the small group format, there were plenty of opportunities for individuals to address their own issues and to receive invaluable feedback and support from the other blood brothers in the room. It was truly a transformative experience for me, and one for which I am eternally grateful.

— J. F., Knoxville, TN

If there was one thing that I took away from the Fall Men's Retreat, it was being able to connect with the fathers in our community—whether it was with fathers who were going through a rough time facing hemophilia or those fathers who stepped up to the plate when taking care of a child who isn't theirs. Being able to share life experiences with hemophilia was important to every individual at the retreat. There was a space where not only we could laugh and have fun, but we could also get serious and talk about deeply personal things.

— M. L., Erie, PA

I had an unforgettable time at the fall men's retreat. I finally got some time to reset and de-stress with all the hemophilia B, blood brothers and dads. The bond that is shared at the event is unlike anything I've experienced. Undoubtedly made memories that will stay with me forever. I got to meet some fantastic new people that I've kept in contact with since. I also learned a lot about the future of hemophilia treatment, especially for inhibitors. That session really gave me hope for the future.

— V. R., Rosemead, CA



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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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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?

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- any ingredients in IDELVION

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What should I tell my healthcare provider before using IDELVION?

Discuss the following with your healthcare provider:

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- 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.

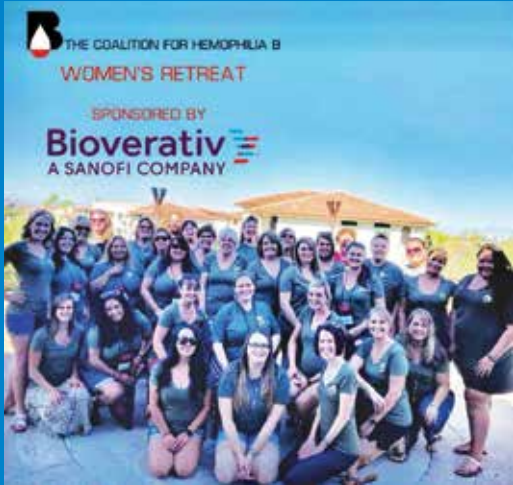
A common side effect of IDELVION is headache. This is not the only side effect possible. Tell your healthcare provider about any side effect that bothers you or does not go away.

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.

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2018 FALL WOMEN'S RETREAT



By Chris Villarreal

The Coalition for Hemophilia B was excited to hold our **Fall Women's Retreat** in Phoenix, Arizona at the spectacular Arizona Grand Resort and Spa Thursday, September 27th to Sunday, September 30th. The women began to arrive early Thursday afternoon and were warmly greeted by our team with hugs and agendas outlining the retreat events. Then they were ushered into the *Lobby Grill* for networking over a delicious lunch.

To combat the long hours of travel and the stressful it causes the body, we offered relaxing chair massages before beginning the wellness and education retreat. Our first session on Thursday evening was with Dr. Michael Zolotnitsky, who spoke on *Kinesiology and Joint Support*. Dr. Zolotnitsky demonstrated the science of kinesio taping and how to properly apply it to reduce swelling and provide joint support in various areas of the body. He explained kinesio taping is more effective than bracing because it does not limit overall range of motion and has been shown safe in those with bleeding disorders. Samples were given to take home and practice on themselves and their family members.

Afterward, everyone was welcomed to the dining and lounge area to share a meal and socialize. After a tasty dinner, the ladies attended the last session of the day with Tina Sacchi who taught the women how to tap into their inner strength and focus on core wellness. As the night ended, everyone gathered around the firepit and were encouraged to let go of the bad and let in the good through meditative breathing exercises and physical visualization methods.

Friday and Saturday mornings kicked off with a patio snack and group rejuvenation exercises. To jump-start their day, the ladies had 3 options to choose from: *Tai Chi* with Cassandra Starks, a nature hike with Brittany Williams, or water aerobics with Erin, a professional aerobics instructor. All the ladies participated - many felt their calm with Cassandra, some reached new heights with Brittany, while others kicked up water with Erin!



FINDING UNITY

Later on Friday, the ladies gathered for a breakfast of made-to-order omelets and various fruits and breakfast foods. The first session was a *Welcome and Introductions* by Coalition Vice President Kim Phelan and Bioverativ representative Jane Cavanaugh. Following, Nikita Lyons-Murry showed everyone how to cultivate self-assurance in their everyday lives in *Power of Empowerment*. Together, the women discussed ways to become more empowered by acknowledging strengths and individuality, creating safe environments, enhancing confidence and establishing supportive partnerships.

The ladies then learned about hemophilia B carrier tendencies to bleed with Dr. Robert Sidonio. One statistics he shared is that there are likely 3 female hemophilia B carriers per affected hemophilia B males in the United States. Dr. Sidonio highlighted the unique challenges faced by hemophilia B carriers and opened a discussion about appropriate nomenclature for those females with mild, moderate and severe deficiency.

After this informative session, the group moved on to something lighter – *Core Balancing*, where they learned to move their hips and let loose. Mahin Sciacca, a professional belly dance instructor, led the session. Next up, lunch was enjoyed and the ladies gathered for a group picture to show their unity in the hemophilia B community.

Following was psychotherapist, Robert Friedman, who explored stress release using unique methods. This session covered the healing powers of the drum and the physical, mental and emotional benefits that humor brings, and how to achieve and incorporate these benefits in their daily lives. The ladies wrapped up an impactful Friday full of educational sessions with a *Sunset of the Mountain Dinner* and a champagne toast. All lifted a glass in unison for the success of this time together.

CREATIVE COPING AND OTHER THERAPEUTIC TECHNIQUES

On Saturday, the ladies gathered for a morning workshop aimed at teaching creative coping and therapeutic techniques to use when dealing with stressful



moments. Art therapists led an engaging and educational session on being grounded at the core and protecting your energy and the things that matter most. The ladies had the opportunity to customize wooden boxes with paint, jewels and inspiring words. Within the boxes, each placed a rock on which they wrote a message to represent the most important thing they wanted to protect. Words they used in common included *family, passion, love* and *gratitude*. The women were able to take these treasures home to keep as a reminder of what is most important to them and what they hold dear. They were then allocated networking time with each other, which we know helps cultivate space for the women to build bonds that continue even after the program ends.

The next session titled *Chit-Chat and Chocolate*, included 3 peers sharing their story – Gwyn Weixler, a spouse, Milinda DiGiovanni, a caregiver, and

Heidi Hart, a woman bleeder. This session proved to be very intense as emotions were released and the women opened up with each other. The session helped foster an atmosphere of trust, emphasizing the women are not alone and have a support system on which they can rely. With that, everyone went back to their rooms to ready for the final night of the retreat.

The theme for the evening was *Haunted Hotel* and we provided witch hats and decorative brooms and the ladies danced through the night, played fun team-building *Minute to Win It* games and explored their very own mobile escape room that was brought in and built on-site!

On Sunday morning, some women took part in relaxing yoga, while others said their goodbyes and departed to the airport. Though sad to leave, many were comforted in knowing this was the beginning of fruitful relationships with women of



the hemophilia B community who share many of the same experiences.

Many thanks to Bioverativ for sponsoring the 2018 Fall Women's Retreat!





COMMENTS

The Fall Women’s Retreat was my first retreat. I especially enjoyed hearing other hemo wives’ and moms’ testimonials about living a hemophilia life – even with all of the obstacles and hardships they faced, whether it was for themselves, their spouses or children. They overcame and persevered through all of the bad times. It was an incredible experience and so amazing to get the opportunity to spend four days with other women and mothers who know my hemophilia struggles. Truly amazing!

— E. L., Madison, AL

My experience at the Fall Women’s Retreat was nothing short of breathtaking, inspiring, and healing, to name a few. There is often times a void in processing social and emotional trauma, which ultimately heals oneself. In families, especially for women and moms who deal with not only their children’s chronic health issues on a daily basis but also their own health battles, this type of healing is invaluable and priceless. This year’s retreat was like no other. New connections were made and former bonds were made tighter, and together as a group we laughed and cried listening to each other’s stories. We tapped into our creative sides through art, we danced, we sang, and through all of this the one thing we most certainly had in common was that we healed. I am forever grateful for the opportunity to renew through these retreats, to keep me going strong in advocating for myself and others, because in a world of chronic life-threatening conditions, it is our reality that every day is a gift and not promised. Thank you for making me a better person, and I truly hope I can continue to be a part of something so needed in our community!

— B. J., Nisswa, MN



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GENERATION IX PROJECT

ALL ABOUT ADVOCACY

By Wayne Cook

This past September, the Generation IX program was held in Traverse City, Michigan. This program is for adult mentors and leaders in the hemophilia B community to come together, hone their skills, get outside their comfort zone and challenge each other individually and as a team by engaging in various challenges.

This event reminds me of when I was a kid going to music camp every year. Sleeping in bunk beds and eating cafeteria food brought back many good memories of my youth. After the arrivals and once everyone was settled in, the program began. Introductions were made and then Jacose Bell and Haylyn of GutMonkey explained the guidelines of the camp and the purpose of the program.

During the kickoff session, we played a game with picture cards. Everyone had to choose a card but not look at it. Then once everyone received their card, we placed it on our forehead and walked around the room to pair up with someone else, who would give you clues to help you try to figure out just what your card was. We learned how we can all teach each other. Afterward, we enjoyed dinner and conversation, and then some people played games and others just sat back and talked some more.

The next day we had an early breakfast and infusions (including myself) and a short discussion about how what we had learned the night before would tie into the new day's activities. Later we loaded a bus and embarked on a journey to a marina on Lake Michigan, where the next part of the program was to take place. When we arrived at the marina, we broke into two groups of about 20 people. Group one was going to stay onshore for the first half of





the program while the second group went out on a 90-foot schooner – one of only four in the world.

My group was the one that initially remained onshore, and we split up into four teams of five. Each team was given a bin with parts and motors in them. Our task was to take the parts and design and build an ROV – a *Remote Operated Underwater Vehicle*. After receiving brief instructions, we all went to work on building our ROVs.

The objective was to work as a team to come up with a plan and then put the plan into motion so that we'd have a working ROV that could navigate in the water and retrieve a ring and bring it to the surface. It was an impressive team-building exercise.

When the schooner arrived back to shore it was our turn to board. During this half of the program, 20 of us worked alongside the crew of the schooner making it sail. It was very windy on the lake and a perfect day for sailing. Some of us worked on hoisting the sails, others worked on taking lake samples, another group learned how to read a navigational map, and then there was the opportunity to pilot the ship. Everyone worked together for the common goal, and the goal here was the importance of teamwork to sail the ship or anything else you do in life.

Later we reunited with the other team and everyone loaded the bus back to camp. After dinner we all sat in a circle and discussed what we had experienced and learned





that day and how it tied to advocacy. The take-away – by working together we can figure out a solution. Once a possible solution is reached, it can be presented and tested. It may take some trial and error before you can come to the best possible solution.

The next day the weather was beautiful for the planned day of bicycling. We were biking to the majestic Sleeping Bear Dunes park, located on the lake. These dunes are a national state preserve that rise 450 feet above Lake Michigan. The trek was 12 miles along a scenic biking path. After riding about halfway, we reached an area of Lake Michigan that looks very much like the New England coastline. Some of us continued on to see the dunes, a spectacular natural environment. Then we rode back to meet up with everyone else and we all had lunch together. Some of us took the chance to lead the group back to the bike shop, and some of us stayed behind to help those who were having some difficulty keeping up with the group with the goal of making sure everyone made it back safely to the bike shop. Again, teamwork at play.

The weekend ended with a program of meditation and yoga with Haylyn, which was very relaxing. We discussed all of the weekend's activities and how they tied into advocacy and how we all should work together on issues that pertain to our community.

Watching everyone help one another was one of my greatest joys, as I can see this strengthens bonds and our community. We are so happy to put on this program in partnership with GutMonkey and give special thanks to our sponsor of the Generation IX Programs, Aptevo.



COMMENT

I have been honored that I have been selected to attend Generation IX Retreat in Michigan, and I am so thrilled to see that every year this retreat program gets bigger and better. Community leaders, both men and women, are brought together from across the country to network with friends and form new friendships with new attendees by discussing

various issues and topics which affect members of our community and advocating for bleeding. I highly recommend that everyone should attend this outstanding retreat because it's definitely worth your time and energy.

— A. J., Espanola, NM



2018 NHF BLEEDING DISORDERS CONFERENCE



It was wonderful to see our Coalition members at the National Hemophilia Foundation's Bleeding Disorder Conference in Orlando. Thank you to everyone who stopped by our booth!





MEETINGS ON THE ROAD

PENNSYLVANIA, NEW MEXICO, NORTH CAROLINA, COLORADO and VIRGINIA



A SPECIAL THANK YOU TO OUR GENEROUS SPONSOR CSL BEHRING!

PITTSBURGH, PENNSYLVANIA

CSL Behring sponsored our meeting at the Pittsburgh Marriott City Center September 22nd. Ben Shuldiner presented to attendees on tools to help advocate for their children using 504 plans and individualized educational plans (IEPs). This presentation explored ways for students and families with bleeding disorders to receive additional support as they navigate the education system. While adults attended various sessions throughout the day, the kids were taken to the Pittsburgh Zoo and PPG Aquarium to learn about a variety of spectacular animals!

ALBUQUERQUE, NEW MEXICO

We gathered October 6th at the Albuquerque Marriott. Felix Garcia's presentation, *Brave Is in Our Blood*, gave attendees a unique perspective on a defining chapter of the hemophilia community's

history during the 1970s and '80s. His rousing tale drew inspiration from one of history's most famous warriors – the Spartans – with relatable anecdotes and real-world advice for continuing the call. This is one story that speaks to all generations.

CHARLOTTE, NORTH CAROLINA

Also on October 6th, another meeting was held at Embassy Suites Charlotte-Concord Golf Resort and Spa. One of several speakers, Robert Friedman, led two interactive sessions. In one, he introduced the concept of *The Drum and Its Power in Healing*. In another titled *What's So Funny?*, attendees focused on the physical, mental and emotional benefits of humor, and how to achieve and incorporate the benefits into daily life.

DENVER, COLORADO

November 10th, found us at Denver

Marriott South at Park Meadows. Kevin Harris and physical therapist Grace Hernandez encouraged everyone to use fitness to fight back. They helped attendees discover how physical fitness can create a powerful defense against injury for people with hemophilia. Attendees learned how to safely practice flexibility, core stability, strength training, and body movements to prepare their body for a healthy, active lifestyle.

RICHMOND, VIRGINIA

Another meeting took place simultaneously on November 10th at the Westin Richmond. Donnie Akers, Esq. gave a presentation on *Legal Tools for the Road of Life and Avoiding Poverty while Keeping Public Benefits*. He focused especially on children transitioning to adulthood and also provided information on using tools like special needs trusts, the ABLE





(Achieving a Better Life Experience) Act, and others to shelter assets and maintain Medicaid and other public benefits without having to live in poverty.

Tai Chi instructors Rick Starks, Cassandra Starks and Don Drolet traveled to our meetings to teach attendees a system of coordinated body postures and subtle

movements, along with breathing and meditation techniques. This interactive session allowed attendees to participate in a low-impact, slow-moving exercise used to promote health and wellness.

Speakers Dr. Lisa Boggio, Dr. Claudio Sandoval, Patricia Amerson, Dr. Michael Guerrero and Sue Geraghty brought direct

information from the *B-HERO-S* survey about psychosocial issues in the hemophilia B community to our meetings on the road. This survey was taken by 290 people with hemophilia B and 150 caregivers of children with hemophilia B. The survey summarized experiences and responses to help better understand how to address unmet needs in hemophilia B related to





education, employment, and quality of life.

The Power of Empowerment, led by Edgar Vega, Danielle Durham and Tanya Stephenson focused on how to cultivate self-assurance and how to feel “empowered” when experiencing new or challenging situations. Acknowledging

strengths, individuality, creating safe environments, enhancing confidence and establishing supportive partnerships were among the methods discussed to become more empowered.

Attendees were very excited to participate in the *Kinesiology and Joint Support* session with Dr.

Michael Zolotnitsky. Kinesio taping, properly applied, can reduce swelling and provide joint support to reduce difficulty with walking. As he explained and showed by example, it is more effective than bracing because it does not limit the overall range of motion. Kinesio taping has also been shown to be safe in those with bleeding disorders.





During the sessions, Dr. Zolotnitsky practiced live taping with volunteers from among our audience. Tape samples were given to everyone in attendance.

At all of our meetings, attendees played the Coalition's game *Are You Smarter Than Your Hemophilia?*, answering multiple-choice questions

on common and less familiar knowledge in the hemophilia B community.

We congratulate all our raffle-drawing prize winners. Prizes included an Amazon Echo Dot, a Kindle Fire, a custom-designed DNA necklace, a set of Tai Chi DVDs and a trip to our 2019 Coalition

for Hemophilia B Symposium in Orlando, Florida!

We are exceedingly thankful to our generous sponsor, CSL Behring, for helping us hold these fantastic and essential meetings across the country.

CSL Behring



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.

Rebinyndm® 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 Rebinyndm® 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 Rebinyndm® 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.

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

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

INDICATIONS AND USAGE

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

Rebinyndm® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Rebinyndm® is used to treat and control bleeding in people with hemophilia B. Your healthcare provider may give you Rebinyndm® when you have surgery. Rebinyndm® 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 Rebinyndm®?

- **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 Rebinyndm®.

Who should not use Rebinyndm®?

Do not use Rebinyndm® if you:

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

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

Tell your health care provider if you:

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

How should I use Rebinyndm®?

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

What are the possible side effects of Rebinyndm®?

- **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 Rebinyndm® 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.

Rebinyndm® 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 rebinyndm.com



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

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rebinyndm®

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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USA17BIO03951 12/2017





MEETINGS ON THE ROAD NEW JERSEY

A SPECIAL THANK YOU TO OUR GENEROUS SPONSOR
PFIZER!



On November 3rd, Pfizer sponsored a meeting in Princeton, New Jersey at the Westin Princeton at Forrestal Village. Linda Pollhammer started off the day's sessions with *Step It Up! Being More Active with Hemophilia*. Staying active is key especially when you have hemophilia. As important, she discussed the variations in dosing requirements, depending on activity level. She also covered how to communicate better with your doctor, patient or loved one by having "constructive conversations."

Next, Dr. Claudio Sandoval shared information from the B-HERO-S

survey about psychosocial issues in the hemophilia B community. Taken by 290 people with hemophilia B and 150 caregivers of children with hemophilia B, the survey summarized experiences and responses to help better understand how to address unmet needs in the community, especially as related to education, employment and quality of life.

Also on the agenda was Robert Friedman, who talked about managing the stress of living with hemophilia B. In this very informative and interactive presentation,





participants were provided with the latest information on how to manage stress and learned specific solutions for their stress management challenges. Families then met Jody Rubel, who taught attendees how to connect with their core and actively practice Tai Chi through a set of slow meditative movements.

This active session allowed Dr. Stringham to demonstrate k-taping on participants showing the proper placement of the kinesio tape to relieve pain and tension. Samples were handed out to the attendees. Lastly, families attended our wrap-up session and played our popular multiple-choice game, which asks

questions on common and uncommon facts about hemophilia B.

We are very thankful to our sponsor Pfizer for helping make this event happen!



The kids, meanwhile, enjoyed their time at Bonkerz Amusement Center, where they played mini golf, laser tag and a variety of arcade games!

In the afternoon, Dr. Douglas Stringham presented his talk on kinesio taping (sometimes called k-taping) and its health benefits.





Life doesn't have a pause button

The right treatment can keep you moving forward.
Learn more at RIXUBIS.com

Indications for RIXUBIS® [Coagulation Factor IX (Recombinant)]

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

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

Detailed Important Risk Information for RIXUBIS®

You should not use RIXUBIS if you are allergic to hamsters or any ingredients in RIXUBIS.

You should tell your healthcare provider if you have or have had any medical problems, take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies, have any allergies, including allergies to hamsters, are nursing, are pregnant or planning to become pregnant, or have been told that you have inhibitors to factor IX.

Allergic reactions have been reported with RIXUBIS. Call your healthcare provider or get emergency treatment right away if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty

breathing, lightheadedness, dizziness, nausea, or fainting.

Your body may form inhibitors to factor IX. An inhibitor is part of the body's defense system. If you form inhibitors, it may stop RIXUBIS from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for development of inhibitors to factor IX.

If you have risk factors for developing blood clots, the use of factor IX products may increase the risk of abnormal blood clots.

Common side effects that have been reported with RIXUBIS include: unusual taste in the mouth, limb pain, and atypical blood test results.

Call your healthcare provider right away about any side effects that bother you or if your bleeding does not stop after taking RIXUBIS.

Please see following page for RIXUBIS Important Facts.

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



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RIXUBIS is a registered trademark of Baxalta Incorporated, a wholly owned, indirect subsidiary of Shire plc. 541874 09/18

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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Baxalta US Inc.

Westlake Village, CA 91362 USA
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527967 02/17



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.

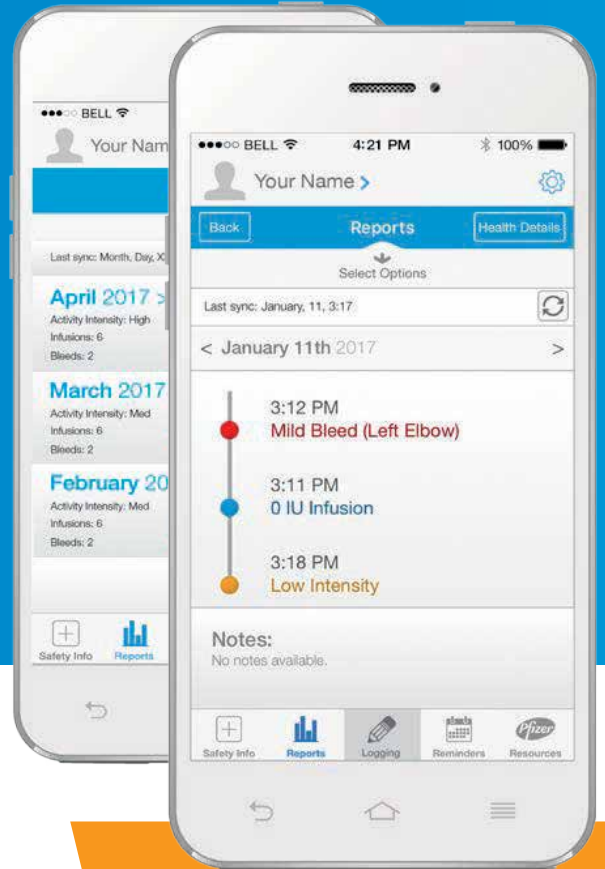


- Log daily activities, infusions, and bleeds
- Share single consolidated reports with your treatment team
- Set reminders for resupply, appointments, etc
- Sync with fitness apps and wearable devices

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.

*HemMobile™ is not intended for curing, treating, seeking treatment for managing or diagnosing a specific disease disorder, or any specific identifiable health condition. iPhone is a trademark of Apple Inc., registered in the US and other countries. App Store is a service mark of Apple Inc. Android and Google Play are trademarks of Google Inc.

GETTIN' IN THE GAME 2018 JUNIOR NATIONAL CHAMPIONSHIP



It is always very gratifying for us to be able to nominate two youngsters from the hemophilia B community to attend the Gettin' in the Game Junior National Championship (JNC). This one-of-a-kind program for the bleeding disorders community lets young members of our Coalition, ages 7–18, show off their baseball, golf or swimming abilities and take part in clinics to improve their skills in their sport.

The winners of the 2018 Gettin' in the Game essay contest, nominated by the Coalition, were Damian

Barraza and Chase Tulledge. Damian (age 16) and Chase (age 14) both submitted original essays on why they love baseball. They both attended the games, sponsored by CSL Behring, in September in Phoenix, Arizona. Damian also was a JNC winner in the Most Improved category.

We are so proud of all the young athletes who challenged themselves to write and submit an essay about their love of sport. We encourage everyone to apply next year.



COMMENTS:

Gettin' in the Game was a blast—even though I didn't do as well as I had hoped. One of the most exciting parts is meeting up with some friends I have met over the years at different hemophilia events. Obviously, getting to play my all-time favorite sport baseball was awesome and hot. Thank you for the opportunity. It was truly amazing.

— Chase, age 14, Mishawaka, IN

Going through this experience was very inspiring; I am grateful to have been able to get back on the field after so many years and make new friends. I hope that other kids will be able to have the same experience and gratitude that I have. Thank you, Coalition for Hemophilia B, for this amazing opportunity.

— Damian, age 16, San Mateo, CA



ASK THE EXPERT

Q&A on the B Connected Online Forum

The Coalition for Hemophilia B | bconnected@hemob.org

TOPIC: PRODUCTS IN DEVELOPMENT AND GENE THERAPY

JANUARY 24, 2019

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



ASK THE EXPERT
DR. DAVID CLARK

Chairman of the Coalition for Hemophilia B

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



Current B Connected Members:

Log in and post your questions in the Ask the Expert channel before Jan. 24th. Questions will also be taken during the live session.



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



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“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:

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

Tel: 212-520-8272
hemob.org



TREATMENT NEWS

Alnylam Receives Approval for First-Ever RNAi Drug

Alnylam Pharmaceuticals

recently received U.S. Food and Drug Administration (FDA) approval for Onpattro (patisiran), the first RNA interference (RNAi) drug approved anywhere in the world. Onpattro is for a rare nerve disease, but this development is important for hemophilia patients because Alnylam has also been developing fitusiran, a similar RNAi drug for hemophilia. This approval shows that the concept of RNAi therapeutics is viable.



Clinical development of fitusiran has been taken over by Alnylam's partner Sanofi. Fitusiran uses RNAi to reduce the body's production of antithrombin, an anticoagulant. This helps to restore the balance in the clotting cascade so that the blood clots more normally. Fitusiran, a monthly subcutaneous drug, is currently in Phase III studies for both hemophilia A and B. Sanofi is expected to file a license application in 2020.

Genes are made of DNA and reside in the nucleus (central compartment) of a cell. To make a protein like factor IX, the cell makes a copy of the factor IX gene using RNA, a similar molecule. This copy is called a messenger RNA (mRNA) because it takes the "message" about how to produce factor IX from the pattern in the gene to the protein production machinery in the cell. The factor IX mRNA is secreted from the nucleus into the main body of the cell where complex molecules called ribosomes make the factor IX protein using the mRNA as a template.

RNAi works by blocking the production of proteins coded by the mRNA. It uses small interfering RNA pieces (siRNA) that bind to the mRNA and block it from being used to make a protein. This concept won the Nobel Prize in Physiology or Medicine in 2006, but it has taken much longer for it to be developed into usable drugs.

Aptevo Announces New Vial Size and Pediatric Study for IXINITY

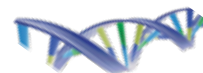
Aptevo plans to produce a new 3000 IU vial size for IXINITY, its recombinant factor IX product. It is expected to be available by mid-2019.



Aptevo is also planning a pediatric clinical study for IXINITY, treating approximately 20 patients under 12 years of age with the goal of getting a label indication for pediatric use. No further details on the study have been released.

Gene Therapy—New Methods

Academic researchers have become increasingly interested in gene therapy and are developing new methods to implement it. None of these methods, so far, are specifically targeting hemophilia, but they are broadly applicable to hemophilia and many other diseases.



Johns Hopkins

Researchers are developing a method to deliver genes to the liver using endoscopy. Endoscopy is a minimally invasive method to perform internal surgery using only small incisions. The Hopkins researchers believe that they can use endoscopy through the bile duct of the liver to transfer new genes into the liver safely and more effectively than using viral vectors. For those of you who like big words, their technique is called endoscopic retrograde cholangiopancreatography, or ERCP. It is currently used to diagnose and treat problems in the pancreas, gall bladder, and liver.



Massachusetts Institute of Technology (MIT)

Researchers are focusing on using RNA instead of DNA as a vehicle for getting cells to produce proteins. As previously described in the Alnylam report, mRNA molecules are the templates that cells use to actually make proteins. The MIT researchers believe that by using mRNA instead of DNA genes they can overcome some of the safety and delivery issues in gene therapy. They have developed methods for controlling the expression of proteins from mRNA, and other researchers have developed methods to improve the stability of the mRNA molecules so that they last a long time in the cell.



University of California, Santa Barbara (UCSB)

Researchers are developing nonviral methods for delivery of gene therapies to cells. They use gold nanoparticles coated with the gene editing molecules, along with near-infrared light, to control the nanoparticles. The nanoparticles are also coated with proteins that help them penetrate into cells. When the nanoparticles enter a cell, they are inert. However, when the cells are irradiated with near-infrared light, the nanoparticles shed their coverings, which can then find their ways into the nucleus to edit genes or do other tasks.





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TREATMENT NEWS

Israeli Researchers Target Inhibitor Treatment

Researchers from Tel Aviv University and the Israeli National Hemophilia Center have discovered that combining two bypassing agents may help improve the care of hemophilia B patients with inhibitors. Only about 3% to 5% of hemophilia B patients develop inhibitors, but those that do have significant issues. Since normal factor IX products do not work for them, inhibitor patients are usually treated with one of two bypassing agents: FEIBA or NovoSeven. They are called bypassing agents because they bypass the step in the clotting cascade that requires factor IX. Both contain activated clotting factors that get the clotting process started through other pathways. The researchers discovered that a combination of the two bypassing agents gave improved efficacy over either one alone.



cause of the decline is unknown. The researchers suggest that some of the cells from the patient's original liver might have grown back into the new liver, diluting its capacity to produce enough factor VIII.

Rate of Total Joint Replacement Similar in Hemophilia A and B

There has been a lot of discussion in the medical literature about whether hemophilia A or B is the more severe disease. Which one is worse is probably not important since both are significant diseases that have a major effect on a patient's quality of life. It's not a completely irrelevant question, though, because in looking for differences, researchers have made a number of new discoveries about both diseases.



In comparing the effects of hemophilia A and B on joint health, a group of Taiwanese researchers analyzed the number of total joint replacements for their patients. They found no significant difference between the rates. However, their findings may not translate to the United States, where hemophilia treatment is quite different. Taiwanese hemophilia patients are only treated on demand and often for only a few bleeds a year. According to the researchers, the average age for joint replacement in Taiwan is 37.2 years for the combined A and B group. The most common joints replaced were the knee and hip.

Janssen and Arrowhead Partner on Hepatitis B Treatment

Janssen Pharmaceuticals (a division of Johnson & Johnson) and Arrowhead Pharmaceuticals, a gene therapy company, are partnering to develop a treatment for hepatitis B. Hepatitis B was transmitted by a number of older plasma-derived factor products but has not been an issue for decades. However, some older hemophilia patients who were treated with whole blood, plasma, or the early concentrates may be infected with hepatitis B. In most patients, hepatitis B resolves itself, but a significant number of patients develop a chronic infection. There is no current cure. The companies plan to develop an RNAi treatment (RNAi is described in the Alnylam report also in this issue) to silence the genes of the hepatitis B virus.



Shire Discontinues Bebulin

Shire has announced that it is discontinuing manufacture of Bebulin, the company's plasma-derived factor IX complex product. Factor IX complex products were the first factor IX concentrates used to treat hemophilia B. At the time, they were a huge improvement over the use of plasma or whole blood, but they had their own issues. They could not be used prophylactically or for surgery because they tended to cause thrombosis (unwanted clotting) when used in larger amounts.



Liver Transplants May Not Completely Cure Hemophilia

It has always been thought that a liver transplant from a non-hemophilic donor would cure hemophilia, since the new liver contains normal genes for factor VIII and factor IX. A number of hemophilia patients have received new livers that have apparently cured their hemophilia. However, a report from Iwate Medical University in Japan suggests that the change might not be permanent. Medical researchers followed a hemophilia A patient who had a liver transplant that increased his factor VIII level into the normal range. However, over the next year his factor VIII levels declined into the mild hemophilia range. The patient did not develop an inhibitor, and the



Factor IX complex is a mixture of the clotting factors II, VII (in some products), IX, and X and the anticoagulants Protein C and Protein S. These proteins all have similar structures and are difficult to separate from each other, which is why they were originally used as a complex. The cause of the thrombosis problem was never determined definitively, but it was probably due to an overload of the other clotting factors, especially factor X.



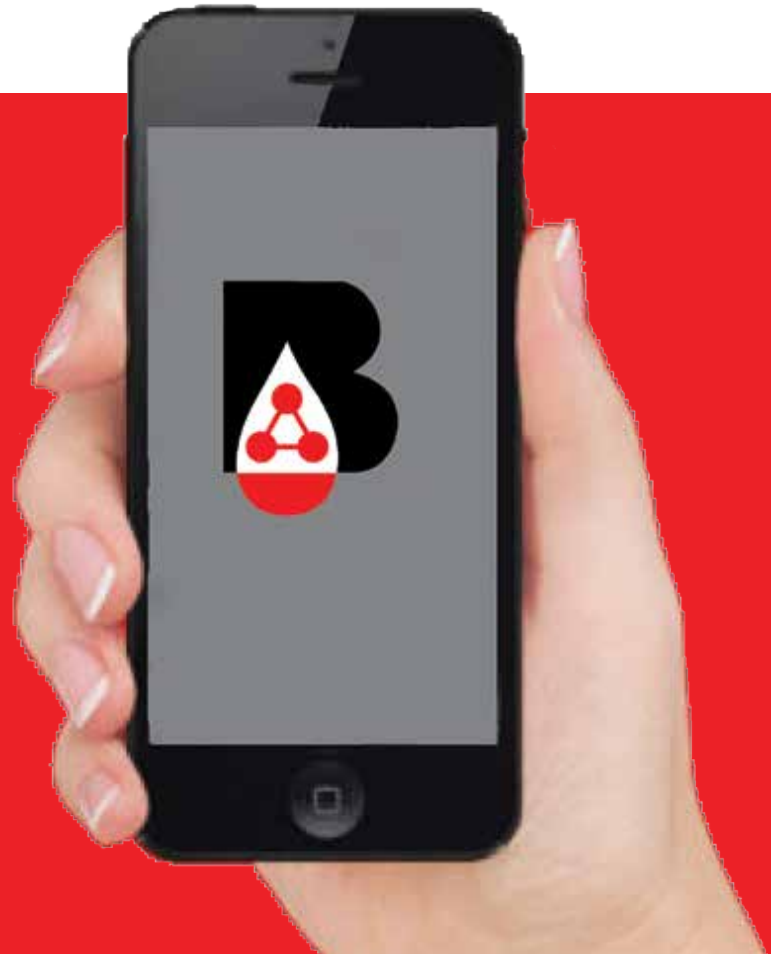
FREE for individuals and families with
HEMOPHILIA B.

To get instructions on how to join
B Connected, contact administrators
Rick Starks and Shad Tullidge at:
bconnected@hemob.org

THERE'S A NEW WAY

TO STAY CONNECTED TO

PEERS-FAMILIES-EXPERTS



PRIOR PROGRAMS HAVE INCLUDED:

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- » 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

TREATMENT NEWS

The discontinuation of Bebulin is not an issue for hemophilia B patients since there are much better products available that should be used. However, it could be an issue for people with rare bleeding disorders. Some of them are treated with factor IX complex because there are no available single-factor concentrates for their conditions. Grifols' Profilnine remains the only factor IX complex product on the U.S. market.

“Spread the Cure” Hopes to Provide Gene Therapy for All Hemophilia Patients



Ryan Miano, the father of two boys with hemophilia in the St. Louis area, started the nonprofit organization *Spread the Cure*. According to the website, SpreadtheCure.org: “After battling the insurance companies, government programs, healthcare companies, and the seemingly endless bureaucracy standing between patients and a solution to this costly and deadly disease, we created Spread the Cure to find ways to break down barriers and open up safe, affordable and timely access to newly available CRISPR and gene therapies.” The organization hopes to raise enough money to eventually help all hemophilia patients worldwide afford the cure promised by gene therapy.

uniQure Announces Initial Results in Gene Therapy Trial



uniQure has announced data from three hemophilia B patients treated in a Phase IIb study of its AMT 061 gene therapy treatment under development. This was a dose-confirmation study to bridge the gap between the previous experimental treatment AMT-060, which used a normal factor IX gene construct, and the newer AMT-061, which uses the more highly active Padua factor IX gene variant. The three patients reached factor IX levels of 23%, 30%, and 37% several weeks after AMT-061 administration. The treatment was well tolerated with no serious adverse events and no patients required immunosuppression therapy. One patient had a mild, transient increase in liver enzymes that resolved itself with no further treatment. The patients will be monitored for 52 weeks to assess factor IX levels, bleeding rates, and the need for factor replacement therapy. They will be followed for five years to evaluate safety. uniQure is currently enrolling patients for its Phase III study of AMT-061.

uniQure Announces New Promoters for Gene Therapy

uniQure has announced the development of new promoters for its liver-directed gene therapy treatments.

A promoter is the part of a gene that tells a cell when and how much of the gene's protein to make. A promoter can turn off gene expression (production of a protein from the gene) or ramp up production if the body needs more of the protein. Most factor IX gene therapies under development use the natural promoter from a normal factor IX gene.

uniQure has developed some highly active promoters that are able to drive protein production to much higher levels than the natural promoters. These new promoters are not used with the AMT-061 factor IX gene therapy currently in Phase III clinical studies, but may be used for improved methods in the future.

University of Utah Developing Nanoparticles for Oral Protein Administration



Researchers at the University of Utah have discovered that lipid nanoparticles (miniscule globs of fat) can travel from the intestines into the bloodstream when the nanoparticles are coated with bile acids. (Bile acids are secreted by the liver and help the body digest fats.) That opens the possibility that nanoparticles containing factor IX could be taken orally and make their way into the bloodstream. There, the nanoparticles would dissolve and release their factor IX into the circulation. So far, this has only been tested in rats and not on factor IX itself, but it could be a promising finding toward developing an oral factor IX product.

Washington University and Novartis Target Immune Cells to Relieve Pain



Researchers at Washington University School of Medicine in St. Louis and drug company Novartis have found that a non-opioid painkiller being developed by Novartis actually acts on immune cells called macrophages rather than on the nervous system as previously thought. A macrophage is a type of white blood cell that cleans up debris and pathogens (bacteria, viruses, etc.) after an injury. The researchers found that the reactive oxygen species (ROS) that are released by macrophages also trigger a pain pathway in nearby nerve cells. According to studies done in mice, blocking the receptors on the macrophages that cause the ROS release also reduces pain. While Novartis is not currently developing its painkiller for hemophilic joint pain, this drug and others that may be developed to target the same pathway might be useful in treating that condition in the future.



FACTOR NINE HOLIDAY FUND

We invited all who were able to contribute to our 2018 Factor Nine Holiday Fund and, as always, so many of you gave generous donations. Thank you, everyone!

With your generosity we were able to buy 20 coats, 15 boots, 8 pairs of shoes, 18 food baskets, and gifts for 83 children in need this holiday season!

It's times like this, when we come together to take action and care for one another, that prove our ability to make a difference.

Thank You for Making a Difference!

WISHING EVERYONE WONDERFUL HOLIDAYS AND A HAPPY NEW YEAR!



THE WILLIAM N. DROHAN SCHOLARSHIP



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

Dear Scholarship Applicant,

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

The William N. Drohan Scholarship was formed in memory of Dr. William N. Drohan who passed away in February 2007. Dr. Drohan was a well-known microbiologist and educator who will long be remembered for his many contributions to science. He was a pioneer in using molecular biology to produce recombinant proteins and a visionary scientist who dedicated his life to improving the safety of blood and blood products. Other important contributions include investigating prion diseases in the blood supply, and his development of novel ways to treat traumatic injuries including fibrin-sealant bandages to stem hemorrhage.

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

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

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

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

Regards,

Dr. David B. Clark

SAVE the DATE



Thursday, March 14
to Sunday, March 17

The Coalition for
Hemophilia B
Annual Symposium

2019

RENAISSANCE ORLANDO at
SeaWorld!

Register at
www.hemob.org/symposium2019



THE COALITION FOR
HEMOPHILIA



THE COALITION FOR HEMOPHILIA B

UPCOMING EVENTS 2019!



ETERNAL SPIRIT AWARD GALA

Thursday, February 28, 2019

Terrace on the Park

52-11 111th Street

Flushing Meadows Park, NY 11368

Honorees: Glenn Pierce, MD, PhD and

Hope Woodcock-Ross, RN

To purchase tickets to the gala, please contact

Kim Phelan at kimp@hemob.org

or call 212-520-8272



ANNUAL SYMPOSIUM

Thursday, March 14 to

Sunday, March 17, 2019

Renaissance Orlando at SeaWorld

6677 Sea Harbor Drive

Orlando, FL 32821

Tel: 407-351-5555

The 2019 gathering is extended by one full day!

Registration is free and includes access to all sessions, meals and admission to our Saturday

night final event. Register online at:

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THE BEATS MUSIC PROGRAM

Wednesday, July 31 to

Sunday, August 4, 2019

Gaylord Opryland Hotel

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Apply online at:

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Deadline January 30, 2019

Celebrate!

It's a boy!

**Congratulations to our team member,
Nathy De La Cruz, and husband, Jonathan,
on the birth of their first child, a son!**

NATHAN DE LA CRUZ

December 3, 2018

6 lbs, 14 oz – 20.5 Inches

**We wish the family all the best for a
happy and healthy life!**



Happy Holidays!

***The Coalition for Hemophilia B team
would like to wish you all a healthy,
joyous and happy holiday filled with love!
We look forward to seeing you in 2019!***

KIDZ KORNER!

Fall Harvest

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O R T M B J L B P R K K W S S
Q C R V U V P C Y P P D M F D
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Z I I R C L E H U M F E C L L
N X E O N L X P U Y D D S L S
H V R T P R E C W Q I N D Q J
D N X A T V K C U X C N U E T
S B M T N B A I J Q I I M T R
S C A R E C R O W W R C E X E
C Z F Z D D F M Z R K F W N E
R I T T J H Q Y E K R U T S S
E A K E X K K L M T A X Y O R

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The Coalition for Hemophilia B

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