



Factor Nine News

The Coalition for Hemophilia B

Spring 2017



Topics in Hemophilia

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11th ANNUAL SYMPOSIUM



11th ANNUAL SYMPOSIUM

It was an exciting time for The Coalition for Hemophilia B as we held our **11th Annual Symposium** in sunny Florida at the beautiful Sawgrass Marriott Resort and Spa in Ponte Vedra Beach March 31st to April 2nd!

This year, we had an amazing turnout with over 450 attendees! Families began arriving Thursday and continued to arrive throughout Friday afternoon. Our event officially kicked off on Friday morning with *Tai Chi* on the Spa Lawn with Rick Starks, followed by a family breakfast. Rick held invigorating Tai Chi sessions for all ages each morning throughout the Symposium. In the afternoon, we hosted a *Meet and Greet Luncheon*, sponsored by Aptevo for families to connect and bond. Following lunch, Wayne Cook and Bill Pataskos headed up the *Men's Meet-Up* at the Gator Lodge, while Celeste Schimmels and Pam Willams led the *Women's Social* on the Cascade Lawn.

Throughout the weekend from early morning to late at night, childcare services were provided for infants and children up to 4 years old. Professional nannies and our team members kept careful eyes on the children in a room filled with fun toys, play mats, stuffed animals, movies, snacks, and cribs for nap time. Children ages 5-12 were entertained throughout the weekend with their own room stocked with movies, an Xbox, which was raffled off at the end of the event, games, arts & crafts, entertainment by the Great Charlini, and a bounty of snacks.

Loads of fun-filled activities, such as *How The West Was Fun* and *Beach Party Bonanza*, provided by Kids Camp Company, also kept the children active. They also enjoyed interesting rap sessions with Gen IX mentors, Manuel Lopez, Cody Bishop, Marcus Orr, and Heidi Ramsey, and a session on bullying sponsored by Shire.

The teens' space was well equipped with beanbag chairs, Play Station 4, movies and games. Activities included a drumming session with Robert Friedman, rap sessions with mentors, a session on bullying sponsored by Shire, and a half-day





A FANTASTIC SUCCESS!



experience with Patrick Torrey, who shared how persistence and confidence can help them achieve their goals. After the weekend, the PS4 was raffled off and the beanbag chairs donated to a local charity.

Sponsored by Bioverativ, Friday night wrapped up with a *Born For This* dinner, which highlighted the notion that our passions make us whom we are. Passions ignite our creativity, our curiosity, and our connection to the world around us. Best of all, when we find something we love, we can't help but share it with others. In addition to the delightful dinner, attendees had the opportunity to visit the industry booth representatives and learn about their products and programs.



A fantastic industry-sponsored breakfast and presentation was graciously hosted by Pfizer Saturday morning and featured Patrick Torrey of GutMonkey. Patrick presented *What Is Your GutMonkey?*, a journey into discovering that personal passion is a positive motivator and a great way to get engaged with what challenges are faced. Keynote speaker Dr. Christopher Walsh then spoke on hemophilia updates covering information from new products to hepatitis C treatment options and gene therapy.

Up next, Dr. Christopher Walsh and Dr. Tyler Buckner offered *Hemophilia B Roadmap*, with a sessions for patients and another for physicians. Sponsored by Med Learning Group with funding from Novo Nordisk, the interactive topics discussed improving the quality of life for people with hemophilia B and their caregivers.



A unique interactive program that explored the new science of drumming and wellness





was called, *The Healing Power of the Drum*. Recent research demonstrates that hand drumming can improve the immune system and reduce stress. Robert Lawrence Friedman, a recognized expert in this field and published author of *The Healing Power of the Drum*, books 1 and 2, taught participants how to use rhythm-based exercises to demonstrate how the hand drum can help people release stress, experience joy, feel energized, and release negative emotions.

CSL Behring sponsored a very nice lunch while sharing a video on *David Quinn's Personal Story*. David played professional hockey and is now a coach at Boston University. His story was very inspiring in that he is also affected by hemophilia B.

Following lunch, Dr. Robert Sidonio spoke on *Women and Bleeding Disorders*. He shed light on the challenges of bleeding throughout the lifespan of females with hemophilia and hemophilia carriers, von Willebrand Disease, and other rare bleeding disorders.

Dr. Marvin Poole and Yinnell

Nunez (separate Spanish session) discussed *Health Insurance Roadmap* in a program sponsored by Shire. As the health insurance debates become more prevalent, this program provided families with the information needed to make knowledgeable decisions about health insurance. The program included an overview of insurance options, information to help navigate transitions that impact coverage, and the tools needed to respond to insurance denials of coverage.

Industry exhibits and the Wellness Area, which included chair massages, were open throughout the day. Three-minute video clips were also shown to raise awareness of the wonderful programs available to the B community. We wrapped up the day with our fun raffle drawings, and everyone took a little break before our much-anticipated *Beach Party*.

To take advantage of our beautiful Florida beach setting, we designed a special *Saturday Final Night Beach Party Dinner*, sponsored by Bioverativ and Aptevo. Families from across the USA gathered for the evening in the private Marriott



Sawgrass Cabana Club for a beautiful night under the stars with the sounds of the ocean as a backdrop as we celebrated the spectacular evening.

Our deejay rocked it with a little help from our very own co-deejay, Parker Feagins. Adding to the ambience was a guitarist, colorful beach balls, glow sticks, and a warm, moonlit beach. The families kicked back, relaxed and enjoyed each other's company after a great weekend of education and connection.

Sunday's breakfast and video presentation, *Gettin' in the Game*, were sponsored by CSL Behring, followed by Hope Woodcock's *Infuse with Hope*. With patient volunteers,

Hope demonstrated live infusions, allowing community members to ask questions and gain knowledge!

Being our first held outside of New York City, our 11th Annual Symposium proved to be a fantastic success! We give special thanks to our sponsors for their gracious and generous support. Thank you to our fascinating speakers, our enthusiastic team and dedicated volunteers, along with the continued participation and engagement of hemophilia B patients and families. For the past quarter of a century, we have been able to make great strides in accomplishing our goals.

We look forward to seeing you at the 2018 Symposium!

GREAT APPRECIATION TO
DIAMOND LEVEL Bioverativ  **and GOLD LEVEL Aptevo** 
FOR GENEROUSLY SPONSORING OUR FINAL NIGHT EVENT!



THANK YOU TO OUR GENEROUS SPONSORS!

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FRIENDS



THANK YOU TO  Alnylam[®] FOR PROVIDING WI-FI FOR OUR ATTENDEES







Whitney Johnson was wonderfully surprised as her boyfriend, Blaise Hartwig, dropped to his knee and proposed! Blaise serves in the Air Force and was soon heading back to base and then shipping out to serve in Korea.



Just B Independent

“Coming to IXINITY, I feel much more like I’m in control of my own life now.”
—Heidi has hemophilia B and uses IXINITY

▶ See why Heidi switched to IXINITY at JustBIXperiences.com

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

INDICATIONS AND IMPORTANT SAFETY INFORMATION

What is IXINITY[®]?

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

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

IMPORTANT SAFETY INFORMATION for IXINITY[®]

- You should not use IXINITY if you are allergic to hamsters or any ingredients in IXINITY.
- You should tell your healthcare provider if you have or have had medical problems, take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies, have any allergies, including allergies to hamsters, are nursing, are pregnant or planning to become pregnant, or have been told that you have inhibitors to factor IX.
- You can experience an allergic reaction to IXINITY. Contact your healthcare provider or get emergency treatment right away if you develop a rash or hives; itching; tightness of the throat, chest pain; or tightness, difficulty breathing, lightheadedness, dizziness, nausea, or fainting.

- Your body may form inhibitors to IXINITY. An inhibitor is part of the body's defense system. If you develop inhibitors, it may prevent IXINITY from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for development of inhibitors to IXINITY.
- If you have risk factors for developing blood clots, the use of IXINITY may increase the risk of abnormal blood clots.
- Call your healthcare provider right away about any side effects that bother you or do not go away, or if your bleeding does not stop after taking IXINITY.
- The most common side effect that was reported with IXINITY during clinical trials was headache.
- These are not all the side effects possible with IXINITY. You can ask your healthcare provider for information that is written for healthcare professionals.

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

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



IXINITY® [coagulation factor IX (recombinant)]

Brief Summary for the Patient

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

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

What is IXINITY?

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

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

Who should not use IXINITY?

You should not use IXINITY if you:

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

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

What should I tell my healthcare provider before using IXINITY?

You should tell your healthcare provider if you:

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

How should I infuse IXINITY?

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

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

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

What are the possible side effects of IXINITY?

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

- Rash
- Hives
- Itching
- Tightness of the throat
- Chest pain or tightness
- Difficulty breathing

- Lightheadedness
- Dizziness
- Nausea
- Fainting

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

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

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

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

How should I store IXINITY?

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

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

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

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

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

What else should I know about IXINITY?

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

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

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



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10th ANNUAL FUNDRAISING DINNER



BY NATHY
DE LA CRUZ

The Coalition for Hemophilia B held its *10th Annual Fundraising Dinner* on Thursday, March 2nd at the Penthouse of the Terrace on the Park banquet hall, overlooking Flushing Meadows Park in central Queens and boasting breathtaking views of the Manhattan skyline. Approximately 200 partygoers were in attendance, including families, community members, industry, and private donors. All funds raised during this special evening benefit the Coalition's educational programs and the William N. Drohan Memorial Scholarship fund.



The evening began with a lovely cocktail hour featuring live music. Once the guests were seated for dinner, Dr. Dave Clark, Chairman of The Coalition for Hemophilia B, warmly welcomed everyone. While dinner was enjoyed, Wayne Cook, President of The Coalition for Hemophilia B, introduced the first *Eternal Spirit Award* recipient, Perry Parker. Golf professional and founder of Perry Parker Golf, Perry has been teaching children in the hemophilia community how to play golf for over 15 years through CSL's Gettin' in the Game Program. William McCarthy, a teen who has looked up to Perry for a number of years, spoke about the valuable impact Perry has made on his life. William and Andrew DiGiovanni presented Perry with the Eternal Spirit Award.



Wayne Cook then introduced the second Eternal Spirit Award recipient, Patrick Torrey, Founder of GutMonkey. For over 15 years, Patrick has conducted amazing programs for kids and adults in our community. Marcus Orr and Manuel Lopez both spoke about how much Patrick's mentoring has meant to them and how his valuable leadership skills and programs have benefited many in the bleeding disorders community. Marcus and Manuel then presented the Eternal Spirit Award to Patrick.



Perry and Patrick have touched many lives in the hemophilia community and we are very proud to honor them for their years of service and dedication to the hemophilia B community.

The 2017 William N. Drohan Scholarship recipients were announced by Wayne who also introduced two of the winners in attendance: In uniform was William Patsakos who begins his studies at University of New York Maritime College, and Alecia Sclafani who will study for a legal career at St. John's University in New York.

The evening continued with guests enjoying the wonderful sounds of the Bill Gati Jazz Ensemble and special entertainment from "America's Got Talent Comedian," John Pizzi who had us laughing all night with his clever magic, jokes, and special puppeteer act. Amanda Torrey made a special appearance at the end of the evening and sang a beautiful rendition of *Somewhere Over The Rainbow*.



In addition to participating in the exciting raffle, guests enjoyed having their photos taken by Hi Tech Events Photography, moving on the dance floor, and sharing smiles and mingling with one other. We are so very grateful to our kindhearted and generous contributors who made this delightful evening a huge success!













THE INAUGURAL COALITION FOR HEMOPHILIA B



Thursday, March 30th, 2017 was a perfect day with blue skies sky and temperature in the 80s for the Coalition for Hemophilia B's first ever golf tournament held at the prestigious TPC Sawgrass, Players Club in Jacksonville, Florida. A total of 48 golfers joined us for a four man scramble format. The day began with registration and practice on the driving range and putting greens.

At 12:30 p.m., a clinic was held by PGA touring pro and fellow hemophiliac, Perry Parker. Perry offered tips to all of the players on the various mechanics

of the golf swing. He also gave a little demonstration of a few tricks that amazed everyone! Perry has been a huge part of the hemophilia community for many years through *Gettin' in the Game*, a youth program sponsored each year by CSL Behring. We are honored that Perry took time from his PGA tour schedule to participate in our tournament and offer not only the clinic, but played a hole with each team!

After quick boxed lunches, everyone was ready for the shotgun start on the beautiful Valley course.





GOLF TOURNAMENT

BY WAYNE COOK

After 18 awesome holes of golf, more of our community folks join us for a cocktail hour and dinner at the TPC Sawgrass Champions Room. Following the fantastic dinner, an exciting auction was held and awards presented to the winners. A great time was had by everyone who participated. Monies raised benefit the Coalition's Patient Assistance Program and the Joe Feagin's Trust Fund.

Plans are currently underway for the 2nd annual Coalition for Hemophilia B golf tournament, so mark your calendars

for Thursday, March 22, 2018 at the TPC Sawgrass Players Club. We are very thankful to everyone who helped us host this fantastic event including, Perry Parker, Jim and Becky VanSant, Matt Sclafani, Hope and Jim Ross, Neal and Celeste Schimmels, our Coalition for Hemophilia B team, employees of the TPC Sawgrass Players Club, and our Sponsors who, with their support, made it all possible! Thank you all for your dedication and commitment to our organization. We eagerly look forward to seeing you on the course next year!



Congratulations to Tournament Winners! Team Bioverativ - Tres Major, John Parler, Keith Hanglin and Scot Mascioli



Tournament Winners!
Tres, John, (course caddy), Keith & Scot





TOURNAMENT SPONSORS

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MAY BE RIGHT FOR YOU

Visit RIXUBIS.com to find your local Shire sales representative

Indications for RIXUBIS [Coagulation Factor IX (Recombinant)]

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

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

Detailed Important Risk Information

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

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

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

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

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

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

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

Please see following page for RIXUBIS Important Facts.

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



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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?

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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?

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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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2017 WOMEN'S RETREAT

BY CHRISTIAN VILLARREAL

On April 20th, ladies arrived from their scheduled private transport to the beautiful Carefree Resort and Conference center in Phoenix, Arizona. They were instantly greeted by the Coalition Team members and signed up for relaxing chair massages after their long flights. From California to Massachusetts, the Coalition flew in ladies from all walks of the USA to gather together for an educational and exciting weekend women's retreat.

After reading through many surveys for the men and women asking for more time at our retreat, the Coalition's Board of Directors decided to extend the retreat by flying everyone in a day earlier. From Thursday to Sunday, the women were set up for a variety of educational meetings and activities to allow them to truly explore the art of self-care.

The first session was with Maria Iannone, Social Worker

from the local HTC. Her talk was on *Anxiety and Depression* with emphasis on the impact for interpersonal relationship effectiveness. Afterwards the women all gathered for a special hamburger night in the resort restaurant. They enjoyed dinner together and the bonding of sisterhood began.

On Friday morning, we kicked off our day with fresh coffee, baked muffins and fruit. The ladies were able to choose from 3 very exciting morning exercises; Tai chi with Cassie Starks, a nature walk with Deena Lipinski, and water aerobics with Pam Williams. Following breakfast, the group gathered for the *Welcome Introductions* with the Coalition team. This served perfectly as a means for the ladies to learn some quirky new things about each other and of the Coalition team.

Afterwards, holistic and spiritual leader, Tina Sacchi led a session on *Living Passionately and Learning How*





to *Have Your Inside Match Your Outside World.*" Tina spoke to the ladies about how to seize opportunities and enjoy all moments of life regardless of what life presents. She led them to a circle of empowerment where the ladies were able to write down things that were blocking their happiness on pieces of paper. Tina gave them the opportunity to release those blocks and throw them into an outside fire pit. This session helped the ladies release tensions they arrived with, allowing them to open to possibilities of self care, and the power of releasing and letting go of things that no longer serve them.

Next up was a presentation from Donnie Akers on *Legal Tools And Learning To Be The Best Patient Advocate* to help facilitate the patient/doctor relationship. Armed with newfound tools, the ladies took a moment to return to their rooms to freshen up for their next off-site activity. Gathered in the lobby, the women departed for afternoon tea at The English Tea Room in Carefree, Arizona.

Beautifully dressed and adorned with tiaras, the ladies enjoyed conversing over crumpets and tea!

The evening gave way to a western cookout-themed dinner where the ladies had the opportunity to dress up in old western outfits and take photos together. After dinner, everyone gathered around the fire pit for s'mores and talks. Later, the ladies participated in an icebreaker called *Project Runway: Hemophilia*. In teams of 4, the ladies were given a supply of color streamers, toilet paper, and popsicle sticks. With scissors and tape, they created hemophilia-meaningful designer dresses such as a infusion-inspired dress, modeled onto one of their fellow team mates. This icebreaker had everyone moving, mingling and having a blast as they were only given 15 minutes to create their couture designs! Talk about breaking the ice!

On Saturday, after a busy first couple of days, the



ladies again had three options for their morning exercise - Tai Chi, water aerobics or a nature walk. They enjoyed breakfast and went into a session titled *Be the Best Patient Advocate*, where the women learned how to navigate through medical diagnosis and treatment. They bonded over similar stories and speaker Donnie Akers led the discussion to help the ladies better advocate for themselves and their families.

The ladies participated in a fun, core-balancing session where Mahin Sciacca taught the art of belly dancing. Not many women get to get out of their comfort zone and try belly dancing, so we supplied them with a coin belt and scarf, and Mahin explained that belly dancing is a low impact form of exercise as it does not jolt or jar the body. It also helps your posture, tones muscles and reduces stress.

After lunch, the ladies headed to the meeting room for a session called *Chit-Chat and Chocolate* with Psychologist Dr. Karen Peterson and Pam Williams and Nina Duggan. Pam and Nina shared their trials and tribulations with hemophilia and this opened up to a lively discussion and sharing. Dr. Peterson spoke about the importance of self-care and had the ladies do several exercises to raise awareness and identify areas in their life that need attention. Chocolate



was shared with the attendees during the session.

For our last session, Cassie Starks presented *Tapping into the Power of Meditation and Stress Relief*. The ladies learned how to deal with obstacles caused by hemophilia to unleash their mental and physical fitness potential.

After a full day of events, for our last evening together, we all gathered

over a champagne toast to cheer the successful and empowering weekend the ladies had together. We enjoyed a lovely *Taste of Tuscany* dinner.

To wrap the fantastic event, Sunday morning offered a beginner's yoga class and a casual breakfast gathering.

Old friends were reunited and new friends were made. The bond the women made with each other will last

a lifetime, the memories created are priceless, and the tools learned will help them realize better self care and empower them with strength.

Feedback offered by attendees on past retreat surveys was instrumental in bringing these new and improved programs to this retreat. We had an amazing time hosting the ladies and look forward to continuing to grow our popular and much anticipated women's retreat!





**WOMEN'S RETREAT
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WOMEN'S RETREAT COMMENT

By HEIDI RAMSEY

The Coalition for Hemophilia B's Annual Women's Retreat is truly one of the greatest experiences I've had within the bleeding disorders community. To be able to come together with so many women: mothers, spouses and those affected, is so empowering. You get to connect and grow with these women and learn so much, not only about them, but

about yourself as well.

The retreat is a great way to make new friends, to gain better understanding around matters of mental health, and to touch on some of the legal aspects that you may be missing when it comes to your husband, child or yourself. If you ever get the opportunity to attend one of

the retreats, please go. I've made so many lifelong friends from past retreats I've attended and I wouldn't trade my experience for the world!

Thank you, to The Coalition For Hemophilia B for creating such an amazing program and giving the women in this community an outlet to let their voices heard.





He's free to infuse only once every 14 days.

Are you?

The only FDA-approved treatment for hemophilia B with up to 14-day dosing.* **Visit us at IDELVION.com.**



Dosing schedule that fits into your lifestyle



High and sustained Factor IX levels at steady state^{1,†}



Zero median annualized spontaneous bleeding rate (AsBR) when dosed at 7 or 14 days in clinical trials

Protection with peace of mind—**low incidence of side effects**

*Appropriate people 12 years and older may be eligible for 14-day dosing. Talk with your doctor.
†Average FIX levels with 7-day dosing over 92 weeks in clinical trials.

Important Safety Information

IDELVION is used to control and prevent bleeding episodes in people with hemophilia B. Your doctor might also give you IDELVION before surgical procedures. Used regularly as prophylaxis, IDELVION can reduce number of bleeding episodes.

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

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

Stop treatment and immediately contact your healthcare provider if you see signs of an allergic reaction, including a rash or hives, itching, tightness of chest or throat, difficulty breathing,

lightheadedness, dizziness, nausea, or a decrease in blood pressure.

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

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

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**.

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

BRIEF SUMMARY OF PRESCRIBING INFORMATION

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

What is IDELVION?

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

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

Who should not use IDELVION?

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

- hamster proteins
- any ingredients in IDELVION

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

What should I tell my healthcare provider before using IDELVION?

Discuss the following with your healthcare provider:

- Your general health, including any medical condition you have or have had, including pregnancy, and any medical problems you may be having
- Any medicines you are taking, both prescription and non-prescription, and including any vitamins, supplements, or herbal remedies
- Allergies you might have, including allergies to hamster proteins

- Known inhibitors to Factor IX that you've experienced or been told you have (because IDELVION might not work for you)

What must I know about administering IDELVION?

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

What are the possible side effects of IDELVION?

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

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

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

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

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

Based on November 2016 PI revision.

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



IDELVION is manufactured by CSL Behring GmbH and distributed by CSL Behring LLC. IDELVION® is a registered trademark of CSL Behring Recombinant Facility AG. Biotherapies for Life® is a registered trademark of CSL Behring LLC.

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www.CSLBehring-us.com www.IDELVION.com IDL16-02-0032(1) 1/2017



5th ANNUAL MEN'S RETREAT

BY WAYNE COOK

This year marked our 5th Annual Men's Retreat in beautiful sunny Carefree Arizona at the Carefree Resort and Conference Center April 27-30, 2017. We made a couple of changes to our retreat lineup by adding an extra day for the guys to come in, relax and gear up for a very educational and fun-filled weekend. We also decided to take the men to a National League baseball game between the Arizona Diamondbacks and Colorado Rockies at beautiful Chase Field.

The weekend kicked off on Thursday with the arrivals of the guys from all over the USA. Upon arrival, they settled in, took time to enjoy the warm weather, enjoyed a nice chair

massage, and met up with old friends and made new ones at lunch. We later gathered for dinner at the hotel restaurant for their famous burger night. After dinner, I welcomed all and opened our weekend retreat with a rap session, where everyone was provided with an open forum for various topics of discussion. After the rap session, the guys played cards, played pool, or just relaxed together to continue talking and bonding.

The next morning had us refreshed and ready for our Tai Chi session with Rick Starks. Rick's program helps to get the mind and body in sync, and helps alleviate anxiety and stress. With Tai Chi and a hearty breakfast on board, everyone was





welcomed again; further introductions made, and fun icebreakers were enjoyed.

Donnie Akers provided the first session of the day. Donnie, an attorney, spoke on Americans with Disabilities Act laws, and our rights and benefits in employment. This interesting topic prompted many questions and answers that followed. Dr. David Clark, Chairman of the Coalition for Hemophilia B, then share information on hemophilia B treatments currently available and those in development. Dr. Clark explained the many new treatments that have been developed, including factor products, alternative approaches to improving coagulation, inhibitor treatments, and gene therapy. We then broke for lunch and sat outside to take in the fresh air on the Sunset Terrace.



Felix Garcia, a man with hemophilia, and Matt Sclafani, a father raising a child with hemophilia, presented the afternoon session on "I am Man, I am Manly." This interesting program took some negative stereotypes and shined light on what it's like to be a man, a father, and a brother in the hemophilia B community.

The educational portion of the day wrapped up with, "The Healing Power of the Drum" presented by Robert Freidman. This very interactive session had everyone participating in rhythm-based exercises and highlighted how practice through the power





of the drum can be used to attain psychological, physiological, and spiritual well being.

Then it was time to enjoy a professional ball game! The game at Chase Field was a lot of fun and the men seemed to genuinely enjoy themselves. For some of these guys, this was the first time they ever been to a major sporting event and that made it even more special.

Rick Starks' Tai Chi session on Saturday morning had us all up and going. Wide-awake and properly fed, our day of education began with Dr. Bruce Luxon, who spoke on "New Treatments for Hepatitis." He outlined treatment options and success rates, and also the risks of untreated cirrhosis of the liver. Following a short break, Donnie Akers held his second session on "Being Prepared and the Legal Tools for the Road

Through Life." Donnie discussed medical directives and medical power-of-attorney, and legal tools needed to get through life.

Next up was Maria Iannone, a Social Worker from the local hemophilia treatment center. Maria has been speaking at our Men's Retreats since we first began. She addressed "Anxiety and Depression and their Impact on Relationships." This topic addressed depression and anxiety, how it impacts interpersonal relationships, and offered life tools to help address these problems. Our last session for the day was an aquatic exercise program delivered by Dr. Michael Zolotnitsky, a physical therapist who also has hemophilia. Michael led a 45-minute session in the pool and demonstrated to the guys how aquatic exercises can help strengthen joints.





The completion of sessions opened way for an amusing Coalition tradition called the "Bleeder Olympics," where we participate in some really fun backyard games. Grouping in teams of two, Bleeder Olympics gives the guys a chance to compete with one another and just laugh. For a little while, we get to forget our hemophilia and laugh like we were kids again. This part of the retreat is very meaningful to me because sadly, there are many guys that haven't smiled in a long while. We are able to witness their feeling relaxed, happy, and carefree.

As the weekend wound down with dinner, card games and fireside chats, we drew another successful retreat to a close with our good-byes, our hugs and smiles, and the sincere thanks from the guys for hosting a program that has helped enrich their lives. They walked away knowing

they are never alone again...they have brothers.

Many of the men attend several programs throughout the year, yet they acknowledge that this particular retreat is a highlight for them. We look forward to continuing this program for years to come.

We are very thankful to the planning committee - this program would not be where it is without them. We greatly appreciate all their hard work in "bringing us together." Thank you!

Special appreciation to Pfizer for sponsoring our Men's Retreat!





A DAD'S VIEW OF THE MEN'S RETREAT

Over the past several years, I have been aware the Coalition for Hemophilia B hosted the Men's Retreat and that it was typically only for men with hemophilia B. I've had the opportunity to speak to several of the men that have attended this retreat and have learned how powerful the experience is for them and how it makes a difference in their lives. This most recent retreat was the first time that a few fathers of children with hemophilia B were included. I was fortunate enough to be selected to attend as a father of a 15 year-old son with severe hemophilia B.

Even though I was asked to contribute on the planning committee and have heard many stories about this retreat

over the years, I still wasn't sure what to expect, or how I would fit in with these men that have lived with hemophilia their whole lives - after all, I am just a dad. After the first evening, all my concerns were put to rest.

The rap session of the first evening set the tone for the whole weekend. This was one of the most powerful experiences I have had within the hemophilia community since first becoming involved over 12 years ago. Though the room was filled mostly with individuals that really didn't know one another, I was so impressed with the powerfulness of the open, honest and inclusive discussions that followed. The men living with this





BY MATT SCLAFANI

bleeding disorder had such empathy for one another, as well as for the fathers. All the dads were made to feel we belonged.

We listened to one another's stories, and shared the fears and challenges, which became intensely emotional at times, but always ended on a positive note with a smile or even laughter. Everyone's voice was heard and our powerful discussions validated feelings, issues, and concerns. Most of us entered the session as strangers, but left as friends, making the weekend to come that much more enjoyable. The rest of the weekend was structured with opportunities to talk and attend

workshops where valuable information was provided, and the downtime allowed us to unwind and take in the magnificent setting.

As a dad with a young man with hemophilia, the opportunity to hear the shared stories by both those living with hemophilia and the other fathers was incredible. It proved to be a truly valuable growth experience for me, and one I won't soon forget. In closing, I'd like to say thank you to the Coalition for Hemophilia B for hosting this event, but also to all of the men in attendance for the heartfelt discussions, laughs, and camaraderie!



Industry News

BY DR. DAVID CLARK



Aptevo's Ixinity Found Safe and Effective in Children Under 12

Aptevo Therapeutics has announced that data from its ongoing Phase III clinical trial of Ixinity recombinant factor IX shows that the product is safe and effective in children under 12. Ixinity is currently approved for treatment of patients 12 and older. The study followed twelve children younger than 12 over time, most on prophylaxis. The median annualized bleeding rate was 0.3. The product was generally well tolerated and no inhibitor development was observed. Aptevo will continue the study with the aim of extending their approval to children under 12.



Bioverativ's Alprolix Found Safe and Effective in Children Under 12

Bioverativ has reported results from their ongoing Phase III trial of Alprolix in children under 12. Thirty patients under 12 (median, 5 years of age) received once-weekly infusions of Alprolix. Overall, 80% of patients were able to reduce their infusion frequency from that on their previous product. The mean half-life was 68.6 hours. Ten patients reported no bleeding and 19 patients exhibited no joint bleeding. Four patients experienced severe adverse events, but no inhibitor development was observed.



Catalyst Receives IND Approval from South Korea

Catalyst Biosciences has received IND approval from South Korea for a Phase I/II clinical study of their subcutaneous recombinant factor IX candidate CB 2679d/ISU304. The product is a factor IX variant that was developed by making thousands of mutated factor IX molecules and then screening them to identify ones that had desirable properties. Catalyst plans to start their clinical study by mid-2017.



CSL Receives NORD 2017 Award for Idelvion

CSL Behring has received the National Organization for Rare Disorders (NORD) 2017 Industry Innovation Award for Idelvion, their longer-acting factor IX product. NORD is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them.



Dimension to End Development of Hemophilia B Gene Therapy

Dimension Therapeutics has decided to end their DTX101 development program for hemophilia B gene therapy. After reviewing the data from their Phase I/II clinical trial, they found that the results were not meeting the company's expectations.

Industry News



FDA Approves Novo Nordisk's Rebinyn Longer-Acting Factor IX Product

On May 31, 2017, FDA approved Rebinyn, Novo Nordisk's longer-acting GlycoPEGylated recombinant factor IX product. It is indicated for on-demand treatment and control of bleeding episodes and for perioperative (before, during and after surgery) management of bleeding. Rebinyn has polyethylene glycol (PEG) polymer chains attached to the carbohydrate (glyco) side chains of the factor IX molecule to give it a lifetime in the bloodstream approximately five times longer than normal factor IX. Rebinyn also appears to maintain higher factor IX levels between infusions.

Note that Rebinyn was not approved for prophylaxis, although its European approval (it's called Refixia in Europe) did include a prophylaxis indication. This may be a reflection of concern about the unknown effect of PEG over time in the body. Although there are currently several PEG-containing drugs on the market, most of them are not taken chronically over a long period of time as Rebinyn would be for prophylaxis. Presumably, Novo Nordisk will do further studies to try to demonstrate the safety of the product in prophylaxis, since the longer half-life and higher factor IX levels would be real benefits in that scenario. Novo plans to introduce the product in the U.S. market in the first half of 2018.



Sangamo to Begin First Human Trial of in vivo Gene Editing

Sangamo Therapeutics has announced that they are ready to start the first-ever trial of gene editing in the human body with a study of gene therapy for hemophilia B. All hemophilia B gene therapy studies so far have inserted new factor IX genes into the nucleus of cells in the body, but those new genes have intentionally not been integrated into the genome of the cells. Sangamo will use molecules called zinc finger nucleases to actually insert the new factor IX gene into a location on the cell's chromosomes. Sangamo plans to insert the new factor IX gene next to the albumin gene in liver cells where it would be under the control of the albumin gene's regulatory elements. Since the body produces large amounts of albumin, the hope is that it will also produce factor IX the same way. Sangamo's Phase I study is currently recruiting patients. More information can be found on www.clinicaltrials.gov under study identifier NCT02695160.



uniQure Developing Method for Re-administration of Gene Therapy

One of the issues with gene therapy using AAV vectors is that patients develop neutralizing antibodies against the vector, which may keep the patient from receiving a second dose of the gene therapy treatment, if needed. Other patients may have anti-AAV antibodies from naturally acquired infections that could keep them from receiving a first dose. uniQure has shown that in non-human primates, an immuno-adsorption technique can reduce the level of anti-AAV antibodies enough that a factor IX AAV vector can be successfully re-administered. This has the potential to extend the applicability of gene therapy to nearly all patients regardless of their antibody status.

A MOTHER'S GIFT

BY MEGAN KING

When you become a mother the gift of a child strings along a thread of endless and irreplaceable memories. We remember all the big things; walking, riding a bike, losing a tooth, and all the milestones you document in pictures or journals. These memories of joy exceed our heart's capacity, fill it to the brim, and are stored away to pull out occasionally.

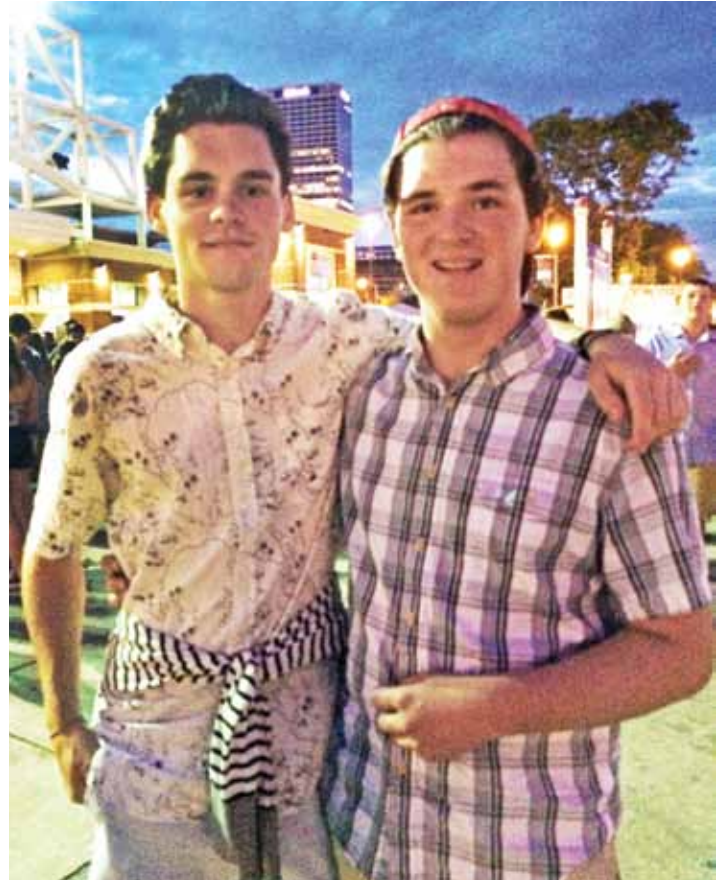
With my children, memories often change. I thought of this when I was at my 20 year-old son, Liam's, and 16 year-old, Finn's biannual appointments with their HTC. The appointments are now easier; no longer juggling all my kids, strollers, snacks, and nap schedules. We now go in and the boys get soda and crackers, and wait for the battery of questions, "Have you had any bleeds?" "How are you doing in school?" My role is now that of an observer. I relinquished happily the job of speaking on behalf of both of them and trying to keep the details of their lives accurate.

However, it was at this last appointment when I saw the medical binders for my boys - four large binders for the 20 year-old and three binders for the 16 year-old. While we were waiting, I sat at the desk and opened up the binders. I scanned the date "July 22, 1998 - Liam admitted for possible infection. PICC line placed." I scroll my memory and vaguely trip and fall into that moment I had long forgotten, leaning against the procedure door while he was screaming for me, I feel my throat constrict clogged with emotions I buried along with that day.

"Oct. 7, 2001 - Finn came in through ER with a terrible frenulum tear. He is bleeding from the mouth and from the 12 attempts to get vein access on him." I swallow hard. I had completely forgotten that day. His first bleed. I pretend to yawn so the tears collecting in my eyes will be viewed as watery eyes from the yawn so my boys don't ask me.

Like a sadist, I continue to flip through the pages joint bleed, port infection... I know I was there for all of it, but I remember glimpses. Like remembering childbirth is painful you can't recreate the pain of those moments but your blurry memory remembers it was awful and hard and it felt like time froze and that the moments they had to suffer went on like the horizon.

I poke into some of the social media sights that keep hemophilia moms together. "My five year old is screaming and we hold him down for infusions - any tips are welcome." I read it and I tiptoe into that tender part of my



memory that recalls the screaming and the holding them down, but I quickly pull myself out like a plane coming out of a nosedive. I pull up and take myself out of the spin into the swirl of memories.

What I want to say is that the moments are hard and God-awful. When you think you can't hurt more for your child in episodes they have to go through, but here we all are continuing in the journey with our kids. Watching our roles morph into something we have less and less to do with, and keeping all the parts tucked away where time and money chip away and keep them from being as sharp and poking us so deeply. We use each wonderful memory to wipe out a year's worth of traumatic ones because it what the soul demands; it's the blur and anesthesia that kept us from staying in bed and pulling the covers up. I look at all the binders that hold the truth and I am grateful my heart has room for all the wonderful things; getting a license, going to a dance, packing for college. Those make my heart sing and fill me in the places the history the binders hold can never touch.

GETTIN' IN THE GAME 2017 ESSAY CONTEST

The Coalition for Hemophilia B is pleased to offer 2 winners of our essay contest to attend the *Junior National Championships Gettin in the Game* this year! This event will be held November 3-5, 2017 in Phoenix Arizona. CSL Behring is pleased to announce that swimming will be in this year's program - swimmers must be able to swim 25 yards without assistance and tread water for 30 seconds, and will be tested on these skills.

During the program, nominees will have the opportunity to participate in baseball, golf and swimming activities, learn the fundamentals, enhance their skills, and learn the importance of physical fitness in managing a bleeding disorder; and their abilities in a national competition with their peers. The JNC features accomplished *Gettin' in the Game*

athletes who themselves have been diagnosed with bleeding disorders.

To enter the contest please submit an essay on "*Why I Love Baseball, Swimming or Golf*". Deadline is August 15th, 2017. Essay length will vary upon age. This contest is for ages 7-18 years old with hemophilia B. Please be sure to have your child write it! It's about the passion, not perfection!

Please email your essay to:

chrisv@hemob.org or
kimbo1217@live.com

Or mail to:

The Coalition For Hemophilia B
825 Third Avenue, 2nd Floor,
New York, NY 10022

Questions? Please call:

212-520-8272

Winners will be notified by
August 30th!

GOOD LUCK!

Each participant must be accompanied by one adult (a parent or caregiver)

CSL Behring will sponsor each nominee and one accompanying adult to participate in the program.

This sponsorship will include the coordination and cost of airfare, ground transportation in the program city and hotel arrangements (attendees will be responsible for transportation to and from airport).

SAVE THE DATE!



GETTIN' IN THE GAMESM
JUNIOR NATIONAL
CHAMPIONSHIP

November 3–November 5, 2017
Phoenix, Arizona



NHF WASHINGTON DAYS 2017

This year from across our great nation, over 480 advocates participated in The National Hemophilia Foundation's Washington Days. This event took place March 8 – 10, 2017 on Capitol Hill in Washington DC.

Community advocates met with members of Congress and their staff members to explain how the Affordable Care Act (ACA) helps individuals and families living with a bleeding disorder obtain and afford health

insurance. Participants did a great job of telling their personal stories to remind Congress of how real children and adults with costly, chronic health conditions could be affected by repeal and replacement of the ACA.

The elimination of annual and lifetime caps, the federal essential health benefits requirement, and Medicaid expansion were three of the key ACA components that advocates asked Congress to maintain in

any replacement legislation being considered. Advocates also asked their Congress members to accept NHF's Red Tie Challenge by asking them to take a picture wearing a red tie and sharing it on social media in support of bleeding disorders awareness.

This essential cause is definitely worth being involved with and we at The Coalition for Hemophilia B are happy to again have been involved!



HFA SYMPOSIUM 2017 PROVIDENCE, RHODE ISLAND

During this year's Hemophilia Federation of America's Symposium, our booth was booming with attendees of all ages! The Coalition For Hemophilia B's team included Chairman Dr. David Clark, President Wayne Cook, and Christian Villarreal, Programs Director and Community Relations.

The B Team welcomed new families and all other attendees to the exhibit booth and provided them with information from the Coalition and goodies for the kids.

We thank HFA for a wonderful and memorable Symposium!



Science matters. Because patients matter.™

It's because of this belief that we:

Brought the leading extended half-life therapies to people with hemophilia
—innovation that has changed the way hemophilia can be managed.

Sponsor free genetic testing for people with hemophilia and carriers
through *My Life, Our Future*. Together with program co-founders the American Thrombosis and Hemostasis Network, Bloodworks Northwest, and the National Hemophilia Foundation, we are advancing disease understanding and research for the entire community.

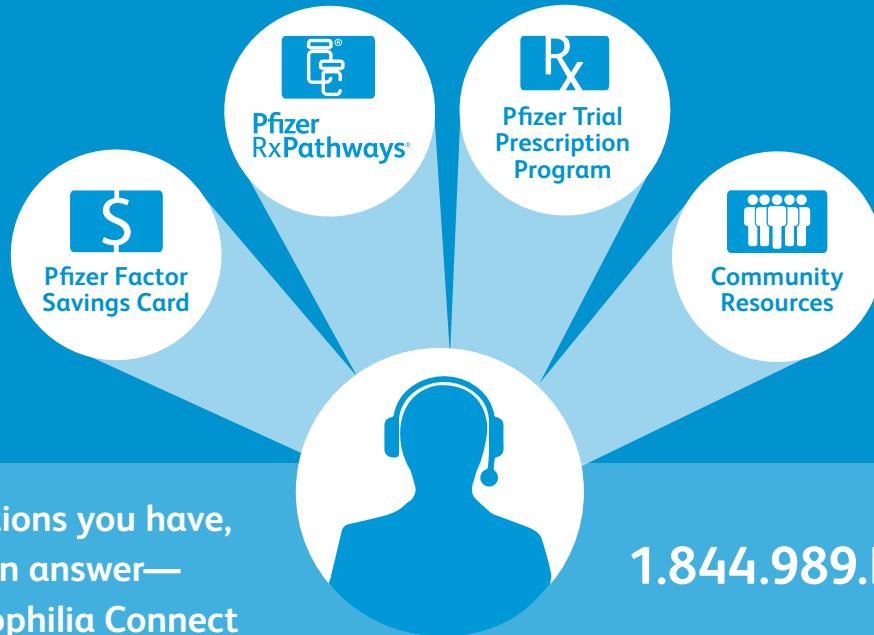
Transformed humanitarian aid in hemophilia, with Sobi, by committing to donate up to one billion IUs of factor therapy over 10 years to help close the treatment gap in the developing world. More than 12,300 people have been treated through the WFH Humanitarian Aid Program, which is receiving 500 million IUs over five years.

We not only believe great science can conquer the toughest medical challenges, we live it every single day.



Pfizer Hemophilia Connect

Call one number to access all of our resources



Whatever questions you have, we'll help find an answer—call Pfizer Hemophilia Connect

1.844.989.HEMO (4366)

The Pfizer Factor Savings Card*

\$12,000 annual support for eligible patients in 4 simple steps—the card can be used to help cover copay, deductible, and coinsurance costs associated with Pfizer factor products.

Pfizer RxPathways^{®+}

Eligible patients can save up to \$10,000 with this comprehensive assistance program that provides a range of support services.

Trial Prescription Program[†]

A one-time, 1-month supply up to 20,000 IU of Pfizer product delivered at no cost to your door.

Community Resources

Learn about support programs like HemMobile™, Patient Affairs Liaisons, scholarship assistance, and the educational speaker series.

*Terms and conditions apply; visit PfizerFactorSavingsCard.com for complete terms and conditions. For commercially insured patients only. Medicare/Medicaid beneficiaries are not eligible. The Card cannot be combined with any other rebate/coupon, free trial, or similar offer for the specified prescription. The card will be accepted only at participating pharmacies. This coupon is not health insurance. If you have any questions about the use of the Pfizer Factor Savings Card, please call 1.888.240.9040 or send questions to: Pfizer Factor Savings Program, 2250 Perimeter Park Drive, Suite 200, Morrisville, NC 27560. For more information, please visit www.HemophiliaVillage.com.

⁺The Pfizer RxPathways Savings Card is not health insurance. For a complete list of participating pharmacies, visit PfizerRxPathways.com or call the toll-free number 1.877.744.5675.

[†]Terms and conditions apply. You must be currently covered by a private (commercial) insurance plan. For questions about the Pfizer Hemophilia Trial Prescription Program, please call 1.800.710.1379 or write us at Pfizer Hemophilia Trial Prescription Program Administrator, MedVantx, PO Box 5736, Sioux Falls, SD 57117-5736. You may also find help accessing Pfizer medicines by contacting the Pfizer RxPathways Program.



OMAHA, NEBRASKA

September 16, 2017

Omaha Marriott Hotel
10220 Regency Cir
Omaha, NE 68114
(402) 399-9000
\$94 room-rate

SALT LAKE CITY, UTAH

November 4, 2017

Marriott Salt Lake Downtown at City Creek
75 South West Temple
Salt Lake City, UT 84101
(801) 531-0800
\$139 room-rate

COLUMBUS, OHIO

September 23, 2017

Columbus Airport Marriott
1375 N Cassady Avenue
Columbus, OH 43219-1524
(614) 475-7551
\$115 room-rate

LOUISVILLE, KENTUCKY

November 4, 2017

Louisville East-Hurstbourne Holiday Inn
1325 South Hurstbourne Lane
Louisville, KY 40222
(502) 426-2600
\$109 room-rate

ANN ARBOR, MICHIGAN

September 23, 2017

Sheraton Ann Arbor Hotel
3200 Boardwalk Street
Ann Arbor, MI 48108
(734) 996-0600
\$129 room-rate

PHOENIX, ARIZONA

November 11, 2017

Marriott Scottsdale McDowell Mountains
16770 N Perimeter Drive
Scottsdale, AZ 85260
(480) 502-3836
\$149 room-rate

HOUSTON, TEXAS

October 7, 2017

JW Marriott Houston
5150 Westheimer Road,
Houston, TX 77056
(713) 961-1500
\$99 room-rate

INDIANAPOLIS, INDIANA

November 11, 2017

Crowne Plaza Indianapolis Downtown Union Station
123 West Louisiana Street
Indianapolis, IN 46225
(317) 631-2221
\$149 room-rate

Breakfast, lunch and dinner included. Parking is free; gas and tolls will be reimbursed. Childcare is available on premises. Children 5 years old and over will go on a day trip.

Consumer registration is free.

**Consumer and Exhibitor Registration forms are available online:
www.hemob.org**

SAVE THE DATE

THURSDAY, MARCH 8TH, 2018
TERRACE ON THE PARK, NEW YORK



THE COALITION FOR HEMOPHILIA B

11TH ANNUAL ETERNAL SPIRIT AWARDS DINNER

1940s THEME

UPCOMING EVENTS 2018!

**The Coalition For Hemophilia B
2nd Annual Forelife, Golf Outing and Fundraiser
Thursday, March 22, 2018
TPC Sawgrass
Ponte Vedra Beach, FL 32082**



**The Coalition For Hemophilia B
12th Annual Symposium
Friday- Sunday, March 23-25, 2018
Sawgrass Marriott Golf Resort & Spa
Ponte Vedra Beach, FL 32082**





2017
Red Tie Challenge

Bleeding Disorders
Awareness Month

Visit hemob.org
contact@hemob.org

THE COALITION FOR
HEMOPHILIA



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
825 Third Avenue, 2nd Floor
New York, New York 10022

Please respond by **November 15, 2017**,
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 15, 2017**. Your name and information will be kept strictly confidential. Send mail this form to:

The Coalition for Hemophilia B Holiday Cheer
825 Third Avenue, 2nd Floor; New York, New York 10022

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!



CHALLENGES
SOLUTIONS
GRATEFUL
ALTERNATIVES

Jay lives with severe hemophilia B with inhibitors.

Change the way you picture living with a rare bleeding disorder

Novo Nordisk is helping people like Jay write his story.

That's why we are continuously seeking new ways to achieve science, support, and education for the bleeding disorders community. Because at Novo Nordisk, we're always committed to helping you make your potential possible.

changing
hemophilia™

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KIDZ KORNER!

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

BLOSSOM
 BUTTERFLY
 CLEANING
 DANDELION
 FLOWERS
 GARDEN
 GREEN
 MAY
 PICNIC
 RAINBOW
 ROBIN
 SHOWERS





The Coalition For Hemophilia B

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Facebook: www.facebook.com/HemophiliaB/

Twitter: <https://twitter.com/coalitionhemob>



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