Factor Nine News

The Coalition for Hemophilia B

SUMMER 2017

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MENTOR PERSPECTIVES OF GENERATION IX

Since 2014, The Coalition for Hemophilia B and Gutmonkey have held weeklong programs in the woods of the Northwest, which have been integral in creating experiences filled with amazing memories for young people with hemophilia B. The program, called Generation IX, has a unique format where 18 to 35-year olds with hemophilia B mentor fellow teens with hemophilia through challenging exercises of strength and courage. Those who have experienced the program express how the programs have positively impacted their lives. They speak about Generation IX with a reverence as one of those life experiences that leaves a lasting impact.

For participants, the program is filled with skill learning through challenging exercises in a fun and supportive environment. The mentors receive multiple day experiential training prior to the teens arrival. This training is focused on interpersonal skill development, and exploring leadership styles and group dynamics. The mentors also receive additional online training and support beyond the residential program to facilitate their mentorship within their home communities.

In this feature, we speak to Heidi and Marcus about their experiences as mentors within the Generation IX program. Both Marcus and Heidi thoroughly enjoyed being part of the Generation IX program, and they spoke about how it has impacted their personal lives.

Marcus loved being part of the Generation IX program. He thinks the program is a space where an individual can grow in an environment that encourages creating and maintaining relationships with others. Above all, he loves the program because “it is genuine.”

Heidi, who is a counselor year-round in various hemophilia programs, says that being a mentor in

Generation IX is different than being a counselor. As a mentor, she says she feels like she is an equal with her teens. She says that it has been a moving experience, and she has grown a lot personally. She most likes the atmosphere of walking besides the teens and experiencing Generation IX together with them.

Marcus thinks that being involved in Generation IX has helped him by giving him the realization that "you need to step back sometimes." He recounts when he first started in the program he and was very afraid of heights. Initially, he tried to take this fear head-on; however, he says the program's "non-pushy" atmosphere gave him the opportunity to step back and evaluate his fear, which really helped him to overcome it. Marcus has now taken this taking-a-step-back approach to other parts of his life, saying, "you can't always take everything head on without thinking first."

Heidi especially enjoys being a mentor in Generation IX because she says it is just as much for her as it is for anybody else, and she grows tremendously by learning about herself in the program. The program encourages her to leave her comfort zone, but at the same time, not leave it too far behind.

Mentors in Generation IX receive leadership

development classes. Marcus says that through the training he was able to evaluate his weaknesses and strengths to become a great leader. Through the classes, Marcus realized he has a knack for leadership.

Heidi, who calls herself a kid at heart, looks forward to continuing being a mentor in Generation IX. She cares deeply about the people with hemophilia, and greatly admires the Generation IX program. To be a better mentor and leader, she wants to integrate aspects of the Generation IX program into her year-round camps.

Heidi shares that being a mentor in Generation IX has helped her personally by going through what she calls “a humbling experience”. She says that it provides her the opportunity to have multiple roles and to see that she can fulfill them. Additionally, through being a mentor in the program, she feels like she knows people everywhere in the U.S., and she can call on them whenever she visits their state. “I didn’t know anybody when I started. I was taken in like family, it has been such a great experience,” Heidi says.

We are thankful to Aptevo for sponsoring this wonderful program!

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To find out more about how you can get involved in Generation IX, please visit our website www.hemob.org.

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Indications for RIXUBIS [Coagulation Factor IX (Recombinant)]

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

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

Detailed Important Risk Information

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

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

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

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

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

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

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

Please see following page for RIXUBIS Important Facts.

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

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RIXUBIS
[COAGULATION FACTOR IX (RECOMBINANT)]
MOVING FORWARD

RIXUBIS
[COAGULATION FACTOR IX (RECOMBINANT)]

Important facts about

RIXUBIS [Coagulation Factor IX (Recombinant)]

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

What is RIXUBIS?

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

Who should not use RIXUBIS?

You should not use RIXUBIS if you

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

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

What should I tell my healthcare provider before using RIXUBIS?

You should tell your healthcare provider if you

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

How should I infuse RIXUBIS?

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

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

What are the possible side effects of RIXUBIS?

Allergic reactions may occur with RIXUBIS. Call your healthcare provider or get emergency treatment right away if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting. Some common side effects of RIXUBIS were unusual taste in the mouth and limb pain. Tell your healthcare provider about any side effects that bother you or do not go away. These are not all the side effects possible with RIXUBIS. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about RIXUBIS?

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

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

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

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

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THE COALITION FOR HEMOPHILIA B AT NHF IN CHICAGO!

The Coalition For Hemophilia B had a wonderful time at the National Hemophilia Foundation's Annual Meeting held in Chicago August 24th thru August 27th. It was so nice to meet new people and see old friends again! The "Impact Awards" hosted by Patrick Lynch and sponsored by Shire was a truly wonderful program to attend as we see our young community members acknowledged in several categories for their good work, passion and dedication to making the world a better place. Some of our hemophilia B members acknowledged at this event were Collin Johnson, Fiach Echandi, Weslee Ryan Whitaker, Gabriella DiGiovanni and Tyler Lipinski.

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.

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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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CHRIS BOMBARDIER

MAN WITH A MISSION TAKES ON MOUNT EVEREST

BY MICHAEL PERLMAN

"I have been dreaming of climbing Mt. Everest for the past ten years, when I began having an interest in climbing and the outdoors, and I was able to summit on May 22nd," said 31-year old Denver, Colorado resident Chris Bombardier, who earned a Bachelor's in biology at Doane College and is pursuing a Masters in global health at Northwestern University.

Hemophilia B was no match for Bombardier, who became the first individual with the hereditary bleeding disorder to accomplish the 29,029-foot trek along the highest mountain worldwide. He recalled, "It was an incredible feeling to stand on the top of the world and let the world know that someone with hemophilia can dream of doing anything with the right treatment and drive. I don't think I have ever been so happy and proud of myself."

"We were at base camp and on the mountain for 47 days," he said. Additionally, trekking to base camp took 9 days. Specialized gear included 8000m mountaineering boots, a down suit, oxygen tanks, and a mask alongside regular mountaineering gear. Bombardier explained, "The Himalayas are incredibly daunting mountains, and during the climb, I had some doubts if I was strong enough to make it to the top. Mountaineering is a grueling undertaking which pushes your limits mentally and physically, but I was able to stay positive." Simultaneously, he took inspiration from the area's spirituality, as he felt

immersed in the Nepali culture.

Bombardier became acquainted with the Nepal hemophilia community for a week prior to the trek. “It was incredibly emotional, since I felt guilty preparing to climb a mountain, while those with hemophilia in Nepal just struggled to live. The community believed in my journey, which meant a lot to me.”

Mt. Everest posed a most intricate journey. The first obstacle was the Khumbu Icefall. “This is the part of the glacier that has many open crevasses and huge seracs along the route. Since it was moving very slow, ice was constantly falling,” he recalled. Most intense is the elevation. “Human bodies cannot really survive over 26,000 feet, and above that, it’s actually called the death zone, so managing oxygen and acclimating to the elevation is the key to success.”

As a hemophiliac, it also presented some unique challenges. He explained, “The main obstacle was trying to keep my Factor from freezing. At night, I would stash my Factor in my sleeping bag, and while climbing, it was either wrapped in wool socks in my backpack or stuffed into my down suit. Infusing on the mountain could have been another challenge, but I devised a really good plan with my HTC for treatment, and was able to infuse on convenient days.”

To date, he has also climbed the 19,341-foot Mt. Kilimanjaro in Africa, the 22,841-foot Aconcagua in Argentina, 18,510-foot Mt. Elbrus in Russia, the 20,310-foot Denali Mountain in North America, and 16,024-foot Carstensz Pyramid in Indonesia. Bombardier holds the will-power to succeed in other feats, so in December, he plans to take on the 16,050-foot Mt. Vinson in Antarctica; the last of the Seven Summits, which is comprised of the tallest mountains on each continent.

Throughout life, he has faced struggles relating to his condition, but that has also shaped his strengths. He said, “Although I would consider most of those dark times, it has made me more resilient, strong, determined, and compassionate. I struggled with acceptance of having my

disorder, and still struggle with infusions since I hate needles. I also struggled with depression, since I felt different than other people, but once I engaged with our hemophilia community, it really helped."

Among Bombardier's role models is Laurie Kelley, the founder of Save One Life, who he considers a major mentor. "She has taken me under her wing, as far as global efforts in hemophilia, and really believed in me for these climbs, when many people wouldn't." His uncle Dave sparked his involvement with the outdoors. "I was searching for something physical in my life after college, and he introduced me to an incredible world. He never questioned whether I could do it or not because of my hemophilia, but just said 'let's go for it.'" In addition, he owes utmost gratitude to his wife. "She has always believed in me and my dreams, even when I didn't. She's been my rock throughout our relationship and has helped me become the man I am today."

Bombardier is a man of determination, passion, and good deeds who embraces the future. "I am hoping to complete my Masters in Global Health, and I would really enjoy working to combat the disparity in care globally, and not only in the hemophilia community but in other disease states."

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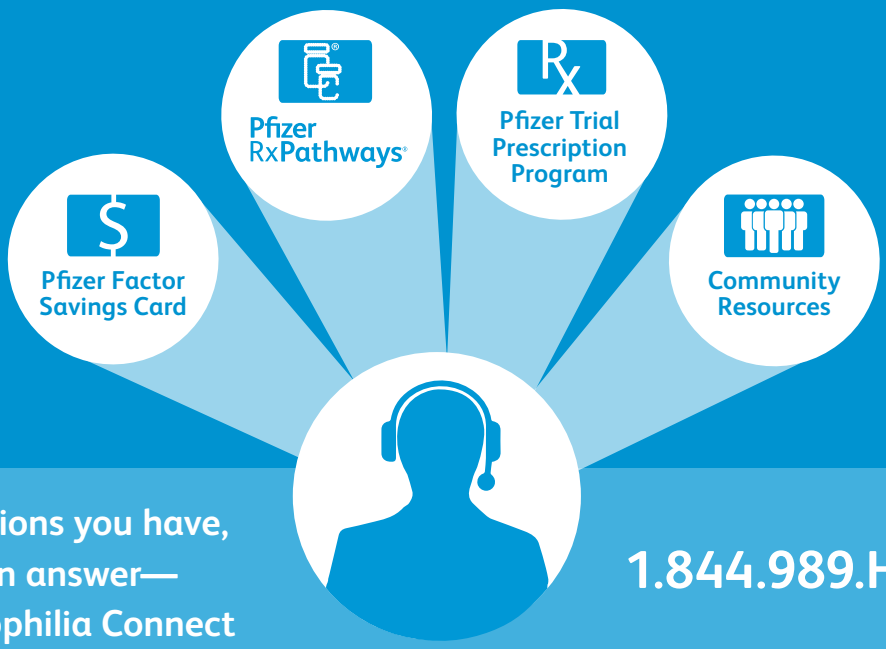

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If you have any questions about the use of the Pfizer Factor Savings Card, please call 1.888.240.9040 or send questions to: Pfizer Factor Savings Program, 2250 Perimeter Park Drive, Suite 200, Morrisville, NC 27560. For more information, please visit www.HemophiliaVillage.com.

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‡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.

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DANNY'S DOSE ON A MISSION TO SAVE LIVES

BY MICHAEL PERLMAN

When Dexter, Missouri resident Darlene Shelton discovered that her grandson Danny (now age 6) was diagnosed with a severe form of hemophilia B in 2011, she not only acted as a loving grandma. She stood up, exhibited her humanitarian spirit, and not long after founded "Danny's Dose," the voice behind a change in emergency medical protocols for chronic illnesses and rare diseases.

"Whatever happens in life, it happens for a reason, and it's up to us to find that reason," said Darlene. "When Danny was diagnosed, it knocks the wind out of you. You're in shock, and you don't know what this new life will bring, but when negative things happen, it is especially a reason to help others." With her family by her side, she resorted to prayer and became active in the hemophilia community.

In 2014, Darlene's daughter-in-law Kristin Shelton attended a meeting with Wayne Cook, president of The Coalition for Hemophilia B, and the topic of safety in the car was raised. Darlene explained, "We knew that if Danny and his father Daniel had an emergency, we needed a plan for Danny to receive treatment. That led to creating an emergency bag with a dose of Factor with the necessary supplies and treatment instructions." The bag, which is affixed to Danny's car seat with a carabiner, is marked with a medical alert symbol for paramedics to quickly distinguish it. Additionally, a medical alert symbol can be spotted on his seat belt, and a bright yellow head rest cover would also capture the attention of paramedics.

Darlene nearly encountered a roadblock after learning that paramedics are unable to administer medications not present on their ambulance, but that would not place a damper on her goal. "People's lives are at risk," she said. She networked with a number of organizations to see how the challenge can be addressed, but received a minimal response. Then The Coalition For Hemophilia B became the first organization to stand behind her family's endeavor. She said, "The coalition is family-oriented, truly caring, and goes above and beyond by personally consulting with families through emails and phone calls, coordinating outreach programs, setting aside funds for families facing financial problems, and even giving Christmas gifts to those in need."

She explained, "The number one goal of Danny's Dose is to change the existing protocols in all 50 states by 2022, and I believe that we will. If you don't set your goals high then you never reach them." They began advocating in their

home state of Missouri, and after two years, legislation passed, benefiting treatments for people with special medical needs and special medications.

"With having new regulations for our paramedics, it will mean the need for additional education, and we are also trying to help coordinate educational opportunities as requested," she said. In 2016, Missouri began offering specialized education for the most common of rare diseases and chronic illnesses. Their EMS Protocol Bill passed on May 12 and they achieved success by having the governor do a public signing on July 11. "We are very proud of Missouri to step up, even before we had a bill," she continued.

Darlene recalled, "As we worked on the legislation, we took our children to the Capitol monthly, and they were part of the whole process. I wanted them and all of our families to realize that when you recognize a problem, as long as you are consistent and strong, you can make a change with lots of prayers."

Danny's Dose Alliance also captured the attention of Minnesota and Kansas' departments of health, and Darlene envisions protocol modifications in 2018. "We will continue to build teams of families in each state, so we can have a more united voice to get the attention of their regulators," she said, before pinpointing a stronger family backbone in states such as Oregon, Texas, and Florida. Danny's Dose is part of the Global Genes Alliance and has built a relationship with NORD and Every Life Foundation among other rare disease groups to strengthen their voice.

In collaboration with The Wingmen Foundation, Danny's Dose Alliance will coordinate the inaugural "Family Education Event" on September 3, where the topic will be "Having emergency plans at home and play – at school and work – in travel." She explained, "This event will be for all Missouri families affected by rare disease or chronic illness causing special medical needs. It will be great to bring them together in a secure and fun environment, while allowing parents to form friendships and providing meaningful information to ensure safety." The alliance is already planning a second educational event in Florida this October, with Texas, California, and Illinois on the horizon.

For Darlene, her four grandchildren are among her many blessings, and monitoring their health is a priority. In addition to Danny's condition, Lilly, age 5, has moderate hemophilia B. Elianna at age 2 appears to be unaffected, and it is too early to tell for 7-month old Zoey.

Darlene draws upon much inspiration from her past, which made her into a humanitarian. She owes much gratitude to her father who was a preacher. She reminisced, "My dad was always caring for families that didn't have enough food and needed clothes and shelter. He passed away when I was 11, which changes your life a lot. Friends stepped up and were almost like parents to me, and I saw how caring and loving someone can really make a difference in their life."

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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**.

Please see brief summary of prescribing information for IDELVION on next page.

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®
Coagulation Factor IX (Recombinant), Albumin Fusion Protein

SPOTLIGHT: A.C.C.E.S.S. HEMOPHILIA HOTLINE

Patient Service Inc. is known to many in the hemophilia community as an organization that provides financial support to assist with health insurance coverage. What many don't know however is about their A.C.C.E.S.S. program, which provides legal advice and representation to those who are eligible for SSD or SSI federal disability benefits. Additionally, through their Hemophilia Hotline, they try to assist with any legal advice for issues that people with hemophilia may have.

The A.C.C.E.S.S. program has been providing legal advice and representation since 1989 to individuals with hemophilia and other chronic disorders. According to William Leach, the staff attorney for the program, about half of those who have been represented by the program are individuals with hemophilia. "We provide legal advice from the pre-hearing level throughout the entire process for those eligible for federal disability assistance," he says.

Having hemophilia alone is not enough to qualify for federal disability benefits. Requirements include three emergency hospital visits within a year, and additional significant impairment, which prevents them from being able to work. "It's gotten more difficult over the years to receive disability benefits," Leach says.

PSI's Hemophilia Hotline tries to help with any issues facing those with hemophilia, even if they are not

MAXIMIZING POSITIVE OUTCOMES FOR ALL

legal questions regarding federal assistance programs. "Often people are afraid to speak to an attorney and ask questions when the meter is running. We do all our services entirely free. We'll try to help people with hemophilia with any questions or concerns they may have," Leach says. He further told us about a call he had received the other day on the Hemophilia Hotline. The caller had questions about a will, and was thinking that he would have to hire an attorney. It turned out that it was a fairly simple will, and William was able to advise him on it – of course, free of charge.

Asked whether the program would advise regarding non-disability benefit related issues, such as insurance appeals on refusal of coverage, Leach said that the program would advise the person regarding the process; however, they do not have the resources to represent these non-federal disability cases. "Our Hemophilia Hotline could be most helpful to those with hemophilia by being a place where anyone with hemophilia could talk to someone with experience and ask questions, particularly legal questions, without needing to pay for the advice," Leach says. He added, "people with hemophilia should not hesitate to contact us, and we will do whatever we can to assist them."

To contact PSI's Hemophilia Hotline, call: 877-851-9065

Website:
http://www.patientservicesinc.org/For-Patients/ACCESS

Brochure:
http://www.patientservicesinc.org/Portals/0/PDF/PSI%20ACCESS%20Brochure%202015.pdf

Dedicated Patient Champion

PSI®
Patient Services, Inc.

GENE THERAPY UPDATE

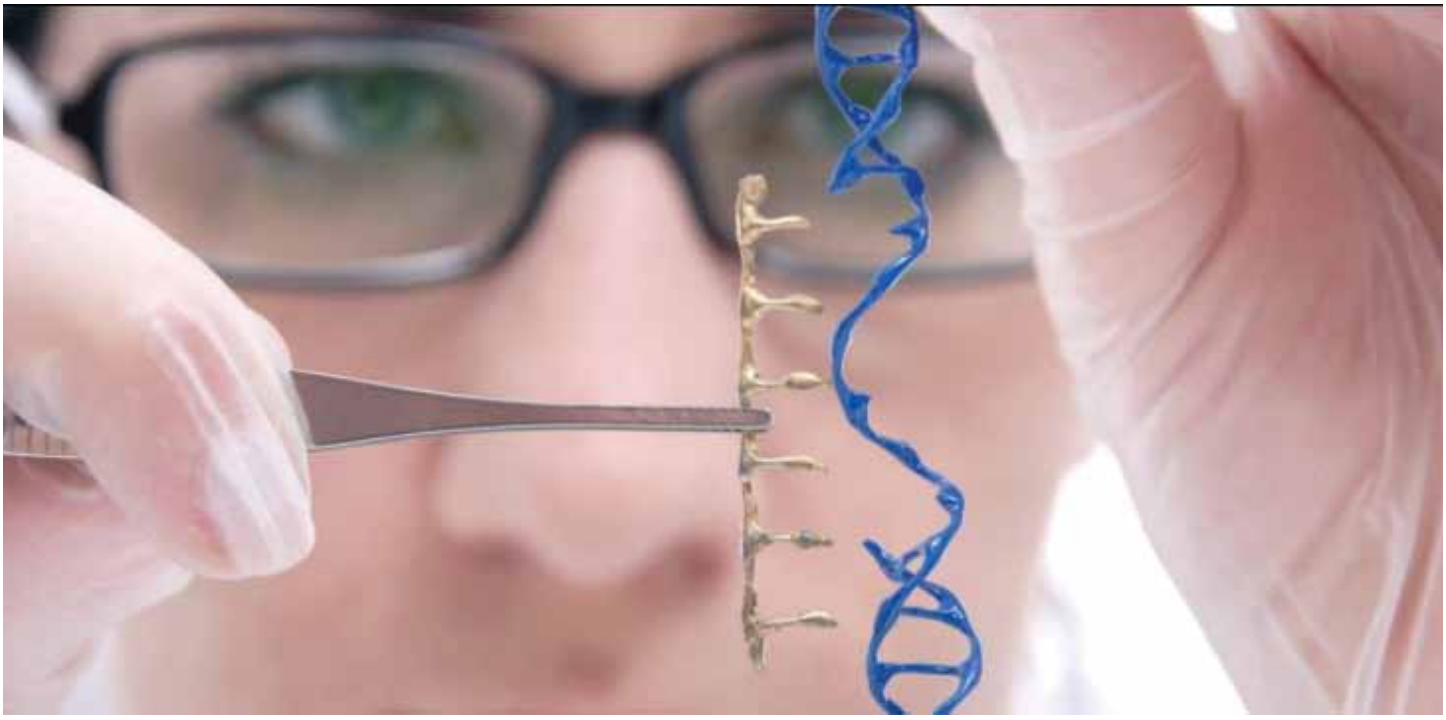
BY DR. DAVID CLARK

The general term “hemophilia B gene therapy” encompasses a number of different methods to modify the genetic material in the body of a person with hemophilia so that the body can produce normal factor IX to facilitate clotting. Hemophilia B is caused when the body’s factor IX gene is damaged or mutated. The mutated gene can either be inherited from the previous generation or it can occur spontaneously. A gene is a template or recipe that tells a cell how to make a certain protein. With a mutated gene, the recipe is wrong, so the protein is made incorrectly or not made at all. The aim of gene therapy is to give the body normal copies of the gene so it can make the protein correctly. Hemophilia B was one of the first diseases targeted with gene therapy, but after some success in the factor IX arena, hemophilia A and many other genetic diseases are now also being addressed.

There are several ways to deliver a new factor IX gene to the body, but the most commonly used are viral vectors. Virus particles are genetically-modified to contain a factor IX gene instead of the infectious viral genes. The virus essentially “infects” the body with the means to produce factor IX instead of with a disease. A number of organizations are using adeno-associated viruses (AAV) to deliver the new factor IX gene to liver cells. AAV is a small virus that infects humans but does not appear to cause disease. AAV infects liver cells, which are one of the desired targets for factor IX since it is normally made in the liver.

One issue with AAV is that many people already have antibodies to it from previous, often symptomless, infections. Therefore, their immune system is primed to attack AAV. Researchers have tried to use less prevalent sub-types of AAV, such as AAV-5 and AAV-8, to which fewer people have been exposed. However, this remains an issue that could preclude some patients from being able to use these treatments because their bodies would react against the virus. Several companies have experimented with using immune-suppressing drugs to minimize any immune reaction, with fairly good success. Still, most companies restrict participation in their clinical studies to patients without anti-AAV antibodies. Whether that will still be the case once the products are on the market is unknown.

That’s only one of many unanswered questions about gene therapy. This is still a work in progress. The various clinical studies that are underway or being planned will help to answer some of the questions. In addition, the National Hemophilia Foundation (NHF),



McMaster University in Canada, and the Green Park Collaborative, an organization that works to improve clinical research, are launching the CoreHEM project to develop a set of consensus standards to evaluate gene therapies for effectiveness.

The following is a description of what the various companies working in this area are doing. A number of studies on gene therapy were presented at the XXVI Congress of the International Society on Thrombosis and Haemostasis (ISTH), July 8-13, 2017 in Berlin, Germany.

Bioverativ and SR-TIGET

Bioverativ and San Raffaele Telethon Institute for Gene Therapy (SR-TIGET) are collaborating on an early-stage program to develop a gene therapy treatment using lentiviruses, instead of AAV, to deliver a factor IX gene.

Dimension Therapeutics

Dimension Therapeutics has discontinued its gene therapy program, DTX101, for hemophilia B after finding questionable safety issues. Five of the six patients treated so far developed elevations in their liver enzymes. The elevations were all resolved by treatment with corticosteroids. Dimension will continue to follow the patients for five years and will present further results at a future scientific conference.

Expression Therapeutics

Expression Therapeutics is developing an AAV-mediated gene therapy treatment for hemophilia B. They have released little information about their program.

Freeline Therapeutics

Freeline Therapeutics is continuing the work published by Nathwani and collaborators in 2011 and 2014 in which ten patients were treated with good results. They use an AAV-8 vector with a wild-type factor IX gene.

LogicBio Therapeutics

LogicBio Therapeutics is developing a gene therapy treatment using AAV vectors. Unlike most other companies, they plan to insert the new factor IX gene into the genome under control of an existing promoter, hoping that will give it longer life.

Sangamo Therapeutics

Sangamo Therapeutics is currently in Phase I/II clinical studies with their SB FIX gene therapy treatment. Sangamo uses AAV vectors and Zinc Finger Nucleases (ZFNs) to insert a new factor IX gene under the control of the albumin promoter in the patient's genome.

Shire

Shire discontinued their (Baxter/Baxalta's) original gene therapy program because of inconsistent results. However, Shire is developing SHP648, a next-generation factor IX gene therapy based on AAV 8. They presented positive results in mice at the recent ISTH meeting.

Spark Therapeutics/Pfizer

Spark Therapeutics and Pfizer are currently in a Phase I/II clinical study with their SPK-9001 gene therapy treatment for hemophilia B. The mean steady state post-12 week factor IX level for the ten patients in the study is 33%. The annual bleed rate decreased from 11.1 pre-treatment to 0.4 annual bleeds post-treatment. There have been no serious adverse events, including no inhibitor development and no thrombotic episodes.

St. Jude Children's Research Hospital

St. Jude Children's Research Hospital is also continuing the work published by Nathwani and collaborators in 2011 and 2014 in which ten patients were treated with good results. They are currently in a Phase I clinical study.

uniQure

uniQure is performing a Phase I/II clinical study of AMT-060, their AAV-5 gene therapy treatment for hemophilia B. They've shown an average factor IX level of 6.9% in their higher-dose cohort and no spontaneous bleeds after 26 weeks of follow-up. There have been no serious adverse events. They have also shown that patients with pre-existing antibodies against AAV 5 can still benefit from treatment with AMT-060. uniQure has discontinued their collaboration with Chiesi Farmaceutici and now has full global rights to AMT-060.

Factor VIIa Gene Therapy

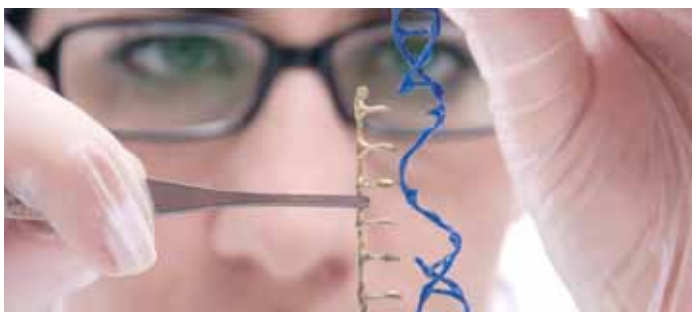
Two organizations are trying a different approach. Instead of inserting a new factor IX gene, they are exploring use of a gene for activated factor VII (FVIIa). FVIIa is often used as a bypassing agent to treat hemophilia A and B patients with inhibitors because it can induce clotting without the presence of factors VIII or IX. They believe FVIIa could restore clottability for both hemophilia A and B patients, with or without inhibitors.

Amarna Therapeutics

Amarna Therapeutics is developing a gene therapy approach for factor VIIa. Little information is currently available on their program.

Novo Nordisk

Novo Nordisk presented data at ISTH on gene therapy for FVIIa in rats. The results showed that hemophilic rats can be successfully treated by FVIIa gene therapy.



Industry News

BY DR. DAVID CLARK

A number of studies were presented at the XXVI Congress of the International Society on Thrombosis and Haemostasis (ISTH), July 8 – 13, 2017 in Berlin, Germany. Gene therapy news is included in the accompanying *Gene Therapy Update* article.

Alnylam Presents Data on Once-Monthly Fitusiran

Alnylam Pharmaceuticals and Sanofi Genzyme presented data from their clinical studies of fitusiran, a subcutaneous RNA-interference drug that reduces the amount of antithrombin produced by the body. By reducing the amount of antithrombin, an inhibitor of clotting, Alnylam expects to restore the clotability of the blood in patients with hemophilia, including those with inhibitors. The study found an approximately 89% reduction in antithrombin at the highest dose tested, which was sustained between monthly doses. In a related Phase II study, that amount of antithrombin lowering was associated with an annualized bleed rate (ABR) of 1.0 in patients without inhibitors and an ABR of 0.0 in inhibitor patients. The only adverse events were mild, temporary injection site reactions.

However, in early September, Alnylam reported a fatal thrombotic event in a hemophilia A patient without inhibitors in their ongoing Phase II study. While on fitusiran, the patient developed a pain in his right hip after exercising. The possible bleed was treated with factor VIII over a period of several days, but after the third dose, the patient developed a severe headache. He was admitted to the hospital where he was diagnosed with a subarachnoid hemorrhage (bleeding between the brain and its covering). Over a 14 day hospital stay, he continued to be treated with factor VIII, but his condition worsened and he died from subsequent cerebral edema. Post-mortem, he was determined to have had a cerebral venous sinus thrombosis (a blood clot in the brain), not a hemorrhage. It is not yet clear whether the fitusiran treatment contributed to the patient's death. Alnylam has announced a suspension of all ongoing fitusiran studies while they figure out what happened.

Bioverativ Presents Data on Subcutaneous FIX-Fc-XTEN

Bioverativ is developing a longer-acting once-weekly subcutaneous recombinant factor IX concentrate. They are using the high-activity Padua variant of factor IX. It is fused to an Fc antibody fragment to give it a longer half life in circulation, the same method used for Alprolix. The added XTEN portion is a poly-amino acid peptide that further extends the half life. In pre-clinical studies in cynomolgus monkeys, subcutaneous dosing produced a half life of 69 hours with no adverse effects.

Bioverativ Presents Data from B-LONG/B-YOND Studies of Alprolix

Bioverativ is continuing to follow patients from its B-LONG Phase III study of Alprolix. They presented results showing that 100% of patients who entered the B-LONG study with target joints had the joints resolved. Annualized bleeding rates (ABRs) were reduced compared to the baseline upon entering the study.

Bioverativ Forms Imaging Collaboration for Joint Health Management

Bioverativ and Invicro, LLC, an imaging provider for pharmaceutical R&D, have developed a collaboration focused on expanding the use of imaging technologies to improve the diagnosis

and management of joint disease in people with hemophilia. Using state-of-the-art ultrasound and radio-labeled imaging, they plan to investigate the impact of different factor replacement treatments on joint health.

Bioverativ and Bicycle Therapeutics Partner to Develop Hemophilia Therapies

Bicycle Therapeutics focuses on bicyclic peptides, which are small proteins that have some interesting properties. Bioverativ plans to use the bicyclic peptides to develop treatments for hemophilia and sickle cell disease, but no further details are available.

Bioverativ Alleges Patent Infringement by CSL's Idelvion

Bioverativ has filed a complaint with the U.S. International Trade Commission (ITC) alleging that CSL Behring's longer-acting factor IX concentrate Idelvion infringes three of Bioverativ's U.S. patents. Bioverativ is seeking to have Idelvion removed from the U.S. market. All of the national organizations are working together to ensure this does not become an access issue for our community.

Catalyst Biosciences Announces Results from Dosing of First Factor IX Patients

Catalyst Biosciences and ISU Abxis completed dosing of its first patient cohort in their Phase I/II clinical study of their variant factor IX product CB 2679d/ISU304. The product is a genetically-modified version of factor IX that has a higher potency and a longer half-life. It is designed for daily subcutaneous dosing. Results from the first three patients showed that CB 2679d is approximately 22 times more potent that BeneFIX and has a half-life in circulation of about 34 hours, compared to 25 hours for BeneFIX.

CSL Presents Data that Idelvion Can Positively Benefit Patients

CSL Behring presented several posters with continuing follow-up of patients from their clinical studies of their longer-acting Idelvion factor IX concentrate. In a study of prophylactic dosing they found mean trough levels of 22.4% and 12.7% with 7- and 14-day dosing, respectively. Another study found adherence levels over 90% for 7- to 14-day dosing. Prophylaxis with Idelvion was found to result in a substantial decrease in factor IX consumption. Finally, they found an improvement in Health-Related Quality of Life for pediatric patients treated with Idelvion.

CSL Presents Data on a Longer-Acting Factor VIIa for Inhibitor Treatment

CSL Behring is also developing a longer-acting activated factor VII (rVIIa-FP) for treatment of hemophilia patients with inhibitors. rVIIa-FP is a fusion protein incorporating albumin to give it a longer half-life. Activated factor VII (FVIIa) can bypass the factor VIII/factor IX step in the clotting cascade to promote clotting for patients that have antibodies (inhibitors) to factor VIII or factor IX. However, normal factor VIIa has a very short half-life, so patients have to be infused often, sometimes several times a day. CSL has shown in a Phase II/III clinical study that rVIIa-FP has twice the half-life of rVIIa and that daily injections produce a trough factor VIIa level of 11.0 IU/mL. No patients developed inhibitors and there were no serious adverse events.

Novo Nordisk Presents Data on Rebinyn

Novo Nordisk presented several studies on their newly-licensed Rebinyn factor IX concentrate (formerly called N9-GP) at ISTH. A safety study showed that Rebinyn is generally safe and well-tolerated with only one adverse reaction likely related to its use for the 115 patients treated. Rebinyn is fused to polyethylene glycol (PEG) molecules to give it a longer half life, and two studies looked at the fate of PEG in the bodies of recipients. The studies show that PEG is eliminated from tissues over time, decreasing to a steady-state level over six months to two years in humans.

Novo Nordisk Presents Data on Longer-Acting Factor VIIa for Inhibitor Treatment

Novo Nordisk is developing a variant, activated factor VII (FVIIa) with a longer half-life for inhibitor treatment. They have identified a genetic variant (a FVIIa molecule with a few mutations that give it improved properties) that has a 15-fold longer half-life in rats and an activity similar to normal FVIIa.

Pfizer Presents Data on TFPI Inhibitor for Hemophilia Treatment

Pfizer is developing an inhibitor to tissue factor pathway inhibitor (TFPI). TFPI is an anti-coagulant in the blood that inhibits clotting. By inhibiting the inhibitor, Pfizer hopes to restore the clottability of the blood. Pfizer's PF 06741086 is a potentially-subcutaneous monoclonal antibody that binds to TFPI and inactivates it. They presented data from a Phase I clinical study showing that PF-06741086 is safe and well-tolerated. This supports progression to a Phase II study to determine the optimum doses.

Pfizer Presents Data on Extended Half-Life Products

Pfizer presented three studies at ISTH exploring the cost and utilization of standard half-life (SHL) factor concentrates versus extended half-life (EHL) concentrates. They found that, based on data from the U.S. and Japan, switching from SHL to EHL products was associated with use of higher amounts of factor and increased costs. Note that this is in contrast with CSL's report above that use of their EHL product was associated with lower factor use. Pfizer is planning a larger study.

Pfizer to Build Gene Therapy Facility

Pfizer announced a $100 million project to expand a gene therapy production plant in Sanford, North Carolina that they acquired when they bought Bamboo Therapeutics last year. Pfizer is working with Spark Therapeutics on a gene therapy treatment for hemophilia B and with Sangamo Therapeutics for hemophilia A.

HOUSTON, TEXAS
October 7, 2017

JW Marriott Houston
5150 Westheimer Road,
Houston, TX 77056
(713) 961-1500
$109 room-rate
Sponsored by CSL Behring

INDIANAPOLIS, INDIANA
November 11, 2017

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

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
Sponsored by Pfizer Hemophilia

PHOENIX, ARIZONA
November 11, 2017

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

LOUISVILLE, KENTUCKY
November 4, 2017

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

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. To register, please contact:
Nathy at nathyd@hemob.or or call 929-231-4324

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

2017
Red Tie Challenge

Bleeding Disorders
Awareness Month

Visit hemob.org
contact@hemob.org

THE COALITION FOR
HEMOPHILIA

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

SAVE THE DATE!

GETTIN' IN THE GAME℠

JUNIOR NATIONAL

CHAMPIONSHIP

November 3 - November 5, 2017

Phoenix, Arizona

GETTIN' IN THE GAME℠ JUNIOR NATIONAL CHAMPIONSHIP
Presented by CSL Behring

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. Mail this form to:

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

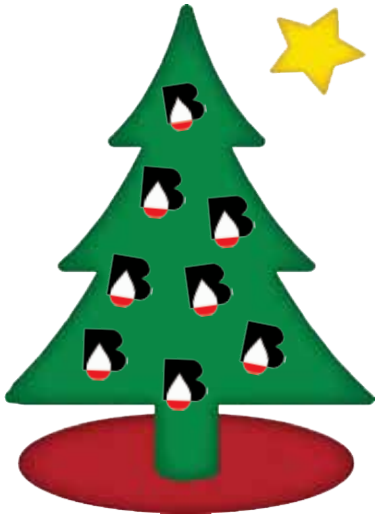
Name: _____

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.



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

Child's Name and Age:	Child's Name and Age:	Child's Name and Age:
_____	_____	_____
Wish List:	**Wish List:**	**Wish List:**
_____	_____	_____
_____	_____	_____
_____	_____	_____

Kidz Korner!

Word List

amusement
break
diploma
family
friends
fun
graduation
happy
holiday
relaxation
summer
sunshine
vacation

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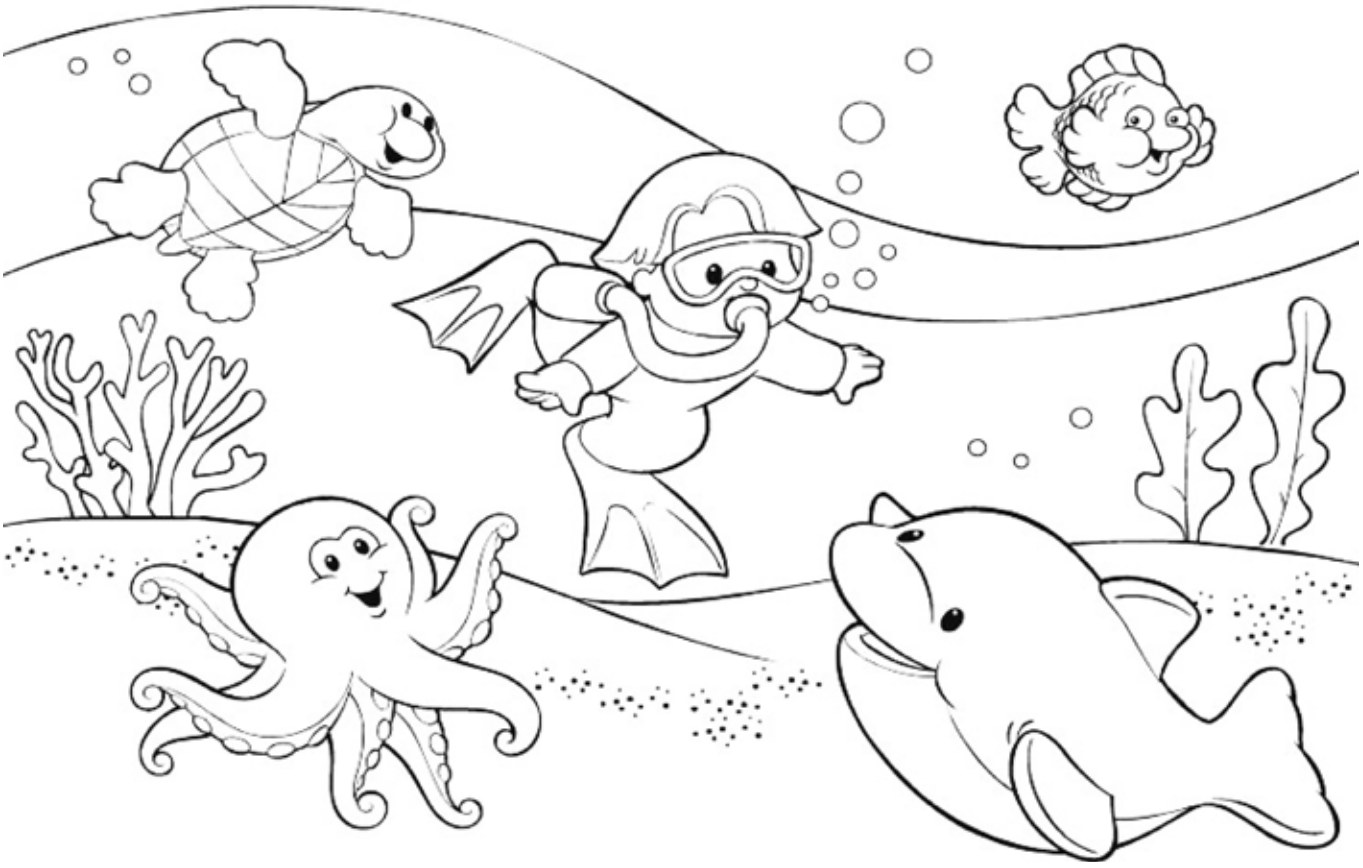

The Coalition For Hemophilia B

825 Third Avenue, 2nd Floor; New York, New York 10022
Phone: 212-520-8272 Fax: 212-520-8501 contact@hemob.org

Visit our social media sites:

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

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