



# Factor Nine News

## The Coalition for Hemophilia B

Winter 2017



### Topics in Hemophilia

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*Meetings on the Road!*

**O**ur *Third Annual Meeting on the Road* kicked off in Austin, TX on November 5<sup>th</sup>, 2017 at the Austin Marriott North. where the kids enjoyed a trip to the Cave Creek in downtown Austin while Joanne Garza with Pfizer presented her talk on Exploring Emotional Well Being in the Hemophilia Community and was followed by Angela McCoy speaking on the importance of Sharing your Story and advocacy in the bleeding conditions community. All topics were very well received by our members.

After lunch, TaiChi instructor Rick Starks led the attendees in a smooth and calming tai chi lesson. Dr. David Clark then followed with a session on product updates and current hot topics in the community. We love seeing our texas families and look forward to coming again!

## On the Road... AUSTIN, TX!



**W**rapping up our fourth and final *Meeting on the Road*, we traveled to wonderful Chicago, IL on November 11<sup>th</sup>, 2017 to visit our community members in the East! We enjoyed speakers Chris Poynter and Gladis Murillo presented on Advocacy in the Hemophilia community and the importance of exploring your Emotional Well being respectively. While the adults attended the meeting the kids went out to Round1 Bowling and Amusement for lunch, arcade games and glow in the dark bowling!

Upon our return we assembled for our TaiChi lesson by famous Rick Starks. With over 60 people we had to move the Tai Chi lesson into the main Ballroom hallway! Last but not least we played our famous game of "Are you smarter than your Hemophilia?" game and trophies were given out to all participants! It was great being able to travel to Chicago to see our Coalition for Hemophilia B members. We look forward to seeing everyone again in a town near you! A special thanks to Pfizer for sponsoring our four meetings on the road!

## On the Road... CHICAGO, IL!





# BeneFix + YOU = GIVE FORWARD

19  
YEARS  
YOUR  
EXPERIENCE  
MATTERS

**BeneFix**  
Coagulation Factor IX (Recombinant)  
Room Temperature Storage



## The BeneFix Give Forward™ Program allows patients and caregivers to

- Learn about hemophilia and things that can impact your health
- Have fun and earn points
- Make charitable donations



Visit [BeneFixGiveForward.com](http://BeneFixGiveForward.com)  
and get started right now!

## What Is BeneFix?

BeneFix, Coagulation Factor IX (Recombinant), is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease.

BeneFix is **NOT** used to treat hemophilia A.

## Important Safety Information

- BeneFix is contraindicated in patients who have manifested life-threatening, immediate hypersensitivity reactions, including anaphylaxis, to the product or its components, including hamster protein.
- Call your health care provider right away if your bleeding is not controlled after using BeneFix.
- Allergic reactions may occur with BeneFix. Call your health care provider or get emergency treatment right away if you have any of the following symptoms: wheezing, difficulty breathing, chest tightness, your lips and gums turning blue, fast heartbeat, facial swelling, faintness, rash or hives.

- Your body can make antibodies, called "inhibitors," which may stop BeneFix from working properly.
- If you have risk factors for developing blood clots, such as a venous catheter through which BeneFix is given by continuous infusion, BeneFix may increase the risk of abnormal blood clots. The safety and efficacy of BeneFix administration by continuous infusion have not been established.
- Some common side effects of BeneFix are nausea, injection site reaction, injection site pain, headache, dizziness and rash.

Please see the Brief Summary for BeneFix on the next page.

You are encouraged to report negative side effects of prescription drugs to the FDA.

Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.

\*BeneFix was approved February 11, 1997.

R<sub>x</sub> only

### Brief Summary

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.Pfizer.com](http://www.Pfizer.com) or call our medical communications department toll-free at 1-800-934-5556.

Please read this Patient Information carefully before using BeneFix and each time you get a refill. There may be new information. This brief summary does not take the place of talking with your doctor about your medical problems or your treatment.

### What is BeneFix?

BeneFix is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease.

BeneFix is **NOT** used to treat hemophilia A.

### What should I tell my doctor before using BeneFix?

Tell your doctor and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies.

Tell your doctor about all of your medical conditions, including if you:

- are pregnant or planning to become pregnant. It is not known if BeneFix may harm your unborn baby.
- are breastfeeding. It is not known if BeneFix passes into the milk and if it can harm your baby.

### How should I infuse BeneFix?

The initial administrations of BeneFix should be administered under proper medical supervision, where proper medical care for severe allergic reactions could be provided.

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

You should always follow the specific instructions given by your doctor. If you are unsure of the procedures, please call your doctor or pharmacist before using.

### Call your doctor right away if bleeding is not controlled after using BeneFix.

Your doctor will prescribe the dose that you should take.

Your doctor may need to test your blood from time to time.

BeneFix should not be administered by continuous infusion.

### What if I take too much BeneFix?

Call your doctor if you take too much BeneFix.

### What are the possible side effects of BeneFix?

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

wheezing	fast heartbeat
difficulty breathing	swelling of the face
chest tightness	faintness
turning blue (look at lips and gums)	rash
	hives

Your body can also make antibodies, called "inhibitors," against BeneFix, which may stop BeneFix from working properly.

Some common side effects of BeneFix are nausea, injection site reaction, injection site pain, headache, dizziness and rash.

BeneFix may increase the risk of thromboembolism (abnormal blood clots) in your body if you have risk factors for developing blood clots, including an indwelling venous catheter through which BeneFix is given by continuous infusion. There have been reports of severe blood clotting events, including life-threatening blood clots in critically ill neonates, while receiving continuous-infusion BeneFix through a central venous catheter. The safety and efficacy of BeneFix administration by continuous infusion have not been established.

These are not all the possible side effects of BeneFix.

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

### How should I store BeneFix?

DO NOT FREEZE BeneFix. BeneFix kit can be stored at room temperature (below 86°F) or under refrigeration. Throw away any unused BeneFix and diluent after the expiration date indicated on the label.

Freezing should be avoided to prevent damage to the pre-filled diluent syringe.

BeneFix does not contain a preservative. After reconstituting BeneFix, you can store it at room temperature for up to 3 hours. If you have not used it in 3 hours, throw it away.

Do not use BeneFix if the reconstituted solution is not clear and colorless.

### What else should I know about BeneFix?

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

If you would like more information, talk to your doctor. You can ask your doctor for information about BeneFix that was written for healthcare professionals.

This brief summary is based on BeneFix® [Coagulation Factor IX (Recombinant)] Prescribing Information LAB-0464-9.0, revised August 2015.

# Welcome Baby Anthony

By Wayne Cook  
(Aka Grandpa)



Anthony Francis Cook was born August 29th, 2016. He was born to our daughter Kasie Cook. Anthony was born two months early and weighed only 2lbs 15oz. He had an uphill battle, being on a life support system and feeding tube. But each day he fought and was getting stronger. He was also diagnosed with severe factor nine hemophilia, but so far he hasn't had any problems. Anthony was born at the University of North Carolina (UNC) hospital where they have a fantastic Hemophilia Treatment Center, and a NICU center that is just fantastic these nurses are the greatest and the care and treatment Anthony received was just remarkable.



Anthony is now 6 months old and weighs 13 lbs 11 ozs and is flourishing each and every day. Kasie is a remarkable woman and a remarkable mother. Since Anthony's birth our son Wayne III and his wife Morgan stepped in and have done a wonderful job by having Kasie and Anthony move in with them. We are so grateful for what they have done as it speaks volumes about how much love and compassion our children have for one another, we are so proud of that. I am so excited about this year's Coalition symposium to introduce Anthony one our newest members to the hemophilia family. We all look forward to seeing you all - our extended family.

## The Generations

By Gwyn Weixler

My husband has Hemophilia B, so does my daughter, and both of my granddaughters. The luck of genetics! We knew about my husband, and we knew our daughter would be a carrier. She would have a 50/50 chance of having a son with hemophilia and a 50/50 chance of having a carrier daughter. But we first learned about female bleeders when our daughter reached puberty. She went from just being a carrier to being a mild-moderate bleeder herself. She had her first issue when she got hit in the eye with a softball. And her eye bled onto the tissue until you couldn't see her eyelashes. She had knee bleeds, hand bleeds and developed terrible periods. She had quite a bit of bleeding issues when her first daughter was born. Now she finds she bleeds every couple of months, unless she injures herself—then she bleeds more often!

Both of her daughters are carriers. My older granddaughter required factor when she hit her head, and when she had tonsil surgery. As a result, she's just crossed the milestone of her first stick! My younger granddaughter has a higher factor level so has not



required factor. But they both are learning about being females with a bleeding disorder! The benefit of growing up in a hemo-family is that they've seen infusions all their lives. I often say that life with hemophilia is lived on shifting sand—you just never know what a day will bring. What starts out as a trip to church is aborted due to a back bleed. A fun day at Disney becomes

a dash back to the hotel room for a dose of factor. Every surgery must be considered in the light of the bleeding disorder. And yet, after 35 years of living in the middle of this, I find joy and satisfaction that my family is precious, maybe even more because of the possibilities that lurk!

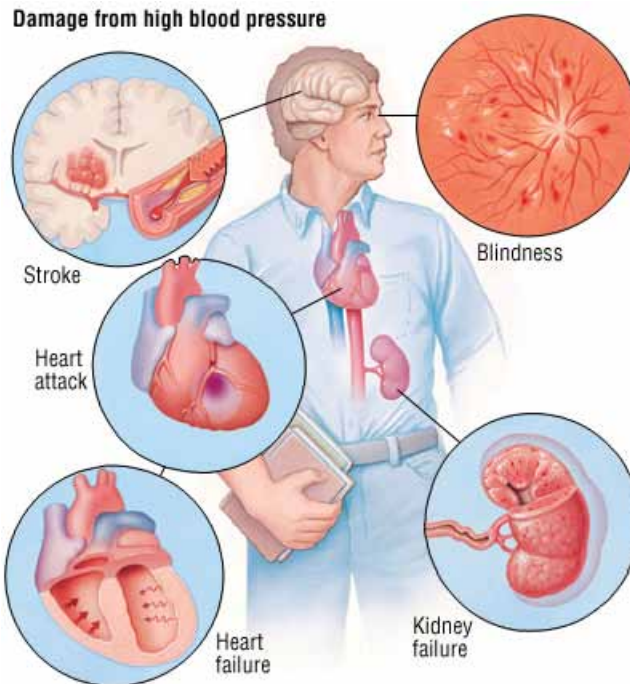
Each day is a celebration of what we've been given—the chance to grab time with each other and hopefully reach out to others at the same time. After all, as elusive as sand castles are, they are a beautiful thing!! Shifting sand can be tricky, but definitely worth the adventure!! As I watch my daughter and granddaughters carry on the legacy, we have a special connection that I think many families never experience. In our family, three generations of bleeders do life, and do it to the fullest!!

# Hypertension in People with Hemophilia

**H**ypertension or high blood pressure is one of the age-related conditions in hemophilia that has not been explored very thoroughly. Historically, before the advent of factor products, people with hemophilia often did not survive childhood. Treatment with clotting factors significantly increased life expectancy, but then the AIDS crisis came along and devastated much of the hemophilia population, so they never reached old age. It is only more recently, now that life expectancy is approximately that of the general population, that it has become possible to study aging in people with hemophilia. High blood pressure is a concern because it is associated with heart disease, stroke, eye disease and kidney disease. It is also one of the major risk factors in intracranial hemorrhage (ICH), which is 20 to 50 times more common in people with hemophilia than in the general population and can be fatal.

Hemophilia patients tend to have higher blood pressures for unknown reasons. A recent study from three U.S. hemophilia treatment centers (Barnes et al, *Int J Hypertension*, Epub 2014201, Nov 14, 2016) has shown that the usual cardiovascular risk factors do not explain the greater incidence of high blood pressure in people with hemophilia compared to the general population. The researchers compared 469 male hemophilia patients, both As and Bs, to age-matched male controls from the National Health and Nutrition Examination Survey, a series of surveys to evaluate the health status of the U.S. population.

Risk factors for high blood pressure in the general population include age, obesity, cholesterol, kidney function, diabetes, smoking, hepatitis C virus infection (HCV) and race. The hemophilia patients in the study showed both higher systolic (top number) and diastolic pressures (bottom number) than the general population regardless of the risk factor examined, except HCV. HCV did appear to be a risk factor for the older age group ( $\geq 30$



**By Dr. David Clark**

years), but it only explains part of the variation. Even comparing patients being treated with blood pressure medication, treated people with hemophilia had higher pressures. The hemophilia patients in the study actually had fewer risk factors than the controls: their weights and cholesterol were lower, they had better kidney function and they had lower rates of smoking and diabetes, yet their blood pressures were worse.

Note that this does not mean that people with hemophilia can ignore the risk factors. They will still

affect their blood pressure. It's just that there is apparently more going on for hemophilia patients than just those risk factors. Something else is also causing their blood pressures to increase.

One interesting clue from the study is that there is not as much of a drop from systolic to diastolic pressure in people with hemophilia as there is in the controls. This suggests a greater stiffness of the blood vessel walls, which may indicate vascular changes occurring in hemophilia. Other studies have also identified vascular abnormalities in people with hemophilia, but overall little is known. Another unexpected finding was that the youngest age group ( $< 30$  years) of hemophilia patients had markedly higher blood pressures than their age-matched controls. This is a worrisome result that warrants further investigation.

This study has uncovered some significant information about high blood pressure and hemophilia, but much more remains to be learned. Meanwhile, all hemophilia patients, even younger ones, should pay attention to their blood pressure. High blood pressure is known as a silent killer because there are usually no apparent symptoms until it is too late. The only way to tell if you have high blood pressure is to measure it. Normal blood pressure is 120/80 when sitting quietly. If either or both numbers are much higher, you should consult your physician about possible treatment.



## CSL Sponsored Gathering With David Quinn at BIU

By Wayne Cook

**W**e've all been told not to let our kids with hemophilia play hockey. One kid had no choice—he grew up in Rhode Island surrounded by sports lovers, and gravitated toward hockey. He excelled at it. So much so that he tried out for the US Olympics team in 1988.

Meet David Quinn, now head coach of one of the country's best college hockey teams, the Boston University Terriers. How can all this be? A guy with hemophilia, playing hockey?

David shared his remarkable story Saturday evening at Boston University, at a "Common Factors" event hosted by CSL Behring. In the audience were families with hemophilia B, some of whom came from as far away as New York to see David, and to attend a hockey match after the presentation.

Key to note is that David went undiagnosed most of his life, until he tried out for the Olympics. He knew he got bruised bigger and harder than his teammates; his ankles and elbows would ache. But he somehow avoided any broken bones and major contusions. That in itself is miraculous, given the brutal nature of the sport.

During the tryouts for the 1988 Olympics, he developed compartment syndrome, which happens when blood seeps into the fascia surrounding muscle tissue and is essentially trapped. This can result in nerve damage and even amputation. But David had excellent care, and had to wait six weeks to recover from surgery. When he healed, he was back on the ice. His doctor made him get a blood test, where they discovered he had mild hemophilia B.

Even knowing all this, he eventually was drafted professionally, in 1992 by the New York Rangers, and in 1992-3 with the Cleveland Lumberjacks. He never made it to the nationals, as he admits he had missed too much practice and training. Instead, he turned to coaching and never looked back.

David easily engaged with the audience, was witty and warm, and his







message was: find your passion, take your factor, live your life. He has a major position now as head coach, and so with a smile and wave, he had to dash out to coach that night's game. The families stayed a bit longer to hear Gina Perez, mother of two boys with hemophilia B, and final words from Janet Reimund of CSL Behring.

It was a great evening of learning and motivation, and socialization. I got to see so many friends that I rarely get to see anymore as our hemophilia meetings become more numerous and frequent. In particular Jessica Graham and Wayne Cook—hey guys! And I had actually met David 20 years ago, when I wrote an article about him for one of my children's magazines. I can actually say I knew him way back when.

Thanks to CSL Behring for hosting this, and having it in my backyard practically. My apologies to David, but I'm not into hockey (I kind of like boxing, actually) so I skipped the game but kept the memories. Wonderful evening!



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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](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.**

**Baxalta**

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**RIXUBIS**

[COAGULATION FACTOR IX  
(RECOMBINANT)]

**MOVING FORWARD**

# **RIXUBIS**

## **[COAGULATION FACTOR IX (RECOMBINANT)]**

FDA-approved Patient Labeling

### **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 are the RIXUBIS dosage strengths?**

RIXUBIS comes in five different dosage strengths: 250, 500, 1000, 2000 and 3000 international units. The actual strength will be imprinted on the label and on the box. The five different strengths are color coded, as follows:

<b>Light Blue</b>	Dosage strength of approximately 250 international units per vial
<b>Pink</b>	Dosage strength of approximately 500 international units per vial
<b>Green</b>	Dosage strength of approximately 1000 international units per vial
<b>Orange</b>	Dosage strength of approximately 2000 international units per vial
<b>Silver</b>	Dosage strength of approximately 3000 international units per vial

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

#### **How should I store RIXUBIS?**

- Store at refrigerated temperature 2° to 8°C (36° to 46°F) for up to 24 months. Do not freeze.
- May store at room temperature not to exceed 30°C (86°F) for up to 12 months within the 24 month time period. Write on the carton the date RIXUBIS is removed from refrigeration. After storage at room temperature, do not return the product to the refrigerator.
- Do not use after the expiration date printed on the carton or vial.
- Reconstituted product (after mixing dry product with wet diluent) must be used within 3 hours and cannot be stored or refrigerated. Discard any RIXUBIS left in the vial at the end of your infusion.

#### **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.

#### **Resources at Baxalta available to patients**

For information on patient assistance programs that are available to you, including the Baxalta CARE Program, please contact the Baxalta Insurance Assistance Helpline at 1-888-229-8379.

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#### **Baxalta US Inc.**

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# **Baxalta**

# Industry News

By Dr. David Clark

## **Alnylam Pharmaceuticals, Inc**

*Alnylam Reports Positive Phase I and Phase II Results for Fitusiran*

Alnylam Pharmaceuticals, Inc. is developing fitusiran, an RNA interference drug. Fitusiran reduces the liver's production of antithrombin (AT), an anticoagulant that helps to regulate the clotting system. In patients with hemophilia, the lack of Factor VIII or IX tends to shift the coagulation system away from being able to form clots. Alnylam's idea is that reducing the amount of AT will shift the balance back toward neutral, so the blood will clot when necessary. Fitusiran is a once-monthly subcutaneous drug that is also expected to work in hemophilia patients with inhibitors.

At the recent American Society of Hematology (ASH) meeting, Dec. 3-6, 2016, in San Diego, they presented some interim results from their Phase I study of inhibitor patients with either hemophilia A or B and their Phase II study of A and B patients without inhibitors. In both studies, fitusiran consistently reduced the production of AT resulting in a median annualized bleeding rate (ABR) of 1.0 in the 16 non-inhibitor patients and zero in the 16 inhibitor patients. These results compare to pre-study median ABRs of 4.0 for the non-inhibitor patients and 31 for the inhibitor patients. In both studies the drug was well-tolerated with no thromboembolic events, that is, no episodes of dangerous, unwanted clotting. Alnylam plans to start Phase III studies with both inhibitor and non-inhibitor subjects in early 2017.

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## **Bioverativ, Inc.**

*Bioverativ Launches as a Spin-off from Biogen*

On February 1, 2017, Bioverativ, Inc. launched as a spin-off from Biogen. Bioverativ is an independent, global biotechnology company focused on therapies for hemophilia and other rare blood diseases. Bioverativ will produce and market the extended half-life products Alprolix for treatment of hemophilia B and Eloctate for hemophilia A. Bioverativ's pipeline includes BIVV 002, a subcutaneous factor IX product. Bioverativ will also

continue Biogen's previous work as a sponsor of My Life, Our Future, the program to provide free genetic testing for hemophilia patients.

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## **Catalyst Biosciences, Inc.**

*Catalyst Announces Promising Animal Data for their Daily Subcutaneous Factor IX*

Catalyst Biosciences, Inc. is developing CB2679d/ISU304, a variant factor IX (FIX) product that has higher potency and longer half-life than typical recombinant FIX products.

Catalyst creates variants by substituting different amino acids in molecules like FIX to identify versions with improved properties. They presented data at ASH from their pre-clinical studies in hemophilia B mice. They found that CB2679d/ISU304 has approximately 17-times greater potency than normal FIX, which gives it the ability to be used as a subcutaneous treatment. They estimate that a daily subcutaneous injection can bring FIX levels in severe patients up into the mild range. Catalyst expects to begin a Phase I/II clinical study in hemophilia B patients in the second quarter of 2017.

Catalyst is also working on a variant factor VIIa product for treatment of inhibitor patients. In pre-clinical studies in hemophilia A dogs, subcutaneous dosing achieved levels of factor VIIa sufficient to correct their clotting abnormalities. The half-life of Catalyst's factor VIIa was 50–136 hours, much longer than current products. They plan to start a clinical study in 2017.

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## **Dimension Therapeutics, Inc.**

*Dimension Announces Interim Results in Gene Therapy Trial*

Dimension Therapeutics, Inc. has announced preliminary safety and efficacy results from their Phase I/II clinical study of gene therapy for hemophilia B. Dimension uses an AAV serotype rh10 vector to deliver a codon-optimized factor IX gene to the liver. Patients treated with a low- and an intermediate-dose of the vector have now been

# Industry News

followed up for 6 to 52 weeks. Those in the low-dose cohort levels have stabilized at FIX levels of 3-4% after 24-52 weeks. Those in the intermediate-dose cohort achieved peak FIX expressions of 12-20%, which leveled off at 5-8% after 7-12 weeks follow-up. None of the patients in the intermediate-dose cohort have required prophylactic or on-demand FIX treatment since dosing

Liver inflammation occurred in five of the six patients, which was treated with corticosteroids. As with other FIX gene therapy studies, the inflammation was associated with a decrease in FIX level. There were no other safety issues reported.

## **Spark Therapeutics and Pfizer, Inc.**

*Spark and Pfizer Present New Data from their Gene Therapy Trial*

Spark Therapeutics and Pfizer, Inc. presented data on the first nine patients (seven severe and two moderate, ages 18 to 52) treated in their ongoing Phase I/II clinical trial of gene therapy for hemophilia B. Their treatment, called SPK-9001, uses the high-potency FIX-Padua variant gene administered using an AAV vector. The first patient treated has been bleed-free for 52 weeks with a FIX level of 33% while requiring no infusions of FIX. In the year before treatment, he was on twice-weekly prophylaxis and still experienced four bleeds. The seven patients who are at least 12 weeks post-treatment have a mean FIX level of more than 28%. No serious adverse events have been observed and no patients have experienced inhibitor development or thrombotic events.

All nine patients have discontinued prophylaxis and eight of the patients have required no FIX infusions since treatment. One patient with severe joint disease twice self-infused a precautionary FIX dose due to suspected ankle and knee bleeds, even though his FIX level was 36%. Two patients experienced temporary liver inflammation associated with immune responses to the AAV vector during the first four to eight weeks post-administration. Both patients were treated with corticosteroids to reduce the immune response but saw decreases in their FIX

levels over time. The first patient saw a drop in FIX from 32% to 12%, while the other patient, who was treated more promptly with corticosteroids only saw a drop from 71% to 68%. Both patients have been bleed-free and have required no FIX infusions.

## **uniQure**

*uniQure Announces New Clinical Data from their Phase I/II Gene Therapy Trial*

uniQure N.V. presented new data from their Phase I/II clinical study of their gene therapy treatment AMT 060, including up to 52 weeks of follow-up for five patients in their low-dose cohort and up to 31 weeks of follow-up for five patients in their higher-dose cohort. AMT-060 is a codon-optimized normal factor IX gene delivered with an AAV-5 vector. They saw a dose response (the resulting FIX level increases with increasing dose) with a mean FIX level in the low-dose patients of 5.2% and a mean FIX level in the higher-dose patients of 6.9%.

The treatment was well-tolerated with no severe adverse events and no evidence of inhibitor formation. Three patients experienced mild immune responses, which were treated with corticosteroids. The immune responses did not appear to affect the FIX levels.

Interestingly, the frequency of spontaneous bleeding decreased significantly over time with no patients reporting bleeds in the last 14 weeks of observation. Of the nine patients who were previously on prophylaxis, eight have discontinued it, including all of the patients in the higher-dose cohort. ABRs in the low-dose cohort fell from 8.3 to 3.4 and in the higher-dose cohort fell from 3.0 to 0.7.

uniQure was also granted Breakthrough Therapy designation by FDA in January 2017. Breakthrough Therapy designation expedites the development and review of new drugs that may offer a substantial improvement over currently available therapies for patients with serious or life-threatening diseases



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 help support and educate the bleeding disorders community. Because at Novo Nordisk, we're always committed to helping you make your potential possible.

# Research Updates

By Dr. David Clark

## CSL Presents Data on Optimum FIX Trough Levels

CSL Behring presented new results from their Phase III clinical study of Idelvion, their new longer-acting FIX product, that shed light on optimum trough levels for FIX activity. The optimum trough level has been a subject of controversy since the beginning of prophylactic treatment. Originally, it was thought to be sufficient to increase FIX levels for severe hemophilia patients from less than 1% to above 1% to convert their severe hemophilia to moderate hemophilia. More recently, with the availability of improved FIX products, including longer-acting products, many have proposed higher levels to bring patients into the mild, or even the normal range. The longer-acting products are usually thought of as providing a longer period between infusions, but they can also be used to more conveniently provide higher trough levels. CSL's study shows that keeping FIX levels above 5 or 10% reduces the risk of bleeding episodes by approximately 80% over one year. They further found that only keeping levels above 2% was not associated with a significant reduction in bleeding risk over a period of one year.

## My Life, Our Future Announces Research Repository

My Life, Our Future, the genotyping program for hemophilia patients and carriers, has announced that their Research Repository is now open. The Research Repository is a collection of gene sequence data and blood/plasma samples that were contributed by more than 5000 hemophilia patients who consented to participate in that part of the program. The data and samples are de-identified to protect the contributors' privacy. The repository is now available for scientists to apply for permission to use the material for research studies. Access to the material is controlled by the MLOF Research Review Committee, an independent, international, multidisciplinary panel managed by the American Thrombosis and Hemostasis Network (ATHN).

## Salk Institute Developing mRNA Treatment for Hemophilia B

Scientists at the Salk Institute are developing a method to treat hemophilia B using messenger RNA (mRNA) to produce factor IX in the liver. To manufacture a protein like factor IX, the body's cells produce mRNA from the gene for the protein. The mRNA is a template that tells

the cell's protein production machinery how to produce the protein. The Salk researchers, working with biotech company Arcturus Therapeutics, have been able to administer mRNA for normal factor IX to hemophilic mice, causing them to produce their own factor IX. The mRNA is encapsulated in lipid nanoparticles and injected intravenously in the mice. The nanoparticles with the mRNA are taken up by liver cells, which then use the mRNA to produce factor IX. Normal clotting occurred in the mice about four hours after the infusion and lasted for up to six days. These are very early results in an animal model, but it shows the potential of another possible treatment for hemophilia B.

## University of Pennsylvania Use CRISPR/Cas9 Gene Editing to Cure Hemophilia B Mice

Researchers at the University of Pennsylvania are developing a gene therapy treatment using the CRISPR/Cas9 gene editing technique. They presented results at the recent ASH meeting showing that they could cure hemophilia B mice using this approach. They delivered the Cas9 and CRISPR portions of the treatment using two separate adeno-associated virus (AAV) vectors and were able to insert a human FIX gene under the control of the mouse FIX gene regulatory elements. The mice were able to express human FIX at or above normal levels over four months. A group of the mice also underwent partial liver resections (removal of part of the liver), which they survived and continued to express FIX.

## University of Texas Developing Oral Capsule for Hemophilia B Treatment.

Researchers at the University of Texas at Austin are developing an oral capsule to deliver FIX to patients without the need for an intravenous injection. Inside the capsule, FIX is bound by trypsin-cleavable linkages in a swellable hydrogel. In the highly acidic environment of the stomach, the hydrogel is in a shrunken state, which holds the FIX tightly inside the hydrogel and protects it from being degraded by the stomach acid. Once the capsule passes through the stomach into the small intestine, the less-acidic environment allows the hydrogel to swell. This exposes the FIX to trypsin and other digestive enzymes, which reside in the small intestine. The trypsin cleaves the linkage, releasing the FIX, which can then be absorbed through the intestinal wall and into the bloodstream. This research is promising but still has a long way to go.



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](http://IDELVION.com).**



Dosing schedule that fits into your lifestyle



High and sustained Factor IX levels at steady state<sup>1†</sup>



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](http://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.

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# Rules and Rackets

By Christian Harris

If you could design your own Island, what would it look like? What type of man-made structures would it have? How would you govern it? These are a few of the questions asked to attendees of the last GenIX Leadership Experience sponsored by Aptivo Therapeutics

It wasn't very difficult to imagine and illustrate ourselves on a private island with Pigeon Key as the backdrop of our excursion! The five acre isle of Pigeon Key was home to the team of men who actually built the famous 7 Mile Bridge in 1912.

We worked on the illustrations of our islands and discovered new leadership skills while doing so. In all of the exercises I participated in, we didn't carve out our weaknesses in an effort to fix them but instead the Gut Monkey team encouraged us to think about how we can use our strengths and weaknesses in leadership roles. With authentic leadership in mind, we explored self-awareness, mission and relational transparency within ourselves and with others.

On the first full day of programming, we sat down in a sunny spot on the southern tip of the key to have an honest conversation about façades or as our group leader Jacose put them, our "rackets". We use these façades to make ourselves more relatable at work, to convince mom and dad we're successfully managing adulthood or to charm our way through life. We thought about where we do the most racketeering, what we gain and what it costs. For me, the gains are hollow and the cost a little too severe for my liking. These rackets can hide and hinder progress just as well as they hide our shortcomings and insecurities. This exercise taught me a lot about myself that I otherwise would not have explored.

In another exercise, we found out what happens when you take a seat at the table but fail to communicate with the other players. Some stood up to argue their case, a few others decided to settle the score rock-paper-scissors style and the rest of us just sat perplexed. In life, we find ourselves in situations where the rules we live by are not observed by others. We're likely to experience a few uncomfortable emotions in these situations but how should we manage these emotions? How does one lead



a group of individuals who operate by a different set of rules? As we illustrated; you can argue, find a fair solution or do nothing. Most importantly, we can ask others "what rules do you observe?" Then, listen to their response without allowing those naturally occurring uncomfortable emotions bar you from respecting someone else's point of view!

As the trip came to an end, we took another look at the illustrations of our islands. My mile long cay was close enough to the civilization to be a part of the world but far enough away to retreat to when it all becomes too exhausting. Having a few new tools of understanding, I don't think I'd spend too much time on my little private island. I'm far more interested in leading a connected and authentic life. And of course, I have to be close enough to my blood brothers and sisters for them to continue to remind me just how beautiful the world really is.



# The History of Hemophilia

By Dr. David Clark

The history of hemophilia goes back centuries. The earliest written reference may be that found in the Mishnah, a second century AD compilation of Jewish law. There it states that if a mother has had two sons circumcised who both died as a result, then a third son must not be circumcised. Although it is not specifically stated that the deaths were due to bleeding, other sections of these writings do refer to “loose blood”. Another early reference is the legend of the Curse of Tenna. In 1769 a judge in the small Swiss village of Tenna condemned an innocent man to death. The legend states that this act led to the inflicting of a curse upon the judge and his family. This curse was believed by the citizens of Tenna to be the cause of a serious bleeding disorder, sometimes leading to bleeding to death, which afflicted the family for generations.

This was, in fact, a family of hemophiliacs. Using detailed church and civil registers, which have survived through the ages, modern investigators have compiled a family tree covering 13 generations from 1600 to 1955. This is the oldest and largest family of hemophiliacs ever described comprising 3072 members of whom 55 had hemophilia. The first known bleeder of the family died in 1741 (28 years prior to the act which supposedly resulted in the curse being inflicted). Interestingly, the terms bleeders (“blutters” in German) for the affected hemophiliacs and carriers (“conductoren”) for women who transmit the disease were created by the people of Tenna, not by physicians. Also of note is that the family disease turned out to be hemophilia B rather than the more common hemophilia A.

An early medical account published in 1803 correctly described the disease as one which affects males but is transmitted by females. Remarkably, this was a half century before Mendel discovered the laws of inheritance and more than a century prior to the discovery that such diseases are carried by the X chromosome. The myth that only males are affected remains prevalent to this day, but we now know that females can also be affected as well as being carriers.

In 1937 the existence of an “antihemophilic globulin,” a component absent from the blood of hemophiliacs, was discovered. Antihemophilic globulin, which was later identified as a material rich in factor VIII, could reverse the bleeding tendency of the blood of most hemophilia patients, but not all. It

was not until 1947 that the existence of the two separate forms of hemophilia was finally determined. This is not surprising since the clinical symptoms of the two diseases are essentially identical. Factor VIII and factor IX work together to activate factor X in the clotting process. A deficiency of either factor causes the process to stop at that step.

In 1952, researchers in Oxford, England described Christmas disease, “a condition previously mistaken for hemophilia.” Christmas was the family name of the patient they studied. At the same time researchers in San Francisco independently described PTC deficiency, “a new disease resembling hemophilia.” PTC referred to the newly-identified missing clotting factor Plasma Thromboplastin Component, now known as factor IX. In 1954, at the Paris Congress of the International Society of Hematology, the terms hemophilia A for factor VIII deficiency and hemophilia B for factor IX deficiency were officially adopted.

At this point the histories of the two diseases diverge as they follow the search for two different treatments. Around the turn of the century the transfusion of serum was determined to be effective in treating bleeding episodes. However, by the 1930’s this practice was being condemned as useless. The reason for this inconsistency



Victoria and Albert  
with Alfred, Bertie, Alice, Vicky and Helena

is that the physicians of that day did not yet realize that they were dealing with two separate diseases. Serum is the liquid portion remaining after plasma has been allowed to clot. Factor IX remains active in serum while factor VIII is degraded and becomes inactive. Thus serum worked for the hemophilia B patients, but was not effective for the larger population of hemophilia A patients.

Until the late 1950's serum, and later plasma, were the only treatments available for hemophilia B. Then in 1959 the first purified factor IX concentrate derived from plasma was developed in France. This was followed by the development of similar concentrates in Britain and the U.S. The first factor IX product in the U.S. was licensed in 1969. These became known as Factor IX Complex concentrates. The word "complex" in the name refers to the fact that in addition to factor IX these products also contained several related clotting factors such as factor II, factor X, and in some cases factor VII. Because of the similar properties of these factors, it is difficult to purify factor IX away from the others.

The availability of Factor IX Complex and its effectiveness in treating bleeding episodes significantly improved the

health and well-being of hemophilia B patients. The use of Factor IX Complex, however, soon became associated with thromboembolic complications, that is, unwanted, and potentially life threatening internal clotting. This happened most often when the product was used in large amounts for extended periods of time, for instance in hemophilia B patients undergoing surgery. The reason for these complications is still unknown. One theory is that this unwanted clotting is due to overloading the patient's blood with the other clotting factors in the complex. To eliminate this problem, more highly purified plasma products containing only factor IX were developed with the first one being licensed in the U.S. in 1990. Another important advance has been the development of better methods for inactivating or removing viruses from these plasma-derived products.

In 1997, the first recombinant factor IX product was licensed by FDA. Since then, the use of genetic engineering has led to the development of additional recombinant products as well as genetically-modified products like the longer-acting concentrates. The wheels of history continue to turn today. On the horizon is even the potential "cure" for hemophilia via gene therapy.

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# In Memoriam



**Starlyn L. Tyree**

Jun. 19, 1945 – Jan. 18, 2017

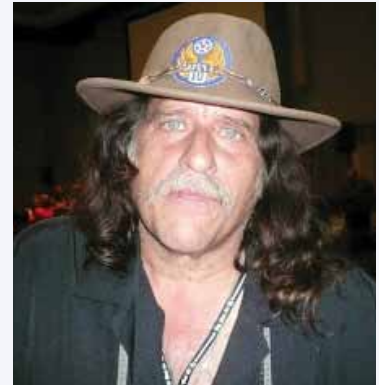
**S**tar Tyree was a great woman of integrity and humility. Star originally had no ties to the hemophilia and bleeding disorders community. She had worked for another non profit before joining the staff of Hemophilia of Indiana (HOI).

She started out at HOI in the 1980's, and provided the community with numerous educational and social events. Star also educated local, state and federal elected officials on hemophilia and worked for access to care long ago.

After decades at HOI, Star went to work for a small speciality pharmacy as the Director of Community Resource Coordinators. Essentially she equipped her staff to be a resource to the bleeding disorders community in such areas as insurance education, state and federal resource programs, and support

Star was also a long time board member of the Hemophilia Federation of America (HFA). She chaired the Symposium and Helping Hands committees as well as did numerous "Member Organization Development" workshops to help with best practices and creative ideas.

Star quietly made serious impacts on our community out of the generosity of her heart.



**Corey Dubin**

Mar. 3, 1955 – Jan. 5, 2017

**T**here are not many people I would call a legend, but Corey is definitely one. Unfortunately, Corey passed away in January 2017 from hemophilia related issues.

Corey was a very outspoken, intense and passionate man. Some even thought he could be intimidating. He was very knowledgeable in his areas of passion and put actions to his words. He was a Champion's Champion. He was a journalist and activist who took action and wasn't worried if the truth offended anyone. He had the ability to discuss complex issues in terms that you could understand.

As a journalist he covered the stories of the Pacific Rim, the Caribbean, Indigenous America, and the Nation States of South, Central, and North America.

As an activist Corey, along with others, called for a safe American Blood Supply and that HIV / AIDS was a blood pathogen. He called for the Institutes Of Medicine (IOM) to investigate the U.S. governments role in the mass infection of the hemophilia community through the clotting factor. He was also the first consumer to be appointed to the Blood Products Advisory Committee (BPAC).

Corey was one of the founding members and longtime President of the Committee Of Ten Thousand (COTT.) An advocacy group for the ten thousand people with hemophilia that contracted HIV / HCV. He was also instrumental in the founding of the Hemophilia Federation of America (HFA.)

Now Corey was no saint. He could be difficult to talk to when he became passionate about a discussion (aka argument). Some saw his methods of debate as over the top.

This is only a brief part of the legacy that was Corey Dubin. He stood up for what he believed and cared very deeply for our community. His presence will certainly be missed.

# KIDZ KORNER!

## Winter Word Search Puzzle

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

BOOTS  
DRIFT  
FISHING  
FLAKES  
FLURRIES  
FUN  
HOCKEY  
ICY  
PLAY  
PLOW  
SALT  
SAND  
SCRAPER  
SCULPTURE  
SHOVEL  
SKATING  
SKIING  
SLIDING  
SLIPPERY  
SNOWBALL  
SNOWBLOWER  
SNOWMAN  
SNOWMOBILE  
STORM  
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For more information, please contact Kim Phelan:

[kimp@hemob.org](mailto:kimp@hemob.org) or call 917-582-9077