Vital Link

...For Hoosiers Living with a Bleeding Disorder

December 2017

The Vital Link is published quarterly by Hemophilia of Indiana, Inc.

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2017 Year In Review

As we approach the end of the 2017, it is always good to reflect back upon the year. 2017 was a great year! Hemophilia of Indiana (HoII) was able provide more than 1200 members and families within the bleeding disorders community with assistance, educational and advocacy opportunities. This is made possible by our fundraising events, private donors, and industry partnerships. The year started with the Hearts for Hemophilia "Masquerade Ball" with over 225 in attendance and included a special speaker NHF CEO Val Bias. Washington Days in March provided the opportunity for Indiana patient advocates to meet with Indiana's senators representatives to advocate for all members of the bleeding disorders community. The Bowling Marathon was a huge success! Proceeds from this event go directly to the Judy Moore Memorial Scholarship. HoII is extremely proud that this year we were able to award a record high $20,500 to 7 deserving individuals to be used for their higher or graduate education. The Course for the Cure was also another successful fundraiser that isn't just a fundraiser but also brings awareness of the bleeding disorder community and the programs and services of Hemophilia of Indiana to individuals and companies outside of the bleeding disorder community. The 2017 Annual Meeting was held in August at the Crown Plaza Indianapolis Airport hotel and had a record attendance! The program kicked off with incredible key note speakers from the Indiana Hemophilia, and Thrombosis Center, Dr. Amy Shapiro, Dr. Anne Greist, and Jen Maahs, PNP. The day successfully continued with multiple educational break out sessions of various topics include "Pain Management", vWD, "Hemophilia…The Female Connection", "The Unaffected Sibling", and many more! Day 2 concluded with key note speaker Chris Bombardier and his inspirational program "What's Your Gut Monkey"! Planning has already begun for the 2018 Annual Meeting! This year's NHF Annual Meeting was incredibly special! HoII was able to take a record breaking 67 patients to the event held in Chicago, IL! Indiana had the largest number of representatives of the bleeding disorders community at the multi-day event! The 2017 Hemophilia Walk was held in September at the beautiful Fort Harrison State Park in Indianapolis. There was a record # of registered walkers! Big news coming for 2018, the Walk will no longer be the Hemophilia Walk and will now be the Unite For Bleeding Disorders Walk! Visit website at www.hoii.org for more info!! Following the walk was the Polo on the Prairie Event held at the Hickory Hall Polo Club! It was a beautiful afternoon of watching polo and raising awareness!

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The final two events of the year were the Fit Livin' Thankgivin' Day Run and the Year End Educational Event! The Fit Livin' Thanksgivin' Day Run had over 500 registered runners and walkers! The event was held in Noblesville, IN and included a 4 mile run and 1.5 mile run/walk! In partnering with Fit Livin' and several local sponsors allow HoII to raise funds for our many programs and services as well as awareness individuals and businesses outside the bleeding disorders community. The Year End Educational Event was held at the Wellington Banquet and Conference Center in Fishers, Indiana. It was attended by over 160 patients and families as well as multiple industry partners and sponsors! It brought an opportunity for educational displays for our industry partners and more importantly another opportunity for fellowship and interaction for our families. The children (and adults!) enjoyed crafts followed by a delicious lunch, and concluded with a very special visitor! Fun was had by all that attended! Hemophilia of Indiana would like to thank all of our sponsors, donors, supports, and partners! Without their support, HoII would not be able to provide the programs and services that are provided to over 1200 members of the bleeding disorders community. HoII wishes a very happy holiday season to all of our patients, families, supporters, and partners and stay tuned for upcoming events and information for 2018!

Pfizer Hemophilia

DEDICATION AND PERSONAL SUPPORT

The Patient Affairs Liaison role was created based on community feedback about the importance of helping to connect patients and caregivers with Pfizer Hemophilia tools and resources.

PATIENT AFFAIRS LIAISONS

Working for you—From the home of Motown to the Bluegrass State

Name: Chris Liddell

Home state: Michigan

Fun fact: If I'm watching TV, it's most likely sports-related. Go Tigers!

Ideal vacation spot: Anywhere quiet, unplugged from all electronics

What past experiences can you bring to this job?
I've worked in hemophilia for over 10 years, so I've collaborated with and advocated for different members of this community.

What we do:

- Provide helpful information about Pfizer Hemophilia programs and services
- Serve as a resource to hemophilia treatment centers to help patients obtain access to Pfizer medicines
- Serve as a primary point-of-contact for local advocacy groups
- Participate in local and national events and programs
- Upon request, meet with patients and caregivers to answer questions related to Pfizer Hemophilia resources

"IT'S IMPORTANT TO CONNECT ON ALL LEVELS: HTCs, PATIENTS, FAMILIES, THE WHOLE COMMUNITY."

—Chris Liddell

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Pfizer

PEN's Insurance Pulse 2017

www.kelleycom.com

Ask the Expert

Michelle Rice
Senior Vice President, External Affairs, National Hemophilia Foundation

QUESTION: Recently I received a notice from my pharmacy benefit manager (PBM) stating that the amount paid by my factor manufacturer assistance program does not count toward my deductible and copay. Is this correct?

ANSWER: Unfortunately, yes. Health plans, specifically high-deductible plans offered by self-insured employer groups, have implemented one of two programs designed to drive savings by ensuring that patients personally share in the cost of healthcare. The programs are often called either an "Accumulator Adjustment Program" or a "Copay Maximum Allowance Program."

QUESTION: Why were these programs implemented?

ANSWER: The PBMs argue that a patient who has no "skin in the game" will potentially choose higher-cost drugs and get unnecessary tests, procedures, and labs. PBMs also worry that a manufacturer's copay assistance programs can be used to incentivize patients to choose non-preferred drugs (such as the manufacturer's) without considering cost, because the patients' out-of-pocket cost would be zero.

QUESTION: But this means that our costs are higher, or that we may not be able to get the drug we want or need. What is NHF's position on these programs, and what is it doing to help patients?

ANSWER: NHF sees the value of using cost reduction programs or other mechanisms aimed at lowering payer costs only when generic alternatives are available or the medications are considered low value (not necessary). NHF strongly feels that adopting these programs for patients who use high-cost or high-value (lifesaving) drugs with no generic alternatives, and who have high-deductible plans, have the reverse effect—leading to increased costs for both patients and payers.

NHF is partnering with National Alliance of Healthcare Purchaser Coalitions, a national nonprofit 501(c)(6) that is a membership organization of purchaser-led healthcare coalitions (self-insured employer groups or institutions), to produce and deliver a webinar to its member agencies including self-insured employer groups. The webinar will explain the unintended consequences that cost reduction programs may have on people affected by chronic conditions requiring high-cost, specialty therapies with no generic alternatives.

2018 Hearts for Hemophilia "Mad Hatter's Ball"

With over 250 people in attendance, the Hearts for Hemophilia Gala is one of Hemophilia of Indiana's largest, annual special event fundraisers. We're kicking this year off with a new "Mad Hatter's Ball" theme. You won't want to miss the magical evening we have planned! Cocktail hour and a Silent Auction start the event at 6:30pm with dinner following at 7:30pm. The very exciting Live Auction begins at 9:00pm. Dancing to the sounds of "***Stella Luna and The Satellite's*** adds to the fun and excitement of the evening.

Proceeds from the event are used to support the work of Hemophilia of Indiana, specifically, *Project Lifeline,* which provides more than 1,200 Hoosiers affected with bleeding disorders vital services such as, education, dental insurance, camp/youth programming, emergency financial assistance, and MedicAlert identification. In 2017, the cost of these services exceeded well over $300,000. Proceeds from Hearts for Hemophilia will go directly to support these vital programs and services.

Event details:
28th Annual Hearts for Hemophilia Gala
Friday, February 9, 2018
6:30pm - Midnight
Union Station Grand Ballroom - Crowne Plaza
123 W. Louisiana St.
Indianapolis, IN 46225

For more information please visit our website, www.hoii.org or contact Kristy McConnell at 317-570-0039 or kmcconnell@hoii.org

INDIANA HEMOPHILIA & THROMBOSIS CENTER, INC.

The Best Outcomes for You and Your Family

Indiana's only Center of Excellence in bleeding disorders

- Comprehensive clinics with our expert multidisciplinary team
- Integrated pharmacy program accessible 24/7
- Nationally renowned for the treatment of bleeding and clotting disorders
- First HTC to receive Medical Home certification (AAAHC)
- Free CME education and 24 hours, 7 days a week consultative services for providers throughout the state
- Outreach clinics across Indiana, education and training for families
- Research to advance care and provide savings to patients and families

For more information, please contact us at 317.871.0000

To contact our Pharmacy, please call 317.829.7778

Visit us online at www.ihtc.org and www.facebook.com/IndianaHemophilia

Now Approved

A ONCE-WEEKLY SUBCUTANEOUS (GIVEN UNDER THE SKIN) INJECTION FOR PEOPLE WITH HEMOPHILIA A WITH FACTOR VIII INHIBITORS

We extend our appreciation to the individuals, families, and healthcare providers who participated in the clinical trials that led to the approval of HEMLIBRA®. We thank you and celebrate with the community who made it a reality.

Discover **HEMLIBRA.com**

WHAT IS HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children with hemophilia A with factor VIII inhibitors.

WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use. HEMLIBRA may cause the following serious side effects when used with aPCC (FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the signs and symptoms of TMA during or after treatment with HEMLIBRA.
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung or head. Get medical help right away if you have any of the signs or symptoms of blood clots during or after treatment with HEMLIBRA.

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

HEMLIBRA™
emicizumab-kxwh
injection for subcutaneous use
150 mg/mL

HOW SHOULD I USE HEMLIBRA?

See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

WHAT ARE THE OTHER POSSIBLE SIDE EFFECTS OF HEMLIBRA?

The most common side effects of HEMLIBRA include: redness, tenderness, warmth, or itching at the site of injection; headache; and joint pain. These are not all of the possible side effects of HEMLIBRA.

You may report side effects to the FDA at (800) FDA-1088 or www.fda.gov/medwatch. You may also report side effects to Genentech at (888) 835-2555.

Please see Brief Summary of Medication Guide on the following page for more important safety information, including **Serious Side Effects**.

Medication Guide Brief Summary
HEMLIBRA® (hem-lee-bruh) (emicizumab-kxwh) injection, for subcutaneous use

WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use. HEMLIBRA may cause the following serious side effects when used with aPCC (FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - feeling sick
  - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

See "**What are the possible side effects of HEMLIBRA?**" for more information about side effects.

WHAT IS HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children with hemophilia A with factor VIII inhibitors.

- Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.
- HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

BEFORE USING HEMLIBRA, TELL YOUR HEALTHCARE PROVIDER ABOUT ALL OF YOUR MEDICAL CONDITIONS, INCLUDING IF YOU:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

HOW SHOULD I USE HEMLIBRA?

See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.
- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose before the next scheduled dosing day and then continue with your normal weekly dosing schedule. Do not double your dose to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

WHAT ARE THE POSSIBLE SIDE EFFECTS OF HEMLIBRA?

- See "**What is the most important information I should know about HEMLIBRA?**"

The most common side effects of HEMLIBRA include:
- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

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

HOW SHOULD I STORE HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than 7 days at 86°F (30°C) or below.
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

Keep HEMLIBRA and all medicines out of the reach of children.

GENERAL INFORMATION ABOUT THE SAFE AND EFFECTIVE USE OF HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

WHAT ARE THE INGREDIENTS IN HEMLIBRA?

Active ingredient: emicizumab

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048

For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Issued: 11/2017

HEMLIBRA™
emicizumab-kxwh
injection for subcutaneous use
150 mg/mL

Genentech
A Member of the Roche Group

ADVATE [Antihemophilic Factor (Recombinant)] Important Information

Indications

ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia).
ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A.
Your healthcare provider may give you ADVATE when you have surgery.
ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

You should not use ADVATE if you:
- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

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

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 mice or hamsters.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE 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 VIII.

You can have an allergic reaction to ADVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Side effects that have been reported with ADVATE include: cough, headache, joint swelling/aching, sore throat, fever, itching, dizziness, hematoma, abdominal pain, hot flashes, swelling of legs, diarrhea, chills, runny nose/congestion, nausea/vomiting, sweating, and rash.

Tell your healthcare provider about any side effects that bother you or do not go away or if your bleeding does not stop after taking ADVATE.

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 the following page for the ADVATE Important Facts.

For full Prescribing Information, visit www.ADVATE.com.

References: 1. Grillberger L, Kreil TR, Nasr S, Reiter M. Emerging trends in plasma-free manufacturing of recombinant protein therapeutics expressed in mammalian cells. *Biotechnol J*. 2009;4(2):186-201. **2.** ADVATE Prescribing Information. **3.** Elsayed M. Hemophilia Treatment. London, United Kingdom: Datamonitor Healthcare; 2016.

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ADVATE
[Antihemophilic Factor (Recombinant)]

ADVATE
[Antihemophilic Factor (Recombinant)]

Important facts about

ADVATE [Antihemophilic Factor (Recombinant)]

This leaflet summarizes important information about ADVATE. 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 ADVATE. If you have any questions after reading this, ask your healthcare provider.

What is the most important information I need to know about ADVATE?

Do not attempt to do an infusion to yourself unless you have been taught how by your healthcare provider or hemophilia center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing ADVATE so that your treatment will work best for you.

What is ADVATE?

ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia). The product does not contain plasma or albumin. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A.

Your healthcare provider may give you ADVATE when you have surgery. ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

Who should not use ADVATE?

You should not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

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

How should I use ADVATE?

ADVATE is given directly into the bloodstream.

You may infuse ADVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADVATE to use based on your weight, the severity of your hemophilia A, and where you are bleeding.

You may have to have blood tests done after getting ADVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

Call your healthcare provider right away if your bleeding does not stop after taking ADVATE.

What should I tell my healthcare provider before I use ADVATE?

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 mice or hamsters.
- Are breastfeeding. It is not known if ADVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What are the possible side effects of ADVATE?

You can have an allergic reaction to ADVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Side effects that have been reported with ADVATE include:

cough	headache	joint swelling/aching
sore throat	fever	itching
unusual taste	dizziness	hematoma
abdominal pain	hot flashes	swelling of legs
diarrhea	chills	runny nose/congestion
nausea/vomiting	sweating	rash

Tell your healthcare provider about any side effects that bother you or do not go away.

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

What else should I know about ADVATE and Hemophilia A?

Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE 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 VIII.

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

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADVATE. The FDA approved product labeling can be found at www.ADVATE.com or 1-888-4-ADVATE.

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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PEN's Insurance Pulse 2017

www.kelleycom.com

Get Out of Jail Free—This Time

Ian Thomas

It's hard to imagine that $86 almost cost us our health insurance and resulted in financial hardship. But our story shows how careful you must be when dealing with health insurance. One slipup can almost ruin you, financially and medically. We want to ensure that no other family with bleeding disorders has to go through what we did. Thankfully, our story had a happy ending.

In mid-February 2016, I was notified by University of Kentucky HealthCare Hemophilia Treatment Center (UKHTC) about a billing issue with two shipments of factor from January and February of 2016. UKHTC (our factor provider and medical provider) informed us that reimbursement for the two shipments of factor was being rejected by Anthem, our insurance company, due to termination of my policy. *Termination?* I had already paid my premiums for January, and I was getting ready to pay February's premium. What had happened?

I reviewed my notes and my memory to get the most accurate account. In late December 2015, I had called Anthem to add my wife Elaine to my insurance policy. I'd spoken with a representative, whose name I documented (though I didn't document the call's recording number). She added Elaine, which increased my monthly premium for December. I paid the December balance over the phone, and I recall asking the rep at least twice what my new monthly balance would be. She told me $530 and some change. So I went ahead and also paid the January 2016 premium over the phone, $530, and thought it was taken care of.

In the first week of January, I received a bill for an odd amount, $86.
I had no clue what this was for. Under the amount was a statement like "Please disregard if you have already sent your payment." No big deal, I thought to myself. I had just paid the January premium of $530. I even checked my bank account to ensure that the payment had gone through. I assumed the $86 invoice must have been an error. I didn't give it another thought. Big mistake!

In the first week of February, I received my monthly insurance bill, which showed the amount due was higher than $530. At that time we were struggling financially, and I waited until the middle or later part of the month to pay my premium, knowing that I had a 31-day grace period. When I called Anthem to set up an over-the-phone payment, I was informed that my policy had been canceled because I hadn't paid the premium in full in January. I felt confused, then frustrated. What had happened, and how could I fix it?

I told the Anthem rep about my January payment of $530. She said that wasn't the correct amount. Apparently, our monthly premium had increased to $616 in January 2016! So I owed $86 for January, and because it hadn't been paid by the end of the grace period (beginning of February), my policy had been terminated.

I told the rep about my previous phone call with Anthem, adding my wife to the policy, and the monthly quote I was given. She determined that the quote was correct—for 2015! It did not take into account the premium increase for 2016. *Really?* She asked why I had not responded to the January bill. I told her the bill had said to disregard if I had already paid. I asked to hear the recording of the initial call. But I hadn't documented the recording number, and she couldn't track it down. We'll never know if I misunderstood the initial quote, or if I received wrong information.

In the meantime, I applied for reinstatement to Anthem, but this was denied. I called our HTC social worker, Julia Kluesner. Julia helped me appeal the case before Anthem, but the appeal was denied.

By then, I had already received my January and February factor shipments from the UKHTC pharmacy—before I ever knew about the insurance problem! The HTC worried that if my insurance

weren't reinstated, I would eventually be billed for the factor, to the tune of $63,000. This had become a serious issue with an uncertain outcome.

Now the questions began: Who's responsible for paying the outstanding bill of $63,000 for the factor shipped? Me? The UKHTC pharmacy always confirms coverage with Anthem before any shipment can occur. How could I have received the factor if I wasn't covered? How do I get my insurance coverage back, with enrollment only once a year? How do I order factor for March?

This was potentially devastating financially for my family. I couldn't pay the $63,000 or pay to fight a legal battle. I'm a self-employed, first-generation farmer. In the last two years, the US farm economy has tanked from low commodity prices. Our farm operation has seen a lot of red ink. It has been a struggle to keep our heads above water.

I went through March with no healthcare coverage, surviving only on donated factor through our factor manufacturer's compassionate care program. Then Elaine was promoted to full time at her work, enabling us both to have coverage in April. This was an absolute blessing!

I reached out to the hemophilia community for advice. My mother contacted Laurie Kelley, who was on the case immediately. Laurie put me in touch with an insurance expert at National Hemophilia Foundation. I continued speaking with Julia, who was extremely helpful as well. And I talked with our attorney and my uncle, Bob Massie.

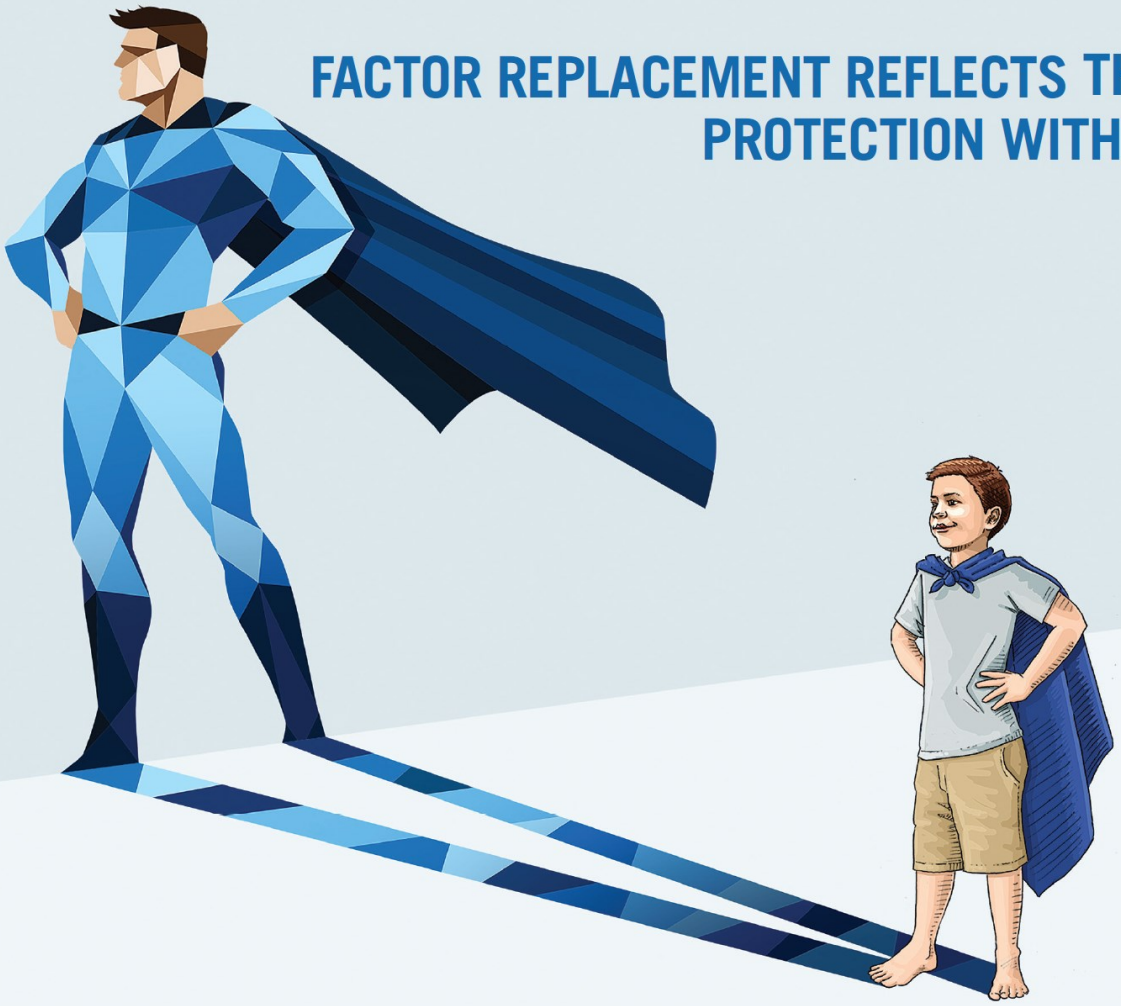
We basically had to fight Anthem to get the factor covered, or work with UKHTC in negotiating the bill. Elaine and I weighed the possible outcomes. I felt I had a legitimate case with Anthem. But I worried that I had made a mistake or misunderstood something, and would still be responsible for the bill, plus legal fees. On the other hand, I certainly didn't want to saddle the HTC with our bill.

Eventually, the UKHTC pharmacy billed me $63,000 for the factor, but we negotiated the bill to $0. How? We had a loss from farming on our tax return, which allowed us to have the bill erased. We're thankful that the issue was settled, but I didn't like having the UKHTC pharmacy pay the bill. I wish we'd gotten Anthem to reimburse the HTC, and I think there was a legitimate case for Anthem to pay our claim.

Now, I watch like a hawk anything and everything insurance or medical related. We were given our "get out of jail free" card, and I don't want to be in that situation again. My message to everyone else in our community: 1. Document every call you have with insurance companies, and get every number or code. 2. Check all bills and read all letters and policies, monthly. 3. Engage your HTC to help you with insurance claims. In this age of healthcare uncertainty, it's more important than ever to safeguard your policy, services, and factor supply by reading, asking, and challenging the system.

Ian Thomas has severe hemophilia A, and lives in Kentucky with his wife Elaine and their new baby boy, True. Ian is a first-generation farmer, raising cattle and crops on 750 acres. Ian and Elaine work for a crop insurance agency in Kentucky, and are passionate about agriculture and rural life. They're active in the Episcopal Church and local community, serving on boards of several organizations. Ian's grandparents are Robert K. and Susanne Massie, authors of Journey, a book about the life of Ian's well-known uncle, Bob Massie, who was cured of hemophilia following a liver transplant.

FACTOR REPLACEMENT REFLECTS THE PROTECTION WITHIN



For people with hemophilia, Factor treatment temporarily replaces what's missing.[1] *With a long track record of proven results, Factor treatment works with your body's natural blood clotting process to form a proper clot.*[2,3]

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Stay empowered by the possibilities.

References: 1. Peyvandi F, Garagiola I, Young G. The past and future of haemophilia: diagnosis, treatments, and its complications. *Lancet*. 2016;388:187-197. **2.** Wolberg AS. Plasma and cellular contributions to fibrin network formation, structure and stability. *Haemophilia*. 2010;16(suppl 3):7-12. **3.** King MW. Introduction to blood coagulation. http://themedicalbiochemistrypage.org/blood-coagulation.php. Last modified January 2, 2017. Accessed January 2, 2017.

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*The material provided in Vital Link is only for general information purposes. HoII does not give medical advice or engage in the practice of medicine. HoII recommends in all cases that you consult your physician or HTC before pursuing any course of treatment.

Mark your Calendars!

Here are some of our upcoming events…

- Hearts for Hemophilia Gala, February 9th, 2018
- Camp Brave Eagle, June 10th-15th, 2018
- 2018 Annual Meeting, August 11th & 12th, 2018

Call our office @ (317) 570-0039 or email Kristy McConnell @ kmc-connell@hoii.org if you would like to get involved in any of our events!

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