

DATELINE

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Best One Yet: Community Member Creates Successful Fundraiser

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The Importance of Self-Advocating with Doctors

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Dear Friends,

Quite often our family feels like we have Kinzie's bleeding disorder down and nothing fazes us. We infuse as we are supposed to and are successful in preventing many bleeds. Then as usual, a bleed happens and reminds us we need to stay ready.

As she has been busy with volleyball and two basketball teams, a couple of those moments have popped up. At the same time these opportunities have been great to remind us she is taking control of her bleeding disorder.

This past basketball season we had our first joint bleed. The fact it held off for 10 years was great in our minds, but we always knew there was a chance it may happen. A couple days before a tournament, Kinzie fell on her left knee during P.E. class at school. The injury didn't seem too bad and I left for a work trip the next morning. When I came home again right before her next practice, I picked up my girls and helped coach the practice. During practice she jumped off of her left leg and came down limping.

As coach and dad, at times I forget to wear my coach hat more heavily. I thought she was not working as hard as usual. This injury continued to be reagravated during the season, which we began to watch for more closely.

Teaching Kinzie to slow down and sit out when she has a bleed is not something she can see. It has been a new challenge — one in which we hope doesn't happen very often.

Josh Hemann



Board Chair



Assisting, educating, and advocating for the bleeding disorders community since 1994.

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ON THE COVER.

HFA's Web Specialist, Michael Bishop, found himself in the hospital, far from his usual HTC, with hematologists unfamiliar with his typical care. It was up to him to stand up for himself and he shares his story in this issue of Dateline on page 10. Photo credit: Michael DeGrandpre

HFA's Summer Internship Goes Virtual

Hemophilia Federation of America has welcomed two advocacy interns for the summer of 2020, but in a new and unique way.

For many years, HFA's advocacy interns spent 10 weeks of their summer living in Washington, D.C., where the HFA office is located, engaged in hands-on activities related to policy and advocacy. But with travel restrictions and safety concerns in place for a global pandemic, HFA had to rethink the annual tradition. The result is a virtual summer internship!

Interns are participating in regular webinars and online training about legislative, policy and advocacy issues, learning more about hearings and what it means to work on Capitol Hill, building communications and media skills, and more. HFA is pleased to welcome the following virtual interns:

My name is Tameelah Dawson. I am 21 years old from Lexington, S.C. and currently a senior at Claflin University in Orangeburg, S. C., pursuing a bachelor's degree in psychology. I have been heavily active in the hemophilia community for well over five years. I've served as a junior board member for Hemophilia South Carolina and I am also a part of the Advocacy Coalition for bleeding disorders in South Carolina. I enjoy working with HFA – I love to be a big helping hand whenever I am needed and making an impact on the younger



generations is a true blessing. I constantly work with teens and young adults, making sure they are aware of the impact they can have on the community just by using their voice.

My name is Will Hubbert, and I'm a soon-to-graduate



history major at the College of William and Mary, hailing from northern Virginia. I've volunteered in the bleeding disorders community since I was a kid, when I started attending venipuncture clinics at my HTC as a patient mentor. Since

then I've been involved in all sorts of ways, from helping out with childcare at HFA Symposium to developing programming that chapters all over the country can use to reach their young adult members. When I'm not studying history or playing frisbee, you can find me at one of the two SeriousFun Camps I've been lucky enough to work at during the last five summers. From facilitating my camp trips to teaching me to self-infuse, the bleeding disorder community has done a great deal for me over the years. This year I'm excited to pay it forward as an advocacy intern for HFA, where I hope to help the bleeding disorders community secure life-preserving healthcare even amid a global pandemic. 🩸

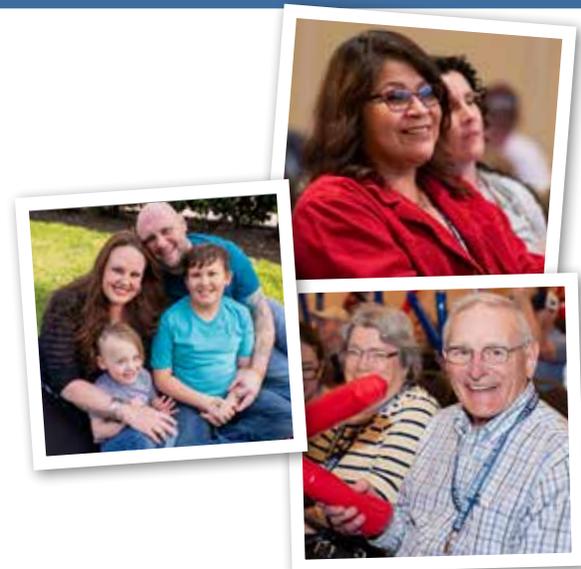
Join Live Aug. 24-29 or Watch On Demand!



The same content you know and trust, delivered in our exciting and cutting edge virtual experience!

Available on-demand following Virtual Symposium week, through the end of the year.

We are thrilled to continue offering the best tools for advocacy, education and assistance in bleeding disorders. Our team has assembled top notch information to ensure our community has access to great content and connections to your friends and industry partners during our virtual Symposium!



www.hemophiliafed.org/symposium





Best One Yet

Bleeding disorders community member creates successful annual fundraising event

BY SHAWN NEASE, GUEST WRITER

“**Y**ou have got to be kidding me! Are you sure that is just for this year?” That was me after wrapping up this year’s Delves for Donors fundraising event and checking in with the hosting store owner for a rough total of how much was raised this year.

A little more than six years ago I came up with an idea for a fundraiser to help Hemophilia Federation of America’s Helping Hands program, which provides emergency financial assistance to families in the bleeding disorders community. Delves for Donors was born! Using my love and passion for the game Dungeons and Dragons, I created an event that seems to have caught on.

More than 70 players – many of whom have no connection to the bleeding disorders community – paid for a seat at the table in one of six two-hour Dungeons and Dragons games. Players get a goody bag with items donated from gaming companies I reach out to for donations. There are also raffles they can take a chance on for \$1 per raffle ticket. Goody bag and raffle items have all been generously donated by companies willing to help a good cause.

At the time of this year’s Delves for Donors event, it was just when the COVID-19 pandemic was becoming more widespread and public health guidelines were being established. We were under a state order requiring that gatherings have no more than 250 people in attendance. But at our busiest, we had 50 people in the store.

We did our best to take everyone’s health into consideration – I made sure tables and chairs were wiped down after each game. Despite a few participants cancelling, no one asked for their money back because they understood they were making a donation to a charity.



**Have an idea for a fundraiser for Helping Hands?
Contact us at TeamHFA@hemophiliated.org to learn more.**

Our raffles have been getting better every year, as I find more new companies to help and returning companies donate more. This year was amazing with 15 raffle items, some of which were big ticket items and designed to catch the eye of dedicated gamers.

One company that got all the gamers excited was D&D Beyond, which is the company with the official online copies of all the current editions of Dungeons and Dragons books and adventures. They donated three of their Legendary Bundles, valued at more than \$600 each, which include every book and adventure put out by the Dungeons and Dragons parent company.

Largest Amount Raised to Date

My hope was that we would be able to beat 2019's fundraising record of \$1,625.

"I checked it myself, Shawn," said Whit, the store owner. "You made \$3,498!" To make it an even number, Steff, the shift manager, pulled two \$1 bills from her pocket for a total of \$3,500.

The fact that so many people, who don't really know anything about HFA or hemophilia, other than what I have told them, are willing to help me raise this much is humbling. As we are living in very uncertain times, it is very much needed.

While many people see Dungeons and Dragons as "just a game," I see it as a way to bring the heroes on the table into the real world. Every one of the people who played this year, or took a chance on a raffle, is just as brave and heroic as the characters in the game. 📍



Thank you to the participants and donors to Delves for Donors!

Thank you to the following companies for donating items to the fundraising event:

 D&D Beyond (<https://www.dndbeyond.com>)

 SkullSplitter Dice

 PolyHero Dice

 WizKids

 The Deck of Many

 Arcknight

 Chaosium Inc.

 GateKeeper Games

 ArmorClass10.com

 Fowers Games

 Leigh Armentrout Crafts

 MakeMeMine of Abingdon, Md.



The Art and Science of Goal Setting and Achieving

HFA board member shares valuable tips to accomplish more

BY CLYDE J.R. BRAWNER, MBA, HFA BOARD OF DIRECTORS

Goal setting is often the foundation of success. We set goals for our education, our finances, our health, our careers plus many other important milestones in our lives. We often think about accomplishing our goals, rarely understanding the art and science of implementing an effective strategy to achieve these important milestones.

Goal setting is the act of selecting a target or objective you wish to achieve. Simple enough right? Well, goal setting is the easy part. The challenge lies within the willingness to make the necessary sacrifices and adjustments to achieve your goal.

For example, many people desire to live a healthier lifestyle, however few make the required sacrifices to achieve this goal. Taking the stairs rather than the elevator can provide many health benefits. While using the stairs instead of an elevator will not make you healthy, it will help shape and develop positive behaviors that will aid in creating a more health conscious and disciplined lifestyle. Do you want the lifestyle that comes with obtaining your goal? Simply put, are you willing to make sacrifices to achieve your desired goals?

Types of Goals

Goals can be divided into three broad categories based upon their desired timeframe: 1) short-term goals, 2) long-term goals, and 3) lifetime goals. Generally, short-term goals can be achieved in less than one year and are often the stepping stones toward achieving long-term goals. If you exercise three times per week, for example, it will lead to a healthier, more active lifestyle, and could support you on your path to the long-term goal of completing a triathlon.

Long-term goals are usually more complex and require a longer period of time to achieve, for example, enrolling in school again to obtain a graduate degree or starting your own business. Lifetime goals are the goals you wish to accomplish at some point during your lifetime. Retiring at age 60 and traveling the world is one example of a lifetime goal. When planning for lifetime goals, it is important to include capstone goals or checkpoints. Saving a specific amount of money by a specific date in preparation for early retirement is an example of a capstone goal.

When developing goals it is important to ensure that the goals are personally compelling and inspiring. In doing so we are more likely to endure the time, energy and sacrifices required to achieve our goals. There are two critical questions that must be asked prior to setting achievable goals. 1) What is the exact objective that you desire? and 2) why do you want to achieve this goal? To remain disciplined in achieving our goals we must ask specific questions and have a clear outcome in mind. Reasons come first, then the answers.

Effective goal setting can be achieved by using the S.M.A.R.T. acronym. This acronym represents goals that are Specific, Measurable, Achievable and Realistic, given a specified Timeframe. For example, saying that I want to lose weight is too vague. However, saying that I want to lose 20 pounds by summer of 2020 is more effective. Stating your goal in this manner helps to keep you on track, progressing toward your goal given the specified timeframe. The more specific the goal the better.

As you embark on achieving your goals there are three important tips to keep you on task. 1) Write your goals down. The Dominican University of California conducted a study

and found those who write down their goals are 42 percent more likely to achieve them. 2) Check in regularly. Regularly assessing how you are coming along with the goal will allow you to evaluate your progress and ensure you remain on track as well as provide an opportunity for adjustments if necessary. 3) Celebrate the small victories! Celebrating your accomplishments (even the small ones) as you progress can be helpful in refueling your motivation.

Now that you have a greater understanding of how to develop effective goals, use the S.M.A.R.T. goal-setting method to develop a personalized goal for yourself. As you begin to create and clarify your goal, remember to ask the two important questions discussed earlier as well as remember the three helpful tips to keep you on track as you progress toward completion. Setbacks are natural and delays can occur but surrounding yourself with a like-minded support system will ultimately help achieve your desired goals. We may fall short of some of our goals and that is okay, so long as we have made meaningful, positive changes in our lives. Setting S.M.A.R.T. goals is about progression, not about perfection. 📌

S.M.A.R.T. Goal Example

Goal:

To lose 20 pounds by fall of 2020.
To achieve this goal reduce food serving sizes, limit soda intake to one can/bottle per day, and ensure at least 60 minutes of physical exercise/activity three times per week.

Why is this Specific?

The goal specifically states how much weight to lose.

Why is this Measurable?

One has the ability to track the number of pounds lost using a weighing scale.

Why is this Achievable?

Assume this goal is written in March.
That provides about six months to lose 20 pounds, an achievable task.

Why is this Realistic?

The goal and parameters set can be realistically achieved given the specified timeframe.

Why this has a Timeframe?

A specified timeframe is clearly defined.
i.e. fall of 2020.

"Are you willing to make sacrifices to achieve your desired goals?"

—J.R. Brawner, HFA board member



I Know Me Best

A visit to an unfamiliar hospital reminds patient of the importance of self-advocacy

BY MICHAEL BISHOP, STAFF WRITER

Self-advocacy is the quintessential and necessary skill for people with hemophilia. It's something I've been taught my entire life, and it's something on which Hemophilia Federation of America frequently focuses its education.

It's incredibly important, and I've heard story after story reaffirming its importance. Whether it's living through Emergency Room horror stories, advocating for the right medication, or enduring difficult hospital stays, every hemophilia patient has heard about or experienced a need for self-advocacy.

I have severe hemophilia B with an inhibitor and anaphylactic allergy to factor IX products, which is a fairly complicated diagnosis. I also have a healthcare team that I've been with most of my life, who understands me very well. A couple years ago I moved two hours away from my Hemophilia Treatment Center, which wasn't a problem for me until recently. Although I have severe hemophilia, treat on-demand, and bleed fairly frequently, I've been able to manage my hemophilia entirely on my own for many years. I still attend my annual HTC clinic visits, infuse at home, and am able to manage my bleed pain. Unfortunately, 2020 began with a bleed that landed me in the hospital for the first time in more than a decade.

I had a terrible knee bleed that I could not control on my own. The pain was too severe, I wasn't able to do my infusions because of it, and I knew I needed help. I also knew I wasn't going to be able to make the two-hour drive to get to my HTC and its affiliated hospital, so, I went to the closest hospital with an HTC, hoping the doctors there would be able to adequately understand my diagnosis and treat me

accordingly. I quickly learned otherwise — this experience was going to be a harsh reminder that I always need to be able to advocate for myself.

“This experience was going to be a harsh reminder that I always need to be able to advocate for myself.”

I was so used to treating myself or being around doctors who knew me very well, that I had forgotten what it was like for a doctor not to trust my instincts about my hemophilia treatment. As soon as I got there, the doctors did not understand why I was treating with factor VII and not another bypassing agent. When I asked what bypassing agent they had in mind, they mentioned products that had activated factor IX in them. When I once again explained my allergy, they ignored me and began testing my inhibitor levels to see if they could begin tolerization or treating me with one of the bypassing agents I had already told them I couldn't use.

When you're in the hospital with a bleeding disorder, it's not uncommon to receive regular blood draws for testing. It wasn't until late into the first night of my stay, when I was getting one of the blood draws, that I finally asked what that particular blood draw was for. When the nurse told me they were checking my inhibitor levels to see if they could change my treatment, I was dumbfounded. I asked to speak to the hematologist about it the next morning and tried to get some sleep.



ADVOCACY PROFILE

The next morning, I was informed my admitting hematologist was not the one I would see, and in fact, I most likely would have a different hematologist every day, since they were very busy and had to rotate frequently. I also wasn't guaranteed to see a hematologist from the HTC and would probably be seen by hematologists who did not regularly treat hemophilia patients. Consequently, the coming days consisted of explaining my situation to the new hematologist every morning, until I was finally able to get the message across on the fourth day. My fifth hematologist was one from the HTC. She listened to and trusted me, and she promised to make a note for any other doctor who would see me.

Thankfully, I didn't have to argue with anyone else about my treatment, and I only spent a couple of more days in the hospital before I was discharged. I'm happy I found a hematologist who would listen to me, but I couldn't help but think of what could've happened had I not known myself as well as I do or didn't have the confidence to firmly tell a doctor what I needed for successful treatment. Had I let them try

a different bypassing agent, I could've had an unnecessary, life-threatening reaction. Had I let them continue to test my inhibitor levels, which are not very high because I haven't used factor IX since I was a kid due to my allergy, they might have thought it was safe to try to tolerize.

It's important to trust doctors. They studied for years to gain an understanding of the human body and the medicine used to treat its ailments, and patients should never take that knowledge for granted. But every hemophiliac is different. An understanding of the human body does not automatically give someone an understanding of your body. Many hematologists understand this, and different treatment can sometimes improve your quality of life. However, in the event that you find yourself in a situation like mine, it's incredibly important to remember that you are often the best person in the room to explain the way your body works and what it needs. Make sure you know what's best for you, and never be scared to fight for it! 💧





Hemdifferently

Exploring the science behind gene therapy research

Gene therapy research has the potential to bring an entirely new option to people with specific genetic conditions. Many gene therapies are in clinical trials to evaluate the possible risks and benefits for a range of conditions, including hemophilia. HemDifferently is here with gene therapy education, providing accurate information on the basics and beyond.

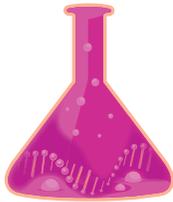
What questions do you have? Get them answered. Explore gene therapy at **[HemDifferently.com](https://hemdifferently.com)**.

No gene therapies for hemophilia have been approved for use or determined to be safe or effective.

B:OMARIN

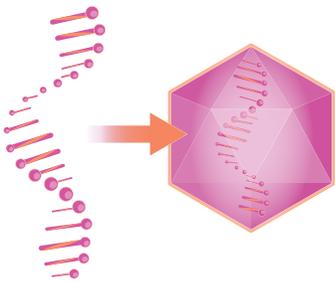
THE 5 STEPS OF INVESTIGATIONAL GENE TRANSFER

One method of gene therapy currently being explored in clinical trials is called gene transfer. This approach aims to introduce a working gene into the body to determine if it can produce a needed protein.



STEP 1 CREATING A WORKING GENE

A working copy of a mutated gene is created in a laboratory.



STEP 2 BUILDING A THERAPEUTIC VECTOR

A therapeutic vector is used to protect the working gene and serves as a transport vehicle for the gene to enter the body. The therapeutic vector is created from a neutralized virus, meaning no viral genes remain inside.



STEP 3 DELIVERING THE WORKING GENE

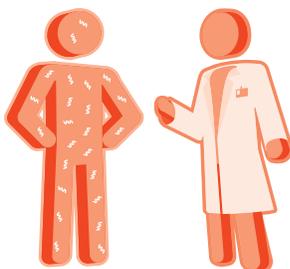
A single, one-time infusion delivers large numbers of therapeutic vectors into the body.



STEP 4 MAKING PROTEINS

Once in the body, the new working gene is designed to provide instructions for the body to make the protein it needs on its own.

 = Proteins.



STEP 5 MONITORING AND MANAGING HEALTH

Clinical trial participants are regularly monitored to better understand the safety of the gene transfer and to evaluate its effect on the body.

A Little Peace of Mind

HFA develops relief fund for bleeding disorders community directly impacted by COVID-19

BY EMILY ROUSH-BOBOLZ, STAFF WRITER

When a pandemic hit the United States in early 2020, no one knew what to expect. Schools and businesses began to close, and people were being laid off from their jobs, but it wasn't yet clear how the bleeding disorders community would be directly impacted. It was clear, however, that Hemophilia Federation of America would continue its mission to educate, assist and advocate for the community throughout the unforeseen crisis.

HFA immediately responded by developing a hub of information on its website to provide up-to-date information on product availability, COVID-19 information specific to bleeding disorders, and resources for health insurance and assistance for those who found themselves in a difficult situation.

But as COVID-19 further threatened the livelihood of bleeding disorders families across the U.S. with job loss and mandated shutdowns, the need for a national resource to apply for and receive emergency financial assistance became immediately necessary. In response, HFA created the COVID-19 Relief Fund within its Helping Hands program.

Individuals, families and industry partners who found themselves safe from the ravages of the pandemic stepped up and donated hundreds of thousands of dollars and continue to do so. Thanks to those donations, since the COVID-19 fund was established,

HFA has helped more than 350 families with more than \$230,000 in relief. Relief has been for housing assistance, utilities and transportation to help the families who have had trouble making a mortgage or rent payment while laid off or covering transportation expenses to get to HTC visits.

“It truly means so much having this resource during a time where none of us were prepared. It helps us worry less when bills are paid.”

—Bleeding Disorders Community Member



Lending a Helping Hand

Wendy*, 29, of California has a rare factor 13 deficiency. In early 2020 she was placed on furlough due to COVID-19 concerns. After some time on furlough, her employer asked her to return to work, but anxiety and concerns that it was too soon to return to the workplace plagued her.

Her employer demanded her return to work first thing on the following Monday morning, but with the family childcare provider closed on quarantine and her husband an essential worker, unable to take time off, Wendy was forced to resign.

"I felt robbed from my job," she said. "There was no choice but to resign. It's been a tough road to make decisions so fast because of this pandemic."

In April, a member of her family began to experience symptoms of coronavirus – severe headaches, body shakes, high temperature and extreme fatigue. An emergency room visit led to a diagnosis of coronavirus with pneumonia, followed by a five-night stay in the hospital. Medical bills topped \$17,000. Insurance helped with the medical bills, but the family still had difficulty making the mortgage payment. HFA's COVID-19 Relief Fund was able to help.

"It meant a lot to have the team at HFA find ways to lessen the stress for some people dealing with money issues," said

Wendy. "I also received a gift card for \$200 for groceries, which was an amazing thing since we were all out of jobs. It's amazing when we all work together."

To have the bleeding disorders community pull together in times of need is nothing new. In 2017, when hurricanes, tornadoes and other natural disasters hit the U.S. mainland and Puerto Rico, HFA worked quickly to establish the Together We Care fund. The fund was also maintained using the Helping Hands infrastructure, and again numerous donations from the community and partnerships with numerous bleeding disorders organizations allowed HFA to distribute a significant amount to those impacted by the natural disasters. At that time donations went toward replacing roofs, purchasing generators and helping with transportation to HTC visits.

For the families in 2017 and now for families impacted by the pandemic, like Wendy's family, Helping Hands and funds like Together We Care and the COVID-19 Fund bring a little peace of mind.

"It truly means so much having this resource during a time where none of us were prepared," she said. "It helps us worry less when bills are paid." 💧

**Name changed for privacy purposes.*



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COVID-19 Resources and Information for the Bleeding Disorders Community

Hemophilia Federation of America quickly responded to the needs of the bleeding disorders community during the coronavirus pandemic by creating a hub of valuable information at www.hemophiliafed.org/covid19.

HFA's COVID-19 Hub includes:

Patient Care and Product Availability

For patients and families concerned about access to care and the availability of bleeding disorders products and services during the pandemic:

- ⚙️ The Patient Voice inbox (or visit <http://bit.ly/PtVoiceSafety>)
- ⚙️ List of statements from pharmaceutical companies on product availability

Insurance Coverage Concerns

Maintaining comprehensive health insurance is important and options exist for those facing job loss or other economic impacts:

- ⚙️ A list of possible insurance options
- ⚙️ Downloadable resources: HFA's What Health Coverage is Available to Individuals & Families Without Job-Based Coverage & Newly Uninsured – Your Possible Paths to Insurance Coverage handouts

Financial Assistance, Food Needs and Family Resources

Relief for families facing loss of income and inability to pay essential household bills or address nutritional needs, plus family resources include:

- ⚙️ HFA's COVID-19 Relief Fund & Patient Assistance Portal
- ⚙️ National emergency assistance, food assistance & government benefits
- ⚙️ HFA's A Whole New World: Parenting in a Pandemic webinar series
- ⚙️ Parenting and sibling toolkits, educational resources and how to talk to kids in time of crisis

Mental Health

We're all in this together! Admitting this time (or any time) is a mental health challenge is nothing to be ashamed of. The hub includes:

- ⚙️ HFA's Mental Health Check-in Video Series & Let's Talk Mental Health in Times of Crisis webinar
- ⚙️ Advice on preventing loneliness and crisis toolkits

Text HOME to 741741 for the Crisis Text Line or call (800) 273-8255 for the National Suicide Prevention Lifeline if you need immediate help. 📞

Visit www.hemophiliafed.org/covid19



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^aOf 1% trough factor levels for standard half-life (SHL) products in adults and adolescents.

^bCompared with SHL products.

^cData shown are from 42 adults who received a pharmacokinetic (PK) assessment around the first Esperoct[®] 50 IU/kg dose.

^dTrough level goal is 1% for prophylaxis.

^eData shown are from a study where 175 previously treated adolescents and adults received routine prophylaxis with Esperoct[®] 50 IU/kg every 4 days.

Pre-dose factor activity (trough) levels were evaluated at follow-up visits. Mean trough levels for adolescents (12-<18 years) were 2.7 IU/dL.

^fSteady-state FVIII activity levels were estimated in 143 adults and adolescents using pharmacokinetic modeling.

^gFor up to 3 months.

What is Esperoct[®]?

Esperoct[®] [antihemophilic factor (recombinant), glycopegylated-exei] is an injectable medicine to treat and prevent or reduce the number of bleeding episodes in people with hemophilia A. Your healthcare provider may give you Esperoct[®] when you have surgery

- Esperoct[®] is not used to treat von Willebrand Disease

IMPORTANT SAFETY INFORMATION

Who should not use Esperoct[®]?

- You should not use Esperoct[®] if you are allergic to factor VIII or any of the other ingredients of Esperoct[®] or if you are allergic to hamster proteins

What is the most important information I need to know about Esperoct[®]?

- Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center
- Call your healthcare provider right away or get emergency treatment right away if you get any signs of an allergic reaction, such as: hives, chest tightness, wheezing, dizziness, difficulty breathing, and/or swelling of the face

What should I tell my healthcare provider before using Esperoct[®]?

- Before taking Esperoct[®], you should tell your healthcare provider if you have or have had any medical conditions, take any medicines (including non-prescription medicines and dietary supplements), are nursing, pregnant or planning to become pregnant, or have been told that you have inhibitors to factor VIII

- Your body can make antibodies called "inhibitors" against Esperoct[®], which may stop Esperoct[®] from working properly.

Call your healthcare provider right away if your bleeding does not stop after taking Esperoct[®]

What are the possible side effects of Esperoct[®]?

- Common side effects of Esperoct[®] include rash or itching, and swelling, pain, rash or redness at the location of infusion

Please see Brief Summary of Prescribing Information on the following page.

Discover more at [Esperoct.com](https://www.esperoct.com).



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

Esperoct[®] is a registered trademark of Novo Nordisk Health Care AG.

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esperoct[®]

antihemophilic factor (recombinant), glycopegylated-exei

esperoct[®]

antihemophilic factor (recombinant), glycopegylated-exei

Brief Summary information about ESPEROCT[®] [antihemophilic Factor (recombinant), glycopegylated-exei]

This information is not comprehensive.

- Talk to your healthcare provider or pharmacist
- Visit www.novo-pi.com/esperoct.pdf to obtain FDA-approved product labeling
- Call 1-800-727-6500

Patient Information

ESPEROCT[®]

[antihemophilic factor (recombinant), glycopegylated-exei]

Read the Patient Information and the Instructions For Use that come with ESPEROCT[®] before you start taking this medicine and each time you get a refill. There may be new information.

This Patient Information does not take the place of talking with your healthcare provider about your medical condition or treatment. If you have questions about ESPEROCT[®] after reading this information, ask your healthcare provider.

What is the most important information I need to know about ESPEROCT[®]?

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

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

What is ESPEROCT[®]?

ESPEROCT[®] is an injectable medicine used to replace clotting Factor VIII that is missing in patients with hemophilia A. Hemophilia A is an inherited bleeding disorder in all age groups that prevents blood from clotting normally.

ESPEROCT[®] is used to treat and prevent or reduce the number of bleeding episodes in people with hemophilia A.

Your healthcare provider may give you ESPEROCT[®] when you have surgery.

Who should not use ESPEROCT[®]?

You should not use ESPEROCT[®] if you

- are allergic to Factor VIII or any of the other ingredients of ESPEROCT[®]
- if you are allergic to hamster proteins

If you are not sure, talk to your healthcare provider before using this medicine.

Tell your healthcare provider if you are pregnant or nursing because ESPEROCT[®] might not be right for you.

What should I tell my healthcare provider before I use ESPEROCT[®]?

You should tell your healthcare provider if you:

- Have or have had any medical conditions.
- Take any medicines, including non-prescription medicines and dietary supplements.
- Are nursing.
- Are pregnant or planning to become pregnant.
- Have been told that you have inhibitors to Factor VIII.

How should I use ESPEROCT[®]?

Treatment with ESPEROCT[®] should be started by a healthcare provider who is experienced in the care of patients with hemophilia A.

ESPEROCT[®] is given as an infusion into the vein.

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

Your healthcare provider will tell you how much ESPEROCT[®] to use based on your weight, the severity of your hemophilia A, and where you are bleeding. Your dose will be calculated in international units, IU.

Call your healthcare provider right away if your bleeding does not stop after taking ESPEROCT[®].

If your bleeding is not adequately controlled, it could be due to the development of Factor VIII inhibitors. This should be checked by your healthcare provider. You might need a higher dose of ESPEROCT[®] or even a different product to control bleeding. Do not increase the total dose of ESPEROCT[®] to control your bleeding without consulting your healthcare provider.

Use in children

ESPEROCT[®] can be used in children. Your healthcare provider will decide the dose of ESPEROCT[®] you will receive.

If you forget to use ESPEROCT[®]

If you forget a dose, infuse the missed dose when you discover the mistake. Do not infuse a double dose to make up for a forgotten dose. Proceed with the next infusions as scheduled and continue as advised by your healthcare provider.

If you stop using ESPEROCT[®]

Do not stop using ESPEROCT[®] without consulting your healthcare provider.

If you have any further questions on the use of this product, ask your healthcare provider.

What if I take too much ESPEROCT[®]?

Always take ESPEROCT[®] exactly as your healthcare provider has told you. You should check with your healthcare provider if you are not sure. If you infuse more ESPEROCT[®] than recommended, tell your healthcare provider as soon as possible.

What are the possible side effects of ESPEROCT[®]?

Common Side Effects Include:

- rash or itching
- swelling, pain, rash or redness at the location of infusion

Other Possible Side Effects:

You could have an allergic reaction to coagulation Factor VIII products. **Call your healthcare provider right away or get emergency treatment right away if you get any signs of an allergic reaction, such as:** hives, chest tightness, wheezing, dizziness, difficulty breathing, and/or swelling of the face.

Your body can also make antibodies called "inhibitors" against ESPEROCT[®], which may stop ESPEROCT[®] from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

These are not all of the possible side effects from ESPEROCT[®]. Ask your healthcare provider for more information. You are encouraged to report side effects to FDA at 1-800-FDA-1088.

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

What are the ESPEROCT[®] dosage strengths?

ESPEROCT[®] comes in five different dosage strengths. The actual number of international units (IU) of Factor VIII in the vial will be imprinted on the label and on the box. The five different strengths are as follows:

Cap Color Indicator	Nominal Strength
Red	500 IU per vial
Green	1000 IU per vial
Gray	1500 IU per vial
Yellow	2000 IU per vial
Black	3000 IU per vial

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

How should I store ESPEROCT[®]?

Prior to Reconstitution (mixing the dry powder in the vial with the diluent):

Protect from light. Do not freeze ESPEROCT[®].

ESPEROCT[®] can be stored in refrigeration at 36°F to 46°F (2°C to 8°C) for up to 30 months until the expiration date stated on the label. During the 30 month shelf life, ESPEROCT[®] may be kept at room temperature (not to exceed 86°F/30°C) for up to 12 months, **or** up to 104°F (40°C) for no longer than 3 months.

If you choose to store ESPEROCT[®] at room temperature:

- Record the date when the product was removed from the refrigerator.
- Do not return the product to the refrigerator.
- Do not use after 12 months if stored up to 86°F (30°C) **or** after 3 months if stored up to 104°F (40°C) **or** the expiration date listed on the vial, whichever is earlier.

Do not use this medicine after the expiration date which is on the outer carton and the vial. The expiration date refers to the last day of that month.

After Reconstitution:

The reconstituted (the final product once the powder is mixed with the diluent) ESPEROCT[®] should appear clear and colorless without visible particles.

The reconstituted ESPEROCT[®] should be used immediately.

If you cannot use the reconstituted ESPEROCT[®] immediately, it must be used within 4 hours when stored at or below 86°F (30°C) or within 24 hours when stored in a refrigerator at 36°F to 46°F (2°C to 8°C). Store the reconstituted product in the vial.

Keep this medicine out of the sight and out of reach of children.

What else should I know about ESPEROCT[®] and hemophilia A?

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

Revised: 10/2019

ESPEROCT[®] is a trademark of Novo Nordisk Health Care AG.

For Patent Information, refer to: <http://novonordisk-us.com/patients/products/product-patents.html>

More detailed information is available upon request. Available by prescription only.

Manufactured by:

Novo Nordisk A/S

Novo Allé

DK-2880 Bagsværd, Denmark

For information about ESPEROCT[®] contact:

Novo Nordisk Inc.

800 Scudders Mill Road

Plainsboro, NJ 08536, USA

1-800-727-6500

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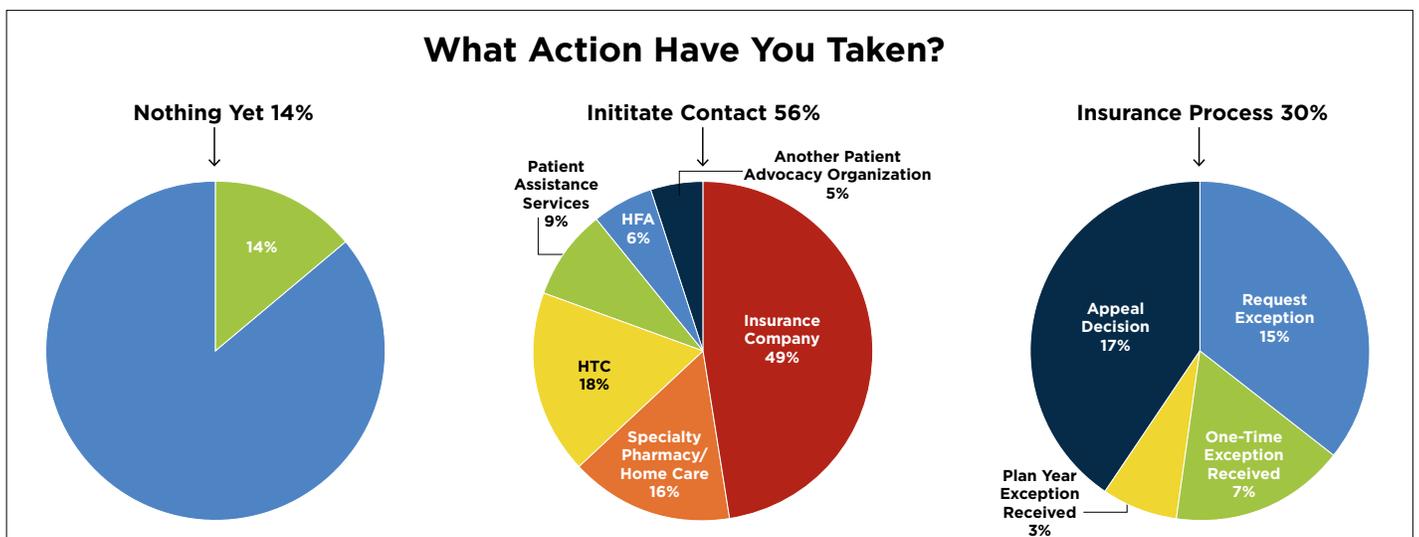
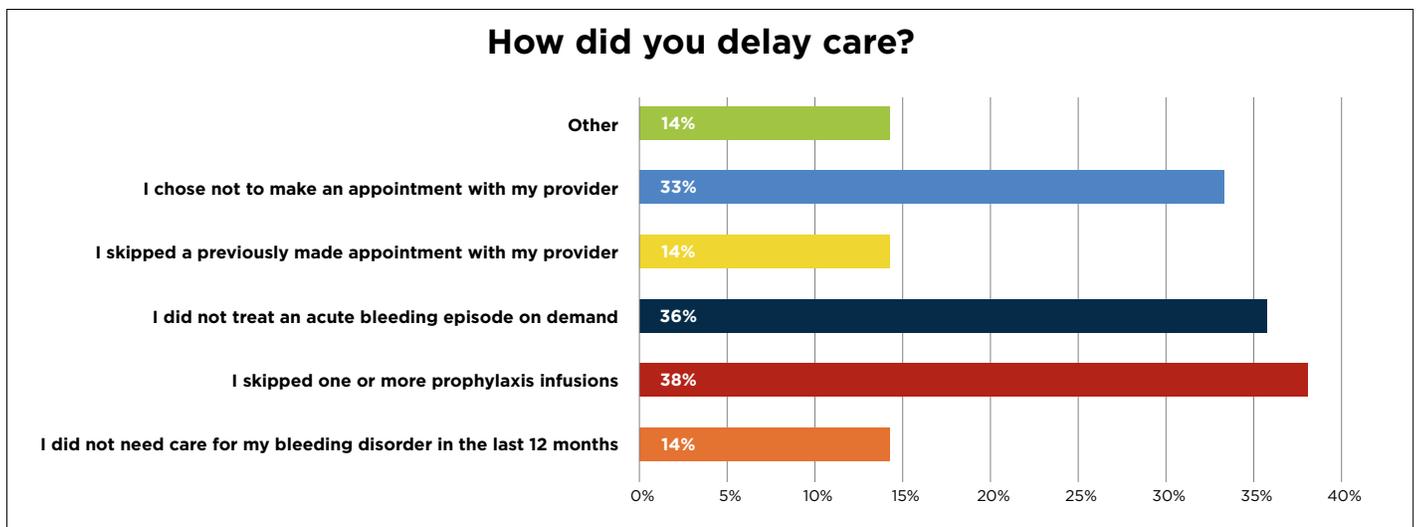
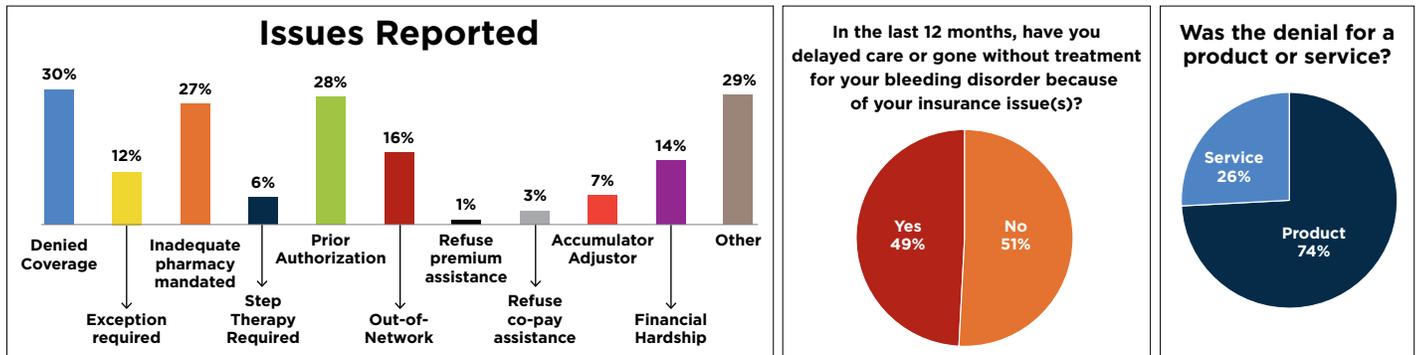


novo nordisk[®]

Project CALLS

Creating Alternatives to Limiting and Lacking Services

The Hemophilia Federation of America created Project CALLS to collect data and personal stories of how techniques employed by insurance companies create barriers to care for patients. In 2020, HFA will highlight stories of CALLS respondents. In addition to highlighting their stories, the data collected from more than 200 submissions since 2015 offers a baseline view of the issues the bleeding disorders community faces, the delays in care associated with those issues, and the actions the individual has taken to resolve the issue.



Copay Accumulator Adjusters Create Confusion, Obstacles for Consumers

BY MARK HOBRACZK, STAFF WRITER

Health insurers continue to develop new methods to limit access to care for members of the bleeding disorders community. Through Project CALLS, Hemophilia Federation of America has collected more than four years of reports from consumers that help to identify these new barriers.

HFA is using this data to develop resources to educate decisionmakers and community members about the harm caused to consumers by these restrictive insurance company practices. The following case study describes one of the insurance challenges recently reported to HFA through Project CALLS and suggests some ways consumers and HFA can work to ensure continued access to care.



A Recent Case Study

A young adult male with hemophilia A aged out of his parents' group health plan after age 25. He initially obtained individual platinum-tier coverage offered by the Affordable Care Act Marketplace in his home state. During this time, this enrollee had received cost-sharing assistance from the manufacturer for his factor product. Because this assistance covered his out-of-pocket (OOP) costs, he decided to switch to the bronze plan for the 2020 plan year, since it had the lowest premium.



Before switching plans, the enrollee did his homework to prevent any disruption in care. He confirmed that the provider network for the bronze plan included his physician and providers. He also made sure the new formulary covered the medications he required.

He learned from HFA presentations that health plans were increasingly using copayment accumulator adjusters to contain costs. These accumulators do not allow the value of an enrollee's third-party assistance to be applied to the enrollee's annual cost-sharing obligations. As a result, the enrollee could be forced to pay the full \$8,150 amount of the annual deductible under the bronze plan (which is the same as the annual out-of-pocket limit), despite receiving assistance.

This greatly concerned the enrollee and so he also took affirmative steps to determine whether the plan options available to him would apply an accumulator. He went into the local plan office shortly before the end of open enrollment but received conflicting information. Lower-level employees assured him the plan would not apply accumulators. However, a regional manager subsequently stated that the plan would start applying accumulators "across-the-board" for the 2020 plan year.

The enrollee never received any written notice confirming his plan would apply an accumulator. Instead, he was told by the office that the language could be found in "plan documents". On his own, the enrollee was able to find such language buried on page 123 of a 203-page document. The language in that document merely states that the health plan would apply accumulators at the plan's "discretion."

As a result, the enrollee decided to go ahead and sign-up for the bronze plan (since it had much lower premiums with only a slightly higher OOP limit). However, when he notified the manufacturer that an accumulator might be applied to his plan, the manufacturer stopped sending checks to the enrollee's insurer to cover his OOP costs.

The enrollee was very confused by the conflicting information he received from the insurer, which forced him to seek out emergency sources of funding (such as family loans) in the event he is forced to incur the \$8,150 deductible. Adding to this confusion is the fact that he had not been billed for any OOP cost following his first shipment of medication in 2020. He is requesting assistance from HFA on how to proceed.

Questions that arise with this case:

1. Should the enrollee ask the manufacturer to resume paying his cost-sharing assistance? Does it make sense to make such a request before the plan clarifies whether or not it is applying an accumulator?
2. Because the plan is being offered in a federally-facilitated ACA Marketplace, it must follow federal rules that prohibit midyear formulary changes that substantially increase OOP costs without "reasonable notice." Thus, is it even permissible for the plan to apply accumulators for 2020 since they have not issued advance notice to subscribers? Will Centers for Medicare and Medicaid Services enforce the prohibition against midyear formulary changes in cases such as this one? Or will CMS conclude that the discretionary language appearing on p.123 of the health plan document satisfies the "reasonable notice" requirement?
3. Is the health plan exercising discretion to apply accumulators only for its highest-cost enrollees? Would that violate the ACA's anti-discrimination provision? Will CMS enforce those anti-discrimination provisions?
4. Does the health plan intend to apply accumulators starting with the 2021 plan year, with clearer notice? With the same notice?

How HFA Uses Project CALLS to Help the Bleeding Disorders Community

- ◆ Educate community members about how to identify and receive clear notice of accumulators prior to plan selection.
- ◆ Educate community members about their rights when accumulators are applied.
- ◆ Educate community members about other sources of copay assistance that may not be subject to accumulators (e.g., third-party charitable assistance).
- ◆ Use this case study as an example of how insurers play "hide the ball" with accumulators and how such practices can lead patients astray, even when patients take advance steps to identify whether their cost-sharing assistance will be credited towards their cost-sharing obligations. ◆

Have you or family member experienced an insurance issue?

Share your experience at www.hemophiliafed.org/projectcalls by calling (202) 836-2530.



What We Learned About Inhibitors and Where We Need to Go

A Summary of HFA's Blood Brotherhood & Families Inhibitor Survey Data

BY DEBRAN TARVER, STAFF WRITER



Many people with hemophilia A or B or type 3 von Willebrand disease (vWD) treat by infusing clotting factor concentrates into their veins, which helps form clots, and stop or prevent bleeding episodes. Of those who infuse with clotting factor, some will develop an inhibitor, or an antibody, to that clotting factor, making the treatment less effective or in some instances ineffective, which results in bleeding episodes that are more prolonged or difficult to stop.

Inhibitor development is one of the most serious and costly medical complications of having a bleeding disorder. The sooner an inhibitor is identified, the sooner treatment to get rid of the inhibitor can begin. Prompt diagnosis and treatment of an inhibitor increases the success rate of getting rid of the inhibitor and reduces complications of bleeding. For these reasons, it is recommended that people get tested for an inhibitor every year.

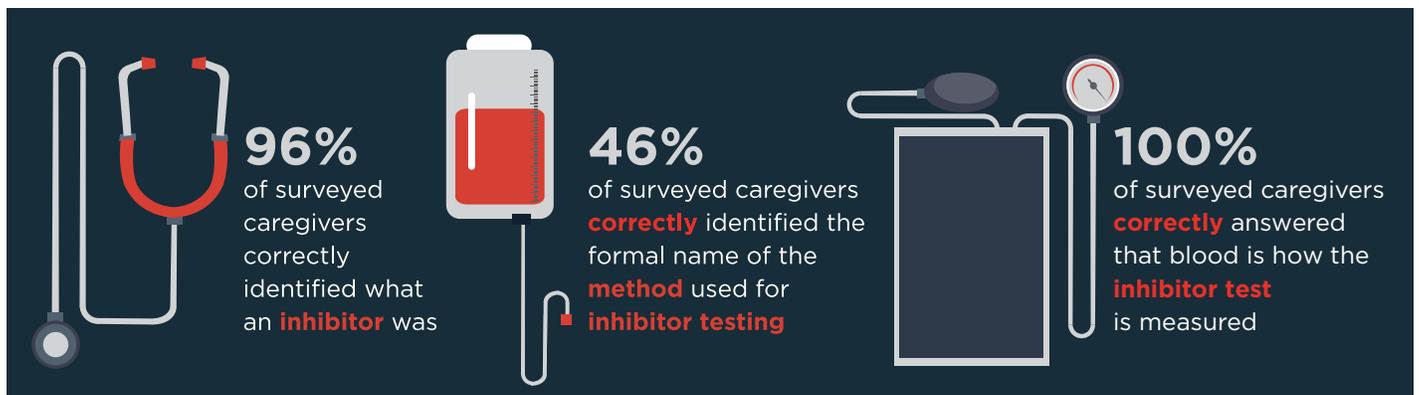
Hemophilia Federation of America surveyed participants enrolled in its Blood Brotherhood and Families programs

to better understand their knowledge and awareness about inhibitor development, risk factors and testing. A total of 107 men (diagnosed with hemophilia A or B) in the Blood Brotherhood program and 95 caregivers (of children younger than 25 years old and diagnosed with hemophilia A or B) in the Families program completed the survey. HFA used this knowledge to inform our educational programming activities. The following highlights what program participants reported about inhibitors and gaps in knowledge and awareness that is now being addressed in HFA programming.

Knowledge and Awareness of Inhibitors

To learn more about participants' current knowledge of inhibitors, we examined if respondents knew that an inhibitor is the development of antibodies by the immune system because it sees the infused clotting factor as a foreign substance that needs to be destroyed. We also examined if respondents knew one of the formal names of the method

Blood Brotherhood



Families



96% of surveyed caregivers correctly identified what an **inhibitor** was



50% of surveyed caregivers **correctly** identified the formal name of the **method** used for **inhibitor testing**



100% of surveyed caregivers **correctly** answered that blood is how the **inhibitor test** is measured

used for inhibitor testing was the Nijmegen-Bethesda Assay (NBA). Finally, we asked respondents to select the medium or how inhibitor testing is measured, in the blood, and not urine or saliva. The results for the Blood Brotherhood and Families participants are below.

Most participants from both programs correctly identified what an inhibitor was, and that blood is how the inhibitor test is measured. However, only approximately half of the participants were able to correctly identify the formal name used for the method of inhibitor testing.

Knowledge and Awareness of Inhibitor Risks

We also asked participants about their knowledge of the risks for inhibitor development. One question asked if they could correctly identify one or more risk factor(s) for inhibitor development, specifically genetic mutation, type and severity of hemophilia, age and number of exposures to factor product, intensive factor therapy, race/ethnicity, and family history of an inhibitor. Another question asked if individuals could identify that people with hemophilia A and B and individuals with type 3 von Willebrand disease were at risk for inhibitor development. We also asked if people believed they (or their child) were at risk based on their (their child's) self-identified bleeding disorder diagnosis. While most participants could identify one or more inhibitor risk factor(s), only 35 percent of men were able to identify the genetic mutation as a risk factor.

Blood Brotherhood:

While approximately 90 percent of participants could correctly identify one or more risk factors for inhibitor development, only 36 percent were able to identify that the genetic mutation was a risk factor. Only 71 percent of men and 62 percent of caregivers could correctly identify who was at risk (by their bleeding disorder). And half of caregivers did not believe, or did not know, their children were at risk for an inhibitor.

The genetic mutation causing the participants hemophilia, is currently the strongest risk factor for inhibitor development, and health education and promotion is needed to increase HFA members knowledge regarding this. Additionally, more education is needed for men and caregivers that people with hemophilia A, B and type 3 vWD who infuse with clotting factor products are at risk for inhibitor development.

Knowledge and Awareness of the Frequency of Inhibitor Testing

- 46% of men and 66% of caregivers at risk for inhibitor development identified they should be getting tested for inhibitors at least annually.
- Caregivers who were not aware of the importance of getting tested annually had never had their child tested for an inhibitor or didn't know about inhibitor testing.
- Most caregivers had children who were using on-demand therapy, whereas among men who were not aware of the importance of getting tested annually, the majority did not perceive they were at risk and were on prophylaxis.

Patient-Provider Relationships

Patient awareness of inhibitors, including risk factors, how testing is done and treatment for inhibitors, often requires a strong relationship with medical providers. To better understand how survey participants came to their answers to the questions about awareness and risks, we asked:

- if at the participant's last comprehensive visit, had they talked to their (or their child's) provider about getting tested for an inhibitor?
- how comfortable they were talking to their doctor about getting tested for an inhibitor?

Our results show that most participants feel comfortable talking to their provider about getting tested for an inhibitor, but many HFA Blood Brotherhood and Families program participants are not engaging in those discussions with their provider at their comprehensive visit. There may be a need to focus on patient-provider engagement regarding inhibitor testing.

Source of Inhibitor Information

In addition to learning about inhibitors through their doctors' visits, we wanted to know what other ways participants of the HFA Blood Brotherhood and Families programs received information about inhibitors.



Blood Brotherhood and Families participants received inhibitor education from HFA mainly through educational webinars and social media. However, only approximately 25 percent of both Blood Brotherhood and Families participants received a majority of information on inhibitor development/testing from HFA.

Conclusions

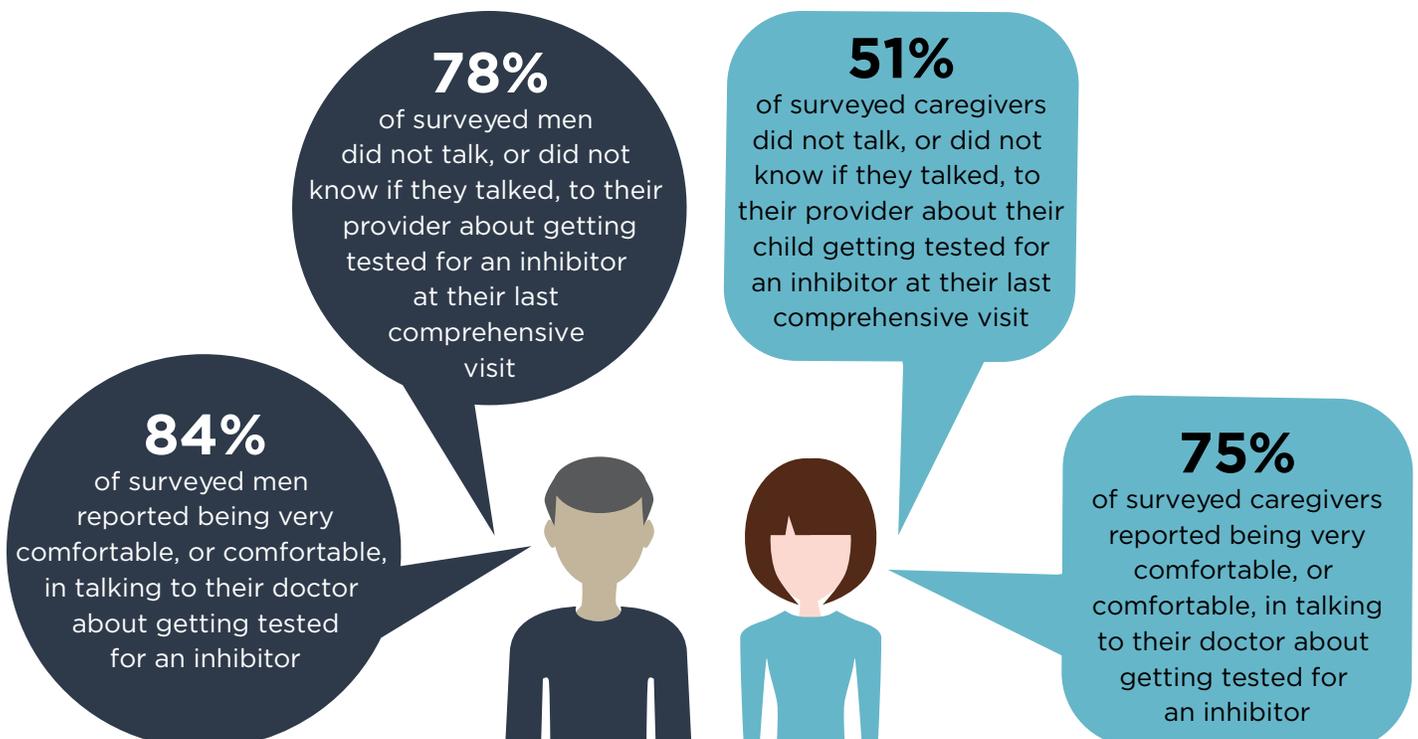
Our findings regarding inhibitor knowledge are consistent across both Families and Blood Brotherhood program participants, and suggest that both groups can correctly identify what an inhibitor is, but additional education is needed for individuals to be able to:

- Identify if they are at risk
- Correctly identify the inhibitor testing method name (for advocacy)
- Correctly identify all the risk factors for inhibitor development
- Promote individuals at risk to get tested for an inhibitor
- Encourage provider-patient conversations surrounding inhibitor development and testing.

HFA Symposium and Member Organization sessions appear to have the potential for the greatest educational impact, but one concern is the reach and impact of education using this delivery method as not everyone is able to attend local sessions or Symposium.



Patient-Provider Conversations



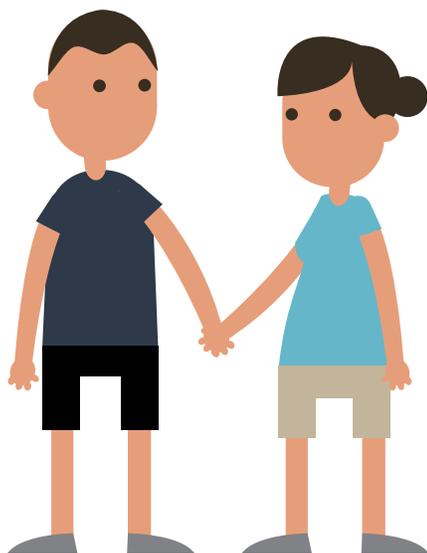
HFA recognizes the need to further improve awareness and knowledge of inhibitor testing and treatment among patients, families and caregivers. As a result, HFA has an educational inhibitor module in HFA's Learning Central, HFA's online learning platform. The module offers the opportunity for interactive, up-to-date, online learning about inhibitor information.

We would like to thank the HFA program participants who took their valuable time to complete the baseline survey. The information collected from this survey provided HFA with a better understanding of the knowledge about inhibitor

development and where HFA could engage the community to increase knowledge and awareness. This information is not meant to be reflective of the knowledge of all Blood Brotherhood and Families program participants, however, the gaps identified provide HFA with a better understanding about what education is needed and how HFA can best deliver this education to meet the needs of our program participants. HFA will continue to use this data to develop interventions aimed at increasing knowledge and awareness about the signs, symptoms, risk factors and testing at risk individuals for inhibitors. 🩸



Families



Identification of Inhibitor Risks

90%

of surveyed caregivers correctly identified one or more risk factors for inhibitor development

36%

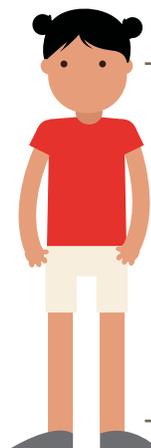
of surveyed caregivers correctly selected genetic mutation as a risk factor for inhibitor development



Who is at Risk

62%

of surveyed caregivers correctly identified individuals at risk for the development of an inhibitor



Self-perceived Risk

51%

of surveyed caregivers did not believe or did not know, their children were at risk to develop an inhibitor

This work was supported by Cooperative Agreement Number, NU27DD001151-05, funded by the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.



Turned Away

Hemophilia organization hopes to change current Medicare reimbursement that leads aging hemophilia patients struggling to enter nursing facilities

BY SONJI WILKES, STAFF WRITER

During National Hemophilia Foundation's Washington Days, NHF announced The Hemophilia Skilled Nursing Facility Access Act had been introduced in both the House and the Senate. This critical legislation will rectify a long-standing problem that has blocked access to skilled nursing facilities by Medicare beneficiaries who have hemophilia or other bleeding disorders.

Under current law, Medicare reimburses SNFs on a bundled, daily rate for patient stays. This payment is not high enough to cover the costs of medication used to control bleeding in a person with a bleeding disorder. As a result, most SNFs do not care for people with bleeding disorders due to the significant losses the SNF will incur as a result of those individuals' treatment needs.

"Access to skilled nursing facilities is critical for Medicare beneficiaries with bleeding disorders and we have been advocating to improve access for many years," said Michelle Rice, Chief External Affairs Officer for NHF. "NHF applauds Senators Menendez, Enzi and Whitehouse and Representatives LaHood, Higgins, Dingell and Bilirakis for their leadership in introducing this legislation that will improve care for hundreds of people with bleeding disorders in the US – and remove some of the strain on taxpayers."

The Hemophilia SNF Access Act would address this problem by adding bleeding disorders treatments to the list of high cost, uncommon services that SNFs may separately bill under Medicare Part B. There is precedent for creating such additional payment categories: under current law, Medicare can provide separate and additional reimbursement for chemotherapy, radioisotopes and certain prosthetic devices, when Medicare beneficiaries requiring such treatments receive care in SNFs.

The SNF legislation is the culmination of years of continued efforts by NHF and other bleeding disorders organizations. NHF heard from many community members over the years about challenges accessing SNF facilities due to the way Medicare reimburses bleeding disorders treatments.

The bill was a top talking point for the approximately 450 volunteer advocates with bleeding disorders who visited with their legislators at NHF's advocacy event, Washington Days in February.

"We hope that together, we'll be able to convince Congress to take action on this bill. It may seem small, but it has the ability to have a big impact on many people's lives," said Rice.

HFA was pleased to offer a letter of endorsement in support of the House and Senate bills.

*The Senate version of the Act, S. 3233, sponsored by Senators Menendez (D-NJ), Enzi (R-WY) and Whitehouse (D-RI), was introduced in late January. The House bill, H.R. 5952, is sponsored by Representatives LaHood (R-IL), Higgins (D-NY), Dingell (D-MI), and Bilirakis (R-FL).

People with bleeding disorders may need access to SNFs after a hospitalization related to surgery for joint disease or a co-morbidity like HIV or hepatitis. Doctors feel it is the best setting for them to access nursing care to help them recover more quickly.



People with bleeding disorders may need access to SNFs after a hospitalization related to surgery for joint disease or a co-morbidity like HIV or hepatitis. Doctors feel it is the best setting for them to access nursing care to help them recover more quickly.

This change to the Medicare law will allow people with bleeding disorders to receive care in SNFs, often the most medically-appropriate rehabilitative setting. People who can't access SNFs often stay in the hospital longer—costing Medicare and taxpayers more money—or may go home where their families are unable to properly care for them and then often return to hospital. There are about 1,000 people with bleeding disorders on Medicare and a much smaller number need access to SNF care each year. The bill will not increase Medicare costs as the policy is budget neutral.



SNFs won't accept Medicare beneficiaries with bleeding disorders because they get paid a bundled payment rate for patients that isn't high enough to cover treatment costs.

Treatment costs could be as high as \$10,000 per day right after surgery and SNFs can't afford to cover those costs.

Medicare allows SNFs to bill separately for a few rare, expensive services like chemotherapy and prosthetic devices.





MoRe CoRe.

Our new CoRes.

The Sanofi Genzyme Community Relationship and Education (CoRe) team is growing. With our larger team, we'll be able to bring a higher level of personalized attention to patients affected by rare blood disorders.

To us, it's personal.

We're here for you. Let's connect.

Call us at 855-693-5628

Visit Facebook @HemophiliaCoRes