

DATELINE

F E D E R A T I O N

Issue 58 | Volume 18 | Fall 2018

Understanding Chronic Pain, Psychological Changes, Opioid Dependency and Alternatives



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Bicycle Ride
Isn't Just About
Fundraising

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EXECUTIVE CORNER

Dear Friends,

Over the course of the past eight plus years we have been blessed to have our Hemophilia Treatment Center nurses in our lives.

Without a bleeding disorder and likely with other conditions, patients may not become familiar with the nurses they see. But our HTC nurses have been with us through a lot, from hospitalizations to hemophilia camp.^w

Our HTC has three nurses, all of whom have played a significant role in our journey so far. To my daughters, Kinzie and Jayla, they are a familiar face at camp and our annual clinic visit.

During every hospital stay or procedure, Kinzie has been able to count on seeing one of her nurses or hearing from them afterward to check in on her. They know Kinzie! They know she loves to play sports. They know she can be clumsy, and they know she has a big heart.

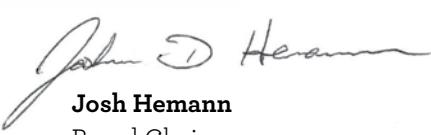
To Heather and me they have been the comforting voice walking us through some very difficult times and invested so much time into our family.



Michelle Krantz with the University of Iowa Children's Hospital HTC with Josh's daughter, Kinzie.



From left to right, Tami Bullock with the University of Iowa Children's Hospital HTC, along with Josh's daughter, Kinzie, Karla Watkinson with the HTC, and Josh's other daughter, Jayla.



Josh Hemann
Board Chair



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

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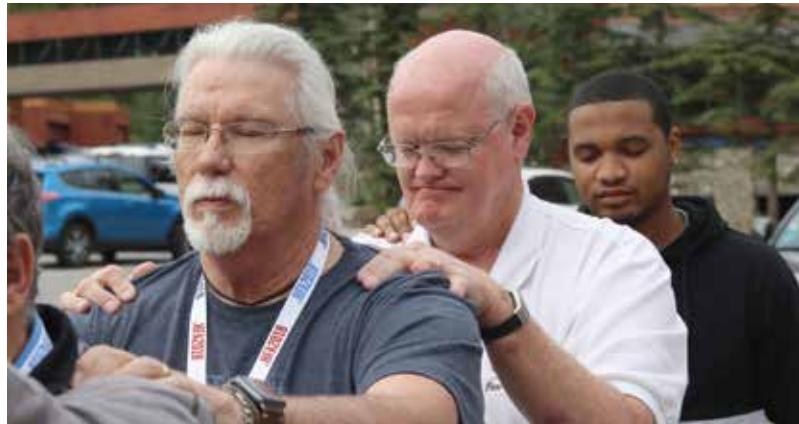
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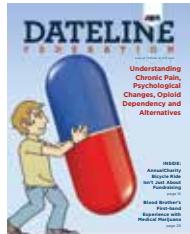
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ON THE COVER. A lot can happen to a body, mentally and physically, when someone experiences chronic pain. Handling the pain can feel like a heavy burden. We explain what happens in the body and brain, how to understand opioids, other pain relief substances and approaches to managing pain.

ARTIST: MICHAEL BISHOP. Bishop is a hemophilia patient and community member from Ohio, who works full-time for HFA as our Web Coordinator and in-house artist.

HAPPENING HIGHLIGHTS



A Legacy to Learn From

HFA to honor bleeding disorders history at 2019 Symposium

By Sonji Wilkes, staff writer

As Hemophilia Federation of America began preparations for its 20th anniversary five years ago, it quickly became apparent a retrospective of HFA's history would not be complete without a look back at the history of bleeding disorders over several decades.

Through the dedicated input of a volunteer steering committee, a first-of-its-kind historical exhibit covering 70 years of hemophilia was developed for HFA's Symposium that year.

"This was my favorite part of Symposium. I could have spent hours in this room," said a Symposium attendee in 2014.

HFA will soon be celebrating 25 years of serving the bleeding disorders community and will continue honoring the history with a similar exhibit at the 2019 Symposium in San Diego.

Community members are invited to experience this special exhibit once again. HFA is updating the exhibit with more archival documents, videos and

personal stories from the community. It will be an incredible experience honoring the past and building a future legacy.

In 2014, two rooms were filled with easy-to-read timeline boards dating back to the 1940s, binders of documents, hundreds of community resources, the Ryan White and Ricky Ray AIDS Quilt, and hundreds of community photos dating back to the 1950s.

"These history boards helped me to understand our community's important milestones, adversities and achievements," said a 2014 Symposium attendee. "I left inspired and hope more teens around the country can see these."

The room evoked powerful emotions from new as well as long-time participating community members alike. In the five years since, HFA has made the historical timeline available to its member organizations and has digitized the archives in an interactive format on its website. ♦

**“
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more teens around
the country can
see these.”**

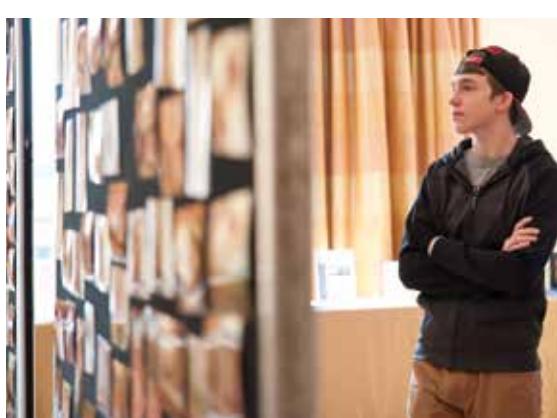
~a 2014 history room visitor

**SAVE
THE DATE!**

HFA's 2019 Symposium
April 4-6 ♦ San Diego



“
We owe it to the previous
generations, to ourselves,
and to our children to
not forget the past.”
~a 2014 history room visitor



HAPPENING HIGHLIGHTS

SCHOLARSHIP WINNERS

Each year, Hemophilia Federation of America awards scholarships to promising students in the bleeding disorders community seeking post-secondary education at a college, university or trade school. HFA asked applicants to submit an essay answering how being a member of the bleeding disorders community has influenced how they see the world or what they feel is the most important issue facing the community. HFA awarded the following scholarships:

Dillon Parsons

HFA Educational Scholarship | \$2,000
Grand Canyon University | Phoenix, AZ



I am beyond honored to be accepting this scholarship from the Hemophilia Federation of America. This money will go straight to paying for my tuition at Grand Canyon University.

This year will be my freshman year there, I am majoring in nursing. My goal is to become a nurse specializing in hemophilia one day. I realized that's what I wanted to do with my life very early. My nurses were always a huge influence in my life and always found ways to help me out. They helped me to learn to live with my disorder and not let it take over my life. I am truly blessed to be where I am in life and excited for the future!

Emily Sampson

HFA Educational Scholarship | \$2,000
Maryville University | St. Louis, MO



Ever since I was a child, I've always dreamed of having a job in the medical field. I grew up around my grandma and aunt working in a hospital and medicine was consistently a top interest of mine. Before I was even born, hemophilia was introduced to my family when my mom was diagnosed with Von Willebrand Disease when she was in her twenties. Since then, my sister and aunt have been diagnosed with the same condition. Although hemophilia affects our family differently than others, we have grown to be a part of the hemophilia community and have been involved in it for many years. The hemophilia community has just made my passion for medicine increase as I work with the program to advocate for a condition that is widely uncommon. I am so grateful for this scholarship and will put it towards my studies at Maryville University. Becoming a neonatal intensive care unit nurse will allow me to follow my passion and provide care for other families like the hemophilia community has done for mine.

Jasmyne Flowers

HFA Parent/Sibling/Child Educational Scholarship | \$2,000
Xavier University of Louisiana | New Orleans, LA



When my father passed from hemophilia my family and I were left with a great financial burden. So receiving this scholarship means so much to me. I will be attending Xavier University of Louisiana majoring Bio-Pre Med with plans to graduate and attend medical school. The loss of my father last year was due to lack of hematologists and knowledge of hemophilia in our area. Therefore I have plans to become a hematologist and come back to our hometown so that there is better treatment for blood disorders here in our community.

Nikunj Patel

HFA Medical/Health Services Educational Scholarship | \$4,000
Albert Einstein College of Medicine | Bronx, NY



I would like to thank you so much for offering me this scholarship, it is very much appreciated and will help me a lot financially! Thanks so much for everything! ❤

Educational Scholarship Two \$2,000 scholarships to students in the bleeding disorders community.

Parent/Sibling/Child Educational

Scholarship One \$2,000 scholarship to the immediate family member of a person with a bleeding disorder.

Medical/Healthcare Services Educational Scholarship

One \$4,000 scholarship to a student pursuing a degree in the medical/healthcare services field.

A BETTER DESIGN

Patient's voice influences the design of clinical trials

By Kyle McKendall, staff writer

When Bobby Wiseman enters a room, he doesn't go unnoticed. With a smile plastered on his face and a gregarious personality, Bobby is one of those people who makes you wonder, 'gosh, how is he *always* on?'

Despite a more than four-hour plane ride from his hometown in California to Ohio to participate in our annual Symposium, he arrived at the hotel right from the airport and ready for our interview. Though, we couldn't get started until he replied to an email confirming the shipment of goats and sheep to his family's recently-purchased 40-acre property.

Wiseman's life has seen a whirlwind of changes in just a few years. His biggest concern used to be which plane he had to board for a trip. Now, his life revolves around daycare programs and school teachers.

Actually, that's an understatement: Wiseman and his husband are the proud foster parents of five children ranging from ages 4 to 17. Toss in the care required to manage his own severe hemophilia B, the ongoing realities of aging (he's 47 but likes to describe himself as a "youthful 25" when asked), and his desire to make an impact within the bleeding disorders community, and his schedule is packed.

His personal story of living with hemophilia is one which many in the community can relate to. Born in the early '70s with severe factor IX deficiency, Wiseman ran into complications with

HIV and hepatitis C, the latter of which he's been fortunately cleared. He has a vivid memory of telling his mother "I don't want to have hemophilia anymore." That feeling is one that, as for so many others the community, has followed him his whole life as scientific advancements continue to point to a cure for hemophilia on the horizon.

"When I was 12, they said a cure is coming in five years," he recalls. "When I was 17, they said it again. Now, at 47, they are still saying it."

While there is still no cure for hemophilia, Wiseman has decided to invest himself fully in the search for what some might describe as one: he's participating in a clinical trial. Though, in true Bobby form, he's not just participating in the trial, he was involved in its design. After a referral from his hematologist, Wiseman was invited to attend the trial company's international meeting of clinicians, essentially the executive committee of the clinical trial, to bring a patient voice into the conversation. And that he did.

Bobby Wiseman shares his experience with a clinical trial.

Photo credit: Gina Richards.



Serving as the only patient representative in the group, Wiseman sat alongside a nurse coordinator and 25 clinicians, to discuss his thoughts and provide input on the trial. Two of his biggest critiques of clinical trials are the time requirement and strict schedules to which participants must adhere. Only operating during the work-week schedule of 9 a.m. to 5 p.m., trials create an inconvenient and almost impossible-to-meet demand on a person's schedule. He suggested using technology, such as video conferencing, texting and phone calls to allow for check-ins and updates with participants instead of requiring solely in-person meetings. Greater flexibility would allow for more participation. Wiseman also highlighted the disconnect that can occur between participants and clinicians on the formatting of questions. He believes having a diverse group of people involved in the formulation of questions is important to identify any misinterpretations or misunderstandings ahead of time.

He provided an example of a question that referenced a participant's sexual activity and highlighted the many interpretations that could come from that question given an individual's personal view of what constitutes sex. Another one of Wiseman's concerns is that in all of the clinical trials he's seen have been designed for men, despite the fact women comprise a significant portion of the bleeding disorders population.

If you've ever looked into participating in a clinical trial, you might agree with Wiseman when he says that the process is not easy to navigate. He describes the process of determining which clinical trials to participate in as convoluted, emphasizing there is no one-stop shop for comprehensive information.

"Yes, there is a website [with information], but then to find out if your HTC is [participating], and if they aren't, you have to try and to get them in: road blocks galore."

There have been times in his life when he would look at the medical staff in the hospital or hemophilia treatment center and think 'they don't get it, the pain I'm going through.' But the experience of sitting in on the meeting with the clinicians, "opened my eyes to realize that they are people too. People trying to make a difference."

He found his participation in the trial's design was personally rewarding and feels as though he was able to make an impact with his thoughts and contributions. More than a year before

he was asked to participate in the design of the clinical trial was when Wiseman and his hematologist simply began talking about the possibility of participating in one. Wiseman, the one to initiate the conversation with a peaked interest, didn't want to make a quick decision to participate in a trial that ultimately didn't help with his own hemophilia care and might then disqualify him from being considered for additional trials.

With so many companies entering the bleeding disorders realm, they decided to put the conversation on hold for a year to see how the landscape might change. When the two picked up the conversation again and Wiseman was presented with all of the clinical trials for which he might be considered, he felt ready to participate.



"My hematologist truly became a partner in the process of exploring options, learning about the trials, thinking through the outcomes, and what they would do for my life," he said.

While this experience was a first for him, Wiseman is of course no stranger to the bleeding disorders community. He is currently serves as co-director of Hemophilia Foundation of Northern California's annual summer camp program which just celebrated its 40th anniversary. He has been involved 37 of those 40 years. He serves as the chair of the summer camp planning committee, coordinating with all four local HTCs and the two national advocacy organizations, HFA being one of them. Wiseman was the honorary chair of the HFNC walk, coordinator of the Blood Brotherhood program for Central California Hemophilia Foundation and former chair of World Federation of Hemophilia's international youth congress.

With 47 years of hemophilia care under his belt, he's been on only four products. When longer lasting, extended-life products were coming out he was skeptical. He recalls asking friends in a half-joking, half-serious tone "are you growing any extra limbs



Bobby participated in research and so can you!
Are you registered in our Community Research Portal?
Register today at www.hemophiliafed.org/research

because of it?" He wanted to know "the real stuff, like does it have side effects?" He's always been skeptical about jumping from product to product and the decision to participate in a clinical trial wasn't one he took lightly. The thought of taking part in the design of a clinical trial and participating in it did however make the concept of cure seem all that much closer.

Wiseman was quick to point out the different interpretations of term "cure." For him, treating every seven to 10 days feels like a cure. The thought of treating just once every few months, would be even more life-changing. If you asked the parents of a child their thoughts on those scenarios, their answers may differ. In Wiseman's words, "it's relative by population."

When asked what people who are interested in participating in a clinical trial should know before they dive in, he was quick to answer, "be prepared for a lot of phone calls." The contracts, paperwork and confidentiality disclaimers continue to make their way in front of patients and the company's advocacy contact becomes a bit of a household name.

Wiseman's involvement in the design of the clinical trial is an example of patient-centered research at its finest: involving the people affected by research and research results in the process from the beginning. ❤

HFA's Research is Another Way to be Involved



HFA has just wrapped up its research project, "Gene Therapy and You," and I want to extend a **Big Shout Out** to those who participated!

I am so excited about the impact HFA research has on our community; it will shape our programming, advocacy and all we do!

I am also pleased to introduce HFA's new Research Director, Meg Bradbury.

Kimberly Haugstad, MBA, HFA President & CEO

While I am new to the HFA staff, I am not new the bleeding disorders community—I have been a Symposium speaker for several years and am very excited to be steering the HFA Research Team and applying what I have learned from other rare disorders.

If you have not yet participated in our patient-centered research, it's not too late! HFA has more projects to come. Stay tuned!

We are looking forward to sharing the results of our surveys!

Meg Bradbury MS, CGC, MSHS, HFA Research Director





THE

Understanding psychological and physiological changes in the brain caused by pain

PSYCHOLOGY OF PAIN

By Emily Roush-Bobolz, staff writer

Illustrations by Michael Bishop, HFA staff & community member

I sit at the edge of the worn-out recliner in my living room, my head in my hands, wondering what I'm going to do. How did it ever get this bad and how will it ever get better?

It started with just a few aches and pains, but I thought I was too young to worry and didn't think about it getting worse. The pain was just a minor side effect of my chronic condition. It would probably go away. But here I sit, years later, and the pain is worse, and now, more than I can handle. I don't even want to try getting up to get my bottle of pills in the other room. I know the raging discomfort will hit me again when I get up out of this chair.

That scenario might be familiar to sufferers of chronic illness. An inherited or acquired disease or an injury can provoke the body to respond with what starts as acute pain but may lead to chronic pain.

In a study released by the Centers for Disease Control and Prevention's National Center for Health Statistics, **one in four U.S. adults experienced pain lasting an entire day**

and one in 10 reported experiencing pain lasting a year or more. That could easily include bleeding disorders patients.

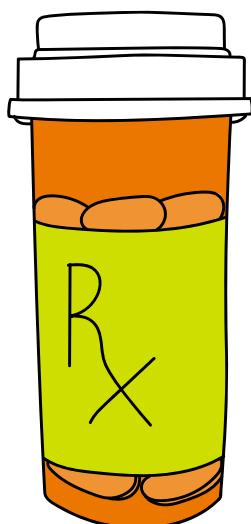
"For someone experiencing physical pain, they have two things go on. There are physiological and psychological effects," said Dr. Kim Mauer, Medical Director at Oregon Science and Health University's Comprehensive Pain Center and clinical associate professor. "Physiologically their body is getting to a point where they're living in a chronic inflammatory stage at a cellular and tissue level, which leads to receptor changes."

Besides the physiological effects, pain has a psychological effect. But Mauer says the psychological effects tend to come later.

"As pain lingers and they start to realize it may not be going away, you start to see depression and anxiety," said Mauer.

At that stage, when acute pain transitions to the chronic, inflammatory stage, the body's neurotransmitters begin to change, the brain experiences a decrease in serotonin, and fear-based behaviors such as anxiety set in.

"Some people do OK and can cope with the pain. They decide they'll be OK and modify their life," said Mauer. "But I see



people in pain still have somewhat mild depression. It's not enough to call it clinical level depression, but it's present because they realize they do have to modify their life."

But is there anything that can be done to reverse or control the psychological reaction?

"We now know the earlier you catch pain, when it's in the acute stage, the less likely the physiological and psychological effects will occur," she said. "You'll break the cycle of depression."

Many living with bleeding disorders are past that stage but Mauer encourages them not to lose hope. At that point, patients should seek out a comprehensive pain center which incorporates integrative medicine.

"It's never too late. Attack it from multiple levels—physical therapy, nutrition, massage, medication and maybe injections," she said.

She said patients, their physicians and caregivers need to recognize what is known as the biopsychosocial model and take an interdisciplinary approach to management of pain.

According to ClinicalPainAdvisor.com the biopsychosocial model is when pain begins in the nervous system in response to a physiologic stimulus, but an individual's pain experience depends on a complex interaction between various biological, environmental, psychological and societal factors.

Studies have shown pain management programs taking this approach, including behavioral therapy, physical exercise and medication management, led to reduced pain, increased activity and improved daily functioning in patients with chronic pain.

According to the print journal Practical Pain Management, traditional pain research tends to focus on the sensory reactions and the neurological transmissions. More recent research centers around a mind, body and spirit or societal approach, essentially balancing biological, psychological and social factors unique to each individual.

The Opioid Epidemic

Mauer, who discloses she's not an addictionologist, says in her clinical experience, she sees people become tolerant to medications after a period of time, so they increase their dose. With each increase, they start to get a reward—a temporary euphoria. That euphoric feeling can clear a pathway of needing progressively more and more.

Another thing that happens that isn't necessarily addiction but rather misuse (which she says is the new word for addiction), is patients start to self-medicate, adding other mood-altering substances such as drinking a glass of wine or smoking a cigarette with their pain medication.

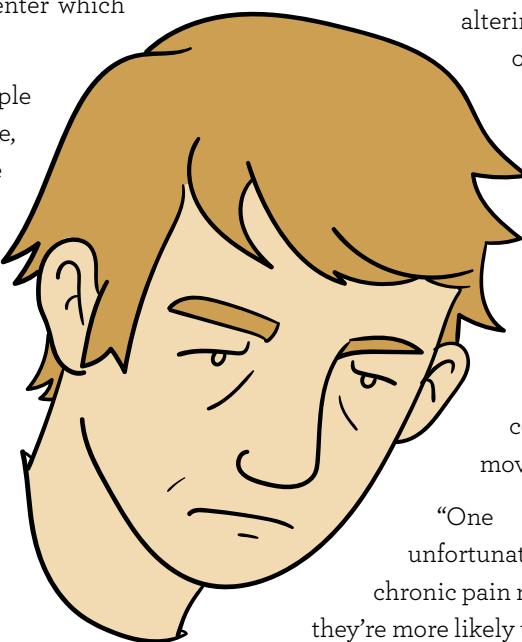
"They're not abusing or misusing each individual thing but putting lots of substances together. It starts putting everything into a package, which can lead to misuse," she said.

As concern for patients and an increase in government regulations of opioids continues, Mauer says there is a movement to wean patients off opioids.

"One of the things we're seeing now, unfortunately, is that as patients get taken off their chronic pain medications, if they don't go slow enough, they're more likely to turn to substances you don't get from a medical provider," she said.

A common approach she takes is to decrease opioid usage gradually, in percentages such as 5 to 10 percent per month. As patients approach lower dosages, she lowers the percentage decrease further to avoid withdrawal effects.

She also says the opioid buprenorphine may be prescribed in place of current medication. Buprenorphine is different from other opioids in that it produces less euphoria, has a lower chance of dependence or misuse and fewer withdrawal symptoms. She says it's becoming the drug that is surviving the opioid crisis because of the strict regulations on others. But it is only prescribed after the patient and physician have tried what they believe to be other options.



"It's never too late. Attack it from multiple levels—physical therapy, nutrition, massage, medication and maybe injections,"

...one in four U.S. adults experienced pain lasting an entire day and one in 10 reported experiencing pain lasting a year or more.

"It's OK if you can't get off opioids," she said. "I truly believe people can come off opioids and find alternative therapies to manage pain, but if they can't, it's OK."

For patients who can drop opioids, physicians are recommending other substances. Cannabionoids are showing promise in reducing inflammation. Cannabidiol oil, known as CBD, is sometimes being recommended and some physicians are closely watching the 2018 U.S. Farm Bill, which would completely remove hemp from the Drug Enforcement Administration's controlled substance list.

"CBD will likely become legalized soon, because of the promise it's showing," said Mauer.

Regardless of opioid or CBD use, Mauer strongly encourages interdisciplinary treatments, such as considering physical therapy, massage and meditation in combination with pain management to create an overall comprehensive approach. ♡



Comprehensive Approach to Pain Management

Consider integrating multiple methods to manage pain, which could include:

Physical Therapy

Massage

Acupuncture

Nutrition

Spiritual & Emotional Care



An article written for Hemophilia Federation of America by Mauer identified the **three main categories of pain**:

Neuropathic:

Examples include nerve pain/damage.

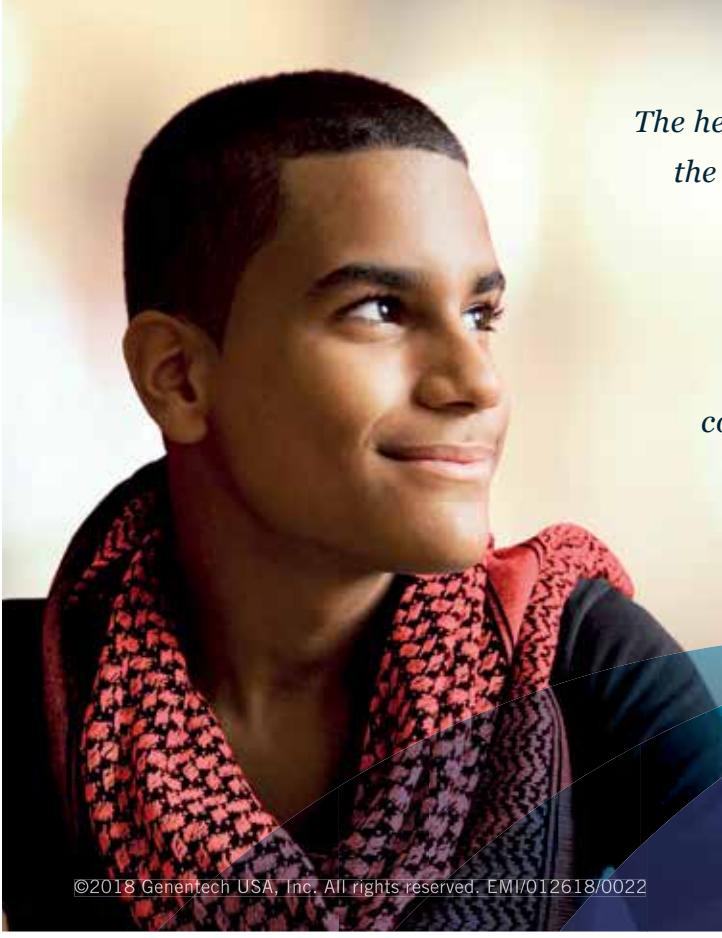
Nociceptive:

Examples include arthritis, bone pain, tumor pain.

Inflammatory:

Examples include pain from infections and dental pain. Most hemophilia pain would be a combination of inflammatory and nociceptive.

This article is for educational purposes only and is not intended to be construed as direct medical advice or the official opinion/position of HFA, its staff, or its Board of Directors. Readers are strongly encouraged to discuss their own medical treatment with their healthcare providers.



*The hemophilia treatments of today were once
the dreams of yesterday. Proof that when*

SCIENCE AND THE COMMUNITY

come together, great things happen.

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Let's put science to work

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Annabelle
Sibling
Massachusetts

Alex
Hemophilia A
Massachusetts



Clearing Away the Smoke Surrounding Medical Marijuana

By Catherine "Andy" Anderson, staff writer

Physical pain impacts quality of life in the bleeding disorders community. Not only does it inhibit our ability to participate at work and school or to be present for loved ones, but the uncertainty of when or whether relief will come creates a psychological dilemma.

In people with bleeding disorders, even teens and young adults, pain and joint disease are not uncommon. Even without a bleeding disorder, living to advanced age often comes with increased pain and limitations on mobility. For the first time, our community has an emerging geriatric population who will experience a high pain burden due to \ bleeding disorders and a history of inadequate treatment.

Anti-inflammatory drugs like aspirin are out of the question because they increase bleeding, leading many doctors to recommend stronger medications to help patients manage chronic pain. Considering the associated side effects and risk for dependency, patients may feel they must choose the lesser of two evils.

The good news is there are other options for pain relief with fewer negative side effects. Despite its reputation as a recreational drug, cannabis holds potential in combating pain without decreasing overall quality of life.

Let's clear away some of the smoke.

"Medical marijuana" may refer to using dried flowers of the Cannabis sativa plant and/or its extracted oils for medicinal purposes. Therapeutic substances found in cannabis can be inhaled, ingested or applied to target different symptoms. During the AIDS crisis, tetrahydrocannabinol (commonly called THC) became the first of these substances to gain notoriety, thanks to its ability to control neuropathic pain and increase appetites.

Recently another compound in cannabis, known as CBD (cannabidiol) has gained attention because it offers benefits without the mind-altering effects. In other words, it won't get you high. This is promising news for patients who want relief but are concerned about neurological development (especially in youth) or the risk for addiction.

The World Health Organization promotes a "ladder" process of treating pain, beginning with the simplest medications first and progressing only if pain isn't sufficiently managed. At a certain point during pain treatment, opioids may be

recommended. While they are effective, they come with side effects like constipation, itchiness, sedation and a risk for dependency.

Dr. Kim Mauer of Oregon Health and Science University, who specializes in pain medicine, recommends that at the same time opioids are proposed for pain management, physicians and patients should consider CBD as an alternative.

Before prescribing opioids to control pain, doctors evaluate a patient's quality of life and risk for substance abuse. Same with medical marijuana. When an individual decides to try cannabis, they are referred to a dispensary, where they receive help in choosing the right products for managing their symptoms.

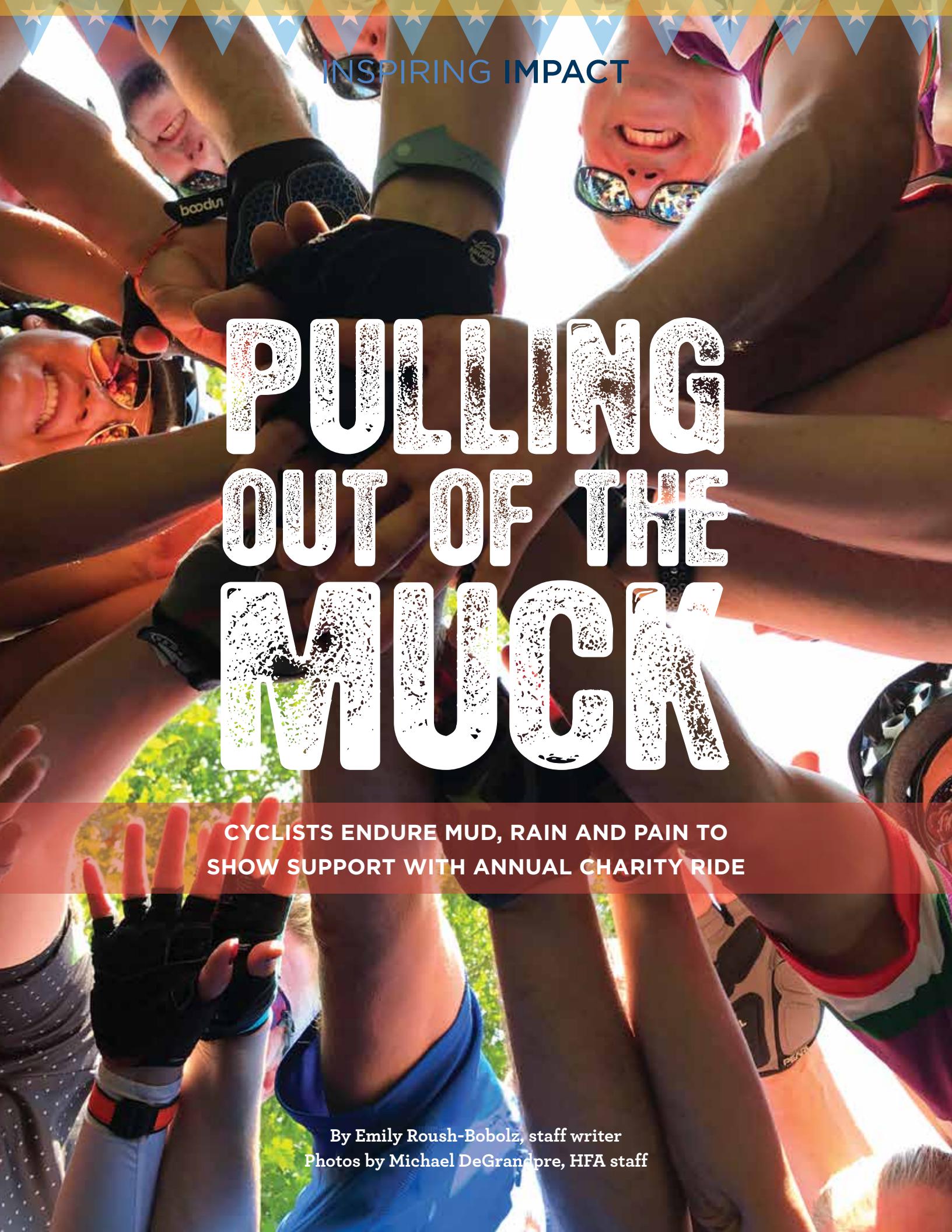
While topical applications or edible CBD oils hold the most promise for bleeding disorders pain, Dr. Donald Abrams with the Osher Center for Integrative Medicine believes patients and providers should remain open-minded about the potential benefits of using vaporized, not smoked, cannabis.

Though THC and CBD are the most heavily studied, there are hundreds of other compounds in the plant which aren't currently utilized in extracts or synthetic pharmaceuticals. Time and further study will tell the best practices for managing bleeding disorders pain with medical marijuana, but if a patient is concerned about the negative effects of opioid use, it may be worth initiating the conversation with their doctor.

Whatever the method of pain management, ongoing monitoring and communication are essential to striking a balance between pain abatement and side effects which decrease overall quality of life. The bleeding disorders community has come a long way thanks to medical advancements, but pain remains a major concern. Treating pain requires a multifaceted approach including exercise, good quality of sleep, and preventing and addressing bleeds.

In our journey to live fulfilling lives with, but not limited by, bleeding disorders, medical marijuana is part of the evolving discussion on how to manage pain. Patients who use marijuana illegally for medical or recreational purposes should be honest with their healthcare providers about their use. ❤

**HFA does not make recommendations on care and products for pain relief. Please speak with your healthcare provider. Refer to your state or tribal website to learn more about medical marijuana laws in your area.*



INSPIRING IMPACT

PULLING OUT OF THE MUCK

CYCLISTS ENDURE MUD, RAIN AND PAIN TO
SHOW SUPPORT WITH ANNUAL CHARITY RIDE

By Emily Roush-Bobolz, staff writer
Photos by Michael DeGrandpre, HFA staff

INSPIRING IMPACT

As I head along the Virginia highway on a crisp September morning, I turn on my wipers for a brief rain shower and I think of the 40 Gears for Good riders I'm meeting.

'I hope it's not raining on the trail,' I think to myself. I'm almost to Maryland's Big Slackwater Boat Landing along the Chesapeake and Ohio Canal Towpath when the rain stops, the sun pops out and a rainbow appears ahead.

The end of the rainbow seems to fall on the trail where the riders, both veteran and novice, have already cycled some 60 of the total 156 miles they'll cover over three days.

What's in the pot of gold at the end? More than \$100,000 going into Hemophilia Federation of America's Helping Hands program; money raised by riders and donors.

I finally arrive at the lunch stop near Antietam Battlefield, and although the calendar indicates autumn and a few leaves fall to the ground while I wait for the riders to arrive, the trees and grass remain green.

The slight breeze makes for a beautiful and comfortable day for the ride. But the next day, however, would be a different story, as the riders endured cold, rain, lots of mud and parts of the trail that had been washed out.

What possesses people to give up an entire weekend for this ride year after year? What's the draw, knowing the ride could be beautiful like day one and two this year, but it could end up with such harsh conditions as day three?

What makes them sweat their way along what seems like an unreasonable number of miles or get splattered with mud and rain or endure pain and sometimes bleeds, but still persevere?

It's because as the riders pedal through the mud and muck, stopping to clear their tires to be able to continue the trek, they realize it's emblematic of those they're helping pull through the muck of unfortunate circumstances and financial hardships with the money they're raising.

"It's an endurance ride. It's meant to be tough," said Sharon Meyers, HFA's Vice President of Development. "It resembles

the struggle of those in the bleeding disorders community and their resilience. Everyone here is mindful of those who can't be here."

"One of the best things we can do as human beings is lift someone up when they're at their lowest point," said Manny Lopez of Pennsylvania who joined the ride for the first time this year to represent Cottrills Specialty Pharmacy. "I always say we should be the light in someone's darkest moments and I think Gears for Good and the Helping Hands program are someone's light. It's an opportunity to lift someone up when they're down."

Lending a Helping Hand

HFA has provided emergency assistance to hundreds of families over the years, all through generous donations to the program either from fundraising events like Gears for Good or from individual and corporate donations.

"This ride is a blessing," said first-time rider, Frank Garcia of New York. In the past, Helping Hands was there for him in his time of need. "My family is doing well and we're in a place now that we can give back."

Vanessa Ridgway of New Jersey, whose husband, sister, brother-in-law and nephew participated this year, knows what it's like to wonder how the next bill is going to get paid. She remembers a time when her son was very ill. She was sitting in the hospital room, trying to keep it together. She remembers the anxious feeling each time she'd walk to the mailbox after that, worrying if there would be a new bill to pay.

"A parent shouldn't have to worry about what test their child needs and how much it will cost," said Ridgway. "They should only need to think about the care of their child."

"I think about when I couldn't pay bills," she said. "I know programs like this will be there for people."

In recent years, the fund has helped victims of Hurricane Maria in Puerto Rico. A week before the 2018 ride, which marked the seventh year of the ride, Hurricane Florence hit some of the states where the ride would take place.



Manny Lopez shows solidarity for the victims of the hurricane in Puerto Rico during Gears for Good.

INSPIRING IMPACT

As a show of solidarity and resilience, the riders carried flags for the states of Virginia and Maryland on the first day and donned the Puerto Rican flag on day two, as well as flags for Texas and the Carolinas, which have all been struck by natural disasters.

The Human Connection

As the riders roll into Harpers Ferry, W. Va., at the exhausting end of day two, I sit among them, quietly observing their friendly banter and laughter, knowing they would rather shower and lie in bed than socialize.

But they stick around, not wanting to miss a moment of time with their “old” friends and the new ones they’ve made.

It’s there I capture what I believe is the true essence of Gears for Good—the instant affinity that’s built between people who are meeting each other for the first time or seeing each other after many months apart. It’s the human connection with like-minded souls that is unique to the bleeding disorders community.

“The camaraderie! The people you meet on this ride are so great,” said Forrest McCaleb of Kansas, a second-year rider. “Over the weekend you learn their stories. It’s an educational and emotional journey.”

What surprised Lopez about his first time on the ride was the fellowship and the energy among riders. It wasn’t entirely about raising money. It was about connecting as people and building each other up.

“Everyone is tired, but they motivate each other to keep pushing through,” he said. “It’s not like the traditional educational events.”

Whether the riders have a bleeding disorder, are related to someone with a bleeding disorder or work for the pharmaceutical industry, there is a unique bond that’s forged through the three-day event.

Tom Knoerzer, owner of Get Out and Go Tours, which has provided valuable support for ride since it began, this year strapped on his helmet and cycling shoes to join the group, rather than drive the support vehicles.



From left: Lonn and Christina Vreeland and Joe and Vanessa Ridgway (Christina's sister) have participated in the past. This year the Vreeland's brought their son, Jace (center).

He, too, has formed a bond with riders and HFA staff despite the fact he didn’t know much about bleeding disorders when he was approached years ago to develop the ride. He also showed his support by raising funds as well as making donations to the other riders to help them meet their fundraising goals.

This year, Gears for Good raised \$101,656 toward Helping Hands. The average assistance per family is around \$450, which means more than 200 families could be helped through this one, special event. ♡

THANK YOU to our 2018 Gears for Good Sponsors:

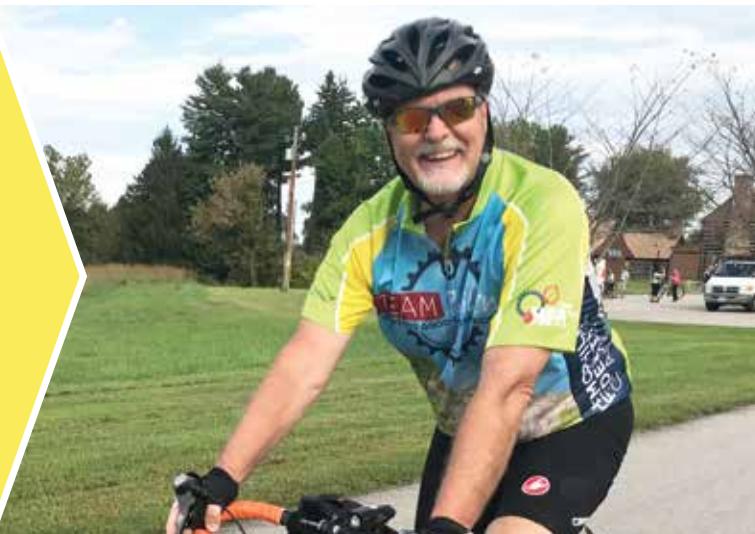
PLATINUM: CSL Behring

GOLD: Aptevo Therapeutics

SILVER: Grifols and Diplomat
Specialty Infusion Group

BRONZE: CVS Specialty

And special thanks to
Get Out and Go Tours



INSPIRING IMPACT

Building Future Cyclists

Donation of youth bicycles put smiles on little faces

Hemophilia Federation of America was grateful this past June to receive five youth bicycles from a group called the Funsters at the Salamander Resort and Spa in Middleburg, Va. HFA was connected to this group from long-time friend and supporter of HFA's Gears for Good national charity ride, Tom Knoerzer, of Get Out and Go Tours, through the United Way of the National Capitol Area.

HFA donated the bicycles to families in the D.C., Maryland and Virginia area, and are excited to see our future cyclists in action. A huge thank you to HFA Board Member Steve Long for receiving the bicycles and volunteer Dana Brayshaw for storing and distributing the bikes to the families. As always, we couldn't do what we do without our amazing volunteers! ❤



FACTOR REPLACEMENT REFLECTS THE PROTECTION WITHIN



For people with hemophilia, Factor treatment temporarily replaces what's missing.^{1,2} With a long track record of proven results, Factor treatment works with your body's natural blood clotting process to form a proper clot.²⁻⁶

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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. Canadian Hemophilia Society. Factor replacement therapy. <http://www.hemophilia.ca/en/bleeding-disorders/hemophilia-a-and-b/the-treatment-of-hemophilia/factor-replacement-therapy/>. Accessed May 18, 2018. 3. Franchini M, Mannucci PM. The history of hemophilia. *Semin Thromb Hemost*. 2014;40:571-576. 4. Hvas AM, Sørensen HT, Norengaard L, Christiansen K, Ingerslev J, Sørensen B. Tranexamic acid combined with recombinant factor VIII increases clot resistance to accelerated fibrinolysis in severe hemophilia A. *J Thromb Haemost*. 2007;5:2408-2414. 5. Antovic A, Mikovic D, Elezovic I, Zabczyk M, Hlutneny K, Antovic JP. Improvement of fibrin clot structure after factor VIII injection in hemophilia A patients treated on demand. *Thromb Haemost*. 2014;111(4):656-661. 6. Berg JM, Tymoczko JL, Stryer L. Many enzymes are activated by specific proteolytic cleavage. In: *Biochemistry*. 5th ed. New York, NY: WH Freeman; 2002. <https://www.ncbi.nlm.nih.gov/books/NBK22589/>. Accessed May 18, 2018. 7. Shire. Shire's 70+ year commitment to the hemophilia community. <https://www.shire.com/en/newsroom/2018/january/7sossj>. Accessed June 6, 2018.

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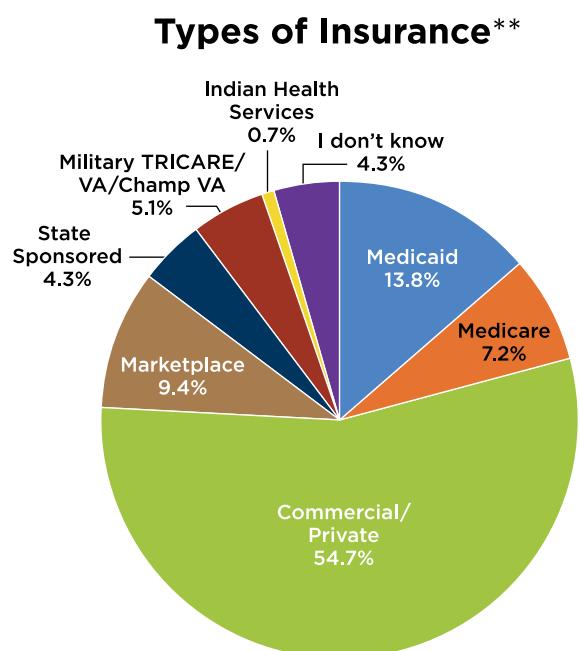
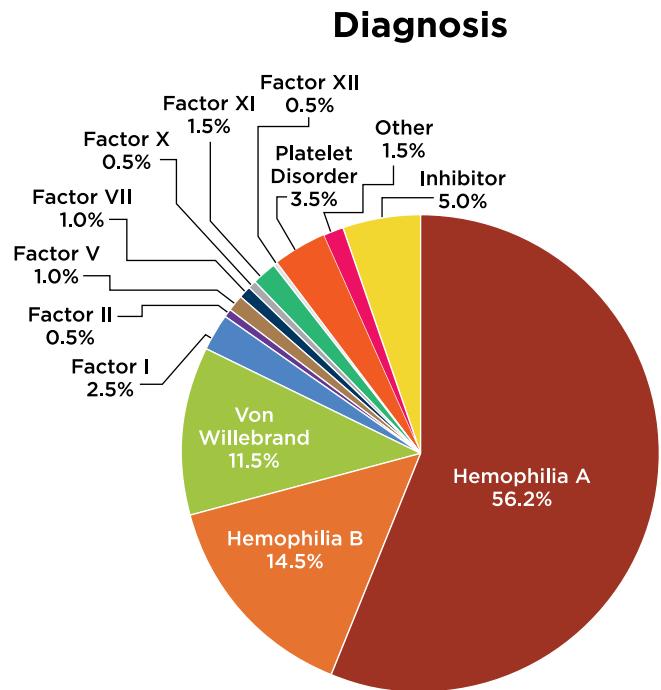
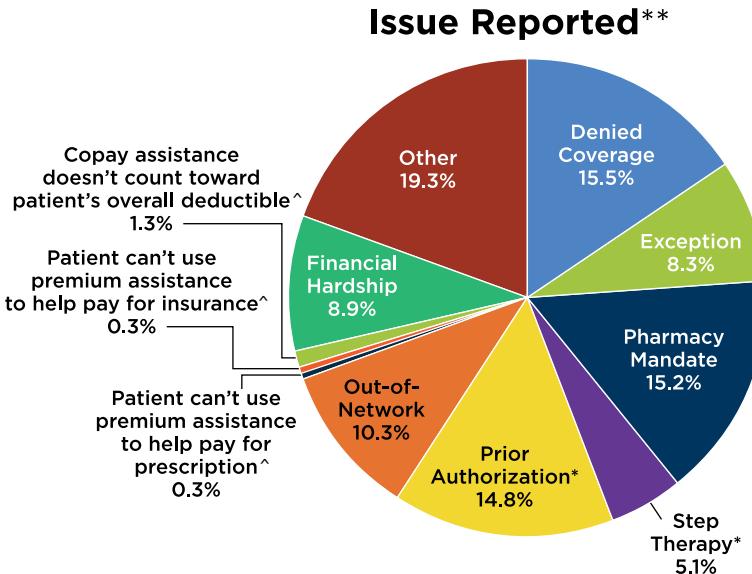
Project CALLS Report

Creating Alternatives to Limiting and Lacking Services

Project CALLS is an initiative designed to collect data and personal stories about how changes in insurance company policies are impacting the care of those with bleeding disorders. The data collected over nearly three years offers a baseline view of the types of insurance issues encountered by the bleeding disorders community. Overall, participants reported more issues in access to product vs. access to service. Most telling is the number of participants reporting delayed care, in which patients are not treating or receiving service when they are supposed to. Current data collected from Project CALLS demonstrates that insurance issues may correlate with negative health outcomes.

In February 2018, additional questions were incorporated to address evolving health insurance issues. With this new information, HFA is able to better understand how patients delayed care, how issues are being resolved, and how products are billed, as well as patient's experience with premium assistance.

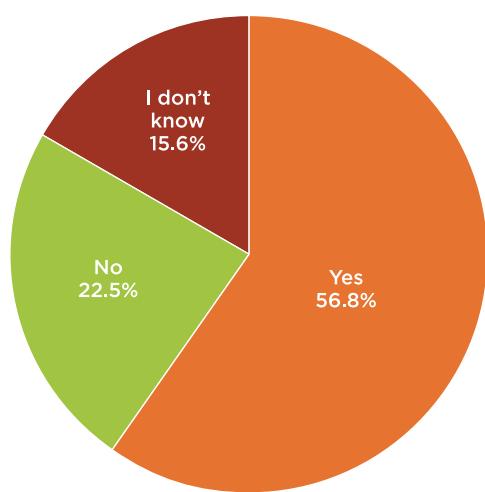
More than 170 members of the bleeding disorders community have completed Project CALLS.



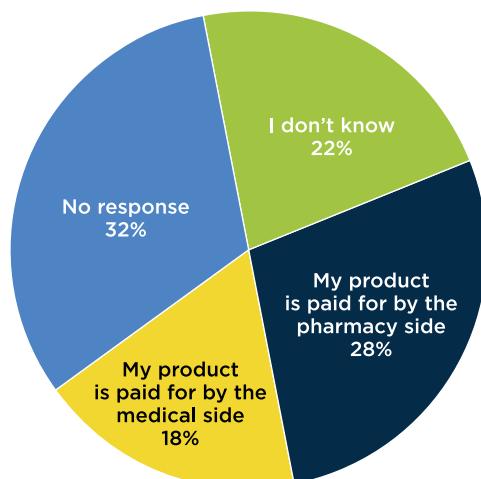


ADVOCACY PROFILE

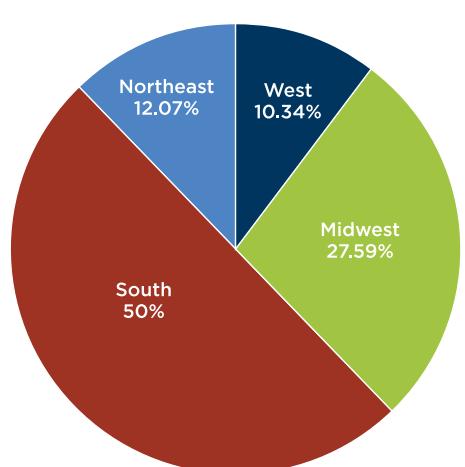
Specialty Pharmacy Mandate**



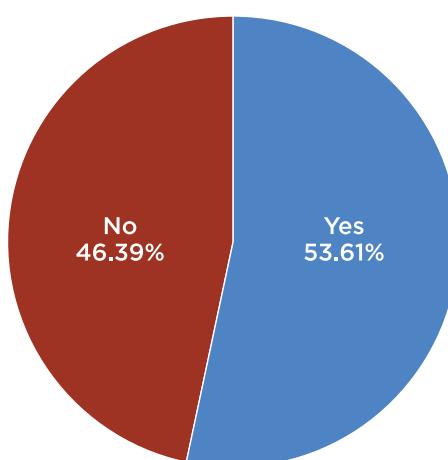
Pharmacy or Medical Billing for Product?



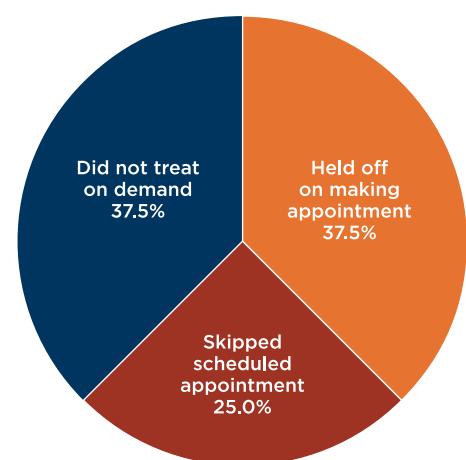
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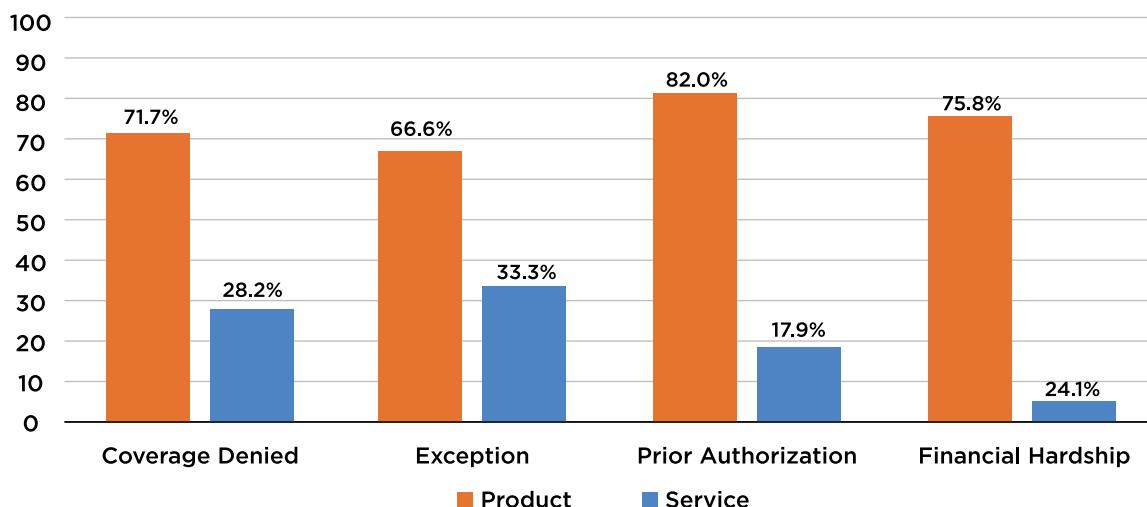
Delayed Care?



How Did You Delay Care?^



Product or Service?



*all reports not for bleeding disorder treatments

**percentages do not add to 100 because multiple answers reported

[^]new question as of February 15, 2018

Have you experienced any of the following challenges with your health insurance?

- ✓ Waiting for weeks to get factor?
- ✓ Being told you can't use your preferred doctor?
- ✓ Not being able to use the pharmacy that has been your long-time provider or being required to use a pharmacy that doesn't meet your needs?
- ✓ Financial hardship in the form of new or unexpected deductibles, copayments, or balance billing?

Across the country, HFA has heard of many cases of patients and their families facing limitations and restrictions from their health insurance provider. In an effort to respond to these challenges, HFA created Project CALLS. HFA's goal for Project CALLS is to identify trends in health insurance that create barriers to accessing care and treatment by collecting stories from the bleeding disorders community. The more data we collect, the more information we will have to educate policymakers, insurance companies, pharmacies, and other providers, and build a case for change.

**To create change, we need your help.
Share your experience with health
insurance issues at projectcalls.org
or by calling HFA: 202-836-2530.**



The main reason I chose to submit a Project CALLS report is because I understand the need for data to back up decision making. When we speak out and report the problems we encounter, our voices combine to become a powerful **tool towards change**. We are stronger and more likely to be heard by policy makers when we work together for change."

- Selina, Project CALLS Participant and Advocate

Bleeding disorders groups speak up for blood safety, HFA issues joint statement

In September, the federal Advisory Committee on Blood and Tissue Safety and Availability met to discuss "defining a tolerable infectious disease risk in blood safety from a patient's perspective."

The committee heard from a variety of speakers, including blood bankers, clinicians, researchers and patients over the course of an all-day meeting. Speakers surveyed the landscape of infectious disease risk, the use of risk assessments, and the sustainability of the blood supply.

Hemophilia Federation of America presented testimony during the public comment period, as did the National Hemophilia Foundation, and community member Catherine "Andy" Anderson. HFA's testimony reminded the committee about our community's painful history with a contaminated blood supply. HFA also laid out the following key principles of blood safety from the patient perspective:

- Patient safety must take the highest priority;
- Blood safety policy must be based on rigorous science;
- The federal government bears responsibility for maintaining a strong regulatory framework;
- The policy-making process for blood safety must be transparent and inclusive, involving meaningful patient/end-user input;

Users of blood and blood products are entitled to clear disclosures, so that they are able to give informed consent; and

- The federal government should consider establishing a compensation system for individuals who suffer adverse consequences from the use of blood or blood products.

You can read HFA's full statement at bit.ly/HFA2018ACBTSASStatement.



On the Other End of the Needle

By Emily Roush-Bobolz, staff writer

For someone with a chronic or lifelong medical condition, their first support network is often their parents and family.

For those with bleeding disorders, their second biggest support is often their hemophilia treatment center nurses. They are, essentially, family.

Becki Berkowitz, a nurse coordinator with the Hemostasis and Thrombosis Center of Nevada, has been in nursing for 42 years. She has spent a good part of her career in hematology and oncology.

"You're either addicted (to nursing) or you only stay for about three years," she said. "I'm addicted."

She characterizes herself as protective. She learns all she can about each of her patients and strives to be protective in her care. She has been with her patients and their families from the happiest moments, like watching them grow up, attending their birthday parties, graduations and marriages, to the most difficult moments, like the death of a patient.

"They're all family. We live through a lot with our family," said Berkowitz.

Truly Family

Karen Bishop of Ohio isn't like family—she truly is family. The nurse of 38 years, who now manages an assisted living facility, is the mother of Michael Bishop, Hemophilia Federation of America's Web Specialist, who has hemophilia.

She had dreams of being a hairdresser, but her mother encouraged her to be a nurse. She's worked in a hospital, in recovery and for nursing homes. She never imagined she'd need to use her nursing skills at home with her son, who was diagnosed at 11 days old. She had to learn quickly how to handle bleeding disorders.

"As a mom, being a nurse doesn't help. You're a mom at that moment," she said. "I can stick people all the time but doing it

with your child, it's different. I was never so nervous putting in an IV as I was with him."

Bishop is tough enough to handle death—it's part working in a nursing home—but seeing her son in pain is a different story. She says it's the hardest part of being a mom.

From Babes to Blood

Linda "Lew" Wyman-Collins, who is originally from D.C. and now lives in Texas, has volunteered for HFA since 1999, serving on the board and as a nurse in the infusion suite at HFA's Symposium.

She has worked as a nurse in a Neonatal Intensive Care Unit for 40 years. Her mother had seven premature babies, so being around children was familiar to her. Wyman-Collins was diagnosed with hemophilia and a platelet disorder later in life, realizing it must run in the family, but she didn't know about it.

She volunteers at hemophilia camps, where she says she's taught children as young as 5 to self-infuse. She also offers programs on hemophilia treatment and is published.

Whether a nurse is the beloved HTC nurse, a volunteer at camp or mom, the trust placed in the hands of nurses is something special.

"Our nurse has a sensitivity like no other nurse. She is always aware of every detail related to my son's treatment," said Raquel Almestica of Puerto Rico. "She has the memory of an elephant, from our appointments and of all the history of my son without looking at his record. She is the best nurse to have around"

"I had the same pediatric HTC nurse for almost 15 years. She was a constant through my visits, someone who I could count on to be there, know me and take care of me," said Eric Burgeson, HFA's Blood Brotherhood Coordinator. "Just as importantly, she was involved in the community, attending camp every year I went. She was a rock." ♦

"Michelle tiene una sensibilidad como ninguna otra enfermera. Siempre está pendiente de cada detalle relacionado a el tratamiento de mi hijo. Tiene una memoria de elefante se acuerda de nuestras citas y de todo el historial de mi hijo sin mirar el registro médico. Es la mejor enfermera." Raquel Almestica

That's a Wrap

HFA's summer interns sum up their summer in D.C.

By Catherine Anderson and Alexandra Abreu Boria, intern writers

Earlier this summer we welcomed our summer policy and government relations interns to our D.C. office.

Alexandra and Catherine are part of the bleeding disorders community and were chosen to participate in a 10-week internship because of their leadership qualities and interest in the field of policy and advocacy.

Throughout the summer they gained legislative, policy and advocacy training, attended hearings and Capitol Hill office visits, worked on federal and state projects, toured a plasma donation center, and assisted HFA staff with projects.

Q What was your favorite part of your summer with HFA?

ALEXANDRA: One of my duties was to write a research paper based on a topic of choice. I decided to focus on the healthcare crisis in Puerto Rico prior to and post-hurricanes Irma and Maria. Undoubtedly, one of my favorite parts of the summer was being able to research a topic that I'm so passionate about.

I was also able to attend a committee hearing on economic growth in Puerto Rico on the Hill, where I had the opportunity to hear the resident commissioner of Puerto Rico speak about hurricane relief on the island.

CATHERINE: I have really enjoyed living and working in Washington, D.C. There is always something to do, no matter what you are passionate about. For those of us who are especially interested in the role of social structures in health care, this is a great place to be!

Q What was the most surprising thing you learned?

ALEXANDRA: Prior to going to the plasma center, I was unaware of how many plasma donations are needed to treat hemophilia patients per year. It takes about 1,200 donations to treat just one hemophilic per year. I think more individuals within our community and non-community members

ADVOCACY PROFILE

should be aware of this number to further emphasize the importance of plasma donations for our community.

CATHERINE: One of my priorities was to learn more about the life cycle of policy. I now realize how slow the process can be, as legislators, constituents and relevant experts conduct a thorough conversation about proposed policy.

Washington is a busy city, so this conversation takes place in small chunks, at hearings, briefings, office meetings, over a long period of time. Alexa and I had the chance to sit in on a number of these discussions, most of which started before our arrival and will continue well past the end of our internship!

Q What was the most important thing you learned?

ALEXANDRA: I learned that it is so important for constituents to advocate to their legislators about issues importance to them. Most of the staffers on the Hill, senators and representatives we had the opportunity of meeting with were so receptive and cared about the stories of their constituents.

I think it is important for community members to be aware of how important their stories and voices are on the Hill. A lot of change can happen when individuals are consistent and express their opinions on how various policies can have an impact on their lives.

During HFA's Patient Fly-In, it was so fascinating to see some staffers on the Hill remember stories and some of the patients that had previously advocated. Our voices matter!

CATHERINE: If you pursue what you are truly passionate about, you will find a way to make that your profession.

Q How has this internship helped you to become a stronger advocate and leader?

ALEXANDRA: It has allowed me to push myself beyond my comfort zone. My knowledge on health care policy was limited to my personal experiences. However I was able to research, learn from others and gain knowledge from my coworkers at HFA, patients and others in the community. This internship has provided me with the tools necessary to continue being an advocate at a state and national level.

CATHERINE: The internship has given me opportunities to work on my public speaking skills and helped me to feel more informed and empowered as a representative of our entire community



Thank you to Shire and CSL Behring for their unrestricted advocacy grant to make our summer 2018 internships possible!

Q How are you going to stay involved in the bleeding disorders community?

ALEXANDRA: I hope to continue staying involved in advocacy efforts by attending future Patient Fly-Ins, HFA's annual symposium, and events held for the bleeding disorders community. After discussing with my local chapter in New York, I will continue participating with their advocacy committee.

CATHERINE: I've learned that a combination of solid, reliable data, and the stories of real people are the best way to demonstrate impact to legislators. As a social scientist, I will continue researching to change the lives of people with bleeding disorders for the better.





YOUR LIFE. YOUR ELOCTATE.

IN THE ASPIRE EXTENSION STUDY: 99.6% OF TARGET JOINTS RESOLVED^{*†}

150 previously treated people (age 12 years or older) who completed the pivotal study (A-LONG) were enrolled into the extension study (ASPIRE). In A-LONG prophy patients (n=117) had a median of 0 spontaneous bleeds and 0 joint bleeds.[‡]

^{*}A target joint is defined as a major joint with more than 3 bleeding episodes in a consecutive 6-month period. Target joint resolution is defined as less than 2 spontaneous bleeds in a 12-month period.

[†]Data is from the third interim cut of ASPIRE taken on January 11, 2016. In patients on ELOCTATE prophylaxis for at least 12 months, who had target joints at baseline, 234 out of 235 target joints were resolved. Forty-eight subjects had no target joint bleeding episodes.

[‡]Median of 1.6 overall bleeds per year. 0 bleeds in 45% of adults and adolescents.

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IMPORTANT FACTS ABOUT ELOCTATE® [Antihemophilic Factor (Recombinant), Fc Fusion Protein]

Please read this information carefully before using ELOCTATE and each time you get a refill, as there may be new information. This information does not take the place of talking with your healthcare provider about your medical condition or your treatment.

WHAT IS ELOCTATE?

ELOCTATE is an injectable medicine that is used to help control and prevent bleeding in people with Hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ELOCTATE when you have surgery.

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

You should not use ELOCTATE if you are allergic to ELOCTATE or any of its other ingredients. Tell your healthcare provider if you have had an allergic reaction to any Factor VIII product prior to using ELOCTATE.

Allergic reactions may occur. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash or hives. Your body can also make antibodies called "inhibitors" against ELOCTATE. This can stop ELOCTATE from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

THE MOST COMMON SIDE EFFECTS OF ELOCTATE INCLUDE:
Headache, rash, joint pain, muscle pain and general discomfort. These are not all the possible side effects of ELOCTATE. Talk to your healthcare provider for more information and about any side effect that bothers you or does not go away.

WHAT SHOULD I TELL MY HEALTHCARE PROVIDER BEFORE STARTING ELOCTATE?

Tell your healthcare provider about all your health conditions, including if you:

- Have or have had any medical problems.
- Are taking any prescription and non-prescription





medicines, such as over-the-counter medicines, supplements, or herbal medicines.

- Are pregnant or planning to become pregnant. It is not known if ELOCTATE may harm your unborn baby.
- Are breastfeeding. It is not known if ELOCTATE passes into breast milk or if it can harm your baby.

AFTER STARTING ELOCTATE:

If your bleeding is not controlled and you experience a lack of clinical response to Factor VIII therapy, call your healthcare provider right away. Medicines are sometimes prescribed for purposes other than those listed here. Do not use ELOCTATE for a condition for which it was not prescribed. Do not share ELOCTATE with other people, even if they have the same symptoms that you have.

HOW SHOULD I RECEIVE ELOCTATE?

ELOCTATE should be administered as ordered by your healthcare provider. You should be trained on how to do infusions by your healthcare provider. Many people with Hemophilia A learn to infuse ELOCTATE by themselves or

with the help of a family member. See the booklet called "Instructions for Use" packaged in your ELOCTATE for directions on infusing. If you are unsure of the procedure, please ask your healthcare provider.

QUESTIONS?

The risk information provided here is not comprehensive. To learn more, talk about ELOCTATE with your healthcare provider or pharmacist. The FDA-approved product labeling can be found at www.eloctate.com or 1-855-MyELOCTATE (693-5628). 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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TAKING AN ALTERNATE ROUTE

HFA's Web Specialist, Michael Bishop, recently spoke to a fellow blood brother about his experiences with medical marijuana.

The experience of having hemophilia can vary greatly from patient to patient. With different types, severities, added complications such as inhibitors or allergies, hemophiliacs can live very different lives.

One aspect of having hemophilia that is consistent amongst most patients is pain. Bleeds hurt. Our joints will likely take a lot of damage, which often leads to chronic pain. The treatment of pain is an important, and sometimes difficult, topic to discuss.

The opioid crisis in the United States has led many patients to seek alternatives. Perhaps the most popular of which is medicinal marijuana. I sat down with a hemophiliac, whose name has been removed to protect their anonymity, to discuss their journey from opioids to marijuana.

Q What is your personal history with prescription pain pills (opioids)?

A As a young child laying in the hospital with horrible joint bleeds, the Darvon and Darvocet they would give me had little benefits. It wasn't until I became an adult that I realized that my genetic make-up is such that I don't metabolize opioids, my gut doesn't break them down into a usable form. Therefore, unless IV, opioids are almost useless.

Q Did your relationship with opioids change over time? (i.e., did you find yourself using more and more as time went on?)

A Once as a child I had took a nearly fatal dose of Darvon because I had a very bad bleed start late at night and didn't want to wake my mom to take me to the hospital. As an adult, I was taking three to six times the amount of hydrocodone prescribed to get relief.

Q Without naming anyone in particular, have you seen other people in the community taking too many opioids?

A I know, or have known, brothers and sisters that have been addicted to their opioids. Some have gone through rehab, and one overdosed. It is a major problem that most people don't want to admit or talk about.

Q What made you want to make the switch to medical marijuana?

A I remember as a teen experimenting with pot and realized that it did wonders for pain when having a bleed. Unfortunately, I had limited access and had to hide it from my parents and the police. As an adult learning that opioids didn't work, it was easy to consider medical marijuana.

Q How has using medical marijuana differed from using opioids for pain?

A Medical marijuana actually works and there is a residual effect that I feel that you don't get with opioids. Unfortunately, one must be careful crossing state lines as it isn't legal in all 50. What we haven't explored (in this article) yet is the use of CBD which IS legal in all 50. CBD in its many forms has done wonders for working on the causes of my chronic pain. CBD1 & CBD2 works on nerve pain and inflammation helping to reduce symptoms. CBDs are worthy of their own article.

Q What do you think is a common misconception people have about medical marijuana?

A That it is always a “gateway” drug to harder, more dangerous drugs. There are so many different strains of medical marijuana that you are NOT guaranteed to become a *pot head, stoner*, or couch potato. When well-managed, it can be controlled and extremely helpful.

Q Some patients worry that medical marijuana won't be enough for their pain and won't give them the relief that opioids do. How to you feel about those worries?

A There are many methods of using medical marijuana, with various strengths. Most likely, one will find that it is more than enough.

Q Do you think medical marijuana could benefit the hemophilia community at large?

A Yes, but it is not for everyone. Just like alcohol, it can be addictive and abused. Of course, minors being able to use it is also a widely debated topic.

Q If you were asked to give advice to someone thinking about switching from opioids to medical marijuana, what would you tell them?

A First, is it legal in your state? If not, you may not have a trusted source and run the risk of trouble for your relief. Learn about different strains and delivery methods. Edibles are great but take longer to metabolize than vaping or smoking. Consider the cost difference and how you can obtain the marijuana. Are you drug tested at work? If so, could it affect your employment? Do you have an addictive personality, and a support system to help you keep it in check? Realize that you can vary your dosage of marijuana just like you can with opioids.

Q Do you have any final thoughts regarding this topic?

A Medical Marijuana has some clear benefits over opioids but must be controlled, too. Experimenting with finding the strain(s) that work for you can be a lot of fun. Just be careful and responsible. ♡

*HFA does not make recommendations on care and products for pain relief. Please speak with your healthcare provider. Refer to your state or tribal website to learn more about medical marijuana laws in your area.





WARNING TO IMMIGRANTS ABOUT MEDICAL AND LEGALIZED MARIJUANA

The Immigrant Legal Resource Center released an advisory, warning immigrants on the risks of purchasing and using medical and legalized marijuana.

The advisory says:

Across America, states are moving to legalize some use of marijuana. As of January 2018, 29 states and the District of Columbia have legalized medical marijuana. Nine states and the District of Columbia have legalized recreational marijuana for adults.

Noncitizens residing in these states may think using marijuana in accordance with state law will not hurt their immigration status or their prospects for getting lawful status. Unfortunately, that is wrong. *For immigration purposes*, it is federal law that controls, and it remains a federal offense to possess marijuana.

In particular, a noncitizen who admits to an immigration official that she possessed marijuana can be found inadmissible, denied entry into the United States, or have her application for lawful status or even naturalization denied.

Depending on the circumstances, it can make a lawful permanent resident deportable. This is true even if the conduct was permitted under state law, the person never was convicted of a crime, and the conduct took place in her own home.

State laws legalizing marijuana provide important benefits, but, unfortunately, they also are a trap for unwary immigrants.

The message is simple: Immigration law treats any marijuana-related activity as a crime, with harsh penalties, even if it is permitted under state law.

The advice is:

- Stay away from marijuana until you are a U.S. citizen.
- If you truly need medical marijuana and there is not a good substitute, get a legal consult.
- Do not carry marijuana, a medical marijuana card, or marijuana stickers, t-shirts, etc. Remove any text or photos relating to marijuana from your social media and phone.
- If you have used marijuana or worked in the industry, get a legal consult before leaving the United States or applying for naturalization or immigration status.
- Never discuss conduct involving marijuana with immigration, border, consular or law enforcement authorities, unless your immigration attorney has advised that this is safe.

The full advisory warning, which was published in January 2018, can be viewed at www.ilrc.org. 





ADVERTENCIA A LOS INMIGRANTES SOBRE LA MARIHUANA MÉDICA Y LEGALIZADA

El Centro de Recursos Legales para Inmigrantes publicó un aviso, que advierte a los inmigrantes sobre los riesgos de comprar y usar marihuana médica y legalizada.

El aviso dice:

En todo Estados Unidos, los estados se están movilizando para legalizar el uso de la marihuana. A partir de enero de 2018, 29 estados y el Distrito de Columbia han legalizado la marihuana medicinal. Nueve estados y el Distrito de Columbia han legalizado la marihuana recreativa para adultos.

Los no ciudadanos que residen en estos estados pueden pensar que consumir marihuana de acuerdo con la ley estatal no perjudicará su estatus migratorio ni sus posibilidades de obtener un estatus legal. Desafortunadamente, eso está mal. Para propósitos de inmigración, es la ley federal la que controla, y sigue siendo un delito federal poseer marihuana.

En particular, una no ciudadana que admite a un funcionario de inmigración que poseía marihuana puede ser declarada inadmisible, se le puede negar la entrada a los Estados Unidos o se le puede negar su solicitud de estatus legal o incluso de naturalización.

Dependiendo de las circunstancias, puede hacer que un residente legal permanente sea deportable. Esto es cierto incluso si la conducta fue permitida por la ley estatal, la persona nunca fue condenada por un delito y la conducta tuvo lugar en su propia casa.

Las leyes estatales que legalizan la marihuana brindan importantes beneficios, pero, desafortunadamente, también son una trampa para los inmigrantes incautos.

El mensaje es simple: la ley de inmigración trata cualquier actividad relacionada con la marihuana como un delito, con penas severas, incluso si está permitido por la ley estatal.

El consejo es:

- Manténgase alejado de la marihuana hasta que sea ciudadano de los Estados Unidos.
- Si realmente necesita marihuana medicinal y no hay un buen sustituto, consiga una consulta legal.
- No cargue marihuana, una tarjeta de marihuana medicinal o calcomanías, camisetas, etc. de marihuana. Cualquier texto o fotos relacionadas con la marihuana de sus redes sociales y teléfono.
- Si ha consumido marihuana o ha trabajado en la industria, obtenga una consulta legal antes de salir de los Estados Unidos o de solicitar la naturalización o el estatus de inmigración.
- Nunca discuta la conducta relacionada con la marihuana con las autoridades de inmigración, fronteras, consulares o policiales, a menos que su abogado de inmigración haya informado que esto es seguro. A small red three-dimensional-style exclamation mark.

From Condemned to Passionate Advocate

TEACH Immersion Participant Learns to Embrace Advocacy

By Emily Roush-Bobolz, staff writer

With love and joy in their hearts for their upcoming wedding, Elaine and her fiancé James Everett set off to get a marriage license, back when many states required a blood test to obtain the license. The joy diminished when she was informed she was a carrier of hemophilia because of that blood test.

"My first question was 'do you still want to marry me?'" said Elaine. "It's 40 years later and we're still married!"

It's one of the questions some with a bleeding disorder ponder when entering a relationship or getting married: will they want to be with me? Should we have children? It didn't stop the Everett's from having three children—their first born without hemophilia, but the latter two had hemophilia. When their son, Jeremy, died in 1984 at the age of 9, things changed in Elaine's heart.

"The guilt, shame and condemnation—I didn't know how to address it and deal with it," she said.

Elaine lived many years with those feelings of guilt and condemnation until she says God revealed to her that she was beating herself up by thinking it was her fault, when it wasn't.

"Women need to hear it's not their fault," she said. "We walk around thinking everything our children have gone through, the pain, the tribulation, we think it's our fault."

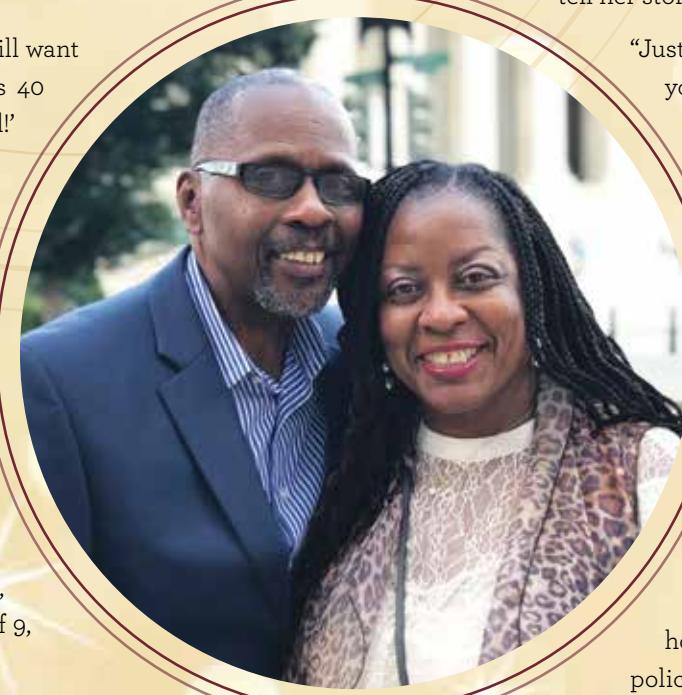
In recent years, the personal assault she placed on herself has given way to a new way of thinking, a desire to get more out of life, and the ability to embrace being an advocate for bleeding disorders. She has attended more events, gained more knowledge, and has found the strength and resolve to tell her story.

"Just tell your story! Just share what you're going through," Elaine exclaims.

Earlier this year Elaine, her husband and their son, Jon, were among more than a dozen people who attended Hemophilia Federation of America's TEACH Immersion in Washington, D.C.

"The purpose of TEACH is to really give community members an experience of coming together to learn how to be better advocates in the policy sense," said Lauren Neybert, a program director at HFA. "But also in a personal and self-advocacy sense."

The event included sessions on advocacy, civics, mental health, ways to become more involved in the community, a kinesio taping demonstration and a tour of Capitol Hill. It also included a lot of time for socializing, aiding in the development of friendships and mentorships.





“The knowledge was good, but EMPOWERMENT is what I got from TEACH Immersion.”

◀ James Everett listens attentively to a presentation at TEACH Immersion. Photo credit: Michael DeGrandpre

“There are more intimate moments that participants wouldn’t necessarily find by attending a larger event,” said Neybert. “It allows them to learn in a smaller, safe and supportive way.”

For Elaine, TEACH provided some lightbulb moments of realization that she has the power to be an advocate.

“I was empowered. I felt encouraged and felt I could stand strong!” she said. “The knowledge was good, but EMPOWERMENT is what I got from TEACH Immersion.”

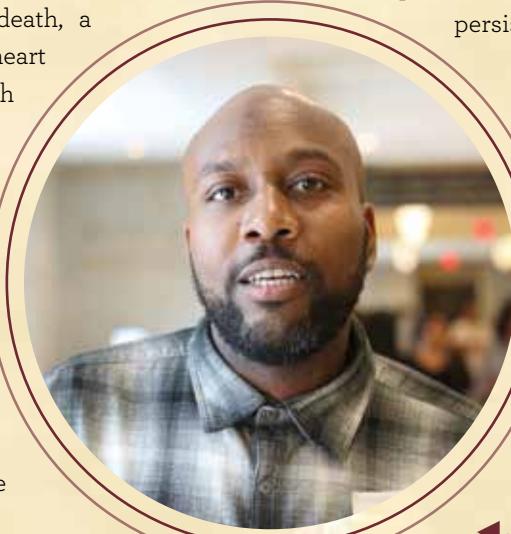
Although Elaine has spent recent years coming to terms with the condemnation of her son’s death, a moment during TEACH touched her heart deeper and caused her to deal with emotions she didn’t realize she had not dealt with.

“When they brought up the history (of bleeding disorders), I broke down. I left the room weeping,” she admitted. “My brother died in 2010. He was part of the group which contracted HIV/AIDS due to ‘bad blood.’ I understood more, and it brought the grieving process to the surface.”

Elaine said her family didn’t know about hemophilia treatment centers. No one, not even when her 9-year-old passed away, told her about HTCs.

“If I had known then what I know now, I don’t think my son would have died. A cancer doctor doesn’t know anything about hemophilia, so he wasn’t treated properly,” she said. “My (other) son is now 35-years-old and his first time to an HTC was a couple months ago!”

Over her sons’ lifetime they have faced uncertainty, denials from insurances and other uphill battles. When she returned home from TEACH, she went to his primary care physician and advocated on behalf of her son, writing requests to be seen by specialists and pleas for approval. “You’ve got to be persistent.”



The newly-empowered and grateful Elaine says the TEACH experience made her feel like a cohesive team with the other TEACH participants—advocates with a purpose!

“We were there to help each other. I was made to feel like my voice matters,” she said.

It does matter, Elaine. It does! ♡

◀ Jon Everett, son of James and Elaine Everett, also participated in TEACH Immersion. Photo credit: Michael DeGrandpre

“Women need to hear it’s not their fault,”

she said. “We walk around thinking everything our children have gone through, the pain, the tribulation, we think it’s our fault.”



Campout Sparks Unparalleled Brotherly Bond

By Emily Roush-Bobolz, staff writer

As the 29 men at this year's Hemophilia Federation of America Blood Brotherhood Campout sat around an evening fire, sparks flew, both literally and figuratively.

"The campout definitely sparked something in me," said Mohammed Hoque, 29, of Michigan. "It fueled my fire to be more involved."

Hoque explained the event, held in August in Breckenridge, Colo., led to two things—that desire to become a stronger, more involved advocate for the bleeding disorders community, but more importantly it led to a deeper bond with both new and old friends.

"In those three days, most of them became closer to me than friends I've had for years," he said.

He found personal value in the individualized rap sessions at the 2018 Symposium in Cleveland and was looking for an event that would capture the atmosphere and intimate setting of the

rap sessions, but for a longer period of time. He learned about the Blood Brotherhood Campout and applied to be considered to attend.

This was the second campout held by HFA. The first was held in 2016 on the 10th anniversary of the Blood Brotherhood program. Feedback from the first campout showed it was a wanted and needed event, explained Blood Brotherhood Coordinator, Eric Burgeson.

The adult campout harkens back to a significant time in the lives of many in the bleeding disorders community — summer camp.

"There is a need to return to the root of the community, which is camp," said Burgeson. "The campout celebrates the cohesive and strong community that is our group of men and provides them an opportunity to receive valuable resources and strengthen their interpersonal bonds."

During the campout, attendees participated in camp-like, team-building activities, such as trust walks, advanced rock-paper-scissors, and exercises like yoga. They also learned about kinesio taping, emerging therapies and attended sessions.

"They attended sessions on coping with grief and depression," said Burgeson. "I got the feeling the men left feeling more empowered, and supported by their brothers."

The campout provided an opportunity for connection among the men, not just the understanding of the physical and emotional experiences among the men, but a spiritual connection, explains Hoque.

"No matter how close you are to your wife, no matter how close you are to your family, there are just certain things you can only experience with blood brothers," said Hoque. "There are some personal issues that can only be lessened by talking to a blood brother. What a wonderful thing it was for those three days to





Photos Credit: Michael DeGrandpre

not only give us this education and blood brotherhood connection, but a reminder to be grateful for what we have and this group we belong to!"

Since then, many of the men have connected on social media and remain connected through calls and texts. After the campout, Hoque received a random text from another attendee, just to check in and see how he was doing. That led Hoque to text another brother, starting a chain of checking in on each other and to let the other brothers know they're not alone.

That chain of checking in on each other can be a powerful tool in warding off feelings of isolation and depression.

Besides the summer camp-like activities, the campout created a better understanding of the differences between the younger brothers and "more experienced" brothers. The men shared stories of a time when there was no treatment for hemophilia and prophylaxis was not an option, and how that has shaped the men they have become today.

"The campout reminded me of what we far too often take for granted and that's to be grateful. I'm originally from Bangladesh and I went back in 2015. It was almost like going back to what the U.S. was like in the 1980s," Hoque said. "I realized how grateful we should be for what we have here. It has sparked in me a desire to be grateful every day." 

Getting to Know HFA's

→ KIM ISENBERG > Vice President, Policy & Advocacy



Kim's primary role at HFA is to work collaboratively on the Federal and State level to help ensure people living with bleeding disorders have timely access to quality medical care, therapies, and services.

She is committed to help members of the bleeding disorders community to become informed advocates and is eager to be a champion for bleeding disorders.

Kim enjoys gardening and spending time with her family. She has been to every state in the U.S. but one (Alabama)...hoping to change that through her work with HFA!

→ SERINA TABISOLA > Project Coordinator



Serina assists the office manager in making sure the HFA office runs smoothly and is often your first point of contact when you call the HFA office. She is there to listen and help when she can, or to refer you to someone who can help.

Serina enjoys reading, curling up with her computer, traveling, and chilling out at the beach, river, or lake.

Prior to working at HFA, Serina interned at the National Mall in Washington, D.C., working events such as President Obama's last tree-lighting ceremony, the National Park Service Centennial Celebration, and two Independence Day Celebrations in Washington, D.C.

→ ASHLEY SMITH > Development Coordinator



Ashley coordinates development projects including all HFA Special Events: Gears for Good and Marine Corps Marathon, as well as stewardship for our members. She is here to assist with all areas of special event planning and member appreciation.

In her spare time, Ashley enjoys sitting on the beach listening to the waves and taking in the breathtaking views! Ashley tells us she is an avid Alabama Crimson Tide football fan—Roll Tide Roll!

Newest Staff Members

MEG BRADBURY > Research Director

Meg, a certified genetics counselor, comes to HFA with more than 10 years of research experience. Her primary focus as Research Director will be patient-centered outcomes research.

Meg describes herself as curious, passionate and empathic, qualities which support her focus on identifying research questions from the community and then facilitating research aimed at improving the lives of individuals with bleeding disorders.

In her free time, Meg enjoys hiking, snowboarding, cooking and spending time with her family.



MABEL CRESCIONI > Associate Research Director

Mabel is committed to advancing a patient-focused research agenda by learning what matters most to patients and their families. She is looking forward to community members asking questions and sharing how HFA can best support their interests.

In her free time, Mabel likes to listen to music, paint with watercolors, read and support the theater. She loves to travel and learn about other people and their culture, customs and language.



CATHERINE "ANDY" ANDERSON > Project Coordinator

Andy is a Project Coordinator with Blood Sisterhood. She helps organize and deliver programming for women with bleeding disorders and also contributes to HFA's history projects. If you have any questions about how bleeding disorders were treated in the past, she would love to talk with you!

Committed to providing support, education and advocacy for women and girls with bleeding disorders, Andy believes in empowering community members to take an active role in managing their health.

Andy likes to spend her free time cooking Mediterranean food, hiking and perfecting a 10-step Korean skincare routine. (Sheet masks, anyone?) Though she originally hails from Columbus, Ohio, Andy also shared that she used to live on a 350-acre monastery and dairy farm in the beautiful Pacific northwest. ❤





SISTERHOOD APP

You asked, we listened

HFA knows how critical an early diagnosis is for treatment and quality of life for women and girls with a bleeding disorder.

That is why we created Sisterhood, a mobile app designed for women to track menstrual and non-menstrual bleeds and symptoms.

Information logged by the user is secure and accessible only to the user. The user can have the app email that secure information to themselves to then share with their medical services provider.

New features include:

Recording details on product strength. Users may now note the strength of menstrual products used when logging menstrual bleeding by choosing the detailed data entry in the preferences tab.

More accurate blood loss score (PBAC score) for providers. Having more detailed information allows providers to more accurately assess blood loss that assists in diagnosis.

Ability to add a photo. • Spanish language option.

Other features of the app include:

Symptom logging/tracking. • The ability to record and track treatments used.

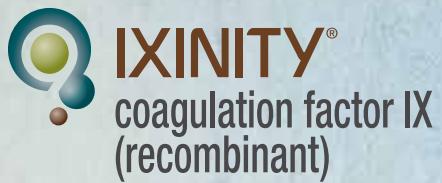
Reminder alerts for periods and treatments. • A place to log and rate joint and/or muscle pain.

Space to jot additional notes. • A wealth of information on bleeding disorders and a variety of topics pertaining to women and bleeding disorders.



It's free and easy to use. Download it for FREE!





Discover more about IXINITY®

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Knowledge is power. Whether you've been successfully managing your bleeding disorder for years and just feel curious about the science of it, or you are newly diagnosed and facing all kinds of difficult decisions, HFA's Learning Central can help!

Please join us at
HFAlearning.org
to find out more!



NEXT ISSUE:

Managing Personal Well-Being

- An honest look at depression caused by chronic illness, managing holidays and winter months, and handling grief within the bleeding disorders community.
- Plus a wrap-up of HFA's first time as a charity partner in the Marine Corps Marathon.

HONESTY