What’s a CoRe Manager?

Sanofi Community Relations and Education Managers (CoRes) have years of experience working with patients on ELOCTATE and can provide you with helpful resources and education.

**DEDICATION**
CoRe Managers are dedicated to providing education and empowering those within the community.

**UNDERSTANDING**
CoRe Managers are driven professionals with decades of combined experience who understand and appreciate the community’s needs.

**ACCESSIBLE**
Your CoRe prioritizes face-to-face conversations. They’re just a call or email away.

Scan with your phone to contact your local CoRe.
HI FRIENDS,

Fall is here! I hope you all had a wonderful summer and a smooth transition into fall. I ended my summer with a wonderful but challenging three-day backpacking trip, and then a few weeks later my husband and I welcomed fall with a trip to Copenhagen. Traveling reminds me how big this world is, yet how connected we all are. It’s similar to how having a bleeding disorder can feel so rare and isolating at times, but once we get connected to this community, it feels like such a smaller and friendlier world.

Living as a “Mild”

I’m excited that this month’s cover article is focused on mild hemophilia. Though I have mild von Willebrand disease, I can relate to some of the challenges of being diagnosed as a “mild.”

I didn’t get diagnosed until my teenage years in a medical emergency, and once I was diagnosed it felt like all the pieces finally went together. Those symptoms that had been overlooked for years finally made sense, but, frustratingly, there aren’t as many treatment options as I thought there’d be, and it’s often a hard path to navigate.

Those with mild hemophilia can often feel forgotten. In fact, it’s only been in recent decades that the medical community has begun to acknowledge that women hemophilia gene carriers can actually have mild hemophilia. Those with factor levels that fall into the mild category face challenges such as proper diagnosis, factor levels that fluctuate and may appear normal at times, and finding others who understand what it’s like.

Page 20 features community members with mild hemophilia, including the treatments that might work for individuals, the challenges they face and the things they need to consider every day.

Using Marijuana and CBD

On page 26, Dateline Federation takes a look at how some community members are using various cannabis products—including more traditional marijuana and a variety of CBD products—to help with pain and stress. It can be tricky to navigate because laws vary widely from state to state and you need to know what’s allowed—using recreational marijuana is still illegal at the federal level. But whether a product is legal where you live or not, you also need to know what’s safe and how to choose a product right for you. This article walks you through some of those choices and shares the experiences of a few people with bleeding disorders who use cannabis.

Dateline Live

Please join HFA November 14–15 as we present the virtual event Dateline Live. This event will cover two main topic areas: insurance and approved products/emerging therapies. See page 6 for more information.

Allie Ritcey

Chair, HFA Board of Directors
Executive Corner
Allie Ritcey, chair of the HFA Board of Directors, can relate to living as a ‘mild.’

Happening Highlights
Upcoming Dateline Live virtual event covers two important topics, and HFA hosts mental health first aid training.

Kids Corner
Fun facts about Halloween.

Member Organization Spotlight
Eastern Pennsylvania Bleeding Disorders Foundation prepares for a full fall calendar.

Inspiring Impact
Producer Robert Cooper shares his TV show ‘Unspeakable,’ about Canada’s tainted blood crisis, with the HFA community.

A Healthy Grief Process
Grief does not have a timeline and is a normal part of the healing process.

Mental Health Resources
A list of resources and helpful tips when searching for a mental health professional.

Milds Matter
Those with mild hemophilia can face challenges of proper diagnosis and treatment—and can often feel like they’re swimming alone upstream.

The Marijuana Question
Can cannabis help manage your pain and stress?

Internship Program Returns to DC

Young Adult Advocacy Summit 2022

CORRECTION
In the summer 2022 issue of Dateline Federation, in the Inspiring Impact article on page 10, we misspelled the name of the country Colombia (it is not “Columbia”). We are sorry and regret the error.
**KIDS CORNER**

Halloween is such a fun time of the year! Some people like this holiday more than any other. Is Halloween your favorite too?

**Here are some fun facts about Halloween:**

1. Halloween is always on October 31.
2. The name Halloween is a shorter version of All Hallows’ Eve.
4. Last year, Spiderman and Batman were the two most popular costumes for kids. (The No. 1 costume for adults was a witch.)
5. Some people even dress up their pets for Halloween! Do you do that? The most popular costumes for pets last year were pumpkins, hot dogs, superheroes and cats.
6. Halloween came to the U.S. from Ireland in the 1840s when many Irish people moved to the U.S.
7. Irish people also came up with the idea for the jack o’lantern. In Ireland, they carved them out of potatoes, beets and turnips! But the U.S. had pumpkins, so that’s what Americans have been using ever since.

Sources: National Retail Federation, Goodhousekeeping.com

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**Upcoming Dateline Live Virtual Event Covers Two Important Topics**

Join HFA November 14–15 as we present Dateline Live, a virtual event first brought to the community in 2021. This year the event has expanded beyond our yearly Product Guide and will cover two main topic areas: insurance and approved products/emerging therapies. Save the dates and plan to join us for two evenings of presentations.

- **Monday, November 14, 5–9 p.m. EST: Insurance Bootcamp**
- **Tuesday, November 15, 5–9 p.m. EST: Navigating Approved Products and Emerging Therapies**

More information on each evening, including a full schedule of presentations, can be found on our website: www.hemophiliafed.org. There is no cost to attend, but registration is required.

**HFA Hosts Mental Health First Aid Training**

HFA is proud to continue its support of mental health initiatives with the offering of free Mental Health First Aid (MHFA) training through an internationally renowned program by the National Council for Behavioral Health.

The MHFA training provides participants with knowledge regarding common mental health conditions, how to identify when someone is struggling emotionally and how to communicate with someone in despair. In addition, the curriculum provides training on suicide prevention and information on national mental health resources for care and support.

Participants who complete the training course will receive a Mental Health First Aid certificate indicating they have been trained in recognizing the signs and symptoms of common mental health and substance abuse challenges, how to have an effective conversation about those challenges, and where to direct people for mental health care and support.

Upcoming classes will be announced on the HFA website: www.hemophiliafed.org.
The Eastern Pennsylvania Bleeding Disorders Foundation is unique in that it has six hemophilia treatment centers (HTCs) in its boundaries, including four HTCs in Philadelphia. The foundation serves 41 of the 67 counties of Pennsylvania.

Executive Director Sarah Ross Pilacik started her role in March 2022 and is looking forward to a busy fall. “I am most excited about getting to know the patient community and their families,” she said.

The fall programs include Adventure Sports, Family Camp, Annual Meeting, Wheels for the World, 1Walk, Women’s Retreat and some educational programming events with industry.

Pilacik knows these programs will be more successful than her rocky start back in May, which she can laugh about now. The foundation had planned a dinner reservation for Mother’s Day weekend at the world-renowned Longwood Gardens. As Pilacik explained: “Well, it started raining on Friday and did not stop until late Saturday night. It was cold and windy and just terrible. Some brave community members went, but I ended up returning the majority of the tickets.”

KIDS CORNER

What are you going to be for Halloween? Draw a picture of yourself in your best Halloween costume.
Medication Guide
HEMLIBRA® (hem-lee-bruh) (emicizumab-kxwh)
Injection, for subcutaneous use

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.

These serious side effects include:

• Thrombotic microangiopathy (TMA), a condition involving blood clots and injury to small blood vessels, occurs in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

• Blood clots (thrombotic events), which may form in blood vessels in your arm, leg, lung, or head

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including Serious Side Effects.

What is the most important information I should know about HEMLIBRA?

• Thrombotic microangiopathy (TMA). This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

• Blood clots (thrombotic events). Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:

- weakness
- swelling of arms and legs
- feeling sick
- decreased urination

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; Feiba®), including:

• Thrombotic microangiopathy (TMA). This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

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- weakness
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- weakness
- swelling of arms and legs
- feeling sick
- decreased urination

Your body may make antibodies against HEMLIBRA, which may stop HEMLIBRA from working properly. Contact your healthcare provider if you notice that HEMLIBRA has stopped working for you (e.g., increase in bleeding).

• How should I use HEMLIBRA?

How should I store HEMLIBRA?

• Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C).

• Do not freeze.

• Keep HEMLIBRA in the original carton to protect the vials from light.

• Do not shake HEMLIBRA.

• If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator.

• After HEMLIBRA has been out of the refrigerator for more than 7 days or at a temperature greater than 86°F (30°C), HEMLIBRA should be used right away.

• Thaw away (dispose of) any unused vials of HEMLIBRA left in the vial.

Keep HEMLIBRA and all medicines out of the reach of children. See “What is the most important information I should know about HEMLIBRA?” for information about the safe and effective use of HEMLIBRA.

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

What are the ingredients in HEMLIBRA?

Active ingredients: emicizumab-kxwh
Inactive ingredients: L-graicine, L-histidine, poloxamer 188, and L-glutamic acid.
Canadian writer and producer Robert Cooper is best known for showrunning and co-creating the “Stargate” television franchise. But in 2019 he released his most personal project yet, “Unspeakable,” an eight-episode Canadian TV miniseries about the country’s tainted blood crisis that started in the 1980s. Similar to the blood scandal in the U.S., thousands of Canadians were infected with HIV and hepatitis C from contaminated blood products. “Unspeakable” chronicles the decades-long saga of two families, each with sons who have hemophilia, as they struggle to cope with the impact of AIDS and hepatitis C.

Cooper, who has moderate hemophilia A, contracted hepatitis C from tainted blood in Canada and finally cleared the virus in 2014 after three exhausting attempts. He will be engaging with the HFA community in a four-part series beginning with an October 25 webinar about AIDS/HIV awareness and “Unspeakable.” He will be joined by other panelists connected to the show. Community members can register for the webinar on HFA’s website and request to receive a special code to access the show for one free month, generously provided by AMC (See page 14 for more information.) Parts two and three will also take place online leading up to part four, which will be live at HFA’s Symposium in 2023, where Cooper will be one of the featured speakers.

One of the families in “Unspeakable” is loosely based on Cooper’s family. Before the tainted blood scandal came to light, Cooper’s parents became concerned about the replacement factor their son was receiving because they knew it was derived from a pool of thousands of individual blood donors. His hematologist dismissed their fears, so they switched their son to a new clinic where the doctor agreed to treat him with cryoprecipitate infusions. “Cryo” is found in blood plasma and has high concentrates of factor, a discovery made in 1965 that revolutionized treatment for people with hemophilia. While more inconvenient, the benefit of using cryo was the reduced risk of exposure to blood-borne pathogens because each unit came from a single donor.

“My dad was a biochemist and also my parents were both extremely cautious,” Cooper said. “Their persistence probably saved my life.”

Telling the Story
Cooper admitted to Dateline Federation that he was in a kind of denial most of his life about having hepatitis C. He couldn’t ignore his

“I knew it would be hard to watch when I heard about this series. I was aware that it would bring up some very raw memories for me and my family. However, I wanted to see how the story was told. I was not disappointed. I am glad that it was divided up in segments because it gave me time to digest it and feel those emotions flow over me again. The series did a wonderful job telling the story from a very personal perspective. It showed some of the pain and challenges that families with bleeding disorders went through. I could relate to all of it. I am so thankful that Rob Cooper and his team tackled this most difficult issue in such a thought-provoking way. We must continue to tell these stories so that everyone knows what happened to our families, our community. I feel it is our goal to educate the population at large so that something like this never happens again. We must remain vigilant.”

—Kathy Gerus-Darbison, Blood Sister

continued on page 14
“I’m deeply thankful for ‘Unspeakable’ and all the brilliant, committed individuals—giants, really—responsible for bringing it into being. ... I recognized a lot from my past: the march of events bringing the gradual realization that this is real; the torment and dread around the prospect of leaving my young family fatherless; the momentary disbelief, and then despair, on learning that yet another member of the community had died; the long derailing of my career because HIV, hepatitis C and those punishing early generations of medications made it impossible to be the lawyer my clients deserved. You might think it’s hard to watch experiences similar to one’s own being portrayed, one moving episode after another, but that wasn’t the case for me. Instead, there was affirmation in seeing so many dimensions of the crisis—all that tragedy and breakage—gathered up as a valid, honored lament. In the end, ‘Unspeakable’ did me the great, great favor of telling some pieces of my own story that I find just too difficult to tell, even to people I love.”

—Mark Borreliz, Blood Brother

continued from page 12

Hemophilia but tried to keep it from others because of the stigma the AIDS crisis created. “I didn’t want to admit that this was my problem,” he explained. “I wanted to live my life as though it was normal, and I didn’t deal with it.”

But once his hepatitis C cleared, he said he came to a more mature place. “I was also shocked that it was a story that had never been told. I knew that my own personal connection to it would resonate with people.”

Plus, Cooper was a successful producer and writer by this point and knew he might have a shot at telling the story of the blood scandal for CBC, Canada’s national broadcasting network. “So, I pitched it, and it certainly wasn’t an easy road, but they were very interested from the beginning. It took us almost three years of development, and then financing, to get it off the ground,” he said. “The other impetus was that I felt awareness of the blood scandal was evaporating—the people who were involved and who were most affected by it were getting older, and it felt to me like if I didn’t get to them and hear their stories and find a way to tell them firsthand, they would be lost.”

Cooper said that during his research, when he asked people about the tainted blood crisis, a lot of them didn’t know what he was talking about. Even in the medical and bleeding disorders community, younger generations might have heard of it but didn’t know the details. However, he said, these are important issues still relevant today. The tainted blood crisis showed the failures of bureaucracy and that citizens couldn’t necessarily trust institutions, including government agencies, blood banks and public health organizations.

At the time, the Canadian Red Cross, which was a charitable organization then responsible for Canada’s blood system, took little action to prevent HIV from contaminating the blood system, despite warnings. The organization purchased tainted blood from the U.S. that was supplied by “blood brokers,” whose supplies came from incredibly high-risk populations such as people who were incarcerated or homeless. Later, the Canadian Red Cross distributed old stock of tainted factor even when safer heat-treated product was available.

Creating Memorial Art

Cooper hopes the series will help educate younger generations and pay tribute to the victims of the crises in Canada and the U.S. “The experience I had in making the show—and making the decision to embrace the bleeding disorder community in order to really feel qualified to represent it when making the show—has led to me becoming more active in the community.”

Cooper joined the board of directors of the Canadian Hemophilia Society (CHS) and has become involved in a memorial art project created by his friend and CHS Vice-President Rick Waines. Memorial art is a creative way to reflect and honor a piece of history. The AIDS Quilt is a famous example.

“Unspeakable” serves as a piece of memorial art. Cooper has also been helping Waines, who is spearheading a campaign in Canada to create a memorial art center or monument for people with bleeding disorders from around the world. Ultimately, the idea is to have a website that people can go to and honor the experiences of people with bleeding disorders.

Cooper is also involved in mental health awareness, and he recognizes that watching and discussing “Unspeakable” can be triggering for some people, those who lived through the scandal, who were infected or knew people who died from hepatitis C or AIDS. (For mental health resources, please see page 17.) Even so, he hopes the show is educational and sparks conversation in the community.

“While the show explores a tragedy, I think it is also inspirational and shows you the strength of the human spirit,” he said. People affected by the blood crisis who have watched the show have told Cooper that “they feel like, in many ways, the things that they lived through have now been reflected in a way that makes them feel more seen. I hope people watch it and then join us to talk about it and that something positive can come out of that.”

Watch “Unspeakable” before the October 25 webinar panel discussion “AIDS Awareness/Unspeakable Series...Let’s Talk About It”


AMC has generously provided access codes for one month free so you can watch the show. HFA is not receiving any compensation for this project, and we are thankful for the opportunity to collaborate with AMC for educational purposes.

Tuesday, Oct. 25
7 p.m. EST
“Unspeakable” creator Robert Cooper and his cohort will take part in a panel Q&A. Part one of a three-part webinar. Stay tuned for information on parts two and three.

HFA Symposium 2023
April 13-16
Meet Robert Cooper and panelists live in Orlando!

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A Healthy Grief Process

Grief does not have a timeline and is a normal part of the healing process.

BY DEBBIE DE LA RIVA, LPC

I would like to thank HFA for its intentional efforts to help our community understand our collective history, as well as create and maintain an open bridge connecting our older and younger generations. These efforts are evident in their programs such as Blood Brotherhood/Sisterhood, HFA’s Timeline Project and most recently in raising awareness about the television series “Unspeakable.” As I watched the series, I was taken back by the amount of loss and trauma taking place not only in the life of the individual but also in the lives of their family members. We’ve heard this type of narrative time and time again in our community. While everyone was impacted differently by the tainted blood crisis, a common theme is grief.

Grief is the emotional response a person has following a loss. A person’s loss is not limited to a death—it can be something else important to you. With grief, most people experience profound sadness and temporary changes in the way they feel, think and behave. While healing is possible, it is a process affected by protective factors and risk factors.

A Healthy Grief Process

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Helpful Tips When Searching for a Mental Health Professional

- Consult your insurance provider directory.
- Get a referral from a medical professional such as your hemophilia treatment center or general practitioner.
- Look for a mental health professional within your university, your job’s human resource department or your place of worship.
- Search for mental health care in organizations that specialize in the area of concern. Many times, professionals will become a member of an organization dedicated to a common mental health condition and that contains a registry.
- Become informed about the type of mental health professional you feel will address your concern.
  - Age of the client: child, adolescent, adult, geriatric
  - Types of mental health professionals: substance abuse (LCDC), marriage, family therapist (LMFT), social worker (LSW), professional counselor (LPC), psychologist (PhD), psychiatrist (MD)
- Search an online database by credentials:
  - American Psychiatric Association — www.psychiatry.org
  - American Psychological Association — www.apa.org
  - American Counseling Association — www.counseling.org
  - Psychology Today —— www.psychologytoday.com/us

CERTIFIED COMMUNITY BEHAVIORAL HEALTH CLINICS

Certified Community Behavioral Health Clinics (CCBHC) are comprehensive care clinics that are required to serve anyone who requests care for mental health or substance use, regardless of their ability to pay, place of residence or age—including developmentally appropriate care for children and youth.

For a list of CCBHCs in your area, visit https://bit.ly/CCBHCLocator.

A person’s grief and loss is not limited to a death—it can be something else important to you.

2. Since the death, there has been a grief response characterized by one or both of the following nearly every day for at least the past month:
   - Intense yearning or longing for the deceased person
   - Preoccupation with thoughts or memories of the deceased person (in children and adolescents, preoccupation may focus on the circumstances of the death)

3. As a result of the death, at least three of the following eight symptoms have been experienced nearly every day for at least the past month:
   - Identity disruption (such as feeling as though part of oneself has died)
   - Marked sense of disbelief about the death
   - Avoidance of reminders that the person is dead
   - Intense emotional pain (such as anger, bitterness or sorrow) related to the death
   - Difficulty with reintegration into life after the death (including problems engaging with friends, pursuing interests or planning for the future)
   - Emotional numbness (for example, an absence or marked reduction in the intensity of emotions, or feeling stunned) as a result of the death
   - Feeling that life is meaningless as a result of the death
   - Intense loneliness (such as feeling alone or detached from others) as a result of the death

4. The loss causes clinically significant distress or impairment in social, occupational or other important areas of functioning.

5. The duration and severity of the bereavement reaction clearly exceeds expected social, cultural or religious norms for the individual’s culture and context.

6. The symptoms of grief are not better explained by major depressive disorder, post-traumatic stress disorder or another mental disorder, or are not attributable to the physiological effects of a substance (such as medication or alcohol) or another medical condition.

The bleeding disorders community went through a tragedy during the 1980s and 1990s that continues to affect individuals on a person level and on the community level as a whole. If you feel this adversity, or anything else in your life, has exceeded your ability to deal with it, you might want to talk to a mental health professional or use the resources listed on the previous two pages. It is OK to not be OK.

Debbie de la Riva, LPC, is a bleeding disorders community member, licensed professional counselor and certified Mental Health First Aid Instructor. She is also the founder of Mental Health Matters Too (https://mentalhealthmattersрус.com).
Those with mild hemophilia can face challenges of proper diagnosis and treatment—and can often feel like they’re swimming alone upstream.

BY ELLEN RYAN, FREELANCE WRITER

“I spent half my life not knowing what this condition is, not knowing to be careful or how to be careful,” said Timothy Friend, 19, a Connecticut College student who learned his diagnosis in fifth grade.

Bob Graham, 57, was diagnosed at age two in the late 1960s and spent much of his childhood with no available treatment. Life for him and his three affected brothers was largely “Should I do this? Should I hide it from Mom?” he said.

Despite being diagnosed at birth—at their mother’s insistence—Carrie Barnes Recker’s two daughters have faced difficulty getting treated even from the regional hematology center, which has wanted the girls’ hematologist to grant permission to treat, for example. The Iowa City retail pharmacist has the same condition and has been told not to treat soft tissue bleeds, only joint bleeds.

“They’ve wanted me to come in and get an MRI or ultrasound to prove I was bleeding or my child was,” she said in frustration.
“We’re hopeful there’ll be some room to study non-severe hemophilia patients,” said Robert F. Sidonio Jr., MD, MSc, treatment centers (HTCs) on the treatment of severe focused their efforts and the creation of hemophilia treatment centers (HTCs) on the treatment of severe hemophilia patients,” said Robert F. Sidonio Jr., MD, MSc, medical adviser and associate professor of pediatrics. "The research community and government have largely agreed. Those diagnosed as mild are often on their own, which can be dangerous. Borderline normal factor levels can make mild hemophilia hard to diagnose—and overall, levels can fluctuate with stress (including from testing itself), changes in hormone levels and infection. Lack of family history, too, can delay a diagnosis. “Mild” also means being a minority within the bleeding disorders community—which creates challenges in everything from finding the right information to finding knowledgeable medical personnel nearby.

Supportive Science
The research community and government have largely focused their efforts and the creation of hemophilia treatment centers (HTCs) on the treatment of severe hemophilia patients,” said Robert F. Sidonio Jr., MD, MSc, HFA medical adviser and associate professor of pediatrics at Children’s Healthcare of Atlanta and Emory University. “We’re hoping there’ll be some room to study non-severe hemophilia and some of the pharmaceutical companies that have new products will tailor their therapies for this underserved patient population.”

Treatment options are generally the same for everyone, though dosing and frequency vary by patient weight and age. In combination with factor products, tranexamic acid helps keep clots from breaking down early. This is used primarily to treat and prevent dental, mucosal, nose, mouth and gastrointestinal bleeding and heavy periods. Amino-caproic acid (Amicar) does essentially the same and is available in liquid, pill and topical nasal form; the liquid is often used in children.

In 2017, emicizumab (Hemlibra) was approved for treatment of hemophilia A, which allowed for less frequent subcutaneous injections, rather than more regular intravenous factor infusions. But the prophylactic treatment has major drawbacks for people diagnosed as mild, said Rebekah Heckathorne, RN/BSN, of the Hemophilia Center at Children’s Healthcare of Atlanta and Emory University. “This patient could benefit from a modified lighter version of factor prophylaxis compared to some of the severe patients,” he said, “but there’s little data to guide that.”

Instead, it’s trial and error: “We start off with once or twice a week and escalate until we feel the bleeding is controlled and prevented. It would be nice to have more targeted studies to guide us to the optimal regimen for this patient population,” he said.

Advice for Milds
Having mild hemophilia can sometimes be lonesome. Here is some advice from other “milds” and hemophilia experts:

Call on expert help. If you’re not sure if you should call your physician or HTC with a question or concern, just call! “That’s how you learn what’s normal for you,” said Rebekah Heckathorne, RN/BSN, who co-created HFA’s “Milds Matter” webinar last spring.

Document your case. Take photos of bleeds. Document what helped and what didn’t in detail—where, when, how much—because memory is fallible. Then, bring your records, in summary or in relevant part, to appointments because “having data and a history is the best way to get providers to listen to you,” Heckathorne said. “Patients who are less prepared and knowledgeable find it much harder to convince a doctor that they need factor and convince an insurance company to pay for it,” Graham said.

Advocate for yourself. Seek second opinions, said Bob Graham, who has mild hemophilia: “Push until you understand the answers to your questions. You’re the one who will live with the consequences.” Added Robert F. Sidonio Jr., MD, MSc: “Help the physician come up with a plan that works.”

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“Mild” also means being a minority within the bleeding disorders community—which creates challenges in everything from finding the right information to finding knowledgeable medical personnel nearby.

Supportive Science
The research community and government have largely focused their efforts and the creation of hemophilia treatment centers (HTCs) on the treatment of severe hemophilia patients,” said Robert F. Sidonio Jr., MD, MSc, HFA medical adviser and associate professor of pediatrics at Children’s Healthcare of Atlanta and Emory University. “We’re hoping there’ll be some room to study non-severe hemophilia and some of the pharmaceutical companies that have new products will tailor their therapies for this underserved patient population.”

Treatment options are generally the same for everyone, though dosing and frequency vary by patient weight and age. In combination with factor products, tranexamic acid helps keep clots from breaking down early. This is used primarily to treat and prevent dental, mucosal, nose, mouth and gastrointestinal bleeding and heavy periods. Amino-caproic acid (Amicar) does essentially the same and is available in liquid, pill and topical nasal form; the liquid is often used in children.

In 2017, emicizumab (Hemlibra) was approved for treatment of hemophilia A, which allowed for less frequent subcutaneous injections, rather than more regular intravenous factor infusions. But the prophylactic treatment has major drawbacks for people diagnosed as mild, said Rebekah Heckathorne, RN/BSN, of the Hemophilia Center at Oregon Health Sciences University. It’s “super expensive” and not necessary for most non-severe disorders, she said.

However, it has since been investigated in the HAVEN 6 study series for mild to moderate deficiency and showed promising results. Sidonio said. In people with significant bleeding in need of factor prophylaxis, it can be a good prophylactic treatment option. One drawback of emicizumab (in comparison to factor replacement) is the lack of ability to tailor to the patient’s bleed severity.

Some mild patients may also respond to high-dose DDAVP (desmopressin), an antidiuretic hormone, for hemophilia A, Sidonio said, to avoid the use of factor products. This medication is administered intravenously or via nasal spray or subcutaneous injection. Often, medical treatments are based on educated guesses and titrating until finding the appropriate dose. Sidonio has treated a patient with mild hemophilia levels of about 10%.

“This patient could benefit from a modified lighter version of factor prophylaxis compared to some of the severe patients,” he said, “but there’s little data to guide that.”

Instead, it’s trial and error: “We start off with once or twice a week and escalate until we feel the bleeding is controlled and prevented. It would be nice to have more targeted studies to guide us to the optimal regimen for this patient population,” he said.

Everyday Medical Considerations
When Friend, the college student, gets home after work at a grocery store—on his feet, carrying heavy cases—rest, ice, compression and elevation help the daily dull ache in his legs.

Paying attention day to day is a useful habit, Graham has found. Anything from a crack in the sidewalk to a sudden neck twist might become trouble. “Think through your life,” he urged. Does your job have good medical insurance? Might its cost lead a small employer to find a reason to drop you from the payroll (illegal as that may be)?
There’s sometimes a tendency for those with mild hemophilia who haven’t experienced many problems or who visit their HTC infrequently to travel without a travel letter or emergency plan or medications, Sidonio said. But these individuals may end up somewhere without good treatment options, and not every hospital carries factor or related medications.

In addition, it’s useful to know how to self-inject: “You're not typically sticking yourself very often if you have mild hemophilia,” Sidonio said. “It's very easy to lose those venipuncture skills. Just practicing is important.”

Exercise Pros and Cons

Exercising five or six days a week “improves both physical and mental conditioning,” Graham pointed out. But that’s not easy for most people to achieve.

Recker’s 14-year-old daughter is a dancer, a decision that she’s building muscle and cardiovascular strength, and she’s happy, but bleeding in a knee has already caused arthritis and joint damage. She’s achieved this milestone.

“Is it a bleed?” if he has to infuse, there’s his lifelong fear of needles, as well. Phoning Maine Medical, the nearest HTC, brings answers and some relief.

More relief has come from learning to infuse himself, though it was a traumatic ride. To avoid severe nausea, anxiety and frustrating, hours-long emergency department waits—they wouldn’t know what to do—he and his mother eventually achieved this milestone.

Lowering stress is critical, others agreed, because it takes an emotional toll on the mind and body. After decades in the community, Graham has seen a lot of self-destructive behavior—complete withdrawal on one hand, dirt bike racing and extreme sports on the other. “Medically that’s not prudent, but psychologically, how do you tell them otherwise?” he asked. “You can’t live in a constant state of fear. ‘I’ll die sometime,’ they tell people.”

Graham has felt a bit of this. He doesn’t remember being as cautious physically for a while after aging out of hemophilia summer camp: “I guess I thought, ‘I’ve always been like this, so what’s the problem?’”

But those with mild hemophilia have dealt with chronic pain and debilitation so severe that they’ve fallen into depression, drug dependence and/or suicide. Graham said he has known several people like this. He’s a fierce advocate for healthy habits, such as plenty of sleep, a nutritious diet and keeping up social contacts. “Having people to talk to is crucial,” he said.

You’ll Be Fine!

To receive a not-so-mild reaction from someone with mild hemophilia, ask them about misdiagnosis and being overlooked.

Just getting diagnosed at all can be hard. Without a family history, most mild cases are discovered in the teens or later because bleeding disorders are not high on a general diagnostician’s list of what to look for. There may have been tests for allergies, cancers, fibroids, meningitis or liver disease.

“Don’t worry; you’ll be fine” is a line all of these individuals interviewed have heard from at least one medical professional when the truth was far from certain.

“I’ve lost track of the number of doctors who’ve said, ‘Oh, you’re a mild; you don’t have to worry’ or ‘you don’t have problems,’” Graham said.

“It’s incredibly demeaning to have a diagnosis and they tell you you’re making it up and they want you to go away,” said Recker, who encountered this situation when trying to get her elder daughter treatment.

It’s annoying to explain to people that a paper cut won’t kill him, Friend said. But not being taken seriously is worse than annoying.

Finding Community Support

One way to educate and empower yourself and help others with mild hemophilia is to get more involved in the bleeding disorders community.

“It would be nice to see some more engagement in the community” from those with mild hemophilia, Sidonio said. “Those are the kinds of things that lead to collaborations, research projects, even therapies that are directed against this disorder.

“If we don’t see these patients out and about, then lots of groups think that there’s no issues, no need for research, and maybe the focus should just be on moderate and severe,” he said.

Find a support group, online or in person, and ask about programs through your local HTC and HFA chapter. “You’ll gain moral support, you can ask questions the medical people aren’t addressing, and you can find medical people if you need some,” Graham said.

Women, the Unseen Milds

Those with mild hemophilia are a smaller proportion of the bleeding disorders community, and women with hemophilia are considered an even smaller portion. However, there may be more women with hemophilia than some think.

Documented cases show that about 30% of those with mild A and B hemophilia are female, said Robert F. Sidonio Jr., MD, MSc. However, Sidonio believes the true figure is closer to 40%.

Because the focus for centuries has been on male patients, it can be hard for women and girls with hemophilia to be acknowledged, diagnosed or treated.

Carrie Barnes Recker, diagnosed as having mild hemophilia, leads an international Facebook support group, Women With Hemophilia. Members have talked of near-death birthing experiences, periods that last for five weeks, factor levels that vary with hormone levels, unclear diagnoses as a result, inability to secure treatment and more.

“The tides are turning for women,” Heckathorne said. “I do see improvement ahead.”

Recker’s elder daughter has recorded varying factor levels, including one test in the normal range, leading to a hematologist’s note in her chart that the girl wasn’t “a real hemophiliac” and “the mom is a problem.” Recker brought legal action but has been unable to get the note changed. She did succeed in having the local hospital’s insurer stop paying another hematologist who told her that factor was “too expensive to waste on women.” That hematologist retired, according to Recker.

Only recently has even the medical community realized that women can have less than normal factor levels, said Rebekah Heckathorne, RN/BSN, of the Hemophilia Center at Oregon Health Sciences University. In the past five years, her center has moved away from the term “carrier” and refers to female patients as “having hemophilia.”
In 2013, Cesar Gonzales, 38, decided to try marijuana to help with the stress associated with his moderate hemophilia A. His cousin, who also had hemophilia, encouraged him to give it a shot. Gonzales lives with his wife and kids in Lynwood, California, where both medical and recreational cannabis is legal. His cousin is the reason, Gonzales said, that he doesn’t take narcotic drugs. Instead, Gonzales saw his relative feel better after using the plant, which calmed Gonzales’ nerves about trying cannabis.

“It changed my whole perspective on smoking cigarettes and drinking beer,” Gonzales said. “I stopped all of that. It was making me heavy. It was making me angry, and it wasn’t helping me breathe.”

Gonzales shared an example of how cannabis has helped relieve his pain: Once when he was moving and carrying a large couch, Gonzales fell forward and nearly broke his ankle, which swelled up. To treat the pain, he used two types of cannabis products: He ate two CBD bars and smoked some THC. Within 40 minutes, he said, the pain was nearly gone. He compared the relief to the effects that morphine would have in 20 minutes.
CBD products come from hemp plants. A chemical CBD exists in both plants, medical marijuana and hemp bred with 0% to .3% THC, making it legal. While the hemp plant is a cousin to marijuana that has been used for generations in the United States, it is illegal at the federal level, though they are legal in some states. Including marijuana, with more than .3% THC is illegal at the federal level so it cannot be covered by health care insurance. Cannabis products, a chemical called delta-9-tetrahydrocannabinol, or THC, which is what gives users a “high.” Cannabis products, including marijuana, with more than .3% THC are illegal under federal law, though they are legal in some states.

What Is Cannabis?
For people with bleeding disorders, managing both physical and mental health is top of mind. Many people are prescribed opioids to reduce physical discomfort, but there are concerns of abuse and addiction with opioids. Given this, some people are considering cannabis as an alternative method for the management of pain and stress.

Marijuana and a chemical compound called cannabidiol, or CBD, both come from the cannabis plant. Marijuana has a chemical called delta-9-tetrahydrocannabinol, or THC, which is what gives users a “high.” Cannabis products, including marijuana, with more than .3% THC are illegal under federal law, though they are legal in some states. The hemp plant is a cousin to marijuana that has been bred with 0% to .3% THC, making it legal. While the chemical CBD exists in both plants, medical marijuana and CBD products come from hemp plants.

While cannabis is illegal at the federal level, laws vary state-to-state. People living in one state might have easy and legal access to cannabis products, while those living in another could face serious consequences for illegal possession. Overall, there are a number of legal and cost prohibitions that can affect people’s access to care and treatment.

However, medical cannabis can be a tool to help people living with bleeding disorders manage pain and wean off opioids, said Ellen Kachalsky, MSW, a social worker at the Hemophilia and Thrombosis Treatment Center (HTC) at the Henry Ford Health System in Detroit, Michigan. In addition, cannabis does not have the same uncomfortable side effects as opioids and narcotics, which can include constipation and other gastrointestinal problems.

It’s important that people with bleeding disorders discuss their potential use of cannabis products with their HTC or hematologist, just as they would any other medication, and be honest about their reasons for wanting to use marijuana or CBD. Kachalsky said. She does not recommend those in their early 20s and younger use cannabis because it can affect brain function and development. The prefrontal cortex, which plays a major role in attention, impulse control, memory and cognitive flexibility, is not developed until about age 25, she explained.

She also warned that older adults need to take precautions, given that their metabolism is slower and it can take longer for the effects of cannabis to take hold and wear off.

Different strains have different levels of THC and CBD, so people will have to go through a process of trial and error to find what works best for them. Kachalsky suggests that people living in states where cannabis is legal work with dispensaries. In doing so, folks can ensure that a given product is reputable and has been tested for lead, mercury, other heavy metals and toxins. In addition, dispensary employees should know the potency of strains they have available.

“If you’re buying off the street, you don’t know what you’re getting in terms of potency. And higher potencies, over consistent time, can trigger mental health issues, such as schizophrenia,” Kachalsky cautioned. “This is another reason we don’t recommend cannabis for adolescents because late teens and early 20s is when certain mental health conditions may appear.”

Another important factor to consider when using medical cannabis is cost. Marijuana, including medical marijuana, is still illegal at the federal level so it cannot be covered by health insurers. Therefore, users will need to pay for it themselves.

“You’re going to have to figure out your cost, depending on how often you use it,” Kachalsky said. “Every state has a limit on the quantity you can buy at one time, probably on a per-month basis. And other than Oklahoma, which will honor other states’ medical marijuana certifications, you can’t just go into a dispensary in another state with your home state’s certification.”

While cannabis may be a gateway drug to other drugs and possible substance abuse, Kachalsky said this affects only a small portion of people. For those using cannabis for serious pain management, it is likely more about tolerance than addiction: People might need a slight increase in potency over time to alleviate symptoms.

Kachalsky encourages people to learn more about the different strains of cannabis and their associated benefits. She said it is worth asking whether or not a given strain has a stimulating or calming effect and how it can assist with pain management for people with bleeding disorders.

Accessing Cannabis
Trevor Graham, 33, lives in Newark, New Jersey, a state where medical cannabis has been legal since 2010 and recreational use of the plant since 2020. He is a board member of the Hemophilia Association of New Jersey and was diagnosed with severe hemophilia A at birth. Graham has been using cannabis since age 19.

In the beginning of the state’s legalization, only a few diseases were approved to be treated with medical cannabis and hemophilia was not one of them. Graham applied for medical cannabis but was initially denied. Instead, he was offered a prescription for opiates, which he declined. Graham had already experienced the powerful withdrawals that come with opiates as a teenager.

“I was a pretty active kid. I played ice hockey and lacrosse and skateboarded. I wasn’t too safe growing up,” Graham said. “I remember this one time where I got really messed up and had to take painkillers for about two months. After, I was home in bed for three days with cold shakes from not having opiates in my system anymore.”

Graham grew up around artists and musicians. The allure of substance abuse was near constant. “By the time I was 10 minutes to go and smoke. This allows him to calm down, relax and feel grounded. Gonzales mainly consumes cannabis using a bong and grows his own plants.

Above and right: Cesar Gonzales with his wife, Armi Isaac Gonzales, and their son, Izziah King Gonzales, one of their six children.

“What heals you does not kill you,” Gonzales said. “People see cannabis as a plague when you should see it as a flower.” Since he began consuming cannabis, Gonzales said he has become less shy and better equipped to have conversations with people. The plant has also helped him manage his anger. Whenever he feels himself getting heated, he takes 10 minutes to go and smoke. This allows him to calm down, relax and feel grounded. Gonzales mainly consumes cannabis using a bong and grows his own plants.

People living in states where cannabis is legal should work with dispensaries ... to ensure that a given product is reputable and has been tested for lead, mercury, other heavy metals and toxins.
I’d already been to six or seven funerals for people who had overdosed on opiates,” Graham said. “That was always a big aversion for me to not get hooked.” Not wanting to find himself addicted to opiates too, Graham sought out alternative forms of pain management.

“When I was in college, I started experimenting with cannabis more and found that it does really help end-of-the-day aches and pains.”

—Trevor Graham

Parra grew up in an open-minded household. Her father lived with HIV, hepatitis C and severe hemophilia and was honest about his health with her. At the time, doctors prescribed marijuana to patients with certain conditions, such as cancer and AIDS. As a result, her father was able to gain legal access to the plant.

“My primary care physician didn’t treat me as a hemophiliac,” Parra said. “Instead, my pain was treated with ibuprofen, or I was told to buy Tylenol over the counter. My peers and kids younger than me were given heavy medication—lithium, codeine. Some of my relatives were treated only with psych meds but never treated for their pain.”

For a long time, Parra suffered with pain and anxiety due to not being taken seriously, nor treated properly, as a woman with hemophilia. As a mother living with hemophilia, Parra developed hip pain after pregnancy and giving birth. She treats the affected area with cannabis-infused creams and lotions and has learned how to make her own rubbing alcohol to alleviate symptoms of hemophilia. She shares her insights with other women who have gone undiagnosed and untreated in the hopes they can find relief, too.

In the future, Parra hopes that women can receive the care and treatment they desperately deserve. She also hopes that one day medical cannabis will be covered by insurance so that people aren’t forced to shell out significant amounts of money to access pain management.

“I’m the first woman in my family to get the diagnosis, and I actually had to move somewhere for the treatment,” Parra said. “I don’t want to be on psych meds for it. I’d rather smoke my way through it.”

Above and left: Trevor Graham, 33, with his wife, Sydney. Graham has been using cannabis for hemophilia-related pain since he was in college.

In 2018, Graham was finally approved for medical cannabis consumption. He uses the plant in nearly every form, whether as an edible, oil or hash. While he has easy access to cannabis, the plant remains pricey with an ounce costing him upwards of $500. He hopes that, in tandem with full legalization, the price will drop as it has in other states, such as California and Colorado.

Christa Parra, 43, was diagnosed with mild hemophilia two years ago. She received her diagnosis in Nevada, where she now lives, a state in which medical cannabis has been legal since 2013 and recreational cannabis since 2017. Previously, Parra lived in San Diego, California, another legal state.

Parra’s son, Joaquin, has severe hemophilia A and is on the autism spectrum. For his 21st birthday this year, Parra enrolled him in a medical marijuana club and took him to a dispensary, where he could learn what products worked for him.

Living in a state that has legalized cannabis has been a top priority for Parra. She wants access to medical cannabis and does not want her son to worry about the risk of arrest and incarceration. Parra is open about her cannabis consumption—the plant is not a “dirty secret” at home. However, she knows there is immense stigma associated with cannabis consumption.

This was not the case for Parra, who struggled with her own pain and bleeding. But her father provided her with cannabis to mitigate symptoms of hemophilia as a teenager.

Left: Christa Parra with her son, Joaquin. When her son turned 21, Parra took him to a marijuana dispensary so he could learn what products worked for him.
After two years of virtual internships, HFA was proud to bring back its in-person Policy and Government Affairs Internship program to Washington, DC, this summer. Interns Brian DuVal and David Leon spent 10 weeks working in the HFA DC offices.

Interns conduct research and analysis to help create educational resources on a variety of issues related to bleeding disorders. Other responsibilities may include attending relevant events, providing support for webinars, assisting with public affairs programs and drafting biweekly blog posts. While in DC, the interns developed a core passion for health care policy and self-advocacy, which will serve them well as they help shape the next generation of advocacy leaders.

Brian DuVal
• Senior, University of Nebraska
• Finance major, political science minor
• From Minneapolis, Minnesota

Hobbies?
I am very into thrifting and vintage clothing. I love listening to music and going to rap concerts. I enjoy working out and being active. I love to travel, I am a huge fan of the Green Bay Packers and Nebraska Huskers, and I spend a lot of time hanging out with friends.

Who is your hero and why?
My hero is my father. He’s the most creative person I’ve ever known. He taught me to always be grateful and stay humble. He was always there for me growing up despite dealing with a lot of health issues of his own.

Describe yourself in three words.
Compassionate, strategic, creative.

David Leon
• Senior, California State University of San Bernardino
• Industrial psychology major
• From Norwalk, California

Hobbies?
I enjoy kayaking, working on my car, hiking and reading philosophy (stoicism, existentialism and Taoism specifically).

Who is your hero and why?
My go-to hero is always my mom because of her empathy, adaptability, positivity and overall resilience.

Describe yourself in three words.
Positive, persistent and passionate.

Internship Program Returns to DC
WHAT’S A CoRe MANAGER?
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