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How the foundation's patient-centered initiative is prioritizing lived experiences.

HEM AWARE

The Bleeding Disorders Magazine

 NATIONAL HEMOPHILIA FOUNDATION | hemaware.org

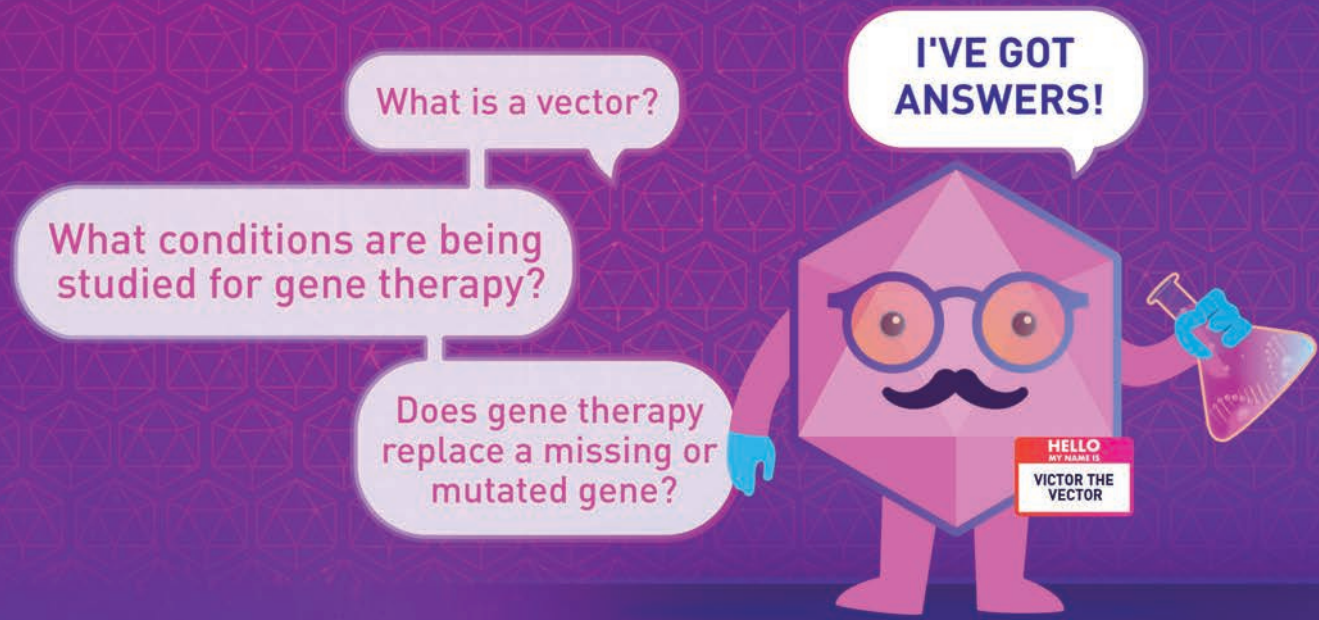


ANSWERS TO YOUR MOST PRESSING QUESTIONS ABOUT NAVIGATING THE JOB MARKET WITH A BLOOD OR BLEEDING DISORDER

The Working World

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DO YOU HAVE QUESTIONS ABOUT GENE THERAPY RESEARCH?



DID YOU KNOW

There are **5,000 to 8,000 genetic conditions caused by a single gene mutation** (monogenic conditions). Hemophilia, Huntington's Disease, and Cystic Fibrosis are just a few of them. In fact, BioMarin has been researching monogenic conditions for close to 25 years. One way we show that commitment is through the BioMarin *Gene Therapy Learning Academy*, where we can help you better understand the possibilities of gene therapy research.



WANT TO STAY IN THE KNOW?

Just sign up for the *Gene Therapy Learning Academy* and get the latest news on gene therapy research and educational resources—delivered right to your inbox.



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Many gene therapies for hemophilia are being studied in people to determine if they are safe and effective. HemDifferently.com and BioMarin Gene Therapy Learning Academy educational content does not focus on any commercially available products or specific gene therapies being researched for hemophilia A or B.

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75 YEARS: A Time for Change

With 75 years of history, hope, and progress, the foundation will soon unveil a rebrand that better reflects the entire community.

As of press time, the rebrand is set to be unveiled at BDC 2023. Learn more about the upcoming changes in the NHF Update section of this issue, and register to see the big reveal in person on **August 17 at hemophilia.org/BDC.**

75 YEARS OF SERVICE
1 9 4 8 - 2 0 2 3
NATIONAL HEMOPHILIA FOUNDATION



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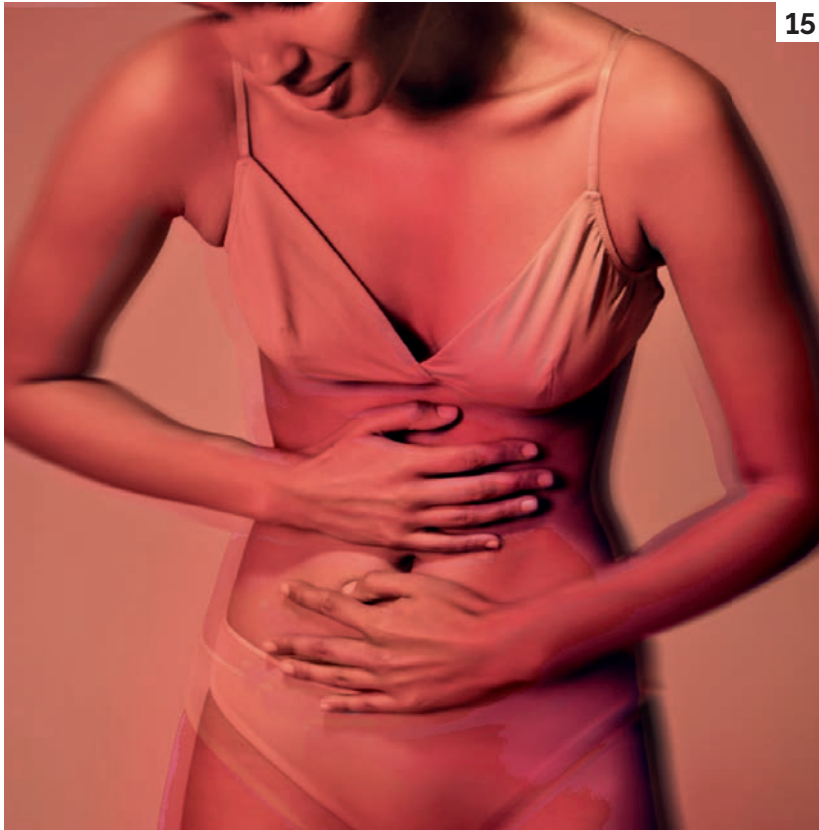
On the Cover

Photo illustration by
SEAN McCABE



CORRECTION:

In the "50 Years of Innovation" article on page 24 of the Fall/Winter 2022 issue of *HemAware*, Dr. David Ginsburg's name was spelled incorrectly.



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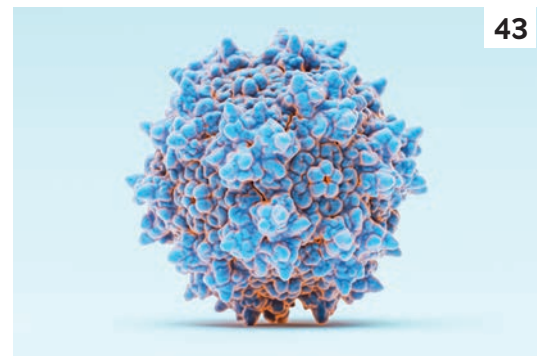
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PRESIDENT AND CEO LEONARD A. VALENTINO, M.D.



**Together, we
can support
one another.
Together, we
can shepherd
a future
of research
and hope.**

A Year of Celebration and Change

It's an exciting time for the foundation. As you may know, we're celebrating the 75th anniversary of the National Hemophilia Foundation this year, and we're commemorating it with a celebratory and reflective campaign entitled The Red Thread. (Visit hemophilia.org/75 to learn more.)

We're also looking forward to gathering as a community at the 75th Annual Bleeding Disorders Conference (BDC), which will take place Aug. 17-19 in National Harbor, Maryland, just outside of Washington, D.C. We hope you and your family members can join us for three full days of educational sessions that will explore novel and future research and treatments, and address the challenges of living every day with a blood or bleeding disorder.

At BDC, you can learn more about the National Research Blueprint, a community-driven journey to shape the future of research into bleeding disorders. Our goal is to bring the experiences of people who live with bleeding disorders to the forefront of transformational research and examine where research can have the most community impact. For more about the blueprint, see Page 32.

At the conference, you'll also hear about the organization's exciting rebrand, which will include a new organizational name, aesthetic update, and more. Get details about the upcoming changes on Page 42.

Together, we can make a difference. Together, we can support one another. Together, we can shepherd a future of research and hope.

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FIRST AND ONLY FDA-APPROVED
GENE THERAPY FOR HEMOPHILIA B

 **HEMGENIX**[®]
etranacogene dezaparvovec-drlb



David
Factor IX level of
37% at 2 years

STEP INTO A WORLD OF ELEVATED FACTOR IX LEVELS THAT LAST FOR YEARS

A one-time infusion delivers
greater bleed protection*

Step into a new world today
HEMGENIX.com



Patient portrayal; HEMGENIX not intended for women.

*In the clinical trial, annualized bleed rate (ABR) for all bleeds decreased from an average of 4.1 for patients on prophylaxis (prophy) during the lead-in period to 1.9 (54% reduction) in months 7–18 after treatment.

IMPORTANT SAFETY INFORMATION

What is HEMGENIX?

HEMGENIX[®], etranacogene dezaparvovec-drlb, is a one-time gene therapy for the treatment of adults with hemophilia B who:

- Currently use Factor IX prophylaxis therapy, or
- Have current or historical life-threatening bleeding, or
- Have repeated, serious spontaneous bleeding episodes.

HEMGENIX is administered as a single intravenous infusion and can be administered only once.

What medical testing can I expect to be given before and after administration of HEMGENIX?

To determine your eligibility to receive HEMGENIX, you will be tested for Factor IX inhibitors. If this test result is positive, a retest will be performed 2 weeks later. If both tests are positive for Factor IX inhibitors, your doctor will not administer HEMGENIX to you. If, after administration of HEMGENIX, increased Factor IX activity is not achieved, or bleeding is not controlled, a post-dose test for Factor IX inhibitors will be performed.

HEMGENIX may lead to elevations of liver enzymes in the blood; therefore, ultrasound and other testing will be performed to check on liver health before HEMGENIX can be administered. Following administration of HEMGENIX, your doctor will monitor your liver enzyme levels weekly for at least 3 months. If you have preexisting risk factors for liver cancer, regular liver health testing will continue for 5 years post-administration. Treatment for elevated liver enzymes could include corticosteroids.

What were the most common side effects of HEMGENIX in clinical trials?

In clinical trials for HEMGENIX, the most common side effects reported in more than 5% of patients were liver enzyme elevations, headache, elevated levels of a certain blood enzyme, flu-like symptoms, infusion-related reactions, fatigue, nausea, and feeling unwell. These are not the only side effects possible. Tell your healthcare provider about any side effect you may experience.

What should I watch for during infusion with HEMGENIX?

Your doctor will monitor you for infusion-related reactions during administration of HEMGENIX, as well as for at least 3 hours after the infusion is complete. Symptoms may include chest tightness, headaches, abdominal pain, lightheadedness, flu-like symptoms, shivering, flushing, rash, and elevated blood pressure. If an infusion-related reaction occurs, the doctor may slow or stop the HEMGENIX infusion, resuming at a lower infusion rate once symptoms resolve.

What should I avoid after receiving HEMGENIX?

Small amounts of HEMGENIX may be present in your blood, semen, and other excreted/secreted materials, and it is not known how long this continues. You should not donate blood, organs, tissues, or cells for transplantation after receiving HEMGENIX.

Please see full prescribing information for HEMGENIX.

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.

You can also report side effects to CSL Behring's Pharmacovigilance Department at 1-866-915-6958.

HEMGENIX is manufactured by uniQure Inc. and distributed by CSL Behring LLC. HEMGENIX[®] is a registered trademark of CSL Behring LLC.

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www.CSLBehring.com www.HEMGENIX.com USA-HGX-0182-DEC22

CSL Behring

BRIEF SUMMARY OF PRESCRIBING INFORMATION

These highlights do not include all the information needed to use HEMGENIX safely and effectively. See full prescribing information for HEMGENIX.

HEMGENIX® (etranacogene dezaparvovec-drlb) suspension, for intravenous infusion
Initial U.S. Approval: 2022

-----**INDICATIONS AND USAGE**-----

HEMGENIX is an adeno-associated virus vector-based gene therapy indicated for the treatment of adults with Hemophilia B (congenital Factor IX deficiency) who:

- Currently use Factor IX prophylaxis therapy, or
- Have current or historical life-threatening hemorrhage, or
- Have repeated, serious spontaneous bleeding episodes.

-----**CONTRAINDICATIONS**-----

None.

-----**WARNINGS AND PRECAUTIONS**-----

- Infusion reactions: Monitor during administration and for at least 3 hours after end of infusion. If symptoms occur, slow or interrupt administration. Re-start administration at a slower infusion once resolved.
- Hepatotoxicity: Closely monitor transaminase levels once per week for 3 months after HEMGENIX administration to mitigate the risk of potential hepatotoxicity. Continue to monitor transaminases in all patients who developed liver enzyme elevations until liver enzymes return to baseline. Consider corticosteroid treatment should elevations occur.

- Hepatocellular carcinogenicity: For patients with preexisting risk factors (e.g., cirrhosis, advanced hepatic fibrosis, hepatitis B or C, non-alcoholic fatty liver disease (NAFLD), chronic alcohol consumption, non-alcoholic steatohepatitis (NASH), and advanced age), perform regular (e.g., annual) liver ultrasound and alpha-fetoprotein testing following administration.
- Monitoring Laboratory tests: Monitor for Factor IX activity and Factor IX inhibitors.

-----**ADVERSE REACTIONS**-----

The most common adverse reactions (incidence $\geq 5\%$) were elevated ALT, headache, blood creatine kinase elevations, flu-like symptoms, infusion-related reactions, fatigue, malaise and elevated AST.

To report SUSPECTED ADVERSE REACTIONS, contact CSL Behring at 1-866-915-6958 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

-----**USE IN SPECIFIC POPULATIONS**-----

No dose adjustment is required in geriatric, hepatic, or renal impaired patients.

Based on November 2022 version



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CLINICAL
TRIALS
TOOLKIT!**

HEMOPHILIA.ORG/TRIALS-TOOLKIT

Healthy Start

STATS, FACTS AND NEWS YOU CAN USE

Celebrating Community

We asked our community, "How long have you been involved with the foundation?"
Here are some of your answers:



**I've known
about NHF
for as long
as I can
remember.**

—KELLY W.



KLAUS VEDEFELT/GETTY IMAGES

"I've known about NHF for as long as I can remember. My family has always been involved."

— KELLY W.

"My family was involved with some of the first studies funded by the foundation in the 1950s."

— MARGARET H.

"It's amazing that I have made it to age 71 and the foundation is still here in my life."

— ELDON H.



GETTING READY FOR

Along with many other activities kids love, the summer camp experience was altered by the pandemic. For the past three summers, children with bleeding disorders may have attended summer camp virtually, in person, or as part of a hybrid experience. In 2023, many camps will be held in person again.

“You can’t mimic the magic of camp anywhere else; you just have to dive in and embrace it all,” says Karin Koppen, camp director for the Great Lakes Hemophilia Foundation’s Camp Klotty Pine, which held in-person camp last year.

What to Know About Gene Therapy for Hemophilia B

In November, the U.S. Food and Drug Administration (FDA) approved Hemgenix (etranacogene dezaparvovec-drlb), gene therapy for adults with hemophilia B. The treatment, which is given intravenously in a single dose, provides a copy of a gene that enables patients to produce more factor IX.

We asked Nigel Key, M.D., director of the UNC Hemophilia and Thrombosis Center in Chapel Hill, North Carolina, for his insights.

WHO IS AN IDEAL CANDIDATE FOR THIS THERAPY?

Adults with hemophilia B may consider gene therapy if they’ve ever had a life-threatening hemorrhage, if they’ve experienced a series of spontaneous bleeds, and even if they use factor IX prophylaxis therapy and haven’t had life-threatening events. It isn’t appropriate for patients who have an inhibitor.

HOW WILL THE TREATMENT AFFECT HEMOPHILIA B?

Gene therapy is being visualized as a cure, but until everyone can be guaranteed a factor level over 40%, it’s not a universal cure. There’s some variability in the patient response. Many patients may reach 30% to 40%, but some may only reach 5% and still need factor IX.

WHAT SHOULD PEOPLE EXPECT AFTER TREATMENT?

The infusion is fairly straightforward, but follow-up is incredibly important, particularly in the first three to four months. Patients must commit to having regular tests on their liver function.

WHAT ADVICE ARE HEMATOLOGISTS GIVING PATIENTS ABOUT GENE THERAPY?

Patients should consider how well they’re doing on their current therapy, how the side effects may affect them, and whether their health insurance will cover the treatment. It’s a truly personalized decision.



WHEN MIGHT GENE THERAPY FOR HEMOPHILIA A BE APPROVED?

The FDA is expected to make a decision about Roctavian (valoctocogene roxaparvovec), gene therapy for hemophilia A, by the end of June. Patient eligibility may be different because more patients with hemophilia A have a history of inhibitors.

— Lisa Fields

CLOCKWISE FROM TOP: MOMO PRODUCTIONS/GETTY IMAGES, COLE MILLER/JUNIPLASH, DBENITOS/STOCK/GETTY IMAGES, IRYNA VEKLIKH/GETTY IMAGES

SUMMER CAMP

Here are Koppen's recommendations for families to ensure that camp is a great experience for kids:

- ✔ Send your child to sleepovers at trusted friends' or relatives' houses well before camp begins so they get used to being away from home.
- ✔ Participate in other chapter events before camp begins to make new friends or rekindle old camp friendships.
- ✔ Ask what protocols camp is following to ensure a safe experience, such as eating meals outdoors or spacing sleeping areas at safe distances.
- ✔ Practice personal care routines to help them build confidence in their ability to be independent.
- ✔ Help your child fall in love with nature by spending time outdoors during the day and at night (for stargazing).
- ✔ Talk to the camp director about any concerns, then create a plan together.

— Lisa Fields

Follow the Red Thread



In honor of its 75th anniversary in 2023, the National Hemophilia Foundation launched a celebratory and reflective campaign called The Red Thread, which tells the organization's history and evolution since its 1948 founding. Visit hemophilia.org/75 to learn more.

WASHINGTON DAYS 2023

In March, bleeding disorders advocates from across the country gathered in Washington, D.C., for NHF's annual Washington Days event to meet with legislators and Congressional staff members. Here's a recap, by the numbers:

27
years of annual Washington Days events

400
advocates

45
states and Puerto Rico represented

over
250
meetings with elected officials on Capitol Hill



LEARN MORE AT: hemophilia.org/advocacy

Finding Her Community

Gabi Flores says her involvement with NHF enables her to get support and give back

When you have a rare disorder, it can be isolating. Gabi Flores, 22, knows that feeling all too well, as it wasn't until she was 14 that she finally learned she had qualitative platelet dysfunction. "It was a relief to finally get the diagnosis, but it was a little bit tough. I grew up in the community because my mother has a bleeding disorder, so I understood hemophilia and von Willebrand disease. But I had never even heard of my diagnosis, so it was completely new territory to me," says the senior at the University of Colorado Denver.

What really helped was the community Gabi found in the National Hemophilia

Foundation and its National Youth Leadership Institute (NYLI), a two-year program that provides young adults ages 18 to 24 with tools and training to encourage personal growth, effect change, and positively influence others. "NYLI has given me so much, a true support system. It's like a big family, and I have met some of my best friends there," Gabi says.

STRUGGLING FOR A DIAGNOSIS

Growing up in a suburb of St. Louis, Gabi experienced a lot of significant bruising. When her period began at age 11, she had abnormally long and heavy flows. At one point, she menstruated for six months

straight. Since there was a family history of hemophilia, she was tested for that and von Willebrand disease, but both came up negative.

"They kept saying I didn't have a bleeding disorder, but they couldn't identify what was the matter," she recalls. It wasn't until she was brought to a clinic in Kansas City, Missouri, that the rare qualitative platelet dysfunction was uncovered. But even then, her life wasn't easy, as the treatment for it isn't clear-cut. Her treatment plan has changed over the years. Right now, she has an intrauterine device and uses desmopressin injections.

LIVING LIFE TO FULLEST, SMARTLY

Gabi didn't let her unique diagnosis limit her. She was an active soccer player, and a goalkeeper to boot. "Not the most ideal thing for a bleeding disorder," she says with a laugh. But her mother encouraged her to continue playing as long as she took her health seriously and communicated honestly with her health care providers. Today, Gabi is healthy and still active.

In 2016, she attended an NHF conference where she first learned about NYLI. She was too young to join then, but she always knew she would when the time came. "They looked like they were having so much fun, and I knew I wanted to give back to the community that gave me so much," she says.

In 2021, Gabi joined NYLI with an interest in advocacy, which fits with her long-term career goals. As a political science major, she wants to become a lobbyist, possibly in the medical field. "NYLI has given me some great professional advancement opportunities and experiences," she says. "I am on

the NHF Board of Directors as the NYLI representative, I have gone to Washington, D.C., to lobby, and I have spoken at conferences about rare disorders. It's prepared me a lot for the professional world."

She adds, "A lot of people with rare disorders don't think that there's a place for them. I encourage them to get involved, because our community is growing, and our voices are being heard."

—By Beth Levine



IN RARE FORM

Gabi Flores says joining NYLI has enriched her life in many ways.



LEARN MORE ABOUT NYLI: hemophilia.org/educational-programs/training/youth-leadership-nyli

**NEWS FLASH**

Reconnecting may be difficult, but it has positive effects on mental health.

The Loneliness Epidemic

Break out of solitary habits with these strategies

As we grow older, we're more likely to experience loneliness. Because of hearing loss, lack of mobility, limited social support, and other factors, 1 in 4 adults age 65 and older are considered socially isolated, according to a 2020 report from the Centers for Disease Control and Prevention.

Experts point to smaller social circles when we leave the workforce and living alone after a spouse dies as reasons why seniors are especially at risk for loneliness. Physical distancing and quarantining during the pandemic made matters worse.

"It's a domino effect. It can start out as loneliness, but the issue just continues to grow and impact the person and their quality of life," says Sabrina Farina, a senior social worker at the Gulf States Hemophilia and Thrombophilia Center in Houston. Feelings of isolation and loneliness can lead to higher stress levels, cardiovascular problems, cognitive impairment, and depression.

Here's how older people can make meaningful connections for better mental health.



Ask for Help



Reach Out to Others



Meet In Person

"FaceTime and other technology ... doesn't really replace one-on-one interaction."

1 SPEAK UP ABOUT LONELINESS

Many older adults are accustomed to tackling problems on their own. But Dana Marie Kennedy, state director for AARP Arizona, says this can be harmful for those dealing with loneliness — the very people who need others' help.

"We definitely have to encourage people it's OK to say you need help," Kennedy says. "If anything, COVID helped us start talking about our mental health more openly."

If you're not sure where to turn, start with a trusted health care provider, who can offer a safe place to talk and resources to help.

2 ACTIVELY CONNECT WITH OTHERS

The people who make you feel connected — whether it's a longtime neighbor or your cribbage club — provide a valuable support system that can help prevent loneliness.

It can be difficult to reach back out to old friends or groups, especially if it's been a while. Be encouraged by how engaged and energized you felt when you were together, and keep in mind that they

might delight in hearing from you again.

With old connections reestablished, think about growing your social circle.

"Consider the ways you can expand your support system where you already feel comfortable, like your house of worship," Farina suggests.

3 PRIORITIZE IN-PERSON INTERACTION

In-person activities are key, especially for those living alone, says Len Kirschner, M.D., past-president of AARP Arizona.

"The ability to use FaceTime and other technology helps, but it doesn't really replace one-on-one interaction," he says.

Continuing-care communities count, as they offer rich social engagement programs. Also consider taking classes at the local community college, joining an exercise group, or volunteering at the neighborhood animal rescue.

"You have a better chance of having a good life span if you have good social relationships," Kirschner says. "Seek out places where you can meet people, develop relationships, and build community."

—By Celeste Sepessy



FIND MEANING BY GIVING TO OTHERS: Volunteering gives people a sense of belonging and purpose. Find tips for getting involved here: hemaware.org/life/find-meaning-through-volunteering



Our beloved founder,
George King (1922-1987)

GEORGE KING BIO-MEDICAL, INC.-

GET TO KNOW US AND OUR COMPANY

George King Bio-Medical is a 3rd generation family owned and operated company located in Overland Park, KS. Prior to starting the company, George J. King became involved with the Hemophilia Foundation in his hometown of Rochester, NY. His involvement led him to eventually serve as a 2-term president of the National Hemophilia Foundation during the 1970's. Throughout his multiple terms as president with the NHF, he had a vision of how he could help and serve people with bleeding disorders. He knew that people with bleeding disorders had very large financial needs for treatment. He also saw the need for further research in the field of bleeding disorders. His vision was to bring these 2 needs together to help each other. He created George King Bio-Medical Inc. with this vision in mind. His goal was to perpetuate his company long after he was gone. He opened George King Bio-Medical, Inc. in 1973 in Salem, New Hampshire. The company moved to Overland Park, Kansas in 1978. Through the years, George King Bio-Medical, Inc. evolved into an internationally renowned supplier of clinical hemostasis products.

Today George King's vision continues, keeping his company goals alive and proudly celebrating our 50th year of business.



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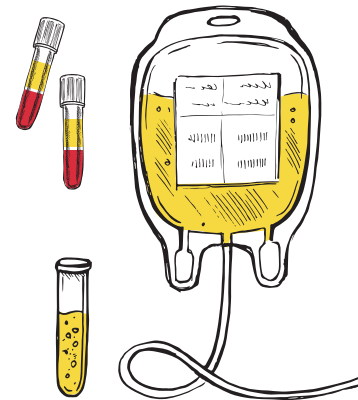
WHY DONATING PLASMA IS ESSENTIAL FOR RESEARCH & DIAGNOSTIC TESTING

IS DONATING PLASMA SAFE WHEN YOU HAVE A SEVERE BLEEDING DISORDER?

In most cases, the answer is yes! Plasma fully regenerates in the body within 48 hours. When you have a bleeding disorder, you will need to donate in a special Source Plasma Licensed facility. These centers went through a rigorous process to obtain their licensing through the FDA.

WHY DONATING YOUR PLASMA IS ESSENTIAL FOR RESEARCH & DIAGNOSTIC TESTING

Laboratories, research facilities, pharmaceuticals, and most importantly patients rely on accurate lab results for effective treatment. Many labs require plasma for research and testing. Despite industry's best efforts to create synthetic material, the ideal source is plasma from patients with a congenital severe factor deficiency. Due to increasing demands for laboratory testing, the need for plasma-based laboratory reagents continues to rise.



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We are growing our plasma donation base for our 50th banner year! We're currently adding FV, FVII, FVIII, FIX, FX, FXI, FXII, FXIII, all types of Von Willebrand's Disease and FVIII w/ Inhibitor. To be considered, you must be severe, <1% activity level, over 18 years of age, greater than 110 pounds, HIV negative, HCV negative (except for FVII, FVIII, FIX, FXI, & FXII) and want to help in furthering research!

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National Harbor, MD

August 17 - 19, 2023

REGISTER AT [HEMOPHILIA.ORG/BDC](https://hemophilia.org/bdc)

Managing Coexisting Women's Health Conditions

How doctors treat people who have PCOS or endometriosis and a bleeding disorder

Polycystic ovary syndrome and endometriosis are two common disorders in women. Heavy and irregular bleeding are hallmarks of both, making these conditions especially concerning in women with blood and bleeding disorders.

“The fact that somebody has a bleeding disorder doesn’t necessarily predispose them to other gynecologic types of problems,” says Kalinda Woods, M.D., an OB/GYN with the Emory University School of Medicine in Atlanta. “However,

if they do incidentally have another diagnosis, then the bleeding disorder will certainly exacerbate whatever abnormal uterine bleeding they’re having.”

ABOUT PCOS AND ENDOMETRIOSIS

In polycystic ovary syndrome, or PCOS, hormonal imbalances interfere with ovulation to the point where someone may not ovulate for months. As a result, the ovaries can develop small cysts that produce excess androgens — male

hormones that are typically present in small amounts in women without PCOS. The uterine lining (endometrium) can become thicker, resulting in heavier and longer periods. Other symptoms of PCOS include excess hair growth, acne, and infertility.

Endometriosis is a condition in which the tissue that usually lines the uterus grows outside of the uterine cavity, such as on the bowel, or on tissue in and around the abdomen. The disorder causes pelvic pain with menstruation. Pain can also occur with bowel movements or during sexual intercourse.

A complication of endometriosis called endometrioma presents the most risk to women with bleeding disorders. An endometrioma is a cyst that forms on the ovaries as a result of endometriosis. The cysts are known as “chocolate cysts” because they contain old, brown menstrual blood.

“These cysts can be huge, and they can rupture,” Woods says. “The internal bleeding can be profound. If somebody has a bleeding disorder and an endometrioma ruptures, that can cause a catastrophic hemorrhage.”

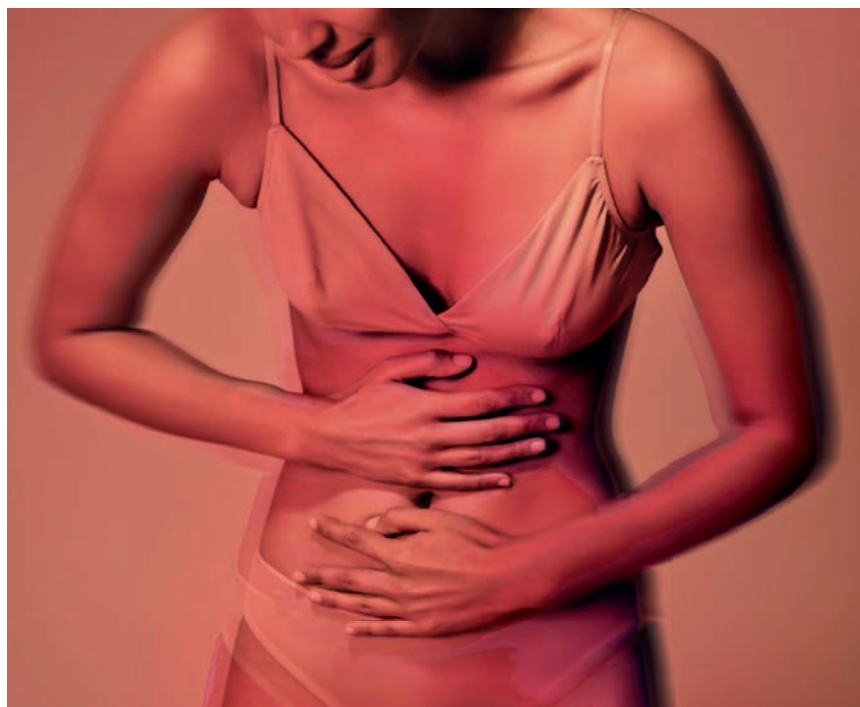
TREATMENT OPTIONS

Woods says PCOS and endometriosis are typically treated with hormonal contraception methods such as the pill, NuvaRing, or a hormone-releasing intrauterine device. “Interestingly, we treat these conditions the same way we treat a bleeding disorder,” she says. “So sometimes treating one will help mitigate the symptoms of the other.

“These contraceptives suppress ovulation, which stops the hormonal cascade, which stops the pain, which stops the bleeding. We can kind of kill two birds with one stone by managing somebody’s bleeding due to PCOS or endometriosis and managing their bleeding condition.”

Woods stresses the importance of diagnosing PCOS and endometriosis early to avoid complications. “Complaints of pelvic pain and painful periods should never be ignored,” she says. “They should always be investigated.”

—By Christina Frank



LISTEN TO YOUR BODY

Pelvic pain and painful periods should never be ignored.



LEARN MORE ABOUT WOMEN AND BLEEDING DISORDERS: victoryforwomen.org

Dealing with Tech Dependency

Screen time might make medical appointments manageable, but too much of it can be harmful

Leigh Myers' son spent significant time in the hospital for a surgical procedure when he was barely 1. After he came out of anesthesia, bandaged and hooked up to an IV, it was imperative he stay relaxed and somewhat still — a big ask for a toddler. Myers turned to screens.

"He was worried, scared, and in an unfamiliar environment," she says. "We used screen time — animated videos — which I didn't really use at home under normal circumstances. I would have read books to him or played games, but I just felt like the screen time was more effective for keeping him calm."

It's been a few years since her son's hospital stay, but screen time is now a mainstay in his life, as it is for many children his age.

"I worry that too much screen time is not good for him," she says. "I worry that it makes him anxious, overstimulated, and contributes to a short attention span."

FINDING BALANCE

For kids who have medical treatments that require limited movement for a while, screen time can be the ultimate soother. In certain cases, comfort should be first and foremost.

But it's also OK to wonder whether screen time is the best pastime.

"While there are some potential benefits to be gained by technology — educational, social, and creative — we see a lot of basic needs being displaced by screen time. Kids need opportunities for physical activity, social engagement in real life, and adequate sleep, all of which may be compromised when screen time use becomes excessive," says Jon Lasser, Ph.D., a professor of psychology at Texas State University and

"Kids need opportunities for physical activity and social engagement in real life."

co-author of *Tech Generation: Raising Balanced Kids in a Hyper-Connected World*.

"Screens are not going away," he adds, "and I'm not suggesting that children should completely avoid screens, but parents need to figure out how much their kids should have without experiencing some of the negative consequences."

SIGNS OF OVERUSE

Lasser says excessive use of screen time in kids can lead to a decline in grades, chronic sleep loss, negative mood when not on screens, reduced interaction with others, conflict when screens are denied, and no interest in activities outside of screen use.

To reduce screen time, set expectations with kids before they turn on a screen to let them know when the time will be up. Then, offer an offline activity as an alternative, such as a family game or a trip to the park. To help comfort a worried child in a clinical setting, offer a stuffed animal to hold, music to listen to, or a book to read.

—By Amanda Kippert

MIND GAMES

Excessive screen use can affect grades, sleep quality, and mood.



How Much Screen Time?

American children average five to seven hours of screen time a day, spent on television, phones, computers, and video games, according to the National Library of Medicine.

The American Academy of Child and Adolescent Psychiatry recommends the following limits. Furthermore, experts advise turning off screens at least 30 to 60 minutes before bedtime to promote better sleep.

Birth–18 months: Avoid except for video chatting with relatives.

18–24 months: Limit to educational programming with a caregiver.

2–5 years: Limit noneducational screen time to one hour per weekday and three hours on weekend days.

6 years and older: Use discretion — encourage healthy habits and limit activities that include screens.



4 WAYS TO REDUCE SCREEN TIME: So much of our lives revolves around tech that it can be hard to unplug — for kids and adults. Find helpful tips at hemaware.org/mind-body/4-ways-to-reduce-screen-time

Beware of Possible Drug Interactions

Here's what you need to know before taking a new medication or supplement

If you or your loved one takes a medication to control a bleeding disorder, you may already know that you need to carefully consider which other medications you use. Drug interactions can lessen the effectiveness of your clotting factor, or worse, thin your blood and put you at risk for bleeding.

Consult your health care provider before introducing anything new, and be sure to disclose all of the medications you are taking, says Jason Adam Wittes, Pharm.D., director of pharmacy programs at the University of North Carolina Department of Medicine.

Never assume that anything is “harmless,” cautions Jonathan C. Roberts, M.D., associate medical director at the Bleeding & Clotting Disorders Institute in Peoria, Illinois.

Everything you put in your body matters, so take a look at these reminders of potentially dangerous drug interactions for people with blood and bleeding disorders.

CHECK, PLEASE

When it comes to adding new medications to your routine, always run them by your health care provider.



AVOID ANTICOAGULANTS:

Blood-thinning medications are often prescribed in response to cardiac events or to prevent strokes, heart attacks, or blood clots. Examples include heparin, warfarin, Plavix, and Xarelto. “There may be specific instances where anticoagulation is indicated for an individual with a bleeding disorder,” Roberts says. “These decisions should be made after thorough discussion with the patient’s hematologist and interdisciplinary team.” (For more about cardiac issues, see Page 26.)

NSAIDS ARE NO-GOS:

Ibuprofen, naproxen, and aspirin are pain relievers that can decrease how well platelets work, putting you at risk for bleeding. If you inadvertently take one of these medications, contact your physician, Roberts says. There are other medications that can help with pain, such as acetaminophen. Keep in mind that many over-the-counter cold and flu products contain aspirin or ibuprofen, so check the labels. There are situations when a provider may allow these medications, typically in patients with mild deficiencies and for a limited time.

VITAMINS AND HERBAL SUPPLEMENTS MATTER:

Some vitamins and herbal supplements could affect the coagulation system, says Roberts, who himself has hemophilia. Most of all, though, vitamins and supplements are not regulated by the Food and Drug Administration. “These don’t have the rigor of scientific investigation behind them to really determine all of the potential side effects with them,” he says, adding that garlic and turmeric supplements may have an anticoagulant effect. Some can also affect the way your platelets work.

USE CAUTION WITH ANTIDEPRESSANTS:

Frequently prescribed for depression, SSRIs (selective serotonin reuptake inhibitors) are a class of drugs known to affect platelet function in some people. “You need to weigh the risks and benefits of the medication and determine if it could complicate your bleeding disorder management,” Roberts says. In general, SSRIs can be used safely in people with bleeding disorders, but patients should be monitored for additional bleeding while using these medications.

—By Andrea Atkins

Proper Storage and Handling Matters

Whatever medications you or your child are taking for a bleeding disorder, it’s always a good idea to review best practices for storing and handling them:

- Be sure your medication is refrigerated if that is required. If you don’t have access to a refrigerator, contact your health care team — you may be eligible for assistance.

- If you’re not sure about the instructions for storing your product, check the product insert or call your hemophilia treatment center.
- Always use clean supplies. Do you have alcohol wipes to clean off the vials? Do you have enough sharps? Are you disposing of them in a tear-resistant and leak-proof container?

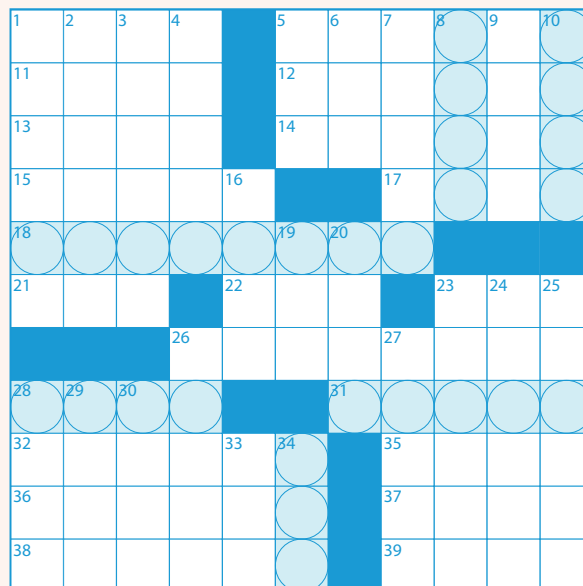


FOR MORE INFORMATION ABOUT NSAID USE, CONSULT THIS DOCUMENT FROM NHF’S MEDICAL AND SCIENTIFIC ADVISORY COUNCIL: hemophilia.org/MASAC276

CAN YOU SOLVE

**FOR A DIFFERENT
HEMOPHILIA A
TREATMENT?**

Test your HEMLIBRA knowledge



ACROSS

- 1. Wine barrel
- 5. Deep fissures
- 11. Mideast gulf port
- 12. District
- 13. Ripped
- 14. Familiar with
- 15. Mean
- 17. Roost
- 18. The #1 prescribed prophylaxis for people with hemophilia A without factor VIII inhibitors*

*According to IQVIA claims data from various insurance plan types from April 2020 - May 2021 and accounts for usage in prophylaxis settings in the US.

- 21. Calendar divs.
- 22. Regret
- 23. Banquet hosts (abbr.)
- 26. International travel necessity
- 28. Check out the _____ treated bleeds data with HEMLIBRA
- 31. Number of dosing options HEMLIBRA offers

† Number of people with hemophilia A treated as of October 2021.

- 32. Small hole in lace cloth
- 35. Central Plains tribe
- 36. Melodic
- 37. Towering
- 38. Reduce
- 39. Spanish cheers

DOWN

- 1. Memorable, as an earworm
- 2. Devotee
- 3. Medical fluids
- 4. Prepare to propose, perhaps
- 5. PC's "brain"
- 6. Owns
- 7. Concert venue
- 8. See Medication Guide or talk to your doctor about potential _____ effects
- 9. Winter hrs. in Denver and El Paso
- 10. HEMLIBRA is the only prophylactic treatment offered this way under the skin

- 16. Pre-Euro currency in Italy
- 19. Subway alternative
- 20. Relax
- 23. Human
- 24. New Orleans cuisine
- 25. Mentally prepares
- 26. Collared shirts
- 27. Instagram post
- 28. Ardent enthusiasm
- 29. Brontë heroine Jane
- 30. Old Portuguese coins
- 33. Opposite of WNW
- 34. More than _____ thousand patients have been treated with HEMLIBRA worldwide†

SOLUTIONS

Across: 1. cask, 5. chasms, 11. Aden, 12. parish, 13. tore, 14. used to, 15. cruel, 17. nest, 18. HEMLIBRA, 21. yrs, 22. rue, 23. MCs, 26. passport, 28. zero, 31. three, 32. eyelid, 35. Crote, 36. arose, 37. tall, 38. lessen, 39. oles
Down: 1. catchy, 2. adore, 3. serums, 4. kneel, 5. CPU, 6. has, 7. arena, 8. side, 9. MSTs, 10. shot, 16. lira, 19. bus, 20. rest, 23. mortal, 24. Creole, 25. steals, 26. polo, 27. photo, 28. zeal, 29. Eyre, 30. Reis, 33. ESE, 34. ten

Discover more at HEMLIBRA.com/answers

INDICATION & IMPORTANT SAFETY INFORMATION

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

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 that may cause harm to your kidneys, brain, and other organs
- **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**.



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. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

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 HEMLIBRA:
 - confusion
 - weakness
 - swelling of arms and legs
 - yellowing of skin and eyes
 - stomach (abdomen) or back pain
 - nausea or vomiting
 - feeling sick
 - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
 - swelling in arms or legs
 - pain or redness in your arms or legs
 - shortness of breath
 - chest pain or tightness
 - fast heart rate
 - cough up blood
 - feel faint
 - headache
 - numbness in your face
 - eye pain or swelling
 - trouble seeing

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

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

See “What are the possible side effects of HEMLIBRA?” for more information about side effects.

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:

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

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

How should I use HEMLIBRA?

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

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.

- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

What are the possible side effects of HEMLIBRA?

- See “What is the most important information I should know about HEMLIBRA?”

The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

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

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

How should I store HEMLIBRA?

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

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

General information about the safe and effective use of HEMLIBRA.

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

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

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

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

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For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised: 12/2021



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CAREERS



AND

Experts answer your most pressing questions about navigating the job market with a blood or bleeding disorder

CHRONIC

CONDITIONS

+ **SHOULD YOU DISCLOSE?**
You're not required to tell your employer about your bleeding disorder, but there are benefits if you do.

Nick McRae-Cyr knew he wouldn't be going into construction like the rest of his family.

Instead of a high-impact occupation, because of his bleeding disorder, he chose a career in social work. Still, it hasn't been without challenges.

One of his first jobs after graduate school was working with children in crisis at a psychiatric hospital. He was prepared for the position to be physical, but it proved to be more hazardous than expected.

"I was working with students who were often combative and aggressive," he says. "We wore a lot of protective gear, and we were getting assaulted on a regular basis. I only made it one school year there because I got hit pretty hard once, and it didn't go well."

McRae-Cyr wasn't about to give up on the profession he loved.

"That situation pushed me to find the places in social work where I was less likely to have the physicality and could do more of the emotional heavy lifting," he says.

His next job, working with homeless youths, was quite a bit safer for him. And for the past four years, McRae-Cyr has been a school social worker and hasn't had any more incidents with combative kids. But hemophilia still affects his work life.

McRae-Cyr met with his employers to discuss his condition and let them know what he needs to remain safe and healthy at work. Such requests are referred to as accommodations under the Americans with Disabilities Act, and as long as they are reasonable — they allow a person with a disability to perform the same job and enjoy the same benefits as other employees — employers are obligated to comply.

"I always let my administrators know, 'I have this disorder, and this is what you might notice if XYZ happens. I have to go in my office and be alone for a half-hour to take my medicine, which is an IV injection,'" he says. "Also, I wanted to explain that when I got a bloody nose, that might be a reason I miss a day or two of work."

Throughout his career, McRae-Cyr has been vigilant about maintaining continuous medical coverage that suited his needs.

"At that first job, the insurance was self-funded, so I was having a really hard time getting coverage for factor," he says. "Before taking my most recent job, I was on a HealthCare.gov plan, and then I started part time with my employer so I could make sure the insurance coverage was good before I went full time."

Ryan J. Rushton, a physical therapist at the Utah Center for Bleeding & Clotting Disorders in Salt Lake City, says McRae-Cyr has taken all of the steps he recommends to his patients when navigating the job market.

Rushton and Brenda McLean, a school and career counselor at the Indiana Hemophilia & Thrombosis Center in Indianapolis, discuss some of the top career concerns of people with blood and bleeding disorders.

HOW DO I CHOOSE A CAREER?

This is by far the most common question McLean gets, and she likes to answer it with a question of her own: If you didn't have to work, what would you do for free?

Your answer to that question can be foundational when exploring a career path.

ENJOY WHAT YOU DO

When exploring a career path, ask yourself: If I didn't have to work, what would I do for free?

WHAT YOU SHARED WITH US ON SOCIAL MEDIA

BLOOD AND BLEEDING DISORDERS "INSPIRED MY LIFE'S WORK."

DON'T TAKE THAT JOB UNTIL YOU CHECK THE INSURANCE COVERAGE

Before accepting a job, be sure to find out about the company's benefits package, specifically the medical insurance coverage.

"Once you've gotten an offer, ask for a copy of the medical plan summary," says physical therapist Ryan J. Rushton. "Take a close look at it to make sure your factor is covered, because if it's not, that's a no-go."

You can even take the plan summary to your hemophilia treatment center for help in deciding whether it meets your medical needs.

Details to consider include:

- Policy type (HMO, PPO, high-deductible health plan, etc.)
- Copayment amounts
- Premium costs per pay period
- Out-of-pocket limits
- Whether it covers factor and other medications to treat your bleeding disorder
- Whether your current doctors are in network

**+ CHANGE WILL
DO YOU GOOD**

Someone at your nearest hemophilia treatment center may be able to counsel you on a new career.



← WHAT YOU SHARED WITH US ON SOCIAL MEDIA

"IT'S INSPIRED ME TO BLEND BIOMEDICAL RESEARCH AND PATIENT CARE IN MY ROLE AS A PHYSICIAN."

"SADLY MY [BLOOD/BLEEDING DISORDER] DESTROYED MY CAREER."

"MY BROTHER'S HEMOPHILIA INSPIRED ME TO BE A DOCTOR. NOW I'M A PEDIATRICIAN"
❤️



WHAT ADVICE DO YOU HAVE FOR JOB SEEKERS?

“SHOOT FOR YOUR DREAMS AND MAKE THOSE DREAMS BECOME REALITIES. PREVIOUS GENERATIONS WITH BLEEDING DISORDERS DIDN'T HAVE AS MANY CAREER ASPIRATIONS BECAUSE THEIR LIFE EXPECTANCY WAS MUCH SHORTER. THAT'S NOT THE CASE TODAY. IT'S FUN TO WATCH OUR PATIENTS BECOME DOCTORS, CEOs, COLLEGE PROFESSORS, AND MORE. YOU DON'T HAVE TO SETTLE.”

— Ryan J. Rushton, DPT, Utah Center for Bleeding & Clotting Disorders

“Let’s say someone says they like football, but there aren’t a lot of job openings for football players, and that’s not the best career for people with bleeding disorders anyway,” McLean says. “But we could think about what other jobs you could do that are related to football. Maybe you could work on the business side of things — in marketing or PR. Maybe you want to be a coach or a trainer. There are lots of possibilities.”

Sometimes the trouble in figuring out what to do is not knowing what’s out there. In that case, a career assessment can help. These online tools ask a series of personality questions, then suggest career options based on the answers.

“These assessments are a good place to start in your process,” McLean says. “A lot of times it’s about expanding your thinking and figuring out what your options are. It’s finding that intersection of what do you like, what’s going to be fulfilling for you, and what’s going to match your physical needs.”

Once you’ve narrowed down your options, “then we discuss your educational and experiential background and figure out a way to bridge that gap” so you can qualify for the job you want, she says.

ARE THERE TYPES OF JOBS TO AVOID?

Although today’s treatment protocols are much better than they were even a decade or two ago, some jobs can still be difficult and dangerous for people with blood and bleeding disorders to perform. And these are often the types of jobs that people do if they didn’t complete high school, trade school, or college.

“Many times, our patients have to take what’s available, and that’s often the more strenuous jobs like delivering packages, loading luggage at the airport, cleaning, construction, things like that,” Rushton says. “And those types of jobs often are the worst types for the hemophilia patient who might have joint arthropathy or a bleeding elbow or a bleeding knee.”

WHAT CAN I DO IF MY JOB ISN'T GOOD FOR MY HEALTH?

If your job is making it difficult to maintain your health, it’s time to think about a change.

“I know it can be scary, but there are ways to transition into a new career,” McLean

says. “It’s not the end of the world to try something new.”

She suggests reaching out to the nearest hemophilia treatment center for career counseling if you need direction on getting where you want to be.

“For instance, say you want to be a nurse, but nursing school isn’t feasible right now,” McLean says. “We might suggest starting with going to EMT school at night and then working up to your nursing degree.”

DO I HAVE TO DISCLOSE MY BLEEDING DISORDER TO A POTENTIAL EMPLOYER?

No, and Rushton and McLean agree there’s no reason to let employers know about your condition before getting a job offer.

“I encourage people to be cautious about the urgency in which they tell people about their disease,” Rushton says. “First of all, it’s none of their business. Second of all, as long as you’re physically able to do the requirements of the job — and you shouldn’t be applying to jobs you can’t physically do — then there’s no need to disclose during the interview process.”

AM I PROTECTED FROM DISCRIMINATION IF I DISCLOSE?

Yes and no. Firing a person or not hiring a person because of a disability — which includes bleeding disorders — is illegal under the Americans with Disabilities Act. Discrimination also includes microaggressions, or subtle ways employers alienate marginalized employees in an effort to get them to quit. It can be difficult, however, to prove such discrimination, experts say.

“There are obviously laws against discrimination of disability, but it does still happen,” Rushton says. “And so those are valid concerns that people with hemophilia have, especially considering the disease is still largely misunderstood by the general public.”

ARE THERE BENEFITS TO DISCLOSING MY BLEEDING DISORDER TO MY EMPLOYER?

Yes, the most important being your safety.

“If you get injured on the job and they know about your condition, it might speed up the process of treatment,” Rushton says. “If you only tell one person, ‘Hey, if there’s an issue, I keep a card in my pocket, and this is what needs to happen,’ that can be lifesaving. It doesn’t even need to be someone in HR or management.”

Another reason to disclose your condition is to ask for accommodations, or adaptations to the job to make it safer or more comfortable for you, such as requesting to sit for a certain percentage of your shift, to work from home when necessary, or to have access to a step stool if overhead mobility is a challenge.

“There are lots of ways people with bleeding disorders can modify the way they work and still get their jobs done,” McLean says. “Sometimes it just takes a little ingenuity.”



MORE CAREER COUNSELING ANSWERS:

Get details on workplace issues, including links to career assessments and your rights as an employee, at stepsforliving.hemophilia.org/step-out/workplace-issues

HEMOPHILIA



Cardiac care can be a delicate balancing act for people with bleeding disorders

HEART



“

*It's like they say:
It felt like an
elephant was
sitting on my chest.*

”

WRITTEN BY BETH HOWARD
PHOTOGRAPHY BY DEREK LAPSLEY

HEALTH



The minute **Pedro Estalilla** → came home from his job as a database administrator one day in 2018, his wife, Diana, a registered nurse, and daughter Ashley, a clinical psychologist, knew something was wrong. He was pale and in pain, and they found that his blood pressure was extremely high.

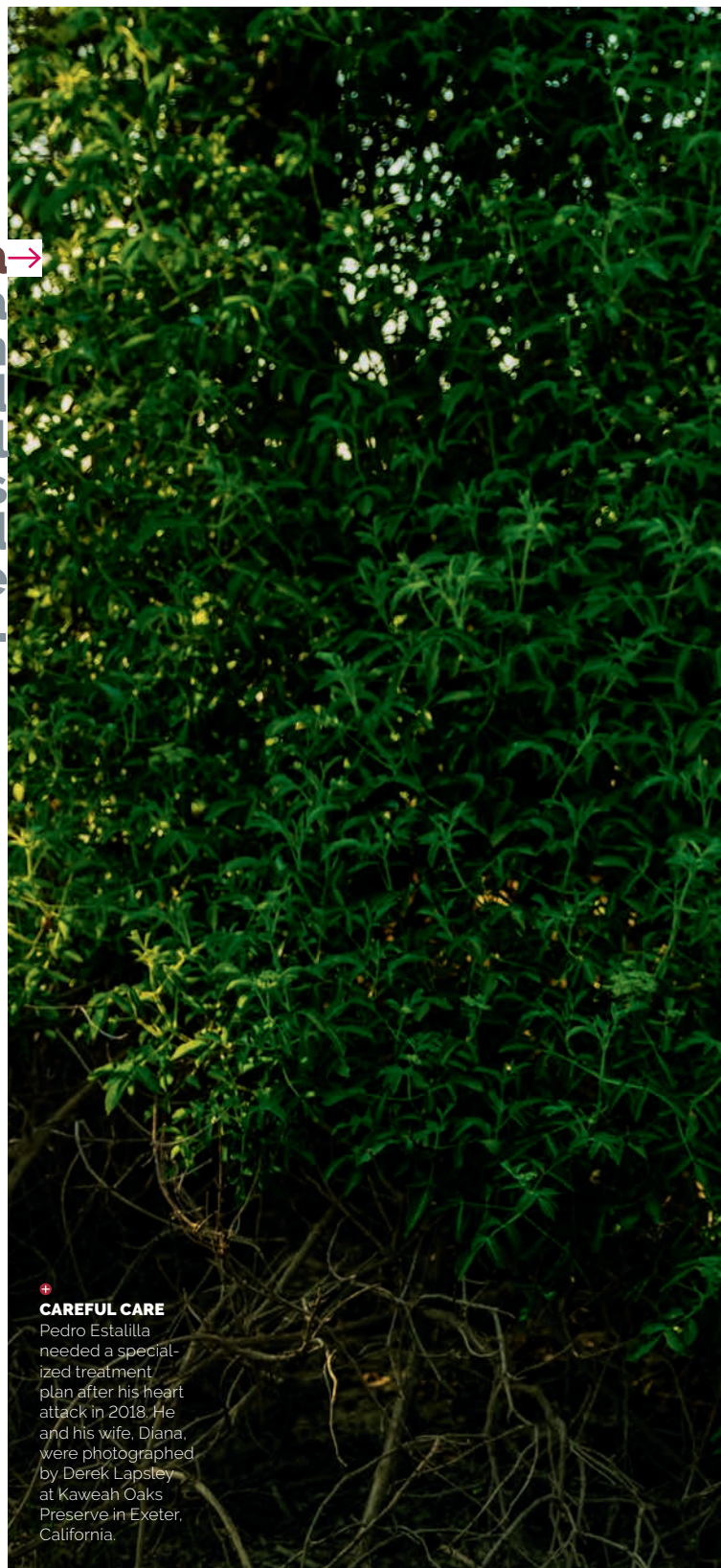
At the emergency room near the couple's home in Tulare, California, doctors determined that Estalilla, who has type 2 diabetes, was having a mild heart attack. Because he also has hemophilia B, doctors started calling other area hospitals that might know how to treat him without triggering a dangerous bleed, since heart attack procedures such as angioplasty and bypass surgery require a treatment plan for managing bleeding during surgery and for handling potential complications afterward, including clots. Anticoagulant medications are also a part of the equation.

Five hospitals turned him down, and 18 hours later, Estalilla was still waiting. By the time he was finally airlifted to the University of California, San Francisco Medical Center (UCSF Health), his mild heart attack had become major.

"It's like they say: It felt like an elephant was sitting on my chest," says Estalilla, 55. "I thought, 'This can't be the end of me. But if this is it, I need to say my goodbyes.'"

Doctors rushed him to the hospital's catheterization lab, where they opened the artery that was stopping blood flow to his heart and inserted stents to keep it open, all while treating and monitoring his bleeding disorder. Fortunately, he survived the scare and spent a week in the hospital while his doctors figured out the best postoperative treatment for him. He now focuses on diet and exercise to avoid future heart problems.

Cases like Estalilla's are becoming more common among the bleeding disorders community. Advances in treatment and improved blood and factor product safety have allowed people with bleeding disorders to better manage their conditions and live longer lives.



CAREFUL CARE
Pedro Estalilla needed a specialized treatment plan after his heart attack in 2018. He and his wife, Diana, were photographed by Derek Lapstey at Kaweah Oaks Preserve in Exeter, California.



**IS IT A
HEART
ATTACK?**

Be alert to these common symptoms, and always call 911 if you suspect a heart attack.

Chest discomfort: Uncomfortable pressure, squeezing, fullness, or pain in the center of the chest that lasts for more than a few minutes, or that goes away and comes back

Discomfort in other areas of the upper body: Pain or discomfort in one or both arms, the back, neck, jaw, or stomach

Shortness of breath

Other signs: Sweating, nausea, or lightheadedness

Source: American Heart Association

Now, they are facing health risks rarely encountered in the past. “With every success comes new problems,” says Andrew D. Leavitt, M.D., director of UCSF’s program for noncancerous blood disorders and co-director of the UCSF Hemophilia Treatment Center. “Now, we’re dealing with disorders of being in your 50s and 60s that we never used to deal with because we didn’t have patients in their 50s and 60s.”

GROWING RISKS AND CHALLENGES

Doctors used to think that hemophilia protected the heart because the blood is naturally “thin.” But that’s not entirely the case. Rates of heart disease are rising for people with bleeding disorders, although they are slightly less likely to die from cardiac causes than people whose blood clots normally.

Like everyone else, people with bleeding disorders become more prone to heart disease risk factors such as high blood pressure, high cholesterol, and obesity as they age — and sometimes at higher rates than in the general population. For instance, the prevalence of hypertension in adults with hemophilia is 49%, compared with about 32% in the population at large, according to a study in the journal *Hypertension*.

Rates of obesity are also growing among people with bleeding disorders, research shows. “Joint disease from past bleeds leads to limited activity, which can lead to weight issues,” Leavitt says. (Frustratingly, a high body mass index results in limited range of motion and increased pain, making it harder to exercise and lose weight to improve heart health.)

When heart attacks, strokes, and other serious cardiac events happen, doctors must weigh the need for anticoagulant and antithrombotic treatment against the clotting factors required to treat hemophilia. Balancing those competing risks requires significant coordination between hematologists and cardiologists, Leavitt says.

“The challenge becomes finding a product to maintain their levels high enough that they can tolerate all of the anticoagulant and antiplatelet drugs needed,” Leavitt says. The good news: “We now have easier ways, including long-acting factor, to maintain higher levels longer to have that nice balance between giving new treatments related to the heart disease and providing a level of safety against bleeding due to their hemophilia.”

PREVENTION IS KEY

Doctors prefer to prevent serious events such as heart attacks and strokes from happening in the first place, however, says Jacob Mayfield, M.D., chief cardiology fellow at the University of Washington in Seattle. “Things like a healthy diet and exercise are important because those are the things that will help normalize risk,” he says.

To fend off cardiovascular disease, experts suggest following these steps:

Eat a plant-based diet. Mayfield recommends two dietary approaches for good heart health. “The Mediterranean diet is what I recommend to most patients,” he says. The DASH diet, which stands for dietary approaches to stop hypertension, is similar and particularly helpful for people with high blood pressure.

Both eating plans feature generous quantities of fruits and vegetables, lean protein such as fish and poultry, low-fat dairy, healthy oils, whole grains, beans, nuts, and seeds, with sparing amounts of salt, sugar, and saturated fat. The Mediterranean diet emphasizes heart-friendly olive oil.

Get moving. Official exercise guidelines call for 30 minutes of moderately intense physical activity five times a week. But, says Mayfield, “everyone’s a little different. The most important thing is to set small, incremental goals for yourself.”

If you are just getting started, walk for five minutes three times a week, then increase the goal after a month. “You’re going for sustainable changes,” Mayfield says. Swimming is another option that is easy on the joints.



BE PROACTIVE
Rick Starks (left) and Jennifer DeGlopper (next page) have both taken steps to lower their risk of future heart problems.

The Power

Rick Starks took up tai chi, the ancient practice of meditative movement, after he had a heart attack 10 years ago.

The 68-year-old former paramedic in Haigler, Nebraska, grew up before the newest





Try to keep a healthy weight. Healthy eating and regular exercise are both key to dropping excess pounds. Losing weight may sound overwhelming, but shedding just 5% to 10% of your body weight can improve your blood pressure, cholesterol, and blood sugar levels, according to the Centers for Disease Control and Prevention. If you weigh 200 pounds, 5% is just 10 pounds.

Kick the habit. Quitting smoking does wonders for every aspect of your health, but particularly for the heart and lungs. “It can be challenging, when someone has a chronic disease, to give up things that provide pleasure,” Mayfield says. “But quitting can really extend your life.”

Educate your provider. It’s crucial to have a relationship with a primary care or internal medicine doctor to monitor your overall health, particularly heart disease risk factors such as cholesterol, blood pressure, blood sugar, and weight, Mayfield says.

But keep in mind that “many providers have a bias that people with bleeding disorders are unlikely to have thrombotic

complications like heart attacks or stroke,” he says. “Patients need to remind their provider that people with bleeding disorders are living longer and that it’s important to try to prevent cardiovascular disease.”

Jennifer DeGlopper, 57, a digital marketing consultant in Punta Gorda, Florida, who has hemophilia B and von Willebrand disease, had to prompt her primary care doctor to take a closer look at her rising cholesterol and blood pressure readings.

“As I got older, I thought maybe it’s time to do something about it,” says DeGlopper, who has a family history of heart problems and was just a year shy of her father’s age when he died from a heart attack. She ended up seeing a cardiologist, which is a reasonable option if you have significant risk factors. She is now on both blood pressure and cholesterol-lowering drugs.

Take prescribed medications. Thankfully, antihypertensive and cholesterol-lowering medications such as statins are generally fine to take if you have a bleeding disorder, Mayfield says. Use them as directed to get the most benefit.

But it may be a different story if you need antiplatelet drugs (blood thinners), such as aspirin or clopidogrel (Plavix), or anticoagulant drugs, which could trigger additional bleeding. “That’s where it gets complicated for people who have bleeding disorders,” Mayfield says. “It really has to be an individualized approach. If someone has a relatively low-risk atherosclerotic process, we may not give them any antiplatelet therapy at all.”

Whether you are trying to wrangle troublesome risk factors or manage an ongoing heart issue, make sure that specialists are working together on your dual health challenges, Leavitt stresses. “Everybody is different, and very close interactions between your hematologist and cardiologist are essential,” he says. “This is definitely not plug-and-play.”

of Zen

therapies for treating his hemophilia B had been developed. After years of practicing martial arts — and sustaining multiple injuries and bleeds — he found himself overweight and in too much pain to exercise.

“Both ankles were pretty much destroyed so bad that I could hardly walk a couple blocks,” says Starks, who also had both hips replaced in his 30s. “I became a couch potato because I couldn’t do anything.”

After his heart crisis, Starks started watching tai chi videos and then took classes online. His weight dropped to 200 pounds, and he went off his blood pressure medication. Soon, he was teaching tai chi

at National Hemophilia Foundation meetings and elsewhere, inspiring others to follow his lead.

“The gentle movement strengthens your body and increases your flexibility,” Starks

says. “Then there’s the meditative part of it that helps all those things that stress you out during the day. Right now, I feel like there’s no reason I couldn’t live to be 100.”



BETTER CARE WITH YOU

begins

RESEARCH
INITIATIVE



NHF'S NATIONAL RESEARCH BLUEPRINT WILL ENSURE THAT LIVED EX



When it comes to chronic and life-changing medical conditions, better care starts with better research. Until a few years ago, clinical investigators drove the direction of bleeding disorders research. The wants and needs of those most affected by inherited bleeding disorders were never strategically harnessed to determine research goals.

BY RITA COLORITO

PERIENCES SHAPE THE FUTURE OF BLEEDING DISORDERS RESEARCH AND CARE.

That's about to change with the National Hemophilia Foundation's (NHF) National Research Blueprint. Since 2020, this initiative has aimed to shape the future of bleeding disorders research, putting people with inherited bleeding disorders, as well as their families and caregivers, front and center.

NHF's efforts to prioritize the voices of those most affected by bleeding disorders within a formal research planning framework began in 2018, when NHF members attended a National Heart, Lung, and Blood Institute workshop on inhibitor research. One of the main recommendations from the event was patient inclusion in prioritizing research.

To improve the lives of people with inherited bleeding disorders, NHF and its nationwide chapters have long relied on community input. Spurred by the leadership of President and CEO Leonard Valentino, M.D., NHF realized it had built-in relationships and know-how to take the recommendation from the NHLBI workshop a step further.

"Imagine the impact we can create by focusing our collective expertise, resources, and energy toward areas that can create the most dynamic impact for people with bleeding disorders and their families. We could change lives for the better and create a lasting generational impact," Valentino says.

He adds: "No one individual or organization can own this challenge. As the largest national organization dedicated to improving lives for people with inherited bleeding disorders, NHF is embracing our role, and responsibility, to champion this effort and serve as the conduit through which the research and patient community can come together to create a national blueprint of patient-centered research with quantifiable outcomes."

Spearheading what the future of research should look like was a logical and important step for NHF, says Michelle Witkop, DNP, FNP-BC, who served as NHF's vice president of research strategy until she retired in 2022. Her successor, Maria Santaella, has had a leadership role in the National Research Blueprint (NRB) since the beginning and now oversees the initiative.

Listening to what patients want not only makes for better community relations, it also makes for better research, Witkop says.



"Patient-centered, coordinated research has fewer Institutional Review Board amendments and has better recruitment. It also finishes the research phases and is assimilated into practice more quickly," she says.



THE START OF SOMETHING DIFFERENT

From the beginning, NHF prioritized listening to all community voices. Since summer 2020, NHF has conducted community working groups and listening sessions to capture patient, caregiver, and family input.

In early 2021, NHF launched a cross-community survey, developed by and administered through NHF's chapters and Hemophilia Federation of America member organizations. As part of the survey, 335 participants — including 125 people with bleeding disorders and 112 health care professionals — identified three major research priorities. At the top of the list was continuing the hemophilia treatment center model of care. Survey participants also prioritized more research on new therapies across bleeding disorders and research on improving access to care, including differences in care in various communities. NHF also gathered input from participants in Community Voices in Research, a community-powered registry supported by NHF.

Input from the listening initiatives formed the basis for NHF's inaugural State of the

Science (SOS) Research Summit, held in September 2021 to help design and implement the NRB framework.

The four-day virtual summit was organized by SOS steering and advisory committees. Donna M. DiMichele, M.D., the former deputy director of the Division of Blood Diseases and Resources at NHLBI, spearheaded the 2018 NHLBI workshop and has served as a consultant on the NRB's leadership team since its launch in 2020.

Through a contract with the Center for Information and Study on Clinical Research Participation, NHF convened several months of virtual listening sessions with diverse working groups representing adults with bleeding disorders, caregivers, patient organizations, chapter and member organization directors, health care providers, and industry representatives to develop research recommendations.

In line with NHF's commitment to the principles of health equity, diversity, and inclusion (HEDI), the virtual summit allowed for greater participation nationwide. Of the 887 attendees, nearly 40 were in remote areas, representing underserved and minority populations.

The central question posed to them: Where can we make the greatest impact? Topics included research priorities for hemophilia A and B and other, ultra-rare inherited bleeding disorders, as well as science around the health of women, girls, and those with the potential to menstruate.



Participants also highlighted the need to prioritize patient-centricity and HEDI principles in health services research.

The community input initiatives pinpointed several areas that warranted further research, including mental health, joint disease, treating the aging population, and pain management.



MAKING YOUR VOICES HEARD

Sammie Valadez, of Peru, Illinois, was one of 10 patients recommended by their local NHF chapters to serve as subject matter experts during the virtual working group sessions. Valadez brings eight years of personal and family experience with bleeding disorders to the discussion. She and her two daughters have von Willebrand disease. Her oldest daughter also has factor VII deficiency.

A name change for the patient subject matter expert working group was the first order of business. “We were getting confused with researchers, since they are subject matter experts in their field,” Valadez says. The group decided that “lived experience experts,” or LEEs, better reflects who they are, says Valadez, who serves as the LEE working group co-chair. The term now refers to people with inherited bleeding disorders, their family members, and their caregivers.

Before she started serving on the NRB group, Valadez says, she didn’t think community members’ voices were heard when it came to research. For the past three years, LEEs have met twice a month to discuss community input and impact on developing the NRB.

The development of the NRB offers hope and empowerment to people directly affected by bleeding disorders, Valadez says. “Most patients have no idea how they can be part of the research and what comes from research, so bringing us into the research from the beginning is wonderful,” she says.

The NRB doesn’t just benefit people with bleeding disorders and their families. “The focus of LEE-centered research means clinical researchers have a new partner with unique insight into what are the most impactful questions we should be answering,” says NHF Chief Medical and Scientific Officer Michael Recht, M.D., Ph.D., co-chair of the NRB Steering Committee alongside Valentino.

“The innovative aspect of the NRB process is including and valuing the LEE voice. It’s the first time where research questions and clinical trials will be centered around the issues brought to the forefront by LEEs,” Recht says.

He and other clinical researchers say the patient-centered approach to research is long overdue. “As I reflect back, I have come to realize the questions I was asking and attempting to answer were the questions interesting to me,” Recht says. “I had never enlisted my patients or families to help me formulate the questions I was trying to answer.”

For LEEs like Valadez, having a seat at the decision-making table is a welcome change, but not everyone embraced the idea initially. “At first, they were hesitant about their place, afraid of speaking up,” Witkop says. But with Santaella’s guidance and encouragement, Witkop says, many more LEEs now embrace their role in determining research goals.

“The goals of the NRB and the pivotal role being played by LEEs in realizing these goals



**MOST PATIENTS HAVE
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SAMMIE VALADEZ



are helping to bring unique solutions to overcoming the knowledge gaps and experiential barriers to active LEE participation in advancing their own standard of care through research engagement, regardless of type of bleeding disorder,” DiMichele says.

An important aspect of the NRB is that it is grounded in the principles of equitable and inclusive access to care and research. “As the LEEs now say, ‘Nothing about us without us!’ And that is as it should have been and should always be, now and in the future,” DiMichele says. “Although this has been a perennial goal for this community, we have never been so close to achieving it in such a strategic and inclusive way.”

For the NRB to succeed, community members must continue to make their voices heard, Witkop says. “They know where the gaps are and what needs to happen to make things move forward,” she says. “By being involved, making themselves knowledgeable, and becoming part of the team, they create change and energy. With the knowledge of the researchers, that synergy creates the spark of innovation. We can all be part of it, but not without each other.”



STAY UP TO DATE: As of press time, the National Research Blueprint is scheduled to be released in early 2024. For more details, visit hemophilia.org/research/national-research-blueprint.



Our beloved founder,
George King (1922-1987)

GEORGE KING BIO-MEDICAL, INC.-

GET TO KNOW US AND OUR COMPANY

George King Bio-Medical is a 3rd generation family owned and operated company located in Overland Park, KS. Prior to starting the company, George J. King became involved with the Hemophilia Foundation in his hometown of Rochester, NY. His involvement led him to eventually serve as a 2-term president of the National Hemophilia Foundation during the 1970's. Throughout his multiple terms as president with the NHF, he had a vision of how he could help and serve people with bleeding disorders. He knew that people with bleeding disorders had very large financial needs for treatment. He also saw the need for further research in the field of bleeding disorders. His vision was to bring these 2 needs together to help each other. He created George King Bio-Medical Inc. with this vision in mind. His goal was to perpetuate his company long after he was gone. He opened George King Bio-Medical, Inc. in 1973 in Salem, New Hampshire. The company moved to Overland Park, Kansas in 1978. Through the years, George King Bio-Medical, Inc. evolved into an internationally renowned supplier of clinical hemostasis products.

Today George King's vision continues, keeping his company goals alive and proudly celebrating our 50th year of business.



GEORGE KING BIO-MEDICAL, INC.

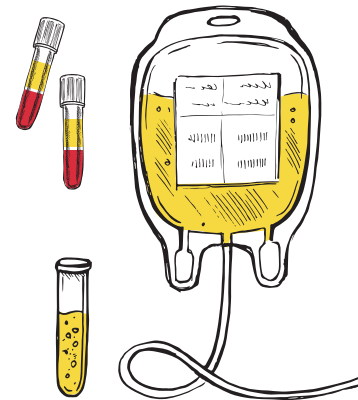
WHY DONATING PLASMA IS ESSENTIAL FOR RESEARCH & DIAGNOSTIC TESTING

IS DONATING PLASMA SAFE WHEN YOU HAVE A SEVERE BLEEDING DISORDER?

In most cases, the answer is yes! Plasma fully regenerates in the body within 48 hours. When you have a bleeding disorder, you will need to donate in a special Source Plasma Licensed facility. These centers went through a rigorous process to obtain their licensing through the FDA.

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SUPPORT

Several chapters contribute funding to the Judith Graham Pool fellowship.



Investing in the Future

Research into better treatments and improved care for people with blood and bleeding disorders is made possible by generous contributions from NHF chapters

Every year, the National Hemophilia Foundation (NHF) supports research to seek cures for, and prevent complications of, inheritable blood and bleeding disorders. And each year, many NHF chapters donate their own funds. In 2022, 26 chapters contributed funding to support NHF research.

Some chapters didn't have to think twice about where to direct their money. For example, the Lone Star Bleeding Disorders Foundation (LSBDF) supported the Judith Graham Pool (JGP) Postdoctoral Research Fellowship in 2022, as it has done for the past eight years.

"Our mission statement says we support research for better treatments and a cure, and JGP's history of research was a great place for us to give that support," says LSBDF Executive Director Melissa Compton. "With the dedication of NHF to support the best researchers out there and provide them with a way to complete their research initiatives, JGP was an easy answer to where we should send our support."

The New England Hemophilia Association (NEHA) also contributed to the JGP fellowship, which it has supported for the past five years.

"It is important for NEHA to make this yearly contribution to support finding medical discoveries that will lead to better treatment options for those with a bleeding disorder," says NEHA Executive Director Rich Pezzillo. "Research plays a vital role in learning how to improve the health and well-being of those living with a bleeding disorder, and the potential to find a cure."

While the New York City Hemophilia Chapter (NYCHC) has donated to the JGP fellowship in the past, in 2022 the chapter chose to support the NHF-ATHN (American Thrombosis and Hemostasis Network) Collaboration.

“The coming together of these two amazing organizations for the betterment of the entire bleeding disorders community has the potential to not only make quality medical treatment more accessible but will also promote a better understanding of the many different bleeding disorders that affect our community,” says Erin Cirelli, an NYCHC board member. “[They] identify and support the research vital to the entire community.”

The promise of new treatments for people with blood and bleeding disorders is what inspires many chapters to earmark their funds for research.

“The potential for life-changing outcomes for our community via the National Research Blueprint is truly exciting.”

“When my 21-year-old son was diagnosed and we became a part of the community, there were only a handful of products,” Compton says. “Look at how many there are now and how many are in research and development! JGP’s novel research and dedication to improving the lives of people with bleeding disorders is very much worth our support.”

In 2024, NHF will release a National Research Blueprint to prioritize local and national research opportunities while identifying gaps in care for underserved

populations that may be addressed by researchers. (To learn more about the blueprint, see Page 32.)

“The potential for life-changing outcomes for our community via the National Research Blueprint is truly exciting,” Cirelli says.

—By Lisa Fields



TO MAKE A DONATION TO NHF TO SUPPORT RESEARCH, VISIT: hemophilia.org/supportresearch

NHF Chapters That Supported Research Initiatives in 2022

Bleeding Disorders Alliance Illinois	Hemophilia Foundation of Greater Florida	New York City Hemophilia Chapter
Bleeding Disorders Association of South Carolina	Hemophilia Foundation of Minnesota and the Dakotas	Pacific Northwest Bleeding Disorders
Bleeding Disorders Foundation of North Carolina	Hemophilia Foundation of Northern California	Rocky Mountain Hemophilia & Bleeding Disorders Association
Colorado Chapter, National Hemophilia Foundation	Kentucky Hemophilia Foundation	Texas Central Bleeding Disorders
Florida Hemophilia Association	Lone Star Bleeding Disorders Foundation	Tri-State Bleeding Disorder Foundation
Gateway Hemophilia Association	Nebraska Chapter, National Hemophilia Foundation	Southwestern Ohio Hemophilia Foundation
Great Lakes Hemophilia Foundation	Nevada Chapter, National Hemophilia Foundation	Virginia Hemophilia Foundation
Hawaii Chapter, National Hemophilia Foundation	New England Hemophilia Association	Western Pennsylvania Bleeding Disorders Foundation
Hemophilia Association of the Capital Area		West Virginia Chapter, National Hemophilia Foundation



A new program for young adult males with hemophilia who are currently in the transition years between 18-29 is recruiting participants.

Email ownyourpath@hemophilia.org for more information.



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders



SEEN
A summit on women and girls with bleeding disorders will bring visibility to an important topic.

The event's goal is to help the community get a step closer to making sustainable care possible for people with bleeding disorders everywhere. Participants will primarily include WFH national member organization staff and volunteers, healthcare providers, representatives of national government institutions, industry partners, international agencies, and other collaborating organizations.

WFH GLOBAL SUMMIT ON WOMEN AND GIRLS WITH BLEEDING DISORDERS

This fall, the WFH will hold the third WFH Global Summit on Women and Girls with Bleeding Disorders (WGBDs). Participants from around the world will come together to move the discussion forward on an important topic that still does not get the visibility it deserves. In addition to learning more about the realities of WGBDs worldwide, participants will have the opportunity to gain insights on care, treatment, and advocacy, and ultimately help empower WGBDs.

The summit will include plenaries and educational sessions where participants can learn from experts, ask questions, and exchange ideas and experiences on specific topics. There will also be workshops covering practical skills and sharing best practices for members of both hemophilia treatment centers and national member organizations. And, of course, there will be opportunities for participants to network.

The WFH Global Policy and Access Summit (GPAS) will take place virtually July 6-7. The WFH Global Summit on Women and Girls with Bleeding Disorders (WGBDs) will take place virtually Sept. 28-29. Registration is open for both events, and simultaneous interpretation will be offered in several languages, including Spanish.



LEARN MORE: wfh.org/wfh-events

Upcoming Events

Two key WFH summits will take place virtually in the second half of 2023

The vision of the World Federation of Hemophilia (WFH) is Treatment for All: a world where all people with inherited bleeding disorders have access to care, regardless of their type of bleeding disorder, sex, or where they live. Sustainable care can be achieved only by giving stakeholders the tools they need to build their own complete support infrastructure.

One way the WFH is facilitating this change is by offering global events that bring together committed people to increase their knowledge, share experiences, and forge long-lasting relationships. At the WFH 2023 Comprehensive Care Summit in May, medical professionals, people with bleeding disorders, and community advocates gathered to discuss new medical research and discoveries, and to assess problems and issues present in the management

of bleeding disorders in all parts of the world.

In the coming months, the WFH will host two other important events:

WFH GLOBAL POLICY AND ACCESS SUMMIT

The WFH Global Policy and Access Summit (GPAS) is a two-day event that covers strategies for sustaining and advancing bleeding disorders care in the fast-changing post-pandemic world. The summit, which is coming up in just a few weeks, is a unique opportunity for participants to learn, discuss issues with their peers, and share strategies to increase equitable access to care and treatment for the global bleeding disorders community. The previous summit was held in October and brought together more than 400 participants from nearly 100 countries.

Gathering Again

Getting together in person is back! Here are a few recent events that were a great success for both chapters and their leaders.



KIDDING AROUND
Goat yoga was a highlight of the 2022 Chapter Leadership Seminar held in Scottsdale, Arizona.

CHAPTER LEADERSHIP SEMINAR

Chapter leaders across the country came together in November 2022 for the annual Chapter Leadership Seminar at the Hilton Scottsdale Resort & Villas. The training event had a record 133 participants and focused on diversity, equity, and inclusion. The seminar's keynote speaker, Italo M. Brown, M.D., M.P.H., a board-certified emergency physician and assistant professor at Stanford University School of Medicine, spoke about health equity and the bleeding disorders community.

"He was amazing and had the highest-rated session," says Kristi Harvey-Simi, NHF's director of chapter development. Also popular was a recreational session of goat yoga, which the foundation used to show chapters the importance of doing activities that benefit mental health and boost creative thinking. "We were trying to model that," Harvey-Simi says. "It went over really well."

WANT YOUR EVENT FEATURED IN CHAPTER ROUNDUP?

We are not able to highlight all programs due to an overwhelming response. However, we appreciate your submissions and look forward to highlighting more in future issues. If you'd like to feature your chapter's event in the next issue of *HemAware*, email Donna.Behen@Manifest.com



COURTESY OF CHAPTERS



GREAT LAKES HEMOPHILIA FOUNDATION NOT YOUR GRANDMA'S BINGO

What's more fun than a rousing game of bingo?

A rousing game of Drag Queen Bingo! On Feb. 8, the Great Lakes Hemophilia Foundation (GLHF) benefited from a third-party fundraising event held at Hamburger Mary's in Milwaukee. It was the third time the venue's weekly bingo event benefited the chapter.

"They bill it as 'Not Your Grandma's Bingo,'" says Danielle Leitner Baxter, executive director of the GLHF. "It's sassy, hilarious, and philanthropic, as they do it every week for charity." Donations and tips from activities — such as a dance-off — have raised about \$1,000 through the three evenings.

Learn more about the Great Lakes Chapter of the NHF:
glhf.org

—By Renee Bacher

NEVADA CHAPTER OF THE NATIONAL HEMOPHILIA FOUNDATION WINTER WINE FEST

The Nevada Chapter of the National Hemophilia Foundation held its 8th Annual Winter Wine Fest on Jan. 28, the chapter's first in-person fundraiser since 2020.

"We had 115 people, which is the most we've ever had," says Executive Director Jacob Murdock, "and we raised more than \$17,000, which is a great amount for us."

The event was held at a new venue, Bella Vita Blue Diamond, on their heated outdoor patio. "Everyone raved about the food," Murdock says. Festivities included an unlimited wine tasting and plentiful hors d'oeuvres, as well as a silent auction and a wine pull raffle. "It was a \$50 ticket for all-you-can-drink wine and delicious food," Murdock says. "You can't get anything in Las Vegas for that price."

Learn more about the Nevada Chapter of the NHF:
hfnv.org



75 Years of Service, with Change on the Horizon

This year, the organization celebrates 75 years of history, hope, and progress. Read on for glimpses of what's been rediscovered in the archives and visit hemophilia.org/75 to see more historic highlights.



ORTHOPEDIC STUDY 1956

Henry Jordan, M.D., a surgeon and medical trustee of NHF, begins a study of the orthopedic treatment of hemophilia patients. The decade-long study includes 110 patients and is funded and conducted in cooperation with NHF at the Lenox Hill Hospital in New York City.

HISTORIC ADVOCACY ASK 1962

NHF Chairman John Walstrom writes a letter to U.S. Rep. John Fogarty in which he dubs 1962 “the most important year in the history of the foundation,” given

the “substantial appropriation for research in hemophilia” in a bill that had just passed the House.

JUDITH GRAHAM POOL RESEARCH FELLOWSHIP 1972

A research fellowship named in honor of Judith Graham Pool is established. The prestigious fellowship program continues today. Learn more at hemaware.org.

AWARENESS MONTH 1986

At the urging of advocates, President Ronald Reagan proclaims March as

National Hemophilia Month. This celebratory awareness month later becomes Bleeding Disorders Awareness Month. The 1980s also mark the beginning of a tragic era, with the AIDS crisis affecting the community. For more on this difficult period, explore the timeline at hemophilia.org/75.

VWD FINDINGS 2004

Results from a Centers for Disease Control and Prevention and NHF study around knowledge of von Willebrand disease are presented at a meeting of the American Public Health Association.

SPANISH LANGUAGE PROGRAMMING 2017

NHF introduces the Guías Culturales program. Guías culturales, or cultural guides, are volunteers within the community who speak Spanish and have navigated care for themselves or family members. Learn more at hemaware.org.

VWD GUIDELINES 2021

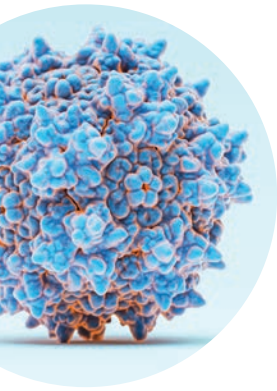
NHF, in collaboration with the American Society of Hematology, the International Society on Thrombosis and Haemostasis, and the World Federation of Hemophilia, publishes guidelines on the diagnosis and management of von Willebrand disease.

REBRANDING UNVEILED 2023

The organization is gearing up to unveil a rebrand in August at the 2023 Bleeding Disorders Conference. The rebrand, which will include an organizational name change and an aesthetic update, intends to be inclusive of the many blood and bleeding disorders represented by this special community.

By being more intentionally inclusive of rare disorders, von Willebrand disease, and other non-cancerous hematological conditions, the organization can continue to fund research to further scientific and medical discoveries.

Over the years, many supporters have grown attached to the name, look, and work of the foundation as it's historically been known. You will still see yourself reflected in the organization, and you'll have many new community members alongside you every step of the way.



Potential New Gene Therapies

Updates on three hemophilia treatments currently under investigation

In late November, the Food and Drug Administration (FDA) approved Hemgenix, the first gene therapy to treat adults with hemophilia B. Here's an update on three other gene therapies for hemophilia under investigation:

ROCTAVIAN FOR SEVERE HEMOPHILIA A

BioMarin announced in March that it had received a notice that FDA had extended its review of the company's application for Roctavian, which is currently in multiple clinical trials to observe its safety and efficacy in adults with severe hemophilia A.

According to a BioMarin press release, FDA determined that the submission of the three-year data analysis from the ongoing phase 3 GENEr8-1 study constituted a "major amendment" due to the substantial amount of additional data, and it set a new target action date of June 30.

"The three-year data enhance our application and further reinforce our belief that Roctavian has the potential to fundamentally transform care for people with hemophilia A," Hank Fuchs, M.D., BioMarin's president of worldwide research and development, said in the release.

BENEGENE-2 FOR SEVERE HEMOPHILIA B

In December, Pfizer announced positive top-line results from the phase 3 BENEGENE-2 clinical study, which is evaluating the investigational gene therapy fidanacogene elaparovec for the treatment of men with moderately severe to severe hemophilia B.

A key measure of the therapy's efficacy is annualized bleeding rate, or ABR. Investigators compared the ABRs of participants after fidanacogene elaparovec infusion versus a standard prophylaxis regimen with a factor IX replacement therapy, which was administered as part of routine care during the so-called lead-in period lasting for at least six months.

According to a press release, the results demonstrated superiority with a mean ABR for all bleeds of 1.3 for the 12 months from week 12 to month 15 compared with an ABR of 4.43 during the lead-in pre-treatment period, resulting in a 71% reduction in ABR after a single dose.

"The BENEGENE-2 data demonstrate the promise of this gene therapy candidate as a potential one-time option for people living with hemophilia B as a means of reducing the clinical and treatment burden over the long term," said Adam Cuker, M.D., M.S., director of the Penn Comprehensive Hemophilia and Thrombosis Program.

SPK-8011 FOR HEMOPHILIA A

In December, Spark announced results from its phase 1/2 clinical trial of SPK-8011, its investigational gene therapy for hemophilia A.

Administered via a one-time intravenous infusion, SPK-8011 is designed to elicit the production of therapeutic levels of the factor VIII (FVIII) protein in people with hemophilia A. A Spark press release detailed the results, the primary focus of which were annualized bleeding rate and annualized FVIII infusion rates achieved by participants. At the time of the data cutoff in early October, 21 of 23 dosed participants across all dose cohorts had experienced sustained expression of FVIII with up to five years of follow-up, including two participants who completed five years of follow-up.

"We are encouraged by these data and the potential for investigational SPK-8011 to further improve on current standards of care by providing a one-time, durable treatment option, and we will continue with participant follow-ups," said Stacey Croteau, a study investigator and medical director of the Boston Hemophilia Center.





IT TAKES A TEAM

"I've been fortunate to work with so many incredible people," says Judith Baker.

Community Health Is in My Blood

I'm proud of the work I've done with so many great colleagues to ensure that all people with blood and bleeding disorders have access to quality care

I came of age in the 1970s, when there was an explosion in the women's health movement. I got involved in a lot of advocacy specific to women's health, and I'm fascinated by why certain things are so hard to discover. Why do some environmental exposures affect us? How do we stop them? How can patients and allies work together to find solutions and develop them to resolve health problems?

I earned my master's in public health in 1983 and worked for the Philadelphia Department of Public Health, where I directed research investigating the health outcomes of children born at different birth weights. When I moved to California in 1990, I learned there was a job as a regional administrator for the

Western States/Region IX Hemophilia Treatment Center Network. It was just the right fit. It had issues I felt passionate about, like women's health issues, as well as HIV, which was hitting the hemophilia community hard. I would be working on multi-institutional federal grants and contracts.

I've worked on many projects that I'm proud of, but probably the one that stands out is helping hemophilia treatment centers (HTCs) grow and sustain themselves financially so that they can be there for patients and families.

Most of the HTCs were established in big cities. But wherever you live in this country, you should have access to the best expertise in diagnosing and treating

hemophilia, von Willebrand disease, and other rare genetic bleeding and clotting disorders. One of the benefits of regionalization is that we can show patients with blood disorders that although their disorder may be rare, they're not alone.

Part of my job was to identify and help develop local expertise in underserved areas, which really spoke to my concerns for equity, and the questions of why some populations have better health than others, and what can we do to solve that. I discovered that there were no HTCs in Nevada, Hawaii, or Guam, so the people there were vastly underserved. Research has shown that when men with hemophilia have access to an HTC and obtain their care there, they're less likely to die. They have fewer emergency room visits, fewer hospitalizations, and lower medical bills. So I helped in the development of the first HTCs in these three areas.

As I retire from full-time employment, my hopes for the blood disorders community going forward are for continued collaboration, to find the best solutions to whatever problems we're facing, and to really listen to one another and intentionally reach across the disciplines — including patients, researchers, physicians, nurses, social workers, physical therapists, the pharmacists, and the administrators — so that we include everyone's expertise and don't leave anybody's voices out.

—By Judith Baker, DrPH, MHSA, as told to Leslie Pepper

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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



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