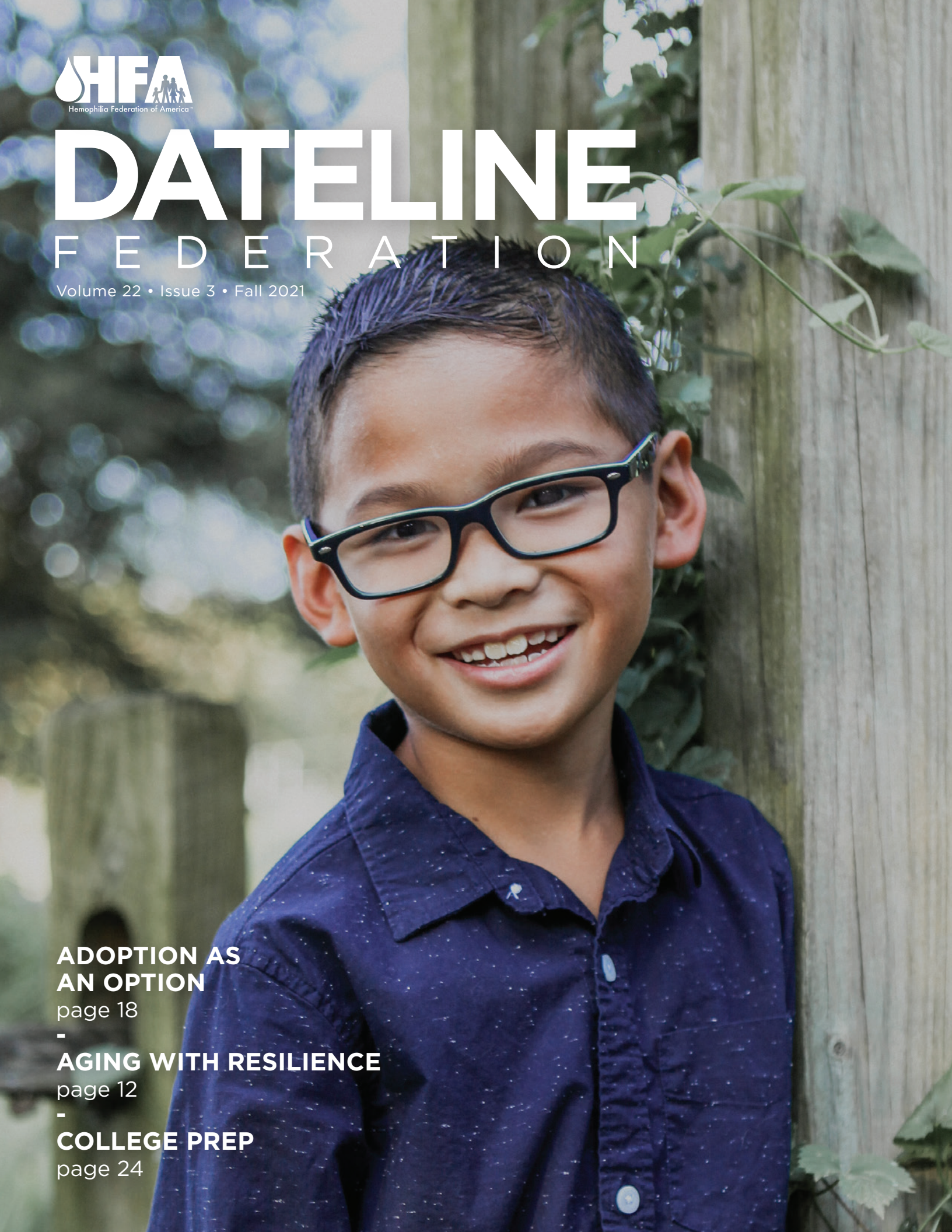

Hemophilia Federation of America

DATELINE FEDERATION

Volume 22 • Issue 3 • Fall 2021

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-

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HI FRIENDS,

Can you believe it's holiday time already? Fall is my absolute favorite time of year. Here in the Pacific Northwest, the leaves become beautiful colors, the air is crisp and everything feels cozier. And despite the busyness of life, I'm also trying to find moments of reflection and gratitude. What are you grateful for in this season?

Have you heard that Sharon Meyers and I are going on Facebook Live each month? Tune in on the first Friday of every month at 12 p.m. Eastern for "Coffee and Conversations"! We chat about life and what's happening at Hemophilia Federation of America (HFA) and answer any questions that come up. We'd love for you to join us!

As I write this, it is full-speed ahead for this year's HFA Virtual Symposium, held in October. I hope you had an amazing experience. Look for a recap in the next magazine issue.

In this issue are a couple of features encompassing all ages of the bleeding disorders community. On page 12, we examine some of the issues related to aging that men with hemophilia may need to address. With advancements in treatment and blood safety, this generation is living longer and longer, which means they will need to address normal aging issues such as heart health, preventive screenings like colonoscopies, cancer risks and high blood pressure.

On page 18, we introduce you to parents in the bleeding disorders community who built or grew their families through adoption. They talk about the joys, challenges and what questions they wished they had asked.

This issue is full of inspiring and positive news, like the Good for Gears cyclists who raised money for the bleeding disorders community (see photo above) and the hemophilia mom inspired by our community to launch a fundraiser in her town. On page 28, see our latest scholarship recipients, and on page 26, read first-person essays from two first-time attendees of the Young Adult Advocacy Summit.

Please enjoy this issue of *Dateline Federation*. As always, if you have questions about anything included within these pages, please reach out to the HFA team. We are here to support you!

Allie Ritcey

Chair, HFA Board of Directors

Hemophilia Federation of America™

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

Volume 22 • Issue 3 • Fall 2021

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Connect with us on social media for daily posts and updates about what's happening at HFA.

Cover photo: Elijah Andrews

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HAPPENING HIGHLIGHTS

Join Team Resilience and runDisney!

runDisney has announced that its 2022 races will be held in-person at Walt Disney World, so Team Resilience will be a part of the fun! Whether you are a beginner or a veteran runner, you will truly enjoy the sites and magic of Disney as you run through Walt Disney World.

You'll also be raising awareness of bleeding disorders and rare genetic diseases and raising funds for the Hemophilia Federation of America (HFA) Helping Hands program. As you run, you'll be helping families keep their homes if they miss work for hospitalizations or you'll be providing them with durable medical supplies or travel expenses to medical appointments.

Team Resilience will take part in the Walt Disney World Marathon weekend January 5–9 and the Princess Half Marathon weekend February 25–27. Visit **www.hemophiliafed.org** today to sign up.

Participate in Our Virtual Hill Day!

HFA's annual Patient Fly-in and Congressional Reception has been reimagined for 2021! You can participate from the comfort of your home the week of November 15–19. Join us as we meet with key congressional offices to explain why expanded subsidies provided in the American Rescue Act should be made permanent and how co-pay accumulators adjustor programs harm patients. Mark your calendar to spend less than two minutes using HFA's Legislative Action Center to write, call or tweet your legislators about issues important to the bleeding disorders community.

Donate Today

As you know, living with a bleeding disorder presents a lifelong series of "what if"s. These unknowns can be very scary for a new parent or a seasoned community member. Bleeding disorders can bring health issues, frequent hospital trips, as well as a battery of situations forcing families to make tough choices.

The good news is that for more than 25 years, HFA has been a support system to hold up families after a "what if" becomes a reality. HFA is a comforting resource where families can get answers—answers that bring relief and stability to a family struggling to adapt to their reality. Our Helping Hands program was designed specifically to help community members who are experiencing a financial crisis with basic living expenses. Helping Hands is there for our families.

Now, we need your help. Would you consider making an unrestricted gift to Hemophilia Federation of America to help a family with emergency assistance or to purchase a necessary medical item? Learn more about how you can help by visiting **www.hemophiliafed.org**.

MEMBER ORGANIZATION SPOTLIGHT

Hemophilia Association of New York Inc.

The Hemophilia Association of New York (HANY) Inc. will celebrate its 70th birthday in 2022, serving thousands of people with bleeding disorders over the years. When the pandemic hit in 2020, the organization knew it had to step up to provide financial assistance to struggling families. In the first year of the pandemic, HANY distributed $40,000 in assistance.

"Most of our clients are introduced to us through referrals of the social workers of the hemophilia treatment centers (HTCs)," Executive Director Linda Mugford said. "Our client support services are very robust, even during the COVID-19 pandemic. I like to say that HANY rarely says 'no' to a request for help."

HANY's assistance program continues, providing support for MedicAlert IDs, transportation for camp and medical visits, co-pays and deductibles, and other things deemed necessary for a client's well-being. HANY also has a scholarship program, awarding $55,500 in 2021 to clients enrolled full time in a college or university. Furthermore, since 1965 HANY has given more than $25 million to support bleeding disorders research.

"Our longevity makes HANY unique, along with our focused vision of making the lives of those with bleeding disorders easier to manage," Mugford said. "We are honored to work closely with the five New York downstate HTCs."

Mugford also wanted to acknowledge Tyshawn Constantine, HANY associate director, who implements the organization's ideas and oversees the various programs and requests. When asked for advice for other organizations to achieve such success. Mugford quoted Constantine, who likes to say: "Let's focus on what we do; make it better—it's quality, not quantity."

"As tempting as it is to start doing many and various programs," Mugford said, "you must be thoughtful of the needs of the community and their time. If you develop something that works, make it better."

HEMOPHILIA ASSOCIATION OF NEW YORK INC. FACTS

Started in 1952

Serves the 14 downstate counties of New York

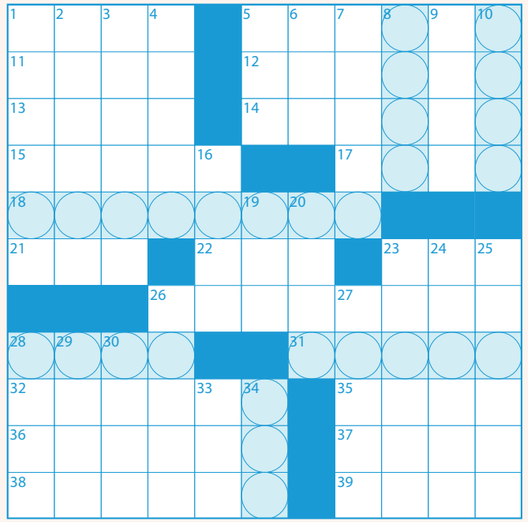
750 people served

Most successful program: The annual Steven L Margolies, MD, Educational Conference

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 hemophilia A*

*According to IQVIA claims data from various insurance plan types from October 2019 to November 2020 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
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. _____ thousand patients have been treated with HEMLIBRA worldwide†

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

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. NCs, 26. passport, 28. zero, 31. three, 32. eyelet, 35. Otoe, 36. anose, 37. tall, 38. lessen, 39. oles
Down: 1. catchy, 2. adorer, 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. steels, 26. polos, 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.**

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

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.

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

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: 10/2018

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

Genentech
A Member of the Roche Group

MULTIPLE TRAILS. MANY LOCATIONS. ONE TEAM.

Gears for Good National Bike Ride back in person in 2021

BY MEGHAN LAWTON,
HFA ASSOCIATE DIRECTOR, ADVANCEMENT

Water bottles were full. Helmets were donned. Shoes were clicked in. It was time to saddle up. Hemophilia Federation of America's (HFA's) 2021 Gears for Good National Bike Ride was underway!

September 17–19 marked the 12th edition of the annual bike-riding fundraiser to benefit HFA's Helping Hands program, which provides assistance with urgent basic living expenses, medically necessary items, plus medical travel and educational support for people with inhibitors.

While ongoing COVID-19 restrictions changed the ride slightly, nine in-person riders set off down the C&O Canal from Arlington, Virginia, with a goal of reaching Harper's Ferry, West Virginia, and back by the end of the weekend. The riders were joined in spirit by two virtual riders logging miles in their hometowns.

HFA would like to extend a special thanks to Tom Knoerzer and Get Out & Go Tours for coordinating the ride's logistics. After the event switched to fully virtual in 2020, riders were eager to get back together in person this year and ride along the C&O. Although ongoing pandemic restrictions forced changes to this year's ride, the cyclists were still able to log over 150 miles on their bikes over the course of the three days.

Even with the paired-down event, riders raised over $16,000 in donations, all of which supports the HFA Helping Hands program. A big thank you to all of our 2021 riders, both in-person and virtual, and those that donated to their fundraising goals.

Information for the 2022 Gears for Good rides will be released soon. Stay tuned to the HFA website at **www.hemophiliafed.org** and be ready to sign up your team to ride!

HFA EVENTS *Motivated* MAINE MOM TO CREATE MUSEUM FUNDRAISER

BY MELANIE PADGETT POWERS,
MANAGING EDITOR

Through Hemophilia Foundation of America's (HFA's) fundraising efforts, Lianne Lapierre, of Limestone, Maine, discovered her love of biking and running at age 40.

Lapierre, whose 14-year-old son has severe hemophilia A, took part in HFA's Team Resilience for the 2019 and 2020 Gears for Good and fundraised for HFA during Disney's

2021 Princess Half Marathon Weekend. During one of her Gears for Good training rides she found herself cycling (with permission) on an abandoned runway of a former Air Force base in her town.

"It was on this ride that I thought it would be a pretty neat thing to host some sort of run for my local community on this historic runway," she said. "I've always loved volunteering, and fundraising for HFA came naturally to me. I thought this would be a great opportunity to take all of the fundraising skills I've learned over the years and do something fun to help out my own community."

Lapierre created a 5K/10K race, held over the 2021 Fourth of July weekend, on the runway at Loring Air Force Base in Limestone, which was decommissioned in 1994. Runners from all over the country attended in-person, and there was a virtual option. So far, they have raised over $1,000 (money is still being donated) for the Loring Air Museum, which pays tribute to the men and women who served at Loring over the years.

Volunteers helped coordinate the event and hand out snacks. There was live music and a surprise National Anthem performance sung by the 195th Maine Army National Guard Band.

"I loved seeing the amount of people that came out to support the museum that morning," Lapierre said. "I honestly wasn't expecting such a great turnout our first year! We had so much positive feedback afterward, as our small town has never seen anything like this."

She said she thinks the event will become a part of her town's annual July Fourth festivities. Her goal next year is to double the turnout and raise even more for the museum.

"My advice to those wanting to create their own fundraiser would be, if your heart is telling you to do it, then go for it, whether it's a bake sale in the cafeteria at school, a car wash, a community-wide yard sale or a 10K—the possibilities are endless!

"We all have the opportunity to give back in ways that can truly help. Get creative and remember: Just because a ship may seem small, it still has the ability to make some pretty large waves."

WHEN THE CRISIS CONTINUES AND COMPOUNDS

Reflections on financial assistance in a pandemic

BY ALLISON HARRISON, MSW, HFA ASSOCIATE DIRECTOR OF SERVICES

Gavin and Nieve* were making ends meet until the COVID-19 pandemic hit. Nieve lost two different jobs in 2020 when the companies that employed her lost business and laid off workers.

Gavin, who has hemophilia A, picked up additional work even though it was hard on his already damaged joints. Nieve found another job and good income until April 2021 when supply chain issues led to another layoff. Gavin's income and Nieve's unemployment benefits carried them through the summer of 2021 until Gavin had a series of bleeds and was let go because of his many absences from work. With only unemployment benefits, they scrimped where they could. They let the car insurance lapse, cut down on food expenses, let go of cable.

But sometimes when it rains, it pours. In August, Nieve caught COVID-19 and was hospitalized for 10 days. Then, Gavin was in a car wreck and, without insurance, could not afford to fix the car. Unemployment benefits ended in early September. And speaking of rain—did I mention that right before I spoke to them, a tree fell on their house during a storm?

I am on the services team at Hemophilia Federation of America (HFA). Our team operates the Helping Hands financial assistance programs (Emergency Assistance, Items Assistance, Inhibitor Support, Disaster Relief, COVID-19 Relief), Helping Forward program (for career and financial planning) and other resources for the community. We are social workers who spend our days hearing the needs of community members like Nieve and Gavin. The job is not just about determining eligibility, collecting information, processing applications and paying bills. It's about listening, validating and supporting.

It's our job to let someone know they are not alone in their struggles, affirming that it is OK to cry, reflecting back to them the ways in which they have been resilient and coped with difficult circumstances.

In between logging data in Salesforce and creating check requests, we are staying up to date on policies so we can provide the most useful information to our applicants: Are they getting the child tax credit? Do they know that they may qualify for a special insurance enrollment period? We track trends and brace ourselves for the end-of-month surge, the end-of-benefits surge, the holiday surge, the unexpected surge of referrals that tells us it is a tough time for our bleeding disorders family.

When the pandemic started in the U.S., we knew it would hit the community hard. On March 18, 2020, HFA received the first Emergency Assistance referral that mentioned the coronavirus. Within four weeks we created the COVID-19 Relief program. We secured funding, created the program guidelines and processes, built a new intake and client relationship manager structure, designed a web presence, publicized the program to stakeholder groups and onboarded colleagues to temporarily staff the program.

What we suspected, but could not have fully imagined, was the devastating impact it would continue to have on our community 18+ months later. It affects finances, mental health, employment, family dynamics, school, physical health and so much more.

As the death toll from COVID-19 in the U.S. compounded from 150,000 to 699,000 (and counting, with more than 2,000 deaths per day), community members' challenges compounded, too. And referrals multiplied for Helping Hands and assistance programs across the country.

We have exhausted and refreshed HFA COVID-19 Relief grant funding three times and are currently approving COVID-19 Relief applications as needed with general Helping Hands funds. Helping Hands has paid 865 bills through COVID-19 Relief in the past 18 months, plus 330 bills for emergency assistance, 125 for items assistance, 20 for inhibitor support and 35 for disaster relief since January 2020. We receive a dozen referrals a week from hemophilia treatment center social workers, home health/pharmacy representatives and local bleeding disorder organizations.

As of October 1, electric, gas and water utilities are no longer postponing disconnections. Some applicants are calling us via Wi-Fi because their cellular phone service has been shut off. Several federal unemployment benefits offered through the American Rescue Plan Act expired September 4. Eviction moratoriums are only in effect in a handful of states. And families still have bleeds, hospitalizations, births and deaths, unexpected financial emergencies. The "typical" emergencies are layered on to the ongoing emergency of the pandemic. Here are a few examples of the situations our community members face:

Robert* and Kanti* had a newborn who experienced bleeding issues right after birth. Robert had to miss work to care for their other children while Kanti and the baby were in the hospital. The missed paychecks left them without enough money for rent.

Diane's* daughter has hemophilia A. Two family members temporarily moved in with them to escape a hurricane, adding to expenses. Then the house was infested with bedbugs and Diane could not afford to replace her daughter's bed.

With diabetes and a history of heart trouble, Shane*, who has von Willebrand disease, was at high risk for COVID-19. Plus, schooling for their children went virtual, so they decided to leave their job and stay home to avoid the risk of death from COVID-19 and help the children with online school. As a single parent, Shane needed help to pay the rent until they could figure out a new plan.

Francesca* has a rare platelet disorder. She cleans houses for a living and lost a lot of work because people did not want visitors in their homes during the pandemic. She is undocumented so she was not eligible for most benefits. Her water bill was two months overdue and at risk of disconnection.

Will*, who has hemophilia B, lost his mother and grandmother to COVID-19. In his depression and without their financial help, he lost his job, his car and his apartment. He lived in a tent while trying to find a lead on a new job or get approved for the Supplemental Security Income program.

LaToya* cares for her son who uses a wheelchair because of joint issues. Their SNAP food benefits randomly stopped eight months ago, but she is so overwhelmed with the health and work issues that she hasn't been able to make the phone calls to get the administrative issue resolved.

NEED HELP?

To learn more about Helping Hands programs, visit **www.hemophiliafed.org/helpinghands**.

Visit our Patient Assistance Portal for resources about financial assistance, financial planning, manufacturer assistance for medications, mental health and more at **www.hemophiliafed.org/patientassistanceportal**.

Learn about employment rights and career planning in the "Planning Office" on Learning Central at **www.hfalearning.org**.

For mental health resources and tips, see **https://bit.ly/HFAMentalHealthResources** or **www.hemophiliafed.org/recursos-de-salud-mental**. If you are in crisis, **text "HOME" to 741-741** to reach a trained crisis counselor.

The financial need in our community is persistent. The virus is relentless. The flow of referrals to our programs is continuous.

I do not know how long it will take for these beloved community members to recover—financially and otherwise—from the effects of COVID-19. All of us are still living in a pandemic while simultaneously trying to cope with and heal from its impacts.

What I do know is that Gavin and Nieve received HFA Emergency Assistance, COVID-19 Relief, and Disaster Assistance to cope with the multifaceted emergencies they faced over 18 months. All the community members in situations like the ones above spoke with a Helping Hands staff person who cared about them, and all received assistance from Helping Hands in one form or another.

Helping Hands must continue to provide help, and hope, to our community. We must ensure that funding flows to keep pace with the flow of referrals. We must be relentlessly generous and persistently compassionate. 2022 will mark 25 years since the Helping Hands program began. We have stood beside families who endured the HIV crisis, stock market and housing market crashes, hurricanes, global recessions and now a pandemic. With your support, we will continue to stand with families, whatever may come.

Donate to Helping Hands at **www.hemophiliafed.org/donate.**

* Names and some details were changed to preserve anonymity.

Aging with Resilience

We welcome the first generation of men with hemophilia living into older age—and explore the medical issues that come with it.

BY HEATHER BOERNER, FREELANCE WRITER

When Dan Liedl, who has severe hemophilia A, wakes up in his Morgantown, West Virginia, home every morning, he feels fine. It's only when he starts to move that he feels every minute of his 58 years. It's an interesting experience for a man whose adoptive mother was told her son wouldn't live to age 21.

There's the arthritis in his hips, ankles, knees and shoulders that tell him what the weather is going to be like that day. There are times he has to dangle his legs over the side of the bed and slowly rotate them so that the pain in his ankles drops from agonizing to just sore. And of course, there is the limp caused by the fused knee and the neuropathy from cancer treatment that remind him with every step he's not a kid anymore. It's a weird realization for a man who, in midlife, is studying to get a PhD in medical sociology.

"Some days my mind tells me I feel like a teenager and my body tells me I'm an old man," Liedl said in a deadpan.

Dan Liedl, at age 58, says, "Some days my mind tells me I feel like a teenager and my body tells me I'm an old man."

What he does know is that his body is older than his years, largely because he's a member of the first generation of men with hemophilia who are living into their 60s, 70s and 80s. He and his peers have experienced the full gamut of hemophilia treatments—whole blood transfusions, cryoprecipitate and every generation of replacement factor out there. This means they also have had a large number of bleeds and the accompanying joint damage and bone density loss, often leading to mobility limitations and pain. Plus, he and his generation are dealing with something that men with hemophilia never had to face before: diseases of aging, such as diabetes, high blood pressure, cancer, joint replacements, even heart disease and organ transplants. And as they do, they—and the health care system that treats them—are having to learn how best to meet all of their needs.

The good news is that everything these men are dealing with can be addressed with the right medical teams and with the help of the discipline that most men with hemophilia learn early, said Richard Vogel, 65, of East Brunswick, New Jersey, who has severe hemophilia A. Vogel is a past president of Hemophilia Federation of America.

"If you don't infuse, you're going to bleed," he said. "So you learn to be compliant with your prophylaxis. I know every third day I'm going to infuse. And I don't miss a day because it's ingrained in me that this is what I'm going to do. The same is true for high blood pressure medication [or any other medication]. That discipline is there."

AGING WITH HEMOPHILIA

Data on people aging with hemophilia are just starting to emerge and aren't yet definitive. There are the hemophilia-related conditions that Liedl described as well as an increased rate of osteoporosis or osteopenia among men with hemophilia compared to men their age without hemophilia.

But there are a number of ways that having hemophilia requires different care. For instance, routine screening for colorectal cancer through a colonoscopy or

As a database administrator, Murali is well-qualified to keep track of all his medical records.

a sigmoidoscopy are low risk for bleeds, but the removal of colorectal polyps to prevent colon cancer is not. Endoscopy to assist with cancer staging in the gastrointestinal tract isn't high risk, but doing the same procedure with the addition of a biopsy with a fine needle is. The list goes on.

As a result, the National Hemophilia Foundation's Medical and Scientific Advisory Council, known as MASAC, recommends changes in how someone doses prophylaxis factor and other hemophilia treatments on the days before, on the day of and sometimes for a week after treatment. And the risks of breakthrough bleeds increase the older a person gets, according to the guidelines.

All of this calls for collaboration between hemophilia treatment centers (HTC) and treatment teams, said Joan Osip, RN, NP, a former HTC nurse in the Minneapolis area. And it's why one of the first things Osip used to tell her clients who were older was that they couldn't depend only on their HTC for all their care anymore.

"As you get older, you need primary care," Osip said. "If your blood pressure is increasing or you need to start on cholesterol meds, that routine maintenance is probably better for primary care."

While some HTCs also offer primary care, most HTCs, she said, are set up only to manage hemophilia. And smaller ones may not have the staff to add primary care or ongoing management of non-hemophilia conditions. Just like the men they care for, HTCs have to adapt to aging needs, too.

"Nurses have to be trained in primary care," Osip said. "HTC nurses are used to managing bleeding and clotting disorders; primary care is a little bit different."

They will also refer you to specialists such as nephrologists, oncologists and others to provide the specialized care people need as they age.

Murali Pazhayannur, 61, of Aurora, Illinois, who goes by one name, "Murali," knows this better than most. Murali lives with severe hemophilia A and has a primary care provider. But he gets most of his care from specialists: an endocrinologist for diabetes, nephrologist for kidneys and so on.

He has also had two major surgeries in his life. In 2003, Murali had a pseudotumor removed from his hip. The result of a childhood growing up without hemophilia treatment in India, the pseudotumor started as a small bleed. But because it never stopped, the body walled off the bleeding, creating a football-sized pseudotumor that compressed his femoral nerve and caused withering and paralysis in his lower leg. That procedure, managed by a hemophilia expert, also included various specialists because of how dangerous it was—carrying with it a 1 in 4 chance of death, he said.

"Obviously I'm still living," he quipped.

So when Murali learned that his chronic kidney disease was threatening to force him to, in his words, be "tied to tubes" for dialysis, he got on the kidney transplant list. After his pseudotumor surgery, the transplant he received in 2015—with a kidney from his brother—seemed much less complicated. However, because he receives his care at Rush Medical Center in Chicago and was having the

transplant at University of Wisconsin Medical Center in Madison, he became his own care coordinator.

Luckily, as a database administrator who calls himself "fixated" on keeping every lab result and piece of medical data about himself, he was uniquely qualified to play the role.

"For the kidney, I had to collect all that information, and I had saved all of it," he said. "Madison was asking me for X, Y and Z thing, and Rush was asking me to sign all these documents for every itty-bitty information they needed. I had all my paperwork, though. All I had to do was upload it in one place and then send the link to the Madison nurse."

MULTIPLYING HEALTH CONDITIONS

Still, aging with hemophilia brings with it a lot of non-hemophilia conditions. For Murali, "it would be easier if you asked me for a specific ailment and then I could give you the medication. I don't know if I can rattle off all the medications."

Like Murali, Liedl and Vogel also have a lot of chronic conditions: diabetes and high blood pressure for all three. Vogel has high cholesterol and kidney problems. Murali no longer has kidney problems, but now he takes immunosuppressants every day to keep his body from rejecting his kidney. Liedl has had pancreatitis and had his gallbladder removed. Now, he's also got narrowing and hardening of the bile ducts on his liver. Both Vogel and Liedl acquired HIV and hepatitis C from tainted blood products in the '80s. (Both men are now cured of hepatitis C.)

The privilege of growing older, it seems, comes with a laundry list of medications, specialist appointments and prior authorizations from insurance. Oddly, one side effect of having uncontrolled bleeds for so many years before factor replacement and prophylaxis is that their blood never got a chance to build up blood clots—and that has been associated with men with hemophilia having lower rates of heart attacks and strokes. But as bleeds become less frequent, Osip said she doesn't expect that protection to endure.

And when blood clots do form—Osip said she's worked with men who have had heart stents placed or other heart-related issues—some require aspirin, an almost unimaginable situation for people with hemophilia decades ago.

"You have to use it, but they're probably not taking it as long as people without hemophilia," Osip said. "And you probably have to be on prophylaxis."

And then there are the multiple medications that men must begin to juggle. Data out of Europe suggest that so-called polypharmacy—taking lots of medications—may be less common for people with hemophilia than those without. But that doesn't mean drug-drug interactions can't happen, she said. And they can send a person to the hospital. That means that periodically primary care providers should also check a person's medications to make sure they still need all of them and at their current dosage—while also doing lab work to look at blood sugar and cholesterol. They should also check that their patient is taking them at the right time of the day and with or without meals as necessary.

"Primary care will monitor the drugs you should be on and tweak it as it needs to be tweaked," Osip said.

QUALITY OF LIFE: THE FINAL FRONTIER

Understanding your medications isn't the end of the story on aging with hemophilia, Osip said. There's more to life than being disciplined in taking your medicines and following up on appointments. Indeed, there's joy, and there's sex.

Trouble enjoying life and sex can increase with age in general. For instance, a Canadian study found that nearly 2 out of 5 men in their late 40s with hemophilia reported erectile dysfunction, with odds of erectile dysfunction rising with age. This isn't something to just give up on, Osip said.

"Having sex is important," she said. "It brings all kinds of great dopamine and serotonin."

Richard Vogel, with wife Suzanne, shows off his big "catch and release" off Hilton Head, South Carolina.

She pointed out that, like many other things associated with age, sometimes sex needs to be adjusted to make it work for your current body. There's even a book, "Sexual Health in Hemophilia: Preventing Joint and Muscle Injuries," written by an HTC physical therapist.

"The thing about aging is that you start to lose stuff that, as a younger adult, you don't think about," Liedl said. "One of the things I lost when I went through cancer treatment was I became impotent. It's just another thing you've lost."

Another big issue to consider as people age: mental health. Dana Francis, MSW, a social worker at University of California, San Francisco, HTC, has facilitated groups so guys could talk about hemophilia and life. But he said he didn't dare call them "support groups" for years.

At one group in 2018, he said, "Somebody said the D word—depression," he said. "By the time we'd gotten around the circle, half of them had said the same thing."

But the same stoicism that keeps men persevering through bleeds can prevent them from acknowledging or getting help for the depression and anxiety that can come from loss of mobility, isolation and aging.

"It feels really good to not be alone," Francis said he tells the men he works with. "It feels good to not be isolated. It feels good to have other guys you can confide in. What we're all trying to do here is expand our humanity beyond the narrow limits of what we've been taught it means to be a man."

For Liedl, the solution to loss isn't isolation; it's teaching himself to be curious about new things. Like sex, for instance. You learn to be intimate in other ways.

"Why say goodbye [to things you've lost] when you can change and do something new?" he said. "Do something else that thrills you. In my life, I've been an air traffic controller. When I lost that job, I went back to school; I became a therapist. When I got cancer, I went back to school, and now I'm getting my PhD so I can be a university professor. There's always opportunities out there. You just have to find what makes you happy."

ADOPTION AS AN OPTION

Several bleeding disorders families share their adoption experiences and advice.

BY HOLLY LEBER SIMMONS, FREELANCE WRITER

Natalie Andrews remembers the first time she saw a picture of her son, Samuel, in 2016. "He looked terrible. He had black eyes and it looked like someone had punched him," she said. "His joints were badly swollen; he couldn't walk."

Samuel, then 4, was living in an orphanage in China. Natalie, her husband Jason, and three daughters—Kyleigh, now 16; Kaelyn, 13; and Aubrey, 10—were told that he had a bleeding disorder that made him bruise easily, but he had not been tested specifically for hemophilia.

The parents knew the word "hemophilia," but that was the extent of it. "I knew literally nothing about hemophilia," Natalie Andrews said. The family brought Samuel home to Central Ohio on a Friday and went to the hospital that Monday. The little boy was diagnosed with severe hemophilia A and received his first factor infusion that day.

That eight-hour day was overwhelming, Andrews said. "I remember being in the car and thinking of all the things he was going to go through and breaking down at that point. It changes what you think life is going to look like and you realize it's going to be a lot harder than that."

Adoption and bleeding disorders both come with their own challenges. Combined, new challenges arise. But there is a lot of joy too, and several bleeding disorders community members have built their families through adoption—while also recognizing that kids with bleeding disorders may be less likely to get adopted.

Shari Luckey, MA, program services manager at the Hemophilia Foundation of Michigan (HFM), works with families considering or in the process of adopting children with hemophilia by providing resources and support. HFM also offers a hemophilia adoption scholarship (see **https://bit.ly/hemophiliaadoption**).

"There are challenges of adoption with any child integrating into a family," Luckey said. "I try to give them the reality that it's not going

The Andrews family

to be all rosy and perfect."

Adoption and bleeding disorders is familiar territory for Luckey. She is a carrier and has mild hemophilia. Her oldest biological son, 27, has severe hemophilia B with inhibitors. She has twin daughters, 21, one of whom has mild hemophilia, and her youngest, Luke, 20, who was adopted from China in 2010, has severe hemophilia A.

Hemophilia is also a familiar world for Horowitz. She has mild hemophilia A and has hemophilia in six generations of her family. "Growing up, they didn't think girls could have hemophilia," said Horowitz, who was diagnosed at age 45.

Horowitz has two daughters, Tehilla, 19, adopted from Addis Ababa, Ethiopia, at age 5, and Eliana, 17, adopted from Xiushan, China, at 10 months. Neither girl has hemophilia, though Eliana has bleeding of unknown causes, sometimes called BUC.

Horowitz started thinking about adoption, rather than being a biological mother, as early as the third grade. "My health didn't even come into consideration with the adoption agency," she said. "They look at health limitations, but hemophilia wasn't listed because at that time it wasn't believed that women could have it. My health doesn't limit me much; I am one of a small subset of women on prophylactic treatment, which keeps me safe and healthy. When looking at adoption versus birth, there are some personal, philosophical questions that there are no right answers for."

Horowitz's sister, who also has mild hemophilia A, has biological children, including a son with hemophilia, who is doing quite well, Shellye Horowitz said. "I like that our family has both. I would hate to see the fear of passing along hemophilia stop someone from their dream of having a biological child. My dream was to adopt."

Communication and Community

Communication is essential—with doctors, within families, with adoption agencies and with fellow parents. During challenging times, the Andrews family has found information, comfort and camaraderie in connecting with their local hemophilia group and online communities for adoptive parents and parents of children with bleeding disorders.

"These families have been going through it," Andrews said. "It's great to get the kids together with others who are like them. It was scary and hard. A lot of days are still really hard, but it's the best thing we've ever done."

It was through a Facebook group for parents of adopted

Kathy and Rob Secinaro with son Shane

Samuel Andrews

Shellye Horowitz and her daughters, Eliana and Tehilla

children with hemophilia that the Andrews family learned about their second son, Elijah, now 8, whom they brought home from China in 2018. Elijah, like Samuel, has severe hemophilia A.

"Since hemophilia is a genetic disorder, a lot of people who have it have a relative to share the experience with," Andrews said. "It was neat being able to adopt another child with hemophilia knowing they would have each other."

Connecting with other adoptive families with hemophilia has been essential for the Secinaro family in New Hampshire: mom Kathy, dad Rob and son Shane, now 20. Shane was adopted at four weeks old and has moderate hemophilia A as well as Hashimoto's disease, in which the immune system attacks the thyroid, and Wolff-Parkinson-White syndrome, which is when there's an extra electrical pathway in the heart that causes periods of abnormally fast heartbeat.

"Our knowledge of hemophilia before adopting Shane was zilch," Kathy Secinaro said. "Looking back we had heard of the Ryan White story, but neither of us had heard of anyone with hemophilia."

They connected with a hemophilia family camp and got to know other parents they could talk to. Secinaro advises prospective parents of children with hemophilia to make those connections with other bleeding disorders families. "You can get support and advice from others, and lean on them." For example, when she had trouble infusing, she'd call another mom. And over the years, Shane has become close to some of his blood brothers, which has been helpful.

Luckey's role is to work with prospective families to help educate them about living with and caring for a family member with a bleeding disorder. While the adoption procedure involves multiple steps for approval, families are not required to receive any training in caring for a child with a bleeding disorder, so getting information from organizations such as Hemophilia Federation of America, HFM or their local hemophilia treatment center is essential.

"I talk to people about how most of the time it's a manageable disorder, much like someone with diabetes," Luckey said. "We talk about how the treatments have come so far, how supportive the treatment centers are—like they teach you how to do infusions or they can send a nurse to come in and do it because it can take a while to transition into doing the treatments yourself."

You Are Your Family's Advocate

But even if a family has a lot of experience with bleeding disorders, there are specific questions they should ask related to the child's medical and life history and education.

Madonna McGuire Smith, MPA, knows bleeding disorders well. She's been working in the bleeding disorders community since 2009 and is the executive director at Pacific Northwest Bleeding Disorders, a patient advocacy organization in Oregon. Her husband and her three biological children, now 21, 19 and 17, all have von Willebrand disease (VWD).

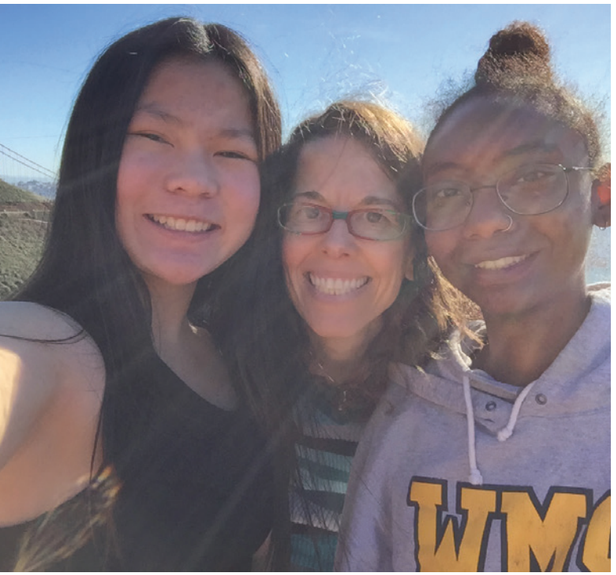
The family adopted Gavin, now 14, from China when he was 10. He has severe hemophilia A. "It was difficult to communicate with Gavin's caregivers because of the structure of international adoptions," McGuire Smith said. Instead of being able to directly speak with the caregivers, the parents had to communicate with the U.S. agency, who communicated with the Chinese agency, who then communicated with the orphanage in China.

McGuire Smith said there are so many questions now that she wishes she would have asked, and she wants to share her "lessons learned" with other families. "We were

so worried about the adoption process, filling out the paperwork properly and about being approved that we didn't think about all the questions we should ask about our son," she said.

It's essential for parents to be well-armed with information and know what questions to ask—about the child's entire medical history, not only the bleeding disorder—to advocate for their child and their family, she said. Here are questions McGuire Smith suggests asking during the adoption process:

- Is it possible to get a complete medical history of the child?
- Is it possible to get a complete list of bleeding episodes experienced by the child?
- Of the injuries listed, which required treatment with infusions?



- How many infusions did he receive with each of the injuries that required treatment?
- If an infusion was not necessary, what other forms of treatment were used to stop bleeding episodes?
- Has he ever had a brain bleed or any sort of head injury?
- Are there any records or notes of his behavior or life at the orphanage?
- Has he had any psychological or educational evaluations done? If so, is it possible to get a copy of those evaluations?
- Has he spent time with a family or been fostered outside the orphanage?
- Did he have friends at the orphanage? Did he interact well with others?
- What has his schooling been? Does he have any previous tests or school projects that you can share with us?

"When people ask me "would you do it again?" I always say resoundingly, capital letters, YES," McGuire Smith said, "but next time I would do a much better job educating and preparing myself."

Strong communication in a marriage and family is essential also. Mothers especially, Secinaro said, need to share

> "I WOULD HATE TO SEE THE FEAR OF PASSING ALONG HEMOPHILIA STOP SOMEONE FROM THEIR DREAM OF HAVING A BIOLOGICAL CHILD. MY DREAM WAS TO ADOPT."
>
> **—Shellye Horowitz,**
> **at left, with her two daughters**

the physical and emotional load. "When our kids have a serious medical condition, we as moms tend to be the major caregivers," she said. "If you have a partner, bring them in early on to learn the processes."

In the Andrews family, it was the dad who learned how to infuse the boys at home. Now, Sam is learning to infuse himself. Likewise, Secinaro said of Shane, who learned to infuse at age 9: "Him learning to infuse himself and manage his own body and his own medical condition has been incredibly empowering for him."

The hemophilia adoption groups on social media, Luckey said, tend to be 50/50 people who are well-versed in hemophilia, such as those who have biological family members with bleeding disorders, and people who don't know much. Those more in the know don't tend to stress too much, she said. They want to know about the child's physical state, whether they are on prophy, how their joint health is and if they have had head bleeds. On the flip side,

The Smith family

someone who hasn't been exposed to hemophilia is usually more worried: What happens if they get cut? Can they play? Can they do the things other kids do?

These groups and bleeding disorders organizations help parents understand that it's more about being prepared for possible outcomes than overwhelming kids with limitations. "I want my boys to be able to experience almost anything," Andrews said, "and not live in fear or put them in bubble wrap."

For instance, she said, Sam wanted to play soccer but his doctors recommended against it. As a compromise, they found a non-competitive scrimmage team with younger children and he agreed to infusions before practice. "But," they told him, "if you twist your ankle, you could have to spend the week in the wheelchair."

In spite of the adjustments and challenges, these parents share the same message for families considering adopting a child with a bleeding disorder: Go for it.

Sisters Tehilla and Eliana Horowitz

"From my perspective and most of the families I'm aware of, it is a worthwhile journey, albeit with its ups and downs," Luckey said. "We have become better people through this process. People used to tell our son, 'you're so lucky,' and I'd say, 'We're the lucky ones; he has blessed our family.'"

The Morton family: parents Taylor and Carissa Morton and sons Thomas and Josh (far right).

6 Lessons to Prepare for College, FROM ONE FAMILY'S ORDEAL

BY MELANIE PADGETT POWERS, MANAGING EDITOR

When Josh Morton rolled his right ankle shooting hoops at college, he thought factor and RICE—rest, ice, compression, elevation—would heal it. But his pain and swelling quickly grew, so he called his mom, who told him to head to the emergency room (ER). What happened next showed Josh and his parents how ill-informed some physicians are about bleeding disorders and how strongly they need to advocate for themselves.

Josh's mom, Carissa Morton, wanted to share their story, with Josh's permission, and the lessons they learned to help other families with kids with bleeding disorders better prepare for going away to college.

"We thought we had done all of the preparations as far as him knowing where hospitals were and having his doctor's numbers in his phone, always making sure he keeps his supply of factor readily on hand. … This should have been just a minor incident," Carissa said.

Josh is now a junior at Auburn University in Alabama, studying civil engineering. He has severe hemophilia A. In March 2021, a few hours after twisting his ankle, Josh and his girlfriend headed to the local ER. His ankle was severely bruised and swollen, and he explained about his hemophilia and infusions. He informed them he had already infused his maximum dose but that his ankle wasn't improving.

"But when he was telling them his medical history and trying to explain to them what was going on, they wouldn't hear it," Carissa said. "I think what they saw was two young kids coming into the ER with a sprained ankle and that's kind of how they treated it: 'This is just a sprained ankle, no big deal; we'll wrap it up, ice it, it'll be fine.'"

Josh tried to tell him that would not work with him, but they sent him home. The next day he called his mom in tears from the pain. "That's not my child; he can tolerate pain because he's so used to having it his whole life," Carissa said. "I knew something was different, so I got in the car and drove."

It was a five-hour drive from their Florida home. Carissa took her son immediately to the same ER. She told the doctor, "He has hemophilia. This is not just a sprained ankle. He's having a joint bleed, and he's in a lot of pain."

Carissa felt like they still weren't listening and even wondered if they thought there were trying to seek pain medications they didn't need. Even though they were there for 10 hours that day, as doctors monitored the severely swollen ankle—and finally gave him pain medication—they were still using factor Josh brought with him and never consulted a hematologist.

Carissa and Josh returned to Carissa's hotel room. His ankle continued to get worse for two more days as they treated it with RICE. After a few days, Carissa called 911, and an ambulance took Josh back to the ER, where they had to give him several narcotics and ketamine before he stopped screaming in pain.

Carissa finally convinced the ER doctor to call Josh's hematologist in Florida. During the call, everyone realized that the small ER was not equipped to handle Josh and that he needed to be transported to his doctor at the University of Florida. The Auburn hospital didn't stock factor, and Josh had used up his entire supply. Carissa was able to contact a specialty pharmacy provider, which was willing to have a courier drive the factor from Tampa, Florida, to Auburn in the middle of the night.

Next, the helicopter to fly him to Florida was grounded for fog, so Josh had to be transferred by ambulance. He arrived in Pensacola at about 4 a.m., nearly four days after he twisted his ankle. He received treatment and spent five days in the hospital. But the damage was done.

Josh's neurologist told the family that Josh had developed complex regional pain syndrome from all the swelling and the bleeding. Now, he had nerve damage throughout his right foot. Six months later, he is still in physical therapy, walking with a brace and doesn't have full flexion of his ankle.

"The joint is still huge, and it probably will never be the same," Carissa said. "What we've got to see at this point now that the bleed has had time to heal is if the joint damage is going to require surgery to clean out that joint. This was just a simple joint bleed that got ignored."

Through Carissa's anger and frustration, she wants to educate other families with bleeding disorders. She thought they had done everything right when sending Josh off to college, and he didn't have a problem for nearly two years. He infused regularly, had been taught how to advocate for himself, knew where the local ER was.

Now, Carissa believes it wasn't enough. "I think one of the most important things that a college kid can do, or that a parent can help them do, is to learn how to represent themselves, how to explain their condition, and how to give a good thorough history of the symptoms, explaining 'this is what happened and this is what I'm feeling.' [The medical staff] need to hear all that."

And if they're still not listening, have a backup plan or two.

HERE ARE SOME OF Carissa's tips FOR COLLEGE STUDENTS AND THEIR FAMILIES:

1

Keep a detailed medical history stored in your smartphone, so you are prepared to provide all the details. Practice telling your story and keep telling it until you get proper treatment.

2

Educate new friends and your girlfriend or boyfriend about your bleeding disorder. Share with them important contact information, so they can contact your doctor and parents if you need medical attention.

3

Connect with the college's on-campus health center so they know about your bleeding disorder and treatment.

4

Before heading off to college, ask your hematologist or hemophilia treatment center to connect you with a local hematologist who can treat you and advocate for you in your college town.

5

Know where the local ERs are, and when you need an ER visit, go to the largest one or one affiliated with a university, if possible.

6

Have a cooler available for your factor in case you need to put it on ice. (Natural disasters such as tornadoes and hurricanes can knock out power, and backup generators might not be available for dorm rooms or apartments.)

For more tips and resources, check out HFA's Emergency Room Toolkit at **bit.ly/HFAERToolkit.**

LESSONS LEARNED

Members of the bleeding disorders community gathered virtually in September for the HFA Young Adult Advocacy Summit. Here, two first-time participants share their stories and explain why they wanted to get more involved with advocacy efforts.

BY EDUARDO RODRÍGUEZ-RIVERA
BAYAMÓN, PUERTO RICO

In September, I attended the Hemophilia Federation of America (HFA) virtual Young Adult Advocacy Summit. I was part of a group of young adults who wanted to become better advocates for themselves and for the bleeding disorders community. For me, advocating is much more than just telling my own story; it's about the story of the bleeding disorders patients of Puerto Rico, where I'm from.

I was diagnosed with a bleeding disorder when I was a baby in Puerto Rico. In the hospital, my doctor ordered various bleeding disorders tests after my IV line exploded and my blood blasted all the way to the ceiling. After my diagnosis, my parents had to face the reality of having a son with von Willebrand disease (VWD). Throughout my childhood I didn't experience spontaneous bleeding episodes. I only thought about VWD once, when I had dental surgery around age 14. I wasn't visiting a hematologist, nor getting proper care. I became a young adult who basically knew nothing about his own diagnosis.

Luckily for me, in 2017 I discovered our bleeding disorders association, Asociación Puertorriqueña de Hemofila y Condiciones de Sangrado (APH). Even though I didn't know much at that point about bleeding disorders, I became a volunteer with APH. Through that, I learned I was not properly educated and I was not taking care of my bleeding disorder. I was being irresponsible with my health, and I was determined to change that.

Through APH, I connected with other bleeding disorders patients on the island, and we shared our stories with each other. I realized I was so lucky throughout my childhood. Their stories were worse than mine. I could not understand how a young man my age could already have a knee replacement. I could not understand how another patient had to spend two weeks waiting for the medication for her bleeding disorder. I could not understand why our health system in Puerto Rico was so inefficient. On top of that, we faced hurricanes and earthquakes, which made everything worse. I knew I had to do something and raise my voice to help patients like us.

By advocating, I can help bring to light the tough reality of our bleeding disorders community in Puerto Rico. While advocating, I like to share my story, but I tell other patients' stories as well. They are often more impactful, and I need to use my voice for those who cannot use theirs. I believe advocating is not a selfish act; it's an act of love and compassion to all the patients.

By participating in the HFA Young Adult Advocacy Summit, I gained new tools and skills to be a better advocate. But more than that, I refreshed my inspiration. I realized advocating is not just something we can do; it's something we all should do. It is our duty to share our stories in every possible scenario. We as a community know what we are capable of and what we need; we have to advocate and the change will be made.

BY TORI ROBBINS
MANAHAWKIN, NEW JERSEY

At a young age I was tested and diagnosed with mild von Willebrand disease (VWD) Type I after a family member nearly bled to death. Growing up, I did not have restrictions on playing sports or activities, but I did experience frequent nosebleeds. I knew if I had a serious injury or surgery that I needed treatment, which meant a trip to the hospital and fluid restrictions.

However, I can count on my fingers the number of times I have needed treatment—something many people in the bleeding disorders community cannot do. My family started attending events held by the Eastern Pennsylvania Bleeding Disorders Foundation to learn about the condition. VWD has always been a part of my story. It is something I have tried to educate others about, including friends and medical professionals, as most people are not familiar with VWD.

I am currently a senior political science student with a concentration in international affairs and minors in public health and environmental studies at Stockton University in Galloway, New Jersey. Additionally, I am in the process of adding a second degree in communications with a concentration in media production. After graduation, I hope to pursue a career in advocacy and education on issues related to these fields, especially using film and photography.

I was excited to be a part of the HFA Young Adult Advocacy Summit in September to learn about issues affecting the bleeding disorders community and to practice advocacy for the first time in a safe and supportive environment.

Throughout my education, I have focused on the overlap of environmental, public health and human rights issues, predominantly on an international level. I had little experience or knowledge in the subjects of health insurance and legislation at the federal or state level. Through the Summit, I learned about these topics, how they relate to my bleeding disorder, the shortcomings of our health industry and how to make a difference. I was shocked to hear stories from other participants about how limitations and loopholes from health insurance impacted their ability to receive medication or the astronomical costs they were forced to pay. One such loophole was lifetime caps.

After attending the Summit, meeting with the staff of congressional representatives and having the guidance of experienced advocates, I feel better equipped to advocate in the future. It was inspiring to hear how others have generated positive change through their advocacy efforts.

Meeting with legislative staff, discussing the issues impacting the bleeding disorders community and witnessing their openness and positive response to legislation that will help people with serious, expensive conditions made me feel like I was making a difference. This Summit confirmed that advocacy is something I want to pursue, not only after graduation but now. I feel better prepared to pursue this kind of work after gaining valuable insight and knowledge.

The Summit was an incredible opportunity to connect with more amazing people in the bleeding disorders community and learn about issues that impact me and people I care about and, most importantly, how to fix them.

HFA SCHOLARSIHP *winners announced*

The Hemophilia Federation of America (HFA) scholarship program was created to assist members of the community who are seeking a post-secondary education from a college, university or trade school with financial aid. Our community is all too familiar with the unique financial challenges of living with a bleeding disorder, and this program is intended to provide financial relief to assist community members with pursuing their educational goals. We award scholarships in three categories:

PARENT/SIBLING/ CHILD EDUCATION SCHOLARSHIP

Awarded to the immediate family member of a person with a bleeding disorder seeking a postsecondary education from a college, university or trade school.

MEDICAL/ HEALTH CARE SERVICES EDUCATIONAL SCHOLARSHIPS

Awarded to a student pursuing a degree in the medical/health care services field. We have noticed over the years that many of our students in the community are studying for a career in the medical field.

EDUCATIONAL SCHOLARSHIPS

Awarded to students with a bleeding disorder seeking a postsecondary education from a college, university or trade school.

Scholarships awarded under this restricted fund are determined by the scholarship committee of HFA, comprised of volunteers from various roles within the organization, including our Board of Directors and member organizations.

This year's scholarship winners are:

RACHEL WILE

University of California, San Francisco (UCSF) School of Medicine

WINNER OF THE HFA PARENT/CHILD SCHOLARSHIP

"This scholarship will be a tremendous help to me as I begin medical school this year at UCSF School of Medicine. Growing up in a family impacted by hemophilia helped initiate my interest in medicine and in serving others impacted by bleeding disorders. Throughout my undergraduate studies at UCLA, I was actively involved in the bleeding disorders community. I volunteered with the Hemophilia Foundation of Southern California, helping with events that provided resources, services and education to individuals and families affected by hemophilia. I also worked as a student researcher in hematology at Children's Hospital Los Angeles, which showed me how progress is currently being accomplished in this field. Additionally, my interest in medicine continued to grow through my volunteer work at the Ronald Reagan UCLA Medical Center, where I assisted hospital staff and shadowed doctors. My experiences of both connecting with patients and performing research further cemented my desire to work as a physician in the bleeding disorders community. I am looking forward to continuing to serve this community throughout medical school and in my future career. Thank you so much for your support!"

SAMIRA ALI

Kansas University Medical Center (University of Kansas School of Medicine)

WINNER OF THE HFA MEDICAL/HEALTH CARE SERVICES EDUCATIONAL SCHOLARSHIP

"It is with deep gratitude that I accept the scholarship awarded to me by HFA. I feel an immense sense of support as I start my first year of medical school at the University of Kansas Medical Center. The scholarship will be applied to my tuition. I chose to study medicine because I believe good health is the foundation to not only surviving in life but thriving. I hope to apply the knowledge and skills I gather throughout medical school to serve others, on both a local and global scale. Once again, thank you HFA!"

NATHAN MERMILLIOD

Chapman University, Orange, California

WINNER OF THE HFA EDUCATIONAL SCHOLARSHIP

"I am so blessed and honored to receive the Educational Scholarship from HFA. Headed into my sophomore year, the money will help tremendously in paying for my tuition at Chapman University, where I major in biology. My greatest aspirations lie in the medical field, where I may become a hematologist. If not, I plan to advocate for and support the hemophilia community in any way I can. Growing up with severe hemophilia B, I have advocated for the hemophilia community in speeches, performances and video presentations. This includes my recent presentation to the U.S. Transportation Security Administration about bleeding disorders. My speech will be used as a training video for employees in airports across America. Thank you HFA for this opportunity to help kick-start my future educational and advocacy goals."

GRANT HIURA

Loyola University Chicago Stritch School of Medicine

WINNER OF THE HFA EDUCATIONAL SCHOLARSHIP

"I am so humbled to receive HFA's Educational Scholarship, which will go directly toward my doctor of medicine program at the Loyola University Chicago Stritch School of Medicine. As a patient with severe hemophilia A, I know firsthand the importance of having access to consistent, reliable medical care. My hemophilia treatment centers played a pivotal role in helping me gain the confidence to manage my disorder; in turn, I have dedicated my life to helping others do the same. From teaching campers how to self-infuse at Camp Hemotion in Northern California, to leading health education programs at the National Hemophilia Foundation, I have a passion for service—one that will be central to my medical training at Stritch and my medical career. My goal is to become a general internist, where I will draw from my patient experience to better empathize with and treat my patients. The bonds that I have formed within the bleeding disorders community remain some of the strongest in my life, and I am confident that they will make me a more informed and holistic physician. In addition, having worked in public health for the past three years, I plan to continue conducting epidemiological research that focuses on reducing health care disparities at the population level. I cannot wait to get started with medical school. Thank you so much to HFA for this incredible honor!"

We're counting down the days
for HFA hugs to resume

Until then, we're here for
you and your family
at **www.hemophiliafed.org**

HFA
Hemophilia Federation of America

Connected to milestones.

Life with hemophilia shouldn't be defined by limits. Through research, partnerships, and support, we're focused on making more possible for you and the people you love.

Let's connect.
rarebloddisorders.com
@HemophiliaCoRes
1-855-SGZHEME

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Connected to you.

As Community Relations & Education Managers, our work with the hemophilia community is deeply personal. It unites us in our efforts to help educate and support you and your family.

Reach out to your local CoRe to learn more.
rareblooddisorders.com | shareyourwhy.com
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