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Cycling Events Raise Awareness & Funds for Bleeding Disorders, page 20

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ON THE COVER.

Members of HFA's new Advocacy Leadership Council gather in Washington, D.C., during the annual Patient Fly-in in June. The group continues to participate in intensive advocacy education to become an army of advocates for bleeding disorders nationally and in their home states.

EXECUTIVE CORNER

Dear Friends,

For nearly 11 years Hemophilia Federation of America has had the same leadership guiding and taking the organization where the community has requested. Throughout this time, HFA has grown by leaps and bounds, not only in the size of the organization, but more importantly in what we are able to offer the community and our Member Organizations.

Kimberly Haugstad, who served as Executive Director and then President and CEO of HFA, has been at the center of all this change. Kimberly recently accepted a position outside of HFA. As a board member, community member and friend, I want to wish Kimberly the best of luck in her future endeavors and sincerely thank her for all she has done for HFA and the bleeding disorders community.

As we reflect on how thankful we are for her leadership, HFA now looks forward to the future and the board of directors works to identify the next leader of our wonderful organization.

During her time, Kimberly helped to build excellent leadership and staff within the organization. We are in a great position with such a positive trajectory—know HFA will continue to serve the bleeding disorders community!



Board Chair, Josh Hemann, has worked closely with former president and CEO, Kimberly Haugstad, over the years. In this photo, Josh and Kimberly hand out awards at HFA's annual Symposium.

Josh Hemann

Board Chair



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

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EXECUTIVE LEADERSHIP

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Meet Our Interim President and CEO

Vice President of Advancement brings strong skillset to temporary role

After the recent resignation of long-time President and CEO, Kimberly Haugstad, Hemophilia Federation of America named its Vice President of Advancement, Sharon Meyers, as interim President and CEO.

Meyers has been with HFA for nearly four years, most recently overseeing fundraising, marketing and communications, and information technology. She began her role as interim President and CEO on Sept. 1 and brings a wealth of experience to the position while HFA's board of directors finds a replacement for Haugstad, who had been with HFA for 11 years.

"As HFA moves into the next phase, I am very excited to have Sharon Meyers step in as the interim President and CEO while the HFA board of directors works through this transition," said Board Chair Josh Hemann.

"HFA is in a great position with the leadership currently in place at various levels and an all-around excellent staff. Sharon has done some great work with the organization already and we are looking forward to her serving in this capacity." — Josh Hemann, board chair

Prior to joining HFA, Meyers was President and Chief Development Officer of the St. Anthony North Health Foundation in Denver, Vice President of the Penrose-St. Francis Health Foundation in Colorado Springs, Foundation Executive Director and Director of Advancement of the St. Michael's Catholic Academy in Austin, and Associate Executive Director of the University of Southern Mississippi Foundation.

She is a Certified Fund-Raising Executive (CFRE) and holds a Nonprofit Management Executive Certificate from Georgetown University in Washington, D.C. She is currently working on a doctorate in education at the University of



Southern California in Organizational Change and Leadership. Additionally, she holds a master's in political science from the University of Southern Mississippi.

She has 15 years of healthcare and university nonprofit leadership experience at the local, state, regional and national level. Meyers previously led major organizational change initiatives, multimillion-dollar fundraising campaigns, and served as an interim organizational leader multiple times in her career.

She is a strategic, energetic, action-oriented nonprofit leader with an innate ability to motivate and lead a team. She is skilled in public speaking, writing, teaching, and coaching. Sharon's background also makes her uniquely qualified to lead HFA's efforts to assist, educate, and advocate for the bleeding disorders community.

Earlier in her career, she was a public servant working on an ambulance as a nationally-certified EMT-I and answering 911 calls. She's also led many financial assistance and scholarship programs at hospitals and in educational settings throughout her career. She has volunteered and served as a board member for various nonprofits serving the poor and those in need.

She has experience teaching nonprofit management, public policy and government at the university levels, and teaches various education sessions across the country on behalf of HFA, including a session on emergency preparedness.

"HFA has always put its mission of serving the community first, and I am honored to continue that tradition while we search for a new CEO," said Meyers. "Our team is dedicated and committed to serving people living with a bleeding disorder and our work will not waver in the coming months. We're excited for the future of HFA and will continue to bring innovative and needed services to the community."

As a nonprofit, the board of directors holds the task of finding a replacement for Haugstad and is already actively moving forward with its search for a new president and CEO. 🔴



A Message from Outgoing President and CEO, Kimberly Haugstad

When I first came to Hemophilia Federation of America in 2008, my babies were 4 and 6. I had done a little volunteering around the country and served on my local bleeding disorders board. Living the dream as a young family with a growing consulting business, we had a fair handle on living with hemophilia, but we were paying \$2,400 per month in health insurance premiums with a \$9,000 deductible. Knowing my son would get his factor made it a necessity. I will never forget getting a notice that year that our monthly premiums would be increasing slightly to just over \$2,800. My husband and I realized one or both of us should find a corporate job with insurance. He did. I planned to continue consulting.

I had vaguely heard of HFA as that little national organization that represented people with bleeding disorders and their families. At HFA, the staff and board were supposed to have huge hearts, a lot of great ideas and a desire to build. I like big hearts. I like big ideas. I like to build. I quickly realized I liked HFA and while it was not our plan, I decided to join the team. I knew how to run a successful business, how different could running a nonprofit be? Not as much as you might think actually! What I absolutely did not imagine was that I would find it so rewarding and grow to love our community so much that I would stay more than a decade!

I came to HFA because of my son. I did not want his hemophilia to limit him. I stayed because of you, our bleeding disorders community. You deserve the right to learn everything about your disorder and the right to advocate for yourselves and have the same opportunity as anyone without a chronic condition. Helping you do that has been my honor and privilege.



A Decade of Growth

Over the last decade, HFA has grown dramatically. The three employees in 2008 are now 34 and our 26 affiliated member organizations are now 50. Each member organization, no matter their size, has a voice on our board.

HFA's direct connection to bleeding disorder families has grown from a few thousand to more than 20,000 strong, and our budget has more than quadrupled. Our advocacy work is formidable and bleeding disorders is recognized nationally as a disease group that can truly accomplish what we set out to do.

What hasn't changed at HFA is why we are here. **HFA is and always will be** about our community. Period, end of story. We do not compromise on that commitment.

My years at HFA have taught me many personal and professional life lessons. More than anything, I learned patience. I try anyway, but that is still a work in progress!

Our history is long and filled with challenges. While I will never truly understand what it is like to be a survivor of the factor contamination tragedy, I became committed to preserving our history. I deeply believe it is every community member's right and responsibility to know our history. It is not pretty, but it is our collective history. I am so honored to have worked with our team to donate artifacts to the Smithsonian to preserve our history. We will not be forgotten.

You, the bleeding disorders community, will always be my family. While I now will be working in global rare disease, my heart will always have this community in it.

We truly are lucky in bleeding disorders to have the active peer support networks that other rare diseases dream of. Remember to invest your time personally to stay connected with each other. Many of our bleeding disorders have one or more treatments. This is something that other diseases also ache to have. We also have organizations that support us, please support them!

I could take an entire Dateline to appreciate, recognize and thank everyone if I could. In lieu of the pages and pages it would take, please know that if you are reading this, it is meant for you. My thanks. My appreciation. My love. My best to you. 📌



HAPPENING HIGHLIGHTS



HFA Given Highest Honors by Nationally-known Nonprofit Watchdogs

Hemophilia Federation of America was recognized with a four-star rating by Charity Navigator and a Platinum Seal of Transparency by GuideStar, two respected nonprofit watchdogs. With an annual operating budget of more than \$6 million, HFA relies on a diversity of funding sources and is proud to regularly acknowledge donors and sponsors, which helped contribute to the recent honors. Low administrative and fundraising expense means HFA is able to direct nearly 94 percent of all donations toward educational programming for patients living with bleeding disorders and their families.

The four-star rating with Charity Navigator is the highest honor given by the organization which evaluates and monitors the financial health, accountability and transparency of nonprofits in the United States. The Platinum Seal of Transparency is the top honor given by GuideStar, indicating HFA has been forthcoming in providing key information to the organization's nonprofit profile, which is available to the public and displays the organization's measurable impact.



HFA Awarded PCORI Capacity-Building Grant to Engage Women

Hemophilia Federation of America has received a Eugene Washington PCORI Engagement Award from the Patient-Centered Outcomes Research Institute for its FIRST (Females in Research Sharing and Translation) Project to improve opportunities for women to be engaged in patient-centered research.

The capacity-building grant will support HFA's FIRST Project which will begin by identifying how women are currently involved in research and discovering any barriers that exist to their participation. Following the initial step of identifying female involvement, the aim of HFA's FIRST Project is to increase female influence and engagement in the development and implementation of research and the dissemination of research results, which ultimately affects the clinical care of women with bleeding disorders. HFA will host focus groups of women at events at local organizations throughout the U.S. To learn more, visit www.hemophiliafed.org/research or email research@hemophiliafed.org to express interest in a focus group.



New YouTube Series Helps Hemophilia A Patients

Challenge Accepted, a YouTube series created by pharmaceutical company Genentech, is helping hemophilia A patients and caregivers face the reality of living with the bleeding disorder. Each episode tackles an issue facing many in the hemophilia community, such as managing routine, aging, self-care and more. While educating patients, Genentech manages to have fun with the series with host Justin Willman with more of a feel of reality TV than a pharmaceutical campaign. Genentech worked with ad agency 21Grams on the series.

HAPPENING HIGHLIGHTS

Mom, Community Member and Advocate Testifies on Capitol Hill



Hemophilia Federation of America's Director of Advocacy, Sonji Wilkes, worked with FamiliesUSA to give a testimony on surprise billing at a hearing with the House Committee on Energy and Commerce (Subcommittee on Health) this summer. She was able to share her story again in September during the launch of People Against Unfair Medical Bills, a new campaign consisting of 14 organizations representing consumers, patients and workers.

After Wilkes's son was born, he was diagnosed with severe hemophilia following a circumcision. While the birth was covered in-network, her family was surprised with a \$50,000 out-of-network bill for factor treatment in the NICU, which was located just steps away from where she gave birth. She and her husband made calls prior to the birth to ensure they were covered and made every effort to work in network. That surprise bill resulted in debt and affected their family credit. While Sonji is an HFA employee, her testimony was made on behalf of FamiliesUSA.

HFA Partners with ATHN for Improved Medical Records

Hemophilia Federation of America has partnered with the American Thrombosis and Hemostasis Network to offer a new integration in HFA's Blood Sisterhood mobile app.

The new integration allows mobile app users to share information with their hemophilia treatment center, if they wish to do so. The app can be used to track symptoms, treatments and types and quantity of menstruation products used each month. HTC's can use the mobile app tracking information to include in medical records for more customized treatment and care. The app can be found in the Apple App Store or Google Play Store. ♦



SISTERHOOD

An app from HFA for women with bleeding disorders!

With NEW FEATURES



- Track Monthly Menstrual Cycle & Non Menstrual Bleeds
- Log Symptoms
- Record Treatments Used
- Period & Treatment Alert Reminders
- Log Notes And Share Information Easily With Your Provider
- Set Reminder Alerts For Tracking Treatment, And More

New Features!

- Detailed Product Strength Use
- More Accurate Bleeding Score (For Providers)
- Add Photo Feature
- Now Available in Spanish

DOWNLOAD FOR FREE!



www.sisterhoodapp.com

Understanding FDA Drug Recall Procedures

It is important to pay attention when a product is recalled, but with all the different sources of information, and the different types of recalls, it can be confusing. Recalls, designed to protect the public's health, are used as a way to deliver information to consumers in an expeditious manner.

A recall is an action taken by a manufacturer to remove a product (food, drugs, medical devices and cosmetics) from the market, initiated either by the manufacturer or by request from the FDA. In either case, the manufacturer removes or corrects a product that is in the market and in violation of FDA rules and regulations. In both cases, the FDA considers the recall to be manufacturer initiated.

Alternatively, an FDA-mandated recall, also known as a mandatory recall, occurs when FDA orders a manufacturer to recall a product or mandates recall requirements. The FDA's role is to oversee the manufacturer's recall strategy, monitor the recall for effectiveness and classify the recall.

Here are the different recall classifications.

- **Class I:** Includes a health hazard situation where there is reasonable probability that the use of the product will lead to serious, adverse health consequences or death.
- **Class II:** Includes a potential health hazard situation in which use of or exposure to a violative product may cause temporary or medically-reversible adverse health consequences or where the probability of serious adverse health consequences is remote.
- **Class III:** Includes a situation in which use of or exposure to the product is not likely to cause adverse health consequences.
- **Market withdrawal:** When a product has a minor violation that would not be subject to FDA legal action a "market withdrawal" occurs. The product is removed by the firm from the market or corrects the violation.

→ **Medical device safety alert:** Released in circumstances where a medical device may present an unreasonable risk of substantial harm. These situations also are considered recalls in certain cases.

A recall named voluntary, requested and mandatory depends on who initiates the process. Based upon the gravity of the situation, the FDA will issue a public warning.

Voluntary Recall: Initiation of a Recall by a Manufacturer

Consistent with its responsibility to protect the public health from products that are defective or potentially harmful, a manufacturer may **voluntarily initiate** a recall. If a recall is manufacturer-initiated, the FDA reviews the information provided by the manufacturer, conducts a health hazard evaluation, classifies the recall, and then advises the manufacturer in writing of the assigned recall classification. The FDA then places the notice of the recall in the FDA Weekly Enforcement Report. Nearly all recalls implemented in the U.S. are begun on a voluntary basis by the manufacturer.

If a manufacturer has **voluntarily initiated** a recall, it is the manufacturer's responsibility to promptly notify each of its direct accounts. If the recall extends beyond direct accounts, then the direct accounts should be instructed by the recalling manufacturer to contact sub-accounts that may have received the product. Once the all accounts have been informed about the recall, they must promptly follow the recall strategy that was previously put in place for that account.

FDA Requested Recall

In urgent situations, the FDA may request a recall. The request is directed to the manufacturer that has the primary responsibility for making or marketing the product. Class 1 category recalls are most often requested recalls. It is important to note the FDA considers an FDA requested recall to be manufacturer initiated.

The FDA's role is to oversee the manufacturer's recall strategy, monitor the recall for effectiveness and classify the recall.

The Associate Commissioner for Regulatory Affairs approves all recall requests from the FDA. A letter outlining the need for a recall is sent to manufacturer. After a recall has begun, the recall is entered in the Recall Enterprise System. The RES is a database used by the FDA to submit, update, classify and terminate recalls.

FDA Mandated Recalls

The FDA's authority to issue a **mandatory recall** is very limited. Subjects of mandatory recalls can include devices, biological products, human tissue intended for transplantation, infant formula, tobacco products and food. The FDA also has discretion to order a mandatory recall if it finds that a human cell, tissue or cellular or tissue-based

product is a source of dangerous infection to humans or does not adequately protect against communicable disease.

Elements of a Recall

Each FDA recall follows specific timelines and procedures depending upon the circumstances. For example, each recall is initiated with a written order that states the violation, the product, lot and serial numbers to be recalled, and the timeline for the recall. Each recall is unique and requires its own recall strategy developed by the Center Recall Unit. The CRU will consider how far the recall should extend, whether the public needs to be warned and if so, in what geographical area, and the appropriate assessment for recall effectiveness. 🔴

FDA DRUG RECALLS

A recall is an action taken by a manufacturer to remove a product from market.

Recalls Can Be Issued By:

VOLUNTARY

Almost all recalls are begun as voluntary

- 🔴 Initiated by manufacturer
- 🔴 Manufacturer is responsible for contacting users about recall

FDA REQUESTED

Urgent

- 🔴 Initiated by FDA due to potential harm
- 🔴 Based on agency determination that action is needed to protect public health and welfare

FDA MANDATED

Very limited

- 🔴 Narrowly restricted by federal statute
- 🔴 FDA can only order recall if it fits within statute limitation
- 🔴 FDA may issue public warning

VOLUNTARY & FDA REQUESTED RECALLS ARE CONSIDERED MANUFACTURER INITIATED

All recalls are initiated with a written order citing violation, product, lot and serial numbers and timeline for recall.





Advocate Finds Her Voice with New Council

HFA begins Advocacy Leadership Council, brings patients to D.C. to learn and advocate for others

BY NATALIE PARKER, GUEST WRITER

I was nervous before walking into a Congressional office. The U.S. Capitol is huge! I didn't know what to expect and I wasn't sure they would listen to me. After all, legislators and their staff meet with numerous constituent groups every day. What could I say that would stand out?

Luckily, I serve on HFA's inaugural Advocacy Leadership Council. The ALC is a program designed to build a strong, engaged army of champions to fight for meaningful healthcare and thus help to improve care and quality of life for all people living with bleeding disorders. Along with the 11 other members of the ALC, I receive training from HFA staff and help advocate for our community on Capitol Hill in Washington, D.C., and in my own state of Pennsylvania.

My favorite aspect of the ALC is working with the other members. Everyone has a slightly different background and the variances in our personal stories paint a fuller picture of our community. We each have something a little unique that compels us to advocate. I wasn't involved with the bleeding disorders community until last year. I thought I had my vWD symptoms under control and I really didn't think much about it. But after engaging with others at the Young Adult Advocacy Summit in Fall 2018, I was energized. I had so much in common with the other young adults and I wanted to learn more about my own health and then find a way to take action. When the opportunity to join the ALC arose, I

was so excited to be able to give a voice to my peers and to learn alongside such special people.

In June, I visited Washington, D.C., for HFA's annual Patient Fly-in where we met with Congressional offices to tell them about specific bills that could impact our community. We split up into groups and were led by HFA staff members to our visits. We met with congresspeople from our own districts where we are the constituent. I also went to a few meetings with legislators from New York, since another member of my group lived there.

The meetings had a general flow, such as introducing ourselves, explaining our relation to the bleeding disorders community, and if necessary, basic background information about bleeding disorders. I was quite surprised the majority of the people we met with already had a pretty good grasp of bleeding disorders. This speaks to the strong relationships HFA has with our elected officials; we are well represented on the Hill! In every meeting I was in, the staff member or legislator listened intently, many took notes, and everyone seemed truly grateful to hear our stories.

HFA's board members joined members of the Advocacy Leadership Council on Capitol Hill.



We were advocating for H.R. 2279, The Safe Step Act and protections against short-term health plans and for support of measures that would enhance the affordability of health insurance. By making a specific ask, we make it easy for the staff member and allow them to know exactly where we stand.

After a couple of meetings, we started to have a good rhythm. I was familiar with the other group member's stories and if they forgot something I thought was important, I was able to prompt them. If we had extra time, I explained how surprise billing has impacted me, or another member of the group talked about the high costs of their medication or about insurance rates.

Before joining the ALC, civics and advocacy were professional interests. For years I've worked as an election worker at the polls, canvassed for political campaigns, registered voters and lobbied at my state legislature. Professionally, I have worked in local, state and federal government and I serve on the local chapter of the League of Women Voters. I thought politics was just old hat for me, but I've discovered that I have so much more to learn!

Before we even stepped foot on the Hill, we had a thorough day of training. We had workshops on the policy landscape where we delved deeper into the healthcare legislation that is in progress now. My favorite part of the day was our session with a Hill staffer who explained what we could do to make our meetings productive and beneficial.

I think I will always be a little nervous as I walk down a long, tiled hallway of the Capitol building, which I've found are either surprisingly empty, or bustling with harried-looking staffers off to do something important. But now my nervousness is more like anticipation; I know what to expect and I understand that our elected officials report to us. We can inform them about the issues facing our community and we can tell our stories, which they can then use to bolster their legislative agenda. We can help them just by being us.

I have come to realize how personal advocacy is to me and how fiercely I want to work to better this community. Advocacy is learning about policy, telling our stories, and helping others find ways to better help us. After all, our blood connects us. Thanks to HFA, the Advocacy Leadership Council is developing the skills to make real change. 📌



During the 2019 Patient Fly-in, HFA recognized Congressman David Schweikert (AZ) and Senator Bob Casey (PA) as Congressional champions. Each participated in legislation addressing access to health care for bleeding disorders patients.



A first-person perspective shot of a person's hands holding an open brochure on a wide set of stone steps. In the background, a woman in a white shirt and yellow shoes is walking up the steps, and two children are running ahead of her. A large, ornate church with a prominent circular window is visible at the top of the steps under a clear blue sky.

GO SEEK. GO EXPLORE. GO AHEAD.

Discover your sense of go. Discover HEMLIBRA®.

[HEMLIBRA.com](https://www.hemlibra.com)

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. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. HEMLIBRA may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). 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.

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



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

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

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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 : 10/2018



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Medicare 101:

Who's Paying for Your Care?

BY KIMBERLY RAMSEUR, STAFF WRITER

With all the talk about health care financing, it is easy to get confused and overwhelmed with all the information being disseminated. If an individual falls under one of the following, they may be eligible for Medicare, a national health insurance program administered by the Center for Medicare and Medicaid Services (CMS):

- ▶ 65 years or older;
- ▶ Living with a disability, entitled to SSDI benefits for 24 months without a waiting period or;
- ▶ Have end-stage renal disease (ESRD)

Medicare is made up of four parts: A, B, C, D

Part A (Hospital Insurance) helps cover:

- Inpatient care in hospitals;
- Care at skilled nursing facilities (SNF);
- Hospice care;
- Home health care;
- Blood

Part C (Medicare Advantage) CMS works with other insurance companies to administer Medicare benefits via:

- Health Maintenance Organization (HMO)
- Preferred Provider Organization (PPO)
- Special Needs Plan (SNP)

Part B (Medical Insurance) helps cover:

- Services from health care providers;
- Outpatient care;
- Home health care;
- Durable medical equipment (DME);
- Preventive services
- Clotting factor and non-factor therapies are cover in Part B

Part D (Prescription Drug) helps cover:

- Cost of prescription drugs (drugs administered in the doctor's office are covered by Part B)

Original Medicare v. Medicare Advantage

Medicare benefits are administered in two ways, Original Medicare and Medicare Advantage.

Original Medicare includes Part A (hospital insurance) and/or Part B (medical insurance). To help pay out-of-pocket costs in Original Medicare (such as deductible and 20 percent coinsurance), individuals can shop for and buy supplemental coverage, otherwise known as a Medigap plan. Patients can also choose to buy Medicare prescription drug coverage (Part D) from a Medicare Prescription Drug Plan (PDP).

Medicare Advantage (MA) plans provide coverage via care organizations such as a health maintenance organization

(HMO) or a preferred provider organization (PPO), which covers Part A and Part B services and supplies. They also may include Medicare prescription drug coverage (MA-PD).

Medigap policies do not work with MA plans. If a patient plans to join an MA plan, the patient can't use a Medigap policy to pay for out-of-pocket expenses.

In addition to Original Medicare and Medicare Advantage coverage options, patients may also be able to join other types of Medicare health plans like Medicare Cost Plans or Programs of All-inclusive Care for the Elderly (PACE) or get certain services through demonstrations and pilot programs.

For more information on Medicare plans, eligibility, and enrollment, check out [medicare.gov](https://www.medicare.gov) or contact at (202) 675-6984

Medicare Supplement Plans (Medigap)

Medicare Supplement Insurance (Medigap) policies health plans sold by private insurance companies to fill gaps in Original Medicare. Medigap policies can help cover some out-of-pocket expenses for Medicare covered services, such as coinsurance, copayments or deductibles, which also cover various benefits not covered under Original Medicare.

Since each plan varies in what benefits they offer, it's extremely important to always compare policies. Each company decides which Medigap plan it will offer and the price for each plan, with state review and approval. Some of the factors that plans take into account when developing a policy include, pre-existing conditions waiting period, crossover of claims from Medicare Administrative Contractor to Medigap policy, guarantee issue and others.



Enrollment

There are specific times designated for potential enrollees to apply for Medicare coverage benefits. The Social Security Administration (SSA) is responsible for enrolling most people in Medicare, however once someone is eligible to apply for Medicare, it is ideal to sign up first during the Initial Enrollment Period (IEP). This period may vary depending on birthday, but the length of time to enroll remains the same – seven months.

This seven-month period starts three months prior to an individual's 65th birthday, the actual birth month and the three months directly after the birth month. This period allows them the ability to select a plan along with any qualifying add-ons needs. If someone is unable to apply during the IEP, there are other opportunities to subsequently apply. ♦

PAID INFORMATIVE COMMUNICATIONS



Patients and science are at the center of everything we do.

At Sanofi Genzyme, we are committed to significantly improving the health and lives of people with rare blood disorders.

Connect with your local community representative (CoRe) to tell your story and learn about what we are doing for our community.

SANOFI GENZYME 



Connect with us: @HemophiliaCoRes

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La Menstruación es un Proceso Natural como Cualquier Otro

POR: ANDY ANDERSON Y MARTHA BORJA, ESCRITORES DEL PERSONAL

“Ahora eres una mujer”. “Aquí están las toallas higiénicas”. “Puedes sostener una toalla de agua caliente en el estómago por los dolores”. ¿Suenan familiares? Para muchos de nosotros, hablar de períodos era solo algo que podíamos hacer con mamá. No lo discutimos en la escuela o con el médico, y rara vez con amigos. Junto con los consejos prácticos de mamá sobre este nuevo capítulo de nuestras vidas, puede haber advertencias misteriosas para mantenerse alejado de los niños. Hoy, la conversación sobre los períodos está cambiando. Los Millennials y Gen-Z están mucho más abiertos a hablar sobre sus cuerpos, su salud y sus relaciones.

La menstruación es un proceso natural como cualquier otro, pero es un tema incómodo para hablar en nuestra cultura hispana. Recuerdo que mi madre me habló muy poco de que las mujeres “sangran”. El día que obtuve la “regla”, tenía 11 años. Era sábado y me acababa de despertar. Fui al baño y cuando vi mi ropa manchada, llamé a mi madre. Con mucha calma me dijo: “Tu menstruación ha llegado”. Ella me explicó que era normal y que tenía que comenzar a usar toallas sanitarias. No se parecían en nada a las toallas de hoy, que son súper absorbentes, ultrafinas y autoadhesivas. Solo había una marca, Kotex, y absorbía muy poco; Tenía que

cambarlas muy a menudo. Mi madre me dio instrucciones sobre cómo usarlas, junto con una explicación de lo que esto significaría para mi vida. Ella usó algunas frases comunes de las madres hispanas de esa época: “Esto te va a pasar todos los meses del año”, “Ahora eres una mujer y debes tener mucho cuidado con los niños”. Sin embargo, no lo entendía. ¿Qué quiso decir ella? ¿Por qué tenía que tener cuidado ahora? ¿Los infectaría con una enfermedad?

Tenía demasiadas preguntas sin responder en ese momento. Los tabúes de la menstruación nos limitan con la creencia de que la menstruación es algo que debe ocultarse, algo que causa vergüenza. Tenía un pequeño bolso negro en el que llevaba mis productos de higiene personal a todas partes y que tenía que esconder cuando iba al baño. No podía dejar que nadie la viera, ¡Qué Vergüenza!

Muchas niñas se han quedado en la oscuridad sobre las conexiones entre los períodos y la sexualidad. Los temores de los padres sobre el embarazo no planificado y los riesgos para la salud, incluso sin un trastorno hemorrágico, son naturales. También hay que considerar las consecuencias sociales del sexo. Nuestros valores tradicionales nos dicen que el sexo y el embarazo fuera del matrimonio pueden tener importantes consecuencias sociales, morales y



espirituales. Sin embargo, el tabú en torno a hablar sobre sexo y sexualidad complica la forma en que aprendemos y enseñamos acerca de los períodos debido a su conexión con el embarazo y la sexualidad. Con el tiempo, la exposición cultural y la asimilación, esto está cambiando.

A pesar de las diferentes actitudes sobre lo que está permitido hablar en público, compartimos algo especial: nuestros trastornos hemorrágicos y nuestra fuerza. Como madres e hijas, podemos aprender las unas de las otras cómo cuidarnos y defendernos. Venimos de generaciones de mujeres fuertes que han puesto a su familia primero. En cada generación, los desafíos evolucionan, y también lo hace nuestra fuerza. Criar a un niño con un trastorno hemorrágico ha enseñado a muchas madres la importancia de asumir la responsabilidad de su situación. Hemos tenido que buscar respuestas y cuidar mejor a nuestros hijos. Las personas más jóvenes han tenido la ventaja de crecer en una sociedad altamente conectada y son naturales al considerar una amplia gama de factores antes de tomar decisiones. Juntos, nuestra motivación e información nos convierten en una comunidad resistente.

Es importante tomarse el tiempo para hablar con sus hijos acerca de vivir con un trastorno hemorrágico, y eso significa todas las áreas de la vida. Incluso si usted es alguien que no tiene problemas para sangrar, usted es parte de la vida de su hijo y comparte su experiencia de convertirse en un adulto saludable. Puede ser difícil navegar en conversaciones que desafían los valores con los que fuimos criados. Enfrentarse a estos temas beneficiará su relación con sus hijos a largo plazo. 💧

Aquí hay algunas preguntas de discusión que las madres y las hijas (o los padres y los niños) pueden hacerse para comenzar la conversación:

- 💧 ¿Qué aprendiste sobre tu cuerpo mientras crecías?
- 💧 ¿Qué aprendiste sobre los períodos?
- 💧 ¿Qué aprendiste sobre tu sangrado (trastorno)?
- 💧 ¿Qué quieres que yo sepa sobre mi / tu cuerpo / sangrado / vida?
- 💧 Seguimiento: ¿Cómo te sentiste al respecto? ¿Como fue?

EL REEMPLAZO DE FACTOR REFLEJA LA PROTECCIÓN INTERIOR



Para gente con hemofilia, el tratamiento de Factor reemplaza temporalmente lo que falta.¹⁻² Con un largo historial de resultados probados, el tratamiento de Factor trabaja con el proceso de coagulación natural de tu cuerpo para formar un coágulo adecuado.²⁻⁶

Takeda lo hace posible con su dedicación a la búsqueda de avances en hemofilia por más de 70 años.⁷

Las posibilidades te mantienen fuerte.

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Cornfields, Camping and Camaraderie

Nationally-known cycling event creates amazing memories for Team Resilience participants

BY EMILY ROUSH-BOBOLZ, STAFF WRITER

While Hemophilia Federation of American has been hosting the Gears for Good National Ride from West Virginia to Washington, D.C., for eight years, the organization had a larger vision — use existing athletic and competitive events around the country to raise awareness of bleeding disorders and funds for the Helping Hands emergency assistance program. That's when Team Resilience was born!

Existing events like the iconic RAGBRAI, a week-long cycling event drawing 20,000 riders a day to trek across the state of Iowa, is one example of an event Team Resilience joined to reach beyond Gears for Good. When 20,000 people are gathered in one place, it's a great space to spread awareness about bleeding disorders!

This summer, bleeding disorders community members and their friends and family created a team of 11 riders who

donned Team Resilience cycling jerseys to ride from the Missouri River approximately 500 miles across Iowa to the mighty Mississippi River, sharing their story along the way.

They understand what bleeding disorders families endure, and they chose to endure a week of heat and exhaustion, sleeping in tents, and miles and miles of nothing but cornfields. But the memories they made and the message they shared is invaluable.

The ride, which stands for Register's (as in The Des Moines Register newspaper) Annual Great Bicycle Ride Across Iowa, has been drawing cyclists from all over the world to the Midwest state since 1973. Team Resilience riders raised more than \$11,000 for Helping Hands. 💧



INSPIRING IMPACT




19,400
FEET TO CLIMB


38
HOURS OF RIDING


7
DAYS


500
MILES



Lots of food, amazing memories and a true show of resilience!



Having a bleeding disorder presents many challenges individuals and families must overcome, and it's their resiliency that inspired HFA to create Team Resilience.



You Can be a Superhero for Bleeding Disorders



As you grow older, the best way to show you care about yourself, your family and others with bleeding disorders is to **know all about bleeding disorders**.

There are **different types** of bleeding disorders. The most common are:

👉 Hemophilia 👉 von Willebrand Disease 👉 Other Factor Deficiencies 👉 Platelet Function Disorders.



In my family, we have: _____

The person (or people) in my family with a bleeding disorder is: _____

Your Family!

Draw a picture of you and your family or a family member with bleeding disorders:

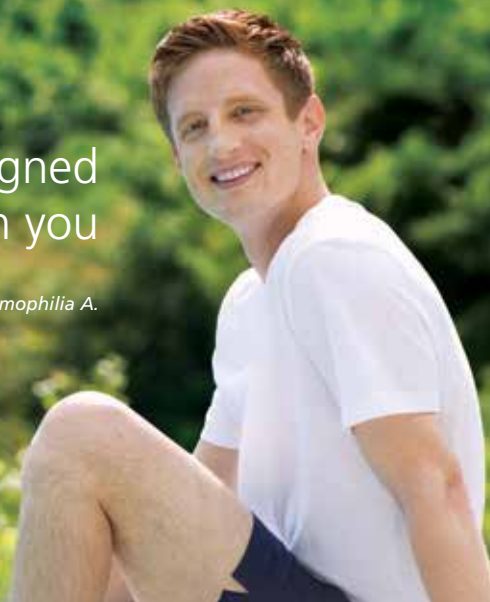


Up to
104°F
for up to
3 months

Please see Prescribing Information
for complete product storage conditions.

Novoeight® is designed to go with you

Julian lives with hemophilia A.



PORTABILITY

Novoeight® can be stored:



Up to
104°F
for up to



3 months



Up to
86°F
for up to



12 months

Longest room temperature storage time after reconstitution—**up to 4 hours at up to 86°F***

Highest storage temperature after reconstitution—**up to 104°F for up to 2 hours***

*Compared with other recombinant FVIII products.

Please see Prescribing Information at Novoeight.com for complete product storage conditions.

BLEED CONTROL

89%

of adults and adolescents
aged 12-65

95%

of children aged
0-11

Bleeds treated with 1 or 2 infusions

EXPERIENCE

OVER

9

years of clinical experience
with Novoeight® in previously
treated patients

What is Novoeight®?

- Novoeight® (antihemophilic factor, recombinant) is an injectable medicine used to control and prevent bleeding in people with hemophilia A. Your healthcare provider may give you Novoeight® when you have surgery
- Novoeight® is not used to treat von Willebrand Disease

Important Safety Information

Who should not use Novoeight®?

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

What is the most important information I need to know about Novoeight®?

- Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia center**
- Call your healthcare provider right away and stop treatment if you get any of the following signs of an allergic reaction:** rashes or hives, difficulty breathing or swallowing, tightness of the chest, swelling of the lips and tongue, light-headedness, dizziness or loss of consciousness, pale and cold skin, fast heartbeat, or red or swollen face or hands

What should I tell my healthcare provider before using Novoeight®?

- Before taking Novoeight®, you should tell your healthcare provider if you have or have had any medical conditions, take any medicines (including non-prescription medicines and dietary supplements), are nursing, pregnant or planning to become pregnant, or have been told that you have inhibitors to factor VIII
- Your body can make antibodies called “inhibitors” against Novoeight®, which may stop Novoeight® from working properly. **Call your healthcare provider right away if your bleeding does not stop after taking Novoeight®**

What are the possible side effects of Novoeight®?

- Common side effects of Novoeight® include inhibitors in patients who were not previously treated with factor VIII products, swelling or itching at the location of injection, and fever

Please see Brief Summary of Prescribing Information on following page.



Visit Novoeight104.com today to learn more.



Stay updated! Follow us at: [Facebook.com/novoeight](https://www.facebook.com/novoeight)



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novoeight®
Antihemophilic Factor
(Recombinant)

novoeight®

Antihemophilic Factor (Recombinant)

Brief Summary information about Novoeight® Antihemophilic Factor (Recombinant)

Rx Only

This information is not comprehensive.

- Talk to your healthcare provider or pharmacist
- Visit www.novo-pi.com/novoeight.pdf to obtain the FDA-approved product labeling
- Call 1-844-30-eight

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

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

What is the most important information I need to know about Novoeight®?

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

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

What is Novoeight®?

Novoeight® is an injectable medicine used to replace clotting factor VIII that is missing in patients with hemophilia A. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally. Novoeight® is used to control and prevent bleeding in people with hemophilia A.

Your healthcare provider may give you Novoeight® when you have surgery.

Novoeight® is not used to treat von Willebrand Disease.

Who should not use Novoeight®?

You should not use Novoeight® if you

- are allergic to factor VIII or any of the other ingredients of Novoeight®
- if you are allergic to hamster proteins

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

What should I tell my healthcare provider before I use Novoeight®?

You should tell your healthcare provider if you

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

How should I use Novoeight®?

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

Novoeight® is given as an injection into the vein.

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

Your healthcare provider will tell you how much Novoeight® to use based on your weight, the severity of your hemophilia A, and where you are bleeding.

You may need to have blood tests done after getting Novoeight® to be sure that your blood level of factor VIII is high enough to clot your blood. This is particularly important if you are having major surgery.

Your healthcare provider will calculate your dose of Novoeight® (in international units, IU) depending on your condition and body weight.

Call your healthcare provider right away if your bleeding does not stop after taking Novoeight®.

Development of factor VIII inhibitors

Your body can also make antibodies called "inhibitors" against Novoeight®, which may stop Novoeight® from working properly.

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

Use in children

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

If you forget to use Novoeight®

Do not inject a double dose to make up for a forgotten dose. Proceed with the next injections as scheduled and continue as advised by your healthcare provider.

If you stop using Novoeight®

If you stop using Novoeight® you are not protected against bleeding. Do not stop using Novoeight® without consulting your healthcare provider.

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

What if I take too much Novoeight®?

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

What are the possible side effects of Novoeight®?

Common Side Effects Include:

- Inhibitors in patients who were not previously treated with Factor VIII products
- Swelling or itching at the location of injection
- Fever

Other Possible Side Effects:

You could have an allergic reaction to coagulation factor VIII products. **Call your healthcare provider right away and stop treatment if you get any of the following signs of an allergic reaction:**

- rashes including hives
- difficulty breathing, shortness of breath or wheezing
- tightness of the chest or throat, difficulty swallowing
- swelling of the lips and tongue
- light-headedness, dizziness or loss of consciousness
- pale and cold skin, fast heart beat which may be signs of low blood pressure
- red or swollen face or hands

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

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

What are the Novoeight® dosage strengths?

Novoeight comes in six different dosage strengths. The actual number of international units (IU) of factor VIII in the vial will be imprinted on the label and on the box. The six different strengths are as follows:

- Dosage strength of approximately 250 IU per vial
- Dosage strength of approximately 500 IU per vial
- Dosage strength of approximately 1000 IU per vial
- Dosage strength of approximately 1500 IU per vial
- Dosage strength of approximately 2000 IU per vial
- Dosage strength of approximately 3000 IU per vial

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

How should I store Novoeight®?

Prior to Reconstitution:

Store in original package in order to protect from light. Do not freeze Novoeight®.

Novoeight® vials can be stored in the refrigerator (36°F to 46°F [2°C to 8°C]) for up to 30 months or up to the expiration date. During the 30 month shelf life, the product may be kept at room temperature up to 86°F (30°C) for no longer than 12 months, **or** up to 104°F (40°C) for no longer than 3 months.

If you choose to store Novoeight® at room temperature:

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

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

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

The reconstituted Novoeight® should appear clear to slightly unclear without particles.

The reconstituted Novoeight® should be used immediately.

If you cannot use the Novoeight® immediately after it is mixed, it must be used within 4 hours when stored at ≤ 86°F (30°C) or within 2 hours when stored between 86°F (30°C) to 104°F (40°C). Store the reconstituted product in the vial.

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

What else should I know about Novoeight® and hemophilia A?

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

For more information about Novoeight®, please call Novo Nordisk at 1-844-30-EIGHT.

Revised: 11/2018

Novoeight® is a registered trademark of Novo Nordisk Health Care AG.

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

Manufactured by:
Novo Nordisk A/S
DK-2880 Bagsvaerd, Denmark

More detailed information is available upon request.

Available by prescription only.

For information about Novoeight® contact:

Novo Nordisk Inc.
800 Scudders Mill Road
Plainsboro, NJ 08536, USA

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US18NEGT00164 12/2018



Pushing Through the Pain

First-time Gears for Good rider discovers the ride means more than raising money

BY LIANNE LAPIERRE, HFA BOARD MEMBER AND GUEST WRITER



Hemophilia Federation of America held another successful Gears for Good National Ride in September, with 38 riders from throughout the country. Riders and donors raised more than \$54,000 for the Helping Hands emergency assistance program.

As the ride came to an end on the third day, first-time rider and HFA board member, Lianne Lapierre, experienced something she didn't expect and something she'll never forget.

I had the incredible opportunity to ride in HFA's annual Gears for Good National Ride — a 156-mile charity bicycle ride from West Virginia to Washington, D.C. And let me tell you, it was an awesome experience!

This was my first Gears for Good ride, and I was definitely a bit nervous heading into it, as the last time I had ridden my bike might have been in middle school! I signed up to ride after a little “coaxing” from a couple of friends in the community, thinking I had all the time in the world to train for an event that wasn't happening until the middle of September. May turned into June, and June to July, and before I knew it, I was less than 60 days away from the ride, and had not ridden my bike once.

That's when I decided if I was going to go into this three-day ride prepared, I needed to start training ASAP. I spent two to three days a week riding around the hills of northern Maine, fundraising and sharing my journey using social media, along the way. Before I knew it, Sept. 20 had arrived, and it was time to ride!

The morning of the first day was a whirlwind. It was like waking up Christmas morning, not sure what you're going to find under the tree! Except for me, my “gifts” were a brand-new team jersey and a bike that I had never used (Get Out

and Go Tours provides bicycles for riders, to help riders avoid the complicated logistics of shipping their own bike to D.C.) that was to be mine for the next three days. While I was extremely excited, I was also pretty nervous, not knowing what to expect.

By the time we got to the drop off point in Paw Paw, W. Va., my nerves had calmed down some. I had already made some new friends on the two-hour bus ride and I was ready to hop on my bike and ride! The first day was just a mere 30 miles. By the end of the first day, I was finally comfortable on my bike, and I was getting to know even more of my fellow riders who came from all over — California, Florida, Missouri, EVERYWHERE!

On the second day we rode a little more than 60 miles. The Chesapeake and Ohio Canal Trail was absolutely gorgeous. So gorgeous that I got brave enough to master the art of taking pictures on my phone while riding. At some point during day two, however, I started having some shoulder pain.

By the third day, I was finally starting to feel like a real cyclist! We had only 60 miles left, and again, the day started off gorgeous. We started the morning in Harpers Ferry, W. Va., where the Potomac River meets the Shenandoah. Between the fog and rising sun and the long bridge we had to ride

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over, I knew it was going to be a memorable day. At mile 138, I really started to feel the shoulder pain again.

Just after lunch, the sun started to get really warm and the trail started to get really tough. I was tired, a little dehydrated, and my shoulder pain was really getting to me. At one point, I slowed way down on my bike, while my team rode up ahead. I was alone. And frustrated. I was exhausted. And I wanted to give up. I didn't think I could ride any more. I couldn't believe it — with only 22 miles left to go, I was on the verge of quitting. I wanted to lay my bike in the grass, and call someone to come get me. And then the tears started. I just didn't know how I was going to finish. I felt defeated.

And then something incredible happened. The ride turned personal for me. This entire time — training, fundraising, the excitement leading up to the ride, the first two days of riding — everything up until that point was all about Helping Hands, HFA's emergency assistance program. Everything I did, I did for other families in our community that might need a helping hand one of these days. I was doing it for THEM. I was raising money, and riding my tail-end off, for them.

Then mile 138 happened. In the midst of my near-meltdown, in the middle of my frustration, and pain, I thought of my son. My 12-year-old son who has severe hemophilia. I thought about his ankles, and the bleeds he gets in them. The pain he feels when he walks too far. The aches that he has every single morning when he wakes up. And the fact that even when he's in pain, he is **still** smiling. He is **still** pushing through. Because like so many of those in our community living with a bleeding disorder, he is so incredibly strong. As I dried my tears and I told myself I was going to finish that ride, we came to the last and final stop, 10 miles before the end. As I rode in, tears fresh in my eyes, I saw my team captain, Tom. He verbalized everything I had going on in my head and asked me a question: 'What's worse: this shoulder pain or a bleed?'

That's when I knew, 100% without a doubt, I was going to finish. Tom rode those last 10 miles with me — side by side. Not only did I finish, but I literally went "that extra mile," and made it all the way to Mile 0. And it felt AMAZING!

Gears for Good has changed me. Not just physically (My legs have never been stronger!), but it changed me on the inside, too. It taught me that even when things get tough, I can and will make it through. Even on my "worst" day, it's nothing compared to what others in our bleeding disorder

Below top: Second year rider, Jace, poses for a photo to gather support and donations for his ride.

Below bottom: First-time rider, Ashley Hall, shares why she rides.



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community are going through. It's taught me it's okay to cry and be frustrated, but even then, don't let your negative mindset get the best of you. I've made friendships that will last a lifetime. Memories that I will cherish forever. And I can't believe I'm even saying this, but I seriously can't wait for Gears for Good 2020! Now, who's in it with me? 💧

Top right: Get Out and Go Tours organizer and rider, Tom Knoerzer enjoys lunch; middle right: Father-son riders Jace and Lonn Vreeland; middle left: Stacy Carmichael and Sherri Bender with TeamPhilo stop for a selfie.



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First-time rider, Nick Griguoli, supports his cousin, Jace. He stopped for a triumphant pose along the C&O Canal.



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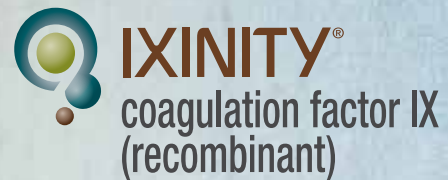
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Project CALLS Report

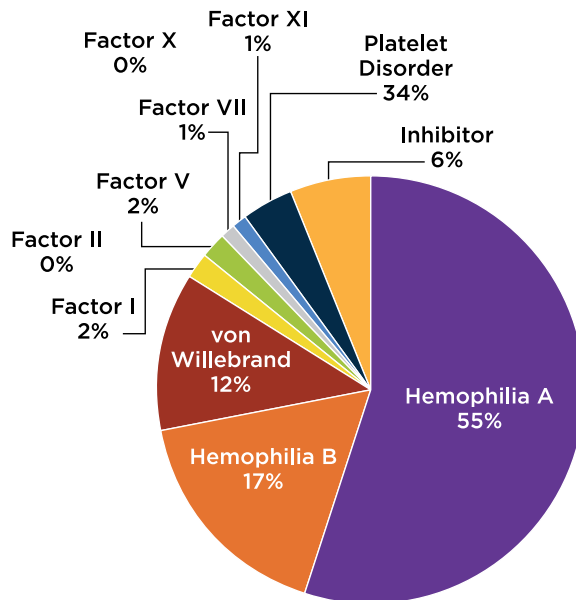
Creating Alternatives to Limiting and Lacking Services

Hemophilia Federation of America continues to gather valuable data through Project CALLS, which collects data and personal stories about how changes in insurance company policies are impacting the care of people with bleeding disorders.

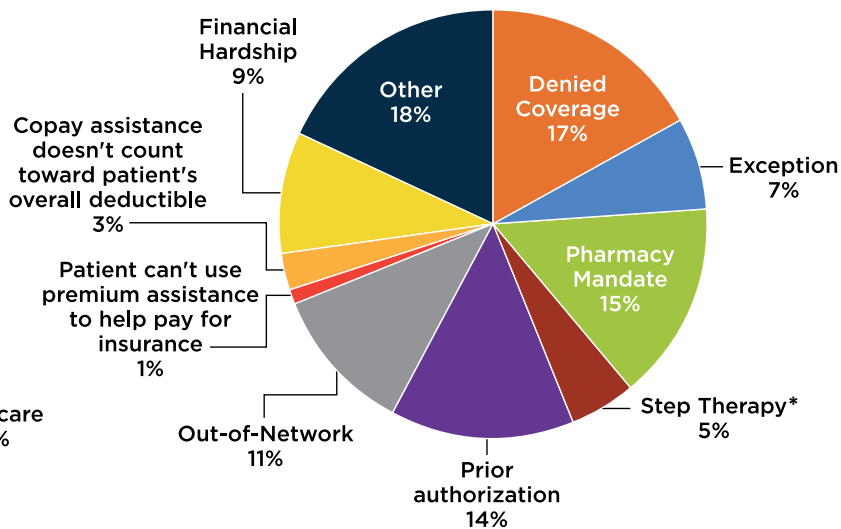
Our 2019 second quarter data is limited due to the launch of a new form, but a full data set will be available in the second half of 2019. Earlier this year, HFA launched an updated, shortened version of the Project CALLS survey form, designed to be a more accessible option for reporting health insurance issues. With the introduction of the shortened questionnaire, outreach efforts for full data collection of the second quarter Project CALLS participants is ongoing. HFA will continue to collect and share information included in this quarterly report from both the long- and short-form surveys.

Since the beginning of Project CALLS, more than 230 members of the bleeding disorders community have completed both our long and short surveys. With increasing numbers of payers looking to manage the class of hemophilia treatments, HFA has been able to cite CALLS data while advocating vital patient safeguards, such as step therapy protections, standardized prior authorization processes and more. 🩸

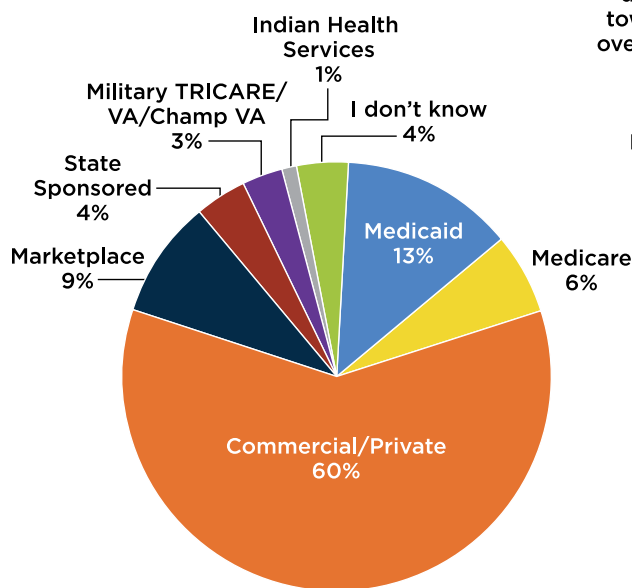
Diagnosis**



Issues Reported

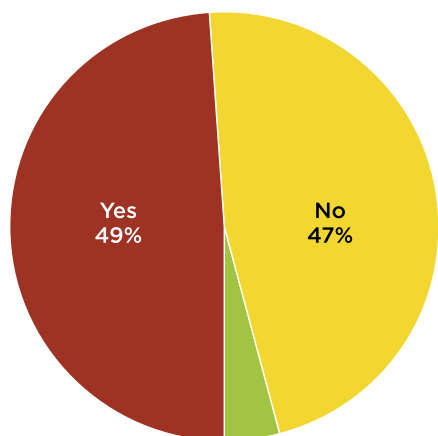


Type of Insurance



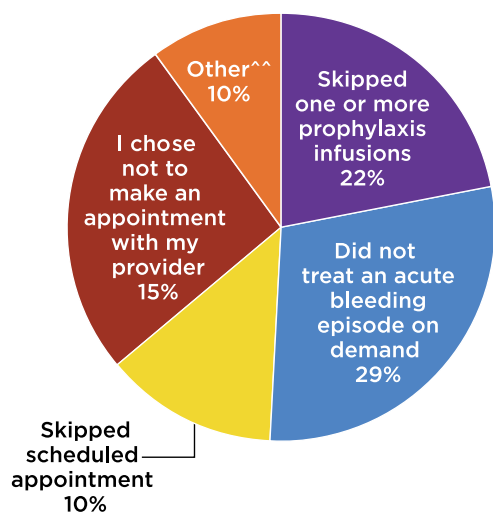
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www.hemophiliafed.org

Delayed Care?



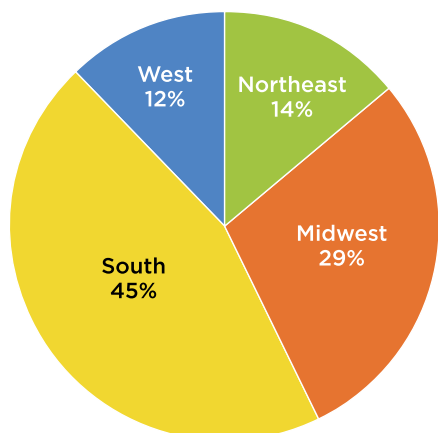
I did not need care for my bleeding disorder in the last 12 months
4%

How did you delay care?^**



^^Responses included (1) didn't have extra dose for emergency as recommended by MASAC and (2) hindrance to providing care and providing medication to child.

Region



*all reports not for bleeding disorder treatments

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

^new question as of February 15, 2018



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